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頭頸癌病人資訊搜尋行為與資訊需求之探討

Investigation on Information Seeking Behavior and Information Needs of Head and Neck Cancer Patients

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（中文）頭頸癌病人資訊搜尋行為與資訊需求之探討

（英文）Investigation on Information-Seeking Behavior and Information Needs of Head and Neck Cancer Patients

本論文係雅薩娜君（R03741066）在國立臺灣大學商學研究所完成之碩士學位論文，於民國 106 年 2 月 6 日承下列考試委員審查通過及口試及格，特此證明

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中文摘要

癌症被認為是現代人的主要疾病之一。在東亞地區尤其台灣，頭頸癌患者相對常見。身為台灣一流的醫療院所，台大醫院優秀的醫療專家與資源使其成為國內公認的癌症治療機構首選。

這份研究旨在透過質性研究了解台大的頭頸癌病人對於頭頸癌相關資訊需求以及蒐集資料的方式。筆者以觀察與深度訪談蒐集研究樣本，並採用 framework content analysis 的分析方法。總共進行了二十一次深度訪談，包含十四次與病人、三次與照護者、以及四次與醫療專家的訪談。筆者從中歸類了三個主要題目與九個主要類別，發現訪談參與者會使用不同的方法蒐集資料，並使用不同的資訊來源。病人的最重要資訊來源之一其他病友與其他病友的家屬，而最缺乏的營養相關的資料。台大醫院相關資源的使用問題也特別被指出。最後，本研究建議如何能提供更全面的資訊服務。

關鍵字：頭頸癌、資訊蒐集行為、資訊需求、資料來源、病人行為

ABSTRACT

Cancer is regarded as one of the major illnesses nowadays. Head and neck cancer (HNC) is relatively widespread in East Asia, especially in Taiwan region. In Taiwan, National Taiwan University (NTU) Hospital is the best medical institution; with excellent medical specialists and resources, it is regarded as one of the best destinations for cancer treatment in the country.

This study aims at understanding information-seeking behavior and information needs of the NTU Hospital's HNC patients and other related problems for this group of patients. The author addressed the research problem using a qualitative approach. Observation and in-depth interviews were chosen as the main data collection methods, and a framework content analysis technique was employed. Twenty-one in-depth interviews were conducted: fourteen interviews with patients, three interviews with caregivers, and four interviews with medical specialists. Three main themes and nine categories were identified and discussed. It was discovered that the participants have different information-seeking strategies and utilize differing information sources. Other patients and other patients' caregivers were indicated as one of the major methods of acquiring information and nutrition-related information provision was stated as insufficient. Problems with utilization of the NTU Hospital's resources were highlighted. The recommendations in regard to a more comprehensive information delivery based on this study's findings were suggested.

Keywords: Head and neck cancer (HNC), information seeking behavior, information needs, information sources, patient behavior.

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1.1　Motivation

One year ago my Taiwanese friend's younger brother who was only 35 years old passed away. He died from colorectal cancer just one year after being diagnosed despite doctors' prediction of five years survival period. Apart from medical professionals, family members, friends, and acquaintances had all been trying to provide any help they could. I personally also tried to provide some help – apart from psychological support, I shared information I had obtained from the doctors in Russia and helped to arrange a correspondence with one cancer clinic in Israel. This story is meant to illustrate how stressful, sad, and daunting suffering from cancer can be to everyone involved, and how much help a patient and relatives of a patient need. Over the time that I had been interacting with my friend, I learned much about the experience family members of a cancer patient has to go through as well as of the problems of the patient himself. The constant search for information regarding new treatments, new drugs, or doctors; being in low spirits and struggling with feelings of hopelessness; living in a state of uncertainty and anxiety – what I observed and the indirect exposure to this situation had a profound impact on me. In fact, it was my

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first time witnessing cancer so closely. One of the prevailing needs was the search for information – the family of my friend has been actively searching for any possible treatments, drugs, doctors, or clinics… Time was precious and acquiring correct and helpful information was of vital importance.

In the era of free access to massive amounts of information online we often find ourselves lost in an abundance of data that can bring uncertainty and perplexity, or actually mislead and distort us from the right direction and correct decisions. Numerous stories, including Steve Jobs' cancer story or the stories in the interviews for this study, have told about how early diagnosed cancer patients postponed treatment in favor of nontraditional treatments such as traditional Chinese medicine or natural medicine and how negatively it impacted their health afterwards. In my friend's case, the family also searched for Chinese medicine solutions in order to avoid painful and potentially harmful surgeries, chemotherapy and radiotherapy treatment. However, as in most cases, traditional Chinese medicine failed to cause the expected miracles to occur. It is evident that in regards to healthcare, the importance of providing trustworthy information in a timely manner cannot be overlooked.

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I have been involved in medicine-related business fields for almost three years. After completing a two-year course in biotechnology management during my bachelor's program, I decided to enter the healthcare sector to start my career, aiming at promoting scientific and business-related cooperation for services or products within this industry between Russia, Taiwan, and China. Healthcare is a critical field in any country, and international cooperation could enhance the development of medical services and products and thus be beneficial to citizens of all countries. It is my opinion that the Russian business sector can offer excellent medical equipment while Taiwan can provide the best practices in medical management as well as expertise in traditional Chinese medicine treatments. Thus, a personal interest in these areas was one of the reasons why I chose a thesis topic related to medicine.

I have observed how medical services differ in Russia, Taiwan and China, and how, for example, in Russia, medical expenditures are constantly rising. Meanwhile, I noticed that medical information available on Russian websites is becoming more and more abundant. However, apart from basic information, treatment recommendations differed a lot between different websites. This is likely to make a person so perplexed they decide to visit a clinic, but the tendency of referring to medical information

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found online signifies that there is a demand for the availability of medical information. This raised my interest in learning how to design convenient and helpful online websites or platforms to deliver services, so during the second semester of my master program I attended a course named "Platform strategy". By chance, Professor Yu Jiun-Yu at the Business Administration department of National Taiwan University (NTU) specialized in health management. I asked Professor Yu to be my advisor for my master thesis and also for permission to participate in related projects.

In the beginning of the second year of my master program, I joined the team working on one of the ongoing healthcare-related projects － ZOHUE platform (ZOHUE作夥台灣頭頸癌病友加油站). This project was a non-profit project that was started in 2013 by two NTU professors, Yu, Jiun-Yu and Kung, Ling-Chieh, in cooperation with National Taiwan Hospital Cancer Resource Center and “Kewang” Head and Neck Cancer Patients' group of the Center. ZOHUE platform was designed to serve as an online network site and as an addition to offline activities of the Head and Neck Cancer Patients' group.

There is a steady growth of the Health 2.0 trend – new online healthcare websites, communities, support groups and platforms gradually come into existence. Some of

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the most famous examples are websites such as PatientsLikeMe.com, Inspire.com, Healthgrades.com, WebMD, etc. – these online healthcare-network facilitators create valuable services for healthcare participants such as patients, patients' families and medical staff. They provide health-related information, enable users to share emotions and treatment records, or help professionals to exchange information and opinions. The ZOHUE platform followed this Health 2.0 Internet trend and its operation was designed according to the business model proposed by Christensen *et al.* (Christensen, C. M., J. H. Grossman, *et al.*, 2009) called Facilitated Networks Business. The ZOHUE website was positioned to act as a healthcare-network facilitator – to provide credible medical information resources and facilitate interaction and information exchange between different parties such as patients, medical professionals, and family members.

The pilot version of the platform was launched at the end of September 2015. However, registered users failed to actively participate on the platform. Contrary to the team's expectations, users did not share their emotional status nor involve themselves much with online social activities (for example, discussions on the forum, information sharing, or giving likes), neither did they interact much with the medical

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professionals that were also registered as members of the platform. Users' main interest was cancer-related information posted on the platform, but after some period of time the frequency of their visits usually decreased. The team came to the conclusion that a proper research of users' needs prior to the design of ZOHUE was lacking.

I participated in the project since its launch online and decided to conduct a qualitative study related to users' needs and behaviors, which became the basis for this master's thesis. Since users of the platform were mostly interested in acquiring information, it would be helpful to learn about what sources of information cancer patients frequently use, which types of information are provided inadequately, what sort of problems they encounter during their search of information, and subsequently offer better service in information provision on the ZOHUE platform. It was decided to focus on understanding patients' experiences after they were diagnosed with cancer and their information-seeking behavior in order to uncover informational and other needs. This understanding would be used to provide constructive suggestions to the ZOHUE platform team and/or to the NTU hospital.

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This project gave me an opportunity to work with the professional team with specialists from National Taiwan University, CCDM (CCDM, 2016) consulting company providing services in design management, and medical professionals from the most renowned Taiwan hospital, National Taiwan University Hospital. I was grateful to be a member of this important project and it was another determinant of deciding to conduct this study.

1.2 Problem description

Cancer is a serious illness that can be fatal and usually results in lifelong health complications shortening the life span of a patient. Overall there were 8.2 million deaths due to cancer and 14.1 million new cases worldwide in 2012, a year when the most comprehensive global statistical report regarding this topic was conducted by WHO (Fact Sheets by Cancer, n.d.). Cancer is a global health issue and, according to the newest data of 2016, one out of seven deaths in the world is attributed to cancer Cancer Facts & Figures 2016, n.d.). It is one of the most covered medical topics in various journals and articles and is researched from different perspectives and disciplines. Not only quantitative, but also qualitative research of cancer patients' experience is becoming common since cancer affects many different aspects of a

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patients' life.

Head and neck cancer refers to a carcinoma type of cancer and affects such areas as the mouth, nose and throat, as well as the larynx, salivary glands and sinuses. According to 2014 WHO data, head and neck squamous-cell carcinoma (HNSCC) affected 550,000 people globally that year, with occurrence in males two to four times higher than females (Union for International Cancer Control, 2014). The WHO report also states that this cancer type occurrence is ranked sixth in the world. One of the most common types of head and neck cancer is nasopharyngeal carcinoma (NPC); the geographic center is situated in East Asia, and Taiwan is a region with high occurrence.

This study will focus on the different forms of head and neck cancer of Taiwanese patients. As to the overall head and neck cancer statistics in Taiwan, in 2014, 52,256 males and 11,996 females were diagnosed with one of the head and neck cancer types, and the ratio of men to women is 5:1. Men aged 45-64 years old have the highest rate of developing head and neck cancer (中華民國衛生福利部, 2017). Risk factors include unhealthy lifestyle habits, environmental factors, as well as hereditary aspects and viruses. It is prevailing that carriers of HNSCC belong to the

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low socioeconomic class as the majority of the people diagnosed with neck and head cancer has one or a few unhealthy habits such as smoking, abuse of alcohol, or chewing betel nut.

The National Health Insurance (NHI) system in Taiwan was established in 1995 and has been praised all over the world. It is well known that Taiwan's NHI is one of the most affordable health insurance programs in the world, and at the same time it provides very high-quality services. One of the reasons of this service quality lies in the fact that in Taiwan only the students with the best academic achievements can apply to medical universities. More than 90% of Taiwan's citizens have healthcare insurance and as to the medical costs, NHI covers a substantial part of all medical treatments. Therefore we can assume that patients in Taiwan receive a high level of healthcare services and that, unlike many other countries, the financial burden is not the prime problem for Taiwanese patients, including cancer patients. As a result, our research settings – Taiwan – can provide us with the opportunity to focus on researching patients' needs other than monetary.

For HNC patients, physical disabilities related to major life activities such as eating and speaking are regarded as troublesome and depressive. Also, uncertainty

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about future health circumstances, especially feelings of being at risk of relapse, is the source of substantial psychological distress. These two aspects, physical and psychological, in turn influence social life and thus aggravate the consequences of being ill with cancer even more. However, the author believes that adequate and timely information acquisition can to some degree prevent deterioration of physical functions along with lessening negative psychological states such as anxiety and fear about the future.

According to statistics, health information search is the third most popular online activity after e-mailing and using a search engine (Zickuhr, K. 2010).

The U.S. Pew Research Center revealed that in 2013 "72% of internet users say they looked online for health information of one kind or another within the past year" (Fox, S., & Duggan, M., 2013). Another report showed that among healthcare consumers "20% have joined a health-related forum or community" (Health 2.0 social media in healthcare, n.d.), and yet another source indicated that "60% of doctors say social media improves the quality of care delivered to patients" (Mollie Ottenhoff, 2012). Research conducted in EU from 2010 to 2011 revealed that information on the Internet was the second source of medical information after consulting physicians.

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These facts indicate that there is a significant need for online medical or wellness-related information.

However, there are several issues related to online medical information. First, the quality of information presented online is inconsistent. While some websites provide adequate and accurate medical information, there are also sites, which provides grossly incorrect information. Second, the search for information can be time-consuming and without helpful results due to the lack of clear classification of information types, such as for search of information for different stages of cancer. Third, the major type of online cancer-related information in Taiwan is general, descriptive and educational. However, there is insufficient information about more detailed treatments, lists of medical institutions, specialists, or food supplements during recovery.

Finally, there is one more issue to discuss. The fact that HNC patients in Taiwan are relatively aged and many are not used to the systematic search of information online due to their socioeconomic status poses a problem for them searching information online. In these cases, help from a patient's relatives or educational interventions organized by medical institutions are needed.

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The author acknowledges that the task of conducting the research in regard to this healthcare issue in Taiwan is challenging. The challenge stems from two facts. Firstly, Taiwan's healthcare environment is already highly developed and high quality healthcare is accessible to the majority of citizens. Secondly, the study concentrates on investigating patients’ needs from the best medical organization in Taiwan – NTU Hospital, where services are already rather comprehensive and highly professional. This implies that the hospital’s services and information provision are probably already satisfactory, however the author is intrigued by the opportunity to discover new findings of head and neck cancer patients' problems and needs in information acquisition.

1.3 Research objective and research questions

The phenomenon of interest of this study is understanding the needs of head and neck cancer patients of NTU Hospital related to information acquisition, whether these needs are satisfied or not, and to investigate information-seeking behavior patterns of the patients. After exploring the previous literature on the topics such as information sources, informational needs, and information seeking behavior of cancer patients, the author can conclude that not many studies were done in regard to head

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and neck cancer patients, especially in a qualitative manner. Still, as was stated earlier, adequate information acquisition is an important part of the medical process and has a significant impact on a patient's disease treatment outcome and further control of the disease.

Nowadays one of the main sources of health-related information is the Internet. However, the majority of people with HNC are relatively aged and usually belong to a low socioeconomic status. The author is inquisitive about how these cancer patients obtain health-related information: Do they rely more on the information provided by the hospital or search for information via the Internet or through other people?

The purpose of this study is to gain an understanding of the information needs and information-seeking behavior of HNC patients using qualitative research methods. Specifically, we plan to explore how information relate to cancer is searched, how information provided by the hospital is used, and what is the role of information from Internet sources or from other people. Apart from the ZOHUE platform design project, the results of the study can be used by medical organizations or other related organizations for designing online and/or offline information providing strategies tailored to patients' needs. Furthermore, the research results from this study can be

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applied to investigate information provision in relation to other types of cancer as well.

Specific research questions that this study attempts to answer are discussed below. The first set of research questions of this study is related to information-seeking behavior of the patients. How do patients search for information? The author aims to investigate how patients select, filter, and verify information. We often doubt the trustworthiness of the information online, but when it comes to medical information, verified and trusted information is even more important and necessary. How do patients choose about which information they deem to be trustworthy and which is not? Do they discuss their doubts and questions about the information they found with doctors?

Another important issue highlighted in the reviewed literature is a connection between information-seeking behavior and attitude or psychological state; a patient's attitude can explain his or her strategy of acquiring information. Moreover, the author believes it is also necessary to uncover the relationship between the methods of information acquisition and demographic factors for a better understanding of patients' problems and needs related to information search.

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The second set of research questions is related to informational needs of the patients. What informational needs do patients (and their families) have during the different stages of cancer treatment? What types of information are lacking? There is a series of stages such as diagnosis, choice of treatment, treatment process, recovery, control and prevention. The main type of information provided in hospitals is regarding treatment procedures and we are interested in investigating whether providing this type of information during the treatment process is considered adequate in the eyes of patients and their family member or if they feel the information currently provided by the hospital is lacking in certain aspects. Also, we are more driven to research other sources of information used during different stages by a cancer patient. For instance, apart from leaflets explaining treatment procedures, a description of side effects and basic nutritional information, NTU Hospital provides other informational resources, for example information online in the form of lectures held by doctors or nurses that are placed on the hospital’s official webpage in the educational resources section. There is the Cancer Resource Center that was established in 2010 as one of the sources of printed information; the Center also lead a community for head and neck cancer patients. Do patients use these in-hospital

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resources often? Do they find them helpful? In conducting this research it is important to understand the current sources of information in order to uncover informational needs.

Answers to these research questions will provide the author with more insights into what information is used and how head and neck cancer patients process it during their disease trajectory. Most importantly, the study results will direct future endeavors of designing the ZOHUE platform and similar online services for cancer patients.

1.4 Research Process

After the research topic was decided, an exploratory literature search was performed. Based on the first findings from the literature review, 3 trial interviews were organized in order to test an interview guide. Afterwards, the research objective was decided and a research method was designed. Subsequent literature review facilitated the definition of the research questions and the practical part of the study began. Observation and in-depth interviews were performed, followed by a framework content analysis. The complete research process is graphically described in Figure 1.1.

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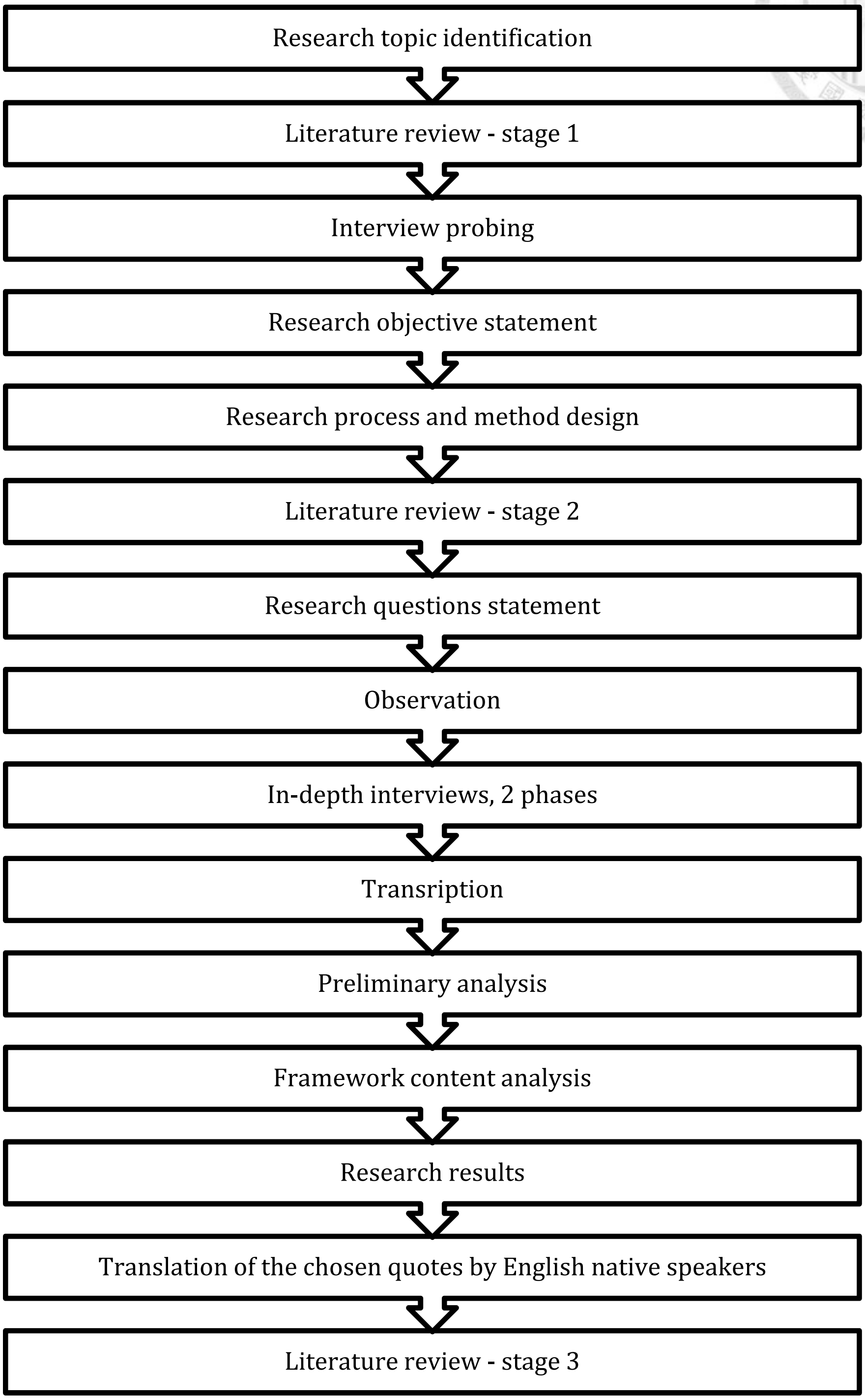
Figure 1.1 Research process



Chapter 2 Literature review

Journal articles investigating cancer-related topics are numerous and approach cancer-related issues from different angles, however, the overall number of papers in English discussing problems related particularly to HNC patients is not high, probably due to the low incidence rate of this cancer type in western countries; for example, in USA this type of cancer constitutes only 3% and in UK only 4% (Ziegler *et al.* 2004, p.120) of all cancer occurrences. Moreover, the majority of previous studies on informational needs and informational seeking behavior of cancer patients were done in a quantitative manner and not through a qualitative approach.

In total, there were three phases of literature review. Prior to a more focused literature search, a general literature search in Chinese was conducted with the purpose to better understand problems encountered by cancer patients or HNC patients specifically. The author searched for related blogs, patients' online sharing and diaries, Facebook groups, and videos or audios of offline patient communities' activities. These search results became the basis for the targeted literature search and this study's first interview guide. For the targeted literature search, research on topics concerning information behavior or informational needs has been done extensively in

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relation to cancer patients in general as well as exclusively to head and neck cancer patients. Literature reviews, systematic review were perused first and then other journal articles were researched. An analysis of the most representative articles related to this study, which were identified by article name, citation rate, and appearance in references to the main articles in the field, is incorporated into this literature review. After the research results were obtained, one more additional literature search and review of the second stage literature investigation was performed in order to gain a better understanding of the derived findings. Only free literature resources from Google Scholar and NTU library were used, and the articles examined were mostly written in English.

The literature investigation revealed that topics on information needs and cancer information seeking behavior of Taiwanese cancer patients were not properly studied, especially when focused on one particular cancer type such as HNSCC. Only two papers in Chinese that tackle the issue of head and neck cancer in relation to Taiwanese patients were found. These studies are (1) a doctoral thesis about informational needs of family members of cancer patients using a qualitative

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approach (Chen, 2012), and (2) a master thesis on information needs of HNC patients using a quantitative analysis (Chen, 2006).

During the literature examination the author focused on understanding the methodological part, research purpose and questions, research design, research findings, and research gaps of each study. The literature search was conducted in regard to four distinct topics that appear to be the central themes in this study – information seeking behavior, sources of cancer information, cancer patients' informational needs, and cancer patients' informational needs at different stages of cancer.

2.1 Information seeking behavior

Information seeking is an indispensable part during the course of any disease and helps people cope with problems that may occur. Information seeking is defined as "a process in which humans purposefully engage in order to change their state of knowledge"(Marchionini 1997, p.5). Patients may employ different strategies when searching for information and vary in their attitudes toward information seeking.

It has been observed that following technological advances and emergence of new communication channels during the 21st century, information-seeking patterns

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are undergoing significant changes (Rutten *et al.* 2016). A common strategy during recent years is a tendency amongst patients to search for information online, yet the issue of online information's quality is a serious concern and is broadly discussed as has been mentioned in this paper's introduction. Rutten *et al.* (2016) completed, with the support of Mayo Clinic, a significant research concerning trends in cancer information seeking between 2003 and 2013 via phone calls and mails. The study states that "the percentage of cancer survivors who reported information seeking increased from 66.8 % in 2003 to 80.8 % in 2013" among 3664 respondents (Rutten *et al.* 2016, p.350). The Internet is indeed becoming a popular source of information, thus an understanding of patients' use of the Internet should be brought to attention. Nevertheless, according to the study's 982 responses, from 2003 to 2008 the percentage of information search online showed stable numbers (35.6% in 2003 and 36.1% in 2008), while there was an increasing tendency of seeking information from healthcare professionals (19.6% in 2003 and 44.4% in 2008). Interestingly, it was also reported that people aged over 75 years old, of male gender, and with lower level of education relied on information given by healthcare professionals more and regarded it as a primary information source, while information online constituted as the major

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source of obtaining information for younger, age ranged 18 to 34 years old, and more educated patients. This is a significant finding and explains that information-seeking patterns differ depending on various demographic factors. In particular, it is highlighted that attention should be paid to the preferences in information acquisition for the higher aged category of patients due to their limited usage of the Internet.

In the following study by Maddock *et al.* (2011) funded by Eurocancercoms, quantitative and qualitative research approaches were combined. The authors hypothesize that Internet information seeking should be actively assisted by medical professionals or medical institutions referring to the results of the online survey of 476 people from 24 countries. Acquired information has a critical influence on quality of life and decision-making by the patients, and the Internet can play an important supportive role for health information seekers. Furthermore, not only the concern related to quality of information, but also issues such as choosing credible websites, interpretation ability, and the issue of individual needs are underlined. The authors discussed the importance of helping patients with identification of information quality by medical professionals and suggested the creation of an online platform that provides trustworthy information.

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Mayer *et al.* (2007) performed a survey study of 619 cancer survivors and identified that 67.5% of all the respondents searched for cancer-related information, 67% of them used the Internet to acquire information, and online information was regarded as useful by 91%. However, 40% of the one third of respondents that did not refer to information online stated the problem of complexity. The study supports the findings from the previous paper by Maddock *et al.* (2011) that healthcare providers should assist patients with online information recommendations. “Health care providers can screen existing websites for credibility and make specific recommendations to their patients. Likewise, providers can be instrumental in developing, contributing to, and evaluating trustworthy health or cancer-related websites.” (Mayer *et al.* 2007, p.349). Online information was also extensively searched by the patients’ caregivers. James *et al.* (2007) suggested as much as 48%, of all caregivers searched online for information and then shared it with the patients, thus increasing overall awareness and compliance of the patients.

Another important issue in cancer information seeking is the patient’s attitude towards cancer management and related coping strategies. Patients participating in this paper’s study who were active in decision-making regarding their treatment

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expressed a desire for more information as will be discussed in the section about patients' information needs. However, what about the patients who show reluctance towards information acquisition? 17 interviews that lasted 45-90 minutes with cancer patients in the beginning stages of cancer care were completed by Leydon *et al.* (2000). The participants were diagnosed with different cancer types, dominated by females (11 patients), participant nationality was mainly British, and the average age was 55 years. In this study, only 6 participants indicated a need of as much information as possible, while in comparison to the limited desire in information acquisition of the other 11 patients. Three possible reasons of information avoidance were identified – faith in the doctors, hope that cancer would not disrupt their current lives, and charity in the sense of sacrificing limited resources for other patients who are in worse conditions than the patients themselves. For instance, cancer information and services' avoidance was clearly demonstrated by males who "maintained hope through silence" (Leydon *et al.* 2000, p.912). Extra information was regarded as threatening and could potentially diminish hope. Also, as opposite to women, male patients usually did not discuss questions with their doctors and were less interested in other patients' experiences.

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The topic of information avoidance and reasons behind the patients' decision to distance themselves from additional but potentially helpful information is complex where preferences for timing and content of information were found to vary among patients. This study only focuses on the patients in the beginning of their illness path, whereas an understanding of patients' information seeking behavior at other stages is equally important. Moreover, qualitative research in the form of in-depth interviews is most likely the most suitable way of uncovering underlying reasons in relation to information avoidance.

Although information needs persist during all the cancer stages according to the previously mentioned paper of Rutten *et al.* (2016), information-seeking degree may vary between pre- and post-treatment phases, as the study of 731 patients from 17 oncology clinics in USA via survey by Eheman *et al.* (2009) also suggests. It was found that patients require more information before the treatment, and active seekers were usually younger, or married patients, or with higher level of education. On the contrary, elder people and patients with poorer health status represented the category of passive information seekers. The authors argue that it is important to uncover other reasons behind changing information seeking behaviors apart from the

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decision-making timing, and that health providers should be concerned with information avoidance behavior of a patient. Moreover, it is assumed that after-treatment information support may be helpful for recovery and better well-being of the patients. In accordance with the previously discussed articles in this section, the authors again propose that medical specialists should offer information about credible online websites to patients.

The interviews of 262 patients' examining information seeking behavior were conducted by Czaja *et al.* (2003). This study raises the issue of such behavior when patients seek related information but do not use it for decision-making regarding the treatment. Medical providers could possibly encourage these patients to apply the information they have acquired during discussions about treatment choices. Also, doctors should be more controlling and proactive with the patients who prefer to delegate decision-making to doctors.

2.2 Sources of cancer information

Although healthcare professionals constitute one of the most important sources of health information, continued evaluation of the sources from which cancer patients seek information is necessary, especially in an era of ever-increasing information

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access. For example, the rapid growth in health information on the Internet has spurred the development of online health resources and consumer health online services, which in general focus on facilitating access to and use of information. Literature search of various articles suggests that web-based resources and healthcare providers are two predominant sources for patients and caregivers during information seeking process.

Overall, a limited number of articles address the issue of information sources for cancer patients. The most fundamental systematic review was conducted in 2005 – "Information needs and sources of information among cancer patients: a systematic review of research (1980–2003)" (Rutten *et al.* 2005). The authors of this study examined 112 articles on the topics of information needs and sources. Not only articles related to diagnosis and treatment stages, but research papers related to post-treatment stage and multiple stages were included into the review, each type of approximate equal percentage about 32% to 34%. The articles' geographical scope included Americas, Europe, Australia, and 2 articles from other countries and articles about different cancer types were researched.

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Information sources were divided into 5 distinct types and 19 subcategories. Results stated that for the period from 1980 to 2003 the major source of information were health professionals (27.3%) and the subgroup “physicians” constituted 47.3%. Printed materials were the second main source indicated, 26.2%, with books being referred to most frequently (25%). The third biggest category was “interpersonal” source of information. The subcategory related to friends and family had the highest percentage, 42.9%; social groups – 30.6%, and other patients – 20.4%. Media and other resources were used to a lesser extent. The main sources used during diagnosis and treatment phases differed from those utilized during the post-treatment period. Importantly, medical professionals and interpersonal connections became two prevalent sources at 40.6% and 25%, comparing to 26.9% and 11.5% respectively during the diagnosis and treatment stages. In the conclusion it was suggested to conduct qualitative interviews for a better and deeper understanding of the needs and sources related to information. The author of this thesis attempted to find more recent comprehensive research of similar scope on the topic done after 2005, but did not succeed. This review is the most comprehensive in regard to the numbers of articles, geographical scope, variety of stages, and cancer types.

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Ankem (2006) completed another systemic review of the 12 articles regarding the usage of information sources. They found that patients often refer not only to main sources of information provided in medical organizations, but often combine with additional external information sources. The most frequently used sources of information, excluding results from two studies, were healthcare professionals (86-100%), brochures (34-79%), and family and friends (46-55%). Interestingly, Internet or patient groups' sources were not used as frequently. The author additionally analyzed helpfulness of information sources with books at the first place even though books were not the most frequently used source. Healthcare professionals and leaflets were the second most helpful types of information. The author also concluded that younger patients actively used multiple sources of information in contrast to the patients aged above 65 years. In the discussion, a following in-depth research was suggested in order to provide better and more helpful information to patients, as well as additional research exploring various variables that influence choice of particular information sources.

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2.3 Cancer patients' informational needs

Information acquisition is significant for cancer patients and their families since, in a very short period of time, patients and caregivers need to digest large amount of specialized information, make crucial decisions with serious consequences, and prepare for the post-treatment recovery period. From the onset of the disease, interaction with new information is ceaseless throughout the illness trajectory. The following discussion will examine informational needs in detail.

The first step of literature analysis on this topic was by identifying systematic or literature reviews. The abovementioned research by Rutten *et al.* (2005) is the seminal work in regard to information needs, with the number of citations exceeding 648 and with 91 reviewed articles related to cancer information needs from 1980 till 2003. The uniqueness of this review for a comprehensive understanding of information needs lies in the time span of the study, analysis of quantitative as well as qualitative research papers, inclusion of different cancer types, and a clear division into categories and subcategories.

Six main categories of needs were discovered with four main types identified: treatment-related information (38.1%), cancer-specific information (12.8%), and

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rehabilitation information (12.2%), followed by prognosis-related information need (10.8%). Rehabilitation included nutrition during the recovery period which is the second biggest subcategory with 21.6%, only surpassed by self care and home care rehabilitation information need (30.9%). Informational need in interpersonal and social aspect accounted only to 6%. Notably, 35% of patients possess a need of treatment-related information in the post-treatment phase as well. In this phase this type of information demonstrates the highest percentage among all the need categories exceeding recovery information need (22.5%). This finding is important and emphasizes the significance of investigating evolution of information needs at different stages of the cancer continuum for solving patients' informational problems.

Ziegler *et al.* (2004) completed a comprehensive literature review of information needs, experiences, and decision-making in regard to head and neck cancer patients. The article states that unlike other cancers, head and neck cancer patients often suffer from psychosocial problems as a consequence of facial disfigurement or impairment of vital functions like speaking or talking. The complexity of this cancer type makes it especially worth to be researched. Papers that examined information needs of neck and head cancer patients stress that information giving is often incomplete or does not

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meet the needs of patients. Moreover, communication skills and personal qualities of healthcare professionals are important. Patients wished to have information presented in a simpler language and be given an overall understanding of the treatment, as opposed to a detailed one. The linkage between information needs and anxiety or psychological problems was identified in two reviewed studies. The authors argue that research of head and neck cancer patients' needs is insufficient and suggest that qualitative investigations via interviews could be insightful.

Husson *et al.* (2011) completed another systematic review of 25 articles that included investigation of information provision for cancer patients and its association with quality of life, anxiety, and depression. 5 articles examining anxiety and depression of cancer patients in general support that a positive relationship exists between provision of information and level of anxiety or depression, but negative correlation was also reported in two studies. It was noted that the time factor is an important variable in influencing levels of anxiety or depression. Another important conclusion of the study is that anxiety can impede information processing due to diminished mental health of a patient. Husson *et al.* (2011) also emphasizes that "the information needs of cancer patients vary by gender, age, cultural background,

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educational level, cancer type, stage of disease and coping style” (Husson *et al.* (2011, p.761), and therefore urges for provision of customized information to patients. According to systematic analysis of 57 articles by Harrison *et al.* (2009), it is tentatively concluded that patients’ needs are the most prevalent during the treatment and post-treatment phases. In their analysis of the types of unmet needs, the need for information placed third after needs related to daily living and psychological state. The researchers affirm that needs constantly change throughout the cancer care continuum, but prospective studies of cohorts of patients which might explain how changes of need evolve are insufficient.

Ankem (2006) conducted a meta-analysis of demographic and situational factors influencing information needs of cancer patients between 19 to 75 years old and presented two interesting findings. First is that younger patients (55 years old or below) expressed a higher need for information. The second finding corresponds with the finding previously stated by Ankem (2005) – patients with an active role in decision-making show greater need for cancer-related information. It is concluded that age and chosen role in decision-making are the variables that predict the need for information most precisely, not gender, level of education, time since the diagnosis,

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or stage of the disease. More research on demographic and situational factors is needed to give a more detailed explanation of all the intricate relationships between various variables. In this article, Ankem *et al.* also list the two most important information needs emphasized by patients – information about the disease and information regarding the treatment. This article clearly underlines the importance of more advanced research on reasons behind the need for information, especially in the case of older patients who are passive in regard to receiving information.

