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Tension in the Chinese doctor-patient-family relationship: a qualitative study in Hunan
Province, China

A Thesis Submitted to the
Yale University School of Medicine
in Partial Fulfillment of the Requirements for the
Degree of Doctor of Medicine

by

Siyu Xiao

2018

ABSTRACT

TENSION IN THE CHINESE DOCTOR-PATIENT-FAMILY RELATIONSHIP: A QUALITATIVE STUDY IN HUNAN PROVINCE, CHINA. Siyu Xiao, Lixuan Wang, Xinchun Liu, Kaveh Khoshnood, and E. Jennifer Edelman. Section of General Internal Medicine, Department of Internal Medicine, Yale University, School of Medicine, New Haven, CT.

Problems facing the doctor-patient-family relationship (DPFR) in China, including violence against doctors, have received international attention. Possible contributors to tension in the medical relationship include systems-level challenges such as imbalances between provider and patient populations and a biased media. Yet, there has been limited empiric prior work examining how interpersonal dynamics, particularly communication, between patients, their family members, and providers contribute to satisfaction or tension. This study aims to identify actionable communication factors contributing to tension in the Chinese doctor-patient-family relationship among breast surgeons, surgical patients, and their family members in an urban, tertiary-level teaching in Hunan Province, China. We conducted a qualitative study between June and August 2015. We recruited a convenience sample of 29 participants, including 11 breast lumpectomy inpatients, 9 corresponding family members, and 9 surgeons. In-depth, semi-structured interviews were conducted perioperatively in Mandarin and English. Interviews were transcribed and translated into English. Transcripts were coded and thematic analysis was applied. We identified three emergent themes regarding tension: 1) Trust degradation occurred before and during the healthcare experience; 2) The healthcare-seeking experience for patients and family members was marked by unmet expectations for achieving a basic understanding as well as powerlessness; and 3) Societal pressures on doctors contributed to a state of learned helplessness. Findings from this study suggest that tension between doctors, patients, and family members is associated with both interpersonal and structural challenges with communication playing an important role. Reforms at all levels are needed to promote empowerment by

providing a more patient-centered experience for patients and family members while ensuring the well-being and security of providers.

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INTRODUCTION

Current climate of the Chinese medical relationship

In recent years, the Chinese doctor-patient relationship (DPR) has received international attention in light of violence against medical providers perpetrated by patients and family members [1-6]. One review of serious physical violence against providers in China in the decade from 2003 to 2013 found 101 incidents that resulted in the deaths of 24 doctors and nurses [7]. The same review concluded that the violence was present across nearly all divisions of medical care and most often occurred in tertiary hospitals, which provide the highest level of medical care. Another website titled DXY.cn, the major Chinese online medical community comprised of over 3 million medical professionals, collated details of violent incidents against medical providers from 2000 to 2011 [8]. It reports 124 incidents that included 29 murders and 52 serious injuries. And yet, these sources are limited by their reliance largely on published media reports. In 2015, the Chinese Medical Doctor Association (CMDA) released a White Paper that included a survey of 9,524 doctors in China. It found that more than 70% of respondents had suffered either verbal or physical abuse [9].

According to the DXY.cn report, perpetrators of the violence had varying motivations. Some were dissatisfied with a treatment's effect; others sought revenge for a negative outcome such as the death of a loved one [8]. There were also 37 cases of *Yi Nao*, phenomenon in which a mob or individual is hired for the explicit purpose of disturbance through harassment of hospital personnel and damaging hospital property. The goal for patients and families who use *Yi Nao* is to force the hospital into compensating them for malpractice, whether real or perceived [10]. With the release of the 2015 White Paper, the CMDA's director of legal affairs echoed the media reports by commenting that the violence can result from unrealistic expectations about medical treatment casting blame on doctors when those interventions fail [9].

Since 2002, China has passed at least six major laws or regulations meant to address the threat to health professionals from violence and complaints [11]. Notably in 2014, five key state institutions¹, including the Supreme People’s Court and the National Health and Family Planning Commission, issued a joint statement that details the penalties associated with violence against medical personnel and facilities, roles of the different institutions in enforcement, and other recommendations for the prevention of disputes and improvement of doctor-patient relations [12]. Moreover, in May of 2016 a series of attacks against doctors—at least one of which was fatal—led to that period being labeled “Black May,” indicating an ongoing problem of enforcement despite the existence of policies and regulations [11].

Violence, however, is on the extreme end of the spectrum of challenges facing modern Chinese doctors. Surveys reveal that negative sentiments reflecting burnout in the medical profession are widespread. In a 2009 survey of practitioners by the Chinese Medical Association, 64% of physicians thought the current practice environment was either “poor” or “extremely bad.” The survey also showed that 62% of doctors did not prefer their children to attend medical school, 92% thought that their income did not match their efforts, and 45% had ever thought of leaving the profession [13]. Survey results published in 2014 by Wu *et al.* of 202 doctors in Zhejiang province found low job satisfaction rates at various levels of care: 3% in high-level care (i.e. county and provincial hospitals) and 27% in primary care [14].

Yet the phenomenon of tension in the doctor-patient relationship appears to be a modern one, with a major challenge being in the issue of trust. The anthropologist Yunxiang Yan describes in a bioethical paper the evolution of the Chinese medical relationship over time, and with it, the status of trust. According to Yan, the historical dynamic was of paternalism and morality,

¹ The five state institutions: Supreme People’s Court, Supreme People’s Procuratorate, Ministry of Public Security, Ministry of Justice, and National Health and Family Planning Commission (reformed in 2013 from the Ministry of Health)

informed by traditions like Confucianism. The physician acted not only as a well-educated and benevolent expert, but also a moral leader to whom the illiterate poor completely surrendered themselves in seeking relief from suffering. Due to the immense imbalance of power and knowledge between physician and patient, decision-making fell solely to the doctor, and poor outcomes were explained by fate [15].

With Mao Zedong's Cultural Revolution, the relationship transformed to one of a professional service to the peasant and working class, along with dispersion of medical knowledge via the barefoot doctor initiative [15]. Another transformation occurred with globalization and the switch to a market economy in China. Individual power and rights of patients began to overturn paternalism. Blumenthal and Hsiao analyze the effects of the 1980s healthcare reform—characterized by radical decentralization and privatization of healthcare—on the behavior of administrators and providers. Hospitals were forced to begin focusing on the sale of profit-seeking services just to stay afloat. The government further incentivized this behavior by permitting healthcare facilities to sell new technologies and drugs, as well as giving bonuses to the doctors who brought in the most revenue [16].

Media coverage that has disproportionately focused on cases of corruption, such as bribery and profit-seeking actions of doctors, has further tainted the image of the Chinese doctor [1, 15].

There are also reports of blackmail by the media toward hospitals to extract payment in return for positive coverage of a medical dispute [13]. News about violent incidents against healthcare providers is actively spread on social media like Weibo, the Chinese analog to Twitter. An analysis of 484 Weibo micro-blogs, including 97 by news media organizations, after a 2015 knife attack against a female doctor in Guangdong province found that condemnation of the attacker was only expressed in a quarter of the posts [17]. In their analysis, the authors noted a lack of discussion about constructive methods to protect doctors and decrease healthcare violence.

Yunxiang Yan argues that the modern doctor-patient relationship, while rooted in a basic level of trust, is precarious in the face of unexpected or negative outcomes. The integrity of trust thus relies on the patient's judgement of the doctor's intention, a factor that until modern times had remained unquestioned [15].

One way to measure change in the dynamic of the doctor-patient relationship would be to examine the trend over time in medical disputes and patient complaints in China. Unfortunately, there is a lack of official records or reports of national data on this issue for China; Jiang *et al.* estimated that from 2002 to 2008, the number of disputes and complaints increased from 10,248 to 13,875 [18]. However, the legitimate methods for dispute resolution face serious challenges. In their qualitative study of complaint management in Shanghai, Jiang *et al.* found that hospitals bear the largest burden in this task. Their challenges included a general lack of willingness to effectively deal with complaints, dependence on a single individual to set the culture, and inconsistency in classifying the disputes within and between hospitals [18]. The authors noted that although many complaints are about problems like long wait times from enormous patient volume, doctors and hospitals are vulnerable to becoming scapegoats for such structural problems. Additionally with regard to litigation, the public is wary of a major conflict of interest that favors the medical side given that the local medical association operates litigation channels [10]. Deficiencies of the healthcare system despite past reforms certainly contribute to this negative climate and are the subject of international critique [16, 19].

The contributions of institutions and systems to tension is further supported by multicenter studies in other provinces [20, 21]. Using a mixed methods approach to study doctors' perspectives in Zhejiang Province, Wu *et al.* found that they carry a sense of guilt about their involvement in unethical practices in a profit-oriented environment. Furthermore in a large qualitative study in Guangdong Province, Tucker *et al.* found that profit mongering and physician conflict of interest were a major source of mistrust in the doctor-patient relationship, and that

primary care-oriented reforms in one hospital was associated with improvement of trust [20]. These qualitative studies expose the interactions between personal/interpersonal and structural challenges within their respective regions. More research is needed to build an understanding of regional characteristics of tension so that solutions can best address the needs of local stakeholders.

Communication in the doctor-patient-family relationship

While deficiencies of systems must be addressed, it is critical to empower both the medical professional and layperson to improve the doctor-patient relationship at the everyday, interpersonal level. One important component to consider is the role of communication in generating or resolving conflict between providers and patients. Communication in the doctor-patient relationship and its impact on patient satisfaction and outcome is well-researched internationally [22, 23]. Effective communication between doctors and patients helps achieve a strong relationship with clear information exchange that promotes inclusive decision-making [22]. It promotes patient-centered care with positive influences on recovery, mental health, adherence, and satisfaction, which can be used as a proxy to measure health [24]. Little *et al.* found patients' perceptions of communication and partnership to be an independent determinant of patient satisfaction [25].

In order to achieve the benefits of communication, it is important to address barriers to communication for all actors, including fear about their wellbeing, deviant expectations, and limited time [22]. The emotional and time burden associated with communication may motivate providers to avoid it [22]. Findings about communication should thus be considered in efforts to ameliorate tension in the doctor-patient relationship.

Despite the rich base of information from international sources, gaps and limitations hinder their generalizability to specific settings and patient groups in China. In their review of doctor-patient

communication, Ha *et al.* noted that the generalizability of findings is particularly limited by the cross-sectional design and sample heterogeneity of many studies [22]. At the same time, quantitative studies about communication are also limited in their generalizability due to the unique stakes for patients, family members, and doctors encountering different medical problems. Gaining a thorough understanding of a specific patient population in need of better communication thus requires a qualitative, in-depth approach to permit exploration about cause-and-effect and generation of hypotheses for future study [26]. Furthermore, rooted in the Confucian tradition is the family members' role in medical decision-making in China [27]. Yet much of the literature on communication has examined only the dyadic relationship between doctor and patient; more research is needed to understand the role of family members. A clearer understanding of communication may inform interventions to prevent and resolve conflicts in the Chinese medical relationship.

STATEMENT OF PURPOSE

We undertook a qualitative study to gain an in-depth understanding of the interpersonal factors associated with tension in the doctor-patient-family relationship (DPFR), with a focus on communication. We included family members' perspectives to enrich our understanding. We decided to recruit participants involved in a surgical procedure due to the discrete nature of phases of treatment (pre-operative, intra-operative, and post-operative) that would allow us to better assess patient and family member expectations and experiences via multiple interviews. We acknowledge that the stakeholders—patients, family members, and doctors—are embedded within a health system that possesses shared and unique challenges compared to others in China. Thus, we sought to also understand the context-dependent daily constraints that stakeholders face in trying to accomplishing their goals as patients, family members, and doctors.

Research Question

What are the communication factors that contribute to tension in the Chinese doctor-patient family relationship (DPFR), in the context of surgery?

Study Aims

- To characterize pre-operative patient and family member expectations for communication with their doctor.
- To characterize post-operative patient and family member experiences of communication with their doctor.
- To characterize doctors' expectations for and experiences of communication with patients and their family members.

METHODS

Overview

The study design was in-depth, semi-structured interviews with individual participants using a the qualitative approach to data analysis of thematic analysis [28]. The data collection of the study took place over a 2-month period from June to August 2015. The study sample was drawn from the breast surgery inpatient ward of an urban tertiary-level teaching hospital in Hunan Province, China. We used convenience sampling to recruit and interview a total of 29 participants were interviewed including 11 patients, 9 family members, and 9 doctors.

Setting and Participants

The healthcare system of which the study hospital is a part comprises in total 2,200 beds and more than 2,560 staff members. There were two main sections of the hospital: the outpatient building and the inpatient building. In order to be admitted to the hospital, patients had to first see a doctor in the outpatient building for an evaluation and possibly initial tests. Unlike the United States, there is no advanced booking procedure for seeing the doctor; instead patients obtain a number when they arrive at the building and wait for their turn to be seen.

We decided to recruit participants undergoing a surgical procedure due to the discrete nature of phases of treatment (pre-operative, intra-operative, and post-operative) that would allow us to compare patient and family member expectations with experiences. The choice of patients undergoing breast lumpectomy was two-fold: we sought patients undergoing a relatively minor procedure due to the need for sufficient time, energy, and mobility (to relocate from the shared patient room to a private office) to complete the interviews including during convalescence; and the willingness of the department leader to allow the research team to conduct the project.

Contact with various department leaders to identify a suitable site was facilitated by the Chinese research mentor (LX).

Inclusion and exclusion criteria

Inclusion criteria for patient and family member participants included: 1) being age 18 or older and 2) admitted and scheduled for a breast lumpectomy procedure, which is classified as a category 1 out of 4 procedure according to the National Procedure Classification scheme in China [29]. Exclusion criteria of patient and family member participants included: 1) refusal or inability to be interviewed twice (once in each of the pre- and post-operative phases), 2) inability to communicate through written or spoken form with researchers, and 3) incapacity to provide informed consent or cooperate with researchers, for instance due to pain or the need for rest. Inclusion criteria for surgeons included being age 18 or older.

Recruitment

Applying within-method triangulation (i.e., the use of multiple data sources in a study to enrich the emergent themes) [30-32], we included three groups of participants: patients, family members, and surgeons. . Patients and family members were recruited in pairs consisting of one patient and his/her accompanying family member in order to understand a similar experience from multiple perspectives. In cases where more than one family member accompanied the patient, the patient was asked to identify the primary member involved in his/her healthcare for recruitment. Surgeons were recruited without regard to whether or not their patient(s) were also recruited. In order to avoid compromising the patient-surgeon relationship, we obtained permission assent for the patient's participation from his/her surgeon when possible.

Regarding method of approach for recruitment, the Chinese mentor for the project (XL) served as the initial liaison to introduce the researchers (myself and three interpreters) to the medical ward

in which the data collection would occur. XL was an existing Chinese collaborator of the initial research mentor for the project, KK. XL's appointments at the study hospital were Associate Professor (of doctor-patient communication, medical ethics, social medicine & health policy) and Director of the Department of International Cooperation & Exchange. Her connection to the attending doctors or heads of various hospital departments helped to establish legitimacy of the research team. I was also introduced to the head nurse of the study ward who ultimately became the primary advocate for study recruitment and shared the message with her nursing staff.

Once introduced to the head surgeon of the ward in which the data collection would occur, I was invited to attend a morning meeting of the entire ward staff including doctors at various levels of training and nurses. I gave a short introduction (in Mandarin) of my role, institutional background, and purpose of the research study. This meeting helped to establish legitimacy of the research team.

