

Research Article

A Qualitative Approach to Cancer Awareness Among Rural Women

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Abstract:

Introduction: The incidence of various types of cancers in India are set to increase thereby putting an increased burden on the health system. There is a need for people to know sufficiently about cancer, the various types, the risk factors, the early symptoms and signs etc. so that they can come for professional diagnosis early. However, the fear of cancer prevents screening, early diagnosis and prompt treatment.

Methodology: A qualitative study was done about cancer awareness among women in the rural areas using qualitative methods like Focus Group Discussions (FGD), In Depth interviews and Key Informant interviews.

Results: Incurability of cancer, stigma, fear of cancer, need for support – physical, emotional & spiritual, lack of discussion in the community, causes of cancer, knowledge about cancer and personal experience with cancer are the themes identified in this study.

Discussion: Stigma concerning cancer is a challenge to cancer awareness and control activities in any society. “Cancer fear” is any fear, anxiety, or worry related to cancer, including causes or consequences of cancer such as fear of treatment for cancer. Social support is necessary for physical adaptation, wellbeing and emotional adjustment in people suffering with cancer.

Conclusion: This study reveals that knowledge about cancer in rural women is low and there are many misconceptions. There is reluctance to discuss about it due to fear and stigma.

Recommendations: Following appropriate cancer education programmes with a stress on rural populations, prevention and screening programmes must be taken up urgently. Healthcare workers and volunteers in rural health care must be given necessary training to be able to give adequate cancer awareness, addressing key misconceptions.

Key words: Qualitative study, Cancer, stigma, fear, support, personal experience

Introduction

Contemporary lifestyle changes are now seen even in rural communities in India, leading to an increase in Non-Communicable Diseases (NCDs), even cancers. The incidence of various types of cancer are also set to increase thereby putting an increased burden on the health system ¹.

Most people believe that cancer is incurable and the word cancer evokes fear ². Fear, trauma or death make up the public image of cancer which is very intimidating ³. The perception of cancer disease and coping with it are significant issues which prompts the victims to go through an introspection of why they got it, accepting the illness, awareness and anxiety about the future as well as a quest for hope, spirituality and social support ⁴.

Needless to say, when one gets cancer, his / her economic, social and psychological life are affected adversely in terms of confusion, anxiety, concern for future, pain and fear. This perception of cancer in the general public, leads to a delay in seeking help for cancer-like symptoms and thereby late diagnosis and treatment ⁵.

There is a need for people to know sufficiently about cancer, the various types, the risk factors, the early symptoms and signs etc. so that they can come for professional diagnosis early. Educational inputs in cancer are met very little interest and the health system also does not give much importance to this aspect

of health care. The negative aspects of having cancer give rise to feelings of helplessness, alienation, powerlessness, and anguish. Poor understanding of the illness, its outcome (impact and treatment), the uncertainty involved and the psychological stress led to a withdrawal from society ⁶.

People's experiences of coming across cancer sufferers in the community and their lived experiences, gives them a confused perception based on the disruption of lives, leaving an impression of fear, stigma and false beliefs ⁷. Fear of cancer prevents screening, early diagnosis and prompt treatment. It emanates from a view of cancer as a vicious, unpredictable, and indestructible enemy ⁸. Arbitrary inference involves making judgments based on insufficient or biased information, often leading to irrational and negative beliefs ⁸.

Cancer awareness is the key to early detection and better health-seeking behaviour. Also, awareness about the curability of cancer has an impact on health-seeking behaviour towards cancer ⁵. Though attitude towards screening modalities was found to be good among the Indian population, the screening practice remains poor as there is a substantial gap in knowledge about the curability.

In the peoples' mind, getting cancer is like being given a death sentence. The very word *Cancer* is frightening, bringing to mind the word “death”. Fearsome synonyms include malignancy, disease, corruption and blight ⁹.

While there are various contradictory and elusive beliefs about cancer in an individual and the society she lives in, a quantitative approach to study cancer awareness in a rural setting is ineffective. Quantitative approaches to look at why people are not willing to talk about cancer is futile. As qualitative approach has the capacity to look beyond numbers and percentages, this study was taken up.

