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A PATIENT'S PERSPECTIVE ON MORAL ISSUES AND UNIVERSAL ORAL HEALTH CARE

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ABSTRACT

The author argues that, in addition to dentists and ethicists, a morally correct conversation about these issues ought to include people who require oral health care services. The author has experience as a health care consumer in four countries and on two continents and writes from a patient's perspective. Using narratives of personal experience she argues that holistic patient care, a dentist-patient partnership, and an excellent quality of care are fundamental aspects of ideal oral health care to which all people should have access. The best chance of improving access to quality oral health care is through a moral framework. Dental professionals, and others who are empowered, have a moral responsibility to work to create a culture in which care for people is the primary value, and the author offers several suggestions toward this end.



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Why do so many people worldwide lack access to adequate oral health care? Is making oral health care access a human right the key to improving access for vulnerable populations? And who is best able to answer these important and troubling questions? Beginning with the last question, an obvious answer is that dentists, and others involved in delivering oral health care, are well-positioned to address questions about access to care. Ethicists are valuable in formulating morally sound answers to these questions. But, I will argue, a morally correct conversation around these issues ought to include people who require oral health care services. Without the last group, an essential perspective on the successes and gaps in the oral health care system is missing. I commend the dental profession for each course, each conference, and each journal in which the voices of patients are included and considered, including the invitations to present my perspective on access to oral health care and human rights at the IDEALS Congress and in this journal.

I am writing, not as an expert in either dentistry or law, but as an oral health care consumer. As a consumer, I cannot contribute research results nor statistics to the issue of access to oral health care. Instead, I can offer stories and reflections on my experiences and the experiences of those around me. I have received health care in four countries and on two continents. I have received both excellent care and poor care, including a misdiagnosed brain

tumor. I have witnessed the benefits of early, preventive care, and I have observed the consequences of inadequate care. It is from this perspective as one health care consumer that I have considered questions of access to oral health care.

I am convinced that all people ought to have access to oral health care, though many people, particularly those from vulnerable populations, do not. While I do not disagree that such access should be a human right, I will argue that framing the issue in moral, rather than legal terms, allows the legal benefits of rights status to be supplemented by a range of changes which together work to provide quality, holistic care to the entire population. First, however, I would like to reflect briefly on the ideal toward which all oral health care should aim.

A PERSONAL CASE

I would like to begin with a case study which seems to me to encapsulate the ideal in oral health care and which points to the principles that undergird excellent oral health care. Moreover, unlike even the most compelling statistics, a case study emphasizes the people involved, and I believe that quality oral health care is fundamentally about caring for people.

I have two daughters. Laurel is two and Alayna is now four years old. Just after Alayna turned three, my father, who is a prosthodontist, noticed that Alayna had a functional crossbite. After consultation with my husband and me, my dad arranged for Alayna to be seen by a friend and orthodontist, Dr. Bob Baker. When we first met with Dr. Baker, he let us know that if Alayna was not comfortable enough to let him examine her mouth, then he would wait until the next visit, or the visit after that. He was friendly and patient and Alayna did

allow him to examine her bite. He felt she would benefit from an appliance to expand her upper jaw and correct the crossbite. Alayna was happy at the thought of getting something like the mouthguards my husband and I wear to reduce the effects of nocturnal bruxing. Over several visits, an impression was made and the appliance was fitted and adjusted. Alayna was allowed to choose the color of both the appliance and the case—both purple. Dr. Baker delayed the final occlusal adjustments rather than push Alayna past what she could tolerate in one sitting. Once the appliance was properly adjusted, Alayna never complained about it. She looked forward to her dental visits and said that Dr. Baker was funny. Several months later, the crossbite was corrected and the appliance was no longer needed. After the last appointment, we celebrated by going out for burgers and fries with Dr. Baker.

I realize that this case is an exception. The crossbite was detected early and the treatment was not painful. And burgers and fries are obviously not a standard part of treatment. Not everyone will have a dental experience that is so much fun.

Nonetheless, I think this narrative can usefully inform any conversation about access to quality oral health care. Dr. Baker provided holistic care, he worked in partnership with Alayna and with us, and he provided excellent dental care. It seems to me that each of these three aspects of care is essential to the provision of oral health care and is worth examining in a little more detail.

First of all, Dr. Baker cared for Alayna as a whole person. He considered her emotional needs as well as her dental needs. He worked to gain her trust and requested rather than required her compliance. This was not exceptional within Dr. Baker's practice. He began dental treatment only when each patient was comfortable, even when that required several office visits prior to any

dental work. It was obvious that, for Dr. Baker, oral health care is much more about caring for people than it is about fixing teeth or making money. I believe that this should be a fundamental principle of oral health care. It seems to me that, as questions of dental ethics are asked and as modifications to the oral health care system are considered, caring for people holistically ought to be the primary point of focus.

