Evaluating the Impact of Palliative Care on Functional Independence and Quality of Life: A Study from Kasaragod, Kerala, India

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KEYWORDS

Palliative care, Motor functions, Cognitive functions, Functional Independence Measure, Quality of life

ABSTRACT

This study examines the impact of palliative care on functional independence and quality of life (QoL) among patients in the resource-limited setting of Kasaragod district, Kerala. It addresses the critical issue of optimizing palliative interventions to enhance functional capabilities and QoL for individuals with complex health conditions. Using primary data from structured interviews conducted at the Akkara Foundation, a non-profit organization, the functional independence of 30 patients was assessed using the Functional Independence Measure (FIM™), which evaluates motor and cognitive functions. The findings reveal significant improvements in physical independence, with 25 out of 30 patients showing measurable gains. Early intervention, particularly for those with lower baseline FIM™ scores, was instrumental in enhancing outcomes. However, a few patients, including Respondent 6, experienced slight declines in total FIM™ scores (72 to 70), indicating that the progression of complex conditions may limit the efficacy of palliative interventions.While cognitive improvements were observed, they were less pronounced than the gains in motor function, highlighting the complexity involved in addressing cognitive impairments within palliative care settings.Old age emerged as the leading cause of illness (36.7%), underscoring the growing need for palliative care to manage age-related complications and comorbidities, alongside increasing age- and lifestyle-related conditions. Overall, this research affirms the importance of early, comprehensive palliative care strategies in enhancing patient outcomes and QoL, while highlighting the necessity for ongoing research and adaptive approaches to meet the evolving needs of diverse patient populations.

1. Introduction

Palliative care is a comprehensive, patient-centered approach aimed at enhancing the quality of life (QoL) for individuals confronting life-threatening illnesses. It encompasses not only the management of physical symptoms but also addresses the psychological, social, and spiritual dimensions of care [7]. Since its redefinition by the World Health Organization (WHO) in 2002 [3], palliative care has gained global recognition for its pivotal role in improving the well-being of patients with chronic conditions [11, 12], such as cancer, while simultaneously offering vital support to their families [4]. Despite this, significant gaps remain in the literature, particularly regarding the holistic well-being of palliative care patients in specific regional contexts.

The articles by Wu, A., Ruiz Colón, G., & Lim, M. (2022) and Tennison, J. M., Fu, J. B., & Hui, D. (2024) emphasize the importance of integrating palliative care and rehabilitation to enhance the quality of life for patients with advanced cancer or brain metastases. They highlight multidisciplinary approaches that address physical, cognitive, and psychosocial challenges. The tailored rehabilitation interventions and cognitive-behavioral strategies can significantly improve symptom management, functional independence, and overall well-being for both patients and their caregivers, allowing engagement in meaningful activities despite illness progression [5]. In this context this study focuses on the Kasaragod district of Kerala seeks to examine the broader QoL outcomes of palliative care patients, an aspect frequently underexplored in existing research. To assess these outcomes, the study employs the Functional Independence Measure (FIM™), a widely recognized tool for evaluating both physical and cognitive independence. Through this lens, the research aims to address critical gaps in understanding how individualized, multidisciplinary palliative care interventions can enhance patient outcomes.

2. Materials

This study is based on primary data collected through direct interviews with palliative care patients from the Akkara Foundation, located in Kottoor, Kasaragod district, Kerala, founded in 2018, the Akkara Foundation Bekal is a non-profit organization located in Kasaragod, Kerala. The foundation was established with the primary objective of providing medical and psychosocial support to enhance the well-being and rehabilitation of individuals with physical and mental challenges [10]. To obtain comprehensive insights into the patients' experiences, a structured questionnaire was administered, capturing both qualitative and quantitative information regarding their medical conditions, psychological well-being, and socio-economic independence. The assessment of the patients' functional independence was conducted using the Functional Independence Measure (FIM™), a well-established instrument for evaluating disability across diverse populations. The FIM™ is designed to measure the level of a patient's functional independence through 18 specific items divided into two primary subscales: Motor and Cognition.The methodology is comprehensively detailed in the methodology section of the paper.

