DEVELOPMENT OF PERSON- CENTERED MODEL FOR PATIENTS WITH HEAD AND NECK CANCER RECEIVING CONCURRENT CHEMORADIOTHERAPY: PARTICIPATORY ACTION RESEARCH

BY

MISS SIRIKORN KONGWATTANAKUL

A DISSERTATION SUBMITTED IN PARTIAL FULFILLMENT
OF THE REQUIREMENTS FOR THE DEGREE OF
THE DOCTOR OF PHILOSOPHY (NURSING SCIENCE)
FACULTY OF NURSING
THAMMASAT UNIVERSITY
ACADEMIC YEAR 2020

DEVELOPMENTOF PERSON- CENTERED MODEL FOR PATIENTS WITH HEAD AND NECK CANCER RECEIVING CONCURRENT CHEMORADIOTHERAPY: PARTICIPATORY ACTION RESEARCH

BY

MISS SIRIKORN KONGWATTANAKUL

A DISSERTATION SUBMITTED IN PARTIAL FULFILLMENT
OF THE REQUIREMENTS FOR THE DEGREE OF
THE DOCTOR OF PHILOSOPHY (NURSING SCIENCE)
FACULTY OF NURSING
THAMMASAT UNIVERSITY
ACADEMIC YEAR 2020

THAMMASAT UNIVERSITY
FACULTY OF NURSING

DISSERTATION

BY

MISS SIRIKORN KONGWATTANAKUL

DEVELOPMENT OF PERSON- CENTERED MODEL FOR PATIENTS WITH HEAD AND NECK CANCER RECEIVING CONCURRENT CHEMORADIOTHERAPY: PARTICIPATORY ACTION RESEARCH

was approved as partial fulfillment of the requirements for
the degree of doctor of philosophy (nursing science)
on Approval August 1, 2020

Chairman
B. Kajornsin
(Professor Emeritus Boonreang Kajornsin, Ph.D.)

Member and Advisor
(Professor Pranom Othaganont, Ed.D., RN.)

Member and Co-Advisor
(Professor Wen-Chii Tzeng, Ph.D., RN.)

Member
Pregamol Rutchanagul
(Assistant Professor Pregamol Rutchanagul, Ph.D., RN.)

Member
Teeranut Harnirattisai
(Associate Professor Teeranut Harnirattisai, Ph.D., RN.)

Dean
Teeranut Harnirattisai
(Associate Professor Teeranut Harnirattisai, Ph.D., RN.)

Dissertation Title	DEVELOPMENT OF PERSON- CENTERED MODEL FOR PATIENTS WITH HEAD AND NECK CANCER RECEIVING CONCURRENT CHEMORADIOTHERAPY: PARTICIPATORY ACTION RESEARCH
Author	Miss Sirikorn Kongwattanakul
Degree	Doctor of Philosophy (Nursing Science)
Faculty/University	Faculty of Nursing Thammasat University
Dissertation Advisor	Professor Pranom Othaganont, Ed. D., RN.
Dissertation Co-Advisor	Associate Professor Wen-Chii Tzeng, Ph.D., RN.
Academic Year	2020

ABSTRACT

The adherence to concurrent chemoradiotherapy can be a practical challenge and a factor influencing patients' choices for treatment. In a bid to enhance true benefits of person-centered care, the radiation oncology team need to focus on quality of relationships and interactions between patients with head and neck cancer and their family, as well as health care professionals. This study applied a participatory action research for the development of a person-centered model towards treatment adherence, symptom management, and satisfaction among radiation oncology team and patients with head and neck cancer and their family during concurrent chemoradiotherapy. The study was divided into 2 phases, with data collection including the interviews and observations of focused-groups and document reviews. Moreover, the Graneheim and Lundman's steps were employed for content analysis throughout the study.

The first phase was designed to explore the experiences and needs of 15 patients and 8 family members with regard to care process and radiation oncology team services during concurrent chemoradiotherapy. The findings revealed 3 main categories: overwhelming information, unpleasant symptom cluster, and strategies to adhere to treatment regimen. Meanwhile, the experiences of 23 radiation oncology team members were also investigated. The results emerged 4 main categories: role and competency, environment of healing, person-centered approaching, and fragmentation of care. All of these data and information can lay a foundation for the development of a tentative person-centered model in the delivery of concurrence chemoradiotherapy services.

The second phase was purposed to develop the person-centered model. This model was based on the approach of participatory action research of Kemmis and McTaggart's (1988), which included the action research spiral of individual and collective self-reflective cycles as a methodology contained four activities, plan, act and observe, and reflect. Then, the revised-plan was continued during the model development with 3 cycles in this study. According to the findings, the antecedent of person-centered model was derived from the participatory action research approach, specifically the crucial role of radiation oncology nurses and their competences as a pivotal part in building the effective radiation oncology teamwork, as well as healing environment towards the efficacious management of unfavorable symptoms. Whereas, the clinical practice guidelines, work procedures, educational and information systems, continuity, empowerment, and person-centered approach were also implemented to contribute the direct care for patients with head and neck cancer, which required a good collaboration between the radiation oncology team and other healthcare professionals. The specific outcomes comprised treatment adherence, symptom status, and satisfaction on the changing towards a better care process in practice for both patients and healthcare team.

For suggestions, some replications and continuous reviews are needed in the person-centered model towards a complete confidence in its effectiveness and efficacy. Moreover, further collaboration with other multidisciplinary health care teams should be promoted and developed in the long run.

Keywords: Person-Centered Care, Model Development, Participatory Action Research, Head and Neck Cancer, Chemoradiotherapy

ACKNOWLEDGEMENTS

My expression of deep and sincere gratitude should be also extended to my research advisor, Professor. Pranom Othaganont, Ed.D., R.N., co-advisor, Associated Professor Wen-Chii Tzeng, Ph.D., R.N. for giving me the opportunity to do research and providing valuable guidance throughout this research. They have taught me the methodology in carrying out and presenting the research works as clearly as possible. It was such a great privilege and honor to work and study under their guidance.

I would also like to thank my colleges, especially Miss Nujaree Petchann and Miss Rattanaporn Nanthong for the great support along the research process. Moreover, I am extremely grateful to my family for their love, caring and sacrifices for educating and preparing me for my future. Besides, I am very much thankful to my husband, Mr. Bhichaya Kongwattanakul and my daughter, April, Nitcha Kongwattanakul for their love, understanding, inspiring, and continuing support to complete this research work.

Importantly, thanks to all patients with head and neck cancer and their family for their willing to participate in this study and share their ideas during my research work. As well, thanks so much to all staffs of the Radiation Oncology Department for their kindness. In particular, my best gratitude is given to the management of Chulabhorn Royal Academy and Nursing Organization for their genuine support for the successful completion of this thesis.

Finally, my thanks go to all the people who have supported me until completing the research work directly or indirectly.

Miss Sirikorn Kongwattanakul

TABLE OF CONTENTS

APPENDICES

LIST OF TABLES

Tables Page

CHAPTER 2

CHAPTER 3

CHAPTER 4

LIST OF FIGURES

Figures Page

CHAPTER 1

CHAPTER 2

CHAPTER 3

CHAPTER 4

CHAPTER 1
INTRODUCTION

1.1 Background and significance of the study

Cancers in the head and neck area include paranasal sinuses, nasal cavity, oral cavity, tongue, salivary glands, larynx, and pharynx (nasopharynx, oropharynx, and hypopharynx) (Tangjaturonrasme, Vatanasapt, & Bychkov, 2018). Head and neck cancer (HNC) is the 6th most prevalent type of cancer, annually with almost 600,000 new cases worldwide (Chaturvedi et al., 2013). The National Cancer Institute, Thailand reported that oral cavity, oropharyngeal, nasopharyngeal, and hypopharyngeal cancers remain a public health concern during the year 2015, with the incidence over 1 per 100,000 population (Imsamran et al., 2015). In addition, the cancer registry at Chulabhorn Hospital reported nearly 200 new cases of head and neck cancer in 2017.Meanwhile, there are some evidences in the US and Europe where head and neck cancer accounts for 3-4% of all malignancies. Approximately 63,000 cases in the US develop head and neck cancer annually with 13,000 deaths, while 250,000 cases in Europe have head and neck cancer with 63,000 deaths per year.(Fitzmaurice et al., 2017; Siegel, Miller, & Jemal, 2017). Risk factors for head and neck cancer comprise tobacco use, alcohol consumption, and oncogenic virus infection. Particularly, the incidence of human papilloma virus-associated oropharyngeal cancer has been increasing in developed countries and could exceed that of cervical cancer by the year 2020 (Marur & Forastiere, 2016). Men are significantly affected more than women, with the rate ranging from 2:1 to 4:1 (Ferlay et al., 2015).

More than half of these patients require radiation therapy (RT)for both palliative care and curative treatment (Baskar & Itahana, 2017).To date, multidisciplinary approaches are based on the combination of surgery, radiotherapy, and chemotherapy for HNC treatment. Whereas, concurrent chemoradiotherapy (CCRT) is suggested as the standard treatment for advanced stage head and neck cancer, especially in non-operable patients or those with poor morbidity for surgery(Mallick & Waldron, 2009; Pignon, le Maitre, Maillard, Bourhis, & Group, 2009; Yom, 2015). Nonetheless, the combined chemotherapy with external beam radiation therapy often increases toxicity and side effects related to treatment, which impeded patients from completing the course of treatment (Iqbal et al., 2017; Pan et al., 2017; Sio et al., 2016). Recent research reported that nearly 50% of the patients lost one to six days of radiation therapy, while 10% failed to receive treatment approximately seven to fourteen days due to hospitalization and toxicity(Kumar, Tudu, Kumari, & Sahoo, 2017; Kimberly Thomas et al., 2017).Also, the loss to treatment for more than two days could result in an almost four-time increased risk of unfavorable outcomes and related to a decreased survival. Besides, patients with laryngeal tumors who lost treatment in radiotherapy had a 68% higher risk of death than those with no loss to treatment (Fesinmeyer, Mehta, Blough, Tock, & Ramsey, 2010). Hence, treatment adherence is typically defined as receiving longer treatment of approximately 7 days, which necessitates for favorable clinical outcomes, theoretically in accordance with the loss to control of 1.7% per non-planned loss to treatment. This also lessens the consecutive rate of treatment control by 10% within 5 years (Kumar et al., 2017).

A recent study on HNC revealed that social and therapeutic barriers are the most common factors of non-adherence to radiation therapy. These social factors include a lack of family support and financial constraints. Also, therapeutic barriers may be caused by the side effects and duration of treatment regimens. Moreover, the lack of education on the course of treatment can result in emotional complications, such as anxiety or depression, leading to non-adherence to treatment. (Rangarajan & Jayaraman, 2017).Nonetheless, common therapeutic barriers are mostly from the side effects of radiotherapy (Ferreira, Sa-Couto, Lopes, & Khouri, 2016). Failure to the scheduled appointments, regardless of the delay in starting treatment or discontinuing treatment, can cause problems in terms of the effectiveness of health care delivery and the overall health outcomes (Miller, 2016). A previous study showed that treatment-related toxicities, such as mucositis, skin reaction, and hematological toxicity, could be the most common causes of non-adherence to radiation therapy, especially in those with head and neck cancer (K. Thomas et al., 2017).

The conformity to treatment is critical for favorable clinical outcomes, which should involve patients and their family, as well as health care providers (K. Thomas et al., 2017). Effective symptom management during radiation therapy is also crucial for the most favorable oncology outcomes due to the continuity plan of adherence to treatment (Fogh & Yom, 2014). Studies have shown the positive outcomes with the involvement and empowerment of patients and their family in any discussions on treatment goals and lifestyle adjustments. Accordingly, health care providers should focus on the main concerns, perceptions, feelings, and expectations of patients towards a more positive attitudes and enhancement of adherence to treatment(Hall, Irish, Gregg, Groome, & Rohland, 2015). A guideline on the measurement of adherence to treatment can be helpful to identify the main causes of non-adherence treatment in patients, leading to quick responses from patient's feedback.(Gupta, Baxi, & Hoyne, 2017; Siddiqui & Movsas, 2017). Additionally, several studies have adapted the feedback intervention, with focusing on individual needs and level/type of treatment-related side effects, to improve treatment outcomes through the method of self-monitoring and perception on health problems and ways to cope with them (Roussi & Miller, 2014).

The literature review provides support for the understanding of patients' expectations on treatment, including self-management activities, particularly as outpatients (Bauer, Laszewski, & Magnan, 2015; Ullgren, Tsitsi, Papastavrou, & Charalambous, 2018). Patients can often take their role in decision making for their own medical treatment, while health care providers should adjust themselves towards a more supportive role (Gebreweld et al., 2018). The medical rights for patients, especially those with chronic illnesses, must be also determined as individual preferences (Odom-Forren & Wesmiller, 2017). Moreover, health care professionals must encourage patients to play a more active role in making their own treatment decisions according to preferences, beliefs, and individual backgrounds (Miller, 2016; Samalin et al., 2018).

The Institute of Medicine (2001) defined a patient-centered approach as one goal for the improvement of health care system in responsive to the needs, values, and preferences of each individual patient to assure overall clinical decisions. The main focus of a patient-centered care is on patients themselves (Institute of Medicine, 2001). The patient-centered care can be described in other terms as person-centered care, personalized care, and user/client-centered care. These terms are all referred to holistic approaches of care in personal context and each individual needs, preferences, and beliefs (Ekman et al., 2011). By focusing on personal needs and preferences, there have been more evidences demonstrating a wide range of services and changes in person-centered designs to enhance patients' experiences and increase nurses' satisfaction (Gray et al., 2016).

There are more research on the implementation of a person-centered approach in various types of diseases, such as patients' involvement in the design process of a tele-healthcare application to monitor symptoms and train on physical fitness in those with lung cancer, which could optimize patients' compliance to treatment(Olsson & Lau, 2015). To facilitate treatment compliance, several skills need to be developed to implement a person-centered approach in patient care among health professionals. The person-centered care requires cooperation between healthcare providers, patients and their family to enhance patients' ability and willingness to participate in their own health care(Delaney, 2018). The implementation of this approach has been shown to improve disease-related outcomes and quality of life through a shared understanding of all parties involved in the treatment. This approach enables patients for their active participation in the choices of care and treatment. Self-management results in the improvement of treatment adherence and control of chronic diseases. In addition, it can supplement patients' ability to handle with adverse side effects and understand the importance of treatment adherence(R. M. Epstein, Fiscella, Lesser, & Stange, 2010).

A team of radiation oncology basically consists of radiation oncologist, medical physicist, radiation therapist, radiation oncology nurse, and allied health personnel to provide radiotherapy for cancer patients. To integrate nursing care for patients and their family during radiotherapy, the radiation oncology nurses daily play their roles as a part of the team to assist patients and their family for the knowledge in management of symptoms and side effects from treatment (P. Rose & Yates, 2015). The standards of nursing care in radiotherapy are in accordance with the international guidelines, such as the National Cancer Institute and the institutional professional practice guidelines. While, the monitoring of acute and late symptoms complies with the Radiation Therapy Oncology Group (RTOG) and the European Organization for Research and Treatment of Cancer (EORTC) for toxicity grading score guidelines. Besides, the weekly monitoring of physical and psychological side effects by radiation oncology nurses becomes a standard of care to weight and address patients' complaints(Hollis & McMenamin, 2014). The main role of radiology nurses is to enrich the involvement of patients and their family in the treatment process. Importantly, it is challenging for nursing professionals to assist patients in dealing with treatment-related side effects (Hollis & McMenamin, 2014; Kujala, 2003).As a result, the nursing care is designed to meet both physical and psychological aspects, as well as educational needs of patients and their family.

In order to optimally achieve patients’ adherence to treatment, it is essential that nursing professionals better prepare patients to handle with their treatment experiences by identifying all parameters related to treatment adherence as stated in the Hospital Accreditation Institute, Thailand, with emphasis on the quality and safety in health care system (The Healthcare Accreditation Institute (Public Organization), 2018). The outcomes of quality health care, especially in radiation therapy, are based on patients’ adherence to any suggested treatment regimens. Adherence may be measured by using either process-oriented or outcome-oriented metrics, with the development of guidelines or protocols among health care professionals. The adherence protocols need to be ensured on the effectiveness of interventional treatment. Recently, there has been an evidence on the skin care intervention during radiation therapy to affirm that the level of patient adherence to any skin care regimens is more important than the treatment product itself towards favorable outcomes in patients(Bauer et al., 2015). The understanding of adherence approach requires multiple concepts and tools to encourage patients’ adherence. In a previous study, key factors were set for adherence to treatment, including assessment of patient’s knowledge and understanding of treatment, clear and effective communication, as well as trustworthiness in therapeutic relationship. Whilst, knowing of “a person”, mutual collaboration, and adherence to measurement should also be coupled to improve and promote positive outcomes (P. Rose & Yates, 2015).

There are many challenges and opportunities to engage patients and their family in cancer treatment. Patients’ preferences and individual factors are not usually key factors for the efficacy of engagement. Sometimes, problems arise from patients’ adverse experiences and lead to more serious issues, such as discontinuity of treatment and poor symptom management, which substantially require the improvement of nursing practice to enhance treatment adherence. A person-centered design encourages patients to take part in treatment planning and health care monitoring, hopefully as a key strategy for better symptom management outcomes (Odom-Forren & Wesmiller, 2017).The core of a person-centered design process is the identification of each individual’s needs and preferences, especially in terms of their perceptions and experiences(Harte et al., 2017; The Healthcare Accreditation Institute (Public Organization), 2018). Moreover, an individual patient is considered as an active participant in the person-centered approach for therapeutic relationship to meet personal needs of health care. Thus, radiation oncology nurses who are willing to engage patients in the management of their treatment-related symptoms and toxicities should identify particular situations, which lead to non-adherence treatment as parameters influencing patients’ motivations, preferences, needs, and barriers to comply with their course of treatment (Hansson, Carlstrom, Olsson, Nyman, & Koinberg, 2017; Samalin et al., 2018; Seewoodharry, Maconachie, Gillies, Gottlob, & McLean, 2017). The principles of person-centered care are well considered in outpatient radiation therapy to handle toxicities and develop nursing relationship towards each individual patient and their family over the course of treatment. However, these issues may be personal-dependent and nursing practice should be administered as standardized procedures. Meanwhile, all processes are largely functional, with limited emphasis on continuity of care, patient education, and individualized interventions. Since the radiation oncology acts as a highly technological unit, it is important that multidisciplinary collaboration and effective communication should be identified as key factors to enhance the implementation of this new model of person-centered care in practice (P. Rose & Yates, 2013).

The adherence to concurrent chemoradiotherapy can be a practical challenge and a factor influencing patients’ choices to adhere with treatment. In clinical practice, it is a common fear at the starting of treatment, disagreement with treatment plans, failure to see the value of treatment, or decision to try alternative therapy. Also, the high cost of radiation therapy treatment may be a particular challenge for patients(Chadwick, 2016). In order to find out the individual problems and needs, the health care providers are usually not taken into account regarding of volume of patients overload and pile of paper works in daily routine. Therefore, patients have no voice for their preferences and needs, particularly in the specialized setting as radiation oncology clinic where multidisciplinary professionals work together. Moreover, other factors which make treatment difficult for a patient to adhere include problems with transportation, working time, and having a relative or a caregiver with the patient during the period of treatment. To realize true benefits of person-centered care, the care providers of radiation oncology need to focus on quality of relationships and interactions between patients and their family, as well as health care professionals (Bolderston, 2016).

A participatory action research can be an appropriate methodology to explore real situations, while implementing changes that contribute to the effectiveness of healthcare systems and outcomes (Padilha, Sousa, & Pereira, 2016). Hence, the researcher purposes to conduct a participatory action research to investigate real situations in existing service system and develop a person-centered model for nursing care to meet the needs and enhance the capabilities of patients and their family towards treatment adherence, symptom management, satisfaction of both radiation oncology team and head and neck cancer patients and their family.

1.2 Research Objectives

To develop a person-centered model for enhancing treatment adherence, symptom management, and satisfaction among radiation oncology team and head and neck cancer patients and their family during concurrent chemoradiotherapy

1.3 Research Questions

1.3.1 What are the experiences of head and neck cancer patients and their family during concurrent chemoradiotherapy?

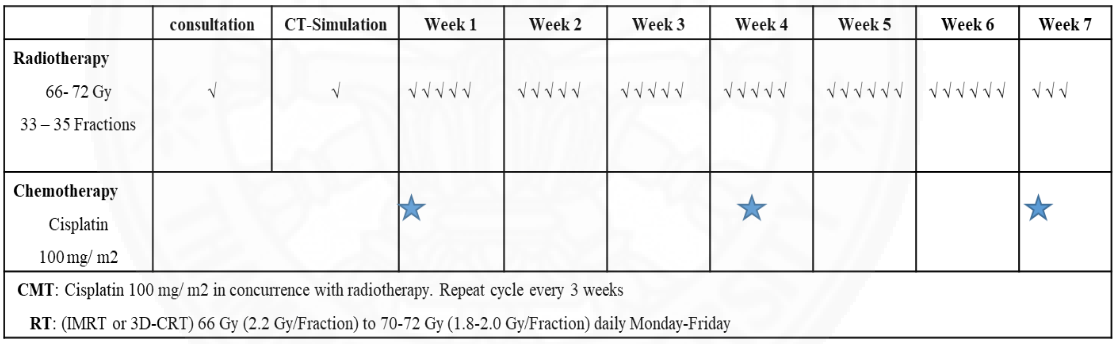
1.3.2 What are the challenges from the perspective of radiation oncology team during concurrent chemoradiotherapy?

1.3.3 What are the characteristics of a person-centered model for enhancing treatment adherence, symptom management, and satisfaction among radiation oncology team and head and neck cancer patient and their family during concurrent chemoradiotherapy?

1.4 Scope of study

The study aimed to develop a person-centered model, with mutual collaboration between the radiation oncology team including radiation oncologists, radiation therapists, radiation oncology nurses, and allied health personnel, as well as HNC patients and their family during concurrent chemoradiotherapy, using a participatory action research methodology proposed by Kemmis and McTaggart's (2000) through self-reflective cycles.

The process was purposed to initiate meaningful and effective healthcare services for HNC patients in terms of enhancing treatment adherence and satisfaction among radiation oncology team and HNC patients and their family during concurrent chemoradiotherapy as shown in Figure1. The care process began at the consultation day until the last day of radiation therapy according to the planned treatment.



	consultation	CT-Simulation	Week 1	Week 2	Week 3	Week 4	Week 5	Week 6	Week 7
Radiotherapy 66- 72 Gy 33 – 35 Fractions	√	√	√ √ √ √ √	√ √ √ √ √	√ √ √ √ √	√ √ √ √ √	√ √ √ √ √ √	√ √ √ √ √ √	√ √ √
Chemotherapy Cisplatin 100 mg/ m2			★			★			★

CMT: Cisplatin 100 mg/ m2 in concurrence with radiotherapy. Repeat cycle every 3 weeks
RT: (IMRT or 3D-CRT) 66 Gy (2.2 Gy/Fraction) to 70-72 Gy (1.8-2.0 Gy/Fraction) daily Monday-Friday

Figure 1 The concurrent chemoradiotherapy treatment for patients with head and neck cancer

1.5 Definition of Terms

1.5.1 Person-centered model

Person-centered model refers to the radiation oncology service process that can enhance the treatment adherence, symptom management, and satisfaction among radiation oncology team and head and neck cancer patients and their family during concurrent chemoradiotherapy, with mutual collaboration approach in ways that concern not only patients’ experiences but also healthcare providers’ viewpoints on their problems and needs.

1.5.2 Concurrent chemoradiotherapy

Concurrent chemoradiotherapy refers to the combination of chemotherapy and radiation therapy at the same time for treatment of head and neck cancer patients.

1.5.3 Treatment adherence

Treatment adherence refers to the continuity of cancer patients receiving radiotherapy and chemotherapy treatment as prescribed without disruption from severe side effects more than 7 days.

1.5.4 Satisfaction

Satisfaction refers to the perceptions, feeling, and fulfillment of the needs among radiation oncology team, head and neck cancer patients and their family towards the mutual-collaboration of person-centered model in the care process.

1.5.5 Symptom status

Symptom status refers to the patient’ perception of physical, mental, and social functioning changes from usual feeling during treatment.

1.5.6 Radiation oncology team

Radiation oncology team refers to “a team of radiation oncology, including radiation oncologist, radiation therapist, radiation oncology nurse, and allied health personnel, with the use of modern technology to destroy cancers with radiation”.

1.5.7 Radiation oncology nurses

Radiation oncology nurses refer to “Chulabhorn Hospital’s registered nurses who work together with radiation oncologists and radiation therapists to care for patients with cancers and their family at the time of consultation, during treatment, and follow-up”.

There are one senior nurse educator with master degree program and accreditation in the specialty of oncology, as well as three registered nurses with additional accreditation in the specialty of radiation therapy, two clinical specialized nurses with master degree program, two registered nurses with no additional accreditation, and one newly-graduated registered nurse.

CHAPTER 2

REVIEW OF LITERATURE

This study purposed to develop a person-centered model for patients with head and neck cancer receiving concurrent chemoradiotherapy by using the participatory action research approach with the framework of person-centered care. There were several related topics which directly and indirectly affected the adherence to the concurrent chemoradiotherapy treatment and satisfaction in participants. **Firstly**, head and neck cancer, treatment, and side effects were discussed. **Secondly**, factors related to treatment adherence were presented. **Thirdly**, the existing care process in radiation oncology department and the service gap were exemplified. **Fourthly,** the participatory action research was demonstrated. **Lastly**, the conceptual framework of this study was proposed.

2.1 Head and neck cancer, treatment, and side effects.

Head and neck cancer (HNC) is among the top five leading cancers in Thailand. When compared to the worldwide rates of head and neck malignancies, Thai populations have a lower incidence of laryngeal and thyroid cancers, and a higher incidence of nasopharyngeal cancer (Tangjaturonrasme et al., 2018). Globally it is estimated that the number of newly diagnosed head and neck cancers exceed 550,000 cases per year. Males are significantly more affected than females with a ratio ranging from 2:1 to 4:1. It is a cause of death in approximately 380,000 people each year (Ferlay et al., 2015; Fitzmaurice et al., 2017). Risk factors for head and neck cancers encompass tobacco use, alcohol consumption, and infection with oncogenic viruses. Human papilloma virus-associated oropharyngeal cancer rate is increasing in developed countries and could exceed that of cervical cancer by 2020 (Marur & Forastiere, 2016).

2.1.1 What is Head and Neck Cancer?

There are various definitions for head and neck cancers. Generally, cancers of the head and neck are centered on the upper aerodigestive tract, including all lesions of the mucosal surfaces of the nasal and oral cavity, nasopharynx down to the larynx, hypopharynx and trachea, while more commonly at the major salivary glands and less commonly at the thyroid and parathyroid. (Tangjaturonrasme et al., 2018).

2.1.2 Head and Neck Cancer Staging

Cancer staging is an important key to consider the effectiveness of treatment, including the evaluation and prognosis of cancer. There are many systems for cancer staging. Nonetheless, the most favorable implementation in clinical setting is AJCC (The American Joint Committee on Cancer). The AJCC implements the TNM system, of which the letter “T” stands for Tumors by size, number, and location, while “N” (Lymph node) is defined as metastasis lymph nodes, and “M” (Distant metastasis) signifies the spreading of cancer to other organs(Paice, Yarbro, Frogge, & Goodman, 2004) as follows:

2.1.2.1 Primary tumor (T)

TX:	Primary tumor that cannot be assessed
T0:	No evidence of primary tumor Tis: Carcinoma in situ
T1:	Tumor 2 cm or less in greatest dimension
T2:	Tumor more than 2 cm but not more than 4 cm in greatest dimension
T3:	Tumor more than 4 cm in greatest dimension
T4a:	Moderately advanced local disease (lip), with tumor invasion through cortical bone inferior alveolar nerve floor of mouth or skin of face i.e. chin or nose (oral cavity), as well as adjacent structures only
T4b:	Very advanced local disease, with tumor invasion through masticator space pterygoid plates or skull base, and/or internal carotid artery

2.1.2.2 Regional lymph nodes (N)

NX:	Regional lymph nodes that cannot be assessed
N0:	No regional lymph node metastasis
N1:	Metastasis in a single ipsilateral lymph node, 3 cm. or less in greatest dimension

N2: Metastasis in a single ipsilateral lymph node, more than 3 cm. but not more than 6 cm. in greatest dimension; or in multiple ipsilateral lymph node, not more than 6 cm. in greatest dimension; or in bilateral or contralateral lymph node, not more than 6 cm. in greatest dimension

N2a: Metastasis in single ipsilateral lymph node more than 3 cm, but not more than 6 cm. in greatest dimension

N2b: Metastasis in multiple ipsilateral lymph nodes, but not more than 6 cm. in greatest dimension

N2c: Metastasis in bilateral or contralateral lymph nodes, not more than 6 cm. in greatest dimension

N3: Metastasis in lymph node more than 6 cm. in greatest dimension

2.1.2.3 Distant metastasis (M)

M0: No distant metastasis

M1: Distant metastasis

2.1.2.4 Anatomic stage/prognostic groups

0: Tis N0 M0

I: T1 N0 M0

II: T2 N0 M0

III: T3 N0 M0, T1-T3 N1 M0

IVA: T4a N0 M0, T4a N1 M0, T1-T3 N2 M0, T4a N2 M0

IVB: Any T N3 M0, T4b Any N M0

IVC: Any T Any N M1

2.1.3 Treatment for Head and Neck Cancer

Treatment guidelines for treatment of head and neck cancer depends on many factors, commonly considered by the staging, location, aims of treatment, and patients' quality of life. Multimodalities are current standard treatments, starting with surgical interventions, followed by radiation and chemotherapy to prevent local recurrence. The advanced technique of external beam radiation therapy has been used to treat squamous cell carcinoma of the head and neck, which transforms from 2 dimensional to 3 dimensional, or intense modulated radiation therapy. The aim is to eradicate tumors while sparing at risk organs to preserve organ functions as much as possible. The curative intent of combining the two modalities has raised the 5-year survival rate of nasopharyngeal cancer patients up to 70-80% (Adelstein et al., 2017; Goepfert, Yom, Ryan, & Cheung, 2015; Iqbal et al., 2017; Yom, 2015).

Treatment of head and neck cancer can be categorized into two stages of disease as follows:

Early Stage Cancer of the head and neck is considered for surgery. In case of high risk inoperable or local or distance metastasis, it is usually followed by radiation or radiation with chemotherapy. The radiation dose is mostly 66-74 Gys, or 2 Gys per fraction for 5 consecutive days.

Local Advanced Stage Cancer is usually treated by surgery as standard treatment, followed by concurrent chemoradiotherapy. In case of inoperable diseases or those with unacceptable morbidity from surgery, the concurrent chemoradiotherapy is considered (Mallick & Waldron, 2009; Pignon et al., 2009; Yom, 2015). The radiation oncologist prescribes radiation therapy within 4-6 weeks after surgery. The total dose of radiation is at 60-66 Gys, or 2 Gys per day. In case of an inoperable patient due to high risk condition, the prescribed radiation dose should not be more than 66 Gys. The current chemotherapeutic regimen is Cisplatin combination chemotherapy with radiation therapy. The combined therapy regimen can increase the 5-year survival rate up to 6.5 % when compared with radiation therapy alone (Burkill, Evans, Raman, & Connor, 2016; Iqbal et al., 2017; Sio et al., 2016). The most widely used chemotherapy regimen is scheduled every three weeks with 100 mg/m2 and a high-dose bolus, while patients normally need hospitalization for a few days (Adelstein et al., 2017).

In this study, participants with both early and locally advanced stage were included according to treatment of choices. The radiation therapy was performed with curative intended treatment.

2.1.3.1 Radiation therapy

Radiation therapy is defined as cancer or benign treatment with ionizing radiation. The target of treatment is to give a high dose of radiation therapy to tumor cells, but low dose or avoidance of healthy tissues as much as possible.

There are two purposes of radiation treatment: 1) curative treatment and 2) palliative treatment. The curative intent therapy with high dose of radiation or combined modalities of treatment, such as chemotherapy and hormonal therapy, is prescribed by the radiation oncologist. Whilst, the prescription for palliative treatment is provided in advanced stage cancer for relieving pain, bleeding, and tumor suppressing to other organs that may cause life threatening symptoms, such as airway obstruction or esophagus deformity. Palliative radiation can alleviate the suffering, reduce the pain, and shrink the tumor to relieve symptom distress.

The radiation treatment can be divided into 3 main steps. First, treatment simulation is important in the radiation treatment process for positioning patients with appropriate positions, immobilization with head and neck mask for treatment accuracy on the marked treating areas, and localization to computerized tomography or magnetic resonance imaging. Second, treatment planning is assigned for each individual patient. Radiation techniques for cancer treatment range from conventional technique, three-dimensional conformal radiation therapy or 3D-CRT, and intensity modulated radiation therapy or IMRT. Lastly, radiation delivery is performed to patients in treatment room with the same radiation treatment process as prescribed in treatment simulation.

2.1.3.2 Concurrent Chemoradiotherapy

The suggested standard treatment for advanced stage head and neck cancer (HNC) is concurrent chemoradiotherapy, which has been established for inoperable diseases or those with unacceptable morbidity from surgery(Yom, 2015). The current chemotherapeutic regimen is cisplatin. Adding this chemotherapy agent with radiation therapy can increase the 5-year survival up to 6.5 % when compared to radiation therapy (RT) alone (Burkill et al., 2016; Iqbal et al., 2017; Sio et al., 2016). The widely used chemotherapy regimen is scheduled for every three week with 100 mg/m2 and high-dose bolus, while patients normally need hospitalization for a few days (Adelstein et al., 2017).

2.1.4 Side Effects from Head and Neck Cancer Treatment

The side effects of treatment radiation depend on radiation dose, technique, and combination of other treatments. There are acute and late effects with increasing toxicities when combined with chemotherapy. The addition of chemotherapy with external beam radiation therapy often increases toxicities and treatment-related side effects, which discourages a patient's compliance to complete the treatment course (Iqbal et al., 2017; Pan et al., 2017; Sio et al., 2016).

2.1.4.1 Symptoms Occurring During Radiation Therapy

Treatment-related symptoms experienced by patients with HNC during the period of radiation treatment include: fatigue, dermatitis, loss of appetite, mucositis, changes in saliva, dry mouth, taste alterations, and dysphagia (Buglione et al., 2016; Gunn et al., 2013; Hofso, Rustoen, Cooper, Bjordal, & Miaskowski, 2013; Pignon et al., 2009; Rosenthal et al., 2014; Villa & Sonis, 2016; W. Xiao et al., 2017; Yom, 2015). The prevalence of symptom can occur at the beginning of treatment with core symptom items, such as fatigue, distress, pain, and sleep disturbance which are almost always present together in advanced cancer patients. However, for head and neck specific symptoms, it relies on the side effects of treatment in any periods (Memtsa et al., 2017; W. Xiao et al., 2017).

During the treatment course of 6-to 7-weeks of radiation therapy regimen, most symptom distresses escalate at week three and worsen through the entire course. There are many evidences that support the effects of radiation therapy to a treated area, causing tissue damages and local symptoms based on specific physiology and organ functions.

Multiple co-occurring symptoms that present in the treatment trajectory can be changed over treatment periods. There are plentiful evidences to support that symptoms occurring in clusters may exacerbate overall symptom experiences (Cheng & Lee, 2011; Kwekkeboom, Cherwin, Lee, & Wanta, 2010). Timely identification and management of those symptoms means better symptom experiences in patients as well as the improved treatment outcomes (C. W. Chan, Richardson, & Richardson, 2011; Thomas et al., 2014).

