





TechCare: Transformative Innovations in Addressing the Psychosocial Challenges of Cancer Care in Kerala, India

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Abstract

Keywords

- psycho-oncology
- ► Kerala model of health care
- ► medical Innovation
- social innovation
- cancer care
- ► Kerala Startup Mission
- ► tech-entrepreneurship

As the global burden of cancer continues to escalate, the holistic care of patients demands innovative approaches that extend beyond medical interventions. This article delves into the transformative landscape of cancer care in Kerala, India, focusing on the intersection of technology and psycho-oncology. Examining the role of the state government, Kerala Startup Mission (KSUM), and individual startups and institutions, including Malabar Cancer Institute and Cochin Cancer Research Centre, we explore how technological innovations, telemedicine, and e-health solutions are actively shaping psycho-oncological support. Leveraging on case studies, we identify notable innovations, including artificial intelligence-based cancer screening, personalized treatment plans, and mental health support. The results signify a paradigm shift toward comprehensive, patient-centric cancer care, potentially influencing broader health care strategies. Despite acknowledging regional specificity and potential biases, the study underscores the transformative role of technological entrepreneurship in revolutionizing cancer care, paving avenues for future research for integrating psycho-oncological support in health care policies and startup initiatives. Overall, the article highlights the evolving landscape in Kerala as a beacon for holistic and patient-centric strategies that prioritize mental health alongside medical interventions.

Introduction

Cancer, a pervasive global health concern, not only manifests as a physical ailment but also intricately weaves through the sociopsychological and emotional fabric and disproportionately affects individuals and communities. In recent years, the global rates of cancer incidence and mortality have witnessed an upward trajectory, particularly in countries such as India. In 2018, cancer accounted for 5.7% of all deaths in India, making it the country's fifth most common cause of death. The National Cancer Registry Program's data show a steady increase in cancer-related deaths in India, with 770,230 deaths in 2020, 789,202 in 2021, and 808,558 in

2022. It is estimated that about one in nine people in India will experience cancer in their lifetime, with approximately 1,461,427 new cases in 2022.^{2,3} Disturbingly, the Indian Council for Medical Research reveal a projected increase in cancer cases to 29.8 million by 2025,4 emphasizing the urgent need for effective prevention, screening, and treatment strategies.

Amidst these concerns, the state of Kerala emerges as a beacon of hope, establishing itself as a hub for technological innovations and government initiatives to reshape cancer care. Kerala has been in the limelight, witnessing cancer incidences of 135 per 100,000 in 2016, surpassing the

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national incidence rate of 100 per 100,000.⁵ Situated on the southwestern coast of India, Kerala has already gained prominence as a successful model of health care.⁵ In recent years, the region demonstrated growth and innovation through collaboration between startups and the government agency Kerala Startup Mission (KSUM), attracting national and international recognition.⁶ This article highlights Kerala's technological prowess and innovative governance in integrating psychosocial considerations into cancer care. Recognizing the interdependence of technology and psychosocial well-being in comprehensive health care strategies, KSUM, a nodal agency under the state government, fosters a conducive ecosystem for startups, fostering breakthroughs in cancer prevention, screening, and treatment.⁷

Delays in patients' help-seeking are attributed to various factors, including personal, sociocultural, and economic factors. One social determinant that frequently dissuades people from getting cancer treatment is stigma. Cancer stigma negatively impacts patients' physical and mental adjustment to the disease, leading to poor quality of life, feelings of isolation, treatment nonconformity, and avoidance of health care providers. This psychosocial problem affects patients' day-to-day lives, resulting in clinical and social repercussions, thereby intensifying the burden of the disease. Simultaneously, issues of accessibility and affordability create disparities in the delivery of care, preventing equitable access to life-saving interventions.

Literature Review

The surge in cancer cases in India necessitates a profound exploration of critical psychosocial factors associated with the disease—primarily, challenges in accessing treatment, affordability, and the overarching issue of stigma.

