The challenges of mental health of staff working with people with intellectual disabilities during COVID-19—A systematic review

Yaohua Chen, MD, PhD
Trinity Centre for Aging and Intellectual Disabilities, Trinity College Dublin, Dublin, Ireland
Inserm, CHU Lille, Lille Neurosciences & Cognition, UMR-S1172, Degenerative and Vascular Cognitive Disorders, Univ. Lille, Lille, France
Department of Gerontology, CHU Lille, Lille, France

Andrew P. Allen, PhD
Trinity Centre for Aging and Intellectual Disabilities, Trinity College Dublin, Dublin, Ireland

Marianne Fallon, PhD
Trinity Centre for Aging and Intellectual Disabilities, Trinity College Dublin, Dublin, Ireland

Niamh Mulryan, MD, FRC Psych
Trinity Centre for Aging and Intellectual Disabilities, Trinity College Dublin, Dublin, Ireland
Daughters of Charity Disability Support Services, Dublin, Ireland

Philip McCallion, PhD
Trinity Centre for Aging and Intellectual Disabilities, Trinity College Dublin, Dublin, Ireland
School of Social Work, Temple University, Philadelphia, PA, USA

Mary McCarron, PhD
Trinity Centre for Aging and Intellectual Disabilities, Trinity College Dublin, Dublin, Ireland

Fintan Sheerin, PhD
Trinity Centre for Aging and Intellectual Disabilities, Trinity College Dublin, Dublin, Ireland

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Abstract

Background: The COVID-19 pandemic has posed a great risk to the mental health of health workers (HWs). There are likely to be particular concerns for staff working with adults with an intellectual disability, where infection control may be more challenging.

Corresponding author:
Yaohua Chen, University of Lille, Place Verdun, Lille 59000, France.
Email: CHENY10@tcd.ie
Method: We conducted a systematic review of original research examining the mental health of HWs working with people with intellectual disability, published between March 2020 and July 2021.

Results: Five original research studies were included. A high proportion of HWs working with people with intellectual disability reported having had poor mental health including stress, anxiety, and depression. This manifested in similar patterns as for other HWs and also some specific patterns seen as the need to manage increased rates of mental health issues of the people they support. Sources of support and resilience were also identified.

Conclusion: The support system should target risk factors, answer unmet needs, and build resilience. More research is also required on the ongoing and long-term effects.

Keywords
COVID-19, health workers, intellectual disability, mental health, vulnerable people

Introduction

Mental health is defined as a state of well-being in which an individual realizes their own abilities, can cope with the normal stresses of life, can work productively and can make a contribution to their community (WHO, 2018). Protecting and promoting mental health is essential for each individual to enjoy life, and for the benefit of society (WHO, 2018). Mental health is a dynamic state continually informed by an individual’s biopsychosocial processes (Engel, 1977).

Increased daily life stress has been shown to adversely impact mental health, including stressful work conditions (Marin et al., 2011). In particular, health workers (HWs) are at higher risk of experiencing burnout, stress, and depression due to workplace conditions including, for example, excessive workloads, hierarchical pressure, psychological and physical impact when caring for patients (Gray et al., 2019). During the previous coronavirus respiratory syndromes outbreaks (Severe Acute Respiratory Syndrome (SARS) in 2002 (McAlonan et al., 2007) and Middle East Respiratory Syndrome (MERS) in 2015 (Lee et al., 2018)), mental health issues were reported in HWs. HWs have greater awareness about virus transmission than the general public and this leads to greater levels of concern (Wu et al., 2009). Weeks after the SARS pandemic, 20% of HWs were still experiencing symptoms of post-traumatic stress disorder (Chan, 2004).

Two and a half years after the first outbreak, there have been 600 million Coronavirus infections globally, with over 6 million people having lost their lives (WHO, https://covid19.who.int/). Furthermore, it is noted that, following the acute phase of the disease, many people have experienced persistent symptoms which limited their mobility and impacted on their quality of life (Huang et al., 2021). Beyond the high mortality and morbidity, the pandemic has also had wider psychological, economic and social impacts (Singh and Bedi, 2022). As with the previous SARS and MERS outbreaks, HWs’ mental health has been particularly challenged.

