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PERSONAL NARRATIVE

Listening to the Unsaid: Utilizing Patient-Reported Outcome Measures (PROMs) to Manage the Dental Anxiety of a Special Child

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ABSTRACT

This article is the journey of a dentist who adopted the additional role of a healthcare manager and embarked on a transformative journey to enhance the realm of pedodontics. The story describes how the care process and related experiences were improved for a special child who came anxious and worried to a dental office for treatment and returned with better outcomes. Dental anxiety is a known barrier to smooth dental care which is further amplified in children and more so for the special children. In addition to providing the best treatment, we ensured a worry-free environment to release the anxiety of the patient. To achieve this goal, we adopted one of the Patient-Reported Outcome Measures (PROMs) related to dental care and integrated this to the care delivery process prior to the initiation of the treatment. This case reinforces the criticality of reducing stress and worry for creating happier and stress-free patients who will experience reduced dental anxiety in the long run. Hence, this is more than just a story of individual growth and professional transformation. It is a testament to the power of listening to the little voices of patients in ensuring that paediatric dental care is not only effective but also positive and empowering for these children.

Keywords: Child-centred care, Dental anxiety, dPROM, Patient reported outcome measures, Special child

1. Introduction

As a young student on the cusp of entering dentistry, my fascination with patient experience was very high. I had an ardent interest in understanding patient experience, especially in the paediatric population, which stemmed from a deep belief in the importance of children’s health and understanding their perspective towards care processes and the environment. The article describes how in the later years of my professional life, I was able to accomplish this in my dental practice.

Dental fear or phobia related to dental procedures has been associated with a wide range of adverse behavioural and dental health characteristics.1 Paediatric Dentistry is a realm where the psychological dealing is more critical than mere clinical treatment because every smile is precious. If the experience is not managed properly in the initial years, the dental fear may pose an arduous challenge to the Pedodontist in later years to make a diagnosis and simultaneously manage anxiety, behaviour and treatment modalities.1 The following sections describe how the Patient-Reported Outcome Measures (PROMs) helped in revealing the unique triggers and concerns of children, helping us to reduce their anxiety and fear during dental visits.

2. The Narrative

This story is about a 7-year-old special needs child who visited my clinic located in one of the suburbs of Pune City in India during September’2019. The
little boy named Shantanu (name changed for confidentiality) was diagnosed with autism spectrum disorder 5 years ago. A school student in second grade, he had come with multiple carious teeth, suboptimal oral hygiene, and irregular dentition. After arriving in the waiting area of the clinic, we could observe his anxiety and fear as he continued to sit on his mother’s lap, not ready to leave her and clinging on tight to his mother’s clothes.

After the registration, as they walked inside and approached the dental chair, to break the ice, I initiated the conversation by cheerfully saying, “Hi, Shantanu!” He then hastily stood behind his mother and gave a slight response with an anxious hand wave after his mother asked him to do so. His apprehension was palpable, and it became apparent that understanding his specific concerns was crucial before proceeding with the check-up and other clinical procedures.

As I was contemplating the strategy for conducting his check-up without eliciting fear, Shantanu’s mother shared her son’s experience of a previous dental visit to another dentist that had left him traumatized and fearful of subsequent dental appointments. She commenced by describing how the previous dentist’s office was overwhelming for him as his unique needs remained unaddressed. The dentist’s communication was abrupt and remained focussed on the clinical process rather than managing his fear. There was a visible lack of understanding about the approach to connect with a special child resulting in heightened distress. His mother, with a mixture of frustration and concern, said, “The previous dentist seemed to treat Shantanu as just another patient without recognizing that his needs are different.” She expressed her deep concern about the lasting impact of this traumatic experience. Moreover, her son has apparently developed a profound fear of dentists, manifested through anxiety, resistance, and even nightmares leading up to the current dental appointment.

To delve deeper into understanding his concerns, I maintained a warm and inviting facial expression to convey a sense of safety and friendliness. Additionally, I used open body language, ensuring that my posture was approachable and I maintained eye contact to establish a connection. Engaging with the child before and getting to know his concerns and his perspective on the dental visit and operative environment seemed like a feasible way to comfort the child. Recognizing the child’s reluctance, I also acknowledged his personal space by maintaining a respectful distance and avoiding any sudden movements.

