Primary health care for adults with intellectual disability

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BACKGROUND In recent decades people with intellectual disability have moved from institutional care into the community and are now reliant on general practice services for their primary medical care. Their complex health needs present a considerable challenge to the general practitioner.
OBJECTIVE This article aims to outline the common physical and psychiatric conditions found in adults with intellectual disability, and the need for a structured approach to health care in patients with limited communication skills.
DISCUSSION Adults with intellectual disability frequently have undiagnosed health problems. In many cases these will only be identified by specific examination and testing. Health assessment tools offer a useful guide to which conditions to look out for. Early identification and treatment enhances quality of life for both people with intellectual disability and their carers.

In the past few decades, deinstitutionalisation of people with intellectual disability has brought more opportunity for integration and greater reliance on mainstream community services. Most primary health care for people with intellectual disability is now provided by general practitioners.

How does general practice care for people with intellectual disability shape up? Most GPs see themselves as the primary health care providers for this group[1,2] but many find it difficult to provide optimal care. Commonly perceived barriers include:

- lack of specific training.[1,2] This is currently being addressed by a number of medical schools[3]
- lack of exposure due to small numbers of patients with intellectual disability[4]
- time restraints[5]
- increased workload caused by patients with complex health needs[6]
- communication difficulty; information may need to come from the patient's carer,[2,5] and
- patchy liaison with specialist disability services.[6]

Preventive care

People with intellectual disability have similar health problems to the rest of the community, but are less likely to be offered health screening.[8] In addition, some conditions occur more frequently in people with intellectual disability. General practitioners may need specific information to enable appropriate screening. Many people with intellectual disability are unable to recognise or describe symptoms, or to localise pain. Specific testing is often needed to identify conditions that would be more obvious in other patients.[7]

Australia currently has no formal health assessment program for people with intellectual disability. A specifically designed tool, the Comprehensive Health Assessment Program (CHAP), is currently undergoing a large scale trial.[9] Patients and their carers are generally positive about the care they receive from their GP, but are concerned about lack of coordination with other services.[7] The Case history illustrates the use of a care plan to identify and address health problems in a coordinated way.

Common health problems

Vision and hearing problems

Adults with intellectual disability have high levels of impaired vision, hearing or both,[10–12] especially people with Down syndrome.[13] Impairment is likely to go undiagnosed without specific testing.

Many problems are amenable to cor-

rection with glasses, hearing aids or even the simple removal of earwax,[7] but many people with intellectual disability are not treated. Many more have out-of-date glasses or nonfunctioning hearing aids. Lack of cooperation and breakages are frequent issues. However, visual and hearing correction often leads to improved overall function.[12] Assessment may be difficult in a general practice setting and referral for testing with appropriate equipment and techniques may be necessary.

Gastrointestinal problems

Gastrooesophageal reflux

Up to 50% of people with moderate to severe intellectual disability have gastrooesophageal reflux.[14] Helicobacter pylori infection is common, especially in those who are, or have been, institutionalised.[15] Strictures, Barrett's oesophagus, peptic ulcer disease and gastric cancer are all more common than in the general community.[16] Predisposing factors include:

- immobility
- scoliosis, and
- drugs, particularly anticonvulsants and psychotropics.[17]

Reflux may present as vomiting, regurgitation, haematemesis, iron deficiency, dental erosions, food refusal, recurrent pneumonia, or behaviour disturbance. Many patients with reflux display no symptoms or signs and remain undetected. Testing may be difficult but can be managed with appropriate support. Response to H2 antagonists has been poor. Proton pump inhibitors have produced improved healing rates.[18]

Constipation

Constipation affects approximately 70% of people with moderate to severe intellectual disability. The causes include neurological conditions, side effects of medications, poor fluid and fibre intake and decreased mobility. Constipation may present as food refusal, restlessness or screaming episodes.[19] Treatment is difficult and often requires chronic use of multiple laxatives.[20]

Case history

Sally is a 27 year old woman with congenital rubella syndrome. She has moderate intellectual disability, mild to moderate hearing impairment and total loss of vision. She lives in a community group home with 24 hour care and visits her mother for one weekend each month. She is not known to be sexually active at present, but sexual abuse has been suspected in the past. She does not smoke or drink alcohol. Her immunisations are current.