For patient and family member participants, the head ward nurse and staff nurses served as the first point of contact with potential participants. The nurse first asked the patient and family member in their room if she/he would be interested in participating in a research study conducted by a student and consisting of interviews. If the individual expressed interest, the nurse either verbally, by phone, or by instant messaging (SMS or WeChat, a messaging app widely used in China) informed the researchers of the individual's location but not their name or other identifying information.

For surgeon participants, the head ward nurse and staff nurses or the researchers themselves served as the first point of contact with potential participants. Surgeons were generally already acquainted with the study purpose and researchers since we worked in the same environment. At least one surgeon volunteered to participate without being directly approached.

The researchers then approached the interested participant in pairs (myself and one interpreter), introduced themselves and the study purpose in Mandarin. The location of approach was the bedside for patients and family members, or throughout the ward and offices for doctors. If the individual desired to participate, we proceeded with the verbal consent process. The consent process consisted of the interpreter reading aloud in Mandarin a standardized consent document tailored to patient/family participants or doctor participants. The document introduced the researchers and the purpose, procedures, reimbursement, privacy/confidentiality, voluntary participation, possible benefits and risks, and contact information of the study (see Appendix B). The individual was given a hard copy of the document to keep. The individual was allowed time to ask questions and then asked whether they agreed to participate in the study by responding “yes” or “no.” We also asked participants for verbal consent to have the interview audio-recorded.

Participants received a small gift worth less than 5 USD to thank them for their participation: at the end of each interview, the patient and family member participants received a blank journal as a gift and surgeon participants received a hand-written thank-you card. At the conclusion of the data collection period, the research team presented a thank-you gift to the ward staff consisting of a locally purchased fruit basket.

Data Collection

Data collection occurred over a period of two months from June to August 2015. Semi-structured, in-depth interviews were conducted in English and Mandarin by myself (SX) and an interpreter. For patient and family member participants, we conducted two interviews per participant when possible: one in the pre-operative phase and one in the post-operative phase. Interviews were audio-recorded.

Interview environment

The interviews were conducted in private offices located throughout the ward, based on availability. Patient and family member participants were always interviewed individually to maintain confidentiality. The interviewer (SX) sat opposite the interviewee and the interpreter sat beside the interviewee. To avoid confusion about the role of the researchers, the researchers dressed in plain, informal clothes. They emphasized to the patient and family participants that they were not involved in the patient's healthcare and the interview dialogue would remain confidential and not be discussed with the patient's medical providers. In the case of interruptions by other individuals entering the office during the interview, the researchers paused or asked the participant to pause until the individual exited.

Interview guide

To facilitate the interviews, we developed a bilingual interview guide (see Appendix A). We used open-ended questions aimed to assess both the content and dynamic of the communication between patients and surgeons, and family members and surgeons. Follow-up questions, or "probes," were used to clarify and expand upon concepts raised by the participants [26]. The interview guide was written in English, translated to Chinese by a bilingual MPH student who also served as a research partner (LW), then back-translated to English by a bilingual Chinese medical student who also served as an interpreter for the interviews. The back-translated version was compared to the original version to ensure accuracy [33].

The interview guide was piloted with 4 participants: 1 patient in the pre-operative phase, 1 patient in the post-operative phase, 1 family member in the post-operative phase, and 1 surgeon. Based on difficulties that participants had with certain questions in the pilot and initial several interviews, the guide was revised to clarify the questions.

Demographic survey

Participants each completed a brief survey after the first interview in the preoperative phase to capture data on demographics (see Appendix C). They were also asked to subjectively rate the degree of personal cost associated with the current hospital visit on a scale of 0 to 4, with 0 being no cost and 4 being highest cost, along four dimensions (financial, work life, family life, and time). The survey was developed in English and translated to Chinese by the same graduate student who translated the interview guide. The survey was administered on paper; when necessary due to a visual impairment, the interpreter read the questions and responses aloud in Mandarin to the participant. The data were extracted and stored in a spreadsheet (Excel 2013, Microsoft Corporation).

Language and Interpretation

The lead interviewer (SX) was bilingual but not proficient in medical Mandarin. Thus, three bilingual Chinese medical students (2 men, 1 woman) served as English-Mandarin interpreters on a rotating basis for all the interviews. The medical students were in their fifth year of study in the 8-year MD program at the medical school associated with the study hospital. They had studied English as part of their education. They were able to understand but could not speak the local dialect used by some patient/family participants. Likewise, those patients/family members who spoke the dialect could understand the Mandarin questions. The interview recordings were transcribed on a rotating basis by the three medical student assistants. The Chinese transcripts were then translated into English by a professional freelance translator with experience in medical translation. Given the translator's Chinese-Australian background, some words have a different spelling than in American English that were preserved in the supporting quotations of the Results section. Hiring and interaction with the translator was facilitated by a virtual freelance work platform (Upwork.com, Upwork Global Inc.).

I did not have experience in qualitative interviews prior to the study. In order to familiarize myself with in-depth interviewing, I consulted with a Yale faculty member (RGC) who was experienced in cross-cultural qualitative research. I reviewed relevant articles on the topic suggested by her and online videos demonstrating the skills. Additionally, I had patient-centered interviewing training as a first-year medical student that I found to have many overlapping characteristics with qualitative in-depth interviewing.

Because the interpreters did not have prior experience in qualitative methods, I developed a training session for them with the assistance of the faculty member (see Appendix D). I conducted the training prior to the data collection period. The training included an overview of qualitative research compared with quantitative research, as well as techniques employed in in-depth interviewing such as open-ended questions, active listening, note-taking strategies, a nonjudgmental and flexible attitude, and the use of main questions and probes [26, 34]. For interpretation, we reviewed the importance of real-time translation, maintaining neutrality, speaking directly to the participant and interpreting his/her words as it was said, avoiding summary or giving advice, and deferring the interviewee's questions to the interviewer to answer [35, 36]. We reviewed videos showing good and bad examples of interpretation. Finally, we practiced delivery of the verbal consent form and introductory parts of the interview guide, as well as non-verbal communication techniques between the interviewer and interpreter that we could employ in the interviews.

In the process of piloting the interview guide as well as during initial interviews, I met with the research assistants to discuss issues related to translation of a question from English to Chinese, and ordering of the questions to be more comprehensible for participants. At times a word had to be changed to align with the cultural understanding of the concept as perceived by the participants. The most notable example was the difficulty conveying the English concept of "expectations" as distinct from the concepts "hopes," "wishes," or "desires." In Chinese, the

accurate translation of “expectations” (预料 yùliào) was not comprehensible to several patients and family members since it is a highly formal term used in written but not spoken language. Instead, most participants responded with Chinese terms that combine the concepts of “expectation” and “hope,” such that the terms overall carry a positive connotation.

Ethics and Data Security

The study protocol was approved by the Yale University Human Subjects Committee (IRB Protocol #1505015787) as qualifying for exemption under 45 CFR 46.101(b)(2), and by the IRB of the Third Xiangya Hospital, Central South University (No: 2015-S136).

The researchers SX and LW passed the online HIPAA and IRB training modules before beginning data collection. The interview audio files and transcripts were stored on an encrypted, password-protected computer and backed-up to an encrypted, password-protected USB drive (IronKey Enterprise D250 flash) provided by the Yale University Information Technology Services (ITS) department for the purpose of research. These two devices were only accessible by the lead researcher (SX). Audio files were uploaded from the recording device to the computer the same day as the interview and immediately deleted from the device. To transfer files for transcription by the Chinese medical students, translation by the translator, and data analysis by LW, SX used the web-based Secure File Transfer service provided by the Yale ITS department, which is approved for file types up to and including ePHI/3-Lock Data. In order to download files, members of the research team were required to enter a password provided by SX, and files stored on the server automatically expired after 10 days. All collaborators were regularly reminded to delete the files after finishing the assigned task (i.e. transcription, translation, analysis).

We designed the demographic form to preserve anonymity of the participants. We did not collect any identifying information such as name, phone number, address, instant messaging usernames,

or photographs/video recordings of the participants. In addition, the form asked for categorical information where possible, such as age range instead of exact age, income range, and province and type of municipality of residence instead of the city name.

Data Analysis

According to Braun and Clarke (2006), thematic analysis is a method for identifying, analyzing, and reporting patterns within data [28]. I took the approach of inductive, semantic thematic analysis using an essentialist/realist epistemology. The inductive approach assumes that themes are strongly linked to the data themselves; the semantic approach involves identifying themes according to the explicit meanings of data; and an essentialist/realist epistemology assumes a unidirectional relationship between meaning/experience and language [28]. I selected this method because it would enable a robust understanding of the perceptions of participants while remaining attentive to nuances. I chose thematic analysis over grounded theory, another related qualitative method of analysis, because of its accessibility to beginners in qualitative research.

Phases 1 and 2 involved becoming familiar with the data and generating codes, respectively.

Translated interview transcripts retained both the Chinese and English text on alternating lines.

Two researchers (myself and LW) coded the data. There were a total of 42 interview transcripts comprising 29 interviewees. The coders independently read and free-coded 5 initial transcripts for manifest content, where LW coded the Chinese text and I coded the English text. We met to compare, organize, and compile free codes into codes according to the research questions. We wrote definitions for each code. The coders then independently applied the draft code structure to one transcript. We met for line-by-line comparison of the coded transcript, then revised and refined the code structure and definitions. We repeated this iterative process on the remaining initial 4 transcripts. Then, LW used the code book to code 20 additional transcripts. Because there was a hiatus in the analysis after this point due to other commitments, both researchers coded in

parallel the remaining 17 transcripts. We again regularly met (in person or by phone/video call) to compare our work and resolve discrepancies. During this phase we also made clarifications to code definitions and merged several codes to better represent the meaning in the data (see Appendix E). Additionally, we wrote memos throughout the coding process that informed the development of emergent themes. Coding was performed using ATLAS.ti (Scientific Software Development GmbH, Berlin, Germany).

Following the coding phase, I re-familiarized myself with the entire data set again by listening to the original interview recordings while following along with transcripts. I wrote profiles for every participant to begin the process of developing emergent themes; this allowed me to compare ideas across several axes (e.g. between patients, within patient-family dyads, between patients and doctors, etc.).

Phase 3 involved searching for themes. In the course of conversations among the team over time, many themes emerged that could address the study aims. In this thesis, we decided to focus on those that were related to tension because of its more immediate relevance to Chinese providers and potential for guiding interventions. As such, I exported the quotations and associated memos under the code 'Tension' from ATLAS.ti to word processing software (Word, Microsoft Corporation) and printed hard copies for ease of use. I re-read the quotations by group (i.e., patients, family members, and doctors), highlighting important text and writing additional memos in the margin. I also took notes on potential themes and sub-themes in a separate notebook, with references to the speaker and line number.

I next drafted the first version of a thematic map (i.e., a visual representation of related concepts) (Fig. 1) based on the emergent themes I developed from the 'Tension' code subset of data and the guidelines for thematic analysis by Braun and Clarke [28]. I discussed the map with my mentor (EJE), who provided feedback based on her independent review of the data. In this process, I

decided to expand my analysis to the quotations and associated memos under the code 'Informed Degree' because it emerged as an important concept during the analysis of 'Tension' data. I repeated the reading and annotation process with these additional quotations. Incorporating the additional ideas from the 'Informed degree' subset of data, I made revisions in order to refine the candidate themes and produce a second version of the thematic map (Fig. 2).

Phase 4 involved reviewing and refining the themes. Considerations I had during this phase included Patton's dual criteria for judging categories, which are internal homogeneity (i.e., data within themes should cohere together meaningfully) and external heterogeneity (i.e., clear and identifiable distinctions between themes) [37]. I wrote short definitions of each theme to ensure that I could demarcate their scope. I produced a third version of the thematic map (Fig. 3) that I discussed with my research partner (LW) and two faculty mentors (EJE and KK).

Phase 5 involved incorporating the mentors' feedback to define and name the themes. I returned to the collated data for each theme and organized them in a way that was internally consistent and in line with a clear narrative both within and between themes. I revised the theme titles and definitions for accuracy and concision. Phase 6 involved producing the report. In doing so, I sought to communicate a clear story about the data and to identify the role of each supporting quotation within that story. Phases 4, 5 and 6 were an iterative process in which I often returned to the collated data to ensure they were organized in the most logical way within the theme story and across themes. This led to generating a fourth version of the thematic map (Fig. 4).

