

Qualitative study on the life dilemmas faced by long-term survivors of primary central nervous system germ cell tumors from a social ecological perspective

Lan Bai

Sun Yat-sen University Cancer Center

周周 zhou

Sun Yat-sen University Cancer Center

Huiying Qin (✉ 821050156@sysucc.org.cn)

Sun Yat-sen University Cancer Center

Qinqin Zhao

Sun Yat-sen University Cancer Center

Research Article

Keywords: central nervous system germ cell tumors, long-term survivors, life expectations, social ecological model, qualitative research

Posted Date: April 1st, 2022

DOI: <https://doi.org/10.21203/rs.3.rs-1505469/v1>

License: © ⓘ This work is licensed under a Creative Commons Attribution 4.0 International License. [Read Full License](#)

Abstract

Purpose

This study aimed to examine the life dilemmas of long-term survivors of central nervous system germ cell tumors based on the Social Ecological Model and provide a reference for targeted interventions.

Methods

A semi-structured interview was conducted on 14 survivors of central nervous system germ cell tumors. The questions were based on the Social Ecological Model. Data were transcribed and analyzed using Colaizzi's method.

Results

Three themes were identified in this study. In the macro system, the physical and mental state of long-term survivors is affected by the disease and treatment, and the quality of life was poor. In the mezzo system, friendly work and community environments were included, but resources were scarce. Moreover, the support system in macro system was weak.

Conclusion

The social ecological system for long-term survivors of central nervous system germ cell tumors was poor. The society should pay attention to the survivors' physical and mental health to promote better integration into society.

1 Introduction

Central nervous system germ cell tumors (CNS-GCTs) account for 2%–3% of all primary intracranial tumors, with a higher incidence in China than in other countries [1]. The age of onset is from 10 to 24 years in 70% of patients with CNS-GCTs [2]. Because they are highly sensitive to radiotherapy and chemotherapy, CNS-GCTs can be clinically treated by radiotherapy and chemotherapy alone, with a 5-year survival rate as high as 85–100% [2]. The long-term complications caused by tumor site, surgery, radiotherapy, and chemotherapy will affect the long-term quality of life of patients [3]. Cancer survivors are individuals with previously diagnosed malignant tumors who have received and are free from treatment [4], and long-term survivors refer to the population surviving > 5 years after tumor diagnosis [4]. Western countries have attached great importance to studies on improving the long-term quality of life of CNS-GCT survivors and proposed relevant targeted strategies and specific measures to help them return to society and improve their quality of life [5–7]. However, Chinese scholars have paid less attention to long-term survivors of CNS-GCTs.

Charles Zastrow, a representative of modern Society Ecosystem Theory (Fig. 1), classified the human social ecosystem into three basic types: micro, mezzo, and macro systems [8]. The micro system is used to describe individual physical and psychological features. The mezzo system refers to small-scale groups where the individual is involved, such as communities, families, and workplaces. The macro system is defined as the social environment that exists in the micro and mezzo systems but the individual does not directly interact with, including communities, public policies, social rules, laws, and cultures. This study aimed to investigate the living situation of long-term survivors of CNS-GCTs in real life and their life expectations and dilemmas based on the Society Ecosystem Theory and provide a reference for the follow-up and intervention mechanism building for this population.

2 Methods

2.1 Subjects

Using purposive sampling, patients diagnosed with CNS-GCTs followed by the Outpatient Department of Neurooncology of a cancer hospital in Guangdong Province from March to October 2020 were enrolled in the study. The inclusion criteria were as follows: ≥ 5 years after diagnosis; ≥ >3 years after treatment; and ≥ no recent tumor recurrence or other newly diagnosed major diseases. The exclusion criteria were as follows: ≥ cognitive or consciousness impairment; ≥ Karnofsky Performance Status score ≥ 60; and ≥ inability to have normal communication. The sampling was ended at saturation based on the repeated presence of respondents' data and absence of new topics during data analysis [9]. All subjects provided written informed consent and voluntarily participated in this study. A total of 14 long-term survivors of CNS-GCTs were enrolled in this study, including 13 men and 1 woman, with an age range of 16–28 years, average age of 22 years, and average time after radiochemotherapy of 4.57 years. The general data of the respondents are presented in Table 1.

