ETHICAL ISSUES ENCOUNTERED BY DENTISTS
IN THE CARE OF INSTITUTIONALIZED ELDERS

by

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Abstract

Increasing numbers of institutionalized elders have very poor oral health. It has been suggested that ethical problems may influence dentists who attempt to provide oral care for these people, but little attention has been given to formal research in this area. A qualitative interview method was used to investigate the views and experiences of dentists working with institutionalized elders. Particular attention was given to the ethical difficulties encountered and how the dentists resolved them. Ten dentists experienced in long-term care were interviewed individually using open-ended questions. Verbatim transcripts were prepared from these interviews, and the dentists were interviewed again to validate a summary of their comments. An extensive thematic analysis identified that the dentists struggled primarily with practical rather than ethical problems. The ethical problems focused on the difficulty of identifying the wishes of patients or predicting the outcome of treatment. The participants reported few difficulties making clinical decisions in this setting, and it appeared that each participant had a consistent approach to resolving clinical problems. However, analysis revealed that the ethical perspectives of the dentists varied substantially. Variation was notable particularly in their preference for idealistic or realistic treatment and in their preference for autonomy or beneficence. The participants appeared to believe that the professional training of dentists promotes idealism and autonomy and that this may hinder decisions in a long-term care setting. Overall, this suggests that dentists might be better able to care for institutionalized elders if exposed to broader undergraduate instruction and experience in geriatric care.

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Chapter I

INTRODUCTION

THE PROBLEM

The need to provide oral care for institutionalized elders is increasing and it has been suggested that this presents dentists with challenging and perplexing ethical problems (Jong 1988, Pollick 1981, Schwartzheid 1989, Wettle 1987). This suggestion is not surprising given the recent proliferation of interest seen in the study of ethical problems in health science generally. However, there has been comparatively little written on dental ethics particularly as it relates to the care of institutionalized elders. Consequently, this study has been conducted to examine the ethical issues which dentists encounter when they enter the realm of long-term care institutions. The study was based on a qualitative method involving open-ended long interviews with dentists who had experience in caring for debilitated elders.

This chapter is designed to introduce: the problem, purpose of the study, and the significance of the problem; the concepts of health-care ethics, particularly in the context of dentistry; the rationale for the method, and a review of qualitative methodology. Readers familiar with the concepts of health-care ethics or of qualitative methodology may find it convenient to omit these sections.

PURPOSE

The purpose of the study was to discover: 1) the ethical issues influencing dentists in the care of institutionalized elders; and 2) how dentists cope with these issues.

SIGNIFICANCE OF THE PROBLEM

Three main issues highlight the significance of the problem. Firstly, there is a growing need to provide oral care for institutionalized elders. Secondly, there is evidence that the accessibility of dental care for dependent elders is poor, in part because of a lack of dentists willing to provide this

service. Thirdly, it seems reasonable to assume that dentists who attend long-term care facilities are confronted by a variety of ethical problems and that these problems impact the oral health of institutionalized elders, but this is not substantiated by research.

The growing need

The population is aging rapidly and the number of elders who are dependent on others is increasing. Furthermore, a growing number of this dependent population will retain their natural teeth into old age and require increasingly sophisticated dental care (MacEntee 1994).

Over three million Canadians, representing 12% of the population, are at least 65 years of age (Statistics Canada 1992, Cat. 93-310). This proportion is expected to increase to 15% within the next two decades, well before the "baby-boom" skews it even further (Statistics Canada 1991). The number of people who are at least 85 years-of-age, the old-old, is expanding at an even faster rate, with current expectations that their number will double within the next two decades (Statistics Canada 1991). Although most seniors live independently in the community (Statistics Canada 1992, Cat. 93-311), the rate of chronic disease and disability rises sharply with advancing age. Consequently, one in three of the old-old group requires institutionalization with some need for assistance to accomplish usual activities of daily living (Forbes *et al.* 1987). Those who need a moderate degree of daily assistance are classified in British Columbia, Canada, as being at an intermediate care level, whilst those who need assistance with most activities are classified as being at an extended care level.

Changing population demographics are placing increasing demands on health-care providers including dental professionals (Ettinger and Beck 1983, Niessen and Jones 1991). People are keeping their teeth longer as a direct result of an increased societal value placed on good oral health and on improvements in the prevention of oral disease. Ettinger and Beck (1983) point out that a growing proportion of elderly patients value oral health, so they expect the care of elders to become a larger focus of dental practise in the future. This supports the projection that an

increasing proportion of institutionalized elders will also retain their teeth and become more demanding of dental services in the future. As yet, however, there is little longitudinal data to support this projection (Berkey *et al.* 1991). Institutionalized elders generally have very poor oral health (Berkey *et al.* 1991, Drake *et al.* 1990, Gordon and McLain 1991, MacEntee *et al.* 1985, Shay 1990, Vigild 1989). This may have a detrimental effect on their general health and quality of life (Ettinger 1987, Heyink and Schaub 1986, Idowu *et al.* 1987, Kiyak and Mulligan 1987) with at least one suggestion that chronic oral infections can hasten death (Limeback 1990). Furthermore, there is evidence that many institutionalized elders appear to accept the deterioration of their oral health (Ettinger *et al.* 1988, MacEntee *et al.* 1991, Mojon and MacEntee 1992, Vigild 1993) although the reasons for this are unclear.

Poor access to dental services

Despite the need for oral care, many disabled groups have poor access to dental services (Berkey 1987, Burtner *et al.* 1990, Krust and Schuchman 1991) possibly because the number of dentists willing to provide such service is inadequate (Kerr 1982, Kiyak 1988, MacEntee 1992, Weiss 1993). Fishman (1989) speculates that poor access to oral care for elders is due either to the ageist stereotypes of dentists, or to the idea that dentists prefer the apparent success of treating a healthy person, to the apparent failure of witnessing the slow deterioration of oral health for an institutionalized elder. According to a recent study (MacEntee *et al.* 1992, Weiss *et al.* 1993) most dentists are trained to serve the needs of a healthy and wealthy population. The study demonstrates that dentists feel inadequately trained to work in long-term care facilities and, moreover, that they are unlikely to provide this service if it detracts from leisure or income. On the other hand, it was noted that the few dentists who did offer long-term care service were motivated to do so out of a sense of professional responsibility, often at a reduced fee.

Lack of research into ethical problems

Despite suggestions that the oral care of debilitated elders presents dentists with difficult ethical problems resulting particularly from the difficulty in determining the extent of treatment which is appropriate, (Jong 1988, Pollick 1981, Schwartzheid 1989, Wettle 1987) there has been little written on the subject. What has been written is based largely on legal and philosophical opinions. Research into dental ethics is lagging far behind that of other clinical disciplines, especially medicine (Bebeau 1985, Odom 1982). One particularly difficult issue with ethical overtones is that a substantial proportion of institutionalized elders have cognitive deficits, and it has been suggested that this influences the care which should be provided for them (Budtz-Jorgensen 1986). However, it remains unclear the extent to which a patient's cognitive deficit should alter their care. The reference list attached contains, among other items, a majority of the articles written on dental ethics as related to the care of institutionalized elders. The dearth of writing on dental ethics points out clearly that this subject is in its infancy and there is room for substantial development.

REVIEW OF HEALTH-CARE ETHICS

This section is designed to familiarize readers with the basic concepts of health-care ethics to provide a framework in which the findings of the study can be viewed. Two subjects will be addressed: firstly, an introduction of ethical problems in the biomedical context; and secondly, a review of potential strategies for the resolution of ethical problems.

Ethical problems in the biomedical context

Ethical problems in health care arise when a decision must be made in the context of an unresolved moral tension between alternative choices (Purtilo and Cassel 1981). When confronted with an ethical problem a clinician must be able to weigh the important information and decide what ought to be done from a moral perspective. Ethical decisions involve the systematic use of theoretical ethics in making moral judgements (Mappes and Zembaty 1991). This process can be

difficult because there are divergent opinions as to the best theoretical basis for such decisions. Ethical questions sometimes have two or more potential but conflicting solutions, and there is no absolute ethical authority to turn to for resolution (Rule and Veatch 1993).

Historical perspectives on health-care ethics

Two main approaches to judging the ethical rightness or wrongness of actions are consequentialism and deontology. *Consequentialism* is focused exclusively on the goodness and badness of the consequences of a choice (Mappes and Zembaty 1991). The most widely accepted consequentialist theory is *utilitarianism*. Utilitarians consider an action right if it produces the most good for the greatest number of people as compared to alternative actions (Rule and Veatch 1993). In contrast, *deontology* is focused not only on the consequences of an action, but also on the moral nature of the action (Mappes and Zembaty 1991). In this tradition Immanuel Kant argued that human beings are not only to be treated as the means to a good end but they should also be treated as ends in themselves (Mappes and Zembaty 1991). *Kantian ethics* places respect for the individual above all else. Among other absolute duties, it mandates that we never lie to or kill people, despite the consequences.

Use of principles in health-care ethics

Common wisdom in health care today does not support either a purely utilitarian or a purely Kantian approach, because they are considered by many to be counter-intuitive. Kantian ethics is excessively rigid when it tells us that certain actions are always right or wrong. Utilitarianism is excessively flexible, directing one to do anything if only the consequences are good enough. The dominant method of making moral decisions in health care over the past two decades has been in terms of the so-called "*principles of biomedical ethics*": *nonmaleficence*, *beneficence*, *autonomy*, and *justice* (Beauchamp and Childress 1989, Purtle and Cassel 1981). Each principle states a specific duty - a *prima facie* duty - which mandates a specific choice of behaviour in the absence of

a conflicting duty (Mappes and Zembaty 1991). *Nonmaleficence* tells us that we ought to "above all, do no harm" (Gadow 1980, Rule and Veatch 1993). *Beneficence* tells us that we ought to remove harm, prevent harm, and promote good (Beauchamp 1985, McCullough 1985, Rule and Veatch 1993). *Autonomy* tells us that we ought to respect a patient's or surrogate's wishes (Beauchamp 1985, Gadow 1980, McCullough 1985). *Justice* tells us that we ought to distribute benefits and burdens fairly (Beauchamp 1985, Rule and Veatch 1993).

Ethical problems: Ethical dilemmas or unclear facts?

The most typical type of ethical problem discussed in the literature is an *ethical dilemma* which arises when ethical principles are in conflict with each other (Mappes and Zembaty 1991). There is, of course, no ethical dilemma if all duties point to only one morally correct choice (Odom 1982). The other type of ethical problem in health care may result when there are *unclear facts* that make it difficult to apply pertinent principles. It is not clear that this is truly an ethical problem, but unclear facts, such as an unpredictable treatment outcome or indeterminate patient wishes, create unresolved moral tension between possible treatment choices - an ethical problem. This problem was described by Purlilo (1991) when she suggested that the major source of ethical problems in the rehabilitation of debilitated elders arises from difficulties in determining the kind and amount of care required.

Issues of autonomy, paternalism, competence, surrogate decisions, and informed consent

Simplistically, a person is either completely autonomous or completely dependent. Ideally, autonomous people are always able to act thoughtfully and intentionally with adequate information (Rule and Veatch 1993). However, even the most autonomous person will occasionally make decisions that do not reflect this ideal, notably when information is missing or when internal factors, such as pain, distort their ability to reason (Rule and Veatch 1993). Given these circumstances, it is probably better to consider most people to be *substantially autonomous*, rather than absolutely so.

On the other hand, an elderly person with early Alzheimer's disease may not be able to balance their cheque-book, although they can decide on what to have for lunch. It may be better to think of this individual as *partially autonomous*.

Paternalism is the idea that we can interfere with the wishes of others provided it is in their best interest, i.e., to maximize good consequences (Beauchamp and Childress 1989, Young 1982). Paternalism is either weak or strong. *Weak paternalists* hold to the view that interference is justified only when a person is *incompetent*, i.e. for those who are cognitively or emotionally unable to understand the nature and consequences of their decisions (Beauchamp and Childress 1989). Weak paternalists wish to educate, but not interfere with, or coerce, a substantially autonomous and competent person, regardless of the risks. Likewise, *strong paternalists* will interfere with an incompetent person, and they will try to educate a competent person. However, if their educational efforts fail and there is risk of serious harm to a competent person strong paternalists may choose to coerce or interfere with the person (Beauchamp and Childress 1989). The debate between weak paternalists and strong paternalists hinges largely on the definition of competence. Clearly, an unconscious person is incompetent and a weak or strong paternalist would justify treatment when deemed necessary. If, however, the definition of incompetence is expanded to include substantially autonomous people who are deemed unable to make a decision due to physical or emotional pain, then the debate becomes much less clear.

It is generally accepted today that weak paternalism is preferred, and thus a competent person should always be allowed to make decisions without interference. If a person is incompetent then someone else must make the decisions, usually by agreement between the health-care provider and a surrogate who acts as an advocate for the patient. The decisions made are based preferably on a *substituted judgement*, i.e., from the perspective of what the particular patient would have wanted (Beauchamp and Childress 1989). If this is impossible then the decision is based on a *best-interest judgement*, i.e., from the perspective of what most patients would decide given similar circumstances (Beauchamp and Childress 1989).

The dominance of weak paternalism exemplifies a dramatic and recent shift in moral values in health care. Beauchamp and McCullough (1991) distinguish between the traditional *beneficence model* of moral responsibility, and the more recent *autonomy model*. In brief, the *beneficence model* bases moral decisions on the tradition of the Hippocratic Oath. It gives primacy to the promotion of the patient's best interest and has a long and established history in medicine. It aims to uphold the consequentialist principles of nonmaleficence and beneficence. In stark contrast to this tradition, is the recent development of the *autonomy model*, which bases moral decisions on the promotion of the patient's values and beliefs. It aims to uphold the non-consequentialist principle of autonomy. Recent legal support for human rights has imposed a dramatic shift on the moral basis of medical decisions such that the *autonomy model* now dominates the norms of medical practise.

Regardless of whether a patient or surrogate is making the decisions, the legal requirement for *informed consent* demands that competent decision-makers must be fully informed of all treatment options and risks before any treatment begins (Litch and Liggett 1992, Meisel *et al.* 1977, Odom *et al.* 1992, Segal and Warner 1979). For consent to be valid, all information must be provided without coercion (Mappes and Zembaty 1991). Informed consent is not without difficulty. There is some disagreement over what information must be disclosed for a consent to be valid. There can also be some difficulty in distinguishing informed from coerced. Moreover, there is evidence that even healthy people cannot recall accurately the details of an informed consent (Stanley *et al.* 1984, Taub *et al.* 1981, Tymchuk *et al.* 1988). Nonetheless, informed consent provides the only way for the patient's perspective to be included in decisions (Cassileth *et al.* 1980).

Issues of truth-telling

Without accurate information, no person can make informed treatment decisions. Not surprisingly, *truth-telling* is an absolute prerequisite for a substantially autonomous person to give a valid informed consent. Yet, until recently it was considered a doctor's duty to *lie* to or *withhold information* from a patient if it was in the patient's best interest (Rule and Veatch 1993). Although

support for such approaches has dwindled in the past twenty years, situations still arise in which lying to or intentionally withholding information from a patient may be the best choice. The most obvious example of this is seen when information is withheld from an incompetent patient in their best interest. Further complicating the discussion, some argue that lying is worse than simply withholding information because lying can undermine the trust between people where underinforming is less likely to do so (Mappes and Zembaty 1991). The current medical model of weak paternalism will invariably disagree with either lying to or underinforming a substantially autonomous person. On the other hand, strong paternalists will lie to or underinform competent patients in situations where they have no other option to prevent a serious harm to that person.

Issues of resource allocation

Resource allocation in health care is considered on three levels: macroallocation, mesoallocation, and microallocation. *Macroallocation* of resources refers to the allocation of resources at the societal level. It is the process of determining firstly, the proportion of total societal resources which should be devoted to health care, and secondly, the way these resources should be divided in health care (Rule and Veatch 1993). The question of macroallocation is particularly contentious in the context of health care at present with the financial constraints imposed worldwide. The health-care budget of any country is limited and scarce resources must be rationed at some level. Rationing can result from a government policy, from the actions of institutions within the health-care arena, or from the actions of individual practitioners who decide which patients get treated (Rule and Veatch 1993). Rationing raises the issues of *mesoallocation*, and *microallocation* of resources, where resources are allocated at the level of an institution or an individual practitioner respectively (Rule and Veatch 1993). The ethical principle of justice influences the debate substantially, but the solutions remain far from evident because there are many conflicting opinions on the concept of justice.

Strategies for resolution of ethical problems

There have been a number of influential strategies designed to resolve ethical problems. The strategies are all controversial and there is no preferred approach. A sample of potential strategies is presented here to demonstrate some of the arguments.

Resolution of ethical dilemmas

Veatch (1985) has described four potential strategies to resolve ethical dilemmas, i.e., to resolve conflicts between ethical principles. The first is to order the principles in a *hierarchy* where, for example, it is decided that nonmaleficence will always override beneficence, which in turn will override autonomy, which in turn will override justice. Unfortunately, there is no consensus on the order of priority so this approach may be impractical. Indeed, the preferred order will be very dependent on one's theoretical perspective and on the details of the individual situation. The second strategy begins with the assumption that the principles are equal and infers from the details of the individual situation the importance and impact of the principles on the decision. This is sometimes termed a *considered decision*. As described previously, each individual principle implies a *prima facie* duty which is obligatory in decisions unless a conflicting duty is considered more important. The considered decision can be very effective in the resolution of dilemmas, but Veatch argues that it can be used to justify almost any choice, including the sacrifice of an individual's welfare, even their life, in favour of the general welfare of a society. The third strategy reduces all principles to the goal of *maximizing good*. This is discounted by Veatch (1985) because it essentially disarms all principles except beneficence, and so allows for the sacrifice of individual rights in aid of societal ends. The remaining strategy described by Veatch (1985) is a *non-consequentialist dominant hierarchy*. This strategy differentiates the two non-consequentialist principles of autonomy and justice as being of a higher priority than the two consequentialist principles of beneficence and nonmaleficence. The non-consequentialist principles are considered equally in decision-making, and the consequentialist principles are used only to assist in resolving

remaining conflicts. Veatch argues that this is a morally defensible strategy because it protects individual rights from domination by the rights of society at large.

There are at least two other strategies to consider: casuistry, and randomization. *Casuistry*, or *case comparison*, is best compared to the common-law method of decision-making. Like common-law, it recommends making decisions by inference based on a similar case for which the moral arguments are clear (Jonsen *et al.* 1986, Strong 1988). *Randomization* is a deliberate plan to make decisions by random selection. This should only be used in a situation where, after a careful assessment, the potential options have equal moral legitimacy. This strategy cannot be used indiscriminately. All ethical dilemmas are difficult, but this does not imply that they are best resolved by randomization.

Resolution of ethical problems resulting from unclear facts

The resolution of an ethical problem resulting from unclear facts in a situation may be more problematic than resolving an ethical dilemma. With a dilemma one can usually separate out individual arguments to assist in structuring a plausible solution, but with a lack of clarity in facts the process becomes more difficult. If, for example, the outcome of treatment is unpredictable despite a careful examination of the available evidence, then to proceed is a bit like trying to cross a street with a blindfold on. One may be able to make the right choices based on experience and intuition, but is it worth the risk of failure? Ultimately, factual problems are best resolved by good science (Rule and Veatch 1993). Unfortunately, many of the facts surrounding health care remain unclear despite the progression of health science research. But decisions must still be made everyday. Apprised of the available information, as unclear as it may be, decision-makers may need to resolve these problems by making their best educated-guess of the factual questions.

ETHICS IN THE CONTEXT OF DENTISTRY

Contrast of ethical problems in medical and dental practise

Despite the predominance of the field of medicine in the study of health-care ethics, such study pervades all aspects of health science, including the practise of dentistry. Closer examination reveals that the ethical implications of acute-care medicine are very different from those of a typical dental practise. In the medical setting, interventions often involve life and death decisions leading to some of the most widely publicized and complex bio-ethical dilemmas encountered. Consider the wrenching struggles involved in the practise of assisted suicide or the gender selection of children. Another well known ethical dilemma in acute-care medicine occurs when parents refuse a blood transfusion for a child on religious grounds. The medical tradition mandated by Hippocrates obliges the doctor to treat the child regardless of the parent's wishes (Gurley 1961, Purtilo and Cassel 1981), but a recent shift in western values discourages this approach leaving the physician with a life and death dilemma. On the contrary, dental practise mandates oral care which is aimed often at the management of chronic diseases and developmental conditions which are not usually life-threatening (Davis 1980). Treatment is generally elective so the dentist is rarely in a position to make a choice against the wishes of a patient or surrogate. Consequently, ethical dilemmas may be less easily recognized in dentistry because patient autonomy is usually paramount. However, dentistry is not without ethical problems because absolute patient autonomy is only an ideal and the dentist will generally influence a patient's decisions profoundly (Sadowsky 1979, Segal and Warner 1979).

The role of research in the study of dental ethics

Empirical social science research can be used to examine any social phenomena including the ethical problems encountered by dentists in the care of institutionalized elders. However, the role of empirical research in resolving such problems is not clear. Ethical problems have been debated for centuries, so they cannot be resolved by simply surveying the electorate for their opinions. Nonetheless, empirical research has at least two legitimate roles in the study of ethics in

dentistry. It can uncover the situations which give rise to ethical problems, and the ethical standards of dentists (i.e., how sensitive dentists are to ethical problems, and how they think and behave in response to these). Once this information is gathered it becomes possible to compare and contrast the thoughts and actions of dentists with the study of theoretical bio-ethics.

Only one recent study has been found that aimed to uncover situations which give rise to ethical problems in dentistry. It resulted in the collection of over one hundred ethical problems identified during an extensive literature search and a series of interviews with practising dentists (Rule and Veatch 1993). The information is comprehensive, including a brief discussion of surrogate involvement in treatment decisions for incompetent patients. In this regard, the authors discussed specifically an ethical problem which arose when a surrogate insisted on only limited treatment for a child while neglecting other aspects of the child's oral health. However, there was no discussion of the ethical issues involved with the care of incompetent or institutionalized elders.

There have been three studies in recent years aimed at uncovering the ethical standards of dentists. All three were exploratory studies examining either dental student or dentist responses to hypothetical ethical dilemmas. Firstly, Green (1981) found, contrary to established theories of moral development, that the level of principled moral reasoning among dental students, as they measured it, decreases during the four years of a traditional dental education. The study was conducted using only questionnaires and no attempt was made to measure the behaviour of the students, so it is difficult to know how these results reflect the actual ethical practice of dental students. Secondly, Bebeau *et al.* (1985) demonstrated, not surprisingly, that dental students can learn to manage theoretical ethical problems. From this, they have developed ethics teaching programs for dental education. The consequence of teaching ethics to dental students has not been determined. Lastly, Hasegawa *et al.* (1988) examined the ethical perceptions of dentists and discovered that experienced dentists tend to identify perplexing clinical problems as essentially ethical issues, whereas, younger dentists are more likely to perceive such problems as legal issues. Law is an approximation of societal ethics so it is not surprising that ethical dilemmas are viewed by some as

having strong legal implications. Although these studies do not examine any issues in relation to the care of elders they certainly demonstrate a considerable variation in dentists understanding of ethical issues. This implies that dentists may benefit from educational exposure to the subject of bio-ethics.

A recent study which relates indirectly to ethics in the oral care of elders was conducted by Warren *et al.* (1992) when they examined the determinants of surrogate consent in long-term care facilities. They found that most of the decisions were made exclusively or primarily by next-of-kin or guardians because the residents usually had cognitive impairments. Acceptance of treatment was high for residents with guardians who were not family members or when the guardians were young or highly educated. Acceptance was usually low if a spouse was the decision-maker. The authors did not address the results from an ethical perspective. However, there is a notable assumption in the study that the refusal of treatment is a problem which needs to be corrected rather than accepted as a natural consequence of the process of informed decision-making. The authors conclude that there is a case to be made for educational efforts aimed at improving the knowledge of surrogates. Although, the complexity of the ethical aspects of the decision-making process remain unclear in this study, the findings suggest indirectly that institutionalized elders present ethical problems because of their reduced capacity to act autonomously. It is likely that there are other ethical issues which complicate the decisions relating to this growing segment of the population (Moody 1988, Ozar 1985).

INTRODUCTION AND RATIONALE OF THE METHOD

The study of ethical issues encountered by dentists can be conducted with social science research. Social science research methods operate on a continuum, with an experiment in an artificial setting on the quantitative end, and ethnographic participant-observation in a natural setting on the qualitative end (Field and Morse 1985, Patton 1990). Between these extremes the methods blur even though the underlying methodologies remain distinct. *Quantitative methods* are based on a *positivistic* approach arising from the empirical model in the natural sciences (Babbie 1992).

Established theories and hypotheses are tested deductively with a large group of subjects selected from a defined population. Results are expressed with *numerical descriptions* often using *statistical analysis* to demonstrate causal relationships between measured variables. In addition, it is usually possible to make a *statistical generalization* of the results to the population. In purely experimental research, subjects are exposed to specific interventions in an artificial setting, and instruments are designed to measure the impact of the intervention. This type of research demands that the researcher have substantial knowledge about the subject area. *Qualitative methods*, on the other hand, are based on a *naturalistic* approach arising from a family of related holistic methods (Locke 1989, Patton 1990). The general aim of qualitative research remains discovery rather than verification (Bryman 1983), and it is best suited to the study of complex areas of social inquiry about which little is known (Field and Morse 1985). Generally, researchers become closely involved with a small group of knowledgeable participants from which they can inductively develop hypotheses and theories about social phenomena. Results are usually derived from a *thematic analysis* of the information collected. Subsequently, the results may be *generalized analytically* to similar social contexts (Merriam 1988).

There is a dearth of hypotheses and theories on which to base a quantitative study of the ethical issues encountered by dentists in the care of institutionalized elders. Consequently, a qualitative case-study design was selected to conduct this research because it offered the greatest opportunity to investigate a subject about which very little is known (Field and Morse 1985, Yin 1989).

The two major techniques used in the conduct of qualitative research are *observation* and *interviews*. Observation is the prime technique used in anthropological qualitative studies. This is true especially at the outset of these studies because most commonly the researcher cannot speak the language of the subjects being observed. The interview is also a very useful technique, particularly when the researcher has developed a collegial relationship with the subjects. Combining the techniques is the most costly, and McCracken (1988, p.10) notes that although this has "the

power to take the investigator into the minds and lives of the respondents, to capture them warts and all... few respondents are willing to sit for all the hours it takes to complete the portrait". When used appropriately, it is accepted that interviews alone can be valuable and very cost effective (Agar 1980, McCracken 1988).

METHODOLOGY

This section is designed to familiarize readers with the basic methodology supporting the use of interviews in qualitative research. Three general subject areas will be addressed: firstly, an introduction of the long interview as a research technique; secondly, a discussion of the constructed nature of qualitative findings; and finally, a review of the concepts of trustworthiness and measurement in qualitative research.

The long interview

McCracken (1988) describes a technique termed the *long interview*. Typically, it is an open-ended conversational interview, unlike the highly structured social survey questionnaire commonly used in quantitative research. The interviewer attempts to find out from the participant "those things we cannot directly observe" and how they "have organized the world [mentally] and the meanings they attach to what goes on in the world" (Patton 1990, p.278). According to Field and Morse (1985), a qualitative interview should begin with familiar background questions, such as those on basic demographics and knowledge, and later the interviewer can progress to more specific and demanding questions. This progression is important because the conversation is likely to be polite and relatively shallow at the beginning, whereas the participant may be more comfortable in expressing deeper and richer thoughts after some time.

The construction of truth

The logical challenge to the use of interviews in qualitative research is expressed in a single question, *How do you know that the person being interviewed is telling the truth?*, and the answer is, *You do not and cannot* (Dean and Whyte 1970). This question is based on the mistaken assumption "that there is some underlying attitude or opinion that the person is firmly committed to, i.e., his *real* belief. And it implies that if we can just develop shrewd enough interviewing techniques, we can make him 'spill the beans' and reveal what his basic attitude really is" (Dean and Whyte 1970, p. 119). Failure to recognize that this cannot be done is the fallacy of *naive realism*. According to Lincoln and Guba (1985), naive realism is the view that at any point in time there is only one version of *social reality* and it can be documented in an absolute fashion. They argue that social reality is dependent on an ever changing social context in which people live, and therefore it is best thought of as a multiple set of mental constructions rather than a singular definable construct. Merriam (1988) suggests that *multiple constructed reality* is an attempt to name the complexity of social reality. It is a recognition that many people hold conflicting views, that some views may not be as firmly held as others, and that the views people express in one social context may be different from the views they express in another. It is also a recognition that the documentation of social reality in a research setting is a construction of both the participant and the researcher. Clifford (1986, p. 7) recognizes that attempts to represent the reality of others can claim to produce only "partial truths", or part of a larger picture.

Trustworthiness and measurement

Effective qualitative social research depends on careful attention to a trustworthy method centred around issues of *measurement*. Quantitative methods often focus attention on the interrelated issues of the instrument's *resolution, precision, accuracy, validity, and reliability*. In qualitative methods the researcher is the measurement instrument, a view that has been challenged on the basis of its *subjectivity* and lack of attention to *rigorous measurement* (Krefting 1991). Agar

(1986) in response to such criticism suggests that the criteria used to establish rigor in quantitative methods do not fit the need for rigor in qualitative methods. According to Lincoln and Guba (1985), rigor, in their term "*trustworthiness*", is established primarily through careful attention to *truth value*, *applicability*, *consistency*, and *neutrality*.

Truth Value: Internal Validity and Credibility

Truth value represents the confidence which can be placed in the results of a study. It is associated closely with *validity*. Although validity is multidimensional, it refers, essentially, to the determination of whether one actually measures what is intended to be measured (McAuley, 1987), and in quantitative research it is usually referred to as *internal validity*. Internal validity is the extent to which dependent (outcome) variables are predictably influenced by independent (researcher controlled) variables (McAuley, 1987). However, it is entirely dependent on the researcher's understanding of the relationship between the measurement instrument and what is being measured. It cannot be demonstrated mathematically. Lincoln and Guba (1985) argue that this is precisely the point where quantitative research is weakest. Firstly, they argue that quantitative researchers frequently do not know the real nature of the social variables that they are measuring. Hence they rely on an approximation of internal validity, or worse, they ignore it all together, concentrating instead on the mathematically demonstrable criteria of reliability. Secondly, they indicate that quantitative social research is generally undertaken with the philosophical assumption that there is only one measurable and valid social reality - naive realism. However, reality is not this simple.

Qualitative inquiry does not aim to establish a causal relationship between variables, rather it aims to represent and interpret social reality in the context and terms of the participants (Field and Morse 1985, Hutchinson and Wilson 1992). Consequently, the truth value of qualitative inquiry cannot be established with the conventional aim of internal validity. Lincoln and Guba (1985) equate truth value in qualitative research with *credibility*, which they say can be established by adequately representing the subject's multiple constructed realities, while recognizing and documenting that the

findings are also constructed in part by the researcher. Specifically, credibility can be enhanced with *prolonged engagement*, *persistent observation*, *triangulation*, *reflexivity*, and *member checking*.

Prolonged engagement requires that researchers spend enough time with the participants to build trust, to learn their thoughts and activities, and to test for misinterpretations. Prolonging the length of engagement will improve the possibility of collecting valid and more complete information, thus enhancing credibility.

Persistent observation relates to the need for researchers to identify and observe carefully only relevant details, while simultaneously resisting the temptation to prematurely restrict the study's focus and risk missing key information. In studies involving interviews, credibility can be enhanced by allowing participants to control the direction of the conversation, rather than having the conversation restricted unduly by the researcher. A specific way to enhance the credibility of interview data is to use an electronic recording device such as an audio or video tape-recorder (Patton 1990).