During the COVID-19 pandemic, health services across the world began preparing for a very large increase in patient numbers, and challenges in service provisions that had never before been seen in the lifetime of their workforces. It is reported that one-third of frontline HWs have been experiencing high levels of distress (Zhu et al., 2020). Those reported to be at greater risk of stress, depression and anxiety include younger people, women, those with concomitant chronic illnesses or
history of mental disorders, and those having family members or relatives with a confirmed or suspected diagnosis of COVID-19 (Zhu et al., 2020).

Beyond the demographic characteristics, more challenging employment conditions may also pose a risk to mental health. Working in emergency or COVID-19 wards could be particularly stressful for HWs, because of the workload, the fear of getting infected, the long and irregular hours, the lack of or requirement to use personal protective equipment (PPE) and the reduced contact with other colleagues or family (Alshekaili et al., 2020).

At the start of the pandemic, the majority of research focused on the well-being and mental health of frontline HWs in emergency and COVID-19 wards. However, similar levels of stress may be experienced by HWs in other settings, particularly when working with people who may be particularly vulnerable to the infection and its sequelae. Prior to the pandemic, staff working with people with intellectual disability were already at a higher level of stress and burnout due to, for example, challenging behaviour, excessive workplace demands and inequality in the relationships between staff, their clients and colleagues (Ryan et al., 2021). However, this area of employment and its effect on mental health of staff during pandemic has received little research or policy attention to date.

Our aim was to undertake a systematic review on the mental health of staff working with people with intellectual disability during the COVID-19 pandemic and associated lockdown.

Material and methods

Selection criteria

We included original research whose main objective was to determine the mental health of staff working with people with intellectual disability. As we did not wish to limit our search to studies with a particular methodology, studies could be either quantitative or qualitative. The types of the setting were defined as follows: residential care; community group home; day care services; and supported living. As the focus of our review was on those providing frontline support to adults with intellectual disabilities, the staff groups to be included were frontline HWs (nurses, physiotherapists, health care assistants) and social care workers (social care workers, key workers, personal assistants, professional caregivers) who had prolonged daily interaction with the specified client group. The client group of interest was adults with intellectual disabilities. We reviewed studies in English, French, and Chinese (as these were the languages spoken by the research team). We included research published during the period March 2020-July 2021 (i.e. between the WHO declaring COVID-19 a pandemic and the time of our literature search).

As the focus of our review was on original, peer-reviewed, research, reviews, conference abstracts, editorials, and opinion statements were excluded. As the focus of the review was on staff providing day-to-day care on an ongoing basis, studies performed solely in acute care settings (acute hospital, intensive care unit, emergency department, hospital ward) were also excluded, as were those involving health or social professionals who did not have prolonged daily interaction with the client group defined in the above criteria.

Search strategy

The following databases were searched: CINAHL, PsychInfo, Web of Science, Medline and EMBASE. We predefined four concepts based on our main objective: #1 Mental health; #2 Care staff; #3 Intellectual disability; and #4 COVID-19. For each concept, the keywords and search
results are detailed in the supplemental data (appendix 1). Searches were undertaken combining the concepts using the Booleans AND/OR.

After the initial list of publications had been drawn up, we performed the following steps in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2009): Screening of the titles and abstracts, with application of the study inclusion and exclusion criteria; double-blind assessment of the selected full-text articles by two researchers. In the event of disagreement, a third reviewer decided whether to include or exclude the publication and specified the reasons for the decision (Figure 1). Five references remained and were included in this review.

In the data extraction step, the first author extracted the data, reviewed by APA and FS. The variables extracted from the studies were: country, type of study, study period, population, outcomes, main findings and recommendations. We prepared a narrative summary of the themes, based on the findings from the included studies. The two reviewers met to reach consensus on the themes from main findings. In the event of disagreement, a third reviewer decided on the final outcome and themes.

**Figure 1.** Flow chart of included studies.
Quality assessment

The Consensus-Based Checklist for Reporting of Survey Studies (CROSS) guidelines was used to assess the quality to develop a universal checklist for both web and non-web-based surveys CROSS (Sharma et al., 2021). It contains 19 sections with 40 different items, including “Title and abstract” (section 1); “Introduction” (sections 2 and 3); “Methods” (sections 4–10); “Results” (sections 11–13); “Discussion” (sections 14–16); and other items (sections 17–19). We defined low methodological quality as fulfilling less than 50% of the criteria.

