Exploring the Psychological Challenges and Mental Health Support Needs of Palliative Care Patients in Rural Communities in India

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ABSTRACT

Palliative care has seen rising interest in the times post-COVID. However, besides developing empathy and a surface level understanding of care and the emotional load, nothing much has been done. The present study was conducted in collaboration with Koshish, an NGO based in Jharkhand, that attempts to provide palliative care at the grassroot level. The study investigated the lived reality of palliative care being received by patients and the ones who offer it. Understanding of palliative care and its significance was investigated in urban and rural cities simultaneously, while interviews were conducted with patients in rural towns who need palliative care. It was seen that while awareness is slowly reaching the smaller towns, actual care still lacks behind. People still desire to have better support systems and actual facilities too. With the support of NGOs like Koshish, the possibilities of all that happening seem higher.

Keyword:, *Palliative care, critical care, support systems, well-being, rural towns*

1. INTRODUCTION

Palliative care aims to take care of people suffering from life threatening diseases by helping them physically, socially, emotionally and financially. In India physical symptom management has garnered a lot of attention and is well cared for however the psychological challenges that patients, caregivers, etc face particularly in rural areas has been largely ignored.

In rural India people have to suffer through debilitating issues such as anxiety, depression, a fear of death due to the lack of proper facilities to address these issues and the sociocultural norms which stigmatize taking help from mental health professionals.

Even when proper facilities are established they often adopt urban centric or western clinical models which may not align with the communities' cultural values. In India most palliative care hospitals are in urban areas, this leaves the majority of the nation (those who live in rural areas) without proper care. Moreover, western models tend to prioritize the individual autonomy of patients this contrasts with the idea of community-based decision making in India This mismatch creates a gap in care where the emotional and psychological needs of a patient are overlooked in favour of just treating their physical symptoms. There is an urgent need to address this gap of care.

This study aims to investigate psychological challenges faced by palliative care patients and caregivers in rural India to come up with community-based support systems which do not conflict with local culture that can improve their emotional well-being..

This study was conducted in collaboration with Koshish the Hospice, which was the first NGO in Jharkhand founded in 2006. Koshish aims to improve the quality of life for terminally ill and elderly patients using locally available, affordable and culturally acceptable resources.

2. REVIEW OF LITREATURE

Palliative Care in India has been largely focused on physical treatment of patients with an emphasis on physical symptom management and pain control (Rajagopal & Kumar 2010). However, this has led to a neglect of psychological and emotional suffering in the field. For palliative care to give holistic treatment for patients psychological treatment must be included. While psychological treatment particularly around questions of fear, death and anxiety has been studied extensively in high income nations (Kissan, 2004) they have remained unanswered in the rural Indian context.

Several studies conducted in India have concluded that high rates of depression with a research paper by Chaturvedi, Strohschein, Saraf and Loiselle (2009) showing that depression with patients with advanced cancer in India is around 12-23%. Even in urban areas where better facilities are found patients found emotional and psychological treatment lacking due to time constraints, limited staffing and a poor integration of mental health. These findings, even though valuable, have been focused purely on an urban perspective ignoring the lack of support for mental health in rural areas. This issue is further exacerbated when we consider that rural areas have to face even more challenges than patients in urban areas when issues such as geographical barriers, illiteracy, lack of proper institutions and education are factored in.

The issue of a lack of mental health support is not limited only to palliative care patients. It is a well-documented fact that there is a serious lack of mental health professionals. The WHO has stated that the ideal number of psychiatrists for 100,000 people is 3 but in India that number is 0.75. The utilization of these mental health services in rural areas also remains low with treatment gaps exceeding 80% according to a survey conducted by the National Mental Health Survey of India in 2016. This lack of care directly impacts palliative care patients. The stigma around mental health that exists in rural areas further discouraged people to seek help (Raguram et al., 2002)

Patients are not the only ones who face mental health problems in the field of palliative care. Family and community-based support are often the primary caregivers in India according to Khosla and colleagues (2000). Family and the community are the primary support system if not the only support these patients have but they face their own share of mental problems. They suffer from a lack of guidance and proper education in the field.