Upon observing Shantanu’s apprehension, we decided to hit a pause on the treatment plan. Our dental staff engaged in a brief discussion on how to enhance his overall experience. I thought of utilizing the EuroQol (EQ) child-friendly version EQ-5D-Y (youth) in the clinical process which we had just started to regularly use in the dental practice. This scale was developed from the adult EQ-5D and validated for measurement of Health-Related Quality of Life (HRQoL) in children and adolescents aged 7–12 years as well as for special children. The EQ-5D-Y consists of 2 sections – the EQ-5D-Y which covers the descriptive system and the EQ visual analogue scale (EQ VAS). The descriptive system comprises of the 5 dimensions in a child-friendly language, namely, mobility (walking around), looking after myself, doing usual activities (like, going to school, sports, oral hygiene), having pain or discomfort, and feeling worried, sad, or unhappy. Each dimension comprises of 3 items that are scored at three levels wherein, Level 1 indicates no problem, Level 2 indicates some problem and Level 3 indicates a lot of problems. Respondents can self-report their health as experienced on that day. Given that autistic children may experience unique sensitivities and difficulties in expressing their emotions, the EQ-5D-Y’s format allows for nuanced evaluations across multiple dimensions.

We decided to use the descriptive system over EQ VAS as it was simple for Shantanu to understand and respond efficiently. We encouraged him to express his feelings using a structured format: “I am/am not worried OR sad OR unhappy.” When asked about his emotions regarding the visit, he candidly shared, “I still feel a bit scared about being here.” When probed further about the source of his fear, he pinpointed the hospital-like smell, explaining, “I really don’t like it; it makes me very unhappy.” Expressing our concern, I asked, “Your feelings matter a lot to us. Is there anything else that makes you feel worried or uncomfortable during your visits?” In response, he shyly admitted, “Well, those tools you use are kind of scary too. They look really sharp. I am very worried it’ll hurt me,” while tightly holding his mother’s hand and beginning to cry. Subsequently, discussion with the mother revealed his oral hygiene practices, specifically pertaining to the routine of brushing teeth and flossing. He conveyed a reluctance towards brushing his teeth, disclosing that compliance was encouraged by his mother through the promise of a reward, such as chocolates or other confections the next morning. His mother confirmed this by saying, “Despite his initial reluctance, we’ve found that this reward system helps create a positive association with oral care for him.”
The final EQ-5D-Y score for him was as follows: mobility at Level 1, looking after myself at Level 3, doing usual activities at 2, having pain or discomfort at 3, and feeling worried, sad, or unhappy was 3. Therefore, the unique health state was 13233 (A unique health state is defined by combining 1 level from each of the 5 dimensions. For example, state 11111 indicates no problems on any of the 5 dimensions). Our findings revealed not only problems in the discomfort measure but also in the emotional state and self-care measures.

As Shantanu entered the clinic for his consecutive appointment, the dental staff greeted him warmly, “Hello Shantanu! It’s great to see you again.” Shantanu responded with a shy but genuine smile, a subtle shift from his previous visit. I engaged in empathetic non-verbal communication during the initial assessment, maintaining a reassuring demeanour. Shantanu, noticing the familiar, friendly expressions, appeared more at ease, and his mother observed the positive change in his body language with reduced dental anxiety.

Throughout the appointment, the dental staff made a conscious effort to involve Shantanu in the process, explaining each step with child-friendly language and visuals. Shantanu, in turn, responded by nodding and occasionally offering verbal affirmations, showcasing a newfound sense of understanding and cooperation. Through PROMs, we were able to understand his specific concerns and fears. For example, in our initial conversation, the young patient expressed a fear of the “hospital-like smell” associated with the sanitization of the dental office and sterilization process of dental equipment. This revelation struck a chord, prompting me to reassess the clinic environment. Determined to transform his experience, I made it a point to infuse the area with a scent reminiscent of fresh flowers—a fragrance he found comforting. During his subsequent visit, the positive change was evident not only in his verbal expressions but also in subtle non-verbal cues. As I approached him, I noticed a softening in his body language—a relaxation of tense shoulders and a less guarded posture. His eyes, once filled with apprehension, now exhibited a glimmer of curiosity. Curious about his evolving emotions, I asked, “How are you feeling now compared to when you first arrived?” To my delight, Shantanu’s response signalled a positive shift: “I feel a bit better. The smell isn’t bothering me as much.”

