

Original Paper

Ostomates' Daily Struggles to Improve Quality of Life — Cases of Those Who Had the Ostomy in the Prime of Their Life and Lived to an Advanced Age —

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Abstract

The purpose of this research is to make explicit ostomates' daily struggles to improve quality of life at home. The subjects had the ostomy (the formation of stoma) in the prime of their life, lived for more than ten years after the operation to an advanced age.

As a result of a qualitative and inductive analysis through a semi-structured interview, it was made clear that in the daily struggles to improve their quality of life, the longtime ostomates make a change or a fine adjustment in response to their recognition of inconvenience and disadvantage. In this paper, I refer to the judgments by the longtime ostomates on the inconveniences and disadvantages in their daily life.

From the judgments by the ostomates, 5 categories and 14 subcategories are extracted; the five categories identified are '*to gather information*', '*to give up the solution*', '*to maintain the current condition*', '*to analyze the cause*' and '*to evaluate with regard to age*'. Although most of them made the judgments without consulting a medical institution, the ostomates' inconveniences and disadvantages accompanied by the change in situation were obvious. It is suggested that although they currently stand on their own feet, the ostomates who live to an advanced age need to be provided with information on how to utilize stoma care in response to the change in the method of stool evacuation and on the selection of ostomy appliances under the proper guidance of ostomy nursing specialists to achieve a better quality of life.

Introduction

Many of the attacks of colon cancer occur in the prime of one's life, and the number of longtime patients who live to an advanced age is increasing [1]. The aging of ostomates is obvious even when taking a look at the changes in the themes of articles that appear in the Journal of the Japanese Society of Stoma Rehabilitation. At the time of the inauguration of the society, most of the topics are "ostomy appliance", "ostomy management", "the way of colon lavage (irrigation of intestine)" and so forth, but from the year 1993 to the present, articles taking up the problem of aging such as "care for the aged", "long term

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follow-up” are very much in evidence [2].

There are two types of senior ostomates; firstly, those who had the ostomy at an advanced age and, secondly, those who had the ostomy in their youth or in the prime of their life and lived to an advanced age, thus going through a long period necessitating self-help. Though they had the ostomy in common, their background in life and their problems in life vary according to the difference in each type [3].

Although the necessity of care for the senior ostomates who lived a long period of time after the ostomy is suggested in some surveys [4,5], no concrete proposal for their care support has ever been established. It can be assumed that ostomates who had the stoma for a long time and maintained their life at home struggled to keep their life style close to their pre-stoma life style, but their actual trials have never been made clear.

The survival rate of ostomates has been going up, and the chances are high that the number of ostomates living to an advanced age is increasing. Up until now, the guidance offered at a stoma out-patient clinic is centered on learning methods of self-caring suitable for immediately after the ostomy; therefore, the guidance for the long term care is not sufficient [6]. Also, there occurred some cases of inconvenience despite the facts the patients were acting in strict compliance with the directions given at the time of discharge from hospital. For this reason, to know how ostomates have been trying to adjust themselves throughout an extended period of their life gives meaningful suggestions concerning problems in the conventional instructions given at the time of hospital discharge. Therefore, I would like to set out the goal of this research, to reveal the daily struggles to maintain a safe and comfortable life at home of aging ostomates who have experienced a long period and self-caring.

Definition of Terms

Daily struggles to improve quality of life: to make a change or a fine adjustment based upon judgments about the inconveniences and disadvantages encountered by the ostomates who try to lead a safe and comfortable life.

Long term ostomates: ostomates who have lived more than 10 years after undergoing ostomy; those who manage their lives for a long period of time with a stoma, rather than those living a life as a patient with the original disease of colon cancer.

Judgment: ostomates’s decision based on their analysis of the inconvenience and disadvantages of their daily life.

Research Methods

1. Research Design

It has been said that long term ostomates perform certain daily struggles to improve their quality of life, but no definite explication of them has been made. In particular, no disclosure of the daily life of long-term ostomates who lived to an advanced age has ever appeared. In view of this absence, I have conducted a quest-for-factor research through a qualitative and inductive method.

