ORIGINAL RESEARCH The Knowledge, Experiences and Perceptions of Nursing Students in Caring for a Patient with a Learning Disability: A Qualitative Study

Maxine Cromar-Hayes¹, Carolyn Lees¹, Denis Parkinson¹, Karen Deane², Helen Marshall¹

¹School of Allied Health Professions and Nursing, University of Liverpool, Liverpool, Merseyside, UK; ²Mersey Care NHS Foundation Trust, Liverpool, Merseyside, UK

Correspondence: Helen Marshall; Maxine Cromar-Hayes, School of Allied Health and Nursing, Institute of Population Health, University of Liverpool, Whelan Building, the Quadrangle, Brownlow Hill, Liverpool, L69 3GB, UK, Email Helen.marshall@liverpool.ac.uk; Maxine.Cromar-Hayes@liverpool.ac.uk

Purpose: There is a known inequality in the healthcare provision for people with a learning disability, they have a poorer experience and a higher mortality rate than the general population. All registered health and social care organisations are required to provide training for staff in learning disability and autism, including how to communicate effectively and to provide reasonable adjustments. It has been suggested that this training needs to be available to those completing their nursing degrees.

Methods: Focus groups were conducted with 21 adult nursing students. The qualitative data collected was analysed using a thematic framework to identify the main factors that contributed to how adult nursing students cared for those adults with a learning disability while on a clinical placement.

Results: Generally, participants felt unprepared to care for adults with a learning disability. They described how they lacked knowledge and confidence, yet increased time on clinical placement was a facilitator to improving this. Role modelling of confident healthcare staff and personal experiences of having a relative with a learning disability all positively contributed to increasing confidence. Simulated practice and learning from those with lived experience were cited as a mechanism to enhance their knowledge. Communication with patients and between healthcare staff and families was seen as integral to being able to provide patient centred care.

Conclusion: In a bid to ensure that those people with a learning disability have access to adequately skilled healthcare staff, adult nursing students need to be better prepared to provide care while on clinical placements. This will involve universities, clinical practice partners and those with a learning disability working together to collaboratively focus on training and education that develops confidence, knowledge and understanding which will then translate to excellent patient care.

Keywords: intellectual disabilities, practice learning, nursing education

Introduction

There are approximately 107.6 million people globally who have a learning disability which equates to 1.39% of the world's population,¹ with 1.5 million people in the United Kingdom alone.² This population experiences various health inequalities associated with higher mortality rates than the general population.³⁻⁶ This is a significant issue for the effective provision of healthcare that is equitable and safe. The deficiencies in the quality and effectiveness of health and social care provision are exacerbated by the fact that many healthcare professionals are either not aware of or do not include in their usual practice approaches that adapt services to meet the needs of people with learning disabilities.^{7–9}

People with a learning disability often have a reduced ability to understand new or complex information or to learn new skills.¹⁰ The onset of disability starts before adulthood, with a lasting effect on an individual's health, and people with a learning disability will have greater healthcare needs than their non-disabled peers.¹¹ The National Institute for Health and Care Excellence¹² supports this by explaining a learning disability as having a lower intellectual ability alongside social and adaptive impairment and an onset in childhood. It is evident that patients with a learning disability continue to experience health inequalities and a contributing factor is a lack of knowledge and confidence by healthcare

161

professionals.¹³ The *Health and Care Act 2022*¹⁴ introduced a requirement that regulated service providers are to ensure their staff receive training on learning disability and autism which is appropriate to the person's role.¹⁵ In England, The Oliver McGowan Mandatory Training on Learning Disability and Autism has been named as the preferred choice. This training been co-produced and will be co-delivered by trainers with lived experiences of learning disability and autism (Health Education England, 2023). In Wales, the Paul Ridd Learning Disability Awareness training is mandatory for all public facing National Health Service staff to complete.¹⁶

People with a learning disability continue to have a much shorter life expectancy than the wider general public, with 6 out of 10 dying before the age of 65, compared to 1 out of 10 for people from the general population. Those with epilepsy and from minority ethnic backgrounds are more likely to die younger.³ The most common cause of death based on death certificates during 2021 was COVID-19. The estimated excess deaths during 2021 for people with a learning disability compared to pre-pandemic years were double that of the general population. Approximately, half of all deaths of people with a learning disability was deemed to be avoidable during this time, compared to less than a quarter for people from the general population.³ A potential rationale for this was that those with a learning disability have higher rates of diabetes and obesity than the general population, which are known risk factors to Covid-19 mortality.¹⁷ Furthermore, they also receive a higher amount of social care support on a regular basis thus increasing the risk of transmission due to staff visiting different locations and people.¹⁷

There is a strategic emphasis placed upon improving health outcomes for those with a learning disability. This includes improving the knowledge of healthcare staff.¹⁸ It has been identified that qualified nurses' knowledge and confidence when caring for a patient with a learning disability requires improvement.^{19–21} Furthermore, negative attitudes from nurses, including healthcare students, towards people with a learning disability can contribute to health disparities and the provision of poor care.^{22–24} It can be argued that the goal of improving standards of awareness and education should be present within nurse education also. Therefore, this study will aim to explore the knowledge, experiences and perceptions of adult student nurses when caring for an adult patient with a learning disability. It is imperative that the future generation of nurses practice in a compassionate and knowledgeable manner to reduce the inequality gap that adults with a learning disability face. Hence, this study wanted to explore current perceptions from a cohort of undergraduate student nurses in the United Kingdom, to support curriculum planning and provision.

