UNIVERSITY OF SOUTHAMPTON

FACULTY OF MEDICINE, HEALTH AND LIFE SCIENCES

School of Psychology

The Development of a new Quality of Life Measure for Japanese Female Breast Cancer Patients with Lymphoedema

by

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ABSTRACT

FACULTY OF MEDICINE, HEALTH AND LIFE SCIENCES
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THE DEVELOPMENT OF A NEW QUALITY OF LIFE MEASURE FOR JAPANESE FEMALE BREAST CANCER PATIENTS WITH LYMPHOEDEMA

by Miyako Tsuchiya

The main aim of the study is to develop a new Quality of Life measure among female breast cancer patients in Japan, and the main research question is to investigate how perceptions of information provision are associated with the Quality of Life.

Three studies were conducted, with participants being recruited from self-help groups in Japan. First, a symptom checklist and physical discomfort scale in lymphoedema was developed. Test-retest reliability and the internal structure of the scale were investigated by a prospective study. Second, a qualitative study was conducted in order to explore perceptions of lymphoedema and how they were formed in the society. A dual analytic approach was applied to primary transcripts: thematic analysis and conceptual analysis using symbolic interactionism. Based on the findings of the conceptual analysis, a psycho-social discomfort scale was developed. Psychometric properties were investigated. The WHO QoL-BREF Japanese version was used to check criterion validity in a cross-sectional survey study.

Test-retest reliabilities of the check list and physical discomfort scale were acceptable. Perceptions of information provision at diagnosis and loss of strength were associated with reported discomfort. The qualitative analysis revealed cognitive and emotional processes in breast cancer and lymphoedema. Experiences of lymphoedema were often interpreted in breast cancer contexts. The third study showed that the 'breast cancer' subscales of the psycho-social discomfort scale had good internal consistency, and good convergent and divergent validity. However, the lymphoedema subscales had a weak internal structure. 'Perceptions of information provision' were associated with the 'resources to live with breast cancer' subscale.

In conclusion, the validity of the symptom checklist, physical discomfort scales, and breast cancer subscales were acceptable. Since the lymphoedema subscales had a weak internal structure, further work is needed in the development of the measure.

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Preface

The development of breast cancer self-help groups in Japan has been surprisingly rapid. When I first studied information needs among breast cancer patients eight years ago, there were only four or five groups in the Tokyo area, and there was no accessible information about groups in other areas. Now if you browse the Internet, you easily find that there are more than 70 breast cancer self-help groups! This development is really appreciated since it can provide an opportunity to access members with breast cancer.

Due to the development of the groups and computer technology, cancer patients may access medical information easily, compared to ten or twenty years ago. However, a question is raised; can patients get the information that they really need from doctors? If not, how do they feel about the lack of information and their doctor-in-charge? How do these perceptions affect their Quality of Life?

These questions were formed by the qualitative study I undertook as part of my M.Sc degree, by reviewing the literature, and my personal experiences; my mother died of cancer thirteen years ago. At that time, the practice of truth telling in oncology was not well established in Japan, and most cancer patients did not know their true diagnosis and the aims of treatment. My mother did not know anything about the disease and treatment and my family, including me, did not know much about what would happen to her (after surgery and chemotherapy). She underwent surgery several times even though the cancer had metastasised to her bones, and she believed that she would be cured and walk again. All my family believed all the treatment would work well. Then one day, she cried out, ‘what is my life for?’ Till then I did not know how much pain she was in, and how unhappy she was in the hospital.

The studies in this thesis were conceived because I wish that all cancer patients will be provided with adequate information that helps them to share their concerns with loved one and doctors, and make life as good as possible for them.

Overview of the thesis

In this research programme, the long-term effect of breast surgery, lymphoedema, on women in Japan is the focus of interest, and influential factors which facilitate or inhibit women's adjustment to the effects are investigated; social factors and women's needs are emphasised.

Because there are no adequate measures for this population to assess these effects, the development of a new measure for breast cancer (BC) patients with lymphoedema is proposed. Three empirical studies conducted in Japan are reported accordingly; in the first, a prospective mail survey study, symptom checklists for lymphoedema and physical discomfort associated with lymphoedema are developed, and their reliability is investigated. Next, in a qualitative study, perceptions of lymphoedema, and how the perceptions are constructed in Japanese society, are explored. In the second cross-sectional survey study, psycho-social discomfort scales are developed using the results of the qualitative study, and their psychometric properties are investigated.

The structure of this thesis is briefly introduced. In Chapter 1, following descriptions of BC and treatment, the concept of Quality of Life (QoL) is discussed comparing between psychology literature and psycho-oncology literature. The insufficient base of research and methodological issues in psycho-oncology are also discussed. To understand BC patients' needs and how they are associated with QoL, a literature review on social support is presented in Chapter 2. In Chapter 3, to understand why we need to pay more attention to post-operative complications (secondary lymphoedema), physiology, aetiology, and risk factors of secondary lymphoedema are briefly introduced, and a literature review on QoL research among BC patients with lymphoedema is presented. In Chapter 4, the first empirical survey study is reported. In Chapter 5, issues of cross-cultural studies are discussed, and the methodology applied for the second study is justified. In Chapter 6, the second empirical study is reported. In Chapter 7, the third empirical study is reported. In Chapter 8, the findings of the three studies, methodologies, and theoretical contributions are discussed. Finally, study implications and further research are suggested.

1. Introduction

INTRODUCTION

In this chapter, following a brief description of breast cancer (BC) and its treatment, the concept of Quality of Life (QoL) is broadly discussed in order to identify important aspects of QoL. Next, health-related (HR) QoL research in psycho-oncology and frequently used methodologies are introduced. Finally, issues of HRQoL research are discussed in terms of the concept of QoL, methodology, and insufficient research in the area.

EPIDEMIOLOGY OF BREAST CANCER

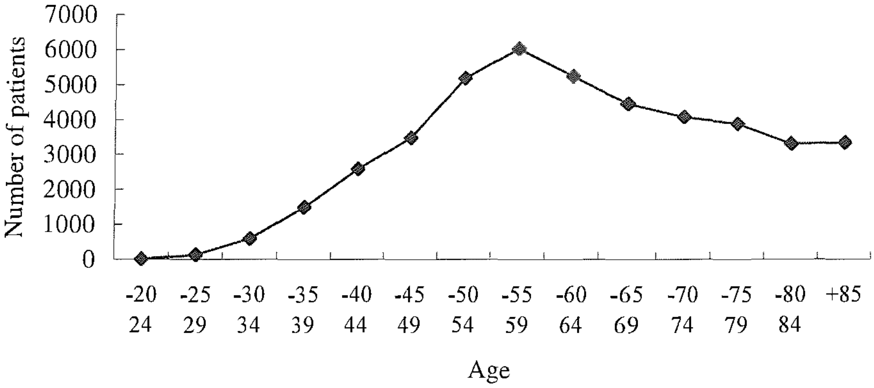
BC is a life-threatening disease and chronic illness, and in the West it is the commonest disease among women, with a high mortality rate. For example, in the UK one in nine women develops BC in her life, and 40.4 (per 100.000) were estimated to die from the cancer in 2004 (Cancer Research UK 2006a). On the contrary, in the East it is a less common disease among women although the mortality rate is still high and the incidence rate has been increasing. For example, in Japan, one in thirty women developed BC in her life in 2002 (the Ministry of Health, Labour and Welfare 2004), but in 2004 one in twenty women developed BC in her life, and 16.3 (per 100,000) were estimated to die from the cancer (the Ministry of Health, Labour and Welfare 2006).

Nowadays, BC in the early stage is curable owing to improvements in medical technologies and to early detection of the disease. As a result, disease-free survival years after the completion of treatment have become prolonged among many patients. For example, in the UK (England and Wales) the overall five year survival rate was 80 per cent in 2001-2003 (Cancer Research UK 2006b). If the cancer is treated at an early stage, the five year survival rate from that stage increases to 87.8 per cent. In Japan, the overall five year survival rate was 75 per cent in 2001 (National Cancer Institute 2001). If the cancer is treated at an early stage, the survival rate from that stage increases to 90 per cent. Accordingly, most early stage BC patients in both countries can live on as survivors.

Risk factors for breast cancer

There are several risk factors contributing to developing BC. First, it is related to female hormones that are called estrogens, so the longer the duration of producing estrogens, the higher the risk. Thus, an early menarche, a late menopause, and a late first pregnancy are high risks. Second, age is an important risk factor. It is well established that the high risk age varies among countries. For example, as Figure 1.1 shows, in the UK the frequency gradually increases between age 25-29 and age 50-54, and peaks between age 55-59 years old. This pattern is different in Japan, as Figure 1.2 shows; the estimated number rapidly increases around age 35-39, and peaks between 45-49 years old. Therefore, in the UK, most women who develop BC do so after the menopause (over 50 years old), whereas in Japan most women who develop BC do so before the menopause.

Figure 1.1 *The Frequency of Newly Diagnosed Breast Cancer Patients in the UK*



(Source: from UK Breast Cancer Incidence Statistics in 2003; Cancer Research UK 2006c)

Figure 1.2 *The Estimated Number of Newly Diagnosed Patients in Japan*

(Source: From Cancer Statistics in 1999; National Cancer Institute 2001)

BC developing after the menopause may be grouped as a nutrition-related type. On the other hand, BC developing before the menopause may be grouped as an ovary-related type; that is, related to problems in ovarian functions (Miura 1999). However, since Japanese life styles and eating habits have been westernised, the pattern of the onset of age in Japan is predicted to become more similar to that in the UK in the future.

MEDICAL TREATMENT OF BREAST CANCER

In this section, medical treatment of BC is briefly introduced. BC is classified into four types: invasive ductal breast carcinoma, invasive lobular breast carcinoma, inflammatory BC, and Paget's disease. Among these types, the most common type of cancer (70 to 80 per cent) is invasive ductal breast carcinoma (Cancer Research UK 2006d). Although invasive lobular breast carcinoma develops in different sites of the breast from invasive ductal breast carcinoma, the treatment is the same for both types of cancer. Treatment and diagnostic procedures for the two types are focused on during the rest of this section.

The types of the treatment that patients undertake are initially determined by the cancer stage. Before surgeons diagnose a patient with BC, they conduct several medical examinations, such as mammography, ultrasound, fine needle aspiration, blood tests, and so on. If the results obtained from these examinations are contradictory, surgeons conduct further examination, such as needle biopsy or excision biopsy. As a result of these examinations, surgeons classify the cancer into a stage (see Table1.1). Considering the stage, the tumour size, patient's age, and the other relevant information obtained from the examinations, surgeons determine treatment plans.

Table 1.1 *International Classifications of Breast Cancer Stages*

	Tumour sizes	Lymph glands affected	Metastasis
Stage 0	Tis	N0	M0
Stage I	T1	N0	M0
Stage IIa	T0, T1	N1	M0
	T2	N0	M0
Stage IIb	T2	N1	M0
	T3	N0	M0
Stage IIIa	T0, T1, T3	N2	M0
	T3	N1, N2	M0
Stage IIIb	T4	Any	M0
	Any	N3	M0
Stage IV	Any	Any	M1

Note: Tis = Not invasive, T1 =/< 2cm, T2 = 2 to 5 cm, T3 =/>5 cm, and T4 = fixed to chest wall or skin. N0 = no spread to axillary lymph nodes, N1 = spread to axillary lymph nodes, N2 = lymph node are attached to each other, and N3 = spread to lymph nodes inside the chest wall. M0 = no metastasis and M1 = metastasis.

First of all, the initial treatment that a surgeon usually recommends is surgery, attempting to remove cancer cells from breast tissue as much as possible. The types of surgery are classified into five types: radical mastectomies modified radical mastectomies, simple mastectomies, quadrantectomies, and lumpectomies. Radical mastectomies remove the breast, lymph glands, and some muscles of the chest wall. Modified radical mastectomies remove the breast and lymph glands. Simple mastectomies remove the breast tissue alone. Quandrantectomies remove more breast tissue than lumpectomies. Lumpectomies remove only the lump and surrounding tissues. Quadrantectomies and lumpectomies are often called conserving surgery. For patients who have had mastectomies, breast re-construction surgery is now an option.

In addition, a surgeon usually removes one or more axillary lymph glands under the arm on the operated side in order to check the prognosis and determine adjuvant therapy; if there are any cancer cells in the lymph glands, it means that cancer cells have already spread to the other organs.

While the axillary lymph gland dissections are beneficial to check prognosis, they are also a risk factor of post-operative arm complications (Herd-Smith et al. 2001; Johansen et al. 2000; Keramopoulos et al. 1993). To overcome the demerit, recently a more sophisticated method - sentinel node biopsy (SNB) - is available in some countries; the new method can detect whether there are cancer cells in nodes during surgery, and the surgeon can remove only the node involving cancer cells at the same time.

Whether this new method will decrease the risk of arm complications has been investigated in a clinical trial. For example, Mansel et al. (2006) sampled BC patients without positive node status, and they were randomly assigned to either axillary lymph node dissection (ALND) or SNB. Mansel et al. found that participants in the SNB group were less likely to report arm and shoulder morbidity than those in the ALND group. However, it is as yet still arguable whether SNB is beneficial for long-term outcomes, such as recurrence (Pater and Parulekar 2006).

Next, depending on the type of surgery and the lymph node status, surgeons may recommend that a patient takes adjuvant therapy, such as radiotherapy, chemotherapy or hormone therapy. Conserving surgery is usually followed by adjuvant radiotherapy. This may give patients side effects, such as 'red, sore skin, tiredness, and nausea' (Fallowfield and Clark 1991: 11). The axillary fossa, supraclavicular fossa, and/or breast are usually irradiated.

If a patient has not reached the menopause, surgeons usually recommend chemotherapy. This gives some patients side effects, such as 'hair loss, nausea, and vomiting' (Fallowfield et al. 1991: 12). If the patient has the type of estrogen receptor that helps to increase cancer cells, surgeons also recommend hormone therapy, such as Tamoxifen. This gives some patients side effects, such as hot flushes and mood disturbance. Although the side effects are not as severe as in the other adjuvant therapies, patients need to take the drugs for five years or sometimes longer.

In summary, BC is a life-threatening disease but, if it is detected at an early stage and treated properly, most patients can survive. Each treatment may lead to severe side effects.

QUALITY OF LIFE RESEARCH

Overview of psycho-oncology research

Until the 1970s, early psycho-oncology research investigated the impact of surgery and treatment from the viewpoint of how long patients could survive. Many doctors did not tell their patients the true diagnosis (Greer 1994), so little research about cancer patients' psychological aspects and social aspects was conducted. As the survival rate increased and the true diagnosis was told, the impact of cancer disclosure was extensively explored; consistent results have been reported, for example, negative responses towards the diagnosis, such as shock, anxiety and depression (Cassileth et al. 1985; Fallowfield et al. 1990; Hosaka and Aoki 1996). Also the impact of cancer treatment was explored; consistent results have been reported, for example, negative responses toward side effects of adjuvant therapy and types of surgery that patients undergo (Fallowfield et al. 1990). These reactions have been also reported by the patients' family members, such as spouses and offspring (Cassileth et al. 1985).

In order to find ways of minimising these negative responses as much as possible, further studies have been conducted to explore patients' coping strategies and social support (Bloom 1982) including information needs (Luker et al. 1995, 1996; Hamajima et al. 1996) and a sense of personal control (Northouse and Northouse 1987).

In the 1990s, the term Quality of Life (QoL) was frequently added to adjustment and coping (Zebrack 2000a). Researchers attempted to explore patients' total life quality using a multidimensional, bio-psycho-social approach. In determining how best to maximise treatment effects and simultaneously minimise patients' negative responses, the concept of QoL has been an important end-point in clinical settings.

What is QoL?

The objective of the rest of this chapter is to discuss the concept of health-related QoL (HRQoL) and the methodology in psycho-oncology research. To do this, first of all, the wider concept of QoL is illustrated.

The concept of Quality of Life

> L'homme qui a le plus vécu n ' est pas celui qui a compté le plus d'années, mais
> celui qui a le plus senti la vie.
>
> (Rousseau 1973, Book 1, ¶41)

The term 'QoL' has been widely used not only in the research world, but also in the lay world. In both worlds, achieving a good life seems to be accepted as human beings' goal, but what is 'good' for human beings has not yet been fully answered. Although QoL has been recognised as an important concept nowadays, the definition of QoL has not reached a consensus; for example, as Table 1.2 presents, researchers in various disciplines have defined the term differently, according to their research purposes and interests (Raphael et al. 1996).

Table 1.2 *Examples of the Definition of Quality of Life*

Author	Year	Definitions
McDowell et al.	1996	Quality of life relates both to the adequacy of material circumstances and to one's feelings about these circumstances.
Ferrans	1990	A person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her.
Schipper	1990	QoL is defined as representation of people's day–to–day function.
Raphael et al.	1996	The degree to which a person enjoys the important possibilities of his/her life.

However, it has been accepted that there are two important aspects that determine one's life quality: objectivities and subjectivities. In the next section, the two aspects are presented with reference to literature in gerontology, social indicator research, and psychology.

Objectivities

First, according to a dictionary definition of 'life' (Collins Cobuild 1995), people's life refers to 'a period of time during which they are alive' and 'particular activities which people regularly do during their lives'. Based on the dictionary definitions, a good life is how long people are alive and how well people are able to do activities in everyday life.

This definition leads to the question: does aging inevitably decrease one's life quality? In general, the elderly cannot live longer than the younger can. Nor can the elderly do as many activities as they did previously. In fact, gerontology research has answered negatively to the question. For example, Pitkala et al. (2004) conducted a longitudinal study, investigating life satisfaction among people who were above 75 years old. They found that most participants who were above 85 years old reported that they were satisfied with their lives at ten year follow-up.

This study implies that one's life quality might be more than life span and physical capability.

Other objective conditions - wealth and income - have been considered as predictors of life quality in social indicator research; whether economic conditions can bring happiness has been examined. For example, Easterlin (2001), who investigated the relationships between income and feelings of happiness in the USA, found that higher income than the average was associated with feelings of happiness, but the association was weak (correlation = 0.21).

Studies in both gerontology and social indicators research have suggested that objective measures alone cannot explain people's life quality, and that it is important to understand why people feel happy in objectively bad conditions. As quoted at the beginning in this section, the French philosopher, Jean-Jacques Rousseau, wrote in his book 'Emile' that 'the man who has lived the most is not he who has counted the most years but he who has most felt life' (Roosevelt 2004). Rousseau suggested the importance of subjectivities in our life.

What are subjectivities? How can we assess them? How do we subjectively view and evaluate our world? In the next section, selective theories of cognitive appraisal are illustrated.

Subjectivities

Subjectivities refer to internal environments, such as personal judgement. Even if people have experienced the same events, they could evaluate the experiences differently. The importance of understanding these cognitive appraisals is frequently addressed in well-being literature; there are three main theories -- positive-negative affect, internal sources of information, and social comparisons.

First, Bradburn (1969) proposed that happiness is determined by the balance of positive-negative events (positive-negative affects). Bradburn argued that if an event appraised as negative (a negative event) occurs to people, or an event appraised as positive (a positive event) does not occur to them, then people will not feel happy. However, if a positive event occurs immediately after a negative event, people might feel happy. Thus, the positive event offsets feelings of unhappiness. As a result, people will judge that they are happy overall.

Bradburn's theory has been investigated in many empirical studies. For example, Charles et al. (2001) conducted a longitudinal study between 1971 and 1994, and examined positive-negative affect among 2804 people, using the Bradburn Affect Balance Scale (Bradburn 1969). Charles et al. found that negative events decreased as people grew older, but that positive events were relatively stable. Charles et al. concluded that the findings may be useful to interpret the reasons why older adults reported higher feelings of happiness than younger people did, which was consistent with Bradburn's theory.

Second, Schwarz and Bless (1992) proposed a cognitive process of intra-individual comparisons using three terms -- information, target, and standard. They argued that when people think about how their present lives are, they quickly review events of their whole life. In fact, however, people rarely recall all events, but usually recall high impact events or events of current concern for people (a target category). Thus, people judge their current lives by using the most accessible events (information). Depending on how people use the information, the outcome of the judgment varies; for example, a positive recent event (target) enhances feelings of happiness for current life. A negative past event (standard) also enhances feelings of happiness for current life, even though the current life is not so good (e.g. my life of the past few years was terrible, so I am feeling happier now than at that time). In the case that people believe that their lives should be better in the near future (standard), they are not satisfied with their present situation, so this expectation does not enhance feelings of happiness for the current life.

Third, Festinger (1954) proposed the theory of social comparison. According to Woods (1996), there are three processes of comparison: 'acquiring social information, thinking about the information, and reacting to social comparisons' (Woods 1996: 521). At the second stage, people are thinking about how the acquired information connects to themselves. The source of information is inter-individual; as a result of comparisons with others' conditions, people judge their lives. One of the comparisons that people make is to compare their current life with others who seem to be worse off (a downward comparison). People who use the downward comparison will feel happy, since others are worse off than them, even when they themselves are not in a good condition. The other sort of comparison that people make is to compare their current life with others who seem to be better off (an upward comparison). People who use the upward comparison will not feel happy, since others are better than themselves.

Some researchers have explored the theory of social comparison using a qualitative approach. For example, Farquhar (1995) explored the meaning of QoL among older adults. Farquhar quoted one of the participant's utterances as 'when you hear of some people what they go through - I've been lucky really' (Farquhar 1995: 1442). The association between the social comparison and QoL has been supported in a quantitative longitudinal study in people with Meniere's disease (Dibb and Yardley 2006).

In summary, using some of these complicated cognitive appraisals, people evaluate whether or not their own lives are good or happy or not. This means that one's evaluation process will vary depending on contexts and situations (Ryan and Deci 2001; Schwarz and Strack 1999). These cognitive theories in the well-being literature have contributed to our understanding of the process of evaluation.

Now it is important to clarify the term 'happiness', which seems to be considered as an important element of QoL (Kahneman 1999). In the next section, the structure of happiness is explained with reference to psychology research.

The structure of happiness.

As described above, happiness has been considered as a representation of emotional state in

QoL, and happiness has been studied in relation to cognitive appraisal in psychology. In the well-being literature, the word happiness has been used interchangeably with life satisfaction.

Some researchers have attempted to examine the structure of happiness using a philosophical concept (Ryff and Keyes 1995). For example, Waterman (1993) attempted to examine associations between happiness and the concept of eudaimonism; human beings have a certain potentiality that is called *daimon*. The *daimon* will give people meaning when they complete something important to themselves (self-actualisation). To examine this distinction empirically, Waterman conducted a questionnaire study among university students, and found that the concept of happiness could be classified into two structures: hedonic enjoyment (subjective well-being) and eudaimonia enjoyment (psychological well-being). Waterman reported that hedonic enjoyment was correlated with feelings of relaxation, whereas eudaimonia enjoyment was correlated with feelings of challenge for a variety of activities.

However, the clear distinctions have been questionable from functional points of view, since some studies have shown that subjective well-being overlaps with psychological well-being. For example, Ryff et al. (1995) attempted to investigate their integrated model of well-being among three age groups -- young, midlife, and old age. They categorised psychological well-being into six areas, being self acceptance, environmental mastery, positive relations with others, personal growth, purpose in life, and autonomy, and found that self-acceptance and environmental mastery was weakly associated with the rest of the items through all three age groups. More recently, Keyes et al. (2002) conducted a questionnaire study amongst adults in the USA; they found that both self-acceptance and environmental mastery were extracted under subjective and psychological well-being factors.

In summary, these studies have shown that the concept of subjective well-being has a different root from that of psychological well-being, but the two concepts seem to be functionally overlapping. In terms of the concept of QoL, both subjective and psychological well-being are important aspects of subjectivities (King and Napa1998).

The relationship between meaning, relatedness and well-being

In this section, other important factors which affect subjective and psychological well-being are introduced -- motivation, attainment of expected outcomes, and social support.

The importance of goal attainment and needs satisfaction has been explored by motivation theory (e.g. Maslow 1970). Research on the relationship between goal attainments and well-being has been conducted from two points: the importance of goal attainment as the end point (competence) and the importance of goal attainment as the process (intention). For example, Sheldon and Elliot (1999) conducted a questionnaire study among university students, exploring their semester goals. The participants were asked to rank the goals and choose the reasons in a questionnaire, and QoL was assessed by positive-negative moods and life satisfaction. They found that intention to attain the goals and the attainments were associated with improvements of mood and life satisfaction.

Other studies have shown that attainments give people feelings other than satisfaction. For example, McGregor and Little (1998) examined whether attaining goals (effectiveness) and attaining goals that people perceived most important (goal integrity) were associated with QoL (life satisfaction, depression, stress, positive affect, and meaning) among university students. They found goal effectiveness was associated with feelings of happiness, but that goal integrity was not associated with feelings of happiness but was associated with meaning.

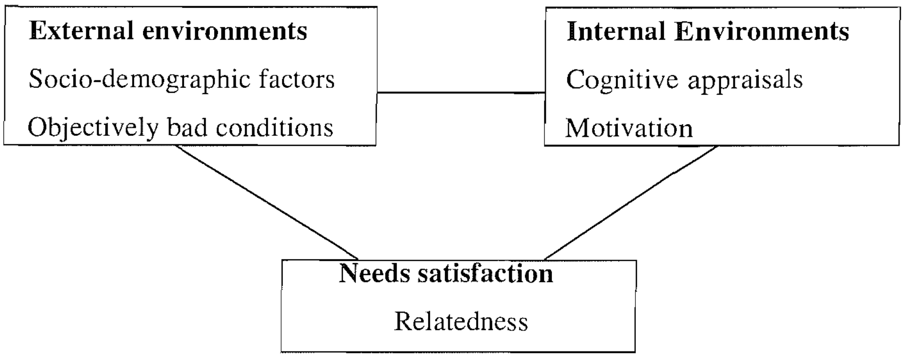
Some studies have shown that not only goal integrity but also other factors seem to be needed to improve QoL. For example, Sheldon et al. (1999) found that attainments of self-concordance goals alone did not change university students' mood or life satisfaction but that, if the students experienced support from important others (relatedness) during the attainment process, the students' well-being did improve.

Summary

Although there is no precise definition of QoL so far, it is agreed that not only objective indicators but also subjective indicators are important for the concept. Research in psychology has shown that cognitive appraisals play an important role for people in evaluating external environments and their own lives. The research has contributed to identifying two structures of happiness: subjective well-being and psychological well-being, but this distinction is functionally uncertain.

Since objective factors alone are weakly associated with subjective factors, subjectivity has been emphasised. One of the aspects, goal attainments has often been investigated together with needs satisfaction. Several studies have shown that self-oriented goal attainments give people meaning and that relatedness is important to improve QoL when a self-oriented goal is attained. Therefore, in order to assess QoL, it is essential to explore both cognitive and motivational factors relating to need satisfaction (see Figure 1.3).

Figure 1.3 *The Concept of Quality of Life*



Health-related Quality of Life (HRQoL) research in psycho-oncology

The concept of QoL in health contexts is different from the well-being that has been described in the previous section. According to the World Health Organisation (WHO; 1948), 'health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.' Under this definition, the broad concept of QoL has been narrowed down to HRQoL.

Most HRQoL research has used quantitative methodology, and researchers in different groups have developed a range of questionnaires including generic and disease-specific or population-specific scales (McGee 2004). Generic scales are designed for any illness and population. The scales are advantageous when researchers are interested in comparing patients' QoL across diseases. In contrast, disease-specific scales are designed for specific diseases; for example, cancer. Although the disease-specific scales are not able to compare patients' QoL across diseases like generic scales, they can explore more disease-related concerns; for example, disease-specific symptoms and treatment-related problems.

In this section, a summary of HRQoL scales that are often used in psycho-oncology research is first provided, followed by a review of literature of psycho-oncology research using the scales and, finally, the concept of HRQoL, the methodology, and the insufficient research base are discussed.

Health-related Quality of Life Scales

Table 1.3 presents a summary of HRQoL scales; generic scales, such as the Profile of Mood States (POMS) (McNair et al. 1981) and the Karnofsky Performance Status (KPS) (Karnofsky and Burchenal 1949) measure only one dimension such as the emotional or physical dimension respectively. However, the other generic scales are multi-dimensional. In contrast, disease-specific scales are all multi-dimensional.

Table 1.3 *A Summary of Health-related Quality of Life Scales*

Scales	Author (Year)	No of questions	Dimensions
Generic			
The Profile of Mood States (POMS)	McNair et al. (1981)	65	Emotional
The Karnofsky Performance Satus (KPS)	Karnofsky et al. (1949)	11	Physical
The Sickness Impact Profile (SIP)	Bergner et al. (1981)	136	Physical, social, and emotional
The Modified Berkaman-Syme Social Network Index (SNI)	Berkman et al. (1979)	11	Marital status, sociability, church group memberships, and other voluntary organisations
WHO Quality of Life Questionnaire (BREF)	WHOQoL group (1998)	26	Global, physical, psychological, social and environmental
The General Health Questionnaire (GHQ)	Goldberg (1978)	60	Physical symptoms, anxiety and insomnia, social limitation, and depression

Table 1.3 (continued)

Scales	Author (Year)	No of questions	Dimensions
Generic			
The Medical Outcomes Study Short Health Form (MOS SF-36)	Ware et al. (1992)	36	Physical, social, role-physical limitations, role-emotional limitations, bodily pain, general mental health, vitality and general health perceptions
Cancer-specific			
Quality of Life Index (QLI) Cancer module	Ferrans et al. (1985)	35	Health and functioning, psychological/spiritual social and economic, and family,
Cancer Rehabilitation and Evaluation Systems (CARES-SF)	Schag et al. (1991)	59	Global, physical, psychosocial, medicinal, interaction, marital, and sexual
The Functional Living Index Cancer (FLIC)	Schipper et al. (1984)	22	Total, physical, emotional, functional, social, cognitive and symptom

Table 1.3 (continued)

Scales	Author (Year)	No of questions	Dimensions
Cancer-specific			
European Organisation of Research and Treatment of Cancer Quality of Life Questionnaire-Core 30 (EORTC QLQ-C30)	Aaronson et al. (1993)	30	Global, physical, role, emotional, social, cognitive and symptom
EORTC QLQ-Breast 23 (EORTC QLQ-BR23)	Sprangers et al. (1996)	23	Body image, sexual, sexual enjoyment, future perspective, and symptoms (arm, breast, side effects, hair loss)
The Functional Assessment of Cancer Therapy-Cancer (FACT-G)	Cella et al. (1993)	33	Physical well-being, social/family, emotional, functional well-being
The Functional Assessment of Cancer Therapy-Breast (FACT-B)	Brady et al. (1997)	44	FACT-G, breast cancer sub-scale

Among the disease-specific scales, the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire - Breast 23 (EORTC QLQ-BR23; Sprangers et al. 1996) and the Functional Assessment of Cancer Therapy-Breast (FACT-B; Brady et al. 1997) are designed especially for BC.

Several multi-dimensional scales have been translated into languages other than English, such as Japanese: SF36, WHOQOL-BREF, GHQ, FACT-G, FACT-B, EORTC QLQ C-30, EORTC QLQ BR23, and FLIC. There is also a cancer-specific QoL questionnaire originally developed for cancer patients who undertake chemotherapy in Japan (Cancer Patients Treated with AntiCancer Drug (QOL ACD); Kurihara et al. 1999).

In terms of Japanese versions, the validity and reliability of the questionnaires have been tested, and SF36 (Fukuhara et al.1998) and WHOQOL-BREF (Nakane et al. 1999) have been standardised. Regarding the disease-specific questionnaires, there are very few published papers on the psychometric properties (personal discourse with Dr. Shimozuma; Okamoto et al. 2003); only two instruments - FACT-G and QOL ACD - are available to assess how well they have been validated and whether or not they can be usable among BC patients.

A few reports on FACT-G and QOL ACD are available. Regarding FACT-G, there is a problem of low internal consistency. For example, Fumimoto et al. (2001) examined the validity and reliability of FACT-G (version three) among lung cancer patients. About 80 per cent of the sample was male, and most of the participants were aged above fifty years with advanced cancer. Fumimoto et al. reported that friend and neighbour relationships were not loaded under the same construct as family relationships, which was inconsistent with an American population, and that the social and family domain had relatively lower internal consistency (Cronbach's Alpha = 0.55). Fumimoto et al. concluded that they would need to take into account the inappropriateness of the existing social-family domain for a Japanese population and would need to improve this domain in the next version, version four.

Considering the results above, FACT-G is not an appropriate instrument for use in QoL research in Japan, because the family factors are unreliable. Although some studies have been conducted using version four in Japan, the validity and reliability have not as yet been published (personal discourse - Dr. Kobayashi). Thus, it is not possible to examine how much the domain is improved.

Regarding QOL ACD, the problems are low internal consistency and the developmental process of the questionnaire, even though this questionnaire has been often used among BC patients in Japan (Okamoto et al. 2003). For example, Kurihara et al. (1999) described the developmental process; first, several items were selected from FLIC and EORTC QOQ C30 by health care professionals. The selected items were used to make a new questionnaire and examined by both health care professionals and patients with advanced stage cancer. As a result, some items that the investigators agreed were selected again, and additionally two new items and one faces scale representing a global score were added. Finally, Kurihara et al. examined the 22 item scales among cancer patients. Sixty per cent of the sample was male, and most patients had lung, stomach, or colorectal cancer (6.6 per cent had BC). The authors reported that the instrument had four domains - daily activity, physical, psychological, and social attitudes - and that each scale gave Cronbach's Alpha above 0.70 except the psychological domain (Alpha = 0.58).

Considering the results above, QOL ACD is not an appropriate instrument either, for use for Japanese BC patients since, even though a few new items were added, QOL ACD is neither a theory nor a data driven questionnaire and, as in Fukumoto et al's study, the sample characteristics were quite different from the BC sample. Further, the psychological domain was unreliable. These results may suggest some limitations of cross-cultural studies.

Generic or disease-specific instruments?

Which instruments, generic or disease-specific, should be used to assess patients' QoL in illness contexts is a matter of debate (Bloom et al. 2001a; Cella and Bonomi 1995). However, some studies have shown that generic and disease-specific instruments contribute to QoL measures independently. For example, Bloom et al. (2001a) sampled BC patients and administered the MOS SF-36 together with the Intrusiveness of Illness Scale (Devins 1994) and several cancer-specific measures that ask about patient-physicians communication, self-image, and future concerns, and surgical sequelae of BC. The data were analysed using a hierarchical regression model; after entering demographic/treatment variables (model one) in the second model, generic scales were entered. At the third model the specific measures were added to model one. There were no differences between the second model and the third model in terms of correlations ($R^2 = 0.48$ for model 2; $R^2 = 0.48$ for model 3). Further, when both generic and disease-specific measure were entered, the correlations became higher ($R^2 = 0.53$).

The study indicated that generic scales such as MOS SF-36 are sensitive enough to detect changes in the short-term, but specific scales are more appropriate to grasp patients' illness related problems. For example, Ganz et al. (1996) found that BC patients reported high scores on all dimensions of MOS SF-36 but, when they were individually interviewed, they frequently addressed their problems relating to rehabilitation; the problems were detected by CARES.

In spite of the arguments, most psycho-oncology research has usually used more than one instrument, which can reduce measurment error, to evaluate the impact of diagnosis, surgery, and adjuvant therapy on cancer patients in the short term. In the next section, a review of literature regarding factors that affect BC patients' QoL is presented.

Literature Reviews

Table 1.4 presents a summary of HRQoL studies among BC patients. Research investigating the impacts of demographics and cancer treatment is presented initially.

Demographic impacts on health-related Quality of Life.

Early studies attempted to identify the association of demographic factors with patients' QoL. Previous studies have consistently reported that age is an important predictor. For example, Ganz et al. (1992) conducted a cross-sectional study, exploring the relationship between age and QoL among BC patients who had all undergone mastectomies. They administered five instruments to the patients one month after surgery: FLIC, CARES-SF, KPS, POMS and the Global Adjustment to Illness Scale, and found that older patients (above 60 years old) had better QoL than younger patients on CARES Global score but not on FLIC. Since these authors did not report the relationship between age and specific domains of CARES, it is not clear whether the older patients had any particular problems in each dimension.

More recent studies - for example, King et al. (2000) - support Ganz et al.'s findings. King et al. conducted a prospective study exploring the relationship between age, marital status and education, and QoL among BC patients who underwent either conserving surgery or mastectomies. They administered two instruments to the patients at three months and one year after surgery - EORTC QLQ C-30 and early BC-specific questionnaires for the study - and found that younger age patients reported worse scores in both social and emotional functioning in QLQ C-30 than those of older age.

Some studies have investigated the impact of age at diagnosis on the long term QoL. For example, Cimprich et al. (2002) conducted a cross-sectional study in order to examine the relationship between age at diagnosis and long-term QoL. They sampled BC survivors who were five years disease free since the diagnosis, and assessed their QoL using the Quality of Life Cancer Survivors (QOL-CS). Cimprich et al. divided the patients into three age groups - a younger group, a middle-aged group and an older group at diagnosis - and found that those in the older age at the diagnosis group reported worse physical functioning than the other age groups, that the younger group reported worse social well-being than the other age groups, and that the middle-aged group reported better overall QoL than the other groups.

Table 1.4 *A Summary of Health-related Quality of Life Research*

Author (Year)	Study design	N	Time of assessment	Instruments
Ganz et al. (1992)	Cross-sectional	229	1 month after surgery	FLIC, CARES, KPS, POMS, GAIS
Andrykowski et al. (1996)	Cross-sectional case-control	160	3-60 months after completion of a primary treatment	MOS-SF36, CES-D, POMS, the Positive and Negative Affect Scales, the Cancer, Patient Behaviour Scale, the Perceived Health Questionnaire, Spiritual concerns
Cimprich et al. (2002)	Cross-sectional	105	5 years after diagnosis	QOL-CS
Ganz et al. (1996)	Cross-sectional	139	2-3 years after diagnosis	FLIC, CARES, RAND36, POMS
Nissen et al. (2001)	Prospective	198	1, 3, 6, 12, 18 and 24 months after diagnosis	MUIS, POMS, FACT-B
Shimozuma et al. (1999)	Prospective	227	1, 4, 7 and 13 months after surgery	CARES, KPS, POMS
King et al. (2000)	Prospective	307	3 and 12 months after surgery	EORTC QLQ-C30, ESBC-specific questionnaire

Table 1.4 (continued)

Author (Year)	Study design	N	Time of assessment	Instruments
Greimel et al. (2002)	Prospective	248	1 day before initial treatment, 10-15 days after treatment, after 4 cycles of chemotherapy	EORTC QLQ-30, Quality of Life Index, KPS
Rayan et al. (2003)	Prospective randomised trial	86	1 week, 3, 6, and 12 months	SF-MPQ, EORTC, QLQ-C30, QLQ-BR23
Arora et al. (2001)	Prospective	103	6 and 11 months after diagnosis	FACT-B
Michael et al. (2002)	Prospective	708	2 and 4 years after diagnosis	MOS-SF36, CARES-SF, SNI
Bloom et al. (2001b)	Cross-sectional	336	6-7 months after diagnosis	MOS-SF36, SNI

Note. FLIC = the Functional Living Index Cancer, CARES = Cancer Rehabilitation Evaluation System, KPS = the Karnofsky Performance Status, POMS = the Profile of Mood States, GAIS = the Global Adjustment to Illness Scales, QLI = the Ferrans and Powers Quality of Life Index, MUIS = the Mishel Uncertainty in Illness Scale, FACT-B = the Functional Assessment of Cancer Therapy - Breast, EORTC QLQ-C30 = European Organisation of Research and Treatment of Cancer Quality of Life Questionnaire - Core 30, ESBC = Early Stage Breast Cancer, SIP = the Sickness Impact Profile (SIP), SF-MPS = McGill Pain Questionnaire Short Form, QLQ-BR23 = European Organisation of Research and Treatment of Cancer Quality of Life Questionnaire Breast cancer module, MOS-SF36 = the Medical Outcomes Study Short Health Form, QOL-CS = the Quality of Life-Cancer Survivors the Quality of Life Cancer Survivors, SNI = the Social Network Index, CES-D = the Centre for Epidemiological Studies Depression Scale.

The impact of cancer treatment on health-related Quality of Life.

With regard to the impact of type of surgery, post-operative body image among BC patients was found to be one of the key elements in psychological adjustment in an early study (Fisher et al. 1985). Conserving surgery has been shown to help patients maintain their good body image; patients who undergo conserving surgery are more likely to adjust psychologically to the surgery than are those who undergo mastectomies (Shakespeare and Postle 1999).

Although the importance of body image has been supported in QoL research, several studies have shown that conserving surgery or breast reconstruction alone is not helpful in improving body image and, consequently, BC patients' QoL. For example, Shimozuma et al. (1999) examined the relationship between the type of surgery and QoL among BC patients, who either underwent modified radical mastectomies or conserving surgery. They assessed the patients' QoL at one month, four months, seven months, and thirteen months since surgery using three instruments - CARES, KPS, and POMS - and found that treatment-related variables, such as positive node status, negative body image, and mood disturbance at one month after surgery could predict worse QoL at one year after surgery. However, the authors concluded that these predictors were not different between the radical mastectomy group and the conserving surgery group.

Additionally, Nissen et al. (2001) reported similar findings. Nissen et al. examined the relationship between type of surgery and QoL among BC patients, who underwent mastectomies alone, mastectomies plus reconstruction, or conserving surgery. They assessed the patients' QoL at one month, three months, six months, twelve months, eighteen months, and twenty four months after diagnosis using three instruments - MUIS, POMS, FACT-B. They found that, after controlling for age and tumour size, the mastectomy plus reconstruction group reported worse functional well-being in FACT-B than the conserving surgery group. Nissen et al. also found that, after controlling for age, chemotherapy, radiotherapy and hormone therapy, the mastectomies with reconstruction group reported more depression on the POMS than the mastectomies alone group. They reported that the mastectomy plus reconstruction group had a better body image than the mastectomy alone group, but that this was not statistically associated with patient's QoL scores.

Similarly, Arora et al. (2001) presented results that are difficult to interpret about the relationship between body image and emotional well-being. They targeted younger (29 to 60 years old) BC patients and conducted a prospective study, and assessed patients' QoL at one month and six months after diagnosis using FACT-B. Patients were divided into three sub-groups by type of surgery - a lumpectomy group, a mastectomy alone group, and a mastectomy plus reconstruction group. It was found that the mastectomy plus reconstruction group reported worse body image than the lumpectomy group did. However, the mastectomy plus reconstruction group reported better emotional well-being than did the lumpectomy group.

Social impact on health-related Quality of Life.

Studies have examined how social factors, such as social networks, affect QoL, but inconsistent results have been obtained in HRQoL research. For example, Michael et al. (2002) conducted a prospective study, examining the relationship between social networks and QoL among BC patients. Michael et al. (2002) assessed BC patients' QoL at two years and at four years since diagnosis using three instruments - MOS SF-36, CARES-SF, and the Social Network Index (SNI). The findings were that the most socially integrated patients for SNI reported better role functioning, and that the patients reported good vitality and mental health, and fewer physical problems, on MOS SF-36.

Bloom et al. (2001b) conducted a similar study among BC patients to that of Michael et al. (2002). Bloom et al. conducted a structured interview with BC patients using two instruments - MOS SF-36 and SNI. The findings were that married patients received both emotional and instrumental support more than single patients, and patients who underwent radiotherapy received more emotional and instrumental support than those who did not. However, the instrumental support was not associated with good physical well-being on MOS SF-36, which was inconsistent with the findings of Michael et al. (2002).

These two studies show that patients who have many social ties have an increased chance of receiving help when they have either emotional or physical problems. However, these studies focused on the size of patients' social network or on how many resources patients have. Social support should not be assessed on these quantitative factors alone, since it has been argued that the kinds of help patients receive and how the patients think about the help is more important than the objectively countable numbers of helpers when people are under stress (Cohen and Wills 1985).

THE ISSUES OF HEALTH-RELATED QUALITY OF LIFE RESEARCH IN PSYCHO-ONCOLOGY

The literature review in QoL has helped to identify an insufficient base of research on the concept of QoL. In this section, issues of HRQoL in psycho-oncology are discussed and directions for this research programme are suggested.

The Concept of health-related Quality of Life

Regarding the definition of HRQoL, it has been criticised for focusing on 'functional living' (Schou and Hewison 1999) and what some researchers believe is questionable about the WHO definition - is 'health' synonymous with QoL? Under the HRQoL definition, human beings are treated as passive agents; since external environments are already set around people, they cannot change the external environment, and neither can they have an active role to play. Thus, the active role is lacking in HRQoL research, although some researchers (Ferrell et al. 1997; the WHOQOL Group 1995) have been aware of the importance of more active aspects of human beings and have attempted to include the dimensions in existing scales or to develop new extended scales. As literature in psychology has shown, motivation and needs satisfaction should be included as important aspects of QoL. Additionally, the social domain in HRQoL scales has only included the relationship between a patient and others and has not included the relationship between a patient and society. It may be necessary to explore how patients' perceptions and cognitions are formed in the particular societies in which researchers are interested.

The need for paying attention to patient's life stage and to social impacts on emotional and cognitive processes

From the epidemiology, we know that early BC is curable, that most early BC patients have a good chance of surviving, and that most women develop the cancer in their prime of life. We also know that these facts are similar between the UK and Japan. However, there is no evidence about how well BC patients manage their life changes and social responsibilities through their illness experiences (Zebrack 2000b).

In their prime of life, most women change their life course due to, for example, giving birth, getting promoted, their child(ren) becoming independent, or taking care of their elderly parents. Of course, not every woman undergoes these changes and responsibilities, but most women have at least one or two such responsibilities in their lives. The dual social role responsibilities are stressful amongst even healthy women (Stephens et al. 1994). It is presumed that BC patients have a hard time facing both the life changes and their own disease, since BC is a life-threatening illness and since the diagnosis and active cancer treatment are so stressful; many patients have negative responses, such as shock, anxiety, and depression towards the diagnosis and the treatment. These emotional responses have been reported in both the UK and Japan (Cassileth et al. 1985; Fallowfield et al. 1990; Hosaka et al. 1996).

As a result of such difficult experiences, the patient may need to withdraw from some social roles in either the short or long term. The withdrawal has an effect not only on the patient's life but also on their family's' life, since family members rely on each other. This could be illustrated as follows: assume that each family member grasps a string stretching from each other. When each family member's role operates well, the string stretches tight. However, if a person in the family releases the string (e.g. due to developing cancer), it becomes loose. In order to have the string be tight again, the other members might pick up the string (e.g. compensating for the patient's role).

Social roles are important in one's life to maintain a sense of identity and well-being (Thoits 1994), but how the person who has released the string feels varies depending on what others (the society) expect(s) the person to do (Oishi and Diener 2001; Suh et al. 1998); for example, Suh et al. (1998) explored whether others (society) had an influence on citizens when they evaluate their lives. They conducted a survey study among adults from 41 nations, and found that citizens in collectivist societies tended to judge their lives by their social norms or socially expected values more than by individualism. Even though Japan was grouped into neutral (neither collectivist nor individualist) in Suh et al.'s study, presumably Japanese women might have felt guilty about the person who helped her out since they are expected to play a central role in managing family matters by others (the society), and this might affect the women's well-being.

Not only interaction with others, but also with the society where a patient belongs, has a vital influence on the meaning of illness experiences. It is necessary to take a symbolic interactionism point of view to consider patients' QoL. This could lead to improved understanding of patients' 'real' experiences, since patients belong to a certain society and community which has unique characteristics. Therefore, social norms and expectations from others, which may form one's value system, should also be taken into account (Suh et al.1998).

The insufficient base of research

Most HRQoL studies have explored the immediate impact of types of surgery or adjuvant therapy experienced as a part of treatment. The impact has been assessed on either inpatient or outpatient wards, which are isolated from the real world. After completion of the treatment, patients return to live in their society. Since most early BC patients can live on as survivors, it is more important to determine how treatment will affect patients' lives in the long term than in the short term; don't patients who are disease-free after surgery have any concerns? If something changes, how do the patients feel the change, negatively or positively? How do the patients appraise their lives after the change has occurred? Is it possible for the patients to find something new to maintain the sense of identity? How do the patients perceive their relationships with others in their society? How well do the patients live their rest of life through their illness experiences?

Previous studies about short-term effects after surgery have shown that many BC patients have trouble with pain or arm swelling after discharge (Carpenter et al. 1998; Graydon 1994; Mock et al. 2001). Issues of arm complications have also been reported among BC patients in Japan by a preliminary qualitative study (Tsuchiya and Horn in press). Little research on psycho-social issues of lymphoedema has been conducted in either the West or the East.

Methodological issues

With regard to the methodology, the problems of HRQoL research in psycho-oncology have been discussed in terms of study designs and statistical analysis (Aaronson et al. 1991) in a scientific paradigm. In order to identify factors impacting on cancer patients, the study design is an essential concern for researchers; a cross-sectional study is the weakest design to explore cause-effect relationships, so a prospective study is recommended to control confounding factors and to obtain baseline scores. However, prospective studies have other problems, such as attrition and missing data. To solve the problems, guidelines for data management in clinical trials have been suggested (Bernhard et al. 1998; Fayers et al. 1997; Hahn et al. 1998), and statistical methods for missing data have been proposed (Troxel et al. 1998). These suggestions may have contributed to an improvement of the validity and reliability of research findings.

Of course, quantitative research, which most HRQoL research has used, has contributed to the identification and prediction of some factors that impact on patients' QoL. A fundamental problem of HRQoL research is whether the complexities of subjective experiences, such as appraisals, motivation, and social aspects, can be measured by scales developed in countries other than the study sites.

Most researchers devoted to developing 'universally' appropriate questionnaires (the 'needs' approach, McGee 2004: 237) tend to think that excluding culturally unique items is the best way to attain their goals (Fumimoto et al. 2001). However, including culturally unique items is the preferred way to detect certain issues that patients have in specific communities, using a cultural psychology approach; perceptions and evaluations of experiences are formed by interaction with others and society so that, if the culture changes, people's perceptions might also change, a central component of symbolic interactionism (Charon 1992).

As well-being research shows, people will evaluate their current life using various sources of information or using internal or external comparisons. In most HRQoL questionnaires, instructions are written in the first line; for example, please recall your experiences within the last two weeks and answer the questions below. When the participants fill in their responses in the questionnaires, each person may recall a different event, which may relate to their disease or may not. People who recall the happiest experience within the last few weeks may report that their current life quality is good because of positive-negative affect. People who expect their future be better may report that their current life quality is low because the expectation colours their present mood. Therefore, it is difficult to ensure that all participants use the same information sources when they fill in questionnaires. Because of these limitations, it is necessary to apply methodology other than a quantitative approach when researchers explore cognitive and emotional processes (Rosenberg 1995), and it is necessary to identify how patients evaluate their own experiences, such as intra-comparisons or inter-comparisons, or anything else.

Qualitative approaches

Research into patients' coping processes in illness that has applied qualitative methodology has shown a more positive and active side of human beings, and revealed more detailed information about the impact of illness on patients' lives and about how patients attempt to move ahead step by step. For example, Asbring (2001) explored how the illness had changed identity and how a new identity had been perceived among female patients with chronic fatigue syndrome and fibromyalgia. Asbring conducted semi-structured interviews, and found that patients had identity changes before and after the illness. One of the patients reported that 'this having lived a little over 2 years with a "me" that is no longer the "real me"... and still, I must socialize with this person (CFS-9)' (Asbring 2001: 315). Another patient who, due to illness, had given up skiing, reported that 'I can go to the mountains of course, it's true I've discovered that, but I can't ski anymore. I have to learn these things ... find things that I can do and that are good for me. (FM-19)' (Asbring 2001: 317). In terms of a perceived new identity, Asbring reported that most participants had been struggling with finding the way.

With regard to cancer patients, Schou et al. (1999) described the impact of BC treatment on patients' social roles using a qualitative study; one of the patients lost her job due to cancer treatment, and she described how her business was her 'centre' and that she had lost her 'role' (Schou et al. 1999: 88). The patient continued 'I like to keep something happening, such as sort of going out somewhere' (Schou et al. 1999: 89).

Patients attempt to accept the change but, at the same time, they attempt to search for something good or a purpose which compensates for the change. Something new or purposeful should have the same values for the individual as previously, and this gives the individual a sense of self-consistency. Such areas as purpose of life or meaning of life, which is an important component of identity (Fife 1994) and QoL, have not been fully explored in HRQoL research.

CONCLUSIONS

In this chapter, besides the epidemiology and medical treatment of BC, the concept of QoL together with brief literature reviews have been presented and discussed. Previous research in well-being literature has shown the importance of both objective and subjective indicators of QoL. In health contexts, the concept of HRQoL has been applied in exploring patients' QoL relating to treatment regimens. In psycho-oncology, quantitative survey research is the main methodology, and various different scales have been developed.

As discussed so far, HRQoL research has contributed to identifying factors associated with patients' QoL, but it is questionable whether the scales, which have been developed in the West, have been able to fully explore patients' subjective experiences among Japanese BC patients. In addition, previous HRQoL research has not sufficiently addressed the long term effects of treatment, positive aspects of human beings, and the idea that the social or cultural environment creates and influences patients' perceptions. Further, other important factors relating to illness adjustment, such as patients' needs, have not been explored.

To shed light on these, it is proposed that a long-term effect of breast surgery, such as post-operative arm complications (lymphoedema) be focused on, and studies be carried out among Japanese female BC patients in Japan to explore how perceptions of lymphoedema are formed in the context of Japanese society.

In this research programme, the main research question is how (un)met needs affect the patients' QoL, and the aim is to develop a 'culturally', rather than universally, appropriate new measure in Japanese, with enough sensitivity to detect lymphoedema specific concerns among female BC patients, and with good psychometric properties.

2. Social Support, Chronic Illness and Quality of Life

INTRODUCTION

Previous studies on social support have investigated how it affects health outcomes using three different approaches - social integration, perceived support, and satisfaction with enacted support.

First, on social integration, early studies attempted to show a clear epidemiological relationship between social integration and disease outcomes (Seeman and Syme 1987). Later, it was hypothesised that people with wider social networks are more likely to be provided with support by others than those without, and that people with various social resources (friends and family members) are more likely to cope with stressful life events than those without. It was also hypothesised that demographic factors, for example age and sex, have an influence on the size of social networks, and consequently on health outcomes. Thus, the more integrated people are, the more resources they have (Lynch et al. 1999; Schwarzer et al. 2004) and, consequently, the better their health outcomes (Van Grootheest et al. 1999).

Second, on perceived social support, studies have investigated the relationships between perceptions of availability of support and health outcomes. It was hypothesised that people who perceive that somebody will take care of them when they are sick have a better health outcome than those who do not. So far, several studies have consistently reported that perceived support is associated with positive health outcomes (Thoits 1995).

Finally, on satisfaction with support, studies have investigated relationships between one's evaluations of enacted support and health outcomes. It was hypothesised that people who feel appreciative of, or satisfied with, provided support are more likely to have better health outcomes than those who do not. Some studies have examined this relationship, but evidence has not been sufficiently clear (Taylor and Seeman 1999).

Although previous studies have applied the three different approaches described above, how can we best define social support?

According to Schwarzer et al. (2004: 160), social support may be defined as 'the function and quality of social relationships', and social integration can be excluded from the definition. More specifically, other scholars have identified two or three types of social support; for example, instrumental, emotional support (Taylor et al. 1999) and informational support (Schwarzer et al. 2004). First, instrumental support refers to practical help, such as helping with household chores, driving the car, and providing financial support. Emotional support refers to something that can let people feel loved and cared for; for example, talking to close others about one's concerns and sharing time with others pleasantly. Finally, informational support refers to being given advice, encouragement, and information relevant to one's concerns.

To explore how social support affects Quality of Life (QoL), a selective review of literature on social support published over the past fifteen years was conducted by using Medline, PsychoLit and Bath Information and Data Services (BIDS). The search was limited to English articles that were published between January 1990 and December 2006. To ensure a comprehensive view of issues on social support, relatively broad literature was first searched using two keywords - social support and chronic illness. After selectively reading abstracts, it was found that there were two focuses: as perceived and received support. Next, literature was searched using four keywords - social support, information needs, breast cancer and QoL. Abstracts that appeared relevant to the research question (how perceptions of information provision affect QoL) were selected; both quantitative and qualitative studies were included. Finally, full texts of selected abstracts were read.

In the first half of the chapter, studies on the effects of perceived social support and enacted support on health outcomes are presented respectively. In the second half of the chapter, the need for social support among breast cancer (BC) patients is illustrated. Throughout the chapter, attempts are made to show a possible linkage between enacted social support, needs of patients, and QoL among patients with chronic illness, especially BC.

SOCIAL SUPPORT AND HEALTH OUTCOMES

Perceived social support and health outcomes

Benefits of perceived availability of social support have been consistently reported, and there is an association between perceived support and physical conditions, such as pain. For example, Bergman (2005) investigated the relationship between reported pain and social support among the general population in Sweden. Bergman mailed the Medical Outcomes Study Short Health Form (SF-36; Ware and Sherbourne 1992) and his own pain questionnaire to the sample; there was one question asking whether or not there was somebody around when participants would need help and 'cope with distress and problems in life' (Bergman 2005: 677). Bergman found that people who perceived that personal support was unavailable were more likely to report either chronic regional pain or widespread pain than those who did not.

Additionally, possible psychological benefits of perceived availability of support have been consistently reported by cross-sectional studies in oncology. For example, Koopman et al. (1998) conducted a cross-sectional study among patients with late stage cancer in the USA. Social support was measured by the number of persons who could help participants, and mood was measured by the Profile of Mood States (POMS; McNair et al. 1981). They found that participants who had perceived support as more available were less likely to report mood disturbance in POMS than those who had not. Other studies among younger-aged BC patients have reported similar findings to those reported by Koopman et al. For example, Bloom et al.

