

RESEARCH ARTICLE

Treatment Experiences of Women with Reproductive Cancers in Odisha, India: A Qualitative Exploration of Enablers and Barriers

Sanghamitra Pati^{1*}, Abhimanyu Singh Chauhan², Sandeep Mahapatra³, Sabita Nayak⁴, Sukdev Nayak⁵, David Weller⁶

Abstract

Introduction: Cancer continues to be a major menace to our Indian society notwithstanding significant progress in diagnosis and treatment. In India cancer mortality rates in women are high compared to other countries, despite efforts to improve survival through the development of effective detection techniques and increased numbers of viable treatment options. Indian women's advanced stage of disease at diagnosis is largely attributable to delay in seeking treatment. The present qualitative inquiry was conducted with the aim of capturing the treatment experiences of patients with gynecology cancer at a tertiary care hospital and understanding the barriers, enablers, stress and apprehension they experience during the treatment phases. **Methods:** Twenty-one in-depth interviews were conducted with women diagnosed with gynecological cancers and undergoing at least one treatment intervention in the Inpatient Department (IPD). Theme guides were developed with a review of the literature and consultation with experts in the field. Data were collected by trained investigators who were well versed with the local language and analyzed using an inductive approach. Results are presented in the form of core- and sub-themes evolved during this process. **Results:** Out of the 21 respondents, 19 were married and 2 were widows. Nineteen had attained more than secondary qualifications. Nearly all women described themselves as 'housewives'. Amongst participants, 13 were diagnosed with breast cancer, 5 with ovarian cancer and 3 with cervical cancer. Thematic framework analysis of the transcripts yielded six key themes: 1) best and worst experiences during the treatment process; 2) financial and emotional stress; 3) care giving and social support; 4) satisfaction with the medical staff; 5) preferences for a female gynecologist and female gynecology ward; and 6) prompt and free treatment. Quotable quotes were presented in the table against every theme. **Conclusion:** Strengths in the Indian health care delivery system need to be built upon, while attention should be paid to developing effective psychosocial interventions, with a robust financial protection plan for patients and their involvement in decision making. Counselling of patients should be made part of a routine protocol.

Keywords: Gynecologic cancer- patient experience- treatment experience- odisha- India

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Introduction

Cancer continues to be a major threat to our society despite advancements in diagnosis and treatment (Kotnis et al, 2005). It is the second largest cause for mortality around the world after cardiovascular diseases (Jemal et al, 2007). In women, the burden of reproductive cancer is increasing, particularly in developing countries (Jemal et al, 2011). Breast cancer is the most commonly diagnosed malignancy in women worldwide (22%) and in India (18.5%) it ranks second to cervical cancer (Kamath et al, 2013). There are roughly 87,500 newly diagnosed cervical cancer patients each year in India, 16% of the world's total cases (ICO Summary Report 2014). About 80% of cervical

cancer cases occur in developing countries where, in many regions, it is the most common cancer among women (Boyle and Levin, 2008; Ali et al, 2011).

In India, cancer mortality rates in women are high compared to other countries, despite efforts to improve survival through the development of effective detection techniques and increased numbers of viable treatment options (American Cancer Society, 2005; Joslyn and West, 2000). The most prevalent finding concerning decreased survival for Indian women has been their presentation for diagnosis and treatment at a more advanced stage of the disease, as evidenced by increased tumor size and an increased frequency and number of positive axillary lymph nodes (Li et al, 2003; Beenken 2003). Indian women's

¹Director, Regional Medical Research Centre, Chandrasekharpur, ³Indian Institute of Public Health, ⁵All India Institute of Medical Research Sijua Bhubaneswar, ⁴Department of Health and Family Welfare, Government of Odisha, Odisha, ²Public Health Foundation of Plot 47, Sector 44 Gurgaon, Haryana, India, ⁶Centre for Population Health Sciences, University of Edinburgh Old Medical School, Teviot Place, Edinburgh EH8 9AG, United Kingdom. *For Correspondence: drsanghamitra12@gmail.com

advanced stage of disease at diagnosis has been attributed largely to a delay in seeking treatment (Fretas and Weller et al., 2015; Pakseresht et al., 2014). Multidisciplinary research over the last several decades has examined the association of demographic and psychosocial factors with delay in seeking diagnosis and treatment for cancer symptoms – this has included retrospective studies and comprehensive reviews. Delay has been attributed primarily to patient characteristics such as fatalistic attitudes and distrust of the healthcare system (Powe and Finnie, 2003).

