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Online Support Group for Chinese Women with Ovarian or Cervical Cancer

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ONLINE SUPPORT GROUP FOR CHINESE WOMEN WITH OVARIAN OR CERVICAL
CANCER

By

YUAN XING

A thesis submitted in partial fulfillment of the requirements
for the Honors In the Major in Nursing
in the College of Nursing
and in the Burnett Honors College
at the University of Central Florida
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Thesis Committee Chair: Dr. Victoria Loerzel

ABSTRACT

Women with gynecological (GYN) cancer experience a wide spectrum of physical, emotional and social effects after diagnosis and treatment of their cancer. The insufficient availability of local support groups, limited transportation for the rural Chinese population and a shortage of oncologists make it difficult to have face-to-face support groups for Chinese GYN cancer patients. However, the wide access of Internet has provided an opportunity for people to have online support groups. The purpose of this study was to observe and describe the types of support given to and by Chinese GYN cancer survivors in the QQ chat group. This was a qualitative study that used the directed content analysis approach. A QQ group was observed for two weeks between March 10th (12:01am) and March 24st (11:59pm) 2018 Beijing time. Observed online posts were copied and pasted into a WORD™ document for analysis. There were 4 themes observed: sharing experience, information exchange, emotional support and Guardian Against Cancer group member benefits. The results of the study suggested that women supported each other but little evidence-based support was observed. Healthcare providers should be monitoring and engaging in conversations with group members. Well-planned and organized information sessions should also be beneficial for members. Further research on understanding members' needs on online support groups and the effectiveness of intervention should be conducted.

DEDICATION

To my husband Jon,
for your support, love and humor.

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TABLE OF CONTENTS

INTRODUCTION.....	1
PURPOSE	6
DESIGN	7
SAMPLE AND SETTING	8
PROCEDURE	9
DATA ANALYSIS	11
FINDINGS.....	13
Sharing Experience.....	14
Information Exchange.....	18
Emotional Support	22
Guardian Against Cancer Group Member Benefits	24
DISCUSSION.....	25
LIMITATION.....	29
RECOMMENDATION FOR PRACTICE AND RESEARCH	30
CONCLUSIONS.....	32
APPENDIX A: NOT HUMAN RESEARCH DETERMINATION.....	33
APPENDIX B: NOTICE FROM THE GROUP OWNER.....	35
APPENDIX C: NOTICE FROM PI ABOUT COMPLETION OF THE STUDY	37
REFERENCES.....	40

LIST OF TABLES

Table 1: Frequency of Each Type of Support. n=172.....	14
Table 2: Subthemes Under Sharing Experiences n=91.....	15
Table 3: Subthemes Under Sharing Experiences n=56.....	22

LIST OF FIGURES

Figure 1: Example of Data Translation into Chinese and Coding	10
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INTRODUCTION

In 2013 in China, there were approximately 3.8 million people with newly diagnosed cancer (Yu & Baade, 2017). In females, breast cancer was the most common cancer, accounting for 17.07% of all new cancers, followed by lung, colorectal, stomach and thyroid cancers (Yu & Baade, 2017). Cervical and ovarian cancer are the two most common gynecological cancers and the incidence rate increased six-fold between 2003 to 2013 (Li et al., 2015). Ovarian and cervical cancers combined were estimated to cause 53,000 deaths in China in 2015 (Yu & Baade, 2017). Women with cancer experience wide spectrum of side effects after diagnosis and treatment in terms of physical, emotional and social aspects.

In China, most research related to women's experience has been done with women with breast cancer. Therefore, this paper will present literature related to Chinese women with breast cancer when no literature was found on women with GYN cancer because it is likely that women with cancer share similar experiences. One research study stated that pain and fatigue were the most common and distressing physical symptoms reported by women with breast cancer throughout treatment (Bower et al., 2000). Breast cancer patients also reported reduced quality of sleep during chemotherapy, loss of appetite, nausea and vomiting (Beck et al., 2009). One study was found related to Chinese ovarian patients' physical symptoms. Huang et al. (2016) conducted a study on cluster symptoms of ovarian cancer patients with chemotherapy after surgery. Five clusters were noted: pain-related symptom cluster included pain, feeling bloated and dizziness and menopausal symptom cluster consisted of lack of energy, dry mouth, difficulty sleeping, lack of appetite, and feeling irritated. Ovarian patients also experienced

gastrointestinal symptoms, including nausea, vomiting, weight loss, change the way the food tasted. The severity of nausea and vomiting was most common in the first chemotherapy cycle. Body image-related cluster consisted of hair loss, constipation and change in skin were common. Neurological-related symptoms were also seen in ovarian patients, including numbness, tingling in the hands and/or feet and dizziness. These studies showed that women had numerous physical concerns after treatment regardless of diagnosis (Huang et al, 2016).

Being newly diagnosed with cancer can also induce strong emotional distress for many women, however very little information about emotional distress in Asian or Chinese women with cancer exists. Literature specific to Chinese ovarian cancer patients stated the prevalence of symptoms of depression was 47% and the prevalence of symptoms of anxiety was 51.5% (Li et al., 2015). Women with ovarian cancer reported feeling the greatest anxiety, nervousness and sadness at the start of first round of chemotherapy. Similar to U.S ovarian cancer patients, Chinese women experienced a decrease of severity of psychosocial side effects throughout the chemotherapy (Huang et al, 2016).

