(ISSN Online: 3006-1113) Full Paper

Libyan Journal of Medical and Applied Sciences

Journal homepage: https://ljmas.com/index.php/journal/index

RESEARCH ARTICLE

Knowledge, Attitude, and Perception of Family Members regarding the Effects of Anaesthesia on Down Syndrome Patients in Benghazi

Hiba A. Alshami [a], Maryam S. E. Hussein [a], Ghada AlShafei [b], Hadeel Rizk [b], Ainor A. Elmsmary [a], Dareen Al Shareef [a], Hadeel Samer [b], Nour Ibrahim [b], Wafaa Khaled [b]

[a] Department of Pharmaceutical Technology, College of Medical Technology Benghazi, Libyan Ministry of Technical and Vocational Education, Benghazi, Libya.
[b] Student Researchers, College of Medical Technology Benghazi, Libyan Ministry of Technical and Vocational Education, Benghazi, Libya.

Article Information

Article history:
Received on: 16/Feb/2026
Revised on: 13/Feb/2026
Accepted on:14/Mar/2026
Published on: 17/Mar/2026

Keywords:
Family members,
Knowledge,
Attitude,
Perception Down Syndrome,
Anaesthesia

Abstract

Down syndrome (DS) is the most common chromosomal abnormality, associated with unique anatomical and physiological challenges that increase the risk of complications during anaesthesia. Family members, particularly parents, play a critical role in the perioperative care and decision-making process for these patients. However, their level of awareness and perception regarding anaesthetic risks remains under-researched in Libya. This study aimed to assess the knowledge, attitudes, and perceptions of family members in Benghazi regarding the risks and effects of anaesthesia on patients with Down syndrome. A descriptive cross-sectional study was conducted in Benghazi, Libya, targeting family members of patients with Down syndrome attending the Benghazi Medical Center (BMC) and various rehabilitation centers. Data were collected using a pre-validated questionnaire distributed between November and December 2025. A total of 54 family members participated in the study. The majority of respondents were mothers (66.7%) and parents (81.5%) of the patients. The study revealed a significant communication gap; 72.2% of participants reported that they were not informed about specific anaesthetic risks by healthcare providers, and 53.7% stated they did not understand the information provided. Despite this, a high percentage (81.5%) demonstrated awareness that DS patients face increased anaesthetic risks compared to the general population. Anxiety levels were high, with 55.6% of family members reporting being "extremely anxious" about the procedures. Furthermore, 92.6% of respondents believed that healthcare providers require additional specialized training to manage these patients safely. Family members of Down syndrome patients in Benghazi exhibit a high level of vigilance and concern regarding anaesthetic safety but face significant gaps in effective communication from healthcare teams. While families are aware of the heightened risks, their anxiety is exacerbated by a lack of clear information. There is an urgent need to establish structured preoperative communication protocols and educational programs to support families and ensure informed decision-making.

1. Introduction

Down syndrome (DS), or trisomy 21, is the most common chromosomal abnormality globally, affecting approximately one in every 800 to 1,000 live births. It is a multisystem disorder frequently accompanied by congenital anomalies that significantly impact an individual's health and life expectancy. Individuals with Down syndrome often present with a unique constellation of anatomical and physiological features, including congenital heart defects (CHD), which affect 40–60% of these patients, as well as respiratory comorbidities, gastrointestinal anomalies, and distinct airway anatomy [1, 2].

As medical care has advanced, the life expectancy of individuals with Down syndrome has increased, rising from 10 years in 1930 to over 60 years today. Consequently, these patients often require anaesthesia for both corrective surgeries (such as cardiac repair) and incidental diagnostic procedures. However, the administration of anaesthesia in this population is fraught with challenges due to their complex physiology [3].

The safety of anaesthesia in patients with Down syndrome is a primary concern. Key challenges include difficult airway management due to macroglossia (enlarged tongue), subglottic stenosis, and hypotonia, which contribute to a higher risk of obstructive sleep apnea and airway obstruction . Additionally, research indicates that children with Down syndrome exhibit an altered sensitivity to volatile anaesthetics. Studies by Borland et al. and others have shown a significant propensity for severe bradycardia and hypotension during induction with sevoflurane, even in patients without structural heart defects [4,5]. Furthermore, laxity of the ligaments between the C1 and C2 vertebrae (atlantoaxial instability) poses a risk of spinal cord injury during intubation and positioning [1].

Down Syndrome in Libya; In the local context of Libya, Down syndrome represents a significant portion of congenital anomalies. A pivotal study conducted at Al-Jamahiriya Maternity Hospital in Benghazi reported a prevalence of 1.93 per 1,000 live births (approximately 1 in 518), which is notably higher than many global averages. Demographic data from local studies indicates a strong correlation with advanced maternal age, with a significant percentage of mothers being over the age of 30 [6,7]. Despite this high prevalence, there is a scarcity of local research focusing on the perioperative care of this segment of the population and the preparedness of their caregivers.

While the technical management of anaesthesia lies with healthcare professionals, the role of family members—particularly parents—is critical to the safety and success of the perioperative process. Family members are the primary advocates for the patient; they are responsible for providing accurate medical histories, consenting to procedures, and managing postoperative recovery. However, the prospect of surgery and anaesthesia is often a source of immense anxiety for families. In patients with Down syndrome, who may have limited communication skills or cognitive delays, high levels of anxiety can trigger sympathetic responses that complicate anaesthetic induction [4]. Therefore, the emotional state and knowledge level of the family directly influence the patient's experience.

Effective communication between medical teams and families is the cornerstone of safe practice. However, preliminary observations suggest a gap in Benghazi regarding how well families are informed about the specific risks associated with anaesthesia for Down syndrome. Misconceptions or a lack of knowledge can lead to increased anxiety, delayed consent, or inadequate postoperative monitoring at home.

Therefore, this project aims to assess the Knowledge, Attitude, and Perception (KAP) of family members in Benghazi regarding the effects of anaesthesia on patients with Down syndrome. By evaluating what families know about specific risks and understanding their attitudes toward the healthcare services provided, this study seeks to identify communication gaps and recommend strategies to improve the perioperative experience for both patients and their caregivers.