(2001b) conducted structured interviews among BC patients aged under 51 years old in the USA. Perceived instrumental and emotional support was measured by the Instrumental Support Scale that Bloom et al. developed, and the Perceived Social Support Scale (Flamer 1977) respectively. Physical and mental health was measured by SF36. They found that participants who reported perceived emotional support as being available were more likely to report higher mental well-being scores in SF36.

Similar findings have been reported by studies among people other than with cancer. For example, Turner and Noh (1988) conducted a longitudinal study among adults with physical disabilities in the USA. Depression was measured by the Centre for Epidemiological Studies Depression Scale (CES-D) (Radloff 1977), and social support was measured by the Revised Kaplan Scale. These assessments were performed at a baseline and four years later. It was found that little perceived support was associated with depression across all age groups (18-44, 45-64, above 65 years old) four years later.

These cross-sectional studies have shown an association but cannot determine either a causal relationship or its direction, although the previous studies have reported positive associations between perceived availability of social support and health outcomes. Do these studies indicate that, if people receive social support, physical and psychological states will improve? Theoretically, the actual provision of social support seems to have positive effects on health. For example, arthritis and fibrositis make people feel fatigue, pain, and disabled. People with such symptoms may face some difficulties in their every day lives so that instrumental support may be helpful for them, to compensate for their physical limitations, and instrumental support could decrease daily hassles associated with physical disability. Moreover, emotional support may be beneficial to people under stressful conditions as, according to Cohen and Wills (1985), when people are feeling stressed they may also feel helpless and have low self-esteem. People often blame themselves - 'I cannot do this any more due to my illness, and I feel myself worthless'. If emotional support is provided, people may no longer feel helpless and consequently they may have higher levels of self-esteem than before the support was provided. Finally, informational support may be useful to reappraise stressful events and find a new way to tackle stressful events and problems (Lazarus and Folkman 1984).

What have empirical studies shown in terms of enacted social support? In the next section, studies on relationships between enacted support and health outcomes will be presented.

Enacted support and health outcomes

Previous studies have shown that the relationships between enacted support and physical and psychological outcomes are not as straightforward as the theories proposed. Some studies have reported that enacted support improved neither the physical nor the psychological states among cancer patients and non-clinical samples. For example, regarding instrumental support, Walker et al. (2006) conducted a cross-sectional survey study among lung cancer patients in the USA. Social support was measured by the Social Support Inventory that asks about directive emotional, instrumental, nondirective emotional and instrumental support. Depression was measured by the Beck Depression Inventory (Beck 1972). They found that directive instrumental support was positively associated with levels of depression. Regarding emotional support, Bolger et al. (2000) investigated associations between anxiety levels and emotional support among senior students in the law school and their partners in the USA. The couples kept a diary to report given emotional support during the investigation. Anxiety levels were measured by POMS during a one-month period around the States Bar Examination. It was found that emotional support provision from partners was positively correlated to levels of anxiety.

Additionally, a longitudinal study among disabled people has shown that overall social support does not enhance patients' well-being. For example, Bolger et al. (1996) conducted a longitudinal study in the USA, investigating associations between enacted support, physical disabilities, and psychological distress. Physical disabilities were measured by the scales developed for the Framingham Disability Study (Jette and Branch 1981), and social support (instrumental, emotional, and informational support) was measured by the scale that House et al. (1988) developed. Finally, psychological distress was measured by the Hopkins Symptom Checklist (Derogatis et al. 1974). Bolger et al. found that given support from close others improved neither physical disabilities nor psychological distress during the period of four to ten months after cancer diagnosis.

Why does enacted support improve neither physical nor psychological states?

Some researchers have attempted to interpret the findings in terms of the inappropriateness of timing of provision of support. For example, Cohen et al. (1985) argued that if people are not ready to receive support in order to tackle stressful events, they may not perceive the support as beneficial. Other researchers argue that the important factor is whether the provided support meets the needs of recipients (Bolger et al. 2000). Moreover, close others, such as family members and friends, are expected to offer unconditional help by people under stress, but if this expectation is not met in reality, people will feel negative emotions (Rook and Pietromonaco 1987). Thus, the perceived quality of, or satisfaction with, given social support may be more important in improving health outcomes under stressful situations; Norris and Kaniasty (1996), who conducted a longitudinal study among the general population in the USA, investigated associations between received social support, perceptions of received social support and psychological distress caused by natural disasters, such as hurricanes. They hypothesised that perceived social support (evaluations of received support) would have a mediating effect on psychological distress, and found that received support did not have a direct effect on distress, but received support was beneficial in the long-term if the support was evaluated as positive.

In the next section, studies taking into account recipients' appraisal of provided support are presented.

Enacted support and satisfaction with support

Several studies on chronic illness have shown that the evaluation of provided support may impact on patients' psychological status. For example, Stroud et al. (2006) conducted a cross-sectional study among patients with spinal cord injury in the USA, exploring the impact of partners' reactions to pain behaviour on participants' depression levels. Partners' responses to pain behaviour were measured by the West Haven-Yale Multidimensional Pain Inventory (Karns et al. 1985). Social support was measured by the Social Support Questionnaire (Sarason et al. 1983) which asks about perceived availability, actual provided support, and satisfaction with the support that a specific person provided. Stroud et al. found that patients who perceived partners' responses to their own pain behaviour as being negative were more likely to feel depressed than those who did not.

Similar findings have been obtained from cross-sectional studies in oncology. For example, Koopman et al. (1998) conducted a cross-sectional study among BC patients in the USA. Social support was measured by the Yale Social Support Index (Seeman and Berkman 1988) which asks about the quality of support and satisfaction with support. Psychological states were measured by POMS. Koopman et al. found that mood disturbance was associated with too many demands and criticism from support providers.

Recent studies among BC Patients in the USA have found similar findings to those reported by Koopman et al. For example, Kornblith et al. (2001) conducted structured telephone interviews among early BC patients in the USA who had registered for a clinical trial six years previously. Perceived support was measured by the Medical Outcome Study Social Support Survey (Sherbourne and Stewart 1991) which asks about emotional, informational, instrumental, affectionate, and positive social interactions. Psychological states were measured by the Mental Health Inventory (Veit and Ware 1983). The authors found that participants who perceived received social support as 'excellent' reported less distress than those who did not.

On the other hand, some studies have shown that, when recipients are satisfied with the support provided, more intimate relationships with support providers are created and this could lead to better well-being. For example, Friedman et al. (2006) examined relationships between QoL and perceived satisfaction with social support from close others among BC patients in the USA. QoL was measured by the Functional Assessment of Chronic Illness General (FACIT-G; Cella et al. 1997), and satisfaction with actual provided support was measured by the Social Support Questionnaire (Sarason et al. 1983). They found that satisfaction with social support was associated with social and family dimensions in FACT-G. Another study (Ethgen et al. 2004) in Belgium reported that satisfaction with problem-oriented support was associated with most of the QoL dimensions in SF-36 among patients with hip and knee osteoarthritis - physical, social, vitality and role-emotional dimensions.

In summary, some benefits of perceived social support have been consistently reported, but benefits of enacted support are unclear as yet. Perceptions of received social support seem to play an important role in QoL (Norris et al. 1996); if people perceive received social support as inadequate or are dissatisfied with it, they do not think that the person who provides the support, is any longer one of their resources. Consequently, this perception affects QoL.

It is worthwhile exploring whether received social support meets patients' needs. In the next two sections, studies on social support needs among people with chronic illness, especially BC, are presented from two aspects - short-term and long term needs and the benefits of social support respectively.

NEEDS, SOCIAL SUPPORT AND OUTCOMES

Short-term needs

Sources of social support tend to be focused on family and friends as the studies above have shown. For patients with chronic illness, however, health care professionals, especially doctors, are one of the important support providers (Chalmers et al. 2001; Van Harten et al. 1998). However, several studies have reported that the support, especially informational support, is often perceived as being insufficient by patients (Meredith et al. 1996).

Several studies (see Table 2.1) have identified unmet needs regarding medical information provision. For example, Ingleton et al. (2001) compared findings from three projects on palliative care in the UK. They reported that patients with chronic obstructive airway disease had needed more comprehensive medical information about their diseases. Similarly, several studies in oncology revealed perceived insufficient information about the disease itself and treatment regimens. For example, Luker et al. (1995) conducted structured interviews among newly diagnosed BC patients in the UK, and found that participants needed information about the side effects of treatment, characteristics of cancer and treatment options. Other studies conducted in Canada have reported similar findings to those of Luker et al. (1995). Graydon et al. (1997) conducted a cross-sectional study among BC patients. Some of them were undertaking adjuvant therapies at the time of the study. Information needs were measured by a questionnaire designed for the study which included five topics - disease, medical tests, treatments, physical, and psychosocial information. The authors reported that most participants needed information on disease, medical test and treatments, regardless of types of adjuvant therapy. Similarly, Harrison et al. (1999) reported that BC patients in Canada needed information about medical regimens.

Table 2.1 *A Summary of Studies on Needs Assessment (Short-term)*

Author	Year	Country	Study design	N	Methodology	Sample
Ingleton et al.	2001	UK	Cross-sectional	-	Face-to face interviews and mail survey	Patients receiving/not palliative care and carers
Luker et al.	1995	UK	Cross-sectional	150	Face-to-face interviews and questionnaires for this study	Newly diagnosed BC patients
Graydon et al.	1997	Canada	Cross-sectional	70	Self-administered questionnaires (TINQ-BC)	BC patients who completed either surgery, radiotherapy, or chemotherapy
Harrison et al.	1999	Canada	Longitudinal	125	Face-to-face structured interviews (TINQ-BC, health opinion survey)	BC patients receiving radio-therapy
Beaver et al.	1999	UK	Cross-sectional	198	Face-to-face structured interviews (Information Needs questionnaire)	BC and colorectal cancer patients

Table 2.1 (continued)

Author	Year	Country	Study design	N	Methodology	Sample
Kumar et al.	2004	UK	Cross-sectional	302	Face-to-face structured interviews Questionnaire for this study	Asian and White British cancer patients
Peel et al.	2004	UK	Cross-sectional	40	In-depth interviews	Newly diagnosed type 2 diabetic patients

Note: BC = breast cancer, TINQ-BC = the Toronto Informational Needs Questionnaire.

Additionally, the need to know the chance of cure has often been reported by women and men with cancer. For example, Beaver et al. (1999) conducted structured interviews among BC patients and colorectal cancer patients in the UK; all BC patients were females, and around seventy-two per cent of the colorectal cancer patients were males. They found that both breast and colorectal cancer patients prioritised the chance of cure as the first information need.

Similar findings have been obtained from studies conducted among ethnic groups other than Caucasians. For example, Kumar et al. (2004) conducted a cross sectional survey study among both Asian and White British with cancer in the UK, and found that those of Asian ethnic origins (most of them were Indian) needed to know treatment options, side effects of treatment and the chance of cure, and that these needs were quite similar to those reported by White British people.

As described above, most patients with chronic illness need more information than doctors generally provide during consultations, and most patients need medical information regarding characteristics of diseases and treatment procedures.

The issue of information provision is related not only to patients' understanding of their own disease and treatment, but also to dissatisfaction with doctors (Bertakis 1977) and health care. For example, Peel et al. (2004) conducted interviews exploring relationships between information provision at diagnosis and emotional reactions among patients with type 2 diabetes in the UK. They found that most participants complained about insufficient verbal explanation of the disease and life style changes; one participant described the consultation and doctor's attitude as 'yeah, thanks for coming in. Goodbye. Here's a couple of booklets' (Peel et al. 2004: 273). The reason why the participant was dissatisfied with the information provision was perceived lack of support from the doctor; 'right at the beginning you need somebody's arms around you to explain it all' (Peel et al. 2004: 273).

Short-term benefits

Why do patients with chronic illness want to be provided with as much medical information as possible at the diagnosis phase?

Several studies (see Table 2.2) have shown that medical information provision at diagnosis seems to have short term benefits for some patients with chronic illness; this includes, for example, treatment decision-making (Allen et al. 2001; Beaver et al. 1999; Maly 2004), association with their sense of control over illness (Hack et al. 1994), and compliance with treatment regimen (Toljamo and Hentinen 2001).

Additionally, medical information provision at diagnosis affects patients' emotional state at the time when active therapy is over. For example, Rainey (1985) conducted a longitudinal randomised study among cancer patients in the USA who had undergone radiotherapy. Participants were randomised either to a standard information group or an intervention group (high amount of information group). Coping styles were measured at two points by the Avoidant-Vigilant Sentence Completion Test and the modified Repression-Sensitization Scale, at the beginning of radiotherapy and during the last week of treatment. Rainey found that patients in the high information group were less likely to report mood disturbance when radiotherapy was nearly finished than the standard information group, and this was not affected by participants' coping styles.

Table 2.2 *A Summary of Studies on Information Needs and Short-term Benefits*

Author (Year)	Country	Study design	N	Methodology	Sample
Maly et al. (2004)	USA	Cross-sectional	222	Face-to-face interviews telephone interviews (Questionnaires for this study)	BC patients aged above 55 years, diagnosed six months previously, and one-month post-treatment
Toljamo et al. (2001)	Finland	Cross-sectional	213	Face-to-face interviews (Questionnaire for this study) Metabolic control measurement	Type 2 diabetic patients
Ong et al. (2000)	Netherlands	Randomised control	96	Face-to-face interviews Assessment at 1 week and 3 months follow-up (the Rotterdam Symptom Checklist, The Patient Satisfaction Questionnaire	Cancer patients who were not included in experimental group
Hack et al. (1994)	USA	Cross-sectional	35	Face-to-face interviews Card sort tasks on decision-making	BC patients with stage I and II and diagnosed 2-6 months previously

Table 2.2 (continued)

Author (Year)	Country	Study design	N	Methodology	Sample
Rainey (1985)	USA	Randomised control	60	Face-to face interviews Assessment: at the beginning of and during last week of RT (the Avoidant-vigilant Sentence Completion Test, the Modified Repression-sensitization Scale, Radiation Therapy Questionnaire, STAI, POMS	Cancer patients undertaking radiotherapy
Allen et al. (2001)	USA	Cross-sectional	19	Focus groups discussions	BC patients aged below 50 years

Note. BC = breast cancer, RT = radiotherapy, STAI = the State-trait Anxiety Inventory, POMS = the Profile of Mood States.

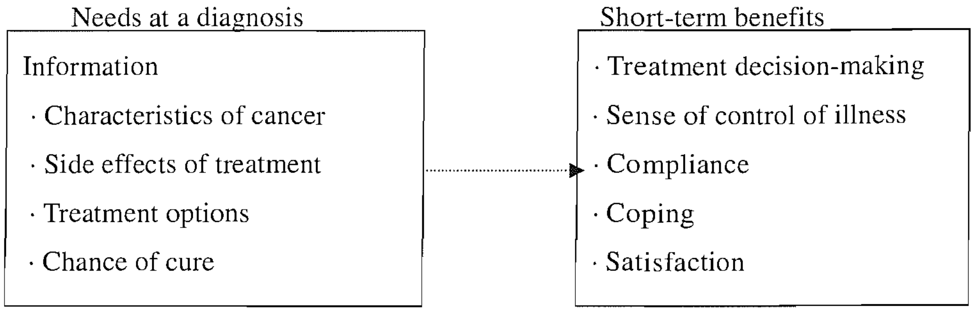
Another study in the Netherlands (Ong et al. 2000) has shown that information provision from doctors is associated with patients' satisfaction. Ong et al. conducted a mail survey among cancer patients. Patients' satisfaction with consultation and global satisfaction were measured by the Patient Satisfaction Questionnaire (Blanchard et al. 1986) at one week before the first consultation and three months after the consultation. It was found that information provision was associated with patients' satisfaction at three months after the first consultation.

In Japan, communication issues between doctor and patients have begun to be investigated, and a few studies have shown that satisfaction with doctors' communication styles is associated with lower anxiety levels. For example, Takayama et al. (2001) conducted a cross-sectional study among cancer patients in Japan using a self-administered questionnaire and an audiotape of the medical consultation. Anxiety levels were measured twice - before and after consultations - by the State-Trait Anxiety Inventory scale. They found that patients who were satisfied with doctors' communication styles reported lower anxiety levels than those who were not.

However, the focus of this study was doctors' communications styles, such as patient-centred and facilitative styles (e.g. offering an opportunity for patients to express their opinions), and did not include satisfaction with information provision as a predictor of emotional states. Thus, the associations among information provision, satisfaction, and emotional states were not explored.

By way of summary, Figure 2.1 shows the relationships between patients' needs and short-tem outcomes.

Figure 2.1 *The Relationships between Information Provision and Outcomes (Short-term)*



Long-term needs

As described above, at the diagnosis phase most patients with chronic illness need to be provided with as much medical information by doctors as possible. At the recovery phase, several qualitative studies (see Table 2.3) have shown that patients' needs shift to information on self-care management and complications of surgery. For example, Hughes et al. (2000) interviewed cancer patients in the USA, exploring information needs during the home care period. The majority of participants were males and above 65 years old. A content analysis revealed that half the participants needed advice on pain management associated with surgery, and that BC patients needed advice on lymphoedema.

Similarly, Gray et al. (1998) conducted focus groups in Canada, asking about information needs among BC patients who had been diagnosed around ten years previously. They found that most participants in the study perceived their physicians as an important information source but that, in reality, physicians did not provide information as comprehensively as participants wished; 'I had no information at all about lymphoedema and had never been given any information on dos and don'ts' (Gray et al. 1998: 249).

When some problems happen several years after the initial diagnosis, patients still consider doctors as primary sources of informational support (McIllmurray et al. 2001). In addition, a sympathetic doctor's attitude seems to be desirable for patients diagnosed a long time previously. For example, Thewes et al. (2004) conducted telephone interviews, exploring the needs of BC patients in Australia who had completed adjuvant therapy, and found that a sense of security and reassurance was very important for survivors, regardless of participants' age; 'I can ask [my oncologist] anything I would like to know ... you know I just feel these people are there to help me' (Thewes et al. 2004: 183). Another study in Australia (Marlow et al. 2003) has shown one reason why emotion focused continuous care was needed by BC patients who were diagnosed more than four years previously. In the study, some participants reported that 'the cancer itself didn't worry me ... having the breast off didn't worry me ... it was that after process [of treatment and coping on one's own]' (Marlow et al. 2003: 325).

Despite patients' needs, this psychosocial support from doctors is not often perceived as sufficient, and doctors' perceived insensitive attitudes sometimes prevent patients from help-seeking behaviour. For example, Fong et al. (2006) conducted in-depth interviews among older people with multiple sclerosis in the USA. They found that emotional support from doctors was perceived as insufficient, and that patients were not willing to seek further help from doctors due to their attitudes; for example, 'one doctor was really snotty said, "does anyone else in your family have MS?" I said "Yes". He said, "See, you just want to have MS and you want to be like her." .... and that's reason why I put it off and didn't fight' (Fong et al. 2006: 702).

Table 2.3 *A Summary of Studies on Needs Assessment (Long-term)*

Author	Year	Country	Study design	N	Methodology	Sample
McIllmurray et al.	2001	UK	Cross-sectional	402	Self-administered questionnaire (the EORTEC C-30, the Psycho-social Needs Inventory)	Cancer patients diagnosed more than one month previously
Gray et al.	1998	Canada	Cross-sectional	70	Focus groups discussions	BC patients with 4 year-disease free
Hughes et al.	2000	USA	Longitudinal	148	Face-to-face/telephone interviews	Older people with cancer in an Intervention group
Thewes et al.	2004	Australia	Cross-sectional	18	Semi-structured telephone interviews	BC patients with stage I II and knew neither recurrence n or metastasis
Marlow et al.	2003	Australia	Cross-sectional	80	Focus groups discussions	BC patients
Fong et al.	2006	USA	Cross-sectional	27	In-depth interviews	Older people with multiple sclerosis

Note. EORTEC C-30 = the European Organisation of Research and Treatment of Cancer Quality of Life Questionnaire-Core 30; BC = Breast cancer.

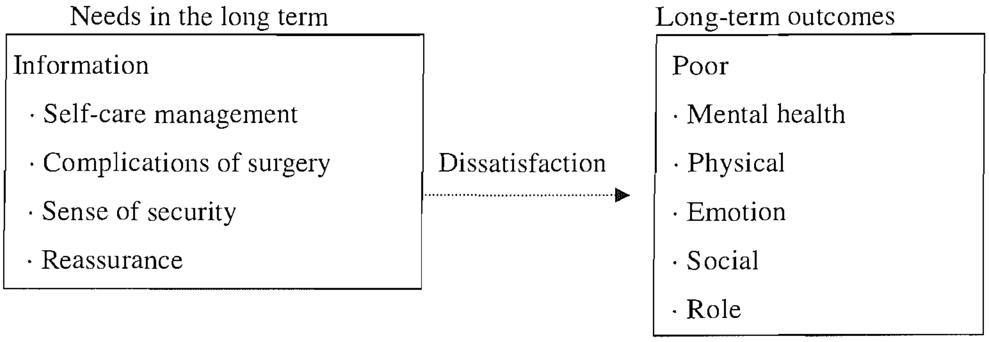
Long-term benefits: informational support and health-related Quality of Life

Some studies on people with HIV suggest long-term effects of perceived unhelpful support on patients' psychological states. For example, Burgoyne and Renwick (2004) conducted a longitudinal study among patients with HIV/AIDS in Canada. Social support was measured by the Medical Outcomes Study Social Support Survey (Sherbourne et al. 1991), and QoL was measured by SF36 at the time of the initial consultation, then two years and four years later. It was found that perceived unhelpful emotional-informational support (e.g.' understanding, encouragement, guidance, and information', Burgoyne et al. 2004: 1355) was positively associated with mental health scores in SF36 at the four year follow-up phase.

Similar findings to those reported by Burgoyne et al have been reported in studies in oncology. For example, Kerr et al. (2003) prospectively examined relationships between information provision and QoL among BC patients in Germany. They distributed European Organisation of Research and Treatment of Cancer (EORTC QoL-C30) and EORTC Breast Cancer Module (BR23), and information provision by doctors was assessed by their own designed scales. Kerr et al. found that around 45 per cent of participants perceived that the information given was unclear, and that this was associated with poor QoL scores on all domains except the sexual relationship domain, up to four years after the initial diagnosis.

In summary, Figure 2.2 shows the relationships between patients' needs and outcomes in the long-term.

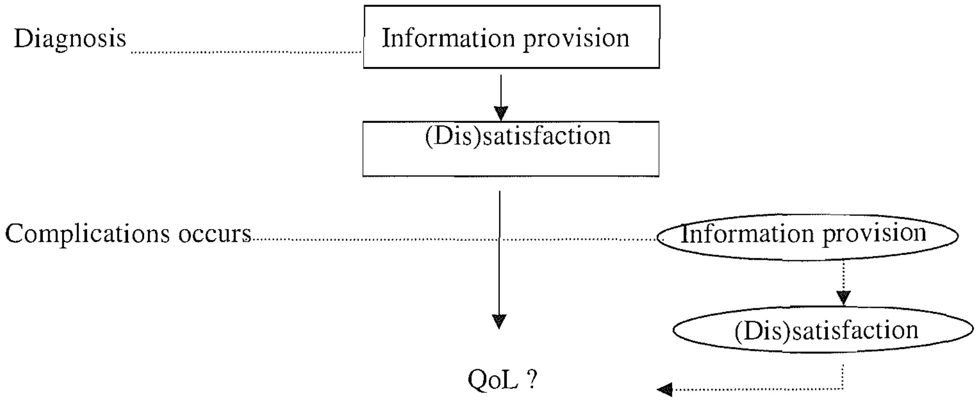
Figure 2.2 *The Relationships between Information Provision and Outcomes (Long-term)*



As presented, a few studies have been conducted examining the relationship between information provision at the diagnosis phase, (dis)satisfaction with support, and long-term QoL. Few studies have examined the relationship between information provision about patients' concerns several years after the diagnosis, (dis)satisfaction with support, and long-term QoL. Figure 2.3 shows these relationships.

According to the previous studies, adequate information provision and, to some extent, emotional support, are important especially when complications occur. The time line should be included when assessing QoL.

Figure 2.3 *Foci of this Research Programme*



CONCLUSIONS

Social support may be defined as positive support allowing recipients to feel at ease in their lives, and three types of support - instrumental, emotional, and informational - have been identified. Previous studies on social support have revealed that perceived social support is a good predictor of health outcomes. Additionally, studies on enacted support and satisfaction with support have revealed that perceived unhelpful support might negatively affect health outcomes.

As reported, most social support studies have examined whether or not support from family members could facilitate health outcomes. However, when patients with chronic illness are focused upon, medical doctors should be an important source of support provision; many studies have shown that, even several years after an initial diagnosis, patients with chronic illness need both informational support and emotional support from their doctors.

However, this psycho-social support is often perceived as being insufficient by patients, and may lead to dissatisfaction with doctors and hesitation with help-seeking behaviours. The relationships between information provision at diagnosis and short-term benefits have been extensively examined, whereas the relationships between information provision at diagnosis phase and long-term benefits have not been fully examined. Further, few studies have investigated the association between information provision in a different time frame, such as before surgery and after surgery, and health outcomes. Therefore, the main research question in this research programme is: how do (un)met needs affect QoL of BC patients with arm complications (lymphoedema)?

3. Breast Cancer and Post-operative Arm Complications

INTRODUCTION

As reported in Chapter 1, health-related Quality of Life (HRQoL) research in Oncology tends to focus on immediate impacts of cancer treatment, rather than on the long-term impacts of cancer treatment. Side effects of surgery - for example, lymphoedema - have been relatively underestimated in clinical settings, and there is not adequate care provision that can meet patients' needs (Morgan et al. 2005; Tsuchiya and Horn in press).

Lymphoedema is a chronic condition caused by inadequate lymphatic system functioning in the human body. It is classified into two types: primary and secondary lymphoedema. Primary lymphoedema is related to genetic malfunction of the lymphatic system, while secondary lymphoedema is acquired following diseases, treatment or other events. Thus, lymphoedema following breast surgery is called secondary lymphoedema.

Several, relatively subjective, symptoms of lymphoedema have been reported: swelling, a feeling of heaviness, a sensation of tightness of the skin, discomfort and pain (LymphNotes.com. 2004). Problems associated with lymphoedema include inflammation and infection caused by damaged tissues of the affected skin; the skin is so stretched that it easily gets hurt by daily activities. Thus, it is particularly important that patients protect their affected arm in their every day lives.

Among these symptoms, swelling can be measured objectively. Circumferential measurement is suggested to detect differences between the affected and unaffected arms. Medical tests, such as those using contrast medium, are recommended (Hirota 1999). However, the gold standard of diagnosis measure has not as yet been established.

As reported in Chapter 1, breast surgery often includes axillary lymph node dissections (ALND). Even when lumpectomies are chosen, adjuvant radiotherapy is essential following the surgery. This treatment may affect the lymphatic system because it leaves scar tissue which can cause blockages, and this may increase the chances of infection and inflammation. Consequently, patients undergoing the treatment are more likely to develop lymphoedema (Herd-Smith et al. 2001; Johansen et al. 2000; Keramopoulos et al. 1993).

Why does malfunction of the lymphatic system lead to secondary lymphoedema? How does this post-operative complication affect breast cancer (BC) patients' lives?

In this chapter, first, in order to understand what lymphoedema is, the physiology of the lymphatic system and the aetiology are briefly presented. Second, risk factors and risk behaviours of lymphoedema, and therapeutic management are introduced. Next, a literature review on BC-related arm complications is presented consisting of two sections: a descriptive study of arm complications and a study of the impact on the patients' Quality of Life (QoL). The literature may be helpful in understanding what type of symptoms BC patients frequently complain of after breast surgery, and how lymphoedema impacts on patients' lives.

THE LYMPHATIC SYSTEM

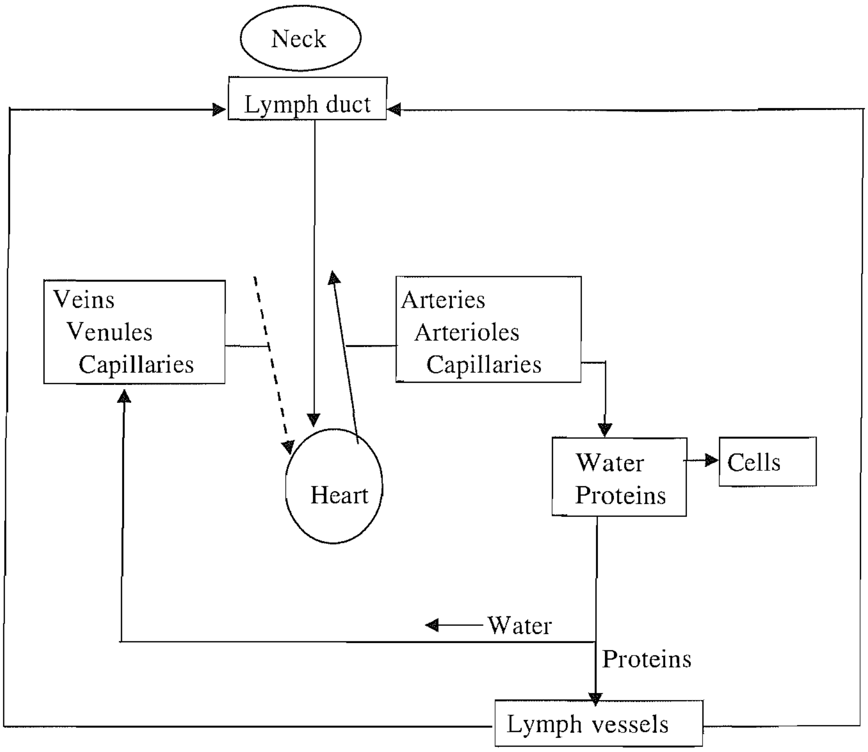
In this section, in order to understand the underlying aetiology, the role of the lymphatic system (lymph fluid and nodes) is presented briefly.

The lymphatic system, consisting of both lymphatic vessels and lymph nodes, covers the entire human body, and is connected by lymphatic vessels conveying fluid. This fluid (lymph) contains a lot of white blood cells. Lymph nodes (glands) consist of several small glands, and are located in the armpits, neck, chest, legs, abdomen and pelvis.

The system has two functions: the prevention of infection and dealing with waste products in blood. Regarding the prevention of infection, there are two levels of blocks for pathogens invading the body. First, since the fluid contains a lot of white cells, it can destroy external pathogens (e.g. bacteria) and can prevent the development of inflammation. However, white blood cells in lymphatic fluid are not always the winner. In this case, some cells (macrophages) in the lymph nodes can block further invasion of the pathogens. Second, regarding clearing waste products, lymph nodes filter waste production in blood. As Figure 3.1 shows, after blood circulates from arteries to capillary vessels, small amount of substances including water and proteins in the blood go to cells through capillary vessels. After being used in cells, the water is returned to the bloodstream (veins). Because fat particles (proteins) in the blood are too big to pass into the vein directly, they are returned to the heart through the lymph vessels. This activity is continuous. If the filter function does not work adequately, the tissues between lymph vessels and veins have both more protein and water. When the volume of protein and water becomes imbalanced, the tissues contain excess water and they swell.

However, impairment of the lymphatic system does not always spontaneously trigger the onset of swelling. This is because the body tries to find the alternative lymph vessels to normalise lymphatic function. Hirota (1999) illustrated this compensatory role using a traffic jam; when you are driving a car (lymph fluids) and you have a long traffic jam in front of you (no flow of lymph fluids), you might try to find a side road (the alternative lymph vessels) to avoid the long queue. If you successfully find the side road and reach your terminus (the heart), your journey will have finished (which means normal lymphatic function). If you cannot find the side road and if you cannot reach your terminus (which means impaired lymphatic functions), you have to queue (the increase of water in tissues). This leads to swelling.

Figure 3.1 *Factions of the Lymphatic System and the Vascular System*



RISK FACTORS AND BEHAVIOURS OF LYMPHOEDEMA

All patients undergoing ALND and adjuvant radiotherapy will not necessarily develop lymphoedema. Several risk factors and behaviours other than cancer treatment and the lymphatic system have been identified as a contribution to individual differences; these include age, weight gains, and daily activities. For example, Liljegren et al. (1997), conducting a prospective randomised study in Sweden, found that younger age (40 years old) was significantly associated with any arm complications at both 3-12 months and 13-36 months after surgery.

Regarding general clinical history, it has been reported that weight gain rather than body mass index is associated with lymphoedema. For example, Yap et al. (2003) conducted a cohort study in Canada, and found that body mass index was not significantly associated with reported swelling on the arm of the operated side. Petrek et al. (2001), conducting a retrospective cohort study in USA, reported that weight gain in the year after treatment was significantly associated with lymphoedema.

Finally, daily life activities seem to have something to do with the differences. According to LymphNotes.com (2004), 'getting trauma, lifting and carrying heavy stuff, and getting sunburn' are considered as increasing the risk of lymphoedema.

However, despite the evidence, it is difficult to predict the timing of the onset of symptoms, since it varies among individuals; some develop it immediately after breast surgery, but others develop it several years later, for example three years (Petrek et al. 2001) or eight years (Kamiyama 2002) since the surgery. Some symptoms will not naturally disappear; some people continuously complain of pain even five years after the surgery (Tengrup et al. 2000). This uncertainty is problematic in terms of therapeutic management.

THERAPEUTIC MANAGEMENT OF LYMPHOEDEMA

It is suggested that when the circumferential measurement is performed, a difference of more than two centimetres between the arms on the operated and unoperated sides is a clinical sign for treatment (Harris et al. 2001) but, if BC patients have any of the symptoms, immediate treatment is usually required to prevent a more severe condition. To put pressure on the affected arm and help excess fluid back into the lymph vessels, several therapeutic management regimes have been suggested: skin care, exercises, compression sleeves, multi-layer bandaging, compression pumps, manual lymphatic drainage (MLD), and simple lymphatic drainage (SLD). Therapists usually combine several of these methods, which is called combined decongestive lymphatic therapy (CDLT). As a result of these therapies, people may feel that the swollen arm is lighter, or that the actual volume of the arm is reduced.

However, the efficacy of the therapies has not as yet been confirmed (Harris et al. 2001) since most studies are preliminary in nature (Howell and Watson 2005; Morimoto et al. 2003). A few studies have applied randomised clinical trials, but have not confirmed the efficacy of MLD. For example, Andersen et al. (2000) carried out a study in Denmark comparing the existing therapy in the clinic and the therapy plus MLD. They found that the existing therapy plus MLD did not significantly reduce arm volume among patients with mild lymphoedema.

At present, therapeutic management is not always available in an accessible place for patients in the UK and Japan (Morgan et al. 2005; Okada 2002). For example, in the UK all therapeutic management except MLD can be provided in some National Health Service Hospitals (British Lymphology Society 2005), and MLD can be provided only by specialist clinics (e.g. MLD ^{UK}). In Japan, therapeutic management except MLD can be provided in some national and private hospitals, but the number of the facilities is limited (Okada 2002). In addition, only a few therapists are qualified MLD therapists in Japan. The costs are not automatically covered by the National Health Insurance, even though patients with lymphoedema are provided with some therapy. The patients must individually go through paper work to request the cost, but this is not always successful.

LITERATURE REVIEW

The general and basic ideas of lymphoedema, of the lymphatic system, risk factors, and therapy have been introduced. In this section, the literature on BC research is focused on, in order to present the incidence of lymphoedema amongst BC patients, and the psycho-social impacts on BC patients with lymphoedema.

Descriptive studies on post-operative arm complications

Previous studies (see Table 3.1) have explored the incidence of post-operative arm complications amongst BC patients. The incidence of frequently reported arm complications seems similar among the studies; the most commonly reported arm complication is numbness. The least commonly reported arm complication is swelling. For example, McPhail and Wilson (2000) conducted a cross-sectional survey study in the UK among BC patients who had undergone conserving treatment two years previously. They found that the half of participants reported post-operative arm complications; the participants were more likely to report numbness (43 per cent) and stiffness (36.7 per cent), but were less likely to report swelling (16.7 per cent). Another study in the USA (Bosompra et al. 2002) reported that participants were more likely to report numbness (51 per cent) and swelling (22 per cent). More recent studies in the UK (Rampaul et al. 2003) reported that patients who had swelling were more likely to complain of pain (45 per cent), but the prevalence of swelling was low in their sample (17/677).

Some studies have reported the most frequently reported site where patients experienced the complications. For example, Bosompra et al. (2002) reported that the most frequently numbed site was under the armpits and that the most frequently swollen site was on the shoulder, upper arm, and forearm. Another study (Warmuth et al. 1998) reported that participants were more likely to report numbness (35 per cent) under the arm pits or on the chest.

Table 3.1 *A Summary of Descriptive Studies on Post-operative Arm Complications*

Author	Year	Country	Methodology	Type of arm complications	N	Sample
McPhail et al.	2000	UK	Cross-sectional Self-report questionnaire	Numbness Stiffness Pain/discomfort Swelling	61	BC patients who underwent conserving treatment 2 years previously
Pampaul et al.	2003	UK	Longitudinal Self-report questionnaire Objective measurements	Swelling	677	BC patients attending at a follow-up
Bosompra et al.	2002	USA	Cross-sectional	Numbness Swelling	148	BC patients who underwent surgery 3-4 years previously
Warmuth et al.	1998	USA	Cross-sectional	Numbness Pain Poor range of motion Swelling Infection/inflammation	432	BC patients who underwent surgery 2-5 years previously, with both stage I and II, and without recurrence

Table 3.1 (continued)

Author	Year	Country	Methodology	Type of arm complications	N	Sample
Taylor	2004	New Zealand	Cross-sectional Self-report questionnaire	Numbness Stiffness Pain Weakness Swelling	182	BC patients who underwent surgery on breast and axilla, and without recurrence
Ivens et al.	1992	UK	Cross-sectional Objective measurements	Pain Weakness Numbness Swelling Shiftness	126	BC patients who underwent full axillary dissection 6 months previously
Paskett et al.	2000	USA	Cross-sectional Survey interviews	Lympphoedema	40	BC patients with lymphoedema

Note. BC = breast cancer, ALND = axillary lymph node dissections.

It might be expected that, if surgery has included ALND (usually carried out if there is evidence of cancer cells in the lymph nodes in order to prevent the spread of the disease), the risk of lymphoedema is greater. However, studies targeting those with ALND have obtained similar findings to the studies reported above which did not specifically target BC patients who had undergone ALND. For example, Ivens et al. (1992) conducted a cross-sectional survey study in the UK among BC patients who had undergone ALND. They found that participants were more likely to report numbness (70 per cent), but were less likely to report pain (30 per cent) and swelling (18 per cent). Similar findings have been reported by Taylor (2004), who conducted a cross-sectional survey study in New Zealand, and found that over 70 per cent of participants reported any types of arm complications and that participants were more likely to report numbness (60 per cent) and pain (45.3 per cent), but were less likely to report swelling (26.4 per cent).

Surprisingly, most previous studies have shown that more than 50 per cent of BC patients in their sample experienced the symptoms of lymphoedema. Some of the studies above were conducted several years since breast surgery. Most BC patients may recover physically and psychologically. However, it is not well understood how the onset of another chronic illness associated with BC treatment impacts on the patients, since relatively few studies in this area have been published so far (McWayne and Heiney 2005). Regarding the Japanese population, a literature search using Medline, PsycINFO, and Bath Information and Data Services (BIDS) shows that there are no published studies (written in English) in Japan.

Psychosocial impacts of post-operative arm complications

In this section, first, the findings of quantitative studies and, second, of qualitative studies are presented (Table 3.2 shows a summary of the studies).

Quantitative research

Studies using generic QoL questionnaires have shown that post-surgical BC patients with lymphoedema report worse emotional and social well-being than those without. For example, Tobin et al. (1993) conducted a case-control study using several generic questionnaires: the Hospital Anxiety and Depression Scale (Sigmond et al. 1983), Karnofsky performance scale (Karnofsky et al. 1949), the Psychosocial Adjustment to Illness Scales (PAIS; Derogatis 1986), and the Social Stress and Support Inventory (Jenkins et al. 1981). Tobin et al. sampled BC patients aged less than 70 years (the mean time since treatment was 80.2 months for the study group and 77.1 months for the control group). They found that the lymphoedema group was more likely to report a worse score on the PAIS (e.g. vocational, domestic, social environment, sexual relationships, and psychological distress) than patients without lymphoedema group. This finding has been supported by other studies in the UK. Velanovich and Szymanski (1999) reported that lymphoedema affected both social and emotional aspects; they conducted a cross-sectional study using the Medical Outcomes Survey Short Form 36 (SF36; Ware and Sherbourne 1992). They sampled BC patients who had undergone surgery between six months and four years previously, and compared the SF36 scores among three groups: a surgery without ALND group, a surgery with ALND but no lymphoedema group, and a surgery with both ALND and lymphoedema group. The findings were that patients in the third group were more likely to report worse role-emotional domains and mental health domains in the SF36. Additionally, a more recent study, Rietman et al. (2004) found that BC patients with arm complications reported worse scores in terms of physical functioning, vitality, and health perception on the RAND 36-item Health Survey than did a female norm group in the Netherlands.

Some studies using cancer-specific questionnaires have shown associations between the global score and lymphoedema, but have not shown associations between sub-domains and lymphoedema, which are inconsistent with the results from studies using the generic QoL questionnaires. For example, Hack et al. (1999) conducted a cross-sectional study in Canada using the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30; Aaronson et al. 1993), the Mental Health Inventory (Ware et al. 1979), and other generic pain questionnaires. They sampled BC patients undergoing ALND, radiotherapy, and chemotherapy between six months and ten years previously, who did not have recurrence (the mean time since ALND was 33.2 months), and found that pain intensity at the time of investigation significantly predicted worse global scores on the EORTC QoL Questionnaire and total Mental Health Inventory score.

Other studies using the Functional Assessment of Cancer Therapy (FACT-B; Brady et al. 1997) have shown that there are no significant differences between BC patients with and without lymphoedema in terms of emotional and social well-being. For example Beaulac et al. (2002) conducted a retrospective cohort study in the USA. They sampled BC patients who had undergone surgery with ALND (the mean time since surgery was 4.8 years) and radiotherapy. They found that patients with lymphoedema reported worse scores in the total score than those without lymphoedema. On the other hand, differences in emotional and social well-being between the two groups were not found.

These findings are difficult to interpret; why were the total FACT-B scores significantly different when scores of sub-domains were not? What is the real problem that the patients with lymphoedema have? Is this because BC specific questionnaires are less sensitive to detect lymphoedema-specific issues? Is it too simplistic to compare QoL between BC patients with and without lymphoedema - is there any potential predictor associated with QoL?

As another possible explanation, if the other variables (subscales), for example, lymphoedema treatment, social support (as reported in Chapter 2), and attributions had been included as independent variables, more understandable findings might have been obtained. For example, Woods et al. (1995) expanded Tobin et al's study (1993), and collected data prospectively including at base line and at six months following treatment of swelling. They obtained consistent results with those reported by Tobin et al. at the baseline (BC patients with lymphoedema reported worse scores in PAIS). Because of the small sample size of the lymphoedema treatment group and study design in Woods et al's study, there were no significant differences in PAIS scores between patients who were provided with lymphoedema treatment and those who were not. However, it may be worth while to include this variable, which may contain physical symptoms, in order to investigate associations with QoL.

Other studies (Maunsell et al. 1993; Ververs et al. 2001) have shown that doctor-patient communication, such as information provision, is often perceived as unsatisfactory. As reported in Chapter 2, this perception seems to affect patients' QoL. For example, Engel et al. (2003) conducted a prospective study in Germany, examining the relationships between arm complications, satisfaction with medical consultation or information provision and QoL. Engel et al. sampled BC patients and administered a questionnaire developed for the study and the EORTC QLQ-C30. They found that patients with arm complications reported worse global scores and worse scores on all domains over five years than those without, and also found that dissatisfaction with medical consultations was associated with the worst global score over three years since BC diagnosis.

Additionally, perceptions of lymphoedema may be a good predictor of QoL, since patients often perceive lymphoedema as negative. For example, Voogd et al. (2003) conducted a cross-sectional study in the Netherlands examining the relationship between objective swelling and QoL. They sampled BC patients undergoing ALND who had completed any treatment three months previously and had neither axillary radiotherapy nor recurrence (the mean time since the completion of any treatment was 4.2 years). QoL was measured using a specially developed questionnaire including physical functioning, psychological functioning, levels of independence, social relationships, and environment. The findings showed that participants with big differences in abduction between the two arms (>/= 20cm) were more likely to perceive themselves as disabled. This perception of lymphoedema may affect BC patients' QoL, even though this association has not as yet been investigated quantitatively.

Several qualitative studies have explored perceptions. The detailed findings of the qualitative studies are presented in the next section.

Table 3.2 *A Summary of Studies on Psychosocial Impact of Arm Complications*

Author (Year)	Methodology	N	Sample
Hack et al. (1999)	Cross-sectional survey study in Canada (the Physical Therapy Assessment, the Post-operative Pain Questionnaire, the Pain Disability Index, the McGill Pain Questionnaire Short-form, EORTC QoL Questionnaire, the Mental Health Inventory)	222	BC patients who underwent ALND 6 months previously, but no more than 10 years since ALND, adjuvant chemotherapy and radiotherapy at least 6 months previously, without axillary radiation, recurrence, psychiatric history, and chronic pain before ALND
Velanovich et al. (1999)	Cross-sectional in USA Self-reported questionnaire (SF-36)	101	BC patients who underwent surgery between 0.5 and 4 years previously, and biopsies, lumpectomies, simple mastectomies, modified radical mastectomies or lumpectomies with ALND
Tobin et al. (1993)	Case-control study in UK Questionnaires (HADS, KPS, the Psycho-social Adjustment Illness Scales Interviews) Interviews (the Social Stress and Support Inventory)	100	BC patients who underwent surgery 1 year previously, aged under 70 years, and disease-free, and with arm swelling

Table 3.2 (continued)

Author (Year)	Methodology	N	Sample
Rietman et al. (2004)	Cross-sectional survey study in Netherlands Questionnaires (RAND-36, shoulder disability questionnaire)	55	BC patients who underwent mastectomies 2.7 years ago, without operation on both breasts, metastases, and recurrence
Beaulac et al. (2002)	Retrospective cohort study in USA Self-reported questionnaire (FACT-B) Objective measurements (arm volumes, range of motion, and handgrip strength)	151	BC patients who underwent either mastectomies or breast conserving surgery 1 year previously, radiotherapy, ALND I and II, without recurrence and neojuvant chemotherapy
Woods et al. (1995)	Prospective case-control study in UK Questionnaire (PAIS)	50	BC patients who underwent surgery 1 year previously and free from active disease
Engel et al. (2003)	Prospective study in German Self-report questionnaire (EORTC QLQ-C30)	990	BC patients
Ververs et al. (2001)	Cross-sectional study in Netherlands Questionnaires for this study (Physical, psychological, independence social relationships, and environment)	400	BC patients who underwent ALND, completed a treatment least 3 months previously and without recurrence

Table 3.2 (continued)

Author (Year)	Methodology	N	Sample
Maunsell et al. (1993)	Prospective study in Canada Self-reported questionnaires (the Diagnostic Interview Schedule, the Psychiatric Symptom Index)	201	BC patients who underwent surgery 3 months previously and without metastasis at the time of diagnosis
Voogd et al. (2003)	Corss-sectional study in Netherlands Self-reported questionnaire (physical, psychological functioning levels of independence, social relationships and environment) Objective measurements (swelling)	332	BC patients who underwent ALND, completed any treatment 3 months previously, without axillary radiation and recurrence
Woods (1993)	Semi-structured interviews in UK Objective measurements (limb volume) Self-report questionnaire (PAIS)	37	BC patients with lymphoedema
Williams et al. (2004)	Qualitative in-depth interviews in UK	15	Lymphoedema patients

Table 3.2 (continued)

Author (Year)	Methodology	N	Sample
Carter (1997)	Qualitative interviews in USA	10	BC patient with stage I or II, who underwent surgery at least 1 year ago, and have lymphoedema at least 2 months after surgery, without recurrence, psychiatric problems, alcoholism, and substance abuse.
Johansson et al. (2003)	Qualitative interviews in Sweden	12	BC patients with lymphoedema, who had paid-job outside, and experienced lymphoedema at least for 1 year
Radina et al. (2001)	Qualitative interviews in USA	-	BC patients with lymphoedema, who underwent surgery and/or radiotherapy, and aged above 18 years

Note. BC = breast cancer, ALND = axillary lymph node dissections, FACT-B = the Functional Assessment of Cancer Therapy-Breast, EORTC = the European Organisation for Research and Treatment of Cancer, HADS = the Hospital Anxiety and Depression Scales, KPS = the Karnofsky Performance Status, RAND-36 = RAND36-item Health Survey, PAIS = The Psychological Adjustment to Illness Scale.

Qualitative research

Although fewer qualitative studies have been conducted exploring the psycho-social impact of lymphoedema among BC patients (McWayne et al. 2005), the findings are arguably of greater help in understanding the patients' perceptions and attributions of experiences of lymphoedema than are those obtained in quantitative studies.

Previous qualitative studies have revealed that some patients need to restrict the use of the affected arm and to limit actual physical activities, meaning that, to some extent, patients have physical burdens. For example, Johansson et al. (2003) conducted a semi-structured interview among BC patients with lymphoedema who all had a paid job. A phenomenological approach revealed that patients perceive lymphoedema in terms of physical burdens: 'I have to think ahead. I can't lift very heavy things with this arm ... then I let my other arm take the punishment.' (Johansson et al. 2003: 39). Carter (1997), who conducted in-depth interviews among patients with lymphoedema and applied a phenomenological approach, reported similar findings to those reported by Johansson et al:

> It bothers me a great deal. I just bought a jacket ... I had to take the shoulders up, and this arm is kind of tight. And it just doesn't look normal. It looks like there is something wrong with me ... I just wish [the lymphoedema] would go away.
>
> (Carter 1997: 879)

Also, another woman in Carter's study reported:

> [the lymphoedema] is a financial burden and a physical burden. I even have a hard time going for a walk because as soon as I'm swinging my arm, it swells up and is uncomfortable. So we tend to not even go for a walk.
>
> (Carter 1997: 879)

Some studies have revealed that wearing bandaging and compression sleeves restricts arm movement. For example, Radina and Armer (2001), who conducted interviews in the USA and applied an ethnographic approach, reported that a participant had difficulties in playing a mother's role due to arm therapy:

> Giving my daughter, Anne, a bath was hard. It wasn't that I was not capable, it was just a huge production to remove eight layers of bandages ... Also doing Anne's hair is difficult because of the glove. It catches on her hair and makes it harder for me to grip her hair tightly.
>
> (Radina et al. 2001: 290)

Some women perceive that being offered help seems to affect perceived normality, and consequently others' reactions lead to negative self-image. Johansson et al. (2003: 38) reported 'I really hate having to ask … it feels like a big defeat. Yes, that I felt like a strong woman before and I feel like a weak person now.'. Another study (Radina et al. 2001: 292) reported similar findings; some patients felt that support from others deprived them of independence: 'I don't like it. I want to do it myself. When you think of something you want to do, you want do it now and not have to wait for someone else.'.

Additionally, social embarrassment has been reported. For example, Johansson et al. (2003) reported that compression sleeves were so visible that they let others know about the arm problems. As a result, patients encountered difficulty in social disclosure. A woman in the study described how she had learned it was better to explain her arm problems and BC dishonestly when she was asked. Her discourse shows that embarrassment can happen both ways between patients and others:

> Once when I was at the bank someone asked: what in the world have you done to your arm? I said: Ah, I've had a mastectomy. And I sort of saw how she went all pale and then I felt like I shouldn't have said anything … because I saw how she reacted and what she was thinking; She just wanted to disappear into thin air.
>
> (Johansson et al. 2003: 37)

Next, similar to the quantitative studies, communication issues between doctors and BC patients have been revealed; dissatisfaction with insufficient information provision, with unenthusiastic instruction and education about management, and with unsympathetic attitudes. For example, Woods (1993) conducted a semi-structured interview in the UK and found that most of the participants had undertaken arm therapy, but 90 per cent of participants admitted they had not been given information about the risk of lymphoedema after cancer treatment.

Other studies show that perceived insufficient information provision and understanding provoked feelings of uncertainty. Williams et al. (2004) conducted interviews among cancer patients with lymphoedema in the UK, and found that a woman, having kept on seeking medical help for her arm complications for a long time, was released from 'fishing in the dark' when the lymphoedema diagnosis was given, but that afterwards the woman started to feel fear of uncertainty:

> Eventually I was given a diagnosis of lymphoedema and was basically told that was it. I wasn't given any help, nothing, so I didn't know how to keep it under control ... given a bit more information but even then I don't think I really understood … what it was going to be like … it was all too new and I hadn't come to terms with what was wrong with me.

(Williams et al. 2004: 282)

Studies in the USA and Sweden have shown that patients are more likely to feel distress when they encounter physicians' insensitive attitudes. For example, Carter (1997) reported dissatisfaction with doctors' attitudes:

> As far as the medical profession is concerned, I would like to see more [the physicians] more aware, more concerned about the lymphoedema ... [A lot of people] that I have come in contact with ... just shrug it off and say 'It's there, there is nothing that can be done, just live with it.
>
> (Carter 1997: 878)

Similarly, Johansson et al. (2003: 38) reported that doctors tended to underestimate how lymphoedema was impacting on patients: 'It feels like they (doctors) just think that lymphoedema is just a trivial matter in comparison to cancer and it is, but it can still be very annoying.'.

Regarding evaluation of experiences of lymphoedema, some studies show that comparison to BC is used, and patients draw a conclusion that it was a 'trade-off': 'the fact I had my surgery 22 years ago - that's something to be thankful for [even though I've got lymphoedema]' (Williams et al. 2004: 294). Johansson et al. (2003: 39) reported similar attributions (social comparison) in the study: 'I try to think positively. I've got lymphoedema but other women have lost their breast. I haven't. Maybe that compensates for it'.

CONCLUSIONS

Lymphoedema appears when the lymphatic system is impaired either by congenital or acquired causes such as disease, treatment, and daily activities. The latter is called secondary lymphoedema. Even though BC treatment may have impaired the lymphatic system, every BC patient will not necessarily develop secondary lymphoedema. The timing of the onset is not easily predictable. This is a problematic aspect of prevention and management of lymphoedema. Several therapeutic management regimes have been suggested, but scientific evidence of efficacy has not yet been confirmed.

Previous research in the West has extensively explored what type of arm complications have developed after breast surgery, and what the risk factors are. First, studies have consistently shown that numbness is most frequently complained of, whereas swelling is least complained of. Second, studies have shown that demographic factors (age), breast cancer treatment (ALND and radiation) and clinical history (weight gain post-operatively) increase the risk of arm complications.

Most quantitative studies using either generic or BC specific questionnaires have shown that BC patients with lymphoedema are more likely to report worse QoL than those without. However, some studies have shown that QoL assessed by a generic questionnaire is not different from the norm. It is sometimes difficult to interpret the findings since studies have used different QoL instruments. Further, some studies using the BC-specific questionnaire have shown that there are no associations between lymphoedema and sub-domains of the questionnaires, but there are associations between lymphoedema and the global score.

Qualitative studies have reported the psycho-social impact of lymphoedema more than quantitative studies; physical burdens in daily life, negative self-image, social embarrassment, communication issues between doctors and patients. Also the studies have shown that comparison to BC and social comparison are important for BC patients to evaluate their experiences of lymphoedema. However, since only a few studies have been conducted so far in this area, how patients' perceptions and attributions have been constructed, and the cognitive and emotional processes of adaptation, are not fully understood, especially in Japan.

4. The Quantitative Study: Validity and Reliability of the Arm-lymphoedema Physical Discomfort Scale

INTRODUCTION

The previous three chapters have identified an insufficient base of health-related Quality of Life (HRQoL) research in psycho-oncology, including the concept of QoL (motivation, need satisfaction, and influences of social norms), long-term effects of cancer treatment (secondary lymphoedema) and effects of perceptions of information provision on QoL.

Issues of information provision are particularly important in terms of symptom management of lymphoedema, since it is difficult to predict which patients will develop lymphoedema after breast surgery as well as the timing of the onset; not all patients who undergo axillary lymph node dissections (ALND) will necessarily develop lymphoedema, and the timing of the onset varies among individuals, as reported in Chapter 3. This uncertainty is problematic in terms of therapeutic management; seeking advice or adequate treatment provision tends to be delayed. A preliminary qualitative study in Japan (Tsuchiya and Horn in press) revealed that some breast cancer (BC) patients with ALND complained of some of the arm complications after surgery, but that their complaints were underestimated in clinical settings. Other studies have similarly reported that doctors tended not to refer BC patients with lymphoedema to physiotherapists (Lee et al. 2001), and that information and care provision were inadequate (Moffat et al. 2003).

In order to improve patient care, information provision about the risk of lymphoedema is vitally important. This could prevent the patients from carrying out risk behaviours after discharge. In addition, patients who detect some early signs should be encouraged to visit a doctor without delay. Similarly, doctors also need to detect early symptoms, which are relatively subjective, if appropriate care is to be provided. If therapies are not available at their own hospitals or clinics, doctors should refer patients to specialists who can provide appropriate care - such as manual lymph drainage, bandaging, and use of compression sleeves - since it is considered important to contain the condition.

