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Caring for older adults with learning disabilities

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Summary

Older patients with learning disabilities have greater physical and mental healthcare needs than the general population. However, because of a lack of knowledge about learning disabilities and low confidence in working with this patient group, their healthcare needs are often misinterpreted or neglected. By learning more about this group and developing skills that can aid the nurse-patient relationship, nurses will become more confident in their working practice and older patients with learning disabilities can receive the same quality health service as other patients.

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Aims and intended learning outcomes

This article aims to explore some of the difficulties faced by nurses providing health care to older patients with learning disabilities as well as the implications for the quality of care provided. After reading this article and completing the Time out activities you should be able to:

- ▶ Understand the health challenges of older patients with learning disabilities.
- ▶ Understand the effect that a learning disability has on a patient's ability to express his or her healthcare needs.

- ▶ Describe the importance of using the caring relationship between nurses and older patients with learning disabilities to promote good patient care.
- ▶ Identify strategies to improve the care of older patients with learning disabilities.

Introduction

People with learning disabilities are now living to an average of 50-55 years of age and in some cases up to 70 years (Yang *et al* 2002). This challenges previous beliefs that individuals with learning disabilities do not survive into old age. As recently as a decade ago, it was not recognised that ageing is a life phase for those with learning disabilities; recognition first appeared in the United States in the 1980s. The UK has been slow in reaching this recognition, but this is beginning to change because of the large numbers of people with learning disabilities outliving family carers (Walker and Walker 1998).

To understand the implications of this for nursing, the issues faced by older people with learning disabilities are explored, by discussing the definition of a learning disability and the ageing process. The Department of Health (DH 1995) has defined a learning disability as:

- ▶ Reduced ability to understand new or complex information or to learn new skills – impaired intelligence.
- ▶ Reduced ability to cope independently – impaired social functioning – that started before adulthood with a lasting effect on development.

Learning disabilities can be mild, moderate or severe. Some people with a mild learning disability do not need much support in their daily lives,

whereas those with a moderate learning disability might need support with getting dressed, going shopping, filling out forms and a variety of other daily living skills. Some people with a learning disability also have a physical disability meaning that they need support 24 hours a day. This is known as profound and multiple learning disability (Mencap 2007). This article is focused on older people with mild to moderate learning disabilities, who can make independent decisions with support. However, severe learning disabilities will be discussed with reference to the Mental Capacity Act 2005.

One and a half million people in the UK have a learning disability and 25,000 of these are in the older population (Mencap 2007). Most people with learning disabilities have greater health needs than the general population (Disability Rights Commission (DRC) 2006), as is commonly the case with older adults. Therefore, older people with learning disabilities can be faced with complex physical and mental health needs.

A lack of provision was identified in the Foundation for People with Learning Disabilities (FPLD) (1996) inquiry into services and opportunities for adults with a learning disability, and in a national survey on services for older people with learning disabilities (Harris and DH 1997). The Growing Older with Learning Disabilities (GOLD) programme was a four-year (1998-2002) UK-wide programme to address the unmet needs of many older people with learning disabilities (FPLD 2002).

Time out 1

- ▶ Write down the potential unmet needs of older people with learning disabilities that you think would have been identified in the GOLD programme.
- ▶ Repeat this once you have completed reading this article.
- ▶ Compare your two lists and identify any changes in your thinking.
- ▶ Consider how you could use this knowledge in your practice.

Physical health

Some studies have examined the prevalence of physical health problems in people with learning disabilities (Day and Jancar 1994, Hand 1994). Epilepsy, cerebral palsy and neurological impairments were the most common conditions (Hand 1994). In ageing adults with learning disabilities, common health problems include hearing and visual impairments, mobility, heart conditions, diabetes, fractures and osteoporosis (Cooper 1998, Jancar and Jancar 1998).

Older individuals with a learning disability are highly likely to have one or more sensory impairments. Sensory impairments can result in a reduction in information received; difficulties understanding activities, objects and words; and limited, distorted or inaccurate perceptions of the environment.

