

Original Article

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The impact of COVID-19 on palliative care workers across the world: A qualitative analysis of responses to open-ended questions

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Abstract

Objective. With over two million deaths and almost 100 million confirmed cases, the COVID-19 pandemic has caused a “tsunami of suffering.” Health care workers, including palliative care workers, have been severely impacted. This study explores how the COVID-19 pandemic has impacted palliative care workers around the world and describes the coping strategies they have adopted to face their specific situation.

Method. We conducted a qualitative analysis of written, unstructured comments provided by respondents to a survey of IAHPC members between May and June 2020. Free text was exported to MAX QDA, and a thematic analysis was performed by reading the comments and developing a coding frame.

Results. Seventy-seven palliative care workers from 41 countries submitted at least one written comment, resulting in a data corpus of 10,694 words and a total of 374 coded comments. Eight main themes are emerged from the analysis: palliative care development, workforce impact, work reorganization, palliative care reconceptualization, economic and financial impacts, increased risk, emotional impact, and coping strategies.

Significance of results. The pandemic has had a huge impact on palliative care workers including their ability to work and their financial status. It has generated increased workloads and placed them in vulnerable positions that affect their emotional well-being, resulting in distress and burnout. Counseling and support networks provide important resilience-building buffers. Coping strategies such as team and family support are important factors in workers’ capacity to adapt and respond. The pandemic is changing the concept and praxis of palliative care. Government officials, academia, providers, and affected populations need to work together to develop, and implement steps to ensure palliative care integration into response preparedness plans so as not to leave anyone behind, including health workers.

Introduction

With over two million deaths and almost 100 million confirmed cases at the time of writing (WHO, 2020), the COVID-19 pandemic has caused a “tsunami of suffering” (Radbruch et al., 2020b). Palliative care (PC) plays a key role in the relief of this suffering by managing the symptoms and associated health-related problems for persons with COVID-19 and other conditions, as well as those of their caregivers/family members (Radbruch et al., 2020a). Unfortunately, the PC field is under-resourced, has a limited number of appropriately trained workers, and limited recognition by other medical specialists, politicians, and administrators (Hawley, 2017).

The nature of their work makes health care workers more susceptible to infection and death due to COVID-19 (Kates et al., 2020; Lapolla et al., 2020; Wu et al., 2020). This, plus the increased demand for care due to the pandemic, has resulted in heavier workloads for health professionals, adding to the burnout and existential distress many had reported prior to COVID-19 (Pessin et al., 2015).

After the WHO declared COVID-19 a pandemic, the International Association for Hospice and Palliative Care (IAHPC) launched a survey to explore how the pandemic was affecting their global membership both personally and professionally. An initial quantitative analysis revealed that more than 80% of the participants felt that their ability to continue working in their usual PC job, and to continue providing care to non-COVID patients, was highly or somewhat affected. They also reported that the pandemic had affected staff availability in their institutions/services, regardless of their respective countries’ income levels. Thirty-seven percent also reported that the pandemic has affected the availability of and access

to opioids for breathlessness and pain relief, more so in lower-income countries. This data are included in a separate paper submitted for publication.

The objective of this study was to conduct a qualitative analysis of how the COVID-19 pandemic has impacted PC workers around the world, and to describe the coping strategies they have adopted to face this situation.

An ethics review board of the Fundacion FEMEBA in Argentina approved the study.

Method

We performed a qualitative analysis of the written comments provided by respondents to the 2020 survey of IAHP members. The survey covered their perception of their own competence to face the situation, access to personal protective equipment (PPE), and in the impact of the COVID-19 pandemic on care provision. Respondents could add unstructured comments up to 300 words ("Please explain/expand your answer"). Our intention was to generate "stories" for qualitative analysis. Researchers have highlighted the importance of asking and analyzing open-ended questions in structured questionnaires (O' Cathain and Thomas, 2004).

The survey was developed using Survey Monkey© and distributed to 979 IAHP individual members by email. The invitation to participate with a link to the survey was sent out on May 28, a reminder issued on June 22, and the survey was closed on June 30, 2020. Participants were provided with general information about the study as well as the objectives of the survey.

Respondents had to confirm that their participation was voluntary and that they were 18 years of age or older. As an incentive to complete and return the survey, IAHP extended their annual memberships by 3 months. The survey was not anonymous, but the responses were anonymized for the analysis.

Free text was exported to MAX QDA (v. 2020), and a thematic analysis was performed (Braun and Clarke, 2006) by reading the comments and developing a coding frame to describe the contents of the comments (TP). Two authors (LDL and TP) separately applied the frame code to all comments. Coding disparities were resolved by discussion. Verbatim comments have been displayed to illustrate the themes identified.

