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A Qualitative Study of Caregiving Experiences and Emotional Responses of Family Primary Caregivers of Patients Undergoing Brain Tumour Surgery

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Abstract: *Objective:* To understand the psychological dilemmas, emotional responses and caregiving experiences faced by family primary caregivers of patients undergoing brain tumour surgery in the process of caregiving, to explore problems in caregiving, and to provide a basis for the development of effective caregiving strategies and support measures. *Methods:* A phenomenological research method was used to interview the family primary caregivers of the enrolled 31 patients undergoing brain tumour surgery, and to analyze their emotional coping deficits, disease management experiences and social support needs during the patients' perioperative period and in family caregiving. *Discussion:* The study found that caregivers' caregiving experiences and emotional responses at different stages of patients' illnesses were personal emotional coping deficits, lack of experience in disease management and urgent social support needs. *Conclusion:* Understanding the caregiving experience and emotional responses of family caregivers of patients undergoing brain tumour surgery helps caregivers better identify the psychological dilemmas and needs faced by caregivers during the caregiving process, which in turn helps them develop personalized emotional support, professional knowledge training and skills guidance, and has a positive clinical impact on facilitating the smooth adaptation of the primary caregiver's role change, reducing the burden of caregiving, enhancing caregiving confidence and competence. It has positive clinical application value to promote family primary caregivers to adapt to the role change smoothly, reduce the burden of caregiving, enhance the confidence and ability of caregiving and improve the patients' therapeutic effect and life quality.

Keywords: Brain tumours; Home care; Carers; Caring experience; Phenomenological study

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1. Introduction

The brain tumour is a serious neurological disease, the incidence of which is increasing year by year globally. It not only has a great impact on patient's physical health but also is often accompanied by cognitive, behavioural and neurological dysfunction, which significantly reduces patients' quality of life. Clinical treatment of brain tumour patients mainly relies on surgical protocols, and although they can effectively prolong patients' lives, the pain and complications brought about by the surgical treatment process can easily impose a huge physical and psychological burden on patients and their families [1]. Family primary caregivers are the primary source of support for brain tumour patients during treatment and rehabilitation, not only providing daily life care but also being responsible for the multiple physical and psychological care of the patient. Therefore, as the primary family members of brain tumour patients, especially spouses, parents, or children, they are under unprecedented pressure to not only coordinate the patient's medical treatment, rehabilitation, and daily life, but also often have to deal with complex emotional responses and psychological dilemmas [2]. Many carers report feeling overwhelmed and psychologically burdened by this process, and even experience emotional problems such as anxiety and depression. Currently, clinical research on the caregiving experience and emotional responses of family caregivers of patients undergoing brain tumour surgery is still scarce and lacks an in-depth understanding of the psychological needs of caregivers. Therefore, exploring the experience and emotional responses of family primary caregivers of patients undergoing brain tumour surgery in the process of caregiving is of great significance in improving the patient care model and optimizing the caregiver support system. This study aims to explore the caregiving experiences and emotional responses of family primary caregivers of patients with brain tumour surgery through qualitative research methods, and to reveal the challenges and needs they face in this process, to provide theoretical support and practical guidance for future caregiving practice and policy development.

2. Objects and methods

2.1. Study objects

A purposive sampling method was used to select the primary family caregivers of 31 patients who underwent brain tumour resection at a hospital from January to August 2024 as the study population (only 1 family caregiver was selected for each patient). Inclusion criteria: (1) primary family caregivers (spouses, parents, or children) of patients who underwent brain tumour resection treatment in our hospital between January and August 2024; (2) informed about the purpose and methods of this study and voluntarily participated in this study; (3) with normal language skills and able to clearly express their caregiving experiences; (4) aged between 20 and 51 years old, without serious psychological disorders or history of psychiatric disorders, able to accurately provide relevant information about the patient's treatment and rehabilitation process during the interview. Exclusion criteria: (1) family caregivers with obvious cognitive dysfunction or history of mental illness, unable to complete the interview; (2) those who refused to participate in the study or withdrew halfway; (3) patients who were not diagnosed and treated by our hospital or patients who were not hospitalized in the hospital after surgery; (4) the caregiver failed to provide continuous care for at least two weeks, or the caregiver could not be contacted during the interview.

