



ELSEVIER

Contents lists available at ScienceDirect

Information Processing and Management

journal homepage: www.elsevier.com/locate/infoproman

The Information Needs of Chinese Family members of Cancer Patients in the Online Health Community: What and Why?

Dan Ma, Meiyun Zuo^{*}, Liu Liu

Research Institute of Smart Senior Care, School of Information, Renmin University of China, No. 59 Zhongguancun Road, Beijing, China, 100872

ARTICLE INFO

Keywords:

Information needs
Stressful events
Family members of cancer patients
Online health community
Chinese culture

ABSTRACT

Meeting the information needs of cancer patients' family members is critical for improving care quality and family members' well-being. An online health community (OHC) can be an effective channel to provide information support, thus attracting many cancer patients' family members. Several studies have examined the information needs of cancer patients' family members in OHCs. However, most of them only focused on health-related information needs for improving patients' physical well-being and did not consider the context of information seeking. Furthermore, most of these studies were conducted in Western countries; thus, their findings may not be generalizable to Chinese culture that emphasizes family-centered decision-making, protection of family members toward the patients, and collectivism.

In this study, we investigated what kinds of information Chinese family members of cancer patients seek in the OHC and why they seek them. Hence, we analyzed 8,334 messages for information seeking posted by 2,788 family members in one of the most significant Chinese online cancer communities. Stressful events that trigger information needs were also identified for further studying the context of information needs. Based on qualitative content analysis, we discussed the information needs of cancer patients' family members in the OHC and the potential impacts of Chinese culture on family members' information needs. Furthermore, the results confirmed that information seeking could be a method to help family members of cancer patients cope with stressful events in the journey of cancer.

1. Introduction

Cancer is the second leading cause of death globally. There were 9.6 million deaths caused by cancer in 2018, according to an estimate by the International Agency for Research on Cancer (Bray et al., 2018). In China, cancer rates have maintained a growth rate of 3.9% per year, and the rate of cancer mortality has also increased over the past ten years (Chen et al., 2016). Medical payments for cancer reached 221.4 billion RMB in 2015, accounting for 17.7% of the Chinese government's health expenditure (Cai et al., 2017).

However, cancer mortality rates and treatment costs could be reduced if patients were treated with timely target interventions (Silver, 2015; WHO, 2018). Moreover, the shortage of healthcare resources due to population aging and increased emphasis on outpatient treatment have shifted the responsibility of cancer management from hospitals and healthcare professionals to patients and their family members (McCarthy, 2011). Hence, family members play a critical role in cancer management and must understand cancer to engage in treatment effectively.

The diagnosis of cancer disturbs the routine of patients and their family members. When family members engage in caregiving, they

^{*} Corresponding author.

need to provide physical and physiological support to their patients and adapt to some changes that affect their health and well-being (Lee & Bell, 2011; Leonidou & Giannousi, 2018). For example, the caregiving burden may result in sleep disturbances and fatigue for caregiving family members, especially for those who must continue to work (Northouse et al., 2012). Previous studies have also confirmed that the risk to family members' health (e.g., cardiovascular) is positively associated with their caregiving burden (Kurtz et al., 2004; Lee et al., 2003). Concerning physiological changes, anxiety, depression, stress, distress, and more negative emotions are frequently mentioned in existing research on family members of cancer patients (Leonidou & Giannousi, 2018; Northouse et al., 2000). These negative emotions increase as patients' health status decline (Northouse et al., 2012).

Besides influences on physical and psychological well-being, other changes may occur in family members' lives due to caregiving, such as switching to less-demanding jobs and reducing social activities (Leonidou & Giannousi, 2018). Moreover, caregiving can also create interpersonal conflicts between patients and family members or among various family members. For example, overprotection from family members in caregiving may make patients angry (Leonidou & Giannousi, 2018). Therefore, information about the patients' health and well-being are both needed by family members when their loved ones are diagnosed with cancer. However, previous studies have indicated that family members of cancer patients often have unfulfilled information needs (Adams, Boulton, & Watson, 2009; Leonidou & Giannousi, 2018; Sklenarova et al., 2015; van Eenbergen et al., 2019), prompting the need for more accessible channels to get information beyond receiving information from healthcare professionals.

The popularization of computers and mobile devices has motivated individuals to seek social support via the internet (Lu, Zhang, & Deng, 2013). An online health community (OHC) consisting of individuals with similar health concerns can be an effective channel to support family members (Zhang et al., 2018). Specifically, an OHC can accommodate varied literacy levels (Donelle & Hoffman-Goetz, 2008), and the health information available on an OHC is tailored by participants who provide information, making it highly relevant to queries (Donelle & Hoffman-Goetz, 2008). This accommodation contrasts with many medical websites that require a high level of literacy (Berland et al., 2001). Moreover, most information disseminated in an OHC is accurate with participants' self-correcting and moderators' maintenance. Most false or misleading claims can be identified, corrected, or removed by other participants and moderators (Esquivel, Meric-Bernstam, & Bernstam, 2006; Young, 2013). The 24/7 response of an OHC allows participants to obtain information at will (Liu, Liu, & Guo, 2020). The anonymity of an OHC allows individuals to feel less embarrassed when disclosing their stressful experiences (Kang, 2017) or accessing information about sensitive topics (Cline & Haynes, 2001). Additionally, participants in an OHC can easily look for others with similar experiences who can understand their emotional reactions and practical concerns (Liu et al., 2020). However, most OHCs are created and designed for patients and do not distinguish between patients' and their family members' needs. Thus, these patient-oriented OHCs may not fully serve family members as expected, impacting user retention rates.

Several studies have investigated the information needs of family members of cancer patients via interviews (Schook et al., 2014), surveys (Cho et al., 2011), and analysis of content generated by family members in OHCs (Lu et al., 2017; Lu et al., 2013; van Eenbergen et al., 2019). However, most of these studies were conducted in Western countries. Given the potential impact of culture on information needs, the findings from these studies may not be generalizable to Chinese culture. Furthermore, although Cho et al. (2011) examined Korean caregivers' information needs, they collected data with a survey that only covered a small number of samples (161 caregivers). Therefore, what kinds of information sought by Chinese family members of cancer patients through OHC still requires further investigation.

Three inherent characteristics of Chinese culture suggest that the information needs of Chinese family members of cancer patients may differ from those of family members in Western cultures. First, instead of individuals, families are the basic structural and functional unit in Chinese society (Simpson, 2005). Thus, the Chinese favor a family-centered medical decision-making model in cancer treatment (Back & Huak, 2005). Second, Chinese culture places greater emphasis on the protection of family members towards the patient than patient autonomy; hence, Chinese family members are more likely to resist disclosing the true diagnosis to the patients (Sun et al., 2015). Finally, China has a collectivist culture that may affect family members' information-seeking behaviors. Researchers in sociology have discussed the impact of culture on individuals' support-seeking behaviors. Individuals in a collectivist culture prefer seeking support for addressing practical difficulties rather than for improving their mood because collectivists seek to maintain a positive face, avoiding drawing attention to their distressed emotional state (Mortenson et al., 2009). Thus, family members in a collectivist culture are more likely to seek information about physical rather than psychological problems. Researchers on health information needs have called for considering cultural backgrounds (Adams et al., 2009). The design of a website should be culturally appropriate for its users in appearance, content, and themes (Zhang, Sun, & Xie, 2015). Therefore, it is necessary to investigate what information needs cancer patients' family members prefer to seek through OHCs in Chinese culture.

Understanding information needs must consider the context out of which they arise (Pian, Song, & Zhang, 2020). Stress and coping theory argues that individuals seek information to cope with stressful circumstances (Wilson, 1997). Events appraised as stressful can increase negative affect (e.g., uncertainty, fear, anxiety) and prompt information-seeking behaviors (Savolainen, 2014). Information support from others can help individuals cope with negative affect (House, Umberson, & Landis, 1988; Thoits, 1995), especially when the support matches the stressful events (Cutrona & Russell, 1990; Wright, 2016). By examining the relationship between stressful events and different information-seeking behaviors, researchers have demonstrated that individuals can cope with stressful events through information seeking (e.g., Fridfinnssdottir, 1997; Leung, 2006; Rains, Peterson, & Wright, 2015). However, what kinds of information are needed by individuals using an OHC during stressful events has not been studied.

In OHCs, participants rarely limit posts to their questions. They also provide much contextual information to elicit detailed answers from other participants (Oh, Zhang, & Park, 2016). Therefore, stressful events that trigger participants' information needs may be identified from the contextual information, which could help community operators target information to fit the context. Hence, in this study, we examined why Chinese family members of cancer patients seek information in an OHC to determine which stressful events trigger information needs.

The remaining paper is organized as follows. We present a literature review and clarify research gaps in [Section 2](#). Then, we describe the theoretical background and research questions in [Section 3](#), followed by the research method in [Section 4](#). [Section 5](#) presents the results of this study. Finally, we conclude with a discussion of theoretical and practical implications.