Cancer patients have to cope with a great deal of distress (Nancy and Ann, 2008). Even though reproductive cancer is a widely acknowledged health issue in India, little is known about the experiences of these patients. A better understanding of how women live with reproductive cancer and their treatment experiences is needed to help health practitioners meet the needs of this group of women (Bonsu et al., 2014). It is imperative that health care providers, policymakers, and the public examine the quality of care provided to the ever-increasing number of individuals at risk for, living with, and surviving cancer. A recent study among patients with inoperable lung cancer showed that for 27 percent of these patients their experiences with healthcare services were among their most important concerns. Waiting times, problems with information and communication and a lack of continuity in healthcare professionals are among the healthcare experiences that cause distress (Tishelman et al, 2010).

Individuals facing a possible diagnosis of cancer are confronted with multiple physical, psychological, and educational challenges. A diagnosis of cancer increases susceptibility to stress (Salleh, 2009); indeed, cancer patients are at high risk for a variety of emotional disorders including anxiety, traumatic stress, and depression (Salleh, 2009; Adler and Ann, 2008). Patients' stress can be amplified by long waiting room times, lack of information, poor communication between clinic staff and patients, and inadequate psychosocial care (Lis et al, 2009).

In this context, the present study was conducted with the aim of documenting the treatment experiences of gynecology cancer patients at a tertiary care hospital and understanding the barriers, enablers, stress and apprehension they experience during the phase of treatment at the hospital.

Materials and Methods

Study Design, settings and participants

This cross-sectional study was conducted in the Acharya Harihar Regional Cancer Center (AHRCC), Cuttack, a tertiary cancer specialty center in the state of Odisha, India. It caters to the patients of Odisha and its neighboring states including Andhra Pradesh, Madhya Pradesh, Bihar, Jharkhand and Chhattisgarh. Over the last five years AHRCC has provided annually more than 5000 chemotherapy cycles per year to its inpatients, and 10,000 cycles per year in outpatient clinics. We included a sample of women, diagnosed with gynecological cancers and undergone at-least one treatment intervention at the Inpatient Department (IPD).

Selection of participants

Using hospital records, we prepared a list of eligible patients discharged from AHRCC in past one month. We assumed one month as an adequate recall period for rich information. To achieve maximum variation (Vitcu et al., 2007) ,patients were randomly selected from the list. Contact details of the selected patients were then obtained from the hospital records. Participants were briefed regarding the objective of the study prior to seeking their consent. Twenty one women gave consent to participate in the study. Participants were interviewed at the place of their convenience, mostly at their home.

Interview guide and data collection

Through extensive literature review and consulting the experts of the domain, an interview guide was prepared to collect information on; 1. Patients' demographic profile, 2. Diagnosis & treatment history, 3. Experiences during treatment, 4.Views regarding care, 5. Support received and suggestions for improving treatment pathways. All the interviews were conducted by two authors (SP and ASC), who were well-versed with qualitative interviewing skills and were proficient with the local language.

Data Analysis

Preliminary analyses of qualitative data was undertaken while data collection was in progress, and results were discussed with the study team. The data collection process was stopped when information received from the respondents reached a stage of saturation and no new themes were emerging. The interviews conducted with initial classified themes were recorded and transcribed by two of the authors (SP, ASC). Emerging themes were reviewed through existing literature and in consultation with oncology specialist. To ensure the accuracy and quality of data transcription, another co-author gave a final quality assessment for the necessary paraphrasing. We used software NVivo Version 8.0 for analyzing the qualitative data, adopting a “thematic framework approach” (Qualitative Research Methods Overview – Internet, 2016).