Results

Seventy-nine IAHP members working in PC from 41 countries of all income categories participated in the survey. Ninety-seven percent (77/79) of the participants submitted at least one written comment, resulting in a data corpus of 10,694 words. The extent of the data ranged from a few sentences to long texts. Eight main themes emerged from the analysis (Box 1) are described below.

PC development

Participants reported that the pandemic has reversed or stalled previous development of PC policies as health authorities and health systems focus on COVID-19 at the expense of "neglecting" PC. Some PC services and programs have been completely shut down or partially closed.

COVID-19 posed lockdown for a very long duration, so we are unable to continue with routine home visits and outpatient & inpatient services.

Box 1 Categories of themes identified in the qualitative analysis of comments.

1. Palliative care development
2. Impact on workforce
3. Reorganization of work
4. Reconceptualization of palliative care
5. Economic and financial impact
6. Increased risk
7. Emotional impact
8. Coping strategies

Though we followed up people over the phone, many who are in need couldn't be reached due to transportation issues. (India)

An opposite effect was also reported:

...from an Australian Government perspective there has been an increased interest and investment in palliative care, particularly through measures like advance care planning. Politicians and bureaucrats are becoming more aware of the efficacy and economic benefits of broad access to palliative care, which is reflected in their dialogue and funding opportunities. I am very pleased with this development. (Australia)

"(...) we were eventually asked to create a COVID comfort measures unit for those dying from COVID with comfort goals for their care" (USA).

Impact on workforce

Containment measures, sickness and death of staff members, personnel issues, and childcare obligations have reduced the workforce.

The hospital was on skeletal force. (Philippines)

Number of the staff working in each shift reduced to 50%. Shift timings were increased/day and followed by 3 days off/week. (India)

Staff reductions have followed institutional measures such as re-assigning PC workers to other duties in newly formed COVID-19 units. With increasing COVID-related activities, this has led to work overload:

Very difficult [to] replace staff in nursing home and home care setting. We have to work double. (Italy)

Lots of COVID-19 related work, which has increased my workload along with helping out at the local hospice. So I have been very busy! (Uganda)

Work has shifted from home to office: "A challenge to find a new balance between family and work life and adapt to the new situation" (Philippines). Home-offices replaced regular office space for team meetings, and remote consults replaced in-person visits.

The impact of the pandemic on the workforce is twofold: it affects the workers' ability to carry out their professional duties as well as their personal well-being. The distress and fatigue have negatively affected patients and the health personnel:

There is a decrease number of nurses. So it means more work with fatigue showed up as bad practice or errors, bad tempered, less self-protection from Covid because of too much work, etc. (Guatemala)

Lockdowns affect mobility and without public transportation many staff members have been unable to travel to work. That also changes the organization of work and resources:

There [is a] lockdown in our country and we are being ferried home in the company (sic) car. We are working only half days because one car has to deliver all staff to their homes so it means patients who need our services in the afternoons also suffer. (Malawi)

Some measures have resulted in the segregation of health workers:

“Nurses were being segregated in public transport and this forces our organization to be taking and dropping staff from their homes, and made us to be working half days so as to have enough time of deliveries” (Malawi)

Strategies used to solve this burden required additional institutional reorganization, affecting colleagues, patients, and families.

We had to hire a driver and used one of our team member’s vehicle to transport those who used to travel by the now banned public means. (Uganda)

We requested our patients to pick up the nurse/CGs assigned to them. Some agreed – stay-in with the patients (temporary) until lockdown is lifted. (Philippines)

Reorganization of work

Additional tasks such as screening PC patients for COVID-19 are onerous, time-consuming, and create more barriers to access:

Prior to conducting the home visit, a COVID-19 screening questionnaire protocol. Patients are visited only if the screening is negative. In case of any suspicion of a COVID-19 infection, the nurse refers the patient to a COVID-19 facility for testing and management accordingly. If the screening done by the nurse is negative, the patient is visited with the nurse or healthcare professional wearing full PPE (gloves, mask, gown, head, and shoe cover). (Lebanon)

These practices were criticized, as their ostensibly protective function carried a risk of contamination.