Presenting problems

- frequent night waking and daytime sleepiness
- withdrawal, lack of engagement in activities, occasional aggressive behaviour
- inappropriate sexual behaviour: public masturbation and nakedness

Medications

- pericycazine 10 mg in the morning, 5 mg at night
- benztropine 2 mg per day
- Nordette 28 once per day

Positive findings on examination

- very limited communication (hearing aid lost), quiet and withdrawn
- height 146 cm, weight 56 kg, BMI 30
- CVS: soft systolic murmur, no other signs
- eyes: enophthalmos, no red reflex obtainable
- teeth: gingivitis
- breast examination: normal
- vaginal examination: refused with physical gestures
- urinalysis: glucose 3+

Investigations

- microurine: glucose 3+, no infection
- fasting BSL 6.9 mmol/L
- glucose tolerance test: 2 hour glucose 16.7 mmol/L
- normal FBC, U&Es and LFTs
- echocardiograph: structurally normal heart, trivial mitral and pulmonary regurgitation

A care plan[44] was devised for Sally after discussion with her carer and her mother (Table 1).

Cardiovascular disease

As life expectancy increases for people with intellectual disability, so does the risk of age related diseases such as cardiovascular disease and stroke. Many people with intellectual disability have untreated risk factors including hypertension, raised cholesterol, obesity, physical inactivity and tobacco smoking.[21–23] Testing, treatment and appropriately tailored education are needed.

Dental problems

Dental problems in people with intellectual disability are both common and easily overlooked. Common conditions include poor oral hygiene, gingival disease, untreated caries and heavy tooth wear due to grinding of the teeth.[24] Although dental care is not part of the GP's role,[25] the GP may need to consider dental problems as a possible cause for apparent pain or behaviour change and refer appropriately.

The dentist's job is often made difficult by communication problems and lack of cooperation due to behavioural or psychiatric problems. People with more severe disability may need sedation or even general anaesthesia for dental examination. As with GPs, many dentists lack specific training in this area.[26]

Table 1. Case history care plan

Problem	Needs	Goals	Tasks	Provider
Diabetes	Initiate treatment	Glycaemic control	Initiate treatment Review in 1 week	GP
Diabetes	Initiate home monitoring	Home BSL recording	Access and learn to use blood glucose monitor	Diabetes educator Care staff
Overweight	Weight control	Healthy weight loss	Review diet and physical activity	Dietician Care staff
Gum disease	Dental care Retain teeth	Improve dental hygiene	Dental check	Dentist
Hearing loss	Maximise hearing	New hearing aid	Hearing aid assessment	Hearing services
Sexual behaviour	Reduce risk of sexual abuse Behaviour acceptable to others	Awareness of public vs private behaviour Preparation for vaginal examination	Sexual health education	Disability educator FPA Health clinics
Possible mental health problem	Optimal mental health	Medication review	GP/psychiatrist Psychiatric assessment	
Communication difficulty	Better communication	Communication aids	Speech assessment	Speech pathologist

The plan was reviewed three months later

Diabetes: good home BSL readings, HbA1 6.7

Weight: no change. Further measures were discussed with Sally's carer

Dental health: still awaiting appointment

Hearing: still awaiting appointment

Sexual behaviour: no further inappropriate behaviour, still refused vaginal examination

Mental health: medication was changed to amisulpride with improved alertness and better engagement in activities

Communication: to be followed up after hearing assessment

Ongoing review and annual care plans are planned for Sally

Epilepsy

Epilepsy is common in people with intellectual disability, especially in those with other disabilities such as cerebral palsy. This epilepsy is often severe and difficult to treat, with high rates of clusters of seizures, prolonged seizures and status epilepticus.[27]

Specialist neurological care is usually required, but GPs need to be aware of the potential benefits of referring for reassessment. Regular review of antiepileptic medications is important, particularly with the advent of newer antiepileptic drugs. More sedating agents such as phenobarbitone, and those which may exacerbate behavioural problems such as phenytoin, may be gradually substituted with newer agents.[28]

