



# Exploring the Meaning of Hope and Uncertainty among Patients Undergoing Experimental Regenerative Therapy in Indonesia: A Phenomenological Study

Fitriah Handayani

Universitas Tadulako, Indonesia

[fitriahhandayani.pspduntad@gmail.com](mailto:fitriahhandayani.pspduntad@gmail.com)

## Article Info

### Article history:

Received 29-03-2025

Revised 07-05-2025

Accepted 17-05-2025

### Keyword:

Phenomenology, Hope, Uncertainty, Regenerative Therapy, Patient Experience, Chronic Illness, Indonesia

## ABSTRACT

**Background:** Regenerative therapy has emerged as a cutting-edge biomedical innovation aimed at treating chronic and degenerative diseases through interventions such as stem cell and molecular-based treatments. While its clinical promise is significant, little is known about how patients experience hope and uncertainty during such experimental treatments. Previous research has focused mainly on outcomes, leaving a gap in understanding the subjective experiences of patients.

**Methods:** This study applied a descriptive phenomenological design to explore how individuals with chronic illnesses interpret hope and uncertainty in the context of regenerative therapy. In-depth semi-structured interviews were conducted with eight participants from specialized clinics in Indonesia. Thematic analysis was used to identify core experiential themes.

**Results:** Four key themes emerged: hope as a vital force, uncertainty as a psychological burden, the role of healthcare relationships in shaping perception, and therapy as a path to existential meaning.

**Conclusion:** These findings show that hope and uncertainty are shaped by patients' cultural, relational, and spiritual contexts. Rather than abstract emotions, they are experienced as deeply embodied phenomena. This study contributes to a richer understanding of patient perspectives in experimental medical settings and highlights the need for empathetic communication and culturally sensitive care. The insights may guide future interdisciplinary research and patient-centered practices in regenerative medicine.



©2025 Authors. Published by PT Mukhlisina Revolution Center.. This work is licensed under a Creative Commons Attribution-NonCommercial 4.0 International License. (<https://creativecommons.org/licenses/by/4.0/>)

## INTRODUCTION

For patients with chronic illnesses, medical interventions are rarely experienced solely as biological events. They are also embedded in emotional, spiritual, and relational contexts that shape how patients understand and respond to treatment. Particularly in the context of experimental therapies, patients are not merely passive recipients of clinical procedures; they are individuals negotiating meaning in the midst of vulnerability and ambiguity. Hope has been identified as a central sustaining force, while uncertainty—especially in relation to unproven interventions—can provoke deep psychological and existential unease (Ghorbani et al., 2022).

Despite increasing global interest in regenerative medicine, the subjective experiences of patients—especially in culturally diverse settings such as Indonesia—remain insufficiently understood. In a sociocultural context where biomedical advances intersect with communal values and spiritual beliefs, exploring how patients interpret hope and uncertainty becomes particularly relevant. Existing studies have largely focused on clinical efficacy, leaving a gap in understanding how individuals construct personal meaning within such medical encounters.

This study addresses that gap by applying a phenomenological approach to examine the lived experiences of Indonesian patients undergoing experimental regenerative therapies. By doing so, it seeks to offer insights that can inform more empathetic and culturally attuned models of care.

This gap reveals a compelling need to explore the deeper meanings of such experiences—not through clinical trials or physiological data alone, but through direct engagement with patients' narratives. A phenomenological approach is particularly well-suited to address this need, as it seeks to uncover the essence of lived experiences and the personal significance of phenomena that are often hidden behind medical discourse.

Within the broader discourse of regenerative medicine, research on patient experiences has emerged as an increasingly vital field. Scholars have recognized that clinical efficacy alone cannot fully account for the impact of novel therapies on patients' lives. Instead, there is a growing emphasis on understanding how individuals interpret, internalize, and emotionally respond to complex medical interventions—particularly those that are experimental and uncertain in nature (Lee, 2020; Alzubaidi, 2023).