I am still aware that the strategy does not protect health providers because they are always exposed during testing, sample collection. (Mozambique)

Isolation measures and changes in hours and shifts were also reported:

I was home in isolation for over 8 weeks before going on to the COVID CMO unit. On the unit, to limit exposure, we were asked to do 7 days of 12 hr shifts. All of the experiences have been very isolating. (USA)

Participants also reported a decrease in the number of PC consultations and “disruptions in the ability to deliver palliative care” (USA), which is reduced to the “as is needed” (Haiti). In Trinidad and Tobago, the need was when “patients who have active symptoms or are in the imminent phase of death (were visited at home as needed)” and in Lebanon “[only] active patients (who have any symptoms and those who are in the imminent phase of death) were visited. Only emergency visits.”

We no longer routinely visit, so only those patients where a face-to-face assessment is essential are seen. (UK)

Reconceptualization of PC

As care provision has been limited to the essential clinical services (medical, nursing, and social work), volunteers, spiritual

caregivers, and others deemed non-essential have been dismissed. This raises definitional issues around what is considered essential.

The traditional model of care provision has also changed in an effort to find alternatives that can guarantee continuity of care. Examples include networking and taking on new tasks:

Linking to nearby clinics, primary health centres for symptom management. Linked to a nearby pharmacy for medicine refills. (India)

Many PC workers have been forced to contact their patients using telehealth or phone, especially for follow-ups, reducing ward rounds (Malawi) and outpatient visits (Israel).

We continued palliative care consultations and clinic visits with new and established patients via telehealth with a great deal of success and significant volume — though lower than normal. The numbers escalated quickly once that route of patient care began. (USA)

As a participant stated: “Some new opportunities with telemedicine and Zoom training have unexpectedly emerged” (Nepal).

Telemedicine made key PC tasks more challenging, as communication requires “the clearest and most objective communication” (Peru), as well as assessment:

My consultations have moved to mainly telehealth and I have concerns particularly with initial consults, that important assessment ques [sic] are missed, and the personal contact is removed from face-to-face consultations when they occur. (Australia)

Some reported on the limits of the technology, including limited internet access (Uganda) limited IT support (New Zealand) and exhaustion from being online. Also, the protective measures pose many challenges and altered the medical-caregiver–patient relationship:

COVID is a total opposite of palliative care: Patients die alone. Families cannot be close to them. Religious ceremonies are on hold. It’s not the quality of life anyone would want. (Tanzania)

In our culture, and most likely with the rest of the world, the most important part of caring is PRESENCE. Touch, intimate conversation, allowing the patient to sit close, face-to-face interaction — essentials in palliative care — are no longer accessible for everyone due to social distancing. (Philippines)

Economic and financial impact

Nonprofit organizations are struggling with funding and fundraising events have been canceled as “donations have diminished, but costs increased” (South Africa); “It [would] possible for us to survive if the pandemic is not staying for several weeks/months in the same severity” (Sweden), indicating they were reaching their limits. The pandemic is also affecting peoples’ personal situations, putting their jobs at risk, and increasing financial uncertainty “[d]ramatic drop in hospital income has meant staff have had to take leave etc” (Nepal). Some reported that the economic effect of the pandemic impacted their emotional lives:

(...) financially affected as the economy in the country has been affected too and this disturbs my psychological status. (Malawi)

The livelihood of health work affected due to the pay cut. (Kenya)

The costs of containing the pandemic and of developing and establishing care centers constituted a heavy burden. In addition,

Personal Protective Equipment (PPE) is quite expensive, and some health care workers required to pay for it out of their own pockets, adding to the economic burden.

Increased risk

Several providers reported being afraid as colleagues fell sick and some died:

I feared getting infected with COVID from symptomatic and asymptomatic patients. 24 doctors in the Philippines have died from COVID. (Philippines)

Staff are afraid of contracting the disease and because they have to go home every day, they are also worried they cannot protect their families. (Uganda)

Personal factors such as age and medical condition, and family circumstances such as children or older persons at home, all of which are usually irrelevant to job performance, are now determinant:

I recently had to step back on home visits due to my own personal risk to get complicated Covid. (Peru)

Being a doctor, my family is aware that I may get infected and bring it to them. The fear my staff see every day in the eyes of their loved ones and also the domestic disputes which occur as a result of this fear and how it affects the health care workers morale needs to be addressed. (India)

Health care workers feel unsafe in some cases due to a lack of appropriate infection control measures:

Staff fear and distress at being moved without notice to Covid wards and at having to work between Covid and non Covid wards with no quarantine period (Trinidad and Tobago)

In Australia, Malaysia, UK, and the USA, limited availability of PPE was reported only in the early stages of the pandemic. In South Africa, PPE availability was reported as “have sufficient but could be a challenge if case numbers escalate,” and in other countries as limited to insufficient:

