

# Experiences of Indonesian women with breast cancer underwent treatment decision-making: A qualitative study

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## Abstract

**Background:** Patients with breast cancer face a complex situation upon receiving their diagnosis and considering future treatment options. In Indonesian culture, relatives and others significantly influence decision-making processes. Understanding the perspectives of Indonesian women with breast cancer regarding treatment decision-making can enhance satisfaction with the care provided.

**Objective:** This study aimed to explore the experiences of Indonesian women with breast cancer regarding treatment decision-making.

**Methods:** A qualitative descriptive study design was utilized. Purposive sampling was employed to select the study participants. In-depth interviews were conducted with 15 women with breast cancer between March and June 2023. The data were analyzed using thematic analysis.

**Results:** Three main themes were developed: 1) Emotional impact and uncertainty in cancer care, 2) Clear communication and support for patients, and 3) Family-centered decision-making in treatment planning.

**Conclusion:** This study highlights the perspectives of Indonesian women with breast cancer on treatment decision-making. Nurses play a crucial role in providing clear information to patients and their families during the decision-making process. Understanding the experiences of women with breast cancer can help support and empower patients through effective communication while they undergo treatment.

## Keywords

Indonesia; experience; women; breast cancer; treatment decision-making; family; communication; uncertainty

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## Background

One of the most prevalent cancers among women globally is breast cancer. In Indonesia, breast cancer ranks first in terms of the highest number of cancers and has become one of the leading causes of death. As cancer progresses, patients face several treatment choices, including chemotherapy, radiotherapy, hormone therapy, and surgery (Moo et al., 2018). Patients need to choose between various treatments in a very short time (Solikhah et al., 2020). In general, patients with breast cancer require information regarding their illness and prefer to be involved in treatment decision-making (Josfeld et al., 2021). However, breast cancer patients experience problems with their involvement in treatment decision-making (Mackenzie et al., 2021). This might be due to a lack of certainty and information (Josfeld et al., 2021), a lack of knowledge and understanding (Maes-Carballo et al., 2021; Rainey et al., 2018), anxiety, and worry (Nies et al., 2017). This makes decision-making more challenging.

In Indonesian culture, a lack of patient knowledge and willingness from healthcare professionals to reveal the

diagnosis and prognosis make decision-making even harder. Previous studies have found that the decision-making process is highly preference-sensitive and may produce conflict due to limited aid and support from healthcare professionals (Lux et al., 2013; Wulandari et al., 2017). Doctors and families somewhat influence treatment decisions, sometimes suspending treatment (Kim et al., 2021). Patient engagement in healthcare decision-making is influenced by several factors, including time allotted for participation, healthcare professionals' skills, patient knowledge, and the relationship between doctors and patients (Vahdat et al., 2014). Involvement of patients in treatment options may promote shared decision-making. This may relate to the hierarchy of physicians who are the main decision-makers (Setiadi et al., 2017). However, the paternalistic style between doctors and patients (Iskandarsyah et al., 2014), financial burdens, lower educational background (Suarilah et al., 2023), and cultural issues within the family could affect patients' engagement in decision-making.

Shared decision-making effectively reduces confusion and dissatisfaction with health decisions, resulting in increased

compliance, improved health outcomes, fewer lawsuits, and more meaningful interactions with healthcare professionals (Vucemilovic et al., 2016). Previous studies on treatment decision-making for women with breast cancer have primarily been conducted in Western countries. In Indonesia, only one study discussed a similar topic with women who had obstetrics and gynecology cancer (Suarilah et al., 2023). However, since the study was conducted in one healthcare setting where all patients lived in the same place, there was a possibility of bias due to peer influence. In contrast, this study focused on women with breast cancer in Banten, Tangerang. In a recent study, women with breast cancer were interviewed individually in their own homes, which enabled them to speak freely and reduced the possibility of being influenced by others.

Treatment decision-making is a complex process that involves decisions related to diagnosis, treatment options, and the outcomes of each treatment (Pyke-Grimm et al., 2020). Although the literature has shown that involvement in treatment decision-making improves the quality of life and reduces health inequities for women with breast cancer (Grabinski et al., 2018; Turkson Ocran et al., 2021), it remains a significant challenge in Indonesia. As far as the researchers know, this study will be the first to explore the experiences of Indonesian women with breast cancer in treatment decision-making. Thus, qualitative research will help the researcher explore these women's experiences.

