Target Outcomes for Long-term Oral Health Care in Dementia: a Delphi Approach

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Abstract

This study developed a list of target outcomes for long-term oral health care in persons with dementia. A three-round Delphi study was used to develop a list of target outcomes. Participants included 99 staff and 171 family members associated with the Dementia Special Care Unit in Bedford, MA. In Round 1 participants were asked to list five outcomes for long-term oral health care. Items were grouped, redundancies removed, and fed back in Round 2, when participants scored the items from 1 (least important) to 10 (most important). Round 2 responses were tabulated and the top 20 were fed back for scoring in Round 3. The top 10 target outcomes in decreasing order of importance were: patient will be free from oral pain, patient will not be at risk for aspiration, emergency dental treatment will be available when needed, prevent mouth infections, daily mouth care is as much a part of daily care as shaving or brushing hair, prevent discomfort from loose teeth or sore gums, teeth will be brushed thoroughly once a day, staff will be able to provide oral hygiene care as needed, provide dental care to prevent problems eating, and recognize oral problems early. Family and professional caregivers were remarkably consistent in their identification of the top 10 outcomes. Further work is needed to ensure broad international and interdisciplinary acceptance (including families and the long-term care residents themselves) of target outcomes for long-term oral health care in persons with dementia. [J Public Health Dent 2000;60(4):330-34]

Key Words: outcomes, dental care, long-term care, dementia, Delphi process.

The turn of the millennium has seen a movement toward the promotion of successful aging (1). Elders in America and throughout the developed world are living longer and more productive lives than ever before (2,3). Yet 1.5 million American elders are dependent enough to reside in nursing homes (4). In 1990 one in four (24%) of the oldest old (85 years or older) lived in a nursing home (5). What should be the goals of their long-term oral health care? We conducted a MEDLINE search of the literature from 1966 through 1999 using the search terms "long-term care," "patient preferences," and "dental care." Only one article was identified using all three search terms; 98 were listed for the latter two. Titles of the 98 articles were reviewed; abstracts and complete articles for six (6-11) were selected for more in-depth review and guided our thinking on this topic.

The American Society for Geriatric Dentistry (ASGD) identified four objectives for oral health care in the long-term care setting (6,7). They include the following.

1. Oral health care should be provided to prevent disease; maintain chewing; maintain speaking; and preserve comfort, hygiene, and dignity.
2. Both the standard of oral health care and the access to it should be equal to that in the community at large.
3. Residents and or their representatives have the right to choose whether or not to receive care, who will provide that care, and what specific oral health services will be provided.
4. All caregivers should advocate against neglect of oral health problems suffered by vulnerable adults who cannot advocate for themselves.

Dolan (8) indicated that the selection and interpretation of outcome measures in the elderly is more complex than in other age groups because of their comorbid health conditions and variable access to dental care. Kay and Nuttal (9), in a series on clinical decision making, suggest that optimum treatment is the one that is regarded as the most favorable by the patient.

In contrast to the professional dental viewpoint, only a few authors have sought to ascertain the perspective of the long-term care patient, their representatives or other health care providers. Mojon and MacEntee (10) interviewed and examined 269 residents of long-term care facilities in Vancouver, British Columbia. They found that while 83 percent either used a denture with a major fault or were missing a denture and 54 percent identified a problem, only 36 percent would seek and benefit from treatment if offered. Ragnarsson et al. (11) studied 400 persons in Iceland older than 67 years of age in residential or nursing homes. Only 17 percent had a dental visit in the last year, and 34 percent had no visit in more than 20 years. While 75 percent self-reported a dental need, only 36 percent would make use of free dental check-ups. Thus, we have

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very limited information from patients, their representatives, or other health professionals to corroborate the recommendations from the ASGD. This perspective is important from a policy perspective, particularly in an era when patient-centered outcomes of care are becoming ever more important in the health care industry.

