

## Original Article

# A parental perspective concerning barriers to care for neural tube defects in China

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## Abstract

**Background:** The People's Republic of China (PRC) has the highest incidence of neural tube defects (NTDs) in the world. NTDs remain a significant contributor to the global burden of disease amenable to surgical care; however, no studies to date have evaluated the patients' perspective regarding perceived barriers to care.

**Methods:** The study was conducted at the Shanghai Children's Medical Center (SCMC) between 6/11/2014 and 7/17/2014. Surveys were administered to families presenting to the clinic of the SCMC director for Pediatric Neurosurgery. Additionally, orphaned patients under the care of the Baobei Foundation were surveyed for comparison. Participants were allowed to mark as many barriers on the survey as they deemed relevant to their experience.

**Results:** A total of 69 patients were surveyed. The most frequently chosen barrier to care, with a  $P$  value  $< 10^{-5}$ , was that the referring physician did not know enough about the child's condition. As compared to the Baobei Foundation orphans, surveyed patients presented at an older age for initial treatment (7 months versus 1 month,  $P$  value = 0.001), and visited more hospitals before reaching SCMC (3.14 versus 1.0,  $P$  value  $< 10^{-5}$ ).

**Conclusions:** The results of this study highlight the referring physician as a primary barrier to care. The younger age at time of treatment for Baobei orphans born with NTDs supports this finding, as they essentially bypassed the referral process. An elaboration on reasons for this real or perceived barrier may provide insight into a means for expedited diagnosis and treatment of NTDs within the PRC.

**Key Words:** Barriers to care, neural tube defect, People's Republic of China, referral system, surgery, survey

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## INTRODUCTION

The People's Republic of China (PRC) has the highest incidence of neural tube defects (NTDs) in the world.<sup>[39]</sup> NTDs result from failure of the neural tube to close completely during embryogenesis and comprise a broad spectrum of disease processes

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encompassing certain cranial defects (e.g., anencephaly and encephalocele), open spinal dysraphism (e.g., meningocele and myelomeningocele), and closed spinal dysraphism (e.g., spinal lipoma and tight filum terminale).<sup>[11,15]</sup> To its credit, the PRC has implemented sweeping healthcare reforms in recent years, including maternal folic acid supplementation programs that have resulted in declining NTD rates.<sup>[5,27,39]</sup> Nevertheless, NTDs remain a significant public health concern with certain regions within the PRC having an incidence four times that seen in the United States.<sup>[27,35]</sup>

The more severe manifestations of NTDs demand medical attention within the first 24–72 hours of life for ideal long-term neurologic function.<sup>[19,32]</sup> Without treatment, neurologic impairment can be significant, resulting in large disability-adjusted-life-years (DALY).<sup>[9]</sup> Though the proper treatment of NTDs remains a complicated topic, often, early surgical intervention is warranted. As such, NTDs remain a significant contributor to the global burden of disease amenable to surgical care.<sup>[12,17,21]</sup> Low- and middle-income countries (LMIC) carry the majority of this weight, with an estimated reduction in global disease burden of 76% should surgical coverage in LMICs achieve levels similar to those seen in high-income countries.<sup>[12]</sup>

Access to surgical care for NTDs remains a broad subject that has not been extensively addressed in the literature. To date, the evaluation of barriers to timely surgical treatment has come primarily from retrospective institution-based analysis of gaps in care.<sup>[21]</sup> This approach fails to consider the patients' and patient families' perspective regarding perceived barriers to treatment. Thus, the aim of this study is to investigate the barriers to surgical care for NTDs from the patient perspective, thereby expanding the debate concerning global barriers to surgical care by considering relevant cultural factors.

We had the opportunity to explore this issue at the Shanghai Children's Medical Center (SCMC), a tertiary care hospital in the PRC with one of the country's premiere neurosurgical units. Those surveyed presented to SCMC through one of two primary routes: either as patients with their family member(s) or as orphans through the assistance of the Baobei Foundation, a horizontal program orchestrating the medical care of children in the PRC orphanage system. SCMC coordinates care for children from a wide geographic range centered in eastern China and, given its diverse patient population, represents an ideal location to ascertain the perceived barriers to surgical care for both of these groups.

