

The Use of Chinese-language Internet Information about Cancer by Chinese Health Consumers

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Abstract

We investigated the use of Chinese-language Internet information about cancer by Chinese health consumers, and its impact on their cancer care. We applied a grounded theory approach and undertook semi-structured interviews with 20 participants in China to learn their experience of using the Internet for cancer information as a patient or a family member. Thematic analysis of the interview data identified three key themes: (1) information needs evolve during the treatment journey; (2) Traditional Chinese Medicine (TCM) and adverse effects of treatment are the topics of greatest interest; and (3) most participants have encountered Internet health information with questionable quality. These findings suggest that although the Internet has great potential to empower Chinese cancer patients and their family through cancer care journey, the information quality issues, cultural considerations and current health care paradigm constrain this potential. Further research is needed to address these issues in improving cancer care in China.

Keywords China, Internet, neoplasms, consumer health information, qualitative research.

1 Introduction

Patients with cancer and their family members need information to prepare for treatment, to enhance compliance to therapy and to promote recovery (Revenson and Pranikoff 2005; van der Meulen et al. 2008). About 63% of people with cancer in the US searched for cancer information online, and 13.3% of patients who accessed Internet cancer information said that their decisions towards treatments was affected or changed because of it (Castleton et al. 2011). However, poor quality of Internet information on cancer is commonplace, and may lead to unrealistic expectations and adoption of unapproved remedies over conventional treatment (Chan et al. 2012; Lawrentschuk et al. 2012; Ogah and Wassersug 2013; Wicks et al. 2010). Various tools have been developed to help consumers identify reliable health information online, e.g. the services of the Health on the Net (HON) foundation (Health On the Net Foundation 2013) and the DISCERN instrument (British Library and University of Oxford 1997), but with little usage data reported regarding consumer use of such tools.

Cancer treatment in China is quite different from that in western countries. Although cancer treatment in China applies evidence based medicine (EBM; i.e. so-called 'western medicine'), using Traditional Chinese Medicine (TCM) as an adjunct therapy to EBM based anticancer treatment is very common (Lao et al. 2012). The main purposes of using TCM are to alleviate symptoms and side effects, or to treat the primary disease itself (Lao et al. 2012). In the Chinese language Internet, information about TCM for cancer appears frequently, but the quality and impact of this information is unclear.

In addition, most Chinese consumers seeking cancer information are the family members rather than patients themselves. In China, *nondisclosure* to the patient regarding the cancer diagnosis is considered to be appropriate (O'Donnell et al. 2013), and doctors in China always ask the patient's family for permission before telling a cancer diagnosis to the patient. Information about cancer diagnosis, treatment and prognosis is often kept away from patients by family members who play a much more significant role in the decision-making process than the patient (Cheng et al. 1998). Thus, family members constitute a large group of health consumers who search online for cancer information.

Little is known about the extent of the influence of Chinese Internet health information on Chinese health consumers, especially the impact regarding their decision making process, treatment compliance behavior, and clinical outcome. We conducted a qualitative study to establish a framework for understanding the impact of health information in the Chinese language Internet on people with cancer.

2 Methods

We applied a grounded theory approach (Charmaz 2006; Glaser and Strauss 1967) given its ability to construct a theoretical framework based on the study data and its suitability to explore fundamental issues in a domain that is less understood and therefore not appropriate to hypothesize in. Applying the grounded theory philosophy, data collection and analysis were undertaken concurrently to inform the study design. Methods of open coding, axial coding and constant comparison were used in the data analysis taking a general inductive approach (Thomas 2006). The research protocol was approved by the University of Auckland Human Participants Ethics Committee on 28 June, 2013 (Reference: 9829) and was supported by the Vice-President, Research, at the Southwestern Institute of Physics (SWIP) in Chengdu, Sichuan, People's Republic of China (PRC), where participants were recruited through SWIP institutional email and onsite posters. The recruitment was not confined to physicists, but included support staff and family members of employees. Participants were health consumers who had sought cancer information on the Internet for themselves or for family members or friends. Recruitment and data collection continued until data saturation was reached.

