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## Through Their Eyes: Lived Experiences as Emotional and Psychological Anchors in Navigating Life's Storms

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### ABSTRACT

This study explored the critical role of lived experiences in shaping personal coping mechanisms, enhancing medical understanding, and enriching research methodologies, with a focus on cancer survivorship. Using an autoethnographic approach, the author, who was also the sole participant, documented her journey through cancer diagnosis, treatment, and survivorship, offering a deeply personal perspective on the emotional, psychological, and practical challenges of living with and surviving cancer. Thematic analysis of the author's narrative revealed key themes, including the emotional and psychological impact of survivorship, barriers to sharing lived experiences, the therapeutic benefits of storytelling, navigating identity and disability, uncertainty and unmet expectations, and the advocacy for documenting lived experiences. These findings highlighted the transformative power of personal narratives while addressing gaps in existing literature and practice. The study underscored the need for a more inclusive, patient-centred approach to healthcare and research, advocating for the systematic integration of lived experiences into policy, practice, and academic inquiry. By valuing and sharing lived experiences, this study contributed to a more empathetic and supportive healthcare environment, fostering resilience, connection, and well-being for individuals navigating serious illnesses.

**Keywords:** Lived Experience, Cancer Survivorship, Autoethnography, Patient-Centered Care, Storytelling, Emotional Resilience, Psychological Impact, Healthcare Narratives, Survivorship Challenges, Patient Advocacy, Qualitative Research, Illness Narratives, Coping Mechanisms, Identity and Disability, Healthcare Policy

### Introduction

Cancer, as a life-altering diagnosis, transcended the boundaries of clinical pathology, embedding itself deeply into the emotional, psychological, and social fabric of those it touched. While medical advancements had significantly improved survival rates, the broader psychological and emotional needs of individuals navigating cancer—whether during treatment,

remission, or survivorship—remained inadequately addressed. When one smelled cancer and also saw the shadow of death, but by divine grace had them perfumed out and blown away, only that person understood the nature of the smell and the thickness of the shadow. Others could perceive it and speculate, but only the one who had experienced it could recount its true nature and feeling; there could never have been another story like it.

This poignant reflection underscored the irreplaceable value of lived experience in understanding the multifaceted realities of cancer. Yet, for too long, the focus in cancer control had been predominantly on clinical care, often neglecting the broader, more nuanced needs of those affected by the disease<sup>1</sup>. Similarly, research and public health programs had frequently been designed by individuals without direct experience of the conditions they aimed to address, resulting in a disconnect between the services provided and the actual needs of patients<sup>2</sup>.

The concept of lived experience, defined as knowledge gained through direct, first-hand involvement in everyday events rather than through secondary constructs or assumptions<sup>2</sup>, had gained increasing attention in recent years. It offered a unique perspective that academic or clinical knowledge alone could not capture. As Schultz<sup>3</sup> noted, lived experience provided insights that were deeply personal and contextually rich, enabling individuals to share what it truly felt like to endure illness, navigate treatment, and grapple with survivorship. These narratives, when combined with academic insights, had the potential to enhance understanding and inform more effective, empathetic approaches to care<sup>3</sup>. However, despite its growing recognition, the integration of lived experience into research and practice remained inconsistent, leaving significant gaps in the literature and in the support systems available to patients.

This journal sought to address these gaps by exploring the critical role of lived experience in meeting the psychological and emotional needs of individuals dealing with serious illnesses like cancer. It aimed to highlight how personal narratives fostered psychological healing, resilience, and community connection<sup>4,5</sup>, while also informing policy and service improvements in healthcare<sup>1</sup>.

Personally, when I was diagnosed with cancer, I searched the internet to find someone with symptoms similar to mine—to understand their diagnosis, how their journey unfolded, and whether they survived. Somehow, I believed that if a person with the same or similar symptoms and diagnosis had survived, it meant I had a better chance of survival too. This search for shared experiences reflected a universal need for connection and understanding, one that was often unmet by traditional clinical frameworks.

Through this dual approach, the journal aimed to offer insights into the value of documented lived experiences for people at various stages of cancer diagnosis, treatment, and remission. It was hoped that this work would resonate with psychologists, healthcare professionals, caregivers, and patients alike, fostering a more inclusive and empathetic understanding of the cancer experience. By amplifying the voices of those who had lived through cancer, this journal sought to contribute to a paradigm shift in how care, research, and policy were approached. It encouraged individuals to share their lived experiences, ensuring that the broader needs of those affected by cancer were no longer overlooked. This shift not only enhanced individual well-being but also drove systemic improvements in how cancer care was conceptualized and delivered.

## Problem Statement

Despite the increasing recognition of patient-centred care, lived experiences remained underrepresented in both medical research and healthcare practice. Traditional research

methodologies often prioritized theoretical constructs, clinical trials, and abstract knowledge over firsthand narratives, resulting in a gap between medical expertise and the actual experiences of individuals facing serious illnesses such as cancer. While physicians provided essential clinical guidance, their insights were often limited to textbook knowledge, which did not fully capture the emotional, psychological, and practical realities of a patient's journey.

Existing literature underscored the importance of illness narratives in shaping coping mechanisms, providing validation, and guiding individuals through their challenges<sup>6,7</sup>. However, research continued to marginalize these perspectives, leading to a disconnect between academic inquiry and the lived realities of those undergoing treatment. Patients frequently sought relatable stories to make sense of their experiences, anticipate challenges, and develop strategies for managing pain and emotions. Without access to such narratives, individuals struggled to navigate their journey, relying solely on clinical information that lacked the depth and relatability needed for holistic coping.

This gap highlighted the urgent need for researchers to integrate lived experiences into medical and psychological studies, moving beyond hypothetical projections and abstract models. By neglecting these narratives, research risked failing to address the real-world concerns of patients, caregivers, and healthcare providers. Moreover, the absence of lived experiences in scholarly discourse limited the development of more empathetic, patient-centred approaches in both policy and practice.

This study addressed this gap by advocating for the systematic documentation and inclusion of lived experiences in research and healthcare discourse. By recognizing the similarities across individual narratives, even within unique experiences, this study emphasized the predictive and guiding role these stories played for newly diagnosed patients. Integrating lived experiences into research methodologies fostered a more comprehensive understanding of illness, ultimately bridging the divide between clinical expertise and patient realities, enhancing support systems, and improving healthcare outcomes.