There might be patients with minor conditions for which intensive therapy is not necessary. These patients, however, need reassurance by doctors (Carter 1997; Johansson et al. 2003). To meet these needs, doctors should be sensitive enough to understand how much discomfort patients have experienced or are experiencing. Thus, in order to improve detection of the relatively subjective symptoms of lymphoedema and discomfort in daily life, a concise and reliable measure will be invaluable in clinical settings, since the gold standard of diagnosis has not been established.

Aims of this quantitative study

Since few studies have been conducted among BC patients with lymphoedema in Japan, lymphoedema-related information was minimal regarding, for example, what types of arm complications are most complained of, what lymphoedema therapies the patients have actually followed, and how much discomfort the patients experienced - or are experiencing - as a result of lymphoedema. It is also uncertain how these variables are associated with patients' QoL.

In order to shed further light on these issues, a survey study was conducted among BC patients in Japan. It is important to use a reliable symptom checklist measure in order to access relatively subjective symptoms of lymphoedema. After a careful review of the literature, it was concluded that no adequate scales are available to assess lymphoedema-related physical symptoms. One scale, the Functional Assessment of Cancer Therapy - Breast + 4 has been investigated for reliability (Coster et al. 2001); five questions are asked on arm symptoms, such as swelling, pain, range of movement, numbness, and stiffness, but how much discomfort patients had experienced, were experiencing and the duration of having arm complications were not included. This module was not available in Japanese at the time the study was carried out.

The purpose of this study was to develop a new measure in Japanese in order to identify the symptoms and physical discomfort of arm-lymphoedema amongst Japanese BC patients.

Summary of the first quantitative study

In the rest of this chapter, the process of developing a new questionnaire is presented; first, the questionnaire including a lymphoedema symptom checklist and a six-item five-point faces scale (the Arm-lymphoedema Physical Discomfort Scale, ALPDS) was designed after a comprehensive literature review and the qualitative study (Tsuchiya et al. in press). A small pilot study (study one) was conducted in Japan in order to explore the relevance and comprehensibility of the questionnaire (face validity). Taking participants' comments into account, the questionnaire was revised wherever necessary.

Second, a prospective mail survey study (study two) with a larger sample is reported; test-retest reliability was assessed on the symptom check list, the global score, and the ALPDS to confirm whether the same results are obtained from the same participants on a different occasion. Next, the underlying structure of the ALPDS with internal consistency was examined (construct validity). Finally, factors predictive of reported discomfort of arm complications were examined (criterion validity).

STUDY ONE: FACE VALIDITY OF THE QUESTIONNAIRE

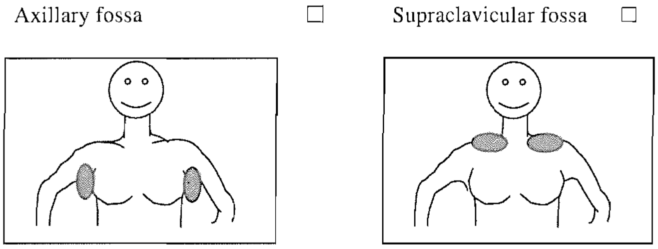
Method

Description of the questionnaire

The pilot questionnaire was a self-report type and consisted of four parts: questions about patients' demographic characteristics, BC treatment, clinical history, and a free comments page (see Appendix 4.1).

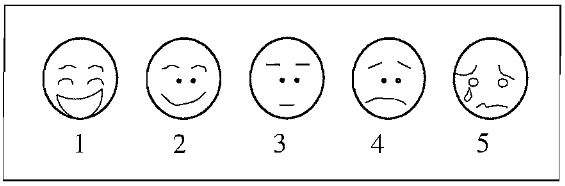
In the second section, on the question of site of radiation, figures were used showing site of radiation (see Figure 4.1).

Figure 4.1 *The Question about Sites of Radiation*



In the third section, a lymphoedema symptom check list, a one-item global scale, and the ALPDS were presented together with questions about clinical history other than lymphodema. First, the symptom checklist comprised eight items - the presence of arm complications, affected arm side, five types of arm complications and the duration. Dichotomous and polytomous categorical responses were used. Second, a one-item global scale was created to assess overall discomfort as a result of lymphoedema. Third, the ALPDS consisted of six items - paid work, household chores, grooming, hobbies, sleeping and meeting somebody. Five-point faces scales (see Figure 4.2) were used in the global scale and the ALPDS in order to assess the discomfort, ranging from a big smiling face (the lowest discomfort score of 1) to a crying face (the highest discomfort score of 5).

Figure 4.2 *Five-point Faces Scale*



One of the merits of such visual scales is that patients can indicate subjective experiences readily by choosing the most appropriate facial expression in the scale. Patients do not need to search for the most appropriate words to describe, for example, the level of pain experienced. Such scales (e.g. Wong-Baker FACES Pain Rating Scales; Wong and Baker 1988) are particularly useful for young children who are unable to verbalise their feelings properly. However, it can be assumed that a dilemma between subjective feelings and word choices is also experienced by adults. In Japan, the faces scales have been used to assess adult cancer patients' experiences of chemotherapy (Kurihara et al. 1999) and of palliative therapy (Ishihara et al. 1995), and there is evidence that Japanese respondents preferred five-point scales to seven-point scales; this tendency was found especially among females (Nagata et al. 1996).

Study site

Japan consists of five main islands (378.000km^2), and the land is located from the north to the south. The population is about 127 million; the majority is Japanese, and the common language is Japanese. Most Japanese do not believe in a particular religion, but their life style and customs are influenced by Zen Buddhism, Confucianism, and *Shinto*. The first nine years of school education is compulsory, from elementary school (between 6 and 12 years old) and junior high school (between 13 and 15 years old). Following the compulsory education, the majority proceeds to a high school and higher education.

People living in a big city or adjunct cities enjoy a westernised life style and advanced technology. In the capital city, Tokyo, there are many hospitals including an oncology centre. Also in prefectures adjunct to Tokyo, such as Kanagawa and Chiba (see Appendix 4.2) there are national or local oncology centres. As long as treatment is covered by the National Health Insurance, 30 per cent of total medical costs need to be paid when people consult doctors or are prescribed medicine. Since there are no general practitioners, in general patients tend to go to see a doctor in specialised or university hospitals rather than private clinics even though they may have only a minor illness.

Procedure: preliminary checking of the questionnaire for clarity and ease of use

Following ethics approval from the School of Psychology, University of Southampton, in August 2003, fourteen breast cancer patients in a lymphoedema self-help group in Tokyo were purposively selected. A questionnaire package including information letters (see Appendix 4.3), the questionnaire, and return envelopes with stamps was mailed to the patients via the group coordinator.

In the information letter, the nature and purpose of the study were described, and assurances regarding confidentiality and anonymity were provided. In addition, it was mentioned that returning a completed questionnaire was taken as evidence that participants gave consent for participation in this study.

Participants

Ten female BC patients with lymphoedema in a lymphoedema self-help group voluntarily participated in this study. The mean age was 58.6 years (age ranged between 45 and 66 years). The mean duration since surgery was 8.5 years (year ranges between 2.1 and 22.8 years).

Analysis

Descriptive analyses were conducted to detect the frequency of missing data, and free text comments from the participants were summarised.

Results

Participants' characteristics are presented in Table 4.1. Most participants were married and housewives, and had completed high school education. Some participants did not know what surgical method had been performed, but all knew whether or not ALND had been performed. Most participants had taken or were taking hormonal therapy following breast surgery.

Table 4.1 *Participants' Characteristics (Study One)*

Variables	n
Marital status	
Single/Divorced/Widowed	0
Married	9
Children	
Yes	9
No	1
Levels of education	
Junior high school	2
High school	3
Technical school	3
University	2
Paid-work	
Yes	1
No	9
Occupations bearing household income	
Employees at LLC1	2
Directors at LLC2	1
National servants	2
Local servants	1
Self-management	3
Other	1
Type of surgery	
Quadrantectomies	3
Modified radical mastectomies	3
Unknown	3
Axillary lymph node dissections	
Yes	10
No	0
Chemotherapy	
Yes	4
No	6
Hormone therapy	
Yes	6
No	3

Table 4.1 (Continued)

Variables	n
Radiotherapy	
Yes	5
No	5

Note. LLC1 = limited liability companies that go public at stock market; LLC2 = limited liability companies that do not go public at stock market.

There were a few missing data in several variables as Table 4.2 shows. Variables in the clinical history section had more missing data than the other two parts.

Table 4.2 *A Frequency of Missing Data*

Section	Question No.	Variables	Frequency
Part I	Q3	Marital status	1
Part II	Q3	Type of surgery	1
	Q7a	Irradiated areas	1
	Q8	Stages	1
	Q9	Information provision at diagnosis	1
	Q10	Information provision after surgery	1
Part III	Q1	Prescription	2
	Q3	Hyperlipidaemia	2
	Q4a	Medical tests for lymphoedema	2

Participants commented on five questions: stages, hormone therapy, information provision at diagnosis, information provision after surgery, and medical tests for a diagnosis of lymphoedema. All participants' comments are presented in Table 4.3.

Table 4.3 *A Summary of Free Texts*

Variables	Comments
Stage	Does the stage mean the area or cancer stage?
Hormone therapy	Does the hormone therapy mean anti-cancer drugs?
Information provision	My doctor might have explained breast cancer itself and treatment, but I was blank. I did not remember what he had said, so I don't know if I was informed enough.
Medical tests for a diagnosis of lymphoedema	I am wondering if there could be any medical tests for the diagnosis.

Conclusions

Overall, most participants appeared to understand the wording and phrasing, especially in the symptom check list and the ALPDS. Since the participants in this study were knowledgeable about lymphoedema and BC, their comments were very helpful. Considering both missing variables and the free texts, possible improvements were suggested.

First, some participants could not select an appropriate answer because there were no right choices under the question; for example, on the types of surgery (Part II Q3), the participant who did not answer the question was operated on ten years ago. Presumably, the types of surgery that were described in the questionnaire did not apply to her case. So, 'other' and 'describe' plus parentheses were added as a new choice under the question. Next, on irradiated areas (Part II Q7-7a), the participant who did not answer the question was operated on in 1976, and the type of surgery she had undergone was unknown. She wrote down a memo that she had been irradiated on breast, axillary fossa, and infraclavicular fossa in a blank space. For such patients, 'other', and a picture were added as the new choice, and the instruction 'please show the area in the picture below' was added. Next, on medical test for lymphoedema diagnosis (Part III Q4a), four participants marked 'other' and described that no test was performed. Although there is a way to check lymphatic functions using a medical test, such as contrast medium (Hirota 1999), the test is less likely to be used in practice than inspection and palpation. Thus, the question was changed to 'what did the doctor perform in order to make the diagnosis?', and both inspection and palpation were added as the choices.

Second, considering the free texts, attempts to clarify the words were made; for example, regarding stages (Part II Q8), the patient who commented on the question had wondered if the term had meant the areas of or the stages of BC. The patient may not have understood the meaning of stage, so more detailed classifications (I, IIa, IIb, IIIa, IIIb, IV, and Unknown) and explanations of each stage were presented next to the question. Regarding hormone therapy (Part II Q6), the patient who commented on the question asked whether the term had meant anti-cancer drug therapy. Presumably, even though there was that question under the breast cancer section (Part II), the participant had thought about hormone therapy for a menopausal disorder. Thus, it was necessary to make the statements; for example, 'Part I. I will ask about you', 'Part II. I will ask you about your breast cancer', and 'Part III. I will ask about clinical history other than breast cancer.' Regarding prescriptions (Part III Q1), initially, attempts were made to find out about participants with psychiatric problems through this question. However, the participants reported the name of medication (e.g. medication for hormone therapy or for high blood pressure). Nobody reported medication for psychiatric problems. Thus, the question was changed to 'have you had any medicine prescribed or treatment for your mood?'

Finally, regarding the structure of the questionnaire, information provision (Part II Q9, Q10, and the sub-questions) seemed to have the participants confused. For example, if participants felt that the information provision at diagnosis was enough (Q9), they ticked the 'Yes' box and they can move straight to the next question (Q10); they do not need to answer sub-questions of Q9. However, in fact, the participants in this study often ticked sub-questions of Q9, even though they ticked 'Yes' at Q9. Thus, in order to avoid this confusion, some instructions and examples on the first cover page were presented.

These necessary amendments were made after discussions with supervisors, and it was then planned to distribute the revised questionnaire to a larger sample in BC self-help groups in Japan; validity and reliability would be tested for the ALPDS and the symptom check list.

STUDY TWO: VALIDITY AND RELIABILITY INVESTIGATION

Method

Procedure

Between September and October 2003, participants were recruited from two BC self-help groups in Japan: one group was based on Kanagawa Prefecture. The other was based on Chiba Prefecture. A questionnaire package including an information letter (see Appendix 4.4), the revised questionnaire (see Appendix 4.5), and a free-post envelope was mailed to a total of 380 people in the mailing lists; participants' contact details and willingness to participate in the next study were requested. One hundred sixty-six patients returned their questionnaires (a response rate of 43.7 per cent).

To test repeatability, 80 patients out of 166 were selected by systematic random sampling without referring to their responses in the first questionnaires; the list of identification numbers of the returned questionnaires was randomly ordered in an Excel sheet, using RAND function. After deciding the interval size (166/80), the number two was selected. To select 80 patients, all multiples of two were selected in the list.

After a one-month interval, a similar questionnaire package was mailed to these 80 people again, including an information letter (see Appendix 4.6), the same questionnaire as the first time, and a free-post envelope. Fifty-six patients returned the second questionnaire (response rate of 70 per cent).

In the information letter, the nature and purpose of the study were described, and assurances regarding confidentiality and anonymity were provided. In addition, it was mentioned that returning a completed questionnaire was taken as evidence that participants gave consent for participation in this study.

During the data screening process, one participant was found to be a male, so these data were excluded from the statistical analyses.

Analysis

First, participants' household income was calculated using three tables published by the Japanese Government: direct national tax statistics (National Tax Agency 2003), the tables of national public servants' salaries (National Personnel Authority 2003), and the tables of local public servants' salaries (The Ministry of Internal Affair and Communications 2003). Three variables in the questionnaire, marital status (part I Q3), occupation (part I Q6), and occupation bearing livelihood (part I Q7) were also used. These tables and variables were used as follows: if a participant was a housewife without any paid work, and was married, the answer for Q7 should be her husband's occupation. Using one of the three tables that best represented the occupation, each participant's household income was estimated. Then, a new variable 'Income' was created and was dichotomised by the median (5,000,000 Yen), which was approximately 40,000 US dollars.

Next, descriptive analyses were performed on socio-demographics and BC-related variables in the baseline sample (n = 165). To examine differences between the two BC groups, following Kolmogorov-Smirnov tests and normality plots to assess data characteristics, non-parametric statistics (the Mann-Whitney test) were performed on continuous variables, and Chi-square tests were carried out on categorical variables.

Second, in order to examine the construct validity of the ALPDS, a sub-sample who reported lymphoedema on the arm of the operated side was sought (sub-sample). Participants with stage IV cancer were excluded; this was because where cancer cells have spread to the lymph nodes and grown in that region, the cells may push into surrounding nerves in the region (malignant lymphoedema), which may lead to pain or swelling.

The strength of relationships among the six items was examined using the Pearson correlation, Bartlett's Test of Sphericity, and the Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO). To explore whether or not a single factor was underlying the six items, a principal component factor analysis (PCA) with Varimax rotation was performed. Eigenvalues greater than one were selected. A scree plot was also produced. Additionally, internal consistency was examined by Cronbach's Alpha. Correlations between the global scale and summary scores of the ALDS were examined.

Regarding criterion validity, research questions were pre-determined in order to examine whether or not physical discomfort was associated with (1) perceptions of information provision at BC diagnosis, (2) perceptions of information provision from the time of breast surgery to the time of this study, (3) type of arm symptoms - pain, swelling, numbness, loss of strength, and poor range of motion, (4) provision of arm therapy by doctors or specialists, (5) practice of self-care management, and (6) years since the onset of lymphoedema - less than 1 year, between 1 year and 2 years 11 months, between 3 years and 4 years 11 months, and 5 years and over. In order to examine relationships between the outcome variables and predictors, normality and homogeneity of variance were examined. When the assumption was satisfied a one-way analysis of variance (ANOVA) was performed. Interaction effects were examined by a two-way ANOVA between the independent variables that were significant results in the bivariate analyses and demographics, BC treatment, and history of mood disturbance. When interaction effects were statistically significant, follow-up tests of the effect of the independent variable at each level of the moderators were performed. Then, the significant independent variables obtained by the bivariate analyses were entered into a multiple regression stepwise model. A residual analysis was performed to examine the assumptions of normality of the random errors and linearity of the regression coefficient in order to ensure non-multicollinearity among the significant variables in the model.

Finally, in order to investigate test-retest reliability, dichotomous categorical data were analysed by Cohen's Kappa (*K*) and by the average correct classification rate (ACCR; Chinn et al. 1987). The ACCR can compensate for the results obtained by Kappa when the Kappa is unable to be calculated or shows very low agreement. Since Cohen's Kappa is more likely to be affected by a small frequency of outcome responses, the ACCR, which is not affected by the frequency, gives useful information (Peat et al. 2002). Both ordinal and nominal polytomous data were analysed by Cohen's weighted Kappa *(Kw) quadratic* which is equivalent to intra-class correlation (ICC) (Fleiss and Cohen 1973), and continuous data were analysed by ICC.

All the statistical analyses were performed by the Statistical Package for the Social Sciences (SPSS, version 11.5). The statistical significance level adopted was 0.05.

Results

Participants (baseline)

Participants' characteristics are presented in Table 4.4. On demographics, levels of education, (χ^2 (N = 162) = 12.53, p = 0.01), number of children (U = 1781.00, p < 0.00), and the number who were housewives (χ^2(1, N =160) = 4.69, p = 0.03) were significantly different between the two groups. On the BC-related variables, the years since surgery were significantly difference between the two groups (U = 1109.00, p < 0.00).

Table 4.4 *Participants' Characteristics (N = 165) (percentages in parentheses)*

	Groups (%)	
Variables	A	B
Total participants (RR)	123 (44.0)	42 (41.5)
Demographics		
Mean years of age (*SD*)	54.5 (9.4)	54.9 (7.3)
Marital status		
Single/divorced/widowed	23 (18.6)	4 (9.5)
Married	100 (81.3)	38 (90.4)
Mean number of children (*SD*)	1.5 (1.0)	1.9 (0.7)
Levels of education		
Junior high school	3 (2.4)	0 (0.0)
High school	37 (30.5)	24 (58.5)
Technical school	20 (16.5)	8 (19.5)
College	25 (20.6)	3 (7.3)
University	36 (29.7)	6 (14.6)
Work status		
Full time paid work	32 (26.2)	6 (14.2)
Part time paid work	23 (18.8)	7 (16.6)
Housewives	58 (48.7)	28 (68.2)
Other	6 (5.0)	0 (0.0)
Breast cancer Stage		
I	42 (34.7)	12 (28.5)
II	65 (53.7)	20 (47.6)
III	8 (6.6)	4 (9.5)
IV	1 (0.8)	2 (4.7)
Breast cancer		
Type of surgery		
Conserving surgery	56 (45.5)	10 (30.3)
Mastectomies	57 (46.3)	23 (56.0)

Table 4.4 (Continued)

Variables	Groups (%) A	B
Lymph node dissections		
Yes	95 (77.2)	36 (85.7)
No	28 (22.7)	6 (14.2)
Adjuvant chemotherapy		
Yes	58 (47.5)	22 (52.3)
No	64 (52.4)	20 (47.6)
Adjuvant radiotherapy		
Yes	59 (47.9)	13 (30.9)
No	64 (52.0)	29 (69.0)
Adjuvant hormone therapy		
Yes	81 (65.8)	31 (73.8)
No	42 (34.1)	11 (26.1)
The mean years after surgery (*SD*)	6.4 (5.7)	2.4 (2.0)

Note. Percentages in the table are raw percentages.

Construct Validity

Sub-sample with lymphoedema.

One hundred and ten participants reported that they had experienced arm complications since the surgery. However, two participants did not report arm complications on the arm of the operated side. One participant did not report on which side the complications appeared. These three participants' data were treated as missing values on arm complications relevant variables. In this sample, one hundred and seven patients (64.8 per cent) reported the presence of symptoms of lymphoedema on the arm of the operated side. Two participants with stage IV cancer were excluded from the analysis.

Of the remaining 105, 100 participants were eligible. The mean age of this sub-sample was 55.2 years (SD = 8.7). Most were married (80.0 per cent) with children (76.0 per cent), and 99.0 per cent had completed high school education. Sixty-two per cent of participants did not have a paid job, and household income was relatively high (>/ = 500 million Yen, 53.8 per cent). Most participants (89.3 per cent) were at an early stage of BC (stage I or II). More than half of the participants (53.0 per cent) had undergone mastectomies, 42.0 per cent had received radiotherapy, 49.0 per cent had received chemotherapy, and 69.0 per cent had received hormonal therapy after breast surgery. The mean years after the surgery was 5.5 years (SD = 5.7). More than half of the participants (58.0 per cent) did not report a history of mood disturbance which had required psychiatric treatment. Twenty four per cent of participants had been diagnosed with lymphoedema.

Factor analysis.

On structure, the Pearson correlation coefficient between the six items (based on the findings of the qualitative study;Tsuchiya et al. in press) ranged from 0.23 to 0.72 (see Table 4.5).

Table 4.5 *Correlation Matrix of the Six Items*

Items	Paid-work	Household	Grooming	Hobbies	Sleeping	Meeting
Paid-work	-	-	-	-	-	-
Household	0.23	-	-	-	-	-
Grooming	0.23	0.72	-	-	-	-
Hobbies	0.39	0.49	0.45	-	-	-
Sleeping	0.29	0.41	0.59	0.57	-	-
Meeting	0.23	0.47	0.60	0.61	0.60	-

Bartlett's test of Sphericity was significant (χ^2 (15) = 251.14, $p < 0.00$) which indicated the correlation matrix was not identical. The value of KMO was 0.76, which was middling (Kaiser 1974). The PCA solution extracted one factor accounting for 56.1 per cent of the variance, and the scree plot also showed one factor. Since only one factor was extracted, the Varimax rotation was not performed.

On internal consistency of the ALPDS, Cronbach's Alpha was 0.83. However, the communality of the item 'paid-work' was 0.47 after extraction. As Table 4.6 shows, this value was lower than the other items (>/= 0.76). Further examination was necessary to decide whether or not this item should be retained in the scales. After deletion of item 'paid work', Cronbach's Alpha value slightly improved from 0.83 to 0.85.

Since one factor with a high internal consistency was extracted, a summary score of the six items was used to examine correlations between the global scale and the summary score. The Spearman's rho correlation showed that the summary score was moderately correlated with the global scale ($r = 0.68$, $p < 0.00$).

Table 4.6 *Communalities of the Six Items*

Items	Factor
Paid-work	0.46
Household	0.76
Grooming	0.83
Hobbies	0.79
Sleeping	0.79
Meeting	0.81

Summary.

The Pearson Correlation test showed moderate to strong correlation among the six items. Bartlett's test shows that the correlation matrix was not identical. KMO is middling (Kaiser 1974) which indicates a sufficient sample size. PCA and the scree plot showed that there was one factor underlying the six items. The scale had high internal consistency. Extracted commonality of the item 'paid work' was lower than other items, but the reliability test showed that excluding the item from the scale still yielded a high Cronbach's alpha value. Thus, it was decided to retain this item in the scale. Since one factor was extracted, a summary score was used to examine the criterion validity of the scale.

Criterion validity

Perceptions of information provision.

Perceptions of information provision were explored with two questions: 'Do you feel you had been given enough information at the time of breast cancer diagnosis?' and 'Do you feel you have been given enough information from the time of breast surgery to now?' using dichotomous responses (Yes/ No). Fifty-six participants perceived information provision at the BC diagnosis as insufficient, and 65 participants perceived information provision between the time of surgery and the time of this study as insufficient.

Symptoms of lymphoedema.

Several symptoms of lymphoedema were reported – swelling (19.7 per cent), loss of strength (19.3 per cent), numbness (18.6 per cent), poor range of motion (17.8 per cent), pain (17.0 per cent), and other (e.g. inflammation, 7.6 per cent). The duration of symptoms varied – < 1 year (28 per cent), 1 =>/ < 3 years (30 per cent), 3 >/= < 5 years (14.0 per cent), and >/= 5 years

(27.0 per cent).

Therapeutic management.

On therapeutic management, 38 participants had taken therapy provided by doctors or specialists: compression sleeves (n = 13), arm exercises (n =11), manual lymph drainage (n = 8), and a compression pump (n =1). Seventy-one participants had made an effort at self-care at home, such as massage (n = 56), exercise (n = 36), and compression sleeves (n = 11), and skincare (n = 6).

Physical discomfort and the predictors.

Distributions of the predictors were normally distributed. As Table 4.7 shows, the one-way ANOVA yielded four variables which had significant effects on the reported physical discomfort: participants who perceived information provision at BC diagnosis as insufficient (mean = 15.66) reported more severe physical discomfort than those who did not (mean = 10.56) [F = 12.77, $p < 0.00$]. Participants who perceived information provision since breast surgery as insufficient (mean = 15.03) reported more severe physical discomfort than those did not (mean = 10.41) [F = 9.20, $p < 0.00$). Participants who had had loss of strength (mean = 15.88) reported more severe physical discomfort than those who did not (mean = 10.69) [F = 14.28, $p < 0.00$). Participants who had had poor range of motion (mean = 15.66) reported more severe physical discomfort than those who did not (mean = 11.28) [F = 9.72, $p < 0.00$].

Next, interaction effects were found between perceptions of information provision at diagnosis and age (F (1, 93) = 4.46, p = 0.04), paid jobs, (F (1, 93) = 4.71, p = 0.03), type of surgery (F (1, 83) = 4.71, p = 0.03) and between the loss of strength and years since surgery (F (1, 95) = 4.60, p = 0.04) (see Appendix 4.7). However, on the variable 'perceptions of information after surgery' and 'poor range of motion', no interaction effects were found among the demographics, the BC treatment factors, and/or history of mood disturbance.

The follow up test detected mean differences between the independent variables within each level of the moderators (see Appendix 4.8); perceptions of information provision at diagnosis was significantly different for younger age (F (1, 93) = 17.07, $p < 0.00$) for those having paid job (F (1, 93) = 14.71, $p < 0.00$) and for those having undertaken lumpectomies (F (1, 83) = 15.25, $p < 0.00$). The reported loss of strength was significantly different for fewer years since surgery (F (1, 95) = 18.16, $p < 0.00$).

Table 4.7 *Normality, Homogeneity Variance, and Analysis of Variance for the Physical Discomfort Scale*

Variables	*M*	SD	F	Shapiro-Wilk z	Levene z
Information at diagnosis			12.77*		2.07
Sufficient	10.56	6.20		0.96	
Insufficient	15.66	7.44		0.98	
Information after surgery			9.20*		0.18
Sufficient	10.41	6.70		0.95	
Insufficient	15.03	7.23		0.98	
Pain			3.78		0.03
Yes	14.89	7.21		0.99	
No	12.07	7.21		0.97	
Swelling			0.07		0.01
Yes	13.52	7.49		0.98	
No	13.15	7.19		0.97	
Numbness			2.50		0.22
Yes	14.51	7.40		0.98	
No	12.22	7.12		0.98	
Loss of strength			14.28*		0.06
Yes	15.88	6.73		0.97	
No	10.69	7.00		0.96	
Poor range of motion			9.72*		1.99
Yes	15.66	7.60		0.98	
No	11.28	6.44		0.98	
Doctor's therapy			0.44		0.35
Yes	13.89	7.10		0.98	
No	12.89	7.48		0.97	
Self-care at home			1.32		1.93
Yes	13.94	6.70		0.98	
No	12.07	8.67		0.95	
Duration of arm problems			0.03		0.71
< 1 year	13.54	6.32		0.97	
1</> 3 years	13.33	8.08		0.96	
3 = </> 5 years	12.79	7.15		0.94	
>/ = 5 years	13.26	7.91		0.98	

* $p < 0.05$

Multiple regression stepwise.

The four variables which were significant in the bivariate analyses were entered into the multiple regression analysis stepwise. Table 4.8 shows standardised coefficients of regression of two models predicting physical discomfort of lymphoedema. The second model accounted for 20 per cent of the variance.

Table 4.8 *The Model Summary of Multiple Regression Stepwise*

Variables	F	*P*	R^2	*B*	p	95% CI
Model 1	14.15	0.00^*	0.13			
Loss of strength				0.36	0.00^*	2.5-8.1
Model 2	11.57	0.00^*	0.20			
Loss of strength				0.29	0.00^*	1.5-7.0
Information at diagnosis				0.27	0.00^*	1.2-6.8

Note. Code of information provision at diagnosis was 0 = sufficient, 1 = insufficient, and code of loss of strength was 0 = absence, 1 = presence.

$^*p < 0.05$, n = 97.

In terms of assumption of normality of the random error, a normal probability plot of standardised residual showed that a plot was a nearly straight line (see Appendix 4.9).
Two partial residual plots (see Appendices 4.10 and 4.11respectively) showed a linear line, which indicated no multicollinearity between the variables.

Test-retest reliability

Two participants' data were excluded from the second time survey data because of missing values on two variables, such as arm side and the overall discomfort (fifty-three participants' data were eligible).

Table 4.9 shows the agreement of responses in both the check list and the ALPDS.

Table 4.9 *Repeatability of the Lymphoedema Checklist, the one-item Global Scale, and the Physical Discomfort Scale*

Items (n)	*K* (95% CI)	ACCR	*Kwq* (95 % CI) ICC (95 % CI)
Lymphoedema check lists			
Arm problems (53)	0.69 (0.47-0.92)	0.94	-
Affected arm (37)	0.95 (0.84-1.00)	0.99	-
Symptoms			
Pain	0.73 (0.51-0.95)	0.93	-
Swelling	0.67 (0.44-0.91)	0.91	-
Numbness	0.54 (0.23-0.84)	0.89	-
Loss of strength	0.49 (0.24-0.78)	0.86	-
Poor range of motion	0.52 (0.25-0.78)	0.86	-
Years suffering symptoms	-	-	0.60(0.26-0.94)
Discomfort scales			
Global scale	-	-	0.64(0.12-1.00)
Summary score			0.70 (0.48-0.83)
Paid work	-	-	0.65(0.33-0.98)
Household chores	-	-	0.76 (0.25-0.04)
Grooming	-	-	0.65 (0.32-0.99)
Hobbies	-	-	0.36 (0.01-0.71)
Sleeping	-	-	0.72 (0.48-0.96)
Meeting somebody	-	-	0.45 (0.07-0.84)

Note. *K* = Cohen's Kappa; ACCR = the average correct classification rate; *Kwq* = Cohen's weighted Kappa quadratic, ICC = the intraclass correlation.

The agreement of responses in the lymphoedema check list was *K* = 0.49-0.95 and *Kwq* = 0.61, in the global scale was *Kwq* = 0.64, and in the ALPDS assessing subjective accounts were *Kwq* >/= 0.64 except two items: hobbies and meeting somebody. A *K* less than 0.60 indicates fair agreement, a *K* above 0.60 indicates good agreement, whilst a *K* above 0.75 indicates excellent agreement (Fleiss 1981). Thus, the agreement was acceptable overall.

Discussion

The aim of this study was to develop the ALPDS together with the lymphoedema checklist and one-item global scale among female BC patients with lymphoedema in Japan. The ALPDS had six items underlying one factor. The summary score of the six items was moderately correlated with the global scale. The results showed that perceptions of information provision at a cancer diagnosis and type of arm complications were associated with physical discomfort. Participants who perceived information provision at the diagnosis as insufficient and experienced loss of strength tended to report severe physical discomfort with the lymphoedema.

With regard to the structure of the ALPDS, the inter-item correlation matrix revealed that all items were moderately to highly correlated (Pett et al. 2003). The PCA extracted one factor underlying the structure of the ALPDS, accounting for 56.1 per cent of the variance. In terms of internal consistency, internal validity is very important for a scale designed to assess patients' subjective arm complications. In this study, Cronbach's Alpha was 0.83 which was excellent (Chinn et al. 1987). The extracted communality of 'paid work' was relatively low so that including the item was in question. As the reliability test showed, deleting 'meeting somebody' slightly increased the Alpha value to 0.85. However, since the Alpha was already very high and the increase after deletion was so small, it was decided to leave the item 'meeting somebody' in the scale.

With regard to test-retest reliability, all the measures had a good overall reliability. Test-retest reliability is sometimes considered as unreliable since correlations between scores at two difference occasions can depend on one's memory. If respondents remember well about their previous responses, they tend to respond in the same way. In this study, the time interval between the two occasions was around a month, so increasing the probability that the high correlation was relatively unaffected by memory effects (Nunnally and Bernstein 1967).

In terms of sampling and sample size, the sampling method for test-retest reliability was systematic, and the sample size was enough to test repeatability (Sim and Wright 2005). In the study where the first time questionnaire was mailed, the sample size was enough to perform the factor analysis; the rule of thumb is that 10 to 15 participants per initial item are needed (Pett et al. 2003). Further, the KMO test showed an adequate sample size.

Finally, on criterion validity, the findings are consistent with the previous studies which have shown associations between unmet needs (social support) and health outcomes (Arora et al. 2002; Kerr et al. 2003). Reported discomfort was associated with both perceived insufficient information provisions at cancer diagnosis and loss of strength in the multivariate analysis. The residual analysis shows the assumption of normality and multicollinearity seems to be satisfied. However, this model only accounts 20 per cent of the variance. This indicates that there are other important factors that could explain the physical discomfort.

Interestingly, in this study utilisation of lymphoedema therapy and practice of self-care management were not associated with the physical outcome, although BC patients with lymphoedema often demand therapeutic management provision in their local community (Morgan et al. 2005). Since the frequency of taking up therapy was not asked in the present study, it was uncertain whether or not participants regularly and continuously take up the therapy. It is worthwhile to explore frequencies of therapy, how BC patients with lymphoedema perceive the existing therapy and self-care management, and also to investigate associations between this perception and health outcomes, in order to enhance care and services in Japan.

There was a relatively low response rate in the study, although not unusual for a postal survey. It might be helpful to follow up non-respondents and to examine any differences of characteristics between respondents and non-respondents. However, it was not feasible in this study. Additionally, demographics were skewed as most participants were well educated housewives with high household income. These were characteristics of women living in the Tokyo area (The Ministry of Health, Labour and Welfare 2005). Due to these limitations, the findings are not generalisable to all BC patients with lymphoedema in Japan.

In conclusion, the lymphoedema checklist and the global scale have good repeatability. The ALPDS six-items had good repeatability, a one-factor structure with good internal consistency and criterion validity.

THE NEXT STUDY

Since the ALPDS is designed to measure physical discomfort associated with lymphoedema, it cannot measure another important factor - psycho-social impact - of patients' QoL. In order to explore these aspects, a qualitative study was proposed for the next study; participants with a symptom of swelling were targeted since this symptom was not statistically associated with physical discomfort, and since literature in the West, especially in qualitative studies, suggests that the symptom impacts on QoL (see Chapter 3). Potential participants were to be selected from respondents who both took part in this survey study and provided their contact details in the questionnaire.

In the next chapter, the importance of the qualitative study will be discussed from the point of view of cultural psychology. Additionally, its methodology will be discussed compared to cross-cultural methods that psycho-oncology research has often utilised.

5. Symbolic Interactionism: an Application of Cultural Psychology

INTRODUCTION

Cultural Psychology is an interdisciplinary field primarily between anthropology and psychology.

(Norasakkunkit 2004)

Psychological research considering cultural differences can be divided into two streams: cross-cultural psychology and cultural psychology. Cross-cultural psychology has been attempting to investigate human behaviours quantitatively, by comparing between Western and Eastern cultures (comparative method; Much 1995). Typically, instruments are first developed and validated in the West, and they are translated into languages other than the original one in order to apply them to cultures other than the West (e.g. the psycho-oncology research reported in Chapter 1). There are several criticisms of cross-cultural studies; for example, there are few or no underlying conceptual frameworks or theories. In addition, cross-cultural psychology considers that there is no uniqueness of subculture (e.g. ethnic groups in the White culture in the USA), and that a theory of the majority can be applicable to the minority: the pre-supposed ideology - the majority is superiority to the minority in nature - is seen (Much 1995).

On the contrary, cultural psychology has challenged the pre-supposed categories, and attempts to investigate qualitatively the 'localised' uniqueness in each community. Most cultural psychological studies have been conducted based on social constructionist theories (Applegate and Sypher 1988); they propose that emotions and perceptions about certain phenomena may vary among countries or cultures. Additionally, cultural psychology emphasises the importance of subcultures or subsystems, such as family, work place, friends, social membership (Much 1995), and gender (Nicolson 1995). They are seen as primary sources, creating individuals' value systems and secondarily creating shared value systems (social norms) and knowledge in the wider community.

To explain the proposed methodology of the next study, in the first half of this chapter the importance of cultural psychology will be discussed compared to cross-cultural studies. In the latter half of this chapter, one of the social constructionist theories - symbolic interactionism - will be introduced as an application of cultural psychological studies. Finally, the methodology of the proposed study will be briefly described.

CULTURAL PSYCHOLOGY

In this section, to illustrate the importance of cultural psychological viewpoints, pre-suppositions of cross-cultural psychology will be discussed with reference to empirical studies.

Cross-cultural psychological studies

Cross-cultural psychology pre-supposes that Western cultures are categorised as 'individualistic', while Eastern cultures are categorised as 'collective', and claims that these categories can capture behavioural characteristics unique to each culture; for example, individualists value individual activities, autonomy, and independence, while collectivists value group activities, group benefit, and harmony (Triandis 1989). Additionally, 'ego-focused emotions' such as anger and frustration are more often expressed in individualists, while 'other-focused emotions' such as sympathy and shame are more often expressed in collectivists (Markus and Kitayama 1991). Relating to these, members of individualist cultures tend to evaluate themselves by self-accomplishment, while those of collectivist cultures tend to evaluate themselves by group values (Watkins et al. 1998).

These differences are often explained by religious influences (Ho 1995; Sampson 2000) and linguistic usages (Sukle 1994) in everyday living. First, on religious influences, in the West relationships with others, such as independence and autonomy, are taught in Protestant Christian religious contexts (Sampson 2000). In Asia, especially East Asia, relationships with others such as interdependence and harmony are taught in the context of Confucianism (Ho 1995). These religious differences create different individual attitudes in each culture. Second, on linguistic usages, for example, the Japanese language clearly distinguishes ingroup and outgroup using '*Uchi*' (ingroup) and '*Soto*' (Sukle 1994) or '*Seken*' (outgroup). *Uchi* literally means a house, but often represents 'I', 'my', or a family. When the plural form ('*Uchi-ra*') is used (this is frequently used by youngsters), '*Uchi-ra*' represents 'we', which is the ingroup. Similarly, '*Soto*' or '*Seken*' *literally* means outside, but often represents significant 'others' or outgroup. Atsumi (1980) claimed that the distinction between ingroup and outgroup was particularly important to understand Japanese social behaviour since Japanese tend to change their behaviour depending on how close the relationship is with others (e.g. true friends, colleagues, acquaintances and strangers).

However, no supportive evidence of the clear distinction between individualists and collectivists has been demonstrated empirically in terms of emotions and relatedness. First, on emotions, several cross-cultural studies have shown that some emotional experiences are shared between Japanese and American youngsters. For example, Kleinknecht et al. (1997) investigated social phobia among university students in the USA and Japan. Kleinknecht et al.

hypothesised that if common views of individualists and collectivists were true, individualists, such as American students, were less likely to be embarrassed by others. Contrary to this hypothesis, Kleinknecht et al. reported that there were no significant differences between students in the two countries.

Other studies have shown similarities of emotional expression patterns across cultures. For example, Matsumoto et al. (1998) examined emotional expression rules, such as anger, contempt, disgust, fear, happiness, sadness, and surprise among university students in the USA, Russian, Japan, and South Korea. They found less emotional control was observed in intimate relationships - such as family and close friends - among students in both the USA and Japan.

On relatedness, studies have shown that there are no significant differences between Western and the East Asian countries. For example, Kashima et al. (1995) investigated sharing feelings and time among university students in Australia, the USA, Hawaii, Korea, and Japan. They found that relatedness (sharing feelings and time) was associated with gender differences rather than the collectivism/individualism distinction; females were more likely to show sympathy to others and to spend more time with others.

This finding may lead to illogical ways of interpreting gender (Lutz 1988) by people who think that a logical way of thinking is superior to an emotional way (Nicolson 1995); for example, women are inferior to men because women are more likely to be relational so that they are more sensitive to others' feelings and situations (Clancy and Dollinger 1993). Moreover, the influence of others is more significant among females than males (Kashima et al. 1995) so that females are willing to spend more time with others than males. Consequently, women are often labelled as 'emotional' and considered inferior to men.

Importance of cultural psychology

As several studies cited above have demonstrated, no clear distinction between individualists and collectivists has been found empirically. Although there are fundamental methodological flaws in the studies (e.g. they used neither systematic random sampling nor people other than university students), some cross-cultural researchers have claimed that Japan is no longer collectivist due to modernisation (Sasaki 2004). Certainly, modernisation is evident, especially in cities in Japan; compared to two decades ago Japan is now much more industrialised, and life styles including diet have been 'Americanised'. Also the economy, including overseas workers has been globalised; current residents having nationality other than Japanese are around 1,910,000 (Immigration office 2004), a 45 per cent increase on ten years ago. Seeing this from a long history of national seclusion up to the 19th century, the number is not insignificant. These influences may go some way to explaining that there were not distinct differences between youngsters in the USA and Japan. However, some questions arise - was Japan a collectivist society? Are pre-defined instruments, which are validated among the

Western population, also sensitive enough to explore psychological processes in countries other than the West?

Rather than the modernisation and globalisation, the issue is that cross-cultural psychology assumes that psychological processes in the West are considered as a 'universal norm' (Much 1995). The application of developed instruments based on this assumption is too simplistic to account for psychological processes in countries or cultures different from the Western ones (Kitayama 2002). Rather, the focus should be on culturally structured meaning, for example, when people feel angry, why they feel angry, and how the feeling is created, since these psychological processes are 'interwoven with cultural meaning and social interaction' (Lutz 1998: 8).

This cultural psychological viewpoint will lead to better and deeper understanding of human conduct in specific countries. Otherwise, stereotyped emphasis may lead to cognitive distortion (Takano and Osaka 1999); for example, every East Asian country is categorised as collectivist, and there are no differences between developing and developed countries, or between relatively homogeneous and heterogeneous countries in East Asia (Miyahara et al. 1998; Triandis 1989).

Additionally, on gender, several cultural psychological studies have shown that social expectation and salient roles seem to determine women's perceptions. For example, Chiavacci (2005) conducted interviews exploring social roles and family among senior university students in Japan and found that the female students had a clearer image of 'mothers' in their mind than did male students. One student described what a mother was as 'It is only my personal opinion but I think a mother who does not take care of her children is not a mother' (Chiavacci 2005: 124). The student also mentioned that only a full-time mother should be called a mother. Interestingly, Chiavacci reported that female students planning to work in a few months tended to criticise working mothers more than did male students. However, both male and female students mentioned that they had never thought about fathers taking up part-time jobs and sharing parental responsibility with their wives. Chiavacci concluded that caring for children was considered as the major responsibility of mothers in Japan.

The findings of Chiavacci's study may be useful to compensate for the findings of cross-cultural studies on working women. For example, Chandola et al. (2004) quantitatively investigated the relationships between multiple social roles and mental health among working adults in Finland, Japan, and the UK. They found that Japanese women struggled with the balance between their paid-work and home, which affected their mental health, more than women in the other two countries. Interpreting the result using Chiavacci's study, Japanese working women are expected to play housewives' roles the same as those without paid jobs, and this social expectation may be related to the women's perception and decision-making to take active housewives' roles after work. However, there are few people to share the women's responsibilities at home so that pressure of time management may affect their mental health.

Summary

Cross-cultural psychology pre-supposes categories and has investigated them using instruments which have been developed and validated in the West. Cross-cultural psychology believes that theories of the majority (e.g. the white in the USA) can be applicable to anybody else. On the contrary, cultural psychology believes that each culture including subcultures has their own meanings, and individuals' value systems are constructed by subcultures and larger communities. These three - individuals, subculture, and the whole society - are not mutually exclusive; rather they are related. Cultural psychology proposes that researchers should focus more on the process of interactions and 'indigenous' theory in order to understand human behaviours (Much 1995). This relativist view could enhance our understanding of human behaviour and psychological processes in cultures other than the West, which are, as discussed in Chapter 1, insufficiently covered in the psycho-oncology field.

CULTURAL PSYCHOLOGY AND SYMBOLIC INTERACTIONISM

In this section, one of the social constructionist theories - symbolic interactionism, which shares concepts with cultural psychology - will be introduced. First, the background of social constructionist theories will be briefly presented and, second, basic concepts of symbolic interactionism (SI) will be presented.

Background of social constructionism

There are varieties of theories among social constructionism (Danziger 1997; Denzin 1995) since the theories are rooted in different philosophical and disciplinary backgrounds. For example, theories rooted in phenomenology (e.g. Husserl 1954) claim that knowledge is formed by tendencies of information processing within individuals (Danziger 1997). Back to the early phenomenological theory, Husserl (1954) claimed that one tends to look at objects or events intentionally and perceives the selected information as important (selective perception). As such, Husserl distinguishes between the external (immanent) and internal (transcendental) world (Macann 1993), and phenomenology claimed that only one's internal states such as cognitions are seen as knowledge (Gergen 1985). However, the other theory, rooted in sociology, argues that another dimension, social influences, as well as subjectivities, can form knowledge (Gergen 1985; Yardley 1997).

The two philosophies, phenomenology-rooted and sociology-rooted social constructionism, will explain the same phenomenon in different ways; for example, assume that there is a woman who, detecting a lump in her breast accidentally, delays seeking medical help. From a phenomenological view point, she may intuitively feel that something is wrong with her body, but immediately after the lump detection, she may attribute that she will be all right since she does not feel any pain. Consequently, she will delay seeking a medical consultation till she feels severe pain or a worsening physical condition. On the contrary, from a sociology-rooted social constructionist view point, since the society where she lives has a low incident rate of breast cancer (BC), she does not feel the lump to be a sign of it, and consequently she decides not to go to see a doctor immediately. However, if family members or friends encourage the woman to see a doctor (informal referral systems), she may change her mind and go to see a doctor. As such, sociology-rooted social constructionism would argue that not only subjectivities and but also society can create perceptions and attributions, and in the end they determine behaviours (Gergen 1985).

As described, sociology-rooted social constructionism shares the idea of cultural psychology; it proposes that we, as human beings, form cognitive schemata while we are interacting with others in the society where we are born and grow up, and that these schemata navigate us to 'appropriate' behaviour and help us to understand social norms. Thus, if countries or cultures are different, individuals will acquire different schemata.

In the next section, as an application of cultural psychology, one of the sociology-rooted models, SI, will be presented. SI does not eliminate the importance of cognitions and emotions from the theory as other approaches tend to do; for example, discourse analysis tends to focus on language itself in text and to ignore cognitions (Willig 2001). First, an overview of SI and, second, the core ideas of SI will be presented.

Overview of symbolic interactionism

SI has its roots in the work of Western philosophers in the early twentieth century, such as William James, Charles Horton Cooley and George Herbert Mead (Denzin 1995). An American philosopher, Mead is well known as a contributor to the development of SI theory, but there have been many symbolic interactionists since Mead.

SI theorists are mainly categorised by two streams in the USA: the Chicago School and Iowa School (Benzies and Allen 2001). In the Chicago School, Mead's SI theory was mainly delivered to students using the form of lectures. After his death, Blumer, one of Mead's students, collected his lecture notes and published the first book titled '*Symbolic Interactionism: perspective and method*' (1969). Whereas the Chicago School is in succession to Mead's, Blumer's theory and his methodology - the Iowa School - is not. For example, the Iowa School proposes that human behaviours are relatively stable (Benzies et al. 2001) so that some scholars (e.g. Manford Kuhn) aim to make a set of universal principles in SI contexts. Naturally, the two schools apply different methodologies from each other; commonly used methods in the Chicago School are a qualitative approach including ethnography, interview, and life history (Blumer 1969; Nancy et al. 2003). On the contrary, the Iowa school applies a quantitative experimental approach. Thus, these two schools stemmed from Mead's theory but developed in different directions.

Although SI has been evolving and applied to several disciplines, such as medical sociology (Benzies et al. 2001; Denzin 1995; Fine 1993), and an application of cultural psychological studies has been proposed (Denzin 1995), there are several critics of SI. First, from a sociological viewpoint, though SI emphasises the importance and significance of social interaction, SI does not fully and clearly explain how interaction at an individual level affects social organisations. As a result, SI is often categorised as being a 'micro' theory (Ritzer and Goodman 1983), as is phenomenology. This may be arguable from a psychological point of view, since SI can be distinguished from phenomenology in terms of the processes of perceptions and cognitions. Second, from a feminist viewpoint, SI is considered as an American middle class male theory. It may be also arguable that the labelling of SI as male dominated and excluding minorities (women, race, and cultures other than American culture) is partially inappropriate since the SI which Mead proposed was gender free (Denzin 1995).

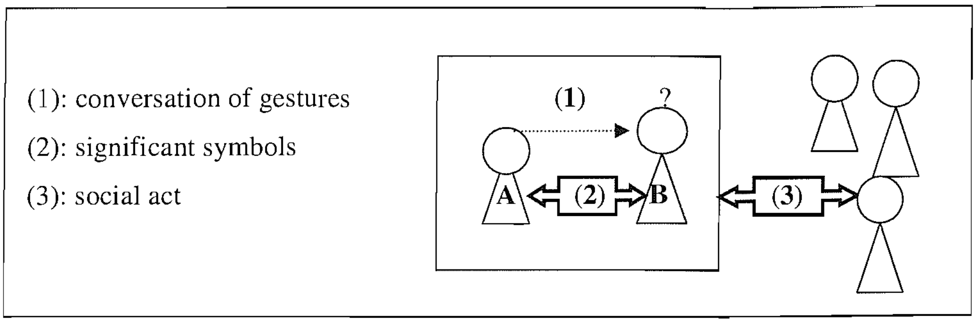
Core concepts of symbolic interactionism theory

There are several core ideas among SI theorists; human beings are thinking, acting, and feeling creatures, so both cognitions (but SI is more likely to put emphasis upon cognitive processes) and emotions are important for the understanding of human behaviours. Additionally, the theory emphasises that cognition and emotions are formed by interaction with others or the society in which people belong. As in other social constructionist theories, SI proposes that language ('symbols') are important media to understand thoughts, feelings, and behaviours (Hewitt 1976). These media also convey 'cultural meaning' (Denzin 1995) to people in the same society. To understand the basic core idea of SI, early SI theory (Mead, Blumer and Goffman) will be presented in the next section; first, the term, 'symbols' will be briefly introduced and, second, cognitive and emotional processes in the self will be presented.

Symbols

Mead argued that interaction between human beings and the environment (others) is not simply a stimulus-response relationship (Blumer and Morrione 2004), and that interaction continuously occurs among at least two agents. Among them, 'symbols' are the communication media, such as language and gestures. Assume a person sends a message, and another person receives it. As Figure 5.1 shows, there are three stages of information processing - a conversation of gestures, significant symbols and social acts (Blumer et al. 2004).

Figure 5.1 *Information Processes in Symbolic Interactionism*



First, at the stage of conversation of gestures, B does not attempt to interpret A's message automatically, which means that an interaction is not considered to occur at this stage. Next, at the stage of significant symbols, B attempts to interpret the underlying meanings of A's message. If B understands what A really wants to say, the conversation is meaningful for both persons, and a real interaction occurs among them. This mutual understanding, which Mead called significant symbols, is the most important level of interaction representing a 'joint action' (Blumer et al. 2004), according to SI. Finally, the significant symbols can be expanded to a third person or a larger group, which is called a social act. When a third person takes and interprets the message in the same way as B, the message has a certain meaning among the small group. If the interpretation can also influence the larger group, and if then the majority holds the same meanings, the significant symbols at the second stage would be group rules, norms, or common meaning (Blumer et al. 2004). In this way, 'symbols' have significant influences on not only individual, but also on social, level interactions.

The Self

As described above, SI emphasises the importance of interaction (significant symbols). Mead (1913) also explains this interpretative cognitive process using the terms - 'Me' and 'I'. Before explaining how the self is associated with the interpretation, the general idea of the self will be briefly presented in this section.

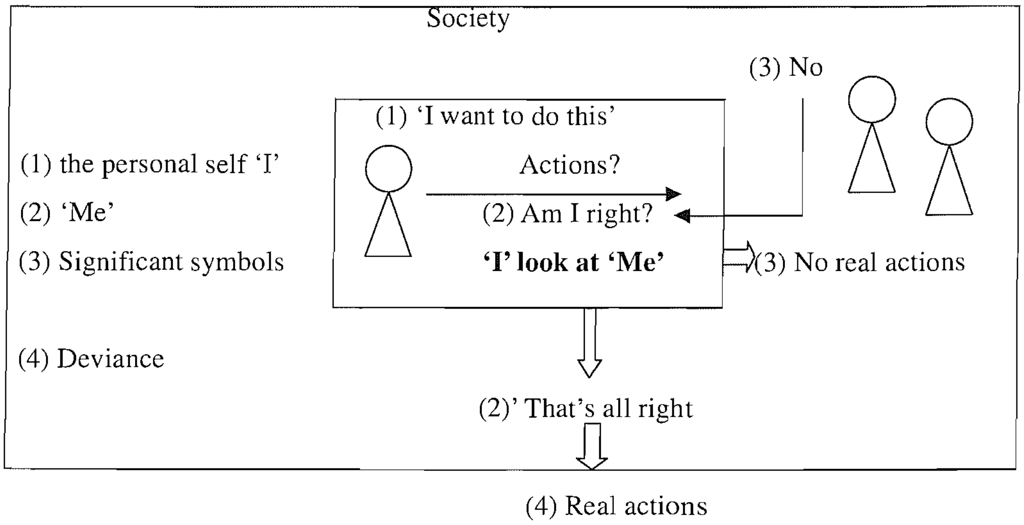
SI proposes, as do other micro theories, that there are three types of self: the personal self, the situated self and the social self (Hewitt 1976). First, the personal self lasts longer than other selves, and the personal self is 'one's own property' (e.g. 'this is me' or 'my first obligation is myself', Hewitt 1976: 111). Second, the situated self is attached to social roles in a society, so the situated self will not last if the situation changes; for example, assume that the situation changes from work place to home, one's social role will change from workers to parents when people have children. Additionally, the role change happens even on single occasions. For example, assume there are a couple of people sharing a room in a company. They recognise that they are colleagues to each other, but once their boss comes into the room, they know that they are employees and the boss is an employer. Simultaneously, their behaviour to the boss may be different to that with their colleagues. Finally, the social self lasts longer than the situated self, and the social self is given by where people belong; for example, assume people participating in a baseball team have membership. This membership does not determine one's role in the team, but distinguishes between a member and a non-member. Thus, the social self gives a broader sense of belongingness rather than a sense of taking up a specific role.

The Self, behaviours, and control in social contexts

In this section, the process of determination of behaviour will be presented using Mead's term 'I' and 'Me'.

As Figure 5.2 presents, in SI, there are three processes between intentions and actual behaviours: individual internal states - I, perceptions from others or society - Me, and marginal evaluation between I and Me.

Figure 5.2 *The Relationships between the Self and Processes of Social Interactions*



First, on individual internal states, intentions or motivation are considered as leading to spontaneous impulsive acts. At this stage, significant others will not be involved in judgements of intentions and motivations. The person has autonomy with respect to intended behaviours (e.g. 'I want to do this, so I will do this'); that is the personal self. Mead called this state 'I'.

Second, however, when this impulsive intention or motivation attempts to be transformed into actual behaviour in the real world, the intended behaviour is usually constrained. People may need to rethink their intended behaviour in their social contexts; for example, when young children have an idea of drawing a picture on a white wall (impulsive 'I'), they might simultaneously imagine what their parents will think of their behaviour ('me'). If the children imagine their parents' negative reactions (e.g. being scolded) they might not perform the intended action (self-control). Consequently, the parents in the children's imagination are enough to constrain their behaviours (Blumer et al. 2004; Charon 1992; Goffman 1963).

In terms of significant others, it is possible to take conceptualised others into account; when people are thinking of 'others', they do not often imagine specific persons in their mind (Mead 1913). Assume that they ask themselves 'is my idea acceptable for my neighbours?' In this case, one may not imagine very specific persons, such as Mrs XX, but vaguely imagine a group of neighbours or community. If their desire and actions are beyond the consensus within a community, people may be labelled as deviant which may lead to a social stigma (Goffman 1963). Most people attempt to accommodate between significant others and 'I', and their behaviours are constrained after all.

Emotions

SI is focused more on cognition than emotions, but the latter do play an important role in SI theory. According to Goffman (1963), emotions are also formed by a society in a similar way as that illustrated in Figure 5.2 above. Goffman, influenced by Cooley's (1902) concept 'looking-glass self', proposed that significant others also affect emotions; people attempt to maintain 'face' in their society, so if a certain behaviour is considered as 'minority' or as being or revealing an 'abnormality', then people may feel negatively about themselves, such as depressed or embarrassed. People may think that they do not meet the expectations of society, or they may perceive themselves as unacceptable in their society (e.g. perceived denial and refusal, Hewitt 1976). Goffman used the term 'losing face' in describing this process, which leads to low levels of self-esteem consequently.

