Psychiatric Conditions Prevalent Among Adults With Down Syndrome

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Abstract

The authors assessed available prevalence information regarding neuropsychiatric conditions among adults with Down syndrome (DS) and compared these findings among adults with other intellectual disability (non-DS). The study entailed a survey of 291 adults with DS living in Ohio (USA). Twenty-three percent of adults with DS reported having a co-occurring psychiatric disorder, a smaller than the reported occurrence of such conditions in the general adult intellectual disability population. Depression, anxiety disorders, and dementia or Alzheimer's disease were the most frequently reported neuropsychiatric disorders by adults with DS. The likelihood of experiencing a psychiatric disorder increased with age but did not vary by sex among adults with DS. Lower rates of problem behavior were reported in adults with DS compared to adults with intellectual disability (non-DS). The authors’ findings indicate that adults with DS may present different rates and types of co-occurring psychiatric disorders than the larger population of adults with other intellectual disability. These findings warrant additional research and could provide critical information for planning and intervention.

Keywords: Down syndrome, health, intellectual disability, mental health, neuropsychiatric conditions, trisomy 21

Introduction

Individuals with intellectual disability (ID) can experience any of the existing mental health disorders found in the DSM-5 (American Psychiatric Association, 2013) or International Classification of Diseases (World Health Organization, 2001). In fact, research has established that persons with ID are at much higher risk of experiencing these problems than persons in the general population (Dykens, 2007; Reiss, 1994; Tassé, Bertelli, Kates, Navas & Simon, in press). Some authors (Cooper, Smiley, Morrisson, Williamson, & Allan, 2007; Emerson, 2003) have estimated the point prevalence of so-called dual diagnosis to be approximately 15%–40% depending on which diagnostic system is used (see e.g., Mantry et al., 2008). However, the prevalence of mental health problems in those with mild limitations in intellectual functioning and who are in essence not known to the developmental disability service delivery system remains difficult to ascertain (Cooper et al., 2007). In a recent population-based study, Morgan, Leonard, Bourke, and Jablenski (2008) estimated that 32% of the individuals with ID, including borderline intellectual functioning, had a psychiatric disorder.

Higher prevalence of mental health disorders in individuals with ID has been associated with life stressors such as social exclusion, stigmatization, institutionalization, lack of social support, and exposure to negative life events (Cooper et al., 2007; Hulbert-Williams et al., 2014; Martorell & Tsakanikos, 2008). This, along with biological vulnerability, increases the risk of psychiatric disorders in this population group. Anxiety and depression are the most prevalent psychiatric disorders within the adult population with ID (Dykens, 2007; Emerson, Baines, Allerton & Welch, 2011; White, Chant, Edwards, Townsend, & Waghorn, 2005) and prevalence of schizophrenia has been reported to be three times higher than the general population lifetime estimates (Morgan et al., 2008). Prevalence of major depression seems to increase in old age among adults with ID but not for the elderly without ID (Hermans, Beekman, & Evenhuis, 2013) which has led to identification of the exacerbating impact of comorbidity of mental health/neurological disease in adults with ID (McCarron et al., 2010).

The diagnostic process of mental health disorders in persons with ID is complicated by factors such as the frequently recognized “diagnostic overshadowing” (Reiss, Levitan, & Szyszko, 1982), where clinicians show a tendency to minimize the significance of emotional disorders and misattribute these signs and symptoms to the intellectual disability itself. It is possible that the presence of Down syndrome (DS) could mask mental health signs and symptoms. People with ID may be less able to report on psychiatric signs and symptoms due to acquiesce bias,
difficulty with abstract concepts, and difficulty placing events and emotions in a temporal context (Finlay & Lyons, 2001). In addition, individuals with intellectual and developmental disabilities who have a diagnosed psychiatric disorder report difficulty accessing mental health care services in the community (Ward, Nichols, & Freedman, 2010). Diagnosing psychiatric disorders in individuals with ID and providing effective treatments continue to be challenging, thus justifying the continued need for research in the area of mental health and ID.

Although the United Nations Convention on the Rights of Persons with Disabilities identifies health as a key factor leading to increased independence and quality of life (United Nations, 2006), individuals with developmental disabilities (DDs) continue to report poorer health outcomes, increased secondary conditions, poor access to preventive health services, and a lack of routine health care compared to individuals without disabilities (Drainoni et al., 2006; Duggan, Bradshaw, & Altman, 2010; Minihan et al., 2011; Pharr & Bungum, 2012).