2.2 Research methods

Based on the Society Ecosystem Theory [8], an interview outline was developed by literature review. The main topics were as follows: ≥ Building relationship with the respondents: explain research topic, objective, and method and rights of the respondents; self-introduction of both parties: elaborate with three adjectives or roles. ≥ Views on the disease: Could you tell me your views on the disease when it was initially diagnosed? What do you think about this disease now? Who or what caused you to change your views? ≥ Influence of the disease on the patient: How do you feel your body is different from that before the onset of the disease? What is the difference in personality or emotion from before? What did you feel and experience after the diagnosis? ≥ Influence of family and work on the patient: How are your parents and colleagues (classmates) getting along with you at present? How is your current work (study)? ≥ Interaction between the patient and environment: What kind of help have you received since your diagnosis? Could you share something particularly impressive? What is the greatest pressure you feel? ≥ Expectations of the patient: What are your current expectations of your life? Do you have any special feelings you can share with us?

Table 1
General data of the respondents (n = 14)

No.	Occupation	Age	Sex	Tumor site	Place of residence	Treatment	Time after treatment (year)	Current symptoms
N1	Unemployed	24	Male	Sellar region	Urban	Radiochemotherapy	6	Central diabetes insipidus, hypothyroidism
N2	Third-grade junior student	16	Female	Left thalamus	Urban	Radiochemotherapy	6	Central diabetes insipidus, memory decline
N3	Second-grade senior student	18	Male	Pineal region	Urban	Radiochemotherapy	5	Panhypopituitarism
N4	Salesclerk	26	Male	Pineal region	Rural	Radiochemotherapy	6	Hypothyroidism
N5	Salesclerk	25	Male	Pineal region	Urban	Radiochemotherapy	4	Left limb muscle strength grade IV
N6	Government employee	26	Male	Pituitary stalk	Urban	Radiochemotherapy	5	Panhypopituitarism, central diabetes insipidus, hypothyroidism, post-bilateral hip arthroplasty
N7	Unemployed	16	Male	Right basal ganglia	Rural	Radiochemotherapy	4	Left limb muscle strength grade IV
N8	Unemployed	20	Male	Sellar region	Rural	Radiochemotherapy	3	Central diabetes insipidus, hypothyroidism
N9	Clerk	27	Male	Pineal region	Rural	Radiochemotherapy	5	Blurred vision, memory decline
N10	Clerk	25	Male	Pineal region	Urban	Radiochemotherapy	6	Memory decline
N11	Second-grade senior student	18	Male	Right basal ganglia	Urban	Radiochemotherapy	3	Left limb muscle strength grade IV
N12	Junior college student	20	Male	Pineal region	Urban	Radiochemotherapy	3	Central diabetes insipidus, memory decline
N13	Clerk	28	Male	Right basal ganglia	Urban	Radiochemotherapy	4	Memory decline
N14	Junior college student	19	Male	Third ventricle, pineal region	Urban	Radiochemotherapy	4	Memory decline

2.2.1 Data collection

In this study, the data were collected using a semi-structured interview. Before the interview, the patients were provided complete information regarding the study, which was recorded, and written informed consent was obtained, with the interview time set. The interview was conducted in the conversation room of the department. During the interview, the interviewee listened to the

responses of the patients carefully and observed their emotion, intonation, facial expressions, and physical behaviors to obtain and record their real feelings through intake interview [10]. The interview lasted 45–60 min.

2.2.2 Data analysis

Within 24 h after the interview, the researchers transcribed the recorded contents into texts and marked the emotional changes, movements, and expressions during the interview at the corresponding positions. The data were analyzed using Colaizzi's method of phenomenological enquiry [9]. ☐ All interview materials were recorded and analyzed in detail; ☐ meaningful and matching statements were extracted; ☐ significance was summed up and refined; ☐ the common features or concepts of significance were explored to form topics, topic groups, and categories; ☐ the topics were connected to the research phenomenon, and a complete description was given; ☐ the research phenomenon was described in detail; ☐ the results were fed back to the subjects for verification. The original data were transcribed and sorted by two researchers jointly; then, the topics were classified and refined.