2. Materials and Methods

2.1. *Study design:*

A descriptive cross-sectional study was conducted using a pre-validated questionnaire.

2.2. Data collection tool:

A pre-validated questionnaire for family members consisting of 3 sections. Section 1contains 12 questions about demographic data. Section 2: Questions for family members healthcare providers to ask about knowledge and attitude. Section 3: General questions for both family to ask about perception and concerns. The questionnaire is sent to 3 practitioners for validation and edited based on their feedback. Fifty-four questionnaires were collected from the family members.

The reliability of the questionnaire was assessed using Cronbach’s alpha, resulting in a coefficient of 0.7, indicating good internal consistenc

2.3. Data collection:

Data was collected from Benghazi Medical Center and the rehabilitation centers in Benghazi city from January to December,2025.

2.4. Inclusion criteria:

Family members who are relatives to DS patients and aging above 18 years old were included in this study.

2.5. Exclusion criteria:

Family members who are below 18 years or unwilling to participate in the study were excluded.

2.6. Data analysis:

Data were analyzed using SPSS version 25. Each correct answer in knowledge questions was assigned a score of 1, while incorrect or "don't know" answers were assigned a score of 0. Participants' knowledge levels were categorized based on Bloom's cut-off points: Good Knowledge: Score ≥ 75%, Poor Knowledge: Score < 75%. While attitudes were measured using a 5-point Likert scale ranging from "Strongly Agree" (5 points) to "Strongly Disagree" (1 point). The total attitude score was calculated by summing the scores of all items. A higher score indicated a more positive attitude towards down syndrome. Descriptive statistics were presented as frequencies (N) and percentages (%) for categorical variables (e.g., gender, education, and KAP levels). Bivariate analysis was conducted to assess the association between demographic characteristics and KAP levels (e.g., Good vs. Poor).

2.7. sample size

The sample size of 54 was determined based on the available population of Down syndrome patients attending the Benghazi Medical Center and local rehabilitation centers during the study period. Given the specific nature of this population in the Benghazi region, this size represents a significant portion of accessible primary caregivers.

3. Results and Discussion

3.1. Statistical analysis of family members questioner

3.1.1. Section one: Demographic Data

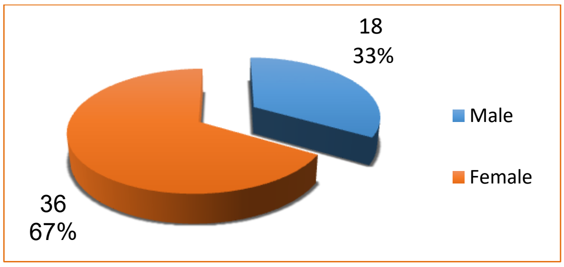

Figure 1. Distribution of Participants according to Gender

Figure 1 indicated that, female participants constituted the majority of the sample. Specifically, 66.7% (n=36) females participated, representing 66.7% of the total sample, whereas males accounted for 33.3% (n=18) of participants.

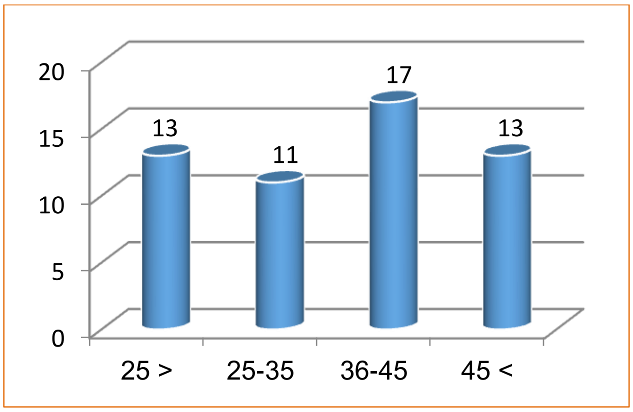

Figure 2. Distribution of Participants according to Age

Figure 2 showed that, the distribution of participants by age showed a relatively balanced sample with representation across all age groups. The largest proportion was within the 36–45 age category, accounting for 31.5% of the participants. Both the youngest group (<25 years) and the oldest group (>45 years) representing the same percentage, each comprising 24.1% of the sample. Meanwhile, participants aged [25–35] constituted 20.4% of the total. Overall, the data indicated that the study includes participants from diverse age ranges, with a slight concentration in the mid-adult group (36–45 years).

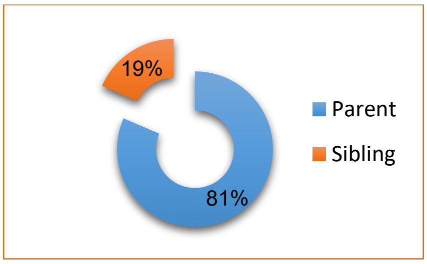

Figure 3: Distribution of participants according the relationship to the patient

The data in Figure 3 indicated that, the majority of participants were parents, representing 81.5% of the sample. In contrast, siblings accounted for only 18.5% of the respondents. This distribution showed that the study heavily relies on parental perspectives, with a relatively small contribution from siblings. Overall, the sample composition highlighted that most responses reflect the experiences and viewpoints of parents rather than other family members.

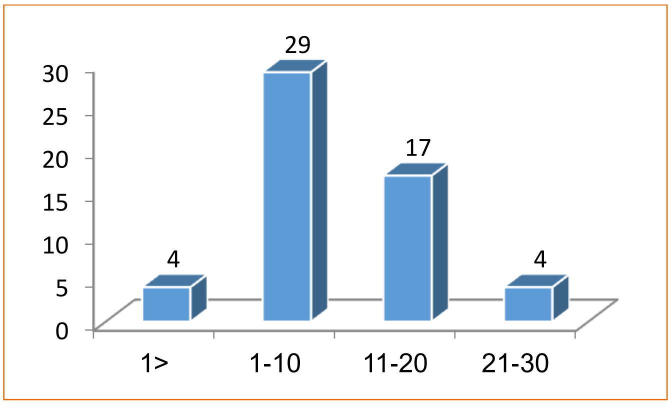

Figure 4. Distribution of participants according to the patient age

This distribution is significant for the interpretation of the study’s findings for several reasons. First, parents are the primary legal guardians and decision-makers responsible for providing informed consent for anaesthetic and surgical procedures. Therefore, their knowledge and perceptions are the most consequential regarding the safety and preoperative preparation of patients with Down syndrome. Consequently, the high parental participation validates the study’s results as accurately reflecting the "frontline" anxiety and information gaps present in the current healthcare environment.

