

Self-management through Perceived Symptoms Impact among Patients with Nasopharyngeal Cancer during Phase 1 of Cancer Trajectory

Che Azunie Che Abdullah¹, Sanisah Saidi^{1*}, Siew Pien Lee²

¹Medical-Surgical Nursing Department, Kulliyah of Nursing, International Islamic University Malaysia, Kuantan Campus, 25100, Kuantan, Pahang, Malaysia

²Special Care Nursing Department, Kulliyah of Nursing, International Islamic University Malaysia, Kuantan Campus, 25100, Kuantan, Pahang, Malaysia

Corresponding email: *sanisahsaidi@iium.edu.my

ABSTRACT

Objective: This study is conducted to understand in-depth the self-management experience among the patients with nasopharyngeal cancer during the phase 1 of identification of the symptoms.

Method: Individual semi-structured interviews were held with patients diagnosed with nasopharyngeal cancer (N=16) in two general hospitals in Malaysia. Data were transcribed and analysed using framework analysis. Four phases of cancer trajectory identified. In this article, themes emerged in phase 1 is in focus.

Results: The finding suggest that during phase 1, patients self-manage their early symptoms of nasopharyngeal cancer based on their perception of the impact of the symptoms towards their life, because of the absent of knowledge on nasopharyngeal cancer.

Conclusion: Adequate, appropriate knowledge and information provision on nasopharyngeal cancer among public is highly in demand. It is crucial in promoting effective self-management on symptoms identification and subsequently early detection of nasopharyngeal cancer.

Keywords: self-management, nasopharyngeal cancer, symptoms identification, early cancer detection

Correspondence:

Sanisah Saidi

¹Medical-Surgical Nursing Department, Kulliyah of Nursing, International Islamic University Malaysia, Kuantan Campus, 25100, Kuantan, Pahang, Malaysia

Corresponding email: *sanisahsaidi@iium.edu.my

INTRODUCTION

Self-management refers to an individual's ability to manage the symptoms, treatment, physical, psychosocial, and lifestyle changes inherent in living with a chronic condition. This concept is translated based on the perspective of oneself or from a different field (1). In order to achieve the best outcome of self-management (as measured with good clinical outcome, reduced health care expenditure and subsequently improves quality of life), active participation from the patients, family, community and health care providers is essential during management of the disease. Knowledge and resources become as the basic elements to ensure active participation and autonomy on decision making after well-equipped with information regarding the treatment given (1) and has been reported in many studies earlier (2-4)

However, perceive needs of sufficient knowledge and information through various phases of cancer trajectory had been reported in many previous studies (5-10). During treatment, sufficient knowledge and information was needed because the patients felt that they were inexperienced and lack of knowledge because living with cancer and side effects of the treatment was not a usual thing they faced. But, they also highly concern that the information or knowledge given must acknowledge their inexperience with cancer, so that they may absorbed the information given more effectively (7). Meta-syntheses of 21 qualitative studies into symptom experience of adult cancer patients after treatments from systematic review by Bennion & Molassiotis (10) revealed that despite of variety of cancer types and symptom experience, shared themes found across the studies was 'interacting with the health service and need for information'. Patients did not get sufficient information for their condition from their health care provider (HCP) during their meeting after

treatment. In long term care, cancer survivors need to see their HCP face to face, ensuring accurate information, ownership, and access to their medical records in order to reassure sufficient information and knowledge for them to self-manage their condition (8). Discrepancies in information provided with what they experience throughout the cancer treatment really disappointed them make them distressed from the disrupted expectation (6). Continuous information provision is crucially needed so that they would know how to react to this disruptive situation which may promote them to effectively self-manage themselves (9). Needs on various types of information was reported among 360 cancer patients (5) including nasopharyngeal cancer (NPC) patients (11).