Hewitt (1976) proposed that social roles (the situated self) are helpful to maintain face. For example, in bereavement, assume a woman lost her husband by a traffic accident. Because of the sudden loss, the woman may not feel sad, but people surrounding her might think that the woman is feeling sad and depressed, or might imagine she is too sorrowful to eat anything for a few days. The woman knows how to behave and feel as a widow at the funeral and also what other people's expectations are. To maintain face, she will behave as people expect. Otherwise, she may be labelled as a cold-blooded wife. In this sense, the expression of emotions 'can be seen as a social object' (Charon 1992).

METHODOLOGY IN CULTURAL PSYCHOLOGY AND SYMBOLIC INTERACTIONISM

So far, first, the importance of cultural psychological points of view has been discussed and, second, SI as an application of cultural psychology has been introduced. In this section, issues of methodology which have been commonly applied in both cultural psychology and SI will be presented and, secondly, a proposed methodology for the next study will be discussed.

Issues of methodology of ethnography

As described, cultural psychology aims to induce indigenous theories in specific cultures and countries so that cultural psychologists apply methodologies other than a quantitative approach. Among them, the technique of ethnography has been the most preferred (Much 1995).

Ethnography is commonly used in anthropological studies, and can provide us with rich and detailed descriptions in certain racial or ethnic groups (Lutz 1998). Especially in the colonial era, researchers in the West visited unfamiliar or 'primitive' places to observe local people. When communicating with locals, researchers used interpreters. To record local people's behaviours and social customs in the community, several methods have been used: making field notes of what researchers were observing and writing down locals' discourses which researchers were listening to through interpreters. However, these methods are often problematic because they can represent neither people's discourses nor behaviours in a socially meaningful way.

In addition to the recording strategies, there are sometimes problems when someone from one culture studies another (Denzin and Lincoln 2000). For example, Much (1995) introduced her experiences in India. Much planned to interview a young married Indian lady, but was not allowed to interview her alone since the lady needed to be supervised by an older woman (mother-in-law) when talking to strangers. So, there were four people including an interpreter in the interview place. Much asked a question exploring the young lady's attitudes to her husband. In fact, the questions were not socially acceptable for the lady since a young married lady without children could not discuss her husband in public due to social hierarchy (husbands are higher status than wives). Instead, her mother-in-law answered and described her son. During the interview, the interpreter did not warn the investigator not to ask such a question. Later the interpreter explained that she thought that she should 'respect' the investigator in public. If Much had known this social rule in advance, she would not have planned to interview young married ladies without children.

Similarly, Lutz (1998), an American anthropologist, introduced her misunderstanding of manners in the Ifaluk. Lutz lived with a real Ifaluk family for around one year, and observed and listened to their conversations through an interpreter. She extensively explored the Ifaluk's emotions; why they used a certain word expressing their emotions, and how the emotional word was related to others in the community. Lutz's descriptions of the Ifaluk's emotion were very rich. On the other hand, Lutz admitted that there were many 'unspoken assumptions involved in conversations about self and others' (Lutz 1998: 85). She exemplified her experiences on the first day in the local community; she was asked by an interpreter whether or not she would like to sleep in a separate building from the host family or in a same place as them. Lutz chose the separate place to sleep, since she was longing for privacy. However, this was extraordinary for the Ifaluk since Lutz was a stranger, so that the presence of Lutz meant danger to them. In this case, Lutz should have stayed at the house of the host family so as not to let people feel fear. A year later, this experience was laughed at by the host family. Lutz mentioned in her book that if she were a host family's relative she would not have been asked such a question by the interpreter, who knew well about Americans. Here, similarly to Much, Lutz was treated as a foreigner.

To get familiar with different cultures, researchers need to follow a quite similar process to child development (Much 1995). Both Much's and Lutz's stories showed that foreign investigators definitely need reliable and informative persons teaching them social rules in the community in which the investigators are interested. Surely conducting research in an unfamiliar culture requires sensitivity to the culture and efforts to understand the invisible social rules. However, if an investigator was born and grew up in the culture of interest, an ethnographical approach is advantageous.

Proposed methodology in the next study

In this section, the proposed methodology of the next study will be discussed.

First, the ethnographic approach can be useful and beneficial for the study; the author is a Japanese woman who was born and grew up in Japan. Since the author has naturally acquired unspoken social rules in Japan, she is thought to be sensitive enough to conduct a study exploring emotions and cognitions among Japanese female BC patients with lymphoedema.

From a practical viewpoint, it is not feasible to live together with patients for a year or shorter period of time as Lutz did. However, it would be possible to create very similar research settings to the real world when focus group discussions (FGDs) are applied. As several people are invited to attend at group discussions and discuss a specific topic in friendly atmosphere some Japanese researchers (Well-being 2003) describe FGDs as 'backstairs gossip.' In this sense, FGDs may be considered as small communities representing real 'mini' worlds (Krueger 1998).

Additionally, there are several advantages over face to face individual interviews; for example, FGDs enable the collection of a range of rich data in an economic manner, group dynamics and interaction can better promote participants' thinking and facilitate their recall, and interactions among participants can elicit issues not covered by previous research (Morgan 1998; Vaughn et al. 1996).

In the next study the data will be collected retrospectively, and a wide range of BC patients - for example, with a variety of numbers of years since breast surgery - were recruited. In a sense, the author needs to rely on participants' memory. Face-to-face individual interviews may miss something important for patients because researchers tend only to ask questions based on the findings of previous studies. However, in FGDs, since each participant is given an opportunity to ask questions of each other and to add their own experiences to those of the others, then unexpected topics or interesting discussions are allowed to arise through the group interactions.

On the other hand, however, there are some disadvantages of group dynamics and interactions; they may also work to introduce response bias via group conformity. Although this disadvantage can be seen, in turn, as a natural process of human behaviours (Krueger 1998) in terms of the quality of the data, the skill of the researcher in identifying and redressing such bias is an important factor.

On qualitative analysis, it may be fair to say that analysis in ethnography is often considered an unclear process (Ratner 1999). To aim for a rigorous analytic approach, dual step analyses are proposed; an inductive thematic analysis (Boyatzis 1998) with well-defined and recorded stages and a conceptual analysis (Denzin 1989; Nicolson and Anderson 2003). In the second stage, SI theory, which shares the ideas of cultural psychology, will be used.

CONCLUSIONS

In this chapter, first, a comparison between cross-cultural psychology and cultural psychology was made; the concept and methodology of cross-cultural psychology was questioned since the pre-suppositions - individualism and collectivism - have not been supported by empirical studies applying a quantitative approach using instruments developed in the West. The issue here is that cross-cultural psychology is simply interested in internal states of human beings, not interested in social influences. In addition, cross-cultural psychology seems to treat subcultures or subpopulations in a society as inferior. In contrast, cultural psychology has challenged these pre-supposed categories and views on subcultures. Cultural psychology argues that emotions and perceptions can be formed by both internal states and social influences.

Second, one of the social constructionism theories - SI - was introduced as an application of cultural psychology. SI emphasises the importance of language (symbols) as a communication medium. When mutual understandings happen between two agents, real interactions are considered to occur (significant symbols). According to SI, this understanding can be expanded to subgroups and consequently to the larger community. At the interpretation process, SI proposes that significant others play an important role to control one's cognitions and emotions. Consequently, significant others can constrain human behaviours. If people do not meet social norms or expectations (lose face) then they may be labelled deviant.

Finally, the methodology of cultural psychology was discussed. Anthropological ethnography is the most preferred technique to induce indigenous theory.

In summary, although ethnography has several problems when researchers are unfamiliar with cultures in which they are interested, an ethnographic approach is beneficial for the next study because - as a Japanese woman - the author shares social norms and 'unconscious' rules with Japanese BC patients with lymphoedema. Additionally, since the purpose of this research programme is to design a culturally appropriate measure in Japan, then cultural psychological viewpoints and anthropological methodology will be best. To create research settings similar to the real world, FGDs, which have advantages over individual face to face interviews, are proposed for the next study. Qualitative data are analysed using SI theory at the stage of interpretative conceptual analysis following the thematic analysis.

6. The Qualitative Study: Focus Group Discussions

INTRODUCTION

As reported in Chapter 3, little qualitative research on the personal experiences of women with lymphoedema has been conducted among women with breast cancer (BC). However, some issues other than physical constraints have been reported consistently in research carried out in Western country settings; these include communication issues between doctors and patients and their emotional impact, and the social impact, and evaluation, of the onset of lymphoedema. For example, the perceived insensitive and inconsiderate attitudes of doctors (Carter 1997) make patients desperate (Johansson et al. 2003), and the perceived inadequate provision of information and insufficient patients' understanding about lymphoedema lead to anxiety (Williams et al. 2004). Next, the visible treatment of lymphoedema (e.g. compression sleeves) may lead to the social disclosure of BC and consequent social embarrassment (Johansson et al. 2003). Social support is not always perceived positively, since patients wish to maintain an appearance of normality and independence (Radina and Armer 2001). Finally, an evaluation of the experiences of lymphoedema may be made by comparison to BC (Williams et al. 2004) and to others with breast loss (e.g. 'even though I've got lymphoedema, I did not lose my entire breast'; Johansson et al. 2003).

In terms of an analytic approach, most of the studies mentioned above applied a phenomenological analysis, which focuses on subjective attributions. The aim of the present qualitative study was to understand how perceptions and emotions about lymphoedema were constructed in Japanese social contexts. Social influences were explored using symbolic interactionism (SI) theory (see Chapter 5).

Summary of the qualitative study

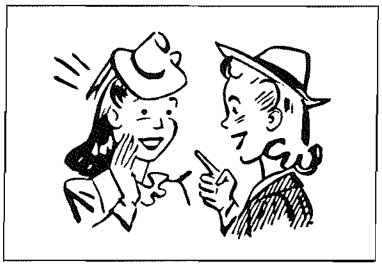
In this chapter, the methodology used and the results of the focus group discussions (FGDs) are presented. First, the process of the development of the question route for FGDs is described; the semi-structured question route was designed after a comprehensive literature review and discussions with supervisors, and questions were carefully constructed to cover all important aspects of Quality of Life (QoL) as identified in Chapter 1. Second, a small pilot study in Japan is reported; this enabled the phrasing of the question route and the procedure to be assessed, and necessary improvements to the question route and FGDs to be made. Next, two more FGDs in Japan using the revised question route are outlined. Finally, the two step analytic procedure for the transcripts is presented; first, using an inductive thematic analysis (Boyatzis 1998) and, second, a conceptual analysis in a SI framework (Nicolson and Anderson 2003).

DEVELOPMENT OF THE INITIAL QUESTION ROUTE

Following comprehensive literature reviews (Chapters 1, 2, 3 and 5) and discussions with supervisors, a semi-structured question route with twelve core questions was designed covering four main topics - (1) the concept of good life, (2) arm problems, (3) change after breast surgery, and (4) perceptions of present and future life. Several open-ended questions and probe questions were included (see Appendix 6.1). Although both core and probe questions were pre-determined, participants were encouraged to talk freely around the topics.

First, regarding the topic of a good life, to elicit general ideas of what a good life would be, a picture of two ladies talking each to other was presented (see Figure 6.1), while a scenario of the picture was given: 'you are walking down a street, and seeing the two ladies talking to each other. When you are passing by, you hear "what a good life it is!" by chance. Tell us how you can imagine the life is'.

Figure 6.1 *The Picture in the Good Life Question*



Next, introducing the second topic - arm problems - the statement 'you all have similar experiences after breast surgery' was introduced at the beginning because this may allow participants to feel close to each other, even though they had never met before (Morgan 1998). Following the statement, and in order to explore the key issues after breast surgery, open-ended questions rather than direct closed questions were used, such as 'please think back to what happened to you after surgery. Could you tell us what you noticed?'. This was because it was possible that lymphoedema (arm swelling) would not be an issue among all BC patients after breast surgery.

When participants reported any arm complications, several questions were asked exploring physical constraints, emotional responses to the constraints, help and information seeking behaviour, and emotional responses after these behaviours. First, regarding physical constraints and emotional responses, four questions were asked: 'please describe how it was (e.g. a range of arm movement and any restrictions of daily activities)', 'when did you notice that?', 'how did you feel about that?', and, finally, 'did you have any ideas about that?'. Second, regarding help and information seeking behaviours, four questions were asked: ‘could you tell us what you did afterwards?’, ‘did you talk to somebody?’, ‘what did you do to obtain the relevant information?’, and ‘how long did it take for you to do it, after you first noticed it?’. Finally, regarding emotional responses after help and information seeking behaviours, one question was asked: ‘how did you feel after you had done that?’.

On the third topic - change after breast surgery - several questions were asked exploring the impacts of breast surgery, significant others and social support. First, regarding the impact of breast surgery, two questions were asked: ‘could you tell us how your life changed from the time of the operation to now?’ and ‘how did you feel about the change?’. Next - regarding the impact of significant others - two questions were asked: ‘could you tell us how others changed toward you from the time of the operation to now?’ and ‘how did you feel about the change?’. Communication between patients and health care staff significantly affects patients’ long term well-being (see Chapter 2) so that perceived changes in relationships with doctors and nurses were a particular focus of interest. Relating to these questions above, it was assumed that, if participants felt that others’ attitude had changed, participants themselves may also change their attitude (Blumer and Morrione 2004). Thus, two more questions were asked: ‘could you tell us how you changed toward others from the time of the operation to now?’ and ‘how do you feel about the change?’. Next, regarding social support, two questions were asked: ‘could you tell us what the most helpful thing and person was from the time of the operation to now?’ and ‘could you tell us what the most unhelpful thing and person was from the time of the operation to now?’.

Regarding the last topic - perceptions of a present and future life - five questions were asked exploring feelings about present life (QoL): ‘could you tell us how you are feeling about your present life’, ‘When is the most pleasant time for you?’, ‘when is the most unpleasant time for you?’, ‘please describe your feelings’, and ‘how often do you feel that?’. Additionally, two questions were asked exploring feelings about and attitudes towards future life: ‘could you tell us your idea about improvement of your life?’ and ‘could you tell us how your future would be?’.

THE PILOT STUDY

Method

Participants

Two BC patients participated in this study. One woman, aged 65 years, had undergone breast surgery just over five years previously, and the other woman, aged 69 years, had undergone breast surgery 26 years previously.

Sampling Procedure

Two inclusion criteria were pre-determined: first, women who reported the presence of arm swelling in the first time questionnaire (54 of the initial 107) and, second, those who provided their contact details (18 of these 54).

First, for group composition, the eighteen respondents were divided into four groups according to both age and location of residence. In particular, participants' age was taken into consideration, since it is an issue to facilitate FGDs in Japan where seniority is of great value. Because of this, mixed age groups could be an obstacle to create a friendly atmosphere; when Japanese adults talk to strangers or older people, they, in general, choose a middle level of politeness. This often gives an impression that emotional distances among speakers are greater. If this happens in FGDs, younger participants may not be able to talk and behave frankly towards older participants. To minimise the effect, an attempt was made to compose similar age groups.

Since the main purpose of this pilot study was to check the wording and phrasing of the question route and the procedure, the oldest aged group was chosen. This was because, first, it was assumed that, if older aged participants could understand the questions, then younger aged ones also could do so and, second, if older aged participants could not understand the facilitator's questions or the others' comments, they were more likely to ask questions frankly to clarify what they could not understand. Thus, the oldest aged group was thought suitable to identity any problems in the questions and procedure.

Next, four women were invited using information letters (see Appendix 6.2): consent forms (see Appendix 6.3), a map of the FGD's venue (see Appendix 6.4), and stamped envelopes were also enclosed (the printed address was the author's home address in Japan). Three women returned the signed consent forms. In advance of the day of the pilot study, the photocopy of the signed consent forms was mailed to each woman for their future reference. On the day of FGD, one woman withdrew from this study due to her health condition.

In February 2004, a group discussion was conducted by the author in Japan that lasted around two hours. All conversations were audio taped. At the beginning of the discussion, tea and snacks were served. At the end of the discussion, debriefing sheets (see Appendix 6.5) were provided. Immediately after the discussion, field notes were made (see Appendix 6.6).

Venue

A public meeting room in Yokohama, Kanagawa Prefecture was used. The building is a familiar landmark and is near a railway station so that there was little chance to get lost on the way from the railway station.

Analysis

The audiotape was transcribed verbatim. Because of the purpose of the pilot study, specific qualitative analysis was not applied here. Upon reading the transcript several times together with the field notes, several problems were identified.

Results

Overall, the discussion was felt to be hard to control; the two participants had opposite characteristics. One woman was relatively talkative and instructive, while the other was quiet. Further, conditions of lymphoedema at the time of the FGD seemed to be related to each participant's focus of interests. For example, the former, who had undergone breast surgery over twenty years ago, did not have a severe swelling at the time of FGD, and she tended to concentrate on the topic of BC alone. The latter was developing a visible hand and arm swelling so that she tried to talk about the topic of lymphoedema. Although the author sometimes probed to draw more lymphoedema related stories, the older woman tended to interrupt and go back to the topic of BC.

Regarding the question route, a few issues which had not been covered were identified. On the second topic - arm problems - several issues on lymphoedema treatment, such as inaccessibility of manual lymphatic drainage (MLD) clinics, inconvenience and quality of compression sleeves, were reported. Additionally, on the third topic, changes in diet and clothes were reported as occurring between the time of surgery and the time of FGD. However, psycho-social changes as a result of arm complication were seldom reported.

On the other hand, two inefficient questions that did not provoke any detailed information were identified. The first question using the picture did not fit the discussion at all, since soon after the participants introduced each other they started to talk about lump detection. Second, on the final topic - perceptions of the present and future life - responses to the two questions, such as 'could you tell us your idea about improvement of your life?' and 'could you tell us how your future looks like?', were very similar each other. Especially in relation to the second question, the participants tended to summarise their ideas about QoL, which had been already presented in the earlier question.

Finally, on the procedure, since the author was the only person available to prepare for room settings, serving teas, facilitating, recording and so on, it felt somewhat overwhelming. Additionally, since there were too few participants in this study, the advantages of FGDs were not fully optimised.

Discussion and Conclusions

After discussions with supervisors and the coordinator of a self-help group, some suggestions were made to address the problems identified as far as possible.

First, to control the discussion, more assertive facilitation, clearer instructions and presentation of the group rules were suggested. For example, using a white board, the main topic of discussions and group rules could be emphasised, and the instructions should be verbally explained, too: 'the main discussion topic today is about QoL after breast surgery. There are three rules that you should follow: please don't speak simultaneously; please start to tell your story after somebody finishes talking, or we cannot record conversations; please don't criticise somebody's opinions or experiences in the group, since we think that there are no right answers and since we want to know everyone's opinion or experience, and please let me interrupt the discussion, when necessary, as I would like to ask you some questions or give you a summary if needed'.

Additionally, as the results have shown, participants needed to be offered opportunities to talk about their experiences before surgery (e.g. lump detection) and adjuvant therapies. Asking the same questions as in the questionnaire may not be good use of time. However, in the present study, if the opportunity had been offered at the beginning, the participants could have developed discussions about experiences after breast surgery rather than before breast surgery. Exploring the experiences after the surgery was the main objective of the qualitative study. Thus, the suggestion was to ask participants to briefly summarise their experiences before surgery within a few minutes. For example, 'everybody may want to know each others' experience before breast surgery. Please tell us your story briefly for one minute. You may want to say about lump detections, types of surgery, types of adjuvant therapy, how many years have passed after surgery, and so on'.

Second, regarding the non-covered topics - on perceptions for lymphoedema treatment - four questions were to be added: 'could you tell us if you are taking doctors' (therapists') therapy now or did you take it in the past?', 'what types of therapy are you taking or did you take?', 'how often are you taking or did you take it?', and 'how do you feel or did you feel about the therapy?'. The first two questions would overlap the questions in the questionnaire, but these questions were thought necessary to introduce the topic of lymphoedema treatment smoothly. Additionally, on the topic of changes, probe questions - on topics such as clothes and diet - were to be added.

Third, regarding the inefficient questions, it was suggested that the first question, with the picture, could be used as a game to identify who is a dominator or is a quieter person (Well-being 2003) as well as breaking the ice in the researcher - researched relationship at the beginning (Krueger 1998). Because the author is not a BC patient, sharing some general experiences with participants is useful to build rapport, so some TV programs which had been most popular around two decades ago were chosen. An introductory sentence was to be 'please look at this picture. I would like to play a game, first. Do you remember the TV program called '*Renso Game*' [association game] a few decades ago? If you remember, please raise your hand.'. Then, presenting the picture, a game will start: 'the situation is - you are walking down a street. You see two people talking about their neighbour. You hear the word "a good life" by chance when you are passing by. Could you tell us how you imagine the person's life?'. A few minutes were given to participants to think about their possible answers.

Next, regarding the last topic - perceptions of the present and future life - the last question 'could you tell us how your future looks like?' was omitted from the question route. Regarding the few reports on psycho-social changes associated with lymphoedema, this seemed to be most problematic; it was felt hard to let participants talk about experiences of lymphoedema when they thought that arm/ hand swelling was less serious than BC. However, it was necessary to know how lymphoedema (swelling) had emotionally and socially affected the participants' life as well as BC. Thus, an additional specific question about the impact of lymphoedema (swelling) was suggested. For example, 'could you tell us if your life changed from the time of the onset of swelling to now? How has it changed?'.

Finally, regarding administrative problems, an assistant for preparation was suggested. To implement this, re-explanation to the coordinator of the self-help group was crucial. Consulting the Chair, a female assistant was suggested since a sexual issue sometimes arises, which is still taboo for Japanese women to openly discuss with men. Thus, the author's female colleague at the National Children Hospital (Japan) was asked to become an assistant for the next FGDs.

Additionally, re-composition of groups was suggested to encourage more women to attend at the next FGD. In this study, three out of four women agreed to participate. When four to five participants are required for each discussion, it is necessary to recruit at least seven women. Because only fourteen women were left as potential participants, a two group composition was suggested.

Summary

In summary, a small pilot FGD was conduced using the semi-structured question route but, in fact, the FGD was rather an open discussion. There were several problems identified and room to improve, such as the facilitator's assertiveness, amendments and omission of questions, female assistant arrangements, and group composition. Based on the suggestions above, the question route and procedure were modified for the next study.

THE MAIN STUDY

Method

Participant

A total of eight (four for each session) BC patients with lymphoedema participated in two FGDs (Groups 1 and 2). The overall mean age was 49.8 years (with a range from 39 to 60 years). The average number of years since surgery was 2.8 (ranging from 1.2 to 4.8). Table 6.1 shows the mean age and years since surgery in each group.

Table 6.1 *The Group Mean Age and Years Since Breast Surgery*

Group	Mean age (range)	Mean years since surgery (range)
1	48.2 (39.0 - 60.0)	3.2 (1.6 – 4.8)
2	51.5 (47.0 – 54.0)	2.5 (1.2 – 4.4)

Procedure

As suggested in the Discussion and Conclutions above, group re-composition was carried out; the remainder of the fourteen eligible women were divided into two groups (Group 1: a Yokohama session, Group 2: a Tokyo session) according to location. This time, age was not an absolute criterion, since participants' convenience was prioritised to increase the attendance rate and also the age differences were not very great.

First, seven women were invited for the Yokohama session (Group 1) using information letters, consent forms, and a map of the venue (see Appendix 6.7 for the Tokyo session), and stamped envelopes were enclosed (information letters, conset forms, and a map of Yokohama session were same as those of the pilot study). These documents, except the information letters, were the same as in the pilot study. One woman requested to change to another session. As she wished, re-arrangement was made, and a map of the venue in Tokyo was mailed. There was another woman living far away from both Yokohama and Tokyo so, considering her convenience, an alternative date for the Tokyo session was made.

Of the seven, three women returned the signed consent forms. Two women contacted the author: one woman reported on the phone that she was unsure about attending the session. One woman reported her unwillingness to attend, via email. The photocopies of the signed consent forms were returned to the three women in advance of the day of the FGDs. On the day of the session in Yokohama (Group1), the woman who had mentioned her uncertainty on the phone showed up. Written consent was obtained before the session started, and the photocopy was sent to her later on.

Second, seven women were invited for the Tokyo session (Group 2) using a simialr procedure as for Group 1. Five women, including the women having requested re-arrangement, returned the signed consent forms. One woman reported her unwillingness to attend via email. On the day of the session, one woman withdrew on the phone due to her health condition.

In March 2004, two FGDs were conducted using the revised question route (see Appendix 6.8), and the female colleague joined as a recorder; she also helped out with room setting and serving tea and snacks. Both sessions lasted around two hours, and all conversations were audio taped. At the end of the discussions, the same debriefing sheets as in the pilot study were provided for all participants. Immediately after each group discussion, field notes were made (see Appendices 6.9 and 6.10) and discussions with the colleague were held.

Venues

The session in Yokohama was held in the same meeting room as the pilot study. The session in Tokyo was held in a meeting room in a public hall, which is well known as a concert hall. The hall is located in east Tokyo near a subway station, so it was convenient for participants living in both Tokyo and Chiba Prefecture.

Analysis One: thematic analysis

All audiotapes were transcribed verbatim immediately after each session. Because the sample size was small, the pilot transcript was included for qualitative analysis (participants' characteristics obtained from the survey study are presented in Table 6.2). An inductive thematic analysis (Boyatzis 1998) was applied to the Japanese transcripts. A coding unit was determined as one sentence. All labels, locations of discourses, and discourses themselves were recorded in Excel as a code book.

First, a pilot transcript was coded regardless of any psychological aspect. This was because background information not obtained in the survey study was important more deeply to understand each participant's life events (Appendix 6.11 shows an example of coding in the pilot transcript). Forty-three labels were derived and defined. Second, the Group 1 transcript was coded using the labels. Four new labels were derived and defined. Third, the Group 2 transcript was coded using the forty-seven labels. No new labels were derived from the Group 2 transcript. Thus, in total, forty-seven labels were derived from the three transcripts (all labels and definitions are presented in Appendix 6.12). Some similarities among the labels were found, and some labels were combined together, renamed and redefined (forty-five labels).

Next, in order to focus on psychology relating to breast surgery, the forty-five labels were divided into three categories: general background information, BC treatment-related information overlapping with the survey data and emotional responses to BC and lymphoedema. Category three was the focus of further analysis. The twenty-three labels were divided into two topics, such as lymphoedema and BC (Table 6.3). To compare and contrast each label across the groups, participants' discourses were assembled in one table (see Appendix 6.13). Finally, over-arching themes among these labels were sought and identified (see Appendix 6.14)

Two weeks after the initial coding, exactly the same procedure as described above was repeated using non-marked transcripts to check the internal consistency of the analysis. When inconsistency was found, the necessary amendments were made.

Subsequently, all the transcripts in Japanese were translated into English by Japanese native speakers studying at University of Southampton. The author performed back translation and discussed necessary amendments with the students. Supervisors individually read the English transcripts, and the findings were discussed with supervisors.

Table 6.2 *Participants' Background Information Obtained by the Questionnarie*

Variables	Pilot			Group 1				Group 2		
	U	M	K	H	T	S	T	S	H	I
Age	69	65	39	43	51	60	47	52	53	54
Marital status	M	M	S	M	M	M	M	M	M	M
Children	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Education	HS	HS	HS	C	TS	C	U	C	HS	TS
Paid job	No	No	Yes	Yes	Yes	No	No	Yes	No	Yes
Income (million Yen)	< 5	-	-	>/ = 5	< 5	< 5	< 5	>/= 5	>/ = 5	< 5
Years since surgery	5.3	26.5	4.3	2.2	4.8	1.6	1.4	4.4	3.0	1.2
Type of surgery	MRM	RM	MRM	QTM	QTM	QTM	LTM	RM	-	QTM
Stage	IIB	I	IIIB	IIA	IIA	IIB	IIA	I	IIA	IIA
Sufficient information (at diagnosis)	Yes	No	Yes	No	No	Yes	Yes	No	No	No
Sufficient Information (after surgery)	No	No	Yes	No	No	Yes	Yes	No	No	No
Years having LEM	1-2.9	3-5	3-5	1-2.9	3-5	<1	<1	>/=5	3-5	< 1
Therapies by doctors	Yes	Yes	Yes	No	Yes	Yes	Yes	No	No	No
Self-care	Yes	No	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
The Global score	4	3	4	5	4	-	2	5	5	4
ALPDS	20	12	11	24	20	-	8	27	22	22

Note. M represents married, and S represents single in marital status; HS represents high school, TS respresents technical school, C represents college, and

U represents university in education. MRM represents modified radical mastectomies, RM represents radical mastectomies, QTM represents quandractecomies, and LTM represents lumpectomies in type of surgery; ALPDS represents the Arm-lymphoedem Physical Discomfort Scale. Both the Global score and the ALPDS, higher scores are severer physical discomfort.

Table 6.3 *Labels and Definitions under Two Topics*

Topics	No	Labels	Definitions
Lymphoedema	13	Feelings towards arm swelling	Mention of how participants felt (are feeling) about arm swelling
	15	Feelings towards the therapies of arm problems	Mention of how participants felt (are feeling) about the therapy that doctors gave (are giving) participants (in No. 14)
	17	Feelings towards doctor's reaction (arm problems)	Mention of how participants felt about doctors' reaction described in No. 16
	19	Help from others relating to arm problems regarding arm swelling	Descriptions of what others actually do for participants in daily life,
	20	Self protection	Descriptions of what participants are aware of in order to prevent the further arm complications

	31a	Limitations in daily life	Descriptions of what participants' daily activities have been constrained as a result of arm swelling
	40a	Financial support	Participants' needs of financial support related to the consequences of breast surgery (arm complications)
	36a	Unhelpful people	Descriptions of what (and who) is unhelpful for participants after discharge
	46a	Perception of others	Mention of how participants perceive a self-help group where they are joing to, regarding arm swelling
Breast cancer	8	Fear of recurrence	Mention of how participants feel about recurrence after discharge
	23	Perceptions of breast surgery	Mention of what participants perceive partial and entire breast loss
	30	Difficulty in breast cancer	Descriptions of how breast cancer affects participants' daily life
	31b	Limitations in daily life	Descriptions of what participants' daily activities have been constrained as a result of breast loss

32/33	Perceptions of life after breast cancer	Mention of how participants perceive their present life through experiences of breast cancer
34	Helpful people	Descriptions of what support is helpful for participants after discharge
35	Sexual relationships	Mention of how participants perceive sexual relationships with their husbands after surgery
36b	Unhelpful people	Descriptions of what (or who) is unhelpful for participants after after discharge
37	Feelings for unhelpful people	Mention of how participants feel about unwelcome questions from others
38	Disclosure of having cancer to others	Mention of how participants feel when they tried to tell the cancer diagnosis to others
39	Perceptions of participants by others	Mention of how others perceive participants after breast surgery from participants' perspectives

40b	Financial support	Participants' need of financial support related to the consequences of breast surgery
42	Future plans	Descriptions of what participants want to do in the futureand its reason
43	Worries about own daughter	Mention of how participants are feeling about their daughters who may or may not develop breast cancer in their lives
45	Relationships with health care staff	Mention of how participants perceive the relationship between their doctors/nurses and themselves after discharge
46b	Perceptions of others	Mention of how participants perceive others regarding breast cancer
47	Self-help groups	Mention of how participants perceive the self-help groups that they are joining regarding breast cancer

Findings One

Five main themes emerged on the topic of lymphoedema and seven on the topic of BC. The main themes, subcategories, and definitions are presented in Appendix 6.14. In the next section, themes on lymphoedema are presented, with illustrative quotes, and discussed.

Theme 1. Physical constraints

Several physical constraints as a result of axillary lymph node dissections (ALND) were reported. First, efforts to prevent severe conditions, such as avoidance of infection, the use of the arm on the non-operated side, and not swinging the affected arm were often cited: 'I didn't used to wear gloves when I did washing [dishes], but I wear a thick pair of gloves nowadays because I might be infected with bacteria while washing' (I, Group 2); 'whenever I have a blood sample taken for other things ... I would tell nurses about it [lymphoedema] just in case' (M, Pilot group); 'when I go shopping I try using my left hand [not operated side] to carry the groceries' (S, Group2); 'I do walking with my friends; during walking I tend to wave my arm back and forth. It makes my hand actually heavier, so I put my right hand in my pocket not to wave' (T, Group1).

Some women perceived these preventive behaviours as problematic: 'I am doing gardening sometimes, but I need to wear gloves (yes) (two layers). Really inconvenient' (S, Group 2); 'I put a cushion on top [when I go to sleep], er, as the body moves it goes like this and I've started having shoulder aches' (U, Group1).

Next, actual inabilities in performing several activities were cited. The most commonly reported inability was grasping something for household chores: 'at the beginning, I couldn't even hold a pencil or a dishcloth' (U, Pilot group); 'when I use chopsticks, especially long chopsticks for cooking, I feel that I'm holding food, but actually I'm not (laugh)' (H, Group1); 'it is quite hard for me to cut a pumpkin and grate a Japanese radish' (I, Group2). Additionally, holding children was cited: 'I cannot hold my grandchild' (S, Group1); 'When I started with lymphoedema, well, my hands' swelling, my daughter was about one year old ... For that reason, I could not cradle her so that I felt pitiful' (H, Group1).

Limits in choosing clothes and in hobbies were cited: 'I myself cannot do the cuff here [the wrist] on this side. There are two centimetres or so difference' (U, Pilot group); 'I choose clothes which I do not have to raise my arm to wear' (K, Group 1); 'I have played tennis for decades. After surgery, I couldn't raise my hands (yeah). I toss a ball only to lose games (laugh)' (H, Group2); 'I used to be playing soft ball before I got cancer' (H, Group 1).

Additionally, limiting or quitting professional jobs was cited: 'Even when I assist them [the elderly] to take a bath, I would be exposed to all sorts of germs which might affect my arm. So I was too nervous to get back to the work' (I, Group2);

> I am a dental hygienist. Tartar cleaning takes about 30 minutes for each patient. I cannot do detailed treatment any more. I cannot have my own patients any more, but I am doing treatment which a dental hygienist is allowed to do without taking a long time.
>
> (T, Group 1)

Theme 2. Emotional responses to lymphoedema

As theme 1 has shown, most participants experienced some restrictions of their activities. However, emotional responses to the physical constraints were clearly divided into two types: an acceptance and burden. These different responses were closely related to information provision regarding the risks of lymphoedema. Participants who reported having been told of these risks by surgeons were more likely to perceive the onset of lymphoedema as acceptable: 'Although my arm swells, it's not as bad as I need to wear sleeves' (S, Group 1); 'Since then (breast surgery had been completed), it's been as before ... as about 20 lymph nodes were taken out, it was impossible to avoid lymphoedema' (K, Group1).

In addition, comparison to BC was cited among women who had been given information on the risk of lymphoedema: 'it is not too inconvenient for everyday life ... That's because I worry more about my life. Compared with the life, it can be endured (laugh)' (S, Group1); 'I thought I couldn't be helped as I had such a big operation. I try to force myself to think that I had an accident' (K, Group 1); 'Since this much of lymph glands have been taken out, and since I made this decision at that time, I mean, this was my decision. I think it [lymphoedema] couldn't be helped' (H, Group1).

On the contrary, participants who had not been told the risk tended to perceive the onset of lymphoedema as burden: 'I am really desperate so that it is not curable in whole my life' (S, Group 2); 'I felt as if I suffered something I didn't have to' (U, Pilot group). These participants also initially felt the onset of lymphoedema as 'worries' (T, Group1), 'nervous' (U, Pilot group), and 'bitter' (S, Group 2). These views seem not to have changed over time.

Theme 3. Negative emotional responses to surgeons

Negative feelings towards surgeons and their support were often cited. These feelings were provoked when participants encountered surgeons' relatively inconsiderate attitudes in consultation, which was consistent with a previous study in the USA (Johansson et al. 2003). This also related to insufficient provision of information about the risk:

> 'Uh, it's got slightly swollen, hasn't it?' He [her surgeon] just said that certain percentage of people found *Sairento* [Chinese medicine] effective and that I should take it. That's all. It was told ... I then thought the surgeon wasn't reliable.

> I wished my doctor warned me earlier.
>
> (U, Pilot group)

Another woman, who had attempted to seek the surgeon's help, commented that satisfactory explanations were not given. Consequently, the participant was convinced she must fight her lymphoedema on her own:

> I asked him [the doctor-in charge] whether this was lymphoedema ... but he said it's not lymphoedema ... Frankly speaking, the hospital is useful for me only to do the regular check-ups [of BC], and for the numbness or something I would search for information and go to a different place to consult.
>
> (T, Group 1)

Theme 4. Practical and informational support

Surprisingly, very few sources of social support, such as family members and colleagues, were cited. Since most participants reported several physical constrains under theme 1, it was assumed that they had asked for more help from others. For a few participants, practical support such as lifting or carrying heavy things was provided: 'My husband aired futon and carried heavy things ... My husband didn't let me carry a heavy thing' (M, Pilot group); 'They [her colleagues] helped to carry things saying that "you cannot carry stuff "' (K, Group1).

Additionally, self-help groups were cited as informational sources: 'I also bought compression sleeves, but I was advised that I'd better make an effort to always wear this [sports type sleeves] ... I have been told that sleeves aren't good and the sports type would be more comfortable to wear' (H, Group1).

Theme 5. Scepticism about efficicacy of lymphoedema treatment

Dissatisfaction with lymphoedema treatment was cited: the use of compression sleeves, compression pumps, massages and Chinese medicine. Among them, dissatisfaction with the quality of compression sleeves and feelings when wearing them were commonly cited: 'it is unpleasant ... Didn't you find that loses elasticity?' (U, Pilot group); ' it's not very nice' (T, Group1); 'because my skin is sensitive, if I wear compression sleeves which are made of chemical fibre, I would feel itchy' (K, Group 1); 'I lose the sense of fingers' (K, Group1); 'I used to use the one that covers up to here [upper arm], but I stopped using as this part [shoulder] got stiff which was troublesome' (S, Group1).

Also, some participants questioned efficiency of the treatment; 'I suppose these [sleeves] serve just as thermal ones' (U, Pilot group). Another woman claimed:

> It [compression sleeve] only could cover from here [armpit] to here [wrist] and couldn't cover shoulder where I really wanted to cover the most. So I felt my shoulder unwell … I also did Hadmer [compression pumps] at home ... but it is also unable to cover up to shoulder.
>
> (T, Group 1)

One participant seemed to expect a more acute visible effect on her swollen hand: 'I was given this medicine and tried it. I then thought it wasn't very effective' (U, Pilot group).

Relating to these dissatisfactions, financial issues were cited. Both compression sleeves and MLD were perceived as expensive: 'I wish the things [sleeves] like mine would be covered by [the National] Health Insurance … I wish the insurance would cover the cost of massaging and so on' (U, Pilot group).

Summary

Most participants experienced limits or inabilities in relation to various activities. However, some perceived these physical constraints as acceptable whilst others perceived them as a burden. These different perceptions were clearly related to information provision on the risks of lymphoedema by surgeons. Participants not having been given sufficient information sought surgeon's help but, because of the surgeons' perceived inconsiderate attitudes, participants did not consider surgeons as sources of support. Rather, family, colleagues, and self-help groups were considered as practical and informational sources. However, unexpectedly, few support networks were reported. Lymphoedema therapies did not seem helpful since most participants who had taken up some lymphoedema therapies perceived them to be uncomfortable and inefficient. Consequently, most participants did not persist with the treatment.

Analysis Two: conceptual analysis in a SI frame work

Following the thematic analysis, a more conceptual and interpretative analysis was performed in the framework of SI (Denzin 1989: Nicolson et al. 2003) in order to understand how experiences of, and in particular feelings about, lymphoedema had been formed in Japanese cultural contexts. During interpretations, it was anticipated that the women's cognitive and emotional processes would be revealed.

The transcripts guided which themes should be considered for this conceptual analysis; first, as Theme 2 in thematic analysis has shown, when women felt well informed about the risk of lymphoedema, they made comparison between experiences of BC and lymphoedema, and consequently they perceived lymphoedema as acceptable. What did BC bring to the participants after all? What cognitive processes were involved in the evaluation? It is necessary to look closely at the themes representing both negative and positive experiences after breast surgery.

Second, as Theme 4 in the thematic analysis has shown, participants had relatively small social networks. This was because help-seeking behaviour was not conducted when arm problems were perceived as minor (people in all FGDs did not have extreme swelling as far as I could see, but I could not tell how much their arms were swollen, since most of them had put on long sleeved clothing). Why did participants perceive support as unnecessary? Was it because their physical limitations were not regarded as being severe? Did participants wish to maintain sense of control (Radina et al. 2001)? It is necessary to look at the theme relating to help-seeking behaviour, such as disease disclosure and others' reactions to the disclosure (Johansson et al. 2003).

Therefore, several themes from both topics of lymphoedema and BC were selected to consider: emotional responses to lymphoedema, practical and informational support, negative emotional responses to surgeons, learning from experiences of BC, and cancer disclosure to others (see Appendix 6.13). In addition, the label 'General background information', omitted at the early stage of the thematic analysis, was also considered. This was because the theme might include some clues to understanding the social influences upon each woman and their individual life events other than BC.

Findings Two

Theme 1. Self-esteem and adjustment to lymphoedema in BC contexts

As the thematic analysis has shown, most participants experienced physical constraints (Theme 1), but these physical constraints were not perceived as a disruption of life and being 'disabled' (Voogd et al. 2003) by most participants. Neither were most participants isolated from friends due to the physical constraints (Charmaz 1983), nor did they blame themselves (Nicolson et al. 2003). Most participants made internal comparison between the past (BC) and the present (lymphoedema) as 'it is not too inconvenient for everyday life … that's because I worry more about my life. Compared with the life, it can be endured (laugh)' (S, Group1), and undertook pleasant activities, such as travelling and doing exercises actively, as if nothing had happened to their arms after breast surgery, which is inconsistent with some previous studies (Carter 1997; Johansson et al. 2003; Velanovich and Szymanski 1999).

Does this simply indicate a trade-off between life and non-life threatening illness (Williams et al. 2004)? Why can patients accept lymphoedema caused by breast surgery? Didn't patients have negative feelings about BC only? What had BC brought to the participants after all?

The transcripts reveal that participants had both negative and positive experiences. For example, after being diagnosed with BC participants all felt that several aspects of life, especially their philosophy or principles, had changed when they were faced with the fear of death. 'Life is not stable' was commonly cited in all three groups. The idea that life never lasts as people wish had a great impact on their ways of thinking and philosophy: 'People cannot tell when something is going to happen nor what is going to happen to the future. Because of such an experience of mine, I've learned uncertainty of ones' future, and fragility of life' (M, Pilot group); 'Because of the illness, I was convinced that one's life would be limited' (S, Group 2).

A woman who used to be stubborn in sticking to her plans seemed to struggle to accept the change of her way of thinking at the beginning. However, she has had to learn to live with uncertainty,

> Even if I make a great effort to complete something, my life wouldn't go like I wish. In a word, I used to plan to do like this and like that, and used to try my best to achieve that plan ... I had expected I would be cured if I had an operation. But I was told that I needed to live my life with it [BC]. After listening to many people's experiences, I can think like that, well, 'Que sera sera'. I am getting less struggle now.
>
> (H, Group 1)

Besides these painful changes, some women perceived changes to be gains rather than 'loss' (Charmaz 1983): 'I did gain many things rather than just lost' (M, Pilot group). Similarly, another woman described her emotional process when her friends grew apart from her:

> I used to agree to other people's opinion no matter what ... since I got cancer, I somehow started to be a little bit more opinionated like 'I don't think so' ... Then my friends whom I really trusted and have known of a long time started to grow apart from me ... I was quite depressed but I started to realise that the quantity of friends doesn't matter. The quality of friendship is more important.
>
> (S, Group 2)

As such, participants experienced several positive changes, such as acquisition of proactive attitudes, friendships and appreciation. These are seen as a reappraisal of both self and the external world, and new findings that women had never noticed. These changes arose from their experiences of BC and are also seen as resources in living with and coping with BC.

> Before I became ill, I used to worry how people think about me all the time. You know that kind of timid character. When I look back, I wonder at how strong I became during the five years ... no matter if the cancer recurs or not, I don't

> know but I wanted to gain confidence to live with my head up.
>
> (S, Group 2)

One woman, having already had the concept of 'life and death' due to chronic illness other than BC, reported that she could build more intimate relationships with her friends than before the BC surgery: 'my friends have come to talk their personal things over with me ... I feel that I like to try to help them as much as possible' (K, Group 1). Another woman saw making new friends with BC as a gift:

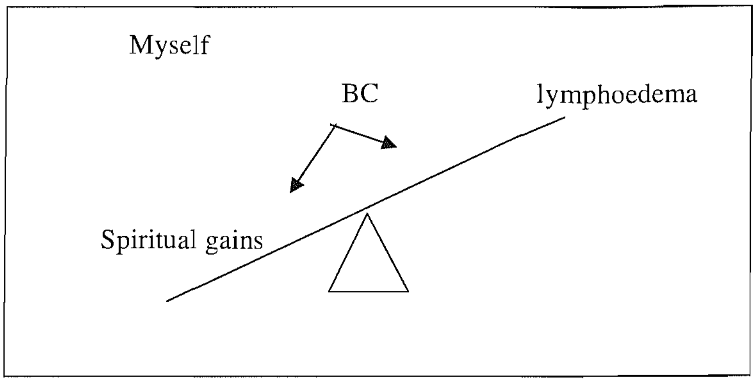
> The number of friends is increasing now. This is actually what has changed in my life. Without the illness, I would have never got to know them and made friends there. They are really nice people, so in a way, this is something I benefited from the cancer.
>
> (H, Group2)

Additionally, appreciations for families and friends - and even nature - were cited, which is closely related to the women's painful change. Because women had already changed their views towards life, they could see the usual world through fresh eyes and felt that they were reborn: 'without such [BC] experience, I would have lived happily and had a confidence in my health and life without concerns ... Owing to them [my family and friends] I am here, I think ... I have acquired a feeling of gratitude'(M, Pilot group): 'I am happy to be alive ... when I was looking at the stars I started to feel like that and I realised life is beautiful' (K, Group 1);

> I used to move around by car ... [after breast surgery] starting walking and looking at flowers. I was very surprised at such beautiful scenery around me. 'Til I developed breast cancer, I realised neither the sky was so blue nor Mt. Fuji could be seen in my place.
>
> (S, Group1)

When women perceived that something precious in their lives was given to them after the painful change they appeared to have a relatively high level of self-esteem. This evaluation was made by the internal state 'I' looking at 'me'. In this process, significant others (social norms) were not important. The onset of lymphoedema may be categorised as negative experiences, but for women who felt more spiritual gains, they may accept the negative experiences (see Figure 6.2).

Figure 6.2 *Internal Comparisons between Breast Cancer and Lymphoedema*



However, when women evaluated BC by significant others' viewpoints they were not able to view the changes as positive gains or use them as resources to live with BC. One woman, having had the image of women since her childhood, lost her confidence by breast loss. The woman recalled her childhood: ' ... Still now, the words impact on me. [Somebody said] "A girl should be cute and girlish, but should not be good academically." [I had thought] the cuteness is all about how males judge', and she continued, 'In my family, we all have rather small breasts, especially me. Because of that, I felt so inferior' (S, Group 2). Additionally, consultation with her male surgeon seemed to reinforce the sense of inferiority. She discussed possible surgical methods with her surgeon: 'I was embarrassed to ask for it [breast retention], but eventually I asked my doctor. Then, he said "Have you said you wanted to keep such a *small* breast?"' Since her childhood, she imagined 'breasts' as a symbol of woman. Thus, she perceived her breast loss as lack of femininity and of sexual attractiveness. Because her husband is a 'man' who may share the image of 'women' above, she had a low level of self-esteem: 'sexual activities ... actually, I feel inferior even with my husband. Well, he is being very nice to me, but ...'

Because lymphoedema is a side effect of breast surgery, which gives such a sense of inferiority, the participant has a low level of self-esteem. Lymphoedema may remind the participants that they are not 'normal' (Goffman 1963), yet 'whenever looking at this [hand swelling], I feel I am still sick [even after five years have passed after the surgery]' (Pilot, Mrs.U). Subsequently, some participants felt that the lymphoedema makes them feel inferior and they wished to be 'normal' as a means to an end: 'if there is any possibility to cure it [lymphoedema], for example, by surgery. If I am told it curable by surgery in the future, I will definitely do it. I don't really bear lymph, lymphoedema' (S, Group 2).

In summary, perception of lymphoedema seems to have something to do not only with information giving, but also with how participants evaluated their experiences of BC overall. Participants who had spiritual gains as a result of BC are more likely to accept lymphoedema than those who did not.

Theme 2: Interaction with society and social support for lymphoedema

Although most participants experienced physical constraints (Theme 1 thematic analysis), they were provided with only a little social support, and tended to have a small support network. The relationship between help-seeking behaviour and social disclosure was seen in the transcripts.

Some participants did not disclose their illness to others, even those who spent time together with the participants. Some participants accounted for non-disclosure as an attempt to maintain 'normality' and self-esteem (Johansson et al. 2003; Radina et al. 2001):

> I only talked about [my illness] to closer friends whom I spend most of time with, but for the others I did not say anything and go to trips and stuff together as usual. Of course, [those who do not know about my illness] I don't hear a word of consideration from them, but it is necessary for me.
>
> (S, Group1)

This attempt was also seen as a result of uncomfortable social norms and social interactions when women disclose BC. First, the transcripts revealed our society's norm, 'cancer is still equal to death' (H, Group 1) and 'I felt as if I were a loser because of the cancer'(S, Group2).

Not only cancer patients, but also patients with any disease and disabilities, could be labelled as 'a loser', which is inappropriate labelling. 'A loser' does not mean that you will be unable to accomplish something in *your* life. Rather the word means that you will be a loser in *our* society. Literature in the West has often reported that disclosure of disease is both physically and psychologically beneficial (Butler et al. 1999), but this is not always the case (Greenberg and Stone 1992).

Second, the transcripts revealed that breast surgery had more difficult meaning than surgery for other life threatening diseases: 'I don't hesitate to tell about the colorectal cancer to my neighbours ... but still now, I cannot tell about the breast cancer' (H, Group2); '[I did not tell] even to my husband's siblings ... only to my sisters'(S, Group2); 'I was also asked if I had the whole breast removed ... I myself didn't want to tell it at all ("of course") ... ("you felt unpleasant, didn't you?") That's right' (U, Pilot group).

Encountering these negative responses above seems to determine how patients behave in their own community (Goffman 1963). There were differences between women who did not encounter others' negative responses and those who did; the former were more likely to play the role of patient, whereas the latter were less likely to do it in their community. For example, one woman described how, if she did not help with her child's club activity (carrying tables), other mothers would speak ill of her behind her back. To avoid this criticism she was feeling that she would need to tell why she could not help carrying things to the other mothers: ‘I cannot come to help [set on a table for table tennis]. If I don’t tell about my illness, the other people in the school will assume that I just don’t want to help them’ (T, Group 2). To meet others’ expectations – do your job for your children, and be cooperative – the woman was wondering if she could tell them about her lymphoedema and the causes. The woman seemed to anticipate that the other mothers would understand her illness as an ordinary illness. She continued ‘besides, it will be quite encouraging if there is anybody in the meeting who knows any cancer patients [any friends with cancer]’. She did not mind playing the role of a patient in the meeting.

However, another woman in the same focus group, encountering neighbours’ embarrassment about her illness and insensitive questions to her son, discouraged social disclosure: ‘I cannot say it ... [because] my child was asked like “how’s the family? How is it like to be a child of a cancer patient?” ... I don’t want to show my weakness to others’ (H, Group2). Also, she refused to play a situated self of ‘patient’ in her small community: ‘because of my pride, you see, I don’t want to be looked at as a cancer patient by our neighbours’ (H, Group2). The ‘pride’ the woman mentioned could be interpreted as ‘face’ as Goffman (1963) proposed.

In addition, the pre-conceptions about the disease in our society may affect patients’ perceptions, making a distinction between people with cancer and those without, and between women without breasts and those with. This sometimes leads to difficulty in building an intimate relationship with ‘healthy’ others. Again, women had anticipated that close others would understand their feelings, but some women felt desperate when they confided their worries and fears to others who had already known about their illness: ‘even the sister who took care of me and talked about a lot of things to each other do not understand my feelings’ (T, Group2).

Another woman said:

> People around me ... nobody can understand, well, cannot understand my feelings. I guess the patients do it, but my friends cannot ... when I asked him [her husband] for advice about details of my illness, he did not seem to understand much.
>
> (H, Group1)

Consequently, the women feel reluctance both when they disclose BC (Goffman 1963; Johansson et al. 2003) and when they seek help from people with whom they cannot share their feelings as they would wish.

On the other hand, not telling family members about BC has different underlying reasons from those described above, even though women still perceive themselves from significant others' viewpoints. Women feeling emotional ties with immediate family members did not want to cause them to be worried. Women often took into account family members' situations and emotions: 'my father has developed diabetes and cannot move freely. I did not want to worry my mother even more, so I could not say about my illness easily' (K, Group1); 'I didn't tell my mother because I couldn't dare making her worry about me. She is living alone and is quite old now'(S, Group2).

By the same token, participants, as mothers, had difficulty in telling younger children their illness: 'I did [tell] to my daughter, but I did not do my son because he was only in elementary school' (T, Group1); 'I didn't tell my children about my cancer because they are still in a primary school and in lower secondary school. I couldn't tell; they were adolescent' (S, Group2).

Regarding lymphoedema, one woman expressed her reluctance when she had imagined her husband's reactions and the consequences if she told him about her arm complications; she imagined that if she did not take responsibility for her work, her husband must take it instead. She also imagined if she said she was unwell her husband would be able to do something for her, but feelings of guilt prevented her to seek any help from her husband.

> My family was very worried about me from before the operation, and I didn't want them to worry about me more ... I knew that if I said that I was not in good condition, my husband or others absolutely would help me out. Things related to my job ... [If I asked for help] I would give them some burdens relating not only my body, but also work, so I did not want to put more load ... well rather I felt sorry for my husband.
>
> (T, Group2)

Feelings of guilt were also seen in another woman's discourse, undergoing breast reconstruction surgery. She needed to ask her colleagues to help lifting and carrying things not simply because of her swollen arm. She felt sorry for the colleague rather than appreciation:

> I have a very hard time when I have to ask people to carry heavy stuff as I could not carry it ... In my case, I had my abdomen cut and the muscle there has been pulled up, so it is really hard to lift up stuff. I feel sorry for asking others to do.
>
> (K, Group1)

Why did the participants feel guilt? Within their families, women appear to have believed that being their normal social self was the first priority. As a result, they did not seek help from family members. However, this belief was perceived later as endurance and sacrifice of the personal self: 'having finished bringing up my child, I'm trying to live cheerfully, cherishing those remaining years' (M, Pilot group); 'I have left myself behind others, so from now on I would like to do what I want, freely' (T, Group1); 'I suppressed myself for a long time in my families, so I try to change a bit myself. I suppose what I want is probably to be accepted for what I am' (I, Group2). These indicate that the women had needed to become the situated selves of patients within their families.

Were there any other places for the women to become the situated selves (patients with BC and lymphoedema)? Some discourses showed situations where taking the role of patients was permitted among people experiencing BC: 'I am meeting up with them [friends with breast cancer], we all cry with looking back on our experiences. After all, I am confronting myself there'(H, Group2). This lends support to Goffman's (1963) theory - people with social stigma tended to make a homogeneous group sharing a similar stigma. This tendency - patients, having been embarrassed, tend to participate in 'mutual' self-help groups - has also been reported in the USA (Davison et al. 2000).

Additionally, participants expected to be able to play a patient role in front of surgeons. When participants did not become patients fully, they were reluctant to seek for further physical and emotional help from surgeons, as the thematic analysis has shown. When participants could become patients in front of surgeons, they tended to appreciate surgeons' efforts: 'my doctor (and a nurse) has been kind from the beginning and I would like to leave everything to them till I die (S, Group1); 'I think that I met good doctors. It was fortune (laugh)' (K, Group 1).

In summary, when patients encountered the negative responses from others - including surgeons - their self-esteem seemed to decrease. In this case, social disclosure and help-seeking behaviours were minimised or not performed. Consequently, little social support for lymphoedema was provided. In addition, participants tended to take into account families' viewpoint so that they were less likely to seek social support, and more likely to endure their situated selves (patients).

DISCUSSION AND CONCLUSIONS

The main objectives of this qualitative study were to explore feelings about lymphoedema among female BC patients in Japan and interpret how women's feelings and perceptions were formed in SI contexts. To attain each objective, a dual analytic approach was applied - thematic analysis and conceptual analysis.

First, thematic analysis extracted several issues on lymphoedema: physical constraints, perceptions (acceptance and burden) of several physical constraints, negative emotional responses to inconsiderate attitudes of surgeons, little practical and informational support, and scepticism about the efficacy of lymphoedema treatment.

Next, conceptual analysis revealed several important cognitive and emotional processes in terms of adjustment to lymphoedema, which were closely related to experiences of BC. When women perceived that they gained proactive attitudes, intimate friendship with friends, appreciation or gratitude following BC, they tended to have a high level of self-esteem, and perceive lymphoedema as acceptable. In this evaluation, internal comparison is more important than the presence of significant others. On the contrary, when women evaluated their experiences of BC from significant others' points of view, they tended to have low self-esteem. The women tended to feel inferiority.

