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Parental awareness and perspectives on newborn screening in China: a questionnaire-based study

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Abstract

Background Low parental awareness and knowledge about newborn screening have been identified as a public issue. This study explored Chinese parents' self-evaluation of awareness, knowledge, and methods of receiving information about newborn screening.

Methods Using convenience sampling, we included 614 respondents who were expectant parents or parents of children aged 0-3 years. Our self-made questionnaire comprised four sections: sociodemographic characteristics, self-evaluation of awareness, detailed knowledge about newborn screening, and practical and expected methods of receiving newborn screening information.

Results We found that 72.9% of participants were classified as aware of newborn screening. However, only 14.2% of the participants received a passing score on the newborn screening detailed knowledge questions. Knowledge level about newborn screening was significantly associated with gender ($P < .001$), age ($P < .05$), education level ($P < .05$), residence ($P < .05$), family income ($P < .05$), and number of children ($P < .05$). The knowledge acquisition about newborn screening mainly came from hospital-related training (62.1%). Additionally, nearly half of the respondents (48.0%) expressed a preference for learning more about newborn screening through social media platforms, such as WeChat.

Conclusions While the majority of expectant or new parents were aware of newborn screening, only a minority had a thorough understanding of it. Various sociodemographic factors were associated with the level of parental knowledge about newborn screening. It is recommended to use hospital lectures or social media initiatives to educate parents in China.

Keywords Newborn screening, Parents, Knowledge, Sociodemographic factors, China

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Background

Newborn screening (NBS) refers to routine tests performed in most developed and many developing countries within the first hours or days of a newborn's life to detect congenital conditions and prevent serious health problems [1, 2]. The NBS program in China began with pilot studies in Shanghai in 1981 and Beijing in 1989, subsequently expanding to almost all provinces over the following two decades [3]. The most recent administrative order affecting NBS, the *Measures for Administration of Newborn Screening for Diseases*, was promulgated in 2008 and came into effect on June 1, 2009 [4]. This regulation stipulates that the types of diseases covered by national screening include congenital hypothyroidism (CH), phenylketonuria (PKU), other genetic metabolic disorders, and hearing impairment. Early diagnosis and treatment of diseases identified through NBS can significantly improve long-term health outcomes [5]. It has been over 60 years since NBS was conducted globally, yet significant differences exist in the conditions screened for among different countries and even across regions within the same country [6]. Therefore, exploring the awareness and practices of NBS in the context of China is particularly important.

Since the awareness of NBS is still developing in China, there are sociodemographic differences in the extent of parents' awareness. Previous studies have shown that mothers generally have higher awareness about NBS than fathers [7], and older parents are more aware than younger parents [8]. Economic status and area of residence disparities contribute to differences in parents' awareness of NBS across Chinese provinces. Regions with limited financial and technical capacity tend to have less comprehensive screening programs, resulting in lower awareness [9, 10]. Higher education levels correlate with better NBS awareness [11]. Considering that parental awareness significantly influences medical decisions for their children, it is crucial to increase awareness of NBS among parents [12, 13]. However, limited research has been conducted on the extent of parental perspectives regarding NBS in Asia, and the impact of sociodemographic factors on their understanding has not been fully explored in the Chinese context.

Parental lack of awareness and detailed knowledge about NBS can lead to children missing critical screenings. Insufficient understanding may result in missed or delayed screenings that are essential for early detection and treatment of serious conditions [14]. Many parents incorrectly identify common conditions tested for in NBS; for example, most mothers are unaware of CH and its implications, which reduces screening rates and diagnoses [15]. Current studies focus more on parents' awareness of NBS rather than their in-depth knowledge of NBS itself, which is also crucial in influencing their decision-making.

