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RESEARCH

A qualitative exploration of fear of progression in patients with nasopharyngeal carcinoma treated with proton and heavy ion therapy

Mimi Zheng[1] · **Shuman Wang**[1] · **Yu Zhu**[1] · **Hongwei Wan**[1]

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Abstract

Objective To investigate fear of progression (FOP) in nasopharyngeal carcinoma (NPC) patients treated with proton and heavy ion therapy.

Methods Thirty NPC patients were selected for face-to-face semistructured interviews through purposive sampling while using the phenomenological approach in qualitative research. The interviews were transcribed, organized, and analyzed by applying Colaizzi's seven-step analysis.

Results Seven themes were summarized, namely, illness uncertainty, trapped into insecurity (including four categories: insecurity about the possibility of discrimination, insecurity about the possibility of the inability to tolerate the pain of retreatment, insecurity about the difficulty of retreatment after recurrence, and insecurity of waiting for test results), hopelessness, loss, guilt toward children, enhancing tolerance toward family, and self-emotional comfort.

Conclusion We found that women with children and patients who experienced their first episode underwent significant FOP. Patients at the postgraduate level and above were more inclined to feel loss. The finding that respondents expressed is intense FOP while waiting for test results, which provides a reference for the analysis of the trajectory of FOP. Health care professions should be cognitively aware the importance of eliminating patients' uncertainty and insecurity about disease to enhance their positive experience in coping with cancer.

Keywords Nasopharyngeal carcinoma · Fear of progression · Phenomenology

Introduction

Fear of progression (FOP) is defined as fear, worry, or concern about disease progression or cancer recurrence [1]. FOP is recognized as the most common psychological problem among cancer survivors. Approximately 49 to 70% of cancer patients experience moderate to severe FOP [2]. Nasopharyngeal carcinoma (NPC) is a common head and neck tumor in China, and is most commonly found in the southeast and southwest regions, accounting for approximately 38.29% of all cases of NPC worldwide [3]. Approximately 20% of NPC patients still have local recurrence and poor prognosis [4]. A retrospective analysis of 77 patients with locally recurrent nasopharyngeal carcinoma who received secondary radiotherapy in Shanghai (median follow-up time 25.7 months) found that 44.2% of patients died (n=34), 53% of whom died from serious adverse effects such as nasopharyngeal bleeding caused by retreatment [5]. Therefore, NPC patients face the realities of high recurrence rates and difficulty in retreatment, triggering the fear of progression. According to statistics, 67.14% of NPC patients in China were found to have experienced high levels of FOP [6]. FOP in NPC patients treated with proton and heavy ion therapy needs attention.

The feeling of FOP is a complex experience involving emotion, self-perception, and behavior. Several studies in the USA, UK, and Canada have conducted qualitative interviews

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Mimi Zheng and Shuman Wang contributed equally to this work and should be considered co-first author.

✉ Hongwei Wan
hong_whw@aliyun.com

[1] Department of Nursing, Shanghai Proton and Heavy Ion Center, Fudan University Cancer Hospital, Shanghai Key Laboratory of Radiation Oncology (20dz2261000), Shanghai Engineering Research Center of Proton and Heavy Ion Radiation Therapy, Shanghai, China

in breast, ovarian, leukemia, lymphoma, myeloma cancer patients, and condensed their multilayered and multifaceted perceptions and experiences of FOP. Including 20 breast cancer patients in Australia and Canada, the study revealed that patients' fears were mainly related to the side effect of chemotherapy, worries about children's lives, and unfulfilled self-worth. Patients' coping strategies with FOP include positive thinking, cognitive avoidance, building a healthy lifestyle and group support [7]. In extreme cases, women may experience excruciating anxiety over the prospect of being separated from their husbands, kids, and other loved ones [8]. However, the latest evidence shows that approximately 50.5% of studies related to FOP were conducted on breast cancer patients [9]. Thus, more phenomenological research in NPC patients treated with protons and heavy ions is need.

