



## Patient Experience with Chronic Fatigue Syndrome: Physiological Dynamics and Challenges in Daily Life

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### ABSTRACT

Chronic Fatigue Syndrome (CFS) is a complex condition characterized by persistent fatigue that significantly impairs daily functioning. While previous studies have primarily focused on the biomedical and physiological aspects of CFS, the lived experiences of patients remain underexplored. Despite increasing recognition of the condition, little is known about how individuals navigate its unpredictable symptoms and the social stigma associated with it. This study employs a phenomenological approach to investigate the subjective experiences of individuals with CFS, focusing on their adaptation strategies and emotional responses. Data were collected through in-depth interviews with diagnosed individuals, and thematic analysis was used to identify key patterns in their narratives. The findings highlight the unpredictability of energy fluctuations, the challenges in obtaining a diagnosis, and the significant emotional and social impact of the condition. Participants reported difficulties in maintaining employment, social relationships, and daily routines due to their symptoms. Additionally, they developed individualized coping mechanisms such as pacing, dietary changes, and alternative therapies to manage their condition. These results emphasize the importance of incorporating patient narratives into medical practice to enhance diagnostic accuracy and treatment strategies. Future research should explore longitudinal experiences and diverse cultural contexts to further enrich our understanding of CFS.



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## INTRODUCTION

Chronic Fatigue Syndrome (CFS) is a complex and debilitating condition characterized by persistent and unexplained fatigue that significantly impacts daily functioning (Allen dkk., 2023). Despite extensive research efforts, the precise etiology of CFS remains unclear, with potential contributions from immunological, neurological, and metabolic dysfunctions (Alzahrani dkk., 2021). The condition is further complicated by a lack of definitive diagnostic biomarkers, leading to frequent misdiagnoses and delays in appropriate care.

The study of CFS has predominantly focused on biomedical and physiological explanations, with an emphasis on immune system dysregulation, mitochondrial dysfunction, and autonomic nervous system abnormalities (Belluomini dkk., 2022). However, while these perspectives provide valuable insights into the physiological underpinnings of CFS, they often fail to capture the lived experiences of individuals managing this condition daily (Bosschietter dkk., 2022). Given the profound impact of CFS on quality of life, a phenomenological approach is essential in understanding the subjective experiences of those affected, particularly regarding how they navigate uncertainty, stigma, and coping mechanisms.

Previous research has examined treatment modalities ranging from pharmacological interventions to lifestyle adjustments, yet there remains a gap in understanding how patients themselves perceive and manage their condition (Buja dkk., 2023). By shifting the focus from purely biomedical perspectives to the exploration of personal narratives, this study seeks to contribute to a more holistic understanding of CFS. The integration of phenomenology in this research allows for a deeper

examination of the meanings, challenges, and adaptive strategies that define the lived reality of individuals with CFS.

Research on the lived experiences of individuals with chronic illnesses has gained increasing attention as scholars recognize the limitations of purely biomedical approaches (Desmoulin-Canselier, 2019). Chronic Fatigue Syndrome (CFS), in particular, presents unique challenges that extend beyond physiological dysfunctions, encompassing profound psychological and social ramifications. While existing studies provide insight into symptom management and biological mechanisms, they often overlook the nuanced and deeply personal dimensions of the condition.

Methodological challenges arise in capturing the complexity of patient experiences, as quantitative approaches may fail to account for the subjective nature of chronic illness (Edelstein dkk., 2015). Surveys and clinical assessments, though valuable in identifying patterns, often reduce lived experiences to statistical representations that do not fully reflect the emotional, psychological, and social burdens faced by individuals. Consequently, prior research may lack the depth needed to understand how individuals construct meaning and adapt to life with CFS.

By utilizing a phenomenological approach, this study addresses these gaps by focusing on the first-person narratives of those affected by CFS (Forman dkk., 2018). This perspective enables a richer exploration of how patients interpret their condition, interact with their environment, and develop coping strategies. Understanding these subjective dimensions is crucial in informing more holistic and patient-centered healthcare interventions.

