People with learning disability, and ageing

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Abstract

With the increase in lifespan, age-related mental and physical health problems have become evident in people with learning disability. Owing to the heterogeneity of the population, the nature and extent of age-related changes has not been explored fully. This article describes the mental health problems in older adults with learning disabilities with a focus on dementia, and highlights current evidence-based practice. To date, the main focus of research and service initiatives related to ageing has been on dementia in Down syndrome, despite the fact that a substantial proportion of older people with learning disabilities in general suffer from a variety of health problems. Clinical practice varies considerably within UK, and the link between community learning disability teams and mental health services for older people is not well established in many areas. The clinical challenges are related to a lack of standardized assessment processes and difficulties in carrying out the full range of investigations in some cases. The recently published national guideline on dementia in people with learning disabilities has now set the expected service standards and provides an audit tool against which quality of care can be measured. It is to be hoped that this will encourage the development of a dementia care pathway, removing the barriers in access to services for older people with learning disabilities.

Keywords ageing; assessment; dementia; Down syndrome; genetic disorders; learning disability; management; older people

Introduction

People with learning disability are living much longer now. The mean life expectancy has increased from less than 20 years in the 1930s to well over 60 years today.[1] The development of healthcare over the years has had a major impact on the longevity of people with learning disability. However, the increase in lifespan is not uniform across the population with learning disability. People with severe/profound learning disability and those with multiple health problems have a lower life expectancy. The average life expectancy of people with Down syndrome is about 55 years.[2]

People with learning disability show a decline in behavioural and physical abilities earlier than expected in the general population (Table 1). However, owing to the heterogeneity of learning disability, the nature and extent of age-related change may vary widely. Factors such as the cause and degree of learning disability and associated ill-health have a significant impact on how people are affected by ageing. The significant differences in social support networks compared with those in the general population may also have an impact on how people with learning disabilities are affected by the ageing process.

The impact of ageing on health inequalities in this population as a whole is largely unexplored. For example, most of the community learning disability services are not equipped to manage the changing needs of the older people among their service users. Lack of clear service provision for older people with learning disability is a key issue for both health and social care services.

Factors affecting the ageing process

Ageing in people with learning disability is affected by a number of contributing factors across the biological, psychological, and social continuum.

Genetic syndromes

An underlying genetic disorder may affect the ageing process. The most dramatic evidence is seen in the case of people with Down syndrome, where the onset of an Alzheimer's type of dementia may occur from as early as 30 years of age, reaching a peak prevalence in the fifth and sixth decades of life.[2] In particular, free radical involvement may be involved in the premature ageing in people with Down syndrome.

Other syndromes, such as phenylketonuria, have been reported to be associated with deterioration in behaviour and skills in later life as a result of increased levels of phenylalanine. Cockayne syndrome, a rare autosomal recessive disorder that is usually identified in the second year of life, has been used as a model of accelerated ageing. It was first described in 1936 and is characterized by growth retardation, learning disability, skeletal and retinal abnormalities, progressive neurological degeneration, and severe photosensitivity. The mortality rate is high, with a lifespan of approximately 20 years.

Ageing and ill-health

Older people with cerebral palsy appear to develop certain age-related changes that include becoming lethargic and developing significant bone changes, muscle atrophy, and spasms. There is a high prevalence of other physical health conditions such as hypothyroidism, epilepsy, obesity, and repeated respiratory and urinary tract infections, which often are not diagnosed early and treated appropriately. As people age, the impact of long-standing health problems on general well-being is likely to become more marked.

