Spiritual care and learning disability nursing: an exploratory review of the literature

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Abstract

Spiritual support is a key component of holistic nursing care for people with learning disabilities and individualised spiritual care should be integral to learning disability nursing. By developing a trusting therapeutic relationship with the person with a learning disability, the nurse can determine the person’s spiritual care needs and contribute to addressing them. However, research into spiritual care and learning disability nursing is scarce.

This exploratory review of the literature provides initial groundwork to pave the way for more extensive research. It highlights the potential benefits of spiritual care provision in terms of enhancing people’s quality of life; discusses some of the barriers to spiritual care provision; and highlights recent advances in spiritual care education, including the development of core competencies. More primary research on spiritual care is needed to add to the evidence base that learning disability nurses draw on to provide holistic care.

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Keywords

curriculum, education, holistic care, learning disability, nursing care, pre-registration education, professional, professional issues, spirituality
Method
The databases Cumulative Index to Nursing and Allied Health Literature (CINAHL), Scopus and PsycINFO and the database of journals published by SAGE were searched in July 2023 using the terms ‘intellectual disabilities’ or ‘learning disabilities’ in conjunction with ‘spirituality’ or ‘spiritual care’ or ‘religion’ and ‘intellectual disability nursing’ or ‘learning disabilities nursing’. The date parameters were set to research conducted between 2000 and 2023. The initial search resulted in a total of 74 sources, of which 16 were deemed relevant to the review’s aim. The sources included qualitative, quantitative and mixed-methods studies conducted in Ireland, the UK, Norway, the Netherlands, Malta, Canada, the US and Israel. In addition, textbooks, research reports and policy documents were reviewed. A simple thematic analysis was used for this exploratory review, with insights gleaned from Corbin and Strauss (2014).

Definition and dimensions of spirituality
The European Association for Palliative Care (2024) provides the following definition of spirituality: ‘The dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred’. Weathers et al (2016) conducted a concept analysis of spirituality and described its defining attributes as meaning in life, connectedness and transcendence.

Sango and Forrester-Jones (2022) noted that a consensus on how to define spirituality has yet to be reached and emphasised the need for a multidimensional approach, with dimensions that ‘can be rooted in one of two aspects of spirituality, including religious spirituality (i.e., social practices and expression of belief such as church attendance, worship, prayer, etc.) or non-religious spirituality’. McSherry et al (2020) also wrote about the multidimensional property of spirituality, explaining that the spiritual field has three dimensions:

» Existential challenges – the person with a learning disability may need support with existential challenges, including sense of identity, suffering, death, love, despair and hope. Offering support to the person with a learning disability in relation to existential challenges can be an important part of learning disability nursing practice.

» Value-based considerations – in its code of professional conduct, the Nursing and Midwifery Board of Ireland (NMBI) (2021) identifies the centrality of understanding the person’s values and perspectives on life. Understanding the person’s perspective involves establishing trust, getting to know the person and developing rapport (Barr and Gates 2019, Moulster et al 2019). A person-centred approach to care is crucial here.

» Religious considerations and foundations – person-centred care and respect for choice are at the centre of learning disability nursing (Northway and Hopes 2022, Mafuba 2023) and it is essential to listen to the perspective of the person with a learning disability and to their needs, wishes and preferences about the spiritual dimension of their care. The person may decide to practise a faith and they need to be given the opportunity to partake in services and events relating to their spirituality or religious beliefs if they so wish.

NHS Education for Scotland (2009) emphasised that human contact and a compassionate relationship is where spiritual care starts. From there, spiritual care moves in the direction the person needs it to move. For learning disability nurses, providing spiritual care involves getting to know the person with a learning disability and establishing a relationship with them that will be fundamental.

Key points
- Spiritual support is an important element of the overall holistic care provided by learning disability nurses
- Addressing their spiritual care needs can improve the quality of life of people with learning disabilities
- For learning disability nurses, providing spiritual care involves establishing a relationship with the person to determine their needs
- Improving competence in spiritual care provision can prevent this important aspect of holistic care from being neglected
- More research on spiritual care and learning disability nursing is needed to develop the evidence base
in determining their care and support needs (Hartnett 2020). By developing a trusting therapeutic relationship with the person, nurses can become more aware of their spiritual care needs and therefore help address them.

**Spirituality and quality of life**

Research indicates that supporting spirituality or providing spiritual care can be associated with improvements in certain aspects of the quality of life of people with learning disabilities and their families (Boehm and Carter 2019, Michaelson et al 2020). The concept of quality of life and how to improve the quality of life of people with learning disabilities have been well researched (Verdugo and Schalock 2003, Verdugo et al 2012, McCarron et al 2019), providing healthcare professionals with evidence to bring to their practice.

One important dimension of quality of life for people with learning disabilities is social belonging, with Verdugo et al (2012) shedding light on how supporting people with learning disabilities to feel a sense of social belonging can improve their quality of life. Timmins et al (2023) emphasised the significance, for older people with learning disabilities who may depend on others for their social interactions, of engaging in community activities.

