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Review Article

ARCHIVES OF
CLINICAL AND
BIOMEDICAL RESEARCH

ISSN: 2572-5017

Tertiary Palliative Care Model in South Africa: A case of the Gauteng/Wits Centre for Palliative Care

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Abstract

Background: Palliative care is an essential part of universal health coverage. Access to palliative care remains limited. The Wits Centre for Palliative Care (WPC) at the Chris Hani Baragwanath Academic Hospital (CHBAH) in Soweto, South Africa, is one of the pioneer institutions addressing this gap. By adopting a multifaceted model of care, WPC aims to provide equitable access to comprehensive palliative care services.

Aim: This review aims to evaluate the WPC model of care and assess the extent to which the model provides access to palliative care services, enhances patient and family support, and promotes sustainability and replicability.

Program Strategies: The WPC boasts three models; in-patient model supporting patients admitted in the CHBAH wards, out-patient model supporting discharged and walk-in patients; as well as the home care model for patients with low functional status. These models are complemented through five strategies: Collaboration, Clinical Services, Training, Research, Advocacy and Awareness.

Outcomes: Major achievements include provision of comprehensive patient-centred care, producing peer-reviewed publications and training health professionals.

Lessons Learned and Replicability Potential: Sustaining the WPC model required integration within the health care system. All models reduce pressure on hospital services and empower families and patients, improving patient`s quality of life. Training and research are key to support service delivery. This model can be replicated by any country/region with adaptation of strategies to local needs/conditions.

Conclusion: WPC's multifaceted model of care serves as a valuable framework for advancing palliative care provision, offering insights into operational strategies, successes, challenges, and replicability potential.

Keywords: Model; Palliative care; Hospital; Home care; Out-patient

Background

Palliative care, which is recognised as an essential international human right, embodies a pivotal component of healthcare, delivering aid to individuals and their families who are grappling with life-limiting illnesses [1]. Palliative care is an approach that improves the quality of life of patients and their families' facing problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification,

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Citation: Mpho Ratshikana, Lawrence Mandikiana, Sukoluhle Pilime, Phillip Makume, Mfanelo Sobekwa, Karl Lorenz, Cara de Breuk, Merika Tsitsi. Tertiary Palliative Care Model in South Africa: A case of the Gauteng/Wits Centre for Palliative Care. Archives of Clinical and Biomedical Research. 8 (2024): 317-325.

Received: June 06, 2024
Accepted: June 25, 2024
Published: August 06, 2024

Ratshikana M, et al., Arch Clin Biomed Res 2024
DOI:10.26502/acbr.50170413

assessment and treatment of pain (physical, psychosocial, and spiritual interventions) [2].

Approximately 56.8 million individuals globally could benefit from palliative care each year, with a vast majority of this unmet need residing in low and middle-income countries, with 98% of children who require palliative care found these regions countries [3]. However, the accessibility of such services remains critically low, as only 14% of those in need can access them [2]. In Africa, where the demand for palliative care is particularly pronounced, at least 9.67 million individuals could benefit from such services [3]. Despite this pressing need, a recent survey conducted across centres of excellence and hospices throughout African nations uncovered a concerning reality: a substantial 45% of African countries do not provide any form of palliative care services [4]. Moreover, among the limited facilities offering palliative care, a mere 9% have succeeded in integrating these services into mainstream healthcare provision [3]. This palpable deficit can be attributed to a myriad of critical gaps, including a shortage of skilled palliative care professionals, inadequate facilities for care provision, resource constraints, medication scarcities, and a lack of comprehensive national policies governing palliative care [5].

