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# How did the COVID-19 Pandemic Affect Palliative Care Social Work Services? A Scoping Review

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## Abstract

The SARS-CoV-2 coronavirus-19 (COVID-19) generated life-defining challenges on a global level, affecting healthcare professionals, who faced the same imminent public health threat as patients and families. Reduced face-to-face contact, wearing personal protective equipment and enforcing visitor restrictions generated moral distress in healthcare professionals, unable to provide holistic care. This scoping review explored the impact of the COVID-19 pandemic on palliative care social workers (PCSWs). PubMed, CINAHL and PsycINFO were systematically searched. Empirical studies and reflective articles about palliative care social work during the pandemic were screened. Data extraction used Arksey and O'Malley's framework. Thematic analysis was underpinned by Braun and Clarke for identifying, analysing and reporting patterns. From 706 citations retrieved, 125 were selected for full-text review and 32 were included in the scoping review. Thematic analysis revealed three themes: (i) moral distress, (ii) transitioning and (iii) inequality. Implementing visitor restrictions caused moral distress and raised questions about their justification. Not being present at the time of death generated feelings of anger among bereaved family members. Virtual communication replaced face-to-face contact, yet improved access to Telehealth. Inequalities were

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illuminated and PCSWs advocated for disadvantaged populations, worked creatively to minimise suffering or stigma and supported peers.

**Keywords:** COVID-19, hospice, palliative care, pandemics, social work

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## Background of palliative social work

Social workers have been involved in palliative care since it evolved in the latter half of the 20th century (Saunders, 2001; Reese, 2011). Palliative care social workers (PCSWs) are generally employed within the community, in home-based hospice care agencies, hospices or hospitals to deliver specialist palliative care services and are described as core members of the interdisciplinary team (Stein *et al.*, 2017; Head *et al.*, 2019). The role and experiences of PCSWs vary internationally depending on the setting and environment as people living in many parts of the world have limited access to palliative care (Knaul *et al.*, 2018; Sleeman *et al.*, 2019). The PCSW role includes, but is not limited to, involvement in policy and legal issues, as caseworkers, offering psychotherapy, group work, psychoeducation, programme planning and development, research and advocacy (Ragesh *et al.*, 2017).

According to Brandsen (2005), PCSWs address the psychosocial concerns of patients and family members, they promote advance care planning and offer bereavement support services. Despite this, Head *et al.* (2019) reported that they often struggle to claim their role as their skills and capabilities are often undervalued or underused (Reese, 2011). To enhance the involvement of social workers and maximise their contribution to palliative care, Taels *et al.* (2021) conducted a scoping review to identify the prerequisites for meaningful involvement in palliative care. The most mentioned prerequisites included the need to enhance the competence and confidence level of social workers, collaborative relationships between social workers and [para] medical professions and pursuing holistic social work. The lesser-mentioned prerequisites included a clear role description with core competencies, evaluating social work contributions, increasing job satisfaction and preventing burnout, peer support through social work networks, manageable caseloads and early introduction of palliative care in the illness trajectory.

Core competencies have been developed for palliative care social work for a number of countries. Members of the European Association of Palliative Care social work task force developed core competencies for European countries (Bitschnau *et al.*, 2020), Glajchen *et al.* (2018) developed core competencies for generalist palliative care social work in the

USA and the All-Ireland Institute for Hospice and Palliative Care published a competence framework for all palliative care professionals (2014), which underpins undergraduate and post-graduate training across Ireland. However, there is recognition of the global differences in palliative care and the way in which PCSWs are integrated or utilised (MacRae *et al.*, 2020; Gerson and Firth, 2022). When exploring commonalities across PCSWs during the SARS-CoV-2 COVID-19 pandemic, they identified the adaptability and flexibility of social workers and their commitment to advocacy and social justice. Interviews with fifteen PCSWs from around the world found that social workers mobilised to promote and advocate for equity and access to care, including water, food and PPE, grief literacy and community-based bereavement support (Oltmann and Gerson, 2022).

## Challenges posed by the COVID-19 pandemic

Within a very short time, the COVID-19 pandemic generated life-defining challenges on a global level. According to the United Nations (UN) policy briefing (2020, p. 3), it emphasised 'long-ignored risks, including inadequate health systems, gaps in social protection and structural inequalities' prompting urgency for universal health coverage, which would allow countries to efficiently provide essential health and social care services, and reduce the socio-economic impact of the pandemic. COVID-19 posed the greatest threat to those living in poverty, older people, those with pre-existing or serious health conditions, women, children and migrants (UN Policy Briefing, 2020).

Elevated stress, including moral distress among health, social work and social care staff, due to working long hours and adhering to strict instructions for infection control has been previously documented (Morley *et al.*, 2019; Dobrikova *et al.*, 2022), as has the increased risk of burnout (Gorbenko *et al.*, 2020; Southwick and Southwick, 2020). To contain the spread of COVID-19 and minimise the overload on the healthcare system, mandatory protective and isolation measures were implemented. During formal periods of lockdown, people with and without COVID-19, residents in hospitals and care homes were isolated from their relatives and friends due to the restriction of visits (Plunkett *et al.*, 2021). People living at home faced a restriction on formal and informal support, resulting in some managing complex symptoms in isolation or experiencing caregiver burnout (Rattner, 2021). Face-to-face contacts, with medical or nursing staff, were hampered by PPE. Other professionals pivoted to virtual contact with patients and relatives, which caused some professionals to experience moral distress (Wallace *et al.*, 2020; Fish and Lloyd, 2022) or feel that the delivery of holistic care was compromised (Hatzipashalis and Greenwood, 2020). For relatives, having telephone or virtual contact in place of face-to-face visits was challenging (Carver, 2021). Furthermore, relatives were seldom able to sit at the bedside or say goodbye to their loved ones in person (John *et al.*,

2020). A major impact on the experience of death, dying and bereavement has also been observed (Mortazavi *et al.*, 2021). Many grieving relatives reported distress, anxiety, guilt and sadness and some described the death of their loved ones as traumatic (Mayland *et al.*, 2021).

