

The Lived Experience of Patients with Brain Tumors Following a Positive Diagnosis: A Phenomenological Study

Alireza Abdi¹ , Behzad Imani² , Shirdel Zandi² , Mohamad Reza Zamani¹ 

¹Student Research Committee, Hamadan University of Medical Sciences, Hamadan, Iran

²Department of Operating Room, School of Paramedicine, Hamadan University of Medical Sciences, Hamadan, Iran

*Corresponding Author: Behzad Imani, Email: behzadiman@yahoo.com

Abstract

Introduction: Brain tumors, as a life-threatening diagnosis, often lead to profound psychological and existential crises. Understanding the lived experiences of these patients is crucial for providing holistic care. This study explored the lived experiences of patients with brain tumors following a positive diagnosis.

Methods: This qualitative study employed a descriptive phenomenological approach. Participants were purposefully selected based on their experiences, and data were collected through in-depth, semi-structured interviews with 12 patients at Besat Educational Hospital in Hamadan, Iran. Data analysis was conducted using Colaizzi's seven-step method to ensure a rigorous and systematic exploration of participants' experiences.

Results: The analysis revealed four main themes: (1) *Emotional Storm* (shock, anger, anxiety, sorrow, and depression), (2) *Psychophysical Transformations* (physical deterioration, identity crisis, and personality changes), (3) *Social Disintegration* (self-imposed isolation, shifting roles, and social stigma), and (4) *Adaptation to the Illness* (hope-fear confrontation, seeking life's meaning, gradual acceptance, and coping strategies).

Conclusion: The findings highlight the severe psychological and social challenges faced by patients with brain tumors following a positive diagnosis. These experiences underscore the need for comprehensive, culturally sensitive interventions that address emotional, psychological, and social dimensions. Healthcare systems should prioritize patient-centered care, including counseling, support groups, and public education to reduce stigma.

Keywords: Brain neoplasms, Lived experience, Qualitative research, Phenomenological study, Coping skills, Stress, Psychological

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Introduction

As complex organisms, human beings are a product of the dynamic interaction of body, mind, and society. Any damage to the central nervous system—mainly caused by brain tumors—not only disturbs biological functions but also profoundly changes the existential dimensions of life. Despite their relatively lower prevalence compared to other cancers, brain tumors are recognized as one of the most terrifying diseases of the present century, characterized by poor prognosis (a five-year survival rate of 36%) and a heavy burden of severe symptoms (second only to lung cancer), which significantly deteriorate quality of life (1-3). However, it is essential to note that the global incidence of brain tumors is steadily increasing, with a rise of over 40% in adults over the past two decades (4). This disease directly affects the brain—the core of perception, identity, and bodily control—and creates multilayered crises that can lead to the collapse of both body and mind (1, 4, 5).

Facing a diagnosis of a brain tumor, especially in its malignant forms, is considered an existential shock,

affecting up to 90% of patients with symptoms of anxiety and depression (6-8). Meanwhile, healthcare systems, often concerned about exacerbating emotional distress, tend to avoid full disclosure of the diagnosis—a practice that perpetuates a vicious cycle of “ambiguity-distrust” (9). Moreover, the social stigma of being labeled as having an “incurable disease” induces a sense of imminent death, plunging patients into a swamp of isolation and despair (10).

Despite the growing incidence of brain tumors globally, few studies have examined the culturally shaped lived experiences of patients in Middle Eastern contexts, particularly Iran, where cultural, familial, and religious dynamics uniquely influence coping strategies. Culture directly influences concepts of illness, affective response, and coping strategies, presenting the challenge of creating context-based supportive care interventions. An interpretative phenomenological strategy is utilized for this research to excavate meanings around patients' lived experiences. This study aimed to investigate the post-diagnostic experiences of Iranian patients with brain



tumors. The phenomenological findings address this gap by revealing their psychological, social, and existential challenges, thereby establishing a foundational framework for culturally adapted interventions in Iran's neuro-oncology care.

Methods

Study Design

This study employed descriptive phenomenology as its methodological framework to explore the lived experiences of patients diagnosed with brain tumors. The philosophical virtues that form the basis of descriptive phenomenology offer a deeper insight into the phenomenon at hand (11). The Husserlian approach, emphasizing four key stages—bracketing, intuition, analysis, and interpretation—enabled an authentic understanding free from theoretical preconceptions (12). In this study, the Standards for Reporting Qualitative Research (SRQR) guidelines have been followed.

