

Accepting Gastrostomy with Elderly Relatives: a family caregivers' perspective

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Abstract: The development of medical technology has extended life expectancy, but it has also brought in some unwanted effects to our life. We report a case study of a family who chose to feed their elderly parent with cognitive difficulties using a gastrostomy. The decision-making process for adopting gastrostomy was investigated with a series of semi-structured and informal interviews to the family caregivers. Collected data were analyzed and compiled as ethnography. We investigated the everyday life of the elderly parent at home and at a care home to discover the following three points. The meaning of gastrostomy is determined by the circumstances perceived by people involved in the process. Prior knowledge of gastrostomy and preparation to facing the end-of-life are effective in handling the elderly's rapidly deteriorating health condition. The family members found a peaceful moment in their daily life by regarding gastrostomy as a tool for caregiving.

1. Introduction

The progress of medical technology has extended life expectancy. Gastrostomy, one method of artificial hydration and nutrition, is a medical technology to support the patients who have difficulty to swallow liquid food. Gastrostomy is a fistula of about 5mm to directly feed hydration or nutrition into the stomach from the epidermis with a tube. PEG (Percutaneous Endoscopic Gastrostomy) requires no abdominal surgery and, as a standard surgical procedure, can be placed in less than 20 minutes by a skilled doctor. The fistula closes naturally if the tube is removed when the gastrostomy is no longer needed. Oral ingestion can be combined with PEG.

PEG benefits a number of children with problems such as oesophageal stricture, oesophageal atresia, severe head injury, or craniofacial abnormalities [Samuel 2003]. [Puntis 2009]. [Henderson 2008]. Its application to the elderly with dementia as a life-support treatment is, however, accused by the media and the general opinion. PEG is often criticised as a futile life-prolonging therapy [Ganzini 2006][Cervo 2006][Lang 2004], an invasion to patient's rights [Dennehy 2006], or an unnatural treatment of a human being [Ishitobi 2010]. It is also criticized as a waste of medical resources [Yap 2007]. However, according to the Japan Geriatrics Society symposium 2011, more than 60% of families support the use of PEG [Nishimura 2011] in Japan, where the gastrostomy extends the elderly's life longer than in other regions of the world [Toba 2011].

The gastrostomy does not cure the patients, but it becomes part of long-term care at home because it is a highly effective feeding method. It also allows the elderly to let their cognitive function decline continuously, which leaves some impact on the family members who care for them at home. However, the actual situation of the families is not clear to us as they care for the elderly people with cognitive difficulty using gastrostomy. The current study aims investigating the process in which family

caregivers at home accept gastrostomy in everyday life. Our research considers the role of medical technology in everyday life and examines how family members came to know of gastrostomy, how they made decisions, and how they interpreted gastrostomy.

2. Survey and Methods

2.1 Survey

The subjects of this research were an elderly person with cognitive difficulty (named X, female, age 93), her son (named M, 69), and his wife (named W, 60's) at the time we started our research in 2011. The family caring for the elderly decided to install a gastrostomy on her one year prior to our investigation and it was already installed on her when we started our research. They live in their own house in suburbs. X is fed all nutrition and hydration through the gastrostomy and has never resumed an oral intake. Her caregivers are mainly W and M. X's husband, named Y, was hospitalized in 1998 because of prostatic hypertrophy when he was 89 years old and was never discharged until he died in hospital in 2003. (X and Y are in alphabetical order, M and W indicate genders).

2.2 Methods

The fieldwork survey was carried out in the family's daily life at home from 10th July to 20th September, 2011 followed by a brief visit on 27th September, 2012. A series of semi-structured interviews were conducted at the family's home five times, spending 6 hours in total. We collected through the survey a set of verbatim records extracted from the audio data taken with an IC recorder, a set of written notes, and sheets of field notes [Sato 1992], which were compiled based on informal interviews and fieldwork. The field notes and the verbatim records were examined repeatedly to classify them with titles indicating the contexts in which the event occurred [Umesao 1969]. The data were arranged in a timeline in order to clarify the family history and the relationships between X's caregivers [Sato 2009] because the records collected through semi-structured or informal interviews are otherwise just memories or random stories. The organized data were classified into three categories;

