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The association between behavioural and emotional problems and age in adults with Down syndrome without dementia: Examining a wide spectrum of behavioural and emotional problems

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ABSTRACT

The literature on the association between behavioural and emotional problems and ageing in adults with Down syndrome (DS) without dementia is limited and has generally not reported on a wide range of behavioural and emotional problems. This research aimed to extend the field by examining the associations between age and a wide spectrum of behavioural and emotional problems in adults with DS without dementia. A preliminary analysis of the association between potential covariates and behavioural and emotional problems was also undertaken.

Parents and caregivers completed a questionnaire on behavioural and emotional problems for 53 adults with DS aged between 16 and 56 years. Twenty-eight adults with DS and their caregivers were part of a longitudinal sample, which provided two time points of data approximately four years apart. Additionally, 25 participants with DS and their caregivers were from a cross sectional sample, which provided one time point of data. Random effects regression analyses were used to examine the patterns in item scores for behavioural and emotional problems associated with age.

No significant associations between age and the range or severity of any behavioural and emotional items were found. This suggested a more positive pattern for ageing adults with DS than has been previously described. Given that behavioural and emotional problems were not associated with age, investigation into other factors that may be associated with the behavioural and emotional difficulties for adults with DS is discussed.

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1. Introduction

Down syndrome (DS) is one of the most common genetic disorders associated with intellectual disability (ID; Fidler & Nadel, 2007; Nadel, 2003; Silverman, 2007), and has a complex cognitive, adaptive, neurobiological and behavioural phenotype (AAIDD, 2010; Di Nuovo & Buono, 2011; Rachidi & Lopes, 2007). It is suggested in the contemporary literature that the DS phenotype is generally not stable across the lifespan, but rather it changes with ongoing development and ageing (Couzens, Cuskelly, & Haynes, 2011; Dykens, Hodapp, & Evans, 2006). Given these possible developmental phenotypic changes, research on trajectories is generally considered more fruitful for understanding genetic syndromes than are studies that focus only on a particular age group (Cornish, Bertone, & Scerif, 2012; Elsabbagh & Karmiloff-Smith, 2012). Cognitive (Burt et al., 1995; Cornish, Scerif, & Karmiloff-Smith, 2007), biological (Berger-Sweeney, 2003; Pietrini et al., 1997) and adaptive behaviours (Esbensen, Seltzer, & Krauss, 2008; Hawkins, Eklund, James, & Foose, 2003) in people with DS are often studied within a developmental trajectory framework.

Less research focus has, however, been placed on the trajectory of behavioural and emotional problems in individuals with DS. This is surprising given the growing literature on such trajectories of people with ID syndromes in general (e.g. Day & Jancar, 1994; Deb, Thomas, & Bright, 2001; Einfeld & Tonge, 1996). For ID syndromes in general, while some population-based studies suggest no associations (Cooper, Smiley, Finlayson, et al., 2007; Cooper, Smiley, Morrison, Williamson, & Allan, 2007a; Cooper, Smiley, Morrison, Williamson, & Allan, 2007b; Einfeld & Tonge, 1996) or positive associations (Deb et al., 2001) between behavioural and emotional problems (and psychiatric diagnoses) and age, a number of papers also report decreases in such symptomology from adolescence to older age. Specifically, population-based studies have generally described significant decreases in the levels of behavioural and emotional problems associated with ageing for people with ID from adolescence into early (e.g. until 23 years of age; Einfeld et al., 2006) and then later adulthood (e.g. until 86 years of age; Day & Jancar, 1994; Mohr, Tonge, Einfeld, & Taffe, 2011; Pennington, 2010; Taylor, Hatton, Dixon, & Douglas, 2004).