2. The Choice of the Subjects

According to a survey done by the Japan Ostomy Association on its members [8], 70 percent of the members surveyed are over the age of 65, and the percentage of members in their advanced years is increasing year by year. Those who spent from 10 to 20 years after the ostomy are most prevalent. As to the type of stoma, those with colostomy account for a little less than 70 percent. Thus, I made a

request to the Prefecture A branch of the Japan Ostomy Association for cooperation from members who satisfy the following conditions: ① over-10-year ostomates resulting from colon cancer, ② ostomates who already received and have the full recognition of the notification, ③ ostomates who have already acquired self-caring of the stoma and have had a life at home, ④ ostomates without dementia and aphasia who can communicate properly.

3. Method for Gathering Data

As for gathering data, I explained in writing to the office of the Prefecture A branch of the Japan Ostomy Association about the purpose and content of the research, and they introduced to me the joining ostomates who satisfied the conditions set up as described above. Making use of a semi-structured interview guide, I had an interview with 10 ostomates upon their acceptance of participation after the repeated explanation of the purpose and content of the research. The interviews were done at places of each subject's designation. With the subjects' agreement, the interviews were recorded and notes were also taken. The duration of an interview was from 60 to 120 minutes and the term of gathering data was from July to September of 2003.

4. Method for the Analysis of Data

Under the regular guidance and advice of a specialist in qualitative research, I conducted the analysis as follows. ① From the word-by-word transcription of the recorded interview, extract those parts referred to as "daily struggles to improve quality of life". ② Give proper consideration to the extracted data for each subject, divide into groups, and name them. ③ Give proper consideration to the names by repeatedly examining the concordance of the names of groups with the content of interviews with the subjects. ④ Organize the results of the analysis for each subject, analyze it as a whole, divide again into groups, reconsider the names, and examine the contents.

5. Ethical Consideration

Upon the acceptance granted by the ethical committee at Kochi Women's University, I explained in writing to the subjects about the purpose and content of the research. The subjects were only those who agreed upon the explanation. I explained that participation in the research is at the subject's free will and that refusing to participate never results in any damage to the subject's benefit. I also saw to it that the request from the association never generated psychological pressure on the subjects to sign up to this research. Each interview was done at the place the subject and I agreed on and all the places picked ensured a good level of privacy. Each of the interviews was exclusively between a subject and me in the selected place. I also explained to each subject that the content of the interview would never be used beyond the purpose of this research and that the subjects have the right not to answer any question they do not want to answer. I recorded the interview after confirming the subject's consent at each interview. In order to protect privacy, I processed the data so as not to let out the identity of the subject. I received their consent on my publication of the research outcome at a conference and in a published article. Those parts of data that a subject wants to be made public without any adaptation were designated by the subject and used with the subject's agreement.

Research Results

1. Profiles of the Subjects (Table 1.)

The subjects consisted of five males and five females aged between 67 and 84. The average age was 75. All of the subjects had had an ostomy with colon cancer at an average age of 57.7. They had lived with

the ostomy from 10 to 26 years. The average length of time lived with the ostomy was 17.3 years.

Table 1 Profiles of the Subjects

	Sex	Age	Years After the Ostomy	Ostomy Management
C	female	late 60s	23	spontaneous
D	male	early 80s	22	lavage→spontaneous
E	male	early 70s	18	lavage
F	male	early 70s	11	lavage
G	female	early 80s	18	lavage
H	female	early 80s	26	lavage
I	male	early 70s	10	lavage
J	female	late 70s	15	spontaneous
K	female	early 70s	20	lavage
L	male	early 70s	10	lavage→spontaneous

2. Judgments by the Long-term Ostomates on the Inconveniences and Disadvantages

Ostomates face a variety of inconveniences and disadvantages even though they attain the knack of self-caring after the ostomy. There is, for example, an expected occurrence of a leak of feces, and problems after problems that disturb the daily life of an ostomate.

From the judgment the subjects made, 5 categories along with 14 subcategories were extracted. The categories identified are *'to gather information'*, *'to give up the solution'*, *'to maintain the current condition'*, *'to analyze the cause'* and *'to evaluate with regard to age'*. (Table 2.)

Henceforth, a category is indicated by *'bold italic'*, a subcategory, by *'italic'*, and a quote from code, by double quotes " ".

