Chapter 16

Aging and Dual Diagnosis

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Learning Objectives

Readers will be able to:

1. Identify the nature of the health problems experienced by persons with developmental disabilities as they grow older.
2. Describe the main features of various mental disorders in older persons with developmental disabilities.
3. Explain how aging has been conceptualised as a biomedical phenomenon.

Introduction

"Aging is a collective term for all those progressive deteriorative changes that occur in mature individuals and lead to a reduced expectation of life with increasing age" (Wright & Whalley, 1984).

This chapter reviews various disorders associated with aging in a context of universal experiences also associated with age. In daily practice it is important to examine the mental effects

of chronic illness, sensory impairment, loss of loved ones, and residential relocation, all common in later years. For the purposes of presentation, the next section deals with general health problems, the following section with mental health disorders, and the chapter concludes with a brief comment related to various theories of aging.

General Health Problems

This section considers three sub-groups of persons with developmental disabilities. These sub-groups reveal different patterns of aging and longevity.

Those with mental retardation only are most often mildly or moderately retarded, are mobile, able to look after themselves with some supervision, and often able to do simple tasks. The aging process in these individuals follows closely that of the general population. Since many patients in this group have problems verbalizing their health complaints (Van Schrojenstein Lantman-deValk et al., 1997) screening techniques to detect conditions associated with aging are advisable and perhaps even more important than in the general population.

The Case of Fred

Fred had a moderate degree of intellectual impairment. The cause of this impairment was not known. While he could understand what he heard, his ability to speak clearly was severely limited. He chose to be by himself, could do menial tasks such as picking up litter, and he had few health problems until he reached his seventies. At that time, he developed cataracts, had an occasional bout of pneumonia, and died of a myocardial infarction at age eighty-four years.

A second sub-group has mental retardation with neurologic signs and/or epilepsy. Aging in this group involves consideration of their mental retardation, associated medical problems (such as epilepsy), secondary medical problems (such as a predisposition to aspiration) and, for many, genetic predispositions that may contribute to deteriorative changes.

The Case of Betty

Betty was a profoundly intellectually impaired woman with tuberous sclerosis who died of pneumonia at age thirty-three. She had experienced several episodes of spontaneous pneumothorax. She was non-ambulatory because of spasticity and had a seizure disorder.

Betty showed the mental retardation, the genetic predisposition, and associated features of tuberous sclerosis. It is possible that aspiration, a secondary process, contributed to her pneumonia and early death. Chronologically Betty was not old, but on the other hand, multiple, progressive, deteriorative processes led to her death.

Individuals with Down Syndrome represent a third subcategory. It has been known for years that persons with Down Syndrome have a unique aging profile. Martin (1977) using 21 criteria for aging found that Down Syndrome scored higher than any other syndrome. As well as the well known increased frequency of Alzheimer's dementia, there are increases in chromosomal aberrations, malignancy, premature greying or hair loss, aging pigment deposition, hypogonadism, diabetes mellitus, autoimmunity, degenerative vascular disease, cata-

ract, and skin and adipose tissue changes (Lott & Lai, 1982; Martin, 1977; Wright & Whalley, 1984).

The Case of Beatrice

Beatrice began to walk at two years of age and said her first words at age five. She was considered to be moderately intellectually impaired. She grew to be a happy woman who liked social contact and was able to work in the laundry. Menopause occurred at age forty-three. She developed cataracts and had a cataract extraction and lens implant at age forty-seven. Hypothyroidism began at age forty-nine, and also at this time, she developed tonic clonic seizures. Memory loss and other signs of dementia started in her early fifties, and she was described as "severely demented" at age fifty-seven. She died of pneumonia at age sixty years. Autopsy showed cerebral atrophy with other signs of Alzheimer's disease.

The mental adjustment of older persons, regardless of their particular sub-group, can be affected by sensory impairments or discomfort related to such problems as gastroesophageal reflux, urinary retention and osteoporosis. Maintaining mobility and fitness has many benefits for physical and emotional health (Frizzell, 1997). It is an important factor in preventing osteoporosis. The goal should be to accumulate thirty minutes of moderate intensity physical activity most days of the week (Frizzell, 1997).