3 Results

3.1 Micro system: The physical and psychological state was affected by the disease and treatment, and the quality of life was poor.

3.1.1 Physical function was affected by the disease and treatment

Complications caused by tumor sites or large-scale high-dose radiotherapy increase the risk of adverse effects on the long-term quality of life of survivors [1]. Additionally, radiotherapy for head tumors is also the main cause of poor quality of life [11]. In this study, there were five cases of central diabetes insipidus, five cases of memory decline, four cases of hypothyroidism, two cases of hypopituitarism, and two cases of limb function grade IV. The 14 patients had risk of fatigue in daily life. N6: "Because of high-dose hormone replacement therapy and my bilateral hip joints have been replaced due to necrosis, I cannot perform many sports." N11: "I always feel very tired and even fall asleep in class. Sometimes, I think it would be better if I did not go to school." N12: "Sometimes I forget to eat Minirin, so I have to get up and use the bathroom several times at night, I cannot sleep well."

3.1.2 The psychological state was not optimistic

Due to constraints by body functions, the normal work and life of survivors were affected. Moreover, the fear of tumor recurrence, decline in cognitive function, and worry about fertility led to feelings of self-accusation, inferiority, anxiety, and helplessness. N5: "I am still living with my family and supported by my parents and brothers even though I am over 20 years old. I feel that my father and mother are working so hard (cry loudly)." N9: "Sometimes I feel that I cannot even do simple things well. I think my life is quite boring." N14: "My memory declined significantly. I cannot remember what the teacher has said immediately after the class, and I cannot keep up with my homework. Although my parents think it does not matter how well I do at school and health is the most important, I still feel useless. I think it may be better to drop out."

3.1.3 Life trajectory changes

Because of the disease, the patients cannot return to their previous study or life, thus changing the originally envisaged life trajectory. N4: "Before I got sick, I did quite well in my college studies. I could have a promising career. Now, I can only look after our family shop. Is taking care of the family shop a job?" N6: "I majored in logistics management in college, but I did not return to school after I got sick. In the past, everyone envied my father as his son was admitted to a famous university. Now, no one envies him." N12: "Before I got sick, I was a business manager. Now, I work as a clerk in a company near my home, with a monthly salary of only 3,000 yuan, way lower than my last job. This is barely enough to support me, let alone start a family."

3.2 Mezzo system: The community, family, and working environments are friendly, but resources are insufficient.

3.2.1 The community, family, and working environments are friendly

In this study, the patients all felt the community, family, and working environments were friendly. They did not experience unfair treatment and even felt that they had received more care and attention from the family, school, or working environments. N5: "With the help of the county government, I worked as a clerk in the office of the neighborhood committee." N12: "The teachers knew I was ill, so they exempted me in my PE class. My classmates also knew my condition, and their attitudes toward me are not that different. Only when they hang out drinking, they may not invite me. Everyone knows that I cannot drink or stay up late." N13: "My current boss is very kind to me. Knowing that I have been ill, he will not push me so hard or let me work overtime."

3.2.2 The support of social and family resources is insufficient

In this study, although the patients felt that the surrounding living environment was friendly, the resources were insufficient. Most survivors can only support themselves or even have to rely on their families, leaving certain economic pressure for their families. The resources they had were almost all from the support of parents, brothers, or friends, which were extremely limited. N6: "Our village committee is quite small. Everyone is so nice to me, and they offered me a clerical job, with an income of less than 3000 yuan a month." N8: "I have spent all my family savings on medical treatment, and I have not found a suitable job. I think my parents are struggling, and my brother did not get married because of me." N10: "I look like a normal person and have a job. My family income cannot meet the standard for government subsidy, but actually, it is just enough to make ends meet."