Other related literature from Taiwan indicates that breast cancer chemotherapy patients experienced multiple types of fear. According to a recent study by Chen et al. (2016), women with breast cancer fear permanent separation from families, side-effects and the disease getting worse. Many women also can develop a negative body image (Chen et al., 2016). It is likely that Asian or Chinese women with GYN cancer experience similar issues and these issues are common regardless of country of origin. For example, Keim-Malpass et al. (2017) found that in the U.S, psychosocial problems such as depression, isolation and fear of recurrence in women with GYN cancers has been reported. These symptoms were secondary to physical problems

and decreased over time. These women also have psychological unmet needs such as fear of the cancer spreading, being informed about things to help get well, and uncertainty of the future (Keim-Malpass et al, 2017).

Several cultural factors may make it difficult for Chinese women with cancer to get support for psychosocial issues. Again, most research related to psychosocial aspects of the cancer experience in China has been conducted in women with breast cancer. First, compared to Western individuals, breast cancer patients in China have a stronger reluctance to reveal their feelings and thoughts about their cancer to family, friends and acquaintances. They worry that sharing feelings can cause them to lose face, be shamed or be criticized because cancer is viewed by many as a result of karma (Lee et al., 2017). In China, breast cancer patients are sensitive to any avoidance from other people, fearing that the reason is their cancer (Warmoth et al., 2017). Women with ovarian cancer in Canada were found to have impaired social functional roles as they were largely kept away from work and household (Osoba et al., 1994). At the same time, studies have shown that social support is significantly and negatively correlate to PTSD symptoms in patients with ovarian cancer in China (Liu, Zhang, Jiang, &Wu, 2017). All of these can isolate women with GYN cancers.

Second, because women with breast cancer in China feel that they are being avoided by others (Warmoth et al, 2017), it may lead to difficulty in finding emotional and social support compared to individuals in the United States. An online search for breast cancer support also shows that there are fewer face-to-face resources available in China than in the U.S. Multiple quality support organizations were found in the U.S, such as hospital-based support groups, and nationwide organizations such as the National Breast Cancer Foundation

(www.nationalbreastcancer.org) and the Susan G Komen Foundation (www5.komen.org) which provide information and support to women with breast and other cancers. In comparison, only one breast cancer support organization Pink Ribbon (www.zhfhds.com) was found when searching on Baidu (the most popular searching engine in China) and although there were some results about hospital-based support, further information such as contact, date and place of event were not available.

Third, because China has a deep culture of kinship and collectivism, most family members are expected to provide financial or emotional support for the cancer patient. Studies suggest that patients perceived more support from family members than from outside of the family (Ding, Zhang, & Zhu, 2007). On the other hand, family support may have limitations. Because medicine is a highly specialized field, family members of cancer patients may not have adequate understanding of the diseases. Studies showed that the needs of knowledge about disease and treatment is particularly high in family caregivers (Cui, Song, Zhou, Ming & Zhao, 2014). Family may also be in an emotional state of shock when their loved one was diagnosed with cancer. This might prevent them from providing adequate and effective support that the cancer patient needs (Ding et al., 2007).

Most Chinese patients with cancer, regardless of diagnosis, lack access to strong support from social networks and religious groups, something commonly available to patients in Western countries (Wen et al., 2017). The insufficient availability of local support groups, limited transportation access for rural Chinese population and a shortage of oncologists make it difficult to have face-to-face support groups for Chinese GYN cancer patients (Goss et al., 2014). However, the wide access of Internet has provided an opportunity for people to have online

support groups. As of December 2016, 53.2% of total Chinese population use Internet. More impressively, 95% of Internet users are on mobile phones (China Internet Network Information Center, 2017). The top two most popular communication apps in China are WeChat and QQ. Both can be accessed through websites and mobile apps. These tools have provided communication opportunities among cancer survivors. A quick search on QQ found over 30 ovarian cancer patient groups and 40 cervical cancer patient groups that exceed 100 members each. This demonstrates the need for support among cancer survivors in China. Although there are many support groups available through WeChat and QQ, there is no study to date that has examined the experience of these groups and how the groups function to provide support for women with cancer.

PURPOSE

The purpose of this study was to observe and describe the types of online support given to and by Chinese GYN cancer survivors in a QQ chat group.

DESIGN

This study was determined by the UCF IRB to be not human subject research (Appendix A) because de-identified data was used. This was a qualitative study that used the directed content analysis approach. According to Hsieh and Shannon (2005), the goal of a directed approach is to validate or extend conceptually a theoretical framework or theory. Using existing theory or prior research, researchers begin by identifying key concepts or variables as initial coding categories (Potter & Levine-Donnerstein, 1999). Next, operational definitions for each category are determined using the theory. The main strength of a directed approach to content analysis is that existing theory can be supported and extended (Hsieh & Shannon, 2005).

SAMPLE AND SETTING

The group was named 抗癌卫士卵巢宫颈癌群 (Guard Against Ovarian and Cervical Cancer Group). This online group was established in 2015 by Make Miracle Science and Technology Co., Ltd. According to the group's description, it was the earliest and largest QQ chat group for ovarian and cervical cancer patients and their families in China. The description also states that members can find all necessary information about cancer treatment, recovery and seeking medical attention and states doctors and nurses are present in the group chat. The intent of the group is to provide a platform for Chinese women with ovarian and cervical cancer and their families to communicate with women with similar diagnoses. There were almost 50 members in the group and they all used pseudonyms and nicknames. It was unlikely that members could be identified. According to the group profile, most members were born in the 80s. Observations for this study was conducted over a period of two weeks.

