PARENTAL AWARENESS AND DELAYS IN SEEKING SURGICAL CARE FOR PEDIATRIC CONGENITAL ANOMALIES

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ABSTRACT

Background

Congenital anomalies are one of the foremost reasons for neonatal deaths and childhood illnesses, especially in LMICs. Such outcomes can be reduced by timely surgical intervention, but that is not always followed and is dependent on the parents' knowledge and availability of healthcare systems.

Objective

This study was aimed to assess the level of parental knowledge and establish possible causes of early presentation of children with congenital anomalies and delayed referrals for surgical intervention.

Methods

This cross-sectional study was conducted for about 6 months from May, 2011 to Oct, 2011 in the Department of Paediatric Surgery, Khalifa Gulnawaz Teaching Hospital, Bannu Medical College, Bannu, Pakistan on 384 parents or caregivers of children with congenital anomalies. Information was gathered via administering of structured questionnaires focusing on demographic characteristics, knowledge, access to healthcare, and possible causes of delay. Chi-square tests were conducted to determine whether there was a relationship between delays and possible factors.

Results

As for the awareness of the condition, 59.9% of parents reported that they knew about it, while only 65.1% had information about the treatment. However, 21.9% of families were not able to seek surgical care within over six months from the diagnosis. The other reasons for delays were absence of knowledge regarding the surgery (40.1%), fear on Surge (26.0%), structural deficit like longer waiting time (26.0%) and poor access to specialized personnel (21.9%). It was also established that delays were higher for families with low education and for those in rural settings.

Conclusion

The implication for public health practice, therefore, lies in the imperative to increase parental assurance in surgical procedures along with increased healthcare access and operating efficiency. Overcoming these barriers can greatly minimise gaps and enhance the quality of life of patients with congenital anomalies in developing areas.

Keywords: Congenital anomalies, Parental awareness, delayed surgical care, Pediatric health, Healthcare accessibility.

INTRODUCTION

Birth defects can be defined as morphological and/or functional abnormalities that develop during intrauterine period and may lead to impaired health, growth and functional ability in children (1, 2). These anomalies are a major cause of neonatal death and childhood illnesses and even more so in

LMICs. For such conditions evaluation and treatment at an early stage is crucial to help effectively manage the disorders–surgical intervention plays a central role in achieving this objective (3). However, patients continue to delay seeking and receiving surgical care, including those in low- resource environments.

According to the study, parental awareness is important as far as the early diagnosis and treatment of congenital anomalies is concerned. Parents who have understanding about the child's condition and its consequences are in a better position to provide the child with medical attention (4). On the other hand, reduced awareness of the disease, cultural beliefs, and myths together with applying fear towards medical procedures results to delayed treatment. Such delays may lead to complications that worsen the child's outcome and also the overall family and health care system burden (5).

Another determinant of the management of congenital anomalies is access to healthcare. However, common issues affecting families located in rural settings such as Bannu in Pakistan include distance to care, lack of availability of pediatric surgeons, and integrated referral networks. These challenges are worsened with socioeconomic indicators including low income and poor parental education which also delays treatment.

Although global attempts have been made to enhance the diagnostic procedures and remedial solutions for congenital anomalies, deficits still remain in comprehending the concerns of families dealing with these complications, especially in the less developed areas. The objectives of this study are to assess the current level of parental knowledge and determine the causes of delayed referrals for surgical treatment of congenital anomalies in District Bannu. Thus, this study was aimed at presenting findings that would help in the design of enhanced early detection and treatment of diabetic Patients in such a low resource setting.

METHODOLOGY

The cross-sectional study was conducted for about 6 months from May, 2011 to Oct, 2011 in the Department of Paediatric Surgery, Khalifa Gulnawaz Teaching Hospital, Bannu Medical College, Bannu, Pakistan with an aim to explore the level of parental knowledge about the congenital anomalies of the children and the surgical delay in Bannu, Pakistan. The study adopted a structured questionnaire to identify various details required from parents with affected children. Informed consent was obtained from parents to participate in the study. The right to privacy and data was upheld throughout the study process as well as data anonymization while conducting analysis and documentation. The study population included parents or primary caregivers of children diagnosed with congenital anomalies. Only children requiring surgical interventions were included in the study. The sample size was calculated using a standard formula for cross-sectional studies, with an expected prevalence of delays in seeking surgical care set at 50% to allow for maximum variability. At a 95% confidence level and a 5% margin of error, the required sample size was 384 participants.

