



## Short Communication

# Psychosocial Challenges in Palliative Care: Bridging the Gaps Using Digital Health

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Received: 09 July 2021

Accepted: 10 August 2021

Epub Ahead of Print: 09 Sep 2021

Published :

### DOI

10.25259/IJPC\_381\_20

### Quick Response Code:



## ABSTRACT

Psychosocial health is a major palliative care concern globally. Patients and caregivers engaged in palliative care may experience deteriorated mental and social health conditions. Global evidence informs a high burden of depression, anxiety, psychological distress and other mental health problems among the palliative care populations. Those challenges aggravate the preexisting palliative care issues, such as lack of access and suboptimal quality of care. Palliative caregiving, both in the institutional and community settings, should be strengthened, incorporating psychosocial support for the patients and their caregivers. The recent advancements in digital health technologies have shown promising impacts in facilitating health communication, decision-making and delivering psychosocial interventions using digital devices and platforms. Adopting evidence-based interventions can help the users to access mental health resources and communicate with each other to promote shared decision-making and management of health problems. Health-care organisations and systems may explore opportunities to advance psychosocial care using digital technologies. Leveraging advanced technologies in palliative caregiving may require multifaceted research exploring potential barriers and opportunities at the user, institutional and systems levels. Nonetheless, palliative care policies and health systems measures should be strengthened to develop and implement digital support systems that may improve psychosocial health and overall palliative care outcome.

**Keywords:** Digital health, End-of-life care, Hospice care, Palliative care, Telemedicine

## INTRODUCTION

Palliative care has critical psychosocial impacts on the patients and their informal caregivers.<sup>[1,2]</sup> The magnitude of such problems can be examined from different perspectives. First, the patients receiving palliative care may have poor mental health statuses due to their primary disease as well as persistent psychological stressors in their altered lifestyle.<sup>[1,3]</sup> Second, access to mental health services remains a major challenge globally.<sup>[4-7]</sup> For this reason, people under palliative care who has clinically significant mental health issues may not receive the care they need. Third, caring for someone with palliative conditions can be burdensome, especially if the caregiver is also experiencing socioeconomic challenges resulting in a cluster of psychological stressors for them.<sup>[1-3,8]</sup> Fourth, palliative care is neither available nor accessible to a major proportion of the global population.<sup>[9]</sup> A lack of care keeps affecting the health and quality of living among the affected individuals and their caregivers, which subsequently impacts their psychosocial well-being.<sup>[10]</sup> Nonetheless, people who serve as palliative care providers often spend long hours,

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stressful work-life and limited mental health resources.<sup>[11]</sup> Therefore, critical issues such as emotional burnout, sleep deprivation, depression and other mental health problems appear to be highly prevalent in palliative care providers.<sup>[11,12]</sup> It is essential to examine and address such psychosocial challenges that are impacting primary stakeholders in palliative care, including the patients, family caregivers and health-care providers.

Several studies have shown a high burden of psychological problems among palliative care patients. A study assessed psychological health conditions among 381 cancer patients who were receiving palliative care and found that the prevalence rates of anxiety and depression were 13.9% and 20.7%.<sup>[13]</sup> Another study from Australia reported a dual burden of anxiety and depression among about 25% of the 266 palliative care patients.<sup>[14]</sup> Similar studies from multiple global settings have shown a high prevalence of psychosocial challenges in patients receiving palliative care. A meta-analytic review of 24 studies with 4007 individuals from seven countries found that the pooled prevalence of depression, major depression and minor depression was 16.5% (95% confidence interval [CI] 13.1–20.3), 14.3% (95% CI: 11.1–17.9) and 9.6% (3.6–18.1), respectively.<sup>[15]</sup> Moreover, the prevalence rates of adjustment disorder and anxiety disorders were 15.4% (10.1–21.6) and 9.8% (6.8–13.2), respectively. Furthermore, the synthesis of 70 studies with 10,071 individuals from 14 countries in haemato-oncological settings reported that the prevalence of depression, anxiety, adjustment disorders, dysthymia and any mood disorders was 16.3% (95% CI: 13.4–19.5), 10.3% (95% CI: 5.1–17.0), 19.4% (95% CI: 14.5–24.8), 2.7% (95% CI: 1.7–4.0) and 38.2% (95% CI: 28.4–48.6).<sup>[15]</sup> Such psychological challenges are also common among informal caregivers of patients receiving palliative care services. A study found that 62.7% of informal caregivers to palliative care patients had symptoms of depression.<sup>[16]</sup> Furthermore, health-care providers working in palliative care settings experience occupational stressors resulting in burnout and other psychosocial problems. A systematic review of eight cross-sectional studies comprised 1406 health professionals found a prevalence of burnout of 17.3% among the health professionals.<sup>[17]</sup> This review also revealed that palliative care nurses had higher emotional exhaustion (19.5%) and depersonalisation (8.2%), whereas palliative care physicians had lower levels of personal accomplishment (41.2%). Moreover, 27% of the social workers who served palliative care patients experienced burnout. These studies indicate a high burden of psychosocial problems among palliative care patients, caregivers and health-care providers. Furthermore, the available evidence informs the importance of tackling this enormous psychosocial burden through evidence-based approaches