Nonetheless, most of the previous studies reported on the experience of self-management during the phases where cancer patients already diagnosed with cancer, during treatments and after treatment ends. How about their experience of self-management before they coming to have their first health check up with the symptoms? Patients were reported to commonly come at late stages of NPC, which is at stage III and IV (12-14). Most of the patients diagnosed with NPC usually have unavoidable risk factors, therefore this type of cancer is hardly prevented (15,16). Even so, some modifiable risk factors had been identified (Epstein-Barr virus (EBV), salt-preserved fish, lack of fresh fruits and vegetables, chronic respiratory tract conditions, tobacco smoke, herbal medicines, occupational dusts, and formaldehyde) that could help in prevention of NPC (16). Yet, the situation when patient identified the symptoms before coming for health check-up still not fully understand, which brings them to late presentation of NPC. Therefore, the present study aimed to explore and understand how patients with NPC manage their condition upon they identified the

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symptoms before coming to professional health check-up and understand their late presentation.

Methods

Qualitative design was applied for this study to gather in-depth information among sixteen patients diagnosed with NPC from two general hospitals in Malaysia by using purposeful sampling (17). Inclusion criteria were set prior to recruitment; Malaysian, diagnosed with NPC, 18 years old and above, able to communicate in Malay or English, and willing to participate in this study. Ethical approval has been obtained prior to the access into the hospitals. Individual semi-structured interview (18) was conducted in a specific room that allowed for private communication between patients and researcher. Example of topic guide used is as in Table 1. Data from interviews were transcribed verbatim and analysed using framework analysis (19).

Table 1. Topic Guide for Patients with NPC

Start question.
- Background/demographic questions to get particulars demographic from the participants; age, income, education, job status, and other relevant demographic data
Open questions:
- Opinion and value question where the researcher is interested in the NPC patients understanding, belief, feelings, attitude, and what the person think of NPC and its treatment.
- The way they manage their condition with NPC.
- Understanding and perspective of self-management
- The barrier/challenges they experience when managing their condition.
- The factor that can help them to manage their condition better.
- The need they perceive that is lacking to manage themselves.

Results and discussion

Participants' description

Sixteen patients with NPC had participated in this study, with 11 from them were Chinese. Another five patients were Malay. Thirteen of the patients involved in observation as another method of data collection in this study. Their age ranged from 38 to 67 years old with mean age of 53. Majority of them that was 13 of them were male. All of them were married (except for one patient) and their spouse is staying with them. Eight of them were having small children who were still in preschool, or in other educational level. Nine of the patients are in their productive age range that was from 38 to 60 years old (Table 2) and most of them are the head of the family. Unfortunately, six of them need to quit their job once they were confirmed with NPC to pursue treatment. Only one patient was able to obtain three months of unpaid sick leave for his treatment. Three of them whom completed treatment two years and above were able to return working, even at part time basis to suit with their new health condition after treatment of NPC. The rest were retirees and housewives.

From the aspect of medical-related information, majority of the patients (12 participants) were diagnosed with Stage III and IV NPC. Only three of them presented at early stage of cancer. They were either still in treatment (10 patients) or had completed their treatment (5 patients) during participation in this study. There was one patient who came to the clinic to request for re-examination for his NPC after defaulting his first treatment for a few months. Most of them were treated with combination of radiotherapy chemotherapy, commonly as neoadjuvant chemotherapy and once weekly during radiotherapy course.

Table 2. Percentage of Demographic Characteristic and Medical-related Information of Nasopharyngeal Cancer Patients Interviewed

Characteristic	n	%
Age range (Mean = 53)		
38 - 40	2	12.5
41 - 50	4	25.0
51 - 60	3	18.8
61 - 67	7	43.7
Gender		
Male	13	81.3
Female	3	18.7
Race or ethnicity		
Chinese	11	68.8
Malay	5	31.2
Marital status		
Married	15	93.8
Unmarried	1	6.2
Current employment status		
Unemployed	7	43.8
Self-employed	3	18.7
Retiree	4	25
Housewife	2	12.5
Educational level		
Primary	1	6.2

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Secondary College/university	11 4	68.8 25
Case study site		
Site 1	7	43.8
Site 2	1	6.2
Site 3	8	50
NPC stage		
Stage 0	1	6.2
Stage I	1	6.2
Stage II	1	6.2
Stage III-IV	12	75
unknown	1	6.2
Treatment type		
CCRT	11	68.8
RT only	3	18.8
CCRT with palliative chemo	1	6.2
Default treatment	1	6.2
Treatment status during study participation		
In treatment	10	62.5
Post-treatment	5	31.3
Treatment defaulter	1	6.2