Exploring cancer-related stigma reveals its pervasive impact on health equity, giving rise to exclusion, rejection, and societal blame. The stigma also leads to fear and shame, which negatively affects people's health and willingness to engage in screening and care services. While research on the correlation between cancer stigma and health outcomes remains limited, compelling studies suggest links to delayed diagnosis, heightened depression, and the attribution of the disease to perceived social norm violations or a "bad personality." 12 Drawing on theoretical foundations, Erving Goffman's exploration of the concept of stigma and its impact on individuals in society 14 and Susan Sontag's cultural and metaphorical perceptions surrounding illnesses¹⁵ provide valuable insights into the understanding of societal perceptions and stigmatization related to health conditions. These perspectives are similar to the experiences of those grappling with cancer. 16 Arthur Kleinman also emphasizes the sociocultural dimensions of illness experiences, underscoring the significance of cultural beliefs and community dynamics.¹⁷ Unveiling the intricacies of stigmatization, shared beliefs, and cultural concepts such as Karma, researchers have identified tangible consequences, including "social isolation, gossip, verbal abuse, diminished marriage prospects, and even physical separation within households," often highlighting the pervasive impact of cancer stigma on

both patients and caregivers, uncovering the secondary stigma experienced by the latter. ^{18,19} Moreover, societal perceptions and cancer-related stigma act as formidable barriers to screening, early diagnosis, and treatment in India, profoundly affecting the overall quality of life for cancer patients. ²⁰

Looking at the challenges of health care accessibility and affordability, geographical barriers and economic disparities often lead to delays in seeking medical assistance and adversely affect primary, palliative, and survivorship care.^{21–23} Sixty-nine percent of India's population lives in rural areas, where access to tertiary cancer centers is severely limited by issues with accommodations, long travel distances, and linguistic and cultural barriers.²⁴

Cancer care in India is relatively less expensive compared with developed nations like the United States, but most Indian patients face high costs relative to their annual income. Due to India's skewed wealth distribution 57% of the national income is held by the top 10%, therefore cost of cancer care is miniscule for the creamy layer, while for the majority, even basic cancer care can be catastrophically unaffordable. The complex interplay of government structures, state budget allocations, low health insurance coverage, and a predominantly privatized health care system results in substantial out-of-pocket payments for cancer care even within the framework of existing governmentinitiated health insurance schemes such as Government of Kerala's Karunya Arogya Suraksha Padhathi (KASP) Cancer Suraksha Scheme and the Central Government's Health Minister's Cancer Patients Fund (HMCPF).²⁴⁻²⁷

However, despite efforts to resolve the issues of accessibility and affordability through free-of-cost cancer screening, tertiary cancer care, patient navigation, free transportation and diagnostic services, rural medical camps, and subsidized medicines and treatment, acceptance remain low even among high-risk groups, highlighting a critical gap in understanding patient preferences, early treatment and screening facilitators, and the multifaceted social barriers and enablers of cancer care. ^{24,28} In other words, accessibility and affordability are major psychosocial concerns which civil societies and state has been trying to resolve, apparently these efforts has not been fully successful, often due to the lack of emphasis on the third psychosocial factor—cancer stigma, and its influence on societal participation and use of these facilities. ¹⁹

Shifting to a broader health care landscape, the transformative impact of the Internet unfolds, with next-generation networks incorporating sensing capabilities and multimodal information. This encompasses smart medical and mobile devices, collectively known as the Internet of Things (IoT). Simultaneously, exploring large-scale domains the "Omics" paradigm gains prominence. The confluence of the IoT revolution, Omics, and artificial intelligence (AI) emerges as a potent force poised to reshape health care delivery. ²⁹ In envisioning the future, Dr. Eric Topol's revolutionary perspective in "The Patient Will See You Now: The Future of Medicine is in Your Hands" envisages a future where the power of smartphones and biosensors shifts authority from doctors to consumers, advocating for the "democratization" of medicine. ³⁰ These technological advancements provide

autonomy, ensure that people can readily receive medical advice and support by enabling consultations with health care specialists without requiring actual travel. Digital technology, in particular, empowers patients, increases awareness, and minimizes the stigma attached to receiving cancer treatment, thereby providing privacy and closing the gap in accessing health care.