Another important dimension of quality of life for people with learning disabilities is self-determination (Verdugo et al 2012, Wehmeyer et al 2017). It is important that the person with a learning disability is autonomous in their care, including its spiritual dimension. It is crucial that they have choice and ownership in decision-making about their life and care. The person may require the support of a learning disability nurse and others to be able to flourish in the spiritual dimension of their overall well-being. That spiritual support should be shaped on the values and needs of the person.

Spiritual support needs will often depend on the point the person is at in their life. Spiritual care can be important for people with learning disabilities and their families at various stages across the lifespan, during life transitions and at the end of life. Studies on quality of life, spirituality and learning disability have focused on different stages of life (Boehm and Carter 2019, Michaelson et al 2020, Timmins et al 2023).

Timmins et al (2023) found that taking part in faith-based activities was important for many older people with learning disabilities, particularly when the person had experienced a bereavement, was in poor health or experienced loneliness. Boehm and Carter (2019) asserted that involvement in a faith congregation and associated activities, such as volunteering, can be an opportunity for young adults with learning disabilities to expand their social connections and sense of belonging. For some young people with learning disabilities, leaving school means a loss of social connections. For those who are interested, participating in a faith community can offer opportunities to be a part of a social group.

**Faith-based and non-faith-based spiritual support**

A study conducted by Taub and Werner (2016) in Israel provides an example of research carried out in a particular community, that is, Jewish families with children with learning disabilities. Taub and Werner (2016) researched how religiosity affected families’ quality of life. They interviewed 170 parents and found that religious families had higher quality-of-life scores than secular families. In particular, mothers who followed a religious path reported higher levels of well-being and personal growth than mothers who did not (Taub and Werner 2016).

Sango and Forrester-Jones (2022) examined whether and how spiritual support was provided to people with learning disabilities in two types of community care services, a faith-based (Christian) care service and a non-faith-
based care service. The faith-based care service offered its users a community characterised by shared values, where individuals experienced a sense of unity and supported each other. The social bonds developed in that community provided a sense of unity and a shared sense of self. An example of how the community worked was communal meals: after a prayer of thanksgiving, each service user was involved in sharing out the food, rather than this being done exclusively by staff. By contrast, the non-faith-based care service focused more on practical and nurturing care, with an emphasis on serenity, safety and physical care (Sango and Forrester-Jones 2022). Timmins et al (2023) emphasised that for older people with learning disabilities, spiritual and religious practices can be important aspects of social belonging and can bring solace.

In line with a person-centred approach, and to promote the ‘self-determination’ domain of quality of life, it is important that nurses can support people with learning disabilities to access a specific cultural, religious or faith community. It is equally important that nurses can provide spiritual support to people with learning disabilities who do not wish to access a cultural, religious or faith community. The essential point is to listen to the person and, by establishing a relationship with them, determine their spiritual care support needs, preferences and choices. A flexible approach is crucial to be able to provide person-centred nursing care. O’Brien (2021) offered frameworks to structure spiritual nursing care for people from any faith or none.

Learning about the faith community of others can be a valuable endeavour. Clooney (2010) explained how learning about Hinduism and its similarities to and differences from Christianity allowed him to grow further in his own Catholic faith. Sango and Forrester-Jones (2022) pointed out that focusing solely on a Christian faith community limits learning.

**Barriers to spiritual care provision**

Barber (2013) and Timmins et al (2023) identified the need for nurses to support the person with a learning disability to access activities offered by local faith communities. One potential obstacle to the provision of spiritual care may arise when the person with a learning disability wishes to attend their local church and participate in its activities, but the community is not welcoming of the person. Carter et al (2016) pointed out that places of worship differ in the type of support they are prepared to give to those wishing to be part of the community. The need for faith communities to work on accessibility and inclusion for people with learning disabilities has been emphasised (Boehm and Carter 2019, Fellinger et al 2023).

Another barrier to participation in a faith community is the perception that the person with a learning disability would not have the skills to grasp complex theological concepts and would therefore not be a suitable member of the congregation. Swinton (2004) found that certain religious communities excluded people with learning disabilities, and Michaelson et al (2020) stressed that awareness needs to be raised when faith communities exclude people with learning disabilities. An overemphasis on academic knowledge of theology can make many people feel that they are lesser members of a particular faith community.

One example of communities where academic theological knowledge is not a prerequisite is the L’Arche communities. In the 30 L’Arche communities in Canada, people with and without learning disabilities live alongside each other and everyone belongs and contributes to the community, which is based on mutual care, respect and compassion. The Dutch theologian Henri Nouwen (1989, 2022) explained how joining one L’Arche community meant stepping down from the ‘academic pedestal’ he had previously occupied and learning to live alongside people with learning disabilities. Nouwen (1989, 2022) described the emphasis...
put, in L’Arche communities, on people’s individual spiritual perspectives rather than on academic knowledge of theology. Community living and the sense of social belonging it produces is central in the L’Arche communities (Nouwen 2022), which echoes the findings of Sango and Forrester-Jones (2022).

