



Original Article

# Effects of parental level of income and visual presentation of spina bifida occulta in decision making process

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## ABSTRACT

**Background:** Parents are active participants in the referral process of children with non-life-threatening surgical pathologies. Nonetheless, there is scarce literature about the influence of parent's level of income and perception of their children's conditions on their decision process. Our study aims at expanding our knowledge about this parameter. We focused our research on parents of children spina bifida occulta (SBO), a condition that with a broad clinical impact and that often requires timely referral.

**Methods:** Questionnaires in Mandarin were administered to parents of patients presenting to the neurosurgery clinic of a children's hospital in Shanghai. Participants were grouped according to the level of income, above and below 50,000 Yuan. The SBO was classified into two groups, with and without evident subcutaneous mass.

**Results:** One hundred and forty-five participants completed the questionnaire. Regardless of the type of lesion, families with lower income attributed their concerns for seeking care to their local physicians and the lack of health resources. Families with higher income exhibited fear of treatment. The lower income cohort presented for treatment at an older age than a higher income group. Patients with subcutaneous mass presented for treatment at a younger age than those that did not exhibit mass.

**Conclusion:** Parental social economic background and visual presentation of SBO have to be factored when analyzing their decision-making process when seeking care for their children. Parental factors can be barriers to surgical care. Healthcare providers must bring parents to the forefront of the treatment process.

**Keywords:** Barriers to care, Parental perception, Socioeconomic status, Spina bifida occulta

## INTRODUCTION

Medical literature has explored the physician parental interaction in cases where life and death decisions are required, such as hospice care or experimental treatment for cerebral neoplasm.<sup>[9,13]</sup> It is implicit that a robust relationship between the physician and the parents of a sick child is primordial for optimizing the treatment plan. A unidirectional conversation from physician to parent does not enlarge the level of cooperation from the parents. Particularly today, when there is a growing trend toward increasing the participation of the parents in the treatment decision process.<sup>[6,8]</sup> To maximize the potentials of the long-term relationship between surgeon

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and parents, it is relevant for the former to be cognoscente of some aspects of the personal history of the parents.<sup>[4,12]</sup> Studies pointed to the relevance of parent's health literacy (HL) during their conversations.<sup>[2,15]</sup> However, closely related issues, parental income and visual presentation of the pathology, have not received similar attention.

Neurosurgical textbooks define the treatment algorithm for neural tube defects (NTDs): spina bifida aperta (SBA) has to be repaired as soon as feasible, whereas children born with spina bifida occulta (SBO) do not carry a similar level of urgency. SBO does not represent an immediate threat to the child's life, as could be with SBA. Nonetheless, the presence of an SBO implies the almost certain danger of neurological disorder secondary to tethering of the spinal cord later on. The debate about the indications of preventive untethering of the cord is still current with two diametral opposed lines of thought.<sup>[10,16]</sup> This calls for the parents to be active participants in the decision-making process. Champion *et al.* reported that parents of children born with NTD do have an active thought process about the health care system and the providers.<sup>[3]</sup> Nonetheless, in the pediatric and neurosurgical literature, the process of diagnosis and treatment of SBO has one protagonist; the treatment team, be either the pediatrician who diagnoses or the surgeon who treats the lesion. The purpose of our study is to determine if parental income and visual presentation of the NTD lesion are factors in contributing to the time of diagnosis and treatment.

## MATERIALS AND METHODS

### Participants

The study was approved by the Institutional Review Board and conducted at the one of the children's hospitals in Shanghai, People's Republic of China (PRC). This hospital is one of the tertiary care centers for pediatric neurosurgery in the PRC. Parents of the pediatric patients presenting to the neurosurgery clinic for any stage of treatment of SBO were eligible for the study.

### Questionnaire administration

The questionnaire was written in Chinese and administered to the participants along with proper verbal consent. Two interviewers fluent in Mandarin Chinese conducted the questionnaire. The questionnaire was completely anonymous, and participants were instructed to not include any identifiers. The participants were allowed to select as many concerns as they deemed appropriate regarding seeking care for their children with SBO. Concerns #1–7 are classified as infrastructural while #8–14 are classified as personal [Figure 1]. In addition, the questionnaire included demographic information.

### Classification of SBO groups and income

The SBO presentations were classified into Group 1, conditions with subcutaneous mass (lipomyelomeningocele, meningocele, and spinal lipoma), and Group 2, conditions without a subcutaneous mass (caudal agenesis, dermal cyst, dermal sinus, diastematomyelia, intradural lipoma, tethered spinal cord, and tight filum terminale). Parents were classified into lower income (LI, annual household income below 50,000 Yuan) versus higher income (HI, annual household income above 50,000 Yuan).

