Developmental Disability, Lack of Appropriate Dental Care, and General Anesthesia: An Ethical Dilemma

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Every day oral healthcare providers make clinical decisions based in governing ethical principles. The five principles of dental ethics - respect for patient autonomy, beneficence, nonmaleficence, justice, and veracity - help to guide us in making clinical decisions that provide the most benefit to the patient with the least amount of burden. Many cases are straightforward from an ethical standpoint and require less reflection. But those with more complexity often result in many ethical challenges. This is especially the case when a patient is legally incompetent and decisionally-compromised.

Description of the Case:

A 47-year-old male presented with his mother for a new patient exam to a clinic specializing in the treatment of individuals with special needs. The patient was non-verbal and cared for by his mother, who was his legal guardian. His mother was adamant that she was his "advocate" and that she did not trust at lot of healthcare providers as they had been taken advantage of by "many physicians" in the past. During the interview, the patient's mother reported that the patient continues to see a pediatric dentist, his previous dentist retired and that he was able to remain under the care of the new dentist for routine cleanings and exams. She explained they were referred to the clinic for general anesthesia to take care of a carious lesion on a front tooth as the new dentist was not comfortable providing this treatment. She described that her son was sensitive to the noise of the hand piece and claimed that he was "afraid of needles." She indicated that restorative treatment had been attempted at his previous dental office but they were unable to complete the treatment due to patient "noncompliance." The patient's mother was emphatic that he "only have fillings under general anesthesia" and that we "cannot give him any shots due to his anxiety."

In addition to Down Syndrome, the patient's medical history was significant for gout. His mother reported that he received routine corticosteroid injections for this condition. A call was placed to the referring dentist's office to request recent radiographs and to confirm the services for which they had referred him. After reviewing the dentist's chart notes, a staff member reported that the patient was actually being referred to us for comprehensive care. The chart notes stated that the referring office could no longer take

care of the patient's needs. As a result of the phone call, previous radiographs and chart entries were requested.

Initial extraoral and intraoral exams were conducted in a traditional clinical setting without the use of any behavior modification or medical immobilization strategies. The intraoral exam consisted of visualization and palpation of the soft tissues, examination of the dentition with an explorer, and a complete periodontal exam, including full mouth probing. The patient followed directions well and, with some reassurance, he allowed all aspects of the exam to be thoroughly and safely completed.

The Intraoral examination revealed 6-7 mm probing depths throughout the mouth, generalized bleeding on probing, heavy generalized plaque and, heavy generalized supra- and sub-gingival calculus. The radiographs revealed severe bone loss and generalized heavy calculus. All of these findings were indicative of active generalized severe chronic periodontitis. Furthermore, teeth #8 and #9 had active carious lesions on multiple surfaces that clinically and radiographically appeared to be approaching the pulp space. Following the examination, the records from the previous dentist were reviewed. These revealed that the patient had been receiving a dental prophylaxis every six months for at least the last two years with no mention of ever receiving scaling and root planning. The radiographs were approximately six-months old and while diagnostic, were of poor quality.

Summary of patient assessment:

- Inconsistencies in the information reported by the patient's mother
- Patient's surrogate requesting the patient to be treated under general anesthesia
- History of prophylaxis in a pediatric dental clinic
- Lack of previous periodontal treatment
- Anxiety at the dental office/previous inability to complete restorative care in clinic setting
- Active generalized moderate to severe chronic periodontitis (plaque/calculus induced)
- Extensive #8-MD recurrent caries and #9-ML primary caries approaching the pulp
- Patient tolerated exam and periodontal probing well with a history of ability to take radiographs
- Patient receives injections in his toes regularly for gout and tolerates them well
- Surrogate's demand for GA would result in significantly delayed treatment

Summary of the Ethical Dimensions and Concerns:

The patient was legally determined to be incompetent and was accompanied by his mother who was his legal guardian and surrogate decision-maker. Communication between the patient's mother and healthcare provider proved difficult as it was clear that she was mistrustful and questioned many of the recommendations. Her mistrust could have affected her willingness to accept treatment for her son that, from a care perspective, was in his best interest.

Assessment of the patient's history and clinical examination revealed inconsistencies in the surrogate's story as well as treatment requests which may not have been in the best interest of the patient. A clinician's ethical obligation is to provide the best reasonable care for a patient in the safest manner possible. In this case, there is an added obligation of determining whether a surrogate's request is in the patient's best interest. As such, the ethical concerns were:

- What was the best approach to provide safe and effective treatment for the patient?
- Given the non-autonomous status of the patient, were the decisions being made in the best interest of the patient?
- Given the concerns about the adequacy of diagnosis and treatment rendered by the previous dental care providers, how should this be addressed?