The occurrence of cancer increases logarithmically with age (Wright & Whalley, 1984). Cancer prevalence in adults with mental retardation aged sixty - ninety years was found to be

comparable to that of the aging Dutch population (Kapell et al., 1998). There are two apparent exceptions. There is an increased incidence of chronic myeloid leukemia in Down Syndrome (Wright & Whalley, 1984), and esophageal adenocarcinoma is higher in the mentally retarded group, possibly due to the increased prevalence of gastroesophageal reflux (Evenhuis, 1997a).

Cardiovascular problems appear to occur more frequently in some syndromes associated with mental retardation. For instance, in both Down Syndrome and fragile x syndrome individuals there is an increased risk of mitral valve prolapse (Goldhaber, Brown, & Sutton, 1987; Loehr, Synhorst, Wolfe, & Hagerman, 1986). There is some question whether the rate of hypertension among adults with developmental disability is the same as, or less than, the general population. In an unpublished study comparing 220 adults with developmental disabilities to 80 adults without developmental disability in Southeastern Ontario, Ouellette-Kuntz and Craig (1999) found the rate of hypertension in the developmentally disabled group to be 13.6 percent compared to 15 percent in the non-developmentally disabled group. Evenhuis (1997a) reported a lower prevalence of hypertension in those with intellectual disability aged sixty-five years and older than has been reported in the general Dutch population (Evenhuis, 1997a).

There is a perception that health care for the developmentally disabled is often not what it should be (Turner & Moss, 1996). If this is so, it is unlikely that the aging person with this condition will receive any better care than younger patients. Improving health care may require training programmes for family physicians and other primary care professionals (Turner & Moss, 1996). Because of communication difficulties, even

those with mild intellectual impairment cannot be counted on to express their symptoms adequately (Turner & Moss, 1996). Changes in behaviour may be the only way that they can communicate a medical problem.

Mental Health Disorders

This section reviews the mental disorders that occur in older persons with developmental disabilities and the management of these disorders in relation to universal experiences of growing old. The difficulties involved in the differential diagnosis of mental disorders in persons with developmental disabilities (King, De Antonia, McCracken, Forness, & Ackerland, 1994; Verhoeven & Tuinier, 1997) are no less in older individuals. Of the various disorders, dementia is obviously one that commences in later years. This contrasts with other disorders that begin early and are variably persistent over many years. "Behaviour problems" tend to be less prevalent in older persons (Day, 1994), affective disorders and dementia more prevalent, and other disorders unchanged. (Van Schrojenstien, Lantman-deValk et al., 1997)) In managing individual referrals, clinicians must carefully assess the impact of recent or current stressors along with the features of any identifiable mental disorder.

Behaviour Problems

The Case of Sally

This sixty year old woman has a mild degree of intellectual impairment. She grew up in a lower socio-economic environment in northern Ontario, and was committed to a special residential setting for delinquent females in her

late teens. This was characterized by severe aggression and destructiveness. She was treated with high doses of thioridazine and was often secluded because of dangerousness to others. She was transferred to a residential setting for persons with developmental disabilities at 34 and discharged to the adjacent community at 36. She performed domestic duties in a boarding home for many years, is proud of her good adjustment in the community, and now plans to retire. Unfortunately, she has recently developed failing vision because of a thioridazine-induced retinopathy.

Sally's case illustrates the fact that many mildly intellectually impaired individuals who have major problems in early life can stabilize over time. Also illustrated, is one of the unfortunate side effects of treating disturbed behaviour with thioridazine, a special concern given that it is a popular agent in the group of neuroleptic drugs prescribed for 42% of older persons with developmental disabilities (Pary, 1993). There are alternative medications for aggression (Fava, 1997) and neuroleptics should be used ideally only for those with psychotic symptoms.

Behaviour problems tend to be more persistent in those with severe intellectual impairment who reside in residential centres. Reid, Ballinger, Heather, & Melvin (1984) note that "hostile irritability," stereotypy, overactivity, self injury and social withdrawal continued over a six year interval in a British follow-up study. In Arkansas, Bihm, Poindexter, and Warren (1998) observed that 11% of a residential population were seriously aggressive; they were more often diagnosed as "psychotic" or described as being "demanding and needy", prompting a wise recommendation: "Aggression should not be

viewed in isolation, but seen as part of a complex set of factors, including related behavioural disturbances, psychiatric disorders and environmental determinants."