Research on understanding Iranian cancer patients' informational needs was done by Heidari & Mardani-Hamooleh in 2015 using a qualitative research method. The authors organized 25 semi-structured interviews with each spanning 40-55 minutes with patients from 32 to 51 years old, 14 females and 11 males diagnosed with 5 different types of cancers. Importantly, the position of the participants in cancer journey differed from 2 months to 4 years. The interview data was transcribed and conventional content analysis was employed. Two main categories were revealed – (1) the need for information related to the disease including two subcategories as disease and prognosis and (2) the need for information about daily life, including information about regular life activities and healthy lifestyle. Healthy lifestyle included topics such as nutrition, exercise, and prevention. The authors highlight the importance of the findings through this deep-level analysis, but admit limitations such as heterogeneous cancer types and multiple stages as well as sample size of only 25 patients.

A few papers pay attention to the specificity of head and neck cancer. For instance, Koster & Bergsma (1990) posit that due to facial impairment, head and neck cancer is highly traumatic to patients and it has a significant influence on interpersonal aspect of patients' lives, emotional health is impacted as well. What is also special about the majority of HNSCC patients is their low socioeconomic status and relatively low educational level. This implies that these patients require considerable help from medical professionals. One of the methods to support these patients is information provision in a customized, clear, and understandable way.

Semple *et al.* (2012) provided a significant argument about the importance of information provision for HNSCC patients: "many of the side-effects of head and neck cancer treatments are predictable." (Semple *et al.* 2012, p.589). The authors reviewed the previous body of research about information needs of cancer patients with particular focus to head and neck cancer and suggested that provision of

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appropriate written information is highly important in addressing patients' needs and serves as a complimentary tool for oral consultations. Specifically, importance of finely designed leaflets is highlighted.

Information provision is closely related to patients' expectations regarding cancer treatment and recovery. Llewellyn *et al.* (2005) completed 15 semi-structured interviews and revealed that head and neck cancer patients have different preferences about information and different opinions on timing of information provision. They argue that timing and amount of information should be individually assessed to better prepare patients for upcoming treatment challenges. This argument corroborates with suggestions proposed by Newell *et al.* (2004) in his study regarding information provision prior to surgery – information for patients should be individually designed. Additionally, Newell *et al.* (2004) reveals another issue related to information provision – inadequate provision of the information after surgical treatment, especially after a 3 to 6 month period.

Research conducted by Maddock *et al.* (2011) was already partially discussed in the information seeking behavior section. The results in relation to information needs are graphically presented below (Figure 2.1). 7 main information needs out of 14 are

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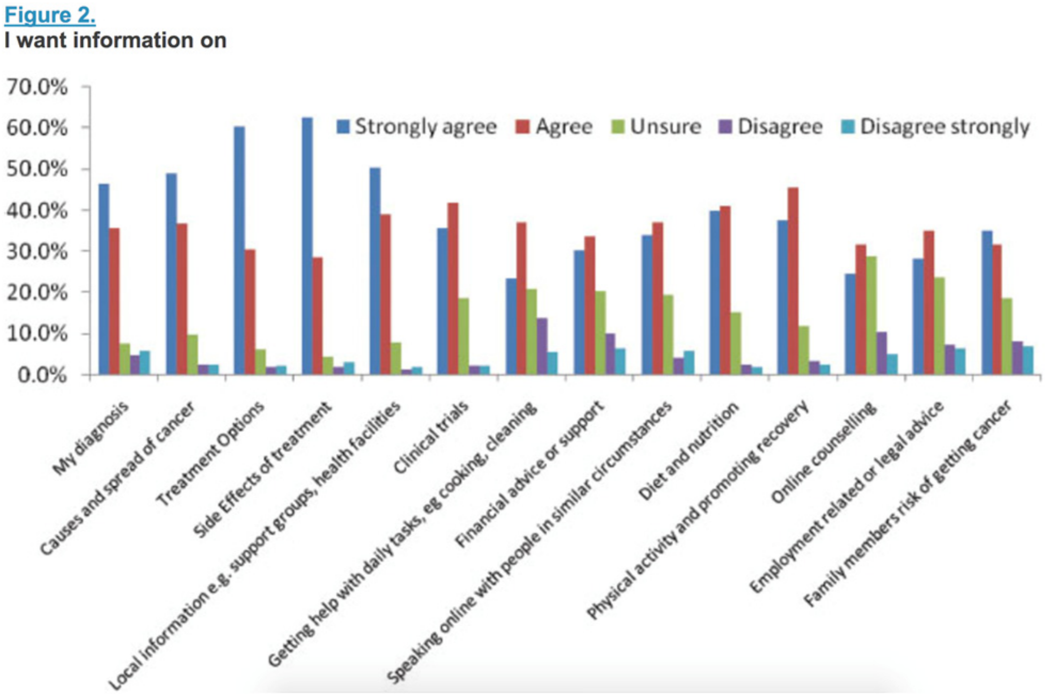
listed in descending order: side effects (about 62%), treatment options, local information (support groups, health facilities), causes and spread of cancer, my diagnosis, diet and nutrition (about 39%), and physical activity and promoting recovery.

Figure 2.1 Information needs (Maddock *et al.* 2011)



2.4 Cancer patients' informational needs at different stages of cancer

A cancer patient undergoes a few stages in his cancer journey, and a growing number of research aims at investigating how a patient's needs in and of information evolve and change during the illness. Nevertheless, currently the majority of related research usually addresses information needs at diagnosis or treatment phases.

A recent scoping review (Fletcher *et al.* 2016) of existing literature on the topic from 2003 to 2015 from USA, Canada, European countries, Asian countries and Australia, including quantitative and qualitative studies, highlights this issue and states that research data on post-treatment and following phases is not well documented. For instance, post-treatment phase represents only 16.3% of the total number of studies in the field, and recurrence/metastasis and end of life stages are described in only 2.9% and also 2.9% of studies respectively. With the focus on diagnosis and treatment stages, it is reported that patients' most important need is information about treatment options, 33.4%. This need occupies the first place among the 17 categories of all needs and their related subcategories. It is also stated that both demographic factors and treatment phases need attention for tailoring information provided to patients, especially considering that an individualized approach to patients is becoming more necessary in the era of patient-centered medicine with shared decision-making.

Squiers *et al.* (2005) corroborate the statement about inadequacy in research regarding information needs at cancer stages other than diagnosis and treatment, or an

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integrated analysis of all the stages. A sample of 19,030 calls to the National Cancer Institute's (NCI's) Cancer Information Service (CIS) from 2002 to 2003 was analyzed and received findings were as follows: (1) women and higher educated people sought for information more actively (2) female callers tended to ask a few additional categories of questions, including support services and psychological issues, whereas male callers primarily asked more about specific treatment (3) needs of the callers divided into five groups by the treatment differences (under treatment, after treatment, in recurrence stage, no treatment, and unknown status of treatment) distinctly varied through the cancer care journey. Also, patients in such stages as no-treatment and pre-treatment stages exhibited their interest in certain types of information that is not often discussed in the literature. A more comprehensive research of informational needs at various cancer stages via longitudinal studies and interrelationships between them is recommended. Additionally, a design of formalized assessment of patients' needs based on demographic and situational variables is called for.

One more study underscores the problem related to insufficient research of the patients' needs after the treatment phase (Mistry *et al.*, 2010). The study of 187 cancer patients' cross-sectional surveys was completed in an attempt to find out differences

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between pre-treatment and post-treatment phases, whether needs vary across the cancer care continuum, and also how demographics influence the informational needs. One of the major findings is that “collectively patients felt that they were under-informed regardless of the information domain concerned” (Mistry *et al.*, 2010, p.4), therefore equal attention should be paid to all the information categories. Patients stated that information about their prognosis is most sought after, but “post-treatment patients continued to have information needs comparable to patients undergoing treatment or at the pre-treatment stage, except with reference to treatment-related information (p =< 0.01),..” (Mistry *et al.*, 2010, p.1). This finding once again emphasizes the importance of providing information to the patients at the post-treatment stage. Another issue that this study raises is that research on the needs of patients with rare types of cancer is scarce. This thesis concerns with head and neck cancer, a cancer type that is uncommon in western countries, and after completing the literature review it can be admitted that research on informational needs at different stages in regard to this particular type is insufficient.

It is worth to note that patients become significantly distant from the healthcare providers after the end of the treatment, in general have less contacts with medical

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organizations, and yet still demonstrate a need for specialized medical information during the follow-up or cancer surveillance periods. Shea-Budgell *et al.* (2014) explored the topic of information needs and information sources for the patients in a follow-up phase of cancer continuum. 411 patients with diverse types of cancer who completed their treatments participated in this research conducted during 2011-2012. In fact, this was the first study that provided a substantial research with the focus only on post-treatment subjects. The questionnaires' results indicated that the need for information did not decrease after treatment finished, and patients specified that treatment-related and screening information were the two most sought-after types of information. The Internet was the most frequently used channel for acquiring information, but only 38% of the patients discussed online information with their healthcare providers. At the same time, the level of trust in relation to the Internet was less than 20% while above 90% of the patients acknowledged that healthcare professionals was the most trusted source. Furthermore, 84% of the respondents considered medical professionals as the most preferred medium for receiving cancer information and 75% stated that personal reading materials was the second most preferred way of acquiring information followed by Internet search. The authors of

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the study suggest that one of the ways to satisfy patients' informational would be medical professionals, as a trusted source of information, to provide a list of websites to their follow-up stage patients.

In this section dedicated to literature review, the existing body of research on topics on information-seeking behavior, sources of information, and informational needs of cancer patients which has become popular after 2000s (Rutten *et al.*, 2005) was examined and discussed. One of the major issues that was highlighted in the majority of the articles is the lack of comprehensive understanding of how information-seeking behavior, informational needs and the choice of informational sources differ and evolve along the cancer continuum. Most of the studies are focused on discrete stages of cancer treatment and are cross-sectional rather than longitudinal. A number of papers suggested that in-depth qualitative investigation can be insightful in providing possible answers to the underlying causes of cancer patients' changing information-seeking behavior. Moreover, focus on particular a cancer type during research can address the limitations of the majority of earlier qualitative studies in the field.

The majority of examined articles in regard to the topic of information needs

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emphasize the benefits of cancer information to patients such as better decision-making, higher compliance, and improved quality of life. Fletcher *et al.* (2016, p.2) also stated that “people who are provided with accurate and timely information also report decreases in anxiety and fear about cancer and treatment”. Anxiety and psychological problems remain one of the central concerns for cancer patients that are not easily solved and a number of studies suggest that information provision can play a positive role in this aspect.

The papers suggested that healthcare professionals should learn more about the patients’ informational needs and information-seeking behavior and provide information in an individualized and comprehensive manner, thus enhancing the quality of communication with the patient, which in turn can have an important influence on overall treatment outcomes. For successful information customization various demographic and situational variables should be taken into account. Informational services, written information in the form of leaflets, diversified channels for acquiring information and other forms of interventions are proposed for practical implementation by healthcare providers.

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Chapter 3 Research design

When there is need for a context-specific and descriptive research focused on understanding the dynamics of a problem, the best method to be used is a qualitative research approach. The author conducted a basic qualitative study using interpretivist philosophical framework that aims at describing and understanding the phenomenon researched. Literature reviews were done in regard to such topics such as cancer patients or head and neck cancer, oral, nasopharyngeal and other types of cancer, cancer patients' information needs, information behavior, or sources of information. Systematic reviews, literature reviews, quantitative and qualitative studies were perused and analyzed. A more detailed description was provided in the literature review section of the chapter two.

The study's data was collected during the observation and in-depth interviews with head and neck cancer patients at the NTU Hospital. The observational setting was NTU Hospital, principally (1) otolaryngology department's medical consultation and health education area and (2) radiotherapy treatment waiting hall. The author was curious to observe the patient-doctor interaction and as well as to investigate what sources of information were presented in these places. In-depth interviews provided

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abundant data to understand head and neck cancer patients' thoughts, feelings, and behaviors, and the data was subsequently analyzed using the framework method of content analysis.

3.1 Recruitment of the interviewees

Interviewees were selected by convenience sampling with the assistance of two doctors at the NTU Hospital's ear, nose and throat department, Dr. L. and Dr. W., who cooperate with the author's advisor on the ZOHUE project related to this study. Prior to the recruitment, two weeks of in-person and e-mail discussions with the doctors were held in April 2016 and recruitment itself was conducted in the NTU Hospital over three weeks in May with recruitment sessions lasting two to three hours each week. All of the recruited patients were treated in the past or are currently in treatment or post-treatment phases under the guidance of NTU Hospital's specialists and were recruited during their regular visits to the doctors.

Initially we planned to organize half of all the interviews with family members and half with patients, but the majority of patients visited the doctors alone or decided to be interviewed without other people, thus access to family members was limited. Furthermore, there were some family members who refused being interviewed. As a

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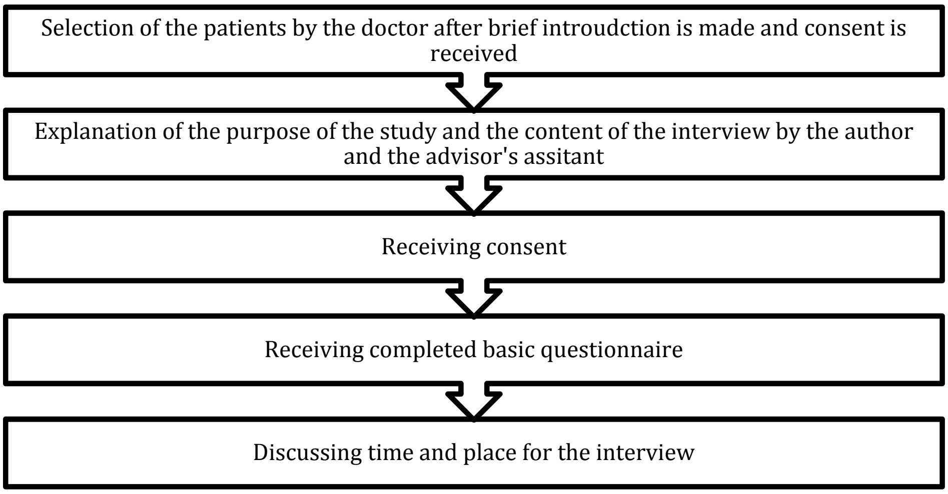
result, only 3 family members participated in our interview sessions.

All of the participants were given a brief explanation of the project by the two collaborating doctors and more complete written and oral explanation of the purpose of the study and the content and topics of an interview by the author of this study and the author advisor’s assistant. Patients were selected as interviewees only after their written consent was obtained and after they completed a basic questionnaire. For ethical issues, a clause assuring information confidentiality was included in the consent form. The recruitment process of the interviewees is shown in Figure 3.1. The document used during this process, such as consent form and basic questionnaire are provided in Appendix1.

Figure 3.1 Recruitment process



Interviews were divided into two rounds using two different interview guides. In total, 24 participants were recruited in the initial phase, but after the follow-up contact only 14 agreed to be interviewed during the first interview phase; 4 patients and 1 family member gave their consent to participate in the second interview phase. Some of the initially recruited people did not respond to messages or replied that they had changed their minds and did not want to be interviewed. As to the second interview round, only participants with active information-seeking behavior from the first round were chosen, however, two of them refused to participate in an additional interview. Moreover, four healthcare providers, 3 doctors and one nurse, participated in interviews; all were from the ear, nose and throat department at the NTU Hospital. Prior to the interview the participants were contacted by text messages or e-mails.

With participants K, L, F, and G the contacts were more frequent and included exchanging of additional information, and in the case of patient G who did not have family taking care of him, we wanted to support this patient psychologically while he was undergoing the treatment. We expressed gratitude for taking time to be interviewed to each participant at the end of each interview, and the stories from each interviewee were compiled based upon the transcripts and sent to them for verification. One of the stories is displayed in Appendix 2.

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3.2 Basic questionnaire and interview guides

The purpose of completing the basic questionnaire form was to aid in designing tailored interview guides and timelines prior to the interviews with the participants. In the questionnaire, a patient was asked to indicate the following information:

1. surname
2. sex
3. age
4. occupation
5. age when was diagnosed with cancer
6. cancer stage
7. treatments received
8. problems encountered
9. sources of information
10. whether participated/participates in the activities of any cancer-related associations or patient groups and which ones
11. whether usually follows any blogs of other patients, other patients' family members, or medical doctors

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The interview guide for the first interview phase was structured based on the main themes found in the blogs or other online information posted by head and neck cancer patients or their family members. Additionally, this guide was tested in three exploratory interviews that took place in October and December 2015, two with patients and one with a caregiver. It consisted of three main parts:

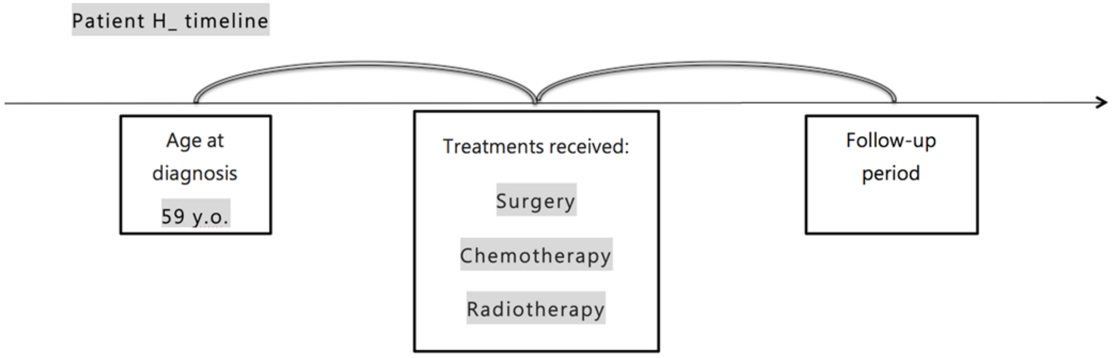
(1) treatment experience that included questions about thoughts, emotions, and encountered problems along the continuum of cancer care; (2) sources of information, information-seeking behavior and (3) communication with other patients or medical specialists.

Figure 3.2 Interview guide sample for the first round of interviews

The cancer journey (thoughts, emotions, and problems)		**Source of information**	**Communication with other patients, medical staff**
What thoughts did you have in mind when you found out about your condition? What are possible underlying reasons for the disease?	Would you like to share your treatment experience? What difficulties did you face?	When the illness started, or during the treatment, what information did the hospital provide? Could you give an example? Was the information sufficient?	During your illness, whom did you contact the most, what did you talk about? How did you communicate with the medical staff?
During the beginning of the disease, how did you feel, what kind of emotions did you have?	What kind of impact did your conditions have on your daily life?	How did you search for information on the internet? Did you search for it by yourself? What were some of the websites that you browsed?	Did you have contacts and/or communication with the patients suffering from similar conditions?
How did you relieve stress and handle your emotions?		What preparation did you do prior to treatment?	

By this design we sought to trigger patient's memories and attempted to uncover as much as possible information related to the whole cancer journey in order to understand more of the context: how a patient chose to be treated in NTU Hospital, what treatment procedures he/she underwent, how his/her current life is. To facilitate the interview, a brief timeline consisting of age at onset of the disease, types of treatments received, and current age and state of health before each interview was constructed, as shown below:

Figure 3.3 A patient's timeline sample



The first interview guide was relatively exploratory in nature in comparison to the second interview round's interview guide. The second round of interviews included, depending on an interviewee, a set of 9-10 more specific questions related to information acquisition process and information needs, and the sample of this

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interview guide consisting of 9 questions is presented in Table 3.1. These questions were designed based on the results of the first interview round, when information behavior and needs were selected as the primary objective for investigation, and the interviews with 4 medical specialists from NTU Hospital.

Table 3.1 Question set for the second round of interviews

1. After relapse/prior or after the surgery/after the surgery: Which information sources did you use the most during these phases? Which sources were the most helpful?
2. NTU Hospital arranges a "case manager appointment" prior the treatment. Could you share the counseling content and your opinions on it (was it helpful)? Did you contact the case manager?
3. Information sources provided by NTU Hospital: Cancer Resource Center | Public lectures (Kewang Association[1])| Educational videos on NTU hospital official website | HOPE Foundation for Cancer Care's booklets | Leaflets from Dr. Wang, Chun-Wei |Pamphlets from the health education room | Other health education pamphlets Which information sources of the above did the hospital provide? Did you use any of them? Which were the most helpful?
4. In your opinion, at which phase did you feel short of information: prior, during, or after the treatment?
5. Could you share your nutrition information sources, as detailed as possible? Did you counsel a dietitian?
6. Have you started rehabilitation? How do you access information about rehabilitation?
7. In your opinion, which information is helpful for relieving your stress?
8. Could you share your experience of verifying the information from another person or from the Internet?
9. During the beginning of the disease, what kind of information from other patients would you need the most?

---

[1] 渴望聯誼會

Interviews with medical professionals took place in the NTU Hospital and the interviews spanned from 50 to 79 minutes. The interview guide (Table 3.2) was designed with the purpose of facilitating interaction at the second stage of the interviews as well as deepening our understanding of the answers from all the participants of this study.

Table 3.2 Question set for interviews with medical professionals

1. During their first appointment, how did you tell the patient about the conditions and the needed medical treatment? How long was the appointment?
2. Does patients often ask questions concerning the illness including rehabilitation, nutrition, and prevention?
3. Do you take the initiative to provide information not directly related to the medical treatment? What information do you provide concerning the patient's rehabilitation? What about illness prevention-related information? And about the patient's diet? Do you introduce your patient to nutritionists or other rehabilitation physiatrists?
4. Which websites do you recommend to patients to visit?
5. Do you recommend patients to use information sources provided by NTU Hospital? Cancer Resource Center | Public lectures (Kewang Association) | Educational videos on NTU Hospital official website | HOPE Foundation for Cancer Care's booklets | Leaflets from the health education room| Other health education pamphlets
6. Does patients or their families discuss with you information from the Internet?
7. What do you think about the interaction between the patient / patient' family and the medical staff?
8. What do you suggest to patients in order to relieve stress?

3.3 Data transcription and data analysis

All of the 12 interviews of the first round were fully transcribed during the period from May 24th to June 7th, 2016 and 5 second-stage interviews as well as 4 interviews with medical personnel were transcribed by December 5th 2016. Transcription of the interview data was made by the students mainly recruited from National Taiwan University who all signed a non-disclosure agreement, were given transcription guidelines, and all the transcribed texts were reviewed by the author.

ATLAS.ti software program designed for qualitative data analysis was used for classifying the data from all the transcripts into codes. Data analysis is usually guided by research questions of the study and predefined themes. In this research, open coding, auto-coding, and analytical coding techniques were employed. Open coding was completed by first using word documents and ATLAS.ti, inductively assigning codes to the transcribed data while reading through the texts. Thereafter a more deductive approach was applied based on the main topics of the study such as information-seeking behavior and information sources; analytical coding was partially used as well. Subsequently, auto-coding function in ATLAS.ti was used for retrieving all the information related to major themes without omission ensuring the quality and comprehensiveness of the analysis. All the 17 interview transcripts were combined together and the following strings of keywords (example is shown in Figure 3.2) were used in order to collect all the related information, the most important of them are

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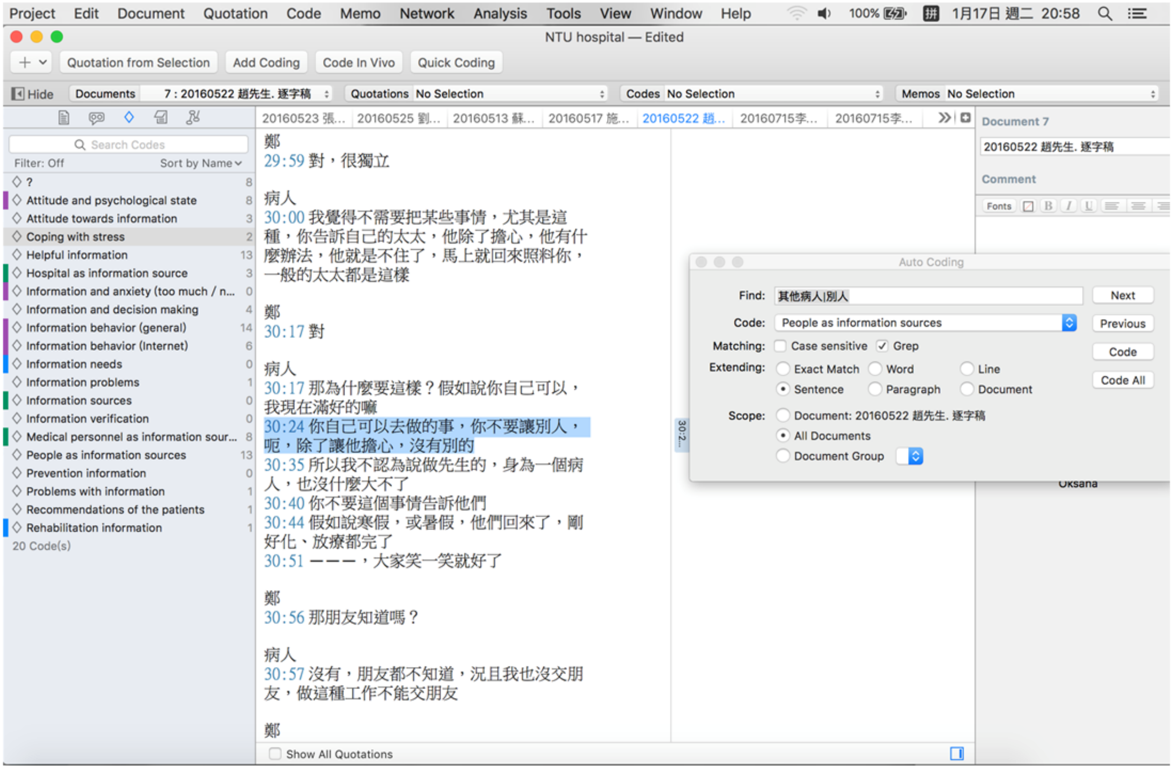
presented below[2]. Finally, the codes were grouped by analytical coding and major themes were identified.

Figure 3.4 Interface of the software during auto-coding



Documents 7 : 20160522 趙先生. 逐字稿

Quotations No Selection

Codes No Selection

Memos No Selection

?	8
Attitude and psychological state	8
Attitude towards information	3
Coping with stress	2
Helpful information	13
Hospital as information source	3
Information and anxiety (too much / n...	0
Information and decision making	4
Information behavior (general)	14
Information behavior (Internet)	6
Information needs	0
Information problems	1
Information sources	0
Information verification	0
Medical personnel as information sour...	8
People as information sources	13
Prevention information	0
Problems with information	1
Recommendations of the patients	1
Rehabilitation information	1

20 Code(s)

鄭
29:59 對，很獨立

病人
30:00 我覺得不需要把某些事情，尤其是這種，你告訴自己的太太，他除了擔心，他有什麼辦法，他就是不住了，馬上就回來照料你，一般的太太都是這樣

鄭
30:17 對

病人
30:17 那為什麼要這樣？假如說你自己可以，我現在滿好的嘛
30:24 你自己可以去做的事，你不要讓別人，呃，除了讓他擔心，沒有別的
30:35 所以我不認為說做先生的，身為一個病人，也沒什麼大不了
30:40 你不要這個事情告訴他們
30:44 假如說寒假，或暑假，他們回來了，剛好化、放療都完了
30:51 ———，大家笑一笑就好了

鄭
30:56 那朋友知道嗎？

病人
30:57 沒有，朋友都不知道，況且我也沒交朋友，做這種工作不能交朋友

鄭

Document 7: 20160522 趙先生. 逐字稿

Find: 其他病人|別人

Code: People as information sources

Matching: ☐ Case sensitive ☑ Grep

Extending: ○ Exact Match ○ Word ○ Line ● Sentence ○ Paragraph ○ Document

Scope: ○ Document: 20160522 趙先生. 逐字稿 ● All Documents ○ Document Group

The framework content analysis, which was developed in 1994 by Jane Ritchie

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[2] 病人|其他病友|朋友

其他病人|別人

面對|態度|心態

擔心|緊張|急|害怕|恐懼

網路查|上網查|查網路

驗證|確認|問醫師|跟醫師討論

飲食資訊|保健資訊|營養師|營養|保健品

and Liz Spencer, was chosen for this study as data analysis methodology and structured in the following way:

1. Full transcription of the audiotaped interviews (in Chinese)
2. Familiarization with the transcripts
3. Identification of a thematic framework
4. Open coding (inductive and deductive) according to the research questions of the study
5. Second-stage coding using the auto-coding technique
6. Selection of the most relevant codes, merging and deleting codes
7. Data analysis: thematic (categorizing) and explanatory (interpretation)
8. Additional step: translation of Chinese quotes into English by two English-Chinese bilingual native speakers

3.4 Research quality

The issue of quality and credibility of qualitative research is highly important and was ensured in a few ways in this study. First, consistency was achieved by using almost identical interview guides for each of the interview phases. Second, triangulation, i.e. usage of multiple methods, is employed in the form of multiple investigators. All the interviews were conducted by two people – the author and the

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supervisor's assistant, Cheng, Pei-Yi. This supported making interview-sessions comprehensive, smooth, improved preparation and discussions after the interview that enhanced our understanding of the received information afterwards. The content analysis presented in this chapter was reviewed and commented by Cheng, Pei-Yi (peer checking), thus making it more complete and credible. In case of the second stage interviews, the content of the interviews recorded at the first meeting was discussed with the participants; therefore partial member checking took place as well.

Moreover, during the period of time from July 11th to the middle of August 2016 four workshops with the CCDM consulting company were organized, and in June 20st one discussion session with NTU Hospital doctors in NTU Hospital took place for the purpose of discussing the transcripts' content and preliminary research results. Additionally, another type of triangulation – data triangulation – was used in this study. Specifically, two methods of data collection were applied – observation and in-depth interview methods.

Third, utilization of the software ATLAS.ti guarantees a more complete data analysis by preventing omission of any related data as compared to rereading transcripts and using in-text search. Most importantly, by extracting the data using a

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few keywords at the same time, it is possible to get a more holistic understanding of each interview text and identify the most relevant themes.

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Chapter 4 Research results

As was stated earlier, this study uses two types of data collection: observation and in-depth interviews. In-depth interviews are the major source of data while observation is an additional method. One more data source – a basic questionnaire – was designed as a preparatory tool before conducting the interviews. Observation results will be presented first, followed by the analysis of basic questionnaires and interviews' content research results will be presented last.

4.1. Observation

The following text is written in first person and in present tense in order to make the observation description as vivid as possible.

I am in the old building of National Taiwan University hospital, on the second floor, in the otolaryngology department. The waiting room is full of patients; the time is 13:30. The afternoon consultation sessions are about to start, but there is already a patient inside the consultation room. I knock on the door and doctor L.'s assistant let me in. Dr. L. is one of the doctors who is involved into the Management department's ZOHUE platform project, and he is one of the most famous specialists in treating neck and head cancers in NTU hospital. Today the doctor will help me recruit patients

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for the subsequent interviews. I am told to stand in the back of the consultation room and have the opportunity to observe a few real-life consultations.

Dr. L. cheerfully greets each patient and checks their current situation in a very rapid manner; I see him switching between two adjacent rooms, almost running. Standing in the back, I am contemplating about the limited time of consultations – by my estimation, each consultation last on average about five minutes, and there are as many as almost fifty patients registered for consultation this afternoon. Maybe five minutes or less is enough for a specialist to screen a patient’s condition, but is it enough for the patients? What if they have questions they want to ask? If time does not allow them to discuss their questions with a doctor, how do they cope with them? It is not the first time I witness medical consultations in Taiwanese medical organizations that last for a very short time. However, most of the patients visiting Dr. L. are cancer patients or cancer survivors, so I assume that suffering from such a serious disease, they must have numerous questions or doubts about treatment or after-treatment procedures, etc. Also, the fact that I come from a country (Russia), where medical consultations are on average no shorter than fifteen minutes, makes me feel even more puzzled.

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I keep pondering about these questions until I am asked to move to a tiny room intended for health education (which is written on the door) but is also used as a medical treatment room and ultrasound room. I notice how crowded it is there as I wait for patients – there are patients, doctors, and researchers in there. In that room, I meet a doctoral student in nursing, researcher F. After observing me for a while, researcher F. reveals her curiosity by asking me about our project. Ten minutes later we are involved in an active conversation lasting half an hour (an unplanned interview), and researcher F. is indeed a treasure trove of information. Not only does researcher F. give me the contact information to one of the health case managers of the ear, nose, and throat department, but she also shares very valuable information regarding information provision to patients with me from the perspective of a nurse and a researcher. I asked researcher F. about the printed materials distributed to patients and is told that comprehensive and well-structured educational materials exist only for one type of cancer – oral cancer. The reason is that there is a large non-profit medical Yangguang Foundation[3] in Taiwan, which, among other projects, additionally leads oral cancer care development. During my next visit for recruitment

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[3] 陽光基金會

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the following week, researcher F. kindly brings those printed materials about oral cancer care to me. I continue reflecting upon this finding and two weeks later talk to researcher F. one more time to make sure that in Taiwan there are no good sources of well-organized information about other types of cancer provided by authoritative foundations or organizations. Researcher F. states that there are two other organizations, the Hope Foundation and Association of Laryngectomees, that provide some related information, but it is still relatively scattered and incomplete. A question rises in my mind – why is there so little official information provided in regard to nasopharyngeal cancer and from what sources do NPC patients search for information? According to statistical data, NPC cancer is the leading type among HNC cancers in Taiwan (this statistical fact was stated by the abovementioned Dr. L. during a public lecture he held last year which I attended at NTU hospital). Furthermore, this type of cancer shows a dangerous trend of an increasing number of younger men to be among the newly diagnosed (this was also stated by researcher F., during our first conversation, and all of the youngest interviewees from our sample were NPC cancer patients, 1 woman and 3 men). I ask researcher F. how and where the health-related informational leaflets are distributed and is told they are primarily placed in wards

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and patients are free to take them. However, researcher F. have noticed that they are not taken very often. Another channel of distribution is via nurses or doctors. For instance, researcher F. usually recommend patients to refer to these printed materials and encourage them to check Yangguang foundation’s webpage (primarily for oral cancer patients) since she believes that information is better presented and explained there than in the hospital’s leaflets. Personally, I had not notice any leaflets in the health education room I was in during my time there.

While being in the radiotherapy section’s waiting hall I have spotted a few posters on the walls with rather rich information regarding side effects from treatments and coping methods. Also, informational lectures have been broadcasted non-stop on the two TV’s screens. I have also located a health education room and found it more comfortable and larger than the one on the second floor. Interestingly, this room was not used during my time being in the waiting hall. I spent approximately two and a half hours in the waiting room in the radiotherapy department.

Two venues in NTU Hospital were observed – ear, nose, and throat department and radiotherapy department, both located in the old building of the hospital. A

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greater understanding of the context of a patient’s treatment process and informational sources in the waiting halls and health education rooms was gained and was helpful for discussing information issues with the patients and caregivers.

4.2 Basic questionnaires’ analysis and interview data

In this section the basic questionnaires’ findings from a limited sample size of the participants will be presented. These findings are nonetheless interesting and useful for the following interviews’ content analysis.

