REVIEW ARTICLE

Dental informed consent challenges and considerations for cognitively impaired patients

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1 | INTRODUCTION

Information regarding this topic was gathered from different sources, including medical, dental, psychologic, and neurologic bioethics, as well as medicolegal, literature. Individuals with cognitive impairment who require extensive dental treatment must be evaluated for decisional capacity prior to obtaining informed consent. Decisional capacity refers to a patient's ability to make a meaningful decision about a particular treatment. One generally accepted framework for decisional capacity relies on assessment of component abilities in an individual: understanding, appreciation, reasoning, and choice. If a patient is unable to demonstrate these four abilities then another person must make decisions on behalf of the patient. These roles vary depending on US state law; a general framework is presented here. Unbefriended patients and complex cases benefit from multidisciplinary care teams. A review of clinical cases helps to highlight the complex scenarios that warrant different levels of consideration for this population. Often an ethical dilemma arises with complex dental reconstruction because this treatment can fail and this then adversely affects the quality of life and health of this frail population. Therefore, complex dental reconstruction in these patients should be approached with caution or avoided and considerations for simplified treatment plans and maintenance protocols are warranted. Further, the level of cognition may decline over time and during the various stages of dental treatment, further complicating completion of care. In addition to limited cognition, elderly individuals may also exhibit limited manual dexterity and thereby an inability to self-maintain, limited access to dental care, limited finances, and other medical conditions that further exacerbate their dental conditions, such as dry mouth, diabetes, osteoporosis, or cancer.

In patients with cognitive impairment who require extensive dental treatment, decisional capacity must be evaluated when obtaining informed consent. This may be challenging for the practitioner. Further, because of the complex nature of dental reconstruction, length of treatment time, limitations that face the elderly, and concomitant comorbidities, these cases warrant a cautious approach.

2 | BACKGROUND AND OVERVIEW

Periodontal disease is characterized by chronic inflammation and destruction of the periodontal tissues, which often leads to tooth loss. Periodontal disease is prevalent both in developed and developing countries and affects about 40%-50% of the global population including adolescents, adults, and older individuals, making it a major public health concern.¹ Periodontal diseases have been associated with systemic diseases, including diabetes, cardiovascular disease, cancer, and Alzheimer's disease.²⁻⁴

Dementia is characterized by progressive loss of brain cell function, leading to cognitive deficits that interfere with activities of daily living. Dementia is highly prevalent, with approximately 50 million people affected worldwide and about 10 million new cases every year; the total number of people affected is expected to reach 82 million in 2030 then 152 million in 2050.^{5,6} Alzheimer's disease is the main cause of dementia and it begins with impaired memory or cognitive impairment. Alzheimer's disease is an irreversible, progressive brain disorder that affects memory and cognition, and eventually the ability to carry out the simplest tasks. The neuropathologic lesion of Alzheimer's disease includes amyloid plaques and neurofibrillary tangles. Although the etiology of Alzheimer's disease is not

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fully understood, both genetic and environmental factors have been implicated. $^{7}\,$

Because the US population is living to an older age, the number of individuals with cognitive impairment and periodontitis is increasing, as both conditions/diseases increase with age.^{1,8} Thus there is a large number of elderly patients with cognitive impairment seeking dental treatment, including periodontal treatment and complex full mouth dental rehabilitation, as well as reconstruction with the need for advanced bone grafting and dental implants. These dental treatment scenarios present dental practitioners with complex challenges. One of these challenges is in obtaining informed consent from patients with impaired cognitive ability. Another difficult scenario is that full mouth rehabilitation with bone grafting and dental implants can take up to a year or longer to complete. Within that time frame, a patient may become newly diagnosed with cognitive impairment and/or the condition may advance significantly during treatment. In these cases, patients may become confused and not understand the reason for the complex dental treatment that is in progress. The practitioner may be unable to continue with treatment or be in the middle of therapy where dental implants are placed but remain unrestored, leaving patients in a precarious and potentially harmful situation. Another challenging situation is the case of failing dental implants and the need to surgically remove them; the resulting bony defects following the implant removal may limit the ability to reconstruct these patients, and then these patients would have limited oral function. In addition, if failing or infected implants are left in place, patients may suffer from frequent oral infections. To help the dental practitioner navigate these various situations, a review of important considerations for patients with cognitive impairment is presented.

