Why you should read this article:
- To understand how learning disability nurses were affected during the first wave of the COVID-19 pandemic
- To learn how learning disability nurses responded to COVID-19 by adapting service delivery
- To develop ideas so you can continue to provide high-quality care for people with learning disabilities during COVID-19

COVID-19: experiences and contributions of learning disability nurses during the first wave of the pandemic

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Abstract

The COVID-19 pandemic prompted an unprecedented level of change in service delivery across the NHS and nurses needed to adapt their practice quickly. However, to date, there has been little recognition of the challenges encountered during the pandemic by learning disability nurses.

This article outlines a listening exercise that was undertaken to gather insights into the experiences and contributions of learning disability nurses during the first wave of the pandemic. Nine reflective group discussions were held via video conferencing with 26 learning disability nurses. Themes were extracted from these discussions.

The findings revealed negative and positive effects of the pandemic on learning disability nursing practice. They show that learning disability nurses have responded to the pandemic with increased collaboration, creativity and commitment in an effort to maintain the health and well-being of service users. The insights gained from these reflective discussions enabled an understanding of how organisations and learning disability nurses managed the transformation of services during the first wave.

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Keywords

Background

In March 2020 healthcare services across the UK underwent rapid changes to service delivery due to the emergence of the coronavirus disease (COVID-19), with a complete shift to working from home outside of inpatient care settings. Many nurses felt underprepared and ill-equipped to manage the breadth and speed of the required changes (Mitchell 2020) and these feelings were a recognised cause of distress among

healthcare staff exposed to COVID-19 (Lai et al 2020).

Learning disability nurses experienced unique challenges with the changes in service delivery, since people with learning disabilities are more susceptible to mental and physical illness than the general population (Prasher and Kapadia 2006). People with learning disabilities rely on structure and routine (Boyd et al 2014) and have distinct ways of communicating (Grove and Walker 1990). However, during the pandemic the need for staff to wear personal protective equipment (PPE) and use digital methods of communication has resulted in direct barriers to care. Such stressors can increase behaviour by these patients described as challenging, which is itself known to reduce staff morale, particularly in inpatient settings (Hughes and Anderson 2020).

As the negative effects of COVID-19 on physical and mental health become clearer (Holmes et al 2020) it is important to understand the needs of all nurses, but so far there has been little recognition of the challenges encountered by learning disability nurses. This may be compounded by the existing lack of awareness in society of the needs of people with learning disabilities, who are all too often marginalised and ignored (Matuska and Gallagher 2020). It was therefore considered important to gather insights into the experiences and contributions of learning disability nurses during the first wave of the COVID-19 pandemic. The authors of this article undertook a listening exercise and here they share the perspectives gained from listening to their colleagues.

Listening exercise
Method
A listening exercise was undertaken to gather insights into the experiences and contributions of learning disability nurses during the first wave of the COVID-19 pandemic. Learning disability nurses who were members of the Florence Nightingale Foundation Alumni network were invited by email to participate in reflective group discussions held via video conferencing.

In total, 26 participants contributed to the discussions, who were band 5, 6, 7 or 8 learning disability nurses. Box 1 shows participants' usual practice areas and geographical areas. Some participants had been redeployed to inpatient settings caring for people with learning disabilities.

The reflective group discussions were facilitated by the first author of this article (CB) and focused on the first wave of the COVID-19 pandemic. A series of prompts guided participants to consider:
» The effects of the rapid changes to service provision on their engagement with service users.
» The most challenging and emotional moments, and instances of personal pride, they had experienced.
» Professional progress they had made that they hoped to sustain in the future.
Nine group discussions were held between October and November 2020, each attracting between one and seven participants.

Data analysis
The reflective group discussions were recorded, and themes emerged from the recordings through a two-stage coding

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Box 1. Usual practice areas and geographical areas of participants

Practice areas
» Learning disability community mental health – service management: 1 participant
» Learning disability and autism service lead: 1 participant
» Adult community team: 11 participants
» Integrated learning disability team: 3 participants
» Primary care liaison services: 4 participants
» Acute learning disabilities liaison: 2 participants
» High-secure forensic inpatient service: 2 participants
» Primary acute care: 2 participants

Geographical areas
» South east England: 10 participants
» South west England: 6 participants
» Midlands: 3 participants
» London: 4 participants
» Scotland: 3 participants

process. The first stage involved the facilitator taking note of, and applying codes to, words and phrases articulated by participants, paying attention to recurring words and phrases (Carey and Smith 1994). This was aided by iteration and affirming summaries from the facilitator during the group discussions. The second stage involved CB reviewing the recordings and immersing themselves in the data to determine themes. The recordings were also reviewed independently by the second author (GS) and final themes were agreed through discussion with the wider research team (CB, GS, EG, DH). The agreed themes were then confirmed and clarified using member checking (Birt et al 2016).

