SELF-MANAGEMENT OF PATIENTS LIVING WITH NASOPHARYNGEAL CANCER: A CASE STUDY IN MALAYSIA

BY

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A thesis submitted in fulfilment of the requirement for the degree of Doctor of Philosophy (Nursing).

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ABSTRACT

In Malaysia, nasopharyngeal cancer (NPC) is a major health problem. The treatment is a major concern given that patients chronically suffer from side effects. Self-management (SM) has been a promising strategy in managing chronic conditions, including cancer. However, it is very complex and individual, resulting in a complex need for support. This study aimed to explore SM from the perspective of patients living with NPC and their significant others, such as family and healthcare providers (HCPs), which might enlighten specific SM engagement concerns. An exploratory qualitative case study design was conducted based on the study aim. With pragmatism as the philosophical underpinning this study, data were collected using three methods; (1) in-depth, semi structured interviews; (2) participant-observation; and (3) document analysis. A purposive sample of 40 participants of patients (16), family members (7), and HCPs (17) was recruited from two general hospitals. Data analysis was conducted using framework analysis (interviews transcripts/observation field notes) and content analysis (documents). Findings from multiple sources and methods were triangulated to understand in-depth SM as the centre case of this study. The NPC trajectory experienced by the patients was presented in four phases; (1) Pre-diagnosis; (2) When being diagnosed; (3) During treatment; and (4) After treatment. Patients practised several SM strategies across the four phases, mainly based on their health beliefs. Four main themes emerged in each phase. Phase one; *Process to health care seeking behaviour* where patients tried to *comprehend their situation* ineffectively because of lack of cancer knowledge. Phase two; *Process of accepting the disease* to explain the *emotional changes and management*. Phase three; *Dealing with treatment challenges* to explain patients' *self-determination* and *strategies for gaining energy* during treatment. Phase four; *Dealing with the physical and emotional sequel as NPC survivors* to explain how patients managed fears of cancer recurrent and health conflicts after cancer treatment. Patients needed support from family, HCPs and health care facilities. However, patients' perceptions seemed different in certain aspects when compared to each other. Patients perceived they only need *psychological (encouragement and companionship), and financial and logistic support* to help them self-manage. Family had revealed otherwise. The family informed that patients need extended support in *managing physical and social needs*, which introduced challenges to the family to *change life roles and responsibilities* with patients. Although patients highly valued discussion on health problems with HCPs, they had issues in communicating actual needs. Informational support was obtained (advice and support to self-manage physical condition and treatment complications) mainly during the treatment phase. As a result, patients' perceived support received as inadequate since they need specific and long-term support. In conclusion, SM of patients with NPC existed but was greatly influenced by their health beliefs/cultural beliefs and, in most cases, without sufficient and accurate knowledge, especially on symptoms management and psychological disturbances. Support from HCPs was mainly focused on direct medical management and not clearly defined in practice. Family holds a critical role in supporting patients, mainly to help with NPC's physical and psychosocial changes/needs, but they are heavily impacted because of a lack of knowledge and experience in supporting the family with cancer. The study findings could inform recommendations in certain aspects of policy and guidelines, healthcare practice, education, and future research on SM of patients with NPC in Malaysia.

Keywords: Cancer, nasopharyngeal cancer, self-management, self-management support

