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A STUDY OF CHINESE CANCER PATIENTS' HEALTH INFORMATION PREFERENCES AND PRACTICES

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A STUDY OF CHINESE CANCER PATIENTS' HEALTH INFORMATION PREFERENCES AND PRACTICES

by

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Dedication

To me[1], my Mom[2], Dad[3], and those who've made life easier for me.

献给：宇宙无级超级独一无二沉鲸鱼落鸿雁的我，

宇宙无级超级美艳绝伦倾国倾城的我的女神妈妈，

宇宙无级超级才貌双绝盖世无双的我的男神爸爸，

和宇宙无级超级慧眼如炬的那些让我的“活着”变得更加容易的人。

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[1] Yes, I said it! ☺

[2] I know you will always put my first! ☺

[3] Sorry dad, ladies first ☺

Acknowledgements

Thanks to my mom and dad, I have the chance to experience this world and the opportunity to try to make it a better place. That being said, I have never sent an application for being born on this convoluted and complicated planet. I do not think I am trying to say that parents are dictators. Or am I?

I am in gratitude to those who've made things easier for me, done consciously or not, with or without me knowing. Because of you, life is more pleasant to manage. You have invested in me when there was not much guarantee of a return of investment. For this and everything beyond it, I am in debt to you, *ex animo*.

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All the cancer patients who agreed to my interviews, I am beyond thankful for your trust in me!

When I was a teenager, my dad died of lung cancer. He had barely smoked one cigarette in his life. Life is not fair, is it? That sixteen-year-old me was similar to that one-month-old me, five-year-old me, ten-year-old me, fourteen-year-old me: a dumb girl who knew too many shortcuts to mistakes than she should have. Yet, my father loved me, that fat, acne-ridden, short-haired clumsy tomboy. Dad was not a king, but if he had a princess, that person would be me.

Though I try my best to not to miss him, I fail from time to time. Not only do I miss the father I knew, I miss the father that I could have known should I have been a more mature daughter, and the father I would have been able to know should he have lived longer. I did not know how to take care of my dad. I was not there when dad passed away. I did not even have the chance to say “see you later” to my most beloved guardian angel.

The other day, I overheard someone say “it’s never too late to say hello.” So here it goes, 老爹，想我了没？

Preface

I started my could-have-been-better master thesis with a semi-poem for no particular reason. Life, after all, is too complicated for justifications. I will start my doctoral dissertation with three poems, both for the bygones and yet-to-comes. It is also a date-stamped reminder of my yesterday's childishness, for the child in me was there, a child who was fair, kind, and true.

Life goes on, for after all, what's past is prologue.

诗生，诗说

诗，为了祭奠那梦里的孩子
诗，为了记住那孩子做的梦
诗，为了那些年强逼着自己咽下的话
诗，为了这些年纵容自己而哼唱的歌
诗，为了已经长在了脸上的面具
诗，为了可以坦荡荡的脱下伪装
诗，为了满身是伤也要撑起的未来
诗，为了风雨兼程也要到达的远方
诗，为了夏夜里的朗月清风
诗，为了冬日里的金乌暖阳
诗，为了向你道谢
诗，为了和你作别
诗，为了初心
诗，为了慎终
诗，生
诗，说

Illusions

Five cups of coffee enabled “Sorry”
Oblivion is how I choose to not deal with today
Rounds have been fired, roll the dice
Long live the souls that are consciously insane
Ideas, like you, are poisonous trees
Funny, that “Okay” you promised me almost lasted from one to three
Early birds meet early predators in a timely flame
As heat unfolds, truth has ceded to an interesting frame
No, no, no, no, no, you’re not here to play, for you are the game
Dusty roads are where you belong, juggernaut, give way
Your life, what a laugh, you live, you die, you cry, you cry, and you cry
Old friends, morning glories, jaded badmintons, the sun, the moon, and the sky
“United we dream”, she declared, “Death is but a long illusion with a short name”

敬吾母吾父

(老爹，女士优先啦，我爱你和我爱妈妈一样多哦☺)

累时暖粥香，
泿来身筑墙。
授吾为人术，
祈吾永健康。
咎错善包容，
远游勇担当。
叮嘱化倾光，
今生敬仰望。

A Study of Chinese Cancer Patients' Health Information Preferences and Practices

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The University of Texas at Austin, 2017

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Health communications are pivotal to cancer patients' care and management, yet no empirical knowledge exists that could explain how cancer patients' information preferences (needs and wants) and practices (seeking, avoiding, sharing, and accepting) interact and influence their health outcomes, especially for Chinese cancer patients. This grounded theory study focuses on identifying factors that shape the relationship between Chinese cancer patients' health information preferences and practices, with close consideration of Chinese cultural context. This study recruited eighteen cancer patients to be interviewed using the purposive theoretical sampling technique, with data analysis guided by the constant comparative method. The basic social process emerged in response to the research question is: interaction with health information is a family activity. This basic social process is further manifested in the theoretical categories identified: getting prepared for managing cancer, prioritizing questions according to family needs, balancing truth, trust, and respect, navigating around information sources (two sub-categories: nurturing the support network and focusing on productive interactions), and responding to culturally-sensitive cancer care. The findings suggest that it is important to acknowledge and address the family's indispensable role in Chinese cancer patients' interaction with health information. What might be considered self-management of cancer among Chinese cancer patients appears to be more akin to family-management of cancer. Also, Chinese cancer patients' other culturally-sensitive care needs (e.g., socially appropriate interaction with healthcare professionals or HCPs) also emerged as important, as these patients' health information preferences and practices center on the need to be culturally respectful. Results of this study suggest that it is imperative for HCPs, when responding to patients' questions and concerns, to adopt culturally-sensitive communication styles. This includes empathetic consideration of the interests and characteristics of patients and their family members in order to achieve respectful and constructive patient-family-provider communication. The adoption and diffusion of these empathetic communication styles have the potential to improve patients' health outcomes (e.g., quality of life) along with optimizing valuable medical resources. This dissertation discusses, in more detail, the implications that can emerge with the adoption and diffusion of empathetic communication styles.

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Chapter 1: Introduction

A NEED FOR RESEARCH

Cancer is real, happening, and universal. In 2012, 8.2 million people passed away due to cancer, 14.1 million people received a cancer diagnosis, and 32.6 million people had to live and deal with cancer every day (Stewart & Wild, 2014). That is, on a daily basis, approximately 22,466 people die of cancer and 38,630 people become new "victims" of cancer, altogether emphasizing the fact that cancer is real, happening, and universal. China is no exception to this cancer epidemic reality.

Of these worldwide 8.2 million deaths, around one fourth of them occurred in China (Stewart & Wild, 2014). In China, cancer is the leading cause of death nation-wide, accounting for approximately one fourth of all fatalities in China (National Bureau of Statistics of China, 2010). There is an average of twelve thousand predicted new cancer cases each day, and there were an estimated sum of 2.8 million Chinese cancer deaths in 2015 (W. Chen et al., 2016). Compared to around 2.2 million cancer deaths in 2012 (W. Chen et al., 2016), this new figure marks a dramatic increase in mortality rates.

However, there is a lack of evidence-based answers that could respond to questions such as: What roots Chinese cancer patients' needs and wants preferences in relation to their health information? What factors prompt Chinese cancer patients' diverse health practice behaviors? What is the relationship between how Chinese cancer patients prefer their health information and how it is practiced day-to-day? Finally, within the Chinese cultural context, how are Chinese cancer patients' experiences? A large aspect that research has understudied regards the factors that influence Chinese cancer patients' health information preferences and practices within the unique cultural context these patients face (Lim, Butow, Mills, Miller, & Goldstein, 2017; Bo Xie, Su, Liu, Wang, & Zhang, 2015, 2016; Yi et al., 2016).

What is even more daunting is that China is expected to see a greater surge of cancer cases due to the aging of the population, the worsening of environmental pollution, and the failing of chronic infection control mechanisms. In addition, the unprecedented uptake of an unfamiliar westernized lifestyle, rooted in an unhealthy diet, physical inactivity, tobacco usage, and early stages of alcohol overconsumption, contributes to the higher likelihood of the disease (W. Chen et al., 2016; Goss et al., 2014). These factors suggest that the Chinese medical system needs more flexible and adaptive health care to treat old cancer cases and prevent new ones from emerging.

One positive outcome, though, for both veteran and newcomer cancer patients is that more advanced and evidence-based cancer treatment, coupled with further technological developments, allow more and more patients to live with cancer for a longer period (Stewart & Wild, 2014). This outcome suggests that it is imperative to establish sustainable health care solutions for cancer patients. It also serves as an urgent call for more studies in order to investigate and better understand factors that influence cancer patients' interaction with their personal health information. This study defines health information as "any information which is related to the practice of medicine and healthcare" (Cullen , 2006, p.1), whereas health communication is "the study and use of communication strategies to inform and influence individual and community decisions that affect health" (Boykins, 2014, p.41).

The chronic nature of cancer as an illness, coupled with prolonged patient life span, makes it critical for health communication professionals (HCPs) to have a grounded and in-depth understanding of Chinese cancer patients' health communication preferences and practices. Having sufficient high-quality information helps patients to better navigate their care continuum (Lam et al., 2014; Bo Xie et al., 2015). China has a low cancer survival rate, with its five-year survival rate of all cancer sitting at approximately thirty-one percent, which is less than half of U.S. rate of sixty-six percent (W. Chen et al., 2016). Research also suggests that health inequality and physician scarcity, along with the lack of availability of proper treatment and care within rural areas, have contributed to the illness being the second most common cause of death in rural China. Thus, compared to urban China, fewer Chinese living in the rural areas can survive cancer (W. Chen et al., 2016; H. Zeng et al., 2015).

China's poor doctor-patient ratio of 1.4 per 1,000 patients (Sharma & Unnikrishnan, 2013) as well as other health inequalities (Blumenthal & Hsiao, 2015; M. Liu, Zhang, Lu, Kwon, & Quan, 2007; X. Liu et al., 2016) are unlikely to be solved within a short period of time. Compared to the daunting task of enabling equal access to medical resources across urban and rural China, which would involve a colossal overhaul of the Chinese medical system, understanding and better catering to Chinese cancer patients' health information preferences and practices might provide a more economical and feasible solution to alleviate cancer's burden on individual patients, HCPs, and the Chinese medical system. (Dean & Street, 2014; Goss et al., 2014; Bo Xie et al., 2015, 2016).

RESEARCH SIGNIFICANCE AND OBJECTIVES

It is vital for health communication professionals to have an in-depth understanding of cancer patients' interaction with health information to assist these information consumers[4] in better achieving positive health outcomes (e.g., quality of life) (Cheng, Sit, & Cheng, 2016; Bo Xie et al., 2015, 2016). In light of the overwhelmingly devastating impact of cancer, this research focuses on investigating the *underlying rationales and relationships* of Chinese cancer patients' *interactions* with health information, rather than concentrating on how these patient's specific health information relates to a specific setting. Thus, this research included all cancer manifestations. More specifically, this dissertation focuses on factors that influence Chinese cancer patients' health information preferences, practices, and the association between them, within the Chinese cultural context.

Research has shown that relevant and quality health information could stimulate cancer patients to become more informed and involved with their decision-making process within their treatment. This would, in turn, offer these patients more satisfaction with their cancer care and treatment (Au et al., 2013; Lim et al., 2017; Winnie K. W. So et al., 2013). Cancer patients have also widely adopted health information as both a coping strategy and an empowering mechanism within their cancer management endeavors (Q. Li, Xu, Zhou, & Loke, 2015, 2016; Schmidt et al., 2015). However, there is a need for in-depth empirical research regarding cancer patients' overall communication within the context of health

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[4] In the context of this study, "cancer patients", "information consumers", and "medical services or products consumers" are used interchangeably. Explanations will be given later in this dissertation.

information. This could provide healthcare communication professionals a grounded and thorough understanding regarding factors that influence cancer patients’ health information preferences (i.e., needs and wants) and practices (i.e., seeking, avoiding, sharing, and accepting), especially in light of cultural perception and societal attitudes (Bo Xie et al., 2015, 2016). Furthermore, findings of this study could also serve as a foundation for future research attempts that aim to enrich cancer research, especially in the realm of health communication.

To date, HCPs’ perspectives often frame patients’ interactions with health information, rather than being understood directly from the patient’s point of view (Bo Xie et al., 2015, 2016; J. Zhang et al., 2015). This provider-centered framework offers an outdated, paternalistic approach to patient-provider communication. As a result, there are increasing calls to explore more effective patient-provider communication models, such as shared decision-making (Hobbs et al., 2015; Lam et al., 2014; S. Wei et al., 2015). In order to provide an evidence-based understanding of patients’ interaction with health information, it is critical for this research to be patient-centered.

Though technology connected health developments (health-related Web sites, electronic records, telehealth consultations, etc.) have provided multiple interlocutors to improve patient-provider communication and give patients and their caregivers more health information options and resources (Q. Hong et al., 2016; Bo Xie et al., 2016; C. Zhang, Gotsis, & Jordan-Marsh, 2013), critical patient-provider communication is still integral to patient care. Due to the fact that these resources are largely available online, and that HCPs’ time constraints curb them, they have the possibility to worsen the already failing patient-provider communication mechanisms (Cappiello, Cunningham, Tish Knobf, & Erdos, 2007; McDowell, Occhipinti, Ferguson, Dunn, & Chambers, 2010). Hence, developing mechanisms to promote more effective and efficient communication between patients and HCPs, both online and offline, is of great academic relevance and practical significance.

Although there are a number of studies that have previously investigated Chinese cancer patients' specific attributes relating to their health information preferences or practices (Lim et al., 2017; Bo Xie et al., 2015, 2016), they do not include an in-depth understanding of how Chinese cancer patients construct and execute their health preferences and practices. These prior studies have also not been conducted from the patient's perspective in a culturally-respectful manner. This void indicates that the existing literature hardly provides health communication professionals with an evidence-based understanding of Chinese cancer patients' health communication preferences and practices. An in-depth and thorough understanding of Chinese cancer patients' interactions with health information within the Chinese cultural context could help HCPs better assist this large cancer population's care and management endeavors with ease and confidence. Furthermore, a culturally-sensitive understanding of Chinese cancer patients' communication with health could also shed light on research on cancer patients with similar cultural backgrounds, such as Chinese American cancer patients.

To conclude, this research aims to generate an in-depth understanding of cancer patients' interaction with health information, with close consideration of the influence of culture. The remainder of this dissertation is organized as follows. Chapter 2 offers an in-depth review of the extant literature on Chinese cancer patients' health information preferences and practices and the need for research. Chapter 3 details the research design of this dissertation. Information regarding specific research method, participant recruitment procedures, data analysis plans can also be found in this chapter. Chapter 4 presents the results of this dissertation. How to best interpret the research results in the proper context in accordance with existing research is also discussed in this chapter, following each theoretical category that emerged from data analysis. Chapter 5 delivers a succinct discussion of this study's findings and limitations, which is also the last chapter of this dissertation.

Chapter 2: Literature Review: Concepts under Study

Although research has thoroughly examined the quantitative study of health information behaviors (e.g., Xie et al., 2015, 2016), there is a void in understanding cancer patients' health information preference and practices from an in-depth, culturally-sensitive, and patient-centered perspective. It is crucial that further research provide a fuller picture of cancer patients' overall interaction with health information. Specifically, this research needs to focus on the factors that influence patients' health information preferences and practices. In the current literature, there are only limited insights on Chinese cancer patients' underlying rationales behind their health information preferences and practices, especially in light of their cultural positions. That is, *ceteris paribus*, questions such as: Why do some Chinese cancer patients withhold their questions while interacting with their HCPs? Why do Chinese cancer patients always come to their consultations with their family members? How do Chinese cancer patients balance their questions related to western medicine versus that of traditional Chinese medicine? An in-depth literature review is needed to confidently answer these questions, as well as to gauge what has been done in relevant fields of research.

HEALTH INFORMATION NEEDS AND WANTS PREFERENCES

By and large, we are still waiting for a cure for cancer, or many cures for many cancers. In 2017, the key arguments regarding cancer treatments still center on how to find a balance between cancer treatments' effectiveness and toxicity (Suh, Shen, Kuhn, &

Burgess, 2017). Thus, it is safe to assume that cancer patients might have many questions regarding cancer care and health management (Lam et al., 2016; Bo Xie et al., 2015, 2016), especially when there is no cure for cancer.

Further complicating the situation is the fact that some of the most pressing questions regarding cancer treatment and care do not have definitive and transparent answers (Archer, 2016). However, what might not fluctuate upon technological development or information accessibility are the *rationales and relationships* underlying cancer patients' interaction with health information. When research discovers the cure for cancer, the factors that influence cancer patients' health information preferences and practices may apply to other communication or chronic disease contexts.

This study aims to explore the factors that influence cancer patients' health information preferences and practices, with the ultimate goal of contributing to cancer patients' satisfaction with their health communication, health outcomes, and quality of life. With this goal in mind, the researcher reviewed current literature and charted the current research typology that is most relevant to this question.

Current Literature on Health Information Preferences

Previous literature has explored a wide range of topics on cancer patients' health information needs. For instance, many aspects of cancer patients' health information preferences have been identified, such as *media channels* patients use to receive health information (e.g., online information) (des Bordes, Abdel-Wahab, Suarez-Almazor, & Lopez-Olivo, 2016; Bo Xie et al., 2016), *formats of health information* provided to cancer patients (e.g., print materials) (Jewitt et al., 2016; Bo Xie et al., 2016), and *types of health information* that are available to these patients (e.g., psychosocial information) (A. B. Smith et al., 2016; Bo Xie et al., 2015). Overall, cancer patients mainly receive health information through two communication venues: *mass communication/mediated venues* (e.g., the Internet) and *interpersonal communication venues* (e.g., HCPs) (Maschke et al., 2017; Bo Xie et al., 2016). These mass communication methods primarily consist of print and electronic or digital media (e.g., TV) (Maschke et al., 2017; Bo Xie et al., 2016). As for interpersonal communication venues, cancer patients usually access health information via communication with doctors, nurses, family, friends, organizations, and support groups, in addition to other associations (Robotin et al., 2017; Bo Xie et al., 2016). In terms of the presentation of information, the most common formats are print materials (e.g., treatment guides) (Bo Xie et al., 2016), electronic sources (e.g., online health information) (des Bordes et al., 2016) , and verbal communications (e.g., HCPs' consultations) (Robotin et al., 2017).

In general, cancer patients show an interest in many types of health information. For instance, Rutten and associates (2005) identified sixty-four distinct categories of health information across a total of 795 occurrences in a systematic literature review. Some common categories are: patients' information regarding traditional treatment (Lock & Willson, 2016), complementary and alternative medicine (Xie et al., 2016), prognosis-related information (Yi et al., 2016), diagnostic information (Rankin et al., 2017), rehabilitation-related information (Silver et al., 2017), interpersonal information (Lim et al., 2017), financial information (Y. Zafar et al., 2016), and information regarding cancer care and management (Fang & Lee, 2016). However, despite the fact that some studies have investigated cancer patients' health information preferences, the majority of these studies are conducted in a western context. In other words, only limited insights are available on Chinese cancer patients' health information preferences.

These limited insights include a study by Xie and colleagues (2015), when they reviewed Chinese cancer patients' seven types of health information wants, such as information on diagnosis, treatment, laboratory tests, self-care, complementary and alternative medicine, psychosocial factors, and healthcare professionals. The results of this study suggest that the greatest discrepancies between health information wanted and obtained concern information on complementary and alternative medicine and psychosocial factors, with the smallest ones being diagnosis and self-care. These findings suggest that cancer patients might also desire health information that is not directly related to diagnosis, standard treatment, or prognosis (B. Xie, 2009; Bo Xie et al., 2015).

For instance, studies conducted within western contexts advise that cancer patients have indicated that they would prefer to have more "nice-to-have" information regarding complementary therapies. (Holmes, Bishop, & Calman, 2017) Also, information regarding the maintenance of a healthy lifestyle (Maschke et al., 2017), sexual functioning-related information (Crowley et al., 2016), and complementary and alternative medicine (Xie et al., 2015) are helpful. Thus, for cancer patients, there are currently two layers of information preferences: 1) what is presented and thus considered as needed by the medical community, and 2) what is desired, but not currently offered as frequently as the considered-as-needed information. This raises the question*: What are the factors that shape cancer patients' health information preferences?*

The typologies of cancer patients' interactions with health information have been placed into specific categories of information sources. For instance, Rutten and colleagues (2005) classified health information sources into: 1) health care professionals (i.e., physicians, nurses, other health care professionals, other health related professionals), 2) printed material (i.e., books, libraries/unspecified readings/brochures/ magazines & newspapers/materials from a physician), 3) mass media (TV, radio, or video), 4) interpersonal (i.e., friends and family, counseling, support groups, or support services, other patients, clergy, church, synagogue, or other place of worship), and 5) organizational and scientific resources (i.e., telephone information services and charitable or professional organizations). Though these categories provide adequate information for understanding cancer patients' selection of sources of information, they only offer limited insight into the systematic approaches these patients have adopted in their interaction with health information and the logic behind them. However, an aspect that the authors did not address was: *What are the rationales that could help explain cancer patients' information preferences?*

Furthermore, these categories are not mutually exclusive. It is possible that a good majority of the information sources, such as health care professionals and organizational and scientific sources (category 1 and 5, respectively, Rutten et al., 2005), could present information to cancer patients using the vehicle of print material (category 2, Rutten et al., 2005). Hence, the clear labeling of various health information sources proved to be an impossible task, as there are no clear boundaries between categories.

Also, though communication with HCPs might bear a greater significance to cancer patients, by definition and nature, it falls under the category of interpersonal communication. Inevitably, communicating with HCPs falls under both category 1 and 4. This confusion of genres should not be treated lightly, as some of the scientific research, if not all, depends on clearly defined conceptual and operational definitions and categories. However, these might not be the only categorizations of health information that could confuse patients. Worsley (1989) classified health information sources into “formal sources” (information generated from HCPs), “informal sources” (information given by less professional sources, such as family and friends), and “commercial and media sources” (mediated health information from sources such as TV).

Considering that HCPs could also use mass media to communicate health information, this categorization’s fallacy is similar to Rutten and associates’ (2005) classification. This fault might develop out of that fact that these categorizations are considered and construed from the HCPs’ perspective, rather than patients’ point of view. This suggests that cancer patients might adopt different criteria in their identification of health information sources, such as those based on source trustworthiness (i.e., trustworthy, neutral, and untrustworthy sources), social distance (i.e., close social contacts, general acquaintances, and other sources), and source accessibility (i.e., accessible and inaccessible sources). Another possible interpretation of these overlaps is that they contribute to the overlaps within cancer patients’ health information preferences. Hence, this raises the question: *What are the rationales behind Chinese cancer patients' classification of their health information preferences*?

Health Information Needs and Wants

Though there is a body of literature on cancer patients' information needs, or *have to have* information preferences, little is known regarding information they *would like to have* (B. Xie, 2009). Also, even though many researchers (e.g., Line , 1974; Xie, 2009) have investigated the concept of information wants, lacking is a well-developed conceptualization of information *wants* interacting with information *needs*. Furthermore, existing research generates definitions in the context of library or information studies, which differ starkly from those in the field of health communication, especially in the realm of cancer research.

For instance, Chatman and Pendleton (1995) argue that "'want' conveys some degree of enhancement. That is, we would not be worse off if we didn't have the information, but it would be an added benefit if we possessed it" (p.136). Furthermore, some of the definitions given to health information wants are context specific. For instance, Beautyman and Shenton (2009) contend that "a school-inspired information want is considered to refer to a situation in which a pupil feels an urge to investigate, on his or her initiative, a topic previously introduced to the youngster through academic work, either in class or as homework. In this context, a requirement is believed to differ from a school-inspired need in that here the child has not been asked to pursue information as a result of a requirement from a teacher to complete an assignment" (p.71).

Though there are a variety of definitions available for *information wants*, these definitions are seldom empirically tested or evidence-based. For instance, Line (1974) defined information wants as “what an individual *would like* to have, whether or not want is actually translated into a demand on the library… Individuals may need an item they do not want, or want an item they do not need (or even ought not to have) …. A want, like a need, is a potential demand” (emphasis added, p.87). Though Line’s (1974) conceptualization presents a clear picture of information wants, it does not give a matching operational definition that could allow researchers to empirically measure individuals’ information wants.

Furthermore, this research was also conducted within the context of library and information science, rather than the context of health communication or cancer research. Thus, although this definition has merit, it offers little help to empirical research given the lack of proper operationalization of the concept of ‘wants’, let alone the irrelevancy of the research contexts. In general, the majority of *information wants* definitions are not generated from empirical data, or from information consumers’ perspective. This void inevitably poses additional methodological concerns regarding the validity and applicability of these definitions.

Xie (2009) is the harbinger of empirical research in investigating the concept of health information wants in the context of gerontology. She pioneered research on older adult patients’ health information preferences and developed a health information wants theoretical framework from the patients’ perspective. Xie and colleagues (2015, 2016) further extended this research field via examining Chinese cancer patients’ health information wants. Based on Xie's (2009) definition, "health information wants" refers to "health information that one would like to have and use to make important health decisions that may or may not be directly related to diagnosis or standard treatment" (p.514). Though this notion is empirically tested and has great merits in investigating health information wants from patients' perspective, it does not relate to health information *needs*. Despite the fact that the concept of health information wants was later adapted to the field of cancer research, it is empirically necessary to develop the concept of health information wants together with the concept of health information needs. Considering that there might be potential overlaps between needs preference and wants preference of cancer patients regarding their health information, clearly defined and mutually exclusive definitions are fundamental in developing research that aims to gauge relationships between these two concepts. What might be an even more relevant question for cancer research is: *What is the fundamental rationale that prompts Chinese cancer patients' health information needs preferences and wants preferences?*

Concepts of information needs and information wants fall victim to the loose and liberal usage of scholars of various academic backgrounds (Green, 1990; Xie, 2009), which, in turn, has led to the ambiguous and confounding understanding of those terms (Shenton & Dixon, 2003, 2004). Both the concepts of information needs and information wants have been used to broadly describe a user's demand and desire for information either interchangeably (e.g., Gross, 1998) or with no distinctions (e.g., Gratch, 1978). However, since what are considered patients' information needs are often determined by HCPs (Xie, 2009), inferring insights gained from HCPs as desires of the patients might need empirical evidence to justify. In the same vein, evidence is also needed to use the concepts of information needs and information wants interchangeably. On face value, information wants might refer to information that is “nice to have”, whereas information needs might refer to information that is “have to have”. In order to confidently answer the question of whether there is a difference between information needs and information wants, more evidence is needed, as clearly understanding these two terms could help HCPs better serve health information consumers. Furthermore, compared to general information consumers, equivocal and ambiguous conceptualizations of cancer patients’ information needs and wants might flaw health professionals’ understanding of patients’ health information preferences and, consequently, harm patient-provider communications. Thus, there is a need for research on understanding the differences between health information needs and wants.

Summary

To conclude, the overall characteristics of the established findings regarding cancer patients' health information preferences are: 1) highly focused on individuals' health information *needs* without making any differentiation from their health information *wants*, 2) mainly generated by descriptive research, 3) generated from HCP's perspective, 4) not developed in the context of cancer management, 5) not inclusive of the role of culture, and 6) focused on information that the HCPs believe the patients must have, but not inclusive of other information patients also would like to have. Thus, further research needs to establish an understanding of factors that influence Chinese cancer patients' health information needs preferences and wants preferences.

HEALTH INFORMATION SEEKING, AVOIDING, SHARING, AND ACCEPTING

In this section, the researcher will briefly summarize key health information activities that are fundamental to Chinese cancer patients' interaction with health information; that is, health information seeking, avoiding, sharing and accepting.

Health Information Seeking

Health information seeking behavior is one of the most investigated behaviors in the context of health information studies (H. Kim, Paige Powell, & Bhuyan, 2017; Robinson, Venetis, Street, & Kearney, 2016; Rogith et al., 2016). It is defined as "a subset of information behavior that includes the purposive seeking of information about a goal" (Kukka et al., 2013, p.16). Not only is there a rich body of literature on the general public's cancer-related health information seeking behaviors (Alsem et al., 2017; Chae, Lee, & Jensen, 2016; S. Park et al., 2016), but also a considerable amount of research exists that alludes to how cancer patients seek health information (H. Kim et al., 2017; Kimiafar, Sarbaz, Shahid Sales, Esmaeili, & Javame Ghazvini, 2016; Teufel-Shone, Cordova-Marks, Susanyatame, Teufel-Shone, & Irwin, 2015). Collectively, potential causes, content, and consequences of health information seeking have been identified (for a review, see Rutten et al., 2016).

Factors such as education, socio-economic status, income, gender (specifically female), age (specifically younger) have found to be positively related to more active health information seeking behaviors (Playdon et al., 2016; Rutten et al., 2016). Psychosocial factors, such as social support, race/ethnicity, health literacy, health beliefs, and self-rated health, also influence individuals' health information seeking behaviors (Hovick, Liang, & Kahlor, 2014; Hovick, Kahlor, & Liang, 2014; Jung, 2014; Jung, Ramanadhan, & Viswanath, 2013; Kim et al., 2013; Kratzke, Wilson, & Vilchis, 2013; Lewis & Martinez, 2014; Tu & Hargraves, 2003). Literature has identified contextual factors, such as disease characteristics (e.g., stage, severity), life events, and coping strategies adopted as catalysts to cancer patients' health information seeking behaviors (Friis, Elverdam, & Schmidt, 2003; Lambert, Loiselle, & Macdonald, 2009; Radina et al., 2011; Tsuchiya & Horn, 2009). Content-wise, patients usually look for information regarding their diagnosis and prognosis, treatments, drugs/medicines, their HCPs, alternative treatment choices, side effects, quality of life, and complementary and alternative medicine (Maloney et al., 2015; Rutten et al., 2016; Tan et al., 2014).

Also, conflicting results exist concerning cancer patients' sources of health information. Though cancer patients consider HCPs as the most trustworthy information sources, they have shown a greater preference for family and friends as a health information source (Mills & Davidson, 2002). Overall, people invest great trust over interpersonal information sources (Zhang, 2014), a phenomenon which might contribute to the effectiveness of narratives compared to that of informational messages (Falzon, Radel, Cantor, & d'Arripe-Longueville, 2015). Aside from interpersonal information sources, cancer patients also use other sources of health information such as mass media venues like TV, radio, newspaper, and the Internet (Beckjord et al., 2008; Carlsson, 2009; Luker et al., 1996; Rutten et al., 2009).