2. Literature Review

2.1. Information needs of cancer patients' family members

Information needs refer to “the state or process of individuals perceiving the gap between the information and knowledge available to cope with events or problems” ([Lin et al., 2015](#), p. 912). Information need is the core concept of human information behaviors ([Wilson, 1997](#)). Understanding individuals' information needs is essential for information behavior research and system design ([Pian et al., 2020](#)). However, not all individuals with health threats seek information proactively ([Wilson, 1997](#)). They have different preferred health information-seeking behavior patterns ([Lambert, Loisel, & Macdonald, 2009a, 2009b](#)). Someone may be mostly engaged in information seeking, whereas some individuals deliberately avoid information seeking ([Lambert et al., 2009a, 2009b](#)). [Alzougool, Chang, and Gray \(2008\)](#) argued that individuals have different states of information needs, which have certain correlations with information-seeking behavior patterns. They developed a conceptual framework that includes four abstract groups to capture individual information needs: recognized-demanded, recognized-undemanded, unrecognized-demanded, and unrecognized-undemanded ([Alzougool et al., 2008; Alzougool, Chang, & Gray, 2017](#)). Individuals in the recognized-demanded state recognize their information needs and desire information to meet these needs. In this state, individuals could articulate their information needs accurately and seek information actively. Individuals in the recognized-undemanded state recognize their information needs but do not want to seek information because they perceive information seeking as threatening and contributing to unnecessary worry. Furthermore, unrecognized-demanded individuals do not recognize the information they lack, but they hope to acquire more information. These individuals cannot articulate their information needs precisely. Finally, unrecognized-undemanded individuals neither recognize their information nor want to have more information ([Alzougool et al., 2008](#)). This study focuses solely on recognized-demanded information needs.

Family members of cancer patients refer to relatives who can provide any physical, emotional, and practical support and assistance to cancer patients. These family members may not act in a professional or occupational capacity. Once an individual is diagnosed with cancer, family members may need to deal with the physical, psychological, and social changes both in the patient's and their lives ([Leonidou & Giannousi, 2018; Thomas & Morris, 2002](#)). Thus, the information needs of cancer patients' family members fall into two categories: patient-related information needs (i.e., seeking information for cancer patients) and self-related information needs (i.e., seeking information for themselves) ([Oh, 2015; van Eenbergen et al., 2019](#)).

For patient-related information needs, factual information related to the illness is always necessary for family members to provide adequate and appropriate care to patients ([Bevan & Pecchioni, 2008](#)). [McCarthy \(2011\)](#) reviewed the literature about the information needs of family members of cancer patients, discovering that family members need diagnosis information to plan and prepare themselves and their patients for the future. They need information on treatment, medication, and side effects to improve patients' physical health ([McCarthy, 2011](#)). Additionally, the diagnosis of cancer is a significant change for patients, disturbing their routine. Hence, patients may experience distress, anxiety, and fear. They need encouragement and companionship from family members ([Chen, 2014](#)). Thus, family members may need information about patients' well-being to provide psychological support ([Fukui, 2002](#)).

Family members need to reduce effort and time spent on working and socializing to invest in caregiving ([Leonidou & Giannousi, 2018](#)). These adaptations are challenging. Furthermore, caregiving may enhance the relationships between family members and cancer patients. However, this enhanced sense of connectedness may also contribute to interpersonal conflicts because of family members' excessive overprotection ([Leonidou & Giannousi, 2018](#)). Therefore, family members must learn how to get along with cancer patients well. All cancer stages are fraught with uncertainty. Family members must continually seek information to cope with changes in symptoms, drug resistance, and complications, and be aware of how to cope with negative emotions (e.g., anxiety, fear, distress) that accompany the uncertainty of the cancer journey.

As previously mentioned, the context of information needs is critical for information needs research ([Pian et al., 2020](#)). [Wilson \(1997\)](#) suggested that information needs are shaped by stressful circumstances in which individuals are trapped. Patients and caregivers may seek information at specific moments during the cancer treatment process, such as during chemotherapy, the appearance of new symptoms, the progress of the disease, decision-making, and before and after seeing a doctor ([Colombo et al., 2014; Schook et al., 2014](#)). Prior research on the relationships between stressful events and information-seeking behaviors has confirmed that stressful events may prompt individuals to seek information for coping with stresses. Stressful events are associated with seeking information from the internet ([Leung, 2006](#)), OHCs ([Rains et al., 2015](#)), and others with similar experiences and healthcare professionals ([Fridfinnsdottir, 1997](#)). These studies imply that stressful events could trigger family members to recognize their information needs and seek information. Furthermore, stressful events highlight individuals' needs for health-related information while triggering information needs about patients' and family members' well-being. For example, drug resistance triggers information needs about new treatment plans and creates anxiety if the individual does not know about other effective drugs.

2.2. Information needs in online health communities

Participants in OHCs obtain information and suggestions through information seeking ([Chen, Baird, & Straub, 2019](#)). The user-generated content in the OHCs can serve as a rich data source for studying individuals' information needs. Several studies have

used OHCs to investigate individuals' health information needs (e.g., Barney, Griffiths, & Banfield, 2011; Eschler, Dehlawi, & Pratt, 2015; Himmel et al., 2005; Oh & Kim, 2017; Portier et al., 2013). For example, Portier et al. (2013) discussed cancer patients' information needs using the data collected from an online cancer community in the United States (Cancer Survivors Network). Oh et al. (2016) investigated the health topics that users described in questions about cancer on *Yahoo! Answers*. Information about treatment, prognosis, rehabilitation, medications, and side effects are the most common types of information needs in OHCs (e.g., Himmel et al., 2005; Portier et al., 2013). Although health-related information needs are the main topics in these studies, information needs about psychological and social well-being have also been recognized (e.g., Himmel et al., 2005; van Eenbergen et al., 2019). Sometimes, individuals express feelings, seek new hope, and look for fellow sufferers in OHCs (Himmel et al., 2005).

Besides patients, OHCs have also attracted many family members of cancer patients. In the examined OHC of this study, over 25% of participants are family members. Previous studies have examined the information needs of different types of users in OHCs (Cho et al., 2011; Lu et al., 2017; Lu et al., 2013; Parvataneni et al., 2011; Schook et al., 2014), showing that the information needs of patients differ from those of the family members in the proportional distribution (Cho et al., 2011; Lu et al., 2017). For example, caregivers focus more on treatment information than patients do (Cho et al., 2011; Lu et al., 2017; Lu et al., 2013). Furthermore, patients' information seeking may be mainly for managing their current conditions, so some patients do not want prognosis information (e.g., life expectancy and end-of-life expectations). However, caregivers hope to get prognosis information (Schook et al., 2014).

Some researchers have investigated the information needs of cancer patients' family members in OHCs (Cho et al., 2011; Lu et al., 2017; Schook et al., 2014; van Eenbergen et al., 2019). Most of these studies were conducted in Western countries (Lu et al., 2017; Schook et al., 2014; van Eenbergen et al., 2019). Lu et al. (2017) identified caregivers' health-related information needs in three forums of MedHelp.org (MedHelp International, USA). van Eenbergen et al. (2019) studied the concerns of cancer patients' relatives by coding the user-generated content written by relatives on a major Dutch cancer site (kanker.nl). Schook et al. (2014) interviewed 20 Dutch caregivers who asked online lung specialist questions to explore what caregivers look for and why. A study by Cho et al. (2011) was conducted in an Eastern country, surveying cancer information services and needs of caregivers on a Korean cancer site (cancer.go.kr) launched by the government (Cho et al., 2011).

Nevertheless, certain limitations remain. First, some studies investigated the information needs of family members not only analyzing messages for support requesting but also analyzing messages for information providing (Lu et al., 2017; Lu et al., 2013; van Eenbergen et al., 2019). Thus, some information needs identified in these studies may only be recognized but not demanded by family members. Second, some studies only focused on health-related information needs but did not examine information needs for patients' and family members' psychological and social well-being (Cho et al., 2011; Lu et al., 2017; Lu et al., 2013). Third, all studies mentioned above did not consider the context of information needs—why family members of cancer patients seek information. Moreover, most of these studies were conducted in Western countries, and their findings may not be generalizable to family members in Chinese culture. Thus, to address these research gaps, we investigated the information needs of Chinese family members of cancer patients and related stressful events in an OHC grounded on stress and coping theory, which could provide implications for the design of OHCs in Chinese culture.

3. Theoretical background and research questions

In this study, we chose family members of cancer patients as our research objects. They play a critical role in caregiving and comprise a considerable part of the OHC yet have only attracted researchers' and OHC operators' limited attention. Based on the studies of Oh (2015) and van Eenbergen et al. (2019), we divided the information needs of cancer patients' family members into three categories: patient-related health, patient-related well-being, and self-related well-being.

Generally, well-being is "a broad category of phenomena that includes people's emotional responses, domain satisfactions, and global judgments of life satisfaction" (Diener et al., 1999, p. 277). It includes three core dimensions: physical, psychological, and social (Diener & Seligman, 2004). As an OHC is mainly a platform for individuals to exchange disease-related information and improve patients' physical well-being, we regarded the information needs related to physical well-being as the category of "patient-related health", including information needs about symptoms, treatments, and drugs. The categories of "patient-related well-being" and "self-related well-being" mainly focus on information for improving the psychological and social well-being of patients and family members, such as how to alleviate patients' psychological pressure and how to face the death of loved ones.

