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Prevalence and associated factors of problem behaviours among older adults with intellectual disabilities in Ireland

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ABSTRACT

A growing number of adults with intellectual disabilities (ID) are reaching old age, however, little is known about epidemiology of problem behaviours (PBs) in this population. The aim was to identify the prevalence and associated factors of PBs among older adults with ID in Ireland. Data was generated from Wave 2 of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA), a nationally representative sample of adults with ID aged ≥40. Data on PBs was available for 683 (98.3%) of individuals. Over half (53%; $n = 362$) reported displaying any PB (verbal aggression, physical aggression, destruction, self-injury, or "other" PB). Multivariate analyses indicated PBs were independently associated with moderate or severe/profound ID, living in a community group home or residential centre, experiencing a greater number of life events in the last year, taking psychotropic medication, and reporting a doctor's diagnosis of a psychiatric problem. A considerable number of older adults with ID in Ireland display PBs, which may hinder their opportunities to engage in community based activities and form meaningful social connections. High rates of psychotropic medication and doctor's diagnosis of psychiatric conditions and their associations with PBs were highlighted. Future research should examine mechanisms underlying these linkages.

What this paper adds

This is the first study to investigate the epidemiology of problem behaviours in older adults with intellectual disabilities (ID) specifically. Approximately five in ten older adults with ID in Ireland were reported to display at least one form of problem behaviour. Verbal aggression was the most frequently reported behaviour, and the majority of those who displayed problem behaviours reported engaging in two or more types of behaviours. These findings indicate that the prevalence and types of problem behaviours in older adults with ID are similar to those reported for adults with ID. However, methodological differences and variations in criteria used to define problem behaviours make it difficult to compare across studies. Independent associations were found between problem behaviours and living in a residential setting or community group home, receiving psychotropic medication and having a doctor's diagnosis of a psychiatric condition. Findings indicate that factors associated with problem behaviours in older adults with ID span across the personal, lifestyle and support, and mental health domains. The association between experiencing a greater number of life events and displaying problem behaviours is a unique finding in an epidemiological study. Whether this association is unique to older

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adults with ID warrants further investigation.

1. Introduction

Problem behaviours remain an obstacle to community integration for adults with intellectual disabilities (Cooper, Smiley, Jackson et al., 2009; Crocker et al., 2006), are a leading cause of placement breakdown and subsequent re-institutionalisation, and can be detrimental to social participation even within already restrictive residential environments (Emerson & Einfeld, 2011). People displaying problem behaviours may also be subject to aversive practices such as use of physical and mechanical restraints (Heyvaert, Saenen, Maes, & Onghena, 2015) or prescription of 'off-label' psychotropic medication (Sheehan et al., 2015). Family, staff, and co-residents of those who display these behaviours are at risk of physical injury, mental health difficulties, stress, and burnout (Hastings & Brown, 2002; Smyth, Healy, & Lydon, 2015).

Despite their significant impact, the prevalence and associated factors of problem behaviours are not fully understood (Cooper, Smiley, Jackson et al., 2009; NICE, 2015), particularly among older adults with intellectual disabilities (ID). Adults with ID are experiencing increased longevity and in Ireland by 2020 the number of older adults with ID aged 65 and over is expected to double from estimates made in the 1990s (Kelly & Kelly, 2013). However, this increase is accompanied by a paucity of empirical and professional knowledge regarding the unique obstacles facing this ageing population (McCallion & McCarron, 2004). A poorer physical health profile and increased prevalence of mental health problems and dementia (Burke, McCallion, & McCarron, 2014; McCarron et al., 2011), may mean that epidemiology of problem behaviours in this population could vary from that reported for younger adults and children.