Ethics and informed consent

In accordance with ethical principles, participants were made aware that the discussions would be recorded and were informed that anonymous quotes could potentially be used in future publications. Verbal consent was obtained from participants at the start of each group discussion. There were no pre-existing relationships between the facilitator and participants. Participants were informed of the voluntary nature of participation, and encouraged to raise any concerns and reflect on these as they would in professional practice.

Findings

Four major themes emerged from the reflective group discussions:
» Organisational adjustments.
» Preserving health and well-being.
» Virtual transformation.
» Innovations in communication.

Organisational adjustments
Adapting to virtual service delivery

At the start of the COVID-19 pandemic, considering the risks to individual staff members and service users, most routine care was made virtual. There was an immense effort by health and social care organisations providing services to people with learning disabilities to upskill staff and support them to manage the rapid changes to service delivery. Participants generally felt that organisations had taken an appropriate and timely approach. They also felt that staff had been quick to rise to the challenges posed by the pandemic, including uncertainty – not knowing how long restrictions, or indeed the pandemic itself, would last:

'Back in March everyone was working from home. Only seeing people when it was absolutely crucial. Subsequently, as the weeks went on, the trust provided us with tablets to facilitate communication and contact with families and carers. Those first few weeks were quite tricky.' (Participant 6)

'In the beginning there was some confusion regarding policy and preparedness, but we feel our service responded quickly, issuing packages of education and increased training.' (Participant 1)

'PPE was moved to a central storage location so community nurses were able to have access, as some of our buildings were shared with other services.' (Participant 11)

However, working from home was not considered to be an optimal method of providing clinical care and there were feelings of doubt or discouragement, with people wondering what a community healthcare worker could do sitting at home. The message from the government, and in some cases from organisations, was that staff would have to support service users remotely. This gave some learning disability nurses a sense that care was being curtailed, which led to the perception that their work was not being valued:

'It has impacted on the staff that I supervise and their ability to feel that they are doing the job to the best of their ability. That doesn't sit well with very conscientious and very experienced health professionals.' (Participant 2)

As staff began to adjust to new ways of working, these feelings subsided and

thoughts turned to the needs of services users. Staff realised that:

'Suddenly [service users] weren't getting any visits, then it was just a telephone call, then it wasn't a telephone call from me, it was from my colleague.' (Participant 17)

This made them more determined to do everything they could to support people in their care.

In the group discussions, participants communicated how passionate they were about ensuring service users' safety. The vulnerability of service users was a major concern that had prompted teams to adapt. Staff's efforts to ensure service users' health and social care needs would continue to be met led to a sense of shared commitment:

'It has really shown a strength in teamwork that everybody has pulled together to do what was needed to be done to get through the challenges.' (Participant 9)

'As a team we have pulled together even more to try to support our service users. We have just flourished with the teamwork and togetherness.' (Participant 15)

Staff redeployment
Participants described a general assumption that community nurses could be easily redeployed because they were needed less in the community, since many people with learning disabilities live in supported accommodation and many day centres had closed. Some participants usually working in the community had been redeployed to inpatient areas that were experiencing staff shortages because of the pandemic. They described receiving appropriate training and were satisfied with its quality.

There was a perception that staff leaving their posts in the community to work on a ward were seen, in some organisations, as 'going the extra mile'. This led some learning disability nurses who had remained in their community post to feel that they were not viewed as positively as they could have been in terms of their contribution to care during the pandemic.