CCRT: Neoadjuvant chemotherapy with concurrent chemo-radiotherapy RT: radiotherapy

Experience of self-management throughout cancer trajectory

The experience of self-management of patients living with NPC throughout their cancer trajectory is outlined in four divided phases according to the themes and categories emerged from the framework analysis. Cancer trajectory is defined in this study as the live journey, experienced by the NPC patients from the beginning of identification of the symptoms until life years after treatment completion. In this article, phase 1 of NPC trajectory is in focus. Themes and categories emerged for phase 1 is as in Table 3.

Table 3. Theme and Categories Describing Experience of Self-management of Patients with Nasopharyngeal Cancer during Phase One of Cancer Trajectory

Themes	Categories
Self-management through perceived symptoms' impact	Perception and knowledge of NPC symptoms Physical and Socio-economic impact Family enforcement

During the phase 1, description of the NPC symptoms experienced, their perception on the symptoms, and how they finally managed by deciding to go to for medical consultation is detailed in this section. At this time, patients were interviewed about the condition when they first identified that there was something wrong with their health. It is very important to dig down into the experience and perception of self-management of the patients during this phase. This is because they were literally 'left alone' in the community to manage the unpredicted and new experience symptoms without health providers' involvement.

Neck nodes swelling was the most frequent symptoms identified by five of the patients, either bilaterally or unilaterally. They described the swelling as 'painful', 'painless but uncomfortable', that varies in sizes described by 'almost unnoticed swelling', 'swelling like a bursting abscess'. They presented the neck nodes swelling with or without fever. Four of the patients

experienced frequent nose bleeding with or without headache that they perceived stimulated by lifting or doing heavy workload. Another nasal symptom experienced by one of the patients was loss of smell that she related with 'growth inside the nose'. For ophthalmic-neurologic symptoms (20), two of the patients experienced of gradual reduced of one side of eyesight with facial swelling and another two patients were having squinted eyes and double vision. They also complained of ear block and 'feeling like water inside the ear' to describe ear fullness (two patients). Other first symptom identifications were frequent blood-stained saliva (two patients), frequent vomiting after food (one patient), and significant weight loss (one patient).

At this state, they were on themselves to decide the way they need to manage these abnormalities that they have in hand. From the analysis process of interview data with the patients, it was found that they manage the symptoms based on their *perceived symptoms' impact* that explained as follows.

Self-management through perceive symptoms 'impact

From the interview the patients mostly noticed that there was something wrong with their health, but they never expected that the symptoms would lead to a cancer diagnosis, let alone NPC. Once they identified the abnormality to their health, subsequent management towards the symptoms was influenced by three categories which are perception and knowledge of NPC symptoms, physical and socio-economic impact of the symptoms, and family enforcement. Each of the category is explained in detail in the following subsections.

Perception and knowledge of NPC symptoms

It is difficult to separate the explanation of perception and knowledge towards NPC symptoms since both of these dimensions related to each other to influence the way patients with NPC self-manage themselves. In this study, most of the patients perceived that the symptoms they identified were something that associated with other life issues such as related to heavy workload, or other health issues but never expected NPC. It was because they were having for example nose bleeding while working, or

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node swelling that was too small to notice, or very light blood-stained sputum.

Adding to the situation, they admitted that they were very clueless and ignore the symptoms because they perceived that no special impact of the symptoms towards their lives. They are still able to work or do usual activities even with slight disturbances and become uncomfortable with the presence of the first symptoms identified. These statements indicate a very poor knowledge about NPC and its early possible symptoms that affected their health. They never have the information and knowledge that the symptoms might contribute to a cancer diagnosis. This was how some of them kept the symptoms to themselves for one year before their condition become worsen as explain in the excerpt below. There were no active management from the patients when they perceived the symptoms as unalarmed because of no knowledge of this cancer.