Among the 31 family primary caregivers of brain tumour surgery patients enrolled, 17 were male and 13 were female. The age distribution was: 20–35 years old (17 people), 36–45 years old (9 people), 46–51 years old (5 people); the education level was: undergraduate and above 10 people, high school 7 people, junior high school 11 people, primary schools 3 people; the relationship with the patient included: spouse 12 people, parents 6 people, children 10 people, siblings 3 people; the daily caring time: > 15h 4 people, 10–14h 13 people, 5–9h for 11 people, < 5h for 3 people; average monthly income distribution: < 2400 yuan for 1 person, 2400–3500 yuan for 8 people, 3500–4200 yuan for 14 people, 4201–4999 yuan for 5 people, and 5000 yuan and above for 3 people; the patients' medical expenses were: 9 cases at public expense, 19 cases of reimbursement by the health insurance, and 3 cases of self-financed treatment.

2.2. Methodology

2.2.1. Research methodology

A phenomenological approach in qualitative research was used to gain an in-depth understanding of the caregiving experiences and emotional responses of family primary carers of patients undergoing brain tumour surgery. The study was conducted through one-on-one interviews with experienced specialist nurses to ensure the validity and authenticity of the data. Before the interview, the purpose, methodology and content of the study were explained in detail to the interviewees, informed consent was obtained from the interviewees, and they were assured of the strict confidentiality of their personal information and research data, and all the data were restricted to be used only in the present study, to ensure the ethical nature of the study and the protection of the participants' privacy. A semi-structured outline was used in the interview process, with the flexibility to dig deeper based on the respondents' answers, to ensure that comprehensive and authentic emotional and experiential feedback was obtained.

2.2.2. Data collection

Interviews were conducted in a quiet, independent room to ensure that interviewees were able to express their feelings in a private, comfortable environment. The study adopted a semi-structured interview outline, with questions flexibly adapted to respondents' specific answers, to dig deeper into their caring experiences and emotional responses, and to ensure the comprehensiveness and authenticity of the data. The interview outline mainly covers the following contents:

(1) What were your initial feelings when you learnt that your relative had been diagnosed with a brain tumour?
(2) What were the emotional and psychological experiences you went through during the surgical decision-making process?
(3) What was the greatest difficulty you faced during the patient's stay?
(4) What is the most difficult problem you have encountered in caring for a patient after discharge from hospital?
(5) Do you have a comprehensive understanding of brain tumours and what aspects of the disease concern you most?
(6) What specific impact do you think brain tumours have had on families and daily life?
(7) Have you been restricted in your socializing and how has this manifested itself?
(8) What do you need the most help with and how would you like to receive support?
(9) Do family members show understanding and support for your caring behaviour?

During the interview, interviewees were encouraged to speak freely and fully express their feelings, thoughts and experiences, but it was important to ensure that the personal privacy of patients and their families was not involved. The interviews were recorded in detail and synchronized with audio recordings to ensure the accuracy of the information. In addition, we pay attention to the interviewees' emotional responses, body language and mood changes to have a more comprehensive understanding of their caregiving experience.

2.2.3. Analysis of information

Data were analyzed using the Colaizzi seven-step method [3]. The audio recordings and field observation notes were transcribed verbatim within 24 hours of the interview and entered into a Word document to form a complete textual profile. The transcription process was double-checked by two people to ensure accuracy. Subsequently, the interviews were synthesized and analyzed by three researchers with experience in phenomenological research, confirming the interviewer's descriptions one by one through cross-discussions, comparing similarities and differences, and suggesting necessary adjustments. To ensure the authenticity of the data, each step in the analysis process is returned to the interviewee for verification. During the analysis process, the researcher distilled and summarized important phrases and sentences, coding and ranking them. Finally, the data was thematically categorized according to these codes, from which themes reflecting the core experiences of carers were extracted.