2.1 Data Gathering

Semi-structured interviews were conducted (by the first author) in Mandarin or Sichuan dialect and audiotaped. All interviews covered a set of key topics: (a) general questions, such as age, education, job description, and the relationship between the participant and cancer patient; (b) Internet usage, including frequency of using the Internet in general, when they started searching cancer information online and their favourite approach to searching; (c) the kind of information interested in; (d) quality of Internet cancer information encountered; (e) communication with doctors regarding Internet information; (f) impact of health information on healthcare decision making, therapy compliance, knowledge and ability of participants, and (g) open questions, including the general attitude towards online cancer information. The researcher conducting the interviews made notes during the interviews and reviewed the notes after each interview to identify emerging themes and to inform the study design, e.g., adjustment of interview questions to address new concepts.

2.2 Data Analysis

QSR Nvivo 10 (QSR International Pty Ltd., 2013) was used for interview data coding and analysis. All 20 interviews were audiotaped; four were transcribed. Open coding (line-by-line coding) was undertaken on the transcripts by two authors independently (first and third authors). Data codes were compared, grouped and discussed among all authors, and key concepts emerged were categorized into groups. Constant comparison and triangulation were also undertaken between all 20 interviews as well as with literature. All data codes from the interviews were discussed and data categories revised to conceptualize the relationships among the categories. Axial coding identified hierarchical relationships among most key concepts and interrelationship between the key concept groups. Key themes and sub-themes were agreed based on thematic analysis of all interviews and related literature.

3 Results

From June to July 2013, we conducted 20 interviews with employees or family members of SWIP. The length of each interview varied from 11 to 74 minutes.

3.1 Participants' Characteristics and Key Messages

There were 9 females and 11 males included. Participant ages varied from 21 to 58, median 34. Three participants were people with cancer, and seventeen were family members of cancer patients, among whom four had died. Seventeen participants had tertiary education, and three had high school education or below. Their occupational areas include scientific research, engineering, administration, support (such as cleaners and security guards), and other professionals (e.g., marketing and legal professionals). Two of the participants were unemployed at the time of interview. Cancer types encountered varied, with the most common cancers reported as lung cancer and breast cancer. The participant-perceived frequency of searching the Internet for cancer information ranged from high to very low.

Three inter-related themes emerged from the participants' comments:

- i. Health consumers with cancer in China get cancer information from the Internet and other sources. The information they retrieve increases their knowledge, supports decision making, and influences patient-physician communication.
- ii. Information about TCM and side effects is of great interest to health consumers. Sometimes the information leads to using TCM without clinician prescribing.
- iii. Deficiencies in the quality of Internet cancer information have negative impact on its utilization and the care process.

3.2 Theme One: Information Needs Evolve During the Treatment Journey

3.2.1 Triggers: Diagnosis, Complication and Patient-Physician Communication

Most participants described their medical knowledge before cancer diagnosis as poor to nil. One participant related, "My medical knowledge was very poor at the beginning. When my mother was diagnosed with cancer last year, all my family knew nothing about cancer. We were even afraid of this term."

The diagnosis of cancer often triggered strong needs for cancer related information due to anxiety. One participant described her feeling after being informed of her father's cancer diagnosis, "At the beginning, I couldn't calm down. I just wanted to get more information, wanted to cure my father. I looked everywhere for information."

People also searched information when complications arose. "Several weeks ago he got a high fever, I sought for information about that for a period of time. I will search online when some problem arises without clear reasons." Another participant related, "Basically, I will seek for information whenever new problems arise. She got radiation pneumonia after finishing radiotherapy, I have collected dozens of articles about that."

Patient-physician communication sometimes was also a trigger for information searching. "I will check some important things doctors mentioned, such as the procedures of operation, results of examinations. Are they normal? If there are problems, how serious are they?"