Figure 1. Thematic map version 1

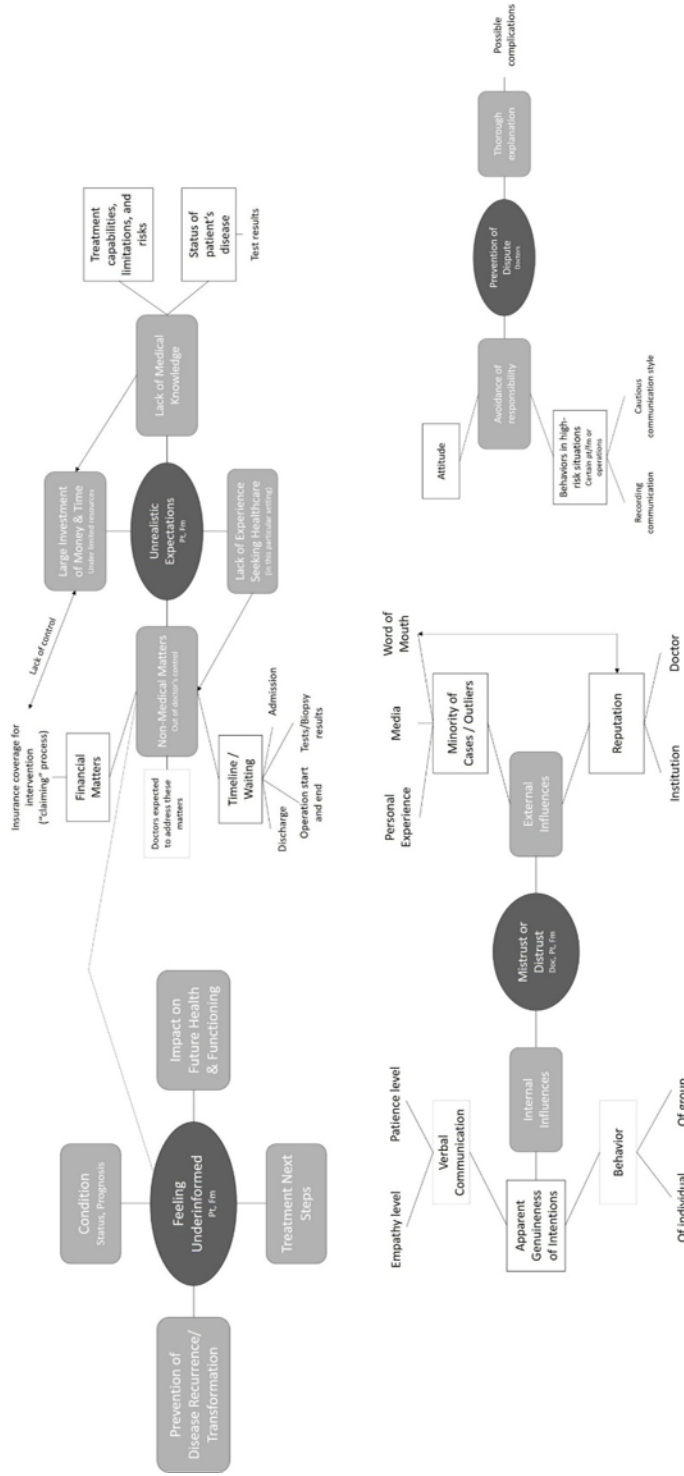


Figure 2. Thematic map version 2

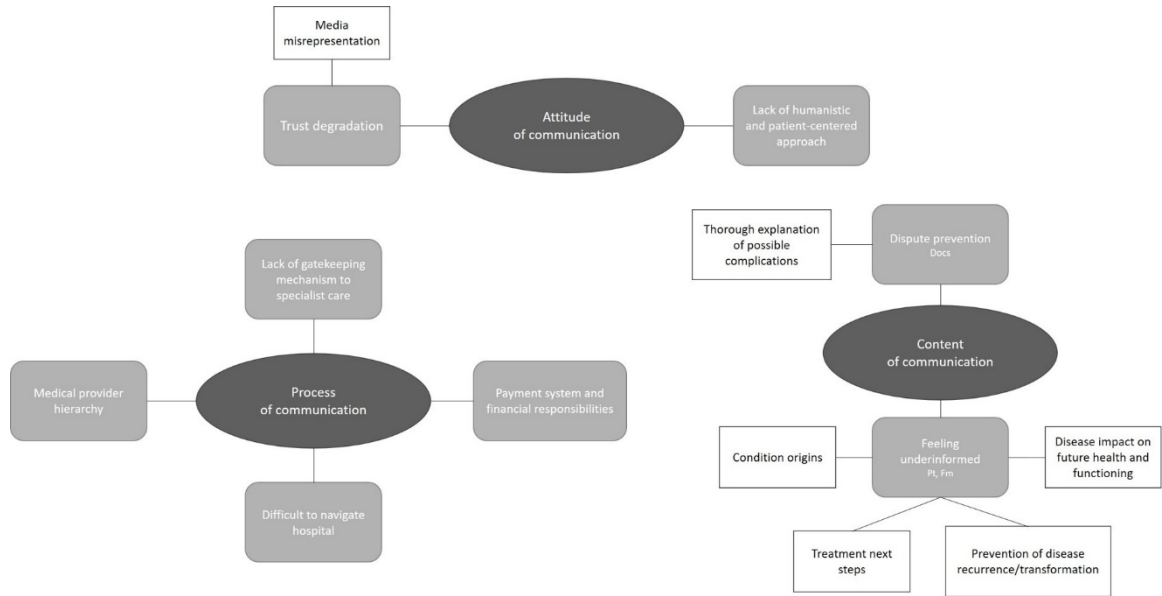


Figure 3. Thematic map version 3

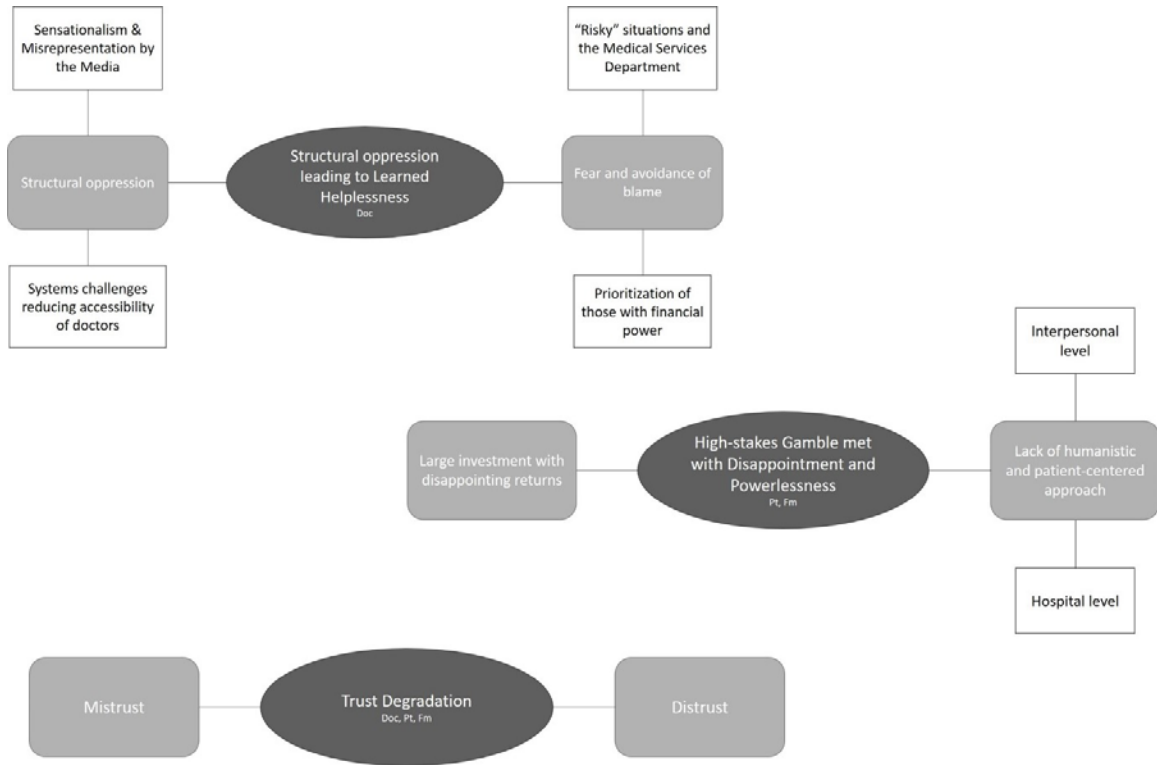
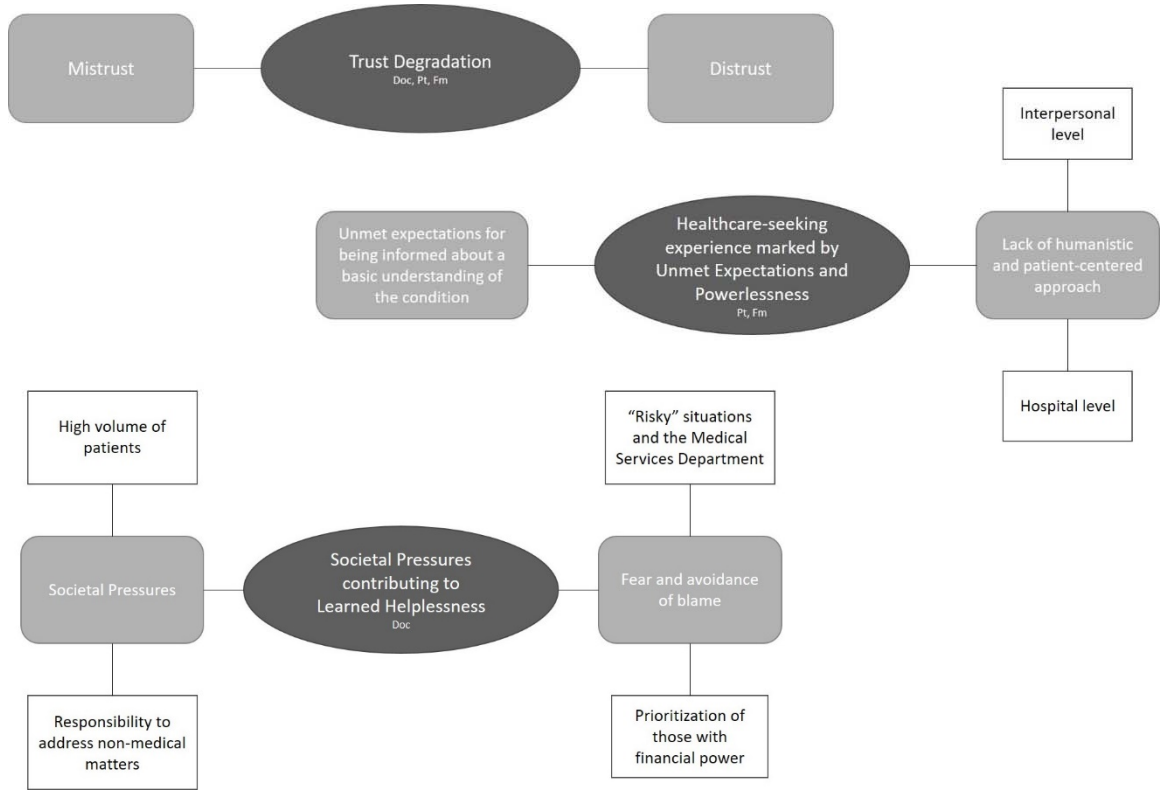


Figure 4. Thematic map version 4



RESULTS

Participant Data

We recruited a total of 29 participants including 11 patients, 9 corresponding family members, and 9 doctors (Table 1). Of note, the majority of patients were female while the majority of doctors were male and at the resident level.

Of the patient participants, we conducted pre- and post-operative interviews (total of 2) with 7 participants and a pre-operative interview only with 4 participants. There were 3 patient participants for whom we did not recruit a corresponding family member to interview, and there was 1 participant for whom we recruited 2 corresponding family members instead of 1. Of the 9 family member participants, we conducted pre- and post-operative interviews (total of 2) with 6 participants, a pre-operative interview only with 2 participants, and post-operative interview only with 1 participant. Among patient and family member participants, the second interview occurred between 2 and 8 days after the first interview, with a median of 3 days. Interviews lasted between 22 and 71 minutes with a mean length of 43 minutes.

Table 1. Patient and family member characteristics from the demographic survey in the preoperative phase

Characteristic, n	Patients (n = 11)	Family members ^A (n = 9)
Age in years		
18-25	1	2
26-35	2	1
36-45	5	2
46-55	3	4

Sex		
Female	10	5
Male	1	4
Highest education		
Elementary school	1	0
Secondary school	7	3
2-3 year post-secondary? program	2	4
Bachelors degree	1	2
Annual income (CNY)		
None	4	0
<10,000	2	2
10,000-25,000	2	2
25,000-40,000	1	3
40,000-55,000	0	2
85,000-100,000	1	0
>100,000	1	0
Region type of residence		
Urban	6	5
Suburban	1	1
Rural	4	2
Travel time to hospital (hours)		
<1	4	1
1-2	0	0
2-5	7	6

>5	0	1
Primary mode of transportation to hospital		
Public bus	3	2
Private bus	5	2
Train	1	2
Personal car	1	2
Driven by car by someone else	0	1
Other	1	0
Relation to patient^C		
Spouse	n/a	4
Parent	n/a	4
Girlfriend/Boyfriend	n/a	1
First time in this hospital?	As a patient	As a family member of a patient
Yes	8	6
No	3	3
Degree of personal cost associated with the current hospital visit on a scale of 0-4, 0=no cost, 4=highest cost (median)		
Financial	2	2
Work life	0	1
Family life	2 ^B	1.5
Time	2	0.5

n/a, not applicable

^AOne family member did not provide data on region of residence. Another family member did not provide data on travel time or any type of personal cost associated with the current hospital visit.

^BOne patient did not provide data on personal cost on family life associated with the current hospital visit.

^CThis question was posed to participants in the family member group only.

Table 2. Doctor Characteristics

Characteristic	Doctors (n=9)
Age	
18-25	2
26-35	5
36-45	2
Sex	
F	1
M	8
Educational background	
Bachelors 5-year program	5
Masters	1
MD 8-year program	2
MD 11-year program	1
Title	
Resident doctor	7
Professor	2
Annual income (RMB)^A	
10,000-25,000	5
40,000-55,000	1
70,000-85,000	1
>100,000	1

Region type where doctor grew up	
Urban	4
Suburban	1
Rural	4

^AOne doctor did not provide data on annual income.

Thematic Analysis

We identified three themes that characterized tension in the doctor-patient-family relationship experienced by the study participants: (1) Trust degradation occurred before and during the healthcare experience; (2) The healthcare-seeking experience for patients and family members was marked by unmet expectations for achieving a basic understanding as well as powerlessness; and (3) Societal pressures on doctors contributed to a state of learned helplessness. These themes capture tension from three main viewpoints including the interpersonal dynamic, patients and family members' perspective, and doctors' perspective.

Box 1. Summary of Themes and Subthemes

Theme 1. Trust degradation occurred before and during the healthcare experience

- A. A baseline level of trust exists in the doctor-patient-family relationship
- B. Factors influencing a climate of distrust
- C. Factors influencing mistrust

Theme 2. The healthcare-seeking experience for patients and family members was marked by unmet expectations for achieving a basic understanding as well as powerlessness

- A. Unmet expectations for achieving a basic understanding
- B. Lack of a humanistic and patient-centered approach at various levels of the institution contributed to feeling powerless

Theme 3. Societal pressures on doctors contributed to a state of learned helplessness

- A. Acknowledgement of the difficulties of seeking healthcare
- B. Societal pressures
- C. Fear and avoidance of blame

Theme 1: Trust degradation before and during the healthcare experience

While patients, family members, and doctors recognized trust as germane to their relationships, they described multiple factors that, in a minority of cases, degraded trust.

A. A baseline level of trust exists in doctor-patient-family relationships

Patients had positive comments about their doctors, including one patient who expressed general trust in the medical profession. However, she had reservations about other doctors consulting on her case, given that her own doctor was most familiar with her case.

Sometimes you come across a doctor, when you ask him he doesn't really answer about your condition then it's not a good feeling, but Doctor J² I have right now... would explain things very patiently and clearly to me, some things you have to worry about, have to pay attention to, she'll even explain clearly the things that I don't need to worry about...the best thing about her is that she's easy-going, sees us in a serious manner, so I trust her.

... if I trust this attending doctor, I would be more or less a bit concerned about other doctors, firstly because I'm not familiar with them, haven't interacted with them before, so I would more or less worry a bit in terms of trust, unlike my own attending doctor, but if my condition requires doctors from outside to help then that's fine...in fact doctors, wherever they may be all work wholeheartedly for their patients...You can't say that doctors from other hospitals are not good, that's not what I meant!

- Patient 6, female, pre-operative

² Names were replaced with random letters to preserve anonymity.

Likewise, doctors believed that the majority of patients and family members are trustful of medical providers, and that it is a minority that cause problems with trust. To one doctor, this meant they come with genuine intentions to seek help for their illness but encounter inevitable challenges along the way.

For me most of the patients in China, the vast majority of patients are very good. He comes here to see the doctor, he definitely doesn't come here for like, to completely nitpick on you or something. For sure it's because they have an illness, so they come to your place to see the doctor, he comes with a kind of purpose, the purpose of seeing the doctor. So it's just that because during this process, I know, because I myself have brought my own family member to see the doctor before as well. Seeing the doctor is something that really challenges your patience, particularly in this situation in China.

- Doctor 9, male

Other doctors described a relationship with their patients that conveyed a sense of fulfilment and harmony, with only a minority of cases being the exception.

The doctor/patient relationship? How should I say it, it's quite ok, we can understand each other. Sometimes it's even like the relationship between friends, I have a patient like that, he's been staying at the hospital for quite a long time, it's like he's family, of course he really trusts me too.

- Doctor 3, male

...Only a minority of patients, a minority of family members may be very distrusting towards us, so under most circumstances we and the patients have a pretty good relationship.

- Doctor 6, male

B. Factors influencing a climate of distrust

Yan defines distrust as “the mirror image of trust, referring to one’s negative expectations of the other person in a dyadic relationship, or a person’s belief that the other person in the relationship will definitely not act in the former’s best interests” [15]. In certain instances, participants described distrust that negatively impacts the doctor-patient-family relationship from the outset. Doctors made initial judgments based on what patients say or do that might trigger defensive responses. Furthermore, the media was seen as a major contributor to the climate of distrust.

