

# PSYCHIATRIC ASPECTS OF HEALTH CARE OF ADULTS WITH DOWN SYNDROME

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Routine health care guidelines for adults with Down syndrome (DS) often get less attention than those guidelines for children with DS. This article reviews recent recommendations including the challenge that psychiatrists (as well as other mental health professionals) be aware of potential health concerns.

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Psychiatrists who evaluate adults with Down syndrome (DS) and rely on other health professionals for providing medical care should find a few recent articles quite interesting. In one article, Henderson *et al.*<sup>6</sup> conducted a detailed analysis of primary care records for a cohort of adults with DS to determine the quality of their medical care. They found complications from diseases such as hypothyroidism much more than pediatric studies found. For their study patients, 48% had not seen a physician in the past year, and 33% had no medical assessment in the previous three years. Because of the high number of medical conditions associated with DS and early aging, it is imperative that they have good quality medical care. Psychiatric clinicians must not assume this care is provided and for many patients, psychiatric care may be the most frequent medical contact for patients. Further, psychiatrists must be careful to conduct a full medical analysis prior to finalizing the diagnosis and treatment plan as many medical conditions may mimic or exacerbate psychiatric illnesses.

In some ways, persons with DS have been fortunate that health guidelines have been revised and published for over 25 years.<sup>4</sup> While pediatricians often may rely on health guidelines to monitor exams and testing, the practice may not be as frequent in adults. Henderson *et al.*<sup>6</sup> welcomes assistance in medical surveillance for health care in adults with DS from geneticists, hospital physicians and psychiatrists. Consequently, it will be useful for mental health professionals to have a basic knowledge of health care issues in adults with DS and assure that medical needs are not being neglected.

Before discussing medical issues in adults with DS, it is important to offer a caveat about guidelines in the general population. Health guidelines are often ignored by adults in the general population. For example, colorectal cancer is the second leading cause of cancer death (over 56,000) in the US.<sup>1</sup> With early detection of colorectal cancer, the five-year survival rate is between 80-90%.<sup>1</sup> Only about half of persons fifty years and older, however, get recommended screening for colorectal cancer, such as fecal occult blood test.<sup>10</sup> Thus, it is not surprising that people with DS may have less than desirable health care, but it is more worrisome, because unlike intellectually normal individuals, they cannot advocate for themselves easily, learn about possible medical problems from the popular media and internet, or verbalize their physical symptoms well.

This paper will review recent updates on cancer, thyroid disease and oral health. Thyroid disease is a most common condition in DS and is implicated strongly in the pathogenesis of major depression. Please refer to Table 1 for Henderson *et al.*'s<sup>6</sup> recommendations on obesity, celiac disease, congenital cardiac problems, hearing deficits, ocular problems and Alzheimer disease.

## Cancer

Sometimes, cancer is overlooked in discussions of health care for adults. Certain cancers such as lung cancer or cervical cancer are rare in DS.<sup>9</sup> This is probably due to lung cancer's link to smoking and cervical cancer's link to early and frequent sexual behaviors. In other instances, studies of cancer in persons with DS are at risk for false negatives. This typically occurs when the

**TABLE 1. MEDICAL CONDITIONS IN ADULTS WITH DOWN SYNDROME**

MEDICAL CONDITION	RECOMMENDATION
Congenital heart disease	Single echocardiogram in adulthood; check with cardiologist/primary care physician about prophylactic antibiotics in potential risk situations (e.g., dental work or urogenital procedures).
Hearing impairment	Assess auditory thresholds, impedance testing, and otoscopy at least once every two years.
Ophthalmic problems	Check vision and eye exam at least once every two years.
Celiac disease	Screen for history of foul smelling feces, chronic diarrhea, unexplained anemia, etc. especially if person has thyroid disease or diabetes. Order blood test for antiendomysial antibody status.
Obesity	Provide guidance with diet and exercise, especially if body mass index is > 35.
Alzheimer disease	Rule out thyroid disorders, depression and hearing loss (at a minimum) before concluding that person has Alzheimer disease.
Adapted from Henderson <i>et al.</i> <sup>6</sup>	

size of the study is too small to adequately detect significant relationships. Some cancers, however, need to be considered in adults with DS. Interestingly, some articles mentioned certain cancers, such as testicular cancer in adult males with DS or leukemia in adults, while others do not. Although leukemia is often viewed as a risk in children with DS, a Finnish survey by Patja *et al.*<sup>9</sup> indicated that the risk for leukemia remained significantly high through the fourth decade. Sullivan *et al.*<sup>14</sup> did not demonstrate an increase of leukemia in adults.

Another cancer with increased risk through the fourth decade is testicular cancer. Satge *et al.*<sup>12</sup> calculated the increased risk in DS as between 6- and 50-fold higher than the general population. This increased risk is based on Satge *et al.*<sup>12</sup> finding testicular cancer in a 23-year-old and a 28-year-old among 120 children and adults with DS. This increased risk was not confirmed, however, in 725 males with DS in Australia (one testicular teratoma).<sup>14</sup> In that western Australian study (725 males and 573 females) between 1982 and 2001, the two main findings were 1) an increased incidence of leukemia in children with DS, and 2) that the overall incidence of cancer was not significantly different from the general population.<sup>14</sup>

Satge *et al.*<sup>13</sup> reviewed digestive tract tumors in persons with DS. They found an increased incidence of bile duct, gallbladder, pancreatic and possibly liver cancers. They found some cancers, such as oropharyngeal, colorectal and possibly gastric, were less frequent than expected. To reduce digestive cancers in adults with DS, Satge *et al.*<sup>13</sup> recommended treatment of H. pylori infections, avoidance drugs that produce gastroesophageal reflux, surgical removal of gallstones, use of fiber-rich diets, and a reduction of obesity.