As summarized, caring for this patient encompassed many ethical challenges. The present analysis is focused on the complex clinical ethical issues directly related to the patient's care in the clinic and does not address professional obligations to assess the adequacy of previous care or lack thereof. But, this professional ethical issue was also of paramount concern.

Possible Ways to Proceed:

In considering the best approach to provide the safest and most effective treatment for the patient and to ensure that decisions were made by the surrogate that were in the best interest of the patient, the following options were possible:

- Decline to participate in the patient's care and help the patient and his surrogate identify care elsewhere.
- Refer the patient for treatment under general anesthesia as desired by his surrogate.

- Accept the patient and discuss with the surrogate strategies for treating the patient in a routine clinical setting. If the surrogate is willing to accept alternatives, then proceed with care.
- If, following initial care, it is demonstrated that the patient is not able to tolerate treatment, investigation of other means by which treatment can be performed must be explored.

What is professionally at stake?

A healthcare provider is professionally obligated to follow state specific laws; one cannot do less than the law but ethically, you may be obliged to go above and beyond. In some situations, an ethical obligation may be in conflict with a legal obligation. In this case, however, the state law was consistent with ethical obligations. Echoing the principles of beneficence and nonmaleficence, dentists "play a vital role in preserving the health and well-being of the people of the state" and "incompetence, negligence, or malpractice which results in injury to a patient or which creates an unreasonable risk that a patient may be harmed constitutes unprofessional conduct."

What is ethically at stake?

Ethical principles and codes guide professionals in all situations that pertain to decision making and patient care. The five principles include patient autonomy (respecting the patient in making their own treatment decisions), beneficence (doing good), nonmaleficence (do no harm), justice (treating everyone equitably), and veracity (being truthful). The principles do not have a hierarchical relationship, meaning one principle does not outweigh another. There are times when conflict arises amongst the five principles which makes clinical decision making even more challenging. Yet in each and every clinical decision, all of the principles need to be considered to enable decisions that are in the patient's best interest.

Section 1: Patient Autonomy

Section 1A of the ADA Principles of Ethics and Code of Professional Conduct[1] denotes that the patient (and in this case, the patient's guardian) must be fully informed of the dentist's findings, the diagnosis, and be involved in the treatment discussion, allowing them to make an informed decision about treatment. Based on this principle, the patient's surrogate (and the patient to the degree possible) needs to understand the findings and the benefits and burdens of possible treatments. This includes a discussion as to why it was believed that he would be able to undergo treatment in a dental clinic setting

and also regarding the increased risks of treatment under general anesthesia[1]. As the surrogate's story had inconsistencies, it was imperative that everything be explained to her in a way to help maximize her understanding prior to expressing a choice about desired care for her son.

Section 2: Nonmaleficence

Under this principle, providers have an obligation to protect the patient from harm[1]. This includes the progression of disease, helping to prevent new disease, or protecting the patient from psychological distress that could be caused during a stressful dental visit. For this patient, there is a conflict between preventing the progression of his periodontal disease and dental caries and the choice of how to most appropriately render care. There is a chance that psychological distress would be elevated by treating him in the clinic, however through behavior management and coping techniques, this potential harm is outweighed by the potential harm and risks posed by using general anesthesia[2]. This is the case for not only the patient, but also for society, as it would be inappropriate to use the limited resource of general anesthesia for a patient who may not need it.

Section 2.B of the Code, which discusses consultation and referral, states that the "dentist shall be obliged to seek consultation whenever the welfare of patient will be safeguarded or advanced by utilizing those who have special skills, knowledge, and experience." If it is decided that treatment in the clinic could not be accomplished in a safe manner, then it is an ethical obligation to refer the patient to a clinic or specialist with advanced skills to better care for him.

Section 3: Beneficence

Under this principle, "the dentist has a duty to promote the patient's welfare" and "the dentist's primary obligation is service to the patient and the public-at-large[1]." Furthermore, "the most important aspect of this obligation is the competent and timely delivery of dental care within the bounds of clinical circumstances presented by the patient with due consideration being given to the needs, desires, and values of the patient[1]." One of the most important considerations for this patient is timely delivery of care. By attempting to provide treatment in a general clinical setting, treatment would be able to be initiated much more expeditiously compared to that available under general anesthesia (~3-year waiting list in the school's special care clinic). Especially in this case, the severity of both the periodontal disease and caries indicated that treatment was needed as soon as possible. Yet, as much as timely care was

important, the quality of care delivered could not be compromised. For example, if the patient would not allow adequate scaling or complete caries removal, simply leaving calculus or inadequate caries removal was not an option. In that case, another approach to treatment needed to be considered.