It is crucial to understand the perspective of Indonesian women with breast cancer on treatment decision-making. Knowing these perspectives might influence their satisfaction, emotions, and survival time. To truly support patients with breast cancer during the decision-making process and respect their preferences, a better understanding of their perspectives on treatment decision-making is required. Thus, this study aimed to explore the experiences of Indonesian women with breast cancer who underwent treatment decision-making.

## Methods

### Study Design

A qualitative descriptive study design (Tenny et al., 2022) was utilized to explore the experiences of Indonesian women with breast cancer regarding treatment decision-making. This study adhered to the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong et al., 2007). This study was conducted between March and June 2023.

### Participants

Indonesian women with breast cancer were purposefully recruited based on their experiences in treatment decision-making. The first author sent out a screening survey and information through a WhatsApp link to the head nurse of a breast clinic in a private hospital in Banten, Indonesia. The head nurse then shared the message with the person in charge (PIC) of the breast cancer support group, who then re-shared it with the women with breast cancer. The information sheet contained details of the study, risks, IRB number, and researcher contact information. The link directed them to questions about the respondent's eligibility criteria. The first author contacted all eligible participants to set up the interview schedule. Fifteen women with breast cancer were selected using the purposive sampling method. The inclusion criteria

were: 1) women above 18 years old, 2) first diagnosed with breast cancer, 3) had chosen the method of treatment and had been treated, 4) communicated in Bahasa Indonesia, and 5) provided informed consent. None of the participants withdrew from the study. The ages of all participants ranged from 30 to 60 years old. All 15 participants were from Banten, Indonesia.

### Data Collection

Data gathering was conducted after receiving Institutional Review Board (IRB) approval. The first author collected the data via in-depth, online semi-structured interviews with each participant via the Zoom platform in Indonesian, lasting approximately 30-45 minutes per session. Both the researcher and the participant were at their own homes.

An in-depth interview was conducted by encouraging each participant to explore more, providing details, and maintaining eye contact during the interview. The participant and the researcher stayed in an isolated, quiet, and comfortable space at their homes where the participants could express their feelings freely and without interruptions. Due to the COVID-19 outbreak, the initial plan for face-to-face interviews was switched to online recorded interviews. All 15 participants had an online interview and were interviewed once. The first author set up the Zoom platform, and the link to the meeting was given to each participant. All participants were aware of and familiar with using Zoom on their laptops, and there were no issues during the interview sessions. Participants' nonverbal responses were also recorded during the interviews. Although these observation records were not used in the analysis, they helped researchers gain a deeper understanding of the context and meaning of the exchanges in the verbatim text when analyzing the data (Lin, 2020).

The Indonesian language was used during the interview, with five open-ended questions (Table 1) developed through discussions with the three senior researchers. A pilot study was conducted with three Indonesian women with breast cancer, who differed from the main study's sample. Each interview session was recorded using Zoom and transcribed verbatim by the first author. Data saturation determined the sample size, and the interviews concluded when no new information was obtained (Given, 2016). In this study, after 15 women with breast cancer were interviewed, no new themes emerged, confirming that saturation was achieved.

**Table 1** Interview questions

| Questions  |
|--|
| Would you please share your experience in the process of undergoing treatment decision-making for breast cancer? |
| Did you get any preparation, help, or difficulty in being involved in decision-making?                           |
| How did you feel while making the decision?  |
| Do you think you are satisfied with the decision made for your cancer treatment?                                 |
| Do you have more information regarding the decision-making regarding the treatment?                              |

### Data Analysis

In each interview, the first author transcribed the data recording. Transcribing was done in Bahasa Indonesia and then translated into English for the second author, who is non-Indonesian. Transcription was completed after each interview.

The data analysis used the thematic analysis method outlined by Braun and Clarke (2006), including 1) familiarizing with the data, 2) generating initial codes, 3) generating themes, 4) reviewing the themes, 5) defining and naming the themes, and 6) writing the report. Transcripts were read several times to identify codes related to treatment decision-making. Twenty-four codes were found, which were then discussed with the second author. Both authors agreed on the discussions to verify the codes and finalize the themes.