Participants and Data Collection

This phenomenological study employed purposive sampling to recruit twelve participants from patients with brain tumors at Besat Educational Hospital, Hamadan, Iran. All participants provided informed consent through culturally-adapted Persian forms, with researcher-guided discussions ensuring comprehension of the study's purpose. For non-literate participants, witnessed verbal consent with thumbprint documentation was obtained. The process emphasized voluntary participation, confidentiality protections, and withdrawal rights, following approval by the institutional ethics committee. The sample size was not predetermined at the beginning of the study; instead, data collection continued until theoretical saturation was achieved, which was determined by two criteria: (1) no new codes or themes emerged in the interviews, and (2) the relationships between existing themes became sufficiently clear and repetitive. To ensure robustness, two additional interviews were conducted beyond the initial saturation point, confirming that no further insights were gained. Additional inclusion criteria included having a positive diagnosis, the ability to recall events and subjective thoughts during the initial diagnosis, psychological and mental stability, favorable clinical conditions, willingness to cooperate with the research team, and the possibility of being re-contacted for a second interview if needed. Exclusion criteria included unwillingness to participate, patients with cognitive or memory impairments, those with a history of psychiatric disorders, and those unable to communicate verbally in Persian.

Data were gathered through in-depth, semi-structured face-to-face interviews in quiet, private hospital rooms to ensure participant comfort and confidentiality. Each interview averaged 54 minutes in duration (45-60 minutes) and followed a structured protocol: The opening phase employed an open-ended question ("Please describe your experience when you first learned about your diagnosis") to establish a narrative flow. The core exploration phase

continued with semi-structured questions (e.g., "How did this diagnosis affect your relationships?"). The in-depth probing phase utilized follow-up questions ("Could you provide a specific example of this situation?") and clarification requests ("What did you mean by that statement?") to enrich the data.

All sessions were audio-recorded following written informed consent, with verbatim transcription completed within 24 hours to ensure data accuracy. All interviews were conducted exclusively by the primary researcher (A.A.), with specialized training and substantial experience in qualitative methodology and phenomenological interviewing techniques.

Data Analysis

Data analysis was performed manually using Colaizzi's seven-step method (13, 14), which includes (1) collecting participants' descriptions, (2) achieving a deep understanding of the underlying meanings, (3) extracting significant statements, (4) conceptualizing key themes, (5) categorizing concepts and topics, (6) constructing comprehensive descriptions of the issues investigated, and (7) validating the data according to Lincoln and Guba's four criteria. This manual analytical process, conducted without qualitative data analysis software, involved iterative cycles of reading, reflective memoing, and team discussions to ensure interpretive rigor. The research team maintained an audit trail documenting all analytical decisions to enhance methodological transparency.

Rigor

Lincoln and Guba's four criteria—credibility, dependability, transferability, and confirmability—were applied to ensure the study's trustworthiness (15, 16). Credibility was established through the researcher's prolonged engagement with the topic and building trust with participants to access rich data. Dependability involved peer review by four independent qualitative researchers, who examined and revised codes and themes. Confirmability was ensured through thorough documentation and member checks to align findings with participants' experiences. Maximum variation sampling and comprehensive documentation were used to enhance transferability, allowing future researchers to assess the results' applicability to similar contexts.

Results

The researchers reached saturation after interviewing 10 patients. Two additional interviews were conducted to ensure completeness, provide redundant data, and determine saturation. A total of 12 participants took part in the study. The mean age of participants was 47.25 ± 12.56 years, with 58.33% being female and 66.66% married. Regarding educational attainment, one participant was illiterate, three had elementary education, five held high school diplomas, and three possessed academic degrees. In terms of employment status, four were unemployed, four were self-employed, two were retired, and two were

government employees (Table 1).

Phenomenological analysis of experiences of patients with brain tumors revealed four core themes, each with distinct subthemes (Table 2): (1) Emotional Storm (Shock of facing an undeniable reality, Multifaceted anger, Obsessive anxiety, Profound sorrow, and The black dog of depression), (2) Psychophysical Transformations (Physical deterioration, Identity crisis, and Altered personality), (3) Social Disintegration (Self-imposed isolation, Changing roles and relationships, Unwise social stigma, and Loneliness despite support), and (4) Adaptation to the Illness (hope-fear confrontation, Seeking life's meaning, Gradual acceptance, and Coping strategies) (Table 2).