Oral health care focused on the whole person will not look the same in every case and requires attentive dialogue between the dentist and the patient. Whole patient care is not possible if a dentist simply adheres to a set of general principles or bases a treatment plan on the limitations of a particular insurance plan. When culture, emotions and personal priorities are taken into account, genuine need differs from person to person and these real needs—which are not merely whims or desires—ought to be considered. For example, one would logically conclude that one of the dentist's primary duties is to reduce a patient's pain as much as possible, through measures such as providing anesthetic for painful procedures. But following this principle does not always provide the patient with the best care. My grandmother prefers the pain involved in a root canal over the numbing sensation of anesthetic and she has no difficulty in cooperating with a dentist during a root canal without it. She is better cared for and has her needs more fully met when she is treated without anesthetic, despite the pain involved. But the only way this can happen is if her voice is heard and if her dentist is focused on caring for people. Age, culture, religion, employment, past experience, and health problems may all affect the needs, concerns and priorities of a patient. Treating people, and not

just their teeth, will require a certain amount of flexibility within whatever system is in place.

A second important aspect of Dr. Baker's care, and one that goes hand in hand with holistic care, is treating the dentist-patient relationship as a partnership. As much as was possible, Alayna was given the power to make decisions about her own oral health. She was able to decide about the color of both her appliance and her case, decisions which made her a partner in the process. Alayna's choices in this process were limited, but it is important to recognize that this was because of her age and not because she was a patient. At three, her ability to make decisions about her oral health care was limited, so it was appropriate for others to carefully make decisions on her behalf when those decisions were beyond her ability. However, for the vast majority of adult patients, this degree of paternalism is not appropriate.

In preparing this paper, I have had the opportunity to read a small portion of the literature surrounding these questions. The attitude of paternalism that seems to be present in the literature on access to care left me concerned. It is undoubtedly true that the patient needs the dentist, since the dentist has the knowledge and skills to care for the patient's oral tissues. The dentist also needs the patient in order to deliver quality care. For example, to correctly use my blood pressure in evaluating my health, it is important to know that, when I am well, my blood pressure is below the normal range. Talking to me and believing what I say is the simplest way for a health care provider to gain this crucial information about me. Only the patient can provide referencing for individual norms, which are as important to quality health care as population norms are. And health care professionals are especially dependent upon patients

when no external reference is available, as is the case with pain. The dentist-patient relationship ought to be one of partnership in which, in the absence of compelling evidence to believe otherwise, healthcare professionals enter into dialogue with the patient, believing in both the reliability and the value of the patient's comments.

Treating oral health care as a partnership requires more than simply soliciting information from the patient. It means putting information and decision making into the hands of the patient. Patients need access not only to treatment, but also to possibilities. Paternalism, often accompanied by good intentions, assumes that the oral healthcare professional knows what is best. But, as I have already argued, both the patient and the dentist bring essential information to the relationship. Patients know well their own emotions, experiences, priorities and context, all of which are relevant and significant factors when deliberating about oral health care. Oral healthcare professionals can analyze the patient's oral health, and are aware of preventative care possibilities, treatment options and the health risks and benefits of each course of action. When the dentist-patient relationship is a partnership, all of this information is shared. In the oral healthcare process, the oral healthcare professional faces legal and financial risks, but the greater portion of risk, financially and physically, is borne by the patient. The best decisions about quality oral health care are the result of conversation between the dentist and the patient, with accurate and complete information, and with the final decision, resting in the hands of the patient. Partnership, rather than paternalism, provides better and more holistic care.

A morally correct conversation around these issues ought to include people who require oral health care services.

I believe that it is more helpful to frame the question in moral, rather than legal terms.

A third aspect of Dr. Baker's care for Alayna which I would like to highlight is the high quality of the dentistry she received. Though I am certainly not an expert in the field of dentistry, my father's assessment and the range of dental care I have experienced give me confidence that the dental care which Alayna received was excellent.

In an effort to increase the number of people who have access to oral health care in a world of limited resources, it seems that there could be a temptation to cut corners—in training oral healthcare professionals, in providing equipment and supplies, and in the time and attention given to the needs of each patient. As problems with access are addressed, it is important to ensure that quality remains high. If we believe that all people should have access to oral health care, then we should make every effort to ensure that the oral health care they receive is excellent in quality. This is not to say that delivery systems and available treatments ought to be identical among all populations worldwide. Indeed, if the dentist-patient partnership is truly to be a partnership, quality care may look quite different among different populations. But, however the dentist-patient partnership configures the oral healthcare system, sloppiness and inattentiveness should not be more acceptable among vulnerable populations than they are among the empowered. We should not require the vulnerable among us to accept a lower standard of care than those empowered to access care on their own.