Recent literature points to the potential of community based palliative care and culturally sensitive models. Rajagopal and associates (2020) advocated for training local health workers in psychological support techniques however implementation has remained inconsistent. The use of telehealth and mental health support through mobile services has shown promise in some studies but large scale scalability and sustainability is still a problem (Thampi et al., 2000).

In summary, while the psychological needs of palliative care are getting increasingly addressed in studies, there has been a distinct focus on urban areas. Most existing studies are urban centric, hospital based or clinical in nature with limited or no exploration in cultural beliefs, family dynamics, and community based support systems in rural areas. This literature gap underscores the urgency and relevance of the present study, which aims to explore these dimensions in depth and propose context specific mental health interventions for rural palliative care.

3. METHODOLOGY

3.1 Research Design

The research employed a descriptive cross-sectional survey integrating both qualitative and quantitative data collection strategies to explore the psychological challenges faced by palliative care patients and the public perception of these challenges. Two distinct surveys were given to two groups, the general public and patients. In person interviews were conducted with patients.

1. Patient (The Patient group had a special focus towards the elderly since most individuals who require palliative care are elderly.)

2. General Public

This allowed the researcher to get an understanding of the situation from multiple perspectives.

3.2 Study Setting and Participants

The patient survey was conducted in the rural villages surrounding Bokaro steel city. The patient surveys and interviews were conducted in collaboration with Koshish the Hospice. A total of 20 patients were interviewed.

The General Public survey was composed of individuals of age groups between 18-30 and 50-71. The survey was conducted both in Delhi and in rural areas surrounding Bokaro Steel City, a total of 35 people participated in the survey.

3.3 Inclusion Criteria

Patients: People who require care due to illness or aging, who are mentally capable of responding and comprehension.

General Public: Anyone 16+ years of age was eligible, The Main age groups in the survey were between 18-30 and 50-71. The General Public Survey had a special focus on urban areas to gain an understanding of how individuals in more developed regions understand the concept of palliative care, ageing, and emotional challenges.

3.4 Data Collection

Patients - Survey
The patient survey consisted of 8 close ended questions in Hindi. The questions were designed keeping the cultural values of the community in mind by purposefully excluding words such as death which are seen as taboo in those villages. The questions aimed at understanding emotional well being, perceptions of illness and sources of support. Questions in the survey were self constructed. Some examples of the questions are:

How often do you feel lonely?
• Never
• Sometimes
• Often
• Always

Is there anyone who understands your feelings?
• Yes
• No

Patients - Interview
In person interviews were conducted with patients, with pre constructed question

General Public - Survey

The General Public survey was divided into 4 sections, these sections being: Basic Information, Awareness and Experience, Beliefs and Solutions, Open Feedback (Optional). Basic Information was information of the respondents such as Age, Occupation, etc. Awareness and Experience were questions about the respondents awareness of palliative care and if they have any experiences of palliative care. Beliefs and Solutions were questions concerned about respondents personal beliefs of palliative care and any solutions they have in mind. The open ended question asked respondents what they believed was the largest emotional hurdle later for people facing serious illnesses or are at the end of their lives. The survey was conducted on google forms and was in English. Some examples of questions are:

In your opinion, do palliative care patients suffer emotionally?(Awareness and Experience)

- Yes, very often
- Sometimes
- Rarely
- No
- Not sure

Would you personally be willing to support or volunteer for the emotional well-being of a palliative patient? (Beliefs and Solutions)

- Yes
- No
- Sometimes

3.5 Data Collection Procedure

Data was collected for the patient survey in face to face interviews with the help from professionals from Koshish Hospice. This allowed for perspectives from illiterate individuals. The survey was administered in Hindi and was conducted in the patients home for their comfort.