One family member, who worked at a different, smaller hospital as a security guard, described instances of malicious intent by patients that he witnessed.

If he really needs to look for it [trouble], sometimes when the doctor is admitting them, if you’re not careful about what you say, or the hospital’s leadership wasn’t careful when they were handling it, then it’ll give the patient an excuse to cause trouble... He’ll get more and more intense in arguing. So in this regard...it’s usually caused by the patient’s side.

- Family member 5, spouse, male, pre-operative

From the perspective of several doctors, distrust was seen as largely the fault of a certain category or “type” of patients and family members possessing malicious intent or a cynical nature.

[A] minority of patients, they would think, including from the time they stay in the hospital they feel doctors are there for some benefits or something, so they have that feeling of resistance, the feeling to reject us, they would think why do you doctors do it this way? For these family members, we quite dislike them.

- Doctor 3, male

Doctors experienced patients’ and family members’ questions in some situations as a reflection of lack of trust, rather than an intention to understand and participate in healthcare. One doctor made

a strong judgment against certain patients and family members whom he believed to be predisposed to listening to alternative sources. He interpreted the tension as arising from a disparity in knowledge between doctors and patients/family members, which translates to a difference in healthcare priorities.

It's really easy if you want to treat someone really well, but if the patient and family member are bad people then it's very hard for you to let them understand, they might have doubts about all your behaviour, when you perform examinations for them, they would show you an unpleasant face, even though they are not professionals, they simply don't believe you, but rather they would believe what other people say, they would sometimes say, "I heard that a hospital in Beijing has other treatment methods for this illness, can you consider this type of method?"...They might believe the information they searched for on the internet...[T]hey might ask you what does this mean, can I take a look at my blood analysis results...but this might not be critical, what's critical is actually in our hearts, and this is what we have to interact with the patient about...but they don't know, they would question us.

- Doctor 7, male

Two doctors described the process of both identifying and managing distrustful patients and family members. Based on his initial interactions with the patient and family members, this doctor described how he sought to make a judgement regarding their trust in the doctor and used that judgement to guide subsequent actions. Specifically, he described using the "medical services department," whereby conversations could be recorded in anticipation of future disputes.

This might have to do with the person, because in a lot of cases when we first meet the patient and patient's family member, we can roughly determine if he trusts us or don't trust us...It might also be that he's not a very friendly person to begin with, he's quite

rude or something, the type of person where he normally don't trust people easily, he definitely won't trust the doctor when he comes to the hospital. You can see in a glance this type of patient, his attitude toward the doctor...For this type of patient and family member, we give them special treatment, any situation where we talk we speak at the medical services department.

- Doctor 6, male

Another doctor discussed the use of technology by patients and doctors alike to allow documentation of their interactions when either party perceived distrust.[S]ome patients, as soon as they come over, they take pictures everywhere, record your audio, that type of person, you have to be careful with. For us, we have a special WeChat³, last time I saw on WeChat that talked about which few types of patients, once they come here, you have to pay attention to this kind of patient.

- Doctor 9, male

The viewpoints of doctors in turn reflected a distrust and prejudice toward certain patients and family members, giving the impression that they remained vigilant about those they serve.

In response to the climate of distrust in the medical relationship, one doctor wished patients and family members would take medical certification seriously by having faith in doctors' skills and knowledge, as well as their genuine intentions. That is, he refers to the need for both more confidence and trust in doctors.

For family members, I think no matter where they seek medical help, whether it's at a good hospital, or a regular hospital, I think they at least need to trust the doctor. Because

³ WeChat, a popular instant messaging smartphone app in China with group chat capability

after all in the medical profession, those who can become doctors are pretty alright. I mean for common sense stuff, if it's not some rare condition, generally we would know about it. Basic treatment principles, because after all the medical profession is a science, it's not just what you say it is...So I think, whether it's the patient's family member or the patient, the most important thing is to trust what the doctor says. Don't always go to the senior level with something minor, to see a specialist, right...[T]he doctors wouldn't use you as a guinea pig. He does thing based on his own standards, according to his own ability, he wouldn't do anything that exceeds his ability. That's how it is.

- Doctor 5, male

a. Influence of the media on the climate of distrust

The media played a strong role in influencing the level of trust in the doctor-patient-family relationship. There were different influences by news media versus television series.

Some people might be influenced by the media, because currently including on the internet, there are a lot of bad information about doctors, they might have been influenced by this information.

- Doctor 6, male

For example interference with media, I don't know whether you have read our papers here in China, most of the reports on doctor/patient relationships, regardless of whose responsibility it is, most falls on the doctor first.

- Doctor 2, male

One doctor situated the media in the larger context of Chinese society. Specifically, he believed that the media exploit the overall degradation of trust in Chinese society, generalize one example to the entire medical profession, and exploit the public's lack of medical knowledge. He

referenced two news stories that gained wide attention in China in which the media deliberately sensationalized isolated medical incidents that negatively impacted the medical profession at large. In the first story, a provider sutured shut a woman's anus after childbirth in retaliation for insufficient remuneration.

[The] tension between doctor and patient, it has a lot to do with the current overall social system in China, also the current overall value orientation in China, the entire value system, the entire leading effect that the media has on the public.

...The trust between person to person, because in these years the Chinese's humanity is not very good, so it created a sense of being on guard between each...The media uses this, in actual fact it's using this lack of trust to expose some highlights, to try and gain a topic that interests everyone. For instance, to draw an example, there's a doctor with the case for 'sewing up the anus for 8 cents', right? ...[H]e sewed up the anus for the woman in delivery...For these it's actually all, all not true, but after catering for this topic, everyone is like [“]take a look at this doctor...the doctor is a really evil doctor, they're just there for the money...They don't treat the patient like a human being, see what they did to the patient.[”]

- Doctor 9, male

In the second story, the media claimed that a provider was able to cure Hirschprung's disease for only 8 cents. However, the media failed to report that the provider provided only a temporary medical treatment for relief but not a definitive “cure,” which would require surgery. They incited the public to question the high costs of medical treatment—and the need for *surgery* in particular, which is not only expensive but invasive.

[“]Eight cents can cure a patient with a prolapsed anus, see I can do it with 8 cents, how come it takes a few tens of thousands of dollars for other doctors to cure it? I can cure

him with 8 cents, why is this?["] Because he has Hirschsprung disease, congenital Hirschsprung disease, using a type of laxative, I can temporarily relieve it. But this illness can't be rid of, it has to be operated on, they have to remove the intestine in this Hirschsprung disease, have to spend money. But the media doesn't care, he takes advantage of everyone's lack of medical knowledge... Take advantage of the lack of trust with everyone, actually it's through this lack of trust, that they intensify this contradiction.

- Doctor 9, male

For one patient, rather than inspiring distrust, the television media had a positive impact on her expectations about doctors. However, her actual hospital experience demonstrated that even a positive portrayal of doctors could have negative consequences by romanticizing the profession.

[T]here's a TV drama called "Young Doctors", that drama was really popular at the time...after I finished watching that drama, I thought wow, shouldn't doctor/patient relationship be like this? Like doctors think a little bit more for patients, then patients also change their perspective in thinking a bit for doctors, I thought wouldn't that be great. Then where there are areas that you don't know about, you communicate together about, I thought that's the way. Then after I got to the hospital, as I thought the acting was all fake...It was like that saying on the internet "the ideal is plump and voluminous yet the reality is a bag of bones." So I felt that there really is a certain discrepancy between reality and ideal.

- Patient 13, female, pre-operative

In contrast, despite having heard a news story about a patient death resulting in doctor-family conflict, one patient expressed empathy for and enduring trust in the medical profession. His

response highlighted potential high-stakes situations in healthcare where communication is critical to prevent dispute.

I just watched the news, firstly it's the doctors not having explained things clearly, the patient family member also has a lot of issues, spent so much money, yet the person was not saved, they have to let off some steam for sure, being overly concerned throws off your senses, of course it's hard to blame anyone. But the doctor gave medical care wholeheartedly, and worked hard, the doctor (better) explain things clearly beforehand, otherwise it's not good blaming him for a mishap either, excluding those who are looking for trouble.

- Patient 12, male, pre-operative

C. Factors influencing mistrust

According to Yan, mistrust is defined as “the perception of a former trust that has been broken or destroyed...Such mistrust may lead to feelings of being betrayed” [15]. Apart from distrust, which describes a negative bias upon entering the medical relationship, instances of mistrust over the course of the relationship were also described by participants. There were two major factors that led to mistrust. One was the patient or family member experiencing or witnessing an event of significance to him/her, such as disingenuous behavior, complications, or errors. A second factor was the presence of knowledge or communication gaps between doctors and patients or family members.

a. Experiencing or witnessing a significant event

The young patient who described a positive influence by television media on her expectations detailed multiple experiences with her resident doctor that jeopardized her trust in him.

Specifically, she described her doctor's disingenuous behavior. She detailed at length the pre-

operative consent process during which the patient's mother tried to advocate for the best care possible on behalf of her daughter. The doctor's unyielding attitude toward her mother's request, along with multiple interruptions during the conversation, made a strong impression.

My mum wanted to ask a few questions quite a few times, he [the resident doctor] said hold on, listen to me finish first, then went blah blah blah reading everything on there once. After he read it once, my mum said, because as parents we're very worried for sure, and nagged for a bit. Then he said, I know about these issues, you don't have to keep repeating this issue...After she waited for him to finish saying those things, in between this time, there would be phone calls coming in. Then he first took a few calls, after taking the calls it felt like his facial expression was like, like the type where he's not really patient...Then my mum said, but we still hope to have Professor U operate personally, then he said, he said then you still haven't understood what I meant. He said I'm a junior, I can't possibly make this kind of request to a senior. But actually my mum's meaning is only that she hopes that he can like, put in a good word or something to Professor U, hope that he could understand.

...My mum said, it's fine I can wait until he [Professor U] has time to do it [the operation]. He [the resident doctor] said, our ward vacancy would be very much in shortage, I can't possibly let you stay so long. Then my mum was really angry, said you're not arranging a doctor that makes me feel reassured, you're saying that the beds are in shortage you can't possibly let me stay so long, I can't help this, I have to be a bit selfish, I have to think for myself.

- Patient 13, female, pre-operative

Later on in the post-operative period, the same patient overheard the resident doctor (Doctor P) complaining about her case to a colleague, causing her to question the doctor's character.

After I lay down, there were people coming on and off. Then I don't remember whether that doctor was Doctor P or which doctor, in any case he said, said twice, like this patient, this young lady, had to have Professor U to perform the surgery for her, he mentioned it twice you know. So I said my God, I let him [Professor U] perform the surgery, so what, could that offend you?...This doctor is so gossipy, it made me speechless, I had no words to describe him you know.

- Patient 13, female, post-operative

The mother of the patient described the potential for regret and retaliation if her daughter's surgery had been performed by an assigned doctor other than the one she requested. Her response revealed that her trust—and capacity for forgiveness—lay in individual doctors rather than the group.

[I]n many areas where the doctor can't achieve, then I must do something, they said to have which doctor for me, have to request which doctor to perform the operation, if I can't even achieve this right, then I absolutely can't do it. If the doctor I requested made a mistake, I won't resent it, I think that if an accident occurs with the one that I requested then it's something that nothing can be done about, if it was another doctor treating her [my daughter] for me, and I'm not reassured, I don't trust it, if the doctor arranged for me doesn't satisfy me in terms of interaction and communication, then I would definitely do something about him...

- Family member 13, mother, female, post-operative

The mother later witnessed an interaction between the resident doctor (Doctor P, also known as the ward or junior doctor) and senior doctor (Professor U) regarding a medical error by the ward doctor that further compromised her trust in the former. It also revealed the family member's

positive appraisal of hierarchy in medicine in order to promote patient safety, as well as the catastrophic potential of any error.

[S]eeing that he's [Professor U's] coming over I wanted to find the opportunity to reflect what happened yesterday to him...so I said, "Professor U, yesterday my daughter vomited, it was particularly bad, what caused this? Is it because there was too much IV drips administered? 7 bottles were administered!" At the time Professor U looked at that Doctor P and used their internal lingo and said what's going on, what medication was prescribed? ... [Professor U] said this was a small surgery, don't let us have issues as much as possible. Even though we don't understand, but we can still see from that expression, there's definitely some error in the medication Doctor P prescribed yesterday...

...[E]ven though Professor U doesn't have time to prescribe medication, I think after Doctor P prescribed the medication, he has to consult Professor U's opinion... [B]ecause you are his subordinate, (you should) communicate to be on the safe side, right? Some things would lead to death with just a bit of error, you know? So just then I was really angry inside.

- Family member 13, mother, female, post-operative

b. Knowledge or communication gaps between doctors and patients or family members

In contrast to the previously mentioned view that knowledge disparity sows *distrust* from the outset, one doctor believed that it was a factor leading to *mistrust* during the course of the doctor-patient-family relationship. That is, the lack of medical knowledge among patients and family members contributed to inaccurate assumptions and conclusions about medical care and, subsequently, disagreement with the doctor's assessment. Importantly, he acknowledges the

doctor's part in contributing to tension by failing to mend the knowledge gap, which requires awareness and patience when communicating.

The patient has little understanding of medical knowledge, little understanding of illnesses, at the same time they have high expectations regarding the prognosis. And doctors are used to seeing these illnesses, he doesn't think it's worth, not willing to explain it in detail. Because from the doctor's point of view these knowledge are all really superficial, they think that everyone could understand it. The doctor didn't think from the patient's point of view. This kind of knowledge is unequal, so it created the lack of understanding and trust when the doctor and patient communicate and interact with each other, this is a root cause of the doctor/patient communication issue. First is the inequality of medical knowledge, second is that the doctor is sometimes too busy, might lack a certain level of patience. This is my main view.

- Doctor 8, male

Another doctor believed that family members may not be able to reconcile the doctor's appraisal of the patient's health status with how healthy or sick the patient appears to be, unless there is an observable change in how the patient is communicating. To him, it was the gap in medical knowledge—specifically the layman's reliance on visual cues to pathology—that fueled the family member's mistrust toward the doctor.

...[B]ecause they [family members] aren't professional medical staff, they've never gone through formal medical training, so they may not have a complete understanding of the actual situation, particularly in regards to the condition's seriousness, for example sometimes they think we're scaring them, exaggerating the situation...[H]e [the family member] would just see that the patient can interact with you on bed, think that they are still ok, like that, but in reality his lab figures indicate that it's [the condition is] already

really bad, but because he, say for example I'm a family member, if I can speak with the patient, he can still speak with me consciously, they would think that the patient is still alright...

- Doctor 2, male

One family member's experience to desperately understand her daughter's health condition in the absence of medical training or information demonstrated the reliance on visual cues. These included pathology and medical interventions. Here she compared the size of her daughter's tumor and intravenous (IV) medications with that of another patient's. Her assessment led to doubt about the doctor's treatment plan.

But yesterday she was administered a lot of IV drips, I saw that girl who got discharged yesterday, she was the same age as my daughter, but what was taken out of her was this big, it was bigger than my daughter's, so I had a comparison in my heart, when [that girl] got out [she] only had three bottles of IV drips administered, this might also have to do with the doctors managing the wards differently, other things are also not the same, but I don't understand this, I said how come my daughter had seven bottles administered? I was trying to think on the positive side, a lot of IV drips administered, the anesthetic is rid of more adequately, I would think that way, but she was so nauseous, the doctor said the discharge is today, so I thought is that a bit rushed, I said to the doctor does she still have to stay for another day tomorrow? To have some other injections for my daughter! He said tomorrow I don't know what other injection to give you, the doctor in charge of the ward said.