"When I was first experienced this cancer, I had severe nose bleeding, headache. After one year I had this (symptoms), I went to see the doctor. I was so young at that time; I did not know (that it was NPC)" (Mrs L)

"I was diagnosed with this cancer in 2016, I had blood-stained 'sputum', and feeling like watery ear. But there was actually nothing found in my ear. I thought was it because of the hot weather? I was a foreman, when I was tired working [under the hot sun repairing boat] I just got myself some alcohol, so just ignore and just let alone the feeling of watery ear"

"I thought I started to have cancer in 2015, since I had the blood-stained saliva since then, but it seemed very light" (Mr O)

One study (21) had reported about almost the same situation happened among cancer patients in Australia where, they tend to appraise the symptoms as not severe and just decide to ignore them. They tried to reason the abnormality they noticed with some other factors, without considering cancer as one of the contributing factors. As found in this study, the same situation happened, and worsen since them actually totally unaware of the existence of NPC and its related features. A Malaysian study (22) had concluded in the discussion that the likelihood of the public engaging in cancer screening depends greatly on how much they perceived that they susceptible to getting cancer. This study explained the reason of late active management and health seeking from the patients experience with NPC symptoms at this phase. They have no perceived cancer susceptibility at this phase within their thoughts.

Health Belief Model (HBM) that being widely used to explain on health behaviours, could explain this situation as well (23). Based on one of the primary concepts in this model that could predict on people's behaviour, or why they take certain action to control their illness is the concept of 'perceived susceptibility'. It refers to beliefs of getting a disease, before them having interest to obtain certain health check-up. However, since all of the patients in this study never exposed to NPC information, no action influenced by the belief of getting the cancer was occurred.

Decision to initiate early health consult is very crucial self-management at this phase in promoting early cancer diagnosis. Hence, effort towards patients' empowerment to initiate effective self-management at this phase is undeniably crucial. One of the efforts towards people

empowerment is by providing adequate knowledge and information on NPC occurrence. This effort was proven to yield more active health screening behaviour among participants whom given information on colon cancer after post-test in a study previously (24). Apart from that, during provision of information on NPC, target population or people at risk should be defined carefully and clearly to enhance the value of the information given out to public based on the concept of 'perceived susceptibility' and the influence of 'perception and knowledge of NPC' in this study towards self-management.

Physical and Socio-economic impact

Patients 'perception towards the symptoms changed to more alarming when the symptoms worsen and gave significant impact to their physical well-being. Significant physical impacts started to create more serious attention from the patients to realize that something was really went wrong with their health. This perception seemed to change when the symptoms started to show significant physical impacts such as unbearable pain from neck swelling, significant impairment of vision (poor vision or duplication) and severe headache. Subsequently, these physical impacts triggered impairment of their normal daily activity as well as working ability. This was the point when they started to have issues in doing normal working task. Then, they started to feel the urge to correct the situation by asking for health consult, since they need to return working and do daily activities.

Excerpts below are examples to portray this critical situation.

"I was baker. I had to quit working because my eyes could not see"

"I was in fear at first because I started to experience poorer and poorer eyesight gradually" (Mrs W)

"It was in previous February [this year], it was very hot climate, I had nose bleeding. It was very frequent, non-stop. A lot. I thought it was something normal, so I just went to clinic. At first, it was not that much [bleeding]. But during the third week, it was becoming a lot, during working time"

"...suddenly I noticed blood. I was shocked when blood coming from my nose when I was lifting heavy loads. It was during working time. So, I stop lifting these heavy stuffs, so as doing other heavy workload" (Mr R)

Realizing that without adequate knowledge and awareness on NPC, patients were only reacted more actively towards the existence of the symptoms when they perceived that the symptoms started to give substantial physical impact to their health. Followed by that, limitation to do normal physical activity including working initiated socio-economic impact to their lives. They admitted that when they were suffering from for example 'unbearable pain' from neck swelling or headache, 'poor vision', or 'frequent nose bleeding upon working', it would gradually force them to quit working and having health consult because of physical limitation in doing normal activity. All of these situations swayed their financial stability. Most of the patients in this study were male at their productive age, mostly between 38 to 60 years old. Above all that, they were all married with wife and children to take care of, which could explain that the urge of health consult started since they need to return to work to earn for the family. A 'functional family'

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or a normal functioning family is believed to have the members to play their roles. A father is expected to become the leader, main breadwinner in the family and 'must have a job' in order to play their role effectively. (25). The ability to maintain the role as the head of the family is crucial in striving for family stability and balance. For most of the patients participated in this study, during this phase 1 of their cancer journey, physical limitation followed by affected working activity had been disturbed the normal functional family. It urged them to manage the symptoms more actively, in effort to regain the stability of the family.