Methodology

A qualitative study was done about cancer awareness among women in the rural areas using qualitative methods like Focus Group Discussions (FGD), In Depth interviews and Key Informant interviews. Women of ages between 18 – 65 years residing in the rural areas were included. The FGDs with resident women were conducted at villages of Inavolu and Dondapadu which are nearby to the Rural Health Center (RHC) of the NRI Medical College. FGDs were also conducted with the patients attending the RHC and healthcare workers (Village Health Nurses -VHNs and Accredited Social Health Activists -ASHAs) at the RHC. Key informants like Multipurpose Health Assistant (MPHA) and (ASHA) at Ayushman Bharat Health and Wellness Center (AB-HWC) Chinakakani, near NRI Medical College were interviewed along with the Staff Nurses and Post Graduate doctors working in the Department of Oncology in NRI Medical College.

Table 1: List of Qualitative interviews and composition of members

FGD 1	Inavolu village	10 Housewives, 25 to 65 years, residents, mostly illiterate
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FGD 2	Dondapadu village	8 Housewives, 25 to 65 years, residents, mostly illiterate
FGD 3	Rural Health Center	10 Village residents, mostly between 5 th class to 10 th , housewives.
FGD 4	Medical College	8 Ayahs and attenders from rural back ground, 25 to 55 years, mostly educated upto class 8 or 10.
FGD 5	Medical College	7 Hospital Ayahs and attenders from rural back ground, 25 to 55 years, mostly educated upto class 8 or 10.

2 Village Health Nurses, 2 ASHAs and 2 post graduate students in the Dept. of Oncology were subjected to Key Informant interviews. 5 In-depth interviews were conducted with rural women from the FGDs. Each group discussion / interview was carried on using a qualitative question guide until reaching an information saturation point. Each session was recorded using an audio recorder and was later transcribed diligently. Emerging themes were identified about knowledge and behaviour.

Results

The Focus Group Discussions with local village women, frontline health workers (ASHAs), Village Health Nurses, including the key informant and in-depth interviews of Hospital Attendants and Staff revealed much information from which certain themes were identified and are presented in Table 2. The issues identified concerning awareness about cancer in rural women are listed in Table 2.

Table 2- Issues identified concerning cancer in rural women

S. No	Identified Themes	Statements
1	Incurability of cancer	<i>“Cancer is a dangerous disease with no medicines. Only treatment with electric shock (radiation therapy)”</i> Rural woman in FGD
2	Stigma	<i>“We know that cancer does not spread by touch. We do not know about its symptoms or signs. Anyway, we’d rather not talk about it”</i> Rural woman in FGD <i>“I always assure patients with cancer that I will keep their information confidential. Still, they hesitate to disclose their symptoms to me. They think that I will discuss their symptoms with others.”</i> ASHA (Village health volunteer) in FGD <i>“Personally, we don’t have any stigma about cancer. But due to the mindset of the society we don’t discuss cancer openly”.</i> Hospital worker
3	Fear of cancer	<i>“I know mainly about breast cancer and cervical cancer. I also have some knowledge about other types of cancers. I educate the people about it too. However, there is a generalized fear about cancer in society in spite of health education”.</i> ASHA <i>Some people are against health education in general and specifically against cancer, saying things like “Don't talk about such diseases” and “Don't attach that kind of disease to us.”</i> Village Health Nurse – Key Informant <i>“I know mainly about breast cancer and cervical cancer. I also have some knowledge about other types of cancers. I educate the people about it too. However, there is a generalized fear about cancer in society in spite of health education”.</i> ASHA

