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*a journal of health policy analysis and debate*

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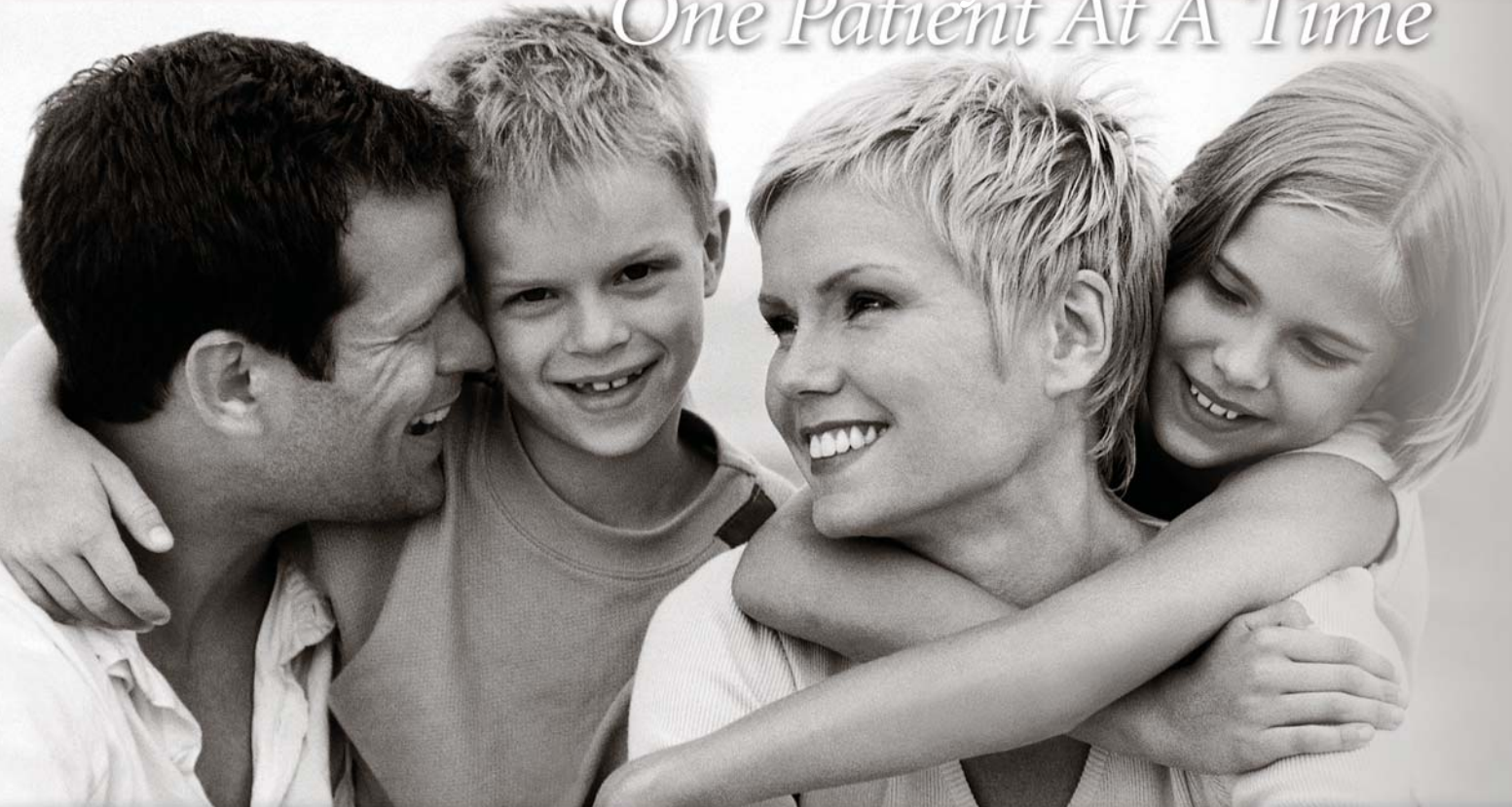
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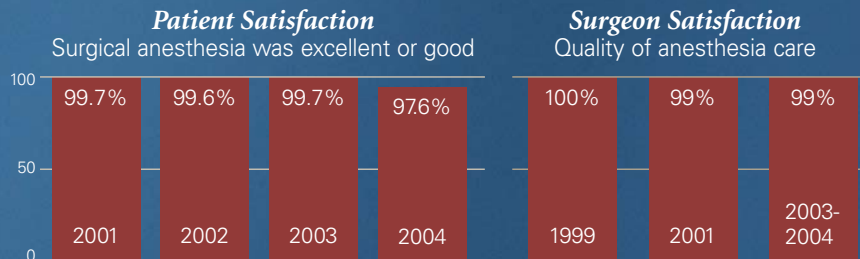
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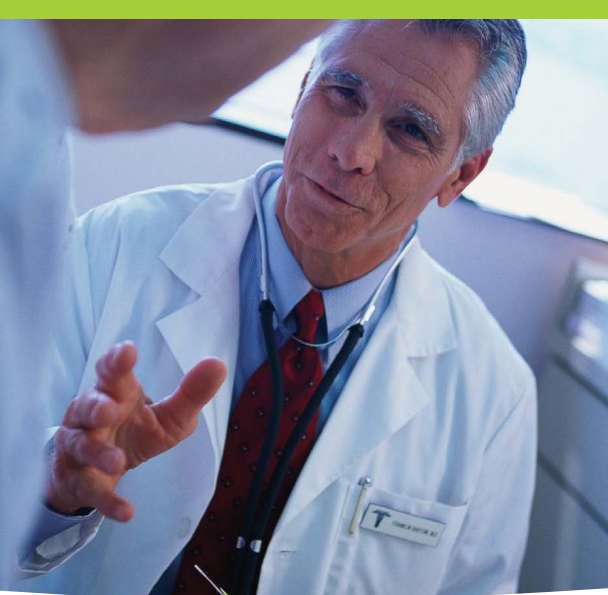
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# North Carolina MEDICAL JOURNAL

*a journal of health policy analysis and debate*

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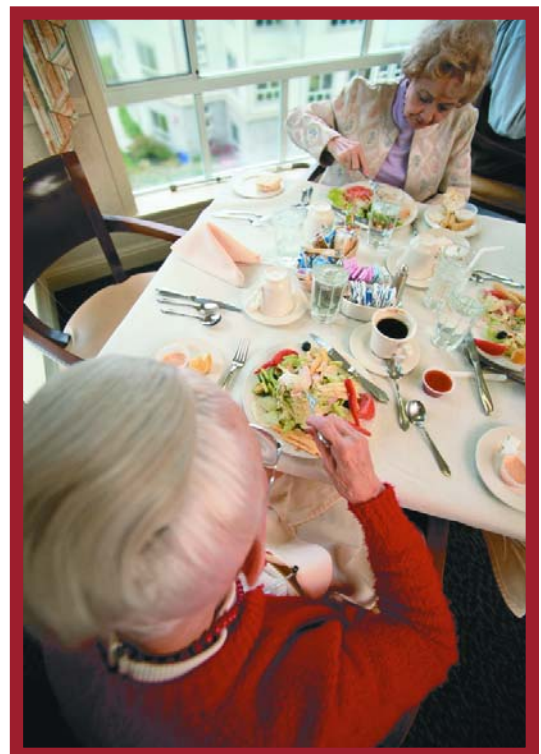
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*"For the frail elderly, mealtime can be the highlight of each day and a key component of health and quality of daily living."*



# Southeastern Regional Medical Center becomes nursing classroom

UNCP four-year nursing program to  
be conducted at the Medical Center

LUMBERTON — Southeastern Regional Medical Center will provide a working environment for students enrolled at the University of North Carolina at Pembroke.

The program facilities will be located at the current SRMC Corporate Services Building and provide 7,000 square feet of clinical settings, classrooms, computer labs, and offices.

"UNCP's nursing program will assist our region by graduating top-quality nurses," Chancellor Allen Meadors said. "The nursing

field is a noble, caring profession, and it is critical to help resolve the increasing nursing shortage in our region."

"We at SRMC are excited about the approval of the UNCP four-year nursing program," Chief Executive Officer and President Luckey Welsh said. "Our citizens will benefit for years to come because of this collaborative effort."

The nursing program is expected to add 100 BSN graduates annually to the Lumberton area.



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# Perceived Racial/Ethnic Bias in Healthcare in Durham County, North Carolina:

## A Comparison of Community and National Samples

Joëlle Y. Friedman, MPA, Kevin J. Anstrom, PhD, Kevin P. Weinfurt, PhD, Mary McIntosh, PhD, Hayden B. Bosworth, PhD, Eugene Z. Oddone, MD, MHS, Cedric M. Bright, MD, and Kevin A. Schulman, MD

### Abstract

**Background:** We sought to compare findings of a national survey of perceptions of racial/ethnic discrimination in healthcare to those of a community survey, with emphasis on the perceptions of Latinos.

**Methods:** Responses from a national survey were compared to a telephone survey of residents of Durham County, North Carolina.

**Results:** Black respondents in the Durham sample were more likely than those in the national sample to feel that a healthcare provider had treated them with disrespect because of health insurance status (28% vs 14%;  $P < 0.001$ ). Approximately one third of Durham Latinos and 14% of Latinos in the national sample felt they had been treated with disrespect because of their English-language ability ( $P < 0.01$ ). Compared to a national sample of white participants, white respondents in Durham were more likely to believe that black persons are worse off in terms of receiving routine medical care (40% vs 27%;  $P < 0.01$ ) and having health insurance (58% vs 43%;  $P < 0.01$ ). As compared to their national counterparts, there was a similar trend for how white respondents in Durham perceived how Latinos fared ( $P < 0.001$  for all comparisons).

**Conclusions:** Overall, the perception of bias in healthcare was greater among Durham residents, especially among newly immigrated Latinos, than among their national counterparts.

### Introduction

Over the past two decades, there has been growing interest in racial and ethnic disparities in the use of preventive health services and medical procedures for many conditions.<sup>1,2</sup> Differential use of appropriate medical therapies is a crucial flaw in the United States healthcare system, impeding our ability to achieve the goals of *Healthy People 2010*.<sup>3</sup> These goals include the elimination of disparities in care for cancer screening and management, cardiovascular diseases, diabetes mellitus, human immunodeficiency virus infection (HIV) and acquired immunodeficiency syndrome (AIDS), and child and maternal health.<sup>3</sup>

Attempts to develop interventions that rectify disparities in healthcare have had varying degrees of success. Interventions have included cultural competency programs,<sup>4,8</sup> screening and

outreach services for minority populations,<sup>9,12</sup> and programs to enhance patient-provider communication.<sup>13,14</sup> Most reports of these programs do not describe a needs assessment component of the projects, although needs assessment is usually the first step in the development of an effective intervention, because it provides a comprehensive description of the problem and its origins.<sup>15</sup>

We set out to describe the local community of Durham County, North Carolina, regarding public perceptions of racial and ethnic discrimination in healthcare, with the goal of developing interventions designed to improve healthcare for minority patients. We were especially interested in exploring the healthcare experiences of newly immigrated Latino residents, a sizable and underexamined segment of the community. Durham County is a diverse community, having almost equal percentages of black and white residents<sup>16</sup> and a rapidly growing Latino population.

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From 1990 to 2000, the Latino population in the Raleigh-Durham metropolitan area increased from 9,923 to 72,580, a 631% increase.<sup>17</sup>

The starting point of this study was the report of the Henry J. Kaiser Family Foundation (KFF) entitled *Race, Ethnicity & Medical Care: A Survey of Public Perceptions and Experiences*.<sup>18</sup> The report offered the first national description of the public's knowledge of and attitudes about racial and ethnic differences in health and healthcare. Among 3,884 adult respondents living in the continental United States, approximately three quarters of respondents viewed racism as a problem in healthcare.<sup>18</sup> However, it was not clear how we were to extrapolate the KFF findings to the local community. Any such extrapolation would be important in efforts to inform interventions that focus on local rather than national concerns and to encourage buy-in and endorsements by local governments and community organizations. Therefore, we sought to determine how applicable the findings of the national survey were to the local community, with special emphasis on exploring how members of the Latino community perceive their experiences with the healthcare system.

## Methods

We compared responses to the KFF national survey and responses to a community-based survey. The KFF survey has been described elsewhere;<sup>19</sup> the community survey is described below. This study was approved by the institutional review board of Duke University Medical Center.

### Sample Design

Eligible subjects were adults living in Durham County, North Carolina, in households with telephones. The sampling design targeted interviews with disproportionately large subsamples of black and Latino adults. The sample was designed to generalize to the Durham County adult population in telephone households and to allow separate analyses of responses by black, Latino, and white respondents.<sup>20,21</sup>

Two separate samples (Survey Sampling, Inc., Fairfield, Connecticut) were used to complete all interviews. The first was a disproportionately stratified sample drawn for telephone exchanges serving Durham County. The sample was drawn using standard, list-assisted, random-digit survey methodology. Active blocks of telephone numbers (area code + exchange + two-digit block number) that contained three or more residential directory listings were selected with probabilities in proportion to the number of listed phone numbers. After selection, two more digits were added randomly to complete the number. The resulting numbers were compared against business directories, and matching numbers were purged. Exchanges with higher than average density of black households were oversampled to increase the overall sample incidence of black respondents.

For the second sample, to achieve an oversampling of Latino respondents, participants were recruited by random-digit dialing from a list of households with Latino surnames. We selected this approach because Durham has few nonclustered Latino households.

### Survey Development and Administration

The KFF survey was the foundation for our assessment.<sup>18</sup> We adapted additional survey items from the California Health Interview Survey (CHIS),<sup>22</sup> the El Centro Hispano/Proyecto LIFE survey,<sup>23</sup> and a review of the literature.<sup>24,25</sup> Specifically, we used the Health Belief Model to identify potential barriers to care. The Health Belief Model was developed to explain why people fail to engage in disease prevention or screening tests before the onset of symptoms.<sup>26</sup> The model proposes that the likelihood of one carrying out a particular health behavior (e.g., seeking healthcare) is a function of personal beliefs about perceived susceptibility, severity, benefits, and barriers.<sup>27</sup>

We augmented the candidate survey items with items derived from a provider survey. The brief, informal provider survey was administered by e-mail to PrimaHealth IPA Network providers (a provider network local to Durham County). The provider survey was used to identify perceptions of barriers regarding the provision of medical care for persons of different cultures. We also provided a draft of the survey to a convenience sample of community leaders (i.e., public health officials, public officials, community group leaders) for comment to ensure that we considered relevant factors that cause or contribute to local barriers to healthcare. Finally, we conducted a small pilot test by conducting cognitive interviews with black and Latino community members to assess content validity and to verify that many barriers to care were considered as pre-coded responses in the survey. For Latino participants, the final survey was translated into Spanish and back-translated for validation purposes.

Given the length of the survey, we split the survey instrument into three components—the core survey, additional items for split-half sample 1, and additional items for split-half sample 2. All subjects completed the core survey items and one of the split-half sets of questions.

Similar to the KFF survey, the survey was administered by telephone from October through December 2002 in either English or Spanish, according to the preference of the respondent, by Princeton Survey Research Associates (Washington, DC). At least 15 attempts were made to contact a respondent at every sampled telephone number. Calls were staggered over times of day and days of the week to maximize the chance of contacting potential respondents. Each household received at least one daytime call. In each contacted household, interviewers asked to speak with the youngest adult male currently at home. If no adult male was available, interviewers asked to speak with the oldest adult female at home. This systematic respondent selection technique is regularly used by the survey firm to produce samples that closely mirror the population in terms of age and gender. The proportion of working numbers where a request for interview was made was 77% (2,615/3,384). The proportion of contacted numbers where consent for interview was at least initially obtained was 54% (1,415/2,615). Eighty-three percent (1,175/1,415) of the contacted numbers were eligible for the study. (A household was considered ineligible if there was no adult in the household or if there was a language barrier). The proportion of initially cooperating and eligible interviews that were completed was 96% (1,131/1,175).

We developed survey weights to adjust for planned effects of the sample design and to compensate for patterns of nonresponse that might bias the results. Additional details on the weighted analysis are available from the authors upon request.

## Measures

Since our survey was based on the KFF survey, our domains mirror themes described in the KFF report.<sup>18</sup> The final survey domains were as follows: demographic characteristics, knowledge of differences in health and healthcare access, personal experiences with being treated unfairly, and perceptions of the influence of race/ethnicity and racism. The coding scheme described below refers to response categories for both the national and Durham surveys, unless otherwise noted.

For all measures described below, except for demographic characteristics, we included “don’t know” and “refused” in the “other” category, because we were interested in examining the probability of a participant responding in a certain manner compared to all other responses.

## Demographic Characteristics

Demographic information included self-identified race/ethnicity, age, sex, country of origin, marital status, education level, income, home ownership, and health insurance status. Respondents were asked to indicate if they were Latino or of Latino descent and then to indicate their race (Asian, black, white, other). For purposes of this analysis, we excluded respondents who identified themselves as Asian or other. All respondents who reported that they were Latino or of Latino descent were coded as Latino, and the remaining sample was coded as black or white. Due to the relative homogeneity of country of origin among Latino respondents (69.4% reported Mexico as the country of origin), we recoded country of origin as a dichotomous variable (1 = United States, 0 = other). We also recoded marital status (1 = married, 0 = other), education level (1 = at least some college, 0 = other), and home ownership (1 = own home, 0 = other) as dichotomous variables. We created four sets of indicator variables for regression analysis. Two indicator variables were created to represent race, with white as the reference category. Three indicator variables (30 to 39, 40 to 49,  $\geq 50$ ) were created for age, with 18 to 29 serving as the reference group. We created three indicator variables for health insurance (i.e., Medicare, other, and no insurance), with private insurance as the reference group. Finally, financial status in the Durham survey was assessed using a single item with five response options, as follows: “you are having difficulty paying the bills, no matter what;” “enough money to pay for bills, but you have to cut back;” “enough money to pay bills, but little to spare for extras;” “bills are paid and still have enough for extras;” and “don’t know” or refused to answer. Due to small cell sizes, we combined the first two categories of financial status, resulting in low income as the reference category.

By comparison, the KFF survey asked respondents to report income in terms of income distribution (e.g., \$25,000 to < \$30,000), and three indicator variables were used to represent low income (< \$25,000; referent category), middle income

(\$25,000 to < \$40,000), high income ( $\geq$  \$40,000). Due to small cell sizes, we combined “don’t know” and “refused to answer.”

## Knowledge of Differences in Health and Healthcare Access

We used two questions to assess knowledge of racial/ethnic differences in health and healthcare access. The first question asked respondents how they thought black persons fared, compared to the average white person, in receiving routine medical care when they needed it, having health insurance, and getting needed healthcare. The second question was identical, except that it asked respondents how they thought Latinos fared, compared to the average white person. Response options for both questions were “better off,” “worse off,” “just as well off,” and “don’t know/refused to answer.” We dichotomized these variables as “worse off” and other.

## Perceptions of the Influence of Race and Racism

We defined racism as being treated worse than others because of race or ethnicity. To give the perceived influence of race/ethnicity in healthcare a frame of reference, participants in both samples were asked about perceptions of the influence of race/ethnicity in major social institutions. Respondents were asked whether they thought racism was a major problem, a minor problem, or not a problem at all in education, the workplace, housing, and healthcare. We recoded the response options so that 1 indicates a major problem and 0 indicates other (including don’t know/refused to answer).

Respondents were then asked if they thought black and Latino persons received the same quality of care, higher quality of care, or lower quality of care compared to most whites. We dichotomized the response options so that 1 indicates lower quality of care and 0 indicates other (including don’t know/refused to answer).

## Personal Experiences with Being Treated Unfairly

Respondents were asked to recall their experiences with healthcare in the past few years and whether they ever felt that healthcare providers or other staff members judged them unfairly or treated them with disrespect because of whether they had health insurance, how well they spoke English, or their racial/ethnic background. Responses included “yes,” “no,” and “don’t know/refused to answer.” We recoded the responses as 1 for yes and 0 for other.

## Statistical Analysis

We used survey weights for all analyses to correct for the complex survey design and nonresponse bias. (A detailed report regarding the weighted analysis is available from the authors upon request.) Our first set of analyses compared responses between the two samples by race/ethnicity for 15 key questions. We used simple statistics to describe both samples, and we used normal approximations to compare the groups to calculate P values. Our large sample size afforded statistical power to detect very small differences. Thus, we considered a difference between the community and national samples practically significant only

if there was an absolute difference of  $\geq 10\%$  and a  $P$  value  $\leq 0.05$ .

For the second set of analyses, we attempted to determine how perceptions of racism in education, the workplace, housing, and healthcare (hereafter termed institutions) differed across race/ethnicity after adjusting for demographic characteristics. Using survey-weighted multiple logistic regression analysis, we developed eight models. The first four models analyzed perceptions of racism across institutions for Durham respondents, and the remaining four models analyzed perceptions for national respondents. We included the following demographic characteristics in the models: age, sex, income, education level, and marital and health insurance status—all factors related to access to care. (We did not include country of origin in the models because it was strongly correlated with Latino ethnicity.) We converted parameter estimates for each variable to approximate relative-risk ratios using the method described by Zhang & Yu.<sup>28</sup>

We performed all analyses using Stata version 8.0 (Stata Corporation, College Station, Tex).

