

This author's PDF version corresponds to the article as it appeared upon acceptance. Fully formatted PDF versions will be made available soon.

**Gaining insight into the awareness, needs, and preferences for resources to manage tube feeding from hospital to home: a questionnaire survey among family caregivers**

doi: 10.6133/apjcn.202502/PP.0003

Published online: February 2025

**Running title:** Tube feeding survey

Zitong Wang BS, Xuemei Li MM, Ya Ma MM, Qian You MS, Yanru Deng BS, Yiyao Zhang BS, Wen Hu MM, Lei Shi MD

Department of Clinical Nutrition, West China Hospital of Sichuan University, Chengdu, China

**Authors' email addresses and contributions:**

Zitong Wang: 304977516@qq.com

Contribution: contributed to the conception and design of the research and drafted the manuscript.

Xuemei Li: susanleechengdu@foxmail.com

Contribution: contributed to the design of the research.

Ya Ma: 1763825703@qq.com

Contribution: contributed to the interpretation of the data.

Qian You: youqian@wchscu.cn

Contribution: contributed to the interpretation of the data.

Yanru Deng: 1207531595@qq.com

Contribution: contributed to the acquisition and analysis of the data.

Yiyao Zhang: 544359788@qq.com

Contribution: contributed to the acquisition and analysis of the data.

Wen Hu: wendy\_nutrition@163.com

Contribution: contributed to the interpretation of the data.

Lei Shi: 271927115@qq.com

Contribution: contributed to the conception and design of the research.

All authors critically revised the manuscript, agree to be fully accountable for ensuring the integrity and accuracy of the work, and read and approved the final manuscript.

**Corresponding Author:** Dr Lei Shi, Department of Clinical Nutrition, West China Hospital of Sichuan University, Chengdu, China, 610041. Tel: 0086-18980603798. Email: 271927115@qq.com

## ABSTRACT

**Background and Objectives:** Globally, there is an increasing trend in the number of individuals utilizing home enteral nutrition (HEN). In China, HEN is currently at a nascent stage. We aim to investigate the current situation of home enteral tube feeding (HETF) caregivers to provide more convenient services and assistance to them in China. **Methods and Study Design:** We conducted a questionnaire survey among family caregivers of enteral tube feeding patients preparing for hospital discharge to assess their awareness, needs, and preferences for resources. **Results:** 108 family caregivers were recruited in the study. 65 caregivers were considered proficient in tube feeding knowledge, while 43 were not, resulting in a non-proficiency rate of 39.8%. Education levels ( $p < 0.001$ ), employment status ( $p = 0.029$ ), and the patients' age-adjusted Charlson Comorbidity Index (aCCI) ( $p = 0.032$ ) were the critical factors affecting the caregivers' tube feeding knowledge. The risk of non-proficiency in tube feeding knowledge was increased for those with lower education levels compared with those with higher education levels (OR=5.08, 95% CI: 1.77-14.52). The family's monthly income and expenditure ( $p = 0.030$ ) was the sole factor impacting the type of tube feeding service needs. **Conclusions:** Providing tube feeding knowledge to HETF patients and their caregivers before discharge is essential. Personalized training, especially for caregivers with lower education levels, can improve their understanding. Additionally, implementing online nutrition follow-ups and Nutrition-Nursing Joint Clinics can help address healthcare resource disparities and offer more accessible services to HETF patients in China.

**Key Words:** home enteral nutrition, tube feeding, family caregivers, tube feeding management, nutrition follow-up service

## INTRODUCTION

Globally, there is an increasing trend in the number of individuals utilizing home enteral nutrition (HEN),<sup>1,2</sup> which normally utilizes home enteral tube feeding (HETF) to help patients with normal gastrointestinal function, but who have difficulty meeting their nutritional needs orally, to come to an adequate level of nutrition.<sup>3-5</sup> In the United States, the prevalence of HEN has increased dramatically since 1992, with more than 440,000 Americans using HEN now.<sup>6</sup> Spain's HEN system is notably advanced in terms of its registration model. Reports indicate a steady rise in Spain's HEN users over the past years, with a stabilization in registration numbers observed since 2018.<sup>7,8</sup> Additionally, a continual rise in HEN user

numbers is observed in countries such as Poland and the UK.<sup>9-11</sup> However, the implementation of HEN varies significantly throughout China, with a notable lack of awareness among patients and caregivers.<sup>12</sup>

Once patients are in stable condition, they may simply require ongoing nutrition support so that they may be discharged as soon as possible. This practice not only facilitates patients' quicker return to daily life but also optimizes the utilization of hospital resources.<sup>13</sup> In this stage, family caregivers play a crucial role in HEN since newly discharged patients receiving HETF usually necessitate caregivers' assistance. Therefore, the basic knowledge and skills of HETF of family caregivers are very crucial. However, family caregivers often lack such knowledge and skills and find themselves struggling for the following nutrition support, thereby posing psychological and lifestyle challenges for both patients and caregivers.<sup>14,15</sup>

In this paper, we spent 8 months to conduct a questionnaire survey among 101 family caregivers (over 18 years) from West China Hospital of Sichuan University to assess their awareness, needs, and preferences for resources related to HETF, such as basic skills and health resources. What we want to achieve with this questionnaire is to enable the hospital to enhance pre-discharge educational initiatives and post-discharge support for patients reliant on HETF.

## **MATERIALS AND METHODS**

### ***Study design***

Through a comprehensive literature review, experiential insights, and group discussions, we developed the questionnaire draft, including the design of questions, selection of research subjects, and definition of inclusion and exclusion criteria.<sup>16-18</sup> In October 2022, 5 respondents who met the inclusion and exclusion criteria were selected by convenience sampling at West China Hospital to evaluate the clarity, comprehensibility, and usability of the questionnaire. Based on the results of the preliminary survey, we conducted discussions and made revisions to refine the questionnaire, resulting in its final version (see Appendix). This questionnaire consisted of 5 aspects of questions, including the following aspects:

(i) **Basic Knowledge and Skills about HETF:** We surveyed caregivers on their tube feeding knowledge through 9 relevant questions in the questionnaire (Table 1). For this study, participants answering 6 or more questions correctly were deemed proficient in tube feeding knowledge.

