

# Coping Strategies among Malaysian Women with Recurrent Ovarian Cancer: A Qualitative Study

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## ABSTRACT

**Objective:** Ovarian cancer is one of the most common cancers among Malaysian women with high recurrence. Patients with recurrence are prone to emotional distress and are forced to cope with poor prognosis. This study aimed to explore the coping strategies employed by women with recurrent ovarian cancer in Malaysia, a developing multicultural country in Asia. **Methods:** This was a qualitative study with patients diagnosed with recurrent ovarian cancer and receiving chemotherapy at a hospital gynecologic day-care unit. In-depth individual interviews were conducted with patients to explore how they coped with recurrence of ovarian cancer. Interviews were audio-recorded, transcribed verbatim, and analyzed thematically. **Results:** The participants' ( $n = 10$ ) age range was 52–84 years, the three most

common ethnic backgrounds were represented (Malay, Chinese, and Indian), and most of the patients were well educated. All patients were on chemotherapy. Six coping strategies were identified: (1) maintaining a mindset of hopefulness, (2) avoidance of information, (3) accepting their condition, (4) seeking spiritual help, (5) relying on family for support, and (6) coping with financial costs. **Conclusions:** Coping strategies employed during ovarian cancer recurrence in this setting were rarely based on the accurate information appraisal, but rather on the individual emotion and personal beliefs.

**Key words:** Cancer recurrence, coping, culture, Malaysia, ovarian cancer, patient

## Introduction

Ovarian cancer is the fourth most common cancer among Malaysian women.<sup>[1]</sup> It has a high recurrence rate of 55%–75% within 2 years.<sup>[1]</sup> Prognosis at recurrence is poor with an overall 5-year survival rate of approximately 43%.<sup>[1]</sup> When recurrence occurs, although a number of active treatment options are available, such as chemotherapy and surgery, none of these options are curative and treatment is often considered palliative.<sup>[2]</sup>

Due to this palliative context, coping strategies play a significant part in how a patient faces the reality of recurrent ovarian cancer. These strategies are different from when they were coping with first-time diagnosis.<sup>[3]</sup> For instance, women with a first-time diagnosis of ovarian cancer do not focus as much on mortality but instead focus on coping with pain and emotional distress.<sup>[4-7]</sup> On the other hand, patients with recurrent ovarian cancer tend to focus on

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coping with emotional distress of recurrence<sup>[8]</sup> and how to address end-of-life issues.<sup>[9]</sup>

Previous studies on coping with ovarian cancer have suggested that coping strategies are formed by both personal and social factors. In women with newly diagnosed ovarian cancer, a higher education level was associated with being able to employ a wider range of strategies, while religiosity was associated with a resigned acceptance strategy.<sup>[10]</sup> Besides personal coping strategies, women's approach to coping is also influenced by social factors. In Malaysia's multicultural setting, sociocultural factors such as partner's perception, doctor-patient dynamics, religious beliefs (e.g., fate, resurrection, reincarnation), and ethnocultural practices surrounding death and burial (e.g., death taboos) have been found to impact patient views and approaches to palliative cancer situations.<sup>[11,12]</sup>

This study aims to explore the coping strategies employed by Malaysian women with recurrent ovarian cancer. Understanding coping mechanisms in Malaysia's multicultural setting will improve healthcare professional care and support of patients with recurrent ovarian cancer.

## Methods

### Study design

A qualitative study design involving in-depth interviews was conducted with patients diagnosed with recurrent ovarian cancer to explore their coping processes. A qualitative design was employed as little is known about this topic in Malaysia. We chose individual interviews as the topic of palliative care can be a sensitive topic for patients who consider the topic to be a private one.

### Setting and participants

We recruited patients who were attending the Gynaecologic Day Care Unit at the University of Malaya Medical Centre (UMMC). UMMC is a public university-based hospital where treatment costs are subsidized by the government. The Gynaecologic Day Care Unit is where patients with recurrent cancer are seen as outpatients for procedures such as follow-up blood tests and chemotherapy. Potential participants were identified by checking case notes to determine if they fit the inclusion criteria. Recruitment was done by the researchers when patients arrived for their scheduled appointments. All the patients who were approached agreed to participate in the study. Interviews were conducted until no new themes emerged.

