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Review Article

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When Evidence is Absent: The Centrality of Data in Medical Decision-Making and the Consequences of Its Deficiency

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Abstract

Modern medicine is fundamentally an evidence-driven enterprise, where clinical decisions are expected to rest upon robust, reproducible data [1,2]. Yet, in many areas of practice—particularly rare diseases, emerging conditions, and complex multi-system disorders—clinicians and patients must navigate uncertainty in the absence of clear evidence [3,4]. This paper examines the critical role of data in informing medical decision-making and explores the clinical, ethical, and psychological consequences that arise when such data are incomplete, inconsistent, or entirely lacking [5]. It argues that absence of data does not equate to absence of disease, but rather represents a structural gap within medical knowledge systems [6]. Addressing these gaps requires not only improved research infrastructure but also a reframing of how lived experience, clinical judgment, and adaptive reasoning are integrated into care [7].

The link below takes you to a musical presentation from a Pacific island point of view about when facts and data are missing.
https://heyzine.com/flip-book/c549ce8bd5.html

1. Introduction

Medicine has undergone a profound transformation over the past century, shifting from a largely experiential discipline to one grounded in empirical science [1]. The rise of evidence-based medicine (EBM) has institutionalised the expectation that diagnosis, prognosis, and treatment should be guided by high-quality data—ideally derived from randomized controlled trials, systematic reviews, and meta-analyses [2,8].

However, this framework presupposes the existence of sufficient data. In reality, large domains of clinical practice exist where such evidence is sparse, fragmented, or entirely absent [3,9]. These include rare diseases, newly emerging conditions, complex syndromes such as multi-factorial autonomic dysfunction, and patient populations historically underrepresented in research [4,10].

The absence of data introduces a profound tension: medicine demands certainty, yet clinical reality often delivers ambiguity [5].

2. The Role of Data in Medical Decision-Making

Data in medicine serves several critical functions. It provides:

- **Diagnostic clarity,** enabling differentiation between similar clinical presentations [11]
- **Therapeutic guidance,** identifying interventions that are effective, safe, and appropriate [2]
- **Prognostic insight,** informing likely disease trajectories [12]
- **Standardisation of care,** reducing variability and improving outcomes across populations [13]

Evidence-based frameworks allow clinicians to move beyond anecdote and intuition, grounding decisions in reproducible findings [2]. This not only improves patient outcomes but also enhances accountability, transparency, and trust within healthcare systems [14].

At its best, data transforms medicine into a discipline of informed precision [11].

3. The Problem of Absent or Inadequate Data

➢ Clinical Uncertainty and Variability

When robust data does not exist, clinicians are forced to rely on extrapolation, limited case studies, or personal experience [3,9]. This often leads to significant variability in care [13]. Two patients with identical presentations may receive entirely different treatments depending on the clinician, institution, or geographical location [15].

Such variability undermines the principle of equitable care and introduces a form of "clinical randomness" that is deeply unsettling for both practitioner and patient [13].

➢ Diagnostic Delay and Misclassification

In data-poor environments, diseases are frequently misunderstood or misclassified (16). Without established diagnostic criteria or validated biomarkers, patients may undergo prolonged diagnostic journeys—often spanning years [17].

This delay is not merely inconvenient; it can lead to disease progression, reduced treatment efficacy, and increased morbidity [18]. In some cases, patients are misdiagnosed with psychological or functional disorders, reflecting a systemic bias toward explanations that require less evidentiary support [19].

➢ Therapeutic Ambiguity and Trial-and-Error Medicine

The absence of data often results in a trial-and-error approach to treatment [3]. Clinicians may sequentially test interventions without clear guidance on efficacy, dosage, or sequencing [20]. While this approach can occasionally yield benefit, it places significant burden on the patient, who becomes the site of experimentation rather than the recipient of evidence-based care [21]. Adverse effects, treatment fatigue, and loss of confidence in the medical system are common consequences [22].

➢ Ethical Challenges

The lack of data complicates the ethical foundation of medical practice. Principles such as beneficence and non-maleficence become difficult to operationalise when the outcomes of interventions are uncertain [23].

Informed consent is also compromised. Patients cannot be fully informed about risks and benefits when such information does not exist [24]. This creates a paradox: patients must make critical decisions in the absence of the very data that would enable informed choice [23].

➢ Psychological and Lived Experience Impact

From the patient's perspective, the absence of data is experienced not as a neutral gap, but as a form of abandonment [25]. Uncertainty breeds anxiety, erodes trust, and amplifies suffering [26].

Patients often describe feeling "invisible" within the medical system—caught between symptoms that are real and a system that lacks the frameworks to interpret them [27]. The absence of data becomes, in effect, a denial of legitimacy [25].