As explained in the second concepts of HBM, the situation where the patients started to realized that the symptoms affected them physically and socio-economically is characterized by the concepts of 'perceived severity'. In HBM, relationship between 'perceive susceptibility' (as discussed in **Physical and Socio-economic impact**) and 'perceive severity' has not been established, but among patients with NPC in this study, the patients depended mostly on their perception of severity of the symptoms before they could do self-management actively.

Family enforcement

Family enforcement is defined in this study as the advice or insistent from spouse/family members for patients to seek for medical consultation. Family enforcement is categorized under perceived symptoms impact as well since it created the supportive urgency on the patients' perception towards the severity of the symptoms. During phase 1, only two out of 16 patients had mentioned about the involvement of wife or family members in the decision of how to manage the symptoms experienced by the patients. Even so, it is still can be considered as one of the most important factors to decide the type of management chose by the patients. This is because, advice to seek for medical consultation from family members or wife act as enforcement to the decision for active symptom management. This situation can be explained from the excerpts from the patients as below.

"...at that time, I was having fever...having high temperature...there was swollen nodes...I went to the clinic for some medicine...antibiotic. There was no change [on the swollen nodes] during this first clinic visit...just stop the swollen nodes to bigger in size for a while, then no change. That thing [nodes] became more swollen...bigger in size at neck. My siblings asked me to go to the clinic again in Balok...went there...got the same medication...still not healing the nodes. So, at last I went to another clinic in Kemaman" (Mr Y)

"I made my own decision [to come for recheck-up]. I had discussed this with my wife. She said that I must come for re-checking to see how my condition is. I said to her if the cancer is still there then I must do the treatment" (Mr A)

Involvement of spouse and family members towards supporting self-management of the symptoms identified by the patients should not be considered lightly because they are the closest people around the patients at this phase. In a collectivist family culture as in Malaysia, spouse and other family members' opinion and emotion are shared among the family (25,26). Thus, if the spouse or any member of the family perceived that the patients should go and have medical check-up for the symptoms, it will increase the potential for the patients to have their

early check-up. These findings also heighten the important of educating and providing adequate information and knowledge to the public regarding NPC. Information and advice from the people in the life circle of the patient could possibly contribute to early presentation to proper medical check-up.

Conclusion

Phase 1 of NPC trajectory could be highly considered as one of the most valuable findings in this study. By describing the experience of the patients using cancer trajectory phases, the real situation of the patients since the first early symptoms of NPC can be understood more in-depth. It seems that they actually have the problem of actively self-manage themselves with the symptoms because of the lack of knowledge of the cancer. These findings were rarely reported in any of the studies previously. Regrettably, the problem towards effective self-management of the patients might originally source as early as from this first trajectory of cancer that subsequently affects the whole life journey. This is due to prolong active management of the early symptoms that will result in late health consultation and late diagnosis.

Apart from that, it is understandable from the findings that patients would initiate their active self-management of the symptoms when they perceived that the symptoms impact their physical health which subsequently affect their normal daily activities including working. This situation affects them significantly since most of the participants were still in their productive age and have families to take care of. Until then, they usually would ignore the symptoms and never expected that it would lead to a cancer diagnosis. Family enforcement also help in some of the patients to go for medical check-up. Patients self-manage their early symptoms of nasopharyngeal cancer based on their perception of the impact of the symptoms towards their life, because of the absent of knowledge on nasopharyngeal cancer. This situation indicates that adequate, appropriate knowledge and information provision on nasopharyngeal cancer among public is highly in demand. It is crucial in promoting effective self-management on symptoms identification and subsequently early detection of nasopharyngeal cancer

Acknowledgement

This project was funded by the International Islamic University Research Grant-Research Initiative Grant 2017. There is no conflict of interests in this project.

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