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## The Influence of Nursing Home Culture on the Use of Feeding Tubes

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### Abstract

**Background**—Nationwide, many nursing home (NH) residents with advanced cognitive impairment are tube fed, despite no demonstrable benefits of this intervention in this population. Studies suggest that organizational features of NHs are associated with this practice, but underlying reasons for these associations are poorly understood.

**Methods**—We conducted a focused ethnographic study of 2 NHs in South Carolina, 1 with a high tube-feeding rate (41.8%) in patients with advanced dementia, and 1 with a low rate (10.7%). Data were collected about physical environment, mealtime and decision-making processes, and explicit and implicit values using 80 hours of direct observation, semistructured interviews with 30 key facility personnel, and abstraction of publicly available material describing the facilities. Data were analyzed using qualitative methods.

**Results**—Striking variations in organizational culture were identified. The low-use NH had a homelike environment centered on food as an important component of daily life, mealtimes staffed with knowledgeable nursing assistants who valued hand feeding, and advance care planning that included family and palliative care options. In contrast, the high-use NH had an institution like environment, poorly staffed mealtimes, and staff attitudes favoring feeding tubes to avoid aspiration and to meet perceived regulatory compliance.

**Conclusions**—The NH culture influences the approach to feeding in advanced cognitive impairment, whether by hand or placement of a feeding tube. Key features of NHs with a low rate of tube-feeding use include a physical environment that promotes the enjoyment of food, administrative support, and empowerment of staff to value hand feeding and shared decision-making processes involving family members.

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Over 5 million Americans have dementia,<sup>1</sup> of whom 70% will receive terminal care in nursing homes (NHs).<sup>2</sup> Eating problems commonly present during the final stage of dementia.<sup>3</sup> When palliation is the goal of care, hand feeding may be continued to the extent it remains comfortable. Alternatively, tube feeding is another approach to eating difficulties experienced by these patients.

Nationwide, 33% of NH residents with advanced dementia are tube fed, despite no demonstrable benefits in this population in terms of key outcomes such as prolonged survival or improved nutritional markers.<sup>4–6</sup> Marked variation in tube feeding exists across states and among NHs within states.<sup>7–9</sup> Large database studies identified factors associated with tube feeding in advanced cognitive impairment, including individual patient characteristics,<sup>5,10</sup> NH features,<sup>5,8</sup> state laws,<sup>9</sup> Medicaid payment,<sup>9</sup> and healthcare transitions.<sup>11</sup> Nonwhite race is the strongest and most consistent individual risk factor associated with higher likelihood of tube feeding.<sup>12,13</sup> Independent of individual characteristics, NH features associated with greater feeding-tube use include for-profit status, higher proportions of nonwhite residents (> 10%),<sup>5</sup> and fewer residents with do-not-resuscitate orders.<sup>8</sup> The reasons for these associations are not easily explained using secondary analyses of large databases.

Qualitative research may provide insights into end-of-life care that cannot be understood with quantitative methods alone.<sup>14–16</sup> Thus, our objective was to conduct a focused ethnographic study to better understand how NH characteristics influence the practice of tube feeding in patients with advanced cognitive impairment.

## METHODS

### FACILITY SELECTION

Two NHs were selected, 1 with a relatively high tube-feeding rate in patients with advanced cognitive impairment, and 1 with a comparatively low rate. To control for regional influences, both facilities were located in the same health referral region in South Carolina, a state with relatively high rates of feeding-tube use.<sup>9</sup> To select facilities, minimum data set (MDS) information was used to determine tube-feeding rates among residents with advanced cognitive impairment in all NHs in the state (n=179) on a randomly selected date in 2001 (the most recent data available at the time of study initiation). Advanced cognitive impairment was defined as cognitive performance score higher than 5.<sup>17</sup> Eligible NHs criteria included feeding-tube use rates lower than 15% (low use) or higher than 35% (high use) among residents with advanced cognitive impairment, and more than 100 beds. Four high-use and 3 low-use facilities met these criteria. The principal investigator (R.P.L.) telephoned senior administrators of eligible NHs, explained the study, and solicited participation. The high-use facilities were approached sequentially (the highest-rate NH approached first) until the administrator at the fourth NH (tube-feeding rate, 41.8%) agreed to participate. The administrator in the first low-use NH (tube-feeding rate, 10.7%) agreed to participate.

