

The experience of family caregivers of patients receiving home nasogastric tube feeding in China: A descriptive qualitative study

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Abstract

Background: The value of caregivers with respect to ensuring safety during home nasogastric tube (NGT) feeding is increasingly acknowledged. However, little attention has been given to the experience of caregivers.

Methods: A qualitative descriptive design using semi-structured interviews via purposive sampling at a comprehensive hospital in China was employed. Family caregivers of patients with home NGT feeding were recruited. Interviews were recorded, transcribed verbatim and analysed qualitatively using inductive content analysis.

Results: Thirteen family caregivers of patients with home NGT feeding were interviewed. Four main themes were generated: negative experience (uncertainty and ambivalence, transition gaps between hospitals and home care services), new role: adapting to the lifestyle (participating in decision-making, being responsible for everything, adjusting own life to NGT feeding), perceived benefit of caregiving (personal growth, development of positive attitudes and achievements) and expectations (expectations from continuity health system services, expectations from social support).

Conclusions: The present study highlights the vulnerability and perceived benefits embedded in the role of a family caregiver. Improving communication and standardising practices between home and hospitals should be considered.

KEY WORDS

family caregivers, home nutritional support, nasogastric tube, qualitative research

INTRODUCTION

Home enteral tube feeding (HETF), a life-sustaining therapy, is commonly used as a treatment modality for patients with dysphagia.¹ With a shift in focus of providing care from acute to community care settings during recent decades, the number of people receiving HETF has increased globally over recent years.² Percutaneous endoscopic gastrostomy (PEG) and nasogastric tubes (NGTs) are commonly placed for nutritional support as reported in the literature.³ Although PEG was associated with improvements in long-term nutritional requirements, increased motivation to return to eating orally was reported in NGTs.⁴ The clinical guidelines suggest that NGT feeding is recommended for 4–6 weeks and PEG is truly suited to

patients who require long-term nutritional requirements.⁵ However, consensus guidance for selection criteria is not universally applied and there is variability in the uptake of this practice.⁶ Most patients in Asian countries, such as in Malaysia⁷ and Singapore,⁸ were put on NGT for long-term HETF compared to those in Western countries, although the literature has shown more complications with the use of NGT.⁹ In Taiwan, 84%–93% of patients who needed home enteral feeding were fed via NGT, which was used for 1 year or more.¹⁰ The high acceptability of NGT in Asia might be related to cultural and religious backgrounds.⁹ Family members were reluctant for patients to undergo further surgical procedures in addition to current disabilities and diseases. The importance of ‘keeping your body intact’ was another reason to use NGT feeding.⁸

Although HETF has been described as a lifeline,¹¹ it also means transferring responsibilities and risks from the hospital to the home. Studies found that actively engaging family caregivers is important in nutritional care to achieve positive outcomes.¹² Patients have a limited ability for self-management and can receive therapy at home only if caregivers can guarantee the safety and efficacy of HETF.¹³ However, caregivers have described the new lifestyle as a struggle and the hazards of caregiving can convert them into hidden patients.¹⁴ Culture crucially influences the use of support or resources, the motives of caregivers and the coping strategies used in caregiving.¹⁵ In China, as a result of the predominant cultures of Confucianism and collectivism, individuals are perceived to be obligated to take care of family members and are strongly advised to make sacrifices for the sake of family harmony and demands. Yeung *et al.*¹⁶ indicated that Chinese American caregivers pay special attention to ‘filial piety’ originating from Confucian philosophy, which integrates ‘responsibility’ with caregiving from family members. Although it is praised in China, there is no government or community social service assistance, which leads to a greater burden on caregivers.^{17,18}

Health policy-makers’ attention is increasingly directed toward the social challenges of caregiver burden and burnout.¹⁹ It is essential for home medical care to include caregiver perspectives and needs as a standard component of its assessment and plan.²⁰ Studies have mostly explored the caring experience of PEG and found that it is more convenient than NGT for caregivers.^{6,21,22} Despite reporting challenges of managing NGT, there is limited understanding of the experience of family caregivers who manage and live with patients with NGT in developing countries, such as China.²³ Understanding the experience of family caregivers is important for knowing how best to support and work with them in the context of home medical care. Therefore, the present study aimed to gain an understanding of the experience of family caregivers, caring for patients with NGT, in China.

