

## Preplanned Studies

## Chinese American Caregivers' Attitudes Toward Tube Feeding for Persons with Dementia — USA, 2021–2022

Yaolin Pei<sup>1</sup>; Xiang Qi<sup>1</sup>; Zhen Cong<sup>2</sup>; Bei Wu<sup>1,†</sup>

### Summary

#### What is already known about this topic?

Little is known about Chinese American dementia caregivers' attitudes toward tube feeding.

#### What is added by this report?

To address this knowledge gap, the paper seeks to characterize participants' attitudes toward tube feeding based on a survey conducted among Chinese American dementia caregivers.

#### What are the implications for public health practice?

It is crucial to develop culturally tailored interventions to promote knowledge on tube feeding and advance care planning engagement in Chinese American communities.

Research has demonstrated a lack of evidence on the benefits and potential risks of tube feeding in individuals with advanced dementia (1). Consequently, national organizations increasingly advocate against the use of tube feeding in persons with advanced dementia (2). Few studies have examined Chinese American dementia caregivers' attitudes toward tube feeding. Based on the data collected from Chinese American dementia caregivers in New York City (NYC), it was found that knowledge about tube feeding and the expressed wishes of patients regarding tube feeding were associated with a higher likelihood of the 'hand feeding' selection among Chinese American dementia caregivers. The results suggest that it is crucial to develop culturally tailored interventions to promote knowledge on tube feeding and advance care planning engagement in Chinese American communities.

Data in the study were collected from 63 Chinese dementia caregivers living in NYC from November 2021 to June 2022. Using a purposive sampling approach, two bilingual social workers at CaringKind, a collaborating agency, referred 114 Chinese caregivers who had used their service. The research team at New York University (NYU) recruited 87 caregivers who were interested in the study. The caregivers'

sociodemographic characteristics and attitudes toward tube feeding were collected via an online survey or a telephone interview. For this study, participants whose care recipients had died ( $n=22$ ) and two participants whose care recipients were using feeding tubes were excluded. The final sample included 63 Chinese dementia family caregivers whose care recipients were not using feeding tubes at the time of data collection. The study was approved by the NYU institutional review board. Table 1 presents the characteristics of participants.

In the study, participants' decision-making regarding tube feeding in the hypothesized scenario was measured by asking, "Imagine your care recipient is in a state where he/she has severe dementia. He/she has poor long-term and short-term memory and is unable to recognize his/her close relatives (e.g., spouse, children). He/she is also unable to communicate, is incoherent, confused and/or disorientated, and requires help in all activities of daily living, including feeding. On top of that, he/she has problems with feeding and swallowing and, as a result, has had several episodes of pneumonia (i.e., lung infection), requiring admission to a hospital. Would you choose tube feeding or hand feeding for your relative?" (0=tube feeding, 1=hand feeding, 2=unsure). Knowledge about tube feeding in individuals with advanced dementia was measured by a 3-item scale that was selected from an existing scale (3). The three items were "tube feeding is recommended for use when oral feeding difficulties arise," "patient survival improves when feeding tubes are used," and "tube feeding improves nutritional status." The three items were summed, resulting in a knowledge score ranging from 0 to 3 with higher scores indicating more knowledge. Cronbach's alpha for this scale was 0.66. The items for the importance of food at the end of life were selected from a previous study conducted in Singapore (4). Data were analyzed with STATA (Stata 15.1, Stata Corp, College Station, TX, USA). Descriptive statistics, correlation, and logistic regression were used to assess the attitudes toward tube feeding among Chinese American dementia caregivers.

Table 2 shows the frequency with which family caregivers decide to use tube feeding or hand feeding in the scenario of a patient with advanced dementia at the end of life. About 34.92% of participants chose tube feeding, 23.81% chose hand feeding, and 41.27% were unsure. Concerning the goal of care, 93.65% of participants preferred to relieve pain and discomfort as much as possible. Knowledge and discussion about tube feeding is shown in Table 2. The knowledge score was averaged at about 0.41 out of 3. About 15.87% of participants discussed tube feeding with providers.

