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"Is it useful to talk to other cancer patients?"

A discourse study of lay perceptions of knowledge and expertise in an online support group

Abstract: A growing body of research highlights how patients' use of the Internet, including constructing, sharing personal stories, and accessing knowledge online, gives rise to a new form of lay expertise, which may further challenge the expertise of medical professionals. Accentuating patients' perspectives, this paper investigates the variety of positions Chinese cancer patients articulate and adopt regarding knowledge and expertise within an online support group. My analyses demonstrate that, despite being highly proactive and reflexive, these patients actually reproduce and reinforce the dualistic positioning of doctor and patient within broader discourses of scientific knowledge and authoritarian hierarchies, which eventually disempower them. I then provide an explanation of this dualism by underlining the unique reality of China in terms of the co-existence of Western scientific medicine (WSM) and traditional Chinese medicine (TCM) and doctor-patient hierarchies. Finally, I outline the implications of this positioning for cancer care and discuss possible solutions drawing on recent humanistic models from the West.

Keywords: cancer support group; discourse analysis; lay expertise; medical science; mind-body dualism; TCM

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1 Introduction

The Internet, with its powerful search engines for information-gathering and various platforms for social interaction, has now become an important resource for patients in coping with their illnesses. According to some research, unlike in Western countries, Chinese patients tend to seek emotional support from close

family members instead of other patients due to possible influences from the distinctive Chinese culture and perspectives on disease management (Chiu 2001; Liu et al. 2005; Ding et al. 2008). However, to take cancer patients as an example, the landscape has now gradually changed with the establishment of large-scale NGO anti-cancer association such as the Chinese Anti-Cancer Association (CACA) and local anti-cancer clubs founded by cancer survivors, as well as online support groups. The rapid and dynamic development of these organizations on the one hand encourages cancer patients to know more about cancer, to connect with other patients, and to face cancer with a positive outlook, and on the other, reflects the growing need of patients to reach out for resources beyond family circles in managing cancer.

In recent years, more and more researchers (Coiera 1996; Hardey 1999, 2001, 2002; Loader et al. 2002; Broom 2005) have been investigating how the information and stories shared by individual patients may challenge the medical expertise of health professionals, and potentially change patients' role in different settings, including doctor–patient interaction. Hardey (2001, 2002) argues that, by producing and sharing personal accounts of illness, patients gain a new role as producers of information and care, instead of being mere consumers of health information. He suggests that patients' homepages interweaving personal experience with advice "constitute the emergence of a new genre that forms part of a broader reconfiguration of the relationship between lay and medical expertise" (2002: 31). Broom (2005), in his study of prostate cancer patients and medical specialists, shows that specialists perceive online support groups as a threat to their expert status and control over decision-making processes. Analyzing specialists' comments on online support groups collected from the interviews, he observes that their accounts consistently use the vulnerability and desperation of cancer patients, and their incompetence in discerning good-quality information to rhetorically justify "the danger of online support groups for patients" (101). These, he concludes, are discursive strategies to assert "expert" control over patients and to limit their power within the medical consultation.

We can further situate this line of research in wider discussions on lay versus medical knowledge and expertise. Drawing cues from the works of Michel Foucault and social constructionism which seek to problematize the apparently stable realities as represented and perpetuated in various disciplines including medicine, a group of scholars working in medical sociology since the 1980s seeks to question the status of medicine as a system of objective, scientific knowledge and practice about human illnesses (Armstrong 1985; Bury 1986). Instead, the production of medical knowledge involving different layers of social practices is studied with an aim to reveal that it is part of "discourses"

