



ENHANCING PALLIATIVE CARE THROUGH DIGITAL PATIENT ENGAGEMENT AND PERSONALIZATION



A rising number of chronic and critical conditions across the globe is further increasing the need for palliative care management. These conditions develop terminal illness and make the patients not only suffer from pain but also build up emotional stress for self and family. Palliative care teams aim to improve the quality of life for such patients and their families. According to recent studies, over the past ten years there has been a more than 25% increase in the prevalence of hospital-based palliative care services.

The COVID-19 pandemic has further heightened the need for palliative care. Post-pandemic home care/remote care services seem to be effective measures for palliative care and are likely to grow the palliative care market further. This market is projected to grow by ~ 8.1% CAGR till 2032. This perspective discusses the drivers for palliative care and how the current digital solutions landscape can help in transformation of the palliative care management programs.

1. Increasing chronic conditions and critical illnesses:

Most adults in need of palliative care have chronic diseases such as cardiovascular diseases (38.5%), cancer (34%), chronic respiratory diseases (10.3%), AIDS (5.7%) and diabetes (4.6%). Palliative care helps such patients with ease of living and managing pain. Many other conditions may require palliative care, including kidney failure, chronic liver disease, multiple sclerosis, Parkinson's disease, rheumatoid arthritis, neurological disease, dementia, congenital anomalies and drug-resistant tuberculosis.

3. Rising costs of care:

The cost burden has increased so much that the elderly people would have to forgo some of the essential means to afford the healthcare costs. As per one estimate, end-of-life care accounts for about 10-12% of all healthcare spending. Annual expenditures for hospice and home care—two healthcare segments that engage in the provision of end-of-life care—are about \$ 3.5 billion and \$ 29 billion, respectively.

Key Drivers for Palliative Care

2. Family and caregiver challenges of patients with chronic/serious illness:

- It is not only the patients who suffer, but the patient's family members as well. Family members feel overburdened and highly responsible for the care of the patient.
- Families of palliative care patients face numerous stressors, ranging from critical decisions about medical care to grieving their impending loss.

A study of conflict in intensive care units found that at least one episode of conflict, which included disagreements within the family, between the family and staff, or among staff members, occurred in 78% of the 102 cases examined.

4. Digital health adoption:

Technology advancements post-pandemic are driving telehealth with effective care and monitoring of the patients by improving care accessibility and coordination. They also are ensuring patient data quality, availability and security for driving remote care. Palliative care programs can leverage digital solutions for driving integrated care for patients while being closer to their family away from hospital environment as needed.

Key Challenges in Implementing Palliative Care Programs

As, the need for palliative care increases, so do the challenges of providing it to such a large number of people. Insufficient access to palliative care, an absence of training and awareness, and misconceptions about palliative care are some of the key barriers to palliative care, as stated by the WHO.

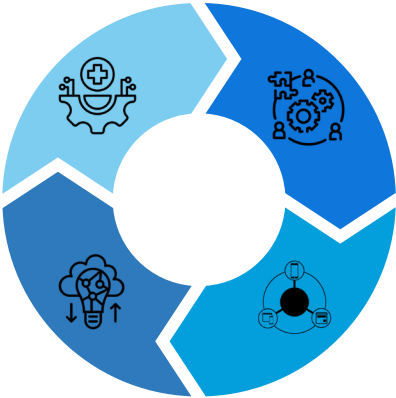
Some of the other specific challenges or impediments also include:

- Inadequate national policies, programs, resources, and training on palliative care among health professionals
- Opioid laws and prescribing regulations that fail to balance the prevention of illegal use of opioids with ensuring accessibility to morphine to relieve moderate and severe pain
- Limited evidence and research to support and invest in palliative care
- Limited funding and under-resourced status
- Quality and uniformity of care at all levels while expanding it to the community level

Industry Trends Around Palliative Care Program Implementation

1. Health network-based palliative care platform:
This platform suite generates real-time health data, or what is known as "Patient-generated Health Data" (PGHD) that is connected to and accessible throughout the entire care network, not just some of the providers. Whole patient records are now managed across the spectrum of providers on behalf of the palliative care patient.

