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CHALLENGED MOTHERHOOD: MOTHERS TO ADULT DAUGHTERS WITH ASPERGER SYNDROME

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Abstract

The present article addresses the phenomenon of challenged motherhood, focusing specifically on the narratives of mothers to adult daughters with Asperger Syndrome (AS). Issues relevant to self-concept including, social expectations of motherhood, and Goffman's concept of *identity* ambivalence are discussed, and previous studies on adult females with AS, and the experiences of their parents are reviewed. The literature review revealed some significant gaps in current scholarly literature: first, the term Autism spectrum disorder (ASD) was used in many studies without a clear differentiation between AS, (ASD) or High functioning autism (HFA), despite significant functional differences between these groups and the resulting influences on the experiences of their parents. Second, studies often investigated the experiences of both parent with less focus on mothers' experiences. Third, in most studies the experiences of parents' to young children were explored, while the experiences of parents to adults with AS in general and adult females with AS in particular did not receive extensive research attention. Fourth, studies on self-concept in parents (and particularly in mothers) to individuals with AS were not found to be common. To address the above described gaps, the paper outlines a narrative study, which is one out of three PhD studies, planned to be conducted in the next 2 years.

Keywords: Identity ambivalence, mothers to adult daughters with Asperger syndrome, self-concept, narrative

1. Introduction

With the increase in the number of individuals diagnosed with Asperger syndrome (AS), there is a growing awareness for the need to develop public services of support for the adult population with AS and their parents. However, notwithstanding the relatively growing research attention on adults with AS in general and on adult females with AS in particular, less research attention was given to the challenges and coping of their parents, with a specific dearth in studies on mothers to adult daughters with AS (MAS), especially in regard to self-concept in MAS. Focus on mothers' experience is significant, since mothers as children's main caregivers; often interact with their children's educational staff. Understanding mothers' experiences by the educational staff may enhance their communication and collaboration with their students' mothers.

1.1. Self-concept

Self-concept (or self-identity) is a hypothetical construct, broadly defined as the individual's perception of his or herself (Guo, 2016), including personality traits, values, and attributes, as well as self-evaluation (Mattingly et al., 2018). Self-concept is regarded as a social product which is strongly influenced by the broader cultural context (Swann et al., 2012), and the immediate social environment. The latter is clearly evident in early childhood and adolescence, where interpersonal relationships with parents, as well as acceptance by peers, significantly affects children's self-concept (Orth, 2018; Swann, et al., 2012). Hypothetical models have described self-concept as a hierarchical multidimensional construct (Yang & Wong, 2020), with different views of self, corresponding to various aspects of one's lives, including academic self-concept (Marsh et al, 2020), music self-concepts, religious, family, peer, and social self-concepts, yet self-concept of mothers coping with a challenging life was not often focused on. A brief reference to the conflicts inherent in motherhood in general, and in a challenged motherhood in particular, is called for.

1.2. Motherhood and identity ambivalence

Motherhood as a gendered conception is a product of a broad network of social influences operating interdependently in a variety of social systems (Bussey & Bandura, 1999), noted by early theoreticians in psychology as influencing children's emotional well-being. Indeed, motherhood as a concept does not refer only to the private experience occurring at home, but also to a universal model that is highly influenced by cultural norms (Terreros, 2017; Wijaya, 2017), as well as the immediate social environment (Parker & Morrow, 2017; Weitz & Karlsson, 2020). Notwithstanding cultural social differences, many universal models portray mothering as selfless, self-sacrificing and emotionally involving endeavour, solely child centred, with complete devotion of physical, emotional, and mental energy to childrearing (Fombele, 2015; Parker & Morrow, 2017; Weitz & Karlsson, 2020).

However, such an ideal model of motherhood embedded with endless myths and expectations often put a heavy burden on mothers to perform flawless motherhood, evaluating themselves against the unrealistic perfect model. Mothers were found to project a positive self-image and avoid sharing challenges (DeGroot & Vik, 2019), leading to what Goffman (1963) designated as identity ambivalence. Underscoring

social impact on self-concept, identity ambivalence refers to mixed feelings of individuals when they perceive themselves as failing to perform their role according to society's expectations. These complex feelings were found to be intensified in mothers of children with AS or ASD, whose child's disabilities greatly affect their ability to perform the quality of motherhood they hoped for.