like all forms of knowledge. As a consequence, the traditional boundaries held between scientific, medical knowledge and lay people's "knowledge" are challenged in a growing trend to argue for a "democratization of knowledge" (Turner 2001) and to study what medical "knowledge" instead of "beliefs" that lay people possess. It also became clear that a concept of expertness among the lay population emerged both within and without medical sociology as exemplified by the use of the term "lay expert" (Arksey 1994; Tuckett et al. 1985; Wynne 1996; Sarangi 2001). However, as observed by Prior (2003), scholars have not reached an agreement on how exactly a lay person might be expert. She reviewed three understandings: 1) experiential knowledge of a condition (Busby et al. 1997; Monaghan 1999); 2) scientific knowledge in bio-medical terms (Arksey 1998; Epstein 1996; Wynne 1996); 3) an emergent form of knowledge that groups (where qualified scientists serve as translators for lay concerns) come to acquire (Brown 1987). Reflecting on this rich literature of lay knowledge and expertise and drawing on her own research data on lay people's knowledge and beliefs, she warns against the dangers of "romantic and reckless extension of expertise" (Collins and Evans 2002: 271) from "issues concerning the use and manipulation of technical knowledge" to including "invariably limited, and idiosyncratic" experiential knowledge.

In this article, I will focus on one issue which is currently not well studied concerning medical knowledge and expertise, that is, how do lay people themselves perceive these notions? The cancer support group I study provides ample data to pursue this question in that its group leaders have explicitly debated the status of lay knowledge and expertise when engaging in a kind of meta-discussion on the purpose and value of patient-to-patient talk.

In the following section, I will introduce the cancer support group after a discussion of Internet use among Chinese cancer patients in general. I then turn to detailed analysis of particular extracts and exploring the discourses the participants draw on in positioning themselves regarding lay knowledge and expertise. I conclude by addressing the implication of this analysis for improving the quality of cancer care in the Chinese context.

2 Sina Cancer Patient Friends Group as a spiritual home for cancer patients

The crucial changes in China's healthcare system took place in the 1980s when a program of economic liberalization was instituted to replace the system of cooperatives, which had been the exclusive form of health care since the

establishment of the PRC. This hands-off approach applied to health-care sectors put Chinese public hospitals in the same situation as other sectors of the economy: They have to be in charge of their own financing, and one corollary of this scenario is to put pressure on the doctors to generate more income through over-investigating and over-treating. Other sources of income include receiving commissions from drug companies and red packets (bribes) from patients (Yang 2016). On the other hand, doctors exemplify problematic attitudes toward patients, and have been criticized for being *sheng* (indifferent), *leng* (callous), *ying* (harsh), *ding* (confrontational), and *tui* (in denial) (Gao et al 1987; Wang 1997). The lack of effective official channels for patients to voice their complaints, together with the fixed impression that legal solutions will not help, exacerbates the situation. Actually the distrust of medical institutions and law enforcement is not an isolated phenomenon: Scholars have pointed out how social reform in Chinese society, imbued with instrumentalism and commodification, has given rise to various forms of "distrust" (Gold 1985; Lin 1999; Peng 2003; Yan 2009).

This also explains why Chinese patients tend to rely on their circles of *guanxi* when seeking medical services. When professional ethics collapse and a general distrust of other social members spreads, one can only turn to sources connected with one's reliable family or friends.[1] Against this backdrop, we can also better understand why, as an emergent platform to exchange information and receive emotional support, the Internet seems to provide a clean fresh space for patients. Taking cancer forums as an example, a search on Baidu, the most-used search engine in Chinese with 70% market share (China Internet Watch 2017), generates a dozen or so cancer support group links. Most of them are forums where members can post on a diverse range of topics about cancer treatment and personal experience.

The complexity of cancer cases, treatment methods available in both WSM and TCM further necessitate turning to the Internet for tips, advice, and solutions. Viewing health as the harmonious interaction of the human body and the outside world, TCM places a great emphasis on regulating every aspect of one's everyday life from diet to posture. The penetration of this holistic view into daily living is evidenced by a strong presence of TCM terms in everyday vocabulary, such as: *qi se* (one's state of *qi*[2] as reflected in his/her complexion), *re qi* (hot qi), *xu han* (abnormal sweating due to general debility), *shang huo*

1 Especially those ordinary patients, which constitute the vast majority. People of privilege, especially top party and state officials, have more resources available to them.

2 *Qi* is believed to be a vital force forming part of any living thing according to the TCM system.