### DATA COLLECTION

Data were collected in the following categories: (1) general facility characteristics, (2) physical environment, (3) mealtime processes, (4) decision-making processes for eating problems, and (5) facility explicit and implicit values (Table 1). Data were obtained by direct observation, semistructured interviews with key personnel, and abstraction of publicly available material (ie, printed brochures, NH Web sites, and Medicare Nursing Home Compare Web site<sup>18</sup>).

Approximately 80 hours of direct observation were conducted by 2 gerontological nurses: 1 who is African American and has a Master's degree and 1 who is white with a PhD. Interviews with key personnel were conducted using semistructured interview guides in a private location at the NH, lasted 30 to 45 minutes, and were digitally recorded:

Domain	Sample Questions
Mealtime processes	What has been your experience feeding residents with advanced dementia? What difficulties have you experienced related to feeding residents with dementia? What strategies do you use?
Decision-making processes	How do you identify residents who have eating difficulty? What happens when residents experience weight loss? Who is involved in feeding decisions? What role do you and others play?
Implicit values	What happens if residents stop eating? What do you see as the risks and benefits of feeding tubes? Do you experience expectations or pressure from others such as family, primary care provider (PCP) (physician and nurse practitioner), NH administration, or regulatory agencies regarding feeding decisions?

Data were collected until theme saturation was reached.<sup>22</sup> Personnel were selected based on the likelihood they played a role in managing feeding problems. The final cohort of interviewees was dependent on their availability at the time of data collection. In the low-use NH, personnel included a director of nursing (n=1), senior administrator (n=1), speech and language pathologist (SLP) (n = 1), registered nurses (RNs) (n=3), licensed practical nurses (LPNs) (n=3), certified nursing assistants (CNAs) (n=2), social worker (n=1), diet technician (n=1), recreation therapist (n=1), and a physician (n=1). In the high-use facility, personnel included a director of nursing (n=1), senior administrator (n=1), SLP (n=1), RNs (n=1), LPNs (n=3), CNAs (n=4), social worker (n=1) diet technician (n=1), recreation therapist (n=1), and a nurse practitioner (NP) (n=1).

General facility characteristics included organizational features, staffing, and quality measures. Aggregated MDS data were used to calculate the percentage of African American residents in the facility, and the Nursing Home Compare Web site<sup>18</sup> was used to describe the following organizational features: number of beds (range is shown to protect anonymity), ownership, and Medicaid beds (percentage). Staffing variables included the number of RN and CNA hours per resident per day. The data on SLP staffing were obtained from senior administrators.

To describe overall NH quality, study personnel completed the Observable Indicators of Nursing Home Care Quality Instrument, version 10.<sup>19</sup> This validated instrument consists of 30 questions on a 5-point Likert rating scale measuring 7 factors: care delivery, grooming, interpersonal communication, environment-access, environment-basics, environment-homelike, and odors. Scores ranged from 30 to 150. Scores higher than 128 indicate better quality, and scores lower than 103 indicate worse quality.<sup>19</sup> Additional quality measures were obtained from Nursing Home Compare, including Center for Medicare and Medicaid Services (CMS) 5-Star Quality Rating System, proportion of high-risk long-term residents with pressure ulcers, and number of deficiencies on most recent state inspection.

Direct observation was used to collect data regarding the physical environment as it related to eating. Components included general atmosphere, structure of dining facilities, and food accessibility.

Mealtime data were collected through direct observation of 13 meals guided by 2 existing protocols designed to capture environment, social and functional context of meal services,<sup>20</sup> and quantity and quality of mealtime assistance.<sup>21</sup> Informal interviews were conducted with CNAs as they fed residents. Questions were (1) What is your experience feeding residents

with dementia? (2) What difficulties have you experienced related to feeding residents with dementia? (3) What strategies do you use to feed residents?

Data about decision-making processes for eating problems were collected through semistructured interviews with key personnel. Questions focused on timing of decisions relative to the onset of feeding problems, responsibility of various NH staff members, and timing and degree of families' involvement.