Methods

Research Question

What knowledge, experience and perceptions do adult student nurses have that influence caring for an adult patient with a learning disability?

Design

A qualitative approach, using a purposive sampling strategy, was selected to explore the knowledge, experiences and perceptions of adult student nurses when caring for an adult patient with a learning disability. The study involved semistructured, face-to-face focus group interviews with 21 adult student nurses. All students at the time of the study were completing an undergraduate nursing programme at a university in the north-west of England. This programme is an adult field course only.

Participants

Participants were recruited from the undergraduate nursing programme. Current undergraduate students on an adult nursing programme and who had experienced at least one clinical placement were included and eligible for this study. All eligible students registered on the programme (n = 180) were emailed a participant information sheet and invited to participate in the study, by the programme lead who consented to undertaking the role of gatekeeper. Those students interested in taking part were asked by the gatekeeper to contact the researcher to log an interest to participate. Written, informed consent was undertaken before the focus group interviews. The study recruited 21 participants in total which was an overall response rate of 12%.

Data Collection

The participants were allocated to the relevant year-specific focus-group which were year 1 (n = 6) year 2 (n = 11) and year 3 (n = 4). There were 17 females and 8 males who participated, with 13 people aged 18 to 30 years old and 8 people aged 31 years old and over. Focus group interviews took place during June 2022. Interviews were conducted at the university, they were digitally recorded and then transcribed verbatim using an external transcribing service. The interviews lasted between 1 hour and 2 minutes and 1 hour 37 minutes. Before the interview began written, informed consent was obtained from each participant, they were verbally assured of confidentiality and anonymity. The research question sought to explore student nurse knowledge, experience and perceptions when caring for an adult patient with a learning disability whilst on clinical placement. Therefore, a semi-structured focus group agenda was created to guide the discussion and redirect conversation when needed. The semi-structured guide asked open questions regarding their own knowledge, skills, confidence and experience whilst on clinical placement and any recommendations they wish to make from the viewpoint of a student nurse which can enhance future curriculum provision.

Data Analysis

All members of the research team participated in the analysis process which began by reading and re-reading transcripts, with the use of a thematic map²⁵ to develop the initial themes. Thematic analysis was then further developed to identify key categories involving systematic identification, charting and sorting of the data.²⁶ What followed included the comparing of data between individual transcripts. Regular meetings between the researchers throughout the research project allowed for the further reduction in themes. Analysis was iterative, using the six-step guidance for thematic analysis as described by Braun and Clarke.²⁷ It began with familiarisation with the data, by identifying initial codes, by looking for themes, reviewing those themes, listing the themes and then agreement on the themes by the research team. During data analysis and the identification of themes, each focus group was identified using a number coding system with each focus group interview assigned an identifier, so focus group year 1 (FGY1), focus group year 2 (FGY2) and focus group year 3 (FGY3). Standards for Reporting Qualitative Research (SRQR) was used to report the study.²⁸ This framework supports a rigorous and systematic approach when reporting qualitative studies.²⁸

Ethical Considerations

Prior to starting the study, ethical approval was obtained from the University of Liverpool Research Ethics Committee (Reference number: 10863). Informed, written consent was gained from all participants before the focus group interviews began, and they were advised that they would be able to leave at any point. The participants were informed that their anonymised responses would be used for publication purposes to raise knowledge and awareness on this topic.

The researchers were known to some of the participants as lecturers and this was acknowledged by incorporating reflexivity throughout the project to minimise bias. This was supported by ensuring no thoughts or opinions of the researchers were shared during data collection, and a semi-structured guide was utilised.

Results

Confidence, knowledge and communication were the three themes identified from the focus group interviews.

Confidence

A lack of confidence was noted to be a recurring theme from all year groups, and something that was only enhanced by placement exposure and repeated experiences with adults with a learning disability. Factors noted across the year groups which were highlighted as useful to increasing the student's confidence was personal experience of having a relative with a learning disability, observing confident, qualified healthcare staff in the placement setting and going to a clinical placement setting with a specific learning disability focus.