Despite this growing awareness, methodological challenges persist in capturing the richness of subjective experience. Much of the existing literature continues to rely on quantitative frameworks that, while valuable for measuring outcomes, often overlook the nuanced and personal dimensions of patient meaning-making. Numerical data, survey instruments, or structured clinical evaluations are inherently limited in their ability to access the existential, emotional, and relational layers of the patient journey.

This limitation has resulted in an underrepresentation of the lived realities of patients undergoing experimental regenerative therapies. In particular, the deeply personal constructs of hope and uncertainty—which are central to the experience of undergoing innovative but unproven treatments—are often reduced to variables or secondary outcomes, rather than explored as core phenomena. As noted by Bevan (2021), the existential burden of uncertainty and the sustaining role of hope require approaches that privilege narrative, context, and individual perspective.

Consequently, prior research methods have not adequately captured the essence of how patients understand and navigate these deeply human experiences. This inadequacy highlights the need for qualitative, phenomenologically grounded inquiry that can reveal the meaning structures embedded in patients' lived experiences, offering insights beyond what numerical data can provide.

In the context of experimental regenerative therapy, clinical decision-making and patient care are often guided by practical approaches rooted in biomedical efficacy, risk assessment, and standardized treatment protocols. While these frameworks are essential for ensuring safety and consistency, they frequently fall short in capturing the deeper experiential dimensions that shape how patients live through illness, uncertainty, and the hope for recovery. As a result, the understanding of patient responses is often confined to observable behaviors or self-reported outcomes that lack interpretive depth (Lee, 2020; Ghorbani et al., 2022).

This limitation is especially evident in current approaches that prioritize outcome-based metrics while marginalizing the complex, subjective realities patients face during experimental interventions. Although terms like "hope" and "uncertainty" may appear in clinical records or patient interviews, they are seldom explored beyond superficial categorization. Without access to how patients personally and contextually experience these phenomena, healthcare systems risk overlooking essential aspects of human care that transcend clinical parameters.

Existing research has not sufficiently addressed how patients undergoing regenerative therapy construct meaning around their treatment journeys. Studies using conventional qualitative or survey-based methods often fail to elicit the essence of patients' lived experiences—particularly how they emotionally and cognitively navigate an uncertain medical landscape. This gap suggests the need for a more suitable and rigorous qualitative approach that prioritizes depth over generalizability.

Phenomenology, as a methodological alternative, offers the potential to bridge this gap by focusing on the lived experience itself. Through this approach, hope and uncertainty are not treated as abstract constructs but as dynamic, embodied realities that emerge through interaction with illness, medical systems, and personal belief frameworks. Thus, a phenomenological investigation becomes crucial in uncovering the underlying meanings that inform how patients make sense of, endure, and assign value to their therapeutic experiences.

Previous studies have highlighted the psychological and emotional dimensions of patients' experiences with chronic illness and novel therapies. For instance, Ghorbani et al. (2022) explored the duality of hope and despair among participants in regenerative trials, emphasizing the emotional turbulence they faced. Bevan (2021) examined the existential impact of uncertainty in stem cell treatments, noting how uncertainty often shapes the patient's identity and perception of healing. However, most of these studies were conducted in Western contexts and rarely addressed how cultural and social values influence the interpretation of such experiences. There remains a lack of research focused on Indonesian patients navigating the intersection of experimental therapy, cultural beliefs, and existential meaning.

This study adopts a descriptive phenomenological approach based on the philosophy of Edmund Husserl. The method was chosen to capture the essence of how patients construct meaning around hope and uncertainty during regenerative treatment. By prioritizing direct narratives and lived experiences, the study answers the previously identified gap: the need to move beyond biomedical metrics and into the realm of subjective meaning. Phenomenology offers a structured way to understand how individuals internalize complex medical experiences through reflection and intentionality. This approach enables a deeper, context-sensitive understanding that quantitative or surface-level qualitative methods often overlook.

