Supportive Care in Cancer (2019) 27:547–555
https://doi.org/10.1007/s00520-018-4349-0

ORIGINAL ARTICLE

Knowledge, fatigue, and cognitive factors as predictors of lymphoedema risk-reduction behaviours in women with cancer

Miyako Tsuchiya[1] · Mariko Masujima[2] · Tomoyasu Kato[3] · Shun-ichi Ikeda[3] · Chikako Shimizu[4] · Takayuki Kinoshita[5] · Sho Shiino[5] · Makiko Suzuki[6] · Miki Mori[7] · Miyako Takahashi[1]

Received: 28 February 2018 / Accepted: 9 July 2018 / Published online: 16 July 2018

Abstract

Objective To identify social–cognitive factors predicting lymphoedema risk-reduction behaviours (hereafter, self-care) after discharge among patients in Japan with breast or gynaecological cancers, using the extended model of the theory of planned behaviour.

Methods A cross-sectional questionnaire study was conducted in an oncology hospital. Items measured were (1) knowledge about self-care; (2) the Cancer Fatigue Scale; (3) social–cognitive factors in the theory of planned behaviour (attitudes, subjective norms, and perceived behavioural control); (4) self-care (limb hygiene, observation, articular movement, recommended risk-reduction behaviours in daily life, and diet and weight control); and (5) demographics. Of 202 respondents, 147 who had not been diagnosed with lymphoedema were eligible for statistical analysis (65.3% with gynaecological cancer, 34.7% with breast cancer).

Results Structural equation modelling was used to examine a hypothesised model based on the theory of planned behaviour. The results revealed that a longer time since surgery, higher levels of fatigue, less knowledge, higher expected efficacy of self-care, and lower perceived behavioural control directly and significantly predicted less self-care behaviour.

Conclusions Besides education about self-care behaviour, levels of fatigue and perceived behavioural control should be taken into account to encourage female patients with cancer to perform self-care after discharge. Continuous psycho-educational programmes after discharge may help to facilitate self-care behaviours among long-term female cancer survivors.

Keywords Breast cancer · Gynaecological cancer · Lymphoedema · Predictive factors · Self-care · Social–cognitive factors

✉ Miyako Tsuchiya
miytsuch@ncc.go.jp

[1] Division of Cancer Survivorship Research, Center for Cancer Control and Information Services, National Cancer Center, 5-1-1, Tsukiji, Chuo-ku, Tokyo 104-0045, Japan

[2] Graduate School of Nursing, Chiba University, 1-8-1, Inohana, Chuoku, Chiba, Japan

[3] Gynaecology Division, National Cancer Center Hospital, 5-1-1, Tsukiji, Chuo-ku, Tokyo 104-0045, Japan

[4] Breast and Medical Oncology Division, National Cancer Center Hospital, 5-1-1, Tsukiji, Chuo-ku, Tokyo 104-0045, Japan

[5] Division of Breast Surgery, National Cancer Center Hospital, 5-1-1, Tsukiji, Chuo-ku, Tokyo 104-0045, Japan

[6] Department of Nursing, National Cancer Center Hospital, 5-1-1, Tsukiji, Chuo-ku, Tokyo 104-0045, Japan

[7] Saitama Prefectural University, 820, Sannomiya, Koshigaya, Saitama, Japan

Background

Lymphoedema (LE) is a chronic condition resulting from impairment of the lymphatic system and accumulation of protein-rich fluid in the interstitial tissue. Secondary LE frequently occurs among patients with breast or gynaecological cancers [1], and the prevalence rate is approximately 20–30% [2, 3]. Although lymph node dissection has been identified as the major risk factor for the onset of LE [4, 5] and the incidence of LE is highest within 2 years after diagnosis or surgery [4], the timing of onset is unpredictable. The International Society of Lymphology [6] classifies at-risk patients as stage 0 of LE, meaning that patients who undergo cancer treatment should be considered to be in a subclinical state. LE is accompanied by several symptoms of discomfort or sensation, including swelling, pain, numbness, tightness, heaviness, and limited physical movement [7, 8]. Such LE-related symptoms significantly deteriorate the quality of life of

patients with cancer [9, 10], so minimising this complication is essential for cancer survivorship care [11].

In terms of LE risk-reduction strategies, several organisations [12, 13] and guidelines [14, 15] have suggested the importance of LE education (e.g. body mass index ≤ 25 kg/m^2 and exercise) for at-risk patients, and clinicians encourage at-risk patients to engage in risk-reduction behaviours (hereafter, self-care). To perform self-care, lifestyle modification (e.g. finding time to perform self-care) may be required, so that without any support, patients may experience difficulties understanding the importance of self-care and integrating it into their daily lives [16, 17]. As at-risk patients do not have any LE-related signs or symptoms, long-term survivors especially may perceive the risk of onset as relatively low, and consequently, they may not adhere to clinicians' self-care recommendations [18–20]. Some studies of LE self-care have taken into account patients' perceptions of LE and self-care with a study population of patients with breast cancer [21, 22]. To develop continuous LE prevention education programmes as part of cancer survivorship care, we need to identify how LE self-care behaviours are perceived among at-risk patients with cancers other than breast cancer.