2. Literature Review

This section will review previous studies on the following topics:

- Autism and Asperger syndrome
- Adult females on the spectrum
- Challenges and resilience in parents to children's with ASD

2.1. Autism and Asperger syndrome redefined

Autism spectrum disorder (ASD) is a lifelong neurodevelopmental disorder, characterized by deficits in social communication and social interaction as well as restricted, repetitive patterns of behaviour, interest, or activities (American Psychiatric Association, 2013). Many individuals with ASD experience tremendous challenges in modulating their emotional responses and coping with depression, anxiety, aggression, tantrums, or self-injury (Chandler et al., 2015).

Individuals with higher IQ (ranging from borderline to above average), without impairments or delays in language and cognitive development, are referred to as high-functioning autism (HFA). The term Asperger syndrome (AS) is often used interchangeably with HFA, referring to a similar population (Jarman & Rayner, 2015). In individuals with AS, the nature of the disability is far less evident than in ASD, the children physical appearance is similar to that of ordinary children, they often attend mainstream schools, and are expected to engage in social activities (Gray, 2003). However, notwithstanding the major differences in mental abilities and in mainstream functioning, many studies did not make a clear differentiation between ASD, and AS or HFA. The described indistinctness was often attributed to the reconceptualization of AS in the last version of Diagnostic and Statistical Manual of Mental Disorders (DSM, American Psychiatric Association, 2013), from a distinct disorder to be included in ASD. However, in other parallel associations such as the World Health Organization (WHO, World Health Organization, 2016), AS is still consider as a distinct disorder. The current paper endorses the conceptualization of WHO and continues to use the term AS.

2.2. Adult females on the spectrum

The characteristics of AS are uniquely manifested in females, often resulting in difficulties in diagnosis. Females with AS are either diagnosed later in life or underdiagnosed (Milner et al., 2019; Sedgewick et al. 2019), with a male to female early diagnosis ratio being 4:1 (Ferri et al., 2018; Lehnhardt, et al., 2016; Zhang et al., 2020).

Several studies had explored the Female Autism Phenotype (FAP*)*, focusing on the unique difficulties in social relationships experienced by females with AS. As opposed to males with AS, who shy

away from social interactions, females tend to have a high level of social motivation. They seek social relationships, initiate friendships (Milner et al., 2019; Sedgewick et al., 2019), are able to engage in a reciprocal conversation, and have similar interest as their neurotypical (NT) peers (Milner et al., 2019). Moreover, females with AS were described as employing a strategy of 'camouflaging' in order to mask their autistic characteristics, consciously mimicking the behaviours of their NT peers (Cook et al., 2018; Milner et al., 2019; Sedgewick et al., 2019; Tharian et al., 2019). However, camouflaging was noted in the literature as an inefficient strategy, requiring a heavy price when employed. Females with AS have described experiencing constant exhaustion, feeling a loss of their own identity (Bargiela et al., 2016), increased stress and anxiety (Cage & Troxell-Whitman, 2019), chronic insomnia, regular emotional outbursts, and self-harm (Stewart, 2012).

In spite of the motivations and efforts invest in social relations, females with AS experience difficulties in developing and maintaining friendships with NT peers (Cridland et al., 2014; Stewart, 2012), often describing peer's rejection, intolerance and marginalization (Stewart, 2012). Such negative responses were particularly noted during adolescent, as the complexity of social relationships is increased (Cook et al., 2018). During adolescent, NT female girls rely primarily on intimate social communication that require complex emotional skills, reciprocal sharing, and social problem solving. Furthermore, NT girls display anger in indirect subtle manners including gossiping, exclusion, and non-verbal behaviours (Cook et al., 2018). Females with AS were reported to have immense difficulties in understanding, mimicking and responding to such complex social behaviours (Cridland et al., 2014). The difficulties experienced by adolescent female with AS were reported as having an impact on their parents, however, the experiences of parents (and mothers) to adult females with AS had not been focused on in research.