## MATERIALS AND METHODS

### Study setting and participants

The study was conducted at SCMC, one of the premiere tertiary care centers for neurosurgery in the PRC. Study

participants were the birth or foster parents of children presenting to the office of the director for Pediatric Neurosurgery at SCMC, Nan Bao, MD for treatment of a NTD between the dates of 6/11/2014 and 7/17/2014. Given that Dr. Bao was seeing patients in differing stages of the treatment process, patients surveyed in a single day included those presenting to the clinic for the first time, those presenting for the operation itself or those in various stages of postoperative follow-up. Regardless of the stage of treatment a patient was in, anyone presenting during the study timeframe was considered eligible for the survey.

Additionally, patients presenting under the care of the Baobei Foundation, who were similarly at various stages of their treatment, were considered eligible participants. The Baobei Foundation orphans who were seen at SCMC prior to the 6/11/2014 start date and who had thorough documentation were also eligible for study inclusion, given that the chief of the foundation who coordinated the care of these prior patients was available for interview.

### Survey design

A barriers to care survey was created with the assistance of an UCLA-based focus group consisting of Chinese immigrants from both rural and urban areas of the PRC in order to design a culturally relevant survey.

### Survey administration

All surveys were administered in a room adjoining Dr. Bao's clinic after proper parental or guardian verbal consent was obtained. Participants were not paid for their participation and it was emphasized that their participation or lack of participation would in no way affect the quality or type of care received at SCMC. The interviewers were two MD candidates at the David Geffen School of Medicine, UCLA with graduate-level training in qualitative methods. A bilingual hospital staff member aided the interviewers in the survey administration. After providing written consent, all participants completed baseline demographic information in addition to a barrier to care questionnaire. The questionnaire consisted of a list of preformed options and participants were permitted to mark as many barriers as they deemed relevant to their experience, including an "other" option where they could elaborate on barriers not contained within the original list. Participants could refuse to answer any questions deemed too sensitive or intrusive. The questionnaire in English is presented in Figure 1. The families answered a version of the survey translated into Mandarin. An adjusted barrier to care survey was developed for children presenting to SCMC under the care of the Baobei Foundation and this is presented in Figure 2.

### Statistical analysis

The median length of time from birth to initial medical treatment was calculated for both the patients who presented with their families and for patients

Barriers-to-Care/Perceived Need of Care Questionnaire: Shanghai Children's Medical Center

Date: \_\_\_\_\_

- 1) How old is your child? \_\_\_\_\_ How old are you (mother)? \_\_\_\_\_
- 2) Where was your child born? Province \_\_\_\_ City\_\_\_\_ District \_\_\_\_ Town \_\_\_\_ Township \_\_\_\_ Village \_\_\_\_
- 3) Which hospital was your child born in? \_\_\_\_\_
- 4) Did your doctor(s) notice that something was abnormal with your child at or before the time of birth? \_\_\_\_\_ Did they mention spina bifida? \_\_\_\_\_
  - o If the doctors did not tell you immediately, how soon after the birth did you discover something was wrong? \_\_\_\_\_
- 5) At what age did your child start to receive treatment at SCMC? \_\_\_\_\_ If initial treatment was not at SCMC, at what age did your child first receive treatment? \_\_\_\_\_
  - o Did any of the following influence your decision and/or prevent you from receiving treatment initially? (check all that apply)
    - i. The child's symptoms were thought to be too severe
    - ii. The child's symptoms were thought to be not severe enough
    - iii. Family members or friends suggested that you do not seek treatment
    - iv. Physician not knowing enough about the child's condition
    - v. Lack of time and family work constraints
    - vi. Fear of the treatment and the side-effects of the treatment on the child
    - vii. Your religious and/or cultural beliefs
    - viii. Cost of the treatment and related services
    - ix. Lack of available transport to the hospital
    - x. Lack of health professionals or health facilities
    - xi. Lack of drugs or equipment at the health facility
    - xii. The child was receiving alternative treatments
    - xiii. Your doctors did not know to refer you to SCMC
      - o Other (please specify) \_\_\_\_\_
- 6) How many different hospitals has your child visited for this condition? \_\_\_\_\_
- 7) What was the last hospital your child visited before coming to SCMC? \_\_\_\_\_
- 8) What medical interventions, if any, did your child receive before coming to SCMC? \_\_\_\_\_
  - o What complications, if any, were there with the treatments that your child received before coming to SCMC? \_\_\_\_\_
- 9) How did you hear about SCMC? (check the one that applies)
  - o Family or a family friend
  - o The television
  - o The internet
  - o The newspaper
  - o A doctor
  - o Any other type of health professional
  - o Other (please specify) \_\_\_\_\_
- 10) What is the annual family income? \_\_\_\_\_
- 11) If you have any other children, how old are they now? Are they daughters or sons? \_\_\_\_\_
- 12) If you have other children, were there any complications with the previous pregnancies? \_\_\_\_\_ Were your other children born healthy? (If not please specify) \_\_\_\_\_

