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CHAPIER 6

# Effects on Well-being and Quality of Life

Fifty years ago the World Health Organization (WHO) defined health as the "complete state of physical, mental, and social well-being and not merely the absence of infirmity" (WHO 1948). In its definition the WHO acknowledged that an individual who is technically "cured" of disease may not necessarily be "well" and went on to indicate three dimensions of well-being. Physical well-being assumes the ability to function normally in activities such as bathing, dressing, eating, and moving around. Mental well-being implies that cognitive faculties are intact and that there is no burden of fear, anxiety, stress, depression, or other negative emotions. Social wellbeing relates to one's ability to participate in society, fulfilling roles as family member, friend, worker, or citizen or in other ways engaging in interactions with

The WHO declaration resonated with ongoing developments in the social sciences as theoreticians recognized the need for multiple indicators in assessing health and treatment outcomes (Bergner et al. 1981, Fries et al. 1982, Hunt et al. 1985, Meenan et al. 1980). These efforts led to definitions of "healthrelated quality of life" (Guyatt et al. 1993) as well as explanatory models. The model proposed by Wilson and Cleary (1995), for example, posits five dimensions by which to measure treatment outcomes: biological and physiological variables, symptom status, functional status, general health perceptions, and overall quality of life. These factors are not independent but may be reciprocally connected. For example, a diabetic patient with symptoms of depression may experience a rise in serum glucose as a result of less vigilant glucose monitoring; the depression may then lead to a deterioration in physical and social activities. Most importantly, measures of biological and physiological factors are often inconsistent with patients' own reports of symptoms, ability to function, general health perceptions, and overall quality of life. In the wake of these developments in general medicine, researchers began to elaborate multidimensional models of "oral-health-related" quality of life.

The efforts to understand these relationships are particularly relevant given the aging of the population. As Gift and Atchison (1995) stated, measuring health-related quality of life allows assessment of "the trade-off between how long and how well people live." Diseases and disorders that result in dental and craniofacial defects can thwart that goal, disturbing self-image, self-esteem, and well-being. Oralfacial pain and loss of sensorimotor functions limit food choices and the pleasures of eating, restrict social contact, and inhibit intimacy.

Oral complications of many systemic diseases also compromise the quality of life. Problems with speaking, chewing, taste, smell, and swallowing are common in neurodegenerative conditions such as Parkinson's disease; oral complications of AIDS include pain, dry mouth, mucosal infections, and Kaposi's sarcoma; cancer therapy can result in painful ulcers, mucositis, and rampant dental caries; and periodontal disease is a complication of diabetes and osteoporosis. Prescription and nonprescription drugs often have the side effect of dry mouth.

The ability to measure the quality of life has the practical value of guiding policymakers, health service researchers, epidemiologists, program evaluators, and clinicians interested in the effects of interventions. The measures can also provide useful information to patients and family members, third-party payers, and employers. For example, measures of the ability to perform activities of daily living may indicate areas where the patient is able and competent, as well as areas where further therapy may be helpful.

This chapter reviews oral-health-related quality of life findings along functional, psychosocial, and economic dimensions, taking into consideration the influence of cultural and spiritual values. The results of studies in which investigators asked adults how they value their oral health and whether they are satisfied with their oral health care are included. The study of the association between oral health and quality of life is a relatively new but rapidly growing field. A variety of questionnaires have been designed to assess oral-health-related quality of life, and the chapter concludes with a discussion of their use in surveys and analytic studies, and their potential importance in outcome research.

# THE CULTURAL CONTEXT

The determination of the health-related quality of life of an individual is implicitly made against a cultural background that includes a set of values, standards, customs, and traditions associated with a particular society.

Decisions about whether to seek care from a dentist, a physician, or other care provider may be influenced by cultural or ethnic perspectives and understanding (Aday and Forthofer 1992, Andersen and Davidson 1997, Davidson and Andersen 1997, Diehnelt et al. 1990, Kiyak 1993, Lee and Kiyak 1992). Different population groups differ in the way they think about health, and in how they define a health problem, determine its seriousness, and decide whether to seek care. In one cultural setting a painful tooth may be enough to motivate care seeking. In another, bleeding, swelling, or fever may be necessary before care is sought. Similarly, decisions about whether to comply with a suggested treatment regimen, whether to engage in self-care, and whether to return for a follow-up appointment are also culturally influenced.

The anthropology and ethnography literature is rich in references to the ways in which different cultures at different times and places have regarded the human body (Hufford 1992, Kleinman 1979). Cultural beliefs regarding the body, health, and disease are often embedded in religious or spiritual traditions, which in turn may govern how diseases and disorders are regarded and treated. A brief description of Western and non-Western perspectives follows.

#### **Cultural Models**

In the medical model typical of Western society the body is partitioned into organs and systems, each with identifiable functions. The body is seen as functioning well unless disease disrupts it. Diseases in themselves are understood to be invariable across cultures. The medical model has traditionally dichotomized body and mind/soul/spirit—science and magic. Such a perspective sees the body as relatively objective and value-free, immune to nonsomatic influences.

That perspective began to change with the pioneering work of Hans Selye in the 1930s on the importance of stress in health and disease (McEwen 1999). Research in the intervening half century has confirmed the reciprocal connections of the nervous, endocrine, and immune systems, not only in relation to stress, but also in terms of the effects of emotions and cognitive processes on health status.

The model that has emerged as a new paradigm in the study of health and disease incorporates biological with psychological and social factors. This biopsychosocial model is defining agendas for research in such fields as behavioral medicine and psychoneuroimmunology. Social and psychological factors are routinely incorporated into health assessments, the better to describe the quality of life. Other societies hold views of the body strikingly different from the medical model. In some cultures, individuals and their care providers conceive of the body as the union of soul and soma. Illness may occur as a result of a "failure in harmony" or "an imbalance of forces." Schools of medicine in China, India, and other non-Western societies incorporate such principles into their teaching and practice (Hufford 1992).

## **Combining Perspectives**

All Americans hold culturally influenced perspectives on healing and illness (Henderson et al. 1997), some of which come from more traditional beliefs. Some people accept pain as an inevitable part of illness, a necessary evil, or even punishment for past iniquities or shortcomings and may shun pain-relieving drugs (Zborowski 1952). Many pragmatically combine cultural, folk, complementary, and alternative healing practices with participation in conventional care delivery systems. A recent survey indicates that over 50 percent of Americans sought nontraditional therapies for a number of ailments (Eisenberg et al. 1998).

Traditional beliefs are often comforting and satisfying to individuals (Selikowitz 1994). Certainly, Western culture and science have not always improved the quality of people's lives (Harris et al. 1993). Dietary changes to refined foods have been associated with dental caries (Godson and Williams 1996, Navia 1994), obesity, and other deleterious health changes (Selikowitz 1994). The marketing of tobacco products has added to the burden of cancer

and heart and lung problems worldwide. Migrations from traditional community rural life to urban centers have been associated with family disruption and violence, drug abuse, sexually transmitted diseases, and hypertension in developing countries.

