Ethical issues in managing the noncompliant child

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Abstract

Children who refuse treatment present a particularly difficult ethical problem in the practice of dentistry. Five areas should be considered when a patient refuses treatment. First, the urgency of the dental needs should be assessed to determine if treatment can be delayed or avoided with no lasting ill effects. Second, the capacity of the child to participate in decision making should be considered, and the child involved to the extent of that capacity. Next, the potential harm of management techniques should be weighed against the benefits of treatment. Then, the informed permission of parents should be obtained. Finally, pediatric dentists have a responsibility to attempt to shape policy to make care more available on the basis of need as part of an overall system of justly distributed health care. (Pediatr Dent 14:178–83, 1992)

Introduction

Children who refuse treatment present a particularly difficult ethical problem in the practice of dentistry. Patient autonomy, or the right of self determination, including the right to refuse treatment, is a fundamental right of all competent patients. Because a child may be incapable of appreciating the consequences of choices, however, we sometimes choose to override a patient's refusal of dental treatment. In doing so, we assume considerable power and responsibility.

In providing care to noncompliant pediatric patients, dentists must manage highly emotional situations, sometimes instantaneously. This is complicated by the fact that parents may refuse essential behavioral interventions, families sometimes cannot afford indicated general anesthesia, and third-party payors may refuse to pay for needed hospital care. These factors can force compromises in management strategy or deny access to indicated treatment, thus risking psychic trauma or jeopardizing the health of a child in our care. Financial considerations, the desires of patient and parents, exacting professional expectations, and personal feelings are all potential sources of conflict. While the legal authority of dentists to use techniques to control behavior has been curtailed in recent years, many children growing up in today's more permissive society resist old-fashioned, stern but gentle paternalism. All these pressures can complicate decision making and obscure our primary responsibility to consider the best interest of each child within a workable system.

Answering the question of what we ought to do in a particular situation requires an ethical analysis. To attempt to answer this question for behavior management interventions, we will proceed stepwise through five areas of consideration: the indications for treatment, patient autonomy, the benefits of dental treatment versus the burdens of a management intervention, the desires of parents, and external factors such as allocation of resources. These considerations often are interrelated, and their relative importance must be assessed to arrive at a conclusion in a particular case.

Dental Indications: Is the Planned Treatment Really Necessary Right Now?

When a patient cannot be persuaded to undergo treatment voluntarily, the first step is to reconsider carefully the urgency of the dental needs and determine if treatment can be delayed or avoided with no lasting ill effects. If watching and waiting will not incur undue risk to the patient, then this approach should be taken. Traditional attitudes regarding behavior management, such as "something must be accomplished at the time of the dental appointment...",[1] and compensation structures that are based on the number of procedures performed, pressure dentists to accomplish planned treatment and do not encourage reflection on the consequences of delaying or forgoing procedures.

Case I

A timid 3-year-old arrives for an initial dental visit. His mother states that he will be starting preschool next month. A clinical exam reveals small occlusal lesions on both lower second primary molars. He tolerates the examination poorly, and a rubber cup prophylaxis barely is accomplished with the aid of voice control and restraint by his mother. He is rescheduled for amalgam restorations to be accomplished using a restraining device if necessary.

It is likely that this child's behavior will improve over time, especially after preschool widens his experience. Because the lesions are small, postponing treatment will expose the child to minimal dental risk and potentially avoid an unpleasant dental experience. Considering the low urgency of his dental needs and his poor tolerance of treatment, delaying treatment with adequate follow-up is in this patient's best interest. Tooth brushing instructions could have been substituted for the rubber cup prophylaxis when it became

clear he would not tolerate the procedure well. Although it is a standard dental procedure, and is sometimes used as a method of accustoming the child to treatment, a rubber cup prophylaxis is itself of no proven benefit and it cannot be argued that the child will be harmed by delaying or omitting it.

Obviously, it may be necessary to provide prompt care for a child with more urgent dental needs. Each case requires a careful weighing of the benefits of immediate dental treatment against the risks of behavior management intervention, but ultimately the judgment will be subjective, since we have little empirical data on the progression of untreated caries in children, the effect of time on uncooperative behavior, or the negative effects of behavior management techniques. It is important to consider long- and short-term goals. If a patient who is subjected to aggressive treatment early in life resists future dental care, the overall effect will not be in that patient's best interest. In this case, the potential discomfort and psychological distress resulting from treatment using restraints are not justified when weighed against the negligible benefits of immediate dental treatment.