## RESULTS

### Demographics

A total of 145 questionnaires were completed. Seventy-six cases fell into Group 1 while 69 cases belonged to Group 2. Fifty-four cases (37%) reported an annual household income to be <50,000 Yuan while 83 cases (57%) reported an annual household income to be more than 50,000 Yuan. Eight cases (6%) did not report the annual household income. Seven (13%) of the 54 LI cases were from Shanghai, while 47 (87%) of the LI cases were from non-Shanghai areas. Nineteen (23%) of the 83 HI cases were from Shanghai, and 64 (77%) of HI cases were from non-Shanghai areas.

### Parental concerns based on income

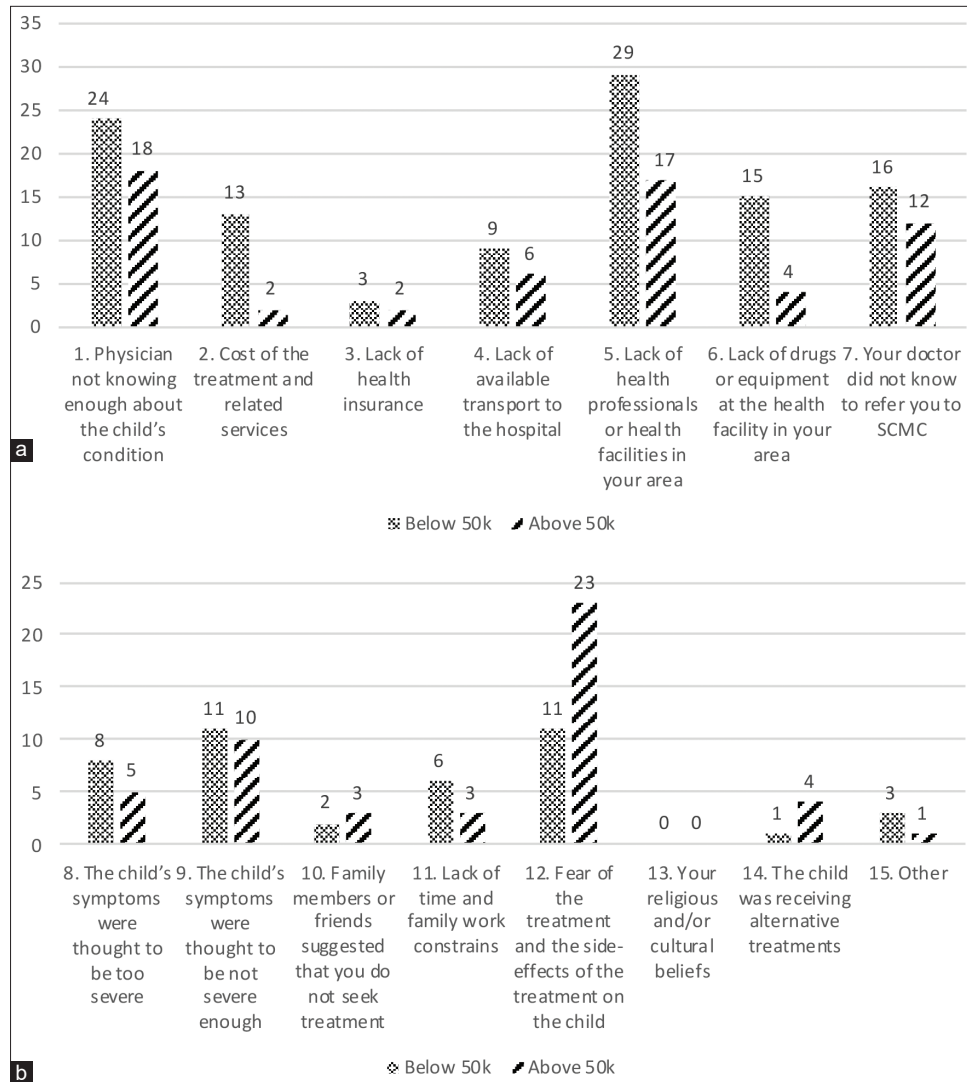
Within the LI cohort, the two most chosen concerns were #1 ( $n = 24$ , physician not knowing enough about the child's condition) and #5 ( $n = 29$ , lack of health professionals or health facilities in your area). In families with HI, concern #12 ( $n = 23$ , fear of treatment and side-effects of treatment on the child) was the most commonly chosen [Figure 1].