3.2.2 Emotional Impact on Participants

Sometimes cancer diagnosis brought panic to participants and the variety of information on the Internet can add to the confusion. As one participant said, “I searched on the Internet very frequently after the diagnosis of cancer, because I was confused at that time, and wanted to look at every piece of information.” Another participant talked about their journey after diagnosis, “When the doctor told us he had cancer, we were terrified. When we came back to home, all of us could not accept it. I read some general information about cancer without any focus. We went to another hospital to do examinations, and compared their results with previous ones. We were totally confused at that time. We just wanted to change hospital and validate the diagnosis.”

After the patient received anti-cancer treatment and was stabilized, most participants felt settled down. And cancer information from the Internet also helped them to calm down, as stated by several participants. One related, “I was anxious at first. But when he began to receive treatment, I felt greatly relieved.”

3.2.3 Consumers Empowered by Internet Information

Almost all participants said that their knowledge about cancer and treatment was increased by Internet cancer information. “For me, the material on the Internet is very useful to understand the condition of my father, as well as to seek out treatment methods.”

Some participants told us that the information they got from the Internet facilitates their communication with their doctors. “The information from the Internet makes me more active in the communication with physicians. After I get the information, I can understand the disease and treatment modalities, and discuss with doctors more deeply than before.”

Sometimes participants would use this information to help decision making. “When the doctor offered us a treatment plan, we would validate it online and then make a decision on it.” And the Internet cancer information sometimes enable participants to contribute input to the treatment plan, as mentioned by one participant, “My father can’t eat or drink now...I found a method called percutaneous gastrostomy may help him to take food. I searched online at first and asked the treating doctor whether my father can use this method. The doctor agreed with me.”

3.2.4 Potential for Negative Effects

Some participants felt that the treating doctors did not take their opinion into consideration. If doctors simply reject their preferences without a satisfying explanation, it can seriously damage the patient-physician relationship. One participant said, “I find many doctors of western medicine are against TCM. But according to the information I find online, the latest development of medicine doesn’t support them [the doctor]. I took the latest knowledge to the doctors, but most of them distrust it in the first place... I would not discuss Internet information with doctors any more after I met with a sharp rebuff.”

However, a consumer’s opinions do not necessarily evaporate because of their being ignored by doctors. Health consumers continued to collect information, which may result in self-prescribing without informing professionals. The same participant further related, “I am doing ‘natural treatment’ for my mother by myself. There is a plant from Japan, some fellow patients told me that it’s beneficial to cancer patients. I have bought seeds of it from Japan and try to grow it at home. I will eat it as vegetables.”

3.3 Theme Two: TCM and Side Effects of Treatment are Topics of Greatest Interest

In the interviews, participants talked about many different topics they were interested in when they searched for cancer information on the Internet. And these topics varied significantly among participants with different characteristics. However, some topics were mentioned by most of them, including TCM and side effects of cancer treatment.

3.3.1 TCM Information

Many participants have sought for TCM information online, sometimes for different purposes. Some participants looked for therapeutic medicine for cancer. One participant said, “Some TCM is widely accepted by the public, like *Ling Zhi* (Ganoderma lucidum)... It is believed to have good therapeutic effects. There is a lot of information (on the Internet) about *Ling Zhi*.”

Since many cancer patients experienced side effect with the cancer treatment, the participants were eager to look for TCM to alleviate side effects. “One patient in my ward used moxibustion to treat

leucopenia by himself. We used that as well.... There are some lecture videos about moxibustion on the Internet. A TCM doctor talked about treating leucopenia with moxibustion.”

Apart from therapeutic purposes for cancer and side effects, interest in TCM as a method to maintain long-term survival and good health also constitutes a rationale for searching TCM on the Internet. “Some *Pian Fang* [unauthorized folk prescriptions], like dietary treatment, has being been performed after chemotherapy finished. It could be effective, since he recovered very well.”

Information of on TCM was not only from the Internet, participants mentioned multiple information channels of TCM information including friends, relatives and commercial flyers. Many participants received flyers with TCM information in hospital. Some of these flyers had information about *Ling Zhi* product for cancer therapy and mentioned supporting research and case reports with excellent outcome. However, these flyers did not present their research methods or provide any references, so it is impossible to verify the reliability of the sources supporting the information.

