Published in final edited form as:

Am J Intellect Dev Disabil. 2016 January ; 121(1): 13–24. doi:10.1352/1944-7558-121.1.13.

Differentiating Aging among Adults with Down Syndrome and Comorbid Dementia or Psychopathology

Anna J. Esbensen, PhD, Emily Boshkoff Johnson, PhD, Joseph L. Amaral, MEd, MA, Christine M. Tan, MS, MEd, and Ryan Macks, PhD

Cincinnati Children's Hospital Medical Center

Abstract

Differences were examined between three groups of adults with Down syndrome in their behavioral presentation, social life/activities, health, and support needs. We compared those with comorbid dementia, with comorbid psychopathology, and with no comorbid conditions. Adults with comorbid dementia were more likely to be older, have lower functional abilities, have worse health and more health conditions, and need more support in self-care. Adults with comorbid psychopathology were more likely to exhibit more behavior problems, and to be living at home with their families. Adults with no comorbidities were most likely to be involved in community employment. Differences in behavioral presentation can help facilitate clinical diagnoses in aging in Down syndrome, and implications for differential diagnosis and service supports are discussed.

Keywords

Down syndrome; dementia; aging; psychopathology

With continuing advances in medical technology, the average human life expectancy has increased dramatically over time. Similarly, individuals with developmental disabilities such as Down syndrome have also benefited, and a diagnosis of Down syndrome no longer comes with the inevitability of a short lifespan. In recent history, individuals with Down syndrome were not expected to survive childhood, with the average life expectancy cited at 9 years of age in 1929 Great Britain (Bittles & Glasson, 2004). Now, however, life expectancy estimates for individuals with Down syndrome have increased to nearly 60 years of age (Bittles & Glasson, 2004). While this life expectancy is still substantially below that of the general population, some individuals with Down syndrome are now living into their 70s and 80s (Englund, Jonsson, Zander, Gustafsson & Annerén, 2013).

As with the general population, one can expect to see an increase in the incidence of physical and psychological health problems attendant with having a larger aging population. Specific to Down syndrome, research suggests that individuals with Down syndrome generally have stability in cognitive and functional ability before age 50, but after age 50, they show greater declines in cognitive and functional ability as compared to their peers

Anna J Esbensen, Division of Developmental and Behavioral Pediatrics, Cincinnati Children's Hospital Medical Center, 3430 Burnet Ave, MLC 4002, Cincinnati, OH 45229; anna.esbensen@cchmc.org.

These findings were presented as a poster at the 2013 annual meeting of the Association of University Centers on Disabilities.

(Carr, 2000, 2003; Collacott & Cooper, 1997; Devenny, Hill, Patxot, Silverman, & Wisniewski, 1992; Devenny et al., 1996; Hawkins, Eklund, James, & Foose, 2003; Rasmussen & Sobsey, 1994). This includes a greater prevalence of dementia, including that with early onset (Zigman, Schupf, Haveman, & Silverman, 1997). Estimates of the prevalence of dementia increase from a rate of 8.9% among adults with Down syndrome under 40, to 17.7% among adults 50–54, and to 32.1% among adults 55–59 (Coppus et al., 2006). Beyond age 60, approximately 50–60% of adults with Down syndrome exhibit dementia (Holland, Hon, Huppert & Stevens, 2000; Zigman et al., 1997; Zigman, Schupf, Sersen, & Silverman, 1996). Furthermore, dementia currently appears to be the most significant cause of morbidity and mortality among adults with Down syndrome (Coppus et al., 2006).