Health information seeking behavior is often considered as a positive information action that bears great benefits to information consumers (Moldovan-Johnson et al. 2014). Some positive outcomes of health information seeking include: enhanced treatment decision satisfaction, improved emotional well-being, heightened self-efficacy, strengthened quality of life, and augmented health behaviors (Lewis et al., 2012; Nagler et al., 2010; Tan et al., 2011; Tan, Mello & Hornik, 2012; Moldovan-Johnson et al. 2014). Similar effects could also be generated by online health information seeking behaviors among individual searchers (Smith et al., 2015). With the development of technology, more and more cancer patients have adopted the Internet as their source for health information (Rutten et al., 2016). Online health information seeking behavior can provide more private, convenient, and comfortable information seeking options for patients, especially for those with limited mobility or who have inquiries they consider embarrassing (Househ, Borycki, & Kushniruk, 2014).

However, the development of health information seeking behavior is not smooth. Regulation loopholes, in terms of a lack of accountability and reliability, has forced online health information to be riddled with poor quality information as well as false and misleading rumors (Bruce, Tucholka, Steffens, & Neuman, 2015; Deng, Liu, & Hinz, 2015; Zhang, Zhang, & Li, 2015). Furthermore, evidence regarding the outcomes of health information seeking behavior suggests that a consensus has yet to be reached. Indeed, findings suggest that health information seeking behaviors might cause negative health outcomes, especially in the case of online behaviors. These behaviors generate misconceptions, misinformation, inappropriate adoption of medical services, added burden to HCPs, and reduced positive physician influence (Alpert, 2006; Henwood et al., 2003; Iverson, Howard, & Penney, 2008; Roberts & Copeland, 2001; Tan et al., 2014). In addition, there are studies that found no significant relationships between cancer patients' health outcomes and their health information seeking behaviors. For instance, Tan and associates (2013) investigated breast cancer patients' health information seeking behaviors from both medical and non-medical sources and found that these patients' behaviors are not significantly related to favorable health behaviors such as physical examination. These mixed findings raise the question: *What are the factors that influence the relationship between Chinese cancer patients' health information preferences and practices?*

The following findings might illuminate the question raised above. Although some of the main drivers for individuals' health information seeking behaviors have been identified, these motivators might also serve as causes for cancer patients' health information avoidance behaviors. Scholars have identified that both cancer patients' health information seeking behaviors and information avoidance behaviors might be attributed to information consumers' need for control, diagnosis-related concerns, trust in HCPs, salient emotions such as hope and fear, and need for normalcy (Germeni & Schulz, 2014). Thus, it is important to investigate the role of cancer patients' health information seeking behavior in regards to their other relevant information practices (e.g., avoiding, sharing, and accepting) in order to provide a fuller and more consistent illustration of their interaction with health information. This is imperative, considering that cancer patients are often faced with great barriers in practicing their health information rights.

Barriers to health information seeking behaviors are still prevalent, even though a great deal of efforts have been invested aiming to convert old paternalistic patient-provider communication into patient-oriented two-way communication (see Wuensch et al., 2013). The flaws of the old health communication model are still rampant, particularly concerning cancer patients' communications with their HCPs (Eysenbach, 2003; Murray, Lo, & Pollack, 2004). For instance, regarding the drivers for patients' information seeking behaviors, researchers have found that delivery of inaccurate, insufficient, and incomplete information by HCPs was the main impetus for cancer patients to look for additional information (Prouty et al., 2014).

Though this research suggests that HCPs should provide adequate information to help patients better estimate their cancer care and management, evidence indicates that this suggestion has often been ignored by HCPs (Davison et al., 2007). Research also demonstrates that sometimes even the most fundamental communication is not established between patients and their HCPs (Ravin et al., 1998; Shim et al., 2014; Thorne et al., 2014). This, in turn, could cause cancer patients to tend to overestimate their chance of relapse while underestimating the outcome of their treatment (Ravin et al., 1998). Furthermore, this might also cause some cancer patients to avoid health information. Overall, these insights suggest that there might be a lack of an understanding of factors that influence cancer patients' interaction with health information, even in western contexts. This suggests that there is a need for research that could provide an in-depth understanding of cancer patients' health information seeking activities.

Health Information Avoiding

Information avoidance is a universal behavior; that is, everyone avoids some information at some point (Chae, 2016; Gaspar et al., 2016; McCloud, Okechukwu, Sorensen, & Viswanath, 2017). The functional definition is "any behavior intended to prevent or delay the acquisition of available but potentially unwanted information" (Sweeny, Melnk, Miller, & Shepperd, 2010, p.341). Many reasons could contribute to cancer patients' health information avoidance behaviors. For instance, researchers have found that cancer patients tend to avoid information when the information is "too pessimistic, or tempting fate" (Chatwin et al., 2014, p.6). Cancer patients have also adopted information avoidance as a coping strategy (Chatwin et al., 2014), which might lead to positive outcomes such as lower levels of psychological stress and prolonged states of hope (Brown, Butow, Culjak, Coates, & Dunn, 2000; Deimling, Kahana, Bowman, & Schaefer, 2002; Jim, Richardson, Golden-Kreutz, & Andersen, 2006; Sheridan, Sherman, Pierce, & Compas, 2010). Another way existing literature has framed information avoidance is that it is considered as a form of self-deception (Lauria, Preissmann, & Clément, 2016) or denial (Salander & Windahl, 1999). Similarly, research shows that, counterintuitively, these two coping strategies could often result in positive health outcomes (Nipp et al., 2016).

Studies have found that people with depressive symptoms (e.g., anxiety, worry, depression) are less likely to seek out information and more likely to avoid information due to their limited coping abilities (Chae, 2016; Y. Yu & Sherman, 2015). Furthermore, people who have a higher level of self-efficacy are considered to be more capable of exercising self-control (Bandura, 1986; Nielsen, Mehlsen, Jensen, & Zachariae, 2013), and thus believed to be less likely to avoid information (Sweeny et al., 2010). Similarly, perceived control, or people's perception of control over a situation, was also considered as a noteworthy factor that could influence their information avoidance behaviors. Empirical evidence is available to support this argument. For instance, persuading individuals to screen for a severe disease has a higher chance of success if the potential participants are led to believe that this disease is treatable, rather than untreatable (Dawson, Savitsky, & Dunning, 2006).

Similarly, in a feedback preference context (Trope, Gervey, & Bolger, 2003), people were more accepting of negative feedback regarding their social abilities if they believed these abilities were controllable, and *vice versa*. These findings validate this study's research questions, that is, it is more grounded and logical to investigate cancer patients' health information behaviors (e.g., health information seeking) with respect to their *health information preferences* and *barriers and facilitators* they encounter while interacting with health information, with a careful consideration of their cultural context.

Within the current literature, there are variety of theories and assumptions regarding individuals' information avoidance behaviors. Previous research has dichotomized individuals into two categories, "monitors" and "blunters", based on their overall information processing tendencies (Miller, 1987; Miller & Mangan, 1983). According to the coping strategies they adopted, Miller (1987) categorized information consumers into four groups: *high monitors, low blunters, low monitors,* and *high blunters*. Within this, high monitors are people "who characteristically seek information, while low blunters are people "who characteristically avoid distraction". On the other end of the spectrum, "low monitors” are people “who characteristically avoid information”, whereas “high blunters” are people “who characteristically distract themselves” instead of being attuned to distracting informational stimuli (Miller 1987, p.348). Scholars have found that in the face of threat, high monitors tend to have more information, compared to low blunters, whereas high blunters and low monitors prefer to have less information (Miller, 1987; Miller & Mangan, 1983). Scholars also argue that instead of treating it as a *trait*, information avoidance behavior reflects individuals’ *state* of interaction with health information. Based on various situational and environmental factors, individuals may seek certain information in some contexts and avoid the same kind of information in other contexts (Thorne et al., 2014).

Within the context of cancer care, cancer patients may also seek certain information in the early stages of treatment, yet ignore the same kind of information in later stages of treatment (D. O. Case, 2002; Donald O. Case, Andrews, Johnson, & Allard, 2005). This behavior raises the question: Instead of attributing information consumers’ avoidance behaviors to trait or state, *would it be better to explain individuals’ information avoiding exercises concerning their information preferences?* It is possible that cancer patients might be more likely to avoid information that they do not prefer, and less likely to avoid information that they have been longing to gain.

Regarding the underlying rationale behind people’s information avoiding behaviors, these findings demonstrate that uncertainty plays a role in information avoidance. Sorrentino and Short (1986) introduced the idea of describing individuals according to a continuum ranging from uncertainty-oriented to certainty-oriented.

Individuals have been labeled in terms of “uncertainty” and “certainty” orientations. This refers to the degree to which an individual “likes to stick to familiar events and traditional beliefs” (Sorrentino & Short, 1986, p.400) or “attempts to integrate new events or beliefs into already existing belief systems” (Sorrentino & Short, 1986, p.399).

Especially when it comes to new information, uncertainty-oriented individuals tend to be more comfortable with uncertain situations where new information is available, whereas certainty-oriented individuals tend to prefer a greater level of information avoidance (Sorrentino (Richard M. Sorrentino & Hewitt, 1984; Richard M. Sorrentino, Hewitt, & Raso-Knott, 1992). Though attributing people’s information avoidance behaviors to their prejudiced disposition could help understand *why* they avoid information (Adorno, Frenkel-Brunswik, Levin son, & Sanford, 1950; Richard M. Sorrentino & Hewitt, 1984), it provides little on *why* and *how* they avoid health information in practicing their health information preferences and other contextual factors.

Once considered as an ‘anomaly’ in human information processing, individuals’ health information avoidance behaviors are now understood as somewhat rational, as researchers continue to investigate the antecedents to and consequences of individuals’ information avoidance preferences (Germeni & Schulz, 2014). This research investigates two aspects of cancer patients’ health information avoiding activities. The first aspect is *what causes* cancer patients’ information avoidance exercises? That is, *what are the underlying reasons behind cancer patients’ information avoiding behaviors*? The other is the relationship between patients’ health information avoiding exercises in relation to other elements of cancer patients’ information activities. That is, *could health information* *avoiding act as a stand-alone behavior of cancer patients' interaction with health information?* If not, *what is the relationship between cancer patients' health information avoiding with their other information activities (e.g., health information seeking)?*

As indicated in the current literature, if not studied as a defining factor influencing cancer patients' interactional with health information, health information avoiding behavior was often investigated in tandem with health information seeking behavior (e.g., Germeni & Schulz, 2014). This leaves a void in understanding individuals', especially cancer patients', information avoidance from a connected perspective, that is, in partnership with other health information behaviors such as *sharing* and *accepting*.

Health Information Sharing

People may share information through various channels, such as intrapersonal (e.g., journal writing, meditation, etc.), interpersonal (e.g., patient-provider communication), and via mass communication venues (e.g., via sharing information on the Internet; Rutten et al., 2016). Furthermore, based on the channel used for sharing, patients' sharing behaviors can be categorized based on their most noticeable role in the information exchange: 1) sender/coder and 2) receiver/encoder. In this study, for the sake of simplicity, consciously sharing information as a message coder/active sender with a receiver is conceptualized as information sharing. Thus, this study defines information sharing as an individual information consumer's active and autonomous information sharing behaviors. Under the mechanism of interpersonal communication in the Internet age, cancer patients could share health information with 1) HCPs, 2) family and friends, and 3) other cancer patients, online or offline. Each recipient group is discussed in detail below.

Sharing Information with HCPs

Cancer patients' active and autonomous information exchange with HCPs is considered as one of the pivotal components in establishing effective patient-provider communication (Prouty et al., 2014). Even though HCPs are considered the most valuable source of information (Rutten et al., 2016), the value of the information provided by HCPs *is contingent on* the information patients share with HCPs. Consultations with HCPs are often intended to be responsive to patients' self-disclosures about symptoms, concerns, etc. The concept of shared decision-making is an idea that builds on patients' information sharing with their HCPs (Légaré et al., 2010).

Shared decision-making could be understood "a process by which a healthcare choice is made jointly by the practitioner and the patient" (Légaré et al., 2010, p.3). One of the most important reasons that shared decision-making communication models are considered as optimal for facilitating responsive, constructive and high-quality care is that they are, essentially, two-way communication mechanisms. That is, in shared decision-making communication models, patients have the opportunity to share their opinions and thoughts with HCPs, and more importantly, make important health-related decisions (Epstein & Street, 2011; Frenkel & Cohen, 2014).

There are many benefits of initiating effective two-way communications that address both patient autonomy and HCPs' professionalism. These benefits include: better patient comprehension of materials, enhanced trust between medical care stakeholders (e.g., patients, caregivers, HCPs, and the medical system as a whole), and greater rapport between these stakeholders (Frenkel & Cohen, 2014; Hirpara, Cleghorn, Sockalingam, & Quereshy, 2016; Stiggelbout et al., 2012). In turn, these will improve patients' health outcomes, such as enhanced communication satisfaction, boosted decision-making confidence, augmented treatment adherence, heightened self-care ability, lessened malpractice litigation, and strengthened overall quality of life (Barrett, Ricco, Wallace, Kiefer, & Rakel, 2016; Jayadevappa et al., 2017; Müller, Hahlweg, & Scholl, 2016).

Furthermore, the development of a sustainable and effective patient-provider communication mechanism could facilitate patients' expressions of their point-of-views or thoughts. Previous studies have indicated, though, that personal disclosure on complementary and alternative medicine therapy adoption, as well as the physical, emotional, and psychosocial experiences of patients is difficult to achieve (den Oudsten et al., 2014; Prouty et al., 2014; Sohl et al., 2015). For HCPs, establishing a positive and effective patient-provider communication is also beneficial to time and effort allocation, and that inexperienced physicians were more likely to experience burnout (Ramirez et al., 1995; Ramirez, Graham, Richards, Cull, & Gregory, 1996).

As indicated above, patient-provider communication is a complicated negotiation process, one that could produce positive health outcomes when handled well. However, a number of studies have found that some patients find the process of shared decision-making demanding and burdensome (Elwyn, Frosch, & Kobrin, 2015; Hong, Gorodzinsky, Taylor, & Chorney, 2016). Indeed, evidence suggests that, in some cases, positive outcomes can result from patients making their own decisions, without involving HCPs (Mead, Bower, & Hann, 2002; Mendick, Young, Holcombe, & Salmon, 2010). One way to shed light on these confounding situations is to map a typology of cancer patients' *preferred* information sharing behaviors in conjunction with other information exercises (e.g., seeking, avoiding, and accepting). Within this typology, close attention needs to be directed to overall context, potential causes, detailed content, and subsequent consequences that arose from that information sharing.

Research indicates that patients are often, against their preferences, given little or no chance to voice their opinions (Ernst et al., 2013; Gray, 2016; Loewenbrück, Wach, Müller, Youngner, & Burant, 2016; Matthews, Peden, & Rowles, 2009). More in-depth understandings of the patient-provider information sharing process are needed to illuminate ways in which they could take a *preferred* role in communicating with their HCPs (Gray, 2016; Loewenbrück et al., 2016). Furthermore, depending on patient's treatment stage, some patients might encounter referrals and transfers from HCP to HCP, ward to ward, and hospital to hospital. This adds an extra layer of complication to the information sharing process, as it requires patients' repetitive sharing of health information with different parties. It also requires additional effort on the patients' part in initiating communications with various groups of HCPs, with a proportion of them being potentially inconsiderate communicators, as they move back and forth between services and HCPs. In turn, this further supports the notion that by investigating the dynamic and stable *relationship* between all possible health information activities *en masse*, rather than studying each concept in isolation, comprehensive interventions could be orchestrated to alleviate these patients' communication burdens.

Sharing Information with Family and Friends

Forming a social support network while managing cancer can positively impact patients' physical and mental well-being (J. E. Chung, 2014; Yan et al., 2016). Patients' social support system may include patient-provider relationships, relationship with family and friends, as well as kinships built with other cancer patients. Of these relationships, close social relationships with family and friends appear to have a consistent significant effect on impacting cancer patients' care, management, and quality of life in general (la Cour, Ledderer, & Hansen, 2015; Warmenhoven et al., 2016). Furthermore, research indicates that the number of cancer patients' close social ties is also positively related to their effective communication (Lewis et al., 2012). Though this research has accumulated ample knowledge, there is still room for improvement.

The primary focuses within these studies concentrates on the forming of social support groups among cancer patients within western societies (e.g., la Cour, Ledderer, & Hansen, 2015), with little emphasis on how cultural background shapes patients' sharing behaviors and mentality. Chinese cultures and philosophies, which form the basis of their own family and social values, are distinct from those of western origins (Cao, Chen, & Fan, 2011). For Chinese cancer patients, an additional sick role might further complicate their information sharing approaches and behaviors (Tang & Lee, 2004). For instance, previous research on western cancer patients suggested that sick role has a passive impact on these patient' information behaviors (Stiggelbout & Kiebert, 1997). That is, these patients are less likely to less likely to actively participate in information gathering. Thus, one focus of this dissertation explores the factors that contribute to Chinese cancer patients' information sharing behaviors concerning their cultural values and positions, as an important compound in these patients' health information practices.

Sharing Information with Other Cancer Patients

Communication with others who are also struggling with cancer could be a significant facet of cancer patients' information sharing activities (Birkelund & Larsen, 2013). This genre of information collaboration often takes the form of a support group, which can be facilitated online or offline, with online groups being a relatively new phenomenon (Attai et al., 2015; Han et al., 2014). Research suggests that among cancer patients, online support groups appeal more to young adults between 18 to 45 years old, compared to their older counterparts (Treadgold & Kuperberg, 2010). Furthermore, support groups also offer a forum for socializing that is *apart* from family and friends. Although the majority of cancer patients indicated their appreciation of having social support from family or friends, for some patients, being dependent on family and friends can cause a sense of identity loss. This has the possibility of spawning negative, upsetting, and uncomfortable emotions (Keim-Malpass & Lindley, 2017; Odh, Löfving, & Klaeson, 2016).

Whether it takes place in the cyber world or the real one, cancer patients often consider sharing information as beneficial in that it enhances knowledge and consolidates experiences between both parties (Coyne, Amory, Gibson, & Kiernan, 2016), improves relationship quality (Bahrami, Namnabati, Mokarian, Oujian, & Arbon, 2017), contributes to the overall function of the group as a constructive support system (Fong, Scarapicchia, McDonough, Wrosch, & Sabiston, 2017; Harper et al., 2016; McCaughan, Parahoo, Hueter, Northouse, & Bradbury, 2017), and improves all shareholders' quality of life (C. Lai, Borrelli, Ciurluini, & Aceto, 2017). However, other than the positive roles mentioned above, there is more to information sharing among cancer patients.

Although sharing information with fellow patients often generates positive outcomes, less typically, some patients experience a burden in their interactions with other patients (Birkelund & Larsen, 2013). These findings suggest that information sharing amongst patients is highly complex, and might be the result of various social and contextual factors. Thus, it is critical to investigate cancer patients' health information sharing behaviors *inclusively* and *comprehensively*, so that a clear representation of the rationales behind these information consumers' sharing communication could be garnered. Furthermore, sharing behaviors only represent one aspect of cancer patients' overall interaction with health information. For instance, information sharing could be *independent* or *interdependent* of accepting behaviors, which makes it essential to consider other aspects of health information practices.

Health Information Accepting

In addition to taking up the role of information sharers, patients also act as information accepters. Frequently, patients play a passive and compliant role in the process of information accepting, partly because they are given neither voice nor choice in proactively interacting with information (Lamers et al., 2016), and partly because they deem that specific information as the best available. Similar to health information sharing, patients may accept information from multiple interpersonal channels, such as 1) HCPs, 2) family and friends, and 3) other cancer patients. The researcher defines information accepting as individuals' passive learning, willingly or unwillingly, of particular information. Compared to information sharing, information accepting is a more passive form of information exchange. Cancer patients might accept information of their preference, however, due to social norms, they may also receive and accept information that they would otherwise avoid.

The study of information accepting is most common in the field of organizational communication, as a reflection of workplace behaviors (e.g., Kramer, Callister, & Turban, 1995). Prevalent theoretical frameworks for this area of research are social exchange theory (Homans, 1974; Thibaut & Kelley, 1959) and the assimilation perspective (Jablin, 1987). Social exchange theory is developed from exchange theory, a theoretical framework rooted in economics, and centers on human interactions concerning contractual obligations and resources exchanges. It often relies on four stages of engagement: sampling, bargaining, commitment, and institutionalization (Thibaut & Kelley, 1959). Though its main application is in organizational communication, information and communication studies also use it to understand research information sharing behaviors (Hall, Widéén, & Paterson, 2010). Information accepting is considered an effective coping strategy that employees use as they adjust and acculturate into their organizations while bringing certain change with them (Jackson, Schuler, & Vredenburgh, 1987; Kramer, Callister, & Turban, 1995). For instance, Kramer and associates (1995) found that unsolicited information exchange has a positive impact on information accepters' job satisfaction and loyalty to the organization.

These findings validate the need for this particular study, as well as other studies that could provide a theoretical reasoning for cancer patients' health information accepting behaviors. Little research on health information accepting is available in the context of health communication, especially regarding cancer care. This motivates the researcher to study cancer patients' *information accepting* of health information interactions, and *if and how information accepting is related to cancer patients' other health information practices, in light of these patients' health information preferences*.

UNIQUE CULTURAL BELIEFS

Influenced by traditional Chinese philosophies such as Taoism, Confucianism, Buddhism, and the beliefs of Yin-Yang, Chinese culture cherishes interpersonal values and collectivistic standpoints (Cao et al., 2011; L.-M. Chen, Miaskowski, Dodd, & Pantilat, 2008; Tung & Li, 2014; Wu & Tseng, 1985). This study defines culture as a set of beliefs, behaviors and social entities held by a group of people that serve as the foundation for their social identities. Social identities are formed as individuals are exposed to multiple cultures' influences. Though culture is an important contextual factor that influences Chinese people's everyday lives, researchers often fail to include its impact in gauging social phenomena.

For instance, Wang and associates (2016) studied Chinese breast cancer patients' experience with insomnia, yet failed to include in their findings the unique cultural grounding these patients hold while experiencing mental and physical discomforts associated with living with cancer. Aside from filling gaps within cancer research, a need to factor in cultural contexts with regard to Chinese cancer patients' health information preferences and practices also drives this dissertation. By doing so, the researcher hopes that this can provide an essential groundwork for establishing a culturally grounded understanding of Chinese cancer patients' interactions with health information.

How Chinese people communicate health and interpret illness should be considered according to their cultural contexts (Cao et al., 2011; L.-M. Chen et al., 2008; Tung & Li, 2014). For instance, one of the most influential and fundamental beliefs of Chinese culture is the balance of Yin-Yang, which states that there are Yin and Yang aspects of common objects and daily phenomena. Yin-Yang is an ancient Chinese philosophy, which is often considered a philosophy of holistic, harmonic, dynamic, and dialectical characteristics (Cao et al., 2011; L.-M. Chen et al., 2008; C. Li, 2008; P. P. Li, 2008). Overall, Yin-Yang encompasses "three tenets" of duality:

> The tenet of 'holistic duality' posits that a phenomenon or entity cannot be complete unless it has two opposite elements…The tenet of 'dynamic duality' posits that opposite elements will mutually transform into each other in a process of balancing under various conditions… The tenet of 'dialectical duality' posits that the holistic and dynamic tenets can stand because two contrary (relatively contradictory) yet interdependent (relatively compatible) elements exist as opposites in unity to mutually affirm (for consistency and equilibrium) and mutually negate (for completeness and punctuated shift) ……The dialectical tenet is the most salient as the anchor for the other two tenets of duality (Li, 2008, p.416).

When an object has a more pronounced trait, the object will be considered a Yin object. For instance, though there are Yin and Yang qualities to the Sun because it is believed to have a prominent Yang feature, it is considered as a Yang object. That is, the pronounced trait is weighted more heavily than less pronounced trait, in this context, the trait of Yin compared to that of the Yang (C. Li, 2008; Wu & Tseng, 1985).

Yin and Yang are often mentioned in pairs and considered inseparable. Referred to as the unity of opposites, common pairs are the Moon (Yin) and the Sun (Yang), earth (Yin) and sky (Yang), cold food (Yin) and hot food (Yang), female (Yin) and male (Yang), and decline (Yin) and growth (Yang) (C. Li, 2008; Wu & Tseng, 1985). Chinese culture also states that the balance of Yin and Yang helps to hold the human body together and keeps it immune to pathogenic factors, such as carcinogens (Efferth, Li, Konkimalla, & Kaina, 2007; Jing Liu et al., 2017; Zhou, Yang, & Kong, 2017). This ingrained harmonious way of construing life and everyday living, the universe, and health has a significant impact on Chinese people’s conceptualization of health and interpretation of illness, as well as approaches to communicating with health information (Wu & Tseng, 1985).

Chinese patients also share a mutual cultural grounding with traditional Chinese medicine and other complementary and alternative medicines in their healthcare choices. Compared to their western counterparts, this background makes patients more susceptible to conformity, and have greater respect toward their HCPs (Cao et al., 2011; L.-M. Chen et al., 2008; Vincent C. H. Chung et al., 2014; J. Hsu, 1985). In the context of communicating health and interpreting illness, Chinese cancer patients’ cultural background might also have a pronounced impact on their interaction with HCPs. For instance, they might be more dependent on communication with HCPs due to both their respect for authority and appreciation of interpersonal communication (Hofstede, 1984; Kakai, Maskarinec, Shumay, Tatsumura, & Tasaki, 2003; Triandis, 1995).

Overall, the significance of the abovementioned cultural beliefs and behaviors to Chinese patients might seem negligible or esoteric to most western-style Chinese HCPs. Many of these HCPs are passive in initiating talks regarding patients' traditional Chinese medical treatments (Ren et al., 2015). As a result, it may further distance patients from their HCPs, since HCPs' attitudes toward patients' cultural beliefs and values concerning health and illness can play a significant role in delivering effective and beneficial communication and health outcomes (He, 2014).

For instance, research on Chinese patients' interactions with their HCPs suggests that these patients often encounter insensitive or ill-trained HCPs who seem unresponsive to their unique needs and interpretations (He, 2014; Bo Xie et al., 2015). This occurs despite many suggestions offered by scholars on the importance of taking sensitive information (e.g., feelings and emotions) into consideration while investigating cancer patients' care preferences (Higginbottom, 2006; Nanton & Dale, 2011). However, for HCPs to be attentive without being patronizing to cancer patients, it is imperative for health communication researchers to provide HCPs with a full picture regarding Chinese cancer patients' overall interaction with health information. Thus, it is important to learn about cancer patients' interactions with health information, from a patient's perspective, with consideration of their cultural values and positions.

Summary

In summary, after discussing the myriad research gaps and inconsistencies identified above, this dissertation aims to accomplish the following research goals: Identify factors that influence Chinese cancer patients’ health information preferences and practices, in light of the obstacles and facilitators Chinese cancer patients face, with a careful consideration of these patients’ cultural context.

Chapter 3: Research Design

Overall, this research will focus on tackling the main research questions mentioned above, specifically: What are the factors that shape Chinese cancer patients' health information preferences (needs and wants) and practices (health information seeking, avoiding, sharing, and accepting)?

IDENTIFY THE PHENOMENA

This section proposes grounded theory guided research that aims to label and explore the factors that influence cancer patients' health information preferences and practices – all from their personal perspectives, with careful consideration of how culture plays a part. The study is organized as follows: First is an illustration of the research purpose, study design, and the parameters of the data collection, followed by research method employed in this dissertation, and concluding with information on data analysis procedures.

PARTICIPANTS AND PROCEDURES

This study recruited Chinese cancer patients to interview for an in-depth understanding of the factors that help shape the way they interact with health information. There are eighteen Chinese cancer patients from hospitals located in Beijing, China. Overall, the selection criteria were 1) having a cancer diagnosis, 2) self-identification as Chinese, 3) being an adult 18 years and older, 4) the ability to understand and speak Mandarin, and 5) being capable of and willing to give oral consent to be interviewed and audio-taped. A semi-structured interview guide was generated based on the research objectives of this dissertation (see Appendix A).

The Chinese Medical System

Based on the ability to provide medical care, the quality of medical education, and their medical research capabilities, there are three grades for hospitals in China, Level 1, Level 2, and Level 3, with Level 3 being the most medically capable. Additional information such as level of service provision, the quality of medical equipment, etc., categorize hospitals within the same grade into three subsidiary grades: A, B, and C, with A being the most qualified of the three. This results in a total of 9 classifications. Because of their special grading levels—for example, 3AAA, Chinese hospitals are graded according to a 10-level system. Overall, Chinese people consider hospitals with a ranking of Level 3 Grade A to be the best.

One of the reasons that these hospitals have a ranking of Level 3 Grade A is that they are more trustworthy, typically due to the fact that they are nationally owned, with more qualified HCPs, and have a more transparent medical billing system compared to hospitals of lower grading statuses (Cai et al., 2017). Level 3 Grade A hospitals are often located in metropolitan areas, a result of China's imbalanced medical resource distribution. According to unofficial data[5], there are around 773 Level 3 Grade A hospitals in China,

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[5] As of May 25, 2016, yet again, the researcher called the official hotline of National Bureau of Statistics of China and confirmed that it has no available data on hospitals in China, such as detailed information on their grading status, location, admission number, etc. For those who are interested in the latest updates on the subject matter, below is the contact information of the National Bureau of Statistics of China. Email address: info@gj.stats.cn ; Phone number: (+86) 010-68783311; website: http://www.stats.gov.cn

with almost all of them located in larger cities. For instance, in Beijing there are thirty-five Level 3 Grade A hospitals to care for the 21,520,000 people living within the approximately 16,410 square kilometers of the Beijing area. Heilongjiang Province, on the other hand, spreads over 473,000 square meters and is almost 30 times the size of Beijing, yet there are only thirty-nine Level 3 Grade A hospitals available to its population of 38,330,000.

Although China has a comprehensive medical health insurance system that covers both its urban and rural citizens, when considering the available medical resources for people living in rural areas, it is safe to assume that urban Chinese and rural Chinese do not have the same access to high-quality health services and medical care (Hou & Ke, 2015; X. Liu et al., 2016). Overall, this context informs both the medical and the social background for the following interviews that are guided within grounded theory.

GROUNDED THEORY RESEARCH AND CONSTANT COMPARATIVE METHOD

Grounded theory is "an inductive, theory discovery methodology that allows the researcher to develop a theoretical account of the general features of a topic while simultaneously grounding the account in empirical observations or data" (Martin & Turner, 1986, p.141). At its core, grounded theory is an *inductive*, *interpretive*, *qualitative* research method that allows researchers to investigate social issues with great theoretical sensitivity and capability to capture the research phenomenon. Compared to when Glaser and Strauss first introduced the approach in 1967, presently there are more ways to conduct grounded theory due to the influence of a variety of paradigms including positivism (B. Glaser &

Strauss, 1967), post-positivism (Strauss & Corbin, 1998), and constructivism (Charmaz, 2006).