3.3.2 Side Effects of Treatment

Because information on the side effects of chemotherapy and radiotherapy has been widely spread among the public by mass media, most participants were well aware of side effects of cancer treatment. Many participants invested a lot of effort on searching for information about side effects. “I am concerned about the side effects of chemotherapy. I know that chemotherapy destroys cancer cells, but it destroys normal cells as well. I pay a lot of attention to side effects.” After gaining knowledge about side effects, it is very common for participants to look for solutions to them. “I searched online for methods to increase white blood cells, for instance, eating prawn.”

The information about side effects supported participants when they made decisions on treatment plans and communicated with the treating doctors. “We got some information about chemotherapy from the Internet. And he had hypertension. We thought the side effects are too serious to tolerate. After communication with doctors, we decide not to do chemotherapy.”

3.4 Theme Three: Most Participants Have Encountered Internet Health Information with Questionable Quality

Most of the websites mentioned by participants are commercial, and some participants got information regarding doctors and facilities of hospitals from hospitals’ websites. The participants had various opinions about the quality of online cancer information, and talked about several dimensions of the information quality.

3.4.1 Reliability

The unreliable information was the most frequently mentioned concern, as one participant related, “Information spread among patients is more trustable, because there is no profit relation among them. The websites directly given by search engines are worse. They give a lot of hospital websites and many people on the website gave me advice.”

A participant believed that she was misled by the information on the Internet and delayed her father’s treatment, “I went to the website to look for recommendations on doctors. I typed in esophageal cancer, and all doctors it gave are surgeons. We didn’t know we also should go to oncologists at that time. We just wished to be admitted to surgery department. However, my father couldn’t have surgery in the end due to metastasis.”

3.4.2 Completeness

Several participants mentioned online cancer information being incomplete. “There is little material about tumours in sellar area [a small region of the brain]. There is only very brief explanation, without detailed treatment modalities and prognosis. Only surgery is mentioned, but without any detail.”

Some participants shared their experiences on collating information on the Internet, “If you want to collect information with completeness, you have to search via various websites... You need to analyse by yourself and combined the information collected from different angles.” “I divided my question into smaller ones, such as the effects of the medicine, its price, its manufacturer, etc. Basically I can get all the answers from multiple websites.”

3.4.3 Interpretability

The degree of interpretability of online information appeared to vary between participants and information sources. For instance, one participant related, “The parts about effects of chemotherapy are

difficult to understand, like which kind of cells are affected and mechanism of it. I can't understand it." "If you are searching the online question and answer in Baidu [a search engine, <http://www.baidu.com/>], it's easy to understand. But there are some technical explanations in Baidu Baike [an online contributable encyclopaedia, <http://baike.baidu.com/>, similar to <https://en.wikipedia.org/>]. That's harder."

Participants with different background often perceived different degrees of interpretability of Internet information. Tertiary education did not necessarily enable them to understand the Internet information fully. A participant who is a scientific researcher with a master's degree said, "It [Internet cancer information] is not hard to understand. Because I learned biology before, I can understand it quite well." But another participant working in marketing with a bachelor's degree found, "Some of the information is very difficult to understand. The language is too technical."

3.4.4 Accuracy and Evaluation Strategies

Accuracy of the information was of concern to some participants, as related by one, "I can't say whether the information is accurate. Because I don't know who provided the information and how good they are." Despite many quality issues being mentioned, a lot of participants still believed that the Internet is a valuable source for cancer information. "Knowledge about breast cancer online is trustable.... For instance, it is said that patients with breast cancer cannot take domperidone and metoclopramide. Doctors confirmed that. We didn't know that at all [before getting the information online]."

Few participants had evaluation tools to distinguish information of high quality from that of low quality. "Quality of cancer information is difficult to judge, since I am not knowledgeable in this area. I mainly depend on comments from other readers. If most of them believed in it, I'll believe in it."