As palliative care social work educators, practitioners and researchers from different countries, we collaborated with the aim of conducting a scoping review on the global impact of the COVID-19 pandemic on palliative care social work, as there appeared to be a gap in focus on palliative care social work in published COVID-19-related research literature.

## Methods

We conducted a systematic scoping review, following the guidelines of Arksey and O'Malley (2005) about the impact of COVID-19 on PCSWs. The guidelines include these steps: identify a research question, develop a search strategy, select studies for inclusion, chart the data, and collate, summarise and report the results. We chose this approach to include both empirical studies and personal reflections to explore the breadth and depth of the impact of the pandemic on PCSW practice and to get to the 'heart' of their actual experiences. An adapted version of Braun and Clarke's (2006) thematic analysis underpinned data analysis, which included becoming familiar with extracted data; generating initial codes; searching for, defining and naming themes; and reporting our analyses. Adopting this approach promoted 'flexibility' and enabled the identification and reporting of patterns (Braun and Clarke, 2006, p.78).

### Identify a research question

Our research question: How did the COVID-19 pandemic affect PCSWs?

### Develop a search strategy

In consultation with a research librarian, we completed searches in PubMed, CINAHL and PsychINFO databases in early April 2022, using relevant keywords for social work, palliative care and COVID-19. See [Supplementary material](#) for further details.

### Select studies for inclusion

Articles selected for review were limited to the English language, and from peer-reviewed journals that directly addressed the impact of the

pandemic on social work practice within palliative care and/or hospice services (Table 1). Articles were excluded if they did not include content specifically related to palliative or hospice social work, and if the research was conducted prior to the pandemic. Articles focusing on the experiences of general social workers were excluded.

## Chart the data

The search resulted in 706 records screened after duplicates were deleted. Figure 1 tracks the results of the selection process. Two reviewers independently reviewed all titles, met to resolve any disagreements and selected 125 articles for full-text review. A third author assisted in the final selection process during the full-text review stage. Google Scholar was used to track citations from the list of final included articles. Thirty-two articles were included in this review. One additional study, that met the inclusion criteria, was identified when tracking citations.

## Collate, summarise and report results

During the process of title and abstract review, articles were categorised based on being an empirical study or the reflections of a PCSW. Table 2 outlines the study design of the empirical studies, country, method of data collection, setting and sample size. Table 3 outlines the country, the setting, aims, objectives and the focus of the publication for the reflection articles.

## Findings

Our review includes thirty-two articles (seven empirical studies, twenty-five reflections), which met our inclusion criteria.

### Empirical studies

From the empirical studies, five originated from the USA (Currin-McCulloch et al., 2021; Gergerich et al., 2021; Pelleg et al., 2021; Rowe et al., 2021; Weaver et al., 2021), one focused on the UK and Ireland (Pearce et al., 2021) and one originated from Hong Kong (Chan et al., 2022). Three used quantitative methods (Chan et al., 2022; Pearce et al., 2021; Weaver et al., 2021), three used qualitative (Currin-McCulloch et al., 2021; Gergerich et al., 2021; Rowe et al., 2021) and the authors described one as a needs assessment (Pelleg et al., 2021). As outlined in Table 2, the number of social work respondents ranged from two to

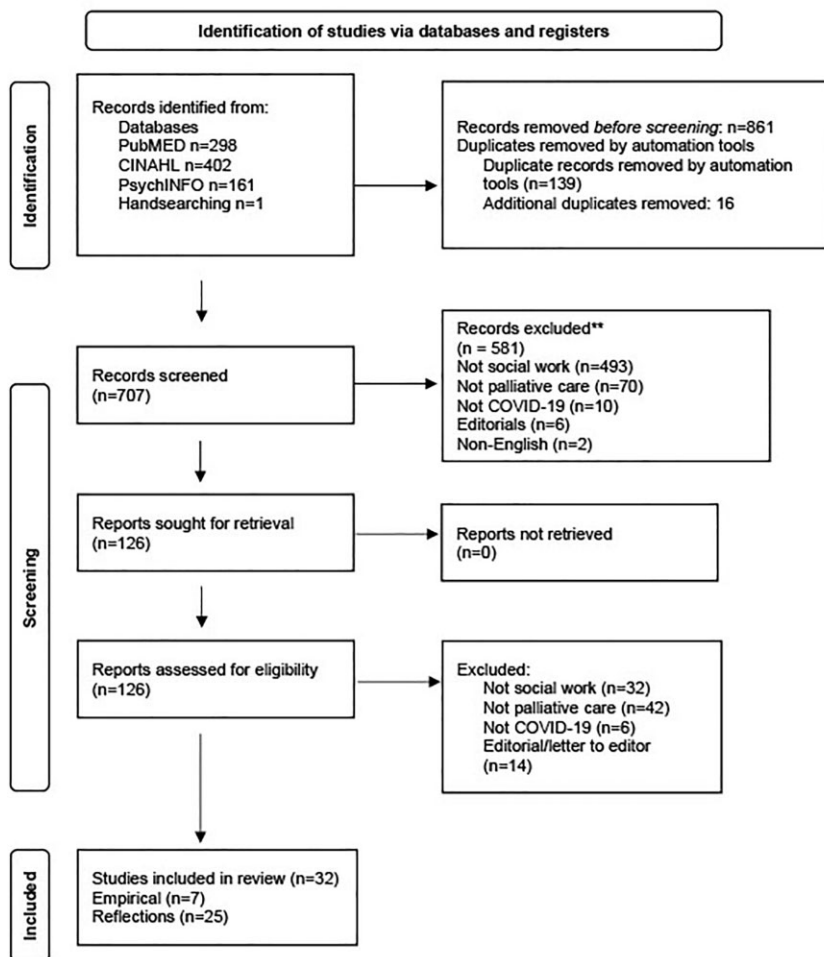
**Table 1.** Inclusion and exclusion criteria