The literature emphasizes the empowering impact of startups and digital innovations, particularly telemedicine and e-health solutions, ushering in transformative changes and fostering patient-centered approaches in psycho-oncological care. Thus, technology is evolving itself as a solution to the psychosocial issues of accessibility, affordability, and cancer stigma.

As we delve into the multifaceted challenges posed by cancer and the potential impact of technological innovation in health care, this research article endeavors to explore the following;

- How does Kerala state government and its welfare policies, alongside institutions like KSUM, use technological innovation to address psychosocial challenges in cancer prevention and care?
- 2. What's the role of Kerala-based startups and institutions in cancer care within the Kerala model of techentrepreneurship?
- 3. What initiatives are taken to mitigate social stigma, increase screening and prevention, improve accessibility and affordability of cancer care, and integrate psychooncological perspectives into the health care landscape of Kerala?
- 4. How effective are these strategies, as observed in policy documents, reports, and programs, in implementing holistic cancer care?

Methodology

Sample Design and Characteristics

The research combines a qualitative case study and an exploratory research design. The study looks into government institutions ($n\!=\!8$), including KSUM, Centre for Biomedical Research, Innovation and Commercialization in Cancer (BRIC), Kerala Medical Technology Consortium (KMTC), Kerala Development Innovation Strategy Council (K-DISC), Centre for Development of Advanced Computing (C-DAC), Centre for Materials and Electronics Technology (C-MET), Malabar Cancer Centre (MCC), and Cochin Cancer Research Centre (CCRC) and startups ($n\!=\!3$) including Sanscan Medtech and Karkinos Pvt Ltd.

Inclusion Criteria

The selection of these cases is grounded in their significant contribution to technological innovations through startups and collaborations with each other toward cancer screening, prevention, and care and presence within the regional geography of Kerala. All startups and institutions involved in technological innovations toward cancer care that were not based in Kerala were excluded.

Procedure

Data collection primarily involves semistructured interviews with key stakeholders (n=23) from the aforementioned entities. Complementing the interview data are an extensive review of pertinent documents such as policy documents, reports, official statements, annual reports, product brochures, and media analyses. The media and document analysis provides a historical context and enhances overall understanding. In addition to interviews and document analysis, direct observations are conducted in relevant contexts. This includes participation in government-sponsored events (n=3), such as CanQuer2019, a 3-day oncology conference on the theme "Technology to eliminate cancer care disparity, HealthTech"; Technology for Better Healthcare Summit 2022; and KMTC Healthcare Summit 2022. Further, visits to company/institute facilities (n=5) were also conducted to gain first-hand insights into collaborative efforts, innovation processes, and organizational dynamics.

Primary and Secondary Outcome

The primary outcome of this study was the examination of the role of key entities in the Kerala startup ecosystem in advancing technological innovations for cancer screening and care. Secondary outcomes include identifying patterns in innovation strategies, challenges, and collaborations, enriched by thematic analysis and a historical context from document analysis and direct observations at relevant events and facilities.

Qualitative Data Analysis

Thematic analysis is applied to identify common themes in the data from literature reviews, government reports, and interviews, focusing on innovation strategies, challenges, and collaborations. Researchers initially familiarized themselves with the data, coded to label key concepts related to cancer care, government initiatives, financial support mechanisms, and technological innovation, and refined preliminary themes through iterative discussions. These themes are then defined, named, and mapped onto research objectives, providing insights into the study's questions and facilitating interpretation.

Results

Cancer poses a significant health challenge, and the state of Kerala has responded with comprehensive government initiatives to ease the burden on patients and ensure access to essential treatments. These initiatives, characterized by financial aid and support mechanisms, underscore the government's dedication to enhancing cancer care in the region.