PROCEDURE

The administrator's nickname- Kang Ai Wei Shi (Guard Against Cancer) was informed about this study and agreed to allow the PI (YX) to become part of the group and observe postings. He posted a notice of the researcher's presence to group members (see appendix B) so they knew their interactions would be observed during the observation period. In this notice, participants were assured that their personal information would not be collected, and they would not be asked about any information regarding their identification.

After the administrator posted the notice about the PI being in the group, the PI waited two weeks before observing and collecting data. This was to allow time for the members to consider if they would like to opt out from the observation (they could also choose not to be observed any time during the observation period). This also helped members to get into, and maintain, their natural daily conversation before the observation started. Data were collected between March 10th (12:01am) and March 24st (11:59pm) 2018 Beijing time.

During the data collection period, observed online posts were copied and pasted into a WORD TM document for analysis. Each day, The PI went through the transcripts after 12:00am Beijing time to ensure each day was captured.

【大学】Ros 3/10/2018 8:04:49 PM

早上该去买菜

3/10/2018 8:24:13 PM

【高中】母亲—宫颈癌 III 期—临 3/10/2018 8:24:13 PM

大家好，我妈妈化疗 3 天后出院了在家，医生只说回家好好休息一个月后去复查，我想问下现在腿痛的厉害正常吧

3/10/2018 8:52:18 PM

【高中】雪花 3/10/2018 8:52:18 PM

@母亲—宫颈癌 III 期—临沂 正常

【高中】雪花 3/10/2018 8:53:01 PM

我每次化疗腿都疼

【高中】雪花 3/10/2018 8:53:38 PM

实在受不了就吃个布洛酚

3/10/2018 9:14:11 PM

【初中】宫颈 1b 江苏家 3/10/2018 9:14:11 PM

Author

"Hello everyone, my Mom is home now after hospitalized for 3 days following chemo therapy. The doctor said to rest well for a month at home and then do a recheck-up. I want to ask that is it normal that she is feeling bad leg pain right now?"

Sharing experience (chemo therapy related symptom, leg pain)

Author

"It's normal. I have legs pain every time after chemo therapy. If it's hurting too bad, I would just take an Ibuprofen".

Sharing experience (chemo therapy related symptom and symptom management, leg pain, Ibuprofen)

Figure 1: Example of Data Translation into Chinese and Coding

DATA ANALYSIS

The process of data analysis started on the first day of observation and was guided by the directed content analysis approach as described by Hsieh and Shannon (2005). The goal of this study was to observe and describe the types of support given to and by Chinese GYN cancer survivors in a QQ chat group. Even though there were no preexisting studies on online support groups specifically for Chinese ovarian and cervical cancer patients, other studies of online support groups for people with other chronic illnesses provided insight and structure for analysis (Crook & Love, 2017; Wright, 2002). Specifically, a study by Mo and Coulson (2014) examined potential empowering and disempowering processes, and empowering outcomes of online support group use among individuals with HIV/AIDS. Their results revealed six empowering processes from use of online support groups: exchanging information, sharing experiences, connecting to others, encountering emotional support, finding recognition and understanding, and helping others (Mo & Coulson, 2014). The findings indicated that information needs appear to be particularly important irrespective of background or disease characteristics. The study also suggested that many members appeared to value the experiential knowledge about the disease. Another benefit of this online support group was that it appeared to help participants dealing with their negative emotions (Mo & Coulson, 2014). The PI and Faculty Advisor (VL) anticipated that these themes could provide a solid framework for the themes likely to be discovered in this study. The PI used these themes as a starting point during analysis. Additional themes were added as they developed from the observations.

The PI reviewed postings each day. Since all postings were in Chinese, posts were reviewed for relevance to the topic and meaningful posts were translated into English and coded

under the comment section. For an example, see Figure 1. For analysis, posts that appeared on the group chat were identified and determined if they represented any of the themes. If they did, specific topics within that theme were then used to develop the subcategories under the theme. If the posts did not represent any of the main themes, they were then highlighted on the text and were examined later to see if they should become a new theme. Next, after all the possible posts were grouped under the main themes, the PI and Faculty Advisor examined the posts that did not represent any of the main themes. New themes were then created, and subcategories were developed as needed.

It is important to note that the PI is Chinese and has grown up within the Chinese culture, resided in Inner Mongolia for over 20 years. Therefore, the results are often interpreted within this cultural lens. The researcher was careful not to introduce personal biases into the analysis, but there are times when statements were made by participants that the PI recognized as being a “typical” Chinese saying or attitude, that was helpful in putting the findings into context.

FINDINGS

During the 14-day observation period, there were on average 27 postings exchanged in the group per day. About 55% of posts were either responses to the previous posts, or they were non-meaningful social replies (e.g. “Thank you” or “Oh, I see”). A total of 172 meaningful posts were recorded during the 2-week period. Typically, there were 1 to 3 topics discussed in the group each day. Although there were not a lot of postings on a daily basis, the flow of conversation was steady, meaning there were always some members engaging in conversations every day. The overall atmosphere in this group was positive and supportive. Most of times, the questions raised by members were addressed by others; however, not every posting had a reply.