4	Need for support – physical, emotional & spiritual	<p>“We will not discriminate against anyone if they have cancer. We will give moral and spiritual support to people suffering with cancer. However, we really don’t want to talk about such things.” Rural woman in FGD</p> <p>“Proper nutrition and family support are key for recovery from cancer. During their follow-up, we focus on the patients, their hygiene, and their diet. We do not give any health education to the family members about the preventive measures that they should take or about screening for cancer. We assume that they have been advised the same in the hospitals where the patient is getting their treatment”. ASHA</p>
5	Lack of discussion in the community	<p>“I would be ignored if I started a conversation about cancer as it is considered as a deadly disease. People will talk about me and also spread rumors about me if I do so.” Rural woman in FGD</p> <p>“We would not start a conversation with our neighbours about cancer and talk about its spread or share information about any preventive measures. There is a stigma in our society. People don’t prefer to discuss about cancer”. Hospital attendant</p> <p>“Cancer is something that only educated people would be aware of. Why will we know about it? Rural woman in FGD</p>
6	Causes of cancer	<p>“The food that we consume is being produced using chemical fertilizers. This is the main reason for occurrence of cancers. “village “I don’t know anything about cancer, All I know that it is caused by a virus. I am afraid that I might get it from them” Rural woman in FGD</p> <p>“The reason for occurrence of cancer is due to food, tensions and mental stress. Also, people working in mills like cotton mill are prone to cancer”. Hospital attendant</p> <p>“Having good self- hygiene can prevent cancers. Relief from mental stress and having proper food can also prevent diseases like cancer”. Hospital attendant</p>
7	Knowledge about cancer	<p>“Is there any vaccine to prevent cancer? We have no idea. Maybe there are. We do not know their names or for which cancer they are given.” Hospital attendant</p> <p>“I know about breast cancer. There is thickening of the nipple or any lumps in the breast which lead to cancer. A doctor told me when I was pregnant.” Hospital attendant</p> <p>“We were given a talk in our village on the occasion of Women’s’ day. We were told about breast cancer and cervical cancer”. Hospital attendant</p> <p>“People don’t mind sharing that they have Sugar or high blood pressure, but not cancer. Why? Because there is some awareness about Sugar or BP. They can be controlled with medicines. But cancer? We have no knowledge about it, how it is treated or even where to go for checkup when we have a doubt.” Rural woman in FGD</p> <p>“We know that cancer does not spread by touch. We do not know about its symptoms or signs. Anyway, we’d rather not talk about it.” Rural woman in FGD</p>
8	Personal experience	<p>“I consulted the doctor for fever and weakness. When they examined me, they have found a lump in my breast. A biopsy was done and I was told that it is non- cancerous”. Hospital attendant</p> <p>“My husband has throat cancer and is undergoing treatment. The doctors and staff are supportive and give good guidance. The doctor understood our financial burden of treatment and referred us to a center where we can avail free treatment”. Hospital attendant</p> <p>“Even though the treatment was free, the other expenses have been a burden to our family. Through the whole process, we were not supported by our relatives. However, my colleagues at work have given me constant moral support”. Hospital attendant</p> <p>“My husband died due to blood cancer. He did not disclose his diagnosis and we came to know about it after a while. He used medications from Hyderabad. He was afraid how the family will receive the diagnosis and so did not disclose the cancer”. Rural woman in FGD</p>

Discussion

In the past, for many decades, cancer treatment had only a few possibilities which included surgery, radiation therapy, and chemotherapy (singly or in combination). However, in recent years many more options are available with newer approaches such as drugs, biological molecules, and immune-mediated therapies ¹⁰. Patients diagnosed with cancer at an early stage have the best chance of curative treatment and long-term

survival. The true potential of early detection and diagnosis remains largely unexploited due to many challenges ¹¹.

Incurability and fatalism

Fatalism involves a feeling of helplessness and a belief in divine control. It is the helplessness that influences health behaviours the most. Cancer fatalism is the perception that encountering cancer is a certain death sentence and that sooner or later, the individual with cancer will die. Cancer fatalism is seen to be a

barrier to screening, and is also a factor in the delay of diagnosis and receiving treatment¹².

Evidence suggests that fatalistic beliefs discourage people from engaging in screening behaviours that can reduce their cancer risk. People who hold fatalistic beliefs about cancer prevention may be at greater risk of cancer because they are less likely to engage in various prevention behaviours¹³. A fatalistic approach towards disease was mobilised by women as a way of reducing the stress associated with the uncertainties of cancer risks⁷.

Fear of cancer

Cancer is still a word that strikes fear into people's hearts, producing a deep sense of powerlessness. It is still widely believed that a cancer diagnosis is a death sentence, and that there is nothing we can do. Cancer is also particularly frightening because in many cases death from cancer involves great pain and suffering. "Cancer fear" is any fear, anxiety, or worry related to cancer, including causes or consequences of cancer such as fear of treatment for cancer⁸.

Fears of cancer stem from a primary view of cancer as a malicious enemy made more fearsome due to the imagined nearness, the lack of strategies to keep it away, the personal and social implications of becoming a victim to it, and dying because of it⁸. Cancer, thus viewed as an indestructible and unpredictable enemy, affects the role of messages from health media concerning prevention and early detection.