A negative effect of side effects and financial burdens on ameliorating FOP has already been confirmed [10, 11]. Proton and heavy ion therapy is currently recognized as the most advantageous radiation therapy technology for tumors worldwide [12]. Compared with traditional radiotherapy, proton and heavy ion therapy which produces a sharp dose profile known as the Bragg peak, kills tumor cells more accurately and effectively while protecting normal tissue surrounding the lesion [13]. One study included 69 non-metastatic NPC patients with a median follow-up of 31.9 months receiving heavy-ion radiotherapy and showed that severe acute toxicities induced by radiation therapy were observed in only two patients (dermatitis) [14]. In addition, due to the large investment costs for building a proton and heavy ion therapy facility, the treatment cost is higher than that of conventional radiation. Proton and heavy ion therapy cost approximately $40,000 [15, 16]. Due to the mild side effects and high cost, patients treated with proton and heavy ion therapy may experience different outcomes than those treated with conventional treatment modalities. An in-depth analysis is essential to provide targeted and scientific support to alleviate FOP in NPC patients.

In the current qualitative study, we aimed to explore NPC patients' real feelings of FOP in a clinical setting and to provide emotional and psychological support for FOP in NPC patients.

Methods

Design

The qualitative study adopts a phenomenological research approach. The phenomenological approach is a qualitative research method that observes a specific phenomenon, analyzes its internal and external components, distils its elements, and investigates the relationship between the elements and the surrounding context, with the goal of promoting an understanding of human beings, explaining the nature of action, and focusing on the search for and understanding of the true meaning of the phenomenon. The phenomenon of this study is an exploration of feelings of FOP in NPC patients treated with proton and heavy ion therapy. The method of data analysis in this study was Colaizzi seven-step analysis [17]. This analysis contains seven steps:(a) read the statements of participants repeatedly; (b) refine certain important terms; (c) code recurring phrases and opinions; (d) summarize coded opinions into the topic; (e) write detailed and complete descriptions; (f) summarize similar ideas and extract themes; (g) if required, clarify ambiguous analytic results with the participants. The interviews were first transcribed word-for-word by the researchers who collected the data (Mimi Zheng and Shuman Wang). The transcripts were reviewed and checked numerous times to obtain a general picture of FOP. Researches identified meaningunits words which were developed into significant statements. Researchers coded the expressions and discussed them until they reached agreement on the coded expressions (Yu Zhu, Mimi Zheng, and Shuman Wang). The coded transcripts were categorized, and subthemes and themes were created. Researches identified meaningunits words which were developed into significant statements and from these into formulated meanings, theme clusters followed and finally a central theme.

Participants

Patients who provided written informed consent were selected using purposive sampling method from November 2021 to December 2022 (sample size was based on data saturation). Study participants met the following inclusion criteria: (a) Age≥18years; (b) good reading and communication skills in Chinese; (c) patients with a clinicopathological histological or cytological diagnosis NPC; (d) voluntarily participated in this study and signed the informed consent form. Exclusion criteria: (a) sudden exacerbation of cancer; (b) receiving psychotherapy during the study.

Procedure

The study was approved by the Shanghai Proton and Heavy on Center Institutional Review Board (ethical approval reference number:2202-53-02) and was performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards. This study selected face-to-face semistructured interviews conducted by two researchers (Mimi Zheng and Shuman Wang). Both researchers have systematically completed the qualitative research program at the School of Nursing, Fudan University, and have already worked with semistructured interviews. Therefore, having the ability to allow a reactive and responsive stance to information raised by individual patients, facilitates a high level of sensitivity in data gathering. Participants were informed about the study's purpose and procedure. We provided participants information about the objective, purpose and possible risk of this research. The interviews were conducted in the conversation rooms of each ward and a quiet and relaxed atmosphere was needed. Researchers should establish a trusting relationship with interviewees before the interview and create a neutral atmosphere during the interview to avoid critical and leading conversation . Each interview lasted approximately 30–60 min/session. The interviews were recorded on a voice recorder.

The Semi-Structured Interview on Fear of Cancer Recurrence (SIFCR) was established with 18 open-ended questions by Simard and Savard to assess various aspects of FOP [18]. On the basis of SIFCR, interview questions of this study were as follows: (a) How did you feel when you first found out about the illness; (b) What do you fear most about your illness; (c) When does the fear of a relapse come up, When is it most intense; (d) How did you feel when you had thoughts related to relapse; (e) How have these feelings changed your life; and (f) In what ways do you manage your fear of relapse? For the participants to express their feelings easily and honestly, sensitive words were adapted to avoid repeatedly stimulating the patients, such as "disease," "feelings" were used instead of "nasopharyngeal cancer," and "fear of progression."