Hearing and visual impairments are the two main sensory handicaps, with up to 45% of people with severe and profound learning disabilities having such impairments (Clarke-Kehoe 1992). Mild to moderate hearing loss is more common in people who have Down's syndrome, as are visual problems, such as squints and long or short-sightedness. Such problems can worsen in later life, but might be under-recognised (Hussein and Manthorpe 2005).

Health complications because of lifestyle are also common in older people with learning disabilities. For example, rates of obesity are significantly higher among women with learning disabilities than women in the general population (Emerson *et al* 1999). Studies have reported a prevalence of obesity in adults with learning disabilities of between 10% and 26% (Wood 1994, Rubin *et al* 1998). These studies have also found that the prevalence of obesity increases with age. Such physical health implications resulting from lifestyle choices will need to be considered as more learning disability services move towards independent and supported living, where people with learning disabilities are provided with more choice and will need different types of support with lifestyle skills. For example, while some older people with learning disabilities can make healthy food choices independently, others may need support with understanding the different nutritional values of foods.

Mental health

As late as the 1980s, the general belief was that people with learning disabilities did not have the cognitive capacity to experience mental health problems and that behavioural disturbances were attributable to the learning disability (Smiley 2005). Over the past 25 years, it has become accepted that people with learning disabilities experience the same mental illnesses as those without these disabilities. In fact, people with learning disabilities have been shown to be at greater risk of developing mental illness or behaviour disorders. Further, older adults with learning disabilities have been found to have a greater prevalence of psychiatric morbidity than younger controls, 68.7% versus 47.9% respectively (Cooper 1997).

Rates of depression and anxiety disorders are high and dementia is common in adults with learning disabilities. About 20% of adults with

learning disabilities have Down's syndrome, with this particular learning disability posing a greater risk for dementia. Prasher (1995) suggests that the following percentages of people with Down's syndrome have dementia: 2% of 30-39 year olds, 9.4% of 40-49 year olds, 36.1% of 50-59 year olds, and 54.5% of 60-69 year olds. Deb *et al* (2001) also indicate an association between the rate of specific mental illnesses, that is, dementia and depression, and increasing age.

Although mental health problems are now recognised in older people with a learning disability, research is contradictory because of the prevalence of mental illness in the differing levels of ability. However, when considering possible aetiological factors, such as epilepsy, physical disability and sensory impairments, it is plausible that there would be an increased rate of mental illness in individuals with a more severe learning disability (Cooper and Bailey 2001). Cooper (1997) has estimated prevalence rates for specific mental health problems in a population-based study (Table 1).

The risk factors for depression in the general population, such as stress, lack of social support and life events, are the same for older people with learning disabilities. However, older adults may be further disadvantaged because of limited coping skills and experiences of discrimination, rejection, stigma and abuse.

The diagnosis of mental health problems in older people with learning disabilities is often difficult because there can be problems of communication and the symptoms might not be typical. Any change in a person's usual behaviour needs to be reported, rather than focusing on specific symptoms. This can be difficult for

healthcare professionals, who might not know the patient well enough to detect behaviour change. However, such detection can be aided by person-centred plans (PCPs), adopted as government policy in the UK through the white paper *Valuing People: A New Strategy for Learning Disability for the 21st Century* (DH 2001a). Patient care could be better informed if nurses actively referred to and used individualised PCPs.

The World Health Organization (WHO) (1992) defined health in its constitution as: 'Health is a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity.' The International Classification of Diseases 10 (ICD-10) states that psychiatric disorder is 'not an exact term', although is generally used '... to imply the existence of a clinically recognisable set of symptoms or behaviours associated in most cases with distress and with interference with personal functions' (WHO 1992).

Time out 2

Compare the definition of psychiatric disorder (ICD-10) with the definition of learning disability at the beginning of this article. Make a distinction between a learning disability and psychiatric disorder.

Barriers to health care

Recognising illness Memory impairment is common in older adults with learning disabilities. Since memory is used in the recognition of previously experienced physical and psychological sensations, older patients cannot always recognise new sensations or signs of ill health. Because they cannot always recognise new sensations or signs of ill health these patients are vulnerable in terms of health and wellbeing. When such sensations are recognised, they can be alarming. For nurses, obtaining a thorough assessment is difficult with patients who are unable to co-operate with conventional forms of assessment. Further allowances need to be made for such sensory impairments, even if specialist services need to become involved.