Kerala's Cancer Control Program: A Holistic Model

Kerala's cancer control program, initiated in 1988, is a robust and adaptive model addressing multifaceted challenges in cancer care. The program's emphasis on primary prevention has proven effective. Another crucial aspect tackling the issue of accessibility is early detection, facilitated by village-level volunteers, screening camps, and the establishment of "Early Cancer Detection Centres," particularly in rural areas. Districtlevel cancer control societies integrate these efforts into the broader health infrastructure, ensuring a comprehensive and sustained approach to early diagnosis and intervention. Human resource development is a cornerstone, with the Regional Cancer Centre (RCC) conducting various training programs for health care professionals. The RCC's role extends to cancer registration, providing essential data for shaping program strategies and evaluating outcomes. The RCC in Kerala demonstrates holistic patient care by offering a free food scheme for below poverty line patients and operating a free medicine bank. These initiatives provide nutritional support and essential medications, including chemotherapy drugs, at no cost, relying on contributions from well-wishers to overcome financial constraints for cancer patients.³¹

The "Kerala Cancer Care Grid (KCCG)," a collaborative network encompassing cancer care facilities, plays a vital role in the state's cancer prevention efforts. Entrusted to the RCC, the KCCG contributes significantly to an inclusive cancer prevention and control program aligned with the Kerala Cancer Control Strategy (2017-2030).³² It ensures equitable access to affordable cancer detection and treatment within a 50-km radius of individuals' residences, emphasizing inclusivity. Kerala's cancer control efforts extend beyond clinical interventions. Palliative care, initiated in 1986 and provided as part of the grid, showcases the state's commitment to addressing the holistic needs of cancer patients. Palliative care units, home visit programs, and initiatives to make pain relief more accessible reflect a compassionate and patientcentric approach.²² This approach not only provides accessibility and affordable care, but tackles the issue of cancer stigma by encouraging societal participation in its activities.

Additionally, unique initiatives like the "Cancer Care for Life" insurance program, launched in 1986, have further democratized access to cancer care by providing financial assistance. This innovative insurance model, entailing a one-time payment for a lifetime of coverage, has benefited thousands, demonstrating a commitment to financial inclusivity. Kerala's cancer control program is a comprehensive, community-driven model characterized by preventive measures, early detection strategies, human resource development, and a compassionate approach to patient care. The integration of these components, coupled with political will and community involvement, underscores the program's success and positions it as a valuable blueprint for cancer control in developing societies.³¹

Government Financial Aid

Kerala has instituted a series of comprehensive initiatives to support cancer patients. Chief Minister's Distress Relief Fund, Cancer Suraksha Scheme, KASP, Sukrutham Scheme, and Comprehensive Health Insurance Scheme Plus provide financial assistance and subsidized treatment for cancer patients.³³ These initiatives collectively demonstrate Kerala's strategic and multifaceted approach to addressing financial barriers, ensuring affordability, and providing support

for emergencies and vulnerable demographics in the realm of cancer care.

Role of Technological Innovation in Cancer Care and Support in Kerala

KSUM has emerged as a pivotal force in fostering innovation and support for startups contributing to the health care sector. The third annual symposium on "Technology to eliminate cancer care disparity," organized by the CCRC and KSUM in 2022,³⁴ exemplifies the state government's commitment to bringing new technologies to grassroots levels, thereby minimizing disparities in cancer care. The symposium facilitated discussions on leveraging technology for improved cancer care outcomes, patient education, and effective linkages between clinicians and startups.

One notable program supported by KSUM is the BRIC, an incubation program in Kochi that intends to reduce cancer deaths through technology-based, socially impactful startups. Furthermore, KSUM's collaboration with the MCC through a memorandum of understanding aims to establish a cancer care startup ecosystem in the state. This collaborative effort emphasizes the establishment of a medical incubator for cancer research, fostering cross-functional innovation. The incubator, situated at the Kerala Technology Innovation Zone, Kinfra Hi-Tech Park, Kalamassery, seeks to bring together researchers and startups to develop solutions for early cancer detection, exemplifying a holistic approach to cancer care.³⁵

