# Beyond the Operating Room: A Mixed-Methods Pilot Study on Structural Healthcare Disparities in Rural China

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## INTRODUCTION

Congenital Heart Disease (CHD) is the most common birth defect in China, affecting an estimated 150,000 newborns each year. It is a leading cause of infant death (Tian et al. 2025). CHD is a heart condition present at birth, where the heart or blood vessels have not developed correctly. CHD can cause abnormal blood flow and oxygen deprivation; additionally, it can lead to strain on the heart. Left untreated, CHD can lead to complications such as heart failure, growth delays, and early mortality, making surgical intervention critical for improving long-term survival and the quality of life for children. In the past century, survival rates have improved due to national health reforms, advancements in pediatric cardiology, and technological and economic development (Ma et al., 2023).

Although great progress has been made, structural complexities and disparities pose challenges for China's healthcare system to meet the growing CHD population. Stark disparities persist between rural and urban regions. Undiagnosed CHD has been dramatically prevalent amongst children in rural areas. A population-based echocardiographic screening study conducted among Luchun County, one of the most deprived counties located in southern Yunnan province in China, shows that CHD was identified in 285 children, with an overall prevalence of 13.0 per 1000. Among this demographic, 252 were unrecognized CHD; a prevalence of 11.5 per 1000 (Zhao et al., 2021). Furthermore, a population-based study in Jinan found an urban CHD birth prevalence of 4.81 per 1000 births. Rural areas face various challenges in managing CHD, including a lack of advanced specialist facilities and professionals, inadequate infrastructure, systemic weakness, and health illiteracy. (Yip et al., 2019).

After surgery, long-term management, such as post-operative monitoring, medication adherence, and follow-up visits, is essential for the recovery of children with complex CHD. Such post-operative care is often inaccessible to families in rural areas. This discontinuity in follow-up in rural areas has largely to do with geographic and economic barriers (Su et al., 2023).

A number of targeted initiatives have emerged in recent years to close this gap in access to adequate healthcare and post-operative follow-up. For example, programs have emerged through the partnership of non-governmental organizations (NGOs) such as the TEDA International Cardiovascular Hospital (TICH) in Tianjin to provide diagnosis, subsidized surgeries, treatment, and post-operative support to children from low-income families in rural areas of China. Through free conducted screenings across rural settings such as Tibet, Qinghai, and Gansu, these efforts demonstrate that collaborations between hospitals, charities, and local governments can have a significant and measurable impact.

This paper investigates the correlation between the specialized care needed and the likelihood that a patient will receive the care, using the case study of rural families in China experiencing and navigating CHD care beyond operating rooms. As a pilot study, this research employs a small-scale, mixed-methods approach to provide preliminary insights and guide future investigations into equitable CHD care. It will investigate how structural disparities such as economic, geographic, and communicative barriers shape medical decision-making, post-operative care, and health literacy. This study will explore the perspectives and lives of

rural families to ground and complement quantitative data with qualitative data I conduct through semi-structured interviews, in order to convey the emotional and logistical burdens that these metrics often overlook.

Specifically, I intend to identify four key dimensions through which these tensions unfold: (1) families' lived experiences of navigating CHD care before and after surgical intervention; (2) the role of family dynamics and cultural values in healthcare decision-making (3) the impact of structural barriers such as economic strain, geographic isolation, and health literacy on access to and adherence to care; and (4) the ways support programs and charitable organizations alleviate these challenges and how rural families respond to them. In this, I demonstrate that CHD care for rural families is multidimensional.

## LITERATURE REVIEW

### *National Policy Context & Structural Reform*

In recent decades, China's national health reform agenda has been shaped by a central goal: achieving universal, equitable, and affordable basic healthcare for all citizens. The 2009 healthcare reform made a decisive pivot from market-driven healthcare towards government-led provisions, which culminated in the *Healthy China* 2030 strategic plan, a plan that framed health as a core prerequisite for national prosperity. This shifted the focus from simple disease treatment to prioritizing equitable access, system transformation, and health promotion. China has also undergone other significant reforms toward universal health coverage through public investment, nearly universal social health insurance (SHI), and improved financial protection for low-income populations (Yip et al., 2019; Ao et al., 2022). For example, in 2022, China's total health expenditure reached ¥8.53 trillion (~US $1.27 trillion), or 7.05% of GDP (Li and Zhang, 2024).

From 2016 to 2021, the *Healthy China* 2030 strategic plan centered around consolidating universal coverage, expanding public health services, and reducing catastrophic household expenditures. Subsequently, from the years 2021-2030, the goal evolved to raise the average life expectancy to 79 years, reducing premature mortality from non-communicable diseases by 30%. There was also a focus on strengthening rural and elderly care through digital and community-based innovations (Ao et al., 2022).

Nevertheless, while reforms intend to mitigate the rural-urban disparity, challenges persist. Increased government funding and nearly universal insurance have led to the doubling of hospital admission rates from 2010 to 2016. Hospital admission rates increased from 7.4% in 2010 to 13.5% in 2016. Individuals with high socioeconomic status had the fastest increase in hospital admissions, while low socioeconomic status families had the highest outpatient visits (Yip et al., 2019). Ao et al. (2022) posit that large gaps remain in reimbursement rates, quality of post-surgical care, and health resource allocation, especially for complex conditions like CHD that require specialist diagnostics and follow-up. Furthermore, tertiary hospitals, which are mostly located in urban areas, continue to attract the majority of investment, skilled professionals, and advanced technology, leaving rural facilities lagging in capabilities and quality.

Wang et al. (2020) add that the central policy frameworks provide substantial funding, but the implementation has been largely decentralized. Provinces and counties have discretion over how the funding is spent and how resources are allocated, leading to heterogeneity in program generosity, benefit packages, health workforce incentives, and infrastructure investments across China. Local governments are able to choose from an array of models when implementing

central policies, so they may prioritize other economic goals, which leads to differences in their ability to provide qualified healthcare personnel, further amplifying disparities amongst provinces (Wang et al., 2020).

Despite universal coverage in insurance, structural barriers hinder equality in access. Fragmentation between primary and tertiary care systems, lack of advanced technology, and weak referral pathways challenge healthcare continuity, especially post-surgical management for conditions like CHD (Yip et al., 2019). While China's robust policy reforms have greatly expanded coverage across the country, the translation of this into equitable, high-quality care is still deeply shaped by the uneven capabilities and priorities of different provinces and local governments.

*Geographic and Socioeconomic Disparities in Access and Outcomes*

Quantitative analyses from a large cohort of studies confirm the disparities between urban and rural divides. These studies highlight stark geographic differences in access, surgical treatment times, and outcomes for children with CHD across China. Zhao et al (2021) use the method of coarsened exact matching in their study, using patient experience as a key measure to evaluate the quality of healthcare. Patient experience is a multi-dimensional construct encompassing elements of healthcare, measured by either patient report (what happened to a patient) or patient evaluation (how patients rate) items, including the process of an appointment (Zhao et al., 2021). In this study, patient experience was measured by healthcare services evaluation with the following question: "What score will you give to healthcare services (0-100)?" In addition, the 0-100 values were further divided into five ordered levels: very bad (value=0), bad (value<60), fair (value ranges from 60-79), good (value ranges from 80-99), very good (value=100).