For the first interviewing round, 12 interviews were successfully conducted during May and 1 interview in July 2016 in NTU Hospital or other locations chosen by the patients. However, the data of patient N was omitted in the results of Table 4.1 for the first round due to a technical problem while recording; no transcript was written and thus no analysis was performed. Thus, only 12 interviews were included in the first phase and exploratory interviews conducted in October and December 2015 were excluded. The second round of the interviews consisted of 4 patients and 1 caregiver, all of whom participated in the first round as well; caregiver L attended the interview with patient K. Lastly, the interviews with medical professionals were held from June 28 to September 4 2016 in NTU Hospital.

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In-depth semi-structural interviews lasted between 24 to 141 minutes and became a major source of this study's primary data. Chinese was used as the communication language for all the interviews and each interview was held jointly by the author and the advisor's assistant.

The subsequent table (Table 4.1) presents basic information of the interviewees who participated in the first stage of interviews obtained from the questionnaires, with additional information about the interview details. It includes an alphabetic code assigned to each patient, gender, age, occupation, interview date, length and location; age at which cancer was diagnosed, cancer type, stage and treatment phase. Information about the medical treatments received is omitted since it is not highly relevant to this section's analysis. Among the interviewees, ten were male and two were female; ages ranged from 37-71 years old. As to the cancer types, the study includes four NPC patients, three from the first interview phase and one from the second; 3 patients with tonsil cancer, 4 patients with oral cancer, and 1 patient with both throat cancer and lymphoma. The sample is seen heterogeneous in terms of age and cancer types. Most of the respondents are in the follow-up stage of cancer treatment. Table 4.2 introduces basic information of participants from the

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second phase of interviews.

Table 4.1 Interviewees' basic information. Interview phase 1

Patient's code	Gender	Current age Age when diagnosed	Occupation	Interview length (mm:ss)	Interview date (DD/MM)	Interview location	Cancer type and stage	Cancer continuum stage
Li: A	Male	56 56	Self-owned business	59:13	4/5	NTU hospital	Oral cancer 0-1	follow-up
Chen: B	Male	40 55	Self-owned business	61:21	11/5	Patient's home	Oral cancer (tongue) 3-4	follow-up
Notes: Patient B was interviewed with the help of his wife and communication was primarily via notes								
Jiang: C	Male	48 46	Services Flexible job	43:26	13/5	NTU hospital	Oral cancer (tongue) 0	follow-up
Su: D	Male	71 61	Commerce	57:43	13/5	Respondent's office	Tonsil cancer 2	follow-up
Lin: E	Male	58 56 and 58	Services Half-retired	50:49	17/5	NTU hospital	Oral cancer 1	follow-up
Shi: F	Male	41 41	Commerce	24:10	17/5	NTU hospital	NPC 4	under treatment
Zhao: G	Male	64 64	Research	94:46	22/5	Cafe close to patient's home	Tonsil cancer 3-4	under treatment
Zhang: H	Male	60 59	Flexible job	136:29	23/5	Starbucks cafe close to patient's home	Tonsil cancer 4	follow-up
Zhuo: I	Female	60	Family member					
Notes: Patient H and family member I were interviewed together								
Liu: J	Male	59 39	Retired	68:43	25/5	NTU hospital	NPC 2	follow-up
Xie: K	Female	37 35	Government office worker	107:31	29/5	Taoyuan city, in a cafeteria	NPC 4	follow-up
Li: M	Male	60 Ms. Zheng: 59 59	Relative of the patient, Ms. Zheng, government official worker	91:23	16/7	Patient's house	Throat cancer 1 Lymphoma 3 (Ms. Zheng)	under treatment

Notes: Ms. Zheng attended the interview, but with very little participation due to weakness

Table 4.2 Interviewees’ basic information. Interview phase 2

Shi: F	Male	41 41	Commerce	24:10	17/5	NTU hospital	NPC 4	under treatment
Zhao: G	Male	64 64	Research	94:46	22/5	Cafe close to patient’s home	Tonsil cancer 3-4	under treatment
Xie: K	Female	37 35	Government office worker	140:59	29/5	Taoyuan city, in a cafeteria	NPC 4	follow-up
Li: L	Female	- 64 59 (Mr.Li)	Family member; patient – father, Mr. Li				NPC (Mr.Li) 3-4	follow-up
Patient K and family member L had a joint interview								
Zeng: N	Male	60 59	Retired	49:58	20/7	Patient’s home	NPC 4	follow-up

The information provided by 12 participants from Table 4.1 (first interview phase) prior to the interviews is analyzed in this section. In chapter 3 the questions from basic questionnaire were listed, and the questions 8-11 will be the focus of the consecutive analysis:

8. problems encountered
9. sources of information
10. whether previously participated/currently participates in the activities of any

cancer-related associations or patient groups and which ones

11. whether they usually follows any blogs of other patients, other patients' family members, or medical doctors

Starting from question 8, some interesting findings are exhibited in Figure 4.1. In total 9 responses out of 12 were received. 7 respondents indicated that psychological stress was one of the major problems; five other problems that were mentioned are insufficient medical information, financial burden, as well as three problems related to communication: with medical personnel, with other people, or insufficient communication with patients who suffer from the same illness. What is noticeable is that in the hospital the author did not observe information provided for alleviating psychological stress apart from one booklet (designed by the Hope Foundation for Cancer Care) that was presented by a cancer patient's family member during one of the exploratory interviews. Moreover, keeping in mind how brief and short consultations in the hospital are, we can infer that doctors and nurses are not able to provide necessary help for stress relief. During our interviews we discovered a few roots of the psychological burden. Detailed description of the reasons for psychological problems exceeds the scope of this paper due to our focus on the

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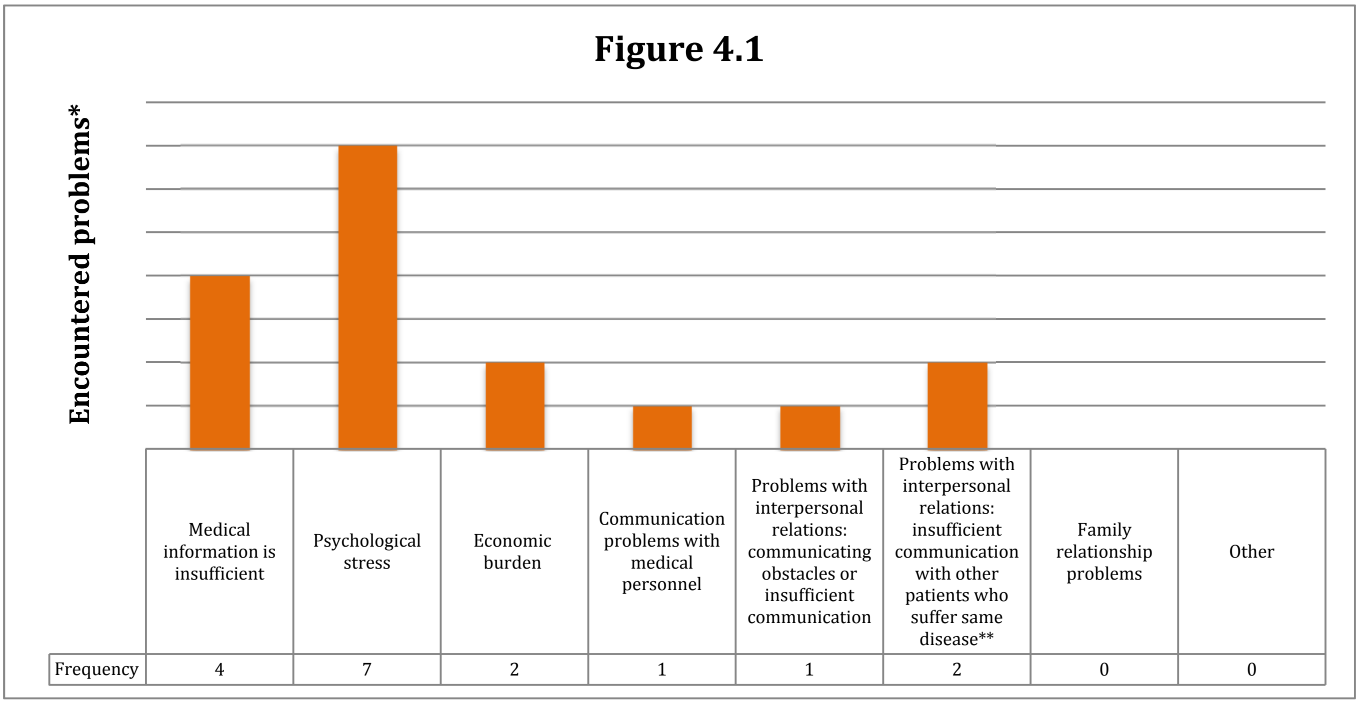
informational needs and sources, but the author preliminary suggests that some stress triggers such as uncertainty, especially about future as repeatedly stated by a few interviewees, might be effectively addressed by information provision.

Figure 4.1 What problems did you encounter after you were informed about your diagnosis or during the treatment process (multiple choice)?



	Medical information is insufficient	Psychological stress	Economic burden	Communication problems with medical personnel	Problems with interpersonal relations: communicating obstacles or insufficient communication	Problems with interpersonal relations: insufficient communication with other patients who suffer same disease**	Family relationship problems	Other
Frequency	4	7	2	1	1	2	0	0

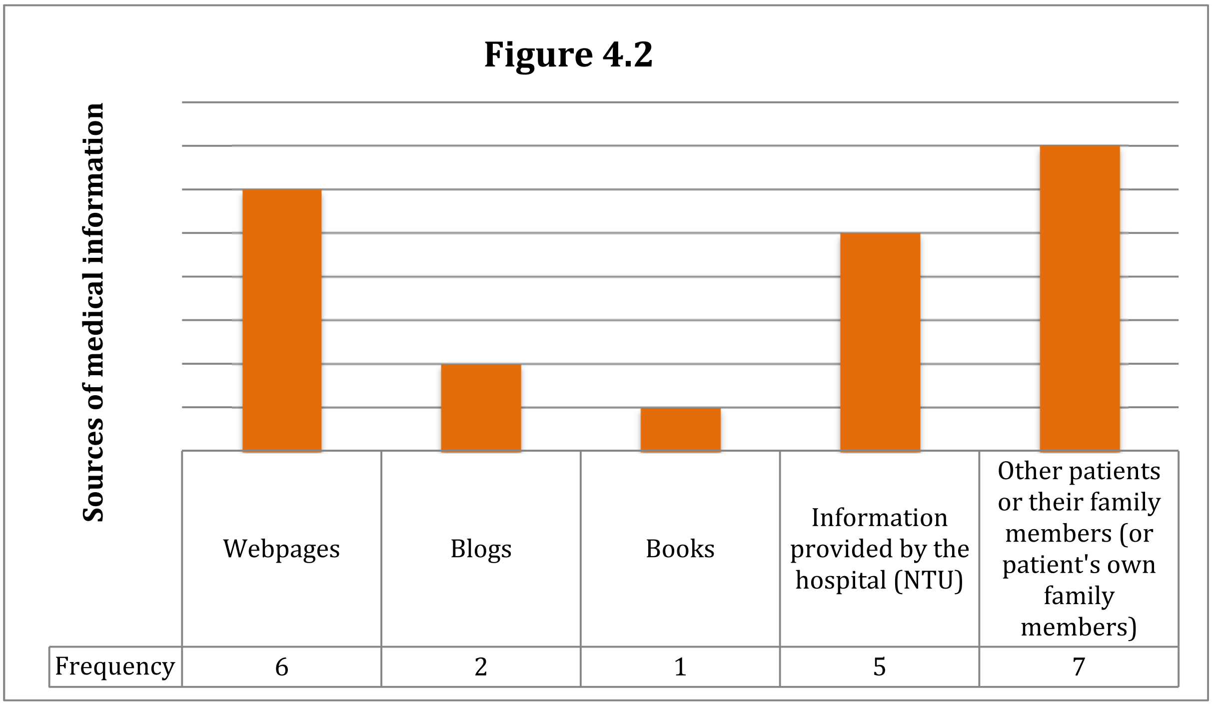
Notes:

*Encountered problems – after being informed about the diagnosis and during the treatment

** 1 response was made in regard to the situation 20 years ago

In the next section the sources of medical information, provided as answer to question 9, were analyzed. Three main sources of information that were stated are other patients or their family members (or in 1 case, the patient's own family members), information provided by the hospital, and webpages; 1 respondent chose none of the listed information sources. It is worth emphasizing that the major source was other patients or their family members. This finding appeared again in the following interview content analysis.

Figure 4.2 Which were your sources of medical information after you were informed about your diagnosis or during the treatment process (multiple choice)?



As to the questions 10 (“whether previously participated/currently participate in the activities of any cancer-related associations or patient groups and which ones”) and 11 (“whether usually follows any blogs of other patients, other patients’ family members, or medical doctors”), only 1 respondent provided answer “yes” and listed detailed names of about ten organizations, patients’ groups, and blogs. It is a striking finding in two aspects: first, it indicates that patients probably do not possess information related to patients communities; second, patients and family members did not recall this information, despite some respondents during the interview mentioning that they did refer to other patients' diaries and blogs.

4.3 Interview content analysis using the framework method

For the content analysis three topics were predetermined – information-seeking behavior, information sources, and information needs – the topics that correspond with this study's research questions. In total approximately 661 pages of the transcripts were analyzed. During partially deductive and partially inductive analysis, a series of codes emerged, in total 22 codes. These 22 codes then were merged or deleted during the process of refinement. Finally, 9 main codes were selected and are presented as categories in Figure 4.3:

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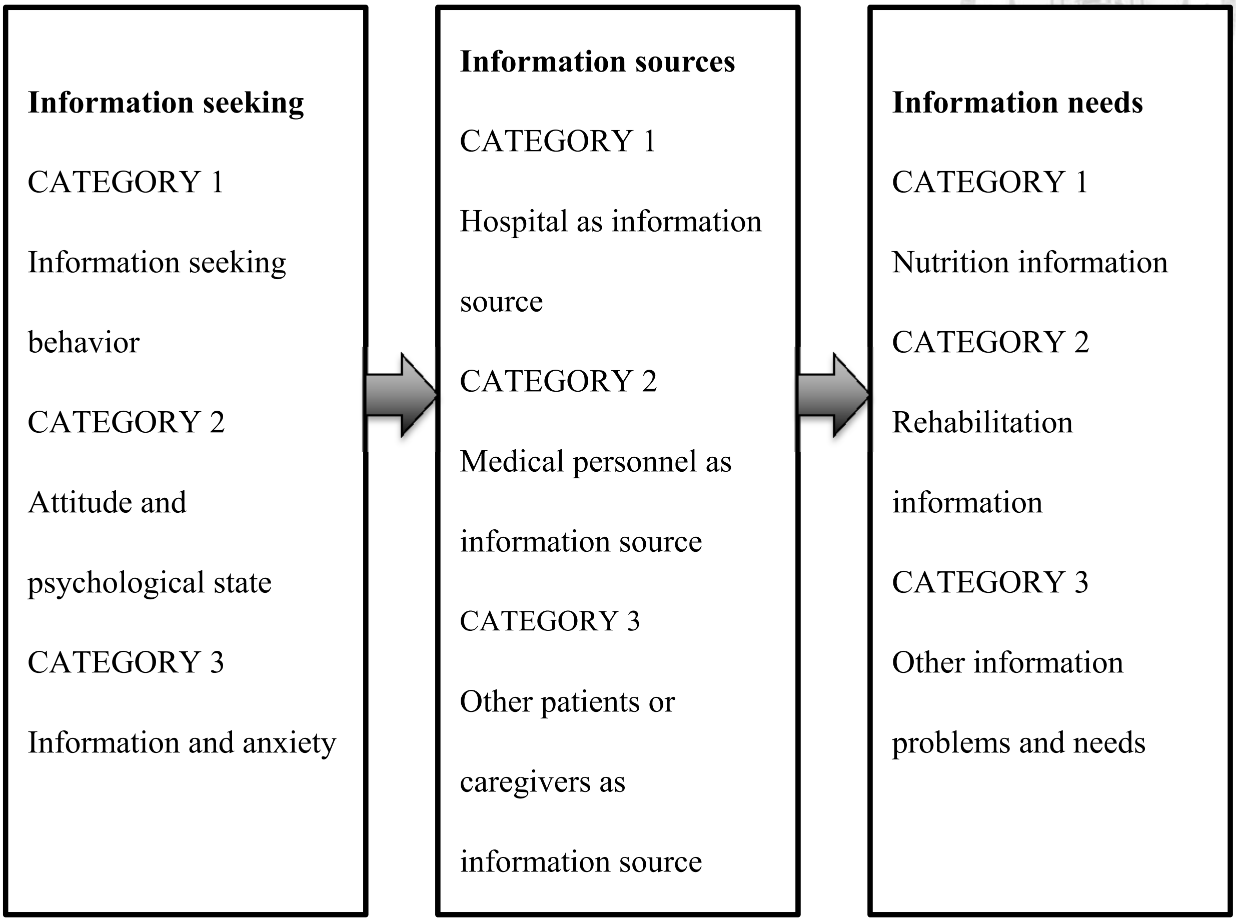
Figure 4.3 Themes and categories of the content analysis



During the first stage of the thirteen interviews, the cancer treatment process was explored, we questioned about the treatment itself, about the patients' psychological state, and the thoughts the patients had at that time. We also discussed aspects such as sources of information and social interactions with people or medical staff. These discussions gave us a more complete understanding of the context of the patients' experience from the onset of the disease to the treatment itself and to the period after the treatment ended. After this stage we discovered that patients did not share much about their social life and feelings. Presumably this is due to the gender disparity of the participants – eleven of them were males. It should be noted, however, that in general the majority of patients with head and neck cancer are males.

The physical process of the treatment was rather similar and standardized among the participants. However, information acquisition process differed, therefore it was decided to conduct additional interviews with the patients and medical professionals to explore the topic of information-seeking behavior.

In the second stage of interviews with the patients the main focus was placed on the specific types of information that was used and how it was searched for. We thoroughly examined the usage of hospital information sources as well since the hospital is one of the most credible channels to acquire the specialized information. In our series of interviews with medical professionals, doctors and one medical case manager shared with us what information was provided, how it was provided to patients at different stages of the treatment, and what types of information lacked adequate provision.

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Only the most representative quotes were selected to be presented in the research results, and one sample of a transcript of an interview with patient K can be found in Appendix 4. The interviewees' quotes were translated into English by Chinese-English bilingual speakers in order to ensure the authenticity and quality of the translations. Original quotes in Chinese are cited as well for comparison. "Stage 1" or "Stage 2" in the description of a quote's source indicates the first or the second stage of the interview with a participant, since there were two interviews in some cases. In this part of the study, "we" implies the author and the professor Yu, Jiun-Yu's assistant, Cheng, Pei-Yi, the two interviewers of the participants.

Information seeking behavior

The first topic "information seeking behavior" is described by the three main categories: information-seeking behavior, attitude and psychological state, and information and anxiety.

CATEGORY 1: Information seeking behavior

This category consists of information acquisition, assimilation, retention, and verification issues.

1. *Searching for information or not searching at all when the symptoms appeared or the diagnosis was stated*

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The participants were asked to call to memory their first symptoms and point in time when they received the diagnosis. Then they were asked whether they undertook any search of information regarding those symptoms or disease; subsequently, they were questioned whether they searched for any other unusual symptoms that emerged during the cancer continuum.

Patient F reported the following:

◆ At that time, I tried searching online by myself, you know? The Internet tells you general information on NPC cancer. If your nasopharyngeal has tumors that are malignant, then your chances of getting nasopharyngeal cancer are above 80-90% (F 03:53 Stage 1)[4]

{Male | 41 y.o. | NPC stage 4 | under treatment}

Surprisingly, this behavior wasn't very common for the participants. Nor did they mention that family members or caregivers searched after information for them at the onset of disease.

2. Looking for answers to questions

Asking questions and searching for information are central steps in the information seeking process. One category of patients was used to only asking doctors in case of any questions:

---

[4] 那時候我會自己上網查嘛，它都說你鼻咽癌的話大概，那鼻咽的腫瘤有沒有，惡性的話，他大概就佔百分之八九十以上了 (F 03:53 Stage 1)

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◆ None of it was useful. I think the only way to know for sure is to go see a doctor (E 42:39)[5]

{Male | 58 y.o. | oral cancer stage 1 | follow-up}

This patient E visited doctors on a very frequent basis and did not search online or for other printed information himself. This behavior is similar to a few other participants as well. Also, one patient and his caregiver, his wife, did not use Internet at all.

A few patients combined two methods of information seeking – actively asking doctors and searching for information online. Yet some of them preferred to use Internet extensively due to the abundant information presented online, but did not discuss questions with doctors.

Two participants, C and G, showed a very passive attitude towards information search for answers: they neither asked doctors nor did they look for information online. Patient G did not seek for information by any method at all:

◆ I don’t know, because I don't use the Internet and also don’t go and ask around (G 47:27 Stage 1)[6]

{Male | 64 y.o. | tonsil cancer stage 3-4 | under treatment}

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[5] 我覺得都沒有，我覺得唯一有用的就是找醫師而已 (E 42:39)

[6] 我不知道，因為我不去上網，也不去打聽 (G 47:27 Stage 1)

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Two other participants felt uncomfortable using limited resources such as doctors' time for themselves:

◆ It's because I don't want to ask too many questions and take away all of the whatever from other patients (M 87:09)[7]

{Male | caregiver | 60 y.o. | throat cancer stage 1, lymphoma stage 3 | under treatment}

◆ So you don't feel much when you're sick yourself, but you feel for the young people who are sick (G 71:09 Stage 2)[8]

{Male | 64 y.o. | tonsil cancer stage 3-4 | under treatment}

3. Interaction with other patients, other family members, or caregivers in the hospital

One family member I and participant K had the following experience in the waiting rooms of the hospital:

◆ People end up coming to ask us and we then share with them (I 39:27)[9]

{Female | caregiver | 60 y.o. | tonsil cancer stage 3 | follow-up}

◆ In order to know more about other people's (pause) experiences, so when I go to the hospital and see people who are there to see the doctor or doing radiation therapy, I would always go ask those who have nasogastric tubes, asking them about their tubes

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[7] 因為我不希望問太多問題相對剝奪其他病人的一切什麼的 (M 87:09)

[8] 所以你對自己生病沒有太多感覺，你反而是對於那些年輕的人生病有感覺 (G 71:09 Stage 2)

[9] 變成人家會來問我們，那我們也會分享 (I 39:27)

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and what they feel like, being very detailed. You have to be proactive in going to find people to ask (K 62:22 Stage 2)[10]

{Female | 37 y.o. | NPC stage 4 | follow-up}

Patient K shared an important comment with us:

◆ …it's because the doctor is unable to tell you definitively what exactly your condition will be like later on (K 62:56 stage 1)[11]

{Female | 37 y.o. | NPC stage 4 | follow-up}

4. A patient or a family member or a caregiver looks for information?

The majority of the interviewees did not mention that family members or caregivers actively looked for information for them. However, caregivers I and L reported they were in control of information seeking and information organization. In response to the question whether they would read the information provided by the hospital, caregiver I replied to the question ending with:

◆ Of course it is me who reads, not the patient (I 79:19)[12]

{Female | caregiver | 60 y.o. | tonsil cancer stage 4 | follow-up}

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[10] 我那時候為了要多知道別人的(停頓)經歷嘛，就是我去醫院如果有看到有人在看門診或是放療的時候，我都會，有插鼻胃管的，我都會跑去問，問他說欸你這個鼻胃管怎麼樣啊，感受什麼什麼，都會問很細，就是要變得要自己主動去找人問 (K 62:22 Stage 2)

[11] ……因為醫生他也沒辦法很明確的跟你說你接下來狀況會怎麼樣 (K 62:56 stage 1)

[12] 看的當然是我啦，不會是病人啦 (I 79:19)

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Apparently, family or caregiver plays an important role in information and resources search, especially during the exhausting treatment period.

5. *Information behavior before visiting doctor*

Few patients said that they recorded their questions or prepared their questions prior to the doctor's visit. Patient K, for instance, used to prepare thoroughly as shown in the quote below:

◆ So, I started doing my own research. Now, every time I have a question, I'll write it down and ask the doctor at my next consultation. I now feel that doctors are too busy. Their time is limited. Within this small window of time, I need to ask the doctor the right questions so that the doctor can answer them (K 46:33 Stage 2)[13]

{Female | 37 y.o. | NPC stage 4 | follow-up}

Furthermore, this patient would search for additional information on the Internet after her visits to doctors.

6. *Information recording and storing*

Participants I and L, both of whom are caregivers, used diaries to record treatment information as well as emotional states, problems, for example as in the case of caregiver I:

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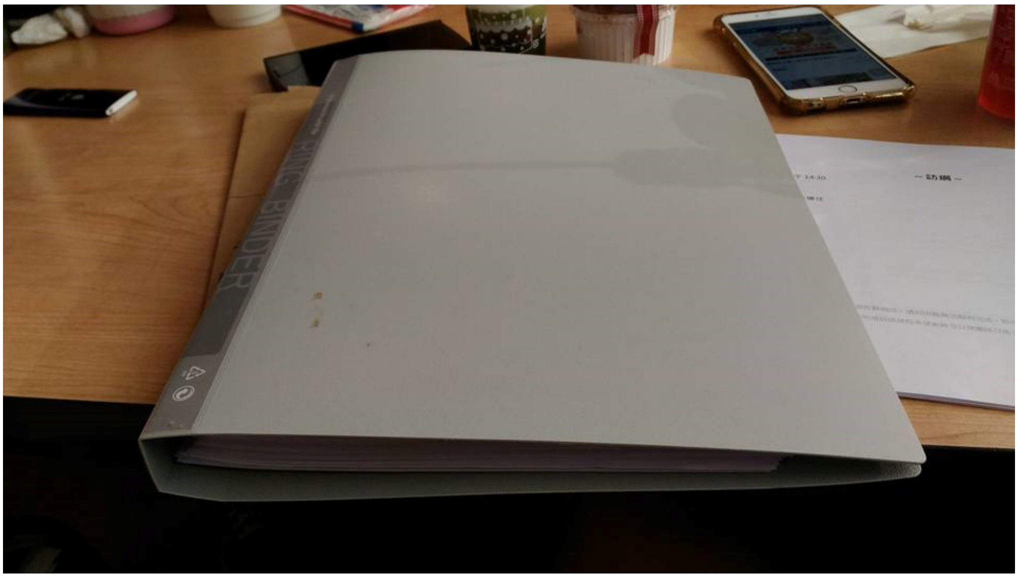
[13] 我就開始會做功課， 所以我現在每次我想到什麼問題我就會寫起來，下一次看診我就會問醫師，我現在覺得說醫生他真的太忙了，他的時間有限，所以我們要在很短的時間抓到重點問醫生，醫生才能回答你 (K 46:33 Stage 2)

◆ When he was ill, I prepared a piece of paper, size A4. It’s because I needed to note down a lot of things about the food I made for him everyday as well as the portions. Also, during this time, I noted down his many emotional reactions. No, no. There’s one more thing…let me be honest, my own emotional release as well…(I 103:24)[14]

{Female | caregiver | 60 y.o. | tonsil cancer stage 4 | follow-up}

Another patient K showed a very active behavior in information recording:

Figure 4.4 Information collection and organization, participant K



Information was collected from different sources, printed out and then put together in a folder in a systematic and organized manner. Parts of information that were not fully understood or were seen as important were usually underlined by the

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[14] 我有在他生病的時候，我自己就準備A4的那種紙，因為我每天要給他做很多食物，吃多少，還有他在這中間有哪些情緒的反應，不，不，還有一點，我現在講實話，也是我情緒的發洩…… (I 103:24)

patient. The patient perused information both in Chinese and sometimes in English. The list of frequently used online sources by this patient is provided in Appendix 3. This behavior of information organization is the only case that we encountered among the participants.

7. *Information on the Internet is regarded only as reference*

Patient F would spend about 3-4 hours a day looking for information online, but he admitted the following:

◆ Yeah, I'd say the information online is only for reference…I just want to get a rough idea. I wasn't all that serious about it (F 10:12 Stage 1)[15]

{Male | 41 y.o. | NPC stage 4 | under treatment}

One of the arguments that was emphasized is that each patient's situation is different and thus information online should not be completely trusted.

8. *Verification of online or other information*

All the participants were asked to comment on how they verify online information or information received from other people, or how they choose information. Patient F explained his view on this as follows:

◆ I don't believe the things I see on the Internet. I only look at it. I'll look. Yeah. Well, I look online. I just want to take a peek and then I can make comparisons. Yeah. That's

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[15] 對啊那個網路上只是做參考而已啊……加減看一下而已啊，並不是說很認真的在看待這個事情 (F 10:12 Stage 1)

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about it (F 08:25 Stage 1)[16]

{Male | 41 y.o. | NPC stage 4 | under treatment}

Another patient, patient J, would look at all the information he found without special selection. What is worth mentioning is that almost all the patients that we interacted with reported they would not discuss information that they had doubts or questions about with their doctors.

In this part we divided information-seeking behavior into eight subcategories. These subcategories illustrate differences in information-seeking behavior exhibited by the participants. It is assumed that this variation can be explained by demographic characteristic differences such as age and gender. Younger participants used Internet more frequently and extensively in comparison to older ones, and female participants showed more active behavior in information acquisition than males.

CATEGORY 2: Attitude and psychological state

The author believes that the patients or the patients' family members who agreed to be interviewed were relatively positive in general in their attitude towards the disease – the majority of the interviewees described themselves as "optimists" or

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[16] 我不會去信網路上的東西啊，我只是看，我會看啦，對呀，因為我會去看說，我也只是說稍微看一下，然後說去多方比對，哦，大概是這個樣子，這樣子 (F 08:25 Stage 1)

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"optimistic" during their narratives when were asked about their feelings. This category is combined of three subcategories: attitude towards the disease, psychological state, and attitude transformation.

1. Attitude towards the disease

Attitude towards the cancer diagnosis and treatment usually undergoes a few stages from rejection to acceptance and action. Importance of maintaining the right attitude can not be overestimated, as family member M shared his view on this very clearly:

◆ Everyone's mentality is…how do I put this? It makes a difference whether you face an issue head-on or shy away from it. Your mentality is more vital than any kind of medicine or nutritional supplement (M 82:26)[17]

{Male | caregiver | 60 y.o. | throat cancer stage 1, lymphoma stage 3 | under treatment}

Two other patients, A and G, were very similar in their attitude towards the disease:

◆ What I want to say is, whatever the situation, just live out a normal life (A 38:38)[18]

{Male | 56 y.o. | oral cancer stage 0-1| follow-up}

◆ I try my hardest to see myself as a normal person. I'm just unemployed (F 19:52 Stage 1)[19]

{Male | 41 y.o. | NPC stage 4 | under treatment}

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[17] 因為每一個人的精神上的一個怎麼講，就是你去面對一個事情你有去面對事情跟你畏畏縮縮的時候效果是不一樣的，比你吃什麼藥比什麼營養品都還重要 (M 82:26)

[18] ……我就想說，反正，就正常過日子 (A 38:38)

[19] 其實我就盡量把自己當作當作正常人這樣子啦，只是沒工作這樣子 (F 19:52 Stage 1)

The attitude of patients A and F is remarkably identical to their behavior in information search. Both of these patients were convinced that “the more you know the more you worry” and adopted a strategy of information avoidance to a larger or lesser extent.

In our study some patients (C, E, G, H) met the diagnosis very unemotionally, did not have an emotional struggle with acceptance, and did not experience such negative feelings as fear very much. It was common for these patients to respond in a manner stated below:

- It happened. It is what it is (C 11:47)[20]

{Male | 48 y.o. | oral cancer stage 0| follow-up}

During the interview it became clear why they have this attitude. There were two reasons: either they had bad habits during their lifetime or a family history of cancer.

- You know how you became like this. You brought it on yourself. It’s your own fault for smoking or eating betel nut. Yeah. You reap what you sow. Had you not taken up these bad habits, the chances of you getting sick would have been lower (E 48:24)[21]

{Male | 58 y.o. | oral cancer stage 0| follow-up}

- I felt nothing even though he said my condition was in its advanced stages. I saw my condition as a minor illness. This is something I had to go through. It is related to my family (H 27:19)[22]

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[20] 阿碰到就碰到了(C 11:47)

[21] 怎麼來就知道了，你自己找來的，誰叫你抽煙、誰叫你吃檳榔，嘿啊，你自己找來的，你沒有這些壞習慣的話，要得的機會就比較少啦……(E 48:24)

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{Male | 60 y.o. | tonsil cancer stage 4| follow-up}

The author can detect commonalities between these patients in their information seeking. They usually did not ask doctors any questions, did not discuss questions during their visits to doctors or they mentioned squandering national resources during our interviews. The author presumes these four patients have some sort of guilt that prevents them from active information seeking behavior in the hospital. Other patients who were diagnosed with cancer despite leading healthy lifestyles and with no records of cancer in their families had one question in the mind - "why me?":

◆ Yes, frankly speaking, I, I, after I heard this I was very surprised, why me ah (D 17:42)[23]

{Male | 71 y.o. | tonsil cancer stage 2 | follow-up}

2. Psychological state

As to the psychological state, most of the respondents were scared, shocked and lost after receiving the diagnosis. Nevertheless, the anxiety level was different throughout the cancer journey for the patients and the family members with the highest levels of anxiety in the pre-treatment and after-treatment periods. Patients had

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[22] 他跟我講末期，我一點感覺都沒有。我把它當成小病看。因為這個是有過程的，這是與我家族有關 (H 27:19)

[23] 對，我坦白跟你講，我，我，我聽到這樣子我自己是很訝異說，why me 啊 (D 17:42)

different strategies for lessening anxiety and stress: watching television (F), coming to the hospital frequently (E), staying busy with their work (G), actively acquiring information and looking for social groups (K), or staying positive (F).

3. Attitude transformation

The interviewees that we interacted with often brought up the topic of attitude transformation as stated in one of the quotes:

◆ I really think that relaxing and being at peace is the way to get through this (L 103:04)[24]

{Female | caregiver | - y.o. | NPC stage 3-4 | follow-up}

It's important to note that the catalysts for transformation were different for each of the interviewee. Some patients changed their attitude after numerous attempts to avoid regular cancer treatment but which all were in vain (patient B, for instance). One family member told us it happened after reading a booklet of HOPE Foundation for Cancer Care's guiding how to face cancer and other books (caregiver L); the booklet is provided in Figure 4.4. Faith in doctors or religion helped some patients to adjust their attitude or emotions as well.

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[24] 我覺得真的就是放寬心之後你才有辦法走過來欸 (L 103:04)

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Figure 4.5 The booklet introduced by caregiver L

The participants differed in their attitude towards the disease: some employed avoidance strategies; some showed active management of their cancer treatment; some patients would not have high psychological stress if they understood the reasons that led to cancer. Finally, a few participants introduced the topic of attitude transformation.

CATEGORY 3: Information and anxiety

Two interesting findings in respect to the link between information and anxiety were identified. Some of the patients stated that they would like to avoid additional information due to the fact that “the more you know the more you worry”. Other patients would instead argue that ignorance would lead to fear or would actively search for information to regain control over the disease. Some examples are provided as follows:

◆ I’m afraid that the more I read the more I worry (A 43:47)[25]

{Male | 56 y.o. | oral cancer stage 0-1| follow-up}

◆ Not knowing is terrifying. Uncertainty, I mean. The uncertainty is terrifying (G 80:33 Stage 1)[26]

{Male | 64 y.o. | tonsil cancer stage 3-4 | under treatment}

This controversial result could possibly be associated with the stage of the cancer journey. Elevated anxiety of the patients A and F perhaps can be explained by the fact that they had just finished their treatment recently and were afraid of possible relapse. Patients at the later periods of the disease continuum expressed more active behavior in information acquisition.