Figure 4 showed the distribution of patients by age, that the largest proportion was within the [1–10 years] age group, accounting for 53.7% of the sample. This was followed by the [11–20 years] age group, which represented 31.5% of the participants. Both the youngest group (<1 year) and the young adult group [21–30 years] constituted the same proportion, each representing 7.4% of the sample. Overall, the data indicated that, the majority of patients were children and adolescents, with relatively few cases in infancy or early adulthood.

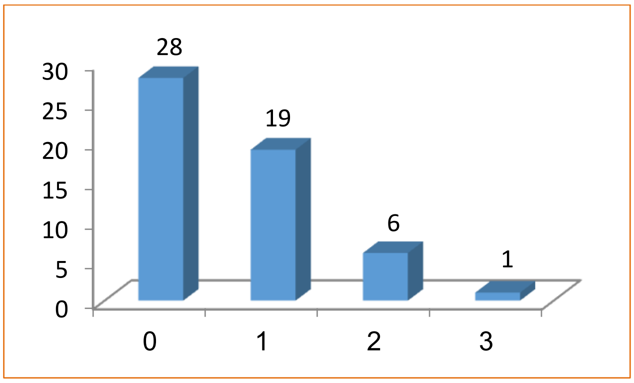

Figure 5. Number of surgical procedure requiring Anaesthesia

Figure 5 showed that, the distribution of patients according to the number of surgical procedures they had undergone under anaesthesia. More than half of the patients (51.9%) had never had surgery, while 35.2% had undergone one procedure. Only 11.1% had two surgeries, and 1.9% had three. Overall, most participants (87.1%) had experienced at most one surgical procedure.

Table 1. Distribution of patients according to the surgical procedure type

Surgical Procedure	No. of responses	%
No surgery	28	51.8
Heart Surgery	6	10.2
Appendix operation	5	8.5
Catheter	1	1.7
Gallbladder	1	1.7
Break	1	1.7
Polyp	2	3.4
Inserting an ear tube	1	1.7
Knee surgery	1	1.7
Lymph node	1	1.7
Rabbit lips	1	1.7
Tonsillectomy	7	11.9
Tooth extraction	1	1.7
Undescended testicle	1	1.7
Adenoidectorm	2	3.4

Table 1. presented the distribution of surgical procedures reported by patients, calculated using the total number of responses (59) rather than the number of patients, as some individuals had undergone more than one procedure. The most frequent response was “no Surgery,” representing (47.5%) of all reported procedures. Tonsillectomy accounted for (11.9%) of responses, followed by heart surgery (10.2%) and appendix operation (8.5%). All other procedures appeared with lower frequencies, each contributing between (1.7%) and (3.4%) of the total responses. These percentages reflected the relative frequency of each procedure within a multiple-response format and therefore did not sum to 100% at the patient level.

3.1.2. Section two: Knowledge

Figure 6. shows participants’ responses regarding whether they were informed about the potential risks of anaesthesia for their family member with Down syndrome. The majority (72.2%) reported that they did not receive such information, while only (27.8%) indicated that they were informed. This suggests a notable gap in communication between healthcare teams and families concerning anaesthesia-related risks in Down syndrome patient.

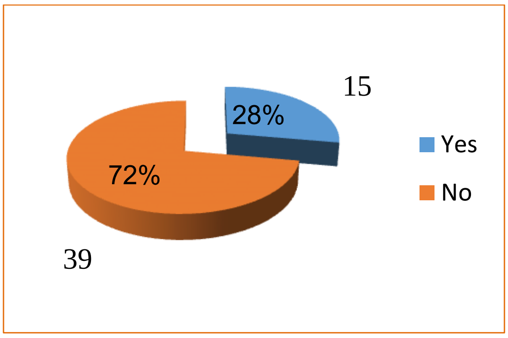

Figure 6. Information provided about anaesthesia Risks for a Family Member with Down Syndrome

In term of participants' understanding of the information provided about the anaesthetic process and its associated risks, slightly more than half of the participants (53.7%) reported that they did not understand the information, while 46.3% indicated that they did. This reflects a communication gap that may affect informed decision-making and highlights the need for clearer or more accessible explanations regarding anaesthesia risks as shown in Figure 7.

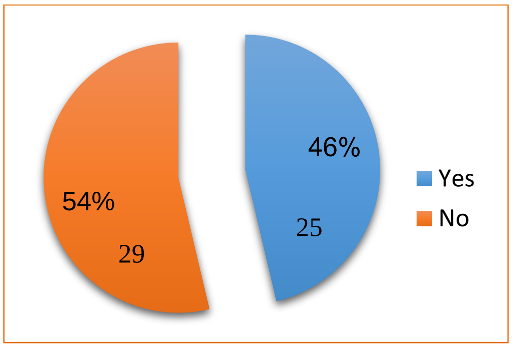

Figure 7. Understanding of Information About the anaesthetic Process and Its Risks

In regards to participants' awareness of the increased risk of complications during anaesthesia for individuals with Down syndrome, the majority of participants (81.5%) were aware of these risks, while 18.5% reported being unaware. This indicates that most participants had a good level of awareness regarding anaesthesia-related complications specific to Down syndrome as illustrated in Table 2.

Table 2. Awareness of Increased anaesthesia Risks in Individuals with Down Syndrome

Awareness	No. of participants	%
Yes	44	81.5
No	10	18.5
Total	54	100

3.1.3. Section three: Attitude and Perception

The analysis of participants' anxiety levels revealed that more than half of the respondents 55.6% reported being extremely anxious, indicating a high level of concern in the studied context. Smaller proportions reported being not anxious 13.0% or very anxious 13.0%, while moderate 11.1% and slightly anxious 7.4% levels were less frequent. These results suggest that anxiety is a significant factor for the majority of participants, with extreme anxiety being the most commonly reported level as shown in Figure 8.