During the observation period, four themes emerged from the data. These were sharing experience, information exchange, emotional support and group member benefits. Sharing experience had the most posts, accounting for 52.9% of the postings. Information exchange accounted for 36.6% of the posting. Emotional support (7.6%) and Guardian Against Cancer group member benefits (2.9%) were also present in the postings. Sharing experience could overlap with other types of support, such as information exchange or emotional support. When it did overlap, the posts were counted under all appropriate themes. See Table 1 for the frequency of each type of support. Each of these themes are explained below.

Table 1: Frequency of Each Type of Support. n=172

Themes	Definition	Frequency	Percentage
Sharing Experience	This theme describes the exchange of personal experiences with ovarian/cervical cancer.	91	52.9%
Information Exchange	This theme discusses the exchange of factual or medical knowledge and information about ovarian/cervical cancer or general health.	63	36.6%
Emotional Support	This theme illustrates the expression of emotions and the exchange of empathy, concern, or affection between members.	13	7.6%
Guardian Against Cancer Group member benefits	This theme describes the benefits of being a member in the Guardian Against Cancer online support group.	5	2.9%

Sharing Experience

This theme describes the exchange of personal experiences with ovarian/cervical cancer.

This was the most common posting and included initial posts and replies. Members shared their

personal experience, most of the time, to seek answers. To differentiate this from the theme information exchange, postings under the subtheme of seeking answers were members searching for answers regarding their new problems from the cancer, such as a new symptom. They were not asking for medical and factual knowledge to understand the disease like they would as in information exchange. Members also shared beautiful sceneries, selfies, personal beliefs and hobbies to encourage others. See Table 2 for subthemes.

Table 2: Subthemes Under Sharing Experiences n=91

Subthemes	Frequency	Percentage
Seeking Answers	67	69.6%
Beautiful Sceneries	10	12.7%
Selfies and Comments	9	11.4%
Personal Beliefs	3	3.8%
Personal Hobby	2	2.5%

Symptom and symptom management was the most common topic women shared in order to seek answers about their experience from others. The symptoms women had questions about most were constipation, leg pain with or without swelling, hemorrhoids and hydronephrosis. Responses to these questions were common if other women also experienced them. For example, constipation was a symptom that many women experienced and thus, it had the most responses. Some members responded with suggestions on how to manage constipation. These suggestions included: drinking honey water, eating sesame seeds and perilla, increasing fiber

intake and exercise. Other responding members simply described their own experience with constipation as pain and difficulty in defecation without offering suggestions for management. For example, one member described her experience as “no poop for a long time, if there was any, it was just small amount of liquid”. Interestingly, this post indicating a possible severe problem (fecal impaction) did not receive replies. Fecal impaction is a serious event that may require immediate medical intervention. However, there was no one, during the observation period who encouraged this member to seek medical attention.

Leg pain with or without swelling after chemotherapy was also a concern of women and discussed many times in the group chat. One Members who experienced leg pain described it as “severe pain that made me cry out”. Suggestions to manage leg pain were limited, but one member suggested taking Ibuprofen whenever it was too painful to tolerate. In both instances, constipation and leg pain were seemingly perceived as normal side effects by many members and suggestions were limited to coping with the symptoms. However, there was no feedback from members who adopted these coping methods. Again, no members perceived the side effect as serious enough to warrant further medical investigation.

While most members were being treated for their cancer within their provinces in China, a couple of members asked about the possibility of seeking medical treatment abroad. This showed a new trend that some well-off Chinese families were turning to developed countries to treat cancer. However, such inquires did not get as many responses. Members agreed that it was still too expensive to go abroad. One member did share his mother’s experience in China and U.S while seeking medical treatment. He was not happy with his mother’s diagnosis in China,

because they were “scared to death” when the Chinese doctor told them that the cancer was metastasized to the lungs while the U.S doctor confirmed that it was not.

While members were looking for answers every day to manage their symptoms, it appeared that their health care providers may not have given adequate information. A couple members explicitly complained about their doctors did not offer enough information. One member stated that they were sent home with medications, and they did not know what to do with them. Another member apparently was not given information about her stage of cancer. She was frustrated that when another doctor asked her stage of cancer, she was not even able to answer this simple question. It is noteworthy that none of the postings mentioned nurses as educators. Education is typically a major role of nurses. The lack of mention may be because group members felt nurses did a satisfactory job when they interacted with them or because patients did not have much experience with nurses during their care. Regardless, the absence of any mention of nurses providing education or nursing in general was interesting.

Besides sharing experience to seek answers, members also used their experience to encourage others by promoting a positive atmosphere. This was mainly achieved through sharing beautiful sceneries of nature and members’ “selfies”. Yunnan province is located in the southwest part of China and it is famous for its beautiful nature sceneries. A member from Yunnan province shared many pictures such as a peaceful lake with a small boat on the shore, or a picture of her smiling while climbing mountains in the mist. Another member shared some photos of herself on the beach. The picture was taken while she was jumping up and laughing. Many members were also comfortable of sharing pictures of themselves. These pictures

received many nice comments from other members, and they also raised more discussion about the benefits of exercise and positive attitude towards life

Another topic that members sought answers about was Traditional Chinese Medicine. This is not surprising because the members were Chinese and living in China. In Chinese culture Traditional Chinese Medicine is often automatically viewed as a treatment option for many diseases, cancer is no exception. There were some members considering taking Traditional Chinese Medicine and asked other members about the outcomes of using it. Surprisingly, there was very little feedback about TCM. One member who had been taking herbal medicine for 5 years said: “I don’t know if it works”. Another member shared her concern that her TCM doctor asked her to stop using western medicine and chose TCM completely. Fortunately, the administrator of the group joined the discussion and strongly advised the member not to give up western medication completely.