Emotional Storm

The diagnosis of a brain tumor plunges patients into a whirlpool of intense and conflicting emotions, and this theme reflects the emotional journey patients undergo during this period.

Shock of facing an undeniable reality

Diagnosis of a brain tumor is the most significant stage for patients, where some first reactions are shock, numbness, confusion, dizziness, and sometimes even physical complaints such as low blood pressure or dizziness. This is what patients say is a sudden knock in the fabric of their lives. Some temporarily deny reality to escape psychological pressure, believing the doctor might have made a mistake or seeking a second opinion to confirm the diagnosis. Ultimately, however, they must confront and accept the reality of their illness.

"...When I heard the doctor say 'tumor,' it felt like my whole world just fell apart." (Patient 5)

Multifaceted anger

Anger is one of the natural and multifaceted reactions of patients diagnosed with brain tumors, which can manifest as either internal or external anger. In internal anger, some patients experience feelings such as self-blame for neglecting their health, resentment toward fate, or a sense of injustice in the world. They may also search for a "culprit"

— genetic factors or past mistakes — to hold responsible. On the other hand, external anger is directed toward the medical system (e.g., delays in diagnosis or dismissal of symptoms) or is displaced onto those around them.

"I kept complaining to God, 'Why me? Where is your justice? Can't I have even one good day?!" (Patient 9)

Obsessive anxiety

Obsessive worry is the most prominent of these patients' experiences, through chronic and pervasive monitoring of bodily symptoms, ongoing seeking of information using the internet, excessive concern for the future, and sleep disturbances. For most patients, the initial feeling after being diagnosed with a brain tumor is a "fear of death," and they interpret every new symptom as a sign of disease progression. Fears of the disease being incurable, pain, treatment side effects (such as chemotherapy or surgery), and uncertainty about the future are also hallmarks of this state. Additionally, the fear of financial burdens (losing

Table 2. The themes and sub-themes

Main Themes	Subthemes
1. Emotional Storm	1.1. Shock of facing an undeniable reality
	1.2. Multifaceted anger
	1.3. Obsessive anxiety
	1.4. Profound sorrow
	1.5. The black dog of depression
2. Psychophysical Transformations	2.1. Physical deterioration
	2.2. Identity crisis
	2.3. Altered personality
3. Social Disintegration	3.1. Self-imposed isolation
	3.2. Changing roles and relationships
	3.3. Unwise social stigma
	3.4. Loneliness despite support
4. Adaptation to the disease	4.1. Hope-fear confrontation
	4.2. Seeking life's meaning
	4.3. Gradual acceptance
	4.4. Coping strategies

Table 1. The demographic characteristics of participants

ID	Gender	Age	Marital Status	Education Level	Occupation	Tumor Type	Duration of disease (Months)
P1	Male	61	Married	Elementary	Retired	Malignant	4
P2	Female	43	Married	Diploma	Unemployed	Benign	10
P3	Male	45	Married	Academic	Employee	Benign	9
P4	Female	32	Single	Academic	Self-employed	Malignant	6
P5	Female	54	Single	Elementary	Unemployed	Benign	8
P6	Male	48	Married	Diploma	Self-employed	Malignant	4
P7	Female	39	Single	Academic	Employee	Malignant	3
P8	Female	51	Married	Diploma	Unemployed	Benign	5
P9	Male	65	Married	Diploma	Retired	Malignant	11
P10	Male	31	Single	Elementary	Self-employed	Benign	7
P11	Female	32	Married	Diploma	Self-employed	Malignant	6
P12	Female	66	Married	Illiterate	Unemployed	Malignant	3

a job, treatment costs, economic pressure on the family) and becoming a “burden” further exacerbate anxiety. Fears of dependency, inability to perform daily tasks, and concerns about the impact of the illness on their personal life, career, and the future of their children after death are other dimensions of this distressing experience.

“...I kept thinking about my young child, wondering what would happen to their future if something happened to me...” (Patient 11)

Profound sorrow

Profound sorrow is one of the most prominent experiences among patients with brain tumors, stemming from the loss of health, everyday life, social roles, and the future they had previously planned. This emotional state is particularly intense in patients with advanced disease or those undergoing prolonged and complicated treatments. The loss of a sense of well-being and the inability to perform daily activities can exacerbate these feelings.