Figure 1: Survey administered to families presenting to SCMC for NTD treatment, translated from Mandarin

Barriers-to-Care/Perceived Need of Care Questionnaire - Baobei Foundation

Date: \_\_\_\_\_

- 1) What is the age of the child? \_\_\_\_\_
- 2) Where was the child located prior to Baobei? \_\_\_\_\_
- 3) What has the child been diagnosed with? \_\_\_\_\_
- 4) At what age did the child start to receive treatment? \_\_\_\_\_
- 5) Did the child visit any hospitals prior to SCMC (if so which ones and how many)? \_\_\_\_\_
  - o What was the last hospital the child visited before coming to SCMC? \_\_\_\_\_
- 6) What medical interventions, if any, did the child receive before coming to SCMC? \_\_\_\_\_
  - o What complications, if any, were there with the treatments that the child received before coming to SCMC? \_\_\_\_\_

Figure 2: Adjusted survey administered to BaoBei Foundation employees caring for orphans presenting to SCMC for NTD treatment, translated from Mandarin

who presented through the Baobei Foundation. The significance in the difference between the median lengths of time for the groups was calculated using the bootstrapping method, given the non-Gaussian distribution of the data. Similarly, the significance in the difference between the median numbers of

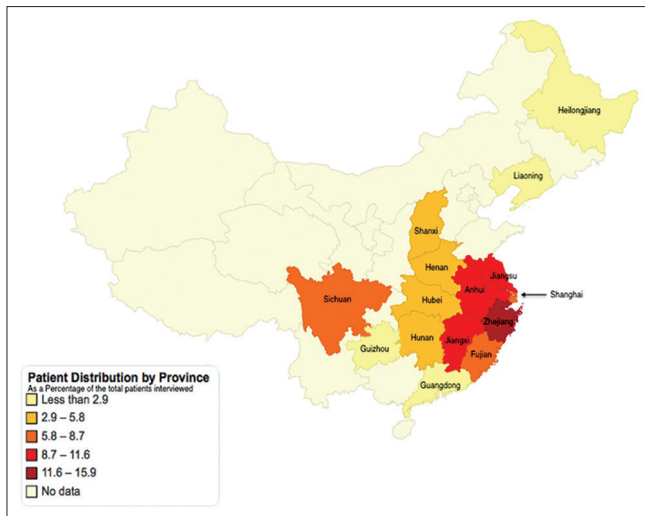
hospitals visited by each group was calculated using the bootstrapping method.

Additionally, the barriers to care options on the survey were numbered 1–14 and bootstrapped to calculate the frequency with which each barrier was selected by patients and families. In so doing, any potential correlation between barriers (e.g., barriers 1 and 2 being linked and chosen together more often than by chance alone) was accounted for, since each family's barrier choices were sampled as a unit as opposed to individually.

To evaluate for any correlation between the type of NTD diagnosed and the perceived barriers to care, a Fisher's exact test was performed, given the relatively small sample sizes within certain groups. In so doing, significance deviation from the null hypothesis could be calculated exactly. The Fisher's exact test was also used to evaluate for significant differences in malformation detection rates by referring physicians with respect to the type of NTD diagnosis.

