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Original Research Article

Psychosocial issues of newly diagnosed gynaecological cancer patients: a qualitative study

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ABSTRACT

Background: The diagnosis of cancer generates significant anxiety and uncertainty. We aimed to identify the psychosocial needs and priorities of women newly diagnosed with gynaecological cancers.

Methods: The study employed a qualitative research design. In-depth interviews were conducted with patients and their attendants to explore their anxieties, information needs, expectations, and treatment priorities. After obtaining informed written consent, 16 patients were included. Data analysis was performed through conventional qualitative content analysis, following a descriptive-explorative approach. This process involved extracting codes, categories, and themes to better understand the patients' experiences.

Results: The content analysis of the transcripts brought forth five themes: 1) cause of cancer and its effects, 2) information needs and expectations, 3) concerns about prognosis and family, 4) dependence versus independence and 5) faith and hope in God. In our setting, patients with gynaecological cancer had low information needs regarding their disease stage and treatment options. They trusted their healthcare providers and preferred not to burden themselves with potentially distressing information. They sought information on prognosis and the chance of cure. Concerns about finances and daily living were prevalent, while worries about sexual activity were less common. Spiritual issues affected many and included despondency and faith in God.

Conclusions: Understanding patients' information needs and anxieties will enhance their care and treatment adherence.

Keywords: Anxiety, Expectations, Information needs, Psychosocial, Qualitative study, Gynaecological cancer

INTRODUCTION

A cancer diagnosis brings significant emotional and psychological distress, and women in India face additional challenges due to financial dependence, low health literacy, and cultural barriers. According to the 2022 global cancer observatory, breast, cervical, and ovarian cancers remain the most prevalent malignancies among Indian women.[1] These patients often struggle to access reliable information, are at risk of exploitation by unqualified practitioners, and rarely receive adequate support for sensitive issues such as sexual health.

Most evidence on psychosocial concerns among Indian women with gynaecological cancers is derived from those with advanced disease receiving palliative care.[2] A 2023 review on psycho-oncology services in India highlights the significant emotional burden on patients and caregivers and underscores the absence of structured psychosocial support systems.[3] A 2022 analytical review reported that

74% of cancer patients experience stigma, with poor adherence (41%) and high treatment discontinuation (28%), mainly due to financial constraints (65%).[4] Additionally, a study on women with incurable cervical cancer found high levels of depression, anxiety, stigma, and unmet sexual-health needs, recommending integrated mental-health services, improved community awareness, and early palliative care.[5] Another study found that compared to breast cancer, gynaecological cancer patients were less satisfied with the information received and reported lower levels of QoL.[6] Miller et al surveyed 95 patients and found that most of them wanted physicians to take an active role in addressing their psychosocial needs.[7]

Despite these insights, limited data are available on the specific concerns of women newly diagnosed with gynaecological cancers in low- and middle-income settings. Access to accurate information early in the disease course is essential for reducing anxiety, supporting decision-making, and improving quality of life.[8] Effective management of psychosocial concerns plays a crucial role in improving treatment adherence and enhancing the overall quality of life of patients with gynaecological malignancies.[9]

In this context, the present study aims to explore the needs and concerns of women with newly diagnosed gynaecological cancer, to strengthen holistic, patient-centred care in the Indian setting.

METHODS

Study design

This study employed a descriptive–exploratory qualitative design using conventional qualitative content analysis. This approach allowed an in-depth exploration of the experiences, concerns, and expectations of women newly diagnosed with gynecologic cancers.

Study setting and duration

The study was conducted in the gynecologic oncology department of a tertiary care hospital in Tamil Nadu, India. Data collection took place over a defined study period of 3 months in 2020(June 1st to August 31st).

Inclusion criteria

Women recently diagnosed with a gynecologic cancer, patients undergoing treatment in the department for the first time and able to understand and communicate in English, Tamil, Malayalam, or Hindi were included.

Exclusion criteria

Patients who were terminally ill and patients with known psychiatric disorders that could impair communication or consent were excluded.

Sampling technique

A purposive sampling method was used to recruit participants who could provide rich, relevant, and diverse insights. Sixteen eligible patients were included. Recruitment continued until data saturation was reached, when no new themes emerged.