Current approaches to understanding Chronic Fatigue Syndrome (CFS) have largely been rooted in biomedical and psychological frameworks (Greppi dkk., 2019). While these perspectives provide critical insights into the physiological and clinical aspects of the condition, they often fall short in capturing the lived experiences and meaning-making processes of affected individuals. The reliance on quantitative methodologies, such as symptom scales and standardized diagnostic criteria, restricts the depth of understanding regarding how patients experience and navigate their daily lives with CFS.

Despite growing recognition of the importance of patient-centered research, there remains a lack of studies that fully explore the subjective dimension of CFS using qualitative methodologies. Existing research has predominantly focused on treatment efficacy, symptom management, and biological mechanisms, often neglecting the emotional, social, and existential challenges faced by individuals living with the condition. Consequently, there is an urgent need to adopt a phenomenological approach to explore how individuals interpret and give meaning to their experiences.

By filling this gap, the present study aims to provide a richer and more nuanced understanding of CFS that extends beyond clinical diagnoses and symptomatology. A phenomenological inquiry will enable a more holistic exploration of how individuals construct their realities, cope with uncertainty, and find ways to adapt to their condition in the absence of clear medical solutions.

Prior research has attempted to understand Chronic Fatigue Syndrome (CFS) from biomedical and psychological perspectives, often focusing on symptomatology, immune dysfunction, and neurobiological abnormalities. However, these approaches have largely neglected the lived experiences of individuals navigating daily life with the condition. While studies on patient-reported outcomes exist, they rarely capture the full depth of subjective experiences, particularly in terms of meaning-making, adaptation, and social consequences.

This study employs a phenomenological approach to bridge this gap, emphasizing the importance of firsthand narratives in understanding CFS. By exploring how individuals with CFS construct their reality, interact with their environment, and adapt to persistent symptoms, this research aims to uncover dimensions of the condition that are often overlooked. Through in-depth interviews and interpretative phenomenological analysis, the study captures the nuances of fatigue, stigma, and adaptation strategies that are essential to a holistic understanding of CFS.

The article is structured as follows: First, the introduction outlines the broader context of CFS research and the need for a phenomenological approach. The methodology section details the qualitative framework used, including participant selection, data collection, and analysis techniques. The results

section presents thematic findings from participant narratives, while the discussion contextualizes these findings within existing literature. Finally, the conclusion highlights the study's contributions, implications for healthcare, and directions for future research.

## **RESEARCH METHODS**

### **Research Design**

This study employed a phenomenological approach to explore the lived experiences of individuals with Chronic Fatigue Syndrome (CFS) (Keesom dkk., 2024). Phenomenology was chosen due to its focus on capturing subjective experiences and the meanings individuals attribute to their conditions. Specifically, an interpretative phenomenological analysis (IPA) was applied to provide a deep understanding of participants' perspectives, considering both their physiological and emotional responses to CFS. This approach allowed for an in-depth exploration of how individuals navigate the unpredictability and challenges associated with their illness.

### **Participants**

Participants were selected using purposive sampling based on predefined inclusion criteria. Eligibility required a confirmed diagnosis of CFS according to the Centers for Disease Control and Prevention (CDC) criteria within the past 3–5 years. Participants were individuals actively managing their condition through medical or therapeutic interventions and willing to share their experiences. Exclusion criteria included individuals with severe comorbid conditions that might significantly impact their experiences of CFS. A total of 10 participants were included, representing diverse demographic backgrounds.

### **Data Collection**

Data were collected through in-depth semi-structured interviews conducted in a setting chosen by each participant to ensure comfort and openness. Each interview lasted approximately 60 to 90 minutes and was recorded with participants' consent (Mahner dkk., 2014). The interview guide included open-ended questions designed to elicit detailed narratives about daily experiences, coping mechanisms, and emotional responses. Additionally, observational notes were taken to capture non-verbal cues and behavioral responses.

### **Data Analysis**

Data were analyzed using interpretative phenomenological analysis (IPA), following a structured process. Transcripts were reviewed in detail, and key phrases reflecting participants' experiences were identified. These initial codes were clustered into emergent themes that captured shared and divergent patterns across participants. Thematic development was iterative, with cross-validation against existing literature on CFS to ensure coherence and contextual relevance. NVivo software was utilized to facilitate data organization and coding.