2.2.4. Quality control

The sample selection in this study took full account of the representativeness of the carers and was based on factors such as age, literacy, relationship with the patient, and financial status to ensure the diversity and coverage of the sample. Interviews were conducted using open-ended questions to encourage interviewees to freely express their emotions and experiences of caring at all stages from a personal perspective. During the research process, the interviewers maintained a neutral stance at all times and avoided leading questions or innuendos to ensure that the interviewees were able to truly reflect their personal experiences and emotional changes. Meanwhile, all interviews were transcribed in detail by the researchers and checked with the interviewees to confirm their accuracy. During the process of data coding and analysis, the research team will review each session several times to ensure the integrity and reliability of the data, thus enhancing the credibility of the research results.

3. Results

3.1. Personal emotional coping deficits

When carers were first informed of their relative's diagnosis of a brain tumour, many were shocked and frightened, unable to come to terms with the sudden shock. They reported that the diagnosis of a brain tumour left them feeling uncertain and extremely worried about the future, with anxiety creeping in and often feeling powerless to do anything about the patient's progress. During the decision-making process for the patient's surgery, carers often felt conflicted and helpless amidst the stress and emotional pull of decision-making, especially when family members disagreed, and carers felt a great deal of psychological distress. Anxiety was present at every stage of the caregiving process, with many carers reporting difficulties in balancing their caring and personal lives, often doubting their ability to care, and experiencing high levels of mood swings, further exacerbating the psychological burden.

3.2. Lack of experience in disease management

Many caregivers lack experience in effective disease management and often feel confused and overwhelmed during the caregiving process. Most carers have not received relevant medical care training and therefore show inadequate coping skills when faced with the management of patients' postoperative symptoms. For example, some caregivers failed to recognize patients' complications or postoperative reactions promptly, leading to fluctuations in patients' conditions. In the transition of caregiving roles, carers often feel role conflict, they have difficulty in finding a balance between family life and caregiving tasks, and very often their needs are neglected and they feel that they have taken on too much responsibility.

3.3. The urgent need for social support

The results of the study show that the need for social support among carers is urgent. Firstly, many carers identified friends as an important source of support for them, and they wished to obtain emotional support and psychological comfort through interaction with friends. Nonetheless, many caregivers expressed a certain degree of stress in the face of concern from relatives and friends, especially when such support was limited to verbal comfort and lacked practical action. Second, caregivers generally reflected that high medical costs were one of the major financial pressures they faced and that many families had limited incomes, and that although some of the patients were supported by health insurance or publicly funded medical care, the treatment process still incurred a large number of out-of-pocket expenses, carers said that the financial pressure adds to their burden and affects the performance of their caring capacity. Therefore, they hope to receive more financial assistance or policy support to alleviate their financial pressure so that they can focus more on patient care.

4. Discussion

4.1. Inner experiences of family primary carers of patients undergoing brain tumour surgery

This study found that family primary caregivers of brain tumour patients experienced extremely complex emotional fluctuations throughout the caregiving process. Firstly, many carers displayed shock and fear upon learning that the patient had been diagnosed with a brain tumour. This emotional response occurs because brain tumour, as a serious and unpredictable disease, is fraught with uncertainty for the patient and family members about their future prognosis [4]. At this point, caregivers often feel deep anxiety about the future, and uncontrollable fear accompanies every detail of daily life. Second, caregivers commonly face ambivalence and helplessness as the decision to proceed with surgery is made. Many family members disagreed on whether to undergo surgery and what treatment to choose, and carers were often in a dilemma, unable to make a clear decision. In the process, they show strong emotional conflicts and inner turmoil [5]. Finally, when the patient’s symptoms did not improve significantly or complications arose in the postoperative period, the caregiver’s anxiety became more intense and even led to feelings of self-blame. Caregivers worry that they will not be able to provide enough care to alleviate the patient’s suffering. These emotional responses suggest that family caregivers of brain tumour patients not only have to deal with changes in the patient’s condition during the caregiving process, but also with their own significant psychological and emotional challenges. Therefore, it becomes particularly important to help caregivers manage their emotions and provide psychological support.