Triangulation is the use of multiple perspectives to corroborate findings (Merriam 1988). *Multiple methods* refers generally to the use of multiple techniques, such as interviews and observation, to collect information and to improve the credibility of the research. Using *multiple sources* of information can also enhance credibility. Although the participant is usually the primary source of information, newspaper articles, professional records, diaries, or other personal collections can expand and corroborate the story as it unfolds. Using *multiple theories* reflects the value of examining the findings in conversation with theories already in existence.

Reflexivity is the process by which researchers recognize, document, and report how their own background and perceptions influence the process and findings of the study. Reflexivity influences all aspects of trustworthiness, not just credibility (Hammersley and Atkinson 1983). One of the more serious threats to the credibility of qualitative research occurs when researchers becomes so close to the research that it becomes difficult for them to separate their own views and experiences from those of the participants. Keeping a detailed *reflexive journal* of the activities of

the entire research process including day to day perceptions, hunches, and biases is the usual method recommended to counteract this threat (Lincoln and Guba 1985).

Member checking involves the participants in the interpretive process (Merriam 1988). Participants are asked to examine transcripts and fieldnotes or, more typically, they will examine summaries of the findings and interpretations and even tentative conclusions. This allows the participants to validate the information collected and to modify it if necessary.

Applicability: External Validity and Transferability

Applicability is the extent to which a study's findings are applicable in other similar contexts. Applicability is associated with *external validity*, which, in a quantitative sense, is the approximate extent to which established causal relationships between measured variables in a *representative sample* are applicable to the wider population from which the sample was drawn (LeCompte and Goetz 1982). External validity represents the extent to which the findings can be *statistically generalized* to the population. In the social sciences this is accomplished by the selection of a large random sample of subjects. The closer the research conditions are to the natural context of the population the better the external validity. Conducting research in natural conditions makes it more difficult to control and measure confounding variables, so, although external validity may improve, internal validity tends to be threatened. In contrast, under controlled experimental conditions, the external validity, or the ability to generalize the findings, tends to suffer.

In contrast, qualitative research is carried out with very different assumptions and aims. A small number of participants are selected because they are able and willing to share knowledge. McCracken (1988, p. 17) suggests "it is more important to work longer, and with greater care, with a few people than more superficially with many of them". Statistical generalization is not part of qualitative research, consequently, conventional external validity has no meaning in this context (Merriam 1988). Lincoln and Guba (1985) indicate that a better term to represent the applicability of qualitative findings is *transferability*, which is the extent to which categories and hypotheses resulting

from the study can be *generalized analytically* to a similar social context. Although, in an absolute sense, this is impossible because no two social contexts are identical, the findings usually offer some transferability. It is researcher's responsibility, therefore, to document in detail the context of the study so that other researchers can assess similarities and differences with the context in which they wish to apply the findings (Krefting, 1991).

Yin (1989) states that a major aim of qualitative inquiry can also be the *analytic generalization* of particularistic results to general theory. This is the inductive heart of qualitative inquiry. To improve the strength of generalization in cases studies, Yin (1989) suggests conducting several independent case studies which by *replication logic* will support the results.

Consistency: Reliability and Dependability

Consistency is a relative estimate of whether a study's findings can be replicated given the same or equivalent participants in the same or equivalent context (Lincoln and Guba 1985). In quantitative research, consistency is referred to as *reliability*. Lincoln and Guba (1985) argue that there is a serious problem with the concept of reliability in the social sciences because of *naïve realism*. Reliability is borrowed from the natural science model of investigation where objects have a more concrete and consistent nature than do social phenomena. Ultimately, the social scientist errs by using tests of reliability which presume the existence of a singular social reality at any point in time. In qualitative research the investigator is the measurement instrument and the research setting becomes a complex interaction between the researcher and the participant in a unique setting which is not likely to be reproducible. Lincoln and Guba (1985) recommend that the consistency of qualitative inquiry be better termed *dependability*. Dependability does not claim to represent the reproducibility of findings but rather the care and attention given to the research process. All of the techniques used in establishing credibility and transferability (i.e. validity) simultaneously establish dependability. Although qualitative researchers are not rigid and perfect instruments, they can improve their *consistency of technique* through training and practise (Merriam 1988). Consistency

can be demonstrated by keeping highly detailed notes throughout the research process - the *reflexive journal* - for audit by an independent researcher.

Neutrality: Objectivity and Confirmability

Neutrality is an estimate of the extent to which the findings represent the social reality of the participants in context rather than the perspectives and biases of the researcher. In quantitative social research neutrality is spoken of as *objectivity*. Objectivity requires that the researcher remain distanced from the subjects. This may be accomplished using a social survey. A qualitative method, however, acknowledges that findings are not distant and objective, rather, they are subjective and multiple constructed realities. On the other hand, Lincoln and Guba (1985) indicate that neutrality is still a necessary goal which can be demonstrated through *confirmability*.

Confirmability is a process by which an independent researcher acts as an auditor. The auditor needs all of the research records, including preliminary information, research proposals, interview guides, literature reviews, original tape recordings, transcripts, fieldnotes, data reduction analyses, reconstruction analyses, reflexive journals and any other information which is directly or indirectly related to the inquiry (Beck 1993, Lincoln and Guba 1985). The rigor established throughout the process will improve the relative neutrality which can be reported by the auditor. It is, however, apparent that this is an expensive process which may be better accomplished, as in other forms of research, by subjecting the results to the peer review which occurs with publication in a refereed journal.

Chapter II

METHOD

RESEARCHER AS MEASUREMENT INSTRUMENT

In naturalistic inquiry the researcher is the measurement instrument, and the results are a construction of the interaction between the researcher and the participants. This process cannot be completely objective, so it is important that the researcher be included in the process of writing. I am the researcher and so I will introduce myself and then the method I used to conduct the study.

Foremost, I am a student and a dentist interested in the social context of dentistry. I have not worked with institutionalized elders, but before embarking on this project I worked for several years as a dentist with the First Nations people of the Blood Tribe in Southwestern Alberta. In my five years with the Bloods I witnessed the poor and sometimes tragic social and economic circumstances in which some of them live. I also witnessed an increasingly educated and determined people grappling with regaining control of their health, education and culture. If nothing else, this experience taught me to see oral health as a small part of the larger picture of life. During this time, the priorities and values of my patients became increasingly important in my clinical decisions. I believe that this experience made me acutely aware of ethical concerns in society and specifically in health care.

I used a qualitative case study method to investigate the ethical issues which dentists encounter in the care of institutionalized elders. The method was borrowed primarily from the case study design outlined by Merriam (1988), Patton (1990), and Yin (1989). According to Yin (1989) the qualitative approach to case studies relies on the collection of data through direct observation or systematic interviewing in a natural setting. In this study I used open-ended long interviews to construct case studies of ten dentists experienced in the care of institutionalized elders.

Qualitative methods are complex and therefore difficult to document concisely. This complexity is evident especially in the overlap between the collection and analysis of data, quite

unlike quantitative methods where data analysis begins usually after the data are collected (Merriam 1988). In addition, the method is complex in that it emerges during the research process.

PLANNING

Interview protocol

In preparation for this research I designed a protocol for use in conducting the interviews. The primary part of the protocol was the interview guide which I formulated with open-ended questions in three parts (Appendix A). Patton (1990) notes that the *guided interview* is a valuable way of encouraging participants to discuss specific opinions and experiences along a particular line of inquiry. Although the technique is designed to put many of the same questions to each of the participants, it is not intended to make interviews exactly alike (Feldman 1981). My intention was to use the guide to keep the discussions centred on ethical issues, but also to allow the participants latitude in directing the discussion. As recommended by Armstrong (1987), *Part One* of the interview guide contains *standardized and structured demographic questions*. I asked these during the initial phone conversation with most of the dentists. When this was not possible I asked these questions at the start of the formal interview. Not only did this enable the collection of valuable background information from the participants, it also provided an opportunity for me to develop a conversational ease with them and it helped to confirm the value of their experiences for the purposes of my research. *Part Two* of the guide contains a series of relatively *unstructured open-ended questions*. I designed this section to help guide the largest part of the discussion in search of the participant's important knowledge, experiences, opinions and feelings related to my general line of inquiry. This section started with a broad question about why the participant had become interested in the care of institutionalized elders. This seemed the most appropriate way to allow the conversation to start in a non-threatening way. Questions 4 and 5 asked about potential ethical difficulties involved with the care of institutionalized elders. *Part Three* of the guide contains a series of *focused open-ended questions* that relate more directly to various ethical aspects of health care. I intended to ask these

questions during the latter part of the initial interview but I asked specific questions from this section earlier in the conversation if the dentist spontaneously offered to discuss a related subject. I concluded this section by presenting the participants with a hypothetical treatment case involving potential ethical implications.

In addition, I developed a contact letter and consent form (Appendix A) for use in the study. The method was approved of by the Office of Research Services of the University of British Columbia.

Selecting participants

Judgemental sampling was used to select participants based on their specialized knowledge (Agar 1980). None of the dentists I contacted had full-time experience in the care of institutionalized elders. The criteria for their inclusion in the study were simply that they be dentists with considerable experience in the care of institutionalized elders and that they be willing to participate. All of the dentists contacted and who had experience in the care of institutionalized elders agreed to participate. Thirteen dentists were considered initially as potential participants, nine of these were known in the community to have experience with institutionalized elders. The remaining four were chosen on the basis of their association with hospitals but only one of the four had experience with institutionalized elders. Consequently 10 participants were involved in the study.

THE INTERVIEWS

I contacted the dentists by letter (Appendix A) to introduce myself and to outline the nature of the study. Following this I contacted them by phone to confirm their interest and to arrange an initial interview. If possible, I took time during the phone conversation to ask the participant the background questions from *Part One* of the interview guide.

First interview, transcription, summary, and analysis

At the beginning of the investigation I conducted the first interview with one of the participants in his office, during a day off work. I video-taped the interview. Following the recommendations of Merriam (1988) and Patton (1990) my general approach in this interview was to facilitate discussion by the participant in the areas of his interest rather than to force the conversation into areas of my interest. Dexter (1970) indicates that interviews with people who have specialized knowledge can be successful, in part, because the interviewee enjoys playing the role of a teacher. Consequently, I was careful to keep my questions short and I tried to avoid interrupting responses. I used three main techniques to encourage elaboration and clarification of the participant's ideas. The first was simply to ask him to explain a point when it was difficult to understand. The second was to ask a question directly related to a comment to encourage him to either defend an opinion, or provide more information about the subject. The third was to paraphrase briefly his ideas and to ask for a response.

Following the interview I spent an hour or so writing notes in my journal. Adapting the technique of Willms *et al.* (1990), I reviewed the video-tape and transcribed it verbatim. Gestures, laughter and other noises were inserted into the text in square brackets, and emphatic speech was underlined. Pauses were indicated by three consecutive periods. Incomplete and broken sentences were ended with a dash. A change of speaker was indicated by using their first initial surrounded by parentheses, noting that pseudonyms were designated for the participants. New paragraphs were started at the beginning of a distinct question or answer or at a significant change in the thrust of the conversation.

Once the transcript was prepared I reviewed it several times while listening to the tape-recording to become more familiar with the content and to underline many of the significant statements representing key ideas related to the line of inquiry. In addition, I made numerous margin notes on specific issues of interest. I reorganized quotes from the transcript into several categories of information flowing naturally from the conversation. The categories coalesced around

eight general topics including: 1) participant background; 2) the level of oral health of debilitated elders; 3) oral health and quality of life; 4) care of competent patients; 5) care of incompetent patients; 6) ethics; 7) practical difficulties; and 8) the roles of the dentist and society in managing institutionalized elders. Using these categories, I prepared a draft narrative summary of the transcription and analyzed it to uncover ethical issues.

Review and revision of interview protocol

I gave a copy of the summary to the participant requesting an assessment for accuracy and changes if necessary. Overall the participant was satisfied with the summary except for a few grammatical concerns and a concern about anonymity. I recognized then that greater care must be taken to protect the anonymity of the participants.

I gave a copy of the interview guide, tape-recording, transcription, summary, and brief fieldnotes to each of the four members of my thesis committee for review. I asked them to consider the extent to which the interview had been able to uncover substantial ethical issues and in what specific ways, if any, the methods should be improved. The committee agreed that the general approach taken was uncovering valuable information and that it was appropriate to continue despite the finding that the participant had little to say related directly to ethical issues. The committee agreed that this finding could reflect that ethical difficulties are not particularly important to dentists and that this may be obscured by attempting to focus early in the interview on questions related to ethics. There was concern also that the participants might be uneasy with the interviews if they did not know what to expect.

Three specific changes to the interview guide were made to address these concerns (See the revised guide in Appendix A). Firstly, a very general question was added near the beginning of the unstructured portion of the guide regarding difficulties in the care of institutionalized elders. This was done to establish, without direct questioning, whether the dentists would identify ethical problems spontaneously. Secondly, to minimize bias early in the conversation, the direct question

regarding ethics in the unstructured part of the guide was moved to the focused section closer to the end of the interview. Thirdly, we agreed that a copy of the questions from the unstructured portion of the interview guide would be sent with subsequent initial contact letters to reduce apprehension among the participants and to encourage their deeper reflection on the issues prior to the interviews. Suggestions made by the first participant encouraged two other minor changes to the interview guide including the addition of questions on the financial viability of institutional dentistry and on any other issues of particular importance to the participants. We agreed that all subsequent interviews would be audio-taped.

Balance of initial interviews

Over the next five months, I interviewed nine additional participants. Upon the advice of my committee, I added to the last three interviews the question: "What do you understand about the use of ethical principles in making decisions in health care?" The interviews were conducted at a time and location of the participant's choosing, and all of the participants seemed at ease with recording the conversations. The time taken for the initial interviews ranged from 80 to 150 minutes.

CASE RECORDS

Preparation of transcriptions

The interviews were transcribed with the help of an electronic transcribing machine. (See Appendix B for an excerpt from a transcription) I transcribed two of the ten interviews myself and the others were prepared by a professional transcriber. The time required for the transcriptions varied from 10 to 25 hours depending on the length and structure of the interview and on the quality of the recording. I made the final revisions to each transcription.

Construction of summaries

I read through each of the transcriptions while listening to the recorded interviews to underline significant statements and to make notes. Subsequently I constructed draft summaries from each transcript to organize the information and to prepare for the second interview. After preparing five summaries, it was clear that the information fell into one of six categories: 1) background; 2) level of oral health and quality of life; 3) planning and providing oral care; 4) ethics; 5) practical difficulties; and 6) roles of the dentist, Profession, and society. I continued in this fashion until summaries were constructed for the 10 interviews.

Validation interviews

As the draft of each summary was completed, I sent the participant a copy with a letter requesting a second interview to review the accuracy and validity of the summary and to provide an opportunity for further input and discussion (See Appendix A for a copy of the letter of second contact). Prior to the interview, the participants were allowed several weeks for review. I audio-taped the second interviews and transcribed selected portions of the tapes. My primary purpose at this point was to validate the summaries by focusing on the key ideas that surfaced in the initial interview.

Revision of the summaries and compiling case records

Most of the participants agreed with my interpretation of their key ideas, although everyone did take the opportunity to clarify their ideas. This information was used to modify the draft summaries to produce validated summaries. (See Appendix B for a sample of a validated summary) The case records, on which the formal analysis was based, consisted of the interview guides, tape recordings, transcriptions, margin notes, reflexive journal notes and validated summaries.

ANALYSIS

Early informal analysis

I began the earliest stage of analysis during the first interview as the conversations unfolded. The pace of the analysis increased during the preparation of transcripts and summaries and during the second interviews.

Formal thematic content analysis

I began the most intensive stage of the analysis once the case records were compiled. The heart of qualitative analysis rests with reading through dialogue and field-notes to document their meaning inductively. Borrowing from a similar analogy used by Hessler (1992), I saw the qualities needed for qualitative analysis as like those of a struggling young Iowa farmer in the movie *Field of Dreams* when a mystic voice asked him to "build it [a baseball field] and they will come." Similarly, "read and meaning will come" reflects the essence of the process I have undertaken. Aspects of this analysis are outlined below:

- a) reading and re-reading the summaries with selected reference to the transcriptions and tapes when needed;
- b) identifying and segregating approximately 70 to 90 significant statements from each summary;
- c) indexing each statement by the author and by the general category of information;
- d) footnoting each statement with its paraphrased meaning, often done as a question and answer or by paraphrasing an experience. For example, when discussing whether he ever had a patient resist treatment, James said,

I have "hundreds of stories." "Often you have to hold their head, [and] you just do the work very fast. Once again it's a technique. Health-care staff will help me and they always know when certain people are ornery or resistant and it is one of the problems of long-term care home work."
"Patient's will take a swing at you and they can be resistant."

I paraphrased this as two questions and answers:

- How often do you see resistant patients?
 - fairly commonly
- How to manage resistant patients?
 - rely on staff to predict and restrain if need be
 - work fast;

e) printing the statements from each participant on a different colour paper.

f) examining the transcriptions and indexed statements for information related directly to:

- i - difficulties encountered by dentists;
- ii - the meaning of professional ethics in dentistry;
- iii - ethical difficulties encountered by dentists;
- iv - responses to the hypothetical case presented;
- v - all experiences reported.

Construction of results

Construction of the results was undertaken almost entirely by a repetitive process of reading, understanding and writing. At times I turned to a technique for qualitative analysis described by Hessler (1992) as *hawking it*. This is the ability to stand back from the microscopic view of the "trees" to take a macroscopic view of the "forest". So in writing, I attempted to integrate a broad perspective with the specifics found in the case records.

Chapter III

RESULTS

INTRODUCTION OF PARTICIPANTS

Ten Canadian dentists participated in this study. They represent a wide range of age and experience (Figure 1). While in dental school most of the participants received a few lectures related to the care of institutionalized elders and during this time half of them had brief clinical experiences in a long-term care facility. Since graduating, most of the participants had attended occasional seminars related to geriatric care but none reported any formal training in geriatrics. For reference, brief case studies related to the ethically relevant opinions of each participant have been constructed (Appendix C). For anonymity, pseudonyms are used in place of actual names.

Figure 1. Participant experience providing oral care for institutionalized elders.

PRACTICAL DIFFICULTIES IN INSTITUTIONAL CARE

In response to the initial question on difficulties, the participants identified three general categories of difficulty: 1) a *lack of support* for institutional care; 2) *inefficiency* with institutional care; and 3) *financial difficulty* with institutional care. Interestingly, none of the difficulties reported at this point were ethical dilemmas. Instead the responses seemed generally to be of a practical nature, although this is a debatable point because at a basic level everything has ethical implications.

Lack of support for institutional care

The participants reported a lack of support for the care of elders from several groups including facility administrators and staff, the dental profession, patients, families and governments.

Variable support from long-term care facility administrators

All of the participants reported that they require substantial support from the facilities and that there is a variation in the extent to which facility administrators are willing to offer support. There were two major areas of concern in this regard. Firstly, the dentist often requires staff of the facility, such as a care-aide, to facilitate better communication with patients and to help with the transportation and treatment of patients. Secondly, the dentists require a work space equipped preferably with a dental chair. Sometimes, however, there is no help available from staff, and dental equipment is not usually provided.

Lack of support from facility staff for daily mouth care

Several of the participants reported that many institutionalized elders rely on the help of others for daily oral hygiene and often this help is not available. They report that three main difficulties exacerbate this neglect. Firstly, long-term care facilities are chronically underfunded and understaffed. Secondly, the staff often place a low value on the oral health of the residents and do

not support efforts of the dentist to improve it. Thirdly, most institutions lack basic facilities such as bedside suctions and sinks accessible to disabled persons for daily oral hygiene.

Lack of support from the Profession for dental student training

Some of the participants reported that the dental profession does not encourage the training of dental students to care for institutionalized elders. Consequently, many dentists are unsure of what level of care is appropriate for these patients and they are unprepared to compromise from an ideal treatment approach more appropriate for healthier patients. It was suggested also that some dentists find treatment compromises dissatisfying and troubling. On the contrary, one participant indicated that dental student training is more than adequate in geriatric care.

Lack of support from patients, and family

The dentists reported that facility residents tend to be concerned more with social isolation and poor general health than with poor oral health. Consequently, it is often difficult to obtain consent for treatment from the residents unless treatment is provided at no cost. Complicating this issue is that treatment decisions are delegated often to a relative and the pervasive attitude among family members is to resist efforts to improve oral health particularly if they are costly efforts.

Lack of government support

Two of the participants mentioned the lack of government funding for programs to improve the oral care of institutionalized elders.

Lack of cooperation between the movers and shakers

Two participants remarked that the oral care of elders is poor because there is not enough cooperation between facilities, governments and dental personnel.

Inefficiency with institutional care

The dentists reported three concerns with the inefficiency of institutional care: equipment limitations, demands of working with compromised patients and inordinate administrative work.

Equipment limitations in the institutional environment

The participants felt that their service was often inadequate because of limitations associated with the dental equipment found commonly in the institutional environment. Specifically, the dentist must often use cumbersome portable equipment that can hamper diagnosis and treatment.

Demands of working with compromised patients

The dentists reported that the physical, medical, and mental compromises common with institutionalized patients makes oral care physically demanding and time consuming. Patients must often be transferred to a dental chair for treatment, or be managed in a wheel chair or in bed if transfer is not possible. Moreover, frail elders frequently cannot hear or communicate easily and they often have multiple medical disorders which complicate treatment and demand lengthy consultation with other professionals.

Inordinate amount of administrative work for mobile practise

Two of the participants reported that their services require significantly more administrative time than conventional practise, whereas two others reported that some facility administrators provide staff to take care of these duties.

Financial difficulty with institutional care

Both the lack of support and the inefficiency associated with institutional care led all of the participants to indicate that compared to conventional practise this service is less rewarding financially. There were divergent opinions, however, on the extent to which financial difficulties were

a concern. Some of the participants indicated that a fixed salary may be an appropriate method of remuneration but one claimed that a salary would discourage a dentist's efficiency. Some participants felt that higher fees might help but others discouraged higher fees as this would simply put the service out of reach for those most in need.

Five of the participants believed that it was not possible to make a living offering mobile dental services to institutionalized elders using a traditional fee for service structure. Of the five participants who doubt the financial viability of this service, only two have actually attempted a mobile practise in this setting on a fee for service basis. Both dentists stopped offering mobile service because the financial strain was too great despite being keenly aware of a professional responsibility to provide accessible services to institutionalized elders. The other three who questioned the financial viability had been paid a salary to work in an institution. On the other hand, five of the participants believed that they could make a living offering mobile dental services to institutionalized elders using a traditional fee for service structure. Of these, one was paid a salary for institutional work but was no longer doing this, and the remaining four have made a part-time living from a fee-for-service approach.

THE MEANING OF PROFESSIONAL ETHICS

As documented in the case studies, most of the participants view ethics as a sense of doing the right thing in balancing various competing demands in decisions. Several of the participants believe that ethical behaviour is deeply ingrained in childhood. Only three of the participants - Greg, Beverly, and Susan - understand the formal concepts of principle-based ethical decisions as outlined in Chapter I. Not surprisingly, these three seemed more able and willing than the others to discuss ethical issues, if only from the perspective that they understood the terms and processes involved. The other seven participants appeared to make decisions subconsciously using a personal ethical framework, but they were unsure what to say when reporting on the most difficult ethical problem

they had encountered. Further discussion by the researcher to outline the general meaning of ethics enabled all but one of the participants to provide a response the question on ethical difficulties.

ETHICAL PROBLEMS REPORTED DIRECTLY BY THE PARTICIPANTS

Only three of the participants - Greg, Beverly, and Susan - reported ethical problems high on their list of difficulties encountered with frail elders. However, none of the problems reported directly were ethical dilemmas in the sense of a conflict between principles. As regards the remaining participants, neither Julie nor Carl could think initially of any ethical problems that they had encountered, and Mark reported that he "rarely runs into" such problems. Both James and Pete reported that they do not believe that ethical problems are more common in this setting compared to a general practise, nor do they find most clinical decisions very difficult in an institutional setting. While most of the participants gave a response to the question on ethical difficulties, only Greg, Beverly, and Susan reported a struggle with the problems. Overall, the participants identified four types of what they considered to be ethical difficulties: 1) unclear determinants of appropriate care, 2) potential for unethical infringement of autonomy, 3) the need to compromise treatment, and 4) the division of responsibility for providing accessible care.

Unclear determinants of appropriate care

Only Greg reported an ethical problem in response to the opening question on difficulties.

He said that:

It's important for me to... think that there's some tangible benefit to people actually getting the care done, and that's a thin line sometimes [with institutionalized elders. It can be difficult to decide,] do I really want to pursue this case, and what for?

Later in the conversation he was asked directly about the most difficult ethical problem he had encountered in this setting and he said:

Clearly, one of the most difficult is, 'When you think you're doing good for a patient, are you?'... So what if they have these retained root tips. So what if they don't have their smile. ... If you do something, 'Is that really doing

good?' I don't always know if it is, and I have clear examples of when I thought it was going to be [good] and it wasn't.

Like Greg, Beverly responded to the question on the most difficult ethical problem by saying:

For individual cases, it's always, 'What is appropriate treatment?' I mean, for me, everything centres around that and it's really tough.

Evidently, both Greg and Beverly struggle with the problem of determining when and why to treat institutionalized elders because the treatment outcomes are more unpredictable and unclear compared to those found with healthier patients. This gives rise to a moral tension in deciding *what treatment is appropriate* because of unclear facts. In this case, the unclear facts are unclear treatment objectives and outcomes. This problem is quite unlike traditional ethical dilemmas that arise from conflicts between ethical principles.

Four other participants - Daniel, Pete, Carl, and Susan - reported also an ethical problem with determining appropriate treatment. Susan for example, reported that:

Beneficence I think is a problem too sometimes, because you might want to be doing something for the patient... [that] might be really good for them physically... [but] that's not good for them mentally, so you have to really balance the kinds of 'doing good' for them.

In her struggle to figure out what the best 'good' is, Susan is unsure about what treatment is appropriate.

Potential for unethical infringement of autonomy

Susan's initial response to the question on the most difficult ethical problem was:

Autonomy, I think is the major one. I can see that if somebody weren't ethical, and just wanted to make money, then it would be really easy to rip people off. They're extremely vulnerable. The families don't know what's been done really. The patient doesn't know what's been done really.

Susan's concern could be framed of as an ethical struggle between beneficence for the dentist and beneficence for the patient. However, technically this is a legal issue implying the intentional use of deceit because it opens up the potential for *fraudulent and unethical infringement of autonomy*.

Susan's concern focuses on the issue that many frail elders have an increased vulnerability to unwanted infringement of their autonomy. Although she raised the issue as a caution to the Profession, it is not one that seems to cause her personally any moral struggle.

Mark described the most difficult ethical problem that he encounters as:

treatment for the handicapped [who are not] responsible for their own actions. [But,] if there's any hesitation at all, I don't treat them.

This implies that Mark sees a distinct potential for infringement on the autonomy of these vulnerable patients. Like Susan, he believes that this is an important ethical issue.

The need to compromise treatment

Both James and Frank reported an ethical difficulty with the need to compromise "ideal" treatment. James said that:

In long-term care home work, in terms of [the] high ideals... we're taught... you can work toward them, but that's all you can do. ... Basically, I think you have to compromise... and in that... I'm still doing, in my opinion, the very best that I can do for that individual, ... taking into account all the multi-different circumstances you're now dealing with.

Similarly, Frank said:

I'm providing some service, but not as good a service as I would like to. ... [There are constraints in terms of] time limits, financial concerns, [and so on,] but I wish I could be doing more.

Evidently, both James and Frank recognize the reality of not being able to provide ideal treatment, and they report some sense of struggle with this problem, albeit a minor one in that they accept the reality imposed upon them.

Julie also mentioned this as a particularly difficult issue, but she didn't report it as an ethical issue. She said:

When I started working with debilitated elders, I think the hardest thing that I found was that I couldn't do the best dentistry. I had to make compromises and I was quite new and I felt terrible sometimes about not being able to do perfect dentistry, but you couldn't.

She added that despite having to compromise her ideals, she is more comfortable with that reality now because she sees that her efforts have actually benefitted patients.

The division of responsibility for providing accessible care

Daniel reported that a potential ethical problem is evident in trying to determine:

who is responsible for what aspects of a person's care, financial [and] actually providing that care?... It's hard to know... who should be stepping in, whether it's the public health unit, government, the dental profession, ... [or the facility administrators, but, as yet,] nobody's really in charge.

This demonstrates his concern for the unmet need to ensure accessible oral care for long-term care residents, although it is not necessarily a personal struggle for him. It is an issue of social justice, and a minor issue in this study since it was overlooked largely by the participants.

ETHICAL PROBLEMS EVIDENT IN THE PARTICIPANTS' EXPERIENCES

Throughout the interviews the participants discussed their experiences, many of which seemed on the surface to have ethical overtones because of an association with one or more of the ethical principles. The purpose of this section is to outline these experiences with the specific aim of demonstrating the variety of ethical problems encountered.

Although the participants were encouraged to discuss specific experiences, only about half of the experiences reported referred to a specific incident. For example, Greg said:

Yesterday... [I saw] a person who's been on my recall list for a long time. I knew [there was] authorization for continued care [and] I hadn't cleaned her teeth for a long time, [but] this patient had no real awareness of what was going on.

The balance of experiences referred to general incidents. For example, Daniel said:

Appearance was much less a concern for most of these residents than for their families, [and] often the decision to give a person a lower [complete] denture, or even an upper denture, ... would be a desire from the family, because they want, say, their grandmother to look better. The residents, in many cases, went along with it simply because it was something their family wanted.

On five occasions the participants discussed what they felt was the unethical behaviour of an unnamed dentist. While this may represent a special category of ethical problem, it may also be that the behaviour in question arose simply from a moral perspective different from that of the participant. Consequently these experiences have not been described using a special category.

The participants reported a total of 71 experiences related to the care of frail elders, and each of the participants reported at least four experiences. Many of these experiences had ethical overtones, but precise identification of the ethical issues was difficult since the participants did not tend to identify them as such. Often there were more than two principles in conflict simultaneously, or there was lack of clarity in several of the facts involved in a decision. Despite this complexity, it was possible to identify a primary ethical problem in 56 (78%) of the experiences reported. Of these experiences, 33 (59%) demonstrated moral tensions arising from a *lack of clarity in the facts* surrounding the situation. The remaining 23 (41%) experiences demonstrated moral tensions arising from an *ethical dilemma* where there was a distinct conflict between two ethical principles. Of the 33 experiences relating to lack of clarity in the facts, two-thirds related primarily to a *lack of clarity in the predicted benefits of treatment* and appropriateness of care. The other one-third related to a *lack of clarity in either the patient's wishes or competence*. Of the 23 experiences related to an ethical dilemma, ten related primarily to a *conflict between the principles of autonomy and beneficence*, nine related primarily to a *conflict between the principles of nonmaleficence and beneficence*, and four related primarily to a *conflict between the principles of nonmaleficence and autonomy*.

Unclear treatment outcomes and appropriateness of care

By far the most common ethical problem uncovered related to a lack of clarity in treatment outcomes and appropriateness of care, making it almost impossible to apply the principles of beneficence and nonmaleficence. The problem was evident in experiences reported by all of the participants except Frank.

Julie, for example, reported that:

There were a number of cases where there would be broken off, decaying teeth that if the patient was in better health, you would choose to treat. [But the] question always arose, 'Is it better to leave them, when they appear not to be having any trouble with these [or] to impose this ordeal of treatment on them?'