Since behaviour problems decrease in prevalence over time in those who have mild intellectual impairment, and persist in those more severely impaired, the development of behaviour problems for the first time in later years in any individual with a developmental disability should alert the clinician to consider dementia, an affective disorder, or an adjustment disorder.

Schizophrenia

The Case of Gerald

Gerald was adopted at three and raised on a farm in Southeastern Ontario. A poor student, in his late teens Gerald became "easily led" and involved in a variety of delinquent behaviours. At 19 he stole a truck and was referred to a psychiatric hospital when the police observed symptoms suggestive of a mental disorder. On examination, Gerald had a severe thought disorder, reported auditory hallucinations, and simply laughed about his delinquent activities. Now 50, and living under supervision in a group home for the past three years, his psychotic symptoms have yielded only partially to treatment with various antipsychotic medications. A recent tendency to depressive moods, and in particular to attempts at bodily self harm (pierces his skin with sharp objects, swallows foreign objects) has prompted the addition of an antidepressive medication. Gerald is fortunately free of side effects associated with long term use of psychotic medications.

The diagnosis of schizophrenia can be made in the usual way in those with mild intellectual impairment. Referred to in the past as "pfropfschizophrenie," a recent study of 39 cases revealed more negative symptoms, episodic memory deficits, and chromosomal variants than in a control population (Doody, Johnstone, Sanderson, Cunningham-Owens, & Muir, 1998). As illustrated by Gerald's case, psychotic symptoms are variably present over many years and current practice, at least in cases where the patient may be dangerous to themselves or others, is "relapse prevention" with antipsychotic drugs (Kissling, 1992). Although Gerald has been free of worrisome side effects, clinicians should carefully monitor those on long-term therapy. Polydipsia and water intoxication occur in a small number of cases receiving extended treatment (Bremner & Regan, 1991); worsening of behaviour as the day proceeds and the development of confusion or seizures are often observed. Polydipsia and water intoxication are reported to be less likely when clozapine or risperidone are prescribed (Canadian Clinical Practice Guidelines for the Treatment of Schizophrenia, 1998). Much more prevalent, 34% of 53 individuals reviewed by Sachdev (1992), and potentially very disabling is tardive dyskinesia. Neither level of mental retardation nor indices of "brain damage" were shown to be associated with risk but increasing age, and especially "total neuroleptic load" (i.e., dose level and years of administration) are risk factors. Sachdev reported little difficulty in distinguishing various stereotypic movements in their patient population from the features of tardive dyskinesia. The dyskinetic movements were mainly seen in the lingual, perioral and other facial muscles; the disorder was rated as mild in 75% of those affected, and in only 2 individuals (12.5%) judged to produce any degree of incapacity. Vitamin E, 400 IU twice daily has been reported useful in the treatment of tardive dyskinesia

(Elkashef, Ruskin, Bacher, & Barrett, 1990).

Dementia

The Case of Joan

Joan, a lady with Down Syndrome, died at age 59. Post-mortem examination of the brain revealed severe Alzheimer's neuropathology. Since age 7, Joan had lived in an institution. She was independent in self help skills, stubborn but friendly and affectionate, and she enjoyed sheltered employment and a variety of leisure activities. At age 50, her work skills deteriorated. By 54, she was described as apathetic and less sociable. Between 56 and her death she was supervised in the infirmary unit because of aimless wandering, incontinence, and yelling at/ hitting her caregivers. The post-mortem examination, in addition to Alzheimer's neuropathology, revealed aspiration pneumonia.

Although the prevalence of dementia is higher in persons who are mentally retarded than in the general population (Cooper, 1997), this is especially true for those, like Joan, with Down's Syndrome. A continuing puzzle relates to observations of universal brain changes characteristic of Alzheimer's disease in those with Down's Syndrome beyond age 40 when clinical evaluation has shown much lower rates of dementia (Zigman, Schupf, Zigman, & Silverman, 1993). The prevalence rate of dementia increases with age; the rate in the age range over which Joan demented (i.e., 50-59) is 40% (Holland, Huppest, Stevens, & Watson, 1998). Although there are case reports of much older individuals who are free of cognitive deterioration

(Chicoine & McGuire, 1997), prospective studies reveal signs of progression and the usual course of dementia seen in members of the general population with Alzheimer's disease (Oliver, Crayton, Holland, Hall, & Bradbury, 1998). Contemporary research suggests a role for alleles of the Apolipoprotein E system on chromosome 19 in determining the progress of the dementia (Alexander et al., 1997). Use of antioxidants like selegiline and vitamin E may delay functional decline, although these preparations have not been studied specifically in persons with Down Syndrome (Pary, 1997).