Down Syndrome and Mental Health

Life expectancy of individuals in the US with DS has increased by 456% between 1960 and 2007 (Presson et al., 2013). Because of this dramatic increase in life span, persons with DS will likely be confronted the same chronic health conditions associated with aging as those faced by others in the general population (Fishier, 2004), including mental health problems. Although bipolar disorder and schizophrenia have been reported as relatively less common in adults with Down syndrome (Dykens, 2007; Mantry et al., 2008; Morgan et al., 2008), conditions such as depressive mood, anxiety disorders (Mantry et al., 2008; Haveman et al., 2010; Stancliffe et al., 2012), and Alzheimer’s disease (Chapman & Hesketh, 2000; Emerson et al., 2011; Haveman et al., 2010; Holland, Hon, Huppert & Stevens, 2000) are reportedly more prevalent in persons with DS than the general population and others with intellectual disability of etiologies other than DS.

Despite these rates, some studies have reported on the undertreatment of depression in DS (Walker, Dosen, Buitelaar, & Janzing, 2011) and the challenges associated with the reliable identification of Alzheimer’s disease (Bishop et al., 2015; Määttä et al., 2011). Individuals with co-occurring DS and mental health problems have faced obstacles to accessing effective mental health services. Some researchers have attributed part of these challenges to the fragmentation of the service delivery system between the ID/DD and mental health services (Määttä et al., 2011; Morgan et al., 2008), which also contributes to the underestimation of the prevalence of “dual diagnosis” (Morgan et al., 2008).

The aim of this article is to contribute to our understanding of the mental healthcare needs of adults with DS by examining and comparing the prevalence and types of mental health and behavior problems they experience as well as their type of health insurance and access to services and compared to adults with ID (without DS). To accomplish this, we present data from an online survey we obtained on 291 adults with DS and compared this information to existing data from a comparable random sample of 370 adults with ID (without DS) receiving DD services drawn from the National Core Indicators (NCI) survey 2012–13.

Methods

Participants

A total of 291 adults with DS and 370 adults with ID (without DS) were identified from two different databases (online health survey and NCI). Sociodemographic characteristics for both samples are shown in Table 1. Chi-square tests were computed to compare groups on their demographic characteristics. Chi-squares were not computed in situations where there were fewer than five cases.

The sample of individuals with DS was composed of 154 (52.9%) men and 137 (47.1%) women. Consistent with previous findings (Esbensen, Mallick, & Krauss, 2008; Shin et al., 2009), a slightly higher proportion of adults with DS were male, but no statistically significant differences were found for sex between the DS and ID groups.

The age of the adults with DS ranged from 18 to 79 years old ($M = 33.7, SD = 12.5$). The analysis of the Pearson standardized residuals showed that the proportions of men and women by different age groups (i.e., 18–24, 25–34, 35–44, 45–54, 55–64, +65) were equiprobable: $\chi^2 (5, N = 291) = 6.511, p = .260$. As expected, due to the lower life expectancy of individuals with DS, age distribution was slightly skewed with a skewness of .78 (SE = .14).The chronological age of the adults with ID (without DS) ranged from 18 to 97 years old ($M = 44.1, SD = 14.3$). Individuals with ID were significantly older than the DS group (Table 1).

Most cases of DS (74%) were reported to result from trisomy 21. Four percent ($N = 11$) reported either a chromosomal translocation or mosaicism (2.1%) and the remaining 19.9% ($N = 58$) did not know the chromosomal cause for the DS. These rates are very similar to those previously reported (Chapman & Hesketh, 2000). A majority of participants with DS presented either mild (20.3%) or moderate (64.9%) ID. Data about level of ID was missing for one participant with DS (<1.0%) and 11 participants with ID (without DS; 3.0%). No significant association was found between gender and level of ID. Compared to those with ID (without DS), the odds for those with DS to present moderate ID was $3.784, p < .001, 95\% CI [2.731, 5.245].

As reported by Stancliffe and his colleagues (2012) a large majority (71.5%) of adults with DS live with their parents or other family members. Although a large percentage of persons with ID (without DS) also reported living with their parents or relatives, they were significantly less likely than adults with DS to be living with a family member and more likely to be living independently or in a group home (Table 1).