Information Exchange

This theme involved the exchange of factual or medical information about ovarian/cervical cancer and about general health. Information exchanged in the group was either due to questions from others, or it was unsolicited helpful information that members posted for each other. Questions that received replies involving medical knowledge were understanding labs/report, cause and prevention of cancer, staging and prognosis of cancer, therapies which included hormone therapy, chemo therapy and targeted therapy with genetic testing. When it came to general health information, however, members mostly just posted links to health-related

articles, such as ways to increase immunity or correcting misconceptions of health recovery. See Table 3 for subthemes.

Many members posted their lab results and image reports in the group chat and asked for help interpreting them. Other members expressed their confusion over tests and other terms in lab reports. For instance, one member raised the question regarding the difference between SCC (Squamous Cell Carcinoma) and HPV, other members were able to correctly explain it. Information provided by members in this group was informative and helpful, although it could also be misleading and incomplete at times. For example, one member posted a picture of her lab report and asked for help to understand why her white blood cell count was so high. Another member replied, “this is probably after you had the injection to increase WBC count. You need to pay attention to your platelet count”. Although this member did take medication to increase WBC count and close monitor of platelet count is meaningful, other reasons that could cause elevated WBC should also have been evaluated especially as the report also showed elevated neutrophil count. This could indicate an acute bacterial infection that needed to be investigated (MedlinePlus, 2017), particularly for a cancer patient. Again, no one recommended the member with the questions contact the provider. At times, the administrator of Guardian Against Cancer engaged in ongoing conversations with members during the observation period, but this was rare. In one instance, he/she helped to read 2 reports for members and answered 1 question regarding the staging of cancer. Unfortunately, pictures of the report did not download properly, so it was hard to know if the readings were accurate.

In other postings, members exchanged useful information regarding the cause and/or prevention of ovarian cancer. Although some information was copied and pasted from the

Internet, members did admit that they were not professionals, and recommended others look up more information on Baidu (the most popular searching engine in China).

When members were discussing their treatment, chemotherapy seemed to be the most common treatment. Some questions were about reactions to therapy. For example, A woman inquired as why her mother reacted so strongly this time to chemotherapy, almost all the replies agreed that it was a good thing. One member explained that strong reaction to chemotherapy indicated that the patient was still sensitive to the chemo drugs used. This showed a common misconception, because when the chemotherapy side effects were too strong or stronger than they used to be due to cumulative effects, a lower drug dose or longer break between chemotherapies may be required. Premedication and pre-chemo therapy management may also be reevaluated to work effectively. In the same conversation, the antiemetic drug Aprepitant was recommended prior to chemotherapy by a member. The same member also recommended another member do more research about this medication to see if it would be helpful in treating nausea not caused by chemotherapy.

Besides traditional chemotherapy, new treatments such as targeted therapy with genetic testing were also discussed in the group chat. Some members were interested in getting targeted therapy and thought it was unattainable to them until another member told them it was available in China. Members perceived that targeted therapy was very expensive and difficult to get. However, one woman shared three ways to get relatively cheaper targeted medications. She suggested buying it from someone residing abroad, direct mailing the medication from abroad or going to India to buy it. Although it seemed that some members did consider getting medication

from out of the country, they were doubtful that the medications from abroad would be legitimate.

While members were discussing their treatment options, the prognosis of their cancer was brought up a few times. One member asked if cancer is a death sentence, and the replies included: “who knows”; “don’t be too worried. It’s just a chronic disease”; and “we still have a lifelong to live”. Another member shared her 5-year survival rate, other members were all very supportive. They agreed that the survival rate was just an estimate. An older cervical cancer patient used her own experience to demonstrate that she outlived many years than what her doctor thought she would.

An interesting phenomenon was sharing links of health-related articles in the group chat. It appeared many times throughout the daily conversations, but never received replies from other members. The content of the articles was also not discussed during the period of observation. Many shared articles were related to diet and cancer, and they were mostly from toutiao.eastday.com (东方头条). This is a phone app that provides news and articles based on a customer’ preference and interest. It is noteworthy that readers can get cash back from sharing and commenting on the articles. The credibility of the articles was varied. Some articles had authors credentials and organizations, but some did not. It was uncertain that the purpose of members sharing articles was to promote health, to get financial reward, or both.

Table 3: Subthemes Under Sharing Experiences n=56

Subthemes	Frequency	Percentage
General Health Links	21	35.6%
Understanding Labs/Reports	10	16.9%
Therapies: Hormone, Chemo, Targeted	9	15.3%
Staging and Prognosis of Cancer	7	11.9%
Cause and Prevention of Cancer	5	8.5%
Recommendations of Medications/Doctors	4	6.8%

Emotional Support

This theme illustrates the expression of emotions and the exchange of empathy, concern, or affection between members. The overall atmosphere in this group was positive. As a result, there were very few members who expressed feelings of depression, fear or anger. But, at times members did vent their emotional distress as a caregiver from watching family members with worsening cancer, or as a cancer patient themselves. They also felt persistent physical symptoms and feelings like anxiety and uncertainty before starting another long-lasting cancer treatment. When they expressed distress, they were comforted and supported by other members. Many typical Chinese sayings such as “加油 (stay strong)”, “坚持就是胜利 (perseverance leads to victory)” were used to support them. The administrator also encouraged members to try to

prolong life in the hope that cancer may be cured or better managed a few years later with new medications.