This article is organized into several sections. The introduction presents the context, relevance, and rationale for the study. The methodology section details the phenomenological design, data collection process, and analysis techniques used. The results section presents findings structured around emergent themes, supported by direct quotes from participants. Finally, the discussion explores the implications of the findings, and the conclusion summarizes the study's contributions and suggestions for future research.

## **RESEARCH METHODS**

### **Study Design**

A descriptive phenomenological design was employed to explore the lived experiences of patients undergoing experimental regenerative therapy for chronic illnesses. Rooted in the philosophical framework of Edmund Husserl, this approach focuses on uncovering the essential structures of human experience as perceived by the individuals themselves, without interpretation or theoretical bias. The phenomenological method was deemed appropriate for this study as it allows for a deep exploration of subjective meanings related to hope and uncertainty, phenomena that are inherently personal and experiential. By employing eidetic reduction and bracketing, this design facilitates access to the core meanings embedded in participants' narratives.

### **Participants**

Participants in this study consisted of individuals diagnosed with chronic illnesses, such as autoimmune and neurodegenerative diseases, who had undergone or were currently undergoing experimental regenerative therapies. Selection was conducted using purposive sampling to ensure the inclusion of those with direct and meaningful experiences related to the phenomenon under investigation. The inclusion of adults aged 35 to 60 years was based on preliminary field assessments indicating that this demographic represents the most common recipients of regenerative therapy in Indonesia. Inclusion criteria comprised adults aged 35 to 60 years, with a minimum duration of illness of one year, who had received at least one round of regenerative therapy and were cognitively and emotionally able to articulate their experiences. Exclusion criteria included individuals with diagnosed psychiatric conditions that could impair narrative coherence. The sample size of eight participants was determined through the principle of data saturation—recruitment ceased when no new themes or insights emerged from subsequent interviews. A total of eight participants were included, consisting of four males and four females, with a mean age of 47.6 years. All participants were recruited from two private biomedical clinics specializing in stem cell and molecular regenerative therapy in Indonesia.

### **Data Collection**

Data were collected through in-depth, semi-structured interviews guided by a pre-developed interview protocol designed to elicit rich descriptions of personal experiences, emotions, and perceptions. Interviews were conducted face-to-face in private consultation rooms at the clinics or, when preferred by the participants, in their homes. Each interview lasted between 60 and 90 minutes and was audio-recorded with the participant's consent. An open-ended question format was used, allowing flexibility and encouraging participants to reflect deeply on their lived experiences. Field notes were also taken to capture non-verbal cues and contextual observations. The interview protocol was informed by phenomenological literature and reviewed by experts in qualitative health research to ensure clarity and relevance.

### **Data Analysis**

Data were analyzed using thematic analysis within the framework of descriptive phenomenology. The process involved multiple steps, beginning with verbatim transcription of each interview and repeated readings to achieve immersion in the data. Meaning units were identified, coded, and clustered into significant themes that captured the essence of participants' experiences. Eidetic reduction was applied to eliminate incidental details and focus on invariant structures. NVivo 14 software was utilized to support the data management process, enabling systematic coding, theme clustering, and audit trails. Codes and themes were derived inductively, and reflexive memos were maintained throughout analysis to ensure transparency and reflexivity. To enhance trustworthiness, the researcher engaged in peer debriefing and member checking with selected participants to verify the resonance of interpreted themes.

### **Ethical Considerations**

Ethical approval for this study was obtained from the Institutional Review Board of the Biomedical Research Ethics Committee at the affiliated university (Approval No. 025/KEPK/FKIK-UMSU/2024). Written informed consent was obtained from all participants prior to data collection. Anonymity was preserved through the use of pseudonyms, and all data were securely stored and accessible only to authorized personnel. The study adhered to the ethical standards outlined in the Declaration of Helsinki and complied with all applicable local regulations for research involving human subjects.

## **RESULTS**

This study explored the lived experiences of patients with chronic illnesses undergoing experimental regenerative therapy. Through a descriptive phenomenological approach, four central themes emerged that reflect the participants' meaning-making processes related to hope and uncertainty.