Criteria	Inclusion	Exclusion
Type of sources	Peer reviewed articles Reflections	Book review Opinion pieces Editorials/letters to editor Case studies Commentaries
Setting	Community care Home based Hospice Inpatient Nursing home/care home Outpatient Primary care Residential care	
Population	Adult Paediatric	Pandemic other than Covid-19
Intervention	Bereavement  End-of-life care Hospice Palliative care Social work Social care practice	Not about social work practice, social care, bereavement, hospice, palliative care or end-of-life care

fifty-two. [Weaver et al. \(2021\)](#) did not report this information. Five used surveys to collect data, one conducted semi-structured interviews and one conducted a narrative analysis of personal journals by PCSWs.

## Reflection articles

From the twenty-five reflection articles included, all were authored or co-authored by PCSWs. As outlined in [Table 3](#), the majority reflected on the impact of COVID-19 for PCSWs professionally, whereas some reflected on the impact for other multi-disciplinary team members and one reflected on coping with the loss of a parent ([Currin-McCulloch, 2021](#)). Fifteen were written by authors in the USA ([Bakar et al., 2020](#); [Burke et al., 2020](#); [Wallace et al., 2020](#); [Altilio et al., 2021](#); [Carver, 2021](#); [Crawford, 2021](#); [Currin-McCulloch, 2021](#); [Dobie, 2021](#); [Giamportone, 2021](#); [Jonas et al., 2021](#); [Linick and Smolin, 2021](#); [Luck, 2021](#); [Luck and Moody, 2021](#); [Suntai, 2021](#); [Tenorio et al., 2021](#)), six originated from Australia ([Hatzipashalis and Greenwood, 2020](#); [John et al., 2020](#); [Johns et al., 2020](#); [Raftery et al., 2020](#); [Fox et al., 2021](#); [Plunkett et al., 2021](#)), one is an international collaboration ([Oltmann et al., 2021](#)) and there is one each from Canada ([Rattner, 2021](#)), Portugal ([Casquilho-Martins, 2022](#)) and South Africa ([Mathe, 2022](#)). The settings included hospitals,



**Figure 1:** PRISMA flow chart. Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., McGuinness, L. A., Stewart, L. A., Thomas, J., Tricco, A. C., Welch, V. A., Whiting, P. and Moher, D. (2021) 'The PRISMA 2020 statement: an updated guideline for reporting systematic reviews', *British Medical Journal*, 372, p. n71.

hospices, community and outpatient services, some of which were intensive care units, palliative care wards/teams or paediatric services. Based on the thematic analysis of the empirical and reflection articles using [Braun and Clarke \(2006\)](#), three main themes were identified: moral distress, transitioning and inequality.



**Table 2** Description of empirical studies

References	Country	Study design	Methods of data collection	Setting	Sample size of PCSWs included	Summary
<a href="#">Chan et al. (2022)</a>	Hong Kong	Quantitative—descriptive	Online Survey	Public hospital	Twenty-four social workers of 142 respondents	Preliminary findings demonstrated that the pandemic affected the mental health of PC professionals. Those who are younger, female and without a religion represented the most vulnerable group, who require additional psychological support. PC professionals felt distress due to limitations of services such as spiritual support and post-death support. Tightening of the restrictions on visitors brought difficulties to patients, family caregivers and professionals. Some PC professionals were deployed to other units, and PC might even be suspended
<a href="#">Currin-McCulloch et al. (2021)</a>	USA	Qualitative—descriptive	Journaling about PCSW roles, innovative strategies for engaging patients and families, and personal reflections about how the virus impacted their ability to find meaning (narrative analysis)	Inpatient Palliative Care Team	Two social workers; five nurses on PC team	Findings from this study showed that families, patients and care providers experience unique and disenfranchised grief responses due to COVID- related trauma. The following changes were found in PC teams' daily practice: routine Zoom calls and conference calls with family that are unable to be present; strong interdisciplinary work includes encouragement of early PC referrals and PC engagement; and an intentional daily debriefing with hospital staff and the fellow PC team members
<a href="#">Gergerich et al. (2021)</a>	USA	Qualitative—exploratory	Survey—three open-ended questions—recruitment from a SW listserv	Home Hospice, Community and Hospital	Twenty hospice social workers	This study revealed challenges faced during the COVID pandemic by patients, families and hospice social workers
<a href="#">Pearce et al. (2021)</a>	UK and Ireland	Quantitative—descriptive	Online survey distributed widely across health and social care organisations; snowball sampling	Hospice, community and hospital settings across the UK and Ireland	805 various health care workers; 52 social workers/ social care workers	Bereavement care has undergone major change in both acute and community settings affecting bereaved people, clinicians, support workers and the wider health and social care system. Increased need for bereavement care has challenged practitioners as they have taken on new responsibilities and skills and shifted to remote and electronic working

(continued)