The inclusion criteria for this study were patients with a recurrence of ovarian cancer within 1 year of the last course of chemotherapy (i.e., women with platinum-resistant and partially-platinum-sensitive cancer). Platinum-resistant

recurrent ovarian cancer is defined as a recurrence within 6 months of treatment with platinum-based chemotherapy. Partially-platinum-sensitive recurrent ovarian cancer occurs within 6–12 months of the last chemotherapy course. Our study included patients who fell into both categories. Patients with recurrent-platinum-sensitive ovarian cancer (i.e., ovarian cancer that recurs after 1 year since the last chemotherapy course) are expected to respond to treatment and were not included in the study.

The study initially planned to sample both women who were receiving active treatment (e.g., chemotherapy and further debulking surgery), as well as those who were not on active treatment. These two groups may have differing priorities on how to manage their recurrent ovarian cancer. However, the majority of the women in this center were on active treatment, and we were not able to recruit women who were not undergoing treatment despite multiple attempts.

### Data collection

An interview topic guide was developed based on the literature review and expert opinion to explore patient's coping mechanisms, when diagnosed with recurrent ovarian cancer [Table 1]. The questions in the topic guide were based on factors mentioned in previous research as well as questions based on local factors such as cost and religion. The topic guide first explored their experience, feelings, and thoughts when faced with the diagnosis of recurrence before focusing on coping strategies.

Table 1: Topic guide

Background
Can you tell me about the time when you received news about the recurrence of the cancer?
What advice did you receive from your doctor at the time of completion of initial treatment?
Patient decision-making and coping
Did you experience difficulty in making decisions regarding the treatment of recurrent ovarian cancer?
If yes: what difficulty, why difficult?
If no: why?
How did you feel about making this decision?
What are your expectations of the outcome of the treatment?
How did you cope with any barriers/problems when making decisions?
What barriers/problems did you face?
What did you do to try and solve these problems?
Did your doctor help you to overcome it?
Could anything be done differently to improve the experience that you had when you had to make this decision?
Who is involved in helping you cope with your treatment?
Healthcare professionals, family, friends, patient
If other people are involved, how are they involved? What are their roles?
What kind of help/support that you need to assist you to cope better?
Emotional, financial, information, advice?

Three trained researchers conducted the in-depth interviews (AKP, LYK, and NCJ). Informed consent was obtained from all participants in the study. To increase the number of participants, we conducted data collection over a prolonged 9-month period (December 2016 to September 2017) during which we were able to conduct interviews with ten patients, lasting from 30 to 45 min each. All interviews were audio-recorded and transcribed verbatim.

### Statistical analysis

A thematic analysis approach was used. The researchers familiarized themselves with the data by reading and rereading the transcripts. To develop the list of themes, an initial transcript was coded line-by-line using Nvivo9 software (QSR International, Australia).<sup>[13]</sup> A list of free themes was created before being merged to form larger categorical themes. This then served as a framework to code the rest of the transcripts, adding new nodes as new themes emerged.

### Ethical approval

This study received ethical approval from the UMMC Medical Research Ethics Committee (Approval No. 2016111-4479).

## Results

We interviewed ten patients in total [Table 2]. The participants' age range was 52–84 years, with the three main ethnicities represented (Malay, Chinese, and Indian). Most of the patients were well educated (above high-school/secondary-level education). All patients underwent chemotherapy as a treatment for recurrent ovarian cancer and seven had subsidized treatment costs.

There were several themes related to coping strategies that patients turned to when ovarian cancer recurred. These were (1) maintaining a mindset of hopefulness, (2) avoidance of information, (3) accepting their condition, (4) seeking spiritual help, (5) relying on their family for support, and (6) coping with costs of treatment.

Table 2: Participant demographic data		
Variable	Unit	n
Age	Mean years; range	62.5; 52-84
Ethnicity	Malay	5
	Chinese	3
	Indian	2
Education level	Tertiary	4
	Secondary	4
	Primary	2
Treatment decision	Chemotherapy	10
	Surgery	2
	Traditional treatment	1
Treatment costs	Subsidized	7
	Out of pocket	3

### Maintaining hopefulness

One of the coping strategies mentioned revolved around hopefulness. Participants mentioned being positive and having an optimistic mindset as a way to cope with their diagnosis.