2.1 | Informed consent

Informed consent is based on the concept of respecting autonomy, which entitles adults to govern their lives according to their own values and preferences. Informed consent has been defined as "an individual's autonomous authorization of a medical intervention or participation in research" and consists of seven elements: patient capacity (also called competence), voluntariness, disclosure of material information (such as risks, benefits, and relevant alternatives), recommendation of a plan, understanding, decision, and authorization. Informed consent can be given verbally or via signed documents,⁹ with the latter often favored by institutions when risks are higher (eg, when anesthesia/sedation or invasive procedures are required) to protect against liability.

Some accounts of informed consent suggest that clinicians' roles should be limited to providing information and presenting the patient with options. However, a preferred concept of informed consent is the model of "shared decision-making," in which clinicians and their patients or caregivers work together to decide on the best care options for the patient, especially if there is more than one reasonable option.^{10,11}

2.2 | Decision-making capacity as an element of informed consent

As above, patient capacity is an element and indeed a prerequisite of valid informed consent. In general, adults are presumed to have decision-making capacity, and do not generally need to provide evidence of this capacity to make their own medical, financial, legal, and personal decisions. However, when patients of any age present with cognitive impairments, the presumption of consent can be called into question, in which case clinicians (or lawyers and judges) may need to assess decisional capacity. The informed consent process for geriatric populations with cognitive impairment and seeking dental treatment has not been well documented, despite its importance.¹²

Earlier, clinicians or judges would make sweeping judgments about a person's "competence," often resulting in a global determination that an individual was unable to manage their own affairs. Recently, this all-or-none approach has shifted with the recognition that some decisions are more complex than others. Because cognitive impairment is a spectrum, many people may lack sufficient ability to make decisions about some matters (eg, complex financial investments) while retaining ability for simpler or more familiar matters (eg, handling money when going to the grocery store). Thus, judgments about patients' decision-making capacity are now recognized to be decision-specific, and a finding that a patient has or lacks capacity for one decision does not necessarily imply that the patient has or lacks capacity for other decisions that may have their own cognitive demands.

2.3 | Clinical capacity assessment

In most circumstances, determinations of patient capacity are made by clinicians and only rarely by lawyers or judges; these clinical determinations thus have profound legal consequences. While the specific legal standards for decision-making capacity are determined by statute and therefore vary from state to state, in practice, clinicians generally apply a common framework informed by the various state laws in capacity assessment. In this framework, four abilities (see below) are required for capacity to make a given decision: understanding, appreciation, reasoning, and the expression of choice.¹³

2.3.1 | Understanding

Understanding consists of a patient's ability to understand the basic relevant information, including the nature of their condition, the proposed intervention, the alternatives available, as well as their risks and benefits, including no treatment.

2.3.2 | Appreciation

Appreciation consists of a patient's acknowledgement of their medical condition and the probable consequences of treatment options.

2.3.3 | Reasoning

Reasoning consists of a patient's ability to weigh the risks and benefits, and to reach a decision that is consistent with that assessment.

2.3.4 | Choice

Choice consists of a patient's ability to express a decision indicating a preferred treatment option.

In many cases, the decisional abilities of patients with age-related cognitive impaired diseases like Alzheimer's disease may depend on context and support. Patients may benefit from strategies to assist with the process of obtaining informed consent, such as timing, corrective feedback, plain language, and multimodal presentation of information, including summaries of information.¹⁴

2.3.5 | Timing

Because cognitive impairment can vary or wax and wane in individuals with dementia, one option is to schedule the informed consent discussion for a "good day," that is, when the individual demonstrates adequate understanding.¹⁵ This is a useful strategy, although it is not always feasible during emergency scenarios or when individuals refuse treatment.