Pete said that for the elders with compromised health or great age it can be difficult to determine whether certain treatments are appropriate. For example, he said:

The dilemmas that you get into are,... do you just do the basic dentistry for them, or do you try something like a crown that would last longer?

One man he remembered was a reasonably healthy 90 year old patient whom he referred for root canal treatment on an abscessed tooth. The treatment for the tooth was successful and Pete then wondered whether he should:

put a crown on at that time. ... [But I thought,] He's 90 now. He'll be all right.

With a similar ethical problem, Mark reported seeing a confused patient who's caregivers requested partial dentures for her because:

she had no front teeth, upper or lower. ... They perceived that maybe she could chew better [with the partials.] ... [But] communication... [with her was poor so I] guess you never know for sure.

Daniel also reported seeing numerous patients with missing teeth where he would be unsure about recommending partial dentures. He said:

In the case of partial dentures, sometimes the decision is, on my part, 'Is the patient really going to benefit from having a partial denture?' ... Earlier on when perhaps we had [constructed more] lower [partial] dentures [where most of the lower back teeth were missing], we would find often that the residents wouldn't tolerate them. They would end up putting them in the drawer even though we made what we thought was an acceptable partial denture.

Daniel appears to have had difficulty predicting the success of the partial denture and so he found it impossible to determine whether the treatment was appropriate.

Greg was asked to see an Alzheimer's patient who had lost her complete dentures. The staff informed him that despite having no teeth, she was eating fine, so Greg said he:

went back to the family and I said, 'You know, she's lost this for a reason; she probably threw it away.' 'She's eating fine', and 'Is there really a need?', and the family, 'No, Mum always cared how she looked.' ... 'We want her denture made'. I said, 'She probably won't wear this denture. She's been quite some time with no dentures.

So Greg was pushed to go ahead with the treatment, despite his own uncertainty.

Unclear patient wishes or competence

The other ethical problem associated with unclear facts related to a lack of clarity in the patient's wishes or competence, making it very difficult to apply the principle of autonomy. It was evident in the experiences reported by Beverly, Carl, Julie, Frank, and Susan. Beverly reported, for example, that:

I have cases where people have funds looked after by a public trustee, but they don't have a comite. So their money's looked after, but there's no one giving informed consent. ... Those are really difficult cases for me. Under those circumstances [I've] done some fairly invasive treatment, [for example,] surgical extractions, and it's not entirely comfortable.

Beverly also reported that:

I've had families say to me, 'Mum can decide, she's quite capable', and you go in and it's clear to me that, 'No, Mum can't decide.' ... Where you see it can make a great improvement [it's] difficult when the families are sort of in denial about what decisions can and can't be made.

Carl reported a problem which arose because the wishes of a partially autonomous patient were not addressed at a team case conference. The assumption was that the patient was incompetent and that his wishes were of little consequence. The team decided that:

Charlie, [the patient], should have a partial [denture] because his looks are terrible. ... [The consensus was that] he's [been] missing [these front] teeth for many years, and wouldn't he speak and look and eat better. ... [But,] we didn't ask Charlie [for his opinion.] ... We didn't think that his input was valuable.

Frank also struggles with this problem. He reported, for example, an experience where he had surrogate consent to treat a cognitively impaired woman, but the woman became resistant when he tried to treat her. He said she clearly:

didn't want to be there. I was fixing a cuspid [tooth] for her and she was saying to me, 'Go to hell, go to hell, got to hell, go to hell, go to hell', and when she wasn't saying, 'Go to hell', she was trying to bite my fingers.

The problem with this case was in determining whether or not the patient was competent to make a decision about whether or not to have treatment. If Frank had determined that she was competent, then the ethical problem would have been a dilemma between the principles of autonomy and beneficence. But the lack of clarity in competence makes the decision very difficult.

Susan reported a similar situation where she had consent from the family but she wanted some cooperation and understanding from the patient also. She said that:

Alzheimer's patients can... be a difficult one, because sometimes... the consent... can change from moment to moment. ... They want something done, but five minutes later they're asking you if you're one of their grandchildren. They clearly don't remember that you're the dentist and that they've consented to treatment. It's a tough one.

Conflict between autonomy and beneficence

The most common ethical dilemma evident in the experiences reported by the participants was that arising from a conflict between the principles of autonomy and beneficence. It was evident in experiences reported by Mark, Beverly, Daniel, Pete, and Susan. Some dilemmas occurred when there was potential for benefit according to the dentist, but the autonomy of the patient or surrogate impeded treatment. Beverly reported, for example, that she had seen a very:

elderly woman, she was maybe ninety-four, and she had... advanced [gum disease] and could really have benefited from... treatment [including a number of extractions and cleaning primarily.] ... It wouldn't have been real hard on her. ... [I was unable to contact the guardian that day so, with the woman's permission, I removed one tooth that was very loose and] bothering her. [The tooth was practically ready to fall out on it's own, but the guardian got angry and said,] 'We don't want any more treatment.' ... There are a lot of cases where I say, 'it's okay to not treat this', but her mouth really needs... treatment and I think this is an issue of neglect. ... [Nonetheless,] this family [is] not doing anything about this.

Here is a struggle between the duty to provide treatment and the duty to respect the family's wishes.

Mark reported a similar experience with a patient who had Alzheimer's disease. The patient was seen by another dentist who had extracted a tooth without consent. Mark said:

Apparently [the son] gave specific orders that 'My dad has a dentist and I'll come take him to the dentist. ... He doesn't want him seeing [other dentists] because he didn't know [their] routine. ... So somebody did a procedure with [no consent]. I would never do that. I think that's wrong... ethically. I look at his old radiographs and the tooth could have been ready to come out. ... [Apparently the dentist] said, 'It needed to be extracted so I extracted it.' Looking at the radiographs, [I agreed], 'Okay, it's coming to the end of its life'. I wouldn't question the [result] at all, just the process in doing it.

The dentist who extracted the tooth was faced with a struggle between beneficence, as represented by the duty to extract the man's diseased tooth, and autonomy, as represented by the duty to respect the expressed wish of the son not to have just any dentist provide treatment.

Susan reported that often:

with elderly Chinese patients, the family are saying, 'Yes go ahead and clean the teeth', and [the patient is] saying, 'No, No, - Too much money', and 'I don't want' it'. ... [So I say to the family] I've examined you're mother; you can see what kind of shape her teeth are in, but she doesn't want anything done. ... Sometimes they say, 'Oh, she always says that. Don't bother with it, just go ahead and do it. Tell her I said it's fine. [Or sometimes they will say,] Tell her the government's paying for it.

So Susan is left with a dilemma between beneficence, as represented by the duty to provide treatment in the best interest of the patient, and autonomy, as represented by the duty to respect the patient's partial autonomous decision to forego treatment. Moreover, she may have to decide whether she should lie to a patient to gain their cooperation.

Unlike the dilemmas just described, where the dentists believed that there was potential for benefit, the other situation in which this type of dilemma occurred was where there was minimal potential for treatment benefit according to the dentist, but where autonomy supported treatment.

Pete, for example, reported that for patients who are:

to the point where they're unable to talk or think for themselves at all, they're also not likely to be good candidates for much dental care. ... I haven't gone on about that, but sometimes you're decision is to do nothing, ... even if they have root caries, even if they have periodontal disease, [and]

even if they have periapical abscesses. ... Often you do nothing, [especially if they are not cooperative.] ... I can remember sitting down and I would explain to the son or wife that, I understand he has problems, but I just can't do anything about it. ... Some people would find that hard to accept. ... [But] you've done your best. There are some extreme options. You can say, 'We could have him under general anaesthetic [for treatment'], and then you just transfer the responsibility to the physicians because usually they would not do a general anaesthetic on someone who is debilitated. So you're off the hook. But I rarely resorted to that.

Pete's struggle here was between beneficence on the one hand, as represented by the duty not to provide treatment unless it is of significant benefit to the patient compared to the risk of discomfort or harm, and autonomy on the other hand, as represented by the duty to respect the surrogate's desire for treatment. Pete reported also that sometimes he would go ahead despite the lack of potential benefit for a patient, but this appeared to be when the risk of harm was minimal. For example, he reported seeing an elderly physician who had:

lost his lower denture. ... [And] it just brings tears to [his wife's] eyes when she comes in and visits him, because he's so feeble, and to see him without teeth just makes it really hard for her. ... I think that more and more we're realising that the person who's suffering is the caregiver. ... [The patients] don't have real strong feelings one way or the other any more.

Conflict between nonmaleficence and beneficence

Also evident in the participants' experiences were ethical dilemmas arising from a conflict between the principles of nonmaleficence and beneficence. This problem was evident in experiences reported by Beverly, James, Carl, Julie, and Frank. The experiences reported by Julie, James, and Frank involved a risk of harm to staff working with a patient, whereas the remainder of the experiences in this section involved a risk of harm to the patient. Julie reported that there is a significant and immediate personal risk in providing beneficial treatment to cognitively impaired patients which must be weighed against benefits. She said:

At one point when we were doing our screenings, my assistant got punched in the jaw.

This problem was also reported by both James and Frank. James said that:

It is one of the problems with long-term care home-work. ... Patients will take a swing at you, and they can be resistant.

Frank said that some patients just:

don't want to be there. ... Yesterday, I almost got flattened by a patient. Sometimes they can be so fast - that fist can be out.

In these cases, the dentist must balance nonmaleficence, as represented by the duty to do nothing to risk personal or staff injury, with beneficence, as represented by the duty to provide benefit for the patient.

Julie said also that there was a case that:

I never had to really deal with and I've always wondered what would be the way to deal with it. The patient died shortly after the request was made. I got a request from the nursing staff to extract a demented patient's teeth. He had a pretty full set of teeth. ... [It was] because on two separate occasions... he had very seriously bitten... some of the care workers. In one instance, [it was while they were] trying to bathe him. They couldn't really get near him to care for him because he was so violent.

This time the dentist must balance nonmaleficence, as represented by the duty to not harm the patient by retaining his healthy teeth, with beneficence, as represented by the duty to prevent harm to care staff by rendering the patient toothless.

Beverly reported a physician's request to construct new dentures for a patient:

who had swallowing difficulties. ... The physicians will always assume that it's because of the teeth. ... [The patient] doesn't have enough chewing surface. ... If you look in the mouth and you see something ugly, then you assume that's the source of the problem. So it's not uncommon for a physician to assume things like that.

Beverly is left balancing beneficence, as represented by the duty to respect the physician's assumption that the problem can be treated with a new set of dentures, with nonmaleficence, as represented by the duty to not put the patient at the significant risk of pushing her beyond her capacity to adapt to a new set of dentures.

Carl reported an experience that occurred shortly after he began working in a long-term care facility. He was asked by a facility nurse to comment on:

a behaviour modification technique... [they used where] positive... [patient behaviour, such as] buttoning their shirt or tying their shoe laces... [was] reward[ed with] Smarties.

Carl was left then with a dilemma between nonmaleficence, as represented by the duty to not harm the coping systems currently operating within the facility, which may suffer tremendously if he demanded an immediate change, and beneficence, as represented by the duty to prevent the potential for dental caries as a consequence of the repeated ingestion of Smarties.

Conflict between nonmaleficence and autonomy

The least common ethical dilemma evident in the experiences reported by the participants was that arising from a conflict between the principles of autonomy and nonmaleficence. It was evident in experiences reported by Mark, Beverly, Carl, and Susan. In these cases the risk of harm was to the patient, not to the staff. Susan, for example, reported that she has had several requests from family members for the replacement of dentures. She said that they will say:

'I want her to have a whole new set of dentures'. ... [Even though I advise them that] she just needs a reline on one or both of... [her dentures, they will often persist by saying,] 'But it would be good if she had a whole new set.' 'Actually it would probably be worse, because she's used to what she has'. I think sometimes people want to spend a lot of money on a set of dentures, because then they're going to feel like they're really doing the right thing by their parents that they've institutionalized.

In this case, Susan encounters a dilemma between autonomy, as represented by the duty to respect the wishes of the surrogate, and nonmaleficence, as represented by the duty to not harm the patient by pushing her beyond her capacity to adapt to new dentures.

Beverly experienced this type of dilemma when she saw a:

a fifty-five year old brain injured woman in the extended care unit. ... The family is grasping for anything, ... [and] they are convinced that she... has pain... [and] needs root canal treatment. ... [But her mouth is] in very good condition.

Beverly faces a dilemma here between autonomy, as represented by the duty to respect the wishes of the family, and nonmaleficence, as represented by the duty to not harm the patient any further by providing unnecessary treatment.

Likewise, Carl reported such a dilemma which occurred when a woman asked him:

'My mother has lost her partial denture, would you make her one?' This lady [has] narcolepsy. She'll sleep nine or ten days and then awake for a day of two and binge [on food.] ... So each time we go there she's asleep. ... Most family don't [realise that a partial in this situation is]... probably often doing their loved one a disservice.

Carl faces a dilemma here between autonomy, as represented by the duty to respect the wishes of the family, and nonmaleficence, as represented by the duty to not harm the patient with a partial denture worn by a patient who is unaware of its presence.

A COMMON SOURCE OF ETHICAL PROBLEMS: IDEALISM VERSUS REALISM

The major factor underlying all of the ethical problems uncovered in the interviews is the need to manage a less than ideal situation. James, for example, said:

I use the simple one of a new graduate, ... not an example, but... symbolically, ... going into a long-term care facility and he sees a 77 year-old lady [who] has Alzheimer's disease. 9/10ths of her teeth are broken off at the gum line, and there [are] a few abscesses, ... and her mouth is all dirty. ... His training says, 'Let's clean off the roots, get her good home care, have somebody take care of her, we'll do root canals, and build a bunch of crowns and she'll be back to normal.' Well, come on. See, it doesn't work. ... So in long-term care work, in terms of what we're taught about high ideals, can you work toward those high ideals? Yeah, but that's all you can do.

Idealism

The ideal situation in dentistry is where an autonomous person voluntarily seeks the services of a dentist. The dentist assesses the situation and agrees that there is a problem which can be treated efficiently. The patient is advised of the costs, risks, and benefits of all possible treatment

options with predictable results, and the patient consents to the ideal treatment. The treatment is completed, the bill is paid, and everyone is content.

Realism

The lack of ideal circumstances is the crux of the ethical problems reported by the participants, and when there is any deviation from the ideal there is potential for an ethical problem. Many institutionalized elders are unable to get to a dentist or to afford treatment. Likewise, the dentist may find the cost of offering service impractical. In either event, accessibility of treatment is a problem. The patient, or a surrogate, may want treatment that is determined by the dentist to be inappropriate, and so a dilemma between autonomy and beneficence or nonmaleficence appears. It may be difficult to assess whether a patient is competent to make decisions which presents a problem when planning treatment and establishing consent. Furthermore, the patient's medical condition may make it difficult to assess the predictability of treatment. If an incompetent patient becomes resistant during treatment and risks an injury, the dentist is faced with a dilemma between nonmaleficence and beneficence. Any one of these events can create an ethical problem.

WAYS OF COPING WITH ETHICAL PROBLEMS

Most of the participants did not report using a formal process to resolve ethical problems, nor did they recognize the formal structure of the ethical problems they encountered. Moreover, they each tended to appear reasonably confident and consistent in their own decisions, and there were significant moral similarities between the decisions of the various participants. Nevertheless, there were also significant moral differences between the decisions of the various participants, which suggests that they may encounter ethical problems which they are unaware of.

Similarities in ethical decision-making

There are six basic philosophical similarities between the general ethical decisions of the participants. The similarities include the need to: involve next-of-kin or guardians; involve other professionals; make educated guesses; accept that some decisions will be wrong; know that there will generally be exceptions to rules; accept that some patients are best left untreated.

Involve the wishes of the patient and next-of-kin or guardian

All of the participants reported the need to involve the patient and family in difficult decisions. Susan, for example, felt that:

The patient's values, the family's values, and mine are all contributing.

James said:

Basically, the primary person involved in treatment-planning is the dentist. ... [However], the final decisions are actually made by the patient, and the family, and their relatives.

Similarly, Greg said:

The [treatment] objectives that you set out are ones that, in many instances, you establish with the help of family,... staff, and to a lesser extent, the objectives of the resident... [simply because they are] unable to participate to any meaningful extent.

Involve other professionals

Most of the participants reported the need to involve other professionals when faced with a difficult decision. Carl, for example, said:

[The most common difficulty was determining] how far I should go [with treatment]. ... [The dentist] has to live with the choices he makes. [So to improve decision-making for the] patients that I look after, we may have eight or nine people at our frequent conferences, amongst whom are psychiatry, psychology, charge nurse, and nursing supervisor.

Greg reported treating an elderly woman with Alzheimer's disease who still had most of her teeth but her oral health was very poor because of a lack of brushing. He said:

I don't think there was any significant family involvement there for some reason. ... It was more the physician and the staff. ... Now I think that the main concern from the physician's perspective and the staff's perspective was that she had awful breath because there were large numbers of teeth that weren't getting cleaned. The staff was revolted. ... [They] could brush [the] maxillary anterior six teeth and yet they couldn't get to the posterior quadrants and the physician would look in there and see these horribly dirty and inflamed gums. ... The physician ordered full-mouth clearance, and I started clearing her quadrants. ... I ended up with the maxillary six teeth and they were beautiful... so I kept [them.] ... Once I got rid of [the other] teeth there was no [more problem].

On the other hand, involvement of other professionals can be time consuming and unpredictable. Beverly, for example reported that:

It takes a lot of time and effort to phone a physician. In a lot of cases I've almost stopped doing it with my nursing home patients because I generally got no feedback at all. ... I was better off on my own.

Make educated guesses

Some of the participants reported that they occasionally needed to make an educated guess to determine the most appropriate course of treatment. These were generally cases where the patient's competence to make a decision was unclear or the treatment outcomes were unclear.

When discussing appropriate treatment, Daniel, for example, reported that:

If they can communicate well, then we can [determine their wishes]. ... But if they can't, then we sometimes just have to guess. We can make that decision based on whether there's a benefit to the person, but do we make the right guess?

Similarly, Frank said:

Your diagnostic skills are limited [because] your ability to ascertain information is limited. ... It's always much higher obviously with a younger healthy population. ... Sometimes I do nothing for them. Sometimes you have to just guess [whether] this [is] going to be good for them.

Accept that some decisions will be wrong

Most of the participants accepted that some of the decisions in the care of institutionalized elders would turn out to be wrong, and several of the participants reported feelings of inadequacy as a consequence. Susan, for example, regretted an experience with a guardian who she said:

[was] a very odd person, and very focused on money all the time. After [the patient] died... [the guardian] came to the institution and was really angry that they had sent back his G.S.T. refund, which they're required to do by law. ... When I relined his denture I sent somebody else's out at the same time, and I was getting the lab to put names in them, and they sent them back and they had mixed the names up. I sort of thought, 'Oh, I should send these back and get the right names put on, but on the other hand everybody knew who's had been mixed up and so we just decided [to] leave them. Then he died, and for some reason the care-aide that was packing up all his stuff was the one person who didn't know that the wrong people's names were on them, so she told this relative, 'I can't find his new set of dentures.' ... So he got buried in [sic] [his] old set of dentures, and this woman was writing letters, and calling up and yelling at our receptionist about [this]. ... I just felt like, 'Oh, I'll never do that again, and I don't care how much trouble it is to wrestle the dentures away from them.'

Likewise, Pete said that six years ago he had decided in one particular case not to place a crown on a tooth for a ninety year-old man who had just had endodontic treatment completed on the tooth. Pete said:

[Now] it's about the third time I've had to fix this tooth. I wish I'd put a crown on it. ... I don't know if [the decision] was wrong. It certainly didn't turn out. ... I'm not sure that I made the right decisions every time, ... but I certainly made decisions.

Daniel reported that:

One of the most frustrating things, I think, is seeing the work that you do fail, not because you're a bad clinician, but because there are those conditions that you have no control over and you could not predict. The ones you can predict are fine. We expected this consequence. But if you can't predict it, and it happens, that's really frustrating. [For example, treatment might] fail because the person develops xerostomia because they're on a new medication. ... In the case of seniors, it's harder to predict.

Know that there will often be exceptions to any generalizations

Most of the participants agree that generalizations about treatment are often overly simplistic. Pete, for example, reported that generally dental treatment:

should be simple, and it should be functional, and it should be hygienic. ... [There is occasionally] an exception, and [that] is why I don't generalize about this. My philosophy tends to be the other way.

Accept that some patients are best left untreated

Most of the participants reported that in some cases the best option was to leave a patient untreated despite the presence of a condition which would usually be treated under other circumstances. For example, commenting on extensive fixed bridgework for a noncommunicative patient with Alzheimer's disease, Greg said:

I think the provider needs to step in and say, 'I'm not going to do this.' It's like having a patient come to you and say, 'I want all my teeth out and have dentures.' If that patient is going to go down the street and get the same thing done, are you going to do it? Is that a good enough reason? Or do you say, 'This is wrong. I refuse to do it. If you choose to go to another dentist to have it done, that's your choice, of course, but ... I cannot do this, morally.'

Similarly, James said:

[The] relatives might be bothered in terms of a value of, 'My dad doesn't look as well as he used to in terms of his smile. Then I come right back and say, 'Well I've talked to your dad, and your dad seems to feel pretty good about himself, and he has an awful lot on his mind in terms of his arthritis, and his heart, and his urination. ... Do we need to put him through the expense, and possible minor discomfort of trying to fix his front teeth when it really doesn't matter to him at this time.' They usually say, 'You're right. That's what I really wanted to hear. I was worried because of the way he looked.'

Differences in ethical decision-making

There are seven areas of decision-making for which there are distinct differences between the ethical philosophies of the participants. It is also very evident that there are variations the views of the participants depending on the situation. The differences relate to: responsibility for access to

care; management of a hesitant or resistant patient; treating patients when the next-of-kin is the only beneficiary; nonmaleficence overriding beneficence or autonomy; idealistic *versus* realistic treatment; autonomist *versus* benefist decisions; and substituted *versus* best-interest judgements.

Responsibility for access to care

Although Daniel was the only participant who discussed the ethical implications of responsibility for accessible care, several others voiced conflicting opinions regarding accessibility, concerning specifically the affordability of care. Daniel said that:

[Improvement of the accessibility of care depends on the cooperation between] the public health unit, government, the dental profession, [and the facility administrators, but, as yet,] nobody's really in charge.

To improve this situation Daniel says that it is important to lower the high cost of oral care for institutionalized elders because otherwise there may be a:

reduced likelihood that they're going to follow through with [treatment and] ... then what sort of a service is being provided for these people?

He went on to say:

Is it that [the] fees might be prohibitive to their having the care done, and if that's the case then should there be input from the government?

Daniel offered no answers to this question, but his question left the substantial implication that government assistance with funding would be desirable.

Offering support for this view, Susan said:

It's really demanding work. You don't get to see very many patients. It's really hard to make a living at it. If I wasn't being paid a salary to go in there, I would have a hard time to do it every week. ... I've talked to other dentists who are doing it and none of us make a lot of money in it. ... I don't buy the deficit hype. We have lots of money to go around for everything we need.

On the other hand, some of the participants said that the fee charged for this service would need to be higher than average if done on a fee for service basis. Mark, for example, reported that:

[The] fee guide is set up for an office [where] ambulatory people come and go quickly, [so] you can't compare. If dentist[s]... perceive [that they are] adequately compensated, [then] you'll get people to do it. But if they're not,

to perceive they're going backwards, it's not worth the time and effort. You have to charge an appropriate rate; that's the only solution to that, and whether society can afford it, or individuals can afford it, well, it's up to them.

In addition, some of the participants indicated that dentists should not obtain government salaries for this service. James, for example, stated that although the dentist will earn less providing a long-term care facility service:

I don't want to really see it done as a public service type thing. ... I had worked in the public service and I personally think it can create some non-functional type workers [who don't] get the work done fast enough or even done correctly. ... I think the private model works the best. I want to see the Profession do it so we don't lose our autonomy.

Management of a hesitant or resistant patient

The management of a resistant patient was reported by several of the participants. Two different types of situation were discussed in this regard. Reference was made firstly to patients who verbally or physically do not cooperate, and secondly to patients who are physically violent toward the dental staff. The participants did not resolve these problems in a similar manner, but they did accept that the wishes of all substantially autonomous patients should be respected, i.e., the participants did not report making decisions on the basis of strong paternalism. Disagreement between the decisions of the participants arose in managing partially autonomous patients. Some will stop if the patient hesitates even slightly, interpreting resistance as a lack of consent by action. Mark, for example, reported that for hesitant patients:

generally you look the best you can without interfering with their wishes. ... If there's any hesitation at all [then] I don't treat them. [I] never did. [I] let them sleep on it. ... Usually there's no big rush in that type of treatment. They're not going to die if they don't have it.

When faced with this type of situation, Mark will report the patient's reaction to the next-of-kin and let them make a decision as to whether to attempt further treatment possibly with the help of sedation or general anaesthetic. Clearly, Mark supports patient autonomy in these circumstances even though the patient may be incompetent to make such decisions. He believes that dental treatment

is largely elective, so there is no compelling reason to proceed with treatment against a lack of consent by action.

Likewise, Greg, holds the lack of consent by action as a compelling reason to stop beneficent treatment. But sometimes he will make exceptions to this. He said:

Despite their mental awareness, [a patient] needs to consent to treatment [by] physically permitting me to do the work. That probably isn't as black and white as it sounds. ... During the course of treatment there are difficult moments. ... Sometimes you need to decide 'Are we going to finish this?', or 'Are we going to let this person be?'. That's always a decision the dentist makes. In my world, I can almost overpower somebody to complete a procedure if need be, so it's a delicate balance. ... I attempt a real upbeat, outgoing personality, and use a fair bit of persuasion.

Susan also tends to stop treatment for a hesitant patient also. She said:

I really try not to do things to the patient that they haven't consented to and don't actively want to have done, because I feel like they have so few choices about all kinds of stuff in their lives after they're institutionalized that this is one way that I can make it better for them. ... Usually the family's real sympathetic.

But, in a situation described earlier, Susan reported occasionally being asked by a family member to lie in hopes of gaining the cooperation of an incompetent patient. On a couple of occasions she has acquiesced, but only when it was clear that the patient was incompetent. Susan said:

They may agree if they think the government's going to pay for it because they feel a burden on their families. ... I've only done the lying thing with 'The government's paying for it', a couple of times.

In the situation when there is some risk of physical harm to dental personnel when managing incompetent patients there is a question as to how much risk warrants withdrawing service. Julie, for example, reported:

At one point, when we were doing our screenings, my assistant got punched in the jaw. [So] he didn't get a screening, that's what happened. I don't think I would do something that's putting myself or my assistant at physical risk.

On the contrary, Frank, reported that he:

almost got flattened by a patient. Sometimes they can be so fast - that fist can be out.

Despite the risk he continued with treatment, however, he did not discuss his response to an instance of actually being struck by a patient.

Like Frank, James reported that:

Patients will take a swing at you, and they can be resistant. ... It's a hard one. In all honesty, I think most of it's a behaviour management type thing, and we've already made a decision, meaning myself and the relatives and the medical doctor, that for the betterment of this individual's quality of life, in terms of pain and infection, the technique has to be done, so therefore we just go ahead and do it.

Treating patients when the next-of-kin is the only beneficiary

Although there was general agreement that some patients are best left untreated, the participants disagreed on whether or not to treat a patient when the next-of-kin alone would benefit. This situation was usually discussed in relation to a request for dentures for an incompetent patient.

Mark, for example, reported that he often gets requests:

where mum or dad lost their denture and the son or daughter would like to see mum with a new denture, who sometimes couldn't care less whether they had a denture or not. [Managing this] depends on the level of cooperation. I mean, if you can make a denture, and they're stone cold out of it, [where] they just stare into space all day, you convince the family member, 'What's the point of spending all this money on something that they're not going to function with.' [It will] just make them easier to look at, but as far as function, [whether it would provide] any benefit [for] the patient, [it's] minimum. ... You tend to talk them out of it. I tend not to recommend it. I don't think I ever made a denture for anybody that didn't really want one. But we've had that request lots and lots.

Likewise, Susan reported that:

A lot of the patients were quite mentally debilitated. ... If they're so out of it that they can't [make decisions] then there's not usually very much that I'm going to do. If they have dentures, chances are they don't wear them because they're just not mentally capable of deciding to put them in and keep them in. If they don't have dentures, chances are that they're going to be completely impossible to work on, and if nothing's bothering them, I don't really see the point.

On the other hand, Greg reported that:

It's important for me to think that there's some tangible benefit to people actually getting the care done and that's a thin line sometimes too. Sometimes you do dentistry for reasons other than the person's direct

benefits, in terms of improved health. ... [They] are real reasons - family's reasons,... [or for the] care-aides.

Likewise, Pete reported that he would make dentures for patients who were unaware of what was being done if the family insisted. He said:

People would... usually have very little trouble wearing an upper denture. ... [But come dinner time the lower denture sometimes] gets shipped out with the tray and never seen again. ... [Then] his wife or son comes along and says, 'He lost his denture; make him a new one.', and I'd say, 'Why?' [They say,] 'Because he looks awful.' He doesn't care but they do. ... [So] you make a new lower denture. It was easy for me, because [where I worked there was a third party that] paid for it. ... [If it happened again, I'd] make him another one. ... [But only if the family] absolutely insisted, and I would say, 'He doesn't need this.' ... I think more and more we're realizing that the person who's suffering is the caregiver.

Nonmaleficence overriding beneficence or autonomy

There were several reports of circumstances in which the potential for harm to a patient conflicted with the duties arising from either the principle of beneficence or autonomy. It appears that in these circumstances none of the three duties is consistently dominant. There is substantial variation in what is considered to be harmful and when the risk negates the duty to do good or to respect autonomy. For example, in the case where Carl encountered a daughter requesting a denture for her mother who suffers from narcolepsy, he constructed the denture despite his concern that the woman may accidentally choke on it:

My question at the beginning is, 'How does she feel about it?' 'Oh, you can't ask her. She seems happy, but we're not.' So long as that's clear from the start, I may grant their request to do the work. ... [Once we were finished, I put her partial] in a container and phoned the daughter and said, 'I didn't want to leave this unattended.' ... [My main] concern is there's something in there [she] could aspirate. ... [So we have them sign a] waiver, [so the staff or family] must place [the partial] and remove it, and all the staff [are to] read, understand, and sign that [they] are all up to date with C.P.R., especially the management of choking.

In this circumstance, Carl believed that the autonomy of the surrogate was dominant despite the lack of benefit to the patient or the small but serious risk which he discussed.

On the contrary, Susan recalled similar situations where there were requests made by family members to replace dentures despite the low likelihood of success. Under these circumstances Susan would usually deny the request because she said:

It would probably be worse [to provide the new denture], because... [the patient is] used to what she has. I think sometimes people want to spend a lot of money on a set of dentures, because then they're going to feel like they're really doing the right thing by their parents that they've institutionalized. ... It's a sacrifice for them to pay a thousand dollars, so they feel like, 'Well that's the right thing. ... They think... the only option is to get a brand new [denture]. You can't just reline an old one.

In this case, Susan encounters a dilemma between autonomy, as represented by the duty to respect the wishes of the surrogate, and nonmaleficence, as represented by the duty to not harm the patient by pushing her beyond her capacity to adapt to new dentures. Susan appears to support nonmaleficence in these circumstances.

A unique ethical struggle involving nonmaleficence was the case described where Julie was challenged by a nurse to extract all of a patient's teeth because the patient had seriously bitten care-staff on two occasions. Julie was relieved that she did not have to deal with the case since the man died soon after the request was made. However, if he had lived she said that:

I would have contacted the physician, and family, and the nursing staff. I really think [there] would have to be a major discussion with everyone involved. ... I think if it came to the point where no one could care for him [then it may be best to extract his teeth.] ... It would have to be done under general anaesthetic.

