

Effect of Community-Based Health Education on Misconceptions Related to Caregiving for Cancer among Elderly in a Rural Area of Puducherry: A Pre–Post-Intervention Study

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Abstract

Background and Aim: Families are crucial in providing comprehensive support to cancer patients, including physical, psychological, spiritual, and financial assistance. Unfortunately, cancer-related myths and stigma can have detrimental effects on those affected and their caregivers. This study aims to remove the misconceptions prevailing in a rural population of Puducherry regarding caregiving for cancer among elderly through a health education campaign. **Materials and Methods:** A pre- and post-intervention study was conducted among 217 adults above 18 years of age in a rural area of Puducherry. The intervention was delivered through pamphlet distribution, health talks, and discussion. Attitude, beliefs, and knowledge regarding the misconceptions about cancer were assessed in a five-point Likert scale and then the difference in the proportion of subjects with misconceptions about cancer before and after the intervention was tested using the McNemar test. **Results:** Among the respondents, 77% were females, 15% were illiterate, and 9.6% had a history of cancer in the family. About 23% felt cancer lends a bad name to the family and 24% considered palliative care as not necessary since end-stage cancer patients would die. Post-intervention, the perception that herbal items or diets may treat cancer declined from 45% to 18%, and that a cancer patient in the family lends bad name to the family declined from 23% to 3% ($P < 0.001$). **Conclusions:** Community-based intervention can effectively reduce misconceptions related to caregiving for cancer among elderly in rural areas. These interventions can also improve the quality of care and support provided to cancer patients.

Keywords: Attitude, beliefs, cancer, caregiver, misconceptions, neglect

INTRODUCTION

Cancer is a devastating and life-altering disease, and its prevalence is frighteningly increasing throughout the world.^[1] With nearly 10 million deaths in 2020, cancer has become the primary cause of mortality worldwide, claiming one in every six lives, responsible for the majority of deaths under the age of 70 in 112 of 183 nations, ranking third or fourth in another 23 countries.^[2] The Global Cancer Observatory (GLOBACON) reported 851,678 cancer-related deaths in India in the year 2020, with breast cancer being the most prevalent (13.5%), followed by cancers of the lip and oral cavity (10.3%) and cervix (9.4%).^[3] In urban and rural regions of India, cancer ranks as the second and fourth leading cause of adult mortality, respectively.^[4] In India, cancer incidence was 92.2 per 100,000 people in 2022,^[5] which is usually associated with late diagnosis.

Living with end-stage cancer and chemotherapy is physically and emotionally taxing for patients and carers, particularly family members.^[6,7] As cancer progresses and reaches its last phases, patients must deal with overwhelming fear of death, a sense of powerlessness, and related psychological concerns that must be addressed by the family.^[7] Families are exceptionally qualified to provide physical, psychological, spiritual, and financial support to cancer patients, and they play an important role in all forms of palliative care.^[7] There are

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several myths surrounding the condition, and the associated stigma has far-reaching implications for the people affected and their caretakers.^[8] A lack of knowledge, generally worse in the rural areas, can cause significant barriers to accessing health care and often neglect, especially for the elderly cancer patients. The elderly, dependent on care from the younger members of the family, face stigma leading to neglect, resulting ultimately in poor treatment outcomes. It is quite tragic if the quality of care provided by family members is compromised by cancer myths and misunderstandings prevalent in our culture.^[9,10] To avoid neglect of care due to a lack of correct knowledge and the presence of incorrect information, it is necessary to uncover all of society's myths and misconceptions. Cancer attitudes and treatment options are heavily influenced by one's beliefs, values, personal experiences, and cultural background.^[11]

The awareness and perception level of cancers among the rural populations is low in Puducherry.^[12] The effect of misconceptions on cancer caregiving, especially for the elderly, has not been studied so far. But it is seen from experience that caregiving by the family members for elderly cancer patients is lacking in rural areas. Health education campaigns may improve the people's perspective of cancer, and thereby lead to an improvement in caregiving for elderly cancer patients. But the impact of community-based health education in mitigating misconceptions related to caregiving for cancer among elderly has not been studied in India. This study aims to remove the misconceptions among the rural populations in Puducherry regarding caregiving for cancer among elderly, through a community-based health education campaign.