On the other hand, Western science may inform some cultural groups that certain traditional childrearing practices can be detrimental to oral health (Kolasa 1978, Scheper-Hughes 1990). Early child-hood caries is a form of tooth decay with complex etiologies. Researchers studying high rates of infant caries among some cultural groups are exploring the extent to which traditional means of soothing crying babies or handling bedtime routines play a role, as well as investigating prenatal nutrition and transmission of infection from caregiver to child (Febres et al. 1997, Kelly and Bruerd 1987, Ripa 1988, Tinanoff and O'Sullivan 1997).

People who hold different cultural perspectives may distance themselves from Western, scientific worldviews (Lee et al. 1993), a behavior that must be addressed in any program of health promotion and disease prevention. Health professionals who understand indigenous or local healing practices and concepts are better able to motivate patients and thereby enable them to integrate elements from various healing systems (Kleinman 1979).

America is undergoing major demographic changes, with the expectation that at some point before 2050 the white population will no longer represent the majority (Henderson et al. 1997). As these changes occur, cultural elements that now reflect minority groups may become more accepted and dominant. However, cultural values are neither static nor omnipotent in shaping people's lives. Furthermore, individuals within a culture manifest their cultural identity in different ways. Therefore, both the direction of these changes and their effects may be hard to predict.

# ORAL-HEALTH-RELATED QUALITY OF LIFE DIMENSIONS

Multiple factors act and interact in determining one's quality of life, as Wilson and Cleary (1995) and others have observed. Thus the idea of assessing quality of life along multiple "dimensions" implies a departure from a simple linear scale with excellent quality of life at one end and greatly diminished quality of life at the other. The following sections explore several dimensions, beginning with effects along functional and psychosocial dimensions and concluding with a discussion of economic effects on quality of life.

# **Functional Dimensions**

Investigators have reported on the effects of dental and craniofacial diseases on the ability to eat and enjoy the full range of dietary choices. The impact of less-than-optimal oral health also has been studied in relation to sleep problems, primarily in relation to oral-facial pain.

#### Eating

Both dental and systemic diseases can profoundly affect appetite and the ability to eat, and hence can compromise overall health and well-being. Because chronic illness and medications increase in aging populations, these effects may be particularly evident among the frail elderly (Ship et al. 1996). Undernutrition was observed in 50 percent of geriatric residents in a U.S. long-term care facility; in many cases, it was linked to eating and swallowing problems (Keller 1993).

Less severe oral disorders have more subtle effects on functions relating to eating, although the high prevalence of those disorders elevates their relative importance among health problems. For example, data from the National Health and Nutrition Examination Survey III indicate that 33.1 percent of people aged 65 and older have no teeth (Marcus et al. 1996). Furthermore, clinical studies indicate that the masticatory efficiency of replacement teeth is at least 30 to 40 percent lower than that of natural teeth (Idowu et al. 1986). Consistent with these findings, surveys of elderly populations in the United States indicate that self-reported chewing problems affect significant proportions of people. For example, in California 1 percent of Medicare enrollees were unable to swallow comfortably, whereas 37 percent of senior center residents reported trouble biting or chewing foods (Table 6.1).

A number of studies have indicated that having missing teeth is linked to a qualitatively poorer diet. For example, in studies of U.S. veterans (Chauncey et al. 1984), Canadians (Brodeur et al. 1993), and Finns (Ranta et al. 1987), people with impaired dentitions preferred soft, easily chewed foods that were lower in fiber and had lower nutrient density than foods eaten by people with intact dentitions. Quality of life clearly suffers when individuals are forced to limit food choices and the foods chosen do not provide optimal nutrition. For example, they would be hard put to comply with the healthful diet recommendation of "five-a-day" helpings of fiber-rich fruits and vegetables. In the elderly, edentulousness and poor oral health may contribute to significant weight loss,

Dysfunction Attributed to Oral Condition(s)	Percentage of Population Group Reporting Dysfunction		
	Elderly Persons i	n Californiaª	
	Senior Center Residents	Medicare Enrollees	
Had trouble biting or chewing	37	13	
Limited the kinds of foods eaten	23	10	
Unable to swallow comfortably	10	1	
	Elderly Persons in Floridab		
Mouth sometimes dry	39		
Noticed an unpleasant taste in mouth	23		
Unable to chew hard things	19		
Experienced change in sense of taste	9		
Difficulty tasting some foods	6		
Noticed change in sense of smell	. 5		
	Elderly Persons in North Carolinas		
•	African Americans	Whites	
Difficulty chewing any foods	18	6	
Felt sense of taste had worsened	13	3	
Uncomfortable eating foods	13	6	
Had to avoid eating some foods	10	4	
Felt digestion had worsened	8	<1	
Had to interrupt meals	6	<1	

which may affect overall health (Blaum et al. 1995, Ritchie et al. 2000, Sullivan et al. 1993).

 $c_n = 440$  persons aged 70 and older in five North Carolina counties (Hunt et al. 1995).

Clinical research has demonstrated a general reduction in chewing function as the number of missing teeth increases, even when dentures are worn (Carlsson 1984, Feldman et al. 1980, Helkimo et al. 1978). However, clinical studies in Scandinavia have observed relatively good chewing performance when no more than 12 teeth are missing and the remaining 20 teeth are distributed fairly equally, providing good contact between the upper and the lower jaw (Agerberg and Carlsson 1975). This finding has led some researchers to advocate the concept of a "shortened dental arch" as a treatment goal for older adults, that is, retention of at least 20 well-distributed teeth (Kayser 1981). A consistent finding from research into treatment of tooth loss is that removable dentures produce only partial improvement in chewing performance (Garrett et al. 1996, van der Bilt et al. 1994, Witter et al. 1989). Dentures anchored by implants result in significantly better chewing performance than conventional, removable dentures (Geertman et al. 1996).

Self-reported measures of eating ability, satisfaction with eating, and avoidance of foods are widely

used to evaluate the effects of tooth loss and replacement. These measures capture aspects of eating that are not necessarily reflected in the clinical measures of chewing performance with specific foods (Demers et al. 1996). Such studies of self-reported chewing ability confirm several relationships already noted, including the findings that chewing ability declines as the extent of tooth loss increases and that removable dentures do not fully compensate for the reduction (Hildebrandt et al. 1997, Leake 1990, Slade et al. 1996, Wayler et al. 1984). In a study of male veterans with varying levels of tooth loss, Wayler et al. (1982) reported that levels of taste, smell, texture, perceived ease of chewing, and frequency of ingestion were adversely affected only among people with severely compromised dentitions. However, in some studies of prosthodontic treatment, self-reported chewing ability improved following treatment, even

in the absence of significant change in clinical measures of chewing performance (van der Bilt et al. 1994).

