



Parental Concerns of Surgical Care for Children with Spina Bifida Occulta in China

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Objective

- To investigate the parental concerns to surgical care for pediatric patients with spina bifida occulta in China.

Background

- Neural tube defects (NTD) are common congenital malformations, especially Asia. The most usual presentation of a NTD is myelomeningocele, or spina bifida aperta (SBA). If this is not treated within 48 hours after birth, the subsequent infection carries dire consequences. The decision process to initiate surgical treatment is usually very straight forward for SBA since the lesion is apparent. This is in contrast to a very large subgroup of NTD: spina bifida occulta (SBO). This condition is not as noticeable as SBA. The lesion is covered by normal skin, thus it may convey to the inexperienced observer a false sense of normality. The spinal cord of the newborn with SBO has its caudal end anchored to a lipomatous mass, a bony spur, or a thick filum terminale. The consequences are noticed years after birth when stretching of the spinal cord damages its lumbar and sacral segments. While early untethering of the cord does not always prevent the outcome, it is advisable to attempt releasing the cord from its attachment either before the presentation of symptoms or at its early manifestations. If left untreated, these children have the potential of suffering from irreversible motor and sensory disabilities.
- We hypothesize that parental level of education, level of income, and the visibility of subcutaneous mass influence the parental concerns of surgical care for their children with SBO and play a role in the treatment process. We conducted our study at the Shanghai’s Children’s Medical Center (SCMC) in the People’s Republic of China (PRC), a country that has one of the highest incidences of NTDs. The SCMC is a regional referral center for NTDs, serving children with NTDs from rural and urban regions of the PRC.

Methods

- The study was approved by the UCLA IRB and conducted at the SCMC in Shanghai, PRC between 6/5/18 and 8/14/18.
- The questionnaire was in Mandarin and administered to parents of patients presenting to the clinic of SCMC Director of Pediatric Neurosurgery. Demographic information was collected as part of the questionnaire, and participants were allowed to select as many concerns as they deemed appropriate to their experiences seeking care for their children with NTD.
- The SBO patients were classified into Group 1 or Group 2 (Figure 1) based on SBO presentation, as well as LE (12th grade or below parental level of education), HE (above 12th grade parental level of education), LI (annual household income below 50k Yuan), and HI (annual household income above 50k Yuan).