Findings

Methodological aspects

The included studies came from developed countries, four from Europe (two from the UK (McKenzie et al., 2021; Murray et al., 2021), one from the Netherlands (Embregts et al., 2021), and one from Ireland (McMahon et al., 2020)) and one from Canada (Lunsky et al., 2021).

All studies reported data during the first wave of pandemic (before August 2020). The characteristics of the studies are detailed in Table 1.

Three of the five studies used structured online surveys (Lunsky et al., 2021; McMahon et al., 2020; Murray et al., 2021), one used semi-structured interviews (McKenzie et al., 2021), one used self-recorded audio messages (Embregts et al., 2021) and thematic analysis or similar was used in four studies. Two studies actually derived from the same project, which aimed to apply the Positive Behaviour Support (PBS) program (McKenzie et al., 2021; Murray et al., 2021) which offers a functional, proactive, constructional and values-based approach to cope with some behavioral disorders (Gore et al., 2013). Hence, the main objective of these two studies was the impact of a such an intervention on services users, with the second being the impact on staff well-being.

All the studies reached the cut-off of 50% in the quality assessment, though methodological quality was not high. The mean score was 58%

Key themes identified

Anxiety, perceived stress, and fear. Anxiety was a commonly-reported mental health challenge in qualitative studies (Murray et al., 2021). The PBS program helped some participants to better apprehend their own anxious feelings and those of their colleagues, in order to deliver support. Additionally, an online survey showed that 34% of the respondents met criteria for anxiety, based on the two items of the PHQ-4 (Lunsky et al., 2021).

A small qualitative study with 11 care staff in the Netherlands, using recorded voice messages, tended to reflect the day-to-day feelings of the staff, as a diary (Embregts et al., 2021). The participants frequently reported concerns about becoming infected. There was a feeling of profound fear and, although this fear was present during the whole study period, participants mostly mentioned it at the beginning of the pandemic, when there were shortages of PPE. Given the long incubation time of the virus, participants were also worried about being on the “bridge” between the “inside world” (the workplace) and the “outside world” (private home). They reported being scared that they would infect their own family and friends.
### Table 1. Summary of the five studies included in this review.

| Studies | Location | Type of study | Study period | Population | Outcomes | Main findings | Recommendations | Quality index, % |
|---------|----------|---------------|--------------|-------------|----------|---------------|----------------|-----------------|
| 1 (Embregts et al., 2021) | Netherlands | Qualitative study from recorded voice messages | March to May 2020 | 11 direct support staff in residential service - 8 women, 3 men - Mean age: 41.7 years old - Average years of experience: 19.8 years | Experience and needs of the direct support staff through a thematic analysis | 4 themes: Emotional impact, cognitive impact, practical impact and professional impact | - To recognize the emotional impact, the fear of the COVID-19 pandemic on direct support staff. - To help direct support staff in their transformed work environment. - To strengthen the collaboration between direct support staff from group homes and day care facilities | 62 |
| 2 (McKenzie et al., 2021) | UK | Semi-structured survey | April to May 2020 | 19 staff from 19 organizations - Different roles but they all followed the Positive Behaviour Support (PBS) program - 14 women, 5 men - Mean age: 44.1 years old | Impact on the provision of PBS in social care settings through a thematic analysis | 3 themes: The challenges to maintaining quality of life and PBS of the people being supported, the ways in which PBS was implemented and the impact on behaviours that challenge, the ways in which PBS principles were applied at organisational levels to help to understand and address staff stress and distress | No recommendations | 54 |