Waters EA et al, suggest that health behaviour theories recognize perceived risk as a prime mover of people's acceptance of healthy behaviours. Ignorance, insufficient motivation and sheer stubbornness may prevent some to accept and articulate this risk perception to cancer thereby refusing to heed to or take health messages seriously¹⁴.

The principal role of health-related information is to help people become capable of making knowledgeable and thoughtful choices. The uncertain and ambiguous information meted out by today's popular social media, which is inadequate and has no reliability or credibility leads only to lower perceptions of the preventability of cancer, its higher perceived risk and higher cancer-related worry¹⁵.

"The public have access to health information. Many people are however, afraid to disclose the symptoms they may be having". **Village Health Nurse**

Stigma

Health-related stigma is associated with many health conditions and is a known barrier to health seeking behaviour, availing healthcare and treatment adherence¹⁶. In some particular diseases or conditions, society is prone to ascribing an adverse social judgement upon the sufferers leading to social ostracization¹⁷.

Stigma related to cancer, in India, is apparent in the forms of social isolation (within the home or community), gossip, verbal abuse and reduced marriage prospects (for self or children). Physical separation within the home, such as separate living, eating places and washing of utensils, clothes etc. Nyblade L et al in their qualitative research found that the three major themes that drive cancer stigma are fear of transmission of cancer,

personal responsibility for having caused cancer, and fatality of a cancer diagnosis¹⁸. Cancer stigma was evidenced as lived experiences like verbal abuse or isolation and fear of revealing diagnosis in anticipation of stigma.

Stigma concerning cancer is a challenge to cancer awareness and control activities in any society. The myths and taboos regarding the disease may continue unabated leading to financial, social and emotional effects on the victims. As cancer awareness improves, the silence as a result of stigma may be lifted giving way to healthy discussions about issues like screening, treatment and outcomes¹⁹.

"If a person is diagnosed with cancer people talk among themselves about it. They will not talk directly to the person about his illness". **Attendant in Hospital**

"Individuals come to us for examination during camps if they have certain symptoms. They prefer camp situation than our health center to maintain anonymity". **Village Health Nurse**

"More patients with cancer come here from rural areas. There is much stigma about cancer in rural areas. We provide moral support to the patients and their family members during their treatment". **Staff Nurse in Cancer Centre with 5 years' experience.**

Need for support – physical, emotional and spiritual

The physical, social, emotional and spiritual adjustment of patients to cancer is linked to the social support that is available to them from family, neighbours and community. As there is significant association between social support and cancer progression, Usta YY suggests that it is necessary for physical adaptation, wellbeing and emotional adjustment in people suffering with cancer²⁰.

Katapodi MC et al in their discussion on social support in breast cancer screening, suggest that it can be seen as emotional support, instrumental support, appraisal support and informational support²¹. Emotional support is respect, trust, concern and listening which may be provided by family and neighbours. Instrumental support consists of assistance in kind, money, labour, and time. Appraisal support is that which is provided by peers to lifts the individual's self-esteem. Informational support consists of advice and suggestions for problem solving.

The National Cancer Institute in the USA, suggests that spiritual coping in terms of spiritual beliefs and practices based on individuals' spiritual needs, culture and traditions is seen to help many patients with cancer to cope with their illness. Spirituality deals with an individual's beliefs about the meaning of life which imparts a sense of peace, purpose, and connection with others. Spiritual distress on the other hand may make it harder for cancer patients to cope with their disease²². It is important for health personnel and communities dealing with people suffering with terminal cancer, to understand and support their spiritual journey which contributes to their wellbeing in the midst of their struggles²³.

"I have no stigma in relation to cancer. I have also provided mental support to a person suffering from cancer. With mental and emotional support, the life span of a cancer patient will increase". **Hospital attendant**

"We will not discriminate against anyone if they have cancer. We will give moral and spiritual support to people suffering with cancer. However, we really don't want to talk about such things." **Village woman in FGD.**

Causes of Cancers

Tobacco use, poor nutrition, curse of the Gods, fate, poverty, hereditary disease, previous surgeries etc. are some of the many causes attributed to cancer by people. Ideas such as only old people get cancer and cancer can spread from one person to another are also seen in the societies. 19, 24.

"I don't know anything about cancer. All I know that it is caused by a virus. I am afraid that I might get it from them"

Village woman in FGD

"We get to know that a person has cancer only after she has undergone some kind of treatment for it. We then just provide some moral support to that person and empathize with her family about their financial burden and emotional trauma".

