

Health Guidelines for
Adults with an
Intellectual Disability

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Health targets were developed by individual members of the Special Interest Research Group on Physical Health, on behalf of the International Association for the Scientific Study of Intellectual Disabilities. The targets were presented and discussed at various international meetings and were further refined by experts in each target area and were restyled guidelines. The guidelines identify the health disorders that are most prevalent in people with intellectual disability and make recommendations for their prevention and management. The guidelines have been presented to WHO and it is hoped that international recognition of these frequent conditions will improve the health and healthcare of disabled people. This paper will discuss the development and implications of the guidelines.

2.1 Dental health

While the epidemiology of dental disease in people with an intellectual disability has not been extensively studied, several studies have indicated high rates of dental disease in this population. An Australian study (Scott et al 1998) noted that various types of dental disease, particularly periodontal disease, oral mucosal pathology, and moderate to severe malocclusion, were up to seven times as frequent compared to the general population. In a population study of adults with an intellectual disability, Beange et al (1995) found that dental disease was the most frequent health problem, occurring in 86% of subjects.

Recommendations

- Education and behavioural interventions, which ensure that appropriate dietary habits are established and oral hygiene practices are made a part of the daily life of persons with ID, should be directed toward individuals with ID, and their caregivers, to the maximum extent possible.
- Schedule dental visits for oral examinations and prophylaxis at three-month intervals for those with active disease and those at high risk for oral disease (most ID patients) and every six months for persons judged to be at low risk by the dental care team. This should be part of the overall health maintenance program for persons with ID.
- Preventive therapies such as fluoride or anti-microbial agents should be implemented where indicated.
- Multidisciplinary team approaches incorporating input from medical professionals and mental health providers, as well as dentists and dental hygienists, need to be adopted in many patients to ensure optimal oral health. (Santos et al 1999).

2.2 Sensory impairment

Sensory impairments amongst people with an intellectual disability have health, educational and environmental implications. Individuals with such impairments may be relatively more handicapped because of the superposition of age-related losses upon childhood impairments, and the frequent combination with a motor handicap or a dual sensory handicap.

2.2.1 Vision

High frequencies of ocular disorders have been found in several surveys (Wilson & Haire 1992; Warburg & Rattleff 1992; Warburg 1994; Cathels 1993; McCulloch et al 1996). In a large community survey, Warburg (1994) found that non-correctable visual impairment was present in 10% of adults, at least 7 times higher than in the general population. Adults with Down syndrome aged 30 years and over are at risk for premature age-related cataract (Eissler & Longenecker 1962), increasing refractive errors, and degenerative corneal changes (Völker-Dieben et al 1993).

Recommendations

For adults with an intellectual disability, routine screening for age-related visual loss at 45 years and every 5 years thereafter has been recommended (Evenhuis & Nagtzaam 1998). If possible this should be done by an ophthalmologist. An extra vision check at age 30 years has been recommended for adults with Down syndrome.

2.2.2 Hearing

Deafness is common in this population, often unrecognised, and if recognised poorly managed (Wilson & Haire 1992; Howells 1986). Hearing loss as a result of impacted earwax is a frequent problem in adults with an intellectual disability (Crandell & Roeser 1993). Adults with intellectual disability aged 30 years and over, especially those with Down syndrome, are at risk for early age-related hearing loss (Evenhuis et al 1992).

Recommendations

Routine screening for age-related hearing loss of all adults at age 45 years and every 5 years thereafter has been recommended (Evenhuis & Nagtzaam 1998). If possible this should be done by an audiologist. Screening of the hearing function of adults with Down syndrome is recommended every 3 years throughout life.

2.3 Nutrition

Nutritional well-being is recognised as an important factor in maximising growth potential, maintaining health, and improving quality of life and longevity. Nutrition related health problems, particularly obesity and chronic constipation, are more common in people with intellectual disabilities than in the general population (Stewart et al 1994). People with severe disabilities and people with cerebral palsy have a high prevalence of dysphagia and gastro-oesophageal reflux disease (Böhmer et al 1996; Waterman et al 1992). This places them in a high-risk group for severe under-nutrition.