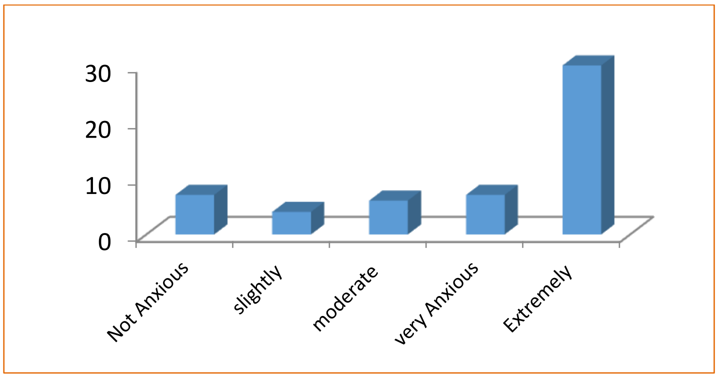

Figure 8: Level of Anxiety About Anaesthesia for Family Member

Figure 9 presented participants' satisfaction with how the healthcare team addressed their concerns and questions prior to the procedure. Responses were evenly split, with 50% of participants indicating that their concerns were adequately addressed, while the other 50% felt they were not. This suggests an equal division in perceived effectiveness of communication between the healthcare team and participants.

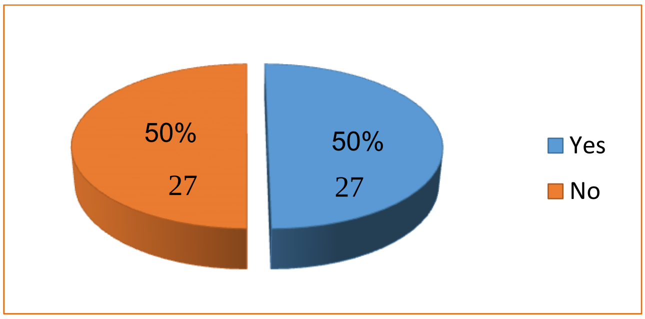

Figure 9. Satisfaction with How Healthcare Team Addressed Concerns Before the Procedure

Figure 10 showed that, the majority of participants (72.2%) believed that healthcare providers are well-informed about the special needs of patients with Down syndrome during surgery and anaesthesia, while 27.8% do not share this perception.

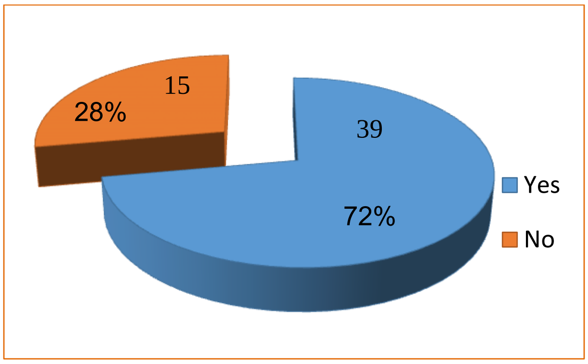

Figure 10. Perception of Healthcare Providers' Awareness of Special Needs of Down Syndrome Patients During Surgery and Anaesthesia

In term of participants' perceptions regarding the need for additional education and training for healthcare providers in the anaesthetic management of patients with Down syndrome; among the 54 respondents, a large majority (92.6%) agreed that more training is necessary, while only (7.4%) believed it is not needed. This indicates a strong consensus on the importance of enhancing healthcare providers' knowledge and skills to ensure safe anaesthetic care for this patient group. This is shown in Figure 11.

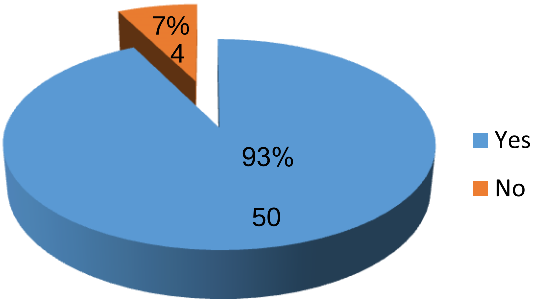

Figure 11. Need for Additional Training of Healthcare Providers in Anaesthetic Care for Down Syndrome Patients

Table 3. summarizes participants' perceptions of communication effectiveness between healthcare providers and family members during surgical preparation for patients with Down syndrome. The responses were categorized into key themes; High Effectiveness by (55.6%) of participants, indicating general satisfaction with communication quality. Moderate Effectiveness (Acceptable, Fairly Good) accounted for (20.4%), suggesting that while communication is adequate, there is room for improvement. Low/No Effectiveness (Not good, Unfortunately, No communication, Nothing) represented (7.4%), highlighting instances where communication was insufficient. Perceived Benefits of Communication (Reducing stress/fear, Improving understanding, Strengthening trust, Improving outcomes, My role continues at all times) were mentioned by (9.3%), emphasizing the qualitative impact of effective communication. Other/Individual Mentions (Surgery not undergone, Communication is very important, other individual comments) comprised (7.4%) of responses. Overall, the data indicate that most participants consider communication to be effective, with significant emphasis on its role in reducing anxiety, enhancing understanding, and fostering trust between families and healthcare providers.

Table 3. Effectiveness of Provider-Family Communication in Surgical Preparation for Down Syndrome Patients

Theme	No. of participants	%
High effectiveness	30	55.6
Moderate Effectiveness	11	20.4
Low/no effectiveness	4	7.4
Perceived benefits of communication	5	9.3
Other/ individual mentions	4	7.4
Total	54	100

Table 4 shows that the most frequently mentioned theme was Medical History (22.2%), indicating that participants consider information about past illnesses, chronic conditions, and previous anaesthesia reactions essential for ensuring a safe anaesthetic experience. This is followed by the theme All Information Is Important (13%), reflecting the belief that comprehensive knowledge of the patient is crucial. Current Health Status (11.1%), and Basic Patient Data (9.3%) were also commonly highlighted. Themes related to Medications and Allergies, and Family-Provided Information were mentioned less frequently (5.6% each). Additionally, a large percentage of unique, non-repeated responses were grouped under Other Responses (33.3%), indicating high variability in participants' perspectives.

