

Research

Characteristics of Nursing Care for Patients with Lymphedema after Cancer Surgery

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ABSTRACT

OBJECTIVE : To clarify the characteristics of nursing care to support patients with lymphedema after cancer surgery, who need to perform long-term self-care as part of symptom control.

METHODS : Semi-structured interviews were conducted with 8 nurses engaged in lymphedema care for patients after cancer surgery, whose consent had been obtained. Data were collected to extract those regarding the characteristics of the above-mentioned nursing care, and analyze them, focusing on their contents, as well as similarities and differences among them.

RESULTS : Nursing care for patients with lymphedema after cancer surgery was characterized by 5 categories : <improving acute-stage symptoms>, <preventing complications>, <supporting continuous self-care>, <guiding toward healthier life patterns>, and <providing information regarding social resources>. The care delivery system consisted of 8 components : <arrangement of the form>, <securing of place>, <securing of time>, <team structure and the patient in charge system>, <the number of outpatients>, <management of medical articles>, <instructional materials>, <the presence of a supervisor and mentor>.

KEY WORDS : lymphedema after cancer surgery, self-care support, outpatient lymphedema treatment

Introduction

Methods to completely cure lymphedema after cancer surgery have not yet been established, and the first-choice treatment approach combines skin care, compression, therapeutic exercise under compression,

and lymphatic drainage. Once the disorder occurs, it is necessary to prevent it from deteriorating and control its symptoms by continuing such treatment. In conventional oncological services, mainly aiming to kill cancer cells, the level of interest in treatment-related complications and inconvenience to patients has been low¹⁾.

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Manuscript received : 3 October 2016

DOI : 10.15010/LRAP.2016.10.03.07

According to data, some patients suffering from postoperative lymphedema are told by their doctors : 'Now that you are free from cancer, you should endure the swelling²⁾. As a consequence of this attitude, the activities of groups organized by patients themselves to enhance awareness of symptom control³⁾, efforts and positive outcomes achieved by clinicians continuously engaged in medical and nursing services for patients with lymphedema⁴⁻⁷⁾, and findings of basic and clinical studies on the disorder⁸⁻¹⁴⁾ have been favorably evaluated, leading to a revision of medical fees in 2008, and consequently enhancing recognition of lymphedema in medical fields.

In Japan, the insurance coverage of lymphedema treatment started in 2008 when 100 points were allocated to lymphedema guidance and management, and this was followed by the allocation of subsidies for elastic clothing and other items for the treatment of limb lymphedema. In 2010, the number of medical fee calculations for lymphedema guidance and management was reviewed, leading to a revision of the requirements of such calculations (to enable insurance-covered medical institutions providing outpatient services for postoperative patients in communities, in addition to those performing surgery, to also provide patient education after discharge in consideration of patients' consultation-seeking behavior) in 2012. In line with these movements, combined lymphedema treatment fees became insurance-covered in 2016 when medical fees were revised again.

Professionals qualified to calculate combined lymphedema treatment fees are limited to doctors, nurses, physical/occupational therapists, and masseurs (there are some conditions for masseurs to perform such calculations). Currently, there are 180 facilities, in which nurses provide outpatient care for patients with lymphedema as private practice¹⁵⁾. Now that combined lymphedema treatment is insurance-covered, the number of facilities that adopt systems to perform it is likely to rapidly increase. The insurance coverage entitles all Japanese people suffering from lymphedema to receive high-quality, combined treatment approaches, while placing medical institutions and professionals providing such medical services under the obligation of ensuring their sufficient quality. Therefore, as an urgent issue, it

may be necessary to develop an appropriate model of nursing care for patients with lymphedema after cancer surgery, and use it as a standard for quality assurance.

Objective

To clarify the characteristics of nursing care to support patients with lymphedema after cancer surgery, who need to perform long-term self-care as part of symptom control, this study examined nurses with experience of actually caring for patients with the disorder in departments performing outpatient lymphedema treatment, with the aim of obtaining basic data for the development of a model of such nursing care.