Development of widely accepted target outcomes for long-term oral health care is a task made complex by the fact that 45 percent of long-term care residents have at least some degree of dementia (12). Often these persons cannot speak for themselves. Because Delphi surveys can address complex problems by harnessing the collective judgment and "informed intuition" of experts (13), they may be an acceptable approach to this situation. This paper describes the use of a modified Delphi approach to the development of goals for long-term oral health care in persons with dementia. Our objective was not to answer definitively the question of what the target outcomes of long-term oral health care should be. Rather, it was to extend an international interdisciplinary dialogue on this topic, a dialogue already begun by the ASGD.

Methods

An interdisciplinary Delphi survey to develop target outcomes for long-term oral health care was conducted at the Edith Nourse Rogers Memorial Veterans Hospital in Bedford, Massachusetts (VA Bedford). VA Bedford has been the site of an ongoing longitudinal study of dementia since 1978; patients originally diagnosed with dementia are typically followed first in the outpatient clinic, then through respite and day care programs, and finally through long-term care and postmortem.

Sample. Participants included all persons directly involved in the care of patients with Alzheimer's disease and other dementias, including family members and health professionals caring for these persons. We identified seven groups of individuals involved in varying capacities with Alzheimer's care and invited all to participate at each round. These groups were collapsed into three groups composed of direct caregivers (family members), health professionals (doctors, nurses and nurses aides, dental professionals, nutritionists, and occupational therapists), and social workers. Even though the number of respondents in the third group was small, we kept them separate because their responses differed substantially from the other two groups.

The Delphi Process. Originally developed by the Rand Corporation in the 1950s (14), Delphi surveys minimize individual opinions using the reasoning that collective consensus is more likely correct (13). Linstone and Turoff (14) characterize the Delphi as "a method for structuring the group communication process so that the process is effective in allowing a group of individuals, as a whole, to deal with a complex problem." Its purpose (15) is to "generate discussion and enable a judgment on a specified topic to be made so that policy decisions can be taken which can claim to represent a given group's wants and views." Lang (16) described four main features of Delphi surveys. First, they include structured questionnaires, which allows the survey to be focused and compact. Second, Delphi surveys include several iterations or rounds, allowing respondents to reconsider their choices. The third feature is controlled feedback from the entire group and/or subgroups. Finally, responses are anonymous, which allows for more freedom of expression, particularly in groups with strong opinion leaders or where there are superior-subordinate relationships.

We employed a Delphi approach that included the four features identified by Goodman (15) that distinguish the Delphi process from other decision-making processes. The iteration with feedback was accomplished through several rounds of questions that sought to form a collective group opinion. With each round expert input was used to condense responses, clarify wording, and eliminate duplication for subsequent questionnaires. The democratic processes of feedback and anonymity enabled the final opinion or judgment to be considered truly representative of the group. By ranking the responses of the group by their mean scores, individuals could determine where their response fell relative to the scores of others, achieving a prioritization of target outcomes by importance.

We conducted the three rounds between June and October 1996. Round 1 began with facilitated brainstorming with staff, real-time E-mail to 57 staff, and letters to 164 family members. Participants were asked to list five goals of long-term oral health care. Responses were collected, any redundancies removed, and items reformed into a master list for Round 2. In Round 2, 270 participants (those from Round 1 plus 42 additional employees and 7 additional family caregivers) were asked to score the original responses from Round 1, with 1 indicating least important and 10 indicating most important. Responses were then collected, scored, ranked, and arranged thematically. Redundancies were removed again, items edited for clarity, and arranged by discipline. Round 3 asked participants (133 family caregivers and 62 health care providers) to rank the top 20 Round 2 items. These responses were collected, mean rankings computed for each discipline and group, and then arranged in order of importance.

Results

Response rates for Round 1 were 42 percent for staff (27 of 57) and 33 percent for family members (54 of 164). The respondents listed a total of 215 items. Redundancies were removed and 112 items were fed back to participants for Round 2. Major themes included diagnosis of oral diseases, provision of preventive and restorative care, the preservation of nutrition, maintaining comfort and safety, education of caregivers, and miscellaneous items.

In Round 2, participants (58 of 270, or 21%) scored the 112 items from 1 to 10. These items were then ranked, redundancies removed, and the top 20 items from Round 2 were fed back to participants for Round 3.