Since older people with learning disabilities find it difficult to convey their health concerns in a conventional way, they may express that something is wrong in a subtle or indirect manner, such as through changes in personality or behaviour. Illness can be detected through facial expressions, body language, changes in routine and episodes of aggression, violence or antisocial behaviour. Such changes often become even more extreme due to the frustration of not being able to express what is wrong.

TABLE 1

Prevalence rates of psychiatric disorders

Disorder	Percentage
Dementia	20.0
Severe problem behaviour	10.0-15.0
Autism	7.0
Generalised anxiety disorder	6.0
Specific phobia	6.0
Depression	4.0
Schizophrenia	3.0
Obsessive compulsive disorder	2.5
Bipolar disorder	1.5
Agoraphobia	1.5

(Cooper 1997)

Time out 3

Imagine having an illness or put yourself in the position of a patient you have cared for. Consider how you would feel if you could not inform others of your symptoms, and how you would feel if you received medication, operations or other treatments that you did not understand. How might you behave in such circumstances? Now consider the behaviour of a patient you are or have been caring for who is confronted with these difficulties. Has your perception of him or her changed?

For nurses and other healthcare professionals, observation can be a fundamental tool in detecting illness, its causes and location and the best way to treat it. This can be difficult for nurses who work shifts and who might not know the individual well. However, collaboration between all involved in the care of the patient can assist the provision of adequate health care to older people with learning disabilities. This can enable nurses to recognise potential problems in the early stages and provide immediate help and medical support.

There are some common signs and symptoms, which may indicate underlying health problems in older people with learning disabilities (Box 1). All of these signs and symptoms could be misinterpreted as being the result of 'bad habits' or 'challenging' behaviour and because of this they could be dismissed. This is also the case for the expression of pain. Because of exposure to frequent medical interventions, older people with learning disabilities are more at risk of experiencing pain than the general population (Davies and Evans 2001). This is why there is a need to refer to patients' PCPs, which should include information on how the person expresses pain. **Communication** One of the greatest barriers between older people with a learning disability and the nursing community is communication (Hogg *et al* 2001). The patient might be unable to verbally communicate information about their health. It is, therefore, the responsibility of nurses and others involved in the care of the patient to ensure they communicate in a way that is most accessible to them. It is worth noting that communication difficulties will vary and while some individuals will be highly verbal, they can still lack the vocabulary necessary to express symptoms, emotions or changes in health. They might also lack the cognitive ability to understand healthcare procedures.

Whatever the patient's level of communication skills, any degree of communication difficulty can

BOX 1

Common signs and symptoms of illness

Physical: Coughing, sneezing, rashes, spots, vomiting, diarrhoea, pallor, temperature, swelling, redness, sweating, breathing difficulties, bleeding, discharge and bad breath.

Body language: Fidgeting, grimacing, curling up in a ball, holding parts of the body continuously, frowning and shivering.

Behaviours: Head-banging, poking inside the mouth or rectum, screaming, crying, shouting, staying in bed, irritability, isolation, hitting out, self-injury, scratching and seeking attention.

(Brown and Benson 1994)

lead to feelings of isolation, anger, helplessness, paranoia, confusion, inadequacy and feelings of being ignored. Adults with restricted communication skills may be experiencing these feelings most of the time. They might even give up trying to communicate with others. This does not make them withdrawn, unco-operative or lazy, it merely demonstrates that they have not been provided with the time and support needed to explore how they can best communicate with others. Patients who appear to be behaving aggressively or in a challenging manner might, in fact, be demonstrating behaviours that have previously proven effective in ensuring they are listened to. There are numerous communication methods that may enhance the quality of care health professionals give patients (Box 2).

