Problem behavior in patients with pervasive developmental disorder or with intellectual disability during dental treatment under general anesthesia

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Original Article

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Abstract:

People with pervasive developmental disorder (PDD) or intellectual disability (ID) are very vulnerable and disadvantaged when visiting a healthcare facility as patients. They do not have their daily needs and rituals fulfilled and feel threatened. We present the professional community with a qualitative research report to determine whether the implementation of a personality trait questionnaire for patients with PDD or ID will bring to light the individual needs of the patient and enable a perioperative healthcare team to apply an individual approach during the introduction to general anesthesia.

Introduction to the issue

Problem behavior is characterized as "culturally abnormal behavior" that is so intense, frequent, or persistent that it can seriously threaten the physical safety of a given person or others (Emerson, 2008). Problem behavior is an umbrella term that includes a variety of behaviors that can affect the psychological and behavioral characteristics of an individual. Such behaviors include aggression, aggressiveness, impulsivity, ADHD, avoidance of instructions, meltdowns, being emotional, mood and affect disorders, hyperactivity, and destructiveness. Although these behaviors may occur separately, they are often exhibited in a combination in people with different psychological or behavioral problems (**Čadilová**, **Žampachová**, 2012). They often occur together, and co-occurrence with PDD is possible in up to 85% of patients. The comorbidity of such disorders increases the problems in the areas of behavior, attention, and adaptation (Thórová, 2016). More than half of patients have problem behaviors severe enough to require strategies to manage them (**Čadilová**, **Žampachová**, 2012).

Visiting a healthcare facility for dental treatment that requires general anesthesia can be an extremely stressful and frustrating experience for patients with PDD or ID. The unfamiliar surroundings, pain, separation from loved ones, and the interruption of rituals and established routines often cause anxiety, resistance, and difficulty cooperating, which can make the entire treatment process very difficult. This situation is a real challenge for healthcare professionals and requires a high level of empathy, communication skills, and a willingness to react flexibly to patients' individual needs.

Hypothesis and research objectives

A personalized approach to the patient is an essential element of quality healthcare, especially for patients who have difficulty cooperating or whose behavior is not easy to predict. Understanding a patient's personality traits not only allows healthcare professionals to better tailor their communication and approach, it also helps to minimize stressful situations, reduce the risk of problem behaviors, and increase the effectiveness of the care.

We began our research with the hypothesis that the personality trait questionnaire we designed would enable the better identification of individual patient needs and contribute to the development of sustainable strategies that would enhance collaboration and make the work of healthcare professionals easier. The aim was not only to gain deeper insight into the factors influencing patient behavior, but more importantly to provide a practical and applicable tool that would lead to long-term improvements in the care of non-cooperative or anxious patients.

Methodology and procedures

In order to achieve this objective, it was necessary to independently and objectively map the current practices of the perioperative team when caring for these patients and to capture all variations of problem behaviors. We conducted this process both before and after the implementation of the personality trait questionnaire. Our own roles also changed during the research process - first we acted as observer-participants and tried to understand the reality of care without actively intervening. Only subsequently did we move into the role of participant-observers, meaning we actively intervened and engaged in providing care. This change allowed us to look at the same problem from different perspectives and to better understand what factors influence the daily reality of both healthcare professionals and patients.

This approach not only gave us the opportunity to better understand the dynamics of care, but we were also able to observe how the introduction of the new tool was reflected in practice and how healthcare professionals responded to changes regarding their approach to patients. We recognize that changing our position and actively engaging in care may have raised ethical questions about the extent to which we influenced the studied phenomena and reality. However, this approach was necessary in order to achieve change in the real situations being studied, or at least to show that such change is possible.

Data analysis

The approach in our research was not purely phenomenological, but rather an interpretative phenomenological analysis (IPA). While traditional phenomenology aims to capture the lived experience without external interpretation as objectively as possible, in our case we actively entered into the process of analysis as researchers and made the lived experience meaningful (Hendl, 2005). The aim was not only to describe the reality as it is lived by healthcare professionals and patients, but also to interpret it in the context of the wider healthcare system and organizational processes of care. This meant that we not only documented the participants' experiences, we also looked for deeper meaning, connections, and possible implications for practice.