When my dental assistant asked him, “Shantanu, can you hold this mirror for me? You can see your teeth while we work.” He cautiously but willingly took the mirror, his mother noting the positive change in his engagement with the tools. As the appointment concluded, Shantanu’s mother expressed her appreciation for the personalized approach and said, “He seemed so much more comfortable this time.” This transformation was not just about addressing sensory aversion; it was about acknowledging the individual needs of a young patient and fostering a trusting relationship that transcended the clinic setting. Something as simple as adding fragrance played a crucial role in creating an atmosphere where Shantanu felt understood and cared for, contributing to a more comfortable dental treatment environment for him. This understanding led to a tailored and gentle approach that not only addressed his dental fears but also set the stage for a journey towards improved oral health and reduced dental anxiety. The positive impact extended beyond the patient to include his parents, who found solace in the evidently improved child’s experience.

As a healthcare provider, this outcome reinforced the importance of personalized care. It underscored the significance of actively listening to patients, not just hearing their words but deciphering the unspoken nuances that shape their fears and anxieties. Recognizing the constructive impact of PROMs in Shantanu’s case, our decision to comprehensively integrate PROMs into the practice helped us achieve enhanced patient care.

3. Reflections and recommendations

As a dentist and a healthcare manager, I can attest to one of the most significant impacts of integrating PROMs in paediatric dentistry—the newfound understanding of dental anxiety in our young patients. This personalized approach not only aligns with clinical needs but also considers the emotional and psychological aspects of our young patients, fostering an atmosphere of comfort and trust. It’s vital that paediatric dental practices utilize PROMs to inform and adapt treatment approaches, addressing clinical needs and emotional and psychological aspects and strengthen the bond of trust between patients and clinical team. The data derived from PROMs is instrumental in creating personalized and customized treatment plans. Understanding how to utilize PROMs effectively is crucial for enhancing patient care. Therefore, pedodontics should be better trained in administering and integrating PROMs to care processes.

Every effort should be made to evaluate the child for dental anxiety prior to dental treatment to decipher...
the reasons that induce fear. Necessary behaviour modification techniques should be used to make the dental treatment a pleasant and uneventful occasion. Dental practices should strive to provide more personalized and empathetic care, reducing dental anxiety and improving overall patient experiences. The child-centred approach should remain at the core of pediatric dental care. This involves creating a welcoming and non-intimidating atmosphere and addressing the emotional as well as psychological aspects of a child’s experience. The desired outcome is to empower children to be able to actively participate in their oral health decisions. Empowering children to take ownership of their dental care can lead to better long-term oral health habits and more positive dental experiences. Ultimately, the purpose is to see a positive transformation in both the patient experience and the overall approach to healthcare delivery in the context of paediatric dentistry.

4. Power of observation and empathy

It’s all about understanding and addressing the unique needs of patients, particularly those with dental anxiety. The importance of this power of observation lies in its ability to reveal nuanced details about a patient’s emotional state and comfort level, providing crucial insights that may not be explicitly communicated. The pivotal role is in fostering patient-centred care, especially for individuals with unique needs or anxieties. It emphasizes the importance of a holistic approach that goes beyond verbal communication, recognizing the significance of non-verbal cues in providing empathetic and tailored healthcare.

Empathy is not merely a soft skill but a fundamental aspect of patient-centered care. It fosters a compassionate and understanding environment, essential for addressing the emotional well-being of patients, particularly those with unique challenges like dental anxiety. The importance of empathy in healthcare lies in its ability to humanize the patient experience, promoting a collaborative and supportive relationship between healthcare providers and patients.

5. Conclusion

Little did I know that my journey into the world of dentistry and healthcare management would introduce me to the invaluable PROM tools. It marks a profound change in the way we understand and approach the health of young patients who often face a bewildering array of medical conditions, from chronic illnesses to complex dental issues. PROMs revolutionized our approach, providing a vital platform for children to articulate their emotions and experiences beyond standard clinical evaluations. Paediatric dentistry, in particular, is a realm where the significance of little smiles cannot be overstated. The care we provide to children goes beyond treating teeth; it’s about creating an environment where young patients feel safe, comfortable, and empowered to take control of their oral health. It is essential to embrace and expand the use of PROMs while maintaining a strong commitment to compassionate and child-centred paediatric dental care. In the spirit of compassionate care and patient-centred excellence, let us continue our journey to brighter smiles and healthier futures for our little patients.

Conflict of interest

The authors declare no conflict of interest.

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