It was found that rural patients rated healthcare accessibility higher than their urban counterparts, with the mean standard deviation (SD) score of patient experience for rural and urban residents at 72.35 (17.32) and 69.45 (17.00) (Zhao et al., 2021). This result may have reflected lower expectations, as for rural pediatric CHD patients, 'accessibility' likely entailed distinct challenges such as navigating logistical and transportation barriers, referral networks, and post-operative follow-up in resource-poor regions.

Xiang et al (2018) reported in their observational cohort study at Fuwai Hospital in Beijing that although pediatric cardiac surgery numbers are increasing nationally, the majority of the high-complexity operations are performed at a small number of urban cardiac centers. The study also finds that children from rural or poverty-stricken counties tended to be older and heavier at the time of the operation, indicating delayed diagnosis compared to the children in urban areas. Delays in surgical intervention were linked to higher rates of complications and worse long-term survival (Xiang et al., 2018).

Geographic barriers, such as distance from specialist centers and lack of advanced pediatric cardiology personnel, affect mortality and morbidity. In the cohort study at Fuwai Hospital, it was found that postoperative follow-up visits at tertiary centers were significantly lower for children from low socioeconomic status and rural areas. Nearly 70% of rural children travel more than 180km to access CHD care, and only 13% of rural children live adjacent to CHD facilities (Xiang et al., 2018; Su et al., 2023). This limits opportunities for follow-up post-surgery and increases the risk of complications.

Xiang et al (2018) also found that children from families with low socioeconomic statuses had a risk of death nearly three times higher, with unplanned readmissions at rates four times higher than those with high socioeconomic status.

Regions with Higher GDP have a denser network of hospitals, health professionals, and specialist centers. The National Health and Family Planning Statistics Yearbook reports that urban areas have roughly 2.6 times more health technicians and more than double the hospital bed density compared to rural areas, with eastern China better resource-equipped than western provinces (Zhao et al., 2021).

*Health Literacy, Communication, and Language Barriers*

Health literacy and effective communication are imperative in managing complex conditions like CHD. Culture and linguistic competence affect how people communicate, understand, and respond to information acquired. In China, there are 10 major dialects and hundreds of local variants spread across regions. Linguistic barriers arise when people speak different dialects, even in the same language. Barriers to understanding medical information, coupled with traditional family structures influencing healthcare decisions, all impact treatment adherence and overall health outcomes. Patients in diverse dialect regions may express fear or nervousness in hospital settings due to communication difficulties and inability to clearly describe their symptoms, or to understand doctors' explanations (Zhang et al., 2022)

Shamsi et al (2020) conducted study that found language barriers in healthcare lead to miscommunication between professionals and patients, reducing both parties' satisfaction and decreasing the quality of healthcare delivery and patient safety. Patients who do not speak the local language will also have less access to healthcare, decreased understanding of their diagnoses, and increased medication complications (Shamsi et al., 2020).

Parental understanding of a child's medical condition and treatment is a key determinant of a family's adherence to treatment. Factors such as communication quality, access to social support systems, and the parents' health literacy are crucial (Ittenbach et al., 2009). A failure to adhere to medical and surgical management of CHD can have life-threatening consequences for a child with the complex disease.

In China, medical decision-making is strongly influenced by family, with values deeply rooted in Confucian culture, such as filial piety, deference to elders, and prioritizing family harmony and community-benefit over individual autonomy. This contrasts greatly with Western models that emphasize individual autonomy and personal responsibility and benefit (x, 2015). This can pose both a benefit and a challenge. If patients are poorly educated and struggle to fully comprehend the diagnosis or treatment, the family's advice is crucial. However, if the family lacks literacy in healthcare or does not believe in the severity of a diagnosis as complex as CHD, treatment can be compromised.

Research indicates that adherence to treatment in children with cardiac disease is relatively understudied compared to many other chronic health conditions affecting children (Ittenbach et al., 2009). Communication and cultural barriers identified in the context of CHD reflect broader systemic challenges in providing equitable healthcare for chronic conditions across linguistically and culturally diverse populations in China.

*Follow-up Care, Telemedicine, and Technology-Based Solutions*

Researchers have argued that technology-mediated care can potentially alleviate rural gaps in providing care. WeChat is one of the most used apps in China, featuring multiple messaging services. In a study conducted by Xie et al (2022), it was noted that distance travelled, time committed, and costs incurred significantly decreased for children who had recently undergone CHD surgery and used a WeChat-based follow-up (129.6 vs 394.1 mins, ¥375 vs. ¥470); improved medication adherence (95.6% compared to previous 77.8%). Overall satisfaction with he follow-up process also increased (Xie et al., 2022).

Most hospitals lack interpreters, especially in rural areas; however, alternatives do exist. Al Shamsi et al (2020) conducted a systematic review of 14 international studies and observed that some hospitals rely on online tools like Google Translate and MediBabble, which are reported to improve the quality of healthcare delivery and patient safety by 92%. However, while machine translation apps are useful, they are far less reliable for complex medical terminology and various dialects. While Al Shamsi et al (2020)'s study indicated high perceived improvements in the quality of healthcare delivery, it doesn't mean accuracy was ensured in all contexts.

Inadequate interpreter support can lead to medication errors and delayed treatment, with 30% having difficulty understanding and 50% believing it contributed to medical errors. Interpreter services and online translation tools offer promising solutions, yet often go underused in rural or resource-limited contexts.

*Partnership Programs: Toward Culturally-Sensitive, Bottom-Up Solutions*

Financial assistance from philanthropic and charitable organizations has been essential in aiding the regional imbalances and disparities in medical resources. In 2013, a total of 96 charitable organizations initiated 149 critical illness relief projects that provided financial assistance for more than 30,000 children with CHD. The largest charitable relief project for CHD in China is operated by the AiYou Foundation, which launched the AiYou-Tongxin Project (translated as lovingly caring for children's hearts), in collaboration with the Ministry of Internal Affairs in 2006, to establish a nationwide network of 50 designated congenital heart centers providing treatment funding for more than 63,000 children with CHD across China from 2006 to 2020 (Su et al., 2020).

Furthermore, TEDA International Cardiovascular Hospital (TICH) in Tianjin has established various partnerships with multiple non-governmental organizations and major corporations to focus on improving pediatric care through multidisciplinary approaches. Medical screenings are conducted across rural areas in China to diagnose CHD amongst children. These partnerships are important because they not only bridge the financial gap for low-income families but also create sustained pathways for early detection, timely surgical intervention, and continued follow-up care that would not be available in rural areas. By embedding these services within local networks and leveraging charitable funding, these collaborations can mitigate the systemic inequities that government policy alone cannot address.

Despite these efforts, challenges persist. Not all CHD-related medical services are fully covered, and many disadvantaged patients face substantial financial risk and end up missing a life-saving opportunity. A 2018 nationwide analysis revealed that CHD treatment accounted for 32.9% of family-level out-of-pocket expenditure (expenses for medical care that are not reimbursed); the proportion of family expenditure for prenatal screening and diagnosis of CHD is 72.5%. This expenditure remains a problem for poverty-stricken families with complex CHD. Su et al.'s 2023 analysis shows that children with complex CHD had substantially higher

out-of-pocket expenses and a lower proportion of health insurance reimbursements and charitable medical assistance than children with simple CHD. In addition, many families with complex CHD also struggle to cover expenses for post-operative rehabilitation, deterring patients from accessing care. Therefore, government and charitable organizations must deepen their cooperation to improve financing for CHD treatment with a particular focus on complex CHDs and socioeconomically disadvantaged patients.