## Objective of the Study

This study sought to offer insight into the critical need for lived experiences to be documented and shared, emphasizing their role in shaping personal coping mechanisms, enhancing medical understanding, and enriching research methodologies. The paper underscored the necessity for researchers to incorporate lived experiences into academic and clinical studies rather than relying solely on abstract constructs, theoretical projections, or limited empirical data.

Existing literature highlighted the value of lived experiences in improving healthcare outcome data, particularly for patients facing serious illnesses such as cancer. Frank<sup>6</sup> argued that illness narratives served as a means for individuals to make sense of their condition, offering both personal validation and a roadmap for others facing similar challenges. Bury<sup>7</sup> further emphasized that chronic illness disrupted a person's identity, making storytelling an essential tool for reclaiming agency and understanding one's journey. However, despite these insights, research continued to marginalize lived experiences, often favouring clinical data and theoretical models that lacked practical relevance for those navigating real-world challenges<sup>8</sup>.

By encouraging individuals to share their stories, this study bridged the gap between medical knowledge and patient realities. Many patients sought narratives from those who had undergone similar journeys to validate their emotions, anticipate challenges, and develop coping strategies. While physicians provided clinical expertise, their understanding was often limited to textbook knowledge, which did not fully capture the nuanced emotional and psychological dimensions of a patient's experience<sup>9</sup>. Lived experiences, though unique in detail, often shared common themes that helped newly diagnosed patients interpret their journey, sometimes being perceived as a "prophecy" of what lay ahead.

Thus, this study advocated for a more integrative approach in research, medical practice, and psychological support systems—one that valued experiential knowledge alongside scientific inquiry. By documenting and analysing personal narratives, the study fostered a more empathetic, patient-centred approach to care and research, ensuring that those navigating illness and other significant life challenges had access to relatable, practical insights that supported their resilience and well-being.

### **Significance of the Study**

The significance of this study lay in its focus on the critical role of lived experiences in shaping personal coping mechanisms, enhancing medical understanding, and enriching research methodologies. By emphasizing the need to document and share lived experiences, this study addressed a significant gap in existing literature and practice, where firsthand narratives were often marginalized in favour of abstract constructs, theoretical projections, or limited empirical data. The study's findings had far-reaching implications for patients, caregivers, healthcare providers, and researchers, offering a more integrative and empathetic approach to understanding and addressing the challenges faced by individuals dealing with serious illnesses such as cancer.

### **Bridging the gap between medical knowledge and patient realities**

One of the primary contributions of this study was its potential to bridge the gap between medical knowledge and the lived realities of patients. While physicians provided essential clinical expertise, their understanding was often rooted in textbook knowledge, which did not fully capture the emotional, psychological, and practical dimensions of a patient's experience<sup>9</sup>. Lived experiences, on the other hand, offered nuanced insights that complemented clinical data, providing a more holistic understanding of illness. By documenting and analysing these narratives, this study created a repository of relatable, practical insights that guided newly diagnosed patients, helping them anticipate challenges, validate their emotions, and develop effective coping strategies.

### **Enhancing patient-centered care**

The study underscored the importance of patient-centred care, which prioritized the individual needs and experiences of patients over standardized treatment protocols. Existing literature highlighted the value of illness narratives in shaping coping mechanisms and providing validation<sup>6</sup>. However, these narratives were often underrepresented in medical research and practice. By advocating for the inclusion of lived experiences, this study fostered a more empathetic approach to care, ensuring

that patients felt heard, understood, and supported throughout their journey. This approach not only enhanced the quality of care but also empowered patients to take an active role in their treatment and recovery.

### **Enriching research methodologies**

Traditional research methodologies often prioritized theoretical constructs and clinical trials over firsthand narratives, resulting in a disconnect between academic inquiry and the lived realities of patients. This study challenged this paradigm by advocating for the systematic documentation and inclusion of lived experiences in research. By recognizing the similarities across individual narratives, even within unique experiences, the study emphasized the predictive and guiding role these stories played for newly diagnosed patients. Integrating lived experiences into research methodologies led to more comprehensive and relevant findings, ultimately improving healthcare outcomes and informing policy development.

### **Supporting psychological resilience and well-being**

The emotional and psychological toll of serious illnesses such as cancer could not be overstated. Patients often sought relatable stories to make sense of their experiences and develop strategies for managing pain and emotions. Without access to such narratives, individuals struggled to navigate their journey, relying solely on clinical information that lacked the depth and reliability needed for holistic coping. This study addressed this issue by documenting and sharing lived experiences, providing patients with the tools they needed to build resilience and maintain their well-being. By fostering a sense of connection and understanding, these narratives helped individuals feel less isolated and more empowered to face their challenges.

### **Informing policy and practice**

The findings of this study had significant implications for healthcare policy and practice. By highlighting the importance of lived experiences, the study called for a shift in how research was conducted and how care was delivered. Policymakers and healthcare providers used these insights to develop more empathetic, patient-centered approaches that addressed the real-world concerns of patients and caregivers. This shift led to the creation of more effective support systems, improved healthcare outcomes, and a greater emphasis on the human aspect of medicine.

### **Addressing the marginalization of lived experiences**

Despite the growing recognition of the value of lived experiences, these narratives remained underrepresented in both medical research and healthcare practice. This study addressed this gap by advocating for the systematic documentation and inclusion of lived experiences in research and healthcare discourse. By doing so, it challenged the marginalization of these perspectives and highlighted their importance in shaping a more comprehensive understanding of illness. The study's emphasis on lived experiences served as a call to action for researchers, healthcare providers, and policymakers to prioritize these narratives in their work.

### **Fostering a more empathetic approach to care**

Ultimately, this study fostered a more empathetic approach to care, one that valued experiential knowledge alongside scientific inquiry. By documenting and analysing personal narratives,

the study created a more inclusive and supportive healthcare environment, where patients felt heard, understood, and valued. This approach not only enhanced the quality of care but also contributed to the overall well-being of individuals facing serious illnesses.

Overall, the significance of this study lay in its potential to transform how we understood and addressed the challenges faced by individuals dealing with serious illnesses. By emphasizing the importance of lived experiences, the study advocated for a more integrative, empathetic, and patient-centred approach to care and research. This shift improved healthcare outcomes, enhanced psychological resilience, and created a more supportive and inclusive healthcare environment for all.