Information sources

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[25] 我是怕看越多，越擔心 (A 43:47)

[26] 不知就會恐懼，未知啦，未知會恐懼 (G 80:33 Stage 1)

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After the discussion on information seeking behavior and its categories, the focus now will be shifted to the information sources that were used by the interviewees. The three categories that will be discussed below are: hospitals as information source, medical personnel as information source, and patients or other people as information source.

CATEGORY 1: Hospital as information source

In each of our interviews we asked patients what informational resources provided by the hospital that the patients actually used. In the second stage of our interviews we asked what particular resources they utilized and which of them they found helpful.

1. Helpful materials

As to the sources that patients used during the course of their treatment, the data of which patients used what resources is presented below:

Cancer Resource Center	L
Lectures in the hospital	L, N
Official webpage of NTU hospital	K, L, F
Leaflets provided by Dr. Wang, Chun-Wei	Most of the respondents
HOPE Foundation for Cancer Care’ s Booklets	L
Health education room, waiting rooms	F, L

Other resources:	
Special nurse	G
Research group	A, E
Leaflets from other doctors	K, L

Majority of the patients with whom we discussed information resources in detail indicated that the leaflets provided by Dr. Wang (Figure 4.5) were very helpful, as we can exemplify with the quote below:

◆ Helpful, I think that Dr. Wang, Chun-Wei's *(leaflets)* (F 15:21 Stage 2)[27]

{Male | 41 y.o. | NPC stage 4 | under treatment}

◆ I think *(leaflets)* are excellent (L 24:48)[28]

{Female | caregiver | - y.o. | NPC stage 3-4 | follow-up}

The patient explained the reason why this type of materials is useful:

◆ We'd like a flyer like this where the back gives an example for implementation (L 41:18)[29]

{Female | caregiver | - y.o. | NPC stage 3-4 | follow-up}

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[27] 有幫助喔，應該是王駿瑋醫師 (F 15:21 Stage 2)

[28] 我覺得那個超好 (L 24:48)

[29] ……我們比較需要像這樣子的單張，後面告訴你一個實際的執行例子 (L 41:18)

Figure 4.6 Dr. Wang, Chun-Wei's leaflet

版本日期：2016/06/07

頭頸部伸展運動

★要終身持續頸部復健運動，避免頸部肌肉纖維化

左右轉頭：建議每日 2-3 回，每回 8-10 分鐘，每次轉頸動作維持 1 分鐘，切忌突然或過度用力的轉動，以避免頸部肌肉拉傷

轉向右方後停頓	轉向左方後停頓	耳朵貼肩膀後停頓	換邊後停頓

圖片及資料來源:台大醫學院 護理學系 賴裕和教授 研究團隊 & 台大醫學院附設醫院 復健部 王薏茜醫師

2. *Problems with hospital's information sources*

Difficulties were encountered in searching for some sources like Cancer Resource Center or NTU hospital's official webpage videos. Patient F do not want to enter the Cancer Resource Center because he wishes to distance himself from the disease as much as he can while another one, patient K, told us that she knew about this Center but did not know that it is open for patients. Only one interviewee had entered the Center after receiving recommendation to do so from another person, caregiver L, and remarked that:

- Actually, there is a lot of information regarding nasopharyngeal cancer and head and neck cancer in the Cancer Resource Center. But I've never seen them before and no nurse or doctor would recommend that we go down to find these things (L 09:41)[30]

{Female | caregiver | - y.o. | NPC stage 3-4 | follow-up}

Patients also mentioned that they were not very clear about how the Kewang patient group operates; some of the interviewees had not even head about this group. Also, webpage videos on the official site of the NTU Hospital were found helpful by two participants, K and L, but were difficult to find out as was reported:

- If I didn't click on that by accident while searching up something, I wouldn't have known what it was for the rest of my life (L 52:57)[31]

{Female | caregiver | - y.o. | NPC stage 3-4 | follow-up}

In general, our interviewees showed high reliance on the information provided by their doctors, therefore it could be one of the reasons why they did not search for information themselves. To give an example, they did not seek for other hospital information channels such as the Cancer Resource Center on their own. At the same

---

[30] 其實癌症資源中心裡面有關於鼻咽癌的頭頸部癌症的東西不少，但都是我沒有看過的，然後也都不會在護理師或者醫師的建議下去找到這些東西 (L 09:41)

[31] 我要不是，不知道查什麼東西不小心點到那個，我一輩子都還不知道 (L 52:57)

time, the participants had incomplete understanding of how to search for online lectures or how to join the Kewang patient group.

CATEGORY 2: Medical personnel as information source

Doctors were frequently stated as an important or only source of information: patients E, J, G, I, M highlighted and often repeated during the interview that they trusted their doctors as can be illustrated by the following quote:

◆ I think there’s one saying that’s very important; you must trust what the doctor tells you. I really, this time when he was sick I told him, I believe in the professional knowledge of these three doctors. I trust the suggestions and advice these three doctors have given me. I believe in what the doctors tell me to do. I definitely won’t believe in what others say, that was my belief at that time (I 115:42)[32]

{Female | caregiver | 60 y.o. | tonsil cancer stage 4 | follow-up}

These are the words of patient I’s family member. Based on our interview, their major sources of information were the hospital and doctors. Interestingly, patients rarely mentioned nurses or other medical staff as people whom they would ask questions or interact with. In Taiwan nurses usually do not offer much advice, and patients acknowledge that both doctors and nurses are overloaded with work. Other patients

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[32] 我覺得有一句話很重要，要相信醫生跟你講的。我真的，在他這次生病過程中我告訴他，我相信這三個醫生的專業，我相信這三個醫生給我的意見，我相信醫生告訴我該怎麼做，我絕對不相信，外面所有人跟我講什麼，我那時候信念是這樣 (I 115:42)

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disclosed that they rarely contacted medical case manager in case of some questions, and one of the participants explained his opinion as follows:

◆ Because very little… contact, like doctors consultation, this frequent contact, so that's why I think calling her *(case manager)* is strange, because she doesn't only manage my case, she might manage many different cases, so maybe she doesn't know you well like that, yeah (F 08:32 Stage 2)[33]

{Male | 41 y.o. | NPC stage 4 | under treatment}

This patient's concern was that manager probably was not very familiar with his case as compared to the doctor in charge. Another medical professional that is sometimes assigned to a patient with an advanced cancer stage is a health consultant, but in our research only one participant used this type of service and below is what he said:

◆ I feel this person, her role is very important; *(but)* you don't need to tell me everything. I just need to know what I need to do every day (G 82:27 Stage 2)[34]

{Male | 64 y.o. | tonsil cancer stage 3-4 | under treatment}

This participant viewed the health consultant as an additional source of information that he did not want to receive. He also added that he "couldn't listen and take it in".

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[33] 因為很少……聯絡，像跟那個醫生門診，這個常接觸，所以我才覺得打電話問她*（個管師）*怪怪的，因為她可能不只只有管我這個個案啊，她可能管很多個案，可能她也不太認識你這樣子，對啊 (F 08:32 Stage 2)

[34] 那我覺得這個人，他本身的角色很重要，你沒有必要把一切的事情都告訴我，我只要知道說，我每天要怎麼做就好了 (G 82:27 Stage 2)

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According to the results of the transcripts' analysis, for all the participants doctors were the principal source of specialized medical information. Surprisingly, nurses or other medical professionals did not constitute a source of information that the interviewees would actively use.

CATEGORY 3: Patients or people as information source

1. *Other patients as one of the most important sources of information*

For as many as 10 interviewees out of 15,other patients or people were very significant sources for obtaining information. These findings come from the answers on the question regarding whether patients read or would like to read other patients' stories or blogs, other questions related to information acquisition as well as from their own narratives about the cancer experience. Among the respondents were those who do not search for external information, nor they use Internet, yet they will look for and talk to people with similar illnesses. Below are a few representative quotes on this:

◆ I really hope I can share it with other patients because for us who are sick, when I see him like that, when we see others at the hospital, they receive the treatment before we do.

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Actually, I really want to go ask them what they'll encounter in the process, but I'm afraid to ask them directly, afraid they'll be unwilling to answer…(I 06:07)[35]

{Female | caregiver | 60 y.o. | tonsil cancer stage 4 | follow-up}

- ◆ Right now at the beginning stages of the illness the main thing is to want to know what may happen during treatment (G 38:08)[36]

{Male | 64 y.o. | tonsil cancer stage 3-4 | under treatment}

- ◆ Other people will ask you some things. How many times have you guys done it? Did anything happen in the process? They also hope that they'll be able to learn something through our experience (I 84:40)[37]

{Female | caregiver | 60 y.o. | tonsil cancer stage 4 | follow-up}

- ◆ But in the course of my treatment, I actually would want to read about their *(other patients')* experience (K 19:39 Stage 2)[38]

{Female | 37 y.o. | NPC stage 4 | follow-up}

- ◆ Right, or you can call your relatives and friends to see if they know anyone (K 62:45 Stage 2)[39]

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[35] 我也很希望能夠分享給予其他的病友，因為在生病的，比如說像看到他這樣，我們在醫院看到別人，他們比我們先做，其實我也很想去問問人家說，你們的過程會遇到什麼，可是不敢主動去問，怕人家會不願意答…… (I 06:07)

[36] 現在發病初期就是最主要就是看會想知道說治療中會發生什麼事 (G 38:08)

[37] 別人就會問你一些事情啊，你們做了第幾次啊，中間有沒有怎樣，他們也希望從我們這邊吸取到一些經驗 (I 84:40)

[38] 可是我在治療過程中，我其實想更想要看到的是他們的歷程 (K 19:39 Stage 2)

[39] 對，或者是要打電話給親戚朋友 看他們身邊有沒有認識的人 (K 62:45 Stage 2)

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{Female | 37 y.o. | NPC stage 4 | follow-up}

◆ So I feel that if there are more examples of those who have experienced it, after seeing it I'll feel more at ease (K 63:14 Stage 2)[40]

{Female | 37 y.o. | NPC stage 4 | follow-up}

◆ So if the doctor tells us, I've treated a few who are like you at stage 4 and they were like this and that, after hearing it I will feel a bit more at ease. Yeah（K 63:34 Stage 2）[41]

{Female | 37 y.o. | NPC stage 4 | follow-up}

◆ Yes, people who experienced illness and who did not, they are really different, empathy is really different (K 35:41 Stage 1)[42]

{Female | 37 y.o. | NPC stage 4 | follow-up}

2. *Interest in knowing more about daily lives of other patients*

Notably, two respondents (F, K) told about their desire to know how other people with similar health problems lead their lives daily. However, this information would have to be provided by the patients themselves or their family members, as doctors are not at liberty to share such information. One of the quotes is presented below:

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[40] 所以我覺得如果有多一點有經驗的人的例子的話看了自己會比較心安 (K 63:14 Stage 2)

[41] 就是如果醫生跟我們講說欸，我之前治療過幾個像你們這樣四期的，那他們都怎樣怎樣，我聽了會比較心安一點，對 (K 63:34 Stage 2)

[42] 對，而且，有生過病的人跟沒生病的人，他們真的有差，同理心真的有差 (K 35:41 Stage 1)

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◆ From here *(LINE NPC society)* you can see how others live their daily lives and change their thinking (K 82:06)[43]

{Female | 37 y.o. | NPC stage 4 | follow-up}

3. Each patient's situation is different

Other patients, including those who expressed their need for information from others, revealed their concern about the differences among patients' cancer situations, and thus hesitation towards knowing more about other patients:

◆ Because I'm just consulting them, I won't really use them as my own…yeah. I'm just going to use it as reference and not, yeah, because the most important thing is yourself. Your conditions sometimes are not the same as theirs and although the illness may be the same, but the side effects or after effects may be different (F 02:41 Stage 2)[44]

{Male | 41 y.o. | NPC stage 4 | under treatment}

Patients recognized the fact that each cancer case is different from another and should be approached separately. However, the patients still revealed their great interest in other patients' treatment process and problems. It is possible they would find other patients' stories records helpful, especially if the information has been verified by official medical organizations.

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[43] 你可以從這裡面看到別人怎麼過日子跟轉變心態 (K 82:06)

[44] 因為我也是參考，並不是會真正會拿他們來當自己的那個……對啊我只是會參考看一下而已，並不會說，因為，最主要是自己、你本身的狀況有時候跟他們是不一樣的，因為有時候相同的病可是你的那個副作用或是後遺症有時候會不一樣 (F 02:41 Stage 2)

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Information needs

Information sources were investigated first for the purpose of understanding informational needs of the patients, and in this section information needs will be the center of discussion. As our literature review suggests, information needs are different along the course of the disease. What was discovered is that treatment-related information provided during the early stages is relatively sufficient. In contrast, such types of information as nutrition and rehabilitation were reported by our participants as being inadequately provided. In this section a detailed explanation will be provided.

CATEGORY 1: Nutrition information

For the sake of having better treatment outcomes and maintaining a healthy weight, patients are advised to have sufficient nutrition during the course of the treatment as well as during recovery, and for many it becomes a confusing issue.

1. *Nutrition questions are not discussed with the doctors*

The first that was discovered is that patients usually did not discuss nutritional issues with their attending physicians, and the guidelines they received were very general, as was the information presented in the hospital waiting rooms.

◆ I do not discuss *(questions)* with the doctor, anyway, just follow what the doctor told me

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to do (F 09:46 Stage 1)[45]

{Male | 41 y.o. | NPC stage 4 | under treatment}

This can be explained by the short duration of consultations. Patients also understand that doctors have a limited amount of time and other patients need help as well. However, problems related to nutrition and weight gain usually last from the onset of treatment and during the recovery period. In our study, only two out the fourteen participants, interviewees K and L, searched for other nutrition specialists inside or outside NTU hospital.

2. Searching for extra sources of information on nutrition by visiting a dietician

Only two interviewees, K and L, told they were visiting a nutritionist regularly. One caregiver, caregiver L, who paid visits to the nutritionist regularly with her father, expressed her view as follows:

◆ It's actually a big help. It's strange that the doctor won't come out and tell you to do that (L 48:38 Stage 2) [46]

{Female | caregiver | - y.o. | NPC stage 3-4 | follow-up}

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[45] 不太跟醫生討論，反正醫生叫我做什麼就是跟著醫生做就好 (F 09:46 Stage 1)

[46] 其實幫助很大欸……可是很奇怪醫生也不會主動叫你去看 (L 48:38 Stage 2)

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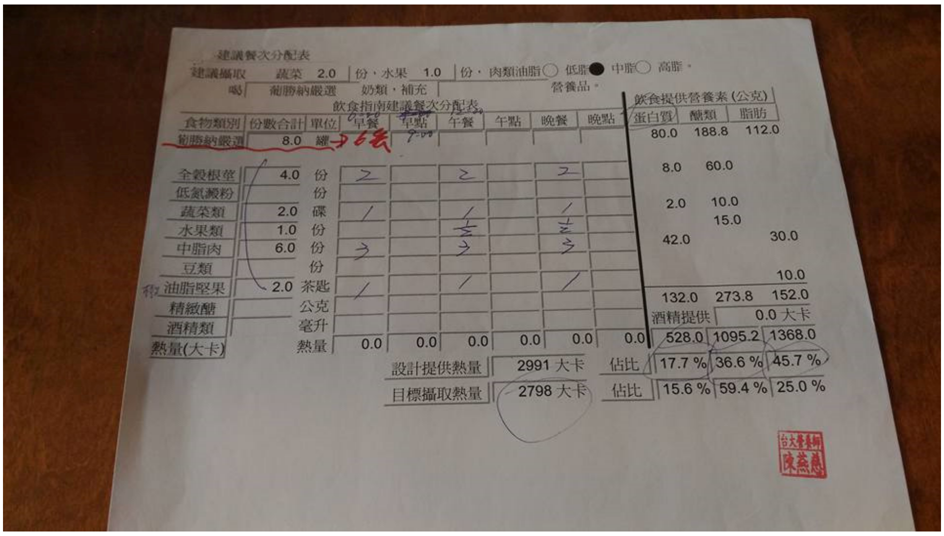
Caregiver L started visiting a nutritionist after one nurse suggested so during the chemotherapy treatment of her father. Since then, they have been visiting the nutritionist in NTU hospital specializing in cancer patients' treatment every three months. Caregiver L expressed her belief that an individualized approach to nutrition is important and shared her father's nutrition card, which she found highly useful (Figure 4.6).

Figure 4.7 The nutrition card of caregiver L's father Mr. Li



建議餐次分配表

建議攝取 蔬菜 2.0 份，水果 1.0 份，肉類油脂○ 低脂● 中脂○ 高脂。

喝 葡勝納嚴選 奶類，補充 營養品。

飲食指南建議餐次分配表

食物類別	份數合計	單位	早餐	早點	午餐	午點	晚餐	晚點	蛋白質	醣類	脂肪
葡勝納嚴選	8.0	罐	→6缶	9:00					80.0	188.8	112.0
全穀根莖	4.0	份	2		2		2		8.0	60.0	
低氮澱粉		份									
蔬菜類	2.0	碟	1		1		1		2.0	10.0	
水果類	1.0	份			½		½			15.0	
中脂肉	6.0	份	3		3		3		42.0		30.0
豆類		份									
油脂堅果	2.0	茶匙	1		1		1				10.0
									132.0	273.8	152.0
精緻醣		公克							酒精提供		0.0 大卡
酒精類		毫升									
熱量(大卡)		熱量	0.0	0.0	0.0	0.0	0.0	0.0	528.0	1095.2	1368.0

設計提供熱量	2991 大卡	佔比	17.7 %	36.6 %	45.7 %
目標攝取熱量	2798 大卡	佔比	15.6 %	59.4 %	25.0 %

台大營養師 陳燕慧

Another patient, patient K, visited a nutritionist once per week during her treatment. However, the doctors in charge usually do not recommend patients to register for a nutrition consultation, so some of the participants asked us whether such specialists were available in the hospital.

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3. Discussing nutrition issues with other patients and caregivers

The majority of the participants did not discuss nutrition problems with their doctors and did not consult professional nutritionists. In this case how did then they handle nutrition-related problems? It was observed that other patients and relatives were an important source of this type of information – a caregiver, a wife, other patients in the waiting room, cancer patients from online groups, or societies. What is remarkable is that patients and their caregivers enjoyed sharing good recipes or tips related to nutrition or healthcare and were very willing to listen to other patients' experience as in an example below:

◆ And then, um, because at the time (pause) the nutritionist recommended taking nutritional supplements. But then, the mother of a friend of mine who had cancer recommended that I go to this other hospital. She recommends those natural foods in those (pause) uh…frozen packets…(L 69:02)[47]

{Female | caregiver | - y.o. | NPC stage 3-4 | follow-up}

In fact, nutrition was one of the most frequently discussed topics among the patients and their relatives or caregivers. The patients discussed the issue of nutrition during

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[47] 然後，呃，因為當時(停頓)營養師都推薦營養品，但是我在另外一個癌友媽媽他有推薦另外一個醫院，他有針對那種天然食物打成的(停頓)呃冷凍包……(L 69:02)

the interviews frequently as well. During the interview, one patient was curious about other interviewees' experience and one of the questions he asked was:

◆ Ah, are they eating any health supplements? (F 47:26 Stage 2)[48]

{Male | 41 y.o. | NPC stage 4 | under treatment}

4. *Other sources of extra information on nutrition*

Other people were not the only source of nutritional information. For instance, participants' patient K and caregiver L used Internet and books extensively in comparison to others:

◆ I went online and did my homework. I ate a lot of nutritious foods. Sometimes I drink nutritious drinks like Prosure or stuff like that…(K 16:46 Stage 1)[49]

{Female | 37 y.o. | NPC stage 4 | follow-up}

The caregiver L perused many books, as we can see from the picture below. The full list of the referenced books, as well as online sources provided by caregiver L is attached in Appendix 5.

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[48] 啊他們有沒有在吃一些什麼保養品嗎？(F 47:26 Stage 2)

[49] 我那時候自己上網做功課，就是吃很多營養的，有時候要喝營養品啊，什麼倍力素什麼的……(K 16:46 Stage 1)

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Figure 4.8 The books used by caregiver L

Many of the books on the picture above are about nutrition. One patient mentioned an online lecture on NTU's online educational center and another one that is a lecture by a nutritionist organized in the hospital that they listened to. Some participants did not specifically search for nutritional-related information at all.

At the same time, caution should be paid, as one caregiver expressed:

◆ Her type of illness is kind of troublesome, so I didn't want to just haphazardly go online and feed her medicine or foods recommended on the Internet (M 66:51)[50]

{Male | caregiver | 60 y.o. | throat cancer stage 1, lymphoma stage 3 | under treatment}

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[50] 所以所以說因為這種病就是要比較麻煩的病所以也不敢隨便看網路上的介紹的一些藥品食品去餵食她 (M 66:51)

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This caregiver strategy was:

◆ It was all the doctor's recommendations. The doctor suggested two or three kinds for us to choose from. We searched the Internet and looked at some online suggestions on which to pick (M 67:08)[51]

{Male | caregiver | 60 y.o. | throat cancer stage 1, lymphoma stage 3 | under treatment}

5. *Nutrition-related problems encountered by the participants*

Two patients shared some serious problems they encountered in regard to nutrition. Patient G shared this story from when he was in the hospital: at one point when he could not take in any solid food or liquid nutritional supplements the hospital still did not agree to give him nutritional injections, something he could not understand:

◆ We want nutrition, but the nutritional injections really can not be given, why not to give? (G 22:09 Stage 2)[52]

{Male | 64 y.o. | tonsil cancer stage 3-4 | under treatment}

He thought that nutritional injections would help him to solve his issue of malnutrition considering the fact that all other methods did not work. He felt highly desperate at that point in time.

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[51] 所以都是醫師建議的，醫師他通常會建議個兩三種然後我們自己決定這樣子，然後再參考網路上的一些建議從中去選擇出來這樣子 (M 67:08)

[52] 我們想要營養，但營養針真的不能打，為什麼不能打？(G 22:09 Stage 2)

doi:10.6342/NTU201700504

Another caregiver, caregiver I, did not put any salt in her husband’s homemade food, and in the end he ended up in the hospital due to lack of sodium and potassium. This caregiver repeatedly mentioned this issue and blamed herself for making this mistake:

◆ I did not think he really, really this is my negligence, at least a bit of salt should, probably should be put (I 41:39)[53]

{Female | caregiver | 60 y.o. | tonsil cancer stage 4 | follow-up}

6. Importance of nutrition

There are also some other views on the topic of nutrition that patients expressed which are worthy of attention:

◆ Like many people who are sick, I thought that I could just buy a bunch of medicine, nutritional supplements and use some home remedies. But it never came across my mind that it was me. In order to help my own body recover, I had to put in the effort. This is something that many people find hard to accept (K 29:41 Stage 1)[54]

{Female | 37 y.o. | NPC stage 4 | follow-up}

Patient K’s statement is insightful, it is impressive how this patient is active in her pursuit of a healthier body and how many methods she use to recover from the illness.

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[53] 我沒有想到人真的，真的這是我的疏忽，應該要或許要或多或少加一點點鹽 (I 41:39)

[54] 對就像生病了很多人就覺得我就是去買一堆藥、營養品就是用偏方，但是沒有想過就是自己，要把自己的身體調養好，自己要努力啊，這是大部分人都聽不進去的對啊 (K 29:41 Stage 1)

◆ Yeah, so it's like this. You need to have enough nutrients in your body. Like, your immune system has to be up and running (pause) (N 30:38)[55]

{Male | 60 y.o. | NPC stage 4 | follow-up}

Patient N was certain that nutrition is the key to strengthening the immune system; he invented his own recipes and actively shared his views with other patients as well. He further recommended how to verify the results of food supplements' effect:

◆ Nutrition you, you finish eating and feel whether you yourself are, right, energetic and that, just like this (N 43:30)[56]

{Male | 60 y.o. | NPC stage 4 | follow-up}

Patients acquired nutrition-related information by different means, but one of the mostly trusted sources was other people, patients or their caregivers, in particular people suffering from similar conditions or disease stages. The doctors responsible for the patients' treatment did not provide much information in this regard and perhaps this is the reason of active information seeking from external sources.

CATEGORY 2: Rehabilitation information

Rehabilitation is an indispensable part of the recovery process and should be maintained throughout the rest of a patient's life. Ten participants stated that they frequently exercised their neck and head parts after the treatment. Among them, only

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[55] 對啊就這樣，你營養一定要夠嘛，就是你的免疫系統一定要起來嘛（停頓） (N 30:38)

[56] 營養你的，你吃完就自己覺得有、是不是 energetic 是不是很那個，就是這樣 (N 43:30)

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two (K, L) reported that they additionally visited physical therapists. The majority of the study’s participants did not search for rehabilitation-related information, neither online nor by other methods, only patient J looked for some information about sports while K and N searched for information related to recovery exercises. Notably, the participants started rehabilitation exercises at different stages of their disease journey, even though doctors often remind patients to do rehabilitation exercises as reported by patient F:

◆ Rehabilitation that, because after treatment the doctors will tell you how to do the rehabilitation, right, the doctor has said all that, before, during and after treatment the doctor says all this, and he also gave me some leaflets, right, so it’s actually ok... (F 16:04 Stage 2)[57]

{Male | 41 y.o. | NPC stage 4 | under treatment}

The vast majority of the participants did only easy and short exercises; they shared with us their exercise routines and even demonstrated it to us physically. Below are the selected quotes:

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[57] 復健那個因為治療後醫生都會跟你講說要怎麼復健，對啊，醫生都有說啊，所以那個治療前治療中治療後其實醫生都說說，而且一些傳單他都會給我，對啊所以說其實還好……(F 16:04 Stage 2)

- 15 seconds. Lower down, 15 seconds. Do it. Then left and right, this is called physical therapy. This is the only physical therapy (G 48:54)[58]

{Male | 64 y.o. | tonsil cancer stage 3-4 | under treatment}

- Treatment…after treatment, how should I say it, I feel like it's…because I feel like I'm not doing much physical therapy. Like when I wake up I'll move a bit, the wound – like this, like this (F 21:58 Stage 2)[59]

{Male | 41 y.o. | NPC stage 4 | under treatment}

- When you have time just do it. When you think of it just do it, like this. Heh… (N 21:44)[60]

{Male | 60 y.o. | NPC stage 4 | follow-up}

As we can conclude from these quotes, not much time nor effort were put into recommended stretching exercises. The main source of these exercises was Dr. Wang's leaflets with pictures that many participants found very helpful.

Participants A and E exerted more efforts by joining the research project organized in NTU hospital where their physical conditions are measured on a regular basis by the nursing researchers. Patient E learned some restoration exercises from them:

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[58] 十五秒，低下去，十五秒，做，然後左邊右邊，這樣會，叫復健，這就是唯一的復健 (G 48:54)

[59] 治療……治療完，怎麼說呢，覺得它……因為我覺得沒什麼在做什麼復健啦，就是早上起床會稍微動一下這樣子，傷口就自己這樣啊～這樣子一下啊 (F 21:58)

[60] 有空你就做啊，想到了你就做嘛就是這樣啊，嘿…… (N 21:44)

◆ They'll all teach me how to continue to be optimistic once I go home and how to do physical therapy (E 16:46)[61]

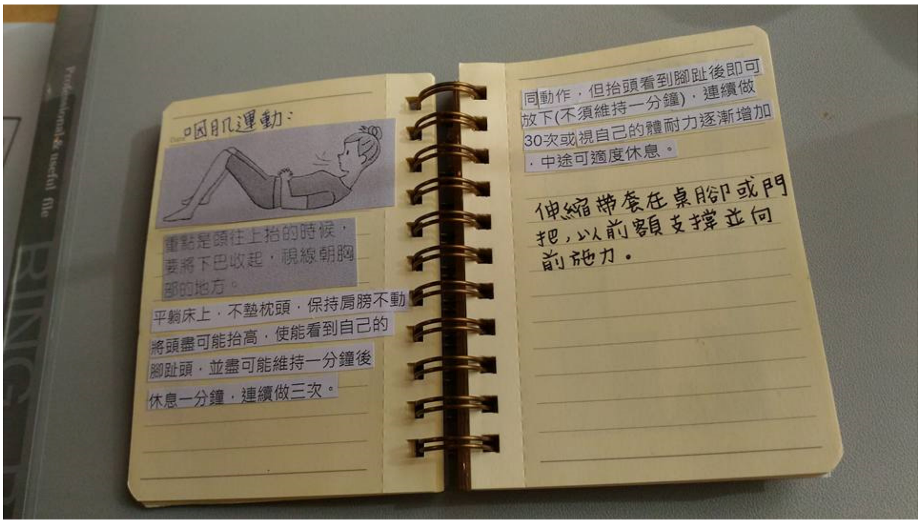
{Male | 58 y.o. | oral cancer stage 1 | follow-up}

On contrary, the patient K (a woman) is an example of a dedicated attitude towards rehabilitation. Firstly, she used multiple sources of information exhibiting active information behavior, and she combined her findings into one notebook:

◆ This film was sent to me by a previous patient. At that time I thought, ah, how come I didn't know about the physical therapy center earlier? Right, and because there was so much on physical therapy that I printed it out myself and made it into a small notebook (K 74:22 Stage 1)[62]

{Female | 37 y.o. | NPC stage 4 | follow-up}

Figure 4.9 A self-designed notebook with exercises, participant K



咽肌運動：

重點是頭往上抬的時候，
要將下巴收起，視線朝胸
部的地方。

平躺床上，不墊枕頭，保持肩膀不動
將頭盡可能抬高，使能看到自己的
腳趾頭，並盡可能維持一分鐘後
休息一分鐘，連續做三次。

同動作，但抬頭看到腳趾後即可
放下(不須維持一分鐘)，連續做
30次或視自己的體耐力逐漸增加
，中途可適度休息。

伸縮帶套在桌腳或門
把，以前額支撐並向
前施力。

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[61] 他們都會教我說，回去的話要怎麼保持心態啦吼，啊要怎麼復健這樣 (E 16:46)

[62] 這個影片也是前陣子有個病友傳給我，那時候我想，啊，我怎麼沒有早點發現，復健中心，對，然後我就自己，因為復健東西很多，我就自己印出來做一個小冊子 (K 74:22 Stage 1)

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Secondly, her rehabilitation exercising time usually lasts for one hour:

◆ Because I exercise for 1 hour and do physical therapy for 1 hour, so I spend 2 hours a day on this (K 26:41 Stage 1)[63]

{Female | 37 y.o. | NPC stage 4 | follow-up}

Thirdly, she visited a physical therapist, which she asked her doctor to help her arrange. Patient K explained the reason behind her proactive attitude towards rehabilitation:

◆ Oh, I do physical therapy because actually I know the patients and they recommended me to go learn yoga. After learning for a bit, I found out that this hand couldn't reach my ears. This hand could only reach here, the highest point was here and then I got scared. And I couldn't raise my neck when lying down. I found out all of this while practicing yoga. Then, Xiaomi always sends me some messages. After matching them I felt that it had to do with swallowing and so I made an appointment with the physical therapy department. Then I found out that these muscles of mine were weak, maybe because of radiation therapy. Also the muscles in the neck were damaged a bit, so now I'm doing physical therapy (K 67:36 Stage 1)[64]

{Female | 37 y.o. | NPC stage 4 | follow-up}

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[63] 因為運動完一個小時復健又一個小時一天就兩個小時都用在這個了 (K 26:41 Stage 1)

[64] 喔，復健是因為我其實都跟病友有關，病友就推薦我去學瑜伽，學一學我就發現我這隻手沒辦法舉到放到耳朵，這隻手，只能舉到，最高舉到這，然後我就嚇到，然後還有脖子沒辦法，躺著沒辦法抬起來，都是在練瑜伽的時候發現的，然後，小米他都有傳一些資訊給我，我對照就覺得好像跟吞嚥有點關，我就去掛復健科，然後才發現說，我這些肌力有點弱，可能是因為放療的關係，還有脖子肌力有點受損，所以就是現在就是在復健 (K 67:36 Stage 1)

This patient repeatedly expressed her concern about negligence and low compliance in regard to rehabilitation:

◆ Yeah, they might all have a sheet of paper that tells you hey you need to do physical therapy. Then you'll do it and when the time comes, you'll forget it. Yeah, but I went online and found out many people have researched, it is said that the implementation rate of physical therapy in Taiwan is very low. Many people didn't pay attention, and it's still currently the case…(K 74:47 Stage 1)[65]

{Female | 37 y.o. | NPC stage 4 | follow-up}

◆ I really want to remind everyone, but I don't know. Maybe you have to wait until you realize you can't do some of these movements to feel scared (K 75:06 Stage 1)[66]

{Female | 37 y.o. | NPC stage 4 | follow-up}

Again, as with the situation with nutrition information, doctors do not urge patients to pay more attention to rehabilitations, as our participant K stated:

◆ …I think I found out the importance of physical therapy a little too late because actually doctors don't emphasize this (K 74:36 Stage 1)[67]

{Female | 37 y.o. | NPC stage 4 | follow-up}

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[65] 對，他們可能都有一張單子跟你說誒要復健喔，你就會，喔，到時候你就會忘記了，對，可是我上網查發現很多人研究，他都說台灣復健的執行率很低，很多人都沒有注意，然後到現在也是…… (K 74:47 Stage 1)

[66] 就我很想提醒大家，可是，不知道，可能，你真的要等到你發現自己有些動作做不來你才會害怕 (K 75:06 Stage 1)

[67] ……覺得我太晚知道復健的重要性，因為其實醫生都不會強調這一點 (K 74:36 Stage 1)

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Similar to nutrition, rehabilitation is a life-long companion of cancer survivors. However, in contrast to nutrition information, rehabilitation knowledge is according to our findings not much discussed between the patients. Thus a more active role from medical institutions is needed.

CATEGORY 3: Other information problems and needs

Information about prevention was unquestionably important to the patients, particularly after they ended their treatment.

◆ *Interviewer assistant Cheng:* What time is most stressful? Going through the treatment process until now, during what times have you felt like giving up?

That… It's like.. Fear of relapse, yes, feel afraid of relapse (F 30:46 Stage 2)[68]

{Male | 41 y.o. | NPC stage 4 | under treatment}

The level of anxiety was also the highest after the treatment came to an end, as the following quote suggests:

◆ During the treatment stage it's yet to happen, it's yet to happen, after treatment, you know? The information you need to read piles up. This illness's reoccurrence is dangerous and happens quite often. Yeah. So avoid saying things like you don't want it to reoccur, or ask the doctor how to avoid it, he says it's hard for them to say too. Yeah. Just continue to be optimistic (F 30:53 Stage 2)[69]

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[68] Interviewer 鄭助理: 什麼時候壓力最大？治療這條路走到現在，什麼時候覺得想要放棄的感覺？就是……好像……怕會復發啦，對怕會復發 (F 30:46 Stage 2)

[69] 治療期還不會、還不會，治療完有沒有，就是資訊越讀越多，好像這個病好像復發蠻嚴重的，蠻、蠻常的啦，對啊，所以盡量就避免說不要去復發，啊問醫生怎麼避免，他說也很難講，對啊，就保持心情愉快啊這樣子 (F 30:53 Stage 2)

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{Male | 41 y.o. | NPC stage 4 | under treatment}

Coping strategies could be either avoidance or active involvement as was noticed. Patient K demonstrated the latter:

◆ Done them all, going online, reading books, and taking a look at other patients' experiences and the department of cultural affairs is nearby. It has some health magazines and such…(K 61:17 Stage 1)[70]

{Female | 37 y.o. | NPC stage 4 | follow-up}

Clearly, doctors cannot provide accurate predictions in this regard, but patients still require this information. The stories of other patients could seemingly be useful in the sense of providing preventive techniques or advice according to their experience.