*Limitations of Quantitative Metrics & Importance of Lived Experience*

Much of the existing research on CHD in China draws primarily from hospital-based data, large cohort studies, and large-scale epidemiological surveys. While these sources can establish prevalence rates, surgical outcomes, and mortality trends, they inherently limit and neglect the nuances of such complex healthcare journeys. Hospital records only capture children who are diagnosed and treated, often excluding the many cases that go undetected and untreated in rural areas where diagnostic facilities are scarce. Epidemiological surveys, which are able to generate broad-level estimates, tend to rely on standardized instruments that also overlook the nuanced social, cultural, and logistical realities shaping how families navigate CHD care. For example, in the Su et al 2023 study, it was found that the proportion of children with CHD lost to outpatient cardiology follow-up was reported to be 28% at age 6 years and 47% at age 13 (Su et al., 2023). This “missed follow-up” recorded in hospital data could stem from various factors, such as transportation costs, mistrust of providers, or local caregiving norms, all factors that cannot be captured by numeric fields in the registry. Without understanding these lived contexts, interventions risk addressing the wrong barriers of reinforcing existing inequities.

Incorporating lived experience into CHD research offers a way to bridge this gap. As such, I seek to answer: How do rural families in China experience and navigate their child’s CHD care before and after surgical intervention? How do family dynamics work together in making healthcare and related decisions? In what ways do economic, geographic, communicative, and cultural barriers shape medical decision-making and post-operative care for rural CHD patients? How do support programs and partnerships between hospitals, NGOs, and local actors intersect with rural families’ lived realities? By approaching the healthcare journeys of rural families affected by complex CHD as a holistic process, we can broaden our perspectives and challenge our own biases and assumptions.

## METHODOLOGY

This pilot study uses a mixed-method approach, drawing on qualitative and quantitative data to explore preliminary insights into rural CHD care. My chosen data collection method was semi-structured interviews. I chose this approach in order to validate and contextualize existing quantitative research by capturing lived experiences, the nuances of the decision-making processes, post-surgical challenges, and the perspectives of all parties involved in the treatment and diagnosis process.

Furthermore, this study includes published interviews with patients, families, and medical professionals found in peer-reviewed articles and reputable media reports, as well as statistical and demographic data found in existing studies. Incorporating these external sources helps

provide a broader context to corroborate my findings, whilst also allowing comparison with my own findings by triangulating across multiple data types.

One qualitative study conducted by Zhang et al. (2023), aiming to explore the stressors experienced by families of children with CHD, was collected at a tertiary referral hospital in Yunnan Province, China, using semistructured interviews. The participants in this study were the parents of children with CHD between the ages of zero and 14. Twenty-one participants (five fathers and 16 mothers) were interviewed in the study, each participant from a different family. Table 1 shows the demographic characteristics of the participants (Zhang et al., 2023).

TABLE 1. Participant Demographics

| Characteristics | Participation, N (%) |
|---|---|
| **Gender** | |
| Male | 16 (76.1) |
| Female | 5(23.8) |
| **Age group, y** | |
| 20-29 | 8 (38.1) |
| 30-39 | 12 (57.1) |
| 40-49 | 1 (4.8) |
| **Education** | |
| Primary school | 4 (19.0) |
| Junior high school | 8 (38.1) |
| High school | 8 (38.1) |
| Bachelor's degree | 1(4.8) |
| **Treatment stage** | |
| Preoperative | 3 (14.3) |
| Postoperative | 15 (71.4) |

My qualitative approach focused on the participants involved in the charity program organized by a corporation in partnership with the Tianjin TEDA International Cardiovascular Hospital (TICH). Screenings for CHD were conducted in several rural regions, including Tibet, Gansu, and Qinghai. My study centers on these three areas due to their geographic remoteness, limited local healthcare infrastructure, and known disparities in pediatric cardiac care. I identified three target participant groups: (1) parents and children who have previously

received care at the TICH hospital, (2) medical professionals involved in CHD treatment and diagnosis, and (3) volunteers and advisors supporting the selection and care process.

My inclusion criteria for families required that the child had received surgery within the past year and either the child (if of speaking age) or at least one parent could communicate proficiently in Mandarin. The one-year time frame was chosen to ensure the recency of experiences, thereby improving the accuracy of recall for both pre- and post-surgery. Mandarin proficiency was necessary to ensure direct, clear communication without the need for interpreters, which could introduce translation errors or omit important details.

Medical professionals were included if they had direct involvement in at least one of the following stages: participant selection, CHD diagnosis, surgical intervention, or post-operative care. Volunteers and advisors were included if they had hands-on roles in the program, such as accompanying families, assisting with logistics, or facilitating communication between hospital staff and patients.

Participants were recruited through purposive sampling. This process was aided by a combination of corporate contacts and personal networks. I had a previously established connection with the coordinators of the arrival of children participating in the charity program, who had access to records of all screenings and surgical cases. I worked with these people to confirm the ethicality of my study, the appropriateness of my questions, and establish my inclusion and exclusion criteria. Subsequently, I was provided with the contact information of those who fulfilled the criteria.

This study received approval from a self-assembled Institutional Review Board (IRB) committee, with all required member signatures obtained before data collection. All participants were informed of the study's details and purpose and provided informed verbal consent to be recorded and included in the study before participating in interviews. Participants were assured that their responses would be kept confidential and pseudonyms would be used.

I spoke to two families who lived in the Gansu area in China. Gansu Province is located in inland western China at the intersection of China's northwest arid region and the Qinghai-Tibet alpine region. Gansu Province is characterized by relatively poor economic development, low per capita income, and low level of urbanization, and therefore is considered an underdeveloped, rural region in China (Ma et al., 2019). In addition, I also interviewed two medical professionals: one specializing in post-operative care and another involved in the screenings and the surgical treatment in rural areas. I also interviewed a Tibetan advisor who accompanied a group of Tibetan families, assisting with logistics, transportation, and translation, as well as a corporate volunteer who attended all screenings across rural areas of China and was the one who provided me with the available contact information for families.

I conducted a series of semi-structured interviews with healthcare professionals, caregivers and advisors, and family members of children with CHD. In total, I interviewed six participants across both clinical and family contexts. Each interview lasted between 40 and 90 minutes and was conducted either in person or via phone call.

As a pilot study designed to generate hypotheses and test feasibility, this research intentionally focuses on a small sample to capture in-depth perspectives. The small sample size for primary data collection in this study reflects both practical and methodological constraints. Recruitment was limited to families, medical professionals, and volunteers, and advisors who met the study's inclusion criteria, were available within the research period, and could communicate proficiently in Mandarin without an interpreter. TEDA hospital and the NGO's partnership have aided 700 children to undergo surgery in the past decade. This number

includes only those who were found to have CHD and agreed to receive surgery at TEDA hospital. Most families who live in rural areas do not speak proficient Mandarin, which further exacerbates the difficulty of finding and recruiting families. Many families also do not have a stable internet connection or are unfamiliar with advanced technology due to their living standards and geographic location. The sensitive nature of discussing a child's medical history further narrowed the pool of willing participants. Among the families, only one Tibetan advisor was available. This reflects the broader shortage of interpreters and people who speak proficient Mandarin in rural areas. The final sample of two families, two medical professionals, one Tibetan advisor, and one volunteer from the corporation was therefore the only group accessible under these circumstances. While this limited sample prevents broad generalization, it allows for in-depth exploration of the lived experience of those directly involved in the charity program.

