

**Development of a nurse-led supportive care program for
Chinese women with newly diagnosed breast cancer
undergoing chemotherapy**

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Abstract of Doctoral Dissertation

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Dissertation Title	Development of a nurse-led supportive care program for Chinese women with newly diagnosed breast cancer undergoing chemotherapy		
<p>This research aimed to develop a nurse-led supportive care program adapted to the needs of Chinese women with newly diagnosed breast cancer undergoing chemotherapy, evaluate this program's content validity by Chinese experts, and explore the feasibility and acceptability of this program in a real-world context. It includes three studies:</p> <p>Study I aimed to formulate a preliminary draft of the supportive care program. It followed two parts.</p> <p>(1) Study I-I identified thirteen Chinese breast cancer women's supportive care needs and coping strategies through a semi-structured interview. During the chemotherapy, patients had needs of physical symptoms management, psychological adjustment, emotional support, information to prepare and cope with chemotherapy, communication, and social support. Patients coped with the chemotherapy by seeking information from multiple sources, minimizing adverse effects, cognitive defense, cognitive reconstruction, finding positive meanings, and seeking support to cope with chemotherapy.</p> <p>(2) Study I-II combined the interview result with the literature review and formulated a preliminary draft of the supportive care program. A nurse-led program (version 1) consists of needs assessment, skilled communication, tailored responses, summary, and referral were designed.</p> <p>Study II aimed to examine the content validity of the supportive care program. A focus group discussion by six Chinese experts (including a physician, nursing managers, nursing researchers, and nursing educators) with two rounds of consultation questionnaires was conducted. According to the experts' comments, we revised the program. Needs assessment, skilled communication, tailored information and emotional support, summary and referral were formulated as version 2, and the content validity of the overall scale of version 2 was over 0.9.</p> <p>Study III aimed to verify the feasibility and acceptability of the supportive care program. A pilot study was conducted. Two nurses implemented the supportive care program to eight patients, three questionnaires with interviews were used to evaluate the outcomes. The participation rate in the intervention was 75% (9/12), the adherence rate was 89% (8/9). Most patients and nurses benefited from this nurse-led supportive care program.</p> <p>Conclusion: The nurse-led supportive care program was feasible and acceptable, and it has the potential to fill gaps in health care services by addressing the supportive care needs of Chinese women with newly diagnosed breast cancer undergoing chemotherapy. Further study is needed to explore the effectiveness of this program.</p>			

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Abbreviations

QOL	Quality of life	DT	Distress Thermometer
PSY	Psychological needs	PL	Problem List
PCS	Patient care and support needs	SCNS	Supportive care needs survey
PDL	Physical and daily living needs	PRO	Patient reported outcome
SEX	Sexuality needs	HADS	Hospital anxiety and depression scale
HSI	Health system and information needs	QLQ-C30	Quality of life questionnaire core
SCF	Supportive care framework	CT	Chemotherapy
SCR K	Supportive care resource kit	CVI	Content validity index
CAMEO	Complementary medicine education and outcomes	FACT-B	Functional assessment of cancer therapy—breast
EdCaN	The national cancer nursing education project	EORTC	The European organization for research and treatment of cancer quality of life group information questionnaire
ALND	Axillary lymph node dissection	INFODIS	Information about the disease
SLNB	Sentinel lymph node biopsy	INFOMEDT	Information about the medical tests
TNM	Tumor, node, metastasis	INFOTREAT	Information about the treatment
AC-T	Doxorubicin and cyclophosphamide, then docetaxel	INFOTHSE	Information about other services
EC	Epirubicin and cyclophosphamide	INFODIFP	Information about different places of care
TC	Docetaxel and cyclophosphamide	INFOHELP	Information about things you can do to help yourself
EC-D	Epirubicin and cyclophosphamide, then docetaxel	INFOWRIN	Written information
TCbH	Docetaxel, carboplatin, and herceptin	INFOCD	Information on CD / video
TAC	Docetaxel, doxorubicin and cyclophosphamide	SATINFO	Satisfaction with the information received
PICC	Peripherally inserted central catheter	RECMORE	Wish to receive more information
CNKI	China national knowledge infrastructure	RECLESS	Wish you have received less information
NCCN	National Comprehensive Cancer Network	OVERHELP	Overall the information has been helpful
Fawu	It is a dietary term derived from traditional Chinese medicine widely spread among the population that may exacerbate surgical problems such as sores and tumors and causes allergic diseases or relapses (e.g.onions, leeks, chicken, mutton, fish and shrimp).		

Chapter 1 Background

1 Research motivation

In previous studies^[1], we explored the status of supportive care needs and quality of life (QOL) of Chinese breast cancer patients during chemotherapy, and the relationships between these two variables. The results showed that patients had many unmet needs in five domains: health systems and information, physical and daily living, psychological, patient care and support, and sexuality. Moreover, the most frequent needs were in the health and system information domain (31.30%), 'Being informed about cancer which is under control or diminishing' was the highest need in this domain. Furthermore, these supportive care needs were negatively correlated with the QOL in all the dimensions except society/family well-being and functional well-being. The correlation coefficient between psychological needs and QOL was the highest. It implied that patients' higher supportive care needs significantly influenced their QOL. Meeting patients' needs (especially in the information and psychological domain) will improve their QOL.

To further explore the dynamic change trend of patients' needs and QOL, a longitudinal study was conducted^[2]. We found that patients' health systems and information, physical and daily living, patient care, and support needs were higher in the first round of chemotherapy. However, these needs gradually decreased over time. On the contrary, their psychological and sexual needs increased from the first to the final round of chemotherapy. Moreover, their psychological and physical and daily living needs significantly impacted their QOL in the first round of chemotherapy. Therefore, it is necessary to conduct a scientific assessment and personalized intervention to help patients coping with chemotherapy at different time points. The available data provides a little in-depth understanding of needs and how they cope with these needs. Otherwise, how to implement a personalized intervention considering Chinese cultural background needs further discussion.

2 Introduction

2.1 Descriptive epidemiology of breast cancer

The International Agency for Research on Cancer reported that breast cancer is the most common cancer and the leading cause of cancer death among females. There are around 2.3 million new cases and 685 thousand breast cancer deaths worldwide in 2020^[3]. In China, breast cancer is the major burden on women' health, with about 416,371 newly diagnosed female cases as indicated by the GLOBOCAN 2020 online database^[4]. According to 2020 Zhang et al. published the data of cancer burden in China, 2015^[5], the age-standardized incidence rates by world standard population (ASIRWs) for breast cancer were higher in urban areas (33.8/100,000) than in rural areas (23.6/100,000). Moreover, the breast cancer incidence rate showed differences across geographic areas. In Northeast China, the ASIRWs for breast cancer were highest (35.4/100,000). In addition, among all new cases of

women with breast cancer in China, over three in four were diagnosed at age 40-69^[4], the mean age at diagnosis is 45-55 years old^[6]. Same as the global trend, the incidence of breast cancer shows an increasing trend with age^[7]. Furthermore, findings from a multicentre study in China showed that 83.92% of 3470 women were diagnosed with breast cancer at early stage (32.8% at stage I and 51.44% at stage II), 16.08% at advance stage (14.03% at stage III and 2.05% at stage IV)^[8].

2.2 Treatment of breast cancer

Medicine and treatment have progressed over the past years, and conventional surgery is not the primary choice for all patients anymore^[9]. Depending on breast cancer subtypes, therapeutic options include systemic therapies (chemotherapy, targeted therapy, endocrine therapy) and local therapies (surgery and radiation)^[10].

For early breast cancer (without detectable distant metastases), local therapy may consist of surgery and radiotherapy. Systemic therapy may be preoperative (neoadjuvant), postoperative (adjuvant), or both. The essential purpose of these therapies is to remove the tumor and to prevent a metastatic recurrence. For metastatic breast cancer, the therapeutic goals are maintaining the quality of life and symptom palliation. At present, neoadjuvant/adjuvant therapy is using in systemic therapy. Local therapies (surgery and radiotherapy) are using for palliation only in metastatic disease^[9,10].

Among these treatments, chemotherapy remains a necessary treatment to prevent recurrence in many patients with stage I-III breast cancer and prolong life in some patients with metastatic breast cancer^[9,10]. In recent years, preoperative chemotherapy (neoadjuvant chemotherapy) has emerged as a standardize treatment provided to some early cancer stage patient who has a chemotherapy indication (e.g., which primary breast surgery is impossible due to large tumor size or the relationship of the tumor and breast size)^[11]. However, due to Chinese patients' low willingness to conserving breast(s) through neoadjuvant therapy and uncertainty of delayed surgery, neoadjuvant chemotherapy was not prevalent in China^[12].

In addition, China's health insurance system has its distinctiveness. As the health insurance is partly funded by local governments and the detailed policies was set by themselves, the reimbursement rates may vary widely across counties, even under the same insurance scheme^[13,14]. Moreover, affected by local economic status, aging level, and medical resource supply among regions, the reimbursement rate, the category of treatments covered under the outpatient insurance are different^[15]. In general, cancer treatment fees can be covered with health insurance in hospitalization. Although the national government has instructed local governments to include the expenses related to radiotherapy and chemotherapy in outpatient clinics for cancer into health insurance^[15], outpatient chemotherapy fees cannot be reimbursed due to the inadequate insurance system of some local governments^[16-18]. In addition, some hospital managers, clinicians, and patients have low acceptance

of outpatient chemotherapy^[16], and inpatient chemotherapy is the primary choice for many cancer patients.

2.3 Treatment side effects on breast cancer patients' health and well-being

Even though progressed treatments increased the survival rate^[19], they lead to different side effects in the long term of survival. Surgery may lead to breast asymmetry, scarring, sensation loss, and lymphedema^[20]. In addition, chemotherapy can lead to impaired fertility and premature menopause, which increase the risk of osteoporosis^[21]. Endocrine treatments may also cause menopausal symptoms, such as hot flashes, night sweats, and atrophic vaginitis, leading to dyspareunia^[22]. Also, breast cancer survivors may experience cognitive impairments and chronic fatigue^[23]. Their QOL decreased because of these consequences ^[24,25].

Thus, cancer patients expected the health care professionals to be aware of the treatment effect on their health and well-being. Patients and relatives still require professional support for their substantial needs and psychological problems even after completing treatment^[26-28]. Some Chinese breast cancer patients also expressed that their need for information is not adequately understood and valued by health care professionals^[29].

Patient-centered care is unlikely to occur without a good understanding of patient needs and factors that influence them^[30]. Silvia et al.^[31] found physical and social impairment, impaired body image, distress, anxiety and depression, a lack of social support, and conflicts in their personal relationships were associated with supportive care needs, and patients who reported higher unmet needs were more likely to be depressed and to have a lower QOL^[32]. However, QOL might be enhanced if interventions are made for specific unmet needs of each patient group^[32]. A previous study^[33] found that providing supportive care during breast cancer treatment will improve patients' treatment compliance, help them manage treatment-related symptoms, and deal with psychosocial and psychiatric problems.

