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Review Article

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Delayed Diagnosis in Ovarian Cancer in Aotearoa New Zealand: Clinical Realities, System Pressures, and the Lived Experience of Emergency Presentation

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Abstract
Ovarian cancer remains one of the most lethal malignancies affecting women, primarily due to delayed diagnosis and advanced-stage presentation. In Aotearoa New Zealand, approximately 46.9% of ovarian cancer cases are diagnosed within 30 days of an emergency admission, reflecting a significant failure of early detection pathways. This paper integrates clinical understanding, epidemiological data, and lived-experience narratives to explore the multifactorial reasons underpinning delayed diagnosis. These include the biological characteristics of ovarian cancer, non-specific symptomatology, diagnostic limitations in primary care, inequities in healthcare access, and systemic delays. The psychological and physiological consequences of late diagnosis are examined, alongside the disproportionate burden experienced by Māori and Pacific peoples. The paper argues that the high rate of emergency presentation is not solely a function of tumour biology but reflects structural challenges within the New Zealand healthcare system. Improved symptom recognition, earlier investigative thresholds, and equity-focused system reform are essential to improving outcomes.

Please click the link below to hear my spoken lament and experience the impact of these factors.
https://heyzine.com/flip-book/925142e528.html

Keywords: Appropriate Complementary Feeding, Breast Feeding, Ataye

1. Introduction

Ovarian cancer is widely recognised as a disease characterised by late presentation and poor prognosis. In Aotearoa New Zealand, this challenge is particularly acute. National data indicate that nearly half of all ovarian cancer diagnoses occur following emergency admission, a pattern associated with significantly worse survival outcomes [1]. This statistic reframes ovarian cancer not simply as a difficult-to-detect malignancy, but as a condition in which diagnostic pathways frequently fail to identify disease before crisis.

Globally, ovarian cancer survival remains low, with five-year survival rates below 50%, largely due to advanced-stage diagnosis [2]. In New Zealand, outcomes are poorer still, with five-year survival estimated at approximately 36% [1]. The high proportion of emergency diagnoses highlights the intersection between disease biology, diagnostic ambiguity, and systemic healthcare limitations.

2. Pathophysiology and Disease Progression

The biological behaviour of ovarian cancer contributes significantly to diagnostic delay. High-grade serous carcinoma, the most common subtype, is now understood to often originate in the fallopian tubes before disseminating rapidly throughout the peritoneal cavity [3]. Unlike malignancies that form discrete, early-detectable masses, ovarian cancer spreads microscopically, leading to diffuse peritoneal involvement before overt clinical detection.

As the disease progresses, tumour dissemination results in:

- Ascites formation
- Peritoneal irritation and inflammation
- Compression of abdominal and pelvic organs
- Systemic metabolic and inflammatory effects

These features explain why early-stage disease may produce only subtle symptoms, while advanced disease manifests with significant physiological compromise requiring urgent medical attention.

3. Symptom Profile and Diagnostic Ambiguity

Ovarian cancer is not truly asymptomatic in its early stages; rather, its symptoms are non-specific and frequently misattributed. Common presenting features include:

- Persistent abdominal bloating
- Early satiety
- Pelvic or abdominal pain
- Urinary urgency or frequency
- Changes in bowel habit
- Fatigue

New Zealand primary care guidance emphasises that these symptoms become clinically significant when they are persistent, new, or worsening [4]. However, these same symptoms overlap with benign conditions such as irritable bowel syndrome, urinary tract disorders, and hormonal changes.

From a lived-experience perspective, this phase is characterised by uncertainty and internal negotiation. The individual recognises that something is not right, yet lacks the clinical language or external validation to escalate concern. Reassurance, while often well-intentioned, can delay further investigation.

4. Diagnostic Pathways in New Zealand Primary Care

Primary care plays a central role in early cancer detection in New Zealand. Current guidance recommends:

- Clinical assessment and abdominal/pelvic examination
- Serum CA-125 testing
- Pelvic ultrasound where indicated
- Reassessment if symptoms persist or worsen [4]

However, each of these steps carries limitations. CA-125 lacks sensitivity and specificity, particularly in early-stage disease, with only approximately 50% of stage I cancers demonstrating elevated levels [1]. Ultrasound access varies across regions, and delays in imaging can prolong diagnostic timelines [4].

The cumulative effect is a pathway that is clinically rational but operationally vulnerable. Patients may cycle through multiple consultations without definitive diagnosis, particularly when initial findings are inconclusive.

5. Emergency Presentation: Why Nearly Half of Diagnoses Occur in Crisis

5.1. Escalation of Disease Burden

As ovarian cancer progresses, symptom severity increases. Ascites leads to abdominal distension and discomfort, tumour burden may cause bowel obstruction, and pleural involvement can impair respiration. These acute complications frequently precipitate emergency presentation [5].