## THE RISE OF DIGITAL HEALTH: PSYCHOSOCIAL INTERVENTIONS IN PALLIATIVE CARE

In recent years, a wide range of digital health interventions is being used to deliver psychosocial support, enhance patient-provider communication and improve health outcomes using a patient-centric approach. Such interventions may bridge the existing gaps of psychosocial care among individuals involved in palliative care processes. For the patients, informal caregivers and health-care providers, digitalisation of existing services or integration of psychosocial care can play a powerful role, particularly through communication interventions that can support pain management and distress relieve as an important part of palliative care.<sup>[18]</sup> Such efforts may have a focus on the strategic approach to alleviate the experience of pain, which is often mediated through personal meaning creation processes. Psychosocial interventions promote understanding and control of pain symbolisation in palliative care patients that can help with chronic and long-term problems with pain.<sup>[19]</sup> Most of these interventions are designed to help the sufferers increase their understanding of the causes, patterns and to mobilise support from health-care providers and informal caregivers. Digital communication tools, including wearable devices and messaging platforms, may enable to access and share information and facilitate evidence-based decision-making in palliative care.

Digital health technologies are increasingly used in delivering psychosocial support to palliative care patients, as noted in a growing body of scientific literature. A randomised controlled trial assessed the effectiveness of an online support system named 'Comprehensive Health Enhancement Support System (CHESS)' in relieving symptom distress among 285 dyads of patients with non-small cell lung cancer and their primary caregivers for up to 25 months.<sup>[20]</sup> This trial reported that the CHESS intervention was significantly effective in reducing physical symptom distress at 4 months ( $P = 0.031$ ; Cohen  $d = 0.42$ ) and at 6 months ( $P = 0.004$ ;  $d = 0.61$ ) highlighting that digital interventions can be useful in palliative care populations. Moreover, electronic health applications are increasingly used in palliative care settings globally. Studies by Kallen *et al.* and Lind *et al.* reported that digital interventions improved the quality of care and facilitated communication between palliative care patients and providers,<sup>[21,22]</sup> thus contributing to reduced psychosocial stress that is commonly reported by the patients. From a holistic perspective, palliative care patients and caregivers experience psychosocial challenges while receiving palliative care services, which can be resolved through digital support systems. For example, Maudlin *et al.* and Paré *et al.* reported that digital tools can potentially reduce the number of hospitalisations, documentations errors, hospital bed occupancy and provide more time for direct care, which may

alleviate stress among the patients and informal caregivers, leading to better health services outcomes.<sup>[23,24]</sup>

Digital interventions may not only target palliative care problems; rather, they may provide additional support related to health access, information or mental health resources.<sup>[25,26]</sup> The adoption of such digital support systems can improve the overall patient experience and satisfaction regarding palliative care. Moreover, such platforms may enable health-care providers to make real-time decisions for their patients and address occupational concerns and stresses that they may experience. Overall, digital tools can be integrated into institutional or health systems interventions where multiple individuals, including patients, caregivers and health-care providers, can interact, emphasising on how those systems can inform the unmet needs among the individuals and facilitate effective caregiving for everyone.<sup>[25]</sup> The level and contents of those services can be customised for different groups based on their unique psychosocial needs. For example, mental health components can be incorporated for patients and caregivers who may experience psychological distress or other mental health problems. In contrast, interventions for a social worker or health-care provider may consist of psychosocial support, preventing burnout or empowering those providers to better manage their workload that may contribute to their psychological and emotional wellbeing. Furthermore, digitalisation may offer unique opportunities to bridge multiple components, engaging decision-makers, service providers and users of digital services at different levels. The broader goals of such interventions may focus on optimising psychosocial outcomes among key stakeholders, whereas specific aims may emphasise team-based outcomes, institutional performances or systems level outcomes in palliative care.<sup>[21-23,25]</sup> An integrated approach can better inform how the health system and its components are working together to address psychosocial challenges that may impact lives engaged at different phases of palliative care.