Data collection procedure

Data were collected through in-depth, semi-structured interviews using an interview guide centred on four major domains: Information needs, emotional concerns, personal priorities and expectations from care. Interviews began with broad, open-ended questions and progressed according to participants' responses, ensuring a flexible and participant-led approach. All interviews were conducted by the primary investigator in a non-directive, open-ended style to encourage free expression. Each interview was audio-recorded with participant consent. Audio recordings were transcribed verbatim by the primary author, with attention to pauses, emphasis, and relevant verbal cues to maintain narrative authenticity.

Data analysis

A conventional content analysis approach was used.[10] The investigators repeatedly read the transcripts to achieve immersion and derive meaning directly from participants' words.

The process included: initial open coding, grouping similar codes into categories and development of broader themes.

Coding and theme refinement were reviewed by the co-authors to enhance credibility and minimize bias. Regular team discussions ensured consensus and maintained methodological rigor.

Ethical considerations

Ethical clearance was obtained from institutional research committee, CMC Vellore [IRB min. No. 13141, dated 08.07.2020]. Informed written consent was taken from all participants.

Confidentiality, anonymity, and the voluntary nature of participation were assured throughout the research process.

RESULTS

A total of 16 patients who satisfied the eligibility criteria were recruited for the study (Figure 1). Their baseline characteristics are outlined in Table 1.

Themes

The content analysis of the transcripts revealed five themes.