## RESULTS

Over a 6-week period, a total of 69 families were interviewed. The patients came from 14 provinces in addition to the city of Shanghai itself, with the furthest province being 2277 km from Shanghai. The number of

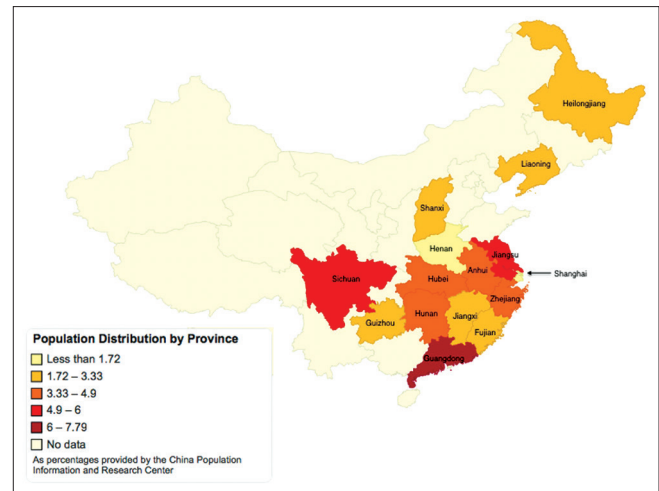


**Figure 3: Patient distribution by province as a percentage of the total number of families interviewed at SCMC**

patients presenting from each province are presented in Figure 3 and the population distribution in those represented provinces are presented in Figure 4. Of the 69 families interviewed, six different types of NTDs were recorded and these are listed with their respective frequencies in Table 1, separated according to closed versus open spinal dysraphism. Among those 69 families, two patients presented with both a spinal lipoma and tight filum terminale. Thus, a total of 71 diagnoses were seen.

Of the 71 diagnoses seen, 36 reported that the referring physician noted an abnormality at or before the time of birth, 33 reported that the physician did not note any abnormality at or before the time of birth, and two were uncertain when the abnormality was noted. This data is presented in Table 2, divided between the different NTD types. Of the 36 families, who reported an abnormality noted at birth, 29 did not receive a NTD diagnosis from the physician at the time of birth, while seven did receive a NTD diagnosis from the physician at the time of birth. Again, this data is presented in Table 2, divided between the different NTD types. Concerning the referring physician detection rate of specific malformations at the time of birth, myelomeningocele was detected significantly more often by the referring physician than tight filum terminale or tethered cord, with a *P* value of 0.005 and 0.036, respectively. Otherwise, the detection rates by the referring physicians at the time of birth did not vary significantly between groups.

Among the 69 families, 18 children received some form of medical intervention related to their NTD or the sequelae of their disease prior to their arrival at SCMC. Four of the 18 children received two separate medical interventions prior to SCMC, amounting to a total of 22 interventions. The types of interventions recorded and their relative frequencies are presented in Table 3.



**Figure 4: Population distribution by province as a percentage of the total population of the PRC**

**Table 1: Final patient diagnosis**

| Type of NTD                     | <i>N</i> |
|---------------------------------|----------|
| Closed spinal dysraphic lesions |          |
| Spinal lipoma                   | 32       |
| Tight filum terminale           | 19       |
| Tethered spinal cord            | 2        |
| Lipomyelomeningocele            | 7        |
| Open spinal dysraphic lesions   |          |
| Meningocele                     | 4        |
| Myelomeningocele                | 7        |

Additionally, each family was asked how they eventually heard about SCMC. All families except for one were willing to answer the question and six families chose two different options, for a total of 74 responses. The results are presented in Table 4. Of the families who selected “other,” two specified that they were employees of SCMC, seven specified that they had lived, worked or gone to school in Shanghai, and had a general knowledge of the hospitals in the area, one specified that a taxicab driver within Shanghai recommended the hospital, and one specified that a third party financing the child’s healthcare directed them to SCMC.

Regarding the different barriers to care for families, the most frequently chosen barrier, with a *P* value < 10<sup>-5</sup>, was that the referring physician did not know enough about the child’s condition (options #4). The second most frequently chosen option, with a *P* value of 0.070, was that the physician did not know to refer to SCMC (option #13). When comparing the most frequently chosen barriers to care between different NTD types (i.e., spinal lipoma versus meningocele, etc.), the only group with a particular barrier chosen significantly more than any other group was lipomyelomeningocele. The families of patients with lipomyelomeningocele indicated on the survey that the patient was receiving



