




# The Turkish Journal of Ear Nose and Throat

## Research Article

## Open Access

## Exploring the Life Experiences of Bell's Palsy Patients: A Qualitative Study



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### Abstract

**Objective:** Bell's palsy is the most common type of peripheral facial paralysis. The sudden onset and unknown cause of Bell's palsy lead to significant psychological distress and social disabilities in patients, which can severely impact their quality of life. This study aimed to explore the experiences of patients with Bell's palsy using a qualitative approach to gain a better understanding of the outcomes from the patient's perspectives.

**Material and Methods:** This study was conducted as a qualitative research employing a hermeneutic phenomenological framework. Inductive thematic analysis was used for data analysis

**Results:** The study included a total of 11 participants (six females and five males) from different phases of Bell's palsy. Because of the inductive thematic analysis, the experiences of patients with Bell's palsy were categorised into six main themes: "First Confrontation with Bell's Palsy," "Treatment and Self-Management Experiences," "Physical Challenges Experienced," "Psychological Effects," "Social Effects," and "Impact of Bell's Palsy on Today"

**Conclusion:** Bell's palsy is understood to be a traumatic experience that affects the physiological, psychological, and social aspects of patients' lives, thereby significantly impacting their quality of life. Although patients receive medical treatment for Bell's palsy, they often face the physiological and psychological challenges alone. Therefore, treatment should not be solely prescription-based; it must address the physiological, psychological, and social challenges through an interdisciplinary approach, including the involvement of nurses.

### Keywords

Bell's Palsy • Experiences • Nursing Care • Qualitative • Quality of Life



“ Citation: Özkan İ, Kar M, Taylan S. Exploring the Life Experiences of Bell's Palsy Patients: A Qualitative Study The Turkish Journal of Ear Nose and Throat 2025;35(2):95-102. <https://doi.org/10.26650/Tr-ENT.2025.1539120>

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## INTRODUCTION

Bell's palsy (BP) is the most common type of peripheral facial paralysis, characterised by its sudden onset and unknown cause, leading to significant psychological distress and social disability among patients (1). Epidemiological evidence indicates that 15 to 23 individuals per 100,000 are affected annually, with a recurrence rate of 12% (2). This condition can severely impact patients' quality of life.

The clinical symptoms of BP vary based on the location of the lesion on the facial nerve and include cosmetic deformities, difficulties with swallowing, eating, speaking, incomplete eyelid closure, constant tearing, pain, synkinesis (involuntary muscle movements), muscle atrophy, loss of taste, and hearing (2-4). Reduced facial movements and noticeable facial asymmetry can result in interpersonal communication dysfunction, psychological distress, depression, and social isolation (5-7). These symptoms can negatively affect daily activities and the overall quality of life.

The sudden onset and unknown cause of BP can lead to high levels of psychological distress (8, 9). Anxiety and depression rates in patients with facial paralysis range from 11% to 64% in the literature (6, 8, 10). Studies involving patients with facial paralysis, including those with BP, report frequent experiences of shame, anger, depression, sadness, significant psychological distress, and social disability due to changes in their appearance following diagnosis (6, 8, 11). These emotional and social challenges can severely reduce patients' quality of life.

The management of BP primarily involves medical treatment (steroids and antiviral medications, alone or in combination) prescribed by physicians to improve facial function and expedite recovery (12, 13). However, psychological care is often overlooked in BP treatment, which can adversely affect patients' quality of life (9, 14, 15). Effective management of BP should involve an interdisciplinary approach, including an otolaryngologist, nurse, neurophysiologist, physiotherapist, speech therapist, psychologist, and plastic surgeon.

Nurses play a critical role in providing holistic care for patients with BP, addressing both their physical and psychological needs. They are uniquely positioned to support patients through education, symptom management, and emotional support. Nurses can provide guidance on managing daily activities impacted by BP, such as eating, eye care, and speech difficulties, thereby reducing the risk of complications like corneal damage from incomplete eyelid closure. Additionally, nurses can serve as a bridge between patients and other specialists, ensuring timely referrals to psychological or rehabilitative care when needed (16-18).

Psychological support provided by nurses can help patients navigate feelings of shame, anger, and anxiety, offering counselling or resources for coping strategies. This aspect is crucial, as the literature highlights the persistence of emotional distress in BP patients, even after physical recovery (6, 8, 10). By incorporating regular mental health assessments and psychoeducation into care plans, nurses can improve patients' quality of life.