### Trustworthiness

The trustworthiness of the data was established using the criteria of Lincoln and Guba (1985) for credibility, transferability, dependability, and confirmability. For credibility, the first author, who holds a master's degree, has been trained in qualitative interviews and has worked in oncology nursing for more than ten years. Building trust with participants is vital in qualitative studies as it increases their willingness to share more honestly (Lin, 2020; Stahl & King, 2020). In this study, the first author introduced herself, explained the research purpose and methods, and inquired about the participants' conditions to build trust before the interviews. According to Gunawan (2015), member checking is crucial to ensuring rigor and trustworthiness. Member checking was undertaken with two participants. The researcher presented the transcribed data in Bahasa Indonesia and asked the participants to validate their experiences and provide feedback. One participant agreed that no new information should be added, while the other participant requested the deletion of some unwanted information, such as physician and hospital names, which the researcher then deleted.

Transferability was ensured by selecting participants who met the inclusion criteria, making the data representative and transferable. The researchers recruited participants with differences in age, marital status, educational background, year of breast cancer diagnosis, grade of breast cancer, and treatment method to enhance the transferability of the study's

findings. For dependability, the first author conducted all interviews alone to ensure consistency in the interview process. After completing each interview, the transcripts were reviewed multiple times while listening to the recorded interview. Both researchers agreed on three themes and eight subthemes from the data analysis. The final themes were confirmed through an external review with three professors specializing in qualitative studies, women's care, and breast cancer. For confirmability, the researchers used reflection logs to continuously reflect on their own biases during the data processing provided by the participants. They adjusted any biases to achieve an objective and neutral stance.

### Ethical Considerations

This study obtained Institutional Review Board (IRB) approval (Number: 027/IRB-UPH/III/2023) from Universitas Pelita Harapan, Tangerang, Indonesia. Each participant was informed that their participation was voluntary and that they could withdraw until data collection was concluded. Consent was obtained orally and in writing. Interviews were recorded with confidentiality assured, using codes to protect identities. Communication with participants continued until the analysis was completed.

## Results

During the three months of data collection, 15 women aged 30-60 years with breast cancer completed the interviews. Table 2 summarizes the demographic data of the participants. The majority of the women with breast cancer were married, and 100% were housewives. Eighty percent of the women were diagnosed with breast cancer between one to three years before the initial interview. Sixty percent of them received chemotherapy, mastectomy, and radiation as their cancer treatments, and more than half of the participants were covered by national insurance (86.7%).

**Table 2** Characteristics of women with breast cancer (*N* = 15)

| Characteristics               | <i>n</i> | Percentage (%) |
|-------------------------------|----------|----------------|
| <b>Age</b>                    |          |                |
| 30-40                         | 7        | 46.7           |
| 41-50                         | 7        | 46.7           |
| 51-60                         | 1        | 6.6            |
| <b>Marital Status</b>         |          |                |
| Single                        | 2        | 13.3           |
| Married                       | 13       | 86.7           |
| <b>Occupation</b>             |          |                |
| Housewife                     | 15       | 100.0          |
| <b>Education Background</b>   |          |                |
| Elementary School             | 1        | 6.7            |
| High School                   | 9        | 60.0           |
| Diploma III                   | 2        | 13.3           |
| Bachelor's degree             | 3        | 20.0           |
| <b>Years of Diagnosed</b>     |          |                |
| 1-3 Years                     | 12       | 80.0           |
| >3-5 Years                    | 2        | 13.3           |
| >5 Years                      | 1        | 6.7            |
| <b>Grade of Breast Cancer</b> |          |                |
| I                             | 1        | 6.7            |
| II                            | 6        | 40.0           |
| III                           | 5        | 33.3           |
| IV                            | 3        | 20.0           |

Table 2 (Cont.)

|                                     |    |      |
|-------------------------------------|----|------|
| <b>Treatment</b>                    |    |      |
| Chemotherapy, Mastectomy, Radiation | 9  | 60.0 |
| Chemotherapy & Mastectomy           | 2  | 13.3 |
| Lumpectomy & Radiation              | 2  | 13.3 |
| Chemotherapy                        | 1  | 6.7  |
| Chemotherapy & Radiation            | 1  | 6.7  |
| <b>Side of Breast Affected</b>      |    |      |
| Left                                | 6  | 40.0 |
| Right                               | 9  | 60.0 |
| <b>Health Insurance</b>             |    |      |
| National Insurance                  | 13 | 86.7 |
| Private Insurance                   | 2  | 13.3 |