Impaired eating due to conditions other than tooth loss has been evaluated less frequently. In a study of dental patients with intact dentitions, Ernest (1993) correlated reduced salivary flow with decreased intake of 18 of 22 nutrients. Locker and Slade (1988) found that 6 percent of the Canadians surveyed who reported symptoms of temporomandibular disorders also reported problems with eating, talking, or swallowing. These conditions are often associated with limited mouth opening and severe pain, which may be constant or present whenever jaw movements are made. The constant dry mouth of patients with Sjögren's syndrome, a disease in which the salivary glands are progressively destroyed, is a major source of discomfort that affects speaking, chewing, and swallowing.

As part of a Performance Status Scale study of oral and pharyngeal cancer patients, List et al. (1990) reported that only one third of patients achieved a perfect score on a measure of normalcy of diet and only 60 percent on a measurement of eating in public. Communication skills also suffered; only 55 percent scored perfectly on understandability of speech.

### Sleeping

Sleep problems associated with oral conditions appear to be most closely related to chronic pain, either directly or indirectly in cases where pain and insomnia are exacerbated by depression. In a survey of elderly Floridians, Gilbert et al. (1993) found that 3 percent of the population reported trouble sleeping because of pain or discomfort from dental problems, whereas in a Canadian study Locker and Grushka (1987) reported that 14.2 percent of those with acute or chronic oral-facial pain (or 5.5 percent of the total population) experienced sleep disturbance related to pain. Goulet et al. (1995) assessed sleep problems not specifically attributed to pain among adults in Ouebec. The prevalence of sleep problems was 13 percent for persons with no temporomandibular (jaw) pain. The proportion with sleep disturbance among persons with jaw pain increased with the severity of the pain, rising from 20 percent for those with mild pain, to 32 percent for moderate pain, and 59 percent for severe pain.

# **Psychosocial Dimensions**

The social and psychological dimensions of wellbeing and quality of life are deeply intertwined in everyday life and so are considered together here. Findings are reported for those oral conditions where the most research has been conducted: dental diseases (primarily those that affect appearance or involve extensive tooth loss), pain conditions, craniofacial deformities (primarily clefting syndromes), and oral and pharyngeal cancers. Psychological distress associated with oral health problems has been measured through individual questions (e.g., items assessing worry) and through standardized psychological instruments such as the Beck Depression Inventory (Beck 1967) or the Symptom Checklist 90 (SCL-90) (Derogatis 1983). Overall, the results point to a poorer quality of life and a tendency to avoid social contact as a result of concerns over facial appearance. Persistent pain has similar isolating and depressing effects.

#### Cultural Significance of Teeth

Cultural beliefs and customs are a major influence on the psychosocial effects of dental disease on individuals. In a historical essay on the art of pulling teeth, Kunzle (1989) noted that "the tooth has always been accorded a special, even magical, role among all peoples and at all times, and has stood for power, and its loss for loss of power." The practice of hiding or burying a lost tooth was based on the fear that its recovery by an enemy could be used magically to inflict harm on the tooth owner. Remnants of that belief persist in the ritual of the tooth fairy, who rescues the hidden baby tooth and leaves a reward. The potency of teeth is well recorded in the metaphors of language. As Ziolkowski (1976) observed, "if something sets our teeth on edge or if someone casts an insult in our teeth, we can gnash our teeth in anger, show our teeth belligerently, grit our teeth resolutely, take the bit in our teeth, arm ourselves to the teeth, and fight tooth and nail in the teeth of great danger and, with luck, escape by the skin of our teeth."

The perception of healthy teeth contrasts sharply with that of diseased teeth. The sixteenth-century French surgeon Ambroise Paré remarked that "toothache was the greatest and most eternal of all pains . . . the fiery torture of the damned in hell" (Kunzle 1989); and a preacher of that time saw the root of original sin in a rotting tooth, as quoted in Kunzle (1989): "We unfortunate humans: We all have toothache and suffer ever and always from the teeth with which Adam bit the forbidden apple." In the nineteenth century, Sir James Frazer reported that African tribal kings could not be crowned if they were symbolically emasculated by having a broken tooth, a theme Freud echoed in declaring that dreams of pulling teeth were symbols of castration (Ziolkowski 1976).

The link between diseased teeth and weakness, impotence, and even moral turpitude and sin has been analyzed by scholars exploring the vast legacy of dental themes in art and literature. These authors offer a variety of political, social, psychological, and economic interpretations of diseased versus healthy teeth, attesting to the seriousness with which humanity has invested dental pain and tooth loss.

Cultures have sanctioned a variety of alterations to teeth by shaping and filing, embedding with jewels, bleaching, capping, or providing orthodontic treatments to improve occlusion and aesthetics. These procedures have been variously designed to enhance the status, power, and attractiveness of the owner. Cultures have also dictated specific practices to indicate social position, such as the former Japanese custom of dyeing a married woman's teeth black to denote her marital status.

Decisions about aesthetic surgery (Kaw 1993), the definition of what constitutes a severe malocclusion, and the need for dental aesthetics (Cons et al. 1986) and surgical intervention (Strauss 1985) depend on social norms. Recently, researchers have begun to examine the perceived attractiveness of the human smile in terms of tooth length, shape, and color, lip line and plumpness, and tooth exposure

(Dunn et al. 1996). Although there are no reliable studies to document the proportion of people who would seek treatment for perceived defects, the growth of practitioner groups and dental supply companies that specialize in aesthetic dentistry attests to a substantial increase in cosmetic dental treatments. Follow-up studies of patients who have undergone tooth bleaching indicate high levels of satisfaction with the extent and stability of the color change (Haywood et al. 1994).

#### **Dental Problems and Social Function**

Given the importance of the mouth and teeth in verbal and nonverbal communication, diseases that disrupt their functions are likely to damage self-image and alter the ability to sustain and build social relationships. The social functions of individuals encompass a variety of roles, from the most intimate in dating and mating behaviors, to other interpersonal contacts, to participation in social or community activities. Dental diseases and disorders can interfere with these social roles at any or all levels (Patrick and Bergner 1990). Whether because of social embarrassment or functional problems, people with oral conditions may avoid conversation or laughing, smiling, or other nonverbal expressions that show their mouth and teeth.

Two surveys of different segments of the adult population in Ontario, Canada, addressed the issue of self-consciousness or embarrassment related to oral health problems. Both inquired into the frequency of such problems in the prior year. Among persons over 18 years old in North York, Ontario, 7 percent reported limiting conversation with others because of oral problems in the prior year, 15 percent reported that they had avoided laughing or smiling because of oral problems, and 19 percent reported being embarrassed at least sometimes by the appearance or health of their teeth or mouth (Locker and Miller 1994). Among persons 50 years of age and older throughout the province, 24 percent reported being self-conscious about their appearance at least occasionally because of problems with their teeth, mouth, or dentures, 22 percent reported feeling uncomfortable at least occasionally, and 13 percent reported that they avoided smiling (Locker and Slade 1993).