Assent: Should We Disregard the Patient's Refusal of Treatment?

Children are not granted the legal autonomy, or right to refuse or consent to treatment, that is assured for unimpaired individuals age 18 or older (in most jurisdictions[2]), because they may not be competent to act in their own best interests. Instead, to the extent that it is possible, we seek the child's assent to treatment in combination with permission of the parent(s) or guardian. The term "consent" is reserved more properly for individuals with the full capacity to make independent decisions. Child assent, a relatively new concept, has been described by Bartholome.[3]

"Children are respected as persons with a developing capacity for participation in decision making. Assent asks that pediatricians involve children to the extent of their capacity; that children participate in making decisions about their health and health care to the extent that they are able."

Decision-making capacity varies among individuals ranging from infants and very young children who demonstrate little comprehension, to adolescents who demonstrate considerable understanding and so should be permitted to make health care decisions within their capacity, despite their legal status. Based on studies of cognitive development, it has been suggested that children younger than 7 years of age have magical views regarding illness and have very little capacity to appreciate the consequences of treatment options. Children in the 7-to-13-year age group usually gave disproportionate weight to present benefit as compared to future effects, so that they may be very reluctant to chose dental treatments which require present pain to achieve future benefits. (This reluctance does not occur exclusively in children.) But, by the age of 14 or 15 years, most children possess health care decision-making capacity equal to that of the average adult.[4] The estimation of capacity and determination of level of involvement in decision making lie within the judgment of the health professional.

Adolescents who are self-supporting or married may be granted the status of emancipated minor, becoming legally responsible for their own health care choices. The judicial determination of emancipation can be made by decree or through litigation in which it is an issue.[2] For nonemancipated minors, the "mature minor doctrine" provides legal exception to the general parental consent rule. Under this common law doctrine, minors who are at least 14 years old and are able to understand the nature and consequences of treatment are considered mature enough to consent to or refuse treatment. Although particular statutes vary from state to state, as long as the refusal of treatment does not result in risk of serious health problems, the courts have upheld the mature minor's right to consent to or refuse treatment.[5]

Case II

A healthy 12-year-old male is brought by his father for treatment of a toothache. Examination reveals a severely carious lower right permanent molar with a periapical radiolucency. The tooth is judged nonrestorable and, with the father's permission, immediate extraction is planned. The patient flatly refuses the injection, despite attempts by the dentist to explain and reassure, offers of nitrous oxide analgesia, and threats from the patient's father. He says that his toothache is not that bad.

This boy is making a decision in which he is weighing his discomfort against his fears of dental treatment. He also may be experiencing rebellious feelings toward his father and the dentist as authority figures. Although we may feel his choice is contrary to his own welfare, he is old enough to understand the benefits of treatment and the consequences of nontreatment. He is, in fact, making a choice often made by competent adults. It is important to realize that patients may have alternative value systems and will not always make the same decision we would make in a similar situation. Forcing treatment on this 12-year-old would require an extreme form of behavior management. Because of the potential for psychological or physical harm, such an action cannot be justified. Giving him adequate information in language that he can understand, sincerely attempting to persuade him, and respecting his decision by delaying treatment until he assents, will afford him the dignity he is due as a developing individual. This process

will help to foster trust and encourage a developing maturity. The child's right to autonomy is, in this case, in conflict with the responsibility of the parent and dentist to protect him from decisions he may make without fully appreciating their consequences. At some point in development, we must accept that a child will not always decide as we think she or he should and limit our interference to advice. Of course, if the patient were unable to understand the situation and consequences well enough to make a rational decision, which might be the case with younger or mentally handicapped patients, intervention would be justified.

Case III

A 4-year-old girl accompanied by her mother came to the dental office for restoration of severely carious maxillary incisors. She did not respond to attempts of the dentist to engage her in conversation and when she was asked to open her mouth she retorted, "No, I don't have to." The dentist informed her in a loud voice, "I'm in charge here and you'll do as I say!"