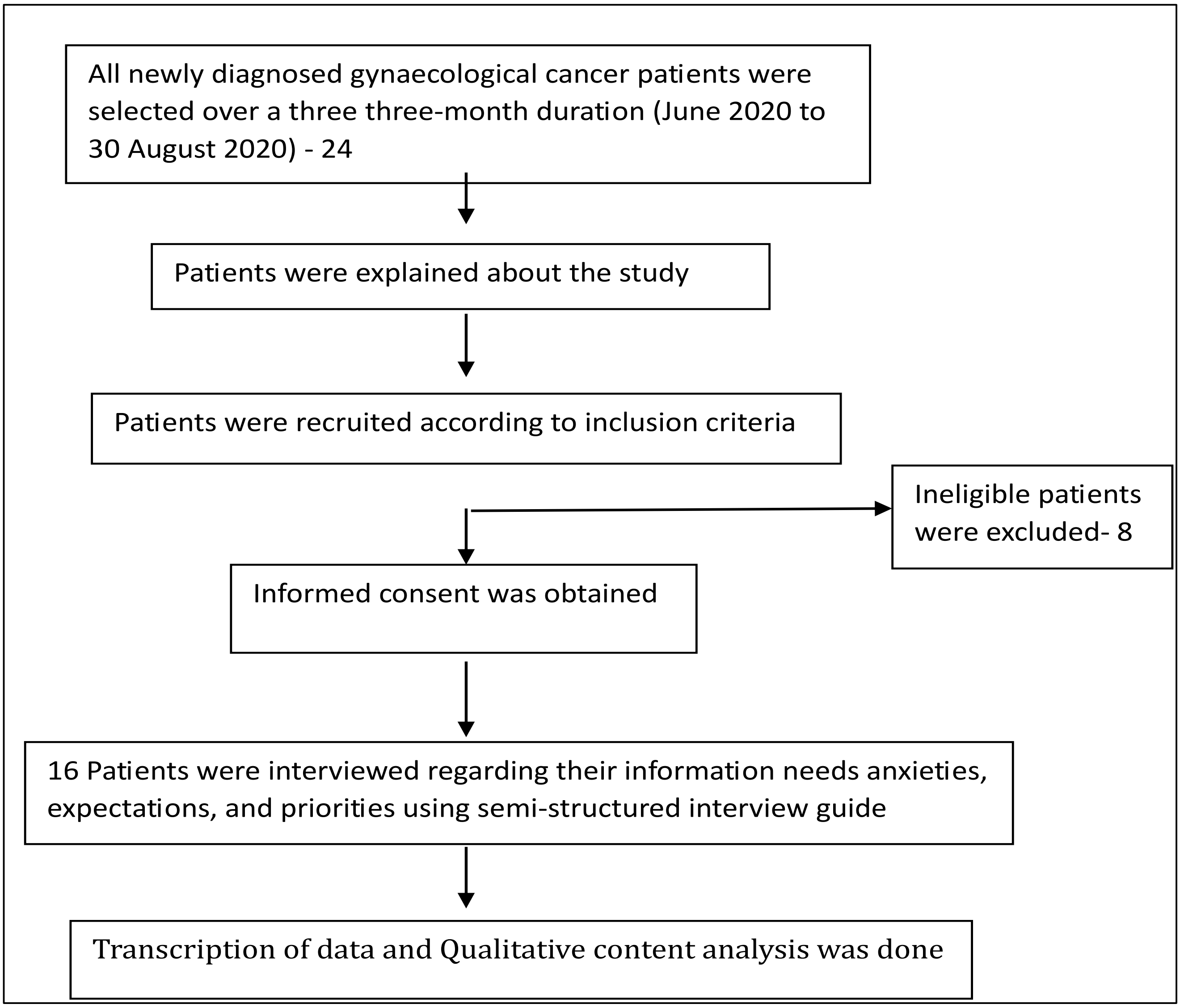

Figure 1: Flow diagram of patient recruitment.

Table 1: Baseline characteristics.

Variables	N
Mean age (in years)	54.8 (SD 9.5)
Median years of education	4.5 (0 to 20)
Income status	
High	5 (31.3%)
Middle	6 (37.4 %)
Low	5 (31.3 %)
Diagnosis	
Carcinoma ovary	6 (37.4%)
Carcinoma endometrium	9 (56.3%)
Carcinoma cervix	1 (6.3%)
Marital status	
Married	16 (100%)
Unmarried	0
Occupation	
Daily wage worker	2 (12.5%)
Lawyer	1 (6.25%)
Housewife	13 (81.25%)

Table 2: Themes.

Theme	Description
Cause of cancer and its effects	Participants' perceptions about what caused their cancer and how the diagnosis affected their physical, emotional, and social well-being.
Information needs and expectations	Need for clear communication, explanations about disease, treatment options, side effects, and expectations from healthcare providers.
Concerns about prognosis and family	Worries about survival, future outcomes, impact on family members, and emotional burden on loved ones.
Dependence versus independence	Struggle between needing help and wanting autonomy; changes in daily functioning and reliance on caregivers.
Faith and hope in God	Reliance on spiritual beliefs, prayer, and trust in God as a source of strength, hope, and coping during illness.

Cause of cancer and its effects

Most patients demonstrated limited understanding of how cancer develops and what its consequences are. Their immediate concern was, "How did this happen and why?" Many women questioned whether their lifestyle choices contributed to the disease. They were confused about how their cancer had progressed to an advanced stage before detection and why they did not notice any warning signs earlier. Patients expressed emotional distress and disbelief regarding their diagnosis. Some questioned their family history, dietary habits, and personal choices as possible causes. Others expressed sadness and frustration over being unable to identify a reason for their illness. Patients felt reassured when survival chances and treatment expectations were clearly explained. They valued hearing positive outcomes from other patients or relatives who had survived cancer. However, when doctors appeared uncertain or avoided giving clear answers, patients perceived this as withholding information. Many wanted direct clarity about cure rates, recurrence, and what to expect after surgery (Table 3).

Information needs and expectations

Although most patients did not actively seek additional information, a few felt that the details provided by the healthcare team were insufficient. Some tried to fill this gap themselves-one patient even turned to YouTube to understand cancer, its treatment, and surgical procedures. Many women, however, preferred not to know the full details of their diagnosis or treatment. Family members sometimes chose to withhold information to protect the patient from distress. In some cases, relatives felt that excessive explanation increased anxiety for both the patient and themselves. Support from friends or others who had undergone cancer treatment provided comfort to some. A few patients expressed satisfaction with the information they received, acknowledging personal limitations such as a lack of formal education. Others regretted their limited awareness about cancer. Overall, women mainly sought reassurance that they would be cured after treatment and did not desire detailed explanations beyond that (Table 4).

Concerns about prognosis and family

The cancer diagnosis generated significant fear and anxiety among all patients. Many were frightened of the treatment process, potential complications, and the possibility of recurrence. Concerns about surgery, radiation therapy, and the long-term impact on their bodies were common. Several patients associated cancer with suffering and death, deepening their emotional distress. Beyond personal fears, many women worried about their families-particularly children, spouses, elderly parents, and grandchildren. Some were anxious about whether their diagnosis increased the risk for their offspring. Others, who were primary earners, worried about the financial impact on their households, including job loss and loan repayments. For some, concerns extended to personal relationships. One younger patient expressed fear about the future of her marriage and how treatment might affect her intimacy and family life (Table 5).