Table 4. Important Information Needed by Healthcare Providers to Ensure a Safe Anaesthetic Experience

Theme	No. of participants	%
Medical History	12	22.2
All information is important/ comprehensive knowledge	7	13
Basic patient data	5	9.3
Current health status/Vital signs	6	11.1
Medications and Allergies	3	5.6
Family-provided information	3	5.6
Other responses	18	33.3
Total	54	100

Table 5 summarizes the perceived barriers to safe anaesthetic care for patients with Down syndrome, categorized into key themes; Lack of Knowledge/Awareness (I don't know, I have no idea, lack of knowledge, awareness) was reported by (37.0%) of participants, highlighting a significant gap in training and familiarity with the specific needs of this patient group. Cardiovascular/Heart Issues accounted for (14.8%), reflecting the clinical complexity related to cardiac conditions. Respiratory/Breathing Issues represented (13.0%), emphasizing challenges in managing airway and respiratory complications. Communication and Interaction Difficulties comprised (7.4%), indicating the need for improved communication strategies. anaesthesia-related Concerns and Training/Specialist Gaps each accounted for (3.7%), pointing to procedural and professional skill-related barriers. Patient Anxiety/Fear/Other Factors represented (20.4%), highlighting additional situational and patient-specific challenges. Overall, the findings indicate that the most significant barriers are related to knowledge gaps and medical complexity, underscoring the need for targeted training, specialist support, and structured protocols to ensure safe anaesthetic care for Down syndrome patients.

Table 5. Perceived Barriers to Safe Anaesthetic Care for Down Syndrome Patients

Theme	**No. of participants**	**%**
Lack of knowledge	20	37.0
Cardiovascular/ Heart Issues	8	14.8
Respiratory/Breathing Issues	7	13.0
Communication and interaction difficulties	4	7.4
anaesthesia-related concerns	2	3.7
Training/specialist gaps	2	3.7
Patient Anxiety/fear	11	20.4
Total	54	100%

4. Discussion

This distribution showed that the sample is predominantly female. This gender distribution is consistent with the socio-cultural dynamics prevalent in Benghazi and the broader Arab region, where mothers traditionally assume the primary responsibility for child-rearing and health management. This finding suggests that mothers are the primary caregivers accompanying children with Down syndrome to medical appointments and rehabilitation centers. Consequently, they are often the frontline recipients of medical information and the primary decision-makers regarding perioperative care. This maternal preponderance aligns with numerous global studies on pediatric caregiving, which consistently identify mothers as the main stakeholders in the health supervision of children with special needs [8,9].

This surgical burden, while significant, appears somewhat lower than figures reported in some international large-scale cohorts, where the cumulative risk of surgery for children with Down syndrome is often described as considerably higher due to the multisystem nature of the syndrome [9,10]. The prevalence of the "no surgery" group in this Benghazi-based sample may reflect the age distribution of the participants (younger children may not yet have required intervention) or potentially indicates variations in local screening protocols for non-emergent conditions. However, for the nearly 50% of families who have experienced perioperative care, the anxiety and need for knowledge remain acute. Among the surgical procedures reported, tonsillectomy was the most frequent, accounting for 11.9% of responses. This finding is highly consistent with global literature, which identifies Otorhinolaryngologic (ENT) procedures as the most common surgeries performed on children with DS [11]. Heart surgery was the second most common specific major procedure reported (10.2%). This aligns with established epidemiological data stating that 40–50% of infants with Down syndrome are born with Congenital Heart Defects (CHD), most commonly Atrioventricular Septal Defects (AVSD) or Ventricular Septal Defects (VSD) [12].

In the context of Down syndrome, thorough preoperative communication is not merely a formality but a safety imperative. Patients with Down syndrome present with unique anatomical and physiological challenges, such as macroglossia, atlantoaxial instability, and increased sensitivity to volatile anaesthetics like sevoflurane [13]. Consequently, the failure to inform families of these specific risks prevents them from acting as effective partners in the patient's care. Literature suggests that parents of children with intellectual disabilities are often the first to notice subtle postoperative physiological changes; however, without knowledge of what to watch for (e.g., signs of post-extubation stridor or delayed recovery), their ability to safeguard the patient is diminished [14].

This lack of information sharing observed in our study contrasts with international guidelines which emphasize that establishing a "partnership of care" reduces parental anxiety and improves patient outcomes [15]. High levels of parental anxiety, which were also noted in this study, are frequently correlated with a lack of understanding regarding medical procedures. When healthcare providers fail to explain the anaesthetic plan and potential complications, it exacerbates the family's stress and may lead to a loss of trust in the medical system [16].

The high rate of uninformed families in Benghazi may be attributed to several factors, including heavy clinical workloads, a lack of private spaces for preoperative counseling, or a misconception among providers that families may not understand complex medical information. However, this gap reinforces the need for a structured communication protocol. Evidence indicates that when anaesthesiologists utilize dedicated time to explain specific risks—such as the potential for difficult airway management—family satisfaction scores increase, and perioperative anxiety is significantly mitigated [17].

The inability of families to understand anaesthetic risks has practical safety implications. Parents of children with Down syndrome are often the primary post-operative monitors. If they do not grasp the specific respiratory or cardiac risks associated with their child’s condition, they may fail to recognize early warning signs of complications after discharge, such as sleep apnea or stridor [18].

This finding underscores the urgent need to move beyond standard verbal explanations. The adoption of the "teach-back" method—where clinicians ask family members to repeat the information in their own words—has been shown to significantly improve retention and understanding in low-health-literacy populations [19]. Additionally, the development of visual aids and educational materials specifically designed for families of special needs patients in Benghazi could bridge this gap.

This high level of awareness is likely attributable to the frequent medical encounters characteristic of Down syndrome. Since approximately 40–50% of children with Down syndrome are born with congenital heart defects and many suffer from recurrent respiratory infections, families are often forced to become "expert caregivers" early in the child's life [20]. This chronic exposure to medical environments likely fosters a heightened sense of vigilance and a generalized understanding that their family member is "medically fragile."