Data analysis

The data were analyzed by the seven steps described by Colaizzi [17]. The text was transcribed in a timely manner 24 hours after the interview to ensure the timeliness of the data. Relevant clinical nursing experts were consulted to ensure the accuracy of data extraction. The text was transcribed in a timely manner 24 h after the interview to ensure the timeliness of the data. And relevant clinical nursing experts were consulted to ensure the accuracy of data extraction.

Results

Characteristics of the participants

A total of 30 NPC patients were interviewed. The 30 included subjects ranged in age from 23 to 70 years. There were 19 males and 11 females; 21 patients were married, 8 were unmarried and 1 was widowed. Eleven patients had no children and 19 patients had children. Six patients had postgraduate education or above, 13 had university education, and 10 had middle school education. One case was primary school and below. Twenty-two patients had primary nasopharyngeal carcinoma, and 8 patients had recurrent nasopharyngeal carcinoma. Three patients were stage I, 8 patients were stage II, 10 patients were stage III, and 9 patients were stage IV. Thirteen patients received proton or heavy ion therapy, 17 patients received only proton therapy or photon and heavy ion therapy, 7 patients received concurrent chemotherapy, and 24 patients received nonconcurrent chemotherapy. The characteristics of the participants are shown in Table 1.

Core themes

A total of 7 themes were extracted, namely, theme 1 illness uncertainty, theme 2 trapped into insecurity (including 4 categories: insecurity about possibility of discrimination, insecurity about the possibility of the inability to tolerate the pain of retreatment, insecurity about the difficulty of treatment after recurrence, the insecurity of waiting for test results), theme 3 hopelessness, theme 4 loss, theme 5 guilt toward children, theme 6 enhancing tolerance toward family, and theme 7 self-emotional comfort. Table 2 contains verbatim quotes illustrating each theme.

Theme 1 Illness uncertainty

After admission to the hospital, patients want to receive a definitive answer from the medical staff about the outcome and prognosis of their treatment. Due to their limited expertise in the disease, patients are prone to uncertainty about the outcome of their treatment.

> N1: "After being diagnosed with the nasopharyngeal cancer, I am now concerned about whether or not there is any residue. I'm not sure if chemotherapy will help. How can I increase my chances of survival? Is this cancer recurrent?"
>
> N4: "What the future holds is unknown. I'm also unsure about the treatment or this disease. It is unclear whether there are no more cancer cells after treatment and the patient returns to normalcy. Or is it if it returns...... so it is easy to worry about things that are not clear."
>
> N5: "I do not know if the disease can be cured or not, everyone just knows the percentage, what about the five-year survival rate, what about this nasopharyngeal cancer in the end?"

Theme 2 Trapped into insecurity

Insecurity about the possibility of discrimination Regular daily radiotherapy and chemotherapy stimulated patients to

Table 1 Demographic characteristics of participants

Participant	Year	Gender	Marital status	Children	Education	Primary/Recurrent	Stage	Treatment
N1	62	Male	Married	No	University	Primary	II	B
N2	35	Male	Married	Yes	Postgraduate and above	recurrent	III	C+B
N3	51	Male	Married	Yes	University	Primary	III	C+B+D
N4	27	Male	Unmarried	No	University	Primary	I	C+B
N5	33	Male	Married	Yes	Secondary Schools	Primary	IV	C+B
N6	54	Male	Married	Yes	Secondary Schools	Primary	IV	C+B
N7	34	Male	Unmarried	No	Postgraduate and above	Primary	IV	B
N8	42	Female	Unmarried	No	University	recurrent	II	C+B
N9	33	Female	Married	Yes	University	Primary	IV	A+B+D
N10	44	Female	Married	Yes	Secondary Schools	recurrent	I	A
N11	34	Female	Married	Yes	Postgraduate and above	Primary	II	A
N12	38	Female	Married	Yes	Postgraduate and above	Primary	III	B
N13	40	Female	Married	Yes	University	Primary	IV	A+B+D
N14	31	Female	Married	Yes	University	Primary	II	A
N15	23	Male	Unmarried	No	University	Primary	II	A+B
N16	39	Female	Married	Yes	University	Primary	III	C+B+D
N17	32	Male	Married	No	Postgraduate and above	Primary	IV	A+B
N18	45	Male	Unmarried	No	Postgraduate and above	Primary	III	B
N19	49	Male	Married	Yes	Secondary Schools	Primary	III	A+B+D
N20	50	Female	Married	Yes	Secondary Schools	Primary	I	A+B
N21	57	Male	Married	Yes	Secondary Schools	recurrent	II	A
N22	26	Male	Unmarried	No	University	recurrent	II	B
N23	28	Male	Married	Yes	Secondary Schools	Primary	III	A+B
N24	59	Male	Married	No	Secondary Schools	recurrent	III	A
N25	40	Male	Unmarried	No	University	recurrent	IV	A
N26	27	Female	Unmarried	No	University	Primary	III	A
N27	43	Male	Married	Yes	Secondary Schools	recurrent	II	B
N28	60	Female	Married	Yes	University	Primary	III	A+B
N29	64	Male	Married	Yes	Secondary Schools	Primary	IV	A+B
N30	70	Male	Bereaved spouse	Yes	Primary school and below	Primary	IV	A+B+D

