Qualitative study of continuing nursing needs in patients with precision radiotherapy for nasopharyngeal carcinoma

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Abstract

Objective: To explore the inner feelings and experiences of patients with precision radiotherapy for nasopharyngeal carcinoma after discharge on continue nursing needs, and to provide theoretical basis for the development of continuing nursing service for patients with nasopharyngeal carcinoma.

Method: By using the phenomenological analysis in qualitative research, face-to-face semistructured in-depth interviews were conducted on 10 nasopharyngeal carcinoma (NPC) patients who received precision radiotherapy, and the data analysis was carried out by phenomenological analysis method, Colaizzi method.

Results: The continuing nursing needs of 10 NPC patients after discharge may be summarized under four main categories: expectation of disease prognosis and self-care related knowledge, expectation of professional psychological counseling and mental care, strong willingness to seek social and family support, and expectation of accessible health services resources.

Conclusion: It is urgent to establish an effective continuous nursing service channel to meet the physical and mental needs of patients with nasopharyngeal carcinoma after discharge, and to continuously improve the life quality of patients with nasopharyngeal carcinoma.

KEYWORDS
nasopharyngeal carcinoma, precision radiotherapy, qualitative studies

1 | INTRODUCTION

Nasopharyngeal carcinoma (NPC) is a malignant tumor that occurs on the top and side walls of the nasopharynx. Eighty percent cases of NPC occurred in the world were found in China. At present, the most commonly medical intervention is comprehensive treatment that includes precision radiotherapy and supplementary therapy combined with chemotherapy and targeted therapy. NPC patients have high rate of occurrence of radiotherapy-induced acute skin and oral reactions which persisted or could be even worsened during and postradiotherapy, and radiation-related severe late complications such as neck fibrosis and trismus and xerostomia. Continuity of care refers to service offered to discharge patients in need of further medical assistant to care for their life, to promote rehabilitation, and give health guidance as an extension of inpatient care service. It is shown that continuity of care given to NPC patients with radiotherapy has effectively improved patients' compliance of rehabilitation training to prevent trismus and contribute to a lower incidence of trismus. In the meantime, the patients have been benefited from better functional rehabilitation.

Most of domestic researches on continuity of care for NPC patients used quantitative research methods and rarely touched on...
the nursing needs from the perspective of patients. Qualitative research which is highly sensitive to the patient's subjective feelings and world view can be used to express true experience of NPC patients about their disease and health. This study used qualitative research methods to understand the health needs after discharge of NPC patients through in-depth interviews to provide reference for the development of continuity of care service.

2 | PARTICIPANT AND METHODS

2.1 | Participant

By using purposive sampling method, untreated NPC patients who were hospitalized in Jiangsu Cancer Hospital from January to December in 2018 were interviewed. Sample size of the study was determined by the principle of data saturation which means when the content of interviews no longer included any new topic; the data reached its saturation. Inclusion criteria: (a) Diagnosis of NPC confirmed by pathological examination with clear pathological staging (T2N2M0); (b) Capacity of expressing their own wishes and communicating without difficulty; (c) Appropriate representativeness showed in samples in terms of status, role, age, gender, and experience; (d) Completion of all treatment plans and discharge from hospital according to the doctor’s advice; (e) Participation voluntarily in the study and signing of the Informed Consent Form. After selection of the preliminary participant, 10 NPC patients were involved in this research considering their representativeness. Participant characteristics are presented in Table 1.

2.2 | Research ethics

Before the interview, the purpose, significance, procedure, method of data collection, treatment and the presentation of the research was explained to the participants, and audio and video recordings were authorized by participants and Informed Consent Form were signed. During the interview, no inducement or intervention were applied upon the participants (patients). All the answers and behaviors of participants were objectively recorded to minimize the bias. To protect participants privacy, all the data collected during this research were anonymized and managed carefully.