## Lived Experience: A Literature Review and Conceptual Framework

### Introduction

Lived experience is a fundamental concept in psychology, healthcare, and social sciences, representing an individual's personal encounters, perceptions, and reflections on significant life events. It encompasses emotional, cognitive, and sensory dimensions that shape a person's understanding of their reality (Murray, 2022). While lived experiences are deeply personal, they often contain shared elements that allow individuals to connect with others facing similar circumstances<sup>10</sup>. In the context of healthcare, particularly cancer care, integrating lived experiences into policy and service delivery is crucial for addressing the broader needs of those affected<sup>1</sup>. This literature review explores the origins, definitions, applications, and benefits of lived experiences, highlighting why people may hesitate to share their experiences and the importance of doing so.

### Defining lived experience

Lived experience has been defined in multiple ways. Talking Health Tech describes it as a person's accumulated knowledge from personal experiences and decisions<sup>2</sup>. The Cambridge Dictionary defines it as firsthand experiences that provide unique knowledge not accessible to those who have merely read or heard about such experiences<sup>2</sup>. Engel<sup>11</sup> emphasized the role of lived experience in shaping subjective reality, highlighting that an individual's psychological responses, emotions, and personal interpretations form an epistemologically distinct understanding of their life events<sup>10</sup>.

Lived experiences are not just recollections of events; they represent deep, personal engagements with reality that shape emotions, perceptions, and behaviours<sup>12</sup>. These experiences can be categorized into sensory, emotional, and cognitive-behavioural aspects, which interact to create a unique personal narrative<sup>12</sup>.

### Origins and evolution of the concept

The concept of lived experience has roots in phenomenology, a philosophical approach developed by Edmund Husserl in the early 20<sup>th</sup> century. Phenomenology emphasizes the importance of personal experiences in constructing knowledge and understanding the world. Later, Maurice Merleau-Ponty expanded on this idea by emphasizing embodiment—the idea that experiences are deeply connected to an individual's physical and emotional state<sup>3</sup>.

In psychology, Engel's biopsychosocial model<sup>11</sup> reinforced the significance of lived experience by acknowledging that health is shaped not just by biological factors but also by psychological and social dimensions<sup>10</sup>. More recently, research has emphasized the importance of lived experiences in mental health, patient care, and recovery processes<sup>13</sup>.

## Applications of Lived Experience

### Healthcare and patient-centered care

Lived experiences have been increasingly recognized in healthcare, particularly in understanding mental health conditions and chronic illnesses. WHO's Global Survey on the Lived Experience of People Affected by Cancer<sup>1</sup> highlights how integrating patients' firsthand experiences into healthcare policies can improve emotional and practical support for cancer patients and their families.

In mental health, personal narratives provide crucial insights into conditions like depression, schizophrenia, and obsessive-compulsive disorder<sup>13</sup>. By incorporating lived experiences into treatment plans, healthcare professionals can develop more effective and empathetic interventions.

### Storytelling and emotional healing

Sharing lived experiences can be therapeutic for both the storyteller and the audience<sup>4</sup>. Storytelling enables individuals to process traumatic events, find meaning in their experiences, and build resilience. Research has shown that storytelling reduces anxiety and stress while improving self-esteem and emotional well-being<sup>4</sup>.

### Peer support and advocacy

Individuals with lived experiences serve as advocates, peer support workers, and consultants in healthcare, education, and policy-making<sup>5</sup>. Peer support groups, particularly in cancer care and mental health, provide a safe space where individuals can share experiences, offer mutual support, and reduce stigma.

### The role of lived experiences in research and healthcare

Lived experiences offer valuable insights into the complexities of illness, recovery, and emotional resilience, yet they are often underrepresented in research and healthcare interventions. Personal narratives provide a depth of understanding that abstract theories or clinical data alone cannot capture, making them essential for a holistic approach to patient care<sup>14</sup>. Research suggests that individuals facing serious illnesses, such as cancer, often seek out stories from others with similar experiences to navigate their own challenges<sup>7</sup>. These narratives act as informal guides, helping patients interpret symptoms, anticipate treatment effects, and manage the psychological toll of illness<sup>15</sup>.

Despite these benefits, the integration of lived experiences in medical practice and academic research remains limited. Traditional research methodologies prioritize empirical data over subjective accounts, often dismissing personal stories as anecdotal rather than as crucial components of understanding illness trajectories<sup>16</sup>. This gap underscores the need for a paradigm shift that acknowledges and utilizes lived experiences as a legitimate form of knowledge.

### The importance of sharing lived experiences

- **Reducing stigma and misconceptions:** Sharing lived

experiences helps break down stigma, particularly in areas like mental health and chronic illness<sup>5</sup>. When individuals openly discuss their experiences, it fosters greater understanding and empathy, challenging harmful stereotypes.

- **Enhancing support systems:** By sharing their experiences, individuals can connect with others facing similar challenges, creating strong support networks<sup>1</sup>. This is particularly crucial in healthcare settings, where patient support groups can provide emotional and psychological relief.
- **Informing policy and service delivery:** Lived experiences provide valuable insights that can improve healthcare policies and services<sup>5</sup>. For example, WHO's Global Survey is designed to incorporate patient perspectives into cancer care strategies, ensuring that medical interventions align with real patient needs<sup>1</sup>.

### Barriers to sharing lived experiences

Despite its benefits, many individuals hesitate to share their lived experiences due to societal stigma, fear of judgment, and emotional distress. Stubbing & Tolin note that some experiences<sup>13</sup>, particularly those related to mental illness or trauma, are highly personal and difficult to verbalize. Moreover, individuals may struggle with validating their experiences, especially when they feel isolated in their struggles.

Karunamuni, et al.<sup>10</sup> highlight that subjective experiences are shaped by personal emotions, perceptions, and cultural contexts, which can influence how individuals choose to express or suppress their narratives. Additionally, some fear that their experiences will be dismissed or misunderstood by those who have not faced similar situations<sup>12</sup>.

### Limited adaptation of lived experiences in research and practice

The underrepresentation of lived experiences in academic and clinical discourse can lead to interventions that are misaligned with the actual needs of patients<sup>17</sup>. Ghosh critiques the common practice of individuals without firsthand experience authoring narratives or designing policies about conditions they have never encountered<sup>2</sup>. This detachment often results in generalized or incomplete portrayals of patient experiences, overlooking the emotional and psychological complexities that accompany serious health conditions.

