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Protocol Study

Explaining the Process of Burnout Among Parents of Children with Cerebral Palsy in the Context of Trauma and Psychological Stressors: A Grounded Theory Study Protocol

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Abstract

Introduction: Cerebral palsy (CP) is a lifelong neurodevelopmental condition that poses significant physical, psychological, and social challenges for both the affected child and the family. Caring for a child with CP often exposes parents to chronic stress, emotional exhaustion, and a persistent sense of burden that may lead to parental burnout. Despite growing attention to caregiver stress, the underlying processes and contextual factors contributing to parental burnout, particularly within the context of trauma and prolonged psychological pressure, remain poorly understood. This study aimed to explain the process of burnout among parents of children with cerebral palsy in the context of trauma and psychological stressors.

Methods: This qualitative study used grounded theory. Participants were the primary caregiver parents (mothers and fathers) from two-parent households whose children had a confirmed CP diagnosis for at least one year. Sampling was conducted using purposive and theoretical approaches. Data were collected via in-depth semi-structured interviews with parents and, when theoretically necessary, with members of the healthcare team. Data collection and analysis were conducted concurrently, following Strauss and Corbin's (2015) approach, until theoretical saturation was achieved. Ethical approval was obtained from the Ethics Committee of Birjand University of Medical Sciences, Birjand, Iran.

Results: This study's findings led to the development of a locally and culturally grounded theoretical model explaining the process, stages, and contextual conditions influencing parental burnout among parents of children with CP in Iran. The model clarified the dynamic interactions between trauma, psychological stressors, and long-term caregiving demands, offering a comprehensive understanding of how burnout emerges and changes over time.

Conclusions: These results guide future empirical research and provide a foundation for developing tailored interventions and supportive policies in this context, ultimately enhancing family well-being and strengthening evidence-based care for children with CP.

Key words: Burnout, Cerebral palsy, Grounded theory, Parents

Introduction

Cerebral palsy (CP), recognized as the most common motor disability in childhood, has an estimated prevalence of approximately 2-3 per 1000 live births (1, 2). This condition represents a non-progressive encephalopathy affecting motor development, but its secondary complications often necessitate long-term, complex, and demanding caregiving from parents (3). This caregiving burden extends far beyond ordinary parental responsibilities, exposing parents to significant physical, financial, and psychosocial stressors (4).

The diagnosis of CP often constitutes a shocking and traumatic experience for families, similar to some sources of grief (5, 6). This initial trauma can be compounded by recurrent medical crises and the child's suffering (7, 8), placing parents in an unexpectedly demanding role (9, 10). This constellation of experiences, accompanied by feelings of failure, guilt, and isolation (11), establishes a foundation for the development of chronic psychological stress.

Persistent and chronic psychological stress can ultimately lead to emotional exhaustion, cognitive burnout, and reduced functioning. Research has demonstrated that parents of children with CP experience higher levels of parental burnout, a syndrome of extreme exhaustion arising specifically from the parenting role, which is distinct from professional burnout, depression, or anxiety (12, 13). Empirical evidence suggests that parental burnout is less related to the child's objective medical characteristics, such as the severity of disability or duration of illness, and more associated with parents' subjective perceptions of psychological stress, feelings of helplessness, and the personal meaning they attach to caregiving (14). Since burnout profoundly undermines the parents' health and the quality of the parent-child relationship (15), gaining a deeper understanding of its development is essential for prevention and management (16).

In reviewing qualitative and quantitative studies on burnout, most research has primarily focused either on the consequences of this phenomenon or on the experiences of patients and their parents (3, 14, 15, 17-21) However, a significant theoretical gap persists: the literature lacks an integrated, process-oriented model that explains how parents' chronic psychological stress and traumatic experiences interact, accumulate, and progressively transform into the distinct syndrome of burnout over time. The dynamic 'process' itself, including the potential stages, turning points, and underlying psychosocial mechanisms that facilitate or hinder this progression, has not yet been systematically conceptualized.