The stress and coping theory proposed by Wilson (1997) offers a useful basis for information needs and information seeking

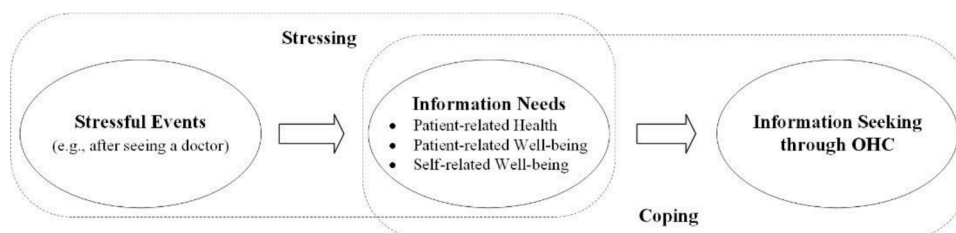


Fig. 1. Theoretical Framework.

research. In this study, we consider information as a coping resource that helps individuals handle stressors (House et al., 1988; Thoits, 1995). Referring to the definition of stress by Folkman and Lazarus (1985), we define stress as “a relationship between the family member and the environment that is appraised by the person as taxing or exceeding his or her resources and as endangering the patient’s health, patient’s well-being, or her/his well-being.” Stressors refer to events that impact patient’s health and well-being or family member’s well-being that triggers the needs for information. Coping is “cognitive and behavioral efforts to manage (master, reduce, or tolerate) a troubled person-environment relationship.” (Folkman & Lazarus, 1985).

As this study focuses on recognized-demanded information needs—the information that individuals realize they lack and desire to get from others, we regard information seeking as coping behaviors of cancer patients’ family members when facing stressful events. Figure 1 shows the theoretical framework of this study.

Based on this theoretical framework, this study proposes the following research questions:

- RQ1. What kinds of information do Chinese family members of cancer patients seek in the online health community?
- RQ2. Why do Chinese family members of cancer patients seek those kinds of information in the online health community? In other words, what stressful events trigger those kinds of information needs of cancer patients’ family members?

4. Method

4.1. Data collection and cleaning

Our data was collected from Yuaigongwu, one of the most significant Chinese online cancer communities (<https://www.yuaigongwu.com/forum.php>). Yuaigongwu is a non-commercial and patient-oriented OHC founded in 2010 to provide a platform for cancer patients and their family members to communicate with others. Yuaigongwu includes 29 sub-forums with different topics, such as general information, clinical trials, and breast cancer. Participants can seek information by initialing threads in any forum, while other participants provide support by replying to these threads.

Regarding our research goal, we limited scraping the participants’ thread-initialing messages for data analysis. We collected 33,079 messages posted by 10,064 participants from 10/01/2016 to 05/05/2020. Notably, 23 participants were staff members of the OHC (i.e., administrators and moderators), and their data was dropped because some of their messages might have been posted for seeking information on behalf of others.

Through observation, we found that family members of cancer patients often disclosed their relationships with the patients when asking questions in the OHC. We can tell whether a participant was a family member by the relative appellative terms (e.g., father, mother, father-in-law, mother-in-law) in their thread-initialing messages. Therefore, we adopted three measures to exclude the participants who were not family members. First, we computed the frequencies of each relative appellative terms and dropped the participants who did not use any relative appellative terms in their threads. Second, we excluded the participants with a frequency of relative appellative terms less than the cut-off value. Participants who were not family members used the relative appellative terms in messages less frequently. To determine the appropriate cut-off value, we randomly selected 500 participants from the retained samples and manually marked whether a participant is a family member. We compared the results of manual marking with the results that used different cut-off values to classify whether a participant is a family member. The performance metrics (i.e., accuracy, precision, recall, F1 Score) with different cut-off values from 0.1 to 0.5 with steps 0.05 were calculated for selecting an appropriate cut-off value. Finally, 0.1 was used as the cut-off value for relatively high performance. Messages posted by participants with a frequency of less than 0.1 were excluded.

Third, we further excluded the participants who were not family members by human judgment. The above steps only helped us exclude a part of participants who were not family members. Some participants who were not family members remained in our samples. To ensure the data analyzed in this study was from family members, we identified participants who were not family members in the first step of data analysis (i.e., developing a preliminary codebook) by reading all threads posted by one participant. Then, we dropped these participants’ messages. Appendix 1 presents the details of excluding the participants who were not family members.

Furthermore, to obtain as many replies as possible, some participants preferred posting the same message in different sub-forums. To exclude duplicate messages, we computed the cosine similarities among the messages posted by one participant. Only the oldest message was kept for subsequent analysis for messages with a value greater than 0.9. The thread-initialing messages posted for forwarding news and research or recording the treatment process were also excluded since they were not intended for information seeking.

Finally, 8,334 messages for seeking information posted by 2,788 family members remained for data analysis. The length of these messages varied, ranging from 5 to 21,924 words (mean=166.016). Long messages not only expressed family members’ information needs, but also described details of patients’ cancer treatment trajectory, including cancer type, treatment process, examinations, symptoms, and other information.

To avoid potential ethical issues and protect the family members’ and patients’ privacy, we followed recommendations from the Association of Internet Researchers (AoIR) Ethics Working Committee (Markham & Buchanan, 2012). First, we only collected public data and did not scrape the inserted pictures as most of these pictures contained patients’ personal information. Second, we avoided using participants’ and patients’ identifiable information (e.g., username, name, age, address, contact information) when quoting the messages.

4.2. Data analysis

The data analysis followed the procedures of deductive-inductive mixed qualitative content analysis (Mayring, 2014), including three steps. The first step was to develop a preliminary codebook through a deductive-inductive mixed analysis. Based on previous studies (Oh, 2015; van Eenbergen et al., 2019), we divided information needs into three categories: PH=patient-related health, PW=patient-related well-being, and SW=self-related well-being. As previously mentioned, PH is related to information for improving patients' physical well-being, while PW and SW are primarily about information for improving patients' and family members' psychological and social well-being.

We read all messages to develop a preliminary codebook. For PH, we used a typology developed by Rutten et al. (2005) as a basic framework because it is comprehensive and has little overlap among different categories (Pian et al., 2020). Rutten et al. (2005) created this typology to review cancer patients' health information needs of 10 categories with 64 topics, including cancer-specific, treatment-related, prognosis, rehabilitation, surveillance and health, coping, interpersonal/social, financial/legal, medical system, body image/ sexuality. To fit this typology within our context, we made some necessary changes.

Specifically, the interpersonal/social category mainly focuses on information needs about social well-being (e.g., effects on employment and work); coping information focuses on psychological well-being (e.g., emotional reactions, emotional support, support from other patients); and financial and legal information addresses financial issues. We did not include any of these categories in patient-related health information needs. Moreover, we dropped the body image/sexuality category because no message was related to it. Other changes were also made to fit this typology within our context. For example, we added the topic of "preventing drug resistance" in the treatment-related information category. Finally, a revised typology with 6 sub-categories and 57 topics was used for analyzing patient-related health information needs.

As for patient-related well-being and self-related well-being, we identified codes through inductive content analysis. We developed three topics for patient-related well-being and six topics for self-related well-being. As the number of topics in these two categories is small, we did not group those topics into sub-categories. For stressful events, we used inductive content analysis and identified 31 events for coding.

The second step was preliminary coding and revising the codebook. We further discussed and revised the codebook after 10% of the messages had been coded. In this step, we only revised the expressions of information needs and stressful events. The number of topics and events in each category did not change (Appendix 2 shows the revised codebook). After the codebook was ready, the first and third authors codified independently according to the codebook. For the qualitative study, intercoder agreement checks are very important for the credibility of findings (Huberman, Miles, & Saldana, 2014). To ensure the intercoder agreement, we compared the results each time we completed the coding of 1,000 messages. For the inconsistencies in coding results, the second author joined and discussed inconsistencies with the other two authors to reach an agreement.

The final step was analysis, calculating frequencies, and contingencies interpretation. In this step, the number of each information topic and its percentage were calculated to answer the first research question. To answer the second research question, we calculated the frequency of each stressful event-information topic pair in each category. For patient-related health, the top three frequent pairs of stressful events and information topics were identified in each sub-category because this category includes two levels. Patient-related

Table 1
Patient-related health information needs and stressful events.