(continued)
| Studies | Location | Type of study | Study period | Population | Outcomes | Main findings | Recommendations | Quality index, % |
|---------|----------|---------------|--------------|------------|----------|---------------|----------------|-----------------|
| 3 (Murray et al., 2021) | UK | Online survey | April to May 2020 | - 58 HWs | - Impact on the provision of PBS in social care settings through a directed content analysis | - The participants rated the learning from their PBS programme as helping them cope with COVID-19 | No recommendations | 56 |
| 4 (Lunsky et al., 2021) | Canada | Online survey | July to August 2020 | - 832 HWs from social supporting sector | - Perceptions of COVID-19 by a 10-item self-report scale | - 25% reported moderate to severe levels of clinical distress | To acknowledge the significant stresses and to develop proactive and responsive policies and strategies | 59 |
|          |          |               |              | - 85% women | - The Patient Health Questionnaire-4 (PHQ4) | - 34% anxiety and 21% depression | Decision-makers must ensure that mental health services are available for these staff when needed | |
|          |          |               |              | - 43% older than 45 years old | - Being younger, having less working experience, COVID-19 related stressors are associated with higher PHQ-4 scores | - To encourage research about how to boost mental health, such as resilience, self-efficacy and reciprocity, and to develop tailored interventions | |
| Studies   | Location   | Type of study   | Study period   | Population                                                                 | Outcomes                                                                 | Main findings                                                                 | Recommendations                                                                 | Quality index, % |
|----------|------------|-----------------|----------------|-----------------------------------------------------------------------------|---------------------------------------------------------------------------|--------------------------------------------------------------------------------|---------------------------------------------------------------------------------|------------------|
| 5 (McMahon et al., 2020) | Ireland   | Online survey   | May to June 2020 | - 285 HWs working with people with intellectual disability                   | - Copenhagen Burnout Inventory                                           | - Moderate levels of personal and work-related burnout                        | - To urge employers to ensure that there are appropriate supports in place.       | 59               |
|          |            |                 |                | - 89.8% women                                                               | - Patient Health Questionnaire-9 (PHQ9)                                    | - Mild levels of anxiety and depression                                      |                                                                                |                  |
|          |            |                 |                | - Most prevalent age group: 46–55 years old, followed by 36–45 years old     | - General Anxiety Disorder-7 (GAD7)                                      | - Higher mean scores for staff who worked in independent living settings    |                                                                                |                  |
|          |            |                 |                | - 134 nurses, 64 health-care assistants, and 59 social care workers         |                                                                            | and from staff who supported individuals with challenging behaviour        |                                                                                |                  |
|          |            |                 |                | - 167 work in residential or congregated care settings                      |                                                                            |                                                                                |                                                                                |                  |
**Depression and isolation**

An online survey showed respondents across all settings were on average reporting mild levels of depression, measured by PHQ-9 (McMahon et al., 2020). The level of depression was higher for respondents who worked in independent living, shared lives settings. The average PHQ-9 score was one point higher for respondents who cared people with challenging behaviours compared to those without. Twenty-five percent of the respondents reported moderate to severe levels of clinical distress on the PHQ-4, and 21% met screening criteria for depression based on two items of this scale (Lunsky et al., 2021). Two studies described isolation, limiting face to face social activities in family or professional context (Embregts et al., 2021; Murray et al., 2021).

**Fatigue and burnout**

In one study, it was reported that people with intellectual disabilities were not permitted to go to day support settings, and most staff had to be flexible and multi-task to deliver service supports within the person’s residential setting or home. In combination with the staff shortages, some had to work longer or extra shifts. To ease the pressure on the daily schedule, some managers decided to postpone other coordination tasks. However, most of the participants still chose to continue to complete the most important coordination tasks, in their own time, so they would be able to maintain good quality care in the long term (Embregts et al., 2021).

On a validated scale to measure burnout, participants reported moderate levels of burnout on personal and work-related subscales (McMahon et al., 2020). This mental health burden was related to the role of each participant. Respondents who worked in independent settings and provided direct care had the highest personal burnout scores, while respondents who were office based had the highest work-related burnout score.

**Anger and frustration**

HWs for people with intellectual disabilities expressed frustration that their role and the vulnerable position of people with an intellectual disability were largely overlooked (Embregts et al., 2021). Some of them were concerned with the daily risks they were required to take, working without proper equipment. At the start of the pandemic, the mental health of the HWs was not recognized and participants felt the intellectual disability field was simply invisible, compared to the frontline HWs.

Some also blamed the support and guidance offered at government level, which were inconsistent and changing (McKenzie et al., 2021). As reported in this qualitative study, participants expressed the guidelines and protocols at governmental level are changing every single day, leaving employees to interpret themselves.

**Risk and protective factors for health workers’ mental health**

Three categories of risk factors (or protective factors) were reported. The first was related to demographic characteristics. Being older (>45 years old) and more experienced (>5 years) led to being 51% and 62% less likely to experience clinical distress, respectively (Lunsky et al., 2021).

Additionally, several specific events related to the pandemic were also associated with significant distress. These events included the reported perception that people avoided HWs’ families because of their work, the fear of spreading COVID-19 to others, the feeling of more stress at work compared
to pre-pandemic level, and the uncertainty of chance of survival if diagnosed with COVID-19 (Lunsky et al., 2021).

