

Hospital care for people with learning disability

Abstract

This review is an educational piece about people with learning disability. We identify this group, present their healthcare needs, and highlight some of the difficulties they experience in accessing appropriate care. Finally we offer practical advice on how to improve care for this vulnerable group.

Introduction

People with learning disability experience health inequalities and die younger than those without learning disability. They often have problems accessing timely and high-quality care and frequently report negative experiences of hospital care. Improving care for people with learning disability is a national priority and can be achieved through a combination of systems improvements and change in individual practice.

Definitions

Learning disability is a lifelong condition defined by three core criteria:

- Significant impairment of intellectual functioning (measured by psychometric testing); *and*
- Significant impairment of adaptive/social functioning; *and*
- Onset within the developmental period (*i.e.* before the age of 18 years)

The term learning disability is synonymous with intellectual disability, the former used in the UK clinical services, the latter used internationally and often preferred in research. Learning disability is still known officially as 'mental retardation' in the International Statistical Classification of Diseases (and coded within F70-F79), although this term has now fallen out of favour due to its negative connotations. It is important to distinguish learning disability from the broader, non-specific term of 'learning difficulties' which is often used in educational or social care settings to denote specific disorders of scholastic skill, such as dyslexia, that occur without global impairment in cognition. Up to 2% of the population has a learning disability, an estimated 1 million people in England alone (Public Health England, 2014).

Learning disability exists on a gradient, from mild to profound, and is sub-categorised by intelligence quotient (IQ) score (table 1). Many people with mild learning disability are not formally diagnosed and not known to statutory services. Learning disability may be caused by a number of factors that affect cognitive development before or around the time of birth, or in childhood (table 2). In many cases the cause of the learning disability is not known.

(Table 1 near here)

(Table 2 near here)

Health needs of people with learning disability

People with learning disability are at greater risk of a range of physical and mental health disorders than the general population and one in seven adults with learning disability rates their general health status as 'not good' (Emerson and Hatton, 2008). They experience higher rates of respiratory disease, gastrointestinal problems, endocrine disorders, epilepsy, and are more likely to be overweight or underweight compared with the non-learning disabled population (British Medical Association, 2014). People with learning disability are therefore very likely to be encountered by the hospital physician, regardless of speciality. Furthermore, the number of people with learning disability is increasing as a result of natural population growth and increased life expectancy.

The learning disabled population has worse access to health care than the general population (Department of Health, 2001). GPs in England are encouraged to offer routine annual health checks to all adults with a learning disability; evidence shows that just over half actually receive such checks in the community although this varies considerably by region (Public Health England, 2016). National screening programmes are less likely to reach people with learning disability, including those for bowel, prostate, cervical, and breast cancer (Osborn et al, 2012). It is perhaps not surprising therefore that people with learning disability are more likely to present at a later stage of illness and to be admitted to hospital as emergencies. This can make it difficult to plan care and often means that people with learning disability see more junior members of the healthcare team.

In 2007 Mencap produced 'Death by Indifference', a seminal report highlighting six cases of people with learning disability who had died in hospital (Mencap, 2007). The authors argued that these deaths were unnecessary and the result of institutional discrimination within the NHS. 'Death by Indifference'

gained widespread attention and was followed by other reports that propelled the care of people with learning disability onto the national agenda. In 2013 the Confidential Inquiry into Premature Deaths of People with Learning Disabilities investigated 247 deaths of people with learning disability found that men with learning disability died 13 years earlier than those without, and women with learning disability died 20 years earlier than their counterparts in the general population (Heslop et al, 2014). Almost a quarter of deaths occur before the age of 50. In many cases there was a significant difficulty or delay in diagnosis, investigation and referral, or problems with treatment and many of the deaths were judged preventable had better medical care been available.

The reasons underlying premature deaths of people with learning disability are complex and multifactorial. There are often organisational barriers to care including rigid appointment systems, an over-reliance on written communication, and poor inter-disciplinary and inter-agency working. The knowledge, skills, and attitudes of professionals can also impact care through, lack of training and awareness of learning disability, assumptions about people with learning disability, and 'diagnostic overshadowing'.