(ii) **Preferences for Access to HETF Knowledge:** When patients and their caregivers were nearing discharge to home without the help of nurses or professional care workers, they

generally wanted to gain relevant knowledge on how to care for tube feeding patients properly. So, the questionnaire provided six ways (Table 2) of acquiring the relevant knowledge, which the caregivers could prioritize according to their preferences.

(iii) Needs for HETF-Related Services: During hospitalization, patients have access to comprehensive tube feeding services, including nutrition preparations, tube feeding equipment, and timely assistance with issues (i.e., nurses are ready to help if any problems arise). We inquired caregivers about their inclination to continue these services post-discharge.

(iv) Preferences for Medical Institutions: Then, we surveyed caregivers on where they would go for medical treatment if they experienced an emergency related to tube feeding, such as constipation, diarrhea, blockage, or gastric tube prolapse.<sup>19</sup> We asked them to rank West China Hospital of Sichuan University, the nearest tertiary hospital, and the community hospital.

(v) Opinions about Online Nutrition Support: Finally, we asked caregivers for their views on the online nutrition services provided by the hospital, aiming at providing better follow-up support.

### ***Participants***

Inclusion criteria included:

- (i) Adult caregivers (over 18 years old) of patients with enteral tubes.
- (ii) Family caregivers (unpaid and informal caregivers).
- (iii) Capability to provide informed consent.
- (iv) Capability to understand the informed instructions.
- (v) Proficiency in understanding and conversing in Chinese.

Exclusion criteria included:

- (i) Professional caregivers for salary purposes.
- (ii) Illiterate or impaired in speech and communication.
- (iii) Irregular caregivers or those at risk of dropping out during the study.

Convenience sampling was adopted in the recruitment of participants. Participants included family caregivers of tube feeding patients hospitalized at West China Hospital of Sichuan University between November 2022 and June 2023. When patients were about to discharge, they were confirmed by their physicians to continue receiving enteral nutrition via tube feeding for an extended period, and their caregivers would continue to care for them at home. The Biomedical Ethics Committee approved the study (No.2019-725). We obtained informed consent from all participants.

### ***Definitions***

Age-adjusted Charlson Comorbidity Index (aCCI):<sup>20</sup> The aCCI, as defined by Charlson et al. in 1987, is a combination of the age equivalence index and the Charlson Comorbidity Index (CCI). In this study, patients with aCCI scores of 4 points and below were defined as patients with a lower risk of death, and patients with aCCI scores of above 4 were defined as patients with a higher risk of death.

Barthel index (BI):<sup>21</sup> The BI is a 10-item scale of basic activities of daily living. The BI's 10 items focus on self-care (bathing, grooming, bladder management, bowel management, dressing, feeding, and toilet use) and mobility (transfers, ascending and descending stairs, and walking). It is generally believed that a total score of 100 indicates that the patient has normal daily living abilities and does not require assistance; a score of 61 to 99 indicates that the patient is essentially able to take care of himself and is mildly dependent; a score of 41 to 60 indicates moderate dependence, and  $\leq 40$  indicates severe dependence, and the patient needs help and is obviously dependent for life.

### ***Data collection***

The researchers received unified training and conducted a face-to-face questionnaire with the caregivers before discharge. The researchers completed the questionnaires with the caregivers and returned them to data analysis researchers. The interviews were conducted in a private room in the inpatient wards to ensure privacy after obtaining the consent of the patients and caregivers. The duration of the interviews ranged from 7 to 15 min.

### ***Data analysis***

Research data were collected and analyzed using Excel and SPSS 27.0 software. Categorical variables were expressed as numbers (n) and percentages (%), and chi-square tests were used for comparisons between groups. Multiple factors were analyzed using binary logistic regression. Parametric continuous variables were expressed as mean  $\pm$  SD, and non-parametric continuous variables were expressed as median (M) and interquartile range (IQR). For all analyses,  $p < 0.05$  was considered statistically significant.

## **RESULTS**

### ***Demographic characteristics***

Among the 108 participants recruited for the study, 101 were family caregivers, and 7 were patients who managed their own care. The mean age of the patients was 58 years, and their

ages ranged from 17 to 91 years. At the time of the interview, these patients had been successfully receiving tube feeding for more than a week. The mean age of the family caregivers was 49 years, and their ages ranged from 20 to 76 years. During the interview, these caregivers have cared for the patients for more than three days, alone or with the help of nurses and professional care workers. Details of the sociodemographic of caregivers and the sociodemographic and clinical data of patients are reported in Table 3 and Table 4, respectively.

### ***Proficiency of information and preferences for acquiring tube feeding knowledge***

Ultimately, out of the 108 caregivers surveyed, 65 were considered proficient (answered 6 or more questions correctly), while 48 did not achieve proficiency, resulting in a non-proficiency rate of 44.4%. The specifics of the responses to the 9 questions are depicted in Figure 1.

The results of the ranking of the ways of acquiring tube feeding knowledge are depicted in Figure 2. Regarding the acquisition of tube feeding knowledge, ‘medical staff verbally explain matters related to tube feeding’, ‘the hospital issues graphic education manuals related to tube feeding’, ‘medical staff demonstrate operation in person’, and ‘the hospital provides tube-feeding-operation teaching videos’ were the first choices for most people, with the proportions of 31.5%, 26.9%, 18.5%, and 18.5%, respectively.