RESULTS:

As existing scholarship shows, children with CHD in rural China experience profound inequities in healthcare. These disparities are embedded in cultural, structural, and familial contexts. I aimed to study how the journey through CHD for rural families is not only a medical process, but a deeply social one that requires navigating various pressures such as limited resources, cultural values, and systemic barriers. This case study has proved that there is a negative correlation between the level of specialization required in care and the likelihood of receiving it, largely due to insufficient resources. The experience of CHD care among rural families reflects broader tensions between structural constraints and the way in which families respond to them.

*Navigating CHD Care*

Before traveling from Beijing to the TEDA International Cardiovascular Hospital in Binhai, Tianjin, I prepared a tailored list of interview questions for each participant group. Upon arrival at the hospital, I was introduced to the newly arrived group of patients from Tibet who were scheduled for surgery in the next few days. These children were adolescents and able to communicate proficiently in Mandarin. The parents of the children were unable to communicate in Mandarin; therefore, a Tibetan advisor was present. Although I was not permitted to formally interview them for this study, I engaged in informal conversation and small talk to better understand their lived experience and to immerse myself in the setting before speaking with medical professionals. None of what these children said is included in this study. It is integral to understand how rural families in China experience and navigate their child's CHD care, examining the emotional, logistical, and medical journey from initial diagnosis to post-operative life.

One of the biggest challenges described was the uncertainty and mistrust about the free surgeries provided by charitable organizations. One of the programs initiated by the various partnerships with TEDA has been running since 2008. They travel via a mobile medical van, which brings CHD medical experts and screening services directly to the doorsteps of rural communities, with the van traveling more than 40,000 kilometers across China.

I spoke with Mei, whose five-year-old son, Ming, from Gansu, was diagnosed with congenital malformation of the aortic and mitral valves with aortic valve stenosis. He received subsidized surgery in 2024. This condition is when the aortic valve is abnormally narrowed, limiting blood flow from the left ventricle into the aorta. Without timely intervention, congenital malformation of the aortic and mitral valves with aortic valve stenosis can severely restrict blood

flow, leading to heart failure, life-threatening arrhythmias, and in some cases, sudden cardiac death (Pachón and Zamorano, 2008). She recalled saying, “At first, we didn’t believe in the validity of this program. We went to Xi’an, a hospital I was familiar with, for a second opinion to confirm the diagnosis results we got from the screening before going to Tianjin.” This hesitation illustrates the lack of trust rural families often have in outside medical interventions. This also reflects a broader challenge in rural healthcare, showing how skepticism and fear can delay and prevent access to life-saving programs. Mei goes on to say, “I tried to do my research on the Tianjin TEDA hospital and look up more information about this program, but I did not find anything.” Mei is a primary school teacher with a Bachelor’s degree, and is considered highly educated in Gansu. She also had the financial capability to travel to Xi’an to verify her son’s diagnosis. Unlike many rural families, she is also literate. Literacy rates remain low in Western provinces like Gansu, at 8.69% in 2010, more than double the national average at the time (World Bank, 2020).

Yet even with these advantages, Mei admitted that she still harbored doubts and concerns about the free surgical program. Her experience suggests that for families with less education or literacy, this fear and distrust are likely to be even more pronounced. Mei also says: “We were skeptical about the diagnosis accuracy because we were never told by the doctors here that [Ming] had any heart conditions.” This further shows the limited expertise and diagnostic capacity in rural healthcare facilities. Even with her education and resources, Mei still decided to seek confirmation in Xi’an, a hospital she was familiar with, highlighting this gap in professional care that creates additional barriers for families, particularly for those without the means or knowledge to verify a diagnosis independently.

Furthermore, major themes were generated from Zhang et al. (2023)’s study findings that explore the associated stressors and hardships for rural parents navigating the CHD medical journey. Zhang et al. (2023) found that confusion regarding the disease was the leading stressor. When children were diagnosed with CHD, the family members did not understand why their children had become ill and what it meant. Some participants thought it was their fault, and others tried finding explanations, leading to feelings of confusion (Zhang et al., 2023). Participant 10 said, “I don’t know whether it is because I have thalassemia that caused him to have CHD, I’m thinking all the time and feel bewildered.”

The Zhang et al. (2023) study found evidence that confusion is not simply a product of literacy or access disparities but an emotional response to complex, poorly understood conditions. A common theme for families in rural areas. Emotional and cognitive stressors intersect with logistical and structural barriers.

The Zhang et al. (2023) study found a second theme: “[T]he hardships encountered during treatment of the disease”. Some participants stated that they had uncertainties about the treatment and changes in their children’s appearance after the operation. This effect was compounded by the difficulties in adhering to post-operative care due to a lack of appropriate care knowledge and skills. Participant 10 said, “I was scared at the time, especially when he just came out, I saw that there was a tube in his nose and his mouth; it must be hard for him.”

This aligns with the empirical data from my interviews: Zi, mother of Wang, echoed a similar sentiment, saying, “He’s still thin and her nutrition is not keeping up, I was not sure why, and it worried me because the local doctors don't fully understand congenital heart surgery.” However, even after getting qualified for the program and agreeing to travel, there are still logistical issues.

In an interview with Dr. Zhang, Charity Assistance Officer and medical professional at Tianjin TEDA International Cardiovascular Hospital, who coordinates patient selection, diagnosis, screening, and support for the hospital's philanthropic CHD treatment program, he mentioned, "For a lot of these families it is their first leaving their village, taking a plane or train, and going to the big city. A lot of these families cannot speak any Mandarin and therefore may find it challenging to adapt to a new environment." In another interview with Tsering Dolma, the Tibetan advisor who accompanied the families, she echoed similar sentiments: "It's only me and another advisor who accompany around 10 families to come here, it's not easy having to translate everything, help order plane and train tickets, even car rides to and from the hospital. I have to explain hotel bookings to them, restaurant names, because a lot of them can not read Mandarin." These accounts highlight how the intersectionality of cultural and linguistic barriers is deeply intertwined with the medical journey. Traveling to an urban hospital requires navigating a new language, unfamiliar public systems, and basic logistics such as accommodations and meals. For families who have never left their villages, these factors contribute to stress. In addition, the burden often falls on a very small number of bilingual advisors, emphasizing the scarcity of human resources in rural areas.