Diagnostic overshadowing

Diagnostic shadowing occurs when people attribute presenting symptoms to the learning disability rather than looking for another cause (Reiss et al, 1982). Thus, people with potentially treatable conditions may not undergo appropriate investigations or receive necessary treatment. Diagnostic overshadowing can mean that people who are in particular need of accurate assessment are among the least likely to obtain it (see case studies).

Diagnostic overshadowing is usually an unconscious process rather than an overt act of discrimination. Cognitive biases might help to explain the phenomenon including a natural tendency to attribute behaviour to the factors that are most obvious, and a tendency to make comparisons; a physical problem may appear less debilitating than it is when compared to the effect of learning disability (Mason and Scior, 2004). This thinking trap can affect how the perception of severity of the presenting symptoms, what diagnosis is assigned, and subsequently how the problem should be managed.

(Case scenarios near here)

Diagnostic overshadowing is not specific to learning disability and has been shown to exist in people who have a variety of long-term conditions including physical disability, autism spectrum disorder, mental illness, and neurological disabilities including traumatic brain injury and epilepsy (Hayhow et al, 2015; Foley and Trollor, 2015; Hendriksen et al, 2015). Experience does not appear to mitigate against the bias, as studies show that both senior and junior clinicians are prone to biased thinking in assessing people with learning disability (Reiss and Szyszko, 1983).

People with learning disability may have poor understanding of symptoms and health literacy, and have difficulty in recognising and conveying symptoms. Due to deficits in verbal ability and communication, people with learning disability often present with non-specific symptoms or behaviour change. In this case a range of differentials must be considered, as disordered or challenging behaviour is by no means an expected or inevitable part of learning disability (table 3).

(Table 3 near here)

Staff often lack of confidence in managing people with learning disability. Responses to a staff survey conducted in several different hospitals showed that staff recognise deficiencies in communicating with people with learning disability and their carers, and that difficulties with gaining consent or responding to behaviour problems can lead to delays in appropriate management (Tuffrey-Wijne et al, 2014). Anxiety and avoidance in healthcare professionals can often be felt by people with learning disabilities who feel upset and stigmatised and might be discouraged from seeking healthcare input in the future. People with learning disability often report poor experiences of hospital care including lack of staff knowledge and understanding of learning disability, negative comments and perceived discrimination (Iacono and Davis, 2003; Gibbs et al 2008).

The Equality Act (2010) and Reasonable Adjustments

Few would argue that people with learning disability have the right to the same level of care those without learning disability. The Equality Act (2010) applies to all healthcare providers and enshrines in law the principle that an individual must not be disadvantaged on the grounds of any 'protected characteristic,' including physical or mental disability. The Act places a legal duty on providers of services to anticipate the needs of different groups and to make 'reasonable adjustments' where necessary. This means that services must be proactive, flexible, and person-centred; they must not

just remove the obvious physical barriers to access, but also amend processes and policies to take account of people with additional needs (table 4).

(Table 4 near here)

Improving practice

Systems change

There are several ways in which services can adapt to become more responsive to the needs of this patient group. Hospitals should consider a 'flagging system' to alert staff to the learning disability and reasonable adjustments that should be considered – this can either be a sticker on the notes or an alert on the electronic patient record. Many hospitals now employ learning disability liaison nurses who can interface between front-line staff and managers in order to achieve better care for people with learning disabilities and provide education and practical advice on treating people with learning disability. Having access to a learning disability liaison nurse has been shown to be associated with modest improvements in care processes (Sheehan et al, 2016). People with learning disability and their carers should be included in providing feedback on services and treated as 'experts by experience'.

Improving individual practice

Doctors working in hospitals must be aware of the needs of people with learning disability and have opportunity to develop skills to best care for this group. Medical schools now routinely include learning disability in the core curriculum and offer opportunities for additional experience in the form of special study modules or elective attachments, although there is evidence that medical students still feel worried about working with people with learning disability and would like more training (Ryan and Scior, 2016). Deaneries have expanded the number of Foundation Years posts in learning disability services in the hope that exposing doctors to people with learning disability early in their career will be of benefit when they progress to more senior roles in a range of specialties. All doctors should be able to attend learning disability training and develop a good working knowledge of the Mental Capacity Act, with specialist advice available when faced with complex situations (Department of Health, 2005). Involving people with learning disabilities in simulation training can improve

communication skills and some post-graduate exams now include actors with learning disability (Thomas et al, 2014).