3. Assessment of Health Issues among Palliative Care Patients under study

This study involved detailed personal interviews with palliative care patients from the Akkara Foundation, conducted through frequent home visits. These interviews yielded comprehensive insights into the patients' health conditions, their levels of personal and social independence, and the challenges they and their families face within the palliative care system. The data collected played a pivotal role in understanding the crucial contributions of palliative care institutions and the multifaceted needs of their patients. Table 1 presents the distribution of various health conditions among the 30 palliative care patients sampled in the study.

Table 1: Distribution Palliative Care Patients by Health Conditions

Health Issue	Number of Patients	Percentage (%)

Schizophrenia	3	10.0
CVA (Stroke)	3	10.0
Hypertension/Diabetes	5	16.7
Parkinson's	2	6.7
Paralysis	2	6.7
Mental Retardation (MR)	2	6.7
Hip Fracture	2	6.7
Dysthymia	1	3.3
Breast Cancer	3	10.0
Psychiatric Issues	1	3.3
Anemia	2	6.7
Memory Loss	2	6.7
Filariasis	2	6.7
Total	30	100

Source: Authors' Calculations Based on Primary Data

The most prevalent condition among the palliative care patients in this study was a combination of hypertension and diabetes, affecting 16.7% of the participants. This underscores the widespread nature of chronic illnesses that necessitate ongoing management within palliative care settings. Additionally, serious conditions such as schizophrenia, breast cancer, and cerebrovascular accidents (CVA) were observed in 10% of the patient cohort, illustrating the complexity of providing palliative care for both acute and chronic conditions. Furthermore, neurological disorders such as Parkinson's disease, mental retardation, and paralysis, along with psychiatric and infectious diseases, contribute to the broad spectrum of medical challenges that must be addressed through a holistic, multidisciplinary approach to care [6]. These findings emphasize the need for individualized, comprehensive treatment plans that are tailored to meet the diverse and intricate health requirements of each patient. The diversity of health conditions reflected in this population highlights the importance of integrating specialized care across various medical domains, including neurological, psychiatric, and chronic disease management, into palliative care services. The results reinforce the necessity for flexible and adaptive care models that address both the physical and mental health needs of patients in a cohesive, patient-centered framework.

4. Duration and Causes of Illness among Palliative Care Patients

The study systematically categorized the 30 palliative care patients based on the duration of their illness prior to receiving palliative care services, as presented in Table 2. The majority of patients (73.3%) had been ill for less than five years before commencing palliative care, indicating that many patients are now receiving palliative interventions relatively early in the course of their illness. This trend suggests an increasing awareness of the benefits of early palliative care, which can lead to more effective symptom management and improvements in overall quality of life (QoL). Early engagement with palliative services can enhance patients' ability to cope with the physical and emotional challenges of serious illness, underscoring the importance of early intervention in palliative care [8].

A smaller subset of patients (13.3%) had been living with their illness for five to ten years prior to receiving palliative care, while 6.7% of patients had experienced their illness for ten to fifteen years. Similarly, another 6.7% had been managing their condition for over fifteen years. These figures reflect a segment of the patient population with long-term chronic conditions who require ongoing care. The data emphasize the need for continuous and sustained palliative support for patients enduring prolonged illnesses, highlighting the crucial role of long-term care strategies in palliative settings.

Table 2: Duration of Illness among Palliative Care Patients

Duration of Illness (Years)	Number of Patients	Percentage (%)
Less than 5	22	73.3
5 to 10	4	13.3
10 to 15	2	6.7
15 and more	2	6.7
Total	30	100