MATERIALS AND METHODS

Study design

A pre- and post-intervention study was conducted among adults aged above 18 years in a rural area of Puducherry.

Study setting

The study was carried out in Pillaiyarkuppam, one of the villages in the service area of the rural health center of a tertiary medical college in Puducherry, a union territory in South India. The center provides outpatient care, emergency services, and specialized clinics for antenatal, under-five, and chronic disease patients, while providing services under all the national health programs in India. Pillaiyarkuppam village, which is in Villianur taluk of Puducherry district in Puducherry, has a total population of 2744, with 1326 males and 1418 females. According to 2011 census, overall literacy rate was 67.35%, with 76.24% males and 59.03% females being literate.

Sample size

Considering the baseline status of unfavorable attitude toward elderly cancer to be 50% and expecting the intervention to reduce it to 35%, at 5% level of significance and 80% power, the sample size was calculated as 184 using OpenEpi software version 3.01.

Sampling technique

Consecutive sampling of households was done proportionately in each of the seven major streets of the village till the required sample size was reached. One adult member from each household was included. As women are mostly the caregivers in the Indian family setup, women were preferred if present. In case of multiple adult women available in a household, one was selected using the KISH technique.

Inclusion criteria

Adults above 18 years of age who were living in a selected area of Puducherry were included.

Study period

The study period was from Sept 2022 till the end of April 2023.

Procedure

Pre-intervention: The area map was obtained from the rural health center, and all houses were systematically visited. Selected participants were interviewed using a prestructured questionnaire in the local language Tamil, after obtaining their written informed consent. The questionnaire gathered information on their sociodemographic details and any misconceptions they held regarding caregiving for elderly cancer patients. Any questions or doubts regarding the questionnaire were clarified by the investigator proficient in Tamil. If a house was found locked or the responses were not recorded, the participants were approached again the following day to complete the interview. The responses obtained from the survey were analyzed to determine the baseline proportion of participants who held misconceptions related to caregiving for cancer among elderly.

Intervention: Intervention was targeted for all adult populations living in Pillaiyarkuppam. Natural divisions existing in the village, like streets, colonies, or any other topography, were identified. Pamphlets were distributed to every house after the baseline survey. Health talks and discussions were organized in each part of the village in collaboration with the anganwadi workers, self-help group members, youth clubs, and other social groups. Street plays were performed for each part of the village. An attempt was made to cover the complete village. The health education intervention covered general concepts like the incidence and prevalence of common cancers in India, the facts about late diagnosis and the need for palliative care for patients suffering from cancers, the prevalence of neglect of care for the elderly and how it worsens the quality of life of these patients, and finally, the common misconceptions regarding cancer that affect the quality of care being provided to elderly cancer patients, giving the people correct knowledge on these aspects. The sessions lasted for ~40 min. ~50 Participants were called in batches at a common place such as an anganwadi center or a temple, where first health talks were given addressing the knowledge about cancer, which lasted for 15 min, followed by a street play that was conducted for 10 min to develop their attitudes toward caregiving for cancer among elderly

and the concepts of palliative care. Pamphlets informing about the common misconceptions of cancer were provided to the participants and they were clarified through discussion.

Endline assessment: A month after the intervention, a follow-up survey was conducted using the same questionnaire to evaluate changes in misconceptions regarding elderly cancer caregiving in the community. If participants were unavailable during the scheduled visit, additional visits were arranged via phone, and interviews were conducted at their convenience.

Study variables

- Sociodemographic characteristics: age in years, gender, education, occupation, marital status, and socioeconomic status
- Prior experience with cancer patients: known cancer patient in the family, known cancer patient in the neighborhood, and adequacy of care provided to them
- Knowledge, attitude, and perceptions toward cancer care.