Section 3.F discusses professional demeanor in the workplace and outlines the need for "respectful and collaborative relationships for all those involved in oral health care[1]." In this case, it was imperative that the surrogate's concerns were respectfully heard as she was a collaborative partner in the treatment discussion and planning.

Section 4: Justice

There is an obligation to treat each and every patient fairly under this principle[1]. In this case, the patient deserves the same quality of care as any other patient regardless of his developmental disability and a surrogate whose decisions may not be in the patient's best interest. If it was determined that the patient's behavior will prevent the standard of care from being delivered, another modality, such as sedation or general anesthesia, must be considered. Section 4.A.1 specifically discusses considerations in treatment of patients with disabilities and the obligation to determine if a clinic is adequately equipped to treat the patient or if referral is indicated. The basis for referral should be related to patient assessment and specific considerations arising from this, as it would be for any patient. The referral must not be simply because the patient has a disability[1]. For this patient, who is being seen in a clinic specifically for patients with special needs, it is imperative that all tools and techniques are used prior to referral for care in another clinic for general anesthesia.

Section 5: Veracity

Under this principle, providers must communicate truthfully and "not represent the care being rendered to their patients in a false or misleading manner[1]." In this case, it was imperative that the clinical findings were discussed objectively using terms the patient's surrogate could understand especially when communicating the recommended treatment. It was critical that the patient and his surrogate understands the extent of the disease in order to make an informed decision about treatment. The surrogate needed to understand why it was believed that the patient would be able tolerate treatment in the clinic and why general anesthesia might not be in her son's best interest.

Ethical Conflicts

When deciding on how to proceed with treatment, there was an ethical conflict between respecting patient autonomy and nonmaleficence/beneficence. The surrogate expressed that the patient could not tolerate treatment in a clinical setting and could not receive local anesthetic injections due to his sensitivity to sounds and "dislike" of needles. Yet, the patient needed extensive periodontal therapy requiring local anesthetic to allow for adequate scaling and root planning as well as two large fillings and possible root canal treatment of his front teeth. Local anesthetic could not be delivered and treatment in the clinic could not begin without the patient's surrogate's informed consent. However, if adequate treatment could not be completed due to patient behavior or resistance, the patient's over all well-being could be affected negatively by putting him in a stressful situation. This experience could affect the patient in such a way that his surrogate would elect to avoid dental treatment all together, a decision that would certainly not be in the patient's best interest.

The decision to use general anesthesia in this case also posed a conflict between autonomy and beneficence/nonmaleficence. As stated previously, the guardian requested general anesthesia for the treatment of her son due to her concern about his fear of needles and sounds of the dental office. If general anesthesia was elected as the means by which to treat the patient, then the patient's overall health is at risk due to the increased risks associated with anesthesia, especially for individuals with developmental conditions or disabilities[2]. Specifically, Down Syndrome is generally accompanied by other clinically significant findings such as cardiac, respiratory, musculoskeletal, or gastrointestinal abnormalities. These are not always discovered until the patient is "placed in a compromising clinical situation such as anesthesia[2]." As stated previously, the patient was able to tolerate the clinical exam without any behavior modifications and it was noted that he receives monthly injections in his toes for gout. Based on these factors, there was a high likelihood that this patient would be able to tolerate treatment in the clinical setting with some reasonable modifications. These would include headphones to drown out the sound of the drill, desensitization procedures to allow him to become more comfortable with dental injections, and provider patience. This approach would not only decrease the risks of complication posed by general anesthesia, but it would allow better access to anesthesia for the community of patients who really need it.

Determining what ought to be done and choosing a course of action:

To review, the options of how to proceed were:

- Decline to participate in the patient's care and help the patient and his surrogate identify care elsewhere.
- Refer the patient for treatment under general anesthesia as desired by his surrogate.
- Accept the patient and discuss with the surrogate strategies for treating the patient in a routine clinical setting. If the surrogate is willing to accept alternatives, then proceed with care.
- If, while following initial care, it is demonstrated that the patient is not able to tolerate treatment, investigation of other means by which treatment can be performed must be explored.