Information topics	N	Percentage	Top three pairs of the stressful events and information topics
Treatment-related information	6,596	82.03	(Adverse changes in symptoms occur; Available treatments/treatment options) (443), (Adverse changes in symptoms occur; Treatment plan and description) (328), (Wait/get a new examination result; Available treatments/treatment options) (443)
Cancer-specific information	911	11.33	(Adverse changes in symptoms occur; Symptoms of cancer/management of symptoms) (261), (Wait/get a new examination result; Specific diagnosis information) (220), (Wait/get a new examination result; Symptoms of cancer/management of symptoms) (31)
Prognosis information	214	2.66	(Start/plan to start treatment; Options if treatment fails) (34), (Adverse changes in symptoms occur; Spread of disease or metastasis) (24), (Wait/get a new examination result; Spread of disease or metastasis) (24)
Medical system information	198	2.46	(Start/plan to start treatment; Hospital/physician/genetic test company) (31), (Plan to have/have examinations; Hospital/physician/genetic test company) (25), (Receive new information; Research) (10)
Rehabilitation information	105	1.31	(Adverse changes in symptoms occur; Homecare during recovery) (18), (Adverse changes in symptoms occur; Nutrition during recovery) (18), (Finish treatment; Immediate post-treatment follow-up care) (7)
Surveillance and health information	17	0.21	(Have no available treatment; Palliative care) (6), (Adverse changes in symptoms occur; Palliative care) (3), (Be uncooperative in treatment; Palliative care) (2)
Total	8,041	100	

Note: a. Patient-related health is a two-level classification, and each sub-category includes multiple information topics. To save space, we only presented the frequent and percentage of each sub-category and the top three frequent pairs of stressful event-information topic in each category. The messages that described more than one information topic of the same sub-category were only counted once here.

b. The number followed by the stressful event-information topic pair is the frequency of this pair.

well-being and self-related well-being are both one-level classification. Thus, we identified the top three stressful events of each information topic for further analysis. We explored the relationships between stressful events and information needs through the analysis of stressful events and information needs. Notably, some messages possibly referenced more than one information topic or stressful event. These messages were double-counted. Some messages only described information needs and did not describe stressful events. These messages were only counted when we calculated the occurrence of each information topic.

5. Results

5.1. Patient-related health information needs and stressful events

7,948 of 8,334 messages examined in this study were related to patient-related health information needs. As one message might describe more than one topic, the total number of information topics (8,041) was more than 7,948. [Table 1](#) presents the distribution of each information topic.

Most messages in this category concerned treatment-related information (82.03%). This sub-category mainly focused on available treatment and treatment options (30.58%), and treatment plan and description (23.72%). The pairs of stressful events and information topics show that family members mainly used the OHC to seek suggestions about treatments. When family members saw symptoms developing in a concerning direction via observation or examination and they did not know how to cope with it, they might seek information about available treatments and treatment options. However, if they had thoughts about the treatment for coping with the adverse changes in symptoms, they might be more concerned about the detailed information about treatment plans. One point that requires special attention is information needs about where to get medical supplies and equipment, accounting for 4.06% of this category. It mainly focused on the purchase channels of drugs, indicating the difficulty of drug purchasing in cancer treatment that boosted second-hand drug transactions in the OHC.

The sub-category with the second-highest number of information topics was cancer-specific information (11.33%), focusing on cancer diagnosis, physical effects, symptoms, and other disease-related information. This category mainly involved information needs about cancer symptoms and management (45.67%) and specific diagnosis and examination information (33.84%). For stressful events, adverse changes in symptoms occurring were events that frequently elicited cancer-specific information needs. When symptoms became aggravated or new symptoms occurred, family members felt stressed and needed information about symptoms to alleviate stress. Receiving a new examination result also triggered family members to seek such information because interpretations of these results require health expertise.

The sub-category of prognosis information (2.66%) was related to estimated information about the future. The top three information topics in this sub-category were options if treatment fails (23.29%), the spread of disease or metastasis (22.37%), and life span or survival rate (12.79%). Information about options if treatment fails was especially needed in blind trials. In blind trials, family members did not make sure if the targeted drug could be effective. They might ask for information about options if treatment fails to prepare for the subsequent treatment. Adverse changes in symptoms might indicate the spread or metastasis of cancer. Family members might hope to get information about the spread of disease or metastasis when symptoms became aggravated or when new symptoms occurred. Receiving a new examination result might also cause family members to seek information support to predict whether the disease has spread or metastasized.

Medical system information was the fourth sub-category (2.46%) focused on various agents and research in medical systems, such as hospitals and medical staff. The top three information topics in this sub-category included hospitals, physicians, and genetic test companies (62.00%), how to apply for donated drugs (11.5%), and research (10.00%). Family members were likely to seek information about hospitals, physicians, or genetic test companies to prepare for treatments and examinations. Seeking information about research was often related to receiving new information. In some cases, family members might confirm the reliability of information by seeking information in the OHC when receiving new information about the latest research from other channels. For example, one participant said,

Does anyone know CB-839? I got the information about the drug CB-839 when I watched the news, which showed that this drug is in the clinical stage. I sought information from foreign websites and indeed found relevant papers. [...] Does anyone know about it? The following information is from the news.[...]

Rehabilitation information (1.30%) and surveillance and health information (0.21%) were the final two categories. While rehabilitation information focused on rehabilitation stages (i.e., after a surgery or chemotherapy), information about nutrition during recovery (40.95%) and home care during recovery (33.33%) were often needed for rehabilitation. These information needs often were triggered by some symptoms (e.g., weight loss, emaciation) occurring during rehabilitation and the end of treatment (e.g., surgery, chemotherapy). Surveillance and health information focused on maintaining and restoring physical health. In this sub-category, 82.35% of messages were about palliative care for terminal cancer patients. This information topic was mainly about relieving symptoms, alleviating pain, improving patients' lives, and hospice care. Family members sought this information when the anticancer treatment did not work. For example, one participant said,

Chemotherapy was ineffective. There are only two months to live for my father. We have tried our best. What can I do to help my father spend the rest of his life well?

5.2. Patient-related well-being information needs and stressful events

Only 67 messages were related to patient-related well-being. Thus, we did not collapse them into broader categories. [Table 2](#) shows

the number and percentage of each information topic in this category. Information needs about patient-related well-being mainly focused on disclosing cancer diagnoses to patients (46.27%). Sometimes family members might choose not to tell patients their actual conditions to maintain morale. However, patients might be uncooperative and thought some treatments were unnecessary if they did not know their actual conditions. Therefore, the choice to disclose cancer diagnoses to patients is challenging. Family members often sought information about this topic when adverse changes in symptoms occurred or when new treatments began.

Learning how to help patients cope with negative emotions (28.36%) was also critical for family members, especially when patients were gloomy. With the disease's progression, some cancer patients might be tortured by pain or indisposed in a manner that created psychological distress. For example, one participant said,

My mother has been very strong for three years since she was diagnosed with cancer. However, the constant pain has made her more and more vulnerable. She, who has never cried, always could not help crying recently. I do not know what I should do next.

Furthermore, patients might also react negatively when adverse changes in symptoms occurred or when the treatment was ineffective. Persuading patients to cooperate with treatment (25.37%) might also challenge family members. The effectiveness of treatment often depends on patients' treatment compliance. However, worries about costs and loss of confidence in treatment could make the patient uncooperative, especially for older adults.

5.3. Self-related well-being information needs and stressful events

The number of messages about self-related well-being information needs was 418, accounting for 5.02% of all messages. Table 3 shows the proportional distribution of information topics in this category and the top three stressful events of each information topic. The information most requested was how to cope with negative emotions (32.30%) triggered by the occurrence of adverse changes in symptoms, new diagnoses, and the start of treatment. Intuitively, the occurrence of adverse changes in symptoms and new diagnosis could distress family members. Moreover, when new or modified treatment was used, family members might feel anxious and stressed because they were worried about treatment effectiveness. When the treatment plan should be changed, family members would be under pressure because their choice had a direct bearing on the life span and survival rate of their patients.

Facing death was the second-highest requested information topic in this category (29.66%). Family members were likely to post messages to mourn when patients passed away because it was difficult for them to accept their loved ones' passing. Furthermore, a lack of available treatment indicated that family members would face death shortly.

The cost of treatment, insurance coverage, and other financial issues was the third topic discussed by family members in the OHC (18.90%). Cancer treatment costs are quite expensive, and whether the costs of some treatments are covered by Chinese medical insurance may change over time. Hence, cancer patients' family members desire the latest insurance information and treatment costs for treatment plan selections.

Facing a negative diagnosis was the fourth topic (16.27%) that family members were concerned about in this category, which was often searched for after a new examination or diagnosis or when the symptoms changed unfavorably.

Furthermore, knowing how to handle conflicts with other family members was also vital in the treatment process (2.39%). Conflicts might occur when family members had different opinions about treatments, and conflicts might also occur among family members (especially siblings) because of caregiving and financial burden allocations. Moreover, caregiving requires increased interactions between patients and family members. Hence, conflicts might occur between them, and family members may need support from others to cope with the stressful circumstances (0.48%).

5.4. Top ten stressful events

The thread-initialing messages in the OHC often describe questions and contain contextual information, such as the time of diagnosis, treatment-related experiences, and patients' personal information. Events stressing family members were often mentioned in these thread-initialing messages, prompting individuals to seek information. In our study, 78.1% of messages described the stressful

Table 2
Patient-related well-being information needs and stressful events.