BOX 2

Methods of enhancing nurse-patient communication

- ▶ Ensure the patient knows the message is meant for him or her by gaining his or her attention and communicating within his or her visual field.
- ▶ Use consistent vocabulary.
- ▶ Use short, straightforward phrases without any unnecessary information.
- ▶ Long multi-message phrases can be broken down into separate messages.
- ▶ Use body language along with speech, such as pointing to an object being discussed.
- ▶ Speak to the patient rather than to carers or family members.
- ▶ Use natural gestures, such as pointing and facial expression.
- ▶ Use a formal signing system, such as the Makaton vocabulary or Bliss symbols.
- ▶ Pictures can be used to indicate to someone what the message is about.
- ▶ Objects can be used to represent activities or messages that are being conveyed to the individual. Objects are even more valuable to those who have a sensory impairment, and can use their sense of touch to explore the object and gain information from it.

(Grove 2000)

Time out 4

Read Godsell and Scarborough's (2006) article on improving communication for people with learning disabilities and answer the following questions.

- ▶ What are the essential communication considerations for nurses outlined in the article?
- ▶ Which strategies are especially relevant to caring for older people with learning disabilities?
- ▶ How could you integrate some of these strategies into your contact with patients?

The nurse's role

The DH (2001a) highlights the role of nurses and primary care in delivering health care to adults with learning disabilities (Powrie 2001). The support provided by nurses might include the provision of care while in hospital or support when patients are discharged from hospital to the community. However, frequent barriers to care provision, such as difficulty communicating and recognising illness, mean that nurses working in mainstream services need support when working with these patients.

A survey of 107 nurses in primary care revealed that 85 nurses had contact with individuals with learning disabilities at work (Powrie 2003). A total of 70% of respondents were unsure about whether the health needs of this group were being met in the community and 36% of practice nurses thought that additional health screening would benefit individuals with learning disabilities. However, primary care providers are concerned that the government is not targeting this patient group financially or at the practice level (DH 2001b). This could be a disincentive for nurses wishing to explore the health needs of this patient group.

Some of the complex issues nurses have described about working with individuals with learning disabilities relate mainly to ethical aspects of care, such as lifestyle and psychosocial issues like overeating (Golden and Hatcher 1997) and drug abuse (Christian and Poling 1997). Such issues raise ethical concerns about control and freedom of choice. The most frequently expressed concern is in relation to individuals with mild to moderate learning disabilities who often miss appointments or do not adhere to medical regimens. Concerns have also been raised about health promotion and how it is difficult to provide this to individuals with learning disabilities

because of a lack of knowledge about their disability and how to approach and teach them at the right level. In a study addressing the primary healthcare needs of older people with learning disabilities, GPs were opposed to providing structured health promotion and health checks (Thornton 1996). For example, women with learning disabilities are less likely to have a cervical smear test than other women because of an assumption that they are not sexually active. This assumption has been challenged by research indicating that these women are at an increased risk of sexual abuse (McCarthy 1999).

Reluctance to offer health checks to this patient group may also be a consequence of a lack of confidence in communicating with individuals who have a learning disability (McConkey and Truesdale 2000). In a survey in New Zealand health professionals who work with patients who have a learning disability identified a number of challenges (Cook and Lennox 2000). These included difficulties in assessment and communication, inadequate training and education in learning disabilities, problems maintaining continuity of care and uncertainty about supportive resources, for example, advocacy groups and aids to communication.

Many nurses feel that health professionals need training in how to work with older people with learning disabilities, especially with regard to human rights and appropriate approaches in relation to physical procedures or intellectual understanding (Powrie 2003). This suggests a need to clarify the rights and responsibilities of health professionals, as well as the rights of older people with learning disabilities.

The majority of multidisciplinary work takes place with GPs, families and carers. None of the nurses out of the 107 interviewed by Powrie (2003) indicated that they were working with advocacy groups, despite the fact that some of the problems identified by nurses illustrated the need for an advocacy role. For example, individuals with learning disabilities often experience extreme distress because of a lack of understanding of medical procedures, including routine blood tests and medical examinations. This can lead to nurses avoiding such procedures through fear of being accused of abuse or of having to stop procedures before completion because of patient distress. Collaboration with learning disability advocacy groups helps to limit these practical problems.