Source: Authors' Calculations Based on Primary Data

In addition to the duration of illness, the study categorized the causes of illness among the patients, as shown in Table 3. Old age was the most prevalent cause, affecting 36.7% of patients, reflecting the increasing demand for palliative care services due to age-related complications and comorbidities. The aging population is a significant driver of palliative care needs, given the complex health conditions that accompany the aging process. As the prevalence of age-related and lifestyle-related illnesses increases, the demand for effective, tailored palliative care services will likely continue to grow, further emphasizing the need for ongoing research and innovation in palliative care practices. Lifestyle-related diseases, such as those caused by poor diet, physical inactivity, and high stress levels, accounted for 20% of the cases. This highlights the profound impact that lifestyle choices have on long-term health and the importance of preventive measures in mitigating the need for palliative care. Accidents were the third most common cause, responsible for 16.7% of cases, underscoring the long-term physical impairments and complications resulting from trauma, which often necessitate ongoing palliative support. Smoking-related illnesses accounted for 13.3% of the cases, underscoring the severe and lasting health impacts of tobacco use. These findings emphasize the need for public health interventions aimed at reducing smoking-related diseases and promoting healthier lifestyle choices. Stroke and alcoholism each contributed to 6.7% of the cases, further illustrating the diverse range of conditions that require specialized palliative care interventions.

Table 3: Causes of Illness Among Palliative Care Patients

Cause of Illness	Number of Patients	Percentage (%)
Old Age	11	36.7
Lifestyle	6	20.0
Accident	5	16.7
Smoking	4	13.3
Stroke	2	6.7
Alcoholism	2	6.7
Total	30	100

Source: Authors' Calculations Based on Primary Data

5. Results and discussions

5.1. Assessment of Functional Independence in Palliative Care Patients: The Functional Independence Measure (FIM™) is a widely utilized and validated instrument designed to assess the physical, cognitive, and socio-economic independence of patients [9]. It is particularly valuable in evaluating the effectiveness of palliative care interventions, providing a comprehensive view of a patient's functional abilities. In this study, FIM™ was employed to assess the functional independence of palliative care patients at the Akkara Foundation in Kottoor, Kerala. Data were gathered through structured interviews using a detailed questionnaire, enabling an in-depth evaluation of each patient's condition. The FIM™ tool

consists of 18 items, divided into Motor and Cognition subscales, with each item rated on a 7-point scale. Scores range from 1, indicating complete dependence, to 7, indicating full independence. The total FIM™ score can range from 18 to 126, offering a comprehensive measure of a patient's functional capabilities. Additionally, the Palliative Outcome Scale (POS) was employed to assess the quality of life (QoL) of patients, addressing both emotional and economic aspects for patients and their families, thus providing a holistic view of patient well-being.

5.2. Methodology

5.2.1. Motor and Cognition Subscales: The FIM™ instrument is composed of two primary subscales: the Motor subscale, which assesses physical activities, and the Cognition subscale, which evaluates cognitive and social skills. Each subscale offers a detailed examination of the patient's functional independence across critical daily tasks.

1. Motor Subscale: The motor component of the FIM™ measures the patient's ability to perform essential daily physical activities, which include:
    - Eating
    - Grooming
    - Bathing
    - Dressing (upper and lower body)
    - Toileting
    - Bladder and bowel management
    - Transfers (e.g., from bed to chair/wheelchair, toilet, bath/shower)
    - Walking or use of a wheelchair
    - Climbing stairs

Table 4:Comparison of Motor and Cognitive Functions in Palliative Care Patients Before and After Admission to a Palliative Care Facility

SL No	Patient	Motor Subscale (Before)	Motor Subscale (After)	Cognition Subscale (Before)	Cognition Subscale (After)	Total FIM (Before)	Total FIM (After)
1	Respondent 1	82	88	16	23	98	111
2	Respondent 2	51	58	22	24	73	82
3	Respondent 3	53	60	19	21	72	81
4	Respondent 4	13	19	5	5	18	24
5	Respondent 5	16	16	8	10	24	26
6	Respondent 6	50	48	22	22	72	70
7	Respondent 7	33	50	15	17	48	67
8	Respondent 8	44	54	16	16	60	70
9	Respondent 9	55	62	22	26	77	88
10	Respondent 10	50	64	25	28	75	92
11	Respondent 11	29	28	9	12	38	40
12	Respondent 12	37	37	11	17	48	54
13	Respondent 13	31	40	15	15	46	55
14	Respondent 14	41	55	16	19	57	74
15	Respondent 15	43	61	20	19	63	80
16	Respondent 16	44	52	17	26	61	78
17	Respondent 17	41	50	14	18	55	68
18	Respondent 18	45	52	18	22	63	74
19	Respondent 19	44	46	14	20	58	66
20	Respondent 20	55	60	20	21	75	81