## Results

Table 1 shows the demographic characteristics of the Durham and national samples. The samples were similar across race/ethnicity with respect to marital status, and white and black respondents in Durham were similar to their national counterparts in terms of sex, country of origin, home ownership, and health insurance status. However, whereas 54% of white respondents and 41% of black respondents in the national sample had at least some college education, these figures were 72% for white respondents and 50% for black respondents in the Durham sample ( $P < 0.001$ ;  $P = 0.02$ ).

Durham Latinos differed from Latinos in the national sample in terms of age, sex, country of origin, education level, home ownership, and health insurance status. Durham Latinos were younger and were significantly less likely to report the United States as their country of origin, to have health insurance, to

have at least some college education, and to own a home ( $P < 0.001$  for all comparisons). A greater percentage of Latino respondents in the Durham sample were men, as compared to the national sample (64% vs 50%;  $P = 0.01$ ).

## Knowledge of Racial/Ethnic Differences in Health and Healthcare Access

As shown in Table 2, when asked if the average black person is worse off than the average white person across a variety of factors, responses of white respondents differed greatly in the Durham and national samples. For example, 40% of white respondents in Durham thought that blacks are worse off in terms of receiving routine medical care, compared to 27% in the national sample ( $P < 0.01$ ). Fifty-eight percent of Durham whites believed that blacks are worse off than whites in terms of having health insurance, compared to 43% in the national sample ( $P < 0.01$ ). In most cases, black participants' responses differed by less than 4% between the two samples.

There was an even greater difference between the white samples on questions of whether Latinos are worse off than the average white person, with white respondents in Durham more likely to perceive that Latinos are worse off ( $P < 0.001$  for all comparisons). Despite being quite different demographically, there were only small response differences on these items between the two Latino samples. The only major difference among the Latino samples was that 70% of Durham Latinos reported that Latinos were worse off than whites with respect to having health insurance, as compared to 54% of national Latinos ( $P < 0.01$ ).

## Perceptions of the Influence of Race and Racism

There were small differences between the national and community samples with respect to whether blacks receive lower quality of care than whites. However, more whites in the Durham sample than in the national sample perceived that Latinos receive lower quality of care ( $P < 0.001$ ).

Overall, black respondents in Durham were less likely than

**Table 1.**  
**Subject Characteristics**

Variable	White		Black		Latino	
	Durham (n=392)	National (n=1,479)	Durham (n=338)	National (n=1,189)	Durham (n=332)	National (n=983)
Age, mean (SE) <sup>a</sup>	46 (1.03)	46 (0.75)	43 (1.02)	43 (0.77)	34 (0.83) <sup>c</sup>	39 (0.87)
% Male sex	47	47	38	45	64 <sup>b</sup>	50
% United States-born	94	97	97	95	5 <sup>b</sup>	51
% Married	51	55	32	31	50	48
% At least some college	72 <sup>c</sup>	54	50	41	15 <sup>b</sup>	29
% Own home	69	68	40	46	15 <sup>b</sup>	43
% Having health insurance	91	88	77	82	32 <sup>b</sup>	69

All values are weighted.

a Eight responses from the Durham sample and 51 responses from the national sample were missing because the respondents refused to answer.

b Indicates a significant difference at  $P \leq 0.05$  and a response difference of  $\geq 10$  percentage points in the comparison with race/ethnicity-matched respondents in the national sample.

c Indicates a significant difference at  $P \leq 0.05$  and a response difference of  $> 2$  years in the comparison with race/ethnicity-matched respondents in the national sample.

SE indicates standard error.

**Table 2.**  
**Comparison of Responses to Selected Questions<sup>a</sup>**

Variable	White		Black		Latino	
	Durham %	National %	Durham %	National %	Durham %	National %
Do you think the average African American is worse off as compared to the average white person in terms of...?						
Getting routine medical care when they need it	40 <sup>b</sup>	27	53	51	14	32
Having health insurance	58 <sup>b</sup>	43	56	59	28	36
Getting needed healthcare	45	36	57	53	10	37
Do you think the average Latino is worse off as compared to the average white person in terms of...?						
Getting routine medical care when they need it	51 <sup>b</sup>	33	54	52	50	47
Having health insurance	72 <sup>b</sup>	48	60	60	70 <sup>b</sup>	54
Getting needed healthcare	55 <sup>b</sup>	35	53	51	51	47
Have you ever felt that a healthcare provider judged you unfairly or treated you with disrespect because of...?						
Whether or not you have health insurance	12	10	28 <sup>b</sup>	14	20	21
How well you speak English	4	1	11	5	34 <sup>b</sup>	14
Your race or ethnic background	2	1	20	12	22	15
Do you think most African Americans receive lower quality of healthcare than most whites?	23	23	56	64	22	43
Do you think most Latinos receive lower quality of healthcare than most whites?	53 <sup>b</sup>	27	61	61	62	56
Do you think racism is a major problem in the following institutions?						
Education	22	27	40 <sup>b</sup>	50	40	40
Workplace	13	21	40 <sup>b</sup>	59	37	41
Healthcare	14	16	27	35	40 <sup>b</sup>	30
Housing	20 <sup>b</sup>	30	41 <sup>b</sup>	59	35	41

a Values are expressed as weighted proportions that agree with the statement, unless otherwise indicated.

b Indicates a significant difference at  $P \leq .05$  and a response difference of  $\geq 10$  percentage points in the comparison with race/ethnicity-matched respondents in the national sample.

their national counterparts to perceive racism as a major problem in education ( $P < 0.01$ ), the workplace ( $P < 0.001$ ), and housing ( $P < 0.001$ ) (see Table 2). While there were small differences between the Latino samples with respect to education, the workplace, and housing, 40% of Durham Latinos thought that racism was a major problem in healthcare, compared to 30% of national Latino respondents ( $P = 0.02$ ).

### Personal Experiences with Being Treated Unfairly

Black respondents in the Durham sample were more likely than those in the national sample to feel that a healthcare provider had treated them with disrespect because of health insurance status (28% vs 14%;  $P < 0.001$ ). Thirty-four percent

of Durham Latinos and 14% of Latinos in the national sample felt they had been treated with disrespect because of their English-language ability ( $P < 0.01$ ).

### Multivariable Analysis

We performed multivariable analyses to determine whether racial/ethnic differences regarding perceptions of racism in the four social institutions held after adjusting for age, sex, income, education level, and marital and health insurance status. The magnitude of the adjusted differences in perceptions of racism was comparable to that found in the unadjusted analyses (see Tables 3 and 4).

**Table 3.**  
**Multivariable Analysis—Durham Sample: Racism as Major Problem in Social Institutions**

Characteristic	Education RR (95% CI)	Workplace RR (95% CI)	Housing RR (95% CI)	Healthcare RR (95% CI)
Race/ethnicity				
White	1.00	1.00	1.00	1.00
Black	1.93 (1.51-2.37)	3.30 (2.51-4.14)	2.23 (1.75-2.73)	1.90 (1.36-2.56)
Latino	2.27 (1.65-2.88)	3.30 (2.25-4.44)	2.05 (1.43-2.73)	3.02 (2.07-4.05)
Age group				
18 to 29 years	1.00	1.00	1.00	1.00
30 to 39 years	1.21 (0.86-1.60)	1.02 (0.70-1.41)	1.09 (0.77-1.47)	1.27 (0.83-1.84)
40 to 49 years	1.03 (0.71-1.43)	0.79 (0.51-1.15)	0.96 (0.65-1.33)	1.18 (0.75-1.77)
50 to 98 years	0.97 (0.68-1.32)	0.75 (0.49-1.09)	0.81 (0.55-1.14)	1.01 (0.63-1.53)
Education level				
No college	1.00	1.00	1.00	1.00
At least some college	1.45 (1.12-1.81)	1.42 (1.05-1.85)	1.44 (1.09-1.82)	1.36 (1.00-1.79)
Sex				
Female	1.00	1.00	1.00	1.00
Male	0.82 (0.63-1.04)	0.94 (0.70-1.24)	0.91 (0.70-1.15)	0.83 (0.60-1.12)
Household income				
Low income	1.00	1.00	1.00	1.00
Middle income	0.77 (0.53-1.05)	0.80 (0.55-1.12)	0.69 (0.47-0.96)	0.80 (0.55-1.13)
High income	1.06 (0.77-1.39)	0.82 (0.56-1.13)	0.82 (0.57-1.12)	0.85 (0.58-1.21)
Don't know/refused	0.97 (0.43-1.74)	0.22 (0.06-0.71)	0.27 (0.09-0.69)	0.29 (0.09-0.82)
Health insurance status				
Private insurance	1.00	1.00	1.00	1.00
Medicare	1.06 (0.53-1.77)	1.19 (0.56-2.06)	1.43 (0.84-2.14)	1.33 (0.62-2.41)
Other insurance	0.88 (0.44-1.50)	0.98 (0.46-1.78)	0.47 (0.19-1.01)	1.05 (0.43-2.13)
No insurance	1.04 (0.74-1.40)	0.90 (0.61-1.28)	0.97 (0.68-1.33)	1.17 (0.80-1.66)
Marital status				
Not married	1.00	1.00	1.00	1.00
Married	0.94 (0.73-1.19)	1.01 (0.75-1.32)	1.06 (0.81-1.34)	1.03 (0.76-1.37)

RR indicates relative risk; and CI indicates confidence interval.

## Discussion

Our goal was to compare the findings of a national survey of perceptions of racial/ethnic discrimination in healthcare to those of a community survey, with a special emphasis on the healthcare experiences and perceptions of newly immigrated Latinos.

Although the demographic characteristics of the samples were quite different, perceptions of racial/ethnic bias among Latinos in the national and Durham samples were similar. However, we found substantial differences in attitudes about health insurance and English-language ability on one's ability to receive medical care. Durham Latinos were significantly more likely than Latinos in the national sample to report that Latinos were worse off than whites in terms of having health insurance, and Durham Latinos were more likely to feel they

had been treated with disrespect by healthcare providers because of their English-language ability. Also, Durham Latinos were more likely to believe that racism was a major problem in healthcare.

One possible explanation for our findings is that a greater percentage of Latinos in Durham, compared to Latinos in the national sample, were born outside the United States (95% vs 49%). Research has shown that more acculturated Latinos have higher rates of insurance coverage and access to care.<sup>29,34</sup> The Durham Latino population may be less assimilated than Latinos in the national sample and may not be as fluent with the English language. Latinos who have lived in the United States for longer periods might speak English better than recent immigrants and may be more likely to have acquired health insurance. A decrease in language barriers and greater access to health insurance may alleviate some of the negative perceptions

**Table 4.**  
**Multivariable Analysis—National Sample: Racism as Major Problem in Social Institutions**

Characteristic	Education RR (95% CI)	Workplace RR (95% CI)	Housing RR (95% CI)	Healthcare RR (95% CI)
<b>Race/ethnicity</b>				
White	1.00	1.00	1.00	1.00
Black	1.80 (1.54-2.07)	2.74 (2.39-3.08)	1.93 (1.69-2.15)	2.14 (1.71-2.60)
Latino	1.47 (1.18-1.79)	1.82 (1.44-2.23)	1.39 (1.13-1.67)	1.78 (1.34-2.30)
<b>Age group</b>				
18 to 29 years	1.00	1.00	1.00	1.00
30 to 39 years	0.92 (0.68-1.18)	1.21 (0.89-1.57)	1.18 (0.91-1.47)	1.52 (1.03-2.14)
40 to 49 years	0.91 (0.66-1.18)	1.01 (0.74-1.36)	1.01 (0.76-1.29)	1.39 (0.93-1.98)
50 to 98 years	0.77 (0.58-1.01)	0.63 (0.45-0.88)	0.83 (0.62-1.08)	1.25 (0.86-1.77)
<b>Education level</b>				
No college	1.00	1.00	1.00	1.00
At least some college	1.34 (1.07-1.63)	1.02 (0.79-1.29)	1.41 (1.16-1.68)	1.05 (0.78-1.39)
<b>Sex</b>				
Female	1.00	1.00	1.00	1.00
Male	0.82 (0.66-1.01)	0.72 (0.56-0.90)	0.78 (0.63-0.95)	0.79 (0.60-1.03)
<b>Household income</b>				
Low income	1.00	1.00	1.00	1.00
Middle income	1.17 (0.89-1.48)	1.13 (0.85-1.45)	1.17 (0.90-1.45)	1.08 (0.76-1.49)
High income	1.15 (0.86-1.48)	1.09 (0.81-1.40)	1.18 (0.89-1.49)	0.98 (0.65-1.41)
Don't know/refused	0.73 (0.41-1.19)	0.75 (0.39-1.27)	0.73 (0.42-1.15)	1.19 (0.62-2.02)
<b>Health insurance status</b>				
Private insurance	1.00	1.00	1.00	1.00
Medicare	0.80 (0.54-1.16)	1.05 (0.72-1.44)	1.07 (0.77-1.38)	1.01 (0.62-1.56)
Other insurance	1.41 (0.96-1.75)	1.47 (0.99-1.92)	1.37 (1.00-1.67)	1.71 (1.07-2.42)
No insurance	1.27 (0.96-1.53)	1.09 (0.80-1.43)	1.17 (0.90-1.41)	1.19 (0.81-1.67)
<b>Marital status</b>				
Not married	1.00	1.00	1.00	1.00
Married	0.79 (0.62-0.97)	0.96 (0.76-1.20)	0.75 (0.60-0.93)	1.03 (0.78-1.34)

RR indicates relative risk; and CI indicates confidence interval.

that Latinos have of the healthcare system. Furthermore, the influx of Latino immigrants into Durham County is a recent phenomenon, and the local healthcare system may still be building up the infrastructure needed for this population. Nevertheless, Durham Latinos face considerable challenges in the healthcare system, and interventions to address their concerns should be developed.

Although black respondents in the Durham sample were less likely than those in the national sample to view racism as a major problem in education, the workplace, and housing, there was no difference between the national and community samples with respect to perceived racism in healthcare. One striking difference between national and community samples of black respondents concerns personal experiences with being treated unfairly. Compared to the national sample, twice as many blacks in the Durham sample felt that a healthcare provider had

treated them with disrespect because of their health insurance status. This may be attributable to the sources of insurance in the two samples: Although equal proportions of black respondents in both samples reported having health insurance, 16% of Durham blacks reported Medicaid as their primary source of insurance, compared to 8% of blacks in the national sample. We conducted a post hoc analysis to address this finding and found that Durham blacks with Medicaid had similar complaints about disrespect as those who reported being uninsured. Respondents with Medicaid may face greater challenges in accessing healthcare than do respondents with other types of insurance.

Compared to the national sample, white respondents in Durham reported a greater understanding of the lower quality of care and poorer health outcomes experienced by blacks and Latinos. These results may confirm the presence of barriers or

may reflect a greater awareness among whites living in the multiracial community of Durham County. Black residents of Durham County make up 39.5% of the population, compared to 12.3% nationwide.<sup>16</sup> As a result, Durham whites may be more attuned to racial/ethnic differences and perceptions than their national counterparts.

A strength of this study was our ability to partner with community groups. Specifically, we collaborated with a grassroots organization that provides services to Latino residents, a community organization dedicated to promoting effective approaches to removing barriers to healthcare, and researchers from a local historically black university. The involvement of these groups ensured that our assessment addressed problems of interest to the local community.

Our study has several limitations. First, our survey method excluded people who did not have telephones, so persons of very low socioeconomic status may not have been able to participate. Also, the phone numbers used in the survey did not include mobile phone numbers, perhaps further contributing to sample bias. The low response rate for both the Durham and national surveys increases the likelihood that those who responded differ from those who did not. While our survey weights attempt to correct for nonresponse bias, this correction was limited to key demographic variables. However, for both limitations, it is difficult to estimate the magnitude of the potential bias. Moreover, the KFF survey was conducted in 1999, whereas the Durham study was conducted in 2002. Given the age of the KFF data, there is the possibility of a temporal bias.

In summary, we found significant variation in the experiences and perceptions of racism in healthcare between national and community cohorts. These differences are especially important at the community level for setting public policy priorities and

informing decision makers about issues of interest to the community. For example, according to Census 2000 data, 35% of black Durham County residents report having at least a college degree, compared to 17% statewide; and 23% of black Durham residents have annual incomes less than \$20,000, compared to 30% statewide.<sup>16,35</sup> These data illustrate that there can be regional variation among state constituents and underscores the importance of conducting local needs assessments.

Furthermore, our findings regarding the perceptions of Durham Latinos could generalize to the experiences of other rapidly growing, newly immigrated Latino communities. Health concerns in these communities are understudied, and our findings provide preliminary data for researchers and community workers seeking to better understand this population. Finally, our findings show that racial/ethnic minorities perceive racism to be a major problem across four major social institutions after adjusting for several factors. Interventions that address the barriers to care identified in both the community and national surveys could be effective in reducing health disparities and improving the health of minority patients. **NCMedJ**

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# POLICY FORUM

## *Quality of Long-Term Care: Nutrition as a Critical Dimension*

### Introduction

Gordon H. DeFriese, PhD, and Kristie Weisner  
Thompson, MA

Issue Brief: Nutrition and the Dining  
Experience in Long-Term Care: Critical  
Indicators of Nursing Home Quality of Care

Polly Godwin Welsh, RN-C

*“Finding the balance  
between medical/  
nutritional need and  
resident preference is  
an on-going effort  
of nursing home  
staff that requires  
individualized  
attention, creative  
thinking, and shared  
decision-making  
between staff and  
residents and their  
family members.”*

### COMMENTARIES

So, Who's Complaining about the Food?  
Ombudsman Perspectives on “the Dining  
Experience” in North Carolina's Nursing Homes

H. Harvin Quidas, Twilla Chavis, Aimee D. Kepler, and  
Nancy Murphy

What's New in Long-Term Care Dining?

Nadine A. Pfeiffer, BSN, RN, Denise A. Rogers, Michelle R.  
Roseman, NHA, MBA, Leslie C. Jarema, NHA, Aimee  
Reimann, NHA, and Debbie Combs-Jones, MT, MHA

May I Serve You, Please?

Ted W. Goins, Jr.

The Dining Experience in Nursing Homes

Beverly A. Speroff, RD, LDN, Karen H. Davis, RD, LDN,  
Kristen L. Dehr, MS, RD, LDN, and Kate N. Larkins, MS,  
RD, LDN

Fluid Intake and Hydration: Critical Indicators of  
Nursing Home Quality

Robert J. Sullivan, Jr., MD, MPH

Creative Hydration Programs

Lanaya Cunningham, RD

Regulating Food Service in North Carolina's  
Long-Term Care Facilities

Cindy H. DePorter, MSSW

A Physicians' Perspective on the Dining  
Experience in Long-Term Care

Christopher M. Herman, MD, CMD

Nutrition in Advanced Alzheimer's Disease

Heidi K. White, MD, MHS

Use of Feeding Tubes in the Care of Long-Term  
Care Residents

Timothy S. Carey, MD, MPH

# INTRODUCTION

## **Policy Forum:** *Quality of Long-Term Care: Nutrition as a Critical Dimension*

Over the next decade or two, the American healthcare industry will experience a dramatic shift in focus as the nation's older adult population grows rapidly—especially the population beyond age 85. There will be unprecedented pressure on the long-term care field as more of our population living to these advanced ages is no longer able to live independently for reasons of physical or cognitive decline. This demographic transition, and the service demand likely to come with it, has created a growing concern that skilled nursing facilities may not be prepared for these mounting expectations.

In addition to our expectations for skilled nursing facilities to provide medical and nursing care of the highest technical level, these facilities are expected to make every effort to provide a residential environment that is safe, nurturing, stimulating, and, wherever possible, like “home.” Unfortunately, no nursing home, regardless of the quality of care provided or the staff efforts to make the facility pleasing and comfortable, is ever “just like home.”

An aspect of nursing home care most frequently mentioned by residents and families is the quality of the food and dining services. In this issue of the *North Carolina Medical Journal*, we have invited some of North Carolina's most knowledgeable individuals in long-term care to examine the challenges and opportunities for addressing food/fluid intake/dining issues in skilled nursing facilities. Polly Godwin Welsh, RN-C, Director of Regulatory Systems for the North Carolina Health Care Facilities Association (NCHCA), has written an Issue Brief outlining the many facets of this important dimension of long-term care quality. A number of Commentaries (by physicians, nurses, dietitians, regulators, and advocacy personnel) describe the complexities and difficulties of meeting the expectations and nutritional needs of nursing home residents follow the Issue Brief. The Commentaries were organized by members of the Quality Standards Work Group, a legislatively mandated, interdisciplinary group that has been working on a wide range of issues related to quality of care in North Carolina's nursing home industry for three years.

No one in our state, regardless of their economic situation, should think these issues have little relevance to their own future. Few of us will escape the necessity of dealing with the availability or quality of long-term care. As we face these matters in our own lives and in the lives of our loved ones, they seem of utmost importance. Yet, the discussion of quality of care definition and measurement in long-term care has received relatively little emphasis in health policy deliberations.