Good practice

Good health care is one of the most influential factors in people's lives and everyone has a right to a high standard of health care. However, studies have shown that, although people with learning disabilities have greater and more varied healthcare

needs, they have been given a low priority in physical and mental health care (DRC 2006). Since people with learning disabilities are commonly viewed as demonstrating challenging behaviour, changes in their behaviour are often misinterpreted. However, changes in behaviour may result from physical or mental health needs not being met.

Bollard (2002) encourages an egalitarian partnership between nurses and older adults with learning disabilities. He stresses the need to move away from a mechanistic behavioural approach to communicating and the importance of adopting a relational approach that focuses on an ability to connect and understand the complexity of the human experience.

Personal health action plans One of the most effective approaches to assessing a patient's health needs and the preferred method of communication is to use their personal health action plan (HAP). This is an initiative that involves working with the individual to identify his or her health needs and how these can be met. If the patient does not have a personal HAP, it might be worth providing information on how to create one. Information on HAPs and how to obtain HAP booklets for patients can be found at

the DH website (www.dh.gov.uk). Personalised HAPs are an effective communication method to use with older adults and those with learning disabilities. If completed before a hospital visit or stay, time would have been allocated to carefully tailor the HAP to the individual. The information included in HAPs is extensive (Box 3), which can be used to inform and improve patient care.

The Mental Capacity Act 2005 Informed consent is a human right for all patients. The Mental Capacity Act 2005, which came into force in October 2007, governs decision making on behalf of adults who have lost mental capacity at some point in their lives or where the incapacitating condition has been present since birth. The act asserts that before decisions are made on behalf of someone, there has to be certainty that the individual does not have the capacity to make that decision.

In terms of mild to moderate learning disabilities, the existence of a caring relationship between nurses can directly affect the process of encouraging meaningful decision making and obtaining consent (Aveyard 2002). Actively involving the patient in obtaining consent can have empowering and therapeutic benefits

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BOX 3**Content of personal health action plans**

Health action plans (HAPs) should be person-centred and in a format that is accessible and understandable, where possible, to the individual whose plan it is. The following content of the personal HAP could be pictorial, written, auditory (on tape), based on touch or a variety of other ways personal to the individual whose plan it is. A personal HAP should include:

- ▶ GP details, along with other professional support, for example, psychologist, dietician, physiotherapist and patient's perceptions of these professionals.
- ▶ Height and weight.
- ▶ Emergency information.
- ▶ Medication, reason for medication, timing of administration, who is responsible for administration – the patient or nurse.
- ▶ Allergies.
- ▶ Cultural considerations.
- ▶ Physical and mental support needed.
- ▶ Past and present illnesses.
- ▶ History of family illness.
- ▶ Life events that have implications for health.
- ▶ Communication preferences.
- ▶ Personal hygiene.
- ▶ Medical history.
- ▶ How to stay healthy – for example, exercise enjoyed.
- ▶ How to identify health and illness in the individual.
- ▶ Health goals.

(DH 2002)

independent of the treatment being offered (Booth 2002). In terms of severe learning disabilities, it may be necessary to make health and treatment decisions for patients, ensuring

that the decision is in their best interests. This can be ascertained by talking to other individuals involved in the life and care of the patient, such as the support worker or occupational therapist.

Nurses can access DH guidelines on gaining consent, such as *Seeking Consent: Working with People with Learning Disabilities* (DH 2001b) and *Good Practice in Breast and Cervical Screening for Women with Learning Disabilities* (DH 2000). For those with cognitive impairments, as is especially the case in older adults with learning disabilities, consent needs to be an ongoing process rather than a single outcome.

Conclusion

Older people with learning disabilities are more susceptible to physical and mental health problems than the general population. Good health care for this patient group requires planning and collaboration between all involved in the care. It also requires a flexible environment for the provision of health care. Responding to the healthcare needs of older adults with learning disabilities remains a challenge for healthcare professionals, especially in terms of communication barriers and ethical issues. However, these challenges can often be eliminated or minimised by interdisciplinary working **NS**

Time out 5

Now that you have completed the article, you might like to write a practice profile. Guidelines to help you are on page 52.

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