2.3 | Data collection method

Followed the phenomenological analysis method in qualitative research, the semistructured in-depth interview method is used. The researcher and the participants agreed on the interview time and place in advance. The choice of the interview location is made based on the principle of quietness, no interference, relaxation, and comfortableness. Before the interview, research explained purpose and methods to the participants, and ensured the confidentiality of the content of the interview. Effective communication skills were used to establish a good relationship of trust with patients, and open-ended questions were used to encourage the participants to express their inner feelings and life experience without unnecessary concerns. Each interview took 20 to 30 minutes, and the whole interview was recorded simultaneously, and nonverbal behaviors and other related observations were recorded in time. The interviews were conducted 3 times with each participant, at the time of discharge, 1 month after discharge, and 3 months after discharge.

The content of the interview includes: (a) As the treatment plan has been completed, what would be the effects of this treatment on your physical, mental, family and social status? (b) What way do you prefer our medical staff to contact you after leaving the hospital? (c) What kind of knowledge guidance do you hope the hospital will give you after discharge and what kind of care to continue to provide for you? Why? (d) During the interview, the content can be rephrased and ways of asking question may be adjusted according to the individual situation of the participant.

2.4 | Data arrangement and analysis methods

Data arrangement method: After the interview, the interview records of each participant are encoded from A to J, and independent files are created. A textual transcription of the recorded material was made in time.

| Code name | Gender | Age | Academic background | Occupation | Medical insurance |
|-----------|--------|-----|---------------------|------------|-------------------|
| A         | F      | 63  | Elementary school  | Farmer     | Rural social endowment insurance |
| B         | M      | 54  | High school        | Worker     | Medical Insurance  |
| C         | M      | 30  | University/college | Student    | Medical insurance  |
| D         | F      | 36  | High school        | Self-employed | Self-payment |
| E         | M      | 50  | University/college | Government officer | Free medical service |
| F         | F      | 55  | Elementary school  | Teacher    | Rural social endowment insurance |
| G         | M      | 62  | High school        | Self-employed | Medical insurance |
| H         | F      | 27  | University/college | Employee   | Medical insurance  |
| I         | F      | 65  | Illiterate         | Farmer     | Rural social endowment insurance |
| J         | M      | 59  | University/college | Teacher    | Free medical service  |
Data analysis method: followed Colaizzi's seven steps, data collected in the interviews were analyzed by using NVIVO11.0 software combined with manual analysis. The specific steps are (a) Read all the information carefully and repeatedly; (b) extract statements with significance to the research questions; (c) Convert recurring ideas into minimal semantic units for coding; (d) Classify the encoded ideas, extract and statements related to continuity of care after discharge; (e) write a detailed, exhaustive description; (f) Identify similar ideas, incorporate and refine the commonalities in the researcher's language to form the subject and theme group of the study; (g) Return to the participant to verify. In this study, these steps were performed for treatment analysis and jointly explored the extracted themes, until a consensus is reached.

2.5 The rigor of research

Representativeness of the subjects were fully considered. After the interview, the observation situation was recalled by the researchers and the recording was listened repeatedly, and converted the interview data into written text within 24 hours. Then, the written results were sent back to the participants to further verify the accuracy and authenticity of the content.

3 RESULTS

After data analysis, four themes were generated.

3.1 Theme 1: Expectation of disease prognosis and self-care related knowledge

All 10 patients showed strong demands on medical information, and they hoped to get guidance and assistance from medical staff, including prognosis of disease and self-care knowledge after treatment. Self-management strategies on side effects of radiotherapy and chemotherapy, especially knowledge of radiation-induced dermatitis, radiation-induced oral mucositis, and exercises to prevent trismus, and so on. Case A: “I heard the process of radiotherapy is very painful and people will be roasted. What should I pay attention after the discharge to minimize the side effects of radiotherapy? Nurse, you are professional and please tell me more information on this subject. what should I do after I go home?” Case J: I also checked a lot of information about nasopharyngeal carcinoma. I heard that Chinese traditional medicine could be beneficial for cancer patients. Is there any side effect while you are using it in long-term?”

