Commentary

The Expanding Role of the Clinical Laboratory in Patient-Centered Care : Lessons from Sweat Testing

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Article Info

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Keywords

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Abstract

Background: The sweat test is a cornerstone in the diagnosis of cystic fibrosis. Despite being a simple and painless procedure, insufficient pre-test information can cause considerable parental anxiety and negatively affect the care experience.

Objective: To highlight the role of the clinical laboratory in patient and family education and communication, based on parents' experiences before and during sweat test appointments.

Methods: A prospective study was conducted between July and December 2023 in a clinical chemistry laboratory. Parents of children referred for sweat testing (quantitative pilocarpine iontophoresis) completed a questionnaire assessing pre-test information, anxiety level, and satisfaction with laboratory communication.

Results: Among 41 included children, 36 (87.8%) of parents reported receiving no pre-test information during clinical consultation, and 22 (53.7%) experienced high anxiety prior to testing. After communication by laboratory staff, 37 (90.2%) of parents were very satisfied and 3(7.3%) satisfied, yielding an overall satisfaction rate of 97.5%.

Conclusion: Structured communication provided by the clinical laboratory is associated with high parental satisfaction and may help reduce anxiety during sweat testing. These findings support a more active role for laboratory professionals in patient- and family-centered care.

Background

Cystic fibrosis is a rare autosomal recessive disease requiring early diagnosis to improve prognosis and quality of life.
The sweat test remains the reference diagnostic method [1]. Although technically simple [2], the diagnostic context and lack of information can negatively affect families, particularly parents of young children facing a potentially serious chronic disease [3,4]. Misinterpretation or incomplete explanations of results can further increase parental anxiety and stress, particularly because cystic fibrosis is associated with reduced life expectancy [5,6]. Parental anxiety is often pronounced in chronic pediatric conditions, where uncertainty about diagnosis and prognosis contributes to heightened stress and information needs. Systematic reviews have shown that caregivers of children with chronic illnesses frequently experience high levels of parenting stress, partly related to communication and care coordination [3].
Patient-centered laboratory medicine has become a strategic priority within modern healthcare systems and professional organizations [7]. Five key domains were identified for laboratory contribution : improved communication, patient education, result access, interprofessional collaboration, and patient satisfaction measurement [7]. In this perspective, the clinical laboratory should be considered not only a technical service, but also an educational and communicative partner that can support clinicians and families throughout the diagnostic process [7]. The European Federation of Clinical Chemistry and Laboratory Medicine (EFLM) Working Group specifically advocates laboratories engaging directly with patients through structured communication protocols [8]. In the specific setting of cystic fibrosis, international guidelines emphasize that parents should receive structured information about the sweat test, including its purpose, patient preparation, procedural steps, potential risks, and contact details for further questions, in order to ensure informed participation and reduce anxiety [2]. The sweat chloride result should be explained in terms of established thresholds (normal, intermediate, and positive ranges) [2].
The aim of this study was to highlight the role of the clinical laboratory by describing parents' experiences of information, anxiety, and satisfaction before and after laboratory-based communication.

Methods

A prospective, single-center study with a before-after communication design was conducted at the clinical chemistry laboratory of Habib Bourguiba University Hospital (Sfax, Tunisia) between July and December 2023. Sweat chloride test (quantitative pilocarpine iontophoresis, Exsudose ® technique) was performed in patients referred for a sweat test between july 2023 and december 2023.
Parents accompanying the child completed a structured questionnaire (Table 1).

Table 1 : Patient questionnaire.

Section	Questionnaire item	Response options
I. General information	Socioeconomic status	Low / Medium / High
	Is this your first sweat test?	Yes / No
	Family history of cystic fibrosis	Yes / No / Do not know
II. Information before the test	Did you receive information about the sweat test before your visit (during consultation, at the department, etc.)?	Yes / No
	The level of information received was:	Sufficient / Insufficient / None
	Would you have liked to receive more information before the test?	Yes / No
III. Anxiety level	Before the test, what was your anxiety level?	5-point Likert scale: 1 = very low; 2 = low; 3 = moderate; 4 = high; 5 = very high
IV. Laboratory experience	Staff communication was:	5-point Likert scale: 1 = absent; 2 = not clear; 3 = somewhat unclear; 4 = clear; 5 = very clear
	How satisfied were you with the quality of the information provided?	5-point Likert scale: 1 = not at all satisfied; 2 = slightly satisfied; 3 = moderately satisfied; 4 = satisfied; 5 = very satisfied
	Do you have any suggestions for improving information or care?	Free-text response

The observed hypocalcemia, in conjunction with elevated PTH, is consistent with secondary hyperparathyroidism resulting from impaired osteoclastic bone resorption. Reduced calcium mobilization from bone leads to compensatory PTH elevation, while ALP elevation reflects increased bone turnover activity. These findings support the underlying pathophysiology of osteopetrosis.

