Experience of Women Living with Lymphedema

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**Purpose.** The object of this study was to explore and describe the experience of women living with lymphedema within a socio-medical context in Korea.

**Methods.** Research data was collected through interviews and participant observation with 9 informants between February 2000 and July 2002. Data was examined using Spradley’s taxonomy analyzing techniques.

**Results.** 5 themes were identified; ‘overwhelming and despair over the ailment condition’, ‘distrust and abandoning of conventional medicine’ ‘shaming of losing maternity and femineity’, ‘returning to the permanent safe shelter’, and ‘struggling for reconstruction of one’s self’. The ‘chaotic’ state of knowledge and health care system for lymphedmea patient affected the experiences of informants.

**Conclusions.** This result will be a basic understanding of psychosocial impact of lymphedema for the women and to develop the comprehensive nursing program including counseling program.

**Key Words:** Women’s experience; Lymphedema; Ethnoscience, Socio-medical context

**INTRODUCTION**

Lymphedema is a common and devastating condition that 2 out of 15 people experience during their lifetime (Casley-Smith, 1997). Lymphedema refers to abnormal accumulation of protein-rich body fluid in the interstitial space (Swirsky & Nannery, 1998). In stagnant lymph, waste products, cellular debris, lymphocytes, macrophages, and other cells are accumulated. The trapping of immune cells, and local proliferation secondary to antigenic responses produce inflammatory process and cause such symptoms as swelling, pain, or flaring of affected limb (Francis, 1998). Beside these symptoms, patients suffer from complications such as fibrosis, loss of range of motion, decreased functional use of the extremity, recurrent cellulites or dermatolymphangitis, psychological and social distress, and rarely, fatal lymphangiosacroma (Casley-Smith, 1992). For women, this condition gives a suffering of disfigurement (Carter, 1997).

During the past 30 years, the knowledge and treatment of lymphedema has been advanced rapidly (Hajdu, 1999). This condition can be managed successfully through complex physiotherapy, life long self-care, and early detection. But this is not the case in Korea. Very often, healthcare providers neglected this condition as an untreatable ailment. As a result, patients had to live with a heavy and huge limb (Kim & Whang, 1999).

Lymphedema is a lifelong health condition that collaborative teamwork is needed to achieve the possible results of treatment. As a member of a collaborative team, nurses take a role of case manager. Nurses are responsible for assessment of physical and psychosocial condition of patients, patient education, and implementation of strategies to motivate and support patients (Smith,
Therefore, the key to nursing the patients with lymphedema is the understanding of their experience.

This study is aimed at exploring the psychosocial impact of lymphedema. To understand the experience of women within a socio-medical context, an ethnoscienctific method was applied. The research question was, "What do women with lymphedema experience in their daily lives and during treatment, what socio-medical context affect her experience?"

**METHODS**

1. **Data collection**

Nine women living with lymphedema were included in this study. Two of them had lymphedema in a leg, two women in both legs, four women in an arm, and one had in an arm and face. Each informant has been suffered with lymphedema from for 4 month to 10 years. The grade of their lymphedema was I or II. The cause of their lymphedema was surgery and radiation for treating breast cancer or uterine cancer, and trauma on a leg.

Research data was collected from February 2000 to July 2002 using interviews and observation. Each woman completed four to ten interviews, exploring her experience accessing health care for lymphedema, complying with recommended regimens, and managing lymphedema through self-care and daily activities. Participant observation was conducted in the informants' home, researcher's office, market, and health care facilities.

2. **Data analysis**

Reflective thinking was applied throughout the process of data analysis. Line by line analyses and highlighting analyses were conducted. Spradley's (1990) taxonomic analysis was adopted. Informants verified the data for truth and meaning. The identified themes were modified with suggestions made by the women informants. Seven nurses crosschecked the themes.

3. **Ethical concerns**

Permission to conduct the interview and participant observation was given verbally and recorded by audiotape. Interviews were recorded only with permission. Interview and participant observation took place while conducting an educational program for self-care. In the case of participating in the daily life of informants, the researcher lent a helping hand with cooking, cleaning, driving, and shopping. Issues that the informants refused to discuss were not addressed. Comments that informants did not wish to disclose were excluded from this report.

**RESULTS AND DISCUSSION**

1. **Socio-medical context**

The states of knowledge and treatment of lymphedema in Korea are aptly described as “chaos”. Unfortunately, there are no reliable statistics for Korean patients with the lymphedema until recent. However, there are many cases of diseases such as breast cancer, uterine cancer, prosthesis cancer in Korea, and these diseases are controlled through operation and radiation therapy. Based on the available data, we can assume that there are many patients suffering from lymphedema.