Most of the time, members discussed their symptoms and prognosis objectively without many emotions involved. It seemed that members accepted the reality of being a cancer patient and were focused on getting better. By sharing their personal beliefs, members also helped to promote a healthy and positive mindset for each other. For example, a woman revealed how her attitude towards life changed after a cancer diagnosis, such that she only cared about being happy at the moment. The lack of negative emotions mentioned in the chats made it feel like members reached a non-verbal agreement of focusing on the good parts of life and not causing any more anxiety in the group.

Although most replies from members were calm and understanding, not all concerns received support. For example, when a new member was persistently concerned about why her HPV test result was still positive even after surgery, another member replied “You are still lingering over this problem? So tiring”. While not a supportive response, it may have indicated a group member’s frustration at not being able to provide answers or support. On the other hand, it may have been something the respondent had been experiencing and worrying herself and she may not have wanted to hear or learn about how remaining HPV after surgery could be an issue.

As was mentioned in the sharing experience section, it was very common for members to seek answers about their symptoms. When members experienced new or unrelieved symptoms, they asked in the group chat if the symptoms were normal and expected after chemotherapy or surgery. If other members experienced similar symptom and had it check out as normal, they

would share it to alleviate some fear for others. It might be very comforting to know that if someone else had same problem and she was fine.

Guardian Against Cancer Group Member Benefits

During the observation period, the administrator posted an announcement for several days. According to this announcement, members of this group were eligible to get a free one-on-one consultation with a healthcare professional that valued ¥365 (CNY). All they needed to do was add Guardian Against Cancer WeChat account. The intent of this program was to help cancer patients and prevent them from taking false information that may delay treatment. There was one feedback from a member regarding the program saying, “It was helpful”.

DISCUSSION

The purpose of this study was to observe and describe the types support given to and by Chinese GYN cancer survivors in the QQ chat group. Consistent with the study about support groups for 115 HIV-positive online support group members completed by Mo and Coulson (2014) which provided the framework for this, members in this online group chat supported each other through sharing experiences, information exchange, emotional support, and benefits as Guardian Against Cancer members. The themes of connecting to others, finding recognition and understanding, and helping others were not apparent in this study with Chinese GYN cancer survivors. However, since this was an observational study without an interview, it is difficult to know if members felt that they were connecting to others or finding recognition and understanding within this online support group. Further observation or one on one interviews with participants could have been able to appreciate additional themes.

While members of the group exchanged postings on a daily basis, they seemed to benefit from being in the chat group in two ways. First, members gained more information through chatting with others. During the observation period, they talked about many aspects of living with cancer, such as ways to manage symptoms, treatment options, cause and prevention of cancers and medical tests and reports. When one member did not receive adequate information from her doctors and had questions, other members who did receive education from their healthcare providers shared what they knew. Meanwhile, many members' experiences in seeking different treatment options such as Traditional Chinese Medicine, hormonal therapy and going abroad for treatment provided other members first-hand information to consider for their

own treatments. Some members in the group had more knowledge than others, and they were able to provide some correct information for others.

Second, this online support group provided members with a place to relieve their emotional distress and to adopt positive attitudes. Some members were observed to vent out their concerns and anxiety in the group chat and received many comforts from others. This finding was consistent with another online support group study by Vilhauer (2009) on breast cancer online support group. In her study, members in the online support group reported that support from group members alleviated their anxiety (Vilhauer, 2009).

While members were getting all sorts of information from each other, there were several concerning problems noted with this online support group. The most concerning thing is the apparent lack of control on the quality and validity of the information that is exchanged in online support groups. This finding was consistent with many other studies of online support. Members may receive misinformation or be referred to false health information (Wright, 2002). As members sought answers in the group chat, other members were giving advice based on their own experience and knowledge. Because members were not medically trained, they can only speculate to give answers and may not be able to identify potential serious events such as fecal impaction and elevated WBC as noted in this study. When talking about symptom relief, some women mentioned taking honey and water chestnuts to relieve constipation. A symptom management search on the websites of the Oncology Nursing Society (www.ons.org) and National Cancer Institute (www.cancer.gov) by the PI did not reveal any evidence or research that supported using honey or water chestnuts as either a treatment or prevention for constipation. Another example is the misinformation about chemotherapy reactions. Strong side

effects from chemotherapy is not a sign that the drug is working and should be evaluated and better managed, so that they do not become serious or result in treatment delays.

It is concerning that given the potential harm members of exchanging inaccurate information, there was no intervention by a healthcare professional in the group. According to the group introduction, there were doctors and nurses in the group, however, when there were opportunities for them to step in and bring up correct information, they failed to do so.