Instruments

Down syndrome online health survey. Data about mental health and access to mental health services of adults with DS living in Ohio were obtained through an online health questionnaire. Health information was collected between July 2011 and May 2013. The questions were written in such a manner as to allow us direct comparisons with responses on the National Core Indicators (NCI) survey undertaken in Ohio in 2012–13.
We will review a subset of the questions on this online survey. The entire survey included questions addressing: (1) current mental health problems, (2) presence of problem behavior, (3) health insurance, and (4) access to mental health services. All data from the online health survey were collected anonymously, with no personal health identifiers. Completion of the online health questionnaire implied consent. The survey was completed in most cases (70%) by a parent of the adult with DS, and the adult with DS completed the survey by himself/herself in 6.5% (N=19) of the cases. The remainder of responses was provided through a direct-support staff or other adult caregiver.

Ohio’s national core indicators. The healthcare data of adult Ohioans with ID were obtained from the NCI 2012–13 Consumer Survey. The NCI Consumer Survey is composed of a series of questions aimed at collecting information regarding various outcome indicators of individuals with DDs. The NCI includes approximately 150 consumer, family, system, and health and safety outcomes indicators that measure the performance of ID/DD services across States (National Core Indicators, 2012). Face-to-face interviews with the person receiving services and proxy respondents were conducted and demographic and health service information was provided from the case file. Sample selection was randomized and usually limited to those individuals receiving at least one service from the State department of developmental disability. Although there could be imperfect agreement between individuals with ID and proxy respondents (Lunsky, Emery, & Benson, 2002) good inter-rater agreement and test-retest reliability has been reported (National Core Indicators, 2012; Smith & Ashbaugh, 2001). Individuals identified as having DS in the NCI 2012–13 (N=48) were excluded from the NCI “intellectual disability” (ID) group to avoid data conflation.

Procedure

Participants with DS were contacted through various disability organizations and service providers established in Ohio such as the Down Syndrome Association of Central Ohio (DSACO), DownSyndrome Achieves, Franklin County Board of Developmental Disabilities Support Service Administrators, and other Down syndrome associations across the state. Information was also sent out through the aforementioned organizations and other Down syndrome groups’ newsletters, listserv announcements, blogs, websites, and conference announcements. These advertisements provided a URL Link to the Survey Monkey-hosted health questionnaire. Information regarding the health status of adults with ID (without DS) living in Ohio was drawn from the NCI survey 2012–13.

We obtained all appropriate approvals from The Ohio State University Human Subjects Institutional Review Board.

Data Analysis

Chi-square tests were used to assess differences in categorical variables. Means and standard deviations were computed for

TABLE 1
Sociodemographic characteristics of individuals with DS and ID due to other etiologies

<table>
<thead>
<tr>
<th></th>
<th>DS (N=291)</th>
<th>ID (N=370)</th>
<th>(\chi^2)</th>
<th>(p^a)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Males</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18–24</td>
<td>85 (29.2%)</td>
<td>30 (8.1%)</td>
<td>(\chi^2(1) = 50.470)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>25–34</td>
<td>90 (30.9%)</td>
<td>77 (20.8%)</td>
<td>(\chi^2(1) = 8.830)</td>
<td>&lt;.01</td>
</tr>
<tr>
<td>35–44</td>
<td>48 (16.5%)</td>
<td>87 (23.5%)</td>
<td>(\chi^2(1) = 4.937)</td>
<td>&lt;.05</td>
</tr>
<tr>
<td>45–54</td>
<td>48 (16.5%)</td>
<td>83 (22.4%)</td>
<td>(\chi^2(1) = 3.614)</td>
<td>&gt;.05</td>
</tr>
<tr>
<td>55–64</td>
<td>18 (6.2%)</td>
<td>69 (18.6%)</td>
<td>(\chi^2(1) = 22.137)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>&gt;65</td>
<td>2 (.7%)</td>
<td>23 (6.2%)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Severity of ID**