Healthcare professionals should recognise that although a 71% improvement in facial nerve function can be seen in patients with BP, those who are not adequately supported during this process continue to experience psychological and social problems (4, 6, 8, 10). The literature reveals a lack of studies focusing on the challenges faced by BP patients. This study aimed to investigate the experiences of BP patients through a qualitative approach to better understand the impact on their quality of life.

## MATERIAL AND METHODS

### Study design

This study was conducted as a qualitative study with a hermeneutic phenomenological framework. Heidegger's hermeneutical phenomenology deals with the human experience as it unfolds. The importance of understanding rather than definition transforms hermeneutics into a research method based on the ontological view of lived experience as an interpretive process (19, 20). Hermeneutic phenomenology also provides a framework for understanding and transforming lived experience into a recognisable meaning that can be used as a knowledge base in clinical practice (21).

### Setting and sample

The participants were selected from patients undergoing follow-up for peripheral nerve paralysis in the Ear-Nose-Throat and Physical Therapy clinics of a state hospital in Turkey. The study included patients who received both inpatient and outpatient treatment, with their status determined on the basis of the severity and stage of BP. Specifically:

- Patients requiring immediate medical intervention or presenting with severe complications, such as incomplete eyelid closure or synkinesis, were hospitalised for short-term inpatient care.
- Others, primarily those in the recovery phase or with mild symptoms, received outpatient treatment and attended scheduled follow-ups and physiotherapy sessions.

**Table 1.** Semi-structured interview questions

<ul style="list-style-type: none"> <li>• Tell me about your experience with bell palsy.</li> <li>• What did you feel and do when you first realised that you were experiencing facial paralysis?</li> <li>• Tell me about your experiences with the treatment process.</li> <li>• How did Bell's palsy affect your physiological, psychological, and social status?</li> <li>• How did you manage this process?</li> <li>• How is the Bell's palsy you experienced affecting your life today?</li> </ul>
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A convenience sampling method was used for the study participants. After identifying the list of patients treated or being treated with the diagnosis of BP (n=35), the participants were contacted via phone and informed about the study. Those who agreed to participate were given an appointment for an interview. The exclusion criteria of the study were determined as having a congenital facial deformity or having a psychiatric diagnosis. Fifteen of the participants agreed to participate in the study. However, one of them was excluded from the study because of the diagnosis of major depression, and the other three were excluded because they did not attend the interview on the specified date. Three participants stated that they gave up participating in the study when they were called again by phone. The study sample included 11 participants over the age of 18 at different stages of BP (flaccid, healing, and continuing).

### Data collection

The data for the study were collected between November 2019 and January 2020 through the Demographic Information Form, House-Brackmann Scoring, and Semi-structured Interview Form (Table 1). The Demographic Information Form included questions on age, gender, level of education, marital status, occupation, and diagnostic duration of BP. The House-Brackmann scoring system, as the most frequently used instrument, was used to assess patients' facial nerve function. The BP stages of the participants were determined using the House-Brackmann scoring system. Participants were invited to a quiet room to ensure privacy and reliable responses during data collection. The interviews were audio recorded with the participants' consent and transcribed verbatim. An average of 40 minutes of interviews was conducted until data saturation was reached, that is, when the discourse did not offer a new direction and when there were no new questions to understand the phenomenon (22).

### Data analysis

Inductive thematic analysis was used to analyse and interpret our data to provide a detailed and complex description

of the BP patients' experiences. Without technological manipulations or a pre-existing theoretical perspective, inductive analysis is the process of coding data without trying to fit into a pre-existing coding framework or the analytical bias of the researcher. In this sense, this form of thematic analysis is data-driven (23). Transcriptions and field notes were read by each research team member and then re-read, and the information was then coded to differentiate the categories identified. To refine the data, any relationships between them were established to obtain potential themes. These were then interpreted with a focus on the usefulness of the findings in clinical practice (24). All authors discussed the final analysis proposal for understanding and accuracy.

### Rigour of the study

The researchers independently evaluated the data to ensure the reliability of the study. For data encoded by more than one encoder, the reliability between the encoders should be calculated. Therefore, Cohen's Kappa coefficient was calculated to evaluate the compatibility between the data encoders. In this study, the agreement rate was found to be 0.73, indicating a good level of compatibility between the researchers (25).

Additionally, the first researcher (İ.Ö) has clinical experience as a neurology nurse, while the second researcher (M.K) is an otolaryngologist and therefore has clinical experience with patients.

### Ethical consideration

The ethics board approval for the study was obtained from the Akdeniz University Clinical Research Ethics Board (Date: 08.01.2020, No: KAEK-39). Participants' written and oral consent was obtained after informing them.

### RESULTS

This qualitative study was conducted with six female and five male participants who had BP. The sociodemographic information and BP data for the participants are presented in Table 2.