As any other country, patients in Korea rely on formal and informal health care systems to treat their health problem. In formal health care system, doctors and herbal doctors are responsible for the treatment of lymphedema as is the case in any other health problem. Medical professional are educated at universities and certified from the Health and Social Agency of Korea.

As Dr. Casley-Smith (1995, 1998) recommended, diagnosis of lymphedema is carried out through reviewing health history, physical examination, and diagnostic testing. Lymphography and lymphacintigraphy are the most common and useful forms of diagnostic tests. In Korean hospital, the doctor commonly applied diagnostic test such as M.R.I., C.T., Ultra Doppler Image, venography, and angiography. The expense to the patient has very high, and besides, most of the tests were not verified as useful for the diagnosis of lymphedema.

The most effective therapy for lymphedema is Complex Physiotherapy (Hajdu, 1999). This therapy should be provided by a trained personal. Otherwise, the condition of the patient may get worse. Unfortunately, there are few trained therapists in Korea. Informants of this study were treated from untrained physical therapists and nurse aids.

The success of treatment depends on a collaborative team approach from doctors, nurses, physical therapists, and patients and his or her family. But, in Korea, there is no network for treatment of lymphedema between health care professionals or health care facilities. The doctors have strong belief that only the doctor treat patient. The nurses avoid to involved in treatment of lym-
lymphedema because they don’t want to infringe on doctor’s right.

Moreover, health insurance does not pay for the C.P.T., but it does pay for the compression pump. So the patient does not receive treatment expenses. If a patient pays by his private money for the C.P.T., it is considered illegal. Therefore, the doctor and physical therapist apply the mechanical pump, drugs, and surgery for their convenience. But, this treatment not recommended by National Lymphedema Network due to its ineffectiveness (Lerner, 1997).

In oriental medical clinic, the herbal doctor used acupuncture, electrical stimulation therapy, moxau cautery, negative cupping, herbal drugs, a mechanical pump, and so on. Very often, the patients experienced complications from this therapy.

Naturally, the patients turned to non-professional sources of information and informal health care systems. Many were even looking for an exorcist in order to get remedies. In informal health care systems, many folk healers are involved in the treatment of health conditions such as lymphedema. The folk healers gain skills in massage, exercise, or acupuncture by themselves. They applied these skills for treatment of all health problems. That is, to the folk healers, treatment of lymphedema does not differ from any other health problem. The treatment by folk healers is not recognized formally by the Health and Social Agency, and not paid for by national health insurance or private health insurance. Moreover, these regimens are not verified its effectiveness. Very often, the patients' health conditions became worse due to folk remedies. But, all informants relied on folk healers to treat their lymphedema, and paid expensive fee for the treatment.

The experience of patients living with lymphedema was affected above socio-medical context.

2. Themes in experiences of women with lymphedema

The following 5 themes were identified in the experiences of informants:

- Overwhelming and despair over the ailment condition
- Distrust and abandonment of conventional medicine
- Shaming of losing maternity and femininity
- Returning to the permanent safe shelter
- Struggling for reconstruction of self

Informants went through many experiences in their daily life and treatment of lymphedema. They were overwhelmed over the ailment condition, frustrated at the scarcity and disorganization of treatment modalities. They were also disappointed and angered at the medical personal’s ignorance and insensitivity to them. They felt shame at incompetent life and imperfect image. Relationship with their family, friends, and neighbors became closer as a result of mistrust to medical personal. Informants went through various phases to integrate self. Through their ordeals with lymphedema, women would develop a strong independent character in them selves.

1) Overwhelming and despair over the ailment condition

Generally, lymphedema is accepted as a more agonizing disease than cancer for patients. The symptoms of the disease give patients ‘inexpressible, uncomfortable feelings’. The patients feel uneasy and disturbed. In addition, doctors tell patients that they should live with the pain because there is no certain treatment for the disease. Living with an incurable disease is deemed as worse than death. The following statement shows this:.

“I would rather die than live like this. Cancer is better than this. I should not have had the operation at that time. Suddenly I felt something. When I came back to my ward after the operation, I thought something was wrong. I didn’t know what it was exactly. Oh, that was it. (Symptoms were) Very uncomfortable! I would rather die now than live like this all my life.”

As quoted above, the fact that the symptoms are obscure and will be persist to the end of life, there are few useful treatments. In addition the current treatments are confusing and force people to recognize that lymphedema is worse than cancer.