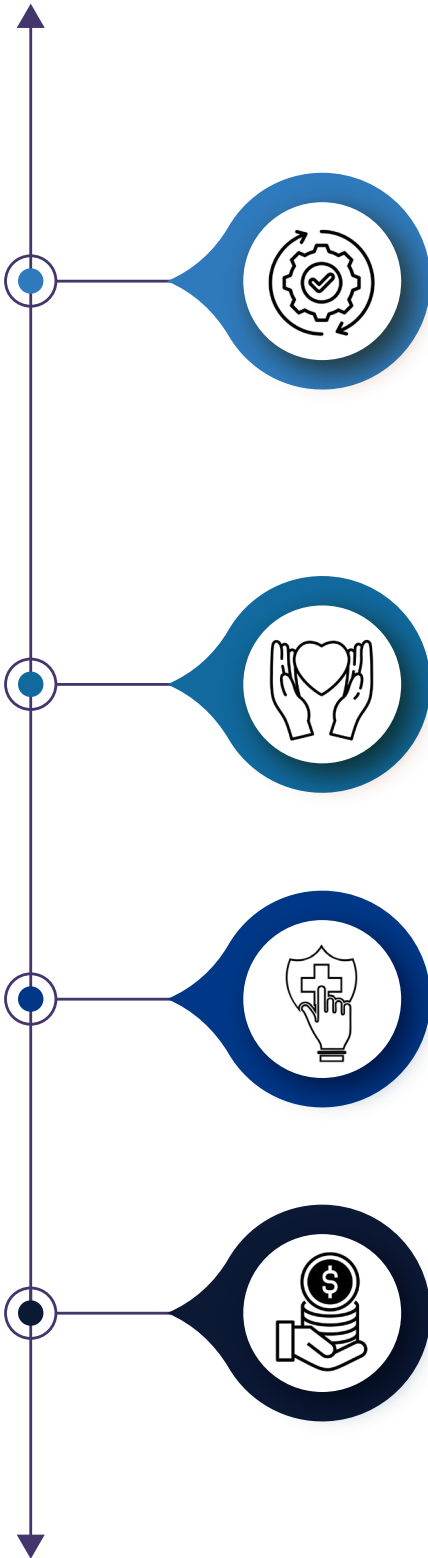
2. Digital solutions:
Wearables can also play a key role in monitoring and assessment of symptoms of advanced diseases. As an example, clinicians might remotely monitor symptoms of breathlessness (dyspnea) with a smart patch, an interpretable machine learning model based on association rules mining for the prediction of anxiety in palliative patients.



3. Coordinate My Care (CMC):
A pilot program of 10,000 users in the UK called Coordinate My Care (CMC) created a shared customized care plan with every healthcare agency connected to the National Health Service (NHS). With this centralized information, not only did most patients receive palliative care at their chosen healthcare facility, but the program saved £2,100 per patient.

4. Serious Illness Digital Ecosystem (SIDE):
This is the intentional aggregation of disparate digital and mobile health technologies into a single system that connects all the factors involved in serious illness patient care. SIDE leverages deployed health technologies across disease continuums and geographic locations of care to ease the flow of information among patients, providers, health systems, and payers.

Palliative Care – Coordinated Care Plan Approach



Driving comprehensive (whole person) care services:

Effective palliative care services for patients need to manage all dimensions of patient care: mental health, physical health as well as social, spiritual, and cultural well-being. As seen on various occasions, the patient, when at the end of their life, experiences emotions like anxiety, depression, stress, guilt, and regret. They also feel pain, breathlessness and trouble doing their daily chores. By addressing problems and needs in each of these areas, holistic care improves the patient's overall quality of life. The care team involving physicians, specialists, care managers as well as home or hospice care staff and nurses, drives a high degree of collaboration for timely interventions. The plan needs to support sharing of information among all these team members related to patient care and the establishment of a comprehensive treatment plan to address the biological, psychological, and social needs of the patient with different plans of diet, lifestyle, medications, and assisted daily living activities. Further digitally integrated care allows for immediate access to medical data related to population health, a review of a patient's medical history, identification of patterns, and recommend personalized interventions. These features aid in targeting unique symptoms and stratifying risk severity while keeping a laser focus on the patient's well-being and quality of care.

Complementary therapies for palliative care:

The management of pain and other symptoms associated with a person's life-limiting condition is often done in conjunction with traditional medical care by practitioners of alternative therapies. Alternative treatment, alternative medicine, holistic therapy, and traditional medicine are a few names for complementary therapy. Acupuncture, aromatherapy, herbal medicine, naturopathy, osteopathy, reiki, and yoga are examples of complementary therapies.

Supportive care plans to drive family health:

Families of patients receiving palliative care are profoundly affected by the challenges of the illness. They are often termed as 'hidden patients' as they need support as well. These families receive support from health professionals in the form of information, counselling, or practical assistance.

Financial support:

Majority of end-of-life support is financed by private health insurance or Medicare. To relieve the financial stress on the family, palliative care teams can also have financial advisors on their team who can help families plan for long-term facility care for the patient. There are also some charities for palliative care which are the Worldwide Hospice Palliative Care Alliance, Marie Curie, and Capital Caring Health. Other charities, like Hope Health and the International Association for Hospice & Palliative Care (IAHPC), support terminally ill patients and their caregivers.