However, there are still many questions yet to be answered related to aging adults with Down syndrome. Because this is a relatively new population, there is little known about the behavioral presentation associated with aging Down syndrome populations that possess co-occurring dementia, or the level of associated functional impairment (Coppus et al., 2006). Few have studied which behavioral variables differentiate normative aging in Down syndrome from aging with comorbid dementia. Preliminary work suggests an elevated rate of maladaptive behaviors among adults with Down syndrome with early to mid-stages of dementia in comparison to adults with no symptoms of dementia (Urv, Zigman & Silverman, 2008). This work has also suggested a differential profile of behaviors present for adults with Down syndrome as they begin to demonstrate symptoms of dementia. Considerable room for investigation continues to exist with regards to determining the nature and implications of dementia in an aging Down syndrome population.

Of diagnostic concern, there is the question of whether there is a relationship between dementia and psychopathology in adults with Down syndrome. In the general population, it is established that a high rate of neuropsychiatric symptoms exist in individuals with dementia, and that because of an initially similar behavioral presentation, it can be very difficult to diagnostically distinguish psychopathology from dementia in aging adult populations (Lamberty & Bieliauskas, 1993; Riedel et al, 2010; Wright & Persad, 2007). The literature reflects a “diagnostic overshadowing” effect, in which depression can look like dementia and vice versa, in older adults. Depression in older adults can have a significant impact on cognitive functioning, and the behavioral changes sometimes associated with dementia (e.g. irritability, social withdrawal, aggression) can also occur in depressed patients of all ages. To add further complication, early symptoms of either of these diagnoses can present as the normal effects of aging.

Unlike the literature among typically developing adults, there is limited research on the relationship between dementia and psychopathology among the aging Down syndrome population. Preliminary research suggests that psychiatric symptoms, such as delusions, hallucinations, and depressed mood, have a low prevalence among adults with Down syndrome and no features of dementia (Urv, Zigman & Silverman, 2010). Adults with Down syndrome and dementia were more likely to demonstrate depressive symptoms for no apparent reason, to have difficulties sleeping and eating, to demonstrate violent outbursts, and to experience delusions and hallucinations (Urv et al., 2010). As such, examining

psychiatric and behavioral symptoms is encouraged in order to precisely diagnose dementia in this population. Consistent with this recommendation, consensus coding has been performed in studies to ensure that groups are accurately diagnosed. And clinical tools have been developed for this population to aid in differential diagnosis (Evenhuis, Kengen, & Eurlings, 2006; Gedye, 1995). However, a significant need remains for more research informing a better understanding of possible diagnostic or behavioral overshadowing among adults with Down syndrome.

To this end, the objective of this investigation is to explore how diagnoses of dementia, psychopathology or typical aging in adults with Down syndrome differ in their behavioral presentation, social life/activities, health, and support needs. Traditionally research has explored aging in adults with Down syndrome along the dementia continuum, comparing adults having no dementia, adults with mild cognitive impairments, and adults with dementia (Zigman et al., 2004). We have included a group with psychopathology in order to help elucidate indicators to help with the diagnostic process, identification of service and support needs, and differences in aging.

First, we examined whether these three groups (dementia, psychopathology, typical aging) differed on demographic variables among aging adults with Down syndrome. Second, we examined group differences on their behavioral presentation, specifically both behavior problems and functional abilities. Third, we examined group differences in social life/activities with regards to their engagement in social activities and their relationships with family members. Fourth, we examined group differences in their health: both overall physical well-being and the frequency of individual health conditions. Last, we examined group difference in their support needs in the domains of residential, vocational, and specific service support needs. We hypothesized that there would be group differences present in the domains examined.

Method

Study Design

The sample reported here were a follow-up of a previous longitudinal study of 461 families caring for an adult son or daughter with intellectual and developmental disabilities, including 169 individuals with Down syndrome, who initially lived at home with their parents (Krauss & Seltzer, 1999; Seltzer & Krauss, 1994). The criteria for inclusion when the study began were that the mother was between the ages of 55 and 85, and the son or daughter lived at home with her. State and agency records and results of intelligence testing using the Stanford-Binet Intelligence Scales-Fourth Edition (SB-IV; Thorndike, Hagen, & Sattler, 1986) were reviewed to confirm disability status for adults with Down syndrome. Nine waves of data were collected from 1988 to 2010/2011, with the first eight waves collected at 18-month intervals, and the ninth wave collected as a follow-up 10/11 years after the eighth wave of data collection. The families initially lived in either Massachusetts or Wisconsin.