Patient H specified another problem:

◆ So sometimes when you've gotten sick, he *(a seller of food supplements)* will tell you this tastes good and that tastes delicious, introduce this nutritional product and that supplement. Many people will introduce you to them because they do this for a living. If you don't take these things how would they live? (H 75:44)[71]

{Male | 60 y.o. | tonsil cancer stage 4| follow-up}

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[70] 都有，上網、看書，還有看病友經驗，還有文化局就在附近嘛，他都有一些康健雜誌什麼的……(K 61:17 Stage 1)

[71] 所以有時候，你生病以後，他會介紹這好吃啊介紹那好吃啊，介紹這營養的介紹那個補給的，很多人都會跟你介紹，因為靠這種，靠這個吃飯的人很多。你不吃他靠什麼生活 (H 75:44)

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This statement can possibly explain the reason why the main source for nutrition and food supplements information is other trusted patients, family, or friends. Another related issue is the constraint that doctors have in recommending food supplements:

◆ I…I think that because now…why do doctors avoid this? They discover that it already got sore *(mouth)*. After they see that it's sore, they suggest this *(food supplement)* because…she can't he can't so early already tell you just…just eat this. There will be interests. The information on health products is insufficient (H 80:20)[72]

{Male | 60 y.o. | tonsil cancer stage 4| follow-up}

Patient J expressed his opinion regarding the need for more information and how it is important for a patient to be provided with information:

◆ For example, diabetes…my wife has diabetes. I will look at the reasons for diabetes, how to prevent and treat it, what the dietary conditions are? I wouldn't go to the doctor. As I see it, doctors are all the same. They only differ in the amount of information they provide you (J 54:50)[73]

{Male | 59 y.o. | NPC stage 2 | follow-up}

Patients' caregivers are the people who need information on nutrition the most:

◆ My *(my wife's)* entire recovery has been bad, for example after getting discharged we hope that we can follow the canned foods provided by the hospital, like milk, but family members always hope they can do an even better job. So actually we don't know what

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[72] ……我我是覺得，因為現在，為什麼醫生迴避這個，到了最後已經破了，發現有破了才建議這個，因為，他不能他不能一大早就，你吃這個就好，會有利益 保健品訊息不足 (H 80:20)

[73] 比方說糖尿病，像我太太有糖尿病，我就會看一下，糖尿病為什麼，怎樣預防、怎樣治療，吃的方面怎樣？我不會去看醫生，醫生在我個人看來，大概都一樣，只是他給你的訊息多不多而已 (J 54:50)

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direction and which food products are better. Of course doctors give you some suggestions about what you need to eat, but if there's a nutritionist then it's better to compare and ask (M 65:39)[74]

{Male | caregiver | 60 y.o. | throat cancer stage 1, lymphoma stage 3 | under treatment}

In this section we discussed issues of nutrition, rehabilitation, as well as other additional informational needs described by the participants. After a patient leaves a hospital he is no longer provided with verified and professional information, however, the disease cycle does not end there. NTU hospital provided ample treatment-related information, but nutrition and rehabilitation knowledge is equally important for the patients, particularly during later phases of the cancer. It is worth repeating that patient wish they could have known more about other patients' experience:

◆ For instance, seeing him *(husband)* being like this. We see others at the hospital, they go through it first. I actually want to ask them what happened during the process, but I'm afraid to ask (I 06:07)[75]

{Female | caregiver | 60 y.o. | tonsil cancer stage 4 | follow-up}

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[74] 我那現在恢復什麼都很差譬如說出院了以後我們也希望就是說，怎麼樣照醫院餵食罐裝食品像牛奶那樣但總覺得好像就是說，因為家人總是希望能做得更好，所以也不知道說朝哪一方面哪一些食品比較好，當然醫師有建議啦是要吃哪些東西，但是如果譬如說又有營養師就是比較諮詢一下的話 (M 65:39)

[75] 比如說像看到他這樣，我們在醫院看到別人，他們比我們先做，其實我也很想去問問人家說，你們的過程會遇到什麼，可是不敢主動去問……(I 06:07)

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◆ Because I also want to know, others …like…what I mean is the experiences of those who've gone through it before can save you some trouble. Of course, I think that it's different for each person (I 07:42)[76]

{Female | caregiver | 60 y.o. | tonsil cancer stage 4 | follow-up}

The participants explained how they searched for information, what role the Internet played in their information acquisition process, and what attitude towards the disease and information they had. The information sources of the interviewees such as NTU Hospital, medical professionals, and other patients along with their family members were defined as one of the major sources of gathering information. Information needs in the field of nutrition and rehabilitation were broadly discussed as well. Three main categories and all the subcategories identified during the content analysis of the transcripts are combined in Table 4.3. Importantly, the highest numbers of the participants' quotes were related to three subcategories: hospital as information source (50), rehabilitation information (50), and nutrition information (36).

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[76] ……因為我也想知道，別人的那個，等於說，前人的經驗，讓你可能不用走太多的路，我覺得，當然每個人各有異 (I 07:42)

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Table 4.3 Themes and categories of the content analysis (detailed version)

Information seeking	
Information seeking behavior	*1. Searching for information or not searching at all when the symptoms appeared or the diagnosis was stated* *2. Looking for answers to questions* *3. Interaction with other patients, other family members, or caregivers in the hospital* *4. A patient or a family member or a caregiver looks for information?* *5. Information behavior before visiting doctor* *6. Information recording and storing* *7. Information on the Internet is regarded only as reference* *8. Verification of online or other information*
Attitude and psychological state	*1. Attitude towards the disease* *2. Psychological state* *3. Attitude transformation*
Information and anxiety	Information and anxiety: general discussion
Information sources	
Hospital as information source	*1. Helpful materials* *2. Problems with hospital's information sources*
Medical personnel as information source	Medical personnel as information source: general discussion
Patients or caregivers as information source	*1. Other patients as one of the most important sources of information* *2. Interest in knowing more about daily lives of other patients* *3. Each patient's situation is different*
Information needs	
Nutrition information	*1. Nutrition questions are not discussed with the doctors* *2. Searching for extra sources of information on nutrition by visiting a dietician* *3. Discussing nutrition issues with other patients and caregivers* *4. Other sources of extra information on nutrition* *5. Nutrition-related problems encountered by the participants* *6. Importance of nutrition*
Rehabilitation information	Rehabilitation: general discussion
Other information problems and needs	Other information problems and needs: general discussion

The observation results, as well basic questionnaires and the content analysis raised some important issues experienced by the patients. However, it is necessary to understand how these issues are viewed by the hospital. In the next section some important findings from the interviews with 4 medical professionals form NTU Hospital will be presented. Specifically, with Dr. L. and Dr. Y. from otolaryngology department, with Dr. W. from radiotherapy department, and with case manager for cancer patients, nurse H.

The problem related to medical information online is an important concern for medical specialists. Information verification is complicated due to the enormous amount of online information originating from various sources. The 4 interviewees were asked whether they usually recommend patients to refer to information online. Usually it is not suggested to patients to look for information online, and one doctor explained that he does not recommend information online due to the following reason:

- ◆ I think currently in Taiwan there is not enough information available…and they may just bring up their questions when they come see us. Our replies are more accurate and faster for them compared to the information they can find on the website (Dr. W. 36:55)[77]

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[77] ……會覺得目前現在台灣的狀況我倒是覺得資訊都還不夠充足，而且他可能直接跟我們醫師在門診中直接有問題提出來我們給他的回覆甚至可能比他找到的網站的資料可能來的迅速而且還

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◆ As far I know, currently in Taiwan there's no website that can provide a complete listing of various types of information for patients. To be more exact, the information provided may not even be enough (Dr. W. 36:29)[78]

Dr. W. supposed that online information is not comprehensive enough and there is no such a webpage that could encompass the various information needed for HNC patients. Alternatively, doctors can provide answers quickly and guarantee the information is correct.

By contrast, nurse H. would recommend patients to consider information from a few online sources:

◆ We will tell them to go to HOPE Foundation Cancer Care and Sunshine Social Welfare Foundation. For patients who are at the first stages of cancer, they'll provide some resources, such as relevant resources, or they'll provide some economic or dietary assistance. So we ask them to check these two websites (Nurse H. 23:28)[79]

Nurse H., being a case manager, usually shares a lot of information with the patients.

比較正確…… (Dr. W. 36:55)

[78] ……那目前據我所知在台灣沒有一個完整的沒有一個病人可以在那個網站找到很多的所有各式各樣他想要的資訊，原則上來講可能都不夠 (Dr. W. 36:29)

[79] ……我們會請他去癌症希望協會，再來一個陽光基金會，他針對癌症頭期的病人會提供一些資源，例如有一些相關的資源，或許他們會提供一些像是經濟或是飲食上的協助，就會請他們去這兩個網站看 (Nurse H. 23:28)

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However, the interviewees of this study usually did not contact managers and no one asked them for information resources. This possibility should probably be communicated to them more clearly at the beginning of treatment.

In the basic questionnaire analysis the problem of psychological stress was highlighted as the main problem for the patients. In the interviews' content analysis some patients were afraid of information acquisition. In addressing the issue of anxiety or stress, Dr. Y. shared the following:

◆ I feel if the instructions are easier the better. You know what I mean? Actually just the mention of cancer can cause people to think about it all day (Dr. Y. 71:17)[80]

The participants, especially those who were undergoing treatment, repeated the problem of constant thinking about the disease, therefore they tried to avoid being exposed to additional information. Doctor Y. acknowledged the problem of stress, and agreed that simpler guidelines by doctors is probably a correct strategy during the treatment. On contrary, some patients or their caregivers expressed their need for more information and expected doctors to provide it.

A number of participants did not discuss any questions with the doctors, yet

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[80] ……我會覺得指令簡單，越簡單越好，這樣有懂我意思吼，因為其實你光癌症這兩個字就已經夠讓人可以想一整天了 (Dr. Y. 71:17)

doctors can answer questions only if they are raised. Please consider the following quote:

◆ Right, but if the patient does not specifically ask about it during consultation, or if they are too embarrassed to bring it up, we of course will not be aware of those problems because there are just too many possible problems to consider (Dr. W. 37:58)[81]

Some patients took a passive attitude in interactions with the doctors, did not ask nor discuss questions even when they did have problems, but yet they asked us during the interviews. However, doctors can not predict what problems may arise in each patient's situation, therefore a more active attitude from the patients is recommended.

The similar viewpoint was expressed by nurse H. in respect to psychological problems:

◆ Well, when it comes to mental stress, sometimes the only way to get it off your chest is to verbalize it. For some illnesses, if patients don't bring it up, we really won't know what type of stress they are under. And it's no help that the majority of our patients are men. Men are not usually forthcoming about these things (Nurse H. 32:26) [82]

Male patients tend to conceal their emotions and do not consult medical staff for help, but the hospital is unable to provide assistance unless they share their problem.

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[81] 對但是如果病人他在門診沒有特別發問他不好意思問坦白說我們當然不會知道病人會有什麼樣的問題因為太多太多問題了……太多太多問題了 (Dr. W. 37:58)

[82] ……其實有些心理壓力，減輕的方式，就是你要講出來，因為有些病你不講，我們真的不會知道你有甚麼壓力，尤其我們的病人大部分是男性，他不太會講出來 (Nurse H. 32:26)

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In one of the interview questions hospital information sources were discussed. Some issues related to the printed materials in the hospital were raised:

- Everybody’s situation is different…actually no matter if we’re at the first stages of health education…speaking of the health education part or the written part…they aren’t able to write down each and every situation (Dr. W. 23:49)[83]

- Do you understand? Medical science is improving every day. When we have meetings it’s like we have something new again. So if a patient speaks to me today, I’ll tell him the newest, but when I go back and look at the pamphlet, maybe it’s information from a few years ago (Dr. Y. 42:08)[84]

- We don’t have much time ourselves to maintain it, so we don’t recommend that they use our *(hospital)* website as reference (Dr. Y. 22:57)[85]

The doctors were concerned that the printed materials can not incorporate all the differences of the patients’ situations. Also, the information should be timely updated, however, it is not easy to regularly revise printed forms of information. These

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[83] 每個人的狀況不一樣……其實我們不管是在初步的衛教……就是衛教的部分或者說在書面的部分……他不可能每一項都寫的各式各樣的狀況 (Dr. W. 23:49)

[84] 你懂嗎，因為我們醫學一直在進步嘛，就是我們隨時去開會怎麼又有新的，那我如果今天病人講我可能直接跟他講最新的，但是這個回去看這個手冊可能是好幾年前的 (Dr. Y. 42:08)

[85] 然後我們自己也不是自己有時間再去維護它，所以我們不會特別去建議它參考我們*(醫院)*的網站，然後反而會建議他不要參考網站的 (Dr. Y. 22:57)

comments suggest that information in electronic forms can contain various stories of the patients and would be more convenient to be updated, thus partially resolving this issue.

In order to learn about some resources such as Cancer Resource Center or additional consultations, patients should be active and discuss questions with medical staff:

- Right, because we hold events on a regular basis. If he *(a patient)* doesn't come and attend, then he won't be able to get this information (Dr. L. 21:18)[86]

- If needed, we have counselors available free of charge…as long as the patient is a cancer patient, they have one free psychological assessment for free (Nurse H. 32:26)[87]

None of the participants reported visiting a psychologist or psychiatrist during their treatment process, and none of them knew about the free consultation resource.

Nutritional information provided by the doctors in charge usually was relatively general as one doctor confirmed:

- Well, for us, there's one general rule for a healthy diet, that is…there's one rule that's absolute. That is, you must never take up smoking, drinking or chewing betel nut again. That's it (Dr. Y. 19:42)[88]

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[86] 對，因為我們是定期在辦活動，他如果沒有來參加，他可能就得不到這個資訊 (Dr. L. 21:18)

[87] 如果有需要我們有心理諮商師,是免費的……只要是癌症病人那他就有一次的心理檢定是不用錢的 (Nurse H. 32:26)

[88] 其實健康飲食的規則對我們來講只有一個，就是……我們只有一個絕對是對的，就是菸酒檳榔

However, during the interviews with patients and caregivers, detailed nutritional information emerged as an important need.

Yet, the hospital provides a specialized nutrition consultation service. If a patient expresses the need for nutritional consultation while staying in hospital a nutritionist was provided as the following quote exemplifies:

- If the patient makes the request, we can have the nutritionist from inpatient consultation services to attend to the patient’s needs (Dr. L. 07:14)[89]

In case of special conditions or chronic illnesses, a consultation by a nutritionist was recommended by the nurse H.:

- If the treatment has ended or if the patient has chronic illnesses like diabetes, high blood pressure or high cholesterol, the patient may not be able to intake a high number of calories or proteins. If that’s the case, we’ll then recommend the patient to consult a nutritionist (Nurse H. 20:08)[90]

In this study, only one of the participants received a suggestion from a nurse to visit a dietitian, although at least 4 patients stated that they had other chronic illnesses.

不能再碰，就這樣子 (Dr. Y. 19:42)

[89] ……如果病人有這些需求，就可以請病房照會營養師，就可以幫他做處理 (Dr. L. 7:14)

[90] ……如果治療完或是本身有些慢性疾病，他可能有糖尿病，高血壓，或者高血脂這類的問題，他可能醫療上面就沒辦法攝取高熱量，高蛋白質，那我們就會建議他去看營養師這樣 (Nurse H. 20:08)

Rehabilitation consultation was not proposed to all the patients, but only to those whom had gone through serious surgeries or with visible problems related to speech, swallowing, or neck stiffness.

- Some patients may need to undergo major surgeries. For these patients, we'll suggest that they go see a physiatrist (Nurse H. 21:19)[91]

- Problems with speaking, swallowing or the stiffening of their neck area make up the majority of the patients' problems. For patients with these issues, we'd suggest that they make an appointment with their physiatrist (Dr. L. 6:19) [92]

There is a common understanding of the problem in regard to food supplements' information provided by the doctors:

- Well, for those types of things, we doctors have to bring up the issues regarding who the patients are ourselves…because first of all, it may not be effective with every patient, and secondly, expenses run high…a small bottle could ring up to 7,000 to 8,000 NTD or 8,000 to 9,000 NTD. For some patients, the financial burden is quite heavy (Dr. W. 25:45)[93]

In this section the findings from observation, basic questionnaire analysis, and comprehensive interview content analysis were discussed. The major themes and

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[91] 可能有些就是比較需要做到比較大的手術,我們就會建議他去看復健科 (Nurse H. 21:19)

[92] 言語、吞嚥、還有頸部僵硬活動的問題，絕大部分就是這幾個了，那這些的話我們就會建議他掛復健科的門診 (Dr. L. 6:19)

[93] 但是那種東西⋯我們醫師端要主動去講這個會有一些身分上的問題⋯因為第一個不是每個病人都有效⋯再來那個費用都不便宜⋯可能小小一瓶就七八千塊八九千塊對有些病人的負擔是蠻大的 (Dr. W. 25:45)

categories were outlined and representative quotes were listed. Analysis of questionnaires and interviews concluded the importance of receiving information from other patients or caregivers; medical professionals and hospital remain a very important and trusted source for specialized medical knowledge and treatment-related information. Perhaps, patients and their family members need some navigation in utilizing hospital's resources by the hospital. In general, all the interviewees for this study have common understanding of the problems in information providing and some of the findings of this research based on the patients' and caregivers' interviews are supported by the interviews with healthcare providers.

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Chapter 5 Conclusion and Suggestions

5.1 Conclusion

The purpose of this study was to investigate the phenomenon of HNC cancer patients' information search and needs in detail rather than in a general way; to raise questions instead of proposing definite answers; to understand possible underlying reasons behind the issues and not only stating the issues. An in-depth understanding of the research problem was central to this study for further application regarding service design in relation to the ZOHUE platform. Specifically, the average length of each interview was one to one and a half hour, there were two stages of interviews, and additional interviews with healthcare providers were performed. Out of all the possible research methods in qualitative research, a framework content analysis for identifying patterns and categories was chosen as being the most appropriate for the interview data analysis with partially predefined themes.

This study's research findings can be summarized into the three main themes: information seeking behavior, information sources, and information needs.

Information seeking behavior significantly differed among the participants depending on age and gender as well as educational attainment. Also, the participants adopted different coping attitudes towards the disease: some of them showed active participation in their treatment, while others chose to avoid involvement. A linkage between information and anxiety was identified – one category of the patients preferred information avoidance and another one chose active information acquisition in order to deal with anxious psychological state. It is possible that these different strategies can be associated with the stage of the cancer journey, with higher level of nervousness during and just after treatment.

Some of the study's results correspond with the findings in literature review. A qualitative study by Leydon *et. al* (2000) identified three possible reasons associated with information avoidance described as such themes as faith in doctors, hope, and charity. These three themes appeared in the interviews with the participants of this study as well. In addition, in relation to male patients' attitude towards disease management we found that 2 patinets, A and F, tended to pretedn that they live normal life. The same finding was stated in one research as well: "Women patients often valued the knowledge and experience of other cancer patients more than medical information, and this personal experience often proved invaluable with treatment decision making. By contrast, the men rarely spoke of relying on the

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experience of other patients; once they left the outpatient clinic or treatment room they preferred a policy of “life as normal” in which cancer could be forgotten (at least superficially).” (Leydon *et. al* 2000, p.911).

In another study by Shea-Budgell *et. al* (2014) it was found that only 38% of the patients discussed online information with their doctors. In this thesis number of the patients discussing questions with medical providers was also relatively low – only one forth of the participants.

As suggested by Rutten *et al.* (2016), patients’ reliance on healthcare specialists does not diminish despite the rise of the Internet. This research supports the fact that hospital and doctors remain one of the major informational sources for both HNC patients and caregivers of patients at the NTU Hospital. Trustworthiness of online information is questioned and a few studies emphasized that the hospital assistance is necessary. Some of the study’s participants referred to online information but the degree of trust was still relatively low, they would instead actively consult other patients and caregivers’ experience. In fact, this is one of the major findings of this study and it was discovered that communication opportunities and channels between patients’ are insufficient.

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Treatment-related information is provided comprehensively compared to such types of information such as nutrition and rehabilitation. The participants demonstrated substantial need in nutrition-related information; other patients and caregivers were described as the main source of this type of information. A need for nutrition-related consultations was revealed during the interviews. Rehabilitation-related information was not actively sought by all the patients, but was still constituted as important need for one patient who encountered impaired physical movements as a consequence of insufficient rehabilitation exercises. The majority of the participants repeatedly postulated that they would like to know more about other patients' experiences particularly in relation to nutrition. Additionally, the medical professionals' perspective was taken into account and discussed in order to compare with the patients' and caregivers' opinions and to have a more holistic understanding of the research problems.

Methodologically, this study added value to the body of knowledge by applying a qualitative research process. The number of qualitative research papers on this topic is substantially lower in comparison to quantitative studies according to this study's literature review. It is one of the very few studies that are completed in a qualitative

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manner in Taiwan, exploring a problem related to Taiwanese patients. Also, this research is dedicated to only one type of cancer, HNC, and exclusively to the patients of NTU Hospital, thus providing a greater in-depth understanding of the topic. Furthermore, the research problem was explored not only from the perspective of the patients and caregivers, but interviews and interaction with healthcare providers was beneficial in understanding patients’ issues and information provision system of the hospital.

The study has direct practical contribution since it was initiated with the purpose of resolving a real practical problem — designing a ZOHUE online platform for information acquisition and social interaction for cancer patients. After the first phase of the interviews was completed a series of workshops was held in the CCDM company for designing a possible interface and functions for the ZOHUE platform during the period July 11th to the middle of August 2016. All the transcripts were printed out and analyzed during two consecutive workshop sessions by the author, the advisor’s assistant, and the company’s researchers. The design thinking method of analysis was employed, in particular three stages: problem definition, ideation, and prototyping. Each patient’s transcript was interpreted and discussed by the workshop

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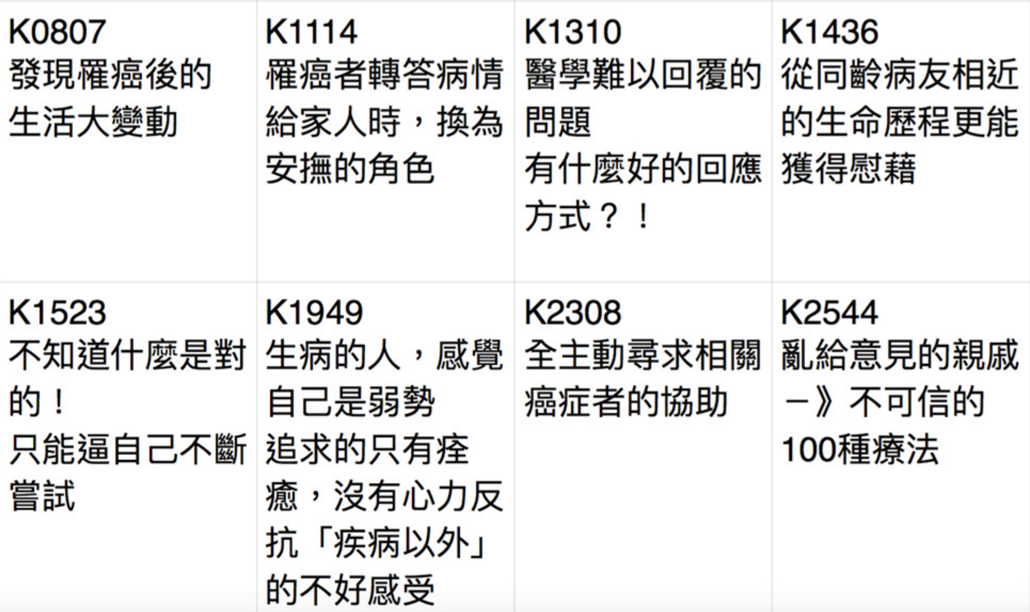
participants as illustrated in Figure 5.1.

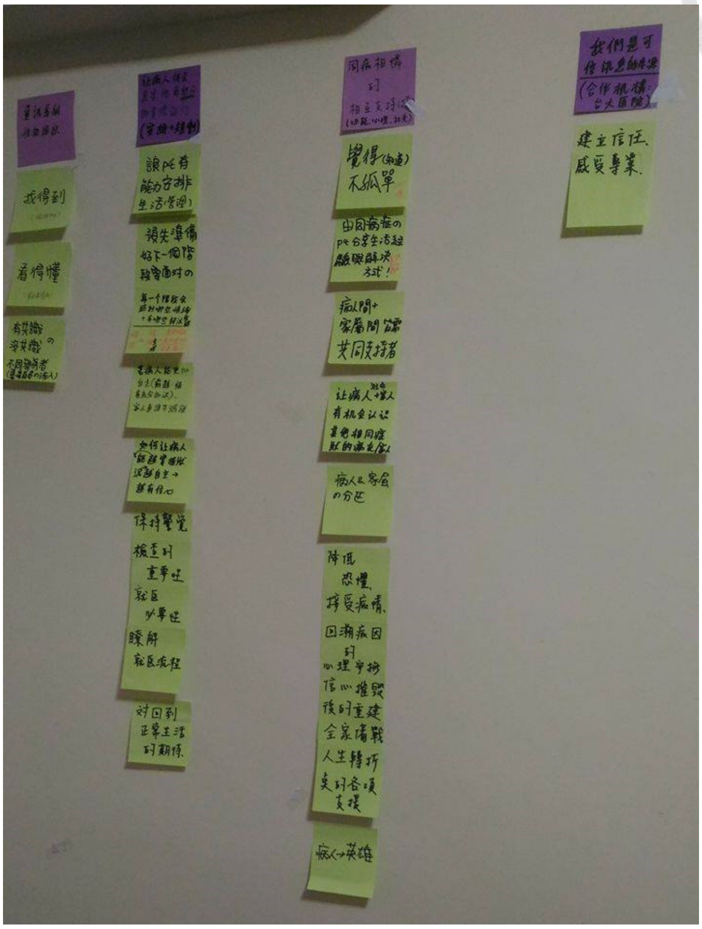
Figure 5.1 Interpretation of patient K’s interview content. Excerpt



K0807 發現罹癌後的生活大變動	K1114 罹癌者轉答病情給家人時，換為安撫的角色	K1310 醫學難以回覆的問題 有什麼好的回應方式？！	K1436 從同齡病友相近的生命歷程更能獲得慰藉
K1523 不知道什麼是對的！ 只能逼自己不斷嘗試	K1949 生病的人，感覺自己是弱勢 追求的只有痊癒，沒有心力反抗「疾病以外」的不好感受	K2308 全主動尋求相關癌症者的協助	K2544 亂給意見的親戚－》不可信的100種療法

In the following workshop all the information derived from interpretation was divided into categories according to possible design principles for the platform, and resulted in four major themes – systematic presentation of information that is easily retrievable, disease management, mutual support between patients, and trusted source of information (Figure 5.2).

Figure 5.2 Four major themes identified during the third workshop in CCDM



Eventually, a prototype of one function that addresses disease management was designed and in future it is planned to invite the participants of the study for evaluation and commenting.

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5.2 Suggestions

In the future it is suggested to conduct a comprehensive quantitative research with larger sample pool for achieving greater generalizability based on the findings of this exploratory study. It is common to have qualitative research performed before the quantitative investigations. Moreover, longitudinal qualitative studies aimed at investigating informational needs and behavior at different cancer stages with a purposeful sample could be significantly beneficial.

Another suggestion is organizing a focus group with caregivers. During this research with the interviews with 3 caregivers it was discovered that the role of caregiver is very crucial in acquiring informational resources for a patient. Furthermore, caregivers are predominantly females, more open for discussions in comparison to patients, thus more data about patients' experience could possibly be obtained.

The third suggestion is continuing the design of new upgraded functions on ZOHUE platform for providing systematic information as well as facilitating social interaction on the website. As to the information provision, a following approach for providing information proposed by Maddock *et al.* (2011) could be considered:

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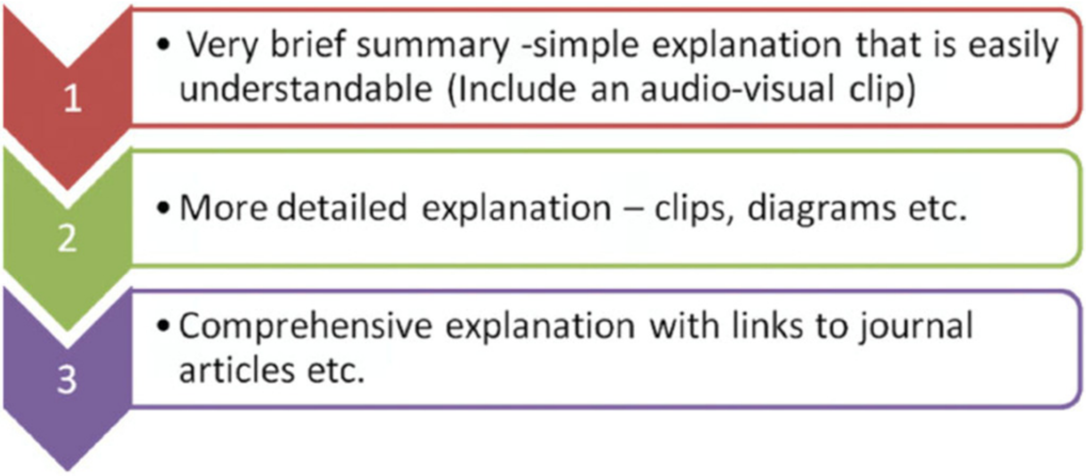
Figure 5.4 Stepped approach to information delivery (Maddock *et al.* 2011)

Figure 6.
Stepped approach to information delivery



- Very brief summary -simple explanation that is easily understandable (Include an audio-visual clip)
- More detailed explanation – clips, diagrams etc.
- Comprehensive explanation with links to journal articles etc.

Additionally, information on the website should cover all the stages of the cancer continuum, especially the before and after treatment phases, fulfilling diverse informational needs. As this study results suggest, special attention should be paid to nutrition and rehabilitation-related information.

Experience-related information of the patients verified by recognized medical institutions is still not common to be provided on the Internet. Such unique information could be presented on the ZOHUE website in cooperation with NTU Hospital, benefiting numerous patients and caregivers. Hopefully, the platform will be popularized in NTU Hospital for HNC patients and their caregivers in the near future.

Lastly, the difficulties in using NTU Hospital resources were reported. To eliminate informational barriers and offering a more comprehensive care for patients

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and their families in regards to optimization of information, delivery of said information could be performed in accordance with the findings of this study. It is recommended to perform an integration of offline informational support in the form of Cancer Resource Center, leaflets, and public lectures with online services delivered on the ZOHUE platform. Not only the patients and caregiver of patients at the otolaryngology department of NTU Hospital will benefit from a comprehensive information provision, but healthcare professionals could also find advantages in reduced explanation time and higher compliance from the patients. To conclude, ZOHUE platform will be able to address most of the suggestions presented in this section. Mayer *et al.* (2007, p.349) suggested: “Healthcare providers can screen existing websites for credibility and make specific recommendations to their patients. Likewise, providers can be instrumental in developing, contributing to, and evaluating trustworthy health or cancer-related websites”, and ZOHUE platform posits itself as such a website containing trustworthy information.

Chapter 6 Research limitations

A series of research limitations of this study should be mentioned. Qualitative research is different from quantitative in sample size, data collection, and data analysis. In this research, the total number of the interviews with patients and caregivers was 17, and with medical specialists – 4. However, contrary to the author's expectations, in the second stage only five interviews were finally conducted. This is to say that in qualitative research it is more challenging to control each stage of the research process and the researcher should be highly adaptive and flexible.

When performing data collection, a sample of the participants was selected randomly and willingness to share was low in some cases; this had a direct impact on richness and quality of the data. However, luckily, we had two active participants, patient K and caregiver L, who provided us with a wealth of detailed information during the total interview time of more than four hours. Another minor drawback was that two participants, D and J, went through cancer treatment ten and twenty years ago respectively, hence they shared more about how they acquire information now during the follow-up phase, since the Internet and other sources were not widely available at the time they were diagnosed with the condition. Another limitation was

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the predominance of the participants in the follow-up stage with only 3 patients being interviewed in the treatment stage.

Qualitative research is usually more time-consuming, unpredictable and requires a prolonged interaction with the data. Sometimes there are moments when a researcher is overwhelmed with the data and requires peer discussion during the data analysis. Ideally, qualitative research should be carried out by a few researchers so triangulation decrease subjectivity in interpretation and facilitated understanding can be achieved. Conducting an interview can be a challenging task since the interviewees are very distinct in their manners to express opinions, to answer questions precisely or vaguely, or to be logical or coherent. There were cases during the study when participants could spend half of the interviewing time sharing unrelated content, so for the interviewers it was on occasion a demanding task to maintain the participants' focus on relevant topics during conversations. In the case of HNC patients, a third of the participants were from low socio-economic statuses, therefore, at times it was not easy to have a comprehensive discussion with them. Domination by male participants aggravated the communication problem as well. Moreover, carrying out interviews

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using a second language and being unable to comprehend Taiwanese language was another obstacle to the author.

Furthermore, the limitation in respect to existing research should be recognized. The prevailing majority of the examined articles discussed the informational behavior and needs of the patients from Western countries, primarily USA and Europe, with little attention to Asian countries. As a result, an understanding of the development of this topic in Asian context was limited.

Finally, since this type of research was conducted for the first time by the author, thus previous experience was insufficient which also might have some impact on the research quality. However, the author has attempted to deliver a credible research complying with qualitative research guidelines.

