



Impact Of Palliative Approach In The Psychological Well-Being Of The Caregivers Attending To The Patients With Acute/Chronic Illness In Chennai

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Abstract: This research assesses the effectiveness of palliative care interventions on the psychological well-being of caregivers tending to patients with chronic and acute illnesses. Utilizing a mixed-methods approach, data from 80 caregivers were analyzed to explore changes in stress, burden, and overall psychological health. Results indicate significant improvements in caregivers' psychological outcomes, highlighting the critical role of tailored palliative care interventions.

Index terms: Palliative Care, Caregivers, Psychological Well-being, Chronic Illness, Acute Illness

I. INTRODUCTION

The landscape of healthcare, in the recent years has undergone a paradigm shift, expanding from conventional curative models that primarily focus on eradicating diseases, to embracing a comprehensive approach, prioritizing the holistic well-being of individuals facing illnesses. Central to this transformation is palliative care which transcends conventional medical treatments to consider the entirety of human experience, involving a multidisciplinary collaboration encompassing medical, psychological, social, and spiritual dimensions. The holistic focus of palliative care is anchored in the recognition that patients and their caregivers face not only physical pain but also the intricate distress, emotional turmoil, and social isolation.

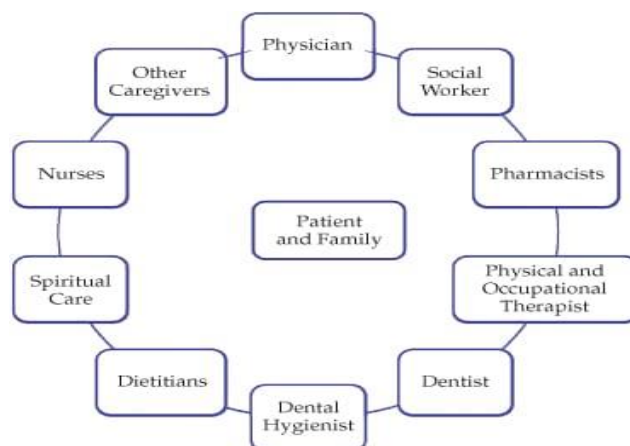


Figure 1: The social circle of the patients receiving palliative care and their caregivers is shown in the above figure.

II. NEED OF THE STUDY

The psychological distress experienced by patients with illness and their caregivers, wherein caregiving is deeply ingrained within cultural norms often remains concealed, leading to unmet emotional and psychological needs. It aims to explore how a comprehensive palliative approach can offer relief that goes beyond pain management, touching on the emotional, social, and spiritual dimensions shedding light on these needs and provide evidence-based insights into how a palliative approach can effectively address them.

III. SIGNIFICANCE OF THE STUDY

The significance of this study lies in its potential to enhance the quality of life for patients with chronic illnesses and their caregivers. By focusing on psychological well-being, this study contributes to the broader discourse on palliative care by highlighting its holistic nature, providing evidence-based insights that may lead to improved healthcare practices. It acknowledges that distress relief extends beyond managing physical symptoms to encompass emotional and psychological dimensions.

IV. REVIEW OF LITERATURE

In the study on “Stress and coping in caregivers of cancer patients” by the author Basit Ansari in 2013, he explores the significant challenges faced by family caregivers who often begin their caregiving journey without formal training or adequate support. This lack of preparation can lead caregivers to prioritize the patient's well-being above their own, leading to high levels of stress. These stressors include emotional and physical strains manifesting as frustration, exhaustion, and loneliness, which can deteriorate the quality of care they provide. The study stresses the importance of recognizing signs of caregiver distress during patient care, as mitigating caregiver burden can directly benefit the patient. Moreover, the research points out that stress disproportionately affects female caregivers, with a significant majority experiencing various forms of stress. Ansari advocates for providing caregivers with the necessary tools and support to manage stress effectively, enhancing the care quality for cancer patients.

In the study of “Palliative care social work in India: Current status and future directions (2017)” by the authors G Ragesh, Lithin Zacharias, and Priya Treesa Thomas discusses the crucial position that a thorough patient evaluation plays which includes aspects of the patient's biological (disease progression, symptoms, and medical history), psychological (coping, risk assessment, and personal goals within the palliative care), spiritual (cultural and spiritual aspects), and social (family, support networks) factors. From this study, the researcher has gained insight into the need for a comprehensive understanding of patients' needs and for tailoring effective palliative interventions, which is essential for improving the psychological well-being of patients dealing with chronic illness.