- Family member 13, mother, female, post-operative

For another patient, the visual experience was pivotal to aligning her understanding of the disease with that of the doctors in addition to making her feel that she understood her disease severity.

Despite being reassured in the pre-operative phase about the operation being minor, the patient needed to see the excised tumor to believe the doctors' words.

The doctors told me a lot, after the examination they said it was a fibrosis tumour. At the time it was said clearly, but I didn't see it, so I was worried, later on I came out, it didn't take a long time, and not painful, I saw a very small tumour, so I was relieved. The fellow patients they couldn't walk, move, it was painful. I think I'm really good, it's really a minor illness. In the beginning I still couldn't believe it, once I experienced it myself, I think it's really small.

- Patient 11, female, post-operative

Believing she had a minor illness was different from hearing it from the doctors and, in her case, enabled her to experience psychological relief.

Another doctor, having spoken with doctors at "grass-root" or lower level hospitals, described the knowledge disparity as a double-edged sword. In his view, lower level hospitals may suffer from more distrust than higher level provincial hospitals like the one he works for.

I think they [the doctors from lower level hospitals] mainly spoke about the fact that there wasn't enough trust for doctors at this grass-root level, it is thought that their standards are not great. Once they get to this kind of unit at the provincial level, and they come to this kind of well-known hospital at Xiangya, they feel like everything is taken for granted, that it doesn't matter. If the patient can't be fixed even here, then this patient is supposed to die. If this patient couldn't be fixed at a lower level hospital, he couldn't be cured at a lower level hospital, even if he is taken to a higher level hospital he still can't be cured. So they think that the doctors at the lower level hospitals are not up to scratch, for higher level hospitals this patient is supposed to be dead already, there's not much you can do to cure him, that's how it is. Maybe for patients currently, they still don't have

enough of an understanding of the medical industry. Perhaps medical knowledge is still not widespread enough.

- Doctor 5, male

In addition to knowledge gaps, communication gaps could also lead to mistrust. One doctor described two cases where parallel channels of communication could become problematic. One case is when multiple family members of the same patient separately seek information from the doctor.

A situation that makes people feel most exhausted is, the patient has many family members, between these family members the explanation is not clear, every family member comes and asks once, it really feels very tiring. The surgery is really tiring to begin with...after they asked they go back and communicate with each other and find contradictions again, and they can't understand, so they come back to ask again...this way the doctor feels really exhausted, and this process would create conflict. In the end it would lead to the lack of trust and coordination in both parties.

- Doctor 8, male

A second case of parallel communication, according to the same doctor, is when a patient receives information about insurance coverage from the doctor that turns out to be inaccurate.

Because the health care reforms have always been going on, so medical insurance has always been changing alongside, a lot of times the doctor's information can't keep up with this change. As a result, the communication on system issues with patients, would sometimes have huge variance. For instance after the doctor has completed certain procedures and talked about some issues with medical insurance, when the patient goes to claim insurance, new procedures are required. So the patient thinks it's a waste of

time and energy for him to run back and forth. He would think this doctor is untrustworthy or irresponsible, and this creates a lack of trust and understanding.

- Doctor 8, male

Theme 2: The healthcare-seeking experience for patients and family members was marked by unmet expectations for achieving a basic understanding and powerlessness

Instances of tension were marked by patients and family members having feelings of being underinformed about a basic understanding of their condition. Furthermore, they expressed powerlessness not only in the doctor-patient-family relationship but also the overall experience of seeking healthcare.

A. Unmet expectations for achieving a basic understanding

A central idea that emerged as a communication expectation and priority for patients and family members was to feel holistically informed about the patient's illness. Based on their actual experience, however, patients and family members were left feeling underinformed about a basic understanding of their condition. One patient's spouse describes the type of information he seeks and how he believes doctors can improve.

I also spoke about it before, the doctor has to tell the patient how this illness came about and what lifestyle habits led to it based on materials, what to pay attention to in future, there's a written material...To improve is to interact more...in regards to this illness.

- Family member 11, husband, post-operative

To this patient, being informed meant knowing detailed instructions prior to signing the consent form, in her case the steps in preparation for her much-anticipated surgery the next day.

It's like that type of nurse, when she was changing wound dressing for someone else she said to me, don't eat after 10 o'clock tonight, don't eat anything, right until tomorrow morning when you can have the surgery then you eat. I went blank for a bit, my God, shouldn't that be something I speak to you about when signing that surgery consent

form? ...[H]e [the resident doctor] just got you to sign your name, then read the conditions on there once, he didn't say this.

- Patient 13, female, pre-operative

For other individuals, being under-informed meant feeling that they lacked a holistic understanding of health matters. A middle-aged patient with a complex gynecologic history describes her contrasting reactions to two different doctors she saw at this hospital visit, a breast doctor versus a gynecologist. With the gynecologist, this patient's attempt to understand the implication of her technical diagnosis was met with condescension. Moreover, she felt that the doctor had failed to communicate a basic understanding of the plan to her.

For the breast, the Professor X here spoke to me quite well. Professor X with us, in the beginning she saw it with the naked eye, touched it. Then took a look at her results then she had me have this microsurgery. If it's in the area of gynaecology...[Doctor V] said there's a high degree of pathological change, if it's pathological changes then I just wanted to take a look at that booklet, then he said what is this you're reading? You don't understand it anyway. I first asked what this means, what extent is the high degree pathological change actually, whether it requires this hysterectomy, or it needs some medication or something. In any case he wouldn't let me read it, you put it there and don't touch it, you don't understand it anyway, the doctor would tell you.

...I feel depressed, feel uncomfortable...I'm really dissatisfied they treat me this way. Feel as though I shouldn't have come here myself...It's after the examination, that I want [Doctor V] to give me a clear answer. What the situation is roughly, whether it's serious. Whether a little bit of precaution has to be taken, or to have an operation if an operation should be done, for you stay to at the hospital...

- Patient 8, female, pre-operative

Sharing the sense that they lacked a good understanding, the following two unrelated individuals, a patient and a family member, still felt under-informed despite being able to recall specific instances of communication with their doctors. Their responses suggest that the doctor's communication was not directed enough toward the patient/family needs.

For my condition, I don't really have a good understanding. I just know that I had a lump, and I could touch where it is, I don't know about other things. Because previously on the night before yesterday before Professor B performed the operation for me, he came to visit ward, he took a marker and drew a circle on my body, he said that in time he'll make an opening from here, then drew a circle, as in drew a circle around the lump, squeeze this over then it'll be gone. I said so that's how you perform the operation. There was nothing other than that.

- Patient 13, female, post-operative

Although he expressed that his doctor was patient and nice, the following family member said that he had expected to be more informed before coming to the hospital than he now felt (quotation not shown). One contributing factor may be his awareness that the doctor had received reports that the patients and family did not, giving the impression that relevant information remained out of their reach.

It feels like we don't even know what the specific outcome is from his surgery. Just know that he removed it entirely. And usually those reports are just a piece of paper, right, we go and take it ourselves. There are some reports that are directly sent to the doctor, we don't know about it at all ourselves.

...I don't feel good about this. Feels like sometimes like you as a patient family member, you're very anxious about the condition for sure, right. The doctor would only tell you

what you need to do, he wouldn't tell you how your condition is actually like, what you should do, or how to treat it. He wouldn't tell you.

- Family member 9, husband, male, post-operative

In addition to feelings of disappointment about how much they were informed, some patients and family members associated their unmet expectations with the large amount of resources they invested into the healthcare experience. The woman who saw both a breast doctor and gynecologist, and who traveled 4-5 hours to reach the hospital, describes her expectations coming to the hospital and contrasts it with her experience.

In my imagination, the doctors at this place you should, because we are patients, we come to their hospital to give you money. I spent some much money, I definitely have to get a satisfactory answer. However beyond my imagination, I spent so much money, they treated me so, like not a bit (of good) at all.

- Patient 8, female, pre-operative

In my expectation it wasn't so slow, I thought you have it examined then the results would be out, in my expectation it wasn't so slow, didn't think I have to wait for so long, almost a month, it's really cumbersome...I also didn't think it requires so much money, going to this big hospital...The room we stayed at was in poor condition, there was no bathroom or toilet, there wasn't even a phone to press after you have an injection, it was a mess, the money for it was so expensive too.

- Patient 8, female, post-operative

The following two family members' accounts demonstrate the powerlessness they felt about being able to achieve an adequate understanding of the patient's condition.

...Feels like I don't even know how he has to treat this kind (of illness), I'm not sure. So I don't know what I want to know either. Sometimes when I go and ask the doctor I don't know how to ask. Just feel that I don't understand.

- Family member 9, husband, male, post-operative

...Because there's some professional aspect to this condition, so we generally can't see it, so for this only the doctors would know, whether the doctor is truthful in this, whether he presented the whole situation to us comprehensively we have no way of knowing, whether he told us about the entire actual situation or told us partially, at the moment we're still not sure about this. In terms of the situation with examinations now, he did tell us, but whether he told us everything, we're not sure about this in depth.

- Family member 5, husband, male, post-operative

The second account also alludes to a sense of distrust that the individual may have toward the provider. This distrust, as discussed in Theme 1, seems rooted in the gap of both knowledge and power between layman and professional. The two accounts also demonstrate an association between feeling under-informed and powerlessness, which will be discussed in the next sub-theme. That is, while they desired to know more, there were interpersonal barriers preventing them from reaching a more informed state.

B. Lack of a humanistic and patient-centered approach at various levels of the institution contributed to patients and family members feeling powerless

While being under-informed was apparent from the lingering questions and concerns voiced by patients and family members, another undertone to their statements was being in a position of powerlessness. Not only did they face the challenge of understanding their disease and its impacts, they were entering the healthcare system, a large and foreign world that felt

overwhelming at times. At the interpersonal and institutional levels, patients and family members felt a lack of concern for their plight, yet they also felt powerless to change their circumstances.

a. Interpersonal level

Two main emergent themes about the patient and family member response reflected tension at the interpersonal level: feeling a lack of concern or empathy by doctors, and having an attitude of deference towards doctors despite lingering concerns.

To preface this data, it is important to note that there were also experiences of empowerment among the participants. For instance, this patient from a rural village whose financial power and lack of a family member as advocate motivated her own information-seeking initiative:

For myself I should be really clear, I paid the money myself as well, I asked about any illness by myself, just then I just told you my husband's Putonghua is not really good, he just accompanied me, I had to ask by myself if there was anything, me and the doctor spoke, and he accompanied me by my side, there's not much else, I'm very clear about things about myself.

- Patient 10, female, post-operative

One family member, the daughter of a female patient, shows how her expectations were unmet regarding the way she and her mother would be treated. She noted the little time and attentiveness the doctor could provide compared with local doctors back home. Notably, the patient had a friend who was an employee at the hospital and played a major role in coordinating her healthcare, including communicating with the doctor. This case is an example of the important role that insiders play in bridging communication between doctors and patients/family.

At the hospital back home, I feel that there would be fewer patients, the doctors would ask a bit more, be a bit more detailed in observations, to begin with (here) there's a lot of

patients, didn't see a lot of doctors, so it wasn't as welcoming as I thought it would be, like me being here, the doctor hopes to get the operation done as soon as possible, recover as soon as possible then you can be discharged...So that he can perform the next operation as soon as possible, to help the next person.

...[I]f it's based on my expectations, maybe he [the doctor] would interact with us a bit more, be more attentive and inquire a bit, but in fact there wasn't, I don't think there was much interaction! Perhaps my mother's friend has already explained some situations to him...

- Family member 7, daughter, female, pre-operative

One patient, who had traveled 4-5 hours to reach the hospital, felt that the doctor did not fully appreciate the position she and her family were in by seeking his medical care.

I think the doctor has to have a better attitude towards us, because after all we are here to see the doctor, we came for a favour, don't put us to the side with a single word, this attitude has yet to be changed...For instance I asked a question, I don't wish that they have that kind of hostile language, I think it should be warmer, more gentle, interact with us patiently.

- Patient 8, female, post-operative

The patient's husband echoes her opinion by adding that he hopes doctors can provide equal, unbiased treatment for all patients.

I hope when doctors face patients, no matter what identity and status this patient has, whether he has money or not, he's a wealthy man or a beggar, I hope they can receive equal treatment from the doctor during the process of seeking medical help.

- Family member 8, husband, pre-operative

The same patient felt uncared-for by various doctors during her time in the hospital, showing how the collective attitude of providers she encountered throughout her time had a negative impact.

This experience was quite difficult...Like for today, I'm really taking that MOBA⁴ today. Like that imaging for breast, maybe a chest radiography. Supposedly that Doctor Z, had me, he said these things are done on the third floor. So on the third floor, we asked every single doctor. Went to this place and asked, I said this thing is here, "We don't do it! We only do this chest radiography." OK so we went to that place and asked, do you do MOBA? "We don't!" All the doctors on the third floor. When it came to that doctor who does colour ultrasound, I asked the doctor, where is the place where you MOBA. He said, third floor, he said where did your doctor say to do it? My doctor said to do it on the third floor. If your doctor said to do it on the third floor then go to the third floor to do it, I do colour ultrasound, we can't care so much. So today was the most embarrassing for me, today I felt the worst.

...They always think that, it's as if every doctor only cares about themselves, like what you ask has nothing to do with me, so I won't tell you, even if I knew I'm not willing to tell you. That's how it is. (They) don't talk to people, don't provide convenience to people.

- Patient 8, female, pre-operative

Likewise, another young female patient juxtaposes her observations of the doctors as a group with those of the nurses. Their nonchalant attitude towards patients contributed to her overall negative impression of the hospitalization experience,

⁴ MOBA, mammogram

Make a bit of time to go to the ward to take a look... chat less with colleagues sometimes, or with the time you [the doctor] have a cup of coffee, go to the ward to check on patients, to see what needs patients have. I think this way, at least it wouldn't feel like the hospital is a cold place, feel like there's not much of a sense of humanity...It's not expected that you are extremely serious and careful in getting a particularly good understanding of others, but you should still need a simple understanding. I stayed in the hospital for these few days, I was really bored, so would go around for a bit, every time I get to the office, some doctors are smoking. They prohibited smoking in the hospital, yet he's openly smoking himself...I thought my God, the nurses are so busy, going around changing medication for others, and the doctors are smoking, chatting and drinking tea when they don't have anything to do, otherwise they're holding their phones.

- Patient 13, female, post-operative

The same patient also compares her expectations with her experiences of interacting with doctors, beginning in the pre-operative phase. Her expectation of passionate, familial and morally-driven doctors was instead met with a business or transaction-like interaction with the doctor.

Strangers, particularly with the saying that doctors treat the sick as their own children, I think I didn't see that.

- Patient 13, female, pre-operative

...In (my) imagination even if everyone met for the first time they would definitely, be a bit more polite or because you're a patient, as a doctor they should show concern for you. But in reality it wasn't like how I imagined it, there were some differences. For the doctor it felt like, it made me feel that the doctor isn't passionate about his own work, like he's working for money, like it's purely just a job. Also he acts quite cold.

- Patient 13, female, post-operative

Both the patient and her mother expressed a lack of empathy from their doctor. They felt the doctor did not treat the patient with the kind of concern a parent would treat her child. Rather than reassuring them, the doctor's responses delegitimized their illness experience and care-seeking efforts, which alienated the patient.

