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[Original Research]

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Exploring Chronic Pain Management Experiences and the Use of Complementary Therapies Among Hemodialysis Patients: A Qualitative Study

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Abstract

Background: Chronic pain is a common and distressing experience for patients with end-stage renal disease (ESRD) undergoing hemodialysis, yet its complexity and management remain insufficiently explored. Understanding how patients perceive and manage this pain is crucial for developing holistic nursing interventions. **Aim:** To explore the lived experiences of chronic pain management among patients receiving long-term hemodialysis. **Method:** A qualitative descriptive approach was employed, using in-depth semi-structured interviews with a purposive sample of hemodialysis patients. Data were analyzed thematically to identify core patterns and meanings. **Results:** Three themes emerged: (1) perceived meaning and impact of pain during hemodialysis, reflecting patients' physical discomfort, emotional distress, and disruption of daily life; (2) patterns and characteristics of pain, described as fluctuating in intensity, duration, and location throughout the hemodialysis process; and (3) complementary and supportive strategies for pain management, including spiritual practices, relaxation, distraction techniques, and reliance on family support. The findings underscore that pain during hemodialysis is not only a physical phenomenon but also a psychosocial and spiritual challenge. Nurses play a pivotal role in recognizing patients' multidimensional pain experiences and in integrating complementary approaches alongside conventional care. **Conclusion:** This study highlights the importance of patient-centered, culturally sensitive strategies to enhance pain management and quality of life in ESRD care. It is recommended that future nursing practice and policies incorporate complementary therapies and patient education programs to strengthen pain management strategies in hemodialysis units.

Keywords: Chronic pain, Hemodialysis, End-stage renal disease (ESRD), Pain management, Complementary therapy

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Introduction

Chronic pain is a frequent and deeply distressing problem among patients with end-stage renal disease (ESRD) undergoing hemodialysis. Although hemodialysis is lifesaving, many patients report persistent pain that undermines physical functioning, emotional well-being, social participation, and overall quality of life (QoL). (Kalantar-Zadeh & Li, 2020). Studies in different populations have found that pain prevalence among hemodialysis patients ranges broadly, up to 80%, with significant interference in daily life and psychological distress.

Globally, a recent cross-sectional study in BMC Nephrology found that about 60.5% of hemodialysis patients report chronic pain, with 43.6% describing it as moderate to severe; pain locations are varied (lower and upper limbs, back, hips, etc.), with nociceptive, neuropathic, or mixed types. As a result, there were 571 hemodialysis (HD) patients per million inhabitants in 2015, then up from 13,000 in 2013 and 33,000 in 2021, and it reached 50,000 in 2030 (Bouchachi et al., 2025). (Razeen Davids & Benghanem Gharbi, 2019) (Jha et al., 2013).

On the other hand, of all the populations with chronic renal disease, patients undergoing HD have the highest symptom load, with symptoms including chronic pain being particularly severe, frequent, and distressing. Another research conducted that from 300 participants, 66.3 % reported having chronic pain. Hemodialysis sessions themselves were the most commonly cited cause for the pain (21.6 %). It was suggested to all healthcare providers to routinely assess the pain among hemodialysis patients as it is considered a significant concern. In Indonesia, pain is also a common but under-explored issue: in one study of 72 hemodialysis patients in Yogyakarta, over half (51.39%) experience moderate pain, 33.33% mild, and 15.28% severe pain; pain is mostly provoked by movement, with “knife-like” quality, and commonly in the hand; most pain is intermittent (97.22%) and more than half of patients say pain affects their daily activities (Almutary et al., 2016; Cox et al., 2017) (Marzouq et al., 2021) (Afifah et al., 2018).

Despite this, there is limited qualitative research specifically on how patients perceive their pain, the detailed characteristics of that pain, and how they actively utilize complementary therapies in managing pain, especially in low- and middle-income countries. Prior qualitative studies on ESRD and hemodialysis have explored patients’ general lived experiences: limitations in physical function, dependency on dialysis technology, uncertainty about future health, and psychosocial and economic burdens (Hustrini, 2023). Then, it prior studies on Indonesian hemodialysis patients tend to focus on sleep disturbances and insomnia (prevalence ~69–80%) or the quality of life, or on service quality and adherence, rather than on lived experience of pain and complementary management strategies (Lufiyani et al., 2019).