(excessive internal heat which gives rise to common inflammatory symptoms due to Yin–Yang imbalance), *pi qi* (*qi* of spleen: temperament) *bu tiao* (an unbalanced, disorderly or irregular state). On the other hand, the attitude of Chinese people toward WSM is ambivalent: Admiration of its scientificity is juxtaposed with an understanding that it does not partake of holistic belief systems, which is a core value in TCM (*tou tong yi tou, jiao tong yi jiao*: the head is treated for headache; the foot is treated for foot pain. This idiom is often used to characterize the atomistic treatment in WSM). It is true that despite the strong presence of WSM in today's China, Chinese people's conceptualization of health is still strongly colored by traditional holistic thinking: WSM is just one of the tools (a preferred one in some cases due to its scientificity) that can be used to treat the disease and regulate health. This explains why it is a common practice for Chinese patients to combine both WSM and TCM practices when seeking medical treatments. Taking cancer treatment as an example, WSM with its scientific associations is perceived to be more reassuring in treating a difficult disease such as cancer, while TCM is taken as an important corrective, a complementary or alternative approach, and is seen in some contexts as working miracles. One can find various information-sharing articles, discussion and debates concerning these two options on the Internet.

However, the problem with resources on the Internet, such as health forums, is that it does not seem easy to tell whether the information available entails true accounts from other patients or disguised advertisements posted by profit-pursuing fake doctors and drug-sellers. Though, as some patients reported, information spread among patients, such as on forums, is more trustworthy compared with other sources, because among patients there is no profit relation (Zhang et al. 2016), the anonymity online and the way forums are run can actually complicate the picture. Who has access to the dialogue threads, and who is in a position to track, monitor, and manage the information – these aspects, not transparent to users, can play a significant role in shaping the quality of information. In fact, Baidu, which runs thousands of forums, including health-related ones, was exposed in January 2016 to have sold some forums to commercial enterprises such as hospitals and clinics so that these for-profit health-care providers could have unique control over health forums and market their services. This scandal has caused a huge outcry among Chinese netizens because "it came as a shock to many who did not expect commercial interests to intrude so pervasively online, especially in the important and personal forum of health" (Wong 2016).

The cancer support group this study focuses on is called *xinlang aizheng bingyouquan* literally translated as Sina Cancer Patient Friends Group (hereafter SCPFG). Established in 2006 by Xu, a lung cancer patient from Tianjin, this

online platform is different from other cancer forums in that it is built as a group centered on blog-keeping. Xu, at that time a 26-year-old, won the title of cancer-fighting hero and was interviewed on CCTV because of her courage in facing cancer despite her young age. Eventually she set up a bloggers' group on the Sina website so that cancer patients could have a platform to exchange and draw strength from personal stories. This close link with sharing one's cancer story has defined the group from the very beginning. Conceptualized as the "spiritual home" in the group introduction, the group encourages sharing of positive messages, exchanging recovery knowledge and tips, and writing about personal stories of fighting and living with cancer (L 2011). Recognizing the isolated status of individual cancer patients both mentally and emotionally, this group makes connection through stories its central theme; the aim is to build an alternative family where one could establish a strong emotional bond with the others who, on account of the shared cancer identity, are always ready to empathize. On the other hand, it is well aware of the varying quality of online information, and works to protect its members from profit-seeking parties. This promotion of spirituality and bonding is also reflected in its inclusive and open attitude toward different types of treatments from both WSM and TCM. Blogs reporting and promoting the benefits of TCM are a strong presence in this group, though some members go against the flow to warn against the danger of blindly following TCM treatments which are fraught with unqualified doctors and unscientific practices. Yet, it can be observed that a holistic view on health-care and cancer treatment encompassing the physical, emotional, and spiritual (as upheld in TCM[3] and traditional Chinese philosophy) is consistently emphasized within the group.