**Table 2.** (continued)

References	Country	Study design	Methods of data collection	Setting	Sample size of PCSWs included	Summary
<a href="#">Pelleg et al. (2021)</a>	USA	Needs assessment	Online survey—assessing after educational training—self-report before and after COVID	Outpatient and Inpatient Hospital	Forty-six total health social workers completed survey	This needs assessment showed that interdisciplinary and cross specialty collaboration between PC providers and health SWs created a positive learning environment, helping improve patient-centred care. As a result, a four-part series of core PC skills with sixty-minute virtual presentations was created with continuing education available for health SWs to prepare them for another COVID-19 surge
<a href="#">Rowe et al. (2021)</a>	USA	Qualitative—descriptive	Individual, semi-structured interviews with palliative care clinicians ( $n = 25$ ).	Hospital palliative care	Twenty-five palliative care clinicians: two social workers	Palliative care clinicians utilised strategies for integration and innovation across hospitals, particularly in intensive care units and emergency departments. A need to build capacity through increased primary palliative care access and training was identified
<a href="#">Weaver et al. (2021)</a>	USA	Quantitative—descriptive	Cross-sectional online surveys were posted on seven professional Listservs from May 2020 to June 2020	Inpatient hospital	Not specified	Whilst the number of children diagnosed with COVID-19 receiving hands-on care from paediatric PC teams was reportedly low, the coronavirus pandemic vastly impacted paediatric PC team structure, daily services and communication models warranting attentiveness to lessons learned and future direction

**Table 3** Description of reflection articles

References	Country	Aims/objectives	Setting	Summary/focus
<a href="#">Altilio et al. (2021)</a>	USA	To develop a communication resource for clinical staff to use when caring for patients	Hospital/hospice	Guidance developed to help health and social care staff to effectively manage communication with patients facing uncertainty or death through COVID-19 to navigate virtual family meetings and to promote self-care and staff team support
<a href="#">Bakar et al. (2020)</a>	USA	To describe how to provide support that creates a therapeutic alliance	Palliative Care Team	PCSWs facilitated end-of-life visits and promoted connection pre-bereavement, provided telephone support to relatives, leadership and consultant roles to colleagues, helped families with anticipatory grief, coordinated bereavement services, provided information on planning funerals and supported children and grandchildren of patients with COVID-19
<a href="#">Burke et al. (2020)</a>	USA	Describe team model based on colour code to determine support for patients with COVID-19	Palliative Care Team, ICU	Condolence calls to normalise grief, to provide information on community and financial resources and on funeral homes. Team-based approach reduced burden on unit/team and promoted consistency of information based on colour-coded system
<a href="#">Carver (2021)</a>	USA	Impact of COVID-19 on service delivery to patients and families	Hospital Social Work	PCSW used three case examples to demonstrate the stress and trauma of cancelled hospital visits, poor Internet, technology, phone calls to connect with families and advocating for patients from Indigenous backgrounds
<a href="#">Casquilho-Martins (2022)</a>	Portugal	Reflect on changes, signal limitations and share concerns with policy makers	Inpatient Units and Community	PCSW reflects on palliative care professionals being diverted during the pandemic and chronic disease management being overlooked. Patients experienced barriers to accessing medical examinations, diagnosis and treatment. Family visits were restricted, patients and families were isolated and financial support was limited
<a href="#">Crawford (2021)</a>	USA	Impact of COVID-19 restrictions on face-to-face contact and touch	Paediatric Hospital Social Work	The importance of offering hope, listening to the needs of individual patients or relatives and bending the rules
<a href="#">Currin-McCulloch (2021)</a>	USA	Privilege and transition of skills from PCSW practice to academia	Hospice	Author reflects on the transition from practice into academia and feeling helpless during the pandemic. Recognised the transition of skills to supporting students, spending quality time with her father in his final days and finding ways to reminisce and say goodbye
<a href="#">Dobie (2021)</a>	USA	Challenges of communicating through PPE in ICU and dealing with an unknown illness	Hospital Intensive Care Unit	PCSW reflects on how she supported the wife of a dying patient to explore resuscitation orders and face the reality of becoming a widow and single parent. She explores the wishes of the patient and wife to help inform how end-of-life/comfort care can be provided in a way that upholds the patients values

(continued)

**Table 3.** (continued)

References	Country	Aims/objectives	Setting	Summary/focus
<a href="#">Fox et al. (2021)</a>	Australia	How PCSWs adapted bereavement support and clinical viewings of bodies during the pandemic in an acute hospital	Hospital	Bereavement support switched to online or telephone versus face to face. Virtual bedside visits were facilitated to enable connection and other options (letters, photos, pictures or music) were used to help relatives connect with dying patients. Viewings were conducted through screens or virtually, or using full PPE. Touch was not permitted and double bagging was required
<a href="#">Giamportone (2021)</a>	USA	Planning a good death when transitioning from oncology to palliative care	Oncology Outpatient	Challenges of siloed health care and the importance of introducing palliative care services earlier and reducing stigma around planning a good death
<a href="#">Hatzipashalis and Greenwood (2020)</a>	Australia	Challenges of promoting values during pandemic and associated restrictions	Hospital Inpatient Palliative Care Ward	Core values of SW were challenged—as felt unable to provide holistic care to patients and families, to value the importance of human relationships, to promote social justice or alleviate distress
<a href="#">John et al. (2020)</a>	Australia	Moral distress during the pandemic alleviated by PCSWs	Hospital	SWs articulate in promoting evidence-based policies, managing ethically difficult conversations and using existing telecommunication skills to provide timely psychosocial care and bereavement support
<a href="#">Johns et al. (2020)</a>	Australia	Complex grief in times of COVID-19	Not specified	SWs need to know the risk factors of PGD to screen and intervene early. SWs can intervene pre-death with ACPS, psychosocial support, help put affairs in order and promote connection with legacy projects. Can help with family video conferencing, virtual visits between relatives and patients. Post-death they help with funeral keepsakes, psycho-education and bereavement support as well as skilfully helping children to express grief
<a href="#">Jonas et al. (2021)</a>	USA	Exploring how the PCSW role changed during the pandemic within paediatric palliative care	Multiple settings—Hospital, Community, Academic	SWs had to think creatively about how to stay integrated into the MDT even when working remotely, how to provide psychosocial support to families who felt isolated, how to alleviate social isolation for parents/carers who felt stressed and how to help children with memory making or legacy building amidst travel and community restrictions
<a href="#">Linick and Smolin (2021)</a>	USA	Development of buddy system by hospice SWs during pandemic	Home Hospice staff redeployed to hospital	SWs worked from home to save PPE for health care/medical staff and reduce footfall in the hospital setting. Hospice was closed and SWs were redeployed to screen hospital patients and families most in need of support. Supported families by phone and facilitated video calls between patients and relatives to help prepare them for seeing patients online and saying goodbye
<a href="#">Luck (2021)</a>	USA	Identifying feelings both negative and positive in response to the pandemic	Hospital	Personal reflection based on identifying positive and negative emotions resulting from SW's role caring for people with COVID-19 and others with life-limiting illness during a pandemic. Identifying how negative emotions previously had a hold on her, until she named them