A paradigm is a belief system that guides actions and behaviors (Guba & Lincoln, 1989) that could be further broken down into epistemological, ontological, and methodological premises (Guba & Lincoln, 1994; Y. S. Lincoln, 1992). Epistemology could be explained as the nature and study of knowledge, ontology is the study and nature of being, and methodology concerns the process of identifying and finding out what can be known (Blaikie, 1993; Sparkes, 1992). Among these philosophical bodies, epistemology often serves as the manifestation of ontology whereas epistemology and ontology are often used to guide researcher's' methodology (Guba & Lincoln, 1994; Y. S. Lincoln, 1992).

Following the lead of Glaser and Strauss (1967), this dissertation adopts grounded theory with a positivist epistemology. A positivist epistemology respects the dynamic and diverse nature of reality with the belief that it can be captured. Furthermore, this research will adopt Glaserian grounded theory as the main guiding theory.

Grounded theory is considered an optimal research tool for understanding deep-rooted social phenomena, since "these areas raise problems of secrecy, sensitivity, taboo topics, stigma, and legality." It is useful because of the difficulty to uncover truth or obtain any reliable data without "some combination of observing what is going on, talking in a rather loose, sharing, fashion with the people in the situation, and reading some form of document that they have written" (Glaser, 1965, p.436). Under the influence of traditional Chinese culture and social norms, Chinese cancer patients may not be willing to share their private and sensitive thoughts and opinions regarding their interaction with health information via quantitative research methods such as self-administered surveys (G. M. Chen & Chung, 1994; Lu, Man, You, & LeRoy, 2015). Furthermore, health preferences and practices are socially and culturally rooted human interactions with the world (Glanz, Rimer & Viswanath, 2008); thus, using grounded theory as the research method fits the general research context of this study. Adopting a grounded theory research method is also congruent with the nature of this research (i.e., in-depth).

Grounded theory has been widely used to demystify complex phenomena (Charmaz, 2006), to tackle social issues (B. Glaser & Strauss, 1967), and to understand complicated social experiences (Charmaz, 2006; Goulding, 2002). It is known for generating novel insights (B. Glaser, 1978; B. Glaser & Strauss, 1967), specifically with its relative independence from prior knowledge (B. Glaser, 1978; B. Glaser & Strauss, 1967), and its applicability to various suitable research interests (Martin & Turner, 1986). Most importantly to this research, grounded theory is considered an efficient method in "the discovery of theory from data—systematically obtained and analyzed in social research" (Glaser & Strauss, 1967, p.1). With the help of grounded theory, theoretical understanding could be effectively gained.

Adopting grounded theory will enable the researcher to conduct a detailed investigation of complex and complicated social interactions and relationships (Denzin & Lincoln, 1998). Cancer patients' potentially dynamic and complicated interactions with their health information preferences and practices can be explored in light of the cultural factors that influence Chinese cancer patients' health information preferences and practices.

Compared to hypothetic-deductive enquiries, grounded theory research does not begin with hypotheses followed by a systematical method to discover evidence to verify them. Rather, grounded theory gives researchers a semi-structured and adaptable interview guide as well as an inquisitive, receptive, and open mind in order to build a profound and rigorous understanding of the subject matter, from the participant's perspective (B. Glaser & Strauss, 1967). Grounded theory is less prone to bias because it is a perspective-based methodology. By receiving data as they are, allowing conceptualizations to emerge from the data, researchers can capture theory as a result (B. Glaser & Strauss, 1967). The constant comparison method, a synonym for grounded theory, could further minimize research bias and ensure the integrity of the research (B. Glaser & Strauss, 1967).

Cancer research studies consider grounded theory as an appropriate and effective research method. A number of these investigations have adopted the grounded theory method to solely focus on the patient in order to gauge various cancer-related research topics, such as research with a focus on mixed diagnoses (Basinger, Wehrman, Delaney, & McAninch, 2015; Knott, Turnbull, Olver, & Winefield, 2012; Matheson et al., 2016); (Dobinson et al., 2015; McKean, Newman, & Adair, 2013; Sandsund, Pattison, Doyle, & Shaw, 2013; M. Wang, Liu, & Xue, 2017).

Overall, this dissertation considers grounded theory method as the suitable research tool, as it generates valuable understanding, bridges critical knowledge gaps, and formulates significant theoretical insights with respect to Chinese cancer patients' interaction with health information.

DATA ANALYSIS

Using guidelines based on the work of Glaser and Strauss (1967), the researcher collected and analyzed simultaneously a wide assortment of data, including audio-taped interviews, field notes, memos, theoretical memos, and demographic questionnaires. All digital recordings of the interviews were numbered, transcribed verbatim, translated, and later repeatedly analyzed using the constant comparative method. In addition, the researcher carefully and repeatedly read a hard copy of the transcript. Numbered transcripts were then coded by hand, unit by unit, case by case, category by category by the researcher, a process detailed below.

Constant Comparative Method

The method of constant comparison is a rigorous and systematic approach to analyze qualitative data, and to generalize new insights and knowledge in the form of theory. As Glaser and Strauss (1967) claim, "The constant comparative method is designed to aid the analyst … in generating a theory that is integrated, consistent, plausible, close to the data" (p. 103). According to Glaser (1992), "using the constant comparative method gets the analyst to the desired conceptual power quickly, with ease and joy. Categories emerge upon comparison and properties emerge upon more comparison. And that is all there is to it" (p. 42).

Glaser (1965) proposed four fundamental steps for conducting constant comparative analysis: 1) comparing incidents applicable to each category, 2) integrating categories and their properties, 3) delimiting the theory, and 4) writing the theory (p.439).

Though there are four distinctive procedures to the constant comparative method, they are connected to each other naturally as the research unfolds (B. Glaser, 1965).

Detailed information on the coding mechanism used in comparison analysis is crucial, especially considering that one of the characteristics of constant comparative method is its joint coding and analysis procedure. Glaser (1978) lists two general coding categories: substantive coding and theoretical coding. Substantive coding is further classified into open coding and selective coding, where both focus on producing categories and their accompanying properties (B. Glaser, 1978). This study modifies and adopts constant analysis due to its specific context in which it was conducted. An integral and modified analytical process flowchart, which starts at "Compare cases to form categories," could provide a more concrete picture of this analytical endeavor (Figure 1).

Compare Cases and Open Coding

In this study, comparing cases entailed the comparisons of 1) case to case or incident to incident in order to form categories, and 2) new incidents to already generalized categories (B. Glaser, 1978). For the second comparison, the researcher went through the data with neutral questions in mind, such as "What category does this incident indicate?" (Glaser, 1978, p.57). When making comparisons, the researcher used the coding mechanism as she examined the data, as Glaser and Strauss (1967) claimed, "The purpose of the constant comparative method of joint coding and analysis is to generate theory more systematically … by using explicit coding and analytic procedures" (p. 102).

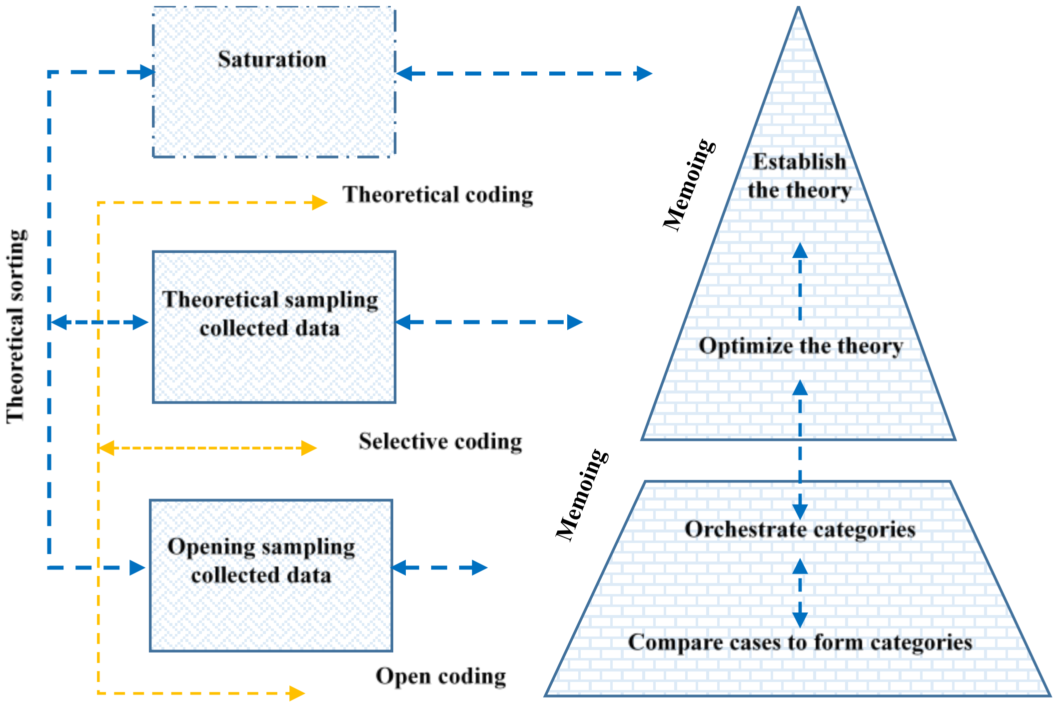

Figure 1: The Modified Constant Comparative Method Adopted in this Study

This study defines coding as "conceptualizing data by constant comparison of incident with incident, and incident with concept" (Glaser, 1992, p.38). Open coding was first adopted to analyze data in constant comparative analysis, consisting of "coding the data in every way possible" and with "running the data open" (Glaser, 1978, p.56). In the open coding process, the researcher coded the data line-by-line with as many categories as possible. Although simple, this process was considered rigorous due to the fact that line-by-line open coding analysis "carries with it verification, correction and saturation" (Glaser, 1978, p. 60).

The researcher also started her memo writing at this initial stage, where the conceptual and theoretical thoughts that emerged during the analysis were carefully and meticulously recorded for further analysis. The four basic goals of memos were: 1) to facilitate the coding process and idea development, 2) to allow theoretical reflections to emerge, 3) should be treated central to the data analysis, and 4) should have great easy-of-use in assisting analysis (B. Glaser, 1978).

Memo writing is important in that it "is designed to tap the initial freshness of the analyst's theoretical notions and to relieve the conflict in thought" (Glaser, 1965, p.440). It is "the core stage in the process of generating theory, the bedrock of theory generation" (Glaser, 1978, p.83). Similar to coding and the comparison of cases and incidents, memo writing was carried out as an iterative process. As Glaser (1965) suggested, "With clearer ideas on the emerging theory systematically recorded, the analyst then returns to the data for more coding and constant comparison" (p.440).

Together with the help of open coding and memoing, categories and theoretical properties were naturally formed. At this stage, the researcher had a fuller analytical picture in mind, in terms of "the full range of types or continua of the category, its dimensions, the conditions under which it is pronounced or minimized, its major consequences, the relation of the category to other categories, and other properties of the category" (Glaser, 1965, p.439).

At this stage of the analysis, the researcher began her theoretical sorting of data, including of the memos generated. As Glaser (1978) stated, "While ideational memos are the fund of grounded theory, the theoretical sorting of memos is the key to formulating theory… Sorting is an essential step in the grounded theory process which cannot be skipped" (p.116). The researcher then moved to the next stage of analysis when she saw a potential theory that could incorporate all of the emerging relationships.

Orchestrate Categories and Selective Coding

Integrating categories and their properties into a core theme was the second step in the constant comparison method. In this process, as analytic results and memos accumulated, the researcher's understanding of the data improved as well. Thus, the coding was continued "from the comparison of incident with incident to incident with properties of the category which results from initial comparison of incidents" (Glaser, 1965, p.440). As the research categories became integrated, they connected the dots between comparisons and made theoretical sense of the data.

Over time, as the data analysis made more sense, the researcher transformed open coding to selective coding, from "running the data" to coordinating the coding process around key categories that had been identified in the data (Glaser, 1978, 1992). This transformation paved the foundation for optimizing the theory in the following comparison stage. Theoretical coding and memoing permeated all four steps of comparative analysis and was given special attention at this stage. Thus, the process became more streamlined: organized and theorized data made the transaction between substantive coding and theoretical coding smoother and faster. As Glaser (1978) noted, "Memos serve as a means of revealing and relating by theoretically coding the properties of the substantive codes." Together with the benefits of theoretical sorting, what accumulated at this analytical stage was later transitioned and translated into the next stage with well-practiced theoretical sorting and memoing.

The researcher prepared for theoretical sampling while developing data analysis and theory formulation. Theoretical sampling is defined as “the process of data collection for generating theory where the analyst jointly collects, codes, and analyses his data and decides what data to collect next and where to find the data as the theory emerges” (Glaser, 1978, p.36). Theoretical sampling is considered to help build potential theory with more rigor and parsimony (B. Glaser & Strauss, 1967). Thus, theoretical sampling was carried out as an ongoing sampling process that ended only at theoretical saturation, or when adding new data to the analysis did not add new information or value to the analytical process. Two steps were then adopted in theoretical sampling process: 1) adding participants who share minimal differences with the current pool of participants, and 2) adding participants who share the maximum differences with current participants (B. Glaser, 1978). These steps guaranteed that the potential categories were fully examined and data saturation was reached (B. Glaser, 1978).

Optimizing the Theory and Theoretical Coding

Glaser (1965) referred to this comparison stage as “delimiting the theory”, but the researcher named this step “optimizing the theory” because the main goal of this step was to guarantee that the theory fits the data and works in the real world, while making sure the original list of categories was not redundant and the theory was parsimonious.

At this stage of comparison analysis, theoretical coding weaved the opening codes and selective codes into an integrated hypothesis and theory. Theoretical codes were generated from the "cues in the data" and could "weave the fractured story back together again" (Glaser, 1978, p.72). They were also flexible; as Glaser (1978) states, "they are not mutually exclusive, they overlap considerably [and] one family[6] can spawn another" (p.73). In his later work, Glaser (2005) further espoused the importance of theoretical coding: "The goal of a GT researcher is to develop a repertoire of as many theoretical codes as possible. The more theoretical codes the researcher learns the more he has the variability of seeing them emerge and fitting them to the theory. They empower his ability to generate theory and keep its conceptual level" (p.11).

While the researcher was switching coding mechanisms between open coding, selective coding, and theoretical coding, she was mindful of the theoretical saturation of the categories. When the coding process reached the point of theoretical saturation, or when adding new coded data to the categories did not contribute extra value to the theory or the data analysis, the researcher soldiered on to the final step of comparison analysis.

Establish the Theory

All important insights gained from data analysis were integrated, and categories and hypotheses emerged from the data while establishing the theory. Glaser (1965) emphasized the importance of memos: "To start writing one's theory, it is first necessary

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[6] Referring to theoretical families, Glaser mentions in his 1978 book *Theoretical Sensitivity*. He further added 9 theoretical families in his 1998 book *Doing Grounded Theory* and 23 one in his 2005 book *Theoretical Coding*.

to collate the memos on each category, which is easy since the memos have been written according to categories" (p.433). He also advised researchers to return to the coded data when indecisive about a potential relationship so that the researcher could begin "'pinpointing' data behind a hypothesis or gaps in the theory, and providing illustrations" (Glaser, 1965, p.443). This reevaluation further strengthened the theory's truthfulness and credibility, and applied to this study as an analysis strategy.

The most rewarding process within the context of this study was the adherence to memoing and theoretical sorting. Firstly, memoing served as an effective means to preserve the researcher's thoughts and ideas, which prompted "the probability that the theory will be well integrated and clear, since the analyst is forced to make theoretical sense of each comparison" (Glaser, 1965, p.444). Furthermore, theoretical sorting and memoing helped foster the researcher's theoretical sensitivity, which later guided her coding process and made her analysis more theoretically sound. It also boosted "the probability that the theory will be well integrated and clear, since the analyst is forced to make theoretical sense of each comparison" and further exposed "the myriad of implicit integrative possibilities in the data" to the researcher (Glaser, 1978, p.72-73). Additionally, memo writing intrinsically includes "hypotheses about connections between categories and/or their properties" (Glaser, 1978, p.84), which helped the researcher better understand emerging theory from the clustered and coded data.

The constant comparative method was an effective analytical tool in gauging the underlying phenomena and relationships between and within cancer patients' health information preferences and practices, as well as in establishing new knowledge and insights in the form of theoretical frameworks. As Glaser (1992) mentioned, “[u]sing the constant comparative method gets the analyst to the desired conceptual power quickly, with ease and joy. Categories emerge upon comparison and properties emerge upon more comparison. And that is all there is to it” (p.42). Thus, the researcher followed constant comparison through faithful immersion in the data, line-by-line coding of the data, open-mindedly letting comparisons emerge, consistently practicing theoretical sorting and memoing, and using theoretical sensitivity to let the substantive theory emerge.

With the help of the constant comparative method, the researcher was mindful of the salient themes that emerged, was able to generate understandings and interpretations, forge connections and relationships, and formulate basic social process and theoretical categories. That is, the researcher walked out of the grounded theory research with inductively generated, evidence-based, and data-grounded understandings and theoretical categories on the subject matter. The basic social process and theoretical categories that emerged from the data analysis will be presented in the following chapter.

Chapter 4: Results and Discussion

This chapter covers the key findings (i.e., descriptive information, the fundamental social process identified, theoretical categories emerged from the data analysis) in the context of prior work, implications for the literature, and directions for future research. Beginning with providing a description of the participants, this chapter presents quantifiable data on participants' demographic and socio-economic characteristics. Next, by offering theoretical findings, this chapter aims to give empirical insights on the following research questions: What are the factors that influence Chinese cancer patients' health information preferences, practices, and the relationship between them?

The basic social process identified from data analysis will be presented, followed by the theoretical categories that emerged from the data. Verbatim quotes will be provided as support for the theoretical findings. After presenting each theoretical category and its accompanying support from data, a detailed discussion of the findings in dialogue with the current literature will put the research findings into context. This chapter will finish with a discussion on the rigor of the research findings, in terms of credibility, transferability, dependability, and confirmability of the analytical results. The phrase "Chinese cancer patients" will be used to refer Chinese cancer patients interviewed in this study. This, however, does not mean that findings of this study could be generalized to all Chinese cancer patients.

PARTICIPANT PROFILES

As a measure to protect individual participants' confidentiality and privacy, the researcher did not ask for any information that could link participants' identity to their statements. Furthermore, not requiring participants to divulge their identifiable information eased their tension during audio-recorded interviews and encouraged the patients to provide more credible information to the researcher. Each participant was assigned an interview number (i.e., Participant No.1), which linked their respective statements to the data.

A demographic questionnaire was used to gather unidentifiable background information about the participants. All eighteen participants were Chinese cancer patients who all had received a definitive cancer diagnosis. The majority of them were breast cancer (N = 4, 22%), stomach cancer (N = 2, 11%), lung cancer (N = 2, 11%), thyroid cancer (N = 2, 11%), and liver cancer (N = 2, 11%). Participants aged from 30 to 72 with a mean age of 51.4 years. They were predominantly between 51 to 60 years old (N = 7, 39%), male (N =11, 61%), married (N =14, 78%), high school graduates (N = 5, 27%), non-smokers (N =10, 55%), and social drinkers (N = 9, 50%). Table 5 provides detailed demographic information.

Variable	Characteristic	N	Percent
Age	30-40	3	17%
	41-50	4	22%
	51-60	7	39%
	61-72	4	22%
Education	Graduate School	1	5%
	College	3	17%
	Some college	3	17%
	High school	5	27%
	Middle school	3	17%
	Elementary school	3	17%
Gender	Female	7	39%
	Male	11	61%
Marriage status	Married	14	78%
	Divorced	2	11%
	Single	2	11%
Cancer Type	Breast cancer	4	22%
	Stomach cancer	2	11%
	Cervix cancer	1	5%
	Ovary cancer	1	5%
	Thyroid cancer	2	11%
	Prostate cancer	1	5%
	Lung cancer	2	11%
	Kidney cancer	1	5%
	Pancreas cancer	1	5%
	Liver cancer	2	11%
	Gallbladder cancer	1	5%
Cancer Stage	Stage I	1	5%
	Stage II	1	5%
	Stage III	3	17%
	Stage IV	4	22%
	Don’t Know	9	50%
Family History of Cancer	Yes	6	33%
	No	12	67%
Time of Diagnosis	Within 6 months	5	27%
	Within 12 months	6	33%
	1-2 years	4	22%
	More than two years	3	17%
Smoking History	Yes	8	45%
	No	10	55%
Drinking History	Self-Identified Heavy drinker	7	39%
	Self-identified social drinker	9	50%
	Never drink	2	11%
Hospital	Western-styled	12	67%
	Traditional Chinese medicine styled	6	33%

Table 1: Participant Demographic Data

Breast cancer and stage IV cancer were the most common characteristics among individual participants. Although these cancer patients came from various parts of China, they were primarily residing in the Beijing area. Participants were interviewed at various top-tier hospitals (Level 3 Grade A), including hospitals focusing on western-style treatments and those centered on traditional Chinese medicine practices. As most Chinese cancer patients prefer western medicine-styled hospitals for treating their cancer, this study is based on twelve interviews (67%) in these hospitals.

A crucial part of the theoretical sampling was based on cancer patients' cancer stage. Previous literature suggests that cancer patients at different cancer stages might have varied information or communication behaviors (Dong et al., 2016; Koh, Kim, & Kim, 2015; Nyrop et al., 2016), a phenomenon this study also corroborates as interviews and constant comparative analysis unfolds. Thus, to gain a balanced view, the researcher purposefully visited wards that the nurses refer to as places where "most cancer patients are in a bad stage."

However, partially due to the nondisclosure culture Chinese oncologists hold (Gu & Cheng, 2016; Wuensch et al., 2013), most of the cancer patients in these wards who agreed to be interviewed were not informed about the stages of their cancer. Even though these patients might be in either Stage III or Stage IV, they may not be aware of the fact that their cancers are really 'bad.' This suggests that the way in which these cancer patients interact with health information might not be influenced by how their diseases are progressing. After careful consideration, the researcher decided to respect these cancer patients' answers and beliefs and category their stage information as "Don't Know".

From the data, theoretical categories emerged that represent participants' thoughts and perceptions and are presented with verbatim quotes. Direct quotations from the interview transcripts appear as excerpts (indented paragraphs), with square brackets ([ ]) and ellipses (…) to represent information added and items omitted by the researcher to clearly and succinctly highlight findings. A bracket with participant's information is featured at the end of each excerpt.

THE BASIC SOCIAL PROCESS AND THEORETICAL CATEGORIES

As the categories emerged, the researcher coded descriptive data along with field notes and memos obtained from the interviews. Theoretical categories were refined by using a constant comparative method under the framework of grounded theory as data accumulated and evolved. Based on the interview data, the researcher utilized an iterative adoption of open coding, selective coding to reflect the dynamic and multidimensional nature of the data and the analytical process. The core theoretical categories are only deemed as logical and truthful representations of the data when they include the most data.

The results from the data analysis indicate that the factors that influence cancer patients' health information preferences, practices, and the relationship between them could be best understood from the basic social process identified as *interacting with health information as a family activity*. The basic social process or the core category is defined as the central phenomenon in data. The core category should be the "main event in the data and be related to the other categories in a meaningful way" (Wahl et al., 2002, p.253). In order to let the basic social process emerges naturally, the researcher consulted the data repeatedly and extensively, with the help of the constant comparative method detailed in Glaser & Strauss (1967). The researcher realized that a quote in particular given by one participant could serve as the epitome of Chinese cancer patients' interaction with health information: "My family is helping me with everything I might need help with. Finding health information that I need is like doing a family activity." Thus, "interacting with health information is a family activity" is chosen to serve as the core category that represents the basic social process.

The theoretical categories that emerged from the data analysis that further elaborate this particular social process, while shedding light on the research question include: *getting prepared for managing cancer; prioritizing questions according to family needs; balancing truth, trust, and respect (two subcategories: nurturing the support network* and *focusing on productive interactions); navigating around information sources;* and *responding to culturally-sensitive cancer care* (see Table 2).

It is important to note that there are potential overlaps between the theoretical categories. Theoretical categories in grounded theory can overlap, as current literature suggests (Ahlqwist & Sällfors, 2012; Higbed & E. Fox, 2010; Holt & Dunn, 2004; Orford et al., 2006; Paal & Bükki, 2017; Robson-Kelly & van Nieuwerburgh, 2016; Shaibu & Wallhagen, 2002; R. Smith & Sharp, 2013). One way to explain the overlaps between categories is that the most important rule to follow in grounded theory is that categories must not be *forced* on the data, rather, researchers should let them emerge from the data analysis process as it unfolds (B. Glaser & Strauss, 1967). This means that the researchers should not be consciously forcing the data into disconnected and distinctive theoretical categories, while at the same time making sure the categories are representative of the data, or comply with the above-mentioned rule.

Interacting with health information is a family activity

- Getting prepared for managing cancer
- Prioritizing questions according to family needs
- Balancing truth, trust, and respect
- Navigating around information sources
  - Nurturing the support network
  - Focusing on productive interactions
- Responding to culturally-sensitive cancer care

Table 2. Taxonomy of Categories

GETTING PREPARED FOR MANAGING CANCER

This main category is the first factor identified in the data analysis. Getting prepared for managing cancer details how Chinese cancer patients organize their personal questions based on the way they perceive and wish to cope with their cancer. The findings indicate that Chinese cancer patients get prepared for managing cancer by developing questions and solutions to answer these inquiries. Prior to cancer diagnosis, cancer patients had relatively more stable and constant life routines, as well as priorities. The initial diagnosis changes these patients' routines and priorities to the ones that require them to constantly manage and monitor their health. This, consequently, results in the development of questions and strategies to cope with these changes. Cancer brings new realities to Chinese cancer patients on many fronts, such as treatment plans, diet reconstruction, and relationship examination. There are many blanks regarding health and cancer that Chinese cancer patients need to fill or wonder about.

> *Participant No.16 (Age 42, Female, Married)*
>
> **RESEARCHER:** Our conversation will focus on the questions you have about your health or cancer. To start, could you please share some of the questions you have about your diagnoses, regardless if you have found the answers for them?
>
> **PARTICIPANT NO.16:** I want to know how I can take better care of my body. I am constantly looking for information about what foods I should eat to improve my heath.
>
> Here it is clear that Participant No.16 has questions about cancer, and cancer's effect on her body. She searches for information and answers that could help her get prepared for managing cancer.

RESEARCHER: Have you asked these questions to your doctor?

PARTICIPANT NO.16: Yes. But she only gave me a general overview in terms of things I should and should not eat.

RESEARCHER: Have you turned to other information sources to answer your questions?

PARTICIPANT NO.16: Yes. I searched for information online and asked other cancer patients about foods they eat to improve their health.

RESEARCHER: What about your family members?

PARTICIPANT NO.16: Yes. They help me find answers as well.

RESEARCHER: But they did not help you answer your question?

PARTICIPANT NO.16: No. I do not think they have experience in answering these types of questions.

RESEARCHER: What do you mean?

PARTICIPANT NO.16: What they know about cancer comes from me. They do not know much about cancer.

……

Participant No.6 (Age 30, Female, Single)

RESEARCHER: Our conversation will focus on the questions you have concerning your health or cancer. Could you please share some of the questions you have in relation to your health or cancer?

PARTICIPANT NO.6: Questions I already have answers to?

RESEARCHER: Both your answered and unanswered questions.

PARTICIPANT NO.6: I did not know there was a different medicine that would not make me bald. When I was talking to other patients the other day, they told me that [information]. Now I want to know more about that medicine. I was told it was expensive and it was not covered by my health insurance. I am not sure if it is possible for me to get it from drug stores or from other places. I need to find out more information about this.

RESEARCHER: How do you plan to find more information?

PARTICIPANT NO.6: By asking around.

RESEARCHER: Could you please elaborate?

PARTICIPANT NO.6: Ask my doctor, other cancer patients, search for it on the internet, you know, ask around.

RESEARCHER: Who told you this drug is expensive?

PARTICIPANT NO.6: The cancer patients who I know use the drug.

RESEARCHER: Do you often exchange information with other cancer patients?

PARTICIPANT NO.6: Yes. I talk to them all the time. They know a lot of things that I do not know. I like to talk to them to find out the answers to things that I am not familiar with.

RESEARCHER: Do you also share information you know with them?

PARTICIPANT NO.6: Yes. But I only recently got diagnosed with cancer. I do not think sharing what I know is worthwhile for them. We do share information about our treatments and information about our doctors. I think the things that I know may be helpful to other cancer patients.

It is important to understand that Chinese cancer patients treat the endeavor of arming themselves with questions or answers to handle the impact of cancer as a family activity. Rather than self-managing and preparing for what cancer brings with concrete questions and solutions, interacting with health information is often orchestrated as a family-management of and preparation for cancer. Most of the cancer patients interviewed considered their family members as the most important allies in their cancer care, especially when it comes to deciding which questions to ask and how these questions should be formulated. Overall, family consistently plays a role in Chinese cancer patients' preparation for managing cancer. This seems to be particularly true to those who are female and married.

Participant No.9 (Age 51, Male, Married)

RESEARCHER: What are the things you found out that could help you to improve your health?

PARTICIPANT NO.9: Stop drinking and smoking. Do not go to out to eat at restaurants, eat less red meat, eat more vegetables and fruits, have a more balanced diet, things like that.

RESEARCHER: How did you find out about these useful tips?

PARTICIPANT NO.9: I asked my doctor and many of my friends. Some of my former classmates are doctors. When I received my diagnosis, I immediately contacted them. They offered me a lot of useful information.

RESEARCHER: What about your family?

PARTICIPANT NO.9: Yes. We talked to some of my classmates and other friends together.

RESEARCHER: By "we," who do you mean?

PARTICIPANT NO.9: Mainly my wife and I. It really depends who is in the house when my friends come to visit me. But my wife and I are the ones who made the decisions.

Here it is clear that Participant No. 9 is depending on his entire family to make decisions regarding his cancer. Below he further explains why his family's involvement in cancer care and management is an integral part to his cancer experience.

RESEARCHER: How well do you think your wife understands the questions and concerns that you have on your health or cancer?

PARTICIPANT NO.9: Very well. Very well. She knows about everything.

RESEARCHER: Why is that?

PARTICIPANT NO.9: [smiles] You ask me why? Well, we live together and we talk.

RESEARCHER: How are these conversations with your wife different from other conversations with other family members?

PARTICIPANT NO.9: There is no difference. I think if there is a difference, it would be that conversations about cancer are a constant subject in our family.

