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Original Research Article

Isolation and its impact on quality of life at end-of-life palliative care services

Weam Ahmed Mohammed Mari, Pooja Sharma*

Department of Hospital Management and Hospice Studies, Jamia Millia Islamia, New Delhi, India

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***Correspondence:**
Dr. Pooja Sharma,
E-mail: psharma@jmi.ac.in

ABSTRACT

Background: Palliative care seeks to provide terminally ill individuals with an improved quality of life, preserved dignity, and increased overall well-being; however, social isolation is one of the most significant and frequently overlooked issues associated in end-of-life care settings. Social isolation has become a growing challenge to global health systems and poses significant psychological and physiological consequences for individuals at the end of life.
Methods: An extensive peer-reviewed literature review was conducted to examine the relationship between social isolation and quality of life among patients receiving palliative and hospice care, using article databases, policy and governmental review documents, and international public health reports published between 2010 and 2024.
Results: Results show social isolation as a significant but least acknowledged impact of terminal illness on quality of life for patients in palliative care. Research indicates that socially isolated terminally ill patients report higher levels of anxiety, depression, and emotional distress, as well as poorer physical and psychological outcomes than those who are not isolated. This review highlighted the importance of developing effective interventions that address patients' psychosocial, emotional, and spiritual needs to improve QoL and overall well-being in palliative care.
Conclusions: The influence of social isolation on the QoL and overall well-being of terminally ill patients receiving palliative care should be recognized as an important factor impacting patient-oriented outcomes in the provision of comprehensive palliative care through targeted interventions designed to support these needs.

Keywords: End-of-Life care, Hospice care, Palliative care, Psychological wellness, Quality of life, Social isolation, Terminally ill patients

INTRODUCTION

Providing care to the patients who are terminally ill is often the most emotional and meaningful experience, yet challenging. Palliative care practices aim to improve the quality of life, promote the dignity, and provide the highest possible level of overall well-being for these patients. The field of palliative medicine has evolved over the past 20 years with its strong impact on pain and symptom management.[1,2] However, research advocates that physical well-being is a significant determinant of an individual's quality of life, but not the only one. Patients experience increased levels of pain and physical discomfort near the end of life which is driven from the sense of sadness and loneliness. Hence, medical management and treatment alone may not provide complete patient outcomes. It includes multidimensional approach like social, emotional and spiritual dimensions to impact the quality-of-life for these patients.[3,4]

Social isolation is a huge concern in palliative care settings that remains overlooked. It has been recognized as a worldwide growing health challenge that has a serious impact both psychologically and physiologically. When considered within the context of dying, there are many causes of isolation, including progressive illness, loss of mobility, extended hospitalization, loss of one's support network, and institutional restrictions that prevent people from having truly fulfilling interactions with others. Existential isolation is described as an intense and distressing experience for terminally ill patients who often feel like they are alone, even if other people are nearby. Existential isolation not only involves the absence of social contact with others, but it also diminishes one's dignity, autonomy, and sense of self through a disruption of relational connectedness.[3,5,6]

Available literature indicates a link between social isolation, palliative care settings, and the experience of anxiety, depression, existential distress, and reduced self-esteem. Patients receiving palliative care are often misdiagnosed for psychiatric co-morbidities, which adds to the emotional burden of illness. In addition, social isolation increases the intensity of disease-related physical symptoms such as pain and fatigue and decrease tolerance to treatment, creating a cumulative cycle of decline across multiple dimensions. Additionally, spiritual well-being, psychological support and effective communication has been recognized to play a vital role in reducing the feeling of isolation, enhancing the protective effect of relational and existential support.[2,5,7,8]

Research indicates interventions to reduce loneliness and increase social connection for patients in their end-of-life care. Strong evidence suggests the positive efficacy of these interventions on the overall quality of life of these patients.[9-11] There is little empirical evidence on how social isolation influences people's experience in terms of psychological distress, the creation of existential suffering, and experiencing lack of dignity. There is lack of any standard model of intervention for providing holistic care for these patients across multiple settings.[12-14] The current research aimed to examine how patients' mental health, dignity, and quality of life are impacted by the feelings of isolation while undergoing palliative care services. It also explores the different approaches to reduce the feeling of loneliness and building relationships amongst the patients at the end of life care.

