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The psychological and physical health of fathers of children with Autism Spectrum Disorder compared to fathers of children with long-term disabilities and fathers of children without disabilities



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ABSTRACT

Background: The psychological and physical health of fathers of children with Autism Spectrum Disorder (ASD) is under-researched. Due to the unique parenting demands, fathers of children with ASD may be at increased risk of experiencing psychological and physical health difficulties compared to fathers of children without disabilities (W/OD) and fathers of children with other long-term disabilities (LTD). What little research there is on fathers of children with ASD is often conducted on small clinical samples, or embeds the experiences of fathers within other groups. Aim: The current study aimed to explore the extent to which fathers of children with ASD experience psychological distress and physical health issues (e.g., general health, smoking, chronic pain) compared to fathers of children W/OD and fathers of children with a LTD.

Method: From a large, nationally representative sample of children, 159 fathers of children with ASD were identified, along with 45 fathers of children with a LTD and 6578 fathers of children W/OD.

Results: The majority of fathers were experiencing good psychological and physical health. Approximately 1 in 6 fathers of children with ASD were experiencing elevated levels of psychological distress and poor global health, and were at significantly greater risk than fathers of children W/OD; although these differences were not found compared to fathers of children with a LTD.

Conclusions: Some fathers of children with ASD may require additional support which not only focuses on their psychological wellbeing but also fathers' physical health. The current findings encourage health services to check-in with, or reach-out to fathers as they too may require additional support.

What this paper adds

Little is known about the psychological and physical health of fathers of children with Autism Spectrum Disorder (ASD). Small sample sizes are an inherent limitations when researching specific disorders, this is also true when recruiting fathers into research. The majority of research related to fathers of children with ASD has focused on small clinical samples with children experiences elevated ASD symptomology and/or behavioural difficulties; these fathers may be experiencing increased demands and distress. This paper adds important foundation knowledge to the scarcity of existing research on fathers of children with ASD by addressing these

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limitations by drawing on data from a nationally representative sample of Australian families. The findings from the current study highlight that fathers of children with ASD are at increased risk of experiencing psychological and physical health issues compared to fathers of children without disabilities.

1. Introduction

One in 10 fathers in the general population experience persistent psychological distress (e.g., stress, anxiety, depression) (Bronte-Tinkew, Moore, Matthews, & Carrano, 2007; Giallo, Cooklin, Wade, D'Esposito, & Nicholson, 2014; Madsen, 2009; Paulson & Bazemore, 2010). Fathers of children with a disability, in particular Autism Spectrum Disorder (ASD) are a specific group of fathers who may be at greater risk of experiencing psychological distress than fathers from the general population. A diagnosis of ASD often results in uncertainty for parents about their child's future, major changes to family routine, along with intensive care and treatment programs (Cheuk & Lashewicz, 2015; Gray, 2002). Within developed countries, the incidence and prevalence of ASD is on the rise (Australian Bureau of Statistics [ABS], 2014; Elsabbagh et al., 2012). Consistent with international estimates, 0.8% of Australian male and 0.2% Australian female children had a diagnosis of ASD in 2012; with a marked peak in prevalence for children aged 5–9 years (ABS, 2014). Parents of children with ASD often provide long-term functional care to their children and these responsibilities may become burdensome, impacting physical and mental health (Malhotra, Khan, & Bhatia, 2012). However, there is a relative lack of research on the wellbeing and experiences of fathers compared to that for mothers (Braunstein, Peniston, Perelman, & Cassano, 2013).

