ABSTRACT

Aim: To explore the stressors experienced by, and coping strategies adopted by support staff assisting people with learning disabilities in residential and supported living settings during the pandemic.

Method: A qualitative descriptive approach, employing semi-structured interviews with 14 staff working in residential or supported-living services in the south of England. Participants were interviewed, data were transcribed verbatim and analysed using content analysis.

Findings: The Covid-19 pandemic caused additional stressors for staff who support people with learning disabilities in residential and supported-living settings. Stressors included anxieties about information overload; challenges to the provision of person-centred, holistic support; and feelings of unfairness or being let down. Positively, staff derived benefit from timely, practical and non-judgemental support from managers, peer support, and celebrating achievements.

Conclusion: A greater focus on non-judgemental listening, celebration of achievements and awareness of potential overwhelming impact of e-mail communication have the potential to reduce staff stress levels.

The impact of Covid-19 on stress and coping strategies of support staff assisting people with learning disabilities: A qualitative descriptive study

Introduction

During the Covid-19 pandemic it became apparent to the authors that support staff working in residential and supported-living services were potentially experiencing additional stressors associated with the pandemic. This led the first author, supported by the 2nd author (a colleague) and 3rd author (the academic supervisor), to undertake a qualitative study to explore staff experiences in greater depth in order to understand how staff were feeling. This work was submitted as part of an Evidencing-Work-Based-Learning module towards the first authors' Masters qualification. This paper reports the methods and findings of the study undertaken, identifying learning and suggesting recommendations for practice settings.

Literature Review

A small but significant range of studies specifically relating to the effects of the Covid-19 pandemic suggest that staff employed to support people with learning disabilities experienced stressors relating to the implementation of lockdown measures, the need to constantly wear PPE whilst working and the fear of contracting Covid-19 (Colizzi et al 2020; Nyashanu et al 2020; Schuengel et al 2020). The wellbeing of staff is of paramount importance in consideration that staff support is an essential aspect of the lives of many people with learning disabilities. Giesbers et al (2019) highlights the detrimental emotional and practical impact loss of familiar staff can have on people with a learning disability. Consequently, stressors experienced by staff need to be identified and support mechanisms provided to avoid detrimental impact on the well-being of the individuals they support, particularly when quality of care is affected. For example, staff sickness, resulting from stressors, may lead to absences to the detriment of the client group for whom familiarity is known to be beneficial.

People with learning disabilities may have a lower capacity to cope with stressful circumstances for a variety of reasons. People with learning disabilities often have limited informal support networks (Emerson et al 2001, McVilly et al 2006, Duggan and Linehan 2013) disproportionately increasing dependence on paid support in the form of direct support workers. Conditions such as autism, Fragile X and epilepsy can further reduce capacity to cope with change (Colizzi et al 2020). People with learning disabilities are also more likely to have experienced trauma in their lives (Spencer et al 2005, Cowles et al 2020) as well as to experience poor mental health (Sheerin et al 2019), further affecting capacity to cope with change. Additionally, individuals may represent frustrations in behaviours that appear challenging especially when feeling disempowered owing to changes out of their control (Allen et al 2013) as reported with the Covid-19 pandemic (Courtenay and Perera 2020, Schuengel et al 2020). These factors reinforce the importance of individuals receiving support from familiar staff at times when there is lots of change, and the need for a consistent and familiar staff team.

Aim

The study aim was to investigate the views of staff supporting people with learning disabilities during the pandemic. The study sought to understand the stressors faced by staff as well as ways staff coped, and what support measures they found to be useful.

Method

A qualitative descriptive methodology (Bradshaw et al 2017) was adopted as the unprecedented nature of the pandemic required an approach suited to ascertaining novel and previously unexplored data. As such, Bradshaw et al (2017) recommends this approach, as it is best equipped to capture those subjective experiences. The methodology was also informed by pragmatism. This is a philosophical position which suggests each individual has unique experiences (Tebes 2012) and the value of knowledge lies in its applicability to improve aspects surrounding the research topic, rather than justifications in what constitutes reality (Kvale and Brinkmann 2009). Focus of research in terms of pragmatism should be on the potential utility of the findings, to ensure usefulness in improving the experiences of those touched by the research topic. It was premised therefore, that understanding staff experiences would inform future working practices.

The lead author identified appropriate residential and supported-living services within one social care Trust in a service in the south of England. A Participant Information Sheet was sent to prospective participants working in these services who expressed interest in participating in the study.