## IMPLEMENTING DIGITAL INTERVENTIONS IN PALLIATIVE CARE: CRITICAL CHALLENGES AND RECOMMENDATIONS

Health-care decision-makers need to acknowledge critical issues that may affect the implementation of psychosocial interventions in the digital era and address the same through evidence-based measures. One of the major challenges associated with the development of digital interventions is the unique psychosocial needs of the potential users of those services.<sup>[27,28]</sup> For example, the levels and contents of psychosocial support for the patients, caregivers and health-care providers can be different necessitating customisation and optimisation of any such interventions. Moreover, some

interventions may involve dyads or groups that may facilitate the sharing of information and work together to manage physical and psychosocial problems.<sup>[25]</sup> One recommendation that can be adopted is to analyse the complex needs of the primary users of digital interventions so that those issues can be addressed in a planned way.

The existing literature on psychosocial interventions leveraging digital technologies shows a growing number of studies from high-income countries.<sup>[29-31]</sup> As low- and middle-income countries (LMICs) have a higher proportion of palliative care needs and associated psychosocial challenges,<sup>[32]</sup> their under-representation in the scientific evidence shows a critical gap of implementation research in those countries. This lack of evidence may be a result of inadequate digital interventions or integration of digital health in palliative care in those contexts. This would require active efforts to promote context-specific research on how emerging digital tools can be used for psychosocial care alongside palliative care delivery. Such interventions should be developed considering the unique needs of the patients, informal caregivers and palliative care providers.

It is worth acknowledging that the psychological needs for informal caregivers and formal palliative care providers such as physicians, nurses and other healthcare professionals might vary.<sup>[33,34]</sup> Most psychosocial health interventions focus on patients themselves and not on those people who are actively or passively engaged in palliative care giving.<sup>[35,36]</sup> However, the psychological health burden among the care givers is increasingly discussed in literature, requiring both clinical and public health measures to address the same.<sup>[37-39]</sup> Strategies to identify specific challenges, their attributes and design targeted interventions tailored to meet the varying psychological needs of the care givers in existing palliative care and non-communicable disease prevention programs are needed.

In the Indian context, geographic constraints in availability and accessibility to both digital technologies and palliative care present as a major challenge. Nearly 68% of the Indian populace resides in rural and hard-to-reach remote areas.<sup>[40]</sup> Accumulating evidence highlights that there is an unmet need for palliative care in such regions.<sup>[41-44]</sup> While digital health interventions promise making palliative care available to such vulnerable population groups, logistical challenges such as poor or lack of optimum internet network, necessary support systems and instrumentation, dearth of service engineers, inadequate or lacking capacity of healthcare staff and community members per se in utilizing digital health services in such regions pose hindrances in the implementation of such services.<sup>[30,42,45]</sup> There is need for context specific implementation research, involving community- and policy- level discussions on identifying critical gaps in delivery of digital health and palliative care services and understanding how the available resources in

rural and remote areas can be best leveraged. Mobilizing resources from the urban areas and engaging and training local communities and local healthcare providers could prove helpful.

Another major issue is the socioeconomic divide in different contexts. Even in high-income countries, all population groups may not have similar healthcare or digital services. People with better internet access, household wealth, insurance and socioeconomic advantages may have higher access to digital health services.<sup>[33]</sup> This highlights that the availability of digital technologies or palliative care in a country may not ensure all people in need can access the same. Moreover, people who are homeless or forcibly displaced may have a higher burden of psychosocial problems.<sup>[34,35]</sup> Delivering palliative care and associated psychosocial support to those marginalised people can be challenging.<sup>[36]</sup> Extensive research is needed to explore such intersections of health challenges that may guide the development of future palliative care overcoming socioeconomic disparities across populations. It is critical to explore the population health challenges and examine how those may impact the use of digital psychosocial interventions in palliative care settings. Health-care organisations and health systems should play a proactive role in addressing such complex multilevel challenges to deliver digital support to palliative care patients and caregivers who may not have the ability to access the same. Designing publicly funded interventions, mobilising social and community resources and engaging philanthropic and non-profit institutions to maximise the usage and coverage of those services may help in this regard.