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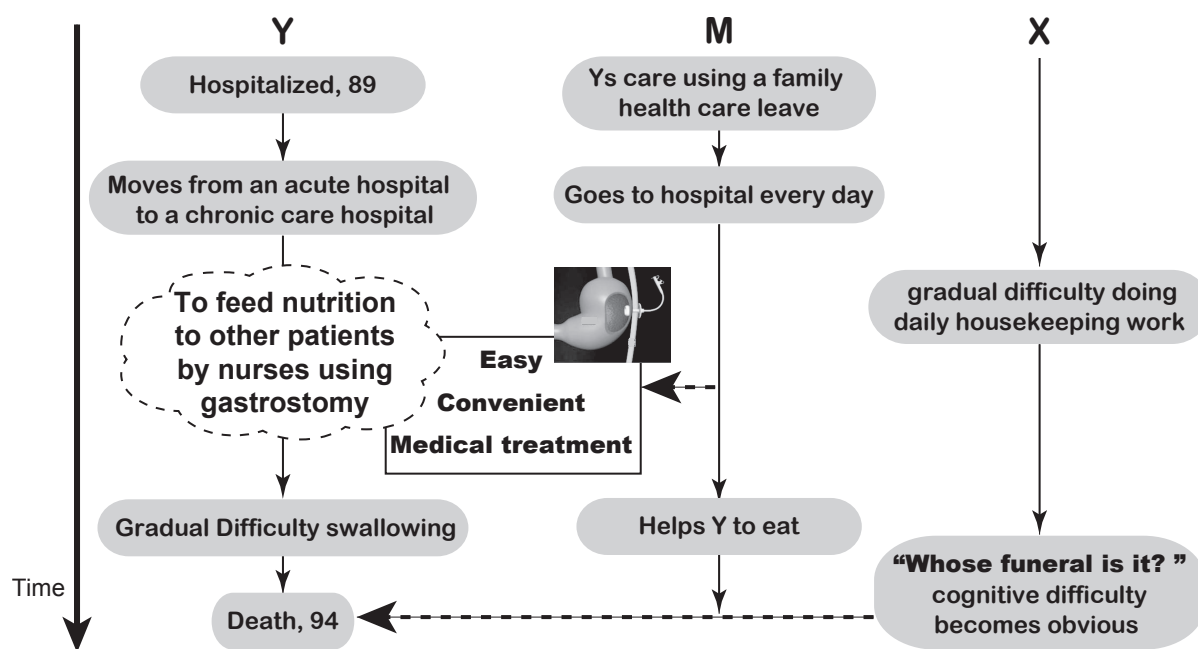


Fig. 1 How the family came to know of the gastrostomy

how the family came to understand the gastrostomy, how it made its decision, and how it interpreted the gastrostomy. The fieldwork was carried out to grasp the daily practice of family care at home, enabling us to understand the contexts of the family's reports and verdicts.

2.3 Ethical considerations

Upon starting our research, we explained to research collaborators about the family's right, its voluntary participation, and issues concerning privacy with written and oral information. The family's consent was then obtained as a written agreement.

3. Results and Discussion

When X stays at home without any plan, she lies awake in bed and watches TV. Her bed is in a back room of about 8 tatami facing the garden in the house. Excretion of X is assisted with a diaper and her hydration, nutrition and medication are all carried out through the gastrostomy. Nutrition of meals is prepared three times a day by W and is fed to X by M with a cylinder, taking more than 10 minutes. Diaper assistance of X is given by M and W. X uses home health care services and elderly care services as described below. A short stay service (four days and three nights) is used three times a month, a day service is used twice a week, the family doctor sees her for clinical treatment twice a month, a nurse sees her once a week, a dental hygienist sees her for oral care once a week, and a physiotherapist sees her for rehabilitation once a week. These plans are organized over a year. When we met her for the first time, we had the impression that "her skin is smooth and looks good." Though her greeting to us was the one to a stranger every time we saw her, she responded to us in a clear language in our conversation.

The following sections explain the family events in chronological order. In the article, the information on the

interviewee was written down (study Days. Month. Year. Kind of data.)

3.1 How the family came to know of the gastrostomy

First, we explain how the family came to know of the gastrostomy. Figure.1 describes the process through which they came to know of it. When Y was hospitalized, M went to the hospital every day by taking a leave for family health care. In hospital, nurses were feeding patients for nutrition and hydration easily by using the gastrostomy. M watched it and thought that gastrostomy was very convenient but it was just a medical cure for patients with difficulty in swallowing liquid foods. Y could eat normal meals. However, Y's strength declined gradually while he was subject to aspiration of food for two years until his subsequent death. M had taken to help Y eat little by little since then. It gradually became difficult for Y to swallow liquid foods for two months before his death, and he "naturally" passed away in the hospital when he stopped eating.