Convenience sampling (Patton 2002) was used to recruit 14 participants who directly support with people with learning disabilities from the lead author's organisation, All interviews were conducted between January and April 2021. Twelve interviews were conducted via videoconferencing. However, two people lacked confidence in using online platforms at the time of the study, hence to ensure inclusivity, those two interviews were conducted over the phone. Inhibitions about using new information and communication technologies are common, perhaps affecting 30% of the population (Nimrod 2018), particularly in the circumstances of the pandemic during which people had to adapt rapidly to using videoconferencing. Insistence on using online platforms only to conduct the interviews with every participant would have been insensitive and the cause of potential, unnecessary anxiety, and could have impaired the relationship between interviewee and researcher.

Consent was sought at the beginning of each interview. Data were collected via semi-structured interviews between January and April 2021, whereby participants were asked about the main stressors and coping strategies associated with the pandemic from their individual perspective. Interviews were audio recorded with the consent of each participant, and subsequently transcribed verbatim by the first author. Following transcription, participants were given the opportunity to review the transcript, and respond within two weeks, to allow for corrections or deletions to the text being made. This was to ensure trustworthiness of transcribed data. Participants were also informed that participant confidentiality would be maintained.

Data were analysed using content analysis (Bengtsson 2016), as this is associated with a qualitative descriptive methodology. Transcripts were repeatedly read to identify patterns across the data. Identified themes were discussed with the 3rd author during this process via academic supervision.

Ethics

The ethics policy of the University of the West of England was followed and ethical approval for the study was confirmed by the academic supervisor. Ethical approval was also granted by the Chief Executive Officer of Milestones Trust, the organisation which employs the first author and the participants interviewed in the study.

Findings

Staff were asked about stressors as well as coping mechanisms that they had found helpful. These are discussed below.

Stressors

Three stressors were identified within the data: Information overload; Challenges to the provision of person-centred, holistic support; and Feelings of unfairness or being let down.

1. *Information Overload*

In the early part of the pandemic, uncertainty caused anxiety for staff, especially when guidelines from the Government and the service provider appeared to provide conflicting recommendations. This was compounded by the continuous changes to guidelines as the pandemic evolved. Participants expressed concern about making mistakes; effectively implementing protocols especially if management cover in a particular service was depleted; and the need to filter out information that was relevant to different settings. For example, guidance was different for supported-living compared with residential settings, and was also implemented differently due to the increased capacity and independence of tenants in the supported-living services compared to those living in care homes.

Participants reported feeling overwhelmed by the data that was communicated mainly from senior management on a daily basis from March to June 2020 but also local agencies such as Community Learning Disability Teams and government agencies like Public Health England. There was a perception of ‘everything hitting us at once’ and feeling thrown into the deep end, including those who were absent from work at the start of the pandemic and were faced with learning new protocols regarding PPE; cleaning; and management of outbreaks of Covid-19.

People in service level management roles felt the need to provide answers to queries from support staff and counteract what participants referred to as ‘catastrophising styles of thinking’ expressed with a high degree of anxiety by junior colleagues. Participants spoke about junior staff seeking answers for extreme situations which had not yet occurred, such as the need for individuals with a learning disability to be admitted into hospital with Covid-19, rather than focussing on the implementation of protocols which addressed more immediate concerns.

2. *Challenges to the provision of person-centred, holistic support*

This was an extensive and varied area of concern which included the following issues. Staff talked about the potential detrimental impact on the mental health of people with a learning disability residing in the service. Staff were concerned that the individuals were not able to go out or fulfil routines during the periods of restrictions. Participants said they felt obliged to ensure that home-based activities were introduced and feared for an increase in behaviours that were challenging particularly for individuals on the autistic spectrum. Staff also had to cope with ensuring that people with limited capacity to understand the pandemic conformed to social distancing requirements and social isolation when necessary and were not frightened by the use of PPE. Participants talked about dilemmas relating to capacity assessments particularly in relation to the use of safe holds to expedite Covid-19 testing or vaccination.

Support workers felt acutely the burden of responsibility to provide information to the people they were supporting in ways which were not frightening. Staff wanted to be able to explain the pandemic in meaningful and accessible ways, as well as to find novel ways to maintain family links. Supporting people with a learning disability to access community settings was particularly challenging due to limitations of venues that could be accessed, social distancing and PPE requirements. Participants also spoke about the sometimes-hostile responses from members of the public towards individuals who had exemptions from wearing masks.