The first option, if chosen, would limit the patient's access to care. Due to the patient's developmental disability, there are a limited number of clinics that would agree to see him and there may be a higher chance that a clinic would refer him for general anesthesia instead of taking the time to work with behavior management to ensure success for the patient.

If the option of making a referral for general anesthesia was chosen, the benefits would be that the treatment would be completed in one setting, there would be no negative psychological effects on the patient, and no behavioral management would need to be exercised in order for treatment to be completed. But, as noted, the risk of general anesthesia is very high, especially for patients with Down syndrome. General anesthesia for dental treatment is also a scarce resource and must appropriately be reserved only for those who truly need it. There was also the lengthy period of time before there was availability for him to be scheduled for care under general anesthesia. Finally, the pattern of care for this patient would become reactive, not proactive. Specifically, the patient would only present when he was having pain or there were significant dental needs. He would then go under general anesthesia for that treatment and would not develop coping methods to be able to receive routine, preventative care in a clinical setting that would hopefully prevent the need for future general anesthesia.

Benefits of the third option include allowing the patient to be treated in a lower risk setting, building life-long coping skills to allow him to receive not only treatment but preventative care in the dental office, and one less patient needing to utilize general anesthesia. The burdens include the

necessity of multiple appointments to take care of the patient's dental needs, some psychological stress as the patient develops coping skills to be able to handle treatment, more chair time used in the clinic that could be used for other patients, and the possibility that the patient ends up not being able to tolerate treatment. If this were to occur, other options can always be explored, including IV sedation to manage his behavior.

Based on the legal and ethical considerations outlined as well as the benefits and drawbacks, the third option was determined to be the most appropriate as it provided the most good with the least amount of harm. The well-being of the patient was of the upmost importance in this case, both by preventing the progression of the active disease process but also ensuring the patient was set up for success to endure the recommended treatment. It was imperative that this was presented to the patient's surrogate in a non-paternalistic and non-threatening way. All of the clinical findings, to include behavioral analysis and the extent of disease, were outlined as well as the risks associated with general anesthesia. The fact that the patient was able to tolerate regular steroid injections was also discussed.

Treatment and Outcome

After a lengthy discussion, the patient's surrogate gave consent for treatment in the clinical setting. Her demeanor, which started out very defensive, changed during the course of the discussion as her trust in the dental team grew. The patient was scheduled to begin periodontal treatment the next day. With distraction techniques and patience, he was able to receive an injection and the first quadrant of scaling was completed. However, patient management proved to be difficult, requiring many breaks and a significant amount of clinic time to complete one quadrant of scaling and root planning. In a situation where a positive patient experience is of the utmost importance and will dictate the ability for future care, it was determined that the patient would be best suited with a more experienced clinician and the next periodontal appointment was scheduled with a faculty hygienist. This ensured that he would receive quality care in a shorter amount of clinic time and in the hands of an experienced clinician who was well-versed in behavior management skills. Silver diamine fluoride was applied to the carious lesions on his anterior teeth to arrest the caries until the attending faculty felt the patient would be able to safely receive care. If the patient was not able to tolerate care in a reasonable amount of time

following desensitization and behavior modification, then other care options such as conscious sedation or general anesthesia would be discussed.

Conclusion

For this patient, it could have been easily argued that he would have benefited from treatment under general anesthesia. He had a lot of dental need that would take several appointments, so why not complete all of them in one appointment while he is asleep? However, based on how he behaved during the exam, he would also benefit from learning how to cope with dental treatment in a clinical setting allowing him to be seen in a generalist clinic in the future. This approach may take longer and require more appointments to address his current dental needs. If he is not able to tolerate the treatment, general anesthesia can always be used, but it appears to be in his best interest to first attempt the less invasive option and help him develop the tools to be able to be cared for outside of a specialty clinic. Obviously, there are grey areas, not a clear black and white, right or wrong answer. This is the case in so many clinical decision-making situations, not just this one. Ethical principles help guide clinical care and we must recognize that at times, they may be in conflict with one another. But, the ultimate goals in caring for a patient are improving their health and preserving their overall well-being. The best interest of the patient must underpin every treatment decision.

References

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2. Meitzner, Mark C, and Julie A Skurnowicz. “Anesthetic Considerations for Patients with Down Syndrome.” *American Association of Nurse Anesthetists Journal*, vol. 73, no. 2, Apr. 2005, pp. 103–107.