(continued)

**Table 3.** (continued)

References	Country	Aims/objectives	Setting	Summary/focus
Luck and Moody (2021)	USA	Changes in work setting and practices during the pandemic and managing emotions	Hospital	As restrictions eased, SWs were back on the ward, seeing patients face to face, to offer psychosocial support and comfort. Constantly adapting skills to suit the environment, stretching skills and interventions to meet identified needs, and leaning on one another for support during rotations of remote working
Mathe (2022)	South Africa	Impact of COVID-19 on impoverished families	Hospice	Well over two million people lost their job in South Africa from February to April 2020. People had difficulty applying for social grants, accessing medication, traditional grief and mourning rituals were interrupted and psychosocial interventions were overlooked
Oltmann <i>et al.</i> (2021)	International collaboration	Novel interventions introduced by PCSWs during the COVID-19 pandemic	Various	Outreach, education and social support, alongside bereavement support, specialist palliative care consultation, dissemination of public health information, end-of-life care, ACP, counselling and remote working were ways in which services were adapted
Plunkett <i>et al.</i> (2021)	Australia	Impact of COVID-19 restrictions on family visits to dying relatives and risk of PGD	Hospital	Questions about rules during the pandemic: were blanket policies justifiable? Did they generate unintended and preventable harm to dying patients (i.e. distressed in unfamiliar surroundings and alone) or relatives (i.e. afraid to visit due to risk of infection or not permitted to visit due to regulations)
Rafferty <i>et al.</i> (2020)	Australia	Teamwork to promote end-of-life communication and Advance Care Planning	Hospital	Legal changes could extend the role of PC nurses and PCSWs. Training should be enhanced to include palliative care. Team members should support the proposal to delegate end-of-life care conversations and alleviate burden on medical staff on front line
Rattner (2021)	Canada	Exploring suffering of patients with palliative care needs, their relatives and palliative care providers	Hospice facility/ inpatient	Palliative care providers struggle with enforcing visitor restrictions for public health reasons, are substituting for family members missing at the bedside and dealing with the threat to their own lives due to the risk of infection. New depths of loss, suffering, isolation and loneliness are apparent in palliative care
Suntai (2021)	USA	Positives of remote access to health and social care services	Grief support group	The pandemic highlighted the feasibility and accessibility to telehealth and alternative ways to deliver services
Tenorio <i>et al.</i> (2021)	USA	Reflections on the role of one PCSW during pandemic	Inpatient Hospice and Palliative Care	PCSW advocated for a tablet placed at patients' bedside to allow patient/family communication, and facilitated legacy projects to capture memories (i.e. handprint etched on glass with poem and thumbprint laminated cards)
Wallace <i>et al.</i> (2020)	USA	Complicated and disenfranchised grief due to the pandemic	Not specified	Professionals experience moral distress when constraints (internal or external) prevent a course of action believed to be right, such as allowing relatives to sit with dying patients, to say goodbye or have normal funeral rituals

## Moral distress

Worldwide, governments and healthcare institutions enforced restrictions with the goal of reducing the spread of COVID-19. However, as illustrated in the included articles, implementing these restrictions within palliative care settings generated feelings of moral distress for PCSWs and other professionals. According to reflections by three licensed social workers and a medic (Wallace *et al.*, 2020), all palliative care professionals experience moral distress when they are suffering with institutional constraints that prevent a course of action believed to be right (e.g. not permitting relatives to sit with dying patients or permitting funeral rituals). Chan *et al.* (2022) who interviewed 142 hospital staff (including 24 social workers) reported that the tightening of restrictions on visitors raised difficulties for patients, families and professionals. Rattner (2021), who reflected on her professional experiences as a PCSW, also reported that all clinical staff were struggling with enforcing visitor restrictions implemented for public health reasons. Rattner (2021) also suggested that people who were dying chose care in the community, despite complex symptoms or caregiver burnout, because they knew restricted visiting at inpatient settings would have prevented them from being with family. Gergerich *et al.* (2021), who surveyed twenty hospice social workers, identified the motivation of families to bring hospice patients home, despite the risk of compassion fatigue, as a strength within the family and community.