Additionally, a relationship between help-seeking behaviour and social disclosure was found. First, women often decided not to report their illness to others in order to maintain perceived normality (Radina et al. 2001) and 'face' (Goffman 1963) because BC is a social stigma. Lymphoedema caused by breast surgery is also a social stigma. Additionally, reluctance was also seen when women could not share their feelings with close others. Within their families, women tended to be reluctant to disclose their illness and to seek help from loved ones because women perceived their first responsibility as being social selves (wives, mothers, and daughters). Consequently, the women were provided with little social support. Under these circumstances, women sought emotional ties with friends with BC and surgeons as patients.

Since SI is a cognition focused theory, as reported in Chapter 5, the findings from the conceptual analysis may be described in terms of cognitive processes. In terms of BC, emotion-focused coping (Lazarus and Folkman 1984) was seen; most participants found meaning of life through experiences of BC, which is quite similar to findings in the West (Fife 1995; Schwarzer and Knoll 2003; Steger et al. 2006; Taylor 1983).

However, neither searching for the causality of BC, nor 'thinking positive' (Wilkinson and Kitzinger 2000) were found. All women in this study felt as if they had fallen into an abyss after the cancer diagnosis, which led to painful changes in their philosophy in life. Because of this, the women perceived that the meaning of life was 'given' rather than sought. Although the Japanese, in general, do not have any religious beliefs, the women may feel something precious was given by the creature with the absolute power; people believing a specific religion cited God. This religion-unrelated spirituality has been reported by the WHO QoL study in Japan (Tazaki et al. 2002). The association between spirituality and well-being has been not as yet widely investigated in Japan, but this may be indirectly associated with well-being (Emmons et al. 2003).

Other important findings in this study were social influences on women's emotions and perceptions, and the influences restricting women's help-seeking behaviours (Tangney et al. 1996) and disease disclosures. First, most women in this study felt obliged to play their social roles, being influenced by Confucianism (Kim et al. 1999). Because women attempted to meet families' and social expectations, they felt guilty when they were offered help or sought help (Baumeister et al. 1994). The feelings of guilt have not been reported in studies on lymphoedema in the USA (Johansson et al. 2003; Radina et al. 2001); women in the USA studies perceived that being offered help deprived them of independence.

Second, most women wished to share their emotional feelings with others, especially those to whom they felt close. Due to the social norms and irrational responses from others, some women seemed to have poor psychological states (Pennebaker et al. 2001). On the contrary, women who experienced the social norms but were not influenced by them were more likely to disclose their BC and to feel more optimistic (e.g. emotional and practical support might be provided) than those who were influenced by them (Henderson et al. 2002).

In summary, experiences of lymphoedema were evaluated by either internal or significant others' views. Less social support provision was related to BC disease disclosure and help-seeking behaviour. These behaviours were inhibited by social encounters.

On methodology, although the findings captured several issues on lymphoedema and BC there are several limitations in this study. First, the sample size was too small to collect wider opinions. However, more data collection was not feasible since there was no larger potential pool of participants; eighteen women with swelling who provided their contact details were all recruited. Next, it is worthwhile to note the advantage of FGDs over individual face-to-face interviews in this study. For example, as reported in the conceptual analysis (theme one), one woman raised sexual issues. If individual interviews had been used, such important issues would have not been acknowleged; this is because sexual issues are still taboo for middle or older aged women to talk about to a stranger. In the less formal atmosphere of the focus group, it was easier for the women to talk about these issues. The findings will be used in the development of a questionnaire which will sample a much larger number of women.

Relating to the sampling, the demographics of the sample might be skewed, since participants were selected from two self-help groups based on Chiba and Kanagawa Prefectures, adjacent to the capital city, Tokyo. Women living in these two prefectures are less likely to take up paid jobs than women living in other areas (The Ministry of Health, Labour and Welfare 2005), which means husbands' income is relatively high. The descriptive analysis in the survey study, as reported in Chapter 4, also showed that participants' household income was relatively high. Therefore, it is uncertain how much the findings in this study reflect experiences of lymphoedema among Japanese women in general. However, it is not the aim of FGDs to search for representativeness, but to identify and highlight themes and issues for further exploration.

Although there are shortcomings in this study, it is worth while to consider the next study. Since the aim of present research programme is to design a new measure, based on the findings of conceptual analysis, psycho-social scales will be added to the questionnaire that was used in the first survey study (see Appendix 4.5). The main six findings will be used to construct questions on: perceptions of lymphoedema, the meaning of life, social norms, feelings about social norms, help seeking behaviour, and needs dissatisfaction. After the new scales are designed, small pilot studies will be conducted to check wording and phrasing. Validity and reliability testing will be performed by administering both the new questionnaire and the standardised QoL questionnaire (WHO QoL-BREF) Japanese versions to a larger sample in

Japan and by analysis of the internal structure of the new questionnaire.

7. The Quantitative Study: the Psycho-social Discomfort Scales

SUMMARY OF THE QUANTITATIVE STUDY

In this chapter, the process of development of a new scale is first presented; based on the findings of the conceptual analysis of the qualitative study (Chapter 6), 30 questions were constructed. These questions covered six important issues including perceptions of lymphoedema, the meaning of life, social norms, feelings about social norms, help-seeking behaviour, and needs/(dis)satisfactions.

Second, two pilot studies are reported; since some questions on social norms were quite sensitive, social desirability response bias was taken into account, and an indirect question format was considered. On the other hand, it was uncertain whether an indirect format would be adequate to explore personal experiences. Thus, it was decided to conduct a small pilot study (study one) in order to check the comprehensibility of the questions and which question formats had personal meanings among Japanese women without breast cancer (BC). As a result, some necessary amendments were made. Next, another small online pilot study (study two) was conducted among Japanese BC patients with lymphoedema in order to explore the comprehensibility of the revised questions.

Finally, a cross-sectional survey study (study three) with a larger sample is reported; the underlying structure of the new measure, internal consistency, and correlation with a standardised Quality of Life (QoL) questionnaire are reported. Criterion validity is also reported. All the variables which were statistically significant in the first quantitative study (Chapter 4) were included as independent variables.

STUDY ONE: FACE VALIDITY EXAMINATION ONE

Method

Description of the new measure

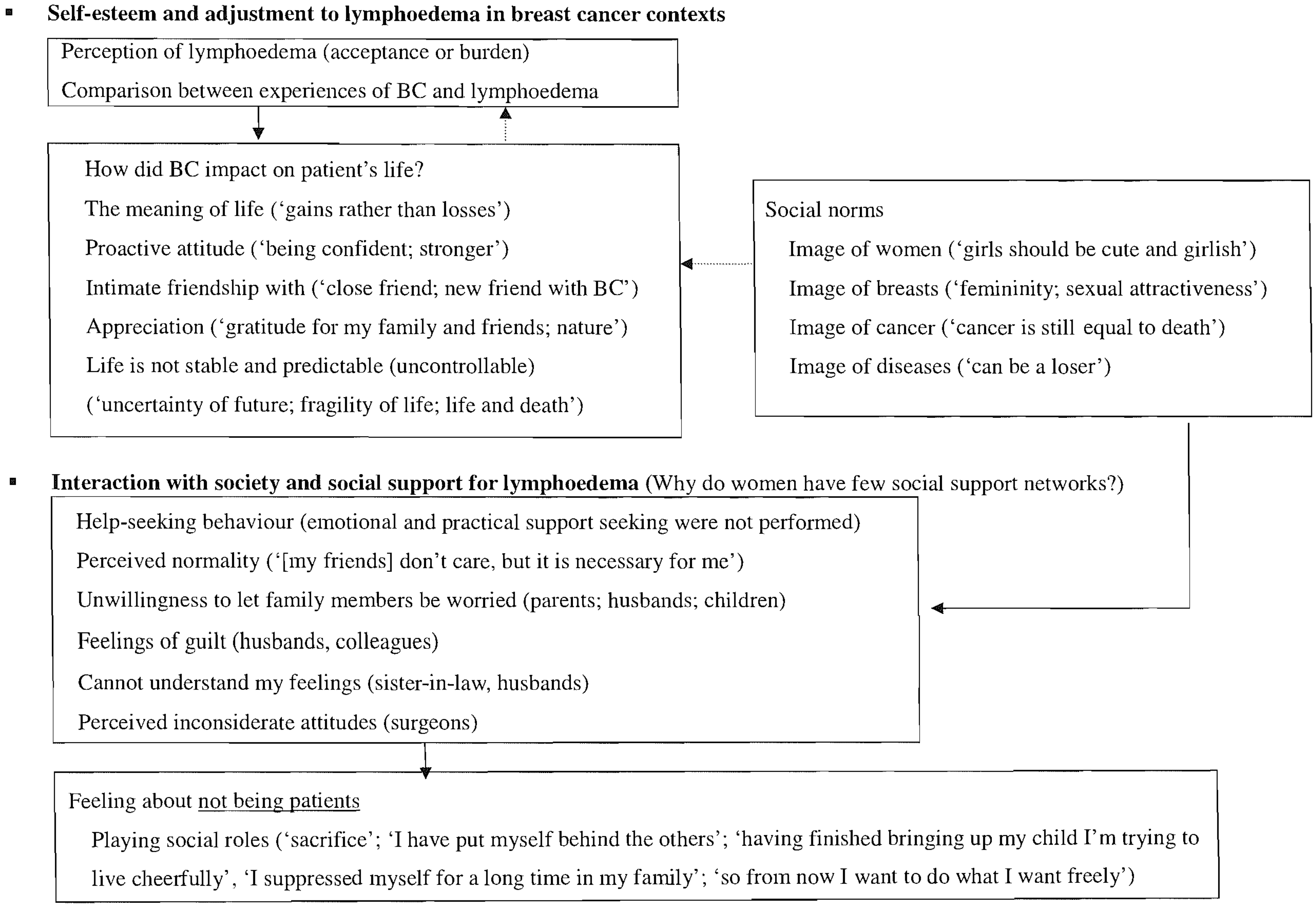
In order to construct questions in Japanese, the findings of the conceptual analysis (reported in Chapter 6) were closely examined; Figure 7.1 shows cognitive or emotional processes of experiences of lymphoedema and BC. Participants' terminology in the focus group discussions were used wherever appropriate. At least two questions - negatively and positively worded statements - were included for each topic. Consequently 30 questions in a direct format (version A) were first constructed.

Questions on social norms were considered to be quite sensitive to ask BC patients. The type of question - direct (e.g. ‘do you think’) or indirect (e.g. ‘it is believed’ or ‘others think’) - was carefully discussed with the supervisors because there is evidence that Japanese people tend to choose their responses according to social desirability; it has also been reported that Japanese people tend to choose mid-points when five-point (Zax and Takahashi 1967) and seven-point scales (Chen et al. 1995) are applied in studies. To minimise this effect, Fisher (1993), reporting study findings in the USA, suggested indirect question formats rather than direct formats. However, since few studies have investigated the relationships in Japan, it was uncertain which type of question would be the best to reduce social desirability effects among the Japanese sample.

A key issue was whether or not indirect questions could convey personal meanings, which were essential in order to explore personal experiences in the present study. Since there was no evidence either way, it was decided to carry out a small pilot study to explore which format was appropriate for Japanese women and, to some extent, which format could best convey personal meanings.

Finally, indirect questions (version B) were also constructed corresponding to the 30 questions in the direct format. 30 questions in each version were randomly listed by Excel (RAND function). Five-point Likert scales were constructed; 1 was ‘strongly agree’, 2 was ‘agree’, 3 was ‘neither’, 4 was ‘disagree’, and 5 was ‘strongly disagree’ (see Appendix 7.1 for all the questions).

Figure 7.1 *Cognitive and Emotional Processes of Experiences of Breast Cancer and Lymphoedema*



- **Self-esteem and adjustment to lymphoedema in breast cancer contexts**

Perception of lymphoedema (acceptance or burden)
Comparison between experiences of BC and lymphoedema

How did BC impact on patient's life?
The meaning of life ('gains rather than losses')
Proactive attitude ('being confident; stronger')
Intimate friendship with ('close friend; new friend with BC')
Appreciation ('gratitude for my family and friends; nature')
Life is not stable and predictable (uncontrollable)
('uncertainty of future; fragility of life; life and death')

Social norms
Image of women ('girls should be cute and girlish')
Image of breasts ('femininity; sexual attractiveness')
Image of cancer ('cancer is still equal to death')
Image of diseases ('can be a loser')

- **Interaction with society and social support for lymphoedema** (Why do women have few social support networks?)

Help-seeking behaviour (emotional and practical support seeking were not performed)
Perceived normality ('[my friends] don't care, but it is necessary for me')
Unwillingness to let family members be worried (parents; husbands; children)
Feelings of guilt (husbands, colleagues)
Cannot understand my feelings (sister-in-law, husbands)
Perceived inconsiderate attitudes (surgeons)

Feeling about <u>not being patients</u>
Playing social roles ('sacrifice'; 'I have put myself behind the others'; 'having finished bringing up my child I'm trying to live cheerfully', 'I suppressed myself for a long time in my family'; 'so from now I want to do what I want freely')

Participants

Nine female Japanese speakers who lived in Japan participated in the first pilot study. Their mean age was 36.8 years (range 31 years to 39 years).

Procedure

After ethics approval was obtained from the School of Psychology, University of Southampton, convenience sampling was applied in order to recruit potential participants in Japan. In May 2006, ten Japanese women living in Japan and known to the author were approached by email with information letters (see Appendix 7.2); the women were asked if they would participate in telephone interviews, at dates and times convenient to them.

Nine women replied with details of their available days and times for telephone interviews and convenient appointments were made. On the day of the telephone interviews, the purposes and nature of this study were explained verbally, and verbal consents were obtained from all participants before the start of interviews.

First, participants were briefly told what secondary lymphoedema was and the associations between breast surgery, radiotherapy and the onset of lymphoedema. After asking demographic questions that had been used previously (see Chapter 4), participants were asked to reply whether or not they could understand the statements using ‘yes’ or ‘no’ instead of the five-point scales; each statement was read out one by one. When necessary, the author asked questions to clarify why wording and phrasing were not appropriate, and why the participants did not spontaneously respond to the statements. Finally, at the end of the interviews, participants were asked which versions - direct and indirect - had a more personal meaning for themselves. The interviews lasted around one hour.

Results

Table 7.1 presents participants’ demographics.

Table 7.1 *Participants' Demographics (Study One)*

Variables	n
Marital status	
Single	3
Married	6
Children	
No	3
Yes	6
Education levels	
College	1
University	8
Paid-work	
Yes	7
No	2
Income	
Employee at LLC that goes public at the stock market	4
Employee at LLC that does not go public at the stock market	3
Other	1
Unknown	1

Note. LLC = limited liability companies

Overall, the participants tended to think about whether or not the statements were appropriate by using their common sense, so if they came across some statements that were opposed to their sense (e.g. 'cancer is curable' or 'lymphoedema is more serious than breast cancer') they did not respond spontaneously. This often happened, especially in version B.

Comments were categorised into four types: inappropriate words for cancer patients, non-understandable words and phrases, inappropriate words for females, and grammatical errors. These problems were equally reported in versions A and B.

First, some participants responded negatively to some words, such as 'incurable', 'a loser', and 'the rest of life', since they sounded very depressive. Second, most participants did not understand several words or sentences: Q5 'immediate family', Q7 '*makegumi*' [a loser], Q21 'acquired (a sense of gratitude)', Q23 'I have learnt that I can predict what will happen in my future.' Q24 'I have no future plans in my mind', and Q29 'I feel lymphoedema is something I suffered when I did not have to'. Third, a couple of participants pointed out the word '*sumanai*' [guilty] in Japanese may not be appropriate to describe females' feelings. Finally some participants pointed out minor grammatical errors in Japanese; in Q15 version B 'it is noticed that nature around women with breast cancer is splendid' and Q28 version B 'it is believed women with breast cancer have lost something more than gained.'

Regarding the personal meanings of version B, most participants felt the questions sounded too general. Their responses were divided into three types: totally impersonal (n = 5), partially personal (n = 2), and 3 totally personal (n = 2). Table 7.2 shows a summary of participants' comments.

Table 7.2 *A Summary of Participants' Comments on the Indirect Format*

Participant	Comments
A	I think you did not ask about each respondent's case. All questions sounded too general. I am not sure whom you were asking about.
B	I was feeling you asked about [breast cancer] patients in general.
C	Because you did not say 'I' or 'my', all questions sounded as if you were asking about patients in general, not 'myself'. I am not a patient, though. Also, it is difficult for me to answer the questions in the latter part.
D	I think patients are always concerned about their illness. Even though you asked indirectly, respondents will answer about their own feelings and thoughts, I guess.
E	All questions sound too general. [If I assume myself a patient], I would feel a distance.
F	I think you asked about patients in general, not about myself [patients]. If you wrote an instruction like 'I will ask about you' ... um, but in that case, some questions sound personal, but the other sound impersonal, still.
G	I felt in the previous part [version A] you were worried about myself [if I were a patient]. But I was not sure whom you asked about [in version B]. Also, indirect questioning is difficult to answer. I cried 'ask me more directly!' in my mind.

Table 7.2 (continued)

Participant	Comments
H	I assume patients think themselves as victims, this is not a good word, though, so respondents will think you ask about themselves. But depending on questions, they may think about patients ingeneral.
I	As I assume patients think of themselves as victims, respondents will reflect their feelings in their answers. I don't think they will answer about patients in general.

Conclusions

Taking the participants' comments into consideration, the necessary amendments were made following discussions with supervisors.

First, on the inappropriate words for cancer patients, the sentences containing the two words, such as 'incurable' and 'the rest of life' were changed; on Q2 ('I think lymphoedema is incurable for the rest of my life'), the new sentence 'I think my lymphoedema will be cured someday' was suggested, since this sounded more positive and could explore whether or not patients were hopeful about their disease. On Q16 ('I would like to spend the rest of my life pleasantly'), the new sentence 'I would like to spend my future life pleasantly' was suggested. Additionally, after reviewing the other questions, Q10 ('I have lost more than gained') was changed to an expression in a positive way: 'I have gained more than I have lost'.

Second, regarding unclear words, on Q7 ('I think others believe that people with disease can be a loser in the society'), one participant commented that 'a loser' was not appropriate for cancer patients, and most participants commented that they could not understand the meaning itself. It is assumed that since a relatively new Japanese word was used, most participants might not think that the word had a definite meaning. Thus, the Japanese word '*makegumi*' was changed to '*make*' that was equivalent to a 'loser'. Carefully considering the appropriateness of the word and sentence for cancer patients, it was decided to retain the statements, since this was the exact participants' discourse in the focus group discussions, and it was a key to explore how social factors would affect patients' behaviours. On Q5 ('I feel fear to disclose my breast cancer to people other than immediate family), the word 'immediate family' seemed difficult to define. The sentence was initially constructed to see whether or not people would distinguish between their own family and others when disclosing their illness. So, the more simple wording 'people other than my family' was suggested. On Q21 ('I have acquired a sense of gratitude'), the verb 'acquired' in Japanese did not fit in the sentence. So simpler verb was suggested; 'I have a sense of gratitude.' On Q24 ('I have no future plans in my mind'), the statement was originally constructed to explore whether or not women with BC were motivated to conduct something pleasant (self-determined goals or activities) for themselves. A more detailed statement was suggested: 'I have no idea what I want to do in the near future'.

Next, two statements seemed to lead to misunderstanding: Q23 ('I have learnt that I can predict what will happen in my future.') and Q29 ('I feel lymphoedema is something I have suffered that I did not have to.') On Q23, some participants imagined fortune telling immediately after they listened to Q23, which was unexpected. This indicated that this statement was too general and related to neither BC nor lymphoedema. The additional phrase 'through my experiences of BC' was suggested. On Q29, most participants thought the question was not direct. A more direct expression was suggested: 'I feel I should not have had to develop lymphoedema'.

Regarding the inappropriate word for women, on Q27 ('I feel guilty when I ask for help from people.'), it was suggested that the word '*sumanai*' which is equivalent to guilty, was changed to '*moushiwakenai*'. This may sound softer than '*sumanai*' in Japanese.

Next, regarding grammatical errors in Japanese, on Q15 version B ('it is noticed that nature around women with breast cancer is splendid') and Q28 version B ('it is believed women with breast cancer have lost something more than gained.') these sentences were corrected by the participants' suggestions.

Finally, regarding the personal meanings of version B, most participants felt the questions in the version B were impersonal, so exclusion of this version was suggested in the next pilot study amongst BC patients.

During the process of revision, it was found that questions about perceived attitudes of surgeons (doctor-in-charge) and perceptions of lymphoedema disclosure were not covered in the original questionnaire. Therefore, four additional questions were added: 'I think my doctor-in-charge understands my feelings well.', 'I have been given reassurance by my doctor-in-charge of breast cancer.', 'I feel afraid to disclose lymphoedema to people other than my family.', and 'I feel comfortable to disclose lymphoedema to people.'

STUDY TWO: FACE VALIDITY EXAMINATION TWO

Method

Participants

Twelve female BC patients with lymphoedema in two web-based self-help groups voluntarily participated in this study. The mean age was 48.5 years (age ranged between 37 and 58 years).

Procedure: preliminary checking for the questionnaire for clarity and ease of use

In order to assess wording, phrasing and ease of use, it was planned to recruit BC patients with lymphoedema from lymphoedema self-help groups, and two lymphoedema self-help groups in Japan were approached by letters including a supervisor's letter; one was based in Tokyo, which had cooperated with study one in the first quantitative study (Chapter 4). The other was based in Osaka. Second, the group co-ordinators were contacted by either phone or email in order to explain the proposed study. The co-ordinator in Tokyo replied via email that the group was not interested in participation. The co-ordinator in Osaka was interested in participation so a meeting was held in Osaka. After a month, positive responses were not obtained from the group. Since there were only the two lymphoedema groups in Japan, the initial plan - selecting BC patients with lymphoedema - was not feasible.

Alternatively, in order to widely recruit eligible patients, web-based BC groups were selected: if the author sent a message about this study to a communication board in the web-based BC groups, members with lymphoedema would access the site where the questionnaire was located. This method was thought to be useful since it was not necessary to identify members with lymphoedema in BC groups beforehand; this would have been very difficult since BC self-help groups usually do not have information about which individuals had developed lymphoedema or post-operative arm complications.

Following ethics approval from the School of Psychology, an information letter (see Appendix 7.3), the demographic questions used in the first survey, the 34 questions that were randomly listed using Excel (RAND function), and one open-ended question (see Appendix 7.4) were created in PsychoSurvey in the School. PsychoSurvey is a program that provides online survey tools. Once the survey is uploaded on the web, people who know the address can freely access the site. The data are automatically stored with respondents' IP addresses in the server in the School. The design and layout were created in a similar way to those used in the paper questionnaire. Next, the author applied for membership of web-based BC self-help groups.

In July 2006, the author joined the two groups as a member, and introduced herself together with a casual advertisement for the present study on the communication board, with details of where the questionnaire could be located. Between July and August 2006, the questionnaire was uploaded on the Web. On the first page of the online questionnaire the nature of this study was described, including mention that participation was on a voluntary basis and that personal information would remain confidential and anonymous. It was also mentioned that submitting a completed questionnaire was taken as evidence that participants gave consent for participation in this study.

A total of 17 identification numbers were recorded, which indicates these people reached the questionnaires after reading the introductory page. Four people looked through all the questions without responding. Two people looked through the questionnaire without responding, but returned later to complete the questionnaire. One person seemed to complete the questionnaire twice, since the same IP address was recorded. Thus, the data which the person filled in on the second occasion were excluded. A total of 12 people's data were eligible.

Analysis

Descriptive analysis was conducted to detect the frequency of missing data, and the free texts were summarised.

Results

Participants' demographics are presented in Table 7.3.

There were a few missing data; two participants did not answer 17 questions between Q18 and Q34.

Five participants wrote their feedback in a free-text format. Three participants mentioned that they could understand all the questions easily, and answer them smoothly. However, two participants mentioned that they had difficulty in choosing the response on the five-point scales, and in understanding Q24 ('I feel I should not have had to develop lymphoedema.'). All participants' comments are presented in Table 7.4.

Table 7.3 *Participants' Demographics (Study Two)*

Variables	n
Marital status	
Single	3
Married	7
Divorced	1
Children	
Yes	6
No	6
Levels of education	
High school	3
College	3
University	4
Paid-work	
Yes	7
No	3
Occupation	
Directors at LLC2	1
Directors at LLC2	3
Self-management	5

Note. LLC2 = Limited liability companies that goes public at stock market.

Table 7.4 *A Summary of the Participants' Comments*

Variables	Comments
Overall	I did not have any difficulties in answering the question. The questions were understandable, so I did not have any problems. In addition, there were no difficult questions to answer. I could finish it easily. I think the questions were understandable. I was not sure what the five-points meant.
Q24	I could not understand what the statement actually meant.

Conclusions

Overall, most participants appeared to understand the wording and phrasing in the questionnaire. However, according to the free-text, possible amendments were suggested.

First, regarding the five-point scale, one participant, aged 58 years old, commented that she had wondered how to choose the response. It was decided to add supplementary explanations at the beginning of the new scale; for example, following the statement (I will ask how you are feeling at the present about the issues below), 'please choose only one answer which best describes your feelings. If you feel that you 'strongly agree' with the statement below, please circle 1. If you feel that you 'neither agree nor disagree' with the statement below, please circle 3 and so on'.

In relation to Q24 ('I feel I should not have had to develop lymphoedema.'), even though this question had been revised as a result of study one, one participant had difficulty in understanding this question. This may be because, if patients were not given information about the risks of lymphoedema by doctors, they would choose 'agree' and, if patients were given information, they would choose 'disagree' and question the statement (e.g. 'the question is not sensible because I was told that by my doctor'). A more direct question was devised: 'I feel that lymphoedema was avoidable.'

As reported, the initial recruitment plan needed to change. For the next study, a sample of around 550 BC patients was required; according to the results of the first survey study (outlined in Chapter 4), approximately 60 per cent of group members were estimated to have post-operative arm complications, and a response rate of between 40 and 50 per cent was expected. However, the response rate of the next study could be lower, since BC patients would be asked to fill in the longer questionnaire and another questionnaire in order to investigate psychometric properties. To perform statistical analysis (factor analysis) Pett et al. (2003) suggested five times items, and Nunnally and Bernstein (1967) suggested 10 times items. Thus, since the new measure had 34 items, the sample size should be somewhere between 170 and 340.

To maximise the response rate, the provision of an incentive was suggested. Additionally, it was suggested that BC patients without lymphoedema be encouraged to respond to the new measure, since there were only seven lymphoedema-related questions that they could not answer. To do this, a scale modification was suggested; on the lymphoedema-related questions, a new choice '6. I have not developed lymphoedema' was added.

STUDY THREE: VALIDITY AND RELIABILITY INVESTIGATION

Method

Procedure

In June 2006, 33 non hospital-based BC self-help groups in Japan were selected from a list containing information of the name of the group, coordinator and contact details, and group coordinators were contacted by letters. Eight groups responded positively, so the proposed procedures and the drafted materials were sent to them by email and verbally explained by phone a week later (since the pilot studies had not yet been completed, it was explained that the new questionnaire was subject to change). Six groups agreed to participate in the study by the end of August, and one group agreed to do so in November 2006; this group was, in fact, a hospital-based group, and they sought medical ethics approval in the hospital which was granted by mid-November.

Between September 2006 and January 2007, participants were recruited from the seven BC self-help groups across Japan (see Appendix 7.5 for the study sites). A questionnaire package including an information letter (see Appendix 7.6), the revised questionnaire (see Appendix 7.7) and World Health Organisation Quality of Life Questionnaire (WHOQoL-BREF) Japanese version (see English version in Appendix 7.8), a correspondence sheet (Appendix 7.9), a stamped envelope, and letters from group co-ordinators, were distributed to members via co-ordinators; four groups mailed the package to members, two groups distributed them in a meeting, and one group distributed them in the hospital.

Five groups were asked to return the completed questionnaires to the co-ordinator's home, and two groups were asked to do so to the National Research Institute of Child and Development in Tokyo where the author was working. The co-ordinators explained the relationships between the institution and the author when they distributed the questionnaire packages (please see in Appendix 7.10 for logistics).

In the information letter, the nature and purpose of the study were described and assurances regarding confidentiality and anonymity were provided. In addition, it was mentioned that returning a completed questionnaire was taken as evidence that participants gave consent for participation in this study. For people who completed the two questionnaires, an incentive (a 500 Yen book token, equivalent to 4US dollars) was offered; those people were asked to fill in their contact details when they requested the incentive.

A total of 620 questionnaire packages were distributed to members including patients other than BC (n =12), and 301 members returned the questionnaires. During the data entry process, it was found that many participants who reported post-operative arm complications did not respond to the lymphoedema items. This happened because of the inadequate instructions and choice in the questionnaire; since most participants seemed not to perceive their arm symptoms as an early sign of lymphoedema, they tended to skip the lymphoedema items. To follow up the non-respondents, a short questionnaire with the relevant seven items was mailed to participants who had provided contact details and were eligible for book tokens; approval from each group coordinator was obtained beforehand.

During the data screening process, one participant was found to have developed ovarian cancer so her data were excluded (response rate of 49.4 % from BC patients). Ten participants reported post-operative arm complications on the different arm from the operated side, so these participants were not considered to have developed lymphoedema, and their data were treated as missing values on the lymphoedema-related variables. Five participants with stage IV BC were also excluded (n = 295).

42 participants returned the follow-up questionnaires, and 38 were eligible. These responses were included in the analysis.

WHO QoL-BREF Japanese version

As reported in Chapter 1, the WHO QoL-BREF is a generic QoL questionnaire, and consists of 26 items; two items measure overall QoL, six items measure the physical domain (e.g. limitations in daily activities, energy for every day life, and sleep), six items measure the psychological domain (e.g. enjoyment, meaningful life, body appearance, and mood disturbance), three items measure the social relationships domain (e.g. personal relationships, sexuality, and support from friends) and eight items measure the environmental domain (e.g. safety, availability of information, opportunities of leisure, and living environment). High scores indicate good QoL.

To investigate the convergent and divergent validity of the psycho-social discomfort scale, a comparative measure should be well validated or standardised in the study site, Japan. As reported in Chapter 1, there is little evidence about how well cancer or BC specific QoL measure have been validated in Japan; only the Functional Assessment of Cancer Therapy (FACT-G; Cella et al. 1993), and Cancer Patients Treated with AntiCancer Drug (QOL ACD; Kurihara et al. 1999) were available. However, the internal consistency of the social domain in the FACT-G, and the psychological domains in the QOLACD were unsatisfactory (Alpha < .60) meaning that they were inappropriate for this study.

In terms of generic measures, WHO QoL-BREF (the WHO QOL group 1998) and the Medical Outcomes Study Health Form (MOS SF-36; Ware and Sherbourne 1992) were standardised in Japan. The reason why the WHO QoL-BREF was chosen over the SF-36 was that the WHO QoL-BREF includes broader concepts of QoL, such as subjective aspects in social and environmental situations, than does the SF-36.

The Japanese version was slightly different from the English version (see Appendix 7.8 for English version); on question 26, the statement in the English version asks about respondents' negative feelings in the last four weeks but, in the Japanese version, the statement asks about negative feelings in the last two weeks. The other items are the same as those in the English version.

Analysis

First, participants' household income was calculated using three tables published by the Japanese Government; direct national tax statistics (National Tax Agency 2006), the tables of national public servants' salaries (National Personnel Authority 2006), and the tables of local public servants' salaries (The Ministry of Internal Affair and Communications 2006). Three variables in the questionnaire, marital status (part I Q3), occupation (part I Q6), and occupation providing livelihood (part I Q7) were also used. These tables and variables were used as follows: if a participant was a housewife without any paid work, and was married, the answer to Q7 should be her husband's occupation. Using one of the three tables that best represented the occupation, each participant's household income was estimated. Then, a new variable 'Income' was created and was dichotomised by the median (3,402,500 Yen), which is approximately 29,000 US Dollars. Descriptive analyses were performed on the demographic and breast cancer treatment variables.

Next, missing value analysis was performed.

Third, the strength of relationships among the 34 items was examined using Pearson's correlation. To explore how many factors were underlying, a principal component analysis initial solution was performed; Eigenvalues greater than 1 were selected. A scree plot was also conducted; as indicated by the scree plot, the number of factors extracted was entered.

Since theoretically the factors were assumed to be somehow correlated, an oblique solution was selected; a principal axis factor analysis (PAA) with promax rotation was performed. Bartlett's Test of Sphericity and the Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO) were examined. Communalities above 0.33 were considered as loaded items on each factor (Tabachnick and Fidell 1996). Additionally, internal consistency was examined by Cronbach's Alpha.

Next, correlations between the summary score of subscales and domains of WHO QOL-BREF were examined using Spearman's R (one-tail test); the correlations were expected to be negative.

On criterion validity, following examination of normality and homogeneity of variance, the mean differences of each factor were examined by bivariate analysis (one-way analysis of variance (ANOVA), or Mann-Whitney U test or Kruskal-Wallis test). Nine research questions were predetermined in order to examine whether mean scores were different between (1) younger age and older ages, (2) patients who perceived information provision at BC diagnosis as insufficient and those who did not, (3) patients who perceived information provision since breast surgery as insufficient and those who did not, (4) patients with stage I, II, and III BC, (5) patients who had undergone conserving surgery or mastectomies, (6) patients who had developed lymphoedema and those who had not, (7) patients who had had loss of strength and those who had not, and (8) patients who had had poor range of motion and those who had not, and (9) patients who had developed lymphoedema more than three years ago and those who had developed it less than three years ago.

Inter-correlations between the subscales, the one-item global score, the physical discomfort scale (following confirmatory factor analysis) were investigated by Spearman's R (one-tail test).

The statistical analyses were performed by the Statistical Package for the Social Sciences (SPSS, version 14.0) and SAS (version 9.1).

Results

Table 7.5 shows participants' characteristics.

Table 7.5 *Participants' Characteristics (baseline n = 295)*

Variables	n (%)
Demographics	
Age (mean years)	57.35 years
Marital status	
Single	42 (14.2)
Married	222 (75.3)
Children	
Yes	224 (75.9)
No	37 (12.5)
Education	
</= High school	130 (44.1)
> High school	133 (45.1)
Paid-work	
Yes	67 (22.7)
No	199 (67.5)
Income (Yen)	
</= 3402500	142 (48.1)
> 3402500	118 (40.0)
Breast cancer treatment	
Stage	
I	87 (29.5)
II	156 (52.9)
III	33 (11.2)

Table 7.5 (continued)

Variables	n (%)
Type of surgery	
Lumpectomy	112 (38.0)
Mastectomy	150 (50.8)
ALND	
Yes	243 (82.4)
No	40 (13.6)
Adjuvant chemotherapy	
Yes	150 (50.8)
No	141 (47.8)
Adjuvant radiotherapy	
Yes	110 (37.3)
No	181 (61.4)
Adjuvant hormone therapy	
Yes	206 (70.3)
No	87 (29.5)
Information at diagnosis	
Perceived sufficient	163 (55.3)
Perceived insufficient	126 (42.7)
Information since surgery	
Perceived sufficient	155 (52.5)
Perceived insufficient	133 (45.1)

Note. ALND = axillary lymph node dissections.
Percentages in the tables are percentages.

Missing value analysis

Missing value analysis revealed that the lymphoedema-related questions (Q2, Q8, Q11, Q24, Q31, Q32, and Q33) had lots of missing data (between 22.7 per cent and 64.1 per cent). In order to perform factor analysis, participants without post-operative arm complications also needed to be included. Additionally, demographics (between 10.2 percent and 12.9 percent) and BC treatment variables (between 2.0 percent and 6.4 e per cent) had missing data. WHO QoL-BREF had also missing data (between 5.1 percent and 8.5 percent).

Structure of the new measure

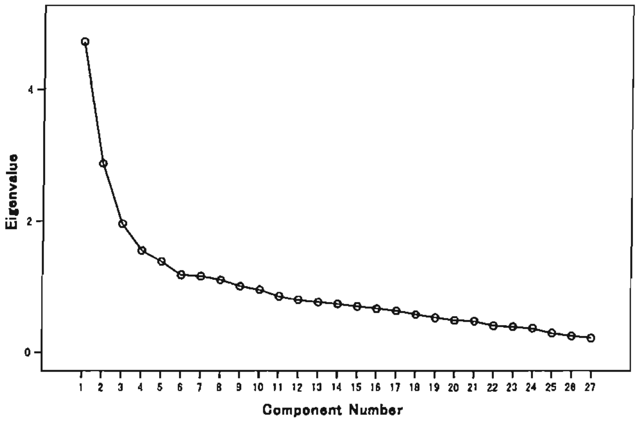
Since there were lots of missing values, factor analysis was performed separately for the 27 items and the lymphoedema-related 7 items. The correlation matrix showed that the items were between 'moderately' and 'highly' correlated to each other (see Appendix 7.11 for the 27 items and Appendix 7.12 for the 7 items).

Factor structure, inter-correlation, and internal consistency on 27 items.

The data from two hundred and fifty-eight BC patients were eligible for the factor analysis.

The scree plot (see Figure 7.2) of principal component initial solution suggested that there were between three and four underlying factors on the 27 items.

Figure 7.2. *The Scree Plot*



To examine which solutions were conceptually preferable, PAA with promax rotation was performed twice; on the four factor extraction, only two items (Q20 'my doctor-in-charge understands my feelings well' and Q25 'my doctor gives me reassurance') were loaded on the fourth factor. According to Nunnally et al. (1967), at least two variables are needed in order to construct a factor. However, conceptually, the two items could be loaded on the other factors. On the three factor extraction, the loaded items seemed to be conceptually relevant each to other.

Table 7.6 shows that the pattern matrix of loaded items of three factor extraction. Kaiser-Meyer-Olkin Measure of Sampling Adequacy was 0.75, and Bartlett's Test of Sphericity was significant ($\chi^2(351) = 1839.06$, $p < 0.00$).

Twelve items were highly loaded on factor 1 (psychological impacts of perceived social norms), five items were highly loaded on factor 2 (social disclosure of BC), and nine items were highly loaded on factor 3 (resources to live with BC). The factors were moderately correlated: the correlation between factors 1 and 2 was 0.36, between factors 1 and 3 was -0.20, and between factors 2 and 3 was -0.38.

Table 7.6 *A Principal Axis Factor Analysis on 27 Items*

Items	Factor		
	1	2	3
I have learnt our life is fragile*	**.63**	-.19	-.26
Others believe women's roles are to deal with family*	**.48**	.09	.05
Others believe women should be feminine*	**.48**	.08	.10
I feel closer to women with BC than those without*	**.47**	.04	.10
Others believe people with diseases can be a loser*	**.45**	.04	-.08
Others believe breasts are the symbol of sexual attractiveness*	**.44**	.07	.07
I feel inferior to healthy women*	**.43**	.17	-.23
I would like to do freely what I want*	**.43**	-.05	.24
I have sacrificed myself to my family*	**.41**	-.11	-.16
I have learnt I cannot predict what will happen to me*	**.40**	-.17	.05
I feel guilty when I ask for help to people*	**.34**	.08	.07
I feel it necessary people treat me as a healthy person*	**.33**	.05	.32
I feel fear to disclose BC to people other than my family*	.06	**.82**	.09
I feel anger when people ask me about my BC*	.02	**.72**	-.08
I feel embarrassed when people ask me about my BC*	.03	**.71**	-.14
I feel comfortable to disclose my BC to anybody	.06	**-.69**	.01
I can show my weakness to anybody	.06	**-.49**	-.05
I have noticed nature around me is splendid	.17	.07	**.55**
I have had a sense of gratitude	.13	.01	**.55**
My doctor-in-charge understands my feelings well	-.05	-.01	**.53**
I have been given reassurance by my doctor-in-charge	-.08	.02	**.51**
I have gained something more than I have lost	-.01	-.07	**.46**
I feel glad when my family show their concerns about me	.16	-.09	**.42**
I have no ideas what I want to do in the near future*	.24	-.02	**-.40**
I would like to spend my future life pleasantly	.26	-.04	**.36**
I have been satisfied with my roles in family	-.14	-.03	**.33**
Others believe cancer is curable	-.05	-.08	.11

Note. * = reverse scored, BC = breast cancer.

On internal consistency, Cronbach's Alpha was high on all factors: 0.74 for factor 1(the mean score = 29.3; SD = 6.0), 0.83 for factor 2 (the mean score = 16.2; SD = 4.1), and 0.70 for factor 3 (the mean score = 18.3; SD = 4.1). Inclusion of the items which had relatively lower communalities was examined (see Table 7.6); Cronbach's Alpha for factors 1 and 3 would not increase if the items were deleted. On factor 2, when the item 'I can show my weakness to anybody' was deleted, Cronbach's Alpha increased to 0.84 but, since the difference was relatively small, it was decided to retain the item.

Convergent and divergent validity.

All subscales were inversely correlated with all domains of WHO QoL-BREF; 'psychological impacts of perceived social norms' and 'resources to live with BC' were significantly correlated with all domains in WHO QOL-BREF. 'Social disclosure of BC' was significantly correlated with physical, psychological, and social domains in WHO QOL-BREF (see Table 7.7).

Table 7.7 *Correlations between the three Sub-scales and WHO QoL-BREF*

Subscales	WHO-phy	WHO-psy	WHO-soc	WHO-env
Impacts of social norms	$-.24^{**}$	$-.35^{**}$	$-.29^{**}$	$-.30^{**}$
Social disclosure	$-.15^{*}$	$-.26^{**}$	$-.21^{**}$	-.08
Resources	$-.33^{**}$	$-.43^{**}$	$-.40^{**}$	$-.26^{**}$

Note. WHO-phy = WHO physical domain, WHO-psy = WHO psychological domain, WHO-soc = WHO social domain, WHO-env = WHO environmental domain.

$^{*}p < 0.05$, $^{**}p < 0.01$. N =239.

Criterion validity.

Among the pre-determined research questions, six questions were examined: age, perceptions of information provisions at BC diagnosis, perceptions of information provision since surgery, stage of BC, surgery types, and reported arm complications.

Table 7.8, Table 7.9, and Table 7.10 show the results of bivariate analyses investigating relationships between psychological impacts of perceived social norms, social disclosure, resources to live with BC and the independent variables, respectively.

As Table 7.8 shows, ANOVA revealed that participants who had undergone mastectomies (mean = 43.38) reported greater impacts of social norms than those had undergone lumpectomies (mean = 41.75) [F (1, 230) = 4.22, p = 0.04], and that participants who had developed post-operative arm complications (mean = 43.32) reported greater impacts of social norms than those who had not (mean = 41.57) [F (1, 256) = 5.17, p = 0.02].

Table 7.8 *A Bivariate Analysis on the Psychological Impacts of Perceived Social Norms Sub-scale*

Variables	*M*	*SD*	F	Shapiro-Wilk z	Levene z
Age			1.46		0.09
< 60 years	42.91	5.96		0.99	
>/ = 60 years	41.90	36.11		0.98	
Information at diagnosis			3.25		0.62
Sufficient	42.11	6.23		0.99	
Insufficient	43.47	5.64		0.99	
Information since surgery			3.58		1.83
Sufficient	42.08	6.37		0.99	
Insufficient	43.50	5.45		0.99	
Stage of BC			2.63		0.08
I	43.42	6.00		0.98	
II	41.95	5.79		0.99	
III	44.21	6.17		0.97	
Surgery types			4.22^{*}		1.28
Lumpectomies	41.75	5.68		0.98	
Mastectomies	43.38	6.17		0.98	
Arm complications			5.17^{*}		0.45
Presence	43.32	5.79		0.99	
Absence	41.57	6.25		0.97	

* $p < 0.05$

As Table 7.9 shows, since the assumption of homogeneity of variance was violated in perceptions of information provision since surgery and numbers in each cell were not equal, a non-parametric test, the Mann-Whitney, was performed on the variable. Two variables, stage of BC and arm complications were not normally distributed but, because ANOVA is robust against non-normality when the sample size is big enough, ANOVA was performed on the two variables. Participants who were aged under 60 years old (mean = 14.29) experienced more discomfort with social disclosure than those aged above 60 years old (mean = 13.12) [F (1, 232) = 4.55 p = 0.03]. ANOVA revealed that there were effects of BC stage on social disclosure [F (2,241) =

3.67, the mean scores = 14.89, 13.33 and 13.48 respectively, p = 0.03]. Post-hoc Scheffè test indicated that the mean scores between stages I and II were significantly different (mean difference = 1.57, p = 0.03, CI = 0.12 – 3.01).

Table 7.9 *A Bivariate Analysis on the Social Disclosure Sub-scale*

Variables	*M*	*SD*	F z	Shapiro-Wilk z	Levene z
Age			4.55*		1.93
< 60 years	14.29	4.26		0.98	
>/ = 60 years	13.12	3.72		0.98	
Information at diagnosis			2.33		1.25
Sufficient	13.47	3.89		0.98	
Insufficient	14.27	4.40		0.98	
Information since surgery			-1.84		5.76*
Sufficient	13.32	3.62		0.98*	
Insufficient	14.36	4.60		0.98	
Stage of BC			3.67*		0.11
I	14.89	4.19		0.98	
II	13.33	4.11		0.98*	
III	13.48	3.73		0.97	
Surgery types			0.01		0.22
Lumpectomies	13.74	4.13		0.98	
Mastectomies	13.80	4.22		0.98	
Arm complications			1.85		0.03
Presence	14.07	4.14		0.98*	
Absence	13.35	4.05		0.98	

*p < 0.05

As Table 7.10 shows, since the assumption of homogeneity of variance was violated in stage of BC and numbers in each cell were not equal, a non-parametric test, the Kruskal-Wallis test, was performed on the variable. Five variables, age, information at diagnosis, information since surgery, surgery types and arm complications, were not normally distributed, but because ANOVA is robust against non-normality when sample size is big enough ANOVA was performed on the four variables.

Participants who perceived information provision at diagnosis as insufficient (mean =

19.19) experienced poorer resources to live with BC than those who did not (mean = 17.61) [F (1, 252) = 9.50, $p < 0.00$]. Participants who perceived information provision since breast surgery as insufficient (mean = 19.86) experienced poorer resources to live with BC than those who did not (mean = 17.04) [F (1,252) = 33.71, $p < 0.00$].

Table 7.10 *A Bivariate Analysis on the Resources of Live with Breast Cancer Sub-scale*

Variables	*M*	*SD*	F χ^2	Shapiro-Wilkz	Levene z
Age			1.13		0.29
< 60 years	18.19	4.27		0.96*	
>/ = 60 years	18.79	3.91		0.98	
Information at diagnosis			9.50*		1.78
Sufficient	17.61	3.85		0.97*	
Insufficient	19.19	4.31		0 .97*	
Information since surgery			33.71*		1.03
Sufficient	17.04	3.65		0.95*	
Insufficient	19.86	4.07		0.97*	
Stage of BC			3.82		3.43*
I	19.19	5.22		0.96*	
II	17.78	3.46		0.98*	
III	18.07	3.74		0.91*	
Surgery types			0.35		0.13
Lumpectomies	17.99	3.90		0.99	
Mastectomies	18.31	4.15		0.93*	
Arm complications			2.42		0.95
Presence	18.59	4.24		0.96*	
Absence	17.77	3.82		0.97*	

*$p < 0.05$

Factor structure, inter-correlation, and internal consistency on the seven lymphoedema items.

In this sample, 182 participants reported that they had developed post-operative arm complications. Ninety-seven participants were eligible for factor analysis on the lymphoedema-related items.

The correlation matrix showed that the items were moderately correlated to each other (please see Appendix 7.12). Principal component initial solution suggested that there were two components. PAA with promax rotation extracted two factors. KMO was 0.61, and Bartlett's Test of Sphericity was significant ($\chi^2 (21) = 73.28$, $p < 0.00$).

Table 7.11 shows the pattern matrix of loaded items. Four items were highly loaded on factor 1 (acceptance of lymphoedema), and two items were highly loaded on factor 2 (perceived controllability). The factors were poorly correlated; the correlation was -0.04.

Table 7.11 *A Principal Axis Factor Analysis on Seven Items*

Items	Factor	
	1	2
I feel afraid to disclose lymphoedema to people other than my family*	**.79**	.32
I feel my lymphoedema is more serious than BC*	**.51**	-.07
I can still enjoy what I used to do after the onset of lymphoedema	**-.47**	.26
I feel comfortable to disclose my lymphoedema to anybody	**-.37**	.06
I think my lymphoedema will be cured someday	-.30	**.68**
I feel my lymphoedema was avoidable*	-.13	**.49**
I have been more worried about my BC than lymphoedema	-.01	.23

Note. * = reverse scored, BC = breast cancer.

On internal consistency, Cronbach's Alpha was not satisfactory: 0.59 for factor 1 and 0.46 for factor 2. Inclusion of the items which had relatively lower communalities was examined. However Cronbach's Alpha did not increase if the items were deleted.

Convergent and divergent validity.

All subscales except perceived controllability were inversely correlated with all domains of WHO QoL-BREF; 'acceptance of lymphoedema' was significantly correlated with the physical domain, psychological domain, and social domain in WHO QoL-BREF. 'Perceived controllability' was not significantly associated with any domains in WHO QoL-BREF (see Table 7. 12).

Table 7.12 *Correlations between the Two Sub-scales and WHO QoL-BREF*

Subscales	WHO-phy	WHO-psy	WHO-soc	WHO-env
Acceptance	$-.19^{*}$	$-.25^{*}$	$-.29^{**}$	-.15
Controllability	-.02	-.02	-.03	.02

Note. WHO-phy = WHO physical domain, WHO-psy = WHO psychological domain, WHO-soc = WHO social domain, WHO-env = WHO environmental domain.

$^{*}p < 0.05$, $^{**}p < 0.01$, N = 87.

Criterion validity.

Among the pre-determined research questions, all the nine questions were examined. Tables 7.13 and 7.14 show the results of bivariate analysis investigating relationships between the acceptance of lymphoedema, perceived controllability subscales and the independent variables respectively.

As Table 7.13 shows, four variables, age, information at diagnosis, surgery types, and years since the onset of arm symptoms, were not normally distributed but, as ANOVA is robust against non-normality, ANOVA was performed on the variables. The assumption of homogeneity of variance was violated on the variable, stage of BC, so the Kruskal Wallis test was performed on the variable. The mean score of acceptance of lymphoedema was not significantly different from any variables.

Table 7.13 *A Bivariate Analysis on the Acceptance of Lymphoedema Sub-scale*

Variables	*M*	*SD*	F χ^2	Shapiro-Wilk z	Levene z
Age			0.57		0.08
< 60 years	10.21	2.74		0.96*	
>/ = 60 years	10.68	2.63		0.95	
Information at diagnosis			1.72		0.29
Sufficient	9.98	2.70		0.97	
Insufficient	10.71	2.77		0.93*	
Information since surgery			1.04		0.50
Sufficient	10.00	2.73		0.97	
Insufficient	10.57	2.76		0.96	
Stage of BC			1.31		3.20*
I	11.30	3.11		0.95	
II	9.90	2.28		0.97	
III	10.60	3.10		0.95	
Surgery types			0.52		0.37
Lumpectomies	10.10	2.83		0.95	
Mastectomies	10.56	2.82		0.96*	
Loss of strength			0.21		0.02
Yes	10.43	2.81		0.96	
No	10.18	2.70		0.96	
Poor range of motion			3.13		2.11
Yes	10.81	2.95		0.97	
No	9.84	2.46		0.98	
Years since arm symptoms			0.45		1.22
< 3 years	10.06	2.48		0.98	
>/= 3 years	10.43	2.82		0.95*	

*$p < 0.05$

Table 7.14 *A Bivariate Analysis on the Perceived Controllability Sub-scale*

Variables	*M*	*SD*	F	Shapiro-Wilk z	Levene z
Age			0.40		0.12
< 60 years	6.15	1.79		0.96^*	
>/ = 60 years	5.89	1.69		0.95	
Information at diagnosis			0.30		0.64
Sufficient	6.00	1.89		0.96	
Insufficient	6.20	1.66		0.95^*	
Information since surgery			1.56		0.48
Sufficient	5.87	1.77		0.96	
Insufficient	6.33	1.80		0.97	
Stage of BC			1.79		0.29
I	6.70	1.74		0.95	
II	5.94	1.62		0.93^*	
III	5.80	2.14		0.95	
Surgery types			1.03		1.43
Lumpectomies	5.90	1.64		0.96	
Mastectomies	6.30	1.83		0.96	
Loss of strength			3.05		0.16
Yes	6.38	1.60		0.94^*	
No	5.75	1.94		0.95^*	
Poor range of motion	1.46		0.69		
Yes	6.31	1.81		0.97	
No	5.88	1.74		0.96	
Years since arm symptoms			4.44^*		0.24
< 3 years	5.73	1.85		0.96	
>/ = 3 years	6.49	1.65		0.96	

$^*p < 0.05$

As Table 7.14 shows, four variables - age, information at diagnosis, stage of BC, and loss of strength - were not normally distributed but, as ANOVA is robust against non-normality, ANOVA was performed on the variables. ANOVA revealed that participants who had developed lymphoedema three or more years ago (mean = 6.49) reported perceived poorer controllability of lymphoedema than those who had developed lymphoedema less than three years ago (mean = 5.73) [F (1, 94) = 4.44, p = 0.04].

Inter-factor-correlations among breast cancer patients with lymphoedema.

Table 7.15 shows correlations between the one-item global score and the six factors including the physical discomfort scale (Chapter 4); 172 cases were eligible for a confirmatory factor analysis. The results of SAS Calis procedure indicated that the hypothesised model (one factor underlying the six items) was good (χ^2 (9) = 18.851 p = 0.03; RMSEA = 0.08; NNFI = 0.94). Cronbach's Alpha was 0.79.

The global score was most strongly correlated with the physical discomfort scale (ALPDS), and moderately and significantly correlated with resources to live with BC scale. The physical discomfort scale was moderately and significantly correlated with all the scales except the social discomfort and perceived controllability subscales. Psychological impacts of perceived social norms were moderately and significantly correlated with all scales except resources to live with BC and perceived controllability. Social disclosure was positively and most strongly associated with acceptance of lymphoedema. Resources to live with BC was positively and moderately associated with acceptance of lymphoedema and perceived controllability of lymphoedema.

Table 7.15 *Correlation Matrix of the Global Scale, Physical Discomfort, and Psycho-social Discomfort Scales*

Scales	1	2	3	4	5	6	7
1. Global scale	-						
2. Physical	$.54^{**}$						
3. Psychological	.15	$.36^{**}$					
4. Social disclosure	-.00	.02	$.33^{**}$				
5. Resources	$.23^{*}$	$.25^{*}$	.05	$.27^{**}$			
6. Acceptance	.13	$.32^{**}$	$.41^{**}$	$.51^{**}$	$.36^{**}$		
7. Controllability	.12	.13	-.03	-.01	$.22^{*}$	.08	-

Note. $^{*}p < 0.05$, $^{**}p < 0.01$, N = 82.

Discussion and conclusions

The objective of this study was to develop psycho-social discomfort scales among BC patients with lymphoedema and to investigate the psychometric properties of the scales. The scales were constructed based on the findings of the previous qualitative study, and it was hypothesised that there would be six underlying factors (five BC core factors and one lymphoedema factor).

A principal axis factor analysis extracted three BC core factors and two lymphoedema factors. On the core factors, although social norms and the impacts of social norms were assumed to be distinct, these items were combined to construct one factor – psychological impacts of perceived social norms. The items were conceptually relevant, so the factor had good face validity. The internal consistency of the three core factors was satisfactory (Cronbach's Alpha >/= 0.70).

On the lymphoedema factor, since lymphoedema-related items had lots of missing values, the seven lymphoedema-related items were separately analysed; the internal consistency of the two loaded factors was not satisfactory (Cronbach's Alpha < 0.60). Therefore, these two subscales need to be revised and the internal structure investigated in a new sample.

There are two possible reasons why the sub-scales had a weak structure; inclusion of follow-up data and conceptually irrelevant items in the sub-scales. First, in this sample, almost half the participants who reported post-operative arm symptoms did not fill in the lymphoedema-related items; this may have happened because the participants did not perceive their early arm symptoms as lymphoedema, and because the instruction that 'if you have not developed lymphoedema, please circle the sixth point 'no lymphoedema' was given in the questionnaire. To follow-up these participants, they were asked again to complete these items, and some of them were returned with their completed short questionnaire. For the statistical analysis, those data were included. Inclusion of the follow-up data might have contributed to the weak structure. Second, the items in the subscales appeared to cover diverse concepts. Conceptual relevance among the seven items should be focused on. Thus, it would be worthwhile revising the instructions, adding relevant items to each factor and examining the factor structure and psychometric properties in a future study.

The sub-scales, except perceived controllability, were moderately and inversely correlated with the WHO QoL-BREF Japanese version. Four factors especially - psychological impacts of perceived social norms, social disclosure of BC, resources to live with BC and acceptance of lymphoedema - were significantly associated with all domains except the environmental domain in the WHO QoL-BREF; negative psychological impacts of social norms, discomfort with social disclosure, and poorer resources to live with BC were most highly associated with poor psychological domain in the WHO QoL-BREF. Poor acceptance of lymphoedema was most highly associated with poor social relationships in the WHO QoL-BREF. The negative impacts of social disclosure and unfavourable interactions with others on emotional well-being (in the RAND 36-item Health Survey) have also been reported by previous studies in USA (Figueiredo et al. 2004).

The results show that the sub-scales can measure the same concept of WHO QoL, but can measure different aspects of QoL from those that the WHO QoL-BREF has defined, with good convergent and divergent validity.

On criterion validity, participants at younger ages reported more severe discomfort with social disclosure. This result was inconsistent with a previous study in the USA (Henderson et al. 2002). Since the social disclosure subscale was significantly correlated with the psychological impacts of perceived social norms scale, it was assumed that there were differences between older and younger ages on the mean score of psychological impacts of social norms; older age participants might have more traditional view points influenced by Confucianism than younger participants, but the differences between younger age and older age participants on the scale were not significant.