Some risk factors were related to working conditions and professional roles. An increased stress level in the workplace lead to higher levels of distress. However, having counselling services available for employee mental health support was a protective factor (Lunsky et al., 2021; McMahon et al., 2020). The level of burnout, anxiety and depression was higher for HWs working with people who engaged in challenging behaviour (McMahon et al., 2020). Respondents who worked in home care or were a personal assistant reported higher levels of anxiety about contracting COVID-19, and they felt the least supported by their employer.

**Building resilience and support**

The different studies showed that most participants were capable of showing resilience in the face of mental health challenges. Some of them described feeling a great sense of responsibility. Having a meaningful purpose is important as one of the personal resources (Embregts et al., 2021). Outside work, having different activities, such as running and hobbies, was protective against mental health issues (Lunsky et al., 2021). Staff were also invited to come up with creative solutions and develop alternative ways of meeting and arranging day programs for people with intellectual disabilities who were unable to attend their regular day care facilities.

By force of circumstances, staff used PBS to help them reflect on their experiences, to directly influence strategic responses to COVID-19 within their organization and to protect their own mental health and well-being (McKenzie et al., 2021).

**Discussion**

Our systematic review showed a high proportion of HWs working with people with intellectual disabilities reported having had poor mental health during this pandemic. This manifested in similar patterns as for other HWs, such as the fear of transmitting the virus or the need for constant adaptability. There were also some specific patterns seen, such as the need to manage increased rates of mental health issues and aggression of the people they support (Lunsky et al., 2021).

**Anxiety**

Our review showed some evidence for anxiety among HWs for people with intellectual disability, which has been commonly reported. It is notable that, in the literature relating to HWs working with other groups of vulnerable service users (such as older people in long-term care facilities), a variety of validated scales were used to measure level of anxiety. Based on the cut-offs of each scale to define anxiety, between 19.8% (Rossi et al., 2020) and 79.3% (Luceño-Moreno et al., 2020) of the participants were reported to have anxiety. In parallel, a large meta-analysis showed 27% of the general population reported to have anxiety during Covid (Kan, 2022).

**Fear**

Fear was expressed in HWs working with people with intellectual disabilities, especially about infecting their own family and friends. It was also expressed in the studies with other categories of HWs; for example, fear of bringing the virus home to children; and fearing not seeing older loved ones again when separated from them (Aksoy and Koçak, 2020; Maciaszek et al., 2020; Nyashanu
et al., 2020; Woodford et al., 2020). Fear also increased the risk of stress. Many also expressed fears about the support available to their most vulnerable service users – for example, people with chronic neurological conditions. Seventy-five percent of respondents reported decreased work efficiency due to fear of transmission and 49% of them regretted choosing their profession (Aksoy and Koçak, 2020).

From a professional perspective, uncertainty about the future effects of COVID-19 impacts very highly on the mental health of staff. In our review, we note that the analysis of different data, recorded over time, demonstrates a higher degree of fear at the beginning of the pandemic. In the literature, one study showed high levels of intolerance to uncertainty on the Intolerance of Uncertainty Scale Inventory (Aksoy and Koçak, 2020). For instance, participants feared being unsupportive to the fellow staff due to time away from clinical environments, caused by redeployment.

**Depression**

Our review shows that depression has been rarely measured among staff caring for people with intellectual disability. When it was measured, respondents all expressed mild level of depression. In the studies of other HWs, the prevalence of depression ranged from 24.7% (Rossi et al., 2020) to 77.6% (Şahin et al., 2020).

Besides depression, 41% of interviewees in another study felt emotionally drained (Luceño-Moreno et al., 2020). Social loneliness was also very prevalent in those studies. The unchosen situation of physical isolation contributed to the feeling of loneliness. Some mentioned feeling ostracized from family or housemates (Woodford et al., 2020). 62% of interviewees reported loneliness in one study, leading to consequences such as increased alcohol or nicotine intake (Maciaszek et al., 2020). The social loneliness of HWs for people with intellectual disabilities was not investigated in the studies identified in our review.

**Burnout and fatigue**

As for HWs with people with intellectual disabilities, burnout was also reported with either bespoke questions or validated scales, such as the Maslach Burnout Inventory (Maslach et al., 1996). Again, HWs in mental health had higher level of burnout and of hopelessness (37.5%) than HWs in multidisciplinary teams (24.0%) (Ruiz-Fernández et al., 2020).