The category *'to gather information'* means that ostomates research in a precise way the timing of ostomy control, compare what they found with their original ways, talk with others about it, and make a decision for a better policy on the basis of this process of information gathering. This category includes two subcategories; *'to find the right answer'* and *'to consult with others'*. For example, in the case of 'K', the subject was talking about the subject's starting to care about the information gathering after the subject experienced a mistake of doing colon lavage soon after eating.

The category *'to give up the solution'* shows that ostomates gave up a solution and faced up to the bad consequences and the difficulty in dealing with problems even though a good command of the relevant problems and its countermeasures is procured. This category includes three subcategories; *'to be difficult to solve even though a considerable attention is paid'*, *'to give up because it is too difficult to deal with'* and *'to give up because of bad results'*. For example, in the case of subject 'I', describing the despairing view that the change in the intervals of colon lavage is impossible, the subject gave up the extension of the intervals of colon lavage as the subject expressed himself as "I tried twice or three times, thinking that it would make me comfortable to make an interval longer, but it did not work because of excretion."

The category *'to maintain the current condition'* indicates that the subjects think there is no problem because the symptoms consequently settle down even though small inconveniences occur. This category includes two subcategories; *'to leave things as they are because the symptoms settle down'* and *'to maintain the current condition because there is no leakage of feces'*. For example, the subjects think that

Table 2 Judgments by Ostomates

Category	Subcategory
to gather information	to find the right answer
	to consult with others
to give up the solution	to be difficult to solve even though a considerable attention is paid
	to give up because it is too difficult to deal with
	to give up because of bad results
to maintain the current condition	to leave things as they are because the symptoms settle down
	to maintain the current condition because there is no leakage of feces
to analyze the cause	to think out how to keep away from trouble
	to be the cause of the leakage of feces
	to think out the cause of a failure
to evaluate with regard to age	to see no problem when compared with the past condition
	to understand the goodness year by year
	to be more careful as age advances
	to think about the way of defecation in the future

there is no problem in maintaining the current condition because the over level of gas in the abdomen or the itch on the part where the appliance is attached settle down in a short period of time.

The category '*to analyze the cause*' points out that, regardless of the appropriateness of the way of thinking of the subjects and of their method, the subjects themselves recognize the need for conducting an analysis. This category includes three subcategories; '*to think out how to keep away from trouble*', '*to be the cause of the leakage of feces*' and '*to think out the cause of a failure*'. In the case of subject 'F', for example, the subject thought that lunch was an excess and *to be the cause of the leakage of feces*. The subject firmly recognized the relation between the total amount of food consumption and the dejection at night, saying "Sometimes I am awoken because of bowel movements. When I have lunch, I have an excess of food." In the case of subject 'K', for instance, the subject analyzed the pressure given to the stoma appliance due to the sitting posture *to be the cause of the leakage of feces*. Also, in the case of subject 'K',

the subject thought the cause of abdominal pain to be the low temperature of liquid for colon lavage. As the subject said “Lukewarm water is not good at all. The bowel mixes it. The temperature is important.” Here we can see the subject learned from failures.

The category *‘to evaluate with regard to age’* indicates that the subjects compare the current condition with what it was like when they were young, and give consideration to the present condition and predict future plausibility. This category includes four subcategories; *‘to see no problem when compared with the past condition’*, *‘to understand the goodness year by year’*, *‘to be more careful as age advances’* and *‘to think about the way of defecation in the future’*. In the case of ‘E’, for example, the subject talked about the subject’s recognition of no trouble even though it takes an hour to do colon lavage and the process deprives the subject of considerable strength. In the case of subject ‘J’, the subject showed no feeling of discomfort as the subject took a look at the daily shape of stoma and expressed the sophisticated cut operation as “I feel this is the way it is, after all these years I spent with it.” In the case of subject ‘K’, the subject showed that the subject did the preparation for colon lavage more efficiently than when the subject was young, as saying “Now that I become old, I am more efficient.” In the case of subject ‘F’, considering the condition of care support for others in the subject’s same generation, the subject commented “As compared with wearing diaper when getting old, it (being an ostomate) is much more comfortable,” showing how they come *to understand the goodness year by year*. In the case of subject ‘L’, concerning the possibility of leakage of feces due to age and the possibility of decline in sufficient skills, the subject determined *to be more careful as age advances*: “I should be careful of leakage. From now on, the precision in the movement of my hands will decline. My sticking to things is getting low and I am getting lazy.” Also, in the case of subject ‘J’, the subject mentioned about the gap formed around the appliance because of the wrinkles on the skin due to age, as saying “As I am getting old, even though I have the two-piece type appliance attached, there is a leak towards the inside.” In the case of subject ‘K’, the subject showed they were *thinking about the way of defecation in the future* in saying “Get rid of unnecessary things. Make it simple, because I get tired easily when I have to do unnecessary things as I am getting old.” In the case of subject ‘H’, the subject discussed shifting from the current way of colon lavage into the spontaneous evacuation of stool, when they said, “In the near future, as my arms and legs are getting weak and I am in trouble, I hope I can do the spontaneous evacuation of stool without colon lavage.”