In the study of “A pilot study to assess stress and coping among primary caregivers of patients with leukemia (2021)” by the authors Sumanpreet Kaur, and Soumitra Ghosh, the authors recognized the significant stress that main family caregivers of hematologic cancer patients frequently experience and sought to examine their stress levels and coping mechanisms. The Perceived Stress Scale (PSS) and the BRIEF-COPE scales were used in the pilot project to measure stress and coping mechanisms among 30 participants. The findings revealed that 63.33% of caregivers reported moderate stress, 33.33% reported mild stress, and 3.33% reported severe stress. The ability to cope varied, with 93.33% showing just ordinary coping skills and 6.67% showing excellent coping capabilities. Notably, stress levels were linked to things like having a nuclear family and working for the government, underscoring their impact on caregiver stress levels. Active and passive coping strategies were used by caregivers. As the study highlights the significance of addressing the particular stressors and coping mechanisms of these caregivers, it is crucial to establish support programs and care interventions to help caregivers maintain their own well-being while providing the best care possible to patients with hematologic cancer.

V. RESEARCH METHODOLOGY

OBJECTIVES

GENERAL OBJECTIVES

- To study the impact of palliative approach in the psychological well-being of the caregivers attending to the patients with acute/chronic illness in Chennai.

SPECIFIC OBJECTIVES

1. To study the demographic profile of the caregivers attending to patients with acute/chronic illness.
2. To assess the psychological distress levels of the caregivers.
3. To study the psychological burden of the caregivers.
4. To understand the psychological state of mind of the caregivers.
5. To understand the palliative approach and measure its impact on the psychological well-being of the caregivers attending to patients with acute/chronic illness.

STUDY DESIGN

- Mixed Methodology - Integrating Quantitative and Qualitative Approaches.
- Sequential Design - Collecting and Analysing the Quantitative Data First, Followed by Qualitative Analysis.

SAMPLE SIZE:

- Sample Size for Quantitative Data: 80 Respondents, the quantitative phase involves data collection from a sample size of 80 respondents.
- Subset for Qualitative Phase: 12 participants who agreed to participate from the quantitative study were selected as the sample for the qualitative approach.

SAMPLING TECHNIQUE:

- Convenience sampling was used for data collection which involves selecting the respondents who were readily available, as the sample population.

DATA COLLECTION:

- Primary data collection by surveys, interviews, and observations, ensuring the participants' privacy consent and data confidentiality.

ETHICAL CONSIDERATION:

- Concern was sought from the participants before collecting data, clearly stating the purpose of survey, and the use of data.
- Data security and protection of their confidentiality was assured.
- The data was anonymized and participants' privacy was be ensured.

DATA ANALYSIS:

- Quantitative Data Analysis: SPSS, MS Excel.
- Qualitative Data Analysis: Thematic Analysis, Deductive Method.
 - The researcher carefully reads & re-reads the qualitative data collected, identifying & interpreting patterns to provide deep insights into participants' experiences & perspectives.
 - The research uses deductive strategy which is also known as sequential explanatory strategy which involves the usage of qualitative research to explore and interpret the findings of the initial quantitative analysis

TOOLS OF DATA COLLECTION:

- Survey Questionnaire for the Quantitative Approach, Semi-structured Interviews for the Qualitative Approach,
 - the Demographic Details, the Psychological State of Mind, the Impact of the Palliative Approach, the Psychological Well-being was assessed by the self-prepared questionnaire of the researcher.
 - the Psychological Distress was assessed by the Kessler Psychological Distress Scale (K10) which was developed by Ronald C. Kessler and his colleagues in the year 2002.
 - The Zarit Burden Interview (ZBI) - Adapted for Indian Context will be used to assess the Caregiver's Burden.