Dependence versus independence

Most patients accepted treatment without questioning it, as they placed immense trust in their doctors. Many believed that surgery-especially the removal of the uterus-would eliminate the cancer. Husbands or children often led decision-making, although patients expressed a deep desire to remain independent and avoid burdening their families. Financial difficulties were common among participants, yet none refused treatment because of cost. Women emphasized their wish to continue caring for their families, remain productive, and maintain autonomy in their daily activities. For some, faith in medical science or previous family experiences with cancer shaped their outlook. Despite financial strain, including loans or selling assets, patients prioritized receiving treatment while worrying about the economic impact on their household (Table 6).

Faith and hope in God

Hope and faith in God played a central role in helping many patients cope with their diagnosis. Several felt that despite living a righteous, prayerful life, their illness was a test of faith. Their belief in divine protection and God's plan gave them strength and reassurance during treatment. Some trusted that God would guide the doctors and lead them toward recovery, while others questioned why they had been chosen to face this challenge despite their devotion. Overall, spiritual beliefs formed a powerful source of comfort, acceptance, and resilience (Table 7).

Table 3: Patient quotes for cause of cancer and its effects.

Patient no.	Quote
P2	“I felt very sad and uncomfortable. Why did this happen to me? No one in my family or my generation has had this disease. It’s not that I married within the family also!”
P6	“I did only good things as far as I know. Why has this happened to me now?”
P4	“I never ate from hotels and had only simple home-cooked meals, strictly vegetarian. I can’t believe I got this. I can’t imagine why!”
P3	“I want to know whether I will be cured after the surgery, will the disease come back later.”
P10	“I wanted to know whether patients with this disease usually get cured or not but, nobody gave me the answers!”

Table 4: Patient quotes for information needs and expectations.

Patient no.	Quotes
P8	“I am watching YouTube daily. What is laser (laparoscopic) surgery? What is cancer? I heard doctors saying cancer can be cured. That was a huge relief.”
P7	“She knows something bad is happening, but doesn’t want to know the details. Hence, we didn’t tell her about the severity of the disease. Once the surgery is over, we are planning to bring the kids to her, and we believe she will feel better with that.”
P7	“Explaining more and more is making me and my patient more disturbed.”
P5	“I am happy with the information I got. Even if you talk more about it, I will not understand. I didn’t go to school.”
P9	“It is more than enough if I get cured. I don’t want to hear any details except that I will be alright.”

Table 5: Patient quotes.

Patient no.	Quote
P1	“I felt paralyzed upon hearing the word cancer. I knew many people who died of cancer, and they suffered a lot.”
P8	“I didn’t sleep. I have been having sleepless nights for the last two months (crying).”
P6	“I know that this is a cruel disease. I am assuming that the cancer patients won’t live long. It is a disease that kills.”
P4	“I fear surgery and radiation a lot because I don’t know whether I will be able to go through all of that. How will it affect my body? Will there be a lot of side effects?”
P2	“I fear that my kids may also be getting a similar kind of cancer.”
P3	“I have only one son, I want to see him married, I don’t know whether I will be alive to see that, I am also worried about losing my work.”
P10	“My husband had spent a lot of money and time on my education. I want to be helpful to him, practice law, and take care of kids and grandparents.”
P10	“I am worried about intimacy with my husband. I don’t know what my situation after surgery will be, I will have to wait and see. I have already told my husband, he can have a second marriage, and I am okay with it.”

Table 6: Patient quotes for dependence versus independence.

Patient no.	Quotes
P5	“The doctor is like a God to me; he can only save me. Whatever the doctor decides, I am okay with it.”
P6	“I want to do my daily activities like using the restroom without help from others. I don’t want to disturb my daughter-in-law.”
P4	“I want to raise my grandkids; I want to help with household work, and I want to be independent as much as possible. I don’t want to be a burden to anyone.”

Continued.

Patient no.	Quotes
P8	"Initially, I was very worried-my mother died of bone cancer. Then I figured science has advanced, there will be better treatments, and I will get cured."
P11	"We borrowed money for treatment. We had to sell our cow. We earn money by selling milk and now the cow is gone. We don't know what to do."
P12	"I took a loan of Rs 40000/- for treatment. I had to sell my necklace and earrings too."

Table 7: Patient quotes for faith and hope in God.