North Carolina is fortunate that NCHCFA, our state's nursing home trade association, has embarked on a monumental effort to make the nursing homes of North Carolina the “best in the nation.” As part of this effort, NCHCFA is making food consumption and dining (and attention to fluid intake and hydration) key components of their expanded effort to change the total experience of long-term care residence.

We hope that by describing these issues, Journal readers will appreciate the challenges facing this healthcare sector. We also hope that this issue will prompt policy makers and other stakeholders to begin working together to prepare for a future long-term care delivery system that will have the capacity to provide high-quality care for the many who will need this level of service.

As always, we invite our readers to comment on these articles in future issues of the Journal.

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## Nutrition and the Dining Experience in Long-Term Care: Critical Indicators of Nursing Home Quality of Care

*Polly Godwin Welsh, RN-C*

Long-term care facilities of all types, those providing skilled nursing care in particular, are at a crossroads. With the predicted growth of the older adult population, and the population of older adults who will require dementia-specific care, long-term care facilities face a probable and rapid increase in the need and demand for skilled nursing services. In fact, the number of adults over the age of 65 in nursing facilities\* is predicted to double by 2020.<sup>1</sup> Currently, there are 16,032 nursing facilities in the United States with more than 1.4 million residents.<sup>2</sup> In North Carolina, there are 424 nursing facilities with capacity for 42,897 residents.<sup>3</sup> In the face of the changing demographics in our society, nursing facilities are re-engineering to embrace the future and successfully meet these challenges. Part of the re-engineering will involve modifications of the physical plant, new construction and innovations in technology and services to match the evolving needs of residents.

This issue of the *North Carolina Medical Journal* focuses on one of the most salient aspects of long-term care quality—food and the dining experience (as well as hydration and fluid intake). Nutrition is one of the major determinants of successful aging and, for most, eating is one of life's most pleasant daily experiences. In the long-term care setting, the medical-nutritional needs of nursing facility residents are often competing with the provision of “consumer-defined” quality of care. To begin with, nursing facility residents often have complex healthcare conditions that limit their function, depress their senses of taste and smell, require multiple medications, and

necessitate therapeutic or mechanically altered diets. These treatments can limit independence, choice, and pleasure and, thus, have a negative effect on quality of life. In the interest of preserving both the health and happiness of their residents, long-term care facilities are trying to find a balance between the residents' required medical treatments and personal preferences. North Carolina's nursing facilities are finding ways to achieve this balance as they also juggle the logistic challenges of feeding large numbers of people in a highly regulated industry. Many of these specific efforts are described in the commentary by Nadine Pfeiffer, BSN, RN, and her colleagues in this issue of the Journal.<sup>4</sup>

*“Though nutrition, hydration, and the dining experience in general is but one indicator of overall quality of care, it is clearly among the most critical indicators of quality from a consumer's point of view.”*

Those of us who have been asked to contribute to this discussion bring a variety of perspectives (viz., industry, regulatory, advocacy, clinical, administrative) and extensive periods of professional experience in dealing with the challenges of providing high-quality nutrition and fluid options to those served by North Carolina's nursing facilities. Though nutrition, hydration, and the dining experience in general is but one indicator of overall quality of care, it is clearly among the most critical indicators

\* Skilled nursing facilities are “institution[s] (or a distinct part of an institution) which are primarily engaged in providing skilled nursing care and related services for residents who require medical or nursing care, or rehabilitation services for the rehabilitation of injured, disabled, or sick persons, and is not primarily for the care and treatment of mental diseases.” § 1819(a) and 1919(a) of the Social Security Act.

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of quality from a consumer's point of view. We view the challenge of addressing these issues as one of our most important tasks.

## The Social and Cultural Importance of Food and Dining to Long-Term Care Quality

Few would question the importance food plays in everyday life. From physiologic, social, and personal financial perspectives, food plays an enormous role in the human experience. Americans spend about 13% of their annual income on food, the third highest household expense, behind housing (33%) and transportation (19%).<sup>5</sup> The food industry markets to the young and old. Restaurants and grocery stores are multi-billion dollar industries, offering nearly unlimited choices to those who can afford them. Most Americans can eat anything they want, whenever they want, and often chose to eat too much. We have television channels, shows, and magazines dedicated to food preparation. Holidays are typically centered on food and dining. We don't think of Thanksgiving, Halloween, or a birthday without thinking of turkey, candy, and cake, respectively. Food is the center of celebration, pleasure, and entertainment throughout life in the United States, even in nursing facilities. For nursing home residents, mealtime may be the highlight of each day and is a key component of health and quality of daily living.

On any given day, approximately 40,000 North Carolinians reside in skilled nursing facilities due to catastrophic health events, disability, frailty, and/or declining health.<sup>3</sup> Each resident has a unique, but usually culturally-defined life history of nutrition, consumption, and food experience. As part of their effort to provide patient-centered care, nursing facilities strive to meet each resident's nutritional needs, dietary preferences, and expected dining experiences at a time when many other personal choices and freedoms are being lost. These losses make preserving resident choice an even more critical component of quality care. The commentary by Beverly A. Speroff, RD, LDN, and her colleagues in this issue of the Journal provides a useful overview of the dining experience in nursing facilities and describes ways nursing facilities balance residents' nutritional needs and preferences.<sup>6</sup>

## Medical Care and Quality of Life: Competing Issues

Long-term care facilities face two, sometimes seemingly competitive, goals with regard to nutrition: (1) maintaining optimal levels of health through dietary means, and (2) assuring the highest possible quality of life. In order to accomplish the first goal, nursing home staff must do a thorough and nutrition-focused assessment and develop an individualized plan for meeting the resident's medically-defined nutritional needs. To meet the second of these goals, it is essential that nursing home

staff frequently assess and document each resident's dietary preferences so explicit arrangements can be made to assure that residents have as much choice and independence as possible. Facility staff try to reach both goals without compromising the health or happiness of the resident. Accomplishing this requires consultation with the resident (when possible), family members, and the resident's physician.

The notion of involving nursing home residents themselves in decisions about diet and fluid intake is consistent with the idea that, for many nursing home residents, living in such a facility is "home." With average length of stay in such facilities being approximately 2.5 years (901 days) for current residents and just over one year (388 days) for discharged residents,<sup>7</sup> it is logical that residents (when they are able, and family members or a guardian if they are not) should have such a decision-making role. Residents have the right to choose (or refuse) specific treatments and services provided by nursing facilities, once the facility has ensured that the patient (or his/her guardian) is fully informed about his/her functional status, medical, and/or rehabilitation needs.

## Therapeutic and Mechanically Altered Diets

The majority of skilled nursing residents are likely to have a chronic disease or condition (e.g., diabetes or high blood pressure) that requires a prescribed diet. There are many different types of therapeutic\* or mechanically altered\*\* diets with varying degrees of restriction and complexity. Armed with the necessary dietetic knowledge, food service managers and dietitians must balance considerations of seasoning, nutrition, taste, texture, and variety to produce meals that residents will consume in quantities that provide adequate nutrition and satisfaction. In addition to preparing and serving special diets, staff members teach and reinforce the benefits, and necessities, of these special diets. At the same time, staff members try to honor the resident's choices.

In the past, nursing facilities have been criticized for using what is perceived to be a predominantly "medical model" approach to the organization and provision of care. Compared to patient-centered care, the medical model focuses more on treatment and is less likely to consider the resident's personal preferences. Because a therapeutic diet can negatively affect individual food consumption patterns and lead to unplanned weight loss, it is possible that a medically-recommended diet could have deleterious effects on both quality of life and physical health status. As Dorner, Niedert, and Welch<sup>9</sup> have pointed out:

*A diet that is not palatable or acceptable to the individual can lead to poor food and fluid intake, which results in weight loss and undernutrition, followed by a spiral of negative health effects. Often, a more liberalized nutrition intervention that allows an older adult to participate in his or her diet-related decisions can provide for the person's nutrient*

\* Therapeutic diets are used to help treat/manage certain chronic diseases (e.g., diabetes and hypertension).

\*\* A mechanically altered diet includes foods that may be pureed or softened to help patients who have trouble chewing and/or swallowing.

*needs and allow alterations contingent on medical conditions while simultaneously increasing the desire to eat and enjoyment of food. This ultimately decreases the risks of weight loss, undernutrition, and other potential negative effects of poor nutrition and hydration.*

The American Dietetic Association recommends liberalizing therapeutic diets when possible,<sup>8</sup> but this remains challenging in some ways. Honoring resident choice, following prescribed therapeutic diets, maintaining resident health, and complying with state and federal regulations are individual variables that are not mutually exclusive. Nursing facilities have to take appropriate steps to assure that dietary restrictions considered medically necessary are followed. But within these boundaries, nursing facilities are challenged to identify multiple options that will allow the maximum degree of individual choice in food and beverage selections throughout the day.

### **Health Conditions Can Affect One's Ability/Desire to Eat**

Catastrophic health events take a heavy toll on our ability to consume and enjoy food. While in the treatment phase of an acute illness, patients are more likely to be at risk for malnutrition and dehydration. They are also more likely to experience depression, which also can decrease appetite. Close attention must be paid to these factors as people who are ill or rehabilitating return to their homes or enter any long-term care setting.

"Long-term care facilities provide 'supportive social services for people who have functional limitations or chronic health conditions and who need ongoing healthcare or assistance with normal activities of daily living.'"<sup>8,9</sup> By definition, nursing facility residents have healthcare conditions that may impact their ability to feed themselves and/or consume enough calories or fluids to stay healthy. Some residents may have added difficulty due to their medications, age-related sensory losses, and/or decreased physical function or cognitive abilities.

### **Medications and Side Effects**

Nursing facility residents take an average of eight prescription medications a day.<sup>10</sup> Medications from almost every category can have profound effects on one's ability to consume and enjoy food. Many medications may decrease appetite, sense of taste and smell, or cause gastrointestinal disturbances. It is difficult to find normal day-to-day pleasure in eating with these side effects. The commentary by Christopher M. Herman, MD, in this issue of the Journal addresses the medical aspects of dietary management among nursing home residents.<sup>11</sup>

### **Age-Related Loss of Senses**

In addition to the side effects of certain medications, normal aging can affect our sense of taste and smell. As we grow older, our sense of taste and smell begins to diminish, and this worsens as we reach the age 70 and beyond.<sup>12,13</sup> Taste and smell greatly affect our desire and ability to nourish our bodies by telling our brains that it is time to eat and digest food. Without these signals,

many residents do not consume enough nutrients.

For this reason, long-term care facilities often use flavor enhancers, primarily powdered odor enhancers mixed with soups, gravies, eggs, vegetables, grits or cereals, or pastas, such as macaroni. The work of Susan Schiffman<sup>14-17</sup> at the Duke University Medical Center has been an important stimulus for further experimentation with flavor enhancement as a way of assuring the desired nutritional intake of long-term care residents who have experienced sensory losses of taste and smell in their older years. In her work on these problems, Schiffman has shown that older persons living in long-term care facilities consume more food when flavor enhancement is used, and the increased consumption is associated with improved immune function and functional status related to nutrient intake.<sup>15</sup>

### **Functional Limitations, Tube Feeding, and Feeding Assistance**

Most people who are admitted to a nursing facility are admitted after a surgery or a sudden illness. These health events can cause unique problems in relation to nutrition and fluid intake. For example, many persons who suffer strokes may have limited abilities to speak, swallow, and/or use their arms and hands. In this case, speech therapists, occupational therapists, nursing staff, and physical therapists in the skilled nursing facility work diligently to restore these abilities, but for some the loss is permanent.

According to federal data for North Carolina skilled nursing facilities, only 47% of nursing facility residents are able to eat independently. Twenty-eight percent eat with some assistance, and 25% are totally dependent on someone else to feed them.<sup>2</sup> About 10% of residents are tube-fed.<sup>18</sup> While all efforts are made to avoid feeding tubes, some severe circumstances make their use necessary, as described in the commentary by Timothy S. Carey, MD, in this issue of the Journal.<sup>19</sup>

For some residents who experience a loss in motor function that interferes with independent feeding, complete rehabilitation may be possible, while others may need specially trained nursing assistants to provide ongoing feeding assistance. This ongoing assistance can be frustrating to the resident because it is an additional loss of personal independence, may seem unnatural to be fed as an adult, and is time-consuming. According to the Commonwealth Fund study by Burger, Kayser-Jones, and Prince-Bell, a dependent resident requires a minimum of 20-30 minutes to assist him/her with eating and still make the experience satisfying to the resident.<sup>20</sup> The heavy staffing requirements of providing a highly personalized approach to eating for these populations is a constant challenge to all skilled nursing facilities and a potential source of dissatisfaction expressed by both residents, families, and guardians. In addition to knowing how to help residents eat, staff members must know how to ease resident frustration and offer support as being fed by someone else can be a difficult, but necessary, process to sustain life.

### **Dementia**

Another medical condition that can present unique nutritional challenges is dementia. The resident with dementia may

greatly decrease his/her consumption of food by simply being unable to remember to eat. For example, the resident may become distracted and leave the table without eating enough or at all. With advanced dementia, the resident may forget how to hold food in their mouth, how to chew, and how to swallow. This may become a part of an encompassing condition commonly referred to as “failure to thrive.”

Trained nursing facility staff must employ special feeding techniques and cues to get residents who suffer from dementia to eat enough. Facilities also use snacks and activities to increase consumption. Staff may target residents who have dementia or reduced consumption with recreational opportunities that offer food and beverages as an integral part of these activities in an effort to increase nutritional and fluid intake. The commentary by Heidi K. White, MD, MHS, in this issue of the Journal provides a thorough discussion of nutrition issues related to the care of persons with advanced dementia.<sup>21</sup>

### **Logistical and Technical Aspects of Meeting the Nutritional Needs of Residents**

Preparing food within the constraints of a congregate healthcare setting is one of the most challenging aspects of long-term care facility management. Operational budgets, the use of safe and sanitary equipment, and proper storage and access to the appropriate quantity and quality of food supplies are often under-estimated daily challenges of a food service department. Facilities must involve registered dietitians and food service managers, who are trained to interface with the operation of an institutional kitchen. The registered dietitian and food service managers plan menus with many considerations, including seasonal food options and regional and cultural preferences. Facilities strive to prepare tasty, nutritionally-balanced meals in large quantities three times a day, 365 days a year. North Carolina's long-term care facilities serve an average of 32 food items to each resident every day.

Food choice does not present the challenge at one's home that it does in a nursing facility. In the average facility, about 90 people are served three meals a day along with periodic snacks.<sup>2</sup> Accommodating large numbers of special requests can easily overwhelm the dietary department. There is no realistic way to accommodate 90 or more menu changes at each meal. Upon admission and throughout their stay, residents and families hold discussions with care planners regarding food and beverage preferences. Many times these preferences are uncomplicated and easily accommodated. Finding the balance between medical/nutritional need and resident preference is an on-going effort of nursing home staff that requires individualized attention, creative thinking, and shared decision-making between staff and residents and their family members.

### **Working within State and Federal Regulations**

Maintaining the health and safety of each resident is the goal of each long-term care facility. As mentioned previously, meeting the individual resident needs and preferences, family expectations, and doctor's orders, while abiding by state and federal regulations, can be challenging. Long-term care is one of the most regulated segments of the United State healthcare system, and nursing facilities strictly adhere to rules and regulations. A commentary by Cindy H. DePorter, MSSW, in this issue of the Journal explains the regulations that pertain to nutrition and fluid intake among nursing home residents.<sup>22</sup>

Facility staff members counsel and educate the residents and family members about the risks of not following a prescribed therapeutic diet. For example, a resident at risk for choking may ask for food that is restricted according to his/her nutritional care plan. Nursing facility staff must explain the risks involved with eating such foods to the resident and/or family. The facility could be held legally responsible if the resident choked on the food that the resident's physician had restricted. While eating restricted food now and then may seem harmless, it could present a significant health risk to residents who are prescribed therapeutic or mechanical diets. In a nursing facility, the negotiation of risks, choice, and benefits are carried out on a minute-to-minute basis.

While mindful of the regulations, facilities try to creatively satisfy the needs, priorities, and preferences of residents and families. For example, many residents want their families to bring them food from home. Nursing facilities permit families to bring home-cooked meals to their loved one; however, the food should not be shared with other residents. Skilled nursing

facilities cannot risk having other residents exposed to possible food-borne illnesses. Although it is unfortunate, in this example, it is impossible for the facility to guarantee the safety of food preparation that occurs in other locations. A number of long-term care facilities have created special

occasions to help provide the residents a variety foods, such as hosting an oyster roast, ordering specialty take-out meals from area restaurants, etc. The commentary by H. Harvin Quidas, et al., in this issue of the Journal describes other ideas that nursing facilities have used to make food and/or the dining experience more interesting to residents.<sup>23</sup>

### **Conclusion**

For all residents in a skilled nursing facility, regardless of medical condition, their life experiences from birth-to-present create needs far beyond the mechanical act of food consumption. Where, when, and how residents wish to dine; their food likes and dislikes; the role of the dining experience as socialization;

*“Food choice does not present the challenge at one's home that it does in a nursing facility.”*

and their ability to exert choice and control affect the amount of satisfaction and pleasure they gain from the act of eating.

In these efforts, today's skilled nursing facilities face a number of substantial challenges, but all agree that finding ways to satisfy residents is one of the most important aspects in creating the nursing facility of the future—within which we would all be willing to reside ourselves, or have a loved one reside, were

the need to arise. As our society's need and demand for skilled nursing care increases, the capacity of existing facilities will be stretched beyond present expectations. But, as these trends occur, careful attention to how food, nutrition, and hydration issues are managed will have much to do with the ultimate success of our efforts to make long-term care a pleasant and health-enhancing experience. **NCMedJ**

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## So, Who's Complaining about the Food? Ombudsman Perspectives on "the Dining Experience" in North Carolina's Nursing Homes

*H. Harvin Quidas, Twilla Chavis, Aimee D. Kepler, and Nancy Murphy*

The Long Term Care Ombudsman Program was established and authorized by the federal Older Americans Act amendments in 1978 (and codified in North Carolina state law in 1989). This legislation mandated that every state establish a program of professional personnel having the responsibility of advocating for those who reside in long-term care facilities. The legislation charged the Long Term Care Ombudsman with protecting Resident Rights and helping to ensure resident safety and quality of care. In addition, ombudsmen should empower families of residents and the consumers of long-term care services by offering educational programs on long-term care issues and options.

The North Carolina Long Term Care Ombudsman Program is part of the Elder Rights and Special Initiatives Section of the Division of Aging and Adult Services within the North Carolina Department of Health and Human Services. There are 29 Regional Long Term Care Ombudsmen located in the 17 Area Agencies on Aging across the state, with each agency serving multiple counties. The efforts of these regional ombudsmen are extended through a network of over 1,100 "grassroots ombudsmen" who receive training and then volunteer their time in their respective communities as advocates for residents in long-term care facilities. They also work with facility staff and administrators in the interest of assuring a high quality of life for those who reside in these facilities.

One would think that complaints about food, the dining experience and the availability and consumption of fluids would

be a major concern and frequent complaint of both residents and the families of residents of long-term care facilities. As Regional Long Term Care Ombudsmen, we receive fewer formal complaints from the residents of nursing homes\* or their family members about either dining or hydration than one might expect. But, in any discussion with residents or family members, it is rare that these topics do not emerge in describing the totality of a loved one's experience in a given facility. Food (including regular meals and snacks/refreshments) and fluid intake are very important parts of the *context* within which the resident's total life experience takes place. Not only are meals (and the opportunity to consume snacks) important anchors in the daily routine of nursing home residents, but the quality (*viz.*, taste, smell, appearance, texture) of food and beverages is an important indicator of life satisfaction among those residing in these facilities. Most residents of long-term care facilities, even those who are not ambulatory and have to be served their meals or are assisted with fluid intake, actually look forward to scheduled food- or beverage-related events throughout the day. But, residents differ (as we would expect among any other population) in the relative weight or importance they attribute to various aspects of food and dining. While many residents actually are excited to begin each day with the smells and anticipated tastes of breakfast foods, others are not "morning persons" and would instead focus their attention on lunchtime options or the dinner meal. In other words, much of the daily rhythm and pace of a typical day as a resident of a long-term care facility revolve around

\* These formal complaints about both food/dining or hydration are more frequent from residents of adult care homes or their family members.

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these opportunities for food and drink. The social interactions with other residents and staff associated with meal times or snack times often provide a positive and much-anticipated uplift to what might otherwise be a mundane and boring daily routine.

It, therefore, figures that if one wanted significantly to change how nursing home residents and families view nursing home care, making changes or improvements in the residents' dining experience or their access to beverages and snacks throughout the day would be an important place to begin. Improvements in dining would ultimately change how the nursing home experience is viewed by persons who are neither residents or family members of residents, but only hear about these aspects of the experience from others.

