

Process of Accepting the Disease: **A Self-management of Patient with Nasopharyngeal Cancer**

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ABSTRACT

Background: To understand and explore in-depth the self-management experience of patients with nasopharyngeal cancer when accepting the cancer diagnosis as part of their cancer trajectory.

Methods: An exploratory qualitative case study design was conducted based on the study objective. One-on-one in-depth semi-structured interviews were held among patients diagnosed with nasopharyngeal cancer (N=16) of two primary hospitals in Malaysia by using purposive sampling. Data were transcribed verbatim and analysed using framework analysis approach (data management, descriptive account, explanatory account).

Results: This article presents patients' experiences during diagnosis and how they managed this situation. A theme called the Process of accepting the disease emerged to portray this experience with a subtheme - emotional changes and management when they receive their nasopharyngeal cancer diagnosis. Feelings and situations were described by emotional discouragement and embracing fate, which had been self-managed by avoidance and trying to comprehend.

Conclusion: Patients experienced grief like other types of cancer patients, although nasopharyngeal cancer was reported to have a good prognosis with effective treatment provision. They were burdened by the cancer diagnosis and avoided having thought about it while struggling to comprehend their own health. It was evidenced that patients critically need and profound for health infacception related to various aspects of cancer and treatment during this phase. Therefore, these findings strongly recommend that healthcare professionals to address this need particularly among those who are newly diagnosed with nasopharyngeal cancer to help them accepting their cancer diagnosis.

Keywords: Self-management; nasopharyngeal cancer; cancer acceptance; cancer diagnosis; emotional management.

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INTRODUCTION

Cancer including nasopharyngeal cancer (NPC), a life-threatening disease with its demanding and burdensome treatment, is continuously associated with a deep emotion. This was evidenced by a previous report that 30%–40% of people diagnosed with cancer are seen at an increasing rate for psychiatric disorders, commonly delirium, depression, adjustment disorders, anxiety, sexual dysfunctions, and sleep disorders, which overall affect their quality of life (1).

Based on the literature, self-management (SM) is evidenced to be one of the remarkable factors in managing a complex and chronic condition as in a cancer trajectory (2). Self-management is defined as the ability of an individual to manage several aspects of his/her life with chronic illness namely, (1) ability to manage his medical condition, (2) ability to manage his life role, and (3), ability to manage emotional sequel after the illness. However, effective SM is also influenced by many factors (3,4). Studies suggested that interrelated factors behind people's beliefs and backgrounds should be considered to understand SM behaviour. People's beliefs, either health beliefs or beliefs in treatment effectiveness, have been explored as one of the important factors in SM engagement. Background, age group, economic status (5–7), knowledge and medical history (8) influenced SM engagement in their chronic illness. The type/nature of the disease and its treatment have also been suggested as other factors to engage with SM (5,7,8).

The impact and severity of side effects experienced from treatment, lack of confidence to choose SM activities, and lack of control in minimising the consequences of cancer treatment were the key barriers to cancer patients (4,5,9). Besides, treatment duration and prognosis of the disease are also (3) other factors that could influence SM, either as the facilitators or barriers (3). Therefore, it could be seen that SM is unique to certain groups of people. Thus, this study aimed at understanding and exploring in-depth the SM process undergone by patients with NPC during diagnosis. This understanding could contribute to more efficient and effective SM support and intervention tailored to the specific

group of people during this phase of their cancer trajectory.

METHODS

Qualitative design, which applies the objective of exploring how people make sense of their lives and experiences (10,11) is in concordance with this study which explores how people living with NPC perceive or make sense of SM in their daily lives when receiving the cancer diagnosis (11–13).

Purposive and snowball sampling were used for patient recruitment based on inclusion criteria (13). They would be included if they were diagnosed with NPC, Malaysian, age 18 years old and above, able to communicate in Malay or English, and willing to participate in this study. They were recruited from the ear, nose, and throat (ENT) specialist clinic, oncology ward, and oncology and radiotherapy department of two tertiary hospitals in Malaysia. These hospitals provide tertiary services to Pahang (one of the biggest states in Malaysia) residents and act as one of the major referral centres for NPC patients (14)

In-depth semi-structured interviews were carried out as a data collection method and voice recorded upon written informed consent. The interview was conducted in a room or place that could provide privacy and comfortable to both participant and interviewer. Data from the interview were transcribed verbatim and analysed using framework analysis by Ritchie, Lewis, & Elam (15,16).