Therefore, identifying and managing unmet supportive care needs is an essential component of health care for people with cancer^[34].

3 Literature review

3.1 Status of breast cancer patients' supportive care needs

Supportive care needs are diverse. Those needs could relate to coping with the physical effects of cancer and its treatment to psychological and psychosocial sequelae such as anxiety, depression, and feelings of isolation^[34]. The generic needs of patients with cancer were formulated in five domains by Bonevski et al.^[35], including psychological need, health systems and information need, physical and daily living need, patient care and support need, and sexuality need.

3.1.1 Psychological needs (PSY)

Psychological needs are the needs related to emotions and coping^[35]. It is reported^[36,37] that breast cancer patients have high psychological needs, especially in 'Fears about cancer spreading', 'Concerns about the worries of those close to you' and 'Uncertainty about the future'. A Japanese study^[38] found the most frequent unmet needs were over 50%, and almost all of these unmet need items belonged to the Psychological domain or the Health system and information domain, 78.8% of patients have the needs of 'Fears about the cancer spreading'. German women also reported^[39] significantly greater unmet psychosocial need strength in psychological domains, and greater unmet psychological needs associated with high anxiety and depression scores, as well as greater symptom burden.

3.1.2 Patient care and support needs (PCS)

This domain consists of needs that are related to health care providers showing sensitivity to physical and emotional needs, privacy, and choice^[35]. Sook et al.^[40] analyzed the data of 459 patients, 39.9% of them have unmet needs in the 'patient care and support' domain, and patients who live alone were significantly more likely to report some need for help in the 'patient care and support' domain. More Chinese women expressed a moderate-to-high unmet need for 'More choice about which cancer specialists you see' compared with German females (77.5% Chinese vs. 50% German)^[39].

3.1.3 Physical and daily Living needs (PDL)

Physical and daily Living needs are the needs related to coping with physical symptoms, side effects of treatment, and performing usual physical tasks and activities^[35]. Patients experienced a cluster of physical problems before and during adjuvant cancer treatment, such as fatigue, sleep and mood problems^[41,42]. More than 70% of women were experienced nausea/vomiting after chemotherapy, less energy, or difficulty with physical activities within one month after surgery^[43]. Fatigue is common in physical and daily life needs in other investigations^[44,45]. Half of the top 10 unmet needs at three months post-diagnosis were in the physical and daily living domain, 'lack of energy and tiredness' was reported as being an unmet need by approximately one in three (31%) respondents in the study of Minstrell et al.^[37]. Single women had higher physical and daily living needs, suggesting that patients lacking spousal/family support are likely to seek support from clinicians to manage physical symptoms and self-care^[46].

3.1.4 Sexuality needs (SEX)

Sexuality needs are the needs related to sexual relationships^[35]. Sex is a personal and sensitive problem; the level of sexuality needs of breast cancer patients was different among studies. In one study^[47], the unmet sexual needs were low, and these needs were likely to take a lower priority. A possible explanation for that observation could be that women concentrated much on active anticancer treatment effects^[36]. In various cultural contexts, women react differently on the issue of sex. German women reported higher unmet sexuality needs than Chinese women did as over 90% of Chinese

women expressed no sexuality-related concerns^[39].

3.1.5 Health system and information needs (HSI)

Health system and information needs are needs related to the treatment center and for information about the disease, diagnosis, treatment, and follow-up^[35]. Acquiring the information was to reduce confusion, anxiety, and fear, to inform the persons' and family's decision-making and to assist in skill acquisition^[48]. Numerous studies^[32,39,44,46,49] have shown that the most common needs belong to the health system and information needs, and some patients have the highest information needs on "Being informed about cancer which is under control or remission" ^[1]. Liao et al. ^[36] investigated 124 women with newly diagnosed breast cancer, and the highest unmet needs were measured at diagnosis, 1 month, 2 months, and 3 months after diagnosis with regards to the health system and information. Also, Asian women reported greater information needs compared with Western women^[49] as 39.1% German Caucasian reported having unmet information needs on 'Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment and follow up', the Chinese who have this kind of needs reached 69.9%^[39]; Au et al.^[46] found that 72% of the patients have needs on 'having one member of hospital staff with whom you can talk to about all aspect of your condition, treatment, and follow-up'; Xing et al.^[50] interviewed 16 breast cancer patients and found the information needs of patients were very high. Therefore, compared with developed countries, Chinese people have a stronger demand for current nursing intervention, especially need information support. Most Chinese patients expect to have a specialized medical staff to talk about all aspects of their conditions, treatment, and follow-up.

3.2 What the information means to breast cancer patients

Cancer patients reported that information plays a significant role in helping them to cope with the effect of treatment and manage it^[51]. They hope to get more information to adapt to their conditions, decrease or control stress and anxiety, and learn more about the disease^[52,53]. Simultaneously, information would help patients understand the outcome of treatment and deal with unexpected experiences^[54]. Otherwise, knowing the type and amount of information preference by different patient groups makes it easier for health professional to provide appropriate information s^[55].

3.2.1 Information needs and content

Several studies found breast cancer patients had kinds of information needs^[52,56-58], whatever the period or type of treatment they received or any period they were going through^[59,60]. Around diagnosis, they hope to know more about diagnosis, treatment side effects, the chance of cure, and prognosis^[61-63]. Moreover, treatment related information is the most important (i.e., the effect of treatment, management of side effect, self-care, and risk of family members)^[58,64-66] for patients who are undergoing treatment, especially at the time of their planning appointment and when they start the

first oncological consultation^[67,68]. Halkett et al. also found that the level of information needs and anxiety still high until treatment commencement^[69]. Furthermore, patients' needs were related to their demographical characteristics. Younger patients have a higher tendency to seeking information than elders^[53]; patients with a high level of education and cancer stage, and who are at a working age have more information needs than the others^[64]. However, if patients have higher health literacy or are provided helpful information by the physician and social service workers, their information needs will be lower^[64]. Therefore, to reduce patients' psychological distress, information needs and concerns effectively, information should be provided before treatment planning^[68], and combined with patients' personality, offering them a customized information delivery plan is essential.

3.2.2 Information source

There are many ways for breast cancer patients to acquire information (i.e., physician, nurse, friends/family, website). Ghazavi et al. ^[52] mentioned the most crucial information sources were 'Brochure and catalog provided by hospital', 'other cancer patients', and 'physicians and nurses', patients also preferred to get more lifestyle information (such as diet, physical activity) from family/friends^[56]. In one study^[57], the researchers found 50% of the participants use the Internet as the media source information, especially by younger patients. Whereas other researchers^[70,71] pointed the weakness of website information, the uneven quality, conflicting claims, redundancy problems that existed on the web, and only a few websites had a health care professional or expert as the author, it makes it difficultly to find information and assess its accuracy and applicability. Katherine et al. ^[72] reported that health care practitioners were the most preferred information source for surgical breast cancer patients. And nurses played a crucial role in addressing patients' information needs^[73].

3.2.3 Information formats and seeking obstacle

Breast cancer patients prefer to get information in various formats. The elderly patients reported educational materials would help them better understand their treatment options^[74]. Another two studies showed patients preferred written and verbal formats of information. One study mentioned that more than half of patients appreciated a combination of both written and verbal information^[69], another one said an additional face-to-face session would be helpful^[68]. Meer et al. ^[56] also highlighted that 64% of patients preferred to receive information and services face-to-face, but there is no difference in information format (face-to-face VS. telehealth) on body weight, diet, and physical activity.

In other aspects, patients' information-seeking behaviors were essential for their information needs. However, patents' information-seeking behaviors can be impacted by some obstacles. The most critical information-seeking barriers were 'High cost of information sources', 'Lack of response from physicians and nurses', and 'uncertainty about the accuracy of web information'^[52], and 'little

familiarity with medical terminology and information sources'. Also, the inaccessibility of reliable information sources make patients feel challenging to obtain information about their disease^[53]. Other researchers^[75,76] found the readability, comprehensibility and cultural relevance of information might influence patient's understanding of health information.

Furthermore, breast cancer patients and nurses have different views on the importance of information in the same subscale. The mismatch of provision by nurse and patients' desire may be another vital obstacle^[77]. Therefore, it is essential for nursing practitioners to assess patients' needs and personal situations, and then provide the suitable content, format of information.

3.3 The framework and module of supportive care for cancer patients

Many frameworks and modules were built to guide the intervention or train the nurse to provide supportive care for cancer patients.

3.3.1 Supportive care framework (SCF)

The supportive care framework for Cancer Care was formulated by Fitch^[48], as a tool to conceptualize what type of help cancer patients might require and how planning for service delivery might be approached (Fig.1). The SCF recognized that individuals have different needs, and therefore they required different levels of response. As the complexity of patients' needs increases, the strategy to address needs must also change. The SCF helps managers and health care professionals to assess patient needs and distribute resources appropriately, and identify where in the model the supportive care services offered by the health service and the primary care service may fit^[78]. Moreover, it has been presented in various fields as a helpful framework and applied in many programs^[79-81]. For example, the intervention of the complementary medicine education and outcomes (CAMEO) program^[79] was organized hierarchically based on SCF, and the SCF played a good role as a theoretical foundation in interventions.

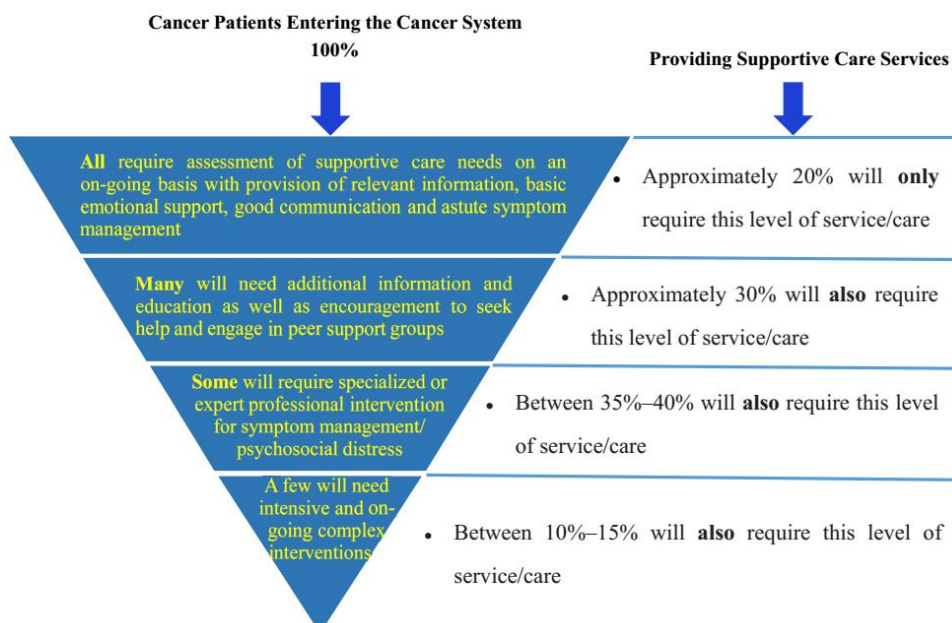


Figure 1. Supportive care framework (SCF) by Margaret I. Fitch

3.3.2 The supportive care pathway

The supportive care pathway^[82] (Fig.2) is a module concentrates on the screening and referral process. The pathway acknowledges the need for an individualized approach to assessing the patient only when required. Moreover, it highlights that some requirements can be met by clarifying and providing information and supportive communication^[82]. And the referral stage is suggested for "Some" or "Few" patients. Ristevski E et al. developed the supportive care resource kit (SCR K)^[83] for healthcare professionals. The SCRK included the supportive care pathway, tools, and resources, to guide the healthcare professionals to conduct the supportive care screening and referral process. The research team also examined the acceptability and feasibility of this process with cancer patient and the clinician^[83-87]. For the clinicians, they perceived that supportive care screening benefited their practice by improving communication and rapport with patients^[84]. Moreover, the clinicians' practice matched well with guidance from the protocols on discussion and referral, and provided information to patients^[86]. For patients, they felt the screening and referral process enhanced their communication with health professionals, assisted them to initiate a discussion with the clinician. It also encouraged them to seek help and support and focus clinician attention on unmet needs^[85]. Both patients and clinicians found the supportive care process highly acceptable^[83,87].