Social cognition models of health behaviour, such as the theory of planned behaviour (TPB), propose how people decide to perform health behaviour. TPB suggests that three components—attitudes towards the behaviour, subjective norms, and perceived control—predict behavioural intentions and the actual behaviour [23]. Attitudes towards the behaviour indicate a person's belief that, if they perform the behaviour, beneficial outcomes will be obtained. Subjective norms indicate a person's belief that significant others expect them to perform the behaviour. Perceived control refers to whether or not a person has internal control factors (e.g. personal deficiencies, emotions) and external resources (e.g. opportunities, barriers) to perform the behaviour [23]. Although some studies have shown that TPB predicts physical activities [24] and human papillomavirus vaccine intention [25], the confirmation of the model may vary depending on the population or targeted health behaviours, and extending the model has been suggested if theoretically and empirically appropriate [26]. Because LE patient education including the provision of information is already practiced in Japan and because previous studies have consistently shown the effect of knowledge on self-care [21, 22], we hypothesised that patients' levels of knowledge about self-care predict their self-care behaviour. Additionally, although little research has included this factor in the LE context, we hypothesised that health status, such as fatigue, predicts patients' self-care behaviour, because the fatigue that appears to be persistent after cancer treatment [27] may affect the internal resources contributing to perceived behavioural control or self-efficacy [28]. The aim of the present study was to identify factors predicting lower levels of LE self-care behaviour after discharge among at-risk patients with breast or gynaecological cancers in Japan, using the extended TPB model.

Methods

Subjects

Inclusion criteria were women aged ≥ 20 years who had (1) undergone gynaecological surgery (for cervical cancer, cancer of the uterine body, or ovarian/fallopian tube/peritoneal cancer) with either pelvic or para-aortic lymph node dissection ≥ 2 months previously, or those who had undergone breast surgery with axillary lymph node dissection ≥ 1 month previously; (2) no swelling in their lower limbs or on the operated side of their upper limb; (3) stage I, II, or III cancer; and (4) proficiency in the Japanese language. Exclusion criteria were (1) women with stage IV cancer; (2) those who were previously diagnosed with LE; and (3) those who were judged by oncologists as too vulnerable to participate in the present study.

Procedure

Ethics approval was obtained from the National Cancer Center (No. 2015-319) and the Graduate School of Nursing, Chiba University (No. 27-11A). From April to September 2016, a cross-sectional questionnaire study was consecutively conducted in an oncology hospital. Patients were individually recruited by either oncologists or the first author. Regarding the inclusion criterion (2), oncologists clinically judged whether patients developed swelling. Patients were asked to fill in the questionnaires at their homes and to return their completed questionnaires using envelopes that were provided. Informed consent was obtained from all individual participants. Returning the completed questionnaire was taken as agreement to participate in the present study.

Measurement

Outcome measure: LE risk-reduction behaviours (self-care)

We assessed the frequencies of LE risk-reduction behaviours using five items measuring limb hygiene, limb observation, articular movement, recommended risk-reduction behaviours in daily life, and diet and weight control. We asked participants whether they had performed each self-care behaviour in the past week, with four-point responses (1 = every day, 2 = a few days a week, 3 = once a week, and 4 = never).

Knowledge of LE risk-reduction strategies

We developed a new scale to assess knowledge of LE risk-reduction strategies [29]. The scale comprises 25 items,

including hygiene and skin care, avoidance of stimuli to limbs, observation of limb condition, and urgent medical consultation for unusual signs, with dichotomous responses (1 = correct and 0 = incorrect). Higher scores indicate better knowledge of self-care. The coefficient alpha (KR-20) of the total score, summing the 25 items, was 0.89 in the present sample.

Fatigue

The degree of fatigue was assessed using the Cancer Fatigue Scale, which was originally developed for Japanese patients with cancer and has been validated with good psychometric properties [30]. This scale includes 15 items consisting of physical (seven items), psychological (four items), and cognitive (four items) dimensions of fatigue, with responses assessed across a five-point Likert scale (1 = no, 2 = a little, 3 = somewhat, 4 = considerably, and 5 = very much). Higher scores indicate more severe fatigue. Cronbach's alpha of the total score, summing the 15 items, was 0.90 in the present sample.

Patient background information

Current age, educational level achieved, job status, marital status, the presence of cohabitants, and the presence of family members requiring home care were asked in questionnaires. Medical information, cancer stage, month, and year of surgery; type of surgery; radiotherapy; and chemotherapy were obtained through medical records.