Annotation: A: proton, B: heavy ion, C: photon, D: concurrent chemotherapy

Table 2 The core and subthemes of FOP

Core Themes	Sub-themes
Theme 1 Illness uncertainty	
Theme 2 Trapped into insecurity	Insecurity about the possibility of discrimination Insecurity about the possibility of the inability to tolerate the pain of retreatment Insecurity about the difficulty of retreatment after recurrence Insecurity of waiting for test results
Theme 3 Hopelessness	
Theme 4 Loss	
Theme 5 Guilt toward children	
Theme 6 Enhancing tolerance toward family	
Theme 7 Self-emotional comfort	

have cancer. Misconceptions about cancer from colleagues or friends, such as "cancer is contagious," prevent patients from returning to normal work and social life. The fear of being rejected by family, friends and colleagues after cancer recurrence triggers negative emotions such as anxiety and worry.

> N2: "What do you think of us? Is it true that nothing happens to us? At least the daily treatment reminds us that we are different from others, right?"
>
> N10: "When I need to go to friends' house for New Year's Eve and you cannot be bald. People will think you're quite different, right? I have this feeling that being bald makes people uncomfortable, it can be truly uncomfortable."
>
> N12: "Only my closest friends are aware that I have cancer. I'm concerned that people will see me through tinted glasses, and no one wants to be labeled . The labe easily makes me have low self-esteem and feel awful."
>
> N19: "I can only be positive about things that they are not aware of. The first thing is to tell colleagues and friends that cancer is not contagious. In addition,cancer was found early and well-treated, and they should not worry."
>
> N22: Maybe people hate and far away from us who have this nasopharyngeal cancer. People are afraid that cancer will be transmitted to them.

Insecurity about the possibility of the inability to tolerate the pain of retreatment Concurrent radiotherapy side effects, such as pain, nausea, and vomiting, impair patients' basic physiological functions, boost their psychological burdens, and reduce their quality of life. Patients are worried that their bodies will be unable to handle the side effects of another treatment, as well as the pain of treatment following a relapse.

> N6: "I despise metastasis and relapse the most. People will toss and die over time. This tossing…… Finally, if the stomach and lung are metastasized, it must be cut. I always feel like I cannot stand it, and I truly cannot."
>
> N10: "Following the relapse, the treatment was excruciatingly painful, to the point of death. I felt awful the last time I had an injection to boost my white blood cell count. The pain had been going on for a week and was quite frightening."
>
> N13: "I'm not sure I can do it again. This is correct. I'm concerned about the next treatment."

Insecurity about the difficulty of retreatment after recurrence Compared to the initial attack, cancer cells are less sensitive to radiotherapy and chemotherapy after a recurrence, and larger doses of radiotherapy trigger the incidence of serious adverse reactions. Patients are lulled into insecurity by the dread of not being able to treat themselves after a recurrence and that there is no prospect of a cure.

> N4: "I prefer to have my hand in things so that if I relapse, I have more alternatives. I'd want to know whether Proton Heavy Ion Hospital will still admit me if I relapse.?"
>
> N7: "Nobody knows whether or not cancer may return after therapy. There is a considerable risk of metastasis in the lungs, bones, and liver. I am aware that nasopharyngeal carcinoma has possibility of recurrence and metastasis. If cancer has progressed and there is no treatment,how else can it be cured? There is no treatment."
>
> N12: "My main concern after a recurrence is if it can be treated again. Will it spread to other areas? It is the most important thing. If it extends to other areas, I'll assess if I need to treat it again; if I do, I will suffer, and so will my money."

