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Resilience Intervention for Families of Autistic Children: Reviewing the Literature

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Abstract: Given the rising diagnostic rates of autism, it is imperative to investigate the well-being of families with autistic children. Families of autistic children report more mental health difficulties than families of typically developing children. Resilience is identified as a key protective factor for mental health difficulties in many populations, and research suggests that this construct is effective for coping with mental health difficulties in families of autistic children. However, reviews on resilience interventions for families of autistic children are lacking. Accordingly, this paper aims to report (a) common mental health difficulties that families of autistic children experience, (b) how resilience may reduce mental health difficulties, (c) interventions to enhance resilience in families of autistic children, and (d) discuss implications for practice and future research. Our review identified that mental distress resulting from feelings of uncertainty and helplessness following a diagnosis, in addition to caregiving stressors, is especially common among families of autistic children. Enhancing resilience is suggested to reduce those difficulties by tapping into strengths related to various positive psychological resources such as internal locus of control, positive cognitive appraisal, acceptance and self-efficacy. Interventions such as Dance Movement Psychotherapy and spirituality-based approaches, are deemed especially helpful to families of autistic children. However, research in this area is still under-developed, and there is a pressing need to build a more rigorous evidence base. Findings reviewed in the current work can aid families of autistic children, healthcare practitioners, and researchers to support the mental wellbeing of families of autistic children, which in turn would support the wellbeing of autistic children.

Keywords: family stress; autism; uncertainty; hopelessness; mental wellbeing

Introduction

Autism, also known as autism spectrum conditions (ASCs; Baron-Cohen et al., 2009), is described as a lifelong neurodevelopmental condition marked by social communication difficulties, sensory challenges, and repetitive behaviours and restricted interests. Autistic profiles contain significant heterogeneity, with social and cognitive skills ranging from intact to impaired across individuals (American Psychiatric Association, 2013).

While the cause of autism remains unspecified, an amalgam of genetic and environmental components has been proposed to influence its development (Chaste & Leboyer, 2012; Sylvie et al., 2014). On another note, there seems to be discrepancies between the clinical and scientific understanding of autism. The clinical understanding of autism is mainly rooted in the language of 'disorder'; for example, autism is referred to as 'autism spectrum disorders' in the DSM-V. On the other hand, the scientific understanding of autism has changed in recent years. There is growing scientific evidence that autism is a neurological and cognitive 'difference', rather than 'disorder' (i.e., dysfunctional in some way) (Lai, acknowledging that human brains do not come in a one-size-fits-all neurologically 'normal' package.

Global estimates suggest that between 1/100 and 1/132 individuals receive an autism diagnosis (Baxter et al., 2015; Hahler & Elsabbagh, 2015). However, there is a disparity in prevalence data which is thought to be associated with delayed diagnosis, barriers in accessing services (Hahler & Elsabbagh, 2015), variations in the assessment and diagnostic practices used to identify autistic children, and reporting methods (Hansen et al., 2015). Despite this, there is no evidence to suggest that prevalence of autism is influenced by geographic location, ethnicity, or cultural and socioeconomic factors (Hahler & Elsabbagh, 2015).

Autism is considered a 'male-biased condition' as more males than females receive a diagnosis (Ruigrok et al., 2014). It is argued that females have been under-recognised as being autistic due to gender stereotypes and differences in the diagnostic assessment criteria, as females typically need to exhibit more behavioural or cognitive problems to be diagnosed (Lai, Lombardo & Baron-Cohen, 2014). Autism has a high rate of comorbidity, with around 70% of autistic people living with single or multiple co-occurring conditions (Lai, Lombardo & Baron-Cohen, 2014). Comorbidities associated with autism can be further disabling for an autistic individual, and include intellectual disability, language delay, epilepsy, gastrointestinal issues, depression, anxiety, and attention deficit and hyperactivity disorder (Hahler & Elsabbagh, 2015; Giovagnoli et al., 2015).

Epidemiological studies indicate that the prevalence of autism is increasing internationally (Chiarotti & Venerosi, 2020; Hahler & Elsabbagh, 2015). A number of possible explanations for a rise in autism have been posited, including enhanced awareness of autism characteristics, which leads to an increase in reporting, the development of diagnostic tools,

changes in assessment practices and the expansion of diagnostic criteria (Hanson et al., 2015; Hayes et al., 2017). A longitudinal study based on United Kingdom school census data identified that surges in prevalence of autism could be concurrent to an improved understanding that autism can be present alongside other developmental conditions, as opposed to autism being a primary condition (McConkey, 2020). It has also been proposed that a recent rise in the portrayal of characters with autism in film and television could be a contributing factor in symptoms of autism being recognised by parents (Nordahl-Hansen et al., 2018).