METHODS

Design

A qualitative descriptive study design was conducted to allow participants to voice their opinions and share their experiences through in-depth interviews.

Participants

A purposive sample of participants were recruited from October 2019 to July 2020 from a tertiary comprehensive hospital in Jinan City, Shandong Province, China. The family caregivers were chosen based on gender, age, level of education, relative relationship and duration of caring, providing a diverse sample of experiences for analysis. The inclusion criteria were: (i) being the main caregiver of patients who needed HETF and who were fed via NGT; (b) aged 18 years or over;

(iii) caregivers with a family relationship with care recipient (such as spouse, adult children, siblings, or relatives); and (iv) understanding of and fluency in Mandarin. Family caregivers with cognitive impairment or those who were unable to give written consent were excluded. Inclusion of participants continued until new interviews no longer provided additional information, which was understood as a sign of saturation.

Data collection

Face-to-face, semi-structured interviews were conducted by the primary researchers and were audio-recorded. The time and location of interviews were arranged in accordance with the convenience of participants. The interview guideline originating from the review of literature and the researchers’ clinical experience within the field was adjusted by conducting pre-interviews with two participants. After group discussion, the interview guide included open-ended questions (see Supporting information, Table S1). Before conducting the interviews, participants were explained the aim of the study and their written informed consent was obtained. Both interviewers were registered nurses who were trained in qualitative interview techniques. Field notes were taken, and clarification was sought from the participants during the interview whenever speech was difficult to understand. No repeat interviews were undertaken in this study. The interview was complete when the participant had nothing further to add. The duration of the interviews ranged from 26 to 75 min. Privacy was assured at all interview venues, hence enabling the participants to talk freely about their caregiving experience without any disruption or concern.

Data analysis

The interviews were transcribed verbatim into transcripts by researchers and then anonymised. These were analysed using inductive content analysis approach.²⁴ The first step was to gain familiarity with the data by repeatedly reviewing the transcripts, which required the researchers to practice complete immersion in the data. Subsequently, meaningful word patterns and recurring concepts were extracted through thorough discussion with the team. Following the initial coding, themes were developed using a process of constant comparison, applying the emerging codes and themes to the entire data set until data saturation was achieved. The researchers consulted with one another to address any ambiguities or disagreement on methodological issues or data analysis. The final set of themes and subthemes was agreed upon by all of the investigators.

Rigor

The interview transcripts were checked and coded by two researchers, and the second researcher validated the analysis. The fact that the researchers who analysed the data did not have any previous contact with the patients and family caregivers

minimised a potential bias from previous observations, conclusions or prejudices. Concurrently, memos were written about thoughts, ideas and reflections, helping the researcher to focus on and understand the phenomenon during data analysis. The themes extracted from the collected data were repeated to the participants via telephone. Substantial descriptions and direct quotes from the interviews were also provided.

RESULTS

In total, 13 family caregivers completed the interviews (15 were approached; two declined with reasons of no time or no interest). Four were interviewed alone, whereas nine family caregivers were interviewed in the presence of patients because they had to care for them. The participant characteristics are provided in Table 1. Participants were aged between 29–67 years (male = 51.1). Table 2 shows the four themes and nine subthemes that emerged.