In some instances, inpatient settings were so short of staff that it became a case of needs must. Because learning disability nurses are assumed to possess a certain core skill set, there was an assumption that any learning disability nurse would be able to deliver care in any area of the healthcare system. However, this caused increased anxiety and feelings of inadequacy among some learning disability nurses who had been asked to redeploy:

'I had one member of staff who basically got to the front door of the ward, he was redeployed to an inpatient unit where people were on forensic sections and he was just so anxious that he couldn't do it, so I had to refer him to occupational health to get it signed off that he wasn't able to fulfil that request, which was seen as a reasonable request.' (Participant 2)

In some areas, learning disability nurses had been redeployed but had continued to manage a proportion of their existing caseload. This had caused them to experience increased anxiety and concern for service users on their existing caseload. Learning disability nurses working in practice areas where they did not have a caseload to manage – such as research – were more amenable to the idea that staff redeployment was a rational way of addressing some of the challenges caused by the pandemic. As one participant remarked:

'I didn't have a community caseload of patients to worry about when I was deployed back to the inpatient areas, so it made sense for me to be deployed there.' (Participant 25)

Expanding services and reducing social isolation
Participants explained that learning disability nurses had done everything they could to ensure service users would receive the care and support they needed. On-call cover was organised so that services could be contactable 24/7. Many participants considered it crucial to focus on reducing social isolation for service users:

'We spent a lot of time reassuring people. We are usually a Monday to Friday 9 to 5 service, but we started working weekends as well just to make sure there was some sort of learning disability cover over the weekends. But no one has ever experienced this before in terms of our day-to-day service and it has been quite a challenge.' (Participant 15)

'I worked extremely hard to connect people during the pandemic… that was really important for me, for them to feel connected and not isolated.' (Participant 9)

However, for many participants extended working hours, back-to-back appointments and assessments, and long periods of time spent making decisions on their own led to increased levels of fatigue:

'I said to my manager, after supervision, that I am actually feeling more tired and exhausted after a working day than I used to be before. Mentally it's quite draining because now you're having to deal with your job and individuals are going through personal things as well… some trauma of some sort because of COVID.' (Participant 6)

Nevertheless, all participants felt well-supported by their immediate management team and there was a sense that services had been more accommodating of staff needs, as well as the needs of the service, because of the effect of the COVID-19 pandemic.

Preserving health and well-being
Preserving the physical health of service users
As COVID-19 spread across the UK there was a pragmatic process of implementing the red, amber, green (RAG) risk-rating system (Public Health England 2017). Staff worked tirelessly across inpatient and community settings to ensure service users would be prioritised according to risk. There were, however, concerns about communication and how information was being disseminated within organisations, particularly about restrictions to visits in inpatient settings.

One participant explained how inpatient services were encountering cases of COVID-19 in addition to conditions they would normally see in people with learning disabilities, such as aspiration pneumonia, constipation and prolonged seizure. Participants who had been redeployed to inpatient settings acknowledged the challenges in managing the physical health of service users. They also expressed a sense of pride when inpatients on their ward who had been treated for COVID-19 had fully recovered.

All participants explained that they had worked over and above their normal hours to address the needs of service users. Participants described how they became increasingly proactive in their approach to care, particularly since they were acutely aware of the need to preserve the physical health of service users and of the risk of diagnostic overshadowing. Diagnostic overshadowing occurs when the actual cause of a physical condition is overlooked and not adequately explored because it is assumed that the condition is due to the person's co-occurring disability or mental health condition (Simpson et al 2020), and it can lead to suboptimal treatment outcomes and increased mortality (Javaid et al 2019).

Participants explained further that in the early days of the pandemic the message from Public Health England was that if one person in a home tested positive and anybody else exhibited symptoms, then they should be treated as having COVID-19. This generated concerns that respiratory conditions such as pneumonia – which is a common cause of mortality in people with learning disabilities (NHS England and NHS Improvement 2019) – would not be adequately treated because any respiratory symptoms would be assumed to be due to COVID-19.

In terms of managing conditions that existed before the pandemic, participants shared concerns about how to ensure that service users would not get lost in the system:

Key points

- More consideration needs to be given to the effects of digital methods of healthcare delivery for people with a learning disability

- In future, processes should be evaluated and designed in consultation with learning disability nurses and service users to identify challenges in access to digital methods, prevent their inappropriate use and avoid digital exclusion

- The unique skills of learning disability nurses should be emphasised across the nursing profession to avoid incorrect assumptions about their core competencies, therefore ensuring their effective use in any future event that requires redeployment of staff

- Further research is needed to explore the experiences of learning disability nurses during the second wave of the COVID-19 pandemic to ascertain changes made as a result of lessons learned from the first wave, which will provide insight into the longer-term effects of the pandemic and inform future policy, education and practice

'*A lot of people had surgeries planned. As a service we were worried about missing people, or people falling off the radar, people not getting primary care and treatment. We looked at how we could create a fail-safe so these people don't get lost. We created a spreadsheet and logged everybody who had had a procedure postponed or cancelled, and as we return back to normal we will work out urgencies and plan that way.*' (Participant 15)

Proactive risk assessment was one method participants thought would assist in ensuring service users would receive essential treatments once the pandemic was over. Integrated teams were flagged by participants as being a distinct advantage. Learning disability services with integrated teams would have had access to a complex health team, so they would have been able to continue to offer routine clinical procedures to service users.