I feel a lot better in the situation that I am now because of having like the experience in the past and I have had like different patients with like different learning disabilities and I feel like it's just building it up like across the years. (Y3)

It was noted that students in year 1 questioned their ability to care for someone with a learning disability, due to a lack of clinical experience which in turn affected their own self-confidence, but in time, they suggested this would increase. This was mirrored within the year 3 focus group when one participant acknowledged that it may have been due to a lack of exposure to patients with a learning disability during clinical placements, which impacted on their own confidence but thought this could be addressed by the use of simulation.

I think confidence building would be yeah, more exposure to looking after patients with added needs I think would be really, really helpful and the use of simulation would definitely help. (Y3)

For another year 3 participant, it appeared that their confidence and preparedness to care for those with a learning disability had increased during their time on the nursing programme due to attendance at multiple placement sites. Furthermore, a placement experience within a learning disability organisation was positively reviewed as a measure to increase self-confidence across all year groups. It was noted that this practical experience of caring for someone with a learning disability every day increased confidence as opposed to reading about a person in their case notes. A year 1 student explained that their confidence had increased by learning from staff who had the skills and expertise in caring for patients with a learning disability.

Just seeing different scenarios and watching other skilled professionals, that's how I grow and learn how to develop my skills not by reading documentation. (Y1)

Experiencing a lack of confidence was echoed by a year 2 student who described how they would feel nervous when faced with a patient who had a learning disability. They suggested that this was due to their lack of knowledge of the different types of learning disabilities. Another year 2 student suggested that the longer they were looking after a patient with a learning disability the more confident they became.

I feel the more you get to know a patient, patients who are long term on the ward, the way you treat them on the first week of knowing them compared to the fourth week of knowing them is so different. (Y2)

It was noted that the use of simulation within nursing education was a way to increase confidence, particularly in relation to communication skills. It was seen as a safe space to increase confidence.

We could use the opportunity of simulation. We did communication skills. We gave ourselves the extra time to get it right. (Y1)

One year 3 participant suggested that confidence was a necessary trait required to engage effectively with those with a learning disability during a clinical placement. This was echoed by a year 3 student who admitted that although they were naturally reserved and shy, they needed to demonstrate a level of confidence in placement when they cared for a person with a learning disability as they felt it would enable them to communicate more effectively.

Afterwards, I have like said I could have probably done that better by just being a bit more confident in my ability, because I think that would have communicated better. (Y3)

It was suggested by one year 2 participant that having confidence in the ability to communicate was key to effectively caring for someone with a learning disability as they implied that although they may have the relevant skills, they were unsure how to modify them when required.

It's just the knowledge of maybe adapting them skills into helping someone with a learning disability. I feel like we do have the skills, we just do not know how to apply them in that specific situation. (Y2)

It appeared that what happened during handover while on placement influenced how confident students felt about how they approached those with a learning disability. One year 2 student advised when a patient with a learning disability was discussed during a shift change, this made them nervous, and they questioned their ability to care for that person.

When I have heard things on handover, it scares me and I get really uncomfortable and when I get uncomfortable I get clumsy. I start knocking things over around the patient and it puts me on edge. I feel like I am going to do something wrong or I am going to upset them. (Y2)

This was supported by a year 3 student who admitted that although they felt confident conducting an admission assessment, when they were informed that the patient had down syndrome, they then felt uncomfortable doing this and questioned their ability and as a result, asked for support.

It's like this preconception that they are going to be so different because they have got this condition. (Y3)

For one year 3 participant having a lack of confidence, feeling nervous or uncomfortable was an obvious barrier in being able to communicate effectively with those with a learning disability.

I think if you are shy and feel awkward yourself then you'd be reluctant to engage with them. (Y3)

Knowledge

Having adequate knowledge on learning disabilities was an important theme that emerged from all of the focus groups. When asked what they understood about learning disabilities one year 3 participant admitted that they knew very little. Another admitted that although they had been taught something, the knowledge had not had a significant impact due to other things taking a priority.

Learning has been basic and it has not stuck. There's been other stuff that overridden it. (Y3)

Across all focus groups, discussions around knowledge and understanding about learning disabilities appeared to suggest that personal experiences, university learning or practical knowledge gained from clinical experience were all influential factors. One participant described a member of their family who has a learning disability so that is where their understanding came from. They described how that lived experience or knowing someone with a learning disability helped increase their knowledge.

Me having that personal experience has helped me in practice because I do actually take my time and learn their ways. I find out as much as I can. (Y3)

I have got a family member with learning difficulties so I have kind of drawn on that a little bit. (Y1)

However, this was still perceived to be limited to the particular disability they had been exposed to. This became evident when all groups talked about their understanding of the term learning disability itself.

A learning disability always seems to be secondary to something else. There's always slightly different definitions. It feels like it's quite broad. (Y2)

When discussing the knowledge they had gained from lectures and seminars at the university, it appeared that there may have been some learning provided but participants felt that it was not sufficient.