Nutrition risk screening has been recommended and implemented in programs for the elderly, for hospitalised patients and for early intervention in children (Campbell & Kelsey 1994). However, it has not been used widely with adults with intellectual disability.

Recommendations

Nutrition risk screening provides a systematic approach to improving recognition and management of nutrition problems that should also benefit adults with intellectual disabilities. Screening for nutrition related problems could be performed by anyone

working with people with disabilities provided a simplified screening tool is developed. The tool should use indicators of weight and weight change, eating abilities, general appearance and a simple assessment of their food and fluid intake. Some basic knowledge of nutrition and knowledge of and access to a referral system is also required. The criteria for referral should be clear and as specific as possible. Simple and safe nutrition interventions should be applicable with the use of basic nutrition educational materials (Amundson et al 1994; Foltz et al 1993).

Individuals at high risk should be referred for a more systematic assessment of nutritional status by an experienced dietitian. People with persistent underweight or overweight, eating and drinking problems, chronic constipation or specific medical conditions requiring more complex nutrition interventions (such as Coeliac disease) would be amongst those needing systematic assessment. A dietitian, preferably working with an interdisciplinary health care team, should review the screening form and conduct assessment of nutritional status. To be comprehensive, the process involves using medical, nutritional and medication histories; physical examination and anthropometric measurements; and biochemical data.

2.4 Prevent and treat chronic constipation

Constipation is significantly correlated with immobility, medication such as anticonvulsants, benzodiazepines, H₂-receptor antagonists or proton pump inhibitors, food refusal, and IQ<35 (Bohmer, 2001). Jancar described death from complications of constipation, with symptoms not always recognised. (Jancar, 1994)

Recommendation: There is a need for dietary assessment, as described under nutrition, and pro-active medical treatments.

2.5 Epilepsy

People with an intellectual disability have a significantly increased lifetime risk of developing epilepsy (Corbett 1988). There is an association with higher prevalence of epilepsy and increasing disability. Community data suggest prevalence figures of approximately 22% (Welsh Office 1995). The aetiology of epilepsy is complex reflecting that of the disability itself, though in some cases it would appear that the epilepsy itself causes the intellectual disability (Binnie 1990).

There is good evidence that epilepsy adds both additional morbidity and mortality (Forgren 1996). The morbidity includes the physical trauma of the seizures leading to fracture and soft tissue injury, hospital admission, the impact on learning and development through seizure activity and the complex social impact of seizures (Baxter 1999). Less well defined is the negative impact of anticonvulsant medication on learning and attention. It is also apparent that epilepsy adds to carer strain and burden (Wilson 1998). There is reduced life expectancy for people with an intellectual disability who have epilepsy – though this may be correlated with the degree of disability and thus additional morbidity.

Health guidelines should aim to

- Reduce seizure frequency
- Reduce epilepsy-related falls and fractures
- Reduce epilepsy-related admissions to hospital and emergency rooms
- Reduce atonic seizures
- Reduce side effects consequent to treatment (in particular, cognitive, emotional and behavioural)

- Reduce mortality due to seizures or accident in seizures
- Reduce epilepsy related morbidity in carers.

Recommendations

- Ensure all individuals with epilepsy:
 - have a plan for the acute management of seizures
 - have a yearly assessment for medication side effects
 - are assessed for accuracy of epilepsy diagnosis, appropriateness of current therapy and potential for improvement with further treatment
 - are not restricted in terms of social, educational or employment access as a result of their epilepsy
- Provide education on epilepsy to all individuals and their carers.
- Ensure all individuals and their carers have appropriate education on hazard, especially safe bathing and water hazard.
- Ensure respite services are available which can support the management of seizures, in particular the administration of rectal diazepam.

2.6 *Thyroid disease*

Thyroid disease can be difficult to diagnose, particularly so in patients with developmental disability. Often the only 'symptom' is reported by the carer, usually mother, who observes that the patient's behaviour has changed in some non-specific way. (Wilson & Haire 1992).

Recommendations

Thyroid disease should be considered at any new presentation. Thyroid function tests should be performed on any unusual presentation and annually in high risk subgroups (patients with Down syndrome and patients with a previous history of thyroid disease). Thyroid function tests should be performed every three to five years in other patients with development disability. The management is usually straightforward but may involve supervision of medication.