Social–cognitive factors

Social–cognitive factors were assessed by 15 items based on TPB (attitudes, subjective norms, and perceived behavioural control).

Attitudes

We assessed participants' attitudes by asking whether they perceived the recommended self-care behaviours as beneficial for preventing the onset of LE (expected outcome). We adapted the 'treatment control' subscale from the Japanese version of the Revised Illness Perception Questionnaire [31, 32]. Expected outcomes comprised five items measured on a five-point Likert scale (1 = strongly disagree, 2 = disagree, 3 = neither agree nor disagree, 4 = agree, and 5 = strongly agree). Higher scores indicate better expected outcomes of self-care behaviours.

Subjective norms

We assessed subjective norms by asking whether participants thought significant others expected them to perform self-care behaviours. We developed a six-item scale for use in LE educational contexts, referring to Aizen's scale [33], with responses assessed across a five-point Likert scale (1 = strongly disagree, 2 = disagree, 3 = neither agree nor disagree, 4 = agree, and 5 = strongly agree). Higher scores indicate stronger perceptions of social pressure to perform self-care behaviours.

Perceived behavioural control

We assessed perceived behavioural control by asking whether participants had internal and external resources to perform self-care behaviours. We developed two items, referring to the findings of a previous qualitative study among patients with gynaecological cancer [17], with responses assessed across a five-point Likert scale (1 = strongly disagree, 2 = disagree, 3 = neither agree nor disagree, 4 = agree, and 5 = strongly agree): 'It is a burden to perform self-care in my daily life'. Additionally, two items about emotional regulation for LE-related stress and anxiety were added [21]. Higher scores indicate better internal and external resources to perform self-care behaviours.

Analysis

Participants' demographic details, medical information, and self-care behaviours were summarised by mean, range, or percentage. First, we performed an explanatory factor analysis (EFA) with varimax rotation to examine the dimensionality of the outcome measures (self-care behaviours) and of the measures assessing attitudes, subjective norms, and perceived behavioural control. The internal consistency of the measures was examined using Cronbach's alpha. Next, to identify the hypothesised latent factors underlying the outcome measures and the measures assessing attitudes, subjective norms, and perceived behavioural control, a confirmatory factor analysis (CFA) was performed on the covariance matrix. The outcome measures were hypothesised to load on a single latent factor. Each measure of attitudes, subjective norms, and perceived behavioural control was also hypothesised to load on a single latent factor. To evaluate how well the observed data fit the hypothesised latent factors, several goodness-of-fit statistics with recommended cut-off points were applied [34]: the chi-square statistic ($p > 0.05$), the comparative fit index (CFI, > 0.95), the non-normed fit index (NNFI, > 0.95), and the root mean square error of approximation (RMSEA, < 0.06, with a 90% confidence interval [CI]). When normality was violated (Mardia's normalised estimate > 5.0), other goodness-fit statistics with recommended cut-off points were applied: the Satorra–Bentler scaled chi-square statistic (S–B $\chi 2$, $p > 0.05$), the Bentler–Bonett NNFI (> 0.95), the adjusted CFI (> 0.95), and the adjusted RMSEA (< 0.06, with a 90% CI). If the measurement model did not fit the observed data satisfactorily and the measurement was confirmed as unidimensional, we

used the item-parcelling method (factorial algorithm) to construct parcels according to the magnitude of the loadings [35]. Finally, we used structural equation modelling (SEM) to determine whether the structured model (Fig. 1) fit the observed data and to examine the magnitude and direction of the relationships among the measures using the covariance matrix. CFA and SEM were performed using EQS version 6.3 for Windows, which deals with both observed categorical data and continuous data with non-normality. Statistical analyses other than CFA and SEM were performed with SPSS version 23.

Results

Participant characteristics

Table 1 presents participant characteristics. Questionnaire packages were distributed to 254 patients, and a total of 202 patients completed their questionnaires (responses rate of 79.5%). Excluding the data that did not meet the inclusion criteria, 147 patients (34.7% with breast cancer and 65.3% with gynaecological cancers, including 46.9% with cervical cancer, 35.4% with cancer of the uterine body, and 17.7% with ovarian/fallopian tube/peritoneal cancer) were eligible for statistical analysis. The mean age was 52.5 years, 70.7% were married, and 59.2% had paid jobs. Regarding self-care behaviours, approximately 31% of the participants reported never performing skin care, 15% reported never performing observation of their limbs, about 21% reported never performing light exercises (articular movement), about 16% reported never performing recommended risk-reduction behaviours in daily life, and about 12% reported never performing diet and weight control.