- **Inclusion Criteria:**
  - Parents or caregivers of children aged 0–18 years diagnosed with congenital anomalies.
  - Children whose anomalies required surgical intervention.
  - Parents who consented to participate in the study.
- **Exclusion Criteria:**
  - Parents who were unwilling to provide

consent.

- Cases where the child's condition was not clearly diagnosed.
- Children with anomalies that did not require surgical treatment.

Convenience sampling was used to recruit participants. Parents attending the selected healthcare facilities during the study period were approached and invited to participate. Efforts were made to ensure a diverse sample by including patients from both urban and rural areas.

A structured questionnaire was developed in both English and the local language (Pashto) to ensure comprehension. The questionnaire was divided into the following sections:

1. **Demographics:** Age, gender, education level, occupation, and residence of the parents.
2. **Child's Details:** Age, gender, type, and severity of the congenital anomaly.
3. **Awareness:** Parental knowledge about the condition, sources of information, and perceived severity.
4. **Healthcare Accessibility:** Availability of healthcare, transportation methods, and type of provider consulted.
5. **Delays:** Time from noticing the anomaly to diagnosis, and time from diagnosis to surgical intervention, along with reasons for delays.

Trained data collectors conducted face-to-face interviews with parents using the questionnaire. Interviews were held in private to ensure confidentiality and encourage open communication. On average, each interview took 15–20 minutes to complete.

Data were entered into a statistical software package (e.g., SPSS) for analysis. Descriptive statistics such as frequencies and percentages were used to summarize demographic characteristics and awareness levels. Chi-square tests were applied to identify significant associations between delays and other variables, with a p-value of <0.05 considered statistically significant. Results were presented in the form of tables and graphs.

RESULT

The results reveal a notable distribution of congenital anomalies among children based on age, gender, and type. The largest proportion of affected children (39.1%) were between 1 to 5 years old, suggesting that early childhood may represent a critical window for identifying and addressing these anomalies. Male children comprised a slightly higher percentage (57.3%) compared to females, although this difference was not statistically significant (p = 0.15). Among the types of anomalies, cardiac defects were the most prevalent (39.1%), followed by cleft lip and palate (26.0%). These findings emphasize the importance of age-specific interventions and the need for specialized pediatric cardiac and craniofacial surgical services in the region.

Table 1: Demographic Details of Children with Congenital Anomalies

Variable	Category	Frequency (n)	Percentage (%)	p-value
Age of the child	<1 year	120	31.3	0.02
	1–5 years	150	39.1	
	6–10 years	80	20.8	
	>10 years	34	8.9	
Gender	Male	220	57.3	0.15
	Female	164	42.7	
Type of congenital anomaly	Cleft lip/palate	100	26.0	0.03
	Cardiac defects	150	39.1	
	Limb deformities	80	20.8	
	Others	54	14.1	

Parental demographics indicate that most caregivers fell into the 31–40-year age group (52.1%), reflecting the prime child-rearing years. Males were the predominant primary caregivers

(62.5%), possibly reflecting cultural norms in the region. Education levels showed a concerning trend: nearly 40% of parents had no formal education, while only 8.9% had attained higher education. This lack of educational attainment may contribute to limited health literacy and delay in seeking care. Occupational data revealed that a significant number of parents (39.1%) were labourers, pointing to economic vulnerabilities that may also impact timely access to healthcare. These findings highlight the importance of community-based health education and support programs targeting low-income and less-educated families.