The data analysis of patients' experiences of BP revealed six primary themes.

#### Theme 1: First confrontation with Bell's Palsy

All the participants reported that they would never forget the moment they noticed the change in their faces and that their lives changed from that moment on. More than half of the participants said they felt terrified and terrified when they first saw themselves in the mirror.

*"I saw the panic on my spouse's face when we woke up in the morning; she said: 'your face'. I ran to the mirror. I will never forget the 'me' I saw in the mirror. Most of the right side of my face was drooping. It didn't look like it belonged to me. I couldn't speak or blink. I was horrified. I really wanted it to be a bad dream. We immediately rushed to the hospital." (P3; female)*

Some of the participants reported that they could not understand the change in their faces, as they had never experienced it before, and continued their daily tasks in dismay until others warned them. This was because they were not aware of a condition called BP.

*"I was working at a bakery and felt something weird." I went to the bathroom and looked in the mirror. My mouth and face were weird. I washed my hands and face in surprise and thought it was exhaustion. I went back inside and continued to bake bread, until my friend warned me..." (P9, male)*

## Theme 2: Treatment and self-management experiences of Bell's Palsy

Almost all of the participants reported receiving steroid treatment, and three of them mentioned experiencing the severe side effects of steroid treatment. Some participants believed that it was too late for their treatment and that there were problems with the health system.

*"I was feeling exhausted while receiving steroid treatment; it was like I was run over by a truck." (P5; female)*

Half of the participants reported that they had received physiotherapy and that it had been beneficial to them. The majority of the participants stated that they needed psychological support. In particular, the female participants

experienced more anxiety and fear due to their appearance. However, no one reported receiving psychological support.

*"Not being able to close my eyes, the drooping of my mouth, and the lisping of my speech made me feel real, but bad. I am now wondering why I did not receive any psychological support during that time." (P4; female)*

Two participants mentioned that they used healing waters and acupuncture in addition to their medical treatment. Six participants said they went to a hodja; four of them believed that BP occurred due to the evil eye, and two believed it was because of their sins. All the patients reported that they prayed more after being diagnosed with BP, performing Salaat, which made them feel more comfortable.

*"I performed Salaat and prayed to Allah every day for two months. I could only bear this situation because of this." (P3; female)*

Almost all of the participants indicated that they were informed that BP is temporary and that steroid treatment would expedite the treatment process; however, they were not sufficiently informed on how to manage the symptoms they experienced. As a result, they felt alone and had to learn to cope through personal experience.

*"They said I will be okay; steroids would help. However, no one explained how to eat. I found a way on my own. I had my soup with a straw. While eating, I was leaning on the strong side and swallowing that way." (P10; male)*

## Theme 3: Physical challenges experienced

In addition to the change in facial appearance, all participants reported experiencing various physical challenges due to the loss of function. All participants described having bites drop

Table 2. Characteristics of the participants

Participation	Age	Gender	Education	Occupation	Marital Status	The time of diagnosis of bell paralysis	Bell's palsy phase
P1	39	Female	High School	Housewife	Married	20 day	Flaccid
P2	35	Female	Primary school	Housewife	Married	30 day	Flaccid
P3	50	Female	Primary school	Farmer	Married	2 year	Recovery
P4	38	Female	University	Dentist	Single	2 year	Recovery
P5	43	Female	Primary school	Farmer	Married	1 year	Sequale
P6	33	Female	University	Teacher	Married	3 year	Sequale
P7	32	Male	Primary school	Farmer	Married	50 day	Flaccid
P8	58	Male	Primary school	Retired	Married	65 day	Flaccid
P9	25	Male	High School	Baker	Single	2.5 year	Sequale
P10	35	Male	Primary school	Farmer	Married	4 year	Sequale
P11	56	Male	High school	Retired	Married	3 year	Recovery

from their mouths while eating; half reported problems with taste, incomplete eyelid closure, eye watering, and speech problems. Two participants reported experiencing severe ear pain, while two others had synkinesia during that period. All participants expressed feeling more tired than usual during that time.

*"I struggled to eat and had difficulty eating. I remember biting my cheek on the affected side many times." (P2; female)*

#### Theme 4: Psychological effects

Participants reported that their psychologies were negatively affected due to the sudden change in their facial appearance despite being told to fully recover. All participants said they felt rage, sadness, disappointment, shame, guilt, and anxiety from time to time, and these emotions can be mixed up. Their most intense feeling was guilt, and they interpreted it as a punishment given to them by God.