For example, a study on complementary therapies for sleep disturbances (music therapy, acupressure, Benson's relaxation) showed improvements in sleep quality among hemodialysis patients, suggesting potential for non-pharmacological support, but did not focus specifically on pain or the patient perception of pain management (Rasmiati et al., 2023). However, very few studies have delved deeply into the triad of (a) patients’ subjective perceptions of their pain during hemodialysis, (b) qualitative descriptions of pain’s characteristics (intensity, timing, location, variation), and (c) the use and role of complementary/supportive therapies (such as spiritual practices, relaxation, distraction, or family-based coping). Most work to date has been cross-sectional quantitative (e.g., measuring severity and interference) or focused broadly on quality of life, without disaggregating these themes.

Thus, this study fills a gap by investigating in-depth how ESRD patients undergoing hemodialysis in Indonesia perceive and experience chronic pain, what specific characteristics this pain has, and how they use complementary therapies alongside conventional treatment to manage it. The local cultural, spiritual, and familial contexts may shape these experiences in ways not captured by international studies, making this exploration especially valuable for informing nursing practice in Indonesian settings.

This study was conducted to explore how do patients with end-stage renal disease undergoing hemodialysis in Indonesia perceive, characterize, and manage their chronic pain—particularly through complementary therapies—and what meanings do these experiences hold for their daily lives. To answer this question, a qualitative descriptive design using in-depth semi-structured interviews was employed. The purpose of the study is to explore the lived experiences of chronic pain management among ESRD hemodialysis patients in Indonesia, specifically focusing on patients’ perceptions of pain, detailed characteristics of pain, and their use of complementary therapies in pain management.

Methods

Data were collected through in-depth semi-structured interviews conducted in a private setting at the dialysis unit of a tertiary hospital in West Sumatera Indonesia on December to March, 2024. An interview guide was developed based on the research objectives, covering patients’ perceptions of pain, pain characteristics, and complementary strategies used in pain management. Interviews lasted 40–60 minutes, were audio-recorded with consent, and transcribed verbatim. Field notes were also taken to capture non-verbal expressions. Data were analyzed thematically following Collaizi framework, involving familiarization, coding, theme development, and interpretation (Creswell & Cresswell, 2018). To ensure trustworthiness, credibility was maintained through member checking and peer debriefing, dependability through audit trails, conformability through reflexivity, and transferability by providing rich, contextual descriptions.

All participants received information about the purpose and procedures of the study, were assured of confidentiality and anonymity, and provided written informed consent before participation. The rights of participants were protected by ensuring voluntary participation and the option to withdraw at any stage without consequence. The study approval was obtained from Ethical Committee of Fort De Kock University (Approval number: 550/KEPK/XII/2023 on December 27, 2023).

Results

Eight participants were included in the study, consisting of both men and women aged between 35 and 65 years, who had been undergoing hemodialysis for 1 to 10 years (See table 1). A total of eight participants were involved in this study, consisting of four males and four females aged between 45 and 62 years (Table 1). The majority of participants had undergone hemodialysis for more than five years, with dialysis duration ranging from two to ten years. All participants reported experiencing chronic pain during their dialysis treatment, with pain severity scores ranging from 5 to 9 on the Numeric Rating Scale (0–10).

Pain was most commonly reported in the back, legs, and joints, and tended to increase with longer dialysis duration. Participants who had been on dialysis for more than six years (P3, P5, P7, P8) generally described higher levels of pain intensity compared to those with shorter dialysis experience. These variations in age, gender, duration of dialysis, and pain severity provided diverse perspectives that enriched the exploration of patients' lived experiences of chronic pain management.

Table 1 General characteristics and severity of participants pain

Participant	Age (years)	Gender	Dialysis Duration (years)	Pain Severity (0–10)
P1	45	Male	3	7
P2	52	Female	5	8
P3	60	Male	7	6
P4	48	Female	4	5
P5	55	Male	6	7
P6	50	Female	2	6
P7	58	Male	8	9
P8	62	Female	10	8

Thematic analysis revealed three main themes: (1) perceived meaning and impact of pain during hemodialysis, (2) patterns and characteristics of pain experienced, and (3) complementary and supportive strategies for pain management. Each theme is illustrated with participant quotes to reflect the depth of their lived experiences, the scheme shown below (see table 2):

Theme 1: Perceived Meaning and Impact of Pain during Hemodialysis

Participants described pain as a persistent and disruptive experience that affected multiple aspects of their daily lives. The meaning and impact of pain were reflected through three sub-themes: pain as a persistent and disruptive experience, emotional distress and anticipatory anxiety, and loss of independence and social withdrawal.