It was noteworthy that members in the group never mentioned their experience with nurses. This could be because of lack of interaction between patients and their nurses during treatment. In China, nursing skill mix consists of nurses, nursing students, and health care assistants (Jiang, Li, Ma & Gu, 2015). The registered nurse typically carries out skilled, professional tasks for the patients (nursing assessment, medication administration, and patient education) (Jiang, Li, Ma & Gu, 2015). A study on nurses' role in direct nursing care delivery in China revealed that on an inpatient neurology floor, only 1.79% of nursing workload was given to patient education (Jiang, Li, Ma & Gu, 2015). It is reasonable to speculate that if nurses were only able to spend minimum amount of time to conduct patient education, the patients may not be getting the necessary education from registered nurses.

According to the study done by Wang, Whitehead and Bayes in 2016, there are many challenges in the Chinese nursing profession. First, there are no national standards for pre- and post-registration nursing education. There is also a lack of motivation to take up nursing as a profession is a major concern in China. In 2010, only 16.4 per cent of university nursing graduates selected nursing as their first choice major. The remaining number of graduates (83.6

per cent) had originally chosen other majors but failed to attain the necessary entry level requirements for those professions and chose nursing as their fallback choice. Additionally, in China, nurses tend not to stay in the profession due to several reasons including job instability, inconsistency between training and practice and low professional status. Nurses are traditionally viewed as submissive and passive and subservient to doctors (Wang, Whitehead & Bayes, 2016). This could explain the lack of education they personally provide to patients and also how patients view the nurse as a credible educator.

LIMITATION

Several limitations were noted in this study. The women who were involved in this support group were mostly born in the 1980s, while this study is not meant to be generalized, it is possible that this sample was very young, and their problems may not be the same as an older sample. Since older adults may have limited access to internet on their mobile phones, other strategies may be used to understand their support mechanisms. In addition, the observation period of two weeks may also have been too short to fully represent the group and appreciate the full range of support among members. Finally, members were informed ahead of time about the exact time period of observation, this may have affected how they normally engaged in conversations with other members. Some members may have chosen not to participate and be observed.

RECOMMENDATION FOR PRACTICE AND RESEARCH

The finding of the study showed that members in the GYN cancer support group in China have considerable amount of questions, and they have the desire to understand the disease and take better care of themselves or their loved ones with cancer. To prevent members from delaying seeking medical attention and getting inaccurate information, it would be beneficial if healthcare professionals monitored the daily conversations among members. By doing so, potential medical emergency could be identified, and members could be encouraged to seek immediate medical attention. At the same time, if there are any misconception or question, it could be addressed correctly on time. Administrators of online support groups should consider having healthcare professionals answer member questions as are asked. It may also benefit members if administrators planned information sessions about ovarian and cervical cancer related topics . For example, having one topic per month related to ovarian or cervical cancer could provide more knowledge about the disease and its management to members. This would increase the credibility of the information shared and educate women about what may happen. A schedule of the information sessions could be posted in the group ahead of time so that members could choose which ones they would like to attend. Members who are not able to attend can also listen to the recordings of the information session posted in the group file. In this way, members in the group could have a basic understanding about the diseases and develop the awareness and habits to wisely manage their health.

Future research could include more demographic information about the members of the online support group. Members of different ages may not experience cancer treatments the same way, and they may also have different goals and focus of life. Information about members in the urban vs rural areas may also be beneficial to understand their needs. Future research can also benefit from longer observation period to fully capture the activities in the group chat. To better understand how members view online support groups, interviews can also be conducted.

CONCLUSIONS

Chinese GYN cancer survivors supported each other in online support groups mostly through sharing experiences and information exchange; however, the lack of control on the quality and validity of the information makes it crucial to have health care professionals monitor their daily conversations. Well-planned information sessions about ovarian and cervical cancer can also be beneficial.

APPENDIX A: NOT HUMAN RESEARCH DETERMINATION



University of Central Florida Institutional Review Board
Office of Research & Commercialization
12201 Research Parkway, Suite 501
Orlando, Florida 32826-3246
Telephone: 407-823-2901, 407-882-2012 or 407-882-2276
www.research.ucf.edu/compliance/irb.html

NOT HUMAN RESEARCH DETERMINATION

From: UCF Institutional Review Board #1
FWA00000351, IRB00001138

To: Victoria Loerzel and Co-PI Yuan Xing

Date: February 19, 2018

Dear Researcher:

On , the IRB determined that the following proposed activity is not human research as defined by DHHS regulations at 45 CFR 46 or FDA regulations at 21 CFR 50/56:

Type of Review: Not Human Research Determination
Project Title: Online Support Group for Chinese Women with Ovarian or Cervical Cancer
Investigator: Victoria Loerzel
IRB ID: SBE-18-13814
Funding Agency: UCF Burnett Honors College
Grant Title:
Research ID: N/A

University of Central Florida IRB review and approval is not required. This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are to be made and there are questions about whether these activities are research involving human subjects, please contact the IRB office to discuss the proposed changes.

This letter is signed by:

A handwritten signature in cursive script that reads "Renea Carver".