At the ninth wave of data collection, families of the adults with Down syndrome participated in interviews, primarily at their home, and completed a questionnaire about their relative with Down syndrome.

Sample

The current analysis used data from the ninth wave of data collection which included 75 adults with Down syndrome. The individuals with Down syndrome included 49 men and 26 women, all of whom were Caucasian and primarily diagnosed as having mild/moderate intellectual disability (74.7%). Their ages ranged from 37 to 65 years ($M = 51.08$, $SD = 5.97$) at the ninth wave of data collection.

Seventy-five parents/caregivers completed questionnaires regarding a wide range of issues surrounding family members with Down syndrome. Thirty-four of the respondents were their mothers and 41 were other family members of the adult with Down syndrome (6 fathers, 35 siblings). Demographics of family members are presented in Table 1. Their current median household income was \$50,000–\$59,999 as identified by self-report.

Measures

Group status—Adults with Down syndrome were categorized into one of three groups: having comorbid dementia, having comorbid psychopathology, or having no comorbid diagnoses.

Dementia status was classified using consensus coding between two licensed clinical psychologists blind to the outcome variables. Consensus coding to classify dementia status was modeled from the system developed by Silverman and colleagues (2004), using assessment measures, reports of previous direct assessments of cognitive ability, current and previous health conditions, current diagnoses, and current medication. Assessment measures used in consensus coding include the Dementia Questionnaire for People with Learning Disabilities (DLD), the Dementia Scale for Down Syndrome (DSDS), and the Psychiatric Assessment Schedule for Adults with Developmental Disabilities (PAS-ADD) (Esbensen, Mailick & Silverman, 2013; Evenhuis et al., 2006; Gedy, 1995; Moss, 2002). Dementia status was categorized as (0) no dementia or (1) possible or definite dementia. Initial coding resulted in 89% agreement among the psychologists. Further discussion resolved any disagreements.

Psychopathology diagnoses were obtained through caregiver reporting on the presence of various current or previous mental health diagnoses and the year of diagnosis. Caregivers reported on the presence of anxiety disorders (general anxiety, PTSD, OCD), bipolar disorder, depression, ADHD, oppositional defiant disorder and schizophrenia, and had the option to list other past and current mental health diagnoses. Current mental health diagnoses were confirmed with the PAS-ADD interview and review of current medication for determining (0) no psychopathology or (1) current psychopathology.

Behavioral presentation—Two measures were used to assess the behavioral presentation of adults with Down syndrome. One assessed behavior problems and the other, functional abilities. The Scales of Independent Behavior-Revised–SIB-R (Bruininks, Woodcock,

Weatherman, & Hill, 1996), which captures the frequency and severity of eight types of behavior problems, was used to assess behavior problems. A scoring algorithm converts raw scores on the SIB-R into index scores for overall generalized maladaptive behaviors and three additional subscales: internalized maladaptive behavior (hurtful to self, unusual or repetitive habits, and withdrawn or inattentive behavior), asocial maladaptive behavior (socially offensive behavior and uncooperative behavior), and externalized maladaptive behavior (hurtful to others, destructive to property, and disruptive behavior). Index scores for the four subscales provide ratings of the seriousness of the problem behavior as normal (90 to 110), marginally serious (111 to 120), moderately serious (121 to 130), serious (131 to 140), or very serious (141 or above). Reliability and validity are excellent for the Maladaptive Behavior subscales (Bruininks et al., 1986). A total score of behavior problems endorsed (range 0–8) was also calculated.