3 Data collection and methodology

SCPFG is hosted on the Sina website (a major blog-hosting platform) with links provided to connect with its members' blogs. There are in total around 600 bloggers linked to this group as at 1 September 2017. In the left column of the group's front page, 24 members are highlighted as "recommended key bloggers." These members also hold some "administrative functions" for the group, such as principal, secretary, and ministers, well-suited to their strengths

3 A leader in this group mentioned to me in a personal communication the importance of keeping TCM philosophy separate from the available TCM practices (which, sadly, most of the time do not live up to, or even blatantly conflict with the former).

and capabilities. Importantly for my analysis here, though this blog group is publicly accessible and no membership is required to read and comment on the articles, their primary audience is the group members themselves[4]. This feature makes it possible to trace the interaction between group members in a close-knit environment, and investigate how they position themselves in these interactions. The group holds another facet of particular interest for my study. The fact that these data are not elicited from research interviews but from the group's voluntary reflection and discussion implies that there may be more authentic data providing valuable insights into patients' understanding of knowledge and expertise.

This study of the data generated in the blog space has been approved by the Sub-Committee on Research Ethics at Lingnan University. The corpus of data for this study includes all blog articles (in total 73 articles) posted by three group leaders between 1 October 2014 and 30 June 2015 (permission to cite their articles has been obtained from the authors when necessary). A thorough content review of the corpus was undertaken to locate and code articles on knowledge and expertise. I have identified three main articles, starting with the discussion of the value and content of patient-to-patient talk and extending to knowledge and expertise of patients and doctors. Details are listed below:

Table 1: Corpus details

Title	Author and title	Word Count
"More and more hesitant over talking about cancer treatment"	L, Group Manager	about 1200
"What I feel about L's growing hesitation over talking about cancer"	J, Group Secretary	about 1000
"To break the isolated state of having no responses"	G, Group Principal	about 4000

These three articles carry out concentrated discussions on knowledge and expertise in cancer-care contexts. For the very good reason that these high-stakes topics concern the very existence of the group as a cancer support group built for patient-to-patient communication, all three group leaders have asserted their opinions and stances.

4 Though it is an online community where members do not use real identities, I have personally met some key members of this group through an off-line support group in the Shanghai area. My exchanges with them and my contextual readings of their blog posts could well attest to the validity of the collected online data.

I employ thematic discourse analysis to analyze the collected data (Singer and Hunter 1999, Taylor and Ussher 2001). Through using this approach, the themes concerning wider social realities in the Chinese context that these group leaders rely on in construing the status of professional and "lay" knowledge and expertise will be highlighted. In the discussion section, I will further contextualize these discourses by drawing on the particular social, political situations in China and provide some solutions to the observed problems.

4 Data analysis

4.1 "Scientific" view of knowledge vs. lay knowledge

Text one

The discussion started with L's article titled "More and more hesitant over talking about cancer treatment" (L 2014), which expresses her feelings that the more she knows about cancer, the less she dares to share with others her views on cancer treatment. The article opens with a shifting of positions:

> I have been a member of this group for more than eight years; eight years as well, as a cancer patient and the group manager. So I have always been fluent and eloquent when talking about cancer, thinking that my knowledge of cancer could match up with that of a doctor. I really thought I had a good right to speak considering all my experiences and knowledge. I could patiently share a lot with all kinds of patient friends and their family members who came to me for advice. However, I realize now that the more I know about cancer, the less I dare to say anything. (L 2014)

This confession expresses her shifting from an expert-like stance on cancer treatment (like a doctor) to choosing silence. "Not dare to say" demonstrates a certain lack of knowledge despite her knowing more and more about cancer. This seeming paradox needs to be contextualized in the case of cancer, as she states: Cancer is as diverse as people living in the world; not a single case is the same as another case (L 2014). So knowing more about cancer only makes her realize the diversity of it, thus the daunting task of mastering a knowledge of it is beyond her. This echoes what Davison, Davey-Smith and Frankel (1991) noted concerning lay knowledge: What generates from lay experience is not universally-based, but confined to singular cases.