FRAMING THE PROBLEM CORRECTLY

These three elements, holistic patient care, a dentist-patient partnership, and an excellent quality of care, are, to me, fundamental aspects of ideal oral health care to which all people should have

access. I am also acutely aware that this type of care is not even a dream for far too many people in our world. Statistics presented throughout the literature on access to oral health care convincingly illustrate the lack of access to oral health care in the United States (Catalanotto, 2006; Crall, 2006; Smith, 2006). I add only that these devastating gaps in access are not just limited to the United States. My husband and I had the privilege of living and volunteering in Bosnia and Herzegovina from 2000 until 2003. Among the wonderful people we met there, we witnessed the pain and indignity many of these people suffered from lack of access to quality oral health care. The gap between the ideal of holistic, quality oral health care and the painful reality for many people around the globe is tragic and unacceptable. This massive gap needs to be closed so that all people have access to oral health care.

One possible approach to closing the gap in access would be to make access to oral health care a human right, which would give the option of legal recourse to those without access. In my view, systemic changes are necessary to correct this serious problem, but I believe that it is more helpful to frame the question in moral, rather than legal terms. Having a right to something means that one is entitled to make a claim, often through legal channels, for that right. But, those who lack the power to gain access to oral health care also lack the power to make a claim for themselves. Legislation, without empowerment, will not help the majority of people who lack access to oral health care. So, while I believe that legislation can be a valuable component of the systemic changes necessary to improve access to oral health care, I do not believe that legislation alone will be sufficient to bring about a substantial change in access. I also believe that, whether or not access to oral health care is a human right, the dental profession

has an obligation to provide at least some care to the underserved and that this obligation is shared by society as a whole. Those of us who are empowered have a responsibility to act so that all people have access to quality, holistic oral health care.

I also believe that this moral responsibility extends beyond basic questions of access to care and systems of payment. Problems with access to oral health care are connected to wider societal problems such as general healthcare access, employment, and insurance. I believe that access to oral health care is also affected negatively by issues such as poverty, military conflict, economic sanctions, and even the effect of our lifestyles upon climate change. Each of us who is empowered has a responsibility to ensure that our lifestyle, whether pursued individually or advanced through the policies of our governments, does not impoverish others. Cumulatively, the lifestyle choices we all make have an impact on quality of life for vulnerable populations. We have a responsibility to live in such a way that the vulnerable have the possibility of whole and healthy lives, including access to oral health care.

I believe that the best chance of improving access to oral health care is through a creative and multifaceted effort to change the culture of oral health care, and care more generally, for vulnerable populations. We need to work together to create a culture in which care for people is the primary value, whether those people are patients, dental assistants, or dental students. We need to create a culture where sharing—of time, information, and services—is a natural part of caring for the needs of society. Such a cultural shift will require time and creativity.

Here are a few changes which could contribute to a culture of care:

1. Classes in ethics that are required of dental students should not simply cover formal ethics or questions of liability and other legal issues. These classes should remind students about holistic care and about treating the patient as a partner in the process. Furthermore, these ethics classes should also explore lifestyle issues such as transportation, housing, and investments and spending habits of healthcare professionals. Incidentally, during Dr. Baker's years as director of a graduate orthodontics program, an ethics course of this type was required.
2. All oral healthcare professionals could be expected to provide pro bono work. This could be encouraged through a simplified bureaucracy, through making volunteer work a condition of membership in dental associations, as a condition of licensure, or through programs in which volunteer hours would be used to calculate a credit towards reducing student loans.
3. The training of excellent oral healthcare professionals can be encouraged by lowering tuition costs and raising expectations of students. Students who have been held to a high standard in terms of both dental competence and in holistic care of patients, and who graduate without such an overwhelming debt load, will be more inclined to practice with a focus on people rather than on money.
4. Programs can be developed which establish international standards of excellence in oral health care. These programs should include resources to provide training, equipment and supplies to oral healthcare professionals in poorer countries, so that dentists worldwide are empowered to offer up-to-date, quality oral health care.
5. Universal health care, including oral health care could be a widely shared point of advocacy for oral healthcare professionals. Universal care would be a significant step toward mitigating current barriers to access, such as poverty and the profit-driven design of insurance programs.

I laud all those within the dental profession who advocate on behalf of the vulnerable and unempowered within society, those working to eliminate gaps in access to oral health care and those listening to the voice of the patient. I hope that I have supported those efforts as I have suggested that holistic, quality, partnering care for all people ought to be the collective goal and that oral healthcare professionals and the empowered within society share a moral responsibility to work diligently toward this goal. From the naïve perspective of a health care consumer, I have offered some means by which this can be accomplished. I do not believe that the necessary changes will be quick or easy, but it is my hope that together we can change the culture of oral health care so that the story of Dr. Baker's care for Alayna is no longer an exception. ■

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