Methods

1. Subjects

Eight nurses engaged in lymphedema care in departments performing outpatient lymphedema treatment were studied with their consent (**Table 1**).

2. Period and method of data collection

Data were collected within the period between July and December 2015 through semi-structured interviews, focusing on the following items : the detailed contents of care being actually provided, systems to provide lymphedema care (the pattern of nurse assignment, service provision frequency, number of staff members, and others). During the interviews, the nurses freely answered questions regarding their patient allocation systems, experiences related to the management of, difficult patients, and others. Each interview session was held in a private room, and its duration was 60 to 90 (mean : 65) minutes. With the nurses' agreement, the contents of the interviews were recorded, while data regarding their basic attributes, such as the age and years of experience, were previously collected from them.

3. Method of data analysis

Narrative records were created for each of the nurses. Subsequently, data related to the contents of care, systems to provide lymphedema care (the pattern of nurse assignment, service provision frequency, number of staff members, and others), patient allocation, and experiences related to the management of difficult patients were extracted, classified, and analyzed through comparison. Also, for each stage in the process

Table 1 Subject Outline

Subject	Age	Sex	Qualification	Duration of nursing experience (years)	Duration of lymphedema care provision (years)	Educational background
A	30s	F	Nurse	15	10	Nursing junior college
B	40s	F	Nurse	23	8	Nursing college
C	40s	F	Nurse	25	15	Nursing graduate school (master course)
D	40s	F	Nurse	19	7	Nursing junior college
E	40s	F	Nurse	24	7	Nursing college
F	40s	F	Nurse	18	6	Nursing college
G	30s	F	Nurse	17	6	Nursing graduate school (master course)
H	30s	F	Nurse	10	5	Nursing college

of analysis, researchers had a meeting in an effort to increase the validity.

4. Ethical considerations

Prior to the study, the approval of ethics committees of the institutions the researchers belonged to was obtained. The nurses were introduced after showing the study plan to the directors and head nurses of the relevant facilities, and obtaining their agreement. The nurses were provided with written explanations of the study content, voluntary participation, and protection of participants' rights to obtain their consent.

Results

1. Subject outline

Table 1 outlines the 8 nurses' attributes. All of them were female, and their mean age was 40. The mean durations of nursing experience and lymphedema care provision were 19 and 8 years, respectively. They received specialized nursing education at : nursing colleges : 4 ; nursing junior colleges : 2 ; and nursing graduate schools (master courses) : 2. All were licensed ; 2 and 1 were certified nurses and certified nurse specialist, respectively. All of them had also completed lymphedema training programs.

2. Factors related to the provision of care for patients with lymphedema after cancer surgery

1) Systems to provide lymphedema care in hospitals (1) Patterns of nurse assignment

Systems to provide lymphedema care (the patterns of nurse assignment) in hospitals were classified into 3 patterns. Pattern A, in which the nurses in charge of

lymphedema care were assigned to wards on the days of outpatient lymphedema treatment, was the most common : 6, followed by Pattern B, in which ward nurses collaborated with doctors of outpatient medical departments to perform and operate outpatient lymphedema treatment : 1, and Pattern C, in which the nurses in charge were exclusively engaged in outpatient lymphedema treatment : 1.

(2) Spatial arrangements

Patterns A and C ensured locations exclusively for the provision of specialized outpatient services. In Pattern B, such services were provided simultaneously with outpatient medical services.

(3) Temporal arrangements

In the most common Pattern A, outpatient lymphedema treatment was performed twice per week : 4 or once per week : 2. In all cases, the nurses in charge were engaged in specialized outpatient services for patients with lymphedema throughout service hours on the days of such treatment. In Pattern B : 1, the treatment was performed once weekly. In contrast, in Pattern C : 1, it was performed daily and managed by the nurse working the day shift. In all patterns, the operation and rest times were determined by contracts.