3.2 Theme 2: Expectation of professional psychological counseling and mental care

Patients have side effects during radiotherapy and postradiotherapy are likely to have various degrees of negative psychological experience such as self-blame and depression. In addition, uncertainty of the disease among NPC patients usually caused by the unpredictable outcome of the treatment and the prognosis of the disease. The second is the nonspecific symptoms. Six patients in the interview expressed fear of side effects that coming along with radiotherapy, concerns about the prognosis of the disease, and uncertainty about the disease. Three young patients have concerns about their coming back to normal life and society. They are wish to establish emotional communication and can be recognized by others. Case C: “Is it true that nasopharyngeal carcinoma can be cured? What about the recurrence? How long does it take before it comes back? I am still worried whether it can be cured or not.” Case I: “I just talked with another patient. She said that she had relapsed. I am afraid that my cancer will come back soon.”

3.3 Theme 3: Strong willingness to seek social and family support

The patient’s symptoms during the treatment and after treatment are likely to cause various negative psychological experience such as self-blame, depression, so on, and lack of sense of security and belonging after discharge, which needs to be supported by the family and society. Five older participants were particularly concerned about family care after discharge. Case B: “The treatment is finished but I can’t step out of the door with such bad looking. I don’t want others to see me differently.” Case D: “Can I still return to work in the future? I really hope that someone can create a group chat to allow the patients talk with each other and support each other.”

3.4 Theme 4: Expectation of accessible health services resources

Late side effects of radiotherapy can appear months or years after the end of radiotherapy. Only when the patients come back for reexamination, they could get rehabilitation guidance from medical staff. Most of the time after discharge, they do not have the access to a doctor when they have problems and their needs are unmet. Eight patients said that “there is an urgent need for help from hospitals and communities.” “I was discharged from the hospital too soon and the serious side effects of radiotherapy bothers me a lot.”

Strong demands for outpatient follow-ups and telephone follow-ups: Case C “I think post-radiotherapy exercise and nasal irrigation should be a life-long habit. But this is very difficult and I am afraid that if I can stick to it for a long time. I hope that doctors and nurses can contact us often to give us care and support. I will be more determined and confident on it.”

Demand on Convenient Medical Service Channel: Case H “If only you could build a WeChat group or QQ group, then I could ask you for advice when I have a problem.” Case I “When I go home, if my skin condition is aggravated or my nose is bleeding, I will be very
worried. If I don't know what to do, should I come to the hospital immediately? I wish I can have your advice before I went to the hospital."

4 | DISCUSSION

This study shows that NPC patients have diverse and high-demanding needs for out-of-hospital care, including health education, psychological support, family and social support, and health service resources.

4.1 | Strengthen the specialty knowledge education, ameliorate symptoms, and improve self-care ability

NPC has a long treatment cycle, and there are many acute complications during the treatment. After the treatment, chronic complications could persist, resulting in the patient's fairly poor physical and mental state, and lowered quality of life. In addition, many patients suffered from cancer-related fatigue after discharge, characterized by weakness, lack of passion and vulnerability. And it cannot be relieved by rest or sleep.

As reported, nearly 100% of patients wish to get health education related to their own disease treatment, which is consistent with the results of this study. The study found that education on self-care knowledge and methods were significantly inadequate and limited, and patients cannot respond to and deal with mental and physical problems after their discharge. This result suggests that more attention should be paid by clinical nurses to extend the idea of patient-centered holistic care from patient's hospitalization to the time period after the discharge. Therefore, we should continue to make efforts on symptom management, health education with medication guidance, dietary guidance, complications management and response, prevention of disease recurrence, and improvement of patient self-care ability.

4.2 | Provide emotional support, reduce negative psychological experience, and improve patient self-efficacy

NPC patients are affected by various radiotherapy sequelae after discharge, it can result in a depressive emotional reaction of patients, and eventually lead the failure of taking the responsibility for the family and society. Especially for young female patients who pay more attention to their appearance, it is more likely to contribute to the sense of inferiority and depression. Studies have shown that the degree of depression in NPC patients increases at the beginning of treatment and is related to the symptoms; the level of anxiety increases first with the treatment process, and then relieves. After 1 year after the completion of treatment, the level of anxiety about relapse will increase again. This anxiety may lower the immunocompetence and increase the probability of recurrence.