RESEARCHER: Why is that?

PARTICIPANT NO.9: Because they are not like conversations we have about my child's job, which we have stopped talking about when he found one.

RESEARCHER: Does your cancer have an impact on your family?

PARTICIPANT NO.9: That is for sure. My cancer is the big thing that is happening in our family.

RESEARCHER: Do you think how your family is reacting to your cancer is unique to your family? Or do you think it is something that other cancer patients are experiencing as well?

PARTICIPANT NO.9: It is unique to our family. My wife and I do not fight like other couples. But I think even for the families that do not have a cordial atmosphere, cancer would be something that they talk about. At least something that they fight about.

RESEARCHER: It seems that you are talking about this from your experience?

PARTICIPANT NO.9: Yes. I have seen families with cancer fight.

RESEARCHER: Do you consider your health status as something that has an impact to your other family members?

PARTICIPANT NO.9: Not so much. Maybe my siblings, as what is happening to me might happen to them later. But we don't talk as much (as I do with my core family members).

Understanding "Getting Prepared for Managing Cancer" in Context

Findings of this study suggest that cancer patients interact with health information as a way to prepare themselves to manage the disease. Chinese cancer patients wish to have better control over their cancer care and management, indicating that there is a wide spectrum of potential after-diagnosis realities that they want to get prepared for. These realities concern their prognoses, treatments, physical and psychological well-being, as well as their daily functioning, such as requiring detailed care and management information and involvement of their family members.

Results of this dissertation enrich the current literature by revealing the role of "getting prepared for managing cancer care" in shaping Chinese cancer patients' health information preferences, practices, and the relationship between them. Additionally, this study shows that rather than self-managing cancer, Chinese cancer patients' interaction with health information is often carried out as a family activity, or as *family-management of cancer*. Family-management involves Chinese cancer patients' cancer care activities, especially in their interaction with health information, and which is often carried out with some or all family members involved in the care process. What patients typically consider individual activities, such as information seeking exercises by cancer patients themselves, are often carried out in the family unit.

There is a body of evidence that indirectly supports the role of managing cancer in spurring patients' health information activities (Beeken, Williams, Wardle, & Croker, 2016; Fuchs et al., 2017; Robinson et al., 2016), including studies conducted in the Chinese context (Bo Xie et al., 2015, 2016). However, the majority of these studies are cross-sectional, meaning that they identify phenomena rather than explain deep-rooted relationships. For instance, though a harbinger in investigating Chinese cancer patients' health information preferences, Xie and associates' studies (2015, 2016) only address the types of information cancer patients wants, that is, only the phenomenon of information preference and practices, not "why" this phenomenon is present, or the rationales underlying these patients' information activities.

In a recently published study, researchers use qualitative methods to investigate the differences between Chinese breast cancer patients and their HCPs in their assessment of patients’ needs (C. Wei, Nengliang, Yan, Qiong, & Yuan, 2017). This study found that of four need themes that emerged, information/knowledge, communication, social support, and symptom management, Chinese breast patients and HCPs only agreed on their assessments of symptom management need (C. Wei et al., 2017). Although the research in this dissertation is similar to the research by Xie and associates (2015, 2016), the findings of the latter study do not answer the same research questions that are raised in this dissertation. Furthermore, it does not acknowledge the indispensable role family plays in Chinese cancer patients’ health information activities.

Family could be understood as “a social unit or a system is comprised of two or more people who live together and are related by blood, marriage, or adoption” (Fan , Zhang, & Wang 2017, p.130). Different from western family structures, Chinese adult cancer patients often live with their family members (Fan et al., 2017), which makes it possible for them to have close and frequent conversations about their health. This holds especially true for elderly Chinese cancer patients(A. H. Y. Ho et al., 2013), as senior Chinese people are often taken care of by their adult children or even their grandchildren (Jinyu Liu & Bern-Klug, 2015; Luo & Chui, 2016). Other than physical prerequisites that make “interacting with health information is a family activity” possible, there are many sociocultural factors that pave the way for family-management of cancer.

The role of family in shaping Chinese patients’ information activities can be further understood from two perspectives: 1) the important and indispensable family structure that is deep-rooted in traditional Chinese culture, which calls for family involvement in healthcare (Cao et al., 2011; H. H. Hu, Li, & Arao, 2015); 2) the health inequalities and the scarcity of physicians that Chinese patients face (e.g., China's doctor–patient ratio is problematic: 1.4 per 1,000 patients) ("Data: Physicians (per 1,000 people)," 2012; Sharma & Unnikrishnan, 2013) make help and support gained from family caregivers indispensable to cancer patients. The difficulties Chinese patients face in accessing and affording healthcare services, especially those that their needs require (H. Chen, Komaromy, & Valentine, 2014), further underscore the role of family caregivers.

Family caregivers are family members who are "most knowledgeable about the patient's health status and most involved in their care" (Phipps et al., 2003, p.551). Overall, these factors contribute to family members' involvement in Chinese cancer patients' cancer care, which could shed light on why family members are pivotal in assisting Chinese cancer patients' access to care and why Chinese cancer patients' cancer care is often carried out in the form of family-management of care.

Previous literature rarely investigates the role of family members' involvement in Chinese cancer patients' care. In a study on Chinese older people with advanced cancer, researchers find that family members constituted these patients' main support system (H. Chen et al., 2014). In this particular study, which centers on investigating the meaning of hope to Chinese cancer patients, the researchers find that against the unfavorable medical environment, "interpersonal connectedness" gained from patients' social support is key to understanding older Chinese cancer patients' cancer coping mechanism (H. Chen et al., 2014). Overall, a number of studies have also revealed that family members are important information sources for Chinese cancer patients (C. W. Chan, Hon, Chien, & Lopez, 2004; Bo Xie et al., 2015). However, most of these studies are cross-sectional. Also, the role of family in Chinese cancer patients' information activities is often not the center of these investigations, which means that only limited insights could be gained from these studies.

Overall, no in-depth studies exist that address the indispensable role that the family plays to Chinese cancer patients in their interaction with health information. This void suggests that findings from this study could bridge this research gap and provide understanding that could help healthcare professionals acknowledge and address the role of family members in Chinese cancer patients' health communication process. It is important to understand that failing to involve patients' family members in their interaction with health information might be detrimental to these patients and their family members' satisfaction with communication and quality of life. As research suggests, cancer patients' quality of life is closely associated with that of their family members (C. W. Chan et al., 2004; You & Lu, 2014; H. Yu et al., 2017). Also, not involving family members in the patient-provider communication process might harm these informal caregivers' quality of life (Q. Li et al., 2016). For Chinese cancer patients, especially the elderly who are dependent on their adult children (W. Chen et al., 2016), their quality of life may be negatively impacted by the poor quality of life of their family members and by the lack of involvement of their family members in their interactions with their HCPs.

Considering that Chinese cancer patients' health information activities interactions are often carried out as a family activity, one possible solution to help these patients better get prepared for managing cancer is via involving and integrating patients' family members in their information activities (Hei et al., 2016; Lo, Wong, Wong, Wong, & Yeung, 2016; Ran, Chan, Ng, Guo, & Xiang, 2015). This is a possible solution that scholars have been advocating for within the context of cancer research (Cao et al., 2011; You & Lu, 2014). However, limited evidence-based insights are available to support the feasibility and effectiveness of the integration of family members in patients' healthcare process. Still, research on other health conditions and their relation to the family's involvement in patients' healthcare might shed some light on the subject matter.

Overall, research conducted in other disease contexts suggests that family involvement in patients' care is beneficial to their health outcomes and quality of life. For instance, using psychoeducational family intervention for Chinese patients with schizophrenia, researchers found that compared with the control group (without family members' involvement in the education program), the intervention group had significantly better medication outcomes and working abilities (Ran et al., 2015). In another investigation, researchers examined the role of family relations on the well-being of people living with HIV (Y. J. Yu, Li, Qiao, & Zhou, 2016). In this study, family members played a pivotal part in shaping and sustaining social bonds of people living with HIV, especially in the face of stigmatization (Y. J. Yu et al., 2016).

Additionally, a number of ongoing randomized controlled trials might further shed light on the role of integrating family members in patient care (Hei et al., 2016; Lo et al., 2016; Tsoh et al., 2015). Although studies with available results conducted in various disease contexts have offered some empirical evidence on the benefits of including family members in patients' healthcare, whether these insights could be directly applied to the Chinese cancer care context, and particularly to Chinese cancer patients' interactions with health information, still needs the support of empirical evidence.

Additionally, when the discussion centers on the family, current interventions often involve only two parties: patients and family members (Ran et al., 2015; Y. J. Yu et al., 2016). This leaves out HCPs, an important party in patients' communication mechanisms. Overall, most of the current research on improving cancer patients' communication satisfaction either excludes patients' family members (e.g., Easley et al., 2016) or HCPs (e.g., Han et al., 2014). Furthermore, research that discusses the importance of the patient-family-provider communication triad in facilitating better communication outcomes is often confined within western contexts (R. Laidsaar-Powell et al., 2016; R. Laidsaar-Powell, Butow, Bu, Fisher, & Juraskova, 2017; R. C. Laidsaar-Powell et al., 2013). For example, researchers found that HCPs rarely initiate conversations with Australian cancer patients' family members, despite the fact that a third of these family members have three or more patient-family-provider communicational roles (i.e., history taking, information exchange, decision-making, and logistics) (R. Laidsaar-Powell et al., 2016).

Researchers also identified various characteristics of family involvement in consultations, including variability of roles, supportive presence, emotional support, patient advocate, informational support, measures of checking patient accuracy, practical support, and family liaison (R. Laidsaar-Powell et al., 2017). This particular study further suggests that HCPs welcome family members' participation in consultations (R. Laidsaar-Powell et al., 2017). However, these findings fail to address the important role family members play in cancer patients' everyday information activities. Furthermore, despite the valuable insights these findings could provide, they cannot be directly applied to the Chinese cancer research context. While many phenomena concerning cancer patients' information activities have been identified, there is a void of evidence-based research on understanding *how* to better integrate family members in formal consultations or patients' everyday interactions with health information from a connected view.

As findings of this study suggest, family involvement in the communication process comprises a central part of Chinese cancer patients' information activities. It is only practical to develop health interventions that involve all major shareholders in patient communication, both patients, their family members, and HCPs. This calls for evidence-based research in understanding the effect of integrating Chinese cancer patients' family members in patients' cancer care and communication activities through patient-family-provider communication modes or other productive mechanisms. For instance, a randomized controlled trial comparing the effectiveness of patient-family-provider communication with that of patient-family communication or patient-provider communication might be a possible research direction. The insights gained may serve as the potential solutions to better assist Chinese cancer patients' interactions with health information and generate positive (health) outcomes among all communication shareholders (i.e., patients, family members, HCPs).

PRIORITIZING QUESTIONS ACCORDING TO FAMILY NEEDS

Prioritizing questions according to family indicates that Chinese cancer patients center their questions determining their cancer care and health management on what they believe is most pertinent to their family's well-being and quality of life. The majority of Chinese cancer patients talked about the importance of addressing the interests of the entire family in framing questions and findings answers for their health-related concerns. The family-centeredness of Chinese cancer patients' consideration of which question to ask, how to ask these questions, and who to ask these questions are important for these patients' interaction with health information. When asked how they categorize their questions and their solutions to these questions, participants refer to the important role their family plays in shaping how they manage their cancer-related activities, and more importantly, how their families are at the center of their cancer-related concerns. Most cancer patients live with their family members, including their adult children, which makes it easier for them to involve their family members in deciding how to best interact with information.

> *Participant No.3 (Age 47, Male, Married)*
>
> **RESEARCHER:** Could you tell me how you determine which questions are more pertinent and that you need to solve in a timely manner, whereas what other questions you give a more flexible timeline to address?
>
> You mentioned the questions you have concerning your daily activities are really important. I assume there are other factors or considerations that influence your consideration what questions to solve first?
>
> **PARTICIPANT NO.3:** Yes, you are right in assuming that. I think I might have to rephrase what I said. It is the things that influence not just my daily activities, but my whole family's daily activities which are the most important factor that determines how quickly I wish a question to be addressed.
>
> **RESEARCHER:** Could you please give me a concrete example?
>
> **PARTICIPANT NO.3:** I am not sure how many interviews you have done by now. But at some point, you would understand that cancer is something that takes an entire family to deal with.

Take my cancer for example. Treating it would use money that would be otherwise used on other things, like buying my son an apartment for his marriage. My cancer treatments will cost my family a fortune to the extent that my whole family would have to deal with its financial consequences.

And it does not stop at here. My family members, those who know I have cancer, would have to deal the fact that I am no longer a healthy person. Some of the things my wife does these days, like changing light bulbs, used to be my responsibilities.

It is not that I cannot do these chores that I used to do. It is because they think of me differently, as a cancer patient not a healthy man. It really makes feel bad to see her do the things that she used to simply assign me to do.

And worst of all, it is possible that one day she would have to tell her grandchildren that their grandpa died from cancer before they were born. These thoughts about dying and leaving my family mourning about my death are really poisonous.

I was only able to get over it after I shared what I was thinking with my brother. He really has helped me get out of my own head. It really takes the whole family to deal with cancer. It is only right for me to arrange my questions in consideration of their needs. Sometimes it feels like that they are the ones who are more in need of answers.

Here it is clear that Participant No.3 considers the need of his family as an important factor in his interacting with information and managing of cancer. In a different part of the conversation, he further explained how his family impacts his interaction with information.

RESEARCHER: That is really insightful. This explains why your wife had a list of questions and you asked your doctor all of questions on the list. [smiles]

PARTICIPANT NO.3: Yes, exactly. [smiles]

……

RESEARCHER: Do you share what you have learned from these volunteers with your family members?

PARTICIPANT NO.3: Yes, as I said, I share everything I know about my cancer treatments with my brother and my wife. But only them. I share what I know with them, because they would get really worried knowing there are things I know that I have not shared with them. I made it a rule to share what I know with them whenever possible.

RESEARCHER: They are really interested in everything that's happening to your health?

PARTICIPANT NO.3: I think they know more than me. [smiles]

Here it is clear that Participant No.3 is thinking carefully about the needs of his family members when deciding which question to ask to his doctor. Below Participant No.3 further explains why his family is important in his information activities.

RESEARCHER: Sounds like they are your cheerleaders? [smiles]

PARTICIPANT NO.3: I think they are more like my bosses. [smiles] There were times when my wife wasn't able to accompany with my doctor's appointment, she wrote me a list of questions that she wanted me to ask my doctor.

RESEARCHER: Did you ask your doctor those questions?

PARTICIPANT NO.3: Yes, I did, for peace of mind. [smiles] Otherwise she would be constantly bugging me for answers. It's better that she got her answers.

RESEARCHER: Sounds like your wife is really taking a part in understanding your health and treatments?

PARTICIPANT NO.3: Yes. I'm really glad I have her at my side, and my brother. I wouldn't have the leisure to still enjoy life if it won't for them. They helped me with many things.

RESEARCHER: What do you mean by ‘the leisure to still enjoy life’?

PARTICIPANT NO.3: I think they make things easier. It’s almost like the story about 3 monks (三个和尚的故事). I think I might choose to not get any water for myself if I were the only one dealing with all these. But because my wife and my brother have been helping me and pushing me to do the things I have to do, I get to drink water.

……

Participant No.4 (Age 58, Male, Married)

RESEARCHER: Do you consider your family as a source of information for you?

PARTICIPANT NO.4: Yes, of course.

RESEARCHER: Could you please elaborate?

PARTICIPANT NO.4: We talk about things we want to know.

RESEARCHER: You said “we” when you are talking about your thoughts on what questions to ask?

PARTICIPANT NO.4: Yes. Whenever there is something that is necessary to know, it’s usually because it’s something that’s important to me, which means that it’s important to my family as well.

There are also times when my wife and my children believe that it’s more important to know something. Like a lot of families, we do things usually as a family, which makes things easier.

Here it is clear that Participant No.4 make decisions regarding what questions to ask and how to interact with health information in the unit of the family. Below, the participant further elaborates his way of integrating family members in decision making.

RESEARCHER: What do you mean by “easier”?

PARTICIPANT NO.4: More people means more strength (人多力量大).

RESEARCHER: Could you share an example with me where finding an answer has been made easier because family endeavors have been invested?

PARTICIPANT NO.4: I’ve been drinking *Ling Zhi* (灵芝) daily. We thought it might be better if we could buy it directly from the sellers to make sure what we have are wild *Ling Zhi*. You know, wild *Ling Zhi* is more potent.

Also, buying in bulk could also save some money. We contacted almost all of relatives and asked them to see if they know where we could get our hands to wild *Ling Zhi* in a large amount. One of the rural relatives on my wife’s side was the one who helped us. I didn’t even know I had this relative. [smiles]

Things were made easier because my family members were there helping me.

RESEARCHER: There must be many cases like this?

PARTICIPANT NO.4: Exactly. That’s why I say it’s easier.

Chinese cancer patients and their family members constantly talk about questions and solutions to their health-related questions. When Chinese cancer patients and their family members go to doctor’s appointments together, how these patients prioritize which questions to address often has direct influence from their family members. This might be especially true for senior cancer patients, as most of them are dependent upon their adult children in taking care their affairs regarding cancer, especially things related to health information (e.g., searching for information online). Also, as indicated in the findings, not only blood relations, but also relatives forged via marriages and close friends are very influential in shaping how well cancer patients execute their behaviors with regard to health information. How cancer patients could respond to their cancer-related concerns, as well as how they translate these concerns into concrete questions and later find relevant answers are often contingent upon the degree to which their family members or friends are involved in their cancer care. In addition to being providers of social support, having family members of friends as their champions in cancer care bears a unique meaning to Chinese cancer patients.

> *Participant No.15 (Age 63, Male, Married)*
>
> **PARTICIPANT NO.15:** I also want to know what causes my cancer. I know something I inherited from my parents might be the reason. But not all my siblings have cancer.
>
> **RESEARCHER:** Why do you want to know this?
>
> **PARTICIPANT NO.15:** It will help my son in preventing cancer.
>
> **RESEARCHER:** This is another question you have about your family member, rather than yourself. Do you have many questions about how your cancer might influence your family member's health or well-being?
>
> **PARTICIPANT NO.15:** Yes.
>
> **RESEARCHER:** Do you have questions about your wife and your siblings?
>
> **PARTICIPANT NO.15:** Yes. I worry that they might have cancer as well.
>
> **RESEARCHER:** What do you do about these worries?

PARTICIPANT NO.15: What do you mean?

RESEARCHER: Do you actively seek answers for these questions, like asking your doctor, looking it up on the Internet, etc.?

PARTICIPANT NO.15: Yes.

RESEARCHER: Could you elaborate on how you actively seek answers for these questions?

PARTICIPANT NO.15: I'm old. I think what considered as active health information seeking for me might different from younger people, with smartphones and the internet, things like that. But I still do my best to absorb as much information as I can.

There is no such thing as bad information or good information. There is only information you paid attention to and information you didn't care about.

I also believe being active in this [cancer care] could help me with my spirit. It's almost like exercise. It's an information exercise. I think the exercise itself counts.

RESEARCHER: What do you mean by 'absorb as much information as I can'?

PARTICIPANT NO.15: I have a notebook where I make notes of what I learned from the TV and the newspaper. I want to find as much information as I can about what might cause cancer and how to prevent cancer.

RESEARCHER: What might cause cancer and how to prevent cancer? You are looking for information for your family members?

PARTICIPANT NO.15: Yes.

RESEARCHER: Why not looking for information for yourself?

PARTICIPANT NO.15: My doctor would help me understand questions I have regarding my cancer. I don't need to know more than that as knowing too much will not change the fact that I have cancer. But learning more things about how to prevent cancer would help my family members from developing cancer.

RESEARCHER: You share what you found on how to prevent cancer with your family members?

PARTICIPANT NO.15: Yes.

RESEARCHER: Could you describe to me how?

PARTICIPANT NO.15: I talk to them about the recent news I read or things I learned about cancer prevention.

RESEARCHER: Do you also share your notebook with family members?

PARTICIPANT NO.15: No. My notebook is for me. It's not well-organized. I wouldn't share it with other people.

RESEARCHER: How does knowing new information on cancer prevention make you feel?

PARTICIPANT NO.15: It makes me feel happy because it means I know something that is helpful to my family.

Understanding "Prioritizing Questions According to Family Needs" in Context

A key finding within this dissertation is how Chinese cancer patients prioritize their health information preferences and practices based not only their individual needs, but also the needs of their family. The family does not only influence how Chinese cancer patients prepared for managing cancer by answering their questions about cancer care, but also influences the way these patients construct and organize their questions. Rather than being interested in questions and answers that are related to patients' individual well-being, Chinese cancer patients' questions about their cancer care or health conditions often concern the overall well-being and quality of life of their family. Though the important role of family on these patients' information preferences and activities are well discussed (e.g., Cao et al., 2011), this finding provides a new perspective on Chinese cancer patients' interaction with health information.

What makes this conclusion novel is that it addresses how Chinese cancer patients actively form their information preferences and practices based on their family needs. Differentiated from the broad concept of shared decision-making that involves family members, Chinese cancer patients' "prioritizing questions according to family needs" may not be a result of their family members' joint decision-making or direct input. As these discoveries suggest, Chinese cancer patients independently decide to put the needs of their families at the center of their information activities and prioritize their questions according to what these patients think might influence or interest their family members the most.

Results of this study indicate that although cancer patients have varied perceptions and prioritize their information preferences differently, they consider the needs of their family as the most important aspect of their health information activities. Not only does this finding add to the literature; it also can be understood within the context of role theory. Families, rather than individuals, are the basic social units in the Chinese society (Cao et al., 2011; J. Hsu, 1985; Simpson, 2005). Not only is the role of family more important to Chinese people, compared to those from other cultural backgrounds (J. Hsu, 1985), Chinese people are more vulnerable to and prone to avoiding interpersonal conflicts as well (G. Lai, 1995). For Chinese cancer patients, family support provides not only social support, but also an integral and indispensable part of their cancer care and health management (Mu et al., 2015). Findings of this study add new insights to the literature concerning the indispensable role of family in shaping cancer patients' health information activities, which may or may not involve patients' family members' knowledge.

According to role theory, individuals hold various social positions simultaneously, and, in turn, various sets of responsibilities and duties (Biddle, 1986). Cancer patients they also undertake the additional role of being sick (Haigh, 1993; Hirschman, 2001; Kasl & Cobb, 1966; Parsons, 1951), which further complicates their prioritization of information and health. Researchers studying role theory also suggest that family comprises an important pillar in people's lives (Phan, Banerjee, Deacon, & Taraky, 2015; Rossetto & Tollison, 2017). Together, this might further explain why Chinese cancer patients place their family needs at the center of their health information preferences and practices. Findings of this study add to the current literature by suggesting that Chinese cancer patients voluntarily decide whether to include their family's interest at the center of forming their health information preferences. In addition, studies on family-centered care may further help put these conclusions into context. One aspect in which this study recognizes the role of the family in Chinese patients' informational practices is within family-centered care (e.g., in the context of Chinese adult intensive care patients) (W.-L. Wang, Feng, Wang, & Chen, 2016).

Family-centered care is defined as "an innovative approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care patients, families, and providers" (Mitchell, Chaboyer, Burmeister, &

Foster, 2009, p.544). Family-centered care becomes essential in that similar to cancer patients, family caregivers experience stress and burden as well (Cui, Song, Zhou, Meng, & Zhao, 2014; Q. Li & Loke, 2014). This stress on the entire family could be alleviated by involving both patients and their family members at the center of cancer education (Ballard-Reisch & Letner; Michael, O'Callaghan, Baird, Hiscock, & Clayton, 2014). Also, the fact that information discrepancies between patients and their family members may cause harm (e.g., anxiety) to patients' cancer management (W. C. H. Chan, 2011; W. C. H. Chan, Epstein, Reese, & Chan, 2009) could be solved by forming constructive communication mechanisms between patients, family members, and HCPs. Finally, family members are key caregivers to patients who also serve as a great source of support for these patients (e.g., information) (Tao, Songwathana, Isaramalai, & Wang, 2016).

Current literature has repeatedly acknowledged the role of family-centered care in facilitating cancer patients' daily activities (e.g., Grant, Sangha, Lister, & Wiseman, 2016) However, rather than within the context of cancer care, the majority of these studies addressing the importance of family-centered care are conducted in other disease contexts (Duncan et al., 2016; Kogan et al., 2016; W.-L. Wang et al., 2016). Furthermore, research that could explain cancer patients' need for family-centered care often focuses on children who have cancer, especially within western societies (Branowicki, Vessey, Temple, & Lulloff, 2015; Engvall et al., 2016; Landier et al., 2016). The paucity of research on the role of family-centered care in the Chinese cancer context has made it unclear how family-centered care could be best tailored to serve Chinese cancer patients' health information preferences and practices.

Overall, there is little data to support evidence-based health communication practices and interventions that focus on patient-family education in the context of Chinese cancer patients. Considering the cultural uniqueness of Chinese cancer patients, (Han et al., 2014) this gap of understanding needs to be studied in future research. Different from cancer patients in western societies, Chinese cancer patients have unique health perceptions and practices in the way that they interact with family members during their healthcare process (Cao et al., 2011; Leng et al., 2014). This calls for research on patient-family-provider communication interventions in the context of cancer care.

This line of inquiry could shed light on whether having these three stakeholders involved in cancer care (e.g., patient-family-provider communication) might yield more positive outcomes. Future research that wishes to study cancer patients of different sociocultural backgrounds should also pay attention to the potential cross-cultural differences among these patients, as these differences might be critical factors that influence cancer patients' information behaviors. For instance, Kayser and associates (2014) studied the cultural differences between couples coping with breast cancer from China, India, and the United States and found that the three differed regarding family boundaries, gender roles, personal control, and interdependence.

BALANCING TRUST, TRUTH, AND RESPECT

How Chinese cancer patients form and pursue their health-related questions and information activities is deeply influenced by balancing trust, truth, and respect. Balancing truth, trust, and respect means that when deciding how, whether, or whom to ask a question, Chinese cancer patients usually negotiate between the desired degree of truthful information exchange, trust they assign to different sources of information, and respect they give to these sources. This is done to maintain a balanced and harmonious relationship with these information sources.

For Chinese cancer patients, having a good balance of what they wish to know, what they consider as reliable answers, and how they should react to different sources of information (i.e., HCPs) in gaining potential answers for their questions is vital to their interactions with health information. For instance, though cancer patients' relatives might lack expertise and sophistication in the suggestions they share with these patients, their good intentions might still be well-received by the patients. As results of this dissertation suggest, it is unlikely that Chinese cancer patients would point out the mistakes in these suggestions because of their need to balance truth, trust, and respect in this particular information activity.

Being socially appropriate in finding answers to their questions is an important social norm that Chinese cancer patients are bound by. Building a harmonious balance between reliable answers, trust toward the information source, and corresponding respect to the source of information serves as a foundation for Chinese cancer patients' subsequent information activities. Before they embark on more in-depth information activities, cancer patients need to have a clear understanding of what is the truthful answer, whether the dispositions of their information sources make them trustworthy, and how much respect needs to be emphasized in the communication process, based on the unique temperament of their HCPs.

Participant No.8 (Age 60, Female, Divorced)

RESEARCHER: Do you do everything you children advise you to do?

PARTICIPANT NO.8: Yes. They went to college and know more about things. Their brain runs faster than my brain as well.

RESEARCHER: You trust them as important information sources?

PARTICIPANT NO.8: I trust them with my life. They are the ones who are going to sign all sort of forms for me at the end of the day.

RESEARCHER: What about your other family members, distant relatives, or your friends? Do you always follow their advice?

PARTICIPANT NO.8: No. They are not all well-educated as my doctor or my children, and some of things they share with me might be gossip that have no foundations. You can't believe in everything people tell you. That's why I always check what I learned from them with my doctor.

RESEARCHER: But you trust their good intentions?

PARTICIPANT NO.8: Yes. They care about my health and wish to help.

RESEARCHER: People have many ways to deliver their good will. Do you think they might hide things from you when there is bad news?

PARTICIPANT NO.8: You mean if my family would hide things from me to protect me?

RESEARCHER: Yes.

PARTICIPANT NO.8: Yes. I think they would do everything to protect me. Just like why I don't want to ask my children to do a full body check-up right now.

RESEARCHER: Are you comfortable with this? Having your family member hide information from you and you not being aware of the things that you might otherwise know?

PARTICIPANT NO.8: All the decisions I made so far in relation to my cancer are made together with my family. Whether it's about which hospital to go, which doctor to consult with, which traditional Chinese medicine herb to take, and how to balance my diet.

Even before cancer, whenever I'm sick, or any of my family member is sick, it would be a family endeavor to help the sick family member back to health as soon as possible. If they decide there is something that I would be better not knowing, then that's some information I don't necessarily want to know.

Here it is clear that Participant No.8 is comfortable knowing her family members might hide things from her. Below she offered more explanations regarding her attitude toward balancing information.

RESEARCHER: You seem like you have more to add?

PARTICIPANT NO.8: Yes. Everybody has questions. Not all questions need to be answered. If it's necessary for me to know, my doctor would tell me sooner or later, if he hadn't already done so.

There is no need for me to know too much information. Knowing too much will do me no good. It will only confuse my head. In addition, there are too many false statements and lies when it comes to anything cancer-related. I simply listen to my doctor.

RESEARCHER: And you think if the information your family hides from you is important enough, you would get that information from your doctor eventually?

PARTICIPANT NO.8: Exactly! I mean doctors have responsibilities, right? Otherwise they would end up in trouble.

For some Chinese cancer patients, being able to maintain a balance between the diagnosis and solutions to cancer is crucial to their daily functioning. While cancer patients are in the process of answering their questions, they interact with themselves as the seekers of information and people with whom they are having conversations, such as family members, friends, general acquaintances, doctors, and other cancer patients. While Chinese cancer patients indicate that they want to answer their questions, they react to the answers they gained not only based on their truthfulness, but also on other merits such as the reliability and trustworthiness of the information sources and the respect they should give to the information sources in the process of answering their questions. Cancer patients might not disclose their true feelings toward the potential answers or act upon the knowledge gained if they believe that not addressing these answers or this knowledge might be more productive for them.

Participant No.18 (Age 60, Male, Married)

RESEARCHER: Have you shared your diagnosis with people you know?

PARTICIPANT NO.18: I didn’t tell my friends that I had cancer. I don’t want to hear their opinions about my cancer at all. I don’t want their pity. I don’t want to be a subject people talked about during or after dinner. So only my family knows that I have cancer.

RESEARCHER: When you say “people,” who are you referring to?

PARTICIPANT NO.18: Some of my friends.