Significantly, changes in the ability to taste is the most severe symptom in head and neck cancer patients throughout treatment periods with increasing severity from pre-treatment by a factor of five (Pan et al., 2017; Rosenthal et al., 2014). The consequences of taste disturbance are associated with symptoms of dry mouth, pain dysphagia, and xerostomia. These acute side effects of treatment stem from cumulative doses of radiation therapy to the mucosa in the oral cavity and the salivary glands, which disrupt eating habits, choice in food, and difficulties in swallowing that might cause malnutrition in patients (Marcelo & Katharine, 2015; Yom, 2015). The incidence of severe toxicities (grade 3 or 4) can lead to at least one admission due to acute toxicities in 40% of the patients as reported in a clinical trial (Iqbal et al., 2017).

2.1.4.2 Symptoms Occurring During Concurrent Chemoradiotherapy

Chemotherapy is a systemic treatment delivered by intravenous route every three weeks in combination with external beam radiotherapy. The current chemotherapeutic regimen is cisplatin. The adding of this chemotherapy agent with radiation therapy can increase 5-year survival up to 6.5 % when compared with radiation therapy (RT) alone (Burkill et al., 2016; Iqbal et al., 2017; Sio et al., 2016). The common side effects of cisplatinum-based are renal toxicity and nausea-vomiting, which can cause consequential symptoms. The diseases and treatments also contribute to distresses in advanced cancer patients (Jiang, Zhao, Jansson, Chen, & Martensson, 2017; Majid et al., 2017).

A recently cross-sectional study showed that the symptoms occurring in nasopharyngeal cancer patients who receive chemo-radiotherapy appear in the same cluster of problems with mucus, mouth/throat sore, difficulty swallowing/chewing, and taste of food (W. Xiao et al., 2017). Similarly, the results from a previous longitudinal study with focusing on patterns of symptom burdens during radiotherapy revealed the cluster of local symptoms, such as dry mouth, mouth/throat mucus, difficulty chewing/swallowing, mouth/throat sore, and tastes of food (Rosenthal et al., 2014).

In 2013, Rosenthal et al., reported a pattern of symptoms in head and neck cancer patients receiving radiation with and without chemotherapy (Rosenthal et al., 2014). The pattern of symptoms and severity confirmed results from previous studies, which demonstrated that a combination of treatments could cause more toxicities and may interfere with a patient’s routine working and normal activities (Fodeh et al., 2013; Hofso et al., 2013; C. Xiao et al., 2013). In core cancer symptoms, the most prevalent one was fatigue followed by dry mouth. (Rosenthal et al., 2014;

Canhua Xiao et al., 2013b). The problem with tastes of food had the highest prevalence, with the peak during the third week of treatment course and worsen until the end of treatment.

The side effects of combined radiation therapy and the toxicities of chemotherapy contribute to the co-occurrence of both local and systematic symptoms, provoking a patient’s physical and psychological distress (Pan et al., 2017; Ullgren, Kirkpatrick, Kilpelainen, & Sharp, 2017).

2.1.4.3 The Most Prevalence and Severity Symptoms in Patients with Head and Neck Cancer During Radiation Therapy

Cancer patients rarely present with a single symptom as they encounter multiple symptoms. Meanwhile, the differences in each individual can affect how patients rate the sufferings from those symptoms (Barsevick, 2007a, 2007b; Fan, Filipczak, & Chow, 2007; Miaskowski, Dodd, & Lee, 2004). The prevalence and severity of cancer symptoms depend on disease-related or treatment-related symptoms, which can be changed over the stage of disease and the duration of treatment trajectory. Dodd et al. (2001) introduced the concept of a symptom cluster in three or more concurrent symptoms related to one another and may or may not share the same etiology (Dodd et al., 2001). Whilst, others defined the term as at least two related symptoms which occur together and form a stable group, relatively independent from other clusters (H. J. Kim, McGuire, Tulman, & Barsevick, 2005). A cluster of symptoms including dry mouth, mouth/throat mucus, difficulty chewing/swallowing, mouth/throat sore, and problems in the tastes of food in patients with head and neck cancer, may be typically developed during the active treatment phase of radiation therapy and chemo-radiotherapy (Rosenthal et al., 2014; Canhua Xiao et al., 2013a; W. Xiao et al., 2017)

(1) Mucositis or Mouth/ Throat Sores

Mucositis is an acute injury to the mucosal lining of the head and neck region. It is associated with cancer treatment and characterized by erythema, edema, and ulcerations (J. W. Kim et al., 2012). Mucositis is the most common toxicity reported in patients treated with radiation therapy or certain forms of chemotherapy for HNC (Trotti et al., 2003). The condition usually begins during the first week of treatment with symptoms such as burning sensation and mucosal erythema (Sonis, 2009). Within 2 weeks, breaks in the mucosa are apparently evidenced by the appearance of irregular ulcers, generally on the movable mucosa of the lips, cheeks, lateral or ventral tongue, or soft palate (Sonis, 2009). More severe stages occur once the total accumulated dose exceeds 30 Gy, usually after the third week of treatment (Moslemi et al., 2016). The proposed aetiopathogenic model defines mucositis development into five phases: initiation, message generation, signal amplification, ulceration, and healing. The NF-κB pathway is among one of the most studied mechanisms related to mucositis, which illustrates the robustness of biology underlying oral mucositis (Eilers & Million, 2011; Sonis, 2009). Marked xerostomia and dysgeusia can also occur during the same period of treatment. (Chen et al., 2015).

(2) Xerostomia or Dry Mouth or Problem with Mouth/ Throat Mucus

Xerostomia is the subjective sensation of dry mouth deriving from a lack of saliva, which represents a common complaint in patients who undergo treatment of HNC (Pinna, Campus, Cumbo, Mura, & Milia, 2015). Xerostomia may be secondary to true salivary gland hypo function or qualitative changes of saliva. Radiotherapy may lead to hypo salivation (within a week), decreased saliva pH, and altered saliva consistency (Dirix, Nuyts, & Van den Bogaert, 2006). Moreover, radiation causes destruction of progenitor cells and stem cells. The severity and incidence of xerostomia in patients receiving intensity-modulated radiation therapy is lower compared to those with HNC receiving conventional radiotherapy (Pinna et al., 2015). Decreasing salivary output can result in oral discomfort, sore throat, altered taste, and difficulty in speaking, chewing, and swallowing that can occur during the acute or late period following RT (Memtsa et al., 2017).

(3) Dysgeusia or Problems with Tasting Food or Taste Disturbance

Taste disturbance is a commonly reported symptom from radiation therapy treatment, especially in the HNC region. About 90% of patients were affected at some degrees (J. B. Epstein, Smutzer, & Doty, 2016). Those with HNC may experience taste alteration (dysgeusia), loss of taste (ageusia), heightened sensitivity (hypergeusia), or reduced taste sensitivity (hypogeusia) (Bartoshuk, Catalanotto, Hoffman, Logan, & Snyder, 2012). In particular, previous studies showed that patients treated with Cisplatin may develop taste changes, including ageusia or hypogeusia. Chemotherapeutic agents rapidly target the dividing cells and may damage taste buds or receptors (Irune, Dwivedi, Nutting, & Harrington, 2014). Patients may complain of a metallic or chemical taste during the delivery of chemotherapy (Bartoshuk et al., 2012). Dysgeusia is also an early complication of radiation treatment and may precede mucositis (J. B. Epstein et al., 2016). Xerostomia is an additional reaction to radiotherapy treatment and may also lead to taste changes when saliva dissolves food particles in the presentation of testate to taste receptors.

4) Dysphagia or Difficulty Chewing/ Swallowing

Dysphagia is defined as difficulty in swallowing because of structural or movement abnormalities involving the oral cavity, oropharynx, velopharynx, hypopharynx, larynx, and upper esophageal sphincter (Schindler et al., 2015). Patients with cancer of the head and neck have signs and symptoms of swallowing problems because the primary neoplasm affects the organs of swallowing, and/or the treatment itself impacts swallowing (Russi et al., 2012). Resulting pain, copious mucous production, xerostomia, and tissue swelling contribute to acute dysphagia (Murphy & Gilbert, 2009). Acutely, radiation therapy results in damage to the mucosa and soft tissue within the radiation treatment volume (Murphy & Gilbert, 2009; Rogus-Pulia, Pierce, Mittal, Zecker, & Logemann, 2014). Pain, thickened and more viscous mucous production, xerostomia, and tissue swelling can all contribute to acute dysphagia. Acute mucositis can worsen dysphagia (Schindler et al., 2015).

In conclusion, the most prevalence and severity physical symptoms in patients with head and neck cancer during radiation therapy are mucositis, xerostomia, dysgausia, and dysphagia. Moreover, there are many researches on symptom-related treatment toxicities, such as symptom burdens, toxicity grading, malnutrition status, and quality of life.

2.1.4.4 Symptom Assessment

The major challenge in assessing the prevalence, severity and distress of treatment related toxicities is lack of uniformity in the design and use of scoring scale (Stone, Fliedner, & Smiet, 2005). Each tool that a clinician or researcher has developed for clinical trials aims to monitor patient's tolerance and experience during treatment. Symptoms related to treatment toxicities and outcomes in HNC patients are reported in Table 2.1

Table 2.1 Head and neck cancer related concerns and recommended measures developed from clinical trials (Dirix et al., 2006; Eilers & Million, 2011; Irune et al., 2014; Memtsa et al., 2017; Quinn et al., 2008; Ringash et al., 2015; Trotti et al., 2003).

Symptom/ Outcome	Assessment Tools
Mucositis	The World Health Organisation (WHO) scale
	Oral Assessment Guide (OAG)
	Oral Mucosa Rating Scale (OMRS)
	Oral Mucositis Index (OMI)
	Oral Mucositis Assessment Scale (OMAS)
	The MacDibbs Mouth Assessment Tool
	National Cancer Institute Common Toxicity Criteria for Adverse Events (NCI-CTCAE V4)
	Daily Mucositis Score (DMS)
	Oral Mucositis Weekly Questionnaire– Head and Neck Cancer
	Patient-Reported Oral Mucositis Symptom (PROMS) Scale.
	Patient diaries
	Oral Mucositis Weekly Questionnaire – Head and Neck Cancer;(OMWQ-HN)
Xerostomia	RTOG/EORTC grading system.
	Late Effects Normal Tissue (LENT)-Subjective, Objective, Management, Analytic (SOMA) scoring
	National Cancer Institute Common Toxicity Criteria (version 3.0)
	Sialometry
	Xerostomia Questionnaire (XQ)
Dysgausia	Chemosensory questionnaire
	Taste change survey
	The Scale of Subjective Total Taste Acuity (STTA)
Dysphagia	modified barium swallow (MBS)
	Swallowing-Quality of Life Questionnaire(SWAL-QOL)
	MD Anderson Dysphagia Inventory (MDADI)
	Performance Status Scale for Head and Neck Cancer (PSS-HN)

These acute side effects of treatment are the adversities from cumulative doses of radiation therapy to mucosa in the oral cavity. The affected organs are salivary glands which disrupt eating habits, choices of food intake, and difficulty swallowing. The symptom-related outcomes include nutritional status, acute or late symptom toxicities, symptom burden, and quality of life. The symptoms that occur during active treatment, especially with radiation therapy, may cause the development of malnutrition in patients (Bressan et al., 2016; Marcelo & Katharine, 2015; Yom, 2015). The incidence of severe toxicities (grade 3 or 4) leads to one hospital admission at least in 40% of patients as reported in a clinical trial (Iqbal et al., 2017). The synergic effects of symptoms experienced by cancer sufferers may impact treatment outcomes, including quality of life. The status of symptom can be an independent variable or outcome depending on research objectives (Quinn et al., 2008). The symptom-related outcomes are shown in **Table 2.2**

Table 2.2 Measurement of the Symptom-Related Outcomes

Outcome	**Assessment Tools**
Acute toxicity	CTCAE v 4
Symptom burden	MD Anderson Symptom Inventory–Head and Neck Cancer module; (MDASI-HN)
	Vanderbilt Head and Neck Symptom Assessment Scale;(VSSN)
QOL	European Organization for Research and Treatment of
	Cancer Quality of Life Questionnaire-Core 30/Head and Neck 35-questionnaire; (EORTC QLQ-C30/H&N35)
	Functional Assessment of Cancer Therapy-Head and Neck;(FACT-H&N)
	University of Washington Quality of Life (UW-QOL)
Nutritional status	Anthropometrics
	Malnutrition Universal Screening Tool (MUST)
	Short Nutritional Assessment Questionnaire (SNAQ)
	Nutritional Risk Index (NRI)
	Eating Assessment Tool (EAT-10)

2.1.4.5 The Risk Factors of Increasing Symptom Severity

Factors contributing to an increased risk for symptom severity include the disease, staging, and location. Treatment-related factors are robustly evidenced in the combination of chemotherapy with radiation therapy. Consuming tobacco, alcohol, poor oral hygiene, and co-morbidities are patients-related factors. (Dirix et al., 2006; Memtsa et al., 2017; Rodriguez-Caballero et al., 2012; Stone et al., 2005; Trotti et al., 2003)

Symptom clusters occur with some underlying biological or behavioral mechanisms. Certain clusters are common in oncology patients, while others can be disease-and treatment-specific clusters. The available studies have reported on symptom clusters and symptom burdens in this type of cancer among populations in America, and more specific in nasopharyngeal cancer patients in China. To predict a high risk group of patients in a cluster, demographic data could be predictive for symptom cluster characteristics such as race (white) and education (more than 12 years) (C. Xiao et al., 2014). Research findings about symptom clusters in advanced lung cancer patients among Thai population reported on some interesting information concerning the uniqueness of cultural context, such as a lower score in sexual activity. Thai culture is different from western or other cultures in term of sexual activity due to a delicate issue. In particular, many Thais have no confidence in talking to others regarding sexual topics because they are private and very personal issue. Thus, there is a low scoring for this symptom (Khamboon et al., 2015).

There are multiple symptoms during active treatment. In core cancer symptoms, the most prevalent symptoms are fatigue and dry mouth. A problem with taste of food has the highest prevalence and it becomes peak at week three of treatment course before worsening until the end of treatment. A recently reported, cross-sectional study showed similar symptoms in nasopharyngeal cancer patients receiving chemoradiotherapy. The problem with taste of food was in the fourth rank of symptom prevalence after problems with mucus, difficulty swallowing, and dry mouth (W. Xiao et al., 2017). These treatment-related symptoms have been studied in the field of oncology nursing to encourage patient’s self- management to alleviate their suffering during treatment trajectory and improve clinical outcomes.

There is a limited number of research studies on symptom management in head and neck cancer patients receiving radiation therapy. Understanding and knowing the risk factors that enhance symptom burdens or symptom distress in sub-groups, such as demographic, educational status, cultural context, and gender, may help researchers to design or prioritize the interventions to evaluate a risk of severe symptom clusters and personalize management strategies (Hanna et al., 2015; Kwekkeboom, 2016).

2.1.4.6 Symptom management

More attention is given to self-management strategies by patients. An outcome of personal efforts is to shift the responsibility of managing symptoms to each individual. Patients essentially become their own primary caregiver and manage the symptoms themselves on a day-to-day basis. A theory to guide symptom management in practice is the symptom management theory (SMT), which can be classified into symptom experience and symptom management strategies. Symptom status outcomes can also be applied to deal with negative symptoms (Dodd et al., 2001). Any subjective experiences that reflect changes in bio-psychosocial function, sensation, or cognition can be defined as symptoms (Dodd et al., 2001). The perception of physical or emotional change is termed as a symptom experience and a patient needs to evaluate the change before responses. The change is measured as frequency and severity. If the symptoms get worse and disrupt normal living, one should seek help to eliminate or suppress those symptoms. Symptom management strategies are developed to intervene at the onset of other related symptoms, while symptom status outcomes result from implementing the strategies.

Symptom management strategies depend on an understanding of the complexity in patient’s symptom experiences and the underlying causes. A symptom cluster approach to address the multiple symptom experiences of cancer patients may lead to new symptom management strategies. Identification of symptom burdens from a symptom assessment checklist and statistical analysis may help to more easily organize to reveal multiple symptoms in a cluster, as well as to manage and target symptoms in a whole category. Besides the quantitative approaches, there are also qualitative methods to confirm patients' experiences or distresses from symptom clusters, and then prioritize the most distressing results in more valuable interventions derived from the active involvement of patients.

(1) Symptom Management Interventions for Symptom Cluster of Mucositis, Xerostomia, Dysgausia, and Dysphagia in Patients with Head and Neck Cancer Receiving Radiation Therapy

Evidences of symptom clusters and their effects on individual outcomes in head and neck cancer patients, especially when they received radiation therapy are limited and few recent studies have been undertaken (Miaskowski, 2016; W. Xiao et al., 2017). Currently, the management of symptom clusters is still being questioned and studied. To classify or identify symptoms in clusters should be more beneficial for a healthcare provider to manage the symptoms, prompt on the range of important symptoms, and evaluate the symptom status outcome for effective management. To improve patients' self-management and adherence to treatment without disruption can promote experiences and outcomes (Aktas, Walsh, & Rybicki, 2012; Armstrong & Gilbert, 2012; Barsevick, 2007a; Jimenez et al., 2011).

A number of interventions has been proposed and verified to be effective in dealing with the symptoms of patients with HNC. Management of each symptom both pharmacologically and non-pharmacologically could be described in **Table 2.3**

Table 2.3 Head and neck cancer-related management strategies and interventions (Chung et al., 2016; Eilers & Million, 2011; Moslemi et al., 2016; Murphy & Gilbert, 2009; Nevens & Nuyts, 2016; Porter, Fedele, & Habbab, 2010; Rodriguez-Caballero et al., 2012; Rosenthal & Trotti, 2009; Trotti et al., 2003)

Symptoms	**Interventions**			
	Non-Drug Treatment	**Results**	**Traditional and Drug Treatment**	**Results**
Mucositis	- Patient education, hydration, nutritional support, infection control, supportive care	Recommended	- Honey, Manuka, Kanuka oil	E.S.
	-Oral preventive care (improve oral hygiene, clean oral cavity every 4 hours, employ a soft tooth brush, dental floss, alcohol - free mouthwash)	Recommended	- Sucralfate	E.S
	- Artificial saliva and water-soluble jellies	Recommended	- Zinc sulphate/ Zinc supplement	E.S
	- Saline or baking soda mouthwashes	E.S	- Allopurinol	E.S
	- Drinking sufficient liquids	Recommended	- Human placental extract	E.S.
	- Nutritional care	Recommended	- Essential oils	E.S.
	- Avoid smoking, alcohol, consumption of irritating foods	Recommended	- RhEGF	E.S.
	- Sucking ice cubes	Recommended	- Benzydamine HCL	E.S.
	- Laser therapy	E.S	- Indigowood root	E.S.
			- Cryotherapy	E.S.
			- Chlorhexidine	No E.S.
			- Aloe vera	No E.S.
			- Prostaglandins E1	No E.S.
			- Glutamine	No E.S.
			- Amifostine	No E.S.
Mucositis			- Vitamin E	No E.S.
			- Povidine iodine	No E.S.
			- Pilocarpine	No E.S.
Xerostomia	- Stringent oral hygiene with fluoride agents and antimicrobials to prevent dental caries and oral infection	Recommended	- Antimicrobial mouthwashes, such as chlorhexidine and hexitidine, play a central role in reducing bacterial load and inhibiting cariogenesis.	E.S.
	- Regular dental care and appropriate oral hygiene.	Recommended	- Pilocarpine / saliva substitutes	E.S.
	- Drinking water/ taking sips of fluid, garglingwith bicarbonate mouthwash	Recommended	- Cevimeline	E.S.

Symptoms	Interventions			
	Non-Drug Treatment	Results	Traditional and Drug Treatment	Results
	- Using an artificial saliva spray	Recommended	- Antifungal drugs, Benzydamine, and natural agents	E.S.
			- Sialogogic agents to stimulate saliva production from remaining intact gland tissue.	E.S.
Dysgausia	- Provision of food choice and eating suggestions	Recommended	- Amifostine	E.S
	- Dietary counseling and modification by the addition of seasoning	E.S	- IMRT technique	E.S
	- Avoidance of unpleasant foods and extending dietary choice	Recommended	- Zinc sulphate	E.S
	(e.g. pleasing color, form and smell)		- Clonazepam	No E.S.
			- Saliva substituted	No E.S.
Dysphagia	- Enteral nutrition	E.S	- PEG (Percutaneous endoscopic gastroatomy)	E.S
	- Swallowing training	E.S	- Parenteral feeding/ Naso'- Gastric'- tube	E.S
	- Dietary teaching/ modifications	E.S		

Note: E.S., Statistically Significant Results

From various management strategies focusing on pharmacological and non- pharmacological approaches in HNC patients during active treatment, there are more evidences to support the statistically significant differences in those studies. Limited studies are identified to solve symptoms in clusters or multiple symptoms altogether, while the majority are acute treatment-related toxicities (Miaskowski, 2016). Patient-education on intensive oral care protocol, cessation of smoking and dietary-counseling is likely to be effective, based on many research findings across the symptoms in patients with head and neck cancer during active treatment. These non-pharmacological management strategies are demonstrated to prevent unexpected complications, delay onset of oral toxicities, and minimize the severity of symptoms in clusters (Moslemi et al., 2016). Patient education is an integral part of a nurse's roles in supporting patients to alleviate the symptom severities throughout treatment trajectory. Appropriate education should discuss the prospect of oral complications, adequate nutrition, and list of signs and symptoms of infection (Eilers & Million, 2011).

(2) Symptom Management Interventions Related to Symptom Distress: Fatigue and Taste Disturbance

A priority of interventions is recommended for key symptom clusters which distress patients the most and have the greatest impact on health-related outcomes (Xiao et al., 2016). There are two types of interventions designed to treat multiple symptoms, with focusing on cancer symptom clusters, but not specific to only patients with head and neck or radiation treatment. Psycho-educational and behavioral interventions are developed to help patients understand about diseases and treatments, as well as empower them to monitor and report symptoms. Various mode of interventions are also applied with this population, including face to face and web-based designs. This also engages them in a variety of self-management behaviors targeted to individual symptom experiences. Some investigators have tested the effects of an intervention on a single target symptom as a primary outcome and then evaluate the secondary outcome from those impacts; for example, psychological strategies as a guided imagery to evaluate overall symptom distresses. Targeting the symptom in a well-documented cluster is theorized to influence other downstream symptoms in the cluster. Moreover, web-based programs are developed to monitor and support cancer patients to control their symptom burdens (Foster et al., 2016).

There was a study to test a multi-modal symptom management intervention using structured exercise, relaxation training, and individual psycho-social support in patients during admission. A statistical analysis was applied to cluster symptoms at the entry phase, then assigned the subjects' intervention strategies. It was found that this process could reduce the severities and burdens of symptoms during hospitalization (C. W. Chan et al., 2011; Chang, Mu, Jou, Wong, & Chen, 2013; Luckett, Britton, Clover, & Rankin, 2011; Skerman, Yates, & Battistutta, 2012)

Recommendations for symptom management strategies across symptoms, especially in circumstances of fatigue, suggest that cognitive and/ or behavioral strategies (e.g., activity pacing, relaxation, meditation), touch/ body-based strategies (e.g., massage, acupuncture), exercise (e.g., physical therapy, yoga, walking), nutrition or dietary changes, psycho-education, social support, and sensory/art therapies are likely to be effective (Borneman et al., 2007; Capozzi et al., 2015; Du et al., 2015; FitzHenry et al., 2014; Koornstra, Peters, Donofrio, van den Borne, & de Jong, 2014; Meneses-Echavez, Gonzalez-Jimenez, & Ramirez-Velez, 2015; Ream, Gargaro, Barsevick, & Richardson, 2015; Samuel, Maiya, Babu, & Vidyasagar, 2013).

Recommended treatment interventions for taste dysfunction or related-symptoms of anorexia include exercise, nutrition or dietary changes, psycho-education, social support, and pharmacological treatment with corticosteriods as suggested by the National Comprehensive Cancer Network and Oncology Nursing Society Putting Evidence Into Practice (PEP) guidelines (Buglione et al., 2016; C. W. Chan et al., 2011; Farhangfar et al., 2014; Hovan et al., 2010; Porter et al., 2010; Yamashita et al., 2009; Yamashita et al., 2006).

The recommendations for integrated multimodal interventions that are likely to be effective with fatigue and taste disturbance symptoms include exercise, nutrition or dietary changes, psycho-education, and social support with categories of symptom management strategies across symptoms (Mason et al., 2016; Miaskowski, 2016; Mustian et al., 2016).

2.2 Factors related to treatment adherence

Factors influencing treatment adherence in various situations or diseases have been addressed by many researchers, including barriers and facilitators. Accepting and declining cancer treatment has also been investigated by a qualitative research design. Patient’s perceptions on the side effects of cancer treatment, such as restoring and maintaining normalcy to daily life, other value activities, constructive support, and positive beliefs about the efficacy and outcomes of treatment, are important challenges during chemotherapy (Husebo, Karlsen, Allan, Soreide, & Bru, 2015). A study focusing on breast and prostate cancer patients revealed important factors in agreeing to treatment, including the convenience and success rate, necessity of treatment, trust in a physician, and recommendations. Reasons for declining treatment are the discomfort of treatment, fear of side effects, and transportation difficulties (Puts et al., 2015). Similarly, issues from a study about the adherence to treatment in patients with severe cancer pain showed factors to encourage treatment follow-up, which include the perception of physical and psychological benefits to follow recommendations, self-efficacy in pain control, and trust in healthcare team. The barriers to treatment adherence are negative attitudes towards opioid use, side-effects from drug use, and refusal to pain as a sign of disease (Torresan et al., 2015). Other barriers of treatment adherence are depression, potential adverse effects, and complexity of treatment regimens (Devine, Edwards, Feldman, & adherence, 2018). The barriers to radiation treatment adherence are reported in male more than female when head and neck cancer is diagnosed with the planned combination treatment of chemotherapy and radiation therapy. Identification of these barriers that lead to non-treatment adherence can be designed as strategies to overcomes those factors (Rangarajan & Jayaraman, 2017).

In conclusion, factors influencing treatment adherence include facilitators and barriers, which are both physiological and psychological factors. Understanding of these factors requires a multi-method approach to summarize and synthesize each individual for initiating interventions.

2.2.1 Promoting Treatment Adherence

Regarding non-adherence to radiation therapy, the most common causes included admission to a hospital and severe acute toxicities, such as mucositis, skin dermatitis, and hematological toxicity (A. Chan, Teoh, Sanghera, & Hartley, 2009; K. Thomas et al., 2017). The toxicities related to concurrent chemoraiotherapy should be assessed, monitored, managed, and put evidence-based into a plan of care along the treatment continuum, particularly patients with head and neck cancer. Treatment adherence should be promoted to achieve optimal clinical outcomes with collaboration among healthcare providers, patients and family.The method for a health care delivery approach should be guided by a symptom management theory, so that patients with head and neck cancer can develop strategies for their own care that fit the life as an outpatient. The strategies for reducing symptoms in terms of physical and emotional discomfort can be guided by certain activities, such as where, when, who, how, and why they receive treatment. In this case, the system management theory continues to evolve as a framework for understanding symptoms, both physical and emotional, designing and testing management strategies for evaluating outcomes (Dodd et al., 2001). Moreover, SMT is offered as a conceptualization to guide in the selection of effective management strategies. Patients should be at the center of a focus during every step of care (The Healthcare Accreditation Institute (Public Organization), 2018). Further, the researcher should practice active listening towards a patient's observations and understand the barriers to treatment. In order to empower patients to perform self-management strategies, the holistic care is needed for these participants. Giving the information and education that patients need is necessary whileempowering thems to get involved in decision-making. In addition, the concept of patient-centered care can be used as a framework to enhance treatment adherence, resulting in the improved clinical outcomes and patient's satisfaction.

2.3 Existing Care Process for Patients with Head and Neck Cancer during Concurrent Chemoradiotherapy

Although the treatment outlook has centered on technological innovation, equally important is service quality in order to improve patient's satisfaction, engagement, compliance, and ultimate outcomes. Increasingly, the research in radiation oncology outcomes is moving to a patient-centered era, with the utilization of patient-reporting of adverse events as a specifically desired outcome (Calisi, Boyko, Vendette, & Zagar, 2016). Patient-centered care (PCC) is a key theme in desiging and redesigning health care services. The principles of PCC are reflected in health care provider approaches that respect a patient's preferences, values, physio-psychological comfort, plus provide open communication, emotional support, continuity, transition and involvement of family and friends, in coordination and access to care (Picker Institute, 1993). Currently, PCC approaches seek to redress imbalances in health care and represent a shift from previous approaches with medically dominated and disease orientated (Santana et al., 2018). Evidences show that patient-centered care enhance and improve health outcomes and overall patient's satisfaction(Ekman et al., 2011). Further, PCC means a move away from a paradigm in which a patient is simply a passive target of medical intervention to a more progressive pattern of care centering on a contractual arrangement, which involves the patient as an active part in his or her care and decision-making process (Picker Institute, 1993). The PCC approach seeks to establish collaborative partnerships and adopts a holistic approach, seeking to meet and acknowledge patients’ values by enhancing their engagement and involving them in decisions (Delaney, 2018). Radiation oncology has been recognizing the patient-centered care with ambition to achieve the optimal efficacy in treatment outcomes (Mackenzie, Sanson-Fisher, Carey, & D'Este, 2013).

Head and neck cancer-specific patient support and education programs for patients and families have been developed to help patients and families in managing their symptoms (M. McQuestion & M. Fitch, 2016).Existing nursing care service model in radiation oncology department divides the nursing care process into three parts: before, during, and after radiation therapy.

2.3.1 Before Treatment

Patients with head and neck cancer are treated with multimodalities by a multi-disciplinary team. Patients and their families have to see the specialists as an ENT doctor, dentist, radiation oncologist, and medical oncologist. Patients’ scheduling for the commencement of radiation coupled with chemotherapy treatment depend on effective coordination from the nurses between departments. The CT-Simulation procedure is performed with special request for immobilizing and contrast media injection. The first day of radiation has to be the first day for chemotherapy as well. Patient’s preparation includes physical and emotional readiness. The information for physical preparation includes appointments to receive prescribed treatments, accommodation, financial, or treatment plans. Emotional preparation includes distress screening and early nursing interventions such as anxiety assistance arising from a lack of knowledge about treatment, fear of radiation and chemotherapy side effects, social support, and self-care strategies. However, patient overloads and paper works are the most barriers for assessing their needs and concerns.

2.3.2 During Treatment

Symptom assessment and management are crucial during concurrent chemotherapy. Treatment-related toxicities have to be understood by patients and their caregivers to comprehend what is going to happen during treatment. Symptom monitoring for acute toxicities by the radiation oncologist and nurses occurs during weekly radiation therapy. Patient reporting of symptoms and toxicities should be encouraged. Monitoring of daily vital signs and symptoms will occur before treatment. Mild to moderate toxicities in terms of CTCAE scoring will be measured in every patient by the oncologist to confirm treatment continuity, such as mucositis, dysphagia, skin reaction, and xerostomia. Severe grades of radiation induced toxicities can cause interrupted or delayed radiation or chemotherapy treatment. As a course of prescribed radiation therapy takes six weeks to complete, this complex treatment requires the best in health care approaches coupled with sound cooperation between the health care provider and the patient throughout the treatment period. Treatment of head and neck cancer involves oral intakes that might cause the reducing of food consumption and weight loss during treatment. Therefore, maintaining their nutritional status and achieving treatment adherence can be the most challenging issues in continuity along treatment journey.

2.3.3 After Treatment

The late effects incurring from completed treatment arise within about four weeks. Some effects are long lasting or lifetime in nature, such as xerostomia, dysphagia, and trismus. There are standard guidelines to follow-up with the patient after conclusion of treatment. Health education for the prevention of long term side effects is a vital nursing role. Physical examination and digital imaging to ensure the rate of treatment success are according to the NCCN guidelines.

The major concerns of nursing care during radiation therapy treatment is symptom management, especially in patients with head and neck cancer. Thus, the patient-centered care is a holistic approach in health care, not only focusing on physical but also paying attention to psychological comfort for patient’s satisfaction and well-being. Quality healthcare, in term of nursing capability in a multidisciplinary team, is to provide care to cancer patients and their families, respecting an individual’s preferences and values, while at the same time emphasizing effective communication and supportive care. Especially, during the active treatment of radiation therapy, radiation oncology nurses should consider the appropriate service to achieve optimal health outcomes of cancer

Due to an increasing number of cancer patients, delivery treatment to patients and service management in the hospital becomes challenging tasks. Patient empowerment to enable a convalescent to take care themselves at home and monitor signs and symptoms are of paramount importance for head and neck cancer patients. However, patient's experiences, preference, and share decision making have not taken into account. Therefore, the patient' experience with radiation therapy have been reported in refusing, discontinuing, and interrupting during treatment in many researches. The treatment adherence becomes challenging for radiation oncology nursing to better design nursing care process by using patient' experience and participatory approaches in every process of care for enhancing patient self-management and satisfaction during radiation therapy.

2.4 Participatory Action Research

The philosophical underpinnings of participatory action research (PAR) are harmonious with "postmodern custom that grasps an argument of moving understandings", whereby "objectivity is inconceivable" and "different or shared substances exist" (Kelly, 2005, p.66). Attwood (1997) clarified that PAR's rationality exemplifies "the idea that individuals have a privilege to decide their own particular improvement and perceive the requirement for nearby individuals to partake seriously during the time spent breaking down their own particular arrangements, over which they have (or share, as some would contend) power and control, with a specific end goal to prompt for manageable advancement"(MacDonald, 2012a). As indicated by Stringer (1999), traditional groupings are tested by activities of seeking a full coordinated effort by all members, who are regularly experiencing sociopolitical changes. By utilizing PAR there might be an arrangement of open spaces, whereby participants and researchers can reshape their insight into how political, social, financial, and familial settings in groups may affect day by day life (McIntyre, 2002).

2.4.1 What is Participatory Action Research?

Participatory action research refers to a research methodology that emphasizes on participation and action (or implementation), using methods that involve repetitive processes of reflection and action, "carried out with and by local people rather than on them."(Creswell, 2009; S. Kemmis & McTaggart, 2000; Spinuzzi, 2005). Also, the participatory action research is defined as "systemic collection and analysis of data for the purpose of taking action and making change" by generating practical knowledge (MacDonald, 2012b).In participatory action research, a distinctive feature is that the control and power over the process mainly relies on the participants themselves. This feature is similar to the person-centered care (Ekman et al., 2011). Emphasis is also on coping with conflicting interests, where there needs to be a negotiation between a current situation and a future vision to complement each other (Spinuzzi, 2005). It is also concerned with the ambition of the researcher to focus on other people's knowledge and ideas, instead of his or her own (Steen, 2013).

2.4.2 Process of Participatory Action Research

A typical system for PAR incorporates a "patterned procedure of truth discovering, activity, reflection, prompting to further request and activity for change" (Minkler, 2000). This then offers other radical options for learning improvement in order to remain an aggregate, self-intelligent request with the end goal of enhancing a circumstance (MacDonald, 2012a). In addition, PAR includes a cyclic procedure of research, reflection, and activity (Marshall and Rossman, 2006; Selenger, 1997) that "offers a scrutinizing of and testing for the prevailing positivist sociology which inquires about the main true and substantial source of learning" (Maguire, 1987, p. 10). Maguire characterized PAR from a feminist point of view with consolidating the exercises of social examination, training, and activity in an aggregate procedure. The social examination action of PAR incorporated "a technique for social examination of issues, including the support of persecuted and standard individuals in a problem posing and solving". Wadsworth (1998) additionally added to the meaning of PAR by consolidating the impression of authentic, political, monetary, and geographic settings, with keeping in mind the end goal to understand issues and encounter the requiring activity for changing or enhancing a circumstance. PAR is not just a research that is followed by action, but it is an activity that is looked into, changed, and re-examined inside the exploration procedure by the participants (Wadsworth, 1998).

This study followed the research spiral of the action research based on the action research spiral method with four cycles. Each cycle used a spiral of individual and collective self-reflective cycles as a methodology of four steps: planning, acting, observing, and reflecting (Stephen Kemmis & McTaggart, 1988).