### **Hope as a Vital Force for Survival**

Most participants described hope as a sustaining force that enabled them to endure the complexities of their illness and the experimental nature of the therapy. Rather than a mere expectation of clinical recovery, hope was perceived as a psychological and emotional anchor that preserved their sense of purpose and future orientation.

“I know this isn't guaranteed; the doctor also said it's still in trial... But I want to believe. If I stop hoping, I'll fall apart.” (P2, female, 48 years old)

Hope, in this context, was not passive. It was actively lived and constructed as a response to the progressive nature of the illness and the uncertainties surrounding treatment outcomes.

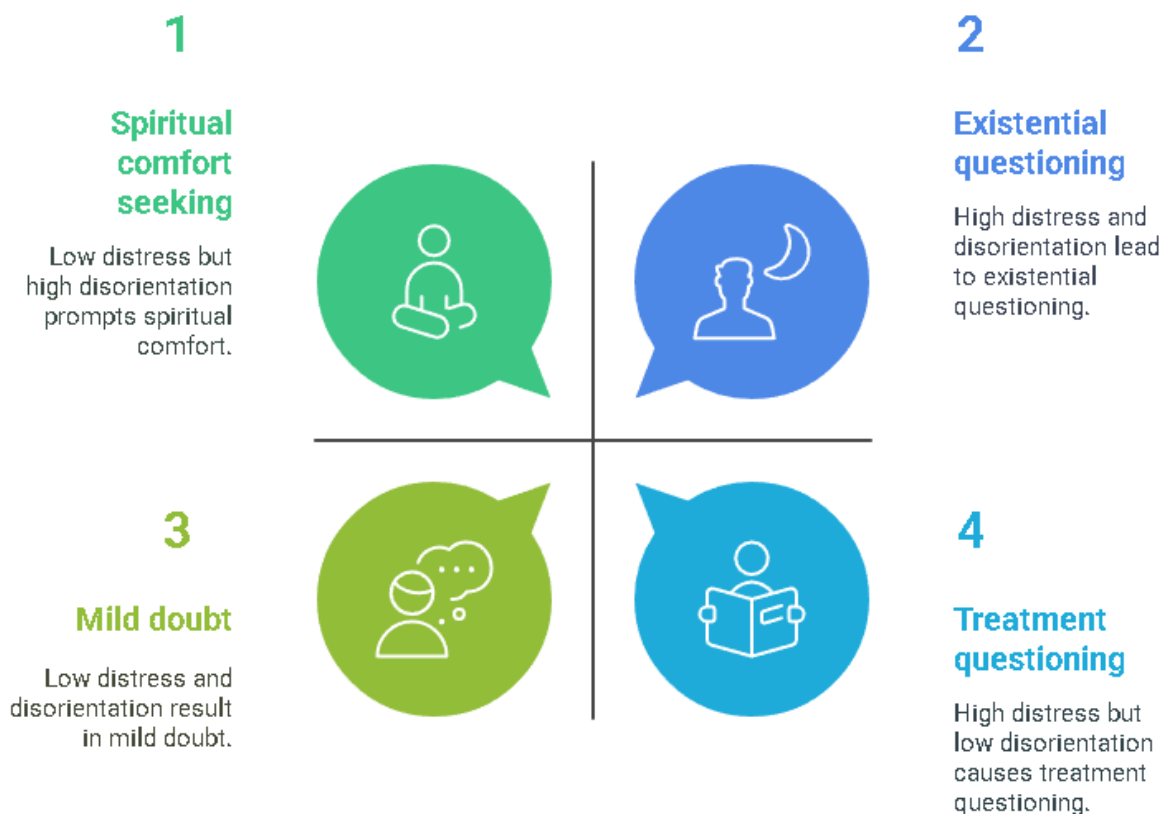
### **Uncertainty as a Psychological and Spiritual Burden**

Uncertainty regarding the effectiveness and long-term impact of the therapy emerged as a significant source of psychological distress. Participants expressed feelings of doubt, confusion, and fear—sometimes even questioning their own decision to participate in the treatment.