As emphasised by Sango and Forrester-Jones (2019), further barriers to spiritual care provision for people with learning disabilities include communication challenges, insufficient staffing – for example for accompanying people to church – and inadequate staff training in providing spiritual support. Nurses’ anxieties and apprehensions in relation to supporting people with the spiritual dimension of their care are well documented (McSherry et al 2020, Dobrowolska et al 2022). Staff education is crucial, and nurses and nursing students need to be supported to develop competence in providing spiritual care to people with learning disabilities.

Recent developments in spiritual care provision have included the development of a two-question assessment model for determining the holistic care needs of patients in acute care settings, including their spiritual care needs (Ross and McSherry 2018). The two questions are: ‘What is most important to you now?’ and ‘How can we help?’. Ross and McSherry (2018) argued that this simple informal tool, with two questions that can be asked in different ways as part of normal conversations with patients, can help overcome barriers such as lack of time and a focus on physical care (Ross and McSherry 2018). This two-question assessment model provides a good starting point for learning disability nurses to include the spiritual dimension in the care they provide.

The EPPIC Network is a network of nursing and midwifery educators and practitioners created to promote evidence-based spiritual care education and practice in Europe and beyond. EPPIC stands for ‘enhancing nurses’ and midwives’ competence in providing spiritual care through innovative education and compassionate care’ (EPICC Network 2024). The EPPIC Network originates from a three-year European research project that resulted in the development of four core spiritual care competencies for undergraduate nursing and midwifery students (EPPIC Network 2019):

- Intrapersonal spirituality – that is, being aware of the importance of spirituality for health and well-being.
- Interpersonal spirituality – that is, engaging with other people’s spirituality and acknowledging their unique spiritual and cultural worldviews, beliefs and practices.
- Spiritual care: assessment and planning – that is, assessing spiritual needs and resources using appropriate formal or informal approaches and planning spiritual care while maintaining confidentiality and obtaining informed consent.

Spiritual care competencies
The European Commission has called for members of the caring professions to have the necessary education to meet the cultural, spiritual and religious need of the people they care for (McSherry et al 2020). Nursing regulatory bodies, such as those in the UK (Nursing and Midwifery Council 2018) and in Ireland (NMBI 2023), require registrants to be able to provide spiritual care to their patients (McSherry et al 2020). All dimensions of holistic care are important to meet the needs of people with learning disabilities (Barr and Gates 2019, Mafuba 2023), including spiritual care, so nurses working in learning disability settings must be competent in providing spiritual care. However, how nurses acquire spiritual care competencies is not always clear (EPICC Network 2021) and McSherry et al (2020) identified that a lack of clarity about the meaning of spirituality and spiritual care prevails in the nursing and midwifery professions.

FURTHER RESOURCES
EPPIC Network – Spiritual Care Education Standard
Spiritual care: interventions and evaluation – that is, responding to spiritual needs through the provision of interventions and resources in the context of a caring, compassionate relationship.

The importance of integrating these spiritual care competencies in nursing education has been emphasised (Dobrowolska et al 2022) and a growing body of literature is emerging in relation to their validation and their application in nursing education (McSherry et al 2020, Kleiven et al 2021). As part of the EPICC project, resources have been developed that nurses and nurse educators can use to integrate spiritual care into their practice or into nursing education programmes. These resources include:

- A matrix for spiritual care education which shows the cultural, social and political environment in which spiritual care competency develops (blogs.staffs.ac.uk/epicc/files/2019/06/EPICC-Gold-Standard-Matrix-for-Spiritual-Care-Education.pdf).
- An adoption toolkit which provides teaching and learning resources on each of the four core competencies, thereby supporting the integration of spiritual care education into curricula (blogs.staffs.ac.uk/epicc/resources-and-tools/epicc-adoption-toolkit/).

Recommendations for further research

This review of the literature was exploratory in nature and there is a need for further research on this topic to develop the evidence base that learning disability nurses draw on to provide holistic care. Future research could include primary data collection in collaboration with people with learning disabilities and their families. It could explore on how nurses can improve the quality of life of people with learning disabilities from different faiths or none, and into the training and education of nurses and nursing students so that they are better equipped to provide spiritual care to people with learning disabilities.

Conclusion

Spiritual care is an essential aspect of holistic care and can be important for people with learning disabilities and their families at various stages, for example during life transitions and at the end of life. Developing a trusting therapeutic relationship with the person with a learning disability enables nurses to recognise the person’s spiritual care needs. However, spiritual care is often neglected and there is a paucity of literature on spiritual care and learning disability nursing. It is crucial that nurses and nursing students develop their competence in providing spiritual care to meet the holistic needs of people with learning disabilities. An important step towards this would be to integrate spiritual care education into nursing curricula. Future research will need to focus on how learning disability nurses can use spiritual care to improve the quality of life of people with learning disabilities from different faiths or none.

References