21	Respondent 21	24	38	10	17	34	55
22	Respondent 22	48	63	21	24	69	87
23	Respondent 23	50	62	19	27	69	89
24	Respondent 24	23	34	7	14	30	48
25	Respondent 25	34	53	14	19	48	72
26	Respondent 26	53	81	17	33	70	114
27	Respondent 27	57	65	21	27	78	92
28	Respondent 28	17	40	12	21	29	61
29	Respondent 29	53	60	12	25	65	85
30	Respondent 30	23	45	5	24	28	69

Source: Authors' Calculations Based on Primary Data

2. Cognition Subscale: The cognitive component of the FIM™ focuses on assessing the patient's cognitive and social abilities, which are critical for independent living. The cognitive activities evaluated include:
    - Comprehension
    - Expression
    - Social interaction
    - Problem-solving
    - Memory

Each item in both subscales is scored on a scale from 1 to 7, where a higher score reflects a greater degree of independence in performing the respective task.

5.3. FIM™ Scoring System: The FIM™ scoring system is designed to reflect varying levels of independence, ranging from total dependence to complete independence. The scoring categories are organized into three main levels of functional assistance:

- No Helper Required:
    - 7: Complete Independence – The patient can perform the activity safely and in a timely manner without any assistance.
    - 6: Modified Independence – The patient performs the task independently but may require an assistive device or experience minor safety concerns.
- Helper Required – Modified Dependence:
    - 5: Supervision – The patient performs the task independently but requires oversight or verbal cues for safety or accuracy.
    - 4: Minimal Assistance – The patient can perform 75% or more of the task, requiring minimal physical help.

3: Moderate Assistance – The patient is able to perform 50% or more of the task but needs more substantial assistance.

- Helper Required – Complete Dependence:
    - 2: Maximal Assistance – The patient performs less than 25% of the task, requiring extensive physical assistance.
    - 1: Total Assistance or Not Testable – The patient is unable to perform the task or requires complete assistance.

5.4. FIM™ Score Calculation: The overall FIM™ score is calculated by summing the scores from both the Motor and Cognition subscales, providing a comprehensive assessment of the patient's functional independence. The total Motor subscale score ranges from 13 to 91, while the total Cognition subscale score ranges from 5 to 35. The cumulative FIM™ score, therefore, ranges from 18 to 126, offering a complete measure of the patient's ability to function independently across a variety of physical and cognitive domains. This multidimensional evaluation allows for an accurate assessment of the impact of palliative care interventions on a patient's functional abilities and overall quality of life.

5.5. Key Observations: The dataset presented in Table 4 compares the motor and cognitive functions of 30 palliative care patients before and after their admission to the palliative care facility. This data offers crucial insights into how palliative care interventions affect the functional independence of patients across both physical and cognitive domains.

5.6. Motor Subscale Results: The motor subscale of the Functional Independence Measure (FIM™) evaluates the patients' ability to perform essential physical activities. In this study, the majority of patients exhibited significant improvements in their motor function after receiving palliative care services. For example, Respondent 1's motor subscale score increased from 82 to 88, demonstrating a notable enhancement in their physical independence. Similarly, Respondent 10 showed considerable progress, improving from a score of 50 to 64, while Respondent 26 experienced a dramatic increase from 53 to 81.These improvements suggest that palliative care interventions, including physical therapies, nursing care, and daily assistance, are effective in promoting the maintenance or restoration of motor functions in patients. Overall, 25 out of the 30 patients demonstrated measurable improvements in their motor subscale scores, reinforcing the positive impact of palliative care on physical independence. However, a small subset of patients showed little to no improvement in their motor subscale scores. For instance, Respondent 6 experienced a slight decrease in their motor score, declining from 50 to 48, potentially indicating the progression of a complex condition that requires further tailored interventions. These cases highlight the inherent challenges in managing certain chronic or degenerative illnesses within the context of palliative care, emphasizing the need for highly individualized treatment strategies.