To address this theoretical gap, a methodology capable of generating a theory about a process is required. Since parental burnout is a complex, dynamic, and multifaceted phenomenon, grounded theory (GT) is well-suited to this task. We utilized Corbin and Strauss's (2015) approach, which is particularly effective for examining phenomena within specific structural and social contexts. This study is situated within the Iranian sociocultural landscape, characterized by strong family-centric values and traditional expectations of maternal caregiving. Specifically, the research was conducted in South Khorasan province, a less developed region in eastern Iran with limited access to specialized rehabilitation services compared to metropolitan areas. Consequently, the study population is expected to comprise families from both urban and deprived rural areas who often endure significant logistical and financial burdens to access care. This intersection of cultural pressures and regional resource scarcity provides a unique environment for examining the intensification of parental burnout.

Therefore, the study explored how burnout develops among parents of children with CP facing trauma and psychological stressors. It generates a GT to capture this complex process.

Methods

Study Design

This study was a qualitative research with a GT approach, categorized as a basic–applied type of inquiry, designed to explain the process of burnout among parents of children with CP within the context of trauma and psychological stress. GT enabled researchers to deeply explore and theorize process-oriented phenomena that are influenced by cultural factors, interpersonal interactions, and organizational or social experiences. The main objective of the GT method is to identify and understand the basic social processes that explain how individuals interact, interpret, and act within specific contexts. Considering the aim of this study to develop a paradigmatic model applicable to family mental health policymaking, GT provides the most appropriate methodological pathway to construct a credible and contextually relevant model (22, 23).

Given that burnout is a complex, developmental, dynamic, and multidimensional phenomenon influenced by various factors, including individual, economic, social, and cultural determinants and considering the lack of sufficient information regarding the process of burnout among parents of children with CP, as well as the absence of a specific theory in this area, the GT approach is deemed appropriate for the present study. Its unique capacity to capture the meaning of burnout from the lived experiences of those directly involved, and thereby to reduce burnout in such families, makes it particularly suitable for this study. This study employed the Corbin and Strauss (2015) version of GT, which, through its systematic guidelines for data analysis, enables the development of a context-specific paradigmatic model grounded in the Iranian sociocultural setting.

Participants

The participants in this study included parents of children with CP. This group was selected due to their direct lived experience of the disease process, treatment, caregiving, and its psychosocial consequences. To enhance data diversity and enrich the emerging theory, and if necessary, based on the theoretical sampling process, members of the treatment team, such as physicians, nurses involved in pediatric care, psychologists, physiotherapists, occupational therapists, speech therapists, and social workers, may also participate in the study.

Sampling was conducted in two stages. In the first stage, purposeful, judgment-based sampling was employed to select participants who could provide in-depth experiences and were qualified in the context of burnout, thereby facilitating theoretical sampling. Subsequently, theoretical sampling, which was the dominant sampling method throughout the study, was applied. In this approach, sample selection was purposeful and sequential, guided by emerging concepts from the data. Accordingly, subsequent participants were selected based on the specific information required after the initial findings. In other words, the selection of future participants depended on those previously chosen and the information provided. In this study, sampling continued until data saturation was reached, indicating that the researcher concluded that the primary categories had been adequately developed regarding depth and diversity, and the connections between categories had been clarified. Additionally, when direct identification of participants was difficult, the snowball sampling method was employed to identify suitable individuals.

In the present study, efforts were made to carefully select the first participant using purposeful sampling, through consultation with the rehabilitation team and the researcher's preliminary assessments. The chosen participants were expected to possess a rich experience of the phenomenon under study and the ability to articulate it effectively. Conducting interviews and analyzing the data simultaneously guided the selection of subsequent participants. Furthermore, by including participants with diverse characteristics and considering variations in educational level, the severity and rehabilitation status of the child, and the child's age and gender, the study sought to ensure maximum diversity among participants.

Participants were recruited based on the following criteria: they were required to be the mother or father of a child diagnosed with CP who was living with them. The child's diagnosis had to be confirmed at least one year prior to participation, allowing for the development of chronic caregiving stress. Moreover, participants needed to demonstrate the willingness and ability to participate in in-depth interviews and communicate effectively in Persian. Participants who did not provide consent were excluded from the study.