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Appendices

Appendix 1. A consent form and a basic questionnaire

您好！

希望您能與我們分享**您** 的生病過程，讓我們更加了解病人的需求、感受以及所遇到的問題。

藉由訪談所獲得的資料，本團隊將會試圖設計一個對頭頸癌病人與家屬有幫助的網路平台。

～訪談時間與地點由您決定～

本研究團隊介紹

國立台灣大學商研所
商研所碩二學生雅薩娜
台大醫院耳鼻喉科及癌症資源中心
國立台灣大學資訊管理系的教授及學生們

隱私安全

您的個人資料與訪談內容僅供本研究使用，
未經您的同意不會給予第三方及作為其他用途。
我已詳細閱讀上列說明並同意本研究團隊蒐集、處理個人與訪談資料。
請打勾及簽名

□

基本資料

1. 請問您貴姓？

____

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2. 性別：

□男　　□女

3. 年齡：

____

4. 職業：

____

5. 請問您家屬癌症名及發病時年紀是？

癌症名 ___________　發病年紀 ___________

6. 請問您現在的期別為第幾期？

□零期　　□第一期　　□第二期　　□第三期　　□第四期

7. 請問您接受過何種治療：

□中醫

□西醫:

□化學治療　　□放射性治療　　□切除手術　　□其他

8. 請問您發病後或治療過程中曾遇到以下何種問題（可複選）：

□醫療相關資訊不足
□心理壓力
□經濟負擔過重
□與醫護人員溝通有問題
□人際關係：交流障礙或不足
□人際關係：缺乏與相同病症的人交流
□與家人的關係受影響
□其他_______________

9. 請問您發病或治療過程從哪裡獲得醫療資訊（可複選）：

□網站

□部落格
□書籍
□醫院資料來源
□其他病人或病人的家屬

10. 請問您生病過程中是否參加過任何協會或病友會舉辦的活動？
請舉例

□是　　□否

□協會
協會名稱：____________

□病友會
病友會名稱：____________

□其他 ____________

11. 請問是否習慣關注其他病友、家屬或醫師部落格？

□是　　□否

部落格名稱：____________

◆ 聯繫方式 （**煩請至少填一種聯繫方式**）

手機號碼：　____________

E-mail：　____________

您偏好個人受訪或者跟家屬一同受訪？
□個人　□與家屬一同　□皆可

Appendix 2. Patient K’s story

【主動搜集資料，掌握自己的身體狀況，而且知道後要真的去做】

鼻咽癌四期，確診時35歲，公務員，轉移後嘗試免疫藥物（KEYTRUDA 單株抗體）。

2014 年過農曆年前後，脖子突然腫了一大塊，我以為只是感冒嘛，腫起來。去看耳鼻喉科，醫師給我吃抗生素，然後排一兩個禮拜後的電腦斷層。我那時候是工作狂，藥吃一吃覺得腫有消一些，雖然沒有全消，但我就沒理它，電腦斷層也沒去。等一段時間，腫還是沒有消，我又去醫院看，拿了更重的抗生素，腫也有消一點，想說那應該差不多，有點鴕鳥心態。大概 6、7 月覺得還是有點腫，回診醫師說要排兩天一夜，做切片。我不想請假影響工作，就換到另一家醫院求診。醫師一看覺得不妙，當場做鼻咽切片，一個禮拜後就發現是鼻咽癌四期，腫瘤長好幾個，一個很外面，一個在裡面看不出來。

其實我完全沒有懷疑我會生病，因為我從小到大幾乎沒生過病，連感冒都不太有，也沒有鼻塞什麼症狀，只有脖子腫起來，所以剛聽到這個消息真的晴天霹靂打擊非常大。我沒有家族史，也問過醫師原因，他們回答不出來，有醫師反問我，「妳知道為什麼自己會生病嗎?」。

我直接去工作的地方請假，跟同事道別，開始治療。因為腫瘤很大，醫師先排了 4 次化療，再放療。化療非常痛苦，食慾不振、嘔吐，看診的時間又很短，醫師、護理師可能太忙，沒有辦法回答我的問題跟安撫我的不安，也因為沒有這個年紀的朋友生病，生病帶來的恐懼別人可能幫不上忙。那段時間是人生最黑暗的時候，還好我同事朋友非常好，每天傳訊息鼓勵我。

10 月治療完，三個月後要追蹤。隔年 1 月追蹤，脖子兩側看起來還有點亮亮的，放療醫師說可能是殘留的發炎，所以三個月後再來追蹤。2015 年 4 月，追蹤發現脖子已經不亮了，MRI 檢查無異狀，但是正子照出光點，骨頭有 3 點，肝有 1 點，轉移的可能性很大。那時候很灰心，因為轉移後不會再做放療，主力應該會是化療，我到高醫林醫師那裡詢問免疫細胞療法，也去其他大醫院尋求更多意見。在高醫有抽血，但後來沒接到電話通知，應該是基因不符實驗計畫要求。當時衛福部尚未修法，所以林醫師不能收受非實驗對象做治療。

後來台大一位醫師分析幾項療法的風險跟成功率，建議我先採用傳統化療。我很害怕骨頭切片，聽說非常痛，醫師建議不要切片了，看起來大概就確定是轉移了，直接馬上化療，不要再拖時間。我禮拜五去看醫生，禮拜天醫院就打電話來要我禮拜一去治療。

復發的時候我心情反而變好，因為已經經歷過這一切，沒有那麼怕。而且我前階段怕的是會轉移，可是現在都已經轉移了，我已經沒什麼好怕的。心情反而不會更糟，慢慢回升。加上有參加病友會，我覺得幫助非常大，因為參加了才知道，原來有這麼多人在面對，病友會比較有同理心，就不會那麼怕。

有一個病友的老婆講話很犀利，她說，你自己的病你自己都不清楚，那醫生要怎麼幫你?她說你自己要掌握自己的身體。她問我很細，肝指數、ＥＢ、血壓，我都不是很清楚。然後我就開始自己做功課，大量搜集資料，做很多研究。

經過 4 次化療到約 2015 年 8 月，EB 指數有控制住，於是開始吃口服藥友復。但到了 11 月，EB 指數開始攀升，代表口服藥控制效果不佳，於是醫生建議再治療。這次醫生建議可以搭配局部放療+化療+KEYTRUDA 單株抗體免疫藥物(由醫生向衛福部聲請專案藥物)。

在網路上做功課，終於弄清楚免疫細胞療法(高醫)跟單株抗體藥物免疫療法(即免疫檢查哨抑制劑)是不同的免疫治療方法。而且單株抗體藥物免疫療法的效果約 2 到 3 成，

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醫生也說免疫沒有這麼神，使用免疫要追求的是控制久一點而非治癒，甚至說免疫在腫瘤越小時越有用。且若搭配多元治療方法會更好(搭配化療+口服藥+放療)，他說也看過很嚴重已無法醫治的病友，搭配多元治療方法後又控制住的案例。

KEYTRUDA 單株抗體免疫藥物這個治療很花錢，用體重去算一針要多少錢。我的體重約 45 公斤，當時一針約需 26 萬，一個療程打 4 針。藥廠建議要連續打 2 年，總花費要千萬的，沒幾個人能負擔得起。醫師建議我打 4 針試試看，2016 年 4 月剛完成。

目前持續追蹤，效果如何還不是很明確。但上次抽血 EB 有下降到 100 多，不過醫生說到底是化療或放療或免疫的效果還不清楚。醫生說我現在能努力的就是好好提升自己的免疫力(從作息、運動、飲食各方面下手)。

病友推薦我去學瑜伽，學一學我發現我的手沒辦法舉到放到耳朵，還有躺著脖子沒辦法抬起來，我嚇了一跳。我去掛復健科，才發現肌力有點弱，可能是因為放療的關係。在醫院排了六次的物理治療，物理治療師會教我怎麼復健，然後要我自己在家要做。因為復健的東西很多，我就自己印出來做成一本小冊子，提醒自己。

我現在就是好好保養，每天運動一小時，復健也是一小時，早睡早起。也準備回到職場，回到正常生活。

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Appendix 3. Online sources provided by patient K

(1)卡斯柏(衛福部那位提案人，已病逝，但仍有人在回覆網友醫問，有非常深入的免疫治療記錄)

http://lazarsfeld.pixnet.net/blog

(2)星希亞(肺腺癌，blog 資訊頗多)

https://www.facebook.com/cincia0816/

(3)馬克世界(npc 同學會創辦人)

http://puppy2178.pixnet.net/blog

(4)智癌幫(背後是台中醫院放射腫瘤科主任 廖志穎醫師，穀雨健康社會企業)(癌症資訊與營養即時免費諮詢、營養品低負擔方案、癌症營養師線上飲食指導服務)

https://cancernewlife.blogspot.tw/2015/02/nutrition101.html

https://www.facebook.com/DrJimLiao/?fref=nf

我搜尋到的網站：

(1)凱倫(好像是卡斯柏的太太)

http://kiko520.pixnet.net/blog/category/1584987

(2)頭頸部腫瘤知識網(高雄榮總李清池 醫師)

https://www.facebook.com/HNCCCL/?fref=ts

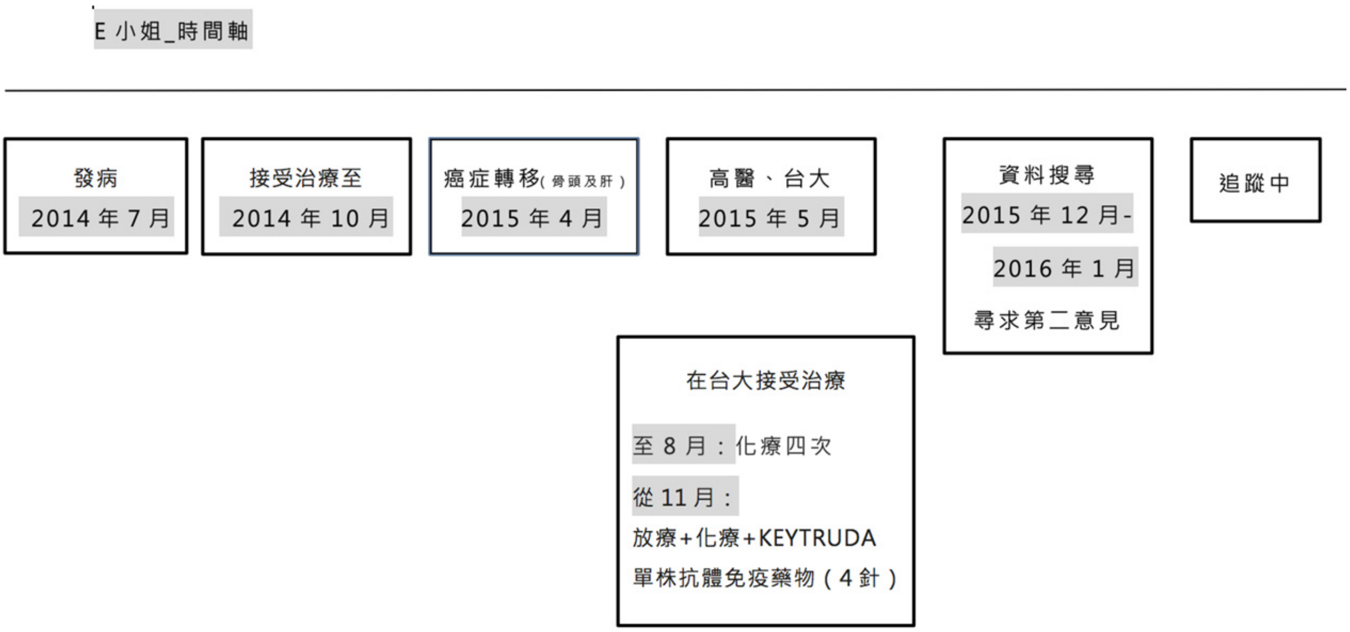
Appendix 4. Transcript sample, patient K

❍ 受訪對象基本資料

姓名：E 小姐
性別：女
年齡： 37 歲
職業： 公務員
癌症名 ： 鼻咽癌
期別 ： 第 4 期
發病年紀： 35 歲
現狀 ： 追蹤中

訪談時間：2016.05.29｜下午 14:30
訪談地點：桃園
訪問者：雅、鄭
病人：受訪者的朋友

❍ 時間軸



❍ 逐字稿

鄭
0:00 所以您也是病友會的人？
E
0:02 我是家屬
鄭

0:04 家屬
E
0:04 對
鄭
0:06 所以也是同樣的病？
E
0:07 對，一樣的病
0:15 那我就當代表
0:17 我當代表
鄭
0:17 好，那你要開始囉
E
0:19 好
雅
0:22 可以移動一下下
E
0:22 沒問題，因為這樣會擋住，收音不好
雅
0:26 啊沒有，我們等一下會有
鄭
0:32 所以要稱呼 E 小姐還是謝小姐
E
0:34 謝小姐就好
雅
0:42 接來就是，可能訪談的內容，也會用一個字代號，我們可以用 E 這個字母
E
0:50 哦，可以可以
鄭
0:56 好，然後今天大概會想要知道從發病然後到現在就醫整個過程，不管是生理的、心理的，然後跟醫生之間，跟家人、跟朋友，找資訊這些等等都會問（E：好），然後盡量放輕鬆也不要太，因為我們其實也不是醫生，也不是護士，只是想要當純用，恩，因為我們是管理學院，跟醫院那邊耳鼻喉科合作，那最主要是把那個病人，或者是家屬的需求找出來之後再去跟醫院溝通哪一方面可以加強，所以很多醫學方面我們不是專家，所以可能沒有辦法回答，但是會想要你整個歷程，經歷過哪些事情，然後這邊薩娜他大概有整理了一下，所以大概是兩年多前發現？（E：對、對）那時候怎麼發現的啊？
E
1:57 欸，其實我在那個 2014 年大概過年的時候，我脖子突然腫了一大塊（鄭：二月左右？）對，然後那時候一月的時候，一、二月，然後那時候我以為只是感冒嘛腫起來，因為我妹也曾經這樣子，然後後來發現是感冒，所以我上班的時間就去看那個，耳鼻喉科，然後他就先給我吃抗生素，然後給我排電腦斷層，電腦斷層是排一、兩個禮拜以後，可是我沒有去，因為那時候我就，呃，聽我家屬的建議，我妹啊，他就說，好的醫生不應該直接讓你做檢查，應該先給你吃抗生素，觀察一、兩個禮拜，如果沒有消的話再做，所以我就沒去，然後我吃一吃覺得有消，沒有全消，有消一些，我就沒理他，因為我那時候是工作狂嘛，就一直在上班，後來還是沒有，等一段時間還是沒有消，我又再去慈濟，那個新店慈濟看，然後那時候耳鼻喉科醫生就是說，可能你的那個抗生素吃了不夠重，他就給我開更重的藥，吃了之後又再消一點，吃了一點點，想說那應該差不多了，我就有點鴕鳥心態嘛，就沒有理它，可是後來過 5，就是大概六月，就覺得還是有一點，我就不放心，我就還是去回診，然後那個醫生就說，啊那很正常，沒有消你怎麼還來這

樣，他就勉強看一下，他就說，欸，好像有一點大，他就拿尺量，量一量他就說，那要排一個時間，直接作切片，要做手術，兩天一夜要開刀，看裡面有沒有什麼惡性的東西，然後，我那時候就想說，影養我上班，因為還要請兩天假，我就不想，我就掛長庚，對，然後就大概七月的時候就掛到長庚，結果長庚醫生一看就覺得不妙，是一個名醫，然後他就直接當場做那個鼻咽切片，然後鼻咽切片一個禮拜後就出來，就是，就發現是，那時候是，呃，第四期，對，就是他們有分期，第四期等於是兩邊淋巴加起來好像超過五公分，對，因為有長好多個，一個是很外面，一個是裡面的看不出來的

雅

4:25 哦～那摸不到嗎？

E

4:26 不知道，就長在很裡面

鄭

4:29 你也沒有感覺？

E

4:31 沒有感覺

鄭

4:31 那這一段時間你從覺得是感冒，然後一直沒有好，你有沒有想說，欸，發生什麼事情？或是去問問看誰？或有去找過相關資料嗎？感冒一直不好

E

4:44 其實我完全沒有懷疑我會生病耶，因為我是屬於從小到大幾乎沒生過病的人，連感冒都不太有，然後我也沒有什麼鼻塞，什麼任何症狀，完全沒有任何症狀，就真的只是脖子腫起來，所以我一直以為說只是良性的，或者是發炎這樣子，對，就完全沒有去懷疑

鄭

5:10 所以怎麼會想找長庚？

E

5:12 噢，因為我就是不想要在慈濟請兩天假，要住院開刀，就是那時候就是工作狂，我不想影響工作，我想說如果去長庚也許不用做到要住院、動手術看良性惡性這樣子，對

鄭

5:29 所以是因為不想要這個療法，所以就去找另外一家

E

5:33 對 4，不想用這種方式

鄭

5:37 那那時候聽到這個診斷，有什麼反應嗎？

E

5:40 就是，晴天霹靂啊，打擊非常大啊，對啊

鄭

5:44 旁邊那時候有人陪你看診嗎？

E

5:49 呵，我先哭

雅

5:52 啊～沒關係

6:05 我們訪談的病人就是用，第三期、第四期，是可以穩定，看起來像，對，小姐看起來精神很好

鄭

6:15 我們這兩個禮拜訪談滿多，有些都是四期的，然後到現在，我們訪談，他說他確診是十年前，到目前為止其實都還不錯，只是那個過程的確會需要人家幫忙，甚至是我們今天想訪談這主要的目的

雅

6:34 您記得還有一位先生，就是，恩，四十二歲的那位先生，他有講什麼，哪一種癌症是最容易治癒的，就是鼻咽癌，他說如果一生中，就是，有癌症讓你選，最好得鼻咽癌，雖然是第四期，我們真的訪問的病人第四期有兩、三位，都很好，恩，對

鄭

7:03 不過那過程辛苦是一定的，然後可能因為我們之前遇到都是男性病人，所以他們都，恩，沒事的樣子

E

7:12 所以他們都很堅強

鄭

7:13 我們就是因為想說為什麼可以隱藏得這麼好

E

7:16 對啊，因為我這個人感情比較澎湃一點

鄭

7:19 這是人很正常的反應

E

7:20 對啦

雅

7:22 像我剛剛我______，因為父母都在俄羅斯，有時候是重感冒，今年三個禮拜都沒有好，就是我怕是不是肺炎啊什麼，都有可能，但是一樣，工作狂，學業也很辛苦，對，台大，課業很重，所以這種感覺，我不會跟他們講，但是在家裡的時候覺得，哦，沒人照顧，真的會，朋友會說這個橘子你要不要拿一顆去，我說，喔不要，我都很好，但是自己哭，就是可能女生就這樣

E

7:57 對啊

鄭

7:57 沒有關係我們可以先，那段先，跳過

E

8:00 噢沒關係，我發洩完了，對啊，發洩完了

雅

8:02 沒關係這樣很好，這樣很好，這樣發洩我覺得很重要

E

8:07 然後我就，我就發現了，就是，其實那時候我們有，恩，很遠的親戚在長庚，所以其實在看診的前幾天，我就已經請他先幫我看報告了，因為知道了，還沒有看醫生前我就知道了，對，所以就直接去、去工作的地方，直接就請假，然後那天去也是，就是哭哭啼啼的，就跟同事告別啊，然後就請假，對，然後就，那時候本來在台北租房子，工作在台北，然後就因為知道要治療嘛，所以就，馬上搬家，搬回家，搬回桃園，然後就開始在長庚治療，對

鄭

8:53 這裡去長庚大概要多久？

E

8:57 這裡喔，大概要三十分鐘，二、三十分鐘

鄭

9:01 你都怎麼去？

E
9:02 嗯，幾乎都是我爸，或者是我，那時候還是我男朋友，我男朋友載我，對
雅
9:07 哦～有人載，這樣很好
E
9:11 因為我爸是退休了，對，啊我男朋友的話他工作是不用打卡，沒有綁住，所以他有空會載我，就輪流載我，對
雅
9:20 那請問剛剛說醫生，有沒有跟你說可能的病因？發病的原因
E
9:26 其實（停頓）醫生好像都不知道耶，到現在應該沒有醫生可以解答
鄭
9:32 那你有問過嗎？
E
9:34 我有問過，他們回答不出來，也有醫生反問我，欸你知道為什麼自己會生病嗎？
鄭
9:40 蛤？他這樣問你喔？
E
9:41 對，洪醫師有問過我啊，他說為什麼你會罹癌？我就說，恩，可能我，自己給自己的工作壓力大，還有喝太多咖啡，那時候他就一直笑，因為他喝很多咖啡，他桌上那時候還擺一杯咖啡，那時候他就一直笑，哈哈哈哈一直笑，對啊，我也不知道什麼原因，可是二手菸我覺得也有可能，因為我工作的地方，旁邊剛好有繼診室，然後他們每天都抽菸，可是只有我啊，別人，同事都好好的啊，對啊，我是覺得，基因欸，基因，跟壓力吧，恩
雅
10:21 那有家族病史有類似的疾病嗎？
E
10:25 鼻咽都沒有，對，外公外婆是癌症，但是（停頓），我爸那邊的話是都很健康，對
鄭
10:32 所以那時候確診的時候，怎麼跟家人講？就是你剛剛有講說其實就是有認識請他幫你看（Ｅ：對）那這件事情是他來說還是你來說？
E
10:43 哦沒有，我就請我妹講，我就要回家前叫我妹講，我妹也很難開口，就跟我爸媽講，然後就在家裡等他們，對
鄭
10:56 所以他們那時候有什麼反應嗎？
E
10:59 欸我就是裝堅強嘛，我就跟他們說這個很好治療啊什麼的，就像你們剛才安慰我的那樣嘛，就是很堅強

雅
11:08 這是事實
鄭
11:10 這是真的
E

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11:14 然後我就跟他們說，要積極啊，什麼什麼的，就跟他們講很多讓他們有信心這樣，那我爸，因為男生都很壓抑嘛，他當場就是，就是，沒有說什麼，表現啊，看得出來他應該，打擊很大，但是他表現得還好，對

鄭

11:32 那媽媽呢？

E

11:34 啊我媽比較反常，因為我媽是屬於比較，情感很冷漠的人，但當下她有稍微，忍不住有哭了一下，但只哭了一下而已，大概兩秒而已

雅

11:46 哇，這樣很堅強

E

11:48 就哭了兩秒這樣子，對

鄭

11:52 在之後，你要接受治療，那他給你的是怎樣的治療方案？

E

11:59 嗯，那時候他是說，因為我的那個腫瘤很大，所以他是先給我排，那時候化療，化學治療嘛，先排，那時候是先排四次，那時候是一個醫生，我不能講他名字，可是我是要批評他欸，這樣ＯＫ嗎？

雅

12:18 可以講姓就可以

E

12:17 大力批評，哈哈哈

雅

12:24 姓什麼

E

12:24 徐，一個男生

雅

12:24 沒關係我們大概知道，因為我們不是針對醫生做研究的

E

12:29 對 3，就是那時候是一個徐醫師，對，然後他就是給我排四次嘛，然後就是打____ ____的，但是每次打一打他都，脖子摸一摸，他就說，恩，好像感覺好像有比較鬆比較小了，然後四次之後就給我排說可以放療了，對，但是我是覺得他、他給我的感覺就是很敷衍，問他什麼問題他都說，這個以後再講以後再講，先不要講這些問題，然後五分鐘之內一定把我們都趕出去，所以他看診非常快

雅

13:04 是在這個時間嗎？

E

13:06 對，在長庚的時候，林口長庚

鄭

13:07 你大概都問哪一些問題啊？

E

13:10 我都問，譬如說，我會問一些跟，恩（停頓），譬如說，我那時候會上網查一些東西啊，那時候亂查，譬如我跟他講說，欸如果中醫的觀點，如果說讓身體熱一點的話，會不會比較有辦法，免疫力提高？他就會講說，這個很難講啊什麼的，然後我又問他說如果之後情況，恩，化療的話，腫瘤沒有消的話怎麼辦？他就說，這個到時候再講到時候再講，就好像，把你的話給撇掉，他都不會正面回答

鄭

13:43 所以等於都，都讓你帶著問題去，還是帶著問題回來這樣
E
13:46 對，而且會覺得馬上就被他趕出去，沒辦法待超過五分鐘，然後譬如說（停頓），噢，反正就是感覺就很差就對了，對，所以他看診非常快
鄭
13:58 所以你做完化療，有繼續在那邊做放療嗎？
E
14:02 對，可是放療科醫師是一個女醫師，林醫師，跟他差非常多，人非常好，每個病人她都可以看三十幾分鐘，只有你有問題他一定會回答你，甚至他會跟你說他查到的理論是什麼，他會不厭其煩跟你講解，甚至還會畫圖，兩個就覺得，對比實在差太多了，對，那個就是一個很好的醫師，恩
鄭
14:27 化療過程有什麼印象比較深的事情？生理、心理
E
14:36 噢，非常痛苦，那個時候，因為就是，那時候身邊沒有人可以問，沒有這個年紀的朋友生病嘛，然後醫生又，每次都花幾分鐘就把我趕出去了，跟他說食慾不振啊、會吐啊，他都說那個正常啊，這本來就是，什麼的，對啊
雅
14:56 那請問醫師有沒有提供類似這種手冊，或是對一些簡單的說明？
E
15:04 那個時候，我們那時候有配一個專科護理師，對，醫生好像都懶得跟我講這些，他很快地把我打發掉，那我們有問題就要問專科護理師
雅
15:16 那是怎麼問的？打電話或者要？
E
15:17 打電話問，對，但是
鄭
15:21 那他有回答到你的問題嗎？專科護士
E
15:23 他有回答，但是，呃，知易行難啊，他們一定會說，少量多餐啊，然後怎麼樣啊，之類的啊，對啊，但是心裡的恐懼我覺得，這個，別人可能幫不上忙，對啊，我那時候就是，我自己有上網做功課，看了一些癌友的部落格，然後看到某一個，好像是一個中年的老師，他的方法，我那時候採用他的方法，現在想想覺得，有點，手段有點太極端，因為他為了維持體重他一天要吃六餐，那我那時候就學他，我就六點吃一餐、九點吃一餐、十二點吃一餐，我每三個小時就吃一餐，所以很痛苦，就是每三個小時我就吃東西
雅
16:09 逼自己吃東西
E
16:11 對，所以我的體重從來沒有降過，只有上升，可是我覺得這樣非常痛苦，雖然體重維持了，但是，每三個小時就要吃一餐，變成你哪都不能去啊，你不能去很遠的地方，因為妳隨時還要等下一餐，那，我吃完我就會不可能坐著，因為我會想說我要趕快消化，我就要去外面走一走啊幹嘛的，對，然後再趕快吃下一餐
鄭
16:36 所以給自己很大的壓力？
E
16:37 對，給自己很大的壓力
雅
16:39 那請問你是吃什麼，是自己煮的嗎？或者

E

16:46 我媽煮的，通常都是我媽煮的，對，或我妹也會幫我準備，因為我妹也住附近，對，我那時候自己上網做功課，就是吃很多營養的，有時候要喝營養品啊，什麼倍力素什麼的，有時候要吃（停頓）呃，豆製品，什麼豆腐、豆花都好，然後，正常的話三餐要吃飯菜嘛，對，就吃很多，甚至連睡前，晚上九點，都還要再喝一杯那個安素，對，才能睡覺，就很痛苦就對了，每天都被灌食，然後肚子都沒有飢餓的那一天

鄭

17:22 那這段時間有什麼舒壓的方式嗎？

E

17:25 舒壓的方式就是看書，因為我喜歡看書嘛，看書然後種種花，然後（提頓）其他的，噢有，就是那時候我本來不太會用ＬＩＮＥ，但是我的，我以前的同事他就說，你可以上網啊跟我們聊聊天，所以有稍微用一下ＬＩＮＥ，但因為那時候心情很憂鬱，又很害怕，所以也沒有用的很頻繁，那時候是人生最黑暗的時候，在長庚的時候，那時候是最黑暗，到谷底這樣

鄭

18:03 所以是偶爾在ＬＩＮＥ上面跟朋友互動

E

18:06 對，但很少，但是我同事友人非常好，就是每天傳簡訊給我，對

鄭

18:15 那他傳簡訊他都會說什麼？

E

18:19 就是都是鼓勵、打氣的話，對，會問說，欸今天怎麼樣啊，這樣子，然後我那陣子傳的通常都是滿黑暗的東西，就是，朋友就輪流傳訊打氣這樣子，對啊，對

鄭

18:32 會有人幫忙說找醫生或是告訴你要吃什麼嗎？

E

18:37 其實大家都不知道，因為我們身邊的人真的沒有人生病，噢有，那個時候我工作的同事，有一些不熟的，媽媽級的，他們可能自己的，恩，家人有，他會提供一些意見，譬如說跟我說嘴巴破要喝什麼啊，就是會傳訊跟我講，對，所以我後來會去台大就是因為有一個媽媽，他就跟我說你一定要去台大，他就說他的一個（停頓）他的哥哥還弟弟，也是得癌症末期，然後林口長庚跟他說我們沒辦法治了，轉到台大他說後來就生龍活虎的這樣，還有辦法去大陸出差，他就一直叫我要去台大，對

鄭

19:24 那，化療完再作放療？（Ｅ：對）放療的過程還記得嗎？

E

19:29 放療的過程也是很痛苦，就是每天幾乎都要去照啊（停頓）講到這個又要，哈哈，我不會哭，我怕講一講會不會長庚告啊

鄭

19:43 不會、不會啦

E

19:46 批評長庚欸

雅

19:46 沒關係這個我們全部不會遺漏，我們對您的感受有興趣

E

19:49 因為我是有比較，我覺得落差太大，在長庚等放療的時候是，恩，放療室在很裡面，外面都是等待的，然後，放療的人完全不會跟你講話，就是冷冰冰的，所以我們就坐在外面等，然後你的號碼到了進去，他們就跟你裝備一些東西，可是我會感覺裡面有

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個男生讓我覺得很不舒服，會覺得他有點要吃豆腐，因為我們照的時候，衣服必須要剪開一點，稍微露出來，要照脖子，然後裡面是有穿一件小可愛，可是你就會覺得，有一個男的他有意無意，明明就用脖子，他就是一直要碰到這裡，你就會覺得，可是你知道，你那時候是生病的人，你要照，躺在那裡，根本不可能跟他吵架，但是感覺就是很差，沒有很多次啦，就遇過這麼一、兩次，可是感覺就是很差

鄭

20:40 這遇過一次應該就已經

E

20:41 對，可是我們那個情況，你也不可能說去檢舉或做什麼，就是覺得感覺很差就對了

鄭

20:49 你有跟家人說嗎？或是朋友？

E

20:51 沒有沒有，對

鄭

20:53 所以跟醫護之間幾乎沒有互動

E

20:58 他們不想跟病人互動，就是，長庚我覺得可能太壓榨員工，他們可能太忙了，所以他們，恩，大部分的護理師跟醫生有，感覺就是用最短的時間把你請走

鄭

21:13 如果你問他們問題呢？他們會比較有反應嗎？

E

21:16 他們就是，用很快的時間打發，幾乎都不太想回答，對，就說，不要想那麼多，想那麼多怎麼生活啊，這樣子，如果我問護理師的話。那問醫生不用講，那個化療醫師他根本就是五分鐘把你趕走，然後那時候因為我還有掛肝膽腸胃，就是也有追蹤，肝膽腸胃更不用講，那個感覺更差，那個進去之後他連眼睛都沒有對到你，他就是從頭到尾看螢幕，你會覺得自己好像不是一個人類，就是感覺很差，後來我在電視上看到他還上節目，笑容可掬，就是是那種談話性健康節目，就覺得好假好假喔，就是感覺很差就對了

鄭

22:03 所以你在

E

22:04 我那時候對醫生非常失望，對

雅

22:08 那你有沒有問過醫生還有沒有其他的資料來源，譬如說什麼網站，或者有沒有部落格他們建議你看，有沒有問過這些意見？

E

22:19 沒有，那時候都問醫生一些，恩，那時候會擔心自己治療情況，所以會問治療，譬如說我的那個ＥＢ指數多少，欸這樣子是高還是低啊？像我這樣子，那時候其實就是擔心腫瘤會不會蕭，會不會轉移，對，就問醫生那個比率什麼的，那只有那個放療林醫師他會很耐心地跟我們講，其他人就是冷冷的，或者他有時候跟你說這個就是機率，沒有辦法跟你說，就是機率這樣，對，恩

鄭

22:54 所以在那個過程，那你怎麼知道怎麼照顧自己，看網路上的資料嘛？你的資訊來源，等於醫生那邊都沒有跟你說？

E

23:08 我還有，就是靠朋友欸，恩，我那個時候很無助的時候，剛好我妹他有同學的同事得過，我就那時候常常會請教他，傳訊息請教他，還有我有一個大學同學，沒有很熟，

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可是他的上司剛好也得過，他就來看我好幾次，還把他上司帶過來，對，所以幾乎都是靠朋友
鄭
23:36 嗯，那他們這些病人，就是一樣生病的，他們大部分給你什麼樣的訊息？
E
23:42 他們，恩（停頓）
鄭
23:45 印象深刻的事情
E
23:46 印象深刻是，恩，我那個大學同學的上司，他非常樂觀，他現在是我到目前為止看過最樂觀的人，他就很開心跟我說，他覺得得這個沒什麼，他是說，他在台大應該很有名，他在台大一開始去好像是初期，然後他不想治療，然後他就跟，好像是跟王俊維醫師他們講說，他想要走自然療法，然後醫師就一直勸他一直勸他，但他聽不下去，他就自己去喝胡蘿蔔幹嘛的，做很多嘗試，但是他其實學歷很高，台大機械研究所，但他就是要走自然，然後他就過了大概幾個月，期間台大都還有打來勸他回去，然後他還去澳洲玩，去好多國家玩，享受人生，我就說這種人真的是
鄭
24:41 好另類
E
24:42 對，而且還是男的，沒有大我幾歲，但是後來他說回診的那一天，他剛從機場，從澳洲玩回來下飛機，他就馬上去看報告，發現腫瘤沒有變小，還變大，他就乖乖接受治療了，對
鄭
24:58 所以他把這一路的轉變跟你說
E
25:01 對，他就跟我講說，他一路這樣過來，就他非常樂觀，覺得沒有什麼，我還有很多朋友身上有五、六種癌，也很多吃飯聚餐啊，他還說他還會吃鹹酥雞什麼的，一個禮拜吃一次，還是很開心這樣
鄭
25:19 他還是有吃就對了
E
25:19 對，他說他准許自己一個禮拜吃一次不好的東西，對，就是一個非常陽光非常樂觀的人，還說自從生病以後他整個人格特質都變了，變得非常樂於助人這樣子，對
雅
25:37 所以您剛提到上司還有做過很多的嘗試，像喝紅蘿蔔，（E：對）類似這樣療法，那你們有常識嗎？

E
25:44 噢，我有嘗試過，我自己都覺得很笨，因為親戚都會亂給你意見嘛，那時候我有個親戚，中南部的，他們就是說，恩，他們有一個遠親也是，好像喝什麼芋頭的根莖熬成的水，然後好像對身體很好，可以抗腫瘤，然後他 3 就是主動送了一箱上來給我，喝起來很普通就像水一樣，因為是植物嘛，喝一喝他還鼓勵我說可以去買，跟他們的親戚買，然後我就去買了一次，但是我喝了大概幾罐，我想說還是毛毛的，我就再也沒喝了，偏方就那麼，就嘗試那麼一次，對
雅
26:31 中醫的部分呢？
E

26:31 中醫的話其實我那時候是完全沒有接觸，然後我也不太信，對啊，所以那個時候也有人叫我說要買中藥什麼的，我就沒有聽進去，對啊

鄭

26:46 接下來，之後我們，恩，收到的訊息是，到了去年中，這個部分是怎麼發現的？

E

26:55 對，這個是因為治療完十月，三個月以後要追蹤，就是一月的時候，2015 年一月的時候追蹤，那時候脖子兩側看起來還有點亮亮的，然後我那個放療醫師他很細心嘛，他就說也有可能是殘留的發炎，所以要再追蹤，所以他又再給我排三個月，所以到四月的時候追蹤發現脖子已經不亮了，可是骨頭跟肝就有光點，對，他就覺得可能性非常大，但是那時候淋巴癌是照不出來的，____才看得出來，然後那個時候我還有去那個肝膽腸胃科看，他有幫我照超音波，肝的部分他就很肯定地說，那個只是水泡，就是我說那個很不尊重人的醫師，眼睛都不會看我的，那是水泡 2，就懶得理我，對，就是他很篤定，我不知道他到底在篤定什麼，對，然後發現轉移之後，我那時候，很灰心嘛，那時候同事就是一直勸我說你要轉去台大，因為轉移之後其實就不會再做放療了，主力應該就是化療，然後我覺得長庚那個化療醫師，如果我要再信任他，不可能，我覺得我死我也要死在一個我覺得我能信任的醫生手上，所以我就覺得，那我要轉到，我就去台大看診，我那時候還沒有確定要去，因為我覺得去台大車程比較久，會麻煩到我家人，我那時候在長庚就是因為我覺得離我家近，大家載我不會花那麼多時間，然後我那時候還有，甚至還有跑到高醫去，（鄭：跑到那麼遠？）對，去找那個林陳龍醫師，對，去問他免疫細胞療法