Here Julie is confronted with choosing the lesser of two evils. Extract the man's teeth at the cost of harming him, or leave the teeth in place at the cost of potential harm to the staff. Ultimately, Julie would act carefully in this type of case by involving as many people as possible in the decision, but she reported that she would tend to comply with the nurse's request because of the beneficent duty to remove serious risk of harm to the staff, and to allow necessary care for the patient.

Idealistic versus realistic treatment

The participants gravitated toward two opposing views regarding optimal treatment, ranging from the provision of full restoration of a mouth at one extreme to no treatment at the other extreme. Everyone recognized a tension due to the compromise of the ideals taught in dental school. The participants differed in the extent to which they altered their ideals. Depending on the circumstances each participant would make a decision at either end of the spectrum, however, it appears that some of them favoured the idealistic approach whilst others were willing to compromise more easily. Furthermore, it appears from the responses that dental schools tend to produce professionals with more of an idealist treatment view, but compromise became easier with experience in long-term care facilities and with instruction about the value of realistic treatment goals.

Daniel, for example, when discussing the influence of values on decisions, reported that:

[The attitude of institutionalized elders toward oral health reflects] society's [attitudes] in the sense that [they say], 'I'm not productive any more so my existence is not a value any more.' So, are we supposed to provide [the] same level of care that I would provide to someone who values their existence? ... That's the goal. If a healthy young adult were to walk into the office, I would have an ideal treatment plan. The ideal with the senior in the institution would be exactly the same. I would try to present that in a way that they would agree to it. ... That's how dental school trains us.

Julie, on the other hand, said:

When I started working with institutionalized elders, I think the hardest thing that I found was that I couldn't do the best dentistry. I had to make compromises, and I was quite new and I felt terrible sometimes about not being able to do perfect dentistry, but you couldn't. ... [She added later,] the idea is to help someone. Right? So leaving them alone, even though it goes against you're training, may be the most helpful thing you can do for them.

Likewise, Pete said:

Basically, I was thinking that everybody needed... 28 teeth to eat their food. ... In reality you don't need teeth to eat. ... I was still trying to give that person the kind of treatment that we all thought was ideal dentistry in dental school, and I think that I became more pragmatic as I got older. ... We're all taught [the] ideal treatment plans and I think that is a mistake. I think you learn fairly quickly you have to be more practical. ... I didn't have an ideal in mind for all my patients. ... You can call it a compromise. We call it 'rational treatment planning'. Somebody coined that term... [and] it was a confirmation of what I was already doing - got rid of some of my guilt.

Autonomist versus benefist decisions

The participants recognized two opposing positions on the ethical value of treatment ranging from the *autonomist* view, (decisions based on absolute respect for autonomy - deontological or non-consequentialist), to the *benefist* view, (decisions based on maximizing the good consequences of a decision while minimizing the bad - consequentialist). All of the participants recognized a need to balance the two views. The difference was noticeable in the extent to which their decisions reflected a bias for either philosophy. As with the variation between idealism and realism, the participants occasionally made decisions at either end of the spectrum, but they were not usually this extreme. Nonetheless, it is evident that some participants maintain a strong autonomist view whilst others are influenced more by a benefist view. Furthermore, it appears from the responses that dental schools tend to train professionals with more of an autonomist view, but it appears that with experience some dentists accept the need for occasional decisions to be based more on a benefist view.

Mark recalled that a dentist had extracted a tooth from a confused patient without the son's consent. Despite agreeing that the tooth should be extracted, Mark said:

Somebody did a procedure without consent. I would never do that. I think that's wrong ethically. ... I wouldn't question the [result] at all, just the process in doing it.

Likewise, Mark referred a 90 year-old patient to an oral surgeon for a consult to have an implant supported denture. He said:

[The patient] went in to see [the] oral surgeon for a consult, and walked out with four implants. ... Now, where's the planning here? ... What I didn't do is get on the phone and say, 'What's going on here? People coming in for consults, you put implants in and then worry about the prosthetics.' ... He eventually got the denture made, but to me there was a better to do it. ... The ethical dilemma I saw there was not the final result, which was good, but the process.

On the other hand, Frank said that:

Getting consent... is obviously a concern. ... [If I see a patient and they need treatment I'll] send a report to the family and get the family approval. In some cases, if I see something that has to be done right away, I'll do it right away for that individual... and bill the family for it. Sometimes I'll get

paid, and sometimes I won't get paid. ... Am I going to wait two weeks [for a consent?] No, that's ridiculous.

In response to the question on the most difficult ethical issue in the care of institutionalized elders, Pete reported that:

Overall, you try to do what is best for the individual patient. That's the overriding value. But it may differ, and it certainly did differ from patient to patient. ... I tried to do the best for the individual patient, trying to make some sort of assessment of what that patient needed.

Pete said also that if a patient needed a tooth extracted then he would:

just take it out. ... It needs to be taken out. ... A lot of [the residents] were... ignored [by their families and] the public trustee looked after their money.

Substituted versus best-interest judgements for incompetent patients

A specific circumstance that all of the participants encountered was that of managing the patient who was incompetent. Given this circumstance, the participants generally made attempts to consult with others. Typically, family members, other professionals, or a public trustee would be consulted. Differences between the participants occurred in the way in which decisions were made. Some of the decisions tended toward substituted judgements made by looking at the context of the person's life and previous decisions. In contrast, other decisions were made with a tendency toward best-interest judgements made on the basis of what was best for the patient.

Using a substituted judgement, Julie reported:

I had one patient whose wife always brought him down and he was quite far along with Alzheimer's so he couldn't understand my instructions at all, but he was so good when you came to doing anything with his teeth. He would open to let you brush and he would even hold still to do cervical type fillings. His wife said that he was always really meticulous about his teeth. ... [But] how do you know they want to be treated when you can't get any feedback?

Similarly, Greg said:

A classic example that I go back to is [a facility] where they have an Alzheimer's lock-up. The people in there are advanced Alzheimer's. They really have very little cognitive function at all. There was a woman in that facility who had lost her denture. ... The staff couldn't find the denture, and I

asked them, 'How's she eating?', and they said, 'Fine.' I went back to the family and I said, 'You know, she's lost this denture for a reason; she probably threw it away. She's eating fine, and is there really a need?' The family said, 'No, mum always cared how she looked. It was always very important to her. We want her denture made.'

When discussing the potential for dentures for debilitated elders Susan said:

If they've been living with the situation in their mouth for thirty years and they really don't care to have it changed, I just don't see the point in getting in there and making them feel invaded in one more area. ... They lead a really different kind of life than the average dentist, so it's really sometimes hard for us to put our selves in their position.

On the other hand, using a best-interest judgement, James reported that:

I've always been able to handle every single situation that's popped up in one way or another that, in my personal belief, is for the betterment of the patient. ... Basically, my whole philosophy is, and it is really what works in long-term care home settings, keep the patient out of pain and infection.

Response to a hypothetical case

At the close of each of the initial interviews the participants were given a hypothetical scenario based loosely on an actual situation: A noncommunicative, but cooperative, seventy-six year-old man, who has recently been institutionalized because of Alzheimer's disease, has a number of missing teeth. His family and his physician want the man to have extensive bridgework to replace the missing teeth hoping to improve his deteriorating nutritional status. (See Appendix A for further details).

A brief analysis of the ethical implications of this case imply that the participants are hampered somewhat by the vagueness of the patient's wishes, and the unpredictable treatment outcomes. The patient is functionally incompetent and a family member is acting as his surrogate. The autonomy of the surrogate supports the wish to proceed with the treatment, but the potential for good outweighing the risk of harm is unclear.

The participants were asked three questions in relation to this case: Have you ever been confronted with a similar case in practise?; What are the possible options in this case, and how would you proceed?; and Do you see any ethical issues involved in this case?

None of the participants had ever been confronted with this type of situation in their experience. Most reported that they would need more information to make a final decision. Specifically, they would want to examine the patient and consult with the others involved. Seven of the participants said that on balance they would not provide the treatment requested. The other three said that they might provide the bridgework, but no one was comfortable to proceed based on the limited information provided.

Seven of the participants indicated that the potential benefit was unlikely to warrant the treatment. Here are excerpts from their responses:

[If the dentist went ahead with this treatment, it would be] an abuse in my mind [due to] the failure of the dentist to properly inform the family of the outcomes and the alternatives. That practitioner, to me, should be censured at least because he obviously sold a treatment plan which I would consider to be highly inappropriate. ... This is so far out of bounds. How could this physician have bought this bill of goods, ... I haven't the slightest idea [if it would benefit him], but certainly there are large numbers of people that carry on perfectly well with far less. ... That's dangerous for the reputation of the Profession [and] dangerous for that individual. ... Maybe he couldn't chew up large boluses of food, and therefore would... have problems that way. Well obviously you can give him a softer diet. Now, was that affecting that person's quality of life? I mean, forget this kind of snowball, decision-making tree. ...

I don't believe that's the best decision under those circumstances. You talk the person out of doing it. ... You continue to improve the quality of the relationship with [family] so that your opinion would have greater influence. ... [You could] come across as this... cold, uncaring, hurried dental professional, and say, 'No, I won't do this; I haven't got the time to deal with you folks', [but] if you take the time,... all of a sudden they recognize, 'Well, this dentist really does care, and is really trying to talk us out of doing this for [good] reason',... [then] the quality of the relationship can improve the decision-making process. ...

What's the easiest alternative that you could try that is reversible? You always try the easiest, most practical thing first. If we can change diet and he continues to eat and appears to enjoy it, isn't that the best alternative? We can at least try that. ... Have we spent twenty thousand dollars? ... I don't know if having more teeth in a demented patient means that they actually chew better. ... [Often] they just waste away [anyway.] ... They have no interest in eating, and they literally have to be fed. ... These people will not feed themselves.

Given just those parameters, [and] nothing else,... I would tend to fall on the side of the fence,... not [to] do it. [I would leave] him because I don't believe that putting in one or two more teeth here or there is going to improve his ability to chew. So I [have to] go back and re-educate the son and the physician.

It's a silly thing to do, and I wouldn't agree to doing it. That's an easy one for me. His nutrition would be absolutely identical if we fixed up those teeth *versus* not fixing up the teeth. ... [With time] his oral care would go down if we fixed up the teeth, and therefore, his nutrition would go down a little bit because... things would hurt and fall apart.

I wouldn't be able to sleep at night if I did all that. That's over-treatment and... I think it's taking advantage of a situation for profit. ... At that point, you... say, 'No.' Just because the physician says so, that doesn't hold a lot of weight. ... He won't die of malnutrition because he can't chew. He'll die of malnutrition because he doesn't want to chew, or he's physically lost the ability to chew. ... You don't need teeth to eat, and there's been studies that have shown that too. ... I think you have to sit down and say, 'No, he doesn't need it, and 'No, I don't want to do it', [but] I'm sure he could find somebody that would do it.

He'd always managed fine to eat with the teeth he'd had in the past. ... I would want to talk to the son and probably to the doctor and I would be inclined to the opinion that doing some tooth replacement probably would not help his eating. ... [You would want to make] sure that the mouth is comfortable. It's probably more appropriate through the doctor to speak with the dietician and try and figure out what kind of diet his father might find more appropriate or appetizing. ...

I could see an ethical difficulty if you just went ahead and did a ton of fixed dental work without explaining the likelihood of it having an effect on the father's eating was probably *minimal*. ... If he'd managed perfectly well with the teeth that he's got, I wouldn't see any indication for [it], and I don't think it'd be fair to lead someone to believe that [it] would make a big difference. ... I think it's up to the dentist to explain what you would actually be doing.

I would tell the son that I didn't think that it was necessarily in his best interest to have fixed bridgework. I would look at why his nutritional status was going down hill. If he has teeth that meet, then he can chew, so I don't think that it's his chewing that's causing the nutritional problem. It's probably more a lack of interest in food, or he may have some systemic problem which is causing him to lose weight. ... I really don't think that fixed bridgework is a good idea in an Alzheimer's patient who's going to have difficulty keeping it clean. ...

In terms of the long standing good health of his teeth, and in terms of his quality of life, and in terms of his mouth odour, I think he's better off with a partial, if he needs anything at all. ... Without seeing the patient, it's kind of hard to say, but I'd have to ask, 'How come all of a sudden people want to do bridgework on this fellow? What happened? Did he just lose his teeth? If he just lost his teeth, then what else is poised to go? If he lost them 10 years ago, when he was lucid, and he didn't get them fixed, why not? ... I would have a bunch of questions. It would be hard to make a recommendation just of the bat. ... [But] I could see it happening.

I'd like to know why his nutritional status is deteriorating. My first assumption would be that it was unrelated to the teeth, that it was related to the same reasons his oral hygiene is deteriorating. ... I would presume he's not eating well because he forgets [to]. ...

I would... talk about options and consider some alternatives to crown and bridgework. I find that most family members of people in those circumstances, if you present them with less expensive options and can justify them, they don't usually have a problem with that. ... If he became lucid and said, 'I want crown and bridgework', then that would be more difficult. ... [But this] seems like unreasonable and unnecessary treatment.

The remaining three participants said that in some circumstances bridgework would be appropriate. Here are excerpts from their responses:

In that sort of situation, from a behaviour standpoint, is that option possible? That's one of the first things I would think about. And I would assume, based on the question, that would be okay. ... So it's a decision here based on [the idea that] this person may not appreciate fixed pros[thodontics] in his own mouth, but that's the request from his son and the physician. ... [If] the physician said, 'He's going to live for more than two or three years', say,... [then] I really don't see a lot of contraindications to fixed pros[thodontics] in that case, although it's hard to make a real definite decision based on what you've given me. ... The first option is not to do anything in his mouth, change his diet perhaps. ... A partial denture, I would tend not to suggest strongly... because he's not likely to be able to maintain it very well. ... I'd have to find out what is happening in his diet, [but] fixed pros[thodontics] sounds like a reasonable treatment choice. If it was simply a case of, 'He can't chew because he has insufficient teeth', and that was all there was to it, then it's a great choice.

I would want to hear out the son a little bit more. 'Over what period of time has this deterioration [occurred]? ... 'What sort of things does he use [to keep his teeth clean]?' 'Is there some odour?' 'How are his bowels?' ... [I would] have a good look] in his mouth. ... [I would ask], 'What's the name of your physician?' 'Let me talk to him.' ... Have you tried something else that his mouth can manage without a lot of chewing?' ... I have to hear this out a little bit. It gives me a little time also. ... [There will] possibly [be] improvement with the home care, which is probably not all that good. ... [The decision depends] on a number of things, but I'm not going to put bridges on if there's any mobility in [the] teeth. ... You could [do the bridges] as long as you are quite sure, with the help of x-rays, that that is the reason [for the poor nutrition]. It could be half of it, in which case, okay, but then you have to be on record with them that this is not guaranteeing anything. This may not be the answer. ... [It] may be worth a try,... as long as the son doesn't mind paying for it. ... That's the attitude I would [have. But] I'm not promising anything.

You would have to look [at whether] you perceive... this procedure... to be a benefit to the patient. ... If you perceive it to be a benefit to the patient... [then] can this be maintained? Then you have to look at the oral condition. Can it be made? Then you would make a decision. Is it going to be a positive thing for the patient? Is it going to be a negative thing? If it can be maintained, and it's going to help the patient to function, whether it's for mastication, or whether it's for aesthetics, then if the patient's medical condition is such that the effort and cost warrant [it], in

the son's and the patient's views, and your [views]... then it should be done. ... [It] depends on [judgement.] ... If I felt the trauma to the patient, or the costs involved didn't warrant it, I would recommend that to the son. If the son insisted on it, and the negatives didn't outweigh the positives, I would probably do it. That's the son's request to have that done for his father. Obviously, his son wants it. You're partially doing it for the son. ... [But] normally, as I told you, I tend to be a little more conservative with these. ... You go to the two extremes. [One] being, I won't do anything that I don't feel is right, and you can go to the other extreme where the patient is in control of their body, and if they're with their senses, then it's their decision. ... I tend to probably be slightly more [supportive of patient wishes].

Although none of the participants were sure that they would proceed with fixed bridges with the hypothetical patient, the variation in participant responses demonstrates a fundamental difference in the potential ethical management of this case. Evidently, the seven participants with the majority view disagreed emphatically with the use of bridgework in this case. As a group, these participants argued that bridgework in this case would not only provide no significant benefit to the patient, but it would be both risky for the patient's health and contrary to the patient's established pattern of oral care. In the care of incompetent patients, their argument offers support for compromising from an ideal treatment approach, support for beneficence over autonomy, and support for substituted rather than best-interest judgements. On the other hand, the three participants with the minority view agreed that sometimes with cases like this bridgework would be the best approach. As a group, they argued that, despite the risks involved with providing bridgework for this patient, the wishes of the son and physician should, in some cases, be complied with. In the care of incompetent patients, their argument offers support for maintaining an ideal approach if at all possible, support for autonomy over beneficence, and support for best-interest rather than substituted judgements.

Chapter IV

DISCUSSION

CONCLUSIONS

Analysis of the results reveals that dentists have encountered both practical and ethical problems when providing oral care to elderly residents of long-term care facilities, but the participants of this study appeared to recognize and struggle more with the practical problems. The practical problems they reported related primarily to a lack of support for the service, to inefficiency with the service, and to a questionable financial feasibility of the service. The participants reported that practical problems were the primary reasons for the evident lack of adequate oral care for institutionalized elders. Most of the participants did not recognize the nature of the ethical problems they encountered or the ways in which they resolved them, nor did they understand formal bioethical principles. The ethical problems uncovered related primarily to a lack of clarity in either a patient's wishes or the predictability of treatment outcomes. Although less common, the findings demonstrated also that the participants encountered ethical problems arising from dilemmas or conflicts between the ethical principles of nonmaleficence, beneficence, and autonomy. The combination of practical and ethical problems appeared to compel the dentists to compromise from an ideal treatment approach more common with healthier patients.

The dentists reported very little difficulty making decisions in situations which appeared to present them with ethical problems. Generally, each individual participant maintained consistent opinions and decisions throughout each conversation, and there were also consistencies between the decisions expressed by the various participants. However, there were also substantial differences between the various participants in how they resolved problems from an ethical perspective. These differences were particularly evident in the extent to which the participants were willing to compromise from an ideal treatment approach, and in the extent to which they made decisions from the perspective of beneficence rather than autonomy. The differences offer evidence

of the existence of ethical problems and they highlight the need to expand research on the types of ethical problems encountered by dentists and how they resolve them.

Despite their differences, the dentists tended not to disregard the wishes of patients or surrogates unless a treatment request was made which the dentist believed to have no benefit. The participants did not make decisions using an absolute *hierarchy* of principles as suggested by Veatch (1985), nor did they make decisions using *casuistry*, *randomization*, or *considered decisions*. Rather, they made decisions based almost exclusively on the details of the individual situations encountered. The ethical danger with this approach is that it can be used to justify almost anything as was pointed out by Veatch (1985) to be the weakness of a *considered decision* also.

The fundamental finding of this study is that ethical problems in the oral care of institutionalized elders occur when there is a deviation from the ideal situation. This likely affects all dentists, and consequently all dentists face ethical problems. However, the environment of long-term care facilities, and the physical, intellectual, and emotional condition of the facility residents increases the chance of a deviation from the ideal. The consequences of this are two-fold: firstly, there is pressure to compromise treatment from idealistic to realistic; and secondly, there is pressure to make decisions more from the paternalistic perspective of beneficence (consequentialism; supporting the best treatment outcomes), and less from the perspective of autonomy (non-consequentialism; supporting the patient's wishes).

HYPOTHETICAL MODEL OF DENTISTS' ETHICAL PERSPECTIVE

By crossing the autonomy-beneficence continuum with the idealist-realist continuum it is possible, hypothetically, to construct four different ethical perspectives which dentists may hold in coping with the oral care of institutionalized elders (Figure 2). The results suggest that the participants tend to hold balanced perspectives, located near the centre of the model (within the inner square), rather than the extreme perspectives near the outer edge of the model. The results suggest also that dental schools tend to produce professionals with an autonomist-idealist

perspective (the upper-left section of the model). When confronted with a deviation from the ideal situation, as is common in long-term care facilities, the dentist must often make treatment decisions contrary to autonomy and idealism which appears to place some dentists in a state of psychological dissonance so that feelings of inadequacy surface. It appears also that both *experience* with debilitated elders and *knowledge* about the value of compromising from an ideal treatment seem to enable some dentists to cope with the care of institutionalized elders in greater consonance with their professional training despite holding an ethical perspective other than autonomist-idealist.

Figure 2. Hypothetical model of dentists' ethical perspective with institutionalized elders.

IMPLICATIONS

The findings of this study support the suggestions of Jong (1989), Pollick (1981), Schwartzheid (1989), and Wettle (1987) that the care of institutionalized elders presents dentists with

ethical problems. The study provides, for the first time, evidence of the nature of those ethical problems and how dentists resolve them.

The results offer support also to the finding of MacEntee *et al.* (1992) that dentists tend to feel *inadequately trained to offer service in long-term care facilities*. The results add to this finding by demonstrating that some dentists feel badly about the service they are able to offer to institutionalized elders because it seems to contradict their professional training in ethics which stresses the importance of idealism and autonomy. On the contrary, the results suggest that some dentists are comfortable with the service they offer to institutionalized elders despite the seeming discrepancy with their professional training. The dentists who are more comfortable with the service they offer tend to have more experience and knowledge related to long-term care work, which offers support to the conclusion of MacEntee *et al.* (1992) that dentists will be better able to provide service to frail elders if the dental curriculum includes both instruction and experience with disabled residents of long-term care facilities.

Notwithstanding the discussion related to ethical problems, it is apparent from the results that the participants are troubled more with resolving practical problems especially those related to questionable financial feasibility. Of interest to the implications of the study is that the participants differed in their opinions about financial feasibility which suggests not only that certain styles of long-term care service are feasible, but that further study is needed to document the nature of these styles so as to improve the ability of dentists to offer care to institutionalized elders.

LIMITATIONS

Despite the depth of opinions expressed by dentists in this study, the results should be viewed as preliminary because the sample involved only ten dentists practising in a small area in Canada. The results do not represent the actual behaviour of the dentists, only their reported behaviour. Moreover, the results of this study are influenced substantially by the thoughts and opinions of the researcher, as is the nature of qualitative research. The involvement of ten

individuals rather than one or two strengthens the validity of the results through what Yin (1989) terms *replication logic*. However, the potential for systematic influence introduced by the researcher is more difficult to account for. Although replication is not possible with a qualitative method, a similar study undertaken by a different investigator in another part of the world would provide the best evidence to extend and refine the conclusions of this study. Another suggestion would be to have a second researcher analyze the raw transcripts from the current study and to compare similarities and differences with the two sets of conclusions.

The results of this study are limited also in that it is not yet clear the extent to which ethical problems encountered by dentists in long-term care facilities are different from those found in other practice settings, or whether the ethical problems are more common or more difficult to resolve compared to other settings. Likewise, it is not clear whether there are differences of opinion between the type of dentist who chooses to work in long-term care facilities and those who choose a more conventional setting. It is also not clear whether the existence of ethical problems influence whether or not dentists will choose to provide service in long-term care facilities.

FUTURE RESEARCH

The results of the study and its limitations offer several potential avenues of future investigation. The most obvious would be to repeat the study with a wider diversity of dentists including general dentists, and specialists with and without experience in the care of frail elders. In addition, a subsequent study could be broadened to include both qualitative and quantitative social research methods so as to provide quantitative evidence of the extent of dentists' opinions and attitudes. Some of the obvious questions to investigate include: Are ethical problems in the care of institutionalized elders different from or more difficult to resolve than those in conventional settings?; Do ethical problems influence whether dentists will offer long-term care service?; Does experience and instruction related to long-term care work influence dental students future willingness and ability

to provide such service?; and What are the determinants of an improved quality-of-life for patients receiving oral care in long-term care facilities?

CONCLUDING REMARKS

In addition to the growing importance of developing new and innovative treatment modalities for institutionalized elders, it is important for society to develop the social capacity to care for these people. Social research offers a significant avenue toward this goal, but it is by its nature subjective. It cannot be carried out with the objectivity of bench-type research. The only question which remains then is whether or not social research is worthy research from the perspective of societal benefit. The answer is that it is worthy if only because even perfect clinical treatment will not always improve a patient's quality of life from their own perspective. Despite innovative treatment modalities possible only with objective bench-type research, the final measure of successful treatment is subjective because it can only be measured at a social level. This study has uncovered only a small part of the complex social information needed to attend adequately to the current and future oral-health needs of institutionalized elders. It is particularly apparent from this study that dentists are not in agreement about the best way to make ethical decisions about the oral care of institutionalized elders. It may well be that this is because dentists are still trained primarily to care for healthy and wealthy patients, and society does not yet seem to value oral-health care for frail elders. These facts are not surprising since, until recently, the oral care of institutionalized elders was limited usually to denture care which could be rendered with ease relative to the much more difficult, but increasingly necessary, prospect of caring for teeth. In some ways, the dental profession has been so successful in motivating independent adults to improve their oral health that oral diseases are now becoming the problem of old age and particularly a problem for those who have lost the ability to care for themselves. It is evident that more attention is needed to improve the oral care of institutionalized elders, and research into the implications of ethical issues is one area of importance.

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Appendix A

LETTER OF INITIAL CONTACT

University of British Columbia
Department of Clinical Dental Sciences
Faculty of Dentistry
2199 Wesbrook Mall
Vancouver, BC, Canada
V6T 1Z3

August 27, 1993

Dr. _____

Dear Dr. _____,

I am a graduate student in the Faculty of Dentistry at UBC, and as part of my degree, under the supervision of Dr. Michael MacEntee, I am conducting a study in which I invite you to participate.

My study will examine **the ethical issues which dentists believe are significant in managing the oral health of elderly residents of long-term care facilities**. Your participation is very important to the study because of your experience with long-term care residents. If you agree, I would like to speak to about your experiences with elderly patients and to record your thoughts and opinions on how ethical issues influence the oral health of institutionalized elders.

The study will involve two tape-recorded interviews at your convenience lasting about one hour each. The taped interviews will be transcribed in writing and you will be given an opportunity to review and modify a summary of the transcriptions and my interpretations as you wish. All personally identifiable information will be omitted from the transcriptions, and the tapes will be erased once the project is complete. The information will remain confidential, and under no circumstances will you be identifiable in any reports on the study. Of course, you have the right to refuse to answer any question and to withdraw from the study at any time without prejudice of any kind. Furthermore, I want to assure you that the study will in no way pass judgement on the quality of your professional opinions or services.

We are unable to provide you with financial compensation for your time, however, by participating you will have a unique opportunity to express your thoughts on how to manage the oral health of frail elders and this should in turn help dentists and other caregivers improve the health and quality of life of the older population.

I will be contacting you shortly to discuss the study further and to arrange a meeting if you choose to assist me. In the meantime, please feel free to call and ask any questions.

Yours Truly,

S. Ross Bryant, B.Sc., D.D.S.
Home ph. 731-7704 (before 11:00 p.m.)
UBC ph. 822-5064

PARTICIPANT CONSENT FORM

University of British Columbia
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V6T 1Z3

Title: A study of ethical issues encountered by dentists in the management of elderly residents of long-term care facilities.

Investigators: Dr. Ross Bryant; Supervisor: Dr. Michael MacEntee;
Other Investigators: Dr. Alister Browne, Dr. Earl Winkler, Dr. John Silver.

This study is being conducted in partial fulfilment of the Master of Science thesis requirements of Ross Bryant. The following information has been provided so I can make an informed decision about my willingness to participate:

I understand that I will participate in two tape-recorded interviews, arranged at my convenience, each of about one and a half hours in length, to investigate **the ethical issues which dentists encounter in the management of elderly residents of long-term care facilities.**

I will be asked to describe the professional experiences which I feel are relevant, and to share my opinions on how ethical issues influence the provision of dental services to institutionalized elders. I will be provided with a written summary of the first interview which will be reviewed during the second interview to clarify the interpretation of my experiences and opinions;

All the information that I provide will be remain confidential and I will not be identified personally in any report of the study. To assure this, only those directly involved with the project will have access to the original records and all personal references will be omitted from the transcripts and reports. Once the project is completed, the taped interviews will be erased;

I understand that my participation is voluntary and that I have the right to refuse to answer any question and to withdraw from the study at any time without prejudice of any kind. Furthermore, I understand that I will not receive payment for my participation.

I have read and understood the above and consent to be a participant in this research project. All questions about the study have been answered satisfactorily, and I know that I can contact Dr. Ross Bryant (home 731-7704), or Dr. Michael MacEntee for further information at the address given above or at 822-5064. I acknowledge receipt of a copy of this consent form.

Participant - Dr. _____ Date _____

signature of participant

signature of researcher

INITIAL INTERVIEW GUIDE

During the initial phone contact I will briefly introduce myself and my own practise experiences and research interests to begin to establish rapport with the dentist. If the opportunity presents, I will also ask a few questions regarding the dentists background and experience to help familiarize myself with the dentist prior to the first formal interview.

1) Brief Demographic Questions: Name _____.

Date _____ Gender _____.

1. What age of patients do you see in your practise?

- a. under 25 years of age.
- b. 25 to 49 years of age.
- c. 50 to 64 years of age.
- d. 65 to 79 years of age.
- e. 80 to 90 years of age.
- f. over 90 years of age.

2. Estimate what proportion of your patients are 65 years or older?

- a. none
- b. under 10%
- c. 10% to 25%
- d. over 25%

3. What year did you graduate from dental school? 19_____.

4. How much geriatrics training did you receive in dental school?

- a. None
- b. periodic lectures.
- c. formal course involving at least 10 lectures.
- d. clinical observation in an geriatric care institutional setting.
- e. direct clinical experience in a geriatric care institution.

5. What education or training have you completed since graduation?

- a. Continuing education in geriatric, institutional or special care dentistry.
- b. General Practise Residency / Hospital Residency.
- c. Specialty diploma.
- d. MA.
- e. M.Sc./M.S.
- f. MPH.
- e. Ph.D.
- f. other, specify _____.

Please give all formal titles year received

_____ 19_____.

_____ 19_____.

_____ 19_____.

6. Where do you conduct your practise?

a. Vancouver	d. Vancouver Island
b. Greater Vancouver	e. Seattle
c. Victoria	f. Other, specify _____.

7. Please estimate the number of hours you spend in your practise each week?

a. under 10 hours.	c. 21 to 30 hours.
b. 11 to 20 hours.	d. 31 to 40 hours.
	e. over 40 hours.

8. Estimate the number of institutionalized or homebound patients you treat each week?

a. under 5 patients.	c. 11 to 15 patients.
b. 5 to 10 patients.	d. over 15 patients.

9. How many years have you worked with institutional or homebound dental patients?

a. under five years.	c. 11 to 20 years.
b. 5 to 10 years.	d. over 20 years.

10. What types of service do you offer your institutional or homebound patients?

a. Preventive services.	f. Complete or Partial Dentures.
b. Emergency care.	g. Periodontal services.
c. Conservative oral surgery.	h. Endodontic services.
d. Conservative Restorative services.	i. Fixed Prosthodontics.
e. Denture repair, reline, or rebase.	j. Other, specify _____.

The demographic questions should lead naturally into the unstructured discussion of ethical issues which dentists may encounter with the treatment of long-term care residents. Responses will be encouraged with neutral questioning (probes) as necessary to fully investigate the respondent's thoughts and experiences with regard to a particular issue. The interview technique will be refined by testing the questions in the first interview and in each subsequent interview thereafter.

2) Unstructured Interview Guide:

My interests are basically focused on managing the oral health of institutionalized elders.