Indeed, parents' and family's support for an autistic child is essential to maintain wellbeing of the child and family. The high prevalence of autism indicates the importance of mental health in the caregiver families, and resilience has been identified as a key construct for them to maintain their wellbeing. Accordingly, the present review paper aims to report (a) common mental health difficulties that families of autistic children experience, (b) how resilience may reduce mental health difficulties, (c) interventions to enhance resilience in families of autistic children, and (d) discuss implications for practice and future research.

Impacts on Family Mental Health

Given the rising diagnostic rates of autism and the increased need for support, the experiences of those with a lived experience of autism and their families are receiving more attention from the scientific community. Families, in particular, highlight mental distress following their children's autism diagnosis - voicing a sense of 'uncertainty and helplessness' (Hahler & Elsabbagh, 2015). It has been suggested that parents can experience a grieving process following their child's diagnosis of autism (Mulligan et al., 2012), with the diagnosis representing the loss of a 'healthy' child (Fernańdez-Alcántara et al., 2016). This experience of uncertainty has been associated with ambiguity around the diagnosis and the impact of support, or lack thereof, on the child's development. Moreover, parents have described the loss of the future that they had envisaged for their child (Desai et al., 2012; Fernańdez-Alcántara et al., 2016; Poslawsky et al., 2014). The emotional reactions of parents, resulting from an autism diagnosis include feelings of shock, denial, fear, anxiety, guilt, anger, sadness, and distress (Fernańdez-Alcántara et al., 2016; Gentles et al., 2020).

Studies have consistently identified that parents of young autistic children report higher levels of stress than parents of typically developing children or children with other developmental conditions, and that parental stress was strongly predicted by the child's behavioural and emotional problems (Giovagnoli et al., 2015; Osborne et al., 2008). Further, parents of autistic children are at an increased risk for developing mental health problems (Hastings, 2007; Manning et al., 2020).

Literature reports that the coronavirus disease 2019 (COVID-19) pandemic has resulted in major challenges for families of autistic children (Alhuzimi, 2021; Colizzi et al., 2020; Manning et al., 2020). Autistic

children often find adapting to a changing environment difficult, as they can respond with agitation and frustration in the face of disruption to pre-existing, well-established routines (Oomen et al., 2021). The distress caused by an ever-changing situation can lead to an increase in behavioural problems and acts of self-harm among children and adolescents in general (Singh et al., 2020). In addition, many in-person support services have been suspended, and online schooling can be particularly disorienting for some autistic students (United Nations International Children's Emergency Fund, 2020). The culmination of issues related to lockdown restrictions means that families of autistic children can find it extremely difficult to cope (Manning et al., 2020; Singh et al., 2020).

On the other hand, positive outcomes have also been reported among families raising autistic children, such as an increased sense of family unit (Myers, Mackintosh, & Goin-Kochel, 2009) and increased empathy and compassion among family members (Neely-Barnes, Hall, Roberts, & Graff, 2011). A key component underlying positive outcomes is family resilience (Gunty, 2020; Latzer, Leitner & Karnieli-Miller 2021).

Resilience in Families Raising Autistic Children

Across the 1990s, there was a movement from a deficit-based model towards a strengths-based model in autism research (Hawley & DeHann, 1996), and within a strength-based model was the concept of resilience—the process of adapting or coping with situations when faced with trauma, adversity, threat, tragedy or stress (American Psychological Association, 2021; Lee, & Cranford, 2008; O'Dowd et al., 2018). Following the movement, the development of resilience extended from an individual level to a family level, conceptualized as 'family resilience' that allows family members to focus on their strengths to overcome family's crises and challenges (Walsh, 2003). McCubbin, Thompson and McCubbin (1996) suggested shifting the focus from family deficits to the identification of factors that contribute to healthy family functioning. Walsh (2003) highlighted that resilience in families with autistic children could reduce stress, vulnerability in times of crisis and increase wellbeing. More recently, Gunty's systematic review (2020) noted that inherent strengths of the family should be identified and further developed in order to nurture family resilience. Resilience has been associated with many positive outcomes for families with autistic children, such as positive family mental health (Ekas & Whitman, 2010), greater psychological wellbeing and life satisfaction (Ekas & Whitman, 2010), manage adversity (Luthar, Cicchetti & Becker, 2000), better coping mechanism (Ruiz-Robledillo, et al., 2014), lower stress levels (Plumb, 2011), lower depression (Bitsika, Sharpley & Bell, 2013; Ilias, Cornish, Kummar, Park, & Golden, 2018) and better spousal relationships (Duca, 2015; Siman-Tov & Kaniel, 2011). Research indicates that resilient families with autistic children were more protected from negative wellbeing, stress, anxiety and depression (Bitsika, Sharpley, & Bell, 2013; Ilias et al., 2018). Predictors of resilience include social support