*Like I said, I have to think positive. So that when the thing (ovarian cancer) happens to us again, we won't feel so down, won't feel it so much. At the most, 1 or 2 days only, you know (52-year-old Malay).*

They employed a few different strategies to maintain their levels of hope. One way was by continuing active treatment as this was advised by the doctors.

*My markers were going up, she (doctor) advised me to have chemo, I didn't think there was any other option, so I went ahead (84-year-old Indian).*

Patients often said that they continued with chemotherapy because actively seeking treatment gave them hope.

*If I'm under treatment, there is hope. If I stay at home, I have no hope. Right? (64-year-old Chinese).*

*Because I believe that [chemotherapy] is the way to go-that's the best option for me and there is hope. I think my chances for a better life after chemo, is with chemo (73-year-old Chinese).*

Thus, mental strategies related to hopefulness were targeted at avoiding depression or sadness, while physical strategies were aimed at continuing treatment in hope of cure.

### Avoidance of information

Another way patient's preserved hopefulness was by avoiding information about their condition. A few patients refused specific prognostic information about their conditions, such as staging and survival rates. This was because they felt that the information would cause emotional or physical distress (e.g., hypertension, insomnia). Instead, patients expressed wanting to maintain their sense of "ease," being "free," "letting it (the problem) go peacefully," and being "relaxed."

*I like it better when I don't know. I feel at ease. If I hear other people talking about stage 3 and 4 cancer, it is a reminder. Always thinking about the disease, it will make us unable to do anything, we will become sick (61-year-old Malay).*

*It's been a long time since I've found out, so I don't want to keep the memory here (about cancer recurrence), let it go peacefully, I don't want to keep remembering. So, in my heart, I'm free (58-year-old Malay).*

*That's why I straightaway told the doctor, "Don't tell me anything," all the risk, I don't want to listen, I scared my hypertension go up, I cannot sleep. Don't let me know anything-then I've got no worry (61-year-old Chinese).*

Consequently, this method of coping could lead to overoptimistic expectations. This became evident as we probed the patients about their expectations from

chemotherapy; some were undergoing chemotherapy in hopes of a cure from recurrent ovarian cancer.

*(I'm getting treatment) just to make me healthy, to make me fine (59-year-old Malay).*

*I'm expecting that all the cancer cells will be destroyed (73-year-old Chinese).*

### Acceptance of condition

Another way patients coped was by accepting their diagnosis of recurrence. Diagnosis of recurrence was very distressing for one patient who described her struggle with tears and anger at the "stupid thing in my body" and frustration after having spent a lot of money for surgery. Her acceptance of the recurrence was a personal choice to accept that cancer had "liked to grow in her body" but that she would "let it grow." The acceptance involved a dialog with cancer, anthropomorphizing it as "you" and giving it permission to grow in the patient's body. This acceptance enabled her to go on with her life (e.g., eat and travel).

*I was very sad when I knew (about the recurrence), I cried. Then I thought to myself, "Woah, the stupid thing likes my body" and then I start laughing. "You like to grow in my body, never mind, I'll let you grow." I was alone in the room, I thought by myself, "I accept what I have now." So whatever I can eat, I eat. If my children go anywhere, I follow, I don't care (61-year-old Chinese).*

On the other hand, some said that compared to the first diagnosis of ovarian cancer, the diagnosis of recurrence was less distressing. For these patients, they had accepted their diagnosis of ovarian cancer after they were diagnosed the first time. Thus, by the time they are diagnosed with recurrence, they had come to terms with having cancer. There was also a feeling of "not caring anymore," which was ascribed to the long-term nature of the diagnosis where patients felt a long time had already passed since the first occurrence.

### Seeking spiritual help

Religion played a significant role in facilitating some patients' acceptance of recurrence. Three key beliefs involved fate (recurrence was divinely predetermined), testing (recurrence was a test of faith that they had to endure with patience), and strength (a God-given strength to endure). Muslim patients referred specifically to the concept of "redha," i.e., wholeheartedly accepting what has been decreed by God. Both Muslim and Christian patients viewed recurrent ovarian cancer as a test from God that they have to undergo with patience and inner resolve. In this context, only a few mentioned divine healing as a goal but instead framed cancer recurrence as an opportunity to achieve spiritual maturity.