The Waisman Activities of Daily Living (W-ADL) Scale for adolescents and adults with developmental disabilities was used to assess functional abilities, or the level of performance of common daily activities, for the adults with Down syndrome (Maenner et al., 2013). The 17-item scale is rated on a 3-point scale (0 = does not do at all, 1 = does with help, 2 = independent), and items summed to produce a total score.

Social life/activities—We assessed both social activities of the adults with Down syndrome, and the quality of the relationship they have with their family member. Social activities measured contact with family/relatives, coworkers, neighbors, friends, and participation in recreational and group/community activities. Ratings were made on a 5-point scale (0 = never/less than yearly, 1 = several times a year/1–10 times, 2 = about once a month, 3 = about once a week, and 4 = several times a week).

Relationship quality was assessed using the caregiver-report with the Bengtson Positive Affect Index, a ten-item instrument comprised of two five-item subscales (Bengtson & Schrader, 1982). The first five items assessed the rater's views of their relative's perceptions, and the second, their own perceptions. Items assessed perceived trust, respect, understanding, fairness, and affection. Items were formatted in a six-point Likert-type scale ranging from 1 = not at all, to 6 = extremely. A total score was calculated by summing all ten items.

Health—We assessed both the current health status of the adult with Down syndrome and any current associated health conditions. Current health status was rated on a 4-point scale (1 = poor, 2 = fair, 3 = good, 4 = excellent). Such global ratings of health have been found to be accurate measures of health status (Idler & Benyamini, 1997).

In addition, a 9-item scale was used to measure the presence (1) or absence (0) of health conditions in the past year. Items include problems with respiratory/lung, sleep, thyroid, dental, cardiac/blood, sensory, gastrointestinal, pain/joints/bones, or other internal organs.

Support needs—We assessed the residential status of the adults with Down syndrome, their vocational level of independence, and their use of service supports. Information was provided about the current living situations and coded as living independently (n=2; living

alone independently or independently with others), living with family (n=31; with parents, siblings or a foster family), receiving some support (n=5; living alone with support, home share with staff support), or receiving full support (n=37; group home, nursing home).

Vocational independence was originally measured using a 10-item scale of daily activities, which encompassed employment, and vocational and educational activities. The original 10-item scale was collapsed to form a vocational index consisting of a 4-category rating scale based on level of independence that has been used with other adolescents and adults with intellectual and developmental disabilities (Taylor & Seltzer, 2012). The vocational independence ratings were volunteering/no vocational/educational activities (1), sheltered vocational setting (2), supported employment (3), and competitive employment (4).

Service use was assessed by family member's ratings of whether each of 13 services was received, and if not, whether it was an area of unmet need. These services include: nursing services, nutritional services, physical therapy, occupational therapy, speech and language therapy, psychological or psychiatric services, social work, self-care services, legal assistance related to need or disability, recreational and/or social activities, transportation services, respite care, and income support. Services were categorized on a 3-point level of need (0 = service not needed and not received, 1 = service needed but not received, 2 = service needed and received).

Data Analysis

Group differences on demographic variables were assessed using chi-square tests and ANOVAs. Demographic variables assessed included gender, level of intellectual disability (0 = severe/profound, 1 = mild/moderate), age, and socio-economic status (household income categorized in \$10,000 intervals). Where significant group differences were evident, these demographic variables were controlled for in subsequent analyses of variance as indicated in the Results.

To test differences in behavioral presentation, ANCOVAs were used to test for group differences in behavior problems and functional abilities, controlling for identified covariates. To test differences in social life/activities, ANCOVAs were again used to test for group differences in relationship quality, and the index of social activities. To test differences in health, an ANCOVA was used to test for group differences in current health status controlling for identified covariates, and chi-square tests to assess for differences in the frequency of health conditions. To test for differences in support needs, chi-square tests were used to assess for differences in residential status, vocational setting, and service use.