2.3.6 | Corrective feedback, plain language, and multimodal presentation of information

Using visual aids, figures, and plain language can improve understanding.¹⁶⁻¹⁸ Also, an iterative process of repetition for assessing understanding, identifying areas of misunderstanding, and providing corrective feedback and summarizing information can improve the understanding and appreciation of the information given.^{19,20} However, as cognitive impairment progresses, these measures may no longer be effective.

2.4 | Making decisions for patients without capacity

If patients are still unable to meet the criteria for capacity despite such assistive approaches, someone else must speak on their behalf. First, if the patient had expressed clear wishes about their care in an advance directive prior to losing capacity, and/or had executed a durable power of attorney for health care naming an agent to speak on their behalf (this is often done as part of an advance directive), decisions in accordance with the advance directive or by their agent are understood to represent the patient's wishes. (Terminology for a person named to make decisions in a durable power of attorney for health care varies by state, such as agent, proxy, or representative). Periodontology 2000

In some, but not in all US states, if a patient loses capacity without executing an advance directive or durable power of attorney for health care, a "default" surrogate is empowered to make decisions on the patient's behalf. The order of default surrogacy also depends on the state; a typical ordering is: first the patient's spouse (if available); next an adult child; then a parent; then a sibling; or then a friend. In many states, default surrogates have more restricted decisional powers than agents named as a durable power of attorney for finances. For agents and default surrogates, their role is to make the decision that the incapacitated patient would make if they had capacity: this is known as "substituted judgment,"²¹ If patients had previously expressed wishes about their care, then executing these wishes may be relatively straightforward. In most cases, however, decision-makers must extrapolate from what is known about the patient's prior general values and beliefs to try and judge how patients would have chosen. If no such determination can be made, a decision may then be made by reference to the patient's "best interests," that is, the course of action judged as being best for the patient, even if it is not known whether that is the course of action that the patient would have chosen.

Finally, in some cases patients do not have a health care agent or default surrogate. This could be because a patient did not execute a durable power of attorney prior to losing capacity and lives in a US state without a default surrogacy statute, or because the patient has a health care agent or default surrogate who is unable to properly fulfill their role. In such cases, the court may need to appoint an individual to make decisions on behalf of the patient. Depending on the state, this appointee is called a guardian, a conservator, or a conservator of the person.

For unbefriended patients who are decisionally impaired and who have no living relative or friend, the dentist should consult an ethics committee before any dental care decisions are made.²² For unrepresented cognitively impaired and incapacitated patients lacking a surrogate, treatment teams should be multidisciplinary and understand the local ethics and laws. US state ethics committees are usually composed of members from diverse professional backgrounds, such as physicians, nurses, social workers, ethicists, and lawyers, to avoid unilateral decisions.²³

2.5 | Clinical cases and dental considerations

Because the US population is living longer, more patients are presenting to dental practitioners with the need for advanced dental reconstruction. Many individuals with years of denture wearing and concomitant resorbed alveolar bone in the maxilla and mandible experience difficulty with retention of their dental prosthesis and thereby speech and mastication. Thus, these individuals seek to improve this situation by requesting implant-supported dental prostheses. For healthy elderly individuals with no systemic or cognitive diseases or conditions, this process proceeds uneventfully. However, for those with systemic comorbidities, existing cognitive impairment, or subclinical and undiagnosed cognitive impairment,

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the course of treatment and outcomes may present significant challenges. In the three clinical case studies that follow below, some of these challenges are described, and additional considerations for dental and medical providers are discussed.