Data Collection Tools

The primary data collection method in this study was in-depth semi-structured interviews. This approach, a central method in qualitative research and particularly in GT, allows researchers to explore participants' subjective experiences, meanings, and internal processes (22, 24). To ensure participants feel comfortable and can speak freely, interviews were conducted in a private and quiet setting chosen by the participants. The locations included the participants' homes, private rooms in rehabilitation centers, or hospitals, ensuring confidentiality and minimizing distractions. Most participants were expected to participate in a single in-depth interview session. However, to clarify ambiguities or further explore emerging theoretical concepts, follow-up interviews (second sessions) were conducted with selected participants. The duration of each interview ranged from 45 to 90 minutes, with an average of approximately 60 minutes, depending on the participant's condition and willingness to continue. At the beginning of each interview, the purpose was explained, and permission was obtained to audio-record the session. If participants did not consent to recording, key points were noted and later verified. Participants were assured of the confidentiality of their information and recordings, enabling them to share their experiences and perspectives more openly.

Each session began with a broad, open-ended question (e.g., "Please tell me about your overall experience of caring for your child and how this process has affected your life"). Subsequently, questions were gradually guided by emerging concepts and the need to deepen understanding of main categories, such as psychological stress and burnout. Examples of such questions include: "What have been the most significant sources of worry and stress for you over the years?" "How has this long-term caregiving experience affected your relationship with your child or others?", and "What strategies do you use when you feel tired or discouraged?"

Based on participants' responses, various probing techniques were employed to explore further and deepen their experiences. For instance, prompts such as: "Could you elaborate further?" or "Can you give an example?" or "What do you mean by that?" may be used, as well as follow-up questions, such as: "Earlier, you mentioned …, could you explain this a bit more?" As the study progressed and the research objectives were achieved, further specific questions were posed.

In the interviews, questions were based on the themes and categories emerging from previous interviews. During the interviews, the researcher observed participants' non-verbal behaviors and recorded them as field notes. In this study, observation was also used as a supplementary data collection method; the researcher observed interactions among parents, their child, therapists, and others, and documented their verbal, non-verbal, and emotional behaviors in field notes.

The researcher's reflections and interpretations were recorded as memos during data analysis. These memos helped the researcher describe concepts, identify relationships among them, understand what was present in the data, and interpret findings. Additionally, the memos assisted the researcher in determining which questions to ask, where to seek further data, and how to refine and complete data collection for subsequent interviews (22). At the time of writing this protocol, 14 participants were recruited, and data collection was ongoing. Approximately 20-30 participants were selected through purposeful sampling, followed by theoretical sampling. The interview process continued until theoretical saturation was achieved, and the final sample size was determined based on this criterion (25).

Statistical Analysis

The methodological approach of Corbin and Strauss (2015) was used to analyze data concurrently with data collection. This GT analysis seeks to understand the hidden social processes and to build a theoretical framework, in contrast to traditional content analysis, which primarily focuses on descriptive categorization. The three overlapping steps of the analysis were conducted in MAXQDA software (version 2020). Open Coding (Concept Analysis): Line-by-line coding of verbatim transcripts is the first step in the analysis. To find underlying concepts, the data were broken down into distinct sections rather than just labeling text. By determining each concept's dimensions (variations throughout a continuum) and qualities (characteristics), it was further developed. Lower-level categories were created from concepts that share comparable traits. Axial Coding (Process and Context Analysis): This phase distinguishes the study from content analysis. Here, we reassembled the data to establish relationships between categories. We utilized the 'Coding Paradigm' to identify:

- Conditions: The structural and contextual factors causing or influencing the phenomenon.
- Actions/Interactions: How parents respond to these conditions (strategies and emotional responses).
- Consequences: Outcomes of these actions. Furthermore, we specifically analyze the 'Process,' examining how parents' experiences and burnout trajectories evolve over.
- Integration (Refining the Theory): The final phase involves selective coding to identify a 'Core Category,' a central, abstract concept that integrates all other categories and represents the research's central theme. The relationship between the core category and other categories is validated against the data to ensure the resulting theory has logical consistency and explanatory power.

Throughout these stages, constant comparative analysis was applied, comparing data with data, codes with codes, and categories with categories. Additionally, integrative memos were written extensively, not just to record ideas, but as a primary analytical tool to develop theoretical insights and guide theoretical sampling until theoretical saturation was achieved.

Theory Development

The purpose of this study was not limited to describing parents' experiences; instead, it sought to achieve a deeper understanding and to propose a theoretical model explaining how burnout develops and progresses within the context of traumatic experiences and psychological stressors. After identifying the main categories, the final phase of analysis integration was conducted to construct the theoretical model.