M said about gastrostomy the following. "It's convenient and not necessary to help patients eat. I don't know the details but I thought it's used for patients who cannot eat." (27 Jul. 2011. IC). M also said about Y's condition, "I felt it to be the end when he was unable to eat." (27 Sept. 2012. IC).

To summarize how the family knew of gastrostomy, M came to know of gastrostomy at the hospital and learned how it works by watching nurses using it for patients. At that time, M was unused to care. Therefore, one can consider that M understood that the gastrostomy was a convenient medical tool for patients who cannot eat. As Y's physical strength had been on a gradual decline for five years since he was 89 years old, he could not eat enough food orally. However, M did not think about placing the gastrostomy on Y. One can consider that M thought at that time that not being able to eat means reaching the end of life.

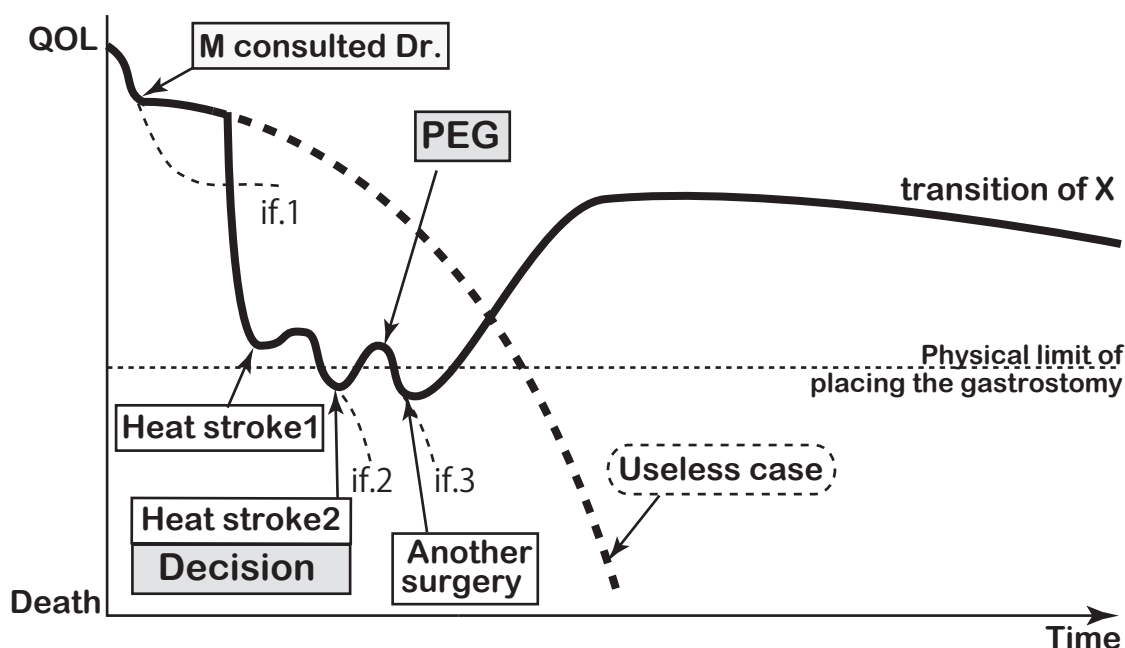


Fig. 2 How the family made the decision

(if.1: to place gastrostomy, if.2: not to place gastrostomy, if.3: not to accept surgery. [Drawing with reference to figure. Shimizu 2010, p.185])

3.2 How the family made the decision

Second, we explain how the family made the decision to place the gastrostomy. As shown in Figure.1, during Y's hospitalization, the physical strength of X had also gradually declined in daily life. M and W had thought that X was just forgetful due to natural aging. However, at the funeral of Y, X asked them "Whose funeral is it?" At that time, M and W noticed that X was affected by dementia. X's physical strength had declined gradually and she had become very reluctant to eat. About four months prior to placing the gastrostomy on X, she was unwilling to eat little by little, then, she had eaten very little. M and W made an effort to give her food anyway because the family doctor instructed them to keep X's weight higher than 36 kg. M said of those days, "feeding Mom was hell every day and every time because she hated to eat." (24 Aug. 2011. Field Notes).