### ***Health resource needs***

#### **Needs for tube feeding services**

The final survey showed that 64.8% of caregivers needed all three services: nutrition preparations, tube feeding equipment, and timely assistance with issues. The implication was their expectation to avail themselves of analogous tube feeding services akin to those received during hospitalization. Within the remaining 35.2% cohort of caregivers, they chose one or two services, and no one said they needed none. The need for each service is shown in Figure 3.

#### **Needs for hospital**

Results showed that a majority of the caregivers, 88 (81.5%), preferred seeking treatment at West China Hospital of Sichuan University. Meanwhile, 19 (17.6%) caregivers favored the closest tertiary hospital, and only one caregiver gave priority to a community hospital.

### ***Transportation costs for medical treatment and willingness to pay for online nutrition follow-up services***

We investigated patients' distance from home to hospital, transportation costs, and travel time. The results showed that the distance ranged from 1 km to 2,000 km, and the median distance was 60 (15, 300) km; the round-trip toll ranged from 0 to 556 USD, and the median round-trip toll was 9.7 (2.8, 33.4) USD; the round-trip time ranged from 10 minutes to 72 hours, and the median round-trip time was 3 (1, 6) hours.

Subsequently, inquiries were made to determine if caregivers were interested in receiving online nutrition follow-up services and agreeable to incurring the associated costs. Of those surveyed, 80 (74.1%) indicated a preference for online nutrition follow-up services, with 83.8% of this cohort willing to bear the related expenses. The majority (83.6%) of caregivers preferred to pay for follow-up services per time, ranging from 0.4 to 13.8 USD each time, or on a registration fee basis; the remaining 16.4% were willing to pay on a monthly basis, but did not know how much they should pay.

### ***Analysis of factors influencing caregivers' tube feeding knowledge and needs for tube feeding services***

#### **Analysis of factors influencing caregivers' tube feeding knowledge**

In order to understand the factors that may influence caregivers' tube feeding knowledge, a chi-square analysis was performed. The results showed that the patient's aCCI ( $p = 0.032$ ), the caregiver's education level ( $p < 0.001$ ), and working status ( $p = 0.029$ ) had an impact on their knowledge of tube feeding. Caregivers with patient's aCCI  $\leq 4$  demonstrated greater proficiency in tube feeding knowledge (67.6%) compared to those with patients' aCCI  $> 4$  (47.5%). Caregivers with a high school education or above exhibited significantly enhanced proficiency in tube feeding knowledge (81.3%) compared to those with a junior high school education or below (43.3%). Unemployed caregivers (83.3%) were more proficient in tube feeding knowledge than those who were employed (61.8%) or retired (45.7%). Comprehensive details are presented in Table 5.

Subsequently, the aCCI of patients, caregiver's gender, age, education level, and working status were incorporated into the logistic regression model. The results showed that after adjusting the caregiver's gender and age, people with a junior high school education or below had a higher risk of lacking tube feeding knowledge compared with people with a high school education or above (OR=5.08, 95% CI: 1.77-14.52) (Table 6).

### **Analysis of factors influencing the needs for tube feeding services**

According to our survey findings, 64.8% of caregivers expressed a desire to continue receiving the same tube feeding services provided during hospitalization. In comparison, 35.2% of the caregivers indicated a need for only one or two of these services. In order to understand the factors that may affect caregivers' needs for tube feeding services, a chi-square analysis was performed. The results showed that the family's monthly income and expenditure ( $p = 0.030$ ) was the sole factor impacting the type of tube feeding services needs. Caregivers with a monthly family income exceeding their expenditure exhibited a significantly higher need for tube feeding services than those whose income was equal to or less than their expenditure. Complete details can be found in Table 7.

### **DISCUSSION**

Our survey results showed that even though caregivers have learned how to care for tube feeding patients with the help of nurses and professional care workers, their tube feeding knowledge was still not optimal, as indicated by a non-proficiency rate of 44.4%. Given their pivotal role in supporting patients with HETF, caregivers' tube feeding knowledge and care levels are critical to the patients' quality of life, nutrition maintenance, and recovery process. A study conducted in central Taiwan found that caregivers who underwent systematic nursing training demonstrated higher knowledge and skill levels compared to those who received conventional training. Additionally, care recipients in the systematic training group experienced lower incidences of constipation, diarrhea, and abdominal distension.<sup>22</sup> Similarly, another survey highlighted that elderly caregivers and those with lower education levels require greater support in managing enteral nutrition for tube feeding patients.<sup>23</sup> Therefore, it is necessary to conduct tube feeding training before discharge to ensure that caregivers can acquire tube feeding knowledge as much as possible. The emphasis and methodologies of tube feeding training hold significant importance. According to our survey, caregivers demonstrate limited awareness of managing home emergencies and appropriate time to withdraw the tube, areas that our training program could specifically address. Therefore, it is essential to assign specialized individuals like nurses or nutritionists to assess the understanding of tube feeding among key groups, particularly caregivers with lower educational backgrounds. In cases of inadequate proficiency, the provision of targeted supplementary training is recommended.

In addition, based on the preferences of caregivers in the questionnaire for accessing tube feeding knowledge, tube feeding knowledge lectures can be regularly held in the ward, with



medical staff explaining theoretical knowledge and operating demonstrations. Providing printed materials and tube-feeding-operation teaching videos also constitutes an effective method to improve the caregivers' tube feeding knowledge.