Next, I interviewed another family from Gansu. I spoke to Zi, mother of a two-year-old daughter, Wang, who had a ventricular septal defect (VSD) and was surgically treated with patch repair and closure of a patent foramen ovale (PFO). Ventricular septal defect (VSD) is a congenital heart condition characterized by a hole in the wall separating the heart's lower chambers, which can lead to symptoms such as poor growth, fatigue, and reduced oxygenation. In this case, the defect was surgically treated with patch repair, along with closure of a patent foramen ovale (PFO) to prevent abnormal blood flow between the atria (Mayo Clinic, 2022). Zi recalled her experience with adapting to a new environment, saying, "Since we are an ethnic minority group from Gansu, adapting to the food was difficult. We had to specifically look for halal restaurants in Tianjin, which was hard, as I was not familiar with the area. I had to stay in Tianjin for around a month because [Wang] got a cold and the surgery was delayed." Tsering Dolma further emphasized, saying, "Because Tianjin is a coastal area, there is a lot of seafood. Most of us are from the mountains and are used to owning and eating livestock." Tsering Dolma also comments on adapting to the climate of a new environment: "All of us are from areas of extremely high altitude like Tibet, with an average elevation of over 4000 meters. A lot of people go to these areas and feel like they lack oxygen, whereas we actually are overwhelmed by the oxygen."

These reflections further demonstrate the complex journey of rural families navigating CHD care. Families must manage unfamiliar diets, religious dietary requirements, and environmental differences, which compound the already emotional and financial burdens of CHD surgery. These experiences reveal how intersectional barriers interact to shape healthcare experience, access, and outcomes. The Zhang et al. (2023) study explains how children's health conditions and diseases also affected the children's academic performance and general development, all of which put a strain on the family (Zhang et al., 2023).

The third theme of the study was the heavy financial burden. In the study, all participants mentioned the direct and indirect burden of CHD on their families. The burdens comprise the cost of CHD treatment, food, lodging for medical treatment, travel expenses, and a reduction in family income during their children's hospitalization, with Participant 15 saying "[a]s long as [my husband] asks for leave to take care of the sick child, our income is gone."

Collectively, these findings reveal that many rural families in China navigate multifaceted emotional, logistical, and medical challenges when facing CHD care. These challenges are shaped by infrastructural inequities in rural areas. However, acknowledging these disparities and exploring how family decision-making and systemic barriers further shape access to and experiences of CHD treatment in rural China is a helpful first step to filling these gaps.

*Family Dynamics in Healthcare Decision-Making*

Family dynamics can be complex when it comes to making healthcare decisions, especially in rural areas where health literacy is less prevalent and family structures are different. I aimed to explore the way these family dynamics work and the influence of cultural values and systemic barriers on medical decisions.

In an interview with Cun, a Post Operative Care Coordinator responsible for postoperative discharge education and scheduling follow-up visits, at the TEDA hospital she said that "[c]hildren without fully functioning parental support or children with welfare institutions, for example a child needing six months of medication and non-Mandarin-speaking parents, are the families that struggle the most with following post-operative instructions." In rural areas, family dynamics intersect with systemic barriers to shape healthcare outcomes. Cun points out two critical issues that impact post-operative recovery: language barriers and the availability of consistent parental support. Families with limited literacy, language knowledge, and a lack of both parents present often face challenges in following instructions, following up with visits in hospitals, suggesting that postoperative care is not only a medical challenge but a social one that is largely influenced by family structures.

Furthermore, Mei, mother of Ming, recalls an experience during the screening in Gansu: "I remember there were nine families who were qualified for the subsidized surgery, but only one ended up choosing to go," she says, "There was a young girl in high school who was with her grandmother and was qualified for the surgery. The grandmother decided for her and turned the surgery down, saying that they didn't have the financial resources to fly over. The young girl's parents were rarely at home due to their work. The grandmother also thought that the surgery wasn't necessary because it didn't seem like a "big deal," and she was about to go to college." An untreated CHD in a teenager can lead to a cascade of life-threatening and long-term health consequences as they enter adulthood. The severity of risks depends on the individual, but nearly all untreated CHDs can eventually lead to heart failure and early death. Currently, there is no recent update on the status or condition of the girl. There are countless stories like this for families in rural areas, where parents are rarely home due to work and trying to make an income to support their families, leaving grandparents in charge of the children. Due to inadequate health literacy, a lot of conditions go undiagnosed and unknown amongst rural children, and when they are revealed, they are not taken seriously.

The Zhang et al. (2023) study explores the family affairs that predate a child's diagnosis that can lead to impaired family functioning, debt, unemployment, and stress on the family. Participant 3 said, "[a] few years ago [the child's] father became unemployed, and then the child got sick, which made things worse."

Most families also describe feeling vulnerable while dealing with disease in their children. Caregivers, who were mostly mothers, often reported feeling trapped because they spent most of their time and energy caring for their children, whereas fathers were occupied with balancing work (Zhang et al., 2023). In some cases, both parents are not present, which could lead to further neglect of a child's health condition.

Families also reported facing negative perceptions and attitudes due to little knowledge of CHD and the stigmatization of the disease in society (Zhang et al., 2023). Participant 16 reported saying, “I don’t want other people to know that my child got CHD. Some neighbours think that we are unhealthy and avoid contacting us, whereas some people show sympathy for our family just because we have a child with CHD. I have to hide my child’s illness, which is a big concern for our family.” For some families in rural areas, illness is not only a medical condition but a social identity that can generate exclusion, shame, and secrecy. In a setting where community networks are tight-knit and alternative forms of support are scarce, families are further deterred from taking advantage of life-saving opportunities, compounding stress and isolating families.

Unlike Western family models, China utilizes a process of shared decision-making based on family consultation. This family-based approach is rooted in Confucian culture, which tends to view the family as a basic unit of society. Major decisions regarding personal well-being and healthcare are often made collectively by family members. This ideology has created a unique “doctor-family-patient” model of the physician-patient relationship where physicians are dealing with the patient along with the patient’s family (Xu and Yuan 2024).

While this collectivist model reflects a deep cultural adherence to values such as filial piety and shared responsibility, it can also complicate access to care in rural areas. When grandparents or extended kin take on caregiving roles due to parental absence, decisions are filtered through an intersectionality of generational perspectives, limited health literacy, and constrained financial resources. In practice, this means that life-saving surgeries are declined because of cultural obligations and cultural norms. This connection between family dynamics, the Confucian decision-making model, and medical decisions allows us to see how cultural values, socioeconomic constraints, and institutional structures intertwine to influence healthcare-related decisions.

*Structural Barriers to Access and Post-Operative Care:*

Families in rural areas face a multitude of structural barriers to access medical healthcare and post-operative care. While surgical interventions and medical infrastructure in China have made significant reforms, rural families have yet to be able to utilize these newfound resources. I aim to explore the persistent structural barriers that shape both access to treatment and long-term post-operative care through the dimensions of economic, geographic, communicative, and cultural.

Wang’s mother, Zi, brought up the immense financial pressure their family faced despite the surgery being subsidized: “I had to borrow money from my neighbours and family relatives just to afford the flight ticket.” Public relations and Corporate Social Responsibility Mr. Lo corroborates Zi’s point: “Beyond the subsidized surgery, the government of areas like Tibet will provide an external subsidy of around 8000 yuan for their citizens to travel for surgery. However, this money is given to families after they return from surgery, so the financial pressure is still on the shoulders of the parents. Flights from Tibet to the city are also more expensive over the summer, ranging from 4000-6000 Yuan, which is already more than half of the subsidy used. Families who do not have the financial resources before the subsidy usually give up on this opportunity.”