“The future I had built for myself, the plans I had made, all my dreams and desires... everything went up in smoke...” (Patient 10)

The black dog of depression

Depression in patients with brain tumors is a complex condition characterized by low energy, chronic fatigue, diminished self-confidence and self-esteem, lack of interest in activities, reduced appetite, and even suicidal thoughts. This state requires special attention, psychological support, and careful management through appropriate therapeutic interventions. Providing a supportive environment and fostering hope in patients’ hearts can help alleviate these feelings.

“...I don’t have the energy for anything anymore. Life has lost its meaning for me. Even if I die, it wouldn’t make a difference...” (Patient 4)

Psychophysical Transformations

This central theme reveals that patients perceive a brain tumor not merely as a physical illness but as an assault on their identity, cognition, and self-concept.

Physical deterioration

A brain tumor transforms the body into an unrelenting battlefield, where multifaceted physical suffering—from pounding headaches resistant to painkillers to visual and motor disturbances—reigns supreme. Unpredictable seizures strip patients of control over their bodies, leaving them in the grip of helplessness.

“...When I have a seizure, it feels like the whole world slips out of my control... I can’t even scream for help...” (Patient 1)

Identity crisis

The diagnosis of a brain tumor confronts patients with the collapse and transformation of their identity. An identity crisis refers to the loss of a sense of continuity and coherence in one’s self-perception. Patients feel that core aspects of

their identity—such as social roles, skills, or values—have been destroyed by the illness. Cognitive changes, such as brain fog, frequent memory lapses, sensory hallucinations, and the loss of specialized skills, blur the line between the “familiar self” and the “stranger within”:

“... I’m an engineer. I used to handle the most complex calculations, but now I can’t even manage my daily shopping expenses...” (Patient 3)

Altered personality

Beyond physical damage, a brain tumor can also affect the core of a patient’s personality, including their moral, emotional, and behavioral traits. Damage to certain key areas of the brain may lead to significant changes in behavior, emotions, and reactions, such as sudden irritability, impulsive actions, or a loss of interest in previously enjoyed activities. These transformations are sometimes irreversible and leave patients fearing rejection. They feel as though they are living in a “new self”—a stranger unfamiliar not only to others but even to themselves.

“Lately, I’ve been snapping out of nowhere and starting to swear. I’m scared this will drive my friends away...” (Patient 6)

Social Disintegration

This theme focuses on the tumor’s impact on social relationships and the transformation of familial and personal roles.

Self-imposed isolation

Self-imposed isolation reflects a conscious decision by patients to withdraw from social interactions to escape the psychological pressures of their illness and fear of negative reactions or feelings of shame. Patients may avoid participating in social activities out of fear of exhibiting physical symptoms (such as seizures) or being labeled negatively (e.g., as weak or incompetent). Additionally, some distance themselves from social settings to avoid the discomfort of receiving pity or sympathy from others.

“...I hate it when people look at me with pity; I’d rather be alone...” (Patient 3)

Changing roles and relationships

The diagnosis of a brain tumor brings profound changes to patients’ social roles and relationships. Due to physical and psychological limitations, patients lose traditional roles (such as being the breadwinner or managing household responsibilities) and become dependent on their families. While the illness strengthens deep, emotionally committed relationships, superficial ties gradually fade or are severed. The impact of the disease on marital relationships is also evident in some patients, threatening their role as both emotional and sexual partners. Patients, feeling vulnerable, seek emotional support and deep understanding from those around them, yearning for genuine companionship in facing the challenges posed by their illness.

“...As a man, it’s tough to see my wife working and caring

for me simultaneously...” (Patient 6)

Unwise social stigma

Most patients believe that brain tumors are perceived by society as an incurable disease synonymous with death. Additionally, the illness carries a stigma that may be associated with misconceptions (e.g., “a result of sin”), leading patients to conceal their condition. This stigma often triggers avoidance behaviors from others. Symptoms such as brain fog, memory lapses, or low energy are frequently misinterpreted as laziness or irresponsibility, especially in the workplace.

“...My boss thought I was making excuses when I said I had a headache and couldn't work...” (Patient 7)

Loneliness despite support

Despite the support of family and friends, patients with brain tumors often experience profound loneliness. This paradox stems from the inability of others to fully understand the unique lived experiences of the patient, such as cognitive changes and physical-psychological symptoms. While emotional support boosts morale, many feel no one truly understands their inner struggles. This gap in mutual understanding exacerbates feelings of isolation and diminishes trust in social support.