The Wits Centre for Palliative Care (WPC), part of the Chris Hani Baragwanath Academic Hospital (CHBAH) and affiliated with the University of Witwatersrand, is one of the leading institutions in the field [6]. Initiated under the leadership of Professor Ken Huddle, WPC's inception at CHBAH marked a significant milestone, followed by the N'doro project led by Dr. Natalya Dinat, emphasising quality of life for patients and families [6]. Initially, WPC focused on advocacy, networking, integration into primary health care, and equitable access [7]. Adopted by the Gauteng Department of Health in 2008, WPC expanded its services, including paediatric palliative care in 2012, addressing the rising demands for palliative care, particularly for HIV/AIDS and cancer patients in Soweto. The vision of WPC is to improve access to quality palliative care for all. The objectives include Clinical Services, Training, Research, Advocacy and Awareness and collaboration, aiming for inclusive and high-quality palliative care [7].

This article presents a detailed case study of the WPC, situated within the CHBAH in Soweto, South Africa. Through examining the centre's model of care and impact, this study seeks to provide insights into the centre`s operational strategies and success factors contributing to its role as a key player in the provision of comprehensive palliative care. Furthermore, this study aims to expound on strengths, challenges, and opportunities for improvement and replicability, with a particular focus on enhancing the provision of optimal palliative care. This examination is informed by insights gained from a comprehensive review of pioneer facilities like the St Christopher's hospice pertaining to palliative care models and operations of centres of excellence.

Pioneering Palliative Care Models: *"Contextual Insights from St. Christopher's Hospice (England), Mulago-Makerere Palliative Care Unit (Uganda) and Island Hospice (Zimbabwe)"*

The WPC model of care acknowledges the multifaceted models and methodologies employed by pioneering centres of excellence, such as St Christopher's Hospice in England. By 1967, St Christophers had implemented what were at the time innovative care models, including an inpatient unit with a capacity for 18 patients, an outpatient clinic, a long-term residential care home unit, and a home-based care service model [8]. Furthermore, St Christopher's demonstrated an unwavering commitment to excellence in education and research, and over the years has trained over 100,000 healthcare professionals [9]. Their scholarly endeavours have significantly influenced palliative care practices across more than 120 countries [10].

The Mulago-Makerere Palliative Care Unit (MMPCU), situated within Uganda's premier referral hospital, Mulago Hospital, in collaboration with the Makerere University's medical school is another pivotal centre of excellence. Since its inception in 2008, this centre has adopted a hospital-centric model, employing an Interdisciplinary Team (IDT) for patient consultations [11]. Rooted in the imperative of universal access, the MMPCU serves as an exemplar of progressive palliative care provision. Integral to its operational ethos are evidence-based strategies, underscored by robust research initiatives, and integrated within its comprehensive training programs, and capacity-building endeavours [11].

The Island Hospice and Health Care centre in Zimbabwe, established in 1979, pioneered innovative palliative care models, addressing limited nationwide access [12,13]. Their approach includes clinic/hospital visits, roadside clinics, caregiver/healthcare worker training, and community home-based care [13]. Utilising a network of hospitals and clinics, their outreach incorporates discharge and referral systems, linking patients with community health workers and ensuring medication access through medical pickup points [14]. This model's impact extends beyond Zimbabwe, influencing palliative care in over 15 African countries [15].

Study Aim: *Evaluating the implementation of the WPC`s multifaceted model of care.*

This case study aims to draw lessons from the Wits Centre for Palliative Care's (WPC) multifaceted model of care, which encompasses community outreach, hospital inpatient, and outpatient care models. The study will assess the extent to

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which the model achieves equitable access to comprehensive palliative care services, enhancement of patient and family support, and promotes sustainability amid uncertain funding. Additionally, the case study will explore the integration of the WPC model with South African national policy frameworks and strategies for palliative care, as well as its alignment with international guidelines and recommendations towards informing policies. Moreover, study findings will assess research, training and the replicability of the WPC model of care to other countries/regions.

WPC Model of Care

The Wits Centre for Palliative Care (WPC) adopts a comprehensive approach to delivering palliative care services, encompassing various models tailored to meet the diverse needs of patients facing life-threatening illnesses. These models, including the Hospital Inpatient Unit (IPU) model, Community Outreach model, and Outpatient Care model, are designed to provide holistic support to patients and their families at different stages of their palliative care journey (Figure 1).