Statistical analysis

The data entry was done in Epicollect 5 version 4.0.0 and exported as a Comma Separated Value (CSV) file and imported to Statistical Package for Social Sciences (SPSS) software version 22 for analysis. Continuous variables were summarized as mean with standard deviation (SD) or median with interquartile range (IQR) depending upon the normality. Categorical variables were summarized as frequencies and percentages. Attitude, beliefs, and knowledge related to misconceptions about cancer were assessed in a five-point Likert scale and then the difference in the proportion of subjects with misconceptions about cancer before and after the intervention was tested using the McNemar test.

Ethics statement

The research proposal was reviewed and approved by Institutional Ethics Committee (IEC), and the study was registered prospectively with the Clinical Trial Registry of India.

Interviews of the participants were taken after explaining the study procedures and obtaining their written informed consent. Confidentiality of the data was maintained.

RESULTS

We interviewed 217 participants to understand the misconceptions, beliefs, and attitude toward cancer. The mean age of participants was 41 years, ranging from 30 to 49 years; 77% of them were females and 15% were illiterate. Among the study participants, 9.6% had a family history of cancer, 19% had seen a cancer patient in the neighborhood, and only 44% had received sufficient care according to them. Table 1 describes the details of the study participants.

Awareness about cancer causation

Around 43% of the participants felt that *cancer patients should be barred from visiting other family members*. About 36% of

Table 1: Sociodemographic characteristics of the adult population residing in a rural area of Puducherry, 2022 (n=217)

| | Characteristics | Frequency | Percentage |
|-----------------------------------|--------------------------------------|-----------|------------|
| Age category (in years) | 18–30 | 59 | 27.1 |
| | 31–40 | 65 | 29.8 |
| | 41–50 | 47 | 21.6 |
| | 51–60 | 23 | 10.6 |
| | More than 60 | 24 | 11.0 |
| Gender | Male | 51 | 23.4 |
| | Female | 167 | 76.6 |
| Education ^a | No formal education | 33 | 15.2 |
| | Primary (class 1–5) | 13 | 6 |
| | Secondary (Class 6–12) | 126 | 58.1 |
| | Graduate and above | 45 | 20.7 |
| Occupation | Government | 10 | 4.6 |
| | Private | 23 | 10.6 |
| | Daily wage | 22 | 10.1 |
| | Self-employed | 17 | 7.8 |
| | Unemployed | 41 | 18.8 |
| | Housewife | 94 | 43.1 |
| Marital status | Student | 11 | 5.0 |
| | Married | 170 | 78 |
| | Unmarried | 26 | 11.9 |
| | Widowed/widower | 19 | 8.7 |
| Socioeconomic status ^b | Separated/divorced | 3 | 1.4 |
| | Upper class | 14 | 6.4 |
| | Upper middle class | 20 | 9.2 |
| | Middle class | 54 | 24.8 |
| | Lower middle class | 91 | 41.7 |
| | Lower class | 39 | 17.9 |
| | Known cancer patient in the family | 21 | 9.6 |
| | Known cancer patient in neighborhood | 42 | 19.3 |
| | Adequacy of care provided to them | 95 | 43.6 |

^aIndian standard classification of education. ^bSocioeconomic status: BG Prasad scale 2021

the participants between the ages of 31 and 40 felt that *biopsy or surgery may speed up the spread of cancer* and 17% people believed that *cancer was contagious or infectious in origin*.

Table 2 presents a comparison between the initial (baseline) and final (endline) levels of unfavorable responses regarding the causation of cancer. After the intervention, the misconceptions about cancer’s infective origin came down from 16% to 2% and cancer being a curse from God for their sins was reduced from 11.9% to 3.7%. There was a significant reduction in biopsy and surgery being stated as a cause for increasing the spread of cancer, from 25% pre-intervention to 2.8% post-intervention. Figure 1 shows the shift of individuals who responded to “neutral” in the baseline survey regarding palliative care and treatment, indicating whether their responses changed to favorable, unfavorable, or neutral.