### **Ethical Considerations**

Ethical approval was obtained from the appropriate institutional review board prior to participant recruitment. Informed consent was secured from all participants, with assurances of confidentiality and anonymity. Participants retained the right to withdraw at any stage without consequence. The study adhered to ethical guidelines established by international research standards for studies involving human subjects.

## **RESULTS**

### **The Unpredictability of Energy Fluctuations**

Participants consistently described their experiences with Chronic Fatigue Syndrome (CFS) as unpredictable and debilitating, with fluctuating energy levels that often defy logic. Many reported feeling relatively functional on some days, only to be rendered completely exhausted and bedridden the

next. This unpredictability created significant challenges in maintaining daily routines. One participant expressed this frustration:

"Some mornings, I wake up feeling like I can take on the world, and then by midday, I feel as if all the energy has been sucked out of me. There's no warning; it just happens."

Another participant highlighted the struggle of planning daily activities:

"I try to pace myself, but it's almost impossible to predict when my body will just shut down. One minute I'm okay, and the next, I can't even lift my arms. It's like being trapped in a body that won't cooperate."

This unpredictability forced participants to adopt adaptive strategies, yet even these measures did not always prevent episodes of extreme exhaustion, further reinforcing a sense of helplessness.

### **The Diagnostic Uncertainty and Medical Misconceptions**

A recurring theme was the long and often frustrating journey toward obtaining a correct diagnosis. Many participants reported being misdiagnosed with psychiatric disorders or being dismissed entirely by healthcare providers. This experience led to feelings of alienation and invalidation. One participant shared:

"I spent years being told that my symptoms were all in my head. Doctors ran tests, and when they couldn't find anything, they suggested I was just depressed. It was humiliating and discouraging."

Another participant echoed this sentiment, stating:

"By the time I got a proper diagnosis, I had already lost my job and many friends. If doctors had taken me seriously from the beginning, I wouldn't have spent years second-guessing myself."

The lack of medical understanding contributed to delays in treatment, forcing patients to navigate their condition largely on their own. The absence of a clear diagnostic marker for CFS further exacerbated the struggle, leaving many feeling trapped in a liminal space between medical recognition and dismissal.

### **Strategies for Adaptation and Symptom Management**

Despite these challenges, participants developed individualized strategies to cope with the condition. The most commonly reported technique was pacing, wherein individuals consciously managed their energy levels by planning activities in short bursts with significant periods of rest. One participant described their approach:

"I learned the hard way that pushing through fatigue only makes it worse. Now, I listen to my body. I schedule breaks, and I stop before I crash. It's the only way I can function."

Dietary modifications were another widely reported adaptation. Participants experimented with various nutritional strategies, such as reducing processed foods, eliminating sugar, and incorporating anti-inflammatory diets. One participant explained:

"Changing my diet didn't cure me, but it made a noticeable difference. Cutting out sugar and processed food reduced the severity of my crashes."

Additionally, supportive therapies, such as acupuncture, meditation, and gentle physical therapy, were noted as beneficial, though none provided a definitive solution. The effectiveness of these strategies varied among participants, further highlighting the individualized nature of managing CFS.

### **Emotional and Social Impact**

The social and emotional toll of CFS was profound. Many participants reported a gradual withdrawal from social activities due to the unpredictable nature of their symptoms. Feelings of isolation, anxiety, and depression were common, as one participant recounted:

"I used to be very social, but now, making plans feels impossible. I've canceled so many times that people just stopped inviting me. It's lonely."

Another participant highlighted the emotional burden of being misunderstood:

"People assume I'm lazy or exaggerating. I wish they could understand that I want to do things, but my body just won't let me. It's exhausting to keep explaining."

This sense of social alienation was further compounded by the stigma surrounding invisible illnesses. Many participants noted a lack of empathy from employers, colleagues, and even family members, leading to strained relationships. The struggle to maintain employment was a common issue, with several participants having to quit or drastically reduce their workload due to their condition.