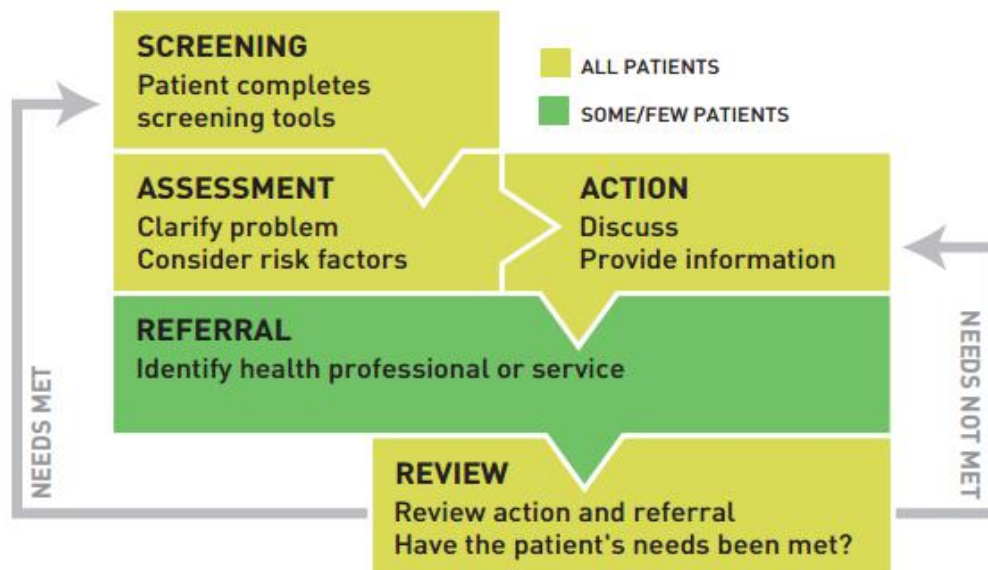


Figure 2. The supportive care pathway

3.3.3 The Tiered model of supportive care

A national government agency (Cancer Australia) developed 'The national cancer nursing education project' (EdCaN) to guide the development of nurses' professional ability to provide high-quality care that meets the needs of cancer patients^[88]. Fifty-one publications have cited EdCaN and the EdCaN Framework, and some publications also mentioned the usefulness of resources from the EdCaN project in guiding local professional development and research initiatives^[89]. This project

did excellent work in cancer nursing development within Australia and in many other countries.

In this project, they provided some learning resources to support nurse in cancer management. The supportive care module is a resource for developing specialist cancer nurse knowledge and skills in supportive care screening, assessment, and referral^[78]. This module lists the definition of supportive care, guides nurses to screen and assess supportive care needs, approaches to education and information provision, and the link of crucial relevant resources. Three frameworks were mentioned in this module. Supportive care framework (SCF) and the supportive care pathway have been introduced above^[48,82]. The Tiered model of supportive care^[90] (Figure 3) was developed by Supportive Cancer Care Victoria, which adapts the approach described by Fitch^[48]. The supportive care framework (SCF) by Fitch proposes that all cancer patients have needs. As the complexity of their need increases, the strategy to address needs must also change. "The Tiered model of supportive care" was developed based on SCF; it recognizes that effective, efficient allocation of resources is required to respond to the diversity of needs. Also, this model is easier to understand for nurses during clinical practice.

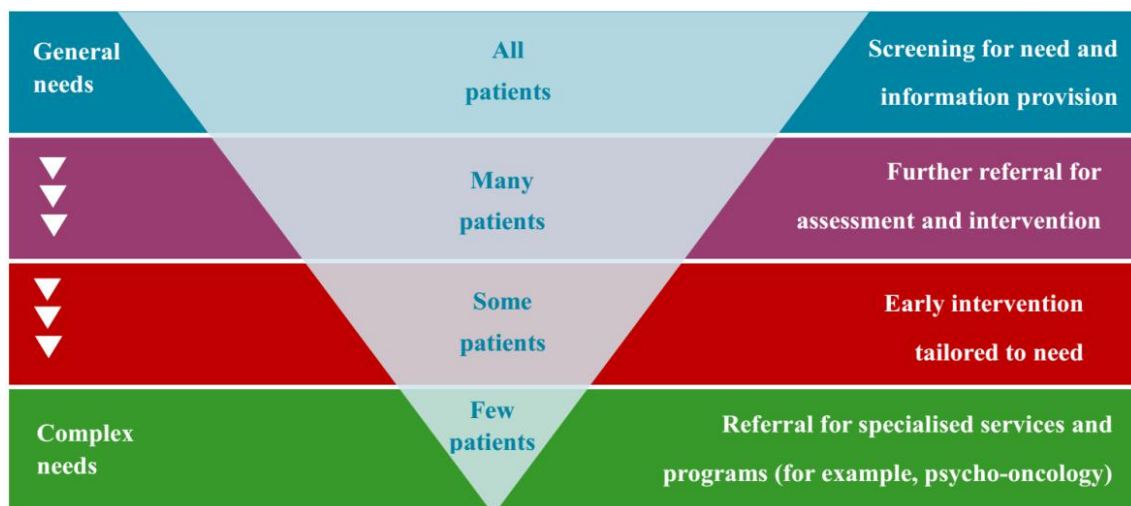


Figure 3. Tiered model of supportive care

3.4 The role of nurse for breast cancer patients in the provision of supportive care

Breast cancer patients have much unmet need during the treatment^[32,46], and they expected one member of hospital staff to talk to them about all aspects of their condition, treatment, and follow-up^[46]. Kinta et al. ^[91] found that compared with traditional hospital follow-up by other health professionals, breast cancer patients reported a higher level of satisfaction when they received the telephone follow-up by specialist nurses. Many women preferred to consult cancer-related symptoms with a breast cancer nurse rather than consult patients' general practitioners^[92] because of the cost of appointments or other factors. Cancer patients believed that nurses liked to use simple and easy language when they explain information^[93]. They also reported that nursing support by experienced oncology nurses made them feel safe and secure, helped them understand the effects of the disease and treatment, and prepared for coping^[94]. Nurse navigators have the unique ability to connect patients

with the clinicians and referrals they needed, thus becoming an access point to obtain supportive and palliative care^[95].

Most studies reported that nurses' high value in delivering treatment and support, especially in improving patients' QOL and satisfaction of care and meeting patient's needs^[92,96-101]. The nurse was seen as a bridge between the patient and the doctor and is considered a more appropriate health team member when information was needed^[55]. Breast care nurses offered valuable information, support, and advice. They did great work to patients in regional, rural and remote environments^[100]. Campbell D et al. also found patients who received systematic care by specialist breast nurse reported being supported well and enough information provided than others who did not^[98].

3.5 The supportive care or information support interventions by the nurse for breast cancer patients

Some publications designed the support care intervention for breast cancer patients. They have varying degrees of effectiveness in decreasing the level of needs or meeting patients' supportive care needs. Kinta et al.^[102] indicated that the telephone intervention conducted by breast cancer nurses is a feasible and acceptable approach in meeting patients' information needs. Aranda et al. ^[103] combined face-to-face communication and telephone follow-up for advanced breast cancer patients, the patient's mainly concerned problems were recognized through the communication. Then the nurses provided support and communication strategies through information cards. This kind of intervention by a breast cancer nurse significantly reduced the psychological and emotional needs of patients with high initial needs. However, one week interval between face-to-face session and follow-up seems too short for patients to adapt the care plan. Liao et al. ^[104] set up an education and psychological support intervention consisting of three individual face-to-face educational and psychological support sessions and two telephone follow-up sessions for breast cancer patients three months after surgery. In different sessions, they offered different educational and psychological information and support patients according to their main concerns. This intervention effectively improved the patient's unmet supportive care needs at one and three months after surgery. Also, the effect of face-to-face communication with telephone follow-up intervention was tested by Lai et al. ^[97] for patients with breast cancer in the chemotherapy day center. Decreased distress and improved patient satisfaction implied that this kind of intervention was beneficial for breast cancer patients. "I can cope" program and "survivorship care plan" are effective at addressing patients' needs^[105,106]; and "Specialist Breast care Nurse model of care" improved some aspects of care^[107]; "health information prescription" enhanced patients' self-care power^[108]. These interventions showed the essential role of nurses in supporting patients and meeting their needs. In China, the studies focusing on cancer patients' needs are more than before^[1,109,110]. However, evidence-based needs assessment and supportive care tailored

to individual's needs adapted to Chinese culture is still lacking [111-113].

3.6 Predictors of unmet needs for patients with breast cancer

Many studies analyzed what variables may be associated with or predict of unmet needs in women with breast cancer, such as socio-demographic characteristics, cancer stage, and treatment method.

3.6.1 Socio-demographic Characteristics

3.6.1.1 Age

One of the influencing factors of unmet supportive care needs was age. Some studies showed that younger breast cancer patients had more unmet needs than older ones^[36,114]. In Korea and Japan, younger patients reported high sexuality needs^[40,115], but younger patients living in New South Wales had many psychological needs^[116]. Otherwise, younger patients in Kuching, Sarawak had high physical and daily living, psychology, patient care and support, and sexuality needs^[117]. Furthermore, the tendency to seek information was higher for those who were less than 46 years old^[53]. Older patients had a high need for information about disease and treatment. In Fitch et al.'s study, information about the medical condition, treatment options, and side effects of treatment was the most needed resource for older cancer patients^[51]. They preferred to know more about the impact, safety, and efficacy of treatment when they diagnosed with breast cancer^[118]. Jennifer et al. found that older breast cancer patients needed more information to cope with disease and treatment decision-making^[74]. Therefore, age is a predictor of patients' unmet needs, and providing different kinds of help for the different age groups is needed.