“...My family tries to help me, but sometimes I feel completely alone, like no one understands what I'm going through...” (Patient 2)

Adaptation to the Illness

This theme represents a stage where, over time, many patients gradually understand the true meaning of life, come to terms with their fears and the reality of their illness, and, with hope for the future, seek ways to adapt to their new circumstances.

Hope-fear confrontation

Patients with brain tumors navigate a complex interplay of fears and hopes as they adapt to their illness. Despite challenges such as fear of treatment, its consequences and side effects, uncertainty about prognosis, and even the possibility of recurrence, a glimmer of hope remains alive in some patients. Hope plays a crucial role in maintaining emotional strength and continuing the fight against the disease, serving as the first step toward integrating the illness into their lives.

“...I know the surgery is tough, but my doctor said I have a high chance of success. I want to stay hopeful...” (Patient 8)

Seeking life's meaning

A brain tumor diagnosis prompts patients to reflect on the meaning of life and their values deeply. This process leads to redefining life goals, identity, and priorities. Patients seek new meanings by focusing on their remaining abilities (rather than their limitations). Shifting priorities from material/professional success to valuing family, personal relationships, and joyful moments in life is a hallmark of this transformation. This redefinition directs life toward

deeper connections and human values.

“...I spent my whole life chasing money. What did it all amount to? In these final days, I want to savor every moment of joy...” (Patient 1)

Gradual acceptance

This key stage in integrating a brain tumor into one's life moves patients from initial shock, denial, and depression toward accepting the reality of their condition. Gradually, patients accept the illness as part of their lives, shifting their mindset from resistance to actively managing their circumstances. They focus on improving their quality of life and finding joy in positive moments. This transformation enables a conscious coexistence with the illness and a redefinition of hope within the framework of their new reality.

“...Now, I see the illness as part of my life. Instead of dwelling on it, which doesn't help, I try to take it easier and enjoy life...” (Patient 7)

Coping strategies

Coping mechanisms are the final step in the process of integrating the illness for patients with brain tumors, playing a central role in their mental and physical well-being. Adaptive strategies, such as seeking information, joining support groups, engaging in art, or turning to spirituality, can improve quality of life and reduce stress. In contrast, maladaptive strategies—such as denial, avoiding medical care, relying on superstitions or magical thinking, extreme isolation, dependence on painkillers, or substance abuse—can exacerbate problems. For many patients, spirituality serves as an anchor of peace, with practices like prayer, reciting religious texts, or engaging in rituals providing comfort.

“...On nights when I'm struggling, I recite prayers and read the Quran. It calms me because I feel like God is with me...” (Patient 12)

Discussion

This phenomenological study reveals that a brain tumor diagnosis triggers a multidimensional crisis encompassing emotional turmoil, identity fragmentation, social isolation, and ultimately, a search for meaning—a process profoundly shaped by Iran's socio-cultural context, particularly the interplay of collective family dynamics and religious coping mechanisms. The emotional process in patients with brain tumors begins with an existential shock and an avalanche of overwhelming and conflicting emotions. Initial reactions—shock, numbness, and denial—reflect a profound disruption of patients' sense of normalcy, a phenomenon amply described in studies on the psychological experience of life-threatening illness, e.g., the survey by Fitch et al. (17). These reactions are followed by multifaceted anger, obsessive anxiety, deep sorrow, and depression, which together form an “emotional storm.” Our findings regarding multifaceted anger (18), obsessive anxiety (19), deep sorrow (20), and depression (21) align with established neuro-oncology literature while revealing

culture-specific manifestations in Iranian patients. These responses resemble the five stages of grief proposed by Kübler-Ross (denial, anger, bargaining, depression, and acceptance), which individuals experience after facing loss or profound crises. According to Kübler-Ross, these stages are not fixed, and not all individuals experience every stage; people may have different grief experiences (22). Moreover, these emotions are not merely transient reactions but are rooted in the existential threat posed by the illness, aligning with findings from studies on the psychological burden of cancer (17, 23, 24). In Iran, cultural and religious beliefs linking severe diseases like brain tumors to fatalism or divine punishment amplify emotional distress through social stigma and public misunderstanding (25, 26). Reducing these barriers requires nationwide awareness campaigns and clinician education programs to foster supportive patient environments (27).