Latent variable for self-care

EFA revealed a one-factor solution with the five variables (limb hygiene, observation, articular movement, recommended risk-reduction behaviours in daily life, and diet and weight control) explaining 45% of the variance. Cronbach's alpha for the five items was 0.74. CFA showed that the observed data fit the latent factor satisfactorily ($\chi^2_{(5)} = 7.35$, $p = 0.19$; CFI = 0.98; NNFI = 0.97; RMSEA = 0.05, 90% CI 0.000–0.137).

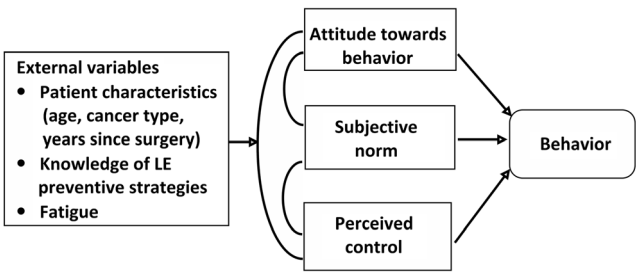

Fig. 1 A theoretical model of self-care behaviour

The five items loaded significantly on the latent variable at the $p < 0.05$ level, and the standardised loadings ranged from 0.55 to 0.70 (Fig. 2).

Latent variables for social–cognitive factors

Attitudes

EFA revealed a one-factor solution with the five variables (expected outcomes of LE self-care) explaining 56% of the variance. Cronbach's alpha for the five items was 0.80. Mardia's normalised estimate was 23.29. CFA showed that the observed data fit the latent factor moderately (S–B $\chi^2_{(5)} = 16.23$, $p = 0.006$; adjusted CFI = 0.90; Bentler–Bonett NNFI = 0.79; adjusted RMSEA = 0.12, 90% CI 0.060–0.193). The five items loaded significantly on the latent variable at the $p < 0.05$ level, and the standardised loadings ranged from 0.37 to 0.89.

Subjective norms

EFA revealed a one-factor solution with the six variables (perceptions about the doctor in charge, nurses, rehabilitation staff, family, peers, and people surrounding the participants) explaining 70% of the variance. Cronbach's alpha for the six items was 0.85. Mardia's normalised estimate was 27.23. CFA showed that the fit of the measurement model was unsatisfactory (S–B $\chi^2_{(9)} = 46.62$, $p < 0.001$; adjusted CFI = 0.81; Bentler–Bonett NNFI = 0.67; adjusted RMSEA = 0.16, 90% CI 0.123–0.218). The six items loaded significantly on the latent variable at the $p < 0.05$ level, and the standardised loadings ranged from 0.59 to 0.79.

Perceived behavioural control

EFA revealed a one-factor solution with the four variables (difficulty finding time, psychological burden, and two items on emotional regulation) explaining 50% of the variance. Cronbach's alpha for the five items was 0.80. Mardia's normalised estimate was 8.27. CFA showed that the fit of the measurement model was not sufficient (S–B $\chi^2_{(2)} = 7.66$, $p = 0.021$; adjusted CFI = 0.89; Bentler–Bonett NNFI = 0.68; adjusted RMSEA = 0.139, 90% CI 0.045–0.249). The five items loaded significantly on the latent variable at the $p < 0.05$ level, and the standardised loadings ranged from 0.59 to 0.69.

Structural equation modelling

The fit indices of the three measures of social–cognitive factors (attitudes, subjective norms, and perceived behavioural controls) were not satisfactory. Because each measure was unidimensional, we conducted item parcelling of the three measures using a factorial algorithm [35]. Figure 3 shows

Table 1 Participant characteristics ($N = 147$)

Variables	Total ($N = 147$)	Gynaecological cancer ($n = 96$)	Breast cancer ($n = 51$)
Age (years), mean, range	52.5 (29–81)	53.9 (29–81)	49.9 (34–77)
Marital status (*N*, %)			
Single	43 (29.3)	27 (28.1)	16 (31.4)
Married	104 (70.7)	69 (71.9)	35 (68.6)
Job status (*N*, %)			
Yes	87 (59.2)	52 (54.2)	35 (68.6)
No	60 (40.8)	44 (45.8)	16 (31.4)
Education level achieved (*N*, %)			
Junior high school	3 (2.0)	2 (2.1)	1 (2.0)
Higher school	46 (31.3)	33 (34.4)	13 (25.5)
Technical/college	62 (42.2)	40 (41.7)	22 (43.1)
University or above	35 (23.8)	20 (20.8)	15 (29.4)
Missing	1 (0.7)	1 (1.0)	0 (0.0)
Cohabitants (*N*, %)			
Yes	144 (97.9)	95 (99.0)	50 (98.0)
No	1 (0.7)	0 (0.0)	0 (0.0)
Missing	2 (1.4)	1 (1.0)	1 (2.0)
Family members requiring home care (*N*, %)			
Yes	10 (6.8)	6 (6.3)	4 (7.8)
No	137 (93.2)	90 (93.8)	47 (92.2)
Type of surgery			
Simple total hysterectomy	48 (32.7)	48 (50.0)	–
Modified radical hysterectomy	3 (2.0)	3 (3.1)	–
Radical hysterectomy	44 (30.0)	44 (45.9)	–
Missing	1 (0.7)	1 (1.0)	–
Mastectomy	33 (22.4)	–	33 (64.7)
Breast conserving surgery	18 (12.2)	–	18 (35.3)
Stage (*N*, %)			
I	62 (42.2)	53 (55.2)	9 (17.6)
II	52 (35.4)	15 (15.6)	37 (72.5)
III	33 (22.4)	28 (29.2)	5 (9.8)
Chemotherapy (*N*, %)			
Yes	83 (56.5)	33 (34.4)	50 (98.0)
No	64 (43.5)	63 (65.6)	1 (2.0)
Radiotherapy (N, %)			
Yes	36 (24.5)	14 (14.6)	22 (43.1)
No	109 (74.1)	80 (83.3)	29 (56.9)
Missing	2 (1.4)	2 (2.1)	0 (0.0)
Years since surgery, mean, range	2.3 (0–10)	2.4 (0–9)	2.2 (0–10)