*"I couldn't eat or drink anything without spilling. I was feeling ashamed and humiliated. I couldn't bear them seeing me like this and had rage attacks without any reason." (P10; male)*

More than half of the participants expressed that they experienced a decrease in their self-respect after BP. Some female participants felt like a freak. Male participants, on the other hand, did not feel as strong as before. They were incompetent in the roles assigned by the society.

*"I didn't feel beautiful at all. I was constantly worried about whether my husband would leave me." (P6; female)*

#### Theme 5: Social effects

All participants said they felt very uncomfortable with the changes on their faces, and they felt the need to hide themselves. They covered their faces with scarves, sunglasses, hair, and beards when they had to go out.

*"At first, I didn't tell anyone that I had Bell's palsy except my family." (P1; female)*

All participants reported that they initially avoided going out, talking to people, eating in front of others, and returning to work. Participants with sequelae continued to isolate themselves.

*"I couldn't go out for fifty days because of my face and speech. I only went to the hospital. The number of people I saw was not more than ten." (P7, male)*

#### Theme 6: Impact of Bell's Palsy on today

Most participants reported that the effects of BP still affect their lives today. Some participants said that they felt that the changes in their faces were continuing, even though they had recovered.

*"Although I recovered, I still cannot smile comfortably, my hand goes to cover my mouth." (P4; female)*

The majority of participants reported that they worried about experiencing BP again, and two participants reported that this worry became an obsession. A few participants used the metaphor of waking up from a bad dream.

*"You know when you wake up from a bad dream and you feel the effect all day, worry that something bad will happen. Bell's palsy is like that, the worry of it repeating is always there" (P4, female)*

All the participants expressed that they had never heard of BP until it happened to them; that they were exposed to different reactions because people were not aware of it either; or that this was very destructive for them.

*"I had to quit work. When I went to a new job interview, the appearance of my face disturbed the others. I told them that I had Bell's palsy, but they didn't understand. In the end, I couldn't get that job. I want to raise awareness on Bell's palsy and explain to everyone that it is not a stroke or mental deficiency." (P9; male)*

## DISCUSSION

This study is one of the first qualitative studies conducted with a group of people with BP. Therefore, it is believed that the findings will make an important contribution to the literature and raise awareness among health professionals regarding the need for holistic care for people with BP. All participants expressed that they would never forget the moment they realised that they were experiencing facial paralysis and that their lives would never be the same. More than half of the patients said they felt horrified when they saw their faces, thinking that they were having a stroke, and went to the hospital in a panic. A study conducted in Singapore with 41 BP patients also found that 76% of the patients reported thinking that they had a stroke (14). Some participants reported not realising what happened and continued their daily routines until someone warned them. BP not being well-known by the public and the low rate of being seen can be the reasons for participants' lack of awareness, not understanding the situation, and their dismay.

Some participants stated that they received acupuncture treatment, used healing waters, and went to hodja in addition to their medical treatment. A study found that almost half of the patients with BP also tried some kind of complementary treatment (vitamin supplements, traditional Chinese medicine, acupuncture, traditional massage, health supplements) in addition to their prescribed medical treatment. The same study highlighted that traditional



Chinese medications can interact with steroids and cause Addison's attack (14). Thus, it is important in BP treatment to provide sufficient information to the patient, eliminate their suspicions, and question the complementary treatments they use.

Participants from this study reported that they had been informed that steroid treatment would improve BP but were not explained how to deal with the symptoms and they felt alone during this process. With BP, patients unexpectedly experience problems with eating, drinking, and blinking functions, and this causes both psychological and physiological destruction for them (6, 7, 26). During this acute phase, nursing care is as important as the prescribed medical treatment. Managing the physical and psychological symptoms due to facial nerve dysfunction should be a priority for nursing care services. Patients should be especially supported and monitored for diet and nutrition, as well as mouth and eye care, to prevent potential complications (27, 28).

All participants said they experienced rage, sadness, disappointment, shame, guilt, anxiety, and low self-confidence following the BP diagnosis. Only two qualitative studies were found in the literature, which were conducted with peripheral facial paralysis patients including BP. Similar to this study, both studies indicated that patients experienced shame due to problems in eating and drinking and felt uncomfortable and angry when people asked questions about their faces (7, 26). Descriptive and analytical studies indicate that psychological wellness affects facial paralysis patients and revealed that their depression and anxiety rates vary between 11.4 and 60% (5, 6, 8-10). In the study, even the fully recovered patients described that they do not feel psychologically well as they fear having facial paralysis again. This shows how traumatic the BP experience is. Participants mentioned that the impact of BP continues, and especially the female participants who recovered intensely experienced the fear of the disease repeating itself, and they obsessively protected themselves from wind and cold. In particular, women experience more intense psychological distress due to the social pressure of beauty for them (6, 15, 29). The findings of this study and other studies remind us that BP can cause post-traumatic stress in women (6, 10, 30). It is crucial to implement an anxiety or depression scale by a doctor or nurse to determine patients in the risk group and help them access psychological support.