Our study reveals that patients with brain tumors experience profound physical deterioration—seizures, incapacitating headaches, and progressive motor impairment, which is closely consistent with previous neuro-oncology research documenting the debilitating somatic effects of CNS tumors (28). Yet crucially, our results demonstrate that the malignancy's devastation extends beyond the biological realm to mount an existential assault on patients' identities. In fact, along with the physical symptoms, the disease brings along an identity crisis as the patients grapple with cognitive changes, memory loss, and the forfeiture of expert skills, corroborating international studies on the psychological sequelae of brain cancer (29, 30). The changes blur the line between the 'familiar self' and the 'stranger within,' creating a powerful sense of alienation—a phenomenon that is corroborated by Anderson-Shaw et al. (1). Also, this existential disruption empirically validates Bury's (1982) biographical disruption theory while demonstrating its cross-cultural applicability to neuro-oncology populations (31). The personality change is highlighted by the sophistication of this process, by the theme. Damage to these large brain areas can cause profound behavioral and emotional changes, such as irritability, impulsivity, and loss of interest in previously enjoyable activities. These findings agree with the work of Loughan et al, who explored the lives of patients with brain tumors (23). Such changes can potentially lead to social rejection and isolation and, therefore, require integrative care that addresses both the physical and psychosocial features of the illness (24).

The diagnosis of a brain tumor has a significant impact on the social roles and relationships of patients. Our findings reveal four interconnected dimensions of social disruption following brain tumor diagnosis. First, self-imposed isolation emerged prominently, mirroring Boccia et al.'s (2022) findings (32), yet intensified by Iranian cultural norms of social dignity. Patients self-isolate themselves, driven by fear of being judged, reacted to negatively, shamed, or did not wish to be pitied and made to feel a burden (33). Second, changing roles and relationships, where the loss of the breadwinner or

caregiver roles is precipitated by family dependency on the patients because they require loved ones for care and attention. This result has been supported by other studies (20, 25, 26). Third, social stigma contributes to the deterioration. Brain tumors, in Iranian society, are mostly considered incurable diseases tantamount to death and hence lead to avoidance behaviors and misconceptions. Such stigma is particularly destructive in the workplace environment, where manifestations such as brain fog or forgetting are interpreted as laziness or irresponsibility—a finding complemented by social difficulties experienced by lung cancer patients studied by Fitch et al. (17). In addition, current findings validate Becker's labeling theory (27) and Goffman's theory of stigma (28), where stigma and pejorative labeling are highlighted as factors perpetuating and further complicating patients' experience. Fourth, we identified loneliness despite support, where participants reported profound isolation even when surrounded by caring families—a phenomenon which is supported by previous studies and termed 'relational disconnection' in neuro-oncology literature (32). This arises when cognitive changes (e.g., personality shifts) create empathy gaps with caregivers, compounded by cultural norms prioritizing practical over emotional support (34). Notably, such loneliness correlates with unmet emotional needs rather than support quantity (35). Reducing these social disruptions requires an overall approach to public education, workplace adjustment, and community-oriented support programs.

Despite the global adversity, most patients adapt to their disease with time and find a new purpose in life. Our study reveals four critical phases in patients' adaptation to brain tumor diagnosis. First, the hope-fear confrontation emerged as a fundamental tension, where some of the participants oscillated between optimism about treatment and existential dread, a dynamic consistent with Loughan et al.'s (2023) findings on emotional duality in neuro-oncology (36). Second, our study documented the critical phenomenon of meaning reconstruction, where patients underwent profound existential reprioritization. The search for meaning in life typically leads to priorities shifting from attaining material and professional success to putting family, relationships, and enjoyable moments first (37). This meaning-making process aligns with Park's model of meaning-making, where stress events precipitate a quest for new meaning in life (38). This process of re-establishing priorities is key to integrating the disease into the patient's life, and this process was also highlighted by Loughan et al. (23) in their account. Third, gradual acceptance represents a crucial stage in patients' psychological adaptation. Our findings show that this progression marks a transition from initial shock, denial, and depression to a point where they consciously integrate the disease into their lives, and this transformative process occurs through letting go of resistance, actively managing their reality, and positively reorienting their mindset. This result has been supported by other studies (39-41). Finally, patients utilized coping strategies to manage stressors, aligning with Lazarus and

Folkman's stress and coping theory (42). In this study, regarding coping strategies, we identified a clear dichotomy: adaptive approaches correlated with better psychosocial outcomes, while maladaptive patterns exacerbated distress. It means, patients who use adaptive coping strategies, for instance, membership in support groups or religious coping, are more likely to have improved long-term quality of life and less stress, while maladaptive coping strategies, for example, denial or chemical dependence, exacerbate problems. These findings align with established evidence demonstrating the critical role of coping strategy selection in neuro-oncology outcomes (43, 44). To this end, spirituality, particularly in the Iranian culture, is significant, providing patients with calmness and comfort—a finding supported by studies of the role of religion and spirituality in coping with disease (45, 46).