The World Health Organization (WHO) also acknowledges this gap, emphasizing that while clinical care has traditionally focused on biomedical factors, there is a pressing need to incorporate lived experiences to understand the emotional and psychological dimensions of illness<sup>18</sup>. Without these perspectives, healthcare providers may struggle to offer truly patient-centred care, as their guidance is based solely on medical literature rather than real-world experiences<sup>9</sup>.

Furthermore, the reliance on purely clinical perspectives can lead to ineffective communication between patients and healthcare professionals. Studies have shown that patients often feel unheard when their emotional struggles are not acknowledged, leading to increased distress and disengagement from treatment<sup>19</sup>. Incorporating lived experiences into research and healthcare practices can help bridge this gap, ensuring

that patients receive not only medical treatment but also the psychological support necessary to cope with their conditions.

### Gap in Literature

Despite increasing recognition of lived experiences in healthcare and psychology, several gaps remain:

- **Underrepresentation in policy-making:** While organizations like WHO emphasize lived experiences, many healthcare policies still prioritize clinical data over patient narratives<sup>1</sup>.
- **Limited integration in education and training:** Although lived experiences are valuable for understanding conditions like mental illness, they are often excluded from academic curricula<sup>13</sup>.
- **Barriers to sharing:** More research is needed on the psychological and societal factors that prevent individuals from openly discussing their experiences<sup>12</sup>.

### Conceptual framework on lived experience

The conceptual framework below illustrated how lived experience was shaped by multiple interconnected factors and how it contributed to personal growth, emotional well-being, and policy development, and how it was centered in the paper.

#### Key Constructs

- **Personal experience:**
  - Emotional, sensory, and cognitive dimensions<sup>12</sup>.
  - Influenced by individual perception and cultural context<sup>10</sup>.
- **Barriers to expression:**
  - Stigma, fear, and emotional distress<sup>13</sup>.
  - Societal perceptions and validation concerns<sup>12</sup>.
- **Modes of expression:**
  - Storytelling, therapy, peer support groups<sup>4</sup>.
  - Artistic and literary representations of experiences.
- **Outcomes and impact:**
  - Psychological healing and resilience<sup>4</sup>.
  - Social support and community connection<sup>5</sup>.
  - Policy and service improvement in healthcare<sup>1</sup>.

### Diagram representation of conceptual framework on lived experience

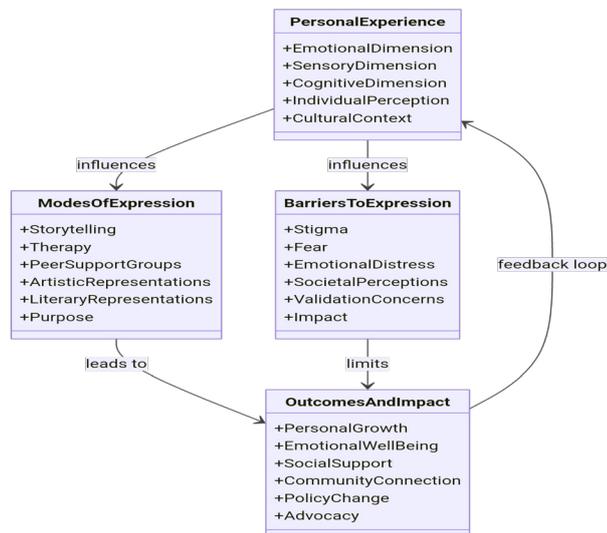
This framework highlighted that while lived experiences were deeply personal, overcoming barriers to sharing them led to broader benefits, both individually and socially.

It also illustrated how lived experiences, when effectively shared and integrated, contributed to personal growth, emotional well-being, and systemic change. By addressing barriers and fostering supportive environments, the full potential of lived experiences was realized, benefiting individuals and society alike.

### Research design

This study adopted a qualitative research design to explore the critical role of lived experiences in shaping personal coping mechanisms, enhancing medical understanding, and enriching

research methodologies. The methodology was grounded in autoethnography, a qualitative approach that combined autobiographical and ethnographic elements to analyse personal experiences within a broader cultural, social, and political context<sup>20</sup>. Autoethnography was particularly suited for this study as it allowed the author, who was also the sole participant, to reflect deeply on her lived experience with cancer, offering a rich, first-person perspective that bridged the personal and the universal. This approach emphasized subjectivity, reflexivity, and the emotional depth of lived experiences, making it ideal for exploring the nuances of coping with serious illness.



**Figure 1:** Personal Experience → Modes of Expression → Barriers to Expression → Outcomes and Impact.

### Data collection

Since the author was the sole participant, the study relied entirely on her personal lived experience as the primary data source. This approach eliminated the need for external recruitment and focused on the author's firsthand account of navigating cancer diagnosis, treatment, and survivorship. The data collection process involved the following:

- **Primary data:** Personal Narrative
- **Source:** The author's lived experience, including her emotional, sensory, and cognitive reflections on cancer diagnosis, treatment, and recovery.
- **Data generation:** The author documented her experiences through reflective journaling, a method that allowed for detailed exploration of thoughts, feelings, and perceptions over time<sup>20</sup>. Journal entries focused on:
  - The emotional, sensory, and cognitive dimensions of her experience<sup>12</sup>.
  - The role of storytelling and sharing experiences in her coping process<sup>4</sup>.
  - Barriers she faced in sharing her experiences<sup>21</sup>.
  - The impact of her lived experience on her psychological resilience and well-being<sup>5</sup>.

**Ethical Considerations:** As the sole participant, the author ensured that her narrative was shared with sensitivity and respect for her own emotional well-being. Reflexivity was employed to maintain ethical integrity and avoid self-exploitation<sup>20</sup>.

### Secondary data: Literature and case studies

- **Sources:** The study drew on existing literature, including peer-reviewed articles, books, and reports, as well as publicly available patient narratives and case studies. Key sources included:
  - Academic studies on illness narratives<sup>6,7</sup>.
  - Reports on the role of lived experiences in healthcare<sup>1</sup>.
  - Case studies highlighting the impact of peer support and storytelling on patient outcomes<sup>4,5</sup>.
- **Focus:** The secondary data was used to contextualize the author's personal narrative, identify common themes, and highlight gaps in the existing literature.