Table 2: Demographic Details of Parents

Variable	Category	Frequency (n)	Percentage (%)	p-value
Age of parents	20–30 years	100	26.0	0.04
	31–40 years	200	52.1	
	>40 years	84	21.9	
Gender of primary caregiver	Male	240	62.5	0.18
	Female	144	37.5	
Educational level	No formal education	150	39.1	0.01
	Primary	120	31.3	
	Secondary	80	20.8	
	Higher education	34	8.9	
Occupation	Unemployed	100	26.0	0.02
	Laborer	150	39.1	
	Teacher	50	13.0	
	Government employee	40	10.4	
	Business person	44	11.5	

The findings related to parental awareness underscore significant gaps in understanding congenital anomalies. While nearly 60% of parents were aware of their child's condition, 40% were not, reflecting the need for improved diagnostic communication. Among parents who perceived their child's condition as moderate or severe, a higher likelihood of seeking treatment was observed ($p = 0.02$), demonstrating the role of perceived severity in driving healthcare decisions. Encouragingly, 65.1% of parents had knowledge about treatment options, though this still leaves a sizeable portion uninformed. Healthcare professionals emerged as the primary source of information (46.9%), while reliance on family, friends, and traditional healers (combined 37.5%) suggests that informal networks still play a role in shaping perceptions. Educational outreach needs to focus on dismantling misconceptions and reinforcing trust in professional medical advice.

Table 3: Parental Awareness

Variable	Category	Frequency (n)	Percentage (%)	p-value
Awareness of the condition	Yes	230	59.9	0.01
	No	154	40.1	
Perceived severity of condition	Mild	100	26.0	0.02
	Moderate	150	39.1	
	Severe	134	34.9	
Knowledge about treatment	Yes	250	65.1	0.03
	No	134	34.9	
Sources of information	Family/Friends	100	26.0	0.05
	Healthcare professionals	180	46.9	
	Internet	60	15.6	
	Traditional healers	44	11.5	

Accessibility data revealed a positive trend, with 72.9% of parents reporting that healthcare facilities were available to them. However, logistical barriers such as transportation still played a significant role, with 34.9% relying on public transport and 13% traveling on foot. Pediatricians (46.9%) were the most commonly

consulted healthcare providers, reflecting their central role in managing congenital anomalies. Nevertheless, 26% sought care from general practitioners, which may lead to delays due to a lack of specialist referrals. The timeframe for seeking care showed that nearly half of the families (46.9%) waited 1–6 months after noticing the anomaly, which may exacerbate complications. Addressing delays through improved referral systems and transportation infrastructure is critical.

Table 4: Healthcare Accessibility

Variable	Category	Frequency (n)	Percentage (%)	p-value
Availability of healthcare	Yes	280	72.9	0.01
	No	104	27.1	
Mode of transportation	Walking	50	13.0	0.02
	Private vehicle	200	52.1	
	Public transport	134	34.9	
Healthcare provider consulted	General practitioner	100	26.0	0.03
	Pediatrician	180	46.9	
	Specialist	104	27.1	
Time to seek care	<1 month	120	31.3	0.01
	1–6 months	180	46.9	
	>6 months	84	21.9	

The results associated with the timing of surgically treatable conditions are suggestive of an alarming or troubling scenario. While 39.1% of the families made the diagnosis within the first one month of the realization of the anomaly, delay in the conduct of the surgery was still prevalent with 21.9% initiating the process more than six months after diagnosis. The most mentioned reasons were the lack of information (40.1 % of cases) and' fear of surgery' (26.0 %) suggesting the need for educational activities including the importance of removing surgery misconceptions. Other barriers, which were system related, included long waiting time (26.0%) and unavailability of specialist (21.9%). This information highlights the need to increase the availability of pediatric surgical services and to establish efficient referral networks to facilitate access to appropriate treatment.

Table 5: Delays in Seeking Surgical Care

Variable	Category	Frequency (n)	Percentage (%)	p-value
Time from noticing to diagnosis	<1 month	150	39.1	0.02
	1–3 months	180	46.9	
	>3 months	54	14.1	
Time from diagnosis to surgery	<1 month	120	31.3	0.01
	1–6 months	180	46.9	
	>6 months	84	21.9	
Reasons for delay	Lack of awareness	154	40.1	0.03
	Fear of surgery	100	26.0	
	Lack of referral	80	20.8	
	Cultural beliefs	50	13.0	
Health system-related delays	Long waiting times	100	26.0	0.02
	Unavailable specialists	84	21.9	

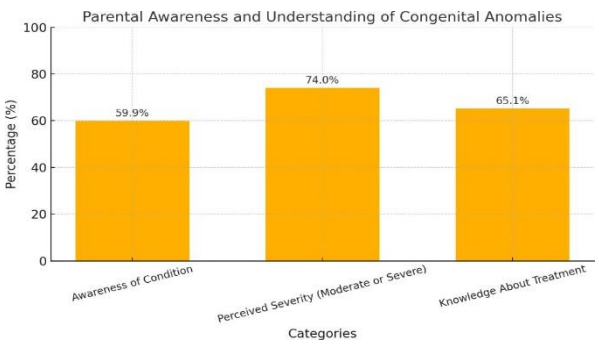

Figure 1: Figure illustrates key aspects of parental understanding of congenital anomalies.