Dementia in persons who are mentally retarded not due to Down Syndrome appears to have similarities to the general population in terms of etiology and natural history. Evenhuis (1997b) studied 11 cases: Alzheimer's disease in 4, vascular disease in 2, mixed Alzheimer and vascular in 2, and unclear in 3 cases; and noted: "Frequent and severe physical comorbidity, especially sensory loss and mobility impairment, additionally affected the patient's level of social functioning and hampered our interpretation of their cognitive function loss." Aylward, Lai, and Dalton (1997) have proposed standardized criteria for the diagnosis of dementia in individuals with intellectual disability. They stress the desirability of "baseline" observations prior to the onset of cognitive or behavioural changes and the importance of excluding other disorders such as hypothyroidism and depression in those with Down Syndrome, folic acid abnormalities in patients on anticonvulsants and cognitive deterioration secondary to prescribed or non-prescribed medications. Gedye (1998) has documented four cases of reversible dementia associated with the use of neuroleptic medications. Clinicians will find a set of practice guidelines for the assessment and management of Alzheimer's disease and other dementias among adults with developmental disability

(Janicki, Heller, Seltzer, & Hagg, 1996) helpful in managing these challenging individuals, and in supporting their caregivers.

Affective Disorders

The Case of Wilfred

Wilfred, now 64, presented 10 years ago at the psychiatry clinic at a regional institution for persons with developmental disabilities. Since his admission there at age 13 he was described as having "behaviour difficulties" along with a mild degree of intellectual impairment. Like many residents in the institution, his behaviour difficulties had been treated with various phenothiazine tranquillizers. It became clear on careful review of the pattern of Wilfred's behaviour that he was subject to extended periods of depression characterized by agitation, weight loss, insomnia, hypochondriasis, irritability and aggressive outbursts. His antipsychotic medication was tapered and discontinued; treatment with antidepressants and electroconvulsive therapy (on two occasions since he was first assessed) has been quite successful. Between episodes of depression he is well adjusted, friendly and cooperative. His sister reports that their late mother and two maternal first cousins were subject to severe depressive episodes.

Over recent years it has become clear that persons with developmental disabilities may reveal a depressive disorder in a somewhat atypical manner (Charlot, 1998; Myers, 1998). Wilfred's case is a good example in that major behavioural features overshadowed the more classical features of depres-

sion such as lowered mood, crying, or wishing for death. The positive family history for depression also serves as an indicator of risk. Persons with developmental disabilities and affective disorders, including those in the bipolar subgroup, (King et al., 1994) can be treated in the usual manner with antidepressant drugs (Guidelines for the diagnosis and pharmacologic treatment of depressions, 1999) or with electroconvulsive therapy (Lazarus, Jaffe, & Dubin, 1990). Suicidal behaviour appears to be less common in persons with developmental disabilities although occasional case reports reflect its presence even in individuals with severe intellectual impairment (Walters, 1999).

Grief reactions represent an important differential diagnosis. Symptoms such as irritability, lethargy and hyperactivity and significant scores for depression and anxiety on the PIMRA (Psychopathology Instrument for Mentally Retarded Adults) were reported in a controlled study of bereaved adults by Hollins and Esterhuyzen (1997). A parent's death frequently leads to other stressful "life events" – for example, 39% of the subjects in the study needed to change their residence as a result of the deceased parent's final illness. In counselling those who are bereaved, clinicians may wish to use books specifically designed to support persons with developmental disabilities in their mourning process (Hollins & Sireling, 1994a; Hollins & Sireling, 1994b). As well, younger mothers and fathers should be encouraged to engage in "permanency planning" (i.e., preparing plans for living arrangements, guardianship and financial security after the parents' death) so that the developmentally disabled family member does not experience simultaneously the double blow of bereavement and residential relocation.