Insecurity of waiting for test results Patients' primary concern following cancer diagnosis is the change in their physical state. Any abnormal test findings are interpreted as evidence that the cancer has returned or worsened. Throughout therapy, patients must have regular check-ups to assess the efficiency of the treatment as well as the location and size of the tumor. Three participants shared their fears about waiting for test results and a doctor's diagnosis in this interview.

> N3: "The doctor previously requested that I get a CT scan. I was not afraid of the test itself, but I was terrified of the results. I was frightened about if it would return, whether the tumor had grown larger, or whether it had metastasized while I was waiting for the findings."
>
> N6: "I was worried about the exam. It turned out that I was never worried throughout my medical exams, but I was scared once the cancer was discovered."

> N8: “As I returned from the check-ups and waited for the findings and the doctor's discussion, I felt like time was moving extremely slowly. That was the most terrifying period, when I both desired and feared knowing the findings.”

Theme 3 Hopelessness

As cancer patients confront the possibility of mortality, they suffer feelings of worry, dread, and despair. Patients are often cautious about revealing too much about themselves while addressing death.

> N1: “I'm afraid I will not get cured and will die as a result of metastases. There are several forms of radiation, chemotherapy, and other therapies. After metastases and recurrence, I am unable to stand.”
>
> N5: “I'm frightened of dying and of not being cured. Throughout the middle and late stages, there is a sense of dread, whether due to temperament or otherwise. I'm afraid I will not be able to eat or drink anything since my body has collapsed and I'm weak. Cancer is an incurable disease that makes you feel desperate.”
>
> N7: “I want to weep after I become sick. I feel like I'm not quite normal, but sometimes I feel at peace and simply want to live.”

Theme 4 Loss

Individuals with higher academic degrees do better in their classes and occupations, and they have more control over their health and pace of life. However, after a cancer diagnosis or recurrence, the majority of patients are out of work or jobless, with lower personal worth given for their family or society, and they are prone to self-denial and loss of love for their previous life.

> N2: “Being in my 30s is the golden age. There used to be a lot of plans about what I wanted to accomplish. Now I feel tired on everything since I became sick, and I do not have any motivation anymore.”
>
> N17: “After I got cancer, no matter what I say, all the laughs and smiles are not the most sincere ones.”
>
> N18: “I feel as if I'm waiting for the death penalty. I have not been and will never be a healthy person since being diagnosed with nasopharyngeal carcinoma.”
>
> N21: “When it initially happened six years ago, there was a beggar in front of the cancer hospital, and I gave him money multiple times. I relapsed 6 years later, and he is still there. I feel pity not for him but for me, who will pity me? My disease (nasopharyngeal cancer) has recurred.”

Theme 5 Guilt toward children

Family takes up the vast majority of the patient’s life, and the six interviewed patients who were female-sexed and married with children were worried about losing the care and dependence of their children’s parents after cancer recurred or metastasized, and felt guilty that they had not fulfilled their parental responsibilities.

> N6: “To put it bluntly, I will live two more years if I can. I will definitely be more present with my children, and I am definitely better than before.”
>
> N10: “The most important thing right is now that my children grow up healthy and happy. Even if I die, I will have no regrets as long as my health permits me to see my children grow up and have a family.”
>
> N11: “I myself often regret that I did not take care of my children before. I should accompany my children all the time, but I often use the expression no way to comfort myself.”
>
> N14: “Staying up every night, hugging the child every day, I think about how young the child is, what if the mother dies? What if your stepmother physically abuses you? And what if Dad does not inform you about menstrual period? I feel terrible for the youngster."N16: " I have heard that cancer seems to be hereditary, that it's genetically related. I'm scared that my child will get it again, truly, if it is truly because I inherited it, I might as well die”
>
> N27: “My whole life has been a lack of care, a lack of love. Both children are also relatively young, what will happen to them in case of a relapse and I am no longer here**”**

Theme 6 Enhancing tolerance toward family

Three female patients indicated a wish to shift their attitude following the sickness, to enhance their tolerance toward their husbands and children, to develop a harmonious family relationship, and to integrate family resources to avoid cancer recurrence or metastasis.

> N11: "I used to dispute with my husband over little things, and I had some disagreements with my mother-in-law about who should care for the kids. After being diagnosed with nasopharyngeal cancer, I realized it was not a big deal and that I could ignore it totally."
>
> N14: "I feel that I can forgive her as long as it is not a moral issue. I do not want my child to be a good student either, I just want her to be good and decent.."
>
> N20: "Now I remind myself that being upset is harmful for the sickness. In reality, we had a poor relationship before. During my sickness, my husband has taken time off work to care for me, and I am quite thankful to him."