Providing healthy or prenatal education can increase participation rates and the identification of true positives [16, 17]. Once parents are well-informed through education, they tend to make informed choices about NBS [18, 19]. Maintaining public trust in NBS programs is paramount for ensuring parental compliance and acceptance, both of which are critical for the success and effectiveness of these programs [20–22]. It has been suggested that governments should collaborate with families, primary care physicians, and prenatal healthcare professionals to develop well-defined pretest systems for parents [17, 23]. These efforts can significantly improve parents' understanding and support of NBS. Although various suggestions have been made to enhance parents' awareness of NBS, there is limited research on how Chinese parents currently access NBS information and their preferences for receiving this information.

Given the rapid increase in awareness of the importance of NBS among Chinese parents, it is vital to explore Chinese parents' current awareness of NBS and the related factors influencing their awareness. This study also summarizes the common methods through which parents currently acquire NBS information and explores their preferred ways of obtaining this information, providing references for developing more practical methods of delivering NBS information in the future Chinese context.

Methods

Study design and participants

A cross-sectional questionnaire survey was conducted. The participants included expectant parents and parents of children aged 0-3 years. Eligible participants were Chinese, 18 years or older, able to read Chinese, and willing to voluntarily participate. The survey was administered at the Children's Hospital of Zhejiang University School of Medicine.

Measurements

The questionnaire was designed based on previous reports [11, 24]. It consisted of four sections: (i) sociodemographic characteristics such as age and occupation; (ii) self-evaluation of NBS awareness and whether respondents had received NBS education using a 5-point Likert scale ranging from 'completely unaware' to 'fully aware.' The identification of "good NBS awareness" in this study includes "know", "know a lot", and "fully aware"; (iii) thirteen closed-ended questions about NBS details were included, with scoring based on an empirical system: 5 points for questions 12 and 22, 4 points for questions 11 and 16, and 3 points for the remaining questions. Multiple-choice questions 11, 12, 16, and 22 each received 1

point per correct choice. The maximum possible score was 45 points, with a score of 60% correct answers or ≥27 points considered a "passing" grade; and (iv) practical and preferred methods of receiving NBS knowledge.

Procedures

Two research assistants received training before data collection. Using a convenience sampling method, individuals who met the inclusion criteria were invited to participate in the study in person. After obtaining informed consent, the survey was conducted in a single room and took approximately 15 min to complete.

Statistical analysis

To calculate the sample size for this descriptive research, a G*power analysis was conducted prior to the study. A group size of 429 provided 95% power with a 0.05 level of significance. Considering that 15-25% of the questionnaires might be invalid [25], 614 valid questionnaires were included in this study. The dataset generated during the current study has been uploaded to FigShare (https://figshare.com/). Statistical analysis was performed using SPSS 25.0 (SPSS Inc., Chicago, IL, USA). The distribution of scores followed a normal distribution. Independent sample t-tests were used to compare the knowledge scores of two groups, and ANOVA was used for three or more groups. The Chi-square test was used for categorical variables. A two-sided Pvalue<0.05 was considered statistically significant.

Ethical consideration

This study was approved by the Ethical Committee of the Children's Hospital, Zhejiang University School of Medicine (reference number: 2023-IRB-0325-P-01). Participants were informed of the study's aim, their right to withdraw at any time, and that their confidentiality and anonymity would be maintained. All participants signed written informed consent forms.

Results

Respondents' characteristics

The descriptive data are summarized in Table 1. A total of 614 participants over the age of 18 were included in the study. The respondents comprised 497 females (80.9%) and 117 males (19.1%). Of the respondents, 68.9% had at least one child. Education levels were as follows: 9.9% had a master's degree or above, 43.3% had a bachelor's degree, 21.8% had an associate degree, 15.3% had a senior high school or technical secondary school education, and 9.6% had a junior high school education or below. The largest age group was 26-30 years (41.7%), while those aged 41 and above comprised the smallest group (2.8%). The top three occupations among respondents were general staff (30.6%), freelancers (13.4%), and non-medical staff (9.1%). The monthly family income (in RMB) was reported as follows: 52.4% earned more than 5000, 31.4% earned between 4000 and 5000, and 16.2% earned 4000 or less.