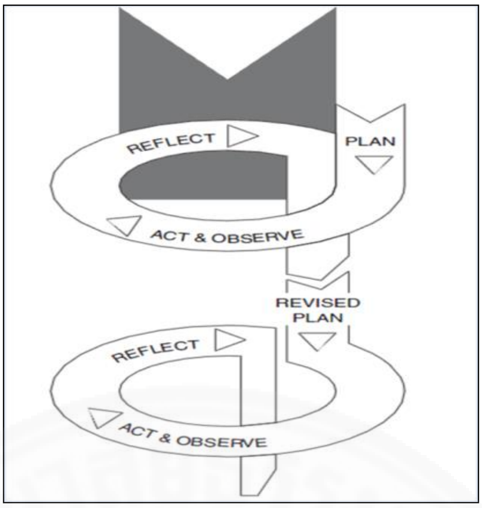


Figure 2.1 Kemmis and McTaggart’s (1988): Action Research Spiral

2.4.3 Participatory Action Research in Nursing and Health Care

The participatory action research has been increasing popularity across disciplines in healthcare, including nursing. It was design to bridge the gap between theory, research, and practice (Holter & Schwartz & Barcott, 1993b). Town's (1978) proposed that a fruitful activity has a tendency to be concentrated in associations, where there is a "prevailing force and sound part structures which sensibly and obviously explain objectives" for the characteristics of nursing profession by a chain of importance and practice of services (Robinson and Strong, 1988). Late nurses have increasingly utilized the inductive methodologies with the point of building up a more noteworthy comprehension of the way towards nursing. Holter and Schwartz-Barcott (1993), notwithstanding, proposed that nursing research has overemphasized naturalistic types of enquiry and they recommended that shortcomings with this approach have driven towards PAR to conquer any limitations between practice, observation and theory (Sparrow S., 1994).

Using patients’ experiences to improve the quality of healthcare services has been accepted by healthcare policy makers and nursing professions in several countries as a core component in healthcare quality as well as clinical outcomes and patient safety (Robert, 2013). In healthcare system designs, using patients’ input with the implementation of changes in the process of planning and designing care improvement can bring about changes and enhance patient engagement (Khodyakov et al., 2017).

Many research studies, to date, have focused on the advanced technique and efficacy of treatment modalities, as well as assessment and management side effects and toxicities. Meanwhile, a few studies have tried to understand patients’ experiences and how they manage their cancers (McQuestion, 2006).

Currently in Thailand, the updated version of hospital and healthcare standards (2018) suggested the framework of 3C (concepts, context, criteria), Purpose, Design, Action, Learning, and Improve for developing healthcare quality design processes that are focused on user needs and outcomes. In part III-5, it was mentioned about information and empowerment for patients and families, aiming to enhance their abilities to take care themselves. This approach enhances the effectiveness and efficiency to improve patient’s well-being, safety, performance, and sustainability in healthcare industry (The Healthcare Accreditation Institute (Public Organization), 2018).

2.4.4 Application of PAR in Clinical Nursing Practice

In a research article (Miguel Padilha, Sousa, & Pereira, 2016), the use of PAR and the initial philosophical underpinning were demonstrated. The purpose of this research was to use PAR in facilitating changes in the process of clinical practice that promotes knowledge development. This article showed the importance of PAR to implement changes in health care perception for the development of self-care management skills in patients with chronic pulmonary disease (COPD).The results demonstrated that PAR is an appropriate methodology to identify and drive changes that can contribute to patient safety and quality outcomes. Moreover, the use of participatory action research in nursing practice was depicted by nurse researchers in Denmark, with a focus on reorganizing the follow-up after fast-tract colorectal cancer surgery patient’ experiences to identify nursing interventions, such as a nurse-led outpatient clinic, emphasizing bowel disorders and using patient-centered approach to the follow-up talks (Thomsen & Hølge-Hazelton, 2017). The efforts created a participating care and elevated the more expert role of clinical nurses in advancing nursing practice. It was hypothesized that the participatory action research was an appropriate system to inspire health professionals in their practice, similar to the encouragement of patients to participate in their care and engage the control of their own situations.

2.4.5 Ethical Consideration in Participatory Action Research

Winter (1987) laid out various moral rules that analysts must consider when directing PAR. In the first place, the researcher should guarantee that every pertinent individual, boards of representatives, and experts have been advised, and that the standards managing the work are acknowledged before starting the inquiry. All members must be permitted to impact the work, especially the desires of individuals who do not wish to partake must be respected (McNiff, 2010). In practice, moral issues may emerge; for example, how to ensure cooperation, informed consent, shared basic leadership, anonymity, and hierarchy to determine clashing necessities (McNiff and Whitehead, 2006). An individual's intention can be a moral issue. When a group is formed, it might be troublesome for a person to pull back from the initial commitments (Meyer, 1993). Special consideration is important towards individuals who can't adequately comprehend the information given to gain any initial approval. Adequately obtaining any authorization from parents or a guardian, if applicable, needs to be recognized and addressed. Anonymity is an issue when a group is requested to undertake a joint venture. In practice, many participants do not object to be named, while others may want to stay unknown (McNiff and Whitehead, 2006). The investigator has the obligation to guarantee that no participant is harmed during the course of research and knowledgeable about any clashing interests and conceivable results of choices made (Walker and Haslet, 2002). Participants are in a double role as they are (co)researchers and also responsible for the alterations in the researched situation and these outcomes, not always recognized by collaborators, can challenge their positions. Issues arise when the effects of action research are in opposition to the interests of management or existing administrative policies. These conflicting interests can spell troubles for the successful conclusion of action research projects. This unwanted outcome enforces the need to involve a whole organization in a project, so that the research reflects the shared values of the institution (Vallenga, Grypdonck, Hoogwerf, & Tan, 2009).

2.5 Conceptual framework of this study

The development of a person-centered model to enhance treatment adherence was guided by the person-centered care approach (PCC) from Picker Institute (1993,2004). The person-centered is an ideal as one of the aims for health care system improvement for providing care that is respectful and responsive to individual patient preferences, needs, and values, ensuring that patient values guide all clinical decisions. From the phenomenon of patients with HNC receiving concurrent chemoradiotherapy, it is apparent that they have to take a more active role in decision-making about their health care delivery service. Treatment-related unpleasant symptoms and personal concerns for patients and their families without patients treatment exceeding one month may present a difficult situation. Accordingly, the researcher and radiation oncology team need to create a change in practice, which commit to the continuity of care with appropriate information and education in order to enhance physical comfort and emotional support. The findings provide a better understanding of the experiences of patients with head and neck cancer during concurrent chemoradiation therapy who are suffering from many unpleasant side effects and the impact on their life along the treatment journey. Moreover, the healthcare system consists of care receivers to foster excellence services and ensure optimal patient and family satisfaction. In addition, the radiation oncology care system and the person-centered care enhance the partnership between healthcare providers and patients and their family to support patients' ability and willingness to participate in their own care(Delaney, 2018). The priority should focus on patients as the center of care, with a collaboration between the researcher and the participants to find a solution in practice that fits individual circumstances.

The participatory paradigm proposed by Heron and Reason (1997) influences the participatory action research process by developing a person-centered model. Mutual-Collaborative is one type of action research project that the researcher and the practitioners coming together to identify potential problems, their underlying causes, and possible interventions (Holter & Schwartz & Barcott, 1993a). The highlights of participatory action research inquire about a promise to the liberationist development, with respect to the experiences and knowledge of participants included, and the guarantee to authentic cooperation in research (Reason, 1994). The assumption is that the participants can comprehend about their lives and experience while participating in a learning process and acting in the self-guided and deliberately political approaches to change their social setting. Therefore, the researcher and participants come together to conduct a participatory action research for developing a person-centered model to ensure that the nursing care meets patient and family needs and capabilities in terms of enhancing treatment adherence and satisfaction among radiation oncology team and patients with head and neck cancer and their family based on the participatory action research approaches.

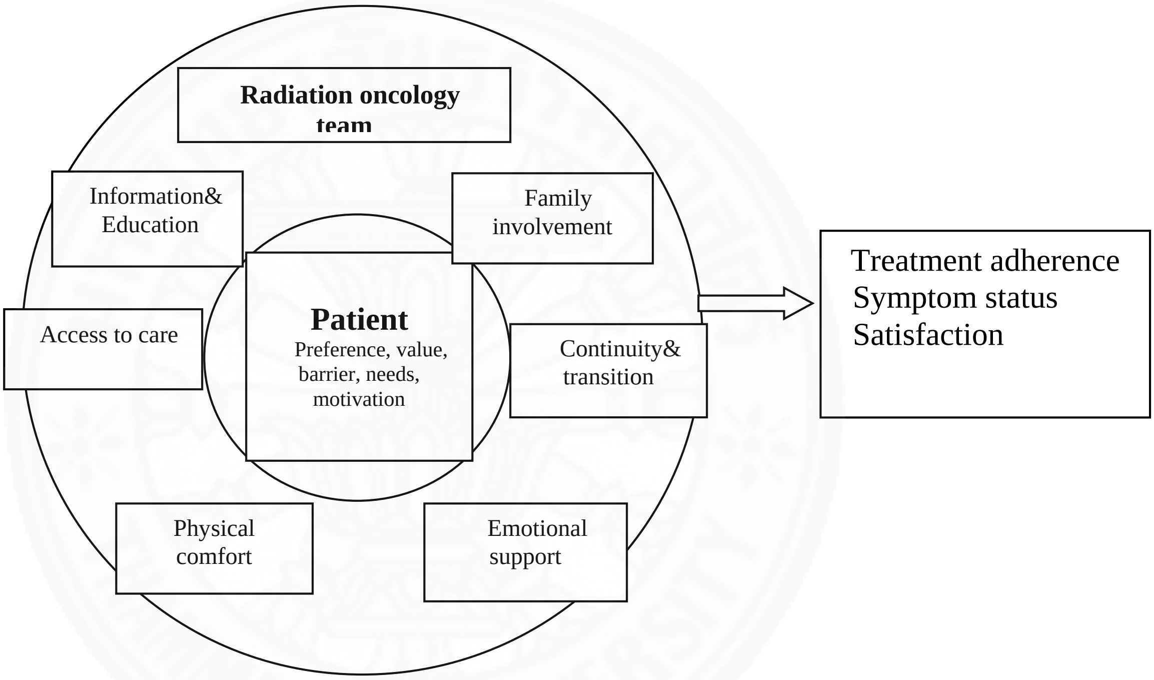


Figure 2.2 Conceptual Framework of the study “The development of a person-centered model for patients with head and neck cancer receiving concurrent chemoradiotherapy”

CHAPTER 3

RESEARCH METHODOLOGY

This study aimed to develop a person-centered model, truly with mutual active collaboration and decision-making within the radiation oncology team towards a design and management of customized and comprehensive process of care for HNC patients and their family, usinga participatory action research as proposed by Kemmis and McTaggart's (2000) with self-reflective cycles. The study was divided into two phases. **Phase 1** was to explore the experiences of patients with head and neck and their family during concurrent chemoradiothetrapy, as well as the perspectives of the radiation oncology team. **Phase 2** was to develop a preliminary person-centered model and tested for the effectiveness and efficiency.

3.1 Phase I: To explore experiences of head and neck cancer patients and their familyand radiation oncology teamduring concurrent chemoradiotherapy (CCRT)

3.1.1. Participants

Therewere 2 groups of participants: 1) HNC pateints and their family and 2) radiation oncology team. All participants were interviewed on their experiences of care.

Group 1: HNC patients and their family were invited for interview at Department of Radiation Oncology to explore the needs and problems of the existing pattern of radiotherapy care services. Moreover, the needs of those services were determined to achieve treatment adherence and tentatively eliminate overall barriers. Purposive sampling was used to identify head and neck cancer outpatients who currently received CCRT and those who were planned for CCRT during the study period, with the selection of most prevalent and relevant factors for effective use of limited resources, as well as a variety of specific encounters during radiation therapy (Patton, 2002). Patient appointments within the time frame of this study were categorized by criterion-inclusion.

3.1.1.1 Inclusion criteria; HNC patients:

(1)Thai male or female patients with primary head and neck cancer in early stage (T1-Y2, N0) and locally advanced stage (T3-T4, N+), who received the combination of radiotherapy and chemotherapy as curative treatment (D Gomez et al., 2011)

(2) Ambulatory and ability to perform self-care according to the Eastern Cooperative Oncology Group (ECOG) score (Oken et al., 1982), defined as 0-2 (0- asymptomatic and fully active, 1- symptomatic, but completely ambulatory, and able to carry out light work or office work, 2- symptomatic and capable of self-care, but unable to carry out any work activities, >50% of waking hours

(3) Age between 18-75 years (average age of HNC >50 years or 63.84 ± 12.65 years) (JA Ridge. et al., 2016; GS Stonov, 2017) (or 18 years from the hospital cancer registry)

(4)Ability to communicate in the Thai language

(5) Willing to participate in this study, with the signed consent form

(6) Prior experience of radiation therapy within 1 year of study (as the usual length of time to adjust with treatment) (G. Kjellsson., 2014)

3.1.1.2 Exclusion criteria

(1) Significantly with severe co-morbidities or another illness required for hospitalization, such as dyspnea, SVC obstruction, and sepsis, which could obstruct the interview and may impair participation in caring process and research process.

(2) Incurable cancer or palliative radiation therapy as defined by radiation oncologist, such as metastasis cancer and end of life stage cancer

3.1.1.3 Discontinuation criteria

(1) Request to stop participation in the study

(2) Need to stop radiation treatment by participant or family caregiver and/ or referred to a radiation center close to hometown

3.1.1.4 Inclusion Criteria; Family caregiver:

(1) Family member with relationship to HNC patients, including wife/ husband/partner/son/daughter/sibling/cousin, as the main caregiver of the patient during radiation therapy

(2) Ability to communicate in Thai

(3) Accompanying with the patient to Department of Radiation Oncology department for radiology treatment

(4) Voluntary agreement to participate, with the signed consent form

(5) Age more than 18 years

3.1.1.5 Exclusion Criteria:

(1) Care giver with illness or unable to communicate with the researcher

(2)Family member with temporary care to the patient during radiotherapy

3.1.1.6 Discontinuation Criteria:

(1) Request by the participant to discontinue the study

(2) Need to stop radiation therapy by the participant or family caregiver and/ or referred to a radiation center close to hometown

3.1.1.7 Sample Size

The interview was used in this study, generally with saturation concept. A previous study explored the experiences of 17 patients with head and neck cancer by the interview (M. McQuestion & M. I. Fitch, 2016). Cresswell (1998) suggested the number of 20-30 subjects in qualitative research. Therefore, the total number of group 1 participants in this study were 23, including 15 HNC patients and 8 family caregivers.

Group 2: This involved the key health care professionals in radiation oncology service to voice their perspectives. The radiation therapy department comprised 6 radiation oncologists, 10 radiation therapists, 9 radiation oncology nurses, 7 practical nurses, and 5 allied health staffs.

A wide variety of staffs were selected for interview based on their working experience of more than 5 years in providing direct care for patients. Data from approximately 12-15 interviews provided sufficient insights to represent and reflect the experiences of staffs. Thus, the total number of radiation oncology team were 23participants, including 5 radiation oncologists, 6 radiation therapists, 8 radiation oncology nurses, 1 clerk, 1 nurse aid, and 2 radiation therapist’ assistants.

3.1.2 Instruments

The research instruments for data collection in phase I include da demographic questionnaire, semi-structured interview guide, audio recorder, and field notes.

3.1.2.1 A demographic questionnaire was developed by the researcher. The questionnaire comprised personal information, head and neck cancer staging, and data of treatment.

3.1.2.2 A semi-structured interview guide was adopted for the study and composed of open-ended questions. The questions were developed by the researcher from literature review, which reflected the objectives of research and focused on in-depth responses about individual experiences, perceptions, opinions, feelings, and knowledge related to the process of concurrent chemoradiotherapy care service. One goal was to investigate their presumptions and awareness on the existing process of care, as well as the perspectives about the characteristics of person-centered approach. The semi-structured interview guide in this study was reviewed by 3 experts.

3.1.2.3 An audio recorder was used to record dialogues between the researcher and participants.

3.1.2.4 Field notes were employed to describe the verbal and non-verbal reactions or behaviors in naturalistic situations. The reactions were immediately recorded after individual interviews. Field notes could provide important contexts for the interpretation of audio-recorded data and help remind the researcher of potentially significant situational factors during data analysis.

3.1.3 Procedure

After approved by the Ethics Review Sub-Committee for Research Involving Human Research Subjects of Thammasat University (No. 3) and Chulabhorn Hospital, the researcher made appointments with the chief of nursing officer and the head of radiation oncology department to provide information about the study. Then, the researcher engaged in the recruitment with the following steps:

3.1.3.1 The researcher met with each participant at the clinic for introduction and research objectives, with the signed consent form to participate in the study.

3.1.3.2 The researcher trained radiation oncology nurses to understand the study process and emphasize the inclusion criteria of HNC patients and their family caregivers, confidentiality, rights, and risk management.

3.1.3.3 The researcher provided the information sheet and invited potential participants to participate in the study.

3.1.3.4 The potential participants were interested in the study and directly contacted the researcher. The potential HNC patients and their family contacted radiation oncology nurses. The participants met with the researcher.

3.1.3.5 The researcher provided the rights and opportunities for participants to ask questions about the study. At the first meeting, the researcher engaged in active dialogues to encourage participants.

3.1.3.6 Written consent forms were signed after discussing all the questions with participants. Interviews were conducted by the researcher.

3.1.4 Data collection

In HNC patients and their family caregivers, the researcher conducted semi-structure in-depth interview of approximately 45 minutes each in the Thai language. All patients and family caregivers described their experiences of care, especially during the radiation therapy treatment. The researcher asked for permission to record the interview and took notes. Before the end of each interview, the researcher shared the understanding of significant information obtained from participants.

For radiation oncology team, the researcher contacted the lead clinicians to get involved and establish the name list of radiation oncologists, radiation therapists, and allied healthcare professionals to participate in the interview as scheduled. The structure of in-depth interviews took place in the clinic when participants were available, with an average time of 30-45 minutes. A variety of patients' experiences were useful for the input of information about the existing problems regarding the care service model. The participants identified their needs in developing a tentative person-centered model.

Participants’ observation and the reviewed documents were gathered along with monitoring their practice and understanding of the concerns to serve as a basis for formulating and refining further plans and changes.

An audio recorder was used to record all the processes and conversation of the interview. Before recording, the researcher asked for permission, together with the signed consent form. The researcher explained to the patients that a digital recorder was employed to record the discussions for analysis. The recorded information was kept private and confidential. The researcher could be the only person with access to those records.

3.1.5. Data Analysis

The audio recorded interviews were transcribed and the data were analyzed thematically. Following the data collection, a staff meeting to review the items arising from interviews and observational data was held in order to identify the tentative person-centered model. Data from interviews, audio recordings, and field notes were integrated to ensure the trustworthiness of all information. Data generation and data analysis was performed continuously throughout the process. The concepts were developed by the level of data analysis, including latent content, unit of analysis, meaningful units, condensing, abstracting, content area, code, category, and theme (Graneheim & Lundman, 2004). The study aimed to synthesize and summarize the participants’ experiences for the development of data-driven tentative person-centered model to enhance treatment adherence and satisfaction among radiation oncology team, patients and their family who had experiences of receiving radiation therapy.

The first step of data interpretation was to read and re-read the verbatim text transcript, field notes, and document review to gain an understanding of participants’ perspectives. The texts were divided into smaller parts or meaningful units. The next step was to consider the contexts, label the condensed meaning of units by formulating codes, and make grouping of these codes into categories (Erlingsson & Brysiewicz, 2017).

The summary of research process in this phase was shown in Table 3.1

Table 3.1 The summary of research process in phase I

Study phase	Purpose	Participant	Method
Phase I **Explore the situation and identify problems and needs**	Identify patients and their family's experiences and needs during CCRT care process	15 HNC patients and 8 family cargivers	-In-depth Interview -Participant observation -Document review
	Establish the key healthcare professionals in radiation oncology service and identify their sharing concerns	23 Radiation oncology staffs; 8 Radiation oncology nurses, 5 radiation oncologists, 6 therapists, 4 allied health staffs	

3.1.6 Rigor and Trustworthiness

The principle of trustworthiness suggested by Guba and Lincoin (1989) was applied to assure the rigor of study as much as possible (Guba & Lincoln, 1989). The four qualitative trustworthiness criteria included credibility, transferability, dependability, and conformability, with the use of specific strategies throughout the research process (Krefting, 1991). Credibility was illustrated by choosing participants in group 1 with various experiences, age, gender, and perspectives for a wide variation of inputs. Also, the selection of in-depth interview and the focus group for data collection methods and suitable meaning units was established to enhance the credibility. Moreover, the agreement between co-researchers and participants provided support for the credibility of findings. At least two strategies were suggested particularly in the qualitative study, such as triangulation, reflexivity, and member checking (Hadi & Closs, 2016). Therefore, this study applied the triangulation together with co-researcher and advisory board in checking the findings.

Dependability was maintained in this study to deal with data change over time by addressing an open dialogue within the action team and nursing participants. Transferability was illustrated with a clear description of context, culture, selection of patients, data collection, and analyzing process.

Transferability referred to the degree of details about the context of a situation in deciding whether something was similar or dissimilar when compared to another situation (Lincoln & Guba, 1985). Rich and appropriate quotations enhanced the transferability.

Confirmability was used by multiple methods of data collection, or triangulation was applied to compare a variety of data for the confirmed accuracy of findings, such as focus group discussions, in-depth interviews, group meetings, and reflection records to ensure credibility and conformability (Guba & Lincoln, 1994). In addition, the conformability of findings was discussed with an advisory team to verify accurate interpretation not invented by the investigator(Elo et al., 2014). A clear audit trail was detailed to show all findings derived directly from the data and to help ensure accuracy.

3.1.7 Ethical Considerations and Human Subjects' Protection

The study was submitted for ethical approval to the Ethics Review Sub-Committee for Research Involving Human Research Subjects of Thammasat University, (No.3) (Faculty of Health Sciences and Science and Technology). All ethical principles were respected in the study. The design of change was orientated by the principles of commonality and responsibility between the researcher and the participants (McTaggart, 1991). The ethical issues in this research were divided in three parts; before, during, and after study. To conduct a qualitative research, the negotiation of researcher's role in the clinical unit was clearly identified by the group. The purposes of study were discussed before the study(Orb, Eisenhauer, & Wynaden, 2001). It was important to gain the understanding of researcher-participant relationships and researcher's role during data collection.

Before the study, patients must clearly understand their rights of advanced directives, treatment decision-making, and consent for research participation (Munhall, 1988). The participants provided their informed consent and full confidentiality. Anonymity was guaranteed. During the study, participants could withdraw from the study at all time. The participants were given explanations about the right of privacy. They were protected from unauthorized individuals to gain the access to their health information. During interviewing, some of the questions may prompt participants to potentially recall their uncomfortable experiences. In such cases, the participants were advised to share as much about their experiences as they found convenient and comfortable.

The participants were informed that they could decline to answer any issues that may cause their discomforts. Additionally, they were allowed to refuse to participate, withdraw consent, or stop participating at any time. The confidentiality of participants' information was ensured through data management. This was achieved through the elimination of identified information from the transcribed data and careful storage. Audio recordings of interviews were administered with participant`s knowledge by using a digital recorder throughout the interview sessions. To minimize confidentiality threats, the researcher performed data transcription and promptly started data analysis. The transcribed data were devoid of personal identifiers and the hospital number was deleted. A participant number was assigned to every transcribed interview. Every audio recording was stored in password-protected flash drives and kept in fire-proof cabinets. The researcher was the only person with access to data. After study, the audio files were destroyed. The participants were explained how research findings or reports were published (Orb et al., 2001). Registered nurse' autonomy was respected in research process or in case of ostracism.

3.2 Phase II: To develop a person-centered model for enhancing treatment adherence, symptom management, and satisfaction among radiation oncology team and patients with head and neck cancer and their family during concurrent chemoradiotherapy

3.2.1 Participants

Participants from phase I: the representatives from radiation oncology team were invited for group discussion and development of person-centered model, including 5 radiation oncology nurses, 4 radiation oncologists, and 6radiation therapists. Also, it was opened for other interested staffs in sharing and learning about the new model of care. Moreover, during the concurrent chemoradiotherapy care process, the 7 patients with head and neck cancers and 4 family members were invited to participate in this phase.

3.2.2 Instruments

The research instruments for data collection in this phase included a demographic questionnaire, an audio recorder, and field notes.

3.2.2.1 A demographic questionnaire was developed by the researcher. The questionnaire included personal information and data of illness, such as head and neck cancer staging and treatment data. These data were used to describe the participants and provide information related to personal background, symptom status, and treatment adherence.

3.2.2.2 An audio recorder was used to record dialogues between the researcher and participants during the focus group.

3.2.2.3 The open-ended questions for reflection and focus group discussion were employed to explore the participants' feeling, perception, their needs and idea towards the person-centered model and data was analyzed be content analysis. Moreover, the unstructured questions used to explore the level of satisfaction and general feeling among participants towards all components in person-centered model. In addition, the qualitative data obtained were used as a guideline to revise and improve the person-centered model for the future.

3.2.3 Procedure

After exploring the situation and identifying problems and needs of the existing service process, data obtained from phase 1 were discussed, synthesized, and summarized to explain about existing phenomenon**.** Based on Kemmis and McTaggart's (1988), the action research spiral of individual and collective self-reflective cycles as a methodology contained four activities: plan, act and observe, and reflect. Then, the revised-plan were continued during the model development. There were 3 cycles in this study for model adjustment according to the participants agreement as shown in Figure 3.1

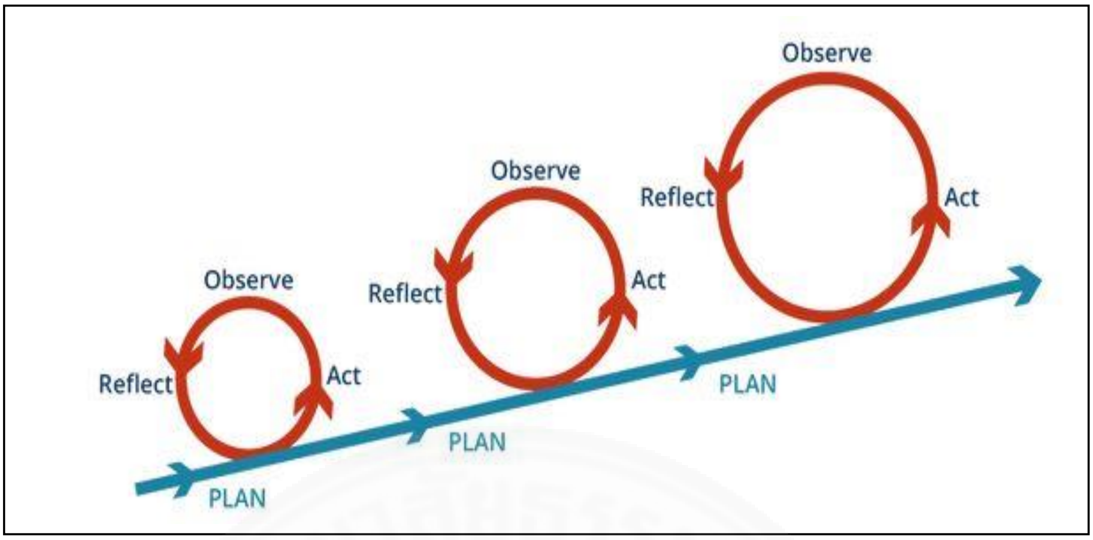


Figure 3.1 Four activities and three cycles in conducting the participatory action research

Activity 1: Plan

On 8th November, 2019, at .12.00-13.00 p.m., a work shop was organized for planning of a change at Radiation Oncology Department. There were thirteen participants, including radiation oncologists, radiation therapists, and radiation oncology nurses. The planning step took almost 4 weeks to identify the key stake holders and concluded the tentative model.

The researcher built a good rapport among all participants and created mutual understanding on a tentative person-centered model(Fig.3, p.43) and a collaboration for the development of a person-centered model by participatory action research spiral (Fig2, p.38).The gap of practice and service needs were identified and the radiation oncology team created the purposes and performance indicators related to care process for patients with head and neck cancer receiving concurrence chemoradiotherapy.

The participants developed a road map of activities in developing the tentative person-centered model for solving priority problems and improving their practice. They considered to change for better outcomes in the specific context of Chulabhorn Hospital from all participants’ agreement in the following issues: clinical practice guidelines for caring HNCs patient during CCRT, information and education system, work procedure or care map for caring patients during CCRT, and contact of nutritionists for lecture and training on the needs from participants. All of these issues were distributed to responsible persons who related to those topics and volunteered to report the progress. The planning phase in concurrence chemoradiotherapy care process was presented in Table 3.2

Table 3.2 Action plan for developing the person-centered model

WHAT	RESPONSIBLE	TIMEFRAME	INSTRUMENT	HOW TO MEASURE
Develop clinical practice guidelines for caring HNCs patient during CCRT	- Radiation Oncologist - Radiation Therapist - Radiation Oncology Nurse	5 months	CPG CNPG Evidenced-based practice	Each professional has clinical practice guideline
Improve information and education system for HNCs during CCRT	- Radiation Oncology Nurse	5 months	Individual booklet Information sheet Knowledge assessment and evaluation form	Patient readiness, knowledge, Patient and family satisfaction
Develop work procedure or care plan during CCRT	- Radiation Oncology Team	5 months	Individual symptom profile Work procedure Plan of care	Symptom severity and patient satisfaction
Knowledge improvement by lecture in the topic related to care for HNCs during CCRT	- Radiation Oncologist lecture - Radiation Oncology nurse contact the nutritionist, physical therapist	5 months	Lecture from multidisciplinary team Referral form Knowledge management	Staff satisfaction

Activity 2&3: Act and observe

The tentative person-centered model was implemented in the radiation oncology clinic for 4 months (December 2019-April 2020).The acting and observing regarding participatory action research steps were done continuously during implementing the model.

The participants as a team of radiation oncology conducted all activities and the researcher attended as a participant observer and facilitator. The participatory learning concept and sharing knowledge were used in learning process.

Radiation oncologists were volunteered for a lecture on the topic of basic knowledge of radiation and chemotherapy. Radiation oncology nurses took their responsibilities to update the health education system, including information materials, patient's knowledge assessment and evaluation. Radiation therapists volunteered to update the accommodation and location, as well as revised their working instructions in order to prepare patients before the radiation treatment procedure. The senior radiation oncology nurses volunteered to contact other specialists for a lecture on the topic related to the care of HNC patients during CCRT.

The clinical practice guidelines for caring HNCs patient during CCRT, information and education system, work procedure or care plan for patients during CCRT, and knowledge constructed were developed and implemented among seven new cases of patients with head and neck cancer and their four family members along the concurrent chemoradiotherapy care process.

Observation process of implementation and results were done by recording subjective and targeted human conduct. Informal interview or mini interview from participants in daily routine in the clinic was done by the researcher. The participants voiced their concerns and tried to input their opinions for problems solving. The interactions of participants with HNC patients and their family were observed. While, the researcher practiced in the morning round as daily routine.

Activity 4: Reflect

The evaluation of usability and outcomes of the person-centered model were done by reflection and feedback strategies. The reflection and discussion between the researcher and participants during the action and observation process provided a basis for re-planning by the accumulation of knowledge from real situations and various perspectives. There were two perspectives from reflections among patients and their family and radiation oncology team to share their ideas in achieving the goals. The radiation oncology team was invited to provide feedback and evaluate the process and outcomes of practice changes.

The instruments used for process and outcome evaluation were developed as the open-ended questions for reflection and focus group discussion. The patients and their family were the greatest concern, so the suggestions from patients and their family took into account for improvement and revision of the plan in the next cycle.

Each cycle of study included plan, act and observe, reflect, and revised plan with continuation during the model development. There were 3 cycles in this study, in which the model was adjusted according to the participants’ agreement.

CHAPTER 4
RESULTS AND DISCUSSION

This studywas a participatory action research (PAR), aiming to develop a nursing servicewith emphasis on a person-centered model for patients with head and neck cancer during concurrent chemoradiotherapy. The model development divided into two phases. **First phase** was to explore the experiences of patients with head and neck cancerand their family during concurrent chemoradiotherapy. In addition, the experiences of the radiation oncology team were also investigated. All data and information were used as a baseline to develop a person-centered model. **Second phase** was to develop a preliminary person-centered model and tested for the effectiveness andefficiency.The findings in each phase can be described as follows.

4.1 Phase I: To explore the experiences in patients with head and neck cancer and their familyand radiation oncology teamduring concurrent chemoradiotherapy

The findings of phase I could be presented in 4 sections including: 1) patients and their family characteristics, 2) experiences in patients with head and neck cancer and their family during concurrent chemoradiotherapy, 3) radiation oncology team's characteristics, and 4) experiences of radiation oncology team while providing care for patients with head and neck cancer during concurrent chemoradiotherapy.

4.1.1 Patients and family caregivers' characteristics

There were fifteen patients diagnosed with head and neck cancer, including nasopharyngeal cancer (n=7) and non-nasopharyngeal cancer (n=8). This study included five women and ten men, with ages ranged between 31 and 75 years or an average age of 51.8 years. Almost all of them were employed and three were retired. The patients' interviews were conducted during the treatment process (n=7) and the follow-up after completing treatment within 6 months (n= 8). Eight family members came to the clinic with patients and agreed to participate in the interview. The patients and their family' characteristics were summarized in Table 4.1.

Table 4.1 Patients and their family caregivers' demographic and medical characteristics

Patient' characteristics			**Family caregivers**		
Demographic	**Data/ status**	**N= 15**	**Demographic**	**Data/ status**	**N= 8**
Gender	Male	10	**Gender**	Male	0
	Female	5		Female	8
Age	31-45	5	**Age**	31-45	2
	46-60	7		46-60	3
	60-80	3		60-80	3
				>80	
Education	Less than college degree	5	**Education**	Less than college degree	2
	College degree or higher	10		College degree or higher	6
Occupation	Yes	12	**Occupation**	Yes	7
	No	3		No	1
Marital status	Married	12	**Marital status**	Married	6
	Other	3		Other	2
Comorbidities	No	9	**Relationship**	Daughter	3
	Yes	6		Sister	1
Religious	Buddhist	15		Mather	1
Feeding tube	No	9		Wife	3
	Yes	3			
Site of head and neck cancer	Non- nasopharyngeal cancer	8			
	Nasopharyngeal cancer	7			
Chemotherapy	Cisplatin	14			
	Carboplatin	1			

4.1.2 The experiences in patients with head and neck cancer and their family on problems and care process

Data analysis from the participants' experiences (participant 1-23; p1-p23) was identified as several categories related to concurrent chemoradiotherapy and the process of care in this study setting, as shown by the codes as follows:

4.1.2.1 Overwhelming of information

During the RT process from week 1 to week 4, the patients and their family caregivers sought information about how to take care themselves and adhere to their course of treatment. The important information was provided by radiation oncology providers when patients needed to know how to begin the treatment process.

"I have sought for information about cancer treatment, but what I heard from doctors makes me panic." p18

Numerous booklets and leaflets were given by doctors, nurses, and radiation therapists on the first day to take home for reading and making sure that they remembered and understood everything.

"I do not know what to ask doctors and nurses at the first time I came here. They gave me a lot of information. The only thing I know is I want to be cured." p15

Talking with healthcare providers was the main channel for obtaining the information they needed. Informal discussion with other patients made some of the participants more frustrated.

"Talking with other cancer patients showed many mixed results. It is overwhelming. Sometimes, they make me panic more and the other time I feel better to have someone to talk to. So, I decided to talk with no one. P17

"I have no ideas about cancer treatment. How many times of radiation treatment and how many doses of chemotherapy are needed? I have heard from other cancer patients… Do I have to lose my hair? P 18

"I and my family are afraid of radiation exposures. At the beginning, we did not stay with our grandchild. P01

(1) Seeking tailored information

According to the interviews, the majority of participants needed information about the plan and costs of treatment, treatment duration, and self-preparation to receive treatment. Some of the patients did not even consider what they should know or ask, especially the elderly people. These patients let their family members manage their routine activities and did not want to know the stage of the disease because they believe that "whatever will be, will be."