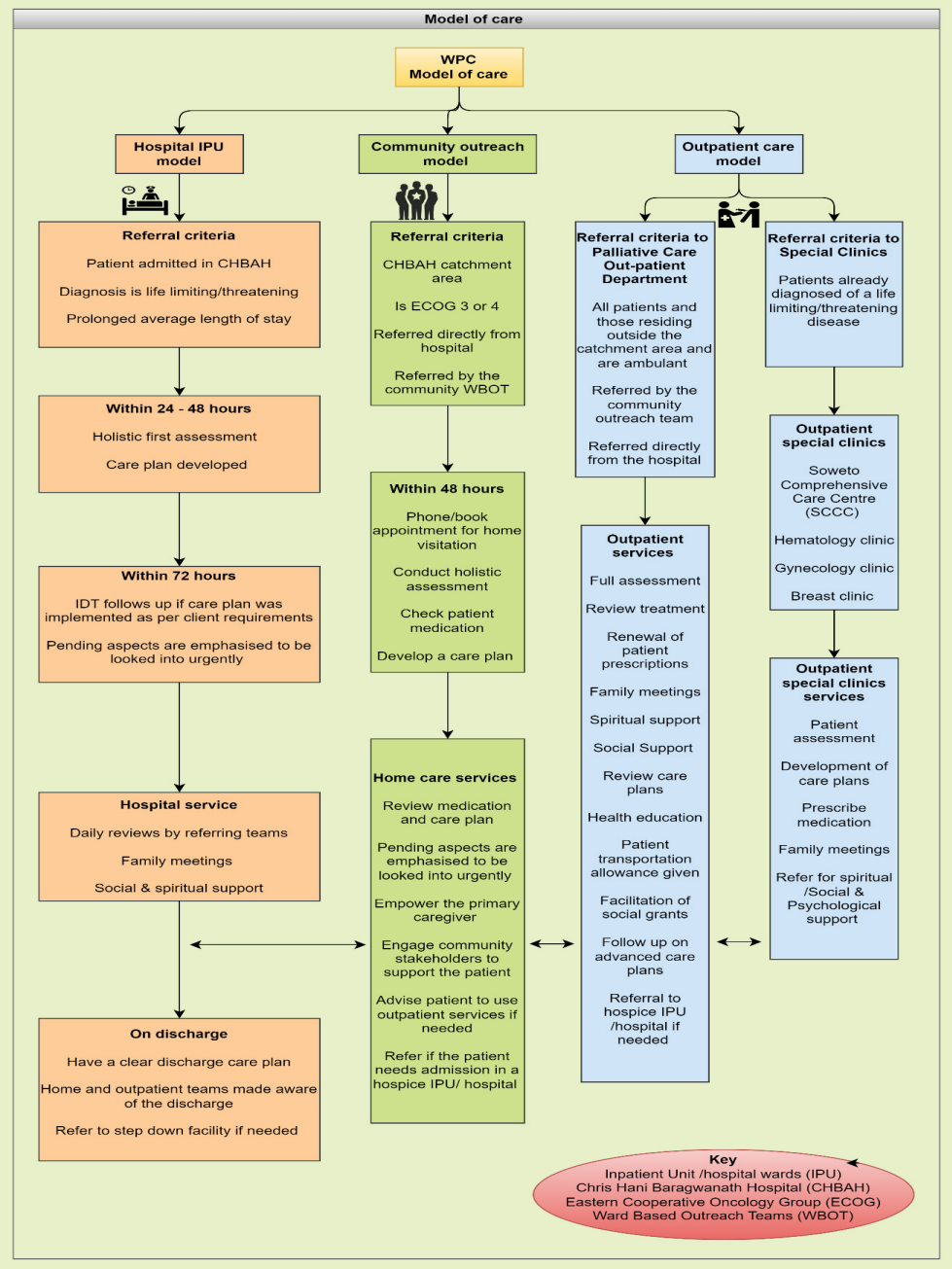

Figure 1: WPC model of care.