Negative experience

Uncertainty and ambivalence

Uncertainty and ambivalence were two feelings mentioned by most caregivers, which is related to the importance of tube feeding for patient survival and to the ever-changing and complex situations to which they were exposed as caregivers. The feeding tube was considered to be an advantage

because it ensured that adequate nutrition was provided. However, they described the challenges of managing and living with an NGT, which exhausted all their time and energy. Moreover, they expressed great appreciation for the fact that the use of NGT relieved patients of the pressure of painful or difficult oral eating. They also described that they were not confident taking care of patients:

It is a good choice for us that she can stay at home, but I'm worried I can't handle the problems we face when taking care of our loved ones. There may be a lot more that can happen and ... and ... it's too much and so overwhelming. I think I will really panic

(C6)

I am deeply convinced that the tube can make him stronger and speed up his recovery time [...] I'm really afraid, afraid ... I don't know how to care for the tube and what's going to happen in the future

(C7)

We don't know anything about how long this tube is going to last, and when we can feed him (the patient) through his mouth

(C9)

Transition gaps between hospitals and home care services

Most participants mentioned that they learned some skills with respect to taking care of patients. However, over half the participants felt they were left to deal with issues with little or no support and expressed that they did not know who to contact for help with tube management. Some participants noted that information and tube-related education on the management of NGT was inconsistent across hospitals:

One hospital told us to replace the tube every 2 months, now another hospital suggests changing it every month. I don't know what to do ... I'm afraid I always did the wrong thing

(C13)

New role: Adapting to the lifestyle

Participation in decision-making

Caregivers were not familiar with the different modalities of enteral feeding. When faced with a choice they were often caught in a dilemma. Some participants expressed that they weigh up the benefits and concerns, and then choose NGT, because the perceived positive outcomes far outweigh the potential negative consequences:

TABLE 1 Description of the participants

Participant characteristic	Number of participants
Age (years)	
> 20 to ≤30	2
> 30 to ≤40	1
> 40 to ≤50	2
> 50 to ≤60	5
> 60 to ≤70	3
Mean (SD) age	51.1 (12.7)
Gender	
Male	6
Female	7
Length of time with the tube (months)	
≥ 1 to < 6	6
≥ 6 to < 12	5
≥ 12 to < 18	1
≥ 18 to < 24	1
Mean (SD) time	7.1 (5.0)
Relationship	
Spouse	6
Parents	3
Adult children	3
Siblings	1

TABLE 2 Themes and subthemes from semi-structured interviews

Themes	Subthemes
Negative experience	Uncertainty and ambivalence Transition gaps between hospital and home care services
New role: adapting to the lifestyle	Participation in the decision-making Being responsible for everything Adjusting own life to NGT feeding
Perceived benefit of caregiving	Personal growth Development of a sense of positive attitudes and achievements
Expectations	Expectations from continuity health system services Expectations from social support

Abbreviations: NGT, nasogastric tube.

For my wife, the process of inserting the tube (NGT) was very uncomfortable, as she experienced nausea [...] I was worried ... as changing the tube was not as smooth as expected. If there were other methods (PEG or other route) for nutritional support, I would choose them ...

(C10)

Another participant reported being distressed when they were involved in decision-making:

I've thought a lot about this. Did I do the right thing or not? I understood that we were asked to consent, and I am very distressed and confused about what I should do

(C1)

Being responsible for everything

Participants reported that the commitment is closely related to traditional cultural values. Some participants spoke about how caring for their loved one meant making sacrifices, which was seen as something that was done without question. They had to take great responsibility to make daily life workable as a result of the patient's decreased ability to handle tube feeding:

When you look at her and you see her so helpless, so dependent ... After so many years of marriage, well, you feel this affection, so you will get on with it ... Despite the greatest or overwhelming difficulties, we chose to endure and never thought of giving up

(C11)

Like we all know, when we were young, we saw our parents taking care of their sick parents and it is just like a natural thing you just saw all the time. He is my father. I must take good care of him. No matter how, I will try my best to do

(C2)

Some participants emphasised caregiving as an obligation and strongly expressed the commitment and sense of obligation of caregivers:

We must help each other when there is adversity. I can't leave my sick spouse or pass her on to anyone else. It's unacceptable. I am her husband. This is my obligation to take care of her

(C6)

Adjusting own life to NGT feeding

Several participants described that they experienced shifts in daily routines and struggled to adjust to the new life situation. They gradually integrated tube feeding into their lifestyle and viewed caregiving as a normal part of life:

In the beginning, the situation was experienced as chaotic, but as time went by, things settled down. Now, I'm used to it, that it is OK. Without having feelings about it

(C12)

Anyway, we do the same thing every day, you know, everything has its own tactics and once you get used to it, it becomes nothing

(C5)

Perceived benefits of caregiving

Personal growth

Most participants mentioned that they not only acquired knowledge and skills, but also raised healthy awareness and action through caring. They described having grown intrinsically as a result of their role including increased patience and self-awareness:

I had learned online and read lots of books about nutrition, and I recognised the importance

of feeding appropriately (Evidence-based nutrition and dietary guidance, such as disease-specific enteral formula) since he had an NGT. Now I often use nutritional supplements (e.g., nutrition powder)

(C1)

I supervised my mother's nutrition and exercise; also, for myself and other family members, now health is the most important thing in our life, and we give priority to health

(C7)

I am more careful than before; I often check the tube. I used to be careless, but after she fell sick, I care about everything, I am careful. I'm afraid of making mistakes (e.g., blockage)

(C6)

Other participants emphasised that they acknowledged the importance of self-management abilities, but they usually ignored their own health issues:

We were aware of the importance of having knowledge about how to eat, how to exercise, and how to keep healthy. But now everything goes on as before. It doesn't alter anything

(C5)

Development of positive attitudes and achievements

Some participants stated that they began to look on the bright side and cherish the things that they do have. Meanwhile, they also referred to a growing dependency strengthening their relationship and bringing greater emotional closeness. The sense of achievement went beyond simply carrying out caregiving duties, to a feeling that they had achieved something they did not think they were capable of. This held a significant amount of social value for caregivers:

Nothing can alter the fact that she relies on tube feeding. You have the option to live a life happily or sadly. So why not stay with your loved ones and live a happy life

(C8)

He sits by himself watching television when I cook alone in the kitchen, we have each other, and we live together. I treasure what I have

(C11)

Caregiving includes experiencing a sense of pride in carrying out care-related activities. Participants found a new sense of purpose in the caring role:

You really have a sense of accomplishment when you see that everything is going well. My relatives and neighbours respect me, and they think what I am doing is great

(C6).

The biggest goal of my life now is taking good care of her

(C8)

Expectations

Expectations from continuity health system services

Additional practice and time were needed for caregivers to be competent in caregiving. Participants described support, including follow-up contacts, and emotional and practical support from the health system, as being very limited. Others described a chaotic and uncoordinated response to urgent situations:

As first-time caregivers, we were not ready to manage the patients with tube at home ... They [nurses] showed me how to do it at the hospital, but I was not asked to try it. If I did, I would feel more confident ...

(C6)

I wish they had followed up with phone calls, home visits by the hospital, and consultancy services related to their problems, once in a while, like, once a month. Now there's nothing

(C12)

I do not always have confidence in primary health-care institutions, I don't think they can handle it

(C1)

Only in the emergency department can we change the tube. Not anywhere else

(C10)

Expectations from social support

Some participants felt slightly helpless and isolated, which was associated with the low social support they accepted:

I worry about the cost. I have no money and I don't know what will happen to him if we can't afford it

(C13)

I'm on the go all day long ... I have to wash and rinse the syringe between each meal. There is so much I have to do ... everything! She can't do anything and I'm there for her 24 hours a day. I haven't had any help

(C11)

DISCUSSION

The present study provides new evidence about the experiences and needs of family caregivers of patients with NGT feeding within the Chinese cultural context. The findings highlight the uncertainty around potential future problems and benefits from practical aspects of tube care. Access to health professionals or services in transitional care was often described, and support to manage routine and urgent problems was considered particularly limited. This highlights the importance of improvements in this area.