Recently, investigators have begun to develop quantitative tools to assess patterns of facial animation, including normal facial expressions, in order to assess functional impairment in these movements (Trotman et al. 1998)—and ultimately to address implications for quality of life. The effects of facial

expressions, particularly smiling, on social relationships warrant further research.

The more subtle aspects of social function may also be affected by relatively common oral conditions such as tooth loss. In a study of elderly people with tooth loss in the United Kingdom, 30 percent reported difficulty chewing. Although only 5 percent had changed their diet, 9 percent felt uncomfortable chewing in front of others, and 13 percent reported embarrassment during social interactions (Smith and Sheiham 1979). Bergendal (1989) acknowledged tooth loss in adults to be a serious life event with a more difficult period of readjustment than retirement. In a study by Fiske et al. (1998), 25 percent of people without teeth reported that they had avoided close relationships because of fear of rejection when their toothlessness was discovered. The authors reported that reactions to tooth loss by the elderly include lowered self-confidence and altered selfimage, bereavement, dislike of appearance, and the perception of being more advanced in age. A national study surveying 3,000 homes in Great Britain regarding the effect of oral health on the quality of life was performed in 1997-98. Seventy percent of respondents reported that their oral health affected their quality of life—either positively or negatively. Older people in higher socioeconomic groups, especially those who had seen a dentist within the last year, were more likely to report an enhancing effect (McGrath and Bedi 1998). In a study of older Californians, people who viewed themselves as more attractive than other people their age were more likely to have a greater number of natural teeth. They were also more likely to report less emotional anxiety, to rate their health as excellent or very good, and to be less likely to wear full or partial removable dentures (Matthias et al. 1993).

Less severe oral conditions may also have adverse effects on social function. Table 6.2 summarizes self-reported levels of impact on personal contact and social integration from surveys of numerous population groups within the United States. Generally, the prevalence of adverse effects ranges from 1 to 10 percent, although 20 percent of senior center residents in California reported feeling uncomfortable when eating with others. Avoidance of smiling or conversation tended to be more frequent than limitation of social interaction. However, the largest amount of variation appeared to be among population subgroups, even within studies. For example, within the Boston area, Veterans Affairs ambulatory care patients in the Veterans Health Study had substantially higher prevalence rates of adverse effects than community-dwelling, healthy men enrolled in the Normative Aging Study.

The effects on people's perceived ability to pertorm their usual social roles appear to be more subtle Table 6.2). Depending on the phrasing of questions and the population subgroup surveyed, the prevalence of limitation in social roles varied from 0 to 5 percent, although as many as 10 percent of Veterans Affairs patients reported that their daily activities were affected because of oral conditions.

There are very few studies of the effects of dental treatment on specific forms of social function. One study of handicapped adults in the United Kingdom did. however, report large improvements in five aspects of social functioning following provision of

general dental care, including prosthodontic care (Fiske et al. 1990).

# **Impacts of Oral-Facial Pain**

Acute pain from dental caries can usually be treated effectively or, as in the case of recurrent aphthous ulcers (canker sores), will resolve over time. Chronic pain in the oral-facial region presents a different situation in that the cause may not be removable and treatment focuses on pain management. Researchers have compared chronic oral-facial pain to other types of pain in terms of severity and emotional impact. In a study of adult enrollees of a large health maintenance organization, Von Korff et al. (1988)

FABLE 6.2 Reported impacts of oral condit ocial Function Dimension(s) Assessed	Percentage of Population Group Reporting Effect					
		Elderly Persons in North Carolina <sup>a</sup>				
ntimacy	±°	Good Effect	Bad Effect	No Effect		
Perceived effect of mouth on:		75	21	5		
Sex appeal		78	18	4		
Kissing Romantic relationships		81	17	3		
Personal contact/social integration Avoid conversation		Persons Aged 18 to 61 in Five U.S. Sites <sup>b</sup>				
		4				
Personal contact/social integration			Elderly Persons in California <sup>c</sup>	A P. Franklass		
Reported impacts due to oral condition	ns:	Senior Center Residents		Medicare Enrollees		
Limiting contact with people		10		4		
Feeling uncomfortable eating with ot	hers	. 20		7		
Personal contact/social integration			Elderly Persons in Floridad			
Avoid laughing or smiling			. 6 3			
Avoid conversation						
Social roles  Limit activities			5			
Citilit activities		Selected Populations in Boston Areae				
Personal contact/social integration		Normative Aging Study	Veterans Health Study	Women's Health Project		
Avoidance of conversation		2	10	7		
Social interaction affected		1	9	7		
Social roles			10	10		
Daily activities affected		1	• •			
			Elderly Persons in North Carolina <sup>r</sup>	White		
Personal contact/social integration		African Americans		Whites 3		
Avoided smiling		10		1		
Unable to enjoy people's company		5		0		
Avoided going out with others		3		0		
Less tolerant of others		3				
Social roles		1		0		
Difficulty doing jobs Unable to work		3		0		
unable to work						

compared pain in the temporomandibular region to back pain, headache, chest pain, and abdominal pain on a number of dimensions. The usual intensity of temporomandibular disorder (TMD) pain (4.3 on a 10-point scale) was similar to that of chest pain (4.3) and back pain (4.7); abdominal pain and headache were rated as more intense (5.1 and 5.9, respectively). TMD pain and back pain were more persistent than other pains, with 28 percent of persons with TMD pain (and 29 percent of those with back pain) reporting pain on more than half of the days in the prior 6 months. The daily duration of pain was also relatively high for TMD pain, with 27 percent reporting pain for 9 or more hours per day; this proportion was roughly the same as for headache and back pain. In this setting, persons with TMD pain sought care for their pain at about the same rate as persons with other pain, with about one quarter having sought care in the past 6 months and about 60 percent having sought care at some time in the past.

Locker and Grushka (1987) reported that more than 70 percent of persons with all types of acute and chronic pain worried about their dental health. Using scales of the Symptom Checklist 90 (SCL-90), ageand sex-standardized to the population under study, persons in the general population who reported TMD pain had substantially higher levels of anxiety and depression than those without a current pain condition (Von Korff et al. 1988). In the same study, items from the SCL-90 were used to assign an algorithm for diagnosis of depression. The percentage of persons with TMD who met the criteria for a possible diagnosis of major depression was 11 percent, compared with 2 percent among those without a current pain condition and 3 to 5 percent in the general population. Recent studies suggest that depression in TMD patients follows the onset of symptoms and reflects uncertainty about the cause(s) and the lack of effective treatments.

# Social Responses to Facial Appearance

Just as cultural considerations color an individual's response to dental disease and tooth loss, so, too, does culture play a major role in the psychosocial impact of craniofacial deformities. More than any other body part, the face bears the stamp of individual identity, a fact neurobiology confirms in identifying an area of the brain that is dedicated to the recognition of faces.

In ancient Greece the face was seen as the mortal reflection of the gods, and those faces deemed most beautiful were also judged to be morally superior. Although cultures differ in the details, there appear

to be some invariant factors in the judgment of facial beauty and deformity (Stafford et al. 1989), and they are learned early in life. One U.S. study concluded that perceptions of what does and does not constitute an attractive face are established by age 7 (Cross and Cross 1971).