### **What Are the Major Complaints about Either Food or Hydration?**

Most of the (usually informal) complaints we Ombudsmen hear about food, food service, or hydration in North Carolina's nursing homes come from residents themselves. Most of these complaints are about matters that are beyond the ability of the Ombudsman to handle. For example, many of the negative comments are about the general taste (flavor) and consistency (manner of preparation) of typical food items. Many North Carolina nursing homes serve populations of older adults who have been raised in rural communities where families are accustomed to raising much of the food they consume. Many residents were used to preparing food using high-fat and sodium flavorings (e.g., ham or "fatback"). Institutional food service staff and dietitians are not likely to prepare food in the same ways, nor are they likely to use artificial flavorings to achieve a similar taste or the appearance of standard food items. The food just isn't what one would have been accustomed to at home. The ombudsman can open a formal complaint if the resident finds the food unsatisfactory, lacking in quantity/appeal/preference, or failing to meet medically indicated directions, etc., and long-term care facilities are generally receptive toward finding a resolution for the resident.

Other complaints about food and the dining experience are highly variable among residents, but a few are frequent enough to seem routine. The presentation of food is extremely important. Many residents do not like several food items served in such a way that they "run together." Since residents do not typically serve themselves from a buffet table or in a family-style arrangement, food placed on a plate by a food service staff member may not look like food the resident would have chosen for him/herself, either in placement on the plate or in quantity of serving. To take another example, bread laying on top of vegetables or meat can become soggy and unappetizing. Sectional plates or trays also have

a clear "institutional" food service appearance, and do not evoke feelings of a home-like environment.

With regard to food, one might conclude that *little things make a huge difference* in how a skilled nursing facility is viewed by those who reside there.

Most of the "formal" complaints in this area relate to hydration (or fluid intake). Often these are related to the way in which water pitchers, drinking straws, and cups are placed in resident rooms. Non-ambulatory residents often complain because water is not offered frequently throughout the day; the water pitchers, cups, etc. may be placed on top of a dresser across the room or placed in a window sill out of reach of the resident; milk is served as a beverage on every tray at every meal or just before bedtime, yet many older adults have never consumed milk with meals, or are lactose-intolerant and cannot consume this beverage; or iced tea (which many North Carolina residents have consumed regularly, in a sweetened form, and in substantial quantities throughout their lives) is served with little or no ice in short, round glasses, instead of tall glasses with lots of ice and lemon. Persons who have grown old living in a southern, rural environment are often accustomed to eating a heavier meal in

*"...much of the daily rhythm and pace of a typical day as a resident of a long-term care facility revolve around these opportunities for food and drink..."*

the middle of the day, and a lighter one in the evening. Hence, "soup and sandwich" at noon may be boring and a heavier meal in the evening may not be an easily adapted pattern. Some residents are accustomed to having a bowl of cereal just before bedtime. Adding cereal to the options for pre-bedtime snacks could help assure these residents that living in a long-term care facility is not so radically different from what they experienced when living at home. These are

the "cultural differences" that are the source of expectations and valuations of the way nursing homes serve their clientele. Often the steps taken to deal with these expectations are not costly, but require special, even personalized, effort, which can be a burden on already over-burdened staff of these facilities.

Family members have complained that sometimes the pitchers from which water is consumed are not washed and sterilized with any frequency, only refilled. These are standard procedures that should be addressed by any facility in a standardized way, and there are specific regulations pertaining to such matters.

### **What Are the "Lessons Learned" from Resident and Family Reactions?**

It is important to recognize that those of us who have worked in long-term care for many years are seeing positive changes in a wide spectrum of areas related to food, nutrition, and hydration in nursing homes. These changes are welcomed by all stakeholders, especially residents and family members.

One of the most important lessons to be learned from the

comments (and often the complaints) of long-term care residents and families is that the allowable (and recognizable) independence of living in these facilities is indicated by the feeling that one can choose from several options with regard to food/dining and beverage consumption. It is often not the number of options, but the fact that a *choice* is possible among types of food, beverage, or time and venue within which consumption of either occurs.

Second, it is important to realize that choices made now may not be the same choices tomorrow or next month. Individual preferences and functional abilities change over time, and it is important to give residents frequent opportunities to reconsider these choices. For example, as the ability to chew certain textures of food change, so do the residents' options for mealtime, and new options should be offered in consultation with nursing and medical professionals involved in the care of these patients.

This underscores the importance of periodic and frequent *assessment* so that facilities can have up-to-date information on the functional status, as well as the preferences, of each resident. For example, we have seen instances where a given resident is unable to feed him/herself using common tableware (fork, knife, or spoon), but the resident can eat using his/her hands. Hence, adapting to this situation by offering "finger food" options, once these functional limitations/abilities are noted, can have a tremendous influence on the nutritional status of the individual resident and contribute to overall life satisfaction. Periodic re-assessment of resident capacities and medical needs is essential to providing the optimal and most life quality-enhancing dining and hydration experience.

Long-term care residents are often treated by multiple healthcare providers, both within and external to the facility. When one care provider suggests trying a different type of diet, the need for such a diet and the progress of the resident in adapting to it should be reassessed frequently. We have all seen instances where a resident's physician prescribed a temporary therapeutic or mechanically altered diet for a resident who ultimately lost weight because facility staff failed to reassess the resident's needs in an appropriate time frame. Some residents in this situation have remained on temporarily prescribed diets for months longer than they should have. Prescribed dietary plans need frequent reassessment to prevent such occurrences. Dramatic changes in dietary intervention plans can cause undue concern among family members, especially if their loved one does not adapt well to the changes introduced by the prescribed diet. When facility staff make hurried determinations that a resident has difficulty swallowing, or if staff confuse a slow eating pattern for such difficulty, this can often lead to the prescription of a therapeutic diet, which is unappetizing and, therefore, not consumed. Careful assessment of functional abilities, such as swallowing, can often determine the actual problem and lead to changes in the way food is served, not in the texture of the meal itself.

Long-term care facilities have been given high positive marks for efforts to incorporate fresh fruits and vegetables into the planning for meals and snacks served to residents. The acquisition

and processing of these food items can be both time-consuming and expensive, but many facilities have made a serious effort to add these elements to their overall food and dining experience. Wherever these efforts have been made, there is widespread appreciation from both residents and family members.

It is our observation that long-term care facilities are constantly innovating and discovering new and better ways to address the food and dining preferences of their residents, often with little or no public acknowledgement of their efforts. There are literally hundreds of examples of facilities going out of their way to serve meals in an attractive and pleasant way, or scheduling special events (like periodic "order out" evenings when pizza and other food items can be ordered from area restaurants to be delivered for a particular meal, or scheduling a "tropical week" during which fruit slushies are served to encourage more fluid consumption in a festive atmosphere). We believe more should be done to recognize and compliment these facilities for these efforts.

Though the Long Term Care Ombudsman Program is often seen as conveying only the "bad news" associated with resident or family complaints, we feel it important to point out the number of times that we actually hear from residents and family members some very positive comments about the way our North Carolina nursing homes have been attempting to make food and the dining experience a positive and enjoyable aspect of everyday life in these settings. One recently discharged resident, who was in a North Carolina nursing home for a post-acute rehabilitation period, asked one of us if she could return to the nursing home on a daily basis and pay for lunch since she enjoyed dining at this facility so much.

Finally, it is our observation that nursing homes are faced with serving the long-term care needs of two very different populations. One of these populations is composed of residents who are cognitively functional and able to express their preferences, and many of these residents are mobile enough to partake in any and all activities related to dining. The other population is composed of residents with limited cognitive and physical functional abilities, for whom individual choices are difficult to express. Family members and residents in the first group are strong advocates for their dining and hydration choices, and staff are responsive. However, the second group of residents have very few advocates on their behalf. The data cards for these patients usually have blank spaces where dietary choices or preferences should be noted. When residents in this category are actually given choices in food/dining or beverage options, family members are pleased and often surprised.

The challenge for long-term care is going to be how to serve these two populations of residents and give some level of choice to both, while attempting to make the experience of living in such facilities feel safe, comfortable, and pleasant. Food and the dining experience are an important part of the totality of the long-term care experience, and we are fortunate in this state to have so many nursing facilities who care enough to address these issues as part of an overall effort to make long-term residence in a nursing home an experience of high quality. **NCMedJ**

# North Carolina Division of Aging and Adult Services Long Term Care Ombudsman Program

NC Division of Aging and Adult Services / 2101 Mail Service Center / Raleigh, North Carolina 27699-2101  
919-733-8395 / 919-715-0868 Fax / [www.dhhs.state.nc.us/aging/ombud/ombstaff.htm](http://www.dhhs.state.nc.us/aging/ombud/ombstaff.htm)

## North Carolina Regional Ombudsmen

### Region A

Southwestern Planning Commission  
PO Box 850  
Bryson City, NC 28713  
(828) 488-9211 ext. 3032  
*Counties served: Cherokee, Clay, Graham, Haywood, Jackson, Macon, and Swain*

### Region B

Land-of-Sky Regional Council  
25 Heritage Drive  
Asheville, NC 28806  
(828) 251-6622  
Toll Free: 1-800-727-0557  
*Counties served: Buncombe, Henderson, Madison, and Transylvania*

### Region C

Isothermal Commission  
PO Box 841  
Rutherfordton, NC 28139  
(828) 287-2281 ext. 1222  
Toll Free: 1-800-331-09891  
*Counties served: Cleveland, McDowell, Polk, and Rutherford*

### Region D

High Country Council of Governments  
PO Box 1820  
Boone, NC 28607  
(828) 265-5434 ext. 126  
Toll Free: 1-866-219-3643  
*Counties served: Alleghany, Ashe, Avery, Mitchell, Watauga, Wilkes, and Yancey*

### Region E

Western Piedmont Council of Governments  
PO Box 9026  
Hickory, NC 28603  
(828) 485-4213 and (828) 485-4266  
*Counties served: Alexander, Burke, Caldwell, and Catawba*

### Region F

Centralina Council of Governments  
PO Box 35008  
Charlotte, NC 28235  
(704) 348-2714, (704) 348-2712  
Toll Free: 1-800-508-5777  
*Counties served: Anson, Cabarrus, Gaston, Iredell, Lincoln, Mecklenburg, Rowan, Stanley, and Union*

### Region G

Piedmont Triad Council of Governments  
2216 W. Meadowview Road, Suite 201  
Greensboro, NC 27407-3480  
(336) 294-4950  
*Counties served: Alamance, Caswell, Davidson, Guilford, Montgomery, Randolph, and Rockingham*

### Region I

Northwest Piedmont Council of Governments  
400 W. Fourth Street, Suite 400  
Winston-Salem, NC 27101  
(336) 761-2111  
*Counties served: Davie, Forsyth, Stokes, Surry, and Yadkin*

### Region J

Triangle J Council of Governments  
PO Box 12276  
Research Triangle Park, NC 27709  
(919) 558-9401, (919) 558-2703  
Toll Free: 1-800-310-9777  
*Counties served: Chatham, Durham, Johnston, Lee, Moore, Orange, and Wake*

### Region K

Region K Council of Governments  
PO Box 709  
Henderson, NC 27536  
(252) 436-2050  
Toll Free: 1-866-506-6223  
*Counties served: Franklin, Granville, Person, Vance and Warren*

### Region L

Upper Coastal Plains Council of Governments  
PO Drawer 2748  
Rocky Mount, NC 27802  
(252) 446-0411 ext. 234  
*Counties served: Edgecombe, Halifax, Nash, Northampton, and Wilson*

### Region M

Mid-Carolina Council of Governments  
PO Box 1510  
Fayetteville, NC 28302  
(910) 323-4191 ext. 25  
*Counties served: Cumberland, Harnett, and Sampson*

### Region N

Lumber River Council of Governments  
4721 Fayetteville Rd.  
Lumberton, NC 28358  
(910) 618-5533  
Toll Free: 1-866-582-4251  
*Counties served: Bladen, Hoke, Robeson, Scotland, and Richmond*

### Region O

Cape Fear Council of Governments  
1480 Harbour Dr.  
Wilmington, NC 28401  
(910) 395-4553 ext. 208  
Toll Free: 1-800-218-6575  
*Counties served: Brunswick, Columbus, New Hanover, and Pender*

### Region P

Eastern Carolina Council  
PO Box 1717  
New Bern, NC 28563  
(252) 638-3185 ext. 3010 and ext. 3007  
Toll Free: 1-800-824-4648  
*Counties served: Carteret, Craven, Duplin, Greene, Jones, Lenoir, Onslow, Pamlico, and Wayne*

### Region R

Albemarle Commission  
PO Box 646  
Hertford, NC 27944  
(252) 426-5753  
*Counties served: Camden Chowan, Currituck, Dare, Gates, Hyde, Pasquotank, Perquimans, Tyrrell, and Washington*

### Region Q

Mid East Commission  
PO Box Drawer 1787  
Washington, NC 27889  
(252) 974-1838  
*Counties served: Beaufort, Bertie, Hertford, Martin, and Pitt*

## What's New in Long-Term Care Dining?

*Nadine A. Pfeiffer, BSN, RN, Denise A. Rogers, Michelle R. Roseman, NHA, MBA, Leslie C. Jarema, NHA, Aimee Reimann, NHA, and Debbie Combs-Jones, MT, MHA*

Throughout the years, nursing homes have traditionally been viewed as medically oriented with rigid schedules and limited choices, decorated with institutional-type furnishings and stark white painted walls. Visitors were few. In many cases these views were validated by actual practice. But in the early 1990s, the “medical model” nursing homes began to change as a few culture change philosophies emerged. Facilities started implementing innovative concepts, which are called “enhancements” in North Carolina, to make these facilities more home-like.

The term “culture change” has become synonymous with “environmental transformation” in the realm of culture-change enthusiasts. The concepts are now many, but they all have the same goal. They all implement an enhancement that transforms the medical model into a more home-like model, thus improving resident quality of life. Some opt to follow the named philosophies in their entirety, while others opt to base the changes on a particular model, altered to suit their facility’s individual needs or goals.

One of the original culture-change philosophies was the Eden Alternative,<sup>1</sup> started by Dr. William Thomas. This philosophy focuses on 10 principles to incorporate staff empowerment with team building and to then use plants, animals, and visits by children as the enhancements to complete the environmental transformation of the facility into a more natural and less “institu-

tional” human habitat. This philosophy focuses on improving the quality of life and quality of care for residents and staff.

The WellSpring Model<sup>2,3</sup> was started in 1994 and focuses on a collaborative effort between several nursing homes to cross-train and form a coalition. The homes in this coalition pay a licensing fee and monthly fee to the WellSpring Alliance, which supplies all training materials, clinical training experts, a data reporting system, and technical support during the implementation process. Spearheaded by a nurse practitioner, all staff are trained in eight quality of care modules, and they are managed in each home by a coordinator. Care resource teams, comprised of various staff members, are developed in each home to devise and implement culture-change strategies. The coalition-member homes share the costs of the program. There is continuous review of performance

*“The ability to choose your own food, socialize with friends, interact with attentive staff members, and enjoy a delicious and healthy meal provides a dignity unmatched by most other services.”*

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data related to resident outcomes in a variety of areas. This model focuses on the quality of care aspect of culture change.

The Pioneer Network<sup>4</sup> is yet another model for culture change. It informally began in 1992 with educational sessions on culture change. The first organized meeting of the movement was held in 1997, and in 2000 the Pioneer Network was officially named and took on its general mission of being a network of people dedicated to facilitating deep-system culture change. This concept directs each nursing home to acknowledge that culture change is an on-going process, base their enhancements on a core set of values, establish a clear vision for change, and establish a mission statement. The implementation of best practices tailored to individual needs is also stressed.

The concept of Person-Centered Planning<sup>5,6</sup> was initiated by the husband and wife team of Eric and Margie Haider (administrator and Director of Nursing at Crestview Nursing Home in Missouri). In 1998, they began a pilot project adopting person-centered planning into the long-term care setting. This philosophy focuses on each individual and offers more freedom, choices, and independence. This model puts the person in the center and provides more individualized care that is in the best interest of the person.

There are six critical components of person-centered planning: (1) supporting personal satisfaction in the lives of residents; (2) creating individualized living spaces; (3) empowering staff as advocates for the residents; (4) respecting individual life patterns, preferences, and needs; (5) providing opportunity for personal growth, development, and contribution; and (6) fostering a connection to the greater community.

According to data from the 2005 North Carolina Nursing Home license renewal applications, 54% of the facilities across North Carolina have self-reported that they embrace these care philosophies, and 19% of those facilities (73) have reported implementing innovations in the dining experience. The following are some best practice dining enhancements that stem from a divergence from the medical model and signify a transformation into true culture change in long-term care.

### **Best Practice Dining Enhancements in Long-Term Care**

Creating a positive mealtime is a balancing act secured through attention to detail, compassion for the residents, and culinary expertise. At Abernethy Laurels in Netwon, North Carolina, the dining experience involves delicious food served by attentive wait staff and is combined with an inviting atmosphere that allows social interaction. In September of 2004, the age-old tray style dining service was replaced by a more personal table side dining program. Residents enter into a remodeled dining room filled with warmth and friendliness, eager to partake in the fare offered by Executive Chef Eddie Williams and his staff. Residents are free to choose from a menu of entrees and side items based on their individual preferences. Meals are served by friendly staff members who engage each resident in informal conversation, while remaining attentive to the individual needs of the diners. This conversation promotes social interaction, as

## **May I Serve You, Please?**

Ted W. Goins, Jr.

A growing number of healthcare professionals are climbing on the bandwagon of "culture change" in long-term care. Resident-centered care and services are replacing the old, institutional, assembly-line approach of the past. Residents get a voice and vote in how they live. A collaborative, team philosophy is replacing the autocratic model. Those who have embraced these changes have created a much better home in which people can live and work. Facilities who don't change will not thrive, and may not even survive.



Lutheran Home–Hickory residents, families, and staff are excited about buffet dining.

Some of the more notable innovations are occurring in food service. The old system is dying: a system characterized by meals served at 7:00 am, 12:00 pm, and 5:00 pm; residents receive the meal the dietician planned whether they like it or not (with few alternates); meals served from a central kitchen in institutional, dome-covered plates often with luke-warm "hot" food, and luke-warm "cold" food. Meals have been served in the worst traditions of institutionalization, encouraged, if not mandated by punitive federal regulations.

A new day is dawning. Resident-centered care is opening eyes and attitudes. Healthcare professionals, state regulators, and others have joined in asking, "Why can't we do this a new way?" The answer is now "why not!"

Lutheran Home–Hickory is a wonderful example. With support from a Long-Term Care Enhancement grant from the state of North Carolina, the Lutheran Home has transformed a once institutional dining room into a "restaurant." Gone are the institutional colors, observation windows from two halls and a nursing station, and trays delivered from a distant kitchen. All have been replaced with a warm décor, wooden blinds to soften the windows, and a restaurant-style buffet at wheelchair height. Depressing, dark, coffee mugs for all liquids have been replaced with clear cups so

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well as offers an insight into the condition and health of each resident. This daily interaction re-connects the staff member with the resident, allowing for specific requirements to be identified and met, while creating an atmosphere of compassion.

In specific instances where a pureed meal is required, the Pureed Food Enhancement Program (PFEP) offers visually appealing and delicious choices. In days gone by, pureed foods were prepared on-site with a blender. This method created a situation where caloric content, nutritional value, taste, color, and texture were compromised. The mechanical alteration resulted in a bland, shapeless, unappetizing meal being served to residents to fulfill the need for pureed food. Residents often will not eat a meal they cannot recognize. Therefore, residents did not meet their individual dietary requirements, sustenance needs, or morale buoyancy. The PFEP presents pureed meals with uncompromised taste, formed in the shapes and colors of the items being served, with measured calories and nutritional values necessary for the well-being of the resident. Imagine a pureed pork chop, in the shape and color of a pork chop that looks so close to its non-pureed counterpart that the resident uses her fork to cut around what appears to be a bone. Spirits can be uplifted through serving a meal containing identifiable items that possess an enticing and aromatic flavor like other tablemates enjoy.

Since instituting table-side dining services, Abernethy Laurels has experienced a phenomenal rise in resident satisfaction with the food quality and atmosphere. Weight loss has been reduced and malnutrition is non-existent. The ability to choose your own food, socialize with friends, interact with attentive staff members, and enjoy a delicious and healthy meal provides a dignity unmatched by most other services. The dining experience is one more example of Abernethy Laurels' mission to "...add life to years."

The Forest at Duke, a continuing care retirement community in Durham, North Carolina, recently completed an addition/renovation project. Thirty-four adult care apartments were added and integrated into the existing Health Care Center. The project created six neighborhoods connected to an interior street with shared common spaces in a virtual village environment. Each neighborhood serves residents with a different set of care needs.

The creation of the new and innovative Health and Wellness Center gave The Forest at Duke the opportunity to offer more normalization of the dining experience in a long-term care setting. Each "neighborhood" has its own "restaurant" with individualized themes and décor. The secured special care unit, *The Riviera*, has a Mediterranean style "outside" café, *Niko's Bistro*. The intermediate special care unit, *Regency Square*, serves its residents in the Italian themed, *Denali's*. The skilled residents in the *Olsen* neighborhood dine in *The Metro*, an American "restaurant." Residents in the *Biltmore*, who have both medical and cognitive challenges, eat in their own home, 1950s-styled kitchen. *Carlton* residents enjoy their meals in an art deco restaurant, *The Gatsby*. *La Maison*, a country French restaurant accommodates the *Holbrook* neighborhood.

Each restaurant has natural lighting and a garden view to

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people know what they're drinking. It's the little things that make the difference.