An aspect of respect for patient autonomy that should be kept in mind relates to the goal of behavior management intervention. Are we trying to accomplish needed dental treatment safely, or are we attempting to impose discipline on the child just to establish who is in charge? Although we may need to assume control to accomplish treatment, it is inappropriate as a health care provider to assert dominance for its own sake. Rather, we are obligated to respect the dignity of our patients to the fullest extent possible. In calm moments, this seems obvious, but in the heat of a challenge from a defiant patient, it may be forgotten. It is appropriate in this case to overrule her objections to treatment, but despite her behavior, she is entitled to attempts to gain her assent to treatment. She is due an age-appropriate explanation of what needs to be done and why, an explanation of the immediate consequences of her refusal to cooperate, and possibly an apology after ignoring her refusal to assent to treatment.[3]

What Management Techniques Are Indicated, and Are the Benefits Outweighed by the Burdens?

Assuming that we have decided that treatment is necessary and that it is appropriate to proceed despite the patient's refusal to assent to treatment, the next step is to determine what management techniques are likely to make treatment possible in a given situation, and if they are in the best interest of the patient after weighing the risks of harm against the benefits of treatment. The objective of a behavior management intervention is to allow the reasonably efficient delivery of dental care of satisfactory quality. Unfortunately, very little scientific evidence exists to indicate the effectiveness of most protocols in use. For the most part, assessments are based upon personal and shared clinical experiences. In choosing among various management options, we take into consideration the technical demands associated with accomplishing needed treatment, the quality of the dental treatment possible under the chosen conditions, and the quantity of treatment required. Among the techniques in use, clearly general anesthesia is effective, and several sedation protocols also have been determined to be effective a certain percentage of the time. Data are not available on the effectiveness of the various positive psychological techniques, voice control, restraint, hand-over-mouth, or nitrous oxide analgesia, although all are time-honored practices regarded as effective by the practitioners who use them. General guidelines for the selection of patients for whom techniques are likely to be effective can be found in the Standards of Care for Behavior Management developed by the American Academy of Pediatric Dentistry.[6] These guidelines point out that behavior management is partly an art, that approaches vary with the personality and training of the practitioner, and that individual techniques are used as part of a larger scheme in response to the individual child. These multiple variables make objective assessment of effectiveness extremely difficult.

When deciding to use a management technique, the associated risks must be assessed. Future health-seeking behavior should not be jeopardized, and the child should not be physically or emotionally harmed in the course of treatment. Physical and psychological pain and distress should be minimal, and must be justified by the benefits to the oral health that the management technique will make possible.[7] Unfortunately, very little scientific evidence exists to indicate the potential psychological or physical risk to the child. Restraint may protect the patient from injury caused by movement during treatment, but physical discomfort may occur. The overzealous use of hand-over-mouth may result in minor injury.[8] Traditionally, pediatric dentists have been reluctant to use general anesthesia. Although about 1 in 10,000 of all anesthetized patients die of causes primarily attributable to anesthesia,[9] the risk to healthy patients anesthetized for dental treatment is probably considerably lower. This risk is less than that of one year of normal automobile travel during which death rates are 2 in 10,000 persons.[10] Reliable data for sedation occurring in dental offices do not exist, but studies have demonstrated mortality rates of about 1 per 500,000 in oral and maxillofacial surgical practice. Morbidity data are not available.[9] The potential for psychological damage occurring as a result of behavior management interventions is difficult to assess. There is no reason to

suspect any harm will result from the positive psychological techniques used to elicit patient compliance such as tell-show-do, positive reinforcement, and modeling. These techniques are informative, and as such, can be considered part of the duty of the dentist to the patient to explain procedures in language the patient can understand. When compared to the risks of general anesthesia, it is worth questioning the risks of techniques which may be considered aversive, such as hand-over-mouth, restraint, or voice control. A great deal of variability characterizes the use of these techniques historically and individually, and this variation is critical in assessing the degree of psychological risk to the child. Most techniques either can be used kindly and supportively, coupled with appropriate positive reinforcement, or used in a punitive or threatening manner; the way in which they are used is much more important than the techniques themselves. Although the punishment approach may produce immediate effects on the child's behavior, and therefore, be convenient for the operator, it may result in increased anxiety, resentment and overt or covert anger.[11] Psychological effects have been demonstrated as a result of pharmacologic management with both oral sedation and general anesthesia, although both positive and negative effects on behavior of approximately equal magnitude were demonstrated.[12] In the absence of clear evidence, an estimation of the potential for psychological and physical harm must be left to the individual practitioner's judgment.