Internationally, very few studies have reported the prevalence of psychological distress for fathers of children with ASD. An American study found that approximately 30% of fathers (N=135) of adolescents and young adults with ASD reported clinically significant depressive symptoms (Hartley, Seltzer, Head, & Abbeduto, 2012). While in the UK, Hastings and Brown (2002) found that approximately 15% of fathers (N=20) of children with ASD (mean age = 12.15 years) experienced elevated symptoms of depression and 25% experienced elevated levels of anxiety. Furthermore, in Griffiths et al.'s (2011) UK based study on parent wellbeing, 33% of fathers (N=7) of children with ASD (aged 3–15 years) experienced elevated levels of anxiety. However, these findings are based on very small clinical samples (e.g., children living in residential care or displaying daily aggressive/self-injurious behaviour). These findings may therefore only apply to families whose children display frequent challenging behaviour along with parents who are concerned about their child's needs and committed to seeking support.

Australian research focused on fathers of children with ASD is limited. Early intervention and disability support services in Australia are primarily focused on children and mothers. A better understanding of the extent to which fathers of children with ASD experience health and wellbeing issues will help inform appropriate support for fathers. A recent study of 315 fathers of children with an intellectual disability (45% comorbid ASD) found that 28% experienced elevated depressive symptoms, 17% reported elevated symptoms of anxiety, and a third experienced elevated symptoms of stress (Giallo et al., 2015). These findings were based on fathers participating in a parenting program to manage difficult child behaviour. Again, this sample might be more representative of a particular group of fathers concerned about their children and motivated to seek professional support compared to fathers of children with ASD from the general community. Additionally, no comparison sample of fathers of children without disabilities (W/OD) was provided

Parents of children with ASD report greater psychological distress than parents of children W/OD (Benjak, Vuletić Mavrinac, & Pavić Šimetin, 2009; Giallo et al., 2015; Herring et al., 2006; Kuusikko-Gauffin et al., 2013). For example, Herring et al. (2006) found that 12-months post child diagnosis, fathers of children with ASD reported significantly more stress than fathers of children W/OD. Furthermore, in Giallo et al.'s (2015) study, fathers of children with an intellectual disability (45% comorbid ASD) experienced significantly more symptoms of depression and stress compared to Australian normative data.

Research also suggests that parents of children with ASDs are more likely to experience greater psychological distress than parents of children with other developmental, genetic, and physical disabilities (e.g., Fragile X, cystic fibrosis, developmental delay, Down Syndrome) (Bouma & Schweitzer, 1990; Dabrowska & Pisula, 2010; Eisenhower, Baker, & Blacher, 2005; Estes et al., 2009; Micali, Chakrabarti, & Fombonne, 2004). Dabrowska and Pisula (2010) found that parents of children with ASD (mothers N = 26; fathers N = 25) reported higher levels of stress than parents of children with Down syndrome (mother N = 27; fathers N = 27) and children W/OD (mother N = 28; fathers N = 29). Furthermore, Hartley et al. (2012) found that fathers of adolescents with ASD (N = 135) reported significantly higher levels of depressive symptoms than fathers of children with Down syndrome (N = 59) and fathers of children with Fragile X syndrome (N = 46).

While there is a small but growing body of research regarding the mental health of fathers of children with ASD, there is comparatively less research concerning the prevalence of more general health issues (e.g., physical health, smoking, alcohol misuse). Children with ASD often require increased care and vigilance, meaning that parents might get little or disrupted sleep, rest and/or time to relax, which is likely to result in a reduction of physical resources. Physical health is important for parents of children with ASD as they need to be in good health in order to continue to meet the demands of raising a child with a disability along with the competing demands of life in general (Schor, 2003). Benjak et al. (2009) found that parents of children with ASD reported significantly poorer self-perceived health (e.g., chronic medical conditions, lethargy, pain) than parents of children W/OD. However, the experiences of fathers were embedded within those of mothers.

Health and wellbeing may differ in important ways for fathers and mothers of children with ASD. Drawing on research into the differences between males and females, there is evidence that men might experience, express, and respond to psychological distress differently than females; possibly through more externalising symptoms (e.g., poor physical health, chronic pain, drug and alcohol abuse) (Addis, 2008). Men are also less likely to seek help and professional support than females (AIHW, 2010; Smith, Braunack-

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