Information topics	N	Percentage	Top three stressful events
Whether to disclose cancer diagnoses to patients	31	46.27	Adverse changes in symptoms occur (7), Start/plan to start treatment (6), Wait/get a new examination result (3)
How to help patients cope with negative emotions	19	28.36	Adverse changes in symptoms occur (5), Treatment does not work well (4), The emotion of patient disorder (4)
How to persuade patients to be cooperative in treatment	17	25.37	Be uncooperative in treatment (6), Have conflicts with patients (3), Start/plan to start treatment (2)
Total	67	100	

Note: a. Patient-related well-being is a one-level classification and only includes three information topics. We presented the frequency, percentage, and top three stressful events of each information topic.

b. The number followed by the stressful event is the frequency of this stressful event.

Table 3
Self-related well-being information needs and stressful events.

Information topics	N	Percentage	Top three stressful events
How to cope with negative emotions	135	32.30	Adverse changes in symptoms occur (18), The patient is diagnosed with cancer (12), Start/plan to start treatment (11)
Facing the death	124	29.66	The patient passed away (119), Have no available treatment (1)
Cost of treatment, insurance coverage, or other financial issues	79	18.90	Receive new information (12), Start/plan to start treatment (11), Plan to have/have examinations (11)
Facing negative diagnosis results	68	16.27	Wait/get a new examination result (13), Adverse changes in symptoms occur (12), The patient is diagnosed with cancer (12)
How to deal with the conflicts with other family members	10	2.39	Have conflicting opinions with others (5), Have conflicts with other family members (5)
How to deal with the conflicts with patients	2	0.48	Have conflicts with patients (2)
Total	418	100	

Note: a. Self-related well-being is a one-level classification and only includes six information topics. We presented the frequency, percentage, and top three stressful events of each information topic. Some information topics were related to less than three stressful events.

b. The number followed by the stressful event is the frequency of this stressful event.

events (6,776 stressful events were identified from 6,509 thread-initialing messages). Table 4 shows the top ten stressful events in our context, closely related to family members' information-seeking behaviors in the OHC.

These stressful events could be viewed as triggers that elicit family members to recognize deficiencies in their knowledge and experiences and feel uncertain. For example, when treatment was ineffective, some family members wondered what they should do next, causing them to recognize deficiencies. Moreover, stressful events could cause uncertainty for family members, including whether the adverse changes in symptoms were normal, whether the treatment plan was suitable, whether the results of the new examination indicated a good condition, whether the doctors' advice was appropriate, and whether the information from other channels was correct. To reduce uncertainty, family members might seek information from others in the OHC. For example, one participant posted a message because the mother had a bit of fever and no appetite after ingesting a specifically targeted drug. The family member did not know whether these symptoms were normal reactions to the targeted drug, therefore posting a message on the OHC to seek support from others.

6. Discussion

6.1. Theoretical implications

This study investigated the information needs of Chinese family members of cancer patients in the OHC. The results partially revealed how Chinese culture might affect family members' information needs in OHCs. Furthermore, this study also examined stressful events that trigger family members to seek information. The results confirmed that information seeking is a coping behavior when family members face stressful events. This study has important implications for research on information behaviors, especially in the Chinese context.

6.1.1. The information needs of family members of cancer patients in the online health community

Our study enriches the research on the information behaviors of cancer patients' family members by identifying information needs articulated in an OHC. Several previous studies have focused on this topic. Table 5 shows a summary of these studies.

The vast majority of messages for information seeking posted by family members concerned health-related information. This outcome is similar to the findings of previous studies in Western countries (Lu et al., 2017; Schook et al., 2014) and Eastern countries

Table 4
Top ten stressful events triggering information-seeking behaviors in the OHC.

Stressful events	N	Percentage
Adverse changes in symptoms occur	1918	28.31
Start/plan to start treatment	1095	16.16
Wait/get a new examination result	1091	16.10
Treatment does not work well	635	9.37
After seeing a doctor	412	6.08
Receive new information	356	5.26
Have conflicting opinions with others	154	2.27
The patient passed away	129	1.90
Plan to have/have examinations	124	1.83
The patient was diagnosed with cancer	122	1.80

(Cho et al., 2011). However, this outcome is contrary to the findings of van Eenbergen et al. (2019). One possible reason for this discrepancy is that part of the data analyzed in the study of van Eenbergen et al. (2019) is from the specific discussion forums for family members, which may better support family members to articulate self-related information needs. For the information needs related to well-being, family members posted more messages about self-related well-being than patient-related well-being, which aligns with previous studies showing that self-related well-being is discussed more frequently by relatives than patients' well-being (van Eenbergen et al., 2019). Other studies from Eastern and Western countries also report that cancer patients' family members sought information from others in OHCs to manage their emotions (e.g., Schook et al., 2014).

In the category of health-related information needs, all information needs have been discussed in previous studies. van Eenbergen et al. (2019) demonstrated that topics about diagnosis, prognosis, and symptoms/complaints/side effects are most discussed in the disease category. Lu et al. (2017) identified five types of health information needs: procedure, drug, symptom, examination, and complication. Cho et al. (2011) found that the highest proportion of family members' information needs is treatment, followed by cancer support, prevention and diagnosis, news and education, and statistics and research. Moreover, we did not identify information needs about sexuality and appearance that were mentioned in the study of van Eenbergen et al. (2019). One possible explanation is that 95.9% of family members are the offspring of patients who may not care much about disease impacts on sexuality and intimacy (Adams et al., 2009).

To improve patients' well-being, Chinese family members seek information about disclosing actual conditions to patients, helping patients cope with negative emotions, and persuading patients to cooperate with the treatment. In previous studies, the most discussed information need in this category is helping patients cope with negative emotions (van Eenbergen et al., 2019). Whether to disclose actual conditions to the patient and how to persuade the patient to cooperate during treatment are two newly identified information needs in our study. However, disclosing actual conditions to patients has been studied in clinical practice. For example, Sun et al. (2015) investigated different attitudes toward disclosing patients' cancer diagnoses and reported that family members prefer not to inform patients of diagnoses or to inform them partially. Patient compliance in treatment is crucial; thus, research on clinical practice has also studied why patients are uncooperative in treatment, as well as how to address this problem (e.g., Knight et al., 2018).

Information needs about coping with negative emotions and facing death were the most articulated topics by the family members of cancer patients to manage their emotions in the OHC. These information needs have been discussed by van Eenbergen et al. (2019).

Table 5

The primary findings related to the information needs of family members of cancer patients in online health communities.

Source	Country	OHC	Data	Related Findings
This study	China	Yuaigongwu.com	8,334 messages for seeking information posted by 2,788 family members	Family members were more concerned about health-related information more than patient-related well-being and self-related well-being information. Treatment-related information was mainly requested in the health-related information need category (82.03%). Compared with patient-related well-being information (n=67), family members were more concerned about self-related well-being information (n=418).
Cho et al. (2011)	Korea	Cancer.go.kr	161 caregivers	Information most needed by caregivers was treatment, followed by cancer support, prevention and diagnosis, news and education, statistics, and research.
(van Eenbergen et al., 2019)	Dutch	Kanker.nl	Blog and group posts written by 123 blog posters and 62 group posters	Blog posts and group posts are relatively relating to "well-being" more than about "disease". Self-related well-being was discussed much more by the posters than patients' well-being. In blogs and group discussions, these topics in the "disease" category were most discussed: diagnosis and prognosis, symptoms/complaints/side effects.
Lu et al. (2017)	the United States	MedHelp.org	1,607 messages posted by 1,053 caregivers in the lung cancer forum, and 9,727 messages posted by 6,343 caregivers in the breast cancer forum.	In the lung cancer forum, 27.01% of topics that caregivers were concerned about were about the symptom, followed by complication (23.42%), procedure (19.51%), examination (19.02%), and drug (11.03%). In the breast cancer forum, caregivers mainly focused on the information about examinations (31.19%), followed by procedures (28.32%), symptoms (17.83%), complications (11.48%), and drugs (11.17%).
Schook et al. (2014)	Dutch	Dutch Lung Cancer Information Center's website	Interviews with 20 caregivers	Caregivers searched for the general information of any kind. Caregivers wanted to get prognosis information. Caregivers hope to get emotional support from others.

Furthermore, van Eenbergen et al. (2019) also discussed financial issues and called for providing this information for family members. Information need about how to accept negative diagnoses has not been mentioned in the studies listed in Table 5. However, previous research that is not in the context of online health communities has discussed the issues about the acceptance of cancer diagnosis (Leonidou & Giannousi, 2018).

Conflicts with other family members may be encountered in the process of cancer treatment. Financial and caregiving burdens, as well as different opinions about treatments, could strain relationships between family members. Thus, family members may need information to handle conflict with other family members. However, this information need has not been identified in the studies listed in Table 5. Furthermore, a few messages asked how to deal with conflicts with patients. The study of Leonidou and Giannousi (2018) conducted in Cyprus has discussed the interpersonal conflicts between family members and patients, stating that interpersonal conflicts occur because of overprotection, but studies on family members' information needs in OHCs have not examined this topic.