鄭

28:45 你怎麼會知道這個？

E

28:46 噢，那個時候四月的時候，我妹啊，他就怕我很憂鬱，他就推薦我參加那個，一個病友會，就是ＮＢＣ同學會，對，他就，加入之後，我講一下我的情況，私下就有病友ＬＩＮＥ我說，他老婆跟我情況有點像，他老婆去高醫做，他就叫我說可以去問一下塔斯柏，有一個癌友很有名，對，他就說可以問他免疫的東西，然後我自己上去看一下他的資料，我就想說那我去高醫問問看，所以我就自己去高醫問，對

鄭

29:23 那在那邊得到什麼答案？

E

29:24 高醫的話他是先幫我抽血，然後他是先叫我簽那個同意書嘛，他就說到時候一個禮拜會回覆我，看我的基因符不符合，因為那時候免疫細胞療法衛福部還沒有核准，所以他只能符合他的實驗對象才能治療，不符合他也不收，對，結果，我就說好，那那個禮拜還沒有回覆我，我就去台大看，洪瑞隆醫師，洪醫師就跟我說高醫那個風險很大，他說那個成功率沒有很高，然後化療穿插在免疫裡面，他說那個還不知道成功率，那個是要自己可能隨意排，他就說你要做風險那麼大的醫療行為嗎？他就勸我考慮，他就說，他覺得我還是先用傳統的化療會比較好，那我去看洪醫師我覺得是可以信任的，而且他很積極，我禮拜五去看他，他問我要不要接受，我就被他說服了，然後我就禮拜一，禮拜天喔醫院就打電話叫我去治療，我禮拜一就去治療，很快，對，那我當下會覺得是因為我覺得態度差太多了，就洪醫師他那麼忙，每天看那麼多診，可是他不會想要用最短的時間把你打發走，他會跟你分析然後講話不疾不徐地，那你問他問題他都會回答，就覺得差太多了，我就跟我老公說，噢，我們大概在 2015 年 3 月啊，我跟我男友就去登記

雅

30:59 哦，現在是老公

鄭

31:06 很好耶，對呀

雅
31:10 就會有個心理的支持
鄭
31:11 他應該扮演很重要的角色
雅
31:15 還有一個家庭，不只是原來的家庭，還有新的家庭，真的很棒
E
31:19 對啊，只是，有點對不起他而已（哭）對啊，所以我那時候就跟我老公說，要死也要死在台大醫院，因為跟林口長庚真的差很多，對啊，去台大就有被尊重的感覺，對啊，而且，我覺得差別很大是洪醫師，可能他看過很多例子吧，他沒有很震驚，他表現地很從容，可是我那時候發現，剛發現轉移的時候，在林口長庚的時候，那個化療的醫師他是很驚嚇的，他是，他的表情很害怕，好像被嚇到，我那時候覺得說，對，我想說有那麼嚴重嗎？他就很緊張，我就覺得說，天哪，我也被他嚇到，所以我對他沒有信心，對
雅
32:13 哦～很專業
E
32:17 而且那時候他是建議我說，那時候那個化療醫生建議我說，要做骨頭切片，要把我骨頭切一塊拿來檢驗，對，然後那時候我就很害怕，因為聽說非常地痛，對，我那時候，他都幫我排好了，禮拜五下午那天要作切片，早上的時候我去看洪醫師，洪醫師就跟我說，不要作切片啦，他說你做切片有傷口會耽誤你的治療，他說其實他看，已經很確定是轉移了，他建議我直接做化療，馬上治療，不要再拖時間，其實我去高醫的時候那個林成龍醫師也是這樣建議，他也是建議馬上治療，他說他覺得九成九就是轉移，可是，林口長庚那個徐醫師他是認為說你應該要先做骨頭切片，對呀，所以，我後來就是，選擇就是在台大治療，對呀
雅
33:13 所以醫生意見不同，對病人您覺得會造成很多的問題嗎？
E
33:18 對，那但是我，我會選擇，我那時候，那時候我會選擇我能信任的，誰跟我聊天，我覺得比較能信任他，對，因為我覺得至少你的態度要讓我感覺到你有認真在看待我，把我當成一個人，對，那個林成龍醫師人也很好
鄭
33:41 第一次發病到再來這個第二次診斷，你覺得有什麼轉變嗎？心情上或是面對疾病的感覺？

E
33:50 其實我到這個時候反正心情變好，（鄭：心情變好？）對啊，可能是因為已經歷經過這一切，所以我在做化療的時候已經沒有那麼怕，而且我前階段我怕的是什麼，我就是怕會轉移，可是我都已經到轉移了，我已經沒什麼好怕了，所以我就覺得，心情反而不會再更糟，慢慢回升，哈哈哈，對，然後那時候再加上有參加病友會，那時候真的是，噢，差很多，我覺得參加病友會幫助非常大，因為你才會覺得說，哦，原來還有很多人也很嚴重，你就會比較不會那麼怕，對
鄭
34:34 那那個病友會大概有多少人？
E
34:36 大概五十出頭吧（鄭：滿多人的耶）對呀
雅

34:39 那都是實體的見面會？或者你們是這樣見面的，這樣面對面，或者都是透過ＬＩＮＥ或者網路？
E
34:48 都是透過ＬＩＮＥ，可是當你在上面聊天聊久了，有些人跟你，或是他特別關心你，比較溫暖，他私下就會跟你有聯繫，慢慢就會變成朋友關係，然後也許就會約出來，就會從網路上的朋友變真正的朋友，對 3，像我跟他就是這樣，我那時候剛進去的時候就是很無助，但是就是覺得，那邊好多人都可以給你意見，你問什麼都會有人回你，然後甚至我那時候在台大治療的時候，我會傳說我很害怕，因為我其實很怕化療，到現在還是非常害怕，結果我一傳啊，馬上就會有人來看我，有那個病友會就有人說，欸我下班了，我去看你，那天就有兩三個人來看我，對，我覺得差很多
雅
35:38 這樣很有幫助，而且病症類似的比較可以相信
E
35:41 對，而且，有生過病的人跟沒生病的人，他們真的有差，同理心真的有差，對
雅
35:49 他們都經過了這一切
E
35:51 對，他們會知道你會害怕，因為像我剛發病，剛確診的時候去公司請假的時候，我那時候哭得很慘，可是我印象很深就是，我有一個同事，他就跟我說你哭什麼，他說我們有一個同事他也是癌症，他每天都開開心心地上班，你應該要堅強一點，我那時候就覺得，呃，我就覺得好像自己很遜這樣子，可是你沒有辦法啊，你晴天霹靂呀，就是有些人會覺得說你要正向思考，對，有些朋友會傳給我說，你要正向思考呀什麼的，可是如果做得到的話，對，心裡就會想說，哪一天你遇到你看你能不能那麼正向，對呀
雅
36:35 已經變成口頭禪，哈哈
E
36:38 對 3，或者是會傳一些什麼心靈導師的標語啊，傳一些文章，叫你要
鄭
36:44 會傳一些什麼神的圖之類的
E
36:46 呃神的哦，神的是還好，對 4，有 3 那個宗教信仰的，可是我覺得有宗教信仰的朋友都滿善良的，雖然我是無神論，我覺得我會那麼痛苦是因為我是無神論者，如果我有宗教信仰可能會開心一點，可是我就是，恩，沒有辦法，所以我有去嘗試了，我有去______，然後我有朋友是基督教，他有給我聖經，我有看一下，我都沒有辦法接受，但是我喜歡他們來找我，就是取暖啦，因為他們有宗教信仰的人我覺得都特別有愛心，有行動力，他們都會積極地來跟你聊天或幹嘛，對
鄭
37:29 他們聊什麼是你覺得比較好？對你有幫助？
E
37:33 嗯（停頓）譬如說我遇到兩個有宗教信仰的朋友，都是同學，他們就是會介紹譬如說，他們的方式都是會介紹病友
鄭
37:48 反而是透過宗教在認識病人
E
37:52 對，譬如說他們在他們做禮拜的時候有病人，他就會介紹給我，那些病友都樂觀又堅強，因為他們都有非常堅強的信仰，他們都會帶那個經文，他們可能，他們的方式不會一直跟你說什麼主啊、耶穌，他們會跟你聊天，聊完之後跟你一起禱告，對，（病人：我的這種是前面聊天，那後面的禱告我就會）所以我在台大住院有時候外面會有那

個，恩，那種基督教還是天主教團體，他們說，欸我可以幫你禱告嗎？我都說歡迎歡迎，其實我是為了取暖，所以他們那天禱告禱告，我就享受一點點很多人的感覺這樣子，但是其實，那些書我都放在書櫃上我都沒有打開來哈哈對啊，就是沒有辦法接受那些觀念啦

雅

38:44 所以他們介紹給你很多病人嗎？大概有幾位？

E

38:49 欸，其實不多耶，就大概都兩位吧，對

雅

38:54 那現在還保持聯繫嗎？

E

38:55 噢，有 2，都還有保持聯繫，也是變朋友，我覺得有宗教信仰的人，我真的佩服他們耶，他們真的很有愛心，譬如說我有一個，就是，同學的教會的朋友，他自己也是洪醫師的病人，他第四期很嚴重，他那時候打的化療藥很強，頭髮都掉光光，光著頭，然後他還會安慰我，然後他治療完三個月他就回去上班，他現在也常常會打電話鼓勵我幹嘛的，很積極，對，恩，所以我真的很佩服他們，只是我真的沒有辦法像他們有這麼堅強的信仰

雅

39:36 很好奇他們的愛心的來源是什麼，真的有時候太神

E

39:40 對，他們的宗教好像就是給他們這個力量，對

鄭

39:46 所以你在 2014 年十月治療完，然後休息一陣子，有回去工作嗎？

E

39:54 呃我只有去報到一個半天，對，那個時候因為我就，我同事就幫我從台北申請調到桃園，就在生病的時候調成功，然後桃園報到的那一天，因為我是公務員嘛，所以想說報到我就去一下，我就去這樣，就去個半天而已，後來因為我還要治療，因為我幾乎都沒有停過嘛，所以我會一直請假，只有報到半天而已，對

鄭

40:25 所以這段時間就是專注治療？

E

40:28 對，而且我覺得，到現在我都想說我的心理（停頓）承受度不知道有沒有辦法回去上班，因為我怕跟人家聊一聊到時候會哭，很丟臉，對呀

鄭

40:41 不會呀，這是很正常的反應啊

E

40:45 對，這個時候心裡應該還是沒辦法，對，這個時候還在治療，可是那時候加入同學會就認識很多朋友，有些人真的很好，她會私下關心你，對，跑到醫院去看你，甚至，呃，有住我家附近的病友，還會約出來拿東西給你，（病人：不是我不是我）那時候還沒認識她，那時候她還沒進去，（病人：對還沒進來）還沒認識她，對

雅

41:18 了解，那在這邊治療過程中您接受的治療有很多種，那像這種你特別有查詢很多的網站，但是都是自己查詢的，或是其他人有幫你介紹，或者，還有你查詢的時間有很久嘛，好像一兩個月？

E

41:36 喔對，對，其實啊我加入那個病友會認識病友，我覺得是人生的轉折點，因為就認識一個，他自己沒有生病，是她老公生病，可是他就跟我說，他講話是很犀利的喔，

她會跟我說，你自己的病你自己都不清楚，那醫生要怎麼幫你？說你自己要掌握，你去看診的時候你不要被動等醫生就是告訴你，你要主動問醫生問題，你要掌握自己的身體，所以他都問我很細，你的肝指數？你的ＥＢ？你的血壓？我都不是很清楚，他說這些東西都要清楚，然後我就開始自己做功課，我就被他啟發的，像我，呃，洪醫師要建議我這個治療的時候我也不知道，他就跟我說你自己要做功課，我就開始自己大量搜集資料，做很多研究，對

鄭

42:30 怎麼找這些資料？

E

42:30 就是，ＧＯＯＧＬＥ，用ＧＯＯＧＬＥ找，用關鍵字，喔我有帶來，帶我的資料給你們看，大概你們會比較知道

鄭

42:45 這些也太驚人了

E

42:46 我這個，我會傳給我老公，然後叫他幫我印出來，或者是六月的時候去他辦公室，稍微把他印出來，然後做一點筆記

42:59 喔對對對對，這個是後來可以跟你們分享，啊前面，這個是我最新的，啊後面的話都是免疫的，因為我要了解那些藥，還有效果，所以我就要把這些東西都好好查一查，所以我那時候有做一點筆記然後稍微查，因為我是第一類組，所以其實這些東西我都似懂非懂，就自己要從頭摸索，那我的感慨就是啊，其實生物應該必修課，對，因為這種東西跟身體切身相關，可是我念第一類組的真的好多東西都不了解喔，都要自己慢慢學，反而我覺得像數學會有些東西真的沒那麼重要，生物我覺得還滿重要的

鄭

43:43 所以像你說的有些東西你是懂，那不懂的時候怎麼辦？

E

43:48 不懂就是，一個接一個查，譬如說我看前面的有一些，恩，什麼關鍵字我不懂，我就再查下去，就一直查 4，就查成這樣，就大概掌握了一點概念

鄭

44:00 會問醫師或是病友或是護理師嗎？

E

44:05 病友那時候其實沒有人給我意見，因為洪醫師說我是台大第一個這樣做的鼻咽癌病人，所以我其實找不到，我找不到有經驗的人可以問，然後病友給我的意見就是他們會跟我說你要自己去做功課，對，然後我還有那時候想要找第二意見，所以我又掛林口長庚，可是我是找我信任那個放療的醫師（鄭：哦，你覺得比較舒服的那個）那是唯一信任的，對，唯一信任的醫師，我就去找他，問他，他就跟我說他不了解，但是他幫我推薦一個他覺得可以回答我的醫生，當然不是那個徐醫師，他推薦一個很有熱忱的醫師，對，然後他很好，他也不收我的診療費，喔那個醫師超好，我發現轉移的時候他還哭耶，因為我那時候哭得很慘，我老公也哭得很慘，他也有哭，就覺得一個醫生可以為你掉眼淚真的太難得了，就是真的，恩視病如親，對，他就介紹我去看，呃，長庚的一個醫師，姓謝，他說他對免疫好像比較有概念，會出國做研究，對，所以我就想說，我那時候已經做了這些資料了，我就自己把問題都列出來，我最擔心的其實是副作用，但是有沒有副作用我覺得真的很難講，我是抱著說，沒效也沒關係就是試試看，對，然後我就去問那個長庚那個醫師，那個醫師就很有熱忱，我那時候就想說，為什麼我當初沒有遇到這些醫生，覺得這也是學習耶，雖然我比較晚懂，就是醫生還是要挑的，那時候只覺得說林口長庚很有名，醫生應該很厲害，不知道說有好醫生也有爛的醫生，對，所以我那時候遇到那醫生，他就很肯定洪醫師的看法，他說這個方法非常積極，如果是我自己我也會這樣做，他就鼓勵我說，可以試試看

雅

46:16 了解，您剛有提到你會記錄你想問的問題，那你還會記錄什麼嗎？在生病過程中從發病到現在，你有沒有這種習慣？
鄭
46:29 有些人會寫日記呀，有些人會寫網誌呀
雅
46:31 對，我們遇到的有一些會
E
46:33 一開始我妹是有建議我要寫日記，但是我寫了幾篇，心情很差，寫不下去，對，我其實一直到心情好，就是到，大概，呃，這個時候，開始搜集資料的時候，我就開始會做功課，所以我現在每次我想到什麼問題我就會寫起來，下一次看診我就會問醫師，我現在覺得說醫生他真的太忙了，他的時間有限，所以我們要在很短的時間抓到重點問醫生，醫生才能回答你，對，所以我現在就是，呃，掌握自己的情況，然後每次問醫生問到關鍵，醫生才能夠回答，對
雅
47:15 所以日記像跟自己說話你比較不會寫，但是問題會記錄？
E
47:22 對，如果心靈的舒壓其實我就是看一些旅遊文學的書，對呀
鄭
47:28 那像這一本資料你什麼時候會拿出來看，除了你搜集放進來之後
E
47:35 像前面這些就是之前我做治療的時候會看，然後還有就是，因為我就是算是，做這個的，台大的第一個嘛，所以之後有人想要做免疫會問我，如果問我，私下約出來，我就會跟他們講，然後我就會，看他們要不要拿回去印，還是網頁給他們，讓他們自己印，我就會建議他們要這樣做，對啊，但是願意這樣做的人很少，很少 2，對啊，大家都希望聽到你的結論，但是過程他們不想要花這些心力，對
鄭
48:13 所以你把自己搜集整理完了以後，還把它跟人家分享？
E
48:18 對呀對呀，大家互相呀，因為人家也有幫我呀，大家就是互相交流呀，對呀，然後後來，之後我陸續搜集，最近就是因為復健的問題，然後就開始，這是比較後面搜集的，復健的東西，對啊

雅
48:39 那請問在這個過程中，醫院有沒有提供像這種資料，或者其他的資訊？
E
48:47 呃有
雅
48:49 例如說台大，你後來都在台大治療，那他們有提供什麼你還記得嗎？
E
48:53 在台大的時候，像這種好像沒有，因為我在前期在長庚的時候，外面都會有，可以自己拿，所以都給了，對，到這裡其實已經就是，熟門熟路了，做化療那些，對，所以就，就沒有，對
鄭
49:12 你說做放療什麼會遇到病友嗎？會跟他們有交談嗎？
E
49:17 做放療的時候，呃，在林口長庚的時候會遇到，會去，我會請我爸，我爸會陪我去嘛，我會去我爸去請教他們，對，可是，然後在台大的話好像，比較沒有，對，恩，幾乎都是靠那個病友會，對，但是後來病友會我好像，後來有退出了

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鄭

49:46 為什麼會退出？

E

49:48 因為有一些，欸，其實這就是很矛盾，人事的糾閣（病人：因為我還在裡面）你在一個團體裡呀，就是，我有參加其他的一些像是臉書的那種，那種可能成員有上萬個，一萬多人，那種就是沒有什麼情感交流，純粹就是分享經驗，或是問問題、查資料，但是，我參加那個ＮＢＣ同學會他是大概五十個人，那個情感交流就是很濃烈的，甚至私下會變朋友的，但是，呃，有時候你交流地很密集就會容易有問題，可能你跟某些人合，你跟某些人就是合不來，就是會有一些，最後都會衍生一些問題，到最後我會覺得，不太能認同那一個病友會的，呃，應該是創設的人，他的理念，所以我就退出了，但是我退出是，其實我之前早就已經跟裡面聊得來的人私下，我們都已經有自己的小團體了，都會約出來了，所以我們就自己另外出來，對，我們就是沒有要靠那個，原來的那個創辦人這樣

鄭

51:01 創辦人的理念跟你有點不太一樣？（Ｅ：對）他的理念大概是哪一方面？

E

51:06 我們會覺得他，有點變自私，對，因為我們會覺得大家都是癌友，妳參加那個應該是需要幫助的你就要幫助他，但是，恩，就是你慢慢會覺得他，會有一些排擠一些其他的病友，譬如說，呃，想法很負面的、很消極的，或者是（停頓）很有知名度的，或者是（停頓）這可以講嗎（病人：你自己決定）講到這麼明（雅：可以）講到你，講到他們可以嗎（病人：可以呀，我無所謂）跟你們都還有關耶，那個時候他很熱心，他受訪之後呢，他就在那個病友會說，看______願不願意分享，結果就被那個創辦人

雅

51:58 對，我們後來有跟他聯繫

E

52:01 有跟他聯繫？

雅

52:01 對，教授親自有跟他加ＬＩＮＥ，但是他都謝絕，他覺得，他就是都會回覆，沒時間、很忙，沒時間、很忙

E

52:12 你們為什麼要跟他聯繫啊？

雅

52:13 因為我們想訪談病人，而且剛好都是鼻咽癌，我們覺得很好的族群，我們可能可以成為我們平台的用戶，那就是也可以協助你們，但是後來不知道原因是什麼，他，教授親自出面，然後還，因為我們只請他就是那個複製我們的連結，也不是要他做任何事情，就是跟你們分享這個消息（Ｅ：這樣也不行？）我們也沒有問其他的事情，結果這個

E

52:45 對呀，連他只是ＰＯ一個你們的團對網址，他都被罵，私下被教訓

鄭

52:53 不好意思耶

病人

52:54 沒關係，這不是你們的問題

E

52:56 然後那個時候，結果因為這件事，還有人退出，因為他被罵，有的人覺得這個創辦人太過份了，怎麼可以這樣，大家都是互相要幫忙，我會覺得那個創辦人走偏了，他覺得，好像他自己是什麼秦始皇嗎還是什麼，覺得就是我是皇帝，這是我的王國，你們

都是我的人，你們對外的發言要經過我的同意，獨裁者嗎？暴君嗎？不知道，用詞有點激烈

雅

53:23 那他的醫生是不是王軍為醫師嗎？（鄭：對5）那個王軍為醫生當時有說好像還有其他的考量，所以才不會讓我們進去，那其實王醫師當初也本來想幫我們跟他聯繫，後來他覺得應該背後有什麼原因才不讓他跟我們，所以後來也建議我們不要再繼續聯繫

E

53:50 他有他特別的地方跟很大的優點，但是，他也有他很獨裁嗎？獨裁的那一面，如果在古代他應該就是秦始皇，就會覺得大家生病，裡面各個年齡層我們都是成年人了，然後你憑什麼要管我們在外面的言行舉止，而且我們是大家互助分享為什麼不行？還說要談合作、要簽約、要有什麼權利金，我覺得好奇怪喔

雅

54:20 但是他當初他都沒有跟我提出來，也沒有問過有什麼程序，就是我要填什麼資料，保密資訊這個，我們都可以學校代表

E

54:33 他不願意，我就覺得他有私心，他覺得那些東西是他一手創辦出來的，這些成果榮耀都歸於他，他應該不想要給你們分享吧，我也不曉得

雅

54:45 但是教授當時很有興趣跟他，那位，對陳先生，面對面這樣訪談的原因，因為他是創辦一個學會，就覺得很珍貴，就是我們可以訪談這位，對那些病人會很有幫助，而且他其實跟我們面談也不行（Ｅ：對Ｙ）他沒有說沒興趣，他是說很忙很忙，連續三次（Ｅ：他一點都不忙，你只要跟他約六日他絕對跟你見面）而且你們有實體的病友會，不只是線上的，（Ｅ：對）所以這個做得非常完整，我們想要向你們學習，但是學習不到

E

55:27 但是沒關係，我有其他，我曾經也是被他抓到那個，他有一個平台管理小組，就是等於是幹部，我曾經是裡面的一員，然後裡面還有好幾個幹部都因為他太自私，他很多行為都太自私了，我們都退出，我們自己另外有一個 group，我可以叫他們來受訪，他們實在是，裡面有一個幹部就是因為他這件事退出的，就是我說的那個女生，鼓勵我要做研究的那個女生，他就是因為覺得太可惡了怎麼可以這樣，他就退出了

鄭

56:00 其實我還是想找人做那個教會的初衷，因為我們是沒有任何利益的，就是管理學院跟耳鼻喉科這裡合作，然後其實我們管理學院這邊會知道是因為美國有一個網站，叫做 patient like me，跟我一樣的病人

E

56:18 哦有有有，這個我朋友也有推薦我

鄭

56:20 對，然後我們就發現說，欸在美國人家做的那麼好，大家可以上去把你治療的過程，你用了什麼藥，然後成效怎麼樣，甚至做圖表化做得這麼好，為什麼台灣的網路這麼發達，可是很多病友卻覺得很孤單？所以我們目前都是用，像是薩娜他就是用自己的論文，然後我們老師、醫生都是願意幫忙，所以就比較想知道他們的那個理念，是不是，因為還跟經驗有關，所以我們的確是需要請教有經驗的人，對啊，然後如果真的是訪問不到他會覺得很可惜

E

56:57 其實不用訪到他，因為基本上他也沒在做事，他都是發號施令，下面的人在做，像病友會我們那個退出的那些好朋友，有一個也是住附近，是男生，他就是負責幫他籌劃的啊，呃，約場地、問人、定名牌，全部都是他一手辦的啊，主持人又是另外一個退出，就是為了他退出的那個女生，當主持，然後在裡面就是有教大家一些操的，又是另

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外一個，其實他沒有在做事，他只是發號施令，他是精神領袖應該這樣講，對，所以有時候，我私下挖苦他，我說他以為他是聖嚴法師啊？就把自己偉人化、形象化了，對，就是絕對的權力帶來絕對的腐化，這句話是他的座右銘，放在他身上，哈哈哈

雅
57:52 了解，那這樣我們也比較安心，不是我們做錯什麼

E
57:56 不是，我覺得是因為他被他私心蒙蔽了，對，所以其實你們不用訪問到他，你們訪問下面幫他做事，其實大家都是為了要幫助病友，我們互相幫忙我們才願意做的，對啊，所以（停頓）我不曉得

鄭
58:17 所以比較難想像就是，在這個團裡面有人權力比較高，照理來說大家都是一樣的

E
58:26 對，可是其實

鄭
58:27 頂多有誰經驗多有誰經驗少這樣

E
58:27 對，但是並不是裡面每個人都覺得他真的是聖嚴法師，很多人其實是抱著說，裡面有很多很好的人，我們要留下來，不是為了他，有些人是很討厭他，還是得留下來，為了其他朋友啊，其他需要幫助的人，可是他可能覺得自己很偉大吧，很厲害吧，對啊

鄭
58:51 所以即便你退出了這個病友會，還是有其他的連結、其他資源？

E
58:55 而且小米還有在裡面嘛，他還是會幫我，我們曾經有一個，我覺得很可憐的病友，就是很嚴重了，他就是曾經復發過又治好，可是他吞嚥已經喪失，他又______，然後他失業，他一度去台大醫院賣彩券，對，結果因為他發言很負面，他都會說哎人生啊什麼沒有希望，結果那個創辦人覺得他的發言太負面了，把他踢走

鄭
59:29 但是這種人最需要人家的幫助

E
59:31 對，而且，然後所以我們有一個以前的幹部，也是因為那個人被踢走，他也離開了，他覺得說這種人最需要留在裡面，你怎麼可以因為他的發言很消極、很負面，你就把他，而且他還失業耶，對，但是我們最近就是跟他合力又把那個人私下又再找回來，我們自己另外成立一個小小的

雅
60:09 我想問一下就是你當初這些資料是一天？花多久的時間查詢？

E
60:15 大概一天，一兩個小時，慢慢慢慢查，對

雅
60:20 都是中文的資料？沒有

E
60:23 喔也有英文的，但是英文的很花時間，所以有時候就直接用翻譯的，對

鄭
60:30 那查的就是資料你會問醫師嗎？就像你剛剛講的

E
60:34 會會會，會問醫師

鄭
60:36 醫師也都有回答到你的問題嗎？

E
60:38 會，醫師也會，我覺得，我在台大遇到的醫師都可以跟你討論，可以跟你溝通，對，跟在林口長庚遇到的差好多，我不知道為什麼，是整個醫療體系結構嘛？所以我討厭林口長庚之後我就討厭台塑集團，整個集團我都討厭，我覺得他們的企業文化應該是出了問題，對啊，恩
雅
61:08 我想問一下，預防相關的資料，你是怎麼查詢的？也是由上網，或是有看書？或是有問誰嗎？
E
61:17 都有，上網、看書，還有看病友經驗，還有文化局就在附近嘛，他都有一些康健雜誌什麼的，就每個月有空我就去翻一下，如果有很好的我就影印搜集起來，對
雅
61:35 哦～會搜集，像這種資料夾？
E
61:37 對，其實我是很想，一直有在鼓勵我認識的病友說要自己做功課，對，但是，願意做的人不多，對啊
鄭
61:50 而且我覺得你做得好深入，畫重點
E
61:52 因為我這個人就是有時候，研究會過頭，對啊，不小心會過了這樣子
鄭
61:58 這樣很好，因為你還把這個東西整理完跟人家分享，其實也是在幫助人
雅
62:05 我記得李小姐當初也有做整理
病人
62:07 我只有做我爸自己的，我沒有做網路資料的

雅
62:10 但是也一樣，就是厚厚的資料
病人
62:13 我所有的東西都是台大醫院給我的
E
62:15 其實他更熱心耶，要找到像他這種人，他有點像是女版的那個創辦人，但是他是無私的，那個創辦人是自私，對
鄭
62:26 我覺得他很親切啊，完全不會有那個
雅
62:30 我們教授很敬佩
病人
62:32 謝謝謝謝
雅
62:33 對，這半年都跟我們保持聯繫，這樣非常難得
E
62:38 對啊，因為他真的是很有心的，他參加那些病友會，人家有問題他都會很熱心地回答，而且他是沒有私心的，對啊，他其實也有能力自己創辦一個（病人：不要）所以，他有辦法，可是這樣子會很累啊，但是你說像那一個ＮＢＣ同學會，我都叫他校長，因為他自己說是同學會嘛，說那個校長真的有花那麼多心力在上面嗎？沒有，都是靠下面的平台管理小組在幫他，對

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鄭
63:12 那我們先回到這個部分來，這個過程，因為你剛才說你是台大的第一個，那好像，我這樣講不知道對不對，會多了一些些不確定感？（E：對）那有沒有什麼方法去克服它，或是？
E
63:29 克服就是（停頓）想的極端一點，我那時候就跟我的，呃，病友討論，就說，如果副作用很大，因為也有人大到去世的，很大也好，趕快走，不要拖累家人，對，我會覺得，生病之後要馬就走快一點，我不想要就是，到最後過程然後撐好幾年，因為我覺得這樣家人負擔太大了，對呀，所以我覺得要馬就控制，不然就趕快離開，就是這樣，對
雅
64:03 那請問當初跟家人交流如何，你有妹妹，有爸媽
E
64:10 呃我妹妹是我可以跟他講所有的一切，對，可是我爸媽，我就是很隱諱，因為父母親會擔心，所以他們就不太知道怎麼情況，我都含糊帶過，問什麼我都說哦很好 3 啊，像我要做這些治療的時候，我爸媽就是說為什麼你突然要做那麼多治療？他們會擔心，我就會跟他們講說，醫生覺得我希望、機會很大，所以才會建議我做這些方式，對啊，就是我會用比較積極的話跟他們講，對
雅
64:43 那請問你這時候都在住院，或是在家裡？
E
64:48 嗯，這個時候，有住院，住五次，然後都住兩三天這樣子，其實我也很害怕住院，對啊，我到現在還是沒有辦法克服，害怕住院、害怕化療，對啊
雅
65:03 住院害怕什麼？

E
65:04 住院的話因為我住的病房我都會遇到快走的人，對
雅
65:10 所以你沒辦法自己選擇你自己的？
E
65:15 沒辦法，那邊都是很嚴重的，還有遇過急救一個晚上的，對，即將要走的，或者是，很慘，一直在哀嚎的，太多太多，就是我會覺得，走得很痛苦的人，所以我會覺得，癌症如果可以，呃，趕快走，真的是很，算是很幸福的事，可是很難，很少癌症有人有辦法走很快，都是會拖一段很長的時間
雅
65:43 他們都是癌症病人嗎？
E
65:46 都是癌症，因為我們那個病房就是腫瘤病房，對，都是很嚴重的，還有遇過就是護理師跟我說，你斜對面那個伯伯他晚上隨時會走，如果他走的話你要不要去會客室避避風頭這樣子，對啊，那個心理壓力真的很大，對啊，但是沒有辦法啊
雅
66:11 台大醫院病房有限，所以他們才會
E
66:14 對啊，這應該是沒有辦法的事，對啊
鄭
66:18 那這個治療，因為我看你有寫到那個經濟壓力，所以，是這個部分嗎還是？
E

66:29 喔，因為這個治療花太多錢了，這個時候一針，他用體重喔，我 45，他那時候一針大概要二十六萬，很可怕耶，我只打了四針，第四針的時候有降十萬，變十六萬，這樣就花了快一百萬，可是這個治療其實打四針是，只是試驗，這個的話醫生說他的藥廠建議要連續打兩年，是要花千萬的，對，但是沒有幾個人負擔得起，所以他說你打四針試試看這樣子，對啊，所以就是打了這四針，一百萬就飛了，積蓄就那個了，對啊

鄭

67:15 所以治療到目前為止告一段落，狀況都很好？

E

67:22 嗯，還ＯＫ，目前還ＯＫ，對，現在我就是，積極養生啊，就每天都要運動一個小時，然後早睡早起，然後吃東西也很注意這樣子

鄭

67:33 像你剛才說的復健是指？

E

67:36 喔，復健是因為我其實都跟病友有關，病友就推薦我去學瑜伽，學一學我就發現我這隻手沒辦法舉到放到耳朵，這隻手，只能舉到，最高舉到這，然後我就嚇到，然後還有脖子沒辦法，躺著沒辦法抬起來，都是在練瑜伽的時候發現的，然後，小米他都有傳一些資訊給我，我對照就覺得好像跟吞嚥有點關，我就去掛復健科，然後才發現說，我這些肌力有點弱，可能是因為放療的關係，還有脖子肌力有點受損，所以就是現在就是在復健

鄭

68:18 在醫院復健還是自己做？

E

68:20 在醫院，呃，先排六次的物理治療，物理治療師會教我怎麼復健，然後他就是會叫我自己在家要操作，對

雅

68:30 所以護理師在教嗎？護理師會教嗎？或者醫生？

E

68:36 醫生不會，他就請物理治療師教，對

雅

68:42 因為我們這個婁醫師，婁醫師那邊有個團隊，是做研究，兩年的時間，那他們都會幫病人做很好的測驗

E

68:55 哦～有我有個病友他有說，他有這樣做

雅

68:58 您有興趣嗎？我們認識那位，就是那個團隊的主導人，我們有他的聯繫方式，因為他們連續兩年都會，我們看過整整大概半個小時都會全部測完你的肌力啊，就是各方面，有沒有進步或者退步，如果退步呢就要馬上補強

鄭

69:16 所以他測完，不過他測驗都是病前，手術前

E

69:22 治療前他就會先

鄭

69:23 他會先測定一次，等到治療後再測一次，然後其實會發現很多病人他，我們以為會變差，但是其實我們遇過好幾個其實反而是，後來他好好做復健，或是好好休息，他反而力氣、肌力什麼的比之前更好，對啊，他們應該是會有一些運動或是復健的治療，對

雅

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69:46 可以幫你問一下
E
69:48 謝謝，這就是我很訝異的地方，因為我復健遇到問題，我就嚇到，我想說我怎麼不知道，我一直不覺得自己會有這些問題耶，我如果今天沒有去練瑜珈，我根本不知道這些動作我不能做，因為我平常絕對不會做這些事，我就開始上網查這些資料，發現說，裡面有一些研究，他們都說，去國外，國外他們都是在你治療前就會先跟你評估了，然後治療中也會有衛教，治療後還會持續再做追蹤，可是台灣好像都沒有，我不知道現在有沒有
鄭
70:25 還是沒有
雅
70:24 像他們就會，因為是專業團隊做研究，所以才會很詳細
鄭
70:29 對，只有他有研究的才會有，目前還不是例行的
E
70:31 為什麼呢？是因為
雅
70:35 但是他們會問病人，如果對他有興趣，病人也同意，那就連續兩年都跟，專注在這方面，但是這訊息，我不知道是不是只有在婁醫師診間那邊
病人
70:49 這一本是我覺得，恩
鄭
70:54 可以拍照嗎？