Aristotle also thought that the face, because of its position in the uppermost part of the body, pointed to the highest, most spiritual parts of the cosmos. Something of this mystical belief is preserved in linguistic traditions that regard what is "higher" and "ascending" as nobler than what is "lower" and "descending," whether in reference to body parts, human feelings, or classes and castes in society.

But if facial beauty is the mark of truth, moral superiority, nobility, and the soul, what of the opposite? Faces judged ugly or disharmonious, or those marred or scarred by birth defects or injury, have been associated with defects in character, intelligence, and morals. There is a long tradition of reading character on the basis of facial and head shapes according to one or another school of "physiognomics." Some schools likened human faces to animal species, such as cats, monkeys, or horses, endowing the human with the traits of the animal in question. Others constructed facial geometries that purported to show which races were nobler, which closer to animal ancestors. During the nineteenth century, Cesare Lombroso, an Italian physician and criminologist, developed a measuring scheme linking certain facial types to criminality (Magli 1989).

Given such a tradition, it is not surprising that people continue to "judge a book by its cover." A large body of research indicates that attractiveness has an important effect on psychological development and social relationships (Berscheid 1980). Noteworthy among early social psychological studies was the demonstration that physical attractiveness plays a key role in social expectations (Clifford and Walster 1973). Schoolteachers who were asked to evaluate the educational potential of students from school records and facial photographs judged attractive students to have higher educational potential and social ability than unattractive students. This finding has been replicated in a variety of school settings and grade levels.

The process of attributing positive characteristics to physically attractive persons is called the "beauty is good hypothesis." The positive impact of attractive appearance has been demonstrated to influence a wide range of social activities, from legal proceedings (Sigall and Ostrove 1975) to psychotherapeutic prognosis. This body of research indicates that appearance affects social expectations not only in educa-

tional performance, but also in vocational, marital, legal, and health care endeavors. However, the concept may not apply to all personal attributes. Bennett and Stanton (1993) found that appearance may have little effect on perceptions of intelligence or honesty.

Discrimination and stigmatization have historically characterized social responses to deformities. People whose appearance is significantly different from what society considers "normal" continue to be stigmatized. Examples in literature abound, in fable and myth, novels, movies, and plays (e.g., Beauty and the Beast, The Elephant Man, The Hunchback of Notre Dame, The Phantom of the Opera, and Scarface). Goffman (1963) provided a theory of stigmatization useful in understanding social responses to human differences and health conditions (Ablon 1981). Persons seen as deviant experience social devaluation associated with prejudices about the causes and consequences of congenital and acquired deformities (Macgregor 1974).

Ethnographic studies of facial deformities demonstrate marked variation in how birth defects are explained and treated (Cheng 1990, Meyerson 1990, Scheper-Hughes 1990, Toliver-Weddington 1990). Many cultures have regarded birth defects and the appearance of multiple births as ill omens, with the infants fated to be abandoned or killed. Even today, when it is understood that birth defects may result from an inherited genetic disorder, decisions about what that means and what if anything should be done about it are affected by religious or spiritual beliefs (Strauss 1988).

Progress in dentistry, medicine, and surgery has raised expectations that deformed or injured persons can be treated to enhance their appearance. Although critics have objected to the high value that U.S. society places on attractiveness and youthful appearance, and on how this emphasis influences opportunity, advocates of remediation counter that social values are hard to change and that individuals must adapt to a society's norms and stereotypes. Corrective surgery does produce positive assessments from others (Berscheid and Gangestad 1982). People in postoperative photographs following reconstructive and plastic surgery were seen as kinder, more sexually appealing, more likely to be better marriage partners, and more employable and successful than the same individuals in preoperative views.

# Cleft Lip/Palate and Malocclusion

Persons with cleft lip/palate have a variety of problems related to appearance, eating, and speech. Studies of self-concept (Broder and Strauss 1989, Kapp-Simon 1986), psychosocial development (Richman and Eliason 1982, Richman et al. 1988), and social perception by peers (Schneiderman and Harding 1984, Tobiasen 1987), parents and teachers (Mitchell et al. 1984, Schneiderman and Auer 1984), and the public (Middleton et al. 1986) highlight the psychosocial problems of children with cleft lip/palate (Broder and Richman 1987).

These problems often continue into adolescence, with appearance and speech remaining problematic (Richman et al. 1985), even when the individual has had comprehensive care (Strauss et al. 1988). Studies show an association between cleft lip/palate and the increased reporting of conduct problems at home (Tobiasen and Hiebert 1984) and of behavioral and learning problems at school (Tobiasen et al. 1987). Although children with cleft lip/palate have not been shown to suffer from a negative self-concept (Kapp 1979, Richman 1983) or psychological disorders, they often become socially inhibited and self-conscious (Richman and Eliason 1982).

Adolescent girls with cleft lip/palate have higher rates of social adjustment problems, particularly related to appearance (Leonard et al. 1991). Using psychological projection methods, one study (Pillemer and Cook 1989) also concluded that children with facial deformities may have inhibited personality styles as well as reduced expectations for success in social interactions. Kapp-Simon (1986) found that social relationships negatively influence overall self-esteem and that adjustment of adolescents is associated with the degree of inhibition (Kapp-Simon et al. 1992).

Many of the earliest studies of the consequences of oral disease examined the impact of developmental disorders such as facial clefts and malocclusion on personal contact and social integration. There are few outcome studies that demonstrate how social, marital, and occupational status may be affected in adults with facial deformities or cleft lip/palate. In studies dating from the 1970s, persons with cleft lip/palate achieved greater educational levels than did their fathers, but did not exceed their fathers' occupational status (McWilliams and Paradise 1973). Persons with cleft lip/palate were less upwardly mobile than their siblings and achieved lower adult incomes (Peter et al. 1975). Although persons with cleft

lip/palate had higher occupational desires, they had lower income expectations than did controls; adults felt socially inept and had a tendency to shy away from group activities (Van Demark and Van Demark 1970). Subtle forms of discrimination and stigmatization were experienced among adults with cleft lip/palate (McWilliams 1970).

Studies of marital status have indicated that persons with cleft lip/palate are less likely than nonaffected peers to date (Peter et al. 1975) or marry (McWilliams and Paradise 1973), and that when they marry, they marry later (Heller et al. 1981, Peter and Chinsky 1974). Persons with cleft lip/palate were also more likely to remain childless or have fewer children (Peter and Chinsky 1974).

The evidence concerning anatomical misalignments of the jaws (e.g., overbite, open bite, crossbite) is less consistent, with some early studies showing no clear relationship between the malocclusion and job opportunities or social discrimination (Shaw et al. 1980a). However, people with severe malocclusions are likely to be teased and to have difficulty interacting socially. These problems improve following orthodontic and orthognathic treatment (Cunningham et al. 1996, Helm et al. 1985, Shaw et al. 1980b).