The most frequently used strategy to verify the Internet information mentioned by the participants is to compare with other information sources, especially clinicians. "A lot of information online isn't comparable with what the doctor's saying. I thought it was worth practicing cell treatment according to the online information. However, my doctors showed me an opposite opinion." Some participants chose to believe in certain information sources. "I focused on the news reports from reputable media. I get information of medical development and new medicines from them." Another common strategy is to reject all commercial information. "I didn't participate in any interactivities online. And any advertisement will be rejected, including those promoting drugs, medical services, doctors and hospitals." The participants who had specific ways to evaluate information often had higher education level and more experience in using the Internet for general purposes.

3.4.5 Quality Comparison of Information from All Channels

Since the participants got cancer information from multiple information channels, some participants talked about the information quality levels between these channels. Most participants believed in information from other patients, their family members or relatives, and they were strongly inclined to take their advice. "I didn't search for any TCM doctor online, because other patients would make comments on their TCM doctors. I can take their advice." However, this information from other people sometimes caused side effects. As one participant said, "I have seen a patient who ate bufo [Asiatic toad] and was poisoned. He believed in the saying among patients that bufo can treat cancer. It was terrible."

Paper flyers, which are often delivered by salespeople into hospitals, are the most frequently criticized information channel, "The flyers handed out in the ward influenced many patients, including my mother. Some patients even look for them actively. These flyers are more unreliable than Internet information."

Despite the low trustworthiness of flyers as agreed by most participants, some patients think otherwise. "Like my father, he would collect a bunch of flyers at home and put them in a very significant place. He believed in them." "Some patients will believe them (flyers)... especially someone from rural regions. They had not seen such information ever before. So they treat the flyers as treasure." One of the participants shared his opinion on why the flyers are popular among certain patients:

These flyers are very easy to understand. Much easier than the words of doctors. The text they use is very evocative. And they will give some specific cases, for instance, some patients saying something like 'I got cancer... I was cured after using this drug.' That sort of thing. The hospitals did not dare to say like that. They could only tell you the survival rate...

4 Discussion

Our interview study highlighted the evolving information needs of Chinese healthcare consumers throughout the cancer treatment journey, their information interests and the quality issues they encountered while acquiring online information.

4.1 Evolving Information Needs

Information needs appear to inspire consumers to seek health information actively, including on the Internet, which contribute to consumers becoming more informed, engaged, and empowered. This is consistent to reports that suggest using the Internet for cancer information can facilitate consumers in being actively involved in their medical care and medical decision making (Lee et al. 2010).

A survey in the US reported various cancer information channels, including treatment staff, family, Internet, books, friends, support groups, research reports and foundations, while information from other patients was not considered as a main source for cancer information (Walsh et al. 2010). In contrast, our participants regarded fellow patients as a very important information source, most had received cancer information from other patients and many of them followed the advice from fellow patients.

Our participants did not use online support groups or seek emotional support from the Internet despite the strong emotional impact of cancer. This differs from the findings in western countries that suggest emotional support as one of the most important things consumers sought on the Internet, and online support groups as a way to break the social isolation and to live with cancer (Klemm et al. 2003; Liu et al. 2012). This difference might be related to the distinctive Chinese culture and perspectives on disease management. For Chinese people, dealing with disease is often limited within a private and extended family scope (Mok and Martinson 2000). Patients value support from family more than that from outside of family (Ding et al. 2008). Chinese cancer patients tend to express emotional needs only to close family members, and would not expect emotional support from healthcare professionals or other people (Liu et al. 2005). On the other hand, research in western settings suggests that encouraging cancer patients and their care givers to seek support outside direct family could improve their quality of life, relieve pressure and improve information dissemination (Hoybye et al. 2005). Hence, development of specialized platforms for online patient support groups and/or of websites similar to PatientsLikeMe (Wicks et al. 2010) may enhance communication among Chinese health consumers.