Participants provided multiple perspectives on treatment decision-making. These perspectives were described following the treatment decision-making process, from receiving a breast cancer diagnosis to reaching a decision agreement. The perspectives were grouped into three themes:

1) Emotional Impact and Uncertainty in Cancer Care, 2) Clear Communication and Support for Patients, and 3) Family-Centered Decision-Making in Treatment Planning. All the themes and subthemes are summarized in [Table 3](#).

**Table 3** Themes and sub-themes for experiences of Indonesian women with breast cancer on treatment decision-making

| Themes  | Subthemes  |
|---|--|
| Emotional Impact and Uncertainty in Cancer Care       | Being in an emotional state<br>Uncertainty in cancer care  |
| Clear Communication and Support for Patients          | Obtaining a clear explanation of treatment options<br>Receiving encouragement  |
| Family-Centered Decision-Making in Treatment Planning | Considering the best treatment options<br>Allowing time to discuss with the family<br>Obtaining family agreement to receive treatment<br>Confirming the decision |

### Theme 1. Emotional Impact and Uncertainty in Cancer Care

The first theme highlights the emotional and informational challenges participants faced following their breast cancer diagnosis, which made it difficult for them to engage in treatment decisions.

#### **Subtheme 1.1. Being in an emotional state**

Participants experienced a range of emotions, including fear, nervousness, shock, and distress, after receiving their diagnosis. They reported being unable to think clearly about treatment plans. For example: *“When the doctor mentioned breast cancer and the treatments, I was quite shocked and could not think of anything. I found the disease so frightening that I didn’t even want to think about the treatment or what I should do.”* [P15]

#### **Subtheme 1.2. Uncertainty in cancer care**

Participants expressed uncertainty about their treatment plans due to a lack of relevant information. One participant noted having never heard of treatments like chemotherapy before: *“The doctor asked me about my opinion on the treatment, but I didn’t know what to do. It was the first time I had heard the term ‘Chemo.’ I had no idea about things like mastectomy or chemotherapy.”* [P12]

### Theme 2. Clear Communication and Support for Patients

This theme highlights the importance of providing patients with clear information about their treatment options and offering encouragement to help them make informed decisions and feel supported throughout their healthcare journey.

#### **Subtheme 2.1. Obtaining a clear explanation of treatment options**

Clear information about the disease and treatment options empowers participants to engage in treatment decision-making. Some participants noted that they received detailed explanations about their treatment choices: *“I gained knowledge about breast cancer and received a detailed explanation of the treatments. I guess he (the doctor) didn’t just tell me what to do; instead, he explained and provided suggestions, making sure I understood before making a decision.”* [P2]

#### **Subtheme 2.2. Receiving encouragement**

Some women with breast cancer reported receiving encouragement and motivation from their doctors to participate in their treatment decision-making. This included being introduced to other patients to discuss treatment options. For example: *“I told the doctor I had no idea about a future treatment plan. He encouraged me by connecting me with another patient undergoing chemotherapy to share her experience. The doctor also mentioned that the patient looked well despite her treatment and encouraged me to be courageous.”* [P9]

### Theme 3. Family-Centered Decision-Making in Treatment Planning

This theme emphasizes the significance of involving the family in the decision-making process to ensure that the chosen treatment option is agreed upon and confirmed by all relevant parties.

### **Subtheme 3.1. Considering the best treatment options**

Overall, women with breast cancer were relatively satisfied with the treatment decisions made. They considered the treatment suggested by the doctor to be the best option. Participants shared: *“The doctor asked me whether I wanted a lumpectomy or mastectomy. Considering the density of my breasts and their size, he explained that both options are viable, though each has its pros and cons. However, he recommended a lumpectomy because it is effective.”* [P3]

Another participant reflected: *“The doctor informed me that I would need about eight rounds of chemotherapy, followed by a mastectomy. I believe he chose the best treatment for my condition.”* [P7]