As we mentioned earlier, the family's monthly income and expenditure were the sole factor impacting the type of tube feeding service needs. Another research from southwest China showed that many Chinese families with neurological disorders complained that the enteral nutrition preparations were important but too expensive, so they had to choose the cheap homemade tube feeding mixtures.<sup>24</sup> However, long time and single feeding of homemade mixtures would lead to malnutrition with high probability, because the nutrient density of it is much lower than enteral nutrition preparations. Consequently, reimbursement of expenses like nutrition supplements and tube feeding equipment could enable more patients to access better services, mitigate the financial burden of tube feeding, and potentially increase patients' follow-up rates.<sup>24</sup> An international survey conducted in 22 European countries points out that enteral nutrition reimbursement is a critical factor in effectively combating malnutrition.<sup>25</sup>

In prioritizing medical treatment, a significant majority (81.5%) of patients and caregivers would opt for West China Hospital of Sichuan University, even if it took more time and money on the road. With the gradual increase of residents' income and the continuous improvement of the medical insurance system, Chinese people's demand for pursuing higher quality and better medical and health services has been released.<sup>26</sup> This preference largely stems from the concentration of high-quality medical resources in large hospitals that patients trust more.<sup>27</sup> Even for minor problems such as headaches that community hospitals can solve, patients may be more willing to go to large hospitals. Consequently, this indicates a demand for a more equitable allocation of medical resources, favoring smaller institutions like community hospitals. Such redistribution would enable larger hospitals to focus on complex and severe conditions, while smaller hospitals can be more accessible and efficient.<sup>28</sup>

In the short term, narrowing the disparity between large and small hospitals and achieving a more equitable distribution of medical resources may seem unattainable. Consequently, we suggest two approaches to address the healthcare resource imbalance for HETF patients in China.

Online nutrition follow-up services: In comparison to European and American countries, the registration and follow-up of HEN in China need to be more developed. Our survey also revealed that a majority of patients and caregivers express a desire for nutrition follow-up services, though access to these services remains constrained. Online modalities for nutrition follow-up services could represent a viable alternative. Research indicates that the utilization

of online clinics is associated with increased follow-up engagement in HEN patients,<sup>24</sup> thereby potentially enhancing the efficacy of HEN.

The type of tube feeding services needs of patients and caregivers were related to their family income. Online nutrition follow-up after discharge is a way to save time and money.<sup>24</sup> Diverse modalities of nutrition follow-up services could be provided, allowing patients to select based on their family's economic situation.

·Nutrition-Nursing Joint Clinics: HETF necessitates extensive daily care. In the US and UK, national guidelines mandate comprehensive training for HETF patients, along with 24-hour emergency telephone support.<sup>2,29</sup> These pose a significant challenge for nutritionists. Currently, the number of nutritionists in China's tertiary medical institutions is insufficient.<sup>30</sup> And for tube nursing, nutritionists are not as proficient as nurses. Consequently, we plan to conduct a Nutrition-Nursing Joint Clinic with nurses to deal with emergencies that occur in the daily lives of HETF patients as well as their daily care. Upon maturation of this work, training for nurses and nutritionists in primary healthcare settings will commence, aiming to expand the reach of the Nutrition-Nursing Joint Clinic, thereby enhancing accessibility for HETF patients.

In 2013, West China Hospital of Sichuan University initiated the H2H (Hospital to Home) database, registering numerous HEN users, yet the adoption of this database has yet to be widespread at a national level. In the future, more medical institutions in China need to develop a unified and standardized HEN database collaboratively. Concurrently, offering HEN patients a broader array of convenient nutrition follow-up options will significantly aid their recovery.<sup>31</sup>

Our study has several limitations. This study has certain limitations. Firstly, the patients and caregivers surveyed were all from a single hospital, primarily representing the southwest region. This limits the generalizability of the findings to a national scale and may introduce regional bias. Expanding the survey to include participants from across the country in future studies would help address this limitation. Secondly, the survey was conducted exclusively in a hospital setting, excluding caregivers from communities and rehabilitation institutions. Since caregivers in different settings may have distinct needs, future research should consider including these populations to provide a more comprehensive understanding.

### ***Conclusion***

This single-centre survey of patients and their caregivers who were being discharged from the hospital and continuing to receive tube feeding showed that education level, employment

status, and the patient's aCCI were critical factors influencing caregivers' tube feeding knowledge. Additionally, the family's monthly income and expenditure emerged as a significant factor affecting the type of tube feeding services needs. It is necessary to impart tube feeding knowledge to HETF patients and their caregivers prior to discharge. Tailored training on HETF, particularly personalized instruction for caregivers with lower education, is recommended to enhance their understanding of the process. In addition, online nutrition follow-up services and Nutrition-Nursing Joint Clinics can be developed to reduce the inequality of healthcare resource distribution among HETF patients and provide convenient services and assistance to more HETF patients.

### **CONFLICT OF INTEREST AND FUNDING DISCLOSURE**

There is no conflict of interest regarding the publication of this study.

Funding was provided by the Clinical research incubation project of West China Hospital, Sichuan University, China (grant number 21HXFH006). The funding body had no role in the design, analysis or writing of this study.

### **REFERENCES**

1. Mazur CE, Zago RCC, Schieferdecker MEM, Maluf E. Home enteral nutrition: clinical-nutritional analysis and outcomes of 10 years of public policy. *Nutricion hospitalaria*. 2019;36(4):758-63. DOI:10.20960/nh.02606
2. Ojo O. The challenges of home enteral tube feeding: a global perspective. *Nutrients*. 2015;7(4):2524-38. DOI:10.3390/nu7042524
3. National Institute for Health and Care Excellence: Guidelines. Nutrition support for adults: oral nutrition support, enteral tube feeding and parenteral nutrition. London: National Institute for Health and Care Excellence (NICE)  
Copyright © NICE 2019.; 2017.
4. Rowat A. Enteral tube feeding for dysphagic stroke patients. *British journal of nursing* (Mark Allen Publishing). 2015;24(3):138, 40, 42-5. DOI:10.12968/bjon.2015.24.3.138
5. Lim ML, Yong BYP, Mar MQM, Ang SY, Chan MM, Lam M, et al. Caring for patients on home enteral nutrition: Reported complications by home carers and perspectives of community nurses. *Journal of clinical nursing*. 2018;27(13-14):2825-35. DOI:10.1111/jocn.14347
6. Mundi MS, Mohamed Elfadil O, Olson DA, Pattinson AK, Epp LM, Miller LD, et al. Home enteral nutrition: A descriptive study. *JPEN Journal of parenteral and enteral nutrition*. 2023;47(4):550-62. DOI:10.1002/jpen.2498