4.2 Information about TCM

TCM is very popular among Chinese healthcare consumers, including for cancer treatment (Xu et al. 2006). There are an estimated 1.5 billion people globally believing in TCM (Hosbach et al. 2003). The TCM principle of “fighting fire with fire” has been practiced for more than a thousand years in China to restrain cancer (Wang et al. 2012). Poisonous herbs and other materials are used in TCM for severe diseases, particularly cancers. Some of these are highly toxic, like bufo, for which the safe dose is only 0.015 to 0.03 gram (Wang et al. 2012). Use of such TCM without consulting experienced TCM specialists may harm patients.

Apart from the long existence of TCM in China, the assumption of harmlessness is one of TCM’s main perceived strengths. These perceptions of safety and effectiveness of TCM (both as reported in literature and as shared by many of our participants) may lead to self-medication. In a Hong Kong study, nearly two-thirds of the cancer patients did not tell their physicians when they used Chinese medicine (Lam et al. 2009). In a 2012 survey, 38.9% patients reported that they used TCM because they thought it was nontoxic, while 14 (4.5%) of the 311 cancer patients who took TCM reported side effects from it, including three patients experiencing severe symptoms such as renal failure and cardiac arrhythmias (Liu et al. 2012). Such severe effects may have been caused by prolonged use of TCM without consulting with doctors.

4.3 Information about Side Effects

The significance of information on side effects is well recognized. About half of patients with breast cancer and prostate cancer, as well as 27% of colorectal cancer patients, have actively sought information about side effects of cancer treatment (Nagler et al. 2010). To provide detailed information about cancer treatment, including side effects, should be a central task of online information services for health consumers.

4.4 Information Quality Issues

Our participants generally thought that a lot of profit-oriented information was embedded in Internet cancer information. Other researchers have expressed similar concerns regarding reliability of health information on the Internet. A study on arthritis related information found that among the first 100 hits from WebCrawler (a search engine, <https://www.webcrawler.com/>), only 40% discussed conventional therapy, and only one third were owned by nonprofit organizations or universities; and of the websites with financial interests, 71% promoted alternative medicine directly or indirectly (Suarez-Almazor et al. 2001). Similar concerns were raised in another study on Internet health information quality regarding acute myocardial infarction and stroke (Bastos et al. 2014). Even when the information is from reputable nonprofit organizations or universities, it is not always detailed or up-to-date (Ogah and Wassersug 2013). This concern has taken on a much higher profile recently as Chinese regulators have begun an investigation into Baidu after the death of a college student who said he received distorted information on cancer treatment from the company's search engine (Ramzy 2016).

To evaluate information quality, our participants used various methods. The accreditation bodies, e.g. HON, or assessment tools, e.g. DISCERN, were not mentioned. Most participants judged the reliability either by themselves or by asking clinicians to comment on it. However, they also reported the time for patient-physician communication was too short to discuss Internet information in depth. Similar time constraints regarding patient-physician communication were reported before (Greer et al. 2011). Interventions could be designed and applied to improve health consumers' competence in assessing quality of Internet cancer information. Quick and easy-to-use tools, e.g. the Brief DISCERN (Khazaal et al. 2009), could be introduced to health consumers. And clinicians need to play a more active role in discussing information quality issue with consumers and guiding consumers to credible information sources.

As mentioned by many participants, Baidu Baike and other online encyclopaedia are heavily used by health consumers for health information. Wikipedia (Wikimedia Foundation 2015) has been studied to illustrate strengths and weakness of this type of health information sources. Although Wikipedia articles are considered as relatively reliable information sources (Javanmardi and Lopes 2010), readability of them remains poor (Jatowt and Tanaka 2012), with 75% of all Wikipedia articles deemed too difficult to understand for most users (Lucassen et al. 2012). Improvement in readability of online encyclopaedia might make this kind of information source more applicable for health consumers.