Discussion

I would now like to give some consideration to the judgments made by the subjects on the inconveniences and disadvantages that arise in the subjects’ daily struggles for improving their quality of life at home after the ostomy.

The ostomates are doomed to face a variety of inconveniences and disadvantages even after they master the skills of self-caring and readjusting to life at home. Their life changes as time goes by, for example, having an unexpected leakage of feces and other unanticipated problems one after another [3,9].

The subjects managed *to gather information*, and made judgments such as deciding the temperature of liquid for colon lavage, duration of colon lavage and the troubles in the process of colon lavage. These should generally be included in the instruction of colon lavage [9], and it is natural to think that these should be taught in a medical institute during a consultation. However, most of the subjects gathered information by themselves and made their own judgments. In other words, it can be inferred that the subjects were in the situation where they can not depend on a medical institution. It can be seen from this that there were defects in the system of consultation and instruction of colon lavage when the subjects

had the ostomy.

In a situation where the ostomates have *to give up the solution*, the changes in the interval of colon lavage were included. Those ostomates who are anxious for defecation of the remaining stool after colon lavage are many [10]. Colon lavage is supposed to be done at regular intervals. The interval varies according to individuals, but some of the subjects think that they would like to make a change in the interval even though they have already got used to the present level of interval. This shows that even if there is no problem at all in the regular operation of their daily life, some of the subjects are thinking of changing the interval of colon lavage, in a quest for a more comfortable life.

Patients are not discharged from hospital upon the resolution of all the problems. There are cases when the patients come to fully realize the extent of their problems when they get back home and restart 'normal' life [11]. The subjects use the process of *analyzing the cause* of failures in the past, thus preparing for the future. Many ostomates have the problem of leaking feces. [12]. The problem not only results in irritation of the skin, but it also makes the ostomates feel ashamed about the odor and mess, and it hurts their pride a great deal [11]. Each subject analyzed the cause of the leakage of feces by looking at the appliance, the amount of feces, the pressure from outfits, the posture of sitting, and so on.

There are ostomees who only know about the appliance at the time of the instruction at the hospital and continue to use it even though they encounter troubles using it [13]. Thus, the content of the instruction by a nurse will be reflected directly in the patient's level of self-control [14]. Once the recognition of the relationship between the cause of the leakage of feces and their motion is made, the ostomates can make the next judgment by making use of the experience of failure. Making daily judgments on a variety of circumstances and situations, the subjects are assumed to deepen their understanding and to think out the countermeasures naturally rather than causing limitations to their daily life.

If an ostomate does not tell others, it is hard for people around them to recognize a stoma from their appearance. The ostomates are those who can live an ordinary life, and they are proud of their particular form of caring for themselves. Most of them live with colon lavage; however, as Tajima, *et al.* [15] say, "the introduction of the skin conditioning medicine made colon lavage out of fashion, and we are now in the session of reflection," there have been, in recent years, some specialists who advocate the spontaneous evacuation of stool. However, it is not a matter of choosing either one way or the other. I think that the proper application of ostomy management relative to circumstances will give ostomates more expansive ways of life.

According to basic research on the actual life of ostomates [8], a study carried out in 2003 by the Japan Ostomy Association, 70 percent of those ostomates who lived more than 10 years after the operation were those with colon lavage, which indicates that colon lavage was most prevalent in the 1980s; subjects that had the ostomy in the period of 1981 to 1994, when colon lavage was prevailing. This might be the reason that over half of the subjects selected colon lavage as their form of ostomy management. This background factor concerning the ostomy may be affecting the result of the research.