7. Wanden-Berghe C, Campos Martín C, Álvarez Hernández J, Burgos Peláez R, Matía Martín P, de la Cuerda Compés C, et al. [The NADYA-SENPE Home Enteral Nutrition Registry in Spain: years 2018 and 2019]. *Nutricion hospitalaria*. 2022;39(1):223-9.DOI:10.20960/nh.03663
8. Wanden-Berghe Lozano C, Campos C, Burgos Peláez R, Álvarez J, Frias Soriano L, Matia Martín MP, et al. [Spanish home enteral nutrition registry of the year 2016 and 2017 from the NADYA-SENPE Group]. *Nutricion hospitalaria*. 2019;36(1):233-7.DOI:10.20960/nh.02365
9. Folwarski M, Kłęk S, Zoubek-Wójcik A, Szafranski W, Bartoszewska L, Figura K, et al. Home Enteral Nutrition in Adults-Nationwide Multicenter Survey. *Nutrients*. 2020;12(7).DOI:10.3390/nu12072087
10. Hubbard GP, Andrews S, White S, Simpson G, Topen S, Carnie L, et al. A survey of bolus tube feeding prevalence and practice in adult patients requiring home enteral tube feeding. *The British journal of nutrition*. 2019;122(11):1271-8.DOI:10.1017/s000711451900223x
11. Klek S, Hermanowicz A, Dziwiszek G, Matysiak K, Szczepanek K, Szybinski P, et al. Home enteral nutrition reduces complications, length of stay, and health care costs: results from a multicenter study. *The American journal of clinical nutrition*. 2014;100(2):609-15.DOI:10.3945/ajcn.113.082842
12. You Q, Li X, Ma Y, Shi L, Hu W. A retrospective analysis on epidemiological characteristics of home enteral nutrition: results from a Chinese tertiary hospital in 2018. *European journal of clinical nutrition*. 2021;75(3):473-9.DOI:10.1038/s41430-020-00755-8
13. Lloyd DA, Powell-Tuck J. Artificial nutrition: principles and practice of enteral feeding. *Clinics in colon and rectal surgery*. 2004;17(2):107-18.DOI:10.1055/s-2004-828657
14. Gea Cabrera A, Sanz-Lorente M, Sanz-Valero J, López-Pintor E. Compliance and Adherence to Enteral Nutrition Treatment in Adults: A Systematic Review. *Nutrients*. 2019;11(11).DOI:10.3390/nu11112627
15. Pars H, Soyer T. Home Gastrostomy Feeding Education Program: Effects on the Caregiving Burden, Knowledge, and Anxiety Level of Mothers. *JPEN Journal of parenteral and enteral nutrition*. 2020;44(6):1029-37.DOI:10.1002/jpen.1747
16. Green SM, Townsend K, Jarrett N, Westoby C, Fader M. People with enteral tubes and their carers' views of living with a tube and managing associated problems: A qualitative interview study. *Journal of clinical nursing*. 2019;28(19-20):3710-20.DOI:10.1111/jocn.14972
17. Mooi NM, Ncama BP. Perceived needs of patients and family caregivers regarding home-based enteral nutritional therapy in South Africa: A qualitative study. *PloS one*. 2020;15(2):e0228924.DOI:10.1371/journal.pone.0228924
18. Ang SY, Lim ML, Ng XP, Lam M, Chan MM, Lopez V, et al. Patients and home carers' experience and perceptions of different modalities of enteral feeding. *Journal of clinical nursing*. 2019;28(17-18):3149-57.DOI:10.1111/jocn.14863
19. Amaratunga H, Bostock K, Cunich M, Steffens D, Carey S. Systematic review of service improvements for home enteral tube feeding in adults. *Nutrition in clinical practice : official publication of the American Society for Parenteral and Enteral Nutrition*. 2023;38(2):329-39.DOI:10.1002/ncp.10900