He [the doctor] just started, (then he said) oh you're such and such (a situation)? Then he said it's fine, he kept repeating, it's fine this is a small operation. Then my mum said I'm an only child, she said such and such, so she's definitely very concerned, even if it was a small surgery she would be very concerned. Doctor A said well that's you not understanding this kind of situation, we've done this operation many times here, we've had many of these. He also said that there was a 13-year-old girl, who had a lot of lumps in her breast, think it was 5 or 6 lumps, after the surgery she was fine, blah blah blah. So it felt like, there was this feeling that I was pretending to be very vulnerable, so I didn't listen to what he was saying.

- Patient 13, female, post-operative

I think, the doctor has to stand on the patient and parent's side to think, for instance I didn't ask about something because I didn't know about it, didn't arrange it, then that's fine. If the parents know about some aspects, but they keep saying it's ok, it's ok, the operation is really simple, you can come out in a few minutes, other doctors are the same, then I'm annoyed when I hear this, I'm really annoyed, I think that they don't have concern for my child, I think that this operation is just like killing a pig, it's just making an incision and taking it out anyway, then sewing it back up, as a parent, my daughter's lifelong happiness...

...So I think in this regard the doctor can't have their own way, this kid isn't having a very big surgery, it's really simple. Put yourself in one's shoes and try it out with your own kid.

- Family member 13, mother, post-operative

The mother recounted in detail her efforts to secure the professor of choice to be her daughter's surgeon, showing that her confidence and trust were narrowly focused on an individual rather than the profession. However, the barriers she faced in achieving that goal demonstrate the struggle that was regaining control over her daughter's care. These barriers included the medical hierarchy, the difficulty in reaching the professor and his vague response, and potentially her position as a woman making the request to a male surgeon.

[I]n my heart it has to be 100% without errors, so in the end I chose [this hospital], in the afternoon I came over to stay at the hospital, so we asked that professor to see us, right?...[B]ut we didn't think that yesterday afternoon there has to be another doctor as replacement...I asked around here and heard that it's a doctor in advanced studies, to them those in training and advanced studies all learn from an apprentice level, but I have to be responsible to my kid...in case something goes wrong, then that's it for the rest of my life, so I said no, I said it won't do asking any doctor, I'm here for the professors...[H]e [the ward doctor] said whichever doctor here are all the same. I said yes, to you hers is a small surgery...I just hope as a mother, I hope you can understand me...[I]n the end he said then you go and communicate by yourself, he said he doesn't have time...I said can you do me a favour, can you request this professor to do it for me, he said he's a subordinate, I don't have the authority to do much.

...[S]o I went to the outpatient clinic by myself and found that doctor...I said professor can I bother you for a second...When can you personally perform the surgery for me, he

said if you're staying at the hospital then it's fine, our department would arrange, I would also go there and take a look...go out go out, I understand him as well, after all there are so many patients he has to see.

...[M]y husband came over in the afternoon, I got my husband to look for that professor again, I said this time I go he wouldn't be happy with it, I said you're a guy, looks like there's a bit more weight to it, so my husband went, when he came back I said what did he say, He said there's no time tomorrow, otherwise you set it to the day after tomorrow, I said ok...[R]ight now in this situation I'm just waiting here, no matter what the professor does I still trust his profession, whatever there is in future it's determined by fate, it can't be helped.

- Family member 13, mother, pre-operative

The mother brought up the subject again in the post-operative interview. Her suggestion about how doctors could approach family members' requests highlights the impact of communication delivery on family member satisfaction.

...[O]f course if the doctor could treat every patient as their own relative in this regard, when they communicate, to satisfy us patients' wishes as much as possible, for instance you can explain slowly, for instance if you must get Professor U⁵ to perform it, it can be done, but you have to wait patiently, like that Doctor P said then you have to wait a few days, then I'll wait for a few days, if you wait for a few days there aren't any vacant beds, so it's your problem for staying here a few days, so I was really annoyed, you know?

- Family member 13, mother, post-operative

⁵ The same professor (Professor U) and ward doctor (Doctor P) as referenced by this patient-family dyad (13) in Theme 1.

While patient-family dyad 13 is notable among the participants for being persistent and self-advocating, the patient recognizes that this may not be the case for everyone. She believes patients without high health literacy are especially disempowered and urges them to educate themselves about medical decisions in order to help prevent bad outcomes. Her account also suggests that while she has a baseline level of trust in doctors, she is wary of some doctors' condescending and "casual" attitude about informing patients, which she finds to be disrespectful to patients and detrimental to the doctor-patient relationship.

[A]s a patient, if you don't have a good understanding of doctors to begin with, then he might very blindly obey the doctor and do what he says, that's why there would be so many of those medical cases where mistakes were made...They [patients] should go and get an understanding of knowledge or relevant content in this regard. Then combine it with what the doctor says, change their perspective and think about it from the doctor's perspective. Like if that doctor says this, then it definitely is beneficial for me, so I definitely would look up information by myself and think that what the doctor says in this regard is very true, then I should have to obey what the doctor says.

The most important thing is that I still think that doctors are an occupation for saving people to begin with...So I think that the most important thing is that the doctor should have, can't say a kind heart, but have a heart in respecting others. You can't say that you know more than others, so you feel that you're a cut above, like this type of stuff is a small case in my eyes, how come you don't even know this. Like the type that casually briefs about something, I think that this won't do. This would only make (the relationship) between doctor and patients worse.

- Patient 13, female, pre-operative

In contrast to the self-advocacy and empowerment demonstrated by her and her mother, the above patient alluded to the attitude of deference by other patients and family members towards doctors. Knowing how busy and stretched the doctors were, patients and family members withheld their questions and concerns. One patient noted the lack of interaction with doctors in the post-operative phase despite her discomfort with the intravenous fluids.

They finished work already, I didn't see anyone in person, waited till past 2pm then a nurse came to give me an injection, that lasted until 12am, it was meant to finish at 5pm, when it came to the last bottle of water I felt unwell suddenly, in the end it really got very, very slow, one bottle of water took 5-6 hours, so it went on till 12am, then my husband said he couldn't wait anymore, he had to go to sleep, so I told the nurse to unplug it. The whole day yesterday I didn't really interact with the doctor, they have so many patients anyway, if you kept looking for him and nagging it would just be counterproductive, he's got too much to do, once it's done if you feel fine then you won't need to find him, if there are too many people he'll be annoyed.

- Patient 10, female, post-operative

Likewise, when asked about her expectations for the amount of time the doctor should spend communicating, this patient acknowledges the doctor's workload. Yet, her expectation is potentially at the cost of gaining a deeper understanding of her condition.

In any case I just need to get a rough understanding of my situation, because the doctor is quite busy after all, don't take too much of their time. There are so many patients.

- Patient 8, female, pre-operative

One patient's husband, despite being dissatisfied with his current understanding of the patient's condition, resorts to rationalizing the lack of communication from the doctor rather than directly addressing it.

I can only say that it doesn't seem to be ideal. Because I want to know whether her condition is actually serious or less serious? What's the detail situation? Because we don't have any idea, even now I don't have any idea.

There shouldn't be a big issue, I mean it's not really a problem. That's what I'm guessing, because if there were any more issues the doctor he should have to let us know.

- Family member 3, husband, post-operative

Later in the interview, while commenting on the effectiveness of the doctor-patient-family communication, he also takes personal responsibility for issues. That is, he cites his and his wife's lack of communication skills.

At the time this was actually probably my problem, because we, both me and my wife don't know how, how to communicate. So we're probably not too (good) at talking. Particularly with these nurses sometimes. That's probably our problem, as the doctor he was alright.

- Family member 3, husband, post-operative

His statement demonstrates that while patients and family members may desire to become more informed, they do not necessarily perceive themselves as empowered to do so. It highlights a potential role for providers to take on a more patient- and family-centered approach to accommodate their information needs and create a mutual dynamic.

b. Hospital level

While interpersonal interactions at times lacked a humanistic or patient-centered approach, patients and family members also saw the process of navigating the hospital system in this way. Two emergent themes at the hospital level included the inconvenience of the system and the difficulty of obtaining the best care due to inexperience.

Inconvenience centered on unknown timelines and their impact on the rest of the patient or family member's life. This patient, who traveled 2-3 hours by private bus to reach the hospital, comments on the inconvenience of the admissions process and reaching a doctor, particularly for people coming from out of town. She imagines having a direct phone number for the doctor would alleviate some of her concerns.

If there could be great order when I'm seeing the doctor...if they can improve the reservation queue number if they can push it forward a bit more, enable reservations in advance, as long as I don't have to wait here for too long...Another thing is, with the doctor, say my own attending doctor, if there's a phone number I could always communicate information with, where I can ask about my condition...if I can call him in advance, then make an appointment, or ask about my condition, when I need to come for a check-up, if there's a channel to deal with these matters that would be good. I think these people who came to see the doctor wouldn't need to come and find there are no doctors today, tomorrow they come and find there are no queue tickets or something.

- Patient 6, female, pre-operative

Another patient's husband comments on the impact of unknown timelines in the discharge period—an inconvenience that causes him anxiety and worry. Yet, he recognizes that it is a systemic problem stemming from the lack of standardized procedures, not the doctor's problem. Like the previous patient, he traveled 2-3 hours to reach the hospital.

I hope the hospital, it isn't the doctor's problem, the hospital should set some institutional provisions, because after all it's a provincial hospital, these patients may not be from surrounding areas, most are probably outsiders... We still have to drive a few hours to get home, if it's taking public transportation that's even more of a hassle... If the doctor tells us from the start, you can make payment tomorrow at 11 o'clock, then we'll have an idea in our head, we wouldn't be so anxious and worried, waiting 'til we feel this way, if you set some institutional provisions that this has to be done at 11, then people wouldn't have any expectation, they won't expect, so if they could be more standardised in this regard, then we could be more assured. Then after receiving treatment and being hospitalised, no matter what the outcome is, people can return home in a good mood.

- Family member 5, husband, post-operative

In addition to being an *inconvenience*, the healthcare-seeking process for patients and family members was hindered by inexperience. In the context of communication deficiencies within the hospital, their inexperience led to difficulty and frustration with finding what they considered to be the best care.

One patient is frank about her inexperience in the pre-operative interview: her response to the question of which healthcare providers she hopes to participate in her care shows a lack of manifest expectations.

Just me and the doctor in charge of me. I'm not familiar with anything here, I don't know which doctor is good... I've told you everything, I've just been to the hospital for a day, there's a lot that I don't know about.

- Patient 3, female, pre-operative

Her lack of manifest expectations echoes Family Member 9 cited above who admitted he did not know what questions to even ask the doctor to gain a better understanding of the patient's condition. That is, he lacked manifest expectations about what it means to be well-informed. Because of their inexperience, these individuals potentially lack the power to effectively advocate for themselves.

For another patient's husband, inexperience with time delays in surgery coupled with the lack of communication during the operation were a source of distress.

It was like this yesterday, we went in the operating room at 7:30, it's supposed to be a minor operation, it should be done in an hour, but it went on until 10:30 when we came out, we were all very nervous, didn't see, couldn't find the doctor, couldn't find my wife. Later on my wife said that they were queuing up there, it has to be like that, there were so many people having surgery. The people waiting outside were really anxious. It would be good if there were a screen for the operation, to say who's having an operation. That would make people feel a bit more certain, because having an operation is a risky matter.

- Family member 11, husband, post-operative

For another family member, the difficulty of finding a doctor and then getting his wife admitted to the hospital caused him to become angry with the doctor. However, the fact that his view had changed after spending some time in the hospital and witnessing its high patient volume shows that unrealistic expectations played a role in that initial anger. Furthermore, the family member's reliance on the doctor to arrange his admission shows the burden of administrative work left to medical providers.

We looked for them [the two doctors] but we don't know them, so we contacted him on the phone, we don't know anybody. So we kept calling him. After that we came here directly to look for them and found this one. The day we found him, he said we have to

wait here, we waited past 9 o'clock. At the time I lost my cool for a bit to be honest, I got a bit angry.

...I said you [the doctor] kept saying there are no beds when I call, but what I understood when I came to the reception the other day was, it was another person, I think he said there were vacant beds, I said I called him and he said there weren't any, now they have beds here, so of course I thought, I felt a bit angry, how can they be like that? ...But the people in this hospital seem to have an understanding that these few days, there really were, there were no beds, it's at full capacity. That's the truth. If there are no beds, then there really are no beds. Maybe I mistakenly blamed them back then, I mean when I was angry.

- Family member 3, husband, post-operative

One patient raised an important point that her difficulty in achieving her goals was related to not having a personal 'insider' contact in the hospital.

Next time if I don't feel well I wouldn't come to this hospital again, I'd go to another hospital...It's hard to get things done here, perhaps I don't have any acquaintances here, if there aren't acquaintances then you take a lot of detours, also spend a lot more money, waste a lot more money...[O]thers might think it's not hard, personal channels are different anyway, after all for us we are from a rural town, perhaps it has to do with this, it was hard to find a suitable doctor, to find a suitable answer.

- Patient 8, female, post-operative

By contrast, another patient and her daughter relied on a close friend who is an employee in the hospital to handle the patient's major healthcare matters, including directly communicating with the doctor and vetting the hospital as a whole. As an insider and personal advocate whom they

can trust, their friend's literacy in the healthcare system served as a proxy form of empowerment. At the same time, his middle man role reduced the doctor's direct interactions with patients and family members.

There hasn't been much interaction with the doctor, he'll just talk about stuff that he's responsible for, that's about it, because my mother has a friend who works in finance at this hospital, and he has this experience, so he told my mother almost (everything), so when we saw the doctor we didn't say much.

- Family member 7, daughter, pre-operative

My mother was having the operation yesterday from 7:40 AM right till 4:30 PM. So when it became really long, we waited outside...So my mother's friend rang and asked that attending doctor, he rang quite a few times.

...The effect that [my mother's friend] had was even greater than mine. Because he works at this hospital, so when there are people from my mother's family who needs to take some medical exams, who are sick, he would help make appointments and stuff, help with the admission process for hospitalization...so we trust him quite a bit, right? I mean if you came to the hospital on your own you wouldn't even be able to find your way, even if you made an appointment you wouldn't know where to stay in the hospital, you wouldn't know what procedures you need to go through.

...[B]ecause he [the mother's friend] has a good understanding of this attending doctor's medical technology and surgical technology, that it's quite alright, like they are quite experienced in this operation, so he asked the doctor, told the doctor about my mother's situation, hoping that the doctor would try to help my mother's situation as much as possible.

- Family member 7, daughter, post-operative

The above excerpts demonstrate a disconnect between patient and family member's expectations or hopes and their actual experiences navigating both the system and the doctor-patient-family relationship. While some blamed the doctor for their disappointment, other individuals recognized the systemic nature of the tension—including those who adopted a deferent attitude towards doctors. We next turn to the perspective of doctors to gain an understanding of some of the factors, in addition to the trust degradation already discussed, they see as contributors to tension in the doctor-patient-family relationship.

Theme 3: Societal pressures on doctors contributed to a state of learned helplessness

Doctors acknowledged the difficulties patients and families face in seeking healthcare. Yet they felt pressured by societal challenges that rendered them unable to meet all the communication needs of patients and their families. Challenges included reduced accessibility of doctors and struggling with problems that are out of the doctor's control. Doctors also expressed a substantial fear of liability that directed their communication behaviors. Their experiences describe a state of learned helplessness, a psychological state whereby an individual descends into feelings of loneliness and futility after repeatedly failing to receive rewards where they should be forthcoming or deserved [38].