Chen et al. (2023) highlight how rapid increases in healthcare expenses impose huge financial burdens on people, especially rural families. Urban residents have a disposable income approximately three times higher than that of rural residents. People with low income usually

have a greater need for healthcare because of their health status; however, higher healthcare expenses may deter them from seeking treatment when sick (Chen et al., 2023). Here, health status refers to a person's overall physical condition, presence of chronic illnesses, and general vulnerability to diseases. Low-income populations are already susceptible to poor health, which makes it possible for those conditions to worsen without adequate infrastructure.

The study conducted by Sun et al. (2009) analyzes the extent to which patients suffering from chronic disease in rural China face catastrophic expenditure on healthcare and how the New Co-operative Medical Insurance Scheme (NCMS) offers financial protection against this. This model is a government-run rural health insurance program in China, launched in 2003 to address the healthcare needs of the rural population, funded by individual contributions and government subsidies. This scheme is managed at the county level and is China's first large-scale attempt at universal rural health coverage after the 1980s collapse of the Rural Cooperative Medical Scheme (RCMS) (Sun et al., 2009). The study comprises a household survey conducted in six counties in Ningxia Autonomous Region and Shandong Province, with a total of 6,417 rural households, including 3944 individual chronic disease patients. This study shows the average proportion of chronic disease expenditure to annual non-food expenditure for NCMS members was 27% in Shandong and 35% in Ningxia, with the poorest households spending up to 45%. Even with membership, fewer than half of chronic disease patients receive reimbursement, and when they do, rates are extremely low, with only 11% of expenditure in Ningxia and 9% in Shandong reimbursed (Sun et al., 2009).

This illustrates how insurance is unevenly distributed and tied to local county-level management, leaving many rural families underinsured. Zi's story in the context of the NCMS structure helps explain why borrowing money from neighbors was still necessary despite surgery being subsidized. The design of subsidies with delayed reimbursements, low coverage for higher-level hospitals, and no coverage for costs of flights and accommodations further places a financial burden on families upfront.

Furthermore, a study by Chen et al. (2023) shows the extent to which the Medical Financial Assistance (MFA) policy provides social health insurance and medical cash assistance for low-income people. Their study shows that MFA does not significantly reduce financial burden for care for low-income populations, partly because it does not cover indirect costs such as transportation and lodging, also impacting long-term, post-operative care and follow-up. The results show that MFA has no significant impact on the medical financial burden on low-income people in rural areas. The ratio of out-of-pocket health expenditure (OOPE) to per capita household non-food expenditure was 0.582 for MFA beneficiaries (treatment group), still considerably higher than that of the non-beneficiaries (control group), which had a ratio ranging from 0.472 to 0.591. None of the estimated effects were statistically significant, indicating that the medical financial burden on low-income people remains heavy even after accounting for MFA support (Chen et al., 2023). Taken together, these findings illustrate that while China has implemented insurance programs and subsidies, rural families still face economic strain, forcing families to borrow money or forego care despite being eligible for support.

In addition, in rural China, the shortage of skilled healthcare professionals and the geographic distance to medical facilities significantly hinder access to timely and effective treatment and post-operative care. Mei comments on her son Ming's physical state post-surgery: "He's still underweight, and very picky with food, though his immunity has improved and he is more energetic. I have tried Traditional Chinese Medicine (TCM) and consultations available here in Gansu, but there are no clear reasons found."

Charity Assistance Officer and medical professional at TEDA hospital, Dr. Zhang, posits: “Contrary to popular belief, the medical infrastructure in rural areas is new and renovated; however, there is a shortage in skilled healthcare professionals and trained doctors in specialized diseases such as CHD.” Studies indicate that urban hospitals attract most health professionals, leaving rural areas with serious shortages. For instance, in 2012, China had only 0.43 pediatricians per 1000 children, far below the global average. This maldistribution is exacerbated by policies that favor urban placements for medical graduates, leaving rural families to rely on tertiary centers (Hou and Ke, 2015). Post-operative health professional Cun echoed this sentiment, saying, “[w]e don’t have contact with local hospitals and they don’t have specialized professionals in CHD.”

Dr. Zhang also brings up another barrier: “A lot of these families live in areas that are geographically far from hospitals, some do not even drive cars, making it burdensome to return consistently for check-ups or follow-up care.” A study in Shaanxi Province found that the travel time to health services is associated with lower utilization, with longer distances leading to decreased healthcare access, posing challenges for families requiring frequent post-operative visits. A total of 30.9% of patients traveled more than 15 minutes to the nearest medical facility, 33.3% of participants lived in rural areas, and 22.6% in urban areas (Bai et al., 2022).
The lack of regional coordination in healthcare services contributes to fragmented follow-up care. This lack of experience with CHD can lead to inconsistencies, paired with the distance from hospitals, further deterring families from seeking follow-up care, impacting the recovery process.

However, perhaps one of the most challenging barriers rural families face is the limited health literacy and communication challenges, both of which affect families’ ability to follow post-operative care instructions. Cun says, “Many rural parents cannot read or write, relying on voice messages in their local dialects in WeChat groups. These voice messages are then translated by an interpreter [Tsering Dolma] before being understood by doctors in cities like Tianjin.” The translation process slows down communication, often stripping messages of urgency or nuance, which delays medical responses. Cun goes on, “A lot of parents often pretend to nod and say they understand when I give the post-surgery instructions, but later forget medication timing or wound care, negatively impacting recovery and long-term health outcomes.”

These experiences reflect broader trends identified in a large cross-sectional study of 78,646 residents in Henan province, where the health literacy level in rural populations was 8.09% compared with 16.92% in urban areas, and far below the national average (Wang et al., 2020).

The study also found that older adults in rural areas were significantly less likely to exhibit basic health literacy. Residents aged 45-54, 55-64, and 65+ have 84.6%, 71.6%, and 67.9% lower odds, respectively, of demonstrating basic health literacy than those aged 15-24 (Wang et al., 2020).

TABLE 2. Health Literacy Levels and Age-Related Disparities in Henan Province

| Age Group | Odds of demonstrating basic health literacy compared to 15-24 age group | Source |
|---|---|---|

| | | |
|---|---|---|
| 45-54 | 84.6% lower odds | Wang et al., 2020 |
| 55-64 | 71.6% lower odds | Wang et al., 2020 |
| 65+ | 67.9% lower odds | Wang et al., 2020 |

These findings underscore how communication and comprehension barriers in rural families are widespread and structural, highlighting the need for tailored health education interventions and multilingual, culturally sensitive communication strategies in post-operative care in rural China.

*Impact of Support Programs and Partnerships*

Charitable programs such as the partnerships with the TEDA Hospital provide subsidized surgeries and post-operative follow-up for children with CHD from rural and remote areas. These programs aim to reduce financial and geographic barriers by covering surgery costs. Despite these provisions, many rural families remain unaware of surgical opportunities, limiting the utilization of these available resources.