2.5.1 | Case 1: Aborting treatment and planning for a "dental surrogate"

A 76-year-old female presented with mild cognitive impairment. She presented for initial consultation and a request for reconstruction of the left maxillary alveolar ridge with dental implants (Figure 1). Her husband attended the initial consultation and he contributed to part of the conversation during the appointment. The conversation with the patient and her husband revealed that the patient was cognitively aware and ready to proceed with treatment. The husband reported that his wife was well aware of her situation and that her cognitive impairment did not limit her ability for making health care decisions. The patient did appear to be aware of her situation, and both she and her husband asked appropriate guestions about the advantages and disadvantages of treatment, as well as the time frame. Because the patient already had implants, placed on the right maxilla by another provider several years earlier, both she and her husband knew what to expect in the current procedure, as similar treatment would be performed. At a subsequent appointment approximately 1 month later, after the surgeon had obtained advanced radiographic images of the site and had consulted with the restoring dentist, the patient returned to the surgeon's office. However, during this appointment, it became clear that the patient's cognitive impairment had significantly progressed since the last appointment, and the husband expressed concerns about proceeding with the proposed dental implant treatment. Using the shared decision-making approach, conversations between the husband, patient, surgeon, and restoring dentist led to a decision to abort the proposed implant-based treatment, and instead not restore the site but proceed with a nonimplant-based removable partial denture. The latter did not require surgery and would give the patient a prosthesis that could be taken in and out of her mouth and allow for greater long-term oral hygiene access by the patient, or eventually by a "dental surrogate" if needed. A dental surrogate may be needed in the future to care for the other dental implants already in the patient's mouth, and for routine oral hygiene.

2.5.2 | Case 2: Objection to treatment despite progressing infection

A 72-year-old female presented with moderate cognitive impairment. She attended the initial consultation with her husband. Although the patient could explain to a limited extent the need for evaluation of her ailing and failing implants, her husband provided a detailed explanation of the situation; the patient was not a good dental historian. The husband explained that his wife's dental implants had been placed approximately 20 years earlier and that recently she had been experiencing problems with her implants, consisting of chronic inflammation, suppuration, and pain (Figure 2). He explained that, after multiple consultations with various surgeons and dentists, no one was willing to treat or address his wife's implant situation. He was also concerned that the chronic implant infection might have contributed to a worsening of his wife's cognitive impairment/ Alzheimer's disease over the last few weeks, concurrent with the exacerbation of the implant infection. This possibility existed given increasing evidence about the association between periodontal disease-associated bacterial pathogens and Alzheimer's disease²⁴; also, bacterial pathogens associated with periodontal disease, such as Porphyromonas gingivalis, are associated with peri-implant inflammation and disease.²⁵⁻³⁴ The situation was further complicated by the fact that the couple had to travel internationally within the month for urgent family reasons. The initial consultation led to multiple subsequent visits over the next few days to discuss the potential treatment of two ailing and failing implants, and to obtain dental and health records for further consultations. The discussions centered on the advantages and disadvantages of treatment, including the potential removal of one of the ailing/failing implants, which was at the floor of the nasal sinus. The patient returned several times, displaying varying levels of comprehension, and also making occasional objections to treatment. The husband tried to convince his wife that treatment of the dental implant infection was the way to proceed. On one of the appointment days, the patient presented with a clear understanding of the situation and requested to proceed with the treatment of the infected implants. It was therefore decided that treatment should proceed and the implants were successfully treated without a need to remove them. The patient was satisfied with the outcome in the end. However, this case illustrates the challenges and potentially difficult outcomes that cognitively impaired patients and their providers can face.

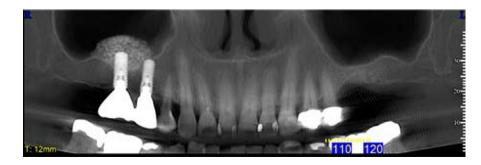


FIGURE 1 Radiograph showing the patient's maxillary alveolar ridge and dentition

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FIGURE 2 Surgical photograph showing bone loss around the infected dental implant crown

2.5.3 | Case 3: Failed treatment resulting in limited options for further dental reconstruction

A 68-year-old female presented with mild cognitive impairment and a history of breast cancer treatment. She also had a history of an unsuccessful bony reconstruction of the upper left maxilla with a history of maxillary sinus complications and infections. She presented with a request for dental implants but there was insufficient bone to place the implants (Figure 3). Given her previous complications and the mild cognitive impairment, the recommendation was to not proceed with a second attempt to reconstruct the maxillary bone. She was advised to proceed with a removable partial denture, even although the design would be complicated by having teeth on only the right side of her maxilla. The patient was not satisfied with the proposed plan and continued to request implant-based reconstruction.