6.1.2. Chinese culture and family members' information needs in the online health community

Existing research has suggested that culture may impact family members' information needs (Adams et al., 2009; Chen, 2014; Leonidou & Giannousi, 2018). However, the attention to family members' information needs in Chinese culture is limited. In this study, we examined the information needs of cancer patients' family members by analyzing 8,334 thread-initialing messages seeking information via one of the largest Chinese online cancer communities. The results partially revealed the impacts of culture on family members' information needs.

Although this study, in agreement with other existing studies, showed that cancer patients' family members mostly need treatment-related information and cancer-specific information, nuances exist in the proportion distribution. Our study found that the proportion of treatment-related information is much higher than cancer-specific information, consistent with studies conducted in Eastern countries (Cho et al., 2011). However, studies in Western countries showed that family members are more concerned about cancer-specific information (van Eenbergen et al., 2019), or there is not much difference in family members' interest in the two types of information (Lu et al., 2017). The high proportion of treatment-related information needs may reflect the impact of the family-centered medical decision-making model in Chinese culture (Back & Huak, 2005), whereas Western culture emphasizes patient autonomy in decision-making (Ballard-Reisch & Letner, 2003; Ruhnke et al., 2000). Furthermore, the family-centered medical decision-making model also indicates the high involvement of family members in treatment, which reflects the role of "decision-makers". From the top three pairs of stressful events and information topics in the treatment-related information category, we found that stressful events raise questions about the appropriateness of existing or subsequent treatment and raise questions about how to cope with physical conditions, prompting family members' information-seeking behaviors.

Medical decision-making models also affect beliefs about disclosing a cancer diagnosis to patients. A culture with a family-centered medical decision-making model holds that preventing patients from painful information is merciful. Conversely, a culture with a patient-centered medical decision-making model believes that patients should know their actual conditions to avoid family members from overriding or misinterpreting patients' desires (Ballard-Reisch & Letner, 2003; Ruhnke et al., 2000). In China, physicians prefer to offer a diagnosis to family members first, and family members decide whether to inform the patient the truth (Yi et al., 2016). The protection emphasized in Chinese culture results in family members being less likely to disclose the cancer diagnosis to patients (Sun et al., 2015). However, it may be difficult to persuade patients to cooperate with the treatment when they do not know their actual diagnosis. Thus, Chinese family members will be left in a quandary and hope to acquire such information.

Furthermore, this study showed that Chinese family members mainly focus on patient-related health information and seldom articulate the information needs about the well-being of patients and themselves. This finding differs from the study of van Eenbergen et al. (2019) that showed relatives of cancer patients are more concerned about well-being information than the disease-related information. Besides a lack of a specific sub-forum for family members, one possible explanation may be that Chinese culture discourages people from publicly displaying negative emotions. Both patient-related well-being and self-related well-being may be related to negative emotions. China has a collectivist culture, in which people do not desire to disturb the harmony of groups and attract others' attention to their distressing emotional states (Mortenson et al., 2009). In addition, there were no messages relating to the information needs about sexuality and appearance. Except for the reason that most family members discussed in this study are the offspring of patients, another possible explanation is that the Chinese are ashamed to publicly discuss sexual relationships because they think sexual relationships are highly personal and private (Lim et al., 2017).

6.1.3. Information seeking as a method of coping with stressful events

This study confirmed that information seeking is a coping method for stressful events (Der Molem, 1999), thus extending stress and coping theory by identifying these stressful events and exploring the relations between stressful events and information needs. Previous studies on stress and coping theory have mainly focused on the relationships between stressful events and various information-seeking behaviors (e.g., Fridfinnsdottir, 1997; Leung, 2006; Rains et al., 2015; Wright, 2016). Our study investigated the information needs of cancer patients' family members in the OHC and the stressful events that trigger these information needs to further understand the context from which information needs arise.

Furthermore, our study also calls for further studies based on stress and coping theory. For example, future research can measure the controllability and duration of consequences to characterize these events further. In a healthcare context, controllable events refer to the events that their negative consequences can be avoided or mitigated through prevention (Rains et al., 2015). Duration refers to the length of time that a stressful event may affect individuals' lives (Rains et al., 2015). Events with different characteristics may differ in psychological demand (Cutrona & Russell, 1990). Individuals may use different strategies to cope with different events. For example, controllable events (e.g., adverse changes in symptoms occur) may cause more health information seeking to prevent the

distressing situation. Uncontrollable events (e.g., The patient passed away) may be addressed by seeking information about self-related well-being to diminish the intensity of negative affect.

6.2. Practical implications

Initialing a thread and asking questions in OHCs could be viewed as a manifestation of participants' information-seeking behavior. This study extracted the information needs of cancer patients' family members and identified stressful events that prompted them to seek information from these thread-initialing messages. The results suggest that operators of OHCs should consider specific information needs of family members and the impacts of Chinese culture in service design. Additionally, the results also offer implications for government agencies in charge of healthcare to improve cancer patients' life quality and their family members' well-being.

6.2.1. Service design in online health communities for family members

Family members have become an essential part of OHCs, accounting for over a quarter of the participants of the OHC investigated in this study. However, this group has not been taken seriously by the operators of OHCs yet. Existing research has shown that family members' and patients' information needs are different (Cho et al., 2011; Lu et al., 2017). Few forums and discussion groups have been created for family members. In this study, we investigated the information needs of cancer patients' family members in an OHC. Particularly, information needs about patient-related well-being and self-related well-being were discussed in this study. These results may provide implications for the operators of OHCs.

In our study, only a few messages were about patient-related and self-related well-being. Apart from the potential impacts of culture, a lack of specific forums for patient-related and self-related well-being in the examined OHC may also account for this finding. In the examined OHC of this study, each sub-forum has its unique theme, and any irrelevant messages are unwelcome. This rule may discourage family members from posting messages related to patients' and their well-being in this OHC. To improve patients' and family members' life quality, the OHC should establish specific sub-forums for family members to communicate information about patients' and their well-being. Some offline activities could also be carried out to increase their social connectivity and help family members improve their well-being.

Seeking information is a method to cope with stressful events. Most family members prefer to describe stressful events that trigger their information needs. In this study, we summarized some frequent pairs of stressful events and information needs, which show the relationships between them. When certain stressful events occur, family members may seek similar information to cope with these events. For example, when a patient has a new examination, family members may seek cancer-specific information to understand the examination results, seek treatment-related information to ensure the current treatment plan's suitability, and seek financial information to cope with the costs. Future research can extract more detailed information about stressful events (e.g., the name of the examination, whether the patient receives the examination results) articulated in family members' messages, explore the relationships between stressful events and information needs, and incorporate their relationships into recommendation systems and information retrieval systems of an OHC to improve participants' satisfaction. Moreover, an OHC could establish various discussion groups or sub-forums according to stressful events and cancer types. For example, an OHC could establish a sub-forum for discussing the cause and available treatments for adverse changes in symptoms in the lung cancer journey.

Furthermore, some information needs, especially those concerning cancer-specific information, may be unrelated to personal details and can be met by reading other participants' messages rather than initialing new threads. Messages that meet most participants' information needs could be displayed at the top of forums as sticky threads for easy retrieval. The OHC operators can select these sticky threads and update them according to participants' information needs.

6.2.2. Policy-making for cancer patients and their family members

Cancer patients' family members are vital in caregiving and decision making. The government should attend to family members' information needs because if these needs are unmet, family members' physical and physiological well-being could be affected. Hence, patients would not receive optimal care from their family members. The findings of our study suggest that Chinese patient education should be family-centered. Government agencies in charge of healthcare can harness online healthcare resources to enhance family members' roles in caregiving. Certain interventions may assist with this process.

First, the government should strengthen internet infrastructure construction, especially in rural areas, to improve family members and patients information access. Second, the government could initial family-centered education programs relying on the advantages of OHCs. Compared with other organizations, the massive amounts of user-generated data give OHCs inherent advantages to discover the information needs of cancer patients' families and the times when information is needed (i.e., the occurrence of stressful events). Thus, OHCs can provide tailored information to family members and patients when they detect their participants' information needs. Moreover, OHCs can also provide focused online and offline lectures and training for cancer patients' families.

In addition to using online resources, governments could also initial programs to meet specific family members' information needs. For example, some family members hope to acquire second-hand drugs. We also found some threads for reselling and donating drugs to patients in need in the data cleaning process. Collecting and redistributing these unused drugs by the government-appointed agencies could help reduce the waste of medications, as well as avoid some problems in the private second-hand transactions (e.g., fake drug, fraud). There have been some trials to solve personal drug donation and resale issues in other countries. For example, some states in the United States have passed drug donation laws and created programs for collecting and redistributing cancer-related prescription drugs to eligible patients (NCSL, 2020). However, private sale and donation of drugs are prohibited in China. Chinese governments in charge of healthcare may draw experiences from other countries' trials to meet Chinese cancer patients' and family members' needs for

second-hand drugs.

6.3. Limitations and future work

Four limitations of this study are noteworthy. First, we only focused on the information needs of family members and did not study patients' information needs in the OHC. We developed our conceptual framework based on the target users of information seekers, which can show the specific information needs of family members to some extent. For example, a fraction of messages indicates the information needs for self-related well-being, which should be different from patients' self-related well-being. However, it is not enough to demonstrate the specific information needs of family members fully. Future research could extend our study by comparing the information needs of patients and family members.