Preserving the well-being of staff

Participants expressed pride in how their team had come together. There was wide recognition of the need to maintain staff well-being and staff had found various ways of supporting each other such as weekly catch-ups or encouraging each other to take time out:

'*We joined Move for Mencap [mencap. org.uk/get-involved/move-mencap], we encouraged each other to get out and about more, to stay active. We sent pictures to each other when we were doing it.*' (Participant 18)

In one geographical area, well-being hubs had been developed for inpatient staff. Participants who had been redeployed to inpatient settings found these helpful:

'*The hubs were a really good idea, because if you were feeling stressed you could get time off the ward to go up.*' (Participant 26)

It was anticipated that these well-being hubs would be maintained after the pandemic as an additional strategy to improve staff well-being, particularly to support staff who had been more exposed

to death and dying. Participants expressed the hope that the effects of loss and grief on individual members of staff would be recognised at national level in the future.

Participants working in hospital settings discussed how, in the early days of the pandemic, there had been an overwhelming influx of advice and guidance about infection prevention and control. Staff were acutely aware of the need to prevent and control the spread of infection, but sometimes felt as if they were drowning in information. The knowledge all nurses believed they possessed was challenged by the information overload. This is because so little was known about the SARS-CoV-2 virus, how to contain it and how to manage COVID-19:

'*That instability within yourself having to second read things, that has been a real challenge for me. There were also the reasonable adjustments on top of the reasonable adjustments and that was a real challenge. I qualified in 1981 and everything I have worked along my career path is not as we know it.*' (Participant 17)

Virtual transformation
Challenges and advantages of virtual working

The challenges of virtual working were evident in all group discussions. For most participants, home had become the office for most of the time. As working hours increased, the boundaries between work and private life became progressively blurred. Participants described feeling more pressure to be available, largely due to increased concerns for the health and well-being of service users.

Participants from black, Asian and minority ethnic (BAME) backgrounds expressed concerns about their own and their family's health and well-being, especially since it was thought that people from BAME backgrounds were more at risk of death or serious illness from COVID-19 (Moorthy and Sankar 2020):

'*I have needed to go to the ward to provide emotional support and help one*

of my services users with interventions. I come from a BAME background and my parents have underlying health conditions, so for me it was very scary to go to hospital regularly because I was worried my parents might get COVID.' (Participant 8)

'Adjusting to things has caused anxiety, and also being at risk didn't help, not because I am black but because I have underlying issues as well as being black. That doesn't help.' (Participant 7)

In some cases – for example, in participants who had to shield – work needed to be shifted entirely to home working, which had the positive effect of reducing the person's anxieties about contracting the virus:

'I have had to shield. I am one of those people who got one of those letters. For the first few months I have very much felt benched. I have come to realise that even though I am at home I can still make a difference.' (Participant 15)

Virtual working was also seen as having distinct advantages. It enhanced flexibility in working patterns, which made it easier to balance work and private life. Not having to commute to work reduced participants' stress and gave them more time to interact with service users. Virtual meetings were described as more time efficient. Participants considered that a degree of virtual working should be maintained after the pandemic, since it appeared to enable a healthier work-life balance.

Digital exclusion

The absence of families can have knock-on effects for people with a learning disability, such as increasing behaviours described as challenging (Mencap 2021). This was one aspect of care that participants described as a big challenge. Participants working in inpatient settings explained that service users had been negatively affected by the absence of the support normally provided by families. For participants working in the community it was important to ensure that service users would continue to receive support from people close to them and that families were able to visit a service user who had been admitted to hospital. In some areas, visits had been facilitated to some extent but restrictions on travel had continued to make it challenging for relatives to be physically present.

