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Review Article

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Delayed Diagnosis and Therapeutic Uncertainty in Ovarian Cancer: Integrating Lived Experience with Clinical Evidence

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Abstract

Ovarian cancer remains one of the most lethal malignancies affecting women, primarily due to delayed diagnosis and non-specific early symptomatology. In New Zealand, approximately 50% of diagnoses occur following emergency presentation, reflecting advanced-stage disease at detection. This manuscript integrates clinical evidence with lived experience to examine the trajectory from early symptom ambiguity to diagnostic delay, crisis presentation, and therapeutic uncertainty. By embedding patient voice alongside biomedical understanding, the paper highlights the psychological burden, systemic limitations, and complexity of treatment decision-making in ovarian cancer. The findings emphasise the need for earlier recognition, narrative-informed clinical assessment, and more responsive health systems.

The link below captures the lyrics and performance in a bilingual setting to simply communicate what the delays mean to a person.
https://heyzine.com/flip-book/1afa7a5c4c.html

So

Keywords: Store-Operated Calcium Entry, SOCE, ORAI, PBMCs, Biomarker, Neuroplasticity, Psychedelic, Psychoplastogen, Neuroplastogen, 5-HT2A, Translational Neuroscience

1. Introduction

Ovarian cancer is characterised by high mortality, with survival outcomes closely linked to stage at diagnosis [1,2]. The absence of reliable screening tools and the presence of vague, non-specific symptoms contribute to diagnostic delay [3,4]. In New Zealand, the reality that approximately half of all ovarian cancer cases are diagnosed following emergency presentation underscores the systemic and biological challenges inherent in early detection [5]. Yet beyond epidemiology lies a deeper truth: the journey to diagnosis is not merely clinical—it is lived, felt, and often endured in silence.

"The illness did not begin with a diagnosis. It began with a quiet unease that slowly grew into something I could no longer ignore."

This paper seeks to integrate that lived reality with the clinical evidence base.

2. Early Symptomatology: When the Body Whispers and Is Not Heard

Early ovarian cancer typically presents with symptoms such as abdominal bloating, pelvic discomfort, early satiety, and fatigue [3,6]. These arise from tumour expansion within the peritoneal cavity, leading to irritation, altered gastrointestinal function, and fluid accumulation [7].

However, these symptoms overlap extensively with benign conditions, resulting in low clinical suspicion [4,8].

The lived experience of this phase is marked not by alarm, but by ambiguity:
"It was not pain that stopped me—it was persistence. The symptoms did not leave. They lingered, quietly insisting that something was wrong."
"I adjusted my life around the discomfort, rather than recognising it as something that required investigation."

This reflects the clinical reality that symptom recognition alone is insufficient for early detection [3].

3. Diagnostic Drift: Living in the Space Without Answers

Diagnostic delay is a recognised feature of ovarian cancer, involving patient hesitation, clinician interpretation, and system-level constraints [9]. Investigations such as CA-125 testing and imaging may fail to provide definitive answers, particularly in early disease [10,11].

Women often undergo multiple consultations before diagnosis is reached [12].

From a clinical perspective, this represents a failure of convergence. From a lived perspective, it becomes something far more profound:
"I began to feel as though I was disappearing between appointments—presenting symptoms, but not being seen."
"Each test ruled something out, but nothing explained what I was living with."
"There is a particular exhaustion that comes from not being believed—not explicitly dismissed, but quietly reassured into silence."

This phase—**diagnostic drift**—is not simply a delay in time; it is an erosion of certainty, trust, and self-confidence.

4. Crisis and Emergency Presentation: When the Body Forces Recognition

In many cases, diagnosis occurs only when symptoms escalate to a crisis requiring emergency care [5,13]. Clinical features may include severe abdominal pain, ascites, bowel obstruction, or respiratory compromise [7].

Emergency presentation is strongly associated with advanced-stage disease and poorer outcomes [13].
The lived experience of this transition is abrupt and destabilising:
"I did not reach a diagnosis through clarity—I arrived there through collapse."
"What had been gradual suddenly became urgent. What had been questioned was now undeniable."

This moment represents not only medical escalation, but a psychological rupture—the shift from uncertainty to confrontation with mortality.

5. Diagnosis: Clarity That Expands the Unknown

Ovarian cancer encompasses a heterogeneous group of malignancies with varying histological and molecular profiles [14]. High-grade serous carcinoma predominates and is often diagnosed at an advanced stage [14].

Genetic factors, including BRCA mutations, influence both prognosis and treatment response [15].

While diagnosis provides a name for the illness, it does not resolve uncertainty:
"I expected the diagnosis to bring answers. Instead, it brought more questions—bigger ones, heavier ones."
"The word 'cancer' clarified everything and nothing at the same time."

Clinically, this reflects the complexity of the disease. Experientially, it represents a transition into a new and unfamiliar landscape.

6. Therapeutic Uncertainty: Choosing Without Certainty

Standard treatment includes cytoreductive surgery and platinum-based chemotherapy [16], with decisions regarding sequencing (primary surgery vs neoadjuvant chemotherapy) influenced by disease burden and patient condition [17].

Targeted therapies such as PARP inhibitors offer promise but add layers of complexity [18].