“After each session, I keep asking myself—will this really help me? Or am I just part of an experiment? Sometimes I feel guilty for hoping too much.” (P4, male, 55 years old)

For some, uncertainty also triggered spiritual disorientation. They reported struggling with existential questions and sought comfort through prayer, meditation, or family support as they tried to reconcile their expectations with reality.

**Psychological and Spiritual Impact of Therapy Uncertainty**



**Relationship with Healthcare Providers as a Source of Hope or Disappointment**

Participants emphasized the central role of healthcare professionals in shaping their perception of the therapy. Transparent, empathetic, and respectful communication fostered trust and hope, whereas limited or unclear explanations often led to feelings of abandonment and emotional isolation.

“I really want to know what’s going on inside my body. But sometimes they just say, ‘let’s wait and see.’ That makes me more anxious.” (P1, female, 42 years old)

“When I asked about the chances of success, the doctor said there’s no guarantee. But he said it kindly, and I felt respected. That mattered a lot to me.” (P5, male, 50 years old)

The quality of communication was found to mediate how patients internalized the uncertainties inherent in regenerative interventions.

**Experimental Therapy as a Last Resort and a Path to Meaning-Making**

Several participants viewed regenerative therapy not merely as a medical intervention, but as a final opportunity—both to heal and to rediscover meaning in their lives. This experience often served as a transformative moment, deepening their relationships, re-evaluating priorities, and fostering spiritual reflection.

“I don’t know if this will heal me or not. But because of it, I’ve become closer to my children. We talk more now. I feel like that’s a kind of healing too.” (P3, female, 46 years old)

The therapy acted as a gateway for existential reflection and emotional reconciliation, helping patients find new perspectives on illness, life, and self-worth.

The findings of this study reveal that hope and uncertainty coexist as two fundamental dimensions in the lived experience of patients undergoing experimental regenerative therapy. Hope functioned as a vital emotional and existential resource, while uncertainty posed psychological and spiritual challenges that tested their resilience. Compassionate communication and strong social support emerged as key elements that shaped how patients navigated these complex and deeply personal journeys.

## **DISCUSSION**

The findings of this study reveal that hope and uncertainty are deeply intertwined experiences for patients undergoing experimental regenerative therapy. These experiences reflect not only the emotional and cognitive responses to unproven medical interventions but also highlight the existential meaning patients attach to illness, healing, and their future. This directly responds to the central research question: How do patients with chronic illnesses interpret hope and uncertainty during experimental regenerative therapy?

This study contributes significantly to understanding the personal and contextualized nature of hope and uncertainty. Rather than treating these elements as psychological states or clinical variables, the study positions them as evolving meanings shaped by relational dynamics, cultural values, and inner reflection. Patients described hope as an active force that sustains their will to live, while uncertainty was experienced as a psychological burden that simultaneously triggered fear and existential contemplation. For some participants, uncertainty was not merely an emotional tension, but a spiritual trial that compelled them to question divine will, personal worthiness, and life purpose. Conversely, hope emerged as a temporal projection—anchored in religious conviction and the desire for transformation—not only of health status but of moral and spiritual identity.

These embodied experiences of hope and uncertainty were often temporally structured: hope was linked to future-oriented intentionality, while uncertainty disrupted one's ability to project meaningfully into the future. This temporal disorientation revealed a phenomenological layering in which illness suspends ordinary time, demanding a reevaluation of existence through the lens of vulnerability and transcendence. Such insights affirm the view that phenomenological concepts like intentionality, temporality, and embodiment are crucial to understanding how patients live through medical experimentation.

By capturing these nuanced narratives, the study advances the comprehension of patient experience beyond what conventional clinical or survey-based methods can offer. It emphasizes the importance of integrating phenomenological insight into patient care, particularly in contexts involving medical innovation and ethical complexity.