RESEARCHER: So only your family members, cancer patients you know, and your doctor know about your cancer?

PARTICIPANT NO.18: Yes.

RESEARCHER: How does knowing that some of your friends don't know about your diagnosis make you feel?

PARTICIPANT NO.18: It makes me feel even (打平了).

RESEARCHER: What do you mean by "even"?

PARTICIPANT NO.18: They don't share bad news with me either. They always brag about things, show off this and that.

RESEARCHER: So it's possible that some of them may have cancer as well but they didn't share this news with you?

PARTICIPANT NO.18: Exactly. For all I know, they might have cancer as well. It only makes sense that I don't share my things with them.

RESEARCHER: But sharing your diagnosis with them might mean that you would have more sources of information to help you answer your questions.

PARTICIPANT NO.18: No. Even though they would share things they know about my cancer, they won't just share everything. There will be important things they hold back.

Here it is clear that Participant No.18 does not trust some of his friends as possible and reliable information sources. But for people he trusts, such as his family members and his doctor, the information sharing is open and candid.

RESEARCHER: You don't trust them?

PARTICIPANT NO.18: I don't.

RESEARCHER: Who do you trust as information sources that could help you answer your questions?

> **PARTICIPANT NO.18:** My family and my doctor.
>
> **RESEARCHER:** But you said you don't trust your doctor as a source for your traditional Chinese medicine related questions?
>
> **PARTICIPANT NO.18:** He has a bad opinion about traditional Chinese medicine, I think. It could be simply solved by me not asking him anything about traditional Chinese medicine. Other than this, he is professionally trained, which means that he knows things about cancer.

As cancer patients' experiences evolve and cancer realities progress, questions and desired answers about their health and cancer advance as well. This process often results from balancing the answers they consider as reliable, the trust they impart to different information sources, and the way they balance respecting and "questioning" their information sources. In a way, how Chinese cancer patients decide which questions to address is a result of multiple questions they ask themselves, such as: "What is it that I truly want to know?", "Is this answer true and reliable?" "Who do I trust as a reliable information source?", "Will asking this question make my source of information feel that I'm disrespectful or socially inappropriate?" For Chinese cancer patients, a well-balanced harmony between the conversations they have and their information sources is important, as this harmony is usually considered grounds for more peacefully, if not productive, conversations and could contribute to long-term communication outcomes.

Participant No.1 (Age 62, Male, Married)

RESEARCHER: How is your relationship with your doctor?

PARTICIPANT NO.1: Fine. I respect my doctor.

RESEARCHER: Do you think the way that patients react to their doctors is something that is unique to the Chinese society?

PARTICIPANT NO.1: What do you mean?

RESEARCHER: Do you think western societies have the practice that patients or their caregivers offer HCPs bribes to take better care of their patients?

PARTICIPANT NO.1: No. I think it is something that only happens in China. It is a good thing that patients want to express their gratitude to their doctors. You know, reciprocity (礼尚往来). But things change if the HCPs only behave nicely when there is bribe present.

RESEARCHER: Do you use traditional Chinese medicine treatments for your cancer?

PARTICIPANT NO.1: I recited a passage of *Huang Di Nei Jing* (*Inner Canon of Huang Di* or *Yellow Emperor's Medicine Classic* 《黄帝内经》) during my consultation. I prepared for it for a long time. It was difficult. I am too old for school stuff.

My doctor was surprised. He did not think I would know it and to be able to recite it, I suppose. But I did it. I did it so that he would not feel like I was nodding for face-saving's sake.

Also, it would be better for him to understand that I know his language. I trust him. But there are doctors who are ill-qualified charlatans who often don't know what they are talking about.

One way or the other, I believe it's important to let your doctor know you are prepared. I only did my homework.

RESEARCHER: You've done your homework!

PARTICIPANT NO.1: Yes. I don't know much about western style medicine, but I know a lot about traditional Chinese medicine. I have to know more [information]. The more the merrier.

One cannot be ignorant while one has cancer. I know there are people who don't want to know anything at all. They are afraid. I'm not. Right now, I'm having a fight against cancer. It is important to know oneself and his enemy in order to win this fight (知己知彼百战不殆).

I've always had some understanding of the traditional Chinese medicine, but now I learn it systematically. We not only have books such as *Ben Cao Gang Mu* (《本草纲目》), the ones everybody knows from here and there. We also have books like *Huang Di Nei Jing*, which are important as well.

Traditional Chinese medicine is different from western-style medicine. In order to better understand my cancer and my doctors' instructions, I need to have a solid understanding of traditional Chinese medicine. Our ancestors have left us such invaluable treasure. I didn't understand the value of traditional Chinese medicine until now.

RESEARCHER: There are many fake traditional Chinese medicine doctors who claim a lot of things.

PARTICIPANT NO.1: I know there are fake doctors and charlatans who say they could cure cancer with traditional Chinese medicine. That's the reason I only go to big hospitals for my questions about traditional Chinese medicine.

I'm really happy that I have all these resources at hand. There are people who went abroad and had to fly back to get a good prescription and some of the herbs they couldn't find in the U.S.

……..

Participant No.13 (Age 72, Male, Divorced)

RESEARCHER: In terms of questions or concerns you have about your cancer or health, are there things that you really curious about but could live with not knowing?

PARTICIPANT NO.13: There are some questions that I have seem to be always there, like when and how would I die. I've been having this question ever since one of my old friends passed away. He was only 35.

Now I think I have a partial answer. I know cancer will be my cause of death. What I don't know is when. This question felt different now. It's more real now. It is possible, I think, my children are thinking about this question as well.

RESEARCHER: Do you consider the way you treat your questions as unique? Or do you think it is common for cancer patients to be okay with not knowing certain things?

PARTICIPANT NO.13: I feel like I'm more at peace than some of the younger patients. It might take them a longer time to stomach the fact that they have cancer.

So even though I still have some urgent questions about my condition, I can pace myself with my interaction with my doctor or nurses. Not like them, they seem to be always in a hurry.

RESEARCHER: Could you please explain more?

PARTICIPANT NO.13: I don't need to know as much as some of the younger patients I've met. They are constantly looking for information and answers to their information inquiries.

I'm not like them. I do have questions, but I don't need them to be answered in a hurry.

RESEARCHER: But there are things you want to know immediately, like how to take your medicine properly?

PARTICIPANT NO.13: Yes. But I think my questions that need immediate answers are less than that of young people's.

RESEARCHER: By young people, I assume you mean younger cancer patients? Do you have someone in mind when you comparing yourself to younger cancer patients?

PARTICIPANT NO.13: Yes, I've met many young cancer patients.

RESEARCHER: They made an impression on you?

PARTICIPANT NO.13: Yes. They made an impression on me.

THE RESEARCHER: Could you please elaborate?

PARTICIPANT NO.13: I don't think some of them are old enough to get acquainted with life, let alone the cancer diagnosis. Which only means that they should work hard to learn to be strong.

RESEARCHER: You have seen some young cancer patients who couldn't handle it when they first learned of their diagnosis?

PARTICIPANT NO.13: I think sometimes it is important to accept it (cancer diagnosis) for reality's sake. There was a young couple, the husband got cancer, but it feels like the wife got it, because she was always crying.

Her eyes were always red and bloated, and her husband was always trying to comfort her. I talked to her, I told her that she needs to accept the fact that her husband has cancer, otherwise she would be ruining her husband's mood, along with everyone in the ward. I haven't seen them for a while. I hope they are doing okay.

Here it is clear that Participant No.13 believes that it is important to balance what a cancer patient/caregiver really wants to know, whether this cancer patient/caregiver should disclose information/emotions with people of varying degrees of trust, and how should this cancer patient/caregiver respect himself or herself as well as his or her information sources in addressing their questions.

RESEARCHER: You mentioned that you are at peace with things. You don't think this wife was at peace with the fact that her husband really has cancer.

PARTICIPANT NO.13: She was doing more than just not being at peace with herself. She lost her touch of balance.

RESEARCHER: What do you mean 'touch of balance'? Could you please elaborate?

PARTICIPANT NO.13: There are times that I'm not sure if my doctor's instructions are suitable for me. He asks me to do more exercise in order to be physically stronger. But I'm always tired.

I also don't think being physically stronger is what I need to achieve. I was not physically weak before I had chemo therapies. A lot of my friends are still not in a good in as good shape as I am. But I nodded to his suggestions regardless.

I think our relationship is in harmony right now: he respects me as a senior and cancer patient, I respect him as my doctor. I wouldn't want to break this harmony.

Here it is clear that for Participant No.13, having a well-balanced desire to answer questions and reactions toward potential answers is important. Below, he offers more thoughts on the importance of harmony and balance.

RESEARCHER: What do you mean by harmony?

PARTICIPANT NO.13: Peace of mind, order, the way my relationship with my doctor should be. And for that young wife's case, the peacefulness of our ward, the mood of all cancer patients in that ward, the relationship between her and her husband.

RESEARCHER: The concept of harmony you are referring, is it the reason why you don't want to ask your doctor questions that you consider trivia?

PARTICIPANT NO.13: Yes.

> **RESEARCHER:** Is everything your doctor tells you useful to you?
>
> **PARTICIPANT NO.13:** A lot of suggestions and things that my doctor told me are things that I knew. Probably because I'm old enough to know those things. But I listened to him and gave him the nod. It's probably his routine, a part of his job to give me certain information about this and that.
>
> **RESEARCHER:** Because you want to maintain harmony?
>
> **PARTICIPANT NO.13:** Yes.
>
> **RESEARCHER:** Do you explain everything you do on the basis of harmony-keeping?
>
> **PARTICIPANT NO.13:** I never thought of that. Maybe. Yes.
>
> **RESEARCHER:** Could you give me some examples?
>
> **PARTICIPANT NO.13:** The way you ask me questions and I respond to them is a way for me to maintain harmony between you and I. Do you know why is this my harmony-keeping?
>
> **RESEARCHER:** No.
>
> **PARTICIPANT NO.13:** Because I let you ask me questions, and I let you have the answers.
>
> Though some of the answers I gave you might not be what you are looking for, but regardless, I offered you these answers. And because these answers I offered, you could move on and ask my other questions and so on.

Chinese patients in general have a deep-seated respect for their HCPs, especially doctors. This respect develops out of the doctor-patient hierarchy of expertise, the long-standing respect assigned to the profession of HCPs, and the need to maintain a positive patient-doctor relationship. Though different cancer patients have varied perceptions toward their HCPs, they often consider their doctors as the authoritative source of information for their questions. As the degree of "questioning" needed differs, Chinese cancer patients often have to balance the respect they should show for their doctors and the need to find answers to their questions, meaning that they often defer to the medical professionals with their questions as a sign of respect. Similar to avoiding sharing information with other information sources, staying away from conflicts is a key aspect of Chinese cancer patients' interactions with HCPs about questions they have.

> *Participant No.11 (Age 51, Male, Married)*
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> **RESEARCHER:** Are things you talked about with your cancer patients different from those with your family members or your doctor?
>
> **PARTICIPANT NO.11:** Yes. I don't know about other people. But for me, I feel like I'm able to be insensitive about things related to my cancer treatments.
>
> **RESEARCHER:** Whereas when talking with your family members or your doctor?
>
> **PARTICIPANT NO.11:** I would have to think about what to say, how not to upset them too much but also make sure they understand what's going on.
>
> **RESEARCHER:** Do you need to be sensitive about your doctor's feelings or reactions toward your treatment?
>
> **PARTICIPANT NO.11:** Yes. She's been helping me understand so many things. I think she is doing the best she can to assist me in getting rid of my cancer. Sometimes I feel like if I say I'm not reacting well with this and that would be questioning her arrangements.

RESEARCHER: Does your doctor know you are trying this much to be a good patient?

PARTICIPANT NO.11: I think she knows that I respect her.

RESEARCHER: Please correct me if you think I'm wrong. Though you have a good, or maybe even great, relationship with your doctor, this relationship also hinders you from asking tough questions that you should be asking. Because at the end of the day, you are the one who bears the consequences if you don't have the knowledge you need in order for you to cope with your cancer treatment.

PARTICIPANT NO.11: I don't think you are wrong. I think it's a matter of balancing things. Most of us don't have the opportunities like what you have right now, speaking your mind, asking questions that interest you, and really probing into things that you don't understand. For me, I have to make sure my doctor will always be there to answer my questions, not with an attitude, but with sincerity.

As for the tough questions, I think the reasons they are tough because they are not supposed to be asked or thought of lightly. Let's say I question my doctor why my treatment is not working the way she said it would be, what would she say?

I don't think she would be intentionally misleading me. It might be that just different cancer patients might have different reactions to my cancer treatments. She might know many cancer patients who reacted well to my treatment, which is the reason why she believes that the same situation might apply to me.

If it's something that's related to the drugs or the chemo therapies, I couldn't really ask her to take the full responsibility, right? As there are the drug companies who made those failing drugs and the chemo doctor to blame. And also, what if questioning her might lead her to say 'Sorry' to me? Can I take her apology? What would I do with her apology? I don't really need her apology. I can't afford my doctor to apologize to me.

RESEARCHER: You are thinking about the long run. You are not asking the rough questions because you want to build a good relationship with your doctor so that you could have the rapport built to ask other less tough questions?

PARTICIPANT NO.11: Exactly.

RESEARCHER: I think a lot of patients are doing exactly what you are doing right now. Do you think this kind of patient-provider relationship is a thing that's unique to our society? I don't think western cancer patients might behave like we do.

PARTICIPANT NO.11: I think foreigners (老外) will just ask whatever they wish to ask. I don't think they have the same respect we have for doctors either. We do everything to maintain harmony, building a harmonious society (建设和谐社会), right?

I think not having conflicts is an important part of our society. Foreigners may not be afraid of conflicts. I think they might enjoy having them. They might prefer to put themselves first, above everything else.

Here, the participant explains his perceptions toward how he views himself as a Chinese cancer patient compared to cancer patients from other societies. The participant further explains what he believes are perspectives that are unique to Chinese society.

RESEARCHER: But there are also cases in which Chinese patients hurt their doctors with violence, more and more so.

PARTICIPANT NO.11: Yes. I've read about that as well. I think they are just crazy. It's wrong to hurt people. Regardless of how they've been hurt, they are not supposed to hurt other people. Do you know why I say they are crazy? They were victims, but they turn themselves to criminals. If that's not crazy, what is?

RESEARCHER: So you believe they are wronged by their doctors?

PARTICIPANT NO.11: Yes, otherwise why would they act like that?

RESEARCHER: Back to the harmony point you mentioned, these people and cases are not supporting your harmony point?

PARTICIPANT NO.11: There are always bad apples. In every organization, there are bad apples. I don't think it's right to say all organizations are bad. If so, there are no good places in China, because every organization must at least have one or two persons who are really not up to the standard.

But in general, things are supposed to be carried out with goodwill and harmony. Quarrels are not constructive at all.

RESEARCHER: It feels like you are maintaining a good relationship with a lot of people?

PARTICIPANT NO.11: Yes. When my family and friends heard that I had cancer, they all called me and visited me, as I told you. Some of them sent me tonics and other vitamins that are good for me.... good for my immune system. Others called to tell me what to eat or drink. They all wanted to help. But I only give them a listen.

RESEARCHER: Why you only take a listen?

PARTICIPANT NO.11: There was too much information. And they are not doctors.

RESEARCHER: And you listen to maintain harmony between you and them? [smiles]

PARTICIPANT NO.11: Exactly! You are a fast learner! [smiles]

Understanding "Balancing Truth, Trust, and Respect" in Context

This study adds to the current literature by supporting the contention that Chinese cancer patients' health information preferences and practices are influenced by the way they balance truth, trust, and respect. Despite literature previously noting cancer patients' disconnected weighing of truth, truth, or respect in health information activities (e.g., information disclosure) within Chinese cancer contexts (W. C. H. Chan, 2011; Jiang et al., 2007; T. Zeng, Huang, Zhao, Li, & Fang, 2011), there are no studies that specifically address Chinese cancer patients' in-depth and connected consideration of all of these factors in deciding how they wish to interact with various sources of health information.

Truth can be defined as "the actual facts of a situation and is used to determine, with certainty, whether information is accurate" (Toma , Hancock, & Ellison, 2008, p.1024). Truth, however, is different from that of truth telling, which is "honest communication about prognosis or end of life issues… This does not imply forcing unwanted details upon a patient or family member, rather a willingness to explore and meet the patients' information needs about these topics" (Hancock et al., 2007, p.508). In this study, truth concerns both conversations initiated by HCPs or patients' family members, as well as those that are introduced by patients. Within this context, trust is "a willingness to rely on an exchange partner in whom one has confidence" (Moorman , Deshpandé, & Zaltman, 1993, p.82). On the other hand, respect is "the level of esteem for another individual based on one's own values" (Kopelman & Rosette, 2008, p.68). Truth, trust, and respect in Chinese cancer patients' information activities have been addressed in the current literature, respectively. This section finishes with an emphasis on the importance of connecting these concepts within the same context, and how "balancing truth, trust, and respect" might effectively be integrated into health interventions.

Truth becomes a subject of careful consideration when cancer patients balance information given by their HCPs and family members. Similar to the studies conducted in other sociocultural contexts, the literature on truth in the context of cancer care often focuses on information disclosure to HCPs or family members (Jalmsell, Lövgren, Kreicbergs, Henter, & Frost, 2016; Khalil, 2012; W. Zafar et al., 2016). For instance, a study on Chinese oncologists shows that although Chinese cancer patients desire to know their health condition (W. Sun, Wang, Fang, & Li, 2015), only forty percent of these HCPs choose to disclose information on patients' health condition to these patients' family members first (Gu & Cheng, 2016).

Similarly, in a retrospective study, researchers found that seventy-eight percent of HCPs patients' family members of diagnosis first (Wuensch et al., 2013). Yeung (2017) argues that this information collusion and nondisclosure behavior needs to be considered with the unique cultural underpinnings of Chinese cancer patients. Within the Chinese cancer context, the role of truth and information disclosure interacts with how these patients weigh the role of family (W. C. H. Chan, 2011; Tse, Chong, & Fok, 2003; S. Wei et al., 2015; Yeung, 2017). It also plays a role in how these patients construct and maintain their relationships and communication with their HCPs (Gu & Cheng, 2016; Wuensch et al., 2013).

There are drawbacks in how family's involvement influences Chinese cancer patients' information realities (e.g., the harm of withholding diagnosis information from cancer patients) (Muller & Desmond, 1992; Yun et al., 2004). In Chinese culture, where a poor prognosis is believed to be harmful, rather than beneficial to the patients (C.-Y. Hsu, O'Connor, & Lee, 2009), patients' family members often choose not to break bad news (W. C. H. Chan, 2011; Tse et al., 2003). Due to the unique Chinese medical culture, which patients often lay trust on their family members in taking care of their affairs (Cao et al., 2011), cancer patients' family members have the "right" to make critical decisions without consulting with the patients first. Also, because of the unique medical culture in Chinese society, these cancer patients' family members have the opportunity to control what information gets to the patients, a phenomenon which could contribute to the non-disclosure attitudes HCPs hold (Gu & Cheng, 2016; Wuensch et al., 2013). Furthermore, the hierarchical structure of patient-provider relationship (Hofstede & Bond, 1988; Hofstede & McCrae, 2004; Ying, 2000), forces patients to be respectful of their HCPs, even if the HCPs' nondisclosure decisions might be harmful to patients' long-term health outcomes and quality of life (X. P. Li et al., 2013).

In the context of Chinese medical environment, HCPs often receive wide respect and trust, with patients referring to them as "angels in white" (Vincent Chi Ho Chung, Lau, Wong, Yeoh, & Griffiths, 2009; He, 2014; L. Hu, Yin, Bao, & Nie, 2014). Sometimes, however, patients and their HCPs do not mutually share this respect (E. L. Y. Wong et al., 2011). One phenomenon identified within this study is that to be a "good patient", Chinese cancer patients often withhold questions that they believe their HCPs might dislike or disapprove of. This indicates that patients seldom inform their western-style HCPs of their use of traditional Chinese medicine when they know or assume their HCPs might show a negative attitude toward the practice. As indicated in the interviews, out of respect of their HCPs and the perceived importance of patient-provider relationship, Chinese cancer patients choose not to raise their questions about traditional Chinese medicine or other folk-medicine-like treatment options in front of their doctors if they believe their doctors would judge these questions negatively.

Interestingly, insights presented in this dissertation also suggest that, though cancer patients hold great respect for their HCPs, they also have great distrust of their HCPs. For instance, though one participant lauded the performance of his HCPs, he also indicated that he recorded every conversation he had with his HCPs. When asked why he recorded his conversations, his rationale centered on memory concerns and potential medical accidents or malpractices. Though disturbing, this might demonstrate the lack of trust in the Chinese patient-provider relationship. For instance, one reason that patients distrust their HCPs is due to both verbal and physical violence against HCPs, especially against nurses (Shi et al., 2017; P. Sun et al., 2017) (Jiao et al., 2015; Z. Li et al., 2017). In a retrospective study, researchers found that 7.8% of nurses experienced physical violence, while 71.9% were subjects of non-physical violence from their patients (Jiao et al., 2015).

While it is important to acknowledge that these incidents of medical violence are the exception to the usual mode of patient-provider relationship, they shed light on how the current medical environment and atmosphere in China shapes Chinese cancer patients' construction of their relationships and communications with their HCPs. Especially in their ways of balancing truth, trust, and respect, and considering the power hierarchies between patients and HCPs (Hofstede, 1980; Hofstede & Bond, 1988; Ying, 2000), trust might be more difficult to build between patients and HCPs, and truth-requiring and truth-telling activities might be the first things sacrificed in patient-provider communications. Particularly in the context of patient-provider communication, this sheds light on why Chinese cancer patients need to balance truth, trust, and respect while interacting with various health information sources.

Taken together, these insights demonstrate how key sources of information (e.g., family members, HCPs) shape Chinese cancer patients' interaction with health information. This process differs from shared decision-making studied in western contexts, even if family members are involved, as it is "a process by which a healthcare choice is made jointly by the practitioner and the patient" (Légaré et al., 2010, p.3). Chinese cancer patients' balancing of truth, trust, and respect might be a direct result of the absence of shared decision-making processes. However, this does not lead to the conclusion that Chinese cancer care should promote shared decision-making. As results of this study indicate, Chinese cancer patients show trust and respect toward their family members' good intentions and decisions by not disclosing the "bad news" to them, while stressing that they are open to all information, even the difficult news. This attitude of Chinese cancer patients toward their family members' nondisclosure does not mean that these patients are passively accepting. Rather, this phenomenon should be viewed with consideration of Chinese cancer patients' cultural underpinning. In a macro perspective, Chinese cancer patients' balancing of truth, trust, and respect relates to the practice of harmony keeping.

Harmony encompasses a hallmark cultural characteristic of the Chinese population. Although there are many philosophies and beliefs that influence Chinese culture, harmony is a constant element in almost every strain of traditional Chinese cultures. For instance, in *The Analects* (《论语》; translated by Lau , 1979), a key passage for Confucianism claims:

> Of the things brought about by the rites, harmony is the most valuable. Of the ways of the Former Kings, this is the most beautiful, and is followed alike in matters great and small, yet this will not always work: to aim always at harmony without regulating it by the rites simply because one knows only about harmony will not, in fact, work.” (Lau, 1979, p.79)
>
> 有子曰“礼之用，和为贵。先王之道斯为美，小大由之。有所不行，知和而和，不以礼节之，亦不可行也。”《论语，学而篇第一》

Various fields have acknowledged harmony as an aspect of Chinese culture. For instance, in management, it is considered as “the glue that links members to the social world” (Leung , Koch, & Lu, 2002, p.205). Likewise, psychology defines it as “the reality that one is not separate from one’s environment… assumes that one functions optimally if he or she seeks to contribute to harmonious interactions with others, and it may involve exercising versatile behaviors” (Stevenson & Renard, 1993, p.435). Art considers harmony as “the degree to which the visual resources of a composition’s design from a coherent, unified pattern” (as cited in Kim , 2006, p.488). In the context of the Chinese culture, it has been defined as “a person’s inner balance as well as the balance between individuals and the natural and social surroundings” (Jin Hoare & Butcher, 2007, p.159).

The philosophy of harmony can also be found in everyday contexts and conversations due to its embeddedness in almost all aspects of Chinese relationships (Ying, 2000). The Chinese believe that everything should be in harmony, including people, nature, society, and business (Pitta, Fung, & Isberg, 1999). Though many encourage harmony keeping at various levels, traditionally, its place within interpersonal relationships is key (Hung, 2004). From a philosophical view, it is “the existence of different things and implies a certain favorable relationship among them” (Li , 2006, p.584). Rather than forcing sameness and oneness, harmony acknowledges the differences among people in order to achieve mutual and optimal understanding. As *Shi Bo* (史伯), a pre-Confucian scholar who lived during the Western Zhou period (1066-771 B.C.E.) said, “harmony is indeed productive of things. But sameness does not advance growth” (夫和实生物，同则不继) (as cited in Li, 2006, p.584). This idea of putting aside minor differences to seek more influential common ground is the essence of harmony keeping. The concept of harmony (和) can be found in Chinese sayings such as “harmony is valuable” (和为贵), “everything is in harmony/ everything is harmonious” (一团和气), “harmony brings about prosperity” (和气生财), and “hearts in harmony come hell or high water” (和衷共济).

Overall, the centrality of the maintenance of harmony in Chinese people’s social relationships might help put “balancing truth, trust, and harmony” in a culturally-respectful context. Against the harmony-keeping mentality and behaviors of the Chinese people, it is understandable why cancer patients might screen their thoughts to avoid potential disruptions of their own, as well as other people’s, harmony. This action could also explain why Chinese cancer patients would sometimes sacrifice truth in exchange for the showing of respect for their HCPs, even though they may distrust these medical professionals to varying degrees. Consequently, the role of harmony-keeping also underscores the importance of respecting Chinese cancer patients’ balancing of truth, trust, and respect.

One way of using this knowledge would be to design culturally-appropriate health interventions or communication programs between patients, family members, and HCPs. While acknowledging the importance of mutual respect, having open discussions of patients and family members' questions and concerns might help build trust. Rather than integrating the western idea of shared decision-making into the Chinese cancer research context, researchers should first ask and answer the question "What is the best communication mechanism or intervention program that could acknowledge and address Chinese cancer patients' need for truth, trust, and respect?" Due to the fact that shared decision-making asks for equality between patients and providers in terms of their input in decision making processes, it may fail in the Chinese medical environment. If researchers are invested in testing whether a shared decision-making communication model that involves patients, family, and providers in the communication process would work in China, necessary tailoring of how much "sharing" should be implemented is relevant to the success of this venture.

NAVIGATING AROUND INFORMATION SOURCES

Another theme that emerged from data analysis is how Chinese cancer patients choose to interact with different sources of information shapes their information behaviors. Navigating around information sources means that beyond 'balancing truth, trust, and respect,' Chinese cancer patients consciously adopt different communication strategies to navigate around various sources of information to achieve goals. How Chinese cancer patients behave around their sources of information is often goal-oriented. Two of the key goals that determine how Chinese cancer patients navigate and negotiate their information sources are nurturing the support network and focusing on productive interactions. Sources of information at Chinese cancer patients' disposal could be HCPs, family and friends, other cancer patients, general acquaintances, the internet, and the mass media. While facing different sources of information, Chinese cancer patients often stick to their personal preferences for if or how they interact with these sources. Partly because these information sources have their distinctive characteristics, partly because different cancer patients have different access to or perceptions of these sources, Chinese cancer patients differ in terms of their purposes and focuses on interacting with these sources. Overall, there are two sub-categories identified that could best be used to explain how Chinese cancer patients navigate around various sources of information, which are *nurturing the support network*, and *focusing on productive interactions* with various sources of information.

> *Participant No.5 (Age 52, Female, Married)*
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> **RESEARCHER:** You mentioned that you have a lot of questions. Do you search for information for these questions yourself, rather than simply directing your question to a doctor, or a nurse?
>
> **PARTICIPANT NO.5:** No. These questions require expert knowledge. My doctor or any doctor in a legitimate hospital is professionally trained so he or she would have the right answer for my questions. I don't think asking anyone these questions will do.
>
> **RESEARCHER:** Some people would say that information sources such as the Internet would be a good source for medical questions?

PARTICIPANT NO.5: I don't use the Internet for my health-related questions. I know there are many things there. I don't think information on the Internet is trustworthy.

RESEARCHER: Why do you think that? You don't use it, as you said.

PARTICIPANT NO.5: I listen to TV programs and read newspapers. A lot of journalists say that the Internet is a place for fake news. People go to the Internet for spreading rumors. I read this and that on the Internet from time to time. But I don't trust the Internet as something that could help me answer my questions.

Even I found things on the Internet about what I'm curious about, I wouldn't stop there. I would still talk with my doctor about my concerns. It would only be a waste of time for me to search answers on the Internet.

My daughter agrees with me as well. She uses the Internet all the time, playing with her phone. She thinks I should talk to my doctor about my questions instead.

Here it is clear that the participant has a clear take on how she should behave around various information sources, in terms for focusing on productive interactions. Below, she further explains why she has this position in detail.

RESEARCHER: You've never read good things about the Internet from TV programs or newspapers?

PARTICIPANT NO.5: There are good things happening on the internet. I know people would help farmers sell their produce on the Internet. But the Internet is not a good place to find answers for my questions, as my questions are really difficult ones that could only be answered by doctors.

RESEARCHER: What about other cancer patients? Do you think they might have answers for some of your questions?

PARTICIPANT NO.5: Maybe, it's possible. But since everyone is different, it is really not wise for me to take other people's experiences and apply them to myself. Asking my doctor questions is different, as my doctor knows my conditions, which means that the answer he gives me would be suitable to me.

RESEARCHER: What about your family members? Do you ask them to help find answers for your questions?

PARTICIPANT NO.5: Yes, I do. But not because I want to get answers from them. I share questions I have and what I know with them because they could help me with making better decisions. Their perspectives could help me see things that I'm not able to see. You know, two heads are better than one (三个臭皮匠顶一个诸葛亮).

They agree with me as well, that asking my doctor in terms of what to do is the best strategy. Though they are not happy about me waiting for the right time to ask my doctor questions. They think I'm too timid for not simply asking my questions. They might be right.

Here it is clear that nurturing the support network is another important factor that influences how Participant No.5 interacts with her questions and decision-making process.