Attitudes towards people with learning disability are not always positive and some staff might hold prejudices that translate into discriminatory behaviours. Increasing contact with people with learning disability, both formally and informally, can foster understanding and lead to greater respect (Seewooruttun and Scior, 2014).

Practical advice for consultations with people with learning disability

Doctors should have some expertise in communication and be able to draw on these skills when working with people with learning disability. There are some additional elements to the consultation that might be useful to consider and clinicians should be mindful that a consultation with someone with a learning disability is likely to take additional time.

Establishing communication abilities and preferences is an important first step in gathering information from someone with learning disability – people or their carer can be asked directly or some people carry ‘hospital passports’ that briefly summarise their preferences and medical history. Clinicians should be alert for sensory difficulties and try to ensure these are corrected before proceeding with the consultation. Environmental distractions should be limited where possible, including excessive noise and unexpected interruptions. Language will need to be simple, clear, and should be delivered in a tone appropriate to an adult conversation. Medical jargon is best avoided. Each sentence should convey one main point and be repeated if necessary. Others might try to minimise the difficulties in receptive language, for example by nodding or feigning understanding. Summarising information is often helpful and then checking understanding. Some people with learning disability have a tendency to acquiescence and leading questions should therefore be avoided.

People with learning disability are likely to require additional time to assimilate new information and to formulate and ask questions. Communication can be supported by use of ‘accessible information’, that is, supplementary material that explains procedures or medications in a simple way, often with diagrams or pictures. ‘Books Beyond Words’ are short stories, also available electronically, that convey information about events in a simple form. Procedures can be demonstrated as far as is practicable and patients can be appropriately reassured.

The threshold for further investigative tests may need to be revised in situations where the quality of the history is poor. For example, a CT scan might be sought where it is difficult to rule out intra-cranial causes of acute behaviour change, or where the patient would be unable to easily alert staff to changes in symptoms such as onset of blurred vision or nausea.

Collateral history is often helpful, although it is necessary to gain a patient's consent before discussing their care with others. Advice may be sought from local community learning disability services which may have pre-existing knowledge of the person.

Doctors should be aware of principles of the Mental Capacity Act (2005) and should seek expert advice in situations where there is doubt about capacity to make decisions. Where a patient is deemed to lack capacity, proportionate measures can be taken to act in their 'best interests'. Doctors should avoid making assumptions about a person's quality of life and likely wishes and involve carers or family, where possible. It might be necessary to use procedural sedation or *pro re nata* (PRN) medication, or even general anaesthesia, where procedures are distressing or resisted and junior staff should seek the advice of senior colleagues in such circumstances.

Conclusions

People with learning disability experience health inequalities which might be contributed to by health services and professionals lacking of understanding their needs. Improving the quality of hospital care for people with learning disability is a health service priority and will be achieved by investment in systems change as well as improved training and staff awareness. Clinicians can make a difference by adapting their communication style and avoiding diagnostic overshadowing, thinking laterally and creatively, having a good working knowledge of the Mental Capacity Act, and involving family and carers where appropriate.

Further reading

GMC interactive learning, available at: <http://www.gmc-uk.org/learningdisabilities/default.aspx>

Key points

- Learning disability is a lifelong impairment of intellectual and social functioning.

- People with learning disability have higher healthcare needs than the general population and experience significantly worse health outcomes.
- Health services have a statutory duty to make reasonable adjustments to ensure that people are not disadvantaged because of a disability.
- Reasonable adjustments for people with learning disability include giving more time, adapting communication, and taking collateral information from carers or family.
- Diagnostic overshadowing occurs when people attribute presenting symptoms to the learning disability rather than looking for a potentially-treatable cause.
- Doctors should develop skills in managing patients with learning disability in order to provide high-quality care and promote optimum outcomes.

Conflict of interest statement

The authors have no conflicts of interest to declare.