Our personal beliefs, attitudes, and interpretations that we entered into the research with played a key role in obtaining a deeper understanding of the lived experiences of the individuals studied (**Čermák** et al., 2013). This approach not only allowed us to better understand the reality of perioperative care for patients with PDD or ID, it also aided us in proposing specific measures to optimize it. The small size of the research sample, which is typical for IPA, allowed for a more detailed and careful study of individual cases and deeper insight into the experiences of healthcare professionals and patients (Smith & Osborn, 2015).

Ethical aspects of the research and pilot testing of the patient personality trait questionnaire

The research was performed on the perioperative care of patients with PDD and ID, and it required strict compliance with ethical standards. The study was approved by the ethics committee of the University Hospital Olomouc and by the management of the respective clinics. Key experts from the perioperative team (anesthesiologists, dentists, nurses) agreed with the research. Patients' legal guardians were provided with detailed information, and their participation was based on written consent. The possibility to withdraw at any time was guaranteed without any impact on the healthcare. All data were anonymized and securely stored. A patient personality trait questionnaire was then created as part of the study with the aim of tailoring perioperative care to individual needs. Its content was consulted with anesthesiology experts and subsequently pilot tested on four patients. Based on the feedback from healthcare professionals, the questionnaire was modified for easier use and to better reflect specific patient behaviors. Thanks to these measures, the survey was conducted transparently and safely, with respect to patients, their families, and healthcare professionals. Ethical approval, the consent of guardians, the anonymization of data, and pilot testing of the questionnaire ensured the validity of the results and their practical applicability.

Research population

By selecting a population of patients with pervasive developmental disorder (PDD) or intellectual disability (ID), it was not our intention to present this group as a homogeneous group, but rather to bring attention to a specific problem that its members may repeatedly encounter during their lives.

The research population consisted of six patients who were unable to receive dental treatment without general anesthesia.

Data collection

Data were obtained through unbiased observation of the entire perioperative care process of patients with PDD or ID during their dental treatment. We collected video recordings, photographs, and audio recordings to capture all events in the operating room, including the behavior, actions, and decision-making of all members of the perioperative team. In addition, we took field notes and extracts from documentation to capture as wide a range of information as possible. The records were transcribed verbatim and converted into narrative descriptions to make the texts legible and understandable. These narratives were subsequently entered into the Atlas.ti software.

Atlas.ti 8 software

Atlas.ti is a qualitative analysis software that enables the efficient organization, coding, and systematic processing of text, image, and audio-visual data. Unlike automated analyti-

Figure 1 Research population

Case study no.	Name	Age (years)	Diagnosis
1	Jiřinka	47	Severe Cerebral Palsy, Intellectual disability
2	Pavlík	26	Down syndrome
3	Pája	16	Cerebral palsy
4	Anetka	18	Atypical autism, intellectual disability
5	Péťa	47	Cerebral palsy
6	Filip	27	Cornelia de Lange syndrome, profound intellectual disability

cal tools, it does not interpret data or assign meaning through hidden algorithms. Its main contribution is to support researchers' analytical work - making it easier to work systematically with data, code it, create relationships between categories, and visualize connections.

Using sequential coding and categorization, we obtained a more comprehensive view of the representation of individual phenomena and were able to observe patterns in the data that might have remained hidden during manual processing. Atlas.ti thus does not offer ready-made interpretations, but greatly facilitates the analysis and organization of data, leading to a deeper understanding of its structures and connections.

The first phase of research: key theme identification

The analysis of the texts began with a careful interpretative reading of the first three case studies (Jiřinka, Pavlík, and Pája), which described the situations before the application of the personality trait questionnaire. Each of these patients brought a unique perspective to the perioperative care of people with PDD or ID.

The aim was not only to observe general patterns of behavior, but more importantly to identify factors influencing the quality of care, patient cooperation, and the effectiveness of the healthcare team. Key extracts were systematically coded, allowing for rapid data comparison and a deeper understanding of the dynamics of patient behavior and the responses of healthcare professionals. Recurrent or associated codes were then grouped into overarching themes that served as the basis for deeper analysis and strategies to improve the care of difficult-to-care for or uncooperative patients.