Sociodemographic differences in NBS knowledge

Table 1 also presents the sociodemographic differences in NBS knowledge. Both older parents (over the age of 41) and younger parents (aged 18-25 years) had less knowledge about NBS compared to others ($P<.05$). Male respondents scored lower than female respondents ($P<.001$). Respondents living in cities had better knowledge of NBS than those living in the villages ($P<.05$). Respondents with a monthly family income of 3000-4000 RMB had less knowledge than those in the 4000-5000 RMB and over 5000 RMB groups ($P<.05$). There was no significant difference among the other income groups ($P>.05$). Respondents with a junior high school degree or below scored lower than those with senior high school/technical secondary school education ($P<.05$) and associate or bachelor's degree ($P<.001$). Additionally, respondents with senior high school/technical secondary school education knew less than those with associate degrees and bachelor's degrees ($P<.05$). Comparisons among other education levels did not show significant differences ($P>.05$). For the number of children, the scores of respondents with none or two or more children did not differ significantly ($P>.05$), but respondents with one child scored better than others ($P<.05$).

Self-evaluation of NBS knowledge

In the survey, 72.9% of participants were classified as aware of NBS, while 27.1% admitted to being completely unaware. Among those who were aware of NBS, only 4.1% considered their knowledge to be good, and 68.8% believed they knew only a little about it. Additionally, 68.6% of participants reported never having received information about NBS. Receiving NBS education significantly improved awareness levels ($P<.001$). (Table 2)

Respondents' knowledge of NBS

The question regarding the informed consent requirement for all types of NBS had the highest accuracy rate (78%). Additionally, 72.1% correctly answered that high-risk newborns need annual follow-up for hearing loss for the first three years, and 61.9% identified the need to delay blood collection and hearing screening if discharged early. Furthermore, 54.1% understood that rescreening does not necessarily indicate a problem and knew that thyroid hormone deficiency causes CH. However, only 1.5% and 16% correctly identified symptoms of G6PD deficiency and congenital adrenal hyperplasia (CAH), respectively. Only 13% correctly identified all congenital diseases that need to be screened

Table 1 Demographic characteristics of the respondents ($N=614$)

Variables	Level of knowledge about newborn screening		
	N(%)	M ± SD	*P*
Age (years)			< .05
18–25	52(8.5)	15.92 ± 9.05	
26–30	256(41.7)	18.87 ± 8.60	
31–35	203(33.1)	18.16 ± 7.83	
36–40	86(14.0)	19.99 ± 8.26	
≥ 41	17(2.8)	14.00 ± 8.54	
Gender			< .001
Male	117(19.1)	15.32 ± 7.92	
Female	497(80.9)	19.13 ± 8.36	
Place of residence			< .05
Village	145(23.6)	16.75 ± 8.18	
City	469(76.4)	19.92 ± 8.42	
Occupation			> .05
Government officers/Civil servants	36(5.9)	17.78 ± 7.98	
Enterprise managers	44(7.2)	17.31 ± 8.06	
General staff	188(30.6)	17.55 ± 9.33	
Medical workers	25(4.1)	18.63 ± 6.89	
Non-medical staff (lawyers/reporters/teachers, etc.)	56(9.1)	18.03 ± 8.04	
Ordinary workers (factory workers/manual workers, etc.)	29(4.7)	17.48 ± 8.22	
Service workers (salesman/waiters, etc.)	22(3.6)	17.57 ± 6.54	
Self-employed workers/Contractor	52(8.5)	17.65 ± 7.46	
Freelancer	82(13.4)	18.20 ± 5.79	
Farming/Forestry/Animal Husbandry/Fishery laborer	1(0.2)	17.03 ± 8.63	
Retiree	1(0.2)	17.24 ± 8.16	
No occupation	52(8.5)	18.15 ± 7.42	
Other	26(4.2)	17.95 ± 8.73	
Income per month (RMB)			< .05[a]
< 500	4(0.7)	7.25 ± 1.63	
500-1,000	2(0.3)	16.50 ± 2.12	
1,000-2,000	12(2.0)	15.17 ± 8.86	
2,000-3,000	20(3.3)	18.15 ± 8.41	
3,000-4,000	61(9.9)	16.33 ± 8.45	
4,000-5,000	193(31.4)	18.02 ± 8.26	
> 5,000	322(52.4)	18.72 ± 8.34	
Degree of education			< .05[b] < .001[c]
Junior high school and below	59(9.6)	13.42 ± 7.76	< .05[d]
Senior high school/Technical secondary school	94(15.3)	17.03 ± 7.86	
Associate Degree	134(21.8)	19.66 ± 8.40	
Bachelor Degree	266(43.3)	19.37 ± 8.08	
Master's Degree or above	61(9.9)	18.39 ± 9.40	
Number of children			< .05[e]
None	191(31.1)	17.47 ± 9.24	
One	298(48.6)	19.56 ± 7.75	
Two or more	125(20.4)	17.08 ± 8.26	
Age of the youngest child			> .05
To be born	321(52.3)	17.36 ± 8.40	
Younger than one month old	30(4.9)	18.08 ± 7.24	
1-6 months old	70(11.4)	17.64 ± 8.21	
0.5-1 years old	57(9.3)	17.56 ± 8.81	

