The last 40 years have seen a shift in the provision of learning disability services from people being routinely institutionalised to their being actively integrated into society, with the emergence of increasing numbers of home, residential and day care settings in communities across the UK (Bailey et al, 2016). At the same time, the role of learning disability nurses has evolved and actively incorporated skills of hospital liaison management and behavioural support, alongside an array of leadership and management duties (Mitchell, 2019). There are currently 17,179 learning disability nurses on the Nursing and Midwifery Council register (NMC, 2020) – 1,000 fewer than in 2016. Learning disability care

A multiagency approach is common for the care of people with learning disabilities, their families and carers in the community. This interprofessional approach has many benefits but needs to ensure that all organisations recognise and sustain the need for people with learning disabilities to be empowered and supported in communicating their self-identified needs, especially at the end of life (NHS England, 2017).

Central to providing high-quality care is understanding how a patient communicates, as many mechanisms used by people with learning disabilities are non-verbal. Although carers are often able to interpret on behalf of patients with learning disabilities, healthcare professionals need to understand individual patients and their needs and preferences. Methods of communication may include using:

- Objects as visual aids – for example, a cup to signify thirst;
- Sign language;
- Symbols depicted in photographs, software or drawings (Tuffrey-Wijne and McEnhill, 2008).

The role of learning disability nurses in providing end-of-life care

In this article...
- The current guidance for learning disability care, including during the coronavirus pandemic
- Health inequalities faced by people with a learning disability
- The idea of a new role for learning disability nurses with an end-of-life specialism

Keywords
Learning disability/End of life/Multiagency work/Communication

This article has been double-blind peer reviewed

Key points
- Multiagency care of people with learning disabilities is common in community-based settings
- The coronavirus pandemic means those near the end of life may be cared for by staff who are not experienced in this field
- Integrating the voice of carers is vital to understanding communication and providing optimal levels of care
- Developing a national role for learning disability nurses with a specialism in end-of-life care would provide opportunities for shared learning across care settings
- These nurses could ensure patients’ wishes are communicated to facilitate their dying in accordance with their desires

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Abstract
People with learning disabilities experience increased levels of health inequality compared with the general population and, in end-of-life care, many die without having their individual preferences met, despite carers articulating these needs to those providing professional care. In addition, the number of learning disability nurses in the UK is decreasing. This article recommends progressive change through the development of a new role – that of learning disability nurses with a specialism in end-of-life care.

Citation
addressing their needs, along with respecting their autonomy to make informed choices about their life and actively encouraging this, especially at end of life (Sullivan et al, 2019). There is a need to ensure that communication:

- Avoids jargon and euphemisms;
- Is carried out in manner and place in which the patient feels comfortable;
- Involves carers or family members who can help articulate the patient’s needs and wishes (Bit.ly/MCLDeoLCare).

**End of life**

Life expectancy for people with learning disabilities is significantly lower than the UK average; there are higher rates of both premature and avoidable death (Heslop et al, 2014). Diagnoses of long-term conditions (LTCs) are frequently delayed, which has a negative impact on the planning, choice and provision of support for patients with learning disabilities, as well as their families and carers (Care Quality Commission, 2016).

Thirteen years ago, Mencap’s (2007) seminal report *Death by Indifference* identified “widespread ignorance and indifference” by health professionals towards people with learning disabilities and their informal and formal carers. The five-year follow-up report, published in 2012, highlighted 74 cases that showed limited progress, suggesting little had changed during that time. Contributory factors identified were:

- Lack of essential care;
- Poor communication;
- Delays in diagnosis and treatment;
- Failure to recognise pain;
- Inappropriate application of Do Not Attempt Cardiopulmonary Resuscitation decisions;
- Lack of knowledge or inappropriate application of the Mental Capacity Act 2005 and/or the Equality Act 2010 (Mencap, 2012).

Dunwoodie Stirton and Heslop’s (2018) systematic review examining the medical certificates of cause of death in people with learning disabilities, their families and carers (Care Quality Commission, 2016). This raises important issues in the recording of deaths caused by Covid-19 among people with learning disabilities. These individuals are more likely to experience a death preceded by a prolonged period of dying (van Schrojenstein Lantman-De Valk et al, 2000) and this group demonstrates higher incidence and prevalence of LTCs – many of which are progressive and warrant palliative care – than the general population. During the coronavirus pandemic it is, therefore, even more important that people with learning disabilities who die of Covid-19 have this recorded on their certificate of death. This ensures their vulnerability in such pandemics remains visibly and historically documented as a record of how society cares for people who live with learning disabilities in comparison with those who do not.

The guidelines (at time of writing) on maintaining social distancing, working remotely where possible and redeploying NHS staff, along with the potentially rapid deterioration of patients with Covid-19, means that, although National Institute for Health and Care Excellence (2020) guidance suggests end-of-life plans are executed in accordance with the patient’s wishes where possible, pragmatically it may not always be possible to do so. Presently, it is likely that people with learning disabilities at the end of life may encounter health professionals who do not have the relevant expertise in this area, which means communication is vital.