Results

Group status

The adults with Down syndrome were categorized into three groups (see Table 2): Down syndrome with dementia (n = 19), Down syndrome with psychopathology (n = 13), and a comparison group with no comorbidities (n = 43). Two individuals from the dementia group also had comorbid psychopathology based on caregiver report. As the caregiver reports were not corroborated with the PAS-ADD, these two individuals were classified and retained

within the dementia group. All adults in the psychopathology group were diagnosed with an anxiety disorder, with 7 of 13 adults having a comorbid diagnosis of Obsessive-Compulsive Disorder.

Demographic variables

Groups did not differ with regards to gender, $\chi^2(2) = 3.49$, $p > .05$, or level of intellectual disability, $\chi^2(2) = 2.56$, $p > .05$. However, the mean age of each group was significantly different, $F(2,72) = 10.66$, $p < .001$. Pairwise comparisons revealed that adults with dementia were significantly older than the other two groups. As a result, age was controlled for in all subsequent analyses of variance.

Because of the numerous effects that socio-economic status can have on an individual's health, functioning, and access to services, the average incomes of survey respondents was compared. Analyses indicated that socio-economic status did not differ between groups, $F(2,72) = 0.16$, $p > .05$.

Behavioral presentation

In general, behavioral indices were within normal limits across groups. ANCOVAs controlling for age indicated a significant main effect of group for overall number of problem behaviors, $F(2,68) = 3.23$, $p < .05$. Although the number of problem behaviors demonstrated by each group was low, adults with comorbid psychopathology demonstrated more behavior problems than adults with dementia or no comorbidity (see Table 3).

Significant main effects were found for the mean level of functional abilities, controlling for age, $F(2,68) = 8.53$, $p < .001$. Adults with Down syndrome and dementia demonstrated lower functional abilities than the two groups of adults with comorbid psychopathology or no comorbidity (see Table 3).

Social life/activities

There was no significant difference among the three groups in regards to their level of participation in social activities. Additionally, ANCOVAs revealed no significant differences between the three groups on current ratings of the family relationship between the adult with Down syndrome and their respondent family member (see Table 3).

Health

ANCOVAs indicated group differences in current health, $F(2,70) = 5.88$, $p < .01$. Adults with dementia were more likely to have worse overall health compared to the other two groups (see Table 3).

The number and types of health conditions experienced within the past year prior to survey completion were compared between groups. The three groups differed in the presence of dental concerns, $\chi^2(2) = 11.9$, $p < .01$, and gastrointestinal problems in the past year, $\chi^2(2) = 6.07$, $p < .05$. Adults with dementia were more likely to have dental and gastrointestinal concerns than adults with no comorbidity, who in turn reported more dental and gastrointestinal concerns than adults with psychopathology. Groups did not differ with

regards to the presence of health problems in the past year of respiratory, sleep, thyroid, cardiology, pain, sensory, or internal health concerns (see Table 4).

Support needs

Pearson Chi-Square analysis revealed significant differences between groups, $X^2(6) = 17.78$, $p < .01$. Adults with Down syndrome and dementia were most likely to be receiving full support in their residence than to be living in other residential settings (see Table 4). Adults with Down syndrome and comorbid psychopathology or no comorbidity were more likely to be still living with family than in other residential settings.

Significant differences were found for measures of vocational employment, $X^2(6) = 17.80$, $p < .01$ (see Table 4). Subsequent analyses revealed that adults with dementia were more likely to be grouped within the category of volunteering/no vocational/educational activities as compared to adults with no comorbidity, $X^2(3) = 10.49$, $p < .05$, and individuals with comorbid psychopathology, $X^2(3) = 9.89$, $p < .05$. The adults with no comorbidity were observed to be more likely to be categorized as employed than categorized as volunteering or not engaging in formal community activities.

Few significant differences among the three groups were present in regard to service needs and utilization. For the most part, services were received as needed, or not needed. Due to the large number of individual services assessed, where non-significant findings are present between groups, the needs for the entire sample are described (see Table 5).