Nurturing the Support Network

Chinese cancer patients maintain social interactions by exchanging information (though not necessarily useful information) with their social contacts. Nurturing the support network means that one of the criteria of how Chinese cancer patients wish to interact with their sources of information, especially the sources that are often lacking in usefulness in the information provided, is in what way these patients wish to maintain the health of their support network and social harmony. This category could explain why some Chinese cancer patients choose to interact with a certain source of information (e.g., HCPs) about their health-related concerns, in differing manners. As opposed to another subcategory, *focusing on productive interactions*, this particular category captures Chinese cancer patients' use of information as a currency for social interaction. Although interacting with information sources about their health might not necessarily generate positive information, cancer patients still commit to this activity for the sake of "being social." Indeed, when maintaining social accord is the main goal, Chinese cancer patients often do not give much thought to the usefulness of the information exchanged. Rather, it is the building or managing of the relationship between cancer patients and their sources of information that they consider to be the most important objective.

> *Participant No.2 (Age 32, Female, Married)*
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> **RESEARCHER**: Do you usually share what you know or how you feel with other people, including your doctor, family, and friends?
>
> **PARTICIPANT NO.2**: Yes. When the timing is right.
>
> **RESEARCHER**: What do you mean by "when the timing is right"? Could you give me an example?
>
> **PARTICIPANT NO.2**: Like the other day I was with my female friends. We were waiting for our movie and talking about random things. And it happened that one of my friend talked about waiting to dye her hair red, like the main character in Cheese in the Trap. She is the kind of girl who likes to dye her hair. And there are periods when her hair would look half yellow and half black, like Bumblebee in Transformer.
>
> So we were starting to call her Bumblebee to make fun of her. And because she said that she wants to dye her hair red, we were playing the word Bumblebee on her again, asking her whether she wants to be a red Camry. You know, just joking.

While we were all laughing, I said to my friend that she should be delicate with her hair. Since it's really not nice to wear ponytail every day to cover one's baldness. I felt they were saddened by what I said. But I really have to say something to my friends. Losing my hair has been painful to me, and I don't want that to happen to any of them.

Here it is clear that talking about her condition might not contribute to the relationship between Participant No.2 and her friends; however, she still discusses sensitive topics as an effort to nurture her support network and to offer value to her friends.

RESEARCHER: How did they react to what you said?

PARTICIPANT NO.2: My friend promised that she won't dye her hair red. [smiles]

RESEARCHER: Have your friends talked to you about your health or treatment?

PARTICIPANT NO.2: Yes. And they are very supportive. A lot of the articles I read come from them. They shared a lot of cancer-related articles with me via WeChat. And the day I told them I have cancer, they all changed their status to support me. I really glad that I have them as my friends.

RESEARCHER: So you shared your diagnosis with them the moment you knew?

PARTICIPANT NO.2: I couldn't say 'the moment I knew', but almost immediately. I think I shared the news that I have cancer one day after I knew. I wasn't in good shape and I wanted to talk to people.

RESEARCHER: Have you thought about not sharing your diagnosis? You said you were not handling this news well. Wasn't it better if only some people know so that you didn't have to deal with constantly talking about things that you don't like?

PARTICIPANT NO.2: I thought about that. I wasn't thinking about sharing this news just yet, but I remembered that I was really down and one of my girlfriends called. We talked and she asked if I had a cold, as my tone was really off with all the crying. At that moment, I just told her that I had cancer.

Chinese cancer patients also accept information their HCPs tell them without asking the questions they wish to address because these patients want to maintain a functioning relationship with them as a way to nurture their information network. Instead, cancer patients would rather quietly accept the way their HCPs prefer to communicate with them without asking "difficult" questions that might break the status quo of the current patient-provider relationship. Different from balancing truth, trust, and respect, here the patients are more likely to constructing decisions, rather than forging negotiations between self and others, and between needs and wants.

RESEARCHER: What is the information that you want to know but haven't asked your doctor?

PARTICIPANT NO.2: Oh, I want to know so many things. You know, things that I couldn't ask my doctor, things that even my doctor doesn't have answers for, and things I don't think my doctor might have time for.

RESEARCHER: Can you give me some examples?

PARTICIPANT NO.2: A lot of the questions that I want to ask are about my future treatment plans. I have the habit of planning things ahead. I asked my doctor once about things that have little to do with what is going on with my current treatment plan or the drugs I'm using now, but my doctor made me feel like I was wasting his time.

I don't think I will be asking more of this kind of questions to him ever. There are many things I don't think my doctor would know, as I said.

An example would be the question of whether my cancer might come back. I understand why he doesn't want to give me false hope. He has to be responsible for his words and actions. But to me, this translates to one thing, that is, I can't direct these concerns to him.

And because these concerns are really difficult to answer, I can't direct them to anyone other than myself. Also, I want to know about whether I could get back to my normal shape. I don't think this question is something that my doctor would think I should be focusing on at all. Because appearance is less important compared to my health, but he is not a woman, he doesn't understand.

Here it is clear that after knowing the disposition of her doctor, the participant is more able to understand how to best communicate and navigate her conversations with this doctor. Below, the participant further explains her views on patient-doctor relationship, particularly as it relates to gender.

RESEARCHER: Do you think if your doctor were a female doctor, things would be different?

PARTICIPANT NO.2: Yes. That's for sure.

RESEARCHER: What might change, in your opinion, if your doctor were a female doctor?

PARTICIPANT NO.2: I think female doctors are more considerate. She would understand where I come from when I talk about my concerns about how my cancer treatment or the drugs I take could affect my body shape and appearance.

RESEARCHER: Wouldn't it be easier for you to just ask your doctor these questions, and even though he might not be happy about these questions, you would at least have your questions answered?

PARTICIPANT NO.2: I will give you an example. You know people are always scared of cancer and think of it as a death sentence. I used to think it that way as well. I want to know whether my cancer is a death sentence as well.

I don't think my doctor would give me an honest answer about the chances of a cure or my death sentence. I don't think he would tell me what he really thinks of my situation even if he has the answers. Rather than hearing a false answer or a condescending one, I think I would rather not asking the question. And also, I have to keep a cordial relationship with him. If I just direct those questions to him, he would think I'm disrespectful of him, which is not true.

RESEARCHER: Why do you think asking your questions would make your doctor think that you are disrespectful?

PARTICIPANT NO.2: I don't think doctors like to be challenged.

RESEARCHER: A part of their job is to answer patients' questions.

PARTICIPANT NO.2: I agree. That's how things supposed to be. But in actuality, people don't like to be challenged, even though the patients have no ill intentions.

RESEARCHER: Do you think people in other societies, like western societies, behave like this as well?

PARTICIPANT NO.2: I wouldn't know. I think this might be unique to the Chinese society. But even though western doctors are more open to questions, I don't think they might like to answer difficult questions at all.

Focusing on Productive Interaction

Chinese cancer patients carefully contemplate the best way to approach and interact with sources of information based on who could answer most of their questions (e.g., HCPs) to reach the best long-term communication outcomes. The ability to gain a positive outcome from interacting with various information sources explains some of Chinese cancer patients' information behaviors. This category captures how these patients focus on productive interactions with various sources of information, especially those who often bear answers that cancer patients desire. Chinese cancer patients' evaluation of the best productive method to achieve their long-term communication objectives influences their interaction with information sources. This includes the particular way in which Chinese patients seek out the answer to the questions and concerns they have about their health. As some Chinese cancer patients indicate, they choose to ask the most important question that has the greatest impact on them and their families, rather than all the questions they have, when they think their doctor is in a hurry or a bad mood. Different from using information as a currency for the purpose of social interaction, cancer patients often have desired results in mind when they initiate conversations with a focus on gaining productive outcomes.

> *Participant No.7 (Age 34, Female, Single)*
>
> **RESEARCHER:** Why you decide to wait to seek answers for this question of yours?
>
> **PARTICIPANT NO.7:** I'm the one who is in charge of our family finance. My parents also gave me some money to support me. Actually, they are the ones who supported my current treatment, which is the more expensive option at the time. I just want to know where I stand financially. My doctor is really not talkative about my potential medical bills.
>
> **RESEARCHER:** And you don't feel comfortable initiating that conversation?
>
> **PARTICIPANT NO.7:** Yes. I tried to ask my doctor that question. I worry that she will get really upset with me if I bring that subject again.
>
> **RESEARCHER:** Has she been upset with you before?
>
> **PARTICIPANT NO.7:** No. But I can tell that she is really not happy when I asked her regarding my hospital bills.
>
> **RESEARCHER:** Has her attitude made you less likely to ask her questions?
>
> **PARTICIPANT NO.7:** Yes.

RESEARCHER: Can you please give me some examples?

PARTICIPANT NO.7: I can't tell you exactly how many questions that I failed to bring up to my doctor when she is not happy. But when I think she is having a bad mood, I try to make my appointment with her short and just ask key questions to save time.

RESEARCHER: What do you mean by key questions?

PARTICIPANT NO.7: The most important questions.

RESEARCHER: Could you give me an example of a key question and an example of a question that is unimportant or less important?

PARTICIPANT NO.7: It's really difficult for me to just give you examples. You know, questions of different importance..… Let me think…...A key question would be something like how am I doing overall in general, like if my cancer is being cured and if my cancer treatment is working. A less important question would be a question about the specific things that I don't understand or need clarification, especially when it comes to questions that about things related to my cancer treatment.

RESEARCHER: Do you think what you considered as key questions are also considered as key questions by other cancer patients? Similarly, do you think what you considered as less important questions are also considered as less important questions by other cancer patients?

PARTICIPANT NO.7: Yes, in general. I think the main questions we all want to know are the ones regarding our overall health. I don't think people will rather have the trees than the forest (舍本逐末). I think people should be focusing on the main objectives in general, rather than concentrating on the details of things.

RESEARCHER: Can you give me a specific example of your questions about details and the ones about the main objective you are referring?

PARTICIPANT NO.7: For me, a big-picture question would be how to gain my health back. A question about detailed things would be how well I'm doing today.

RESEARCHER: So you usually wouldn't ask your doctor about detailed things if you think she is not in a good mood?

PARTICIPANT NO.7: Yes. I try to make my appointment short so that she won't remember me particularly if she is having someone to blame for the things that made her mad that day. You know how is it when we are mad, we not only blame the person who made us mad, but also blame the person who made us have the feeling of being bad as well?

RESEARCHER: Yes. I know what you are talking about. But how well you are doing lately is also something that could help your doctor to see whether the drug is working, because daily performances make up your overall health, yes?

PARTICIPANT NO.7: Yes. But if I have to choose, it would be better for me to ask something that I could relate to, like, in general, are my cancer treatments working? I could be focusing on aspects such as my weight, my mood, hair loss, etc., but knowing things regarding them wouldn't give me an overview of my health.

Here it is clear that the participant is making compromises so that the best possible patient-doctor relationship could be achieved for the long run, and in turn, the most productive result could be achieved.

RESEARCHER: It feels like you have thought about this well, which question to ask your doctor if you have to choose?

PARTICIPANT NO.7: Yes.

RESEARCHER: Your way of classifying questions into important and unimportant, is this something you've been doing your whole life, or it's something that you only thought of after knowing you have cancer?

PARTICIPANT NO.7: It's how I ask questions. It has nothing to do with my cancer.

RESEARCHER: Do you consider the important things as something that you have to know, whereas the detailed information as something you could live with not knowing or knowing in a later time?

PARTICIPANT NO.7: Yes. I believe the things that could give me an overview of what is going on are most important questions that I have to answer. As for the detailed information, I think most of them could be solved or dismissed by having the big picture in mind.

……

RESEARCHER: Is being a volunteer worth your time and your energy? I understand some cancer patients feel tired all the time.

PARTICIPANT NO.7: Yes. I think it's just me. I think helping people is something that's meaningful. My cancer friends are really appreciative of my work as well. The first time in my life I was called an angel was when I helped a fellow cancer patient. [smiles] I think he was part jesting. But I took it anyhow.

I like what I do as a volunteer. I learned a lot from interacting with other cancer patients as well. Information about what to eat, which treatment is good, which doctor has bad ethics, which nurse has a bad temper, things like that. I was able to dodge many bullets because of what my cancer friends shared with me.

RESEARCHER: Could you please share some examples with me?

PARTICIPANT NO.7: One example would be…I did my scan yesterday because I know the doctor who is on duty on Tuesday is really efficient. I only know this because one of my friends I met while volunteering told me that.

She said that she spent hours lining up for her scan because the doctor is a newbie. I asked her which doctor was it. She told me the descriptions of that doctor and advised me to only get my tests on Tuesdays and Thursdays.

RESEARCHER: Sounds like being a volunteer is something very important to you.

PARTICIPANT NO.7: Yes. It is one of the most important things happening after I know that I have cancer. Even though my cancer has relapsed, I still volunteer. I'm a people person. I like to talk to people.

I was retired before I knew I had cancer. But cancer has, in a way, helped me engage with more people. I was busy with helping people who were also diagnosed with my kind of cancer. I could share my experience and what I know with them. I feel like I'm useful again. I like that feeling.

Here the participant explains how her productive interactions with information sources have helped her better cope with cancer and life. Below, the participant further explains this position she held, especially in terms of mental health.

RESEARCHER: In a way, being a volunteer made you stronger mentally?

PARTICIPANT NO.7: Yes, exactly! Should you had asked me to take part in your study last May, when I was first diagnosed with cancer, I could have said no. I was in a bad mood. I spent most of my days doing nothing. There was simply too much pondering on questions like "why me?", "what have I done?", "how could this be true?"

RESEARCHER: Last May? You also mentioned that you relapsed?

PARTICIPANT NO.7: Yes. At first things were going really well for me. I thought I was going to be okay. The treatment worked on me in a short period of time as well, I think it only took months for my doctor to declare that things are good for me. I was told that I'm cancer-free. But then there is this relapse.

RESEARCHER: That's some roller-coaster experience.

PARTICIPANT NO.7: Yes. But it's better that I have my relapse now. I mean I would rather not having it. But if I have to have it, it would be better for me to have it sooner than later.

I heard a lot of sad stories of people who have their relapse with a huge lapse in between (the treatments). I feel like their case is more difficult to live with. They've already moved on with their lives and suddenly, their cancer comes back again.

RESEARCHER: Your situation was different because the two treatments are really close to each other?

PARTICIPANT NO.7: Yes. I think I was still in a celebrating mood when I realized that I might have relapsed. I haven't really had the chance to move on with my life and pretend as if I never had cancer.

RESEARCHER: Are your feelings different now, compared to the last time you were treating cancer?

PARTICIPANT NO.7: Yes. I think I'm calmer and more practical.

RESEARCHER: What do you mean by calmer and more practical?

PARTICIPANT NO.7: Now I know not to get panic about the little things, like hair loss, my skin getting colored, and I'm getting more bloated because of all the side effects. Now I know it's important to focus on the big picture, which is if my health is getting better and if my cancer is being controlled well.

Here, the participant further explains what she considers as important or productive over time. And she explains how she is able to truly focus on questions that could generate positive, productive, and meaningful outcomes for her.

RESEARCHER: What about the questions you have about your cancer treatments and health? How your questions or the way you seek answers for your questions different from the last time?

PARTICIPANT NO.7: Calmer and more practical.

RESEARCHER: Anything else?

PARTICIPANT NO.7: No. I've learned the most important lesson, which is to get calm and be practical.

RESEARCHER: Can you share some other examples with me?

PARTICIPANT NO.7: I think I'm no longer surprised by what I don't know and what I do know. I was very much emotionally flustered whenever I heard bad news or good news last time.

Now I'm more settled with the fact that every message I receive will finally constitute a big picture for me to understand. And until the day I have that true big picture, it is not wise for me to be happy or sad about any news. Just like the saying, those who laughs the last laughs the best (笑到最后笑得最好).

I've realized that it's not wise to laugh too hard when it's not my last laugh. I was too happy when I was done with my cancer treatments. Now see where I am.

RESEARCHER: Would you say you wanting to know how much your cancer treatments cost you is you being practical as well?

PARTICIPANT NO.7: Yes, definitely. I think on the one hand, I really need to know. My daughter's father was paying my medical bills. I really need to give him a ball park of how much my treatment will cost him in total. On the other hand, I really want to know how long this round of treatment will last and exactly how bad is my situation.

I've realized now that sometimes doctors don't want to be the bearer of bad news. But I'm really a strong person. By asking my doctor how much will this round of treatment cause me I would gain a clearer idea of how she really thinks how well or how bad I'm doing. My medical bill will tell me the truth.

RESEARCHER: That's really smart.

PARTICIPANT NO.7: Well, this is not my first rodeo.

Understanding “Navigating around Information Sources” in Context

Chinese cancer patients’ interaction with health information are influenced by the way they choose in navigating around information sources, nurturing the support network, and focusing on productive interactions. Overall, these two factors further shed light on how Chinese cancer patients interact with various sources of information while trying to answer their questions or concerns. Below is the relevant context that could put the research findings on “navigating around information sources” into context.

Understanding “Nurturing the Support Network” in Context

There are instances where cancer patients accept information that they consider of little or no value to them out of their intention to maintain and nurture their support network. This conclusion is new to the literature and can be contributed to the unique sociocultural habits of these patients, within the context of harmony keeping. As the findings of this study indicate, interacting with information sources for the sake of nurturing the support network is especially prominent in cancer patients’ interactions with their social network, rather than with their close family members or their HCPs. For instance, when interacting with close family members, Chinese cancer patients actively put input and thought into these conversations, as family members are well-trusted and the subject of a great degree of truth exchange for patients. Family members’ opinions and decisions are often respected by these patients. However, between general social contacts that cancer patients are not particularly close to, situations differ in terms of communication. Though this finding is new to the literature, within the context of current the work, it emerges from the unique cultural traits of the Chinese people.

As stated in the previous paragraphs, harmony functions as an important part of Chinese people's daily living. Harmony, or *He* (和) in Chinese, denotes peace, unity, kindness, and amicableness (Chang, 2001; Gao, Ting-Toomey, & Gudykunst, 1996). Nurturing the support network influences Chinese cancer patients' information activities because of traditional Chinese culture, which states that harmony maintenance is central to Chinese people's construction and maintenance of social relationships (Hung, 2004; Ying, 2000). It is easy to understand why Chinese cancer patients accept useless information from their general social ties out of trying to maintain harmony within social interactions. As Yong (1994) states: "the active pursuit of harmony ultimately aims toward a unity of differences, a synthesis of divergences, a confluence of contrasts" (p.45).

The inclination toward harmonious relationships, overall, makes the pursuit of "conflict-free interpersonal and social relationships" and "a harmonious state of human relationship" becomes the hallmark of Chinese communication (as cited in Chang, 2001, p.156). The indispensable and communally-oriented interpersonal communication network (Bond, 1988; Gao et al., 1996; Young, 1994), a social norm for the Chinese people, explains the need to nurture the support network when Chinese cancer patients "happily" accept useless information gained from their social contacts.

The methods Chinese cancer patients employ to exchange information with their social ties might result from the way Chinese people construct social meaning and relationships. Scholars often attribute certain behavioral traits of Chinese people to their collectivist cultural orientation (Hofstede, 1984; Triandis, 1995), a concept which has been greatly influenced by a key component of Chinese culture, Confucianism (Yum, 1988). Chinese people construe meaning relative to the larger in-group they belong to, if not the grand Chinese cultural milieu (Chang, 2001). Compared to western cultures' adherence to autonomy and independence, Chinese culture emphasizes social harmony and interdependence (Hofstede, 1984; Triandis, 1995). Upon receiving health information sent from people of goodwill, Chinese cancer patients "accept" the information, although it may be incorrect or poor, out of the need for showing reciprocal goodwill, as a way to keep harmony. As findings of this dissertation indicate, similar to the reason why some cancer patients wish to avoid sharing sensitive thoughts or ideas with their social ties, cancer patients' desire to maintain harmony also facilitates their information sharing with their social contacts.

Despite how role that these information sharing activities serve for building relationships between Chinese cancer patients and their general social contacts, more work needs to be done to see if these activities are indeed beneficial to Chinese cancer patients. It is possible that "nurturing the support network" itself, without potential informational gains, provides either psychological or physical health benefits to cancer patients. These social interactions may construct a source of social support for these patients, even though no knowledge can be gained from these interactions. As for Chinese cancer patients, social support shapes their quality of life (M.-Y. Li, Yang, Liu, & Wang, 2016; J.-W. Wang et al., 2015; Yan et al., 2016). Overall, these findings add to the current literature by providing a unique insight on why Chinese cancer patients actively keep the health of their social relationships, even though there is a lack of valuable information exchange.

The complex and multidimensional nature of social support (Bloom & Spiegel, 1984; Harrison, Maguire, Ibbotson, MacLeod, & Hopwood, 1994), calls upon future studies to further investigate whether, compared to informational value, social value might also be a critical contributor to cancer patient's quality of life. Social value could be understood as "the awareness by people of a necessity specific to this social structure" (Dubois & Beauvois, 2008, p.1740). Insights on social value have the possibility to provide additional explanations as why Chinese cancer patients prefer to maintain harmonious interactions with their social contacts even when information gained from these sources is useless or even harmful if taken.

Understanding "Nurturing the Support Network" from A Negative Case

Negative cases are "data that seems to stand far apart from the other data collected and does not coincide with the emergent theory" (Kolb, 2012, p.85). Even from the smallest unit of data, negative cases provide valuable insights that help researchers deepen their understandings of the research phenomena and the study population (Taylor & Bogdan, 1998). Negative case analysis constitutes a possible measure for ensuring qualitative research's trustworthiness (Mays & Pope, 2000; Shenton, 2004; Spiggle, 1994). For instance, some researchers suggest that "if a negative case is identified, the researcher, theoretically, must sample for more negative cases until saturation is reached when synthesis is attained" (Morse , 1994, p.39). However, as Glaser and Holton (2004) suggest, grounded theory study's theoretical sampling could effectively countermeasure the effect of negative cases on research findings, because "Morse's reference to saturation does not imply conceptual saturation. Rather, grounded theory anticipates simple redundancy without conceptual analysis" (p.8). That being said, unique insights gained from interviews may provide valuable understanding of how various factors guide Chinese cancer patients' health information preferences and practices. This is particularly true when "nurturing the support network" passively influences some Chinese cancer patients' health information preferences and practices.

For instance, it is easy to understand from quotes below that the participant used various communication strategies to navigate around different information sources, both in nurturing her support network and focusing on productive interactions. For instance, how she decided *not* to interact with her distant relatives. Different from the way the patient interacted with friends, she chose not to disclose the cancer diagnosis to relatives. Her dislike of her relatives' attitudes is the main reason for her nondisclosure. Despite not saying anything about the participant's current health condition, her relationships with relatives were maintained. In anticipating the potential negative experiences she may face by disclosing the cancer diagnosis, the participant chose to not to say anything about her health to her relatives to maintain the *status quo* of her relationships.

Participant No.7 (Age 34, Female, Single)

PARTICIPANT NO.7: Oh, I have told many people when I had cancer.

RESEARCHER: Could you please explain?

PARTICIPANT NO.7: I've been to many of friends' wedding ceremonies. They've invited me, so I have to pack a *Hong Bao* (红包) and pay my respect. It's only appropriate. Now I have cancer. It's time that they pay their respect to me for a change. It's not just about the money. It's about proper social interaction. So I called them and told them my diagnosis… Some of them came, some of them didn't.

RESEARCHER: You paid your proper respect to them when they called you for various reasons?

PARTICIPANT NO.7: Yes, I would pack a *Hong Bao* and pay my respect when a friend let me know he/she has cancer, especially since I now know how it feels to have cancer. I would also share what I know with my friend because it's the way I've been treated by my cancer friends.

RESEARCHER: Do most of your relatives know as well?

PARTICIPANT NO.7: No.

RESEARCHER: Is it okay for me to ask why?

PARTICIPANT NO.7: I don't want to receive phone calls from my relatives. What can they tell me that I haven't known already? There was nothing they could help me with. They could give me nothing but pity. I don't need their pity. My mom agrees with me as well. She didn't want any of our relatives know that [I had cancer].

RESEARCHER: You must have paid respect to them on various occasions?

PARTICIPANT NO.7: Yes. But they gossip too much. I think it's because I dislike their attitude and their gossip too much that I'm being impractical. [smiles]

RESEARCHER: I think it's possible that your friends might know more evidence-based insights on your cancer and health, which means sharing your cancer diagnosis might be more practical then sharing it with your relatives as well?

PARTICIPANT NO.7: You could say that, I think. [smiles] But it's really difficult to tell what is evidence-based from what is not.

I don't know whether the things my relatives may know is valuable or not. It's just that I would rather not have their knowledge on cancer treatments if it means that I have to deal with their attitude and the way they gossip.

RESEARCHER: Exactly what kind of attitude are you referring to?

PARTICIPANT NO.7: You know, like the fact that I have breast cancer. You know I wasn't sharing my diagnosis with my friends at first either. I was keeping everything to myself for a long while.

RESEARCHER: I don't quite understand.

PARTICIPANT NO.7: I was a single mom at the time. My daughter was still at school when I found out I had cancer. I didn't feel like sharing my diagnosis with my friends. So it was a depressing period for me. It took me a while to get out of it.

RESEARCHER: But you helped someone and even lent her your money?

PARTICIPANT NO.7: Yes. But that's different.

RESEARCHER: Different, how?

PARTICIPANT NO.7: I think it's just being…me. I'm the kind of person who gives beggars money all the time. I didn't help her because of my mood. I did because that's what I usually do. She was just there and she needed my help.

RESEARCHER: How did you grow out of it?

> **PARTICIPANT NO.7:** My mom asked a really nice volunteer to talk to me. She is really positive. What she said to me had really made a difference to me. That's the reason why I'm volunteering right now. I should say that I share what I know and receive what other people's knowledge about cancer through volunteer work.
>
> **RESEARCHER:** Does being a volunteer worth your time and your energy? I understand some cancer patients feel tired all the time.
>
> **PARTICIPANT NO.7:** Yes. I think it's just me. I think helpful people is something that's meaningful. My cancer friends are really appreciative of my work as well. The first time in my life I was called an angel was when I helped a fellow cancer patient. [smiles] I think he was part jesting. But I took it anyhow.
>
> I like what I do as a volunteer. I learned a lot from interacting with other cancer patients as well. Information about what to eat, which treatment is good, which doctor has bad ethics, which nurse has a bad temper, things like that. I was able to dodge many bullets because of what my cancer friends shared with me.

Understanding "Focusing on Productive Interactions" in the Relevant Context

Chinese cancer patients also navigate around various information sources, focusing on productive interactions with their social ties. Within this context, navigating around information sources acts as a means to an end, with the ultimate goal of gaining positive long-term knowledge. Chinese cancer patients use a variety of communication strategies with different sources of information so that they may have more questions answered during these interactions. This phenomenon is particularly true of Chinese cancer patients' interactions with other cancer patients or with their HCPs.

Chinese cancer patients interact with their peer cancer patients, those who are also "in the cancer club", as kindred cancer comrades (Cheng et al., 2013; Lu, You, Man, Loh,

& Young, 2014; C. Wei et al., 2017). For instance, Cheng and associates (2013) find that peer patients are a principal source of Chinese breast cancer patients' emotional and informational support. Rather than confirming this insight, this dissertation aimed to investigate how Chinese cancer patients utilize their relationships with their peer cancer patients in the context of health communication. Chinese cancer patients are actively engaging themselves with conversations among their peers because they know that, in the long run, these conversations might benefit their cancer management. As findings of this dissertation suggest, many participants indicate that being "in the same boat" (同病相怜) promotes particular information activities with other cancer patients. These information activities are very goal-oriented in that when cancer patients realize that they have nothing to gain from the particular peer groups they are exposed to, they move on to finding other patients to interact with, with the aim of gaining more answers they desire.

Findings of this study also indicate that, depending on the individualities and characteristics of their HCPs, patients tailor their communication strategies around these HCPs to achieve long-term productive patient-provider communications. While organizing questions concerning their cancer care, depending on how open-minded and trustworthy their HCPs are, these cancer patients choose specific communication strategies to reach the most desirable communication outcomes in the long run. For Chinese cancer patients, it is important that patient-provider communication answers their most important questions. This finding is new to the literature, as it shows Chinese cancer patients' proactive thinking and negotiations in interacting with their HCPs to obtain maximum informational gain.

One possible explanation for why Chinese cancer patients have to toe the line while interacting with their HCPs might contribute to the paternalistic communication style adopted by some Chinese HCPs, which, though outdated, is still prevalent in the Chinese medical system (Hu et al., 2014).

Paternalistic communication styles denote that HCPs will ignore patients' information preferences and make decisions for the patients regarding what they need to know (Roter, Hall, & Katz, 1987). This communication style might intimidate patients to the extent that they would rather stay quiet, which could explain participants' mentality in choosing to be uncommunicative when they think their HCPs might "have a bad day." This style completely opposes the concept of patient autonomy.

For instance, research conducted on Chinese people living in Singapore finds that Chinese cancer patients and their family members have to wrestle the traditional paternalistic role of HCPs in their medical decision making (Z. J. M. Ho, Radha Krishna, & Yee, 2010). In a national survey, researchers found that a majority of Chinese doctors prefer familialism and paternalism in medical practices (L. Hu et al., 2014). Combined with how Chinese people hold great respect for their HCPs (Bowman & Singer, 2001; Cong, 2004; Hofstede, 1984; Triandis, 1995), it is understandable why Chinese cancer patients need to navigate and negotiate the way they communicate with their HCPs. Primarily done out of the need to build a sustainable and productive patient-provider relationship, this style facilitates long-term information activities.

One theoretical framework for understanding these findings is the social exchange theory, which connects meaningful human interactions to the benefits of exchanging of resources (Cropanzano & Mitchell, 2005; Emerson, 1976). Social exchange theory is “the study of explicit social transactional behaviors between individuals that maximize benefits and minimize costs” (Barner & Rosenblatt, 2008, p.320). That is, social exchange theory considers social transactions as reciprocal exchanges which all shareholders in the exchange could gain benefits from their interactions. Reciprocal exchange occurs when an individual “initiates an exchange by performing a beneficial act for another (such as providing assistance or advice), without knowing whether, when, or to what extent the other will reciprocate” (Molm, Peterson, & Takahashi, 2001, p.162).

In the context of the social exchange theoretical framework, Chinese cancer patients’ withholding of “difficult” questions or asking less questions when they feel their HCPs might in a bad mood acts as reciprocal exchange. This means a short-term sacrifice for the long-term amicable patient-provider that has the potential of yielding more informational values. In the context of this study, informational gains occur when resources are exchanged, whereas human interactions are manifested in patients’ interaction with their various social ties. Findings of this study add to the literature because they identify both “nurturing the support network” and “focusing on positive interactions” as two of the key factors that influence Chinese cancer patients’ health information activities. However, these two theoretical categories might be better understood if additional evidenced-based knowledge is available on how to better translate Chinese cancer patients’ rationales in interacting with health information into fruitful health interventions. Future studies could investigate how to better facilitate more productive social interactions in improving cancer patients’ communication outcomes, especially regarding patient-provider communications, as these findings might shed light on how to make Chinese cancer patients less likely to withhold or sacrifice their questions.