2.6 | Complex dental reconstruction and ethical dilemmas

These cases highlight the challenges of navigating through complex dental reconstruction or treatment of elderly patients with cognitive impairment and further reveal that there are ethical dilemmas that emerge in these scenarios. Ethical dilemmas emerge in this context because of a variety of factors.³⁵ These factors include the finding that complex dental restorations in the elderly may adversely affect their quality of life when problems with the restorations arise. In addition, they may face chronic infections and pain from an inability to perform adequate oral hygiene around difficult-to-clean prostheses. When dexterity and cognition are limited, this becomes an impossible task. Surrogates may be called upon to perform daily oral hygiene, but this may not be adequate. Elderly individuals also experience higher rates of root caries caused by decreased salivary flow or dry mouth related to medications, cancer radiation affecting salivary glands, or other diseases (ie, Sjogren's syndrome), and exacerbated by sugary diets and poor oral hygiene. This again predisposes patients to pain and infections. When these decayed teeth fail and they are critical anchors for large fixed dental prostheses, a collapse of the dentition ensues. This tooth loss impacts the patient's ability to eat and speak and compromises their self-esteem. Many elderly people live in assisted living facilities where there may be limited access to dental care. Even elderly individuals living at home and with limited help may have limited access to dental care. Some elderly patients also face cancer-related sequelae, such as radiation-induced dry mouth and painful mucositis, and osteonecrosis. Because elderly people also frequently have several chronic diseases, such as diabetes, metabolic syndrome, or osteoporosis, the failure of complex dental reconstructions in these frail patients can be catastrophic. These conditions can lead to jaw fractures, explantation of failed implants with the removal of large amounts of alveolar bone, and an inability to reconstruct the dentition. This is further complicated by the need for several lengthy dental and surgical appointments, which present a greater financial burden. Thus, a consideration to avoid complex dental restorations and reconstruction that will require significant maintenance by elderly individuals, especially those with cognitive impairment, is warranted.

The issue of timing of treatment is another special consideration in this population, because implant reconstruction often takes months or a year to complete, and during that time a patient's level of cognition may decline significantly. This poses special problems in that the patient may be only partially restored and they may change their mind, or their level of understanding may decline midway. For

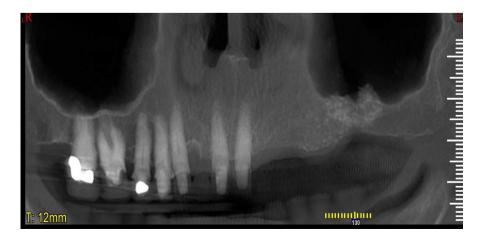


FIGURE 3 Radiograph showing the patient's maxillary alveolar ridge with bone graft material still remaining in the left alveolar bone site

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example, implants may be placed but not yet restored. This may warrant the use of "advance dental directives" so that a patient's wishes regarding their dental treatment are known in advance.

3 | CONCLUSIONS

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The growing number of elderly individuals with cognitive impairment and concomitant periodontal and dental disease presents unique challenges for dental and medical practitioners. It is difficult to address complications from complex dental reconstruction in this population. An ethical dilemma may arise, because when complex dental reconstructions fail they adversely affect the quality of life and health of this frail population. Therefore, complex dental reconstruction in these patients should be approached with caution or avoided. In addition to limited cognition, elderly individuals may also have limited manual dexterity, and thereby an inability to self-maintain, limited access to dental care, limited finances, and other medical conditions that further exacerbate their dental conditions, such as dry mouth, diabetes, cancer, or osteoporosis. Informed consent in this population presents with the need to assess decision-making capacity, the need for a health care agent or other decision-maker, and the potential for advanced dental directives. Emergency scenarios are especially challenging if patients object to treatment. Unbefriended patients and complex cases benefit from multidisciplinary teams. This information highlights that the dental profession will continue to encounter these challenging issues as the elderly population with the need for dental reconstruction or existing dental implants continues to grow.

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