### Age of presentation to the hospital based on income and SBO group

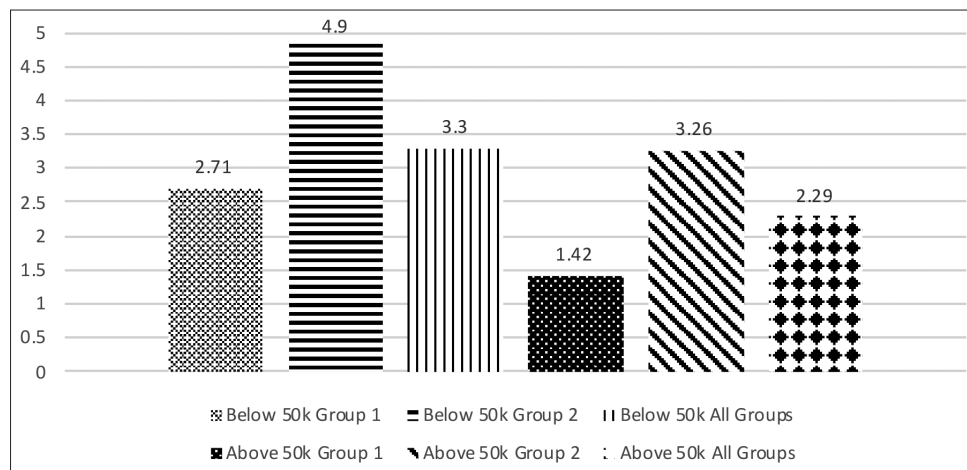
The average age of presentation to this hospital for the treatment of SBO for the LI cohort was 3.3 years, while that of the HI cohort was 2.29 years. Within the LI cohort, patients with Group 1 SBOs presented at 2.71 years while Group 2 SBO patients presented at 4.9 years. Within the HI cohort, Group 1 patients presented on average at the age of 1.42 years while Group 2 patients presented at the age of 3.26 years [Figure 2].

## DISCUSSION

We conducted our study at a children's hospital in Shanghai, PRC. The PRC has one of the highest incidences of NTDs.<sup>[18]</sup> Our results revolve around a well-known concept; the SES of patients links to the gradients of health.<sup>[17]</sup> While the literature stresses the patient's economic background with



**Figure 1:** (a) Frequency of infrastructural concerns selected based on parental annual household income. (b) Frequency of personal concerns selected based on parental annual household income.



**Figure 2:** Average age of presentation to the hospital based on parental annual household income.

regard to access and continuation to care, we underscore that financial history and parental perception of their child's sickness do affect some aspects of the decision-making process. What we report informs individual surgeons and public health planners that the parents have historical and economic backgrounds that can contribute to the barriers of surgical care.

### Parental income in relation to types of parental concerns

The infrastructural concerns, #1 (lack of knowledge by the physicians) and #5 (lack of health professionals or health facilities), yielded the highest responses in the LI group. If we assume that each parent is an active participant in their child's care, we understand that it is reasonable to view them as a potential barrier to care. Grimes *et al.* emphasized that the lack of infrastructure and insufficient knowledge from the local physician looped together with insufficient anesthesiologist are the main impediments to successful treatment.<sup>[7]</sup> Implicit in their findings is the conclusion that adequate generation of national wealth and distribution of resources can solve the problem. What their otherwise stupendous analysis does not emphasize is that in every country, there are many social classes labeled through their economic power. Looping everybody in the category of a patient from a low-middle-income country (LMIC) or an upper-middle income country (UMIC) ignores this nuance. The PRC is considered a UMIC with a health-care system in concordance with that status; the hospital in this study is an example of that situation, and still, SES influenced the decision-making process of the parents.

HI parents focused on concern #12 (fear of the treatments), a non infrastructural concern. These parents were fearful of the treatment and its side effects of on their children. We speculate that when parents have less socioeconomic resources, they prioritize having access to care for their children, beyond the issues related to a single child with a unique pathology. With more advantageous socioeconomic status, the quality of treatment to the individual becomes more important to the parents.

### Presentation of SBO in relation to age of presentation

The physical appearance of the lesion likely contributes to the parental perception of the urgency to obtain treatment, which plays a crucial role in the speed of diagnosis. The innocent appearance of the skin over some of the SBO lesions belies its importance to the parents and often leads to delayed arrival to a tertiary treatment center. Understandably, patients with visible subcutaneous mass presented to the clinic at a younger age than those that did not have a subcutaneous mass. The economic divide was present here, too; patients from families with higher

income presented to the clinic at a younger age than patients with lower parental income. In fact, children from HI group had a visible subcutaneous lesion presented almost 3½ years earlier than children from LI and had no visible subcutaneous mass [Figure 2]. Most of the children from this study are from distant regions and would require long-distance travel expenses to Shanghai and missed workdays by the parents. Parents likely weighted financial factors in relation to how severe they perceived the lesions to be, and this likely contributes to the decision on when parents can bring their children to treatment. Campion *et al.* suggested that the parent's thought that the physician was responsible for the delay in the referral process.<sup>[3]</sup> Our data indicate that awareness of social status and parental perception of the pathology add broader dimensions than the one attributed in the literature.