"I do not think too much. What doctor says is what I should do and I do meditate everyday" P01 (75 years old), "Nothing has changed, just let it be, I am not afraid." P009 (76 years old)

In contrast, the middle-aged cancer patients were accompanied by a list of questions in hand and participated more in their care. Sometimes, they came with literatures or contents from medical journals to discuss with doctors and nurses.

"I was searching tons of information from the internet. I am afraid that I cannot complete the course of treatment as prescribed and also worried about having the tube in my stomach…" P03 (31 years old)

They asked many questions for information not included in the booklets that they received from healthcare providers at the clinic. The patient's concerns and his/her understanding of the provided information were not taken into account. If they were not asked any questions, it was assumed that they understood all of the information given.

"Where can we stay during treatment and who can we talk to or ask any questions? Will the cancer spread out if I start radiation? Can I stay with my grandchild? She is only 2 years. P01

"I and my family are afraid of radiation exposures, at the beginning we did not stay with our grandchild. P09

(2) Provision of chemotherapy information

During the treatment, patients had to face with new experiences. If something wrong arises, they can ask for assistance from doctors and nurses to solve any side effects. Significantly, most of the patients disclosed that they did not receive information about chemotherapy treatment or self-care.

"The radiation therapy processes have been told perfectly, but for chemotherapy, there is no information. I want to have both of the information because I have to receive concurrent chemoradiation therapy."p18

Chemotherapy was not finished in one day at the end of radiation schedule or may be delayed for a week after completing the radiation therapy. Some patients were prescribed adjuvant chemotherapy after radiation treatment was completed. This regimen may cause patients to hesitate for continuing with chemotherapy, especially those with severe side effects from chemotherapy.

"The first time I discussed the plan of treatment with doctors. She said that I have to receive chemotherapy during the radiation for 2 times. Now, I finish the radiation and

she told me to get one more time of chemotherapy. It was such terrible experiences from chemotherapy. Do I really need it?" P10.

In conclusion, radiation therapy is the cause of fear and anxiety, while patients with cancer believe that it is a mysterious aspect in their life. Moreover, radiation therapy-related toxicities are unknown by healthy people. If they have to receive the treatment, patients thus require more information. The combined chemotherapy and radiation therapy also lead to more side effects than radiation therapy alone. This combined treatment develops the most severe symptoms among patients. So, treatment adherence is critical for the improvement of treatment outcomes and person-centered concepts, including patient participation. This should be the main concern of caring system in order to promote good clinical outcomes (Delaney, 2018; Rehaman B, 2018).

In radiation therapy setting, specific information is rarely provided to the general public. Therefore, patients have to search for information from websites or seek help from their family and friends, who are frequently not able to provide relevant, meaningful information or answers. Preparing patients with head and neck cancer for what to expect over the course of treatment has to be individually tailored to each individual's learning style and preferences for information. A previous study showed that the tailored information with effective communication could support nursing care in the relief of treatment-related symptoms distresses among patients with head and neck cancer (Rojthamarat, 2018).

4.1.2.2 Unpleasant symptom cluster

The combination of radiation therapy side effects and toxicity of chemotherapy contributed to both local and systematic symptoms, with physical and psychological distresses. All of the participants identified those symptoms as three or more concurrent symptoms relating to one another, and may or may not share the same etiology.

(1) Physical Symptoms

From the beginning, some patients did not have any symptoms, but during the process they had to make sense of severe toxicity, particularly when radiation was combined with chemotherapy. In some patients, the schedule of treatment could be changed upon their health status. Almost all of the participants rarely presented with a single symptom. They encountered multiple symptoms and all individuals rated their suffering differently.

"I cannot eat anything. It is the worse symptom for me during treatment. Chemotherapy makes me feel nausea and vomit. I could not eat."P10

"The worse symptom is the burning sensation at the wound on my neck." P04

"I received 15 times of radiation treatment. I do not want to eat anything. My neck is burnt and darkened. I lose my weight from 53 to 40 kg."P06

"I cannot eat or even swallow. I vomit from the first chemotherapy. Radiation therapy makes my mouth dry, with a wound at my neck. Especially, during the last 5 days of treatment, my skin is burnt." P05

The consequences of the active treatments were that they disrupted the patient's quality of life with these intense symptoms. The combined dosages of radiation treatment destroyed the mucosa in the oral cavity and the salivary gland, which affected the dietary pattern, decisions on food intake, and difficulty in chewing and swallowing. This might cause the ailing health status on part of patients.

(2) Psychological symptoms

During the visit to the radiation oncology department, patients and their family always came with hope, but at the same time they had anxiety about the treatment process and side effects from radiation with or without chemotherapy. Sometimes, they were afraid of radiation therapy. They also expressed the fear of living close to their love ones because of radiation exposure.

"The big machines and strange immobilization devices are scary." P09

"In the middle of treatment course, I cannot eat and I am afraid that I cannot finish this treatment. My daughter asked the doctor for a set of feeding tube. I was so tired and felt pain in my mouth. I received 20 fractions of radiation."

"It's painful and I am suffering from many severe symptoms. I am crying but I have no tear drops."P10

"Chemotherapy makes me give up, causes nausea, vomiting. It was terrible situations. P20

During the first day of radiation treatment, patients changed from the CT-simulation room to the actual treatment room, which was in a different location. Some patients experienced the new machine and they had to stay alone in the treatment room. This made them afraid.

"At the simulation and the treatment rooms, there was a big and noisy machine. It annoyed me and I was not able to stay still."P09

Therefore, the experiences of symptoms during concurrent chemoradiation treatment can start from the first week and reach the peak in the third week, including alterations in tasting, pain in the mouth, loss of appetite, loss of saliva, burns to the skin, thickening of saliva, and fatigue (Hollander-Mieritz et al., 2019). However, symptom management in head and neck cancer patients suggests only supportive treatment, such as analgesics, anesthesia spray, or feeding tube to maintain nutritional status. Classifying or identifying the symptoms in a cluster would be beneficial for healthcare providers to manage symptoms, with the reminding of every important symptom and evaluating the outcomes of symptom status for effective management. These symptoms often do not decrease in severity, but rather get worse even when treatment is completed (Rosenthal et al., 2014).

Currently, multiple symptom management and involvement of patients in the identification of symptom clusters and alleviation of those factors would be helpful across symptoms and improve clinical outcomes (Kwekkeboom, 2016). Providing information and education from healthcare providers as the guidance of symptom management is necessary, but at the same time patients have to adjust their daily life and routine activities (Rojthamarat, 2018). Therefore, the understanding of symptom cluster burdens of patients with head and neck cancer at the time of treatment initiation is essential in radiation oncology care. Not only physical problem oriented but also psychological symptoms are crucial for managing and improving the quality of life along the continuous treatment course (Hanna et al., 2015).

The treatment course of radiation takes almost two months for each specific group, together with chemotherapy, which can cause the suffering (Pan et al., 2017)(P. Rose & Yates, 2015). Patients need to cope with their suffering throughout the course of treatment. Uncertainty is associated with the severity of symptoms during treatment. Patients have reported different severities of side effects and tried many strategies to handle those symptoms, with different decisions whether or not to continue and adhere to treatment for their disease.

The participants who received concurrent chemoradiation therapy reported more side effects than those who underwent radiation therapy alone. Moreover, they felt uncertain about the combination of treatment at the beginning. Nevertheless, all patients in this study could get through this uncertainty until the accomplishment of treatment as planned. These findings provide the insights into an uncertainty of living through treatments, especially among patients with head and neck cancer during concurrent chemoradiation therapy. One study reported that uncertainty can be correlated with symptom distresses and recommended to investigate other factors that influence the uncertainty during and after treatment (Haisfield-Wolfe et al., 2012). Hence, these results provide the challenges to nursing care for individual patients with head and neck cancer throughout the treatment course.

4.1.2.3 Strategies for adhering to treatment regimens

Patients who received the concurrent chemoradiotherapy would suffer much more from toxicity and other side effects than radiation alone. Even though they had to face with the same situation each time, radiation therapy would give them different experiences. Thus, two sub-categories of strategies for the adherence to treatment regimens, including support and symptom management, could be described as follows:

(1) Support

Cancer patients individually had to take the initiative for their care or receive assistance from their family, with recommendations and support from the radiation specialists. The radiation treatment took 6-7 weeks, 5 days a week. The radiation schedule and service flows would eventually be familiar to patients. They got the radiation time slot two days in advance and received the same screening every day, such as registering, having their vital signs taken, being billed for the cost of treatment, and contacting the cashier. This main information received from the radiation oncologists, radiation therapists, and radiation oncology nurses in the department was routine. Support from family and friends, and also radiation oncology team, had the most positive impact on patients during treatment course.

“Staffs here are very kind and they call me as their relatives.” P01

“Doctors give me good recommendations. I have friends and family support me.”P03

"After I talked with the doctor, he makes me trust. Nurses give me information as friends, not treat me like inferior."P04

They stated that when they suffered from treatment toxicity, they received cheerful words. The accompanying of their family created motivation for them to adhere to treatment as prescribed.

(2) Coping strategies

It was crucial in monitoring symptoms and side effects from treatment with proper management to obtain treatment adherence. During the radiation treatment, patients met the radiation oncologist and radiation oncology nurses at least once a week. They may ask the healthcare providers about his or her concerns related to the radiation side effects and prescribed supportive care, such as medication if there were any pains or skin reactions. Some patients tried to add more nutrients to their diet in order to replace the energy that they lost from treatment. Success was registered in some cases and patients maintained their health status for many weeks. In some cases, patients felt nothing or got worse, such as from skin reactions.

"Now, it is the 16thfractions of radiation treatment. The only symptoms I am afraid is a lack of saliva and a loss of taste. I am doing research on my own by adding more protein and mixed fruits supplements. If I do the right way, I will continue and see the side effects. The side effects from chemotherapy make me feel like jelly". P18

Patients sought new and different strategies to alleviate their symptoms and side effects from informal channels, such as other cancer patients and health care professionals sometimes.

"What I can do is to continue eating what I can eat and add oral supplements as prescribed by the doctor." P20

Some patients utilized food recipes to maintain their appetite.

"I have imagined what I have eaten before and what it tastes like. I cannot eat spicy taste. I do not want to count the days of treatment, just let it go day by day."P18

Some participants liked meditating, praying, and reading books before going inside the treatment room because this made them calmer. After the radiation treatment was finished, the doctor made an appointment approximately 4 weeks later for follow-up on any acute side effects and treatment outcomes.

The course of treatment took 6 to 7 weeks for one RT regimen and it was found that most symptoms of distress escalated during week three and worsened through the entire course. The last two weeks of the concurrent chemoradiation process were the toughest time for the patients and their family. The patients thought that they could adhere to treatment, but at the same time symptoms occurred, which could be discouraging and made the patients feel tired and they could not tolerate the treatment any longer.

"Now, it is the 16th fractions of radiation treatment. The only symptoms I am afraid is a lack of saliva and a loss of taste. I am doing research on my own by adding more protein and mixed fruits supplements. If I do the right way, I will continue and see the side effects. The side effects from chemotherapy make me feel like jelly." P 18

"I do not know what will happen next. Now, I am at the 15th radiation treatment. Sometimes, I pray before going into the treatment room." P17

"The worst experience from radiation treatment was the positioning with the immobilization mask. It was terrible. I cannot breathe normally. Every day before I come to receive the radiation, I have to pray, but eventually some days I cannot make it." p01

"Chemotherapy makes me give up, as well as causes nausea and vomiting. It is a terrible situation." P20

This was the time that patients needed the most support and cheerful encouragement from the health care team and their family. The ideas of fight or flight from the treatment process grew in tandem with the peak of toxicities. Mouth pain, plus skin wounds from treatment, created the most suffering. Some patients dropped out, or strayed from their proscribed course of treatment due to the side effects. A chemotherapy regimen may be given to patients after completing their radiation therapy. This may be due to the unpredicted symptom experiences and the importance of continuity of care.

Therefore, identifying the factors that influence radiation therapy combined with chemotherapy is crucial for success or disruption in the treatment regimens. Some study reported that social and economic situation, healthcare system, individual's health condition, therapeutic treatment, and patients themselves are the five dimensions that impact the adherence to treatment. Moreover, non-adherence to treatment can be intentional or non-intentional on the part of patients (Mathes, Jaschinski, & Pieper, 2014). According to a previous study, the person-centered communication could be a frame of practice for nursing care to consider the patients' ways of reasoning (Ohlen, Carlsson, Jepsen, Lindberg, & Friberg, 2016).

Cheerful speech, understanding of patient's experiences and concerns, patients' preferences for information, as well as language, financial issues, transportation, and other support needs from radiation oncology nurses are very important for helping patients overcome their suffering before, during, and after treatment. Family and social supports are key factors to comfort and encourage the patients during treatment in terms of helping them in daily routine activities, such as cooking, accompanying patients to the clinic, cheerful speech from family members, etc. In this study, the participants came up with many strategies for adhering to treatment, which were identified as being helpful for them to stay calm and positive, such as praying, reading, and seeking information from doctors and nurses.

The patients and their family's experiences during concurrent chemoradiotherapy were described in Table 4.2.

Table 4.2 The patients and their family's experiences

Code	Sub-categories	Category
Too much information Cannot remember Confusion What I need to know Searching from website	Seeking tailor information	**Overwhelming information**
I know nothing Lack of information about Chemotherapy	Chemotherapy information provision	**Unpleasant symptom cluster**
Sore mouth, sore throat, thick saliva, dry mouth, difficulty swallowing Taste change, weight loss Skin burn Nausea, vomiting Fatigue, dizziness, drowsiness Bloating, constipation, GERT Blood, kidney malfunction	Physical symptoms	
Mask tight Worry Fear Suffering Hopeless	Psychological symptoms	
Make sense of the situation Talk with others Support from friends Support from family Support from doctor, nurse, therapist	Support	**Strategies to adhere to treatment regimen**

Code	Sub-categories	Category
Good environment, atmosphere		
Praying Tips from others Asking experts Reading Meditation Family support Wait and see Try and error	Coping strategies	

4.1.3 Characteristics of radiation oncology team

Radiation oncology team including specialized healthcare staffs in this particular setting composed of radiation oncologists, radiation therapists, and radiation oncology nurses. This setting also had the allied healthcare staffs who helped the patients and their family along the process. Eight eligible radiation oncology nurses were invited to both individual and focus groups, based on their willingness and availability (n=8). Radiation oncology nurses worked closely with other interdisciplinary team in the radiation therapy department. The radiation oncology team included radiation oncologists (n=5), radiation therapists (n=6), and allied health staffs (n=4). The participant's characteristics were shown in Table 9. (Expert; E1-3, Focus group; F1-3)

Table 4.3 Radiation oncology staffs and radiation oncology nurses' characteristics

Radiation Oncology Nurse (n=8)	Radiation Oncologist (n=5)	Radiation therapist (n=6)	Allied health (n=4)
1 Senior Nurse Educator 2 Clinical Nurse Specialist 5 Registered nurse	1 Head of Radiation Oncology Department 4 Radiation Oncologist	2 Senior Radiation therapists 4 Radiation therapists	2 Radiation therapy' assistance 1 Clerk 1 Nurses' aid

4.1.4 The experiences of radiation oncology team while providing care for patients with head and neck cancer during concurrent chemoradiotherapy

The key health care professionals in radiation oncology service participated and voiced their perspectives. The radiation oncology team's perspectives relating to their experiences in providing care for HNC patients and their family, as well as the ways to improve radiation therapy services and nursing care, were identified into four key categories and eight sub-categories as follows:

4.1.4.1Environment of healing

(1) Symptom management strategies

All participants had the same feelings about management of side effects, with various organ involvements and close monitoring of the symptoms during the treatment.

"Weekly visit radiation oncologists would be recommended, but sometimes it seemed not enough. Some patients' symptoms occurred during treatment when they stayed at home at weekend or woke up, and found that they scratched on their skin because of itchy dry skin. Some patients faced difficult situations, such as secretion obstruction, fatigue, severe mucositis, and need of NG insertion, but how much we can help them. It's very difficult to deal with those complications in complex problems." E2

"The patients don't know what to do when symptoms occur, but I have already taught them from the information in booklets."F1

"When I give health education to patients, they seem not interested in the information I've given, but I know that they are talking with other patients for some tips of self-care."F2

"The radiation oncology nurses should be expertise in managing symptoms during radiation therapy treatment for early detection, assessing the severity of symptoms, monitoring the side effects, and helping the patients to overcome those suffering symptoms. This help them alleviate the distresses and comply to treatment towards better quality of life."E1

(2) Supportive

Humanistic interactions with patients were mentioned in some participants referred to therapists who controlled treatment machines. The meaningful relationships with radiation oncology staffs became precious environments and impressed patients during and after radiation therapy.

"When I talk with the patients at the end of treatment session, they always thank you the staffs in our department. Service behaviors of nurses make them impress and feel like home. Some patients prefer to be called as Loong, Pah, just as we call our relatives."E2

"I think the radiation oncology nurses should make the patients trust in our professional skills, along with holistic approaches, to make them feel accepted and

understand the treatment side effects and management from the beginning. I have an example. One day, I have just hugged the patient, a middle age lady with Nasopharyngeal cancer during Radiation 16 fractions, who looks sad and fatigue. Suddenly, she cried and told me that she felt so tired and her husband left her alone. Just hug and ask them with sincere heart and look into their eyes. I believe that the empathy and consistency would make the patients not feel alone. When they have problems, they tell us."E1

"Nurses should be in close monitoring and proactive to look after this group of patents."E2

"In our department, the group support or formal health education seems not appropriate because the life style or major population are working men/women and the diseases are not the same."F2

Therefore, advanced technology relating to the evidenced-based radiobiology to treat cancer patients is considered as having more values in caring process for individual patients and healthcare providers who deal with newly advanced environments (Liu, Bozic, & Teisberg, 2017). A previous study on the relationship between individual cancer patients' perceptions of their treatment experiences and the level of their anxiety during radiation therapy showed that the treatment environment and psychosocial climate of the clinic significantly impact the level of anxiety. There are two climates for the increasing or decreasing level of cancer patients' anxiety. A climate of safety can reduce the anxiety level, while having difficulty in treatment experience, worrying about treatment machine, and feeling isolated in the treatment room, can increase the level of situational anxiety during radiation therapy (Mullaney et al., 2016). Moreover, a comforting environment can lower stresses, with physical surrounding and nature-based designs that influence a sense of well-being. Some studies seek the best practice solution with patients' engagement based on their perceptions in designing the visual environment (Blaschke, O'Callaghan, & Schofield, 2018).

In order to achieve optimal health outcomes in patients with cancer during either curative or palliative intents, the healing environment should be well designed for cancer care. More importantly, it is reaffirmed the relationship between practitioners and patients as the center of focuses with favorable conversation, physical environment, and behaviors towards cancer patients and their family (Estores & Frye, 2015). Thus, the radiation oncology nurses' perceptions about their communication skills should be improved in some levels. This can articulate the insights from the nurses' experiences and awareness in creating the optimal healing environment and compassionate approaches to provide effective treatment for patients with cancer in the department of radiation oncology.

4.1.4.2 Nursing role and Competency development

(1) Scope of service

The nursing team focused on the same direction and saw the pitfalls of routine care. All participants mentioned about grey zone of practices between nurses and radiation therapists, as well as between nurses and radiation oncologists in many issues.

"Nurses cannot take action in referring patients to see nutritionists. Doctor haven't taken into account" F2

"Can we prescribe normal saline solution or skin care routine products for patients? If the doctors are not available in the clinic, telling them to prescribe it may make them not satisfy and they may or may not prefer to prescribe the cream." F2

"When patients have something wrong, they will tell technicians in treatment room. They sometimes do not tell us, or they might think those staffs are doctors." F1

"Why Techs don't take the scheduling book into their account, this job makes us have no time. Now, Techs are responsible to advise and educate the patients." F1

(2) Knowledge and skill deficits

The knowledge about head and neck cancer treatment, side effects, and management for individual's problems were added for every level of staffs.

"I have no confidence to educate patients with head and neck cancer. They have too much suffering."F1

"I can tell the patients in daily routine care, but in case of severe side effects or many involved factors, this will make me frustrate to approach."F1

"This group of patients suffers and there are many involved factors, such as financial, personal, and disease problems, which will create the symptom burdens. The Radiation

Oncology Nurses should understand the basic radiobiology or plan of treatment in each case, which will make us comprehend the treatment-related side effects."E1

"They have a lot of problems and suffering, but I cannot help them too much. We don't have any tools or instruments. We can only talk and educate them, or tell them what should to do."E2

Skills of staffs to take care of this group of patients and also their family should be prioritized.

"I have learnt from my experiences while seeing the patients with the doctors or attending the seminars or meetings regularly. This makes me more confidence and talk with the patients and their family every day to enhance my skills."F2

"I work in other fields, not oncology. I need to practice more or maybe I do my attending with senior nurses when they educate patients and their family. This can help me have more understanding. Patients come with different conditions, Sometimes, I can still ask for help if I cannot help the patients." F1

Therefore, the roles of radiation oncology nurses mainly focus on health education for cancer patients in the treatment process. Radiation oncology nurses play a vital part of radiation therapy treatment in preparing patients over the course of treatment and dealing with all factors relating to individual patients for radiation therapy. Radiation oncology nurses, including NP and CNS, are important members in the multidisciplinary team with different roles and obligations to direct patient care and particular treatment procedure of patients receiving radiation therapy. With the complexity of disease itself and the combination of treatment modality, especially in head and neck cancer patients, the radiation oncology nurses with advanced practice can add their value to the quality of patient care and make differences in patients' experiences (Carper & Haas, 2006).

Knowledge and skills of radiation oncology nurses have to be improved in a specialized setting to provide better care in difficult situations, especially in patients with head and neck cancer during radiation therapy (P. Rose & Yates, 2015). Nursing is considered as crucial in the coordination of caring process and mainly in educating patients and their family to perform self-care as outpatients. The specialized clinical nurses can be confident to provide a holistic care, but sometimes they do not get adequate clinical information in terms of treatment areas and specific side effects.

While, the radiation oncology therapists are responsible for daily treatment of patients and see the changes of skin and nutritional status, as well as manage the positioning in treatment room. The radiation oncology nurses need to have knowledge and skills in advanced treatment modality and technology to drive cancer care, with accurate assessment and intervention of possible unpleasant toxicities. Significantly, the radiation oncology nurses are essential to advocate the rights, health education, and care of patients (Gosselin-Acomb, 2006).

Professional competence should be a priority for improvement of nursing confidence to enhance better nursing care in patients. To provide effective nursing care for individual cancer patients, it is important to clearly identify the roles and responsibilities of radiation oncology nurses with other staffs. There are high expectations from radiation oncology team and patients, but competency is mostly needed for improvement. The radiation oncology nurses' perceptions about their communication skills should be improved in some levels, with insights from nurses' experiences and awareness in creating optimal healing environment for patients in the radiation oncology department. Patients with head and neck cancer experience a variety of health problems and side effects from their disease during the treatment process. The patients described their symptoms and side effects as uncertainty and non-expectation. In a recent study, most patients experienced the interactions between themselves and healthcare providers in the healthcare plan and self-management goals, which formed the partnership support as a sense of relief from the disease (Rehaman B, 2018). A primary nursing/collaborative practice framework is the model of care in the radiation therapy department for individual patients. Similar findings in older nurses with more experiences in cancer care were reported more on their acknowledgement and patient supports rather than young nurses (P. M. Rose, 2016). The person-centered approach is a main concern in cancer care process to improve treatment outcomes (Hansson et al., 2017). Currently, healthcare systems focus on patient-centered care concepts to promote the quality of care. Focusing on patient safety and treatment effectiveness should be a priority in the sustainability of healthcare providers using the person-centered model of care (Delaney, 2018; The Healthcare Accreditation Institute (Public Organization), 2018). Hence, adopting the concepts of person-centered care could be a way to improve the quality of nursing care in patients with head and neck cancer during radiation therapy.

4.1.4.3Fragmentation of care and discontinuity

(1) Multidisciplinary involvement

From the interview, they all referred the importance of nutrition, rehabilitation and physical therapy to be involved in caring process.

"Clinical practice guidelines should be revised and developed in providing good clinical practice with multidisciplinary team in clinic, especially nutritionists because patients with head and neck cancer really need to see nutritionists to maintain their nutritional status."E1

"I have discussed with some patients who have to see the rehabilitation staffs before starting radiation therapy. Their oral health status seems better than other patients who do not see specialists." F2

"I think, in case of the organ involvement and effects of treatment, patients should see the physical therapists, especially in case of edema around their neck to prevent the stiffness."F1

(2) Discontinuity

The continuity in this high risk population were discussed in the team and suggested to improve the monitoring, early assessment, and make some guidelines to care for this group of patients.

"The patients with head and neck cancer should be closely monitored for their symptoms and side effects along the treatment journey. Before treatment, they were afraid and ran away from the treatment. During treatment period, they faced with the symptom burdens. After treatment, the delay side effects might occur in next 6 months." E1

"Every profession have their own responsibility, including RON and RTT. If we perform the early detection of side effects and refer the patients to see the doctors for managing symptoms, this will increase the team value and treatment outcomes."E2

"We collaborate with nutritionists for early detection of nutritional status, but we now stop doing it due to lack of staffs."F2

The proactive of prevention from complications during the radiation treatment was the most challenging from their perspectives.

Hence, the complexities of disease itself and treatment-related toxicities should be a concern to involve a multidisciplinary team for each individual patient and their family to increase their treatment outcomes and quality of life. Patients with head and neck cancer require a multimodality treatment, including radiation therapy, with or without chemotherapy, or concurrent chemoradiotherapy for locally advanced head and neck cancer. In addition, the patients need proper and tailored treatment plans. Consequently, the treatment-related toxicities can cause unpleasant symptoms and side effects that impact patients' quality of life (Lo Nigro, Denaro, Merlotti, & Merlano, 2017). Thus, the optimal management of patients with head and neck cancer should involve multiple health care professionals with relevant expertise, such as head and neck surgery, radiation oncology, nutrition, medical oncology, rehabilitation, medical physics, physical therapy, radiation therapy, and radiation oncology nursing. In order to standardize the practice guidelines for radiotherapy in head and neck cancer, the compliant radiation planning and concurrent chemoradiotherapy should be available in all cancer centers (Nutting, 2016). The mixed skills and knowledge sharing from the multidisciplinary team are helpful for more confidence in dealing with the difficulty of nutrition and rehabilitation supports during and after radiation treatment.

The continuity of care and treatment for approximately more than six weeks is the most concern for both healthcare providers and patients with head and neck cancer. A previous study at the radiation therapy clinic reported on the continuity of care improvement with primary therapists from the first visit of cancer patients through the treatment course. The results showed the improvement of satisfaction scores among patients and stakeholders (Lee et al., 2019). In addition, a recent research demonstrated that the continuity of care in individual cancer patients who receive nursing care from the same healthcare providers during a specified period of time could improve patients' experiences of dealing with the disease and treatment-related toxicities (Kuo et al., 2019). Interestingly, the initiative quality improvement in a cancer center yielded the efficacious outcomes of caring continuity in order to optimize the caring delivery services and reduce unnecessary patient visits, with high scores in acceptability and appropriateness (Gonzalez, Moreira, Casanova, & Bettoli, 2019). Therefore, these findings were beneficial for the continuity of care in cancer patients, especially those with head and neck cancer along the treatment course.

4.1.4.4 Person-centered approach

For summary of individual interview and focus group discussion, the major concept was emerged from their perspectives: a person-centered approach for individual patients.

(1) Patient-centered care

Assessment of individual' experiences would provide a person-centered care rather than a focus on problem- or symptom-oriented issues in the clinic.

"The respectful to patients, concerns for their life style, and questions on what they prefer to eat, how they can manage side effects, whether they can follow the recommendations, and if the suggestions make sense for them, are all the problematic issues which I always have to handle due to the complexities of various organ involvements and many factors related to symptoms." F2

"I think that it's difficult for some patients to follow the instructions, such as eating foods with high calories, exchange dietary or liquid diet in case of difficulty swallowing, and no money to buy the blender or no one to take care of aging patents."E2

"Patient's background and their lifestyle should be concerned when we create the health education plan and I think that it's adjustable to teach patients how to take care of themselves if we assess all those things and discuss with them to find the right solutions."F1

(2) Family involvement

In Thai culture, patients always come to receive cancer treatment with their relatives. To make decision on radiation treatment, the healthcare providers encouraged family members to discuss with doctors at the beginning. In older patients with head and neck cancer, who received the radiation treatment with or without chemotherapy, they needed caregivers to take care of them.

"If I have to teach the aging patient, I always invite their family members to help the patients to remember health information."F2

"Sometimes doctors told the patients about plan of treatment and side effects and patients agree to start Radiation, but later on one of family member wanted to discuss with the doctor again and refused the treatment."F1

"In Thai culture, the daughter or son have to take care their parents. So, we need to invite their family members who are the main decision makers to get involve in the treatment process."E1

"I think that I understand the patient's condition. I need to assess their readiness or their health status first if they can understand the instructions. I should teach the patient alone because nowadays their relatives need to work for earning money. It is this way that I have an experience to take care of my mom, but I need to work. I should go with her if I could, but most of the time I am busy. Anyway, I am a nurse and I always ask for the progress. So, I am capable to help my parent."E2

Therefore, patients with head and neck cancer experienced a variety of health problems and side effects during the treatment process. The patients described their symptoms and side effects as uncertainty and non-expectation. In a recent study, most patients experienced the interactions within themselves and healthcare providers regarding healthcare plans and self-management goals, which formed partnership supports as a sense of relief from the disease (Rehaman B, 2018). A primary nursing/collaborative practice framework can be the model of care in the radiation therapy department for individual patients. Similar findings in older nurses with more experiences in cancer care reported their acknowledgement of patient supports as in a person-centered approach among younger nurses (P. M. Rose, 2016) towards the improvement of patient care and treatment outcomes (Hansson et al., 2017). Currently, healthcare systems focus on the patient-centered care concepts to promote quality of care, patient safety, and treatment efficacy as a priority in sustainability among healthcare providers using a person-centered model of care (Delaney, 2018; The Healthcare Accreditation Institute (Public Organization), 2018). Hence, adopting the concept of person-centered care could be a way to improve the quality of nursing care in patients with head and neck cancer during concurrent chemoradiotherapy.

The radiation oncology team's perceptions of caring system when providing care for patients with head and neck cancer and their family during CCRT were illustrated in Table 4.4

Table 4.4 The perspectives from radiation oncology team for head and neck cancer patients and their family during radiation therapy with chemotherapy

Code	Sub-categories	Category
Competency, knowledge, attitudes, being a nurse, skilled, nursing evidence-based practice, Scope of service in educating HNCs, Job description	Scope of service Knowledge and skilled deficit	**Radiation Oncology Nursing role and Competency development**
Trust in healthcare personnel, Service behavior, Seeing the same provider, Good communication, Emotional support Symptom management	Symptom management strategies Supportive	**Environment of healing**
Individual teaching, Tailor information and education, Monitoring nursing outcomes, Reduce patient loneliness and suffering through treatment course, Care for patients as our relatives	Patient-centered Family involvement	**Person-centered approaching**
Clinical practice guideline Collaboration about patient queue and preparation Involve nutritionist, PT, OT in managing care Monitoring side effect from nurse and RTT for early detection	Multidisciplinary involvement , discontinuity	**Fragmentation of care**

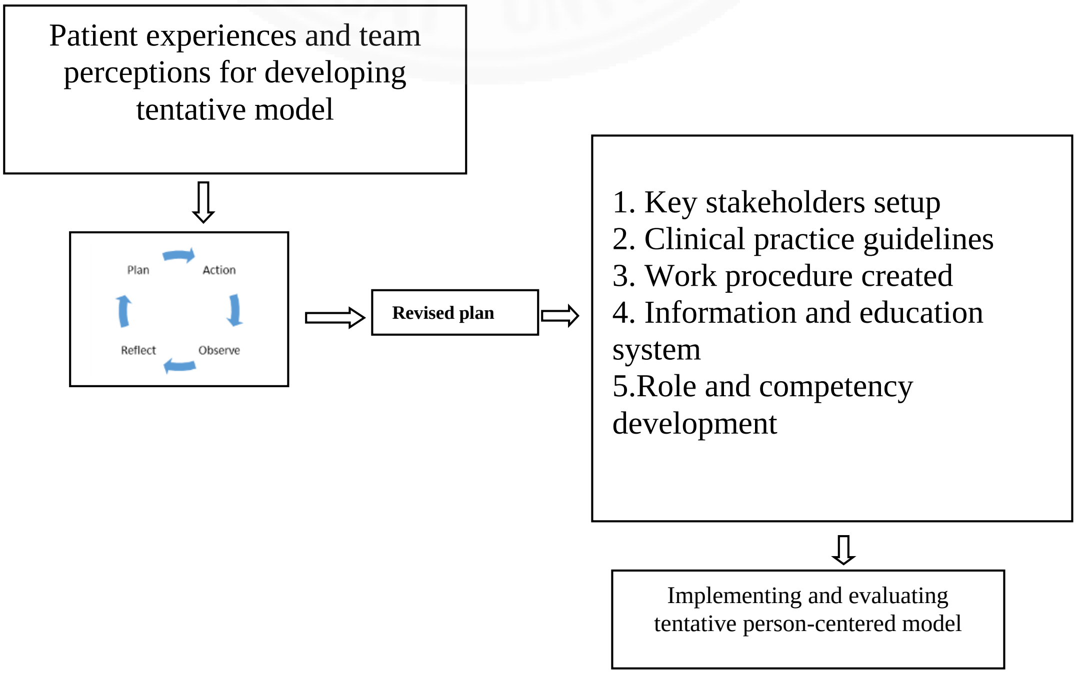
4.2 Phase II: To develop a person-centered model for enhancing treatment adherence, symptom management, and satisfaction among radiation oncology team and patients with head and neck cancer and family receiving concurrent chemoradiotherapy

The person-centered model was developed continuously into 3 cycles. Each cycle have 4 activities: planning, acting, observing, and reflecting (Kemmis& McTaggart, 1997), by using results from HNC patients and their family's experiences, as well as radiation oncology team's perceptions to lay the foundation for the improvement of a tentative practical model. Data obtained from participants group 1 and participants group 2 were presented inTable 11. All stake holders related to patientswith head and neck cancer receiving concurrence chemoradiotherapy care process concerned the gaps of practice and service needs in providing a better care for those patients.

Table 4.5 Caring process gaps of practice and service needs from group 1 and group 2

Caring issues	**Gaps of practice and service needs**
Group 1 Patients and their family caregivers	- Overwhelming of information and seeking tailored information -Inadequate knowledge about radiation therapy and chemotherapy - Symptoms management and self-care during treatment - Supportive care needs: physical, psychological aspects
Group 2 Radiation oncology team	- Ineffective collaboration and communication among radiation oncology team - Fragmentation of care from multidisciplinary approach and discontinuity - Lack of working procedure and guidelines in order to provide nursing care in the same practice - Lack of advanced knowledge and expertise in caring for HNC patients, especially nurses, therapists, and allied health staffs

This phase consumed a period of 4 months to complete. In the middle of this phase, the Covid 19 pandemic was an inevitable event that delayed the PAR process in some issues. However, the participants continued to work in the clinic and required urgent management to reduce the number of patients during the pandemic situation. Accordingly, the informants continued on their action plans and implementation of a person-centered model within the timeframe. Figure 4 illustratedthe process of developing model of PAR cycles in this study.