Awareness about need of palliative care and treatment

The common misconception about cancer treatment was that *herbal products can cure cancer* (45%) and *palliative care*

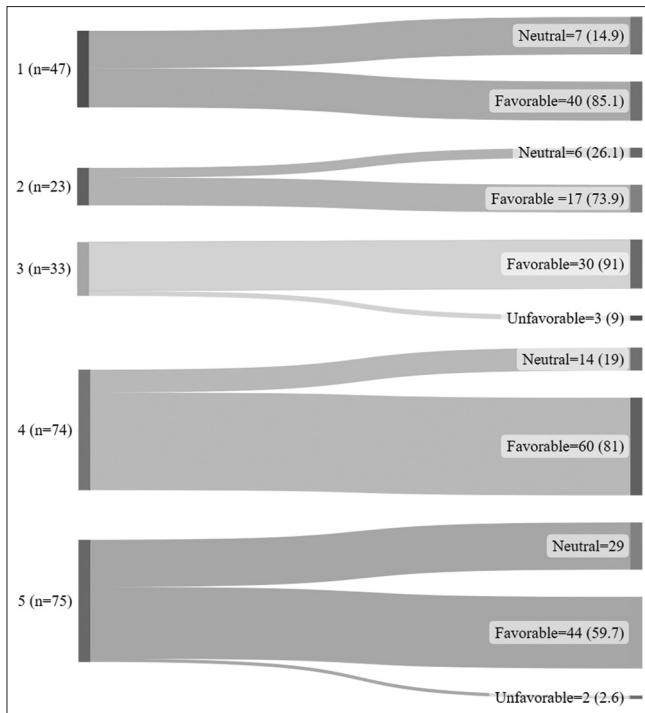


Figure 1: Change in the awareness of the study participants regarding cancer causation, who had responded “neutral” in the baseline survey among the adult population residing in a rural area of Puducherry, 2022

is a financial burden to the family (49%). Around 24% of participants believed that there is no use of palliative care as end-stage patients are most probably going to die.

Table 3 presents a comparison between the initial (baseline) and final (endline) levels of negative responses concerning the awareness of the necessity of palliative care and treatment. Following the intervention, the belief that patients at their end of life do not require palliative care fell from 24% to 2%. The perception of the participants that the palliative care is a financial burden to the family reduced significantly from 25% pre-intervention to 3% post-intervention. Figure 2 shows the shift of individuals who responded to “neutral” in the baseline survey regarding palliative care and treatment, indicating whether their responses changed to favorable, unfavorable, or neutral.

Attitude toward cancer care

Among the participants, 23% felt cancer in one of the family members lends a bad name to the family and 29% mentioned that cancer treatment is a financial burden to the family, and they believed that visiting religious institutions and giving offerings to God can cure the cancer. Around 23% felt that the patient’s attitude impacts the likelihood of recovery and the amount of pain tolerated.

Table 4 gives a comparison of the baseline and endline levels of unfavorable responses regarding the attitude toward cancer care. After the intervention, the perception that herbal items or diets may treat cancer declined from 45% to 18%, and

Table 2: Comparison of baseline and endline levels of unfavorable responses regarding awareness about cancer causation among adult population residing in a rural area of Puducherry, 2022 (n=217)

| Cancer causation | Pre-intervention n (%) | Post-intervention n (%) | P* |
|--|------------------------|-------------------------|--------|
| Cancer is contagious | 36 (16.5) | 4 (1.8) | <0.001 |
| There should be restriction on the patients for going near other family members | 90 (41.3) | 9 (4.1) | <0.001 |
| Cancer is a curse from God for sins done by the patient | 26 (11.9) | 8 (3.7) | <0.001 |
| Increased sexual activity is a cause for cancer, especially of reproductive organs | 36 (16.5) | 3 (1.4) | <0.001 |
| Doing a biopsy or cancer surgery increases the spread of cancer | 55 (25.2) | 6 (2.8) | <0.001 |

*McNemar test (P<0.05 is significant)

Table 3: Comparison of baseline and endline levels of unfavorable responses regarding awareness about the need of palliative care and treatment among adult population residing in a rural area of Puducherry, 2022 (n=217)

| Palliative care and treatment | Pre-intervention n (%) | Post-intervention n (%) | P* |
|--|------------------------|-------------------------|--------|
| Palliative care worsens the disease and decreases the chances of recovery | 22 (10.1) | 8 (3.7) | <0.001 |
| Cancer pain is an essential part of recovery and should not be treated if recovery should happen | 10 (4.6) | 6 (2.8) | 0.24 |
| Since end-stage cancer patients are most probably going to die, there is no use of palliative care | 53 (24.3) | 4 (1.8) | <0.001 |
| Treatment and palliative care are a financial burden to the family | 106 (48.6) | 33 (15.2) | <0.001 |
| Cancer treatment kills more than it cures | 44 (20.2) | 8 (3.7) | <0.001 |
| Cancer needs no treatment and will recede on its own | 5 (2.3) | 3 (1.4) | 0.57 |