Sub-theme 1.1: Pain as a Persistent and Disruptive Experience

Participants described pain as a persistent and disruptive experience that interfered with physical, emotional, and social well-being. For some, pain was seen as part of their illness journey.

Table 2 Themes Development by keywords and categories

Keywords	Categories	Sub-themes	Themes
like being stabbed", "numbness"	Physical sensations	Pain as a Persistent and Disruptive Experience	Patients' Perceptions of Pain
"Tiring" "feeling burnout"	Emotional Burden	Emotional Distress and Anticipatory Anxiety	
"unbearable perceived"	Perceived inevitability	Loss of independence and social withdrawal	

"worsens after dialysis","fatigue"	Pain patterns	Pain severity related to treatment cycle	Characteristics of Pain
"back and legs" "injection section"	Pain Location	Specific pain locations	
"constant" "Severe pain"	Pain intensity	Constant and overwhelming pain feelings	
"massage", "deep breathing"	Non-pharmacological strategies	Non-pharmacological pain relief practices	Complementary Therapies
"herbal drink", "massage from spouse or family"	Cultural practices, family support	Cultural and herbal approaches	
"Listening to the music"	Self-care efforts	Distraction and self-care techniques	

"The pain makes me feel weak and hopeless... sometimes I feel that my life only revolves around the dialysis machine and the pain it brings" (participant 4).

Pain was described as unpredictable and overwhelming, often leaving participants with feelings of helplessness and fatigue. This persistent discomfort disrupted their ability to function normally, leading to a diminished sense of control over their bodies and lives.

Sub-theme 1.2: Emotional Distress and Anticipatory Anxiety

Several participants also reported feelings of anxiety and anticipation before dialysis sessions. This showed from this statement:

"Every time I prepare for dialysis, I already feel afraid. The pain keeps coming back, and it makes me nervous even before I sit in the chair" (participant 6).

Many participants reported exhaustion, frustration, and burnout, especially after long-term hemodialysis

"The pain makes me so tired... I feel burnout. I just want one day without pain." (Participant 6)

These experiences illustrate the cumulative psychological toll of chronic pain, which may lead to increased vulnerability to depression, decreased motivation for treatment, and a diminished overall quality of life. Emotional fatigue and loss of hope emerged as key indicators of the mental burden faced by individuals coping with long-term hemodialysis-associated pain.

Sub-theme 1.3: Loss of independence and social withdrawal

For others, pain was associated with a loss of independence.

"I cannot carry heavy things anymore. I always ask my son to help me, because the pain after dialysis makes my arms useless" (participant 2).

In addition, social withdrawal emerged as a common coping response to unpredictable pain episodes. The fear of experiencing pain in public spaces and disrupting social interactions made participants avoid gatherings they once enjoyed. As one participant expressed,

"I rarely go out with friends now. I feel embarrassed if suddenly the pain comes and I cannot enjoy the moment" (participant 5).

These statements indicate that pain extends beyond physical suffering, influencing emotional well-being, social functioning, and interpersonal relationships. Changes in mobility and social engagement reinforced the sense of isolation, potentially leading to reduced overall life satisfaction and diminished social support—two critical elements for coping with chronic illness.

Theme 2: Patterns and Characteristics of Pain Experienced

Pain experiences varied among participants in intensity, duration, and location. Participants reported patterns and fluctuations in pain intensity linked to the dialysis process and individual conditions. The meanings of characteristics of pain experienced were reflected through three sub-themes: pain severity related to treatment cycle, specific pain locations, and constant and overwhelming pain feelings.

Sub-theme 2.1: Pain Severity Related to Treatment Cycle

Pain intensity was described as worsening after long dialysis sessions or changes in position.

"It becomes worse after dialysis... my body feels so tired and painful." (Participant 7)

Some described it as sharp and piercing, especially around the needle insertion site.