Similar to burnout, fatigue was also reported with either bespoke questionnaires or validated scales. In a study including only psychotherapists who worked mostly with adults and older adults with mental health problems, 74% of the respondents reported to be more tired at work than before the pandemic (Aafjes-van Doorn et al., 2020). In an Italian survey (Franza et al., 2020), using the Short Fatigue Compassion Scale (Adams et al., 2006), the authors investigated compassion fatigue for HWs from multidisciplinary teams. Most of them were social workers and nurses. The overall compassion fatigue scores increased in all HWs (22%). They often experienced emotional tension and physical exhaustion from having to provide care to an increasing number of patients whose condition could deteriorate rapidly.

**Anger and frustration**

Some HWs did not hesitate to express their anger and frustration, especially towards organisations and governments. In one qualitative study, a participant said, page 4 “Everyone needs more PPE. The US government has failed its citizens.” Other interviewees also commented on the health care
system, which was already fragile, “I am so, so saddened at the state of our healthcare system—healthcare employees are not being treated very well.” (Krok-Schoen et al., 2021). Overall, 75.6% of participants reported anger (Maciaszek et al., 2020).

Risk factors

The most common risk factors reported in the reviewed studies were related to demographic characteristics such as younger age and shorter professional experience. In other studies not related to staff with intellectual disabilities, there are some additional risk factors such as being female, having personal history of a past psychiatric illness, and being positive for COVID-19 (Luceño-Moreno et al., 2020; Ning et al., 2020; Rossi et al., 2020; Şahin et al., 2020).

Some studies also tested the hypothesis that job position could be a risk factor for worse mental health. Only one study in our review showed a higher risk of distress if the HWs were working with residents who engaged in behaviours that challenge. In other studies, authors found that being a nurse, and working on the front line, were risk factors for mental health problems (depression, anxiety, insomnia) (Kramer et al., 2021; Şahin et al., 2020). Physicians had higher compassion fatigue and burnout scores, while nurses had higher compassion satisfaction and perceived stress scores (Ruiz-Fernández et al., 2020). Frontline HWs were 1.5 times more likely to report anxiety, stress, and insomnia as compared with those in the non-frontline group (Alshekaili et al., 2020).

Only one study reported an increase of overall compassion fatigue scores in psychiatric HWs compared to all HWs (33% and 22%, respectively). HWs in mental health who did not work in a multidisciplinary team had higher level of burnout and of hopelessness (37.5%) than those that did (24.0%) (Franza et al., 2020).

HWs are experiencing a myriad of mental health challenges, such as stress, anxiety, depression, post-traumatic stress, insomnia, burnout and compassion fatigue. These mental health challenges have been documented to be highly correlated. Each one is, in fact, a risk factor for the other, leading to a cycle of mental health challenges (Figure 2).

A particularly challenging characteristic of this pandemic is a succession of waves, bringing with them hopelessness and, sometimes, disillusion. The cycle is thus constantly fed. It is worth noting that HWs already experienced physical and mental fatigue before COVID-19 due to the complex situations that they had to deal with, and the length/changes in working hours. A recent systematic review and meta-analysis, covering the literature of the pre-pandemic period, suggested that up to 75.2% of HWs were burned out (Rotenstein et al., 2018). Hence, the cycle is actually launched on a smooth incline. States of chronic stress can also lead to poor sleep, impaired nutrition or adoption of other maladaptive coping strategies, such as use of alcohol and/or other drugs.

Compassion fatigue during COVID-19 is an even more complex syndrome and is closely related to professional quality of life, burnout and compassion satisfaction. It leads to emotional drain, depersonalisation and lack of personal fulfilment at work. Compassion satisfaction acts as a protective factor against chronic stress and HWs may experience this when doing their job well, when they have positive relationships with colleagues or when they feel that their work has personal and social meaning.

Protective factors

Some factors might enhance psychological resilience. In our review, participants reported leisure activities and sense of purpose built resilience (McMahon et al., 2020). In other studies in the literature, interviewees reported protective factors from stress. In one study: 80.5% were involved in
activities like prayers, sports, and exercise; 64.7% had clear guidelines for infection prevention, 57.3% were relieved to have proper PPE; and 56% reported support of colleagues (Maraqa et al., 2020).