<table>
<thead>
<tr>
<th></th>
<th>DS (N=291)</th>
<th>ID (N=370)</th>
<th>(\chi^2)</th>
<th>(p)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild ID</td>
<td>59 (20.3%)</td>
<td>156 (42.2%)</td>
<td>(\chi^2(1) = 38.332)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Moderate ID</td>
<td>189 (64.9%)</td>
<td>118 (31.9%)</td>
<td>(\chi^2(1) = 67.153)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Severe ID</td>
<td>34 (11.7%)</td>
<td>47 (12.7%)</td>
<td>(\chi^2(1) = .275)</td>
<td>&gt;.05</td>
</tr>
<tr>
<td>Profound ID</td>
<td>2 (.7%)</td>
<td>38 (10.3%)</td>
<td></td>
<td>&gt;.05</td>
</tr>
</tbody>
</table>

**Living arrangement**

<table>
<thead>
<tr>
<th></th>
<th>DS (N=291)</th>
<th>ID (N=370)</th>
<th>(\chi^2)</th>
<th>(p)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents/relatives</td>
<td>208 (71.5%)</td>
<td>162 (43.8%)</td>
<td>(\chi^2(1) = 50.695)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Independent home</td>
<td>17 (5.8%)</td>
<td>74 (20%)</td>
<td>(\chi^2(1) = 27.504)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Agency-operated apartment</td>
<td>10 (3.4%)</td>
<td>13 (3.5%)</td>
<td>(\chi^2(1) = .003)</td>
<td>&gt;.05</td>
</tr>
<tr>
<td>Foster care</td>
<td>2 (.7%)</td>
<td>7 (1.9%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group home</td>
<td>21 (7.2%)</td>
<td>82 (22.2%)</td>
<td>(\chi^2(1) = 27.660)</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>ICF-DD facility</td>
<td>23 (7.9%)</td>
<td>27 (7.3%)</td>
<td>(\chi^2(1) = .086)</td>
<td>&gt;.05</td>
</tr>
<tr>
<td>Nursing facility</td>
<td>2 (.7%)</td>
<td>5 (1.45)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*DS, Down syndrome; ID, intellectual disability.*
continuous variables. Differences in continuous variables were examined using Mann–Whitney U test when deviations from normality were detected.

Chronological age groups identified in the DS online survey and the NCI (i.e., 18–24, 25–34, 35–44, 45–54, 54–64, >64) were combined (i.e., 18–34, 35–54, >54) to make sure that expected frequencies in each cell were greater than 1 and no more than 20% had fewer than five cases (e.g., only two individuals with DS were older than 65 years old).

Results

Down Syndrome and Mental Health Status

Sixty-five individuals in the DS sample (22.3%) reported having a psychiatric diagnosis made by a healthcare professional. These results are similar to those reported by Mantry et al. (2008) with the overall rate of co-occurring psychiatric problems being 23.7%. Among those with a dual diagnosis, 36 individuals (59%) had more than one psychiatric condition.

Taking into account only those individuals with DS whose level of intellectual functioning was known and excluding those with dementia or Alzheimer’s disease (260 of 291), levels of ID were equally distributed between groups (dual diagnosis vs. no psychiatric diagnosis): \( \chi^2(3, N = 260) = 3.289, p = .349 \). These results are contrary to those reported by Morgan et al. (2008) who found that individuals with a dual diagnosis were significantly more likely to have IQ levels in the borderline and mild ranges.

As reported in other studies (Stancliffe et al., 2012), most adults with DS were living in their parent’s or other family member’s home (71.5%). However, the individuals with a psychiatric condition were less likely to be living in a family member’s home than those with DS only (59.1% vs. 77.1%). Although the percentage of individuals living in other residential settings, such as an Intermediate Care Facility for persons with ID (ICF-ID), was small (6.6% or \( N = 18 \)), adults with DS and a co-occurring psychiatric diagnosis were five times more likely to live in an ICF-ID (20.5% vs. 3.9%; \( \chi^2(1, N = 274) = 16.465, p < .001 \); OR = 5.227, 95% CI [2.199, 12.425]). The small group of individuals living in an ICF-ID facility prevented a detailed analysis of other variables that might explain this type of living arrangement, such as chronological age or level of ID.

No statistically significant differences were found between individuals with DS with vs. without a dual diagnosis regarding employment status: 51.2% and 54.1% reported having some type of job, respectively (\( p = .805 \)). It should be noted that these jobs included work within a sheltered workshop.