In line with previous research,^{23,25,26} a negative effect on caregivers' well-being and daily life was evident. Yang *et al.*²⁷ indicated that the positive quality of the caregiver-care receiver relationship could buffer family caregivers from negative emotions; however, this was not investigated in the present study. The feeling of uncertainty arises from the imprecision of the prognosis related to the illness, for the future that they have to face, and for the lack of information and preparation for the situation; all of which are aspects mentioned by the caregivers we interviewed. It should be emphasised that this uncertainty may affect the provision of care and produce worries and insecurities in the caregiver.²⁸ According to Oishi *et al.*,²⁹ one of the factors that increases uncertainty among caregivers is a lack of coordination between healthcare professionals. More recently, Abrahamson *et al.*³⁰ pointed out that the transition in moving from the hospital to the home tends to be harder than they expect as a result of a lack of preparation with respect to providing necessary care to their family member. Hurried discharge teaching,³¹ planning³² and inadequate communication¹² were also reported to be associated with negative experiences. Therefore, a comprehensive discharge care plan is essential so that caregivers feel confident and safe. More adaptation and learning time for caregivers should be considered when performing discharge planning.

The acceptance and normalisation of caregivers' new role, as found in previous research,³² is related to readjustment in their lives in search of new stability, and parallels can be drawn with patients receiving HETF.^{11,33} This may involve regaining control over their daily lives.³³ Understanding the effectiveness of nutrition and its role in disease contributed to caregivers participating in decision-making.³⁴ Information-giving needs to include the associated evidence to ensure that a decision is made in line with their own values,³⁵ which facilitates decision-making involving caregiver input. Important findings showed that family caregivers begin to realise the difficulty of this task

and the responsibility of well-being of patients being in their hands.³² Some participants claimed that they will silently endure the greatest caregiving difficulties and never consider giving up caregiving even if it results in their exhaustion. This could be interpreted as cultural influences mediating how caregivers fulfil and cope with their role and maintain their motivation.³⁶ Caregivers perceived the caregiving experience as a normal and anticipated course of life as a result of family obligations and role models, which is in line with a culturally prescribed obligation and expression of reciprocal love.³⁷ In this context, overload, distress and overwhelming responsibility are well-known factors associated with depression and a reduced health-related quality of life among caregivers.³⁸ Therefore, the healthcare system's responsibility for providing relevant information and support is crucial to minimise the risk of illness within caregivers and build capacity to promote better health outcomes.

A prominent phenomenon in the present study was the intrinsic growth and sense of achievement in caregivers, which is an emerging area with respect to positive aspects of caregiving.^{39,40} One possible reason for this benefit relates to values originating from culture. Yanhong *et al.*⁴¹ explained that there was an intrinsic reward in upholding their commitment: they expressed pride in being able to uphold the cultural values of caregiving. Although increases in knowledge and the development of a sense of achievement interact to promote the maintenance of healthy behaviours, caregivers described ignoring their own health status, which could be attributable to a lack of information about self-care and lower efficiency.^{42,43} This highlights the importance of practical suggestions to promote self-care and constant medical monitoring offered by health professionals. In addition, caregivers spoke of focusing more on relationships, gaining a broader perspective on life and finding their lives to have new meaning as a result of caregiving. The wider literature reveals that perceived benefit could play a moderating or mediating role in the relationship between caregiver burden and depression.^{44,45} According to Geng *et al.*,⁴⁶ focusing on mindful interventions by family caregivers of cancer patients increased their positive experiences. In this context, practicing a positive attitude, as well as the ongoing implications of this, appeared to be an important step. In particular, caregivers appeared to be empowered to continue to face the challenges of their role by a personal choice to focus on the positives, such as cherishing what remained or choosing to use humour.⁴⁷ Previous research had indicated that the benefits to caregivers and patients are mutual.⁴⁸ Therefore, gaining an understanding of the factors that maintain a higher perception of these benefits may provide a new direction for interventions for caregivers from the positive view.