Psychiatric clinicians must be aware of the possibility of cancers in their patients with DS. Problems of pain, not feeling well, and digestive problems often manifest themselves with behavioral or social symptoms in people with DS. A thorough medical exam and contact with the primary care physician at the initiation of treatment is strongly recommended, as well as ordering lab work.

### Thyroid Disease

Traditionally, annual thyroid blood screenings have been recommended for adults with DS.<sup>4</sup> A recent study by Prasher and Gomez<sup>11</sup> questions this practice. They followed 200 adults with DS who had thyroid function tests in 1990. Their mean age in 1990 was 43 years (range 17 to 76

years). Over 80% lived in the community. There were 58 deaths. The study had significant attrition over the ten years. A number of individuals left the catchment area or refused to have blood work. By 2000, only 49 (24.5%) individuals remained in the study.

Prasher and Gomez<sup>11</sup> found that of the 200 persons tested in 1990, two-thirds were euthyroid. Of the others, about 10% had definite hypothyroidism (high thyroid stimulating hormone [TSH] and low thyroxine [ $T_4$ ]). Another 11% had subclinical hypothyroidism (low TSH and normal  $T_4$ ). The researchers wondered how many of the persons with subclinical hypothyroidism would convert to definite hypothyroidism. Of the 22 persons with subclinical hypothyroidism in 1990, half were still in the study by year four and two had developed definite hypothyroidism. Follow-up for the entire ten years was possible on only five persons with subclinical hypothyroidism at year one. None of those remaining five (presumably excluding the two others by year four that developed definite hypothyroidism) went on to overt hypothyroidism.

Prasher and Gomez<sup>11</sup> conclude that individuals with DS who are healthy and euthyroid can have thyroid screening reduced to every five years. Furthermore, they conclude that subclinical hypothyroidism (i.e., elevated TSH and normal  $T_4$ ) does not invariably lead to hypothyroidism. Perhaps the most immediate reaction for many readers of the Prasher and Gomez study is the great difficulty in doing a decade-long follow-up that includes a large initial community sample. This is a relevant point in how much emphasis one should put on the findings. Yet, given those difficulties, how likely will other research teams be in undertaking a decade-long study to support or refute Prasher and Gomez' conclusions?

Henderson *et al.*<sup>6</sup> offers a different perspective on thyroid screening in adults with DS. Less than 40% of 62 adults with DS had thyroid blood work in the past two years. Moreover, over 40% did not have any thyroid testing for over five years. Perhaps most relevant for mental health professionals, Henderson *et al.*<sup>6</sup> emphasizes that thyroid testing is mandatory whenever depression or dementia is considered and in all persons with DS every two years throughout life.

It is recommended that most adults with DS who are evaluated by mental health professionals probably will need thyroid function tests every one

to two years. Because thyroid disease is strongly associated with mood disorders, the psychiatric clinician must assure that this condition is adequately treated prior to mental health interventions. Those adults with DS who are very needle phobic and who are healthy and euthyroid on previous testing, can have thyroid testing once every five years.

### Oral Health

Respiratory infections are the most common cause of death for persons with DS.<sup>3</sup> Up to 40% of older adults with DS die from pneumonia or other respiratory infections.<sup>3</sup> There is now greater recognition of the association between poor oral hygiene and the risk for pneumonias. In the general population, professional oral health care significantly reduced fatal aspiration pneumonias in elderly individuals.<sup>2</sup>

In persons with DS, congenital oro-facial features contribute to an accumulation of food particles in the mouth and periodontal disease is quite common by early adulthood.<sup>7</sup> Unless the adult with DS brushes daily as well as receives regular cleanings from a hygienist, gingival and periodontal disease is likely. As in the general population, the good news is that regular dental health care with cleaning can slow periodontal disease in persons with DS.<sup>8</sup>

### RECOMMENDATIONS

Not all areas have primary care physicians who have an interest and/or can take sufficient time to adequately screen for medical conditions. As our health care system is stressed in the United States, access to medical providers may not be easy and convenient. In addition, as previously discussed, people with DS are much less likely to self-advocate, self-report symptoms, or ask for a medical evaluation when experiencing pain or discomfort. Further, when ill, many people with DS may react emotionally or behaviorally, generating a psychiatric consultation first rather than a primary care visit. Although mental health professionals are not expected to be primary care providers, it is important to have some familiarity with reported medical problems (including oral problems) in adults with DS. There may be many times when the psychiatric clinician will take a lead in health care screenings and lab work.

This role takes on added significance with the findings of a study of factors predicting mortality in adults with DS. Two problems commonly

referred to mental health clinicians, decline in functional abilities and worsening of challenging behaviors, predicted mortality in midlife in persons with DS.<sup>5</sup> Mental health professionals working with persons with DS do not ordinarily consider themselves as delaying mortality. Yet when evaluating functional decline or worsening of behavioral problems, psychiatric clinicians often can play a vital role in collaboration with primary medical and dental care professionals.

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