The perception of the main purposes for tube feeding in individuals with advanced dementia is shown in Table 3. Prolonging life, not feeling hungry/thirsty, and preventing aspiration were identified as the most common purposes of tube feeding. The percentages for these common purposes were 80.95%, 65.08%, and 55.56%, respectively.

Supplementary Table S1 (available in <https://weekly.chinacdc.cn/>) presents the decision-making style of these caregivers and the perceived importance of different parties in decision-making on tube feeding. Within the family, 55.56% of caregivers thought that

caregivers or other family members were equally important in making decisions on tube feeding for the patients. About 53.97% of caregivers thought that the provider or the family should be equal with regard to making decisions on tube feeding for the patients. Doctors' opinions (39.68%) and patients' wishes (38.10%) were the two most important parties in decision-making on tube feeding.

Supplementary Table S2 (available in <https://weekly.chinacdc.cn/>) shows caregivers' perceptions concerning patients' wishes. About 69.84% of the caregivers stated that patients did not express in writing or in a previous discussion his/her wishes regarding tube feeding. About 46.03% stated they were confident that the patient would not have wanted a feeding tube if he/she could make his/her own medical decision, and 44.44% were unsure about this.

Supplementary Table S3 (available in <https://weekly.chinacdc.cn/>) shows caregivers' views toward food. About 82.54% of caregivers stated that "the provision of food at the end of life is a family obligation", followed by "Providing food at the end of life shows that the family has not given up" (77.78%), "Providing

TABLE 1. The sample characteristics of participants.

Variable	N	Percentage (%) or mean (M)
Age	58	65.86
Female	63	88.89%
High school or higher	63	76.19%
The relationship to the relative with dementia	63	
Spouse		39.68%
Child		38.10%
Other		22.22%
Foreign-born	63	96.83%
The years in the USA for the foreign-born	59	30.58

TABLE 2. Feeding options decision-making, the goal of care, and knowledge and discussion about tube feeding in the hypothesized scenario (N=63).

Variable	Percentage (%) or mean (M)
Hypothesized feeding options decision-making	
Tube feeding	34.92%
Hand feeding	23.81%
Unsure	41.27%
Goal of care	
Prefer to relieve pain and discomfort as much as possible	93.65%
Prefer to extend life as much as possible	6.35%
Tube feeding Knowledge (range: 0–3)	0.41
Providers have discussed tube feeding with caregivers	15.87%

TABLE 3. Purpose of tube feeding (N=63).

Main reason	Percentage (%)
Prolong Life	80.95
Moral obligation	38.10
Prevent aspiration	55.56
Not to feel hungry/thirsty	65.08
Be more comfortable	14.29
Health to be better	25.40
None	6.35

food at the end of life will help strengthen family bonds” (47.62%) and “Filial piety plays a role in determining if food should be administered at the end of life” (47.62%). It is noted that 49.21% stated that they disagreed with the statement, “Finances play a role in determining if food should be administered at the end of life.”

Correlation results showed that knowledge of tube feeding in individuals with advanced dementia ( $r=0.33$ ,  $P<0.01$ ) and knowing the expressed wishes of patients about their wishes regarding tube feeding ( $r=0.25$ ,  $P<0.05$ ) were related to the selection of hand feeding. The association of these two variables with the selection of hand feeding (1=hand feeding, 0=others) was examined in a logistic regression model controlling for age, gender, and education of participants (Supplementary Table S4, available in <https://weekly.chinacdc.cn/>). The results of logistic regression indicated that knowledge was significantly associated with the selection of hand feeding ( $OR\ 5.65$ ,  $P<0.01$ ), and knowing patients' wishes was marginally associated with the selection of hand feeding ( $OR\ 4.59$ ,  $P<0.1$ ).