5.7. Cognition Subscale Results: The cognition subscale assesses the patients' cognitive abilities, such as comprehension, communication, problem-solving, and social interaction. The majority of patients exhibited either improvements or stability in cognitive function following the initiation of palliative care. For example, Respondent 1's cognitive score improved from 16 to 23, and Respondent 9's score increased from 22 to 26.Although improvements in cognitive subscale scores were generally positive, they were somewhat less pronounced compared to the motor subscale scores. This may suggest that cognitive impairments are more resistant to intervention or that they require different, possibly more intensive, therapeutic approaches. Nevertheless, the observed stability or enhancement in cognitive function for most patients indicates that palliative care also plays an essential role in maintaining or improving cognitive health, underscoring the importance of holistic care approaches that address both physical and mental health.

5.8. Total FIM™ Scores: The total FIM™ score is calculated as the sum of the motor and cognition subscale points, providing a comprehensive measure of each patient's overall functional independence. An analysis of the total FIM™ scores before and after admission to palliative care reveals several key trends:

1. Improvements Post-Admission: A significant proportion of patients demonstrated substantial improvements in their overall FIM™ scores after receiving palliative care interventions. For instance, Respondent 1 improved from a total FIM™ score of 98 to 111, while Respondent 26 showed a remarkable increase from 70 to 114. These results suggest that the multidisciplinary approach of palliative care, encompassing physical therapy, psychological support, and nursing care, is effective in enhancing patients' overall independence and quality of life.
2. Stability or Minor Decline: A few patients, such as Respondent 6, experienced slight decreases in their total FIM™ scores (declining from 72 to 70). This may indicate that certain complex conditions are more challenging to manage or that the natural progression of the underlying illness may have limited the effectiveness of the palliative interventions provided. These cases highlight the need for adaptive and

flexible care strategies that can better accommodate patients with deteriorating conditions.

3. Significant Gains in Patients with Lower Baseline Scores: Patients who began with lower baseline FIM™ scores showed substantial improvements, suggesting that early and targeted interventions had a particularly pronounced impact on their functional abilities. For instance, Respondent 4's total FIM™ score increased from 18 to 24, and Respondent 24 improved from 30 to 48. These patients, who likely faced significant functional impairments at baseline, benefited from personalized care strategies that were designed to address their specific needs and improve their basic functional capacities.
4. Consistency Across Diverse Cases: The broad improvements observed in the FIM™ scores across patients with diverse conditions and backgrounds suggest that palliative care services can benefit a wide spectrum of patients, regardless of the nature of their illness or their initial level of independence. This consistency underscores the versatility and efficacy of palliative care interventions in addressing the complex and varied needs of patients, further validating the role of palliative care in enhancing both physical and cognitive health.

6. Conclusion

This study highlights the significant impact of palliative care on enhancing the functional independence and quality of life (QoL) of patients, particularly in resource-limited settings such as the Kasaragod district of Kerala. Utilizing the Functional Independence Measure (FIM™), the research offers comprehensive insights into the effectiveness of individualized, multidisciplinary palliative care interventions. The findings demonstrate substantial improvements in motor and cognitive functions for most patients, particularly in physical independence, where 25 out of 30 patients exhibited measurable gains. These results underscore the vital role that structured interventions, including physical therapy, nursing care, and daily assistance, play in helping patients regain or maintain their independence. Early intervention, particularly for patients with lower baseline FIM™ scores, proved essential, with these patients showing the greatest improvements. Cognitive improvements, while positive, were less pronounced than motor function gains, reflecting the complexity of addressing cognitive impairments in palliative settings. Nonetheless, the general stability of cognitive function suggests that palliative care helps maintain mental health, though further research into specialized cognitive therapies is necessary.

The study found that old age was the leading cause of illness, affecting 36.7% of patients, highlighting the rising need for palliative care due to age-related complications and comorbidities. As the prevalence of age- and lifestyle-related conditions increases, the demand for tailored palliative care will continue to grow, underscoring the importance of ongoing research and innovation.Overall, this research affirms the broad applicability of palliative care in meeting the diverse medical, psychological, and social needs of patients. It emphasizes the importance of early and multidisciplinary interventions.

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