Psychiatric disorders

The rate of psychiatric disorder including schizophrenia, depression and anxiety is much higher in people with intellectual disability than in the general community.[29] Underlying brain damage, social isolation and lack of autonomy may all be contributing factors. Despite the high rate of mental health problems, many people with intellectual disability do not receive treatment, especially if the problem is long standing.[30]

Psychiatric assessment is more difficult in people with intellectual disability, however, specialised mental health screening instruments such as the Psychiatric Assessment Scale for Adults with Developmental Disability (PAS-ADD) and the Diagnostic Assessment for the Severely Handicapped (DASH) enable assessment by appropriately trained professionals.[29]

Community based care was expected to improve the mental health of people with intellectual disability, but the deinstitutionalisation process, in the short term at least, appears to have increased the rate of psychiatric illness.[31]

Premature Alzheimer disease is common, especially in individuals with Down syndrome.[32] Older adults need regular surveillance with good longitudinal records to allow repeated assessment of general function and to detect any deterioration that may have occurred.

Alcohol abuse

People with intellectual disability are less

likely to consume alcohol than the general population, but those who do drink are more likely to develop alcohol related problems. Intervention is needed for these patients and any treatment needs to be tailored to their ability level.[33]

Behavioural problems

Behavioural disorders such as aggression, inappropriate sexual expression, destructive behaviour and self injurious behaviour are common in adults with intellectual disability. Such behaviours may cause injury and/or lead to exclusion from activities. Behavioural problems are more likely in the more severely disabled, particularly those with limited communication skills, and often reflect frustration.[34] Many studies have been carried out to assess both pharmacological and behavioural interventions, but there is little evidence as to whether such interventions actually improve quality of life.[35]

Antipsychotic medications are often used for problem behaviour in the absence of psychosis, especially in residential care settings.[36] If they are used, regular reassessment is important. Many patients benefit from a reduction in medication dosage, and may engage better in social activities if they are less sedated.[37]

Sexual health

People with intellectual disabilities are vulnerable to sexual abuse and often have difficulty communicating that this has occurred. However, even severely disabled people may be capable of accurate communication and decision making with the appropriate support.[38]

Adults with intellectual disability have sexual needs similar to the rest of the community. Despite negative community attitudes, people with intellectual disability do have sexual relationships. They need information on safe sexual practices, sexually transmitted infections and contraception. If disabled people are considering having children, they need careful counselling on parenting support, and any risk of disability in their children.[39]

Cervical screening

Women with intellectual disability have low rates of cervical screening.[40] Reasons include the (often erroneous) assumption of sexual inactivity and physical, psychiatric or behavioural problems.[41] Consent issues may also be a barrier for doctors.[42] It is important to balance the possible gain from the procedure against the level of distress that may be caused.

Breast screening rates are also low in women with intellectual disability, despite the fact that many are nulliparous and therefore at an increased risk of breast cancer.[43]

Conclusion

People with intellectual disability need similar preventive health care to other members of the community. In addition, there are specific health issues that need to be sought and treated. Assessment and treatment presents particular challenges, and specialist services may need to be involved.

Good primary care for people with intellectual disability requires extra time and expertise from GPs. Appropriate training, provision for longer consultations and structured health assessments are essential if GPs are to provide the level of care needed by people with intellectual disability.

Conflict of interest: none declared.

Resources

1. Management Guidelines: People with developmental and intellectual disabilities. Lennox N, Diggens J, eds. Melbourne: Therapeutic Guidelines Limited, 1999. Compact handbook covering a wide range of relevant issues, with chapters on specific syndromes. Available via Developmental Disability Unit, University of Queensland: http://www.sph.uq.edu.au/ddu/ which also has an extensive list of links including disability services, mental health services, advocacy organisations, and support groups for specific syndromes.
2. Physical health of adults with intellectual disabilities. Prasher V, Janicki M, eds. Blackwell Publishing, 2002. A comprehensive coverage of physical health care for people with intellectual disability.
3. Online Mendelian Inheritance in Man (OMIM): http://www3.ncbi.nlm.nih.gov/Omim/. Extensive clinical information on a wide range of genetic syndromes.

References are available for this article. Email afp@racgp.org.au or phone 03 8699 0546. AFP

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