### Data Analysis

The data analysis process was iterative and interpretive, guided by the principles of autoethnography. The goal was to uncover the layers of meaning embedded in the author's narrative and to connect her personal experience to broader cultural and social contexts.

#### Step 1: Reflective journaling and familiarization

The author engaged in reflective journaling over a specified period, documenting her thoughts, feelings, and perceptions related to her cancer journey. She then immersed herself in the journal entries, reading and re-reading them to gain a thorough understanding of her experiences.

#### Step 2: Thematic analysis

The journal entries were analysed using thematic analysis, a method that identified recurring patterns and themes within qualitative data<sup>22</sup>. Codes were generated inductively, based on the author's words and phrases, and captured the emotional, sensory, and cognitive dimensions of her experiences<sup>12</sup>.

#### Step 3: Theme development

Codes were grouped into broader themes that reflected the key aspects of the author's lived experience. For example:

- **Emotional and psychological impact:** Themes related to fear, resilience, hope, and coping mechanisms.
- **Barriers to sharing:** Themes related to stigma, fear of judgment, and cultural factors<sup>21</sup>.
- **Role of storytelling:** Themes related to the therapeutic benefits of sharing stories and the role of narratives in fostering connection and understanding<sup>4</sup>.

#### Step 4: Interpretative analysis

The themes were interpreted within the context of existing literature and theoretical frameworks, such as Engel's biopsychosocial model<sup>11</sup> and Heidegger's phenomenology<sup>23</sup>. This step involved exploring how the author's experiences aligned with or challenged existing knowledge and identifying implications for research, policy, and practice.

#### Step 5: Integration of personal and secondary data

The author's personal narrative was integrated with secondary data to provide a comprehensive understanding of lived experiences. This integration highlighted commonalities and differences between the author's story and existing literature, offering a nuanced perspective on the role of lived experiences in healthcare.

### Validation and Trustworthiness

To ensure the credibility and trustworthiness of the findings, the study employed several validation strategies:

- **Reflexivity:** The author maintained a reflexive journal to document her assumptions, biases, and reflections throughout the research process, ensuring transparency and rigor. Reflexivity was particularly important in autoethnography, as it helped the researcher acknowledge and mitigate potential biases<sup>20</sup>.
- **Triangulation:** The use of secondary data enhanced the robustness of the findings by providing external validation of the author's personal narrative.
- **Peer debriefing:** The author consulted with academic peers to review and critique the analysis, ensuring that the interpretations were balanced and credible<sup>24</sup>.

### Ethical Considerations

The study adhered to ethical guidelines for autoethnographic research, including:

- **Self-care:** As the sole participant, the author prioritized her emotional well-being throughout the research process. Reflective journaling and storytelling could be emotionally taxing, and the author took breaks as needed to avoid burnout<sup>20</sup>.
- **Confidentiality:** While the author's narrative was personal, she ensured that any identifying details about others (e.g., family members, healthcare providers) were anonymized to protect their privacy.
- **Transparency:** The author clearly disclosed her dual role as researcher and participant, ensuring that readers understood the subjective nature of the study.

### Addressing biases

The author's dual role as researcher and participant introduced potential biases that were acknowledged and managed. These included:

- **Personal bias:** The author's lived experience might have influenced the interpretation of data, leading to a preference for narratives that aligned with her own experiences. To mitigate this, the study employed reflexivity and triangulation, ensuring that multiple perspectives were considered<sup>20</sup>.
- **Emotional bias:** The emotional nature of the topic might have affected the author's objectivity. Regular self-reflection and consultation with peers helped maintain a balanced perspective.
- **Confirmation bias:** The author might have unconsciously sought data that confirmed her pre-existing beliefs. To address this, the study prioritized inductive coding and theme development, allowing the data to speak for itself<sup>22</sup>.

### Expected outcomes

The study aimed to:

- Provide a rich, detailed understanding of the lived experiences of individuals dealing with serious illnesses, as seen through the author's personal narrative.
- Highlight the emotional, psychological, and practical dimensions of these experiences.

- Identify barriers to sharing lived experiences and propose strategies to overcome them.
- Advocate for the integration of lived experiences into research, policy, and practice to foster a more empathetic, patient-centered approach to care.

### Implications for research, policy, and practice

The findings of this study had significant implications for:

- **Research:** Encouraging the inclusion of lived experiences in academic studies to bridge the gap between theoretical knowledge and real-world challenges.
- **Policy:** Informing the development of policies that prioritized patient-centered care and support systems.
- **Practice:** Enhancing healthcare delivery by incorporating lived experiences into clinical practice, training, and peer support programs.

By employing an autoethnographic approach, this study sought to offer profound insights into the lived experiences of individuals facing serious illnesses, as seen through the author's personal journey with cancer. The integration of personal narrative and secondary data, along with rigorous analysis and validation, ensured that the findings were both credible and impactful. The author's dual role as researcher and participant added a unique perspective to the study, enriching the depth of understanding while necessitating careful attention to biases and ethical considerations. Ultimately, this study aimed to advocate for a more inclusive, empathetic, and patient-centred approach to healthcare, where lived experiences were valued as a vital source of knowledge and understanding.

### Personal narrative 1

After I was diagnosed with cancer and journeyed through treatment, all involved within the process were focused on getting me to remission. I therefore thought crossing the line to remission or surviving cancer was the final lap. I thought, yeah, that was it, and then I could close the chapter on cancer—at least for now—while hoping there would be no recurrence. However, now that I am here (in remission), I find myself experiencing a mix of emotions I never anticipated. I had assumed that life would return to how it was before, but with little information available on the lived experiences of survivors and how they navigate life after cancer, dealing with the reality of survivorship has been challenging. Each day presents new struggles, and I am now beginning to revise my expectations.

I never imagined that surviving cancer would come with a bundle of emotions and challenges I wasn't prepared to confront. I had looked forward to returning to work and helping others navigate the difficulties of diagnosis and treatment, but instead, I found myself facing yet another hurdle—life after treatment. This transition was particularly difficult because I had resigned from my previous job and spent over a year undergoing diagnosis and treatment.

