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REFLECTIONS

Unwalling the clinic: Redefining medicine through palliative care

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Abstract

This reflective essay explores my experience as a nonmedical volunteer at a palliative care centre, in Elamkulam Panchayat, in the Malappuram district of Kerala for two weeks in October 2023 as a master's student of Medical Humanities. It examines how palliative care functions in a community setting, addressing the needs of terminally ill patients. Through direct observations and interactions, I reflect how the decentralised, interdisciplinary and flexible nature of palliative care service transcends some limitations of modern clinical medicine, offering a holistic approach that embraces individual subjectivity, challenges hierarchical structures, and fosters a profound, compassionate connection with patients

Keywords: *palliative care, end-of-life care, terminal illness, care ethics, quality of life*

Palliative care traces its roots to the hospice movement initiated in the 1960s in the United Kingdom (UK) by Cicely Saunders to address the neglect faced by terminal cancer patients from hospitals marked by prolonged period of physical pain, suffering and social isolation [1]. Hospices were initially administered by the clergy and focused on nurses' care [2]. While the hospices offered vital support, their resource-intensive nature limited access, leading to the development of a decentralised home care model, more economical and better suited to third-world countries lacking infrastructure for standalone hospices. Palliative care reached India in the 1990s and was introduced to Kerala, with the setting up of the first Palliative Clinic at Calicut Medical College in 1993 under the leadership of Dr MR Rajagopal [1]. In Kerala, palliative care advanced in both sophistication and social efficiency with the introduction of the innovative Neighborhood Network Palliative Care (NNPC), based on homecare services, in the northern district of Malappuram in 1996, facilitating Kerala to become the state with maximum palliative care coverage in India as well as among third world [3]. This model, known as the Malappuram model/Kerala model of palliative care, serves as a beacon of efficiency and advancement in the realm of healthcare and acts as a prototype that has been recognised internationally and successfully adopted by other third-world countries [1].

Malappuram's palliative care system thrives on a unique blend of community collaboration. It adopts a multidisciplinary approach inviting volunteers outside the field of medicine, making it rounded and humanitarian. The model operates through two branches: palliative units managed by local government and those run by community-based organisations [4]. However, despite the difference in administration, the care that they offer is provided to all, irrespective of class, caste, and religion. Palliative care, particularly as it is organised in the Malappuram district, marks a perfect collaboration of medicine and humanities that slowly erases the strong demarcation between the two fields, seeking physicians to treat the patient as a whole rather than to symptoms alone, and cultivating a humanitarian work ethic [5].

The palliative unit I volunteered with, managed by a non-governmental organisation, was based in Elamkulam Panchayat of Malappuram district. During my first visit to their palliative care centre, I saw an unassuming, single-story structure, with two ambulances bearing the inscription "Home Care" and the contact details of the centre, parked outside. There were a few stretchers and wheelchairs kept in another corner of the parking lot. The building comprised two rooms — one functioned as a storeroom housing essential medications and equipment, while the other served as the administrative office, where meticulously maintained files and registers were kept. On entering, my instinctual search for a segregated doctor's cabin, as seen in any other medical institution, was subverted. Instead, the office featured a communal arrangement — a long rectangular table at its centre, surrounded by chairs, where the doctor, nurses, driver, and volunteers of the palliative centre administration convened. This egalitarian setting deviated from the traditional hierarchical structure, seen in conventional medical institutions. I learnt that no form of patient consultation takes place at this building, all interaction unfolds at their homes. Unlike hospices offering centralised care, here palliative care follows a home care model, with the palliative team carrying the necessary supplies door to door. What stood out most to me, was the breaking away from separate and rigid institutional or architectural space: the hospital comes to the patient.

I discovered another vital characteristic that separates palliation from other fields of medicine, its origin as a nurse-centric system, granting nurses elevated autonomy and agency compared to other medical institutions that I have come across. Within the centre, I have noticed how the discussions of patient reports, visitation rounds, and necessary supplies unfolded as a collaborative effort, with nurses having comprehensive knowledge of each patient's health chart and conditions as they engage with the patients more frequently. The doctors, nurses, and volunteers complement each other's roles, working together to achieve comprehensive care by fostering a secular and egalitarian workspace. This collaborative approach breaks down traditional power dynamics and hierarchies, ensuring that every team member's contribution is valued equally. As the palliative care team arrives at the patient's residence, the doctors handle prescriptions, while the nurses provide essential medical and sanitary care, such as dressing wounds, changing urine tubes, adjusting external support machines like oxygen supplies, administering medications, and assisting with personal needs like bathing. Volunteers, in addition to helping nurses with physical tasks like moving or carrying bedridden patients, play a key role in offering emotional support. They engage patients in conversation, bring in laughter, and foster a positive atmosphere, aiming to provide total care that nurtures the human spirit.

Unlike the sterile and impersonal environment of hospitals, where the rigid architecture and a clinical atmosphere create feelings of alienation, home-based care allows patients to retain a sense of comfort and individuality, so essential in the sensitive end-of-life phase. In hospitals, the moment a patient is admitted, they are subjected to a narrow, detached, and objective medical gaze, which erases their personal identity. As consultations progress, the patient's name often fades into the background, replaced by a register number or diagnosis. The illness begins to overshadow their individuality. The way this depersonalisation affects the patient's experience of illness really caught my attention. I have often noticed how in many hospitals, they name wards and departments after attending physicians, elevating the prominence of the doctor, the doctor's identification overrides the identity of the individual seeking healthcare, who is reduced to the title of "patient", during consultations. One will come across repetitions of phrases like, "patient's family", "your patient", "patient no." etc during consultations; very rarely is the individual addressed by their name — a glaring example of the power dynamics that control contemporary medical settings.