A. Acknowledgement of the difficulties of seeking healthcare

While patients and family members felt at times that doctors failed to recognize their plight, doctors did express empathy in their responses. One doctor is aware of the two main concerns of family members, which correspond with the first sub-theme in Theme 2 (unmet expectations for achieving a basic understanding).

For family members, there are two issues that family members are concerned about. The first is funding, this is for sure, because he's definitely concerned about the issue of spending money on treating the illness...The second, is the issue of patient prognosis, this patient has had this surgery, how much longer can he live later on, how is his situation later on?

- Doctor 9, male

Additionally, being familiar with the healthcare system—and having been a family member to a patient before—allowed him to empathize with the way inexperience contributes to unachievable goals. Furthermore, his account suggests an actionable step for providers to prevent

disappointment by helping patients and family set more realistic expectations about what is to come.

In China because we don't have an appointment policy...He [the patient] hopes that in one day, I can get everything, the examinations that I do, I can get the test results...[B]ecause a lot of these patients are rural patients, he doesn't understand the complexity of medical care, so he, when he comes he might say to you, "Oh doctor, you have to give me an answer immediately." At this point of time, as a doctor, you have to give a detailed answer to the patient, explain this situation to him clearly. Because his emotions, fluctuates sometimes...[S]o in China the vast majority of patients, his state of mind, his state of mind when seeing the doctor is understandable.

So the key is in you as a doctor, or a nurse, all medical staff, not just including a clinical doctor like me, it also includes medical technician staff performing CT, medical technician staff performing biopsy...also have to have a communication with him, tell him about the situation...But we'd say, not ruling out those very few patients, he is of poor quality, there really is this type, there are some patients, but it's a rare occasion. So I think in this case, as long as you fully communicated with this patient and his family member, the tension in the relationship, you can completely say that this is minimised to a very low level. Sometimes it can even avoid this tension in the relationship.

- Doctor 9, male

Likewise, another doctor recognizes the importance of empathy when interacting with patients and family members.

[D]octors might really need to reflect on some situations, so in the process of us communicating with the patient, are all the problems occurring on the part of the patient and patient family member? Actually if you think about it it's not, because if the doctor

himself or his own family member is ill, if you don't understand you might also have anxiety psychologically!...Because between doctors and patients there is an inequality in knowledge, also we are positioned at a higher place, so we have to be more patient in communicating with patients.

- Doctor 8, male

These two doctors, one a resident and the other a professor, acknowledged the role of the doctor's good communication approach in helping the patient become informed. However, they have different biases regarding the ability of a given patient to understand medical information. Their contrasting perspectives and confidence in dealing with patients of a lower education may reflect a difference in their own backgrounds and levels of experience. The second doctor's account also shows the importance of bedside manner in cultivating a good relationship.

This [how informed the patient feels] probably has a lot to do with education levels, for example some university lecturers with a high level of education, or those who have been through high levels of education, they are very clear on our explanations, but in contrast those with little education and have gone through very little schooling, however you explain it to them, they would still be unable to truly care. In this aspect our approach is a little lacking...

- Doctor 2, resident, male

[C]ommunicating with patients, this has nothing to do with how high or low your level of culture is...for instance there are lots of rural patients in the rural villages, his level of culture is low, but you can't say his quality is low. With level of culture, it's the person's, how should I say it, personality, that's right, this patience, has to do with his quality. Some people might be really wealthy, he studied a lot, but he is of poor quality...Many in the rural villages are like, even though they are not cultured, but this person is really

genuine, honest, extremely nice to you. He can't understand some knowledge, because I myself come from a rural village, I can actually communicate really easily with this kind of patients. Why is that? Because usually I have a very kind attitude towards patients, sometimes hold his hands, pat him on the shoulder... Sit together with him, very friendly actions sometimes. He can understand your situation. So for this low level of culture and quality, I think this isn't a barrier for you communicating, you know.

- Doctor 9, professor, male

B. Societal pressures

Doctors express that they have insufficient time to meet the needs of each patient and family or even their own communication goals due to factors out of their direct control. One doctor compares her brief time in the United States as a visiting surgical trainee with her current work as a surgeon in China.

[F]or surgeons it's all very busy, it's extremely busy every day, have to perform surgeries for patients, also have to arrange time to see outpatients, these are all the same. It's only that for them [American surgeons] perhaps they would be a lot more careful in terms of communicating, because I see that the time they interact at the outpatient department would be extremely long, not like us with only a few minutes.

...I think perhaps there are too many people in China, so I don't have that much time to communicate and interact with patients. If there were only a few patients, I would also spend a lot of time to communicate and interact with them.

...I would speak to him about every aspect, including their life, including some sex life for women I would have to talk about, including some issues on how to recover, then I can

talk about a lot, like right now I can only talk about this illness, discuss a few relevant questions with him, there's no way to talk to him too much.

...I think this is sort of going with the flow, if there are already lots and lots of patients, I just adapt to this type of situation in China, satisfy patients' needs toward illnesses as much as possible, as to other needs, I don't have a way to satisfy them, because time is limited, that's the only way it can be.

- Doctor 10, professor, female

Her attitude towards her current situation suggests learned helplessness toward the demands of her job, despite being in a position of relative empowerment in the medical hierarchy as a professor. Another doctor expresses a sense of insecurity and helplessness in the face of the complexity of contributors to tension in Chinese doctor-patient relationships. However, he admits that his inexperience provides relative shelter to the most extreme instances of tension.

Actually I think the medical profession in China is rather complicated, there are lots of issues that can't be discussed, and I think there is so much tension in doctor/patient relationships because one is an issue with the patient, one is also an issue with the hospital, but for the issue with the hospital, as a junior doctor I can't really talk about it, but I can feel this, the entire medical system has a bit of an problem, with my intelligence I still can't analyse it, where it actually went wrong, but I think it shouldn't be like this, doctors shouldn't be made to feel a lack of security, but this kind of thing still hasn't happened around me yet, so my sense of security is still sufficient... [I]f you ask me, I don't know anything, I just feel insecure, unsure, sometimes feel really tired.

- Doctor 7, male

Despite not personally having experienced severe tension, the resident doctor's comments convey a sense of burnout from a lack of control over his circumstances. Moreover, his colleague's response shows his helplessness in dealing with disputes when they do occur.

Of course for doctors, we doctors here won't get mad easily, but after being attacked on a personal level by the patient, we may sometimes speak in an extreme manner. But that is not advisable, after all when that happens no one really has a standardised way of approaching the matter. It's hard to have a standardised way to solve this kind of issue.

- Doctor 4, male

The above doctors' responses further support the need for systemic change to address the complexity of the tension. This doctor makes a plea for just that, yet he hesitates to provide a suggestion given his lack of power at higher levels.

Under the bigger environment in China, the doctor/patient relationship is not that stable, perhaps the government needs to work harder, to increase the trust that patients and patient's family members have with doctors, I hope that there is more trust, further increase their trust!

...I'm not a decision-maker, I won't discuss this, I can't say too much.

- Doctor 2, male

While the above doctors were unable to provide specifics to address the problem, others did identify systemic issues that needed to be fixed. One doctor believed that the insufficient health literacy of the public must be addressed so that patients and family could triage themselves to the appropriate facility. He believed this would alleviate the over-crowding in hospitals, financial burden on patients and family, and ultimately workload of doctors.

[U]nder this kind of medical environment, I think the most important thing is to disseminate medical knowledge. Everyone should be able to understand these minor issues, and which places they can get it seen. As long as we don't need to guide patients when they come to the hospital...If it's a relatively complicated condition, a rarer condition then you can go to the local hospital, get a referral, then go and see a specialist, that would be alright. There has to be a hierarchy, I think that has to be implemented. So that there wouldn't be, there's never anyone seeing the doctor at the grass-roots level, and there are more patients at the well-known hospitals. Moreover the costs are more expensive, and this, some people can't afford this, but they still crowd up here, try and squeeze themselves in for a stay at this kind of place. I think this is, if we can improve this, I think work would be easier for the medical profession.

- Doctor 5, male

Another doctor's account regarding helping patients obtain medical insurance coverage demonstrated his concern for their plight. Yet he recognized that much of the financial process was out of his control, for instance the terms were updated at a faster rate than he can keep up with. Thus problems with non-medical matters translated to inconvenience for the patient and possibly tension in the doctor-patient relationship.

[S]ome medical insurances are really, we really can't keep up with some of the changes...it might lead to a certain impact on the patient, or some situations where the submission was not timely, but if we know about it we would definitely help him with it, definitely would get it done for him, then tell him what to do, how to handle it, how to strive for the best medical insurance policy, we would tell him about this kind of stuff really honestly. But perhaps because of some reasons in terms of the reform, there might be some omissions with submissions, some delays, these things might happen.

- Doctor 8, male

Echoing the previous doctor's sentiment regarding non-medical matters, this doctor recognized that parts of the hospital experience out of his control inevitably contribute to dissatisfaction.

How satisfied are the patients? I think most of my patients are satisfied when they are discharged. Because I think I still care about them, but as to how satisfied they are it's hard to say. Probably at least 80%, after all there are a lot of situations I can't anticipate, like sometimes he would have some minor complaints, for instance we're late in getting him to the operation, but we can't control the time. Or if the medication was administered late, none of these minor issues can be controlled by us. Of course most of the time they are satisfied, but there's always some minor flaws.

- Doctor 4, male

C. Fear and avoidance of blame

The above factors relate to the pressure imposed by system design and rules or regulations, which subsequently contributed to doctors feeling helpless to satisfy patients and family members.

Another aspect of pressure on doctors was the constant threat of being blamed for complications, which inspires fear. Doctors seemed to perceive that the degree to which patients and family members are informed about possible complications could make or break the doctor-patient-family relationship.

For this doctor, after noting the media's role in casting blame on doctors (quotation shown in Theme 1), his fear of responsibility was evident.

You're doing a research on doctor/patient communication now, but actually a lot of times for us, we try to avoid responsibility as much as possible. After all to prevent conflict

between doctors and patients, we often run away from it, this is the current status in China.

- Doctor 2, male

Another doctor recognized the potential threat—both verbally and physically—posed by family members in the event of a complication.

Some family members may even have disputes, for this type of situation it's usually when there are complications after the operation, he might not understand it, why this problem arises after surgery, why a problem is solved but another arises, this might create some conflict, even arguments sometimes, they might even fight, I've never come across that before.

- Doctor 3, male

As a result of this accusatory and retaliatory environment, doctors felt pressure to practice defensive medicine. However, as one doctor noted, their actions can trap them in a cycle of distrust involving the patient or family as well as the media.

I think, in China this is the kind of situation currently, it feels like the doctor and patient is in a hostile relationship. Why do I say that? Because we as doctors, we definitely think of a way to cure the illness, get this operation done well. But as patient family members they suspect the doctor, because firstly, the media propaganda in China, and also the problem with some doctors themselves, they might think that doctors have the issue of overtreatment. The current existing issue is that doctors and patients don't trust each other, because this is how we're like, because we worry that a situation arises with the patient, so we tell the patient about every situation[.]

[T]hen another thing is examinations, all the examinations are done, mainly out of fear that the patient would have any issues and risks after the operation. If you didn't consider it before the operation, didn't say that this thing would occur after the operation, but it occurs after the operation, then the family member would cause you trouble, so it's a medical dispute. So at the moment our situation is that to prevent trouble after the operation, doctors would perform all the examinations that don't necessarily have to be done, but the patient thinks that you are over-examining.

- Doctor 6, male

The doctor alluded to the importance of setting expectations by informing patients and family members of possible scenarios and the risk of complications associated with treatment. Doctors mentioned using the Medical Services Department of the hospital for such conversations as a defensive tool for preventing or managing disputes. This doctor described a chain of command involved in difficult situations with the Medical Services Department being part of escalation process.

Most of the time we get our resident doctors to communicate with the patient's family member first, generally it's family members, if it's convenient we would directly communicate with the patient as well, but in most instances we would directly communicate with the family member, then it's the attending doctor who is a level above us or associate professor communicating with the family member about this condition, this situation, including treatments, of course if there are some who are more troublesome, where the condition is quite complicated, or if there's a dispute and the like, we would consult the professor or chief, or even the medical services department.

- Doctor 3, male

The fact that the doctor was able to articulate a procedure to manage disputes contrasts with the experience of resident doctor 4 who, in the previous sub-theme, noted a lack of a “standardized way of approaching the matter.” This comparison suggests that the level of awareness of and possibly skill in effective conflict management varied among the doctors.

The following two doctors explained the particular situations in which it would be appropriate to use the Medical Services Department for defense. Their accounts show that the department had versatile uses, ranging from high-risk situations including complicated operations and troublesome patients, to dispute prevention in lower-risk, “normal” cases.

If it's a bigger operation, then I might come to an agreement with her during hospitalisation before the operation, for some that are more serious more complicated then we might have to go to our medical services department to conduct a communication with a full recording of the conversation, this way it prevents some accidental situations that occurs during and after the operation, it prevents the occurrence of disputes after the operation.

- Doctor 10, female

[N]ormal operations but there could be disputes. We'd go over there, sit down to have a conversation. Not only pre-operation conversations, normal conversations can be had here as well. Mainly it's risk prevention. Based on our hospital's experience, the patients who have conversations at the medical service department, so far, have not had disputes together. Because the entire process is voice recorded and videotaped.

...[B]ut for this [distrustful] type of patient, before the operation, we definitely go to the medical services department to speak, no matter if his operation is major or minor.

- Doctor 6, male

While the department was seen as a defensive measure, the doctor also saw its value as a form of empowerment for them to improve patients' and families' attitude toward the hospital. That is, using it could be perceived as a gesture of respect.

If the patient and family member goes there [to the Medical Services Department], he might think that the hospital values him and respects him, he also think that his situation might be really serious, so he would be psychologically prepared. The entire process is voice and video recorded, so they'd think, hmm, there would be fewer post-operation disputes. Mainly it serves a symbolic meaning.

- Doctor 6, male

The department thus served a dual function by aiding doctors to improve their communication towards patients and families while also helping them feel protected from blame in the event of a complication.

Apart from setting expectations about the risk of complications, doctors also found psychological preparation about the medical care 'investment' to be relevant in the decision-making phase, as told by this doctor.

If she [the patient] thinks the results are not good, and the family member's financial situation is quite good, then no matter what she would stay here and have the operation here, if undergoing follow-up treatment. I'll tell her you spend this much, and it can achieve a result of this magnitude, like how effective it is, whether it's good. I would tell her, but not to make her think that everything can be solved if she's willing to spend the money, let her be psychologically prepared, spending the money doesn't necessarily mean you can be saved, let her be prepared psychologically, then that's fine.

- Doctor 5, male

Regarding financial investment, another doctor frankly prioritized the satisfaction of the primary contributor, namely the family member, for their power to hold the doctor accountable.

For the patient's family member we try to make them as satisfied as possible, because after all the patient's family member pay the fees mostly, if you don't explain it to them clearly, they won't be willing to continue the rest of the treatment, that happens.

...Most patients should be quite satisfied, as to those who are not satisfied, usually it's because their treatment results were not so great, so whichever way you interact with them they won't be satisfied.