METHODS

Using a mixed-methods approach, including both quantitative and qualitative methods, this research looks at the effects of isolation on dignity, mental health, and quality of life (QOL) in patients receiving palliative/end-of-life care. Terminally ill patients, their family members providing care, and the HCW providing care for palliative/end-of-life patients were all recruited.

Using Yamane's formula for calculating sample size using a non-probability purposive sampling technique, the researchers determined a total population of 300 to yield a sample size of 172 with a margin of error of 5%. Due to time constraints and limited access to ICU patients, a total of 86 participated in this study.

Study period

This study was conducted between February and May in the year 2025.

Location of the study was in super specialty 700-bedded Hospitals in Delhi NCR, India.

Inclusion criteria

Participants in this study included terminally ill patients cared for in a palliative care system. Terminally ill patients able to communicate verbally were also eligible. Caregivers who provided care to their terminally ill family members were included. Healthcare professionals were eligible if they had provided end-of-life care to terminally ill patients for at least six months.

Exclusion criteria

Individuals with severe cognitive impairment and those unable to communicate were excluded. People in acute psychological distress were not eligible. Healthcare professionals or caregivers unwilling to participate were also excluded. Individuals who were minor children or legally incapacitated were not to be participants.

RESULTS

Impact of isolation on patient dignity

97% of patients indicated that they had experienced some degree of loneliness, indicating that emotional isolation is pervasive throughout end-of-life care.

Table 1: Measurement of feeling of loneliness amongst the patients.

Measurement of loneliness	Feelings of loneliness	Count of patient
51	High to very high loneliness	26
60	Very high loneliness	23
40	Moderate to high	18
22	Moderate	10
33	Moderate	8
0	Low to no loneliness	2

To assess the relationship between loneliness and patient's dignity receiving end-of-life care, Pearson's correlation was used to analyze the aggregate data set from 87 patients. Analysis indicated a strong negative correlation ($r=-0.869$, $p<0.001$) between the loneliness and the dignity scores. As loneliness increases, perceived dignity declines. Patients who experienced no loneliness (0) had the highest dignity score (130), but patients who experienced the greatest degree of loneliness (60) had much lower dignity scores (80). The statistical relationship among these variables ($t=-16.18$, $df=85$, p<0.000001) reveals a very strong relationship (unlikely to be due to chance) between isolation and lower dignity in the patient population receiving end-of-life care.

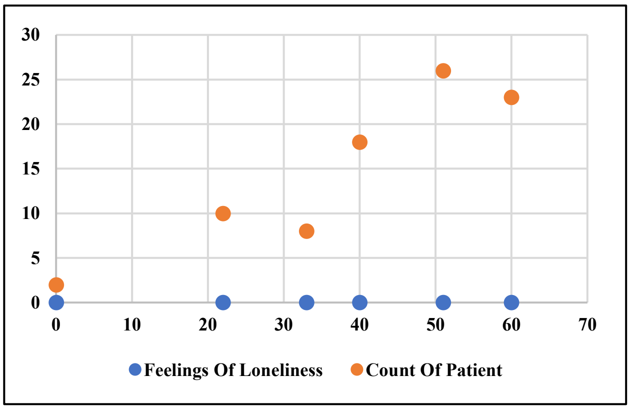

Figure 1: Relationship between loneliness and patient dignity.

The impact of isolation on psychological well-being

Depression

76% of patients experienced moderate to extremely severe range of depression on the DASS-21 depression scale. The pattern indicates a huge amount of emotional distress for patients in end-of-life care.

Table 2: The relationship between patients feeling loneliness and depression.

Depression	Score range	Count of patients
Normal	0-9	13
Mild	10-13	8
Moderate	14-20	29
Severe	21-27	23
Extremely severe	28+	14

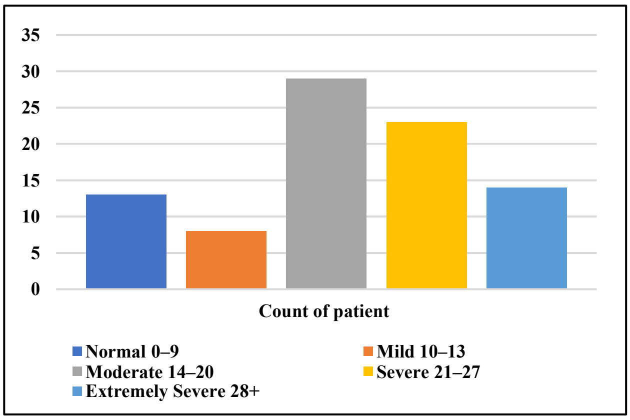

Figure 2: Level of depression in palliative care patients.