In Round 3, participants were asked to rank the top 20 Round 2 responses using the same scoring system from Round 2. Responses were received from 109 of 195 participants (55.9%), including 62 of 133 family caregivers (46.6%) and 47 of 62 health care providers (75.8%). This final round provided the top 20 outcomes as identified through group consensus (Table 1). Of note is that the general themes for the top 10 items include freedom from oral pain (#1, #3, #6), safety (#2, #10), hygiene (#5, #7, #8), and prevention (#4, #6, #9).

The top 10 target long-term oral health care outcomes by provider

TABLE 1
Final Top 20 Outcomes for Long-term Oral Health Care

1. Patient will be free from oral pain.
2. Patient will not be at risk for aspiration of teeth, crowns, dentures, and dental material.
3. Emergency dental treatment will be available when needed.
4. Prevent mouth infections.
5. Daily mouth care is as much a part of daily care as shaving or brushing hair.
6. Prevent discomfort from loose teeth or sore gums.
7. Teeth will be brushed thoroughly once a day.
8. Staff will be able to provide oral hygiene care as needed.
9. Provide dental care to prevent problems eating.
10. Recognize oral problems early.
11. Regular dental check-ups and preventive care.
12. Infected teeth/gums monitored regularly if not possible to treat definitively.
13. Dental Service will provide support/education to nursing staff and to long-term care units.
14. Provide relaxing oral care environment to reduce agitation in AD patients.
15. Patients with dry mouth be afforded palliative treatment with saliva substitutes.
16. Healthy gums (gums do not bleed).
17. Repair decayed/broken teeth.
18. Patient evaluated for self-care ability.
19. All dentures out at night.
20. Dentures worn regularly.

TABLE 2
Top 10 Target Outcomes for Long-term Oral Health Care by Group

	Ranking for		
Item*	Family Members (n=62)	Health Care Workers (n=45)	Social Workers (n=2)
1	3	1	4
2	7	2	2
3	8	3	16
4	1	7	4
5	5	5	10
6	9	4	16
7	2	10	4
8	4	6	10
9	5	11	1
10	11	9	4

*Item numbers are the same as items numbered 1–10 in Table 1. Item scores in the right three columns refer to rankings of top 10 for each of the three groups of respondents.

group are shown in Table 2. The similarities among the family members and the professional caregivers were striking. Almost all of the top 10 overall target outcomes were also in the top 10 for both family members and professional caregivers. Only the social workers (two respondents of three potential participants) demonstrated a slightly different pattern, with nursing staff in-service education and also patient appearance ranking among the top 10 concerns.

Discussion

This study reports on a Delphi survey that sought to develop a broad consensus on target outcomes for oral health care when elders do not age successfully, i.e., for long-term oral health care. Thus, they can be thought of as successful oral health outcomes for optimizing oral health in frail elders. Optimal oral health care for frail elders is important because of the recognized links between systemic and oral health, and quality of life (17).

Of interest is that six of the top 10 oral health outcomes for long-term care are implicit in the American Society for Geriatric Dentistry's first objective: i.e., oral health care should be provided to prevent disease; maintain chewing; maintain speaking; and preserve comfort, hygiene, and dignity (6,7). Thus, this study corroborates and extends earlier efforts of the ASGD and represents another step toward development of a broad international and interdisciplinary consensus of target outcomes. The developed list of target outcomes does not include themes expressed by the ASGD objectives 2 and 3, which address the standard of care and equal access to it, as well as the right to choose the provider and the type of care. Perhaps this difference is because the standard of care and access to it are not a problem in our setting. Further, our institution provides a "hospice approach" to long-term care that allows the patient and/or family to choose the desired level of care from among five available levels: from level 1, full code plus full work-up and treatments, to level 5, palliative care only (18). Thus, patients and their families are always consulted as to whether and what type of care should be provided.