Do Parents Give Permission?

For the protection of children who cannot weigh alternatives and make informed decisions, we must have a mechanism for decision making by another party or "proxy." It has been proposed that "permission" is a more appropriate term for proxy decision-making than the commonly used "consent," which should be reserved for competent individuals deciding for themselves.[13] This terminology helps to clarify the ethical issue and will be used here. It also should be pointed out that the use of the word "proxy" is flawed, since it implies that the person was chosen by the child to act as her or his agent, when, in fact, the child made no such choice.

Who is best able to serve as the proxy for a child? The proxy would decide for the child as the child would decide upon reaching maturity, but of course future preferences cannot be predicted. Given this difficulty, as an alternative we assume that the parent and child share an identity of interest since parents generally will transmit their values to the child, care deeply about the welfare of the child, and know the child better than anyone else.[4] Parents may base decisions on what they think is in the child's best interest or what they would want in the child's position.

Historically, children were regarded as their parents' property, with no separate individual rights, and it followed that parents should decide absolutely for them.[14] Over time, societal standards regarding the rights of children have evolved so that current laws assign to parents the right to make decisions for their minor children but also endow children with certain protections. Laws regarding child abuse and neglect are examples of protections which have been instituted in this century. Cases in which courts have ordered life-sustaining blood transfusions or surgical procedures for children whose parents have refused them because of religious beliefs have been publicized widely. Although we assume that they do, parents do not always act in the best interest of their children. Under our current legal system, parents or guardians may make decisions for their immature minor children unless it is decided that they are acting against the best interest of their child to the extent that significant harm will result. In some cases, informed persons, such as health care providers, may be better equipped to decide for a child than self-interested, incompetent, or uninformed parents.

Treatment decisions for immature patients are made in a dialogue with parents. The dentist's role is to recommend to parents treatment options based on professional judgment. The information provided should include a description of the recommended techniques, possible reasonable alternative forms of management, and an assessment of the risks associated with delaying or refusing treatment. If parents request a treatment that, in the sound professional opinion of the dentist, is not indicated, the dentist is not obligated to provide that treatment. This includes unnecessary use of pharmacologic agents, inappropriate use of force, or treatments unlikely to be effective, such as attempts at restorative care without benefit of indicated physical or pharmacologic management aids. If parents refuse all reasonable treatment options offered, the dentist is obligated to attempt to educate to overcome ungrounded fears or misapprehensions. In cases of failure to obtain needed dental treatment, the dentist may be obligated to report the neglect to the appropriate agency to protect the child. The position of the dentist in this complex system is that of an informed advocate for the patient negotiating with the proxy. This includes not only the obligation to fully inform and obtain the permission of the proxy, but also the obligation to protect the child from the parents through reporting mechanisms when necessary.

How Should External Factors Affect Decision Making?

Although dentistry traditionally has focused on individual patient care, in fact, care does not take place in the isolation of single-patient encounters. Cultural values, economic factors, and institutional arrangements all influence health care decisions. Almost always the dentist's responsibility is to promote the best interest of the individual patient, but decisions must be made as to what extent external factors will influence choices.[15]

Allocating Resources

Operator convenience and resultant efficiency must be considerations in health care delivery. Without some attempt to limit efforts, pediatric dentists could expend extraordinary resources attempting to manage the behavior of a few children, in effect denying care to many others. Obviously, we cannot afford to pursue futile attempts using positive psychological management alone and must occasionally resort to stronger measures. But a child's dignity and safety are primary concerns, and we are obligated to make all reasonable attempts to obtain assent to treatment or, failing to obtain assent, must not sacrifice the patient's physical or psychological comfort to our convenience.

In current practice, children who require behavior control for the delivery of medical and dental care often are managed in different ways. Pediatric dentists routinely use management techniques to achieve a level of patient compliance that permits exacting and uncomfortable procedures to be performed on the majority of young children who require them. General anesthesia is reserved for only a very small percentage of uncontrollable patients. In contrast, physicians use general anesthesia on a routine basis for tonsillectomies, hernia repairs, and myringotomies. These procedures are not substantially more painful for the patient or exacting for the operator than extensive dental treatment.