This negative assessment of lay knowledge threatens to undermine the very existence of the group, which was set up precisely for "writing about recovery

experiences and treatment processes for the purpose of helping and benefiting the others" (L 2014). What comes to her rescue is the emphasis on the crucial value of spiritual well-being: As a basic guarantee of the quality of life, this applies to everyone, regardless of individual differences:

> Thus, I am now more and more hesitant to offer advice to those who ask for it – I don't dare to!
>
> Thus, in this group, I now emphasize more and more the following message: we are a spiritual home and we are only responsible for promoting the common point among diverse cancer treatments: spiritual recovery, this magic power. Only this is the shared truth that we can absolutely guarantee to be useful.
>
> [...] the health of our spiritual world is the basic guarantee of the quality of life. (L 2014)

This universal applicability, she claims, should be the focus in the sharing activities of group members. "We are only responsible for the shared aspect among all the diverse details of cancer treatment"; "this is something we can absolutely guarantee" – a sense of moral responsibility toward the group members in that only truthful information should be provided to them, and they should be protected from ill-intentioned, misleading, and potentially wrong information. Basically she is implying that, by restricting one's sharing of personal experiences and opinions which could cause disagreements, or potentially do harm to others, one is helping to maintain the value of this group, which is a spiritual home promoting spiritual health. Here sharing personal experience is framed as undermining the core value of the group, because it is not based on universal truth.

This text emphasizes the importance of finding the commonality among diverse methods of cancer treatment, and it suggests that only this kind of knowledge is worth sharing within the group. Though it does not use the term "scientific," this view of knowledge draws on a certain version of scientific reasoning: Scientific knowledge is generated through generalizing individual cases, which in turn guarantees that it can be universally applied. Thus, as she claims, "working on the spiritual health" should be promoted as universally applicable treatment for cancer because it is the common point across all cancer treatments. It is interesting to observe how this affirmation of scientific reasoning in managing communication within the group comes in tandem with a certain admission of weakness: Individual cases of cancer vary so much from one to another that one's so-called knowledge is easily proven wrong by new cases. She confesses: "I am very confused and I do not want to explore any more" (L 2014). This lack of will and desire to explore for answers to clear one's

confusion reflects the drawing of a boundary concerning medical knowledge: In the end, patients are not doctors and a group manager of a cancer support group, however experienced and enlightened he or she can be both as a patient and a manager, is not supposed to act like or have such qualities commonly associated with a doctor (such as investigating and promulgating scientific truths). We can see that in this text, the boundary between medical and lay knowledge is clearly drawn, unlike the Chinese idiom, "*jiu bing cheng yi*" ("a long-term patient becomes doctor him/herself") misleadingly claims (L 2014).

Another noteworthy point is, although the importance of spiritual health is framed here as the common factor affecting cancer recovery and as true knowledge worth sharing, no solid scientific evidence is provided to support this claim. The spiritual health she defines as: "having a relaxed attitude," "I am the master of my own life and mood and I decide how every day should be spent," and "a truly relaxed attitude is to be detached towards life and death" (L 2014). In fact, these understandings resonate strongly with a popular belief on cancer treatment held by the public in China, which is the positive effect of being happy. In their study of lay beliefs concerning health and illness of a Cantonese-speaking group, Prior et al. (2000) note that while there are social variations in conceptualizing illness, the group demonstrates a remarkable degree of agreement about how a healthy life can be achieved. "Happiness," more than any other factor, is almost unanimously thought to contribute to health. This belief may have originated from the legacies of the holistic understanding of human health, as the TCM discourse reflects. On the other hand, the strong message of promoting an autonomous self responsible for creating one's own happiness as a method to manage one's health echoes therapeutic self-help literature. This understanding of lay knowledge underlines their responsibilities in maintaining a positive outlook for themselves.

This extract significantly reveals how the perception of the limited value of lay knowledge concerning cancer experience and treatment has effected a retreating back into the "uncertain" and rather vague spiritual domain where exchanges between patients are thought to be valid and valuable.