Explicit values refer to purposefully expressed values in public material prepared by the NH. To obtain these data, the research team abstracted the facility's mission statements and philosophies as documented in brochures and Web sites. Implicit values referred to underlying beliefs related to feeding decisions as expressed by NH personnel during in-depth semistructured interviews. Questions used to guide these interviews were (1) What happens if residents stop eating? (2) What do you see as the risks and benefits of feeding tubes? and (3) Do you experience pressure from others, such as family, PCP, NH administration, and regulatory agencies regarding feeding decisions?

Trustworthiness of the study was supported by prolonged engagement, triangulation, peer debriefing, reflexive dialogue, and member checking.<sup>23</sup> Data collectors spent sufficient time (prolonged engagement) in the NHs to develop trust and until no new information was discovered. Triangulation was conducted by comparing multiple data sources and data collected during various shifts and days of the week. To prevent imposing preexisting views on the raw data, one of us (R.P.L.) led peer debriefing and reflexive dialogue with the research team, all experts in gerontological research and end-of-life care, exploring complementary and divergent understandings of the study situation and revealing beliefs, values, and assumptions. In addition, one of us (R.P.L.) maintained a record of methodological decisions, logistics, and reflections. Finally, member checking was conducted by sharing study findings with key NH personnel.

The University of Pennsylvania institutional review board approved the study. Verbal consent was obtained from NH personnel prior to observations and written consent prior to interviews.

## DATA ANALYSIS

Descriptive statistics were used to present the quantitative data. Interviews were transcribed, checked for accuracy, and entered into the QSR Nvivo software program (version 8.0; QSR International Pty Ltd, Doncaster, Victoria, Australia). Qualitative analysis<sup>24</sup> was conducted using 3 steps: data reduction (R.P.L. and E.J.A.), display (R.P.L.), and conclusion drawing/verification (R.P.L., E.J.A., N.E.S., and S.L.M.). Data reduction involved abstracting the raw data to identify concepts broadly related to eating issues in patients with dementia. Concepts and processes were grouped into 4 categories: physical environment, mealtime processes, decision making, and explicit and implicit values. A matrix was developed for each category to compare data from each NH. Finally, conclusions were drawn, and original data were reviewed to verify that conclusions were plausible, confirmable and valid. Records of qualitative analyses were maintained. All members of the research team agreed on the conclusions drawn.

## RESULTS

### FACILITY CHARACTERISTICS

Table 2 presents general NH characteristics. Both NHs had comparable numbers of beds, were for-profit, and were part of a chain. The high-use NH had a higher mix of Medicaid recipients, more African American residents, and did not have a dementia unit. The ratio of

RNs to residents was lower in the high-use NH, but the level of CNA support was similar. Both facilities had an SLP on staff. Finally, the high-use NH had poorer overall quality, a lower score on the Observable Indicators of Nursing Home Care Quality Instrument, fewer stars on the CMS 5-Star Quality Rating System, more patients with pressure ulcers, and more deficiencies found on state inspection.

In both facilities, administrative staff, licensed nursing staff, and PCPs were white with the exception of 1 African American nurse (an LPN). All CNAs who participated in interviews were African American.

Newly available MDS data from 2006 and 2007 confirmed that the tube-feeding rates in the 2 NHs remained similar to 2001 data used for facility selection. In 2007, the high-use NH had 29 residents with a CPS score higher than 5, of whom 10 were tube fed (tube-feeding rate, 34.5%). The low-use NH had 27 residents with a CPS score higher than 5, of whom only 4 were tube fed (tube-feeding rate, 14.8%). These rates were similar in 2006 (Table 2).

## PHYSICAL ENVIRONMENT

The general atmosphere in the low-use NH was homelike and richly decorated. Residents were observed ambulating and engaging in social exchanges with staff and visitors. The dining room was centrally located. Hot beverages were available in the reception area, residents frequented the ice cream parlor, and there were activities involving food, such as a homemade soup contest and an outdoor barbecue. Conversely, the general atmosphere in the high-use NH was devoid of décor and had a pervasive unpleasant odor. Residents were in bed or wheelchairs for most of the day. Little social exchange occurred between NH staff and residents. The dining room was annexed to the main building, and 1 small room on each nursing unit was used as a dining room for residents needing assistance. Food appeared only during scheduled mealtimes.