3.6.1.2 Material status

Breast cancer patients' unmet needs vary in different marital status. Single patients have higher physical and daily life needs^[46], while married patients have higher sexual needs reported by many studies^[40,46,117]. Women who are not living alone need more information about the risk of their significant others developing breast cancer^[60]. Also, they have higher needs in the patient care and support domain^[40].

3.6.1.3 Educational level

The education level of patients had a significant relationship with supportive care needs. Patients with a higher education level had many needs in the patient care and support^[40], sexuality^[46], and information domains. They also preferred to know more information about treatment options^[60], and long-term side effects^[64]. Compared with patients with higher education, lower educational ones might be limited in the resources of physical and daily life, they had less information on disease and treatment. Therefore, they had more fear of unknown diseases^[40,53,117].

3.6.1.4 Household income and employment

During the period of treatment, patients face substantial medical expenses. Their economic conditions also impacted their needs. The patients with less income had high physical and daily life needs due to the limited resources they got^[40]. On the contrary, patients with higher income had more information needs^[60], and less likely to prioritize the information on "caring for themselves at home" as the top three choices^[116]. The patients at work age hoped to get more information about long-term side effects^[64]. Employed women had high health system and information, and patient care and support needs^[115]. Otherwise, the unemployed women needed more help in psychological and patient care and support^[117].

3.6.2 Clinical characteristics

3.6.2.1 Cancer stage

Many studies reported that the level of patients' supportive care needs with different stages of breast cancer. Some researchers investigated the unmet needs of patients with advanced-stage cancer (stage III, IV and/or metastatic and/or recurrent breast cancer), they were likely to have a high healthy system and information needs, psychological needs, and patient care and support needs^[38,46,47], and there was no difference of their needs between stage III and IV^[46,47]. Other researchers found patients with high cancer stages were positively associated with total supportive care needs^[115,119], and advanced cancer stage was significantly associated with poorer QOL^[120]. For Korean women whose tumor size was more than 2cm, their psychological needs were high; after they were diagnosed with recurrence, they needed more information. Furthermore, patients' physical and daily living needs were high after they had node metastasis^[40]. Akechi et al. found that patients had high physical and daily living, psychological, health system and information needs if they were diagnosed with cancer at stage IV or recurrence^[115]. However, Fong et al. reported that there is no difference in supportive care needs among patients with early-stage (Stages I and II) and later stage (Stages III and IV)^[117], but both of the two groups had high information needs. It means recognizing breast cancer patients' supportive care needs is essential whatever the cancer stage they have.

3.6.2.2 Treatment type

Patients with different cancer stages experienced different types of treatments, which could engender different supportive care needs^[49]. The type of surgery is the main factor. Patients who had mastectomy were more worried about their body image, sexual needs, premature menopause, and other problems^[121], and the ones who received mastectomy only reported more needs than those who had a mastectomy with reconstruction^[46]. Furthermore, patients' needs were increasing from having surgery only, surgery and RT, to surgery, RT, and CT^[49]. Patients undergoing active treatment have a variety of unmet needs, such as psychological needs, patient care and support needs, sexual needs^[117].

Among all treatment types, breast cancer patients currently receiving chemotherapy were significantly associated with the total supportive care needs^[115]. Patients receiving or having received chemotherapy were more likely to report some needs in the physical and daily living need domain^[40], and women received chemotherapy had seven times the odds of reporting physical and daily living need than who never received^[116]. Furthermore, the patients awaiting initial chemotherapy had more information needs than who receiving chemotherapy^[46], which was likely due to the side effects of chemotherapy^[40], the higher level of physical and social impairment and body image impaired, the more supportive care patients needed^[31,122]. Also, in the early stage and following chemotherapy, information about side effects management is the priority need for patients^[55,123]. Therefore, it is necessary to provide information and support for patients who will going to receive or are currently receiving chemotherapy.

3.6.2.3 Timing

Approximately two-thirds of survivors reported at least one unmet need after 2–10 years post-diagnosis of breast cancer^[124]. More than a third of survivors presented unfavorable patterns in supportive care needs over eight months after primary cancer treatment^[125]. Also, patients with a survival duration of less than one year since surgery suffered high needs (except sexual need) than patients with survival duration of fewer than three years and long-term (more than five years) after surgery^[32]. Patients' psychological needs and health system and information needs were highest at one month after diagnosis, whereas decreased at three months post-diagnosis^[37]. The previous study showed that timing is a predictor of supportive care needs, and shorter duration since diagnosis predicted greater supportive care needs among Asian studies^[49,126], especially after diagnosed less than six months their needs is much higher^[115]. Also, it is worth mentioning that women with first-time diagnoses reported greater unmet needs related to health system and information than women with recurrent disease^[46]. It implied that the health care providers offer the information and support for women close to diagnosis were highly valued^[126], mainly for first-time diagnosed patients.

3.6.3 Cultural background

People living in different cultural backgrounds had different needs for disease cognition. Many studies investigated the supportive care needs of breast cancer patients from different countries^[49,126]. Compared with western women, Asian women reported higher information needs and lower psychological needs^[49], and most of the top 10 unmet needs related to the health system and information needs^[32,36,38,46]. German Caucasian women prioritized physical and psychological support, whereas Chinese women prioritize needs for information on disease and treatment^[39]. Such differences reflect the patients' expectations for nursing in different national or cultural contexts. Furthermore, culture had a significant influence on patients' sexual needs. Asian women pay less attention to "sex,"

possibly because this issue is personal and private, and patients have low expectations for support^[36].

To sum up, there are kinds of unmet supportive care needs of breast cancer patients, but their needs are different according to the situation. When health professionals provide services and support to reduce patients' needs, it will be helpful if care providers consider the socio-demographic characteristics, clinical characteristics, and cultural background of patients.

3.7 The supportive care needs of Chinese patients with breast cancer

Most of the Chinese breast cancer patients had moderate to high levels of need for supportive care^[119], especially in the health system and information, and psychological need domains^[39], the majority (84%) reported at least one unmet need about the information on health care^[127]. Some studies ^[39,46,127] identified women's top two needs were healthy system and information needs, and rural patients had these two kinds of needs more than urbanite^[119]. 72% of Chinese women noting 'having one member of hospital staff with whom you can talk to about all aspect of your condition, treatment, and follow-up' as their primary information need^[46]. 67% of patients expected being informed about things they can do to help themselves to get well^[119]. Moreover, more than 60% of patients hoped to be informed about test results as soon as feasible^[127]. The most they want to know from cancer diagnosis to four months later was that the cancer is under control or diminishing^[36]. Also, in patients with high physical and psychological needs, their QOL was poor^[127]. Furthermore, the unmet needs were predicted by symptom distress and anxiety^[36], patients with high needs in healthy system and information, psychological, and physical and daily living domains reported greater physical symptom distress^[47]. Moreover, patients with high unmet health system and information needs reported more depressive symptoms at the initial treatment phase. They showed poor satisfaction with the medical staff's service^[128]. The above studies indicated that meeting breast cancer patients' supportive care needs is meaningful in improving patients' QOL and symptom distress. Meanwhile, patients' satisfaction with health services will also be improved.

3.8 Summary

Breast cancer is the most common diagnosed cancer worldwide, and the incidence of breast cancer in China is increasing year by year^[129-131]. With the development of medicine and improved treatment, the survival rate of breast cancer patients is increasing.

During the long-term treatment and survival, women experienced several consequences of the disease and treatment, such as scarring, cognitive impairments, chronic fatigue, body image impairment, and most of them related to radiotherapy and chemotherapy.

Breast cancer patients had many unmet supportive care needs due to these consequences, particularly for the patient who is going to start a new treatment. Also, different socio-demographic and clinical factors and cultural backgrounds influenced the patient's needs. Furthermore, patients had

different expectations with care. Hence, to be effective, supportive care is supposed to develop based on and matched with patient's needs under consideration of the personal situation, and tailored to the individual's desirable goals^[48].

Most of the Chinese breast cancer patients had moderate to high levels of need for supportive care, 72% of Chinese women noting 'having one member of hospital staff with whom you can talk to about all aspect of your condition, treatment, and follow-up' as their primary information need. It means that in clinical practice, the information is not enough for patients. However, evidence-based needs assessment and supportive care tailored to individuals' needs matching Chinese culture are still lacking.

3.9 Conclusion

Therefore, it is necessary to develop an effective care program to support Chinese breast cancer patients undergoing early-stage chemotherapy based upon and matched with an individual's needs.

Chapter 2 Program statement

1 Purpose and significant of this research

1.1 Purpose

This research aimed to develop a nurse-led supportive care program adapted to the needs of Chinese women with newly diagnosed breast cancer undergoing chemotherapy and explore the feasibility and acceptability of this program in a real-world context.

1.2 The significance of this research

For patients, their specific needs will be comprehensively assessed through this supportive care program. The information and support tailored to their needs will be provided by the trained nurse, helping patients adjust and smoothly transfer to chemotherapy to further improve their quality of life.

In the Chinese medical system, the comprehensive needs assessment and supportive care tailored to individuals' needs matching Chinese culture are still lacking in nursing practice. This program will help nurses allocate resources more effectively, respond to the diversity of breast cancer patients' needs efficiently. This research would employ the resources efficiently and improve patients' satisfaction with nursing services.

2 Term definition

2.1 Need

It can be defined as the requirement of some action or resource that is necessary, desirable, or useful to attain optimal well-being^[132].

2.2 Supportive care

It is defined^[133] as "the provision of the necessary services as defined by those living with or affected by cancer to meet their physical, social, emotional, informational, psychological, spiritual, and practical needs during the pre-diagnostic, diagnostic, treatment, and follow-up phases of cancer care, encompassing issues of survivorship, palliation and bereavement".

2.3 Supportive care needs

Supportive care needs have been described as 'the help required by cancer patients and their families beyond medical, surgical, or radiation interventions'^[133].

2.4 Nurse-led care

Nurses have a leadership or supervisory role or practice without direct supervision by another health professional^[134].

3 Framework

In this program, the framework 'Tiered model of supportive care'^[90] was used to guide the intervention process (Figure 3).