Apart from being easily understood, another key reason for commercial flyers to remain popular, even containing inaccurate information, is that they include personal stories. The personal story is a powerful mode of communication. Such information is somewhat problematic from EBM perspective, but websites providing evidence-based guidance will be less attractive than (TCM) flyers if they fail to provide the same level of personal connection. Some online information services have successfully used this strategy to promote cancer related information. For example, the Breast Cancer Site provides personal stories volunteered by cancer patients or their supporters (The Breast Cancer Site and GreaterGood 2015). These stories are easy to understand and may help health consumers comprehend and utilize information more effectively.

4.5 Opportunities for Improvement

Our analysis suggests a number of directions for potential improvement. Table 1 summarizes the deficiencies we found in the study and our corresponding recommendations.

Deficiency	Recommendation
Lack of online support groups for Chinese cancer patients and care givers.	To establish online support groups specifically for patients and supporters.
Lack of online emotional support	Health consumers should be encouraged to use the channels besides family to seek both information and emotional support.
Inaccurate and misleading information	Self-regulation on quality should be promoted. Approaches to identify high quality Internet information should be taught to health consumers. Clinicians should take time to discuss the information from patients.

Deficiency	Recommendation
TCM information may lead to self-medication	Consumers with cancer should be educated to raise awareness of side effects of TCM.
Readability of Internet cancer information	Plain language should be emphasized while building websites for consumers.
Lack of shared decision making between physicians and patients	Patients and clinicians should be educated to make decisions together
Disadvantage in compelling quality compared to the flyers	Use personal stories to help consumers to relate to health information.

Table 1. Deficiencies and recommendations regarding the Chinese-language Internet cancer information

Among the key points in Table 1, we suggest:

- Online support groups for Chinese cancer patients and care givers should be established. Health professionals should encourage health consumers to use these channels to seek information and support. Improvement in information readability is needed. Self-regulation, like the principles of HON, on information quality should be promoted.
- Comprehensive information regarding TCM, including its side effects, should be made available to health consumers. Consultation with experienced TCM specialists and cancer treating doctors regarding TCM use should be recommended.
- Easy approaches to identify high quality Internet information, e.g. looking for the HONcode logo and use of the Brief DISCERN, should be promoted to health consumers, and clinicians should take time to discuss the Internet information found by consumers.
- We see a particular danger regarding the gaps in communication between patients and clinicians due to perceived lack of time and negative professional perception on patient's interests, such as TCM. Shared decision making between patients and clinicians need to be promoted. To support this, patient-centered care should be at core of education of healthcare professionals.

4.6 Study Limitation and Future Research

This study included a small number of participants from a single institution setting in China representing well-educated middle-class. Findings with these participants may not be generalized to all Chinese health consumers dealing with cancer from various backgrounds, occupations, locations and perceptions. More research is needed to understand the impact of Internet cancer information considering variables such as education, income, and type of cancer. In future research, using theoretical sampling based on the findings of this study, the relationships between the identified themes (such as the mechanism to assure information quality and health consumers' information search behavior in terms of frequency or depth of searches), as well as potential association between participant characteristics (e.g., demographics and education) and their views on the themes and sub-themes should be explored. Future studies could also focus on the steps in the health consumer decision making process towards their treatment journeys, and how to provide online information of better quality to meet consumers' information needs at each step.

5 Conclusion

Our interview study with 20 Chinese healthcare consumers with experience of using the Internet for cancer information have identified three key themes: (1) information needs evolve during the treatment journey; (2) Traditional Chinese Medicine and adverse effects of treatment are topics of greatest interest for participants; and (3) most participants have encountered Internet health information with questionable quality. Although the Internet presents great potential to empower consumers, the information quality issues, cultural considerations and current health care paradigm constrain this potential. Further research is needed to address these issues and to improve cancer care in China, e.g. by establishing online support groups for cancer patients and care givers, educating consumers to raise awareness of side effects of TCM, promoting high quality Internet information, and engaging customers in shared decision making.

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Abbreviations

EBM: evidence based medicine

HON: Health on the Net

PRC: The People's Republic of China

SWIP: Southwestern Institute of Physics

TCM: Traditional Chinese Medicine

WHO: World Health Organization

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