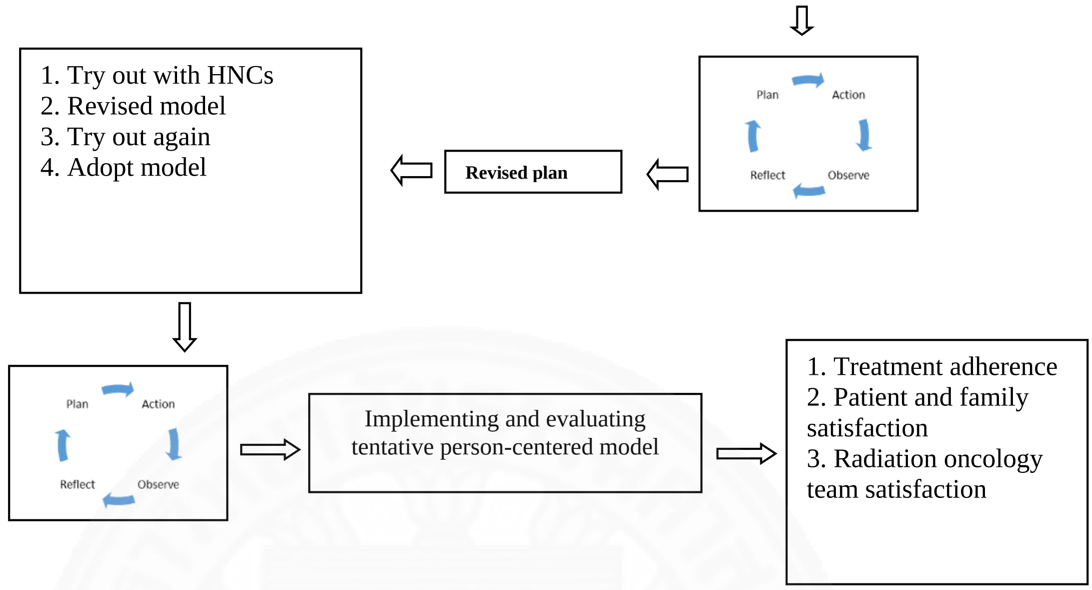


Figure 4 The activities of person-centered model development spiral

According to Figure 4, there were four activities of each participatory action research within **3 cycles**. These activities were presented in details as follows:

4.2.1 Cycle I

4.2.1.1 Activity 1: Plan

In order to develop the person-centered model, the researcher let the key participants play an active role in the research process. The researcher invited radiation oncology team participants and presented the data obtained from phase I together with the participants, and brought the related-caring issues, gaps of practices, and service needs to be discussed for improvement. After that, they conducted several meetings using the department usual meeting schedules. This was seen as a strategy to enable the participatory action research cycle to actively run along with the routinization of the department environment.

(1) Creating the clinical practice guidelines

The clinical guideline consisted of expected outcomes of each period of care for HNC patients during CCRT. It composed of essential elements of care process from first consultation visit, CT-simulation procedure, transfer plan, first day of radiation, during radiation and chemotherapy, and last day of radiation. Each process consisted of assessment, patient education, diet, exercise, symptoms management, and records. The participants considered the care continuity and recourse utilization by integrating social service for these patients.

Along with the professional responsibilities in order to take care of HNC pateints during CCRT at the radiation oncology department, the guidelines were developed by each discipline as follows:

- Radiation oncology nurses: A work instruction of nursing care plan for HNC patients during CCRT
- Radiaiont therapist: A work instruction of CT-simulation positioning for HNCs patients
- Radiation oncologists: A clinical practice guidelines for HNCs

(2) Creating a work procedure

In the planning phase, a new work procedure was established and proposed to the radiation oncology team. While, the previous work procedure mainly focused only the job assignment for each discipline as a service flow. This new work procedure consisted of roles and responsibilities for all members in a team. In this way, collaboration, communication, and clarification of job allocation could be better. From the patients and their family's needs, together with the radiation oncology team's concerns, the intra- and inter-department collaboration with multidisciplinary team was administered towards the optimal outcomes. There were more focuses on each issue with a clear vision to accomplish the person-centered care. The road map of caring patients with head and neck cancer was identified for possible solutions. All members shared their ideas and participated in the action plan of practical problem solving.

The continuity of care was a goal for cancer care, especially HNC patients who received CCRT. Multimodalities and multidisciplinary were fragmented in caring process. Radiation therapy and chemotherapy scheduling made patients and their family confused. Therefore, the radiation oncology nurses took this into account to create the monitoring system for the follow-up of patients' symptoms and side effects. The follow-up during treatment was crucial for monitoring the acute side effects from treatment and giving appropriate treatment. The team of radiation oncology developed guidelines for the follow-up of patients with the appointment system of the hospital.

The registered nurses printed out the name list of HNC patients who underwent radiation and follow-up on appointment in a day for reviewing the medical background and other personal information, such as telephone number and address two days ahead before the appointment date. The practical nurses made the call to remind the date of appointment and prepare the patients approximately 2 days ahead. On the date of appointment, if the patients did not show up, the practical nurses would make the call for updating the patients' status. If the patients were unavailable and required to change the date, the nurses would coordinate with the team to response their needs. For instance, if they were discontinued treatment due to side effects, nurses would do the close monitoring.

(3) Developing the information and education system

The suffering from symptoms could occur throughout treatment course. The caring map and support for those symptoms was written by the team in caring guidelines. For instance, oral mucositis, skin reaction, weigh change, and food consumption were assessed by radiation oncologists every week, with the NSS for rinsing every 2 hours. The NSS plus sodium bicarbonate was provided by radiation oncology nurses from the first day of radiation therapy. Monitoring oral discomforts, skin reactions, and other symptoms were recorded in the individual symptom profiles and monitored by the nursing educators. If the severity of skin reaction was at high grade and found by the radiation therapists during radiation treatment, the patients were referred to the nurses for evaluation and consultation with the doctor.

The symptom management strategies were provided to the patients and their family by radiation oncology nurses during the health education session. The nurses assessed the patients' needs and preferences to deal with any symptoms and engaged the patients and their family to participate in their self-care. Informal group support would be given in front of the radiation treatment room, so the nurses were there for prompting answers and questions.

Regarding the disease itself and complexity of treatment, the patients and their family sought the tailored information to receive treatment. In this study, the tailored information was provided by the radiation oncology team from the first consultation visit until the end of treatment. In the first visit, patients and their family discussed with radiation oncologists about the radiation therapy and chemotherapy to make decisions on the starting of concurrence chemoradiotherapy. After that, the CT-simulation appointment and preparation were given by radiation oncology nurse with a package of important information that patients needed to know before starting radiation and chemotherapy, such as treatment benefits, symptom management, financial issues, and transportation to hospital, chemotherapy process, and daily service flow. The leaflets provided to the patients were equipped with individual information and needs. It was identified by patient' name and organ related leaflets, not the general information. The chemotherapy regimens were prescribed by medical oncologists and given at the inpatient ward. There was collaboration between OPD, IPD, and Department of Radiation Therapy to schedule patients for radiation within 30 minutes after finishing chemotherapy.

The health education system for patients with head and neck cancer lacked the continuity of teaching to patients along the caring process. The radiation oncology nurses focused on the service flow information, symptom-related treatment, and self-care before starting radiation therapy and chemotherapy. The patients' needs and their concerns sometimes were not taken into account due to lack of time. Also, the treatment schedule for receiving radiation and chemotherapy were not the same time every day, depending on the available of treatment room. Therefore, the health educator nurses could not monitor the patients' symptoms at night time for treatment schedule. The patients did not see the importance of seeing the nurses for health education because they saw the doctors every week and met the radiation therapists every day.

The information for patients to receive radiation treatment was related to the procedures and CT-simulation. The CT-simulation was the important process before starting radiation therapy, with treatment planning and accuracy issues. This procedure needed the patients to lie down on the moving couch with special immobilization devices, such as the plastic mask, the oral pipe, and shoulder retractor, while making sure that patients stayed still. This usually took forty five minutes for the whole process. Patients needed contrast media injection during CT-scan for clearer x-ray. The appointment time and the preparation should coordinate with therapists and patients for invasive procedure.

The package of information that the patients should know was provided before starting radiation treatment. The process of radiation treatment were composed of many steps, and staffs should provide all information that patients needed to know before deciding to start treatment. The inadequate information to patients were situational analysis, with the sharing of their ideas to improve in practice. The final conclusion was the development of information package that patients needed to know at the consultation visit, CT-simulation day, and the last day of radiation therapy.

(4) Developing the radiation oncology nursing roles and competency

Radiation oncology nursing roles and competency were the first priority for improvement. The lectures on the topics related to patient care with head and neck cancer during radiation and chemotherapy were held every months, with nutritional issues, rehabilitation, prevention, radiation therapy, and chemotherapy regimens. The updated knowledge from other professionals were raised for nutritionists, physical therapists, and rehabilitation specialists. Therefore, the classroom for lecturing related topics were held by radiation oncologists, nutritionists, and physical therapists in the department and scheduled at the meeting room for a total 3 months.

In order to provide effective care for HNC patients and their family to foster treatment adherence and satisfaction, the person-centered approach was the key success. Individual patient had their background, limitation, and needs differently. Additionally, the focused symptoms usually done in practice now changed to be more person-focused. The educational materials were developed for individual needs. The health education about symptom management was more focused with the assessment of patients' background and preferences to follow the instructions. Some patients did not like sweets in order to maintain their energy. So, the nurses adjusted this solution with patients' agreement to deal with this problem. Family support was very important in Thai culture. Especially, this specific population needed caregivers to support in difficult time. Cheer-up speech and accompanying persons with patients for daily treatment was identified by patients. Hence, the radiation oncology nurses should focus the care to HNCs patients and their family as a center of care.

The patients' needs in term of symptom burdens were physical suffering and psychological distress. The supportive care was integrated into actions from all staffs. The service behaviors of radiation oncology team should be in gentle and clear communication to HNC patients and their family. The participation of patients and their family in every step of treatment was the key to success in dealing with complex situations, such as radiation scheduling, doctor scheduling, and self-care. The nurses were the coordinators in radiation therapy process to communicate, negotiate, and advocate for all stakeholders towards optimal HNCs patients and their family's needs and concerns.

Therefore, the competency of radiation oncology nurses should be included in these topics as follows,

- Physical and psychological symptom assessment and management
- Counselling and empowerment
- Knowledge about basic of radiation therapy, chemotherapy regimens
- Side effects related to radiation therapy and chemotherapy and management
- Nursing care for patient receiving concurrent chemoradiotherapy
- Nutrition management for head and neck cancer patients

The radiation oncology nursing' roles should be as follows;

- The nurse coordinator
- The nurse advocator
- Professional radiation oncology nurse

The planning activities for the person-centered model was developed from participatory action approach with plan of care, which will be illustrated in Table 4.6

Table 4.6 Plan of care for patients with head and neck cancer receiving concurrence chemoradiotherapy

Responsible person	When / Purpose	How/ Process	Tools	Indicators
	<u>Consultation & Care planning</u>			
Radiation oncologist	-The team ensures patients have easy access to the	-Tailored information is provided about the expected outcomes and	-Information leaflets for	

Responsible person	When / Purpose	How/ Process	Tools	Indicators
Radiation oncology nurse	services they need, the admissions process tailored to the health problem or patient needs, timely with good coordination. Under appropriate and efficient systems and supportive environment.	expenses to the patient / family was clear and easy to understand. There was a process for obtaining consent from the patient / family prior to providing services and CT-Simulation. -And ensuring that patients / families receive the necessary information sufficiently with understanding and have time to consider before making a decision. And there was an appropriate record.	patient and family -Referral form for counselling Nutritionist, Rehabilitation clinic	1. 100 % receive information 2. 100% complete consent form
Radiation therapist Radiation oncology nurse Radiation oncologist	**CT-Simulation** All patients were correctly, completely and appropriately assessed for their needs and health problems	- The patient assessment was comprehensive and coordinated to reduce redundancy, the radiation oncology team collaborates, analyzes and correlates the assessment results. Urgent and critical problems and needs were identified. - The initial assessment of each patient consisted of: Health history, physical examination, perception of their needs by the patient and family, assessment of psychological, social, economic factors. - Under a safe environment and adequate resources. A clinical practice guidelines and resources are used to guide patient assessment. - The radiation oncology team explained the assessment results to the patient and their family in clear and easy-to-understand language	-CT-Simulation request form -Psychosocial assessment evaluation -Nursing record form	- 100% assessed and recorded in the HIS
Radiation oncologist Radiation therapist Radiation oncology nurse	**First RT& CMT Symptom assessment** The radiation oncology team creates a well-coordinated patient care plan with clear goals. Corresponds to the health problems / needs of the patients	- Patient care planning was linked and coordinated between professions, departments and service units. - The patient care plan responds to a holistically assessed problem / need of the patient. - Evidence-based practice and a clinical practice guideline were used to guide the planning of patient care.	-Individual RT schedule -CMT booklet -Information leaflet -Symptom profile	- 100 % physical symptom and psychological assessed

Responsible person	When / Purpose	How/ Process	Tools	Indicators
	<u>Informing and empowering patients / families</u> The team provided information on patient / family health conditions and planned activities to empower the patient / family to be competent and responsible for their own health care. Including linking in health promotion into every step of the care.	- Patients / families have an opportunity to decide on a course of treatment after adequate information is obtained. And participate in care planning - There was communication / coordination between professionals of the radiation oncology team and related departments. In order to bring the patient care plan into action at the right time. The radiation oncology team members understand the roles of other stakeholders - The patient care plan was reviewed and adjusted when there was indication of an altered patient condition or severe symptoms. - A patient assessment plan and define learning activities. The assessment covers the patient's problems / needs, competence, emotional state, readiness for learning and self-care. - The team provided essential information and assist learning for self-care and health behavior conducive to good health to the patient and the family in appropriate time with clear and easy to understand. The perception, understanding and ability to implement the information obtained are assessed. - Provided appropriate emotional, psychological and counseling assistance to patients and their families. - The care team and patient / family jointly formulate appropriate self-care strategies for the patient, as well as continuing to monitor any barriers to self-care. - Provider team organizes essential skills-building activities for patients / families. And ensuring that the patient / family can act on their own. Such as making wounds, cooking and sucking mucus - The teams assess and improve learning management and patient / family empowerment processes.	-Knowledge assessment	- 100% received information - Knowledge assessment - Knowledge and skilled assessment - skill training and demonstrated - symptom toxicities grading score

Responsible person	**When / Purpose**	**How/ Process**	**Tools**	**Indicators**
Radiation oncologist Radiation oncology nurse	**Second RT& CMT** Symptom monitoring Empowerment	- The patient care plan is reviewed and adjusted when there is indication of an altered patient condition or symptoms.	-Referral form for counselling Nutritionist/ Dietitian -Knowledge and skill assessment	- symptom toxicities grading score
Radiation oncologist Radiation oncology nurse	**Third RT & CMT** Symptom monitoring Empowerment	- The patient care plan is reviewed and adjusted when there is indication of an altered patient condition or symptoms.	-Referral form for counselling Nutritionist/ Dietitian -Knowledge and skill assessment	- symptom toxicities grading score
Radiation oncology nurse	**Last RT day** - Patient and care giver training (wound care, exercise for preventing complication) -Discharge plans are planned so that patients can take care of themselves and be cared for properly according to the condition of the problem and needs after finishing the course of treatment.	- According to the empowerment principle to give patients and their families the potential and confidence in managing their own health care.	-Patient satisfaction questionnaire -Information leaflet -Knowledge and skill assessment	-Satisfaction

4.2.1.2 Activity 2&3: Act and observe

Once this tentative person-centered model was developed, the participants implemented this model with seven head and neck cancer patients who underwent CCRT. The researcher conducted a participatory observation, while the participants attended activities at the department and documented afterwards. The participants voiced their concerns and tried to input their opinions for problem solving. While, the researcher presented to patients with head and neck cancer and their family’s experiences, with sad and empathic expressions. All participants were interested in participating into the lectures from nutritionists, rahapbilitation specialists, and radiation oncologists on the topics related to the improvement of knowledge for taking care of patients with head and neck cancer. The allied health staffs who never joined the lectures came to sit in this room. However, the contents about the basicradiation therapy were too difficult for them to understand. Therefore, the staffs developed dialogues for the allied health staffs to communicate with patients. The collaboration between inter-disciplinary, inter-department, and multidisciplinary team was emerged from lectures and knowledge sharing between healthcare professionals. Therefore, work instructions and work procedures between departments were announced. The job assignments, in particular for updating the accommodations nearby the hospital, were done by the collaboration of nurses and therapists. There were group meetings with health education materials between the nursing team. The useful symptom management strategies were developed from brain storming to monitor symptoms during treatment in individual patients with head and neck cancer.

The evaluation of process and outcomes of person-centered model and its implementation was observed and reflected simultaneously and continuously. For measuring the outcomes of person-centered model and process development from the radiation oncology team perspective or expert’s views indicated that treatment adherence and satisfaction were the outcomes of the model. During the implementation of this tentative model, the radiation oncology team found out that the feedback from patients and their family during CCRT was identified and they tried to have the solutions. For instance, the patients and their family suggested that the nurses should not stand over the head of patients when teaching of behaviors. They planned caring activities with the care team and implemented. On the last day of radiation therapy, the nurses provided the exit interviewing with patients and their family, also the satisfaction questionnaire for evaluating the care process from person-centered model.

The results from patients and their family caregiver’s part found that the symptom status was maintained in the moderate score and no one had to discontinue during the concurrence chemoradiotherapy in seven cases. The symptom severity rating scale was rated by individual patient and the most severity symptoms included problems with tasting food, difficulty with voice/speech, and sore mouth/throat, respectively. In addition, the concurrent chemoradiotherapy adherence was achieved as planned in those seven HNC patients.

4.2.1.3 Activity 4: Reflect

There were reflections from patients with head and neck cancer and their family and the radiation oncology team after implementing the person-centered model in the clinic. These reflections and discussions between the researcher and the participants during action and observation processes could provide the basis for accumulating knowledge and various perspectives.

(1) Reflect of the patients and their family

The patients with head and neck cancer and their family members were satisfied with the caring process from the first consultation visit. They felt that the staffs at the radiation oncology were polite and friendly with open-mind for their questions. The service behaviors of all staffsin the radiation oncology team were very impressive and very helpful. The information they really needed to know about clinical outcomes was told by the radiation oncologists. The issues related to the radiation treatment as daily routine were told by radiation oncology nurses. The participant stated that "Cheerful speech from all staffs was very helpful and make me feel warm" (p01). Some of the patients and their family stated that "during treatment they were supported by the radiation oncology team, even I really had the suffering moments" (p06).

Thesuggestions for giving health education behaviour of nurses should be done in the way without standing up while giving information to the patients who were sitting on the chairs. Some patients talked about the radiation schedule, which should be the same time every day. The participants mentioned that *"The information given by nurses should be better if you sit at the same level to patients" (p07), "the schedule should be the same day every day, it will be bettter for me for planning everything" (p05).* Their feedback was analzed to confirm the sub-categories of supportive and service behaviors, including service mined, service behaviors, cheerful speech under the category of environment of healing.

The HNC patients and their family stated that the caring process and the service model in this clinic was excellent when compared with other hospitals. The impression they mentioned most was the service minded of all staffs. During active treatment, patients and their family were assessed their nutritional status and 2 patients were referred to the nutritionists and another 2 patients were referred to the speech therapy for early prevention. In this way, the collaboration between department was confirmed the continuity of care. Participants in the person-centered model consisted of 7 new cases of HNC patients and their family who could adhere to the CCRT without disruption during treatment.

(2) Reflect of the radiation oncology team

The participants stated at the beginning that they started the study with a feeling of 'be commanded', but after sharing their feelings and concerns in daily practices, they felt more comfortable to speak out. Especially, when they thought about patients' suffering during treatment, this made them more concerned with the wording they used or communicated to patients and their family. The difficult part of problem solving was a lack of time and the overload number of patients to develop the materials or contacted the specialists for giving lectures. The opportunity from model development was the sharing of knowledge from other professionals regarding the conflicts in routine practices. The participants stated that *"I think we did not do the best because of patient overload sometimes and that made us lack of time to develop something new. After we did something together and shared more ideas, I think we did better things"(F03)*

The radiation oncologists initiated to teach the basic knowledge of radiation therapy for all staffs, with the model of person-centered. They not only gave knowledge to all staffs but also cultivated good attitudes and some useful skills. After completing the nurses's brain stroming, the head of department was appreciated this activity due to the similar conceptswith the hospital in the USA. The roles of radiation oncology nurses and raidation therapists in teaching patients were in the grey zone of practice. The discussions and development of the work procedure for indicating roles and responsibilities were helpful and could strengten the relationship between the two professionals. The profile of symtom stategies was developed from the nursing care team for patients with head and neck cancer during radiation therapy. The individual symptom profile was the tool for monittoring the symptoms and side effects during treatment.

The radiation oncologists reported that they preferred the nurses and therapists who could do the symptom assessment as early detection and referred to them before the symptom getting worse. However, the doctor preference was in prescribing the skin care products to prevent skin irritation from radiation. The prescription of normal saline solution for rinsing to prevent oral mucositis should be done by nurses.

The therapists stated that they just realized that the nurses worked so hard and were busy with the paper work, such as radiation schedule, patient payment, and inform consent. They were willing to help for giving information to the patients and their family about radiation therapy process. It was very helpful to conduct the work flow and identify the nursing roles and responsibilities for contact in case of referring the patients.

The radiation oncology nurses stated that they were proud to be the radiation oncology nurses at this department. This working environment was very friendly in daily routine basis. When each professional did some mistakes, they could speak with open minded in the meeting and sharing the ideas with “no blame no shame”. The basic knowledge of radiation and chemotherapy in individual nurses was gained with more confidence to discuss as complex problems in patients with head and neck cancer and their family. The nurse mentioned that the continuity should be provided to patients after finishing concurrence chemoradiotherapy for monitoring the acute side effects and assessed the self-care ability.

All care provider participants believed that it was the great opportunity to improve their knowledge and skills in order to take care this group of patients. The knowledge gained from this development process could make them more confidence to take care the patients and their family. The relationship between radiation oncology team was described in a better feeling. The participants stated that after listening the patient’s experiences they felt more empathy to this group of patients. However, the suggestions from stakeholders mentioned that the fulfillment of the care model in this group of patients should invite more specialists, such as dentists, radio-biologists, and ENT doctors to share their expertise of caring the patients.

4.2.2 Cycle II

4.2.2.1 Activity 1: Revised plan of care for the 2nd cycle

After implementing the first cycle for a total of four weeks, feeding back from the reflection and evaluation from all stake holders, as well as the revised plan of person-centered model should be implemented in the clinic afterwards.

The continuity of care was the most concerned from the radiation oncology team. Hence, the follow-up after completing treatment was the adding issue in the model of care. The last but not least, the reflection from participants was the supportive care behaviors. For instance, a cheerful speech from the team was most needed from patients. Therefore, the revision of plans was shown in Table 4.7

Table 4.7 Revised plan of care from participants' reflection.

Responsible person	**When / Purposes**	**How/ Process**	**Outcomes**	**Tools**
Radiation oncology nurses	**<u>During RT</u>**	-Cheerful speech -Service behaviors - Service minded	Patient satisfaction	Excellence Service Behaviors
Radiation oncologist Radiation oncology nurse	**<u>Follow Up</u>** The radiation oncology team builds cooperation and coordination for effective follow-up and ongoing care of patients.	- There was an appointment system for patients to resume treatment when indicated. There is a system for helping and advising patients discharged from the hospital as appropriate. - There was continued follow-up care to ensure that the needs of the patient are met. And use the follow-up results to improve / plan future services.	> 80% follow up rate	- Guideline for following up - Telephone reminding before appointment day

4.2.2.2 Activity 2&3: Act and observe

Implementing the revision of person-centered model for three weeks and getting feedback from all stakeholders by mini interview and monitoring the outcomes found that all activities and plan of care were deployed with simplify and more understanding of radiation oncology team. Patients with head and neck cancer and their family were adhere to treatment as planned. Side effects from treatment-related most found were sore mouth and throat, nausea and vomiting, taste disturbance, and problem with mucus, respectively.

4.2.2.3 Activity 4: Reflect

After implementing the second cycle for total four weeks, feeding back from all stake holders were discussed in the meeting. The symptom assessment and management were the most concerned topic to the radiation oncology team. The patients and family mentioned about the self-management, especially in managing symptoms and strategies for adhering to the treatment regimens.

4.2.3 Cycle III

4.2.3.1 Activity 1: Revised plan of care for the 3nd cycle

The reflection from all participants were taken into account in revising plan of care. The service needs and gaps of practice were solved almost every topic-related to the concurrence chemo-radiation therapy care process. Therefore, the revision of plans was shown in Table 4.8

Table 4.8 Revised plan of care from participants' reflection from the second cycle

Responsible person	When / Purposes	How/ Process	Outcomes	Tools
Radiation oncology team	**During RT** -Early detection and management in side effects from CCRT	- Adopted the toxicity grading score from CTCAE for radiation oncology nurse to perform early detection and refer to radiation oncologist.	Symptom assessment Early detection	CTCAE score Mucositis, Skin reaction, weight change.
Radiation oncology team Patient and family	- Self-management and treatment adherence	- The radiation oncology nurses not only provided counselling but also empowering patients to adhere to the treatment. Family involvement was also the key factor to encourage patient success in the treatment journey.	Treatment adherence	Empowerment and family involvement

4.2.3.2 Activity 2&3: Act and observe

After deploying the revised plan of care in person-centered model in practice, the changing practice to meet the needs and close the gaps from participant's concerned were acted and observed.

4.2.3.3 Activity 4: Reflect

In the final meeting, the summary of reflection in every aspects were discussed and shown in Table 4.9

Table 4.9 Summary of closing the gaps of practice and service needs

Caring issues	Gaps of practice and service needs	Satisfied
Group 1 Patients and their family caregivers	- Overwhelming of information and seeking tailored information	√
	-Inadequate knowledge about radiation therapy and chemotherapy	√
	- Symptoms management and empowerment during treatment	√
	- Supportive care needs: physical, psychological aspects	√
Group 2 Radiation oncology team	- Ineffective collaboration and communication among radiation oncology team	√
	- Fragmentation of care from multidisciplinary approach and discontinuity	√
	-Lack of working procedure and guidelines in order to provide nursing care in the same practice	√
	- Lack of advanced knowledge and expertise in caring for HNC patients, especially nurses, therapists, and allied health staffs	√

Finally, in drawing a person-centered model, it was noted that this model emerged from a collaborative practice among radiation oncology team and patients with head and neck cancer and their family to develop the good quality of care. Figure 5 showed that the change of person-centered model was revised for patients with head and neck cancer during concurrent chemoradiotherapy in an overall picture of treatment delivery at a cancer center setting. Obviously, this model focused the patients as a center of supportive care from the radiation oncology team, with caring activities and caring process.

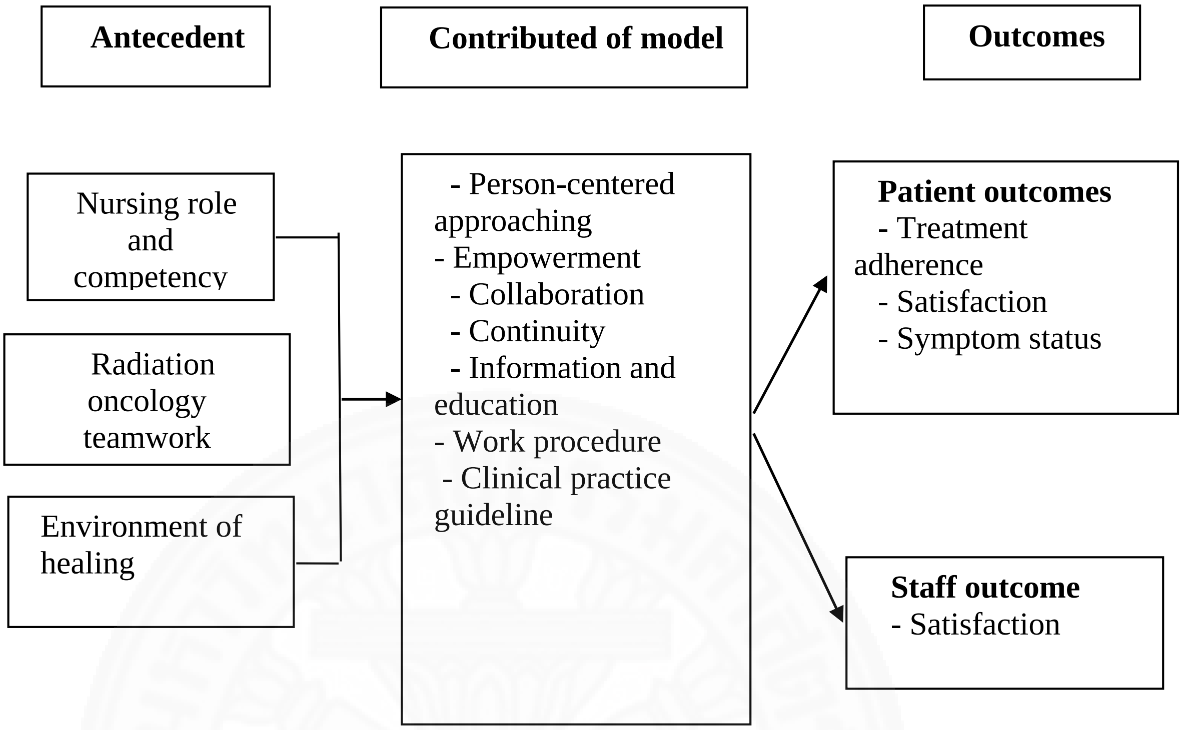


Figure 4.2 The person-centered model for patients with head and neck cancer during concurrent chemoradiotherapy

In conclusion, the outcomes of practice demonstrated the changes in the process of care. Previously, each professional had their own work instructions and service flow for patients. In this new model, there was a collaboration from every discipline in radiation oncology department to work on the caring plan for HNC patients. Therefore, the fragmentation of care would be less in the caring system and enhanced a professional relationship to work together. Evidently, there was a change in the department atmosphere and improved staff satisfaction. The summary of activities and outcomes of improvement during revision of the person-centered model was illustrated in Table 4.10

Table 4.10 The activities and outcomes of improvement during revision of Person-Centered Model

PAR Cycle	**Purpose/ Activities**	**Participant and Methods**	**Outcomes**
PAR Cycle I **Plan** **Act &** **Observe** **Reflect**	-Summarize and synthesize the data from phase I. -Building a common understanding , motivation, and share decision making from all participants and initiated the action plan - Participants reflect the existing problems and share concern to improve model of care.	- Radiation oncology team - Focus group on 8th November, 2019 at 12.00-13.00 o clock -Radiation oncology team -HNC patient and their family -Participant observation -Document review -Radiation oncology team, patient and their family -Focus group -Interview	-Identify stake holders -Identify the service needs and gaps of practice; -Clinical practice guidelines -Work procedure created -Information and education system -Role and competency development
PAR Cycle II ***Re-plan*** ***Act &*** ***Observe*** ***Reflect***	- Identify a process for investigating the issue and formulate the revised plan. -Determine the person-centered strategies and how to change in developing model. - Learning from last cycle -Observe the action process in terms of patient's health behavior, nurse-patient interaction, radiation oncology team interaction, and nursing activities. -Monitoring treatment adherence, patient's symptom experience and satisfaction among radiation oncology team and patients during CCRT process. - Reflecting and getting feedback the impact, process, and outcome of the person-centered model individually and with public sphere.	- Radiation oncology team, patient and their family -Document review -Focus group on 22nd November, 2019 at 12.00-13.00 -Participant observation -Document review -Share and learn on Friday 6, December 2019.	- Not satisfied with service behavior while giving information to the patients and family - Collaboration inter-intra department - Continuity in monitoring symptoms and side effects - Environment of healing

PAR Cycle	Purpose/ Activities	Participant and Methods	Outcomes
Cycle 3nd ***Re-plan***	-Communicate, share, and learn before implementing revised model of person-centered. -Identify a process for overcoming the barrier and formulate an action plan.	- Radiation oncology team - HNC patients and their family -Share and learn -Interview -Focus group on 24 April 2020	-Symptom assessment for early detection - Empowering patients and family involvement
Act & ***Observe*** ***Reflect***	- Identify the succession or limitation to achieve the person-centered model. - The pattern, characteristics and outcomes of person-centered model, together with satisfy from all stakeholder were achieved	- Radiation oncology team - HNC patients and their family	-Treatment adherence -Symptom status -Patient and family satisfaction - Staff satisfaction

The lessons learned from this study were that the person-centered model based on participatory action research was a tool for a better change in practice. As a head nurse of radiation oncology department, I have seen the problems and needs of all stake holders in real situations, but I cannot control or monitor every care process. Nursing care for patients with head and neck cancer who underwent radiation with or with out chemotherapy, in the complex of radiation therapy and chemotherapy process plus disease itself, caused the healthcare professionals to deal with those problems and mentioned symptoms adverse effects, but lack of concerns in the person-centered care. This study not only provides the change in practice guidelines but also presents the attitude of all stakeholders to involve in this study. The radiation oncology team are able to participate in any quality improvements in the clinic, but they need some change agent and opportunuty to voice their concern. Patients and their family are important in the care process, understanding their experiences and needs should be cultivated the individality and person-cenetred care. Importanly, the team of multidisciplinary to take care of this group of patients promote the knowledge management and skill mixes to enhance quality of care. In conclusion, this kind of research approach was suitable for solving problems and encouraging the participation from all individuals in the healthcare system in order to sustain the quality of healthcare service.

CHAPTER 5

CONCLUSION, IMPLICATIONS, AND RECOMMENDATIONS

This chapter presented the conclusion, implications,and recommendations of the findings. Also, the limitations of this study was exemplified.

5.1 Conclusion

This study was a participatory action research aiming to develop a person-centered model for patients with head and neck cancer during concurrent chemoradiotherapy. The activities for model development were divided into two phases. **The first phase** was designed to explore the experiences and needs of those patients and their family regarding the care process and radiation oncology services during concurrent chemoradiotherapy. Whereas, the experiences of radiation oncology team were also investigated in terms of the facilitations and enhancements to patients and their family towards a shared-decision making and full participation while receiving concurrent chemoradiotherapy. All information and data can lay a foundation to develop a tentative person-centered model for the delivery of concurrence chemoradiotherapy services. **The second phase** was purposed to develop a person-centered model based on the approach of participatory action research. Data collection included the interviews and observations with focused-groups and document reviews. Besides, the Graneheim and Lundman’s steps were applied throughout the study for content analysis.

The findings provided a better understanding of the true experiences, problems and needs of head and neck cancer patients during their concurrent chemoradiotherapy, including unpleasant side effects, overwhelming information, and strategies to adhere to treatment regimens. In particular, the professionals’ barriers of radiation oncology team were comprehensively exemplified regarding the role and competency, healing environment, teamwork, as well as fragmentation of care during treatment, which patients and their family was significantly the center of this service delivery model. The antecedent of person-centered model derived from the participatory action research approach, specifically, the crucial role of radiation oncology nurses and their competent as a pivotal part in building the effective radiation oncology teamwork, as well as the healing environment to efficaciously manage the suffering of unfavorable symptoms. Whereas, clinical practice guidelines, work procedures, educational and information systems, continuity, empowerment, and person-centered approach were implemented as the model contribution in providing a direct care for head and neck cancer patients, with good collaboration between the radiation oncology team and other healthcare professionals. The specific outcomes were treatment adherence, symptom status, and satisfaction from changing the practice to better care process for both patients and healthcare team. This participatory action research was conducted based on the Kemmis and McTaggart's approach (1988), including the action research spiral of individual and collective self-reflective cycles as a methodology with four activities to plan, act, observe, and reflect. Then, the revised-plan was continued during the model development, with 3 cycles in this study.

5.2 Implications

5.2.1 Implication for nursing practice

When considering the radiation oncology nursing role in Thailand, a design of nursing service delivery model with appropriate competency should be prioritized.

The nurse-patient ratio has not been set up in the Thai nursing council, especially for the out-patient specialty nursing area. Additionally, the patients and family's experiences while receiving the complexconcurrent chemoradiotehrapy treatment should be paid into attention. Therefore, the consuming time and the expertise of nursing workforce should be reconsidered in accordance with the Thai Nursing Council and the level of cancer center policy maker.