*McNemar test (P<0.05 is significant)

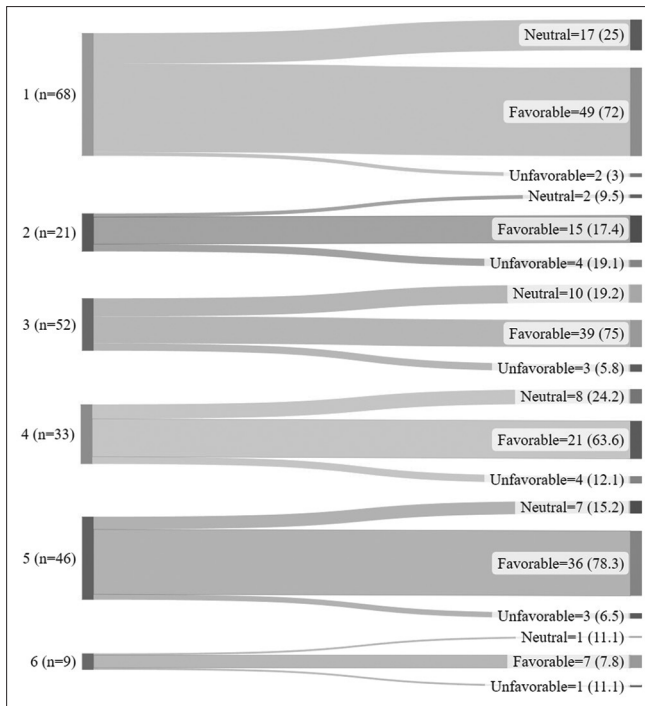


Figure 2: Change in the awareness of the study participants regarding palliative care and treatment, who had responded “neutral” in the baseline survey among the adult population residing in a rural area of Puducherry, 2022

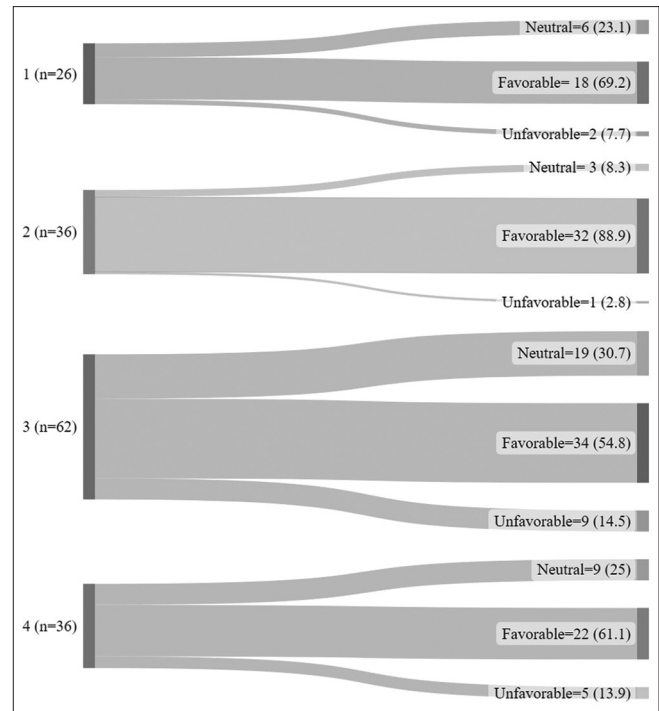


Figure 3: Change in the awareness of the study participants regarding the attitude and beliefs toward cancer, who had responded “neutral” in the baseline survey among the adult population residing in a rural area of Puducherry, 2022