## MEALTIME PROCESSES

In the low-use NH, 7 meals were observed and 6 CNAs were interviewed. Mealtimes were well staffed. Each CNA was responsible for feeding 3 or 4 residents. Visitors assisted with meals, and nurses supervised and fed residents. Most residents ate in dining rooms and were transferred to dining chairs. Interviews with CNAs revealed that they were informed about feeding residents with dementia and described several feeding challenges, including problems swallowing, chewing, aspirating, accepting food, and maintaining alertness. In response to these behaviors, CNAs identified several strategies: coming back later, taking extra time, maintaining eye contact, and verbally encouraging residents. Staff provided physical assistance and social and verbal cues.

In the high-use NH, 6 meals were observed, and 5 CNAs were interviewed. Mealtimes were not well staffed. Visitors and nurses were not present during meals. Each CNA was responsible for feeding 6 to 8 residents. During 1 observation, 2 CNAs assisted 16 residents in a small dining room. One CNA abruptly left to feed residents elsewhere, leaving many residents without further assistance. During the evening shift, only 3 CNAs were available to feed 20 residents. One nurse said, "It pretty much is shove it in, get out, and move on." Few residents attended the main dining room. Many residents were placed in bed after lunch and remained there until the following morning. Residents in wheelchairs were not transferred to dining chairs. The CNAs were not well informed about feeding residents with dementia. When asked about challenges they faced, CNAs reported that residents hit, spit, would not open their mouths, and took a long time to eat. The only strategy identified was reporting the problem to the charge nurse. The CNAs did not provide verbal or social cues during meals.

## DECISION-MAKING PROCESSES

Both NHs had interdisciplinary teams to identify and respond to residents' weight loss but differed on team composition and family role. The low-use NH team included the dietary technician, SLP, director of nursing, administrator, nurses, activity director, social worker, and on-staff physician. The physician evaluated residents who lost weight and discussed his findings with family. His attitude reflected a preference for hand feeding over tube feeding. He said, "I am subtly negative, or not so subtly. I tell [the family] that [a feeding tube] has no effect on mortality. It just changes the complications." The social worker also facilitated family meetings to determine how the options of hand feeding vs tube feeding aligned with the goals of care.

The high-use NH team was composed of the dietary technician, SLP, and nurses. Nurses were responsible for notifying PCPs of weight loss, obtaining orders for nutritional supplements, and notifying families about feeding problems. The social worker denied having a role in feeding decisions. An NP reported that by the time she was consulted, "department heads" had already approached families to suggest tube feeding. The NP found it nearly impossible to "undo" family beliefs that feeding tubes were in residents' best interests. The NP reported that dehydrated residents were often admitted to the hospital and returned with feeding tubes.

## EXPLICIT VALUES

In material distributed by the low-use NH, the mission was to create a "community" of support and to serve each person with "compassion, dignity, purpose, and respect." Residents were considered "family members" who were "entrusted" to the home to create "healing" and "peace of mind." The mission statement emphasized individualized treatment plans with health professionals and family working together to help residents "thrive."

The high-use NH's mission was to "minimize recovery time," "provide quality care," and "obtain positive outcomes." The NH staff were considered "partners" and their goal was "progression through health care services" toward the ultimate goal of "stabilization and recovery."

## IMPLICIT VALUES

The low-use NH implicitly valued care that was consistent with families' preferences and hand feeding residents. If family were "willing to take the risk," staff were willing to hand feed residents, despite the possibility of aspiration. The SLP took an active role in educating and supporting nursing staff and described a situation with a 93-year-old resident with advanced cognitive impairment. She said,

The family knows that she isn't safe [from aspiration], and nursing knows that she's not safe, the physician knows that she's not safe, but [family] wish for us to continue to attempt to feed her as safely as possible just because if you don't, you're actively starving that patient. The only alternative is a tube and at 93, her family doesn't want her to have a tube.

Administrative staff in the low-use NH were not apprehensive about meeting regulations concerning weight loss. Given multiple strategies to maintain weight, meticulous documentation, and family involvement, administrative staff felt that records were adequate to support continued hand feeding despite significant weight loss.