Text two

A direct response to the first article as seen from the title "What I feel about L's growing hesitation over talking about cancer" (J 2015), the second text I will discuss resonates with L's stance, and states that individual cases cannot inform cancer treatment, because they are almost always wrong when summarized as "treatment experience." The author explains:

> First, cancer is too complicated and individual differences are large. [...] Someone's own feelings or clinical indicators and doctors' experience in treating similar cases, none of these could predict a person's treatment results or their destiny.
>
> Second, about someone summarizing their own treatment experiences: it is true that every cancer survivor has the right to talk, yet no one can guarantee that the experiences one person summarizes are absolutely correct; nor can anyone guarantee that a person's summary well highlights the main factor instead of unimportant or even harmful ones. Surviving cancer depends on many conditions, but most of the time they are necessary instead of sufficient conditions. Not to mention those cases in which the patient ascribes his or her survival to a single or wrongly-assumed factor (for example, someone thinks his or her being cured from cancer is all due to drinking raw potato juice). Isn't it also possible that a person could even live better without drinking such juice in this case?
>
> It is exactly based on these two reasons that I think treatment experiences are "untalkable"; as soon as one talks about it, one is wrong. (J 2015)

Consistent with the first article, the writer urges that the commonality among all divergent cases should be communicated as useful information for other patients. Building on the first article, the text further expands the universal-truth-based view of knowledge by mobilizing a whole set of vocabulary strongly tinged with logical reasoning: "predict," "sufficient condition," "necessary condition," "general characteristics," "principles," "formulas." Lay accounts and lay knowledge, according to him, fall short of scientific criteria, and thus are "untalkable." This extract pushes what was advanced in the first article to a new level by explicitly claiming that personal accounts and knowledge generated from singular experiences are "wrong."

4.2 An experiential view of knowledge and expertise

Text three

This discussion on the value of patient-to-patient talk was again taken up in a blog article by G (2015), which advocates the necessity of promoting patients' exchanges despite disagreement from doctors. This article situates patient-to-patient communication in a wider context by bringing in doctors' perspectives. It opens by attributing stances to doctors:

> "You are now recovering so you should spend more time with the healthy ones – do not mess around with those cancer patients. You will never be fully recovered if continuing to be like this."

> "What can these patient friends teach you? Are they better than medical specialists? Sooner or later you will regret it, if you listen to your patient friends instead of the doctors."
>
> "Do not listen to your patient friends' bullshit. Every cancer patient is in a different situation – there's no point in learning from each other's experience."
>
> [...]
>
> Recently a very famous newspaper in Guangzhou, when reporting about a reputed oncologist, used his words as the title: "Communication with other patients does more harm than good". (G 2015)

Confronted with these dissenting voices from the doctors, he characterizes the difficult situation faced by cancer patients as "a dilemma": doctors discourage communication among patients, while patients have a strong desire to communicate with each other. Immediately he resolves the dilemma and states that: "this is not a real dilemma. It is more a misunderstanding due to different stances and perspectives" (G 2015). Then he guides the reader to see the whole picture by empathizing with the stances of the different parties involved. Firstly he takes the stance of medical specialists: due to the fact that "cancer treatment does not allow mistakes at any step, at any stage – one mistake could bring fatal consequences or irretrievable loss" and that cancer treatment is very specialized, "even for the same type of cancer, treatment methods adopted at each stage for different body types would not be exactly the same," he suggests it is reasonable for them to adopt a position of discouraging communication among patients. Next, he moves on to see the situation from cancer patients' point of view by underscoring how cancer affects almost every aspect of a patient's life:

> Cancer patients' suffering goes beyond physical pain and involves more mental and spiritual aspects: the fear, loneliness, helplessness, powerlessness, depression, and the huge shock – all these cannot be solved by medication. (G 2015)

And, he continues that this is where patients' experiences can be helpful:

> They [cancer patients] have experienced all these while doctors, despite their specialist knowledge, remain outsiders – it is very difficult for them to understand the mental state of, and pressure faced by, patients without personal experience. Most of the time, their specialist knowledge can only be applied to a very narrow field – too narrow to cover what is required for cancer patients to truly recover; on the other hand, their armchair knowledge cannot beat that gained from actual battles against cancer. To make things more complicated, due to current problems in our medical system, some doctors are tempted by profits and lose their sense of social justice. At these moments, other patients'

> reminders could help the person concerned recognize the problems and traps laid by some doctors. (G 2015)