Although depression and anxiety frequently coexist, the detection of subjective anxiety (i.e., excessive worry, fear of a particular stimulus, or sensation of choking/palpitation) is difficult in persons with developmental disabilities; observable features of anxiety such as "hides or shields face when confronted with unfamiliar people or situations," "looks down a lot," restless, trembling, shaking, can be reliably diagnosed (Matson, Smiroldo, Hamilton, & Baglio, 1997). Stavrakaki and Mintsioulis (1997) reported that 27% of referrals to an Ottawa clinic had an anxiety disorder; only 3 persons, all females, beyond age 50 were included in this study group. A special concern in older individuals is their emotional reaction to physical disorders associated with aging. Evenhuis (1997a) in a study of mobility, internal conditions and cancer in those over 60 years of age, was struck by the absence of spontaneous complaints even in subjects with mild degrees of intellectual impairment: "Marked visual impairment, hearing loss, chest pain, dyspnea, dyspepsia and micturition problems were just tolerated or experienced atypically as irritability, inactivity, loss of appetite or sleep problems." In meeting the clinical challenge implied in these observations, Evenhuis notes that diagnosis and intervention for these conditions require: (i) knowledge of specific risk factors and atypical presentation of symptoms, (ii) close observations by carers and (iii) regular routine diagnostic screenings. The deficiencies in health care provision observed by Cooper (1997) in Britain and Edgerton, Gaston, Kelly, and Ward (1994) in the USA would suggest that these requirements are unlikely to be met unless much more support is made available to older persons with developmental disabilities.

Autism and Autism Spectrum Disorders

The Case of Jack

Jack, now 54, developed normally until age 2 ½ when he stopped relating to others, no longer used words, and was content to swing or rock. Born to wealthy Canadian parents, he spent 3 years in a New York residential treatment program and another 2 years in a similar program in Boston. His autistic features persisted in spite of treatment, and he was placed in a group home for persons with mental retardation in southeastern Ontario. At times restless and self-injurious, he seemed most content in the company of a mildly retarded teenage girl. He developed grand mal seizures at 16. At 20, when the teenager left the group home, he became very self-abusive and was admitted to a psychiatric hospital. Trials on various medications (haloperidol, fenfluramine, Vitamin B6 and sertraline) were not successful, and he continues only on carbamazepine for seizure control. Two years ago, he was placed in a group home. While he makes some eye contact he remains aloof, makes only grunting sounds, and requires assistance with daily living skills. He is rarely self-abusive now.

Jack's history is typical of autism, although in many instances the disorder appears to be present from birth rather than commencing after a brief period of apparently normal development. Gillberg (1995) refers to autism and "autistic spectrum disorders (including childhood schizophrenia)" as "disorders of empathy." There are significant challenges in establishing the adult prognosis in childhood although severe intellectual im-

pairment and the absence of socially useful language predict the poor adult prognosis illustrated in Jack's history. Since many with less severe symptoms present for the first time in adulthood with depression or antisocial behaviours, clinicians need to search for the characteristic early features if the correct diagnosis is to be made. This is especially true of those with Asperger's syndrome and "high functioning autism" who may remain undiagnosed until well into adulthood or receive diagnoses such as schizoid or schizotypal personality disorder, type II schizophrenia, atypical depression, paranoid disorder or obsessive compulsive disorder (Gillberg, 1998). Gillberg (1995) reports that 30 to 40% of those with autism develop seizures before 30 years of age. Aman, Van Bourgondien, Wolford, and Sarphare (1995) surveyed medication use in those with autism: more than 50% of the sample was taking some psychotropic, anti-epileptic, vitamin or "medical" agent; caregivers were most satisfied with anticonvulsants, antidepressants, and stimulants. Although there was a wide age range in the study (1-82 years), and the likelihood of receiving some form of medication increased by 3.2% for each year of age, the mean age of 16 years for the sample suggests that the survey was predominantly concerned with younger individuals than Jack. An independent study of the reported benefits of the use of high doses of vitamin B6 was recommended. Recent observations on the use of risperidone suggest that this preparation may be particularly useful in treating autistic symptoms (McDougle, Holmes, Carlson, Pelton, Cohen, & Price, 1998).