I've done something in the course, but it's not enough to like, really make an impact. (Y1)

When asked how teaching about learning disabilities at the university could be improved, all three focus groups suggested that having people with a learning disability or those with a specialist knowledge involved in the delivery of the teaching sessions would be beneficial.

We need to be directly taught by people who have the experiences. (Y2)

Another participant also acknowledged that they had a personal responsibility to search for information by accessing reliable academic sources as well finding out about charities who help those with a learning disability.

Because they do support people with learning disabilities, so I do look at their sites and look through all their different resources. (Y2)

Learning from the family and carers of those with a learning disability was an important element as they recognised that they are in the best position to offer insight about how best to communicate, connect and work with someone with a learning disability.

It's so useful if they have got a carer with them even if it's just during the day, helping you to convey the patient's feelings so they would help you for example if this is the best time to take their BM or their obs. This is extremely useful for me. (Y1)

However, for one participant, learning from family and carers about the needs of the patient with the learning disability could result in the patient being disregarded and almost becoming invisible.

You find that a lot of colleagues tend not to talk to the patient, rather talk to their family members and you know and asking them simple things as do they want a drink, do they need the toilet? They do not ask the patient, they do not talk to the patient. The patient's not there. (Y3)

Going forward all groups felt that their knowledge would increase if there was more simulated practice with integrated scenarios involving a person with a learning disability. They would like to be directed to some more reliable sources so that they know what they are reading is trustworthy. All groups felt that more peer learning would help increase knowledge as you would learn through shared experiences. In other words, learning from the experiences of other student nurses about caring for an adult with a learning disability would be beneficial.

People can talk about their experiences, and even if they have not done or see something, they can listen to and learn from others. (Y2)

Communication

Communication was a key theme amongst all year groups. Students discussed the importance of communication when caring for people with a learning disability and acknowledged how their limited experience has highlighted some areas for their own development when caring for this patient group.

I do not really know how to engage thoroughly with someone whose communication is different to mine maybe. With the best will in the world, I have felt a bit lost sometimes. (Y3)

Discussions around communication focused on verbal and non-verbal communication, the patient's perspective, the involvement of families and carers, health passports and how the multidisciplinary team communicated with each other regarding the needs of the patient with a learning disability. One year 3 participant described the avoidance and the fear of communicating with patients with an learning disability, acknowledging it was due to a lack of training. Another participant stressed the importance of effective communication in being able to provide adequate care.

I find it so hard to know what to say and sometimes try to stay away from them. Some more training and guidance would definitely help me feel more confident. (Y3)

I think everyone understands that communication's important, you have got to know what the patient in front of you wants. (Y1)

The ways in which to communicate and the use of appropriate language and non-verbal communication were considered important, including the use of body language, simplified words and significant expressive gestures.

Everything you do expressive wise needs to be quite meaningful and big (Y1)

Another participant acknowledged the need to adapt language and to change the words they used when caring for someone with a learning disability.

It's all about changing how you say things and using the most appropriate language. (Y2)

For one participant in year 1, advice about the use of language came from guidance provided by staff on the placement.

Staff just maybe gave us advice like maybe using easier word. (Y1)

In all focus groups, participants reflected on their observations in practice, identifying areas of good practice and times when it could have been better. This included noting that staff who communicated directly with the patient rather than carers and relatives exhibited a more person-centred approach.

There were instances where you know staff were all addressing the patient. I thought was really, really good practice to observe. (Y3)

In contrast, one participant remarked on the importance of communication from the patients' perspective explaining how the staff had communicated with the carers rather than taking directly to the patient themselves. They described how the patient had challenged the staff and how empowering it had been to witness.

They said, do not talk to me like a baby, do not do this, talk to me. It was quite empowering to see. (Y3)

Confidence and awareness of the student nurses regarding how to communicate effectively with those with a learning disability appeared to improve through the year groups, as practice experience increased, with a year 3 participant providing an insight into the opportunity within their own practice.

I find as being a student, we get time to sit with the patients, we take our time, we do, we get to know their little quirks and we get to know their different communication skills. (Y3)

In relation to communication, what happened during handover involving the multidisciplinary team appeared to be significant in terms of what students learned about learning disability. From the student perspective, they reflected on their own experiences, noting that poor communication during handover impacted their ability to care for those with a learning disability as individuals.

He did not like direct questions; it was not handed over so I caused him unnecessary agitation, I could have been told, but I could have asked as well. (Y2)

It was suggested by all groups that communication amongst professionals was not effective, with many clinical handovers advising that a patient had a learning disability but not detailing what that meant for the patient's individual needs. Similarly, the use of Health Passports appeared variable in different practice settings with many students reporting they were not aware of them. However, those who had utilised them found them to be a useful tool to guide their communication for that individual.

During handover we are told the patient has a learning disability but that's it. No other information is provided which makes it difficult to care for them. (Y1)

A healthcare passport helps so much because you go to the information, and you know what you need to do. (Y2)

It was highlighted that support in how to care for a patient with a learning disability was available in most placement areas but staff were slow or failed to refer to a specialist learning disability teams for support.