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Hospital Inpatient Unit model

The collaborative effort between WPC and CHBAH embodies a synergistic approach to delivering palliative care services within the hospital. It prioritises patients with life-threatening illnesses like cancer, irrespective of their performance status. The process begins with a referral from CHBAH wards to WPC, followed by dispatching an interdisciplinary team (IDT) of doctors, nurses, social workers, and spiritual counsellors (chaplains) to the different wards at CHBAH. An initial assessment within 24-48 hours is comprehensive covering all aspects (physical, social, emotional, and spiritual) leads to a formulated care plan in partnership with the patient and the referring team of doctors. Follow-ups within 72 hours aim to achieve care plan objectives. Reviews cover physical, psychosocial, and spiritual dimensions based on patient needs and preferences. Discharge planning considers various options, including home care and transitional facilities, based on patient and family wishes, with access to necessary medications and support systems guaranteed by the IDT.

Community outreach model

The Community Outreach Model focuses on patients with Eastern Cooperative Oncology Group (ECOG) performance statuses of 3 or 4, with life-threatening illnesses, in Regions D (Soweto) or G (Orange Farm) (Figure 2), referred by Ward Based Outreach Teams (WBOT), WPC IDT, or CHBAH wards. Upon referral, the home care team contacts the patient within 48 hours for scheduling a home visit, typically conducted within 72 hours of referral. The IDT, including physicians, nurses, social workers, psychologists, drivers, and spiritual counsellors, conducts the assessment and consultation in the home of the patient. A tailored care plan is developed in collaboration with the patient, addressing medication, psychosocial, and spiritual needs at home. If needed, community mapping identifies local resources like social services, financial institutions, and transitional care facilities. The home care service relieves pressure on CHBAH wards and prevents unnecessary hospitalisations, promoting a better quality of life. Patients needing ongoing support are directed to WPC outpatient services for continued care and management.

Figure 2: WPC catchment area map [16].

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Palliative Care Outpatient care model

The Palliative Care Outpatient Care Model is a crucial part of palliative care, supporting patients previously seen in CHBAH wards and Community Outreach. WPC has an outpatient (OPD) clinic that provides care to all patients as needed. The OPD is run by a professional nurse and is supported by a palliative care doctor.

Palliative care teams also support special clinics within CHBAH. This support aims to assist patients and families by providing easy access to care in special clinics (Oncology, Haematology, Gynaecology, Breast, Motor Neuron Disease). Services provided in these clinics include seeing newly diagnosed patients, addressing unscheduled care needs, revising care plans, and meeting additional requirements specified by the patient or family. This service is vital as it improves the quality of life by offering immediate access to CHBAH clinical and pharmaceutical services. Additionally, the outpatient service offers access to social grants, legal aid, medical consultations, spiritual and psychosocial support.

Policy Driven Processes and Strategies of Amplifying Palliative Care Services

WPC model of care key strategies

To achieve a comprehensive care model, the WPC utilises five strategies which are Collaboration, Clinical Services, Training, Research, Advocacy and Awareness. These strategies collectively aim to provide equitable and high-quality palliative care to diverse populations.

Training/capacitation

Both the African Palliative Care Association (APCA) and World Health Assembly Resolution 67.19 advocate for addressing the shortage of palliative care-trained healthcare workers in Africa through basic and advanced training, mentorship, and conferences [3]. This aligns with the South African National Policy Framework and Strategy for Palliative Care (NPFSPC), which mandates palliative care training for all healthcare workers [17]. The WPC, following WHO guidelines, focuses on different training initiatives. These initiatives encompass basic, intermediate, and specialised training programs, emphasising the importance of capacity building in palliative medicine [17-21].

Undergraduate training

The WPC, as a Centre under the University of Witwatersrand School of Clinical Medicine, offers palliative care training to medical students from year 3-6 through the Graduate Entry Medical Program (GEMP) program. This training covers various aspects including principles of palliative care, pain management, communication, spiritual and psychosocial care. Additionally, undergraduate training is provided to clinical associates students in their second year. These programs equip students with skills to provide holistic care to patients and families with life-limiting illnesses.