## DISCUSSION

This study provides new knowledge on Chinese American family caregivers' attitudes toward tube feeding their relatives with dementia. The findings from the study showed that a considerable proportion of caregivers would choose tube feeding in the hypothesized scenario. Knowledge about tube feeding and knowing patients' expressed wishes regarding tube feeding were associated with a higher likelihood of preference towards hand feeding among Chinese American dementia caregivers.

It is important to note the finding that 34.92% of caregivers would choose tube feeding, and 41.27% were unsure about which one to choose in the hypothesized scenario. Previous studies conducted in Hong Kong SAR and Taiwan, China suggested that

more than 50% of Chinese with advanced dementia in nursing homes were tube-fed (5–6). The finding that knowledge was associated with the preference for hand feeding highlights the importance of improving decision-making with regard to feeding options among dementia caregivers (7). Knowing patients' expressed wishes regarding tube feeding was associated with a higher likelihood of preference toward hand feeding, which is consistent with previous studies that having an advance directive or an informal discussion is associated with a decrease in life-sustaining treatment (8–9). However, Chinese American caregivers had poor knowledge, and few caregivers knew patients' expressed wishes regarding tube feeding. The study also suggests that the cultural values of Chinese American dementia caregivers, such as family decision-making and filial piety, may play an important role in decision-making about tube feeding (10).

The study is subject to some limitations. The participants in the study were recruited from a community agency, and the sample size was small. The generalizability of the study's findings is not warranted. Also, given the cross-sectional design, the study was not able to establish causal relationships and capture the change of attitudes toward tube feeding in Chinese American dementia caregivers.

In conclusion, the findings suggest that knowledge of tube feeding and knowing patients' expressed wishes regarding tube feeding were associated with a higher likelihood of selecting hand feeding. The findings implies that it is important to develop culturally-tailored interventions to promote knowledge on tube feeding and advance care planning engagement in Chinese American communities.

**Funding:** Supported by Rory Meyers College of Nursing (New York University), School of Social work (University of Texas at Arlington), and the National Institutes of Health (Grant P50MD017356, and P30AG059304).

doi: 10.46234/ccdcw2022.211

\* Corresponding author: Bei Wu, [bei.wu@nyu.edu](mailto:bei.wu@nyu.edu).

<sup>1</sup> Rory Meyers College of Nursing, New York University, New York, USA; <sup>2</sup> School of Social Work, University of Texas at Arlington, Arlington, USA.

Submitted: September 16, 2022; Accepted: November 14, 2022

## REFERENCES

- Davies N, Barrado-Martin Y, Vickerstaff V, Rait G, Fukui A, Candy B, et al. Enteral tube feeding for people with severe dementia. *Cochrane Database Syst Rev* 2021;8(8):CD013503. <http://dx.doi.org/10.1002/>