2) Distrust and abandonment of conventional medicine

Informants hope to manage their condition through a systemic health care program. Afraid of their condition getting worse, they didn’t know what caused their condition, or from whom they could get effective treatment. Thus patients didn’t know how to manages their life with it. Constantly assessing their doctor about their condition, but without availilng any informants about lymphedema. The nurses were unable to aid patients because information in regards to lymphedema was unavailable during their undergraduate course. Physical therapists in some case applied mechanical pressure pumps for treatment.

Uncertain and inconsistent answers from physicians in charge caused patients to misunderstand the disease, and
as a result cancer treatments were applied by mistake. They were also disappointed at the doctors’ insensitivity to the patients and their health problems. Generally there was a limited knowledge about lymphedema and how patients reacted to the side effects of treatment. Patients were so angry at the doctors who told them “Oh, you must lose your body weight” or “It is not my business to treat your swollen arm” or “Lymphedema is nothing special compared to cancer”. Likewise, nurses who tell them that they should accept the disease because it may be God’s will, without giving any information relating to health care to the patients who expect quality treatment. Patients felt they are abandoned from the medical profession.

3) Shaming of losing maternity and femininity

Many female lymphedema patients lost various bodily functions, had an inability to do daily activities, and lost employment. Activities such as going shopping, visiting friends, and going to the hospital as well as cleaning and washing are limited. Korean women believe that they are responsible not only for their children’s education and marriage, but also for the life of the children even after they are married. Some patients even lost this role of mother. They felt guilty and considered themselves as worthless. Patients who quit their jobs after contracting the disease suffered a more severe feelings of defeat. They felt themselves being useless rather than their income just being reduced.

Plump arms and legs not only create inconvenience but also detract from a feminine appearance. The patients feel shy towards everyone and are easily hurt even during normal conversation. Avoidance of public baths’ for years and the wearing of clothes with long sleeves or trailing skirts, covering their arms and legs even in the summer. They avoid contact with people protecting themselves from getting emotionally hurt.

4) Returning to the permanent safe shelter

After being left in the dark corners of the formal health care system, patients are getting closer to their families, neighbors and friends. They depend on their families and neighbors for health care and assistance in decisions for treatment modalities, as well as most aspects of daily life. Their grown-up children play an important role as their friends and guardian, as well as assistants in the treatment. The children also show mature attitudes, responsibility for their own duties. The patients feel sorry yet confident towards their children. Their families become a source of solace for them.

Their neighbors also bring them information about many folk remedies. They used these remedies to keep their good relations with their support network, even though they might not believe in remedies. That is, they confine themselves to their families and neighbors who take care of them.

5) Struggling for reconstruction of self

Lymphedema is more of a suffering health condition for patients rather than being a life-threatening disease. Frequent infection and inflammation, large and heavy limbs, and complications in self-care exhaust them. They take care of themselves all their lives and live a constant struggle with only limited functions. The following statement shows this:

“I think a war against the disease and myself has begun. It is not easy to overcome. I don’t really want to go for a swim or exercise. But, if I live—-, and (my legs) won’t be like an elephant, I should do that, they say. Living is a war.”

The patients endure many things through the struggle against their lives, find out their own merits, get to have self-confidence, and gain more interest in people. Acquiring information about lymphedema and a self-care ‘know-how,’ they call themselves ‘specialists for lymphedema’, and take pride in housekeeping for their married children. The patients who relieve the symptoms by self-care may give advice to those who have the same problems as them or plan to serve the elderly or orphans.

Thus, patients are integrating themselves through a struggle against pain in finding out and maintaining lymphedema with assistance from their neighbors.

CONCLUSIONS AND RECOMMENDATIONS

Women with lymphedema experienced many difficulties in their daily lives and during treatment. They struggled to overcome their health problems and to integrate within the daily routine.

Lymphedema is a health problem to be cared for a lifetime. Interdisciplinary approaches are needed for chronic and complicated health problems like as lymphedema. Assistance by families and neighbors, having the accurate information and the cooperative and systematic approach by those engaged in medical service are absolute
factors in comprehensive health care of patients. As a team member for the care of patients, a nurse should understand emotional experiences as well as physical problems and help them manage their lives successfully. The result of this study will be the basic data used to understand experiences of women living with lymphedema and develop the comprehensive nursing intervention. Based on this study, the following works need to be continued.

First, counseling programs should be prepared to understand and assist the women suffered from lymphedema. Second, educational programs for nurses aimed at high-risk cases should be developed to promote early intervention and prevention for lymphedema. Third, interdisciplinary researches and team approach should be performed to manage health problems comprehensively. Fourth, educational programs for nurses should be prepared to provide qualified nursing care.

References