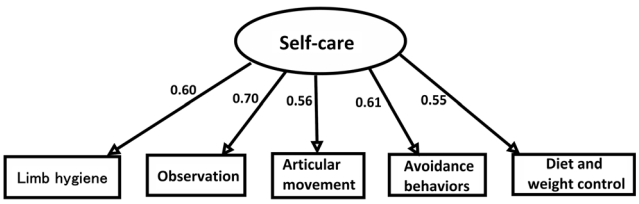

Fig. 2 Confirmatory factor analysis of lymphoedema self-care behaviour

the theoretical relationships and magnitudes among the measures. The theoretical model fits the observed data satisfactorily (S–B $\chi^2_{(97)} = 109.5882$, $p = 0.180$; adjusted CFI = 0.96; adjusted NNFI = 0.95; RMSEA = 0.03, 90% CI 0.000–0.055). More years since the surgery ($\beta = 0.175$), lower scores on knowledge of LE ($\beta = -0.392$), higher levels of fatigue ($\beta = 0.178$), higher expected outcomes ($\beta = 0.458$), and lower levels of perceived behavioural control ($\beta = -0.485$) were

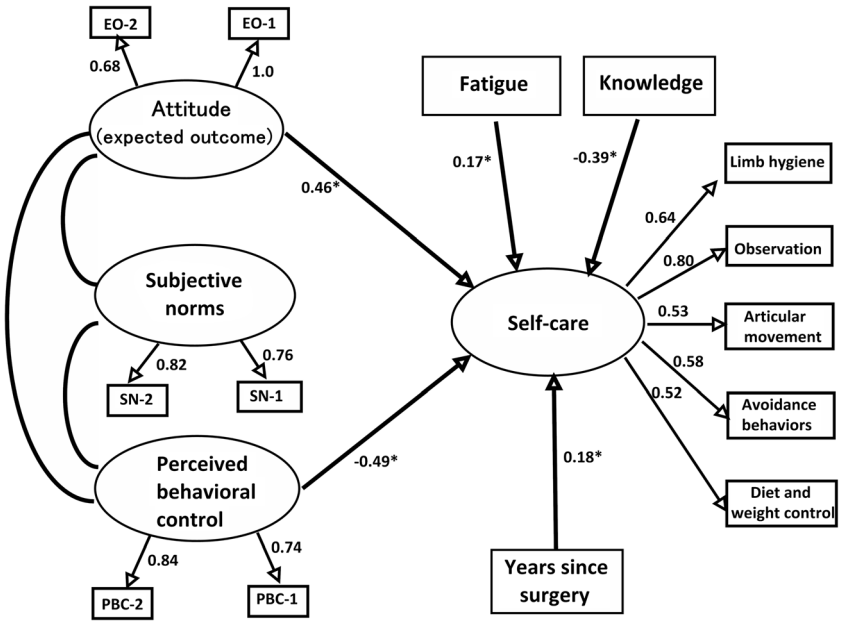

Fig. 3 Social–cognitive determinants of self-care in the extended model of theory of planned behaviour

significantly and directly associated with less frequent LE self-care behaviours. Age, cancer type, and subjective norms were not significantly associated with self-care behaviours.

Discussion

The present study investigated social–cognitive factors associated with self-care behaviours among patients with breast or gynaecological cancers who were at a subclinical stage of LE. As authors acknowledged, this was the first study to investigate these associations using SEM and applying the TPB extension model. Of the three components of TPB, lower perceived behavioural control was significantly and most strongly associated with a lower frequency of self-care behaviours. Attitudes towards self-care behaviours were also significantly and second-most strongly associated with a lower frequency of self-care behaviours, but the direction of the association was not as hypothesised. Subjective norms were not significantly associated with self-care behaviours in this sample.