It's not seen as urgent, but then for this patient, it really might be. (Y2)

Discussion

It has been recognised that the aim of practice learning is to provide nursing students with the opportunities to achieve proficiencies in order to gain the knowledge, skills and competencies of a safe and effective practitioner.²⁹ This should be achieved in partnership with higher education, resulting in fully developed practitioners. Nurse education provides theory and practice both in university and placement settings. The participants in this study are undertaking an adult field-specific programme. Whilst learning disability content is delivered in the university modules throughout the course to provide a theoretical underpinning, it is the clinical environment which should provide the opportunities to put that

knowledge and understanding into practice.²¹ This study has enabled adult nursing students to describe their experiences of caring for adults with a learning disability in clinical practice. It has explored the link between what they learn at university, their experiences in practice and how these impacts on their ability to provide effective person-centred care.

Overall, participants felt unprepared to care for adults with a learning disability while on placement, citing a lack of knowledge and confidence as influencing factors. Whilst it was acknowledged the participants had a responsibility to increase their own knowledge through self-directed reading, they also felt there should be a greater presence of this topic on their curriculum throughout their programme, which concurs with findings from Temple and Mordoch.³⁰ The findings showed communication skills, confidence and the knowledge of the nursing student to be particularly important when caring for someone who may have found it difficult to communicate their needs to staff. Participants expressed their anxiety when they were informed during the handover that a patient had a learning disability when little information was provided about how they should be cared for. This was seen by participants as a significant opportunity for a discussion on how to maximise effective patient care. This is consistent with a study by Kim and Seomun³¹ which identified the essential qualities required for an effective patient handover. Those features were the transfer of adequate information, interaction for exploring specific patient need and time for discussion. The study defined handover as a process for transferring information, for facilitating a dialogue to clarify information and the environment for accomplishing the continuity and safety of patient care. It has long been established that clinical handover has become a process central to effective, high-quality care and for facilitating changes in care delivery.³²

Reasonable adjustments are an integral aspect of care for people with a learning disability. As a result of the Equality Act³³ public service providers must ensure that accessibility to services is maximised for all people, including those with disabilities. It has been emphasised that the relevance of reasonable adjustments is important when providing appropriate care to those with learning disabilities, particularly in mainstream healthcare settings.³⁴ In a study by Read et al³⁵ it was apparent that there were significant gaps in how reasonable adjustments were provided for those with a learning disability accessing hospital care and that staff failed to listen to the perspectives of people requiring reasonable adjustments. One resource that can actively contribute to making reasonable adjustments for those with a learning disability accessing healthcare is a healthcare passport. A passport is designed to be used in hospital settings predominantly and should be completed by individuals and/or carers who know them well. This passport will include important information such as demographic information, medical information such as diagnoses, medication, and any allergies. It also importantly includes information regarding how people communicate, things that make them happy and sad and what support is needed for mobilisation and eating for example.³⁶ In this study, participants acknowledged their significance in promoting effective care and facilitating communication. However, it was noted in this study that student nurses had not routinely seen these utilised in practice during clinical placement. Participants appreciated healthcare passports are a way of understanding patients' needs and recognising how they wanted to be cared for. The provision and use of healthcare passports for people with a learning disability can also act as a valuable tool to enhance patient safety and promote patient driven care.³⁷⁻³⁹ However, there appears to be a lack of standardisation in their implementation.⁴⁰ This lack of availability was highlighted in a study by McCormick et al⁴¹ which recognised the use of healthcare passports as an essential part of clinical governance and effective patient centred care for those with a learning disability.

The use of simulated practice was recognised by participants in this study as a way to promote confidence for those feeling that they lacked the necessary skills to communicate effectively with adults with a learning disability. This also aligns with the Nursing and Midwifery Council who stipulate nursing students can now undertake a maximum of 600 simulated practice hours during their education.^{42,43} Research has shown that using simulated patients can help increase a student's confidence prior to going into clinical practice for the first time.⁴⁴ Furthermore, simulated practice with a specific learning disability focus is seen as a positive contributory factor to increasing confidence in student nurses and in turn patient care.⁴⁵ This is seen as being particularly helpful if the students are being introduced to something new, like caring for someone with a learning disability. Promoting the continued integration of disability-related content into the nursing curricula using simulated practice has to be considered alongside students' preferred way of learning. Not all students are visual or auditory learners. Some studies have shown that over 30% of nursing students consider themselves to be kinaesthetic learning opportunities and for improving nursing students' preceived competence, self-efficacy, and for

facilitating a positive learning experience. Evidence suggests that while most learning occurs at the first simulation exercise, it is the multiple exposure to these experiences that improves students' learning outcomes.⁴⁷ Guerrero et al⁴⁸ have demonstrated that the use of simulated practice should be incorporated with use of traditional hands-on training to enhance nurses' confidence and it can help them develop proficiency and ensure readiness for practice.