In the high-use NH, there was an implicit assumption that families preferred not be involved in residents' care and that African American families preferred aggressive end-of-life care, including tube feeding. When the research team asked to interview families, the social



worker responded, “Good luck finding them.” Some staff members did not value hand feeding. One nurse likened feeding residents with dementia to feeding a “puppy with an automatic feeder.” A CNA said that in patients with dementia, “eating isn’t important anymore.” Some nurses feared that residents with advanced dementia might aspirate during meals and preferred to tube feed such residents. Finally, feeding tubes were implicitly valued as a means of adhering to state regulations concerning weight loss. The director of nursing reported that feeding tubes were inserted “pretty quick” because of “stiff regulations that did not permit a look at the whole picture.” An NP agreed, saying, “I think a large part of it is fear [of regulatory agency] by [NH] administration to act on weight loss. This drives the feeding tube conversations as well.”

## COMMENT

Numerous quantitative studies attest to striking variation in institutional prevalence of feeding tubes in patients with advanced dementia but do little to explain these observations. Our focused ethnographic study of 2 for-profit NHs with widely differing feeding-tube practices provide further understanding of how facility culture may influence approaches to feeding. The contrasting “culture” in our 2 participant NHs was manifested in differences in physical environment, care processes for feeding, decision-making processes, and values.

Our results corroborate previous observations describing a link between physical environment and quality of NH end-of-life care.<sup>15,16</sup> Both observational and quantifiable measures clearly suggest that overall quality of care was higher in the low-use NH, which had a homelike environment focused on enjoyment of food. In contrast, the high-use home had poorer quality by all measures, and an institution like environment devoid of emphasis on food.

Variation in staff assignments, attitudes, and mealtime and decision-making processes suggest that differences in tube-feeding rates go beyond physical environment. Despite similar facility-wide CNA to resident ratios, the ratio of CNAs assigned to feeding residents with cognitive impairment was nearly double in the low-use NH. In the high-use NH, 1 CNA was assigned 6 to 8 residents at each meal, translating to less than 10 minutes per resident per meal, far short of the 35 minutes recommended for adequate oral consumption.<sup>25</sup> Moreover, striking differences were observed in CNAs’ knowledge and attitudes toward feeding residents with cognitive impairment. Inadequate NH staffing contributes to dehydration and malnutrition,<sup>16</sup> which may promote feeding-tube use.

Advance care planning and shared decision making are key processes in addressing feeding problems in cognitive impairment.<sup>3</sup> Our results support other studies suggesting that residents living in NHs with greater engagement in advance care planning are less likely to be tube fed.<sup>8</sup> While both NHs had interdisciplinary teams to address feeding problems, their approaches differed dramatically. In the low-use NH, team representation was broader and had strong PCP involvement. Moreover, staff felt obliged to provide treatment options to families, including palliation, and to elicit and honor family preferences. Conversely, the high-use NH team included fewer disciplines, lacked strong PCP support, and individual staff either abdicated a role in decision making or felt little control over the outcome. Families were not viewed as equal participants in decision making, and the default approach was to transfer residents to the hospital. A recent report<sup>11</sup> shows that most feeding tubes among NH residents with advanced dementia are inserted during acute hospitalization.

Our results suggest that implicit and explicit values are important factors driving tube-feeding practices in NHs. These values emanate from top administrators directly to the caregivers. In the low-use NH, nursing home staff at all levels valued hand feeding over tube

feeding. Those in the high-use NH valued tube feeding as a means of avoiding hand feeding residents at risk for aspiration and as a method of regulatory compliance.

The study also raises serious concern about the role of resources, race, and disparate quality of care. Fiscal resources may, in part, underlie the association between physical environment and quality of care, and this notion is supported by the fact that the high-use NH had a greater number of Medicaid beds.<sup>26</sup> A prior report<sup>27</sup> also suggested a financial incentive on the part of NHs to tube feed rather than hand feed patients with dementia. Moreover, regardless of individual race, residents with cognitive impairment living in US NHs with a higher proportion of African Americans are at higher risk of being tube fed.<sup>8</sup> The resident demographics in our study support this observation but dispel the notion of staff racial mix as a possible explanation. The study, however, fails to explain how fiscal and ethnic factors affect the culture of care, highlighting the need for further investigation.