"The pain in my arm feels like needles piercing... sometimes it spreads to my back, and it gets worse when I move" (participant 1).

Others experienced intermittent but severe pain.

"Sometimes the pain comes suddenly, without warning. One day it is mild, another day it feels unbearable. I cannot predict it" (participant 3).

This variability in pain experiences shows that patients endure a dynamic pain trajectory influenced by physiological strain, vascular access complications, and fatigue. The unpredictability further heightens emotional burden, as patients remain constantly wary of when pain might worsen, making it difficult to plan daily activities or maintain a sense of control.

Sub-theme 2.2: Specific Pain Locations

Pain frequently concentrated at the needle insertion site, back, and legs—areas strained during dialysis.

"Mostly at my back and injection section... that's the painful part." (Participant 3)

In addition to vascular access pain, patients described back and leg pain that developed or intensified during lengthy dialysis sessions, likely due to prolonged immobilization and inadequate posture support. These musculoskeletal discomforts contributed to widespread discomfort that extended beyond procedural pain alone.

The concentration of pain in these specific anatomical regions reflects both mechanical and procedural sources of suffering. This highlights the cumulative burden of chronic treatment requirements and their physical consequences. The persistence of localized pain can reinforce negative expectations associated with dialysis sessions and may lead to decreased tolerance over time.

Sub-theme 2.3: Constant and Overwhelming Pain Feelings

For some participants, the pain was described as a constant pain and heavy burden.

"The pain is constant and sometimes unbearable." (participant 4).

"It feels like my legs are tied with weights... it is so heavy after the machine finishes" (participant 8).

One participant also noted how pain worsened with fatigue:

"When I am too tired, the pain feels stronger. If I rest before dialysis, it is a little easier" (participant 7).

These accounts highlight that chronic pain in hemodialysis is not only persistent but also overwhelming, disrupting patients' capacity to function comfortably and recover between treatment cycles. The unpredictability and ongoing discomfort contribute to a reduced sense of control over their bodies, reinforcing the emotional and physical burden of living with end-stage kidney disease.

Theme 3: Complementary and Supportive Strategies for Pain Management

Participants engaged in various coping efforts to relieve pain, influenced by personal preference, culture, and accessibility. All participants reported adopting complementary or supportive strategies alongside conventional treatments. Spirituality emerged strongly as a coping mechanism. The meanings of characteristics of supportive strategies for pain management were reflected through three sub-themes: non-pharmacological pain relief practices, cultural and herbal approaches, and distraction and self-care techniques.

Sub-theme 3.1: Non-pharmacological Pain Relief Practices

Participants tried easily accessible strategies such as massage and deep breathing for temporary relief.

"Massaging helps me relax... at least for a moment." (Participant 8)

Other then said:

"When the pain is strong, I close my eyes and pray... it helps me to endure because I believe God gives me strength" (participant 6).

These non-pharmacological approaches served not only as physical relief but also as mechanisms for psychological and spiritual adaptation. The reliance on these methods suggests the limited availability or effectiveness of pharmacological pain control during dialysis. It also emphasizes patients' proactive efforts to maintain personal comfort and regain a sense of control over their pain experience.

Sub-theme 3.2: Cultural and Herbal Approaches

Herbal drinks and traditional methods were used as culturally acceptable ways to manage discomfort.

"I drink herbal medicine... it helps my pain a little." (Participant 2)

Sometimes, family support also played an important role.

"My wife massages my legs after dialysis, and it really helps me feel more comfortable" (participant 3). Another added, *"My daughter always reminds me to breathe slowly when I feel the pain. It calms me down"* (participant 1).

These findings illustrate the cultural context of pain management, where caregiving and traditional remedies reinforce a sense of being cared for and reduce the psychological burden associated with chronic pain.

Sub-theme 3.3: Distraction and Self-Care Techniques

Listening to music or resting helped participants divert attention away from their pain.

"I put on some music so I don't think about the pain..." (Participant 9)

Some participants emphasized combining multiple strategies.

"Sometimes I pray, sometimes I talk with the nurses, or just chat with other patients… all of this makes me stronger" (participant 2).

Distraction techniques were also mentioned.

"I watch TV or listen to music during dialysis… it makes me forget the pain for a while" (participant 5).