The questionnaire was specifically developed for this study. It included closed questions with 1-5 Likert scales and was pilot-tested on a small group of parents to ensure comprehensibility among parents with variable literacy levels. The questionnaire assessed three main aspects :

- Information received about the sweat test procedure during the clinical consultation (yes/no),
- Anxiety level while awaiting the sweat test was self-reported with brief descriptors provided to parents : 1 and 2 corresponding to 'Low anxiety level ' ; 3 corresponding to 'moderate anxiety level' 4 and 5 corresponding to 'high anxiety level'
- Satisfaction with the quality of information provided by the laboratory staff was rated as dissatisfied (1, 2), satisfied (3), or very satisfied (4,5).

Inclusion criteria were : parents or legal guardians of children referred for quantitative pilocarpine iontophoresis during the study period, age ≥18 years, and ability to understand the questionnaire language (Tunisian Arabic Dialect). Parents who declined to participate or who had cognitive or language barriers precluding completion of the questionnaire were excluded

Questionnaires were done on the day of the sweat test, immediately before and immediately after the information session provided by laboratory staff. The information session included a brief explanation of how the test works (pilocarpine iontophoresis followed by sweat collection), the expected duration of the procedure (approximately 30–60 minutes in total), the principle of chloride measurement, and the clinical meaning of the three main result categories (normal, intermediate, and positive) and the need to discuss the findings with the referring clinician.

Descriptive data on patient demographics and clinical presentation were also collected from medical records. Data were analyzed descriptively using absolute frequencies and percentages. Chi-square tests were performed to investigate potential associations between clinical factors and parental anxiety/satisfaction.

Results

Forty-one children were included, with a mean age of 3.1 years. Clinical and demographic characteristics are summarized in Table 2.

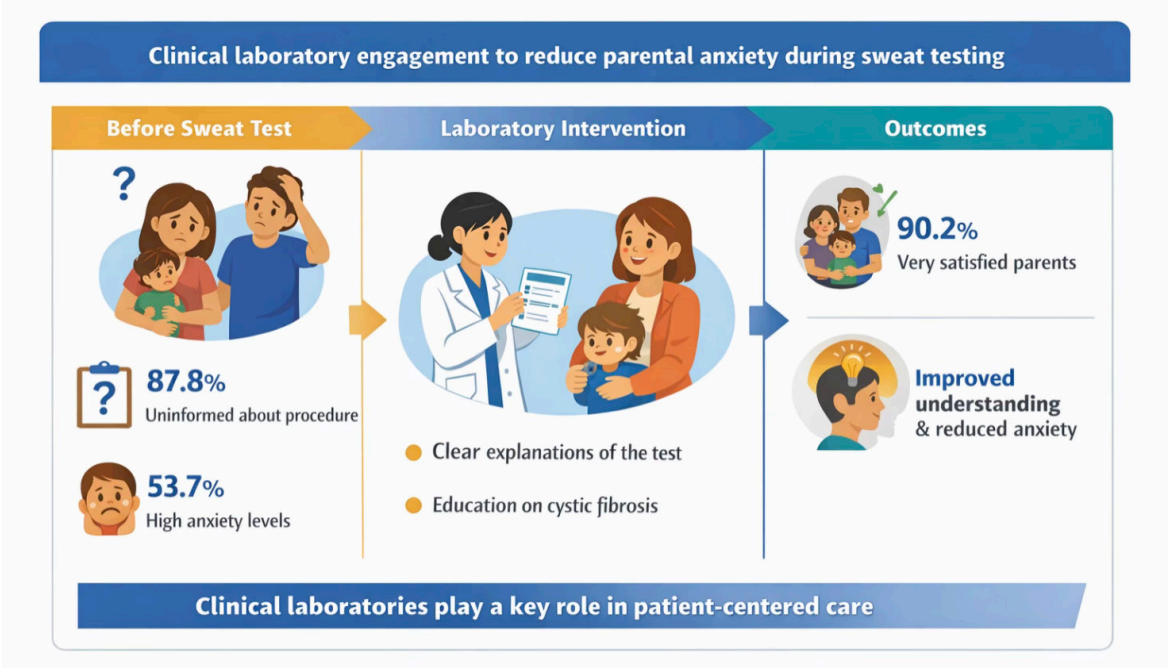
Table 2 : Baseline characteristics of the study population.