This analysis involved three major steps. First, data management; where familiarisation of the interview transcript took place and produced initial themes and concepts that generally go along with the objectives formulated priorly. However, the themes and concepts produced were very superficial in providing the information to answer research questions adequately. Initial themes were labelled, tagged, and sorted based on the similarities or initial patterns that showed, assisted by NVivo software. A preliminary thematic framework will be produced from this step one (**Table 1**).

Table 1: Preliminary Thematic Framework for Patients Interview Data

Q.1 Experience of self-management when receiving nasopharyngeal cancer diagnosis
1.1 psychosocial aspect
1.1.1 emotional and psychological disturbances
1.1.2 lifestyle and behaviour change
1.1.3 spirituality aspects
1.2 Self-management strategies
1.3 Psychological management
1.3.1 deviation techniques
1.3.2 just let go

Second, descriptive account where interview excerpts were assigned to the initial themes or categories to further refine their meaning. This process was conducted by reducing the interview excerpt into more meaningful data and by maintaining the participants' words as much as possible. This stage s conducted by using a framework or table. The descriptive account continues to refine the data further and sort the initial themes and concepts into actual themes and categories. Lastly, explanatory account, where all the findings were explained to make sense of the study findings.

To ensure the study's trustworthiness, the four indicators established by Guba and Lincoln(17) credibility, dependability, transferability, and confirmability - were used to examine the rigour of the research (15,16). Along the process of data analysis, credibility and dependability were ensured by conducting peer examination/member checking during the data collection method and data analysis. During initial phase of data collection, identification of suitable data sources was carried out together with study team members. Later on, during the data analysis phase, the initial thematic framework produced was discussed together to achieve the final themes used to explain the findings of this study. Members consisted of four study team members. Reflexivity, and audit trail had been implemented on how the study is conducted and how the study is analysed to ensure consistency of the findings. To enhance the probability of transferability, a thick, rich description of participants' interview data was acquired and presented so that readers could decide upon themselves whether the study findings could be transferable to their particular situation Conformability, or aware of

the researcher's position or reflexivity (18), is another dimension of ensuring rigorous qualitative study has been conducted by being aware of researcher as a human instrument during data collection and when doing analysis. The researcher's background as a nurse educator also will influence the thought, feelings, perspective and understanding of the findings. To reduce these biases, the researcher had maintained reflexivity by being aware of their personal perspective or belief and bracketing it during data collection and analysis.

RESULTS AND DISCUSSION

Participant's descriptions

Out of 20 patients approached, 16 participated in this study. Five of them were Malay and 11 were Chinese. Their age ranged from 38 to 67 years old with mean of 53. Thirteen were males and the rest were females. The demographic characteristics of the participants were in line with the unique features of NPC occurrence in Malaysia, most commonly among Chinese, followed by Malays and males were two to three times more in incidence than females (19,20) The majority of the patients (12 participants) were diagnosed with Stage III and IV NPC. Only four of them presented at an early stage of cancer.

Theme

A theme called the *Process of accepting the disease* emerged to portray patients' experiences when they were diagnosed with NPC and how they managed this situation. It consists of two subthemes that highlight the emotional changes and emotional management of patients when they receive news on NPC diagnosis, as in **Table 2**.

Subtheme 1: Emotional Changes

This subtheme explains the turmoil when patients first received news of the NPC diagnosis. It could be seen that a group of them had described a devastating feeling that made them discouraged. Surprisingly, another contrary group described a positive emotional attitude upon cancer diagnosis by being optimistic and embracing their fate. They described a mixture of emotional changes upon

Table 2: Theme, Subthemes, and Categories Describing Experience and Self-Management of Patients When Receiving Diagnosis

Theme	Subthemes	Categories
<i>Process of accepting the disease</i>	Emotional changes	Feeling discouraged versus embracing the fate
	Emotional management	Avoidance Comprehending the NPC occurrence

diagnosis acceptance that was further discussed as follows:

Feeling discouragement versus embracing the fate

‘Emotional discouragement’ narrates the ill feelings described when they received news of cancer diagnosis. They described various situations or mentioned many terms that referred to these ill feelings. Patients who felt discouraged and sad described ‘feeling lost’, ‘isolation’ and ‘injustice and disappointment’ that greatly tortured them upon the diagnosis of NPC.