Finally, one participant highlighted self-acceptance:

"I know the pain will not go away completely, so I try to accept it and live with it. That way, I feel less stressed" (participant 8).

Together, these techniques reflect participants' self-awareness and active role in managing their pain, reinforcing that effective coping is not only physical but also emotional and social.

Discussion

The findings of this study underscore the intricate and multifaceted aspects of pain management in patients receiving long-term hemodialysis. Pain was characterized as a continual bodily affliction as well as an emotional and social obstacle that impaired daily functioning and diminished quality of life. This corresponds with prior literature indicating a significant prevalence of both acute and chronic pain in patients with chronic kidney disease (CKD) undergoing hemodialysis, impacting many body regions (back, limbs, joints) and disrupting daily activities, mood, sleep, and social interactions (dos Santos et al., 2021, Szigeti et al., 2025, Schweiger et al., 2025).

Importantly, our data suggest that demographic variables — specifically age and gender — may modulate how pain is perceived and managed by patients. In another study of 261 HD patients, gender (female) and other socio-demographic factors correlated significantly with higher pain severity and interference scores (Mizher et al., 2023). These findings support our observation that some female participants in our study reported more intense subjective distress and emotional burden from pain, while older participants often minimized pain as part of normal aging or chronic disease. This age-related normalization — sometimes described by participants as "just part of dialysis life" — may reflect coping styles influenced by life experience, stoicism, or generational beliefs about illness. On the other hand, the greater reported pain among female patients may reflect known sex-related differences in pain sensitivity, pain reporting, and coping styles (Atik et al., 2016).

Participants consistently reported that pain was not only a physical burden but also an emotional and social challenge that affected their daily lives. This aligns with previous evidence indicating that pain in chronic kidney disease (CKD) patients is often under recognized and inadequately managed, despite its significant impact on quality of life (Davison et al., 2014; Roy et al., 2020). Compared to earlier studies that primarily emphasized pharmacological interventions, our findings revealed that patients actively sought non-pharmacological strategies, such as relaxation, distraction, and spiritual coping, as complementary ways to manage their pain. This underscores the importance of a holistic approach in pain care, rather than relying solely on medical treatment (Zeleke et al., 2021).

A key theme emerging from this study was the role of patient knowledge and self-efficacy in shaping pain experiences. Nevertheless, this was not uniform among all individuals. Only a subset of patients exhibited a heightened comprehension of pain management measures, facilitating more effective coping with their symptoms and preserving a sense of control. These individuals exhibited greater initiative in acquiring information, engaging in complementary therapies, and articulating their requirements to healthcare providers. Similar findings were reported in a study which emphasized that patient empowerment and education contribute to improved pain outcomes in palliative and chronic care settings (Gómez-Batiste et al., 2012). However, our findings extend this by illustrating that knowledge alone is insufficient; the ability to translate knowledge into consistent practice was often hindered by fatigue, emotional distress, and limited family support. This suggests that nursing interventions should not only focus on education but also incorporate supportive counseling and family engagement to reinforce behavioral changes (Rambod & Rafii, 2010).

Another important finding was the influence of cultural and spiritual factors on pain perception and management. Participants frequently described reliance on faith-based practices, prayer, and acceptance as central to their coping mechanisms. This reflects prior research indicating that spiritual well-being is a protective factor in chronic illness and positively correlates with resilience and psychological adjustment (Mateus & Silva, 2025). However, the uniqueness of our study lies in showing how spirituality was not only a coping strategy but also shaped patients' interpretations of pain itself—perceiving it as a test or a meaningful experience. Such perspectives provide valuable insight for culturally sensitive nursing care, where spiritual dimensions are integrated into pain management plans.

Despite the commonalities with previous literature, this study also identified gaps between patient-reported needs and the healthcare system's response. Several participants perceived limited attention from healthcare professionals toward their pain experiences, echoing findings on the underassessment of pain in CKD care

(Mateus & Silva, 2025). Yet, unlike prior studies that highlighted systemic resource limitations, our findings emphasize communication barriers and inadequate therapeutic relationships as primary obstacles. This means that strengthening nurse-patient communication and incorporating therapeutic dialogue into routine care could bridge this gap and foster a more patient-centered approach as the result of patient satisfaction (Ariyanti, 2022; Kartika, 2014; Kartika et al., 2018).