Similarly, another participant stated: *“The doctor said that chemotherapy should be the first treatment, followed by surgery, and then radiation. He knows what’s best for me.”* [P5]

### **Subtheme 3.2. Allowing time to discuss with the family**

Women with breast cancer were given time to discuss their treatment options with their families. For example: *“The doctor asked me to discuss with my husband and family whether I would follow his recommendation.”* [P5]

Another participant noted: *“He (the doctor) allowed me to first discuss the possible treatments with my family.”* [P13]

### **Subtheme 3.3. Obtaining family agreement to receive treatment**

Most participants obtained their families’ agreement to proceed with the recommended treatment. Statements from participants included: *“Yes, my husband was always beside me, listened to all treatment suggestions, and we made the decision together.”* [P13] and *“My husband agreed to whatever medication and treatment the doctor prescribed.”* [P15]

### **Subtheme 3.4. Confirming the decision**

Women with breast cancer finally confirmed their treatment decision, often based on the doctor’s suggestion. For example: *“I followed the doctor’s recommendation to have a lumpectomy instead of a mastectomy, and I’m happy because I didn’t lose my breast.”* [P6] and *“I decided to trust the doctor’s choice for my treatment, but I was clear that I did not want herbal or alternative medicines.”* [P14]

Other participants mentioned that the treatment decision was made collaboratively with their physician: *“In the end, I chose chemotherapy because I felt it was the best option. The doctor and I decided together on the best treatment for me.”* [P11]

## **Discussion**

This qualitative study revealed three themes: Emotional Impact and Uncertainty in Cancer Care, Clear Communication and Support for Patients, and Family-Centered Decision-Making in Treatment Planning. Cancer can change the lives of patients and their families physically, socially, spiritually, and psychologically. In a recent study, participants experienced uncertainty when facing cancer and its treatment. This uncertainty influences the choices that patients make. Indonesian women with breast cancer expressed their uncertainty through emotions and a lack of information. Previous studies have highlighted that patients face

uncertainty due to the cancer diagnosis (Chiaranai, 2016; Pujadas Botey et al., 2020), an inability to imagine the future (Lewandowska et al., 2021), unpredictability and lack of information (Etkind & Koffman, 2016), and invasive treatments (Bristowe et al., 2015). Uncertainty can cause cancer patients to feel a loss of control, impacting their psychosocial well-being and quality of life (Rodriguez-Gonzalez et al., 2022).

Healthcare providers can better navigate uncertainties by explaining cancer treatments to patients. In a recent study, when women with breast cancer were confronted with the decision-making process and provided information about treatment options, most of them followed the physician’s suggestions. This indicates that the majority of Indonesian women with breast cancer tended to rely on the physician’s decision, assuming that the doctor had chosen the best treatment for them. This tendency may be attributed to the encouragement provided by the physician, which fosters a trusting relationship between patients and doctors (De Guzman et al., 2019). These findings are comparable to another study from Malaysia (Wan Mamat et al., 2023). Trusting doctors often leads patients to consent to medical treatments despite lacking detailed knowledge (Susilo et al., 2019). The trust relationship between doctors and patients is considered influential, resulting in patients being less involved in decision-making (Pokhilenko et al., 2021). This reduced engagement in decision-making can cause patients to become passive. This finding reflects Indonesian culture, where there is a tendency to avoid expressing one’s voice.

Similarly, a study of the Asian population highlighted that a passive role might be due to a fear of being judged as outsmarting doctors (Claramita & Susilo, 2014). The tendency to follow a doctor’s decision may also be related to the patients’ educational background in this study, as the majority had only completed junior and senior high school (66.6%). Previous research has also found that a lower educational background is associated with less involvement in cancer treatment decision-making (Suarilah et al., 2023).

Nevertheless, in this study, a few women expressed that they did participate in the treatment decision-making process and had their voices heard. Having sufficient information and knowledge about treatment options would empower patients to make decisions concerning their health (Williams & Jeanetta, 2016). Adequate health literacy can encourage patients to take an active role and be more involved in decision-making (Holden et al., 2021; Seo et al., 2016). Conversely, patients with low health literacy might struggle to understand such information and tend to rely on doctors to make the best decisions for them. Therefore, health literacy is influential in treatment decision-making (Seo et al., 2016). This tendency might also reflect the characteristics of Indonesians during treatment decision-making, where they prefer doctors to decide on treatment because they trust that doctors know what is best for them.