#### Oral and Pharyngeal Cancers

Surgical treatment for oral and pharyngeal cancers can result in functional impairment as well as permanent disfigurement. Problems may include the loss of part of the tongue, loss of taste, loss of chewing ability, difficulty in speaking, and pain. Furthermore, in addition to concerns about their function and their future, oral and pharyngeal cancer patients must cope with an altered appearance. In a study of patients who were disease-free from 6 months to 8 years following surgical tumor removal, Gamba et al. (1992) reported that those with more pronounced disfigurement had greater changes in self-image, a worsened relationship with their partner, reduced sexuality, and increased social isolation. A study by Bjordal and Kaasa (1995) also noted that 30 percent of oral and pharyngeal cancer patients were still experiencing psychological distress 7 to 11 years after treatment. Depression, too, is frequent in cancer patients. Patients with oral and pharyngeal cancers are at an even greater risk for depression than other cancer patients, due to surgeries that alter their appearance (Gritz et al. 1999). Because oral and pharyngeal cancers are also frequently associated with chronic alcohol and tobacco use, depression may be related to withdrawal from these substances or to

preexisting psychopathology. Persistent pain, as noted earlier, may also be a contributing factor to depression.

Gritz et al. (1999) conducted a prospective analysis of changes in quality of life over time with the aim of identifying which factors might be predictive of future improvements or declines. Participants were 186 oral and pharyngeal cancer patients, all smokers or recent former smokers, diagnosed with primary carcinomas of the oral cavity, pharynx, or larynx. The patients were tested at baseline, at 1 month after radiation and/or surgery, and I year later (for a subset of 105 patients available for follow-up). Measures used included the Karnofsky Performance Scale, which uses expert judgments of functional performance scored from 0 to 100; the Cancer Rehabilitation Evaluation System Short Form, in which patients rate their quality of life along physical, psychosocial, marital, sexual, and medical interaction scales; the previously mentioned Performance Status Scale for Head and Neck Cancer Patients (which includes scales for eating and speaking); and the Profile of Mood States, in which patients rate their feelings over the previous week, yielding analyses that enable scaling along six mood states: tensionanxiety, depression-dejection, anger-hostility, confusion-bewilderment, and vigor-activity. Results indicated that in spite of functional improvement on some scales over time, there was continued dysfunction in speech and eating. Patients also reported declines in marital and sexual functioning, as well as an increase in alcohol use. Interestingly, the best predictor of quality of life 1 year after treatment was the scores obtained after initial smoking cessation advice was given, while the patients were undergoing treatment and in recovery. Other predictors were treatment type (quality of life was generally poorer for radiation patients) and score on the vigor subscale of the Profile of Mood States. The investigators concluded that medical follow-up must integrate tailored psychological and behavioral interventions to achieve better quality of life for oral and pharyngeal cancer patients.

#### **Indirect Economic Costs**

The financial impact of oral disease on quality of life is easiest to quantify in terms of direct per capita costs of oral disease and treatment as well as the costs of publicly supported dental care programs. The Health Care Financing Administration includes these costs in its annual total health care expenditure reports. These expenditures are presented in Chapter 9, and the related data on utilization of care are given

in Chapter 4. Estimating the indirect costs associated with oral health conditions and treatments, such as disability days or lost productivity, is more difficult. Several methodologies are used to estimate these costs, although relatively few studies have actually estimated the indirect costs associated with mortality or lost productivity due to dental conditions or treatments (Reisine and Locker 1995).

The annual National Health Interview Survey routinely collects data on disability days associated with selected conditions. As shown in Table 6.3, there were 3.7 days of restricted activity per 100 employed persons 18 years and older reported in the United States in 1996 associated with an acute dental condition, as defined by a dental symptom or treatment visit. Restricted activity days were most prevalent among adults aged 18 to 24 years, women, blacks, and individuals with annual incomes of less than \$10,000. Compared to the 624.0 restricted activity days per 100 persons per year for all acute conditions, the 3.7 restricted activity days for dental conditions represent a relatively small loss on an individual basis. They do, however, add up to a sizable number of days lost from work or school every year for the population as a whole.

In addition, Table 6.3 presents the number of bed days and work-loss days per 100 employed persons aged 18 and older. Also, for youths 5 to 17 years of age, 3.1 days of school were lost per year.

An important aspect of identifying the specific health-related quality of life burden of oral disease will be to acquire more data on how the overall health-related quality of life of persons with oral disease differs from that of healthy persons, those with other diseases and activity limitations, and those with co-morbid oral and general health problems. The CDC's "Healthy Days" measures and population

data—used by all states since 1993 on the Behavioral Risk Factor Surveillance System (BRFSS) and recently added to the National Health and Nutrition Examination Survey (NHANES)—offer the potential of examining quality of life outcomes in relation to oral health and other disease measures used in these surveys (Gift 1996). These productivity-related measures ask about the number of recent days when physical health was not good, mental health was not good, and activities were limited. These measures were found to be valid in use with general populations and among older persons and adults with disabilities (Moriarty and Zack 1999). Related measures on activity limitations and recent days of pain, depression, anxiety, sleeplessness, and vitality are also asked by about half of all BRFSS states andwhen used with oral disease measures-could help to identify the impact of oral disease prevention programs at the state and local levels.

In the 1996 National Health Interview Survey, the percentage of all acute conditions that are medically attended for all ages is 67.9 percent. "Medically attended" is defined as having contacted a physician (or other provider) or having a condition that causes a person to cut back on activities for at least half a day. For acute dental conditions, 59.6 percent are medically attended for all ages (NCHS 1996).

The most dramatic oral diseases by virtue of their high mortality rates are oral and pharyngeal cancers. The Centers for Disease Control and Prevention estimated in 1988 that 16.2 years of life were lost per person dying of cancer of the oral cavity and pharynx (CDC 1991). This exceeds the average for all cancer sites, which was 15.4 years lost.

Researchers are beginning to assess costs associated with chronic craniofacial conditions such as periodontal diseases, pain syndromes, and congeni-

tal anomalies. These estimates may also include the costs to caregivers who take time off from work to attend to these needs or to take children to the dentist. Recent estimates put the lifetime costs of multiple surgeries and the other medical, dental, and rehabilitation therapies typical of the team approach to the habilitation of individuals with cleft lip or palate at a minimum of \$101,000 (Waitzman et al. 1996). Overall costs of chronic pain conditions in America are estimated to be \$79 billion (Bonica 1990). Given the prevalence of headaches and

TABLE 6.3
Disability days due to all acute conditions and acute dental conditions,
United States, 1996

	All Acute Conditions		Acute Dental Conditions	
	Total Days (in thousands)	Days per 100 Persons	Total Days (in thousands)	Days per 100 Persons
School-loss days <sup>a</sup>	152,305	296.9	1,611	3.1b
Work-loss days	358,377	284.0	2,442	1.9 <sup>b</sup>
Bed days	717,868	271.7	4,602	1.7b
Restricted activity <sup>d</sup>	1,648,932	624.0	9,705	3.7b

<sup>&</sup>lt;sup>a</sup> Youths 5 to 17 years of age.