A strong positive correlation was found between the feeling of loneliness and depressive state (r=0.761, p<0.05) indicating as the feeling of loneliness increases, patients' depression rate also increases significantly.

Anxiety

Out of the 87 subjects, 75% had anxiety that was rated as moderate to extremely severe.

Table 3: Count of patients feeling anxiety.

Anxiety	Score range	Count of patients
Normal	0-7	18
Mild	8-9	4
Moderate	10-14	21
Severe	15-19	30
Extremely severe	20+	14

A moderate positive correlation exist between loneliness and anxiety (r=0.44, p<0.05). Patients experiencing higher levels of loneliness are likely to experience higher levels of anxiety. As the loneliness score increases, the anxiety score also appears to increase for patients receiving palliative care.

Stress

Stress levels demonstrated a very different trend in the present study. No patient reported an extreme amount of stress or severe stress; 63% of patients expressed mild or moderate amounts of stress, indicating an ongoing emotional burden.

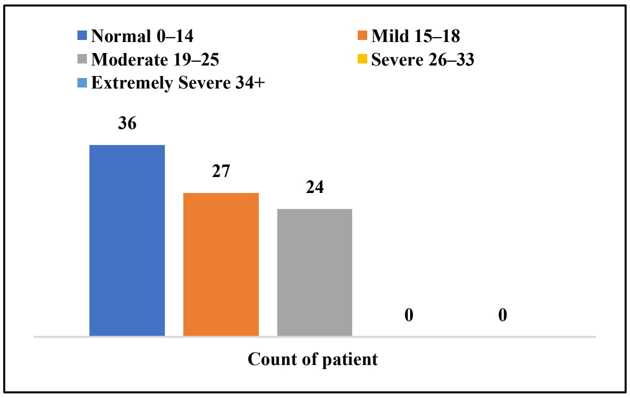

Figure 3: Stress levels in palliative care patients.

A moderate positive correlation (r=0.42) shows that higher loneliness is associated with increased levels of stress amongst the palliative care patients.

A strong positive correlation exists between stress levels and loneliness; furthermore, patients in end-of-life care demonstrated a higher level of loneliness as the number of symptoms attributable to stress increased.

The above results summarize that isolation has a positive relationship with depression, anxiety, and stress among patients receiving palliative care services.

Strategies to reduce loneliness and enhance social connectedness

As per the data collected the top activity that patients prefer is to speak to family members; therefore, family member interaction is the greatest protective factor against isolation. Next (moderately favored), patients preferred reading, religion or spirituality, and visiting the garden. These activities encourage patients to think cognitively and feel comfortable in their existence, all of which help patients stabilize their emotions while in palliative care. Patients selected music therapy, yoga meditation, gardening, and puzzles or games the least. Although they do not receive the same level of preference as family interactions, they provide complementary benefits to the psychosocial well-being of patients within their care environment.

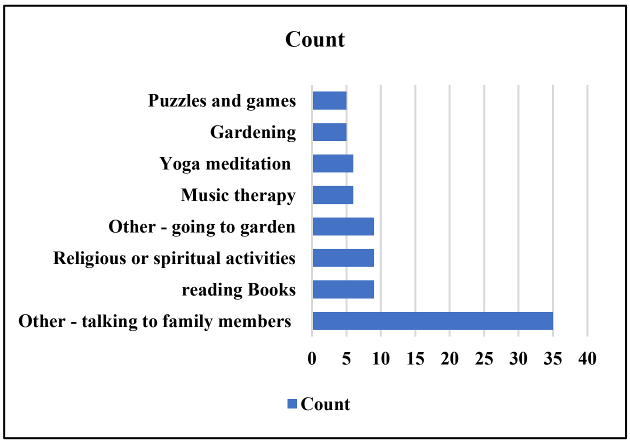

Figure 4: Interventional strategies for palliative care patients.