The implications of these findings are substantial. By illuminating the interplay between knowledge, coping strategies, and cultural factors, this study advances the understanding of how pain is experienced and managed in hemodialysis patients within the Indonesian context. It highlights the need for multidimensional interventions that combine education, psychosocial support, and culturally sensitive care to improve patient outcomes (Al Nazly & Al Khatib, 2021). Nonetheless, the study is limited by its small sample size and single-site recruitment, which may restrict transferability. Future research should include more diverse populations and explore intervention models that integrate both professional care and patient-led coping mechanisms.

Implications for Nursing Practice

The findings of this study provide several important implications for nursing practice. First, nurses should recognize that pain in hemodialysis patients is not merely a physical symptom but also encompasses emotional, social, and spiritual dimensions. This highlights the need for comprehensive pain assessments that go beyond numeric rating scales, incorporating patients' personal narratives and coping strategies. Integrating such holistic assessments into routine nursing care can improve the identification of unmet needs and facilitate individualized interventions.

Second, the study underscores the importance of patient education and empowerment in pain self-management. Nurses should not only deliver information about pharmacological and non-pharmacological options but also provide practical guidance and continuous reinforcement to ensure that patients are able to translate knowledge into effective practices. Structured educational sessions, follow-up counseling, and involving family members in pain management discussions may strengthen patients' ability to apply self-care strategies consistently.

Third, the findings emphasize the critical role of therapeutic communication in bridging the gap between patient expectations and healthcare delivery. The aspects — active listening, empathy, culturally sensitive dialogue, and shared decision-making — are foundational to building trust and validating patients' pain experiences (Lestari et al., 2023; Yun et al., 2024). In the context of hemodialysis, relational skills of nephrology nurses — including empathy, emotional support, and culturally responsive communication — have been identified as essential competencies to improve adaptation to therapy, emotional well-being, and self-management in patients undergoing dialysis (Mancin et al., 2025). Training programs focusing on therapeutic communication and culturally competent care, such as workshops on cultural sensitivity, empathy training, and communication skills enhancement, have demonstrated effectiveness in improving nurse–patient communication, reducing patient anxiety, increasing satisfaction, and supporting pain management outcomes. Therefore, implementing structured communication training and culturally sensitive care protocols should be prioritized in dialysis units to overcome communication- or culture-related barriers that hinder effective pain management.

Lastly, given the prominent role of spirituality in shaping patients' pain perceptions and coping mechanisms, nurses should be prepared to integrate spiritual support into care plans. Collaborating with chaplains, religious leaders, or providing opportunities for spiritual practices during dialysis sessions may enhance patient comfort and resilience. By embedding spiritual care into nursing practice, nurses can align interventions with patients' cultural and personal values, ultimately improving their overall well-being.

Conclusion

This study explored the lived experiences of patients with end-stage renal disease undergoing hemodialysis in managing chronic pain. Three central themes emerged: patients' perceptions of pain as a multidimensional burden, the diverse characteristics of pain experienced during hemodialysis, and the use of complementary therapies as supportive strategies. These findings highlight the complexity of chronic pain in this population, emphasizing that effective management requires attention not only to physical discomfort but also to emotional, social, and spiritual dimensions.

The study contributes to the growing body of knowledge on pain management in hemodialysis patients by demonstrating the value of incorporating patients' voices into care planning. Nurses and healthcare providers should consider integrating individualized pain assessment, patient education, therapeutic communication, and spiritual care into routine practice. While the findings offer meaningful insights, this study was limited by its small sample size and single-site design, which may affect transferability. Future research should involve larger, more diverse populations and explore the effectiveness of nurse-led interventions in improving pain outcomes.

Declaration of Conflicting Interest

The authors declare no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Author's Contribution

IRK contributed to the study's conception and design, data acquisition, and data analysis, wrote the first draft of the manuscript, revised the final draft, and gave final approval of the version to be published. FR contributed to extraction thematic data acquisition, and data analysis, wrote and revision the manuscript.

Data Availability Statement

The dataset generated during and analyzed during the current study is available from the corresponding author upon reasonable request.

Declaration of Use of AI in Academic Writing

The author used ChatGPT in the writing process to improve readability and remove grammatical errors. However, their took full responsibility for the content.

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