Significant differences were found for self-care, $X^2(4) = 11.68$, $p < .05$. Adults with dementia were more likely to need and receive self-care support (52.6%) as compared to adults with comorbid psychopathology (7.7%) or no comorbidity (17.9%).

Discussion

The purpose of this study was to explore how diagnoses of dementia, psychopathology or typical aging in adults with Down syndrome differed, with a focus on behavioral presentation, social life/activities, health, and support needs. In general and consistent with previous findings, adults with co-morbid Down syndrome and dementia were more likely to be older, have lower functional abilities, and need more support in the area of self-care than their peers without dementia. They also had worse overall health, and were more likely to receive full support in their residential placements. An original finding is that these differences are also present in comparison to adults with other comorbid psychopathology. Despite all three groups of adults with Down syndrome having few behavior problems, a novel finding was that individuals with Down syndrome and comorbid psychopathology were likely to have more behavior problems, as well as be living at home with their families than were adults with dementia or with no comorbid diagnoses. Adults with Down syndrome and no comorbidities were most likely to be involved in community employment.

This pattern of findings of differences between the three groups is consistent with the literature. Once diagnosed, individuals with Down syndrome and dementia present somewhat differently than those with psychopathology. Regression in functional abilities

was more common among individuals diagnosed with dementia, consistent with previous findings of declines in these skills among individuals subsequently diagnosed with dementia (Cosgrave, Tyrell, McCarron, Gill, & Lawlor, 2000; Prasher, Chung, & Haque, 1998). In our sample, behavior problems were more likely among individuals diagnosed with psychopathology than in individuals with dementia or no comorbidity. Previous studies have found elevated levels of behavior problems among adults with Down syndrome and comorbid dementia in comparison to adults with no symptoms of dementia (Prasher et al., 1998; Urv et al, 2008). Our findings extend the current literature by suggesting that while behavioral concerns may be elevated among individuals with dementia, they may be even more elevated in individuals with comorbid psychopathology. These findings illustrate the difficulty in differential diagnosis of dementia based on increased behavioral concerns, and the need to closely differentiate the underlying cause of increased behavioral concerns.

The results of this study support the need for greater supports for adults with Down syndrome and comorbid dementia. There is a higher need for support in the area of self-care and functional abilities, suggesting that a more structured living situation may be beneficial. The increased need for this type of residential support as well as the functional declines evident in this sample is consistent with needs documented in the general population (Riedel et al., 2010). Adults with dementia show increasing dependence on structure and residential care, in addition to declines in functional and self-care abilities. Keeping in mind that individuals with Down syndrome are at high risk for developing dementia at an earlier age, it is necessary to meet the changing service needs of this population by being prepared to provide increasingly structured residential supports, and supports to their families, as individuals with Down syndrome age.

Among adults with dementia, it is not unusual for medical illnesses to be difficult to recognize. As such, the fairly comparable prevalence of associated health conditions among the three groups is not a striking finding. There was an increased prevalence of dental concerns among this sample of adults with Down syndrome and dementia. Dental concerns are becoming an increasingly studied topic in the field of dementia in the typical aging population (Chalmers, Carter, & Spencer, 2003; Poole, Singhrao, Kesavalu, Curtis, & Crean, 2013; Poole, Singhrao, & Crean, 2014; Stein, Desrosiers, Donegan, Yepes, & Kryscio, 2007). The inflammation associated with dementia is being posited as a potential risk factor for the increased susceptibility to periodontal disease and dental concerns. The increased prevalence of gastrointestinal concerns among this sample of adults with Down syndrome and dementia warrants replication as no comparable increased prevalence is found in the general population of adults with dementia. It is possible that this increased risk is specific to Down syndrome, given the elevated risk for gastrointestinal concerns across the lifespan (Roizen & Patterson, 2003).