Participants with stage I BC reported more severe discomfort with social disclosure than those with stage II BC. Henderson et al. (2002) also reported that women with advanced BC were more likely to discuss their BC with others. However, in the present study, significant differences between stage I and III, and stage II and III were not found.

The psychological impact of perceived social norms sub-scale could distinguish between BC patients with lymphoedema and without lymphoedema. This result is intuitively sensible since, if women have more physical burdens, they may be unable to play their own social roles - this may lead to a sense of inferiority.

Interestingly, perceptions of information provision at diagnosis and since surgery could distinguish between participants who reported poor resources of life with BC and those who did not. This suggests that information provision does indeed affect BC patients' lives.

Inter-correlations among the subscales were from poor to moderate. This indicates that each sub-scale could be assessing different aspects of experiences since breast surgery. Since the one-item global scale was highly correlated with the physical discomfort sub-scale and poorly correlated with the social disclosure sub-scale, the use of one-item scale as a global scale may not be adequate. It may be worth while putting the global scale at the end of the questionnaire and examining inter-correlations with a new sample; the high correlation may be affected by the order of the scale items.

In summary, for BC the scales have good construct and criterion validity, and can measure QoL among BC patients. However, for lymphoedema, the scales had weak construct and criterion validity, so these two sub-scales should be revised in order to improve their validity and reliability in the future.

8. Summary and discussion

INTRODUCTION

The main question of the research programme was to investigate how perceptions of information provision affect quality of life (QoL), and the aim was to develop a 'culturally appropriate' new QoL measure with good psychometric properties for Japanese female breast cancer (BC) patients with lymphoedema. A literature review (Chapters 1 and 3) revealed that little research exploring adaptation processes to lymphoedema had been conducted in Japan, meaning that our knowledge is minimal, and that there are no conceptually and psychometrically adequate disease-specific QoL measures for this population. It was highlighted that the concept of health-related QoL in psycho-oncology is rather narrow and, further, that positive aspects of human beings (motivation), needs satisfaction, and influences of the society are rarely included in the concept. Second, since the social domain of a disease-specific QoL measure, that was originally developed in English speaking countries, has a relatively lower internal consistency (Alpha < 0.60) among Japanese cancer patients, the application of 'universal' measures was questioned. It was suggested that culture and society construct people's perceptions, so that a symbolic interactionism viewpoint should be taken into account when subjective aspects of QoL are assessed.

To address the question, three studies were conducted in Japan; first, following a careful review of literature and in order to identify relatively subjective lymphoedema symptoms, a symptom check list and the physical discomfort scale (ALPDS) of arm lymphoedema were designed, and their validity and reliability were investigated. Next, in order to explore BC patients' perceived experiences of lymphoedema, a small number of focus group discussions (FGDs) were conducted. Finally, based on the findings of FGDs, the psycho-social discomfort scale was designed, and its validity and reliability were explored in a new sample.

In this chapter, the findings of each study are summarised and discussed with reference to previous empirical studies and theories, and the limitations are also discussed. Finally, the implications of the studies are explored.

THE MAIL SURVEY STUDY
(THE ARM LYMPHOEDEMA PHYSICAL DISCOMFORT SCALE)

Summary

A new questionnaire was designed that asked about demographics, BC treatment, clinical history, post-operative arm symptoms, and perceived discomfort associated with symptoms. The symptom checklist included eight items - the presence of arm symptoms, the affected arm, pain, numbness, swelling, poor range of motion, loss of strength, and the duration of arm complications. Discomfort associated with arm symptoms was assessed by a one-item global scale and a six-item (paid jobs, household chores, grooming, sleeping, hobbies, and meeting somebody) physical discomfort scale (ALPDS). Both scales used five-point faces scales.

First, a small pilot study was conducted in a lymphoedema self-help group; in order to confirm face validity, participants were asked to give their feedback in a free-text format. Ten patients returned their questionnaires and there were a few missing data on demographics, BC treatment and clinical history. Considering the data and the free texts, a response choice and a supplemental explanation of BC stage were added, and the question on history of psychiatric problems was revised. Additionally, the structure of the questionnaire was amended.

Second, a mail survey was conducted using the revised questionnaire, and potential participants (380 BC patients) were recruited from two BC self-help groups. One hundred and sixty-six patients returned their questionnaires (a response rate of 43.7 per cent).

In order to investigate test-retest reliability, 80 respondents were selected from the 166 respondents by systematic random sampling, and the same questionnaire package was mailed with one-month interval. Fifty-six patients returned the second questionnaire (response rate of 70 percent). After exclusion of one participant, who was found to be male, and cases with missing data, 53 participants' data were eligible for statistical analysis. The test-retest reliability ranged, across items, from 0.36 to 0.95 (Kappa (K) = 0.49 - 0.95; Weighted Kappa quadratic (Kwq) = 0.36 - 0.76). For the test-retest reliability of summary scores of ALPDS, the intra-class correlation (ICC) was 0.70.

On the structure of ALPDS, one hundred female participants who had reported arm symptoms on the arm of the operated side were eligible for a factor analysis. A principal component analysis showed that there was one factor underlying the six items accounting for 56 per cent variance (Cronbach's Alpha = 0.83). This scale sum was moderately correlated to the one-item global scale (Spearman's rho = 0.68).

On criterion validity, six research questions were investigated: relationships between reported physical discomfort and (1) perceptions of information provision at BC diagnosis, (2) perceptions of information provision since breast surgery, (3) type of arm symptoms, (4) arm therapy by doctors or specialists, (5) performing self-care at home, and (6) the duration of having arm symptoms.

Bivariate analysis revealed that the mean score of physical discomfort was significantly different between patients who perceived information provision at BC diagnosis as insufficient and those who did not, between patients who perceived information provision since surgery as insufficient and those who did not, between patients who reported poor range of motion and those who did not, and between patients who reported loss of strength and those who did not.

Interaction effects were found between perceptions of information provision at BC diagnosis and age, paid jobs, and type of surgery; perceptions of information provision was significantly different for younger aged participants (</= 53 years old), for those having paid jobs, and for those undergoing lumpectomies. Also, interaction effects were found between loss of strength and years since breast surgery; loss of strength was significantly different for fewer years since the surgery (</= 3 years).

Finally, multivariate analysis showed that participants who perceived information provision at diagnosis as being insufficient tended to report more physical discomfort, and those experiencing loss of strength tended to report more physical discomfort.

Discussion

On the evaluation of test-retest reliability, there are several criteria in order to assess the Kappa values. According to Fleiss (1981), a K lower than 0.60 indicates fair agreement. Cicchetti (1994) proposed that a K lower than 0.40 indicated poor clinical significance, between 0.40 and 0.59 fair, between 0.60 and 0.74, good. In the present study, although there was one item - hobbies - below 0.40 ($Kwq = 0.36$), since the summary score of ALPDS was above 0.60, overall the checklist and ALPDS showed clinically good repeatability.

Regarding the sample size, the minimum sample size is suggested to be 50 (Sim and Wright 2005) when researchers need $K = 0.40$ detected with 80 per cent power. Since in the present study the sample size was 53 for test-retest reliability, it can be concluded that the sample size was adequate.

On the construct validity, the ALPDS had one factor with clinically good internal consistency (Cronbach's Alpha > 0.80, Cicchetti and Sparrow 1990). The ALPDS distinguished between reported physical discomfort among patients with different type of arm symptoms and different perceptions of information provision. Most importantly, perceptions of information provision were a good predictor of reported physical discomfort. This association has been reported by previous studies in the West (Arora et al. 2002; Kerr et al. 2003). However, the model from the multivariate analysis accounted for only 20 per cent of the variance. This suggested that there are other important predictors associated with physical discomfort.

On the sample size for factor analysis, although a gold standard of sample size for a factor analysis has not been established as yet (Pett et al. 2003), Nunnally and Bernstein (1967) suggest a minimum sample size requires ten respondents per item. The ALPDS contains six items, so a minimum sample size would be 60. The sample size for the factor analysis was 100. It can be concluded that the sample size was adequate.

Methodological issues

The first survey study was a cross-sectional design so that neither causality nor a direction among variables could be confirmed. Additionally, random sampling was not carried out (except within the sample for the test-retest reliability investigation), and the study sites were limited to prefectures adjunct to Tokyo where most married women do not have paid jobs but have higher household incomes (The Ministry of Health, Labour and Welfare 2005), and relatively good care for cancer patients is provided (e.g. the national and local oncology hospitals). Further, the response rate was relatively low (43.7 per cent). Thus, the findings cannot be generalised to all BC patients with lymphoedema in Japan. Additionally, since this study used only BC patients with lymphoedema, it is uncertain whether the ALPDS can distinguish between BC patients with and without lymphoedema (Coster et al. 2001) and the healthy population and/or patients with other diagnoses.

In this study, twenty four per cent of participants had been diagnosed with lymphoedema (Chapter 4) by palpation and inspection. There may be several reasons for this inconsistency between the subjective report in the ALPDS and the clinical diagnosis; for example, doctors seem to pay attention to one of the symptoms of lymphoedema alone, such as swelling, so that complex symptoms may be underestimated. Another possibility is that there are only a few hospitals and clinics providing lymphoedema therapies in Japan (Okada 2002) so that this inaccessibility may lead to lower help-seeking behaviours and fewer medical consultations.

In summary, despite these shortcomings, it was shown that the symptom checklist can assess relatively subjective post-operative arm complications, and that the ALPDS was a reliable measure.

THE QUALITATIVE STUDY (FGDS)

Summary

Since the ALPDS assessed physical discomfort only, it was necessary to explore the more subjective aspects of QoL that were identified in Chapter 1. To explore experiences of lymphoedema, FGDs were conducted. The main research aim was to explore how BC patients perceive experiences of lymphoedema, and how perceptions of lymphoedema are formed in Japanese society.

First, potential participants were selected according to responses in the first survey questionnaire; participants who reported arm symptoms (swelling) and who provided a personal contact in the questionnaire were selected (n = 18). A small pilot study was conducted in order to check the semi-structured question route and procedure of FGDs; two participants took part. The session was audiotaped and transcribed verbatim. The transcript suggested more assertive facilitation, clearer instructions of group rules, re-composition of groups and amendments to the question route. Next, two more FGDs were conducted using the revised question route, modified procedure and facilitation. A total of eight BC patients participated. All sessions were audiotaped, and transcribed verbatim. Written consent forms were obtained from all participants.

Three transcripts (Japanese), including the pilot, were analysed by using a dual analytic approach - thematic analysis (Boyatzis 1998) and conceptual analysis (Denzin 1989; Nicolson and Anderson 2003) using symbolic interactionism theory (SI, Chapter 5).

First, the thematic analysis extracted five main themes: physical constraints, emotional responses to lymphoedema, negative emotional responses to surgeons, practical and informational support, and scepticism about the efficiency of lymphoedema treatment. Most participants had experienced physical constraints, and performed preventive actions in order to prevent further, more severe complications. Perceptions of the physical constraints were clearly categorised as *acceptance* and *burdens*. This difference seemed to relate to a priori knowledge of risk factors for lymphoedema (e.g. axillary lymph gland dissections); participants who had been given the information tended to believe that lymphoedema was not life-threatening in the same way as BC and tended to perceived lymphoedema as acceptable. The participants who had *not* been given information on the risk at an appropriate time tended to perceive lymphoedema as a burden, and perceived their surgeons negatively. Surprisingly, little social support from family members was provided for the physical constraints. Even though participants had undertaken therapy for lymphoedema, they tended not to continue with it because they did not find it effective.

Several questions were raised; apart from information provision, why did some participants perceive lymphoedema as acceptable when compared to BC (Williams et al. 2004)? What did experiences of BC bring participants (did they experience something positive)? Did participants seek help? If not, did they wish to maintain a sense of control (Radina and Armer 2001)? To explore the cognitive and emotional processes, several themes from both lymphoedema and BC topics were selected for conceptual analysis using SI.

A conceptual analysis revealed two themes: self-esteem and adjustment to lymphoedema in BC contexts, and interaction with society and social support for lymphoedema. In the first theme, patients who said they had gained more than they had lost through experiences of BC tended to consider lymphoedema as acceptable. Several spiritual gains through painful experiences of BC were cited: intimate relationships with friends with BC, a proactive attitude, and sense of gratitude (for people and nature). This emotional process did not involve others, only 'I' looking at 'Me' (Mead 1913), and, in these cases, participants had relatively high self-esteem. However, when participants devalued experiences of BC by taking 'others' points of view, participants tended to think BC had brought them a negative sense of self (e.g. inferiority) and, consequently, participants had lower self-esteem.

In the second theme, relationships between social disclosure, help-seeking behavior, and influences of others (society) were found. Women who had encountered inconsiderate attitudes of others were less likely to disclose their concerns and to seek further help. This may happen because the women perceived that their relationship with others changed adversely or was less desirable than the women wished. On the other hand, not telling immediate families about BC and lymphoedema had different underlying reasons: not wanting to have family worries, and feelings of guilt. Participants were thinking that their first priority was to play their social roles (mothers or daughters). If adequate social support was not provided by doctors, families, healthy friends, there were few opportunities to take the role of patients. In the end, some participants felt that they sacrificed themselves.

Discussion

Throughout the study, cognitive and emotional coping processes have been revealed; BC patients experienced both negative and positive transitions, which is consistent with previous qualitative studies among cancer survivors (Thornton 2004). Participants often gained something precious as a consequence of difficult experiences: gratitude, spirituality, and perceived benefits. On the other hand, when participants felt that they had lost something rather than gained, they tended to feel inferior to others, especially to healthy women. Experiences of lymphoedema were interpreted in these BC contexts.

In the next section, the impacts of these transitions on QoL are discussed with reference to previous studies.

Positive transitions.

Positive gains following traumatic events have been recently reported by empirical studies, especially qualitative studies, and these findings have expanded existing concepts of gratitude, spirituality, and perceived benefits, and have shown these variables to be somehow inter-correlated. Quantitative studies have shown possible associations between these positive gains and QoL.

First, historically, feelings of gratitude that are a pleasant state have been discussed with moral behaviour (McCullough et al. 2001); for example, Smith (1759/1969) claims that people will feel gratitude when they receive benefits from others (benefactors), and this emotion leads to more moral behaviours from others in the future (moral reinforcers). In this sense, it was believed that feelings of gratitude were evoked as a result of human-to-human interactions only. Recently, it has been proposed that feelings of gratitude may also be evoked as a result of human-nonhuman interactions, such as with a God, nature or the cosmos. For example, Tarakeshwar et al. (2006), who conducted a qualitative study in the USA, reported that most participants attributed HIV diagnosis to God's choice, that they felt stronger than before the diagnosis and were alive due to God.

Other studies have investigated whether feelings of gratitude differ between men and women and how the feelings affect perceived health. For example, Krause (2006) conducted a longitudinal survey study among Christian older people in the USA asking about self-rated health, gratitude toward God, and relationships with neighbours. Krause found in the cross-sectional data that women were more likely than men to feel gratitude toward God. Although gratitude to God did not have direct effects on perceived health, the women who had both high levels of gratitude to God and deteriorated relationships with neighbours reported a better health condition than those who did not.

Next, spirituality has often been discussed in religious contexts (Thuné-Boyle et al. 2006; Rippentrop et al. 2005), although some scholars suggested that spirituality is a multidimensional concept, such as relationships with 'the self, others, a higher power, and nature' (Walton 1999: 36). Walton et al. extracted another dimension of spirituality from a qualitative study among patients with acute myocardial infarction: meaning and purposes in patients' lives.

The assessment of all these concepts has been suggested by Thuné-Boyle et al. (2006) who conducted a systematic review in oncology. They concluded that religious/spiritual resources should be assessed from a more cognitive perspective; for example, whether or not religious/spiritual resources give patients meaning, sense of control and intimate relationships with others, rather than by behaviours (e.g. frequencies of service attendance) that are often a variable of spirituality in psycho-oncology. In the review, studies exploring these cognitions consistently showed significant effects of religious/spiritual resources on life satisfaction, better adjustment to illness and less emotional distress. However, since Thuné-Boyle et al. did not include studies which had been conducted in countries other than USA and Europe, it is uncertain from their review whether people who do not use formal worship instead use religious/spiritual resources to adjust to traumatic events as, for example, illness.

The findings of FGDs can expand our knowledge of the concept of spirituality; as reported in Chapter 6, despite the fact that most Japanese do not worship in specific religions, women in the FGDs felt that 'something precious was given', and this suggests they were feeling that there is an entity with an absolute power in the world. It is assumed that Japanese people have a vague concept of God, but this sense is not religious-related as World Health Organisation QoL studies have already reported (Tazaki et al. 2002). This may be closely related to Japanese customs and culture. It is well established that most customs in Japanese culture are influenced by both *Shinto* and Zen Buddhism; for example, people go to shrines to pray during the New Year and traditional ceremonies, but when they die the services are often carried out in a Buddhist temple.

Finally, the long-term effects of perceived benefit after traumatic events have been consistently reported among lay people and cancer patients. For example, Davis et al. (1998) conducted a longitudinal study among bereaved people in order to investigate how benefit-finding (e.g. finding something positive for own life) and meanings (e.g. making sense of traumatic events or finding reasons why events have happened) impacted on adjustment processes to bereavement. Davis et al. found that respondents who found something positive at 13 months since their loved one's death reported less distress at 18 months, but making sense of the death at 13 months did not significantly predict levels of distress at 18 months. Similarly, Carver and Antoni (2004), who conducted a prospective study among BC patients in the USA, found that benefit-finding (e.g. relationships with others, spirituality, self-control, acceptance of circumstances and so on) at three months since surgery was a good predictor of level of depression at seven years since surgery.

Some studies have shown that the variables of positive gains are somehow related. For example, McCullough et al. (2004) found that feelings of gratitude were significantly associated with spiritual transcendence (e.g. 'I have found inner strength from prayers, all life is inter-connected, and I have a strong emotional tie with someone who has died' (Piedmont 1999: 995), among patients with neuromuscular diseases.

In conclusion, previous studies have consistently shown that many patients and healthy people experience positive gains after painful events, and that the positive gains seem to be correlated with better psychological states. As some scholars have proposed, feelings of gratitude, spirituality, and perceived benefits are inter-related, but spirituality has been often discussed in religious contexts in psycho-oncology. The findings in the FGDs revealed religiously-unrelated spirituality, benefit-finding including personal growth and relationships with BC patients, and gratitude for close others and nature. These positive gains may be synonymous with spiritual growth (Cole et al. in press) and spiritual well-being (Walton 1999).

Negative transitions.

Most patients go through negative transitions following disease diagnosis and medical treatment, as reported in Chapter 1. Patients may feel anxiety, threats to the self, low self-esteem (Leary et al. 2001), and poor acceptance of illness (Golden et al. 2006). Consequently, patients tend to think that they are stigmatised due to their illness. This perception is often formed by interactions with others and the society and intuitive thoughts (social-cognitive processing model; Lepore 1996), and the perception often leads to constraints on behaviors (Goffman 1963).

Several studies have reported that expressing emotions about illness experiences is beneficial for patients' emotional states (Herbette and Rimé 2004; Stanton et al. 2000). This may be true if patients talk about their concerns to people who are willing to listen and are sensitive enough. Are the people surrounding patients always ready to share the experiences? Studies among HIV patients (Parsons et al. 2004) have shown that some patients encountered actual interpersonal rejections when they disclosed their illness and concerns, and patients who were unwilling to disclose their illness to a partner were more likely to be constrained by thoughts of what others think of people who are HIV-positive, and they were more likely to think that their partners were less supportive.

When people encounter or anticipate interpersonal rejection, negative emotions, including hurt feelings, anxiety and depression, are elicited (Leary et al. 2001). For example, cross-sectional survey studies among BC patients in Japan have consistently shown that perceived inappropriate communications among family members leads to patients' feelings of helplessness (Inoue et al. 2003) and depression (Mantani et al. 2007).

Patients who have encountered uncomfortable responses from others may attempt to maintain distance from the person or group (Murray et al. 1998), and maintain 'face' (Goffman 1963). Consequently, patients may make decisions that they would selectively disclose their illness to people who could provide benefits after disclosure (Parsons et al. 2004), or patients may turn their back on existing social networks (Goffman 1963). In the FGDs, constant decision-making about to whom patients talk about their concerns were reported to occur when the patients wished to maintain perceived normality (Radina et al. 2001), avoid social embarrassment (Johansson et al. 2003), and negative feelings (Inoue et al. 2003; Mantani et al. 2007).

Additionally, women in the FGDs who had experienced interpersonal rejection felt isolated from their existing social networks, and tended to return to more comfortable groups, such as friends with BC. This finding may indicate that the women tended to compare themselves to people without stigma rather than people with similar stigma (Johansson et al. 2003). In order to comfort themselves, these women may have attempted to find similar stigmatised experiences rather than using down-ward comparison ('I am better off than other patients'). This tendency has been also reported among patients with HIV and young adults (Frable et al. 1998; Parsons et al. 2004). For example, Frable et al. (1998), who conducted an experimental study, identified the reasons why students with social stigma (e.g. sexual orientation, eating disorder, and lower socio-economic status) preferred to stay with people with similar stigma because the students felt higher self-esteem and better psychological states when with similar people.

Second, another important factor that prevented women in the FGDs from help-seeking behaviours was guilt; women tended to feel guilty when they could not perform their social roles, and this emotion prevented the women from talking about their concerns and, thereby, seeking further help. Patients who felt guilty about seeking further help tended to feel that they were sacrificed. Also, they regretted not taking up patient roles in their social networks. This suggests that the absence of help-seeking behaviour caused by guilt led to adverse effects on emotional and social well-being. This association has not been reported by studies among BC patients with lymphoedema in the West (Chapter 3).

It is unclear from the discussions precisely why the patients who felt guilty were also feeling that they were sacrificed after all. This phenomenon can be explained by Baumeister et al.'s theory (1994); they proposed that if there are exchange relationships (unequal status) between oneself and others, a feeling of guilt may not be beneficial in the long run because the relationships are maintained only by giving anticipated benefits, so that this emotion has a detrimental effect on self-esteem. On the contrary, when there are communal relationships (equal status) between oneself and others, guilt emotions may enhance personal relationships because relationships do not anticipate immediate benefits so that the emotions help to maintain the moral code that holds societies together. In the FGDs, women may perceive that in relationships within the family, especially with husbands, they were not socially equal and, therefore, when the women looked back at their experiences they felt that they served their husbands and rewards were not given, and that they were sacrificed for family or husbands.

Experiences of lymphoedema.

Experiences of lymphoedema were often interpreted in the BC contexts in the FGDs which were illustrated above. Following the negative transitions, such as interpersonal rejections, perceived isolation from existing social networks, changes in own philosophy, and threat to own life, BC patients who experienced more positive gains may find the onset of arm complications nothing harmful; even though most participants reported several physical constraints, compared to experiences of BC, changes caused by arm complications were perceived as 'minor'. On the other hand, some BC patients who felt inferior to healthy women as a result of BC had low self-esteem, and they had difficulty in the acceptance of lymphoedema.

In summary, positive gains are considered as resources to overcome traumatic events, and these lead to better health outcomes. However, an interpersonal rejection prevents patients from social disclosure and help-seeking behaviours, and this adversely affects emotional and social well-being. Experiences of lymphoedema were often interpreted in the BC contexts.

Cultural interpretations.

The findings of qualitative study have well reflected present Japanese society. Attributions of death or life-threatening illness and women's traditional social roles seem to affect social disclosure and help-seeking behaviours.

Regarding attributions of death, Japanese people consider that death is 'polluting and contagious' (Nishimoto and Foley 2001), which idea comes from *Shinto* (Buddhism does not consider death that way, but since Japanese culture and custom are influenced by both *Shinto* and Buddhism Japanese people mix the two ideas in daily life). There is a custom that people who attend Buddhist-style funerals use salt to purify themselves before entering their home, so that they will not bring bad luck or misfortune to their families. A family, who has had a funeral, needs to mourn for forty-nine days. During that period, they should not attend any happy events (e.g. wedding ceremonies, parties, and the New Year event) because their attendance will bring bad luck to others.

Additionally, Japanese people do not usually consider that death is given by a god. This may be because most Japanese people do not believe in a specific religion. For example, Long (2004), who conducted a qualitative study, explored the concept of death among terminally ill Japanese people and health care professionals. Long found that participants (except Christians) did not consider that a god decided the timing of death. This attribution may be compared to that of people who believe in a specific religion, for example Islam; Muslims believe that 'illness, suffering and dying are… a test from Allah' (Cheraghi et al. 2005: 469). The absence of a god may be one of the reasons that Japanese people tended to perceive death as frightening.

Because of these negative attributions, Japanese people wish for a 'peaceful' or natural death (e.g. at an appropriate age, no pain and completion of social roles) and less burden on the family (Hirai et al. 2006; Long 2004). Life-threatening illness, such as cancer, deprives people of their wishes or 'good death'. Cancer attacks people suddenly - people may think that they will suffer from pain, will be unable to complete their social roles, and will give their families great burdens. The word of cancer evokes sudden cessation of life and 'bad death'. Additionally, as the FGDs data have shown, female organ-related cancer, breast cancer, has something to do with sexuality and has special meaning in Japanese society, similar to that in some western countries; women's breasts are treated as sexually attractive in mass media. People are exposed to such information in daily life, and this helps to create a certain image of breasts and women. People may perceive that development of breast cancer and undertaking surgery means partial and total breast loss and lack of femininity. These general consensuses about death and cancer in society prevent women talking about their illness to others.

Second, regarding a woman's position in society, traditional cultural values still remain in Japan (women should stay at home to perform traditional roles), even though the country has industrialised, women's educational levels are as high as that of men, and there are many more women in the labour market (Rindfuss et al. 2004). Rindfuss et al. considers that the family system (*ie*) in the Meiji era (1868-1912) and Confucianism still seem to restrict Japanese women and to create male-dominated society.

The beginning of the Meiji era (1868) meant the end of seven hundred year history of samurai and that the emperor regained political power. In order to operate the new social system, the Meiji government needed to create a new cohesive framework for people, which was called the family system (*ie*). To support the family system, Confucianism, which was developed in ancient China, was made use of in Japan. Confucianism teaches the importance of seniority. For example, old people should be respected, and younger people should not challenge old people's opinions. This idea was particularly important in order to maintain a big family (usually two or three generations lived together in a house). Regarding women, since women were defined as ignorant in the Meiji constitution, they were not expected to contribute to the family's business except bearing, rearing children and taking care of old parents. The most important task of a married woman was to have a son, since only he could inherit everything from his father in the Meiji era.

This traditional view is found among other East Asian countries, for example China and Hong Kong. However, perceptions of women's social roles seem different between the Chinese and Japanese. For example, women in Hong Kong usually continue paid work after marriage and having a child, even though working hours are quite long. Opportunity for promotions and managerial posts is equal between men and women. Many women in middle class in Hong Kong hire a baby sitter who usually provides twenty-four hour baby care, immediately after giving birth. Additionally, the women hire a full time domestic helper who performs everyday household chores. This circumstance may be created by some consensus in the community that child rearing and household chores are no longer women's responsibility only.

On the contrary, women in Japan seem to be more constrained by social roles. For example, women tend to be reluctant to continue paid work especially after having a child, and to have their newborn babies or children taken care of by people other than family members, since the use of a day nursery is often consider as non-traditional behaviour and to have a negative effect on child development (Rindfuss et al. 2004). Additionally, nobody shares household chores with women in their family. A recent report (Gender Equality Bureau 2007) has shown that Japanese women have greater responsibility for every household chore (washing clothes and dishes, cleaning rooms and cooking) than in other countries (Sweden, UK, German, USA, Korea and Philippines). They also reported that the percentage of women engaged in household chores was not so different from that in 1982, and that the idea of sharing household chores with family members including children was lacking in Japan.

Under the circumstances, as the FGDs data have shown, women were reluctant to seek help, and women believed that, if they took patients' roles at home, family members would face difficulty. Thus, women prioritised their husbands (like women in the Meiji era) and children, and attempted to create 'comfortable' homes for their husbands and children. Women knew that these attitudes and behaviours were welcomed by family members and society. When women felt unwell and needed some help, they felt guilty. However, women who tried to wear 'good wife and mother's masks' even after the life-threatening illness, felt pain and isolation, and finally they felt sacrificed.

In summary, the findings of FGDs (negative transitions) have shown that Japanese women with cancer are stigmatised in the Japanese society.

Methodological issues

The advantages of FGDs over individual face-to-face interviews were not fully achieved due to a small number of participants. This was because potential participants were purposively selected from people who both reported swelling and provided their contact details. The number was fewer than expected. It is believed that FGDs are methodologically advantageous, but practically challenging in terms of recruitment. This may have something to do with Japanese culture; as briefly introduced through the word '*uchi*' (insider) and '*soto*' (outsider) in Chapter 5, it is hard for Japanese people to talk about their personal experiences to outsiders with whom they are not familiar. Even though the researcher / author is Japanese, most people in the self-help groups may have thought that she was an outsider and therefore not trustworthy.

Relating to the sample size, it is uncertain whether or not data saturation was achieved, although no new concepts were extracted from the third FGD transcript.

Despite a limited number of participants, the transcripts revealed that the data were rich and contained enough detail to allow fairly detailed exploration of participants' cognitive and emotional processes since breast surgery.

Using the transcripts, a rigorous analytic approach was undertaken, and all themes and subcategories were defined in order to ensure mutual exclusiveness. Compared to thematic analysis, the second step of the analysis - conceptual analysis - was relatively subjective and interpretative in nature. It was guided by SI theory.

THE MAIL SURVEY STUDY (THE PSYCHO-SOCIAL DISCOMFORT SCALE)

Summary

The purpose of this survey study was to design a new psycho-social discomfort scale and to investigate its psychometric properties in a new sample with BC.

First, based on the findings of the conceptual analysis on the FGDs, thirty questions were composed; these asked about perceptions of lymphoedema, the meaning of life, social norms, feelings about social norms, help-seeking behaviour, and needs (dis)satisfactions. An indirect question format (e.g. it is believed that) was suggested in order to reduce social desirability effects (Chen et al.1995; Zax and Takahashi 1967). On the other hand, it was not certain whether the indirect format could convey personal meanings. Thus, it was decided to pilot both the indirect and the direct formats for Japanese women first, and to pilot the version which was found more appropriate with BC patients.

Second, to test the face validity of the new questions and to determine which versions were most appropriate to assess personal experiences, Japanese women were recruited by convenience sampling, and telephone interviews were conducted; nine women participated. The results showed some inappropriate words for cancer patients, non-understandable words and phrases, grammatical errors, and inappropriate words for females. In terms of personal meanings, an indirect question format was not supported. Taking into account the comments, the questions were revised and a direct question format was used for the next study. Four questions concerning the doctor-in-charge and lymphoedema disclosure were subsequently added.

Next, a web-based pilot study was conducted among BC patients via on-line self help groups using the revised questionnaire; patients were allowed to give their feedback in free-text formats. Twelve BC patients with lymphoedema took part. From descriptive analyses, there were found to be few missing data and some participants reported difficulties in understanding the five-point scales and the question about lymphoedema. Taking these into consideration, more detailed explanations of how to use the five-point scale were added, and the question on lymphoedema was revised.

Third, a cross-sectional survey was conducted; seven self-help groups across Japan participated in the study. Questionnaire packages were distributed to members (N = 620), including those other than BC, by group coordinators. A total of 301 questionnaires (including one patient with ovarian cancer) were returned. Questionnaire packs included information letters, letters from the coordinators, correspondence sheets, returned envelopes with stamps, the questionnaire used in the first survey study (Chapter 4), the psycho-social discomfort scale, and WHO QoL-BREF Japanese version. Correspondence sheets were used to provide participants who completed the two questionnaires with incentives (500 Yen book tokens). During the data entry process, it was found that there were a lot of missing data on lymphoedema-related items. A follow-up questionnaire was sent to participants who were eligible for the incentives and had thus provided contact details.

Next, the psychometric properties of the scale were investigated. To examine internal structures, factor analysis was performed between BC and lymphoedema-related items separately, because of considerable missing values. On BC-related items, a principal axis factor analysis with promax rotation extracted three factors, and they were named psychological impacts of perceived social norms (12 items; Cronbach's Alpha = 0.74), social disclosure (five items; Cronbach's Alpha = 0.83), and resources to live with BC (nine items; Cronbach's Alpha = 0.70). The three factors were moderately correlated; psychological impacts and social disclosure was r = 0.36, psychological impacts and resources to live with BC was r = - 0.20, and social disclosure and resources to live with BC was r = - 0.38. Summary scores of each subscale were created; higher scores indicated more severe discomfort.

Convergent and divergent validity were tested using WHOQoL-BREF Japanese version; it is a standardised QoL questionnaire and has good internal consistency (Tazaki and Nakane 1997). Since the high scores of the discomfort scale indicated severe discomfort, and the high score of the WHO QoL-BREF was good QoL, negative correlations were anticipated between the two measures. Correlations between the three factors and WHO QoL-BREF Japanese versions were all negative and significant, and all correlations were moderate (correlations between social disclosure and the environment domain in WHO QoL-BREF were not statistically significant); psychological impacts of perceived social norms, social disclosure, and resources to live with BC all were most strongly associated with the psychological domain in

WHO QoL-BREF.

On criterion validity, women who had undergone mastectomies experienced more severe discomfort with perceived social norms than those who had undergone lumpectomies, and women who had developed lymphoedema experienced more severe discomfort with perceived social norms than those who had not. Younger aged women (< 60 years old) experienced more discomfort in disclosing their BC than older aged women, and women with stage I BC experienced more discomfort in disclosing their illness than those with stage II BC. Women who had perceived information provision at diagnosis as insufficient experienced poorer resources to live with BC. Women who had perceived information provision since breast surgery as insufficient also experienced poorer resources to live with BC.

On lymphoedema-related items, a principal axis factor analysis with promax rotation extracted two factors, and they were named acceptance of lymphoedema (four items; Cronbach's Alpha = 0.59) and perceived controllability (two items; Cronbach's Alpha = 0.46). Summary scores of each subscale were created; a higher score indicated more severe discomfort.

Correlations between the two factors and WHO QoL-BREF were all negative (except correlations between perceived controllability and the environment domain), and only acceptance of lymphoedema was significantly correlated with the physical, psychological and social domains in WHO QoL-BREF. On criterion validity, women who had lymphoedema for more than three years felt less control than those who had so for less than three years.

On inter-factor correlations among the five subscales, the one item global score (Chapter 4) was significantly correlated only with the ALPDS and resources to live with BC, but was moderately correlated with the other subscales (except 'social disclosure'). The ALPDS were significantly correlated with psychological impacts of perceived social norms, resources to live with BC, and acceptance of lymphoedema. Psychological impacts of perceived social norms, social disclosure, and resources to live with BC were significantly associated with acceptance of lymphoedema. Perceived controllability was moderately and significantly correlated with acceptance of lymphoedema.

Discussion

Regarding the sample size of factor analysis, for the BC factors the sample size was 258, and there were 27 items. Nunnally et al. (1967) suggests a minimum sample size requires ten respondents per item; more respondents are needed. Next, for the lymphoedema factors, the sample size was 97, and there were seven items, so a minimum sample size required 70. The sample size seems adequate to perform a factor analysis on the items.

Criterion validity and inter-factor correlations supported the ideas extracted from the FGDs study; psychological impacts of perceived social norms were positively correlated with social disclosure (r = 0.33), and resources to live with BC were positively correlated with the acceptance of lymphoedema (r = 0.36). Also, correlations between the new measure and WHO QoL-BREF revealed that the subscales (except perceived controllability) were associated with QoL; the new questionnaire including the ALPDS can measure the same general concepts as the WHO QoL-BREF, but different aspects of QoL.

Among the BC factors, psychological impacts of perceived social norms could distinguish patients with and without lymphoedema. This indicates that BC patients with lymphoedema are experiencing additional physical burdens (BC plus lymphoedema) which may lead to difficulty in playing their social roles, and consequently the patients feel themselves more inferior to healthy women. This negative view caused by BC also affects appraisals of lymphoedema, as the inter-factor correlations among BC patients with lymphoedema have shown; psychological impacts of perceived social norms were positively and significantly correlated with both the ALPDS and acceptance of lymphoedema.

Regarding discomfort with social disclosure, the mean score of social disclosure significantly differs between younger and older aged patients; younger aged patients experienced more difficulty in disclosing cancer. This is inconsistent with results from a previous study in the West; Henderson et al. (2002) reported that younger aged BC patients in the USA were more willing to disclose their illness, and interpreted this finding in terms of influences of social norms and opportunities to disclose. In the present study, influences of social norms can be assessed by psychological impacts of perceived social norms but, as reported in Chapter 7, there was no age difference found in the mean score of the subscale. Henderson et al.'s interpretation may be applicable in this sample, though it is speculative; younger aged people in general have more opportunity to disclose their illness either intentionally or accidentally and, to some extent, have fewer skills to deal with uncomfortable interactions with others and therefore are more likely to feel discomfort than older aged people.

Additionally, the mean score of social disclosure significantly differs between patients with stage I and II. Henderson et al. (2002) also reported that disease severity predicted social disclosure in their sample; BC patients with advanced stage were more likely to discuss their illness with others. However, in the present study, the difference between stage I and III, and II and III were not found.

The mean score of psychological impact of perceived social norms differs between participants who underwent mastectomies and lumpectomies. This result is consistent with those of several studies in the West; a breast loss is considered to affect women's femininity (Harcourt and Rumsey 2001). A qualitative study in Japan (Takahashi and Kai 2005) also showed that a breast loss impacts on women's femininity and arouses feelings of fear when they consider their partner's reaction.

Perceptions of information provision are only associated with resources to live with BC in the present sample. Considering the findings of first survey study (Chapter 1) together, perceived information provision significantly affects both physical discomfort and perceived resources. This is consistent with a previous quantitative study using the European Organisation of Research and Treatment of Cancer (EORTC QoL-C30); Kerr et al. (2003) reported long-term benefits of perceived information provision in a sample of BC patients.

It may be worthwhile noting that, in the present survey study, perceptions of information provision at both diagnosis and since surgery were related to perceived resources to live with BC and the level of physical discomfort (bivariate statistics in Chapter 4). These findings indicate that it is important to continue providing adequate information whenever patients seek help. This may give patients reassurance (Thewes et al. 2004), feelings of being cared for (Marlow et al. 2003), and a basis to overcome any negative transitions due to BC, as the inter-factor correlation has shown.

On the lymphoedema-related factors, it was assumed that there was one underlying factor, but the factor analysis revealed that there were two factors. The factor structure was weak so that there were few associations with WHO QoL-BREF and the variables in the research questions. Thus, the results need to be interpreted with caution. Acceptance of lymphoedema was significantly associated with the physical, psychological and social domains of WHO QoL-BREF: patients who did not accept the onset of lymphoedema tended to report worse QoL. Additionally, patients who reported more severe physical discomfort were less likely to accept lymphoedema than those who did not. This association between perceived acceptance and QoL has been reported among patients with chronic pain (Viane et al. 2003) and with chronic fatigue syndrome (Damme et al. 2006); Damme et al. reported that perceived acceptance was most significantly associated with emotional stability and lower levels of fatigue.

Methodological issues

The present study was a cross-sectional study so that any causality and direction cannot be determined. Also, as the sample was limited to self-help groups, the findings cannot be generalised to all BC with lymphoedema patients, even though participants were widely recruited across Japan.

As reported in Chapter 7, there are many missing data on the entire dataset, especially the lymphoedema-related items. This is considered to be due to inappropriate instructions and scale modifications; more than half the participants who had developed arm complications did not perceive them as an early symptom of lymphoedema, and then responded to the point of ‘no lymphoedema’. Although this was not expected, if the web-based pilot study had included the entire questionnaire, and had recruited BC patients both with and without lymphoedema, this problem may have been identified in advance. Additionally, the statement should have been ‘people who have reported arm complications, please answer all questions below’, and thereby the extent of missing data could have been reduced.

Additionally, compared to the first survey study (Chapter 4), missing data on demographics, especially the question that asked about household income, were greater. Estimation of household income suggested that average income was lower than that in the first survey study. Forty per cent of participants were over 60 years old. Most of them and their partners may be retired, so that it is assumed that they are living on pensions. Participants may be reluctant to provide personal financial details, even though confidentiality was assured and the question did not ask directly about household income.

On the response rate, compared to the first survey study, the response rate was a little increased (around six per cent) in spite of the longer questionnaire that might have fatigued participants. This may be due to the effects of incentives provision, but this rate was lower than expectations. Compared to recent studies in Japan (Inoue et al. 2003; Mantani et al. 2007), more older people and those who survive longer years since surgery participated in the present study. It may be difficult for them to fill in the longer questionnaire plus the QoL questionnaire without any assistance. This may have influenced the response rate. In terms of research in medicine (in Japan) overall response rates are around 50 per cent (Personal discourse - Dr Saito). Thus, the response rate may be reasonable.

In order to increase the response rate, face-to-face structured interviews may be worthwhile considering but, on the other hand, social desirability may influence responses to questions related to sexuality and social norms; in WHO QoL-BREF, the question about sexuality had more missing values than the other items. This biased response has been reported in a survey study among the Hong Kong Chinese population (Fielding and Lam 2004). It cannot be assumed without any evidence that Japanese people would respond in the same way as Hong Kong Chinese, but it should be kept in mind when considering future administrative methods.

The aim of this research programme was to develop a new measure among BC patients with lymphoedema in Japan, but the aim has not been reached fully since the lymphoedema scales were not found to be sufficiently reliable (Cronbach's Alpha < 0.60). This may be because the follow-up data (Chapter 7) were included in the analysis. More importantly, a few conceptually relevant items were not included in the scale. To improve the scale, more conceptually relevant items should be composed and more adequate instructions given, and then psychometric properties should be investigated in a new sample.

In terms of the items in the psycho-social discomfort scale, BC-related items seem to dominate. However, as reported in Chapter 6, BC patients with lymphoedema interpreted experiences of lymphoedema in BC contexts; they tend to apply neither social comparison (Festinger 1954) nor comparisons between events happening during the past few weeks and the present life (Schwarz and Bless 1992). Thus, it was necessary to include sufficient BC related-items in the new measure in order to discover how the patients formed the perception of lymphoedema, and quantitatively to investigate associations among the subscales.

Finally, although the relationships between interpersonal rejections and help-seeking behaviour were cited in the FGDs, since questions about help-seeking behaviour were not included in the final quantitative study, the relationships are unclear.

In summary, this study has revealed the cognitive and emotional functions formed by interaction with others and society and how this process affects QoL. The findings supported those of the qualitative study guided by SI, and quite similar results to those of previous studies in the West were obtained. It is suggested that the lymphoedema-related factors are revised, and more conceptually relevant items are added.

IMPLICATIONS OF THE STUDIES

Despite several potential shortcomings or limitations, it is worthwhile considering further studies and clinical implications. There are several suggestions for further studies: (1) a clinical application of the ALPDS, (2) an applications of the psycho-social discomfort scale to patients who do not join self-help groups and cancer patients with other than BC, (3) an educational programme for BC patients, (4) further investigation of factors associated with positive gains, (5) revisions of the lymphoedema subscales and further investigation of the association between the subscales and QoL, and (6) development of rehabilitation programmes for post-operative BC patients.

First, the symptom checklist and ALPDS should be distributed to BC patients with and without arm lymphoedema in order to examine any differences between the two samples since, through the three studies, comparative methods were not applied. Additionally, whether the symptom checklist and ALPDS are appropriate and useful in clinical settings should be assessed. In the studies, most patients reported that doctors had diagnosed lymphoedema by inspection or palpation. The checklist and the ALPDS could be helpful in assessing patients' symptoms and discomfort systematically. Also the ALPDS and symptom checklist is concise so that nurses can ask patients to fill it in at out-patient clinics during the follow-up visit. Monitoring individual conditions may help health care professionals to detect early signs of lymphoedema and provide adequate treatment and support.

Relating to this, perceptions of information provision were quantitatively associated with physical discomfort and resources to live with BC. This result suggests that the timing and adequacy of information is important in reducing physical and psychological burdens; if patients encounter any difficulties after discharge, adequate information provision can give them not only knowledge and skills of problem management but also reassurance (Marlow et al. 2003; Thewes et al. 2004).

This finding has also suggested a possibility of clinical trials. For example, following the development of an educational device (e.g. a leaflet or audiovisual programme), patients at the diagnosis phase could be randomly assigned into two groups: control (usual doctor's practice) and experimental (giving additional information provision) groups. Assessment of QoL would be made at baseline and follow-up visits until two or three years after the diagnosis in order to investigate how information provision affects QoL (in the final survey study, more than 90 per cent of participants developed arm complications within three years of breast surgery).

Next, on the psycho-social discomfort scale, whether or not the mean score of the scales are different between BC patients who join self-help groups and those who do not should be explored; BC patients in self-help groups have an opportunity to be provided with peer-support and find new friends with BC, as some participants in the qualitative study reported. Thus, this additional resource provision may affect any differences between the two groups.

Although the research aimed to develop a BC specific measure, it is uncertain if the scales are BC and BC-related lymphoedema specific measures, as comparative studies were not carried out. The BC subscales may apply to patients other than BC, for example, ovarian or uterus cancer patients. There is some evidence that ovarian cancer patients may suffer from infertility due to the surgery, and they often feel inferiority and loss of their sense of femininity (Howell et al. 2003), and the surgery often leads to secondary lymphoedema. Patients in this category should be equally studied. Seventy per cent of lymphoedema patients who join lymphoedema self-help groups in Japan are ovarian and uterus cancer patients and thirty per cent are BC patients. Because of the proportions and similar issues that the patients might experience, it would be worth while investigating the psychometric properties among more patients, and to conduct some comparative studies.

Perceived social norms and discomfort in disclosing illness had a great impact on BC patients' QoL. Patients and others surrounding them seem to hold irrational beliefs (e.g. 'I have (she has) a responsibility to do this as a wife or mother even when I am sick'). These beliefs are formed by the society and others surrounding the patient. Health care professionals and self-support groups should make an effort to provide patients' families with information and, if they have misconceptions of the illness, the health care professionals may need to provide educational programmes in order to improve equality between patients and families (Kuijer et al. 2004). Counselling services for BC patients and husbands have been launched at an out-patient clinic (Hiroshima University, Japan) to improve family functioning and emotional well-being. This may be helpful to improve the interpersonal relationships, and thereby patients' and family members' QoL.

If psychologists are involved in education programmes, cognitive-behavioral therapy may be useful in changing patients' and family members' cognitions. For example, Egan's (1986) problem management approach may be useful; Egan proposed three structured steps for people to identify problems, set their own goals, and take actions, and counsellor help to people reach their own goals. The psycho-social discomfort BC subscales can be used to assess those who report high discomfort scores on each subscale. Then, they would be randomly divided into two groups: control and experimental groups. In the experimental group, several counselling sessions for a short-period of time (e.g. less than 6 months) will be provided; the control group would be offered alternative activities. QoL would be assessed at the baseline and after the completion of the sessions in order to investigate the impact of the sessions on QoL.

Additionally, resources to live with BC are an important factor to improve patients' QoL. In the FGDs, the process of how most participants gained positive aspects of BC was unclear, especially a sense of gratitude and spirituality. Some studies have shown that a sense of gratitude may be associated with personality dispositions, such as extraversion (McCullough et al. 2004), and other studies have shown that personal growth may be associated with talk about one's illness (Cordova et al. 2001). Again, BC patients in the present study who had difficulty in talking about their own illness were younger aged patients. Since previous studies have investigated potential predictors individually, it is necessary to investigate all potential variables quantitatively. Since the area of positive psychology is relatively new in Japan, further research should be carried out to understand the mechanism, and consequently to find ways that maximise patients' QoL.

The lymphoedema subscales need to be revised and psychometric properties and associations with QoL among BC patients with lymphoedema should be investigated. Perceived controllability may be related to help-seeking behaviour (Frostholm et al. 2005) and involvement in rehabilitation programmes (Whitmarsh et al. 2003); in the third study, more than half of the participants who reported arm symptoms did not perceive them as signs of lymphoedema, and lymphoedema diagnosis was made for fewer participants than for those who reported arm symptoms. As the thematic analysis of FGDs revealed, participants tended not to persist with therapy that doctors and specialist provided because of perceived ineffectiveness of medication and the inconvenience of compression sleeves. This may indicate that participants perceived that their arm conditions might be controllable and curable in the future.

The perceived controllability and curability may be associated with how doctors explain the nature of lymphodema and therapeutic management before and after breast surgery. Information provision may play an important role for patients to reduce physical and psychological burdens associated with lymphoedema. Although perceptions of information provision seem to affect acceptability (less psychological burden) in the FGDs, the evidence was not quantitatively obtained in the second survey study. It may be worthwhile investigating how the illness perceptions and perceptions of information provision affect arm therapy-taking and, consequently QoL; as far as the author knows, impacts of illness perceptions (acceptance and perceived controllability) on QoL have not been investigated among lymphoedema patients.

Additionally, a recent study in Australia (Gordon et al. 2005) has shown that BC patients who receive a post-operative rehabilitation programme did not report better QoL other than physical functioning at 12 months since BC diagnosis. Thus, development of more psychological, including illness perceptions-focused, programmes may be needed.

In summary, little research on lymphoedema has been conducted as yet in Japan, and this research programme has been helpful in starting to understand issues among BC patients with lymphoedema. Several directions of further research have been suggested.

Final remarks

It is worthwhile to describe how my personal experiences and M.Sc work formed the idea of this research programme.

First, through my mother's death from cancer, I felt the importance of information and psychological care provision; initially my mother had been diagnosed with fibroids and underwent surgery, and my family had been relieved that the surgery was successful. Around one year later, she found her head swollen, and believed that was because she knocked her head on a dog's house. When I touched her head, I felt afraid because it was not a usual bump, and I encouraged her to see a doctor as soon as possible. As a result of medical examinations, the doctor decided to operate on her head; during the operation, my family was told that there was a lump that had metastasised from the uterus. We could not understand what the doctor was talking about, since we believed that she had developed 'fibroids'.

At that time (nearly fifteen years ago), truth telling practice was debatable in Japan so that doctors did not want to tell patients the truth in person. My mother's doctor asked my father to tell her about the cancer, but my father refused the doctor's request since there was nobody to psychologically support her and himself. My mother underwent chemotherapy without knowing her true diagnosis and the purpose of the treatment. Because her cancer was stage IV, cancer cells had spread over her entire body and a prognosis was very poor. These facts were not told to the family. Since we believed that surgery was the only way to cure her, we agreed with doctor's suggestions of further several surgeries. Because of severe side effects of chemotherapy and several surgeries my mother questioned us about her illness; when she asked me about her real diagnosis, I told a lie. Immediately I found disappointment and sadness in her eyes, and her condition got worse. She fought against cancer for five years since the second operation.

After my mother's death, I wished to find some answers about truth telling practice and psychological care for cancer patients and families. I came across the words 'health psychology and psycho-oncology' in the Internet. Since there were no institutions to study health psychology in Japan, I planned to take a course in the UK (University of Southampton). As a part of my course work, I conducted a qualitative study in Japan, exploring information needs among Japanese breast cancer patients. I found that most participants complained about inadequate information provision and care provision after discharge, and that some participants were anxious about post-operative arm symptoms and lymphoedema. Since surgeons did not adequately explain about the risks of lymphoedema and the management of arm symptoms, participants felt distress and fear for uncertainty. This seemed to somehow associate with QoL. Therefore, in this research programme, the topic of breast cancer related-lymphoedema and QoL was chosen, and a series of studies was conducted in Japan.

Through this research programme, I have learnt how to work with community-based groups in Japan and the importance of interpersonal skills. I encountered some problems with the recruiting process, especially in the second survey study. As I have reported, I first approached lymphoedema self-help groups. Before talking to gate keeping persons, I optimistically thought that they would agree with participation, if confidentiality was assured, the study procedure was clear, the research topic was relevant to the groups (these were learnt through my previous studies). However, the gatekeepers were somehow protective and concerned about the benefits for their own group, not all lymphoedema patients. Additionally, it was found that some groups competed with each other, after I talked to gatekeepers. Due to time constraints, I approached the groups simultaneously by sending a letter, but this may not be the best way when considering competition among groups. I have also learnt that it usually takes three to six months to obtain final permission from gatekeepers, so that good interpersonal skills and frequent contact with people are necessary.

Appendices

Appendix 4.1 ***The Questionnaire of Study One***

Questionnaires for Participants

How to Answer Questions

Example 1 **If you are female, please tick one appropriate box as follows.**

Q: Sex Female ☑
Male ☐

Example 2 **If you are 30 years old now, please write down '30' in a parenthesis as follows.**

Q: You are (30) years old now.

Example 3 **If you see '*You can tick as many as necessary' under the questions,
please tick more than one box, if applicable.**

Q: What are your hobbies? Cooking ☑
*You can tick as many as necessary. Gardening ☑
Cleaning ☐

Example 4 **If you see the five faces just after the questions,
please circle the number which best shows the way you felt.**

Q: How well did you sleep last night?

[✓ 1] 2 3 4 5

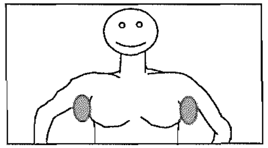
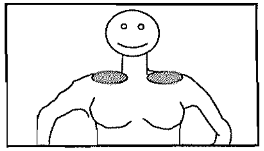
Appendix 4.1 (continued)

Part I: Yourself

1. Sex	Female	☐		
	Male	☐		
2. Age	(	) years old now		
3. Marital Status	Single	☐		
	Married	☐		
	Divorced	☐		
	Widowed	☐		
4. Numbers of Children	(	)		
5. The highest level of education achieved	Elementary school	☐		
	Junior high school	☐		
	High school	☐		
	Technical school	☐		
	College	☐		
	University	☐		
			Full time	☐
6. Do you have any paid employment?	Yes	☐ →	Part-time	☐
	No	☐ →	Housewives	☐
			Students	☐
			Other	☐
7. Which best describes the person's occupation, which bears your livelihood?	Directors at limited liability companies that go public at stock market	☐		
	Employees at limited liability companies that go public at stock market	☐		
	Directors at limited liability companies that do not go public at stock market	☐		
	Employees at limited liability companies that do not go public at stock market	☐		
	Nation servant	☐		
	Local servant	☐		
	Self-management	☐		
	Farmers or Fishers	☐		
	Other	☐		
8. What language do you usually speak?	Japanese	☐		
	Other	☐		

Appendix 4.1 (continued)

Part II: Breast cancer

1. When did you have breast surgery?	( ) Year ( ) Month		
2. Which breasts did you have surgery on?	Right breast	☐	
	Left breast	☐	
	Both breasts	☐	
3. What types of surgery did you take?	Lumpectomies	☐	
	Quadrantectomies	☐	
	Simple mastectomies	☐	
	Modified radical mastectomies	☐	
	Radical mastectomies	☐	
	Unknown	☐	
4. Did you have axillary lymph node dissection?	Yes	☐	
	No	☐	
	Unknown	☐	
5. Did you take chemotherapy after surgery?	Yes	☐	
	No	☐	
6. Did you take hormonal therapy after surgery?	Yes	☐	
	No	☐	
7. Did you take radiotherapy after surgery?	Yes	☐	
	No	☐ →	If you have answered 'No', please go straight to Q8.
7a. Which areas were irradiated?	Axillary fossa	☐	Supraclavicular fossa ☐
			
8. Do you know your stage of breast cancer?	Yes	☐ →	Could you tell me that? ( )
	No	☐	
	Unknown	☐	

Appendix 4.1 (continued)

5. After breast surgery, have you had any arm problems?	Yes	☐	
	No	☐ →	**If you have answered 'No', please stop here and post the questionnaire. Thank you very much for your participation.**
5a. Which arms have you felt uncomfortable?	Right arm	☐	
	Left arm	☐	
	Both arms	☐	
5b. What kinds of arm problems have you ever had? *You can tick as many as necessary.	Pain	☐	
	Swelling	☐	
	Numbness	☐	
	Loss of strength	☐	
	Poor rage of motion	☐	
	Other	☐ →	Could you tell me that? ( )
5c. How long have you been suffering from the problems?	>1 year	☐	
	1≦ >3 years	☐	
	3≦ >5 years	☐	
	≧5 years	☐	
6. Have you ever had therapies for the problems by doctors?	Yes	☐	
	No	☐ →	If you have answered 'No', please go straight to Q7.
6a. What types of therapies have you ever had? *You can tick as many as necessary.	Skin care	☐	
	Compression sleeves	☐	
	Exercise	☐	
	Manual lymphatic drainage	☐	
	Compression pumps	☐	
	Surgery	☐	
	Other	☐ →	Could you tell me that? ( )
7. Do you usually do any therapies for the problems yourself at home?	Yes	☐	
	No	☐ →	If you have answered 'No', please go straight to Q8.
7a. What types of therapies do you usually do yourself?	Skin care	☐	
	Compression sleeves	☐	
	Exercise	☐	
	Massage	☐	
	Other	☐ →	Could you tell me that? ( )

Appendix 4.1 (continued)

8. How much discomfort have you experienced as a result of the problems overall?


1 2 3 4 5

9. What has the discomfort affected in your everyday life?
*You can tick as many as necessary.

Paid work ☐ → How much discomfort?


1 2 3 4 5

Household chores ☐ → How much discomfort?


1 2 3 4 5

Grooming ☐ → How much discomfort?


1 2 3 4 5

Hobbies ☐ → How much discomfort?


