

Palliative Rehabilitation: The Essence of Personalized Care

“The work of all the professional team is to enable the dying person to live until he dies at his own maximal potential performing to the limit of his physical and mental capacity with control and independence wherever possible.”

–DAME CICELY SAUNDERS

Patients with advanced life-limiting illnesses experience the symptom burden of varying severity through the continuum of their illness trajectory. These symptoms negatively impact and impair the normal functioning of the individual.^[1] This ongoing impairment in normal functioning leads to debility, if left unaddressed disables the patient due to increased dependency, psychological distress, neurological and musculoskeletal deconditioning. Progressive disease leads to a cluster of new symptoms such as pain, fatigue, dyspnea culminating in further decline in performance status, decreased activity of daily living (ADL), and significant reduction in the quality of life (QOL) of patients and caregivers.^[2] The importance of comprehensive medical care has been established well, with the two critical components of personalized care being palliation and rehabilitation. At the outset, it may seem the most unlikely combination – palliative care being commonly associated with care of patients with life-limiting illness and dying, while rehabilitation being commonly associated with recovery and full functionality. The relevance of integrating both the specialties as part of the interdisciplinary team is evident from the ethos governing both the services at improving the comfort and functionality,^[3] in keeping with the personal goals of patients and family.

Early introduction of palliative care at the onset of a life-limiting illness is evidenced to improve both the QOL and longevity of life and rehabilitation as the other side of the coin, enhancing the functional independence of the patient leading to improved ADL. Thus, they are interdependent fields of personalized care, helping the patient and family achieve the best QOL, enabling them to be as active and productive as possible regardless of life expectancy.^[4]

There are different concepts of palliative rehabilitation based on the clinical application and relevance to the goals of intervention.^[5]

Restorative rehabilitation, the commonly known and widely utilized application, is aimed at complete to near-complete functional recovery and ability post and injury or a surgical intervention.

Preventive rehabilitation, an approach to prevent possible functional deterioration in patients due to the burden of disease or its treatment, encouraging them to actively participate in the ADL, maintaining QOL.

Supportive rehabilitation is focused care on patients with impairments of functionality in ADL secondary to their

progressive frailty. The goal is to maintain self-care and maximize independent functionality. The approach is prevention of disuse secondary to disability.

Palliative rehabilitation is aimed at patients in the terminal stages of illness. It supports the adaptation of ADL to maintain the best independence physically, with emotional and social backing, to lead a high QOL while respecting their wishes. Rehabilitation intervention in this setting is designed to relieve symptoms, such as pain, dyspnea, and edema, and to prevent contractures and decubitus ulcers, correct positioning, breathing assistance, relaxation, or the use of assistive devices.

Palliative rehabilitation has been gaining a lot of attention in recent years globally. There have been numerous studies that have dealt with the effectiveness of various rehabilitative interventions, and all demonstrated the positive impact of rehabilitation on fatigue, anxiety, mood, physical symptom such as pain, functional status, and the overall QOL. The readiness of acceptance of rehabilitation is more in some malignancies, such as head-and-neck cancers, than in others. Studies have been conducted in varied places of care such as inpatient setting, home care, and hospice, and the results have all shown a positive impact of integration of rehabilitation and palliation. A systematic review in 2015^[6] and 2017^[7] showed that physical exercise, though not easily accepted as a treatment modality for fatigue, shows a significant improvement in QOL, mood, and general well-being when implemented among advanced cancer patients. Education regarding palliative rehabilitation among patients and caregivers has shown better compliance to management and improvement in physical and sexual health of the patients. Palliative rehabilitation for advanced respiratory/cardiac disease, neurological conditions, and dementia is well evidenced. All interventions are individualized and needs assessment is done on a regular basis, taking into consideration the day-to-day variability in the physical and psychological functions of the patient.^[8]

Palliative rehabilitation is provided by an interdisciplinary group of professionals. Rehabilitation encompasses the specialist rehabilitation by the allied health professionals who would be guided by a physiatrist. Occupational therapist, physical therapist, nutritionist, psychologist, speech and language therapist, swallowing therapist, and nursing are a few named allied health professionals.^[1]

Planning for palliative rehabilitation should begin with a comprehensive assessment that establishes the requirements based on the individual's current performance, previous level of functioning, and the potential for functional improvement. The personalized plan for palliative rehabilitation is “person centered” based on the individual's disease

stage, prognostication, symptom burden, comorbidities, cognition, their physical/psychological well-being, and their personal expressed goal of maintaining functionality. The comprehensive assessment includes place of care such as hospital inpatient, outpatient, or home based, as this would determine the intensity of palliative rehabilitation. A clear understanding of the support system available and financial resources of the patient completes this assessment.

The evidence-based functional assessment tools used in palliation and rehabilitation should be used by the performing team and a specific therapy protocol planned as an interdisciplinary approach for each patient.

The therapy initiated and performance improvement determines the ongoing therapy plan that is appraised, modified, and adapted based on the changes in the various performance parameters used in assessment.

Early integration of personalized palliative rehabilitation services can improve the patient's overall QOL by improving their functional status, reducing the burden of care for family. Improved functionality enables the patient toward self-management of their own health and well-being, thus improving the overall psychological, social spiritual, and financial well-being of the patient and the carer.

The collaboration of the governing ethos of comforting and improved functionality of the palliative and rehabilitative specialists with the added concept of interdisciplinary care would be the proactive approach to a holistic and personalized multidimensional care.^[9]

CONCLUSION

The early initiation and integration of palliative rehabilitation in a patient with life-limiting disease at all phases of their disease trajectory would be an important weapon at helping them to retain their individuality and personhood.^[10] The personalized palliative rehabilitation is tailor made, each stitch attempting to bring together the individual the patient envisions themselves to be, by a process of enablement and patient-centered goal setting.

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Submitted: 10-Nov-20 **Accepted:** 10-Nov-20

Published: 19-Nov-20

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Access this article online	
Quick Response Code: 	Website: www.jpalliativecare.com
	DOI: 10.4103/0973-1075.300816

How to cite this article: Ramanjulu R. Palliative rehabilitation: The essence of personalized care. *Indian J Palliat Care* 2020;26:399-400.