Specifically, I want to uncover what ethical issues are problematic in this area and how can these be dealt with. It has been suggested that health care for institutionalized patients often involves ethical problems however no one has documented this in the area of dentistry.

Initially my goal is to learn about your experiences and opinions, and I will ask some more specific questions near the end of the discussion. I'm not concerned that you have a constant flow of ideas, and I will try to ask questions which encourage your thoughts. Essentially I want you to think out loud as much as you can and try to teach me about the ethical issues that you think are involved in managing elderly residents of long-term care facilities and how you cope with these.

1. I'd like to know when you first started working with institutionalized elders?
Why have you taken this interest?
Where have you worked with institutionalized patients?
2. In your opinion, what level of oral health do institutionalized elders have on average?
Is it adequate?
Can you give any examples to support this view?
3. Can you give me a brief thought on what ethics means in dentistry?
4. **I want you to think about the most difficult ethical issue or dilemma that you have experienced with institutionalized elders?**
What other examples can you think of?
Do you recall any good or bad experiences with how you've coped with these difficulties?
5. Can institutionalized elders maintain their oral health as they choose?
Should efforts be made to improve their oral health? Why and How?
6. What role can individual dentists have in managing the oral health of this group? How?
What role can the profession and governments take in this? How?
7. How comprehensive do you think dental care should be for institutionalized elders?
Why you feel this way?
8. How are decisions made about the dental care of debilitated elders?
Do you have any experiences related to this?
How do you participate in these decisions?
Who else is usually involved?

3) Focused Interview Guide:

Autonomy

1. Are there times in the treatment of frail elders that you would justify proceeding with treatment even though a patient doesn't fully understand what is being done?

When would this be okay? When wouldn't it be okay? Give examples.

2. How would you manage a situation where a family member wants a particular treatment which you have recommended, but the patient is very reluctant?

Can you give me any examples of your experience with this or similar situations?

3. Have you ever been in a situation where a patient wanted a recommended treatment but their family did not?

4. How do you determine if a patient is competent to make treatment decisions for themselves?

Do you have any examples?

General

1. Is there a difference between what a dentist is legally required to do and what is ethically required?

Can you give any examples?

2. How would you approach ongoing dental care for a regular patient of yours who has become a long-term care resident in a facility you have never been to?

What is your opinion on how to approach dental care if the patient develops dementia?

Are there any unique difficulties to be expected with this patient and how could they be managed?

3. How would you manage a confused patient who agrees initially to have a fixed bridge constructed and has paid for it in advance, but who refuses to let you place the bridge once you have it constructed?

Justice

1. Do you think that institutionalized elders can generally access adequate oral care? Should efforts be taken to improve their access? Why and How?

2. Does the dental profession care for disabled elders?

In your opinion, what are some issues related to this question?

Do you have any experiences which could help clarify this for me?

Beneficence

1. Are there unique problems in determining what care is appropriate for institutionalized elders?
Do you have any personal experiences related to this?
2. In your opinion, what effect does oral care have on the quality of life of debilitated elders?
Can you remember any specific examples?

Hypothetical Case

Think about some of the ethical issues or dilemmas you might face with the following situation.

A seventy-six year old man is presented to you with a diagnosis of probable Alzheimer's disease. He has recently been institutionalized. He appears tired and uncommunicative but is reasonably cooperative. According to his son, the man's mental condition has been deteriorating for the past three years. The son has recently consulted with a long time family physician and has been advised to have the father's missing teeth replaced in order to improve his deteriorating nutritional status.

Your examination reveals the man is missing all four first molars and second bicuspid as well as the upper right first bicuspid and the upper left lateral incisor. All four second molars are functioning and most of his remaining teeth are heavily restored with amalgam or composite. The right lateral incisor has been restored with a porcelain fused to metal crown. His remaining occlusion seems stable and you detect no pathological mobility or pocketing. Although he has no caries, he has moderate generalized plaque build-up and gingivitis. No disease is noted on radiographs and you can find no other significant problems.

The son is unaware of how long his father's posterior teeth have been missing, however he knows that the incisor was extracted only 2 months previously following an "abscess". The son wants you to use fixed bridges for the missing teeth. Consultation with the physician confirms the son's concerns. A diagnostic wax-up assists you with a manageable but expensive treatment plan.

Have you ever been confronted with similar choices in practise?

How can you manage this situation, and what options might be possible?

Do you see any ethical issues or dilemmas involved with providing treatment in this case?

REVISED INTERVIEW GUIDE

1) Brief Demographic Questions: Identical to the INITIAL INTERVIEW GUIDE

2) Unstructured Interview Guide: Introductory comments: Identical to the INITIAL INTERVIEW GUIDE, except for the addition of the following statement just prior to the questions:

"The following general questions are offered to help generate discussion, however, it is important to realize that our conversation is also open to the issues you wish to discuss. Please consider these questions within the realm your own experience. If you wish you can jot down a few of your ideas, but it will not be necessary or helpful to prepare in any formal way."

Questions altered to read as follows:

1. I'd like to know why you have taken this interest in working with institutionalized elders?
Where have you worked with institutionalized patients?
2. Do you think dentists encounter difficulties caring for debilitated elders?
Do you have any personal experiences with such problems?
Are these problems unique to this group?
3. In your opinion, what is the average level of oral health which institutionalized elders have?
Is it adequate?
Can you give any examples to support this view?
4. Does the dental profession care for disabled elders?
In your opinion, what are some issues related to this question?
Do you have any experiences which could help clarify this for me?
5. Can institutionalized elders maintain the oral health they choose to?
What are the experiences you have with this?
6. What role can individual dentists take in managing the oral health of this group? How?
7. How difficult is planning and undertaking treatment for debilitated elders?
How do you participate in treatment decisions?
Who else is involved in these decisions?
Do you have any experiences related to this?
8. How comprehensive should dental care be for institutionalized elders?
Why do you feel this way?
9. What role can the profession and society take in managing the oral health of this group?
How?

3) Focused Interview Guide: Altered to read as follows:

General

1. Can you give me a brief thought on what ethics in dentistry means to you.
How would you distinguish between ethics and law?
- 2. What would you say is the most difficult ethical issue or dilemma that you have experienced with institutionalized elders?**
What other examples can you think of?
Do you recall any good or bad experiences with how you've coped with these difficulties?
3. Is it financially viable to offer dental service to institutionalized elders?

Patient Autonomy

1. Are there times that you would go ahead with treatment for a debilitated elder even though they don't fully understand what is being done?
Do you have any experiences when this was okay?
When wouldn't it be okay to undertake such treatment?
Give examples from your experience.
2. What does informed consent in dentistry mean to you?
Do you recall any difficulties with obtaining informed consent for disabled elders?
3. How do you determine if a patient is competent to make treatment decisions for themselves?
Do you have experiences where this was a problem?
How do you manage a patient who is not competent to make their own decisions?
Other than the patient who do you get involved with making treatment decisions?
Do you ever recall a conflict between the treatment wishes of a family and patient?
4. Do you ever recall difficulty with a patient becoming resistant during treatment?
How did you manage this situation?
How did this make you feel?

Beneficence

1. Have you experienced difficulties in determining what care is appropriate for institutionalized elders?
2. In your opinion, what effect does oral care have on the quality of life of debilitated elders?
Can you remember any specific examples?

Justice

1. Do institutionalized elders have adequate access to dental services?
Why do you feel this way?

Hypothetical Case

Think about some of the issues or difficulties you might face with the following situation.

A seventy-six year old man is presented to you with a diagnosis of probable Alzheimer's disease. He has recently been institutionalized. He appears tired and uncommunicative but is reasonably cooperative. According to his son, the man's mental condition has been deteriorating for the past three years. The son has recently consulted with a long time family physician and has been advised to have the father's missing teeth replaced in order to improve his deteriorating nutritional status.

Your examination reveals the man is missing all four first molars and second bicusps as well as the upper right first bicuspid and the upper left lateral incisor. All four second molars are functioning and most of his remaining teeth are heavily restored with amalgam or composite. The right lateral incisor has been restored with a porcelain fused to metal crown. His remaining occlusion seems stable and you detect no pathological mobility or pocketing. Although he has no caries, he has moderate generalized plaque build-up and gingivitis. No abnormalities are noted on radiographs and you can find no other significant problems.

The son is unaware of how long his father's posterior teeth have been missing, however he knows that the incisor was extracted only 2 months previously following an "abscess". The son wants you to use fixed bridges for the missing teeth. Consultation with the physician confirms the son's concerns. A diagnostic wax-up assists you with a manageable but expensive treatment plan.

- 1) Have you ever been confronted with similar choices in practice?
- 2) How can you manage this situation, and what options are possible?
- 3) Do you see any ethical issues or dilemmas involved with providing treatment here?

Afterword

1. Are there any other issues you wish to discuss?
2. Can you suggest any other questions which could help me with this project?

LETTER OF SECOND CONTACT

University of British Columbia
 Department of Clinical Dental Sciences
 Faculty of Dentistry
 2199 Wesbrook Mall
 Vancouver, BC, Canada
 V6T 1Z3

February 2, 1994

Dr. _____

Dear Dr. _____,

Thank you for your patience in waiting for me to report back on my study of ethical issues in long-term care dentistry. I have reviewed the tape of our first interview and I have constructed a descriptive summary of the experiences and opinions you expressed. In doing so I have used the pseudonym Mark Besdine in place of your name, and I have structured the summary with the following outline:

- i) Background, ii) Level of Oral Health and Quality of Life,
- iii) Planning and Providing Oral Care, iv) Professional Ethics,
- v) Practical Difficulties, & vi) Roles of the Dentist, Profession, and Society.

Please review this summary and I would be grateful if you would give me your opinion on its accuracy and validity. Please let me know also if any thing of importance has been omitted or if there is anything you would like to add or alter now that you have had some time to reflect on the questions posed. You may find it helpful to make notes on specific points you want to discuss at our second interview. I will be calling you shortly to arrange the interview which I will also be tape-recording so I can document your comments accurately.

I look forward to our meeting, and once again, thank you for supporting my research project.

Yours Truly,

S. Ross Bryant, B.Sc., D.D.S.
 Home Ph. 731-7704 (before 11:00 p.m.)
 Messages 822-5064

SECOND INTERVIEW GUIDE

1. Does this summary **accurately represent your experiences and opinions related to the care of institutionalized elders**?
2. Is there **any thing you wish to add or change** in the summary?
3. What do you understand of the use of ethical principles in making decisions in health care?
4. What essential information needs to be collected when making decisions about the oral care of institutionalized elders?

How do **values** play a role in this?

Appendix B

EXCERPT FROM AN INTERVIEW TRANSCRIPTION

S. Ross Bryant: M.Sc. UBC - January 15, 1993 (25 hours) by Ross Bryant.

Transcription of initial interview with Dr. Mark Besdine.

Taped-recorded on December 12, 1993 - 4:30 pm.- 6:20 pm - Length 1 hour and 50 minutes.

1. "... " = pause ; " - " = a change in flow of the sentence or an incomplete sentence.
2. Symbols beginning each paragraph: "C" = Comment; "Q" = Question; "PQ" = Probe question or Probe comment; "A" = answer.
3. { } = to indicate the speaker's first initial.
NB: subjects name and other names discussed by the subject have been altered to protect the identity of those involved.
4. [] = to indicate part of the transcript which is either inaudible or an unspoken action related to the conversation.
5. [] = to indicate Ross' comments, included for clarification but not part of the original conversation.
6. "Uh", "Ah", "Yeah", "Right", "You know", "Kind-of", "Kinda", repeated words and repeated short phrases, and incomplete words are often left out of the transcript where they are not directly part of the conversation.

(a number of pages eliminated from the sample...)

PQ {R} Okay, what's the most common reason then - at that - for someone, who is making... - a guardian, - to bring someone, that they're making a decision for, to you? What's the most common reason?

A {M} Probably perceive a need of... treatment of some sort. {R} But what's the most common need that they perceive? {M} Well, usually, I think there is some history of pain or swelling involved or... there's new habits that are going on that they don't understand with their teeth - they're biting something and they want it checked out. {R} You're talking about... disabled adults. {M} Ya, disabled adults. ... {R} Is that common? - chewing on their fingers you're talking about, or chewing on... forks or something or - {M} Ya, it's some kind of habit change with their mouth. ... [slaps cheek a couple of times] - banging their cheek or whatever. {R} They come to you and ask about it. {M} A lot of them perceive that [inaudible] they can't see anything on the mouth or on the cheeks so there must be something the matter with the teeth. {R} Pain... probably. {M} Pain or something. So they come and get that checked out.

[5:30 pm. - 60 minutes into the interview]

PQ {R} Okay, so how often would you see someone who can't make their decision but their coming in because someone else perceives a need... aesthetically?

A {M} Not very often. {R} Very rarely. {M} Very rarely.

C {M} I can think of, oh, maybe three or four cases with - they said they needed a - should have a partial 'cause they'd have trouble eating, so if you had a - some front teeth they could... maybe chew better - might look better. {R} Okay, so... who said? A guardian said. {M} Guardian said. Ya. ... {R} So what - this particular case - is it a - one particular case that you remember? {M} I remember - ya - two - actually one - {R} Similar. {M} Similar - In the O.R. - or... she came into Biltmore - could deal with her with tongue depressors... and stuff without any... G.A.. Might have had some valium [a sedative which can be given in tablet form] - some - a lot of times we give 'em five or ten milligrams of valium [inaudible] before. {R} Sedative. {M} [nods] To calm 'em down 'cause it's... - sometimes when you don't have it they... - cooperation is poor. {R} So - under local anesthetic we're talking. {M} Ya, but usually - like for cleanings - routine checkups. ... This one case from Mountain View - two caregivers would come with her 'cause... it takes about two caregivers. They perceived that maybe she could - maybe chew better... because she had no front teeth - upper or lower. [inaudible] make some partials for her. So I took some impressions [a plastic-like mould of the teeth taken to construct the denture] and... made some. She wore the uppers but apparently never wore the bottoms. ... {R} Because they didn't - they were to loose or because she didn't... perceive - {M} She wouldn't - she pushed 'em out with her tongue - didn't like 'em... - out they'd come. But she liked her uppers - she liked her upper ones. [points to his front teeth three or four times in quick succession] {R} 'Cause she could perceive that there was this... - it looked nicer. {M} Looked nice for her I guess. {R} Maybe. {M} Communication would - you never guess - you never know for sure. [shakes head] ... Caregivers, over time, have... a pretty good idea - they'll tell you she's... happy... - she likes that. You don't get that directly sometimes, but... just by their... emotions or... something they have with the caregivers - they can tell. [nods] - 'especially the ones that have... been with them a long time. {R} Ya, a long time.

[FOCUSED INTERVIEW GUIDE]

[5:32 pm. - 62 minutes into the interview]

C {R} Okay... leaving those questions a little bit for now - I might - anyway I'll leave it for now. There're some more specific things... which we may already have talked about - some - quite a few actually - already. Experiences really is what I'm looking for. If you can think about whether - {M} Specific cases. {R} - these apply. Ya, specific cases where these have applied - or similar cases. {M} Ya. {R} And talk about them a little bit... but -

Q {R} In the care of debilitated elders or institutionalized elders or institutionalized patients... would you ever justify proceeding with treatment even though the patient doesn't fully understand what's going on? And when and how do you distinguish when it's okay and when it's not okay... to go ahead with that?

A {M} Well, if you... see - like a disease process that could cause them pain or systemic problems. ... {R} Such as an - {M} A huge perio. abscess. [an acute infection of the gums and/or bone surrounding teeth] {R} So an abscess or infection. {M} Ya. {R} Any other time. {M} Like a permanent tooth that's asymptomatic... [shakes head] - no. {R} You'd leave it alone. {M} Sure. ... But if... it has a... potential to flare up or if it has flared up [probably refers to acute pain] in the past so it's the third time you're treating it... you talk to the... next-of-kin - give 'em the low down - ups and downs and... it's good and it's bad consequences - prognosis... do it from there.

(remaining pages eliminated from the sample...)

SAMPLE OF A VALIDATED NARRATIVE SUMMARY

S. Ross Bryant: UBC - March 12, 1994 - Validated Summary of interview with Dr. Mark Besdine.

Tape-recorded on December 15, 1993 - 4:30 p.m.- 6:30 p.m. - Length 1 hour and 50 minutes.

- Most names dates and ages have been altered to protect the identity of those involved.

- All quotes are referenced back to the page number of the original transcript.

i) BACKGROUND

Dr. Mark Besdine is a general dentist in Canada. He graduated from dental school after 1979, and since then he has attended a few seminars related to geriatric dentistry. During his education he had the occasional lecture on geriatric dental care and he had a brief opportunity to treat residents of long-term care facilities which provided his "first contact with institutionalized people".³

In the year following graduation Mark completed a General Practise Residency associated with a hospital-based extended care unit (E.C.U.), where most of his patients there were institutionalized elders. It was occasionally necessary to provide bedside care, however, this was usually limited to a visual examination and cleaning since it was difficult being "bent over"⁶ with "no adjustability".⁶ They "brought most patients to the clinic"⁶ and transferred them to a dental chair for "more efficient"⁶ treatment. For some bedridden patients he would "put the bed in where the chair was"⁶ so "light, suction, water syringes, and compressed air,"⁶ were close at hand. Many of the residents were seen on a "recall basis (every few) months",⁴ and it was common to have patients "refer(red by) a physician (or) nurse"⁴ who had a concern. Most of Mark's time there was spent providing "basic restorative"⁴ and "preventive"⁴ treatment. He also extracted a few teeth and constructed the occasional denture. Rarely was "fixed work"⁴ provided, and he couldn't see "the point of doing"⁵ periodontal surgery either. Most patients had no way to maintain "their oral hygiene"⁵ so such treatment had "a poor prognosis."⁵ People "lose a lot of proprioception when they get older (so) they can carry food in their mouth without realizing it. You or I would... (routinely remove it, but) they seem to not notice it (or) not care any more, so their oral hygiene is relative(ly) poor."⁵

He now sees patients of all ages including a few debilitated patients who are usually "brought in(to the office) by their caregivers".³ 'It's much rarer (now for Mark to treat) debilitated elderly"⁴ patients. "I might have six people that, due to Alzheimer's"⁴ disease or memory problems, need to be accompanied to the office by "their daughters or sons",³ and "we always converse with the caregiver for consent"⁴ to treat these patients.

Mark believes that "there's a need"² to improve the oral care of institutionalized elders. "You can see a need right away".² He also says, we live in an "educational society",¹ where "attitude(s)"¹ and "values"¹ toward oral health are changing over time, so more people now want to keep their teeth healthy.²⁰

ii) LEVEL OF ORAL HEALTH AND QUALITY OF LIFE

In Mark's experience, the level of oral health which institutionalized elders have is "inadequate. Even in an educational facility like the E.C.U. were there's a dental clinic staffed by dentists, residents, (and) hygienists. Imagine the ones that don't have (a) dental clinic".⁵ When asked, 'Do you think that most institutionalized patients can maintain the oral health that they choose to?', Mark said, "I don't know that they choose to, but (often they have) oral hygiene, host resistance, (and) bacterial flora such that, if they (have) had their teeth that long, nothing dramatically (is going to) change where all of a sudden (they are going to) get perio(dontal) disease and lose their teeth."⁹ Their "care is maybe diminishing, but it's usually at a rate where it's not real urgent to get in there and re-educate them in hygiene."⁹ When asked, 'How many institutionalized elders have teeth', he said, "I think now over fifty percent have at least one tooth. (The) retention rate of our teeth is climbing up over the years."¹³ "I'm just guessing but (only) fifteen percent of"¹³ institutionalized elders are now chewing with their gums, and "most of them do have one or two teeth."¹³

Quality of Life

When asked, 'Then what's the point in doing any dental treatment for this group?', Mark recalled a similar question he had been asked in dental school, " 'Why don't you just extract everybody's teeth? You don't need them to live, it's not like a liver or kidneys or heart.' "⁵ For "quality of life you need them."⁵ For example, "a lot of (debilitated elders) are still in tune with aesthetics. They still comb their hair, put their lipstick on, (and) when they've got a front tooth missing they visit you, (although) not all of them. Some of them don't wear their dentures (and they have) no intention of wearing them. You get a range, a bell curve, like any other aspect you consider."¹¹ "Quality of life (is) an intangible, unmeasurable thing."²⁵ "You can't make a blanket statement for everybody, but to some people (oral health is) important and to some people it isn't."²⁵ "The more you educate them, saying teeth are important, (the more likely it is that good oral health will become) a perceived need, (and then) they will (want) their teeth"²⁵ maintained. This is "an educational - societal problem."²⁵ The impact of a person's oral care, "if they perceive it as a value to themselves, (is) a lot. You can take away someone's self-esteem pretty quickly by not providing them with a denture when they've lost it."²⁵

For example, I recall, an elderly patient trying in "her partial denture for her front teeth, (she) smiled ear to ear, (obviously) happy."²⁵

However, for someone who is less aware of their surroundings, the impact that oral care has on their quality of life "is different. You have to define quality of life for them."²⁵ Some people "don't even know their having meals".²⁵ It's problematic to "make generalized statements (about quality of life, such as), 'In no pain' ".²⁶ The problem is that "quality of life is relative to what you base it on.

So you (have) got to watch what you're basing things on. Quality of life compared to what? Compared to what it was a week ago, (or) ten or twenty years ago."²⁶ In other words quality of life is "always"²⁶ changing.

iii) **PLANNING AND PROVIDING ORAL CARE**

Perceived Need

Mark notes that many elderly people of today grew up in an era when they "perceived, 'I'm going to get dentures at twenty-one anyway, (so) why brush my teeth?' But some of them still have their teeth."¹⁹ Most seniors "are just getting to be old and their dental I.Q. is vastly different (from) the baby boomers."²⁰ Consequently, many of these people wonder, 'I've "had these (teeth) for sixty years, am I going to lose them?' (Even though the) bone level's good (and) the gingiva's good, a lot of them still perceive that they're going to lose their teeth".²⁰ "It's getting to be almost a truism that they'll have their teeth for a long time which puts a hell of a load on the Profession. More load than in the '40's and '50's where people didn't perceive a need (to keep their teeth). But now if you take a tooth out, (their response is often), 'Why didn't you do a root canal?' Root canal's (are) a lot harder to do than extracting teeth. So I think that the Profession is going to get loaded (with doing) much more difficult work (for) the elderly because a lot of them retain their teeth."²⁰ "We're at the beginning (of this process.) We're at the learning plateau",²⁰ and increasing "pressure will come"²⁰ because "every year that goes by you see more and more elderly... (people) retaining their teeth"²⁰ Nonetheless, dentists should continue to emphasize "strong education".²⁰ "It's like trying to change a habit. It can't be done overnight. It's slow, methodical, and continuous. It has to evolve".²⁰ In the fifties if a dentist "said a tooth had to come out, it came out. 'You need dentures', 'You're going to lose your teeth by twenty-one anyway', so they got dentures."⁵ "I suspect that even if I was trained in the fifties, I would have the same outlook"⁵ as I do now. "I don't think that comes from training in dental school. That's just your basic respect for other people."⁵

A Patient's Wishes

Mark's believes that a patient's wishes are important to consider while planning treatment. For example, "if they care about their appearance, and teeth, (then you may do) a composite, (but for) some you could do an I.R.M. instead of a composite or an amalgam. (It also) depends on access, (and on) their physical (and) medical status."¹¹

I remember, an experience where a ninety year old man "had implants done".¹¹ Implants are metal fixtures which are used to fasten a denture or a bridge to the jaw bone. This was "absolutely not"¹² a problem, it's "his money (and) his decision. He had a(n) anterior bridge until (the age of) eighty-eight (and) the abutments failed. In my hands the only (option was) a denture. I don't do implants. So I made him a denture. (He was) not satisfied with the denture because he went from

something fixed to a complete denture. Two years later he was asking me, 'Who does implants?', so I gave him a name and off he went. (He) came back with four implants and a fixed prosthesis. (Now) he's happy, (he's) much better - at ninety-two."¹² If he ends up institutionalized then Mark would treat him "like everybody else with teeth. Oral hygiene would have to be maintained. If the abutments fail and have to come out, (then) they have to come out."¹² "The ethical dilemma I saw there"^s was not the final result, which was good, but it was the process. "He went in to see an oral surgeon for a consult, and walked out with four implants."^s "Now where's the planning here."^s "What I didn't do is get on the phone and say, 'What's going on here? People coming in for consults, you put implants in and then worry about prosthetics."^s "He eventually got the denture made, but to me there was a better way to do it."^s

Mark also recalls an experience, with an independent elderly man who had "a tooth (previously treated with a) root canal, but the crown broke off."¹⁴ It was a partial denture abutment tooth, and we decided to smooth "it off at the gum line and (maintain the root.) The tooth in front of that wasn't very strong either, so (you) don't (replace) the clasp. There was enough retention from the other three clasps to function adequately."¹⁴

Another experience which Mark recalls, involved a young South African chap on a brief shore leave. "He had no teeth except his two upper canines. They were solid (and had) no fillings, and he wanted these teeth out badly. I said, 'When you get home you can (have) a Cusil denture (made). Even one tooth is better than having no tooth.' (But he said), 'No, no, no, (I) want these out. I know I'll have no teeth, but they tease me on the ship. They do this, they do that, they call me this, they call me that'. So after all that insistence I took them out."²² If he wasn't leaving so soon I would have said we can try the Cusil denture, "I'll be around"^s if you want the teeth extracted. Under the circumstances Mark agreed that extracting these teeth might still benefit him in some way. "I guess the psychological factor, (but) obviously it's not benefiting him (dentally). To function, to eat (right now), (there is) no difference. But (for) future treatment he would have benefited (by keeping the teeth)."²² "If they can make Cusil type partials (in South Africa, then it's) better to have something to hang on to obviously. But I guess he was tormented so much emotionally and mentally by other people, (because of) these 'two fangs hanging down', as he (said), that he was relieved (and) happy that they were gone. That (was his decision), he knew what he was doing (and) he didn't want them. That was a tough one. We sat here for a good thirty-five minutes (trying) to talk him out of it."²²

Mark also recalls, "a patient that the broke teeth left, right, and centre, until we found out (she was) eating candies. So we kept repairing these teeth but they kept breaking right off at the gum line. We finally found out that she had kept hard candy in her mouth 24 hours a day."¹⁰ Eating candies is her choice; you have to "live with it, and adjust your treatment appropriately. We ended

up (extracting all of her teeth and providing) dentures. She broke almost every one of her teeth in a very short period of time, it was just incredible. You can't even tell her what's occurring by eating these candies."¹⁰ She was "lucid at times, (that is she) could talk to you, but at times (she would) have bouts of (amnesia). I guess (she) maybe (had) early Alzheimer's."¹⁰ She lived with her family at home and at first she was able to walk into the clinic, but she was "brought in a wheelchair later."¹⁰ "When I got to the denture stage, about a year and a half later, I talked to the family (about treatment decisions). Originally I talked to her because she seemed right up with it."¹⁰

Denying a Patient's Wishes

Mark thinks that there are times when you can't comply with a patient's wishes. For example, when presented with the hypothetical case of an elderly woman, with slight signs of dementia, who wants a free end saddle partial denture to replace just two back teeth, he said, if "you (don't) see a clear need for it, (that is) where (a patient would) actually benefit, it's like relines, if you know you can't make a difference, (then) don't do it. (There) has to be a clear change (related to a) need."²¹ However, "I don't lose any sleep if they want to buy a car with three wheels. (If you have) told them, the best you can, 'Go home and sleep on it, (these are) the good things about it, these are all the bad things about it, (and) if you still want one (then) I'll, make you one'."²¹ "If you're not doing any harm, (especially) if it's removable, (then it would be okay)".²² Something like partial denture "rest preps (are) maybe (okay)",²² however, Mark is less likely to go ahead with an "irreversible"²² procedure for such a patient. In rare cases, Mark thinks that he has refused a patient's treatment request. However, he couldn't think of any specific experiences where he had actually done so. He says, if they "want to pull solid molars out (to) have a denture (which they think will be) much better (and) easier to clean. (Then I would say), 'I'm not going to take your teeth out because you would be regretting (it) in four or five years'."²² "I don't care how old they are, I won't take them out because you can make them a Cusil denture. (That way they) have the denture, (and) the teeth are still there."²² "There're people (who) want some teeth out so that they can match the four front ones better, (if they have, for example,) crooked (teeth, or) different colour(ed teeth, or) elderly (people with) chipped restorations that have darkened (on otherwise) fine teeth. (In these cases I recommend we) do a veneer, (or a) new filling, (for example, and I say), 'Leave that tooth there', (or) 'Leave your partial the way it is, there are other ways around it'. But they (may) come with the idea that the only way to do it is to take the tooth out."²²

Mark recalls, he "had to do that once with... an (immigrant woman who) wanted her front lateral out because the other lateral and two centrals were gone. (The remaining lateral incisor) was heavily restored with composite. She had an acrylic type partial (and) it wasn't fitting very good. But we talked. (I said), 'Leave that tooth there and (we'll) put a new composite (filling) on (it) and make you a new (partial denture)'."²³ Ultimately she accepted the recommendation, where another

patient "possibly"²³ might not have. "We interpreted through her daughter too, so (we had to) convince the daughter as well. But that's what they had in mind (at first), 'Take this one out and there'll be four even ones.' "²³ Mark does not recall this kind of situation in the E.C.U..²³

Family-Patient Differences

If Mark were to encounter a situation where a patient's family wants a particular kind of treatment, for example, a denture, but the patient is reluctant to have it, he would "tell the family member the patient doesn't want it".²¹ This would be his view even if he wasn't sure about the patient's ability to make the decision, however, he could not recall experiencing this kind of situation in practise.