**Table 2: Patient sex, abnormality detection rate, and NTD detection rate by the referring physician at the time of birth**

| Type of NTD           | Patient's sex |        | Abnormality noted by referring physician at birth |     |         | NTD diagnosis made by referring physician at birth |     |
|-----------------------|---------------|--------|---|-----|---------|--|-----|
|                       | Male          | Female | Yes   | No  | Unknown | Yes  | No  |
| Spinal lipoma         | 15            | 17     | 17  | 14  | 1       | 3  | 14  |
| Tight filum terminale | 11            | 8      | 6   | 13  | 0       | 0  | 6   |
| Tethered cord         | 1             | 1      | 0   | 2   | 0       | N/A  | N/A |
| Meningocele           | 2             | 2      | 2   | 2   | 0       | 1  | 1   |
| Myelo-meningocele     | 3             | 4      | 6   | N/A | 1       | 2  | 4   |
| Lipomyelo-meningocele | 4             | 3      | 5   | 2   | 0       | 1  | 4   |

**Table 3: Reported frequency of medical interventions prior to patient arrival to SCMC**

| Intervention                                 | N  |
|--|----|
| Neurosurgery/orthopedic surgery              | 10 |
| Anorectal surgery                            | 3  |
| Rope tied around defect                      | 2  |
| Cast or brace                                | 3  |
| Antibiotics or other prescription medication | 3  |
| Herbal prescription                          | 1  |

**Table 4: Reported means of SCMC discovery**

| Medium                                | N  |
|---------------------------------------|----|
| Family or family friend               | 19 |
| Television                            | 1  |
| Internet                              | 26 |
| Newspaper                             | 0  |
| Physician                             | 17 |
| Other type of healthcare professional | 0  |
| Other                                 | 11 |

alternative treatments (option #12) significantly more frequently than the other NTD groups, with a *P* value of 0.041. The overall frequency with which various barriers to care were selected by the different NTD groups is presented in Table 5.

Among the Baobei Foundation orphans, 11 were identified as having been treated for a NTD, six of whom were male and five of whom were female. Ten of these patients were eventually diagnosed with myelomeningocele and one was diagnosed with meningocele. Survey data from patients presenting to SCMC with their families was compared to the data from patients presenting through the Baobei Foundation and two significant differences were found. First, the median age at initial treatment for the Baobei Foundation orphans was 1 month (ranging from 4 days to 5 months) and for children presenting with their families was 7 months (ranging from immediately after birth to 17 years), with a significant difference in the medians of *P* = 0.001. Second, the median number of hospitals visited (including SCMC) by the Baobei Foundation

orphans was 1.0, while the median number of hospitals visited by children with their families was 3.14, a *P* value < 10<sup>-5</sup>.

## DISCUSSION

Families seeking NTD treatment for their children had a less direct route to appropriate surgical care than children in the PRC orphanage system, as evidenced by a median of six additional months to time of treatment, and a median of two additional hospitals visited before SCMC, as compared to PRC orphans. Parents identified the referring physician(s) as the primary impediment to surgical care, either because they perceived the physician had an inadequate understanding of the disease process or because the physician missed an opportunity to refer to SCMC for further evaluation. Comparatively, PRC orphans experienced expedited medical care. The primary difference in their healthcare experience lies in the Baobei Foundation, a horizontal program whose members have well-established connections with physicians in urban-based tertiary medical centers. Using these relations, the Baobei employees coordinate with the orphanages so that they are immediately alerted to the health issues of any new arrivals and arrange their expedited delivery to appropriate tertiary care. Thus, delayed initial diagnosis and referral, the primary issues faced by the surveyed families, were effectively mitigated as significant barriers to surgical care for the PRC orphans.

To understand the primary barriers faced by one of these families, one must consider the position of the referring physicians. Appropriate management of patients with NTDs can be consolidated to three primary tasks: adequate provision of preventative measures to the mother, accurate diagnosis of the disease should a NTD develop, and appropriate referral of the patient should the hospital not possess adequate means of treatment. Each of these areas has the potential to contribute to the parent's perceived barriers and each will be addressed subsequently.