Diogenes Syndrome (Senile breakdown, senile squalor syndrome)

The Case of Albert

Albert, aged 55, appeared at the clinic only because he wished a mental assessment relevant to having his motor vehicle operator's license reinstated. He reported that he had grown up in an institution for the mentally retarded and had worked on a farm between age 20 and the farmer's death 22 years later. He acknowledged a severe drinking problem on the farm, but abstinence over the past 12 years. He lives alone. He receives a disability pension. He is socially isolated and travels about the city on a bicycle. There are numerous bags attached to his bicycle full of junk or garbage that he collects and hoards. He is poorly groomed, dirty and foul smelling. There were no indicators of psychosis. His concreteness and limited fund of general knowledge suggested a mild degree of intellectual impairment. Satisfied that a letter reporting his assessment would be sent to the license bureau, he rejected any further "help" or follow-up.

Although the Diogenes syndrome was first described over 30 years ago (MacMillan & Shaw, 1996), only recently have cases with mental retardation been reported (Williams, Clarke, Fashola, & Holt, 1998). The literature is obviously biased in terms of various selection factors, like Albert who only came forward because of his license situation, and only half of the individuals reported to date have a recognizable mental disorder. Albert's extreme self neglect, social withdrawal and hoarding are typical; although his living conditions were not

observed one can assume, given the balance of his appearance and demeanor, that there was domestic squalor and a lack of concern about living conditions (Cooney & Hamid, 1995). His case appears to support the hypothesis that the Diogenes syndrome may occur in persons with developmental disabilities as a manifestation of "intellectual disability (e.g., poor social and adaptive functioning) coupled with inadequate support" (Williams et al., 1998, p. 318). Albert was reported to have functioned more normally, his abuse of alcohol notwithstanding, as long as the farmer who employed him survived. The need to balance "individual rights and wishes of patients, and the need to attend to their health needs" (Cooney & Hamid, 1995) in intervening with those with Diogenes syndrome, is no less in those cases where a degree of intellectual impairment co-exists. In Albert's case, his only known "support" is the director of a programme concerned with helping those who wish to overcome drinking problems, a programme that he appeared to have used to advantage.

Comment

Centuries ago Aristotle believed that a living organism started life with an innate latent heat which gradually dissipated over time and eventually disappeared (Roy, 1987). Selye (1980) felt that persons were born with only so much energy or ability to adapt and that stresses of various kinds caused a gradual reduction of this energy leading to aging and eventual death (Selye & Prioreschi, 1960). More recent theories have assumed a "biological clock" that ticks away within the brain, controlling not only the daily, monthly and yearly biological cycles of our lives, but the greater cycle that takes us through infancy, childhood, adolescence, adulthood and old age. Hayflick (1965) has demonstrated that mammalian diploid cells

from certain tissues, when cultured in vitro, have a finite life span, and that embryonic cells double more times than mature cells. Clearly, a factor within the cells changes over time finally leading to loss of vitality in the cell. A worn out telomere may be the aging factor that causes the cell to eventually self-destruct (Shiels et al., 1999). As well, cellular aging may be the result of ongoing damage to the biomolecules of cells from reactive oxygen species which are continuously formed from the oxidative metabolism of glucose. This damage leads to a decline in the ability of cells to function and duplicate, leading to deterioration of function of the entire organism (Mann, 1997). It is interesting and perhaps evidence for this mechanism of aging that Trisomy 21 individuals (Down Syndrome) have an extra copy of the superoxide-dismutase gene. This may accelerate the aging process seen in this syndrome (Dickinson & Singh, 1993).

Developmentally disabled persons make up a diverse group with over three hundred etiologies identified as contributing to mental retardation. We may assume that many of the syndromes associated with mental retardation, as appears to be the case with Down Syndrome, have their own peculiarities in the aging process. Indeed, evaluation of how persons with developmental disability age may answer some of the broader questions of aging that are front and centre as we enter the 21st century.

Do You Know?

1. Why those with multiple disabilities have higher death rates than persons with intellectual impairment alone?
2. Why persons with Down Syndrome are thought to have a unique aging profile?
3. Which categories of mental disorder increase in prevalence with age?
4. Two disorders that may be easily confused with Alzheimer's disease in older persons with Down Syndrome?
5. What is entailed in permanency planning?
6. What characterizes Diogenes Syndrome?

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