In identifying the core category, the central phenomenon around which all other categories are organized, we do not rely solely on code frequency. Instead, we seek a concept with substantial explanatory power that appears across different parts of the data in various forms and logically connects the remaining categories. To achieve such coherence, we draw on two analytic strategies proposed by Corbin and Strauss:

Developing the storyline: At this stage, the researcher composes a coherent narrative that reflects the central problem parents face and how they respond to it. Crafting this storyline helps the main idea gradually emerge, clarifies ambiguous aspects of the analysis, and ensures that the core category genuinely arises from participants' accounts rather than from the researcher's assumptions (26).

Using integrative diagrams: In parallel, visual diagrams were created to illustrate the relationships between the core category and other components of the paradigm model, including causal and contextual conditions, actions and interactions, and consequences. These diagrams function as tools for testing the internal coherence and structural integrity of the emerging model. Once the initial version of the model was developed, the researcher returned to the raw data and conducted a more advanced comparative analysis to evaluate the model's fit and relevance. This step ensures that the resulting theory is not imposed on the data but is truly grounded in it, while also accounting for variations in parental experiences, for instance, explaining why some parents progress more quickly toward burnout than others.

Rigor and Trustworthiness

To ensure the study's trustworthiness and scientific rigor, the eight validation strategies proposed by Corbin and Strauss (2015) were employed throughout the research process (22). These strategies are tailored to the specific context of parents caring for children with CP experiencing burnout:

Prolonged Engagement and Persistent Observation: The researchers immersed themselves in participants' homes, clinics, and rehabilitation centers. Because of the sensitive nature of trauma and psychological pressures, this extended interaction helped promote the development of trust and a close relationship with parents. Using this method, the researcher could distinguish between temporary stressors and long-term parental burnout and develop a thorough grasp of the underlying culture of parenting.

Triangulation: To enhance the credibility of the findings, data triangulation was employed. Information was gathered from multiple sources, including in-depth interviews with mothers and fathers, field notes, and observations of parent–child interactions. Using this diverse range of data sources enabled the research team to examine and verify emerging concepts of parental burnout from multiple angles, thereby producing a more comprehensive understanding of parents' lived experiences.

Peer Review and Debriefing: The study team and supervisors participated in regular debriefing sessions. During these sessions, the coding procedure was reviewed, new categories were discussed, and the researcher's interpretations were rigorously questioned. Peer review helped ensure that the findings were based on the data rather than the researcher's assumption.

Negative Case Analysis: The research team actively sought out "negative cases" or disconfirming evidence. For instance, the study examined parents of children with severe CP who did not report high levels of burnout or trauma. Examining these discrepant experiences helped refine the emerging theory, adjust conceptual boundaries, and ensure that the final model reflected the full complexity and variation within parents' experiences.

Clarifying Researcher Bias (Reflexivity): Given the subjective nature of qualitative research, the researcher engages in reflexivity by maintaining a reflective journal. This involves bracketing personal assumptions, prior clinical experiences with CP, and emotional responses to the parents' traumatic narratives to prevent them from contaminating the data analysis.

Member Checks: Member checks were conducted to establish credibility. A subset of participants received a summary of the results, emergent themes, and the final theoretical model. They were asked to confirm whether the interpretations accurately represented their actual experiences with psychological stress and burnout.

Rich, Thick Description: This study sought to provide a thorough and vivid account of the participants' backgrounds, the severity of the children's illness, and the specific psychological pressures at play. This "thick description" enables readers to determine how applicable the results are to other similar situations or caregiver populations.

External Audits: The research process was reviewed by an external auditor, a qualitative researcher who was not involved in the study. To assess accuracy and determine whether the data support the findings and interpretations, this audit examined the "audit trail," which included raw data, coding schemas, and process notes.

Ethical Consideration

This study was conducted with strict adherence to the ethical principles of the Declaration of Helsinki (2024 revised version) (27). Ethical approval was obtained from the Ethics Committee of Birjand University of Medical Sciences, Birjand, Iran (IR.BUMS.REC.1402.309).

Prior to data collection, necessary administrative permissions were secured from the relevant healthcare and educational centers, and written informed consent was obtained from all participants.