“I am so sad. Because of having cancer. I did not smoke but still have nose cancer. It is very disappointing. I did not drink. I took less sweet and salty food.”

(Mr A)

“...when the result came out and it was cancer, I felt lost. I could not work...just sat pensively...but when I realise that in this life death is a must, I have no option but accept it [the cancer diagnosis].”

(Mr Y)

From these excerpts, patients were depressed, questioning the cancer occurrence, and overwhelmed with fear of dying characterised by denial, anger, and depression as in the stage of grieving(18) This situation was challenging for them to comprehend. They felt it was out of their hands and experienced the hopelessness of living with cancer. Patients majorly portrayed emotional suffering with the NPC diagnosis. Patients tried to suppress their negative feelings, discouraged by dying thoughts, emotional burden, and suppression because they were diagnosed with cancer that

they had never thought about. The stigma propagated over the last decades regarding cancer and death (19, 25) might explain the way patients had felt at this phase.

Patients who were newly diagnosed were reported to have more severe depressive symptoms, anxiety symptoms, and stress levels than those who have a longer history of cancer. (23) From 2008 to 2013, 31 out of 50 suicide cases by jumping from high floors in public hospitals in Malaysia were occurred among cancer patients(1,24). Furthermore, various psychiatric disorders have been reported among them as well (1). This indicated their difficulties in managing emotional stress and discouragement upon a cancer diagnosis.

While saying that, interestingly, the other group of patients had described their feelings as being optimistic, embracing fate when they were diagnosed with NPC. For example, as said by these Chinese patients, Mr B and Mr S;

“My condition was okay at the first time diagnosed with cancer. Not much problem.”

“Mine was so special you know. I have no bleeding and all. It also does not affect my eyes. Only my ear.”
(Mr B)

“I was not shocked [with the cancer diagnosis]. It [cancer] is there then just go and see the doctor. It was not like when having cancer, everything is difficult. Just see the doctor. Please don’t think that way [difficult]. Do not think about dying, when it’s cancer, just see the doctor.”

(Mr S)

Optimism in accepting the fate of cancer diagnosis was related to the ability to manage their emotion during the dreadful event. On the contrary, it has been reported that patients with more cancer-related complaints suffered from a higher level of psychological distress and poorer illness acceptance(20) However, these findings were based on the participants’ symptoms of fatigue, pain, and sleep quality. As in this current study, it was the head and neck symptoms that seriously impaired patients’ daily activities which might include, but not limited to pain and disturbed sleep quality. Therefore, comparison with other cancer types on emotional management should be cautiously interpreted. Besides, optimistic patients were able to decide what to do with

cancer and seemed ready to handle the illness with treatment.

Many studies regarded being optimistic about life-threatening diseases as a denial process. Based on the Five Stages of Grieving model by Kubler Ross, patients who undergo life-threatening illnesses such as cancer experience the five stages: denial, anger, bargaining, depression, and acceptance (21) of SM strategies in this phase of NPC trajectory might indicate that patients started to enter the stage of acceptance in the stages of grieving (21). Thus, patients who accept and manage their condition by making treatment decisions know what to do and seem in a more manageable psychological state. A similar reaction toward cancer was also reported to promote fewer depression/anxiety symptoms and lower stress levels among patients (23).

This situation also can be explained by the 'dual-process model'; grief is a process of fluctuation between two modes, called a 'loss orientation' mode (emotion-focused coping) and a 'restoration orientation' mode (problem-focused coping) (25). Therefore, this group of patients might be capable of engaging in this problem-focused coping as a form of SM sooner than the other group. Patients also sometimes might tie to their social forces of responding to pressures to please the physician by being 'good' patients by feigning optimism to hide their true feelings after cancer diagnosis (26). Patients in this study who claimed positivity to embrace the diagnosis claimed more peaceful without adding further stressful events after the diagnosis, which was also reported previously (27). Nonetheless, denial among cancer patients must be cautiously evaluated.