In recent years the Chinese government has instituted sweeping healthcare reforms that have had a large

**Table 5: Frequency of family-reported barriers to surgical care**

|   | Spinal lipoma | Tight filum terminale | Tethered cord | Meningocele | Myelo-meningocele | Lipomyelo-meningocele |
|---|---------------|-----------------------|---------------|-------------|-------------------|-----------------------|
| Child's symptoms considered too severe                          | 1             | 0                     | 0             | 0           | 0                 | 1                     |
| Child's symptoms considered not severe enough                   | 10            | 9                     | 0             | 2           | 1                 | 1                     |
| Family or friends suggested that treatment should not be sought | 0             | 0                     | 0             | 1           | 0                 | 0                     |
| Physician did not know enough about the child's condition       | 29            | 19                    | 2             | 3           | 3                 | 6                     |
| There was a lack of time and family work constraints            | 0             | 0                     | 0             | 0           | 0                 | 0                     |
| Fear of treatment and treatment side-effects on the child       | 1             | 0                     | 0             | 0           | 1                 | 0                     |
| Religious or cultural beliefs influenced decision               | 0             | 0                     | 0             | 0           | 0                 | 0                     |
| Cost of treatment and related services were prohibitive         | 4             | 0                     | 0             | 2           | 0                 | 1                     |
| There was a lack of transportation services to hospital         | 1             | 0                     | 0             | 0           | 0                 | 0                     |
| There was a lack of health professionals or health facilities   | 1             | 0                     | 0             | 1           | 1                 | 0                     |
| There was a lack of drugs or equipment at the health facility   | 1             | 0                     | 1             | 0           | 0                 | 1                     |
| The child was receiving alternative treatment                   | 6             | 5                     | 1             | 0           | 1                 | 4                     |
| Physician did not know to refer you to SCMC                     | 15            | 6                     | 2             | 2           | 4                 | 2                     |
| Other   | 0             | 1                     | 1             | 1           | 1                 | 1                     |

effect both in the urban and rural settings.<sup>[2]</sup> Among these reforms was the institution of a national folic acid supplementation program wherein all women with a rural household registration were provided folic acid supplements free of charge. The result of this government outreach was staggering, with a reported 22.4% drop in NTD prevalence in rural areas over a 2-year period.<sup>[5,27,39]</sup> However, over 50% of women utilizing folic acid supplements were doing so after they had discovered that they were pregnant, which is past the point of neural tube formation and is generally considered too late to prevent NTD formation.<sup>[16]</sup> Thus, despite the successes of this nationwide program, further maternal counseling is obviously required.

If a NTD does form in utero, the accurate diagnosis of the malformation is the referring physician's second hurdle. In the United States, the prenatal screening and diagnosis of NTDs is well established, with low-risk pregnancies being offered NTD screening in the form of a maternal serum alpha-fetoprotein (MSAFP) measurement at 16-18 weeks gestation or receiving a screening ultrasound at 18-20 weeks gestation. Characteristic findings on ultrasound are the backbone of the prenatal diagnostic process, should screening prove positive.<sup>[7,10,11]</sup> Despite its critical role in the prenatal diagnosis of NTDs, ultrasound detection rates remain highly variable, due in part to factors such as the size and location of the defect, the fetal position, the timing of diagnosis, maternal habitus, the available equipment, and the skill of the sonographer.<sup>[26,28-30]</sup> Several Western studies analyzing prenatal detection rates of major malformations found overall rates ranging from 22% to 50% for first trimester ultrasounds and 47% to 95% for second trimester ultrasounds.<sup>[1,4,8,18,30]</sup> While the PRC has extended genetic testing and prenatal screening techniques, such as ultrasound, to every pregnant woman

in developed regions, proper ultrasound training in NTD detection appears to be lacking in rural areas of the PRC, where rates remain the highest.<sup>[18,37]</sup> The detection of NTDs via first and second trimester ultrasound in these rural communities was 15.6% and 49.6%, respectively, with the former percentage being below the above range reported in western countries, and the latter approaching the low end of the range.<sup>[18]</sup>

The final task of the referring physician is to know when and where to refer the patient once the diagnosis has been made. The World Health Organization's 2012 service delivery profile of the PRC touched briefly on this topic by commenting on the segmentation of the health information system and the lack of a standardized nationwide referral protocol.<sup>[34]</sup> A recent article expounded on knowledge sharing (KS) between healthcare facilities within the PRC by identifying four KS barrier themes: interpersonal trust, communication, hospital management, and inter-institutional.<sup>[38]</sup> Interpersonal trust barriers were founded on issues such as a lack of acquaintance between healthcare providers and a lack of trust towards medical information produced by other facilities. Communication barriers resulted from the lack of a digital means for transferring patient information and the lack of trust between healthcare providers making informal KS via phone or email, unlikely. Hospital management barriers stemmed from a lack of specific hospital requirements for KS and the absence of in-hospital staff for coordination purposes. Finally, inter-institutional barriers resulted from a paucity of national and local government policy on the topic.<sup>[38]</sup> The frequency with which referral to SCMC was seen as a barrier to care in our survey supports the existence of these KS issues among PRC hospitals.