(from families and community) (Kapp & Brown, 2011), internal locus of control (Rajan, Srikrishna & Romate, 2018), positive cognitive appraisal (Terry & Hynes, 1998), acceptance (McAuliffe, et al., 2017), self-efficacy (Carter, et al., 2009), optimism (Kantor et al., 2011), religious or spiritual beliefs (Pandya, 2018) and enrichment (Phelps et al., 2009).

Autistic children often find socialising a hard adaptive skill to master, which can limit the number of social activities that families attend. This may cause the family to become socially isolated (Hall & Graff, 2011; Manning, Wainwright & Bennett, 2011), possibly leading to stress and depression. On the other hand, increasing social support can increase resilience (Roberts, Hunter & Cheng, 2017). Therefore, developing and maintaining social support is essential for families with autism, to enhance resilience, the ability to bounce back from crisis (Peer & Hillman, 2014). Robert, Hunter and Cheng's (2017) study found that positive social support systems increased resilience and in turn improved wellbeing for families with autistic children. For instance, increased resilience was found to play a role in parental coping with poor sleep patterns in autistic children (Malow, MacDonald, Fawkes & Katz, 2016; Johnson, Giannotti, & Cortesi, 2009).

Siman-Tov and Kaniel (2011) suggested that resilient families' better coping mechanisms may be due to having an *internal locus of control* (i.e., an individual perception of the control over a given event). This sense of control could be derived from internal (e.g., one's behaviour) and external (e.g., other people's actions) factors (Rotter, 1966). Therefore, when families with autistic children have an internal locus of control, they feel more empowered (i.e., an increased sense of confidence and being in control; Úcar Martínez et al., 2017) and less stressed, contributing to greater resilience (Rajan, Srikrishna & Romate, 2018). A further protecting factor associated with resilience is *positive cognitive appraisal*. The families that made sense of the situations positively (i.e., positive cognitive appraisal) were associated with higher levels of resilience (Terry & Hynes, 1998). *Acceptance* was another reinforcing factor within resilience. Research indicated that the families that had increased acceptance were found to embrace adjustment and adaptation, helping them to find peace in the present (Luong, Yoder & Canham, 2009; McAuliffe, et al., 2017). Acceptance helped families appreciate what they did have instead of what they did not (Bayat, 2007).

Additional factors associated with resilience in the family are self-efficacy, optimism, religious or spiritual beliefs and enrichment. *Self-efficacy* is the confidence in one's ability to succeed in their goals and challenges. Families with autistic children that had higher self-efficacy reported lower depression and stress levels (Carter, et al., 2009). Additionally, increased *optimism* and being optimistic about the future was another protecting factor for families with autistic children (Kantor et al., 2011). Studies found an association between optimism in mothers of autistic children, and coping mechanisms, psychological wellbeing, and quality of

relationships with their children (Greenberg, Seltzer, Krauss, Chou, & Hong, 2004; Kuhaneck, et al., 2010; Peer & Hillman, 2014). In addition, families with religious or spiritual beliefs had higher levels of resilience, possibly due to connection with the religious community, spiritual lessons and the comfort of prayer (Gona, et al., 2016; Pandya, 2018; Tait & Mundia, 2012). Lastly, resilience was associated with *enrichment*— a positive view and relationship with their children, partner, and themselves (Phelps et al., 2009). Taken together, resilience is associated with various factors, informing interventions.

Interventions to Enhance Resilience in Family

Interventions and research to enhance resilience are widely available, but less so in families with autistic children. Nonetheless positive findings were reported from interventions in families of children with autism based on Dance Movement Psychotherapy (DMP) (Aithal et al., 2020), spirituality resilience training (Pandya, 2018), group resilience training (Mendez et al., 2019) and virtual resilience training (Kuhlthau et al., 2019).

DMP is a body-based creative approach to psychotherapy consisting of body movement and dance to assist integration of emotional, cognitive, physical, social and spiritual aspects of self. DMP enhances resilience through the vitalising movement experiences that facilitate connection to embodied sources of joy and wellbeing (Karkou et al. 2017; Samaritter, 2014). Parents may not receive reciprocal engagement from their autistic children, and DMP can provide a way to express feelings, thoughts, explore strengths and address stress and other family issues. Six DMP sessions (1.5 hours each) across three weeks was shown to enhance resilience through improvement in cognitive (e.g., self-efficacy beliefs, cognitive adaptation and acceptance) and emotion (e.g., emotion regulation and positive affect) factors (Aithal et al., 2020). Hence, DMP enhances resilience through gaining of resilience resources (Luthar et al., 2000; Masten, 2007).