Data from the general public was taken via google form which was shared with participants. This allowed for a wider reach to gain even more opinions.

3.6 Ethical Considerations

Verbal consent given by everyone was taken before participation for the survey. For patients who were physically unable to express their thoughts consent was taken by the caregivers of the patients.

4. Results

4.1 Patients

1. Living Arrangement(in graphs/ or line)

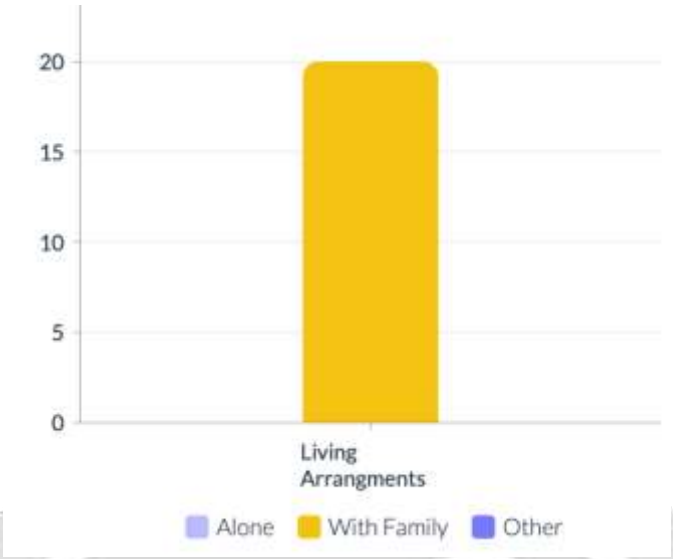

Fig 4.1 Graph of Living Arrangements(Patient Survey)

All respondents reported living with family members. This indicates a strong familial presence in caregiving, which is typical in rural Indian settings where institutional elder care is rare or stigmatized.

2. Sources of Joy

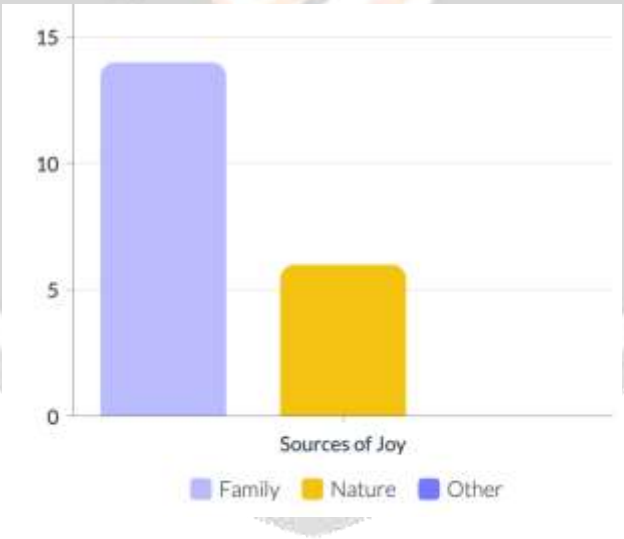

Fig 4.2, Graph of Sources of Joy(Patient Survey)

A majority (70%) derived emotional comfort from family, while others (30%) found peace in natural surroundings. This underscores the importance of relational and environmental factors in emotional support.