20. Lin JX, Huang YQ, Xie JW, Wang JB, Lu J, Chen QY, et al. Age-adjusted Charlson Comorbidity Index (ACCI) is a significant factor for predicting survival after radical gastrectomy in patients with gastric cancer. *BMC surgery*. 2019;19(1):53.DOI:10.1186/s12893-019-0513-9
21. Liu F, Tsang RC, Zhou J, Zhou M, Zha F, Long J, et al. Relationship of Barthel Index and its Short Form with the Modified Rankin Scale in acute stroke patients. *Journal of stroke and cerebrovascular diseases : the official journal of National Stroke Association*. 2020;29(9):105033.DOI:10.1016/j.jstrokecerebrovasdis.2020.105033
22. Chang SC, Huang CY, Lin CH, Tu SL, Chao MS, Chen MH. The effects of systematic educational interventions about nasogastric tube feeding on caregivers' knowledge and skills and the incidence of feeding complications. *Journal of clinical nursing*. 2015;24(11-12):1567-75.DOI:10.1111/jocn.12748
23. Kahveci G, Akin S. Knowledge Levels and Practices About the Enteral Nutritional Practices of Informal Caregivers Caring for Patients Fed Through a Percutaneous Endoscopic Gastrostomy Tube: A Descriptive Observational Study. *Gastroenterology nursing : the official journal of the Society of Gastroenterology Nurses and Associates*. 2021;44(5):E80-e90.DOI:10.1097/sga.0000000000000623
24. Ma Y, Li XM, Tan L, You Q, Shi L, Hu W. Epidemiological characteristics of home enteral nutrition in patients from a Chinese tertiary hospital in 2021: A cross-sectional study. *Asia Pacific journal of clinical nutrition*. 2022;31(3):496-503.DOI:10.6133/apjcn.202209\_31(3).0016
25. Klek S, Chourdakis M, Bischoff S, Dubrov S, Forbes A, Galas A, et al. Economy matters to fight against malnutrition: Results from a multicenter survey. *Clinical nutrition (Edinburgh, Scotland)*. 2017;36(1):162-9.DOI:10.1016/j.clnu.2015.10.010
26. Shi B, Fu Y, Bai X, Zhang X, Zheng J, Wang Y, et al. Spatial Pattern and Spatial Heterogeneity of Chinese Elite Hospitals: A Country-Level Analysis. *Frontiers in public health*. 2021;9:710810.DOI:10.3389/fpubh.2021.710810
27. Wu Y, Gu H, Tang L, Liu Y. Analysis on the change of medical treatment choice and influencing factors of Sichuan residents before and after the implementation of hierarchical diagnosis and treatment system. *Modern Preventive Medicine*. 2023;50(22):4130-5.DOI:10.20043/j.cnki.MPM.202302396
28. Yuan L, Cao J, Wang D, Yu D, Liu G, Qian Z. Regional disparities and influencing factors of high quality medical resources distribution in China. *International journal for equity in health*. 2023;22(1):8.DOI:10.1186/s12939-023-01825-6
29. Carter-Stephens R. Improving the experience of patients who receive home enteral tube feeding. *British journal of community nursing*. 2020;25(4):178-83.DOI:10.12968/bjcn.2020.25.4.178
30. Wang L, Qi Y, Ma X, Liu W, Ma F, Ma X, et al. A survey of Nutrition Professionals in Tertiary Medical Institutions in China. *Chinese Health Quality Management*. 2022;29(08):41-5.DOI:10.13912/j.cnki.chqm.2022.29.08.10
31. Madrid-Paredes A, Leyva-Martínez S, Ávila-Rubio V, Molina-Soria JB, Sorribes-Carrera P, Yeste-Doblas C, et al. Impact of nutritional and educational support on home enteral nutrition. *Journal of health, population, and nutrition*. 2023;42(1):45.DOI:10.1186/s41043-023-00384-4.

**Table 1.** Nine relevant questions about tube feeding in the questionnaire

Q1: What kind of food should be fed through the tube?
Q2: How much food should be fed?
Q3: When should be fed?
Q4: How many times a day should be fed?
Q5: How to prepare these foods?
Q6: How to feed these foods?
Q7: What care else should be done for the tube?
Q8: What should be done if there is a problem during tube feeding, such as constipation, diarrhea, and blockage?
Q9: When can the patient have the tube removed?

**Table 2.** Six ways to obtain tube feeding knowledge in the questionnaire

Would you like to obtain information on your own?
Would you like to obtain information by communicating with other patients and caregivers?
Would you like to obtain information by watching tube feeding videos provided by the hospital?
Would you like to obtain information through face-to-face demonstration by medical staff?
Would you like to learn tube feeding knowledge by studying the graphic manual provided by the hospital?
Would you like to acquire tube feeding knowledge through oral education from medical staff?

**Table 3.** Details of the sociodemographic of caregivers

Demographics	n	%
Gender		
Male	30	27.8
Female	78	72.2
Age		
≤ 40 years	26	24.1
41 - 50 years	25	23.1
51 - 60 years	41	38.0
> 60 years	16	14.8
Relationship with patients		
Oneself	7	6.5
Husband or wife	59	54.6
Children	33	30.6
Other relationships	9	8.3
The number of co-caregivers		
0	44	40.7
1	35	32.4
≥2	29	26.9
Education level		
Junior high school or below	60	55.6
High school or above	48	44.4
Employment status		
Employed	55	50.9
Unemployed	18	16.7
Retired	35	32.4
Time spent caring for patients daily		
<4 h	11	10.9
4 - 8 h	13	12.9
8 - 12 h	10	0.10
>12 h	67	66.2

Values were shown as means±SD.

**Table 4.** Details of the sociodemographic and clinical data of patients

Demographics	n	%
Gender		
Male	81	75.0
Female	27	25.0
Age		
≤ 40 years	10	9.2
41 - 50 years	14	13.0
51 - 60 years	38	35.2
61 - 70 years	27	25.0
> 70 years	19	17.6
Disease that caused tube feeding		
Cancer	63	58.3
Digestive system disease	23	21.3
Nervous system disease	15	13.9
Other diseases	7	6.5
Type of the tube		
Gastric tube	81	75.0
Jejunal tube	27	25.0
BI of patients		
≤ 40	25	23.2
41 - 60	12	11.1
> 60	71	65.7
ACCI of patients		
≤ 4	68	63.0
> 4	40	37.0
Monthly income of the family		
Income > expenditure	31	28.7
Income = expenditure	43	39.8
Income < expenditure	34	31.5

ACCI, age-adjusted Charlson Comorbidity Index; BI, Barthel index.