Therefore, as for continuity of care, we should pay attention to the psychological problems of patients, utilize appropriate communication methods for different patients, encourage young patients to express their inner thoughts and needs, patiently explain the prognosis of the disease, relieve concerns, and encourage exchanges between peers. Effective communication channels such as WeChat group and QQ group are beneficial to physical and mental health of patients. For older patients, it could be more efficient and effective to use easy-to-understand language to explain complex medical questions. Furthermore, high level of involvement and participation of their family members in this process also helps to relieve their anxiety and uneasiness.

4.3 | Establish family and social support system to improve the quality of life

Family is a very important social support system for patients. The attitude and support of the caregiver is essential for the rehabilitation of the patient. He (She) is not able to work or study like he used to and need family care. Heavy economic burden and psychological pressure is also there. And support and care from the family is more important than ever. But some problems are far beyond the range of abilities of family caregiver or individual family. All participants in this study demand to receive professional care and guidance. And more importantly, social and financial support and assistance. Therefore, assisting patients to establish good family and social support is particularly important for patient recovery. We should carefully assess the needs of the main caregivers of the patients and the social background of the patients, and establish convenient communication channels, provide relevant information to the caregivers, provide timely and targeted professional care and psychological counseling services, and effectively reduce the burden on the patients to resolve physical and mental problems for patients and help them reintegrate into society.

4.4 | Provide convenient medical service channels to improve patient satisfaction with health care work

This study demonstrated that 10 NPC patients showed strong needs of continuity of care, and patients with higher education tend to use WeChat to strengthen communication with the hospital; Literature surveys show that with increasing health awareness, patients are willing to be discharged from hospital and receiving continuity of care service, and such needs of patients with chronic diseases are particularly prominent which is basically consistent with the results of this study. The Outline of China’s Nursing Care Development Plan (2016-2020) proposes that the field of nursing services should be gradually extended to families and communities, and plays an active role in elderly care, chronic disease care, and hospice care, and the field of nursing services continuously need to be expanded.
Therefore, we should establish files of patients for their full-process health management. According to the patient’s discharge time, symptoms, care satisfaction and needs, we should take a variety of methods after the discharge, including telephone feedback collection, home visits, and outpatient clinics to provide personalized medical care services for patients. For example, young and middle-aged patients with higher education level and strong self-care ability can choose health lectures/talks, telephone follow-ups, and WeChat consultations, and so on. For older patients with low education level, insufficient self-care ability, and poor compliance, we should pay more attention to daily life care and family visits could be a good option for them. According to the characteristics and changes of the demand, the corresponding follow-up plan, follow-up content and follow-up frequency should be formulated to meet the health care and their needs of medical information should be met to improve their self-management compliance.

5 | CONCLUSION

The study showed that patients have a higher level of demand for continuity of care, and that the change in demand is affected by many factors. In this study, we conducted an in-depth interview among 10 discharged NPC patients by qualitative analysis. For the purpose of objectively presenting their demand for continuity of care after discharge, and afterwards, four themes were extracted. The results of the study can help medical staff provide medical care support, human care and customized extended care service to meet the changing physiological, psychological and social needs of patients to improve their quality of life. However, the sample size in this study is limited in amount, so the conclusion after the interviews can only partially reveal experience(s) of the participants, which may affect the generalization of the results, and further development is needed in the theme extraction. In the future work, more quantitative researches and analyses will be carried out on the basis of the results of qualitative research obtained in this study in order to explore need of continuity of care for patients with NPC at different ages and disease progression to better guide nursing work.

CONFLICT OF INTEREST

The authors have no conflicts of interest to declare.

AUTHOR CONTRIBUTIONS

XL: survey concept and design; assisting in collecting and analyzing data; manuscript preparation and review
JL: assisted in survey concept; assisted in analyzing data
SL: assisted in survey concept and design; manuscript review
YW: assisted in collecting and analyzing data
DX: survey concept and design; manuscript review

ETHICS STATEMENT

The study was approved by the Jiangsu Cancer Hospital Ethics Committee and all patients gave written informed consent.

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