3. Feeling of Being Respected

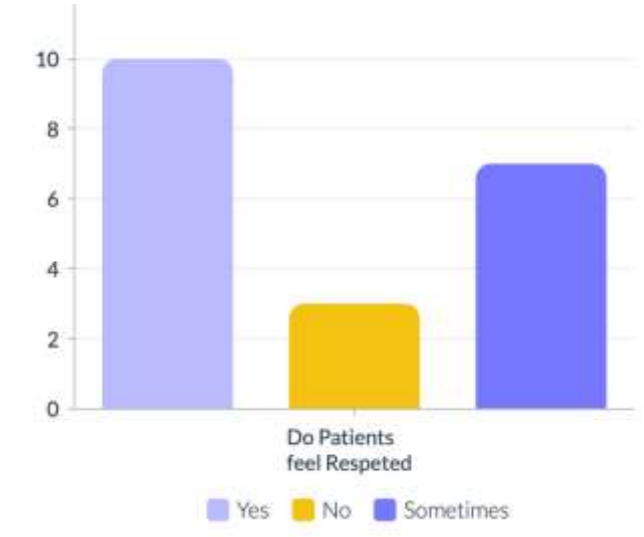

Fig 4.3 Graph of Patients Feeling Respected(Patient Survey)

Half of the patients (50%) felt respected, but 35% reported only sometimes, and 15% did not feel respected at all. This mixed response suggests that dignity in care is lacking

4. Frequency of Loneliness

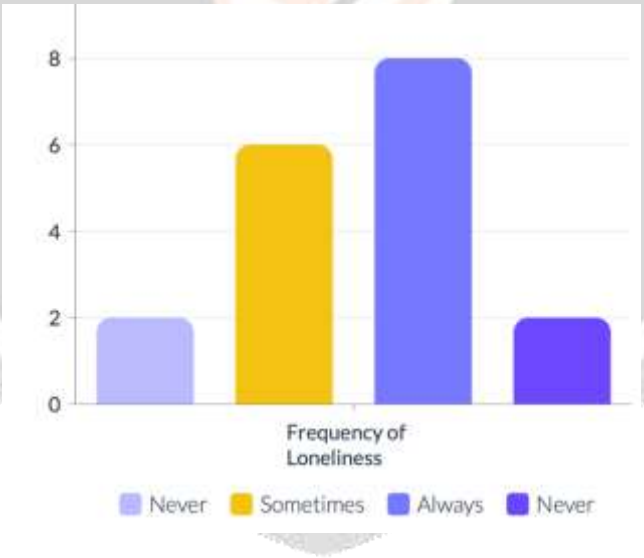

Fig 4.4 Graph of Frequency of Loneliness (Patient Survey)

60% of respondents reported frequent or constant loneliness, and only 10% stating they never felt lonely. This highlights a psychological challenge in palliative care, even when patients are surrounded by family.

5. Emotional Understanding

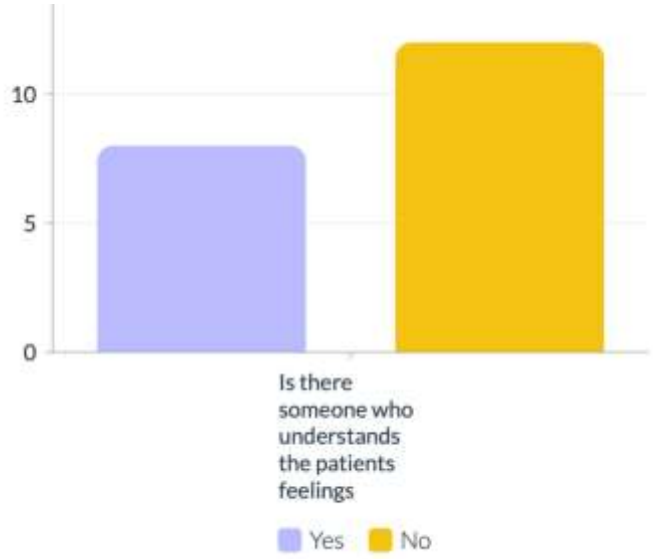

Fig 4.5 Graph of Someone Understanding Patients Feelings (Patient Survey)

Only 40% felt that someone truly understood their emotions. The remaining 60% lacked emotional validation. This suggests that there is a gap of understanding between patients and their family or community.