Mr. Lo, Public Relations and Corporate Social Responsibility Coordinator, describes the biggest challenge he faced in helping families: “It’s hard finding and informing parents in remote areas of our project. Our program has been going on for over a decade, performing screenings and providing surgeries, yet we have only saved around 700 children.” Mr. Lo notes the reason why he thinks the program has not reached as many families as they would like: “A lot of information is transferred orally in rural areas. Messages are passed by word-of-mouth, often unreliable or slow, especially when people move frequently, which rural families often do.” Mr. Lo’s observations are corroborated by recent statistics. A study indicates that only 44.8% of parents in Southern China were aware of charitable assistance programs for CHD, highlighting the limited reach of such initiatives in rural communities (ChinaPower, 2021).

Furthermore, in a study investigating the perceptions, attitudes, and treatment-seeking intentions of Chinese parents toward charitable assistance for CHD, of a total of 220 parents of children, the perception rate for charity assistance for CHD was only 44.8% and the channels of understanding were narrow. Of those who were aware, only 33.8% knew the main evaluation criteria, and 11.9% knew the specific assistance amounts. Despite these gaps in awareness, the majority of parents (98%) approved of charitable assistance, and 79.1% reported that it increased their likelihood of seeking treatment, particularly for low-income families (Xie et al., 2021).

Additionally, when asked about the challenges of post-operative follow-up, Cun said, “Many families actually lack stable internet access and smartphones, making it difficult to use digital outreach methods.” This can not only cause discontinuities in post-operative care but also limit the way charitable organizations can be promoted. “Rural communities typically only listen to a couple of authoritative figures in their community, sometimes it’s religious figures, the government, that’s why it’s so hard reaching out to families,” said Mr. Lo. Understanding how families make decisions in this context is a critical step to improving the exposure of charitable programs. This contrasts with Western models of individualistic decision-making. Programs that do not account for these shared family decision-making structures can risk lower engagement and adherence.

These findings demonstrate that while charitable programs are highly valued, limited promotion infrastructure, geographic distance, and oral transmission of information hinder families from accessing these services and life-saving opportunities. Effective solutions, therefore, must go beyond simply providing financial support and adequate medical services. Outreach strategies must be culturally sensitive to rural social structures, leveraging local figures and learning which channels work best to ensure awareness and comprehension.

DISCUSSION:

This study extends and contributes to the growing amount of research on structural disparities in rural China that undermine equitable access to CHD treatment and post-operative care. My findings illuminate the lived experiences of rural families in making healthcare and related decisions, highlighting the family dynamics and structural barriers that shape healthcare decisions, treatment access, and post-operative care. Collectively, my findings reveal that families navigate through multifaceted, emotional, logistical, cultural, and medical challenges in navigating CHD care.

While most existing studies highlight these issues primarily through quantitative data, my research provides a mixed-method approach focusing on the qualitative perspectives that capture the voices and lived realities of affected families. In doing so, this study offers an up-to-date and nuanced understanding of how these barriers are experienced on the ground. To address these barriers, this paper puts forward a set of context-sensitive solutions for the main problems revealed throughout the study:

*(1) Communication & Health Literacy Barriers*

A persistent barrier in rural CHD care is that parents often leave hospitals without fully understanding the complex post-operative instructions, let alone the diagnosis itself. Written instructions are provided in WeChat group chats they are in and paper pamphlets are also provided; however, these all remain inaccessible due to low literacy, language barriers, and cultural unfamiliarity with medical terms. To address this, I propose a video-based educational model featuring demonstrations of medication administration and wound care by Tianjin health professionals with voiceovers in local dialects. These videos, accessible via QR codes, allow families to download them directly onto their devices. This not only improves comprehension but also builds confidence in caregiving. In the long term, such visual resources can be shared across clinics, community centers, and different dialects can be added to the existing clip. This is a low-cost, scalable tool for medical education in rural areas.

*(2) Financial Barriers*

For many families, financial strain begins not only with medical costs but with hidden expenses such as travel, accommodation, and lost wages, following through with post-operative care. Current subsidies often disburse funds too late, leaving families unable to reach treatment centers on time and having to forego life-saving opportunities. Revising the current loan model to provide advance payments or prepaid vouchers for essential expenses would remove one of the most immediate barriers to care. Instead of families delaying surgery until funds arrive or not going through with the program, children could receive timely treatment. Beyond CHD, this model could inform other healthcare financing reforms by showing how upfront support ensures program accessibility for the poorest families.

*(3) Program Outreach*

Even when healthcare programs exist, rural families may remain unaware of them due to limited communication channels, reliance on word of mouth, or mistrust of institutions. Partnering with public figures, such as celebrities or influencers with rural roots, can amplify program visibility and legitimacy through their established platforms. These figures can serve as cultural "bridges", spreading awareness not only to families that need this opportunity, but to potential donors and sponsors that can further amplify these programs, increasing reliability. Outreach campaigners ought to learn the ways in which rural communities consume information and tailor efforts in those ways. By framing healthcare information as community-driven rather than institutional, this solution can strengthen trust.

*(4) Local Healthcare Worker Training & Integration*

Another long-term solution involves strengthening local healthcare capacity through creating pathways for Mandarin-proficient individuals to become medical interpreters and translators. Currently, many families struggle to communicate effectively with urban hospital staff, leading to gaps in comprehension, mistrust, and poor adherence to instructions. Simultaneously, the shortage of trained rural providers means families must rely on geographically distant tertiary hospitals for routine follow-up. By investing in interpreter training programs, hospitals can expand the pool of language support personnel while also creating new branches of employment in rural areas. Subsequently, providing targeted training for rural healthcare workers through telemedicine routes and urban specialists would allow families to access ongoing medical guidance closer to home.

The implications of these proposed solutions extend beyond CHD and healthcare, pointing toward scalable frameworks for rural healthcare access more broadly, encompassing a family's holistic decision-making process. However, further research is still needed to evaluate their feasibility, long-term sustainability, and adaptability across diverse regions in China.

Nevertheless, this study has limitations. The small sample size means that findings cannot be generalized to all rural families in China or even Gansu. Recruitment challenges, especially the need for Mandarin proficiency and the scarcity of interpreters, restricted the diversity of participants. In addition, the sensitive nature of discussing children's medical conditions constrained the scope of questioning, leaving some aspects unexplored. However, despite these constraints, the study still provides important insights that deepen our understanding of rural families' lived experiences and decision-making processes while providing bottom-up, adequate solutions.

## CONCLUSION

This pilot study investigates barriers to congenital heart disease (CHD) care among rural Chinese families, probing the economic, geographic, cultural, and health literacy challenges that restrict access to diagnosis, treatment, and post-operative management. Using a mixed-methods design, the study integrates qualitative data from six semi-structured interviews with families, medical professionals, and program coordinators with existing quantitative evidence to elucidate systemic inequities. Findings reveal a significant inverse relationship between the specialized care required for CHD and its accessibility to rural families, shaped by structural disparities and Confucian family decision-making dynamics. I propose targeted interventions, including video-based educational resources in local dialects, prepaid vouchers for travel and accommodation, community-based outreach leveraging local leaders, and enhanced training for rural healthcare providers, to mitigate identified barriers. As a pilot study,

its limited sample size serves to test the feasibility of qualitative approaches and identify key themes for future research. Despite this constraint, the findings provide a critical foundation for advancing equitable CHD care and addressing broader rural healthcare disparities in China, reinforcing the imperative of universal access to health services.