1 2 3 4 5

Sleeping ☐ → How much discomfort?


1 2 3 4 5

Meeting somebody ☐ → How much discomfort?


1 2 3 4 5

Other ☐ → Could you tell me that? ( )

→ How much discomfort?


1 2 3 4 5

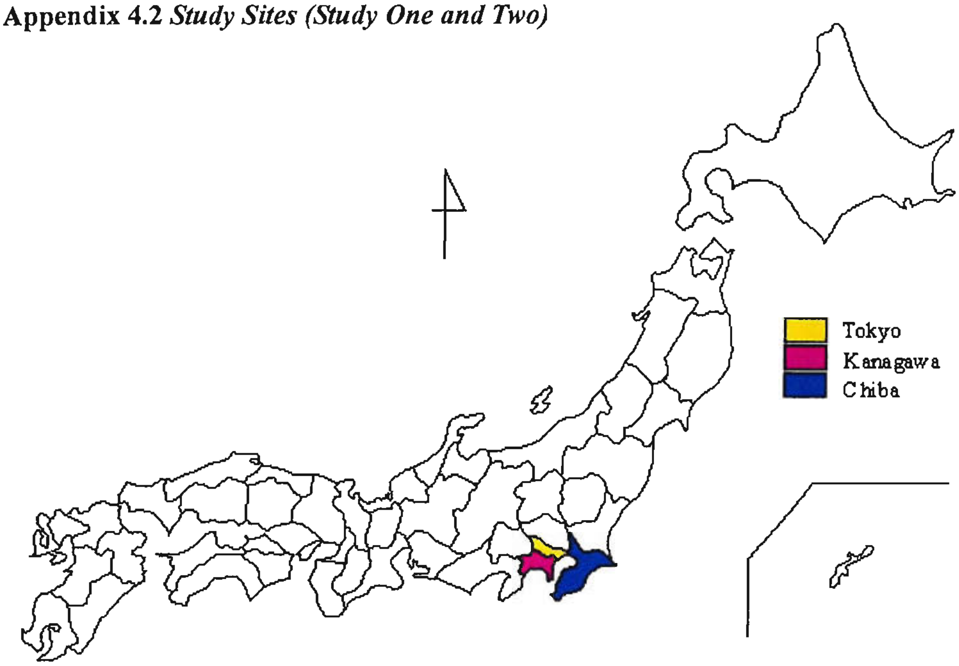
Appendix 4.1 (continued)

Please write down any comments about this questionnaire below.

(e.g. unclear words and pharases or questions you would like to have been asked, the time taken to complete the questionnaire etc.)

Thank you very much for your cooperation. Please post the completed questionnaire using the returned envelope right now.

Appendix 4.2 *Study Sites (Study One and Two)*



Appendix 4.3 *The Information letter of the Study One*

**University
of Southampton**

Dear Madam,

18 Aug 2003

I am sending this letter to members of *name of self-help group*, who may be interested in participation in a pilot study. I appreciate *the name of coordinator* cooperation.

My name is Miyako Tsuchiya, and I am a research student at University of Southampton in the UK. I plan to conduct a research project, entitled breast cancer patients' Quality of Life after surgery. I plan to conduct both questionnaire and interview studies in Japan. I would appreciate that you could take part in the pilot questionnaire study.

Would you give me **15minutes** to answer questions in the questionnaire (printed in coloured paper)? There is a free space on the last page for you to freely write your own opinions and ideas regarding the questionnaire; for example, the layout, difficult words and phrases to understand, or questions that you would like to have been asked and so on. I would like to really know your honest opinions and to reflect them to revise the questionnaire.

Of course, this is on a voluntary basis, and your personal information is anonymous and confidential - this is only used for research purposes. If you begin the study and then change your mind, you have the right to withdraw at any time without giving a reason.

I would really appreciate if you could return the completed form **within two weeks** using the provided envelope with stamps. *If you return your completed questionnaire, I will take that as evidence that you understand the nature of the study and your part in it, and that you give me your consent to take part in the questionnaire part of the study.*

If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact the Chair of the Ethics Committee, Department of Psychology, University of Southampton, SO17 1BJ. Phone: +44 (0)23 8059 3995.

If you have any inquiries, please do not hesitate to contact me via email or mobile phone.

Thank you for your time and attention.

(the author's contact)

Appendix 4.4 *The Information Letter of the Study Two*

University
of Southampton

Dear Madam, 09 October 2003

I am sending this letter to all members of *name of the self-help group*. I appreciate coordinator, *the name of coordinator*'s cooperation.

My name is Miyako Tsuchiya, and I am a research student at University of Southampton in the UK. I am doing a research project on breast cancer patients' Quality of Life after surgery. I plan to conduct some interviews in Japan, and I am looking for Japanese women with breast cancer who are willing to participate in group discussions. I think that this is a good opportunity for you to talk to others, who have similar experiences to yours, and to hear others' opinions. I believe that the session will be enjoyable for you. I plan to have one hour and half group discussions in either Yokohama or Tokyo, and the whole discussions will be tape recorded; audiotapes will be destroyed after an analysis.

If you had **breast surgery**, would you give me **15minutes** to answer questions in the questionnaire (printed in coloured paper)? I would like to explore some of these issues further in group discussions, and I would like to know if you are willing to take part in those, too.

Of course, this is on a voluntary basis, and your personal information is anonymous and confidential - this is only used for research purposes. If you begin the study and then change your mind, you have the right to withdraw at any time without giving a reason. If you are interested in taking part in group discussions, please give me your contact details at the bottom in the questionnaire. I will contact you later on together with more detailed information such as the date, time and venue for group discussions.

I would really appreciate if you could return the completed form using the provided free-post envelope (you do not need to put stamps) to the coordinator's home **by 24 October (Fri) 2003**.

I may ask some later, who return the questionnaire, to fill out same questionnaire again. This is very important and standardised procedure to check the reliability of the questionnaire itself, not your responses. I would appreciate if you could understand this procedure and take part in this study. *If you return your completed questionnaire, I will take that as evidence that you understand the nature of the study and your part in it, and that you give me your consent to take part in the questionnaire part of the study.*

If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact the Chair of the Ethics Committee, Department of Psychology, University of Southampton, SO17 1BJ. Phone: +44 (0)23 8059 3995.

If you have any inquiries, please do not hesitate to contact me via email or mobile phone. If you are not a patient, I apologise that I mailed this letter to you in error.
Thank you for your time and attention.
(the author's contact)

Appendix 4.5 ***The Revised Questionnaire of Study Two***

Questionnaires for Participants

How to Answer Questions

Example 1 **If you are female, please tick one appropriate box as follows.**

Q: Sex
Female ☑
Male ☐

Example 2 **If you are 30 years old now, please write down '30' in the parenthesis as follows.**

Q: You are (30) years old now.

Example 3 **If you see '*You can tick as many as necessary' under the questions,**
please tick more than one box, if applicable.

Q: What are your hobbies?
*You can tick as many as necessary.
Cooking ☑
Gardening ☑
Cleaning ☐

Example 4 **If you see the five faces just after the questions,**
please circle the number which best shows the way you felt.

Q: How well did you sleep last night?

[✓ 1] 2 3 4 5

Example 5 If you see the arrow (⟶) next to your marked answer, please answer the following question as the instruction indicates.

Q: What are your hobbies?
*You can tick as many as necessary.
Cooking ☑ ⟶ How much do you like to do?

[✓ 1] 2 3 4 5

Gardening ☐ ⟶ How much do you like to do?

1 2 3 4 5
(Do not mark)

Q: Do you have breakfast at home everyday?
Yes ☑ ⟶ If you have answered 'Yes', please go straight to **the next page**.
No ☐

Appendix 4.5 (continued)

Date: ___ year ___ month ___ day

Part I: I will ask about you.

1. Sex	Female	☐		
	Male	☐		
2. Age	(	) years old now		
3. Marital Status	Single	☐		
	Married	☐		
	Divorced	☐		
	Widowed	☐		
4. Numbers of Children	(	)		
5. The highest level of education achieved	Elementary school	☐		
	Junior high school	☐		
	High school	☐		
	Technical school	☐		
	College	☐		
	University	☐		
			Full time	☐
6. Do you have any paid employment?	Yes	☐ →	Part-time	☐
	No	☐ →	Housewives	☐
			Students	☐
			Other	☐

7. Which best describes the person's occupation, which bears your livelihood?	Directors at limited liability companies that go public at stock market	☐
	Employees at limited liability companies that go public at stock market	☐
	Directors at limited liability companies that do not go public at stock market	☐
	Employees at limited liability companies that do not go public at stock market	☐
	Government officials	☐
	Local government officials	☐
	Self-management	☐
	Farmers or Fishers	☐
	Other	☐
8. What language do you usually speak?	Japanese	☐
	Other	☐

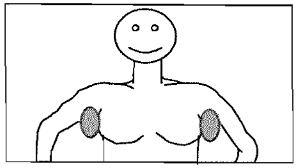
Appendix 4.5 (continued)

Part II: I will ask about your breast cancer.

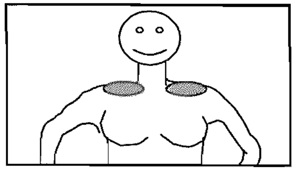
1. When did you have breast surgery?	( ) Year ( ) Month		
2. Which breasts did you have surgery on?	Right breast	☐	
	Left breast	☐	
	Both breasts	☐	
3. What types of surgery did you take?	Lumpectomies	☐	
	Quadrantectomies	☐	
	Simple mastectomies	☐	
	Modified radical mastectomies	☐	
	Radical mastectomies	☐	
	other	☐	→ Could you tell me that? ( )
	Unknown	☐	
4. Did you have axillary lymph node dissection?	Yes	☐	
	No	☐	
	Unknown	☐	
5. Did you take chemotherapy after surgery?	Yes	☐	
	No	☐	
6. Did you take hormonal therapy after surgery?	Yes	☐	
	No	☐	
7. Did you take radiotherapy after surgery?	Yes	☐	
	No	☐	→ If you have answered 'No', please go straight to **Q8 on next page**.

7a. Which areas were irradiated?

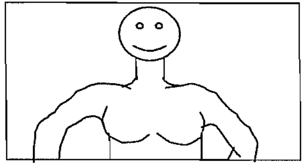
Axillary fossa ☐



Supraclavicular fossa ☐



Other ☐
(Please show the irradiated area below)



Appendix 4.5 (continued)

8. What is your stage of breast cancer as a result of pathological examination?

- Stage I ☐
- Stage IIA ☐
- Stage IIB ☐
- Stage IIIA ☐
- Stage IIIB ☐
- Stage IV ☐
- Unknown ☐

Stage A tumour is smaller than 2 cm and has not spread outside of the breast.
Stage II. A tumour is smaller than 2 cm and has spread to the lymph node under the arm, or a tumour is b
2 and 5 cm, but has not spread to the lymph node under the arm.
Stage II A tumour is between 2 and 5 cm and has spread to the lymph node under the arm, or a tumour is
than 5 cm, but as not spread to the lymph node under the arm.
Stage III A tumour is smaller than 5 cm, has spread to the lymph node under the arm, and the lymph node
attached each other or to other structures, or a tumour is larger than 5 cm, has spread to
the lymph node under the arm, and the lymph node are attached to each other or to other structu
Stage III A tumour has spread to chest wall or skin, or has spread to lymph node in the breast borne.
Stage I A tumour has spread to other organs of the body, or spread to the lymph nodes near the collarbo

9. Do you feel that you had enough information, when you were diagnosed?

- Yes ☐ → If you have answered 'Yes', please go straight to **Q10.**
- No ☐

9a. What kinds of information would you like to have had?
*You can tick as many as necessary.

- Treatment options ☐
- Side effects of surgery ☐
- Side effects of chemotherapy ☐
- Side effects of hormone therapy ☐
- Side effects of radiotherapy ☐
- Other ☐ → Could you tell me that? (   )

10. Do you feel that you had enough information, from the time of operation to now?

- Yes ☐ → If you have answered 'Yes', please go straight to **Part III on the next page.**
- No ☐

10a. What kinds of information would you like to have had?
*You can tick as many as necessary.

- Management of side effects of surgery ☐
- Management of side effects of chemotherapy ☐
- Management of side effects of radiotherapy ☐
- Management of side effects of hormonal therapy ☐
- Other ☐ → Could you tell me that? (   )

Appendix 4.5 (continued)

Part III: I will ask about your clinical history other than breast cancer

1. Have you had any prescribed medicine or treatment for your mood?	Yes	☐	
	No	☐	
; larger			
2. Have you ever been told overweight by doctors?	Yes	☐	
: are	No	☐	
3. Have you ever been diagnosed as hyperlipidaemia?	Yes	☐	
	No	☐	
ıne.			
4. Have you ever been diagnosed as lymphoedema?	Yes	☐	
	No	☐	→ If you have answered 'No', please go straight to **Q5**.
4a. What did the doctor do for the diagnosis? *You can tick as many as necessary.	Inspection	☐	
	Palpation	☐	
	Contrast medium	☐	
	Isotopes	☐	
	X-rays	☐	
	Blood Test	☐	
5. Have you had arm problems after breast surgery?	Yes		
	No	☐	→ **If you have answered 'No', please stop here. Please check omission in entry, and post the questionnaire. Thank you very much for your participation.**
5a. Which arms have you felt uncomfortable?	Right arm	☐	
	Left arm	☐	
	Both arms	☐	
5b. What kinds of arm problems have you ever had? *You can tick as many as necessary.	Pain	☐	
	Swelling	☐	
	Numbness	☐	
	Loss of strength	☐	
	Poor rage of motion	☐	
	Other	☐	→ Could you tell me that? ( )
5c. How long have you been suffering from the problems?	<1 year	☐	
	1≦ >3 years	☐	
	3≦ >5 years	☐	
	≧5 years	☐	

Appendix 4.5 (continued)

6. Have you ever had therapies for the problems by doct Yes ☐
No ☐ → If you have answered 'No', please go straight to **Q7**.

6a. What types of therapies have you ever had' Skin care ☐
*You can tick as many as necessary. Compression sleeves ☐
Exercise ☐
Manual lymphatic drainag ☐
Compression pumps ☐
Surgery ☐
Other ☐ → Could you tell me that? ( )

7. Do you usually do any therapies for the problems yourself at home? Yes ☐
No ☐ → If you have answered 'No', please go straight to **Q8**.

7a. What types of therapies do you usually do yourself at home? Skin care ☐
*You can tick as many as necessary. Compression sleeves ☐
Exercise ☐
Massage ☐
Other ☐ → Could you tell me that? ( )

8. How much discomfort have you experienced as a result of the problems overall?

9. What has the discomfort affected in your everyday lif Paid work ☐ → How much discomfort?
*You can tick as many as necessary.

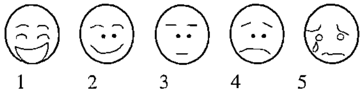
Household chores ☐ → How much discomfort?

Grooming ☐ → How much discomfort?

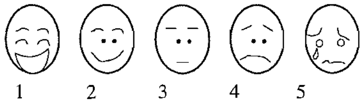
Hobbies ☐ → How much discomfort?

Appendix 4.5 (continued)

Sleeping ☐ → How much discomfort?

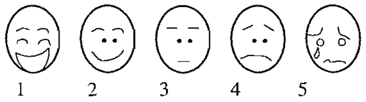


Meeting somebody ☐ → How much discomfort?



Other ☐ → Could you tell me that? ( )

→ How much discomfort?



10. Are you interested in taking part in a group discussion ?

Yes ☐ → If you have answered 'Yes', please write down your name and contact details below.

No ☐ I will contact you later on.

Name: ______________________________

Address: ______________________________

Phone No.: ______________________________

Thank you very much for your cooperation. Please check omissions in entry, and post the completed questionnaire using the returned envelope right now.

Appendix 4.6 *The Information Letter of the Study Two (the Second Time)*

**University
of Southampton**

Dear Madam, 10 November 2003

First, thank you very much for returning your completed questionnaire earlier.

As I mentioned in my first letter dated on 09 October 2003, I would like to ask you to fill out the enclosed questionnaire again to check the reliability of a questionnaire itself. The same person fills out the same questionnaire twice - this is very important and standardised procedure to check the reliability of a questionnaire, not of your responses.

With regard to selection, I have randomly selected some among people who returned the first questionnaire by the deadline. This means that I have not selected you by any answered responses in the first questionnaire.

Finally, I would really appreciate if you could return the completed questionnaire to the coordinator's home by **28 November (Fri), 2003** using the provided free-post envelope (you do not need to put stamps). I eagerly need your cooperation this time, too, but participation in the questionnaire study is on a voluntary basis, and your personal information is only used for research purposes, anonymous, and confidential. If you begin the study and then change your mind, you have the right to withdraw at any time without giving a reason.

If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact the Chair of the Ethics Committee, School of Psychology, University of Southampton, SO17 1BJ. Phone: +44 (0)23 8059 3995.

If you have any inquiries, please do not hesitate to contact me either via email or mobile phone.

Thank you for your time and attention. (The author's contact)

Appendix 4.7 *Two-way Analysis of Variance for Information at Diagnosis and Loss of Strength*

Source	df	MS	F	p
Information (IF)	1	663.709	14.890	0.000
Age (AG)	1	170.248	3.819	0.054
IF X AG	1	198.830	4.461	0.037^*
Error	93	44.574		
Information (IF)	1	734.317	15.944	0.000
Paid jobs (PDJ)	1	32.583	0.707	0.402
IF X PDJ	1	216.995	4.712	0.033^*
Error	93	46.055		
Information (IF)	1	605.817	12.842	0.001
Types of surgery (SGRY)	1	69.334	1.470	0.229
IF X SGRY	1	222.116	4.709	0.033^*
Error	83	47.173		
Loss of strength (S)	1	694.802	15.349	0.000
Years since surgery (YS)	1	61.136	1.351	0.248
S X YS	1	208.259	4.601	0.035^*
Error	95	45.268		

$^*p < 0.05$

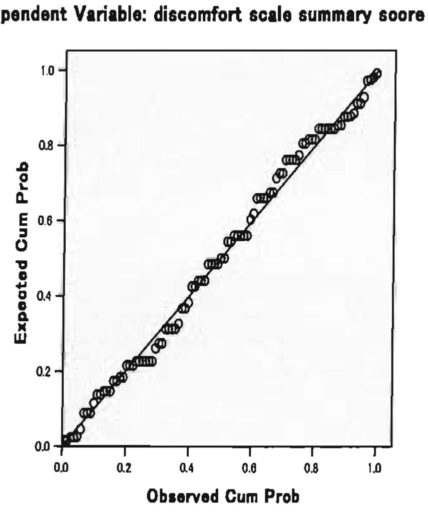
Appendix 4.8 *Simple Main Effects*

Source	SS	df	MS	F	p
IF within AG (1)	760.82	1	760.82	17.07	0.000*
IF within AG (2)	71.15	1	71.15	1.60	0.210
AG	170.25	1	170.25	3.82	0.054
R	4145.37	93	44.57		
IF within PDJ (1)	677.26	1	677.26	14.71	0.000*
IF within PDJ (2)	107.98	1	107.98	2.34	0.129
PDJ	32.58	1	32.58	0.71	0.402
R	4283.09	93	46.05		
IF within SGRY (1)	719.24	1	719.24	15.25	0.000*
IF within SGRY (2)	51.55	1	51.55	1.09	0.299
SGRY	69.33	1	69.33	1.47	0.299
R	3915.35	83	47.17		
LS within YS (1)	822.08	1	822.08	18.16	0.000*
LS within YS (2)	72.00	1	72.00	1.59	0.210
YS	61.14	1	61.14	1.35	0.248
R	4300.45	95	45.27		

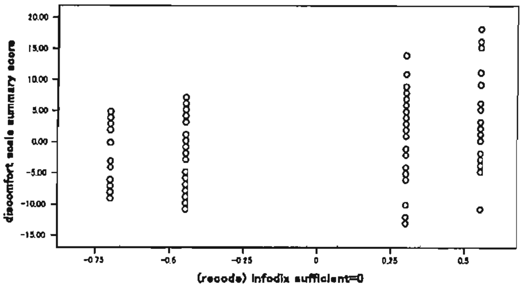
Note. IF represents perceptions of information provision at diagnosis, AG (1) represents age </= 53 years old and AG (2) represents age > 53 years old, PDJ (1) represents those having paid jobs, PDJ (2) represents those not having paid jobs, SGRY(1) represents lumpectomies, and SGRY (2) represents mastectomies. LS represents loss of strength, YS represents years since surgery < 3 years, and YS (2) represents years since surgery >/= 3 years.

*p < 0.05.

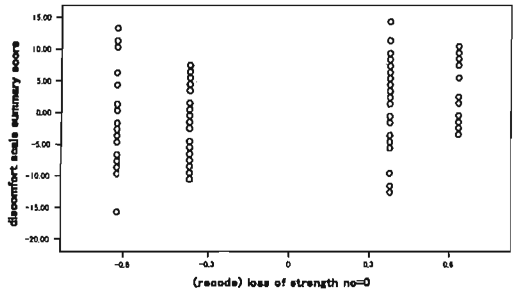
Appendix 4.9 *Normality Probability Plot of Standardised Residual*



Appendix 4.10 *Partial Regression Plot for ALPDS Scores and Information Provision at Diagnosis*



Appendix 4.11 *Partial Regression Plot for ALPDS Scores and Loss of Strength*



Appendix 6.1 *The Pilot FGD Question Route*

Introduction

I would like to thank you very much for coming today while you are busy. Let me introduce myself. My name is Miyako Tsuchiya. I am a research student at University of Southampton in the UK. I am the facilitator today.

First, I will explain this project briefly. I am conducting research on Quality of Life after surgery amongst Japanese BC patients. To understand that well, it is very important to hear patients' opinions and experiences in person, so I have invited you to take part in this group discussion. I plan to carry out several group discussions for a next few months.

During the session, I will tape-record our conversations, as I won't miss your precious remarks. Please give me your cooperation. I emphasise that our discussion be completely confidential and anonymous. When I present the findings at conferences and papers, your name or any other identifying characteristics will not be included. I will use like an identification number, for example, A, B, and C. I also stress that you will be able to leave here any time, when you won't talk any more or when you feel uncomfortable. If you feel that, although I would like to avoid this situation, please do so. I would like to ask you all not to tell whatever you hear in the session to anyone outside of the group after it is finished. Do you all agree that? (Pause)

I would like you all to talk within your group, rather than to me. I am allowed to sometimes ask questions or to give you summary, if needed. I hope that I will hear all the participants' voices. Agreements or disagreements, any opinions are fine. Please talk using your language as you feel. Finally, this discussion will last one hour and half, which you may feel it short. I hope that we all will spend pleasant time. Do you have any questions before we start? (Pause)

Let's start. Please let us call each other last name like Ms...... Could you tell us your name, where you live and your occupation? Shall we start in a clockwise direction from me?

Good Life

(Showing the picture) Imagine you are walking on a street. You see two people talking about their neighbours. You hear the word 'a good life' by chance, when you are passing by. Could you tell us how you imagine the person's life?

Probe: Paid work (study); housing; income; hobbies; relationships with others; education

Arm problems

You all have similar experiences after breast surgery. Please think back what happened to you after surgery.

- Could you tell us what you noticed?

Probe: Please describe how it (a rage of arm movement; restrictions of daily activities) was; when, how did you feel about that?; did you have any ideas about that?

- Could you tell us what did you do afterwards?

Probe: Did you talk to somebody? (your physician, nurses, friends, families, colleague, or breast cancer patients); what did you do to get the relevant information? (books, video, or the Internet); how did you feel after you did that?
(talking to somebody, or searching the information)?; how long did it take for you to do it after you first noticed it? (talking to somebody, or searching the information)

Change

- Could you tell us how your life changed from the time of the operation to now?

Probe: paid work; housework; hobbies; family; friends; neighbours; your doctors; nurses; expenditures; how did you feel about the change?

- Could you tell us how others changed toward you from the time of the operation to now?

Probe: families (children; husband; parents; and siblings); friends; colleagues; neighbours; your doctor; nurses; how did you feel about the change?

- Could you tell us how you changed toward others from the time of the operation to now?

Probe: to families (children; husband; parents; and siblings); to friends; to colleagues; to neighbours; to your doctor; to nurses; to yourself; how do you feel about the change?

- Could you tell us what the most helpful thing was from the time of the operation to now?

Probe: seeing (talking to) your doctor; or nurses; your families (children; husband; parents; and siblings); friends; colleagues; neighbours or breast cancer patients; doing paid work; housework; hobbies; or physical therapies

Present life and future

- Could you tell us how you feel about your present life?

Probe: paid work (study); housework; house; income; hobbies; the relationship with others; health; treatment

Appendix 6.1 (continued)

- When is the most pleasant time for you?
  Probe: seeing (talking to) your doctor or nurses; your families (children; husband; parents; and siblings); friends; colleagues; neighbours; or breast cancer patients; doing paid work; housework; hobbies; physical therapies; taking a rest at home; describe your feelings; how often do you feel that?
- When is the most unpleasant time for you?
  Probe: seeing (talking to) your doctor or nurses; your families (children; husband; parents; siblings); friends; colleagues; neighbours; or breast cancer patients; doing paid work; housework; hobbies; physical therapies; taking a rest at home; describe your feelings; how often do you feel that?
- Could you tell us your idea about improvement of your life?
  Probe: paid work (study); housework; hobbies; house; income; relationship with others; health; physical therapies
- Could you tell us how your future looks like?
  Probe: paid work (study); housework; hobbies; house; income; the relationship with others; health; physical therapies

It is about the end of the discussion. Have we missed anything? Anyone wants to add something? (Pause) I will pass a paper and an envelope; if you recall something to say at home or if you would like to give me comments on the session etc; please use this form to write it down and return it using the free-post envelope. Thank you very much for your contributions today.

Appendix 6.2 *The information letter of the Pilot FGD*

University of
Southampton

08 January 2004

Dear Ms. *Individual name;*

Thank you for returning your completed questionnaire in October; 2003 and for being interested in taking part in group discussions. Today; I am going to explain more about the discussion; I would like to explore some topics further; which was not fully covered in the questionnaire; and I would like to hear your personal experiences on the topics.

As I told you in my previous letter; the purpose of this group discussion is to hear about your experiences after breast surgery. I plan to conduct several group discussions in either Yokohama or Tokyo. I plan to invite five or six women with breast cancer for this group discussion. They may have similar experiences to Ms.*individual name*; but they may have different opinions and ideas about their experiences. I am sure that you will have a pleasant time with them. Again; I am; in particular; interested in hearing your personal experiences; so you do not need any special knowledge and preparations.

Of course; this is on a voluntary basis; and your personal information is anonymous and confidential. Results of this study will not include your name or any other identifying characteristics. If you begin the study and then change your mind; you have the right to withdraw at any time without giving a reason. I will tape-record the whole session; since I won't miss any precious remarks. The audiotapes will be used only for analysis and for research purposes. After analysis; I will destroy the audiotapes.

Please refer to the separate sheet on the date; time; and venues. **If you agree to take part in the group discussions; could I ask you to read the consent form enclosed carefully; sign the form; and return it to me using the provided envelope with stamps.** I will mail the copy of the signed form to Ms.*individual name* before the date of the discussions. Please keep the photocopy for your future reference. If the date is not suitable for your schedule; or if you prefer to attend another session; please contact me via email or mobile phone. If you have any inquires; please do not hesitate to contact me via email or mobile phone.*If you have questions about your rights as a participant in this research; or if you feel that you have been placed at risk; you may contact the Chair of the Ethics Committee; School of Psychology; University of Southampton; SO17 1BJ. Phone: +44 (0)23 8059 3995.* (The author's contact)

Appendix 6.3 *Consent forms*

I ________________have read the information sheet for group discussions.
(Participant's name)

I understand:
(when you understand the following statements; please circle Yes; otherwise; No)

1. the purpose of study is to hear patients' experiences after breast surgery;	Yes	No
2. the participation of study is on a voluntary basis;	Yes	No
3. my personal information obtained by group discussions will be treated confidentially;	Yes	No
4. published results will not include my name and any other identifying characteristics;	Yes	No
5. I can withdraw from this study at any time without penalty or loss of benefit to myself;	Yes	No
6. the discussion will be tape recorded and; after analysis the audiotape will be destroyed;	Yes	No
7. a copy of this consent form will be mailed to me by the date of the discussion.	Yes	No

Therefore; I give consent to take part in this group discussion. I give consent to be audio taped. In signing this consent form; I understand that I am not waiving my legal claims; rights or remedies.

Signature ______________________________ **Date** ______________________

Name ______________________________

I understand that if I have any questions about my right as a participant in this research; or if I feel that I have been placed at risk; I can contact the Chair of the Ethics Committee; School of Psychology; University of Southampton; Southampton; SO17 1BJ. Phone: + 44(0)23-8059-3995.

Appendix 6.4 *The Venue (the Yokohama session)*

Invitation

Date: 11 Febrary2004
Time: 2 PM (around 2 hours)
Venue: Forum Yokohama Meeting Room 3
(13 F Land Mark Tower)
Nearest railway station: JR; *Tokyu Toyoko* Line; or Yokohama subway
Sakuragi-cho station (7 minute walk to the Land Mark Tower)

Please see the map below to check how to get to the meeting room.
*Tea and snaks will be served (green tea; English black tea; and sweets)

~ Please read here ~

We will start discussions at 2 PM; but I would like to respect each participant's time; so please come to the meeting room **10minutes** before the starting time. If you are late with the discussion; I will be unable to include you.
I will be waiting for you in front of the meeting room. There; I will request you to wear your name tag; so please do not dress up like silk or delicate clothes.

<How to get to the meeting room on 13F>

The map from <http://www.women.city.yokohama.jp/sisetu/FYsisetu.html>
Land Mark Tower 13F
2-2-1-1; Minato Mirai; Nishi-ku, Yokohama; Kanagawa
TEL:045-224-2001
(the author's mobile phone No.)

Appendix 6.5 *Debriefing sheets*

Thank you for your contribution for today's discussion. The aim of this discussion was to explore your experiences after breast surgery; and to feed information gained from the discussions back into the health system so that in the future; patients' concerns can be addressed. If you have something to add;¥ or have something to delete; please write down below. If you have comments on the discussion; I also welcome you to do so.

If you wish summary of research findings; please write you name and mail address at the bottom. Results of study will not include your name or any other identifying characteristics.

Would you wish summary of research findings? Yes No

***If Yes;* please write you name and mail address.**
Your Name
Address
____
____

If you have any further questions; please contact me via email or mobile phone.
Miyako Tsuchiya Email: (English & Japanese) Mobile phone:090------------
Again; thank you very much! Please return this sheet using a provided post-free envelope.

Appendix 6. 6 *Field Notes Immediately after the Pilot FGD*

11 February 2004

I felt that it was a bit out of control; two participants were completely different types: one was both talkative and instructive. The other was both passive and shy; and she spoke slower than the talkative one. I often summarised the talkative patients' discourse; and I asked the shy patient if she had similar experiences to the story; but sometimes her talk was interpreted by the other one.

As the shy patient has been developing lymphoedema; and as she had not informed the risk by her physician; her story was really interesting. Although the talkative women had developed lymphoedema after surgery; now she seemed free from those symptoms. She tended to move to her experiences of breast cancer alone. However; the shy patients liked to talk about this kind of experiences; as well.

As the talkative patient was also instructive (she was one of members who had made the self-help group); the shy patients often nodded and did not initiate to tell her experiences. As the talkative patient was too proud of her surgeon and her husband; if the shy patient was satisfied with neither or either of them; she might have not told her true experiences.

Appendix 6.7 *the Venue (the Tokyo session)*

Invitation

Date: 28 Mar (Sun) 2004
Time: 2 PM (around 2 hours)
Venue: *Tiara Kouto* special (small) meeting room
Nearest station:

- Subway: *Hanzomon* Line and *Shinjyuku* Line *Sumiyoshi* station (Exit A4; 4 minute walk to *Tiara Koto*)
- Buses: *Toei* Bus (East 22) *Kinshi-cho* ~ *Toyo-cho* (for Tokyo station North Exit) *Sumiyoshi* station
  Toei Bus (*Nishiki* 11) *Kinshi-cho* ~ *Tsukiji* *Sumiyoshi* station (4 minute walk to *Tiara Koto*)
  Toei Bus (*Nishiki* 28) *Kinshi-cho* ~ *Higashi-Daitojima* *Koutou-koukaido* station (1minute walk to *Tirara Koto*)

Please see the map below to check how to get to the meeting room.
*Tea and snaks will be served (green tea; English black tea; and sweets)

~ Please read here ~

We will start discussions at 2 PM; but I would like to respect each participant's time; so please come to the meeting room **10minutes** before the starting time. If you are late with the discussion; I will be unable to include you.
I will be waiting for you in front of the meeting room. There; I will request you to wear your name tag; so please do not dress up like silk or delicate clothes.

<How to get to the meeting room>

When you arrive at Tiara Koto; please use stairs on your left side; and please enter the building by the door on your right side (there is the tea room at the left side).

The map from <http://www.city.koto.tokyo.jp> Tiara Koto
2-28-36; Sumiyoshi; Koto-ku; Tokyo TEL 03-3635-5500
The author's mobile phone No.

Appendix 6.8 *The Revised Question Route*

Introduction

I would like to thank you very much for coming today while you are busy. I am Miyako Tsuchiya; a research student at University of Southampton in the UK. I am the facilitator; and Ms. Toyoda (my colleague) is the recorder for this discussion.

First; I will explain this project briefly. I am conducting research on Quality of Life (QoL) after breast surgery amongst Japanese BC patients. To understand about the QoL well; which was not covered in questionnaire; it is very important to hear patients' experiences and opinions in person; so I have invited you to take part in this group discussion.

Secondly; I will talk about nature of this study. During the session; I will tape-record our conversations; as I won't miss your precious remarks. Please give me your cooperation. I emphasise that our discussion be completely confidential and anonymous. When I present the findings at conferences and paper; your name or any other identifying characteristics will not be included. I also stress that you will be able to leave here any time; when you won't talk any more or when you feel uncomfortable. If you feel that; although I would like to avoid this situation; please do so. I would like to ask you all not to tell whatever you hear in the session to anyone outside of the group after it is finished. Do you all agree that? (Pause)

Thirdly; I will talk about topics and rules during the discussion (they are put on a white board or a large paper). Today's main topic is about QoL after breast surgery. There are three rules that you should follow: (1) please don't speak simultaneously. Please start to talk your story after somebody finishes talking; or we cannot record conversations; (2) please don't criticise somebody's opinions or experiences in the group; since we think that there are no right answers and since we want to know individuals opinion or experiences; and (3) please let me interrupt the discussion; when necessary; as I would like to ask you some questions or give you summary if needed. (Pause) You all are encouraged to talk within your group; rather than to me. I hope that I will hear all the participants' voices. Agreements or disagreements; any opinions are fine. Please talk using your language as you feel.

Finally; this discussion will last two hours; but no break-please go to a washroom; whenever you wish. I hope that we all will spend pleasant time. Do you have any questions before we start? (Pause) Let's start.

Good Life

(Showing the picture) Please look at this picture. I would like to play a game; first. Do you remember the TV program called *'Renso Game'* a few decades ago? If you remember; please raise your hand. (Pause)

The situation is - you are walking down on a street. You see two people talking about their neighbours. You hear the word 'a good life' by chance; when you are passing by. Could you tell me how you imagine the person's life?

Please let us know your full name fist; then tell us your ideas.

- Probe: paid work (study); housing; income;hobbies; relationships with others; education

A summary of participants' ideas

Experiences before surgery

Let's move on. Everybody may want to know each experience before breast surgery. Please tell us your story briefly for one minute; for example; about lump detections; type of surgery; type of adjuvant therapy; and how many years have passed since surgery.

Arm problems

We're now moving on experiences after breast surgery. Please think back what has happened to you after the surgery.

- Could you tell us what you noticed?

Probe: Please describe how it was? (A rage of arm movement; any restrictions of daily activities);when; how did you feel about that?; did you have any ideas about that?; could you tell us what did you do afterwards?

- Did you talk to somebody?

Probe: your physician; nurses; friends; families; colleagues; or breast cancer patients)

- What did you do to get the relevant information?

Probe: books; video; or the Internet

- How did you feel after you did that?

Probe: after talking to somebody; searching the information

- How long did it take for you to do it after you first noticed it?

Probe: till you talked to somebody; sought the information)

- Could you tell us if you take doctor's (therapists) therapy now?
- What types of therapy and how often do you take? ☐
- How do you feel the therapy? ☐

Appendix 6.8 (continued)

Change

- Could you tell us if your life changed from the time of the operation to now? How has it changed?

Probe: paid work; housework; hobbies; family (children, husband, parents, and siblings); friends; neighbours; colleagues; your doctor; nurses; expenditures;
eating habit; clothes; how did you feel about the change?

- Could you tell us if your life changed from the time of the onset of swelling to now? How has it changed?

Probe: paid work; housework; hobbies; family (children, husband, parents, and siblings); friends; neighbours; colleagues; your doctor; nurses; expenditures; eating habit; clothes; how did you feel about the change?

- Could you tell us if you changed toward others from the time of the operation to now?
- How has it changed?

Probe: to families (children, husband, parents, and siblings); to friends; to colleagues; to neighbours; to your doctor; to nurses; to yourself; how do you feel about the change?

- Could you tell us if you changed toward others from the time of the onset of swelling to now?
- How has it changed?

Probe: a. to families (children, husband, parents, and siblings); to friends; to colleagues; to neighbours; to your doctor; to nurses; to yourself

- How do you feel about the change?
- Could you tell us what the most helpful thing was from the time of the operation to now?

Probe: seeing (talking to) your doctor; seeing (talking to) nurses; seeing (talking to) your families
(children, husband, parents, and siblings); seeing (talking to) friends; seeing (talking to) colleagues;
seeing (talking to) neighbours; seeing (talking to) breast cancer patients; doing paid work; doing housework; doing hobbies; doing physical therapies

- Could you tell us what the most unhelpful thing was from the time of the operation to now?

Probe: seeing (talking to) your doctor; seeing (talking to) nurses; seeing (talking to) your families (children, husband, parents, and siblings); seeing (talking to) friends; seeing (talking to) colleagues; seeing (talking to) neighbours; seeing (talking to) breast cancer patients; doing paid work; doing housework; doing hobbies; doing physical therapies

Present life and future

- Could you tell us how you feel about your present life?

Probe: paid work (study); housing; income; hobbies; relationships with others
(friends, colleagues, husband, children, and parents); health; treatment

- When is the most pleasant time for you?

Probe: seeing (talking to) your doctor; seeing (talking to) nurses; seeing (talking to) your families (children, husband, parents, and siblings); seeing (talking to) friends; seeing (talking to) colleagues; seeing (talking to) neighbours; seeing (talking to) breast cancer patients; doing paid work; doing housework; doing hobbies; taking physiotherapies; taking a rest at home

- Describe your feelings
- How often do you feel that?
- When is the most unpleasant time for you?

Probe: seeing (talking to) your doctor; seeing (talking to) nurses; seeing (talking to) your families (children, husband, parents, and siblings); seeing (talking to) friends; seeing (talking to) colleagues; seeing (talking to) neighbours; seeing (talking to) breast cancer patients; doing paid work; doing housework; doing hobbies; taking physiotherapies; taking a rest at home

- Describe your feelings
- How often do you feel that?
- Could you tell us your idea about improvement of your life?

Probe: paid work (study); housework; housing; income; hobbies; relationships with others (friends, colleagues, husband, children, and parents); health; physical therapies; volunteer work

It is about the end of the discussion. Have we missed anything? Anyone wants to add something?

Appendix 6.9 *Field Notes immediately after the Group 1 FGD*

14 March 2004

One patient suddenly showed up holding with her signed consent form (she had phoned a week ago to tell me she would be unable to attend). I did not prepare for the person's name tag and a returned envelope for debriefing sheet; so I was panic a bit; but my colleague let me calm down and dealt with that.

Group interactions did not occur except very last minutes - most time; each participant talked to me. Nobody asked each other like 'what do you think? or 'How about you?' All participants seemed to hesitate talking their stories a lot because of the forth rule of discussions 'everybody has a chance to speak'. I did not think that I have got a talkative person in the group at all; so the rule might let participants be too quite. My colleagues told me after completing the discussion that breast cancer experience itself was easy to share among participants; but their lives after surgery might be difficult to share because progress of diseases or family situations might affect their lives themselves. Because of these, she assumed that the participants did not talk a lot. I agreed-as only one participant was single; stories about husband and children were not developed within the group- I asked the participant about her parents and siblings; and she answered well. But other participants seemed that they did not want to talk about their husband or children. Were there any other reasons? Atmosphere?

Most participants described what had happened after breast surgery and/or arm swelling; but they did not talk about emotional aspects relating to that. Most participants said that arm swelling had not change participants' life (all participants said that their life had not changed immediately after my question was asked). Although I probed; most participants were silent. However; after being asked an irrelevant question; one participant started to talk that their working style had changed.

On the game; one participant told her idea about good life spontaneously. But other participants looked up a ceiling; holding arms; and drew their brows. I think that most participants have never thought about good life in general or for themselves. Or I think that it was difficult to describe good life verbally when their ideas were vague.

I didn't hear about negative experiences at all; as well as the pilot. Some participants wanted to talk about needs of psychological care before and after surgery. I felt that I had still too many questions in the question route. Environment was unsuitable (room size; or distance between chairs)?

Appendix 6.10 *Field Notes Immediately after the Group 2 FGD*

28 Mar 2004

As two patients did not show up at the start time; I waited for ten minutes after the other participants' approval was obtained. At last; one patient did not show up (she made a phone call to my home).

The participants in this group talked each other rather than talked to me. There were both agreement and disagreement opinions during the discussions. However; each participant talked longer than the 1st group and talked about not directly relevant topics to breast cancer: one patient has developed colon cancer one year after breast cancer. The other has experienced sexual abuse in her childhood. Some participants seemed to need to start to talk about these experiences in order to tell their present life; so I did not interrupt them. Immediately after the FGD; my colleague told me that she was wondering if I could collect needed information (Now I'm not sure if I could do this).

Although most participants reported that they had felt discomfort in daily activities or overall discomfort (4 or 5 point); they did not talk about the arm problems. Most participants talked about their emotional change after breast surgery; which had been rarely heard in the 1st group.

As the participants sometimes talked about what I wanted to ask later on; I had to omit questions or change question order. One participant was staff of one of the self-help group; and she often quoted somebody's words; when she talked her ideas or opinions.

On the day; next rooms were used as orchestra's waiting room-this was really unexpected. Playing instrument; especially brass; interrupted my concentration at the beginning. Moreover; two participants were always writing memo during the discussions. This interrupted my concentration; too.

Appendix 6.11 *An Example of Coding (a Pilot Transcript)*

S1 M ….."If you are so persistent, let's have a cell examination" **[doctor's decision for her 'subjective' lump detection]** The doctor said he would pierce the lump with a needle.
S2 M I thought it would be painful. But I was more concerned about not knowing what was causing it **[uncertainty of the cause of lump]**.
S3 M So I asked him to give the examination. He needed to pierce such a tiny area.
S4 M Then he told me to come back in a week or so. When I did, he said it was too small to examine. (Laughter)
S5 M He proved that he could not even perform a pathology test! ("Really?") "Well, I will examine again. Can you come back after a short while?" He was so carefree **[feelings about the doctor]**.
S6 M Then I became extremely anxious **[more anxious than before]**as I already had undergone this several times. So I decided to visit S Uni. At that time I was living near I Town in N Ward.
S7 M S University, I mean.
S8 M I visited there and found what one would expect of a county hospital.
S9 M It had Mammary Gland Department. And then one patient….
S10 M I was waiting for my turn with this lady. She asked me, "Excuse me, are you worried about your breast cancer of something?"
S11 M This lady was sitting near me. "Uh, yes. I'm a bit worried", I told her. She then said, "Today's doctor is not the Mammary Gland specialist. That doctor is taking a day off."
S12 M She said, "I have undergone an operation. It's my check-up today." "Oh, is it?" Then my turn came.
S13 M I did tell the doctor about my worry.
S14 M I pretended that it was my first time to consult this with a doctor. I didn't want to offend him.
S15 M Then he said, "Well, it is nothing to worry about. It is a mark of Mastitis or something."
S16 M He just briefly said so **[the second doctor's opinion for the lump]**.
S17 M You normally feel relieved when your doctor dismisses your worry.
S18 M I felt as if I was found innocent and acquitted. ("That's understandable.")
S19 M Although I was relieved, I asked him, "Could I have an X-ray or something after all?" **[still anxious]** Oh, he then became so furious **[the doctor's attitude toward her request] .**
S20 M "I would say you needs it if I as a doctor think you need it. Don't you the patient dare ask for it when I said you didn't need to worry about it."**[the doctor's attitude toward her request]**
S21 M He even said, "You are a cancer neuro"**[the doctor's attitude for her].** A cancer neuro means a cancer neurotic, doesn't it?
S22 M Anyway, I was thrown out as a cancer neuro and came home **[indirect expression of dissatisfaction]**.
S23 M In a way, I was relieved when the doctor said so. I mean if there was really nothing to worry about. **[not convinced]**
S24 M So I wondered if I shouldn't go back.
S25 M But I decided to go back to K Clinic.
S26 M The second examination didn't detect anything either.
S27 M In retrospect, I should not have had the two examinations with needle.
S28 M As a non-expert I think they have stimulated the cancer. I know, to a certain extent, that the operation needs to be done quickly without much stimulation.
S29 M I had it done again. **[seek further medical help to identify the cause of lump]**

(**S30 M-S36** The conversation about her neighbour who had an operation and about M having the neighbour's hospital recommended)

Appendix 6.12 ***Forty-seven Labels and Definitions (the Thematic Analysis)***

No	Labels	Definitions
1	Basic information of breast cancer	Descriptions of breast cancer-related experiences till breast surgery, such as a lump detection, medical consultations, further information-seeking, treatment decision making, BC treatment, side effects of treatment, cancer staging, and years after surgery.
2	Background of participants in daily life	Descriptions of what participants have gone through in daily life except breast cancer
3	Physical conditions between at the time of surgery and of discharge	Descriptions of what participants perceived physical conditions between the time of breast surgery and of discharge
4	Feelings during hospitalisation	Mention of how participants were feeling during hospitalisation
5	Nurses' and doctors' advice during hospitalisation	Descriptions of what nurses and doctors told participants during hospitalisation for breast surgery
6	Arm exercises during hospitalisation	Descriptions of what nurses instructed and the participants did, in order to improve mobility of arms during hospitalisation
7	Doctor's explanations about arm problems just before discharge	Descriptions of what doctors advised before discharge relating to arm complications
8	Fear of recurrence	Mention of how participants feel about recurrence between the time of discharge and of the study was conducted
*9	Events in daily life after discharge	Descriptions of perceived events that had participants' physical conditions worse after discharge
*10	Situations surrounding participants after surgery	Descriptions what roles participants were needed to play after the time of surgery
11	Arm problems after discharge	Descriptions of what happened on participants' hand/arm after discharge
12	Reasons why participants have developed lymphoedema	Self explanations of why participants have developed lymphoedema
13	Feelings towards arm swelling	Mention of how participants felt at the time of onset and are feeling at present about arm swelling
14	Treatment for lymphoedema	Descriptions of what treatment or therapies have been given by doctors in terms of arm/hand problems
15	Feelings towards the therapies of arm problems	Mention of how participants felt and are feeling about the therapy being mentioned in the label No14.
16	Doctor's reactions for arm problems	Descriptions of what doctors said to participants when participants consulted about arm complications
17	Feelings toward doctor's reactions	Mention of how participants felt about doctor's reactions being mentioned in the label No 16.

Appendix 6.12 (continued)

No	Labels	Definitions
18	Costs of treatment	Descriptions of how much participants have spent for both breast cancer and for arm therapy after discharge
19	Practical and informational helps from others relating to arm problems	Descriptions of what others actually do to help participants in daily life regarding arm swelling
20	Self protection	Descriptions of what participants are care of to prevent the further development of severe arm complications
21	Information sources of arm problems associated with breast surgery	Descriptions of where participants have got the information about arm problems besides of doctors
22	Reasons why participants have developed breast cancer	Self explanations or others' explanations why participants have developed breast cancer
23	Perceptions of breast surgery	Mention of what participants perceive breast loss or partial loss
24	Perceptions of development of BC itself	Descriptions of how participants perceive breast cancer
25	Feelings about the costs of medication after surgery	Mention of how participants felt the cots of medication after surgery (Label No. 18)
26	Quality of bra and prosthesis	Mention of how participants are feeling about bra and prosthesis that they have used
27	Physical conditions after discharge except arm problems	Descriptions of what happed to participants as a result of adjuvant therapy
28	Facilities	Mention of how participants are feeling facilities, such as rehabilitation unit and psychological care in a hospital
29	Situations surrounding participants at present	Descriptions of what roles participants are need to play in present life
30	Difficulties in breast cancer	Descriptions of how breast cancer affects participants' life, such as financial, life-style, and emotional sides
31	Physical limitations in daily life	What participants' daily activities have been constrained as a result of breast surgery
**32	Perceptions of life after breast cancer	Mention of how participants perceive their present life and themselves through breast cancer experiences
**33	Life style changes	Descriptions of how participants have changed their life style through experiences of breast cancer
34	Helpful people and things	Descriptions of what support is helpful for participants after discharge except lymphoedema
35	Sexual relationships with a husband	Mention of what participants perceive sexual relationships with their husband after surgery
36	Unhelpful people	Descriptions of what support is unhelpful for participants after discharge
37	Feelings for unhelpful people	Mention of how participants feel the unwelcome questions and unwelcome attitude being described in the label No36

Appendix 6.12 (continued)

No	Labels	Definitions
38	Disclosure of having cancer to others	Mention of whether or not participants told their illness (breast cancer and lymphoedema) to others
39	Perceptions of participants from others	Mention of what others told participants about themselves after breast surgery
40	Financial support	Descriptions of participants' needs of financial support related to the consequences of breast surgery
41	Current health status	Mention of how participants perceive their current physical health
42	Future plans	Descriptions of what participants want to do in the future and its reasons
43	Worried about own daughter	Mention of how participants are feeling about their daughters who may develop breast cancer
44	The concept of Quality of Life	Descriptions of what participants perceive good life in general
45	Relationships with health care staff	Mention of how participants perceive the relationship between their doctors/ nurses and themselves after discharge
46	Perceptions of others	Mention of how participants perceive others , such as families, friends, colleagues, and friends, after discharge
47	Self-help groups	Mention of how participants perceive a self help group where they are joining

Note: No1-No43 were emerged from the pilot transcript

No44-47 were emerged from the group 1 transcript

* No 9 and 10 are combined, * * No 31 and No 32 are combined.

Appendix 6.13 *Comparisons across Three FGDs (Thematic Analysis): Examples*

			Pilot		Group 1		Group 2	
Topics	No/Themes	Subcategories	Location	Examples	Location	Examples	Location	Examples
LM	**13. Emotional responses to lymphoedema**	Initial negative responses to lymphoedema	S297 U	I became worried	S113 T	Then I was the only one who didn't have any feelings of touch. I began to be worried	S187 S	I felt bitter, because I couldn't do things I used to be able to do without any problems.
			S292 M	Yes, I had a very hard time.			S228 H	I used to do a lot of sports and I wish I could do sports now and in future
			S316 U	As I read it I thought it was a serious matter				
			S423 U	I thought if I was to get it I would get it soon.				
			S390 M	I, uh, was anyhow explained, wasn't I? As I had undergone such an operation and lymph gland removal, I thought I should be careful. Otherwise my arm would be swollen.				
			S386 U	There wasn't very much fevers, I guess. But I was nervous about this becoming this bad.				
		Acceptance at the time FGs carried out	S462 M	But I imagine myself being different had I not had the operation.	S71 H	Also, on my hand, as the surgery was done on the right side, if I use the right hand heavily, my hand feels heavy. But I am feeling it's OK as It's been like that.		
					S128 S	(laugh) that's because I worry more about my life. Compared with the life, it can be endured. (laugh)		

Appendix 6.13 (continued)

			Pilot		Group 1		Group 2	
Topics	No/Themes	Subcategories	Location	Examples	Location	Examples	Location	Examples
LM	**13. Emotional responses to lymphoedema**	Acceptance at the time FGs carried out			S132 S	Although my arm swells, it's not as bad as I need to wear sleeves		
					S89 K	I thought it couldn't be helped as I had such a big operation. I tried to force myself to think that I had an accident		
					S91 S	It doesn't hinder my life, though.		
					S116 T	even though my arm always feel heavy, I don't need a compression sleeves.		
					S107 H	But still this area (armpit) felt dull, so I told over people in S group that like" it cannot be helped anyway, can it?".		
		Still negative responses to lymphoedema at FGs	S420 U	But after I read the book I thought it was me who needed to overcome it, as it was my own illness.			S188 S	But when it came to gardening, I have to moderately do it, so I felt sad.
			S496 M	We seem to have to fight against it for the rest of our life.			S190 S	So I am really desperate so that it is not curable in whole my life.
			S556 U	When I see it now (that there are creases) it reminds me that I am still suffering from the illness.			S232 H	If I knew this could be an option, I would have chosen that.
			S420 U	I felt as if I suffered something I didn't have to.			S492 S	If there is any possibility to cure it [lymphoedema], for example, by a surgery, if I am told it curable by surgery in the future, I will definitely do it.

Appendix 6.13 (continued)

			Pilot		Group 1		Group 2	
Topics	No/Themes	Subcategories	Location	Examples	Location	Examples	Location	Examples
LM	**17. Negative emotional responses to health care professionals**	Reluctant to seeking further help			S111 T	I asked him whether this was lymphoedema. I kept asking him a lot like this so probably he was annoyed (laugh).		
					S192 T	Frankly speaking, the hospital is useful for me only to do the regular checkups, and for the numbness or something I would search info and go to a different place to consult.		
		Not seriously take my concern	S382 U	"Uh, it's got slightly swollen, hasn't it?" He just said that certain percentage of people found Secretion effective and that I should take it. That's all what I was told,				
			S417 U	I then thought …. that the surgeon wasn't reliable.				
			S418 U	Surgeons are the ones who remove bad areas - of course swelling may not be a big deal when compared to cancer				
			S459 M	Otherwise they treat the issue lightly.				

Appendix 6.13 (continued)

			Pilot		Group 1		Group 2	
Topics	No/Themes	Subcategories	Location	Examples	Location	Examples	Location	Examples
LM	**17. Negative emotional responses to health care professionals**	Not seriously take my concern	S418 U	I wish my doctor warned me earlier. Then I wouldn't have carried such a heavy thing.				
	19/36a/46a. Practical & informational support	Practical help from family and colleague	S562 M	So my husband didn't let me carry a heavy thing, and he hang out futon for me as well.	S260 K	I have a very hard time when I have to ask people to carry heavy stuff as I could not carry it. If I try to carry it I feel pain, so they help to carry things saying that your can not carry stuff.	S163 H	But my child always helps me lift my arm up, like rehabilitation.
					S343 T	I don't know if it might be effective but drifted in to it and had it once. After that I tried to get appointment when she was not there		
		Advice from a self-help groups			S132 H	I have being told that sleeves aren't good and the sports type would be more comfortable to wear.		
					S109 H	I was also told from the president once arm swells like this (gesture showing the serious arm swelling) it could not be back to normal, and I was told I must be careful.		

Appendix 6.13 (continued)

			Pilot		Group 1		Group 2	
Topics	No/Themes	Subcategories	Location	Examples	Location	Examples	Location	Examples
LM	**15/40a. Scepticism of efficacy of LM treatment**	Dissatisfaction with feelings of wear and quality (compression sleeves)	S309 U	It is unpleasant.	S113 T	However, I was doing compression sleeves for a while, but it only could cover from here (armpit) to here (wrist) and couldn't cover shoulder where I really wanted to cover the most. So I felt my shoulder unwell as most of it should be definitely covered by sleeves.		
			S474 U	But didn't you find that loses elasticity?	S118 K	Well, because my skin is sensitive, if I wear compression sleeves which are made of chemical fibre, I would feel itchy.		
			S490 U	I suppose these serve just as thermal ones.	S123 T	Because the arm is swelling, it's hard to put on and take off. However, the sleeves which can be easily put on and take off would have little effect as the pressure is a bit weak.		
					S125 K	I lose the sense of fingers [while I am wearing the sleeves].		
					S130 S	I used to use the one that covers up to here, but I stopped using it as this part (shoulder) got stiff which was troublesome.		
		Dissatisfaction with efficacy of therapy	S484 U	When I was in hospital I had a massage. But I wasn't so enthusiastic after that.				

Appendix 6.13 (continued)

			Pilot		Group 1		Group 2	
Topics	No/Themes	Subcategories	Location	Examples	Location	Examples	Location	Examples
LM	**15/40a. Scepticism of efficacy of LM treatment**	Dissatisfaction with efficacy of therapy	S417 U	But I was given this medicine and tried it. I then thought it wasn't very effective	S114 T	I also did Hadomer [compression pomp] at home. It compresses by air but it is also unable to cover up to armpit.		
		Dissatisfaction with the costs			S132 H	after all it's expensive (laugh)		
	20/31a. Physical constrains	Preventive behaviour	S564 U	I put a cushion on top, er, as the body moves it goes like this and I've started having shoulder aches.	S135 H	Anyway, I'm being careful not to make a scar, (get a germ and carry heavy stuffs, but that's it.)	S490 S	Well, actually, I am doing gardening sometimes, but I wear Gloves (yes) (two layers). Really inconvenient.
					S120 K	In fact, I should have been careful, should I? Insects bit should be careful, shouldn't it?	S516 I	I didn't use to wear gloves when I do washing, but I wear a thick pair of gloves nowadays because I might be infected with bacteria while washing up.
			S293 M	But these days I've been careful myself. Whenever I have a blood sample taken for other things – well, it's unavoidable as I had both taken - I would tell a nurse about it just in case.	S265 S	I can carry it without any problems, which is not good indeed, but I can carry, so my hand grabs things naturally.	S516 I	When I do gardening, I wear two layers of gloves, such as cotton and plastic gloves on both hands.
			S563 M	Uh, I use a rucksack as much as possible as having my arm down causes swelling. So I try not to keep my arm down.			S188 S	When I went shopping, I try using my left hand to carry grocery.
					S249 K	In my case I always rest my head on my arm (laugh).	S495 T	I can't carry any heavy things, either.