3.3 Macro system: The support system is weak.

3.3.1 Systematic social service support is absent

In this study, the average time after treatment was 5 years. Except for the outpatient follow-up in the hospital where the survivors and their families received treatment, remote network service platform, alternative care, in-depth psychological counseling, social assistance, community follow-up, and all-around support services for patients in the physical, psychological, intellectual, and economic aspects were all absent. N12: "Usually, my father takes me back to your hospital for review, and no one in the community would follow-up." N13: "The neighborhood committee or the government did not offer us any support, or at least I have not heard. I have already returned to work; maybe, they think we do not need it."

3.3.2 Cultural environment needs to be improved

In this study, except for two patients who occasionally obtained some useful information in the previously established WeChat group for treatment, other patients did not have a way to obtain relevant knowledge of the disease or long-term survival, which may be related to the rarity of the disease. N9: "Less relevant information can be found on the Internet. Maybe the disease is relatively rare, and few people know it."

4 Discussion

4.1 Efforts should be made to focus on the physical and psychological health of long-term survivors and strengthen follow-up and monitoring

4.1.1 Establish a monitoring and reconstruction system for endocrine dysfunction

Endocrine function affects the growth, development, and immune function of young survivors [12]. Therefore, it is extremely important for long-term survivors to properly deal with the interaction between multiple substitute hormones, meet the personalized needs of growth and development, improve prognosis, and enhance the quality of life [13].

4.1.2 Strengthen knowledge support relevant to long-term survival

This study found that, due to the side effects and complications of radiotherapy, chemotherapy, and surgery, long-term survivors presented a series of complications, such as decreased limb muscle strength, sleep disorders, and fatigue. In this study, self-perception of the overall quality of life was poor, which is consistent with the findings of previous studies that central nervous

system tumors have the greatest impact on the quality of life [14]. Based on the personalized needs of survivors, targeted rehabilitation or recovery courses should be developed, information exchange among survivors should be strengthened, and WeChat groups, QQ groups, or communication platforms should be established for regular information exchange activities and sharing of effective recovery plans to strengthen support. The mutual-aid group of patients regularly organized by the medical staff [15] also promotes physical and psychological health of long-term survivors.

4.1.3 Offer targeted emotional, psychological, or spiritual support

Although the survivors have recovered and lived for a long time, their psychological problems are still difficult. In this study, the average age of the survivors was 22 years, and they are in not only the transitional period of growth but also the fragile and sensitive time physically and mentally. Targeted psychological support or spiritual care can help them regain confidence and belief in life [16], and spiritual care can also help young long-term survivors build hope and explore the meaning of life [17]. Spiritual care methods include therapeutic communication, music therapy, diary writing, painting therapy, and creative art therapy, which can help survivors manage their emotions and realize inner peace [16].

4.2 Develop social support systems for long-term survivors

4.2.1 Encourage families to enhance communication with the outside world

The family has always been the primary caregiver. The worse the patient's physical condition, the higher the dependence on family support. In both work arrangement and care planning, the family is in a very important position, and its function is of great significance. However, the family economic conditions of our 14 patients are poor, so the families did not pay enough attention to the developmental problems of the survivors, such as the independent planning for the future. Families can also send a signal for help to the community to obtain support from other systems.

4.2.2 Facilitate family, school, and community interactions

An intermediary system is a social network formed around the micro system, such as schools, work units, and neighbors. For some respondents, in life, they would say, "I have no friends," "I used to have classmates, but now there is no contact at all." Therefore, survivors can be encouraged to participate in community activities, such as activities of village committees, neighborhood committees, and community organizations.