Here he contrasts doctors' limitations with the strengths of experienced cancer patients to underscore why patients need to communicate with other patients. After thus positioning both parties, he finally concludes: "doctors and patients both possess certain useful knowledge and skills, and they are not in a contradictory position – if we could effectively let them play their respective roles, we could then benefit from both" (G 2015). By designating specific and exclusive roles to doctors and patients, he solves the dilemma: Doctors' expertise is best demonstrated in medical treatment, while patients' first-hand experiences of cancer will be more helpful in addressing the non-medical aspects in cancer treatment. The Chinese idiom he uses here "*ge shan sheng chang*" ("they each excel in their respective fields") clearly captures his views on expertise: Being experts in their own fields, doctors and patients should not find their roles conflicting.

Here we see the clear differences between his positioning and that of articles one and two: Individual experience and knowledge, deemed misleading and wrong in the previous two articles, is here reclaimed as valuable and constituting a form of "expertise," in parallel to doctors' expertise.

Instead of setting "scientificality" and "truth value" as the criterion, this author underscores the value of communication, in and of itself: to break social isolation and create bonding in marginalized groups. Drawing parallels between left-behind children[5] committing suicide due to social isolation and cancer patients suffering from disconnectedness from the world, he highlights the importance of communication for emotional support and survival. This reveals the significant value attached to patients' communicating personal experiences between each other.

5 Discussion

In the above discussions about the value of patient-to-patient communication within the group, drawing on a diversity of discourses on knowledge and expertise, the three group leaders assume different stances in regard to lay

5 Rural children left behind by parents who move to urban areas to seek work. Due to loneliness and lack of love, some of them suffer from severe developmental problems such as depression.

knowledge and expertise. Is lay knowledge necessarily wrong or is there a certain value to patient-to-patient communication sharing personal experiences and knowledge? What patients have gained from first-hand experiences of living with cancer, navigating through physical, emotional, socioeconomic difficulties – does it constitute a form of expertise or not?

However, it is striking to note that, despite these differences, all three texts see patients' exchanges on treatment options and advice negatively. In text one and two, the treatment summary and narrative of individuals is seen as lacking in scientific evidence and rigor, and thus misleading or harmful to advice-seeking patients. In text three, the belief is also advanced that exchanges on treatment options and advice should not be encouraged within the group, since patients do not belong to the same constituency of experts as doctors, who should be more trusted on these issues. As summarized in text three, doctors and patients serve as experts, in the biomedical and psychosocial domains respectively.

In the light of the scholarship on lay knowledge and expertise as reviewed in the Introduction, these patients' self-positioning seems to coincide with some of the cautious lines taken among researchers who purport to draw a boundary around the domain of expertise: Patients' experientially based knowledge and expertise do not constitute real technical expertise (Prior 2003). I will, however, argue that this positioning reveals a dualistic understanding of the human body and health – body versus mind – and thus a biophysical versus a mental/psychological/spiritual epistemology. By assigning the two domains respectively to doctors and patient support groups (the former has technical expertise on the biomedical conditions of cancer, while the latter's experientially based knowledge can only be useful in providing emotional support), the dualistic model, as endorsed within this group, seems to have resolved the dilemma concerning patient-to-patient communication on the surface, but actually has profound implications for cancer treatment and doctor-patient interaction.

One may feel baffled to see the dualistic dichotomy of body and mind lurking behind the abovementioned views on lay knowledge and expertise, which is commonly associated with the biomedical model of illness subscribed to in WSM (see Jewson 1976; Lawrence 1994; Cantor 2000), in the Chinese context. As discussed earlier, everyday living in China is permeated, to a great extent, with a holistic understanding of health matters distilled from traditional cultural legacies, including TCM (Shih 1996). Therefore, as I will explain later, it may be more reasonable to see this dualistic mindset as a calculated compromise rather than an actual belief. According to Yang (2011), patient-centered care is not effectively practiced in China due to ideological

contradictions in policymaking and problems in policy implementation. In the hospital setting, the doctor–patient relationship is still dominated by the doctor, the result being even if patients are not satisfied with doctors' attitudes or service, they are still very likely to keep a peaceful relationship with them so the doctors can look after them and treat their disease. That explains why, for patients, emotional well-being is not an important concern when interacting with doctors, as long as their disease can be properly and professionally treated: Patients are already very satisfied given that they know they are in an unequal relationship. As to psychosocial and emotional aspects, they can find other outlets. This compromising mindset is further strengthened by some patients' beliefs that doctors are not capable of providing emotional support due to their lack of direct personal experience, as text three underlines.