Subtheme 2: Emotional management

The patients described SM practices in phase two mainly referred to the effort to keep their emotions under control upon the diagnosis. This SM was either avoiding the thought of NPC diagnosis (avoidance) or confronting the fact that they were living with NPC (comprehending). Details of the experience are explained as follows:

Avoidance

Avoidance was one of the SM measures among the patients because they perceived it could

control their negative thoughts and become more focused on fighting NPC. The youngest participant said.

"I listen to people's advice not to be so sad, and not think too much. Try to feel peaceful in heart. Because there is no use to think about this, in the end, I still need to go to the hospital."

"But I do not talk about this often. Not talk about it many times. If I talk about this cancer, then I will think too much about it. We are not doctors. There is no good in talking about it like that."

(Mr A)

Patients described avoidance as 'taking it easy' to avoid panic, prevent negative thinking about the disease, and try to talk less about the diagnosis even among family members. Avoidance among cancer patients includes avoiding receiving cancer-related information (28,29) or avoiding discussing any cancer-related topics (27). On the contrary, most of the patients in this study used avoidance as a measure to enable self-control of their negative emotions and proceed with the treatment in the next phase. However, avoidance as an SM strategy could be controversial. Many previous studies have reported that avoidance could result in higher psychological distress and the strongest predictor of poorer QOL outcomes (27-29). Therefore, guiding patients with avoidance is highly crucial and could help promote effective SM upon diagnosis of NPC, rather than letting them manage on their own, which could result in poor psychological management and reduced QOL.

Comprehending the NPC Occurrence

Another SM strategy practiced by patients was *comprehending the NPC diagnosis*. During this period, they had the curiosity and urgency to know about their disease and what they could do to find a resolution to the situation. Thus, the findings informed three significant ways to enable them to understand their situation/condition, which are: (1) seeking informational support and treatment options, (2) a test from God (3) self-blame of the previous lifestyle.

1) *Seeking for Informational Support and Treatment Options*

Patients were found to survey different health organisations, including the private sector and abroad, as well as traditional healers for second opinions and better treatment options. They seek information from many sources, especially websites, social media and acquaintances, to understand their condition.

Being exposed to various treatment options seemed crucial to patients. Having said that, patients, especially Chinese, would pursue a second opinion from abroad, specifically in China. According to a previous study, the perception of Malaysian Chinese cancer patients towards their illness and treatment was strongly influenced by Chinese sociocultural beliefs and practices and commonly co-existed in the treatment journey together with Western treatment (24). Thus, obtaining a second opinion from Chinese therapies might provide them with more information to understand the cancer and the treatment options attributed to the Chinese cultural beliefs that they strongly adhered to.

"I went to China before starting chemotherapy for another opinion. But now no more. The doctor from here said that I can't do both treatments here and there concurrently. Might go there after complete treatment here."

(Mr E)

Other than that, patients commonly used information obtained as supplementary information before finally deciding to proceed with the treatment in the study settings (24). This situation reflected their effort to obtain adequate information before making treatment decisions. This information allowed them to feel empowered with options and information regarding their cancer diagnosis. Seeking another treatment option did not necessarily mean that they would default or refuse the conventional treatment as suggested by health care providers (HCPs), but more to find another solution for their life-threatening illness. As stated in the above excerpt, some patients had discussed the alternative treatment with their HCPs. This situation could portray the need for patients to be able to express their own concerns regarding treatment planning based on their beliefs and be properly consulted about it before any treatment decision is made.

Several participants felt they needed to do something and could barely wait to see their condition getting poorer. However, some of them decided to choose 'more easily and less side effects' and decided to try traditional medicine without discussing it with their oncology team. As said by a patient who defaulted at first before returning to seek treatment at the hospital.

"Because at that time one of my family had given me this medicine. When I took it, here [swelling nodes at the neck] became smaller. So, I decided to wait and see first."