4.2.3 Strengthen social support system

A high density and large number of patients with brain tumors are noted in China [13]. Through the interview, it was found that the social support system for patients with brain tumors and their caregivers was weak and society paid less attention to brain tumors. The researcher found that half a year or one year after the patients returned to the family or society is an important stage to truly test disease acceptance and adaptation by individuals, including colleague relationship, school adaptation, and understanding ability. Of the 14 respondents in our study, most were weak in social interaction and had few friends. According to the characteristics of survivors, suitable and accessible social programs can be developed. Western countries have established the Children's Brain Tumor Tissue Consortium and other organizations committed to scientific research and clinical translational research on children's brain tumors using a large sample size and several data platforms. Moreover, charitable organizations, such as the Brain Tumor Epidemiology Consortium, have set up various long-term tracking platforms for follow-up services. Therefore, we can raise social attention on brain tumors through multi-media, the Internet and WeChat platforms, and set up special funds to help them recover.

4.2.4 Build a follow-up platform for young long-term survivors of brain tumors

Presently, the social follow-up and management services for young patients with brain tumors are incomplete. Referring to relevant existing experience, a follow-up service platform for young patients with brain tumors was suggested to be built to improve the social security mechanism and win more reasonable humanistic and social support for survivors [18]. Especially for

the employment services of survivors with physical and psychological disorders, there are large differences in individual needs after treatment. In employment counseling or assistance, it is necessary to make a comprehensive study of individual conditions.

4.2.5 Raise social attention

Through media convergence, efforts should be made to raise social attention on this population and change the inherent views and attitudes using stories of patients in the form of publications, documentaries, movies, and short films.

5 Conclusion

Through face-to-face interviews with 14 long-term survivors of CNS-GCTs, we obtained a better understanding of their life dilemmas. Their quality of life is poor, and they need social care and assistance, suggesting that greater attention should be paid to the physical and psychological health of young long-term survivors, strengthen follow-up and examination, build a follow-up platform, and provide corresponding support and guidance to help them better integrate into the society.

6 Limitations

The fact that survivors included in this study were only from a third-grade class-A cancer hospital and perspectives and sample size were insufficient may lead to the limitation of analysis results. In the future, a large sample quantitative and qualitative study can be conducted to strengthen the investigation and follow-up research on this population.

References

1. Wang J, Zhao Yiyang YQ et al (2015) Clinical analysis of 219 children with central nervous system tumors. *Guangdong Med J*36:2621–2624
2. Chen Z, Yang Q (2012) *Handbook of Nervous System Tumor chemotherapy*. Peking University Medical Press
3. Acharya S, DeWees T, Shinohara ET, Perkins SM et al (2015) Long-term outcomes and late effects for childhood and young adulthood intracranial germinomas. *Neuro Oncol*741–746
4. Yang G-Y, Sun H-Y (2009) Quality of life in long-term survival of childhood cancer. *J Nurs* 24:94–96
5. Limond JA, Bull KS, Calaminus G et al (2015) Quality of survival assessment in European childhood brain tumour trials, for children aged 5 years and over. *Eur J Paediatr Neurol* 19:202–210
6. Nightingale CL, Quinn GP, Shenkman EA et al (2011) Health-related quality of life of young adult survivors of childhood cancer: a review of qualitative studies. *J Adolesc Young Adult Oncol* 1:124–132
7. Tallen G, Resch A, Calaminus G et al (2015) Strategies to improve the quality of survival for childhood brain tumour survivors. *Eur J Paediatr Neurol* 19:619–639
8. Zastrow A, Ling S (2006) *Human behavior and social environment* (6th edition). China Renmin University Press
9. Zhou Y (2019) *Research on nursing quality: theory and cases*. Zhejiang University Press, Hangzhou
10. Tang L (2013) Application of ingestion talk in the implementation of quality nursing service. *Chin Med Guide* 11:266–267
11. Landier W, Skinner R, Wallace WH et al (2018) Surveillance for late Effects in childhood cancer survivors. *J Clin Oncol* 36:2216–2222
12. Doenyas C (2019) Novel personalized dietary treatment for autism based on the gut-immune-endocrine-brain axis. *Front Endocrinol* 10:508
13. Mei F, Qiu R, Mai Y et al (2020) History, current situation and prospect of pediatric brain tumor treatment. *Chin J Mod Neuropathy* 20:258–262
14. Duckworth J, Nayiager T, Pullenayegum E et al (2015) Health-related quality of life in long-term survivors of brain tumors in childhood and adolescence: a serial study spanning a decade. *J Pediatr Hematol Oncol* 37(5):362–367
15. Yu P (2018) *Action research on developing mutual aid group for breast cancer patients*. Yunnan University