Reported prevalence rates of problem behaviours vary considerably. Rates of between 5–15% have been reported for severe or demanding behaviours (Cooper, Smiley, Allan et al., 2009; Cooper, Smiley, Jackson et al., 2009; Emerson et al., 2001; Holden & Gitlesen, 2006; Lowe et al., 2007; Tyrer et al., 2006), with this figure rising to 45–62% for milder or less frequent behaviours (Crocker et al., 2006; Deb, Thomas, & Bright, 2001; Grey, Pollard, McClean, MacAuley, & Hastings, 2010; Lundqvist, 2013). The wide variations may be due to differences in sample characteristics, the types and range of behaviours investigated and, most notably, the criteria used to define problem behaviours (Cooper, Smiley, Jackson et al., 2009). Most studies have focused on behaviours which are severe and frequent in nature. However, less severe behaviours such as milder forms of aggression may have a negative impact on a person's interpersonal relationships, and limit opportunities to engage in social and educational activities within the community (Crocker et al., 2006; Lowe et al., 2007).

The aetiology of problem behaviours is not fully understood, but a number of interacting personal, lifestyle and support, mental health, and physical health factors are likely to underlie their presence (Cooper, Smiley, Allan et al., 2009; Cooper, Smiley, Jackson et al., 2009; Lundqvist, 2013; NICE, 2015). There is robust evidence indicating a relationship between displaying problem behaviours and having a more severe ID, living in congregated or residential settings, and not having Down syndrome (e.g., Cooper, Smiley, Allan et al., 2009; Cooper, Smiley, Jackson et al., 2009; Crocker et al., 2006; Lowe et al., 2007; Lundqvist, 2013). However, the relationships between problem behaviours, mental and physical health factors, and experiencing adverse life events remain poorly understood (de Winter, Jansen, & Evenhuis, 2011; Grey et al., 2010).

Most prior epidemiological studies have investigated bivariate relationships between problem behaviours and their associated factors, therefore not taking into account overlap or interaction between factors. However, three population-based studies in the UK (Cooper, Smiley, Allan et al., 2009; Cooper, Smiley, Jackson et al., 2009; Tyrer et al., 2006) and one in Sweden (Lundqvist, 2013) used multivariate analysis to further investigate associated factors of problem behaviours comparing individuals who did and did not display problem behaviours. Cooper, Smiley, Jackson et al. (2009) and Cooper, Smiley, Allan et al. (2009) reported having a more severe level of ID, Attention-Deficit-Hyperactivity-Disorder (ADHD), not living with family, and not having Down syndrome were independently associated with both aggressive and self-injurious behaviours (SIB) in a population based sample of 1023 adults in Scotland. Lundqvist (2013) found that having more severe ID, autism, night sleep disturbances, poor communicative abilities, social deficits, psychiatry involvement and psychotropic medication were the most pronounced risk markers in his sample of 915 adults with ID aged 18–87 years. Finally, Tyrer et al. (2006) reported that more severe ID, younger age, male gender, living in institutional settings, not having Down syndrome, and symptoms of mood swings and frustration independently contributed to physical aggression in a sample 3062 adults with ID aged 19–92 years.

However, to date no epidemiological study has investigated prevalence and associated factors of problem behaviours in older adults specifically. Establishing accurate information on prevalence is crucial in order to ensure resources are in place to support these older adults in community settings. Identifying associated factors will mean those who are at greatest risk may be identified and targeted for early intervention (Emerson & Einfeld, 2011). Such information may also be used in the development of evidence-based interventions. This is of particular importance given that psychotropic medication continues to be the leading treatment, despite a lack of evidence base, and ethical issues regarding its use in the absence of a psychiatric condition (Deb, Unwin, & Deb, 2015; Sheehan et al., 2015).

The aim of this study, therefore, was to identify prevalence and associated factors of problem behaviours among older adults with an intellectual disability in Ireland. The aim was achieved by addressing two specific objectives;

1 To identify the prevalence of verbal aggression, physical aggression, destructive behaviour, self-injury, and "other" problem behaviours
2 To determine personal, lifestyle and support, mental and physical health factors associated with problem behaviours

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