6. Perception of Old Age and Illness

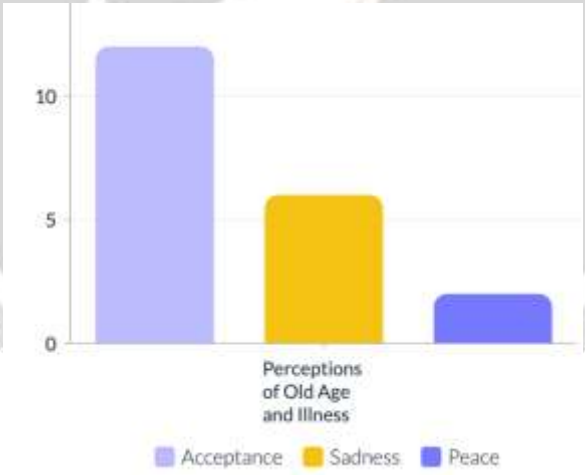

Fig 4.6 Graph of Perceptions of Old Age and Illness (Patient Survey)

Most patients (60%) accepted their condition, and 30% associated it with peace. However, 10% expressed sadness, which signals unresolved emotional problems which are not being treated.

7. Satisfaction with Elder Care in the Village

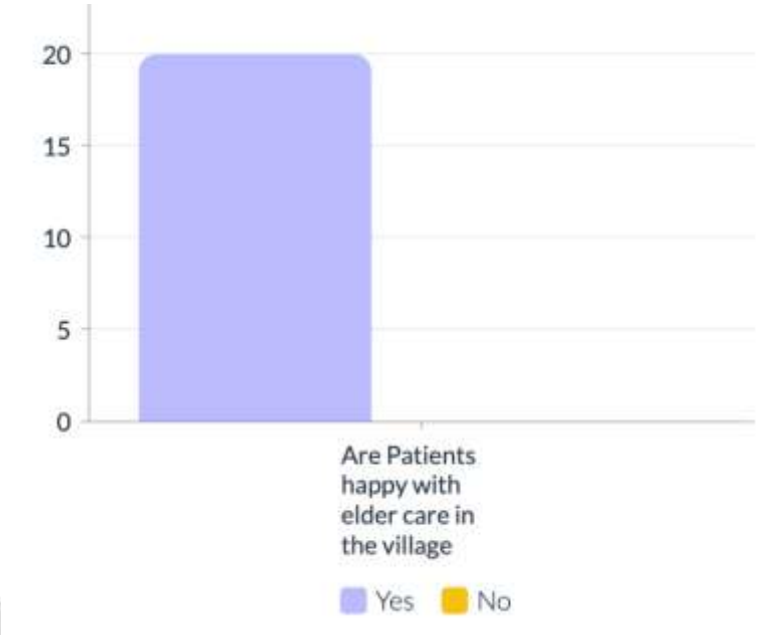

Fig 4.7 Graph of Satisfaction of Elder Care in Village (Patient Survey)

All respondents (100%) reported satisfaction with the general care given to elders in \\their village, which may reflect strong community or familial values regarding elder responsibility.

8. Coping Mechanisms for Fear

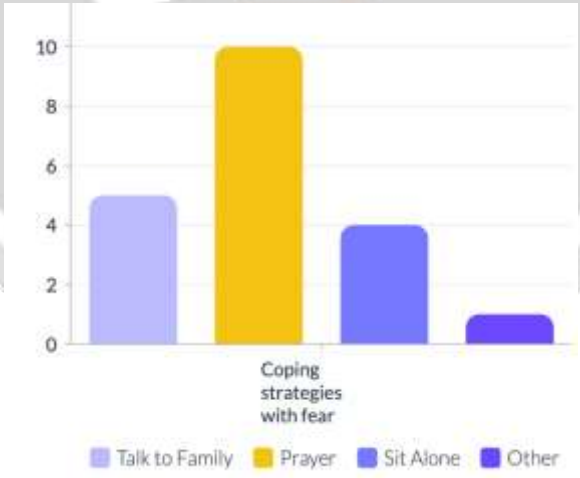

Fig 4.8 Graph of Coping strategies with Fear (Patient Survey)

Prayer was the most common coping strategy (50%), followed by seeking support from family or other areas. This suggests that spirituality and religion are integral to palliative care in the region despite it not being traditionally part of the system.