Signature applied by Renea C Carver on 02/19/2018 09:36:35 AM EST

Designated Reviewer

APPENDIX B: NOTICE FROM THE GROUP OWNER

我们有一个群成员是正在美国读护理学的学生。她是内蒙古人。她的群昵称是 Bear, 她的真实姓名是邢媛。下面有她在美国中佛罗里达大学（位于美国佛罗里达奥兰多市）护理专业的学生证。她对肿瘤病人护理很感兴趣，特别是对护理患卵巢癌和宫颈癌的女性。她想通过了解病友们在群聊中彼此支持鼓励，来帮助提高护士们对病人需求的认识，也想通过这个帮助她自己成为一个更细心和善解人意的护士。所以她想对此进行一个调研。她想观察我们群成员之间的聊天，但是她不会插话。观察的时间仅限于2018年1月17日凌晨0:01分至2018年1月31日晚11:59分。她绝对不会采集泄露任何个人信息，同时群成员可以随时告诉她不想参与观察过程。2018年2月1日开始，大家如果有什么问题，比如美国这边医疗情况，求学，人文或者对到内蒙旅游感兴趣的可以在群里喊她。2018年八月份之前她会写完调研，如果大家感兴趣，她可以把论文上传到群公告里面，并且回答大家的问题。她明白与癌症斗争不是一件容易的事，她想让我告诉大家谢谢对她的支持。

We have a Chinese student who is pursuing Nursing degree in the United States. She is from Inner Mongolia. Her name in the group is Bear and her real name is Yuan Xing. Below is a copy of her student ID from University of Central Florida in Orlando, Florida. She is very interested in nursing care of cancer patients, especially women with ovarian and cervical cancers. She would like to know the experience of online support of women with ovarian or cervical cancer to help improve nurses' care of this population and become a more attentive and understanding nurse herself. So she would like to conduct a study by first observing the kinds of conversations about cancer that members exchange. She will not engage members in any conversations. She will only observe. The observation period is between January 17th (12:01am) and January 31st (11:59pm) 2018 only. There will be absolutely no personal information collected from the members and you can withdraw from the observation any time. Starting from February 1st, 2018, she can answer any questions members might be interested in such as the U.S health care situation, culture and education experience or traveling to Inner Mongolia. She will finish the study before August of 2018 and if members are interested, she will upload the study to the group file and answer any questions. She understands that living with cancer can be difficult and she wanted to say thank you for helping her in advance.

APPENDIX C: NOTICE FROM PI ABOUT COMPLETION OF THE STUDY

大家好!我是邢媛,是前段时间在群里做调研的在美国求学的护理专业学生。非常非常感谢大家这么支持我的学业。我在群里观察了两周时间:2018年1月17日凌晨0:01分至2018年1月31日晚11:59分。以下是我的论文结果小结:

本群成员之间互助的形式主要有四种:分享经历,交换信息,情感支持和作为本群成员的得益。其中分享经历占了52.9%,交换信息占到了36.6%,情感支持占到了7.6%,本群成员得益占了2.9%。群里的总体气氛是非常积极向上的,群成员互相解答他人的疑问。在大家分享经历的时候,69.6%的人在寻求答案。这个寻求答案可能是新产生的身体的不适,特别是在化疗后。最长讨论的身体不适有便秘,疼痛(腿,腋下,肛门)。群成员同时提供了解决方法,比如喝蜂蜜水,吃菱角,多运动等等。成员们还喜欢分享美丽的自然景观,自拍,个人的生活爱好,人生信条等等。群成员在交换信息时,目的是为了从医学角度明白疾病。比如说有成员问到卵巢癌宫颈癌的病因,如何理解医院的化验单,癌症的五年存活率等等。在提供情感支持时,群成员会鼓励彼此,比如“别害怕”,“坚持就是胜利”,同时成员还会用自己相似的经历来安慰他。本群成员得益主要是群里有个活动,可以有机会获得一对一免费咨询(价值365元)。

我的论文将在2018年8月1日前提交到学校。再次感谢大家的支持。如果大家有疑问,请联系我的邮箱:yuan.xing@knights.ucf.edu。最后祝群里的每个成员都能尽快好起来,祝家人和朋友们都健康幸福。

以上,

邢媛

Hello, everyone! My name is Yuan Xing. I am the Chinese student who is studying Nursing in the U.S and conducted a research in this QQ group. I really appreciate your support for my education. I observed this QQ group for two weeks between January 17th (12:01am) and January 31st (11:59pm) 2018. Below is what I found:

There are four types of support in this group: sharing experiences, information exchange, emotional support and group member benefits. Posts that were related to sharing experience accounted for 52.9% followed by information exchange which was 36.6%, emotional support (7.6%) and group member benefits (2.9%). The overall atmosphere in this group was very positive. Group members answered questions for each other. When members were sharing experiences, 69.6% of posts were trying to seek answers. Members seeking answers were mostly regarding new symptoms experienced, especially after chemo therapy. Common symptoms discussed in the group included constipation, pain (legs, armpits and anus). Group members also provided symptom management strategies such as drinking honey water, eating water chestnuts and doing physical exercise etc. Members also enjoyed sharing pictures of

beautiful natural sceneries, selfies, personal hobbies and beliefs. When members were exchanging information, their purpose was likely to understand the diseases from a medical perspective. Examples of this included cause of ovarian and cervical cancer, understanding lab reports from the hospital and five-year survival rate of cancers. When members providing emotional support to others, they often achieved so through encouraging each other, such as “don’t be scared” and “perseverance leads to victory”. They also used their own similar experiences to comfort others. The group member benefits mostly referred to the opportunity for free consultation that valued 365 RMB as a member of this group.

My thesis will be sent to school before August 1st, 2018. Thank you all again for your support. If you have any question, please feel free to contact me through yuan.xing@knights.ucf.edu. Lastly, I hope our members can get better soon and I hope your families and friends all to be healthy and happy.

Best regards,

Yuan Xing

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