One of the most unexpected realizations came when I started searching for a new job and found a position with a UN agency that interested me. While filling out the application, I encountered a section asking about disability status. If the question had been, "Do you consider yourself disabled?" I would have instinctively selected "No" without a second thought. However, the question instead asked, "Are you disabled?" with a hyperlink detailing

what the organization classified as a disability. To my surprise, cancer was included.

At first, I was upset and questioned why cancer was categorized as a disability. I wrestled with the idea, wondering what limitations this status might impose and how it could affect future opportunities. It saddened me deeply.

But after dealing with the effects of radiotherapy and other challenges over time, I began to understand why it might be categorized that way. That realization can be frustrating because you want things to return to how they used to be, yet you also recognize that certain limitations can make it almost impossible to pursue some career goals.

It was difficult to come to terms with this, but I eventually realized that things do get better with time. Other opportunities related to our experiences often emerge, making coping much easier-especially when we engage in meaningful but less strenuous work, such as helping others overcome their struggles, pursuing activities we love, or surrounding ourselves with people whose company we enjoy.

I have now embraced my new reality, though it took time. Looking back, I wish I had been more aware of these challenges earlier. This is one of the reasons I strongly advocate for documenting lived experiences. You never know who might need them as a guide or a source of reassurance in their own journey.

## Personal Narrative 2

Personally, when I was diagnosed with cancer, I searched the internet to find someone with similar symptoms to mine-to understand their diagnosis, how their journey unfolded, and whether they survived. Somehow, I believed that if a person with the same or similar symptoms and diagnosis had survived, it would mean I had a better chance of survival too.

I was also looking for lived experiences that detailed the challenges one faces after surgery and radiotherapy, including how long it takes to recover. While doctors provided estimates-for instance, how long it would take for the swelling on my cheeks to subside or for the pain on my tongue to go away-some of their predictions didn't come true, which often left me worried. They told me the swelling around my cheek should disappear within two to three weeks, but after four months, it was still there, and they couldn't fully explain why. This uncertainty added to my anxiety.

I also needed to understand the side effects associated with both the treatment and the disease, as well as what could be done for comfort and coping. Some of the side effects doctors mentioned never happened to me, while others that I did experience were not discussed. Their primary solution was prescribing pain medication, but its effects would wear off quickly, requiring me to keep taking it just to maintain a certain level of comfort.

At first, it was difficult to find personal stories that included a detailed description of a similar diagnosis, cancer stage, treatment options, side effects, and coping mechanisms for pain and emotions. Over time, I came across different stories, and while no single one mirrored my exact experience, piecing them together helped. Still, I wished I had found one comprehensive

account that captured everything I was hoping to understand about what was to come.

## Data Analysis

The personal narrative above was analysed using thematic analysis, a qualitative method that identifies recurring patterns and themes within the data<sup>22</sup>. The analysis revealed several key themes that reflect the emotional, psychological, and practical dimensions of the author's lived experience with cancer and survivorship. These themes are interconnected and provide a nuanced understanding of the challenges and insights gained through this journey.

### Emotional and psychological impact

The narrative highlights the profound emotional and psychological toll of cancer survivorship. The author describes a mix of emotions she never anticipated, including anxiety, sadness, and uncertainty. For example, she reflects on the unexpected challenges of life after treatment, stating, "I had assumed that life would return to how it was before, but with little information available on the lived experiences of survivors, dealing with the reality of survivorship has been challenging." This theme aligns with existing literature on the emotional complexities of cancer survivorship, which often includes feelings of isolation, fear of recurrence, and difficulty adjusting to a "new normal"<sup>6,7</sup>.

### Barriers to sharing lived experiences

The author's narrative underscores the lack of accessible, comprehensive accounts of lived experiences, which made her journey more isolating. She recalls searching for stories that mirrored her diagnosis and treatment but found only fragmented accounts. This gap in information reflects broader barriers to sharing lived experiences, such as stigma, fear of judgment, and the emotional labour required to articulate deeply personal stories<sup>21</sup>. The author's advocacy for documenting lived experiences highlights the importance of addressing these barriers to provide support and guidance to others.

### Role of storytelling in coping and healing

Storytelling emerges as a central theme in the narrative, both as a coping mechanism for the author and as a tool for helping others. The author reflects on how sharing her story has helped her process her emotions and find meaning in her experience. She states, "This is one of the reasons I strongly advocate for documenting lived experiences. You never know who might need them as a guide or a source of reassurance in their own journey." This aligns with research that highlights the therapeutic benefits of storytelling, including reduced anxiety, improved self-esteem, and enhanced emotional well-being<sup>4</sup>.

### Navigating identity and disability

A significant theme in the narrative is the author's struggle with identity and the classification of cancer as a disability. Initially, she resists this label, feeling upset and questioning its implications. However, over time, she comes to accept it, recognizing that meaningful work and connection with others can help her navigate this new reality. This theme reflects the broader challenges of redefining identity after a life-altering illness, as well as the societal stigma often associated with disability (Sartor, 2023).

## Uncertainty and unmet expectations

The narrative is marked by a recurring sense of uncertainty and unmet expectations. The author describes how doctors' predictions about her recovery did not align with her actual experience, leading to increased anxiety. For example, she notes, "They told me the swelling around my cheek should disappear within two to three weeks, but after four months, it was still there, and they couldn't fully explain why." This theme highlights the limitations of clinical knowledge in addressing the lived realities of patients and underscores the need for more patient-centred approaches to care<sup>9</sup>.

## Advocacy for lived experiences

Throughout the narrative, the author emphasizes the importance of documenting and sharing lived experiences to support others facing similar challenges. She reflects on how her own search for relatable stories helped her cope and expresses a desire to provide that same support to others. This theme aligns with the growing recognition of lived experiences as a valuable source of knowledge and insight in healthcare and research<sup>1</sup>.

The personal narrative and thematic analysis reveal the multifaceted nature of the author's lived experience with cancer and survivorship. The themes of emotional and psychological impact, barriers to sharing, the role of storytelling, navigating identity, uncertainty, and advocacy for lived experiences provide a comprehensive understanding of the challenges and insights gained through this journey. By documenting and analysing her story, the author not only processes her own experiences but also contributes to a broader understanding of cancer survivorship, advocating for a more empathetic, patient-centred approach to care and research. This analysis underscores the importance of lived experiences as a vital source of knowledge and support for individuals navigating serious illnesses.