Second, culture may impact participants' information needs in OHCs. In this study, we only investigated the information needs in Chinese culture. Future work could study the information needs of family members in other cultures and summarize the differences in family members' information needs in different cultures.

Third, we considered that information seeking is a method to cope with stressful events, and we dedicated effort to determine the relationships between stressful events and information needs. However, we did not consider the impacts of family members' characteristics on their information needs. For example, family members with high neuroticism may articulate more information needs about self-related well-being when facing uncontrollable stressful events. In the future, researchers can use a survey method to investigate the information needs of family members with different characteristics.

Finally, this study only confirmed that participants often cope with stressful events by information seeking but did not examine whether information seeking is effective for coping with stressful events. Future research can further analyze the features of thread-initialing messages to investigate how participants construct messages for different stressful events that can obtain the desired information.

7. Conclusion

Understanding the information needs of cancer patients' family members is critical for improving caregiving quality and family members' well-being. An OHC can serve as an effective channel to provide information that helps cancer patients' family members cope with stressful events during cancer treatment. Considering the potential impacts of culture on information needs, we investigated the information needs of cancer patients' family members in Chinese culture. Three categories of information needs were discussed in this study: patient-related health, patient-related well-being, and self-related well-being. Based on the results of analyzing information needs and their related stressful events in three categories, we discussed the information needs of Chinese cancer patients' family members in the online health community, the potential impacts of culture on information needs, and the relationships between stressful events and information needs. We believe this study can provide important practical implications for the development of Chinese online health communities and government interventions in healthcare service delivery.

Funding

The authors would like to acknowledge the partial financial support from the Key Projects of Philosophy and Social Sciences Research of Chinese Ministry of Education [Grant No. 19JZD021], the National Natural Science Foundation of China [Grant No. 71771210], and the Beijing Nature Science Foundation [Grant No. 9182008].

CRediT authorship contribution statement

Dan Ma: Conceptualization, Methodology, Software, Investigation, Formal analysis, Data curation, Writing - original draft, Visualization. **Meiyun Zuo:** Conceptualization, Methodology, Formal analysis, Writing - review & editing, Project administration, Funding acquisition, Supervision. **Liu Liu:** Conceptualization, Methodology, Formal analysis, Writing - review & editing.

Declaration of Competing Interest

None

Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:[10.1016/j.ipm.2021.102517](https://doi.org/10.1016/j.ipm.2021.102517).

References

Adams, E., Boulton, M., & Watson, E. (2009). The information needs of partners and family members of cancer patients: a systematic literature review. *Patient education and counseling*, 77(2), 179–186.

- Alzougool, B., Chang, S., & Gray, K. (2008). Towards a comprehensive understanding of health information needs. *electronic Journal of Health Informatics*, 3(2), e15.
- Alzougool, B., Chang, S., & Gray, K. (2017). The effects of informal carers' characteristics on their information needs: The information needs state approach. *Informatics for Health and Social Care*, 42(3), 261–273.
- Back, M. F., & Huak, C. Y. (2005). Family centred decision making and non-disclosure of diagnosis in a South East Asian oncology practice. *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer*, 14(12), 1052–1059.
- Ballard-Reisch, D. S., & Letner, J. A. (2003). Centering families in cancer communication research: Acknowledging the impact of support, culture and process on client/provider communication in cancer management. *Patient education and counseling*, 50(1), 61–66.
- Barney, L. J., Griffiths, K. M., & Banfield, M. A. (2011). Explicit and implicit information needs of people with depression: a qualitative investigation of problems reported on an online depression support forum. *BMC psychiatry*, 11, 88.
- Berland, G. K., Elliott, M. N., Morales, L. S., Algazy, J. I., Kravitz, R. L., Broder, M. S., & Lara, M. (2001). Health information on the Internet: accessibility, quality, and readability in English and Spanish. *Jama*, 285(20), 2612–2621.
- Bevan, J. L., & Pecchioni, L. L. (2008). Understanding the impact of family caregiver cancer literacy on patient health outcomes. *Patient education and counseling*, 71(3), 356–364.
- Bray, F., Ferlay, J., Soerjomataram, I., Siegel, R. L., Torre, L. A., & Jemal, A. (2018). Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA: a cancer journal for clinicians*, 68(6), 394–424.
- Cai, Y., Xue, M., Chen, W., Hu, M., Miao, Z., Lan, L., & Meng, Q. (2017). Expenditure of hospital care on cancer in China, from 2011 to 2015. *Chinese Journal of Cancer Research*, 29(3), 253–262.
- Chen, L., Baird, A., & Straub, D. (2019). Fostering participant health knowledge and attitudes: An econometric study of a chronic disease-focused online health community. *Journal of Management Information Systems*, 36(1), 194–229.
- Chen, S.-c (2014). Information needs and information sources of family caregivers of cancer patients. *Aslib Journal of Information Management*, 66(6), 623–639.
- Chen, W., Zheng, R., Baade, P. D., Zhang, S., Zeng, H., Bray, F., & He, J. (2016). Cancer statistics in China, 2015. *CA: a cancer journal for clinicians*, 66(2), 115–132.
- Cho, J., Noh, H.-I., Ha, M. H., Kang, S. N., Choi, J.-y., & Chang, Y. J. (2011). What kind of cancer information do Internet users need? *Supportive Care in Cancer*, 19(9), 1465–1469.
- Cline, R. J., & Haynes, K. M. (2001). Consumer health information seeking on the Internet: the state of the art. *Health education research*, 16(6), 671–692.
- Colombo, C., Mosconi, P., Confalonieri, P., Baroni, I., Traversa, S., Hill, S. J., & Filippini, G. (2014). Web search behavior and information needs of people with multiple sclerosis: focus group study and analysis of online postings. *Interactive journal of medical research*, 3(3), e12.
- Cutrona, C. E., & Russell, D. W. (1990). Type of social support and specific stress: Toward a theory of optimal matching. In B. R. Sarason, I. G. Sarason, & G. R. Pierce (Eds.), *Social support: An interactional view* (pp. 319–366). New York: Wiley.
- Der Molem, V. (1999). Relating information needs to the cancer experience: 1. Information as a key coping strategy. *European Journal of Cancer Care*, 8(4), 238–244.
- Diener, E., & Seligman, M. E. (2004). Beyond money: Toward an economy of well-being. *Psychological science in the public interest*, 5(1), 1–31.
- Diener, E., Suh, E. M., Lucas, R. E., & Smith, H. L. (1999). Subjective well-being: Three decades of progress. *Psychological bulletin*, 125(2), 276–302.
- Donelle, L., & Hoffman-Goetz, L. (2008). An exploratory study of Canadian Aboriginal online health care forums. *Health communication*, 23(3), 270–281.
- Eschler, J., Dehlawi, Z., & Pratt, W. (2015). Self-characterized illness phase and information needs of participants in an online cancer forum. *Paper presented at the Ninth International AAAI Conference on Web and Social Media*. UK: Oxford.
- Esquivel, A., Meric-Bernstam, F., & Bernstam, E. V. (2006). Accuracy and self correction of information received from an internet breast cancer list: content analysis. *Bmj*, 332(7547), 939–942.
- Folkman, S., & Lazarus, R. S. (1985). If it changes it must be a process: study of emotion and coping during three stages of a college examination. *Journal of personality and social psychology*, 48(1), 150–170.
- Fridfinnsdottir, E. B. (1997). Icelandic women's identifications of stressors and social support during the diagnostic phase of breast cancer. *Journal of Advanced Nursing*, 25(3), 526–531.
- Fukui, S. (2002). Information needs and the related characteristics of Japanese family caregivers of newly diagnosed patients with cancer. *Cancer Nursing*, 25(3), 181–186.
- Himmel, W., Meyer, J., Kochen, M. M., & Michelmann, H. W. (2005). Information needs and visitors' experience of an Internet expert forum on infertility. *Journal of Medical Internet Research*, 7(2), e20.
- House, J. S., Umberson, D., & Landis, K. R. (1988). Structures and processes of social support. *Annual review of sociology*, 14(1), 293–318.
- Huberman, A. M., Miles, M., & Saldana, J. (2014). *Qualitative data analysis: A methods sourcebook. The united states of America*. SAGE publications.
- Kang, K. K. (2017). Anonymity and interaction in an online breast cancer social support group. *Communication Studies*, 68(4), 403–421.
- Knight, T. G., Deal, A. M., Dusetzina, S. B., Muss, H. B., Choi, S. K., Bensen, J. T., & Williams, G. R. (2018). Financial toxicity in adults with cancer: adverse outcomes and noncompliance. *Journal of Oncology Practice*, 14(11), e665–e673.
- Kurtz, M. E., Kurtz, J. C., Given, C. W., & Given, B. A. (2004). Depression and physical health among family caregivers of geriatric patients with cancer—a longitudinal view. *Medical Science Monitor*, 10(8), CR447–CR456.
- Lambert, S. D., Loiselle, C. G., & Macdonald, M. E. (2009a). An in-depth exploration of information-seeking behavior among individuals with cancer: part 1: understanding differential patterns of active information seeking. *Cancer Nursing*, 32(1), 11–23.
- Lambert, S. D., Loiselle, C. G., & Macdonald, M. E. (2009b). An in-depth exploration of information-seeking behavior among individuals with cancer: part 2: understanding patterns of information disinterest and avoidance. *Cancer Nursing*, 32(1), 26–36.
- Lee, J., & Bell, K. (2011). The impact of cancer on family relationships among Chinese patients. *Journal of transcultural nursing*, 22(3), 225–234.
- Lee, S., Colditz, G. A., Berkman, L. F., & Kawachi, I. (2003). Caregiving and risk of coronary heart disease in US women: a prospective study. *American journal of preventive medicine*, 24(2), 113–119.
- Leonidou, C., & Giannousi, Z. (2018). Experiences of caregivers of patients with metastatic cancer: What can we learn from them to better support them? *European journal of oncology nursing*, 32, 25–32.
- Leung, L. (2006). Stressful life events, motives for Internet use, and social support among digital kids. *CyberPsychology & Behavior*, 10(2), 204–214.
- Lim, B. T., Butow, P., Mills, J., Miller, A., & Goldstein, D. (2017). Information needs of the Chinese community affected by cancer: A systematic review. *Psycho-Oncology*, 26(10), 1433–1443.
- Lin, H. Y., Chen, S. C., Peng, H. L., & Chen, M. K. (2015). Unmet information needs and clinical characteristics in patients with precancerous oral lesions. *European Journal of Cancer Care*, 24(6), 911–919.
- Liu, Q. B., Liu, X., & Guo, X. (2020). The Effects of Participating in a Physician-Driven Online Health Community in Managing Chronic Disease: Evidence from Two Natural Experiments. *MIS Quarterly*, 44(1), 391–419.
- Lu, Y., Wu, Y., Liu, J., Li, J., & Zhang, P. (2017). Understanding health care social media use from different stakeholder perspectives: a content analysis of an online health community. *Journal of Medical Internet Research*, 19(4), e109.
- Lu, Y., Zhang, P., & Deng, S. (2013). *Exploring health-related topics in online health community using cluster analysis*. Paper presented at the 2013 46th Hawaii International Conference on System Sciences, Hawaii.
- Markham, A., & Buchanan, E. (2012). Ethical decision-making and internet research: Version 2.0. recommendations from the AoIR ethics working committee. *Available online: aoir.org/reports/ethics2.pdf*.
- Mayring, P. (2014). *Qualitative content analysis: theoretical foundation, basic procedures and software solution*. Klagenfurt: Open Access Repository.
- McCarthy, B. (2011). Family members of patients with cancer: what they know, how they know and what they want to know. *European journal of oncology nursing*, 15(5), 428–441.
- Mortenson, S. T., Burleson, B. R., Feng, B., & Liu, M. (2009). Cultural similarities and differences in seeking social support as a means of coping: A comparison of European Americans and Chinese and an evaluation of the mediating effects of self-construal. *Journal of International and Intercultural Communication*, 2(3), 208–239.