Figure.2 is a conceptual diagram capturing qualitatively the QOL of X. The time indicated does not coincide with the actual time. As shown in the figure, M consulted the family doctor about placing the gastrostomy on X because he knew of it. The doctor decided to continue this care considering X's condition, a managerial dietician's opinion, and the dental hygienist's opinion because she was still able to swallow liquid foods. About two months later, at the end of June, X had been limp with a high fever when she came back from day care-services. M took X to a hospital by car to be treated immediately, but a doctor only gave her a drip treatment and sent her back home. Two weeks later, X again exhibited the same symptom and was given the same treatment in the same hospital. When she got back home, M and W talked with the family doctor and were determined to place the gastrostomy without hesitation. X was placed on the gastrostomy using PEG after she had been hospitalized for two

weeks to regain her physical strength. Gastrostomy was placed easily. Immediately after the treatment, however, she had another problem in the arteries of her upper arm. She thus underwent another surgery on the same day. Then, after four months, she returned home from hospital with the gastrostomy.

Before placing the gastrostomy on X, M and W had been talking about X's end of life. They decided that if the time came, they would provide X with only natural care as they did for Y. When X had a heat stroke a second time, however, the family doctor said that if M and W wanted to place the gastrostomy on X, her physical strength had reached to the limit. At the time, M decided to place the gastrostomy immediately as a medical cure because X could not physically eat. W agreed with him immediately. W thought it meant that she would "stand by and watch" X (27 Sept. 2012. IC), if she did not choose gastrostomy when X's condition suddenly changed.

How the family made the decision is summarized below. In this case, when M and W must choose a gastrostomy immediately due to a sudden change of X's condition, they decided with the "feeling of that time" without hesitation. We never heard words of regret or hesitation from W and M concerning their prompt decision. The reasons for which M and W could make an immediate decision and do not regret it are as follows. They already knew about gastrostomy and discussed X's end-of-life. The decision-making process is thus important not only for reaching a conclusion but also for discussion itself. A flexible decision is better than clinging to the previous decision. Then, the reason why M and W could make an immediate decision is related to the fact that they have understood X's end-of-life as the story of the whole family, as to whether her life would "decline gradually" or "remain in a stable state."

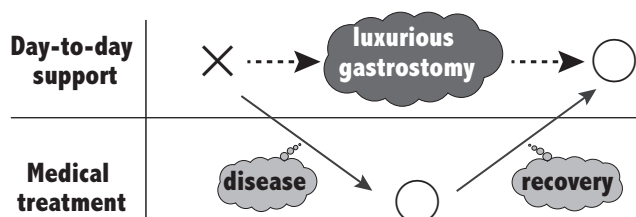


Fig. 3 How the family interpreted gastrostomy

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M calls X's gastrostomy "a little bit luxurious gastrostomy." (17 Aug. 2011. IC). He chose it although X did not require a medical treatment for swallowing foods. Thus, he may feel a little guilty about providing it to her.

Figure.3 illustrates the transformation of the family's interpretation of the gastrostomy. W and M had been thinking that the gastrostomy could not be applied to X because she was not suffering from a swallowing disease. But M decided to place the gastrostomy on X because she had a heat stroke and could not eat anything. Then, X regained her physical strength by taking in nourishment using the gastrostomy. But she did not want to eat anything from her mouth. Therefore, in this case, the gastrostomy is being used as a convenient alternative tool to feed her. For this family, "a little bit luxurious gastrostomy" means "a tool of meal assistance" to get out of an unbearable daily routine to help X to eat. Then more than anything, X was no longer forced to eat thanks to the gastrostomy.

4. Conclusions

To sum up, first, to answer the first question, "how the family came to know of gastrostomy", it was when M knew of the gastrostomy while he was still unfamiliar with the care at a hospital and saw nurses using it easily for patients. As a result, the family understood that the gastrostomy is an easy, convenient, or just medical treatment. In other words, technology was accepted in this context. Next, concerning the second question, "how the family made the decision", it was when it had to make an immediate decision to treat the elderly and they determined with an emphasis on "feeling at that time" without hesitation that it was the right choice. They chose a natural death for Y and placed the gastrostomy on X. This fact explains that the important things are acquiring knowledge of technology beforehand, discussing the time of the end-of-life in every day life, and not sticking to a previous decision. Finally, concerning the third question, "how the family interpreted gastrostomy", the answer is that the family transformed the interpretation of gastrostomy by naming it "luxurious gastrostomy" from a medical treatment into a tool for caring. The family has subsequently regained a peaceful daily life with the gastrostomy. The incident suggests a possibility such that tools or technologies can prevent abuse such as forcing someone to eat.

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