The person-centeredness in the care process is not only the patients' experiences but also the healthcare provider's viewpoints of their problems and needs in real practice. Therefore, creating a person-centered care in the radiation oncology system should include radiation oncology team' perspectives in the care process to obtain an insight into their perceptions concerning challenges in the existing care process for patients with head and neck cancer during concurrent chemoradiation therapy. Focusing on a person's needs and preferences may generate changes and improve patient’s experiences, with some added benefits of increasing the radiation oncology nurses’ satisfaction. The findings from this study could be applied in nursing practice as follows:

5.2.1.1 Outreach services emphasizing the competency of radiation oncology nurses, with tailored information for patients with head and neck cancer and their family, are highly needed .

5.2.1.2 Radiation oncology nurses can promote more patients’ participation towards a shared-decision making and empowerment in the care process. Patients should be encouraged to perform their self-management with positive experiences during treatment, which often involves different levels of suffering.

5.2.1.3 The findings could be adjusted as a guideline in providing services to patients with other types of cancer.

5.2.1.4 Nurses can apply the lessons gained from this study as a guideline for the development of a nursing service model towards quality improvement, such as appointment systems, follow-up shedules, wound caring, etc.

5.2.1.5 A guideline could be developed for nurses who work in a cancer center towards the roles of Thai radiation oncology nurses in the radiation oncology department.

5.2.2 Implications for nursing research

This model should be continously developed and applied as a guideline for the nursing research in diffferent topics as follows:

5.2.2.1 Treatment adherence in cancer patients, focusing on the process of participatory action research and working in partnership with multdisciplinary team

5.2.2.2 Development of an effective model for participatory workin to enhance knowledge and trainning

5.2.2.3 Development ofa person-centered model in other groups of cancer patients, such as breast and gynecological cancers in other cancer centers or different settings

5.2.2.4 Replication and extension in accordance with the contexts of other societies and regions to be applied among patients in other groups towards a nursing model that suits the overall needs

5.3 Recommendations for further study

5.3.1 The participatory process of this study can be applied with other groups of cancer patients in other contexts, such as in-patient ward, community, and palliative care unit.

5.3.2 The process of this model developmentcould be replicated among patients with head and neck cancer in other cancer centers, with different contexts to ensure their particular needs and measure the differences towards the needs for treatment adherence and satisfaction in healthcare services.

5.3.3 A longitudinal study of at least six months should be considered to identify attitudes and perceptions of those participating in this model towards an understanding of nursing service model.

5.3.4 A studyneeds to be conducted to develop a model for the capacity of patients with head and neck cancer and their family towards the proactive self-management in healthcare services.

5.3.5 A study may be performed to find a model for developing the capacity of radiation oncology nurses as the leader in providing knowledge about radiation treatment adherence and person-centered model.

5.3.6 A study is recommended to understand the impact of nursing service at the policy level among cancer centers for the integration of person-centered in nursing service.

5.3.7 Further study should be suggested to explore nursing capabilities in assessing individuals' experiences for a patient-centered care in nursing practice.

5.4 Limitation of the study

This study had some limitations for the generalization of findings due to the scope of research on a person-centered modelwhich based on the needs of participants in a cancer center ofone setting in Bangkok only. Moreover, the nature of participatory action research was done in a specific area of interest. It was likely that the contexts in other groups may require different forms of nursing care model. The applications from these findings met the maximum benefits for only patients with head and neck cancer during concurrent chemordiotherapy, under the context of Chulabhorn Hospital.

In addition, the complexity of disease should require the involvement of more specialists to participate and share their knowledge in taking care of patients, such as ENT doctors, dentists, medical oncologists, biologists, inpatient nurses, and chemo-nurses. Moreover, the person-centered model may need some replications and revisions for the optimal effectiveness.

REFERENCES

Adelstein, D., Gillison, M. L., Pfister, D. G., Spencer, S., Adkins, D., Brizel, D. M., . . . Darlow, S. D. (2017). NCCN Guidelines Insights: Head and Neck Cancers, Version 2.2017. *J Natl Compr Canc Netw, 15*(6), 761-770. doi:10.6004/jnccn.2017.0101

Aktas, A., Walsh, D., & Rybicki, L. (2012). Symptom clusters and prognosis in advanced cancer. *Support Care Cancer, 20*(11), 2837-2843. doi:10.1007/s00520-012-1408-9

Armstrong, T. S., & Gilbert, M. R. (2012). Practical strategies for management of fatigue and sleep disorders in people with brain tumors. *Neuro Oncol, 14 Suppl 4*, iv65-72. doi:10.1093/neuonc/nos210

Barsevick, A. M. (2007a). The concept of symptom cluster. *Semin Oncol Nurs, 23*(2), 89-98. doi:10.1016/j.soncn.2007.01.009

Barsevick, A. M. (2007b). The elusive concept of the symptom cluster. *Oncol Nurs Forum, 34*(5), 971-980. doi:10.1188/07.ONF.971-980

Bartoshuk, L. M., Catalanotto, F., Hoffman, H., Logan, H., & Snyder, D. J. (2012). Taste damage (otitis media, tonsillectomy and head and neck cancer), oral sensations and BMI. *Physiol Behav, 107*(4), 516-526. doi:10.1016/j.physbeh.2012.06.013

Baskar, R., & Itahana, K. (2017). Radiation therapy and cancer control in developing countries: Can we save more lives? *Int J Med Sci, 14*(1), 13-17. doi:10.7150/ijms.17288

Bauer, C., Laszewski, P., & Magnan, M. (2015). Promoting adherence to skin care practices among patients receiving radiation therapy. *Clin J Oncol Nurs, 19*(2), 196-203. doi:10.1188/15.CJON.196-203

Blaschke, S., O'Callaghan, C. C., & Schofield, P. (2018). Cancer Patients' Recommendations for Nature-Based Design and Engagement in Oncology Contexts: Qualitative Research. *HERD, 11*(2), 45-55. doi:10.1177/1937586717737813

Bolderston, A. (2016). Patient Experience in Medical Imaging and Radiation Therapy. *J Med Imaging Radiat Sci, 47*(4), 356-361. doi:10.1016/j.jmir.2016.09.002

Borneman, T., Piper, B. F., Sun, V. C., Koczywas, M., Uman, G., & Ferrell, B. (2007). Implementing the Fatigue Guidelines at one NCCN member institution: process and outcomes. *J Natl Compr Canc Netw, 5*(10), 1092-1101. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/18053431

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2515169/pdf/nihms59998.pdf

Buglione, M., Cavagnini, R., Di Rosario, F., Maddalo, M., Vassalli, L., Grisanti, S., . . . Magrini, S. M. (2016). Oral toxicity management in head and neck cancer patients treated with chemotherapy and radiation: Xerostomia and trismus (Part 2). Literature review and consensus statement. *Crit Rev Oncol Hematol, 102*, 47-54. doi:10.1016/j.critrevonc.2016.03.012

Burkill, G. J. C., Evans, R. M., Raman, V. V., & Connor, S. E. J. (2016). Overview: Modern Radiology in the Management of Head and Neck Cancer. *Clinical Oncology, 28*, 440-450. doi:10.1016/j.clon.2016.03.003

Calisi, R., Boyko, S., Vendette, A., & Zagar, A. (2016). What is person-centred care? a qualitative inquiry into oncology staff and patient and family experience of person-centred care. *Journal of Medical Imaging and Radiation Sciences*, *47*, 309-314.

Capozzi, L. C., Boldt, K. R., Lau, H., Shirt, L., Bultz, B., & Culos-Reed, S. N. (2015). A clinic-supported group exercise program for head and neck cancer survivors: managing cancer and treatment side effects to improve quality of life. *Supportive Care in Cancer*(4), 1001. doi:10.1007/s00520-014-2436-4

Carper, E., & Haas, M. (2006). Advanced practice nursing in radiation oncology. *Semin Oncol Nurs*, *22*(4), 203-211. doi:10.1016/j.soncn.2006.07.003

Chadwick, D. (2016). Veering Off Course: Addressing Challenges in Chemotherapy and Radiation Adherence. Retrieved from https://www.curetoday.com/publications/cure/2016/medication-adherence/veeringoff-course-addressing-challenges-in-chemotherapy-and-radiation-adherence

Chan, A., Teoh, D., Sanghera, P., & Hartley, A. (2009). Radiotherapy compliance is maintained with hypofractionation and concurrent cetuximab in locally advanced head and neck cancer. *Radiother Oncol, 93*(3), 654. doi:10.1016/j.radonc.2009.05.005

Chan, C. W., Richardson, A., & Richardson, J. (2011). Managing symptoms in patients with advanced lung cancer during radiotherapy: results of a psychoeducational randomized controlled trial. *J Pain Symptom Manage, 41*(2), 347-357. doi:10.1016/j.jpainsymman.2010.04.024

Chang, C. W., Mu, P. F., Jou, S. T., Wong, T. T., & Chen, Y. C. (2013). Systematic review and meta-analysis of nonpharmacological interventions for fatigue in children and adolescents with cancer. *Worldviews Evid Based Nurs, 10*(4), 208-217. doi:10.1111/wvn.12007

Chaturvedi, A. K., Anderson, W. F., Lortet-Tieulent, J., Curado, M. P., Ferlay, J., Franceschi, S., . . . Gillison, M. L. (2013). Worldwide trends in incidence rates for oral cavity and oropharyngeal cancers. *J Clin Oncol, 31*(36), 4550-4559. doi:10.1200/JCO.2013.50.3870

Chen, S. C., Lai, Y. H., Huang, B. S., Lin, C. Y., Fan, K. H., & Chang, J. T. (2015). Changes and predictors of radiation-induced oral mucositis in patients with oral cavity cancer during active treatment. *Eur J Oncol Nurs, 19*(3), 214-219. doi:10.1016/j.ejon.2014.12.001

Cheng, K. K., & Lee, D. T. (2011). Effects of pain, fatigue, insomnia, and mood disturbance on functional status and quality of life of elderly patients with cancer. *Crit Rev Oncol Hematol, 78*(2), 127-137. doi:10.1016/j.critrevonc.2010.03.002

Chung, M. K., Kim do, H., Ahn, Y. C., Choi, J. Y., Kim, E. H., & Son, Y. I. (2016). Randomized Trial of Vitamin C/E Complex for Prevention of Radiation-Induced Xerostomia in Patients with Head and Neck Cancer. *Otolaryngol Head Neck Surg, 155*(3), 423-430. doi:10.1177/0194599816642418

Creswell, J. W. (2009). *Research design: Qualitative and quantitative approaches* (3rd ed.). London: SAGE Publication.

Delaney, L. J. (2018).Patient-centred care as an approach to improving health care in Australia. *Collegian, 25,* 119-123.

Devine, F., Edwards, T., Feldman, S. R., & adherence. (2018). Barriers to treatment: describing them from a different perspective. *Patient preference, 12,* 129.

Dirix, P., Nuyts, S., & Van den Bogaert, W. (2006). Radiation-induced xerostomia in patients with head and neck cancer: a literature review. *Cancer, 107*(11), 2525-2534. doi:10.1002/cncr.22302

Dodd, M., Janson, S., Facione, N., Faucett, J., Froelicher, E. S., Humphreys, J., . . . Taylor, D. (2001). Advancing the science of symptom management. *J Adv Nurs, 33*(5), 668-676. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/11298204

http://onlinelibrary.wiley.com/doi/10.1046/j.1365-2648.2001.01697.x/abstract

Du, S., Hu, L., Dong, J., Xu, G., Jin, S., Zhang, H., & Yin, H. (2015). Patient education programs for cancer-related fatigue: A systematic review. *Patient Educ Couns, 98*(11), 1308-1319. doi:10.1016/j.pec.2015.05.003

Eilers, J., & Million, R. (2011). Clinical update: prevention and management of oral mucositis in patients with cancer. *Semin Oncol Nurs, 27*(4), e1-16. doi:10.1016/j.soncn.2011.08.001

Ekman, I., Swedberg, K., Taft, C., Lindseth, A., Norberg, A., Brink, E., . . . Sunnerhagen, K. S. (2011). Person-centered care--ready for prime time. *Eur J Cardiovasc Nurs, 10*(4), 248-251. doi:10.1016/j.ejcnurse.2011.06.008

Elo, S., Kääriäinen, M., Kanste, O., Pölkki, T., Utriainen, K., & Kyngäs, H. (2014). Qualitative content analysis: A focus on trustworthiness. *SAGE open, 4*(1), 2158244014522633.

Epstein, J. B., Smutzer, G., & Doty, R. L. (2016). Understanding the impact of taste changes in oncology care. *Support Care Cancer, 24*(4), 1917-1931. doi:10.1007/s00520-016-3083-8

Epstein, R. M., Fiscella, K., Lesser, C. S., & Stange, K. C. (2010). Why the nation needs a policy push on patient-centered health care. *Health Aff (Millwood), 29*(8), 1489-1495. doi:10.1377/hlthaff.2009.0888

Erlingsson, C., & Brysiewicz, P. (2017). A hands-on guide to doing content analysis. *African Journal of Emergency Medicine, 7*(3), 93-99.

Estores, I. M., & Frye, J. (2015). Healing Environments: Integrative Medicine and Palliative Care in Acute Care Settings. *Crit Care Nurs Clin North Am, 27*(3), 369-382. doi:10.1016/j.cnc.2015.05.002

Fan, G., Filipczak, L., & Chow, E. (2007). Symptom clusters in cancer patients: a review of the literature. *Curr Oncol, 14*(5), 173-179. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/17938700

http://www.current-oncology.com/index.php/oncology/article/download/140/145

Farhangfar, A., Makarewicz, M., Ghosh, S., Jha, N., Scrimger, R., Gramlich, L., & Baracos, V. (2014). Nutrition impact symptoms in a population cohort of head and neck cancer patients: multivariate regression analysis of symptoms on oral intake, weight loss and survival. *Oral Oncol, 50*(9), 877-883. doi:10.1016/j.oraloncology.2014.06.009

Ferlay, J., Soerjomataram, I., Dikshit, R., Eser, S., Mathers, C., Rebelo, M., . . . Bray, F. (2015). Cancer incidence and mortality worldwide: sources, methods and major patterns in GLOBOCAN 2012. *Int J Cancer, 136*(5), E359-386. doi:10.1002/ijc.29210

Ferreira, B. C., Sa-Couto, P., Lopes, M. C., & Khouri, L. (2016). Compliance to radiation therapy of head and neck cancer patients and impact on treatment outcome. *Clin Transl Oncol, 18*(7), 677-684. doi:10.1007/s12094-015-1417-5

Fesinmeyer, M. D., Mehta, V., Blough, D., Tock, L., & Ramsey, S. D. (2010). Effect of radiotherapy interruptions on survival in medicare enrollees with local and regional head-and-neck cancer. *Int J Radiat Oncol Biol Phys, 78*(3), 675-681. doi:10.1016/j.ijrobp.2009.08.004

FitzHenry, F., Wells, N., Slater, V., Dietrich, M. S., Wisawatapnimit, P., & Chakravarthy, A. B. (2014). A randomized placebo-controlled pilot study of the impact of healing touch on fatigue in breast cancer patients undergoing radiation therapy. *Integr Cancer Ther, 13*(2), 105-113. doi:10.1177/1534735413503545

Fitzmaurice, C., Allen, C., Barber, R. M., Barregard, L., Bhutta, Z. A., Brenner, H., . . . Naghavi, M. (2017). Global, Regional, and National Cancer Incidence, Mortality, Years of Life Lost, Years Lived With Disability, and Disability-Adjusted Life-years for 32 Cancer Groups, 1990 to 2015: A Systematic Analysis for the Global Burden of Disease Study. *JAMA Oncol, 3*(4), 524-548. doi:10.1001/jamaoncol.2016.5688

Fodeh, S. J., Lazenby, M., Bai, M., Ercolano, E., Murphy, T., & McCorkle, R. (2013). Functional impairments as symptoms in the symptom cluster analysis of patients newly diagnosed with advanced cancer. *J Pain Symptom Manage, 46*(4), 500-510. doi:10.1016/j.jpainsymman.2012.09.011

Fogh, S., & Yom, S. S. (2014). Symptom management during the radiation oncology treatment course: a practical guide for the oncology clinician. *Semin Oncol, 41*(6), 764-775. doi:10.1053/j.seminoncol.2014.09.020

Foster, C., Grimmett, C., May, C. M., Ewings, S., Myall, M., Hulme, C., . . . Richardson, A. (2016). A web-based intervention (RESTORE) to support self-management of cancer-related fatigue following primary cancer treatment: a multi-centre proof of concept randomised controlled trial. *Support Care Cancer, 24*(6), 2445-2453. doi:10.1007/s00520-015-3044-7

Gebreweld, F. H., Kifle, M. M., Gebremicheal, F. E., Simel, L. L., Gezae, M. M., Ghebreyesus, S. S., . . . Wahd, N. G. (2018). Factors influencing adherence to tuberculosis treatment in Asmara, Eritrea: a qualitative study. *J Health Popul Nutr, 37*(1), 1. doi:10.1186/s41043-017-0132-y

Goepfert, R. P., Yom, S. S., Ryan, W. R., & Cheung, S. W. (2015). Development of a chemoradiation therapy toxicity staging system for oropharyngeal carcinoma. *Laryngoscope, 125*(4), 869-876. doi:10.1002/lary.25023

Gonzalez, L. F., Moreira, L., Casanova, C., & Bettoli, P. (2019). Development and Piloting of a Patient Centered, Risk-Stratified Supportive Care Clinical Pathway for Head & Neck Cancer Patients in a Chilean Cancer Center. *International Journal of Radiation Oncology• Biology• Physics, 105*(1), E453-E454.

Gosselin-Acomb, T. K. (2006). Role of the radiation oncology nurse. *Semin Oncol Nurs, 22*(4), 198-202. doi:10.1016/j.soncn.2006.07.001

Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse education today, 24*(2), 105-112.

Gray, S. C., Khan, A. I., Kuluski, K., McKillop, I., Sharpe, S., Bierman, A. S., . . . Cott, C. (2016). Improving Patient Experience and Primary Care Quality for Patients With

Complex Chronic Disease Using the Electronic Patient-Reported Outcomes Tool: Adopting Qualitative Methods Into a User-Centered Design Approach. *JMIR Res Protoc*, *5*(1), e28. doi:10.2196/resprot.5204

Guba, E. G., & Lincoln, Y. S. (1989). *Fourth generation evaluation*: Sage.

Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. *J Handbook of qualitative research*, *2*(163-194), 105.

Gunn, G. B., Mendoza, T. R., Fuller, C. D., Gning, I., Frank, S. J., Beadle, B. M., . . . Rosenthal, D. I. (2013). High symptom burden prior to radiation therapy for head and neck cancer: a patient-reported outcomes study. *Head Neck, 35*(10), 1490-1498. doi:10.1002/hed.23181

Gupta, A., Baxi, S., & Hoyne, C. (2017). Assessing feasibility, compliance and toxicity of concomitant chemo-radiotherapy in head and neck cancers in the Northern Territory: initial experience and challenges. *J Med Radiat Sci, 64*(2), 131-137. doi:10.1002/jmrs.183

Hadi, M. A., & Closs, S. J. (2016). Ensuring rigour and trustworthiness of qualitative research in clinical pharmacy. *J International journal of clinical pharmacy, 38*(3), 641-646.

Haisfield-Wolfe, M. E., McGuire, D. B., Soeken, K., Geiger-Brown, J., De Forge, B., & Suntharalingam, M. (2012). Prevalence and correlates of symptoms and uncertainty in illness among head and neck cancer patients receiving definitive radiation with or without chemotherapy. *Support Care Cancer, 20*(8), 1885-1893. doi:10.1007/s00520-011-1291-9

Hall, S. F., Irish, J. C., Gregg, R. W., Groome, P. A., & Rohland, S. (2015). Adherence to and uptake of clinical practice guidelines: lessons learned from a clinical practice guideline on chemotherapy concomitant with radiotherapy in head-and-neck cancer. *Curr Oncol, 22*(2), e61-68. doi:10.3747/co.22.2235

Hanna, E. Y., Mendoza, T. R., Rosenthal, D. I., Gunn, G. B., Sehra, P., Yucel, E., & Cleeland, C. S. (2015). The symptom burden of treatment-naive patients with head and neck cancer. *Cancer, 121*(5), 766-773. doi:10.1002/cncr.29097

Hansson, E., Carlstrom, E., Olsson, L. E., Nyman, J., & Koinberg, I. (2017). Can a person-centred-care intervention improve health-related quality of life in patients with head and neck cancer? A randomized, controlled study. *BMC Nurs, 16*, 9. doi:10.1186/s12912-017-0206-6

Harte, R., Glynn, L., Rodriguez-Molinero, A., Baker, P. M., Scharf, T., Quinlan, L. R., & G, O. L. (2017). A Human-Centered Design Methodology to Enhance the Usability, Human Factors, and User Experience of Connected Health Systems: A Three-Phase Methodology. *JMIR Hum Factors, 4*(1), e8. doi:10.2196/humanfactors.5443

Hofso, K., Rustoen, T., Cooper, B. A., Bjordal, K., & Miaskowski, C. (2013). Changes over time in occurrence, severity, and distress of common symptoms during and after radiation therapy for breast cancer. *J Pain Symptom Manage, 45*(6), 980-1006. doi:10.1016/j.jpainsymman.2012.06.003

Hollander-Mieritz, C., Johansen, J., Johansen, C., Vogelius, I. R., Kristensen, C. A., & Pappot, H. (2019). Comparing the patients' subjective experiences of acute side effects during radiotherapy for head and neck cancer with four different patient-reported outcomes questionnaires. *Acta Oncol, 58*(5), 603-609. doi:10.1080/0284186X.2018.1563713

Hollis, G., & McMenamin, E. (2014). Integrating Nurse Practitioners Into Radiation Oncology: One Institution's Experience. *J Adv Pract Oncol, 5*(1), 42-46. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/25032032

Holter, I. M., & Schwartz-Barcott, D. (1993a). Action research: what is it? How has it been used and how can it be used in nursing? *, 18*(2), 298-304.

Holter, I. M., & Schwartz-Barcott, D. (1993b). Action research: what is it? How has it been used and how can it be used in nursing? *J Journal of advanced nursing, 18*(2), 298-304.

Hovan, A. J., Williams, P. M., Stevenson-Moore, P., Wahlin, Y. B., Ohrn, K. E., Elting, L. S., . . . Dysgeusia Section, O. C. S. G. M. A. o. S. C. i. C. I. S. o. O. O. (2010). A systematic review of dysgeusia induced by cancer therapies. *Support Care Cancer, 18*(8), 1081-1087. doi:10.1007/s00520-010-0902-1

Husebo, A. M., Karlsen, B., Allan, H., Soreide, J. A., & Bru, E. (2015). Factors perceived to influence exercise adherence in women with breast cancer participating in an exercise programme during adjuvant chemotherapy: a focus group study. *J Clin Nurs, 24*(3-4), 500-510. doi:10.1111/jocn.12633

Imsamran, W., Chaiwerawattana, A., Wiangnon, S., Pongnikorn, D., Suwanrungrung, K., Sangrajrang, & Buasom, R. (2015). *Cancer in Thailand, Vol.VIII, 2010-2012* (Vol. 8). Bangkok, Thailand: New Thammada Press (Thailand) Co., Ltd.

Institute of Medicine. (2001). Crossing the quality chasm: a new health system for the 21st century. Retrieved from https://iom.nationalacademies.org/w/media/Files/ReportFiles /2001/Crossing-the-Quality-Chasm/Quality Chasm 2001 report brief.pdf.

Iqbal, M. S., Chaw, C., Kovarik, J., Aslam, S., Jackson, A., Kelly, J., . . . Kelly, C. (2017). Primary Concurrent Chemoradiation in Head and Neck Cancers with Weekly Cisplatin

Chemotherapy: Analysis of Compliance, Toxicity and Survival. *Int Arch Otorhinolaryngol, 21*(2), 171-177. doi:10.1055/s-0036-1594020

Irune, E., Dwivedi, R. C., Nutting, C. M., & Harrington, K. J. (2014). Treatment-related dysgeusia in head and neck cancer patients. *Cancer Treat Rev, 40*(9), 1106-1117. doi:10.1016/j.ctrv.2014.06.011

Jiang, N., Zhao, Y., Jansson, H., Chen, X., & Martensson, J. (2017). Experiences of xerostomia after radiotherapy in patients with head and neck cancer: A qualitative study. *J Clin Nurs*. doi:10.1111/jocn.13879

Jimenez, A., Madero, R., Alonso, A., Martinez-Marin, V., Vilches, Y., Martinez, B., . . . Feliu, J. (2011). Symptom clusters in advanced cancer. *J Pain Symptom Manage, 42*(1), 24-31. doi:10.1016/j.jpainsymman.2010.10.266

Kemmis, S., & McTaggart, R. (1988). *The action research planner* (3th ed.). Victoria: Deakin University.

Kemmis, S., & McTaggart, R. (2000). Participatory action research. In *Handbook of qualitative research* (pp. 567–605). Thousand Oaks, CA: Sage.

Khamboon, T., Pongthavornkamol, K., Olson, K., Wattanakitkrileart, D., Viwatwongkasem, C., & Lausoontornsiri, W. (2015). Symptom experiences and symptom cluster across dimensions in Thais with advanced lung cancer. *Pacific Rim Int J Nurs Res, 19*(4), 330-344.

Khodyakov, D., Stockdale, S. E., Smith, N., Booth, M., Altman, L., & Rubenstein, L. V. J. H. E. (2017). Patient engagement in the process of planning and designing outpatient care improvements at the Veterans Administration Health-care System: findings from an online expert panel. *20*(1), 130-145.

Kim, H. J., McGuire, D. B., Tulman, L., & Barsevick, A. M. (2005). Symptom clusters: concept analysis and clinical implications for cancer nursing. *Cancer Nurs, 28*(4), 270-282; quiz 283-274. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/16046888

Kim, J. W., Cha, Y., Kim, S. J., Han, S. W., Oh, D. Y., Lee, S. H., . . . Bang, Y. J. (2012). Association of oral mucositis with quality of life and symptom clusters in patients with solid tumors receiving chemotherapy. *Support Care Cancer, 20*(2), 395-403. doi:10.1007/s00520-011-1126-8

Koornstra, R. H., Peters, M., Donofrio, S., van den Borne, B., & de Jong, F. A. (2014). Management of fatigue in patients with cancer -- a practical overview. *Cancer Treat Rev, 40*(6), 791-799. doi:10.1016/j.ctrv.2014.01.004

Krefting, L. (1991). Rigor in qualitative research: The assessment of trustworthiness. *The American journal of occupational therapy, 45*(3), 214-222.

Kujala, S. (2003). User involvement: A review of the benefits and challenges. *Behav Inf Technol, 22*(1), 1-16. doi:10.1080/01449290301782

Kumar, A., Tudu, A., Kumari, T., & Sahoo, S. K. (2017). Compliance to head and neck radiotherapy in our patient population. *IOSR Journal of Dental and Medical Sciences (IOSR-JDMS), 16*(4), 48-52.

Kuo, T. J., Wu, P. C., Tang, P. L., Yin, C. H., Chu, C. H., & Hung, Y. M. (2019). Effects of continuity of care on the postradiotherapy survival of working-age patients with oral cavity cancer: A nationwide population-based cohort study in Taiwan. *PLoS One, 14*(12), e0225635. doi:10.1371/journal.pone.0225635

Kwekkeboom, K. L. (2016). Cancer Symptom Cluster Management. *Semin Oncol Nurs, 32*(4), 373-382. doi:10.1016/j.soncn.2016.08.004

Kwekkeboom, K. L., Cherwin, C. H., Lee, J. W., & Wanta, B. (2010). Mind-body treatments for the pain-fatigue-sleep disturbance symptom cluster in persons with cancer. *J Pain Symptom Manage, 39*(1), 126-138. doi:10.1016/j.jpainsymman.2009.05.022

Lee, D., Shessel, A., Moyo, E., Koch, A., Ringash, J., Waldron, J., . . . Velec, M. (2019). Progress Towards a Person-Centered Model of Care for Radiation Therapy. *Journal of Medical Imaging and Radiation Sciences, 50*(2), S13-S14.

Liu, T. C., Bozic, K. J., & Teisberg, E. O. (2017). Value-based Healthcare: Person-centered Measurement: Focusing on the Three C's. *Clin Orthop Relat Res, 475*(2), 315-317. doi:10.1007/s11999-016-5205-5

Lo Nigro, C., Denaro, N., Merlotti, A., & Merlano, M. (2017). Head and neck cancer: improving outcomes with a multidisciplinary approach. *Cancer Manag Res, 9*, 363-371. doi:10.2147/CMAR.S115761

Luckett, T., Britton, B., Clover, K., & Rankin, N. M. (2011). Evidence for interventions to improve psychological outcomes in people with head and neck cancer: a systematic review of the literature. *Support Care Cancer, 19*(7), 871-881. doi:10.1007/s00520-011-1119-7

MacDonald, C. (2012a). Understanding participatory action research: a qualitative research methodology option. *Canadian Journal of Action Research 13*(2), 34-50.

MacDonald, C. (2012b). Understanding participatory action research: A qualitative research methodology option. *13*(2), 34-50.

Mackenzie, L. J., Sanson-Fisher, R. W., Carey, M. L., & D'Este, C. A. (2013). Radiation oncology outpatient perceptions of patient-centred care: a cross-sectional survey. *BMJ Open, 3*(2). doi:10.1136/bmjopen-2012-001265

Majid, A., Sayeed, B. Z., Khan, M., Lakhani, M., Saleem, M. M., Rajani, H., . . . Hussain, M. (2017). Assessment and Improvement of Quality of Life in Patients Undergoing Treatment for Head and Neck Cancer. *Cureus, 9*(5), e1215. doi:10.7759/cureus.1215

Mallick, I., & Waldron, J. N. (2009). Radiation therapy for head and neck cancers. *Semin Oncol Nurs, 25*(3), 193-202. doi:10.1016/j.soncn.2009.05.002

Marcelo, B., & Katharine, B. (2015). Supportive Management of Mucositis and Metabolic Derangements in Head and Neck Cancer Patients. *Cancers, Vol 7, Iss 3, Pp 1743-1757 (2015)*(3), 1743. doi:10.3390/cancers7030862

Marur, S., & Forastiere, A. A. (2016). Head and Neck Squamous Cell Carcinoma: Update on Epidemiology, Diagnosis, and Treatment. *Mayo Clin Proc, 91*(3), 386-396. doi:10.1016/j.mayocp.2015.12.017

Mason, H., DeRubeis, M. B., Burke, N., Shannon, M., Karsies, D., Wolf, G., . . . Worden, F. (2016). Symptom management during and after treatment with concurrent chemoradiotherapy for oropharyngeal cancer: A review of the literature and areas for future research. *World J Clin Oncol, 7*(2), 220-226. doi:10.5306/wjco.v7.i2.220

Mathes, T., Jaschinski, T., & Pieper, D. (2014). Adherence influencing factors–a systematic review of systematic reviews. *Archives of Public Health, 72*(1), 37.

McNiff, J. (2010). Concise Advise for New (and Experienced) Action Researchers. *Action Research for Professional Development:* . Retrieved from http://www.jeanmcniff com/ar-booklet.asp

McQuestion, M., & Fitch, M. (2016). Patients' experience of receiving radiation treatment for head and neck cancer: Before, during and after treatment. *Canadian Oncology Nursing Journal, 26*(4), 325-335.

McQuestion, M., & Fitch, M. I. (2016). Patients' experience of receiving radiation treatment for head and neck cancer: Before, during and after treatment. *Canadian Oncology Nursing Journal, 26*(4), 325-335.

McTaggart, R. (1991). Principles for participatory action research. *41*(3), 168-187.

Memtsa, P. T., Tolia, M., Tzitzikas, I., Bizakis, J., Pistevou-Gombaki, K., Charalambidou, M., . . . Kyrgias, G. (2017). Assessment of xerostomia and its impact on quality of life in head and neck cancer patients undergoing radiation therapy. *Mol Clin Oncol, 6*(5), 789-793. doi:10.3892/mco.2017.1200

Meneses-Echavez, J. F., Gonzalez-Jimenez, E., & Ramirez-Velez, R. (2015). Effects of Supervised Multimodal Exercise Interventions on Cancer-Related Fatigue: Systematic Review and Meta-Analysis of Randomized Controlled Trials. *Biomed Res Int, 2015*, 328636. doi:10.1155/2015/328636

Miaskowski, C. (2016). Future Directions in Symptom Cluster Research. *Semin Oncol Nurs, 32*(4), 405-415. doi:10.1016/j.soncn.2016.08.006

Miaskowski, C., Dodd, M., & Lee, K. (2004). Symptom clusters: the new frontier in symptom management research. *J Natl Cancer Inst Monogr*(32), 17-21. doi:10.1093/jncimonographs/lgh023

Miguel Padilha, J., Sousa, A. P., & Pereira, F. M. (2016). Participatory action research: A strategy for improving self-care management in chronic obstructive pulmonary disease patients. *J Action Research, 14*(3), 240-256.

Miller, T. A. (2016). Health literacy and adherence to medical treatment in chronic and acute illness: A meta-analysis. *Patient Educ Couns, 99*(7), 1079-1086. doi:10.1016/j.pec.2016.01.020

Moslemi, D., Nokhandani, A. M., Otaghsaraei, M. T., Moghadamnia, Y., Kazemi, S., & Moghadamnia, A. A. (2016). Management of chemo/radiation-induced oral mucositis in patients with head and neck cancer: A review of the current literature. *Radiother Oncol, 120*(1), 13-20. doi:10.1016/j.radonc.2016.04.001

Mullaney, T., Olausson, K., Sharp, L., Zackrisson, B., Edvardsson, D., & Nyholm, T. (2016). The influence of a department's psychosocial climate and treatment environment on cancer patients' anxiety during radiotherapy. *Eur J Oncol Nurs, 20*, 113-118. doi:10.1016/j.ejon.2015.06.009

Munhall, P. L. (1988). Ethical considerations in qualitative research. *10*(2), 150-162.

Murphy, B. A., & Gilbert, J. (2009). Dysphagia in head and neck cancer patients treated with radiation: assessment, sequelae, and rehabilitation. *Semin Radiat Oncol, 19*(1), 35-42. doi:10.1016/j.semradonc.2008.09.007

Mustian, K. M., Cole, C. L., Lin, P. J., Asare, M., Fung, C., Janelsins, M. C., . . . Magnuson, A. (2016). Exercise Recommendations for the Management of Symptoms Clusters Resulting From Cancer and Cancer Treatments. *Semin Oncol Nurs, 32*(4), 383-393. doi:10.1016/j.soncn.2016.09.002

Nevens, D., & Nuyts, S. (2016). The role of stem cells in the prevention and treatment of radiation-induced xerostomia in patients with head and neck cancer. *Cancer Med, 5*(6), 1147-1153. doi:10.1002/cam4.609

Nutting, C. (2016). Radiotherapy in head and neck cancer management: United Kingdom National Multidisciplinary Guidelines. *J Laryngol Otol, 130*(S2), S66-S67. doi:10.1017/S0022215116000463

Odom-Forren, J., & Wesmiller, S. (2017). *Managing symptoms: enhancing patients self-management knowledge and skills for surgical recovery.* Paper presented at the Seminars in oncology nursing.

Ohlen, J., Carlsson, G., Jepsen, A., Lindberg, I., & Friberg, F. (2016). Enabling sense-making for patients receiving outpatient palliative treatment: A participatory action research driven model for person-centered communication. *Palliat Support Care, 14*(3), 212-224. doi:10.1017/S1478951515000814

Olsson, E., & Lau, M. (2015). When one size does not fit all: using participatory action research to co-create preventive healthcare services. *Action Research, 13*(1), 9-29.

Orb, A., Eisenhauer, L., & Wynaden, D. (2001). Ethics in qualitative research. *J Nurs Scholarsh, 33*(1), 93-96. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/11253591

Padilha, J. M., Sousa, A. P., & Pereira, F. M. (2016). Participatory action research: a strategy for improving self-care management in chronic obstructive pulmonary disease patients. *Action Research, 14*(3), 240256.

Paice, J., Yarbro, C., Frogge, M., & Goodman, M. (2004). Cancer Symptom Management.