Theme 7 Self-emotional comfort

Compared to other malignancies or events such as sudden death, patients feel emotional security in a higher control rate and buffer period of NPC. They can regain confidence and courage to fight NPC.

> N4: "I shifted from not being diagnosed to preferring nasopharyngeal cancer over other cancers." If I feel nasopharyngeal cancer is hope for a cure."
>
> N7: "I am also grateful for this nasopharyngeal cancer. If I hadn't been diagnosed with nasopharyngeal cancer, I have not been able to quietly make amends for some regrettable thing in my life."
>
> N15: "From my point of view, I feel quite lucky. Compared to sudden death, at least the nasopharyngeal cancer did not take me away once."
>
> N21: "We all reassure each other that nasopharyngeal cancer is called "happy cancer" and is better and more treatable than some cancers, so do not worry if your hospital is willing to accept me."

Discussion

The results of the current study show that limited knowledge about NPC and treatment deepens patients' suspicion and leads to illness uncertainty, which increases with the severity of FOP [19, 20]. Illness uncertainty refers to a lack of ability to assess the value of information about disease and to accurately predict outcomes [21]. Patients typically seek medical assistance first because they have faith in the authority of their physicians. Medical workers indeed provide therapeutic information for the purpose of fulfilling patients' demands and lessen their confusion about therapy effects. Medical professionals should give more intuitive knowledge relevant to proton and heavy ion treatment when patients are doubtful about the illness process, such as the severity and duration of radiation. In addition, cancer stigmas and fatalistic beliefs about cancer are prevalent, especially in low- and middle-income countries [22]. Misconceptions such as "cancer is contagious" cause patients to worry about being rejected by colleagues and friends, and lose confidence and courage to return to their normal work and life. Medical staff are encouraged to provide guidance and reinforcement to patients, for the purpose of eliminating the stereotype of cancer from themselves.

Because of its anatomical location and excellent sensitivity, radiotherapy is the main treatment for nasopharyngeal cancer [23]. However, there are up to 22 somatic symptoms caused by radiation and chemotherapy given together [24], such as radiation dermatitis, dry mouth, oral mucositis, loss of appetite, and muscle fibrosis, which severely impair essential physiological functions, fear of not coping with the treatment process [25], and impair the self-efficacy of patients [26]. The incidence of adverse reactions to re-radiotherapy for recurrent nasopharyngeal cancer is as high as 53%,mainly manifested as temporal lobe necrosis, cranial nerve palsy, limited mouth opening and nasopharyngeal hemorrhage, and the incidence of ruptured carotid artery hemorrhage caused by re-radiotherapy is as high as 24%, which seriously affects patients' quality of life [27, 28]. A retrospective analysis of 77 patients with locally recurrent NPC treated with secondary proton heavy ion radiotherapy found that 44.2% of patients died, 53% of whom died from serious adverse effects such as nasopharyngeal hemorrhage caused by retreatment [5]. As a result, NPC patients face difficulty in retreatment after recurrence and the heavy toxic side effects associated with retreatment, which lead to insecurity related to cancer progression. Patients with primary NPC expressed insecurity during the qualitative exploration, because patients with recurrence have already gone through the retreatment process and have greater psychological tolerance than first-episode patients. This result suggests that first-episode patients are a high-risk group for FOP. Adequate education and social support are needed to eliminate patients' FOP and help them build treatment security to overcome NPC.

The results of the qualitative interviews showed that postgraduate and above qualifications were more likely to have a sense of loss, probably due to more achievements in their past work and the disruption of their original rhythm of life due to cancer. After diagnosis, most patients are unemployed or jobless, and their personal value to family and society is impaired. Moreover, it was determined that patients experienced a fear of death. The possibility of cancer recurrence or metastasis is a constant threat to patients' lives, causing patients to focus too much on somatic symptoms and lose their enthusiasm in their struggle for life. Following a cancer diagnosis, the changes in the cancer patient's body are of utmost concern, and any discomfort or abnormal test results are interpreted as a sign that the cancer returned or progressed. Three respondents expressed more intense FOP while waiting for test results than before. A study investigating changes in levels of FOP in 161 cases of female breast cancer patients in the US 1 month before the mammogram appointment,1 week before the scheduled mammogram, before the mammogram was performed immediately after receiving the mammogram results, 1 week after receiving the results and 1 month after receiving the results, showed that levels of FOP increased as the time of examination approached, decreased immediately after receipt of negative mammogram results, and increased 1 month after the mammogram [29].