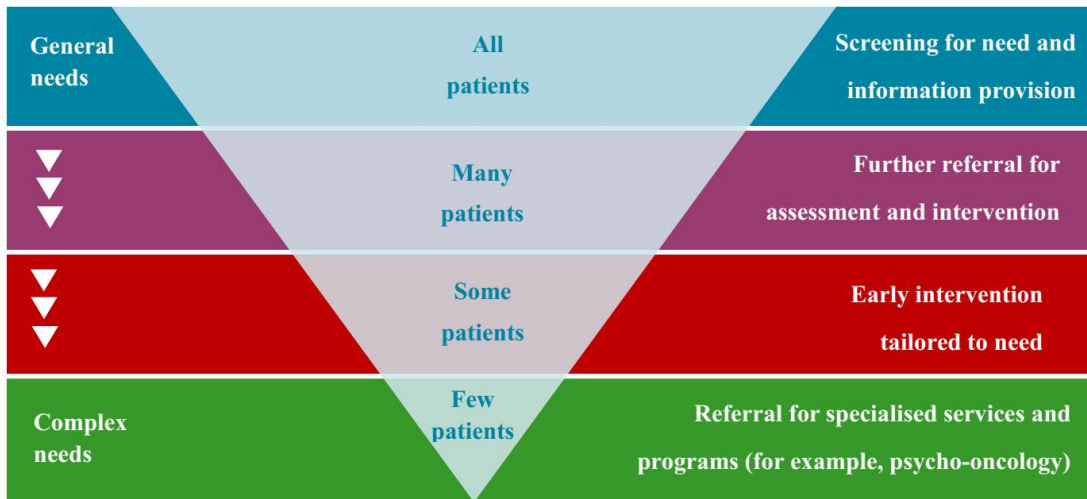


Figure 3. Tiered model of supportive care

4 Research design

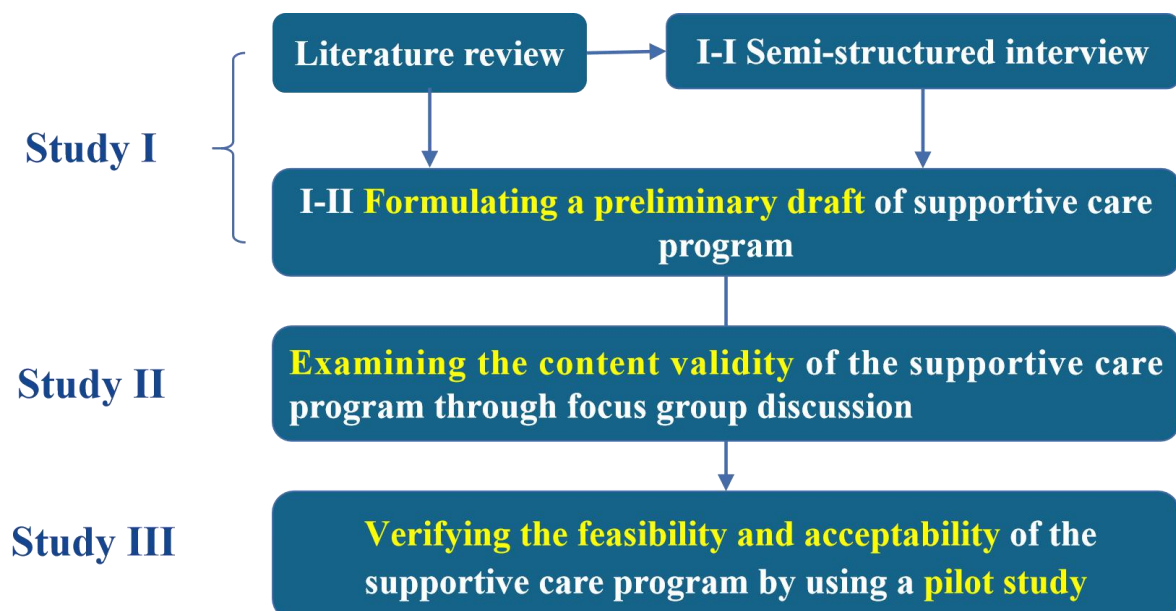
This research included three studies:

First, a qualitative study is conducted to understand breast cancer patients' supportive care needs and coping strategies. A draft of the supportive care program is then designed to combine the result of the interview and literature review.

Second, an expert meeting acted as a focus group is conducted to provide comments for further revision and examine the content validity of this supportive care program with two rounds of questionnaires.

Third, a pilot study is implied to assess this program's feasibility and acceptability for further revision. A final version of the supportive care program was established tailored to the need of Chinese women with newly diagnosed breast cancer.

5 The flowchart of research design



Chapter 3 Study I - Formulating a preliminary content draft of supportive care program

Study I-I: The Supportive care needs and coping strategies of Chinese women with newly diagnosed breast cancer undergoing chemotherapy: A qualitative study

1 Purpose

This study aimed to identify the supportive care needs and coping strategies of Chinese women with breast cancer undergoing chemotherapy and provide a reference for designing a supportive care program.

2 Theory

Lazarus and Folkman defined coping as constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person^[135]. In the revised stress and coping model, coping strategies were classified as problem-focused coping, emotion-focused coping, and meaning-based coping^[136]. Problem-focused coping is goal-directed, includes strategies like trying to come up with several solutions, gathering information, or make plans to solve or manage problems. Emotion-focused coping is to change the understanding of encounter when hard to change the external environment, include seeking emotional, social support, distancing, avoiding, emphasizing the positive aspects of the situation, and self-blame^[135]. Meaning-based coping is the one who draws on his or her beliefs, values, and existential goals to motivate and sustain coping and well-being during a challenging time^[136]. This theory has been widely used in many 'stress coping' studies. We applied it as theoretical frameworks to clarify the coping strategies that breast cancer patients used in the study.

3 Method

3.1 Study design

A qualitative design using a descriptive approach was adopted in this study to explore the supportive care needs and coping strategies of newly diagnosed breast cancer patients during the early stage of chemotherapy.

3.2 Participants

Participants were recruited from a large public teaching hospital in Dalian, northeast China. Purposive sampling was used to choose patients who (1) were newly diagnosed with stages I to III breast cancer and finished surgery, (2) were over 18 years old, (3) were going to receive chemotherapy for the first time, and (4) were aware of their cancer diagnosis. Patients were excluded if they (1) had a history of other malignancies, and (2) were diagnosed with a cognitive or psychological disorder that might prevent them from completing the interview.

3.3 Data collection

Eligible participants from the oncology ward were selected considering their age, cancer stage, marriage status, and education to obtain a wide range of information. After the researcher introduced the purpose and procedures of the study, patients who signed the written informed consent were enrolled. A semi-structured interview was conducted in Chinese.

Previous studies found that patients' needs is much higher after diagnosed less than six months^[115]. Moreover, their psychological needs and health information needs were highest at one month after diagnosis, whereas decreased at three months post-diagnosis^[37]. Therefore, we interviewed the same patients at two-time points when their needs were relatively high: one day before the initial chemotherapy cycle (about one month after diagnosis) and the 2nd chemotherapy cycle (about two months after diagnosis).

The interview guide was developed focused on the supportive care needs and coping strategies of women with breast cancer. The interview questions were as follows: 1) What are your current experiences and feelings? 2) What kind of problems do you need help now (to guide the participants to talk about physical, psychological, and sexual aspects)? 3) How do you cope with these needs by yourself? 4) What are your expectations for the chemotherapy? 5) What kind of information do you want to be provided to help you cope with chemotherapy? 6) What kind of information format do you prefer? Why is that? 7) What are your suggestions or comments on current nursing services? And 8) How do you think nurses can best assist you in coping with chemotherapy?

Interviews took place from October to December 2019 and were audio-recorded. Interviews stopped when new data repeats the data already collated, as data saturation was achieved^[137]. Interviews lasted for 35 min on average.

3.4 Data analysis

The qualitative content analysis method^[138] was used to analyze the interview data. A verbatim transcription of the recorded interviews was conducted by the first author within 48 hours after each interview. Participants' privacy and anonymity was assured. During the analysis process, these steps were followed^[138]: 1) Selecting the material: part of the material relevant to the research question was selected. 2) Building a coding frame: the strategy that made use of progressively more abstract paraphrases of the selected material was employed. 3) Dividing the material into units of coding: the relevant parts of the material were marked, and a thematic criterion (where topic changes signal the end of one unit and the beginning of another) was used in segmenting the material. Finally, the units of coding were marked. 4) Trying out the coding frame: two Chinese researchers (YJ C and XY M) performed trial coding of the same part of the material independently and made notes. 5) Evaluating and modifying the coding frame (in English): the material, codes, and categories of the trial coding

were translated into English by the first author (YJ C). The trial coding results in English were checked by the co-author (HM, fluent in English), and the differences were discussed; the first author further modified the coding frame. 6) Main analysis (in Chinese): the first author (YJ C) coded the entire data under the coding frame, and another Chinese researcher (XY M) blindly coded part of the materials, and they discussed and re-evaluated the whole coding process. Finally, the subcategories and categories were determined.

At this point, all the relevant Chinese text, codes, and categories were translated into English. Three researchers (the first author (YJ C), a co-author (HM), and another researcher (XY M)) rechecked the analysis results for consistency together. Another co-author (TY S) reviewed the translation from Chinese to English, and any inconsistencies were clarified after the discussion (among YJ C, TY S, and HM).

4 Trustworthiness

We employed many strategies to achieve the trustworthiness^[139] of the results. First, the first author is a doctoral student with over one year of experience in health education for Chinese breast cancer patients. Thus, a good understanding of the patients' concerns could be achieved. Second, we developed a coding frame to ensure reliability and validity. Third, the analysis process involved two Chinese researchers conducting the trial coding and main coding. A researcher (HM) with extensive experience in qualitative research checked the code frame and analysis process, and the consensus was achieved after the discussion among these researchers.

5 Ethical considerations

This study was approved by the Ethics Committee institutions of Chiba University (No.31-49) and the first affiliated hospital of Dalian Medical University (No. PJ-KS-KY-2019-106). The purpose, possible risks, anonymity, and confidentiality were explained to participants, who were also aware of their right to withdraw from the study at any time. All participants provided informed consent.

5.1 Guarantee the voluntary nature of the formalities for obtaining research approval and consent

5.1.1 Formalities for obtaining permission from research cooperation facilities

After this study was approved by the Ethics Committee in institutions of Chiba University, the researcher contacted the director of the nursing department of the potential hospital and submitted a Letter of invitation and Summary of the research proposal to them, explained the aim, significance, method of this study to access his/her oral permission. Furthermore, the researcher started this study after Research Ethics Committee approved it of the hospital. The responsible doctor or nurse who charges breast cancer patients was invited to conduct this study smoothly. The purpose and methods of the study and how to assist were explained to them to ask their help in introducing the participants

who meet the researcher's select criteria.

5.1.2 Formalities for obtaining consent from research participants

When the participants finished the chemotherapy consultation meeting with the doctor, the doctor or nurse introduced the participants who meet the criteria to the researcher, and the researcher introduced this study to the participants and their family (If their family accompany them) in both verbal and written form, including the study purpose, significance, methods, how to cooperate, privacy and confidentiality, and the situation of withdrawal of the study. Their participation was voluntary. They have 2-3 days to consider whether to take part if they need. Next step, every participant who agrees to participate signed the consent form. At the same time, they knew they have the right to withdraw from this study at any time. Moreover, even they withdraw from this study, it would not affect their treatment and care.

5.2 Guarantee of safety and reducing burdens when implementing the study

5.2.1 Countermeasures for disadvantages and risks associated with participation in the study

The foreseeable risks involved in the study were fatigue caused by 30-60 minutes of the interview, as well as sensitive issues that might arise during the interview process. Some participants may find it is hard to discuss all aspects of their disease. Interviewees would be informed that they had the choice to decline discussing issues that they found uncomfortable. They can refuse to be recorded, and stop the conversation at any time without affecting their treatment or care.