Table 4: Comparison of baseline and endline levels of unfavorable responses regarding attitude toward cancer care among the adult population residing in a rural area of Puducherry, 2022 (n=217)

| Attitude and beliefs | Pre-intervention n (%) | Post-intervention n (%) | P* |
|---|------------------------|-------------------------|--------|
| Having a cancer patient in the family is bad name to the family | 51 (23.4) | 13 (6) | <0.001 |
| Caring for cancer patients is a burden as they require a lot of time and effort | 62 (28.4) | 12 (5.5) | <0.001 |
| Certain herbal products or certain diets can cure cancer | 98 (45) | 40 (18.4) | <0.001 |
| The attitude of the patient (positive or negative) determines the chance of recovery/ amount of pain felt | 130 (59.9) | 140 (64.5) | 0.37 |

*McNemar test (P<0.05 is significant)

that having a cancer patient in the family lends a bad name decreased from 25% to 3%. Figure 3 shows a change in the awareness of the study participants regarding their attitude and beliefs toward cancer, who had responded “neutral” in the baseline survey.

Perceptions of the psychosocial status of cancer patients reported by caregivers

Participants with previous experience of cancer patients in their family or neighborhood reported that a significant proportion of these patients expressed a desire to end their lives (43%). Furthermore, 26% of cancer patients reported experiencing feelings of loneliness, while 23% reported feelings of neglect in terms of care. Also, 26.8% of patients expressed concerns about being a danger to their families.

DISCUSSION

A pre- and post-intervention study was carried out to evaluate the effectiveness of community-based health education in addressing the misconceptions related to caregiving for cancer among elderly living in a rural area of Puducherry, India. There were 217 participants at the baseline, of which seven dropped out (3%) at the endline.

We employed the same questionnaire and five-point Likert scale as the ones used by Ajith *et al.*^[8] in a previous study (strongly agree, agree, neutral, disagree, and strongly disagree). For purposes of analysis, the responses agree and strongly agree were combined; similarly, disagree and strongly disagree were put together, while neutral was considered as a group. The response agree was regarded favorable for positively stated comments, while disagree was considered favorable for negatively worded statements. Across all domains, individuals who had previous experience with cancer patients in their

family or neighborhood exhibited less-negative opinions compared to those without any previous experience with cancer patients in their family or neighborhood.

Awareness about cancer causation

At the baseline, participants over the age of 60 had a high negative response to the statement that cancer is a curse from God, followed by the statement that cancer is contagious. In line with our study findings, Elangovan *et al.*^[13] reported that 16.5% of individuals were unaware of cancer not spreading from person to person and 17% believed cancer to be a curse. Also, Kishore *et al.*^[14] found that a significant proportion of patients (58.9%) held the belief that cancer was a result of God's curse. Moreover, Srivastava *et al.*^[15] identified that 32% of patients considered cancer to be possibly contagious, while 18% of patients attributed cancer to their current or past sins. These collective results underline the prevalence of misconceptions and cultural beliefs associated with cancer, which warrants attention in cancer education and awareness programs. Our study revealed a significant correlation between the level of education and negative responses in this area, indicating that individuals with secondary education and those with no formal education exhibited higher levels of negative reactions. This finding highlights the persistence of deep-rooted myths in the society, even in the presence of school education. Similarly, the study by Carlsson and Strang^[16] also reported a positive association between the level of education and accurate responses, further supporting the influence of education on people's beliefs and understanding of the subject. Other misconceptions related to cancer causation, such as surgery/biopsy spreading the illness, have also been reported by previous studies. Ajith *et al.*^[8] reported this in 26% of the participants in the rural areas of two neighboring districts of Tamil Nadu, similar to our finding of 26% agreeing with the statement.