**Table 5.** Single factor Chi-square test for caregivers' tube feeding knowledge

Variables	Experienced caregivers	Inexperienced caregivers	Total	$\chi^2$	<i>p</i>
Gender of patients				0.322	0.364
Male	50	31	81		
Female	15	12	27		
Age of patients				1.909	0.767
≤ 40 years	6	4	10		
41 - 50 years	9	5	14		
51 - 60 years	25	13	38		
61 - 70 years	16	11	27		
> 70 years	9	10	19		
Disease that caused tube feeding				4.892	0.177
Cancer	42	21	63		
Digestive system disease	10	13	23		
Nervous system disease	10	5	15		
Other diseases	3	4	7		
Type of the tube				0.322	0.364
Gastric tube	50	31	81		
Jejunal tube	15	12	27		
BI of patients				1.964	0.398
≤ 40	16	9	25		
41 - 60	5	7	12		
> 60	44	27	71		
ACCI of patients				4.266	0.032*
≤ 4	46	22	68		
> 4	19	21	40		
Monthly income of the family				0.044	1.000
Income > expenditure	19	12	31		
Income = expenditure	26	17	43		
Income < expenditure	20	14	34		
Gender of caregivers				0.172	0.425
Male	19	11	30		
Female	46	32	78		
Age of caregivers				5.553	0.138
≤ 40 years	20	6	26		
41 - 50 years	13	12	25		
51 - 60 years	25	16	41		
> 60 years	7	9	16		
Relationship with patients				2.026	0.574
Husband or wife	34	25	59		
Children	22	11	33		
Other relationships	4	5	9		
Oneself	5	2	7		
Education level of caregivers				15.999	<0.001**
Junior high school or below	26	34	60		
High school or above	39	9	48		
Employment status of caregivers				7.145	0.029*
Employed	34	21	55		
Unemployed	15	3	18		
Retired	16	19	35		
Time spent caring for patients daily				0.848	0.846
< 4 hours	7	4	11		
4 - 8 hours	7	6	13		
8 - 12 hours	5	5	10		
> 12 hours	41	26	67		
Co-caregiver				3.122	0.213
0	28	16	44		
1	17	18	35		
≥2	20	9	29		

ACCI, age-adjusted Charlson Comorbidity Index; BI, Barthel index

\*  $p < 0.05$ , \*\*  $p < 0.01$ .



**Table 6.** Logistic regression analysis of factors influencing caregivers' tube feeding knowledge

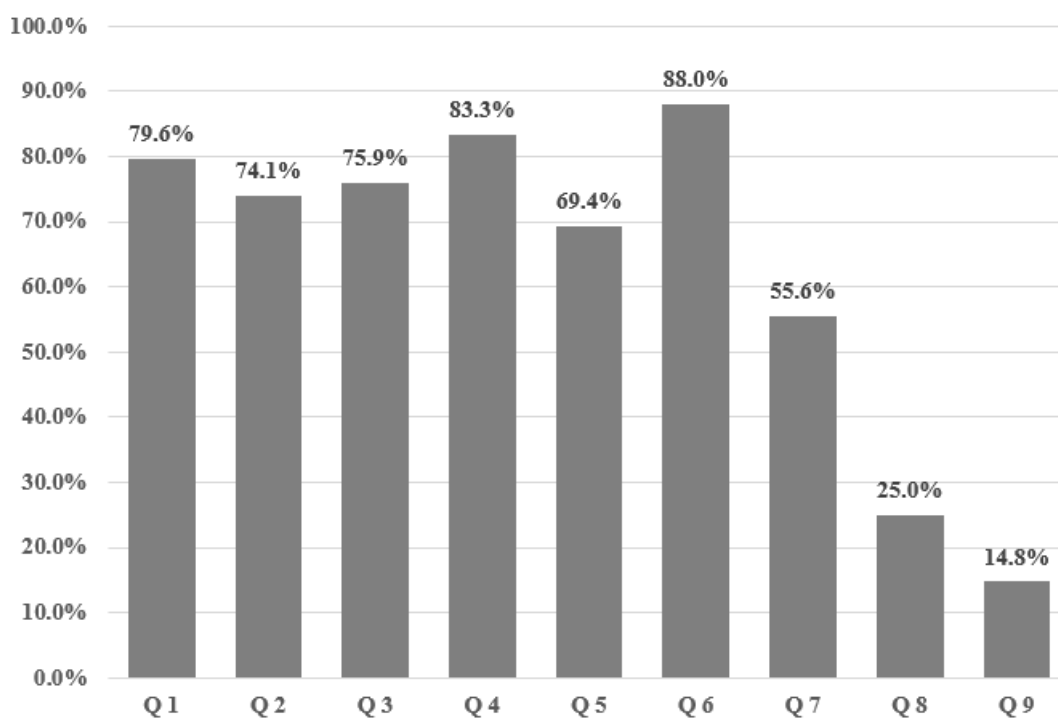
Variables	OR (95% CI)	p
Education level of caregivers		0.003*
High school or above	1	
Junior high school or below	5.08 (1.77-14.56)	

\*  $p < 0.05$ .**Table 7.** Single factor Chi-square test for demands for tube feeding services