Patients are often required to make decisions in the context of evolving and incomplete evidence:
"I was presented with options, but none came with certainty. Each path felt like a negotiation with the unknown."
"The responsibility to choose felt overwhelming—how do you choose when the outcomes are probabilities, not guarantees?"

This aligns with evidence demonstrating decisional conflict in oncology settings [19].

7. Psychological and Physiological Burden

Delayed diagnosis is associated with increased psychological distress, including anxiety, depression, and loss of trust [20]. Chronic stress activates neuroendocrine pathways, influencing immune and systemic function [21].

Fatigue—distinct from ordinary tiredness—is a pervasive symptom driven by inflammatory and metabolic processes [22].
The lived experience reflects this deeply embodied burden:
"This was not tiredness. It was a weight—something that sat within me and did not lift."
"My body no longer felt like something I could rely on—it had become unpredictable, unfamiliar."

8. Treatment Experience: The Body as a Site of Uncertainty

Chemotherapy introduces toxicities including fatigue, neuropathy, and cognitive impairment [22,23]. Surgery may result in lasting physical changes, including impacts on fertility and identity [16].

Even emerging therapies carry uncertain long-term outcomes [18].
Patients must continually adapt:

"Just as I began to understand the illness, the treatment rewrote the experience."
"Recovery was not a return—it was an adjustment to something new."

9. The New Zealand Context: System and Experience Intertwined

In New Zealand, disparities in access to care and inequities affecting Māori and Pacific populations shape diagnostic and treatment pathways [5,24].

High rates of emergency presentation reflect systemic gaps in early detection [5].
From a lived perspective:
"My experience was not only shaped by the disease, but by how and when the system responded to it."

10. Discussion

Delayed diagnosis in ovarian cancer reflects the intersection of biological ambiguity and systemic limitation [2,3]. The absence of specific symptoms and effective screening tools contributes to late-stage detection.

Importantly, lived experience provides insights not captured by clinical metrics alone. Narrative-based approaches may enhance early recognition by identifying patterns of symptom persistence and change [25].

Integrating patient voice into diagnostic frameworks represents an opportunity to improve both outcomes and patient experience.

11. Conclusion

Ovarian cancer is not only a clinical condition—it is an experience of uncertainty, delay, and adaptation.

The lived experience reveals the profound psychological and physiological impact of navigating a disease that often evades early detection and resists simple treatment pathways.

Improving outcomes requires a dual approach: advancing medical science while listening more carefully to the stories patients bring.
"In the end, what mattered most was not only finding the diagnosis—but being heard along the way."

He Whakaari Pōuri — A Bilingual Spoken Word Lament in the Style of Māori Performance - The link below will allow you to listen to the presentation of these lyrics.

https://heyzine.com/flip-book/1afa7a5c4c.html
so

Verse 1 — Te Karanga / The Calling
E te pō, whakarongo mai…
(O night, listen…)
He mate huna tēnei,
a hidden illness that walks softly,
ovarian cancer—
not with thunder, not with fire,
but with whispers beneath the skin.
Ka tīmata i te kore mōhio,
it begins in not knowing,
he āwangawanga iti noa iho—
just a small unease—
that grows… and grows…
In Aotearoa New Zealand,
almost half are not seen until crisis,
until the body cries louder than the system can ignore,
and the karanga becomes a wail.

Verse 2 — Ngā Tohu / The Signs
Ka kōrero te tinana,
the body speaks—
engari he reo pōuri,
but in a quiet voice.
Bloating… mamae puku… ngenge…
symptoms dressed as ordinary life.
"He pai noa iho," they say—
"It's nothing."
Ka tatari te wahine,
the woman waits,
adjusting, enduring,
living around the discomfort.
But the truth?
The truth sits beneath—
persistent, unrelenting—
he pono e kore e ngaro.

Verse 3 — Te Ngaro / The Losing
Ka haere koe ki te rata,
you go to the doctor—
tests, scans, numbers—
yet still no answer.
Kei waenganui koe i te kore me te mōhio,
you exist between not knowing and knowing.
"I am here," you say,
"I feel this."
Engari kāore koe e tino kitea,
but you are not truly seen.
Each appointment a step sideways,
each reassurance a quiet silencing.
He ngaro tēnei—
this is a disappearing—
not from the world,
but from certainty, from trust.

Verse 4 — Te Pakarutanga / The Breaking Point
Ā, kātahi ka pakaru—
and then, it breaks.
Emergency. Urgency.
Te whare haumanu—bright lights, fast voices.
Now the body is no longer whispering—
kei te karanga kaha,

it is shouting.
Diagnosis arrives not as clarity,
but as confrontation.
“Kua tae mai te mate.”
The illness has arrived.
For Māori,
for Pacific peoples,
this moment comes heavier,
later,
carrying the weight of inequity,
of distance—
not just in miles,
but in access, in listening, in care.

Verse 5 — Te Tangi / The Lament and the Call Forward
Nō reira, ka tangi ahau—
so I lament.
Not only for the disease,
but for the silence before it,
the waiting within it,
the system around it.
Ehara tēnei i te pūtaiao anake—
this is not biology alone.
He pūnaha tēnei—
this is system.
We must listen earlier—
me whakarongo wawe.
We must see sooner—
me kite wawe.
Because every story spoken
is data,
is evidence,
is truth.
Ā, ki te whakarongo tātou—
and if we truly listen—
ka ora pea,
there may yet be life.

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