While this study addresses an important question, it has limitations. First, it was conducted using responsible parties and health care providers rather than the residents themselves. This omission is important and should be addressed in future studies. Because half of long-term care residents have some degree of dementia, the survey should not only be posed to family members of demented long-term care residents, but also to other elders from long-term care settings, plus elders of similar age who are asked to answer as if they had dementia and were in a long-term care setting.

A second limitation is that the study was conducted at a single site that has more than a 20-year history of research into the pathophysiology and long-term care for persons with dementia. Thus, the agreement between family and caregivers represents a biased view that might merely reflect the

long-term working relationships of the health professionals and family members. This cross-contamination effect may even be greater than in other sites because the program at Bedford has long included support groups for the families of the persons with dementia, as well as treatment of the affected person. Thus, more sites are needed to allow for interfacility, regional, and international differences.

A third limitation is that response rates in rounds 1 and 2 were relatively low. We increased our sample size in Round 2, but had an even more limited response—likely because of the length of the survey (112 items). Thus, we were more selective of staff in Round 3. Our selectivity plus the shorter questionnaire resulted in a much improved response rate. Future surveys should employ means to improve response rates, including postcard reminders and repeated surveys of nonresponders.

Clearly, the development of target outcomes for long-term care is a work in progress. Nevertheless, the objectives developed by the ASGD and our work can serve as a starting point for development of a rational approach to long-term oral health care. An individualized approach to care is warranted for all patients. It should be available, as recommended by the ASGD objective 2, allowing residents (or their proxy) to decide what type and amount of care they desire (ASGD Objective 3). For residents who cannot make decisions about treatment on their own, the principle of substitutive judgment should be employed (19), reasoning that residents should have the type of care they would chose for themselves. In persons with progressive dementia, it is likewise important to ascertain patient preferences early on, using questions like, "Do you wish to take that bad tooth out now before it bothers you or leave it until it hurts?" Documenting the answer to such questions in dentate persons with dementia could serve as a form of "oral advance directives." Oral advance directives would be useful to help guide the approach to care later in the disease process.

Can improving oral health ensure successful aging for frail, long-term care patients? The answer to this question is clearly no. Yet, like other disciplines, providers of long-term oral health care need guidelines for a rational approach to care in these persons. Based on the ASGD objectives, our newly developed target outcomes for long-term care, and the experience in our Dementia Study Unit, a rational approach to long-term oral health care may include the following:

1. An assessment within 14 days of admission (or 90 days prior to admission), as stipulated in the Nursing Home Reform Act of the Omnibus Budget Reconciliation Act, 1987 (20). [This recommendation is consistent with target outcomes numbered 1, 2, 4, 6, 9, 10, 14, 16, and 17 found in our study and ASGD objectives 1 and 2.]

2. Initial treatment should be provided after the patient and/or family agree upon a plan. Care is provided at a measured pace to take care of accumulated needs. This pace should be slow enough so as to not overburden the patient, but still be completed within a 3–6 month period. [Outcomes 1, 2, 4, 6, 9–12, 17, and 20 and ASGD objectives 1 and 3.]

3. In dentate frail elders who generally cannot care for themselves, frequent and consistent preventive care is critical to prevent new oral disease. This care includes daily toothbrushing with a fluoride dentifrice or stronger fluoride gel (1.1% NaF) and quarterly or semiannual preventive assessments and fluoride treatments (21) with additional prophylaxes as needed. [Outcomes 3–14, and 16 and ASGD objectives 1, 2, and 4.]

4. In-service education for daily caregivers (nurses and aides) so that they learn the essential skills necessary to provide daily mouth care for frail elders. [Outcomes 5, 7, 8, and 13 and ASGD objectives 1 and 4].

5. Annual check-ups by the dentist, followed by the provision of needed dental care. [Outcomes 1–4, 6, 9–11, 14, 16, and 17 and ASGD objectives 1 and 2].

A rational approach to the development of target outcomes for long-term oral health care in persons with Alzheimer's disease and other dementias is being developed. More input and discussion is warranted on this topic. It should be gathered from different areas of the world, and include other health care providers. Finally, but most importantly, we should seek the counsel of current and potential users of long-term oral health care.

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