VI. DATA ANALYSIS & INTERPRETATION

QUANTITATIVE DATA ANALYSIS

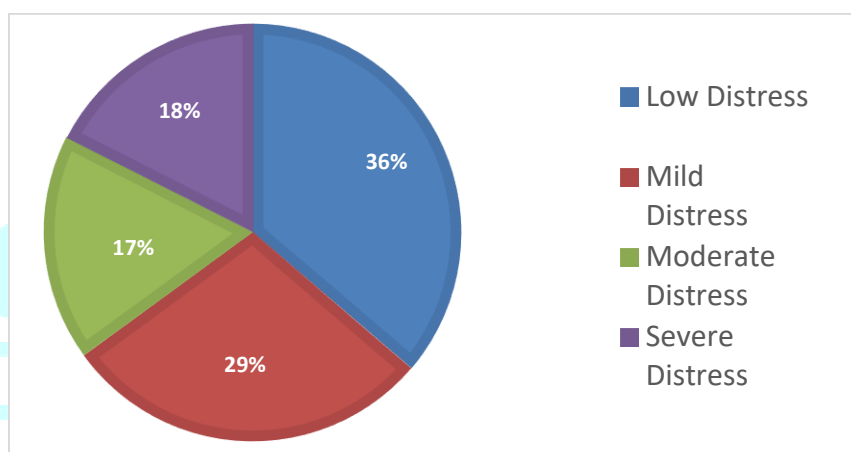


Figure 2: Caregiver Distress Level

The provided data outlines the distribution of 80 respondents based on their reported levels of distress, according to Kessler Psychological Distress Scale (K10). Among the respondents, 35% indicated experiencing low distress, while 29% reported mild distress. Additionally, 18% of respondents reported experiencing either moderate or severe distress, with each category accounting for 18% of the total respondents. This data suggests a varied spectrum of distress levels among the surveyed population, with a notable portion experiencing low to mild distress, and a smaller but significant proportion experiencing moderate to severe distress.

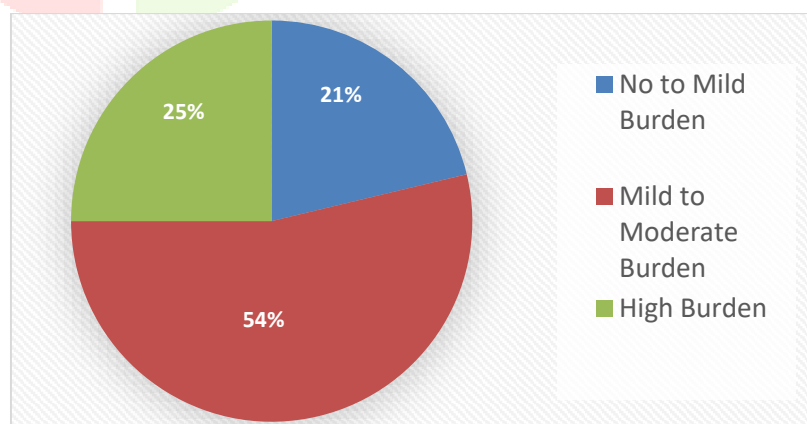


Figure 3: Caregiver Burden Level

The provided data outlines the distribution of 80 respondents based on the level of burden they perceive, according to Zarit Burden Interview (ZBI). Among the respondents, 21% reported experiencing no to mild burden, while the majority, comprising 54%, indicated experiencing mild to moderate burden. Additionally, 25% of respondents reported experiencing high burden. This data suggests that a significant portion of the surveyed population perceives some level of burden, with varying degrees ranging from mild to high.

Table 1: Cross-Tabulation of Age & Distress Level of the Respondents

S.No	Age / Distress Level	Low Distress	Mild Distress	Moderate Distress	Severe Distress	Total
1.	Below 20	1	0	0	0	1
2.	20 to 40	11	7	4	8	30
3.	40 to 60	9	12	8	4	33
4.	Above 60	8	4	2	2	16
	Total	29	23	14	14	80

The cross-tabulation shows the level of distress among caregivers of different ages. One among the 80 respondents in the age category of below 20 reported to have low distress. Out of 30 respondents in the 20-40 range, 11 reported low, 7 mild, 4 moderate, and 8 severe level of distress. Of the 40-60-year-olds, 13 are in low, 12 are mild, 8 are moderate, and 4 are severe level of distress. Of the 16 respondents over the age of 60, 8 reported minimal distress, 4 moderate, 2 severe, and 4 in the low level of distress.

Table 2: Cross-Tabulation of Age & Caregiver Burden of the Respondents

S.No	Age / Caregiver Burden	No to Mild Burden	Mild to Moderate Burden	High Burden	Total
1	Below 20	1	0	0	1
2	20 to 40	6	13	11	30
3	40 to 60	3	22	8	33
4	Above 60	7	8	1	16
	Total	17	43	20	80

The data indicate the burden of the caregivers across different age groups. One among those, in the age category of below 20 bears the no to mild burden. Out of 30 people in the 20-40 range, 6 have no to mild burden, 13 have mild to moderate burden, and 11 have high burden. Out of 33 people aged 40 to 60, 3 reported to have no to mild burden, 22 in the mild to moderate burden, & 8 of them with high burden. Among the rest of them over the age of 60, 7 have no to mild burden, 8 have mild to moderate burden, and 1 has high burden.