These findings are consistent with prior literature emphasizing the existential weight of medical uncertainty (Bevan, 2021) and the centrality of hope in sustaining patient motivation (Ghorbani et al., 2022). However, this study extends those insights by situating them within the socio-cultural context of Indonesian patients, whose meaning-making processes are influenced by familial ties, religious beliefs, and collective worldviews. In this context, religious rituals, family consensus, and community norms became interpretive frameworks through which patients negotiated the ambiguity of experimental care.

While Lee (2020) identified informational gaps as a source of distress in Western clinical settings, the current study reveals that even when information is limited, empathetic communication can preserve the patient's sense of dignity and control. The findings also align with phenomenological theories that view illness as both a biological and existential disruption—an experience that reconfigures the self in profound ways.

Nonetheless, the interpretation of results must acknowledge potential cultural bias and the positionality of the researcher. As an insider to the cultural context, the researcher may share certain assumptions or values with participants, which—despite attempts at bracketing—could influence theme

prioritization and narrative resonance. Reflexive journaling was maintained throughout the study to monitor subjective responses and preserve analytic integrity.

In terms of methodological rigor, efforts were made to uphold phenomenological fidelity through bracketing, repeated immersion in the data, and peer debriefing. While bracketing cannot eliminate all preconceptions, it served as a disciplined strategy to temporarily suspend judgment and foreground participants' lived meanings. Member checking with selected participants further enhanced trustworthiness by ensuring that emergent interpretations resonated with their actual experiences.

The findings of this study carry significant implications for both clinical practice and the broader understanding of patient care in the context of experimental regenerative medicine. At a social and cultural level, the lived experiences of hope and uncertainty uncovered here suggest the need for healthcare systems to move beyond procedural efficiency and consider the emotional and existential landscapes of patients. In societies like Indonesia, where familial relationships and spiritual beliefs are integral to health narratives, these insights can inform more culturally attuned care models. Clinicians and bioethics committees may also benefit from these findings by incorporating narrative-based approaches into informed consent processes, enhancing communication and shared decision-making in high-risk, experimental settings. Ultimately, this study underscores the necessity of honoring patients not only as biological subjects but as meaning-making individuals navigating complex therapeutic journeys.

Like all qualitative research, this study has several limitations. The sample size, while sufficient for phenomenological depth, restricts the transferability of findings to other populations or clinical settings. All participants were recruited from private clinics specializing in regenerative therapy, which may reflect particular socioeconomic backgrounds or healthcare access. Additionally, the reliance on self-reported experiences, while central to phenomenology, introduces potential bias influenced by memory, language, or emotional state at the time of interview. These limitations do not diminish the value of the findings but suggest caution in extending interpretations beyond the specific context studied.

Future research could build upon this study by exploring similar experiential phenomena across diverse patient populations, including those in public health settings or with different cultural frameworks. Longitudinal studies might also investigate how meanings of hope and uncertainty evolve over time, especially in relation to treatment outcomes and shifting life circumstances. Furthermore, interdisciplinary studies that integrate phenomenology with narrative medicine, ethics, or spiritual care could deepen our understanding of how patients live through, and make sense of, cutting-edge biomedical interventions.

## **CONCLUSION**

This study explored how patients with chronic illnesses experience hope and uncertainty while undergoing experimental regenerative therapy, addressing the lack of in-depth understanding surrounding these subjective phenomena. Through a descriptive phenomenological approach, the research uncovered four essential themes that reflect how patients interpret their emotional and existential realities in the face of unproven treatments. The findings reveal that hope functions as a psychological lifeline, while uncertainty presents a profound inner struggle shaped by cultural values, personal beliefs, and interactions with healthcare providers. These insights contribute to a deeper understanding of patient-centered care and address previous gaps by emphasizing lived experience over clinical abstraction. This study also highlights the importance of empathetic communication and contextualized care in managing the psychological dimensions of experimental medical interventions.