Plunkett *et al.* (2021) reported that Australian PCSWs believed they were replacing families at the bedside when patients were dying and additionally highlighted that some patients died alone. This was echoed by John *et al.* (2020) who reported that dying patients were unable to be surrounded by loved ones or were able to say 'good-bye' in person (John *et al.*, 2020). One hospice social worker said that family members being unable to be present at the time of death 'added separation' equal to 'torture' (Gergerich *et al.*, 2021). Findings from an online survey involving 805 healthcare workers, 52 of whom were social workers (Pearce *et al.*, 2021) highlighted longer-term concerns about family members who were unable to say goodbye or felt guilty when not allowed to be present at the time of death. Their findings also illustrated that relatives expressed anger at the restrictions with some having difficulty accepting the death. According to Plunkett *et al.* (2021), reconciling compliance with policies and holistic management of patients caused hospital staff, including PCSWs to experience moral distress. They queried if blanket policies around visiting were justifiable, or if they generated unintended and preventable harm to dying patients, who were alone and distressed in unfamiliar surroundings, or to relatives, who were afraid to visit due to risk of infection or were not permitted to visit due to regulations (Plunkett *et al.*, 2021).

In the USA, a PCSW used case examples to reflect on the stress and trauma when in-person visits were cancelled, and remote visits were hampered by poor Internet connections and limited access to relevant IT equipment (Carver, 2021). Navigating telephone conversations or virtual family meetings in the absence of verbal and visual cues was also a challenge for social workers who normally met families face to face. However, the guidance developed by PCSWs for clinicians encouraged language to validate shared realities, to explore values, histories or beliefs that would inform treatment decision-making and to ensure that information sharing is unambiguous (Altilio *et al.*, 2021). Currin-McCulloch (2021) highlighted the challenges for staff trying to connect remotely with families to discuss the medical wishes of the patient, or advance directives and professionals felt their 'hands were tied' by the visiting restrictions. Gergerich *et al.* (2021) highlighted the social isolation people experienced with no visitors allowed in hospices for ten to twelve weeks. Some palliative care teams described feeling helpless and exhausted trying to support patients and families using telephone or on-line appointments. Another qualitative study, which involved interviews with twenty-five palliative care clinicians (including two social workers) (Rowe *et al.*, 2021), described how traditional approaches to communication were found to be ineffective against an overwhelming sense of helplessness (Rowe *et al.*, 2021).

Reflections by PCSWs highlight the importance of minimising moral distress to professionals and promoting flexibility, where needed at end of life. 'More than ever, during this unprecedented time, there is a need to incorporate psychosocial needs in a more humane and person-centred care equation' (Plunkett *et al.*, 2021, p. 135). Chan *et al.* (2022) reported how the pandemic affected the mental health of palliative care professionals. The most vulnerable were younger, female and without a religion. Reflections by one PCSW during the pandemic (Tenorio *et al.*, 2021) showed how allowing a dying patient's wife to wear PPE and say 'good-bye' in person reduced distress and accommodated end-of-life wishes. Legacy projects helped families find meaning, and psychosocial support helped end-of-life care decision making and grieving. Currin-McCulloch *et al.* (2021), who conducted qualitative interviews with two PCSWs and five nurses, implemented the 'Getting to know my loved one' tool to help staff humanise patients, by knowing more about their lives and what they were like prior to becoming unwell.

Internationally, government restrictions also affected funerals (Johns *et al.*, 2020; Gergerich *et al.*, 2021; Pearce *et al.*, 2021). For example, travel bans prevented people from attending funerals, social distancing during funerals prevented physical contact and the number of mourners in attendance often capped at ten people, emphasised feelings of isolation. Gergerich *et al.* (2021) also highlighted the distress caused by the interruption to memorial services, funerals and body donation.

Johns *et al.* (2020) reflected on the important role of social workers post-death, in terms of helping with funerals, psycho-education and bereavement support, as well as skilfully helping children express grief and identify people with prolonged grief disorder. Pearce *et al.* (2021) conveyed that hospice and hospital teams widened access to bereavement support services when they transitioned online, due to other providers being closed or unable to deliver services during the lockdown. They described lockdown as a 'second bereavement' for those already in receipt of bereavement services, when services were interrupted or stopped. Pearce *et al.* (2021) also reported that reduced face-to-face visits and palliative care staff 'feel powerless and restricted from doing the job they are passionate about'. However, as restrictions ease, Luck and Moody (2021) shared their reflections as social workers in oncology and palliative medicine. They indicated that as COVID-19 restrictions eased, they were back on the ward, seeing patients face to face and offering psychosocial support appropriate to the environment. Visits by relatives in most countries remain restricted, particularly in hospital and hospice settings, with a continued reliance on virtual family visits and family meetings to reduce falls and infection.

## Transitioning

An issue frequently cited in the included studies was family visits being discouraged (Fox *et al.* 2021), restricted (Chan *et al.*, 2022; Currin-McCulloch, 2021; Weaver *et al.*, 2021) or cancelled (Carver, 2021; Gergerich *et al.*, 2021). One reflection by a paediatric PCSW referred to 'bending the rules' (Crawford, 2021) to accommodate the religious needs of dying patients or grieving relatives. In most instances, face-to-face visits by relatives were replaced with telephone calls or virtual visits (John *et al.*, 2020; Carver, 2021; Luck and Moody, 2021; Pearce *et al.*, 2021; Pelleg *et al.*, 2021; Casquilho-Martins, 2022). The transition to virtual visits, facilitated through mobile devices, often resulted in an invasion of privacy (Luck and Moody, 2021). The PCSWs supported families by phone and facilitated video calls between patients and relatives, to help prepare them for seeing patients online and to say goodbye remotely. In one study (Tenorio *et al.*, 2021), the PCSW advocated for an iPad to be placed beside each patient's bed to facilitate regular communication with family. Currin-McCulloch *et al.* (2021), who reflected on the loss of her father and her own clinical social work practice during the pandemic, reported that iPads helped to connect patients with families and helped the family to see the deterioration in loved ones, but left professionals feeling helpless and unable to provide sufficient care to relatives who were online. Relatives relied on daily telephone calls after the ward round (Bakar *et al.*, 2020) and PCSWs had to promote digital literacy within their team of healthcare professionals to enable communication (Weaver *et al.*, 2021; Casquilho-Martins, 2022). Findings highlight the



importance of PCSWs helping relatives to connect through emailing photos, letters and drawings that could be shared with patients who were seriously ill (Bakar *et al.*, 2020; Currin-McCulloch *et al.*, 2021).