To ensure participant's safety, the researcher discussed with the responsible doctor or nurse whether the physical and psychological status of the participants could participate before the study. If the participant feels uncomfortable during the interview, the researcher immediately asks for help from the doctor or nurse. The researcher also explained that all the interview content collected would be anonymous, and this study would not harm their physical situation. Furthermore, before the study, the researcher asked participants if they could start. If they were uncomfortable because of the side effects, the study would be postponed. After the participant is stable, the willingness to participate was confirmed again. The researcher observed the participant's state during the interview. If they show fatigue, discomfort, or have large emotional fluctuations, the researcher slows down or stop the interview from reducing the participant's physical burden. The willingness of participants would be confirmed again.

To reduce the participants' mental burden, the researcher would conduct this interview in a relatively quiet, comfortable, and single room, giving the participants enough time and space to express their needs during interviewing.

The researcher explained to the participants that this interview would conduct within 30 to 60 minutes and completed on time to decrease the time burden.

5.2.2 Guarantee of the applicant's ability to execute research and of the status of the research preparations

I obtained the qualification certificate of a nurse in China. Furthermore, I had nearly two years of internship experience in a teaching hospital and two years of research data collection experience in the breast surgery department. This study would be conducted under the guidance of a doctoral supervisor. The purpose, method, data collection, and analysis of the interview would be discussed with the supervisor. Furthermore, before this study, the researcher interviewed 2 Chinese students according to the interview outline, to improve the interview skill when interview the participants.

5.3 Protection of privacy, anonymity, and personal information during data collection and publication

5.3.1 Consideration of introducing the research and ask consent of the participants

The researcher explained to the participants that all the data collected from them would only be used in this study and promised that the privacy, confidentiality, and security of the information collected would be protected during the study period. There is no impact on the participant's treatment or care, even if she does not participate in or withdraw in the middle of this study. The researcher would seek the participants' consent based on fully protecting their rights and interests.

5.3.2 Considerations for data collection and analysis

Before the study, the researcher explained that to have a comprehensive understanding of the participants' condition, the researcher would look up their medical records, and the interview content collected from them would only be used in this study. Also, the researcher would promise to keep the security of the interview content during the study period. Voice Recorder would be used under the participant's permission. If the participant withdraws from the study, the record would be deleted immediately. To protect the privacy of the participants, the researcher would use English letters to denote their names. Furthermore, in data analysis, if the participant hopes to withdraw from the research, their data would not be taken as the analysis object. All information collected from the interview would not be shared with others except the researcher's supervisor and the research team.

5.3.3 Considerations for data management

All electronic data (e.g., record) would be stored in a secure computer with passwords. All non-electronic data (e.g. consent forms, hand-written notes, and interview transcripts) would be stored in a locked room. Besides, data would not be brought to places other than the researcher's school and home or hospital where the data are collected. The data would be kept for a maximum of ten years following the first publication resulting from the study, and then all electronic data would be deleted, all non-electronic data would be shredded.

5.3.4 Publication of research results and methods to remove subjects and relevant considerations

The researcher explained to the nursing department director and participants that the study's analysis result might be published in conferences or academic journals. The researcher would use English letters to denote their names when the paper was published to protect the participants' privacy. If they want to know the study's analysis results, the researcher will share the analysis results.

6 Results

6.1 The characteristics of participants

Thirteen Chinese women with breast cancer were interviewed; mean age = 54 years old. Among them, ten were married, and six had a middle school education. The demographics, disease, and treatment data are summarized in Table 1.

Table 1 Participant Characteristics (n=13)

Variable	n (%)	Variable	n (%)
Age		Marital status	
<40	2 (15.38)	Married	10 (76.92)
40-60	5 (38.46)	Widowed	2 (15.38)
>60	6 (46.15)	Unmarried	1 (7.69)
Education level		TNM stages	
Bachelor's degree	2 (15.38)	I	4 (30.77)
Junior college	1 (7.69)	II	8 (61.54)
High school	2 (15.38)	III	1 (7.69)
Middle school	6 (46.15)	Surgical type	
Primary school	1 (7.69)	Modified radical mastectomy+SLNB	9 (69.23)
No education	1 (7.69)	Modified radical mastectomy+ALND	2 (15.38)
Occupation		Breast-conserving surgery+SLNB	1 (7.69)
Unemployed	8 (61.54)	Breast reconstruction+SLNB	1 (7.69)
Retired	3 (23.08)	Chemotherapy regimen	
Farmer	1 (7.69)	TC (Four cycles)	2 (15.38)
Nurse	1 (7.69)	EC (Four cycles)	1 (7.69)
		AC-T (Eight cycles)	9 (69.23)
		EC-D (Eight cycles)	1 (7.69)

Note: ALND: Axillary lymph node dissection; TNM: Tumor, node, metastasis; AC-T: Doxorubicin and Cyclophosphamide, four cycles, then Docetaxel, four cycles; EC: Epirubicin and cyclophosphamide, four cycles; TC: Docetaxel and cyclophosphamide, four cycles; EC-D: Epirubicin and cyclophosphamide, four cycles, then Docetaxel, four cycles; SLNB: Sentinel lymph node biopsy

6.2 The supportive care needs and coping strategies of patients before initial chemotherapy

6.2.1 Supportive care needs

The participants reported a variety of supportive care needs, the following five themes emerged: 1) needs regarding physical symptoms management; 2) needs regarding psychological adjustment; 3) needs regarding information to prepare for chemotherapy, 4) needs regarding communication, and 5) needs regarding social support. Although each topic was related to a specific area of supportive care,

there was some overlap between the topics. Table 2 lists the themes, sub-themes, and categories.

Table 2 Themes, sub-themes, and categories of supportive care needs before the 1st chemotherapy

Themes	Sub-themes	Categories
Needs regarding physical symptoms management	● Discomfort symptoms on the surgical side	- Numbness and pain on surgical side - Activity limitation of shoulder on surgical side
	● Sleep disorder	- Difficulty falling asleep - Poor quality of sleep
Needs regarding psychological adjustment	● Uncertainty of chemotherapy and prognosis	- Uncertainty about chemotherapy effect and side effects - Uncertainty about recurrence and metastasis of breast cancer
	● Concerns about the impact of cancer on family members	- Family members putting work aside to care for them made them stressed - Minimum additional distress and burden for family
	● Body image disorder	- Difficulties in facing the lack of breast
Needs regarding information to prepare for chemotherapy	● Daily life information on specific context	- Guidance for individual self-rehabilitation exercises for shoulder - Accurate information on Chinese medicine diet taboo (Fawu) and nutritional foods - Information on sex matters considering conservative background - Information on body cleanliness post-surgery
	● Early treatment-related information for full understanding and decision-making	- Inducing factors and reexamination of breast cancer - Choice of chemotherapy drug and reduction of side effects - Adjuvant endocrine, traditional Chinese medicine treatments - More and earlier information on infusion devices
Needs regarding communication	● Professional, timely, and positive communication	- Professional and timely communication with health staff - Positive communication with peer patients
Needs regarding social support	● Economic support	- Difficulties with finances
	● Friend's support	- Accompanied by best friends

Theme 1: Needs regarding physical symptoms management

Discomfort on the surgical side. Twelve participants (92%) reported discomfort on the surgical side before chemotherapy. The most common symptoms were numbness, pain, and swelling of the surgical incisions and shoulder. The patient wanted to know the reasons, duration, and how to relieve these symptoms.

P1: "I feel a little numb and painful on my arm, why does it happen?... Will the numbness last for a long time? Will it disappear later?... It was a little swollen from the forearm to the upper arm a few days ago. I used a hot water bag to compress it and massaged it... May I do that?"

The discomfort of the surgical side also limited patients' daily activities to a certain extent.

P10: "I am not feeling well when I turn over. Also, I cannot raise my arm, and I feel tight."

P9: "I used to be able to cook at home, but now I cannot do it. I do not dare to move my hand..."

Sleep disorders. A few participants indicated that they were troubled by difficulties falling asleep and poor sleep quality. Most of these sleep disorders were related to their mood swings, especially when they considered immediate hospitalization, cancer and chemotherapy, and family problems.

P2: "The main problem is that I cannot sleep well... I slept for 1 or 2 hours in the afternoon sometimes. When I lie at night, the more scared I am, the more difficult to fall asleep... especially when I am thinking about coming to the hospital soon. Argh!... Is there any way to make me sleep well?"

P6: "I have no physical problems, but it is hard to fall asleep anyway. I just make blind and disorderly conjectures!... I think much about how I can address these (cancer; chemotherapy) bad things... How can I not be worrying?!"

P1: "I just cannot sleep at night currently. (Silence for 6 seconds). About my disease, my child just started university and settled down. I hid my disease from her. I don't know how to face her (in tears)."

Theme 2: Needs regarding psychological adjustment

Uncertainty of chemotherapy and prognosis. Most patients expressed uncertainty and concern about the chemotherapy and their prognosis, especially about the effects and side effects of chemotherapy, and the recurrence and metastasis of breast cancer. They were not sure whether chemotherapy is useful and what kind of side effects they may experience.

P2: "I don't want to treat it anymore. I think chemotherapy is useless. Is chemotherapy equivalent to killing cancer cells? They (peer patients) said chemo would damage the body... I am not afraid of death; I just don't want to suffer."

The biggest concern of patients was chemotherapy's side effects, such as nausea, vomiting, and hair loss, and some of them were even afraid of being laughed at by others because of hair loss.

P3: "Oh, my God! I saw that they (peer patients) experienced heavy nausea and vomiting. If I start vomiting heavily, I couldn't stand it."

P6: "I am afraid of losing my hair. And it will be horrible if others know about it. I fear being laughed at, really. Other people who visit my house may see me in a sick condition (hair loss), I will not contact them... I think I can bear to lose much hair, but I can't accept shaving it."

Compared with the worry about side effects, few patients mentioned their uncertainty about future recurrence or metastasis of breast cancer.

P6: "I have invasive breast cancer. Argh!! I'm afraid of recurrence and metastasis."

P9: "Five or ten years later, is breast cancer over the risk period?... Is it possible that there are no more relapses?"

Concerns about the impact of cancer on family members. Patients of different ages expressed

their concerns about the impact of cancer on their families. For older adult patients, when they were administrated for treatment, their families put work aside to care for them, which made them feel stressed.

P2: "My daughter accompanied me to visit (the hospital) many times... she still had a job, this messed her up, she also felt anxiety... I increased her burden, I think."

For middle-aged patients, they not only suffered cancer themselves, but also tried to minimize the additional distress and burden for all family members and had a heavy psychological burden.

P13: "I am mainly considering my child... I am afraid that cancer may affect her study, so I did not tell her (the cancer diagnosis) ... also, I didn't let my parents know that I was sick, they are getting old, they cannot help me even if they know it, I am more afraid they'll worry about me... I comfort him (husband) in turn, because he is very introverted, and I worry he won't get over it."