In this study, participants reported that having a relative with a learning disability increased their knowledge about caring for someone with specific needs and in developing confidence, in communicating with them and their carers. The findings showed that knowing someone with a learning disability positively impacted their level of knowledge and understanding. Like this study, Golub-Victor et al^{49} also concluded from the 232 respondents to a survey that prior experience of interacting and working with people with a learning disability had greater levels of self-perceived confidence. The incorporation of expertise by experience has in the past been acknowledged as an increasingly valued aspect of care delivery.^{50,51} A study by Oates et al⁵² which looked at nursing students who had experienced mental health issues found that their own personal experience informed their own practice in various ways. Findings suggested that personal experience of mental illness promoted a better understanding of the needs of service users, and they felt it gave them confidence when talking to those they were caring for. The idea of personal experiences informing therapeutic relationships within nursing, including learning disabilities, cannot go unrecognised. Oates et al's study⁵² is relevant to mental health nursing practice but the findings highlight the importance in nurse education of identifying ways in which students' expertise by experience can inform their practice. Recognizing the impact of personal experience on learning across the nursing curriculum is vital to enhancing student learning and how the experiences of nursing students can inform the knowledge base of their peers. However, it appears that shared learning by personal experience and disclosure of those experiences is inadequately reported, and there is limited evidence on this phenomenon.

Shared learning by service user involvement (SUI) has for a long time been regarded as essential to the delivery of health programmes in Higher Education²⁹ and it is considered a necessity by professional bodies in order to enhance student learning. SUI in teaching and learning allows individuals who have personal and lived experience of health-related conditions, to contribute to degree programmes. The genesis for their involvement has often been driven by negative experiences and done so that healthcare professionals can begin to understand what it really feels like to be a patient. A study by Kuti and Houghton⁵³ found that service user involvement in the delivery of nursing education helped nursing students develop insight and understanding of how patients experienced care. The study also highlighted that the process enabled some positive, self-reflective learning for the students and that it had the potential to meet the learning needs of students in a way that enabled a connection between theory and practice. Similarly, Smith et al²¹ evaluating the inclusion of adults with a learning disability in the teaching of first-year nursing students concluded that such opportunities impacted significantly on students' knowledge and understanding regarding caring for someone with a learning disability. Findings also suggested that some students reported an increase in their confidence in being able to communicate and interact with this patient group.

Strengths and Limitations

This study provides valuable information about the knowledge, experience and perceptions of adult student nurses that influence caring for an adult patient with a learning disability. However, these findings should be viewed in the context of their limitations. The sample size was small and confined to one university. When analysing the data, there was no statistical agreement generated across coders when analysing emerging themes.

Conclusions

The NHS has made a specific commitment to ensure people with a learning disability are supported to live happier, healthier and longer lives.¹⁸ This will be done via proactive, individualised care and making reasonable adjustments. Additionally, their experiences of care should not be dependent on whether or not they have access to specialist teams and practitioners. In order to achieve this, an appropriately skilled and knowledgeable workforce of adult nurses is needed to provide adequate care to this population.

The findings of this study have highlighted that participants generally felt unprepared to care for adults with a learning disability that they lacked confidence and that the university failed to provide them with sufficient knowledge

on how to adequately communicate with both patients and their carers. It appears that a placement within a specific learning disability organisation and increased time on clinical placements was a significant influence in increasing self-confidence for all year groups, as the experience of regularly caring for someone with a learning disability increased knowledge and understanding. Simulated practice and learning from those with lived experience were also cited as a mechanism whereby students felt they could learn in a safe space. Based on the findings from this study, preparing adult nursing students to care for those with a learning disability is complex and dependent on a number of factors that involve universities, practice partners and adults with a learning disability sharing their experiences. This should then facilitate the development of registered, adult nurses who provide care that promotes the biological, psychological, and social wellbeing of those with a learning disability. It is apparent that further studies are needed to explore whether the experiences of adult nursing students in this study are consistent with adult nursing students at other universities and in particular the impact that placements have in developing skills, knowledge and perceptions when caring for an adult with a learning disability.

Acknowledgments

Thank you to the nursing students who supported this study by sharing their views and thoughts on this topic.

Disclosure

The authors report no conflicts of interest in this work.