<sup>&</sup>lt;sup>b</sup> Figure does not meet NCHS standard of reliability or precision.

<sup>&</sup>lt;sup>c</sup> Currently employed persons 18 years and older.

d Persons of all ages.

Source: NCHS 1996.

temporomandibular disorders, the amount representing chronic oral-facial pain would certainly be in the billions.

#### RATINGS OF ORAL HEALTH

Researchers use two ways to assess how individuals rate their oral health: global ratings and satisfaction ratings. Global ratings employ a ranking scale, with excellent health at one end and poor health at the other. Satisfaction ratings are more akin to oral-health-related quality of life measures insofar as they ask individuals how satisfied (or dissatisfied) they are with their oral health status in relation to symptoms, physical function, appearance, social function, and psychological status.

# **Global Ratings**

The dental survey conducted in connection with the International Collaborative Survey II (ICS II) asked younger (35 to 44 years) and older adults (65 to 74 years) of various ethnic groups at three sites in the United States to rate their oral health from 1 (excellent) to 6 (poor). The vast majority of younger and older white adults rated their oral health as good to excellent (82 and 80 percent, respectively, in Baltimore, and 71 and 68 percent, respectively, in San Antonio). In contrast, American Indians, Hispanics, and African Americans were more likely to rate their oral health as fair or poor. More detailed analysis found a significant relationship between oral health ratings and perceived general health, dentate status, importance of oral health, income, oral pain, symptoms, and dental visits (Chen et al. 1997).

Studies in the United States (Bloom et al. 1992, Chen et al. 1997, Gift et al. 1997, Matthias et al. 1995) have related global ratings of oral health to demographic, clinical, and psychosocial factors. A special supplement on oral health in the National Health Interview Survey in 1989 asked participants to rate their oral health as excellent, very good, good, fair, or poor (Bloom et al. 1992). The majority of people (67 percent) rated their oral health as excellent or very good, 23 percent rated it good, and only 10 percent rated it fair or poor. Men, younger people, and more frequent users of dental services tended to rate their oral health better than women, older adults, and less frequent users. African Americans, Hispanics, and American Indians were less likely to rate their oral health positively than were whites in similar geographic locations (Atchison and Gift 1997).

A study of Medicare participants in California (Matthias et al. 1995) also found that when asked to

rate oral health as excellent, very good, good, fair, or poor, most people rated it as good or above (74 percent). Interestingly, the relationship between self-rated global oral health and clinical measures used to rate the severity of dental caries or periodontal disease was weak. The finding of such inconsistency has been confirmed in other studies (Gooch et al. 1989, Reisine and Bailit 1980, Rosenberg et al. 1988) and was noted by Wilson and Cleary (1995). The most important correlates of self-rated oral health were worry about teeth and appearance, race, education, general health status, and depression scores.

## **Satisfaction Ratings**

According to Jokovic and Locker (1997), "expressions of satisfaction and dissatisfaction are important oral health status indicators since they synthesize objective health states, subjective responses, and culturally based values and expectations." ICS I represented an early effort at assessing satisfaction with dental status (Arnlijot and WHO 1985). Specifically, it looked at satisfaction with teeth and gingiva among adults and adolescents in metropolitan and nonmetropolitan areas in 10 countries. With the exception of Japanese participants, satisfaction with teeth and gingiva among adolescents was fairly high, but the percentage of adults satisfied with teeth among participants from all countries was relatively low. A decade later, ICS II (Chen et al. 1997) again assessed whether younger and older adults were satisfied with the way their teeth looked. American Indians were the least satisfied with the appearance of their teeth. Other community surveys of satisfaction (Barenthin 1977, Gilbert et al. 1994, Jokovic and Locker 1997, Murtomaa and Laine 1985, Rosenoer and Sheiham 1995, Van Waas et al. 1994) show that most people are satisfied with the performance and appearance of their teeth.

# ORAL-HEALTH-RELATED QUALITY OF LIFE MEASURES

Much of the research on oral health and quality of life focuses on the negative impact of craniofacial diseases and disorders, diverting attention from the positive effects of good oral health. Although it could be argued that the benefits are self-evident, few studies have investigated how people value oral health. Strauss and Hunt (1993) found that older adults in North Carolina felt that the presence of teeth enhanced their appearance, ability to eat, and enjoyment of food, and that teeth also had a positive effect on comfort, confidence, speech, enjoyment, and

longevity. More generally, a large multisite study in the United States found that most adults across ethnic groups believe in the seriousness of oral disease and the importance of oral health for general health (Davidson et al. 1996, Nakazono et al. 1997).

During the last decade, researchers have identified and described specific effects of oral disease on quality of life, and there are now at least 11 questionnaires designed to measure oral-health-related quality of life (Slade et al. 1998). These range from the three-item Rand Dental Health Index (pain, worry, conversation) to the 49-item Oral Health Impact Profile, which includes items relating to function, pain, physical disability, psychological disability, social disability, and handicap.

Other researchers have used generic quality of life questionnaires (Reisine and Weber 1989) or analyzed oral health survey data, statistically summarizing clinical measures with self-reported symptoms, perceptions, and behaviors to create scales of oralhealth-related quality of life (Gift et al. 1997, Gilbert et al. 1997). An essential requirement for these analyses is the establishment of theoretical models that describe and distinguish among quality of life dimensions.

Although the questionnaires have been used in population studies, there is increased emphasis on the need to incorporate concepts of quality of life into outcome research, using the questionnaires in longitudinal or intervention studies to examine changes in quality of life following provision of dental care. Individual items from the questionnaires can be used in describing the impact of oral health status on specific functions. For example, the questions concerning eating dysfunction presented in Table 6.1 are derived from such questionnaires. Multidimensional indicators also can be used to produce quantitative scores that indicate the severity of the impact caused by oral health problems. Because there are seldom any reference values or population norms to indicate thresholds at which such scores represent "abnormal" or "severe" impacts on quality of life, the results are more valuable for analytic studies examining trends and associations than for describing impacts of oral health within populations.

Surveys in the United States and elsewhere have used multidimensional questionnaires and have revealed consistent correlations between reduced quality of life and poorer clinical oral status and reduced access to dental care. Table 6.4 provides an overview of these studies, their populations, and descriptions of the assessment tools used. In the studies using varied tools, there are consistent relationships between quality of life and standard epi-

demiological indices of missing teeth, decayed teeth, and periodontal disease—conditions that are linked to a lack of dental care. In several studies, infrequent dental visits and problem-motivated dental visits were found to be independently associated with reduced quality of life in multivariate models (Gilbert et al. 1997, Slade and Spencer 1994a). Lower socioeconomic status was an additional explanatory factor in five studies (Atchison and Dolan 1990, Gilbert et al. 1997, Gooch et al. 1989, Leao and Sheiham 1995, Locker and Slade 1994).