Residents are served their drink of choice and the soup of the day, while they await their meal. Residents then visit the buffet and order what they desire. If resident still has a lifelong aversion to broccoli and orders a double helping of mac 'n cheese—go for it! No one should mandate when and what an older adult should eat.

*"No one should mandate when and what an older adult should eat."*

The transition has not been easy. In its new approach to redesigning the dining experience, Lutheran Home–Hickory started with lunch, and plans to include breakfast and dinner. Staff members, and even some residents, have found it difficult to discard 43 years of tradition. Persistence pays off. Staff is working to take the same and other dining innovations to the smaller units, including two Alzheimer's-type units, in the 204-bed facility.

The best measure of success came when Administrator Amber McIntosh and the team responsible for the transformation were called to the dining room one day at lunch. The residents, who sought some assistance from activity staff, had prepared an entire meal for the team as a sign of their appreciation. A resident spokesperson reduced the entire team to tears as she thanked them for sharing dignity and a beautiful place to eat. The state of North Carolina can take a great measure of credit through the Long-Term Care Enhancement grant that made this possible.

Meal times are another issue being addressed at Hickory and in many other long-term care facilities. Meal times were set like clockwork, literally. How many of us like to sleep-in occasionally, or finish watching that movie before eating supper? In the nursing home of old you ate at 7:00 am, 12:00 pm, and 5:00 pm, period! Some facilities are finding ways to bend over backward to give residents what they want when they want it. Lutheran Home–Hickory even has a colorful snack cart that makes the rounds of the building. Care for a Moon Pie and a Coke? Now that's livin'!

Lutheran Home–Hickory has helped lead the change/charge for Lutheran Services for the Aging's five nursing facilities and two retirement communities. Each facility

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enhance the dining experience. Signage including the menu of the day is clearly visible for cueing and wayfinding. Elegant table settings are provided, as well as lounge areas that include stocked bars for pre-dining activities. Assistive device rooms are provided to promote the facility's policy of seating all residents in dining room chairs during mealtime. Color coordinated linen napkins and attractive décor are provided, as well as dinner music.

For residents who have been identified to have weight loss, aromatherapy is used to stimulate the appetite. Essential oils known to increase appetite are sprayed in the dining area prior to the meal being served. Research studies are demonstrating the effectiveness of aromatherapy in successfully increasing weight in residents with dementia.<sup>8</sup> The *Biltmore* residents are stimulated by the aroma of coffee, toast, and baked goods cooking in their own kitchen.

For those residents requiring a pureed diet, efforts are made to present them in an attractive way by the use of "food molds" that simulate the food item that has been pureed. To ensure the quality of the food served, they are taste-tested at each meal.

To further encourage independence, choice, socialization, and offer flexibility, any resident in the Health and Wellness Center may dine in any of the "restaurants." Additionally, they may invite family members or friends from outside to join them for meals.

At Rex Rehabilitation and Nursing Care Center in Raleigh, North Carolina, scenic wall murals in several areas have enhanced that facility.<sup>7</sup> Susan Watkins, a restorative nurse, started the transformation by painting her small windowless office with a view of an arched Mediterranean villa balcony over red-tiled roofs that are cascading down hills to a deep blue ocean. With resident input, a beach scene resembling the North Carolina Outer Banks was painted in the big dining room. This mural includes a lighthouse, seagulls, a fishing boat (a resident's request), and a couple seated on a beach. The industrial kitchen in one corner was transformed to look like a crab shack, which made the freezer fit nicely. One wall in a windowless room, which was once a big storage room, now has a huge painted window with a view of the mountains. This pleases the residents who were fond of the mountains. On another wall, a stone fireplace is painted that looks so real one can almost feel the warmth from the fire. The Rehab dining area was turned into a realistic looking French café, and another dining area was turned into a beautiful garden room with a painted gate, stone wall, fountain, and trellis. These murals have made a change in the atmosphere in which the residents gather and eat. They no longer are looking at white walls, but at color, at pleasing scenes, which conjure up memories of favorite pastimes and pleasant experiences.

When Moses Cone Extended Care Center in Greensboro North Carolina, began the Eden Alternative journey in 2002, the first thing they wanted to do was to bring the smell of grandmother's kitchen back to their residents. Since they weren't blessed with the money to re-design their kitchen, they resorted to use of a little ingenuity to achieve their goal and the

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is on their own culture change path, learning from each other and from other innovators. The small 20-bed assisted living residence at Trinity Oaks Retirement Community in Salisbury has installed a buffet serving table to replace another institutional system. Although the dining room is too small for at-the-table choices, residents tell the staff what they desire, and staff serves it from the buffet in the adjoining



Trinity Oaks' Assisted Living residents enjoy dining together.

serving kitchen. This system provides a personalized restaurant-style service, which benefits the residents by adding choices and accommodating preferences. The aroma from the buffet can also help with residents' appetites. This system is an example of how elders and staff can overcome space and other limitations to create a much more enjoyable dining experience. Innovations can work in every nursing and assisted living facility.

Food and nutrition are important for every age. We all enjoy a tasty meal in a comfortable environment. No one has to give that up. The future of long-term care may depend on our ability to offer these important quality of life dimensions.

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Wall mural in the dining room at the Rex Rehabilitation and Nursing Care Center



result was fantastic. They created a small buffet cart that can be placed directly in the dining room. The buffet brings the wonderful smells, which normally stay in the kitchen, out to the residents. The residents can look and smell the selections at each meal and decide what and how much they want to eat. The resident is then escorted to a seat where he/she receives waited service, enjoys the meal, visits with friends, and requests “seconds” if desired.

The buffet and its wonderful aromas have been extremely successful with residents, and they also netted three unexpected benefits. The aromas increased the residents’ appetites, which resulted in a drop in weight loss and an increase in the desire of residents to socialize in the dining room. The third, and perhaps the best, benefit was actually an impact on their visitors. Visitors now regularly come to the Moses Cone Extended Care facility at mealtime, view the buffet, select a meal, and sit with the residents for the type of family gathering they used to experience in their younger days.

The Lutheran Home–Winston-Salem has had remarkable success using flavor enhancers to increase both the enjoyment and levels of food consumption. A large proportion of persons over the age of 65 have smell and/or taste losses sometimes caused by normal aging that can impair nutritional status. There are also many medical conditions that have been reported to cause smell and taste losses in the elderly. These conditions include cancer, Alzheimer’s disease, Parkinson’s disease, and viral infections. A reduced sense of smell and taste can sometimes

be combated by adding flavor enhancers to foods.<sup>9</sup>

Flavor enhancer is defined as a substance that increases the pleasantness of the flavor of another substance. Enhancing food flavors can help our elders maintain appetite and food enjoyment. Long-term care facilities are using flavor enhancers during their cooking process to complement the food product. Some examples of how we are enhancing flavors of foods include using bullion cubes to make sauces and gravies meatier or by using fruit extracts to enhance gelatins or fruit-flavored desserts.

## Summary

A number of long-term care facilities in North Carolina have adopted ways to improve the dining experience for long-term care residents. Wall murals and dining room themes help to create a pleasant atmosphere that also might stimulate resident imagination. Aroma therapies are also positive stimulants that increase the appetite and pleasure in eating. Flavor and food presentation are probably some of the most obvious modifications. We can all understand the desire to have our food taste and look good. There are probably even more ideas that could make eating in a nursing home more pleasant and home-like. Efforts like these are critical to stemming weight loss among residents and also to maintaining resident independence to the extent possible. We hope more facilities across the state will use and build on these ideas as they try to maximize their residents’ quality of life. **NCMedJ**

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## The Dining Experience in Nursing Homes

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According to the United States Bureau of the Census Current Population Survey dated March 2000, there were 32.6 million people living in the United States who were at least 65 years old.<sup>1</sup> In North Carolina, 12% of the state's population, or an estimated 1.04 million people, were in this age group. By 2030, this figure is expected to rise to 18% of the population. North Carolina currently has 424 licensed nursing homes with a bed capacity of 42,897 residents.<sup>2</sup> According to the North Carolina Department of Health and Human Services, 60% of people who live to age 65 will need long-term care sometime in their lives; 40% will need nursing home care.<sup>3</sup>

Many aspects of an older adult's life, such as degenerative diseases, functional limitations, medications, and social considerations can result in a decreased sense of independence. In addition to actual loss of independence, many residents in nursing homes experience "learned dependency" from excessive care given by those working in the nursing home setting.<sup>4</sup> These factors have the potential to result in weight loss, dehydration, pressure wounds, and other negative health outcomes. According to the Minimum Data Set (MDS)\* information transmitted to the North Carolina Division of Facility Services from January to March 2005, 11.2% of residents had 5% or greater weight loss in the 30 days prior to their assessments.<sup>5</sup>

As mentioned, many factors may influence a long-term care resident's independence and, in turn, their weight. Less obvious among some of these factors may be their combined effect on the dining experience. A positive dining experience should foster independence, promote self-esteem, and make the resident as comfortable and safe as possible, while providing a nourishing, pleasant meal and minimizing negative health outcomes.

Providing a positive dining experience to long-term care residents can be challenging. Functional limitations that range from an inability to walk to difficulty swallowing, along with chronic diseases that require therapeutic diets, make it difficult for facilities to provide the type of home-cooked meal each resident might prefer. An effort should be made to maintain each resident's dignity and minimize the possibility of excess dependency during the dining experience.

### Rethinking the Dining Room

The American Dietetic Association's *Practical Interventions for the Caregivers of the Eating-Disabled Older Adult* discusses many aspects in which the dining experience can be optimized.<sup>6</sup> These ideas range from mobility issues in the dining room to food presentation. The dining room layout, for example, directly affects the ease of mobility to and from meals. Long-term care facilities should arrange tables and chairs to allow easy access by residents utilizing wheelchairs and walkers. Facilities should also ensure that dining room table height is at a level that will accommodate residents seated in wheelchairs. Even if the dining room is easily accessible by residents in wheelchairs, staff should be encouraged to transfer residents into dining room chairs when possible.

The dining experience can also be enhanced if care facilities present a home-like environment by using tablecloths, cloth napkins, and seasonal centerpieces. Vibrant contrasting colors can be used for tablecloths, placemats, tableware, and/or napkins to increase the nutritive intake of residents with dementia and other patients who may have vision impairments that make it

\* "The Minimum Data Set (MDS) is part of the federally mandated process for clinical assessment of all residents in Medicare or Medicaid certified nursing homes. This process provides a comprehensive assessment of each resident's functional capabilities and helps nursing home staff identify health problems." For more information visit: The Centers for Medicare and Medicaid Services. MDS Quality Indicator and Resident Reports. Available at: <http://www.cms.hhs.gov/states/mdsreports/default.asp>.

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difficult to distinguish food from table placements (i.e., plates, cups, etc.).<sup>7</sup> Cloth napkins also make a better protective barrier for clothing than paper napkins do.

The dining experience can also be improved by simply offering the residents beverages and pleasant conversation while they wait for their meal. Age-appropriate music, along with proper lighting and room temperature (per resident preference), are other easy ways to make the dining experience more comfortable and interesting.

Two other ideas that improve the dining experience by promoting independence and choice involve the way meals are presented to residents. Facilities should consider presenting meals in a buffet-style setting or using family-style dining, which also promotes a home-like atmosphere. Both of these options allow residents to have increased independence by allowing residents to create their own menus and determine their own portion size.

## Eating with Sensory Loss and Chronic Disease

Residents in North Carolina nursing facilities are admitted with different diagnoses, singly and in combination, which can influence how well they enjoy their dining experience. Sensory losses associated with glaucoma, stroke, arthritis, and other conditions affect a person's ability to consume nutritionally-balanced meals and participate in the social aspects of dining. Many residents cannot see the food placed in front of them, manipulate the utensils very well, or hear conversations at the table. In addition to sensory impairments, chronic diseases and their treatments may contribute to loss of appetite, nausea, vomiting, early satiety, fatigue, lethargy, and decreased ability to feed oneself. In 2003, the North Carolina Long Term Care Ombudsman Program provided 441 training sessions for long-term care staff on sensitivity to sensory losses associated with aging.<sup>8</sup> Staff who received the sensitivity training did not enjoy their dining experience. Many of them wanted to retreat to a private location, felt embarrassment, or simply did not want to eat.

In addition to functional challenges, many residents are also prescribed therapeutic diets.\* The MDS 2005 data show that 47% of residents received a therapeutic diet, and 42% of nursing

home residents received a mechanically-altered\*\* diet.<sup>5</sup> A contributing factor to the high incidence of mechanically-altered diets is the fact that 40% of adults more than 65 years of age have no teeth, and only 2% of adults more than 65 years of age still have all of their natural teeth.<sup>9</sup> Therapeutic diet orders, such as 2gm sodium diets, calorie-controlled diabetic diets, or fat-restricted diets may be too restrictive for the nursing home population and may contribute to existing medical problems through complications, such as weight loss, decreased nutritional status, and diminished quality of life. Some facilities use diet types, such as no concentrated sweets and/or no added salt with recipes for large quantities that can serve most residents in a facility. As a result, these menus can be low in calories, bland in taste, and unappealing. Therapeutic diets may be beneficial for certain disease states in the nursing home setting, but they may result in a decreased calorie intake for those whose health needs do not require as much restriction.<sup>10</sup>

One approach used to combat the feeding challenges caused by chronic disease and functional decline is to provide a liberalized diet. Many nursing homes have embraced a liberalized diet plan, which allows all residents to have a regular diet, with minimal restrictions, such as elimination of a salt packet, altered sweet dessert, or other changes according to the resident's medical condition. In 2002, the American Dietetic Association established a position statement for the support of liberalized diets in nursing facilities.<sup>11</sup> The research demonstrated that therapeutic diets may not be warranted in lieu of the overall effects on a resident's quality of life. Many nursing facilities have adopted liberalized menu plans for their residents who have therapeutic needs secondary to diabetes and other disease states, such as hypertension.

*“A positive dining experience should foster independence, promote self-esteem, and make the resident as comfortable and safe as possible, while providing a nourishing, pleasant meal and minimizing negative health outcomes.”*

## A Team Approach

In addition to providing more liberalized diets, facilities can improve resident dining satisfaction and nutritional health through interdisciplinary care team coordination and communication. Members of the interdisciplinary team include the physician, registered dietitian, physical therapist, occupational therapist, speech therapist, pharmacist, social worker, nursing staff (including registered nurses, licensed practical nurses, and nurse aides), and the activity department. Family and resident involvement in the care planning process is also important. As an example of care team coordination, the registered dietitian

\* Therapeutic diets are used to help treat/manage certain chronic diseases (e.g., diabetes and hypertension).

\*\* A mechanically altered diet includes foods that may be pureed or softened to help patients who have trouble chewing and/or swallowing.

can monitor the consumption of meals for all residents or target those who have a higher risk for malnutrition, dehydration, and other nutrition-related outcomes.<sup>12-13</sup> The registered dietitian can determine if a resident's decreased intake is secondary to drug-nutrient interactions, changes in preferences, or changes in disease state. If drug-nutrient interactions occur, the dietitian may inform the pharmacist who can recommend medications and/or order appetite stimulants to counteract the possible negative outcomes produced by the interactions. Speech therapists can evaluate tolerance to current diet textures and fluid consistencies. As a result of this team approach, a meal can be presented that is individualized to the resident's needs and food preferences.

Dietary and activity team members can play a crucial role in making the dining experience personal for each resident. These departments can create theme/holiday meals, "meal-of-the-month" menus, and other special events. Residents also have the right to consult with the dietary department to design facility menus that express their religious, cultural, and preferred food choices. Facilities should use this information along with Dietary Guidelines for Americans,<sup>14</sup> My Food Pyramid,<sup>15</sup> and the Dietary Reference Intakes<sup>16</sup> to create a nutritious menu. To carry out the provision of nutritionally balanced menus, a facility may spend 7-10% of its total budgeted expenses on food service-related costs.<sup>17</sup>

## Self- and Assisted-Feeding

Feeding difficulties occur in 87% of the elderly population.<sup>18</sup> It is the duty of the direct care staff to inform the rehabilitation department when someone is having trouble. Occupational therapists can evaluate a resident's need for adaptive equipment and individualized needs, such as proper positioning. Proper positioning (in a chair or bed) is one of the most useful ways to increased independence and, therefore, should be used during all dining experiences.<sup>19</sup> Improper positioning can increase difficulty in self-feeding or swallowing, increase frustration, fatigue, and decrease the resident's motivation to eat enough food. For residents with functional limitations, self-feeding is a challenge and may decrease socialization at mealtime. Adaptive equipment may minimize the energy required for self-feeding and, in turn, may improve the residents' ability to socialize.<sup>19</sup> An occupational therapist can develop a plan of care for positioning and train direct care staff.

Other feeding difficulties may be related to visual impairment and/or blindness. Residents with these deficits benefit from standardized placement of food, beverages, and service ware on their trays. The positional "clock system" can be used to inform the resident of the physical placement of specific foods in relation to their tray set-up.

Physical therapists can also be an asset by spearheading programs such as a "Walk to Dine" program. In this program, nurse aides and nurses work with physical therapists to assist residents with transfers from their wheelchairs into dining room chairs and work with occupational therapists on proper positioning of residents. Perry Gains, CNA, in Restorative

Nursing at Charlotte Health Care Center, notes that minimizing chaos in the dining room by transferring residents into dining room chairs, and thus decreasing the number of wheelchairs and Geri chairs in the room, can help achieve a positive dining experience for everyone. This process decreases the risk of aspiration by allowing optimal positioning and provides an increase in resident dignity during dining. To further increase dignity during dining, residents with similar cognition and table manners or those affected by disease states such as dementia should be seated together. Thus, a resident can socialize with other residents who have similar habits and communication skills. Hearing-impaired residents may be reluctant to eat in noisy, crowded dining rooms because they are unable to hear mealtime conversation, which results in a feeling of isolation. Nursing facilities can limit unnecessary staff conversations, use sound-absorbing materials in the design and décor of the dining room, and ask residents for their individual suggestions on how to address noise reduction.

Improving the social aspect of dining is another way to achieve a positive dining experience. A program entitled "Dining with Dignity" was created to use socialization to increase the intake and independence of residents during meals.<sup>20</sup> The program is based on the enjoyment of meals with friends and families. It targets individuals at risk for malnutrition, dehydration, and pressure wounds and provides them with companionship at meals. Specifically, family members and "volunteer meal companions" are trained to appropriately assist residents during meals.<sup>14</sup> The program trains the volunteers on concepts such as cueing, "hand-over-hand" assistance, the "power of touch," and the importance of pleasant conversation. Residents who receive assistance from families or companions during meals consume a larger portion of their meals and decrease their risk of malnutrition, dehydration, and pressure wounds.<sup>14</sup> This supports the concept that nursing staff, families, and feeding companions should be an important part of the interdisciplinary team. One nursing home resident involved in the "Dining with Dignity" program summarized her reaction to the program in this way, "I socialize with different people and get to meet new people everyday. We have become a big circle of friends." This statement demonstrates how important the dining experience can be for a resident's total long-term residential care.

## Summary

The dining experience is an opportunity for residents to experience the independence they once knew and still desire. Through appropriate meal consistencies an optimal dining room setting, and coordination of the total healthcare team, these desires can be reached. The resident benefits from this emphasis on the dining experience, while the interdisciplinary team members gain more insight into the individual needs of residents. The dining experience can be an important part of the clinical care of the resident by assuring appropriate nutritional and fluid intake, and it can help assure a desirable quality of life even while residing in a long-term care facility. **NCMedJ**

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# Fluid Intake and Hydration: Critical Indicators of Nursing Home Quality

Robert J. Sullivan, Jr., MD, MPH

After emerging from the primordial sea, humans evolved a sophisticated system for maintaining hydration in order to survive. Despite extremes of environmental stress, internal fluid and electrolyte balance remain remarkably stable. Compensatory mechanisms required to accomplish this feat begin with a sense of thirst, which stimulates fluid consumption.<sup>1</sup> With adequate fluid intake assured, the kidneys retain or discard fluids and electrolytes as appropriate. Under most circumstances, this remarkable mammalian adaptation to life on dry land requires no conscious intervention. In fact, the overwhelming majority of healthy children and adults pursue their daily affairs blissfully unaware of their hydration requirements, or their efforts to meet them.