## Findings

The findings of this study, derived from the author's personal narrative and supported by thematic analysis, reveal the profound emotional, psychological, and practical dimensions of living with and surviving cancer. The analysis identified several key themes that highlight the transformative power of lived experiences while addressing gaps in existing literature and practice. These findings underscore the importance of documenting and sharing personal narratives to enhance medical understanding, inform patient-centred care, and enrich research methodologies.

## Emotional and psychological impact of cancer survivorship

The author's narrative vividly captures the emotional and psychological toll of cancer survivorship, describing feelings of anxiety, uncertainty, and unmet expectations. She reflects, "I had assumed that life would return to how it was before, but with little information available on the lived experiences of survivors, dealing with the reality of survivorship has been challenging." This aligns with Frank's concept of illness narratives as a means for individuals to make sense of their condition and reclaim agency<sup>6</sup>. However, the author's experience also highlights gaps in the literature, particularly the lack of focus on the long-term emotional and psychological impacts of survivorship. While existing studies often emphasize the challenges during treatment, her narrative sheds light on the often-overlooked struggles of life after cancer, such as redefining one's identity and navigating

the "new normal"<sup>7</sup>.

## Barriers to sharing lived experiences

The author's search for relatable stories mirrors the broader barriers to sharing lived experiences identified in the literature. She recalls, "At first, it was difficult to find personal stories that included a detailed description of a similar diagnosis, cancer stage, treatment options, side effects, and coping mechanisms for pain and emotions." This aligns with findings that stigma, fear of judgment, and emotional distress often prevent individuals from sharing their stories<sup>13,21</sup>. However, the author's narrative also reveals the transformative power of storytelling as a tool for healing and advocacy. By reflecting on and capturing her experiences, she worked through her emotions and extended insight and encouragement to others. This contrasts with the literature's focus on barriers, highlighting the potential of lived experiences to foster connection and resilience when shared<sup>4</sup>.

## Therapeutic benefits of storytelling

The author's emphasis on the therapeutic benefits of storytelling resonates with Coulter's findings that sharing personal narratives can reduce anxiety<sup>4</sup>, boost self-esteem, and improve emotional well-being. She reflects, "This is one of the reasons I strongly advocate for documenting lived experiences. You never know who might need them as a guide or a source of reassurance in their own journey." However, the author's narrative also highlights a gap in the literature: the lack of comprehensive, relatable accounts of survivorship. While existing studies emphasize the benefits of storytelling, they often overlook the practical challenges of accessing and sharing these narratives. The author's experience underscores the need for more platforms and resources to facilitate the documentation and dissemination of lived experiences<sup>5</sup>.

## Navigating identity and disability

The author's struggle with the classification of cancer as a disability reflects broader debates about identity and stigma in the context of chronic illness. Initially, she resists this label, feeling upset and questioning its implications. Over time, however, she comes to accept it, recognizing that meaningful work and connection with others can help her navigate this new reality. This aligns with Sartor's findings that individuals with lived experiences often play vital roles as advocates and peer-support workers, contributing to more inclusive and empathetic healthcare systems<sup>5</sup>. However, the author's narrative also highlights a gap in the literature: the emotional and psychological impact of being labelled as "disabled" after cancer. While existing studies focus on the practical implications of disability status, her story sheds light on the internal conflict and identity shifts that accompany this classification. This underscores the need for more research on the subjective experiences of cancer survivors navigating disability<sup>12</sup>.

## Uncertainty and unmet expectations

The author's experience of unmet expectations and uncertainty during recovery aligns with Kleinman's argument that clinical knowledge often fails to capture the lived realities of patients<sup>9</sup>. She describes how doctors' predictions about her recovery did not align with her actual experience, leading to increased anxiety. For example, she notes, "They told me the swelling around my cheek should disappear within two to three

weeks, but after four months, it was still there, and they couldn't fully explain why." This highlights the limitations of clinical expertise in addressing the nuanced emotional and practical challenges of survivorship. However, the author's narrative also offers a unique perspective: the importance of lived experiences in filling these gaps. By sharing her story, she provides insights that complement clinical knowledge, offering a more holistic understanding of the cancer journey. This underscores the need for healthcare systems to integrate lived experiences into patient care and support<sup>8</sup>.

### Advocacy for lived experiences

The author's advocacy for documenting and sharing lived experiences aligns with the growing recognition of their value in healthcare and research. She reflects, "You never know who might need them as a guide or a source of reassurance in their own journey." This resonates with the World Health Organization's call to amplify the voices of those affected by cancer to inform policy and practice<sup>1</sup>. However, the author's narrative also highlights a gap in the literature: the lack of systematic approaches to integrating lived experiences into research and healthcare. While existing studies emphasize the importance of these narratives, they often fail to provide practical strategies for their documentation and dissemination. The author's experience underscores the need for more inclusive methodologies that prioritize lived experiences as a vital source of knowledge<sup>1</sup>.

The findings of this study highlight the transformative potential of lived experiences in shaping personal coping mechanisms, enhancing medical understanding, and enriching research methodologies. The author's narrative not only validates the importance of personal stories but also reveals gaps in existing literature and practice, emphasizing the need for a more inclusive, patient-centred approach to healthcare and research. By documenting and sharing her journey, the author provides a roadmap for others facing similar challenges, offering insights that complement clinical knowledge and foster empathy, resilience, and connection. These findings call for systemic changes to ensure that lived experiences are valued, documented, and integrated into policy and practice, ultimately creating a more supportive and empathetic healthcare environment for all.

### Discussion

The findings of this study collectively reinforce the central argument of the literature that lived experience is not merely descriptive but constitutes a critical form of knowledge that shapes meaning-making, identity, and engagement with healthcare systems<sup>10,12</sup>. Rather than existing as isolated themes, the six findings interact within the conceptual framework, illustrating how personal experience, barriers to expression, modes of articulation, and outcomes are dynamically interconnected.

Across the findings, cancer survivorship emerges as a prolonged and complex psychosocial process rather than a clearly defined post-treatment phase. The emotional and psychological disruptions described by the author reflect the multidimensional nature of lived experience, where cognitive expectations, emotional responses, and embodied realities intersect<sup>12</sup>. This aligns with phenomenological perspectives that emphasize how individuals construct meaning through their experiences<sup>3</sup>. The tension between anticipated recovery and lived reality further supports the notion of biographical disruption,

where illness necessitates an ongoing reconstruction of identity and life narrative<sup>7</sup>. Importantly, this disruption is not resolved at the end of treatment but persists into survivorship, suggesting that current research and care models may inadequately address long-term psychosocial needs.