ملخص البحث

في ماليزيا، يعد سرطان البلعوم الأنفي مشكلة صحية رئيسية. العلاج مصدر قلق كبير بالنظر إلى أن المرضى يعانون بشكل مزمن من آثار جانبية. كانت الإدارة الذاتية استراتيجية واعدة في إدارة الحالات المزمنة، بما في ذلك السرطان. ومع ذلك، فهي معقدة للغاية وفردية، مما يؤدي إلى حاجة معقدة إلى الدعم. تهدف هذه الدراسة إلى استكشاف الإدارة الذاتية من منظور المرضى المصابين بسرطان البلعوم الأنفي وغيرهم من الأشخاص المهمين، مثل الأسرة ومقدمي الرعاية الصحية، مما قد يثير مخاوف محددة بشأن المشاركة في الإدارة الذاتية. تم إجراء تصميم دراسة حالة نوعية استكشافية بناءً على هدف الدراسة. مع البراغماتية باعتبارها الأساس الفلسفي لهذه الدراسة، تم جمع البيانات باستخدام ثلاث طرق؛ (1) إجراء مقابلات متعمقة وشبه منظمة؛ (2) ملاحظة المشاركين؛ (3) تحليل الوثائق. تم تعيين عينة هادفة من 40 مشاركًا من المرضى (16) وأفراد الأسرة (7) ومقدمي الرعاية الصحية (17) من مستشفيين عامين. وأجري تحليل للبيانات باستخدام تحليل إطاري (محاضر المقابلات/مذكرات ميدانية للمراقبة) وتحليل للمحتوى (وثائق). تم تثليث النتائج من مصادر وطرق متعددة لفهم الإدارة الذاتية المتعمقة باعتبارها الحالة المركزية لهذه الدراسة. تم تقديم مسار سرطان البلعوم الأنفي الذي عانى منه المرضى على أربع مراحل؛ (1) التشخيص المسبق؛ (2) عند التشخيص؛ (3) أثناء العلاج؛ و(4) بعد العلاج. مارس المرضى العديد من استراتيجيات الإدارة الذاتية عبر المراحل الأربع، بناءً على معتقداتهم الصحية بشكل أساسي. وبرزت أربعة مواضيع رئيسية في كل مرحلة. المرحلة الأولى؛ الانتقال إلى سلوك البحث عن الرعاية الصحية حيث حاول المرضى فهم وضعهم بشكل غير فعال بسبب نقص المعرفة بالسرطان. المرحلة الثانية؛ عملية قبول المرض لشرح التغيرات العاطفية والإدارة. المرحلة الثالثة؛ التعامل مع تحديات العلاج لشرح تقرير المصير للمرضى واستراتيجيات اكتساب الطاقة أثناء العلاج. المرحلة الرابعة؛ التعامل مع التكملة الجسدية والعاطفية كناجين من سرطان البلعوم الأنفي لشرح كيف تمكن المرضى من إدارة المخاوف من تكرار السرطان والصراعات الصحية بعد علاج السرطان. يحتاج المرضى إلى دعم من الأسرة ومقدمي الرعاية الصحية ومرافق الرعاية الصحية. ومع ذلك، بدت تصورات المرضى مختلفة في جوانب معينة عند مقارنتها ببعضها البعض. أدرك المرضى أنهم بحاجة فقط إلى الدعم النفسي (التشجيع والرفقة)، والدعم المالي واللوجستي لمساعدتهم على الإدارة الذاتية. كشفت العائلة عن خلاف ذلك. أبلغت الأسرة أن المرضى بحاجة إلى دعم موسع في إدارة الاحتياجات الجسدية والاجتماعية، مما أدى إلى تحديات للأسرة لتغيير أدوار الحياة والمسؤوليات مع المرضى. على الرغم من أن المرضى يقدرون بشدة المناقشة حول المشكلات الصحية مع مقدمي الرعاية الصحية، إلا أنهم واجهوا مشكلات في إيصال الاحتياجات الفعلية. تم الحصول على دعم إعلامي (المشورة والدعم للإدارة الذاتية للحالة البدنية ومضاعفات العلاج) بشكل أساسي خلال مرحلة العلاج. ونتيجة لذلك، اعتبر المرضى الدعم المتلقى غير كاف لأنهم بحاجة إلى دعم محدد وطويل الأجل. في الختام، كانت الإدارة الذاتية للمرضى المصابين بسرطان البلعوم الأنفي موجودة ولكنها تأثرت بشكل كبير بمعتقداتهم الصحية/معتقداتهم الثقافية، وفي معظم الحالات، دون معرفة كافية ودقيقة، خاصة بشأن إدارة الأعراض والاضطرابات النفسية. ركز الدعم المقدم من مقدمي الرعاية الصحية بشكل أساسي على الإدارة الطبية المباشرة ولم يتم تحديده بوضوح في الممارسة. تلعب الأسرة دورًا حاسمًا في دعم المرضى، بشكل أساسي للمساعدة في التغيرات/الاحتياجات الجسدية والنفسية الاجتماعية لسرطان البلعوم الأنفي، لكنها تتأثر بشدة بسبب نقص المعرفة والخبرة في دعم الأسرة المصابة بالسرطان. يمكن أن توجه نتائج الدراسة التوصيات في جوانب معينة من السياسة والإرشادات، وممارسات الرعاية الصحية، والتعليم، والأبحاث المستقبلية حول الإدارة الذاتية لمرضى سرطان البلعوم الأنفي في ماليزيا.