Pan, X. B., Huang, S. T., Chen, K. H., Jiang, Y. M., Ma, J. L., Qu, S., . . . Zhu, X. D. (2017). Concurrent chemoradiotherapy degrades the quality of life of patients with stage II nasopharyngeal carcinoma as compared to radiotherapy. *Oncotarget*, *8*(8), 14029-14038. doi:10.18632/oncotarget.14932

Picker Institute. (1993). Picker institute’s eight principles of patient-centered care. Retrieved from http://cgp.pickerinstitute.org/?page_id=1319

Pignon, J. P., le Maitre, A., Maillard, E., Bourhis, J., & Group, M.-N. C. (2009). Meta-analysis of chemotherapy in head and neck cancer (MACH-NC): an update on 93 randomised trials and 17,346 patients. *Radiother Oncol, 92*(1), 4-14. doi:10.1016/j.radonc.2009.04.014

Pinna, R., Campus, G., Cumbo, E., Mura, I., & Milia, E. (2015). Xerostomia induced by radiotherapy: an overview of the physiopathology, clinical evidence, and management of the oral damage. *Ther Clin Risk Manag, 11*, 171-188. doi:10.2147/TCRM.S70652

Porter, S. R., Fedele, S., & Habbab, K. M. (2010). Taste dysfunction in head and neck malignancy. *Oral Oncol, 46*(6), 457-459. doi:10.1016/j.oraloncology.2010.03.011

Puts, M. T., Tapscott, B., Fitch, M., Howell, D., Monette, J., Wan-Chow-Wah, D., . . . Alibhai, S. M. (2015). A systematic review of factors influencing older adults' decision to accept or decline cancer treatment. *Cancer Treat Rev, 41*(2), 197-215. doi:10.1016/j.ctrv.2014.12.010

Quinn, B., Potting, C. M., Stone, R., Blijlevens, N. M., Fliedner, M., Margulies, A., & Sharp, L. (2008). Guidelines for the assessment of oral mucositis in adult chemotherapy, radiotherapy and haematopoietic stem cell transplant patients. *Eur J Cancer, 44*(1), 61-72. doi:10.1016/j.ejca.2007.09.014

Rangarajan, R., & Jayaraman, K. J. I. j. o. c. (2017). Barriers affecting adherence to radiation treatment and strategies to overcome those barriers. *54*(2), 458.

Ream, E., Gargaro, G., Barsevick, A., & Richardson, A. (2015). Management of cancer-related fatigue during chemotherapy through telephone motivational interviewing: modeling and randomized exploratory trial. *Patient Educ Couns, 98*(2), 199-206. doi:10.1016/j.pec.2014.10.012

Reason, P. (1994). Three approaches to participative inquiry.

Rehaman B, H. M. (2018). The Impact of Service Quality Dimensions on Patient Satisfaction in the Private Healthcare Industry in Pakistan. *J Hosp Med Manage 4* (1:4), 1-8.

Ringash, J., Bernstein, L. J., Cella, D., Logemann, J., Movsas, B., Murphy, B., . . . Ridge, J. (2015). Outcomes toolbox for head and neck cancer research. *Head Neck, 37*(3), 425-439. doi:10.1002/hed.23561

Robert, G. (2013). Participatory action research: using experience-based co-design to improve the quality of healthcare services. *Understanding using health experiences–improving patient care*.

Rodriguez-Caballero, A., Torres-Lagares, D., Robles-Garcia, M., Pachon-Ibanez, J., Gonzalez-Padilla, D., & Gutierrez-Perez, J. L. (2012). Cancer treatment-induced oral mucositis: a critical review. *Int J Oral Maxillofac Surg, 41*(2), 225-238. doi:10.1016/j.ijom.2011.10.011

Rogus-Pulia, N. M., Pierce, M. C., Mittal, B. B., Zecker, S. G., & Logemann, J. A. (2014). Changes in swallowing physiology and patient perception of swallowing function following chemoradiation for head and neck cancer. *Dysphagia, 29*(2), 223-233. doi:10.1007/s00455-013-9500-y

Rojthamarat, S. S., C.; Kongvattananon, P. (2018). Symptom Experiences and Management of Patients with Head and Neck Cancer Receiving Radiation Therapy: Integrated Review. *The Bangkok Medical Journal, 14*.

Rose, P., & Yates, P. (2013). Person centred nursing care in radiation oncology: a case study. *Eur J Oncol Nurs, 17*(5), 554-562. doi:10.1016/j.ejon.2013.02.001

Rose, P., & Yates, P. (2015). Patients' outcomes related to person-centred nursing care in radiation oncology: A case study. *Eur J Oncol Nurs, 19*(6), 731-739. doi:10.1016/j.ejon.2015.05.008

Rose, P. M. (2016). Individualized care in the radiation oncology setting from the patients' and nurses' perspectives. *Cancer nursing, 39*(5), 411-422.

Rosenthal, D. I., Mendoza, T. R., Fuller, C. D., Hutcheson, K. A., Wang, X. S., Hanna, E. Y., . . . Gunn, G. B. (2014). Patterns of symptom burden during radiotherapy or concurrent chemoradiotherapy for head and neck cancer: a prospective analysis using the University of Texas MD Anderson Cancer Center Symptom Inventory-Head and Neck Module. *Cancer, 120*(13), 1975-1984. doi:10.1002/cncr.28672

Rosenthal, D. I., & Trotti, A. (2009). Strategies for managing radiation-induced mucositis in head and neck cancer. *Semin Radiat Oncol, 19*(1), 29-34. doi:10.1016/j.semradonc.2008.09.006

Roussi, P., & Miller, S. M. (2014). Monitoring style of coping with cancer related threats: a review of the literature. *J Behav Med, 37*(5), 931-954. doi:10.1007/s10865-014-9553-x

Russi, E. G., Corvo, R., Merlotti, A., Alterio, D., Franco, P., Pergolizzi, S., . . . Bernier, J. (2012). Swallowing dysfunction in head and neck cancer patients treated by radiotherapy: review and recommendations of the supportive task group of the Italian Association of Radiation Oncology. *Cancer Treat Rev, 38*(8), 1033-1049. doi:10.1016/j.ctrv.2012.04.002

Samalin, L., Honciuc, M., Boyer, L., de Chazeron, I., Blanc, O., Abbar, M., & Llorca, P. M. (2018). Efficacy of shared decision-making on treatment adherence of patients with bipolar disorder: a cluster randomized trial (ShareD-BD). *BMC Psychiatry, 18*(1), 103. doi:10.1186/s12888-018-1686-y

Samuel, S. R., Maiya, G. A., Babu, A. S., & Vidyasagar, M. S. (2013). Effect of exercise training on functional capacity & quality of life in head & neck cancer patients receiving chemoradiotherapy. *Indian J Med Res, 137*(3), 515-520. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/23640558
http://www.ijmr.org.in/article.asp?issn=09715916;year=2013;volume=137;issue=3;spage=515;epage=520;aulast=Samuel

Santana, M. J., Manalili, K., Jolley, R. J., Zelinsky, S., Quan, H., & Lu, M. (2018). How to practice person-centred care: A conceptual framework. *Health Expect, 21*(2), 429-440. doi:10.1111/hex.12640

Schindler, A., Denaro, N., Russi, E. G., Pizzorni, N., Bossi, P., Merlotti, A., . . . Murphy, B. (2015). Dysphagia in head and neck cancer patients treated with radiotherapy and systemic therapies: Literature review and consensus. *Crit Rev Oncol Hematol, 96*(2), 372-384. doi:10.1016/j.critrevonc.2015.06.005

Seewoodharry, M. D., Maconachie, G. D. E., Gillies, C. L., Gottlob, I., & McLean, R. J. (2017). The Effects of Feedback on Adherence to Treatment: A Systematic Review and Meta-analysis of RCTs. *Am J Prev Med, 53*(2), 232-240. doi:10.1016/j.amepre.2017.03.005

Siddiqui, F., & Movsas, B. (2017). Management of Radiation Toxicity in Head and Neck Cancers. *Semin Radiat Oncol, 27*(4), 340-349. doi:10.1016/j.semradonc.2017.04.008

Siegel, R. L., Miller, K. D., & Jemal, A. (2017). Cancer Statistics, 2017. *CA Cancer J Clin, 67*(1), 7-30. doi:10.3322/caac.21387

Sio, T. T., Lin, H.-K., Shi, Q., Gunn, G. B., Cleeland, C. S., Lee, J. J., . . . Frank, S. J. (2016). Clinical Investigation: Intensity Modulated Proton Therapy Versus Intensity Modulated Photon Radiation Therapy for Oropharyngeal Cancer: First Comparative Results of Patient-Reported Outcomes. *International Journal of Radiation Oncology, Biology, Physics, 95*, 1107-1114. doi:10.1016/j.ijrobp.2016.02.044

Skerman, H. M., Yates, P. M., & Battistutta, D. (2012). Cancer-related symptom clusters for symptom management in outpatients after commencing adjuvant chemotherapy, at 6 months, and 12 months. *Support Care Cancer, 20*(1), 95-105. doi:10.1007/s00520-010-1070-z

Sonis, S. T. (2009). Mucositis: The impact, biology and therapeutic opportunities of oral mucositis. *Oral Oncol, 45*(12), 1015-1020. doi:10.1016/j.oraloncology.2009.08.006

Sparrow S., R. J. (1994). Action Research: an appropriate design for research in nursing? *Educational Action Research, 2*(3), 347-353.

Spinuzzi, C. (2005). The Methodology of Partioipatory Design. *Applied Research, 52*(2), 163-174.

Steen, M. (2013). Virtues in participatory design: cooperation, curiosity, creativity, empowerment and reflexivity. *Sci Eng Ethics, 19*(3), 945-962. doi:10.1007/s11948-012-9380-9

Stone, R., Fliedner, M. C., & Smiet, A. C. (2005). Management of oral mucositis in patients with cancer. *Eur J Oncol Nurs, 9 Suppl 1*, S24-32. doi:10.1016/j.ejon.2005.08.004

Tangjaturonrasme, N., Vatanasapt, P., & Bychkov, A. (2018). Epidemiology of head and neck cancer in Thailand. *Asia Pac J Clin Oncol, 14*(1), 16-22. doi:10.1111/ajco.12757

The Healthcare Accreditation Institute (Public Organization). (2018). *Hospital and healthcare Standards*. Thailand: The Healthcare Accreditation Institute (Public Organization).

Thomas, B. C., Waller, A., Malhi, R. L., Fung, T., Carlson, L. E., Groff, S. L., & Bultz, B. D. (2014). A longitudinal analysis of symptom clusters in cancer patients and their sociodemographic predictors. *J Pain Symptom Manage, 47*(3), 566-578. doi:10.1016/j.jpainsymman.2013.04.007

Thomas, K., Martin, T., Gao, A., Ahn, C., Wilhelm, H., & Schwartz, D. L. (2017). Interruptions of head and neck radiotherapy across insured and indigent patient populations. *13*(4), e319-e328.

Thomas, K., Martin, T., Gao, A., Ahn, C., Wilhelm, H., & Schwartz, D. L. (2017). Interruptions of Head and Neck Radiotherapy Across Insured and Indigent Patient Populations. *J Oncol Pract, 13*(4), e319-e328. doi:10.1200/JOP.2016.017863

Thomsen, T. G., & Hølge-Hazelton, B. (2017). Patients' vulnerability in follow-up after colorectal cancer: A qualitative action research study. *Cancer nursing, 40*(2), 152-159.

Torresan, M. M., Garrino, L., Borraccino, A., Macchi, G., De Luca, A., & Dimonte, V. (2015). Adherence to treatment in patient with severe cancer pain: A qualitative enquiry through illness narratives. *Eur J Oncol Nurs, 19*(4), 397-404. doi:10.1016/j.ejon.2015.01.001

Trotti, A., Bellm, L. A., Epstein, J. B., Frame, D., Fuchs, H. J., Gwede, C. K., . . . Zilberberg, M. D. (2003). Mucositis incidence, severity and associated outcomes in patients with head and neck cancer receiving radiotherapy with or without chemotherapy: a systematic literature review. *Radiother Oncol, 66*(3), 253-262. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/12742264

Ullgren, H., Kirkpatrick, L., Kilpelainen, S., & Sharp, L. (2017). Working in silos? - Head & Neck cancer patients during and after treatment with or without early palliative care referral. *Eur J Oncol Nurs, 26*, 56-62. doi:10.1016/j.ejon.2016.12.003

Ullgren, H., Tsitsi, T., Papastavrou, E., & Charalambous, A. (2018). How family caregivers of cancer patients manage symptoms at home: A systematic review. *Int J Nurs Stud, 85*, 68-79. doi:10.1016/j.ijnurstu.2018.05.004

Vallenga, D., Grypdonck, M. H., Hoogwerf, L. J., & Tan, F. I. (2009). Action research: what, why and how? *Acta Neurol Belg, 109*(2), 81-90. Retrieved from https://www.ncbi.nlm.nih.gov/pubmed/19681439

Villa, A., & Sonis, S. (2016). Toxicities associated with head and neck cancer treatment and oncology-related clinical trials. *Curr Probl Cancer, 40*(5-6), 244-257. doi:10.1016/j.currproblcancer.2016.06.001

Xiao, C., Hanlon, A., Zhang, Q., Ang, K., Rosenthal, D. I., Nguyen-Tan, P. F., . . . Bruner, D. W. (2013a). Symptom clusters in patients with head and neck cancer receiving concurrent chemoradiotherapy. *Oral Oncology, 49*(4), 360-366. doi:https://doi.org/10.1016/j.oraloncology.2012.10.004

Xiao, C., Hanlon, A., Zhang, Q., Ang, K., Rosenthal, D. I., Nguyen-Tan, P. F., . . . Bruner, D. W. (2013b). Symptom clusters in patients with head and neck cancer receiving concurrent chemoradiotherapy. *Oral Oncology, 49,* 360-366. doi:10.1016/j.oraloncology.2012.10.004

Xiao, C., Hanlon, A., Zhang, Q., Ang, K., Rosenthal, D. I., Nguyen-Tan, P. F., . . . Bruner, D. W. (2013). Symptom clusters in patients with head and neck cancer receiving concurrent chemoradiotherapy. *Oral Oncol, 49*(4), 360-366. doi:10.1016/j.oraloncology.2012.10.004

Xiao, C., Hanlon, A., Zhang, Q., Movsas, B., Ang, K., Rosenthal, D. I., . . . Bruner, D. W. (2014). Risk factors for clinician-reported symptom clusters in patients with advanced head and neck cancer in a phase 3 randomized clinical trial: RTOG 0129. *Cancer, 120*(6), 848-854. doi:10.1002/cncr.28500

Xiao, W., Chan, C. W. H., Fan, Y., Leung, D. Y. P., Xia, W., He, Y., & Tang, L. (2017). Symptom clusters in patients with nasopharyngeal carcinoma during radiotherapy. *Eur J Oncol Nurs, 28,* 7-13. doi:10.1016/j.ejon.2017.02.004

Yamashita, H., Nakagawa, K., Hosoi, Y., Kurokawa, A., Fukuda, Y., Matsumoto, I., . . . Abe, K. (2009). Umami taste dysfunction in patients receiving radiotherapy for head and neck cancer. *Oral Oncol, 45*(3), e19-23. doi:10.1016/j.oraloncology.2008.04.001

Yamashita, H., Nakagawa, K., Tago, M., Nakamura, N., Shiraishi, K., Eda, M., . . . Ohtomo, K. (2006). Taste dysfunction in patients receiving radiotherapy. *Head Neck, 28*(6), 508-516. doi:10.1002/hed.20347

Yom, S. S. (2015). Radiation treatment of head and neck cancer. *Surg Oncol Clin N Am, 24*(3), 423-436. doi:10.1016/j.soc.2015.03.015

APPENDICES

Appendix A

แนวคำถามที่ใช้ สำหรับสัมภาษณ์ ผู้ป่วยมะเร็งศีรษะและลำคอที่รับการฉายรังสีมี 13 ข้อโดยประมาณ ดังนี้

1. ท่านมีความรู้สึกอย่างไรกับการรักษาด้วยการฉายรังสี

2. ท่านมีเหตุผลใดที่ทำให้ท่านเข้ารับการรักษาด้วยการฉายรังสี

3. ท่านมีแรงจูงใจใดที่ทำให้ท่านสามารถรักษาได้จนครบตามแผนการรักษา

4. ท่านมีเหตุผลอะไรบ้างที่ทำให้ท่านไม่อยากเข้ารับการรักษาด้วยการฉายรังสี

5. ท่านมีปัญหาใดบ้างที่ (อาจ) เป็นเหตุให้ไม่ได้รับการรักษาด้วยรังสีครบตามแผนที่วางไว้

6. ท่านมีส่วนร่วมในการตัดสินใจเกี่ยวกับรักษาอย่างไร

7. ท่านคิดว่า บุคลากรรังสีรักษาได้คำนึงถึง ความชอบ ความต้องการของท่าน และเห็นคุณค่าของท่านมายึดถือเป็นแนวทางในการปฏิบัติต่อท่านหรือไม่ ระหว่างการรักษาด้วยรังสี

8. ท่านรู้สึกอย่างไรกับการที่ท่านได้รับการช่วยเหลือสนับสนุน การช่วยเหลือที่ท่านได้รับจากแพทย์ พยาบาล นักรังสีการแพทย์ ในระหว่างการรักษาด้วยการฉายรังสี

9. ท่านต้องการความช่วยเหลืออะไรเพิ่มเติมอีกบ้างจากบุคลากรทางรังสีรักษาระหว่างการรักษาด้วยรังสี

10. ท่านรู้สึกอย่างไร กับการบริการที่ท่านได้รับ ในหน่วยรังสีมะเร็งวิทยา

11. ท่านมีข้อเสนอแนะในการดูแลของบุคลากรรังสีรักษาระหว่างการฉายรังสีหรือไม่

12. ท่านมีข้อเสนอแนะอย่างไรบ้าง ในการพัฒนาการบริการ และการดูแลระหว่างท่านรักษาด้วยการฉายรังสี

13. จากมุมมองของท่าน มีข้อเสนอแนะในการให้บริการด้านรังสีรักษาอย่างไรเพื่อพัฒนาการดูแลท่านให้ตอบสนองกับความต้องการของท่านมากที่สุด

Appendix B

แนวคำถามที่ใช้ สำหรับสัมภาษณ์ สำหรับญาติผู้ดูแล ผู้ป่วยมะเร็งศีรษะและลำคอที่ได้รับการฉายรังสี มี 13 ข้อโดยประมาณ ดังนี้

1. ท่านรู้สึกอย่างไรบ้างที่คนในครอบครัวของท่านได้รับการรักษาด้วยรังสีรักษา
2. ท่านมีเหตุผลใดที่ทำให้ท่านพาบุคคลในครอบครัวท่านเข้ารับการรักษาด้วยการฉายรังสี
3. ท่านมีแรงจูงใจใดที่ทำให้ท่านสามารถดูแลช่วยเหลือให้บุคคลในครอบครัวท่านรับการรักษาได้จนครบตามแผนการรักษา
4. ท่านมีเหตุผลอะไรบ้างที่ทำให้ท่านไม่อยากพาบุคคลในครอบครัวท่านเข้ารับการรักษาด้วยการฉายรังสี
5. ท่านมีปัญหาใดบ้างที่ (อาจ) เป็นเหตุให้บุคคลในครอบครัวไม่ได้รับการรักษาด้วยรังสีครบตามแผนที่วางไว้
6. ท่านมีส่วนร่วมในการตัดสินใจเกี่ยวกับรักษาอย่างไร
7. ท่านคิดว่า บุคลากรรังสีรักษาได้คำนึงถึง ความชอบ ความต้องการของท่านและเห็นคุณค่าของท่านมายึดถือเป็นแนวทางในการปฏิบัติต่อท่านหรือไม่ ระหว่างการรักษาด้วยรังสี
8. ท่านรู้สึกอย่างไรกับการที่ท่านได้รับการ่วยเหลือสนับสนุน การช่วยเหลือที่ท่านได้รับ จากแพทย์ พยาบาล นักรังสีการแพทย์ ในระหว่างการรักษาด้วยการฉายรังสี
9. ท่านต้องการความช่วยเหลืออะไรเพิ่มเติมอีกบ้างจากบุคลากรทางรังสีรักษาระหว่างที่บุคคลในครอบครัวได้รับการรักษาด้วยรังสี
10. ท่านรู้สึกอย่างไร กับการบริการพยาบาลที่ท่านได้รับ ในหน่วยรังสีมะเร็งวิทยา
11. ท่านมีข้อเสนอแนะในการดูแลของพยาบาลระหว่างการฉายรังสีหรือไม่
12. ท่านมีข้อเสนอแนะอย่างไรบ้าง ในการพัฒนาการพยาบาลระหว่างท่านรักษาด้วยการฉายรังสี
13. จากมุมมองของท่าน ท่านมีข้อเสนอแนะในการให้บริการด้านรังสีรักษาบ้าง เพื่อให้ตอบสนองความต้องการของท่านมากที่สุด

Appendix C

แนวคำถามที่ใช้ สำหรับสัมภาษณ์ สำหรับทีมบุคลากรรังสีมะเร็งวิทยา มี 7 ข้อ ดังนี้

1. ท่านรู้สึกอย่างไรกับการปฏิบัติการพยาบาลในปัจจุบัน เกี่ยวกับการดูแลผู้ป่วยมะเร็งศีรษะและลำคอที่ได้รับรังสีรักษา
2. ท่านคิดว่าอะไรที่ควรปรับเปลี่ยน เกี่ยวกับการปฏิบัติการพยาบาล/ การดูแลสำหรับผู้ป่วยกลุ่มดังกล่าวให้ดีขึ้นและควรปรับอย่างไร
3. ท่านคิดว่า ควรจะปรับเปลี่ยนรูปแบบการพยาบาลให้เป็นแบบใดที่จะเพิ่มคุณภาพการพยาบาล
4. ในมุมมองของท่าน ใครควรทำอะไร ที่ไหน เมื่อไหร่ และอย่างไรในการที่จะทำให้รูปแบบการพยาบาล/การบริการที่มุ่งบุคคลเป็นศูนย์กลางสำเร็จ
5. ท่านคิดว่ารูปแบบการพยาบาลใหม่ที่ท่านคิด จะส่งผลกระทบต่อความสัมพันธ์กับวิชาชีพอื่นๆ ในหน่วยงานหรือไม่ อย่างไร
6. ในมุมมองของท่าน ช่วยบอกถึงปัจจัยที่ช่วยส่งผลทำให้รูปแบบการพยาบาลใหม่นี้สำเร็จ
7. ในมุมมองของท่าน อะไรที่เป็นปัญหา และอุปสรรคในการที่จะทำให้รูปแบบการพยาบาลใหม่นี้ ไม่สำเร็จตามที่ท่านคิด

Appendix D

Section 1:Demographic data and Illness Questionnaire

Note: Please answer the questionnaire about your personal data and fill in the blanks or mark ✓ in ☐that corresponds to your information

Part 1 Personal data

1. Sex ☐Male ☐Female
2. Age .... years
3. Marital status ☐Single☐Married
☐Widow/Divorced/Separated
4. Religion ☐Buddhist ☐Christian ☐Islamic
5. Education Level ☐No ☐Primary education
☐Secondary education☐Bachelor degree
☐Higher than Bachelor Degree
6. Profession ☐Government officer ☐State enterprise officer
☐Office employee☐Business owner
☐ Farmer ☐Housewife☐Students
☐No ☐ Others(please specify ....)
7. Income per month (Socioeconomic status)
☐≤10,000 ☐10,000 – 20,000 ☐20,001 – 30,000
☐30,001 – 50,000 ☐50,001 – 100,000 ☐> 100,000
8. Social supporter ☐Yes ☐No (please specify.........)
8.1 Healthcare supporter ☐No ☐Yes(Relationship ....)
8.2 Travel supporter ☐No ☐Yes(Relationship..............)
8.3 Caregiver at home ☐No ☐Yes(Relationship..............)
9. Healthcare coverage ☐Universal Health Coverage
☐Social Security
☐Government office
☐ State Enterprise
☐Self-payment
☐Others (please specify........................)

Section 2 Illness data (for researcher)

1. Weight (1st day of treatment)………Kg.Weight (last day of treatment)……… Kg.
2. Height ………………… cm.
3. Diagnosis……………………

   Disease site

   ☐….Tongue (oral)

   ☐….Oral cavity, exclude tongue

   ☐….Pharynx

   ☐….Larynx

   ☐….Thyroid

   ☐….Salivary

   ☐….Paranasal sinus

4. Stage…………………………………
5. Comorbidities ☐No ☐Yes(please specify…………)
6. History of surgery ☐No ☐Yes (please specify……….) Date ….……
7. Treatment plan ☐Radiation therapy ☐Concurrent chemo-radiotherapy

   ☐ Radiation therapy -Technique ☐3D-CRT ☐ IMRT ☐ VMAT

   - Dose………………………………………………
   - Area………………………………………………
   - Time ………………………………………….. ……

   ☐ Chemotherapy -Type and dose…………………………………..........

8. Patient with feeding tubes ☐No ☐Yes please specify……… Date……….
9. Feeding tube used for > 1.2 of intake ☐No☐Yes please specify……………
10. Tracheostomy/ laryngectomy stoma ☐No ☐Yesplease specify….Date…….

Appendix E

เอกสารให้ข้อมูลสำหรับอาสาสมัครผู้ป่วย

(Participant Information Sheet)

โครงการวิจัยที่ ....

ชื่อเรื่อง (ไทย) “การพัฒนารูปแบบการมุ่งบุคคลเป็นศูนย์กลางสำหรับผู้ป่วยมะเร็งศีรษะและลำคอที่ได้รับรังสีรักษา: การวิจัยแบบมีส่วนร่วม”

ชื่อเรื่อง (อังกฤษ) “A development of the person- centered model for patients with head and neck cancer receiving radiation therapy: participatory action research”

ชื่อผู้วิจัยนางสาว ศิริกร ก้องวัฒนะกุล
ที่อยู่ เลขที่ 222/454 ถ. งามวงศ์วาน แขวงทุ่งสองห้อง เขตหลักสี่ กรุงเทพมหานคร 10210
โทรศัพท์ (ที่ทำงาน) 02-5766000...ต่อ 6021-3. โทรศัพท์มือถือ 081-9183455

อาจารย์ที่ปรึกษา ศ.ดร. ประนอม โอทกานนท์
ที่อยู่ เลขที่ 40 ซ.น้อมจิตต์ แขวงบางซื่อ เขต บางซื่อ กรุงเทพมหานคร 10800

อาจารย์ที่ปรึกษาร่วม Associated Prof. WenchiiTzeng

ตำแหน่ง นักศึกษา ปริญญาเอก คณะพยาบาลศาสตร์ มหาวิทยาลัยธรรมศาสตร์

สถานที่ติดต่อผู้วิจัย
เลขที่ 99 คณะพยาบาลศาสตร์ มหาวิทยาลัยธรรมศาสตร์ คลองหนึ่ง อำเภอ คลองหลวง
จ. ปทุมธานี 12121E-mail: sirikorn063@nurse.tu.ac.th

ข้อมูลสำหรับอาสาสมัคร

ท่านได้รับเชิญเข้าร่วมในการวิจัยครั้งนี้เนื่องจากท่านเป็นผู้ป่วยที่ได้รับการรักษาด้วยการฉายรังสี มีอายุตั้งแต่ 18 ปีขึ้นไป สามารถสื่อสารภาษาไทยได้ มีความยินดี และเต็มใจเข้าร่วมงานวิจัย ก่อนที่ท่านจะตัดสินใจเข้าร่วมในการวิจัย มีความจำเป็นที่ท่านควรทำความเข้าใจว่างานวิจัยนี้ทำเพราะเหตุใด และเกี่ยวข้องกับอะไร กรุณาใช้เวลาในการอ่านข้อมูลต่อไปนี้อย่างละเอียดรอบคอบ และสอบถามข้อมูลเพิ่มเติมหรือข้อมูลที่ไม่ชัดเจนได้ตลอดเวลา

วัตถุประสงค์ของโครงการวิจัย งานวิจัยนี้มีวัตถุประสงค์

1. เพื่อศึกษาประสบการณ์และความต้องการของผู้ป่วยมะเร็งศีรษะและลำคอและญาติผู้ดูแลที่มารับการรักษาด้วยการฉายรังสี ตลอดจนบุคลากรทางรังสีรักษา
2. เพื่อนำข้อมูลดังกล่าวไปพัฒนารูปแบบการมุ่งบุคคลเป็นศูนย์กลางสำหรับผู้ป่วยมะเร็งศีรษะลำคอได้รับการฉายรังสีตามแผนการรักษาและสามารถจัดการอาการที่เกิดขึ้นระหว่างการรักษารวมทั้งเพิ่มความพึงพอใจทั้งของผู้ป่วย/ญาติและผู้ให้บริการ

ประโยชน์ที่คาดว่าจะได้รับ

การมุ่งบุคคลเป็นศูนย์กลางในการรักษาพยาบาลนั้น สามารถส่งเสริมประสบการณ์ที่ดี และ สร้างความพึงพอใจให้กับผู้ป่วย/ญาติผู้ป่วยและผู้ให้บริการได้ ตลอดระยะเวลาที่มารับการรักษาด้วยรังสีรักษา โดยความมีส่วนร่วมกับญาติ/บุคลากรพยาบาล และสห

สาขาวิชาชีพที่เกี่ยวข้อง จะสามารถสร้างความมั่นใจให้การรักษาประสบผลสำเร็จตามแผนที่แพทย์รังสีรักษาได้วางแผนไว้ การศึกษาประสบการณ์จากทุกฝ่ายที่เกี่ยวข้อง นำข้อมูลจากประสบการณ์มาสร้างรูปแบบการบริการที่สอดคล้องและสะท้อนความเป็นจริงตามความต้องการของทุกฝ่ายที่เกี่ยวข้องเป็นสิ่งจำเป็นที่จะทำให้การดูแลรักษาผู้ป่วยด้านรังสีรักษา ประสบความสำเร็จ มีผลลัพธ์ทางคลินิกที่ดีตามเป้าหมายและช่วยทำให้ผู้ป่วย/ญาติและผู้ให้บริการทุกฝ่าย มีความภาคภูมิใจในงานที่ให้บริการอย่างยั่งยืน

บทบาทของท่านในการเข้าร่วมการวิจัย

ในการวิจัยครั้งนี้ มีผู้เข้าร่วมงานวิจัย ได้แก่ ผู้ป่วยมะเร็งศีรษะและลำคอที่ได้รับการฉายรังสี จำนวน 20 คน ญาติผู้ป่วยจำนวน 20 คน บุคลากรพยาบาล และสหสาขาวิชาชีพที่เกี่ยวข้อง จำนวน 15 คน ท่านจะมีบทบาทตามขั้นตอนการวิจัย 2 ระยะ ดังต่อไปนี้คือ

ระยะที่ 1

- ท่านจะถูกสัมภาษณ์เกี่ยวกับ ความรู้สึก ประสบการณ์ของท่านที่ได้รับการรักษาด้วยการฉายรังสี อาการและการจัดการอาการของท่านกับอาการที่เกิดขึ้น ความต้องการการสนับสนุนให้ท่านสามารถดูแลตนเองให้ได้รับการรักษาจนครบตามแผนการรักษา โดยผู้วิจัยจะขออนุญาตจากแพทย์เจ้าของไข้ของท่านก่อนเชิญท่านเข้าร่วมโครงการเพื่อขอความยินยอมต่อไป โดยท่านจะถูกบันทึกเสียงระหว่างการให้สัมภาษณ์ ใช้เวลาไม่เกิน 60 นาที กรณีที่ท่านมีอาการไม่สบายหรือต้องการหยุดการสัมภาษณ์ ท่านสามารถทำได้ทุกเมื่อ และหากท่านมีภาวะเครียด จะมีบุคลากรทางรังสีรักษา ประเมินอาการและส่งต่อแพทย์เจ้าของไข้ทันที

ระยะที่ 2

จากระยะที่ 1 ข้อมูลของทุกฝ่ายที่ถูกสัมภาษณ์จะถูกนำมาสร้างเป็นรูปแบบ (ฉบับร่าง)และทดลองใช้ รูปแบบการมุ่งบุคคลเป็นศูนย์กลางสำหรับให้ท่านได้รับการฉายรังสีตามแผนการรักษาและท่านสามารถจัดการอาการของท่านที่เกิดขึ้นระหว่างการรักษาได้ด้วย

ในระหว่างการทดลองใช้รูปแบบฯ ท่านจะได้รับการรักษาและดูแลจากทีมรังสีรักษา ดังนี้

1) พยาบาลรังสีรักษาจะสอบถามท่านเกี่ยวกับความต้องการต่างๆ ที่เกี่ยวข้องในการดูฉลตนเองขณะท่านได้รับการรักษาด้วยรังสีรักษา รวมทั้ง คำแนะนำการดูแลตนเองและการป้องกันการเกิดอาการข้างเคียงที่สามารถป้องกันได้ สิทธิ์การรักษา การเดินทาง วัน เวลา นัดหมาย และการเตรียมตัวเพื่อมารับการจำลองการรักษา และกระบวนการฉายรังสี
ระหว่างการทดลอง หากท่านเกิดการบาดเจ็บหรือเจ็บป่วย หรือ เกิดผลข้างเคียงอันไม่พึงประสงค์ที่เป็นผลมาจากการรักษาด้วยรังสีรักษาหรือร่วมกับยาเคมีบำบัด ท่านสามารถแจ้งพยาบาลรังสีรักษาหรือนักวิจัยได้โดยตรง เพื่อพบแพทย์เจ้าของไข้ร่วมประเมินอาการและจัดการอาการต่อไป

2) พยาบาลสุขศึกษาประจำหน่วยงานจะมาเฝ้าติดตามสุขภาพของท่านและสอบถามอาการข้างเคียง ความพึงพอใจ ตลอดระยะเวลาการรักษาด้วยรังสีรักษา ทั้งก่อนเริ่มรักษาและเมื่อสิ้นสุดการรักษา

3) แพทย์เจ้าของไข้ จะมาติดตามอาการระหว่างการรักษาด้วยรังสี สัปดาห์ละ 1 ครั้ง

4) เมื่อสิ้นสุดการรักษาแต่ละรอบ (ประมาณ 30-35 วันของการฉายรังสี) ท่านจะได้รับเชิญเข้าประชุมกลุ่ม หรือ โดยการสัมภาษณ์ เพื่อแสดงความคิดเห็นให้ข้อเสนอแนะในการพัฒนา ปรับปรุง รูปแบบการมุ่งบุคคลเป็นศูนย์กลาง การประชุมกลุ่ม ใช้เวลาประมาณ 45-60 นาที

อนึ่ง การดำเนินการในข้อ 1) ถึงข้อ 4) อาจดำเนินการมากกว่า 1 ครั้ง ทั้งนี้ ขึ้นอยู่กับ ความเห็นและข้อเสนอแนะที่ท่านจะเสนอให้มีการปรับปรุงรูปแบบฯ หากมีการปรับปรุงรูปแบบก็จะมีการทดลองใช้อีกครั้ง ประมาณการว่าจะมีการทดลองใช้ไม่เกิน 4 ครั้ง เมื่อสิ้นสุดทดลองใช้รูปแบบฯ ท่านจะได้รับแบบสอบถามเกี่ยวกับความพึงพอใจที่ท่านได้รับการดูแลและการมีส่วนร่วมในการดูแลรักษาด้วยรังสีรักษา ใช้เวลาในการตอบแบบสอบถาม ประมาณ 10 นาที และจะได้รับการแนะนำเรื่องการดูแลตนเองหลังจากการรักษาด้วยรังสีครบถ้วน รวมทั้งวันนัดหมายและการเตรียมตัวเพื่อพบแพทย์ในครั้งต่อไป

เมื่อเสร็จสิ้นการวิจัยแล้ว ข้อมูลทั้งหมดที่เกี่ยวข้องกับอาสาสมัครวิจัยจะถูกทำลาย ทั้ง ไฟล์เครื่องบันทึกเสียง บันทึกที่เกี่ยวข้องในการสังเกตุพฤติกรรม บันทึกการถอดเทป ข้อมูลที่เกี่ยวข้องกับท่านจะเก็บเป็นความลับ หากมีการเสนอผลการวิจัยจะเสนอเป็นภาพรวม ข้อมูลใดที่ระบุถึงตัวท่านจะไม่ปรากฏในรายงาน และหากมีข้อมูลใหม่ที่เกี่ยวข้องกับโครงการวิจัย ผู้วิจัยจะแจ้งให้ท่านรับทราบต่อไป

หากท่านมีข้อสงสัยต้องการสอบถามเกี่ยวกับการวิจัย หรือมีอาการบาดเจ็บ หรือเจ็บป่วยจากการวิจัย ท่านสามารถติดต่อกับผู้วิจัยได้ที่ นางสาวศิริกร ก้องวัฒนะกุล หน่วยรังสีมะเร็งวิทยา โรงพยาบาลศูนย์การแพทย์มะเร็งวิทยาจุฬาภรณ์ เบอร์ 02-5766021-3, 081-9183455

ท่านมีสิทธิ์ถอนตัวออกจากโครงการวิจัยเมื่อใดก็ได้ โดยไม่ต้องแจ้งให้ทราบล่วงหน้าและการไม่เข้าร่วมการวิจัยหรือถอนตัวออกจากโครงการวิจัยนี้จะไม่มีผลกระทบต่อการบริการและการรักษาที่สมควรจะได้รับแต่ประการใด

“หากท่านไม่ได้รับการปฏิบัติตามข้อมูลดังกล่าวสามารถร้องเรียนได้ที่ : คณะอนุกรรมการจริยธรรมการวิจัยในคน มหาวิทยาลัยธรรมศาสตร์ ชุดที่ 3 ห้อง 110 ชั้น 1 อาคารปิยชาติ มหาวิทยาลัยธรรมศาสตร์ ศูนย์รังสิต โทรศัพท์ 02-986-9213 ต่อ 7358

Appendix F

เอกสารให้ข้อมูลสำหรับอาสาสมัครญาติผู้ป่วย

(Participant Information Sheet)

โครงการวิจัยที่ ....