Postgraduate training

This training encompasses the training of qualified health care practitioners undergoing specialist training. Currently, MSc Physiotherapy, registrars in family medicine and radiation oncology receive palliative care training as part of their curriculum.

In service training

The WPC offers foundational five-day in-service training targeting healthcare workers like allied professionals, nurses, social workers, and general practitioners. Modules cover palliative care principles, psychosocial, spiritual, and physical care domains, with additional courses focusing on spiritual care provision. These courses attract various professionals including faith-based leaders and government officials interested in holistic patient-centred care. Recognising limited access to such training, the WPC extends this in service training to other provinces and countries in Sub-Saharan Africa, aiming to empower healthcare workers. Through collaborations and platforms like the Extension for Community Health Outcomes (ECHO), expertise is shared, and best practices disseminated, benefiting countries including Tanzania, Kenya, Zimbabwe, Lesotho, Eswatini, Mozambique, and South Africa.

Research

Research is crucial for evidence-based palliative care, yet developing countries receive disproportionately low research funding [22]. The NPFSPC 2017-2022 emphasizes research-driven services to enhance policy and clinical practice, aligning with global health priorities [17].

The WPC boasts a cadre of accomplished palliative care specialists and academics. Since inception, over 60 research articles have been published, garnering a combined total of more than 1870 citations and 41,576 reads. Research priorities of the centre encompass various domains as illustrated in Figure 3 below.-

Equitable access to comprehensive clinical palliative care services

To ensure equitable access to comprehensive palliative care, services were expanded to different specialised clinics. Other measures include establishing introducing tools to ensure standardized care practices, advocacy presentations to improve referrals, patient empowerment initiatives, and new staff orientation sessions. Comprehensive initial consultations occur within 24 hours of referral, offering care provided by an interdisciplinary team (IDT) covering the physical, emotional, social, and spiritual components. Beyond the IDT, collaboration is fostered with other disciplines to ensure holistic person-centred care, alongside the implementation

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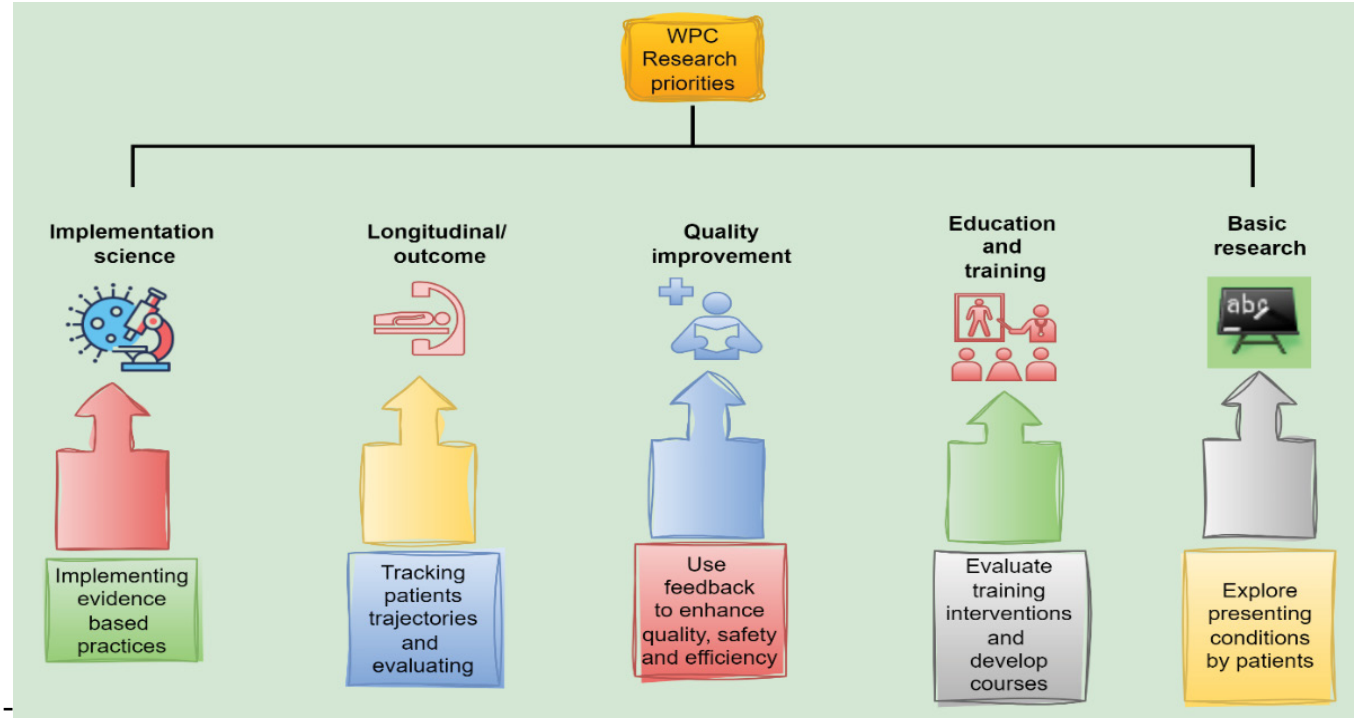