There is fear in all health workers because there is no training and there is lack of PPES in the county (Kenya)

Some professionals refused to provide care in order to avoid risk:

Initially, staff were reluctant to come to work in a clinical space due to fear and mixed messaging from the media. (Australia)

Emotional impact

Participants described how fear, anxiety, grief, and stress are affecting their performance. Work overload, new tasks, new forms of PC service delivery, their personal vulnerability, and that of their families are causing distress and burnout and affecting health and well-being:

How much has this pandemic affected the physical health and psychosocial well-being of the caregivers themselves is an important concern. How do we take care of ourselves when the toll is mounting? Aside from being anxious about addressing the needs of our patients and their families, there are personal issues that carers themselves confront on a daily basis. (Philippines)

The distress and fatigue have negatively affected both patients and staff:

There is a decrease number of nurses. So it means more work with fatigue showed up as bad practice or errors, bad tempered, less self-protection from Covid because of too much work, etc. (Guatemala)

Coping strategies

Coping strategies include self-care, mutual aid, and team support:

The team reported supporting one another through meetings (India).

I have adapted due to the support of colleagues and knowing we have all needed to change and respond during this crisis. (UK)

PC workers are reflecting on their situation and developing self-care strategies:

We have been working as if it is a sprint rather than a marathon and now we need to change in order to protect ourselves (Uganda).

Counseling was mentioned as helpful. Support of friends and family was also mentioned as an additional way to cope with the situation produced by COVID-19. Just as lack of knowledge was reported as a source of insecurity, learning became a coping strategy: “learn as much as possible about the pandemics” (Norway and India). Taking time off as schedules were reorganized was also helpful: “The hospital has implemented schedules to give staff time off on alternate weeks in turns.” (India)

Discussion

We collected and described the lived experiences and perceptions of PC workers from around the world during the COVID-19 pandemic. Thematic analysis revealed eight main themes: PC development, workforce impact, reorganization of work, economic and financial impact, reconceptualization of PC, increased risk, emotional impact, and coping strategies.

Although PC delivery has increased throughout the world in recent years, multiple reports demonstrate that, even pre-pandemic, services were insufficient to meet population need (Clark *et al.*, 2020). In some countries, the pandemic delayed or reversed previous advances in the development of PC policies. Demand for opioid medications, essential for the management of breathlessness and pain, increased substantially during the pandemic, widening the already existing abyss in access, particularly in lower and middle-income countries (INCB *et al.*, 2020; Pettus *et al.*, 2020).

PC has undergone several transformations in recent years (Gómez-Batiste *et al.*, 2017). The IAHP survey revealed how the pandemic has accelerated changes in the conceptual and functional binaries of healthy/unhealthy, vulnerable/invulnerable, and home/work. The pandemic affected aspects of everyday life, forcing re-orientation of the essence and practice of PC. Respondents mentioned basic challenges such as redefining essential PC practices, having to re-learn or perform key tasks differently, including when physical presence was prohibited, mastering new forms of communication, and learning how and when to use technology. Being reduced to essentials has forced providers to reconsider and redefine traditional models of PC delivery. The pandemic has limited patients’ autonomy and decision-making capacity, shifting power back to the physician/administrator (Arya *et al.*,

2020). Patient participation in decision making may also be severely restricted as a result of isolation at end of life, sedation, and inability to communicate.

Although PC is characterized as “high talk,” “high touch” (Pastrana et al., 2008), and actual “presence” (Plessis, 2016), these modalities are no longer considered safe. Immediately after the onset of the pandemic, presence and contact were characterized as threats and had to be replaced by other forms of personal communication and presence. The use of technology and tools such as telehealth spread widely, and families, patients, care providers, and others are increasingly relying on their phones, tablets, and computers to reach out to patients and loved ones. This paradigm shift to virtual presence changed both administrative tasks and health care provision itself.

Telehealth has been used in different medical specialties for decades, and its use in PC was first reported at the end of the 1990s (Hovenga et al., 1998). Some of the advantages include reduced transportation burden, risk of transmission, infection rates, and the ability to ensure continuity of care in the community (Monaghesh and Hajizadeh, 2020). However, access to the internet is also very variable, with persons living in poor resourced countries experiencing less connectivity and higher prices, exacerbating the already existing gap in access to PC (Broadband Commission for Sustainable Development, 2019). Telehealth will never be able to replace physical touch and presence, but in the context of the pandemic, it solves certain problems, so efforts should be made to facilitate access to the required hardware, technology, and software to ensure that PC workers are able to continue caring for patients and families in need.