Such is not the case for infirm elderly individuals. They experience a reduction in the ability to compensate for fluid excess and deficit due to a diminished sensation of thirst<sup>2</sup> coupled with a decline in kidney function. As a result of these changes, for the first time in their lives, older individuals and their caregivers must devote specific attention to fluid intake and elimination.<sup>3</sup> Since changes of aging are subtle, and often are ignored or pass unnoticed, it is not surprising that unrecognized chronic dehydration is a common finding among older adults presenting to emergency departments.<sup>4</sup>

Attention to fluid intake is particularly important for those living in nursing homes. Many of the reasons leading to nursing home placement are associated with significant hydration challenges. Residents with cerebral deterioration or injury may fail to respond to thirst stimuli or be unable to gain access to fluids. Renal function can be reduced by infection, diabetes, kidney stones, and urinary tract outflow obstruction. Medications administered to control illness can adversely influence bodily control systems. As a result of such challenges,

mechanisms that maintain hydration may prove inadequate. In response, nursing facility management must establish systems of care to provide ongoing hydration support, and staff must be trained to assume an active role in promoting fluid intake.<sup>5</sup> Failure to manage hydration can be life-threatening and is a common reason for hospitalization.<sup>5</sup> Fortunately, excellent reviews and guidance are available in the medical literature to guide both novice and experienced caregivers.<sup>6</sup>

## Initial Evaluation

Immediately upon arrival at a nursing facility, the staff should conduct a comprehensive assessment of the new resident's needs and capabilities. In regard to fluids and hydration, the assessment should document prior requirements for hydration assistance, physical limitations on swallowing, and underlying medical conditions and medications that could present problems. Direct observation during meals and throughout the first day will provide additional information regarding intake and elimination patterns and capabilities. An immediate plan of care must be established to address hydration whenever concerns or problems are documented. Virtually all information necessary to understand hydration requirements is addressed in the Minimum Data Set (MDS).<sup>\*</sup> With this information available, a care plan can be created to assure ongoing stability.

When determining fluid intake requirements, all sources of fluid gain and loss need to be considered. Residents exhale moisture with each breath, and their skin constantly exudes moisture that evaporates from the surface. They lose additional moisture through bowel evacuation and the production of urine as they eliminate waste products of metabolism. They gain some fluid through metabolism of foods, but it does not

\* "The Minimum Data Set (MDS) is part of the federally mandated process for clinical assessment of all residents in Medicare or Medicaid certified nursing homes. This process provides a comprehensive assessment of each resident's functional capabilities and helps nursing home staff identify health problems." For more information visit: The Centers for Medicare and Medicaid Services. MDS Quality Indicator and Resident Reports. Available at: <http://www.cms.hhs.gov/states/mdsreports/default.asp>.

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equal losses. Thus, a daily intake of at least two or more liters is necessary to sustain equilibrium.

While most residents can successfully continue self-management of fluid intake as they have done throughout their entire lives, the admission assessment is designed to detect risk factors for dehydration. Generic risk factors discovered from research studies include female gender, age over 85, more than four medical conditions, more than four medications, bedridden, laxative use, and chronic infections.<sup>8</sup> Specific risk factors include fluid loss associated with kidney disease or diabetes. Diuretic medications prescribed to control heart failure and hypertension cause a steady loss of fluids. Fluid problems can be sudden and severe if nausea, vomiting, and diarrhea persist for any length of time. Fever will enhance the loss of fluids in the form of sweat. Intake is reduced for residents with swallowing problems associated with Parkinson's disease, strokes, or dementia. Depression, delirium, anxiety, and agitation cause a loss of interest in food and fluids. These, and many more problems, are commonly encountered in nursing home residents.

Top-quality nursing care organizations have a variety of pre-defined care plans established to deal with hydration issues detected in the MDS evaluation process. Plans provide a structure for ongoing resident support, periodic observation, documentation, and notification when problems arise. Nutritionists or dietitians will establish the plan for food and fluid type, volume, and frequency. Speech therapists assess swallowing skills and provide recommendations regarding fluid consistency and optimal feeding position.

Occupational therapists address requirements imposed by physical disability and provide solutions, such as the use of straws, "sippy cups," vessel with large handles, or resilient grip materials. Once the degree of supervision and assessment for fluid intake is established, every member of the staff is expected to participate in plan implementation. While the focus of most hydration strategies involves improvement and maintenance of function, the nursing home must also have comprehensive plans available for managing nutrition and hydration for the terminally ill under hospice care.

## Daily Monitoring

Success in maintaining hydration requires ongoing attention to the resident's environment and daily demeanor. Staff members should ensure the ready availability of refreshing fluids throughout the day and watch to be sure they are used (see Sidebar on page 298). Hydration is not limited to the dining experience. Residents in nursing facilities must have a wide variety of fluids available hour-by-hour, just as they did prior to entering the nursing home. Staff knowledge of preferences expressed by individuals can guide the choice of fluids offered. That includes juice with breakfast, milk with cereal, coffee or tea with meals, soft drinks and water throughout the day for refreshment, and perhaps wine or beer in the evening. For those capable of

ambulation, a water cooler or drinking fountain offers a suitable source for refreshment. Bed-bound residents and those confined to chairs must have pitchers with fresh, cool water and cups within reach. Resident charts should include regular documentation regarding the amount of fluids and foods consumed at mealtime. Where fluids are readily available, most residents will take care of their needs without needing assistance. If staff members observe a decline in intake or function, an evaluation for dehydration should be promptly undertaken. Periodic weight checks are helpful, although changes may reflect problems with nutrition rather than hydration.

Residents with medical or emotional problems associated with dehydration will require more intensive monitoring of intake and urinary output. Intake volume is easy to estimate by measuring the fluids consumed from bedside pitchers and during meals. By contrast, monitoring kidney output is challenging for most ambulatory residents since collecting and measuring

*"Since the physical manifestations of dehydration are non-specific and often obscured by the aging process and/or illness, it is not surprising that this diagnosis is often overlooked."*

urine is neither easy nor pleasant. Demented patients may lack the mental capacity to cooperate. The frequency of visits to the bathroom provides a useful clue regarding the adequacy of renal function. For incontinent patients, experienced staff members often assess urinary concentration and volume when changing diapers. Although hardly quantitative, diaper evaluation does permit detection of major changes in output.

## Assessing Suspected Dehydration

Dehydration can develop rapidly in older individuals due to illness and changes in medication or environment. If the air-conditioning should fail on a hot afternoon, all residents need to be encouraged to consume extra fluids. Should the nursing home staff become aware of changes in a resident's appearance in regard to either health or function, immediate evaluation is needed.

Since the physical manifestations of dehydration are non-specific and often obscured by the aging process and/or illness, it is not surprising that this diagnosis is often overlooked.<sup>9</sup> Symptoms of dry mouth, fatigue, weakness, restlessness, loss of appetite, nausea, and vomiting are commonly reported. However, signs of pale dry skin and poor skin turgor can reflect normal aging. A dry mouth is more likely to reflect mouth breathing than lack of fluid intake. Constipation and fecal

impaction often occur with dehydration, but commonly occur without it. A drop in blood pressure and a rise in pulse when the resident sits or stands is one method used to detect intravascular volume deficits associated with dehydration.

While physical examination for signs of dehydration is helpful, the single most valuable indicator is a documented drop in urinary volume. The normal urine output exceeds 600cc/day for most adults. When the output falls below 400cc/day, an evaluation is needed. Most residents can successfully collect and submit a 24-hour urine specimen. However, if there is a serious question regarding dehydration, placement of a temporary urinary catheter to document output is worth doing. By having the resident to void prior to catheter placement, the presence of a possible bladder outflow obstruction can be simultaneously documented.

Laboratory tests can assist the evaluation of dehydration provided that baseline levels are available for comparison. A rise in hemoglobin and hematocrit are typical findings accompanied by a rise in the blood urea nitrogen (BUN) and creatinine levels. A normal BUN/creatinine ratio is 10:1. Due to increased urea reabsorption associated with dehydration, the ratio will shift to over 20:1. Finding a urine specific gravity over 1.015 in the absence of urinary glucose indicates the kidneys are working hard to conserve fluids. Checking a urine specimen for sodium concentration is particularly helpful. Documenting a concentration below 25 mEq/L in the absence of renal disease or diuretic therapy is a highly significant indication of a hydration problem. An even more accurate test involves calculating the urinary fractional excretion of sodium by comparing plasma and urine sodium and creatinine concentrations.

## Rehydration

If physical findings and/or laboratory tests suggest dehydration, an immediate response is required. The resident's physician should promptly be notified and rehydration efforts initiated. If the resident can ingest fluids by mouth, drinking water, diluted juice, soft drinks, electrolyte solutions (e.g., Gatorade®), soups, coffee, or tea should be encouraged. Careful documentation of fluid intake and output must be maintained until the resident is stable. There is no formula available to estimate the volume of fluid needed. Instead, staff must rely upon clinical evidence of response using the same indicators used for diagnosing dehydration. An increase in arterial pressure, urine output, and urine sodium excretion are reliable signs. Look for a return to prior levels of mental performance and a resumption of typical daily functions as further indication of success.

## Creative Hydration Programs

Lanaya Cunningham, RD

The staff at Universal Healthcare and Rehabilitation Center in Concord, North Carolina use a nourishment cart covered with a decorative canopy as part of their hydration program. The dietary staff stocks the cooler on the cart with various juices and milk, plus a variety of snacks including gelatin, ice cream, and pudding, which can also contribute to the total liquid intake of the residents. The cart is pushed from room to room, and beverages and snacks are offered at mid-morning, mid-afternoon, and in the late evening.

The afternoon hydration and nourishment pass at Taylor Extended Care Facility in Sealevel, North Carolina is part of the activity program. The cart is decorated with balloons and has music playing while the staff pushes it through the halls in the mid-afternoon. The staff offers snacks to the residents from the cart, which may consist of ice cream, soft drinks, or juices. The snacks and the music are often coordinated to coincide with the planned activity in the facility that day. The activity staff report that the residents often come into the hallway in the afternoon when they hear the music, and they look forward to receiving a beverage and snack.

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## Feeding tubes

Residents who receive food and fluids via a naso-gastric or an enterostomy tube represent a special situation since all nutrition and hydration can be controlled by the nursing staff. Nutritionists will design the protocol for both food and fluid administration. If followed with care and attention, the protocol should ensure stability.

## Summary

Hydration issues are important considerations for the elderly and infirm. What was previously taken for granted often becomes the focus of daily attention. Nursing homes must take a proactive stance in designing systems and training staff to deal with hydration. The minimum daily fluid requirements, and the steps necessary to investigate suspected dehydration, should be well known and understood by all members of the staff. **NCMedJ**



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# 4th Annual North Carolina Conference on Aging

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# Regulating Food Service in North Carolina's Long-Term Care Facilities

Cindy H. DePorter, MSSW

*Based on a resident's comprehensive assessment, the facility must ensure that a resident: maintains acceptable parameters of nutritional status, such as body weight and protein levels... The facility must [also] provide each resident with sufficient fluid intake to maintain proper hydration and health.*<sup>1</sup> — United States Code of Federal Regulations

The provision of food service to residents is among the many regulated services in long-term care facilities. Long-term care facilities face a challenging task in providing three tasty, nutritious meals a day to their nearly 43,000 residents, each with special needs and preferences. In order to ensure that North Carolina's long-term care facilities provide these meals appropriately, North Carolina's long-term care facilities are regulated by the federal Centers for Medicaid and Medicare Services (CMS) through special delegated authority to the North Carolina Division of Facilities Services (DFS).

To understand how long-term care food services are regulated, one must first understand how these facilities are regulated in general. As part of the Social Security Act, Congress included a minimum set of quality and performance standards to regulate all long-term care facilities certified to receive Medicaid and Medicare funding.<sup>2</sup> This legislation covers everything from resident assessments to survey and certification processes to dietary services.

The duty of enforcing this legislation falls under the Centers for Medicare and Medicaid Services (CMS). CMS is also charged with drafting the specific regulations and manuals needed to implement the law. Title 42 of United States Code of Federal Regulations<sup>1</sup> contains the specific regulations long-term care facilities must comply with in order to qualify for federal reimbursement under Medicaid and Medicare. CMS contracts

with each state to inspect facilities, assess their regulatory compliance, and to oversee the licensure process. In North Carolina, the state Division of Facility Services (DFS) performs these functions.

Within the North Carolina DFS, the Licensure and Certification Section's primary responsibility is to ensure that citizens of North Carolina receive safe and adequate healthcare. The Section does this by conducting annual inspections of healthcare facilities, agencies, and clinical laboratories. Eighty percent of the Section's 150 employees are dedicated to performing these inspections, most of which take place in long-term care facilities.

This commentary provides an overview of federal (CMS) regulations pertaining to food service provision in nursing homes\* and the criteria by which these services are evaluated. It also discusses how state regulatory processes address issues of food service and hydration in long-term care facilities, along with examples of how most facilities are dealing with common challenges in this area.

## Understanding Federal and State Regulations

The federal regulations related to long-term care dining issues can be found in the United States Code of Federal Regulations, §483.15 (Quality of Life); §483.25 (Quality of Care); and §483.35 (Dietary Services).<sup>1</sup> To interpret the regulations, states use the CMS *State Operations Manual*, which includes detailed instructions to surveyors.<sup>3</sup>

\* In this commentary, the term "nursing home" refers to an in-patient facility that provides skilled-nursing care 24 hours-per-day by licensed registered nurses.

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## Preserving Resident Quality of Life

*The facility must promote care for residents in a manner and in an environment that maintains or enhances each resident's dignity and respect in full recognition of his or her individuality.<sup>1</sup>*

Each resident of a long-term care facility has the right to be treated with dignity and respect. Preserving resident dignity involves activities that help residents maintain their self-esteem and self-worth (i.e., assisting with grooming and appearance, promoting independence in dining). CMS expects the dining environment to be pleasant and for residents to have a positive dining experience. The dining room should be clean, people at the same tables should all be served at the same time, and the staff providing dining service should be courteous and helpful (i.e., not yelling across the room for assistance). Residents should not have to wear "bibs," and facilities should not serve food on paper plates or use plastic forks on a regular basis.

Tying in directly with the regulation to preserve dignity is a regulation to preserve resident food and beverage choice. Each resident has the right to make choices about his/her life and healthcare in the facility. Their choices include *where* they want to eat (e.g., in their room or in the dining room) and *what* they want to eat. The facility should educate residents about the risks of choosing not to follow a prescribed therapeutic diet. For example, diabetic residents often do not want to eat the 1,800-calorie American Dietetic Association diet. Most facilities have an NCS diet (No Concentrated Sweets) that is intended for diabetic residents. The NCS diet allows residents more food choices and freedom. Facilities also have the flexibility to change the types of foods offered at meals to accommodate the resident's choice.

The resident can choose to eat in his/her room versus in the dining room. If a resident would like to sleep late in the morning without skipping breakfast, this is their right. The facility should work with residents to honor this request and still have some type of breakfast available. It might not be the same breakfast that was served to the other residents at the scheduled mealtime, but as long as it meets the nutritional guidelines, it would be acceptable under federal and state regulations. Family members are also permitted to bring the resident food from home or restaurant. Family members are not permitted to bring food to be served to other long-term care residents.

## Maintaining Quality Care

*Each resident must receive, and the facility must provide, the necessary care and services to attain or maintain the highest practicable physical, mental, and psychosocial*

*well-being, in accordance with the comprehensive assessment and plan of care.<sup>1</sup>*

With regard to dining, providing quality care is geared around the resident's ability to consume foods and fluids. Nursing homes are required to maintain acceptable parameters of nutrition, such as body weight and protein levels, based on the resident's clinical condition and risk status. This means that, if a resident experiences unplanned weight loss, the facility has to assess and implement strategies to ensure that the weight loss is not because of some avoidable issue, such as a resident having mouth pain while he/she eats. The facility has the responsibility of assuring that weight loss is clinically unavoidable. If the resident is losing weight because of a clinical condition, the facility still should assess and attempt interventions to maintain resident weight. Along with this comes the issue of the resident having the right to refuse food. In some instances

the resident may have a terminal illness and may opt to refuse food. Regardless of the resident's condition, all residents have the right to refuse food. If this happens, the facility should discuss food refusal with the resident (when possible), the resident's family, and the resident's physician to make sure that the resident's wishes are being honored. The facility should document the discussion in the resident's record

and support the decision that was reached.

Dehydration falls under the same regulatory requirements. The facility has to provide sufficient fluid intake to assure proper hydration and health. If residents with dementia cannot maintain their own hydration, facilities must offer fluids to these residents throughout the day, not just at meal times. If a resident decides to refuse liquids, he/she has the right to do so. Facilities should document the resident's desire to refuse liquids in his/her record. Facilities should also document that this choice has been discussed with the resident (when possible), the resident's family, and physician. The resident's wishes should be honored.

## Dietary Services

*The facility must provide each resident with a nourishing, palatable, well-balanced diet that meets the daily nutritional and special dietary needs of each resident.<sup>1</sup>*

Regulations specified under Dietary Services address the following areas of food service provision: staffing, menus and nutritional adequacy, food, therapeutic diets, frequency of meals, assistive devices, sanitary conditions, and feeding tubes.

## Staffing

Regulations for dietary services are designed with the general intent for facilities to provide each resident with a nourishing,

*“Each resident of a long-term care facility has the right to be treated with dignity and respect.”*

palatable, well-balanced diet, which also meets the individual daily nutritional and special dietary needs of each resident. CMS requires facilities to have a qualified dietitian as indicated by Dietetic Registration of the American Dietetic Association or have the basis of education, training, and experience to identify residents' dietary needs, appropriately assess and plan, and help implement the dietary program. A qualified dietitian is not required to be at the facility on a full-time basis. Facilities that do not employ a full-time dietitian, must designate a person to serve as the director of food services. The director of food services must receive frequent consultation from a qualified dietitian. The regulations do not specify how often a consultation should occur, but consultations usually occur on a monthly basis. The facility must also employ sufficient support personnel who are competent to carry out the functions of the dietary services. DFS judges whether a facility has sufficient dining staff based on their ability to prepare and provide meals in a timely (e.g., quickly enough to ensure the food is served warm) and in an appropriate manner (e.g., all residents at one table are served at the same time). Facilities determine what works for them in terms of sufficient staffing.

### **Menus and Nutritional Adequacy**

Facilities are required to have menus that meet the nutritional needs of residents in accordance with the recommended dietary allowance of the Food and Nutrition Board of the National Research Council, National Academy of Sciences. In addition, all menus are to be prepared in advance and carefully followed.

### **Food**

Each resident should receive food prepared by methods that conserve its nutritive values, flavor, and appearance. Food must be palatable, attractive, and served at the proper temperature. In other words, the facility has to cook the food in such a manner that it looks, tastes, and smells appetizing. To ensure that food is prepared and served in an appetizing manner, DFS depends, in large part, on the residents' and the residents' families' feedback to survey teams on how the resident and/or family perceives the food. How does the food taste? What does it look like? Does it smell good?

DFS surveyors find that food is a serious concern to residents. Mealtime is a social time and a time when residents interact with each other. DFS survey teams routinely ask resident's how they like the food. The question opens up an important dialog between surveyors and residents and helps establish credibility for surveyors. Meal times are a highlight of many residents' days, and it is important that residents are satisfied with this general category of service offered by the facility in which they live.

### **Therapeutic Diets**

The food has to be prepared in a form designed to meet individual needs. Some residents, for example, have no teeth, and therefore must have their food chopped or pureed (mechanically altered). A physician, in conjunction with the nursing home staff, may prescribe a therapeutic or mechanically altered diet.

The facility must have substitution foods of similar nutritive value available to residents who refuse to eat the foods routinely served in their prescribed diets. The staff should offer these substitutions to the resident whenever this occurs.

### **Frequency of Meals and Snacks**

CMS regulations require long-term care facilities to provide three meals a day at regularly scheduled times, which are comparable to mealtimes in the community. There must be no more than 14 hours between a substantial evening meal and breakfast the following day. Each day a snack must be offered at bedtime. When a nourishing snack is provided at bedtime, then the facility may have 16 hours between the evening meal and breakfast the following day, if a resident group agrees to this meal span. Snacks vary from graham crackers and juice to fruit and milk to other types of healthy snacks. The facility must offer snacks to residents each night. Residents also may have their own snacks in the facility. Proper storage is an important consideration to lessen the chance of pests. The key idea related to both meals and snacks is choice. Facilities in North Carolina have gone to great lengths not to impose simple "one-size-fits-all" approaches with regard to both meals and snacks.

### **Assistive Devices**

Assistive devices, or special eating equipment, may help residents who have functional limitations. The facility must provide special eating equipment and utensils for residents who need them. This would include items such as large-handled/easy grip forks and spoons, plate guards that help keep food on the plate, or postural supports that help residents with positioning.

### **Sanitary Conditions**

In addition to federal laws, long-term care facilities must also follow state laws with regard to sanitation and safe food handling. The Departments of Environment and Natural Resources and the Division of Public Health work together to meet this public health need. County inspectors grade all the nursing home food service departments just like they do restaurants.

To comply with federal regulations, long-term care facilities must procure food from sources approved or considered satisfactory by federal, state, or local authorities. Food must be stored, prepared, distributed, and served under sanitary conditions. The facility must also properly dispose of garbage and refuse. Elderly people are often immuno-compromised and, therefore, are more susceptible to food-borne illnesses, so these stringent requirements are applied. However, this does not mean that families cannot bring food into the facility. Many families bring food to residents, and it is an acceptable practice. In addition, facilities may have fresh seasonable vegetables and other seasonal meals as long as they come from approved sources. There are no regulations that prohibit this practice. Facilities have great latitude in being able to provide meals that meet standard nutritional guidelines, but still meet the unique likes and dislikes of their specific resident populations.

## Feeding Tubes

Residents who have feeding tubes or are at risk for weight loss or dehydration must also have special protections. Facilities are not to place and feed a resident by naso-gastric tube unless the resident's clinical condition makes it unavoidable, and if a resident requires this type of feeding over the long term, a gastrostomy tube would be considered. These regulations also make sure the facility is providing the correct treatment and services to maintain this form of feeding. This includes placement of the tubes, monitoring of intake for proper nutritive levels, and total management of the feeding tube functionality.