Regarding perceived behavioural control, we asked about feelings of burden that were reported as distress and anxiety [36], emotional regulation, and time availability for performing self-care. The significant contribution of perceived behavioural control to self-care behaviours was consistent with previous studies of self-care behaviours among patients with breast cancer [21, 22] and on colorectal cancer screening behaviours [37]. External resources are also an important construct in perceived behavioural control in TPB. In the present sample, approximately 70% of the participants were married. Despite having paid jobs, married Japanese women have been found to have spare time for personal care (e.g. 83–86 min per week) [38], so environmental control may be important for women with cancer to be able to perform self-care after discharge.

Attitudes towards self-care behaviours were also an important predictor of self-care behaviours, but the findings suggested that participants who perceived self-care as beneficial for preventing the onset of LE were less likely to perform it. This may be because participants who perceive self-care as too beneficial think if the signs and symptoms of LE appear, they can use self-care as first aid to make the signs and symptoms disappear immediately. This cognitive tendency as a barrier to self-care has been reported in a previous qualitative study among patients with gynaecological cancer [19].

Regarding subjective norms, we asked about how clinicians (oncologists, nurses, and rehabilitation staff), family, and peers perceived self-care. These items were not significantly associated with self-care behaviours in this sample. This result was consistent with previous studies of colorectal cancer screening behaviour [37]. In this sample, especially, clinicians' direct influence on patients' self-care behaviours may have been weakened because patients were an average of 2 years post-surgery and the coverage of LE education by the Health Insurance is limited to 1 month after surgery. However, the component was associated with attitudes and perceived behavioural control, indicating that the importance of LE education in this early period should not be underestimated—a point that has previously been made by other researchers [37].

Regarding factors other than the components of TPB, three factors were significantly and directly associated with a lower frequency of self-care behaviours: lower levels of knowledge of self-care, more years since surgery, and a more severe degree of fatigue. Neither age nor cancer type was significantly associated with self-care behaviours.

Among the three significant factors, levels of knowledge of self-care were significantly and most strongly associated with self-care behaviours, which was consistent with previous studies among patients with breast cancer [21, 22]. More years since surgery was weakly associated with self-care behaviours in this sample. Participants who underwent surgery several years ago may be less likely to remember recommended self-care or to be aware of the risk of LE [18, 19], or more likely to perceive themselves as being free from the illness [39]. This result suggests that the current practice in Japan is not sufficient to support cancer patients, and continuous care provision may be required to encourage patients with cancer to perform self-care after discharge. The degree of fatigue was also weakly associated with self-care behaviours in this sample, but this association was not explained by perceived behavioural control. This result was partially inconsistent with a previous study among patients with cancer [28], which found an association between the degree of fatigue and fatigue management behaviour, mediated by self-efficacy. This inconsistency may be because we did not measure perceived behavioural control for fatigue itself, so only the direct effect of fatigue on self-care behaviour was observed.

Study limitations

Although the present study showed factors associated with self-care that had not been reported in previous studies of LE self-care, the results should be interpreted with caution because of several limitations. We collected the data from a single oncology hospital, where patient education on self-care has been well delivered. Additionally, the present study was cross-sectional and had a small sample size for structural equation modelling. The results cannot be generalised to all patients with breast or gynaecological cancers. Knowledge about LE (e.g. irreversible conditions) and perceived risk of onset of LE were not investigated in this study. Future studies should include these variables to better understand the associations between attitudes towards self-care and self-care behaviours. Although the data included patients who underwent surgery 0–10 years previously, future studies should use a longitudinal design to understand clearly how patients' perceptions towards self-care and their awareness of LE risk change over time, and how these variables affect self-care behaviours during cancer survivorship.

Clinical implications

Health status and cognitive factors should be taken into account in LE prevention education programmes. In addition to what is already offered, to facilitate the integration of self-care into daily life, clinicians may need to individually assess patients' levels of fatigue and perceived emotional and environmental control to perform self-care. Because this study suggests a negative effect of attitudes on self-care, clinicians may need assess knowledge of LE and reinforce the importance of the observation of limbs and of seeking urgent medical consultation if changing sensations or symptoms are self-detected. Furthermore, longer-term survivors are less likely to perform self-care. Currently, the Japanese Health Insurance covers the cost of only two sessions of LE patient education and only in the first month after surgery. We may need to expand this coverage duration in hospitals or find alternative service providers—for example, public health nurses or primary care professionals—to support cancer survivorship in the community [11, 29].

Conclusions

The present study revealed that attitudes and perceived behavioural control, together with fatigue, knowledge of self-care, and years since surgery, determine self-care behaviours among patients with breast or gynaecological cancers at stage 0 of LE. Continuous LE prevention programmes beyond 1 month after surgery may be required to address fatigue, cognitive factors, and levels of knowledge of LE, as part of cancer survivorship care.