Recent guidance states that, in all learning disability care, health professionals need to:

- Be aware of diagnostic overshadowing, ensuring symptoms of physical health are not attributed in error to the learning disability;
- Remember that communications, such as response to pain, are likely to be different from those of people without a learning disability (NHS England and NHS Improvement, 2020).

The voice of family members and carers must also be taken into account, as they:

- Have information about the patient’s health and behaviour that may provide a greater understanding of their individual needs and preferences;
- May be able to articulate or carry out their needs.

**Involving carers**

Carers can often:

- Interpret the verbal and non-verbal communication of the person with learning disabilities;
- Relay it to others involved in their care.

A study in Cumbria, Northumberland Tyne and Wear Mental Health NHS Foundation Trust found that carers are also important in articulating changes in behaviour as a result of medication changes. This can help health professionals when they are adjusting prescription medicines (Graham et al, 2020) and supports the national agenda to improve quality of life by stopping overmedication in people with learning disabilities, autism or both – this is known by the acronym STOMP (Bit.ly/NHSEStomp).

Many carers lack knowledge and skills in end-of-life planning and care (McLaughlin, 2018), and education and support – including bereavement care – are needed (O’Sullivan and Harding, 2017). The role of the learning disability nurse is crucial in ensuring the carer’s voice is embedded into care plans at all stages of the patient’s life, but especially at the end of life. How society cares for its most vulnerable people is considered a reflection of its regard for humanity and the compassion with which care should be approached; Sulmasy (2013) described this as “inflorescent dignity” in terms of its worth to the human condition we all share.

**Potential new learning disability nurse role**

The coronavirus pandemic emphasises the importance of developing the role of a learning disability nurse with end-of-life specialism as standard across the nation to further support people with learning disabilities, their families and carers, and to
ensure deaths are in accordance with their wishes. Some organisations have formal roles for learning disability nurses in end-of-life care. Areas of good practice include Nottinghamshire Healthcare NHS Foundation Trust and Sherwood Forest Hospitals NHS Foundation Trust. They have developed resources, including DVDs and accessible documents such as Preferred Priorities for Care, as well as producing an information package for GP surgeries to use. Another tool that has been developed is St Oswald’s Hospice’s Distress and Discomfort Assessment Tool (DisDAT, Bit.ly HospiceDisDAT), which identifies distress cues in people with limited communication abilities and is widely used in practice.

In proposing the development of a specific role for the support of people with learning disabilities at the end of life, a debate exists regarding where this role should be positioned in practice and in preparatory education and training. NICE (2018) guidelines:

- Recommend a single lead practitioner to be a point of contact for people with learning disabilities and their families, carers and advocates;
- Suggest this role may be undertaken by a learning disability nurse or by a member of the community learning disability team.

Enabling either group to undertake additional education and training to ensure the optimal support of people with learning disabilities would be pragmatic. However, in terms of professional identity and scope, it could introduce a degree of ambiguity in which a one-size-fits-all curriculum for the support of this vulnerable caseload, unless specifically designed and framed, might fit no-one. As an alternative, we suggest a specialist signature pedagogy is developed that aligns with the specific needs highlighted by NHS England (2018), the Care Quality Commission (2016) and Marie Curie (Bit.ly MCLDEolCare).

It is important that the skillset of this newly posited specialist learning disability nurse is clearly delineated and operationally defined, refined and articulated. This role would provide an opportunity for a specialist practitioner to effectively become a conduit between palliative care and learning disability nursing. However, it is essential that the role is more than a means of enhanced communication between multidisciplinary and multi-agency workers; instead, people with learning disabilities should be given the opportunity to define what needs-led care provision can, and should, be. This is the only certain means of ensuring a democratic approach in which people with learning disabilities, as opposed to tokenistic contributors, are central to needs-led care. The validity and authenticity of the proposed new role would be significantly increased as a consequence.

“Health professionals need to ensure symptoms of physical health are not attributed in error to the learning disability”

Audit

We carried out a retrospective case review audit of our multidisciplinary care approach over a year, involving a hospital trust, a mental health trust and a hospice for people with learning disabilities at the end of life. The audit showed that, of five patients, four died in their preferred place of death; the fifth was deemed to be frail but not dying. It also highlighted areas of good practice, in which patients with complex needs – such as bowel obstruction, pain and behavioural needs – were managed in their own care settings and a range of support was provided to carers (Baker, 2017).

Learning disability nurses were core members of this multidisciplinary team and the audit also revealed job satisfaction among staff. This finding is a positive indicator of the fulfilment experienced by nurses working with people living with learning disabilities and bodes well for the development of roles in the field.

Recommendations

We recommend that organisations across health and social care review the potential of developing learning disability nurses with an end-of-life specialism, with a view to working across healthcare settings to:

- Support patients on the whole journey from diagnosis to death;
- Identify barriers and enablers to facilitate this.

Nursing schools should promote this as a potential career option when recruiting and training the future workforce, and embed end-of-life care into curricula for both undergraduate and continuing professional development courses. NT

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