Finally, our findings revealed that women with breast cancer engaged in treatment decision-making. These participants confirmed and decided to receive treatment after considering the best option for them through discussions with their families and reaching a consensus. It is common for patients to share and discuss their illness with their families, which is a typical practice in Indonesia. As noted in a previous review, most cancer patients tend to discuss treatment options

with their family caregivers (Cincidda et al., 2023). In this study, although women with breast cancer discussed treatment options with family members and reached an agreement, they made the final decision themselves. Breast cancer is often considered taboo in Indonesia, as reflected in a previous study by Solikhah et al. (2020), which found that Indonesian women had negative perceptions toward breast cancer screening due to fear and shame. This sometimes leads women with breast cancer to avoid discussing it, as it is perceived as a sexual issue. Consequently, they may not seek medical help until a later stage.

This study highlights the care needs of Indonesian women with breast cancer in the treatment decision-making process and highlights the importance of nurses' roles in this context. Nurses are crucial in providing clear information to patients and their families, especially during decision-making. The study also emphasizes the need for nurses to offer support and empower patients through effective communication. Therefore, nurses should receive training in both knowledge and skills related to the decision-making process for cancer patients. Further research is needed to explore the specific roles of nurses and their preferred level of involvement in the decision-making process for cancer care.

### Limitations and Strengths

One limitation of this study was that the participants were homogeneous, as most of the women with breast cancer were treated by the same oncologist, leading to similar experiences among them. Therefore, the findings of this study may not represent the entire Indonesian context. Including multiple settings with varying educational backgrounds and ethnicities might influence the treatment decision-making outcomes for women with breast cancer. However, the strength of this study lies in its qualitative approach, which provided valuable insights into the experiences of Indonesian women with breast cancer regarding treatment decision-making. This study has allowed researchers to gain a deeper understanding of Indonesian women's experiences during decision-making, particularly concerning breast cancer treatment.

### Implications for Nursing Practice

The findings of this study highlight several critical implications for nursing practice in the care of patients with breast cancer. Patients with breast cancer often face significant uncertainty during diagnosis and treatment decision-making. Many lack sufficient knowledge about their disease or the treatment options available, which can result in anxiety and worry. To address this, nurses should enhance their communication skills to provide clear, comprehensive explanations of medical options, helping patients understand and navigate their choices more effectively. Support from nurses is crucial for reducing the distress that patients experience during treatment decision-making. This involves offering emotional and psychological encouragement and facilitating discussions with family members to ensure a collaborative decision-making process. Given the cultural tendency in Indonesia to defer to doctors, nurses should also be culturally sensitive and work to empower patients to participate actively in their treatment decisions.

Moreover, nurses need to focus on patient education to improve health literacy, thereby enabling patients to make

more informed decisions. Engaging patients in their care through supportive communication and providing decision aids can also help reduce feelings of helplessness. However, nurses play a vital role in addressing the needs and preferences of breast cancer patients. By offering support, enhancing communication, and advocating for patient involvement in decision-making, nurses can help reduce uncertainty and improve the overall care experience for women with breast cancer.

## Conclusion

The study revealed the experiences of patients with breast cancer regarding treatment decision-making. It may serve as a reference for nurses and other healthcare providers in understanding the perspectives of breast cancer patients when making treatment decisions. Gaining a better understanding of these experiences could lead to more informed and tailored preferences based on patients' needs. Additionally, it is anticipated that nurses and healthcare providers will prioritize education to better prepare themselves to meet patients' needs in making treatment decisions. Moreover, it is expected that all healthcare providers will enhance their skills and knowledge to effectively support patients with breast cancer in the decision-making process.

### Declaration of Conflicting Interest

There is nothing to declare.

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### Authors' Contributions

All authors have contributed to this study. The first author undertook the interview, transcribed and translated it into Indonesian, and made the analysis. The second author contributed to the analysis and interpretation of data. All authors read and approved the final manuscript.

### Authors' Biographies

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### Data Availability

All the datasets are available from the author upon reasonable request.

### Declaration of Use of AI in Scientific Writing

The authors have declared that there is no generative AI was used in this writing.

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