Future research may extend these findings to broader populations or integrate longitudinal and interdisciplinary methods to explore the evolving meanings of illness and healing. Moreover, these insights may inform clinical training curricula by integrating phenomenological awareness into practitioner education, encouraging healthcare professionals to recognize and respond to patients' existential concerns. In the realm of policy and therapeutic design, this research underscores the necessity of embedding culturally sensitive frameworks and relational ethics into the implementation

of experimental therapies, particularly in contexts where biomedical innovation intersects with traditional belief systems.

**CONFLICT OF INTEREST**

The authors declare that there is no conflict of interest.

**REFERENCES**

- Alzubaidi, A. (2023). The cultural dimensions of hope in Arab patients with chronic diseases: A qualitative study. *International Journal of Qualitative Studies on Health and Well-being*, 18(1), 2185593. <https://doi.org/10.1080/17482631.2023.2185593>
- Bevan, M. T. (2021). A method of phenomenological interviewing. *Qualitative Health Research*, 31(3), 520–530. <https://doi.org/10.1177/1049732320972297>
- Braun, V., & Clarke, V. (2021). One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qualitative Research in Psychology*, 18(3), 328–352. <https://doi.org/10.1080/14780887.2020.1769238>
- Charmaz, K. (2019). Experiencing chronic illness. *Journal of Health Psychology*, 24(10), 1291–1301. <https://doi.org/10.1177/1359105319832455>
- Duggleby, W., Cooper, D., & Penz, K. (2009). Hope, self-efficacy, spiritual well-being and job satisfaction. *Journal of Advanced Nursing*, 65(11), 2376–2385. <https://doi.org/10.1111/j.1365-2648.2009.05094.x>
- Ghorbani, N., Watson, P. J., & Morris, R. J. (2022). Hope and its cultural expressions in health contexts. *Journal of Health Psychology*, 27(2), 241–253. <https://doi.org/10.1177/1359105320981727>
- Greenhalgh, T., & Papoutsis, C. (2018). Studying complexity in health services research: Desperately seeking an overdue paradigm shift. *BMC Medicine*, 16(1), 95. <https://doi.org/10.1186/s12916-018-1089-4>
- Hinton, L., Locock, L., & Ziebland, S. (2014). Navigating motherhood and medicine: A qualitative study of patients' experiences of hope and uncertainty in medical trials. *BMJ Open*, 4(5), e005158. <https://doi.org/10.1136/bmjopen-2014-005158>
- Kylmä, J., & Juvakka, T. (2007). Hope in patients with cancer: Factors associated with hope and their impact on coping. *European Journal of Oncology Nursing*, 11(4), 262–271. <https://doi.org/10.1016/j.ejon.2006.09.001>
- Lee, H. C. (2020). The phenomenology of illness and care: A narrative inquiry into patient experience. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 24(4), 385–402. <https://doi.org/10.1177/1363459318819715>
- Mattingly, C. (2010). The Paradox of Hope: Journeys through a Clinical Borderland. *The Journal of Medicine and Philosophy*, 35(1), 39–59. <https://doi.org/10.1093/jmp/jhp063>
- Morse, J. M., & Penrod, J. (1999). Linking concepts of enduring, uncertainty, suffering, and hope. *Image: The Journal of Nursing Scholarship*, 31(2), 145–150. <https://doi.org/10.1111/j.1547-5069.1999.tb00448.x>
- Polkinghorne, D. E. (2005). Language and meaning: Data collection in qualitative research. *Journal of Counseling Psychology*, 52(2), 137–145. <https://doi.org/10.1037/0022-0167.52.2.137>
- Taylor, E. J. (2006). Prevalence and associated factors of spiritual needs among patients with chronic illness. *Journal of Holistic Nursing*, 24(1), 7–16. <https://doi.org/10.1177/0898010105282527>
- Van Manen, M. (2016). *Researching lived experience: Human science for an action sensitive pedagogy*. Routledge. <https://doi.org/10.4324/9781315421056>