Resilience varies from person to person and depends on several factors, such as personality or interpersonal and social backgrounds. The strategies to cope with the current pandemic that have been identified are optimism, social support, staying actualized, avoiding information overload and maintaining online communication.

There were also different kinds of intervention available to support HWs who work with vulnerable people. In a healthcare group supporting service users with complex mental health problems, the organisation offered an evidence-based support to help the staff to cope, especially after the initial phase of the pandemic (Hider, 2020). More supports for HWs are needed in workplaces to build mental resilience. A summary of what HWs have requested from their employer during the COVID-19 pandemic has been suggested from an interview study: “hear me, protect me, prepare me, support me, and care for me” (Shanafelt et al., 2020). Some other specific psychological support was also proposed for HWs. A French team evaluated the feasibility of remote Eye Movement Desensitization and Reprocessing (EMDR) therapy for treatment for stress and PTSD, with encouraging results (Tarquinio et al., 2020).

There are also protective factors that might break the vicious cycle (Figure 3).

A recent review on services for people with intellectual disabilities pointed out the opportunity to recognise the work-force skills with support and resources in regard to HWs’ own mental health and well-being (Trip et al., 2022).

Figure 2. The cycle of mental health challenges in the COVID-19 pandemic.
Review limitations

Our systematic review suffers from heterogeneity in respect of papers, study setting, samples and measurements of outcomes. Due to the urgency of collecting data on mental health of HWs with people with intellectual disability, available studies were not of the highest level of quality. Only five research papers were found within the timeframe examined, and so broad generalisations cannot be drawn about the mental health of people working with adults with intellectual disabilities during the COVID-19 pandemic. However, there is consistency in different specific mental conditions across studies, which are also in line with those other HWs reported elsewhere in the literature. Given the small number of studies additional research is needed to confirm these findings.

The other major limitation is the cross-sectional nature of all the studies. Because of our review period and the delays associated with publication, our included studies only covered the first wave. During the first wave, the suddenness of the pandemic increased the sense of uncertainty. However, because of the successive waves, the impact on mental health could be worse, due to a vicious cycle, or any negative impact may have been lessened, because of a virtuous cycle and adaptive strategies. The time factor has to be considered when quantifying the presence of psychological disorders, and longitudinal data will be needed now to better understand coping strategies among HWs.

Due to time constraints, the language criteria for selecting articles were based on the languages spoken by the research team members. Ideally, future reviews should have no language limitations and should cover grey literature in different countries as well.
The design of survey studies imposed a selection and memory bias. It is inevitable for surveys to have a part of subjectivity, because the questionnaire is based on voluntary participation of the respondents. One could assume that people who are more impacted by the main question would be the most likely ones to answer the survey. And the answers are also respondent’s own declarations. The surveys are usually retrospective, leading to the inevitable memory bias as well. Some core aspects of mental health were not mentioned either, such as post-traumatic stress and sleep disorders.

**Conclusion**

With the onset of the COVID-19 pandemic, services have had to rethink, deconstruct and reorganize themselves. The first step before reconstruction is to acknowledge people’s need; not only the needs of service users, but of those of HWs too. Unfortunately, our systematic review showed that evidence is still limited for HWs working with people with intellectual disability.

**Roadmap for future practice and research**

Qualitative research with semi-structured interviews is needed for exploring the needs of HWs working with people with intellectual disability, and with a focus on the dynamic of mental health and coping strategies.

Future research should also build on research findings from the first wave of COVID-19 in order to determine the impact of ongoing waves and lockdowns on staff working in healthcare. Consideration should be taken on the impact of long-COVID, whether the effects of the pandemic on mental health factors such as anxiety have changed over the course of the pandemic, and whether better supports have been developed and if healthcare systems are “building back better” in a manner that protects the mental health of HWs. Research employing structured questionnaires to assess mental health should endeavour to use similar measures as those employed in the general population.

The pandemic weakened the working conditions and mental health of HWs. This also leads to new opportunities to put the support of HWs with vulnerable adults on the policy agenda. The support system should target risk factors, answer unmet needs, and build resilience. At an individual level, the protection of one’s own mental and brain health should be included in any CPD program. At an institutional level, there is a need for more holistic and flexible support, including peer-to-peer support, innovative positive behavior support, financial acknowledgement, etc. At a governmental and international level, management of infection control is also required to ensure that healthcare systems, and the workers that serve them, are not overwhelmed.

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