For cancer patients, this accommodating attitude maybe the best resolution in the current situation, yet by doing this, they unwillingly, or even unknowingly, subscribe to a dualistic model of health which can have detrimental effects on cancer treatment and research. Separating the "disease" from the person fails to understand the importance of doctors engaging with the patient as a living social being in actually "curing the disease." On the other hand, not expecting to treat cancer patients as social beings who suffer from cancer in many different ways, doctors can comfortably continue treating diseases as dissociated from the bodies that host them; also, individual illness only has meaning for practice to the extent that it could be "mapped onto pathological processes that were common to populations of patients" (Cantor 2000: 348–349). This lowers the impetus for the medical profession to truly embrace patient-centered care, and reduces the chance of achieving effective treatment of cancer patients. As underlined in psychosocial oncology, the patient's personal experience of cancer and what it means to him or her, and how this meaning may influence his or her behavior and interaction with others, should be considered integral components of the disease as a total human response (Grassi 2013).

Moreover, to divide one's needs dualistically into the biomedical and psychosocial and seek help separately for each creates more pressure for patients. They need to manage these different dimensions of being ill, actively seek help, and integrate the information and knowledge they receive from different sources into the process of healing. Managing these experiences separately obviously adds an extra burden to their already weakened state as cancer patients. To cope with this demand, as seen from the blog extracts, they tend to promote and practice a self-help philosophy that urges individual patients to take responsibility for their every choice in dealing with cancer and make sure that they can keep a positive outlook throughout. To a certain extent,

they are simply taught to take care of themselves, instead of requesting and negotiating better care from health-care providers. We can see that by keeping body and mind in two separate domains, despite their initiatives in seeking and promoting patient-to-patient communication and the high reflexivity demonstrated in their writings, these patients actually reproduce the existing structures of authority. This strategy of accepting emotionally comfortable and socially ratified discourses ultimately only serves to burden them further.

This dualistic positioning is thrown into sharper relief by comparison with recent developments in the West which move beyond biomedical models. In many countries now, increasing patient involvement has become a policy imperative in response to wider sociopolitical trends, such as increased skepticism toward professional authority from lay people (Thompson 2007). Marcum (2008) critically reviews the variety of humane or humanistic models which reinstate the human dimension into the patient–physician relationship in response to the quality-of-care crisis in the United States, and examines the ethical implications of each model for the physician–patient relationship. These humanistic efforts maintain that the mind and body often "influence the behavior and state of each other in a reciprocal manner," and thus when making a diagnosis or choosing a therapy, doctors need to take both into consideration as a whole (Marcum 2008: 12). By caring both rationally and emotionally for the health of the patient *qua* person, physicians may know more about the "eidetic" features of a patient's illness, including feelings of losing control over their life, lack of certainty and freedom to act, and the estrangement from the familiar world (Toombs 1993). Moreover, instead of adopting an authoritarian stance, the physician is also more willing to see him/herself as a co-participant with a patient and other health-care providers in curing a patient. They acknowledge that a patient's mind–body nexus (as an integrated entity) may well cure itself: Both physician and patient need to cooperate in order to "assist" in that self-healing process (Marcum 2008: 13).

These new developments in Western medicine are valuable resources for Chinese cancer patients to tap into if they are to move beyond mind–body dualism. Armed with these new discourses on the value of promoting holistic, humanistic, patient-centered care, and drawing on their experiences of complementing WSM with TCM treatments, patients will have opportunities to feel more empowered to claim knowledge and expertise whenever appropriate concerning cancer treatment and care, rather than unanimously ceding this domain to doctors, as observed within the cancer support group.

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