5.2. Systemic Delays in Recognition

The high rate of emergency diagnosis in New Zealand reflects not only disease progression but also delays within diagnostic pathways. These delays may arise from:

- Non-specific symptom interpretation
- Sequential rather than parallel investigation
- Variable access to diagnostic imaging
- Fragmentation between primary and secondary care

5.3. Health Inequities

Māori and Pacific peoples experience disproportionately poorer outcomes, including higher mortality rates and younger age at diagnosis [1]. These inequities reflect broader systemic issues, including access barriers, cultural factors, and differences in healthcare engagement.

6. The Lived Experience of Delayed Diagnosis

6.1. The Phase of Subtle Change

Patients often describe an early phase characterised by a sense that "something is not right." Symptoms are present but difficult to articulate. There is often an internal tension between concern and reassurance.

6.2. Repeated Healthcare Encounters

Many individuals consult healthcare providers multiple times before diagnosis [6]. Each consultation may address individual symptoms rather than recognising the cumulative pattern. This creates a cycle of partial explanations and unresolved concern.
Emotionally, this phase is marked by:

- Growing anxiety
- Frustration
- Self-doubt
- A sense of not being fully heard

6.3. Crisis and Emergency Admission

The transition to emergency presentation is often abrupt. Symptoms escalate to a point where daily functioning is compromised. The individual may present with severe pain, marked abdominal distension, or respiratory difficulty.

This moment represents both a clinical and psychological turning point. Diagnosis, when it comes, is often sudden and overwhelming, occurring in the context of acute illness.

7. Psychological and Physiological Consequences

7.1. Psychological Impact

Delayed diagnosis is associated with significant psychological distress, including anxiety, trauma, and loss of trust in healthcare systems [7]. The experience of being reassured repeatedly before a serious diagnosis can lead to enduring emotional consequences.

7.2. Physiological Impact

Advanced-stage diagnosis is associated with:

- Greater tumour burden
- Reduced surgical options
- Increased reliance on systemic therapy
- Lower survival rates

In New Zealand, one-year mortality is substantially higher among those diagnosed via emergency pathways compared with primary care [1].

8. System-Level Analysis

The high rate of emergency diagnosis in New Zealand reflects a convergence of factors:

1. Biological characteristics of ovarian cancer
2. Non-specific symptom presentation
3. Limitations of diagnostic tools
4. Variability in access to investigations
5. Structural inequities within the healthcare system

This indicates that delayed diagnosis is not attributable to a single point of failure, but rather to the interaction of multiple factors across the diagnostic pathway.

9. Implications for Clinical Practice and Policy in New Zealand

9.1. Lower Threshold for Investigation

Persistent symptom clusters should prompt earlier investigation, even in the absence of definitive findings.

9.2. Enhanced Symptom Awareness

Both clinicians and the public require improved awareness of ovarian cancer symptoms and their significance.

9.3. Equity-Focused Interventions

Targeted strategies are required to address disparities affecting Māori and Pacific populations.

9.4. System Integration

Improved coordination between primary care, diagnostic services, and specialist pathways is essential to reduce delays.

10. Conclusion

In Aotearoa New Zealand, the fact that nearly half of ovarian cancer diagnoses occur following emergency admission is a profound indicator of systemic challenge. It reflects not only the biological complexity of the disease but also limitations within diagnostic pathways and healthcare access.

Behind this statistic lies a consistent lived experience: symptoms that emerge quietly, persist without resolution, and escalate until crisis forces recognition. Improving outcomes requires more than improved diagnostics; it requires a healthcare system that listens earlier, investigates sooner, and responds equitably.

Spoken Word Lament of Delay — The lyrics to the lament are below the musical composition and performance can be found by clicking the link.
https://heyzine.com/flip-book/925142e528.html

Verse 1
I speak of a silence that grows in the body,
quiet as dusk settling over unasked questions.
Ovarian cancer—
not loud, not sudden—
but patient… deliberate…
waiting behind symptoms that look like nothing,
feel like everything,
and are named as “just fatigue,”
“just discomfort,”
“just life.”
Verse 2
In Aotearoa New Zealand,
nearly half—forty-six point nine percent—
do not arrive through doors of planned care,
but through urgency,
through rupture,
through the fluorescent glare of emergency admission.
Thirty days—
a narrow corridor between not knowing
and knowing too late.
This is not chance.
This is a pattern carved into a system.
Verse 3
The body whispers in riddles—
bloating, ache, a fullness that lingers too long—
symptoms that borrow the language of the ordinary.
Primary care listens,
but the tools are blunt,
the thresholds high,
the pathways slow to open.
And so time stretches—
elastic, unforgiving—
while something unseen gathers weight beneath the surface.
Verse 4
And not all bodies are heard the same.
For Māori,
for Pacific peoples,
the distance is longer—
not just miles,
but history, access, trust,
and the quiet erosion of equity.
Diagnosis comes heavier here,
later here,
carrying not just disease
but the burden of being unseen for too long.
Verse 5
So this is not only biology—
not only the nature of a tumour growing in shadow—

this is structure,
this is system,
this is the architecture of delay.
And I lament—
not without hope—
that we must learn to listen sooner,
to look earlier,
to believe the story before it becomes a crisis.
Because survival should not depend
on how loudly suffering is forced to speak.

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