Resilience is a persistent challenge in delivering health services, especially in public health emergencies, when most service networks are disrupted. For instance, during the coronavirus disease (COVID-19) pandemic, the patients, caregivers and health-care providers may have experienced unique psychosocial stressors resulting in adverse mental health outcomes.<sup>[37-41]</sup> Such public health emergencies may impact palliative care services and may contribute to additional psychosocial challenges for people involved in palliative care processes.<sup>[26]</sup> As digitalisation offers teleconsultations and remote caregiving, future digital interventions should be developed considering social and environmental challenges that may affect or alter palliative care services. It is necessary to synthesise the lessons learnt during the COVID-19 pandemic to build resilient palliative care leveraging technological advancements and improving psychosocial health outcomes.

The adoption of and adherence to psychosocial interventions may need closer attention to the complex sociocultural issues such as stigma to mental health issues and cultural appropriateness of non-pharmacological therapies.<sup>[42]</sup> Moreover, the pattern of technology use and

other dimensions of digital health behaviour may play critical roles in this regard. It is necessary to assess the individual and sociocultural issues that may inform the development of digital interventions and affect the adoption of the same. As the current evidence base on sociobehavioural aspects of digital health in palliative care is limited, more research is needed in this emerging domain to better understand the factors that may influence psychosocial health outcomes among individuals and populations.<sup>[27]</sup> Furthermore, engaging mental and behavioural scientists and practitioners in planning and implementing digital services for palliative care can provide expert inputs that may address major concerns in different populations.

Capacity building is another major challenge for implementing digital health interventions globally.<sup>[30,43,44]</sup> Health-care providers and other stakeholders who may contribute to the effective delivery of digital health services may require educational interventions for meaningful participation in digital care systems. It would be critical to incorporate medical and psychosocial care in existing systems, whereas newer systems may have layouts necessitating a brief orientation to the potential users. In addition, information technology providers engaged in digital health services should be introduced to health-care issues that would be relevant for troubleshooting the digital services in palliative care settings. In this context, health-care providers may leverage advanced technologies such as artificial intelligence or geospatial analyses that are increasingly used for improving health outcomes in vulnerable populations.<sup>[43,45,46]</sup> Nonetheless, the evolution of digital health technologies and the changing landscape of palliative care systems would need a continuous, evidence-guided and multipronged approach that aims to improve individual and institutional capacities for offering digital health services in palliative care.

Digitalising palliative care and improving psychosocial health outcomes would need proactive efforts for strengthening health systems. Palliative care is still under-developed in most nations globally. This challenge is more evident in LMICs, where pluralistic health systems may not perform optimally to prevent and treat chronic diseases.<sup>[32]</sup> Furthermore, most people in those contexts may not have equitable access to palliative care that might be available in a limited way. Universal health coverage is often envisaged to reach the marginalised population, but specialised services such as palliative care may not be readily available for everyone. This unmet need for palliative care may not be addressed through isolated efforts taken by individual providers or localised organisations. Scholars and practitioners may explore how health problems requiring palliative care services can be prevented so that palliative care providers have a reduced workload, and more resources can be allocated to provide

psychosocial care to the affected individuals. Moreover, digitalising psychosocial services in palliative care should be consistent with the societal goals of digitalising health systems and other welfare systems. Effective health-care leadership and stewardship approaches would be necessary to make lasting commitments to prevent psychosocial problems and improve palliative care across populations.

## CONCLUSION

Psychosocial challenges continue to impact health and well-being among palliative care patients, informal caregivers and health-care providers. Despite a growing body of evidence on psychosocial burden across palliative care populations, little efforts are made to address such problems. Evidence-based digital interventions are being used for improving health-care services and multiple health outcomes in palliative care settings. Critical challenges may affect the widespread adoption of such interventions, especially in low-resource contexts. Future research should explore individual and population-based barriers and facilitators, whereas health services research is needed to better inform how health-care providers and organisations can contribute to such developments. Finally, health disparities should be addressed through health systems interventions that may empower key decision-makers and organisations to adopt digital services and alleviate the psychosocial burden in palliative care populations.

## Declaration of patient consent

Patient's consent not required as there are no patients in this study.

## Financial support and sponsorship

Nil.

## Conflicts of interest

There are no conflicts of interest.

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**How to cite this article:** Sultana A, Tasnim S, Sharma R, Pawar P, Bhattacharya S, Hossain MM. Psychosocial challenges in palliative care: Bridging the gaps using digital health. *Indian J Palliat Care*, doi: 10.25259/IJPC\_381\_20