These dissimilar approaches may have arisen in part from the different traditions of medicine and dentistry. Perhaps because medicine deals with life-threatening conditions, physicians have been invested with the power and authority to employ extreme or expensive remedies to render treatment, and parents and insurance companies or other third-party payors typically have allowed the expense and risk of these remedies without question. In contrast, dental problems are perceived as less serious, even underestimated, so third-party coverage often is limited, risks associated with general anesthesia are assumed reluctantly, and relatively less costly or medically risky means are sought to accomplish treatment. This has resulted in the routine use of general anesthesia by physicians for procedures sometimes no more imperative, risky, or painful than dental care, and in the routine use of behavior management techniques by dentists to render treatment which may have the potential for psychic distress. This limitation on the options available for delivery of dental care is clearly not in the best interest of patients, and obligates ethical pediatric dentists to try to become influential on a policy level to make dental care more available on the basis of need as part of an overall system of justly distributed health care. (The AAPD has recognized the responsibility of the professional organization as an advocate for necessary resource allocation and actively has attempted to influence decisions regarding the allocation of health care funds by third-party payors and public assistance programs).[6, 16, 17]

Case IV

A 4-year-old with severe caries is brought to a teaching hospital clinic by his mother for an examination. The child is marginally cooperative, but his behavior clearly is affected negatively by his mother's presence. She insists on remaining with her son although the resident explains that the child's behavior probably will improve if she leaves the treatment area. The mother expresses a high level of dental anxiety and dissatisfaction with the previous dental care her child has received. She belligerently states that she wants the work performed under general anesthesia. When informed of the expense, she says she has Medicaid.

Economic factors may limit the use of general anesthesia for many patients, often those who need it most. But when this is clearly the indicated mode of treatment, attempts should be made to obtain funding for care for the patient through public assistance programs or referral to funded programs for provision of care. The dentist's obligation is to the patient, and considerations of public expense and attempts to ration or allocate scarce or limited resources ideally should be dealt with at a policy-making level and should not enter into individual treatment decisions. However, the pool of public health care dollars is limited and shrinking, and the dentist has some obligation to avoid unnecessary expenditures when the benefits may be marginal and expense may limit health care dollars available for other patients.[18] In this case, a decision must be made as to the strength of the indication for general anesthesia. It is not clear how well the patient will tolerate routine dental treatment, and the mother's attitude contributes substantially to the questionable prognosis. Dentists, like all health care providers, work in an imperfect world, contending with irrational factors not only in patients, but also in family members, institutions, including hospitals, third-party payors, and governmental regulators. The best chairside ethical guideline is to try to do what is in the patient's best interest under the circumstances. In this case, it may involve attempts to reassure and educate the mother to allow behavior

management interventions to be attempted, but also should include a willingness to attempt to obtain funding for general anesthesia should persuasion and behavioral interventions fail, so that the child can receive needed dental care.

Educational Benefits

As a necessary part of training for health professionals, treatment is provided to patients by students and residents in training programs. Often these students are not skilled in behavior management techniques and, as a result of inappropriate management, a potentially cooperative patient may suffer an unnecessarily unpleasant dental experience. It is important that students be well supervised and intervention provided when indicated, so that the interests of the patient are protected.

Summary

The following areas should be considered in ethical decision making when a patient refuses treatment.

Indications: Carefully reconsider the urgency of the dental needs and determine if treatment can be delayed or avoided with no lasting ill effects.

Assent: Estimate the capacity of the child to participate in decision making, and involve the child to the extent of that capacity. This may include overriding the refusal of an immature patient or respecting the right of a more mature individual to refuse treatment.

Benefits versus burdens: Determine what management techniques are likely to make treatment possible in a given situation, and decide if they are justified after weighing the risks of harm against the benefits of treatment.

Permission: Obtain parents' permission after presenting a description of the recommended techniques, alternatives, and an assessment of the risks associated with refusing treatment. Ungrounded fears and misapprehensions must be addressed.

External Factors: Finally, pediatric dentists have a responsibility to attempt to shape policy to make care more available on the basis of need as part of an overall system of justly distributed health care.

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