Acknowledgements We thank all patients who participated in this study.

Funding This study was funded by the Foundation for Promotion of Cancer Research in Japan and in part by the National Cancer Center Research and Development Fund (28-A-23).

Compliance with ethical standards

Conflict of interest Chikako Shimizu reports personal consultancy fee from Eizai and Pfizer, and grants from Pfizer, Chugai, MSD and Eli Lilly, outside the submitted work. Miyako Tsuchiya, Mariko Masujima, Tomoyasu Kato, Shun-ichi Ikeda, Takayuki Kinoshita, Sho Shiino, Makiko Suzuki, Miki Mori, and Miyako Takahashi have nothing to declare.

Ethics approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. For this type of study, formal consent is not required.

Informed consent Informed consent was obtained from all individual participants included in the study.

References

1. The Japanese Lymphedema Society (2018) [homepage on the internet]. Lymphedema and its treatment. http://www.js-lymphedema.org/?page_id=848. Accessed 1 Feb 2018

2. Kitamura K, Akazawa K (2010) Nyugan jyutsugo no rinpafushu nikansuru tashisetujittaichousa. [multi-center study in lymphedema following breast surgery]. Jpn J Clin Nurs 36:889–893
3. Takakura S, Yamada K, Sasaki H, Tanaka T (2005) Fujinkagan no kofukumakurinpasetsu kakuseijyutugono rinpafushuno hatsugenritu to sono yoboshujyutuho. [the prevalence rate following retroperitoneal lymph node dissection in gynecologic cancer and its preventive methods of surgery]. Gynecologic and Obstetric Surgery 16:136–136
4. DiSipio T, Rye S, Newman B, Hayes S (2013) Incidence of unilateral arm lymphoedema after breast cancer: a systematic review and meta-analysis. Lancet Oncol 14:500–515
5. Ohba Y, Todo Y, Kobayashi N, Kaneuchi M, Watari H, Takeda M, Sudo S, Kudo M, Kato H, Sakuragi N (2011) Risk factors for lower-limb lymphedema after surgery for cervical cancer. Int J Clin Oncol 16:238–243
6. The International Society of Lymphology (2016) The diagnosis and treatment of peripheral lymphedema: 2016 consensus document of the International Society of Lymphology. Lymphology 49:170–184
7. Salani R, Preston MM, Hade EM, Johns J, Fowler J, Paskett EP, Katz ML (2014) Swelling among women who need education about leg lymphedema: a descriptive study of lymphedema in women undergoing surgery for endometrial cancer. Int J Gynecol Cancer 24:1507–1512
8. Tsuchiya M, Horn S, Ingham R (2008) Arm symptoms and QoL in Japanese breast cancer patients. J Lymphoedema 3:130–135
9. Rowlands IJ, Beesley VL, Janda M, Hayes SC, Obermair A, Quinn MA et al (2014) Quality of life of women with lower limb swelling or lymphedema 3-5 years following endometrial cancer. Gynecol Oncol 133(2):314–318
10. Tsuchiya M, Takahashi M (2016) Psychosocial impact of lymphedema after breast surgery. Curr Breast Cancer Rep 8:47–51
11. Department of Health, Macmillan Cancer Support, National Health Services Improvement (2013) In: Living with and beyond cancer: taking action to improve outcomes. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/181054/9333-TSO-2900664-NCSI_Report_FINAL.pdf. Accessed 2 April 2017
12. National Health Service (2016) In: Lymphoedema-Prevention http://www.nhs.uk/Conditions/Lymphoedema/Pages/Prevention.aspx. Accessed 2 Apr 2017
13. National Lymphedema Network (2015) In: Healthy habits for patients at risk for lymphedema. http://www.lymphnet.org/resources/healthy-habits-for-patients-at-risk-for-lymphedema. Accessed 2 Apr 2017
14. The Japanese Lymphedema Society (2018) Clinical guideline for lymphedema. In: Kanehara & Co. Ltd, Tokyo
15. The Japan Association of Rehabilitation Medicine (2013) Guideline for cancer rehabilitation. Kanehara & Co., Ltd, Tokyo
16. Fu MR (2005) Breast cancer survivors' intentions of managing lymphedema. Cancer Nurs 28(6):446–457
17. Kusaka Y, Nakamura Y, Atogami F, Yoshizawa T (2015) Gynecological cancer patients' impression after taking the lymphedema preventive class: recognizing risk of developing lymphedema. J Jpn Soc Cancer Nurs 29:5–13
18. Masujima M, Sato R (2008) The perceptions and coping behaviors regarding lymphedma of patients who developed lymphedema following breast cancer surgery. Journal of Chiba Academy of Nursing Science 14:17–25