Results

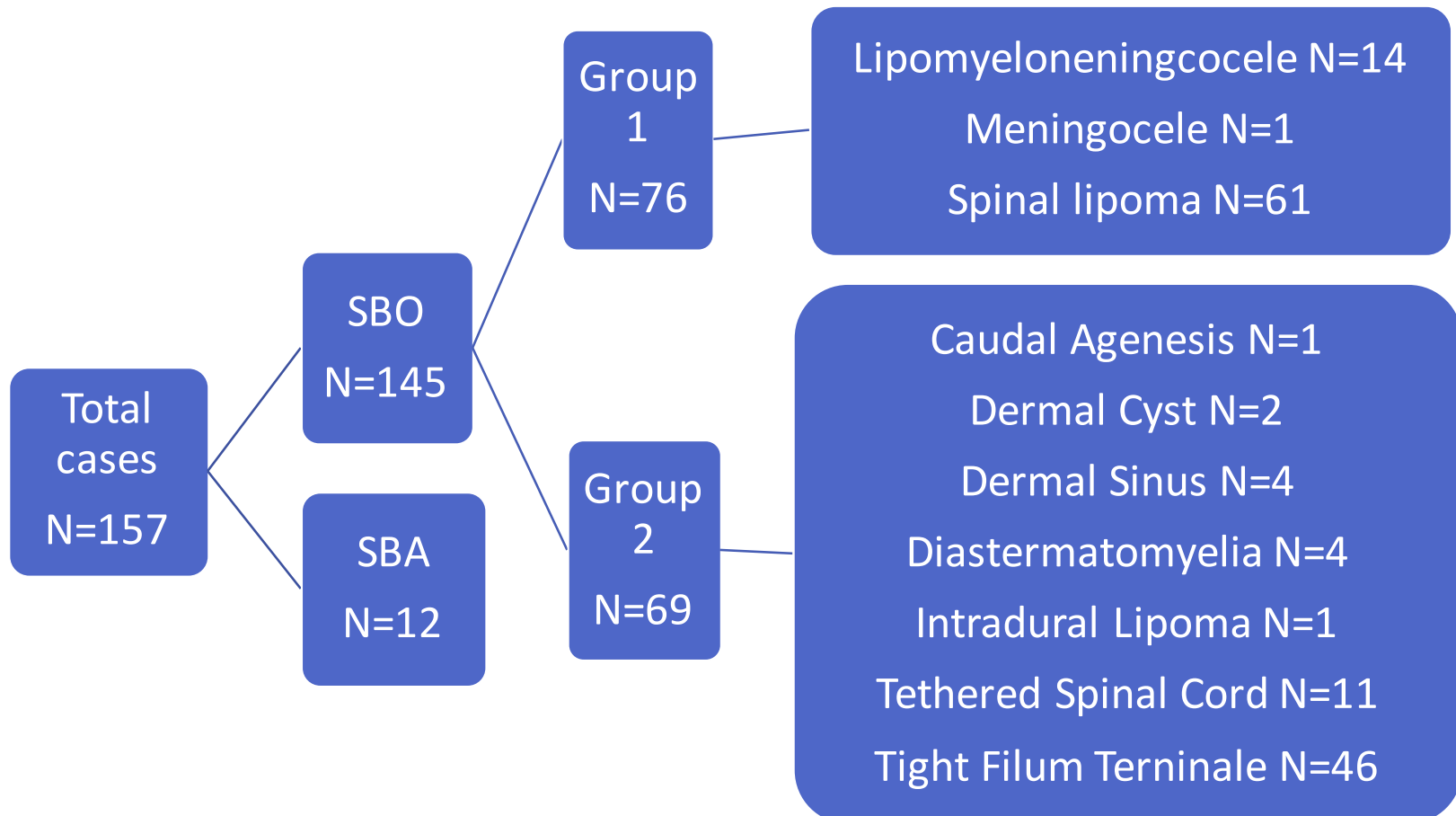