The results of the present study also highlight the expectations of caregivers in relation to urgent and routine continuity service support for the health system.

The importance of support has been identified previously.³³ Insecurity and a lack of emotional, practical, and information-related support have also been found to increase the vulnerability of caregivers, as well as their sense of loneliness.²³ It is noteworthy that caregivers' ability to handle their situation was also strongly related to the amount and quality of information and support received.²⁵ One finding concurs with previous studies⁴⁹ and suggests that caregivers do not always have confidence in their primary care practitioner. This is closely related to insufficient hospital referral information and a lack of standardisation and consistency among the community and hospitals, leading to frequent misunderstandings and distrust.⁵⁰ This suggested that health professionals focused on connecting caregivers to community resources that develop their competencies to meet both the patient's and their own needs. Additionally, substantial evidence suggests that a home enteral nutrition care team linking caregivers to information and resources increased the caregivers' sense of security⁵¹ and reduced the hospital admission rate, as well as the costs associated with enteral tube feedings,^{52,53} which could easily put in practice evidence-based best practices. A recent study indicated a lack of extended community caregiving support services and insufficient delivery of home care programmes in China.³⁶ There is an ardent need to develop national guidelines for home enteral nutrition services that care for patients with NGT feeding, such that they can be carried out effectively and efficiently.

Strengths and limitations

One of the limitations of the present study is that it was carried out in a tertiary hospital for caregivers, and, hence, the experience of our participants may not be generalisable to other centres and countries. Our findings echo the international literature on the experience of caregivers of individuals with other similar diseases, including the burden and benefit of caregiving. Perceived benefit should be a positive intervention to support them in managing this complex and life-changing problem when services vary across regions. During these interviews, the presence of patients resulted in a discussion of whether this restricted what was discussed. In addition, data saturation was a relative concept that was limited only to the findings of the present study and this might change over time.

CONCLUSIONS

This qualitative study underlines the experience and needs of caregivers who assist with NGT feeding of patients at home. It has revealed several key aspects, including negative experiences of caregiving, adaptation to lifestyle, and perceived benefits and expectations. These should be

considered when defining clinical protocols and supporting caregivers. Moreover, focusing only on the negative experiences may limit researchers from understanding the holistic experience of caregivers. The methods targeted at creating or enhancing the perceived benefits of caring would likely have a proactive ripple effect throughout the entirety of the caring trajectory and the care network. We suggest that the organisation of home enteral services should be guided by national standards for the provision of services for patients and caregivers, informed by caregivers and the regional context, aiming to ensure equitable and supportive services.

TRANSPARENCY DECLARATION

The lead author affirms that this manuscript is an honest, accurate and transparent account of the study being reported. The reporting of this work is compliant with SRQR guidelines. The lead author affirms that no important aspects of the study have been omitted and that any discrepancies from the study as planned have been explained.

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CONFLICT OF INTERESTS

The authors have no conflicts of interest.

AUTHOR CONTRIBUTIONS

MX was responsible for the study conception, design, data collection, validation and drafting of the article. MZ was responsible for the methodology, project administration, resources, supervision, validation, draft review and editing. XZ and SL contributed to the study conception, data collection and draft review. NX and JH contributed to the data analysis, validation and draft review. All authors critically reviewed the final version of the manuscript submitted for publication.

ETHICAL APPROVAL

Ethical approval for this study was obtained from the Nursing and Rehabilitation ethics committee of the University of Shandong (No:2020-R-041). The study conformed to the principles outlined in the Declaration of Helsinki. Participants were informed about their voluntary participation and could drop out from the study at any time without penalty. Oral and written consent was obtained from the participants. We also guaranteed the confidentiality of their personal information.

PEER REVIEW

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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