This study has limitations that warrant comment. First, data were collected in only 2 facilities in 1 state. Although NH characteristics were similar to those found in previous large database studies,<sup>5,8,13</sup> generalizability to other facilities and locations is limited. Given that the investigators conducted the data analysis, their bias may have been introduced into the conclusion; however, standard qualitative methods, including the exploration of preconceptions through reflexive dialogue, were used to minimize bias. In addition, family member interviews were not included in this analysis, and we did not examine clinical outcomes of tube feeding vs hand feeding synthesized in prior work.<sup>4–6</sup>

This study reveals a startling variation in the organizational culture of 2 NHs and its influence on approaches to feeding problems in patients with advanced dementia. A culture that promotes hand feeding over tube feeding is facilitated by an organizational mission that strives to create a homelike atmosphere in which food, mealtimes, and family are central and has the necessary clinical resources and expertise to help staff solve feeding problems. Efforts to diminish feeding-tube use requires NH staff who value and are capable of providing high-quality feeding assistance to residents with advanced dementia and who are empowered to include family in shared decision making.

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**Table 1**

Data Describing Organizational Culture Influencing Tube-Feeding Practice in Advanced Cognitive Impairment in 2 Nursing Homes

Data Element	Collection Method
Facility characteristics	
Organizational features	Minimum data set
Resident features	Medicare's Nursing Home Compare Web site <sup>a</sup>
Staffing	Direct observation
Quality measures	Observable Indicators of Nursing Home Care Quality Instrument, version 10 <sup>b</sup> Direct observation
Physical environment	Direct observation
General atmosphere	
Structure of dining facilities	
Access to food	
Mealtime processes	
Staffing	Direct observation
Quality of feeding assistance	Mealtime observation protocol <sup>c</sup>
Decision-making processes for eating problems	Semistructured interviews with key personnel
Values	
Explicit values	Facility Web sites and printed brochures
Implicit values	Semistructured interviews with key personnel

<sup>a</sup>The Nursing Home Compare page at the Medicare Web site.<sup>18</sup>

<sup>b</sup>The Observable Indicators of Nursing Home Care Quality Instrument consists of 30 questions on a 5-point rating scale. Scores range from 30 to 150 with higher score indicating better quality.<sup>19</sup>

<sup>c</sup>Mealtime observation protocol guides observations of mealtimes in nursing homes including environment, social and functional context of meal services,<sup>20</sup> and quantity and quality of mealtime assistance.<sup>21</sup>

**Table 2**

Characteristics of 1 Nursing Home With a High Rate of Tube-Feeding in Patients With Advanced Dementia and 1 With a Low Rate

Characteristic	Low-Use Nursing Home	High-Use Nursing Home
Organizational demographics		
Long-term-care beds, No.	130–150 <sup>a</sup>	130–150 <sup>a</sup>
Ownership	For profit	For profit
Part of a chain	Yes	Yes
Medicaid beds, %	27.7	80.7
African American residents, %	8.8	52.2
Dementia unit	Yes	No
Staffing		
Registered nurse h/resident/d	23 min	19 min
Certified nurse assistant h/resident/d	2 h 4 min	2 h 26 min
Speech therapist on staff	Full-time	Full-time
Quality measures		
Observable indicators of nursing home care quality <sup>b</sup>	133	73
CMS 5-star quality rating system <sup>c</sup>	4 Stars	1 Star
High-risk long-stay residents with pressure sores, %	6	16
Deficiencies of last state inspection, No.	9	11
Feeding-tube use, No. (%)		
Tube-fed residents among those with a CPS score of 5 or 6, 2006	2 of 17 (11.8)	15 of 39 (38.5)
Tube-fed residents among those with a CPS score of 5 or 6, 2007	4 of 27 (14.8)	10 of 29 (34.8)

Abbreviations: ADLs, activities of daily living; CMS, Center for Medicare and Medicaid Services; CPS, Cognitive Performance Score.

<sup>a</sup>Precise bed size is omitted to prevent recognition of sites.

<sup>b</sup>The Observable Indicators of Nursing Home Care Quality Instrument consists of 30 questions on a 5-point rating scale. Scores range from 30 to 150 with higher score indicating better quality.<sup>19</sup>

<sup>c</sup>The CMS 5-Star Quality Rating System rates nursing homes on quality measures from 1 to 5 stars. A higher score indicates better quality.