In the pandemic, location no longer defines activity. Pre-pandemic, home was for family and for some, a refuge from the pressures of work. Now, homes have turned into workplaces, challenging previous notions of separation between the workplace and the home, and upsetting the work–life balance. In order to work effectively from home, schedules have to be reorganized and measures taken to guarantee the security of electronic devices and other technology. Moreover, working from home and in particular through video has brought colleagues and patients into workers’ private space in ways that are too personal and violate rights to privacy. Family routines change when homes become workplaces, creating new logistical issues for activity coordination.

Substantial negative impacts on the growth of the global economy were predicted when the WHO declared the pandemic a global health emergency. The international health crisis has produced a global trade and economic crisis: the cost of containing the pandemic and establishing COVID-19 care centers has placed a heavy burden on countries with limited resources, straining health systems, organizations, and institutions (Maital and Barzani, 2020). PC services have been affected along with everything else, and their long-term survival and financial viability are in question. In a matter of weeks, donors, and systems reallocated funding, grants, and donations to COVID-19 relief efforts, leaving many PC organizations without the financial support they needed to function in a context of rapidly escalating need.

On a personal level, the economic situation has put many individuals and health workers at financial risk. Some survey respondents expressed anxiety about the possibility of losing their job or incomes when their hours were cut. Since many healthcare systems are failing to provide PPE due to financial or time pressures, some workers have had to buy their own PPE, digital devices, or internet hours to meet the increased demand for technology

use. Prevention between medical personnel relies on effective preventive and containment measures, making PPE use, paramount.

PC providers are a highly affected/high-risk category of essential workers. Some health care workers are at a heightened risk due to age or health conditions, thereby amplifying the risk beyond the individual, as tending to patients with COVID-19 also increases the risk to their own families (Larochelle, 2020; Wolff et al., 2020).

The survey highlighted how the pandemic has impacted PC workers emotionally, and affected their ability to work, consistent with recent literature (Pappa et al., 2020). Our study indicated that increased workload results from changes in role and the addition of new tasks, placing workers in vulnerable positions that produce distress and burnout and affecting their emotional well-being. Counseling and support networks are important resilience-building buffers. While some team members stepped up and supported patients, families, colleagues, and health systems, others felt threatened, vulnerable, and emotionally impacted.

Participants reported using coping strategies and showed resilience in adapting to challenging circumstances. They identified personal strategies such as problem-solving, learning, seeking social support, positive thinking, and news avoidance, along with workplace measures (infection control and PPE, staff support and recognition, and clear communication) as helpful. Hospitals and services should consider implementing such measures to improve resilience and decrease the negative impact of the pandemic and quarantine measures on the general well-being of workers. Reducing vulnerability and enhancing coping capacity could potentially reduce some of the suffering resulting from the COVID-19 pandemic.

Limitations

Some authors have classified research such as this as “quasi-qualitative data” (Murphy et al., 1998). However, we considered the free text responses as qualitative data, given the fact that participants were free to provide their comments in an unstructured format, generating short stories (Steckler et al., 1992).

Since our survey did not allow for contacting participants for clarification or additional comments, our ability to gather more information was limited. This impacted the richness and in-depth analysis of the qualitative research, especially in relation to the participant’s context. Nonetheless, we think we captured the essence of the pandemic’s impact on the work and daily lives of PC workers across different regions of the world.

Conclusion

The pandemic has had a huge impact on PC workers’ ability to deliver services, their financial status, and their workloads. It has made them particularly vulnerable to infection, resulting in distress and burnout and affecting their emotional well-being. Counseling and networks are important resilience-building buffers. Coping strategies such as team and family support strengthen workers’ capacity to adapt and respond.

Since traditional models of PC delivery do not apply during the pandemic, priorities have to shift, and tasks have to be reallocated in order for systems to continue functioning. Providers are being forced to reconsider and redefine PC delivery models when physical contact and in-person communication with patients and family members is limited or non-existent. Adaptation, creativity, and flexibility, and the use of inexpensive technologies such as

telehealth, have become increasingly important. The experiences shared by participants may be transferable to others facing similar challenges.

Government officials, academia, providers, and affected populations should work together to develop and implement steps to ensure the integration of PC into pandemic response and preparedness plans so as not to leave anyone behind, including health workers. Enhancing the resilience, capacity, and ability to adapt as well as implementing measures that could protect the most vulnerable and prevent suffering are paramount. Additional research is needed to continue monitoring and measuring the impact of the pandemic and of mitigation measures on health care providers, including PC workers.

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