Across all services there had been an effort to assist people to stay connected using digital tools. Participants working in inpatient settings found iPads particularly useful to enable service users to communicate with relatives and friends. However, there were also challenges associated with the use of digital tools. For example, meetings, ward rounds and psychology sessions had to take place virtually to reduce contact between staff and service users in the ward area, which caused confusion for some service users:

'Doing a meeting on a laptop, even for us it is quite complicated but for patients who've got sensory issues, finding that a face on a screen is talking to them was really overbearing. They couldn't comprehend how they could see themselves on a TV.' (Participant 3)

'For our population of people we support, you know technology is not really, they are not okay with how to use technologies… even the families and carers found it difficult.' (Participant 15)

In secure services there had been increased concerns about how to implement virtual meetings safely while ensuring that service users continued to have the same access to other services in the hospital. For participants working in the community, having to communicate with service users over the phone limited interactions and therefore hindered holistic assessments.

Participants were aware of the importance of touch and physical marks of affection when caring for people with learning disabilities, and that service users would miss that type of interaction. All participants noted that in terms of communication, service users had been largely 'digitally excluded' from services.

Innovations in communication

Participants were driven by a desire to maintain a sense of normality and stability, particularly for service users in long-term inpatient settings. The need to wear PPE was seen as a major issue, since people with learning disabilities often struggle with change and PPE led to a barrier to communication. Participants found innovative ways to support service users to understand the risks of COVID-19 and why nurses needed to wear PPE:

'*Setting up the Facebook page, we did some of those videos. We did one a month in just of us all waving and saying hello. We did our own video clips and sent them to the OT. Then we did another one a couple of months later throwing a bottle of hand sanitiser to each other. We had masks on and stuff like that.*' (Participant 10)

'*Some people have needed social stories to help with explaining, trying to get them to understand the reasons why we can't come out to support them face to face.*' (Participant 11)

One participant working in an integrated team described how they had worked with occupational therapists to develop 'craft packs' delivered to service users to keep them engaged. These examples demonstrate a proactive approach to communication and the use of creative thinking to engage service users.

Service managers felt there could be more engagement and collaboration between services and service users and families. However, service users' issues with communication generally were considered to make it challenging for individuals to share their experiences in a meaningful way. This was one area that all participants agreed could be improved in the future.

Discussion

These findings illustrate the strength, determination, flexibility, creativity and passion of learning disability nurses and show how the COVID-19 pandemic has had negative and positive effects on learning disability nursing practice.

Despite the many challenges encountered, participants adapted their practice to meet service users' needs, intensified patient advocacy as well as their support for one another, and pulled together to keep people connected.

The physical health of service users was a major concern, and the RAG risk-rating system was found to be useful for prioritising service users according to need. There were concerns that missed hospital appointments and cancelled surgeries would get lost in the system, but participants developed pragmatic solutions to keep records of missed appointments so they could be re-booked later. Staff well-being was considered equally important and various strategies were adopted to support it. Camaraderie, a sense of pulling together and increased support from management were crucial in maintaining staff morale.

Initially, virtual working presented the greatest challenge. The blurring of boundaries between work and private life increased fatigue, but virtual working was also thought to be a more flexible and time-efficient approach. Participants were grateful for the quick response of their organisations in terms of providing support and PPE supplies. In inpatient settings, iPads were used successfully to keep service users connected with their families. However, participants felt that service users had been digitally excluded because of the challenges posed to them by virtual communication. Staff found innovative ways – such as posting videos on social media – of assisting service users to understand the risks of COVID-19 and the need for PPE.

Limitations

While reflective discussions via video conferencing were considered an appropriate method to safely share views and experiences, in some discussions the group dynamics may have limited participants' contributions.

The 26 participants were mostly working

in the community and only five of them were working in – or had been redeployed to – inpatient settings. This limited the discussion and reflection on the experiences of learning disability nurses during the pandemic in inpatient settings.

Conclusion

The insights gained from these reflective discussions further an understanding of how organisations and nurses in the field of learning disability have managed the transformation of services during the first wave of the COVID-19 pandemic. Learning disability nurses responded to COVID-19 by adapting service delivery to become virtual, performing proactive risk assessments with service users to ensure their physical health and well-being was maintained, and coming together as a team to ensure staff well-being did not deteriorate. It is hoped that sharing these narratives will prompt a wider recognition of the unique contribution of learning disability nurses.

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