Table 1 (continued)

Variables	Level of knowledge about newborn screening		
	N(%)	M ± SD	*P*
1-2 years old	88(14.3)	18.12 ± 9.43	
Other	48(7.8)	18.01 ± 7.45	

*a. Income of 3,000-40,000 vs. 4,000-5,000 and over 5,000

b. Junior high school degree or below vs. senior high school/technical secondary school

c. Junior high school degree or below vs. associate degree and bachelor's degree

d. Senior high school/technical secondary school vs. associate college and bachelor's degree

e. One child vs. none and two or more children

Table 2 Self-evaluation and situation of receiving education about NBS

	Completely unaware	Know a little	Know	Know a lot	Fully aware	χ^2	*P*
Received (n, %)	16(9.9)	135(83.3)	6(3.7)	1(0.6)	4(2.5)	659.48	< .001
Not received (n, %)	124(35.0)	220(62.1)	7(2.0)	0(0)	3(0.9)		

*98 missing data

Table 3 Respondents' answers to each question

Question	Answer correctly, number (%)
The content of NBS	310(50.5)
Congenital diseases for NBS	80(13.0)
Time of blood sampling	133(21.7)
Harm of PKU	154(25.1)
Causes of CH	332(54.1)
Typical symptoms of G6PD	9(1.5)
Typical symptoms of CAH	95(16.0)
The implications of rescreening	332(54.1)
Time of first hearing screening	133(21.7)
Delay blood collection/hearing screening if early discharge	380(61.9)
Annual follow-up for high-risk hearing loss newborns	428(72.1)
Significance of NBS	243(39.6)
Informed consent for all NBS types	479(78.0)

Table 4 Scores of respondents

Score (x)	Number (%)
$0 \le x \le 4.5$	37(6.0)
$4.5 < x \le 9$	64(10.4)
$9 < x \le 13.5$	72(11.7)
$13.5 < x \le 18$	126(20.5)
$18 < x \le 22.5$	112(18.2)
$22.5 < x \le 27$	116(18.9)
$27 < x \le 31.5$	49(8.0)
$31.5 < x \le 36$	34(5.5)
$36 < x \le 40.5$	4(0.7)
$40.5 < x \le 45$	0(0.0)

for, including PKU, CH, G6PD deficiency, CAH, and neonatal hearing impairment (Table 3). None received full marks on the questionnaire, and only 14.2% of the subjects received a passing score (≥27 points) (Table 4).