(4) Teamwork and patient allocation

In both Patterns A and B, a special team was organized on the days of outpatient lymphedema treatment. In most of the facilities, in which outpatient lymphedema treatment was performed by nurses, such a team was made up of those nurses combined or not combined with physical therapists. In all patterns, each

Table 2 Characteristics of Nursing Care for Patients with Lymphedema after Cancer Surgery

Category	Sub-category
Improving acute-stage symptoms	Assessment (symptoms, knowledge, abilities, and motivation)
	Showing examples of care
	Demonstrating early improvements
Preventing complications	Assessment (environments, working condition, and life pattern)
	Knowledge acquisition in accordance with lifestyles
Supporting continuous self-care	Clarifying factors preventing self-care through assessment (the working condition, life pattern, personality, and sense of values)
	Motivating individual patients appropriately to continue performing self-care
	Showing points of the continuation of self-care (without seeking perfection)
Guiding toward healthier life patterns	Identifying problems preventing lymphedema from improving through assessment (daily, weekly, monthly, and annual life patterns)
	Guiding patients toward the development of feasible and favorable habits
	Making arrangements to improve the relationships with other family members or key persons
Providing information regarding social resources	Providing information to improve symptoms and resolve life-related problems
	Presenting the latest reports on lymphedema treatment
	Providing information regarding national policies on lymphedema treatment
	Introducing patient support groups, as necessary

team member was basically in charge of specific patients.

(5) Number of patients receiving outpatient lymphedema treatment

In Pattern A, the daily number of patients ranged from 10 to 30, while it exceeded 30 in Patterns B and C.

(6) Supplies management

In all patterns, budget inclusion for necessary supplies was performed, and the management of such supplies was performed by the person in charge.

(7) Education materials

In all patterns, patient education materials were originally developed and created.

(8) Presence of supervisors/advisors

Systems to provide technical support for nurses engaged in outpatient lymphedema treatment were established in 2 out of the 8 cases : staff members who were well-versed in lymphedema care were present within the facility in one, and external supervisors were used in the other case. In the 6 remaining cases, official support systems were not available, so the nurses consulted their personal advisors.

2) Characteristics of nursing care for patients with lymphedema after cancer surgery

Based on the nurses’ free statements, nursing care for patients with lymphedema after cancer surgery was characterized by 5 categories : <improving acute-stage symptoms>, <preventing complications>, <supporting continuous self-care>, <guiding toward healthier life patterns>, and <providing information regarding social resources> (**Table 2**). The following sections describe each of the 5 categories : < > : categories ; { } : sub-categories ; and “ ” : the nurses’ statements during interviews, () : include of subject :

(1) <Improving acute-stage symptoms>

This category represented the improvement of the main symptoms causing distress in patients through nursing care, consisting of the following sub-categories : {assessment (symptoms, knowledge, abilities, and motivation)}, {showing examples of care}, and {demonstrating early improvements}. In relation to these, the nurses mainly stated as follows : “In severe cases, the presence of elephantiasis occasionally leads to a difficult situation, but the most important point is achieving improvements in the most marked symptoms.

This is effective not only for patients' comfort, but also to establish trust-based relationships with them (C)" and "When dealing with patients who had been suffering from symptoms for a long period, it is pointless to blame them for the acute deterioration, because such deterioration would not have occurred if management had been appropriate. It is more important to help them realize reduced swelling (A)".

(2) <Preventing complications>

Regarding phlegmon and lymphorrhea as the most common events faced by patients with lymphedema, the nurses mainly stated as follows: "I remember a patient, who sighed over the development of lymphedema despite all her arrangements to prevent it after being provided with explanations of the disorder prior to surgery, such as having her bamboo forest behind deforested and leaving her pet cat in others' care (B)" and "Some patients with untreated lymphorrhea do not seek outpatient treatment. We cannot do anything for them without their access to our department (C)". The sub-categories of this category were: {assessment (environments, working conditions, and life patterns)} and {knowledge acquisition in accordance with lifestyles}.