PCSWs reflected on the changes or transitions to their role (Weaver *et al.*, 2021; Mathe, 2022) and the manner in which they provided services (Dobie, 2021; Linick and Smolin, 2021) or supported colleagues with resiliency and policy writing (Weaver *et al.*, 2021). Jonas *et al.* (2021) reported that paediatric PCSWs in Boston (USA) had to think creatively about how to stay integrated with the multi-disciplinary team when working remotely, how to provide psychosocial support to families who felt isolated and how to alleviate social isolation for parents/carers who felt stressed. A COVID-19 'buddy' system in New Jersey helped redeployed staff ride out complex emotional waves of work, to debrief and care for one another, particularly as females, PCSWs and parents. Weaver *et al.* (2021) who surveyed 207 paediatric palliative care team members (professional breakdown unknown) reported that 61 per cent of the respondents felt the team was more distant, compared to 19 per cent who felt the team was closer and 20 per cent who reported no perceived changes to team cohesion. Luck (2021), whose personal reflections are based on being a palliative medicine social worker, highlighted the positive and negative emotions resulting from caring for people with COVID-19 and others with life-limiting illness during a pandemic. She identifies how negative emotions previously had a hold on her, until she named them and highlights the need to be self-aware, to promote a greater sense of balance.

Fox *et al.* (2021) reflected on the creativity required by hospital social workers who had to 'adapt' to wearing full PPE, which prompted reflection about difficulties communicating through a mask or visor (Currin-McCulloch *et al.*, 2021; Dobie, 2021; Pearce *et al.*, 2021; Pelleg *et al.*, 2021), or conveying warmth or compassion without physically touching people (Crawford, 2021; Dobie, 2021). Linick and Smolin (2021) reported that PCSWs in New Jersey (USA) worked from home to save PPE for health-care staff and reduce footfall in the hospital. In Australia, PCSWs helped families with keepsakes (Johns *et al.*, 2020) and in Texas, PCSWs facilitated legacy projects, such as handprints etched on glass (Tenorio *et al.*, 2021).

The one international collaboration (Oltmann *et al.*, 2021) reflected on the role of PCSWs at macro, mezzo and micro levels and highlighted interventions developed by PCSWs from Argentina, India, Northern Ireland and Zimbabwe. Due to restrictions limiting in-person work with inpatients, some PCSWs offered outreach, education and specialist palliative care consultation to colleagues in other teams and settings. Some provided bereavement telephone calls when deaths occurred in the hospital setting. Others disseminated public health information, facilitated conversations around advance care planning or facilitated virtual visits.

One study demonstrated how PCSWs were integral to the multi-disciplinary team in New Orleans (Burke *et al.*, 2020), where a colour-

coded system identified the severity of patient needs in the COVID-19 Intensive Care Unit. PCSWs took lead responsibility for patients assessed as coping well with COVID-19. They facilitated goals of care conversations, liaised with families for information, facilitated video calls and identified the bereavement needs of families after patients died (Burke et al., 2020). Pearce et al. (2021) reported a 600 per cent increase in the number of deaths, which increased waiting lists for services and prompted the need to change governance processes and confidentiality agreements when bereavement services pivoted online.

## Inequality

Although this theme was not expected to be revealed through our data collection, inequality emerged as a consistent theme across many of the articles identified. Included studies and reflections in this review illuminated inequalities that already existed within communities and service user groups. Paediatric PCSWs across hospitals and community settings in Boston highlighted demographic inequalities, poverty, social isolation and increased stress of family carers who worked from home, lost their jobs and cared for their children with complex medical needs (Jonas et al., 2021). Mathe (2022), who describes herself as a PCSW, reported inequity of housing, economic fall-out of the pandemic and increased financial burdens on individuals and families because millions of people in South Africa lost their jobs at the start of the pandemic (February–April 2020). Carver (2021), who used three case examples to reflect on the goals of palliative care in an era of COVID-19, suggested that PCSWs had to confront discrimination that caused inequities and prevented access to and involvement in health care. PCSWs advocated for ‘unseen’ Indigenous populations who were disadvantaged through limited access to the Internet or technology. Currin-McCulloch et al. (2021) reported additional challenges connecting with families about patients when there were language barriers and a limited understanding of the patient’s cultural background.

Jonas et al. (2021), who reflected on how the PCSW changed in paediatrics during the pandemic, confirmed that more parents caring for their children opted for home care over institutional care due to visiting restrictions. The parents appreciated the benefits of Telehealth to minimise the risk of infection and to ensure the ongoing support. Suntai (2021), a social work academic, who facilitated a grief support group during the pandemic, reported the benefits of Telehealth, particularly for older people, who had improved access to health and support during the pandemic, as it alleviated transport issues and reduced the cost and time needed to attend appointments, which were often far from home. Gergerich et al. (2021) and Suntai (2021) identified inequalities for people with limited or no access to Wi-Fi or mobile phones, no experience with information technology (IT) or were

unfamiliar with the applications used for online meetings. [Weaver et al. \(2021\)](#) suggested that palliative care teams receive training in Telehealth to improve communication during the imposed restrictions on visitation but concluded that Telehealth was not equal in quality to in-person care.

[Rattner \(2021\)](#) highlighted the suffering of patients who refused inpatient care, despite unmet symptom management in the community, and the suffering of professionals, who were at risk of infection by working.

