

TRANSFORMING THE LANDSCAPE OF COPD CARE: BREATHING WITH PURPOSE

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COPD casts a long shadow on millions of lives worldwide and is a leading cause of morbidity and mortality in Pakistan as well. The diagnosis is grim, and the treatment plan is a drapery woven with threads of expensive medications and specialized interventions. It has generated not only individuals but a community struggling with breathlessness, declining lung function, long term oxygen dependence and repeated hospitalizations. Despite its vast toll, the crucial aspect of care remains woefully underutilized-the palliative care. Palliative care flickers into existence, but even that whispers tales of limitations: resources scarce, care fragmented, access a cruel lottery.¹

Palliative care has always been taken as solely end-of-life support, practically and as a perspective, that led to keeping COPD management, like many other diseases, away from integration. The World Health Organization recognizes it as the active total care of patients whose disease is not responsive to curative treatment², which certainly describes the ultimate care for patients with COPD. Palliative care is a holistic approach incorporating emotional, social, physical, and spiritual needs together not just at the end of life but throughout the journey. It aims to improve the quality of life of patients and their families through effective patient- and family-centered communication, identification of the patient's goals of care, shared decision-making, and advanced care planning.

It can have a transformative impact if we embrace it in its true essence.

It must aim to:

Struggling with end-stage COPD in a resource-scarce world, the dream of enjoying a meal without gasping for air seems a futuristic fantasy. While access to cutting-edge therapies remains elusive, optimized oxygen therapy and tailored symptom management steadily transform lives, even in the heart of third-world nations like ours. The harsh wheezing has to be replaced by the gentle clinking of forks against plates - that's the transformative power of symptom management.

Alleviating the symptoms wouldn't just rewrite their story but will pave a way to improved quality of life for her entire family, and each shared breath a testament to the transformative power of even the most basic care.³

Gone are the days of veiled truths instead, open dialogue should center stage, with patients empowered to navigate the illness with a map of their own making. A dedicated palliative care team, their presence akin to a steady lighthouse, guiding the way. This anticipated shift in paradigm, from paternalistic pronouncements to empowered choices, is not merely a theoretical construct. It will be a revolution rippling through the very fabric of healthcare, reaching even the most resource-constrained corners of the world. In developing countries, where access to cutting-edge treatments is limited, the focus on symptom management, emotional support, and open communication is even more crucial and should be counted on.⁴

With the physical health, mental well-being and resilience stand at the forefront of the fight against COPD. The benefits of establishing and maintaining COPD support groups extend far beyond the confines of the meeting room. The sense of belonging fosters a renewed sense of purpose, encouraging patients to engage in self-care and treatment adherence. Of course, access to quality palliative care remains a challenge in our country, particularly in under-resourced communities. However, the very essence of the support group model lies in its adaptability. Online forums, phone-based networks, and even community-based outreach programs can bring the solace of shared experiences to those who lack traditional access. These COPD support groups would be testament to the power of human connection and a reminder that in the face of chronic illness, we are not alone. We are part of a shared journey where understanding and empathy pave the way for a future.⁵

The journey towards ensuring adequate respite care for COPD caregivers is ongoing, demanding advocacy and resource allocation. By recognizing the immense burden on caregivers and providing them with the support they deserve, we can intertwine a future where the melody of care is not one of burnout but of shared resilience. We need to push for policies which would propose for educational programs to empower caregivers and support networks that cradle them in times of need. The compassion extends beyond the patient's

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bedside, encompassing the caregiver's weary heart and ensuring that their journey, too, is one of dignity and hope.

However, integrating palliative care into COPD management presents challenges. Lack of awareness among healthcare professionals, limited access to specialists, and the persistent misconception of its relevance beyond terminal stages are formidable barriers.⁶ To bridge this gap, we need a multi-pronged approach including:

Incorporating palliative care early in the disease trajectory is mandatory. It should not be just during exacerbations or late stages, but regularly to allow for proactive symptom management and timely intervention. This can be achieved through routine screening for palliative care needs during clinic visits and dynamic referrals to specialized teams.⁷

Equipping healthcare professionals with the knowledge and skills to identify and address palliative care needs in COPD patients is of prime importance. The knowledge gap can be bridged with integrated modules for teaching and training of the primary and specialist health care teams.

Investing in dedicated palliative care teams and services tailored to COPD patients will ensure timely access to expert care. Policy changes and increased funding are needed to make this vision a reality.⁸

Advocacy and funding for research on the effective palliative care models in COPD are essential for driving systemic change. Robust research data can inform policy decisions and pave the way for broader implementation from community to country.⁹

This is not just a story of COPD and palliative care; it is a call to arms, a demand for a reimagined landscape where the right to breathe transcends socioeconomic borders, where the tapestry of care is woven with threads of compassion and equity. COPD patients deserve more than medication, they deserve comprehensive care. For those whose lungs struggle for purchase on life's thin air, let this winter wind carry a promise – that their stories will not be lost in the shadows, that their right to dignity, to comfort, to a final breath drawn with peace, will become the compass guiding our actions and shaping our healthcare systems. Palliative care is not a luxury; it is a right for those living with COPD. By dismantling the walls of stigma and allowing palliative care to empower the COPD breaths, we can finally offer patients and their families the holistic support they deserve. To alleviate the hardships associated with end stage COPD we have to incorporate the palliative care earlier into trajectory of illness without waiting for the

terminal stages. We can rewrite the narrative and ensure that no one with COPD faces their journey alone. We can make palliative care a breath of fresh air for those living with COPD. We can make the breathlessness of COPD, a thing of past. We can breathe with the purpose of making it easier for them to breathe

DECLARATION

CONFLICT OF INTEREST

The author has no conflict of interest.

REFERENCES:

1. Iyer AS, Sullivan DR, Lindell KO, Reinke LF. The role of palliative care in COPD. *Chest*. 2022 May 1;161(5):1250-62
2. World Health Organization. World Health Organization definition of palliative care. World Health Organization Website. Available online: <http://www.who.int/cancer/palliative/definition/en>. 2014.
3. Seamark DA, Clare JS, Halpin DM. Palliative care in chronic obstructive pulmonary disease: a review for clinicians. *Journal of the Royal Society of Medicine*. 2007 May; 100(5):225-33.
4. Vermylen JH, Szmuilowicz E, Kalhan R. Palliative care in COPD: an unmet area for quality improvement. *International journal of chronic obstructive pulmonary disease*. 2015 Aug 6;15:43-51.
5. Almagro P, Yun S, Sangil A, Rodríguez-Carballeira M, Marine M, Landete P, Soler-Cataluña JJ, Soriano JB, Miravittles M. Palliative care and prognosis in COPD: a systematic review with a validation cohort. *International journal of chronic obstructive pulmonary disease*. 2017 Jun 9;17:21-9.
6. Yohannes AM. Palliative care provision for patients with chronic obstructive pulmonary disease. *Health and quality of life outcomes*. 2007 Dec;5(1):1-6.
7. Fu Y, Mason A, Boland AC, Linklater G, Dimitrova V, Doñate-Martínez A, Bennett MI. Palliative care needs and integration of palliative care support in COPD: a qualitative study. *Chest*. 2021 Jun 1;159(6):2222-32.
8. Faes K, De Frène V, Cohen J, Annemans L. Resource use and health care costs of COPD patients at the end of life: a systematic review. *Journal of pain and symptom management*. 2016 Oct 1;52(4):588-99.
9. Reinke LF, Meier DE. Research priorities in subspecialty palliative care: policy initiatives. *Journal of Palliative Medicine*. 2017 Aug 1;20(8):813-