(3) <Supporting continuous self-care>

Difficulty in supporting continuous self-care by patients was the most common problem faced by the nurses, and the following statements were observed: "Sometimes I consider patients who do not visit our outpatient department, regarding them as having decided not to do it as their own responsibility. On the other occasions, I consider them more positively, thinking that they may have adapted to their own current physical conditions favorably, so they do not need to visit us (C)", "It is necessary to motivate patients to appropriately perform self-care, but actually all we can do is teach them how to apply bandages. We cannot advance to the next step unless this is cleared (D)", "Bandage application by nurses → symptom improvement → withdrawal from outpatient treatment → deterioration after some years; some patients repeat this cycle, causing a dilemma (G)", "Excessive efforts may result in poor adherence to self-care, possibly due to fatigue (F)", "In the case of patients who are busy working, they tend to withdraw from self-care, as they

also seek perfection in such care despite their limited time for it (E)", and "I cannot help blaming myself for patients' poor adherence to self-care, considering that this indicates poor outcomes of both treatment and patient satisfaction (A)"; some nurses also mentioned the significance of their own existence. This category consisted of the following sub-categories: {clarifying factors preventing self-care through assessment (the working condition, life pattern, personality, and sense of values)}, {motivating individual patients appropriately to continue performing self-care}, and {showing points of the continuation of self-care (without seeking perfection)}.

(4) <Guiding toward healthier life patterns>

This category represented the nurses' deeper insight into patients, compared with <supporting continuous self-care>, and nursing approaches to lead them to review their life patterns as part of symptom improvement and deterioration prevention. Its sub-categories were illustrated by the following statements: {identifying problems preventing lymphedema from improving through assessment (daily, weekly, monthly, and annual life patterns)}: "While performing the treatment procedure, I take sufficient time to listen to patients to confirm their living environments and daily activities (F)" and "On the initial consultation, we interview patients using an instructed format (D)"; {guiding patients toward the development of feasible and favorable habits}: "Even if their poor dressing and grooming suggest a disturbance of daily life, we do not know how patients themselves see this (G)" and "Habits should not be forced (E)"; and {making arrangements to improve the relationships with other family members or key persons}: "There was a patient who was simultaneously engaged in housekeeping and work with her markedly swollen legs. In this case, it was necessary to also provide guidance for other family members (H)".

(5) <Providing information regarding social resources>

This category consisted of the following sub-categories: {providing information to improve symptoms and resolve life-related problems}, {presenting the latest reports on lymphedema treatment}, {providing information regarding national policies on lymphedema

treatment}, and {introducing patient support groups, as necessary}. They were mainly described by the nurses as follows: “I frequently show examples of self-management performed by other patients with similar symptoms (G)”, “Patients actively communicate and exchange information with each other. We occasionally participate in their conversations to confirm the accuracy of the information provided by them (A)”, “I remember that when the cost of compression materials became insurance-covered, patients asked me a number of questions (B)”, and “Communication among patients is very important. I saw even a patient in a depressive state become cheerful after making friends with other patient support group members (D)”.

Discussion

This study aimed to clarify the characteristics of nursing care for patients with lymphedema, based on the experiences of 8 nurses who had provided pioneering nursing approaches in this area.

1. Appropriateness of subjects

In Japan, conservative therapy for patients with lymphedema started around 1995, and it has gradually expanded since 2000¹⁶⁾. Considering such a background, the subjects of the present study, nurses with long-term experience, may be regarded as professionals who had been engaged in pioneering nursing approaches for such patients from the early stages, and are therefore appropriate for a study aiming to obtain findings on systems to provide lymphedema care and their contents, which are useful to address the current situation.