This language of modern medicine is characterised by objectivity and distance, often disregarding the subjective experience of the patient and adopting a dehumanising perspective. The profession necessitates a precise and scientific gaze, rooted in an understanding that cannot be swayed by emotional considerations. However, such an approach proves inadequate, particularly when individuals are confronted with the inevitability of death. In the context of terminal illness, deteriorating health, and imminent mortality, patients no longer seek seclusion, isolation, or relentless medical interventions. Some of the patients that I came across under palliative care simply despised or were scared of hospital visits, a constant reminder of their deteriorating health. And those who have come to terms with their reality often want to spend their remaining time in their comforting space, surrounded by family and friends. I recall an elderly woman sharing that her only desire is to peacefully conclude her journey in the same bed where her late husband had rested. The end of life is a period of extreme vulnerability and heightened emotion, demanding a medical care paradigm that transcends the clinical distance, approaching the patient with unwavering compassion. This palliative care model transforms the patient's residence into an extension of the hospital. In this shift, the patient's name becomes synonymous with the house and its address, preserving their individual identity.

In the home care model, it is impossible to cancel subjectivity when the caregiving team is entering the home, a private space. Each home inhabits its own socio-economic and cultural background. The palliative team attempts to pay attention to the intricate and intimate details of each household and to evolve into a flexible approach to medicine both in structure and functioning, expanding the bandwidth of care. I recall a moment when the palliative team gathered outside a home, patiently waiting as a caregiver performed her evening prayers. This simple act underscored the respect for personal rituals and beliefs that is central to the nature of care they provide. I find this aspect of palliative care particularly powerful. The diverse cultural practices across different communities necessitate a caregiving model that is sensitive, adaptable, and deeply personal. Unlike the secular and objective nature of hospital care, palliative care is inherently relational, honouring the distinct identity of each household and each patient's sense of self and of comfort in their faith.

Once I witnessed my fellow volunteers checking grocery baskets in a household that falls below the poverty line, ensuring families were not burdened by scarcity and, if necessary, reaching out to local charities for support. I was struck by this poignant realisation that in a hospital setting, the doctor's duty often ends with writing prescriptions like "have one tablet after a meal". The system almost never bothers to question if the patient has enough resources to have that meal. The non-medical volunteers bring the human touch to the palliative system and shift the focus from cure to profound commitment to care that acknowledges individual subjectivity and assures quality of life as well as quality of death. Over the course of the treatments, the volunteers developed a really strong bond and a heightened sense of trust with the patients. I saw how the patient's eyes lit up and a smile appeared on their face, as the team arrived, even as they suffered chronic pain. One patient shared how he eagerly waits for Tuesdays for the palliative team to arrive, saying, "Unlike any other visitors, it feels like they're the only ones walking into the room genuinely interested in spending time with the person I am now, than searching for my prior healthy self before diagnosis". This sense of caring is not limited to the patient. Providing care particularly long-term care in case of chronic illness can be physically and emotionally exhausting for the caretaker especially for women who are expected by society to be the primary caregivers. The palliative team through their presence and support, are reducing the weight of caregiving of the immediate family. Many times, I encountered doctors or nurses asking the primary caretakers of the patient about their health and mental well-being, and always maintaining a cordial and empathetic relationship with the family.

While the palliative care model in Mallappuram thrives on the strength of neighbourhood networks and the goodwill of local volunteers, it is not without challenges. From my limited experience, I noticed that a primary challenge of this model is its reliance on charity and public voluntarism, which results in an inconsistent flow of funds and resources. Most non-medical volunteers contribute part-time based on their availability, leading to fluctuating attendance, occasionally delaying provisions of medications or essential resources. Moreover, small palliative teams especially in rural areas, struggle to meet the rising number of patient registrations with visits restricted to once or twice a week. This episodic nature of care leaves families or caregivers as the primary providers, highlighting the need for sustained funding and expanded volunteer engagement. The nurses I interacted with also revealed that the limited funding significantly impacts their salaries. Despite performing tasks akin to those in hospital settings, they face the added challenges of providing care in patient's home — environments far removed from the sterile, controlled conditions of a hospital. Yet their labour is often undervalued, both socially and financially, with compensations falling markedly short compared to their hospital-based counterparts. This disparity highlights a critical limitation in the system, underscoring the neglect of their vital contributions.

Yet, amidst these constraints lies an unwavering commitment and resilience. I witnessed the palliative care team navigating landscapes that mirrored the fragility of the lives they touched — along narrow lanes, and over broken, rough roads. They walked where vehicles could no longer venture, undeterred by scorching sun or relentless rain. One family told me that even during the isolation of the Covid-19 pandemic, when the rest of the world retreated and care seemed impossible, this team remained steadfast, providing care while observing all the precautions, physically or virtually in whatever way possible. While society paused, these caregivers reached out, embodying the very essence of the palliative care model — holistic, relentless, and deeply human. In these intimate exchanges, I discovered that palliative care is not merely a profession, but a profound journey of connection, compassion, and shared humanity.

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