Table 3: Cross-Tabulation of Gender & Distress Level of the Respondents

S.No	Gender / Distress Level	Low Distress	Mild Distress	Moderate Distress	Severe Distress	Total
1.	Male	18	8	3	3	32
2.	Female	11	15	11	11	48
	Total	29	23	14	14	80

The data reveals distress levels categorized by gender among caregivers. Among 32 males, 8 report mild distress, 3 moderate, 3 severe, and 8 low level of distress. Of the 48 females, 11 express low distress, 15 mild, 1 strong, and 11 severe level of distress. This sheds light on gender differences in distress levels among caregivers, with varying proportions across different levels of distress.

Table 4: Cross-Tabulation of Gender & Caregiver Burden of the Respondents

S.No	Gender	No to Mild Burden	Mild to Moderate Burden	High Burden	Total
1.	Male	10	17	5	32
2.	Female	7	26	15	48
	Total	17	43	20	80

The data provides insights into burden levels categorized by gender among caregivers. Among 32 male caregivers, 10 indicate no to light burden, 17 with mild to moderate, and 5 with high burden. Among the 48 female caregivers, 7 report no to mild burden, 26 with mild to moderate, and 15 with high burden. Overall, 43 caregivers report mild to moderate burden, 20 with high burden, and 17 with no to mild burden out of 80 respondents.