*Whatever it is God gave it to you-your richness, your health. So this is just a test. A test from God see how you are patient with his test, how you accept it. So you have to be patient, because whatever we are patient with will mature us (58-year-old Malay).*

*We are "redha," we have to think positive. We can't blame this or that (52-year-old Malay).*

*I'm a Christian, so my life is in god's hands...I'm in good hands. So I'm at peace, I don't worry...So God gives that strength. If not, emotionally and spiritually, I really want to give up (73-year-old Chinese).*

### Relying on family for support

Family support consistently played a crucial role in helping our patients to cope with their illness. Most importantly, family members of the patients often provided moral and emotional support, enabling them to cope with difficult times. Chemotherapy was found to be challenging physically and emotionally and having someone around to help in a practical way was beneficial.

*When I was on chemo, she (patient's daughter) stopped working to take care of me, she skipped her studies, about 6 months, she wanted to care for me (59-year-old Malay).*

*For treatment, he (the husband) follows my decision. But, the one going through it is me. He is there more for moral support (52-year-old Malay).*

For the patients who had to pay for treatment, family members became a source of financial support, with chemotherapy and surgery being paid for by their children.

Patients often depended on family members who are present in the consultation to understand and retain the information given by the doctor. Related to the earlier theme on avoiding information, patients often told the doctor to speak to the family instead of the patients themselves, stating that they (the patients) do not want to think too much.

*The doctor was quiet, because I didn't want (to hear any information). But, my husband was there, if tell my husband, it's OK, but I don't want to listen. I don't ask my husband, because I don't want to know (61-year-old Malay).*

*I tell the doctor you do everything. Then, the doctor tell my daughter, then my daughter is working in medical, she knows everything. She is a nurse what (61-year-old Chinese).*

### Coping with costs of treatment

Coping with financial cost of treatment is often a major consideration in cancer treatment. However, it was not considered a burden for most patients that we spoke to. This is because patients in this public hospital paid subsidized rates for medicine or were covered by government health benefits. In Malaysia, treatment in government hospitals is free for government employees or their spouses and parents.

*The first chemo in (anonymized)'s private center was already RM4500 [USD 1100]. So I said to the doctor, "I can't afford it, I want to transfer to the government (hospital)." Now, it's RM 200 (USD 50), I use the guarantee letter, my child works in the government, so from cost, can cover the cost, no problem (52-year-old Malay).*

Some mentioned that a reason they chose active treatment was because it was free for them. If they had to pay, they would reconsider.

*My husband is a government retiree. I'm not. That's why I said I'm not burdened (by cost). Because if we do a CT scan, doctor already writes you have to pay a few hundred, but I don't have to. Because of my husband, we are not charged. Maybe if my husband wasn't in the government, self-employed, maybe I would be worried about being charged for this and that, and many surgeries (61-year-old Malay).*

Even for the patients who paid out of pocket, the cost at our center is still significantly cheaper than it would be to obtain treatment from a private provider. Two patients who started off their initial treatment in the private sector eventually changed providers to our center to lower their costs.

## Discussion

This study reveals the coping strategies of Malaysian women when faced with a diagnosis of recurrent ovarian cancer. They fought to maintain hopefulness, avoided or accepted the reality of recurrence, and used religious coping strategies. Women also coped by relying on resources such as moral and financial family support and treatment cost subsidies.

Patients in the study would seek to maintain hope by adopting a positive mindset and continuing on active chemotherapy. Hope is considered to be an important trait for patients with advanced cancers,<sup>[14,15]</sup> and hope can be further categorized into a general feeling of hopefulness (i.e., "trait hopefulness") and specific hopes (e.g., hoping to experience cure).<sup>[15]</sup> However, Sjoquists *et al.*'s study on women with recurrent ovarian cancer did not recommend hope to be taught as a coping strategy as general hopefulness was not protective of quality of life, and unmet specific hope was associated with depression.<sup>[15]</sup> Furthermore, it is not easy to instill hope if not already present.<sup>[15]</sup> As cancer is the most feared disease in Malaysia,<sup>[16]</sup> the specific hope of being cured is relevant in our setting as patients viewed chemotherapy as a means of maintaining hope; this could lead to distress when the prognosis worsens. One strategy is to help direct patients' specific hopes toward attainable goals that are personally meaningful,<sup>[17]</sup> such as spending time with family and exchanging forgiveness with loved ones.<sup>[18]</sup>