Figure 3: WPC research priorities.

of standardised referral criteria, facilitating seamless care delivery from the hospital setting to the home of the patient.

Components of palliative care services provided

Physical Interventions

WPC employs evidence-based symptom management, blending pharmacological and non-pharmacological methods. Systematic assessment and symptom management are prioritised. Rehabilitation services, overseen by the IDT improve patient functioning. Individualised nutritional support is provided to meet each patient's nutritional needs.

Social Support Services

Social work services coordinate resources, advocate for patients, and provide practical assistance for financial and social concerns. Support includes accessing social grants and essential documentation, family therapy, placements, counselling and advocating for patients. Advanced care plans are developed, with referrals to facilities such as hospices and legal services.

Spiritual Interventions

Spiritual assessments are conducted to address patients' beliefs and existential concerns. Trained chaplains conduct spiritual care assessments before developing a care plan that may include offering spiritual counselling, prayers, and religious rituals tailored to diverse faith backgrounds, promoting comfort and guidance. Patients engage in rituals aligned with their spiritual practices, fostering reconciliation.

Emotional Support

Counselling interventions by psychologists and social workers provide emotional support and coping strategies for patients and families. Grief and bereavement services assist individuals in navigating loss, promoting emotional healing and resilience throughout the grieving journey.

Advocacy, awareness, and communication

South Africa, aligned with WHA 67.19 Resolution, commits to integrating palliative care into public health systems [17,23]. Palliative care is recognised as a fundamental international human right [1]. With these established policies, treaties and mandates regarding palliative care serving as benchmarks for service delivery, the WPC utilises these instruments as standards to advocate for essential resources, thereby aiming to ensure universal accessibility to palliative care. The WPC utilises various advocacy platforms as illustrated in Figure 4.

Collaborations

Palliative care interventions, grounded in the WHO`s Public Health model and Health Systems Agenda, offer organisations and national health programs significant potential for delivering high-quality palliative care services [24-26]. Palliative care, encompassing various facets of life including spiritual, physical, and psychosocial components, necessitates seamless collaborations to enhance the quality of life for patients and their families [27,28]. Responding to this