In addition, the spiritual believe was not checked by any of the participants (concern #13), regardless of parental level of income and the visibility of a subcutaneous mass. Perhaps this is related to not urgent appearance of SBO as perceived by the parents. What is prevalent in the literature are the papers on the believes of parents when their opinion is required about discontinuation of life support.<sup>[14]</sup> One group has done a thorough review of the parental decision-making process in complicated cases.<sup>[1]</sup> Spirituality was factored as a player in the dialogue between parents and physicians. The literature that this study analyzed was about data collected in Western countries. Our data do not suggest that the parents are not spiritual, but that the personal set of believes did not affect their decision process and the age that their children presented for treatment.

### CONCLUSION

We acknowledge that it is not possible to know how many parents opted for not seeking specialized care. We also acknowledge that the results of our study in one hospital in one country and with one pathology should not be generalized to every other country. Nonetheless, the relevance of parental socioeconomic history and perception of the sickness can be considered universal. The SES of patients links to the gradients of health and the physician is aware of such disparity.<sup>[17]</sup> However, in the literature, this disparity is considered relevant with regard to a *posterior condition* of the patient, such as the continuation of care. Moreover, most of the research is centered, rightly so, on the patient. In contrast our data underline the *a priori* perception of the parents, such as decision of bringing their children to seek treatment.

Perhaps, the most consistent interpretation of our findings is that it expands the personality of the parents from what can be called the "Lockean imperative." The role of the parents of a sick child is often considered as a unidirectional interaction between them and the physician. The parents are bound to do

what is the best interest for their children. The ideal parents were described by Locke centuries ago in the “Two Treatises of Government;” “The power, then, that parents have over their children arises from that duty, which is incumbent on them, to take care of their offspring, during the imperfect state of childhood. To inform the mind, and govern the actions of their yet ignorant nonage, till reason shall take its place and ease them of that trouble, is what the children want, and the parents are bound to.”<sup>[11]</sup> Moreover, it is accepted that who decides what is best for the child is the physician in whom the parents have to deposit unaltered trust. Fildes captured that concept his painting. “The doctor.”<sup>[5]</sup> The mother and the father of the sick child are expectant and distraught but detached from the center of the picture. The gaze of the viewer is caught by the child resting in his bed and by the pensive doctor, who is the essence of the painting. What our study proposes is bringing the parents to the forefront of the treatment process. And indeed, we understand that the task is not exhausted by our limited research and that there are many other social variables open for research and subsequent debate.

There is a social dimension to the problem of spina bifida. The pathology is less frequent in upper income countries (UICs), where the average is about 0.7/1000 live births than in LMIC, where it can be as prevalent at 6/1000 live births. The medical cannon maintains that the most potent factor that affects the incidence of spina bifida of any form is a folic acid deficiency. Epidemiologists and obstetricians recommend that before pregnancy, women start a regime of 400–800 µg of folic acid/day. Interestingly, the concentration of folic acid in the cereal box sold in UIC is below the recommended for effective prevention. Indeed, a yearlong supply of folic acid is in nobody’s wedding list. Thus, we cannot say that the majority of the population fills the dietary requirement.

Nonetheless, the data showing a decrease of NTD in UIC are compelling. Thus, many LMIC adopted the model, but not with similar success. This fact begs the question about the existence of other factors prevalent in LMIC, such as chronic malnutrition linked to a high incidence of poverty. Maybe we should not log onto folic acid alone the role of a catalyst for the closure of the neural tube. The identification of the other factors prevalent in LMIC relevant for NTD is a task that is the responsibility of native neurosurgeons and epidemiologists. Such a multifactorial job is not for somebody who practices in a UIC. Many parents in our study complained about the attitude toward the patients by primary care doctors. One of us has developed an information booklet about spina bifida to distribute among patients and primary care physicians. Our Chinese colleagues received the text of the brochure and modified it into its final version and will continue adapting it according

to the response from pediatricians and other health care workers. As stated at the beginning of this paragraph, there is a social dimension to the problem of spina bifida. Our work addressed just a tiny portion of the vast landscape.

### Declaration of patient consent

Institutional Review Board (IRB) permission obtained for the study.

### Financial support and sponsorship

David Geffen School of Medicine at UCLA provided travel stipend.

### Conflicts of interest

There are no conflicts of interest.

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