Spirituality—understanding the self as well as the self in relation to others and the absolute—may enhance resilience in families of autistic children by increasing resilience-promoting potential (Dunlap, 2010). A spiritual programme may include spiritual lessons and self-practice which may take the form of lectures, group discussions and experiential exercises. A six-day (three hours each) spiritual lessons package undertaken by 1687 parents, was shown to improve resilience. The programme focused on practicing meditation and mindfulness, where self-awareness, acceptance, positive effects, a consciousness of self-absolute self and self-significant others, forgiveness, unconditional love, and senses of unity were emphasised (Pandya, 2018). One limitation is that a greater increase in resilience is observed in participants from European countries and the US, Canada, and Australia compared to Asian and African ones, and following Christianity compared to other religions investigated (Hinduism, Buddhism, Judaism, and Islam) (Pandya, 2018); this may be explained by

potential variances in the ability to relate to the spiritual lessons. Indeed, the positive effects of non-Christian religions on resilience in families of autistic children, have been recently reported (e.g., Buddhism [Keenan-Mount et al., 2016], Islam [Yumpi, 2018]).

Group resilience training, incorporating psychotherapy approaches such as Acceptance and Commitment Therapy and psychoeducation, have also shown positive effects (Blackledge & Hayes, 2006; Chiang, 2014; Keen et al., 2010; Shu & Lung, 2005). For example, a four-week group resilience programme entitled "Together We Are Stronger" attended by couples raising autistic children, improved resilience through increased dyadic satisfaction, co-parenting closeness, and hope (Mendez et al., 2019). The programme is designed to support resilience in parent, and is comprised four sessions focusing on 1) understanding the family history and values, 2) communication, 3) co-parenting, and 4) optimism and humour for stress coping (Mendez et al., 2019).

Lastly, *virtual resilience training* has recently begun to attract attention. For example, Stress Management and Resiliency Training—Relaxation Response Resiliency Program (SMART-3RP), a virtual group resilience programme, has been reported as a promising way to enhance resilience in a family (Kuhlthau et al., 2019). This programme is delivered via video conferencing, consisting of elicitation of the relaxation response, enhancement of stress awareness, and stress management techniques. Though the intervention study had a homogenous sample of highly educated families, the accessible online delivery can be especially helpful for families raising autistic children, who may not be able to be away from the child for a long time. Additionally, this type of training can be used without meeting physically, which is beneficial during situation like the COVID-19 pandemic.

Though more rigorous research is needed (Llias et al., 2018), these promising results suggest that resilience of families of autistic children can be enhanced. It is noteworthy that we have also searched for studies that employed more established interventions such as cognitive behavioural therapy and mindfulness targeted resilience in families of autistic children, but there appears to be a dearth of such research in the literature.

Discussion

It is evident from the literature that families of autistic children are at a higher risk of distress and developing mental health problems than families of typically-developing children, but also that this need not be the case—there are a range of ways that families of autistic children can be supported to achieve improved resilience, which impacts positively on the whole family. Consistent with the interventions introduced above (i.e., 'Interventions to Enhance Resilience in Family'), Miranda et al. (2019) recommended that since eliminating the stressors faced by the family is not a feasible option, enhancing their coping skills and resilience should be the purpose of services and associated research.

There is clear evidence in the literature (e.g., Gunty, 2020; McCubbin et al., 1996; Walsh, 2003) that the move to strengths-based models for working with the families of autistic children has resulted in a positive focus on resilience, which enables families to develop localised, bespoke practices and supporting systems to improve family resilience. However, the wide range of literature discussed throughout this paper indicates that the factors impacting on family resilience are multiple and disparate. Therefore, not all suggested approaches are necessarily relevant, feasible, or accessible to families in need of support (Gunty, 2020). This paper therefore provides a starting point for the development of a tool for assessing a family's existing resilience framework and opportunities for implementing others, so that families and support agencies can identify possible and positive approaches for developing resilience, or that could be used to identify approaches that appeal to different families. For example: does a family prefer support that is located within their usual family practices, or as a separate intervention, or both? Fundamentally, a resilience-based approach appears promising because it offers parents a sense of agency when managing caregiving challenges; especially immediate challenges with regards to support services access following an autism diagnosis. Further study is warranted to better understand how families' resilience is both challenged and enhanced through the process of raising autistic children.