- Doctor 2, male

The asymmetry in doctors' attitude and communication behavior toward patients versus family members had the potential to cause reciprocal asymmetry between a patient and family member's response to the doctor. Yet this doctor's nonchalance towards the awkward scenario where the patient is left uninformed suggests that avoiding dispute was a priority over patient autonomy.

There are times when the family members aren't very understanding, but the patient is quite thankful. But sometimes, the patient himself doesn't understand these things, why? Because he doesn't know about his condition, but we have mostly told the family members, the family members doesn't want the patient to know, so sometimes the family members would understand but the patients don't.

... I feel that as long as they don't come and bother us, if they don't have a dispute then that shouldn't be a problem!

- Doctor 3, male

The above accounts highlight the defensive attitude of doctors in reaction to the high-pressure, litigious environment in which they worked. They convey a state of learned helplessness given the systemic factors contributing to this environment.

The opposing yet optimistic view of one doctor—a professor—on handling these challenges raises the possibility that learned helplessness could be a function of experience level. He argues for the critical role of timely communication and initiative, along with empathy, to empower doctors in difficult situations and mend temporary severances in the doctor-patient-family relationship. In effect, he shifts the source of tension from the external, systemic challenges detailed by other doctors to the interpersonal dynamics between provider and patient or family member.

Any one illness has the presence of complication, there might be more or fewer complications. But it's not possible for every doctor to put an end to these complications, right, even for the best doctors there would be these complications. But when you have a complication, the key is how much the patient understands you at this point of time. When you have this situation, the doctor has to have a positive attitude, can't treat this situation negatively, ah it's fine it's fine, sometimes tell the patient family member don't mind this stuff. If there is this situation, then I have to immediately consider, with this situation, I have to immediately, actively, show that I really care about you, I'd actively have some communication with you, take you to do some tests, see what your situation is like. This is actually also to prevent medical disputes, actually the patient also understands. Most patients are like oh, the doctor does this handling for me, he would understand too. The vast majority of patients can understand this. It's mainly paying attention to this.

- Doctor 9, professor, male

Taken together, the views among doctors on doctor-patient-family tension are in line with those of patients and family expressed in Theme 2. That is, tension can arise from all levels of the healthcare-seeking process—interpersonal to systemic. As such, efforts to prevent and alleviate tension should mirror the complexity by taking a multilevel approach.

DISCUSSION

We conducted a qualitative study to understand the communication factors that contribute to tension in the Chinese doctor-patient-family relationship (DPFR) in the context of surgery. We identified three emergent themes regarding tension in the doctor-patient-family relationship, which were not limited to communication and recognized the broader context of healthcare: (1) Trust degradation occurred before and during the healthcare experience; (2) The healthcare-seeking experience for patients and family members was marked by unmet expectations for achieving a basic understanding as well as powerlessness; and (3) Societal pressures on doctors contributed to a state of learned helplessness.

We found that while patients, family members, and doctors recognized a baseline level of trust in most of their medical relationships, in a minority of cases multiple factors led to trust degradation, specifically distrust and mistrust. Contributors to distrust included a malicious personality type of certain patients or family members and media misrepresentation of medical matters. Doctors' responses demonstrated a stance of vigilance towards potentially belligerent personalities. Contributors to mistrust included a patient or family member experiencing or witnessing a significant event and the presence of knowledge or communication gaps between providers and patients or family members.

Furthermore, we found a shared recognition among patients, family members, and doctors of the difficulty of the healthcare-seeking process in China. However, the contrasting narratives between patients/family and doctors showed that they struggled with unique challenges. For patients and family members, tension arose from their unmet expectations for how informed they would be about the condition, as well as powerlessness from a lack of institutional focus on humanistic or patient-centered care. For doctors, tension arose from societal pressures that inhibit

their availability and ability to meet the requests or needs of patients and family, as well as an environment that motivates avoidance of responsibility and perpetuates fear.

In his essay calling for a trust-oriented bioethics to understand conflict in the modern Chinese patient-physician relationship, Yunxiang Yan argues that mistrust in the medical sector is in line with a decline in overall social trust since the early 1980s in China [15]. Our findings are in agreement with Yan's observation. Yan concludes that "more effective studies of patient-physician mistrust in China should explore the dynamic process of social interactions between patients and physicians in real-life situations, instead of focusing on the stereotypical and static assessment of pervasive patient distrust in physicians. The key is to determine how the initial patient distrust is misplaced, betrayed, and eventually turned into mistrust in physicians." A strength of our study is the approach of inductive qualitative analysis that is in line with the approach advocated by Yan. This approach has allowed us to understand, at a detailed level, the interactions between doctors, patients, and family members that contributed to tension. Moreover, studying interactions in a single institution allows us to understand how they fit into an overall system that is deficient in its focus on the patient experience as well as the wellbeing of its doctors.

Our findings also diverge with certain of Yan's arguments. According to Yan, "the term 'distrust' does not adequately describe the Chinese patient-physician relationship because... most patients will only select physicians for whom they have initial trust in their fidelity and competence."

However, our data suggest that general distrust may motivate behavior to secure a specific doctor for the surgery. Additionally, the data from doctors show a distrust towards their patients and family and contributes to the tense working environment. They adapt by practicing vigilance and taking defensive actions such as recording patient/family conversations, focusing on disclaimers about complications and treatment limitations, and even, for some doctors, over-treating or -examining.

Finally, Yan claims that “[t]hus far, most studies and media reports have focused on the failure of physicians or medical institutions to inform their patients of the complexity of the medical procedures or the high costs of treatment. Yet the much deeper underlying cause of these failed communications is the traditional and hierarchical perspective held by many physicians that neglects the patients’ right to know and does not allow them any voice. This failure to communicate reflects the medical professionals’ failure to recognize the patients’ rights and dignity.” Our findings suggest a more complex picture of the challenges faced by doctors that inhibit their ability to help or more effectively communicate with their patients and the family members. In fact, a strength of our study is the broader focus on communication that allowed us to capture both positive and negative sentiments. It also helped capture the non-sensational aspects of tension that would not necessarily be reported by the media but impact the daily healthcare and working conditions of patients/ family members and doctors, respectively.

For instance, doctors in the study do acknowledge the importance of informing patients and family members; some even expressed empathy for their plight and urge doctors to reflect more on that point. While it is beyond the scope of this study to determine what percentage of doctors think this way, the data do show that doctors are not universally paternalistic. On the contrary, our findings show that doctors may be motivated to warn patients and family members by their constant fear of responsibility and blame—a state of learned helplessness that has negative consequences on doctors’ mental wellbeing.

As such, another strength of this study is the triangulation of perspectives from different stakeholders in the medical relationship. A large qualitative study by Tucker *et al.* and the Patient-Physician Trust Project Team also employed interviews with various stakeholders at hospitals in Guangdong Province, situated southeast from Hunan Province [20]. The authors sought to understand the origins and outcomes of patient-physician mistrust and violence against doctors. Our results are in agreement with the authors’ finding that “knowledge asymmetry” can

lead to conflict and serves as one of the origins of mistrust. They found another origin of mistrust to be the unrealistically high expectations set by patients giving “red packets,” or cash gifts, to doctors in hopes of securing a good outcome. However, our findings suggest that the whole healthcare-seeking process for patients and family members is a high-stakes investment that in itself drives up expectations. Overall the alignment of our findings with those of Tucker *et al.*, given the fact that they involved different provinces (Hunan versus Guangdong Province), shows that the scope of the problem of tension in the medical relationship is geographically broad in China.

Our findings in Theme 2 regarding patients’ and family members’ unmet expectations for being informed suggest that having an insider acquaintance and communication liaison may be associated with a better experience. A study by Wu *et al.* examined the culture of *guanxi*—the concept of personal relationships beneficial to those involved via exchange of favors—in medicine in Zhejiang Province, situated northeast from Hunan Province [21]. They conducted focus groups, interviews, and a survey of doctors (n=111) showing that approximately 40% of specialists and 22% of primary care doctors thought patients would use *guanxi* to obtain better healthcare service. Additionally, approximately 65% of doctors surveyed reported “better dedication when patients were somehow connected” [21]. Their findings raise an important ethical question about the benefit of *guanxi* to certain patients and family members at the expense of justice in the healthcare system. Reforms at the hospital and systems level are urgently needed for all patients and family to have access to a more patient-centered, informed experience.

In Theme 3, we characterize the experience of Chinese doctors under societal pressures as learned helplessness. There are few studies on learned helplessness among physicians. An article on the modern generation of American medical graduates, Charles Bond argues that young doctors are wholly unequipped to thrive in the complex healthcare system that insufficiently rewards them; this puts them at high risk for learned helplessness with regard to their circumstances [38]. In our

study, doctors seemed helpless to enact positive change for themselves and their patients, deferring the responsibility instead to the government or media culture.

Related to learned helplessness, findings from doctors also suggest that they may be experiencing a state of burnout, which is defined in three dimensions as emotional exhaustion, cynicism or depersonalization, and reduced personal accomplishment [39]. The first two dimensions are evident in our sample of doctors through their expressions of being unable to satisfy the recognized needs of patients and family members and applying negative bias and distrust towards certain patients or family members. In fact, signs that cynicism has become a *de facto* position of the profession include doctors' accounts of screening patients and family for signs of trouble and holding communications in a separate department for individuals deemed risky to the institution.

Our findings are consistent with studies of burnout among Chinese physicians [40, 41]. The severe consequences of burnout are illustrated by Wen et al. who concluded that longer work hours per week and burnout were independent risk factors for medical mistakes [40]. Their findings suggest that doctors like those in our study are at risk for the very thing they desperately avoid—responsibility for complications—by continuing to work in the current system. Given the heightened expectations and anxiety expressed by the patients and family members in our study, burnout among their doctors would further jeopardize trust in the doctor-patient-family relationship.

Limitations

Our study has several limitations. First, the distribution of certain participant demographics is imbalanced in this convenience sample; all doctors except one were male and most were at the resident level, while all patients except one were female. Thus the findings would be strengthened if we had a more balanced sample or used a purposive sampling method. That said, the skewed

distribution of gender and training level of the participants increase the likelihood that we achieved thematic saturation for this particular group.

Third, while we had aimed to recruit one family member for every patient to complete a dyad, and conduct two interviews per individual in the dyad, we were unable to complete all four interviews in some cases. This was due to loss to follow-up or inconvenient timelines in the hospital that prohibited a participant from stepping aside to complete an interview. As a result, we may have missed additional information from different perspectives that could have enriched the findings.

Fourth, I am fluent but not literate in Chinese and therefore performed the analysis on data that had been translated to English. This could have resulted in some loss of fidelity of the original meaning in participants' Mandarin or Changsha dialect responses. However, one of my research partners (LW) was literate in Chinese and contributed to the initial stages of analysis.

Additionally, during the analysis of transcripts I often used an online translation tool (translate.google.com) that enabled me to listen to the text. I used the translation tool as well as re-listening to the interview recording in cases of ambiguous or unclear translations, or to better understand a particularly rich section of text.

Finally, we did not have the ability to return to the study site or reach the participants before the analysis was performed in order to solicit their feedback on the findings. However, I do plan to return to the study site at a later date when I will have the opportunity to share the findings with doctors and get their feedback at that time. Their feedback would be valuable to incorporate into future reports and presentations of this study.

Future Research

More research is needed on how tension varies within local healthcare contexts, including across the following axes. First, providers in certain specialties like emergency medicine are known to

be more vulnerable to violence and tension [7]. Second, our data are heavily represented by junior doctors still in training; comparing their responses with senior doctors in the study already shows some differences that may be due to having more experience and wisdom from years of practice and managing conflict. Third, there may be important differences in the challenges faced by patients, family members, and doctors seeking care in rural as opposed to urban healthcare facilities.

In addition, this study examined a cross-sectional sample of patients, family members, and doctors, many of whom were still relatively inexperienced in the healthcare system let alone conflict resolution. Thus, obtaining an understanding of temporal trends in their perspectives—such as acute vs. chronic patients and following individual participants over time—would help target efforts to improve the patient-family experience and preparation or training of doctors.

Finally, more research is needed to evaluate the effectiveness of interventions and healthcare reforms on the status of the doctor-patient-family relationship. In particular, interventions should address sources of tension from a variety of approaches and levels. We offer recommendations to address tension in the doctor-patient-family relationship along the lines of the three emergent themes (Table 3).

Table 3. Recommendations to address tension in the doctor-patient-family relationship

Theme	Problem	Recommendations
1) Degradation of trust	Media misrepresentation	- Public awareness campaign supported/led by doctors to demystify rumors
	Knowledge disparity	- Given patient/family reliance on visual cues, visual aids can be developed to assist doctors in communicating with their patients, especially in cases of abnormal lab results - Integrating review of imaging results with the patient/family
	Communication gaps	- When multiple family members are involved, implement a designated time for family meetings to promote consistent, timely, and thorough communication
2) Healthcare-seeking experience for patients and family members was marked by unmet expectations for achieving a basic understanding as well as powerlessness	Inexperience and inconvenience associated with seeking healthcare	- Implement appointment policy and procedures for outpatient evaluations <ul style="list-style-type: none"> o Make this available via smartphone, online, and telephone channels - Implement patient navigator roles throughout the hospital - Implement intra-operative communication system for family members to notify them of patient's status in the queue and prevent anxiety about the reason for unexpected delays - Provide a welcome packet to all inpatients that addresses frequently-asked questions about

		<p>navigating the hospital, sets expectations about timelines, and includes a clear map of various departments and their purposes</p>
	<p>Patients and family members feel ill-equipped to communicate effectively with the doctor</p>	<p>-Promote patient- and family-centered care:</p> <ul style="list-style-type: none"> ○ Healthcare providers can elicit goals and expectations of patients/family upon admission to help set realistic expectations ○ Providers participate in communication training on techniques like summarizing and eliciting questions/illness beliefs to address gaps in understanding between them and the patient/family ○ Encourage patients/family to write down their concerns in advance ○ Provide patients with discharge summary documents to allow for continuity of future care
<p>3) Societal pressures on doctors contributed to learned helplessness</p>	<p>Doctors bear the responsibility of helping patients with insurance coverage issues</p>	<p>-Designate separate personnel responsible for handling admissions and insurance matters</p> <p>-Leverage expertise of graphic designers to develop patient/family materials including schematics of the insurance claims process; make these accessible in various forms (e.g., online, printed handouts and posters)</p> <p>-Provide policy briefs to doctors regarding region-specific changes to insurance, with educational formats including grand rounds-style, weekly didactic conferences, faculty/housestaff retreat, etc.</p>

	Lack of a standardized way of managing disputes between doctors and patients/family	<ul style="list-style-type: none">- Implement formal policies and procedures to handle disputes; designate a central administrator to serve as a resource to providers- Conduct de-escalation training for all providers about handling conflict situations
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Conclusion

Our study showed that patients, family members, and doctors view trust as integral and generally present in their healthcare interactions. Trust degradation occurred in a minority of cases and seemed to result from a variety of factors, both within and out of their control. The difficulty of seeking healthcare was recognized by all stakeholders. Yet their unique perspectives pointed to the need for systemic reform in order to address unmet information needs and powerlessness among patients and family members, and learned helplessness among doctors. Our research suggests that the Chinese doctor-patient-family relationship in one local community remains functional in many ways, yet, in line with other investigations, continues to struggle in the context of a challenging healthcare environment. Healthcare administrators, educators, and government officials must recognize both local and national narratives to best address their patient and caregiver needs. Interventions are needed to promote empowerment among all stakeholders. They should provide for a more patient-centered experience while ensuring the well-being and security of healthcare providers.

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