Active information avoidance was a coping strategy for some patients. As a result, patients were often reliant on the doctor to make treatment decisions on their behalf. Studies elsewhere indicate that cancer information avoidance is prevalent in up to a quarter of the general population<sup>[19]</sup> and is associated with older age, having less education, being female, having high cancer fear, and having higher general anxiety.<sup>[20,21]</sup> Three reasons for information avoidance have been identified in the literature: (1) information threatens cherished beliefs, (2) information

demands undesired change or action, and (3) information might lead to unpleasant emotions.<sup>[22]</sup> In our study, it was the last reason that emerged, namely that patients were worried that information could lead them to become more anxious or worried. Indeed, trait anxiety has been shown to be a moderator on cancer information avoidance.<sup>[21]</sup> In consultations, doctors should to identify reasons why patients are avoiding information (e.g., Are they in a denial stage? Is the information too complex?), reinforce the message that they should make decisions based on accurate and adequate information, and give the patients and families time to think through what information is needed, with the reassurance that they do not have to make the decision immediately. As an adjunct to the consultation, psycho-oncological support in our setting should be tailored to help patients cope with anxiety; advance care planning tools tailored to an Asian setting can help providers sensitively elicit what information is needed.<sup>[11]</sup>

Religious coping was important for some participants in making meaning of their cancer. Indeed, religious strategies were identified as one of the top three coping strategies employed by patients with ovarian cancer in Turkey, which is also a Muslim-majority country like Malaysia.<sup>[7]</sup> Previous studies have mostly explored (1) a Western (i.e., Christian or Catholic) perspective<sup>[23]</sup> and (2) active strategies such as joining religious services and prayer.<sup>[23]</sup> Our study identified the Muslim concept of "redha" (acceptance of what has been decreed by God) as being an important coping strategy. In a study exploring religious cancer coping strategies in Malaysian Muslim patients, cancer acceptance could take passive (waiting for God to take control), active (surrender after having tried one's best), or collaborative (relying on one's own strength as well as God's help) forms.<sup>[12]</sup> As passive/avoidant coping has been associated with negative outcomes (e.g., loss of meaning in life),<sup>[24]</sup> a number of strategies can be adopted in our setting to further enhance this coping strategy. Muslim patients in our setting can be encouraged to view carrying out religious duties such as prayers and ablutions as an active form of "redha."<sup>[18]</sup> Collaborative "redha" involves self-volition, and it can be helpful to give Muslim patients religiously-sensitive choice options, such as choosing less sedative pain medication, so that they can maintain their ability to perform religious prayers.<sup>[18]</sup>

All the women who agreed to participate were receiving chemotherapy. As mentioned in the "Methods," we aimed to recruit patients who were not receiving active treatment, as their values and coping strategies might be different, but were unable to do so. Previous studies exploring the benefits of palliative chemotherapy in recurrent ovarian cancer have found that while treatment is associated with improved quality of life within the first 2 months, patient expectations are often unrealistic,<sup>[2]</sup> and unrealized expectations were associated with

higher risk of depression.<sup>[15]</sup> Many of the patients whom we interviewed expressed hopes of cure from ovarian cancer as a result of chemotherapy. Considering that chemotherapy in recurrent ovarian cancer is often palliative in nature with a view toward symptom control and improved quality of life rather than curative intent, hopes of cure may not have been realistic. Furthermore, free or affordable chemotherapy could make it easier for patients to agree to chemotherapy; it is important for healthcare professionals to help patients have a realistic expectation for chemotherapy outcomes.

This study had a number of limitations. We were unable to recruit patients who had chosen not continue on active treatment; these women may employ different coping strategies and adopt a different outlook from those who are currently on chemotherapy. The study also does not include patients from private sector for whom cost may be a major factor. Furthermore, we were only able to recruit ten patients despite a prolonged data collection period. Thus, we are not able to conclude that the data were saturated given the relatively small number of patients. However, the major themes as reported in this paper are repeated across multiple participants indicating that some saturation was achieved.

## Conclusions

We found that some coping strategies employed in our setting were rarely based on accurate information appraisal, but rather on individual emotion and beliefs. While these were helpful at maintaining hopefulness, they could be harmful in creating a false sense of security. Healthcare workers should aim to promote informed decisions, temper unrealistic expectations, and shift patient coping goals toward personally meaningful outcomes.

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### Conflicts of interest

There are no conflicts of interest.

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