QUALITATIVE DATA ANALYSIS

THEMATIC ANALYSIS

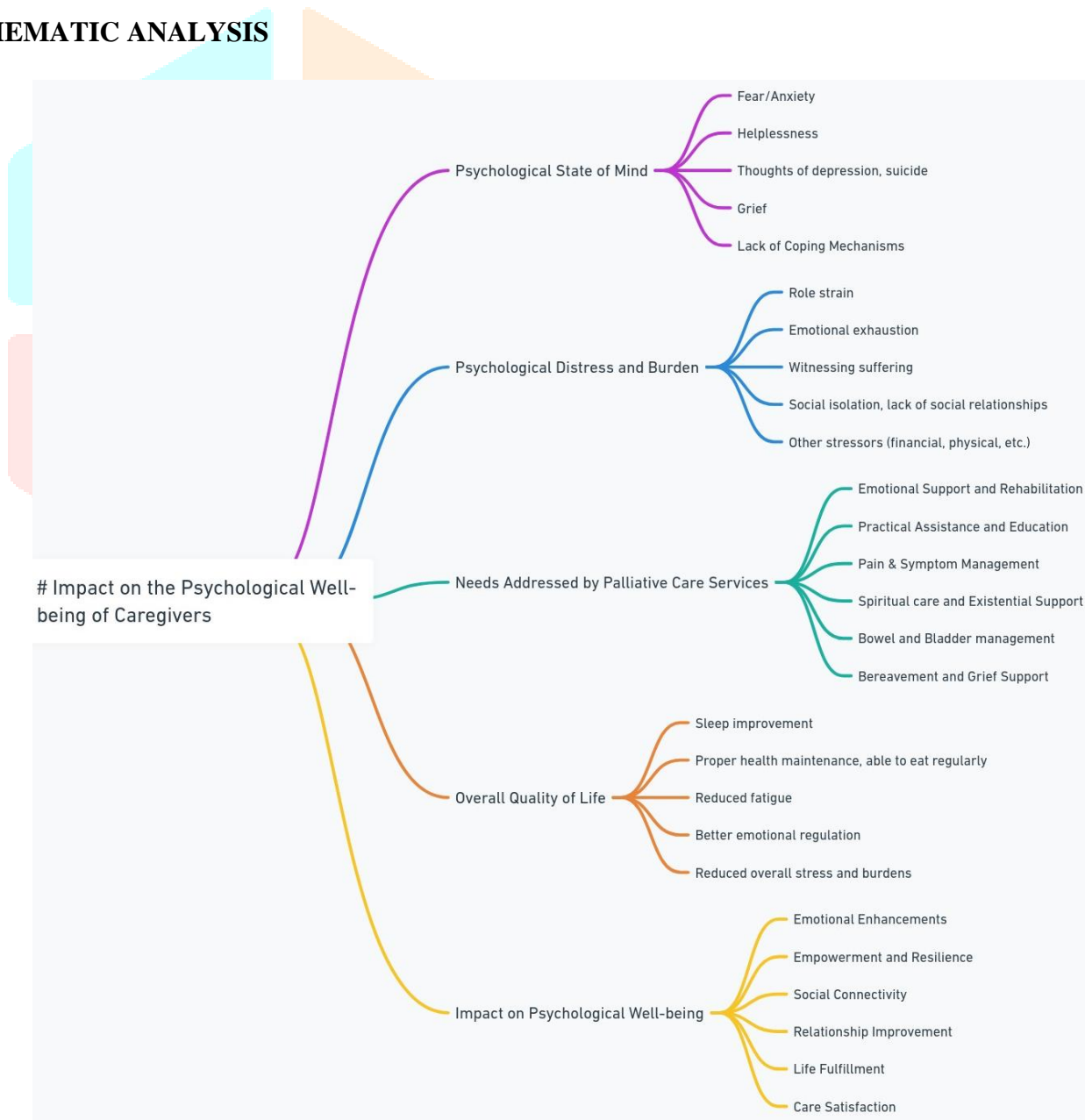


Figure 4: Mind Map of Themes, Sub-Themes & Minor Themes

The thematic analysis illustrates the comprehensive impact of palliative care on the psychological well-being of caregivers, categorizing the effects into various connected sub-themes. Caregivers experience significant psychological distress and burden and palliative care services address these challenges and visible improvements in the caregiver's quality of life can be seen. Ultimately, these interventions foster greater emotional resilience, social connectivity, and satisfaction in caregiving roles, highlighting the essential role of palliative care in supporting caregivers' mental health and well-being.



Figure 5: Psychological State of Mind before the Intervention of Palliative Care

The figure illustrates the initial psychological state of caregivers, marked by negative emotions such as grief, anxiety, depression, and stress. These interconnected emotions reflect the intense psychological burden caregivers bear before receiving any supportive intervention.



Figure 6: Psychological State of Mind after the Intervention of Palliative Care

The figure shows the positive shift in caregivers' psychological states following palliative care interventions. It highlights significant improvements in their emotional well-being, resilience, and quality of life. The presence of hope, self-efficacy, and social support indicates a substantial enhancement in their ability to cope with caregiving responsibilities.