(Mr A)

Although only a few of the patients in this study had decided to use alternative medicine, many studies showed that concealing the practice of alternative medicine had led the patients to default their treatment and present to the hospital with worsening conditions and more advanced stages (33,34). Patient could more openly discuss their treatment choices with their HCPs. Instead of becoming a barrier, traditional medicine could become complementary or supplementary healing to the patients if they were enlightened about the appropriate use of medicine. For example, as stated in the following excerpt from Mr R;

"But I prefer to listen to doctors' advice to not mix those alternative treatments during this RT course but may take it after the course finish. So, when receive the option given by the doctor, I prefer to wait first after finishing the treatment."

(Mr R)

By having this patients-HCPs consensus as exemplified in this excerpt, patients felt more at ease to do the treatment at the hospital and have an appropriate channel to discuss the alternative treatment that is dear to their culture and health beliefs. Therefore, patients should be aware that they can talk comfortably about this concern and get counselled properly, as suggested by a previous study (35). It was seen that traditional medicine would always be within the circle of patients diagnosed with cancer, as supported by many other studies (35,36). It depended on patients' ability to choose between these treatments' choices. These findings re-emphasised the need for a well-informed appropriate choice of treatment and effective two-way communication between patients and HCPs.

Patients were also informed that they seek information that helps them understand their condition, simultaneously facilitating them in their daily life practice, including diet choices and support in SM. Other cancer and chronic illness patients also practised these SM measures like health-related activities (37) treatment and recommendations for hospitals or doctors (35). The feelings of self-control and psychological support obtained online, as claimed by the patients, resonated with other studies' findings in terms of lessening feelings of anxiety/uncertainty (39,40). Patients felt that advice from a peer was practical and real (37). Hence, online platforms are not only utilised for information search but also support groups that could fulfil certain levels of patients' needs and comfort during this time. This reflected patients' effort to improve their ability to self-manage through information search, also improving perceptions of competence in managing diagnosis and treatment (41).

Compared with other cancer types, interesting facts were found for cervical cancer. People were most frequently searched for prevention issues, potential causes, and specific prevention strategies, indicating their pre-existing knowledge and awareness about this type of cancer (39). However, patients in this current study seem different. Patients admitted that they had never heard about NPC before the diagnosis. Thus, information searched was evolved around treatment and SM after NPC diagnosis.

Despite various information provided online, negative information about cancer and discrepancies among the sources could not be denied. For example, as mentioned by Mr G;

"I watched YouTube, Facebook, they gave tips, what to eat, how to take care [of yourself]. But it is not necessarily a trusted information. Some are from China, and Europe, but should not be trusted blindly. Some say that this fruit can be eaten, then another one says cannot."

(Mr G)

Despite being the main source of health information, the Internet was scored as the least reliable source of information, particularly social media ((43,44) This is because not all the information derived online is from trusted sources or might be reliable to certain conditions or contexts. as social media are used

frequently by patients in this study, they were prone to be exposed to these information discrepancies. Similar concerns were reported previously (37). This is also crucial since patients in the current study used online websites and social platforms regularly as sources of health information. Above all, these findings have shown that patients need various types and levels of information related to their disease and condition, including the availability of treatment options, daily life practice, and social support upon NPC diagnosis. Patients indeed should be given adequate chances to discuss all these needs while they are seen by their doctors throughout this trajectory.

2) A test from God

For patients, cancer is regarded as a test against their obedience to God, spiritual strength, and patience in handling the test given. The eldest participant said.

"We must remember, whatever we have right now is already fated. People who never get sick might lose something valuable. Getting ill for months, then only will know how to appreciate the value of health, happiness, the taste of salt and sugar, the pleasure you feel when riding [motorcycle][chuckled]. [People who never get sick] Tend to forget to perform prayers and forget to appreciate all those pleasures gifted to us [by Allah]. Hopefully, we will be granted for this patience. It is a test from Allah, to test myself, also my children, how to face and accept this illness."