ชื่อเรื่อง (ไทย) “การพัฒนารูปแบบการมุ่งบุคคลเป็นศูนย์กลางสำหรับผู้ป่วยมะเร็งศีรษะและลำคอที่ได้รับรังสีรักษา: การวิจัยแบบมีส่วนร่วม”

ชื่อเรื่อง (อังกฤษ) “A development of the person- centered model for patients with head and neck cancer receiving radiation therapy: participatory action research”

ชื่อผู้วิจัยนางสาว ศิริกร ก้องวัฒนะกุล

ที่อยู่ เลขที่ 222/454 ถ. งามวงศ์วาน แขวงทุ่งสองห้อง เขตหลักสี่ กรุงเทพมหานคร 10210

โทรศัพท์ (ที่ทำงาน) 02-5766000...ต่อ 6021-3. โทรศัพท์มือถือ 081-9183455

อาจารย์ที่ปรึกษา ศ.ดร. ประนอม โอทกานนท์

ที่อยู่ เลขที่ 40 ซ.น้อมจิตต์ แขวงบางซื่อ เขต บางซื่อ กรุงเทพมหานคร 10800

อาจารย์ที่ปรึกษาร่วม Associated Prof. WenchiiTzeng

ตำแหน่ง นักศึกษา ปริญญาเอก คณะพยาบาลศาสตร์ มหาวิทยาลัยธรรมศาสตร์

สถานที่ติดต่อผู้วิจัย

เลขที่ 99 คณะพยาบาลศาสตร์ มหาวิทยาลัยธรรมศาสตร์ คลองหนึ่ง อำเภอ คลองหลวง

จ. ปทุมธานี 12121E-mail: sirikorn063@nurse.tu.ac.th

ข้อมูลสำหรับอาสาสมัคร

ท่านได้รับเชิญเข้าร่วมในการวิจัยครั้งนี้ เนื่องจากท่านเป็นญาติผู้ดูแลของผู้ป่วยมะเร็งศีรษะและลำคอที่ได้รับการรักษาด้วยการฉายรังสี มีอายุตั้งแต่ 18 ปีขึ้นไป สามารถสื่อสารภาษาไทยได้ มีความยินดี และเต็มใจเข้าร่วมงานวิจัย ก่อนที่ท่านจะตัดสินใจเข้าร่วมในการวิจัย มีความจำเป็นที่ท่านควรทำความเข้าใจว่างานวิจัยนี้ทำเพราะเหตุใด และเกี่ยวข้องกับอะไร กรุณาใช้เวลาในการอ่านข้อมูลต่อไปนี้อย่างละเอียดรอบคอบ และสอบถามข้อมูลเพิ่มเติมหรือข้อมูลที่ไม่ชัดเจนได้ตลอดเวลา

วัตถุประสงค์ของโครงการวิจัย งานวิจัยนี้มีวัตถุประสงค์

1. เพื่อศึกษาประสบการณ์และความต้องการของผู้ป่วยมะเร็งศีรษะและลำคอและญาติผู้ดูแลที่มารับการรักษาด้วยการฉายรังสีตลอดจนบุคลากรทางรังสีรักษา
2. เพื่อนำข้อมูลดังกล่าวไปพัฒนารูปแบบการมุ่งบุคคลเป็นศูนย์กลางสำหรับผู้ป่วยมะเร็งศีรษะลำคอได้รับการฉายรังสีตามแผนการรักษาและสามารถจัดการอาการที่เกิดขึ้นระหว่างการรักษารวมทั้งเพิ่มความพึงพอใจทั้งของผู้ป่วย/ญาติและผู้ให้บริการ

ประโยชน์ที่คาดว่าจะได้รับ

การมุ่งบุคคลเป็นศูนย์กลางในการรักษาพยาบาลนั้น สามารถส่งเสริมประสบการณ์ที่ดี และ สร้างความพึงพอใจให้กับผู้ป่วย/ญาติผู้ป่วยและผู้ให้บริการได้ ตลอดระยะเวลาที่มารับการรักษาด้วยรังสีรักษา โดยความมีส่วนร่วมกับญาติ/บุคลากรพยาบาล และสหสาขาวิชาชีพที่เกี่ยวข้อง จะสามารถสร้างความมั่นใจให้การรักษาประสบผลสำเร็จตามแผนที่แพทย์รังสีรักษาได้วางแผนไว้ การศึกษา

ประสบการณ์จากทุกฝ่ายที่เกี่ยวข้อง นำข้อมูลจากประสบการณ์มาสร้างรูปแบบการบริการที่สอดคล้องและสะท้อนความเป็นจริงตามความต้องการของทุกฝ่ายที่เกี่ยวข้องเป็นสิ่งจำเป็นที่จะทำให้การดูแลรักษาผู้ป่วยด้านรังสีรักษา ประสบความสำเร็จ มีผลลัพธ์ทางคลินิกที่ดีตามเป้าหมายและช่วยทำให้ผู้ป่วย/ญาติและผู้ให้บริการทุกฝ่าย มีความภาคภูมิใจในงานที่ให้บริการอย่างยั่งยืน

บทบาทของท่านในการเข้าร่วมการวิจัย

ในการวิจัยครั้งนี้ มีผู้เข้าร่วมงานวิจัย ได้แก่ ผู้ป่วยมะเร็งศีรษะและลำคอที่ได้รับการฉายรังสี จำนวน 20 คน ญาติผู้ป่วยจำนวน 20 คน บุคลากรพยาบาล และสหสาขาวิชาชีพที่เกี่ยวข้อง จำนวน 15 คน ท่านจะมีบทบาทตามขั้นตอนการวิจัย 2 ระยะ ดังต่อไปนี้คือ

ระยะที่ 1

- ท่านจะถูกสัมภาษณ์เกี่ยวกับ ความรู้สึก ประสบการณ์ของท่านที่บุคคลในครอบครัวของท่านได้รับการรักษาด้วยการฉายรังสี อาการและการจัดการอาการของท่านที่ให้การดูแลผู้ป่วยกับอาการที่เกิดขึ้น ความต้องการการสนับสนุนให้ท่านสามารถดูแลผู้ป่วยให้ได้รับการรักษาจนครบตามแผนการรักษา โดยผู้วิจัยจะขออนุญาตจากแพทย์เจ้าของไข้ของผู้ป่วยก่อนเชิญท่านและผู้ป่วยเข้าร่วมโครงการเพื่อขอความยินยอมต่อไป โดยท่านจะถูกบันทึกเสียงระหว่างการให้สัมภาษณ์ ใช้เวลาไม่เกิน 60 นาที กรณีที่ท่านมีอาการไม่สบายหรือต้องการหยุดการสัมภาษณ์ ท่านสามารถทำได้ทุกเมื่อ และหากท่านมีภาวะเครียด จะมีบุคลากรทางรังสีรักษา ประเมินอาการและส่งต่อแพทย์เจ้าของไข้ทันที

ระยะที่ 2

จากระยะที่ 1 ข้อมูลของทุกฝ่ายที่ถูกสัมภาษณ์จะถูกนำมาสร้างเป็นรูปแบบ (ฉบับร่าง)และทดลองใช้ รูปแบบการมุ่งบุคคลเป็นศูนย์กลางสำหรับให้ผู้ป่วยได้รับการฉายรังสีตามแผนการรักษาและท่านสามารถจัดการอาการของผู้ป่วยที่เกิดขึ้นระหว่างการรักษาได้ด้วย

ในระหว่างการทดลองใช้รูปแบบฯ ท่านจะได้รับการรักษาและดูแลจากทีมรังสีรักษา ดังนี้

1) พยาบาลรังสีรักษาจะสอบถามท่านเกี่ยวกับความต้องการต่างๆ ที่เกี่ยวข้องในการดูแลผู้ป่วยขณะได้รับการรักษาด้วยรังสีรักษา รวมทั้ง คำแนะนำการดูแลตนเองให้กับผู้ป่วยและการป้องกันการเกิดอาการข้างเคียงที่สามารถป้องกันได้ สิทธิ์การรักษา การเดินทาง วัน เวลานัดหมาย และการเตรียมตัวเพื่อมารับการจำลองการรักษา และกระบวนการฉายรังสี
   ระหว่างการทดลอง หากท่านเกิดการบาดเจ็บหรือเจ็บป่วย ท่านสามารถแจ้งพยาบาลรังสีรักษาหรือนักวิจัยได้โดยตรง เพื่อพบแพทย์เจ้าของไข้ร่วมประเมินอาการและจัดการอาการต่อไป
2) พยาบาลสุขศึกษาประจำหน่วยงานจะมาเฝ้าติดตามสุขภาพของผู้ป่วย และความต้องการการสนับสนุนด้านต่างๆ เพื่อการดูแลผู้ป่วยจากท่านและความพึงพอใจ ตลอดระยะเวลาการรักษาด้วยรังสีรักษา ทั้งก่อนเริ่มรักษาและเมื่อสิ้นสุดการรักษา
3) แพทย์เจ้าของไข้ จะมาติดตามอาการระหว่างการรักษาด้วยรังสีของผู้ป่วย สัปดาห์ละ 1 ครั้ง ซึ่งท่านจะได้ร่วมพบแพทย์เพื่อให้ข้อมูลเกี่ยวกับอาการข้างเคียงต่างๆ
4) เมื่อสิ้นสุดการรักษาผู้ป่วยแต่ละรอบ (ประมาณ 30-35 วันของการฉายรังสี) ท่านจะได้รับเชิญเข้าประชุมกลุ่ม หรือ โดยการสัมภาษณ์เพื่อแสดงความคิดเห็นให้ข้อเสนอแนะในการพัฒนา ปรับปรุง รูปแบบการมุ่งบุคคลเป็นศูนย์กลาง การประชุมกลุ่ม ใช้เวลาประมาณ 45-60 นาที

อนึ่ง การดำเนินการในข้อ 1) ถึงข้อ 4) อาจดำเนินการมากกว่า 1 ครั้ง ทั้งนี้ ขึ้นอยู่กับ ความเห็นและข้อเสนอแนะที่ท่านจะเสนอให้มีการปรับปรุงรูปแบบฯ หากมีการปรับปรุงรูปแบบก็จะมีการทดลองใช้อีกครั้ง ประมาณการว่าจะมีการทดลองใช้ไม่เกิน 4 ครั้ง เมื่อสิ้นสุดทดลองใช้รูปแบบฯ ท่านจะได้รับแบบสอบถามเกี่ยวกับความพึงพอใจที่ท่านได้รับการดูแลและการมีส่วนร่วมในการดูแลรักษาด้วยรังสีรักษา ใช้เวลาในการตอบแบบสอบถาม ประมาณ 10 นาที และจะได้รับการแนะนำเรื่องการดูแลตนเองสำหรับผู้ป่วยและญาติหลังจากการรักษาด้วยรังสีครบถ้วน รวมทั้งวันนัดหมายและการเตรียมตัวเพื่อพบแพทย์ในครั้งต่อไป

เมื่อเสร็จสิ้นการวิจัยแล้ว ข้อมูลทั้งหมดที่เกี่ยวข้องกับอาสาสมัครวิจัยจะถูกทำลาย ทั้ง ไฟล์เครื่องบันทึกเสียง บันทึกที่เกี่ยวข้องในการสังเกตุพฤติกรรม บันทึกการถอดเทป ข้อมูลที่เกี่ยวข้องกับท่านจะเก็บเป็นความลับ หากมีการเสนอผลการวิจัยจะเสนอเป็นภาพรวม ข้อมูลใดที่ระบุถึงตัวท่านจะไม่ปรากฏในรายงาน และหากมีข้อมูลใหม่ที่เกี่ยวข้องกับโครงการวิจัย ผู้วิจัยจะแจ้งให้ท่านรับทราบต่อไป

หากท่านมีข้อสงสัยต้องการสอบถามเกี่ยวกับการวิจัย หรือมีอาการบาดเจ็บ หรือเจ็บป่วยจากการวิจัย สามารถติดต่อกับผู้วิจัยได้ที่ นางสาวศิริกร ก้องวัฒนะกุล หน่วยรังสีมะเร็งวิทยา โรงพยาบาลศูนย์การแพทย์มะเร็งวิทยาจุฬาภรณ์ เบอร์ 02-5766021-3, 081-9183455

ท่านมีสิทธิ์ถอนตัวออกจากโครงการวิจัยเมื่อใดก็ได้ โดยไม่ต้องแจ้งให้ทราบล่วงหน้า และการไม่เข้าร่วมการวิจัยหรือถอนตัวออกจากโครงการวิจัยนี้จะไม่มีผลกระทบต่อการบริการและการรักษาที่สมควรจะได้รับแต่ประการใด

“หากท่านไม่ได้รับการปฏิบัติตามข้อมูลดังกล่าวสามารถร้องเรียนได้ที่ : คณะอนุกรรมการจริยธรรมการวิจัยในคน มหาวิทยาลัยธรรมศาสตร์ ชุดที่ 3ห้อง 110 ชั้น 1 อาคารปิยชาติ มหาวิทยาลัยธรรมศาสตร์ ศูนย์รังสิต โทรศัพท์ 02-986-9213 ต่อ 7358

Appendix G

เอกสารให้ข้อมูลสำหรับอาสาสมัครบุคลากรรังสีรักษา

(Participant Information Sheet)

โครงการวิจัยที่ ....

ชื่อเรื่อง (ไทย) “การพัฒนารูปแบบการมุ่งบุคคลเป็นศูนย์กลางสำหรับผู้ป่วยมะเร็งศีรษะและลำคอที่ได้รับรังสีรักษา: การวิจัยแบบมีส่วนร่วม”

ชื่อเรื่อง (อังกฤษ) “A development of the person- centeredmodel for patients with head and neck cancer receiving radiation therapy: participatory action research”

ชื่อผู้วิจัยนางสาว ศิริกร ก้องวัฒนะกุล

ที่อยู่ เลขที่ 222/454 ถ. งามวงศ์วาน แขวงทุ่งสองห้อง เขตหลักสี่ กรุงเทพมหานคร 10210

โทรศัพท์ (ที่ทำงาน) 02-5766000...ต่อ 6021-3. โทรศัพท์มือถือ 081-9183455

อาจารย์ที่ปรึกษา ศ.ดร. ประนอม โอทกานนท์

ที่อยู่ เลขที่ 40 ซ.น้อมจิตต์ แขวงบางซื่อ เขต บางซื่อ กรุงเทพมหานคร 10800

อาจารย์ที่ปรึกษาร่วม Associated Prof. WenchiiTzeng

ตำแหน่ง นักศึกษา ปริญญาเอก คณะพยาบาลศาสตร์ มหาวิทยาลัยธรรมศาสตร์

สถานที่ติดต่อผู้วิจัย

เลขที่ 99 คณะพยาบาลศาสตร์ มหาวิทยาลัยธรรมศาสตร์ คลองหนึ่ง อำเภอ คลองหลวง

จ. ปทุมธานี 12121E-mail: sirikorn063@nurse.tu.ac.th

ข้อมูลสำหรับอาสาสมัคร

ท่านได้รับเชิญเข้าร่วมในการวิจัยครั้งนี้เนื่องจากท่านมีส่วนเกี่ยวข้องในการให้การดูแลผู้ป่วยมะเร็งศีรษะและลำคอที่ได้รับการรักษาด้วยรังสีรักษา สามารถสื่อสารภาษาไทยได้ มีความยินดี และเต็มใจเข้าร่วมงานวิจัย ก่อนที่ท่านจะตัดสินใจเข้าร่วมในการวิจัย มีความจำเป็นที่ท่านควรทำความเข้าใจว่างานวิจัยนี้ทำเพราะเหตุใด และเกี่ยวข้องกับอะไร กรุณาใช้เวลาในการอ่านข้อมูลต่อไปนี้อย่างละเอียดรอบคอบ และสอบถามข้อมูลเพิ่มเติมหรือข้อมูลที่ไม่ชัดเจนได้ตลอดเวลา

วัตถุประสงค์ของโครงการวิจัย งานวิจัยนี้มีวัตถุประสงค์

1. เพื่อศึกษาประสบการณ์และความต้องการของผู้ป่วยมะเร็งศีรษะและลำคอและญาติผู้ดูแลที่มารับการรักษาด้วยการฉายรังสีตลอดจนบุคลากรทางรังสีรักษา
2. เพื่อนำข้อมูลดังกล่าวไปพัฒนารูปแบบการมุ่งบุคคลเป็นศูนย์กลางสำหรับผู้ป่วยมะเร็งศีรษะลำคอได้รับการฉายรังสีตามแผนการรักษาและสามารถจัดการอาการที่เกิดขึ้นระหว่างการรักษารวมทั้งเพิ่มความพึงพอใจทั้งของผู้ป่วย/ญาติและผู้ให้บริการ

ประโยชน์ที่คาดว่าจะได้รับ

การมุ่งบุคคลเป็นศูนย์กลางในการรักษาพยาบาลนั้น สามารถส่งเสริมประสบการณ์ที่ดี และ สร้างความพึงพอใจให้กับผู้ป่วย/ญาติผู้ป่วยและผู้ให้บริการได้ ตลอดระยะเวลาที่มารับการรักษาด้วยรังสีรักษา โดยความมีส่วนร่วมกับญาติ/บุคลากรพยาบาล และสหสาขาวิชาชีพที่เกี่ยวข้อง จะสามารถสร้างความมั่นใจให้การรักษาประสบผลสำเร็จตามแผนที่แพทย์รังสีรักษาได้วางแผนไว้ การศึกษาประสบการณ์จากทุกฝ่ายที่เกี่ยวข้อง นำข้อมูลจากประสบการณ์มาสร้างรูปแบบการบริการที่สอดคล้องและสะท้อนความเป็นจริงตามความต้องการของทุกฝ่ายที่เกี่ยวข้องเป็นสิ่งจำเป็นที่จะทำให้การดูแลรักษาผู้ป่วยด้านรังสีรักษา ประสบความสำเร็จ มีผลลัพธ์ทางคลินิกที่ดีตามเป้าหมายและช่วยทำให้ผู้ป่วย/ญาติและผู้ให้บริการทุกฝ่าย มีความภาคภูมิใจในงานที่ให้บริการอย่างยั่งยืน

บทบาทของท่านในการเข้าร่วมการวิจัย

ในการวิจัยครั้งนี้ มีผู้เข้าร่วมงานวิจัย ได้แก่ ผู้ป่วยมะเร็งศีรษะและลำคอที่ได้รับการฉายรังสี จำนวน 20 คน ญาติผู้ป่วยจำนวน 20 คน บุคลากรพยาบาล และสหสาขาวิชาชีพที่เกี่ยวข้อง จำนวน 15 คน ท่านจะมีบทบาทตามขั้นตอนการวิจัย 2 ระยะ ดังต่อไปนี้คือ

ระยะที่ 1

- ท่านจะถูกสัมภาษณ์เกี่ยวกับ ความคิดเห็นและประสบการณ์ของท่านที่ได้ให้การดูแลรักษาผู้ป่วยมะเร็งศีรษะและลำคอที่รับการรักษาด้วยการฉายรังสี อาการของผู้ป่วยที่เกิดขึ้นและการจัดการอาการที่ท่านได้แนะนำกับผู้ป่วยและญาติในการดูแลตนเอง ความต้องการการสนับสนุนให้ท่านสามารถดูแลผู้ป่วยให้รับการรักษาครบตามแผนการรักษา โดยท่านจะถูกบันทึกเสียงระหว่างการให้สัมภาษณ์ ใช้เวลาไม่เกิน 45 นาที กรณีที่ท่านมีอาการไม่สบายหรือต้องการหยุดการสัมภาษณ์ ท่านสามารถทำได้ทุกเมื่อ และหากท่านมีภาวะเครียด จะมีบุคลากรทางรังสีรักษา ประเมินอาการและส่งต่อแพทย์เพื่อให้การดูแลรักษาต่อไปทันที

ระยะที่ 2

จากระยะที่ 1 ข้อมูลของทุกฝ่ายที่ถูกสัมภาษณ์จะถูกนำมาสร้างเป็นรูปแบบ (ฉบับร่าง)และทดลองใช้ รูปแบบการมุ่งบุคคลเป็นศูนย์กลางสำหรับให้ท่านสามารถดูแลรักษาผู้ป่วยมะเร็งที่มารับการฉายรังสีตามแผนการรักษา และท่านสามารถแนะนำการจัดการอาการที่เกิดขึ้นระหว่างการรักษาให้กับผู้ป่วยและญาติได้ด้วย

ในระหว่างการทดลองใช้รูปแบบฯ ท่านจะได้ร่วมพัฒนาการให้การดูแลรักษาผู้ป่วยมะเร็งศีรษะและลำคอที่มารับการฉายรังสี ดังนี้

1) ท่านสามารถให้การดูแล รักษาผู้ป่วยมะเร็งศีระษะและลำคอตามมาตรฐานวิชาชีพ
2) ท่านจะได้รับการเชิญเข้าร่วมประชุมกลุ่ม เพื่อร่วมวิเคราะห์แนวปฏิบัติ/รูปแบบการดำเนินงานที่สามารถพัฒนาระบบบริการที่มุ่งบุคคลเป็นศูนย์กลาง
3) ท่านจะได้ร่วมแสดงความคิดเห็นเกี่ยวกับ เป้าหมาย แนวปฏิบัติและผลลัพธ์ของการพัฒนารูปแบบฯ เพื่อการนำไปใช้จริงกับผู้ป่วยมะเร็งศีรษะและลำคอที่ได้รับการฉายรังสี
4) ท่านจะได้รับการสอบถามความคิดเห็นหลังจากที่รูปแบบฯ ที่ร่วมพัฒนาขึ้น ไปปฏิบัติในรูปแบบของการประชุมกลุ่ม

อนึ่ง การดำเนินการในข้อ 1) ถึงข้อ 4) อาจดำเนินการมากกว่า 1 ครั้ง ทั้งนี้ ขึ้นอยู่กับ ความเห็นและข้อเสนอแนะที่ท่านจะเสนอให้มีการปรับปรุงรูปแบบฯ หากมีการปรับปรุงรูปแบบก็จะมีการทดลองใช้อีกครั้ง ประมาณการว่าจะมีการทดลองใช้ไม่เกิน 4 ครั้ง เมื่อเสร็จสิ้นการวิจัยแล้ว ข้อมูลทั้งหมดที่เกี่ยวข้องกับอาสาสมัครวิจัยจะถูกทำลาย ทั้ง ไฟล์เครื่องบันทึกเสียง บันทึกที่เกี่ยวข้องในการสังเกตุพฤติกรรม บันทึกการถอดเทป ข้อมูลที่เกี่ยวข้องกับท่านจะเก็บเป็นความลับ หากมีการเสนอผลการวิจัยจะเสนอเป็นภาพรวม ข้อมูลใดที่ระบุถึงตัวท่านจะไม่ปรากฏในรายงาน และหากมีข้อมูลใหม่ที่เกี่ยวข้องกับโครงการวิจัย ผู้วิจัยจะแจ้งให้ท่านรับทราบต่อไป

หากมีข้อสงสัยต้องการสอบถามเกี่ยวกับการวิจัย หรือมีอาการบาดเจ็บ หรือเจ็บป่วยจากการวิจัย สามารถติดต่อกับผู้วิจัยได้ที่ นางสาวศิริกร ก้องวัฒนะกุล หน่วยรังสีมะเร็งวิทยา โรงพยาบาลศูนย์การแพทย์มะเร็งวิทยาจุฬาภรณ์ เบอร์ 02-5766021-3, 081-9183455

ผู้เข้าร่วมการวิจัยมีสิทธิ์ถอนตัวออกจากโครงการวิจัยเมื่อใดก็ได้ โดยไม่ต้องแจ้งให้ทราบล่วงหน้า และการไม่เข้าร่วมการวิจัยหรือถอนตัวออกจากโครงการวิจัยนี้จะไม่มีผลกระทบต่อการบริการและการรักษาที่สมควรจะได้รับแต่ประการใด

“หากท่านไม่ได้รับการปฏิบัติตามข้อมูลดังกล่าวสามารถร้องเรียนได้ที่ : คณะอนุกรรมการจริยธรรมการวิจัยในคน มหาวิทยาลัยธรรมศาสตร์ ชุดที่ 3ห้อง 110 ชั้น 1 อาคารปิยชาติ มหาวิทยาลัยธรรมศาสตร์ ศูนย์รังสิต โทรศัพท์ 02-986-9213 ต่อ 7358

Appendix H

หนังสือแสดงความยินยอมเข้าร่วมการวิจัยของอาสาสมัครวิจัย

Informed Consent Form

ทำที่...   วันที่...........เดือน................พ.ศ. ....

เลขที่ อาสาสมัครวิจัย............................

ข้าพเจ้า ซึ่งได้ลงนามท้ายหนังสือนี้ ขอแสดงความยินยอมเข้าร่วมโครงการวิจัย

ชื่อโครงการวิจัย “การพัฒนารูปแบบการมุ่งบุคคลเป็นศูนย์กลางสำหรับผู้ป่วยมะเร็งศีรษะและลำคอที่ได้รับรังสีรักษา: การวิจัยแบบมีส่วนร่วม”

ชื่อผู้วิจัย นางสาวศิริกร ก้องวัฒนะกุล

อาจารย์ที่ปรึกษา ศ.ดร. ประนอม โอทกานนท์

อาจารย์ที่ปรึกษาร่วม Associated Prof. WenchiiTzeng

ที่อยู่ที่ติดต่อผู้วิจัย เลขที่ 99 คณะพยาบาลศาสตร์ มหาวิทยาลัยธรรมศาสตร์ ตำบลคลองหนึ่ง อำเภอคลองหลวง จ. ปทุมธานี 12121 โทรศัพท์ 081-9183455 Email:sirikorn063@nurse.tu.ac.th

ข้าพเจ้า ได้รับทราบรายละเอียดเกี่ยวกับที่มาและวัตถุประสงค์ในการทำวิจัย รายละเอียดขั้นตอนต่างๆ ที่จะต้องปฏิบัติหรือได้รับการปฏิบัติ ความเสี่ยง/อันตราย และประโยชน์ซึ่งจะเกิดขึ้นจากการวิจัยเรื่องนี้ โดยได้อ่านรายละเอียดในเอกสารชี้แจงอาสาสมัครวิจัยโดยตลอด และได้รับคำอธิบายจากผู้วิจัยจนเข้าใจเป็นอย่างดีแล้ว

ข้าพเจ้าจึงสมัครใจเข้าร่วมในโครงการวิจัยนี้ ตามที่ระบุไว้ในเอกสารชี้แจงอาสาสมัครวิจัยโดยข้าพเจ้ายินยอมสละเวลา ให้สัมภาษณ์ ตอบข้อซักถามและบันทึกเสียง 1-2 ครั้งๆ ละประมาณ 30-60 นาทีและ เข้ารับการประชุมกลุ่ม จำนวนประมาณ4 ครั้ง ครั้งละประมาณ 45-60 นาที เมื่อเสร็จสิ้นการวิจัยแล้วข้อมูลที่เกี่ยวข้องกับอาสาสมัครวิจัย ไฟล์บันทึกเสียง บันทึกการถอดเทปจากการสัมภาษณ์และการประชุมกลุ่ม จะถูกทำลายภายในระยะเวลา 1 ปี

ข้าพเจ้ามีสิทธิถอนตัวออกจากการวิจัยเมื่อใดก็ได้ตามความประสงค์ โดยไม่ต้องแจ้งเหตุผลซึ่งการถอนตัวออกจากการวิจัยนั้น จะไม่มีผลกระทบในทางใดๆ ต่อข้าพเจ้าทั้งสิ้น

ข้าพเจ้าได้รับคำรับรองว่า ผู้วิจัยจะปฏิบัติต่อข้าพเจ้าตามข้อมูลที่ระบุไว้ในเอกสารชี้แจงอาสาสมัครวิจัยและข้อมูลใดๆ ที่เกี่ยวข้องกับข้าพเจ้า ผู้วิจัยจะเก็บรักษาเป็นความลับ โดยจะนำเสนอข้อมูลการวิจัยเป็นภาพรวมเท่านั้น ไม่มีข้อมูลใดในการรายงานที่จะนำไปสู่การระบุตัวข้าพเจ้าจากข้าพเจ้าไม่ได้รับการปฏิบัติตรงตามที่ได้ระบุไว้ในเอกสารชี้แจงอาสาสมัครวิจัย ข้าพเจ้าสามารถร้องเรียนได้ที่: คณะอนุกรรมการจริยธรรมการวิจัยในคน มหาวิทยาลัยธรรมศาสตร์ ชุดที่ 3 ห้อง 110 ชั้น 1 อาคารปิยชาติ
มหาวิทยาลัยธรรมศาสตร์ ศูนย์รังสิต โทรศัพท์ 02-986-9213 ต่อ 7358

ข้าพเจ้าได้ลงลายมือชื่อไว้เป็นสำคัญต่อหน้าพยาน ทั้งนี้ข้าพเจ้าได้รับสำเนาเอกสารข้อมูลสำหรับอาสาสมัครวิจัย และสำเนาหนังสือแสดงความยินยอมเข้าร่วมการวิจัยของอาสาสมัครวิจัยไว้แล้ว

ลงชื่อ...	ลงชื่อ...
(...)	(...)
ผู้วิจัยหลัก	อาสาสมัครวิจัย
วันที่.........../................/...........	วันที่.........../................/...........
ลงชื่อ...	ลงชื่อ...
(...)	(...)
พยาน	พยาน
วันที่.........../................/............	วันที่.........../................/............

Appendix I

แบบสอบถามที่ใช้ในการเก็บรวบรวมข้อมูลการจัดการอาการของผู้ป่วยมะเร็งศีรษะและลำคอที่ได้รับรังสีรักษาร่วมกับยาเคมีบำบัด
(Personalized self-management symptom cluster profile)

คำชี้แจง แบบสัมภาษณ์อาการ วิธีการจัดการอาการและผลลัพธ์ของการจัดการอาการในรอบ 1 สัปดาห์ที่ผ่านมา

วิธีการจัดการอาการที่ท่านคิดว่าส่งผลต่อชีวิตท่านมากที่สุด ท่านเลือกใช้วิธีอะไรบ้าง ท่านทำอย่างไร ผลลัพธ์การจัดการอาการเป็นอย่างไร

อาการ / วิธีการ	วิธีปฏิบัติ	เวลาที่ปฏิบัติ/ ความถี่	ผลลัพธ์ของการจัดการอาการ		
			หาย	ทุเลา	คงเดิม/ ไม่ดีขึ้น
(ตัวอย่างอาการที่รุนแรงที่สุด) 1. อาการปวด/เจ็บในช่องปาก 2. อาการคลื่นไส้(และหรืออาเจียน) 3. อาการทุกข์ใจ หรือ ผิดหวัง 4. อาการรับรสเปลี่ยนแปลง 5. อาการน้ำลายเหนียว/น้ำลายแห้ง 6. อาการ ไม่อยากอาหาร/ เบื่ออาหาร					

Appendix J

Concurrent chemo-radiotherapy treatment adherence checklist

Radiation treatment				**Chemotherapy treatment**		
Radiation therapy (Fraction)	Radiation Dose (cGy) (Total dose……….)	As planned		Chemotherapy (Cisplatin 100 mg/ m2) (Dose……………)	As planned	
		Yes	No (Remark)		Yes	No (Remark)
Day 1				Cycle 1 :Day 1		
Day 2				Day 2		
Day 3				Day 3		
Day 4						
Day 5						
Day 6						
Day 7						
Day 8						
Day 9						
Day 10						
Day 11						
Day 12						
Day 13						
Day 14						
Day 15				Cycle 2: Day 1		
Day 16				Day 2		
Day 17				Day 3		
Day 18						
Day….						
Day 32				Cycle 3: Day 1		
Day 33				Day 2		
Day 34				Day 3		
Day 35						

BIOGRAPHY

Name	Miss Sirikorn Kongwattanakul
Date of Birth	April 24, 1980
Educational Attainment	Academic Year 2001: Bachelor degree in Nursing Science, Faculty of Nursing, Mahidol University, Bangkok, Thailand Academic Year 2013: Master degree in Nursing Administration, Saint Louis College, Bangkok, Thailand
Work Position	Head Nurse Department of Radiation Oncology, Chulabhorn Hospital, Thailand
Scholarship	2015- International Scholars Program : Nursing Leadership in Cancer Care at The City of Hope National Medical Center, Duarte, California , USA , 12 January- 2 July

Publications

Thanthong, S., Nanthong, R., Kongwattanakul, S., Laebua, K., Trirussapanich, P., Pitiporn, S., &Nantajit, D. (2020). Prophylaxis of Radiation-Induced Dermatitis in Patients With Breast Cancer Using Herbal Creams: A Prospective Randomized Controlled Trial. *Integrative cancer therapies*, *19*, 1534735420920714.

Kongwattanakul., S., Othaganont., P. (2019). Symptom cluster management of mucositis, xerostomia, dysgausia, and dysphagia in patients with head and neck cancer receiving concurrent chemoradiation therapy. *Ann Clin Cancer Ther*, *1*(1), 1-6.

Rojthamarat, S., Somprasert, C., &Kongvattananon, P. (2018). Symptom Experiences and Management of Patients with Head and Neck Cancer Receiving

Radiation Therapy: Integrated Review. *The Bangkok Medical Journal*, *14*(2), 108-108.

Thanthong, S., Rojthamarat, S., Worasawate, W., Vichitvejpaisal, P., Nantajit, D., &Ieumwananontachai, N. (2017). Comparison of efficacy of meperidine and fentanyl in terms of pain management and quality of life in patients with cervical cancer receiving intracavitary brachytherapy: a double-blind, randomized controlled trial. *Supportive Care in Cancer*, *25*(8), 2531-2537.

Work Experiences	2008-Present: Head Nurse at Radiation Oncology Department, Chulabhorn Hospital
	2002 - 2008: Registered Nurse at Radiological Nursing Division, Nursing Department, Faculty of Medicine, Siriraj Hospital, Mahidol University