Table 5 Practical methods for receiving knowledge about NBS

The practical methods for receiving knowledge about NBS	Number (%)
Medical staff (doctors, nurses)	272(62.1)
Family or friends with medical knowledge	59(13.5)
Promotional materials in the hospital. (brochures, lectures, etc.)	164(37.4)
Books, newspapers, television, etc.	79(18.0)
Social media (Moments, official accounts of WeChat, etc.)	104(23.7)
Apps such as Microblog, Zhihu, etc.	52(11.9)
Searching online yourself	115(26.3)
Others	15(3.4)

Practical and preferred methods for receiving knowledge about NBS

In this survey, respondents primarily received education about NBS from medical staff (doctors, nurses, etc.) (62.1%), promotional materials in hospitals (37.4%), and online searches (26.3%). Fewer than 20% of participants recalled obtaining information from other sources, such as books, newspapers, or television (18.0%), family or friends (13.5%), and apps (microblogs, Zhihu, etc.) (11.9%) (Table 5). Regarding preferred methods of learning about NBS, more than half of the participants (52.3%) favored lectures held by hospitals. Additionally, nearly half of the respondents (48.0%) expressed a preference for learning about NBS via social media, such as WeChat (Table 6).

Discussion

This first cross-sectional survey assessing parental awareness of NBS in Zhejiang Province, China, revealed that over 70% of parents were aware of NBS. The respondents were familiar with the need for informed consent and annual follow-up for high-risk newborns but had limited knowledge of the symptoms of G6PD deficiency, CAH, and the congenital diseases require screening.

Table 6 Preferred methods for receiving knowledge about NBS

Preferred methods for receiving knowledge about NBS	Number (%)
Lectures for patients held by hospitals	321(52.3)
Brochures made by hospitals	258(42.0)
Videos made by hospitals	263(42.8)
Doctors' introduction	261(42.5)
Newborn Screening Center website	217(35.3)
Social media such as official accounts of WeChat	295(48.0)
Apps such as Microblogs, Zhihu, etc.	193(31.4)
Others	28(4.6)

Less than 15% answered more than 60% of the questions correctly. Knowledge levels were influenced by demographic factors including gender, age, education level, residence, income, and number of children. Medical staff were the primary source of NBS information and parents expressed a preference for learning more through hospital lectures or social media.

Current awareness of NBS among parents in China

In the present study, 72.9% of participants were classified as being aware of NBS, which revealed higher levels of awareness and knowledge compared to previous studies conducted in Japan in 2010 (26.6%) [7] and in Thailand in 2022 (59.7%) [11]. NBS has been carried out since 1999 in Zhejiang Province. Initially, public awareness was low, with a participation rate of only 6.46% in 1999. By 2009, this rate had increased to 97.75%, driven by strong local government support, economic development, and the efficient management of the screening center [3]. Additionally, advances in NBS technologies have made significant strides in diagnosing and treating rare but severe congenital diseases, providing more opportunities to improve the lives of children and their families, and increasing parental awareness of the importance of NBS [26]. However, it was concerning that only 4.1% of respondents thought that they had good knowledge of NBS, indicating a significant risk of misunderstanding among parents [27]. The low accuracy in recognizing typical symptoms of diseases suggests that parents lack knowledge about the specific conditions included in NBS. These findings highlight the necessity for targeted educational programs that emphasize both the importance of NBS and the understanding of screened diseases. Furthermore, educating obstetricians and nurses to provide pregnant women with information about NBS and involving mothers in the screening process can increase parental satisfaction [21, 28]. A robust and well-organized follow-up system also plays a crucial role in ensuring successful recall [29]. Together, these measures contribute to the success of early detection and intervention programs.