Awareness about the needs of palliative care and treatment

Our study showed a significant difference in unfavorable responses between the age groups. Specifically, individuals aged 31–40 years showed a higher level of unfavorable response (35%) to the statement about palliative care worsening the disease and reducing the chances of recovery in comparison to those aged over 60 years (5%). In contrast to the findings of Veerakumar and Kar,^[12] our study revealed that population under the age of 40 showed a greater degree of unfavorable response, despite having a higher level of awareness compared to the population in the age group of 40 or older ($P < 0.05$). However, almost all participants across the age groups perceived palliative care to be a financial hardship on the family. Several studies conducted across India, including those by Chauhan *et al.*,^[17] Rajpal *et al.*,^[18] and Ghatak *et al.*,^[19] have documented the financial implications of palliative care experienced by families because of various factors. Participants with secondary schooling had a disproportionately higher negative response in this domain, except for the statement that

cancer pain is an essential part of recovery and should not be treated if recovery occurs. Similar results were obtained by Chandra *et al.*^[20] in their study conducted in the villages of Tamil Nadu, where it was found that despite being primary caregivers for cancer patients, a large proportion of elderly individuals in rural areas of Puducherry were not aware of palliative care, suggesting the need for more education and awareness about palliative care and its benefits among all age groups and elderly individuals living in rural areas.

Attitude toward cancer care

People between 18 and 30 years of age and between 31 and 40 years of age fared poorly in this domain. Some others believed that mentioning cancer during the festival days would have negative consequences. Regarding the use of herbal medicines for cancer, we found that 26% were having favorable opinion on the use of herbal medicine at the baseline. Ajith *et al.*,^[8] in their quantitative survey, found that nearly 48% of the participants showed a favorable attitude toward herbal medicine.

Perceptions of the psychosocial status of cancer patients reported by caregivers

We found that participants perceived cancer patients to experience changes in their social relationships, including a sense of isolation from the family and friends and a loss of independence. This highlights the importance of social support for cancer patients and the need for caregivers to provide emotional and social support to their loved ones with cancer.

Effect of intervention

In this study, we designed an intervention package with an attempt to reach the largest number of people in the most effective way addressing the misconceptions about cancer among elderly in the community. The intervention package consisted of three components: street play, pamphlet distribution, and health talks among self-help groups. Chandra *et al.*^[20] proposed in their study that health awareness programs in the community using posters, role plays, interactive sessions, and door-to-door leaflet distribution and information dissemination might raise the knowledge of palliative care among the people living in rural areas of the country. During our intervention, we observed that low literacy levels of the participants acted as a barrier for acceptance of the information regarding cancer, with most participants having either secondary education or no formal education. We found it challenging to effectively communicate the health information and ensure that participants understood the educational material. We found that many elderly caregivers held cultural beliefs and practices related to cancer that were difficult to change through education and awareness campaigns. For example, some caregivers believed that cancer was caused by supernatural forces or was a punishment from God. However, the results showed that the intervention had a significant impact on improving knowledge related to the causes of cancer, palliative care and treatment, and attitude toward cancer care.

Except for two statements, *cancer requires no treatment and will resolve on its own, and cancer pain is an integral component of healing and should not be treated if recovery occurs*, there was a significant decline in the negative responses for statements related to cancer causation, palliative care and treatment, and attitude toward cancer care. However, in the study by Ajith *et al.*,^[8] no one agreed on these two statements. Numerous studies have demonstrated the benefits of health education in increasing awareness on various health-related issues. Indra^[21] indicated in her study that creating awareness through educational intervention can enhance women's health-seeking behavior by increasing their willingness to receive cervical cancer screening and improving their knowledge.

However, further research is needed to evaluate the long-term impact of these interventions and to determine the most effective strategies for implementing them in rural communities.

Overall, the endline survey results of our study indicated that the community-based health education intervention was effective in improving the knowledge and attitudes related to caregiving for cancer among elderly in the rural area of Puducherry.

However, the study has certain limitations. The pre-post-intervention study design limits the ability to determine causality, and the lack of a control group makes it difficult to determine whether the observed changes were due to the intervention or other factors. Also, the study sample was limited to one of the villages in a rural area of Puducherry, which may limit the generalizability of the findings to other villages in the area.

CONCLUSION

The findings of the study suggest that community-based health education interventions, involving a combination of strategies such as distribution of pamphlets, street plays, and interactive sessions, can effectively reduce misconceptions related to caregiving for cancer among elderly in rural areas. Also, it can enhance the quality of care and support provided to cancer patients.

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Nil.

Conflicts of interest

There are no conflicts of interest.

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