4.2 General Public

The General Public Survey involved 35 participants, predominantly from the 18–30 and 50–71 age ranges. This means that the results mainly reflect the opinions of the young and middle-aged groups who are involved in work and family life. The majority of the people who took part in the survey admitted to being knowledgeable about the problems of the old people living in their neighbourhoods, villages and expressed their readiness to people struggling with issues that come with age and illness. Furthermore, the participants acknowledged mental health being a cornerstone of palliative care, but at the same time pointed out that in India the availability of facilities and trained staff to handle the needs of the whole issue is still far from sufficient. The answers given when the participants were asked to express their views on aging were quite different from each other, with many referring to it as “deserving respect,” while others labelled it as “difficult,” which seems to indicate the coexistence of both the cultural background of the respect for old people and the increasing awareness of their suffering in the process of getting old. Participants in the open-ended responses frequently pointed out the financial and emotional strains that come along with old age and sickness, and they centred their argument on the double oppression that is suffered by both the patients and their families.

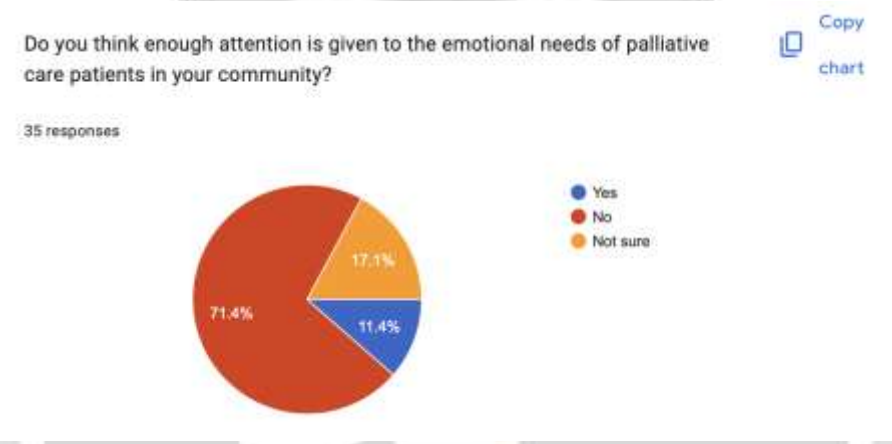

Image 4.9 Pie chart depicting general public responses on attention given to palliative care patients.

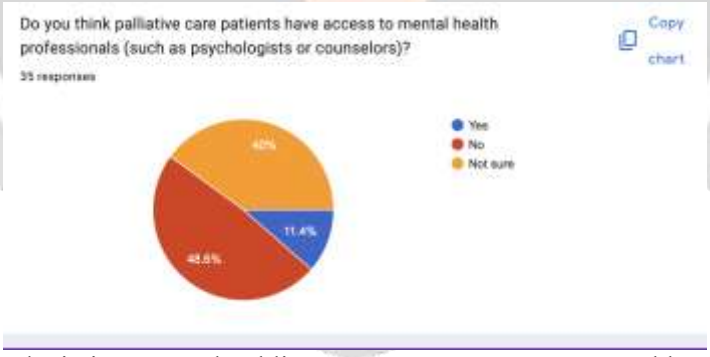

Image 4.10 Pie chart depicting general public responses on access to mental health professionals for palliative care patients.