Factors influencing respondents' knowledge about NBS

In this study, older and younger participants, males, those living in the village, with lower income and education levels, and those with no children or at least two children had poorer awareness and knowledge of NBS. Previous studies have shown that parents aged 21–34 had better awareness (1.4 times higher) than other age groups [11]. Good awareness was observed in older age groups (≥30 years) [8]. Our findings showed that participants aged 18-25 and over 41 had the lowest level of knowledge about NBS, while those aged 36-40 had the highest NBS awareness. These differences might be due to the inconvenience for older parents to access and seek out information through public resources and the inexperience of younger people to know about NBS. Our findings were consistent with recent research showing that a lower level of knowledge of NBS was in males than in females [7]. Therefore, it is essential to encourage fathers' involvement to increase awareness. The respondents who lived in the city knew better about NBS than those living in the villages, which may be attributed to limited access to NBS education in villages. We also found that families with low economic levels did not pay enough attention to NBS. Respondents who graduated with lower educational attainment knew less than those with higher degrees. These were in line with a previous study that showed that parents' better education level and higher monthly income were significantly associated with higher awareness [30–32]. Interestingly, respondents with a master's degree or above did not obtain higher scores than other groups about NBS, which was rather surprising. Regarding the impact of the number of children on NBS, our study suggested that respondents with one child obtained better scores than others. Considering that parents with only one child have received NBS, parents with multiple children may have forgotten some information.

Strategies to improve the awareness of NBS

Our results further revealed that respondents primarily received education on NBS from medical staff and publicity materials distributed by the hospital, indicating that hospital-related education remains the main source of NBS knowledge. Other studies showed that educating parents solely during hospitalization was inadequate for promoting NBS, making it difficult to improve the participation rate and the identification of true positives [16]. Our research showed that in addition to traditional propaganda such as hospital lectures, social media platforms such as WeChat were the second most preferred way for respondents to learn about NBS. Online education is more convenient and accessible for parents who are too busy to attend offline lectures [33]. Social resources such as radio, television, and the internet could be leveraged to provide multi-phased, continuous, and effective

health education. This would allow parents to gain a deeper understanding of NBS, foster cooperation, and improve compliance. The government may implement policies to raise awareness and knowledge of NBS during pregnancy [21, 22]. Additionally, the government should provide guidelines and ensure that the content of courses meets parents' requirements [34, 35]. Fiscal subsidy policies in certain regions have significantly promoted NBS, indicating that subsidies and compensation encourage parental acceptance [36]. Communities can serve as valuable resources in managing family-related challenges. For instance, parents' committees can bridge the needs of pregnant women with hospital requirements and advocate for a healthy lifestyle.

Strengths and limitations

This is the very first study exploring the current status of parents' awareness of NBS in a Chinese context. Moreover, it improves understanding of the association between demographic characteristics and NBS knowledge. Finally, it provides valuable recommendations for healthcare providers and policymakers. However, the study has limitations. There is potential self-selection bias with a higher proportion of highly educated individuals and the inclusion of only parents of newborns in hospitals. Future studies should include a more diverse sample from outpatient clinics, community health centers, and various educational and socioeconomic backgrounds to address these issues. Additionally, the cross-sectional design does not allow causality to be determined, whether NBS education boosts self-awareness or self-aware parents seek it.

Conclusions

According to the results of the study, more than half of the participants were aware of NBS. However, detailed knowledge of NBS is still insufficient. It is highly recommended to increase NBS knowledge accessibility through social media platforms like WeChat, online courses, and educational brochures. A promotion system utilizing social resources, government guidelines, fiscal subsidies, and community is essential to enhance public understanding and compliance.

Abbreviations

NBS	Newborn screening
PKU	Phenylketonuria
CH	Congenital hypothyroidism
G6PD	Glucose-6-phosphate dehydrogenase
CAH	Congenital adrenal hyperplasia

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Author contributions

X.Y., P.W., Q.H., B.W., and X.H. conceptualized the investigation. X.Y., P.W., Z.C., and Z.Y. conducted the investigation. X.Y. and P.W. analyzed the data and drafted the original manuscript. Q.H., B.W., and X.H. reviewed and edited the manuscript. All the authors read and approved the final manuscript.

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Data availability

The datasets used and analyzed in the current study are available from the corresponding author upon reasonable request.

Declarations

Ethics approval and consent to participate

All the participants signed written informed consent and consented to participate in this investigation. The research protocol and process were approved by the Ethical Committee of Children's Hospital, Zhejiang University School of Medicine (reference number: 2023-IRB-0325-P-01). All methods used in the present study were performed following the relevant guidelines and regulations.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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