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Table 1 – Learning disability by degree

	IQ range	Percentage of those with LD	Typical presentation
Mild learning disability	50-69	80%	<p>Conversational language.</p> <p>Can usually read and write.</p> <p>Often live independently with minimal support and might be in work.</p>
Moderate learning disability	35-49	12%	<p>Language ability is varied and sometimes over-estimated.</p> <p>Limited reading, writing, counting skills.</p> <p>Likely to need support in activities of daily living and accommodation.</p>
Severe learning disability	20-34	7%	<p>Very simple or minimal spoken language.</p> <p>Require assistance for basic tasks and self-care.</p> <p>Usually need highly supported accommodation.</p>
Profound learning disability	<20	1%	<p>High rates of medical co-morbidities, sensory and mobility problems.</p> <p>Require full-time specialist care.</p>

Table 2 – Causes of learning disability

Aetiology	Examples
Recognised genetic causes	<p>Chromosomal disorders (number or structure) – Down syndrome (trisomy 21); Patau syndrome (trisomy 13), Edward’s syndrome (trisomy 18), Turner syndrome (45,XO), Fragile X syndrome</p> <p>Single gene abnormalities – phenylketonirua, tuberous sclerosis, Tay Sachs disease,</p>
Antenatal	<p>Teratogens – alcohol (fetal alcohol spectrum disorder), illicit drugs (<i>e.g.</i> cocaine), prescribed medication (<i>e.g.</i> valproate)</p> <p>Maternal infection with ‘TORCH group’ pathogens (toxoplasmosis, other, rubella, cytomegalovirus, herpes simplex virus)</p>
Perinatal	<p>Extreme prematurity, intra-ventricular haemorrhage</p> <p>Hypoxic-ischaemic injury (<i>e.g.</i> secondary to cord prolapse)</p> <p>Metabolic derangement – neonatal hypoglycaemia or hyperbilirubinaemia</p>
Postnatal	<p>Traumatic brain injury</p> <p>Anoxia (<i>e.g.</i> from suffocation or near drowning)</p> <p>Toxin exposure (<i>e.g.</i> heavy metal poisoning)</p> <p>Infection – meningitis, encephalitis</p> <p>Abuse or neglect</p>
Idiopathic	<p>No known cause – may be extreme low end of normal function</p>

Table 3 – Possible causes of acute behaviour change in people with learning disability

Differentials for acute behaviour change in people with learning disability
Physical illness – UTI, delirium, stroke, constipation, infection
Pain – infection, acute abdomen,
Adverse drug effects or drug interactions
Epilepsy – pre or post-ictal phases
Mental illness – anxiety, mood disorder, psychosis
Change in environment, routine, or caregiver
Abuse or neglect

Table 4 – Reasonable adjustments that might be appropriate for people with learning disability

Reasonable adjustments	
Physical environment	Level access
	Designated parking close to the entrance
	Adequate lighting and signage
	Spacious, low-stimulus environment
	Quiet places to wait
Processes and policies	Alternative means of booking appointments or receiving information
	Making provision for carers to stay at the hospital
	No fixed visiting times
	Embedding staff training in learning disability
	Using hospital passports
	Employing learning disability liaison nurses and establishing learning disability ‘champions’ with board level support
Delivery of care	Allowing extra time
	Adapting communication style
	Providing accessible information
	Offering first or last clinic appointment
	Providing advocacy for people who lack mental capacity
	Assigning a named nurse to a person with learning disability to follow the inpatient journey

Case scenarios

- A 22 year old man with a moderate learning disability and Down's syndrome presents to the Emergency Department with his mother. He has limited verbal communication but is obviously highly distressed. His mother states that he has been refusing food and drink for the past 24 hours and has been scratching and hitting his body. The doctor who sees the patient has little experience of people with learning disability and assumes that this must be normal behaviour. The patient seems unwilling to undergo investigations so the doctor discharges him. He returns via ambulance 24 hours later and is found to have a perforated appendix and is rushed to theatre.
- A 62 year old lady with a mild learning disability collapses whilst volunteering at a cafe. An ambulance is called and she is taken to hospital. She regains consciousness but is unable to speak clearly. The healthcare team hear that she has a learning disability but do not gather any collateral information. She is admitted to the ward for observation where her speech continues to decline; staff assume that not being able to speak properly is part of her learning disability. Her condition deteriorates and she now suffers obvious unilateral motor weakness. A head scan finds that she has had a subdural haematoma which progressed as it was not quickly identified and managed.