All participants from the study stated that, during the initial period of BP, they did not inform others of their condition. They hid themselves, avoided talking to people, refrained from eating in front of others, and returned to work only

when it was absolutely necessary. Some participants with sequel still avoided taking photos and meeting new people. In a study conducted with a total of sixteen BP participants, it was determined that with more frequency in those at the sequel stage, all patients experience social obstacles such as isolation, avoidance behaviours, occupational challenges, and marital problems (26). Other studies state that facial expressions or dysfunctions in pronunciation can cause problems in social interactions and stigmatisation. These issues may result in stigmatised individuals hiding, exhibiting phobic avoidance, and isolating themselves from society (15, 30, 31). Thus, it is important to consider the psycho-social factors to maximise patient care in BP cases.

Participants expressed being exposed to impolite behaviour from time to time as people are not informed about BP and they felt anger and sadness in response to such behaviours. Thus, they want to create an overall awareness, they did not also know about BP until it occurred, and health professionals should create more awareness on BP, especially in risk groups. The relevant studies indicate a low awareness of BP (7, 14). As reported by the participants as well, health professionals creating awareness through the media can reduce the psycho-social problems experienced by the patients.

This study highlights the profound psychological impact of BP on patients, emphasising the necessity of integrating psychological support within an interdisciplinary approach to care. The findings show that participants experienced significant emotional distress, including anxiety, depression, and low self-confidence, which persisted even after physical recovery (8-12). These challenges underscore the need for healthcare professionals to proactively address psychological wellness alongside physical treatment. Incorporating routine mental health screenings and offering counselling services as part of the standard care plan could help mitigate the long-term emotional effects of BP. Moreover, psychoeducation programs focusing on resilience and coping strategies could empower patients to better manage their experiences. Such measures, combined with the contributions of psychologists, counsellors, and other mental health professionals, would ensure a holistic approach to care that addresses the interconnected physical, psychological, and social dimensions of BP. This aligns with previous research that highlights the importance of psychological support in enhancing overall recovery and quality of life (10,11,15).

### Strengths and limitations

While qualitative studies inherently have limitations in terms of generalizability, this research provides valuable subjective data that can guide healthcare professionals in the holistic



management of BP. One notable limitation of the study is that it was conducted in a single centre, with participants from a homogeneous cultural background. Expanding the diversity of the participant pool in future research could improve the applicability of the findings across different cultural and geographical contexts. Conducting similar studies in diverse cultural settings is recommended to enhance the understanding of BP experiences globally and to validate these findings in a broader population.

## CONCLUSION

In conclusion, this study provides a comprehensive exploration of the lived experiences of patients with BP, highlighting its profound impact on the physiological, psychological, and social dimensions of their lives. BP emerges as a traumatic condition, with patients often feeling isolated while managing the complex challenges of facial nerve dysfunction, despite receiving medical treatment. Female patients, in particular, reported heightened fear and anxiety about the recurrence of facial paralysis, which in some cases has led to obsessive behaviours aimed at prevention. These findings emphasise the critical need for a holistic and interdisciplinary approach to patient care, integrating psychological support and addressing the interconnected aspects of recovery. Interventions such as routine mental health screenings, psychoeducation, and tailored support programs can play a pivotal role in reducing patients' emotional distress and improving their overall quality of life. This study not only contributes to addressing a gap in the literature but also provides actionable insights for healthcare professionals to enhance patient satisfaction and deliver comprehensive care to individuals affected by BP.



<b>Ethics Committee Approval:</b>	This study was approved by the Akdeniz University (Date: 08.01.2020, No: KAEK-39).
<b>Peer Review:</b>	Externally peer-reviewed.
<b>Author Contributions:</b>	Conception/Design of Study- İ.Ö.; Data Acquisition- İ.Ö., M.K.; Data Analysis/Interpretation- İ.Ö., S.T.; Drafting Manuscript- İ.Ö., M.K., S.T.; Critical Revision of Manuscript- İ.Ö., M.K., S.T.; Final Approval and Accountability - İ.Ö., M.K., S.T.; Technical Support- İ.Ö., M.K.; Supervision- İ.Ö., S.T.
<b>Conflict of Interest:</b>	The authors have no conflict of interest to declare.
<b>Financial Disclosure:</b>	The authors declared that this study has received no financial support.

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