4. Structural Causes of Data Deficiency

➢ Rarity and Heterogeneity of Conditions

Rare diseases, by definition, affect small populations, making large-scale studies difficult [28]. Similarly, heterogeneous conditions resist standardisation and complicate data collection [4].

➢ Research Funding Priorities

Funding mechanisms often prioritise conditions with high prevalence or clear commercial pathways [29]. As a result, diseases that are complex, poorly understood, or less profitable receive limited attention [30].

➢ Methodological Limitations

Traditional research models, particularly randomized controlled trials, are not always suited to complex, multi-system conditions [31]. These conditions may require adaptive, longitudinal, or individualized study designs [32].

➢ Fragmentation of Clinical Data

Healthcare systems frequently operate in silos, with limited integration of data across institutions or disciplines [33]. This fragmentation prevents the aggregation of meaningful datasets that could otherwise inform practice [34].

5. Bridging the Gap: Toward a More Inclusive Evidence Paradigm

➢ Integrating Lived Experience as Data

Patient narratives and lived experiences represent a rich, underutilized source of data (35). While not a substitute for controlled studies, they provide critical insights into symptom patterns, treatment responses, and disease trajectories [36].

➢ Adaptive and Real-World Evidence Models

There is growing recognition of the value of real-world evidence, including observational studies, registries, and adaptive trial designs [37]. These approaches can generate meaningful data where traditional trials are impractical [31].

➢ Collaborative Data Ecosystems

Improved data sharing across institutions, supported by interoperable systems and ethical governance frameworks, can enable aggregation of data from dispersed populations [33].

➢ Clinical Humility and Transparent Uncertainty

Clinicians must be willing to acknowledge uncertainty and communicate it transparently [5]. This fosters trust and enables shared decision-making [38].

6. Discussion

The absence of data in medicine reflects the boundaries of current knowledge and the limitations of research systems [6]. Expanding definitions of evidence and embracing methodological innovation can help address these gaps [31,37].

7. Conclusion

Data is the foundation of modern medicine, informing decisions

and underpinning trust [2]. When absent, the consequences affect clinical outcomes, ethics, and patient experience [5]. Addressing these gaps requires both new data generation and a reimagining of what constitutes valid evidence [7].

Where the Tide Holds No Record — A Pacific Lament for the Unseen - The link will allow you to listen to the musical presentation of these lyrics and capture the feeling that sits behind this message.
https://heyzine.com/flip-book/c549ce8bd5.html

Modern medicine stands on the promise of knowing,
On data recorded, on patterns that are showing—
But what of the places where nothing is kept?
Where the silence is written where knowledge has slept?
E leai se fa'amaumauga… e leai se tali…
(There is no record… there is no answer…)
For the system was built on the strength of the known,
But leaves the unknown to be faced all alone;
And the woman who comes with a story to tell,
Finds no place in the numbers that guard the well.

She says, "There is something not right in me,"
A shifting, a weight, what I cannot see;
The signs are quiet, the tests unclear,
And the system responds, "There's nothing here."
E le o iloa… e le o mautinoa…
(It is not seen… it is not certain…)
But absence of data is not absence of pain,
Nor proof that the body is whole again;
It is only the measure of what we don't know—
A structural gap where the truth cannot go.

The records incomplete, the patterns unformed,
The pathways uncertain, the protocols worn;
In rare and complex and uncharted disease,
The system leans hard on what little it sees.
Ua gau le faiga… ua le atoatoa…
(The system is broken… it is incomplete…)
This is not failure of body alone,
But failure of structure, of seeds never sown;
For when data is missing, decisions must bend—
From evidence-based… to guesses we defend.

And so, comes delay—
in the naming of truth,
And so comes misdirection—
in the absence of proof;
Treatments that wander, diagnoses that wait,
While the body moves quietly closer to fate.
Ua tigā le loto… ua lelava le agaga…
(The heart is in pain… the spirit is weary…)
The cost is not written in journals alone,
But in trust that is broken, in fear overgrown;
In the woman who wonders if she must prove
That her suffering exists… before it can move.

So, gather her story as you would a chart,
For the data is living inside of her heart;
Let narrative stand where the numbers fall short,
Let listening become a clinical report.
Fa'alogo i le tala… o i inā le upu moni…
(Listen to the story… for there lies the truth…)
For absence of evidence is not empty ground,
It is space where new knowing must yet be found;
And the healing we seek, if it's ever to be,
Must hold both the data… and humanity.

E leai se fa'amaumauga… ae o lo'o iai le tagata…
(There is no record… but the person is here…)

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