5. DISCUSSION

The surveys highlight both awareness and some perceptual gaps toward palliative care. Most respondents from the general public were middle-aged working professionals. The majority of the respondents stated that they were aware of the elderly conditions and had somehow helped the aged. This trend is also consistent with the study conducted by Chaturvedi & Loiselle (2009) and Khosla et al. (2012) which found that while urban and semi urban populations recognize the needs of the elderly and are willing to help but lack a structured system to do so. Ageing was largely viewed as worthy of respect from cultural perspectives, while some said it was difficult, admitting health and emotional challenges with ageing. This idea also appears in the study conducted by Das and Halder (2018) which showed that reverence of elders is prominent in Indian communities but they often lack the understanding of the psychological and physical challenges the elders go through. While most claimed that all aspects of palliative care are equally important, a majority also admitted that mental health support remains undervalued in practice. This contradiction indicates that, while people value emotional well-being in principle, they also recognize its neglect when it comes to actual delivery of care.

The patients' survey brought forth additional considerations. Most lived with their family which aligns with research from Singh and associates (2019), however, 60% of them felt lonely, and about the same number felt emotionally misunderstood. There is often dissonance between being there in person and offering emotional support. Half of the patients admitted not always feeling respected, bringing into question the issue of dignity within family care. This question has also been discussed in previous research conducted by Gatrad and colleagues (2000) which discusses a care paradox wherein families are aware and take care of physical needs but cannot meet emotional needs. However, many began to accept their condition and started using prayer or spirituality to cope, a sign that culturally-rooted approaches might benefit emotional well-being. It is quite remarkable that all of them expressed their feelings of emotional neglect and at the same time, they were claiming satisfaction with care by the village elders which leads to the idea that the care provided might only meet the functional needs of the villagers.

When viewed collectively, the discoveries imply that there is a necessity to make the community more aware of the situation, incorporate mental care into palliative care, and make use of such cultural strengths as the respect for the elderly and spiritual coping. The community-based hospices are among the new models that undoubtedly prove the point that the combination of physical and emotional care is achievable when local resources and cultural practices are applied.

6. LIMITATIONS

The study was limited to a small area and a small number of respondents. Consequently, it is difficult to transfer the findings to other regions or to cultures with different backgrounds. In case of survey data, the reporting of the participants themselves is the source of the data, and thus, often, unintended biases can be introduced, such as social desirability and insufficient understanding of technical medical or psychological terms like "palliative care" or "mental health." A great number of respondents may, however, be unaware of what palliative care is really about, and this may have an impact on their answers in terms of correctness or relevance.

7. FUTURE DIRECTIONS

The present research can assist in running awareness programs in order to have rural and semi-urban populations acquainted with the concept of palliative care and the emotional problems faced by patients by spreading information in local languages using folk media and community leaders (like teachers or spiritual persons). Training can be conducted for existing healthcare personnel and ASHAS(Accredited Social Health Activists) about basic mental health first aid, empathetic communication, and psychological screening. Mental health screening should also become a part of palliative checkups. Motivating voluntary groups at the community level to visit and engage emotionally with palliative care patients, something like a buddy system between youths and elderly patients for peer companionship can also have positive effects. Another direction to be considered is that plenty of patients and community members turn to spirituality for comfort, faith-based organizations should be involved in providing emotional care, being trained appropriately for end-of-life mental health.

8. CONCLUSION

This article examined how the general public views the mental health and emotional well-being of patients in palliative care. Survey outcomes revealed that the mental health aspect is still being ignored in the palliative care process even though it is considered as an indispensable part of the care. The responses to the open-ended questions pointed out worry about solitude, dependence on others for money, being neglected, and the requirement of respect and love during the last part of one's life. The respondents particularly underlined the need for more community awareness, organized support networks, and caregivers who can attend to the psychological needs at the end of life.

In conclusion, in general, the public feels some degree of empathy when they see the emotional suffering of palliative care patients but still feel that mental health support is underprioritized. These reflections further propose awareness programs targeted at psychological care integration into palliative services and community-based intervention for holistic and dignified end-of-life care.

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