2. Factors related to the provision of care for patients with lymphedema after cancer surgery

1) Systems to provide lymphedema care in hospitals

From the nurses' statements, the following items were extracted as components of systems to provide lymphedema care in hospitals: the patterns of nurse assignment; spatial arrangements; temporal arrangements; teamwork and patient allocation; number of patients receiving outpatient lymphedema treatment; supplies management; education materials; and presence of supervisors/advisors.

Lymphedema care was provided by the nurses as private practice in hospitals in 3 patterns in accordance with the characteristics of each facility: being assigned

to wards as part of outpatient service arrangements (concurrent duty); through collaboration with doctors of outpatient medical departments (concurrent duty); and being exclusively engaged in outpatient lymphedema treatment. In all patterns, the nurses in charge were engaged in specialized outpatient services for patients with lymphedema throughout service hours on the days of such treatment as a member of a team mainly made up of nurses. In a study by Higuchi et al.¹⁷⁾, insufficient human resources and in-hospital systems for lymphedema care, such as the absence of therapists with specialized knowledge and skills and dependence on individual nurses' and wards' judgments, respectively, were noted as challenges of such care. As a future perspective, marketing, including estimating the number of patients and confirming the presence/absence of similar service providers in surrounding areas, as well as outpatient service arrangements, such as the pattern of assigning nurses, their number for teamwork, and scheduling for service provision on fixed days, may be useful when organizing facilities to provide outpatient lymphedema treatment performed by nurses. Education materials were originally developed and created in most cases, while technical support tended to be obtained from personal advisors. It is desirable for such materials to contain appropriate contents with the newest information, and approaches to maintain and improve technical skills are needed to perform optimal techniques for patients. Therefore, outpatient lymphedema treatment systems should be operated in consideration of the necessity of supporting knowledge and technical skills. From these viewpoints, the results of the present study are likely to provide basic information for nursing departments of medical institutions to organize and operate lymphedema treatment systems.

2) Characteristics of nursing care for patients with lymphedema after cancer surgery

Nursing care for patients with lymphedema after cancer surgery was characterized by 5 categories: <improving acute-stage symptoms>, <preventing complications>, <supporting continuous self-care>, <guiding toward healthier life patterns>, and <providing information regarding social resources>.

<Improving acute-stage symptoms> outlines nursing care to promptly improve distress due to dermatitis

or other symptoms in the early stages of lymphedema and when it suddenly deteriorates. A reduction in distress not only enhances patients' QOL, but also motivates them to perform self-care more actively to alleviate their symptoms. The probability of a person performing a behavior increases when he expects a favorable outcome of the behavior (outcome expectancies), and perceives that he is capable of successfully performing it (self-efficacy)¹⁸⁾. <Improving acute-stage symptoms> may promote the former outcome expectancies. <Supporting continuous self-care> refers to the examination of factors related to the continuation of self-care by patients and approaches to support it. The sub-scales {motivating individual patients appropriately to continue performing self-care} and {showing points of the continuation of self-care (without seeking perfection)} outline approaches to enhance patients' self-efficacy. In these respects, the initiation and continuation of self-care for lymphedema by patients may be supported by <improving acute-stage symptoms> and <supporting continuous self-care>.

<Preventing complications> also refers to assessment and knowledge provision for approaches to prevent the complications of lymphedema. It has been reported that approximately 20% of patients with lymphedema have a history of phlegmon as the most common complication, which is recurrent in the majority of these cases¹⁹⁾, highlighting the importance of prevention, early identification, and management. Such management may be covered by the sub-categories of this category, {assessment (environments, working conditions, and life patterns)} and {knowledge acquisition in accordance with lifestyles}.

<Guiding toward healthier life patterns> represents approaches to improve patients' life patterns as a basis for the continuation of self-care. As housekeeping duties and lifestyles are closely associated with risk factors in patients with lymphedema after breast cancer surgery²⁰⁾, such approaches may be necessary to prevent the development and deterioration of symptoms, and maintain a favorable condition.