الكلمات الرئيسية: السرطان، سرطان البلعوم الأنفي، الإدارة الذاتية، دعم الإدارة الذاتية

APPROVAL PAGE

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DECLARATION

I hereby declare that this thesis is the result of my own investigations, except where otherwise stated. I also declare that it has not been previously or concurrently submitted as a whole for any other degrees at IIUM or other institutions.

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This thesis is dedicated to my mother Faudziah and my father Che Abdullah for laying the foundation of what I turned out to be in life. To my beloved husband Azuan and children Ayyad and Zahra, there are no words to describe my appreciation for your sacrifice and love. The wishes and du'a from family and friends played unspoken roles bringing me to this point in my life. My sincere gratitude to my respected supervisors, Associate Professor Dr Sanisah, Assistant Professor Dr Siew Pien and Associate Professor Dr Zamzil Amin who never tired of guiding me throughout this thesis, which I pray will be useful for the ummah. Alhamdulillah. Thank you Allah.

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LIST OF ABBREVIATIONS

NPC	Nasopharyngeal cancer
SM	Self-management
HCPs	Health care providers
QOL	Quality of life
TNM	Tumor, nodes, metastasis
AJCC	American Joint Committee of Cancer
HN	Head and neck
HNC	Head and neck cancer
CCM	Chronic care model
HODs	Head of departments
MoH	Ministry of Health
MREC	Medical Research of Ethic Committee Malaysia
CRC	Clinical research centre
IREC	IIUM Research Ethics Committee
OME	Otitis media with effusion
PTA	Pure tone audiometry
EBV	Epstein-Barr virus

CHAPTER ONE

INTRODUCTION

1.1 INTRODUCTION

This chapter consists of the research background and problem statement, leading to the research questions and objectives guiding this study. It will guide us in understanding the research phenomenon of self-management (SM) among patients living with nasopharyngeal cancer (NPC). It will also illustrate how critical this study should be to help the patients maintain or enhance their quality of life (QOL) during their cancer care trajectory through SM engagement. Explaining the concept of SM also provided the importance and relevance of the concept towards NPC patients in this study.

1.1.1 Research Background

Nasopharyngeal cancer has a unique feature of regional variation. Even though the incidence of NPC is rare in the United States and most European countries (less than 2 cases/100,000 population/year), it is very common in Asia, especially China (25 cases/100,000 population/year). In 2012, China, Indonesia, Vietnam, India, and Malaysia were the five Asian countries with the highest NPC incidence. Nasopharyngeal cancer has also been native to South East Asian countries (Mahdavifar et al., 2016).

In Malaysia, NPC has been declared a major health problem. It has become the fourth most common cancer among Malaysians and the third most common among Malaysian men. It is the fourth leading cancer after breast, colorectal and lung. There were 5090 cases of NPC registered at the Malaysian National Cancer Registry from 2007 until 2011 (CPG Management of Nasopharyngeal Carcinoma, 2016) and 2030 cases in 2012 (Mahdavifar et al., 2016). This statistic was not significantly different in the current year 2020, where NPC is still the fourth most common cancer among Malaysians and Malaysian men (Globocan, 2021)

Adding to the unique feature of cancer, NPC was commonly found among males, with the incidence more than twofold higher among males than females (Chye et al., 2008; CPG Management of Nasopharyngeal Carcinoma, 2016). It is also more common among Chinese, Malays (Zainal & Nor Saleha, 2011), and Bidayuh (Tiong & Selva, 2005). NPC commonly occurs during productive age (Armstrong et al., 2000; Chee Ee Phua et al., 2013; Siti-Azrin et al., 2014), generally between the 40s to 50s.