Despite these differences among adults with Down syndrome with dementia, psychopathology or no comorbid conditions, the groups were similar on a number of factors. For example, for the majority of health problems (i.e. respiratory, sleep, thyroid, sensory, or internal) the groups experienced comparable concerns related to aging, and service needs were being met at comparable rates across groups. In addition, all three groups were similar in terms of their social engagement in the community, as well as their relationships with

their families. The relationship quality ratings in this sample are consistent with other samples of adults with intellectual disabilities (Esbensen, Seltzer & Greenberg, 2006), and are a positive finding regarding the family relationships of aging adults. The families in this study were pioneers for their time, electing to keep their child with Down syndrome at home during decades where the norm was to have the child institutionalized. It is a positive finding that the relationship quality of the adult with Down syndrome and their family member did not change significantly when the family was faced with comorbid dementia or psychopathology as compared to when the individual with Down syndrome had no additional mental health or cognitive concerns.

Although vocational independence declined for adults with comorbid dementia, their engagement in the community is reported to be commensurate with their peers with psychopathology or no comorbid conditions. These findings could be interpreted as positive, as continued participation in community and social activities may delay symptom progression and provide important social connections and value in life for adults with Down syndrome. The combination of increased physical activity and social modeling inherent in community involvement can only benefit individuals with Down syndrome and dementia. However, the level of social participation across all adults with Down syndrome in the sample was relatively low. Social activities with family, friends, or group recreation were only engaged in on average once a month. Approximately 12–15% of adults with Down syndrome were engaging in at least weekly social activities. This low level of social activity becomes increasingly important for adults with comorbid dementia as they are not afforded the social opportunities available at vocational settings. These findings highlight the need for all individuals with Down syndrome to be provided increased opportunities to engage in social activities on a more regular basis.

Despite having a large sample of aging adults to draw from who had previously been involved in a larger longitudinal study, several limitations of the study are present. First, the number of individuals who met criteria for dementia or psychopathology was small in comparison to the number of individuals with no comorbid diagnosis. However, the rates in the current sample are comparable to those found in other samples. The 25% of individuals with dementia in the current study is consistent with rates observed in other studies of 40–60 year olds (Coppus et al., 2006; Tyrrell et al., 2001). And the 17% of individuals with psychopathology is comparable to rates found in larger studies (Collacott, Cooper & McGrother, 1992; Mantry et al., 2008). In addition, clinical gold standard instruments were used in diagnosis, and confirmed with supplemental information collected in the course of the study. Second, the psychopathology group did not include heterogeneous clinical diagnoses as expected from previous prevalence studies (Mantry et al., 2008). Rather, the current sample included primarily comorbid anxiety disorders. It is possible that this psychopathology comparison group does not reflect all mental health conditions experienced by other adults with Down syndrome and limits the generalizability of the findings regarding this group.

We found that aging in Down syndrome is not homogeneous. Differences in behavioral presentation can be used to help facilitate clinical diagnoses. In a typical elderly population without Down syndrome, it can often be difficult to differentiate between psychopathology

and dementia. However, our preliminary results suggest that these two groups of individuals present differently. Individuals with comorbid Down syndrome and dementia demonstrated functional declines, whereas individuals with comorbid Down syndrome and psychopathology demonstrated higher behavior problems. The two groups also presented differently in how they used service supports. Further research is needed to continue to understand differences in behavioral profiles among adults with psychopathology in comparison to adults with Down syndrome in various stages of cognitive decline. In differentially diagnosing psychopathology and dementia, it will be particularly important for research to differentiate the behavioral profile of adults as they progress from mild cognitive impairment to dementia, in comparison to normative aging in Down syndrome and the presence of comorbid psychopathology.

Acknowledgments

This manuscript was prepared with support from the Eunice Kennedy Shriver National Institute on Child Health and Human Development (R03 HD059848, A Esbensen, PI). The National Institute on Aging (R01 AG08768, M. Mailick, PI) provided the initial dataset which was followed-up for the current study. This research would not have been possible without the contributions of the participating families and our project manager, Renee Makuch, to whom we are extremely grateful.