Patient no.	Quotes
P6	"I lost my husband very early, while my son was in school. God alone was there to safeguard me. He will help me now."
P4	"God was always kind to me and gave me everything: money, a caring husband, and hardworking kids. I believe God is testing me now."
P1	"I leave everything to God, I strongly believe he will take care of me. In every doctor, I see his presence."
P5	"If people are happy all the time, then they will forget God, and that's why now and then he will test you."
P10	"When I was young, I used to pray to Allah all the time. I did not use any makeup, and I used to wear purdah all the time. Despite that, I wonder why Allah has given me this disease. I don't want to go to paradise this early. I want to live my life a little more."

DISCUSSION

In a study conducted by Toubassi et al on newly diagnosed cervical cancer patients about their information needs, analyses revealed treatment-related information to be most important to these women, with practical, emotional/social and sexual issues rated as somewhat less important. Further, most patients stated that having the information they wanted when they were preparing for treatment would have reduced anxiety or stress, enhanced quality of life, and improved treatment and side effect management.[11] Another study by Nicolaije et al on endometrial cancer survivors found that most patients received quite a bit of information about their disease and medical tests. However, a substantial percentage of the patients stated that they were not informed or only partially informed about the cause of their disease, and the possible side effects of their treatment. Endometrial cancer survivors received the least information on topics related to aftercare, such as what to expect in their social and sexual life, where to go for additional help, rehabilitation, or psychological support, and how to cope with cancer at home, different care locations outside the hospital, or things to do to improve their health.[12] In our study, most patients were from low-income, low-literacy backgrounds and showed limited interest in detailed information about their disease or treatment, preferring to know only about prognosis and cure. Many believed that too much information increased anxiety and felt content with what was provided. They accepted treatment without question and often perceived cancer as incurable, relying on social media and anecdotes for understanding. Unlike Western guidelines advocating full disclosure, our findings suggest the need to individualize information based on patient preferences. Expectations seemed linked to education and income, with trust placed fully in doctors and the healthcare system.

The anxieties of our patients often hovered around their families. The patients were always worried, thinking about how their family would cope with their absence. They were also worried about their ability to take care of themselves after the treatment and during the end-of-life phases. They did not want to end up as burdens on their families. A systematic review found that the prevalence of depression and anxiety in women with ovarian cancer, across the treatment spectrum, is significantly greater than in the healthy female population.[13] Another study found that there is a significant association between anxiety, depressive symptoms, low quality of life scores, and sexual dysfunction. Patient's quality of life may be improved by taking precautions to reduce their psychosocial and psychosexual concerns.[14] Financial concerns about meeting the expenses of treatment, repayment of loans taken, and concerns of how the family will make ends meet after their time were uppermost in most patients' minds. Concerns about resuming sexual activity did not seem to worry most patients, though that might have been because of the usual reluctance to discuss these issues among our patients. One young lady did say that she wanted her husband to remarry after her demise.

Spiritual concerns were significant for all participants. Faith in God helped some accept their illness, viewing it as a divine test or reminder of God's presence. Others struggled, questioning their suffering despite religious devotion. Many believed God would give them the strength to endure. Spirituality plays a vital role in promoting peace and should be involved in the healthcare team. Clinicians must recognize and address spiritual distress, offering support and referring patients to trained spiritual care professionals when needed.[15]

Many times, patients and relatives are ill-prepared for the poor outcome which occurs frequently with advanced cancers. This will lead to poor patient satisfaction and resentment among family members. In India, violence against nurses and doctors is not uncommon. We need to spend a lot of time with patients and their families to build a good rapport and explain the course of the disease and treatment complications without making them fearful.

Strengths and weaknesses

Qualitative methods reveal salient matters that patients are concerned about. Often, a story of a patient's experiences is more powerful than statistics. A more diverse population in terms of education, income, occupation, and social status could have revealed more psychosocial issues related to gynaecological cancer.

Implications for practice and future research

The medical team alone may not have sufficient time to address patients' psychosocial needs. Cancer centers should include allied professionals for holistic care. Clinicians must recognize patients' concerns and spiritual distress, referring them to trained support staff. Future research should explore treatment non-compliance and factors contributing to psychological distress.

CONCLUSION

Patients had strong trust in their doctors, preferring not to be overwhelmed with distressing details. They needed more information on prognosis and cure rates. Concerns about financial implications and challenges of daily living were prominent, while worries about resuming sexual activity were less common. Understanding a patient's spiritual needs and anxieties is crucial for improving care and treatment adherence.

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