While 59.9% of parents were aware of their child's condition, gaps remain in broader awareness. A majority (74%) recognized the condition as moderate or severe, reflecting its influence on seeking care. Additionally, 65.1% had knowledge of treatment options, though gaps between awareness and actionable understanding highlight the need for improved health education. The findings emphasize the importance of enhancing communication and support from healthcare providers to address these disparities effectively.

DISCUSSION

These findings indicate that surgical care for paediatric congenital anomalies in District Bannu, Pakistan is badly delayed and parents lack sufficient knowledge and healthcare resources. The results are also in line with previous studies that have established that lack of health knowledge socioeconomic factors; and access to health care in LMICs are primary causes of delayed treatments (6-8).

This study revealed that half the parents in this study never knew about their child's condition or had inadequate information concerning the available treatment. This is consistent with a study which established that there was poor awareness of congenital anomalies among parents and the knowledge that was available was riddled with misconception believed and cultural beliefs (9, 10). Comparable research conducted in South Asian countries has found that illiteracy among parents and dependence on traditional or word of mouth information significantly influence delays in seeking appropriate care (1, 11, 12). These results indicate the need for sensitive health promotion campaigns aimed at enhancing the knowledge and perceived credibility of contemporary medical science among parents.

It was found that healthcare centres were accessible to most families; however due to the barriers of distance, transportation, and long waiting time families faced even to receive initial consultation let alone the required specialised attention. These findings were consistent with a studies which noted that transportation problems and lack of required amenities were some of the challenges facing rural Pakistan (13, 14). Moreover, the first-contact non-specialist consultations reflect other LMICs' experiences revealed in prior research due to restricted specialist accessibility, prolonging the referral process. To continue solving these challenges, healthcare infrastructure investment, particularly in the rural and hard-to-reach areas, is crucial.

'The prolonged intervals between noticing an anomaly and seeking surgical care are a major concern' The observed families could have delayed in seeking treatment because of fear of surgery, non referral or perceived blockage of health facilities despite the availability of health facilities. The same was observed in other studies which reported that misconceptions about the surgery and lack of trust in health care systems were amongst the key factors contributing to delay in Pakistan (15-

18). Further, issues such as long waiting lists for surgery and the scarcity of pediatric surgeons have also been reported in the LMICs and are another key source of delay.

There was a reported high prevalence of socioeconomic factors that acted as barriers to timely access to care. This reflected however in increased delay for parents with lower educational levels documented than in countries with low socioeconomic, as found by global literature on disparities in access to health care. Research also conducted in India and Bangladesh has also pointed to similar observations that poverty and low literacy levels tend to worsen the delays in the management of congenital anomalies (19, 20). In order to eliminate such disparities it is necessary to go beyond the issues of health care access, also it is necessary to adopt the policy and practice related to the subsidy for the low-income families to cover the expenses and transportations needed

From the results of the above study, there are several areas of intervention that have been identified. First, educational programs should be promoted to improve the general understanding of congenital anomalies and the necessity of the early intervention. These campaigns should incorporate local language and the social relations among the community in an effort to target parents. Second, the support of the health systems is also important by bringing more pediatric specialists, decreasing the waiting time, and enhancing the referral process. Finally, provision of community health workers who seek to link families with health improving entities may be useful in overcoming gaps in knowledge and utilization.

CONCLUSION

This study has therefore confirmed the rationale for the development of overall approaches in eradicating hitches in the surgical care provided to Children with congenital anomalies in District Bannu. Educating parents on delays and overcoming the systemic healthcare constraints and providing support in the community means that children can have a much better quality of life with lesser delays. Future studies should identify strategies to address these barriers and assess the efficacy of such strategies in other low-income contexts.

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