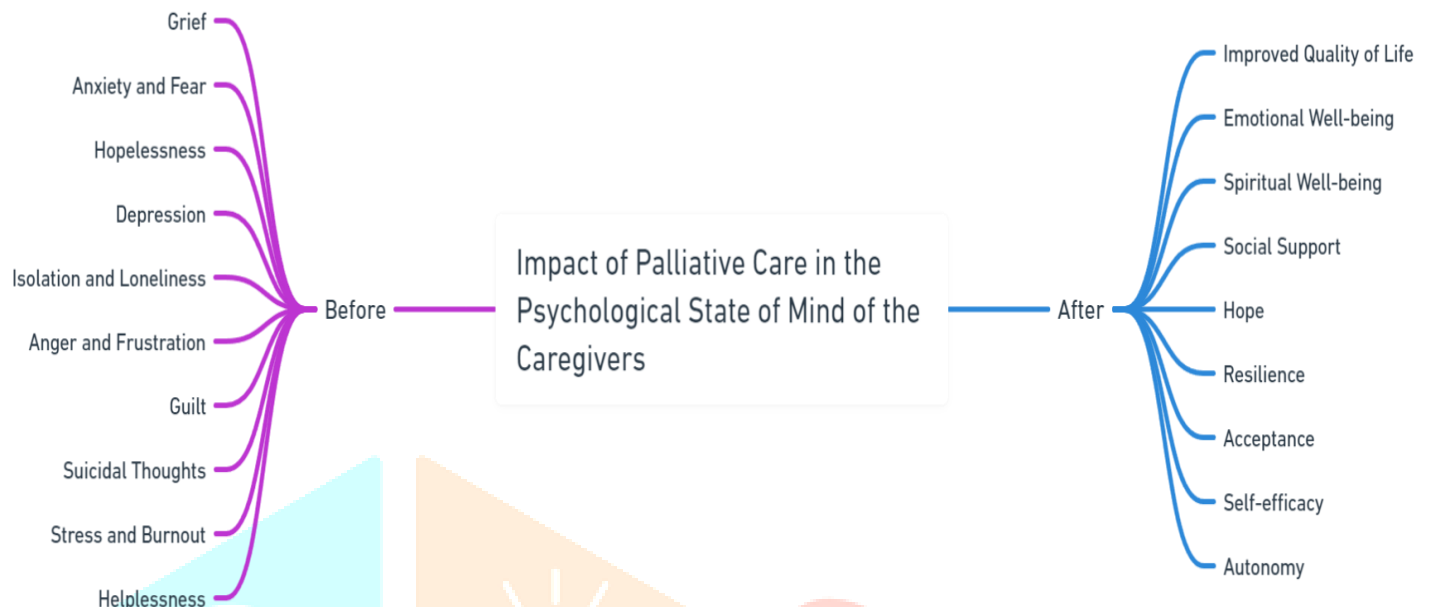


Figure 7: Impact of Palliative Care Interventions in the Psychological State of Mind of the Caregiver

The transition figure summarizes the shift from a predominance of negative psychological states to predominantly positive outcomes due to palliative care. It visually captures the stark contrast between the caregivers' emotional conditions before and after intervention, emphasizing palliative care's effectiveness in transforming their psychological well-being and overall quality of life.

VII. MAJOR FINDINGS

- **Understanding the psychological state of mind of the caregivers**
 - Caregivers described feelings of fear and anxiety about the future health of their loved ones.
 - Feelings of helplessness were common, especially when facing situations, they could not change.
 - Thoughts of depression and suicide were reported, reflecting the deep emotional toll of caregiving.
 - Grief was a constant presence, mourning the loss of the life once shared with the patient.
 - A lack of coping mechanisms made it challenging to deal with the stress and demands of caregiving.
- **Understanding the palliative approach and measure its impact on the psychological well-being of the caregivers**
 - Palliative care services provided essential emotional support and practical assistance, helping caregivers manage patients' pain and symptoms.
 - Spiritual care and help with specific medical needs, including bowel and bladder management, were highlighted as crucial aspects of support.
 - Bereavement and grief support were pivotal for caregivers dealing with loss.
 - Improvements in sleep, consistent eating habits, and reduced fatigue contributed to a significant improvement in caregivers' quality of life.
 - Better emotional regulation and reduced stress led to a more positive caregiving experience, with caregivers feeling more empowered and resilient.
 - Social connectivity improved, with caregivers finding solace in connecting with others in similar situations and enhancing their relationships with loved ones.
 - Caregivers experienced a sense of life fulfilment and satisfaction with the care received, indicating a positive impact on their psychological well-being.

VIII. SUGGESTIONS:

- At the individual level, exploring diverse caregiver experiences is crucial to understanding the unique challenges and supports needed, as each caregiver faces distinct situations. Developing personalized coping strategies should be prioritized to effectively address the specific stresses associated with caregiving. This approach ensures that support mechanisms are directly tailored to individual needs.
- At the macro level, it is important to investigate the various factors causing distress among caregivers to design targeted interventions. Additionally, quantifying the benefits of palliative care can provide a robust basis for advocating the expansion of these services, highlighting their value and effectiveness in enhancing caregiver well-being.
- At the meso level, studying the impact of palliative care on social connectivity is essential for understanding how these services influence caregivers' mental health. Researching the long-term psychological effects of caregiving can help identify persistent issues and assess the effectiveness of existing support mechanisms, ensuring they meet the ongoing needs of caregivers.
- At the community level, creating awareness campaigns and support networks is vital to recognize and validate the roles of caregivers within the community. Developing educational programs specifically for caregivers can aid them in managing care responsibilities and navigating various support services, empowering them with knowledge and practical skills.
- At the government level, based on research findings, proposing recommendations for policy changes to enhance caregiver support is crucial. Assessing the sustainability of well-being improvements post-intervention can inform long-term support strategies, ensuring that caregivers receive continuous and effective assistance.

IX. CONCLUSION

This research study explores the impact of palliative care on the psychological well-being of caregivers in Chennai, focusing on how holistic care not only alleviates physical symptoms in patients with acute or chronic illnesses but also addresses caregivers' psychological, emotional, and existential challenges. Employing a mixed-methodology, the study reveals that comprehensive palliative care significantly enhances caregivers' quality of life by reducing psychological distress and increasing emotional resilience. The findings advocate for integrating palliative care into the broader healthcare system, emphasizing the need for greater awareness, education, and accessible services to support caregivers effectively. This research underscores palliative care's crucial role in creating a more compassionate, caregiver-centric healthcare paradigm.

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