Appendix 6.13 (continued)

			Pilot		Group 1		Group 2	
Topics	No/Themes	Subcategories	Location	Examples	Location	Examples	Location	Examples
LM	**20/31a. Physical constrains**	Preventive behaviour			S284 T	I do walking with my friends; during walking I tend to wave my arm back and forth. It makes my hand actually heavier so I put my right hand in my pocket not to wave.	S484 T	I sometimes do it while I am walking around. If they are swollen, lifting your arms is helpful.
		Inability or limitation of daily living	S446 U	But I myself cannot do the cuff here (the wrist) on this side. There are two centimetres or so difference.	S210 K	[Interviewer] Sorry about the sudden change of the topic, fashion, how about clothes? Has it changed? S210 K: Yes, it has.	S161 H	For a long time, I couldn't tie stings on my dress at my back.
			S447 M	I cannot wear my clothes – blouses I used to wear – being too tight around here. ("The narrow ones.")	S211 K	Well, I could not wear blouses with narrow arms.	S473 H	I can't wear a ring.
			S461 M	When I hold something, I tend to drop it more often than before. I feel I became less sensitive.	S212 K	About my fashion, I become choosing clothes which I do not have to raise my arm to wear. I easily put on weight so I tend to choose clothes which cover that (laugh).	S210 I	it is quite hard for me to cut a pumpkin and grate a Japanese radish .
			S462 M	Well, I can do ordinary chores.	S142 T	After all my right hand seems to lost strength a bit. I can only feel that I do cleaning in this way (gesture of using vacuum cleaner with right hand). Left hand was not good enough as I couldn't put strength.	S164 H	I couldn't even grate a Japanese radish.
					S158 S	Well, I cannot hold my grandchild.		

Appendix 6.13 (continued)

			Pilot		Group 1		Group 2	
Topics	No/Themes	Subcategories	Location	Examples	Location	Examples	Location	Examples
LM	**20/31a. Physical constrains**	Inability or limitation of daily living	S564 U	I've started having shoulder aches.	S159 S	Well, she (he) became very heavy, (laugh) I feel difficult a bit though I'm still holding. Yes.		
					S276 H	For that reason I could not cradle her so that I felt pitiful. I explained to her that I felt pain a bit here. My younger child is a girl. She wanted to have a look the scar..		
					S171 T	I used to be doing embroidery, but I cannot do it now. I was, of course, doing gardening too during this time of year. But stopped it as I heard it is better not touch the soil.	S160 H	I have played tennis for decades. After surgery, I couldn't raise my hands. (yeah) I toss a ball only to lose games. (Laugh)
					S315 T	I am a dental hygienist. It takes about 30 minutes for dental calculus patients. I can not do detail treatment any more. I can not have my own patients	S206 I	But when I keep drawing with my right hand because I had surgery on a right side, it actually hurts. (I see)
BC	**8/23/43. Negative emotional impact**	Fear of recurrence	S62 M	Therefore I was so careful that I had been touch checking on this [my right breast].	S424 S	At first I thought that if cancer was removed, breast cancer would be cure. After I knew that the cancer could spread to a whole body. After operation, I am getting more and more worried than before	S57S	What I could do was just to wait for recurrence.
			S583 U	Uh, somehow I wish I wouldn't have recurrence.	S350 S	Mentally I am most afraid of the recurrence.	S58S	every 3 months, it was like waiting for a sentence, death or alive. For the last five years, I've lived with a lot of worries.

Appendix 6.13 (continued)

			Pilot		Group 1		Group 2	
Topics	No/Themes	Subcategories	Location	Examples	Location	Examples	Location	Examples
BC	**8/23/43. Negative emotional impact**	Fear of recurrence	S593 U	(If recurrence happens, we cannot get rid of death.) -not in English transcript	S352 H	I am worried of recurrence and metastasis. I wish it never would happen, On the other hand, one would never know if it happens or not, so I'm worried. If my wish comes true, I am really pleased with that	S575 S	I have spent this five years with fears.
		Body image	S158 M	Well, you can't tell it if you hide it – it's hidden underneath.	S216 K	So until the breast reconstruction surgery was done there was a hollow very much.	S54 S	Actually, later I regretted doing so [mastectomies].
			S575 M	But I thought this: we can still conceal with clothing, can't we?	S217 K	It looked ok, but the one [her healthy breast] was excessively big	S347 S	Being a woman, I felt quite inferior because of breast
			S579 M	Er, well, I can, mhm, conceal it with clothes.			S668 T	Nowadays, I can touch the part that I had a surgery.
			S574 U	But my sister, who had stomach cancer, has absolutely normal appearance. But my appearance is not…			S670 T	Yeah, somehow, I started to love the part as one of the important parts of my body.
			S274 U	But I wish I had a little bit of it kept.				
			S542 U	I don't want to show it to others as I don't want to see it.				
		Worries about own daughter	S637 M	So I am really concerned, as I just briefly told this earlier, wondering off the main subject.			S274 I	I have two daughters, so there may be a chance for one or both of them to develop cancer.

Appendix 6.13 (continued)

			Pilot		Group 1		Group 2	
Topics	No/Themes	Subcategories	Location	Examples	Location	Examples	Location	Examples
BC	**8/23/43. Negative emotional impact**	Worries about own daughter	S658 M	As she approaches my then age forty, I hope she manages not to have that awful thing. Mhm, I'm worried about her rather than myself. A parent would want to substitute his or her child.				
	30/31b. physical constrains	Fashion	715M	Also when I wear a kimono, I can't get a gentle curve as before.	S217 K	so I could not wear clothes with wide neck open because it [breast loss] can be known.		
			718M	Well, I am trying to wear it in the future, by adjusting it somehow.	S218 K	I noticed recently and this was my case as well-that it must be hard for people who have not done breast reconstruction surgery because they can not wear clothes with wide neck open		
		Social activities	S535 M	I, uh, initially always used a family bath or en-suite one, avoiding to use the same big bath as others.			S285 I	But I couldn't dare to start Japanese drawing for ten months or a year, either.
			S540 U	I wish I could have it with swimming suits on like abroad. (Note: not allowed to take hot spring with swimming suite in Japan)			S286 I	Well, if I draw one, the drawing will be taken to an exhibition. When I thought so, I got quite stresses up. I didn't want to feel such a stress at that time.
		Personal economic situation	S509 M	Financial aspect Mental aspect, In that sense it was hard time.			S306 H	But with the insurance I can't take out any other insurance including a life insurance.

Appendix 6.13 (continued)

			Pilot		Group 1		Group 2	
Topics	No/Themes	Subcategories	Location	Examples	Location	Examples	Location	Examples
BC	**30/31b. physical constrains**	Personal economic situation					S308 H	Well, frankly speaking financial issues were interwoven to my life plans.
	32/42. Lean from BC experiences	Changes	S633 M	Because of such a experience of mine, I've leaned uncertainty of one's future, and fragility of life….	S301 K	In my case (laugh) I don't think that I have changed. I think that the people around me have changed.	S287 I	I got used to the life as a cancer patient and our old age.
			S507 M	And people cannot tell when something is going to happen nor what is going to happen to them.	S146 H	"que sera sera" Even if I make a great effort to compete something, my life wouldn't go like I wish	S532 S	Because of the illness, I was convinced that one's life would be limited.
			S502 U	My mother lived long till the age of ninety-eight. Thus I vaguely expected, at that time I was sixty-four, to live another thirty years.	S147 H	In a word, I used to plan to do like this and like that, and used to try my best to achieve that plan. I had expected I would cure if I had an operation. But I was told that I needed to live my life with it.		
			S502 U	But when I realised there was a limit I thought I should try to survive.	S147 H	It may sound strange but I wish I could control not to recur and metastasize. After I listened to many people's experiences, I can think like that, well, "que sera sera". I am getting less struggled now		
			-		S163 K	There may be no change in my way of thinking. My life style hasn't changed at all.		

Appendix 6.13 (continued)

			Pilot		Group 1		Group 2	
Topics	No/Themes	Subcategories	Location	Examples	Location	Examples	Location	Examples
BC	**32/42. Lean from BC experiences**	Changes			S299 H	I think that I am not nagging than before. I am still told that I am, but I think not than before, I think. I'm not sure.	S29 S	When I look back, I wonder how strong I became during the five years.
-			S510 M	I tried to have green vegetables as much as possible, for my health – uh, making vegetable juice myself, for example.	S156 S	I hadn't been exercising much, but have started walking for one hour everyday. As a result, blood pressure has become lower.	S57 S	So I looked for alternative medicine, like Qigong and aromatherapy, which it was the first time for me to take initiative to do whatever I wanted.
					S303 K	About myself, it is opposite and my friends ask for my help like "what should I do?" when something has happened, things like illness, mental problems.		
					S287 T	I say to my friends 'Go and take a medical examination'.	S317 H	The number of friends is increasing now.
					S195 S	I was like a baby which seems like that she is like my mother than my daughter. (laugh)	S318 H	This is actually what has changed in my life.
							S319 H	I will definitely maintain this good relationship with those friends.
							S28 S	Urn, before I became ill, I used to worry how people think about me all the time. You know that kind of timid character.

Appendix 6.13 (continued)

			Pilot		Group 1		Group 2	
Topics	No/Themes	Subcategories	Location	Examples	Location	Examples	Location	Examples
BC	**32/42. Lean from BC experiences**	Changes					S311 H	There, I made really good friends. This is unexpected (laugh) things in my life. Without the illness, I would have never got to know them and made friends there. They are really nice people, so in a way, this is something I benefited from the cancer.
							S332 S	I used to agree to other people's opinion no matter what. Even when they say something unpleasant, I used to say 'that's right' to them. But since I got cancer, I somehow started to be a little bit more opinionated like 'I don't think so". I happened to let it slip. Then, my friends whom I really trust on and have known for a long time started to apart from me.
							S335 S	J I thought it was actually good thing. I started to realize that the quantity of friends doesn't matter. The quality of friendship is more important. I've got new friends in a different world from where I used to belong. friends, which is something I got from my cancer

Appendix 6.13 (continued)

			Pilot		Group 1		Group 2	
Topics	No/Themes	Subcategories	Location	Examples	Location	Examples	Location	Examples
BC	**32/42. Lean from BC experiences**	Changes					S331 S	Well, I understand others' emotions like pain after the disease.
							S389 H	Well, I am probably the same.. I mean, I want to push me ahead so I walk with my heads up among my neighbours.
							S390H	Without the cancer, well, before the surgery, we wouldn't even think about that. I mean, we don't want to show our weaknesses.
	32/42. Lean from BC experiences	Proactive attitude	S509 M	But I, eh, didn't loose heart very much, and I thought positively	S151 H	I have been beginning to think that it's better to be positive thinking rather than negative thinking which makes people soiled.		
			S511 M	So I did gain many things rather than just lost.	S198 T	I think that my personality is like 'if I try hard I would be able to over come it'	S59 S	Well, no matter if the cancer reoccurs or not, I don't know but I wanted to gain confidence to live with my head up.
					S160 S	I would like to change my character which easily builds up stress. I want to change my character to be positive, but I tend to think too much or get depressed. I need to find the way to release my stress.		
			S632 M	since then I was also trying to cherish day to day	S163 K	As I've been trying to smile even when I was having a hard time,	S532 S	So I want to live up my life with my best so that I wouldn't have to waste the rest of my life.

Appendix 6.13 (continued)

			Pilot		Group 1		Group 2	
Topics	No/Themes	Subcategories	Location	Examples	Location	Examples	Location	Examples
BC	**32/42. Lean from BC experiences**	Proactive attitude	S510 M	as a proverb that says 'do our best and leave the rest to Providence',			S292I	I arrange a 'cake day' to make a cake monthly with my friends with whom I met at a inpatient ward. I work there once a month.
		Appreciation	S581 M	my family and my friends: Owing to them I am here, I think.	S163 K	I feel happy to be alive	S331 S	We have been very much supported by friends in the hospital, and I really appreciate for their support.
			S548 M	I felt grateful that I was surviving	S163 K	I 'm here with help from people around me		
					S320 K	People around me are like that as well, but I like be in touch with nature. Time with nature is important to me. I try to have it close to me-I do things like gardening, trying to keep flowers at the window side all the time, growing, decorating and giving water. I am getting to feel like 'I'll try to live my life" or "take it easy" from the flowers..		
			S582 M	I have acquired a feeling of gratitude	S322 K	Then I felt that life is wonderful. Another is when I was looking at the stars I started to feel like that and I realised life is beautiful...		

Appendix 6.13 (continued)

			Pilot		Group 1		Group 2	
Topics	No/Themes	Subcategories	Location	Examples	Location	Examples	Location	Examples
BC	**32/42. Lean from BC experiences**	Appreciation	S580 M	But I am very grateful that I am still given my life, being able to lead a healthy normal life.	S328 S	I used to move around by car, so I seldom had walked around. Starting walking and looking at flowers, I was very surprised at such beautiful scenery around me (laugh). I became loving walking. I think this is helpful thing. I did not notice that the sky is blue and I can see Mt Fuji nearby (laugh). I started to notice that more and more, and I walk to anywhere. This is it.		
			S581 M	The doctors who undertook the operations, and the nurses – who encouraged me and worked hard to give treatment to me				
		Future plans	S158 M	That's why I have talked my experience to my friends and at various places.	S335 K	I am thinking that I want to do some help from now. but because of my eyes, I cannot work at the moment. … but I would like to make an effort to do some volunteer work.	S566 T	I … I want to do something to contribute to the society
					S180 S	when I was bringing up my children, I was working, so I was trying to keep it for once a month. And I have been volunteering hand woven, which I used to do, at different places every 2-3 months, as I enjoy it for long.	S579 S	I don't know how yet, but somehow I want to show my gratitude to them.

Appendix 6.13 (continued)

			Pilot		Group 1		Group 2	
Topics	No/Themes	Subcategories	Location	Examples	Location	Examples	Location	Examples
BC	**32/42. Lean from BC experiences**	Future plans			S363 S	She is one years old. I had a hope of seeing her bridal dress… Well I think that I have to be healthy until she is old enough to remember (laugh).		
					S370 T	It is a vague thought, but I have left myself behind than others, so from now on I would like to do what I want.		
					S371 T	Freely		
			S632 M	I am now in mid-sixties, having finished bringing up my child. I'm trying to live cheerfully, cherishing those remaining years, with my retired husband,			S533 I	I suppressed myself for a long time in my families, so I try to change a bit myself. I suppose, what I want is probably to be accepted what I am now.
	34/45/47. Social support	Emotional support	S508 M	the power of family unity	S326 H	For daily life matters, I relied on my husband.	S155 H	When I am meeting up with them, we all cry with looking back on our experiences. After all, I am comforting myself there.
			S567 M	The members of my family and relatives, er, also didn't ask silly questions.	S197 T	I knew that if I said that I was not in good condition, my husband or others absolutely would help me out. Things relating to my job…[if I asked for help] I would give them some burden relating not only my body, but also work , so I did not want to put more load	S311 H	Other breast cancer patients in the inpatient ward became quite good friends.

Appendix 6.13 (continued)

			Pilot		Group 1		Group 2	
Topics	No/Themes	Subcategories	Location	Examples	Location	Examples	Location	Examples
BC	**34/45/47. Social support**	Emotional support			S199 T	Well rather I felt sorry for my husband.	S316 H	Doctors in my hospital organise a support group for breast cancer patients called K, and arrange a meeting once or twice a year. (I see) Even a Christmas party is organised as well. I really appreciate that…
					S195 S	I am completely relaying on my daughter.	S58 S	But then, I met a book. One of the articles in the book was talking about a person who had been blaming herself for living in a misery of worries. When I read the article, I thought I wouldn't want to be like him/her.
					S302 K	My friends have come to talk their personal things over me. My mother seems anxious about me constantly as like I am all ways at risk. (laugh)	S240 S	The doctor is male, and he said I was timid because my breasts were small.
					S295 S	People whom don't know about my illness don't have any consideration but they treat me normally. I think it is necessary as well.	S263 S	The doctor assumed the worst scenario-I would die soon like the other mothers.
					S311 T	S310 Interviewer: How about doing work? Did that help to forget uneasy feelings?	S252 S	Well, I didn't actually realize that I was smiling, but the doctor said, "You somehow look quite happy today. You are not seriously working for your disease, aren't you?"

Appendix 6.13 (continued)

			Pilot		Group 1		Group 2	
Topics	No/Themes	Subcategories	Location	Examples	Location	Examples	Location	Examples
BC	**34/45/47. Social support**	Emotional support			S307 T	For me it was friends	S254 S	He implied, surprisingly, cancer patients are not expecting to look happy. (Laugh) We are expecting to look serious (I can't believe it)
					S204 H	He thought, and thought about the operation, but when it comes to other matters he cannot answer like "sorry, I don't have any ideas"	S450 H	Of course, supporting group has supported me a lot…
					S179 S	On changes, my doctor (and a nurse) has been kind from the beginning and I would like to leave everything to them till I die.	S249 T	It is about a year every since. Then finally, I started to greatly appreciate his warmth and sympathy. Till then my heart has been frozen for a long time, I suppose.
					S186 K	I think that I met good doctors. It was fortunate! (laugh)		
					S191 T	That doctor has a very good personality, but I had to search a lot of things by myself since I had a priority of trying to go forward and return to my daily life (laugh). On the contrary, doctors do the operation and that is it. He only seems to observe how I am when having the regular checkups. I think he is a good person in nature, but I feel slightly unsatisfied with that point as professionals.		

Appendix 6.13 (continued)

			Pilot		Group 1		Group 2	
Topics	No/Themes	Subcategories	Location	Examples	Location	Examples	Location	Examples
BC	**34/45/47. Social support**	Physical support	S511 M	the support from people who are concerned about me	S288 T	At that time my friends looked after my children a lot.		
			S566 M	And my husband's sister used to support me by cleaning the house, as my mother-in-law was quite old, before popping in to see me at the hospital.	S206 K	My mother helped with the daily living side.		
			S710 M	I suppose the success was due to the determination among the whole family, not alone my husband, to raise our child.	S281 H	When I was in hospital for about one week, may be about 10 days, during that I asked my parents to look after them.		
	35. Sexual relationships	Sorry	S546 M	He never asks me to show it to him.				
			S548 M	He said the breasts were mere domestic articles, which were no longer in use.			S	
			737 M	I myself once felt guilty towards my husband.				
		Inferiority					S348 S	Sexual activities….Oh sorry, can I talk such a thing? (Carry on, please) Actually, I feel inferior even to my husband.
	36/37/38/39/46. cancer disclosure to others	Barriers between participants and healthy others	S530 U	I was also asked if I had the whole breast removed.	S203 H	But when I asked him for advice about detail of my illness, he did not seem to understand much.	S152H	Like, 'how's the family? How is it like to be a child of a cancer patient?'

Appendix 6.13 (continued)

			Pilot		Group 1		Group 2	
Topics	No/Themes	Subcategories	Location	Examples	Location	Examples	Location	Examples
BC	**36/37/38/39/46. cancer disclosure to others**	Barriers between participants and healthy others	S534 U	"Did you have it taken off?"			S397 H	She actually came when I had a breast cancer. At that time, my heart beat rate has gone up. I don't know why (laugh).
			S534 U	See, I myself didn't want to tell it at all ("Of course.") when I was asked… ("You felt unpleasant, didn't you?") That's right.			S400 H	I tried to deny the hatred because I thought I shouldn't dislike my brother's wife. She is one of my relatives.
		Selective disclosure	S514 M	Uh, my friends found it out as I didn't call them.	S147 H	But still, as cancer equals to death to some people, if I told others I've got a cancer, they appeared embarrassed.	S291 I	I also told my ex-colleagues and all my friends. I also told my classmates in a home-helper course.
			S516 U	Well, only to my very close friends.			S151 H	But still now, I cannot tell about the breast cancer.
			S517 U	Though I somewhat felt that I didn't want them to visit	S292 S	I only said to closer friends whom I spend most of time with.	S293 I	But I still hesitate to see my friends in a Japanese drawings group I used to join.
					S294 S	But for the others I did not say anything and go to trips and stuff together as usual.	S296 I	I have to explain about my cancer when I see them again, so I cannot see them.
			S523 U	It was hard to tell my mother. She was 90-something, 92 or 3 when [I was diagnosed]Somehow it was hard to tell my mother….	S296 S	depending the type of the friend I told about my illness.	S338 S	I haven't told about the cancer to anybody there [her work place].

Appendix 6.13 (continued)

			Pilot		Group 1		Group 2	
Topics	No/Themes	Subcategories	Location	Examples	Location	Examples	Location	Examples
BC	**36/37/38/39/46. cancer disclosure to others**	Selective disclosure			S300 H	Everyone at work knows, well I had to be off work so.	S322 S	Well, in my case, I haven't actually told about my cancer to my family and even to my mother.
					S165 K	At first, I couldn't tell people at my workplace about cancer. So sometimes I had to tell a lie or hedged.	S323 S	Even to my husband's siblings… Only to my sisters.
					S288 T	I did not talk about my illness to my parents.	S325 S	It was my pride not to tell, I suppose.
					S206 K	My father has diabetes and can not move freely. I did not want to worry my mother even more,	S256 S	Well, I didn't tell my children about my cancer, because they are still in a primary school and in a lower secondary school
	40b. Need of financial support		S466 M	As part of medical equipment. Those silicon pads cost between 35,000 to 40,000 yen each. Oh, I've bought so many of them. As I also needed to buy spare ones.			S582 I	If it is the case, we need to appeal the urgent need to the government. I wish the system could change. [sentinel]

Note. LM = lymphoedema and BC = breast cancer.

Appendix 6.14 *Findings One (Thematic Analysis): Main Themes, Subcategories, and Definitions*

Topic	No/Themes	Subcategories	Definitions
LM	**13. Emotional responses to lymphoedema**		**Mention of how participants felt the onset of lymphoedema and how they are feeling about it at the time FGDs was carried out**
		Initial negative responses of lymphoedema	How negatively participants felt the onset of lymphoedema, such as worries, serious, surprised, anxious, and hard
		Acceptance	Perceptions that the swollen hand or arm is acceptable comparing to breast cancer at the time FGDs carried out.
		Still negative responses to lymphoedema at FGs	Perception that the swollen hand or arm is not acceptable because of still needs to fight against the illness and feelings of sad and regret to be having it.
	17. Negative emotional responses to health care professionals		**Dissatisfaction with inadequate guides to reach lymphoedema therapy available for patients**
		Reluctant to seek further help	Mention of how participants perceived their surgeons, when they consulted arm complication with the doctors.
		Not seriously take my concern	Dissatisfaction that surgeons underestimated participants' concerns on the onset of lymphoedema
	19/36a/46a. Practical and informational support		**Experience-based advice given by a self-support group than medical professionals**
		Practical help from family and colleague	Physical help such as lifting and carrying heavy things, doing arm exercise together given by a family and colleague.
		Advice from a self support group	Descriptions of what support was given so far in order to prevent further arm swelling
	20/31a. Physical constrains		**Descriptions of what participants have to care and cannot do in daily life as a result of lymphoedema**
		Prevention behaviour	Descriptions of what participants do to prevent more sever arm conditions, such as infection, being hurt, carrying heavy things, lifting the arm up, swinging the arm, needle injections, and massages.

Appendix 6.14 (continued)

Topic	No/Themes	Subcategories	Definition
LM	**20/31a. Physical constrains**	Inability of do or limitation of daily living	Descriptions of what participants cannot do, such as fashion, household chores, cradle children, hobbies, professional jobs, and maintain of same statue participants try to lift their arms up both day and night time
	No15/40a. Scepticism of efficacy of lymphoedema treatment		**Mention of how negatively participants perceive therapy for lymphoedema available for them**
		Dissatisfaction with feelings of wear and quality	Mention of how discomfort participants feel when they are doing therapy
		Dissatisfaction with efficacy of therapy	Mention of how slow therapy shows its efficacy
		Dissatisfaction with the cost of therapy	Mention of how expensive therapy is and needs of the National Health Insurance coverage
BC	**No8/23/43. Negatives emotional impact**		**Mention of worried that participants have after discharge, such as recurrence, body image, and daughter's risk**
		Fear of recurrence	Mention of how fear recurrence is
		Body image	Mention of how participants perceive total/partial breast loss
		Worries about daughters	Mention of how participants perceive the risk that their daughters may develop breast cancer
	30/31b. Physical constrains		**Descriptions of what participants cannot do or have to care in daily life as a result of breast surgery**
		Fashion	Descriptions of that participants need slightly changing in the way of wearing their clothes
		Social activities	Descriptions of that participants hesitate taking part in social activities, such as hot spring and hobbies
		Personal economic situation	Descriptions of that participants are facing with economic problems due to breast cancer
	No 32//42 Learn from BC experiences		**Descriptions of what participants have leant from breast cancer experiences**

Appendix 6.14 (continued)

Topic	No/Themes	Subcategories	Definition
BC	**No 32//42 Learn from BC experiences**	Changes	Descriptions of that changes have happened after breast cancer in terms of relationships with others, paid job, their philosophy, and life styles
		Proactive attitude	Descriptions of that participants have leant they should motivate to do something for themselves instead they are waiting for something happen to them
		Appreciation	Descriptions of that participants felt grateful to others or something supporting participants physically and emotionally up to now, such as a family, friends, health care professionals, and nature
		Future plans	Descriptions of that participants want to do or plan to do in the future
	34/45/47. Social support		**Descriptions of practical and emotional support from others that participants perceive helpful**
		Emotional support	Descriptions of that participants were given emotional support from friends with breast cancer, families, health care professionals, and a self-help group
		Physical support	Descriptions of that participants were given physical support from families and self-help groups
	35. Sexual relationships		**Mention of how participants perceive sexual relationships with their husbands**
		Sorry	Mention of that participants are feeling sorry for their husbands because of luck of sexual relationship or lack of femininity
		Inferiority	Mention of that participants are feeling inferiority to women with breasts and to relationships with their husband
	36/37/38/39/46. Cancer disclosure to others		**Descriptions of whether participants disclosed breast cancer to others and of barriers participants encountered**
		Barriers between participants and healthy others	Descriptions of that participants encountered and felt toward healthy others when/after they disclosed breast cancer
		Selective disclosure	Descriptions of that participants selectively talk about their breast cancer to people
	40b. Need of financial support		Descriptions of the participants wished the National Insurance Coverage for a prosthesis, sentinel biopsy

Note. LM = lymphoedema and BC = breast cance

Appendix 7.1 *The Pilot Questionnaire (Study One: the Psycho-social Discomfort Scale)*

Part II A: I will ask how you are feeling *at the present* about the questions below.

	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree
1. I have sacrificed myself for my family.	1	2	3	4	5
2. I think lymphoedema is incurable for the rest of my life.	1	2	3	4	5
3. I think others believe that women's breasts are the symbol of sexual attractiveness.	1	2	3	4	5
4. I think others believe women's main roles are to deal with family matters.	1	2	3	4	5
5. I feel fear to disclose my breast cancer to people other than immediate family.	1	2	3	4	5
6. I can show my weakness to anybody.	1	2	3	4	5
7. I think others believe that people with diseases can be a loser in the society.	1	2	3	4	5
8. I feel glad when my family members are worried about me.	1	2	3	4	5
9. I think others believe that cancer is curable.	1	2	3	4	5
10. I have lost more than gained.	1	2	3	4	5
11. I have leant that our lives are fragile.	1	2	3	4	5
12. I feel embarrassed when people ask me about my breast cancer.	1	2	3	4	5

	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree
13. I have noticed that nature around me is splendid.	1	2	3	4	5
14. I feel lymphoedema is more serious than breast cancer.	1	2	3	4	5
15. I would like to do freely what I want.	1	2	3	4	5
16. I would like to spend my rest of life pleasantly.	1	2	3	4	5
17. I feel anger when people ask me about my beast cancer.	1	2	3	4	5
18. I feel inferior to healthy women.	1	2	3	4	5
19. I have been satisfied with my role in my family.	1	2	3	4	5
20. I think others believe that women should be feminine.	1	2	3	4	5
21. I have acquired a sense of gratitude.	1	2	3	4	5
22. I feel closer to women with breast cancer than those without.	1	2	3	4	5
23. I have leant that I can predict what will happen in my future.	1	2	3	4	5
24. I have no future plan in my mind.	1	2	3	4	5

	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree
25. I can still enjoy what I used to after the onset of lymphoedema.	1	2	3	4	5
26. I feel comfortable to disclose my breast cancer to people.	1	2	3	4	5
27. I feel guilty when I ask for help to people.	1	2	3	4	5
28. I feel it necessary that people treat me as a healthy person.	1	2	3	4	5
29. I feel lymphoedema is something I suffered when I did not have to.	1	2	3	4	5
30. I have been more worried about my life than lymphoedema.	1	2	3	4	5

Part II B: Please do not return to the previous part (Part II A) to complete.

	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree
1. It is believed lymphoedema incurable for the rest of my life.	1	2	3	4	5
2. It is believed our lives are fragile.	1	2	3	4	5
3. It is believed women with breast cancer would like to do freely what they want.	1	2	3	4	5
4. It is believed lymphoedema is more serious than breast cancer.	1	2	3	4	5
5. It is believed women with breast cancer feel anger when they are asked about my beast canc	1	2	3	4	5

	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree
6. It is believed we can predict what will happen in our future.	1	2	3	4	5
7. It is believed that women with breast cancer have been more worried about their life than lymphoedema.	1	2	3	4	5
8. It is believed women with breast cancer have no future plan in their mind.	1	2	3	4	5
9. It is believed women with breast cancer feel closer to women with breast cancer than those without.	1	2	3	4	5
10. It is believed cancer is curable.	1	2	3	4	5
11. It is believed women with beast cancer feel inferior to healthy women.	1	2	3	4	5
12. It is believed women with breast cancer are satisfied with their roles in their families.	1	2	3	4	5
13. It is believed women with breast cancer can show their weakness to anybody.	1	2	3	4	5
14. It is believed people with diseases can be a loser in the society.	1	2	3	4	5
15. It is noticed that nature around women with breast cancer is splendid.	1	2	3	4	5
16. It is believed that women with breast cancer feel comfortable to disclose their breast cancer to people.	1	2	3	4	5
17. It is believed lymphoedema is as if women with beast cancer had suffered something they did not have to.	1	2	3	4	5
18. It is believed women's main roles are to deal with family matters.	1	2	3	4	5

	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree
19. It is believed that women should be feminine.	1	2	3	4	5
20. It is believed that women with beast cancer feel glad when their family members are worried about them.	1	2	3	4	5
21. It is believed women with breast cancer feel embarrassed when they are asked about their breast cancer.	1	2	3	4	5
22. It is believed women's breasts are the symbol of sexual attractiveness.	1	2	3	4	5
23. It is believed women with breast cancer can enjoy what I used to after the onset of lymphoedema.	1	2	3	4	5
24. It is believed women with breast cancer would like to spend their rest of life pleasantly.	1	2	3	4	5
25. It is believed that women with breast cancer have sacrificed themselves for their family.	1	2	3	4	5
26. It is believed that women with breast cancer feel fear to disclose breast cancer to people other than immediate family.	1	2	3	4	5
27. It is believed that it is necessary that people treat women with breast cancer as a healthy person.	1	2	3	4	5
28. It is believed women with breast cancer have lost something more than gained.	1	2	3	4	5
29. It is believed women with breast cancer have acquired the sense of gratitude.	1	2	3	4	5
30. It is believed women with breast cancer feel guilty when they ask for help to people.	1	2	3	4	5

Thank you very much so far. *On the next page*, please give your feedback on this questionnaire.

Part III. Please write down your comments in the space provided below.

Q1: What do you think about wording and phrasing in the questions?
(e.g. I could not understand XXX. What did this word (question) mean?

Q2: Which versions did you feel easier to answer, Part II A or Part II B?

Part II A B

Q3: Could you tell us why you preferred the version in Q2 above?

Thank you very much for your cooperation !

Appendix 7.2 *The Information Letter (Study One)*

University of
Southampton

Dear All, May 2006

I am Miyako Tsuchiya, and I am a research student at University of Southampton in the UK. I have been conducting research on quality of life after surgery among Japanese women with breast cancer. So for, a survey and group interviews have been completed. Based on the findings, I have designed a new measure, aiming culturally appropriate manner.

To complete my PhD work, I would like to seek your help – I desperately need your help to improve my designed questionnaires!

What I would like to do is **a telephone interview** (approximately 1 hour) in order to know whether or not **wording is appropriated for Japanese women** (e.g. when you are asked questions in the questionnaire, how you feel or what do you think about **wording**). Since most questions are breast cancer and lymphoedema-related questions, I suppose that they are not directly relevant to you. So, I won't ask you to choose your responses from the five-point scale, such as 'strongly agree, agree, neither, disagree, disagree'. I would like to really know your honest opinions and to reflect them to revise the questionnaire, which is crucial to distribute the questionnaire to 'real' breast cancer patients.

Of course, this is on a voluntary basis, and your personal information is anonymous and confidential - this is only used for research purposes. If you begin the study and then change your mind, you have the right to withdraw at any time without giving a reason.

I would really appreciate if you would reply to me **within one week**, telling (1) whether or not you are interested in participation, and (2) if you are, when (day and time) is your convenient for an telephone interview. Verbal consent will be obtained on the day of interviews.

If you have any inquiries, please do not hesitate to contact me via email.

This study has been given ethical approval. If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact the Chair of the Ethics Committee, Department of Psychology, University of Southampton, SO17 1BJ. Phone: +44 (0)23 8059 3995.

Thank you for your time and attention. (the author's contact)

Appendix 7.3 *The Introductory Page of Online-survey (an Information Letter)*

Dear Madam,

My name is Miyako Tsuchiya, and a research student at University of Southampton in the UK. I have been conducting research on Quality of Life after surgery among Japanese women with breast cancer. So far, three self-help groups in Japan have cooperated with my previous studies, such as a survey and group interviews. Based on the findings, I have designed a new measure in a culturally appropriate manner.

Could I ask you to find your spare **30minutes** and to fill in the questionnaire? There is a free space on the last page (p4). Please give your feedback there on contents of questions, wording, and whatever you have noticed. I would like to really know your honest opinions and to reflect them to revise the questionnaire.

Of course, this is on a voluntary basis, and your personal information is anonymous and confidential - this is only used for research purposes. If you begin the study and then change your mind, you have the right to withdraw at any time without giving a reason. When you fill in the questionnaires if you mood swings, it will be helpful for you to talk to your group staff members.

If you return your completed questionnaire, I will take that as evidence that you understand the nature of the study and your part in it, and that you give me your consent to take part in the questionnaire part of the study. If you have any inquiries, please do not hesitate to contact me via email.

This study has been given ethical approval. If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact the Chair of the Ethics Committee, Department of Psychology, University of Southampton, SO17 1BJ. Phone: +44 (0)23 8059 3995.

Thank you for your time and attention. (the author's contact)

Appendix 7.4 *The Revised Questionnaire (Study Two)*

Part II A: I will ask how you are feeling *at the present* about the questions below.

	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree
1. I have noticed that nature around me is splendid.	1	2	3	4	5
2. I feel my lymphoedema is more serious than breast cancer.	1	2	3	4	5
3. I think others believe that women's breasts are the symbol of sexual attractiveness.	1	2	3	4	5
4. I have had a sense of gratitude.	1	2	3	4	5
5. I feel fear to disclose breast cancer to people other than my family.	1	2	3	4	5
6. I have been satisfied with my role in my family.	1	2	3	4	5
7. I would like to do freely what I want.	1	2	3	4	5
8. I feel afraid to disclose lymphoedema to people other than my family.	1	2	3	4	5
9. I feel comfortable to disclose my breast cancer to anybody	1	2	3	4	5
10. I feel closer to women with breast cancer than those without.	1	2	3	4	5
11. I have been more worried about my breast cancer than lymphoedema.	1	2	3	4	5
12. I think others believe that people with disease can be a loser.	1	2	3	4	5

	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree
13. I feel it necessary that people treat me as a healthy person.	1	2	3	4	5
14. Through my experience of breast cancer, I have learnt that I can predict what will happen to me in the future.	1	2	3	4	5
15. I have learnt that our lives are fragile.	1	2	3	4	5
16. I have no idea what I want to do in the near future.	1	2	3	4	5
17. I feel glad when my family members show their concerns about me.	1	2	3	4	5
18. I have sacrificed myself for my family.	1	2	3	4	5
19. I feel guilty when I ask for help to people.	1	2	3	4	5
20. I think my doctor-in-charge understands my feelings well.	1	2	3	4	5
21. I think others believe that cancer is curable.	1	2	3	4	5
22. I feel embarrassed when people ask me about my breast cancer.	1	2	3	4	5
23. Through my experience of breast cancer, I have gained more than I have lost.	1	2	3	4	5
24. I feel I should not have had to develop lymphoedema.	1	2	3	4	5

	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree
25. I have been given reassurance by my doctor-in-charge of breast cancer.	1	2	3	4	5
26. I can show my weakness to anybody.	1	2	3	4	5
27. I feel inferior to healthy women.	1	2	3	4	5
28. I think others believe women's main roles are to deal with family matters.	1	2	3	4	5
29. I would like to spend my future life pleasantly.	1	2	3	4	5
30. I feel anger when people ask me about my beast cancer.	1	2	3	4	5
31. I feel comfortable to disclose my lymphoedema to anybody.	1	2	3	4	5
32. I can still enjoy what I used to do after the onset of lymphoedema.	1	2	3	4	5
33. I think my lymphoedema will be cured someday	1	2	3	4	5
34. I think others believe that women should be feminine.	1	2	3	4	5

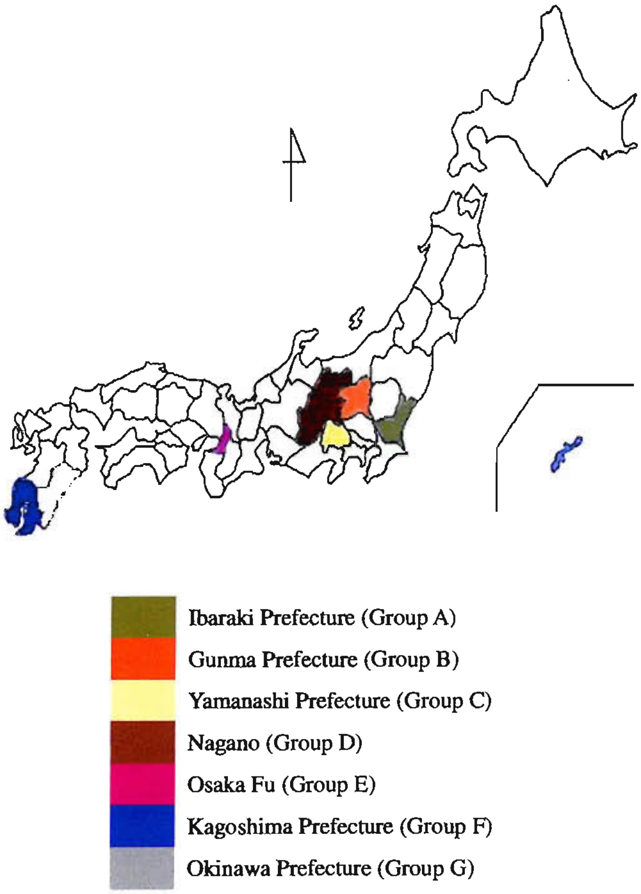
Thank you very much so far.
Please give your feedback on the next page!

Part III. Please write down your comments in the space provided below.

Q: What do you think about wording and phrasing in the questions?
(e.g. I could not understand XXX. What did this word (question) mean?

Thank you very much for your cooperation !

Appendix 7.5 *A Map of Study Sites (Study Three)*



Appendix 7.6 *The Information Letter (Study three)*

University
of Southampton

Dear Madam, Day/Month/ Year

Owing to the group coordinator, *Name* co-operation, I am sending this letter to members of *name of help-self groups.* Firstly, my name is Miyako Tsuchiya, and I am a research student at University of Southampton in the UK. I am carrying out a research project on Quality of Life after surgery among Japanese women with breast cancer who develop lymphoedema. So for, three self-help groups in Japan have cooperated with my previous studies, such as a survey and group interviews. Based on the findings, I have designed a new measure aiming culturally appropriate manner.

Could I ask you find your spare **30 minutes** and fill in the **enclosed two questionnaires**? Please find four materials below in the envelope:

1 WHO QoL26 (published by *Kaneko Shobo*)
2 my designed questionnaire (printed in colored paper)
3 a piece of pink colored paper
4 return envelope with stamps

The purpose of this study is to examine validity and reliability of my questionnaire. I will examine the relationship between the standardised questionnaire (WHO QoL26) in Japan and my questionnaire. This is very important and standardised scientific procedure to check the reliability of the questionnaire itself, not your responses. I eagerly need your understanding and cooperation at this point.

I would like to thank to all participants who completed both questionnaires by sending a small gift (a book token-500 yen-) later. Please provide your name and mailing address in the pink colored paper, if you request the book token; since you do not have to fill in your name in both questionnaires, if you forget to send the pink colored paper with you contact detail, I will not be able to identify you. Please mail both your completed two questionnaires and the pink colored paper by *month/day* using the provided envelope (no stamps required) to the group office (or my office in Japan).

Of course, this is on a voluntary basis, and your personal information is anonymous and confidential - this is only used for research purposes. If you begin the study and then change your mind, you have the right to withdraw at any time without giving a reason. *If you return your completed questionnaire, I will take that as evidence that you understand the nature of the study and your part in it, and that you give me your consent to take part in the questionnaire part of the study.* After completing a data analysis, a brief report will be sent to the group coordinator to share the findings with you. When you fill in the questionnaires if you emotionally move, please consult it with your group (office telephone *No* ____________.).

This study has been given ethical approval. If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact *the Chair of the Ethics Committee, Department of Psychology, University of Southampton, SO17 1BJ.Phone: +44 (0)23 8059 3995.*

If you have any inquiries, please do not hesitate to contact me via email. If you are not a patient, I apologise that I have mailed this letter to you in error.
Thank you for your time and attention.
(the author's contact)

Appendix 7.7 *The Revised New Questionnaire (Study Three)*

Part II A: I will ask how you are feeling *at the present* abont the questions below.

Please circle the number which best shows the way you are feeling.
After reading each statement, when you feel 'I strongly agree', please circle number one.
When you feel ' I do not agree a bit ' please circle number four.

If you have not developed lymphoedema, please circile ' no lymphoedema' . in the lymphoedema-related statements	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree	
1. I have noticed that nature around me is splendid.	1	2	3	4	5	
2. I feel my lymphoedema is more serious than breast cancer.	1	2	3	4	5	No lymphoedema
3. I think others believe that women's breasts are the symbol of sexual attractiveness.	1	2	3	4	5	
4. I have had a sense of gratitude.	1	2	3	4	5	
5. I feel fear to disclose breast cancer to people other than my family.	1	2	3	4	5	
6. I have been satisfied with my role in my family.	1	2	3	4	5	
7. I would like to do freely what I want.	1	2	3	4	5	
8. I feel afraid to disclose lymphoedema to people other than my family.	1	2	3	4	5	No lymphoedema

	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree	
9. I feel comfortable to disclose my breast cancer to anybody	1	2	3	4	5	
10. I feel closer to women with breast cancer than those without.	1	2	3	4	5	
11. I have been more worried about my breast cancer than lymphoedema.	1	2	3	4	5	No lymphoedema
12. I think others believe that people with disease can be a loser.	1	2	3	4	5	
13. I feel it necessary that people treat me as a healthy person.	1	2	3	4	5	
14. Through my experience of breast cancer, I have learnt that I can predict what will happen to me in the future.	1	2	3	4	5	
15. I have learnt that our lives are fragile.	1	2	3	4	5	
16. I have no idea what I want to do in the near future.	1	2	3	4	5	
17. I feel glad when my family members show their concerns about me.	1	2	3	4	5	
18. I have sacrificed myself for my family.	1	2	3	4	5	
19. I feel guilty when I ask for help to people.	1	2	3	4	5	
20. I think my doctor-in-charge understands my feelings well.	1	2	3	4	5	

	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree	
21. I think others believe that cancer is curable.	1	2	3	4	5	
22. I feel embarrassed when people ask me about my breast cancer.	1	2	3	4	5	
23. Through my experience of breast cancer, I have gained more than I have lost.	1	2	3	4	5	
24. I feel that lymphoedema was avoidable.	1	2	3	4	5	No lymphoedema
25. I have been given reassurance by my doctor-in-charge of breast cancer.	1	2	3	4	5	
26. I can show my weakness to anybody.	1	2	3	4	5	
27. I feel inferior to healthy women.	1	2	3	4	5	
28. I think others believe women's main roles are to deal with family matters.	1	2	3	4	5	
29. I would like to spend my future life pleasantly.	1	2	3	4	5	
30. I feel anger when people ask me about my beast cancer.	1	2	3	4	5	

	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree	
31. I feel comfortable to disclose my lymphoedema to anybody.	1	2	3	4	5	No lymphoedema
32. I can still enjoy what I used to do after the onset of lymphoedema.	1	2	3	4	5	No lymphoedema
33. I think my lymphoedema will be cured someday	1	2	3	4	5	No lymphoedema
34. I think others believe that women should be feminine.	1	2	3	4	5	

*** Please post this completed questionnaire and WHO QoL-BREF (together with a piece of paper, pink in color) by the provided envelop**

Thank you very much for your co-operation!

Appendix 7.8 *World Health Organisation Quality of Life Questionnaire (WHOQoL-BREF)*

MSA/MNH/PSf /97.6
Page 2

Instructions

This assessment asks how you feel about your quality of life, health, or other areas of your life. **Please answer all the questions.** If you are unsure about which response to give to a question, **please choose the one** that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life **in the last two weeks.** For example, thinking about the last two weeks, a question might ask:

		Not at all	Not much	Moderately	A great deal	Completely
	Do you get the kind of support from others that you need?	1	2	3	4	5

You should circle the number that best fits how much support you got from others over the last two weeks. So you would circle the number 4 if you got a great deal of support from others as follows.

		Not at all	Not much	Moderately	A great deal	Completely
	Do you get the kind of support from others that you need?	1	2	3	4	5

You would circle number 1 if you did not get any of the support that you needed from others in the last two weeks.

Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

		Very poor	Poor	Neither poor nor good	Good	Very good
1(G1)	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2 (G4)	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last two weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3 (F1.4)	To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
4(F11.3)	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
5(F4.1)	How much do you enjoy life?	1	2	3	4	5
6(F24.2)	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7(F5.3)	How well are you able to concentrate?	1	2	3	4	5
8 (F16.1)	How safe do you feel in your daily life?	1	2	3	4	5
9 (F22.1)	How healthy is your physical environment?	1	2	3	4	5

Appendix 7.8 (continued)

The following questions ask about how **completely** you experience or were able to do certain things in the last two weeks.

		Not at all	A little	Moderately	Mostly	Completely
10 (F2.1)	Do you have enough energy for everyday life?	1	2	3	4	5
11 (F7.1)	Are you able to accept your bodily appearance?	1	2	3	4	5
12 (F18.1)	Have you enough money to meet your needs?	1	2	3	4	5
13 (F20.1)	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14 (F21.1)	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

				poor nor good		
15 (F9.1)	How well are you able to get around?	1	2	3	4	5

The following questions ask you to say how **good or satisfied** you have felt about various aspects of your life over the last two weeks.

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16 (F3.3)	How satisfied are you with your sleep?	1	2	3	4	5
17 (F10.3)	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18(F12.4)	How satisfied are you with your capacity for work?	1	2	3	4	5
19 (F6.3)	How satisfied are you with yourself?	1	2	3	4	5
20(F13.3)	How satisfied are you with your personal relationships?	1	2	3	4	5
21(F15.3)	How satisfied are you with your sex life?	1	2	3	4	5
22(F14.4)	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23(F17.3)	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24(F19.3)	How satisfied are you with your access to health services?	1	2	3	4	5
25(F23.3)	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things in the last two weeks.

		Never	Seldom	Quite often	Very often	Always
26 (F8.1)	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

Did someone help you to fill out this form?..

How long did it take to fill this form out?..

Do you have any comments about the assessment?

....

....

THANK YOU FOR YOUR HELP

Appendix 7.9 *A Correspondence Sheet (Study Three)*

Please fill in this form if you request the book token.

Please check the items below

1. The completed questionnaire in the colored paper ☐
2. The completed WHO QoL-BREF ☐

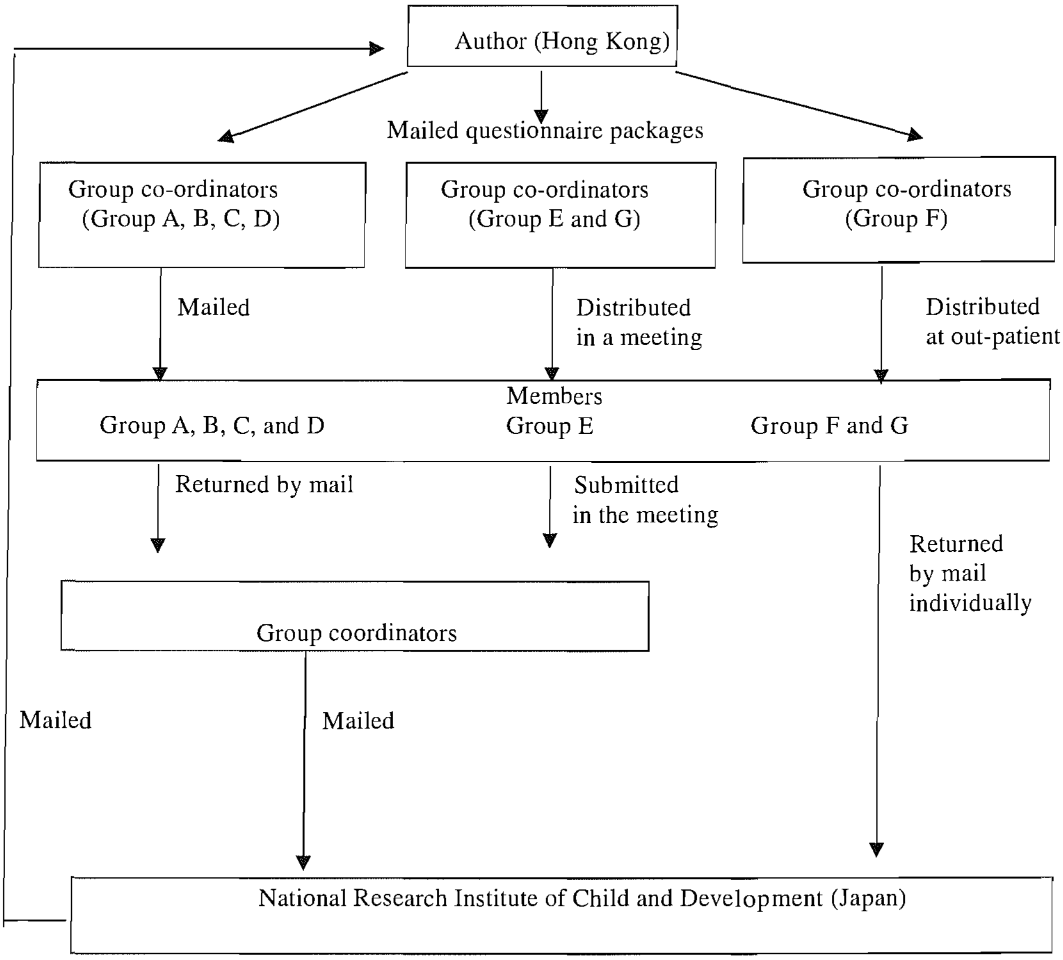
If you completed both questionnaires above, I will mail a 500-Yen book token to you later. Please provide your name and mailing address. *If you do not do so, I cannot identify you and will be unable to mail the book token to you.*

Your Name ____________________

Your Address 〒 ____________________

____

Appendix 7.10 *Logistics of Data Collection*



Appendix 7.11 *Correlation Matrix of 27 Items*

Item No	q1	q3	q4	q5	q6	q7	q9	q10	q12	q13	q14	q15	q16	q17	q18	q19	q20	q21	q22	q23	q25	q26	q27	q28	q29	q30	q34
q1	1.000																										
q3	0.026	1.000																									
q4	0.409	0.025	1.000																								
q5	0.013	0.147	-0.022	1.000																							
q6	0.131	-0.045	0.158	-0.180	1.000																						
q7	0.162	0.158	0.155	-0.003	0.068	1.000																					
q9	0.110	-0.197	0.180	-0.540	0.081	-0.061	1.000																				
q10	0.097	0.349	0.044	0.149	-0.090	0.146	-0.058	1.000																			
q12	-0.050	0.285	-0.041	0.227	-0.144	0.139	-0.119	0.229	1.000																		
q13	0.199	0.104	0.119	0.084	0.102	0.237	-0.021	0.205	0.068	1.000																	
q14	0.052	0.058	0.154	0.001	-0.011	0.228	0.005	0.083	0.130	0.158	1.000																
q15	-0.038	0.148	-0.108	0.136	-0.125	0.206	-0.026	0.159	0.399	0.122	0.339	1.000															
q16	-0.236	0.096	-0.148	0.236	-0.294	-0.063	-0.060	0.093	0.173	-0.068	0.135	0.313	1.000														
q17	0.209	0.012	0.341	-0.092	0.165	0.070	0.149	-0.006	-0.002	0.101	0.201	-0.087	-0.019	1.000													
q18	0.019	0.103	-0.155	0.111	-0.151	0.129	0.013	0.224	0.183	0.003	0.117	0.325	0.203	-0.062	1.000												
q19	0.066	0.153	0.066	0.103	-0.104	0.114	-0.135	0.138	0.092	0.055	0.162	0.188	0.231	0.172	0.163	1.000											
q20	0.219	-0.072	0.147	-0.171	0.237	0.005	0.214	-0.009	-0.089	0.020	0.025	-0.209	-0.204	0.220	-0.080	0.000	1.000										
q21	-0.047	-0.078	0.041	-0.074	0.105	-0.018	0.146	0.002	-0.143	0.087	-0.010	-0.081	0.052	0.051	0.015	-0.114	0.169	1.000									
q22	-0.112	0.062	-0.174	0.644	-0.185	-0.024	-0.542	0.064	0.230	0.039	0.061	0.225	0.260	-0.158	0.117	0.158	-0.238	-0.065	1.000								
q23	0.232	-0.068	0.410	-0.205	0.113	0.059	0.219	-0.006	-0.093	0.098	-0.069	-0.129	-0.203	0.185	-0.097	-0.079	0.213	0.114	-0.271	1.000							
q25	0.192	-0.072	0.110	-0.113	0.183	0.040	0.192	-0.085	-0.027	0.003	-0.071	-0.194	-0.215	0.213	-0.060	-0.020	0.727	0.117	-0.235	0.283	1.000						
q26	0.022	-0.086	0.113	-0.367	0.162	0.008	0.416	-0.040	0.009	-0.022	0.027	0.008	-0.064	0.092	-0.033	-0.153	0.076	0.091	-0.277	0.106	0.080	1.000					
q27	-0.110	0.237	-0.184	0.319	-0.270	0.156	-0.244	0.300	0.284	0.089	0.148	0.367	0.290	-0.124	0.212	0.137	-0.157	-0.187	0.385	-0.214	-0.159	-0.115	1.000				
q28	0.048	0.301	-0.070	0.193	-0.124	0.114	-0.140	0.210	0.236	0.098	0.028	0.273	0.076	-0.039	0.287	0.230	0.014	-0.069	0.138	-0.033	0.006	-0.126	0.258	1.000			
q29	0.200	0.060	0.182	-0.026	0.106	0.219	0.041	0.219	0.003	0.195	0.192	0.034	-0.170	0.251	-0.032	0.069	0.081	0.029	-0.083	0.109	0.055	0.024	-0.018	0.009	1.000		
q30	-0.105	0.122	-0.124	0.625	-0.145	-0.016	-0.431	0.179	0.227	0.005	-0.103	0.162	0.213	-0.204	0.088	0.134	-0.162	-0.119	0.674	-0.154	-0.155	-0.294	0.389	0.171	-0.109	1.000	
q34	0.034	0.371	0.010	0.170	-0.129	0.176	-0.088	0.228	0.188	0.267	-0.028	0.212	0.092	0.016	0.182	0.165	-0.014	0.070	0.111	-0.038	-0.078	-0.098	0.226	0.474	0.053	0.173	1.000

Appendix 7.12 ***Correlation Matrix of 7 Items***

Item No	2	8	11	24	31	32	33
2	1.000						
8	.395	1.000					
11	-.132	.075	1.000				
24	.081	.220	.148	1.000			
31	-.142	-.283	.012	.013	1.000		
32	-.236	-.276	.021	.070	.249	1.000	
33	-.240	-.034	.139	.298	.134	.340	1.000

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