<Providing information regarding social resources> refers to the provision of information regarding social resources, such as living environments, medical ser-

vices, national policies, and support systems, in accordance with patients' conditions. Kudo, et al.²¹⁾ revealed that patients after breast or other gynecologic cancer surgery tend to face sociopsychological distress, in addition to financial burdens, due to limited access to information in the presence of lymphedema. Patients' level of need for information regarding social resources is also high at this point, and <providing information regarding social resources> may represent approaches to accommodate such a need.

In short, the 5 categories representing nursing care for patients with lymphedema after cancer surgery explain support approaches for patients to perform safe, comfortable, and independent lymphedema management through continuous self-care. Among these categories, 4, excluding <providing information regarding social resources>, consisted of sub-categories covering assessment, confirming that care was being provided based on the results of assessment related to each category.

From the point of view of the development of clinical knowledge, Benner focused on the specific knowledge types of nurses in nursing practice. Benner identified 7 domains of nursing care: the helping role; teaching-coaching function; diagnostic and patient monitoring function; effective management of rapidly changing situations; administering and monitoring therapeutic interventions and regimens; monitoring and ensuring the quality of healthcare practices; and organizational work role competencies. Along with the identification of these domains, she noted 5 stages of skill acquisition to practice such nursing, from novice to expert²²⁾. Some of the 5 categories representing the characteristics of nursing care for patients with lymphedema after cancer surgery extracted in the present study are consistent with the 7 domains identified by Benner, but none covered 'effective management of rapidly changing situations', possibly due to the characteristics of the disorder and nursing setting. Furthermore, although some of the nurses' statements referred to the domain 'organizational work role competencies', they were finally summarized into 'systems to provide lymphedema care', based on the results of analysis. Except for that provided as part of nursing during educational hospitalization, lym-

lymphedema care is completed by performing a 60- to 90-minute combined treatment procedure. Therefore, it may be characterized by the process of establishing patient-nurse relationships, and developing nursing practice needed by individual patients, while repeating such a therapeutic session. 5 items are considered relationships, orderliness and mutual are encapsulated. Future issues using quantitative research methods to address the structural mechanism verification of the features of lymphedema care.

Conclusion

Nursing care for patients with lymphedema after cancer surgery was characterized by 5 categories : <improving acute-stage symptoms>, <preventing complications>, <supporting continuous self-care>, <guiding toward healthier life patterns>, and <providing information regarding social resources>. Each category consisted of multiple sub-categories.

Funding sources : This work was supported by JSPS KAKENHI, Grant Number 26293463.

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がん術後リンパ浮腫看護の特徴

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要 旨

目的：がん術後リンパ浮腫患者に特有である長期にわたるセルフケアによる症状コントロールを支える看護の特徴を明らかにすることを目的とした。

方法：がん術後リンパ浮腫ケアに従事する同意の得られた看護師 8 名を対象に半構造化インタビューを行った。収集したデータからリンパ浮腫看護の特徴に関連するデータを取り出し、それぞれの意味と類似性、差異を比較検討しながら質的に分析を行った。

結果：がん術後リンパ浮腫患者への看護の特徴として、1. 「急性期症状の改善」 2. 「合併症の予防を図る」 3. 「セルフケアの継続を支える」 4. 「生活パターンの健全化を方向付ける」 5. 「社会資源の情報提供を行う」の 5 項目を見出すことができた。また、ケア提供システムについては、1. 配置形態, 2. 場所の確保, 3. 時間の確保, 4. チーム体制と患者担当制, 5. 受診患者数, 6. 物品管理, 7. 指導教材, 8. スーパーバイザー・相談相手の存在が構成要素として見出された。

キーワード：がん術後リンパ浮腫, セルフケア支援, リンパ浮腫外来