2.7 *Mental health*

Psychiatric disorders are more prevalent in people with an intellectual disability compared with the general population (Tonge & Einfeld 2000; Borthwick – Duffy & Eyman 1990; Corbett 1979; Gostason 1985; Reiss 1993; Rutter et al 1976). Specialist psychiatric services are available in countries such as the UK and the USA, however the provision of high quality psychiatric services remains a concern in many countries (Parmenter 1988; Lennox & Chaplin 1995; Lennox & Chaplin 1996; Molony 1993; White et al 1995; Beange et al 2000).

Recommendation

Health services should implement strategies to maximise the quality of identification and management of mental disorders.

2.8 *Gastro-esophageal reflux disease (GERD) and Helicobacter pylori*

GERD is a major clinical problem in people with an intellectual disability, overlooked and underestimated (Böhmer et al 1997a; *ibid* 1999; *ibid* 2000). The prevalence of GERD and reflux esophagitis (RE) in people living in institutions is very high, especially in those with specific and well-defined risk factors. In a Dutch institutionalised population, approximately one third of individuals with IQ<50 were diagnosed with RE (Böhmer et al 1999). Possible predisposing factors include scoliosis, cerebral palsy, use of anticonvulsant drugs or other benzodiazapines, & IQ<35. Symptoms indicative of reflux are vomiting, haematemesis, rumination and depressive symptoms. *Helicobacter pylori* infection is increased in populations of children and adults with an intellectual disability (Böhmer et al 1997b). This infection can cause peptic ulcer and gastric carcinoma (McColl et al 1998).

Recommendations

Identify and treat gastro-esophageal reflux disease and illness from *Helicobacter pylori* infection. Treatment should be undertaken with the same indications as for the general population.

2.9 Osteoporosis

Osteoporosis has been shown to occur with high prevalence among people with developmental disability, including an unselected population sample (Center et al 1998). Factors associated were small body size, hypogonadism, and Down syndrome. Sub groups of people with intellectual disability are at increased risk of fracture (Tannenbaum et al 1989), and an increased risk of falling has been documented (Spreat & Baker-Potts 1983). Falls and osteoporosis should be prevented where possible to decrease the frequency of fractures, which cause pain and further disability. Special attention should be given to persons on anticonvulsants, who are at increased risk of fractures (Tohill 1997).

Recommendations

Osteoporosis is common and would be best prevented. This requires a global approach, with the life long goal of optimising activity and nutrition, particularly calcium intake. People with an intellectual disability should be screened by osteodensitometry at least once in early adulthood; further decisions regarding progress screening should be based on that result. Individuals who have low sunlight exposure either due to management practices or to local climatic conditions, or are receiving anticonvulsant therapy, should have Vitamin D status assessed, and a Vitamin D supplement if identified as deficient (Compston 1995). All women should have bone mineral density assessed at the time of cessation of menstruation regardless of the reason for menopause, and all hypogonadal men require assessment (Eastell et al 1998). The local recommendations for treatment of osteoporosis in the general population should be followed and any decision to provide a different standard of care from that of the general population should be explicit.

2.10 Medication review

Polypharmacy (Reiss & Aman 1997) and inadequate medication review (Beange et al 1995) are acknowledged problems in this population. However, many individuals need daily medications because of the high prevalence of epilepsy, psychiatric disorders, and other serious disease. The nature of intellectual disability is such that affected individuals have limited ability to consent to medication or to monitor efficacy and side effects of medication.

Recommendations

Medication should be regularly reviewed, ideally every three months and particularly when polypharmacy exists (Beange et al 1995; Aman 1987; Gowdey et al 1987; Reiss & Aman 1997). Prescribers need to acknowledge the inherent difficulties with monitoring (Tu 1979; Reiss & Aman 1997) and ensure that the patient and carers safely and reliably administer medication, are able to recognise adverse effects, monitor the efficacy of the medication and are aware of the review process. Systems for prepackaging doses for community based patients to maximise compliance and safety should be considered. Structured mechanisms for monitoring efficacy are valuable (Einfeld 1990). Consumer and carer education on the use of medication is important in ensuring compliance, recognising side effects and maximising efficacy. Continuing reevaluation should ensure the least effective dose. Side effects should be monitored and ineffective drugs discontinued.