These topics are essential for clinical care practice:

1. Negative Behavior - Identifying patterns of non-cooperation, defensive reactions, or patient resistance helped us to understand what situations are most challenging for healthcare professionals and how to minimize their impact.
2. Negative emotions - Fear, frustration, or aggression can significantly affect the process of perioperative care. Understanding these emotions is key when choosing the right approaches and techniques to work with a patient.
3. Positive emotions - It was also important to note moments when patients showed calmness, trust, or cooperation. These findings helped us to understand what factors positively influence their comfort and feelings of safety.
4. Accompaniment - The presence of a loved one or assistant plays a crucial role in minimizing

patient stress and facilitating their adaptation to the hospital environment.
5. Teamwork - Coordination among healthcare professionals and the way they communicate and share information among team members has a direct impact on the smooth flow of treatment and the overall outcome of care.

The second phase of research: The active implementation of change

In the second phase of the research, we analyzed cases after the introduction of the personality trait questionnaire. In this phase we were no longer just passive observers, but we actively participated in the modification of the care. The information from the questionnaire allowed us to inform the perioperative team about the specific needs of the patients in a targeted manner and tailor the care to the patient's individual reactions. To minimize stress and promote patient cooperation, we modified the communication between the healthcare professionals, the patient, and the patient's companion. We also recommended limiting the number of people in the operating room, regulating lighting, and reducing noise-factors that can significantly affect patients with PDD and ID. When planning care, we took into account patients' sensitivity to touch, handling, cannulation, and contact with an inhalation mask. We also paid attention to the prevention of self-harm and strategies for coping with stress reactions.

The analyzed cases (Anetka, Péťa, and Filip) were coded and classified into previously created categories, just like in the first phase. This phase not only allowed us to validate the effectiveness of the questionnaire, but also to better understand the key factors in the perioperative care of patients with pervasive disorders.

Results from the first phase of research

The analysis of case studies 1, 2, and 3 showed a prevalence of negative emotions, in particular, uncooperativeness, determination, fear, and unexpected insults. The dominant negative behaviors included shouting, defiance, and running away. Although health professionals tried to perceive patients individually, their personality traits were only taken into account by the empathetic team members based on their personal interest. There was a lack of a systematic approach in standard procedures that led to misunderstandings, especially when trying to establish contact. Critical situations occurred when medical staff touched patients, attempted to place patients on the operating table, applied a face mask, cannulated a venous line, or when patients were separated from a close person. These moments often provoked physical reactions from patients that complicated the procedures. The team's work showed major weaknesses in organization and preparation. The most common codes were physical management of the patient, uncertainty, a lack of information, and improvisation. The team approached patients reactively, without a premeditated plan. There was a lack of systematic preparation, the healthcare professionals did not know the patient, and they had no information about the patient's personality traits, all of which led to random decisions. Nevertheless, they tried to respond empathically to the emotional state of the patients and their companions. In addition to reassuring the patients' companions, they tried to respond to the needs of the patient himself/herself. In the category of Accompaniment, the most frequently occurring codes were uncertainty, passivity, and non-cooperation. The people accompanying the patients often did not understand the situation, were not encouraged to cooperate, and their insecurity was exacerbated by the patient's behavior.

Results from the second phase of research and a comparison with the first phase

The analysis of case studies 4, 5, and 6 showed a major shift in the dynamics of patient behavior. Although fear persisted, it did not escalate into negative behavior - codes such as non-cooperation, defiance, or running away no longer appeared. A new phenomenon was benign self-harm, which patients used as a coping mechanism to deal with emotional distress. There were significant changes in the Teamwork category. Key codes included team interplay, awareness of health professionals, and a well-thought-out care plan, which led to better organization and the elimination of ineffective improvisation. Healthcare professionals were informed in advance about patient specifics, allowing them to work with greater confidence and minimize their negative reactions. In the category of Accompaniment, the code of cooperation and interplay dominated. The accompanying persons were actively involved in the process, facilitating the work of the health professionals and creating a positive impact on the patients. A new element was the emotional expressions of the companions, especially tears as a natural reaction to tense situations.

The comparison of the first and second phases of the research clearly showed that the individual approach to patients in perioperative care resulted in significant changes. Instead of uncertainty, improvisation, and negative emotions, the dominant emotions were awareness, interplay, and cooperation. The personality trait questionnaire provided healthcare professionals with key information about patients that minimized stress, reduced negative behaviors, and enabled more effective care planning. Additionally, the companions became active partners, reducing the need to physically immobilize the patient.

These results confirm that targeted changes in the approach and systematic measures can not only substantially improve the patient experience, but also the efficiency and work quality of the healthcare team. The implementation of structured and individualized care therefore leads to greater professionalism, respect for patients, and safer perioperative care.