Startups incubated or nurtured by KSUM, such as *Sanscan* and *Karkinos*, showcase significant advancements in cancer care. Sanscan Medtech and its innovative OralScan are the first multimodal image-capturing devices that use multispectral imaging technology at their core for noninvasive and real-time screening of oral cancer and biopsy guidance. Their proprietary software, Sascan developed to operate OralScan, is intuitive and easy to use. The service provides higher accuracy and lower per-patient cost, thereby tackling the concern of affordability of cancer screening. This encourages large-scale adoption and helps save millions of lives every year. The startup won the National Startup Awards 2021. The ease of application and affordability of the service offered by the startup is a solution to the major challenges of cancer prevention in India.³⁶

Similarly, Karkinos, another startup nurtured by KSUM, has focused on developing personalized cancer care solutions and offer psychosocial care to cancer patients. They have been recognized by the National Health Authority for their exceptional contribution to the Ayushman Bharat Digital Mission.³⁷ Their platform employs AI to tailor treatment plans based on individual patient profiles. Recognizing the psychosocial challenges associated with cancer, Karkinos integrates features for mental health support, offering inapp resources for coping with emotional distress, connecting users with mental health professionals, and fostering a supportive online community. The results highlight instances where cancer patients utilizing Karkinos' mental health features reporting increased resilience, improved emotional

well-being, and a sense of empowerment throughout their treatment journey.

Moreover, collaborations between research institutions like the C-MET, C-DAC, and MCC have resulted in groundbreaking innovations. Notably, a wearable screening device developed by Ms. A. Seema, a scientist at C-MET, for early breast cancer detection has received national recognition.³⁸ This innovative device utilizes highly sensitive thermal sensors to detect temperature variations caused by cancer cells, providing a noninvasive and user-friendly alternative to traditional mammography. Clinical trials have shown results comparable to standard diagnostic tools like mammograms, ultrasounds, and computed tomography scans, addressing challenges in breast cancer screening in India. This portable, affordable, and easy-to-use diagnostic tool has the potential to reduce the stigma of cancer screening, by getting the device to the doorsteps of common people. The Accredited Social Health Activist (ASHA) workers (ASHA is a health activist in the community who will create awareness on health and its social determinants and act as interface between the community and the public health system) taking the lead to introduce it aim to reduce the stigma and emotional concerns of going to clinics and laboratories for mammograms.

The collaboration of KSUM with K-DISC and KMTC has brought commendable results. Further, this collaboration also known as the KMTC aims to establish Kerala as a medical device and technology hub, fostering innovation, research and development, technology development, and manufacturing through a "Beyond Cluster" model that encourages collaboration and natural development. It brings together key stakeholders in research and development, academia, health care, MedTech companies, startups, and the government in bridging the gaps and empowering individuals and institutions to foster the growth of MedTech in the state. K-DISC is the Kerala Government's nodal agency to facilitate Kerala's transition to the knowledge economy apart from making Kerala an innovation hub.³³ In collaboration, these institutions have developed an AI-based system for automated cervical cancer screening using liquid-based cytology, aiming to streamline pathologists' work and improve case handling. The cervical cancer screening via Pap smear analysis is performed in the form of health care camps in the rural parts of the state by K-DISC trying to resolve the issues of accessibility and affordability.

Further, along with their technology partner Evelabs Private Limited, they use IoT, a technology component employed to create Dripo. This simple, portable, connected infusion monitor is helping health practitioners to set infusion rates accurately and monitor them from anywhere. This project is in trial at the MCC. They are also in the initial stages of developing an e-health portal, a single access point for disseminating all information using a multilingual AI chatbot with voice communication capabilities.³³

Similarly, "I CAN" app developed by Dr. Manu, a cancer survivor and assistant professor at Cochin University of Science and Technology (CUSAT), under the 2-lakh seed money of the CUSAT project titled "Development of Gamified Health Care solutions of patients suffering from cancer," features game elements such as points, badges leaderboards,

storytelling, etc. to help patients interact with the experiences of other patients and survivors and thereby maintain a positive attitude while undergoing treatment.³⁹

In conclusion, government-supervised approaches of KSUM foster innovation in cancer care through technological advancements, incubation programs, collaborative partnerships, and startup support, aiming to revolutionize cancer care and addressing challenges like affordability, accessibility, and stigma.