2.11 Immunisation status

In a group practice survey, Kerr et al (1996) found that individuals with an intellectual disability were less likely to have received regular immunisations when compared with age and sex matched non-disabled controls.

Recommendations

Immunisation schedules for adults with an intellectual disability should follow national guidelines. At a minimum we should ensure that immunisation rates for adults with an intellectual disability are the same as for the general community. Hepatitis A and B immunisations are indicated for people who live in institutions, and Hepatitis B is indicated for contacts of persons who are Hepatitis B carriers. Immunisation against influenza and the pneumococcus is recommended for the medically vulnerable (US Preventive Services Task Force 1996).

2.12 Physical activity and exercise

Physical activity and exercise levels amongst adults with an intellectual disability are generally considered to be low (Beange et al 1995; Pittetti & Campbell 1991; Rimmer et al 1993). A lack of opportunity for exercise in spite of increased cardiovascular risk factors has been documented (Beange et al 1995). Immobility is a predictor for mortality (Hayden 1998) and life expectancy is related to activity in those with severe intellectual disability (Fenhall 1993). Evidence exists that physical activity reduces mortality and morbidity in coronary heart disease, hypertension, obesity, osteoporosis and mental health disorders (US Preventive Services Task Force). All these conditions are increased in intellectual disability.

Recommendations

The American College of Sports Medicine and the Centres for Disease Control and Prevention recommend 30 minutes or more of moderate intensity physical activity on most, preferably all, days of the week for the general population (US Preventive Services Task Force). It should be possible to ensure this amount of moderate activity for most disabled people. Two cardiovascular training programs have been developed for people with intellectual disability (Pittetti et al 1993). Some active or passive movement should be provided daily for those with limited mobility due to physical impairment. Some special services will be necessary for those who cannot access services for the general population.

2.13 Comprehensive health assessments

Many people with an intellectual disability need support to maintain a healthy lifestyle and access health services. There are numerous parallels between the elderly population and people with an intellectual disability. Both populations are heterogeneous, and are known to experience unrecognised or poorly managed health conditions. Periodic comprehensive health assessment has been demonstrated to be effective in people 75 years and over (Byles 2000). Current research suggests this process will result in improved health in people with an intellectual disability also (Webb & Rogers 1999). For a vulnerable population, which has been found to suffer from multiple undetected and often obvious health problems (Beange et al 1995; Howells 1986; Wilson & Haire 1992), this simple measure is likely to be effective.

Recommendation

Organise regular comprehensive physical assessment and review by a medical practitioner.

2.14 Genetics

A genetic aetiology is common in this population. A definitive diagnosis is important to the patient since it allows a better estimate of prognosis and the anticipation of complications. It is important to the family since it enables full discussion and understanding of the cause of the condition and allows informed genetic counselling (Curry et al 1997). Estimates of genetic aetiology vary because of differences in ascertainment and methods of study. In round figures, it is generally agreed that 40-50% of cases are genetic, 15-20% due to environmental factors and in 30-45% the cause is unknown. A significant proportion of the latter is also suspected to be genetic (Raynham et al 1996; Curry et al 1997; Hou et al 1998; Partington et al 2000).

Recommendations

Any patient without an aetiological diagnosis should be referred to a genetic clinic regardless of age. New genetic knowledge is constantly becoming available. Diagnostic reassessment at intervals is worthwhile even into adult life (van Gelderin 1992).

2.15 Women's Health

There is general agreement about the benefits of the main preventive screening services (Sox 1994; US Preventive Services Task Force 1996). Many countries have screening programmes available, and people with intellectual disability should take part in all these programmes. Clinical judgment is necessary to tailor the checkups to the needs of individual patients.

Recommendations

Papanicolaou smears are necessary if women have ever been sexually active. If the examination is distressing or difficult, the risks of a Papanicolaou smear with / without sedation need to be balanced against the benefits (Palmer 1999). Mammograms are recommended according to country policy for the general population.

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