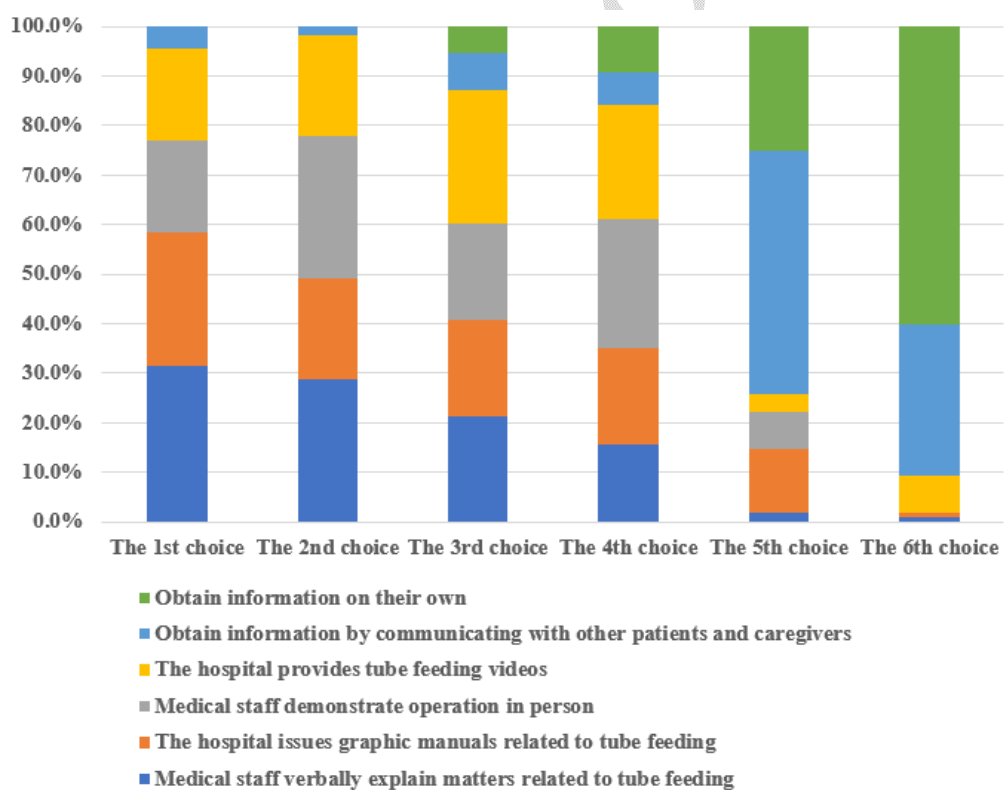
Variables	Caregivers chose all the services	Caregivers chose 1 or 2 services	Total	$\chi^2$	p
Gender of patients				1.353	0.245
Male	50	31	81		
Female	15	12	27		
Age of patients				3.592	0.476
$\leq 40$ years	4	6	10		
41 - 50 years	10	4	14		
51 - 60 years	27	11	38		
61 - 70 years	17	10	27		
$> 70$ years	12	7	19		
Disease that caused tube feeding				1.581	0.677
Cancer	43	20	63		
Digestive system disease	15	8	23		
Nervous system disease	8	7	15		
Other diseases	4	3	7		
Type of the tube				0.487	0.485
Gastric tube	51	30	81		
Jejunal tube	19	8	27		
BI of patients				1.326	0.515
$\leq 40$	17	8	25		
41 - 60	6	6	12		
$> 60$	47	24	71		
ACCI of patients				0.646	0.422
$\leq 4$	46	22	68		
$> 4$	24	16	40		
Monthly income of the family				6.999	0.030*
Income $>$ expenditure	26	5	31		
Income = expenditure	24	19	43		
Income $<$ expenditure	20	14	34		
Gender of caregivers				2.559	0.083
Male	23	7	30		
Female	47	31	78		
Age of caregivers				1.987	0.598
$\leq 40$ years	18	8	26		
41 - 50 years	16	9	25		
51 - 60 years	28	13	41		
$> 60$ years	8	8	16		
Education level of caregivers				1.372	0.166
Junior high school or below	34	14	48		
High school or above	36	24	50		
Employment status of caregivers				5.603	0.066
Employed	37	18	55		
Unemployed	15	3	18		
Retired	18	17	35		

ACCI, age-adjusted Charlson Comorbidity Index; BI, Barthel index

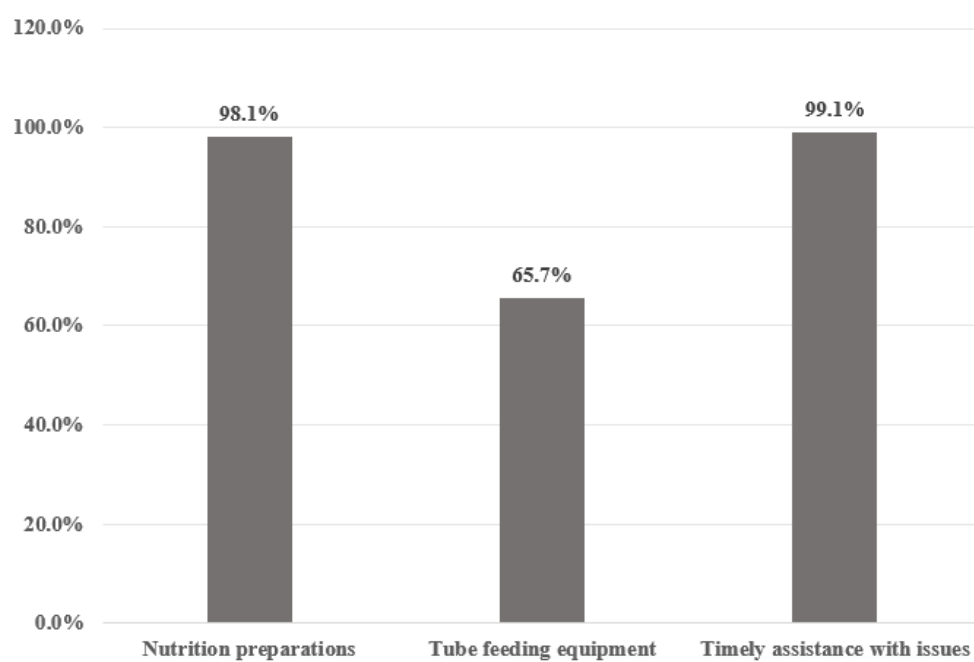
\*  $p < 0.05$ , \*\*  $p < 0.01$ .



**Figure 1.** Percentages of caregivers' correct responses to 9 questions about tube feeding. X-axis: 9 questions in the questionnaire; Y-axis: the correct rate of answering questions



**Figure 2.** Caregivers' preferences for obtaining tube feeding knowledge. X-axis: caregivers' preference ranking of six ways; Y-axis: the percentage of each way chosen in different preference rankings



**Figure 3.** Caregivers' needs for each service. X-axis: three services for caregivers; Y-axis: the percentage of each service caregivers chose