## State Survey Teams

DFS survey teams visit each facility periodically (no less than once per year) to ensure that all facilities comply with the regulations pertaining to the operation of a nursing home. Federal survey teams may also visit these same nursing homes. While federal survey teams typically visit a facility only after a state survey team has noted deficiencies, federal survey teams may visit facilities at any time for any reason.

DFS surveys teams generally include four-to-five professionals—a combination of nurses, dietitians, social workers, and pharmacists. The annual surveys inspect the overall care in the nursing home, which includes using a variety of indicators, such as pressure sores, dehydration, abuse, and nutrition. Inspections typically take three days, and DFS conducts at least 15% of the inspections during weekends, evening, and/or early morning hours. Surveyors observe; review facility documentation; and interview residents, families, and staff to make their determinations. To determine if there is a “deficiency,” the surveyors consider the outcome, what occurred, why it occurred, how often it occurs, the impact, whether the facility has resolved the problem, if they facility knew there was a problem, etc.

If the survey team finds that a nursing home is out of compliance with any regulation or standard (including patients' rights violations), DFS cites the facility for a violation. The facility must then submit a response/plan of correction to DFS

for approval. DFS will conduct another survey to make sure the facility implemented corrective action. If a facility fails to implement corrective action, they may be subject to state and/or federal sanctions and fines. In worst case scenarios, facilities might be required to suspend new admissions, have a temporary manager appointed to operate the facility, or have their license revoked. Fines range from \$50.00 to \$10,000.00 a day. However, in most cases, the facility corrects the problem promptly and is not sanctioned or fined. Facilities also have the right to appeal any deficiency that they incur.

## Summary

Other commentaries in this issue of the *North Carolina Medical Journal* describe innovative food and dining practices in some of our state's long-term care facilities.<sup>4,5</sup> Federal and state regulations do not prohibit these innovations, and DFS supports the concept of “enhancements” of the dining experience in these facilities. The Division of Facilities Services, therefore, encourages facilities to assess and operationalize various dining methods, allowing residents to select their foods, dining times, dining partners, and other preferences. The regulations allow facilities to utilize innovative dining approaches, such as buffet lines, or family-style serving options, which allow residents to order at the table as they would in a restaurant. The regulations do not dictate whether facilities should serve food to residents on trays, in buffet lines, or in a family style. While there are many regulations, they leave room for innovative new ideas as long as these ideas do not compromise resident health or safety.

Food consumption and the dining experience are an integral part of the resident's life in a nursing facility. It is important that resident preferences are being honored, and the dining experience is as pleasant and home-like as possible. The facility's responsibility is to provide adequate nutrition and hydration that assures the resident is at his/her highest level of functioning emotionally, functionally, and physically. Meeting the unique needs of each resident in a facility can be a daunting task, but one of immense importance to the quality long-term care. **NCMedJ**

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# A Physician's Perspective on the Dining Experience in Long-Term Care

*Christopher M. Herman, MD, CMD*

Nursing Homes have long been the location where services are provided to individuals who suffer from chronic functional and cognitive impairments. Hopes to “cure” these chronic conditions are unfortunately unrealistic. The goals of a nursing home can be best summarized as one in which the facility cares for its “residents in a manner and in an environment that promotes the maintenance or enhancement of each resident’s quality of life.”<sup>1</sup> Maintenance and enhancement of quality of life become the focus, not cure.

Since mealtimes are often the highlights of a patient’s day, they can become a significant source of improved quality of life, or a source of frustration and complaint, for the patient, family, and facility. Although there are many specialized diets from which to choose, most of these diets are not appropriate for use in a nursing home setting. Often, a more liberalized diet that provides for the patient’s nutritional needs while considering the resident’s medical conditions can increase the desire to eat and the enjoyment of food. This ultimately decreases the risks of weight loss and undernutrition.<sup>2</sup>

## Prescribing Therapeutic Diets

Diets in nursing homes are often chosen for the patients by the attending physician based on the patient’s medical condition. These are called “therapeutic diets.” Therapeutic diets are defined as diets that are provided to meet the specialized nutritional needs of the patient based on his/her medical condition. The assumption is that the diet will improve the patient’s overall health and condition. There are likely hundreds of specialty diets that are available for a patient. Most of them are chosen based on two parameters: texture and nutritional modifications.

Alterations in texture are chosen in order to minimize the

risks of complications. One obvious choice would be a pureed or thickened liquid diet. This diet might be chosen for a patient with a cerebrovascular accident that has resulted in some amount of dysphagia (difficulty in swallowing). Physicians prescribe these diets to minimize the risk for aspiration.

Nutritional modifications of the diet include such choices as increasing or decreasing calories or the addition of mineral or vitamin supplements. One example is to choose a cardiac prudent diet for a patient who suffers from coronary artery disease.

Initial orders for a patient’s diet are usually contained within the FL-2 form\* that the long-term care facility receives from the hospital. The hospital discharge summary may also serve as source of a dietary order that is either confirmed or changed by the patient’s attending physician. Once a long-term care facility receives an order for a diet, there are several regulatory concerns. Long-term care facilities will create a written care plan that focuses on the specific needs of the patient. One of these needs will be the dietary restrictions that are set forth by the attending physician. “All diets... shall be ordered by the physician or other legally authorized person and served as ordered.” The facility is also responsible to “ensure that each patient is provided with a palatable diet that meets his or her daily nutritional and specialized nutritional needs.”<sup>3</sup>

Unfortunately, these types of “prudent” choices by a clinician may not always reach the intended goal of benefiting the patient in a long-term care facility. The use of therapeutic diets in long-term care is often unpalatable and, therefore, associated with weight loss. In fact, the American Dietetic Association recommends that, whenever possible, facilities offer a more liberalized diet to long-term care residents instead of strictly holding to therapeutic diets.<sup>4</sup> Most clinicians would easily come to the same conclusion, but they are often bound by their training and experience.

\* Most facilities require a physician-completed FL-2 form upon admission. The FL-2 form includes the patient’s level of care and medical diagnoses and conditions.

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The training of physicians in the dietary needs and options of patients is usually limited. Most of the training occurs in a controlled hospital setting during residency. Physicians are then expected to apply this training to other settings, such as the nursing home. Applying his/her training in a new setting often presents the physician with a challenge in understanding what is best for the patient, based on the medical diagnosis versus the patient's preference. Compliance with a therapeutic diet is often very difficult for those patients with the best of intentions. It is even more challenging for those patients who have spent decades establishing their eating patterns, likes, and dislikes.

## Unplanned Weight Loss

Weight loss within long-term care facilities has important clinical and regulatory significance. The prevalence of protein energy malnutrition for residents in nursing home facilities ranges from 17% to 65%.<sup>5</sup> Malnutrition among elderly populations is associated with poor outcomes and is an indicator of risk for increased mortality.<sup>6</sup> Research has shown that most long-term care residents who have evidence of malnutrition are on restricted diets, which might discourage nutrient intake.<sup>7</sup>

Weight loss is a complex issue within nursing homes, but there are several problems that can be identified as contributors. One such problem is that many residents are already nutritionally compromised by the time they are admitted to the nursing home. Acute and chronic medical conditions have often laid waste to their caloric intake. Additionally, medications, smoking, and a decline in taste and smell can all decrease food intake.

It is well established that people consume smaller amounts of food as they age. There are a number of reasons for reduced food intake among elderly people, which range from decreased physical activity to disease conditions to earlier or more powerful signals of satiety. This is called anorexia of aging.

The body of literature that focuses on the systemic effects of illness and food intake has been growing. Many of these studies have focused on cytokines. Cytokines are small proteins that are released by the body in response to most illnesses, such as cancer, heart failure, and infections. These proteins then regulate activities, such as inflammation, blood production, and fighting infection. These studies have shown that cytokines, such as interleukin 1 and 6, tumor necrosis factor, and ciliary neurotrophic factor, tend to cause muscle wasting and can reduce albumin, pre-albumin, and cholesterol.<sup>8</sup> The effects of this anorexia are far reaching, producing systemic effects, such as anemia, immune dysfunction, increased infections, decreased cognition, decreased function, and orthostatic hypotension, to name a few.

When considering the management options for patients in long-term care facilities, it is important to understand that these patients are already at a disadvantage for the previously stated reasons. As a result, facilities should provide residents with adequate calories, eating and fluid intake assistance, along with focusing on treating their underlying medical illnesses.

One situation worth noting concerns the use of supplements

to improve the nutritional status of patients. Many would argue that the supplements should be given during meals in order to avoid early satiety rather than giving them prior to a meal. One study sought to answer this question and showed that when nutritional supplements were given an hour before a meal, an older person consumed more calories than when the supplement was given during a meal.<sup>9</sup> It has been shown that glucose infused into the duodenum produces less satiety in older persons.<sup>10</sup> As a result, nutritional supplements that contain carbohydrates are less satiating than supplements that are high in protein.

Some additional suggestions to enhance the dining experience in older adults in nursing homes would include cooking for simplicity by focusing on flavor and appearance of food. Ideally, only a few simple diets would be offered. However such a restrictive focus would require the involvement of the administrative staff, nursing staff, and the medical director.

My experience has shown that most families do not expect a specialized diet to be provided in a nursing home. Many families realize their loved one is already experiencing nutritional decline. For this reason, family members often are happy if the patient can take in any food. However, families of assisted living facility residents have expressed greater concerns when they feel that an adequate therapeutic diet is not available. These concerns are likely based upon the family's perception that the patient's medical illness is not as advanced and, therefore, requires continued diet modification.

Most clinicians have treated patients whose medical conditions have required changing to a less-textured diet, which then resulted in the resident eating less due to the unpleasant sight or consistency of the meal. In order to maintain appropriate and adequate levels of oral intake, clinicians may decide to return the resident to a more "risky," liberally textured diet. This decision necessitates family involvement. Family and staff education are vital for a facility to successfully implement such changes.

## Summary

Unfortunately, weight loss is frequently an expected part of a patient's normal nursing home residential trajectory. However, the clinical team should determine if the weight loss is reversible. The patient's clinical condition is often such that weight loss cannot be reversed or improved. Currently, life expectancy for a patient who has been admitted to a nursing home is approximately 2.2 years. These patients have been suffering from multiple medical conditions that have ravaged their body and mind and left them in a frail condition.

Food has many personal meanings to each resident that can improve the quality of a person's few remaining years. While many specialty diets are available to patients in a hospital, many of these diets may not be appropriate for patients who reside in a nursing home. Careful attention should be given to the prescription and preparation of meals in long-term care facilities. A focus on liberalizing diets in long-term care facilities can lead to improved quality of life for many patients. **NCMedJ**

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*Margaret lives in her own place  
with her own stuff.*

*Tracie helps to make it possible.*

"Margaret is 85 and sharp as a tack. But her health makes it tough to get around. Tracie wants to help out in her community, but she has a busy job. *Faith in Action* brought them together. It's people of different faiths who volunteer to shop, cook, drive, or just check in on some of the millions of Americans with long-term health needs.

If you're like me and have wondered how you can make a difference, volunteer with *Faith in Action*. A neighbor's independence depends on you and me."



**FAITH**  
IN ACTION

— Della Reese. *Entertainment Legend.*  
**Faith in Action Believer.**





## Nutrition in Advanced Alzheimer's Disease

Heidi K. White, MD, MHS

Nursing facilities that care for patients with advanced dementia strive to provide high-quality nutritional care. The standards set forth in federal regulations state, "Based on a resident's comprehensive assessment, the facility must ensure that a resident maintains acceptable parameters of nutritional status, such as body weight and protein levels, unless the resident's clinical condition demonstrates that this is not possible."<sup>1</sup> Alzheimer's disease (AD) frequently involves weight loss,<sup>2-7</sup> which is a strong predictor of mortality.<sup>8</sup> Weight loss and subsequent malnutrition may be an unavoidable part of the natural history of end-stage AD and other dementias. Whether nutritional intervention can delay functional decline and morbidity is largely untested. However, observational data from subjects with AD indicates that weight gain is associated with a reduced risk of mortality.<sup>8</sup> Similar data in institutionalized subjects including those with dementia show that weight gain of even small amounts can improve morbidity and mortality.<sup>9</sup> An understanding of the nutritional consequences of Alzheimer's disease, along with appropriate assessment and a thoughtful approach to intervention, may help to avoid the complications associated with malnutrition, thus preserving a better quality of life until death.

### Factors Promoting Weight Loss

#### Taste and Smell Dysfunction

Taste and smell dysfunction occurs with normal aging and can be exacerbated by medications and disease.<sup>10,11</sup> Although some changes in taste perception have been reported,<sup>12</sup> multiple studies in subjects with mild to moderate Alzheimer's disease have demonstrated deficits in odor identification.<sup>13,14</sup> In addition,

odor threshold may become progressively more abnormal as the disease progresses.<sup>15</sup> Olfactory dysfunction may not be specific to Alzheimer's disease; similar olfactory deficits have been noted in Parkinson's disease and vascular dementia.<sup>16</sup>

*"...nutritional intervention that seeks to enhance the hedonic reward during mealtime may significantly benefit AD patients who are at risk for nutritional decline."*

#### Inflammatory Mediators

Cytokines,\* such as interleukin 6, are an integral part of anorexia-cachexia syndromes in other disease states, such as cancer and heart failure.<sup>17,18</sup> Cytokines, including interleukin 1 and 6, and tumor necrosis factor alpha, play an important role in the inflammatory process that accompanies the hallmark changes of amyloid plaques and neurofibrillary tangles that occur with AD.<sup>19-22</sup> In essence, these inflammatory mediators may produce important changes in the areas of the brain that control appetite.

#### Abnormal Eating Behavior

Abnormal eating behaviors contribute to weight loss. Typical behaviors include needing frequent verbal cues to complete the eating process, verbally refusing food, pocketing food in the cheeks without swallowing, clenching teeth, and spitting food.<sup>23,24</sup> Abnormal eating behavior may be more subtle, such as a fluctuations in appetite, delusions about food (e.g., believing food is poisoned), increased distractibility at mealtime, and

\* Cytokines are regulatory proteins released by cells of the immune system. These proteins act as intercellular mediators in the production of an immune response.

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changes in food preferences.<sup>25</sup> Destruction of the hippocampus and surrounding cortical areas may explain certain behaviors. In late-stage AD, plaques and tangles have been described in the hypothalamus, the neurologic center of appetite regulation.<sup>26,27</sup>

Dysphagia is a common manifestation of late-stage AD.<sup>28,29</sup> Even in early stage AD, an increased duration of the oral and pharyngeal components of swallowing have been observed.<sup>30</sup>

### Balancing Energy Intake and Expenditure

Although inadequate oral intake is likely the primary cause of weight loss in moderate-to-severe AD, increased energy expenditure could contribute to a mismatch between energy intake and energy expenditure that leads to weight loss. While it has been suggested that resting metabolic rate may be elevated in AD, several studies now confirm that there is no evidence to support this.<sup>31,32</sup> The idea that physical activity in the form of behavioral disturbances (e.g., pacing) may contribute to increased energy expenditure has not been supported either.<sup>33</sup> To date, there are no data on AD patients during the dynamic phase of weight loss. It is evident from our work, and that of others, that not all AD patients are losing weight all of the time.<sup>8,34</sup> There can be periods of acute weight loss, a slow gradual weight loss, and variations in weight, which may include periods of substantial weight gain.

It is possible that relatively subtle and, perhaps intermittent, changes in factors, such as a behavioral disturbance that influences both energy intake and energy expenditure, may tip the balance toward weight loss for patients with AD. This imbalance may be multifactorial and intermittent. Rather than one particular cause or abnormality leading to weight loss, AD may lead to a condition in which changes in energy intake and expenditure are not easily compensated. Preliminary data from institutionalized subjects with AD show that Body Mass Index (BMI)\*\* is inversely correlated with a measure of behavioral symptoms, which indicates that lower BMI was associated with higher frequency and severity of behavioral problems.<sup>35</sup>

In summary, both primary and secondary factors may contribute to weight loss in advanced AD.<sup>36</sup> Primary factors, such as those discussed thus far, are attributable to the pathophysiology of Alzheimer's disease and may or may not be amenable to intervention. Secondary factors are not attributable to the pathophysiology of AD, but are commonly encountered conditions that may contribute to weight loss and are perhaps more amenable to intervention (see Figure 1).

## Evaluating Weight Loss and Malnutrition

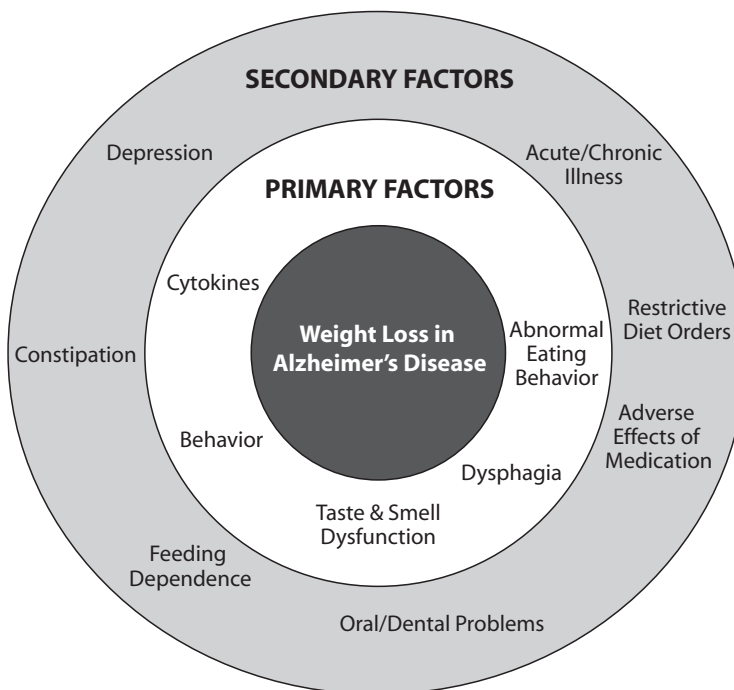
### When to Evaluate

Periodic weight measurements are a primary resource for monitoring nutritional status and recognizing change. Most residents of nursing facilities are weighed monthly unless their condition would warrant weekly monitoring. According to parameters set for the Minimum Data Set, weight loss of 5% in one month or 10% in three months is considered of clinical importance and should entail further evaluation. Older adults with a BMI less than or equal to 21 are likely to be malnourished.<sup>37</sup> Conditions such as pressure ulcers that increase nutritional requirements should also prompt evaluation.

### Other Illness

Common infections, such as pneumonia or urinary tract infections, will often produce anorexia. Cancer, thyroid dysfunction and other common causes of weight loss are part of the differential diagnosis. Constipation is a common condition in institutionalized individuals because of decreased fluid intake, decreased physical activity, and medication that promotes this condition. Chronic constipation can have a profound impact on appetite, yet be difficult to identify in patients with cognitive impairment. Chronic pain may also be difficult to identify, but

**Figure 1.**  
**Weight Loss in Alzheimer's Disease**



Primary factors of weight loss are related to the pathophysiology of AD. Secondary factors are common occurrences that may be more amenable to interventions that promote nutritional well-being.

\*\* BMI, weight in kilograms divided by height in meters squared, is a helpful measurement of nutritional status.

can cause anorexia. Depression is another common treatable cause of weight loss in older adults. Each patient should be specifically evaluated for depression and aggressively treated when it is suspected to be present. Depression is also common occurrence in early dementia, but may also be present in more advanced disease.

**Medications**

Medications should be reviewed. Commonly used drugs can cause many symptoms that potentially limit caloric intake (see Table 1). Acetylcholinesterase inhibitors, which are the primary treatment for the cognitive symptoms of AD, have several potential adverse effects including nausea, vomiting, and anorexia that may contribute to weight loss.<sup>38,39</sup> Additionally, galatamine, an acetylcholinesterase inhibitor, has been associated with an increased incidence of weight loss.<sup>40</sup> Patients with dementia may not be able to voice symptoms attributable to these drugs.

with advanced dementia suffer the consequences of aspiration without any identifiable signs. A swallowing evaluation by a speech therapist that includes visualization of the swallow either in a barium study or by fiberoptic techniques can be helpful in determining the presence and severity of swallowing dysfunction. Although this evaluation can be helpful, many patients experience the sequelae of aspiration, but do not demonstrate aspiration on such testing. On the other hand, many patients who clearly aspirate on testing do not seem to suffer obvious consequences of aspiration, such as weight loss or aspiration pneumonia. Risk factors that predispose patients with advanced dementia to aspiration pneumonia are listed in Table 2.<sup>41</sup>

**Interventions for Weight Loss in AD**

For the most part, getting patients with dementia to eat is a process of trial and error. It is important to make sure that food

is available not just at meal-times, but whenever the patient is inclined to eat. Many patients need supervision, constant reminders, and simple directions to complete a meal. Providing finger foods can be helpful for patients who are challenged by the use of utensils.<sup>42</sup> Appetite and alertness may be better early in the day so breakfast and lunch become more substantial meals. Providing preferred foods can also increase intake.<sup>43</sup> Simplifying the environment so that there are fewer distractions during mealtime may be helpful as well.

