Case report

Approach to obtaining a swallow study in a five-year-old with a disability and significant procedural anxiety: A case report

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Abstract.

CASE DESCRIPTION: A five-year-old male with spastic quadriplegia cerebral palsy and an expressive communication disorder presented because the family desired liberalization of diet. The diet consisted of pureed solids and no liquids due to deficits identified on bedside swallow evaluation; further dysphagia assessment had not been obtained due to significant procedural anxiety. Comprehensive approaches were taken involving premedication with buspirone, desensitization, distraction, and positive reinforcement. The fluoroscopic swallow study was successfully completed, and the patient's diet was upgraded to include moderately thickened liquids.

DISCUSSION: Procedural anxiety management in special populations is not well-researched. The lack of definitive recommendations regarding these issues increases the difficulty of managing these patients. This case highlights one successful approach to addressing individual needs using widely-available pharmacologic and environmental techniques. Additionally, this case reinforces the need to identify underlying causes for procedural anxiety and involve an interdisciplinary team.

CONCLUSIONS: Attempts should be made to identify factors driving procedural anxiety. After discussing with the patient and family, relevant information should be relayed to staff with an open-ended invitation to propose ideas. While not all hospitals have equivalent resources, concerns related to unfamiliarity, underlying anxiety, and locus of control can be addressed with limited resource utilization, as demonstrated in this case.

Keywords: Cerebral palsy, dysphagia, procedural anxiety, systems of care, complex patient populations

1. Introduction

Patient anxiety in the setting of medical procedures is not an uncommon occurrence. The pediatric population may be even more susceptible to this due to greater unfamiliarity with the medical environment and a decreased sense of control [1]. Children with disabilities are more likely to perceive similar events as traumatic than their peers without disabilities [2]. Due to this increased susceptibility, management strategies are needed. While traditional pharmacologic practices to handle severe or refractory anxiety are useful when the patient is not an active participant in the study, such as with MRI, dental work, or interventional radiology procedures [3–5], these can interfere with procedural efficacy when patient participation and muscle coordination are needed, such as swallow studies [6–8]. Management of procedural anxiety in the pediatric population when traditional methods are unavailable or prohibited by the procedure mechanism has not been clearly illustrated in literature. This case report aims to demonstrate one

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approach to dealing with procedural anxiety under such circumstances in a particularly challenging pediatric patient with a disability.

2. Case presentation

A five-year-old male with a history of premature birth at 25 weeks and cerebral palsy (Gross Motor Function Classification System Level IV) presented to the clinic for follow up. The patient was on a diet of pureed solids and no liquids due to observed deficits on bedside swallow evaluation and inability to obtain fluoroscopic assessment of swallow (oropharyngeal videofluoroscopy; OPV). Of note, he had substantial anxiety related to x-rays, which limited ability to obtain clinical imaging. Previous attempts had been aborted due to the patient becoming inconsolable despite using familiar cups, favorite snacks, and rewards. The decision was made to continue to pursue fluoroscopic swallow evaluation due to developmental need to gain oral motor skills necessary for liquid consumption. Benzodiazepines were not used to avoid decreasing study quality via sedation and muscle relaxation. At this time, a more extensive discussion with the interdisciplinary team and parents commenced. The patient's mother noted that he had developed increasing levels of anxiety surrounding x-rays and swallow studies over the preceding 2-3 year period, which she felt were related to the dark room and the lead aprons and masks donned by staff. She did not think conventional methods of dealing with procedural anxiety would work without addressing these underlying concerns. After discussion with the physician, speech-language pathologist, parents, and radiology staff, the following interventions were determined to be feasible: desensitization visits, gradual progression of the encounter including donning of personal protective equipment (PPE; lead, masks, etc.) by staff, change in lighting, movement of fluoroscopy machine, patient positioning, and the addition of buspirone. These interventions were planned in addition to continued efforts of redirection/distraction and soothing. The patient started on buspar 5 mg twice a day. At the next clinic visit a couple of months later, the patient was taken to the radiology suite for a tour. At that time, staff had not donned any PPE and the lights were left on. The patient was asked to sit in the procedure chair for a few minutes and trial an assistive straw. He cried briefly but was easily redirected with bubbles and a calm voice encouraging him. Based on observation,

the speech therapist recommended practice with the adaptive straw for a few months, and OPV was scheduled for three months out. At the next encounter, staff verified anxiolytic medication had been given prior to the appointment. The patient was again escorted to the fluoroscopy suite with the lights on and staff without PPE. The patient was asked to sit in the designated chair and allowed time to acclimate while he was distracted with bubbles and videos of favorite characters on a tablet. The C-arm was advanced towards the patient at slow intervals. The lights were gradually turned off while the patient was distracted and the staff progressively donned PPE. Using familiar utensils and tools, a videofluoroscopic swallow study (VFSS) was executed without issue. The patient's diet was upgraded to include moderately thickened liquids based on findings of the study.

3. Discussion

Management of pediatric procedural anxiety, especially in special populations such as children with disabilities and those who cannot receive benzodiazepines (either due to individual factors that are prohibitive or procedure type as in this case) is not well-researched [9]. The lack of definitive recommendations regarding these issues increases the difficulty of managing these patients and can leave providers feeling unequipped. This case represents one approach that was highly successful at accommodating the individual needs of a patient who otherwise would not have been able to obtain a procedure that was medically necessary, provided essential clinical information, and greatly improved the child's quality of life in the form of a less restrictive diet. This case demonstrated several techniques that can be used widely amongst various hospital settings, including distraction, redirection, desensitization, involvement of a multidisciplinary team, and anxiolytic medications [10,11]. Additionally, this case reinforces the widely held clinical notion that addressing the underlying cause is a critical component of a treatment plan. For this patient, this included identifying the underlying predisposition to anxiety, conveying the appropriate sense of reward, minimizing fearinducing components of treatment, and increasing familiarity with the surroundings. This could not have been achieved without the involvement of an interdisciplinary team to ascertain relevant information and implement the individualized treatment plan. Furthermore, resource utilization is an important factor

when considering possible interventions that could be applied across a variety of settings. Specifically, interventions that require a large ancillary staff or high time commitment are likely not feasible in most clinical settings. The core components of the approach in this case are cost-effective, feasible, and generalizable. These include clear communication between staff, the patient, and the family; targeting underlying causes of anxiety; and coordinating logistics in the least disruptive fashion.

4. Conclusion

Procedures such as VFSSs can provide extremely pertinent clinical information that may drastically alter a patient's quality of life. As such, it is important to exhaust feasible options to combat barriers to obtaining this information. While having general options to choose from can be helpful, the approach may require individualization. Every reasonable attempt should be made to identify underlying factors driving procedural anxiety in the specific patient rather than generically treating anxiety; however, this may include treating an underlying anxiety disorder in some cases. After discussing with the patient and/or family, relevant information should be relayed to staff with an open-ended invitation to propose ideas. While hospital resources vary, concerns related to unfamiliarity, underlying anxiety, and locus of control can be addressed with limited resource utilization as demonstrated in this case. Specifically, care can be taken to maximize participation in VFSS using desensitization strategies listed above, which can be tailored to a patient's individual needs.

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Conflict of interest

The authors of this paper have no disclosures or conflicts of interest.

Ethical considerations

A waiver was obtained from the Institutional Review Board as the above content was not considered human subjects research. Permission was obtained from the patient's guardian.

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