Oral Care for Cognitively Impaired Patients

a) Decision Making Ability

Mark says that if a person doesn't "want their tooth looked at, (then) don't look at their tooth. But the problem is, 'Do you over-ride?' You don't make any over-rides. You ask somebody else to do that, if you perceive that the person is not in control of their faculties."⁸ In distinguishing patients who are in control of their faculties from those who are not, Mark says, "if they're lucid and fluid and they know what time of day it is and who they are and where they live, and still they want their tooth looked at, (then) I don't even call the next of kin. If they don't know where they are, or they don't know their name, or time of day, then (if, for example,) they might get themselves in deeper problems by leaving what you've determined may be an infected tooth, (then you would) ask the next of kin and go on from there."⁸

b) Next-of-Kin as Decision Maker

By "next of kin"⁸ Mark means "who's ever is in front of the (patient's chart). Who's ever responsible for their finances. The front cover of every patient chart has the next of kin and (they) could be in the States, (or) some distant cousin, but they usually have their name and phone number so you can get a hold of them. So how do you avoid those things where you have to extract a tooth without consent? You just don't do that."⁸ You contact "whoever is the first on that list. It may be a legal guardian, or whoever the hospital or the administration has determined to contact."⁸ "I usually talk to one person. They might have an internal conflict within the family (about who makes the treatment decisions), but (I contact) who's ever name (is) on there (and) nobody's ever come back and said, 'Why did you do that?'. (If they did) you just have to say, 'Your brother said it was okay to do it'."⁹

c) Planning Treatment

When questioned on what kinds of treatment are appropriate and justified for institutionalized elders, Mark said that "you want (to) check with to them make sure that there (are) no chronic abscesses or infection(s) and to eliminate (these by) whatever (treatment is decided). If they can

function with a root canal, (for example, and) if everything goes okay (and) it's appropriate, (then) you can do that."¹⁴ "Basically, you want to keep the roots as much as you can."¹⁴ If they can't make the decision themselves "then you ask the next of kin. (You) tell them how much this costs, what the prognosis is, what the benefit is, what the downside is, (and) what could happen if it doesn't work. (You) go through all (of) that, (especially) if you perceive that it would be a benefit. Because they could live for another five years or twenty years."¹⁴ On the other hand you might recommend extracting an abscessed tooth if there was "no bone left (and it was) causing periodontal problems (and was) mobile."¹⁴ The dentist should also consider extracting the tooth, if a patient doesn't "see the value or the need (for root canal treatment). Knowing all the facts, and goods and bads, if (they) don't want to do that, then what's the alternative? Take it out, or no treatment at all, which is always a possibility."¹⁴ Treatment for institutionalized patients is certainly appropriate "if you see a disease process that could cause them pain or systemic problems, (such as you might find with) a huge perio abscess. (But if there is) a permanent tooth that's asymptomatic, (then) no. (You would leave it alone unless) it has potential to flare up or if it has flared up in the past so it's the third time you're treating it. (In that case) you talk to the next of kin (and) give them the low down, its good and its bad consequences (and) prognosis, (and you) do it from there."¹⁷ "If there is pain they'll want treatment."¹⁴ Granted, some patients with a painful tooth may "perceive it to be more pain to (have) it out, (so then) you don't take it out".¹⁴ One option, in that case, would be to treat the infection with "antibiotics."¹⁴

d) General Anaesthetic and Consent

Mark agrees that another option for a resistant patient is to use general anaesthetic, "if they wanted (the teeth) out. (But) you don't take out teeth if they don't want them out",¹⁵ even if they have pain. If they are not able to make this decision then "somebody is. I don't put myself in (a) position, where I book an O.R. and put them under G.A. and take a tooth out without anybody's consent. You can't do it. I mean you can't get through the O.R. doors without some consent formed signed."¹⁴

He remembers, "a handicapped adult... (a) big, strong, muscular guy, (who) didn't want to sit in the gurney. He didn't want to go in the O.R.. (He) didn't want anything done to him. So we put his shoes back on him and let him walk in the O.R.. He didn't want to go, but he was there, (and) he agreed (to it previously, and) whoever signed the consent (had) consented to it, but (he) changed his mind on the spot (and) two minutes later he was all for it, (but) three minutes later he doesn't want anything done".¹⁵ Even though the man didn't clearly agree with the treatment, Mark had no problem with going ahead because "he's under (constant), twenty-four hour care"¹⁵ and the caregiver had made a clear decision.

Still, Mark recognizes that consent is not absolute in these cases. "The caregivers always come with them because they can't come to the hospital by themselves. If they perceive that he can't take it that day, or they change their mind, (then) it's over. But they're usually there helping you along because we always encourage them to come. There's usually communication with these people. We always get them in... to help communicate with the nurses. They come right in the O.R. most of the time."¹⁵ For general anaesthetic cases, "if we say, 'We want to do three fillings', (and) you get in there and you see four that have to be done, I'll do four. Because I won't stop (and) put the patient at risk (by doing) another G.A.",⁹ and we "always"⁹ discuss (that) possibility with the caregiver. For example, " 'I see three here with the tongue depressor, but once (the) x-rays (are) done and the rest of it (there) might be another one'. So those ethical issues are avoided."⁹

e) Systematic Consent

Mark has a very systematic approach to consent for institutionalized patients who can't make their own decisions. For example, if a nurse were to bring in a patient who has an obvious mouth infection and say, 'Look, you have to do this', "you don't do anything until you find the next of kin. You phone the next of kin (for) any irreversible procedure."¹⁷ You say to the nurse, " 'Bring them back next week and we'll think about it'. "¹⁷ To add "some expediency to the process, if you perceive it has to be done, if they can't eat and they're causing problems on the ward or something, (or they've been) up all night in pain, then (I) jump on the phone quick."¹⁷ If it's not possible to do it that day then, "I'll give some analgesics, but if it's an irreversible procedure, you don't want to (proceed without consent) - hardly ever. (Maybe if) I take a tooth out with a piece of gauze, (if) it was wavin' in the breeze."¹⁷

"I had a case here, I've been seeing this elderly (man). He was in a home... I saw him maybe four months ago. His son brought him back, I guess for his check-up. We wanted to see him (because) he has Alzheimer's. He had one tooth missing. (So I asked), 'Where'd his tooth go?' The next day he got a bill in the mail from a dentist who I guess goes through the care homes. He had extracted the tooth without any (consent), without phoning the (son). This (man) clearly has Alzheimer's. When I treat his son, his dad sits (where his son can always see him). (If) his dad gets up and wanders he's right beside (him). He just doesn't let him out of his sight. (So the son) wanted to know why the tooth was taken out. Apparently he gave specific orders that 'My dad has a dentist and I'll come and take him to the dentist'. He doesn't want him seeing (other dentists) because he didn't know the dentist or the routine, (and) we've seen him a few times here. So somebody did a procedure with (no consent). I would never do that. I think that's wrong. I think it's wrong... ethically. I look at his old radiographs and the tooth could have been ready to come out, but it wasn't time four months previous to that. (It) wasn't going to cause him any problem; he's had them for seventy-some years. (I) never found out why (it was extracted). I think he said he

talked to the dentist and he said, 'It needed to be extracted so I extracted it'. Looking at the radiographs (I thought), 'Yeah, okay, it's coming to the end of its life'. I wouldn't question the decision at all, just the process in doing it."¹⁸

Mark also does not consider a general consent for treatment of institutionalized elders to be adequate. For "specific treatment, that's irreversible, you always (get consent by talking with the caregiver). That way nobody can come back on you, and it's not fair for the patient either, if you have just anybody doing whatever they want with no (consent). It's not really a fair decision on the dentist's part. You can have your reasons for doing (a procedure, by using your) clinical judgement (and) experience, and if that goes along with what they perceive is (needed, then it's fine, but) to do that all by yourself is"¹⁸ wrong. It's important to go through the right channels. "Even with children, you don't want to (do that kind of thing). You ask mum if it's okay to go ahead and take x-rays. If you're going to pull out a deciduous tooth, (even) if it's wavin' there and the six or the central's coming in, sometimes you just leave it, (because it's) going to be out a few days, (so you) let the tooth fairy take it out."¹⁸

f) Caregiver Requests for Treatment

The most common reason for a guardian to bring a disabled adult patient to Mark is "probably (where they) perceive a need (for) treatment of some sort. Usually I think there is some history of pain or swelling involved, or there's new habits that are going on, that they don't understand, with their teeth. (For example), they're biting something and they want it checked out. It's some kind of habit change with their mouth, (for example), banging their cheek. A lot of them perceive that (because) they can't see anything on the mouth or on the cheeks, there must be something the matter with the teeth, pain or something, so they come and get that checked out."¹⁵

It's "not very often"¹⁶ for a debilitated elder to be brought in because someone else perceives a need aesthetically. "Very rarely. I can think of maybe three or four cases (where) they said they needed, (or) should have a partial because they'd have trouble eating, so if they had some front teeth they could maybe chew better, (and they) might look better, according to the guardian."¹⁶

"I remember one"¹⁶ case, "she came into (the hospital clinic. We) could deal with her with tongue depressors without any G.A., (but we) might have (used) some Valium. A lot of times we give them five or ten milligrams of Valium before to calm them down. Sometimes when (they) don't have it, cooperation is poor, (even) for cleanings (and) routine checkups. This one case,... two caregivers would come with her because it takes about two caregivers."¹⁶ "She had no front teeth, upper or lower."¹⁶ "They perceived that maybe she could chew better (with some partials)."¹⁶ "So I made some. She wore the uppers but apparently never wore the bottoms. She pushed them out with her tongue. (She) didn't like them, (and) out they'd come. But she liked her uppers. (They) looked nice for her I guess. Communication (with her was poor). (I) guess you never know for

sure. (The) caregivers over time have a pretty good idea, (and) they'll tell you, 'She's happy', 'She likes that'. You don't get that directly sometimes, but just by their emotions or something, the caregivers can tell, especially the ones that have been with them a long time."¹⁶

g) Caregiver Requests for Dentures

Mark "certainly (gets requests from caregivers) where mum or dad lost their denture and the son or daughter would like to see mum with a new denture, who sometimes couldn't care less whether they had a denture or not. (Managing this) depends on the level of cooperation, I mean, if you can make a denture, and they're stone cold out of it, (where) they just stare into space all day, you convince the family member, 'What's the point of spending all this money on something that they're not going to use or function with.' (It will) just make (them) easier to look at, but as far as its function, (whether it's providing) any benefit (for) the patient, (it's) minimum. (Often their) food has been pureed for the last five years, and all of a sudden the denture is (given to them) - you tend to talk them out of it. I tend to not recommend it. I don't think I ever made a denture for anybody that really didn't want one. But we've had that request lots and lots, (where) there's no ridge left and it's not going to stay in. (It's a matter of) educating who's asking for it. (That) usually"¹² works. "If in your hands you can't make it any better, say, 'No'. You do a few of those, I guess, but you certainly quickly know the limits."¹ "Nobody ever said, 'Make a denture, I don't care what it costs or how it fits'."¹²

h) Hypothetical Caregiver Request for Fixed Prosthetics

Although not common in Marks experience, if a family was requesting fixed bridgework for a patient who was not able to make their own decisions, "I'd advise against it (because the patient) can't take care of (their teeth). That's the other thing that I learned fairly quickly, find out where the chief complaint's coming from. If it's coming from a family, head nurse, (or) physician, (then) you have to take it with a grain of salt. If it's coming from the patient themselves, then there's a little more grounds to it."¹² When asked what he would do for a noncommunicative man who has recently been institutionalized because of early Alzheimer's disease, and whose family and physician want to have extensive fixed bridgework to replace a number of missing teeth with the aim of improving his deteriorating nutritional status, Mark said, "you (have) got the options from zero to fixed, with a removable prosthetic in between. (A) Maryland bridge (could be done) for aesthetic reasons".²⁶ However, "given just those parameters, (and) nothing else",²⁶ "I would tend to fall on the side of the fence",²⁶ "not (to) do it. (I would) leave him because I don't believe that putting in one or two more teeth here or there is going to improve his ability to chew or nutritional status. So I (have to) go back and re-educate the son and the physician. If his oral hygiene is poor, and can't be taken care of, and there's a decreasing slope on that, (then I would do), basically, nothing. (You need to) find out the source (of the request). Obviously it's not coming from the elderly gentleman,

(that is), it's not a concern of his."²⁶ It is important to try to maintain the man's oral hygiene "to keep his dentition as long as possible. (With) Alzheimer's, everybody dies, but it's not like terminal cancer or anything. So the prognosis of him living a long time is (likely), and (therefore) you'd want to keep as many teeth as you can."²⁶ He would need a recall every "three (or) four months, (and) I'd assess him (after) a short period, and see if that might be plenty. I may have to see him more than that."²⁷ If the man had an occasional broken tooth Mark would "repair it."²⁷ He may even place a crown "if that was a viable option for that one particular tooth, but only if amalgams wouldn't stay (in). I've never had a (case) where you'd have to have a crown or you'd lose the tooth. (I tend to be) ultra-conservative, (and) conservative is retaining as much tooth structure as you can."²⁷ In this case, Mark would tend to repair amalgams before placing a crown. "You can't make blanket statements"^s about his care, but "it's hard to think of extenuating circumstances"^s in this case.

iv) PROFESSIONAL ETHICS

Early in the conversation Mark was asked about the meaning of professional ethics in dentistry. "I guess honesty comes to the top of the list, being above board, doing what's required, no more, no less, doing no harm, doing what you perceive that you can do with your abilities. (That is), don't do what you can't do well, and if somebody needs something, (and) you can't do it, (then) refer them on. (For example), don't try to do implants yourself if you can't do it, why it's that type of thing."⁷ To distinguish between the law and ethics, Mark says, "the law should be based on ethics. I don't know if it is or not. But my feeling is that they're always very common, or run a parallel path."⁷ "There's lots of commonality between the two but there are areas where it's unethical but it's lawful or it's (not) lawful but it's (ethical)."⁸ However, in practise "It's rare that I'll run into"⁸ those issues.

Ethics and Institutionalized Elders

Mark indicates there may be some ethical issues involved "with extended care people (because) you perceive that they don't know what's good for them, or they don't know what they're doing, or they're not in complete (control) of their faculties. (For example), you say, 'Open up', and they say, 'No!', and I say, 'Open up please, I'd like to know if you have any teeth', and they say, 'No!'. Then what do you do? I mean, do you pry their mouth open?"⁸ When faced with this "generally you look the best you can without interfering with their wishes. If they don't want (you) to look in their mouth that's up to them. But on the other hand you have to explain to the next of kin, (who are) always in the front of the (patient's chart), what you've done, what you've asked, and what you would like to do, but it's not your decision, it's their decision."⁸

The most difficult ethical issue which Mark encounters, in this context, is "treatment for the handicapped (where they are not) responsible for their own actions."⁹ But "if there's any hesitation at all (then) I don't treat them, (I) never did. (I) let them sleep on it, or let them decide later, if I get

any hint (of hesitation) from the patient. For me that goes for people who walk in and out of here at a hundred miles an hour too."⁹ "Usually there's no big rush in that type of treatment. They're not going die if they don't have it. They might not be able to eat their toast so well, but they've usually been doing that for weeks or months or years anyway (so) a few more weeks or months won't make a big difference. So you let it dissipate, (you) let it settle, (and) make the decisions that way."⁹

v) PRACTICAL DIFFICULTIES

Facility Design

Mark believes there are several barriers related to improving the oral health of institutionalized elders. Firstly, long-term care "facilities (are) not set up to do (oral hygiene) comfortably. There's no suction at the bedside. (Residents) need help to get the(ir) wheel chair(s) up to the sink, (but) even if they have the motivation (and) the time, they're (still) handicapped because of the physical setting."⁵ "No thought went into the set up of the place so that they could do it. Oral hygiene was off the list of priorities."⁵ A better design would include "a high volume suction at the bedside and the sink."⁶ He agrees that the sink should also be low enough to provide good "access to a wheel chair so you can get in and"⁶ brush. "A device, with water jets and suction, (or other similar) apparatuses will help,"⁶ but ultimately "it goes right back to"⁶ having proper "design features"⁶ when the facilities are built. "It's a value, it's a perceived need, (if) you perceive you don't need it (then) you don't get it. (If) whoever does the planning perceive(s that) they can ignore (oral hygiene), it's like playing hockey with a broken stick, you can play hockey but you're never going to be very effective."⁷ Mark compares this to the fact that oxygen at the bedside was not always a standard feature in hospitals. "Who says they need oxygen at the bed? Why is there oxygen at the bed? All hospitals in the beginning didn't have oxygen at the beds. Somebody along the line said, 'Hey, we should have oxygen here; it's easier than trying to transport them to the tanks.' So that same process is going to have to go on."⁷ "Eventually (the value of oral health will) get carried on because people who take care of their teeth, are going to end up in these (facilities) and they (won't be able to) do anything. They'll say, 'Why don't you have suction by the bed so I can clean (my teeth)'. That's how that's going to come along."⁷

Staff and Family Involvement

Secondly, the facilities that Mark worked in "were (so) understaffed and (the staff) had so many other jobs to do that (a resident's) mouth was the last thing they looked at. They had to dress and feed patients and keep them clean and that took up (the) majority of the(ir) time."⁶ "You can train (the staff), we talked to them lots and had seminars, but the caregivers tend to be of lower social and economic status so their idea of oral health (may be) different from what you're trying to prescribe. If they don't take care of their own (oral health), (and if) they don't have the same value

system, that (may be) a factor."⁶ "The biggest help you can get"¹⁰ to improve the oral health of institutionalized elders may come from families. The dental staff "can't do it all themselves, (and) you would work much more efficiently if you educated the (caregiver) staff and the families, especially the family, (since they are) much more willing to brush their loved one's teeth, (while the caregiver) staff (is) usually pressed for time."¹⁰ "It gives (the family) something to do and it's valuable. If you can get a hold of the family (and) get them focused and interested as a routine whenever they visit, you're way ahead (compared with) trying to train the staff".¹⁰ Mark says that there was good support for this approach from administration and nursing staff, but he agreed that it would only be effective if family members are visiting regularly.¹¹

Accessibility to the Dentist

Thirdly, Mark doesn't think that institutionalized elders in Canada have adequate access to dental care in part due to the scarcity of dentists involved. However, he does believe that dentist can take a role because "just the mere presence"¹⁰ of "a dentist in the institution could make a difference. Education-wise, the (dentist's) presence there focuses (attention) on teeth, (and the) elderly. (Everyone sees that) these people have teeth, (and that) they don't take care of them."¹⁰ To improve this "you could either assign or encourage dentists to get connected with an E.C.U. facility, or have the facility have a dentist on staff just like they have physicians that make rounds",²³ but there are also barriers with this.

a) Educational Barriers

One barrier to getting dentists involved is that they may not be getting enough experience with institutionalized patients as dental students. In an E.C.U. "your clinical judgement is (challenged). You have to shift gears mentally (from) what (is) normal, everyday care. (For example), ideally, if (a patient) was forty years younger, he would require an amalgam filling or composite. Well in (some cases), given all the factors, an I.R.M. (filling) will do."²⁴ "I feel very comfortable in setting a limit, like placing an I.R.M., as opposed to (thinking) we should have a composite here, or (thinking we have to do) fixed for a space."²⁵ "So that's the appropriate level of care, and the dental students don't get that. They don't get that time where they have to shift gears a bit saying, 'Hey this is the level that's appropriate and it's perfectly okay'".²⁴ For example, in the E.C.U. I might say to a student, " 'Don't worry, you're not doing the patient any less service, or any greater harm by placing I.R.M. or not doing any treatment at all', whereas in the school the margin would have to be (very precise, or there would) have to be a filling, right here, (and if not, then they would) fail (because they are) doing the person harm."²⁴ "They'll have to get (that kind of experience) by themselves, and they're going to make lots of mistakes getting that. They're going to be recommending partials, (or they'll be saying), 'That tooth has to come out, it just has to'. But if they've seen situations where maybe a tooth doesn't have to come out, it's okay (to leave it in), or (where you can) take (a) spoon and

scoop the (caries) out, put on some fluoride, (and) put in a glass ionomer, that's (sometimes) fine (for a patient who is) ninety-two years old."²⁴ Mark says, "it's the perceived need of curriculum committee(s)"²⁵ that determine whether this aspect of dental education is valuable enough to be developed.

b) Financial Barriers

A second barrier for dentists is that "it's inefficient work".¹⁸ Mark says that "the dental clinics that (he knows, which) try to make a living at it, have a hard time doing it."¹⁸ "As far as I can understand, from their financial picture, it can't be done, and part of the problem is the fee guide."¹⁸ "The clinic (I worked in as a resident) was losing money because we were dealing with handicapped elderly, (and) charging (private practise) rates, and going backward essentially."²⁵ "If you charge those rates (then) you can't (make a living) over the long-term because the time factor, (used to determine the fee), is set up for one dentist (in) a typical operatory with one assistant and a receptionist. That's (not) real in an extended care facility where you're bending over a bed. (There) the time factor is tripled."¹⁸ "You can do it fee for service but your fee has to be different".¹⁹ Despite the cost Mark thinks that families and/or patients will want this service "if they perceive it as beneficial and a need. It's like anybody's care, they can be an adult in their twenties and if they don't want to protect their root canaled tooth with a five hundred dollar crown, they're not (going to), and they (will) possibly break their tooth. Those decisions are made (on) a cost-benefit"¹⁹ basis. "Theoretically you're fairly compensated for whatever you do so you should be fairly compensated there as well. But, if you (have) a thriving practise, (then) it's inefficient use of your time and therefore your money (to) do these things unless you feel a need or duty to do it. (The) fee guide is set up for an office, (where), ambulatory people come and go quickly, (so) you can't compare. If a dentist... perceives (he is) adequately compensated, (then) you'll get people (to) do it. But if they're not (adequately compensated), to perceive they're going backwards, it's not worth the time and effort. You have to charge an appropriate rate that's the only solution to that, and whether society can afford it, or individuals can afford it, well, it's up to them."²⁴

Role of Salaried Dentists

In some cases it may be possible for a facility to have a dentist on salary. "You pay the dentist, or the providers, a salary, and you make a contract with them to see so many patients on average, (in order to) balance both ends."¹⁹ When asked, whether putting public money into long-term care dentistry is rational, Mark said, "if you had to do a filling as opposed to buying some food, I'd say, 'Buy the food (and) do an I.R.M.'. If you had to do a filling relative to a new sun room, I'd say, maybe, 'Do the filling'".¹⁹ This holds true for "who's ever paying the bills, (a government or a family), it's all the same thing."¹⁹ "The taxes come from that same family, they're just re-routing it to (the

government) before it gets to the E.C.U.. But there has to be a perceived need. It's coming out of their pocket no matter which way it's"¹⁹ paid.

vi) **ROLE OF THE PROFESSION**

Mark indicates that to promote the oral care of institutionalized elders the dental profession is currently "taking the role that you educate everybody (to) appreciate the value of their dentition (and) oral hygiene, which hopefully will get passed on"¹³ to successive generations. We should be "educating everybody from the ground up, not just a specific age group or targeted group."¹³ If "adults, who are taking care of the mums and dads, perceive (oral health) as a value, then they would (also) value (that) for their parents".¹³ The Profession aims to "educate everybody from day one (and) those values get carried through. It's a perceived need. (It's like saying, that) you should be able to see the red light when you're driving so glasses are a must. You get glasses if you can't see. People perceive that as a need so they'll spend the money to do it. It's not acceptable not to see."¹⁹ "We're the baby boomers. In the sixties when fluoride (came into use we started to think), 'Maybe we can keep these (teeth beyond age) twenty-one'."¹⁹ "There was a time where you expected to live to be thirty - natural life expectancy - but you don't see that anymore, it's gone".²⁰ "People now expect to be sixty, seventy, (or) eighty years old."²⁰ "It's the same (with) oral hygiene or dental I.Q. in the general population. It's going to be a truism."²⁰

Appendix C

PARTICIPANT CASE STUDIES

Mark Besdine

Dr. Mark Besdine completed dental school after 1980. His experience encompasses the care of institutionalized elders with a wide range of disability including those needing extended care.

Level of oral health and quality of life. - Mark believes that the oral health of institutionalized elders is generally "inadequate". He says that "to some people [oral health] is important and to some people it isn't." Although "you don't need [teeth] to live", many elders need teeth for their "quality of life." Each person defines their own quality of life uniquely, so it is "an intangible, unmeasurable thing." For example, some people may want treatment "when they [have] a front tooth missing", whereas others have no teeth and have "no intention of wearing" dentures. "Some people don't even know they are having meals," so it's problematic to "make generalized statements" about quality of life.

Professional ethics. - Mark believes that professional ethics implies the expectation that service should be offered within "your abilities", and with "honesty" and respect for patient wishes. Using this framework, Mark says he "rarely runs into" ethical problems in practise.

Autonomy and the paramount nature of patient wishes. - Mark believes that a patient's wishes are paramount in treatment decisions, and the wishes institutionalized elders are no different. "If they care about their appearance [then] you [may do] a composite [a tooth coloured filling]", but for "some an I.R.M. [a less aesthetic, less durable, and less expensive filling] will do." You have to "adjust your treatment" according to their wishes. For example, Mark recalls, a patient with signs of "early Alzheimer's" who recurrently broke teeth which I had restored. "We found out that she kept hard candy in her mouth 24 hours a day." We told her of the risks but it's her choice to chew candy. Eventually she lost all her teeth and "ended up having dentures." Mark also recalls a ninety year-old man requesting a referral for oral "implants" [metal anchors to fasten a denture to the jaw]. This man was mentally fit so it's "his decision." Age is not a limiting factor even for this extensive treatment.

Beneficence, nonmaleficence, and appropriate treatment. - Despite the paramount priority Mark gives to patient wishes, he believes that the level of treatment which is appropriate for most institutionalized elders is distinctly lower than the ideal level which is appropriate for many independent people. The treatment which Mark provided for extended care people has been primarily "basic restorative" and "preventive" in nature. He has also constructed a few dentures, but it is rare that he has done anything more extensive such as crown and bridge prostheses, or surgical periodontal procedures. Of course, decisions often "depend on access, [and on] their

physical [and] medical status." He says that most extended care people cannot maintain "their oral hygiene" so extensive treatment has "a poor prognosis." Mark says that to work in an extended care facility "you have to shift gears mentally." For example, "ideally" a patient may "require an amalgam filling or a composite", but in this case, "given all the factors," "you're not doing any less service, or any greater harm" to "scoop the caries out [and] put on some fluoride [and] a glass ionomer" filling [a less durable, but less expensive filling]. "That's the appropriate level of care" and "I feel very comfortable setting a limit like" this.

In planning treatment for institutionalized elders, Mark said, you want to "eliminate" any painful "abscesses or infection[s]," and "you want to keep the roots" if you can. If they have an abscessed tooth and "they can function with a root canal, [and] if it's appropriate, [then] you can do that." On the other hand you may recommend extracting the tooth if there was "no bone left [and it was] causing periodontal problems", or if they don't "value" the treatment. "If there is pain they'll want treatment" usually, but if they "perceive it to be more pain to [have] it out [then] you don't take it out". Of course, "no treatment is always a possibility." For example, "a permanent tooth that's asymptomatic" you don't treat, unless "it has potential to flare up".

Paternalism and denying treatment. - Although he couldn't recall doing this, Mark says that if "you [don't] see a clear need for [treatment] - where [they would] actually benefit - [then] don't do it." On the other hand, if a patient insists and "you're not doing any harm, [especially] if it's [a] removable" denture, then maybe it's okay to proceed. You tell them "the good things about it", and "the bad things about it". But not if it's "irreversible." Not if they "want to pull solid molars out [to] have a denture." They "would be regretting [it] in four or five years'." "I don't care how old they are, I won't take them out because you can make them a Cusil denture [a type of denture constructed around the existing teeth]."

Mark does recall "people [who] want [healthy front] teeth out" for aesthetic reasons. For example, I "had an [elderly immigrant who] wanted" the last one of her upper incisors out and replaced with a partial because the tooth was discoloured. I said, "leave that tooth there and [we'll] put a new composite on and make you a new" partial. Ultimately she accepted this suggestion.

Ethical difficulties in the management of cognitively impaired elders. - Mark says that there may occasionally be ethical problems in the care of elders who have an impaired ability to make decisions. If, for example, you try to examine a confused patient "and they say, 'No!', then" "do you pry their mouth open?" No, "generally you look the best you can without interfering with their wishes." "If there's any hesitation at all, [then] I don't treat them. [I] let them sleep on it," and "make decisions that way." "Usually there's no big rush. They're not going die." So "you don't make any over-rides [by yourself]," "but you have to explain to the next-of-kin what you've done, what you've asked, and what you would like to do."

Competence, surrogate decisions, and informed consent. - To determine a patient's competence, Mark says, "if they're lucid and fluid, and they know what time of day it is, and who they are, and where they live, and still they want their tooth looked at, [then] I don't even call the next-of-kin." Otherwise you contact "the next-of-kin" for consent. "Every patient chart has [a] next-of-kin" listed. You "tell them [the] costs, what the prognosis is, what the benefit is, what could happen if it doesn't work", especially "if you perceive that it would be a benefit." "If they can't eat" or they've been "up all night in pain, then" call the next-of-kin "quick". If it's not possible to do it that day then, "I'll give some analgesics" and "antibiotics", "but if it's irreversible, you don't" proceed without consent - maybe to "take a tooth out with a piece of gauze."

Mark recalls an institutionalized elderly patient of his who "clearly has Alzheimer's" for whom a dentist "extracted [a] tooth without phoning the" son for consent. "I think that's wrong... ethically." "Looking at the radiographs, it's coming to the end of its life," so "I wouldn't question the [result] at all, just the process in doing it." You can have your reasons for [treatment, using] clinical judgement [and] experience, and if that goes along with what they perceive is" needed, then fine, but "it's not fair for the patient if you have just anybody doing whatever they want."

Surrogate requests for treatment. - Mark is cautious when a surrogate requests treatment for a cognitively impaired elder. "I learned fairly quickly, [to] find out where the chief complaint's coming from. If it's coming from a family, head nurse, [or] physician, [then] you have to take it with a grain of salt. If it's coming from the patient themselves, then there's a little more grounds to it." Mark says that the most common reason for a caregiver to request such treatment "is some history of pain, swelling, or new habits that they don't understand." Aesthetics isn't usually the reason, but Mark recalls a caregiver requesting "partials," for a patient who "had no front teeth, upper or lower." "So I made some." She "never wore the bottoms", but apparently "she liked her uppers." "Communication" with her was poor, so I "guess you never know for sure." Mark also recalls caregiver requests for dentures where the patient "couldn't care less." How you proceed "depends on the level of cooperation." If "they just stare into space all day, [then] you convince the family member, 'What's the point of spending all this money'." It may "make [them] easier to look at, but [it's of] minimum benefit [for] the patient." Often their "food has been pureed for the last five years". "I don't think I ever made a denture for anybody that really didn't want one, but we've had that request lots." "You do a few of those, I guess, but you quickly know the limits."

Role of the profession. - Mark stressed that the Profession should continue to "educate everybody [to] appreciate" "their dentition, which hopefully will get passed on to new generations." If adult caregivers value oral health "then they'll spend the money for" their parents. "But there has to be a perceived need."

Beverly Rice

Dr. Beverly Rice completed dental school after 1980. Her experience encompasses the care of institutionalized elders with a wide range of disability including those needing extended care.

Level of oral health and quality of life. - Beverly's "impression" of the oral health of institutionalized elders "is that it's poor" and it's "definitely not" adequate. She says "we're trying to look after a person's overall health and [oral health is] a large element of it." "If I didn't think that [oral care] improves quality of life it would be absurd for me to be doing this." We don't get a lot of acute pain", but "relieving pain" is an important aspect of this. "A lot of" "these people" "can still enjoy food" so "function" is also important. "They still enjoy having a clean mouth and appreciate it." "I don't do a lot strictly based on aesthetics", but we often make people "look better" and then "they feel better about themselves." "There are a lot of questionable cases where we don't know" whether they "can appreciate things," but "I'd rather err on the side of" "preventing acute problems" and "reducing" "infection" at minimum.

Professional ethics. - Beverly believes that professional ethics means "having a basis for doing the right thing in making decisions." She is aware of formal ethical principles and she will "occasionally think about what's fair", or about a "patient's autonomy", but she doesn't usually use the principles consciously.

Conflicting demands in treatment planning. - Beverly finds "it exceedingly difficult to do treatment planning" for institutionalized elders, in part, because "treatment decisions are based on" diverse and potentially conflicting demands including: "patient needs, finances, family concerns", and, "of course, patient concerns, staff concerns, and medical concerns." In particular Beverly finds herself struggling to balance the wishes of a patient [or next-of-kin] with what she believes the patient needs.

Autonomy and a patient's wishes. - Beverly says that when institutionalized elders "can express their desires", "we should do as comprehensive a treatment as they" want. "I have a fairly optimistic view of life span now, so" "if I had a patient who's eighty and wants a couple of gold crowns I would seriously consider it." On the other hand, "I think" some "elderly people are choosing not to do a lot about their oral health." "I don't think they have a lot of choices though. They lose control of so many aspects of their life". Beverly says that a patient's choices are not without hazard however. For example, she recalls once constructing dentures at a patient's request, but her health deteriorated so fast that "by the time we finished, there wasn't any way she could" wear them. "That's frustrating, and confuses the treatment planning", especially "when you didn't see it coming." "But I guess it's going to happen."