The variety of approaches and interventions identified in the literature discussed above indicates that different families utilise different strategies for managing and developing their resilience. On that note, we pose two questions for further research. Firstly, when resilience strategies are identified in the family's life practices, are they deliberately applied strategies, or just unconscious everyday activities that happen to support family resilience? In other words, does the family consciously attempt to manage their resilience? And secondly, if the same families were given knowledge of the range of approaches that are available to support their resilience, including interventions, which, if any, would they choose, and why? Research into these areas can help reveal the extent to which families: (a) rely on available resources, (b) seek new resources, (c) require support to achieve (a) and (b).

Across both the inherent resilience factors and the interventions, *spirituality* is one relatively common theme, which seemingly offers three elements to support resilience: i) the 'self-strategies' of optimism, acceptance, gratitude, and self-awareness that are common to spiritual practice and are fundamental to effective resilience; ii) the social aspect of spiritual community which is another key feature of resilience; and iii) the awareness of the other and of the absolute, which is often challenging for families of autistic children to appreciate (Dunlap, 2010). Further research can elucidate the impact of spiritual practice on the development of resilience in families with autistic children.

DMP and group resilience training offer more innovative approaches to resilience. These are of importance to future research because they both have been demonstrated to improve the affective experience of parents by improving the quality of parent-child and parent-parent relationships. While other resilience support strategies may tend to focus on the practical aspects of managing resilience as a family with autistic children (such as social networks, positive self-strategies, awareness of the self and others), these studies reflect the importance of love, hope, joy, and family closeness for developing resilience (Aithal et al., 2020, Mendez et al., 2019). Furthermore, the intervention design of the Aithal et al. study could be replicated with other interventions, given the reasonable package duration and its established impact on participants.

DMP is also noteworthy because unlike any other intervention, it is focused on the embodied experience. This appears to recognise that human experience and connection can manifest in many ways, which has been explored through dance therapy in trauma-sensitive settings (Capello, 2018; Serlin, 2020). Therefore, for families of autistic children, this may be a very valuable tool for enabling shared emotional connections that are not possible through usual family activity.

Lastly, the current difficulties presented by the COVID-19 pandemic may further support the need for online interventions (Eshraghi et al., 2020). Resilience was identified as a key component to counter pandemic-related mental health difficulties amongst families of autistic children (Latzer, Leitner & Karnieli-Miller 2021). As discussed above, virtual resilience training was effective at improving family resilience, and this promising result indicates further utility of virtual training and support for families of autistic children. As psychological stress in families with autistic children has increased during the pandemic (Manning et al., 2020), the efficacy of virtual resilience training should be further examined.

While the current literature regarding resilience in families of autistic children offers helpful insights, some limitations should be noted. First, there are inconsistencies with the language used, with ‘mothers’ ‘parents’ and ‘family’ being used interchangeably. Studies, therefore, need to clearly define target groups. Second, there is over-reliance on cross-sectional designs and self-report measures, which restricts the ability to draw robust estimates of the effects of/on resilience (Kotera, Van Laethem & Ohshima, 2020). Future studies need to employ longitudinal study designs, and possibly biological measures (e.g., heart rate variability; An et al., 2020, to facilitate a robust understanding of resilience as a process (Ekas & Rafferty, 2019).

Conclusion

Though autism awareness has been on the rise, particularly in recent years, research at the interface of mental health in families with autistic children is still at its infancy. This article reviewed literature regarding family’s mental health difficulties, and the utility of resilience in

ameliorating such difficulties. augmenting resilience has been evidenced to positively impact cognitive appraisal and self-efficacy in families of autistic children. Several promising interventions such as dance-based and spiritual approaches are reported, yet further research is required to build a rigorous evidence-base. These findings can help families, healthcare workers and researchers identify effective means to protect family wellbeing from mental health difficulties.

Ethics statement

N/A.

Conflict of Interest

There is no conflict of interest.

Availability of data and materials

N/A.

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Authors' contributions

YK conceptualised; PG, AW, RR and UO drafted the first section (Online Learning as Lifeline during COVID-19); RS, MBU and CR drafted the second section (Teaching and Supporting Healthcare Professional Students); JC and YK drafted the third section (Implications for Other Institutions); YK and GL reviewed and finalised the entire draft.

Authors' note

We prefer to use identity-first language (i.e, autistic people) rather than person-first language (i.e., people with autism) in our manuscript as this adheres to autistic community majority preferences (Bury et al. 2020; Kenny et al., 2015; Vivanti, 2020).

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