However, this finding presents a critical paradox when viewed alongside the data from Figure 6 (where 72.2% reported not being informed by the doctor). While families are aware that risks exist, this awareness appears to be derived from general experience or external sources (such as the internet or peer support groups) rather than direct, specific education from the anaesthesia provider.

This distinction between "awareness" and "informed knowledge" is crucial. A parent may be aware that "anaesthesia is dangerous" (General Awareness), but may not know that the specific risk involves bradycardia during sevoflurane induction or atlantoaxial instability (Specific Knowledge) [21]. Research suggests that when high awareness of risk is coupled with a lack of specific information from the medical team, it often results in disproportionate anxiety [22]. Parents know there is danger, but without the anaesthesiologist explaining how they plan to mitigate those risks, the awareness serves only to increase fear rather than empower the family. Therefore, the high awareness observed in Table 2 should be viewed as an opportunity. The families are already primed to understand that precautions are necessary; healthcare providers in Benghazi must simply leverage this existing awareness by filling in the gaps with accurate, reassuring medical details.

This prevalence is notably higher than anxiety levels typically reported in parents of neurotypical children undergoing routine surgery. This heightened state of concern is consistent with the literature regarding parents of children with intellectual disabilities, who often experience chronic stress related to their child's health and are prone to the "vulnerable child syndrome"—a state of exaggerated protectiveness and anxiety arising from the child's complex medical history [23].

The root of this extreme anxiety in the Benghazi cohort is likely multifactorial. Firstly, it correlates strongly with the previously discussed lack of information; fear of the unknown is a potent anxiety trigger. Secondly, families of patients with Down syndrome are often acutely aware of the "high-stakes" nature of their child's physiology. The knowledge—however vague—that their family member may have an unstable neck (atlantoaxial instability) or a susceptible heart likely elevates their baseline fear of perioperative mortality [24].

For families of children with Down syndrome, who often present with heightened baseline anxiety due to the medical complexity of their children (e.g., potential for cardiac defects or difficult airways), "adequate" communication requires more than standard reassurance [25]. The 50% of families who felt their concerns were not addressed likely represents a missed opportunity for Family-Centered Care (FCC).

Literature consistently demonstrates that parental satisfaction in pediatric anaesthesia is less dependent on the medical outcome itself and more dependent on the process of care—specifically, the feeling of being listened to and having their specific fears validated [26]

Moreover, the trust is crucial, as high levels of trust in physicians have been shown to correlate with better adherence to medical advice and reduced preoperative anxiety [27].

In addition, the parental perception aligns with recent medical education research. A regional survey by Mottana et al. (2024) highlighted significant gaps in anaesthesia residency curricula regarding genetic syndromes, noting that many trainees feel underprepared for the specific physiological challenges presented by these patients [28].

The result aligns with the findings of Mestre et al. (2019), who demonstrated that for parents of children with intellectual disabilities, the quality of the provider interaction—specifically feeling heard and respected—is often a stronger predictor of satisfaction than the clinical outcome itself [29]. Furthermore, the 7.4% who reported "Low/No Effectiveness" represent a high-risk group. When communication fails, parents may feel marginalized in the decision-making process. Research indicates that parents of children with Down syndrome often experience "healthcare fatigue" and require distinct communication styles that acknowledge their unique expertise regarding their child's baseline behavior and physiological needs [30]. Therefore, while the majority are satisfied, the goal should be to standardize communication protocols to ensure that the minority of families receiving "low effectiveness" communication are not left behind.

The fact that over one-third of participants responded with "I don't know" or "I have no idea" when asked about barriers suggests that a large segment of the population enters the perioperative environment in a state of uninformed vulnerability. In the context of Down syndrome, where perioperative mortality is higher than in the general population, this knowledge deficit is a significant safety risk. It hinders the family’s ability to provide a complete medical history or to advocate for necessary preoperative screenings, such as cervical spine imaging or echocardiography [31].

Despite the general lack of knowledge, a subset of participants correctly identified the two most critical clinical barriers: Cardiovascular/Heart Issues (14.8%) and Respiratory/Breathing Issues (13.0%). This finding aligns with established medical literature, which cites congenital heart defects (present in 40-60% of DS patients) and airway obstruction (due to macroglossia and hypotonia) as the primary causes of anaesthetic complications [32].

The participants’ focus on "heart holes" and "difficulty breathing" reflects a valid concern. Research by Borland et al. (2004) underscores that even without structural heart defects, DS patients are prone to severe bradycardia upon induction with sevoflurane. The fact that nearly 28% of families recognized these physiological threats indicates that when education is provided, families can grasp complex medical priorities [33]

5. **Limitations**

This study has several limitations, including a relatively small sample size (n=54), which may limit the generalizability of the findings to the entire Libyan population. Additionally, as a cross-sectional study conducted only in Benghazi, the results may reflect local healthcare dynamics that differ in other regions. Self-reported data from family members may also be subject to recall bias regarding past surgical experiences.

6. Conclusions

In conclusion, this study demonstrates that patients with Down syndrome require special consideration during anaesthesia due to their unique physiological and clinical characteristics. Enhancing healthcare providers' knowledge, and emphasising the significant role of effective communication between the healthcare team and patients' families. A clear explanation of anaesthesia procedures and potential risks help reduce anxiety and improves families' understanding, while involving them in the decision-making process strengthens trust in the proposed treatment plan.

Additionally, continuous professional training, effective communication with patients' families, and multidisciplinary collaboration play crucial roles in optimizing patient outcomes. Further research is recommended to support evidence-based practices and improve the quality of anaesthesia care provided to patients with Down syndrome. This study recommends that :

A. **Enhancing healthcare providers' awareness of the characteristics of Down syndrome patients:** Patients with Down syndrome have specific anatomical and physiological features that may affect anaesthesia management, making adequate knowledge essential prior to any surgical procedure.
B. **Improving communication between the medical team and patients' families:** Clear explanation of anaesthesia procedures and possible risks helps reduce anxiety and increases trust in the proposed treatment plan.
C. **Encouraging further research in anaesthesia care for Down syndrome patients:** Additional studies are needed to expand existing knowledge and improve the quality of anaesthesia care for this patient population.
D. **Including anaesthesia considerations for Down syndrome patients in medical curricula:** Integrating this topic into medical education programs will help prepare future healthcare professionals to manage such cases more effectively.