‘Axial’ coding has been assigned to each fragmented sentence of the text/paragraph (Bohm, 2004). Axial codes are the labels assigned to open coded fragments of the texts. To further combine the different closely related axial codes into more precise core category; ‘Selective’ coding has been done. Continuous revisions of the codes have been done in the analysis process before arriving at final themes. Through both contesting and supportive responses while checking the interpretation, all authors – after necessary inclusions and exclusions – finalized the axial and selective coding. Semi-quantification (Qualifiers) of the responses was done adopting the IPEN methodology. Key themes were emerged and qualifiers were calculated to generate semi quantified findings. Qualifiers are the representations of magnitude of similar kinds of open-coded responses falling under the same theme or family by different respondents. In the current study, if a certain type of open-coded response has been quoted, the percentage is represented in Table 1.

Ethical Clearance

The study was approved by the Indian Institute of Public Health, Bhubaneswar institutional ethical committee. Patients were briefed about the study objectives before the interview and written consent was obtained. Anonymity of the participants and confidentiality of data was assured.

Results

Out of a total 101 patients admitted at ARHCC during the study period, 21 were enrolled in the study. Mean age of the participants was 49, ranging from 28 to 64 years. Out of the 21 respondents, 19 were married and 2 were widow. Nineteen had attained more than secondary qualifications. Nearly all women described themselves as 'housewives'. Amongst participants, 13 were diagnosed with breast cancer, 5 with ovarian cancer and 3 with cervical cancer. Thematic framework analysis of the transcripts yielded six key themes: 1) best and worst experiences during the treatment process, 2) financial and emotional stress, 3) care giving and social support, 4) satisfaction with the medical Staff, 5) Preferences for a female gynecologist and female gynecology ward and 6) Prompt and free treatment. The verbatim quotes have been summarized in Table 2.

Experiences during treatment

Best Experiences

Women (3+) described 'supportive behavior' amongst their health care providers as their best experience of the whole TSP. The features they particularly valued included 'continuous advice', information and support during chemotherapy regarding the forthcoming treatment and most importantly the moral & mental support to 'fight the disease'. Immediate and prompt start of the treatment was reported by (2+) women as their best experience of the whole TSP. While (<1+) women feels early detection as the best thing of the overall treatment.

Worst Experiences

Pain during chemotherapy was reported by most of the women (4+) as the worst event of TSP, though all participants appreciated the palliative care practice at the set-up and reported their pain was managed well. Other negative experiences included long travelling distances for treatment, behavior of some staff and delayed diagnosis.

Stress due to treatment

Financial Stress

Most of the women (4+) reported treatment as a financial burden on their family. Some participants expressed real anxiety in meeting their financial obligations – this included concerns about meeting medical costs and loss of wages. They also reported that treatment costs incurred resulted in degradation of family economic status.

Emotional & psychological distress

Some women (3+) also stated that they were emotionally distressed; there were two main sources of this distress. Firstly, the thought of being a burden on the family, unable to serve their usual role was distressing. to the second key source was the psychological stress of being diagnosed with cancer and apprehension about cure and treatment procedures.

Apprehension of cure and treatment procedure

Interestingly, some (2+) of the women reported that the prescription of chemotherapy, according to their beliefs, meant they were in the terminal stage of their cancer with little chance of survival. Some women also reported concerns about adverse effects of chemotherapy – they highlighted side effects resulting in destruction of basic body functions like joint movement, metabolism and hair loss. A small number of women also stated that women may become 'contaminated' and 'impure' after chemotherapy.