RESPONDING TO CULTURALLY-SENSITIVE CANCER CARE.

Responding to culturally-sensitive cancer care shows how Chinese cancer patients form their questions, how they wish to approach these questions, and how well they are satisfied with the answers they received. All are influenced by their cultural standing and the macro sociocultural milieu (e.g., medical environment). Chinese cancer patients have different perceptions of and responses toward how well they can take care of their cancer, under the macro social and cultural environment (e.g., the unique Chinese medical system and patient-doctor relationship). These culturally grounded perceptions and responses influence the way cancer patients address their cancer-related concerns, formulate questions about these concerns, find answers for these concrete questions, and interact with sources of information about these questions. Some Chinese cancer patients consider their own cultural context (e.g., how to appropriately interact with their doctors) as a factor that could hinder how they wish to take care of their cancer, including the way they prefer to interact with various sources of information. For other cancer patients, although they are not as aware how their cultural environment influences their cancer management (e.g., how the Chinese medical system is different from the ideal medical system or the medical systems in other societies), they follow ‘common sense’ notions in responding to how they wish to carry out their cancer care.

Participant No.14 (Age 55, Male, Married)

RESEARCHER: What are other things regarding your health or disease that you consider as have to have?

PARTICIPANT NO.14: There are a lot of things. Big things like which treatment is the best choice for me and small things like whether food offered by this hospital is good.

RESEARCHER: These things are different in terms of importance.

PARTICIPANT NO.14: Well you can't really say what you eat is not important. I think it is the most important thing to people.

If you don't eat you wouldn't be able to do anything. If you don't eat good food, your health will prevent you from doing anything. Wouldn't you agree?

Here, though the participant does not specifically use the word "common sense," it is clear that the way he assigns importance to food is unique to the Chinese culture. The importance of properly responding to the need of good food, family relationships, and patient-doctor interaction are further explained in the following conversation.

RESEARCHER: Yes. I agree. What are the things that you wish to know but could live without?

PARTICIPANT NO.14: Information about fancy things.

RESEARCHER: What do you mean by 'fancy things'?

PARTICIPANT NO.14: Things like medical experiments, new drugs, clinical trials.

RESEARCHER: Why do you consider them as fancy?

PARTICIPANT NO.14: Because 90% of the times these things are there because either your doctor want to get more money from you, or drug companies want to test their drugs on you.

RESEARCHER: What makes you think that?

PARTICIPANT NO.14: One of my relatives was killed by these things. He thought it could save his life and get into those expensive programs. He was able to live at least for 5 years, if things go well.

He died two months after he got himself into those programs. Those programs are simply there to con cancer patients. I tried to talk him out of it but he wouldn't listen. Now I have cancer and I will never be interested in hearing anything about those shady things.

RESEARCHER: You said 90% of the times. So you think there is a possibility that those things might work?

PARTICIPANT NO.14: Yes. Some of the cancer patients I know got better by taking a new drug.

RESEARCHER: Do you often exchange information with people you know?

PARTICIPANT NO.14: Yes.

RESEARCHER: Could you give me some examples?

PARTICIPANT NO.14: The ones I said are not enough?

RESEARCHER: Yes. The more the merrier, as the examples could help me understand your insights and experiences.

PARTICIPANT NO.14: I will see how many examples I could think of. Does talking to my family members count?

RESEARCHER: Yes.

PARTICIPANT NO.14: I talk about what I feel with my wife and daughter. They've been there with me the moment I know I have cancer.

RESEARCHER: Could you recall the last conversation you had with them?

PARTICIPANT NO.14: Yes. They asked me about how I feel, what do I want to eat, whether I feel like resting. You know, trivial stuff. They also asked me to ask some questions when I see my doctor again.

My family likes to ask me questions about my condition and my treatment. Whenever I'm not able to answer their questions, they would ask me to ask my doctor so that they would have a better idea of my health.

RESEARCHER: That's really nice!

PARTICIPANT NO.14: Yes. They are the people who are closest to me.

RESEARCHER: Are you able to learn things by asking your doctor questions on your family's behalf?

PARTICIPANT NO.14: Yes. I've learned a lot. And I always told my doctor where my questions come from if there are my family's questions. My doctor has already met my wife and my daughter so he would understand.

He would really explain things to me in details. And whenever the answer might cause my family to worry, he would tell me to only say this and that so that my family won't be too worried.

How well Chinese cancer patients' experience cancer care overlaps with their culturally-sensitive needs (e.g., Chinese food therapy) influences the questions or concerns that these patients develop during their cancer continuum. Some Chinese cancer patients are grateful that they are in a society where everything related to traditional Chinese medicine is readily available. This, in turn, results in the development of questions and ways they plan to answer these questions in ways that are congruent with their evaluation of how well they are taking care of their health in a culturally-sensitive manner (e.g., in congruent with their beliefs). Other patients with different perceptions and experiences related to traditional Chinese medicine may have limited concerns or questions related to traditional Chinese medicine. For instance, some cancer patients choose to wait until the right time to formulate their questions regarding traditional Chinese medicine, when they believe their current cancer is being well taken care of.

> *Participant No.5 (Age 52, Female, Married)*
>
> **PARTICIPANT No.5:** I see. The questions I have now are about whether it is wise for me to integrate TCM treatments into my current western style one.
>
> **RESEARCHER:** Have you asked your doctor about these questions?
>
> **PARTICIPANT NO.5:** Not my doctor in this hospital. I do not think my doctor [at this hospital] has adequate knowledge on traditional Chinese medicine. I have asked him many questions about adding traditional Chinese medicine therapy into my current western-style treatment. He barely gave me a definitive answer.
>
> As for my traditional Chinese medicine doctor, he quoted many results to prove his beliefs and told me that it would be okay to integrate traditional Chinese medicine therapy with my current treatment, as long as I do it with caution and in tandem with my current western-style treatments.
>
> Regardless, I did not push him (the western-style doctor) further with my doubts. I did not want to anger him. He will be treating me afterwards.
>
> Here it is clear that the participant is actively seeking answers for her questions as a way to satisfy her cancer care needs. Below, she further explains her activities in responding to her desires for knowing more about traditional Chinese medicine.
>
> **RESEARCHER:** You have two doctors that you talk with frequently?
>
> **PARTICIPANT NO.5:** Yes. I can have as many doctors as I want.
>
> **RESEARCHER:** Why would you want to have as many doctor as you want?
>
> **PARTICIPANT NO.5:** To answer my questions with multiple perspectives.

RESEARCHER: It sounds that you have a lot of questions, or things you want to know that you have not yet asked your doctor?

PARTICIPANT NO.5: I have a lot of things I want to know. I have yet to ask my doctor my questions. He seemed to be busy. Maybe I will ask my questions next time. Sometimes I feel like it's not right to bother him at all. He always looked busy and tired.

RESEARCHER: You just said you could have as many doctors as you want?

PARTICIPANT NO.5: Yes. But my doctor who is giving me my cancer treatment is different. Compared to other doctors I could visit, he knows my condition the best. I do not think I would just change to another doctor and leave my current treatment in the middle of nowhere.

I only sought a traditional Chinese medicine doctor because he (my current western style doctor) really does not know much about traditional Chinese medicine. I was thinking about visiting more traditional Chinese medicine doctors, because different traditional Chinese medicine doctors might have different tips or tricks.

……

Participant No.16 (Age 42, Female, Married)

RESEARCHER: Back to a topic we discussed earlier. You mentioned that you are interested in how to take care of yourself. Have you visited a traditional Chinese medicine doctor for your dietary self-care concerns?

PARTICIPANT NO.16: No.

RESEARCHER: Why not?

PARTICIPANT NO.16: I do not think it is necessary to visit a traditional Chinese medicine doctor for things related to my diet. Traditional Chinese doctors are more useful for people who want to integrate traditional Chinese medicine based treatments in their treatment plan.

RESEARCHER: You are not interested in traditional Chinese medicine based treatments?

PARTICIPANT NO.16: No.

RESEARCHER: May I ask why?

PARTICIPANT NO.16: Because both my friends and my husband think it will not help me right now.

RESEARCHER: What do you mean by ‘right now’?

PARTICIPANT NO.16: I think traditional Chinese medicine based treatment might be useful after I am done with my current western style treatments.

RESEARCHER: You are interested in traditional Chinese medicine based treatments, just not now?

PARTICIPANT NO.16: Yes. Because right now knowing too much would only be distractions that I cannot handle.

……

Participant No.10 (Age 45, Female, Married)

RESEARCHER: Can you share another example of the questions you have concerning your cancer or health?

PARTICIPANT NO.10: I want to know whether my treatment will work or not.

RESEARCHER: Have you asked your doctor this question?

PARTICIPANT NO.10: Yes. He told me that for some patients this treatment is really effective, and for others it is not. And in order to know whether it works or not on a patient, this patient has to try it first.

RESEARCHER: Are you satisfied with this answer?

PARTICIPANT NO.10: No.

RESEARCHER: Did you ask your doctor more about the effectiveness of your treatment?

PARTICIPANT NO.10: No.

RESEARCHER: Why?

PARTICIPANT NO.10: I do not think he would just tell me if this treatment might be ineffective for me. I do not think this hospital would use this treatment if it is not effective. I think his answer is okay, though it does not answer my questions.

RESEARCHER: It seems to me that you are not really worried that these questions are not being answered?

PARTICIPANT NO.10: I'm worried. But there is nothing I could do to make my doctor answer my questions.

The status and quality of their cancer care influences the way Chinese cancer patients interact with health information as well as their satisfaction with it. Chinese cancer patients also organize how they plan to address their questions based on their perceptions of the overall medical environment and cultural practices (e.g., not asking difficult questions as a way to show respect to their HCPs). Factors or conflicts that are commonplace in the Chinese society also shape Chinese cancer patients' interaction with health information, such as when there is a lack of trust between Chinese cancer patients and HCPs. Though cancer patients consider their HCPs a vital source of information, many of them are also skeptical of the HCP's information. In situations like these, patients often consult with their family or friends to balance their lack of confidence in information shared by their HCPs. What is clear in the conversations is that while many Chinese cancer patients consider their HCPs rich sources of information, they also may have alternative motives such as monetary gains from prescriptions or treatment. For instance, a common reaction of Chinese cancer patients toward the information shared by their HCPs advocating for more advanced drugs or treatment options is "my doctor is trying to extract more money from me." Though different patients have varied attitudes toward their HCPs, supplementing information gained from HCPs with additional information is a way for these patients to negotiate trust, triangulate sources, and balance various perspectives.

> *Participant No.17 (Age 44, Male, Married)*
>
> **RESEARCHER:** Where did you hear about medical trials?
>
> **PARTICIPANT NO.17:** I heard them from my wife. She's been researching a lot of information about everything cancer related. I get most of my information from either my doctor or my wife.
>
> **RESEARCHER:** How would you weigh these two sources of information?
>
> **PARTICIPANT NO.17:** I don't understand [your question].
>
> **RESEARCHER:** Whose advice do you follow more, your wife's or your doctor's?
>
> **PARTICIPANT NO.17:** Yes, I almost always follow my wife's advice. But not as much the things that my doctor tells me. My doctor has to make a living. And although there are rumors about implementing tougher rules or regulations, doctors

are still getting incentives from the drugs that they prescribe to their patients. I think this issue still very problematic. Yet my wife, she has nothing to gain with me taking more drugs than I need. Actually, she would actually be happy about the money saved. [smiles]

RESEARCHER: What do you think of your doctor?

PARTICIPANT NO.17: My doctor is very easy-going, I like him. Though he is young and doesn't have all the answers to my questions, I know he is trying. He is different from other doctors I have dealt with. Most of the time, he is extremely approachable. He really wants to do well in his job and I trust him.

RESEARCHER: But you don't trust him very much?

PARTICIPANT NO.17: You could say that.

Here it is clear that participant 17 distrusts his doctor, though he considers his doctor as "different" or better than other HCPs. He further explains how he reacted to his lack of confidence toward his doctor.

RESEARCHER: Have you ever avoided information from your doctor?

PARTICIPANT NO.17: Not obviously. But I'm not planning to believe some of the things he said or take some of the treatments he recommended. They are really expensive and some of my cancer friends told me that they are not effective at all.

RESEARCHER: Are your treatments expensive?

PARTICIPANT NO.17: My treatment is expensive, especially including these new drugs. But I don't want to say that to my doctor. I don't want him to feel like I was complaining or I couldn't afford my treatment. I don't want him to lose hope on me.

RESEARCHER: Are your cancer friends' sources that you use to differentiate ineffective treatments with effective ones?

PARTICIPANT NO.17: I like to talk to my fellow cancer patients. Sometimes it seems like I am simply a job to my doctor. And he has many jobs. My cancer friends are different. We are in this battle with cancer together. We are all in pain and exhausted, which makes our conversations more meaningful.

RESEARCHER: You seem to me like the kind of person who likes to get his facts straight?

PARTICIPANT NO.17: [smiles] I think it's necessary that I do my homework before I talk to my doctor. I used to have condescending doctors who made me feel like I was ignorant. To be honest, at that time, I did not know much, even though my past illnesses were nothing compared to cancer [in terms of how much knowledge is required].

So I searched for information as best as I could, and asked my doctor questions that I had regarding my treatment options. I feel like I might know more than he does now, which is a good thing.

……

Participant No.12 (Age 67, Male, Married)

RESEARCHER: Do you share all of your questions or concerns with your family?

PARTICIPANT NO.12: Yes. They know everything about my health.

RESEARCHER: Do you usually talk about the questions and concerns you have with your family before you even talk to your doctor?

PARTICIPANT NO.12: Yes.

RESEARCHER: Could you please describe a scenario when you shared your questions or concerns about your health to your family members?

PARTICIPANT NO.12: The family was making hotpot and my son was pouring me a bowl of soup (from the hotpot). My wife said that I probably should wait utill it cooled down to eat it, because she learned from TV programs that one of the reasons China has a lot of patients with stomach cancer is because Chinese people like to eat hot stuff and drink hot water.

She said that we should not drink hot water from now on, especially me, as she knows that I like things hot. And also, I should not eat spicy foods, as they would stimulate my stomach, which would be bad for me.

My son thought it was okay for me to eat from the hotpot as long as it was not that spicy. I told them that I will ask my doctor what I can eat or drink.

Here, unique cultural differences are reflected in the answer that the patient provides in terms of what might have caused his cancer and what might improve his health conditions.

The importance of culturally-sensitive cancer care, i.e., understanding family bonds and involvement in cancer management is further explained in the following conversation.

RESEARCHER: What did you keep in mind when deciding what to eat that day?

PARTICIPANT NO.12: I waited for the soup to cool off, but I did eat the spicy hotpot, as it was not that spicy.

RESEARCHER: Sounds like your family is really involved in helping you make decisions that would be best for your health.

PARTICIPANT NO.12: Yes. Having cancer helped me realize that it is really important to have a good family. Dying is not the scary part for people of my age.

The scariest thing I have seen is people fighting cancer by themselves. Though I have cancer as well, I feel as if I am the lucky one. My family is helping me with everything I might need help with. Finding health information that I need is a family affair.

RESEARCHER: You have seen people fighting for cancer by themselves?

PARTICIPANT NO.12: Yes. I do not feel like talking about it though. They have had enough. They do not need me to talk behind their back.

RESEARCHER: Are there things that you would not share with your family?

PARTICIPANT NO.12: No. The deserve to know everything.

RESEARCHER: What about your privacy? [smiles]

PARTICIPANT NO.12: [laughs] Only young people talk about privacy these days and make everything secretive. I do not keep secrets from my family

RESEARCHER: Some cancer patients I have interviewed said that they would not share all the negative feelings or bad drug reactions to their family.

PARTICIPANT NO.12: I think that may be because their family are not there with them every step of the way. There is no way for me hide bad drug reactions because there always is someone at my side.

I also think it is not right to hide things from families, as they are supposed to be the people who need all of the information possible to make decisions regarding my health. I say this all the time.

RESEARCHER: Have you advised other cancer patients when they ask you whether they should share even the bad things to their families?

PARTICIPANT NO.12: Not advised, but we talk. Some of them feel bad about having to drag their children from work to go to their appointments with the doctor. I have always say that it is only right to have children accompanying you while talking with the doctor.

Children will not want to miss their parents' appointments either, so there is no need to feel bad. Also, young people have the ability to understand things more clearly.

RESEARCHER: Is that one of the reasons why you like to have your children at your side when talking to the doctor?

PARTICIPANT NO.12: Yes. And I always record my conversations with the doctor and nurses.

RESEARCHER: Why do you do that?

PARTICIPANT NO.12: It is difficult for me to remember things. It would be easier if I was accompanied by my children, or else I might forget what the doctor said. Plus, it is safe to have recordings for rainy days. One never knows what will happen. I want to make sure that if something happened, I have some evidence at my disposal.

RESEARCHER: What do you mean by rainy days?

PARTICIPANT NO.12: One never knows what may happen next (天有不测风云), so it's better to be prepared than to be sorry.

RESEARCHER: Do you not trust your HCPs?

PARTICIPANT NO.12: I trust them. I think everyone makes mistakes, though. If and when my doctor makes one, I need to be able to prove that I was the victim. I do not hope things like this happen, but I have to be prepared.

RESEARCHER: Who made the suggestion that you should record conversations with your HCPs?

PARTICIPANT NO.12: I did. I was inspired by something I saw on TV the other day. This person was only able to get compensated because she had recordings that could prove her doctor made promises that he could not deliver.

RESEARCHER: I assume that your doctor knows, considering your recorder is really not that small?

PARTICIPANT NO.12: No, she does not know.

> **RESEARCHER:** Have you recommended this practice to other cancer patients you know?
>
> **PARTICIPANT NO.12:** No. It never really occurred to me that I should make such suggestions.
>
> **RESEARCHER:** It might blow your cover? [smiles]
>
> **PARTICIPANT NO.12:** Yes, it might blow my cover. [smiles]

Understanding "Responding to Culturally-sensitive Cancer Care" in Context

Research findings of this study suggest that Chinese cancer patients' health information preferences and practices are shaped by three factors: how patients choose to form their questions, the way they interact with various sources of information, and the way they accept and respond to the cancer care they receive all are negotiated against individual sociocultural contexts. How Chinese cancer patients respond to culturally-sensitive care guides the way they react to culturally-specific needs (e.g., questions related to traditional Chinese medicine, food therapy), the way they interact with their family members and HCPs (e.g., in terms of how many questions they choose to disclose to their HCPs), and how these patients wish their cancer care to unfold (e.g., whether they are satisfied with their current cancer care). Despite how current literature has somewhat addressed the uniqueness of the Chinese culture (e.g., Cao, 2011), the influence of cultural factors on Chinese cancer patients' information activities is less clear. This theoretical category, "responding to culturally-sensitive cancer care," adds to current studies by addressing the fundamental role of culture (e.g., the larger culture milieu, specific cultural practices, such as food therapy) in shaping Chinese cancer patients' health information preferences, practices, and the relationship between them.

Results of this study propose that Chinese cancer patient's cultural standing, how well the care they received could address their culturally-sensitive needs, and larger medical and cultural environments influence the questions that they ask (e.g., "Should I drink chicken soup during my rehabilitation period?"), the way they address their questions (e.g., "Will knowing the answer of to question benefit my family?"), and the way they interact with various sources of information (e.g., "Will my HCPs dislike questions regarding traditional Chinese medicine?"). Culture constitutes a set of beliefs, behaviors and social entities held by a group of people that serve as the foundation for their social identities.

Culturally-sensitive care, then, is "the provision of care that takes into account the particular cultural perspectives of an individual patient" (Hunt, 2007, p.230). Within the healthcare context, the influence of culture shapes how people of a certain cultural group expect "the role that families and communities will play in [their] experience of illness and shapes [their] understanding of what it is to be a virtuous clinician, or a virtuous patient" (Hunt, 2007, p.229). However, the influence of culture alone does not adequately explain why responding to culturally-sensitive care is a key factor in shaping Chinese cancer patients' interactions with health information. Specific cultural aspects of Chinese culture need to be discussed in order to put the findings of this study into a proper context.

The nuanced nature of culturally-sensitive care depends on individual research contexts (M. Park, Chesla, Rehm, & Chun, 2011). This may result from the fact that it is usually difficult to identify what and how cultural factors influence patients' healthcare outcomes (Hunt, 2007). Studies on Chinese patients within various disease contexts have addressed the need to acknowledge the unique cultural context Chinese patients face while trying to understand the attitude and behaviors of these patients (Lee & Bell, 2011; Tao et al., 2016; Xiong, Stone, Turale, & Petrini, 2016). For instance, Tao and associates (2016) discuss the importance of HCPs to develop a collaborative relationship between Chinese rectal cancer patients and their family members.

In another study on Chinese breast cancer patients' decision making processes, Xiong and colleagues (2016) identified factors such as filial piety, male authority within the family, traditional Chinese medicine, and financial burden as the culturally-specific factors that influence these patients' healthcare decisions. However, although these studies offer important insights, they do not shed light on how these sociocultural factors shape Chinese cancer patients' health information preferences and practices. The findings of the present study add understandings of how sociocultural dynamics reveal the way Chinese cancer patients respond to their cancer care. Usually carried out with consideration of their culturally-specific healthcare needs, especially in terms of traditional Chinese health beliefs (e.g., Yin-Yang balance), the way patients integrate their family members in the continuum of cancer care, and the way they should behave around their HCPs is very telling.

One of the hallmarks of Chinese culture is the Yin-Yang philosophy. The Yin-Yang balance is the founding principle to traditional Chinese medicine and food therapy (R. Wong, Sagar, & Sagar, 2001; Xu, Towers, Li, & Collet, 2006). Chinese cancer patients use traditional Chinese medicine in their everyday cancer care(Hesketh & Zhu, 1997), mostly in the form of a supplement to western medicine (H. Y. L. Chan et al., 2014; W. K. W. So et al., 2012; Xu et al., 2006). Research suggests that Chinese cancer patients believe that the philosophy of Yin-Yang, or more specifically, traditional Chinese medicine, helps to strengthen the "origin" of their body and mind (i.e., Qi) by removing toxins and soothing the mind (H. Y. L. Chan et al., 2014). However, though Chinese cancer patients have a positive attitude toward traditional Chinese medicine, they typically are concerned with the lack of knowledge and the unpleasant experience (e.g., the burden of care) they face while using with traditional Chinese medicine (H. Y. L. Chan et al., 2014). The present study reveals that culturally-grounded beliefs (e.g., Yin-Yang beliefs, traditional Chinese medicine, food therapy) are woven into Chinese cancer patients' interactions with health information in various aspects (e.g., questions and the way they interact with information sources).

Chinese cancer patients' responses to the need for culturally-sensitive care or the unsatisfactory results of cancer care that lack culturally-sensitivity are often shaped by these cultural beliefs. As findings of this study suggest, different cancer patients have different degrees of curiosity and, in turn, a range of questions regarding if and/or how to integrate traditional Chinese medicine in their formal treatment. This process, of course, often involves patients' family members in the decision-making and execution processes. This not only confirms the role of traditional Chinese beliefs on health in shaping Chinese cancer patients' cancer care experiences and expectations, but also it reveals that these patients often weigh their questions about traditional Chinese medicine with consideration of the opinions of their family members and the possible reactions of their HCPs.

In addition, outcomes of this study suggest that for Chinese cancer patients, both their micro individualities and macro sociocultural environment are two actors that shape the way they respond to the cancer care they desire. Despite how current literature has acknowledged the arrangement and connection between cancer patients' individuality and cultural uniqueness (Hovick & Holt, 2016; Van Houdt, Sermeus, Vanhaecht, & De Lepeleire, 2014), especially in the context of cross-cultural studies (Im et al., 2016; Zeissig et al., 2015), these studies, typically conducted in western societies, seldom consider the role of family in these patients' cancer care.

For instance, a study on Chinese cancer patients' cardiopulmonary resuscitation decisions identified that gender, age, place of residence, unexpected medical problems prior to death, time interval between cancer diagnosis and death, relationship to patient, and hospitalization in the last month of life influence these patients' decisions (Z. Zhang, Chen, Gu, Liu, & Cheng, 2014). However, Zhang et al provided little empirical evidence on how cultural and family involvement might influence this decision-making or communication process. Overall, findings of this dissertation suggest that factors that influence Chinese cancer patients' health information preferences, practices, and the relationship between them are best captured by the basic social process of interacting with health information as a family activity. This can be illustrated through five theoretical categories: getting prepared for managing cancer; prioritizing questions based on family needs; balancing truth, trust, and respect; navigating around information sources; and responding to culturally-sensitive care.

Overall, findings of this study underscore the role of family in Chinese cancer patients' information activities, and how social relationships and the general cultural milieu influence these patients' health information interactions. This highlights the importance of taking a connected view of cultural factors (e.g., culturally-grounded health beliefs), family involvement (e.g., the centrality of family in Chinese cancer patients' care management), and Chinese cancer patients' individualities in their health information activities, which will be discussed further in the Conclusion.

Summary

Theoretical categories identified in the data analysis are: *getting prepared for managing cancer; prioritizing questions according to family needs; balancing truth, trust, and respect; navigating around information sources (with two subcategories, nurturing the support network and focusing on productive interactions),* and *responding to culturally-sensitive cancer care*. The theoretical categories identified in this dissertation consistently resonate with the basic social process of interacting with health information as a family activity. Chinese cancer patients form the basis of their health information behavior based on how their cancer-related concerns could affect themselves as well as their family members. Taken together, the categories identified in the data analysis illustrate how these factors shape Chinese cancer patients' interaction with health information. To ensure the integrity of these findings, necessary measures have been taken to outline the robustness of research rigor, which can be found in the following section.

RESEARCH RIGOR

The discipline considers rigor in qualitative research in terms of its trustworthiness, a terminology that mirrors the concepts of validity and reliability in quantitative research. As it is important for quantitative research to have desirable validity and reliability, it is important for qualitative research to have the characteristic of trustworthiness, for "the assumptions underlying qualitative research is that reality is holistic, multidimensional, and ever-changing; it is not a single, fixed, objective phenomenon waiting to be discovered, observed, and measured as in quantitative research" (Merriam , 1998, p.202).

In qualitative research, trustworthiness concerns the soundness of the methodology adopted and whether research techniques utilized are adequate to untangle the social phenomenon of interest (Holloway & Wheeler, 2002). Establishing and ensuring research trustworthiness is critical to the integrity of qualitative research findings. According to Lincoln and Guba (1985), there are four elements to trustworthiness of qualitative research: *credibility*, *transferability*, *dependability*, and *confirmability*. The attainment of these four elements secures the research's trustworthiness and achieves the "applicability, consistency, and neutrality" of the study (Lincoln & Guba, 1985, p.143).

A study could adopt many research strategies to claim these four qualities. Researchers have argued that techniques such as prolonged engagement, persistent observation, triangulation, leaving an audit trail, member checking, checking for researcher bias, making comparisons, theoretical sampling, using extreme cases, ruling out spurious relations, peer debriefing, and rich and thick description could help build research rigor (Becker, 1970; Creswell, 1998; Kidder & Fine, 1987; Y. Lincoln & Guba, 1985; Maxwell, 1996; M. Miles & Huberman, 1994; M. B. Miles

& Huberman, 1984; Onwuegbuzie, 2003). A number of these techniques were adopted in this study.

Credibility

Credibility in qualitative research concerns the truthful depiction of the research findings in relation to reality (Lincoln & Guba, 1985). According to Lincoln and Guba (1985), credibility could be produced via prolonged engagement, persistent observation, and negative or deviant case analysis. Though observation plays a key role in both prolonged engagement and persistent observation, the differences between these two constructs are profound. As Lincoln and Guba (1985) explained:

> If the purpose of prolonged engagement is to render the inquirer open to the multiple influences - the mutual shapers and contextual factors - that impinge upon the phenomenon being studied, the purpose of persistent observation is to identify those characteristics and elements in the situation that are most relevant to the problem or issue being pursued and focusing on them in detail. If prolonged engagement provides scope, persistent observation provides depth (Lincoln & Guba, 1985, p.304).

Prolonged engagement and persistent observation were achieved by the researcher spending a great length of time in Chinese cancer hospitals observing cancer patients and researching the subject matter, so that the researcher could better understand the social context and culture setting where Chinese cancer patients interact with health information. In addition, this study adopted a negative case analysis to ensure the credibility of the findings. According to Lincoln and Guba (1985), negative case analysis involves searching for and discussing data that contradicts with the main research findings and patterns. To generate further credibility, the researcher examined the individual case that had the most distinctive data characteristics. After careful examination of this case, the distinctive traits of this case were later incorporated into the research model. This later also served as a starting point for new rounds of theoretical sampling.

Transferability

Transferability refers to the applicability of the findings, whether they could be applied to different contexts and settings (Y. Lincoln & Guba, 1985). It concerns the theoretical and methodological parameters of the research (Marshall & Rossman, 1999). According to Lincoln and Guba (1985), the thick description technique enhances a study's transferability by rendering the social phenomenon in rich and thick detail from various participants' perspectives. This study weaved together interview transcriptions, field notes, memos, and participants' feedback to present a detailed account of cancer patients' interaction with health information. The adoption of the constant comparative method during the data analysis process also ensured the integrity of the research findings, and that the subsequent findings could transfer to other contexts and situations.

Dependability

Dependability ensures that the research achieves consistency across changing conditions of the social phenomenon under question (Y. Lincoln & Guba, 1985). In the context of this study, the technique adopted to ensure dependability was external audits. External audits involve introducing an auditor to examine the process and product of the research study (Y. Lincoln & Guba, 1985). External audits evaluate whether the interpretations and findings of the research were grounded in the data (Y. Lincoln & Guba, 1985). The researcher introduced a former cancer caregiver as the auditor of this study. The research purpose, questions, processes, and methodology were all explained to the auditor. In addition, theoretical categories emerged from the data and the preliminary theoretical framework were also explained to the auditor to ensure the findings were true to the data.