The paucity of behavioural and emotional research focusing specifically on trajectories of people with DS may in part be due to the mistaken view that individuals with DS mostly enjoy positive behavioural outcomes. While it is true that DS is associated with lower rates of behavioural and emotional problems (i.e. a prevalence of 0.6%; Mantry et al., 2008) when compared to other intellectual disability syndromes (Haveman, Maaskant, Van Schrojenstein Lantman, Urlings, & Kessels, 1994; Jones et al., 2008), the DS prevalence of such problems (point prevalence estimated at 23.7%; Mantry et al., 2008) still remains significantly higher than that of the typically developing population (Coe et al., 1999; Dykens, 2007; Einfeld, Tonge, Gray, & Taffe, 2007). Moreover, given the significant impact that these behavioural and emotional problems can have for people with DS including: distress, higher caregiver burden (McIntyre, Blacher, & Baker, 2002), lower quality of life (Esbensen et al., 2008), and reduced cognitive, educational and adaptive behavioural outcomes (Ball, Holland, Watson & Huppert 2010; Burt et al., 2005; Myers & Pueschel, 1995), further research and clinical attention is warranted.

Depression is generally the most common symptomology (5.2% incidence; Mantry et al., 2008) reported for people with DS (Collacott Cooper, & McGrother, 1992; Myers & Pueschel, 1991). Despite earlier reports of higher levels of depression for people with DS when compared to other ID syndromes, recent analyses suggest that depression rates for those with DS are actually lower than in other ID disorders (Walker, Dosen, Buitelaar, & Janzing, 2011). Problem behaviours (3.7% incidence), notably non-compliance and stubbornness, as well as anxiety (1.5% incidence) are also common symptomology noted in both clinical and epidemiological studies for DS (Mantry et al., 2008). These studies (e.g. Collacott, et al., 1992; Mantry et al., 2008; Myers & Pueschel, 1991) are limited, however, in that they have not specifically evaluated the trajectories (or age associations) of behavioural and emotional problems for any developmental period in people with DS. Indeed, such developmental trajectory research is necessary if people with DS are to be provided with appropriate behavioural and emotional supports specific to their needs across all stages of the lifespan. The handful of studies that have examined behavioural and emotional problems and trajectories (or age associations) of young people with DS mostly depict the transitions from childhood to adolescence and young adulthood (e.g. until 18–20 years of age) and are broadly consistent with the findings for young people with ID in general (e.g. Einfeld et al., 2006). Specifically, these paediatric developmental studies indicated higher levels of externalising symptoms (Coe et al., 1999; Dykens, Shah, Sagun, Beck, & King, 2002; Einfeld et al., 2007; Myers & Pueschel, 1991), anxiety (Coe et al., 1999; Einfeld et al., 2007; Myers & Pueschel, 1991), and repetitive behaviours during the childhood years (Coe et al., 1999; Myers & Pueschel, 1991). Throughout adolescence the levels of externalising symptoms and anxiety have been noted to decrease (Dykens, 2007; Einfeld et al., 2007; Myers & Pueschel, 1991). The adolescent trajectory of depression is unclear, with some studies reporting unchanged levels over time (Einfeld et al., 2007), while others describe increases in symptomology (Dykens et al., 2002; Myers & Pueschel, 1991).

More recently, research focusing on the trajectories of behavioural and emotional problems throughout adulthood for people with DS has appeared in the literature. Impetus for this research is likely a result of the significantly increased life expectancy (from 12 to 60 years of age) for people with DS over the last two generations (Bittles, Bower, Hussain, & Glasson, 2007) and the need to care for and support older adults with DS. At present, a particularly popular area of adult DS research relates to the pathological ageing trajectory, where investigation into the behavioural and emotional features associated with early stages of dementia and then subsequent progression are conducted (Adams et al., 2008; Ball et al., 2006; Ball, Holland, Treppner, Watson, & Huppert, 2008; Gregory & Hodges, 1993; Nelson, Orme, Osann, & Lott, 2001; Urv, Zigman, & Silverman, 2003). Given evidence that now refutes the inevitability of dementia in people with DS (Contestabile, Benfenati, & Gasparini, 2010; Head, Lott, Patterson, Doran, & Haier, 2007; Holland, Hon, Huppert, Stevens, & Watson, 1998; Zigman, Silverman, & Wisniewski, 1996), the study of the healthy ageing trajectory of adults with DS (assumed if the individual fails