4.2. Urgent need for knowledge and social support for family primary carers of patients undergoing brain tumour surgery

4.2.1. Disease-related knowledge information support

This study reveals the lack of knowledge of caregivers in the process of disease management, as many caregivers reported that they had very limited knowledge about brain tumours when dealing with the patient’s disease, especially the lack of sufficient information about treatment options before and after surgery, postoperative rehabilitation, and possible complications. As a result of information asymmetry, carers are often left in a state of anxiety and helplessness and are unable to respond effectively to changes in the patient’s condition [6]. In fact, the process of caring for brain tumour patients involves multidisciplinary treatment and management, including the use of medication, rehabilitation, prevention, and management of complications, etc., and caregivers need to have the sufficient medical knowledge to help patients successfully navigate through these difficulties. However, many current carers do not know how to properly manage their patients' conditions due to a lack of professional knowledge and training [7]. It was found that most caregivers were eager to obtain more professional information about brain tumours, especially at the critical stage of patients' postoperative recovery, and they would like to receive clearer treatment guidelines and rehabilitation programs. Therefore, enhancing caregivers' knowledge of the disease, especially through health education and regular professional guidance, can help caregivers better adapt to their caregiving role and reduce their psychological burden.

4.2.2. Family and social support

Research has shown that family carers of people with brain tumours generally face significant caregiving pressures, and their reliance on family members and social support appears to be particularly acute. Many carers reported that although they received some emotional support from their spouses, parents or other relatives, practical help was often limited. Particularly in day-to-day care, caregivers are not only required to undertake a large number of nursing tasks but also to provide emotional encouragement and comfort to the patient [8]. The support of family members is crucial in this process, yet in some families, carers often feel isolated and lack adequate help and understanding. Carers expressed that they sometimes need more practical help, especially in the patient's life care and medical matters. Social support is also an important part of carers' needs. The study also found that carers had high expectations of social support, particularly for social benefits, care subsidies and other forms of financial assistance to reduce the financial burden of caring [9].

4.3. Coping strategies for carers' psychological distress

A study of family primary caregivers of brain tumour patients revealed that caregivers' psychological distress is not only the result of emotional reactions but is also closely related to the lack of effective coping strategies. Many carers often fail to manage their psychological stress effectively due to information asymmetry, caregiving inexperience, and lack of social support, leading to the exacerbation of emotional problems such as anxiety and depression. In this regard, it is recommended that psychological support be provided to carers through various means. For example, special psychological counseling services can be set up in hospitals to provide carers with emotional support and psychological counseling to help them relieve anxiety and stress. In addition, caregivers' disease management skills and psychological resilience can be enhanced through regular nursing education and training, thereby increasing their confidence and ability to cope with the challenges of caregiving [10].

5. Conclusion

This study provides insights into the emotional and psychological stresses faced by 31 family primary caregivers of patients undergoing brain tumour surgery during their caregiving process through interviews with them. Most of the caregivers indicated that they were under great pressure, had significant emotional distress, and had a strong need for external support. As the concept of "family-centered" care is promoted in clinical practice, understanding caregivers' real feelings and experiences of caregiving will not only help caregivers pay more attention to the psychological status and needs of caregivers but also provide the basis for the development of a more personalized care plan. The study suggests that a more comprehensive assessment system should be established to systematically assess the psychological difficulties and caring capacity of carers, and provide targeted support based on the results of the assessment, which will not only provide an important reference for improving the quality of care and the physical and mental health of carers, but also help to develop appropriate care models for high-risk groups.

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