Body image disorder. Some patients who underwent a mastectomy felt scared and found it difficult to face the lack of breast.

P6: "I still do not dare to look at the incision... The whole breast is gone. How scary it is to have such a long surgical incision."

P9: "I feel terrible... it is hard for me... to see it... I don't even like watching it myself. Actually, I cannot accept it at first, but I must accept it even if I cannot. The key point is that it is not comfortable, and it looks even worse than man's breast."

Theme 3: Needs regarding information to prepare for chemotherapy

Daily life information needs. Patients considered the impact of cancer in all aspects of their daily life, and had high information needs regarding this specific context. Due to differences in individual education level, surgical methods, and understanding ability, some patients had an inaccurate understanding of self-rehabilitation exercise and equated it with housework activities.

P2: "Self-rehabilitation exercise is to do housework, huh?"

Other patients chose not to exercise because they were worried about exercise tearing the wound.

P11: "The nurse told me how to exercise, but I was worried that the exercise would tear the incision, I didn't dare to move much."

Patients with a low level of education could not fully understand the textual instructions.

P8: "My education level is not high, and I cannot understand the instruction sheet given to me by the nurse. I always listen to others (patients) say how they exercise."

Patients also hoped to obtain individualized guidance from health professionals.

P10: "For people like me, who had breast reconstruction or have not recovered, I hope health professionals can give individualized guidance, such as in which situation I shouldn't do exercise and when to start it."

Besides, because the participants were in coastal areas, most of them mentioned their need for accurate information about "Fawu" (such as seafood), and nutrition. In their view, diet was the only way they could control and regulate their bodies. And "Fawu" is closely related to a dietary taboo in Chinese medicine^[140] and greatly influences Chinese patients' diet. They collected information through the Internet and conversations with peer patients, but still felt confused.

P7: "What should I pay attention to when eating? E.g., what can be eaten, and what cannot be eaten? Can I eat seafood? Some patients say that "Fawu" such as mutton cannot be eaten. Is that correct?... There is nothing we can do about the treatment, the only thing we can regulate by ourselves is diet. I also hope to aid nutrition through diet. Diet cures more than doctors!"

P13: "I keep searching on Baidu (Chinese website) when I am free... Try to find out how to improve nutrition... But I am still confused about what can be eaten, such as shrimp, sea cucumbers, fish, these belong to "Fawu," I do not dare to eat them."

Due to conservative thinking, patients were embarrassed to ask doctors about sexual matters, and a small number of patients talked about their need for this kind of information.

P10: "This question is private and embarrassing, but I also want to know whether it is possible to have sex during chemotherapy and whether it will affect my recovery. I think we Chinese may be relatively traditional, so I won't ask."

It is worth noting that there were also patients who worried that less sex was the factor inducing breast cancer.

P13: "(My sex life) was less before diagnosis, I think no sexual life caused breast nodules, I am more concerned about this... We are also quite reserved in this respect, and we usually don't ask the doctor, so we don't know."

Considering the incomplete healing of the wound and the retention of infusion devices, a few patients mentioned their confusion about bathing.

P8: "Can I take a bath during this (chemotherapy)? How can I deal with this (infusion port) when taking a bath? After surgery until now, the wound has not healed well, and I have not dared to take a bath. I just wipe it with a towel."

Early treatment information for full understanding and decision-making. A total of 12 participants (92%) had information needs related to the treatment. They hoped to receive early specific information to help them fully understand the treatment and make choices regarding topics such as inducing factors and reexamination of breast cancer, choice of chemotherapy drugs and reduction of side effects, infusion devices, adjuvant endocrine therapy, and traditional Chinese medicine treatment.

P6: "Is the imported one better than the domestic (chemotherapy drugs)? Will the side effects and hair loss will be less?... Which drugs have fewer side effects in your (nurses') practice experience? I

don't know which one to choose."

P5: "I am still hesitant (whether to use infusion port or not), I hope I can get more information early, so I will have enough time to decide... And how to minimize side effects during chemotherapy, or how to deal with side effects? If vomiting occurs, how to reduce it?"

In addition to chemotherapy, some patients wanted information on the use of traditional Chinese medicine treatments.

P13: "Can I use some traditional Chinese medicine during chemotherapy? Combined with this Western medicine, use some Chinese medicine to have the effect of FuzhengJieDu (which means strengthening body resistance and detoxification) ... I am confused as to whether I can use it or not..."

In the interviews, patients with low educational level reported obstacles in asking for information.

P4: "I do not understand (chemotherapy), I can't ask (ha-ha) either. I don't know how to ask."

Theme 4: Needs regarding communication

When patients waited to receive chemotherapy, they hoped to have more professional and timely communication with doctors and nurses to reassure them. Some patients tried to obtain information about the disease and treatment through the Internet at home, but difficulties in understanding medical terms and judging the accuracy of information confused them and made them feel scared. More than half of participants reported their expectation of timely verbal communication with "professional" healthcare workers.

P11: "I hope the doctor or nurse will have time to talk to me face-to-face to solve my doubts... It will make me feel at ease... I've never experienced this before, it is the first time in my life, I knew they were busy, but I really need them... It would be better if I could communicate with them at any time."

In addition to "professional" and timely communication, some patients also expressed that positive communication with peer patients around them decreased their anxiety.

P12: "There are a lot of people around me who have this disease... They are all recovering well, they say they are all right, so I have nothing to worry about."

Theme 5: Needs regarding social support

Economic support. A few participants stated financial difficulties.

P13: "I have financial pressure because only my husband works. I didn't use PICC (Peripherally inserted central catheter) ... For me, chemotherapy, targeted therapy, and radiotherapy are all costly. The economic pressure is huge after all... so I think a lot about costs. "

Friend's support. For a few patients who could not receive enough support from their family, they eager to have the best friends accompany.

P13: "I don't want anyone to know about my cancer and trouble them. But in fact, I particularly hope that someone can accompany me, help me to share my feelings, release my pressure,

companionship is crucial. Sometimes I think about it at home, if there were a best friend, I don't need her to spend a penny, just having her there with me is enough."

6.2.2 Coping strategies

The women with breast cancer applied many strategies to cope with chemotherapy, mainly in four themes: 1) Seeking information from multiple sources, 2) Minimizing adverse effects, 3) Cognitive defense, and 4) Seeking support. The themes, sub-themes, and related coping theory concepts were listed in table 3.

Table 3 Themes, sub-themes, and related coping theory concept before chemotherapy

Theory concept	Themes	Sub-themes
Problem-focused coping	● Seeking information from multiple sources	- Collecting information on treatment and rehabilitation from the Internet, medical staffs and other patients
	● Minimizing adverse effects	- Self-care of physical discomfort symptoms - Changing lifestyle - Anticipate preparation to maintain body image
Emotion-focused coping	● Cognitive defense	- Concealment - Resistance - Accepting the reality of cancer and chemotherapy - Distraction
	● Seeking support	- Successful experience of other patients - Company of friends - Relying on families

Theme 1 Seeking information from multiple sources

The most common strategy used by breast cancer patients was seeking information. Most of them tried to gathering information from the Internet, other peer patients, and medical staff. Moreover, the information's content was extensive, it involved treatment effects and side effects, rehabilitation exercise, examination results, and dietary taboos. Although most patients actively seek information about treatment and rehabilitation to relieve their anxiety, unease, and uncertainty, some patients still encountered obstacles like the information provided by health care professionals was not explicit, and patients lacked the ability to judge the credibility of information from the Internet and other peer patients, these problems made patients feel confused. They were even afraid of knowing more about cancer.

P10: "I mainly learned the disease from my attending doctor, because our situation is different, and the treatment may be different. The attending doctor knows my condition best, so I believe in him."

P5: "I search the drugs and matters needing attention on the Internet because I know nothing about chemotherapy. I need more to prepare myself psychologically. But I don't know whether the information is right or wrong, it still confused me."

P11: "I usually ask other patients about diet. The doctor told me to eat as usual, but he didn't say

what can be eaten, and what cannot be eaten. He also told me not to overeat nutritious food, but what is nutritious?.....My daughter searched online about the treatment, but those words like "Invasive cancer", "intraductal carcinoma " scared me, I won't search it anymore."

Theme 2 Minimizing adverse effects

Self-care of physical discomfort symptoms. Most patients felt numbness, pain, and even swelling on the surgical arm. They tried to use hot compresses and massage to relieve the discomfort by themselves. However, due to the lack of rehabilitation-related knowledge, they were still doubting about what they are doing is correct.

P1: "My arm was swollen a few days ago. I used a hot water bag and massaged it. Can I do like this?..... I did it for more than a week! Will there be any consequences?"

Also, sleep disorder is another prominent symptom, the patients took sleeping pills and self-suggestion to regulate, but it was invalid.

P2: "I can't sleep well again when I am considering I will go to the hospital these two days. I took sleeping pills twice a day, but it doesn't work.....Some messy things in my thought, I hinted to myself, "Don't think about it, go to sleep!" and these disturbing thoughts returned."

Changing lifestyle. Some patients thought that bad eating habits, excessive activity, and bathing might affect wound healing, although they do not know whether these ideas are correct or not, they still changed their eating habits, activities, and other lifestyles to keep safe and minimize the adverse impact on rehabilitation.

P3: "I heard from other patients that seafood and chicken are "Fawu", and the wound is not easy to heal if I eat them. I used to love this food, but now I dare not eat it. Although I don't know if what they said is right, it is definitely safe if I don't eat."

P11: "I followed the instructions by the nurse in the first week post-operation, but the doctor said my wound didn't grow well, so I stopped exercising my arm until now because I think I am overdoing."

Anticipate preparation to maintain body image. Some patients think these damages of body image like the loss of breast or hair led to certain stress. They prepared in advance to maintain the image as much as possible to reduce these injuries' impact.

P10: "Every woman loves beauty, losing hair will make me feel not confident. I've cut my hair shorter, if I lose too much, I'm going to shave it, and then I'll wear a wig. I prepared one, also. Getting ready for hair loss in advance will make me feel more at ease. "

P9: "It is terrible to lose my breast ... I prepared an artificial breast. I heard from the Internet that my spine would be bend if I don't wear it, and it may cause other diseases..... An artificial breast makes me look better and prevents the occurrence of other diseases."

Theme 3 Cognitive defense

Concealment. Some patients reported that they hide their illness to prevent themselves from being laughed at and discussed by friends, or to protect close persons from being affected by cancer.

P9: "My friends asked me, 'how's your cancer going?' recently. I didn't tell them the truth because I don't want them to know it.They could not share my pain and may laugh at me and gossip. It is meaningless to tell them.

P13: "I am afraid cancer may affect my kid's study, so I didn't tell her..... My parents didn't know either. I'm afraid they'll worry me much."

However, some patients also said that concealment did not address her concerns.