The study also found that most of the psychological stress experienced by married patients plays an important role in their families and children. In the event of cancer recurrence or metastasis, patients will fail to take on the responsibilities of childcare and supporting elderly individuals. Even further treatment will worsen the financial burden of the family. The findings show that females pay more attention to childcare than to integrating into the family. Four female patients expressed concerns about their children's future development during the interviews. When living with cancer, women focus on increasing tolerance toward their spouse and offspring to create a harmonious family atmosphere to prevent cancer recurrence. Healthcare professionals can encourage patients to express their inner feelings and needs with their spouses, friends, and family members through psychological interventions such as peer support to relieve negative emotions and build up courage to overcome the disease.

Limitations

The main limitation of the study was that patients were recruited from only one proton heavy ion hospital in Shanghai, with limited representation of all NPC patients. Future large sample studies in multiple proton and heavy ion hospitals are suggested. Longitudinal qualitative studies should also be added to identify resources and challenges for patients to cope with the FOP.

Conclusion

A total of 7 themes were extracted, namely, theme 1 illness uncertainty, theme 2 trapped into insecurity (including four categories:insecurity about the possibility of discrimination, insecurity about the possibility of the inability to tolerate the pain of retreatment, insecurity about the difficulty of retreatment after recurrence, and insecurity of waiting for test results),theme 3 hopelessness, theme 4 loss, theme 5 guilt toward children, theme 6 enhancing tolerance toward family, theme 7 self-emotional comfort.

In-depth analysis revealed that patients with initial onset NPC patients expressed more feelings of being trapped into insecurity. Patients at the postgraduate level and above were more inclined to feel loss than those with less education. Women with children experienced a fear of family being affected and guilt about their children. They focused on increasing tolerance toward family to modify their physical and mental state to cope with NPC. Notably, three respondents expressed an intense FOP while waiting for test results. The findings will provide a reference for follow-up analysis of the trajectory of FOP.

Author contribution **Mimi Zheng:** Conceptualization; data curation; formal analysis; investigation; methodology; project administration; software; validation; writing–original draft; writing–review and editing.

Shuman wang: Conceptualization; data curation; formal analysis; investigation; methodology; writing–original draft.

Yu Zhu: Conceptualization; methodology; project administration; writing–review and editing.

Hongwei Wan: Conceptualization; methodology; project administration; writing–review and editing.

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Data availability The datasets generated during and/or analyzed during the current stud yare available from the corresponding author upon reasonable request.

Declarations

Ethics approval The study has been approved by Shanghai Proton and Heavy on Center Institutional Review Board (ethical approval reference number:2202-53-02).

Conflict of interest The authors declare no competing interests.