Driving Patient Engagement and Personalization in Palliative Care through Digital Transformation

1. AI for disease progression analysis and prognosis:

AI/ML algorithms can analyze large datasets which can be used to predict disease progression and patient prognosis. AI/ML can help in developing personalized symptom management plans by analyzing a patient's everyday data, such as vitals, EHR, etc. Natural Language Processing (NLP) can be used to extract information from unstructured data sources such as clinical notes and patient narratives, which can aid in identifying patient preferences and psychological needs.

2. Analytics for personalization:

Patients and their loved ones will look for a hospice facility based on location and convenience. App developers can create geo-personalized landing pages based on the searcher's location and present them with location-specific information that will enable them to convert. Further web analytics, IoT, social and sentiment analysis techniques and drive personalized alerts, touchpoints and care interventions .

3. Patient data interoperability:

FHIR/HL7 interoperability solutions help connect patient data from EMRs, wearables/medical devices and other systems/apps to consolidate and get complete patient clinical history through harmonized patient data. This 360° patient data access helps drive effective insights for the personalized digital palliative care plan of the patient. It further helps reduce the maintenance costs in administrative and paper-based records.

4. Measuring the Quality-of-life Index (Physical Quality of Life Index – PQLI):

The PQLI is a useful tool for healthcare providers to assess the quality of life of their patients receiving palliative care and to monitor changes over time. It can also help healthcare providers tailor interventions to address specific areas of need and improve the overall quality of life for their patients.

5. Telehealth and Remote Patient Monitoring (RPM):

Palliative care can be best provided at home or near home so that patients remain closer to the family and the family can participate easily in the care. Since it can also be long term care, home care support can help control the care costs as well. Telehealth solutions help with remote care coordination and timely care accessibility. Leveraging wearable and other medical devices can help with effective and timely diagnostics/monitoring of patient conditions. RPM technology can range from handheld medical devices to online platforms that allow patients to input data. Increased patient engagement, improved quality of care and better access to healthcare are some of the benefits of RPM. Having access to longitudinal patient record through telehealth can help further strengthening the monitoring and predict next best actions.



6. Contextual education and training through AR/VR and AI-based solutions: AI-led solutions have the potential to improve education and training in palliative care. Prior to the COVID-19 pandemic there were several positive examples of how technology could support education in our specialty (e.g., virtual reality, online learning environments, social media and high-fidelity simulation). The COVID-19 pandemic has resulted in the development of several online educational resources for healthcare professionals and students. Especially AI videos and other personalized videos can help drive digital engagement of patients as they are unable to interact heavily with devices. This can further help with operational efficiency by reducing call handling costs and promoting self-service.
7. Digital collaboration for care accessibility: Digital communities and forums, manual and automated chat, automated workflow-based communications, and teleconferencing solutions can help improve accessibility of the care team stakeholders which is important from a critically ill patient perspective. These technologies help not only for the purpose of communicating with other health professionals but also for accessing web-based or mobile health palliative care resources, collecting, or managing patient data, and providing information or education.



Conclusion

Palliative care management is not only patient-centered but it's a complete care for a patient as well as the family. Leveraging digital solutions for integrated personalized care plans, health risks stratifications and clinical decision support solutions can improve overall care quality and influence quality of life of such patients. The pandemic has proven that digital health solutions can be effective in managing whole-person care and driving personalization for sharing knowledge, improving communication and influencing care outcomes in-person or remote. These solutions and capabilities can help enhance overall care coordination and the experience of palliative care patients.

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About the Author

Dr. Swapnali Takke,

is a Healthcare Consultant with Infosys Ltd and also a Clinician physiotherapist who has worked for the gone 7 years in Healthcare Industry. She has supported several healthcare specific initiatives and digital health solutions and is one of the clinical SMEs in Infosys Disease Management CoE. She is currently working with renowned Healthcare Insurance company in US to help them transform their Health systems.

Sanjivani Naik,

is a Healthcare Consultant with Infosys Ltd and is part of various healthcare related projects. She has experience working on Business & IT Transformation programs for US & UK healthcare organizations for past 4+ years. She is one of the core SMEs in Healthcare Provider COE at Infosys and has led/contributed towards multiple solution assets building in care management.

Triveni Mohta,

Sr Industry Principal, heads the healthcare consulting practice at Infosys and has overall 23+ years of experience in Insurance and Healthcare IT. Triveni has led and supported several healthcare digital transformation, mandates and interoperability consulting engagements and programs globally. She also is managing several healthcare industry specific solution innovations and CoE.

For more information, contact askus@infosys.com



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