References

- 1. Nair R, Chen M, Dutt AS, Hagopian L, Singh A, Du M. Significant regional inequalities in the prevalence of intellectual disability and trends from 1990 to 2019: a systematic analysis of GBD 2019. *Epidemiol Psychiatr Sci.* 2022;31: e91.
- Statistics OfN. Estimates of the population for the UK, England, Wales, Scotland, and Northern Ireland;2020 Available from: https://www.ons.gov. uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/populationestimatesforukenglandandwalesscotlandand northernireland. Accessed July 19, 2024.
- 3. Bristol Uo. The Learning Disabilities Mortality Review (LeDeR programme): annual report 2020. England; 2021.
- 4. Heslop P, Hebron C. Promoting the Health and Well-Being of People with Learning Disabilities. 1st Edition. 2020 ed ed. Cham: Springer Nature; 2020.
- 5. Lords Ho. Mental capacity act 2005: post-legislative scrutiny; 2014.
- 6. Mencap. Death by indifference; 2007.
- 7. Digital N Reasonable Adjustment Flag; 2023 Available from: https://digital.nhs.uk/services/reasonable-adjustment-flag. Accessed July 19, 2024.
- 8. Ee J, Stenfert Kroese B, Rose J. A systematic review of the knowledge, attitudes and perceptions of health and social care professionals towards people with learning disabilities and mental health problems. *Br J Learn Disabil.* 2022;50(4):467–483. doi:10.1111/bld.12401
- 9. England PH. Reasonable adjustments: a legal duty; 2020.
- 10. Mee S. Valuing People with a Learning Disability. 1 ed. Cumbria: M&K Update; 2012.
- 11. Emerson E, Baines S, Allerton L, Welch V. Health inequalities & people with learning disabilities in the UK: 2011; 2011.
- 12. Excellence NIfHa C. Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges; 2015.
- 13. Drozd M, Clinch C. The experiences of orthopaedic and trauma nurses who have cared for adults with a learning disability. Int J Orthop Trauma Nurs. 2016;22:13–23. doi:10.1016/j.ijotn.2015.08.003
- 14. legislation.gov.uk. Health and Care Act 2022. Available from: https://www.legislation.gov.uk/ukpga/2022/31/contents. Accessed 26 July, 2024.
- 15. Partners announced to deliver the Oliver McGowan mandatory learning disability and autism training for all health and social care staff [press release]; 2020.
- 16. 'The Paul Ridd learning disability education and training programme rolled out to NHS Wales healthcare staff', [press release]; 2022.
- 17. England PH. Deaths of People Identified as Having Learning Disabilities with COVID-19 in England in the Spring of 2020. London; 2020. 18. England N. The NHS long term plan; 2019.
- 19. Care doha S 'Right to be heard': the Government's response to the consultation on learning disability and autism training for health and care staff; 2019.
- 20. Saunder L, Knight R-A. CitySCaPE: moving beyond indifference in education for pre-registration nurses about learning disability. *Nurs Educ Prac.* 2017;26:82–88. doi:10.1016/j.nepr.2017.07.008
- 21. Smith P, Ooms A, Marks-Maran D. Active involvement of learning disabilities service users in the development and delivery of a teaching session to pre-registration nurses: students' perspectives. *Nurs Educ Prac.* 2016;16(1):111–118. doi:10.1016/j.nepr.2015.09.010
- 22. Desroches ML, Howie VA, Wilson NJ, Lewis P. Nurses' attitudes and emotions toward caring for adults with intellectual disability: an international replication study. *J Nurs Scholarsh.* 2022;54(1):117–124. doi:10.1111/jnu.12713
- 23. Noronha MTaP J, Pawlyn J. Caring for people with learning disabilities: the attitudes and perceptions of general nurses. *Learn Disabil Pract.* 2019;22(3):25–32. doi:10.7748/ldp.2019.e1970
- 24. Kritsotakis G, Galanis P, Papastefanakis E, et al. Attitudes towards people with physical or intellectual disabilities among nursing, social work and medical students. *J Clin Nurs.* 2017;26(23–24):4951–4963. doi:10.1111/jocn.13988