References

1. Herschbach P, Dinkel A (2014) Fear of Progression. Recent Results in Cancer Research. fortschritte Der Krebsforschung progrès Dans Les Recherches Sur Le Cancer 197:11–29
2. Butow P, Sharpe L, Thewes B et al (2018) Fear of Cancer Recurrence: A Practical Guide for Clinicians. Oncology (Williston Park) 32(1):32–38
3. Yan Hu, Zhenqi Lu (2020) Practical oncology nursing. China: Shanghai Science and Technology Press, (in Chinese)
4. Lee AWM, Ng WT, Chan JYW et al (2019) Management of locally recurrent nasopharyngeal carcinoma. Cancer Treat Rev 79:101890
5. Kong L, Wang L, Shen C et al (2016) Salvage Intensity-Modulated Radiation Therapy (IMRT) for Locally Recurrent Nasopharyngeal Cancer after Definitive IMRT: A Novel Scenario of the Modern Era. Sci Rep 6:32883
6. Li Y, Liu Y, Wei J et al (2019) Analysis of the level of fear of cancer recurrence and factors influencing it in patients with nasopharyngeal carcinoma. Chin J Gen Pract 17(9):1443–1446 (in Chinese)
7. Thewes B, Lebel S, Seguin Leclair C, Butow P (2016) A qualitative exploration of fear of cancer recurrence (FCR) amongst Australian and Canadian breast cancer survivors. Support Care Cancer 24(5):2269–2276
8. Cruickshank S, Steel E, Fenlon D et al (2020) Specialist breast cancer nurses' views on implementing a fear of cancer recurrence intervention in practice: a mixed methods study. Support Care Cancer 28(1):201–210
9. Mutsaers B, Jones G, Rutkowski N et al (2016) When fear of cancer recurrence becomes a clinical issue: a qualitative analysis of features associated with clinical fear of cancer recurrence. Support Care Cancer 24(10):4207–4218
10. Hall DL, Lennes IT, Pirl WF, Friedman ER, Park ER (2017) Fear of recurrence or progression as a link between somatic symptoms and perceived stress among cancer survivors. Support Care Cancer 25(5):1401–1407
11. Zomerdijk N, Jongenelis M, Short CE et al (2021) Prevalence and correlates of psychological distress, unmet supportive care needs, and fear of cancer recurrence among haematological cancer patients during the COVID-19 pandemic. Support Care Cancer 29(12):7755–7764
12. Grau C, Durante M, Georg D, Langendijk JA, Weber DC (2020) Particle therapy in Europe. Mol Oncol 14(7):1492–1499
13. Park JM, Kim JI, Wu HG (2021) Technological Advances in Charged-Particle Therapy. Cancer Res Treat 53(3):635–640
14. Hu J, Huang Q, Gao J et al (2021) Mixed Photon and Carbon-Ion Beam Radiotherapy in the Management of Non-Metastatic Nasopharyngeal Carcinoma. Front Oncol 11:653050
15. Center SPHI (2023) Your concerns about proton heavy ion radiotherapy are here. https://mp.weixin.qq.com/s/RiZNpW0j9bpRWygBepJW3w
16. Lundkvist J, Ekman M, Ericsson SR, Jönsson B, Glimelius B (2005) Proton therapy of cancer: potential clinical advantages and cost-effectiveness. Acta Oncol 44(8):850–861
17. Edward KL, Welch T (2011) The extension of Colaizzi's method of phenomenological enquiry. Contemp Nurse 39(2):163–171
18. Simard S, Savard J (2015) Screening and comorbidity of clinical levels of fear of cancer recurrence. J Cancer Surviv 9(3):481–491
19. Yu Z, Sun D, Sun J (2022) Social Support and Fear of Cancer Recurrence Among Chinese Breast Cancer Survivors: The Mediation Role of Illness Uncertainty. Front Psychol 13:864129
20. Zhang X, Sun D, Wang Z, Qin N (2022) Triggers and Coping Strategies for Fear of Cancer Recurrence in Cancer Survivors: A Qualitative Study. Curr Oncol 29(12):9501–9510
21. Mishel MH (1988) Uncertainty in Illness. J Nurs Scholarsh 20:4
22. Squiers L, Siddiqui M, Kataria I et al (2021) Perceived, Experienced, and Internalized Cancer Stigma: Perspectives of Cancer Patients and Caregivers in India
23. Chen Y, Zhao Y, Yang X et al (2022) USP44 regulates irradiation-induced DNA double-strand break repair and suppresses tumorigenesis in nasopharyngeal carcinoma. Nat Commun 13(1):501
24. Shen Y, Qing W, Li Z, Liu G, Shen A (2017) Analysis of symptom clusters and factors influencing the late phase of simultaneous radiotherapy in patients with nasopharyngeal carcinoma. J Nurs Educ 32(14):1279–1284 (in Chinese)
25. Simard S, Thewes B, Humphris G et al (2013) Fear of cancer recurrence in adult cancer survivors: a systematic review of quantitative studies. J Cancer Surviv 7(3):300–322
26. Kurt S, Altan SN (2022) Correlation of self-efficacy and symptom control in cancer patients. Support Care Cancer 30(7):5849–5857
27. Kong F, Zhou J, Du C et al (2018) Long-term survival and late complications of intensity-modulated radiotherapy for recurrent nasopharyngeal carcinoma. BMC Cancer 18(1):1139
28. Ng WT, Ngan R, Kwong D et al (2018) Prospective, Multicenter, Phase 2 Trial of Induction Chemotherapy Followed by Bio-Chemoradiotherapy for Locally Advanced Recurrent Nasopharyngeal Carcinoma. Int J Radiat Oncol Biol Phys 100(3):630–638
29. McGinty HL, Small BJ, Laronga C, Jacobsen PB (2016) Predictors and patterns of fear of cancer recurrence in breast cancer survivors. Health Psychol 35(1):1–9