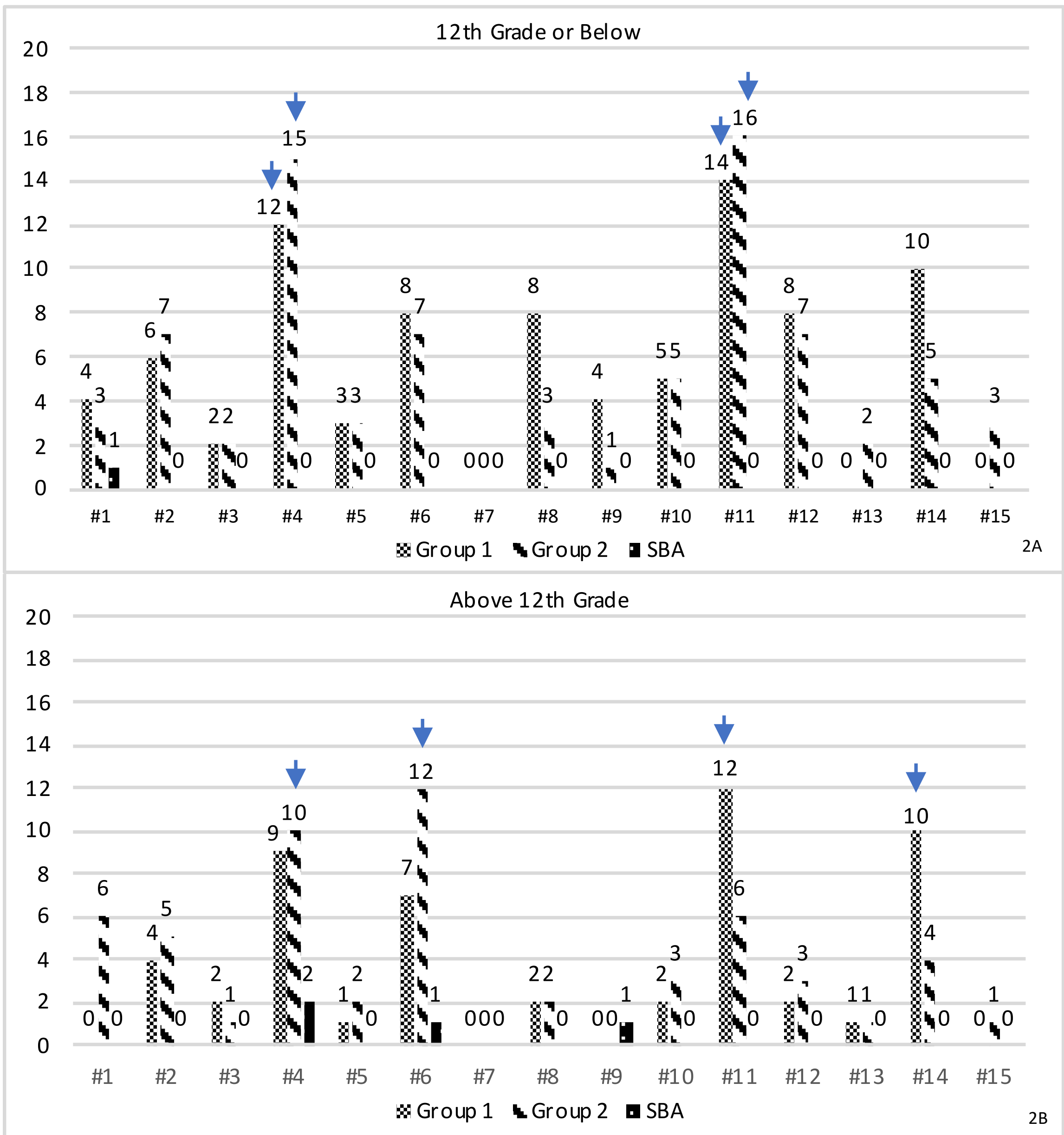