Researchers have demonstrated that improving the ambiance during mealtime in a nursing facility by manipulating social and environmental aspects improves food consumption and nutritional status.<sup>44</sup> Studies that have implemented soothing dinner music for dementia patients demonstrate that this intervention can improve mealtime agitation and food intake.<sup>45,46</sup> Taken together, these studies—although few in number and scope of intervention—suggest that a nutritional intervention that seeks to enhance the hedonic reward during mealtime may significantly benefit AD patients who are at risk for nutritional decline.

Feeding a patient, who can no longer feed himself/herself, can

**Table 1. Medications and Induced Symptoms**

Medication Type	Medication Induced Symptom
NSAIDs, alcohol, nicotine, cholinesterase inhibitors	Anorexia
Toxic levels of drugs (e.g., digoxin, theophylline), antibiotics, NSAIDs	Nausea
Anticholinergics, HIV drugs, antibiotics	Taste and smell dysfunction
Sedatives, opioids	Inattention
Antipsychotics	Movement disorders
Anticholinergics	Dry mouth
Bisphosphonates	Esophagitis
Phenothiazines, haloperidol	Dysphagia <sup>62</sup>
SSRI, antibiotics, laxatives	Diarrhea
Antipsychotics, atypical antipsychotics	Increased appetite

**Physical Examination**

A thorough physical examination is an important part of the assessment of weight loss and malnutrition. The mouth is a particularly important part of the examination that should not be overlooked. Dental abnormalities such as ill fitting dentures, tooth decay, and abscess formation may contribute to weight loss. Dry mouth and antibiotic use can lead to thrush, a yeast infection that can cause discomfort and unwillingness to eat.

**Dysphagia**

Patients with advanced dementia often develop serious difficulties swallowing. They may resist food being placed in the mouth, fail to manage the food bolus once it is in the mouth, or aspirate when swallowing. Caregivers should be encouraged to report changes in eating behavior and signs of dysphagia. Coughing and choking during eating are common signs of aspiration. So called “silent aspiration” occurs when patients

**Table 2. Risk Factors for Aspiration Pneumonia**

Risk Factors
Dysphagia
Feeding dependence
Oral Care dependence
Number of decayed teeth
Tube feeding
Multiple medical diagnoses
Number of medications

be very time consuming, and some patients may respond better to a particular caregiver. Techniques that are particularly effective in feeding a patient should be shared and mimicked by other caregivers. Research indicates that the quality of the relationship between the person being fed and the feeder is an important predictor of food intake.<sup>47</sup> Even severely demented patients respond best to caregivers who are personal, interested, involved, flexible, calm, cooperative, and more willing not to seek control in the relationship.

### **Maximize Taste and Smell**

Dietary restrictions, such as low sodium and low cholesterol, that limit aroma, flavor, and calories should be avoided. Flavor enhancement has been shown to increase food intake and maintain weight in nursing home residents.<sup>48</sup> Facilities and caregivers should take advantage of aromatic foods, which stimulate the physiologic responses that prepare an individual for food intake and stimulate appetite. In addition to mealtimes, activities such as baking bread or popping popcorn can stimulate appetite and provide needed calories.

### **Nutrition Supplements**

Oral liquid supplements should be given between meals to boost calorie consumption.<sup>49</sup> Liquid supplements should not replace food intake, as it could result in decreased calorie consumption.<sup>50</sup>

A routine vitamin/mineral supplement should be considered for all patients with moderate to advanced AD, because inadequacies in micronutrient intake are common among eating-dependent nursing home residents.<sup>51</sup> Like all older adults, most patients with AD will require calcium and vitamin D supplementation. Several studies indicate that even subtle deficits in nutritional status can impact cognitive performance in non-demented older adults.<sup>52-54</sup> Even if nutritional supplementation does not improve cognitive symptoms, nutritional interventions may help to maintain the muscle and bone mass necessary for continued independent physical function and, in more disabled patients, prevent challenging complications, such as pressure ulcers.

### **Appetite Stimulants**

Orexigenic agents (appetite stimulants) are often considered in the treatment of end-stage dementia with nutritional decline. None have been studied for their effectiveness in patients with advanced Alzheimer's disease. Megestrol acetate (a hormone therapy often used to treat certain cancers and other diseases with anorexia cachexia) may be a reasonable choice due to limited data with nursing home patients, but may take several months to have an effect on appetite and weight status.<sup>55,56</sup> Studies of megestrol acetate in patients with cancer and AIDS have only found an increase in fat mass, but no significant increase in lean body mass. No survival advantage has been demonstrated. Side effects include adrenal suppression, fluid retention, deep vein thrombosis, confusion, and impotence. Other agents that have been used to stimulate appetite, but for which there are little or no data regarding their use in advanced dementia include cyproheptadine, dronabinol, testosterone,

growth hormone, oxandrolone, and steroids.

When considering the use of an orexigenic agent the origin and causes of the weight loss and the goals of care need to be carefully defined. If dysphagia is the primary issue hindering caloric intake then appetite stimulation may only serve to make the patients condition more uncomfortable. However, if agitation and distractibility are hindering intake, a greater sense of appetite may help the patient to focus attention on eating. The goals of care are also important to consider when making this decision since the benefits of appetite stimulants may be even fewer in advanced dementia than in other disease processes.

### **Antidepressants**

In the situation of otherwise unexplained weight loss, even when symptoms of depression have not been clearly identified, a trial of an antidepressant may be reasonable. Although tricyclic antidepressants frequently result in weight gain for younger patients who consider this an unpleasant side effect, they may not produce this same effect in frail institutionalized patients. Side effects that include constipation, dry mouth, orthostatic hypotension, and urinary retention make these agents less desirable with the advent of selective serotonin reuptake inhibitors (SSRIs, e.g., sertraline, citalopram). Initial concern that SSRIs may produce weight loss in older adults has not been substantiated.<sup>57</sup> Mirtazapine, a multi-receptor agonist, has been associated with increased appetite and weight gain in younger patients in comparison to SSRIs. However, effectiveness of this agent in producing significant weight gain in frail older adults or patients with dementia is unknown.

### **Minimizing Aspiration Risk**

Altering food and liquid consistency can minimize the risk of aspiration. Semi-solid consistencies are generally tolerated better than liquids. Potentially helpful techniques to minimize the risk of aspiration are upright positioning of the patient during meals and for 30 minutes after meals, tucking the chin during swallowing, swallowing multiple times with each bolus, and keeping the bolus less than one teaspoon. A speech therapist should participate in developing the treatment plan and provide staff education for implementation.

Good oral hygiene reduces the bacterial load in the mouth that can be aspirated and may decrease the risk of pneumonia. A growing number of studies indicate that angiotensin converting enzyme inhibitors may elevate substance P levels and, in so doing, stimulate cough and improve oral sensation, thus decreasing the risk of aspiration and pneumonia.<sup>58</sup>

### **Feeding Tubes**

Even with diligent care, weight loss may continue, and malnutrition may ensue. Both physicians and patients' surrogate decision-makers tend to have high expectations for feeding tube placement to improve nutrition, functional status, and quality of life.<sup>59</sup> These high expectations for improved nutritional and health status are not supported by current research. There have been no randomized clinical trials comparing tube feeding with oral feeding in the severely demented. A review of existing

literature by Finucane and colleagues found no evidence to support that tube feeding prevents aspiration pneumonia.<sup>60</sup> In fact, tube feeding does nothing to prevent the aspiration of oral secretions nor can it prevent aspiration from regurgitated gastric contents. Furthermore, Finucane found no evidence to support that tube feeding prevents other infections, the consequences of malnutrition, or pressure ulcers. There was no evidence to support a survival benefit, improved functional status, or greater patient comfort. Adverse events associated with feeding tubes includes aspiration pneumonia, tube occlusion, leakage, and local infection. Although the mortality during percutaneous endoscopic gastrostomy tube placement is low (0-2%), perioperative mortality ranges from 6-24%.

In circumstances where careful hand feeding has not provided adequate nutrition and has resulted in pneumonia or other complications of malnutrition, the possibility of providing food and liquid as tolerated, but allowing a natural death to occur should be considered. For the patient with severe dementia, the decision of whether or not to institute a feeding tube ultimately lies with the patient's family or guardian. However, families and physicians are often aided by advance directives that allow patients with dementia to convey their wishes regarding this issue either before or during the early stages of disease. It is important for healthcare providers to initiate conversation with the patient regarding care at the end of life when cognitive abilities will still allow a meaningful discussion. In most cases, given the current evidence, the decision for careful hand feeding without the use of a feeding tube is very appropriate. Federal regulations

should not be seen as a barrier to this course of action as long as the eating problems are properly identified and assessed and reasonable efforts to hand feed are being made.<sup>61</sup> Careful documentation by the physician and other care providers should indicate that nutritional decline is not preventable because of the patient's advanced dementia diagnosis.

## Summary Recommendations

A physician should evaluate the patient with advanced AD who is losing weight, has a low BMI, or unmet nutritional needs (e.g., pressure ulcers). A thorough medical history and physical examination should be done. The physician, nutritionist, speech therapist, nurse, direct care worker, and family should contribute to the process of evaluation and the implementation of the nutrition care plan. All of these individuals must work together to ensure that weight loss and malnutrition are recognized, evaluated, and treated. The effectiveness of each intervention must be evaluated. Maintaining nutritional health will not always be possible. All involved should understand the goals of care, which may range from expected improvement in nutritional status to supportive and palliative care in the face of an advanced and terminal condition. The goals of care are likely to evolve as assessments are made and as interventions are evaluated. The nursing home medical director and primary care physicians of individual patients must provide leadership in this process, especially when alternatives to oral feeding are considered. **NCMedJ**

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## Use of Feeding Tubes in the Care of Long-Term Care Residents

Timothy S. Carey, MD, MPH

One of the most difficult decisions faced by a family caring for a disabled elder is whether or not to place a gastric feeding tube. Recent high-profile media coverage of the Terry Schiavo case has brought this issue into the public arena. Prior to the early 1990s, placement of a feeding tube for direct delivery of nutrition into the stomach, or “enteral feeding,” was a surgical procedure requiring general anesthesia and the operating room. During the 1990s, the procedure became simplified, using percutaneous techniques either performed in the endoscopy suite or by interventional radiology. These procedures could be performed using conscious sedation and local anesthesia. Feeding could be initiated within 24 hours. The ease of the procedure was greater, and the immediate complication rate was reduced. Patients who were too ill for the procedure now received enteral feeding. Previously, enteral feeding was often performed through long-term naso-gastric tubes. These tubes frequently clogged or fell out, and were associated with significant patient discomfort. Coincident with the greater ease of gastrostomy tube insertion, the number of tube insertions rose dramatically, almost doubling during the 1990s even after adjustment for the increasing age of the population. Use of feeding tubes was even greater in the southeast, and this rise has continued as increasing numbers of tubes are being placed on an outpatient basis.<sup>1</sup>

### Indications for Feeding Tube Placement

Feeding tubes may be placed for a variety of reasons. Some are for acutely ill patients who are in an intensive care unit and are unable to take food by mouth, but who may otherwise have a reasonably good prognosis. This may be the case after trauma or a severe medical illness such as pancreatitis. Gastric feeding tubes are commonly used in head and neck malignancy patients as a ‘bridge’ around the time of surgery and radiation therapy. More controversial indications include placement of feeding tubes after a cerebrovascular accident (stroke). If the patient otherwise has a fairly good prognosis in terms of level

of consciousness and residual functional status, many tubes inserted after strokes can be removed in the year following the event.<sup>2</sup> The most problematic situation in which feeding tubes are used is for elderly adults with neurodegenerative diseases, including cognitive impairment due to Alzheimer’s disease and multi-infarct dementia. Unfortunately, these diseases are progressive, and the feeding tube is not part of a rehabilitation plan. There is extreme variability in the use of feeding tubes for

*“Given the substantial uncertainties regarding the benefits of gastric tube feeding, discussions with families should include assisted feeding as an option, as long as all concerned recognize that ongoing weight loss may continue to occur.”*

this indication around the country. For unclear reasons, the use of feeding tubes is particularly common in the southeastern United States. According to data from the Medicare nursing home Minimum Data Set (MDS), North Carolina ranks sixth in the proportion of severely cognitively impaired elders in long-term care who receive gastric feeding tubes. In North Carolina, 40% of patients with cognitive impairment have feeding tubes, in Alabama the percentage is 47%, but in Maine, only 9%.<sup>3</sup>

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## Risks and Benefits

When wide variation occurs in the utilization of a diagnostic or therapeutic treatment, it's generally due to uncertainty regarding therapeutic benefit, variations in the supply of providers and technology, and varying preferences for treatment.<sup>4</sup> In the case of feeding tubes, providers are often uncertain regarding benefit, and families have variable preferences regarding the pros and cons of this treatment. Yet, over the past decade, moderate amounts of data have been collected and published regarding the utility of gastric feeding tubes in frail elderly with cognitive impairment. Rationales for insertion of these tubes include the prevention of aspiration pneumonia, prolongation of life, or improvement in quality of life. Unfortunately, the benefits of feeding tubes to prevent such complications appear to be quite limited. Alzheimer's disease and related dementing illnesses are conditions that affect the entire brain and the entire body, not just swallowing functions. Patients with gastric feeding tubes continue to have episodes of aspiration pneumonia after insertion.<sup>5</sup> The pneumonia is likely due to aspiration of saliva into the lungs when the patient is asleep, as well as possible aspiration of the very thin liquid that is placed in the stomach through the feeding tube. In addition, healing of decubitus ulcers (bedsores) and improvement in nutritional parameters, such as blood albumin levels, appears to occur for only a minority of patients who receive feeding tubes.<sup>6</sup> Overall, these frail patients have a mortality rate between 30 and 50% over six months, with some studies reporting even worse survival.<sup>7</sup> Some authors recommend that gastric feeding tubes be considered extraordinary treatment since the benefits are limited at best in demented patients.<sup>8</sup> Certainly, families should have a detailed and shared decision-making discussion regarding the very limited benefits of this technology, as well as its significant risks.

The risks of feeding tubes include some risks associated with tube insertion. While the risk of perforation of a structure such as the colon is rare, such complications are potentially catastrophic. Feeding tube removal in the days following insertion can also be extremely risky as peritonitis can result. When a feeding tube falls out or is pulled out (as by a confused patient) in the days following insertion, the patient needs to be emergently transported to the hospital for assessment for peritonitis and re-establishment of the feeding tube using a technique similar to the original endoscopy or a radiologic procedure. Patients may sometimes require arm restraints so that they do not manipulate the gastric feeding tube. These restraints lead to decreased quality of life. Finally, many of the other commentaries in this issue

address the social significance of food in our society. When a feeding tube is inserted and oral feeding is ceased, the sensory experience of eating is denied. The social interaction that is so much a part of meals is also absent. While some facilities use tube feeding as a supplement to oral feeding rather than as a replacement, many place patients on a "nothing-by-mouth" status.

## Shared Decision-Making and Alternatives to Tube Feeding

Assisted feeding to an amount as much as the elder is able to take is certainly an acceptable alternative to placement of a gastric feeding tube for patients who have some remaining ability to swallow. Given the substantial uncertainties regarding the benefits of gastric tube feeding, discussions with families should include assisted feeding as an option, as long as all concerned recognize that ongoing weight loss may continue to occur.

What are the drivers that have led to the common use of a procedure with such limited evidence of benefit? Assisted feeding takes significant amounts of staff time, much of it one-on-one with the patient. Personnel must be trained, attention to set-up of utensils and foods must be performed, and diets may need to be individualized. Although advantageous to the patient, these interventions are costly to facilities. In contrast, once a feeding tube is inserted, the time involved for a staff member to hang a bag of high calorie liquid takes only a few minutes. Reimbursement to the facility may be increased due to the apparent technical nature of the activity. Labor costs are therefore decreased, reimbursement increased, and the care providers may have the somewhat false illusion that "everything is being done." These cost and reimbursement issues may represent a perverse incentive, leading to increased feeding tube use.<sup>9</sup> Medicare's use of 10% weight loss as a nursing facility quality indicator is laudable, but is not intended to mandate use of tube feedings for patients with end-stage dementia. A palliative approach for such patients, appropriately documented, is certainly acceptable.

Policy interventions to assist families and providers in this extraordinarily difficult clinical situation should include financial incentives to facilities for provision of assisted feeding programs; development of shared-decision making modules for use by patients and providers as they grapple with these difficult decisions; and frank discussions of the limits of technology in its ability to preserve life or improve functional status for this important and frail population. **NCMedJ**

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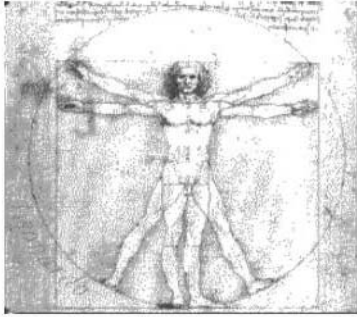
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*From the State Center for Health Statistics, North Carolina Department of Health and Human Services  
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## Patient Flow between Hospitals and Nursing Homes in North Carolina in 2003

The North Carolina Hospital Discharge Data Base consists of more than one million records each year for inpatients discharged from North Carolina hospitals. These records contain information on the source of admission and the discharge status for each patient. This information allows us to describe the volume and characteristics of hospital patients who are transferred directly from and to nursing homes.

During calendar year 2003, there were 1,037,913 inpatient discharges from North Carolina hospitals. Forty-two percent of these hospital patients had their admission source listed as "referral" and 38% had "emergency room" listed. Only 1,411 or 0.1% were identified as being transferred to the hospital directly from a nursing home (skilled nursing facility). Of these 1,411 patients, diseases of the respiratory and circulatory system were the most common principal diagnoses (25% and 18%, respectively), 80% were age 65 and older, 64% were females, and Medicare was the most common expected source of payment (89%).

Seventy-seven percent of all hospital patients in 2003 were discharged to home/self care (routine discharge). Seven percent were discharged to their home under the care of an organized home health services agency. About 7% were transferred to nursing homes: 6.4% or 66,307 to a skilled nursing facility and 0.5% or 4,753 to an intermediate care facility. Another 855 were transferred to "long-term care" and 299 were transferred to a "Medicaid-approved nursing facility."

The following table compares 2003 hospital patients with a routine discharge to those transferred to skilled and intermediate care nursing facilities, by selected patient characteristics.

Percent	Routine Discharge	Discharged to Skilled Nursing Facility	Discharged to Intermediate Care Facility
<b>Age</b>			
Under age 65	75.5	13.9	23.3
65-74	12.0	18.8	14.8
75-84	9.5	37.8	31.8
85+	3.0	29.5	30.1
<b>Gender</b>			
Female	60.4	66.3	65.0
<b>Payer</b>			
Medicare	30.3	89.9	83.3
Other	69.7	10.1	16.7
<b>Principal Diagnosis</b>			
Circulatory system	16.1	15.7	16.2
Respiratory system	9.3	16.9	18.6
Digestive system	8.8	8.0	8.3
Nervous system	4.5	10.8	9.4
Musculoskeletal system	5.1	19.8	6.8
Mental disorder	4.4	1.8	13.3
Pregnancy/delivery/newborn	28.8	0.0	0.6
Other	23.0	27.0	26.8

*Contributed by Paul A. Buescher, PhD, and Pedro Luna-Orea, PhD  
State Center for Health Statistics, North Carolina Division of Public Health*

## North Carolina Institute of Medicine Vice President

The North Carolina Institute of Medicine (NC IOM) with The Cecil G. Sheps Center for Health Services Research at the University of North Carolina at Chapel Hill announces that the position of Vice President of the NC Institute of Medicine is available, on a part-time basis at 50% effort. The Vice President will assist the President of the NC IOM in the administration and oversight of the Institute. The position requires an ability to work with state policy makers, healthcare professionals and trade associations, business and community leaders, and advocacy organizations to involve them in the policy development process, as well as their support in the implementation of key recommendations on health and healthcare issues. Persons seeking this position should have an understanding of health and healthcare issues, extensive experience facilitating diverse groups, public speaking and writing ability, knowledge of the policy analysis process, and fundraising skills. It is desirable that the applicant has quantitative analytical skills necessary to conduct and present results from health policy analyses.

### The applicant must have the following skill set:

- 1) Public policy analysis, including the ability to identify and evaluate different policy options.
- 2) Excellent public speaking ability, including the ability to convey complex health issues and policy options to large and diverse audiences.
- 3) Facilitation skills, leading large task force meetings with varied stakeholder groups including legislators, county commissioners, state and local agency staff, providers, business and community leaders, faith community, and consumers.
- 4) Excellent writing skills, including the ability to translate complex health policy, clinical and/or scientific concepts into information to be presented to policy makers, providers, and/or the general public.
- 5) Fundraising abilities.

An advanced degree (doctorate, medical, or equivalent) plus 5+ years experience in a health policy setting or equivalent experience is preferred. Salary for this position is commensurate with professional credentials and experience. The position is part-time, with the amount of time negotiable with the Board of Directors based on the nature of other commitments, but is assumed to be in range of 50 percent. The position may evolve into a full-time position in the future.

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