Discussion

The results highlight Kerala's commendable efforts in initiating a transformative approach in cancer care, encompassing a multifaceted approach that includes government initiatives, financial aid, and technological innovations. Examining the possible impacts of these results, it becomes evident that the comprehensive cancer control program and financial aid schemes could significantly alleviate the burden on patients, particularly those from economically vulnerable backgrounds. The emphasis on primary prevention, early detection, and the inclusive KCCG implies that individuals might have better access to timely and affordable cancer detection and treatment within their vicinity, ultimately improving health outcomes.

These results translate into tangible benefits in the day-to-day lives of potential patients and survivors. The financial aid initiatives, such as the HMCPF and the KASP, provide substantial assistance, addressing economic barriers to cancer care. For survivors, the on-going support, exemplified by initiatives for rehabilitation through apps like I CAN, suggests a sustained commitment to holistic patient care, potentially easing the challenges faced during and after treatment.

These results carry implications for various stakeholders. For patients and their families, the financial aid programs mean reduced financial stress, increased accessibility to essential treatments, and improved overall well-being. The government's role in initiating and sustaining these programs signifies a commitment to public health, potentially fostering trust and satisfaction among citizens. Hospitals and health care professionals, particularly through the collaborative Cancer Care Startup Ecosystem, stand to benefit from technological innovations that enhance early detection and personalized treatment plans, thereby improving the quality of care.

Furthermore, the new understanding derived from these results holds promise for advancing psycho-oncological support for potential cancer patients and survivors in Kerala and beyond. The recognition of the psychosocial challenges associated with cancer, as exemplified by the startups like Karkinos and the app I CAN, introduces a paradigm shift in cancer care. Tailoring treatment plans based on individual patient profiles and integrating features for mental health support signifies a holistic approach that acknowledges patients' emotional well-being. This could lead to improved coping mechanisms, increased resilience, and a sense of empowerment among cancer survivors. The collaborative efforts between research institutions and startups, as seen in

projects like Dripo and the cancer screening tool by C-MET, also indicate a focus on patient-centric technologies that can enhance the overall cancer care experience. These collaborative efforts initiated with government support increases its acceptance within the public and are a solution to the significant concern of cancer-related stigma. Overall, the Government of Kerala and its welfare policies for improving the lives of the people of the state have come into play in initiating, mentoring, and nurturing various programs to provide technological innovation in medical and psychosocial cancer care.

Conclusion

The intersection of technology and psycho-oncology holds immense promise in revolutionizing cancer care potentially impacting patients, survivors, and various stakeholders. Incorporating telemedicine and e-health solutions has demonstrated tangible benefits in providing accessible and personalized psycho-oncological support. Despite challenges related to stigma and resource constraints, the opportunities for improvement through awareness campaigns, training programs, and collaborative initiatives are substantial. The article highlights the transformative role of technological entrepreneurship in cancer care within Kerala, India, focusing on initiatives led by KSUM and its collaborations with various startups and governmental institutions, exemplifying innovations in early cancer detection and integrated psycho-oncological support. While showcasing notable successes, the study acknowledges limitations, including potential bias in representation and regional specificity. Future research and innovation in cancer care could improve psychosocial support, scalability, and sustainability through tele-medicine and e-health solutions and reduce cancer stigma through targeted awareness campaigns and training programs. This could improve access to timely diagnosis and treatment, reduce financial burden, and enhance patient quality of life. However, replicating these advancements in other states may face challenges like resource constraints, cultural variations, policy differences, and technological infrastructure disparities, necessitating tailored strategies and interstate collaboration.

Authors' Contributions

All authors contributed to the study's conception and design material preparation, data collection, and analysis of the manuscript. All authors commented on all previous versions of the manuscript. All authors read and approved the final manuscript.

Ethical Approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research committee (Institutional Ethics Committee (IEC), IIT Hyderabad (IITH/IEC/2021/12/13)) and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Patients' Consent

Informed consent was obtained from all study participants.

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Conflict of Interest None declared.

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