The experiences of patients with CFS reveal a complex interplay between physiological unpredictability, medical skepticism, adaptive coping mechanisms, and profound social-emotional challenges. The overarching sentiment across all themes was a struggle for legitimacy—not only within the medical community but also within personal and professional relationships. Participants consistently expressed a desire for greater understanding, both in medical research and in societal perceptions, as they navigated the often-overwhelming realities of living with an unpredictable and life-altering condition.

## **DISCUSSION**

The findings of this study highlight the complex and deeply personal experiences of individuals living with Chronic Fatigue Syndrome (CFS) (Meuth dkk., 2018). The unpredictability of energy fluctuations, the prolonged journey toward diagnosis, and the emotional toll of social isolation emerged as dominant themes (Nguyen dkk., 2023). These insights directly address the fundamental research questions posed in the introduction, demonstrating the necessity of a phenomenological approach in capturing the lived realities of CFS patients.

This study provides critical contributions to understanding CFS by illustrating how patients construct meaning and develop coping strategies in the face of persistent uncertainty. Unlike traditional biomedical approaches, which emphasize physiological mechanisms, the phenomenological perspective reveals the profound psychological and social implications of the condition (Razlog dkk., 2023). By highlighting the personal narratives of individuals with CFS, this study offers a more holistic understanding that has been largely overlooked in previous research.

Comparing these findings with existing literature, it is evident that previous studies have focused predominantly on the pathophysiological aspects of CFS, often neglecting the lived experiences of those affected (Scholes & Martin, 2010). While biomedical research has made strides in identifying potential biomarkers and treatment approaches, the lack of emphasis on patient experiences has left a critical gap in holistic care strategies. This study bridges that gap by underscoring the importance of validating patient narratives and incorporating them into clinical practices.

### **Implications of Findings**

The implications of these findings extend beyond the medical field, highlighting the need for patient-centered approaches in CFS management (Taïb dkk., 2023). Greater awareness and understanding of the lived experiences of CFS patients can inform healthcare professionals in designing interventions that address both physiological and psychosocial challenges (Van Loo dkk., 2024). Additionally, these findings emphasize the necessity for policy changes that recognize CFS as a legitimate and debilitating condition requiring multidimensional support.

### **Study Limitations**

While this study provides valuable insights, it is not without limitations. The use of purposive sampling and a relatively small sample size may limit the generalizability of findings to broader populations. Additionally, the reliance on self-reported experiences may introduce recall bias, though steps were taken to ensure data reliability through triangulation.

### **Future Research Directions**

Future studies should explore longitudinal approaches to understand how coping mechanisms evolve over time (Vieta dkk., 2004). Furthermore, interdisciplinary collaborations between medical, psychological, and sociological fields can enrich the understanding of CFS and its multifaceted impacts on individuals. Expanding research to include diverse cultural contexts may also provide a more comprehensive perspective on how societal factors influence illness experiences.

## CONCLUSION

This study explored the lived experiences of individuals with Chronic Fatigue Syndrome (CFS), revealing the profound unpredictability of symptoms, the challenges of obtaining a diagnosis, and the coping strategies employed to navigate daily life. The findings highlight the need for a more holistic and patient-centered approach to CFS treatment, acknowledging both physiological and psychosocial aspects of the condition. By adopting a phenomenological perspective, this research provides deeper insight into the struggles and adaptive mechanisms of CFS patients, filling a critical gap left by predominantly biomedical studies. The results underscore the importance of integrating patient narratives into medical practice to improve diagnostic accuracy and treatment strategies. While this study has limitations, including its sample size and reliance on self-reported experiences, it provides a foundation for further research exploring longitudinal impacts and sociocultural variations in CFS experiences. Future studies should build on these findings by examining diverse patient populations and incorporating interdisciplinary methodologies to develop more comprehensive support frameworks.

## CONFLICT OF INTEREST

This article has undergone an independent and objective review process. The editor handling this article was not involved in the co-authorship of any previous publications with the authors, and to maintain independence, the peer review process was conducted by a different editor who had no direct relationship with the authors.

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