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Table 1

Ages of family members

	Mothers (n=34)	Fathers (n=6)	Siblings (n=35)
Mean age (SD)	85.1 (5.3)	83.2 (1.3)	59.2 (7.3)
Age range	77–97	82–85	39–74

Table 2

Demographic of Adults with Down syndrome

	Dementia (n=19)	Psychopathology (n=13)	Comparison (n=43)
Gender (% male)	52.6%	84.6%	65.1%
Level of functioning (% mild ID)	63.2%	69.2%	81.4%
Mean age (SD)	55.7 (4.7)	47.8 (5.5)	50.0 (5.5)
Age range	46–63	37–56	37–65

Table 3

Means and standard deviations of behavioral presentations, social life/activities, and current health for adults with Down syndrome who have dementia, psychopathology or no comorbidity.

	Dementia (n=19) M (SD)	Psychopathology (n=13) M (SD)	Comparison (n=43) M (SD)
Behavioral presentation			
Behavior Problems			
Generalized	103.1 (3.8)	103.5 (3.9)	101.7 (2.9)
Internalized	103.2 (6.9)	103.5 (5.7)	100.6 (4.0)
Asocial	102.1 (7.5)	103.0 (7.3)	99.9 (5.0)
Externalized	97.3 (1.1)	98.4 (3.6)	97.9 (2.6)
Total	1.4 (1.3)	1.8 (1.4)	0.8 (1.1)
Functional Abilities	0.6 (0.5)	1.2 (0.5)	1.2 (0.4)
Social life/activities			
Social activities	1.9 (0.9)	1.7 (1.2)	1.9 (0.9)
Relationship quality	49.3 (9.6)	53.2 (6.9)	54.2 (5.0)
Health			
Current health	2.3 (0.7)	3.0 (0.4)	2.9 (0.7)

Table 4

Percentage of health conditions, and support needs for adults with Down syndrome who have dementia, psychopathology or no comorbidity.

	Dementia (n=19)	Psychopathology (n=13)	Comparison (n=43)
Health			
Health conditions			
Respiratory	21.1%	7.7%	7.3%
Sleep	21.1%	7.7%	17.1%
Thyroid	42.1%	46.2%	43.9%
Cardiology	31.6%	7.7%	14.6%
Pain	42.1%	53.8%	26.8%
Dental	84.2%	23.1%	58.5%
Sensory	47.4%	53.8%	39.0%
Gastrointestinal	78.9%	38.5%	51.2%
Internal	0.0%	0.0%	2.4%
Support Needs			
Residence			
Independent	0%	0%	4.7%
Family	5.3%	61.5%	51.2%
Supported	15.8%	0%	4.7%
Sheltered	78.9%	38.5%	39.5%
Vocation			
Competitive	5.3%	0%	15.0%
Supported	0%	30.8%	10.0%
Sheltered	21.1%	38.5%	45.0%
Volunteering	73.7%	30.8%	30.0%

Table 5

Percent of service use and need by type of service.

	Service not needed	Service needed but not received	Service needed and received
Speech language therapy	76.4%	16.7%	6.9%
Nutrition	63.9%	13.9%	22.2%
Recreation	19.4%	9.7%	70.8%
Respite	72.2%	9.7%	18.1%
Physical therapy	74.6%	8.5%	16.9%
Occupational therapy	77.8%	8.3%	13.9%
Social work	27.8%	6.9%	65.3%
Transportation	19.4%	5.6%	75.0%
Psychology	81.9%	5.6%	12.5%
Self-care	70.4%	4.2%	25.4%
Legal	86.1%	4.2%	9.7%
Nursing	73.6%	1.4%	25.0%
Income	1.4%	0.0%	98.6%