Our study reveals how demographic factors distinctly shape the psychological adaptation of patients with brain tumors. Regarding age-related differences, younger patients consistently faced challenges associated with lost life opportunities and unfulfilled aspirations, a phenomenon well-documented in the literature as an identity and meaning crisis in this age group (47). In contrast, older patients primarily expressed concerns about maintaining personal autonomy and human dignity, findings that align with previous research on aging psychology and chronic disease (40). Gender differences revealed distinct coping patterns. Male patients typically exhibited withdrawal and emotional silence during early stages of disease, a response potentially rooted in sociocultural gender norms. However, many gradually transitioned to peer support networks. Female patients, while more proactive in seeking social support, simultaneously struggled with internalizing emotional distress and caregiver burdens, a dual phenomenon noted in prior studies (40, 48). Marital status emerged as a critical factor influencing patient priorities. Married individuals predominantly prioritized family stability, often to the point of neglecting their own needs - a finding consistent with family systems theory in serious disease contexts (40, 49). Conversely, single patients focused more intensely on personal identity reconstruction and meaning-making, possibly reflecting greater opportunity for self-reflection. Education level significantly shaped disease interpretation. Highly educated patients frequently experienced confusion due to information overload, a growing challenge in the digital age (47). Those with limited education more often adopted fatalistic or spiritual explanations for their disease, an approach that may serve as a psychological coping mechanism in certain cultural contexts (50). These findings collectively highlight the necessity for personalized psychosocial interventions that account for the diverse experiences shaped by patients' demographic characteristics.

This phenomenological study explored experiences of Iranian patients with brain tumors, revealing critical themes like “emotional storm” and “social disintegration” that highlight unique cultural and spiritual dimensions often overlooked in Western research. This study provides

valuable insights into patient experiences but is limited by its single-center design and focus on only patient perspectives. Future multicenter studies should expand sample diversity and incorporate caregiver viewpoints to develop more comprehensive support interventions. These findings nevertheless advance our understanding of patients' psychological and social challenges, offering culturally sensitive directions for improving neuro-oncology care.

Conclusion

This study revealed that patients diagnosed with brain tumors face profound emotional challenges (shock, anger, anxiety, sorrow, and depression), psychophysical transformations (physical deterioration, identity crisis, and personality changes), and social disintegration (self-imposed isolation, shifting roles, and social stigma). However, the majority of patients come to adapt to their new reality by attributing meaning to life, accepting their condition, and employing adaptive coping strategies such as spirituality. Medical facilities should provide education, counseling, and appropriate support programs from a cultural perspective to minimize psychological trauma and improve patients' quality of life. This study emphasizes the importance of comprehensive, multidisciplinary interventions.

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Authors' Contribution

Conceptualization: Alireza Abdi, Behzad Imani.
Data Curation: Alireza Abdi.
Formal Analysis: Alireza Abdi, Behzad Imani, Shirdel Zandi.
Funding Acquisition: Behzad Imani.
Investigation: Alireza Abdi, Mohamad Reza Zamani.
Methodology: Behzad Imani, Shirdel Zandi.
Project Administration: Behzad Imani.
Resources: Behzad Imani.
Software: Shirdel Zandi, Mohamad Reza Zamani.
Supervision: Behzad Imani.
Validation: Behzad Imani, Shirdel Zandi.
Visualization: Behzad Imani, Shirdel Zandi, Mohamad Reza Zamani.
Writing—Original Draft: Alireza Abdi, Shirdel Zandi, Mohamad Reza Zamani.

Competing Interests

The authors declare no conflicts of interest.

Ethical Approval

This study is the result of a student project that has been registered in Hamadan University of Medical Sciences of Iran with the ethical code IR.UMSHA.REC.1404.201.

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