Of note, defects with characteristically more obvious findings at birth (e.g., myelomeningocele) had

significantly higher detection rates by referring physicians compared to defects with more inconspicuous features (e.g., tight filum terminale and tethered cord).<sup>[14,23,31]</sup> Despite these differences, families who received a timely diagnosis still identified the referring physician as a primary barrier to care. Certainly the factors discussed previously, such as appropriate preventative measures and adequate KS, could have contributed to a retained sentiment that the referring physician was still a barrier to care. However, it is worth considering factors beyond the training of the referring physician – factors relating to the patient-physician relationship as it exists in the PRC.

Edmund Pellegrino, an acclaimed American bioethicist, has proposed seven models of a physician's responsibility toward his patients. The social functionary model is one such framework for evaluating the patient-physician relationship wherein physicians practice medicine to serve society as a whole when treating the individual patient.<sup>[22]</sup> According to this model, a physician practicing in a resource-limited setting would apportion resources in order to maximize health benefits for the entire population.<sup>[3]</sup> In our surveyed population, the referring physicians may have had to weigh the costs of referral and treatment against the potential health benefits that would result for the individual patient. If the physicians believed the costs of referral and further use of medical resources outweighed the benefits, then the physician would be acting appropriately to withhold referral in order to conserve limited resources for a situation where greater health benefits could be derived. Renzong Qiu, a leading Chinese bioethicist, points out that collectivism is fundamental to the ethical framework of Chinese society.<sup>[6,20,24,25]</sup> Thus, the tendency for western physicians to treat the patient as a unique entity and remain essentially unaffected by external pressures might be absent in the PRC, where Chinese physicians are more likely to treat patients as integrated elements within the larger society.

Recent studies analyzing the changing face of the patient-physician relationship over the previous several years describe its dissolution as a result of healthcare commercialization within the PRC.<sup>[13,33,36]</sup> The transition from a government-funded healthcare system to a commercialized one has forced hospitals to adjust to a more business-focused infrastructure. For the patient, this has translated into increasing medical costs and has resulted in mounting patient distrust towards physicians.<sup>[33,36]</sup> The high patient volumes forced upon practicing physicians compound the issue. This has culminated in longer wait times, briefer doctor face-time, and a decreased dialogue between doctor and patient regarding the most appropriate management for each individual.<sup>[36]</sup> Overall, these factors could be manifesting in generalized disdain for the referring physician and may be reflected as a perceived barrier to surgical care by the families once they arrived at SCMC and participated in the survey.

There are several limitations to the present study worth noting. First, given the small study size, limited to 69 children in one hospital in the PRC, generalizing these results to the entire PRC may be difficult. Additionally, the barriers to surgical care elicited from our surveyed families represent the insights of those who eventually arrived at a tertiary medical facility to receive treatment. The experiences of families who were unable to receive treatment or received treatment elsewhere may have yielded different perceived barriers had that population been interviewed. To our knowledge, there are no studies to date reviewing the rates of untreated NTDs, making the full spectrum of possible barriers difficult to surmise. Finally, the results of this study are the product of a preformed survey. Thus, while the referring physician was seen as a primary impediment to appropriate surgical care, study participants did not elaborate upon reasons for this perception.

## CONCLUSION

The barriers to surgical care for NTDs in the PRC are complex. Further evaluation and eventual mitigation of those barriers requires the perspective of the affected patients and families. The results of this study highlight the referring physician as a primary barrier to care. The younger age at time of treatment for Baobei orphans born with NTDs supports this finding, as they essentially bypassed the referral process. An elaboration on reasons for this real or perceived barrier may provide insight into a means for expedited diagnosis and treatment of NTDs within the PRC.

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## Conflicts of interest

There are no conflicts of interest.

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