- NCSL. (August 10, 2020). *State Prescription Drug Return, Reuse and Recycling Laws*. Retrieved from <https://www.ncsl.org/research/health/state-prescription-drug-return-reuse-and-recycling.aspx>.
- Northouse, L., Williams, A.-I., Given, B., & McCorkle, R. (2012). Psychosocial care for family caregivers of patients with cancer. *Journal of Clinical Oncology*, 30(11), 1227–1234.
- Northouse, L. L., Mood, D., Templin, T., Mellon, S., & George, T. (2000). Couples' patterns of adjustment to colon cancer. *Social science & medicine*, 50(2), 271–284.
- Oh, J., & Kim, J. A. (2017). Information-seeking behavior and information needs in patients with amyotrophic lateral sclerosis: Analyzing an online patient community. *CIN: Computers, Informatics, Nursing*, 35(7), 345–351.
- Oh, S., Zhang, Y., & Park, M. S. (2016). Cancer information seeking in social question and answer services: identifying health-related topics in cancer questions on Yahoo! Answers. *Information Research*, 21(3), 718.
- Oh, Y. S. (2015). Predictors of self and surrogate online health information seeking in family caregivers to cancer survivors. *Social work in health care*, 54(10), 939–953.
- Parvataneni, R., Polley, M.-Y., Freeman, T., Lamborn, K., Prados, M., Butowski, N., & Rabbitt, J. (2011). Identifying the needs of brain tumor patients and their caregivers. *Journal of neuro-oncology*, 104(3), 737–744.
- Pian, W., Song, S., & Zhang, Y. (2020). Consumer health information needs: A systematic review of measures. *Information Processing & Management*, 57(2), Article 102077.
- Portier, K., Greer, G. E., Rokach, L., Ofek, N., Wang, Y., Biyani, P., & Mitra, P. (2013). Understanding topics and sentiment in an online cancer survivor community. *Journal of the National Cancer Institute Monographs*, 2013(47), 195–198.
- Rains, S. A., Peterson, E. B., & Wright, K. B. (2015). Communicating social support in computer-mediated contexts: A meta-analytic review of content analyses examining support messages shared online among individuals coping with illness. *Communication Monographs*, 82(4), 403–430.
- Ruhnke, G. W., Wilson, S. R., Akamatsu, T., Kinoue, T., Takashima, Y., Goldstein, M. K., & Raffin, T. A. (2000). Ethical decision making and patient autonomy: a comparison of physicians and patients in Japan and the United States. *Chest*, 118(4), 1172–1182.
- Rutten, L. J. F., Arora, N. K., Bakos, A. D., Aziz, N., & Rowland, J. (2005). Information needs and sources of information among cancer patients: a systematic review of research (1980–2003). *Patient education and counseling*, 57(3), 250–261.
- Savolainen, R. (2014). Emotions as motivators for information seeking: A conceptual analysis. *Library & Information Science Research*, 36(1), 59–65.
- Schook, R. M., Linsen, C., Schramel, F. M., Festen, J., Lammers, E., Smit, E. F., & Westerman, M. J. (2014). Why do patients and caregivers seek answers from the Internet and online lung specialists? A qualitative study. *Journal of Medical Internet Research*, 16(2), e37.
- Silver, J. K. (2015). Cancer rehabilitation and its role in improving health outcomes and reducing health care costs. *Seminars in oncology nursing*, 31(1), 13–30.
- Simpson, P. (2005). Hong Kong families and breast cancer: Beliefs and adaptation strategies. *Psycho-Oncology*, 14(8), 671–683.
- Sklenarova, H., Krümpelmann, A., Haun, M. W., Friederich, H. C., Huber, J., Thomas, M., & Hartmann, M. (2015). When do we need to care about the caregiver? Supportive care needs, anxiety, and depression among informal caregivers of patients with cancer and cancer survivors. *Cancer*, 121(9), 1513–1519.
- Sun, W., Wang, Z., Fang, S., & Li, M. (2015). Factors influencing the attitudes of Chinese cancer patients and their families toward the disclosure of a cancer diagnosis. *Journal of Cancer Education*, 30(1), 20–25.
- Thoits, P. A. (1995). Stress, coping, and social support processes: Where are we? What next? *Journal of health and social behavior(Extra Issue)*, 53–79.
- Thomas, C., & Morris, S. M. (2002). Informal carers in cancer contexts. *European Journal of Cancer Care*, 11(3), 178–182.
- van Eenbergen, M. C., van Engelen, H., Ezendam, N. P., van de Poll-Franse, L. V., Tate, K., & Kraemer, E. J. (2019). Paying attention to relatives of cancer patients: What can we learn from their online writings? *Patient education and counseling*, 102(3), 404–410.
- WHO. (2018). *Cancer*. Retrieved from <https://www.who.int/news-room/fact-sheets/detail/cancer>.
- Wilson, T. D. (1997). Information behaviour: an interdisciplinary perspective. *Information Processing & Management*, 33(4), 551–572.
- Wright, K. B. (2016). Communication in health-related online social support groups/communities: A review of research on predictors of participation, applications of social support theory, and health outcomes. *Review of Communication Research*, 4, 65–87.
- Yi, T.-w., Deng, Y.-t., Chen, H.-p., Zhang, J., Liu, J., Huang, B.-y., & Jiang, Y. (2016). The discordance of information needs between cancer patients and their families in China. *Patient education and counseling*, 99(5), 863–869.
- Young, C. (2013). Community management that works: how to build and sustain a thriving online health community. *Journal of Medical Internet Research*, 15(6), e119.
- Zhang, X., Liu, S., Chen, X., Wang, L., Gao, B., & Zhu, Q. (2018). Health information privacy concerns, antecedents, and information disclosure intention in online health communities. *Information & Management*, 55(4), 482–493.
- Zhang, Y., Sun, Y., & Xie, B. (2015). Quality of health information for consumers on the web: a systematic review of indicators, criteria, tools, and evaluation results. *Journal of the Association for Information Science and Technology*, 66(10), 2071–2084.