Figure 1 – Classification of SBO types



Results (Continued)

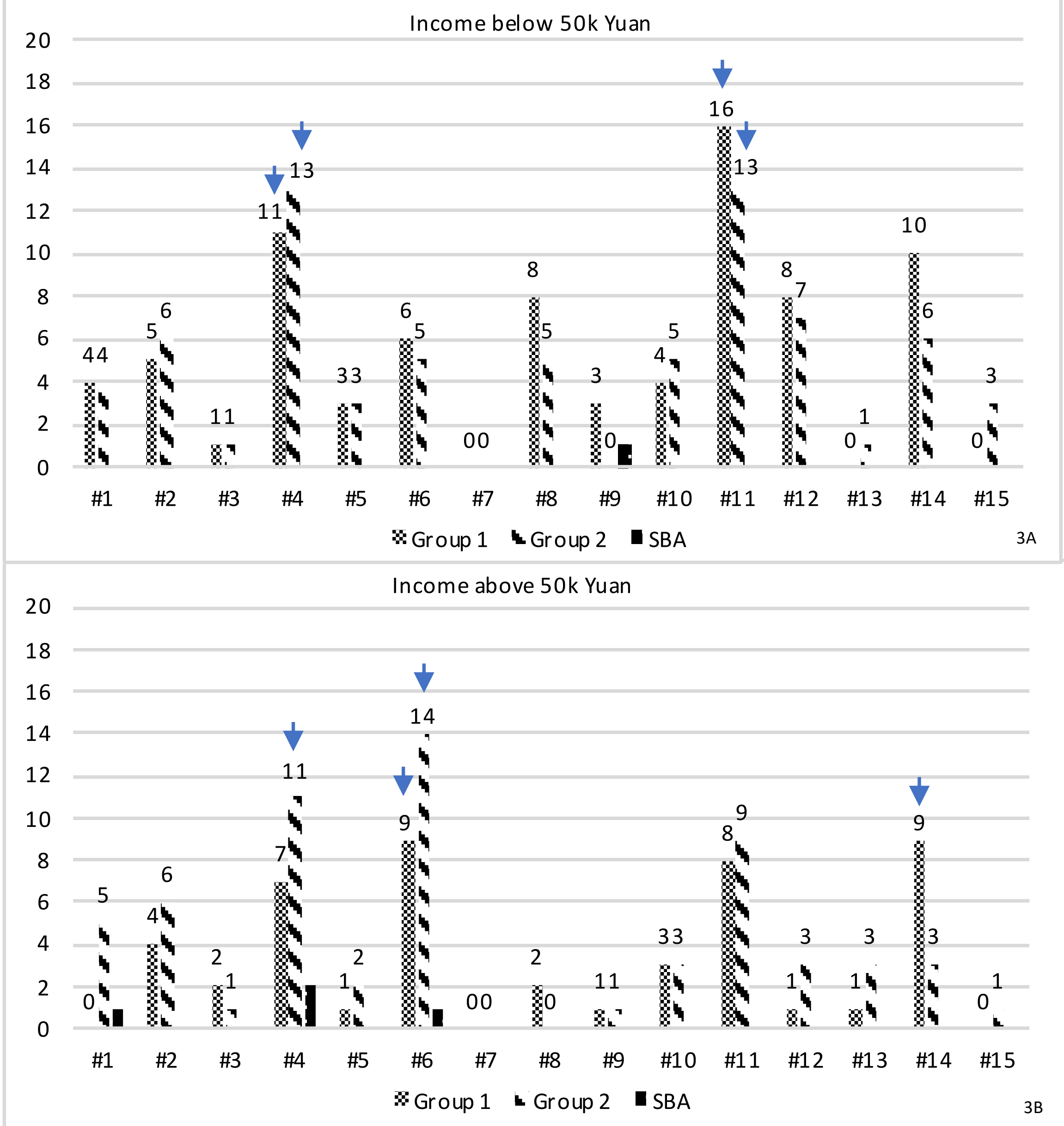


Figure 3A and 3B – Frequency of barriers selected based on annual household income

- Barrier#:
- The child’s symptoms were thought to be too severe
 - The child’s symptoms were thought to be not severe enough
 - Family members or friends suggested that you do no seek treatment
 - Physician not knowing enough about the child’s condition
 - Lack of time and family work constrains
 - Fear of the treatment and the side-effects of the treatment on the child
 - Your religious and/or cultural beliefs
 - Cost of the treatment and related services
 - Lack of health insurance
 - Lack of available transport to the hospital
 - Lack of health professionals or health facilities in your area
 - Lack of drugs or equipment at the health facility in your area
 - The child was receiving alternative treatments
 - Your doctor did not know to refer you to SCMC
 - Other

	LE	HE	LI	HI
# of cases	43% N=67	55% N=87	37% N=58	57% N=89
Male	51% N=34	55% N=48	59% N=34	49% N=44
Female	49% N=33	45% N=39	41% N=24	51% N=45
Shanghai	16% N=11	20% N=17	12% N=7	21% N=19
Non-Shanghai	84% N=56	80% N=70	88% N=51	79% N=70

Table 1 – Patient demographics

	LE	HE	LI	HI
Group 1	3.12	1.21	2.71	1.42
Group 2	4.75	3.21	4.90	3.26
SBA	2.50	1.27	0.14	1.13
All	3.76	2.08	3.30	2.29

Table 2 – Average age of presentation to SCMC in years

Conclusions

- Parental level of education and income as well as the type of SBO are associated with the differences in perceived concerns to surgical care.
- The lack of knowledge is a contributing factor parental concerns. SBO represents one of the many pathological conditions that are not actively addressed by global health planners. Our data suggests that increasing the level of awareness among physicians could be a reasonable starting point.
- We acknowledge that patients included in this study are those who arrived at SCMC for treatment. Nonetheless, we think that our data supports the concept of understanding the parent’s personal history when having them participate in the decision process. While the results of our study in one hospital in one country should not be generalized to every other country, the relevance of parental social and economic history can be considered universal. This is of particular importance for low- and middle-income countries (LMIC), where the prevalence of NTD doubles that of high-income countries (HIC). In LMIC there is a large number of children with the potential of suffering from a motor and sensory handicap that will impair their quality of life. It is almost imperative that opinion of the parents be factored in the treatment process and that the physicians counselling them be aware of different perspectives rooted on social factors.

Acknowledgements

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