(Mr N)

For example, as in the above excerpt, Muslim patients had related their NPC occurrence to their religious beliefs. The believers must seek help from Allah with patience, perseverance, and prayers whenever tested in life. Practising patience and thankfulness will be truly rewarded (45). Many researchers have reported that faith in God's will and the fate of cancer positively influenced coping and acceptance among the patients (46,47) and strong spiritual well-being among lung cancer patients despite having most significantly decreased physical and functional well-being (45).

3) Self-blame

Some patients were also found to blame their way of life for cancer diagnosis. They described

this situation in the excerpts below, for instance.

"Only one reason I got this cancer. I am smoking a lot. One box per day. One after another, people warned me, but I just ignored them. But when I have this [NPC], only then I realised my mistake."

(Mr N)

Patients tend to self-blame for their smoking habits, eating unhealthy food, and alcohol. They justified that this cancer diagnosis resulted from their ignorance of adopting this unhealthy lifestyle. Chinese patients in this study believed that their habits of drinking alcohol and eating pork, certain types of seafood, or eating unhealthy outside food caused cancer. It impacted the patients' psychological states further after the NPC diagnosis itself. This was because self-blame was negatively correlated with QOL and mood outcome, contrary to acceptance which positively correlated with these outcomes (32). They tried to understand their cancer occurrence, showed that they started to have a certain level of knowledge about cancer since they had sought much information upon diagnosis of cancer.

They once again relied on themselves and unprofessional sources to justify the situation when they believed in certain non-related causes, such as eating seafood or taboo cancer. As a result, using this SM practice (49) might waste putting oneself in unnecessary guilt. This was further supported by the findings that none of the participants knew diets high in salt, like preserved meats and fish and pickled foods (common among Chinese dishes) as a cause of NPC (50). This showed a huge gap to a sufficient knowledge of NPC among these patients that could enable them to efficiently self-manage their condition.

CONCLUSION

During accepting the cancer diagnosis, patients were found to go through disruptive emotional changes that greatly challenged their psychological well-being. Two distinct groups were found to describe their feelings and situations (emotional discouragement and embracing fate). Theoretically, the emotional changes experienced by patients were the stages that patients with severe illness would experience to enable them to accept the

diagnosis. They experienced similar stages of grief as other types of cancer patients, even though NPC was reported to have a good prognosis with effective treatment.

In view of this issue, it was further confirmed that patients critically need and are in profound needs for health information related to various aspects of cancer and treatment. However, patients were burdened by the cancer diagnosis and avoided having thought about it while struggling to comprehend the situation with NPC. Apart from that, patients were found to self-manage these emotional changes through avoidance apart from seeking help and informational support. This was done to enable the self to understand and increase the capability to self-manage the situation. However, seeking information from unprofessional sources could result in discrepancies of information and self-blaming. Therefore, patients have had a huge issue with emotional management if it were not in the hands of experts (HCPs) to support them in managing these emotional changes effectively. Therefore, these findings strongly recommend that healthcare professionals to address this need particularly among those who newly diagnosed with nasopharyngeal cancer to help them accepting their cancer diagnosis.

LIMITATION OF THE STUDY

Patients recruited to participate in the study were patients who were or had received hospital treatment for their NPCs. So it should be clarified here that they are the ones who naturally have a strong desire to cure themselves of cancer. So, of course, they were a group that was very determined to self-manage themselves well. However, as opposed to seeing this as a limitation of the study, the researcher believes that this group is the most important to be helped to understand their situation and experience managing themselves while trying hard and struggling to fight their disease in order to be helped as much as possible from all aspects. It should be understood that the findings from this study represented the voices of those who were in the context of the study as people who have a desire to heal and strive towards it as best they can. Besides, the findings of this study are not meant for scientific generalization to the population or universe. The goal of this is to

expand and generalize theories where in this study; the concept of SM for analytic generalization.

CONFLICT OF INTEREST

The Author(s) declares(s) that there is no conflict of interest.

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AUTHOR CONTRIBUTIONS

CACA: drafted the manuscript and contributes to the concept development and design of the article through data collection, analysis and data interpretation for the article.

SS: involved in data analysis and support with literature content.

LSP: involved in data analysis, support with literature content and finalising the manuscript.

ZAA: involved in data collection and support with literature content.

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