Works Cited

Al Shamsi, H., Almutairi, A. G., Al Mashrafi, S., & Al Kalbani, T. (2020). Implications of language barriers for Healthcare: A systematic review. *Oman Medical Journal*, *35*(2). https://doi.org/10.5001/omj.2020.40

Ao, Y., Feng, Q., Zhou, Z., Chen, Y., & Wang, T. (2022, May 28). *Resource allocation equity in the China's rural three-tier healthcare system*. MDPI. https://www.mdpi.com/1660-4601/19/11/6589

Bai, R., Gao, J., & Dong, W. (2022). Is travel time associated with Health Service Utilization in Northwest China? evidence from Shaanxi province. *International Journal of General Medicine*, *Volume 15*, 4949–4957. https://doi.org/10.2147/ijgm.s360582

Chen, Y., Gao, G., Yuan, F., & Zhao, Y. (2023). The impact of medical financial assistance on healthcare expenses and the medical financial burden: Evidence from rural China. *Frontiers in Public Health*, *10*. https://doi.org/10.3389/fpubh.2022.1021435

China Power. (2021). *How web-connected is China?*. ChinaPower Project. https://chinapower.csis.org/web-connectedness/

Ittenbach, R. F., Cassedy, A. E., Marino, B. S., Spicer, R. L., & Drotar, D. (2009). Adherence to treatment among children with cardiac disease. *Cardiology in the Young*, *19*(6), 545–551. https://doi.org/10.1017/s1047951109991260

Li, H., & Zhang, R. (2024). Analysis of the structure and trend prediction of China's total health expenditure. *Frontiers in Public Health*, *12*. https://doi.org/10.3389/fpubh.2024.1425716

Ma, L., Chen, M., Fang, F., & Che, X. (2019). Research on the spatiotemporal variation of rural-urban transformation and its driving mechanisms in underdeveloped regions: Gansu Province in western China as an example. *Sustainable Cities and Society*, *50*, 101675. https://doi.org/10.1016/j.scs.2019.101675

Mayo Foundation for Medical Education and Research. (2022). *Ventricular septal defect (VSD)*. Mayo Clinic. https://www.mayoclinic.org/diseases-conditions/ventricular-septal-defect/symptoms-causes/syc-20353495

Pachon, M., & Zamorano, J. (2008). Mitral annular calcifications and aortic valve stenosis. *European Heart Journal*, *29*(12), 1478–1480. https://doi.org/10.1093/eurheartj/ehn226

Rui, D. (2015). A family-oriented decision-making model for human research in mainland China. *Journal of Medicine and Philosophy*, *40*(4), 400–417. https://doi.org/10.1093/jmp/jhv013

Su, Z., Zhang, Y., Cai, X., Li, Q., Gu, H., Luan, Y., He, Y., Li, S., Chen, J., & Zhang, H. (2023). Improving long-term care and outcomes of congenital heart disease: Fulfilling the promise of a healthy life. *The Lancet Child & Adolescent Health*, *7*(7), 502–518. https://doi.org/10.1016/s2352-4642(23)00053-6

Sun, Q., Liu, X., Meng, Q., Tang, S., Yu, B., & Tolhurst, R. (2009). Evaluating the financial protection of patients with chronic disease by health insurance in rural China. *International Journal for Equity in Health*, *8*(1). https://doi.org/10.1186/1475-9276-8-42

Tian, Y., Gu, Q., Hu, X., Ge, X., Ma, X., Yang, M., Jia, P., Zhang, J., Yang, L., Zhao, Q., Liu, F., Ye, M., Yang, Y., & Huang, G. (2025). Newborn screening for congenital heart disease: A five-year study in Shanghai. *International Journal of Neonatal Screening*, *11*(2), 38. https://doi.org/10.3390/ijns11020038

Wang, W., Zhang, Y., Lin, B., Mei, Y., Ping, Z., & Zhang, Z. (2020). The urban-rural disparity in the status and risk factors of Health Literacy: A cross-sectional survey in Central China. *International Journal of Environmental Research and Public Health*, *17*(11), 3848. https://doi.org/10.3390/ijerph17113848

Wang, Y., Castelli, A., Cao, Q., & Liu, D. (2020). Assessing the design of China's complex health system – concerns on equity and efficiency. *Health Policy OPEN*, *1*, 100021. https://doi.org/10.1016/j.hpopen.2020.100021

World Bank. (2020). Literacy rate, adult total (% of people ages 15 and above) [Data set]. https://data.worldbank.org/indicator/SE.ADT.LITR.ZS

Xiang, L., Su, Z., Liu, Y., Zhang, X., Li, S., Hu, S., & Zhang, H. (2018). Effect of family socioeconomic status on the prognosis of complex congenital heart disease in children: An observational cohort study from China. *The Lancet Child & Adolescent Health*, *2*(6), 430–439. https://doi.org/10.1016/s2352-4642(18)30100-7

Xie, W.-P., Liu, J.-F., Lei, Y.-Q., Cao, H., & Chen, Q. (2021). Chinese parents' perceptions, attitudes, and treatment-seeking intentions toward congenital heart disease with charitable assistance: A cross-sectional study in a congenital heart center in Southern China. *Patient Preference and Adherence*, *15*, 2459–2466. https://doi.org/10.2147/ppa.s335567

Xie, W.-P., Liu, J.-F., Lei, Y.-Q., Wang, Z.-C., Chen, Q., & Cao, H. (2022). Application of WeChat platform in midterm clinical follow-up of children who underwent transthoracic device closure of VSD. *Brazilian Journal of Cardiovascular Surgery*, *37*(2). https://doi.org/10.21470/1678-9741-2020-0376

Xu, H., & Yuan, M. (2024). Family roles in informed consent from the perspective of young Chinese doctors: A questionnaire study. *BMC Medical Ethics*, *25*(1). https://doi.org/10.1186/s12910-023-00999-6

Yip, W., Fu, H., Chen, A. T., Zhai, T., Jian, W., Xu, R., Pan, J., Hu, M., Zhou, Z., Chen, Q., Mao, W., Sun, Q., & Chen, W. (2019). 10 years of health-care reform in China: Progress and gaps in Universal Health Coverage. *The Lancet*, *394*(10204), 1192–1204. https://doi.org/10.1016/s0140-6736(19)32136-1

Zhang, D., Jiang, Z., Xie, Y., Wu, W., Zhao, Y., Huang, A., Li, T., & Ba-Thein, W. (2022). Linguistic barriers and healthcare in China: Chaoshan vs. Mandarin. *BMC Health Services Research*, *22*(1). https://doi.org/10.1186/s12913-022-07744-6

Zhang, Y., Zhou, H., Bai, Y., Chen, Z., Wang, Y., Hu, Q., Yang, M., Wei, W., Ding, L., & Ma, F. (2023). Families under pressure: A qualitative study of stressors in families of children with congenital heart disease. *Stress and Health*, *39*(5), 989–999. https://doi.org/10.1002/smi.3240

Zhao, D., Zhou, Z., Shen, C., Nawaz, R., Li, D., Ren, Y., Zhao, Y., Cao, D., & Zhai, X. (2021). Rural and urban differences in patient experience in China: A coarsened exact matching study from the perspective of residents. *BMC Health Services Research*, *21*(1). https://doi.org/10.1186/s12913-021-06328-0