DISCUSSION

Social isolation in palliative care settings during end-of-life care refers to the absence of meaningful interpersonal connections with family, friends, caregivers, and the wider community. It significantly affects emotional, psychological, and physical well-being during the final stages of life. Isolation may result from disease progression, functional decline, geographic barriers, stigma, or institutional constraints.[3,9] As illness advances, fatigue, pain, and reduced mobility limit social engagement, while the clinical focus on symptom management may inadvertently overlook emotional and relational needs.[2] This creates a cyclical pattern in which reduced interaction reinforces withdrawal, ultimately diminishing quality of life.

Patients in palliative and end-of-life care often do not have meaningful connections with others, including family, caregivers, friends, or other community members. This further impact the emotional, psychological, and physical health of patients during the final stages of their lives, including the progression of disease, decline in the ability to function, residual geographic barriers, stigma associated with illness, institutionalization, etc. As physical symptoms such as pain, fatigue, and limited mobility increases, the amount of time spent in social interaction decreases. The healthcare system's primarily focus on providing support for the physical aspect of illness and may fail to address the socio-psychological needs of patients. This results in an ongoing cycle of social withdrawal, further decreasing the patient's overall quality of life.

Isolation impacts the foundation of good palliative care service. Isolation may create a feeling of invisibility, marginalization, and a passive recipient of care for many patients.[15] The lack of interpersonal affirmations erodes the continuity of the patient’s identity and decreases the patient’s emotional resilience. Patients will also experience a loss of autonomy when there are no trusted individuals to assist them in making shared decisions regarding medical care or in expressing their preferences.[16] Patients may feel helpless and experience a feeling of disconnection from others because of their declining physical condition. This may result in a feeling of being a burden to their family members, losing self-worth, resulting in withdrawal from life, or desiring to die sooner than would naturally occur.[17] Restorative interventions are important for maintaining dignity and enhancing the autonomy of patients in palliative care settings.[7]

Physical comfort, psychological stability, social relationships, are important and interrelated components of patient’s quality of life undergoing palliative care. Social isolation has a detrimental effect on the diverse domains of quality of life. Emotionally isolated patients frequently experience a heightened level of physical symptoms such as pain, fatigue, and decreased levels of functioning.[18] When a patient withdraws psychologically from his or her care environment, motivation for adhering to treatment, self-care, and participating in therapeutic activities is greatly diminished, resulting in a downward trajectory of health improvement. Studies indicate that social isolation interventions such as family participation, volunteer companions, and spiritual support help to enhance emotional resilience and increase satisfaction with living.[11]

Loneliness is largely preventable cause of pain and suffering for people receiving end-of-life care. This study confirms loneliness is related to feelings of anxiety and emotional distress and an overall reduction in well-being, demonstrating the significance of addressing social isolation in providing palliative care settings. Further studies may examine the impact through longitudinal assessment over time. Also studies focusing on multiple sites with larger sample size are recommended to provide more conclusive results.

The research has limitations that affect the generalizability and distinctiveness of the findings. The two-month duration was relatively short. As a result, we could not collect as in-depth data as we might have with follow-up assessments. We also lacked enough data on patient experiences or changes in their palliative care needs. All palliative care was provided by the same hospital. Therefore, even with 120 participants, our understanding may still be limited regarding the population and how they interact with various institutional practices. Our results are limited to one partner hospital. Future investigations should include more participants over a longer time and from multiple sites. This will help strengthen the validity and applicability of the results.

CONCLUSION

To ease the process of dying and to support the patients at their end-of-life, palliative care services should focus on enhanced family involvement, the use of psychosocial interventions, and the provision of loving and compassionate care to these individuals. To minimize the effects of social isolation, a multidisciplinary, human-centered approach that prioritizes emotional presence along with clinical care ensures that all individuals are supported, and no patient feels unseen or alone at the end-of-life stages. The implementation of psychosocial, emotional, and spiritual support should be a primary aspect of providing palliative care services. Creating opportunities for active family participation in care through flexible visiting hours, introducing peer support group services to eliminate feelings of loneliness, to educate providers on communication that contains compassion as well as an understanding of holistic patient-centered care, and to promote the development of community-focused multi-level models of care that enhance community social ties and reduce isolation are amongst the few interventions that can improve the quality of life for these patients.

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