In addition, there were instances identified where individuals with a learning disability who contracted Covid-19 were felt to have been treated in a discriminatory manner by healthcare services resulting in extreme discomfort and what participants felt was poor end of life care. This caused staff distress. Participants spoke about being consumed with feelings of apathy and sadness due to these negative experiences associated with the pandemic. Overall, staff felt distress by not feeling able to continue to support all individuals in a person-centred, holistic way.

3. *Feelings of unfairness or being let down*

Those who continued to work directly with people with learning disabilities throughout the pandemic were irked and dismayed by the knowledge that staff employed for other functions were working from the relative safety of home. These feelings of frustration were exacerbated when phone calls were received form such colleagues during busy times, however helpful the intent behind that communication. Some aspects of redeployment were considered to be unsafe due to initial requirements to work in several locations and also, in the case of those providing community activities, insufficient appreciation was given to the need for support workers in that context to have toilet and break facilities.

Staff also spoke about the refusal of some colleagues to work with individuals who had Covid-19 symptoms, reporting this as being particularly distressing. Participants also talked about frustrations of some staff in becoming complacent about adhering to PPE protocols. The pressure to do extra cleaning and testing, coupled with assumptions by mangers that less community activities meant more time to fulfil these tasks, was also considered stressful.

Coping mechanisms

Four effective coping and stress relieving strategies were identified by participants: Communication and managerial support; Celebrating achievements; Peer-support; and Personal resources, which are discussed below.

1. *Communication and managerial support*

Paradoxically, whilst considered a source of stress by some participants as discussed above, daily communication by email on Covid-19 specific matters was also spoken about in terms of being supportive and therefore helping to relieve stress. For some participants, this daily communication from managers was viewed as a means of providing clear direction and guidance. Summaries created by local managers and the creation of briefing files were deemed to be particularly helpful, as were easy read and poster formats to support people with learning disabilities to understand what was happening. Training videos about Covid related protocols and procedures, were regarded as superior to face-to-face sessions as staff could refer back to them to refresh their knowledge and understanding, and were therefore considered to be good reference material. Staff therefore felt simultaneously overwhelmed by communication relating to Covid-19 whilst also finding the daily communication helpful. Staff both welcomed the briefings but also were relieved when they stopped.

Participants identified the use of novel forms of communication such as WhatsApp groups, a weekly Trust wide ‘Keeping in Touch’ (KIT) meeting and monthly team meetings held via videoconferencing as being useful. Practical support from managers in the form of help with developing Covid-19 related local protocols was identified as beneficial. Staff also spoke positively about the prompt support they received from specialists within and outside the organisation and the ready availability of clinical leads to answer queries.

Overall, participants valued managers admitting that they did not have the answers to queries and their resolve to seek further information and to respond in a timely manner. The opportunity to vent emotions without the fear of judgement or recrimination was particularly welcomed as was support during extremely stressful circumstances such as in the health deterioration of people with learning disabilities. Sometimes, staff felt inhibited about expressing their emotions or disclosing their lack of knowledge during KIT meetings and derived benefit from being able to talk privately to a manager after the conclusion of the public meeting.

2. Celebrating achievements

Helping to alleviate the stress of the people that they supported had a beneficial impact on staff. Examples included staff helping people with learning disabilities to become more independent; and developing new activities, especially home-based activities including those that replicated community activities such as church services. Helping people to celebrate Christmas, and to go on holidays when restrictions were lifted in the summer also helped to relieve staff stress. Staff gained consolation from supporting individuals with learning disabilities to develop their IT skills and so enhancing their ability to keep in touch with family and friends. Finding new ways to maintain relationships was considered challenging but ultimately satisfying and consequently described in terms of improving staff morale.

Celebrating achievements whether personal, or relating to colleagues and people with a learning disability, was cited as being extremely helpful. For example, some staff spoke about supporting individuals with a learning disability to adapt to wearing PPE and social distancing. Other staff spoke about being able to support one another emotionally or participate in public displays of support for health and social care staff. Participants reflected on the pride they felt supporting people with a learning disability to avoid contracting Covid-19 and also the good things in their work life that they had previously taken for granted.

Finding ways to memorialise individuals who had died during the pandemic also was helpful in lifting people’s moods.