Among the different reported psychiatric disorders, participants with DS reported most frequently: mood disorders (12.4% or \( N = 36 \)), anxiety (8.6% or \( N = 25 \)), dementia/Alzheimer’s disease (7.6% or \( N = 22 \)), and problem behaviors (6.5% or \( N = 19 \)). As in other studies (Mantry et al., 2008; Morgan et al., 2008), conditions such as psychosis or schizophrenia, eating disorders, and personality disorders were rarely reported (2.7%, 1.4%, and 1.0%, respectively). The reported prevalence of co-occurring depression in this sample is comparable to the rates reported in other studies, ranging from 5.0% to 11.4% (Dykens, 2007; Mantry et al., 2008).

No statistically significant association was found between gender and psychiatric disorder (\( p = .185 \)) in the DS group. Even when the risk was analyzed for each psychiatric condition separately, males were not more or less likely than females to be diagnosed with depression (13.6% of men and 11% of women of the total population reported this diagnosis; \( \chi^2(1, N = 291) = .483, p = .487 \)), or anxiety (9.7% vs. 7.3%; \( \chi^2(1, N = 291) = .550, p = .458 \)). Contrary to the results reported in Ward (2004), males with DS in our study were more likely to be diagnosed with dementia or Alzheimer’s disease (10.4% vs. 4.4%) though expected values may be too small for the approximation involved in the chi-square test to be valid.

Even when excluding Alzheimer’s disease or dementia, the reported presence of mental health disorders significantly increased with age. Individuals with DS over the age of 35 years were more likely to report a co-occurring mental health disorder (26.8% vs. 6.5%; \( \chi^2(1, N = 269) = 12.102, p = .001 \)).

Access to Mental Healthcare Services

Ninety-two percent of all adults with DS and a reported psychiatric condition also reported having healthcare coverage and were as likely as those with DS but no dual diagnosis to have health insurance (92.8% vs. 92.3%, \( p = .888 \)). Most participants with private health insurance plans (\( N = 131 \)) were younger than 26 years old and, therefore, eligible under the United States Affordable Care Act to be covered by their parents’ health insurance policies. However, no difference was found between individuals with and without dual diagnosis after controlling for age.

Adults with DS and a co-occurring psychiatric disorder were more likely to be on Medicaid health insurance (a public health insurance for persons in poverty or with a qualifying disability), 81.5% vs. 67.7%; \( \chi^2(1, N = 288) = 4.657, p < .05 \). After controlling for age, having a co-occurring psychiatric disorder was a significant predictor of having Medicaid health insurance—vs. Medicare or private health insurance. Individuals with DS and a co-occurring psychiatric disorder were twice more likely to have this type of healthcare coverage (\( b = -.792, Wald \chi^2(1) = 4.892, p < .05 \)). We did not have health insurance information for the individuals in the NCI data set.

Almost 80% of individuals with DS and a psychiatric condition were receiving treatment for the diagnosed psychiatric disorder and 85% were taking some type of medication. Only two individuals were hospitalized over the last 12 months for reasons related to mental health or behavioral disorders. However, it is striking that among the subgroup of participants with a reported psychiatric disorder, 36.9% had not consulted a psychiatrist and 58.5% had not consulted a psychologist in the last 5 years and almost 80% have not received psychotherapeutic services of any kind within the last 5 years.

Dual Diagnosis in Down Syndrome vs. Intellectual Disability (Without DS)

There are a few NCI items (“Does the person currently take medication to treat . . . Mood disorders? Anxiety? Psychotic disorders? Behavior problems?”) that provide an estimate of
prevalence of co-occurring mental and behavioral health issues in this random sample of adults with intellectual disability (without DS) and are presented in Table 3. The rate of dual diagnosis in the NCI adults with ID (without DS) was 47.6%, significantly higher than the adults with DS. Individuals with ID (without DS) were significantly older than the sample of individuals with DS (Table 1). Because of this age effect, we matched the two samples on age groups before conducting other analyses regarding the prevalence of co-occurring psychiatric disorder. The age groups identified in both surveys (i.e., 18–24, 25–34, 35–44, 45–54, 54–64, >64) were collapsed into three groups (18–34, 35–54, 54+) to make sure that expected frequencies in each cell were greater than 1 and no more than 20% contained fewer than five cases (e.g., only two individuals with DS were older than 65 years old).

No statistically significant differences were found for gender between the age groups of DS and intellectual disability, $\chi^2 (2, N = 661) = 1.474, p = .479$ (Table 2).