Village woman in FGD

Knowledge about Cancer

Even as many people have a feeling of dread with regard to cancer and anything to with it, a good number today also believe that it is preventable and can be cured too. Elangovan V et al in their study at Chennai, India, found that people with lower education and older people had a low level of knowledge about cancer. While some believe that only poor people get cancer, a good number do believe that cancer is not contagious, that it is not a curse, that it can be cured ²⁴.

"We don't have any knowledge about cancer nor its symptoms or signs. We know little about breast cancer. It is having a lump in the breast". **Village woman in FGD**

"I know the definition of cancer, its various types, the signs and symptoms of breast and cervical cancer, and other symptoms of other cancers. I am aware of the steps that should be taken to avoid developing cancer as well as those that should be followed after the diagnosis and throughout treatment. I certainly always educate people about the common prevalent cancers during visits, village health, nutrition and sanitation days". **VHN, In depth Interview**

"I got myself transferred from neurology dept. to the oncology dept. two years back as I was curious about cancer and wanted to improve my knowledge about cancer. I have learnt and experienced many new things in the last two years. **Staff nurse in cancer centre**

Personal experience

Future educational programs with anecdotal perspectives of people who had cancer and individuals who have had lived experience with cancer and emerged successfully, will better prepare the communities and motivate and enhance learner confidence and competency in dealing with cancer ²⁵.

While no two patients have the same experience, people who've been through a cancer often have a lot of helpful information to share in terms of first symptoms, treatment decisions, questions to ask and what to expect. Learning from experiences, the various issues involved like cancer fear and the associated

behavioural effects will help in the design of effective public health messages ²⁶.

"I found that I had lumps in my breast. I consulted the doctor and was assured that it was not cancer". Hospital attendant
"My grandmother suffered from cancer of the cervix. She had vaginal bleeding for a long time but she ignored it and never shared her symptom with anyone. She thought it was a part of menopause. She consulted a doctor after a long time and it was diagnosed as cancer. She received two doses of chemotherapy but didn't survive". Hospital attendant

"My aunt had a white vaginal discharge after attaining menopause. She had a checkup and was diagnosed to have cancer. She received treatment for it and survived for 2 years after the completion of treatment. She even used to work in the fields after treatment. She however died later". Hospital attendant

"My husband has throat cancer and is undergoing treatment. The doctors and staff are supportive and give good guidance. The doctor understood our financial burden of treatment and referred us to a center where we can avail free treatment".

Hospital attendant

"Though some people have no symptoms, they listen to us. They may also be familiar with such symptoms as they have come across them in their families or neighbours". MPHW

Conclusion:

This study reveals that knowledge about cancer in rural women is low and there are many misconceptions. There is reluctance to discuss about it due to fear and stigma. Efforts of healthcare providers are mainly hospital based and are directed only towards the patients. Social media exposure is not sufficient or reliable to bring about changes in knowledge, attitude or behaviours. This in turn has a negative effect on screening for early diagnosis and healthcare seeking.

Recommendations:

Following appropriate cancer education programmes with a stress on rural populations, prevention and screening programmes must be taken up urgently. Healthcare workers and volunteers in rural health care must be given necessary training to be able to give adequate cancer awareness, addressing key misconceptions. Simple but effective cancer prevention messages created by experienced educators aimed at rural or less educated people must be widely distributed ²⁷.

Communities must not only have adequate and optimized cancer awareness but also show openness towards it and be able to have cancer-related conversations confidently. People who are exposed to the right and culturally adapted information about cancer, must go on to becoming advocates of prompt help seeking for early cancer symptoms or signs ²⁸. An example is the Cancer Research UK's awareness training programme (Talk Cancer) which equips and empowers grassroots healthcare staff and volunteers to raise awareness of cancer and promote health behaviour changes such as awareness and openness towards cancer in their communities ²⁹.

Individual	Young, educated and employed women are open to gaining awareness on cancer. There is however generally fear and stigma.
Community	Poor cancer education and therefore poor knowledge, no screening facilities in Primary care. Screening camps are not effective.
Health Care System	Mainly curative, preventive aspect is neglected, no shared decision making with patient and family members.
General Psycho-social behaviour	Poor attitudes, beliefs, fear of isolation in society, misconceptions.

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