3. Peer Support

Participants highlighted the beneficial effects of colleagues supporting one another to ensure that everyone had breaks during shifts and days off in which they did not feel that they had to engage with or think about work. Staff also spoke about the importance of giving one another praise and encouragement on a daily basis. One person highlighted that they regarded work as a ‘safe refuge’ where they were working collaboratively with like-minded colleagues to ensure that the environment was as ‘infection free’ as possible. Although recognised as being onerous having to work extra shifts, people appreciated that colleagues did this to ensure that the number of people working in a service was minimised and infection control/safety maximised.

As well as overtly expressed appreciation from colleagues, encouragement from others, such as families, GPs and social workers was highly valued as was practical gestures such as outside agencies gifting scrubs and visors.

4. Personal resources – traits, experiences, activities

Specific ways of responding to the pandemic were highlighted as stress relieving, including initially adopting a survival mode, avoiding too much wishful thinking, and embracing not having to rush as much or drive through heavy traffic. Celebrating the kindness and empathy of colleagues, getting to know different people through virtual meetings and the opportunity to debrief with colleagues who understood the nature of their job role were all considered to be beneficial. Some people emphasised that previous adverse work experiences had helped them develop resilience which helped them cope with the additional stressors during the pandemic.

With regard to activities some people, usually facetiously, mentioned that they smoked and drank more but the focus was much more on the activities that they pursued at home to relive stress, for example, gardening, craft work, yoga, knitting, zoom facilitated social pursuits and walking.

People felt that it was important to try and compartmentalise their lives so that work thoughts and duties did not intrude during personal time and disciplines such as not checking e-mails and switching off work phones on days off were seen as essential for preserving mental wellbeing, as was acknowledging when they were becoming tired and cancelling extra shifts or taking annual leave.

Discussion

Although the Covid-19 pandemic quickly resulted in the creation of a body of literature (Colizzi et al 2020, Garcia and Calvo 2020, Greenburg 2020, Nyashanu et al 2020, Scheungel et al 2020, White et al 2020, World Health Organisation 2020, Green et al 2021, Maben and Bridges 2021), consideration of stressors which arose for direct care staff and approaches adopted to alleviate stress has not been a large feature of that discourse. What is identified within the findings of this small-study is that whilst many direct care staff interviewed found working through the pandemic stressful, identifying a number of stressors, staff also found solutions and ways of managing this stress. Therefore, demonstrating both resilience, and adaptability with respect to learning new ways of working, helping the people they support cope with restrictions and developing novel coping strategies.

There is congruence between some of the findings in this study and those noted in published studies about Covid 19 on this topic. For example, Nyashanu (2020) identified that staff were really anxious and feared for their lives as did the people they supported. The burden of responsibility to adhere to social shielding in order to minimise the risk of infecting vulnerable clients was also felt very strongly. In the area of support for people with learning disabilities, the challenges associated with helping those people to understand the need for social distancing were great. Staff were confused and frightened by the guidance relating to the use of PPE and the lack of testing facilities, identifying 'information overload' as a particular stressor. Maben and Bridges (2020) identified tensions around the need to work more innovatively with people who have complex needs and the difficulties associated with helping people understand and cope with the restrictions imposed on their lives. In this study, participants, supported by managers, found creative approaches. Staff spoke about using accessible information to support individuals to understand what was happening, and celebrating success when individuals with a learning disability adapted to staff wearing PPE and social distancing protocols.

Maben and Bridges (2020) also contend that previous infectious disease outbreaks such as Ebola have resulted in staff experiencing post-traumatic stress disorder (PTSD). Participants in this study spoke about the exposure to a variety of experiences such as fear for their own health and that of others, anxieties about the availability and effectiveness of PPE, loss and bereavement related to actual death as well as changes in work delivery, which could be viewed as being traumatic. Shern et al (2016) assert that repeated exposure to trauma can lead to feelings of helplessness, disempowerment, lessened ability to regulate emotions and hypervigilance to the possibility of threat. Many participants articulated the distress they felt by the restrictions imposed on the individuals they supported, who were often not able to understand the restrictions, exacerbating anxiety. Staff spoke about feeling this anxiety themselves, potentially leading to the phenomenon termed by Kirby (2007) of 'stress contagion', a type of vicarious trauma to which people who support vulnerable clients with complex needs and histories are particularly liable.