19. Abe A, Matsumoto K, Hirota N, Mori H, Hisamura M (2007) Rinpasetu kakuseiwo okonatta fujinkaganjyutsugokanjyaniokeru rinpafushuyobou taishohouhou jissennnojihatuseini eikyousuru youin [factors affecting motivation of lymphedema prevention and coping strategies among female organ-related cancer patients who underwent lymph node dissections]. Yamaguchi University Hospital Department of Nursing. Res Pap 82:52–55
20. Nakamori M, Arao H (2016) A concept analysis: awareness of lymphedema symptoms in post-operative cancer patients with secondary lymphedema. J Jpn Soc Cancer Nurs 30:14–21
21. Sherman KA, Koelmeyer L (2013) Psychosocial predictors of adherence to lymphedema risk minimization guidelines among women with breast cancer. Psychooncology 22(5):1120–1126
22. Sherman KA, Miller SM, Roussi P, Taylor A (2015) Factors predicting adherence to risk management behaviors of women at increased risk for developing lymphedema. Support Care Cancer 23(1):61–69
23. Ajzen I (1985) From intention to action: a theory of planned behavior. In: Kuhl J, Backman J (eds) Action control: from cognition to behaviors. Springer, New York, pp 11–39
24. Buffart LM, de Bree R, Altena M, van der Werff S, Drossaert CHC, Speksnijder CM, et al (2017) Demographic, clinical, lifestyle-related, and social-cognitive correlates of physical activity in head and neck cancer survivors. Support Care Cancer. https://doi.org/10.1007/s00520-017-3966-3
25. FitzGerald S, Cornally N, Hegarty J (2017) Men's perspectives on cancer prevention behaviors associated with HPV. Psychooncology 27:484–491. https://doi.org/10.1002/pon.4515
26. Ajzen I (1991) The theory of planned behavior. Organ Behav Hum Decis Process 50:179–211
27. Schmidt ME, Chang-Claude J, Seibold P, Vrieling A, Heinz J, Flesch-Janys D et al (2015) Determinants of long-term fatigue in breast cancer survivors: results of a prospective patient cohort study. Psychooncology 24(1):40–46
28. Hoffman AJ, von Eye A, Gift AG, Given BA, Given CW, Rothert M (2009) Testing a theoretical model of perceived self-efficacy for cancer-related fatigue self-management and optimal physical functional status. Nurs Res 58(1):32–41
29. Tsuchiya M, Mori M, Takahashi M, Masujima M (2018) Community-based lymphedema risk reduction programs for cancer survivors: an Internet survey of public health nurses. Jpn J Nurs Sci. https://doi.org/10.1111/jjns.12204
30. Okuyama T, Akechi T, Kugaya A, Okamura H, Shima Y, Maruguchi M et al (2000) Development and validation of the cancer fatigue scale: a brief, three-dimensional, self-rating scale for assessment of fatigue in cancer patients. J Pain Symptom Manag 19(1):5–14
31. Katayama F, Kodama M, Osada H (2009) Development of the Japanese version of the Illness Perception Questionnaire: reliability and validity with hemodialysis data. The Japanese Journal of Health Psychology 22:28–39
32. Moss-Morris R, Weinman J, Petrie K, Horne R, Cameron LD, Buick D (2002) The revised Illness Perception Questionnaire (IPQ-R). IPQ-revised. Psychol Health 17:1–16
33. Aizen I (1991) Construction a theory of planned behavior questionnaire. [homepage on the internet]. TPB Questionnaire Construction. people.umass.edu/~aizen/pdf/tpb.measurement.pdf. Accessed 2 Dec 2017
34. Hu LT, Bentler PM (1999) Cutoff criteria for fit indexes in covariance structure analysis: conventional criteria versus new alternatives. Struct Equ Model 6:1–55
35. Little TD, Cunningham WA, Shahar G (2002) To parcel or not to parcel: exploring the question, weighing the merits. Struct Equ Model 9:151–173
36. Drabe N, Steinert H, Moergeli H, Weidt S, Strobel K, Jenewein J (2016) Perception of treatment burden, psychological distress, and fatigue in thyroid cancer patients and their partners—effects of gender, role, and time since diagnosis. Psychooncology 25(2):203–209
37. Honda K, Kagawa-Singer M (2006) Cognitive mediators linking social support networks to colorectal cancer screening adherence. J Behav Med 29(5):449–460

38. Ministry of Internal Affairs and Communication Statistics Japan (2017) In: Heisei 28 Survey on time use and leisure activities 2017. http://www.e-stat.go.jp/SG1/estat/List.do?bid=000001083772&cycode=0. Accessed 2 Dec 2017

39. Tsuchiya M, Horn S, Ingham R (2012) Information provision and problem-solving processes in Japanese breast cancer survivors with lymphoedema symptoms. Scand J Caring Sci 26(1):53–60