Acknowledgements

The authors wish to thank all the family members who participated in this study.

Availability of data and materials

All data generated or analysed during this study are included in this published article.

Ethics approval and consent to participate

Ethics approval was obtained from the ethical committee, College of Medical Technology, Benghazi, Libya No. CMTBEN 459266084 in January ‹10th, 2025

Competing interests

The authors declare that there is no competing interests.

References

1. Alert, V., Riera, A., García, O., & colleagues. (2020). Anaesthesia for children with Down syndrome: A retrospective review of a 5-year period. Revista Española de Anestesiología y Reanimación, 67(9), 485–492. https://doi.org/10.1016/j.redar.2020.04.004
2. Anyanwu, E., Maduka, C., Ayo-Farai, O., Okongwu, C., & Daraojimba, A. (2024). Maternal and child health policy: A global review of current practices and future directions. World Journal of Advanced Research and Reviews, 21(2), 1770–1781. https://doi.org/10.30574/wjarr.2024.21.2.0306
3. Aquin, J. P., El-Gabalawy, R., Sala, T., & Sareen, J. (2017). Anxiety disorders and general medical conditions: Current research and future directions. Focus, 15(2), 173–181. https://doi.org/10.1176/appi.focus.20160044
4. Arefayne, N. R., Getahun, A. B., Melkie, T. B., Endalew, N. S., & Nigatu, Y. A. (2022). Patients' knowledge and perception of anaesthesia and the anaesthetists: Cross-sectional study. Annals of Medicine and Surgery, 78, Article 103740. https://doi.org/10.1016/j.amsu.2022.103740

5. Artal, J. M., Randall, L., Rubeck, S., Allyse, M., Michie, M., Riggan, K. A., Meredith, S., & Skotko, B. G. (2024). Parents of children with Down syndrome reflect on their postnatal diagnoses, 2003–2022. American Journal of Medical Genetics Part A, 194(8), Article e63619. https://doi.org/10.1002/ajmg.a.63619
6. AusACPDM 2024 Abstracts. (2024). Developmental Medicine & Child Neurology, 66(S1), 5–99. https://doi.org/10.1111/dmcn.15990
7. Bhattarai, B., Kulkarni, A., Rao, S., & Mairpadi, A. (2008). Anaesthetic consideration in Down syndrome—a review. Nepal Medical College Journal, 10(3), 199–203. https://pubmed.ncbi.nlm.nih.gov/19253867
8. Borland, L. M., Colligan, J., & Brandom, B. W. (2004). Bradycardia and hypotension during induction of anaesthesia with sevoflurane in children with Down syndrome. Anesthesia & Analgesia, 99(1), 164–169. https://doi.org/10.1213/01.ANE.0000117006.15545.9C
9. Centers for Disease Control and Prevention. (2026). Data & statistics on Down syndrome. https://www.cdc.gov/birth-defects/about/down-syndrome.html
10. Craven, V. E., Daw, W. J., Wan, J. W. Y., & Elphick, H. E. (2025). Respiratory and airway disorders in children with Down syndrome: A review of the clinical challenges and management. Frontiers in Pediatrics, 13, Article 1553984. https://doi.org/10.3389/fped.2025.1553984
11. Egbuta, C., & Mason, K. P. (2020). Recognizing risks and optimizing perioperative care to reduce respiratory complications in the pediatric patient. Journal of Clinical Medicine, 9(6), Article 1942. https://doi.org/10.3390/jcm9061942
12. Everett, L. L. (2011). Pediatric anaesthesia. In C. Vacanti, S. Segal, P. Sikka, & R. Urman (Eds.), Essential clinical anesthesia (pp. 777–836). Cambridge University Press.
13. Fezzan University. (2022). Down syndrome in southwest Libya: Prevalence and characteristics. Fezzan University Scientific Journal.
14. Garnett, A., Hui, L., Oleynikov, C., & Boamah, S. (2023). Compassion fatigue in healthcare providers: A scoping review. BMC Health Services Research, 23(1), Article 1336. https://doi.org/10.1186/s12913-023-10356-3
15. Harfaoui, W., Alilou, M., El Adib, A. R., Zidouh, S., Zentar, A., Lekehal, B., Belyamani, L., & Obtel, M. (2024). Patient safety in anaesthesiology: Progress, challenges, and prospects. Cureus, 16(9), Article e69540. https://doi.org/10.7759/cureus.69540
16. Ingelmo, P. M., & Fumagalli, R. (2018). Pathophysiology and pharmacology of anaesthesia in children with Down syndrome. Paediatric Anaesthesia, 28(12), 1070–1077. https://doi.org/10.1111/pan.13511
17. Leonardsen, A. L., Valeberg, B. T., Danielsen, A., Jonth, C., Brunborg, I. M., & Jørgensen, E. D. (2025). Parent satisfaction with pediatric anaesthesia—A cross-sectional, multicenter study in Norway. Paediatric Anaesthesia, 35(6), 446–453. https://doi.org/10.1111/pan.15094
18. Libyan Journal of Medical Research. (2023). Incidence of Down syndrome at Al-Jamahiriya Maternity Hospital, Benghazi, Libya: 1.9 per 1000 live births. Libyan Journal of Medical Research, 17(1), 19–24.
19. Madrigal, V. N., Hill, D. L., Shults, J., & Feudtner, C. (2022). Trust in physicians, anxiety and depression, and decision-making preferences among parents of children with serious illness. Journal of Palliative Medicine, 25(3), 428–436. https://doi.org/10.1089/jpm.2021.0063
20. Maranets, I., & Kain, Z. (1999). Preoperative anxiety and intraoperative anaesthetic requirements. Anesthesia & Analgesia, 89(6), 1346–1351. https://doi.org/10.1097/00000539-199912000-00003
21. McIntosh, J., & Runciman, P. (2008). Exploring the role of partnership in the home care of children with special health needs: Qualitative findings from two service evaluations. International Journal of Nursing Studies, 45(5), 714–726. https://doi.org/10.1016/j.ijnurstu.2006.12.012
22. Meitzner, M. C., & Skurnowicz, J. A. (2005). Anaesthetic considerations for patients with Down syndrome. AANA Journal, 73(2), 103–107.
23. Mestre, T. D., Lopes, M. J., Mestre, D. M., Ferreira, R. F., Costa, A. P., & Caldeira, E. V. (2024). Impact of family-centered care in families with children with intellectual disability: A systematic review. Heliyon, 10(7), Article e28241. https://doi.org/10.1016/j.heliyon.2024.e28241