All of the studies in Table 6.4 used cross-sectional designs to analyze associations with quality of life; it is thus not possible to infer a causal link between quality of life and the factors under study. Information about change in quality of life from those questionnaires is available from only two population-based longitudinal studies. In one, a study of elderly Floridians, small and statistically nonsignificant changes in the Geriatric Oral Health Assessment Index were observed following an oral health promotion program (Dolan 1997). In the second, a 2-year longitudinal study of elderly South Australians, change in quality of life was measured using the Oral Health Impact Profile. The study did not find that regular dental attendees had consistently better patterns of change than episodic dental attendees (Slade and Spencer 1994b).

In contrast, some information from experimental studies of carefully selected clinical samples indicates effects of specific dental treatments on quality of life. Using the Sickness Impact Profile in a U.S. study of 30 patients treated for TMDs, Reisine et al. (1989) found significant improvements for rest/sleep, home tasks, work, and leisure following treatment. A randomized clinical trial of 63 Canadians treated for TMDs compared changes in quality of life, measured using visual analog scales. The investigators found equivalent improvements in quality of life, which mirrored improvements in pain ratings, in all three treatment groups (Dao et al. 1994). A German study by Schliephake et al. (1996) reported improvements in quality of life, measured using a 22-item scale, among 85 patients following tumor removal and reconstructive surgery.

Two multidimensional scales have been specifically designed to assess global disability (e.g., disability days, pain interference with daily activities) related to recurrent or chronic pain. Both the Graded Chronic Pain Scale (Von Korff et al. 1992) and the Multidimensional Pain Inventory (Kerns et al. 1985) have been used to assess disability related to TMDs, as well as back pain and headache. Although TMD patients are generally found to have lower mean levels

of disability than patients with other types of pain using these scales, both scales can discriminate the full range of disability in TMDs. For example, the Graded Chronic Pain Scale is an ordinal scale that assigns persons with pain to hierarchical grades indicating low-intensity, nondisabling pain (grade II); high-disability, moderately limiting pain (grade III); and high-disability, severely limiting pain (grade IV). In a sample of HMO patients with TMDs, 41 percent were grade I, 43 percent grade II, 11 percent grade III, and 5 percent grade IV (Von Korff et al. 1992). That is, about 16 percent of patients seeking care for TMDs were moderately or severely limited by their pain.

# HEIGHTENED EXPECTATIONS

Advances in public health and biomedical research in the late twentieth century have transformed our lives remarkably, adding years to the life span, providing cures for many diseases and disorders, and promising a new era of genetic medicine and bioengineering. The new field of science aimed at formulating concepts and methods for determining health-related quality of life is a reflection of these advances. People living in societies that enjoy the benefits of this progress are responding with heightened expectations: They want to live long and live well, free of infirmity, impairment, disability, and handicap; they want an optimal quality of life and well-being. In terms of oral health, new social norms and cultural values now dictate that teeth should be retained over the lifetime, and oral pain and dysfunction forever banished. Quality of life measures applied to oral health outcomes will be used to further those goals.

#### **FINDINGS**

Examination of efforts to characterize the functional and social implications of oral and craniofacial diseases reveals the following findings:

• Oral health is related to well-being and quality of life as measured along functional, psychosocial, and economic dimensions. Diet, nutrition, sleep, psychological status, social interaction, school, and work are affected by impaired oral and craniofacial health.

	Population Studied	Numbers of Individuals	Assessment Tool	Description of Assessment Tool
Gooch et al. 1989	U.S. insured adults aged 18-61 years	902 female 756 male	Rand Dental Health Index	Three dental questions written to represent factors contributing to adverse effects of dental disease
Atchison and Dolan 1990	California Medicare recipients aged 65+	1,000 female 755 male	Geriatric Oral Health Assessment Index (GOHAI)	A series of 12 questions measuring patient-reported oral functional problems
Hunt et al. 1995	N.C. elderly aged 70+	440	Oral Health Impact Profile (OHIP)	A comprehensive measure of self-reported dysfunction consisting of 49 questions
Kressin et al. 1996	Male veterans aged 47+	1,242 male	Oral Health-related Quality Of Life (OHQOL)	A brief global assessment of the impact of oral condition consisting of three items
Gift et al. 1997	U.S. aged 18+	760 female 555 male	1981 Health Resources and Services Administration study	Multidimensional concept using data from a large national sample
Gilbert et al. 1997	Floridians aged 45+	491 female 383 male	Oral Disadvantage Assessment	Eight self-reported measures of avoidance in daily activities due to decrements in oral health
Locker and Miller 1994	Canadians aged 18+	299 female 244 male	Subjective Oral Health Status Indicators	Five oral health status indicators based on WHO's International Classification of Impairments, Disabilities and Handicaps
Locker and Slade 1994	Canadians aged 50+	168 female 144 male	Oral Health Impact Profile (OHIP)	A comprehensive measure of self-reported dysfunction consisting of 49 questions
Slade and Spencer 1994b	Australians aged 60+	660 female 557 male	Oral Health Impact Profile (OHIP)	A comprehensive measure of self-reported dysfunction consisting of 49 questions
eao and Sheiham 1995	Brazilians aged 35-44	303 female 359 male	Dental Impact on Daily Living (DIDL)	Thirty-six questions that assess the oral health impacts on daily living
Coates et al. 1996	Australian dental patients	635 (+795 previously surveyed)	Oral Health Impact Profile (OHIP)	A comprehensive measure of self-reported dysfunction consisting of 49 questions

- Cultural values influence oral and craniofacial health and well-being and can play an important role in care utilization practices and in perpetuating acceptable oral health and facial norms.
- Oral and craniofacial diseases and their treatment place a burden on society in the form of lost days and years of productive work. Acute dental conditions contribute to a range of problems for employed adults, including restricted activity, bed days, and work loss, and school loss for children. In addition, conditions such as oral and pharyngeal cancers contribute to premature death and can be measured by years of life lost.
- Oral and craniofacial diseases and conditions contribute to compromised ability to bite, chew, and swallow foods; limitations in food selection; and poor nutrition. These conditions include tooth loss, diminished salivary functions, oral-facial pain conditions such as temporomandibular disorders, alterations in taste, and functional limitations of prosthetic replacements.
- Oral-facial pain, as a symptom of untreated dental and oral problems and as a condition in and of itself, is a major source of diminished quality of life. It is associated with sleep deprivation, depression, and multiple adverse psychosocial outcomes.
- Self-reported impacts of oral conditions on social function include limitations in verbal and nonverbal communication, social interaction, and intimacy. Individuals with facial disfigurements due to craniofacial diseases and conditions and their treatments may experience loss of self-image and self-esteem, anxiety, depression, and social stigma; these in turn may limit educational, career, and marital opportunities and affect other social relations.
- Reduced oral-health-related quality of life is associated with poor clinical status and reduced access to care.

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