- 14651858.CD013503.pub2.
2. American Geriatrics Society Ethics Committee and Clinical Practice and Models of Care Committee. American Geriatrics Society feeding tubes in advanced dementia position statement. *J Am Geriatr Soc* 2014;62(8):1590 – 3. <http://dx.doi.org/10.1111/jgs.12924>.
  3. Douglas JW, Turner LW, Knol LL, Ellis AC, Godfrey AC, Lawrence JC. The attitudes toward tube-feeding in advanced dementia (ATT-FAD) questionnaire: a valid and reliable tool. *J Nutr Gerontol Geriatr* 2018;37(3 – 4):183 – 203. <http://dx.doi.org/10.1080/21551197.2018.1518797>.
  4. Chai HZ, Krishna LKR, Wong VHM. Feeding: what it means to patients and caregivers and how these views influence Singaporean Chinese caregivers' decisions to continue feeding at the end of life. *Am J Hosp Palliat Med* 2014;31(2):166 – 71. <http://dx.doi.org/10.1177/1049909113480883>.
  5. Chou HH, Tsou MT, Hwang LC. Nasogastric tube feeding versus assisted hand feeding in-home healthcare older adults with severe dementia in Taiwan: a prognosis comparison. *BMC Geriatr* 2020;20(1):60. <http://dx.doi.org/10.1186/s12877-020-1464-9>.
  6. Luk JK, Chan FH, Hui E, Tse CY. The feeding paradox in advanced dementia: a local perspective. *Hong Kong Med J* 2017;23(3):306 – 10. <http://dx.doi.org/10.12809/hkmj166110>.
  7. Hanson LC, Carey TS, Caprio AJ, Lee TJ, Ersek M, Garrett J, et al. Improving decision - making for feeding options in advanced dementia: a randomized, controlled trial. *J Am Geriatr Soc* 2011;59(11):2009 – 16. <http://dx.doi.org/10.1111/j.1532-5415.2011.03629.x>.
  8. Brinkman-Stoppelenburg A, Rietjens JAC, Van der Heide A. The effects of advance care planning on end-of-life care: a systematic review. *Palliat Med* 2014;28(8):1000 – 25. <http://dx.doi.org/10.1177/0269216314526272>.
  9. Bischoff KE, Sudore R, Miao YH, Boscardin WJ, Smith AK. Advance care planning and the quality of end - of - life care in older adults. *J Am Geriatr Soc* 2013;61(2):209 – 14. <http://dx.doi.org/10.1111/jgs.12105>.
  10. Hsiung YFY, Ferrans CE. Recognizing Chinese Americans' cultural needs in making end-of-life treatment decisions. *J Hosp Palliat Nurs* 2007;9(3):132 – 40. <http://dx.doi.org/10.1097/01.NJH.0000269993.13625.49>.

## SUPPLEMENTARY MATERIAL

SUPPLEMENTARY TABLE S1. Decision-making style and the perceived importance of different parties in decision-making on tube feeding (N=63).

Variable	Percentage (%)
With the family, who should make decisions on tube feeding	
Caregiver alone	9.52
Mostly caregiver	22.22
Mostly other family members	12.70
Caregiver or other family members equally	55.56
Who do you think should make decisions in tube feeding	
The provider alone or mostly the provider	14.29
The provider or the family equally	53.97
The family alone or mostly the family	31.74
Which party is the most important one in decision-making in tube feeding?	
Patients' wish	38.10
Doctors' opinion	39.68
Family/friend's opinion	6.35
The caregiver's judgment	15.87

SUPPLEMENTARY TABLE S2. Caregivers' perception concerning patients' wishes (N=63).

Variable	Percentage (%)
Has the patient ever expressed in writing or in a previous discussion his/her wishes regarding tube feeding?	
No	69.84
Yes	22.22
Unsure	7.94
Are you confident that the patient would have wanted a feeding tube if he/she is able to make his/her own medical decision?	
No	46.03
Yes	9.52
Unsure	44.44

SUPPLEMENTARY TABLE S3. The importance of food at the end of life (N=63).

Statement	Disagree (%)	Neither agree nor disagree (%)	Agree (%)
The provision of food at the end of life is a means of showing affection	22.58	22.58	54.84
The provision of food at the end of life is a family obligation	9.52	7.94	82.54
Providing food at the end of life will help strengthen family bonds	25.40	26.98	47.62
Providing food at the end of life will help reduce family conflict.	26.98	39.68	33.33
Providing food at the end of life shows that the family has not given up.	11.11	11.11	77.78
Filial piety plays a role in determining if food should be administered at the end of life.	30.16	20.22	47.62
Finances play a role in determining if food should be administered at the end of life.	49.21	17.46	33.33

SUPPLEMENTARY TABLE S4. The logistic regression model predicting the selection of hand feeding (N=58).

<b>Variables</b>	<b>OR (SE)</b>
Knowledge of tube feeding	5.65 (3.11)**
Knowing the expressed wishes of patients	4.59 (3.86)*
Age	1.00 (0.03)
Female	0.81 (0.93)
High school or higher	0.40 (0.33)
Pseudo R <sup>2</sup>	0.23

\*  $P < 0.1$ ;\*\*  $P < 0.01$ .