24. Mottana, L. V., Magalhães, C. R., Bevilacqua Filho, C. T., Barone, P. D., & Jotz, G. P. (2022). Anaesthesiologists' perception on their residency training. Brazillian Journal of Anesthesiology, 72(1), 37–43. https://doi.org/10.1016/j.bjane.2021.06.004
25. Nogami, K., Taniguchi, S., & Togami, K. (2016). Transient cardiac arrest in a child with Down syndrome during anaesthesia induction with sevoflurane: A case report. JA Clinical Reports, 2(1), Article 18. https://doi.org/10.1186/s40981-016-0044-6
26. Ong, N., Lucien, A., Long, J., Weise, J., Burgess, A., & Walton, M. (2024). What do parents think about the quality and safety of care provided by hospitals to children and young people with an intellectual disability? A qualitative study using thematic analysis. Health Expectations, 27(1), Article e13925. https://doi.org/10.1111/hex.13925
27. Ozalp, S., & Gumus Ozcan, F. (2025). The impact of Down syndrome on perioperative anaesthetic management and outcomes in infants undergoing isolated ventricular septal defect closure. Diagnostics, 15(15), Article 1839. https://doi.org/10.3390/diagnostics15151839
28. Presson, A. P., Partyka, G., Jensen, K. M., Devine, O. J., Rasmussen, S. A., McCabe, L. L., & McCabe, E. R. (2013). Current estimate of Down syndrome population prevalence in the United States. The Journal of Pediatrics, 163(4), 1163–1168. https://doi.org/10.1016/j.jpeds.2013.06.013
29. Pueschel, S. M., Findley, T. W., Furia, J., Gallagher, P. L., Scola, F. H., & Pezzullo, J. C. (1987). Atlantoaxial instability in Down syndrome: Roentgenographic, neurologic, and somatosensory evoked potential studies. The Journal of Pediatrics, 110(4), 515–521. https://doi.org/10.1016/s0022-3476(87)80541-3
30. Reedtz, C., Lauritzen, C., Stover, Y. V., Freili, J. L., & Rognmo, K. (2019). Identification of children of parents with mental illness: A necessity to provide relevant support. Frontiers in Psychiatry, 9, Article 728. https://doi.org/10.3389/fpsyt.2018.00728
31. Wassenaer-Leemhuis, A. V. (2015). Maternal and paternal perception of child vulnerability and behaviour problems in very preterm born children. Infant and Child Development, 24(4). https://doi.org/10.1002/icd.1898
32. Yen, P. H., & Leasure, A. R. (2019). Use and effectiveness of the Teach-Back method in patient education and health outcomes. Federal Practitioner, 36(6), 284–289. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6590951/

معرفة أفراد الأسرة ومواقفهم وتصوراتهم بشأن آثار التخدير على مرضى متلازمة داون في بنغازي

الخلاصة

متلازمة داون هي أكثر التشوهات الكروموسومية شيوعًا، وتترافق مع تحديات تشريحية وفيزيولوجية فريدة تزيد من خطر حدوث مضاعفات أثناء التخدير. يلعب أفراد الأسرة، وخاصة الوالدين، دورًا حاسمًا في الرعاية المحيطة بالجراحة وعملية اتخاذ القرارات لهؤلاء المرضى. ومع ذلك، لا يزال مستوى وعيهم وإدراكهم لمخاطر التخدير غير مدروس بشكل كافٍ في ليبيا. هدفت هذه الدراسة إلى تقييم معارف ومواقف وتصورات أفراد أسر مرضى متلازمة داون في بنغازي فيما يتعلق بمخاطر التخدير وآثاره على المرضى المصابين بمتلازمة داون. أُجريت دراسة وصفية مقطعية في بنغازي، ليبيا، استهدفت أفراد أسر مرضى متلازمة داون الذين يراجعون مركز بنغازي الطبي ومراكز إعادة التأهيل المختلفة. جُمعت البيانات باستخدام استبيان مُسبق التحقق من صحته، وُزِّع بين نوفمبر وديسمبر 2025. شارك في الدراسة 54 فردًا من أفراد الأسر. كانت غالبية المشاركين من الأمهات (66.7%) والآباء (81.5%). كشفت الدراسة عن فجوة تواصل كبيرة. أفاد 72.2% من المشاركين بأن مقدمي الرعاية الصحية لم يبلغوهم بمخاطر التخدير المحددة، وذكر 53.7% منهم أنهم لم يفهموا المعلومات المقدمة. مع ذلك، أظهرت نسبة عالية (81.5%) وعيًا بأن مرضى متلازمة داون يواجهون مخاطر تخدير متزايدة مقارنةً بعامة السكان. وكانت مستويات القلق مرتفعة، حيث أفاد 55.6% من أفراد الأسر بأنهم يشعرون بقلق بالغ حيال الإجراءات. علاوة على ذلك، اعتقد 92.6% من المشاركين أن مقدمي الرعاية الصحية بحاجة إلى تدريب متخصص إضافي لإدارة هؤلاء المرضى بأمان. يُظهر أفراد أسر مرضى متلازمة داون في بنغازي مستوى عالٍ من اليقظة والقلق بشأن سلامة التخدير، لكنهم يواجهون فجوات كبيرة في التواصل الفعال من فرق الرعاية الصحية. وبينما تُدرك الأسر المخاطر المتزايدة، يتفاقم قلقها بسبب نقص المعلومات الواضحة. ثمة حاجة ملحة لوضع بروتوكولات تواصل منظمة قبل الجراحة وبرامج تثقيفية لدعم الأسر وضمان اتخاذ قرارات مستنيرة.

الكلمات المفتاحية: أفراد الأسرة، المعرفة، الموقف، الإدراك، متلازمة داون، التخدير