The findings also highlight how barriers to expression are embedded within broader social and institutional contexts. While stigma, fear, and emotional difficulty remain significant deterrents to sharing lived experiences<sup>12,13</sup>, the absence of detailed and accessible narratives points to structural limitations in how such knowledge is valued and disseminated. This reflects longstanding critiques that subjective accounts are often marginalized within research paradigms that prioritize empirical and clinical data<sup>16,17</sup>. As a result, individuals navigating illness may encounter informational and emotional gaps, limiting their ability to anticipate and cope with their experiences<sup>7,15</sup>.

Within this context, storytelling emerges as a critical mode of expression that mediates between personal experience and broader social impact. The author's engagement with narrative reflects the therapeutic and interpretive functions of storytelling identified in the literature, where individuals actively organize and make sense of their experiences<sup>4</sup>. Beyond individual coping, storytelling also contributes to collective knowledge by transforming private experiences into shared resources. This aligns with the framework's emphasis on outcomes, where lived experiences, once expressed, can foster emotional healing, resilience, and social connection<sup>5</sup>. The findings therefore extend existing literature by demonstrating that the value of storytelling lies not only in its therapeutic benefits but also in its capacity to fill critical gaps in experiential knowledge.

The negotiation of identity, particularly in relation to disability, further illustrates the depth of lived experience as an evolving process shaped by internal reflection and external categorization. The author's initial resistance and eventual acceptance of the disability label underscore the complex interplay between personal perception and societal definitions. This reflects the literature's recognition that lived experiences are deeply influenced by cultural and social contexts<sup>10</sup>, while also pointing to an underexplored area concerning the emotional consequences of diagnostic and institutional labelling<sup>12</sup>. The findings suggest that identity reconstruction in survivorship involves not only adapting to physical changes but also reconciling shifts in self-concept and social positioning.

In addition, the author's experience of uncertainty and unmet expectations exposes the limitations of a predominantly biomedical approach to care. While clinical expertise provides essential information about diagnosis and treatment, it often fails to capture the variability and unpredictability of lived realities<sup>9</sup>. This disconnect can lead to increased anxiety and a sense of being unprepared for the recovery process. The findings therefore support calls for a more holistic approach that integrates lived experiences into healthcare delivery, enabling a more comprehensive understanding of patient needs<sup>17,19</sup>. In this regard, lived experiences function as a bridge between clinical knowledge and the subjective realities of patients, enhancing both communication and care outcomes.

Furthermore, the advocacy dimension evident in the findings underscores the transformative potential of lived experience when it is recognized and mobilized. The author's emphasis

on documenting and sharing her journey reflects a shift from individual coping to collective contribution, aligning with literature that positions individuals with lived experiences as key actors in peer support, education, and policy development<sup>5</sup>. This resonates with global efforts to amplify patient voices in healthcare systems, particularly in cancer care, where experiential insights are increasingly seen as essential for designing responsive and inclusive services<sup>1,18</sup>.

Despite this growing recognition, the findings highlight a persistent gap between the acknowledged value of lived experiences and their systematic integration into research and practice. While frameworks and policies emphasize patient-centered care, practical mechanisms for capturing, validating, and applying lived experiences remain limited. This reflects a broader epistemological challenge, where experiential knowledge is still often regarded as supplementary rather than central<sup>14</sup>. Addressing this gap requires not only encouraging individuals to share their stories but also developing structures that support their inclusion in meaningful and sustained ways.

Overall, the discussion illustrates that lived experiences operate as emotional and psychological anchors that help individuals navigate the uncertainties of illness while also contributing to broader systems of knowledge and care. The findings extend the literature by demonstrating that the impact of lived experience is both deeply personal and inherently social, shaped by interactions between individual agency, structural barriers, and institutional practices. Integrating these insights into healthcare and research is therefore essential for moving toward a more holistic, empathetic, and patient-centered approach that fully acknowledges the complexity of human experience.

### Implications for Future Research and Practice

To enhance the relevance and effectiveness of healthcare interventions, there is a need for greater integration of lived experiences in research and clinical practice. Narrative inquiry, participatory research methods, and patient testimonials should be prioritized in medical and psychological studies to capture the full spectrum of illness experiences<sup>25</sup>. Additionally, healthcare professionals should be trained to engage with patient narratives meaningfully, ensuring that treatments address both the physical and emotional aspects of illness<sup>26</sup>.

By valuing and incorporating lived experiences, healthcare systems can move towards a more empathetic, patient-centered approach. This shift would not only improve treatment outcomes but also empower individuals to share their journeys, contributing to a broader understanding of illness beyond clinical symptoms and medical protocols<sup>27</sup>.

### Conclusion

This study has illuminated the profound emotional, psychological, and practical dimensions of living with and surviving cancer through the author's personal narrative. By documenting her lived experience, the study highlights the transformative power of storytelling in fostering personal healing, enhancing medical understanding, and enriching research methodologies. The findings reveal the critical role of lived experiences in addressing the gaps between clinical knowledge and patient realities, offering insights that are often missing from traditional research and practice.

The author's journey underscores the importance of documenting and sharing personal narratives to provide guidance, validation, and support for others facing similar challenges. Her reflections on the emotional toll of survivorship, the barriers to sharing lived experiences, and the therapeutic benefits of storytelling align with existing literature while also revealing gaps, particularly in the long-term emotional and psychological impacts of survivorship and the practical challenges of accessing relatable narratives. The study also highlights the need for systemic changes to integrate lived experiences into healthcare and research, ensuring that these narratives are valued as a vital source of knowledge and insight.

Ultimately, this study advocates for a more inclusive, patient-centred approach to healthcare that prioritizes the voices and experiences of those affected by serious illnesses. By fostering empathy, resilience, and connection, lived experiences can transform how we understand and address the challenges of illness, creating a more supportive and compassionate healthcare environment for all. Future research should continue to explore the role of lived experiences in shaping healthcare policies, practices, and interventions, ensuring that the human aspect of illness remains at the forefront of medical and psychological inquiry. Through this, we can build a healthcare system that not only treats the body but also heals the mind and spirit.

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