Although certain consideration is necessary for the care of aging ostomates because of physical, psychological and social change due to aging, a special care responding to each individual is needed because age and social condition of subjects vary a lot [16]. In the case of colon lavage for an elderly ostomate, though there are a lot of problems such as lack of body strength, the power of understanding, the skills in operation and so on, there is no need to make all of them inappropriate where there is actually no problem [16]. In such a case, the subjects also recognized that there was no problem at all. Although colon lavage is not recommended to patients over the age of 70 [16], subjects over 70 who had got used to it through many years of experience, felt no difficulty at all, compared with those who had to master colon lavage at an advanced age.

It is necessary for caregivers to provide necessary support upon gaining the proper understanding of the feelings of ostomates and the situation of their ostomy management. It is not proper to make a decision only on the basis of their current age, because many have mastered the necessary skills in the long process of their life with ostomy. There is a chance when we have to leave things as they are for now as long as the frequency of the leakage of feces does not increase or the rash on the skin does not appear [16,17]. It is suggested that there is a necessity for preparatory instruction for the ostomates for their gradual understanding of the limit in the future of colon lavage and the current appliance, even though they are now independent.

When an ostomate is in need of care support, although some of the ostomates emphasized the convenience of the ostomy even for the care supporters, the ostomates are more concerned about defecation than other senior citizens. I think this is because the subjects are always conscious of defecation when they live with ostomy. Also, the subjects might be trying to convince themselves about their concern of defecation in the future compared with other senior citizens. There were some subjects who talked about the need for the simplification of stoma management. From all these, a difference can be seen from the long-term ostomates who stick to the old type of appliance and never try a new challenge.

Concerning method of defecation from now on, as Sato [20] points out, there is a need for establishing an institute for helping those continuously with colon lavage to understand the spontaneous evacuation of stool and receive necessary consultation. Moreover, there is a need for a permanent reception for their consultation, even though they are in a situation where they can live an independent life at home.

Conclusions

As a result of the analysis on the judgments made by the long-term ostomates, important suggestions concerning a concrete way of caring are as follows:

- 1) Concerning the decision on the method of colon lavage, the judgment of a medical specialist is needed in the cases such as ① feeling of sickness after colon lavage, ② abdominal pain accompanied by the injection of liquid for colon lavage, ③ comparatively little amount of feces in relation to the amount of injected liquid for colon lavage, ④ feces is very hard, so it is difficult to get it out. All of these are applicable even to the long-term ostomates who have an independent life.
- 2) Concerning the protection of the skin, there is a need for regular checking of the skin around the ostomy and on the way of using the skin conditioning medicine. Providing information on proper appliances in response to the change in life and aging and the necessity for earlier reception of a medical examination depending on the skin condition after diarrhea should be included in the instruction.
- 3) Concerning the stoma appliances, there is a chance of skin disorder after the usage of it for many years. Thus, there is a need for the explanation of the possibility of discomfort with the appliance and the need to have an earlier consultation.
- 4) There is a need for a telephone consultation concerning improvements in daily life, even where there is no need to see a doctor. There is also a necessity for the assessment on the parts where the leakage of feces occurs easily and a total review of the appliances.
- 5) Concerning the effects of aging, there are those ostomates who have an anxiety over the impossibility of colon lavage. They should be provided with preparatory instruction and information on the proper knowledge and skills relating to the spontaneous evacuation of stool from the stage of being independent.

- 6) Concerning ostomy management, if there are no problems in the power of understanding and the strength of body even at an advanced age, there should be no problem with colon lavage. In such cases, a regular check on the inconvenience or the problems in skills is necessary. At the same time, ostomates should be provided with information on the change in ostomy management so that they can be convinced to do so as they recognize the weakening of their abilities. This applies to any ostomates who had the ostomy at any stage of life and live to an advanced age.

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Postscript

This paper is a modified version of a part of my master thesis submitted to Kochi Women's University. Also, part of this paper was read at the 19th (2005) conference of Japan Society of Cancer Nursing.

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