We and the people we love have never before faced the same imminent public health threat as our patients and families. Our mortality has come into even sharper view. And this too, may add to our suffering. ([Rattner, 2021](#), p. 106)

[Pearce et al. \(2021\)](#), who received responses to an online survey from 805 healthcare workers (52 of whom were social workers), reported that families experienced stigma when COVID-19 was stated on the death certificate, as they 'felt they had failed to protect a family member from COVID-19' and they felt that the unfairness of restrictions were exacerbated when someone was tested positive with COVID-19. [Giamportone \(2021\)](#) used her experiences as a PCSW to reflect on the disadvantages of siloed health care, with respect to her mother. She emphasised the importance of oncologists introducing palliative care services earlier to patients to help reduce the stigma around planning a good death.

In Australia, [John et al. \(2020\)](#) highlighted the conflict for PCSWs when safeguarding community health versus promoting social justice, self-determination and psychosocial care. Two PCSWs, [Hatzipashalis and Greenwood \(2020\)](#), reported that during COVID-19 they struggled to uphold social work values, as the delivery of holistic care was compromised, and they were unable to promote social justice or alleviate distress. [Gergerich et al. \(2021\)](#) highlighted increasing, unmanageable workloads, unmet needs and increased distress following the disruption of systems caused by COVID-19 and associated restrictions. Therapist and volunteer services were discontinued when staff were furloughed, and domiciliary PCSW services were stopped, which undermined the value of PCSW conducting face-to-face visits. [Casquilho-Martins \(2022\)](#) published a reflective essay about how some PCSWs in Portugal were 'diverted' to respond to people with COVID-19, which resulted in the needs of people with chronic disease management being 'overlooked' and patients reporting barriers to accessing medical examinations, diagnosis or treatment, as well as limited financial support.

Findings illustrate the suffering that patients, relatives and professionals experienced during the COVID-19 pandemic and show how PCSWs adapted and responded to visiting restrictions, wearing PPE, working remotely or being furloughed, and communicating through Telehealth or other virtual means. They advocated for people experiencing inequality, promoted human rights and respected diversity in line with the definition of the International Federation of Social Workers (2022).

## Discussion

Our review found that all staff, including PCSWs, experienced changes to their working conditions, with most reporting an increased intensity or adaptation to their work activities. Most healthcare professionals, including PCSWs, had first-hand experiences of loss and trauma when providing front line services to patients and families during the COVID-19 pandemic whilst managing the intense threat to their own life by the very nature of their job. According to [Holmes \*et al.\* \(2021\)](#), social workers reported higher than national estimates of post-traumatic distress during the COVID-19 pandemic, indicating a greater need for more emotional support. The COVID-19 pandemic was described as a ‘collective trauma’ that shattered the basic fabric of society ([Hirschberger, 2018](#)).

Some studies highlighted changes to the existing services or the introduction of new services in response to shifting working conditions or practices during the pandemic, including visitor restrictions, imposed for health and safety. According to [Hasson \*et al.\* \(2022\)](#), due to the increased demand, palliative care had to rapidly adapt and reconfigure services.

Findings show that the COVID-19 pandemic affected the delivery of PCSW services in different ways, and illustrated the ability to be flexible, creative and resilient during crisis. The literature demonstrates that the skills of professionally trained and experienced PCSWs are essential for palliative care, regardless of setting, patient group or country. PCSWs assisted with the transition to virtual communication between patients, families and professionals. One of the most significant challenges was visiting restrictions in hospitals, hospices, care homes and private dwellings, which caused moral distress to patients, families and staff. Our findings suggest that PCSWs worked creatively and compassionately to alleviate feelings of loneliness or isolation, and to promote regular communication between patients and families. In keeping with the [National Palliative and End-of-Life Care Partnership’s recommendation for fair access to care \(2021\)](#), PCSWs advocated for individuals, families and communities, who faced inequality due to limited Internet access, language barriers, cultural differences or poverty. Despite the amplified pressure on staff, which affected morale and generated anxiety ([Dobříková \*et al.\*, 2022](#); [Hasson \*et al.\*, 2022](#)), PCSWs worked flexibly in response to remote working, redeployment, increased staff absences and an extension to their normal roles and responsibilities.

## Limitations

We hoped to reveal the experiences of PCSWs who provided front line services during the pandemic through high-quality, empirical studies but found a paucity of empirical studies that exclusively recruited PCSWs as

participants (Gergerich *et al.*, 2021). Whilst three studies (Chan *et al.*, 2022; Pearce *et al.*, 2021; Rowe *et al.*, 2021) recruited social workers as members of the palliative care team, it is unclear which findings are unique to the PCSWs within the team. Weaver *et al.* (2021) did not specify the profession of respondents to the cross-sectional survey. Therefore, this review relies heavily on reflective articles written by PCSWs about their experiences from a professional or personal perspective.

Publication bias and selective reporting may have affected the number and nature of studies included in this review. In keeping with scoping review methodology, there is no quality appraisal in relation to methodology. However, a systematic process has been applied using Arksey and O'Malley (2005) and Braun and Clarke (2006). The review presents an overview of empirical and non-empirical literature, which addresses a gap in our knowledge and highlights how the COVID-19 pandemic affected PCSWs in different parts of the world.

## Conclusion

Our review of twenty-five reflection articles and seven empirical articles demonstrates that PCSW services and PCSWs have been impacted by the pandemic, but their ability to adapt and be flexible in times of crisis has contributed to confirming their essential role within palliative care around the world. The rich PCSW voices in the reflection articles and the paucity of empirical evidence specifically focused on the PCSW role suggest further research about this essential role is necessary.

## Supplementary material

[Supplementary material](#) is available at *British Journal of Social Work Journal* online.

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## Conflict of Interest

The authors confirm that there are no conflicts of interest to declare.

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