Individuals with DS were less likely to present a mood disorder (depression or bipolar disorder) than persons with ID at younger ages (Table 3). As reported in other studies (Prasher, 1995; Walker et al., 2011), we observed higher rates of depression in individuals with dementia or Alzheimer’s disease. Although differences were not statistically significant, it is worth noting that 59.1% of individuals with DS and dementia or Alzheimer’s disease were diagnosed with depression, compared to 33% of individuals with ID (without DS) who had dementia or Alzheimer’s disease and also depression. Although no gender differences were found within the group of individuals with DS, women with ID (without DS) were significantly more likely than men to report a diagnosis of depressive disorder (31% vs. 21%; $\chi^2 (1, N = 370) = 4.217, p < .05$).

Younger individuals with DS were also less likely to present anxiety disorders than older adults with DS (Table 3) and there was no statistically significant association found between gender and anxiety disorders in any of the ID (without DS) groups. Chi-square analysis for the oldest age group was not performed because only two individuals with DS had been diagnosed with anxiety disorder in this age group.

As widely reported in the scientific literature (e.g., Chapman & Hesketh, 2000; Dykens, 2007; Esbensen, Seltzer, & Krauss, 2008), people with DS reported lower rates of behavior problems compared to those with ID (without DS), but these rates were only statistically significant at younger ages (Table 3). Men were as likely as women to present behavior problems in both groups (ID and DS).

Alzheimer’s disease had been diagnosed in 22 individuals (7.6%) with DS. Most of them had moderate (54.5%) or severe (27.3%) levels of ID and a majority were men (72.7%). More than 2/3 (68.2%) of the cases of Alzheimer’s disease were reported in individuals age 45 years old and above. The mean chronological age of the individuals with DS and Alzheimer’s or dementia was 49.5 ± 11.33 years.

Only 2.4% ($N = 9$) of those with ID ($N = 370$) reported a diagnosis of Alzheimer’s disease or dementia. The mean age of the individuals with ID (without DS) who reported a diagnosis of Alzheimer’s or dementia was 64.78 ± 11.60 years. The average age difference between the DS and ID group with Alzheimer’s or dementia was statistically significant ($U = 25, p < .01$), with the DS group being diagnosed at a younger age than the ID (without DS) group. The odds ratio of Alzheimer’s for those individuals with DS was three times larger than for those with intellectual disability (without DS) ($\chi^2 (1, N = 661) = 9.528, p < .01$; OR = 3.280, 95% CI [1.487, 7.239]). Although current literature has also indicated a higher prevalence of this condition in individuals with DS (e.g., Stancliffe et al., 2012), our results should be interpreted with caution due to our relatively small sample size.

The prevalence of ASD within individuals with DS (7.6%) was slightly lower than the prevalence rate of ASD in persons with ID (without DS) (9.2%), but this difference was not statistically significant. Hence, persons with DS were as likely as those with ID (without DS) to be diagnosed with autism spectrum disorder (7.6% vs. 9.2%; $\chi^2 (1, N = 661) = 1.165, p = .280$). These results are consistent with other studies (Capone, Grados, Kaufmann, Bernad-Ripoll, & Jewell, 2005; Lowenthal, Paula, Schwartzman, Brunoni, & Mercadante, 2007).

**Discussion**

We presented data on adults with DS living in Ohio and compared these data to a larger random sample of adults with intellectual disability (without DS) regarding their reported mental health conditions. Although life expectancy for persons with DS has increased significantly over the past decades, not surprisingly, our sample of 291 adults with DS was on average younger than our larger comparative sample of adults with ID (without DS). With increased life expectancy comes increased likelihood of these older adults experiencing mental health problems. Fewer adults with DS reported having a co-occurring psychiatric disorder (23%) than has typically been reported in the general intellectual disability population (35%–40%; Cooper et al., 2007; Reiss, 1994; Rojahn & Tassé, 1996) and that we had in the comparison ID (without DS) NCI sample (e.g., 47.6%). Our findings regarding the prevalence of co-occurrence of mental health conditions...
TABLE 3
Mental health status