Discussion

Domestic and international studies confirm that a properly adjusted individual approach can turn a stressful procedure into a safe and calm process. Our study provides a practical solution that facilitates this approach and makes it effectively applicable in practice.

A study by Wittenberg (2016) showed that systematic preparation of the child for the operating room - either at home or during hospitalization the day before - significantly reduces his or her stress, as well as the stress of parents and healthcare professionals. This model is undoubtedly effective, but difficult to implement in practice. Our study shows that a similar effect can be achieved through another process - the targeted use of a personality trait questionnaire, which immediately provides healthcare professionals with information about a patient's individual needs. Instead of complicated preparations, it is thus sufficient to take a short amount of time to adapt the approach to the patient, leading to a similarly positive effect. The importance of parental involvement in perioperative care was highlighted by Lewis et al. (2015), who came to a clear conclusion - parents are an invaluable source of information for healthcare professionals, and their active participation is crucial for the child to better cope with the procedure. Our case studies confirm that when parents and other accompanying persons are perceived as active partners of healthcare professionals, there is a significant change in the dynamics of care. Patients are calmer and less defiant, and the treatment process is smoother. This approach doesn't require any costly measures - just professional and empathetic communication that enables parental involvement.

Similarly, the topic of how to approach patients with PDD or ID was addressed by Anderson (2016), who highlighted the issue of anonymity in healthcare. Her research shows that these patients often perceive the hospital environment as cold and impersonal, which only exacerbates their stress and uncooperativeness. However, our study shows that this problem is avoidable. If healthcare professionals actively communicate with the patient's companion, show empathy, and ensure that the whole team is informed, the atmosphere of perioperative care can be fundamentally transformed. This approach not only makes the work of healthcare professionals easier, but more importantly increases the patient's feeling of safety and cooperation.

The importance of parent presence in the operating room was highlighted in an interview for Respekt magazine (2020) by the head of the children's department at Havířov Hospital, Hynek Canibal. He emphasized that this is a fundamental step towards humanizing healthcare. Although this approach is still being introduced in some departments, our study confirms it as a key factor in reducing patient stress. In addition, we have gone one step further in our research - not only have we confirmed the positive effect of the presence of a close person, we have also shown that if the companion is actively involved in collaborating with healthcare professionals, their role goes beyond just psychological support and becomes an important element in ensuring the process of the whole procedure goes smoothly.

A summary of the key principles of care for patients with PDD is presented in the expert paper by Jelínková et al. (2021). The authors highlight the importance of an individual approach, the presence of a close person, and clear communication. However, their paper does not offer a specific procedure when it comes to applying these principles in practice. This is the contribution of our study - we provide a comprehensive system that can identify the patient's needs, set up an effective collaboration with the companion, and optimize the organization of the healthcare team's work.

When looking at all the studies mentioned above, a clear trend is confirmed – an individual approach, staff awareness, and cooperation with the patient's companion are crucial for successful perioperative care. Our study shows that these objectives can be achieved by using a simple but effective system that allows for the quick identification of patient needs and tailored care, without the need for complex and financially demanding programs.

Conclusion

Changing established rituals and not having needs fulfilled can cause significant stress for patients with PDD or ID. If these changes are not adequately managed, the stressful hospital environment can trigger defense mechanisms, such as aggression, self-aggression, or complete withdrawal into oneself. Our study showed that the right approach prevents these negative reactions from happening. Individual care, respect for the patient's individuality, and open communication are not only signs of humanity but also signs of true professionalism. Quality healthcare is not just about professional qualifications and technical precision, but about combining professionalism with empathy and understanding. Each step towards a personalized approach increases the safety, comfort, and success of care, all of which also strengthen the patient's trust in the healthcare system. Based on the positive results of the research and feedback from the perioperative team, the patient personality trait questionnaire was adopted by the University Hospital Olomouc through its Quality Department and included in the standardized pre-operation documents. This step allows it to be systematically used in clinical practice, leading to an increase in the quality and individualization of perioperative care for patients with PDD or ID. The standardization of the questionnaire in preoperative preparation allows for more effective identification of patient needs and the adaptation of procedures by healthcare professionals, minimizing the risk of problematic behavior and increasing the comfort of patients and the entire perioperative team.

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