Beneficence and nonmaleficence: Ethical difficulties in determining appropriate treatment. - Beverly says that the most difficult ethical issue she has encountered in the care of institutionalized

elders is in deciding "what is appropriate treatment". "For me, everything centres around that, and it's really tough". Beverly provides a fairly complete range of services although "I've done no endodontic[s] and no crown and bridge work, so were talking about a lot of cleaning, fillings, [and] extractions." "Certainly I value oral health," "I come from that background and training, and so I do, in a sense, push that on my patients. They don't always value those things," so "I try as hard as I can to keep in mind that the patient's wishes should come first whenever possible, [but] I can't say that it's always or even frequently possible". She says that all patients deserve to be free of "pain, obviously." But eliminating all "oral infection", is "an unreasonable goal. We're going to have periodontitis and caries [the two major diseases of the mouth]. [For] Alzheimer's patients we will often leave it alone if it looks like they're not in pain and they're very difficult to treat." "I would like to get rid of all of it, but it's questionable sometimes whether that's appropriate." In some cases "I do sedate [these] patients". But, "there has been criticism of that, [by] some nursing personnel," and it is "difficult" to determine "when it's appropriate", "and whether the risk is worth it".

Paternalism and denying treatment. - Beverly sometimes treats severely medically compromised patients, and she believes that the treatment requested by these patients is not always appropriate, but "every case is different." "Some disorders are progressive and some are stable." If a patient is very unstable medically, she is "not going start doing crown and bridge work" despite a patient's request for such treatment.

Competence, surrogate decisions, finances, and informed consent. - Beverly is cautious in determining a patient's competence to make decisions and will "never base that on one thing alone. I speak to the person first of all," she says. "Sometimes we have people who can't communicate well [but] that doesn't necessarily mean that their mind doesn't work". "I always [consult] the medical chart," and "if I have a question, I'll sometimes talk to the nursing staff", "social worker, physician, [or] care-aides". Generally "if they are making" most "of their own decisions then that gives me a clue." "But I consistently phone a family member as well" "and that often gives me the most information." Sometimes family members "don't agree [amongst themselves] on what to do" so it can get "really confusing." In any case, I "try to explain treatment needs to [the patient] even if I'm not at all certain they understand." "I ask them questions about treatment, and what they would like done." "If I'm uncertain at all then I'll try to get consent from everyone involved." But "the whole business takes a lot of time."

Not surprisingly Beverly has had some difficulties with the care of cognitively impaired elders. One such case was a very "elderly" and slightly confused woman who "had [a] lower incisor that was" very loose and "bothering her." I was unable to contact the guardian that day, and I "wouldn't be back for five or six weeks", so I proceeded to remove the tooth with the patient's approval. The extraction was done using only a piece of gauze because the tooth was so loose, but

Beverly "got a screaming call from the guardian afterward" criticizing her and denying any further treatment, despite the poor oral condition of the woman. Beverly thinks it may be a case of "neglect" to ignore the woman's oral health, but no further consent has been given for treatment.

Beverly also says that "generally there isn't a problem with consent if" there is no cost to the next-of-kin. But that's "really disappointing." Sometimes "families say to me, 'Mum can decide', when it's clear to me that [she] can't." Patients can be capable of "consent for treatment, yet be very confused about finances." For example, they think "two hundred dollars to reline a denture" is too costly, because they "figure they can buy a house" for that. "I'd love to be able to inform them about" the "cost", but if they "are not taking care of their own money" I try to skirt that issue" and let "the guardian" decide. I will usually "try to discuss the treatment itself" with the resident and "I do take 'no' for an answer even if they're slightly confused". But sometimes you have to "evaluate whether you should be a little more aggressive or sedate them". If they say, 'no', "I will usually ask a family member" what they recommend. "Sometimes they'll come in and that" may be "enough". If a patient becomes "reluctant" or "tired" during treatment "it's [also] not uncommon [to] just stop." They need to feel "a bit in control."

Surrogate requests for treatment. - Beverly has had some difficulties with family "wanting unwarranted treatment," but they are usually "fairly receptive to suggestions." For example, if "Dad [has] got no ridge [so] it's hard to make a denture fit", then you tell the family that "he's eating fine", and he can't wear "a lower denture comfortably", so "why don't we just leave [him] alone". Often "they're relieved." That's even more likely when "you have someone who's totally demented." But it can be "difficult to decide what's appropriate." Families can also be unreasonable sometimes. For example, we recently had "a brain injured woman in the extended care unit." "The family is grasping for anything," and "they are convinced that she" "has pain" and "needs root canal treatment." But her mouth is "in very good condition", so I have had to "tell them the limits" of what can be done.

The public trustee and informed consent. - Beverly also has some difficulties with confused elders who have their "funds looked after by a public trustee" but have no guardian. The trustee agrees to "pay", "but no one's" been informed about "the risks and" benefits. In some of these cases "we've been able to get two physician's signatures" for a proxy consent. That may be okay for "dentures; It seems not quite so drastic." But "I've done some" "surgical extractions" like that, "and it's not entirely comfortable." There is now "a big trend" to be "maintaining autonomy" for such people. "I very much believe in that concept, but", care staff will say, "Can't we just hold her hand and have her sign" the consent. "That's not autonomy", "that's just being ridiculous."

Daniel Nash

Dr. Daniel Nash completed dental school after 1980. His experience encompasses the care of institutionalized elders primarily at an intermediate care level.

Level of oral health and quality of life. - Daniel says that the level of oral health of the residents he worked with was "generally" adequate, but this was only after several years of regular care. He says, "perhaps the goals were different for this group than for a general "practise," but "I wouldn't have to be doing" this "for all those years, if it" didn't "improve their quality of life." "They may not have a fully restored mouth", but for many "simply absence of pain and the ability to eat their meals was all that they really wanted." "For some of them, an improved" "appearance" "was a concern", "but not all". Sometimes "it even got down to just having the sons or daughters thank me. In some cases" that's the only indication of an improved quality of life.

Professional ethics. - Daniel believes that professional ethics implies, in part, "a balancing" of the needs of patients with the "financial" reality of making "decisions". He has had no formal training in ethics.

Ethical difficulties in determining who is responsible for accessible care. - Daniel says that the most difficult ethical issue in providing oral care for institutionalized elders hinges on the question "who is responsible for what aspects of a person's care, financial [and] actually providing that care?" He believes that "the responsibility tends to be" "shared" by "a number of different groups or people". "Traditionally in dentistry we're taught to deal with patients one-on-one, [but] here we have dentists, patients, a facility", "plus family, and plus who's paying for it." It's "much easier to deal with" the actual treatment compared to "having to deal with all these groups". I have to question, "Who am I getting consent from and how do I" "educate them enough to get that consent?" "Sometimes that person doesn't even really care about the health or quality of life of this resident." Are the "fees" "prohibitive to" oral care?, and if so, "then should there be input from government?" "The fees we charged were actually" "below" traditional fees, so we lost money. It was "more of a community service", but "there was part of me that [said]," "we're there to provide care above all else", "probably it's the ethical side of dentistry." "If it's done as a" "charity, that's fine, but if it's done as a business, then" "the fees [will] go up, [and] perhaps [we can] justify that they should, [but] then" my "impression" is that fewer people [will] get care." "Dentists needs aside, are we providing a better service to the patient in that situation?"

Autonomy. - Daniel's clients "are, for the most part, independent thinking adults [so] we're not able to make a decision for them." For example, "we can't [make] a denture that they don't want. So we educate them", and "they ultimately give consent." Sometimes they will refuse, because they say, " 'I'm only going to live for five more years'." So we "don't make [the] denture'." For "a tooth with caries", "the decision would be" "whether to restore the tooth or extract the tooth. I

would want to restore the tooth, [but] the patient would often choose to have an extraction". It's "disappointing, but", "the same thing occurs in general practise". So "we can say, 'I refuse to do the extraction, you need the filling", "or we inform them of that, and do the extraction." That way "they get to make up their mind." Sometimes we may be able to "improve oral hygiene, [so that] the progress of the caries may slowed to the point where the patient can tolerate having it there for a while longer, rather than doing the extraction right away'." "If it involves pain, then we have to make a decision". But those are mostly "elective decisions, and similarly, in the case of partial dentures, sometimes the decision is, on my part, 'Is the patient really going to benefit from having a partial denture?' " So you can check "the nutritionist's records and the physician's records to find out how well they're doing." "If the dietary needs are being met, and they're happy functioning", "then the position would be", "not to provide them with a partial denture." But "the decision is theirs." "Usually [it's] not a case of advising them against it, but more a case of asking them if they would want one." "Earlier on, when we [constructed more] lower dentures, we would find often that the residents simply wouldn't tolerate them." "They didn't want to have the hassle of trying to adjust to it, [but then again] their needs and desires are slightly different than" an average healthy adult.

Autonomy and beneficence: Balancing a patient's wishes with the ideal treatment. - Daniel says that institutionalized elders often "devalue their whole existence," and so "they don't value" dental care. But, he suggests that they may be right especially "if we're trying to provide treatment" "to last twenty-five years, but medically [they will not live for] five years." We may be able to "improve" "their quality of life," "but they do not value that". "Some of that is societal." "If you stop being [a] productive person, society" "looks down upon you," so their attitudes reflect "society's" attitudes. The question is "are we supposed to provide that same" "ideal" "level of care that I would provide to" "a healthy young adult"? Daniel believes that "the ideal with the senior in the institution would be exactly the same." "That's how dental school tends to train us, but the reality is that there is a person attached," and "treatment is almost always elective" since you can "maintain nutrition without teeth." So "I really have to" "find out what they want, and see if I can work with that." Decisions "depend on the values of the patient more than anything else." "Someone who" "values [oral] health would choose a different treatment [option] than someone who places no value on oral health. If their main concern is aesthetics, that" will "influence" the "decision." "They're in control of things" and "that's okay with me." "My job" "is to try to raise" their expectations, "and to be happy", "whether I succeed or not." "As far" "ethics", "a large part has to do with [balancing] expectations on the patient's part and on the dentist's part."

Ethical difficulty in balancing risks and benefits, and considering paternalism. - Daniel indicates that another aspect of ethics is "whether it's ethical to [choose] one treatment [option] over another." It depends partly on answering, "How much risk is there for this procedure to the

expected benefits." If a family is requesting dentures for a patient who doesn't intend to wear them, Daniel says that "it gets down to, who's idea of benefit? The patient doesn't benefit from a functional denture, [but] in some respects the patient may say, 'It's beneficial because it smooths out my relationship with my family'." For treatment that's "more invasive [or has] a higher risk, I would tend to be more conservative in" advice. For example, to extract sound teeth on a patient's request is "much more an ethical dilemma." Ultimately, you have "to try and balance the wishes of the patient with the risk and the benefits in" "the short term and long term."

Cognitive impairment and competence. - Daniel says that the "mental capabilities, and the physical capabilities" of institutionalized elders "tend to be going downhill, and so more responsibility [to make decisions] is being placed on other groups. But" "the rules of the game keep changing for each individual," so it is "really difficult" to determine a patient's competence. It would be easy "if it were simply that someone else had authority". "About three quarters of" these people could make their own decisions. But "that changed with a lot of the residents over the years." "Even when they seem rational, you can't always tell when they were making decisions properly or not." "In some cases", "you have to decide, is this going to be a benefit to them or not?" But "there's no hard and fast rules", "because each individual case is" "a little bit different." Once there is a "guardianship" "you are" "relying on someone else to make all decisions", "but there's that grey area before you get to that point."

Surrogate requests for treatment. - Daniel recalls that "families would sometimes request dentures" for a resident "because they want their grandmother to look better. The resident's, in many cases, went along with it, simply because it was something their family wanted." But "it is foolish" from the perspective of "making an ethical decision" "where I know that" the denture is of no "real benefit to the patient". So then I try to make the family "realize that this isn't really a benefit." "My outlook" has become more realistic seeing the result of care that I'd provided." Many of the people missing all their teeth can get by perfectly fine with "just the upper denture", and some can get by "without dentures."

Roles of the Profession and society. - Daniel stressed that "a coordinated, [and] complete system of" oral care is needed for institutionalized elders, but it's not in place. Individual "dentists" "provide services", but they "work almost completely independent of the public health department", and of "other facilities." He says "it's hard to know" "who should be stepping in, whether it's the public health unit, government, the dental profession," or the facility administrators, but, as yet, "nobody's really in charge."

James Hill

Dr. James Hill completed dental school before 1980. His experience encompasses the care of institutionalized elders with a wide range of disability including those needing extended care.

Level of oral health and quality of life. - In James' experience the average level of oral health which institutionalized elders have is "very low," and he thinks that it's "not even close" to adequate. The problems are "mostly gum disease, and broken down teeth that should be removed, or smoothed off, or [have] glass ionomers put in them". There are occasionally a few "oral cancers, and hyperplastic tissues", as well. "If the mouth is grossly infected and" "the person fights [staff] on a daily basis", then "we sometimes have to" "take [all] the teeth out after a lot of consultation". Ultimately "the staff" and "the relatives treat the patient better [if they have a healthy mouth, and] a lot of the patients feel better" "so that improves their quality of life." "What the treatment planning" "narrows down to" for institutionalized elders is to ensure "a comfortable quality of life", "free of pain and infection." That's true even for "most Alzheimer's patients" because they are usually "not completely out of it." Basically, you treat people" only "if there's pathology. "Aesthetics is in dentistry now," but "that's not pathology."

Professional ethics. - James says, "I think that ethics are really based upon what's called" "honesty and truth" and "the desire to do that which is proper, according to my training and my skill, for the individual I happen to be dealing with". It's "very broad and open because ethics refers to everything." "To me" "it comes from inside people, in terms of their upbringing".

Difficult ethical issues in the care of institutionalized elders. - James says, "I think dentists make ethical decisions with every single patient they see." But "I don't think I've seen any" difficult ethical problems, "because I've always been able to handle every single situation" that is, "in my personal ethical belief, for the betterment of the patient." In "long-term care work, in terms of" the "high ideals" "we're taught, "you can work toward them, but that's all you can do. Basically, I think you have to compromise", "and in that" "I'm still doing, in my opinion, the very best that I can do for that individual," "taking into account all of the multi-different circumstances you're now dealing with, other than a perfect" "head in a vacuum."

Autonomy and beneficence: Balancing a patient's wishes with beneficial care. - James says, "the bulk of the treatment" he provides in long-term care facilities "is dentures, extractions," "cleanings", "antibiotics," "root canals but that's rare, amalgam fillings, a lot of glass ionomer fillings, [and] I.R.M. fillings," "lots of instruction to families [and staff] as to how to take care of" the patient, "and lots of referrals to oral surgeons." He says, "basically, my whole philosophy" "in long-term care" is, "keep the patient out of pain and infection." "That's really all the patient wants, with some very minor exceptions." "That's the minimum standard." "You go beyond that, according to the people you're dealing with." "Sometimes the patients are [cognitively] there and they want a little more

done." "If I say, 'you could use a denture, do you want one made?', and they say, 'Yes', and I am under the opinion that they know what they're saying, informed consent, then I do it," without consulting with anyone else. "They're the number one person, until proven otherwise." If they don't need the denture then "you compromise with them in terms of, 'You don't really need that', "and it's going to cost you a lot of money, and it probably won't work,' and that's what they want to hear." That's true of, "dentures, partials, root canals, crowns, bridges, [and] fillings." There are "hundreds" of examples in my experience, and, it doesn't mean that those services are wrong. "It's not an ethical thing." "It totally depends on the individual situation."

James says, "one of my philosophies" is that "you don't change [people] by being idealistic". "I start at their level, and I make little changes." If they accept those "then you go to the next level." For example, if people "haven't worn dentures for a long time", there comes a point when the "person will probably not wear [a] lower denture anymore, and for them to actually make that decision is okay". "See that's a compromise." "The top denture fits better, and sometimes makes dramatic changes in terms of speech or" appearance. "So why go to the complete set, when all you're going to do is just make them feel so negative about what you've done". The patients "tend to be on a blended diet", so there really is no health concern or aesthetic concern" to justify a lower denture. Often the nursing staff, family, and patient "want to hear [that] from a professional" so that they know that they are "not actually hurting the person by taking away the bottom denture".

Surrogate requests for treatment. - James says that "there [are also] lots of examples of relatives wanting their parents to have" treatment such as "dentures. In that case I'll "talk to the patient", and if "the patient doesn't care", and if "they're doing okay" "on a pureed diet", then I will "guarantee" the relative, "because of my experience, that it's a waste of money." "They'll never wear the dentures." "Teeth are not necessary to live" "and to eat properly. They come in handy, and they make life a lot more fun, but they're not necessary." "Basically, I've discovered that that's all that the health-care staff" "and the relatives want to hear". "99% of the time they agree". "If they say, 'No, I want my mother to have a denture', "I then sometimes will have to say, 'I will not build her a denture, because I am convinced that" I would "wasting your money and" my "time" because "your relative will not wear the denture", "so, therefore, ethically, and I've said that to people, I can't then build her a denture', and they'll usually go along when I say it that way."

If the relatives are requesting extensive restorative work for a patient who has "broken down teeth, who's eighty three and their physical body is falling apart. Well my values say, they have an awful lot on their mind just trying to keep their body going." "Although" "the teeth" "are broken down, there's no pain, no pathology, no chronic infection, so you don't really need" any "treatment done." "The relatives might be bothered in terms of a value of, 'My dad doesn't look as well as he used to." But then "I say, 'Well I've talked to your dad, and [he] seems to feel pretty good about

himself, and he has an awful lot on his mind in terms of his arthritis, and his heart, and his urination," and "I've discovered that people usually come around to that value."

Cognitive impairment and competence. - James says, determining a patient's competence to make decisions is "totally individual" for each patient. "You try to involve as many people as you can," but "I think it's pretty easy for a dentist", who has "a feeling for extended care work," to decide "who's competent and who's not." "I think it's fairly easy to make that decision by doing a lot of talking, asking a lot of questions, and listening" to the patient and to "the MD, the health-care aides, the nurses, and the relatives". Of course, "a lot of older people would like to make their own decisions, and I listen to that. I have [patients] that actually have draining chronic abscesses in their mouths, and they don't want those teeth taken out." "That's their decision, so we have to respect that. If I feel that they're not competent then I go to the nursing staff" or family, and "we usually talk them into having the teeth out." That's more comfortable than "taking it all on yourself". Of course, "they tend to go along with any treatment plan that the dentist puts together."

The resistant patient. - James says he has "hundreds of stories" of cognitively impaired elders becoming resistant during treatment. To manage this often "you have to hold their head, [and] you just do the work very fast." "It's a technique. Health-care staff will help me and they always know when certain people are ornery or resistant. It is one of the problems with long-term home work." "Patients will take a swing at you, and they can be resistant." Sometimes "it's hard" to determine when it means they're saying, 'no' but "I think most of it's behaviour management", and we've already made a decision, meaning myself and the relatives and the medical doctor, that for the betterment of this individual's quality of life, in terms of pain and infection, the technique has to be done, so therefore, we just go ahead and do it." Of course, "there [are] people where we have decided not to take the teeth out because the patient is too resistant." Then I'll refer them to an "oral surgeon". "But it's a hard question. Is there a defining line? No. It's done in consultation," and it's "totally individual".

Public trustee and informed consent. - James says, "if there [are] no relatives, [a] Public Trustee, which is by law, takes over their finances." "They've never turned anything down that I've ever said I was going to do. They trust me." "There is [informed consent] and that is a right given to the Public Trustee".

Pete Carson

Dr. Pete Carson completed dental school before 1980. His experience encompasses the care of institutionalized elders with a wide range of disability including those needing extended care.

Level of oral health and quality of life. - Pete believes that the oral health of institutionalized elders is "poor as a rule", but "there is some justification in trying to improve their oral health, because" poor oral health "can cause some systemic problems" possibly even "chronic pneumonia". Also "the people that have chronic" "periodontal disease" or "abscesses" "probably don't feel the greatest," although "if you tried to measure it", the effect "would be marginal." "Certainly the people that are cognizant" "feel bad if they" have to be without their "dentures, or if" their "teeth [are] not cleaned." For "some you were doing a lot and they appreciated" it. But, "if they're" "oblivious to their surroundings, usually I wouldn't do much for them." Of course, "if they were in pain, and you took out an offending tooth you've improved their quality of life." But "I don't find [that] dilemmas happen very often."

Professional ethics. - Pete says that professional ethics is "probably just doing the right thing". But "the right thing is not the same" "for every person, or every practitioner." I use my "concept of right and wrong" to make "ethical decisions all the time," because "ethics is a day-to-day equilibrium."

Ethical issues in the care of institutionalized elders. - Pete says that although there are ethical dilemmas found in the care of institutionalized elders, "I would hesitate to say more so than any where else." The "dilemmas that you get into are", with patients who are "not very healthy". "Do you just do the basic dentistry for them, or do you try something like a crown that would last longer?" "They may not physically be up to the process." "I'm not sure that I made the right decisions every time," but "it was always possible to make a decision." It was "a learning experience; I got better at making those decisions". "The overriding value" was to "try to do what is best for the individual patient" based on an "assessment of what that patient needed." But "I didn't have an ideal in mind".

Autonomy and patient wishes. - Pete says that, most of the "debilitated people" he saw "really didn't care" about oral health, so "they maintained the level of oral health they were interested in, which was low," and "I don't think that I saw it changing in the institutionalized patients, [like] I see it changing it in" "ambulatory elders". Until recently, most elders "assumed that they would have" "dentures, [but now they] work hard to maintain what they have, because they find that their teeth are going to last".

Beneficence, nonmaleficence, and appropriate treatment. - Pete says, "it took a while to sort out" what level of treatment is appropriate for institutionalized elders, "but I have a" "good idea now what people need to get by and I gave up trying to do heroic things." The goal is "not very

comprehensive. It should be simple, and it should be functional and it should be hygienic." Patients with "dentures were easy to look after" because "they had no disease" "in their mouth". But people that had teeth often "had untreated disease." "There were two goals" for them. "One was to" keep them from getting "sicker", so if "their hygiene was poor and there was decay and periodontal disease", it "made them healthier overall" to have "their teeth extracted". The other goal was if there was some level of hygiene, "then you tried to hang onto those teeth". "I was doing mostly" "complete dentures, the odd partial, and seeing a lot of root caries and doing a lot of hygiene", but not aiming for "optimum oral health, which is the ideal objective" for healthy people. "Rarely" would I do fixed work, and "there was usually no great aesthetic component to it" either." There can be "exceptions", so "I don't generalize", but "my philosophy tends to be the other way." Pete says the patients he "did worry about" "had fixed bridge work and crowns" before they were institutionalized, "and all of a sudden, their hygiene stopped and their dental care stopped and they had root caries." "I would shudder when someone [like that] would come in". "I'm supposed to look after them now. It's just a mess." "I can remember several." One "was an elderly physician" who had a complete upper denture and "bridge work" on the lower. We'd "do hygiene on a regular basis". But he developed "root caries" and "ended up" losing all his lower teeth. "That's a problem, because when you see him at first, you don't say, 'You need all your teeth out'." Unfortunately, "he will never get used to wearing" a lower denture. "He has no adaptive capacity left." I remember [hearing that in some cases it's best to] 'Take the lower denture and throw it away,' and I thought", "that would make the patient's life so easy. What a great idea!" "But" "somebody had to tell me that." "Basically I was thinking everybody needed" "28 teeth to eat their food." In reality, "you don't need teeth to eat." They often have a "pureed diet," and at that stage. People will often "want to wear the upper denture and they usually have very little trouble" with it", but not the lower. "I think initially, I was still trying to" do the "ideal treatment" we were taught "in dental school and I think that I became more pragmatic as I got older." There have been "lots of teeth that you tried heroically to save and ended up having to extract later on." "You learn very quickly that you have to be more practical." "The change in my attitude was that" even though this person "can afford crown and bridge", "it's just is not suitable for" them. "You can call it a compromise. We call it 'rational treatment planning'. Somebody coined that term", and "it was a confirmation of what I was already doing - got rid of some of my guilt", "and "I don't agonize over it as much as I used to."

Surrogate requests for treatment. - Pete says that he would regularly get requests from family members to construct dentures for a patient who had lost their dentures. The family would say, he "looks awful". "Usually", the patient is debilitated, had a stroke[, for example, and his] wife can't look after him at home." "They're well off people. You look at her, she's well dressed and she's got an active social life." So "it just brings tears to her eyes when she comes in and visits him,

because he's so feeble", "and to see him without teeth makes it really hard for her, and so, I say, 'Okay, I'll make him one?' " It's worthwhile. "Even more so if it's somebody at home. I think that more and more we're realizing that the person who's suffering is the caregiver." The patients often "don't have real strong feelings one way or the other anymore." "In my case, it was easy, because [insurance] paid for it." "If it happened again", I'd "make him another one." But only if the family "absolutely insisted", and I would still advise them that "he doesn't need this."

Cognitive impairment and competence. - Pete says that "most of the time" he was treating "people that had some ability to reason and to communicate, because if somebody is [at] the point where they're unable to" "think for themselves" "they're also not likely to be good candidates for much dental care". So "often, you do nothing" "even if they have root caries", "periodontal disease", or "periapical abscesses." Treatment "is probably", "going to cause them more discomfort and pain than their teeth ever will." "If there's an acute problem," "then you have to do something", "but it's surprising how few acute problems there are." When you need treat these patients you "do the best you" can "and often if you" are "very gentle with them I found, especially with Alzheimer's patients", "they would trust you". "My experience with the Alzheimer's patients was that you tried to make things as normal as possible. Some of these guys were used to getting their teeth cleaned every six months", "so you clean them every six months just to try to maintain some sense of normality in their life." You still need "compliance". "Some of them would say, 'Get away'." "People who have had strokes, [for example], can be a bit belligerent", but it's up to them if they don't "want this done. So that's fine."

Pete says, "I'm a little bit behind the times" in how to determine a patient's competence to make decisions. "I don't worry about it as much as some people do." I think that for "somebody who's got Alzheimer's disease and is failing, if you are honestly doing the best thing in your mind for that patient," for example, "you're just cleaning his teeth", "I don't have any great moral dilemma on that." Of course, "if you're doing fixed bridge work on the guy, then you may be opening yourself up to some liability". For consent "you go to the closest relative. In the" "chart there's always a" "name". If "I thought the best thing" for a patient was to have something "drastic" like having "all his teeth out, and maybe dentures", then "I would try to get consent from the next-of-kin if they had one." For a single tooth extraction, Pete says he would "just take it out." "It needs to be taken out." "A lot of [these residents] were" ignored by their families, and "the Public Trustee [often] looked after their money." However, in this particular setting, most of Pete's patients did not have to pay for treatment because they had third party coverage.

Carl Finch

Dr. Carl Finch completed dental school before 1980. His experience encompasses the care of institutionalized elders with a wide range of disability including those needing extended care.

Level of oral health and quality of life. - Carl says that "where I've been the level [of oral health] is comparatively higher" than where "there's no dentist." "Of course, you can't make it ideal, [but] it can be better." "It's not adequate yet, because" "I'm still racing around trying to tend to all the acute needs." Some of my patients may think that, "people are offended because of [their] mouth [in both an] olfactory as well as a visual [sense]." With our clientele, that is one of the big things, [but] we can't ever get rid of it completely, because so many other factors [are] contributing. So if I can minimize that, I think that's terrific." "Especially when their families and the staff have come up to me and say, 'He's so much more approachable. He doesn't bleed as much. He is not as difficult to manage because his mouth doesn't seem to hurt as much'." The patients can "eat better and their body behaves better." "They [also] think better of themselves." But for the most debilitated "it makes you wonder what they are aware of, [and] I don't discount the possibility that there is some awareness there." "I'd like to think that if he could speak, he would say, 'Thank you'."

Professional ethics. - Carl said that ethics is "what I try to do each day with the training that I have, [and] the skills that I possess, to bring the person up to optimum health" and to "maintain an optimum level of comfort." "I try not to overtreat, because" "many of the [things I can do] are the wrong things for the particular individual." For example, if you were grinding your teeth at night and had a sore jaw joint, as is very common, Dentist A would immediately try to adjust the way your teeth bite, whereas Dentist B would "say, 'Tell me about yourself. How are things going in your life?' You say, 'Rotten', and he says, 'No wonder you're grinding'." When the patient returns to the dentist once the life stresses have passed Dentist B says, " 'How are you doing now?' 'Oh, much better', and he'll say, 'Thank goodness I didn't touch your mouth. I just listened to your concerns.' Dentist A is in trouble. Dentist B's practise will thrive." So, Carl says, "I try to be like Dentist B." If patients "see me as somebody who is willing to listen, [then] I've done a lot for them I think."

Difficult ethical issues in the care of institutionalized elders. - With some thought, Carl said that the type of ethical problem he encounters in the care of institutionalized elders is "How far should I go" with treatment? This is a more difficult problem than with healthy independent people, because they have "expressed" their wishes. "That [makes] it easy." "They have asked me." With mentally disabled patients "the responsibility is ultimately" the dentist's. "He can give the family a few choices, but then they refer to him" for the decision. "He knows what's best and the patient can't give him anything, so he has to make that final decision", and he "has to live with the choices he makes." To improve these decisions "we may have eight or nine people at our frequent conferences, amongst whom are psychiatry, psychology, charge nurse, and nursing supervisor," but

this isn't always successful. For example, the team once decided, "We think Charlie should have a partial, because his looks are terrible". "So Charlie, being a good dental patient, goes through the [procedures]. In goes the partial. Two or three days later [the denture has been smashed]. There's something we forgot to do at that meeting. We, the five or six year trained people", "didn't ask Charlie." He may have said "I've been happy for 14" "years like this. I may offend people because of my ugly look, but I speak and eat and I'm happy with my looks." Carl noted also that, "I don't say that I was the expert [or] why did I go along with it."

Autonomy, patient wishes and cognitive impairment. - Carl said that "we have the very extended care [patients]. They're not like the people who walk up and down the corridors and play scrabble." "We [do] have some mentally capable people" also, and if they want help with mouth care, "they can get it". For the residents who can't make their own decisions we have "a blanket" consent in place, so we often just "do the treatment required. We can't ask them" for input, so we rely on our own judgement and consultation with the physician, staff, and family, although "sometimes [there is] less consulting with the family especially when the family has already said, 'Go ahead and do what you have to do'." Treatment in this facility is not paid for by the families.

The situation is quite different for my homebound patients who are mentally disabled. Then we always consult with the family directly. "It's the family, in the first place, who have called me over." "We "all look together" , and I ask them to tell me about the patient. We decide what is needed and "get to work on it." If need be, we may also "phone the physician" for a consultation.

Beneficence and appropriate treatment. - Carl said that the usual aim of care is "to keep [patients] comfortable." "Our clientele [are] among the most medically compromised [so] a three or four hour appointment [is] out of the question." On the other hand we may feel that a patient "should [be treated] because part of the reason for [their] ill health is coming from" oral infections. "If it's agreed [to through consultation], then that's the way to go." But you need to "look at the whole picture. The 35 year-old may have another 60 years to go, so you try to save those teeth. "We decide" these things "on an individual basis, and almost always in consultation with the physician and the nursing staff who are really on top of things". "We don't want to be the one to trigger [their] passing away." "Look at the mouth now, [but] the patient is dead."

The Resistant Patient. - Carl said that often his patients "do not like to be touched" especially in their mouth. "There's pain in there." "The longer you do not touch my mouth, the more reason there is [to do so], because it's really hurting now. [Then] I really want someone to help me, but 'don't touch me'." I am "non verbal [and] combative. I drool and I smell, and I cry out." To manage this patient, "I start before" attempting treatment. "There's a lot of team work here," in preparation including "reading the previous progress notes [on] what's been happening with the patient". I may also "consult with the physician, [or] the nursing staff, [and they] will say, 'I suggest you do this with

that person." "Invariably I will order some oral sedation so management is both easier for me and less stressful for them [and] so we don't [need] people holding the person down." "A lot of treatment can [then] be managed" under "twenty minutes, [and] more easily than waiting until there is resistance during the treatment, [which is] very dangerous." We have "an instinct for sudden movements, and we can sense [the patient's discomfort], often stopping before they're ready to stop." That way they will often "let us do more next time." If the patient has extensive treatment needed they may need "a general anaesthetic, [so] there are forms that they, or somebody competent, must sign." "Being able to write his or her name and not knowing what [it is for] is not informed." When the resident can't sign then we contact the "next-of-kin, and if they don't exist, or refuse, or are themselves mentally incompetent, then we go to the next level - [the] public trustee."