The findings of this study indicate both a variety of stressors experienced differently by individuals and also the paradoxical nature of some aspects. For example, although detailed communication from the organisation was seen as being extremely beneficial in giving clarity and direction by some, it was paradoxically also perceived as being overwhelming by others due to the sheer volume and frequency of briefings, protocols and policy guidance. These phenomena appear to be related to the insight asserted by Boles (2017) that trauma is experienced subjectively and cannot be defined by objective parameters and definitions. This suggests that a range of support mechanisms are required to ensure all staff feel effectively supported.

Although participants acknowledged the need for extensive and frequent communication during the pandemic, it is clear that many staff found receiving pandemic related briefings stressful. The experiences of the use of e-mail in this context is a timely reminder that e-mail is now a ubiquitous communication method. The deficits associated with the use of e-mail need to be considered especially when communicating information that the receiver is likely to find stressful. Yuan et al (2020) discuss deficiencies in etiquette, potential for stridency, lack of mitigation by voice tone, body language, or too much detail, suggesting that overt education around this form of communication could be helpful.

A compounding factor was the cessation of access to the usual methods of alleviating stress like seeing family and friends, physical contact with significant others, going to social venues and attendance at recreational outlets such as gyms, sports centres and swimming pools, which of course staff working in the field of care and support experienced just like everyone else in the wider community. Aked et al (2008) remind us that there are five aspects of living that help to maintain good mental health: giving, nurturing social contacts, exercise and activity, mindfulness and reflection and learning. The restrictions imposed by the pandemic severely reduced opportunities to fulfil activities in the majority of these areas, namely social contact, exercise/activity and structured learning opportunities, whilst the overwhelming nature of the outbreak potentially impaired the pursuit of reflection and mindfulness.

The altruism and kindness demonstrated by staff towards colleagues, people that they supported and the family members may be an indicator that the lessened capacity to access other resources meant people were more reliant on the activity of giving as a means to preserve their mental health. These entailed sacrifices like swapping work shifts, cancelling holidays, and checking on one another on days off. This is supported by what appears to be an increased thankfulness in response to thoughtful acts performed by others or kind word of appreciation from colleagues, other professionals, managers, and the families of people with a learning disability they were supporting.

Limitations

Owing to the qualitative nature of the study, findings cannot be seen to represent the whole population of those supporting people with learning disabilities. Nevertheless, the purpose of qualitative research is to gather rich understanding of a topic, as such, depth not breadth has relevancy to such study findings.

The authors acknowledge potential bias in the study, in that there was personal investment owing to this involving their place of work. Reflexivity was employed throughout this study, including consultations with the supervisor, to ensure biases were challenged.

Recommendations

The following recommendations are made informed by the study's findings:

1. Conversations between junior managers and their supervisors can be outcome and objective focused as is the quality audit process. Space needs to be found in one-to-one conversations for non-judgmental listening by senior managers, so that junior colleagues feel able to express their views about difficult situations without feeling that they will be reprimanded or are wasting their supervisors time.
2. Similarly, team values and practice should incorporate opportunities to commend and celebrate the achievements of colleagues and the people supported.
3. There is evidence within this study's findings that staff have coped with the stressors of the pandemic by drawing on reserves of resilience. Training in resilience development may be appropriate to overtly

enhance these qualities. which appear to have been demonstrated in abundance by both staff and people with learning disabilities throughout the Covid-19 pandemic. Framing those training sessions in terms of how resilience can be nurtured in people with a learning disability would potentially have an exponential benefit as it would give opportunity to both ’reflect on’ and ‘learn from’ how individuals display resilience in the face of adversity and trauma. Potentially also providing staff with the opportunity for altruism and giving that they demonstrated throughout the pandemic, therefore congruent with one of the key tenants of the 5 ways to Well Being model (Aked et al 2008).

Conclusion

The participating staff experienced stressors originating from a variety of sources during the Covid-19 pandemic. These included feeling overwhelmed by communication and sometimes feeling let down by managers and colleagues. Concerns relating to the welfare of the people that they supported were also prominent. Conversely, success in overcoming anxieties relating to restrictions and decreased family contact was identified as being helpful in alleviating stress levels as were effective communication, prompt and practical support from managers, celebration of achievements and support from peers. This study identifies areas which have applicability for other services, such as the need to provide more opportunities for non-judgmental listening, training relating to well-being issues and awareness of the potentially overwhelming impact of e-mail communication.

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