Radiotherapy is effective against early-stage NPC (more than 90% curable rate in early-stage). The staging of NPC is based on tumor, nodes, and matastasis (TNM) staging system by American Joint Committee on Cancer (AJCC). The five stages of NPC are Stage 0 to Stage IV (IVA, IVB, IVC) (CPG Management of Nasopharyngeal Carcinoma, 2016; Zanoni et al., 2019). The early stages refer to stages I and II, while the advanced stages refer to stages III and IV (Tiong & Selva, 2005). According to stages, the five-year overall survival was 81.8% for stage I, 77.9% for stage II, 47.4% for stage III and 25.9% for stage IV based on a local study (Chee Ee Phua et al., 2013. Unfortunately, more than 70% of cases presented with late stages at the stages III and IV, which required more vigorous treatment; a combination of chemo-radiotherapy (CPG Management of Nasopharyngeal Carcinoma, 2016; Phua et al., 2012). Unfortunately, up to current, there is still no specific screening programme available in the country for early detection of NPC due to several limitations including insufficient evidence on screening effectiveness on reducing mortality rate, budget constraint and others (Ministry of Health Malaysia, 2017a; Mohd Aminuddin, 2011).

Despite promising outcomes of the treatment, one of the major concerns is the side effects of the treatment on the functional impairment of head and neck (HN) with subsequent reduction of QOL as evidenced by many studies (Fang et al., 2002; He & Liu, 2005a). They usually suffer from acute (during treatment) and late effects (after treatment and possibly persistent throughout the lifetime) of radiotherapy and chemotherapy, which are initially for combating cancer. This includes lethargy, skin breakdown in the neck area, oral soreness (mucositis), swallowing difficulties (dysphagia), taste changes, nausea, vomiting, and severe sore throat (Lee, Lin, & Ng, 2012; Lu et al., 2009). Besides, they also might suffer from tinnitus, hearing loss, otorrhea, trismus, dysphagia, subcutaneous fibrosis, endocrinopathy, second cancer within the radiotherapy field, and dry mouth due to lack of saliva (xerostomia) (CPG Management of Nasopharyngeal Carcinoma, 2016).

These can intensely impact their QOL, as evidenced in previous studies proving that NPC patients had the worst QOL compared to other head and neck cancer (HNC) patients (Fang et al., 2002; He & Liu, 2005a). Even though completing treatment in stipulated time to reach the maximum curative rate is crucial, many studies found that patients mostly delayed or non-compliance with the treatment. This problem was evidenced due to two main factors; (1) because of severe side effects of the treatment or (2) patients failed to manage self during the treatment (Adham, Stoker, et al., 2014; Chajón et al., 2005; Elting et al., 2008; Peerawong et al., 2012; Phua et al., 2012).

Self-management has been extensively described in the literature as an important concept to help chronic illness patients have better outcomes in managing the diseases (Udlis, 2011). Self-management can be described as tasks that persons undertake actively to deal with the medical aspects, e.g. medications, role after being diagnosed with the illness, and emotional management of their health condition(s), with the participation of health care providers (HCPs), family and community during the management of their disease. This active participation is guided by knowledge and resources with autonomy in decision-making throughout the disease management trajectory (Grady & Gough, 2014).

Many studies provided evidence that SM has a crucial role in managing acute and chronic illness and throughout cancer trajectory (Aujla et al., 2016; Foster & Fenlon, 2011; Kvåle et al., 2016; Wagland et al., 2014). To support this evidence, a finding from a recent systematic review (Govender et al., 2017) was that the type of behavioural strategy frequently used in effective swallowing intervention among HNC patients was self-monitoring of patients’ behaviour. This means that self-management related behaviour such as self-monitoring has been studied as an important factor in promoting effective treatment outcomes.

1.1.1.1 The Concept of Self-management (SM)

The concept of SM was introduced in the literature as early as five decades ago by Thomas Creer and colleagues for a paediatric asthma rehabilitation programme in the 1960s. It was widely used then in health care to indicate patient education. Later in the 1980s, researchers started to realise that chronic disease management is about physiological wellness and psychological. Thus, the concept of SM task emerged with three main themes; (1) medical management [e.g. taking medicines, adhering to a special diet], (2) maintaining, changing and creating meaningful behaviours/life roles, and (3) dealing with the emotional sequelae due to chronic illness [which may help the patient to view their future with more positive outlook] (Lorig & Holman, 2003b).