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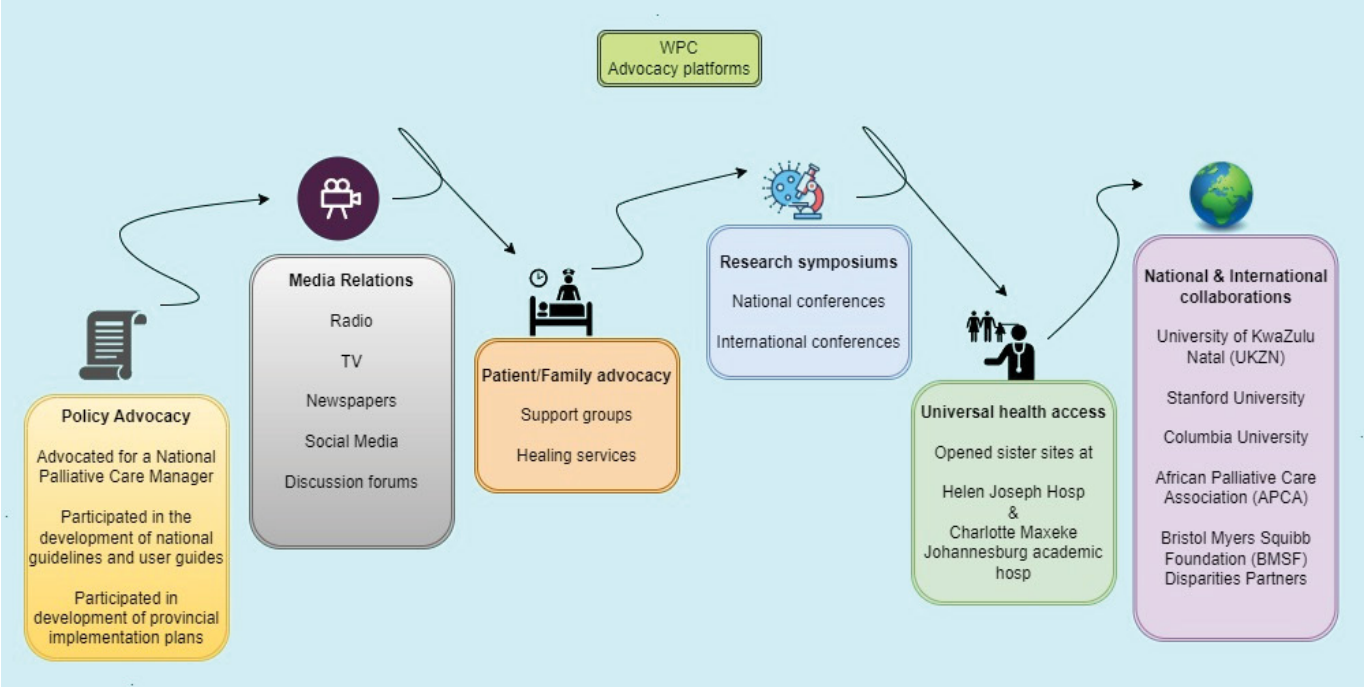

Figure 4: Advocacy platforms.

imperative, the WPC has forged numerous collaborations to ensure patients have access to care when needed.

Robust Monitoring and Evaluation Systems (M&E)

The WPC has implemented robust M&E systems since its establishment in 2008. Initially, the centre relied on a paper-based M&E systems. However, as of 2021, the WPC has transitioned to an electronic system using REDCap [29]. This software enables real-time data capturing, facilitated by the provision of tablets to 95% of the IDT members. The captured data is securely stored in a server hosted at the University of Witwatersrand, allowing for easy accessibility and visibility to the entire team. Furthermore, the REDCAP system includes built-in checks to ensure data completeness, such as flagging missing demographic or diagnosis information during data entry. Additionally, the system is equipped with reminder functionalities to alert IDT members of pending tasks. The data components within the system includes demographics, clinical characteristics and treatment, palliative care symptoms and outcomes, social, emotional and spiritual assessment questions and interventions. Quality of life is measured using the WHO quality of life tools to ensure comprehensive monitoring and evaluation of palliative care interventions [25,30,31].

Program Outcomes

Program outcomes highlight significant achievements, including the comprehensive management of over 3000 patients' visits annually, to ensuring that they have access to holistic care as means of enhancing their quality of life.

The aim of home care is to provide palliative care in the home of patients and provide support to enable patients die in the place of choice, which is home for most patients. Without home care services, most patients are admitted and die lonely in hospitals. Most patient deaths occurred in hospitals since 2021 as the home care services declined in the community since 2020 due to Covid 19.