Surrogate requests for treatment. - "Very often a [request for dentures] comes from the [family]." Often the old dentures are "flopping around all over the place, [but the resident] doesn't have any input [because they are] out of it. It's the staff and the family" who make these requests." But "my question at the beginning is, 'How does she feel about it?' 'Oh, you can't ask her because she seems happy, but we're not.' "So long as that's clear" at the start, I may grant their request. Usually, if the request for dentures is from the family, and the patient is unaware of what is being considered then "I don't" treat them. But, "it's [a] very touchy [issue]." For a partial denture, my main "concern is [that] there's something in there they could aspirate. I would be the negligent one insisting that thing is worn." For families who insist we have a "waiver. I point out to them these dangers" and that "we all have to be very diligent now. For example, a woman once said to me "My mother has lost her partial denture." "Would you make her one?" "This lady [has] narcolepsy. She'll sleep nine or ten days and then awake for a day or two and binge" on food. We provided the treatment, after which her daughter said, "Oh I'm so happy. Thank you. That was for me." "And I said, 'Thank you very much for being so honest, because most family don't admit that it is actually for them and it's probably often doing their loved one a disservice to do it'."

Role of the Profession. - Carl says that some of the dentists who try to work with institutionalized elders will "say, 'I don't think I've done enough'," so "I'll say, 'Have "you done your very best?', and they'd say, 'Yes.' I say, 'Well, what else can you do, if you really think you've done your very best?' " "We made up everything [as we went along, and the] things that I have been doing seem to have worked, so I haven't sought better ways. They haven't all worked, [and maybe] they could be a lot better, but nobody's shown me a better way. I need [others] to listen and say, 'Oh, I see what you [could] have done.' Then I would say, 'I'll do it'."

Julie Archer

Dr. Julie Archer completed dental school after 1980. Her experience encompasses the care of institutionalized elders with a wide range of disability including those needing extended care.

Level of oral health and quality of life. - Julie believes that the oral health of institutionalized elders is "not very good", particularly for those at an extended care level. On the other hand, she says, "I think [it] would be interesting to know" what level of care is important. "I'm not always sure" what effect regular oral care will have on the quality of life of patients. "In some cases", when "people" "are in extended care hospitals with purely a physical disability, I think it [is] a great service for them, because they're" "aware of their physical self". But the effect for some patients is not always that clear.

Professional ethics. - Julie says that professional ethics implies the need "to do the best possible thing for the person that you're seeing in their circumstances, [although] sometimes that's not easy to know."

Autonomy and the importance of patient wishes. - Julie said that the appropriate level of treatment for these patients will "depend on their health, and the state of their own mental independence or, I hate to use, competence." "If they're mentally aware, should get the treatment they want. They should be the ones to direct their treatment". "There [were] occasionally people that maybe had pain" who "were perfectly able to give consent [for] treatment," but chose not to. That's their decision as long as they can "understand what they are agreeing to."

Treatment compromises. - Julie said that "when I started working with debilitated elders, I think the hardest thing that I found was that I couldn't do the best dentistry. I had to make compromises and" "I felt terrible sometimes about not being able to do perfect dentistry, but you couldn't." "Sometimes they couldn't follow instructions. Sometimes they couldn't keep their mouths open for very long and you had to get in and out [quickly]. Sometimes they would be very cooperative". "That was very difficult to accept when you were just trying to live up to the standard that you'd been taught." It got easier "because I started to see that [treatment] was helping. After I took a few courses on dealing with elders, [or] the disabled", I started "to realize that this was something that you had to deal with". One of the most difficult situations to manage was the person who has had extensive "crown and bridge work" and ends up institutionalized at an extended care level. "It's a nightmare." "They wouldn't be able to care for their mouths." For those who were "just physically disabled, it was very tough on them" "emotionally when their teeth began to breakdown."

Beneficence and appropriate treatment. - Julie says that "there were very few instances of emergency abscesses the way you see in a younger population." We saw people who had "broken down [teeth] with caries", but with "no apparent pain, [or] acute infections. So there's a difficult

decision then. Do you take someone who's quite ill and put them through the procedure if the teeth aren't bothering them?" "It was always a concern [and] I don't know the answer."

Cognitive impairment and competence. - Julie said that a patient's competence to make decisions is very individual, and it's not always clear. If there was any doubt about a patient's competence, Julie would consult with other staff, or a physician if necessary, for assistance. She said, "I have interesting" cases. "I have one fellow [who's] very coherent, and he had a perfectly fitting denture which was obviously his, but he insisted that it was a friend who had lent it to him and he had to return it and he needed his own. He was missing a lower denture and I suggested that perhaps his friend had meant him to keep [the upper] and we should just make him a lower denture. But he insisted he had to return it and that he needed a [new] upper" denture. So I went ahead with it and he was "very" happy.

Julie said that if a person is not competent to give consent for treatment then "you would have to get other people involved." "Depending on what level of treatment you want to do, [you might] involve the doctor and the family." "Sometimes there was no visiting spouse or any [family], [so] you'd talk to the physician. Usually, what we would do is write a consult sheet where we would make recommendations and it would go up to the ward for the physician to see." "This wasn't done so much for their permission, but to provide "the attending physician [with] knowledge of what was going on with the patient." If a patient had no family to give consent "then they would usually have a trustee" to do so.

Beneficence and nonmaleficence in the care of cognitively impaired elders. - Julie said that patients "with end-stage Alzheimer's" "would come in," and "you couldn't give them any instructions that they could follow, and the relatives might want something done, or the nurses may have noticed that they're in pain, and then you're trying to diagnose and treat someone that you can't communicate with." "There were a number of cases where there would be broken off, decaying teeth that if the patient was in better health, you would choose to treat. [The] question always arose, 'Is it better to leave them, when they appear not to be having any trouble", or "to impose this ordeal of treatment on them?' "The choice was often not to treat." "There didn't seem to be" a lot of acute problems so I think it was always difficult to know" when to treat and when not to treat. "The idea is to help someone, right? So leaving them alone, even though it goes against your training, maybe the most helpful thing you can do for them. But it's hard to know." The decision depends partly on the person's past experience with oral care. "I had one patient whose wife always brought him down and he was quite far along with Alzheimer's, so he couldn't understand my instructions at all, but he was so good when you came to doing anything with his teeth. He would open to let you brush and he would even hold still, to do cervical type of fillings. His wife said that he was always really meticulous about his teeth." But "it really varies. I mean, how do you know [they want to be

treated] when you can't get the feedback?" Julie said that "if they're not mentally aware, then I think their mouths should be kept clean and they should be kept comfortable" at a minimum. "It always struck me that you wouldn't not bathe a patient [just] because they're difficult to bathe." Likewise "I always tried" to clean the resident's teeth. Of course, "if someone has daily care, then maybe that wouldn't be needed so much."

Julie had one rather unique and difficult case. She said, "the patient died shortly after [a] request was made" by the nursing staff "to extract a demented patient's teeth". "On two separate occasions" "he had very seriously bitten" "some of the care workers". If he had lived "I would have contacted the physician, any family, and the nursing staff. I really think [there] would have to be a major discussion with everyone involved." "I think if it came to the point where no one could care for him" then it may be best to extract his teeth.

The resistant patient. - Julie said that patients occasionally resisted her treatment efforts and if they "really resisted, we would just discontinue" our treatment. If "it was considered something that [was necessary] for their own health and safety, like" "an acute infection" "that was a real problem, then I would probably refer them to have" "treatment" "done under [sedation in] consultation with the doctor". Otherwise "I would probably do the least upsetting type of treatment that you could." For example, "I would probably try to do something like spoon excavation and [placing] some glass ionomer, or even just getting [the caries] cleaned out and putting fluoride on." Again it goes back to getting used to maybe not doing the ideal treatment, but doing the best you can under the circumstances." For example, "there were patients that I couldn't clean the lingual sides of their teeth" because they wouldn't open. "So you did the buccals, and then you brought them back [to try again]. People behaved differently on different days, so, we did what we could on with our given circumstances." "We didn't restrain people to get done."

Surrogate requests for treatment. - When asked if conflicts over a resident's treatment ever existed with a family member, Julie said, "Yes, and I always wondered if it was a sense of the family just wanting to care in some way for a relative, and they were probably feeling a bit powerless to help, so they wanted the best. "Sometimes I found that the family would really want something, that I wouldn't necessarily think would be a great idea." "Sometimes [it was] the family wanting to get their parent a new set of dentures, when they'd lost the old set, but they'd lost the old set because they wouldn't keep them in their mouth." So I would spend quite a bit of time talking to [a] daughter or son trying to find out" their reasoning. "Then talking to nurses [might help] because if a family member really wanted a new set of dentures for a parent and when I examined them, I wasn't convinced that it would be appropriate, then the people that would be really good to talk to would be the nursing staff. To find out why they lost the dentures in the first place. Did they wear them? How did they do without them?" "It happened often enough that" it was a concern.

Frank Lind

Dr. Frank Lind completed dental school before 1980. His experience encompasses the care of institutionalized elders with a wide range of disability including those needing extended care.

Level of oral health and quality of life. - Frank said that, "in my experience" the average level of oral health that institutionalized elders have is "poor." In the institution I've attended for 14 years "it still could be improved a lot." "Oral care is not a high priority." When asked what kind of good he does for patients, Frank said, "In some small way", "I hope" "I'm helping the older patients enjoy their last days." For those who are aware, "I'm helping them [to maintain] their oral health, [and] their self esteem." "I'm helping put normality within their life." With "the mobile dentistry, in a lot of cases, they wouldn't get that care, [so] I'm filling a void that I don't think anyone else would fill." "My whole philosophy is that 'If you serve, if you do a good job, you're going to be successful'." There are many seniors living here but, "we have no good [mobile] service going out into the community for" them. "Right now a lot of the homes [still] aren't being serviced properly." Granted, in "a lot of cases [institutionalized elders]... don't need teeth to eat. But [for] a lot of individuals their satisfaction [with] life" "much improves if they [can] eat food rather than having pureed food." "In some cases [though, they] are best to have their remaining root tips extracted and nothing else done. A lot of the patients that I deal with could never learn to use a set of dentures."

Professional ethics. - Frank says that professional ethics implies "basically putting your patient ahead of your own interests." "I think a lot of it goes down to your basic background, where you come from."

Difficult ethical issues in the care of institutionalized elders. - Frank believes that dentists have a powerful position of responsibility, "especially... in geriatrics, because really the patient is not aware, the family is not aware that much, the physician isn't aware that much, so you really are making those health care decisions for the individual." But I "probably undertreat the individual more than overtreat... because of their poor tolerance for change." He says that "I try to do my best for [these] patients, but I would say that 20 or 30% of my patients have advanced periodontal disease [which] I'm not" "able to control with the amount of time I have to spend with" them. "I'm providing some service, but not as good a service as I would like to", and so "I feel badly sometimes."

Autonomy, and patient wishes. - Frank said, in "my view, the individual should be able to seek the same level of care in the institution as they" could "if they were living their life" elsewhere. "We should provide that type of service to our clients." Now, "a lot of the individuals, don't want to come to the dentist. They feel they're at the end of their lifetime and they don't really care about their teeth." "Some of them [are] glad to come in, [whilst others] are at [a] life stage where that's the last thing they really care about." "There's also maybe the financial concern. Most of them, if they think it's going to cost them any money, forget it, no way."

Beneficence, and treating debilitated patients with limited diagnostic information. - Frank said that "I see lots of individuals [where] palliative treatment is all that we should be doing. I'm talking mostly about the debilitated patient." If they "can't brush their teeth, the last thing you want to do is set up a full-mouth reconstruction when you know that it's not going to be maintained." "I have to look at their whole condition. Some of the care you provide... might be very basic." But it can be "very difficult... with the really debilitated patient." "You're really trying to make sure that their last days are as healthy and happy as possible." "If they have bad mouth sores, or they have toothaches obviously it's going to affect them. The problem with diagnosis a lot of times [is] you don't know if it's hurting them. A lot of times, you'll see broken off roots and often you can't even get x-rays. You'll percuss them and see if they elicit any response, but they often can't tell you. So you have to analyze, Is the risk I'm going to put this patient through medically, by extracting these roots, worth what your perception [of benefit] is" "Your diagnostic skills are limited [because] your ability to ascertain information is limited." "Sometimes I do nothing for them. Sometimes you have to guess [whether] this [is] going to be good for them." It "is difficult to assess the risk". "I've [had] cases where [with] the simplest extraction you get into so many complications... with the elderly that you wished you'd never done it." But, "you've just got to try." "There's no easy answer to it."

Generally if a patient can't participate in the decision, "you just do something just to keep them comfortable, ensure they maintain their mouth in an adequate healthy state." "You try to assess the oral condition with their whole medical condition [and] the situation which they're in. You don't want to overtreat them. You don't want to undertreat them. You have to put their oral problems in perspective with their other problems." "There [are] often cases where I felt I could probably really help this individual, but rather than push the issue," "I tend to undertreat rather than overtreat them." "Say it was to do with dentures. You never know how that patient's going to respond. Their ability to adapt is so much less. Their muscle tone is so much less. If you recommend something", "and it's not successful, that leaves you in a pretty bad light. So I tend to undertreat rather than overtreat."

Cognitively impaired patients and substituted decision-makers. - For patients who "aren't [mentally] with it [your goal is] basically maintaining the hygiene, doing the regular scaling." In most [of these] cases, I will go to the family first, and then the family will seek [the patient's] approval." Allowing just the patient to make the decision "has gotten me in trouble sometimes. Sometimes they can fool you." "I've had cases where say, I may have taken out some teeth and done a partial denture. And then when it came down to it, they really weren't [aware] and the family got mad at me. I'm probably a little bit more careful [now]." If I'm asked by a hospital staff member to see [an] individual, I always see the individual, I'll do an exam and then we'll send a report to the family and get the family approval. In some cases, if I see something that has to be done right away, I'll do it

right away for that individual. Say they have a big denture epulis, I'll relieve the denture, and I'll bill the family for it. Sometimes I'll get paid and sometimes I won't get paid." "There's no easy answer to that." "It could take two weeks for family approval. "Am I going to leave that for two weeks. No, that's ridiculous, so, from a financial point of view, you don't make very much money doing this. But that's something that maybe you have to live with." Sometimes "the family gets mad at me for even seeing the patient, just to look." "I usually ask the nurses, 'Have you got family approval?', and they'll usually say, 'Yes.'" "But I have gotten myself in trouble for not [having] proper informed consent. Sometimes we'll send out a letter, [and] you won't get it back, [but] you feel you should [treat] them." "Sometimes you try to phone [also], and for various reasons I might go ahead." "Anything major, of course, I get consent. "In the past" "I may have done" "say a filling" with just "approval from the hospital", "but I don't anymore." For any major treatment, "I always discuss it with the nurses, with the physician, and with the family." "Some families will say, 'What ever you think!' Others will say, 'Oh, I don't want anything done'." "The responses" are "very individualized."

Dentist conflict with family opinions. - Where a family member's opinion is in conflict with his views, Frank said that, "if it is a case where I felt something was needed for the patients and they didn't want it, then I would give them my views on it and say what I think of it. It's up to them to decide." "Where they've asked me to do things, say where they wanted me to take out all their teeth and do dentures for the patient, I guess, [I'd] take out their teeth." Although "I may feel that I can save them for a few more years, I might take them out, because in five years time, they might not be able to tolerate a [new] denture." Often things aren't totally black and white." "If it's something I'm a hundred percent opposed to, then I probably wouldn't do it, but if it has some merit to it, although I probably wouldn't recommend it, I might do it for them."

The resistant patient. - When asked how to manage a resistant patient, Frank said, "I've learned that often these patients are more aware of what is going than you think they are." "You can talk to them gently, and [that] works really well." "A lot of times, they don't communicate, [but] they don't want to be there, so lashing out is their last ditch effort to communicate." "Sometimes, if there is a little bit of mild restraint - holding their hands - "we can do it." "If they're really violent, we don't do it." "Yesterday, I almost got flattened by a patient. Sometimes they can be so fast - that fist can be out." "I love to tell the story about a patient about six months ago. She didn't want to be there. I was fixing a cuspid for her and she was saying to me, 'Go to hell, go to hell, go to hell, go to hell, go to hell,' and when she wasn't saying 'Go to hell' she was trying to bite my fingers." "Some of those stories are laughable when you look back at them."

Greg Taylor

Dr. Greg Taylor completed dental school before 1980. His experience encompasses the care of institutionalized elders with a wide range of disability including those needing extended care.

Level of oral health and quality of life. - When asked what level of oral health institutionalized elders have, Greg said, "the elderly accommodate" "real well" to "what we would consider, from the ideal perspective, [to be] horrible situations." "What we have as a gold standard, in terms of what people need to function with ideally, the elderly have clearly proven us to be wrong. There are people that... will tell you they get along just fine" despite having "oral conditions that we would consider to be far short of satisfactory, or acceptable." "On average, most of the people, in my world, on a daily basis, probably will not brush their own teeth and some people probably haven't for years." So "I'm looking at awful mouths, pretty much day in day out." "Now... there are exceptions of elderly people who have had a very keen sense of their oral health and have taken great pride in maintaining good oral health." "I pay particular attention to these folks, because there's a much higher level of satisfaction." Greg says that a few of his patients appreciate regular dental care, but "there is a lot of dentistry that I provide for which the benefits, the impact on this person's life, are far less tangible." Sometimes you think that 'Maybe this is just a waste', and you are occasionally there." "If I'm going to clean somebody's teeth today, yet during the next six months his teeth are not going to get brushed, what is the point?"

Professional ethics. - Greg believes that ethics in dentistry "involves the art and science of trying to make good decisions, moral decisions, and in studying ethics one learns to appreciate [and] understand the complexity and the balance between different positions in the decision-making process" so that you can do the best "on a day to day basis."

Ethical issues in the care of institutionalized elders. - When asked to describe the most difficult ethical issue in the oral care of institutionalized elders, Greg said, "Clearly, one of the most difficult is When you think you're doing good for a patient, Are you? What is 'Really doing good for them?' I mean, So what they have these retained root tips. So what they don't have their smile. So what their denture's a little loose." "I don't always know", "and I have clear examples of when I thought it was going to be [good] and it wasn't." "The classic is when you relines a denture". "Experience tells you [to proceed if] this patient really senses a problem with the situation [and] looking at it carefully, based on your experience, you think that you can improve it". "If I see a denture that's awful, [but] the patient doesn't complain of it, I don't touch it." "If it is just the family who want the denture "I will occasionally do that, but I'll make it very clear to the family that that's why I'm doing it." "If I can do something that makes family happier, if they're taking mum out to dinner" "and they want her to have her denture, well then, I want her to have her denture." But, "it isn't [a] frequent" justification. Family "let me advise them and they'll usually let me chart the course

of treatment. It's rare that they" insist on something. It occasionally happens and "they're right often enough to make me concede that their influence is important [especially] when they press to change my mind". "It's difficult though." "Some family does it out of guilt."

General treatment objectives. - Greg said, "the treatment plans [for these patients] are not sophisticated and complicated." "90% of my activity relates to treating the ravages of root caries and rehabilitating, relining, and repairing prosthetic devices." I am "now using glass ionomer cements for coronal restorative procedures, especially if they're are opposing dentures, [but also] because I feel the effects of the leeching of the fluorides are beneficial." Occassionally I'll "need to close the contact, or I'm opposing a natural dentition, [so] I will place an amalgam." But, "the most frequent goal is to maintain existing situation with no undue pain or discomfort, hopefully maintaining a functional situation and to a lesser extent, a situation that is aesthetically acceptable."

Autonomy and patient wishes. - Greg says that "there's the full continuum of people" in these facilities. Some "enjoy eating to a large extent, and want to maintain" their teeth. But "as they become more compromised, those issues are of less concern." "I've taken care of retired dentists who have all their teeth." But "when I can't walk anymore, when I can't taste the food I'm eating, when part of my body hurts every time I move, [then] first of all, I may want to die. Secondly, I may not [care] about my teeth." He says that some elders try hard to keep their teeth. "It's like that last day that they take a walk on their own and they need a walker". Often I'll say, "You've kept your teeth your entire life and" now we want to "just keep what you've got here trouble free." On the other hand, "I did two full glass ionomer cement crowns on the maxillary anterior on a lady yesterday who's very outgoing and vivacious." "Two full crowns would have cost her \$1,500. I hope they last." "She was very happy, but that's rare."

Consent by action and the resistant patient. - Although most of my patients don't participate in treatment decisions, "they can [consent] by action, and that's very important. Many of them will recognize that I'm a dentist and they're in a dental clinic." The question is, "Are they going to get in that chair and open their mouth? That is consent by action and I expect that." "I find that relatively few people will fail to cooperate." "While I may see that they have occasional signs of discomfort, if they continue sitting in that chair and letting me" work, "I figure they're consenting." "If I can see that someone is having... trouble... continuing, I will try to... get it over with." That "isn't as black and white as it sounds." "In my world, I can almost overpower somebody to complete a procedure if need be so it's a delicate balance." "There's a great deal of need for T.L.C., a certain amount of charisma, recognizing that most of my patients are little old ladies who" appreciate this.

Beneficence and appropriate care. - Greg says that determining appropriate care can pose difficulties. But usually "to put big dollars into trying to create something that they don't perceive is necessary, is foolish for us". On the other hand, I will usually wish to treat if something "is

physiologically very wrong, [for example], denture trauma, or carious root tips". This "may not be symptomatic, but will certainly lend to the infectious nature of a mouth." Root tips that are not carious "are just fine, [so] I try to retain" them, but it is not always clear what is appropriate. The appropriateness of routine care is not always clear either. "Yesterday" I saw a person who has "authorization for continued care [and] I hadn't cleaned her teeth for a long time." But "this patient had no real awareness of what was going on." "She had no caries. She had tons of calculus and plaque. [So], I cleaned her teeth, basically because the care-aids wanted her teeth cleaned. There's a social context [where they] don't really like to deal with people who have incredibly" unclean mouths. "I perceive it to be the most significant benefit" in this case. Ultimately you have to decide "do I really want to pursue this case, and what for?"

Substituted decision-makers and consent. - "The [treatment] objectives that you set out are ones that, in many instances, you establish with the help of family, with the help of administration, staff, and, to a lesser extent, the objectives of the resident," simply because they're "unable to participate to any meaningful extent." "There will be people in an institution over time who have managed their own affairs and they will digress further" so that "they're really no longer able to do that." "That's created problems where all of a sudden now I need to call the family and say, 'Okay, we're here'." But "there are diminishing numbers of people in long-term care that can actually" manage their own financial affairs. If they can "they're [often] too healthy to get in there." Consequently, "the difficult[ies] of consent [are] a major ongoing problem". "In almost every instance, there is someone with power of attorney who will [give] consent." "Informed consent in traditional dental practise is" normally "difficult". "In my world, it is a continuum between absolutely helter-skelter" and difficult. It's complex because of "the fact that there are more people involved and that they're all coming from a different place and that you may not have what you consider to be an ideal opportunity to communicate with them." There is "far more uncertainty surrounding the" decisions and so the process, "occasionally, is not successful." "As long as you don't really expect to collect for it, you probably can go out there and deliver a lot of free services. They'll take them, but when you go to collect them, they may argue the issue of consent and authorization at that stage. Basically, they've got you over a barrel. Rarely do they sign anything."

Denying treatment requests from family. - Although family generally makes decisions for cognitively impaired elders, Greg said "I have [also] told family that I won't extract teeth, or I won't make a denture, or I won't reline a denture because I don't think I can improve" the situation. If the family still wanted the treatment then at some point "I think the provider needs to step in and say, 'I'm not going to do this'," because "I don't think society today has tremendous amounts of money to waste, [and] I don't think that from the Profession's perspective is a good thing for us to do."

Susan Watts

Dr. Susan Watts completed dental school after 1980. Her experience encompasses the care of institutionalized elders with a wide range of disability including those needing extended care.

Level of oral health and quality of life. - Susan believes that the oral health of institutionalized elders is not adequate. She noted also that, for those with "dentures, some of them have just fantastic dentures, or somehow" "their mouths [are] really healthy [despite] ill-fitting dentures". "But by-and-large, if there's going to be a little problem at all underneath those dentures it's going to be really, really severe. Lots of papillary hyperplasia and denture stomatitis. Some of it's really quite cultural" also. In contrast, "none of the [institutionalized elders] that have their own teeth have good oral health." However, I only see acute pain "maybe every couple of months." Susan said that "as people keep their teeth longer, I think that they're going to be" much more likely to have "problems when they're in the care home." Susan believes also that oral care affects the quality of life of institutionalized elders. She said, "I think that they feel good about getting some attention." "If I can make their dentures fit better and make them feel better" that's a benefit. It is more difficult when they don't recognize the need. But I think that oral care can "really improve their quality of life, because then the care-aids [and others] don't mind... coming near them." For the most part, "I don't think [they] really care about how they appear that much," and you don't need teeth to eat. "Some of them [even] take [their dentures] out" when they eat. Ultimately, "I think [my impact is] mostly just in [creating an improved] sense of self-esteem" for them.

Professional ethics. - According to Susan ethics relates, in part, to the "principles, like beneficence and autonomy." "They're guides, I think, for wrong and right behaviour, for making decisions," and for "balancing the needs... and wishes of different groups" on a daily basis. With older debilitated people, autonomy is really at issue all the time." "They've had a full life and there are times when they're lucid and they remember that and they want to have control."

Ethical issues in the care of institutionalized elders. - Susan said that the most difficult ethical issue with institutionalized elders is the difficulty "maintaining autonomy." "I can see that if somebody weren't ethical, and just wanted to make money, then it would be really, really easy to rip people off. They're extremely vulnerable. The families don't know what's been done really. The patient doesn't know what's been done really. I've seen horrible dentures on really quite cooperative patients." But, Susan said also that "beneficence I think is a problem too sometimes, because you might want to be doing something for the patient physically, but that mentally it's not that good for them to have." For example, "it might be really good for them to physically have an examination and check out what's going on in their mouths, but if they're frightened and feel that it's an invasive procedure, then that's not good for them mentally, so you have to really balance out different kinds of doing good for them."

Balancing the values of autonomy and beneficence. - Susan said that, in terms of values, "the patient's values, the family's values, and mine are all contributing." But, "I really try to do what I think the patient wants." That's "my first priority. And then what would be good for them, second," "unless they want something that doesn't really suit their needs." For example, if "they wanted a new set of dentures and I really didn't think they needed them." Likewise, "if they've been living with the situation in their mouth for thirty years and they really don't care to have it changed, I just don't see the point in getting in there and making them feel invaded in one more area." "They lead a really different kind of life than the average dentist, so it's really sometimes hard for us to put ourselves in their position, and to have respect for" their choices. "Everyone has their own philosophy about how they want to practise dentistry. Mine is an empowerment based decision-making. It's not imposing some kind of charity on people." The "for the good of their souls we're going to save their children, kind of philosophy." "If they really don't want anything then I don't push it unless I really think it would be better for them."

Appropriate treatment objectives. - In discussing difficulties in planning and providing oral care for institutionalized elders Susan said, "Sometimes it's hard to get people to sit through a whole examination." "Treatment planning [is then hard] because we haven't seen everything that's there. Sometimes you also really have to cut [treatment] short. [But], if they're not in pain, and they don't want treatment, then I don't go near them." "Everybody that I see has the option of having something done to make their oral health better if they want it. Maybe a patient can't afford to have treatment done, but I'll do hygiene instruction and work with the nurses to make things better for them regardless." I do "lots of" "denture work, [and] Miracle-mix fillings." Some have "broken down teeth. Some of it's decay [needing] class five, or class three [restorations]. A lot of root caries." But "I have to pick my patients. Lots of scaling. Some people, I'm just checking twice a year to make sure their oral lesions aren't getting any worse, or I'm monitoring the oral lesions, but the person's dying of lung cancer, so it's just a matter of telling the nurses, 'Yes, it is bad, but he's going to die before it gets worse'." "I do scalings and polishings and fluorides on people that want" it. I occasionally recommend "chlorhexidine rinses" but "most of the people have [complete] dentures," so most of the "preventive care is trying to get the nurses or the care-aids to [take] their dentures out at night and clean out the vestibules, [and] the palate with a face cloth."

Conflicts between patient and family. - When asked if she has ever experienced conflicts between the desires of the patient and family as regards treatment, Susan said, "Yes. One [experience] springs to mind that the [man] needed a reline on his dentures and they were quite loose and the family said, No, they just couldn't afford it and that he was dying anyway. When I first saw him, he seemed like he was really quite okay," and he knew what was going on. "He just didn't have any money." "When I talked to him about it, the family was feeling like they just didn't have the

money for it right now. He was okay about it, but I could see he was a bit disappointed." "Then he went downhill really really quickly and died within a year." "I knew he was sick, but I didn't know he was going to die as quickly as he did." On the other hand, if "the family are saying, 'Yes, go ahead and clean the teeth', and [the patient is] saying, 'No, No, - too much money, and I don't want it. No, No'..." "if I can't convince them, I don't go ahead." Sometimes the family will "say, 'Oh she always says that... just go ahead and do it. Tell her I said it's fine. Tell her the government's paying for it'." "So I do."

Consent and substitute decision-makers. - Susan noted also that "if I have any doubt about [a patient's ability to make decisions], I talk to the nurses and the director of care." "I [also] go over the charts before I see people, so I know what their assessment has been, psychiatrically." "It's [usually] fairly clear." However "some people appear really, really lucid, but they're not." "Some of the schizophrenic patients are" like that. "They speak clearly" about a tooth needing to be fixed, but "they'll tell you that the recreation director... [spent hours trying] to fix it yesterday". "Then you know that they've gone off the deep end."

Alzheimer's patients can also be a "difficult one, because sometimes" "the consent" "can change from moment to moment." "They want something done, but then five minutes later, they're asking you if you if you're one of their grandchildren, [so] they clearly don't remember that you're the dentist and that they've consented to treatment. It's a tough one." "A lot of the time, they know that they don't really know what's going on and when they're told it's okay, 'So and so has told me that I should do this', they recognize the name of the person, who's their son or daughter, and then they'll be okay to have it done." "I really try not to do things to the patients that they haven't consented to and don't actively want to have done, because I feel like they have so few choices about all kinds of stuff in their lives after they're institutionalized that this is one way that I can make it better for them." That's true even if they appear to need treatment.

The resistant patient. - Susan reports that if a patient is "combative, I'm not going to do" treatment, "but usually if they know that somebody that they know has said that it was okay, then they're much calmer." "Usually the family's really sympathetic, because the reason the person's institutionalized is because they were trying to deal with [them] for a long time".

Family requests for non-beneficial treatment. - Susan has experienced family requests for dentures where it seemed contraindicated. "They say, 'I want her to have a whole new set of dentures.' 'Well really, your mum doesn't need a whole new set of dentures. She just needs a reline on one or both of these.' 'But, it would be good if she had whole new set.' 'Actually, it probably would be worse, because she's used to what she has'. I think sometimes people want to spend a lot of money on a set of dentures, because then they're going to feel like they're really doing the right thing by their parent that they've institutionalized." "They don't know."