Confirmability

Confirmability concerns the objectivity and neutrality of the findings of a study (Y. Lincoln & Guba, 1985). Confirmability ensures researcher bias did not generate the study's findings, but that they were shaped by data (Y. Lincoln & Guba, 1985). One technique utilized in this research to generate confirmability was leaving an audit trail, or a transparent and detailed account of every research step taken from the beginning of the research (Y. Lincoln & Guba, 1985). According to Halpern (1983), a series of raw records connects the audit trail. The list of raw records adopted in this study were *raw data* (e.g., audiotapes, field notes, etc.), *raw reduction and analysis products* (e.g., theoretical memos), *data reconstruction and synthesis products* (e.g., categories, themes, definitions, relationships, etc.), *process notes* (e.g., research strategies, research rationales, theoretical model design, etc.), *materials relating to intentions and dispositions* (e.g., reflexive memos, predictions, etc.), and *instrument development information* (e.g., patterns recognized, repeated observations, etc.) (as cited in Lincoln & Guba, 1985). The adoption of an audit trail aligned with the iterative, dynamic, and reflexive nature of grounded theory approach. Thus, interview audiotapes, interview transcripts, memos, field notes, theoretical sorting process, reflexive memos, categories, theoretical categories, relationships, social process underlying the research questions, along with the preliminary development of the theoretical model, were all carefully and thoroughly depicted in this paper to preserve a transparent research path.

Summary

This chapter presented the research findings in detail, and identified basic social process and theoretical categories that emerged. Direct quotations from the interview transcripts are provided to illustrate the findings. Relevant literature connected the findings of this study with the broader research context. In order to obtain optimal research rigor, the researcher adopted various techniques to secure the credibility, transferability, dependability, and confirmability of this study, which was presented in the latter part of this chapter. Implications of the research findings will be discussed in detail in the following chapter.

This is the first study to investigate factors that Chinese cancer patients' health information preferences, practices, and the relationship between them from an in-depth perspective, with consideration of the unique cultural beliefs these patients value. Drawing on data from interviews, memos, and field notes, the researcher illustrated how the basic social process of interacting with health information is a family-centered activity in Chinese cancer patients' interaction with health information. This is further reflected in the methods these patients employ to get prepared for managing cancer; prioritizing questions according to family needs; balancing truth, trust, and respect; navigating around information sources (nurturing the support network and focusing on productive interactions); and responding to culturally-sensitive cancer care. This chapter also discussed relevant literature in relation to these research findings, with particular emphasis on the role of family and culturally-grounded health practices in shaping Chinese cancer patients' health information preferences and practices. In addition, this section offered potential implications for health communication research, practices, and policy.

To conclude, it is critical to underscore the indispensable role of Chinese cancer patients' family members, as not only does Chinese cancer patients' interaction with health information occur within the family unit, but these family members' needs are also key to understanding how and why these patients prioritize their health information preferences. Their relationship with HCPs, aside from the influence of their family members, also heavily influences the interplay between truth, trust, and respect, navigation and negotiation of information sources, and the way Chinese cancer patients respond to culturally-sensitive cancer care. It is practical to design health interventions that includes patients, family members, and HCPs, as well as other key shareholders in Chinese cancer patients' interaction with health information, so that effective health communication can be carried out. In the following chapter, the author will discuss the limitations of the research and offer the final conclusion of this dissertation.

Chapter 5: Conclusions

This chapter begins by discussing the limitations of this dissertation, and how the findings of this dissertation should be interpreted with care. That is, how Chinese cancer patients' interaction with health information is a family activity (the core category), and how this core category could be further interpreted by the way Chinese cancer patients getting prepared for managing cancer, prioritizing questions according to family needs, balancing truth, trust, and respect, navigating around information sources, and responding to culturally-sensitive cancer care should be understood in light of limitations of this study. This chapter ends with the final conclusion of this dissertation.

LIMITATIONS

The explorative nature of this research justifies the adoption of qualitative interview method, with constant comparative analysis as the main interpretation vehicle. This also opens up the possibility of some of the inherent limitations of qualitative research. This research adopted a qualitative research design, and, inevitably, traded the width of generalization for the depth of understanding. The researcher made the decision to build an in-depth understanding of Chinese cancer patients' health information preference and practices. Thus, finite heterogeneity is a limitation to this research. The sample size of this study is eighteen, which is justifiable, as most grounded theory studies' sample size ranges from 10 to 30 (Shyu, Tsai, & Tsai, 2010).

The interpretive approach used in this study, and the fact that the researcher came into this research with a certain world view and knowledge of the subject matter, altogether limits the objectivity of this research. To counterbalance this limitation, the researcher closely followed

Glaser and Strauss' (1967) instructions on how to conduct grounded theory studies, as well as Lincoln and Guba's (1985) measures that could ensure the reliability of research findings of qualitative studies.

Additionally, this study only interviewed Chinese cancer patients who were treated in top tier hospitals located in Beijing. Though Beijing is the first choice for most Chinese patients, especially those who are diagnosed with cancer, there might be patients who lack the resources to travel and treat their diseases in the capital city of China. There are also no interviews with those who do not have basic access to medical resources to validate their cancer diagnosis. This study did not include patients who choose to not treat their cancer, due to lack of access or other reasons. In addition, patients who have the resources to travel abroad for cancer care and management were not interviewed. All the interviewees included in this study were cancer patients who were more open-minded and willing to give their trust to the researcher, so those who refused to be interviewed were not included. Interviewees of this study also had the mental and physical strength to go through the consultation process.

However, it is important to note that the value of this research is not in its predictive abilities, a limitation for the majority of qualitative studies, but in its findings on the importance of cultural factors in influencing Chinese cancer patients' health information preferences and practices, along with the importance of addressing culture's impact on patient-centered communication. One of the many advantages of constant comparative analysis is the depth of analysis it provides the researchers and readers. Rather than taking data from its face value, like a number of quantitative analytical methods do, it gives the researcher the freedom to ask "why" and "why not," and to delve into the causality of relationships. It also gives the interviewees a chance to voice their opinions, rather than check set options in a survey. Considering the nature of this dissertation's research objectives, qualitative interview was the optimal research method.

Another advantage of the constant comparative analytical method to generate grounded theory is that it allows the researcher to develop a set of constantly evolving salient themes based on the most recent data. This ensures the theory forged in this study is data-grounded and evidence-based. The help of accompanying memos and field notes also guarantees the integrity of the theory generated. That being said, it would be better if a mixed method research design could be used to further enhance and solidify the research findings. For instance, instead of using one study design, incorporating a quantitative study to make a mixed methods two-study design could mitigate some of the limitations of the current research.

Patients' lack of knowledge in terms of which cancer stage they are classified into at the time of interview also limits the insights this study could offer. Though the sample size of this study is small, having information on their stages might still facilitate a simple crosstab analysis of the additional relationships the interview data could offer. One way to address this issue in future studies is to use a stratified sampling technique to gain insights on health information preferences and practices of Chinese cancer patients of different stages. Researchers should note that in order to gain accurate data on participants' cancer stage, self-administered surveys might not be a viable option. As most of the Chinese HCPs still choose not to disclose the diagnostic information to cancer patients (Wuensch et al., 2013), Chinese cancer patients who know they have cancer might be limited in their knowledge on where they are in terms of their cancer stage.

CONCLUSIONS

Although insights on Chinese cancer patients' interaction with health information are available (Bo Xie et al., 2015, 2016), less is clear about how Chinese cancer patients weigh their health information preferences and how they choose to translate these preferences into practices. This study aims to close this knowledge gap. The research question, "What are the factors that influence Chinese cancer patients' health information preferences, practices, and the relationship between them?" is asked and answered. The basic social process or the core category that could represent Chinese cancer patients' interaction with health information is that interaction with health information is a family activity. Specifically, the core category is manifested in the way Chinese cancer patients *get prepared for managing cancer*; *prioritize questions according to family needs*; *balance truth, trust, and respect*; *navigate around information sources*; and *respond to culturally-sensitive cancer care*.

Findings of this study emphasize the important role of culture, especially family, in shaping Chinese cancer patients' health information activities. Overall, insights gained from this research call for cancer care that could address the unique role of family in shaping cancer patients' health information preferences and practices, such as mechanisms like family-centered care and patient-family-provider communication mechanisms. One possible step to further acknowledge and address Chinese cancer patients' culturally-sensitive cancer care needs involves integrating culturally-respectful tailored communication interventions to these patients that could involve patients, family, and HCPs into the communication process.

Tailoring could be understood as "any combination of information or change strategies intended to reach one specific person, based on characteristics that are unique to that person, related to the outcome of interest, and have been derived from an individual assessment" (Kreuter & Skinner, 2000, p.1). There are four components that make tailored health communication unique: 1) a method of garnering information on individuals' health information preferences, 2) a database for storing relevant people-centered health information, 3) a set of principles that guide decision-making process, and 4) a two-way communication channel that responses to messages delivered (Kreuter, Farrell, Olevitch, & Brennan, 1999).

Research has found tailored health communication to be more effective than standardized communication mechanisms (Kreuter & Strecher, 1996), due to its ability to make messages more relevant to the communication recipient. It generates positive health outcomes, such as promoting nutrition interventions (Enwald & Huotari, 2010), cancer screening (Durant, Newsom, Rubin, Berger, & Pomerantz, 2014), sexual health interventions for specific ethnic groups (Noar, Crosby, Benac, Snow, & Troutman, 2011), and patient-provider communication (Bonner et al., 2014; Brandes et al., 2014). In addition, tailored health communication better integrates online communication resources, making it a more cost-effective option for communication tasks (Suggs & McIntyre, 2007), like using social media to battle infectious diseases (e.g., dengue) (Lwin et al., 2014). Compared to standardized communication interventions, it also adds cultural aspects that are unique to the target audience in the message design and intervention execution, so that more productive results could be generated (Bartolome, Chen, Handler, Platt, & Gould, 2016).

As it is less clear how Chinese cancer patients could benefit from tailored health communications that involve patients, family, and HCPs, one suggestion for future research is to integrate communication interventions that could allow patients and their family members to voice their preferences. Such questions would be how much they want to integrate traditional Chinese medicine into the care process, and how ready they are to accept HCPs' information, even the difficult news. This strategy requires some HCPs to actively adjust their communication styles based on the preferences and characteristics of the patients. Similar to the practice of precision medicine, which requires sophisticated and disruptive technology innovations (Bar-Zeev, Livney, & Assaraf, 2017; Friedman, Letai, Fisher, & Flaherty, 2015) via active and positive mutually constructive communications with patients' mindful participation, HCPs could engineer patient- and family-centered communication that allow their preferences to be heard and addressed.

There are many possible mechanisms for HCPs to integrate patient-family-provider communications in their daily practice. For instance, implementing a Communication Preference Questionnaire (see Appendix B) with questions regarding patients' information and communication preferences could help HCPs better gauge their patients' preferred style of interaction and facilitate *tailored* and *targeted* information exchange with patients. It is recommended that HCPs invite their cancer patients and their family members to participate in this questionnaire at various stages of their cancer trajectory. By comparing responses, HCPs have the ability to better understand their patients' current communication mentality and, in turn, adjust their communication styles accordingly and with precision.

HCPs could also factor in medical informatics in this equation. Medical informatics is "the interdisciplinary field that studies and pursues the effective uses of biomedical data, information, and knowledge for scientific inquiry, problem solving and decision making, motivated by efforts to improve human health" (Kulikowski et al., 2012). One simple way to integrate medical informatics and culturally-respectful patient-family-provider communication can occur through incorporating a digital element to the implementation, participation, and consultation of the

Communication Preference Questionnaire. It could be beneficial to make this questionnaire mandatory, digitalized nationwide, and kept as an electronic medical record online, available to both patients themselves and their HCPs. This would accommodate situations when patients transfer to a new hospital or change their HCPs, their new HCPs could immediately gain a *precise* understanding of their new patients' preferred communication style, and in turn save precious medical resources and yield better health outcomes, such as patients' enhanced quality of life.

For instance, patients with great psychological vulnerability could be identified by answering certain survey questions. In response, HCPs could adapt their communication styles based on profiling of the patient and their questionnaire via utilizing more *euphemisms*, and adopting more *subtle* and *amicable* methods of communication. This has the potential to improve patients' satisfaction over their consultations. Additionally, this could serve as a preemptive measure to prevent psychological vulnerable patients from experiencing potential mental breakdown.

In addition, based on the responses given by patients and their family members, HCPs could decide whether to disclose private and sensitive diagnostic or prognostic information. Should the patients and their family members develop severe psychological issues due to HCPs' breaking of bad news, HCPs could use these questionnaires to inform their decisions. As the more vulnerable party in the patient-family-provider communication process, patients and their family members need to have a systematic protective mechanism that could not only *respect* their autonomy, but also *protect* their rights as *medical services/products consumers* and *information consumers*. Patients and their family members could make complaints to their hospitals should their HCPs fail to deliver the required information to them, and would have concrete evidence when the preferences they indicated in the questionnaires were blatantly ignored by their HCPs. Instead of creating a set and rigid patient information preference profile based on the Communication Preference Questionnaire, HCPs should *dynamically* and *consistently* interact with their patients and family members to detect potential changes regarding patients' health information exercises, as an effort to facilitate patient-family-provider communication as patients' predilection for information evolves as their cancer or cancer treatment progresses.

Recommendations based on the results of this study also center on paying respect to patients and their family members' role in deciding what they wish to know, and how they wish to address their questions. One recommendation provided here that could address the need for family-centered care is HCP empathy. In the context of cancer study, empathy has been well discussed (Cripe & Frankel, 2017; S.-Y. Fang, Chang, & Shu, 2015). According to Kim and associates (2004), there are two kinds of empathy from the HCPs' perspective: cognitive aspect and affective aspect. HCPs' cognitive empathy could be understood as their "ability to accurately apprehend the mental state of his or her patients (the ability to take another person's point of view) and to effectively communicate this perspective back to the patients" (Kim & Johnston, 2004, p.239), or the affective aspect of HCPs' "ability to respond to and improve his or her patients' emotional state" (Kim, Kaplowitz, & Johnston , 2004, p.239).

Empathy is important to patients' health and wellbeing. Research suggests that for patients, empathy given by HCPs is beneficial to their communication and health outcomes (for a review, see Lelorain et al., 2012). In a study on cancer patients, results suggest that patients who receive more empathy from their partners are less likely to develop depressive symptoms (S.-Y. Fang et al., 2015). However, the concept of empathy is less studied in the context of Chinese cancer care.

In one study, Tao and associates (2016) interviewed two rectal cancer patients aiming to understand ways they could facilitate their adaptation to a permanent colostomy (Tao et al., 2016). Its findings suggest that supportive communication, characterized by respect, description, empathy, and empowerment, might be an effective tool to facilitate these patients' decision making process (Tao et al., 2016). However, though this study could provide some insight on the role of empathy within the context of cancer research, findings of this study could not be directly applied to the health information context without the support of empirical evidence.

That is, results from Tao and associates (2016) could not shed light on how empathy gained from HCPs might impact the way Chinese cancer patients and their family members voice their health information preferences, the way they wish to interact with various communication shareholders, and more importantly, how satisfied they are with the patient-provider communication. Due to the unique hierarchical patient-physician relationship in the Chinese society (Hofstede, 1980; Hofstede & Bond, 1988; Ying, 2000), as well as the tension between Chinese patients and their HCPs (Z. Li et al., 2017; Shi et al., 2017; P. Sun et al., 2017), compared to shared decision-making, a communication strategy which requires patients' direct and upfront input in regard to their treatment and care, implementing HCP empathy in patient-family-provider communication might be a feasible solution to improve patients' and their family members' communication satisfaction.

Current literature suggests that effective empathy requires a great effort from HCPs, as they may have to be 1) attentive and imaginative to patients' needs, 2) ready to correct their own misperceptions when necessary, and they also have to 3) understand the complex and convoluted nature of healthcare for patient-provider relationship to work effectively (Cripe & Frankel, 2017).

This means that it may be feasible to develop a course that teaches Chinese oncologists how to best implement the abovementioned requirements for carrying out effective empathic patient-family-provider communication (Cripe & Frankel, 2017), while emphasizing respect and empowerment (Tao et al., 2016). One potential benefit of such a course is that it is cost-effective. The resources and effort needed to develop a course that teaches HCPs about empathy is less than that of a new drug development, though the course might yield positive health outcomes similar to that of a new treatment solution, with no to little side effects that could harm patients and their family members' health and quality of life. That being said, research is needed to empirically evaluate the feasibility and effectiveness of such courses, as well as other approaches that could integrate HCP empathy in Chinese cancer patients' care management.

CLOSING REMARKS

Studying *health information preferences* in relation to *health information practices* is not a matter of semantics or a practice of rhetoric, nor is investigating the differences between health information needs and wants a matter of splitting hairs. Cancer patients are, essentially, *valuable medical services/products consumers* and *information consumers*, without which there will be no need for HCPs or hospitals.

From a healthcare scholar's perspective, this research is about paying respect to cancer patients' autonomy, individuality, and cultural identity. From an advertiser's perspective, this research pays respect to medical services, products, and health information consumers' money. Every single one of us is a health information consumer and a prospective medical services/products consumer, with untapped potential and unfathomable purchasing power that could be abused by any failing patient-provide communication mechanisms, any failing medical systems, and any failing societies at large. Last but not the least, from a caring human being's perspective, this research is about raising awareness for personalized cancer care and management, above and beyond advocating the implementation of culturally-grounded patient-family-provider communication mechanism.

Every cancer patient has a story, whether these patients are valiantly proactive or surreally silent in fighting the war against cancer. One step that could help Chinese cancer patients voice their opinions is via acknowledging the role of family in shaping these patients' interactions with health information, which could be done via integrating a Communication Preference Questionnaire that could extract patients' and their family members' input on how they wish their questions about cancer care to be answered, as proposed in this study. Another step is to develop a course that could teach Chinese HCPs ways to implement *empathic* patient-family-provider communication to make patients and their family members feel respected and empowered. After all, it is only right to let patients and their family members air their opinions and let their stories be heard, at least by their HCPs, and at least with respect to their preferred communication style that are culturally respectful. That is, health communication professionals and HCPs need to be empathic, invest more time and effort in understanding Chinese cancer patients and their family members' questions, and how they wish to tackle these questions, via asking questions as simple as "Do you wish to be accompanied to hear your diagnosis?", via listening to their patients even on topics that might be as repetitive and mundane as "How long can I live?" For it is not only morally reasonable, but might also empirically practical and beneficial for HCPs to empathically pay attention and cater their communication styles to their patients with consideration of patients and their family members' individual differences and cultural uniqueness, based on an in-depth understanding of the factors that influence Chinese cancer patients' health information preferences and practices.

Appendices

APPENDIX A

Semi-Structured Interview Guide (English)

1. Opening
    a. First of all, thank you so much for agreeing to participate in this academic research.

2. Key Questions
    a. How are you feeling today?
    b. Since this study is about your experience with cancer, I would like to start with some questions about your diagnosis. Is that ok?
        i. What was it like when you first realized you have cancer? Could you please walk me through that journey?

        ii. What were some initial questions you had when you first received the diagnosis?

        iii. Were those questions answered? By whom?

Now I am going to ask a few questions about what I call information needs and wants. Ok?

    c. Let's define **information needs** as pieces of information you ***have to have*** and **information wants** as pieces of information you ***would like to have***.

        i. Overall, what information did you have to have, versus what information did you need?
        ii. What information did you not necessarily *need* but *wanted* to have?

        iii. In your opinion, what separated the information you need from information you want? What qualities made some of the information higher priority?

    d. Could you please tell me some methods you employed to seek answers regarding your health information?

        i. What motivated these **seeking** exercises of yours?

        ii. What **facilitators or barriers** did you encounter while seeking out the answers to these questions?
        iii. In what ways these **seeing experiences** helped you?

    e. Could you please tell me some of your health information **avoiding** experiences?

        i. What motivated you to **avoid** seeking answers?
        ii. What are the **barriers or facilitators** you encountered?
        iii. In what ways these **avoiding experiences** helped you?

    f. Could you please tell me some of your health information **sharing** experiences?

        i. What motivated these **sharing** exercises of yours?
        ii. What are the **barriers or facilitators** you encountered?
        iii. In what ways these **sharing** experiences helped you?

    g. Could you please tell me some of your health information **accepting** experiences?

        i. What motivated these **accepting** exercises of yours?
        ii. What are the **barriers or facilitators** you encountered?
        iii. In what ways these **accepting experiences** helped you?

    h. Overall, how would you describe and evaluate your interaction with health information? Why?

    i. If any, what are the things that you wished you had done differently regarding the way you sought, avoided, shared, and accepted health information?

    j. Are you planning to change the way that you interact with health information?
        i. Why/ Why not?

3. Wrapping-up
    a. We are almost at the end of our interview, are there any additional thoughts/topics that you wish to add to our conversation?

Semi-Structured Interview Guide (Chinese)

中文访谈刚要

1. 融冰问题
    a. 首先，谢谢您参与这个学术研究。请您仔细阅读这份文件并告知我如果您可能有的各种问题。谢谢您同意这个会被录音的访谈。谢谢您！
2. 关键访谈问题
    a. 您今天感觉如何？
    b. 让我们切入正题，谈一谈肺癌对您生活造成的影响。
        i. 您能向我描述一下您得知您得癌症时的状况吗？您能向我描述一下您的抗癌旅程吗？
        ii. 您能向我描述一下您的各种关于癌症的问题，比如说在您确诊为癌症时候？
        iii. 您的这些问题得到解答了吗？
            1. 如何被解答的？信息来源是何处？为什么？
            2. 为何依旧没有获得解答？
        iv. 如果把对关于癌症的**信息的需求**定义为您的一*定要得到*的信息，**信息的渴求**定义为您*希望拥有*的信息。总体而言，您如何把您的各种关于健康的问题分类按轻重缓急为对信息的需求和对信息的渴求？
        v. 对您而言，有哪些原因促使您把您想对各种与健康信息的了解按轻重缓急分类为对健康信息的需求和对健康信息的渴求？
        vi. 您**寻求**过哪些健康信息？
            1. 哪些原因促使您**寻求**这些健康信息？
            2. 在**寻求**这些健康信息的时候，您遇到过哪些**阻碍或方便**？
            3. 您认为您对这些健康信息的**寻求**对您起到了哪些帮助？
        vii. 您**回避**过哪些健康信息？
            1. 哪些原因促使您**回避**这些健康信息？
            2. 在**回避**这些健康信息的时候，您遇到过哪些**阻碍或方便**？

            3. 您认为您对这些健康信息的**<u>回避</u>**对您起到了哪些帮助？

    viii. 您和他人**<u>分享</u>**过哪些健康信息？

            1. 哪些原因促使您**<u>分享</u>**这些健康信息？
            2. 在**<u>分享</u>**这些健康信息的时候，您遇到过哪些**<u>阻碍或方便</u>**？
            3. 您认为您对这些健康信息的**<u>分享</u>**对您起到了哪些帮助？

    ix. 您**<u>接受</u>**过哪些健康信息？

            1. 哪些原因促使您**<u>接受</u>**这些健康信息？
            2. 在**<u>接受</u>**这些健康信息的时候，您遇到过哪些**<u>阻碍或方便</u>**？
            3. 您认为您对这些健康信息的**<u>接受</u>**对您起到了哪些帮助？

  c. 总体而言，您如果描述和评价您与健康信息的互动？

  d. 对于您过去的寻求，分享，和回避健康行为，有哪些地方您希望您做得不一样？为什么？

  e. 对于您的以后的与健康信息的互动，如寻求，分享，回避健康信息，有哪些地方你希望有所改变？
    i. 为什么？为什么不？

3. 结束部分
  a. 我们的谈话将告一段落，有哪些想法/问题是您想进一步讨论的？

APPENDIX B

Communication Preference Questionnaire (English)

1. **How do you wish your HCPs to communicate information regarding your diagnosis?**
   a) Good news or bad news, I wish to have it all.
   b) Please tell the good news only, or the positive part of the bad news.
   c) HCPs should talk to my family/friends first, they know my wishes the best.
   d) It would be great if my HCP could divulge the information slowly, so I would have time to decide whether I'm able to stomach it.

2. **Some information (e.g., information regarding pathology of your illness) might require professional languages or terminologies to explain thoroughly, you wish**
   a) HCPs could explain it slowly to me, I am interested in it.
   b) HCPs could explain it slowly to my family/friends, I could understand it better with their help
   c) HCPs could just explain the general idea to me, no need for detailed explanations
   d) HCPs don't need to explain it to me. I'm not interested in it.

3. **What questions do you have now that you wish HCPs to answer for you?**
   a) Questions regarding my diagnosis
   b) Questions regarding western-style treatment
   c) Questions about traditional Chinese medicine treatment
   d) Questions about integrating folk therapies
   e) Questions regarding other complementary and alternative medicine options
   f) Questions regarding what methods may be best to integrate traditional Chinese medicine and western-style treatments
   g) Questions about my medicine choices
   h) Questions about my medical expenses

i) Questions regarding my daily food intake
j) Questions regarding what physical care should I undertake in daily
k) Questions about methods to boost my immune system
l) Questions about regaining my strength
m) Other__________________

4. How frequent do you wish your HCPs to communicate with you?

a) One or two days
b) Twice a week
c) Once a week
d) Twice a month
e) Once a month
f) My current schedule works fine
g) Other________________

5. Overall, which manner of communication do you prefer?

a) Succinct, right to the point
b) Subtle, with thorough consideration
c) Other__________________

Communication Preference Questionnaire (Chinese)

患者沟通喜好问卷

此问卷用来增加患者和医者的沟通默契度。请根据自身情况如实作答。

1. 您希望医生或护士如何和您沟通关于您诊断的信息？

1) 不论好消息，坏消息，希望医生全部告知
2) 请只告诉我好消息，或坏消息的积极部分
3) 最好先我的家人/监护人沟通，他们可能更加了解我的心理承受能力
4) 希望医生/护士循序渐进地告诉我，如果我预示到我可能接受不了这个信息，我会告诉他们换一种方式和我沟通

2. 有些信息(比如说关于您的病因和病理的信息)，可能需要一些专业知识/术语才可以解释清楚，您希望：

1) 医生/护士慢慢地和我解释，我对这些信息很感兴趣
2) 医生/护士慢慢地和我的家人/朋友解释，有他们的协助我会理解得更透彻
3) 医生/护士和我解释大概的意思就好，不用具体说明
4) 医生/护士可以不用和我解释，我对这些信息不感兴趣

3. 您现在都有关于那些方面的疑问您希望医生/护士为您解答？

1) 诊断方面的信息
2) 西医治疗方案
3) 中医治疗方案
4) 民间疗法的信息
5) 其他辅助治疗的信息

6) 融合中医和西医的治疗方案
7) 药物选择的问题
8) 关于治疗费用的问题
9) 日常饮食的注意事项
10) 日常身体保养的事项
11) 如何恢复身体抵抗力的信息
12) 如何恢复体力的信息
13) 其他______________

4. 您希望医生/护士多长时间和您交流一次？

1) 每 1-2 天
2) 每周 2 次
3) 每周 1 次
4) 每月 2 次
5) 每月 1 次
6) 现在就诊的周期就可以
7) 其他______________

5. 总体而言，您希望医生/护士以哪种方式和您交流

1) 简约的，直截了当的方式
2) 温和的，有人文关怀的方式

Glossary

Culture is defined as a set of beliefs, behaviors and social entities held by a group of people that serve as the foundation for their social identities.

Culturally-sensitive Care is defined as "the provision of care that takes into account the particular cultural perspectives of an individual patient" (Hunt, 2007, p.230).

Family is defined as "a social unit or a system is comprised of two or more people who live together and are related by blood, marriage, or adoption" (Fan, Zhang, & Wang 2017, p.130).

Family-management of Cancer could be understood as Chinese cancer patients' cancer care activities, especially their interactions with health information, which are often carried out as family activities.

Harmony is defined as "a person's inner balance as well as the balance between individuals and the natural and social surroundings" (Jin Hoare & Butcher, 2007, p.159).

HCPs: Healthcare professionals

Health Information is defined as "any information which is related to the practice of medicine and healthcare" (Cullen, 2006, p.1).

Health Information Avoiding could be understood as "any behavior intended to prevent or delay the acquisition of available but potentially unwanted information" (Sweeny, Melnk, Miller, & Shepperd, 2010, p.341).

Health Information Seeking is defined as "a subset of information behavior that includes the purposive seeking of information in relation to a goal" (Kukka et al., 2013, p.16)

Health Communication is defined as "the study and use of communication strategies to inform and influence individual and community decisions that affect health" (Boykins, 2014, p.41).

HIPAPA: Health information preference and practices association

Information Accepting is defined as individuals' passive learning, willingly or unwillingly, of particular information.

Information Sharing is thus defined as an individual information consumer's active and autonomous information sharing behaviors.

Respect is defined as "the level of esteem for another individual based on one's own values" (Kopelman & Rosette, 2008, p.68).

Social Value is defined as "the awareness by people of a necessity specific to this social structure" (Dubois & Beauvois, 2008, p.1740).

Truth is defined as "the actual facts of a situation and is used to determine, with certainty, whether information is accurate" (Toma , Hancock, & Ellison, 2008, p.1024).

Trust is defined as "a willingness to rely on an exchange partner in whom one has confidence" (Moorman , Deshpandé, & Zaltman, 1993, p.82).

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Vita

Su was born a world citizen, so she's been living as one. Everything she did, does, or is about to do is surrounded by meaning, though sometimes the results of her endeavors are quite lost in translation. *Si, Si, C'est la vie!* 梦想和现实就像驴唇与马嘴! Su could be her father's princess and her mother's knight. Which means for Su, life is as desperate, as fearsome, as tiresome, and as interesting as *The Legend of Zelda* video game. Spoiler alert, Su is a Gemini. Su is a fine person to be with when she is not hungry or sleepy. She has a lot of respect and appetite for intelligence, money, and resilience. Su wishes to optimize her intelligence and work resiliently to earn money. She doesn't think receiving could overpower creating. But for those who wish to prove her wrong, please feel free to donate to her "Is There a Place for Lazy Nerds?" project. You could email her your donations. No Bitcoins please, too fishy. The genetically-modified-farm-raised-salmon kind of fishy.

Su believes in love and friendship. When Su realized that diamonds are old spinsters' best friends, she vowed to win an army of best friends to love (Please note: not the man-made kind of diamonds). Su's kind and loyal. She wishes her best friends' friends, that is, gold, platinum, silver, along with other precious metals and stones, to know that she wants to be a keeper of their friendships forever, gold-heartedly forever. (Yes, legend has it, the Chinese are the heirs of the dragon. Do I hear a ka-ching? ☺) Su is humble and grateful. She understands what she has is amazing, like right now, you, reading her words and work. Su will always be a learner. What she learned the best is this: Thank you! Thank you! Thank you! Thank you! Thank you! (Now, can we please talk about donations? ☺)

Su likes her privacy and security. Su believes she is her own castle. Like a true Texan, Su adores the Castle Law and learned how to shoot not to kill. Also like a true Texan, Su enjoys peace and music. So, this is Su, under the most brilliant Lone Star, humming a soft melody, *Song about You* (好好) by Mayday (五月天), peace out.

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This dissertation was typed by the author.