- 25. Voices N. Integrated care: what do patients, service users and carers want?; 2012.
- 26. Miles MBH, M A. Qualitative Data Analysis. 2nd ed. California: Sage; 1994.
- 27. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3(2):77-101. doi:10.1191/1478088706qp063oa
- O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med. 2014;89(9):1245–1251. doi:10.1097/ACM.00000000000388
- Council NaM. Training nurses and Midwives: protecting the public by setting education standards; 2016. Available from: https://www.nmc.org.uk/ globalassets/sitedocuments/nmc-publications/educatorsleaflet.pdf. Accessed July 19, 2024.
- 30. Temple B, Mordoch E. Nursing student perceptions of disability and preparation to care for people with intellectual disabilities. *J Nurs Educ*. 2012;51(7):407–410. doi:10.3928/01484834-20120515-01
- 31. Kim EJS, Gyeong A. Handover in Nursing: a Concept Analysis. Res Theory Nurs Pract. 2020;34(4):297-320. doi:10.1891/RTNP-D-19-00089
- Bruton J, Norton C, Smyth N, Ward H, Day S. Nurse handover: patient and staff experiences. Br J Nurs. 2016;25(7):386–393. doi:10.12968/ bjon.2016.25.7.386
- 33. Equality Act 2010. Stat. c. 15; (2010).
- 34. Wilson NJ, Pracilio A, Kersten M, et al. Registered nurses' awareness and implementation of reasonable adjustments for people with intellectual disability and/or autism. *J Adv Nurs*. 2022;78(8):2426–2435. doi:10.1111/jan.15171
- 35. Read S, Heslop P, Turner S, et al. Disabled people's experiences of accessing reasonable adjustments in hospitals: a qualitative study. *BMC Health* Serv Res. 2018;18(1):931. doi:10.1186/s12913-018-3757-7
- 36. Trust EKHUNF. My healthcare passport; 2014.
- 37. Peate I, Mitchell A, Peate I, Mitchell A. Nursing Practice: Knowledge and Care. 3rd / Edited by Ian Peate, Aby Mitchell. Ed. Hoboken, NJ, USA: Wiley Blackwell; 2022.
- 38. Nursing RCo. Connecting for change: for the future of learning disability nursing; 2021.
- 39. Excellence NIfHa C. Learning Disability: care and support of people growing older; 2019.
- 40. Northway R, Rees S, Davies M, Williams S. Hospital passports, patient safety and person-centred care: a review of documents currently used for people with intellectual disabilities in the UK. J Clin Nurs. 2017;26(23–24):5160–5168. doi:10.1111/jocn.14065
- 41. McCormick F, Marsh L, Taggart L, Brown M. Using a hospital passport from the perspective of adults with intellectual disabilities, family carers and health professionals: a qualitative study. *J Intellect Disabil*. 2024;28(1):170–184. doi:10.1177/17446295221145996
- Council NaM. Open Council; 2023 Available from: https://www.nmc.org.uk/globalassets/sitedocuments/councilpapersanddocuments/council-2022/ open-council—25-january-2023.pdf. Accessed January 25, 2023.
- 43. Council NaM. Simulated practice learning; 2023.
- 44. Doolen J, Mariani B, Atz T, et al. High-fidelity simulation in undergraduate nursing education: a review of simulation reviews. *Clin Simul Nurs*. 2016;12(7):290–302. doi:10.1016/j.ecns.2016.01.009
- 45. O'Boyle-Duggan M, Grech JD, Brandt R. Effectiveness of live simulation of patients with intellectual disabilities. J Nurs Educ. 2012;51 (6):334-342. doi:10.3928/01484834-20120504-01
- 46. Ibrahim RH, Hussein D-A. Assessment of visual, auditory, and kinesthetic learning style among undergraduate nursing students. *Int J Adv Nurs Stud.* 2016;5(1):1–4. doi:10.14419/ijans.v5i1.5124
- 47. Franklin AEB, Petsas N. Simulation in Undergraduate Education. Ann Rev Nurs Res. 2020;39(1):3-31. doi:10.1891/0739-6686.39.3
- 48. Guerrero JG, Hafiz AH, Eltohamy NAE, Gomma N, Jarrah IA. Repeated exposure to high-fidelity simulation and nursing interns' clinical performance: impact on practice readiness. *Clin Simul Nurs*. 2021;60:18–24. doi:10.1016/j.ecns.2021.06.011
- Golub-Victor AC, Peterson B, Calderón J, Lopes AD, Fitzpatrick DF. Student confidence in providing healthcare to adults with intellectual disability: implications for health profession curricula. *Intellectual and Devl Disabil*. 2022;60(6):477–483. doi:10.1352/1934-9556-60.5.477
- 50. Gillard S, Holley J. Peer workers in mental health services: literature overview. Advances in psychiatric treatment: the royal college of psychiatrists'. J Continuing Prof Dev. 2014;20(4):286–292.
- 51. Harding C. Involving adult service users with learning disabilities in the training of speech and language therapy students. *Int J Teach Learn Higher Educ.* 2009;20(2):207.
- Oates J, Drey N, Jones J. 'Your experiences were your tools'. How personal experience of mental health problems informs mental health nursing practice. J Psychiatr Mental Health Nurs. 2017;24(7):471–479. doi:10.1111/jpm.12376
- Kuti B, Houghton T. Service user involvement in teaching and learning: student nurse perspectives. J Res Nurs. 2019;24(3–4):183–194. doi:10.1177/1744987119837594

Nursing: Research and Reviews

Dovepress

Publish your work in this journal

Nursing: Research and Reviews is an international, peer-reviewed, open access journal publishing original research, reports, reviews and commentaries on all aspects of nursing and patient care. These include patient education and counseling, ethics, management and organizational issues, diagnostics and prescribing, health outcomes, economics and resource management, improving patient safety in all settings. The manuscript management system is completely online and includes a very quick and fair peer-review system. Visit http://www.dovepress.com/ testimonials.php to read real quotes from published authors.

Submit your manuscript here: http://www.dovepress.com/nursing-research-and-reviews-journal

If 🔰 in 🕨 DovePress

171