2.3. Challenges and resilience in parents to children's with ASD

Some studies on parents to ASD, AS have explored challenges faced by caregivers of individuals with AS or ASD. These challenges included poor physical and mental health, higher levels of parenting stress and lower quality of life, marital tension, financial strain and limited social life (e.g., Bonis, 2016; Thomas et al., 2017), challenges that were intensified in mothers of children with AS (Giallo et al., 2016; Gill & Liamputtong, 2013). Mothers reported less maternal competence, describing a tendency to 'mask' their negative emotions for fear they may be seen as unfit for motherhood (Gill & Liamputtong, 2013). In one study focusing on mothers to adult female with AS, experiences of exhaustion and isolation were described, indicating to an intense protective involvement of the mothers in their daughters' life, and a profound concern for their future (Cridland et al., 2014).

Notwithstanding the challenges faced by parents to individuals with ASD or AS, some studies explored resilience and coping among these parents, describing the positive buffering effect of psychological resilience on parents' ability to cope with stress associated with raising a child with ASD (Halstead et al., 2018; Jack, 2016; Lawhorn, 2019; Pastor-Cerezuela et al., 2015). Resilient parents of children with ASD were more likely to achieve physical and mental health, and to preserve a positive outlook of their life (Kavaoliotis, 2017; Kuhaneck et al., 2015). Furthermore, the relationship between stress and resilience was found to bidirectional; resilience was found not only to promote the ability to cope with stress, it was also found to be enhanced by stress (Lawhorn, 2019; Manicacci, et al., 2019; Waizbard-

Bartov et al., 2019). Stress associated with raising a child with ASD prompts parents to find available inner and outer resources and to develop coping strategies in order to restore adequate family functions (Jack, 2016)

Studies on resilience among parents of children with ASD, found a variety of protective factors and coping strategies contributing to parental resilience. Both formal community and informal social support were reported as indicators of resilience (Cridland et al., 2014; Kavaoliotis, 2017). Community formal support (e.g., counselling) was found to positively correlate with parental coping, as well as accessing informal support, such as a friend to turn to in a time of need (Lawhorn, 2019), or parental support groups (Jack, 2016).

In addition to underscoring supportive social environment as facilitating resilience, studies found additional coping strategies implemented by parents to children with ASD such as cognitive, emotional, and meaning-making strategies. Cognitive strategies included problem-solving, solution seeking (Giallo et al., 2016; McConnell & Savage, 2015), and planning ahead (Jack, 2016). Emotional coping included, emotional intelligence, emotion regulation (Manicacci, et al., 2019). Meaning making strategies included reframing adversity (Jack, 2016), positive parental perception of the child and his future (Hobson et al., 2015; acceptance, parents' and family's belief (Thomas et al., 2017), and existential perspective (Waizbard-Bartov et al., 2018).

3. Research Method

This paper is theoretical and is based on a comprehensive review of previous scholarly reviews on relevant topics.

4. Analyses and Findings

The literature review revealed some significant gaps in current scholarly literature highlighted in the paper: first, the term Autism spectrum disorder (ASD) was used in many studies without a clear differentiation between AS, (ASD) or High functioning autism (HFA), despite significant functional differences between these groups and the resulting influences on the experiences of their parents. Second, when exploring the experience of parents, studies often investigated the experiences of both parent with less focus on mothers' experiences. Third, in most studies the experiences of parents' to young children were explored, while the experiences of parents to adults with AS in general and adult females with AS in particular did not receive extensive research attention. Fourth, studies on self-concept in parents (and particularly in mothers) to individuals with AS were not found to be common.

5. Conclusion

The current paper reviewed previous studies on ASD and on adult females with AS, delineating the distinct ways in which AS is expressed in females. It described the experiences of their parents, both parents' difficulties and resilience, and highlighted significant gaps in current scholarly literature.

5.1. Future research

In order to address the above-described gaps in scientific knowledge, a narrative study, which is one out of three PhD studies, is planned to be conducted in the next two years. Focusing specifically on the life experiences of mothers to adult daughters with AS, the study aims to explore mothers' negotiations of self-concept, challenges they face, and themes related to coping strategies and to of resilience, as these will emerge in their narratives.

Narrative research design, concerned with the structure, content, and function of the stories told in social interaction (Bamberg, 2020), was selected. Narrative was described as best suited for understanding the wholeness of individuals (Creswell, 2018), considered to reflect (as well as construct) self-concept and identity (Bamberg, 2020; Dunlop et al., 2016; Merino, et al., 2017; Spector-Mersel, 2017).

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