The purpose of the study and the procedures for safeguarding participants' information were clearly explained, and written informed consent was obtained from all individuals who agreed to participate. Participation was entirely voluntary, and participants could withdraw from the study at any time without consequences or restrictions. To protect confidentiality, all identifying details were removed from the transcripts, and audio recordings were securely stored and deleted once the analysis was complete. Given the sensitive nature of the topics addressed in the interviews, particularly those related to burnout, appropriate support was provided to any participant who experienced emotional discomfort or distress during the process.

Discussion

This study protocol aimed to generate a GT that explains how burnout develops and progresses among parents of children with CP. The model expected to emerge is intended not merely to describe experiences, but to capture the dynamic transitions through which everyday stress gradually intensifies into emotional exhaustion. As the analysis unfolds, it is anticipated that specific vulnerable periods, such as the phase surrounding diagnosis or major developmental transitions, become more clearly identifiable. Recognizing these moments may help clinicians offer timely, preventive psychological support that aligns with parents' evolving needs.

The findings are also expected to contribute to the professional development of nurses, occupational therapists, and rehabilitation staff by providing a conceptual framework for identifying early behavioral and emotional signals of parental strain. Such insight may support a shift from a predominantly child-focused approach toward a more comprehensive family-centered model of care, enabling practitioners to incorporate structured assessments and timely referrals for parents.

At the policy level, the theory developed in this study may provide evidence to support the integration of routine parental mental health screening into rehabilitation protocols. By highlighting the culturally specific and socio-economic pressures that families in Iran face, the resulting model may guide policymakers in allocating resources more effectively and reducing the long-term burden on the healthcare system.

Although this study aimed to provide a nuanced understanding of parental burnout, several limitations should be acknowledged. First, in GT research, identifying the exact point at which theoretical saturation is reached is inherently challenging and often relies on the researcher's judgment. To address this, data collection and analysis proceeded in parallel, and the cycle continued until no new properties or dimensions emerged within the emerging categories.

Another limitation stems from the interpretive nature of GT coding. Because the researcher's perspective inevitably influences the analytic process, bias cannot be eliminated. To enhance transparency and accuracy, the research team engages in ongoing reflexive note-taking and document analytic decisions. Peer feedback was sought to ensure that the coding structure remained consistent and credible.

Another concern was the study's sensitivity to the topic. Discussing experiences of trauma and burnout could evoke emotional distress for parents of children with CP. Therefore, protecting participants' well-being was a priority throughout the research. When needed, participants were offered a referral to appropriate psychological support services.

Additionally, the stigma associated with parental burnout may create a tendency toward socially desirable responding. Some parents may feel reluctant to openly share difficulties, such as reduced patience or lapses in caregiving, especially if they fear judgment. To lessen this risk, the researcher invested time in establishing trust, assured participants of strict confidentiality, and created a supportive environment where honest and open reflection felt safe.

Conclusions

This study protocol addresses a critical gap in understanding parental burnout among families of children with CP. By applying a GT approach, the study is expected to generate a conceptual model that captures the complex experiences of parents, their contextual challenges, and the psychological and social consequences of caregiving. The insights gained from this research provide a foundation for developing tailored interventions, informing supportive policies, and guiding future research in this field. Ultimately, this study aimed to enhance the well-being of families and strengthen the provision of evidence-based care for children with CP.

Ethics Approval and Consent to Participate

Ethical approval was obtained from the Ethics Committee of Birjand University of Medical Sciences, Birjand, Iran (IR.BUMS.REC.1402.309).

Consent for Publication

Not applicable.

Data Availability Statement

As this manuscript presents the study protocol, no datasets have yet been collected or analyzed. The data produced during the study were accessible from the corresponding.

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Authors' Contribution

FM and GM conceived of the research idea. FM, GM, and AN designed the study. FM drafted the manuscript. All authors critically revised the manuscript and approved the final version for submission.

Conflict of interest

All authors declared no conflicts of interest.

Declaration of generative AI in scientific writing

During the preparation of this work, the authors used ChatGPT, an AI-assisted tool, to enhance the manuscript's readability and language. After using this tool, the authors carefully reviewed and edited the content as needed and took full responsibility for the published article.

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