Social and developmental influences on ageing

People with learning disability have less opportunity for social relationships outside the family circle. Families with an individual

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Impact of ageing on physical health

System	Effects of ageing
Cardiovascular	Decrease in elasticity of blood vessels and heart valves; restricted blood flow due to thickening of vessel walls and fatty deposits lining the vessels; and decrease in the ability of the heart to pump out as much blood with each beat
Respiratory	Decreased elasticity of lungs
Muscular	Gradual loss of muscle tone, elasticity, and strength; in some areas, the muscle may be replaced by fatty tissue
Skeletal	Gradually changes over the years until it is porous and brittle, as the bones lose calcium and their density; may be more pronounced in women
Metabolic	Gradual decline in activity of thyroid gland, and in the ability of the pancreas to produce insulin, resulting in a decrease in the body's ability to use fats and sugars and to convert them into energy
Digestive	Gradual slowing of the system as well as reduced secretion of saliva and the enzymes necessary for digestion
Central nervous	Cognitive slowing, dementias
Sensory	Visual and hearing impairments
Genitourinary	Ability of kidneys to filter and re-absorb may be reduced. Men show a tendency towards prostate enlargement; women have hormonal changes related to menopause

Table 1

with learning disability may become socially isolated. Most single carers of people with a learning disability are mothers. Elderly carers may have their own needs due to ageing, and this may lead to a reversal of carer role. Such complex care arrangements require close coordination of services from a variety of perspectives, such as learning disability and older people's services.

Physical health

A main cause of death in older people with learning disability is respiratory tract illness, and in those with dementia there is a high risk of choking and aspiration pneumonia.

A study by Cooper[3] showed that incontinence and mobility problems are higher in older people than in younger people with learning disability. The older group suffer from visual impairments secondary to senile cataracts and glaucoma, and hearing impairments. Older adults with Down syndrome have an increased risk of early development of age-related visual and hearing impairment[4] and epilepsy.

Older people with learning disability may receive poor quality of services, have less access to healthcare, and usually receive help only in the later stages of illness.[5]

Mental ill-health

Published studies have shown that those aged over 65 years have higher psychiatric morbidity rates than their younger peers (68.7% versus 48%), particularly depression and anxiety.[6] A study by Patel et al.[7] found that 21% of people over the age of 50 had various mental health problems. Other than dementia, depression and anxiety were the main mental health problems.

There is no evidence to suggest that the presentation of mental health problems is different from that in the younger population.

Dementia in people with learning disability with and without Down syndrome

The neuropathological signs of Alzheimer's disease are evident in nearly all individuals with Down syndrome over the age of 40 years. The prevalence of dementia in people with Down syndrome aged 35–49 years is approximately 8%. In the subsequent years the prevalence rises rapidly, and in those aged 60 years or more it is 50–75%.[8,9] However, some individuals with Down syndrome live beyond the age of 60 years with no evidence of dementia.

The prevalence of dementia in people with learning disability without Down syndrome is three times higher.[6,10] A recent epidemiological study of an ageing cohort suggested that that prevalence rates vary depending on the diagnostic criteria used, with DSM-IV giving the highest and ICD-10 the lowest rates.[10] The rate of dementia using DSM-IV in this study was 13.1 in those over 60 years and 18.3% in those over 65 years. Alzheimer's disease, Lewy body dementia, vascular dementia, and fronto-temporal dementia were the four most common types of dementia identified in older people with learning disability.

Clinical presentation

The clinical presentation of dementia is different in people with learning disability (Table 2). Although all cognitive functions are affected, most of the problems that may precipitate a referral to services concern deficits in activities of daily living. In people with Down syndrome, behaviour and personality changes are seen at the early stages of dementia.[11] There is also a strong association with adult-onset epilepsy (generalized tonic-clonic as well as myoclonic types). Clinical presentation may be hindered by lack of information about previous level of functioning, especially in individuals with severe learning disability.

Staging of dementia is difficult in people with learning disability. The symptoms vary according to the severity of the learning disability. For example, apathy, daytime drowsiness, and loss of self-help skills are more evident in those with moderate learning disability, whereas deterioration of gait, myoclonus, and seizures are more obvious in those with severe learning disability.

Assessment of dementia

Assessment of dementia in people with learning disabilities follows the same general principles as that in the general