病人
70:54 可以啊，我直接傳給你
鄭
70:54 我要拍手機的那個畫面
病人
70:58 對啊，我就是整個手機畫面拍給你，然後
雅
70:59 對，讓我們知道是你們提供的這樣，不好意思
鄭
71:03 對，因為我知道是你們提供的
鄭
71:28 好，因為我現在發現，雖然不是病友，但是我在找資訊的時候遇到最大的問題是所有都是散在網路上的各處（E：喔對）所以網路資訊的整合也是我們想要做的其中一塊
病人
71:47 對，這個的重點是有光碟，然後兩本書是同一個作者，不同的國籍的人整理的，你們可以看看
雅
71:56 國際研究的一種
病人
71:57 我是在香港的病友會找到的
鄭
72:00 所以你特地到香港去
雅

72:03 哇，很厲害

病人

72:05 網路也都有

鄭

72:06 謝謝

病人

72:06 你說那個我也有加入，但是我覺得對台灣的親合度不高，我有嘗試把我爸的資料放上去，但是裡面的討論區東西真的不多，然後大部分都是在治療前，後續的都沒有人寫

雅

72:23 預防的部分

病人

72:25 很少，非常少

鄭

72:25 其實我們想做的是在放療、化療，或是手術階段，但是前後的資訊是需要做到資訊整合，就是我剛才講的，他不應該是一篇一篇零散的，應該是像你這樣做成一本，然後分門別類，不同時期你要看什麼樣的資訊，不同療法要看什麼，這是我們想要努力的方向，對，然後也會想要知道就是，不同角色，變成家屬的角度會覺得這種東西應該怎麼樣可以真的幫助你們，解決你們的問題這樣子，恩

雅

73:06 我們還有一個資源想跟你們分享一下

鄭

73:11 這個是，我不知道你們知不知道台大醫院其實有

Ｅ

73:16 哦有有有，這個有病友傳給我，這個很不錯耶

雅

73:18 您有看這邊有很，對，所以這邊的影片也看過？（Ｅ：對）婁醫師的，還有就是

鄭

73:29 他是健康教育中心裡面的影片，但是這個ＧＯＯＧＬＥ不到

雅

73:36 對那這樣子____醫師他這邊，那個一個多小時，九月二十一號的演幾也都放在裡面

病人

73:43 ＯＫ，我只有看過復健科的，就是我有在健康中心裡面去掃過，沒有翻到這一個

鄭

73:51 他也有喉頸癌的，然後也有針對化療的

病人

73:56 可是我覺得他們的分類啊，就是在這個的分類裡面，像我去看，不容易找到這個影片

鄭

74:04 有我們也有發現，但是因為我們沒有辦法改它，所以我們只好自己做一個這樣子

雅

74:09 對，所以我們在想要怎麼做連結，可能會在平台那邊會有一個連結連結到這個影片，因為我們自己也很幸運就是，鄭助理有找到，我們之前都

Ｅ

74:22 這個影片也是前陣子有個病友傳給我，那時候我想，啊，我怎麼沒有早點發現，復健中心，對，然後我就自己，因為復健東西很多，我就自己印出來做一個小冊子

鄭
74:35 這樣還滿可愛的一本
E
74:36 因為，對啊，平常才能提醒自己復健，覺得我太晚知道復健的重要性，因為其實醫生都不會強調這一點
雅
74:44 他可能會講一次就這樣講過去
E
74:47 對，他們可能都有一張單子跟你說誒要復健喔，你就會，喔，到時候你就會忘記了，對，可是我上網查發現很多人研究，他都說台灣復健的執行率很低，很多人都沒有注意，然後到現在也是（雅：尤其是男生）對對
鄭
75:05 好認真喔
E
75:06 就我很想提醒大家，可是，不知道，可能，你真的要等到你發現自己有些動作做不來你才會害怕
雅
75:14 所以他們做這種研究是對的，就是治療前治療中治療後都會追蹤，（E：對）每一個月，然後好像過一段時間，每三個月，所以就是還滿固定的
E
75:27 對，因為我們有認識一些病友，已經沒辦法吞東西了，已經要做那個僞造膜，才去看復健科，那時候已經來不及了，對啊
雅
75:36 都要鼻胃管
E
75:39 對，那以前會覺得看到他們的情況會覺得不可思議，怎麼會突然一夕之間，但是後來覺得說，一定是經年累月，只是沒有發現
鄭
75:55 其實本來就是存在一個很重要的問題，但是大部分人都不知道有這個東西
E
76:00 對，只是真的也沒有人去強調，我們不知道嚴重性，對啊
鄭
76:05 我可以拍嗎？
E
76:05 可以可以可以啊
鄭
76:06 我覺得你這個真的做得好好喔
E
76:09 這個是我為了要逼自己說，我要隨身帶，譬如說我想到我就要拿出來開始演練，因為太多動作我怕我會忘記
雅
76:18 對，我們看到這個小本子很重要，因為很多病人一樣會拿到這個傳單，就是很簡單
E
76:32 對，就是一張紙而已
雅
76:33 那他們也不一定會做，但如果現在像你就是這樣子
E

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76:38 我是想說如果醫院他自己可以做一本這個，給每個病人，而且跟他們講說，這個真的很嚴重，大家都一定要，跟他們強調，對，甚至大家都應該要去，譬如說，呃，讓復健科提醒一下，我們才會知道嚴重性，對啊
鄭
77:03 而且還要剪這一條條的字跡這真的很
E
77:11 我做第一本的時候才發現，喔真的很麻煩，還要一條一條貼很久
鄭
77:15 而且你剪得很工整，要是我剪到後來就會隨便剪
E
77:18 盡量美觀
雅
77:21 這個應該，如果有機會就可以出版，然後您是作者
E
77:24 如果今天是那個校長，他就會把它拿來賣了，對啊
雅
77:32 但這是你的，對，但是
E
77:37 我的話這個其實我不敢放在網路或幹嘛，因為這都是別人的資料（鄭：有版權問題）我自己剪剪貼貼而已，不是我自己的智慧結晶，我只是覺得大家可以學這種方式，做一個可以砥礪自己每天復健的東西，對
雅
77:54 但如果資料來源放在後面那就也可以是一個整合的方式，就是新的作品，所以也是可以成為作者，對我們會提及這件事情，就是跟那位團隊，那個研究團隊講一下
鄭
78:12 而且把這種需求實際上跟他們反應，就會發現其實有滿多人都想要幫助病人，不一定是營利或是什麼
E
78:24 對，但是有時候，也許，那個ＮＢＣ同學會發展那麼好，可能就是因為他有自己私心吧，所以可能會比較用心，不曉得，不知道
鄭
78:43 校長有工作嗎？有其他的？
E
78:45 這是一個謎，他的身份是一個謎
雅
78:49 難怪醫生也不知道
E
78:51 對，神秘兮兮的，他是有在賣酵素
雅
79:00 噢，這個我們本來也有點懷疑，他是不是有（Ｅ：你們自己知道嗎？），嗯，我們不知道，但是醫生有這種懷疑他有（Ｅ：蛤？醫生知道？），他也不知道，他說可能是不是有這個原因，對，是他有在賣什麼東西
E
79:15 他有在賣東西
雅
79:17 對，所以才不讓我們進去，但是我們純粹是學術研究，也不會賣什麼，但是他可能很害怕
E

79:24 但是，就是因為他在賣什麼，他不想讓人家知道這件事，可能怕他的形象會受到那個吧，挑戰吧，對呀

雅

79:34 那他之前是鼻咽癌的病人嗎？

E

79:37 是，對，然後他復發過，現在又ＯＫ了，所以他就是，等於是一個，呃，成功的象徵，大家都會覺得他一定有他的過人之處

鄭

79:49 那他的病情穩定跟酵素有關嗎？

E

79:54 他自己要把它結合，它甚至已經把它無限上綱了，我們有一個病友後來治療已經成功了，有喝過他的酵素，後來也沒喝，呃，前陣子懷孕生小孩了，校長就會跟我說，都是因為他的酵素，讓他們成功，他說，沒想到我的酵素除了抗癌還可以讓人成功受孕，改變一個人的那個體質，但是她已經退出了，那個退出的夫妻檔就是說，聽他在胡扯，扯太遠了，沒事去看不孕症，我們幹嘛，也要管到酵素身上，而且我們都沒在喝，但是沒有人會知道真相，因為他對外都是這樣跟我們講

鄭

80:35 他這樣講其實有法律問題耶

E

80:38 所以他不能讓別人加入啊，他自己在裡面講，就會有人寫說，讚，好厲害，佩服佩服，這樣子，對

鄭

80:48 那這樣聽起來路線已經整個歪掉了

E

80:50 不是每個人都，恩，有辦法看得出來這一面啦，很多人其實進去是想取暖，或是聽經驗這樣子，對啊，但是也有人對他深信不疑也有啊，對啊，其實不要說他，我覺得他已經算是，呃（停頓）應該說雖然他有私心，但是他優點也滿多的，還有比他更多更壞的，奇奇怪怪的那些東西有沒有，賣人家那些奇奇怪怪的，在台灣也是斂財也是很厲害啊，對啊

雅

81:25 都是賣偏方、中藥

E

81:28 他的話是，應該說是一個好人，但是（停頓）自私自利了一點，稍微自私了一點，但不是一個壞人，但是台灣有很多是壞人，還是一樣很多人信啊，很多信徒都信啊，對啊

雅

81:48 沒關係，可能他自己覺得這樣是沒問題，哈哈，對，背後發生了什麼事情我們也不知道啊，說不定他真的非常相信那酵素

E

81:59 他應該自己很相信，對，他自己應該相信，但是他，呃，也不只是酵素啦，他還會推銷、推廣一些健康常識，噢這一點我不得不說這是他最大的優點，很多人是因為認同他這個理念進來的，因為有些癌友的部落格他會講很多他吃什麼、用什麼、找什麼醫生、做什麼先進的治療，但是校長他不會，他會覺得說是要靠自己的免疫力，所以他會，他的核心思想我們其實都是認同的，才會參加，他覺得說你自己要把自己的身體鍛鍊好，醫生只是輔助而已，所以因為他這個理念，我自己平常才會開始運動，對，吃東西飲食什麼這樣，會注意，對，他就是自己有一套什麼，呃，防癌氣血的，類似氣功，他

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每天都會鍛鍊，對，所以我覺得他最正確的觀念就是鼓勵病友自己要運動，對，這個是很多，他跟其他人不一樣，最大不一樣的地方

鄭

83:13 那我有上去看一些病友的分享，很多時候都會變成那些情緒面，其實功能性還是有幫助，像這種

E

83:23 對、對

雅

83:25 那他分享的健康常識都是關於運動嘛？或是有其他方面？

E

83:28 嗯，他其實，噢，也許他剛創設的時候有，但是他的心已經，我覺得已經冷卻了，就是，他已經有規模了，所以他都交給裡面的人自由發揮，他每天上去大概只會ＰＯ一點點，現在應該也是吧？ＰＯ幾句早安啊，然後，可能會ＰＯ一段勵志的標語（病人：他只有禮拜一到禮拜五的早上會ＰＯ，六日就休息）對，而且他可能就ＰＯ一段什麼「把疾病交給醫生，健康交給自己」就這樣，對，就是聖嚴法師開講，開講完下面就 blablabla 自己討論這樣

鄭

84:10 哦所以大家會在下面討論？

E

84:12 討論就是自己聊自己的啊，他就是有點精神領袖，他已經退居到公司的ＣＥＯ了，譬如說要辦病友會，他就會說，噢來辦個病友會，然後那個平台管理小組的人就會開始籌劃了，全部都是那些人一手做的（鄭：組織已經做得很有條理了），對

雅

84:30 這樣也不簡單，因為他從 2014 年開始經營他的部落格，這樣時間不算長，但是已經有

E

84:38 應該說他，恩，他的優點就是，他的觀念是正確的，然後他有看人的能力，因為他的平台小組，他原來的那些人都是，呃，公司的幹部，在外面都是做得很好的，他自己以前好像也是開公司的，所以這一套他特別那個，但是那些人陸續離開就是因為他覺得我們這不是一間公司，我們不是你的員工，你不能認為我們是要幫你賺錢、幫你做事，我們當初是為了理念，大家無私地奉獻的，對，但是我在推薦一些那些幹部給你受訪，他們是元老級的，他們應該更知道，對啊

鄭

85:21 噢謝謝

雅

85:22 感謝

E

85:22 對啊對啊

鄭

85:24 因為我們目前就是想要收更多病人的經驗，因為之前訪談很多都是男生，然後男生就是，沒有啊，就是這樣啊

病人

85:36 週一到週五都會固定ＰＯ這個

E

85:37 他有自己的名片喔

雅

85:39 哦～名片我看過，對

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病人
85:42 然後就是，每天早上寫的都不一樣，不過我的
85:48 應該可以？這個他有貼在部落格
E
85:48 可以可以可以
病人
85:49 可以吧，他最，我覺得這個，最常貼的是這個
鄭
85:53 其實他還有一點，文學素養還不錯耶，做這個
E
85:58 他有他的才華跟吸引人的一面，對
病人
86:05 好，那我再找一個
86:10 喔對，這個也是他常ＰＯ的
E
86:10 然後我會接觸一點中醫也是因為他，因為他很腫，他很喜歡講那一套，什麼刮痧啊、排毒啊，什麼寒山體質啊
病人
86:22 這個也是，就是他很強調說，這是比較靠我們自己的習慣，比如說規律生活，或水分要足夠，其實醫生都有提醒，但是
雅
86:33 不一定做得到
鄭
86:33 那比較懂為什麼你會說他裡面是不好的？
E
86:38 對，他是有他的領袖魅力，只是他比較自私一點，就是這樣
雅
86:46 哦，這樣終於知道
E
86:49 很複雜的人，但不能一概否定他啦，他有他的優點，對，但是我退出的時候他有問我為什麼，我就跟他說我覺得你放在推銷酵素的心力比你放在經營同學會的心力還要多，因為他每天就傳那個而已啊
鄭
87:07 那他怎麼回？
E
87:09 噢，這就是他厲害的地方，他是，他就是說，謝謝你提醒了，讓我正視到我自己的盲點，這樣子，但是他當然不會承認自己有這一面啦，他都講得很謙恭有禮這樣子
鄭
87:32 所以目前是多久回去？
E
87:37 一個月就要回去一次，對，所以，像我這個其實四月底才剛完成，所以很多人都會私下問我療效，連以前我退出的時候，跟我不熟的病友，私下都會問我，欸你的效果啊什麼的，可是我就是說，我真的不知道，因為還在追蹤，而且連洪醫師也不知道，因為我做這個做這個又做這個，如果到時候有控制好，他說，洪醫師說他也不知道是因為放療還是因為化療還是因為免疫，對
雅
88:08 那國外有沒有做過類似的組合？
E

88:12 國外有研究就是，多元的這個療法，可是研究還很少，因為這個還很新
鄭
88:18 鼻咽癌還是亞洲比較多，所以其實反而是我們這邊比較權威
E
88:25 對，這真的是我們吃虧的地方，因為在國外很少人得鼻咽癌，所以投入那個鼻咽癌的研究很少，標靶藥劑那些都沒有，對啊
雅
88:36 那也是其中一個問題，為什麼到現在也還在實驗中，可能真的沒有做過這個研究，沒有這種需求，他們
E
88:46 對啊
鄭
88:48 那，就是，如果現在有一個機會讓你跟其他病友分享，你會最想提醒他們什麼？

E
88:56 提醒他們喔，我想提醒他們說要主動搜集資料，要掌握自己的身體狀況，對
鄭
89:06 網路啊、看書啊
E
89:07 對，其實真的有很多管道，或是問人啊，而且知道之後真的要去做，就是你知道說要每天運動，要提升免疫力，但是你知道，但是你沒有每天養成習慣的話那還是沒有用，對啊，我覺得真的要每天做真的是最困難的
鄭
89:25 所以，那你都怎麼讓這個習慣養成？因為從不會這麼做到會這麼做（Ｅ：嗯，很難）這中間怎麼克服？
E
89:31 對，你就要慢慢找到一個適合自己的方法，每個人都有適合自己的方法，我一開始是每天會在外面亂走，可是，亂走走到最後你會很膩，因為你能走的地方有限，然後有時候太陽很大，有時候下雨，然後後來我就，我老公就買了一個跑步機給我，所以我就每天固定會，只要有空我就會去走那個跑步機，我會給自己設一定要三公里，至少，大概一個小時，然後前面有個電視機嘛，邊走邊看電視才不會那麼無聊，然後因為最近復健很重要，所以我現在就一心三用，把那個小冊子拿來然後開始復健嘴巴，然後就邊走邊看電視這樣，同時進行這樣（雅：哇～這樣就高高境界）就是自己慢慢摸索做得到的，對，做得到的方式
雅
90:26 那我想問一下你有沒有想過成立一個實體的病友會？那一些習慣養成可能真的需要一個人，對，幫你（Ｅ：對），就是先帶你幾遍（Ｅ：對），你才會習慣
E
90:39 哎，其實這就是我覺得，恩，那個校長他的優點，因為這個也是要花時間，一開始一定要花很多時間心力，他之所以可以搜集到一些幹部願意為他效勞，是因為他花很多時間經營他自己的部落格，然後別人被他吸引進去，認同他的理念，進去之後慢慢慢慢才凝聚成那個的，他就開始坐收那個利益了嘛，但是他前面是付出很多心血，可是有幾個人願意做到這種程度？很少啊，所以那些人就會變很有名，像什麼新西亞、卡斯柏，卡斯柏你們知道嗎？
鄭
91:17 大概有聽過
E

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91:19 他已經去世了，對啊，就是去日本做免疫細胞療法的，他都會很詳細地寫他去日本的經過，對，但是（停頓）但是，哎，因為我覺得校長他比較有本錢做這件事，第一個，我覺得要做這件事人，他要沒有經濟的壓力，校長他自己可能沒有經濟壓力，有公司、有什麼吧；第二個是他的健康狀況要很好，像我們其實我們每天擔心自己要工作，做一點點心力可以去幫助別人，對，如果你自己還是有病之身真的沒辦法，對
鄭
92:00 是走過這條路的
E
92:01 對對對對，所以要符合這些人格特質的人，很少很少
病人
92:12 重點就在這
雅
92:15 所以，同理心

E
92:15 所以還要有具備這個
病人
92:16 對，就是他要同時得過
雅
92:21 各方面都要滿足
E
92:19 就是要哈利波特這樣，倖存者，好難
鄭
92:23 我覺得倒不一定，因為如果我們真的湊起來，我們裡面有醫師在，所以，我們雖然沒有就是病友當那個 leader，可是
病人
92:35 沒有，我只是說，對於病友來說，吸引他們的通常都是成功走過的病友
E
92:42 沒錯沒錯
病人
92:43 像我會這麼吸引人，我願意加入，也是因為他是成功走過來的病人
E
92:46 大家都會覺得他一定有過人之處，他的酵素為什麼有人要買，很貴，因為大家覺得他應該就是喝那個成功的，他也一直把他們做連結，他都會ＰＯ照片，他吃大餐旁邊都一定有一罐那個酵素，對啊（鄭：這麼厲害）
病人
93:15 他的部落格，有文章、有酵素，下面好多人問喔
E
93:17 還有海外的人會想跟他訂
雅
93:19 所以部落格也會放？
E
93:22 這就是我有點氣的一點，他花很多心思在部落格，即便到現在，他可能在同學會他可能丟一兩句話，一兩張照片，但是他會用很多篇幅在部落格寫一個很文情並茂的文章，為什麼？因為同學會的人他已經抓住了，裡面已經自成一個小圈圈了，他不需要去經營，他心力就是在吸引更多的客群，我覺得啦，我自己把他解讀得很壞
病人

93:52 他有一個____，他最近把它做成____，應該是有人經營他，因為他之前都亂，照時間亂排
E
93:57 對啊，一直在強調你看，一直在強調，這個我要好幾罐，你要的話一罐給你，也可以請你們喝，哈哈哈哈
鄭
94:05 我會害怕，哈哈
E
94:06 我們當初，我，像我當初會喝不是因為他，因為他跟我根本沒有私下接觸，我進去都是其他的病友會關心我
病人
94:18 這個可以嗎？因為他是公開的

E
94:18 可以可以
鄭
94:20 一百零七耶
雅
94:24 哇～這都是 comments
E
94:27 他厲害的地方是，他會有很隱諱的方式推銷，對，而且他的酵素上面都會有那個ＮＰＣ同學會什麼的在裡面
雅
94:42 這個酵素的，恩，他的處方是自己研發的
E
94:47 呃，不知道，他不透露，這是一個「謎」
鄭
94:51 這個可以檢舉，他這有問題
E
94:58 所以這就是我們覺得他比較自私的地方，他大可分享，因為他這個一罐一千三四百塊，不是每個人都有辦法負擔的
鄭
95:08 其實應該這樣講，我不應該對這個東西有什麼偏見，但是我覺得如果他是好的，我覺得希望政府去由合格的檢驗（Ｅ：對４），給他一個認證，這樣大家，需要的人都可以
E
95:20 我們曾經有退出的幹部就是要建議他說你應該要這樣做，可是他的理想很大，他希望說你把它送去送驗之後，我們把它商品化，錢我們拿來做公益，推動在裡面，然後我們雇裡面失業的病人來當員工，結果呢，他沒有接受，他只接受商品化，其他的部分就算了
鄭
95:44 商品化他還是可以繼續當ＣＥＯ啊，只是把一些部分的移出來做公益
E
95:50 他有，他就每個月捐兩三瓶酵素，這也是他促銷的方法啊
鄭
95:55 對啊，這算行銷
E
95:57 他也沒有捐錢，他捐酵素

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雅
95:57 所以他是同意送檢嘛
E
96:01 他不願意，他到現在都不願意，因為如果送檢了不通過，那他的生意還要做嗎？對不對，我是覺得你如果要做這個，這些事情，幫病友，你要賺錢無可厚非，可是你不要，這麼，呃，怎麼講，把自己用得那麼清高、那麼偉大，表面上說你完全是公益、無私，明明就是靠這個在賺錢，你可以承認啊，對啊
鄭
96:26 我好好奇，這上面擺的照片，這些人同意？
E
96:31 呃，（停頓），應該說有些人不同意也沒辦法，裡面還有我勒，這個也退出了，這個也退出啦，對啊。他們是不跟他計較，像我的話，我是有請他刪掉我個人的照片，有一張是團體合照，他就會寫說，如果是團體合照的話那他不能刪

雅
96:53 那就算是個資，這還是個資
E
96:54 打馬賽克
病人
96:57 應該要要求打馬賽克
E
96:57 好，那我回去要求他馬賽克
鄭
96:57 因為這樣等於是，因為我不知道你對這個產品，你到底有沒有覺得還是正向，因為等於你的照片被放上去，你是在幫他背書耶
E
97:08 對，我就是不甘心被他拿去利用
病人
97:11 他有一個專門的背書的頁面
鄭
97:15 今天，怎麼有那麼多意外的收穫
E
97:37 那個病友會的時候他就有請一個他的人講成功經驗，但是問題是那個病友是會吃標靶藥，他是吃______，洪醫師的病人，控制住的，但他就會講說，噢因為喝了酵素啊，他的體重怎樣怎樣怎樣怎樣，講完還來一個大擁抱這樣子，對，所以很多人都會信，就覺得是因為這個原因
鄭
98:00 對這種東西存疑性，我們之前才訪一個病人，他說他確診以後他第一件事情是有點逃避，然後後來開始上網，上網之後就查到有任何方法都就去試，結果就是因為這樣子，拖了那幾個月，他才，後來我們問他有什麼想要跟其他病友分享，他就說，他覺得其實不應該拖延，（E：對）他應該要趕快積極地治療，然後網路上的資訊可信度是一個問題（E：對）
雅
98:30 因為他拖延的原因就是他看到那些
鄭
98:32 就是因為被他們講的好像很厲害，我都可以不需要去醫院
E

98:37 他的話，呃，他不會認為說不需要，他會認為說你看醫生，可是你自己要提升，但是我覺得他厲害的地方是，有一些直銷他會很檯面上的，就是你一看就知道這是騙人的，噢你吃這個包你什麼什麼，他是用很含蓄、很隱諱的方式在包裝，你一開始，我加入，我看不出來他是為了要賣酵素，可是我慢慢慢慢到最後，你發現他一些決定很自私的時候你就會想說為什麼，你就會開始連結到跟他的酵素的利益有關，你才會發現他是用很高明的手法去包裝，對

鄭

99:15 因為其實我們訪的病人裡面也有他們會吃直銷的產品，像安利（E：對對對），可是他賣那個是ＯＫ的產品，但是吃其實不會有什麼影響，這種反而太神祕的會讓人家______

E

99:28 所以他為什麼要那麼神秘低調，因為一旦被揭露的話，他就會變，那可能就會可大可小，所以他病友他不讓卡斯柏加入，因為卡斯柏有受訪問，在中天受訪，他有接受雜誌訪問，他說他是媒體人，所以媒體新聞他都不讓他們加入，他的說法是說我要保護這些同學

鄭

99:54 照片都曝光了

E

99:54 對，他是保護同學還是保護他自己呢？

雅

100:00 他如果送檢發現有什麼問題，就是可以再改善，做真正好好的產品

E

100:09 他拿掉囉？

病人

100:09 對

E

100:11 他不敢 2，他應該，可能我有提醒到他是不是

病人

100:20 對啊，不然之前那邊有好幾張，拿著東西然後拍照

雅

100:26 照片？哦～現在換成______

病人

100:28 都不見了，整個都拿掉了

E

100:32 喔他裡面其實很多名字跟人都退出了，對啊，很多人都退出了耶，他還在放他們的照片當宣傳

雅

100:41 這樣有點可惜，因為還是不少錢，病人可以花在更有效的產品上

E

100:46 對

雅

100:51 那有合作的醫師嗎？他有跟醫師合作嗎？

病人

100:54 噢關於這個我一定要拿給你們看

E

100:56 他有嗎？

病人

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100:58 就是（停頓）他的那個，放，台大醫院三個醫師的合照那個系列啊，還記得？（鄭：真的假的）
E
101:04 他都會放醫生的合照，其實那些醫生不知道說
鄭
101:06 那這個______跟醫師說一下
E
101:12 不曉得
雅
101:14 如果他們知道這個人是比較特別，我討論到他的時候只有王醫師知道
病人
101:41 喔我不敢吃甜的
雅
101:41 那我剛好相反，我聽說好像比較喜歡吃甜的
病人
101:42 喔誰？誰喜歡吃甜的？
雅
101:43 其實我們訪談的時候，就是好像口味比較，有時候會好像酸的，或者哪一個味道（病人：哦～了解）但是甜的還會保留
E
101:53 喔我是因為已經很久，所以我味道都恢復了
雅
101:57 哦～已經恢復了，可以帶回家給家人吃
E
102:01 可以可以呀，可以呀
雅
102:12 而且是女性，女性病人是，我們之前有一位三十三歲，對，發病，他就考慮過後決定不受訪
E
102:27 沒有勇氣獎吧
雅
102:29 因為他還沒，他已經做過治療
鄭
102:31 他是舌
雅
102:35 對，舌癌。但是那工作壓力裡面他還在繼續工作，所以可能時間上（E：好厲害，可以工作）覺得
鄭
102:43 好幾個都很堅強很厲害，然後
E
102:47 對啊，好堅強，我好佩服他們喔
雅
102:49 嗯，但是男生我覺得也不一定很堅強他們就是，裝成這種
E
102:54 他們必須要表現那麼堅強
雅
102:58 對，有些人會，就是在工作方面很瘋狂，就不想再想這些事情，所以男生可能會逃避的一個路線就是工作

病人
103:09 對，比如說______啊，他就是詳細記錄他第一次發病，然後到復發中間的歷程，然後到最下面他就是把他畢業的時候跟，比如說柯醫師拍的合照，或者是跟其他（停頓）
鄭
103:24 ______
病人
103:25 對
雅
103:29 我好像那張有看過
病人
103:31 另外一個就是____醫師
E
103:32 對
雅
103:34 他會寫是哪一位醫師嗎？
病人
103:37 當然啊
鄭
103:37 他有寫名字
E
103:38 有有有，他（停頓）他算是一個，恩（停頓），正派的商人嗎
病人
103:45 對啦對啦，正派的商人
E
103:48 他是商人但是他還算正派，還不算是壞人，還算正派，只是，很多人就是不甘心被利用，或是不認同他越來越自私的想法
雅
104:02 但是你覺得如果病人可以提早知道他的理念有問題，那是不是對你有幫助，所以你們現在成立自己的團隊，就是很好的
E
104:14 對啊，可是我們那個團隊就，也沒辦法很大，我們就是找一些我們生活有交集的病人，而且要聊得來的，還要願意加入的，對呀
雅
104:25 哦，那大概有幾位？
E
104:28 大概唷，也沒有很多啊，對不對？
病人
104:32 你說哪一個？
雅
104:32 就是你們自己經營的
病人
104:34 沒有幾個，都是小團體
E
104:36 小小小小的
雅
104:37 有不一樣的團體，（E：對對對）這樣更專業就是分門別類
E

104:44 對，但是也都是因為從那個ＮＢＣ同學會私下分出來的，所以一開始緣份也是由那個校長開始創起來的，對，所以說他有他的功勞、他有他的功勞，所以我會覺得如果他光明正大賣這個東西，我送驗，他就說這只是營養品而已，檯面上講，我覺得如果說我支持他，覺得他貢獻到，我當然願意偶爾買他的東西，對，只是我不喜歡他用這種方式，我會覺得有點欺騙，自欺欺人，對
雅
105:23 你是覺得有點像食品，這樣如果要拿到認證很簡單，（Ｅ：對啊）兩個月就下來了
鄭
105:29 上面有成分嗎？
E
105:31 沒有，沒有人知道
鄭
105:34 所以不知道是____還是什麼
E
105:36 對，那就是一個「謎」
雅
105:39 但是最希望是，不會是害人的、傷害身體的
E
105:43 很多人會覺得他都敢喝，一直喝了，而且他現在那麼健康，應該不會有問題，對
鄭
105:51 所以你有覺得酵素會好，可是如果你去強調他對於癌症的療效，我擔心的是有一些人會把它太神化
雅
106:00 對，是不是他們會取代不是吃喝，比較需要吃的東西
E
106:07 他的話是比較著重在認為說，他可能幫助消化，或讓你有食慾這樣子
雅
106:14 哦，如果單純是這方便那就
E
106:18 比較這方面，那至於說幫忙生小孩那是他私下跟我講的，因為他有點自戀型人格，往自己臉上貼金，都是他的功勞，恩，他覺得他的酵素，他的氣血功改變了很多人的一生這樣子，對，哈哈哈，但是還不至於敢在檯面上
病人
106:41 這就是他完整從，這是他今年復發之後的第九年

____

病人
107:05 這就是我妹挑的，我妹說這個裡面不能有______
107:13 喔這很重耶
E
107:14 很重
雅
107:31 那正式的訪談就到此結束，謝謝

Appendix 5. A list of online sources and books provided by caregiver L

我昨天吃飽手癢把臺大醫院官網已掛上去的（我爸爸曾看過科別/預計帶去看）各部科現有衛教單專區下載點都抓出來放在本信信尾。

另，臺大醫院癌症防治中心-癌症相關法規中，意外找到臺灣癌症防治民間團隊癌症資源手冊（ http://www.ntuh.gov.tw/…/%E8%87%BA%E7%81%A3%E7%99%8C%E7%97%… ）。

打著打著，突然想起打化療住院時我曾考慮拎著爸爸參加臺大醫院輔助暨整合醫學中心提供諮詢服務（ http://www.ntuh.gov.tw/…/%E8%AB%AE%E8%A9%A2%E6%99%82%E6%AE%… ），但後來因為爸爸不想回診以外時間來臺大醫院，最後作罷。

但，也許可以回答鄭助理問我爸爸加護期間，主要照顧者如何調適心情的另一個管道與方式（尋求心理中心專業協助或參加紓壓團體）。

放射科王 P 自製衛教單有張是參考專業性學會資料製成。這讓我想起曾翻過台灣頭頸部腫瘤醫學會網站的頭頸癌互動式學術研討會（http://www.thns.org.tw/medicine/education.asp）中所有提過鼻咽癌年紀較長案例，主要看有沒有與爸爸相近期別的治療過程與後續存活狀況紀錄。

透過 NPC 同學會與另一位剛治療完返家休養的口咽癌病友主要照顧者聊天時，曾經挖出國衛院鼻咽癌臨床診療手冊（ http://www.nhri.org.tw/NHRI_A…/userfiles/…/tcog/100npcpg.pdf ）與口腔癌臨床診療手冊（ http://www.nhri.org.tw/NHRI_…/userfiles/…/tcog/100oralpg.pdf ），還有鼻咽癌治療共識（ http://www.nhri.org.tw/NHRI_ADM/userfiles/file/tcog/npc.pdf ）與口腔癌治療共識（ http://www.nhri.org.tw/NHRI_ADM/userfiles/file/tcog/oral.pdf ）。

也曾因為想知道什麼樣狀況下健保才會給付某種藥品，查過健保用藥品項查詢網站（ http://www.nhi.gov.tw/Query/query1.aspx… ）與藥證業務管理資訊系統（ http://www.fda.gov.tw/MLMS_MOBILE/(S(h3pkdjeuw0vnwznt4xfv3545))/H0001Mobile.aspx ）。

病後人生（ http://afterthatday.blogspot.tw/2014/02/fb-httpwww.html?m=1 ）這網站讓我在爸爸勞保理賠上有比較有概念知道如何申請規劃與安排。家總的照顧 e 點通（ http://www.familycare.org.tw/index.php/2012-07-18-08-45-42 ）有不少現成開放性免費教學影音資源可以參考。

臺大醫院-護理部-衛教單下載點

https://www.ntuh.gov.tw/nurse/DocLib15/Forms/AllItems.aspx

台大醫院-腫瘤醫學部-醫療單位-衛教資訊-衛教單下載點

https://www.ntuh.gov.tw/…/%E9%8…/DocLib1/Forms/AllItems.aspx

臺大醫院-腫瘤醫學部-最新消息頁面右側多了（或之前沒注意到）放射定位流程說明（但需要帳密）

https://www.ntuh.gov.tw/onc/default.aspx

臺大醫院-營養室-衛教單下載區

https://www.ntuh.gov.tw/…/education/1234/Forms/AllItems.aspx

臺大醫院-復健部-衛教單下載區

https://www.ntuh.gov.tw/PMR/DocLib8/Forms/AllItems.aspx

臺大醫院-耳鼻喉科-衛教單元 Q&A-衛教單下載點

http://www.ntuh.gov.tw/…/%E8%A1%9B%E6%95%99%E7%9F%A5%E8%AD%…

臺大醫院-精神醫學部-衛教天地-衛教單下載點

https://www.ntuh.gov.tw/PSY/Healthy/default.aspx

臺大醫院-健康教育中心-關鍵字「老年保健」-文章清單下載點

http://health.ntuh.gov.tw/health/hrc_v3/nform451.aspx…

（經過雅薩娜跟鄭助理提醒）臺大醫院-健康中心健康教育資訊網-影音專區-癌症防治類別，這介面友善好找多了！

http://health.ntuh.gov.tw/health/hrc_v3/nForm5.aspx…

病人家屬 L 看過覺得有幫助的書 (20160713)

<><><><><><><><><><><><><>病友故事<><><><><><><><><><><><>

✤ 抗癌鬥士故事系列 1—轉彎的生命

#財團法人台灣癌症基金會

http://www.canceraway.org.tw/productlist.asp…

✤抗癌鬥士故事系列 4— 飛越・生命

#財團法人台灣癌症基金會

http://www.canceraway.org.tw/productlist.asp…

✤抗癌鬥士故事系列 5-舞動・生命

#財團法人台灣癌症基金會

http://www.canceraway.org.tw/productlist.asp…

✤抗癌鬥士故事系列 6— 燦爛千陽

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