Moreso, the integration of palliative care training into undergraduate medical education, as well as postgraduate training for family physicians and radiation oncology registrars, reflects a commitment to capacity-building. Structured in-service training sessions extend across South Africa and other African nations, contributing to enhanced expertise among healthcare professionals. Key contributions also include the development of policies, clinical guidelines, and curricula aimed at advancing palliative care practices in South Africa.

Lessons Learned And Model Replicability Potential

The WPC faces significant challenges hindering its mission to provide comprehensive palliative care services. Unsustainable funding led to the closure of critical programs like the paediatric program and services at sister branch, the Helen Joseph Hospital. High demand for services, coupled with patients from diverse regions seeking care at CHBAH, strains resources and pressures WPC. Integration of palliative care into the public health sector remains incomplete, impacting accessibility and continuity of care in stepdown facilities.

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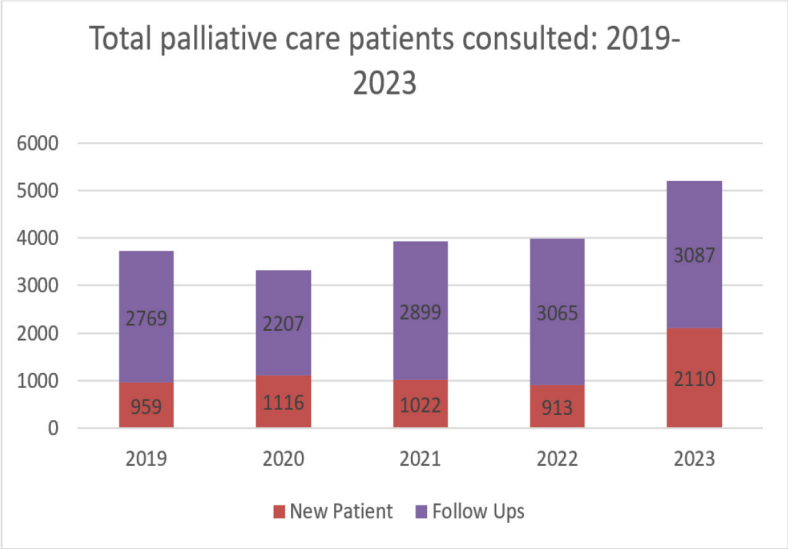

Figure 5 illustrates the breakdown of patient consultations over the five-year period.

Figure 5: Total patient consultations (2019-2023).

Scarcity of step-down referral facilities due to closures from funding challenges further hampers comprehensive care provision. Limited uptake of training opportunities due to financial constraints restricts capacity building efforts. Late referral for services exacerbates challenges, as patients often present at advanced illness stages, and most die without having accessed palliative care. Lack of a standalone in-patient unit due to funding constraints forces WPC to utilise general hospital wards, potentially compromising patient care. Addressing these challenges is essential to enhance palliative care accessibility and quality.

Conversely, WPC's integration within CHBAH underscores the importance of prioritising patients with life-threatening illnesses and fostering interdisciplinary collaboration within the hospitals, in support of IPU models. The Community Outreach Model, offering tailored care plans and home visits, eases pressure on hospital facilities and enables community support for palliative care patients. The Outpatient Care Model enhances patient well-being by providing easy access to specialized clinics and support services. Emphasising training initiatives and evidence-based research strengthens capacity building and informs healthcare practices. Robust monitoring and evaluation systems ensure intervention quality and effectiveness. This collaborative model exhibits high replicability potential, contingent upon collaboration, funding, trained healthcare personnel, community support, and empowerment, making it adaptable to diverse regions.

Limitations

The model did not consider patients and family viewpoints.

Acknowledgements

- Gauteng Department of Health
- Chris Hani Baragwanath Academic Hospital
- University of Witwatersrand, Faculty of Health Science, Palliative Care Advisory Board
- Personnel of Gauteng/Wits Centre for Palliative Care
- Bristol Myers Squibb Foundation

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