Characteristic	Value (n = 41)
Mean age, years [Min–Max]	3.1 [1 month – 14 years]
Sex, male/female	26 / 15
Low socioeconomic background, n (%)	19 (46.3%)
Parental consanguinity, n (%)	11 (26.8%)
Family history of cystic fibrosis, n (%) Unknown No Yes	26 (63.4%) 15 (36.5%) 0 (0%)
Mean age at symptom onset, months [Min–Max]	10 [2 days – 10 years]
Pulmonary signs, n (%)	32 (78.0%)
Digestive signs, n (%)	19 (46.3%)
Growth retardation, n (%)	14 (34.1%)

In our cohort, 36 (87.8%) of parents reported receiving no information about the sweat test during clinical consultation. Parents referred for sweat testing often lack basic understanding of the test's purpose, clinical indications, procedural steps, and result interpretation. More than half of parents (n=22, 53.7%) reported high anxiety prior to the appointment. Subgroup analyses did not show significant differences in parental anxiety according to age group (p=0.264), digestive symptoms (p=0.154), pulmonary symptoms (p=0.295), socioeconomic status (p=0.569) or child sex (p=0.234).

After standardized information provided by the laboratory, 33/37 (90.2%) of parents reported being very satisfied and 3/37 (7.3%) satisfied with communication received, yielding 97.5% overall satisfaction (Figure 1). Notably, the single dissatisfied parent had an equivocal chloride result (30-60 mmol/L), while all parents with normal (<30 mmol/L) or positive (>60 mmol/L) results reported satisfaction.

Figure 1: Impact of clinical laboratory communication on parental anxiety and satisfaction before sweat testing.



Discussion

Our findings showed a practical application of the IFCC Task Force recommendations and suggest that structured communication within the laboratory setting may have a positive impact on parental experience. The laboratory may therefore act as a critical point of contact where anxiety can be reduced and understanding improved. Our results are consistent with previous work emphasizing that effective communication and coordination are central elements of patient-centered laboratory medicine [5,6].

The marked contrast between poor information during consultation and high satisfaction after laboratory-based communication highlights an important gap in the diagnostic pathway for cystic fibrosis. The single dissatisfied parent uniquely had an equivocal chloride result. Diagnostic uncertainty poses significant communication challenges and generates parental concerns regarding their child's health status. Tluczek and al. demonstrated that diagnostic uncertainty from equivocal cystic fibrosis results generates profound parental distress, with parents cycling between enduring and emotional suffering as they navigate ambiguous outcomes [9]. While clinical management guidelines exist for intermediate/equivocal results [10], no internationally standardized protocol addresses the psychosocial impact of inconclusive sweat test outcomes [11].

Integrating laboratory medicine into a three-way partnership involving clinicians, patients, and laboratory professionals represents a key step toward truly patient-centered care. While clinicians are responsible for ordering and interpreting tests, laboratory professionals possess the scientific expertise and procedural knowledge required to explain diagnostic tests.

From a practical perspective, simple, low-cost interventions, such as standardized information sheets, pre-test counseling by laboratory staff, and harmonized messages between clinicians and laboratories may improve the experience of families undergoing sweat testing. Similar models could be potentially extended to other procedures that are technically simple but emotionally charged, such as genetic testing or invasive sampling in children. This approach is particularly relevant in pediatrics and rare disease diagnostics, where parental anxiety is frequent and justified [3].

However, this study has limitations. First, anxiety was assessed only pre-laboratory, while post-laboratory assessment used satisfaction due to study design, precluding direct pre-post statistical comparison. Second, anxiety and satisfaction were measured using non-standardized categorical scales developed for this study, which may introduce subjectivity and limit comparability. Third, the questionnaire did not assess at which step of the diagnostic pathway parents experienced the greatest stress, which limits a more granular interpretation of anxiety sources. Finally, the small, single-center sample (n=41) limits the analysis to descriptive results. Larger studies with validated instruments are needed.

Conclusion

This study supports the expanding role of the clinical laboratory in patient and family communication. Most parents received no pre-test information about the sweat test during clinical consultation, and a substantial proportion reported high anxiety before the laboratory visit. Structured communication provided by the clinical laboratory was followed by very high parental satisfaction. These findings suggest that laboratory

professionals may help address important information gaps during sweat testing and support patient- and family-centered care.

Key practical recommendations, adapted from EFLM best practice guidance, include [8]

- Provide standardized pre-test information during consultation
- Harmonize messages between clinicians and laboratory staff
- Offer brief counseling at laboratory admission
- Ensure accessible post-test contact information

Ethical approval

This study was approved by the Ethics Committee of The Faculty of Medicine of Sfax (approval reference: 36/26, date: 25 :06/2026). The study was conducted in accordance with the ethical standards of the institutional research committee. Informed consent was obtained from all parents prior to participation.

Conflict of interest

The authors declare no conflict of interest.

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Data availability

Data are available from the corresponding author upon reasonable request.

Contributions

R.M conceptualized the study and prepared the figure.
K.M and A.M collected and analyzed Data.
F.M.A conceptualized the study and reviewed the manuscript.

Use of artificial intelligence

Artificial intelligence tools were used to assist in manuscript structuring, language editing and image creation. All authors critically reviewed, edited, and validated the final content and take full responsibility for the accuracy, originality, and integrity of the work. No artificial intelligence tool was used for data generation or data analysis.

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