Care giving and social support

While most women identified the whole family as care givers during the treatment phase, the majority reported their husband as the main care giver. Few women (<1+) stated that they had received support from the neighbors and friends. Social economic status of the respondents was recorded quite low. The majority of women stated that they had received support to access treatment services. Some women also felt that moral support from caregivers helped them out to fight against the disease and to maintain their morale.

Level of satisfaction from the services of medical staff

Verbatim analysis revealed participants' views regarding services provided to them on the part of doctors and nursing care. All women (5+) reported a high level of satisfaction with their gynecologist. Women were quite

Table 1. Qualifier Representation

Proportion of Respondents	Qualifiers and adjectives used for semi-quantitative	Qualifiers used	expression of observation
			Adjectives Used
< 10 %		<1+	Very few
10-24%		1+	Some
25-49%		2+	Approximately half
50-74%		3+	Majority/over half
75-89%		4+	Most
>90%		5+	Almost all

Table 2. Verbatim Quotes

S. No.	Theme	Quotes
1	Stress (Financial)(4+)	<p>“It’s a matter of distress for me, I don’t know how much more me and my family has to spend on the treatment. Already we have sold out our shop for the treatment” (ID 21)</p> <p>“I have four daughters, have to get those married in near future, and don’t know how I will be able to do that, from where the money comes” (ID 18)</p> <p>“He is a daily laborer. My child is only 3 years old. He goes out to the site for earnings. After being diagnosed with the cancer, many a times he has to look after me. Many a time have to take me to clinics and hospital for treatment. He lost his job once because of too many leaves because of me.” (ID 11)</p>
2	Stress (Psychological)(3+)	<p>“It fills my heart with anguish when I see I am worthless as a wife and mother...” (ID 09)</p> <p>“Instead of being a help, I have become a burden for my family” (ID 05)</p> <p>“I should have been taking care of my son, but with illness now he has to fend for himself. It hurts me to see my child’s daily plight” (ID 02)</p>
3	Stress (Apprehension)(2+)	<p>“I was distressed and shocked after listening that I have been prescribed chemotherapy. I started thinking about my family, who will look after my children, how they will grow up. I have a very short time left to live” (ID04)</p> <p>“I will be almost paralyzed after undergoing chemotherapy as it results in loss of fluid from the joints of limbs and body hairs” (ID 05)</p> <p>“I will get old soon, after chemotherapy, the digestion in stomach reduces and body becomes weak day by day” (ID 10)</p>
4	Preference of doctor and ward	<p>“What matters to us is a good doctor who can cure us.” (ID 12)</p> <p>“The doctor should able to treat me well. If a male doctor can do it better, I am happier with him” (ID 08)</p> <p>“We have crossed the youth, how does it matter if the doctor is male or female” (ID 15)</p> <p>“My treatment doctor is male; but I have not experienced any embarrassing situation” (ID 19)</p>

happy about the doctor’s treatment practice, information being provided by the doctor regarding the disease and forthcoming procedures like chemotherapy, as well as behavior and conduct during treatment. In contrast, nearly one fourth of the women (1+) reported dissatisfaction with the nursing services.

Preference of female doctor and ward

Thematic analysis of the patients’ views on gynecologist gender revealed mixed findings. The majority of women (4+) expressed positive attitudes and feeling of comfort regarding having a male gynecologist surgeon. They saw their doctor as a ‘care giver’, surpassing identification based on gender, and prioritizing quality of care, treatment and cure.

Nevertheless, nearly one quarter of participants (1+) Expressed their preference for a female gynecologist. None of the women stated the reason for their choice. Similarly, in terms of choice of ward, a small number indicated a preference for an all-female ward, although reasons for this choice weren’t expressed.

Prompt and Free treatment

Participants (4+) indicated a strong desire for prompt after diagnosis, and for cancer treatments to be provided free of cost. 4+ Women believes that we could fight to combat the disease through preventive approach and community screening. Early diagnosis is emphasized as the important measure to achieve the same.