Self-management needs a critical and holistic approach to cater to its territory's broadness. This is because of two major factors. First, many other terms have been used interchangeably with the word 'self-management' for example, self-care, self-regulation, patient education, patient-centred care, support, and the relationships between patients and HCPs (Grady & Gough, 2014; S. Y. Loh et al., 2012; Omisakin & Purity Ncama, 2011). Second, this concept can be translated based on the perspective of oneself or from different fields since SM has been used in many other sectors apart from health care, business, education and psychology (Omisakin & Purity Ncama, 2011; Udlis, 2011).

In order to achieve the best outcome of SM (measured with good clinical outcome, reduced health care expenditure and subsequently improved QOL), it is believed that active participation from not only HCPs is crucial but also from the patients, family and community during the management of the disease. Knowledge and resources become the basic elements to ensure active participation and autonomy in decision-making. The processes are based on information, self-efficacy, support (mainly from family and HCPs), intention and mutual investment between the patient and healthcare provider (Udlis, 2011). Thus, it can be explained that the concept has many different translation to its meaning but relates to the role of an individual in taking care of their own health and all aspects of their lives together with support from people around them. In addition, the concept of SM is not stagnant, but may fit into a situation to situation based on the perspective of the significant people in that specific situation.

Because the use of SM originated for people with chronic illness, the concept is found embedded in other existing models or theories for the management of chronic illness, but not specific for cancer. The existing model and theory are as follows;

i) Chronic care model (CCM) is one of the most common literature that identifies SM of the patient as one of the six important elements, which could be an active agent to improving their disease progression with proper training and support. Even though the organisational approach (health care system) is more prominent in this model, the integration of SM support element into it also gives the input that active participation from patients is crucial apart from the role of health care providers in managing the chronic disease throughout their lives (Johnston et al., 2008). However, bear in mind that since it is an organisational approach, SM in this model is translated into 'SM support', not SM, from the perspective of the patient. This is similar to the Expanded CCM version.

ii) Individual and Family Self-management Theory is another theory describing the concept of SM in another view. Building from three dimensions (1) context [risk and protective factors], (2) process [information and health belief, self-regulation, social facilitation], and (3) outcome [proximal and distal], this theory generally holds to suggestions from family systems theory, which is believing that a change in one family member leads to changes in the system and all members in it (Ryan & Sawin, 2010). It is good to see the direction of this theory is about describing how every family member (children and adults) may contribute to the SM of a sick person in the family, but still, how to sustain the SM is not clear.

1.1.1.2 Factors to SM engagement

Various factors associated with SM were discussed in the literature. Many studies suggested that the association of many interrelated factors behind a people's beliefs and background 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 (Aujla et al., 2016; Gunggu et al., 2016). Background, age group, economic status (Kidd, 2014; Reeves et al., 2008; Syed et al., 2016), knowledge and medical history (Alcorso, Sherman, Koelmeyer, Mackie, & Boyages, 2016) influenced SM engagement in their chronic illness.

Apart from that, the type/nature of disease and its treatment have also been suggested as other factors to engage with SM. The impact and severity of side effects experienced from treatment, for example, severe, episodic or unexpected, 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 (C Foster & Fenlon, 2011; Gunggu et al., 2016; Kidd, 2014). Besides, treatment duration and prognosis of the disease are also counted as factors (Aujla et al., 2016).

Another important factor which supports SM is the role of family and HCPs support to convince patients of the effectiveness of the treatment (Gunggu et al., 2016) and subsequently promote them to SM engagement. The role of family members in promoting SM among patients with chronic illness is believed to be crucial because they can lead change to another member of the family, as described in Individual and Family Self-management Theory (Ryan & Sawin, 2010). However, for HCPs, many studies have portrayed the challenges in promoting SM to the patients. Among others, it was reported that HCPs themselves still do not fully understand, appreciate, believe, and utilise the SM concept and how to be implemented it in their daily practice (Stanford Patient Education Research, 2012). Besides, they felt less confident in that long-term medication management, care planning, long-term and complex symptom management, care coordination and proactive care (Faithfull et al., 2016).

These factors illuminate the concept that SM is very complex and individual. It depends greatly on people’s health beliefs and background, the type and nature of disease and treatment, and the role of family and HCPs in their disease management. This might assume that SM among patients living with chronic disease will be different from one region to another since health belief which usually originates from cultural belief and background of the people, is different. Different cultures also will introduce the different roles of family members in supporting the ill member. The role of HCPs also might be different due to different healthcare systems and support.