<table>
<thead>
<tr>
<th>Condition</th>
<th>Age group</th>
<th>ID (N = 370)</th>
<th>Down syndrome (N = 291)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
</tr>
<tr>
<td>Mood disorders</td>
<td>18–34</td>
<td>24 22.5</td>
<td>17 9.7</td>
</tr>
<tr>
<td></td>
<td>35–54</td>
<td>43 25.3</td>
<td>16 16.6</td>
</tr>
<tr>
<td></td>
<td>+54</td>
<td>29 31.2</td>
<td>6 27.3</td>
</tr>
<tr>
<td>Anxiety</td>
<td>18–34</td>
<td>14 13.1</td>
<td>8 4.6</td>
</tr>
<tr>
<td></td>
<td>35–54</td>
<td>36 21.2</td>
<td>10 10.6</td>
</tr>
<tr>
<td></td>
<td>+54</td>
<td>12 12.9</td>
<td>2 9.1</td>
</tr>
<tr>
<td>Behavior problems</td>
<td>18–34</td>
<td>19 17.8</td>
<td>7 4</td>
</tr>
<tr>
<td></td>
<td>35–54</td>
<td>27 15.9</td>
<td>9 10.6</td>
</tr>
<tr>
<td></td>
<td>+54</td>
<td>12 12.9</td>
<td>3 13.6</td>
</tr>
</tbody>
</table>

ID, intellectual disability.

Problems in adults with DS is consistent with the rates reported by Mantry and colleagues (2008). The three most frequently reported psychiatric disorders in our sample of DS were depression, anxiety disorders, and dementia or Alzheimer’s disease. Even when excluding dementia and Alzheimer’s disease, the risk for having a psychiatric disorder increased with age. This finding is consistent with similar findings in the general ID population (Hermans, Beekman, & Evenhuis, 2013, 2014).

As widely reported in the scientific literature (e.g., Chapman & Hesketh, 2000; Dykens, 2007; Esbensen, Seltzer, & Krauss, 2008), people with DS in our sample reported lower rates of behavior problems compared to adults with ID (without DS), but these rates were only statistically significant at younger ages (less than 35 years old). Men were as likely as women to present behavior problems in both groups (ID and DS).

The co-occurrence of dementia or Alzheimer’s disease was three times more likely to be reported by adults with DS than adults with ID (without DS). Although dementia/Alzheimer’s disease is a worrisome condition for adults with DS, depression may be the most common psychiatric disorder reported in persons with DS (Walton & Kerr, 2015). We found an intriguing finding related to age and depression in our sample of adults with DS. Except for the oldest individuals in our sample (54 years old and up), adults with DS were less likely to present a depressive disorder than persons with ID (without DS). Although the literature is replete with findings that women are more likely than men to report depressive symptoms, men and women with DS reported depression at comparable rates. This finding begs replication before firm conclusions can be made regarding gender differences in adults with DS and depression.

Our findings indicated that almost 60% of adults with DS had not seen a psychiatrist and more than half had not seen a psychologist in the last 5 years. It would seem, based on the reporting from our DS sample, that the preferred treatment for psychiatric disorders seems to be the almost sole reliance on medication. Where 85% of individuals reporting a co-occurring psychiatric disorder also reported receiving medication treatment but less than 20% reported receiving any type of psychotherapeutic intervention. As cautioned by Eady, Courtenay, and Strydom (2015) older adults with ID are at greater risk for polypharmacy and advanced chronological age may be risk a factor for a greater profile of medication side effects. Clinicians should be more cautious with aging adults with ID and DS in how psychiatric disorders are treated and focus on a more multimodal approach to treatment.

This study presents some limitations within which our findings must be interpreted. First, information about critical sociodemographic variables such as race, socioeconomic status, and rural vs. urban area, was not available. These variables, however, could play an important role with regard to accessing mental healthcare services. Second, some participants completing the questionnaires from the Online Survey and NCI skipped items and hence, some questionnaires were not completed in their entirety. Subsequently, the response rates sometimes fluctuated between different variables. Third, although the adult with DS completed the survey by himself/herself in only 6.5% (N = 19) of the cases, they could have provided biased information if they perceived the response as socially desirable (Adams, Soumerai, Lomas, & Ross-Degnan, 1999). Problems with proxy recall or understanding should also be acknowledged (Straughen, Caldwell, Osypuk, Helmkamp, & Misra, 2013). Finally, our sample of adults with DS was a volunteer sample, so it is possible that the responses from our sample of adults with DS might not represent all individuals with DS.

In summary, our findings indicate that adults with DS may present different rates and types of co-occurring psychiatric disorders than the larger population of adults with ID (without DS). These findings warrant additional research and could provide critical information for planning and intervention.
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