16. Tang H, He W, Cui P et al (2019) Research progress of spiritual care for children and adolescents with cancer. *J Nurs* 34:103–106
17. Weaver MS, Wratchford D (2017) Spirituality in adolescent patients. *Ann Palliat Med* 6:270–278
18. Johnson KJ, Schwartzbaum J, Kruchko C et al (2017) Brain tumor epidemiology in the era of precision medicine: The 2017 Brain Tumor Epidemiology Consortium meeting report. *Clin Neuropathol* 36:255–263

Figures

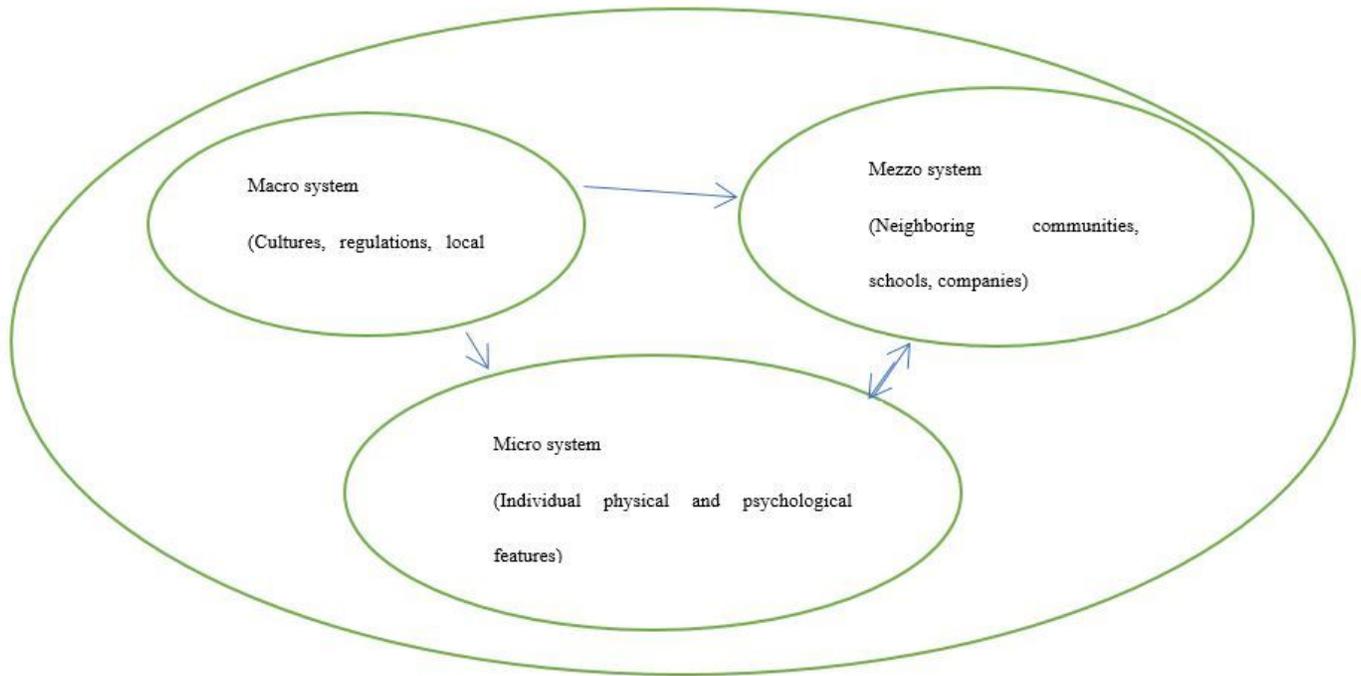


Figure 1

Map of the social ecosystem of Charles Zastrow