Discussion

This study was conducted to document the treatment experiences of patients with reproductive cancer at a tertiary care hospital, and understand the barriers, enablers, stress and apprehension they experience during the phase of treatment at the hospital. Treatment experiences and satisfaction have been reported as the major driver of adherence to the treatment (Chrystyn et al., 2014) (Haase et al., 2016).

The impact of low treatment satisfaction on medication adherence is of particular concern in patients with chronic diseases. It has been found that up to one-half of patients with chronic illness end up making medication-related decisions without looking for medical advice, becoming “non-adherent” to such an extent that they compromise the effectiveness of treatment (Sweileh et al., 2011).

Financial needs arise from the high costs of medical treatment, drugs, and other health support needs, such as medical supplies that are not covered due to a lack of government supported health insurance in India. In the current study the majority of participants reported that there is no financial protection. Adverse effects of no or inadequate insurance are well documented in the literature and include poorer health prior to receipt of care, delayed or no treatment, failure to get needed prescription medications, and poor outcomes of medical treatment for people with cancer. The costs of cancer treatment can

be prohibitive for low income families – and can result in feelings of guilt, self-blame and stigma (Reuter et al., 2006; Rhodes and Lakey, 1999). This financial stress and self-blaming can add to the psychological or emotional stress of a cancer diagnosis. First, patients are not able to perform their usual roles in their family and society and, second, dependency on family members for care giving results in low self-evaluation (Badger et al, 2004). This coupled with uncertainty of treatment outcome, leads to cumulative stress. Similar findings have been reported in the international literature (Lim et al, 2011; Ahlberg et al., 2004; Aass et al., 2004; Satrk, 2002).

Apprehension, feelings of powerlessness, and fearing ‘loss of control’ are linked to treatment therapy for cancer in many participants in our study – indeed apprehension is often associated with a cancer diagnosis (Takahashi et al., 2008). It is evident from the findings of this study that there is a lack of physician and patient interaction prior to chemotherapy. Involvement of patients in decision making and counselling of patients should be made a routine protocol. Evidence suggests that patients who are more engaged in their health care decision making are more likely to experience confidence and satisfaction with treatment decisions which also increases their trust on their health care providers (Arora et al., 2004). Doctors do not feel the need for the same neither it’s a demand from the patient side. Secondly, cancer treatment providers in India typically struggle to keep up with patient demand making it difficult for physicians to invest time in counselling of patients before commencing treatments. Assigning these information provision tasks to other members of the treatment team may be helpful in meeting this gap.

Cancer survival rates are poor in comparison with western countries (Swaminathan and Rama, 2008). Long delays in diagnoses are a leading cause of these poor outcomes (Pati et al., 2013). Pessimistic attitudes about chemotherapy treatment are often reported in the literature - one reason for this could be knowledge of unfavorable survival rates in cancer patients in India (Agarwal and Ramakant, 2008; Gulengul et al, 2016). Similar views were also recorded in the present study. Delayed diagnoses and lack of screening facilities have been cited as major barriers to cancer control.

Uncertainty in treatment outcome could have adverse implications such as non-adherence or drop out from treatment and poor treatment compliance and depression (Jin, 2008). Health system responsiveness is also vital – implying readiness to meet the increasingly complex physical, psychological and social needs among the growing number of patients with cancer in India. Relevant information, education and communication in context to cancer risk and treatment is also important. A financial protection plan for universal coverage of all sections of the society (an idea which has long been mooted in India) would also help significantly in addressing cancer patients’ needs.

The Indian health care system is beginning to recognize the gaps in health service delivery, and patient centered care has become the goal in many health care settings. Participants in our study typically showed

high levels of satisfaction in the care they received - yet significant challenges remain in understanding distress, fear of recurrence, outcomes of treatment and dealing with financial hardships. Psychosocial interventions may benefit women cancer patients both psychologically and physically when treatment and support is adapted to their unique needs. Strengths in the Indian health care delivery system need to be built upon, while attention is paid to developing effective psychosocial interventions - with a robust financial protection plan for patients.

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