P1: "I lied to my daughter. I don't know how to face her (crying)..... She will go back tomorrow. I couldn't hide my disease because of hospitalization. I don't know how I can explain it to her. "

Resistance. Due to the worry of potential side effects, a few patients were frustrated and resistant to chemotherapy.

P2: "Ah. I am bored (in a low tone and sound frustrated). I don't want to treat it anymore. They say chemo will hurt my body.....I am not afraid of death, and I just do not want to suffer this. "

P11: "My husband passed away in this hospital. After seeing his condition after chemotherapy, I thought it would not be a human if I lost my hair. His hospitalization experience also impacted me. I was repulsive of chemotherapy."

Accepting the reality of cancer and chemotherapy. Some patients showed that they accepted the reality of cancer and chemotherapy, and they were actively cooperating with treatment and complying with their nature is the best way to deal with stress.

P7: "I have accepted the disease now. Recovery is a gradual process, and it is impossible to get better at once. I just want to follow nature! Now I am sick, and I will be fine after actively treated. "

P5: "About now (sounds hesitant) I accept the chemotherapy, and don't think much about it. It's not good to overthink. The more nervous you are, the worse it may be. Let nature take its course."

Distraction. Patients believed that distraction is a way to divert their excessive attention to treatment, including watching TV, playing the piano, practicing calligraphy.

P1: "I used to play the piano and write calligraphy. I just want to do something else so that I won't think about what it will be like after chemotherapy."

P7: "When I have nothing to do at home, I just watch some funny entertainment programs on TV. If I don't think about it (chemotherapy), I don't care so much about it."

Theme 4 Seeking support

Successful experience of other patients. Most patients worried and feared about cancer and chemotherapy, and they learned some successful experiences from peer patients around them. The

information of good prognosis and prolonged survival time significantly alleviated the patients' fear.

P3: "Before I had cancer, no matter who had cancer, I was afraid. Oh, my God! Isn't this guy coming to an end? When it's my turn, I'm not afraid at all. Because I asked a relative who had breast cancer, she survived for 30 years after she did surgery three times, so it's all right. "

P1: "I was scared at first, but then I heard other patients who lived for many years after cooperating with the treatment. I accepted this fact and not feared it like before. "

Company of friends. A few patients were under high pressure because they could not share thoughts with their family, and their friends' companionship gave them much support.

P13: "I am afraid that my families will worry a lot, so I can't say much to them. It's stressful..... I have a good friend who often comes to chat with me and support me. I'm grateful to have her around me.

Relying on families. Older patients said that because of the limited movement of the surgical arm, they had to rely on their families' care in daily life.

P8: "I dare not do any work after the operation. I usually rely on two daughters to take care of me for cooking and bathing. Thanks to them, I can rest at ease. "

6.3 The supportive care needs and coping strategies of patients before the 2nd cycle of chemotherapy

6.3.1 Supportive care needs

Five themes emerged from the interview: 1) Needs regarding physical symptoms management; 2) Needs regarding information to cope with chemotherapy; 3) Needs regarding psychological adjustment; 4) Needs regarding emotional support; and 5) Needs regarding social support. The themes, sub-themes, and categories were list in table 4.

Table 4 Themes, sub-themes, and categories of supportive care needs before the 2nd chemotherapy

Themes	Sub-themes	Categories
Needs regarding physical symptoms management	● Relief of discomfort symptoms and functional recovery of surgical side	- Numbness and pain on the surgical side - Recovery of daily function on the surgical side
	● Relief of side effects	- Weight management - Varying degrees of hair loss - Gastrointestinal reaction - Fatigue
	● Rest and exercise	- Coping with sleep disorders - The management of exercise at home
Needs regarding information to cope with chemotherapy	● Daily life information	- Diet taboos and nutritional information on the promotion of leukocytes - Coping information of limited physical cleanliness
	● Other treatments and reexamination information	- Repeated examination Information by medical staff - Benefits and side effects of radiotherapy
Needs regarding psychological adjustment	● Concerns about treatment effect and prognosis	- Worry about the weak effect of the treatment - Worry about recurrence and metastasis of breast cancer - Worry about worsening side effects and interrupting treatment
	● Concerns about the impact of chemotherapy on family members	- Worry that chemotherapy increased the burden of family care - Concerns about the worries of the family to you
Needs regarding emotional support	● Getting a sense of security and comfort	- The support and companionship of the families - Nurses' concern and encouragement
	● Pouring out	- Pouring out psychological pressure to people other than family members
Needs regarding social support	● Information support by medical staffs	- Hoping to get different forms of information support
	● Peer support by those who had the same experiences	- Sharing of patients' treatment experience
	● Be treated like a normal person	- Uncomfortable of others' comfort and sympathy
	● Economic support needs	- Financial difficulties

Theme 1 Needs regarding physical symptoms management

Relief of side effects. All patients reported varying degrees of chemotherapy's side effects, including gastrointestinal reactions, hair loss, fatigue, and weight changes. Nausea, gastric distension, and appetite loss were the most common symptoms among them. Furthermore, it was more obvious 1-10 days after chemotherapy. Most patients chose to endure these symptoms due to lacking the knowledge of how to alleviate side effects.

P5: "Three days after chemotherapy, I didn't dare to eat and vomit often..... I am afraid that vomiting may damage my stomach, so I try to put up with it. Is there any way to make me feel better?"

P11: "I lost a lot of hair when I am bathing. Other patients said that they lost all the hair after the second chemotherapy..... If I lost all, should my grandson call me Grandma or Grandpa? It's terrible!"

P3: "I feel fatigued, so I lay down every day. I feel sick everywhere in the body."

P10: "The doctor said that I would definitely gain weight by taking hormones. I tried to control it, but I failed. Is there anything I can do on exercise or diet to control my weight? "

Relief of discomfort symptoms and functional recovery of surgical side. Some patients still had numbness, pain, movement limitation on the surgical arm, and movement limitation. They did exercise less because they lacked awareness of the importance of rehabilitation exercise or were worried about edema caused by excessive activity. It affected their daily life.

P11: "I'm afraid of arm edema. How and what extent should I exercise? The doctor said I couldn't raise it. Then I didn't move for a week. I used to be able to do some housework, but now I can't do anything. "

P7: "I can't lift my hand yet..... I think it doesn't matter whether I practice or not. Anyway, I can lift it in the future, so I don't treat it seriously!"

Rest and exercise. To better promote recovery, patients want to stay in good condition in terms of rest and exercise. However, they still suffered insomnia because of the anxiety before admission or the pressure of increasing the family's care burden. They needed more advice on how to relieve insomnia and how to exercise safely.

P2: "It's so hard when I can't sleep well because of anxiety and depression..... How can I sleep well? "

P13: "I know the stomach won't move if I just lie from the Internet. But as a cancer patient, what kinds of exercise are safe for us?"

Theme 2 Needs regarding information to cope with chemotherapy

Daily life information. All patients expressed their need to obtain more accurate lifestyle information to promote rehabilitation, and they were concerned with dietary taboo most. At the same time, they wanted to know more nutritional information to increase white blood cells and coping with chemotherapy.

P8: "The doctor said there were no diet taboos. Nevertheless, other patients said that onions, ginger, and irritating food could not be eaten. I am so dizzy and don't know if I can eat them.....My daughter asks me to eat fried pupa to supplement protein every day. How much is appropriate for me every day? "

However, due to the fear of wound infection or damage of the infusion device caused by taking shower, and lack of accurate information, patients' basic need of body cleaning can not be met well.

P6: "I don't know if the wound has healed, and I don't dare to wash my breast when I take a bath. I couldn't clean my body thoroughly. Will water damage the infusion port? It's so inconvenient to take a bath. "

Other treatment and reexamination information. With chemotherapy's progress, some patients began to care about the reexamination and radiotherapy, and they hoped to get some information in advance to prepare. Although the health care staff educated patients about reexamination when they were discharged after the operation, they could not remember the details and hoped to be educated again.

P7: "I am concerned about the reexamination now. I don't know which items I should check. Although the doctor told me when to check post-operation, I can't remember it clearly. Furthermore, I found my memory getting worse than before now. Can you tell me more about the reexamination?"

A few patients hoped to know more about the pros and cons of radiotherapy.

P13: "I checked online that radiation therapy might damage other organs. I don't know if this information is correct. Is radiotherapy good or bad?"

Theme 3 Needs regarding psychological adjustment

Concerns about treatment effect and prognosis. Although the patients experienced chemotherapy once, most of them still concerned about the effect of treatment and prognosis. They worried that chemotherapy's effect was weak, the recurrence and metastasis of breast cancer, and the aggravation of side effects, especially in the chemotherapy suspended.

P13: "I checked on the Internet that radiation also caused cancer. Will the cancer relapse or metastasize after receiving all treatment? I worried about that. "

P8: "I am not sure will the side effect will be more oppressive this time. If it is, my immunity will definitely go down because of nausea and insufficient food intake. Then the white blood cells will decrease, and I must suspend the chemotherapy finally. "

Concerns about the impact of chemotherapy on the family members. Some patients were concerned a lot about their families. Elderly patients needed to be accompanied by their children when they were admitted. It increased their children's burden in their opinion.

P4: "Every time I come to the hospital, my daughter is with me. I influenced her work..... which brings trouble to her, and I feel sorry about it."

On the other hand, middle-aged women were concerned that cancer makes their parents worried or blame themselves for not being able to accompany their children.

P7: "In fact, my son also under much pressure. For example, I can't pick him up from school like other moms. I feel sorry for him sometimes."

Theme 4 Needs regarding emotional support

Getting a sense of security and comfort. Some patients reported that additional emotional attention from families and nurses makes them feel safe and comforting. These supports affected their emotional state a lot.

P1: "I couldn't sleep well when I was alone, but now I can sleep at my sister's house, and I don't take sleeping pills anymore. I feel like I have something to rely on I think her company is essential (said with a happy smile). I feel safe with her. "

P1: "patients like us need much emotional support, I hope the nurses pay more attention to us and give us psychological support. "

P8: "The nurses visit me often and encourage me. I think it is the greatest comfort to me."

Pouring out. A few patients hoped to talk their thoughts and pressures to others except their families, because they wanted to protect their families, or their families couldn't understand them well.

P2: "My husband is sick. I don't share much about my feelings to put him in a bad mood..... Also, I don't want to burden my children because they are all busy. Nevertheless, I don't know who can share my stress. I feel miserable. "

P11: "When I complain that I lost much hair, my daughter stopped me from expressing it. She said I was overreacted and show it. I don't think she can understand how I feel. I just want to talk to someone."

Theme 5 Needs regarding social support

Information support by medical staff. Some patients thought the medical staffs were too busy to answer their puzzles in detail. They hoped to have telephone follow-up or online groups to answer their questions. Other patients suggested that the verbal information was easy to forget. Paper materials about diet, chemotherapy notes, reexamination will be helpful.

P9: "Doctors are very busy in doing many surgeries every day. I hope there is an online WeChat group, it will be convenient for the doctor to answer my question when he is available."

P1: "I think the information about reexamination should be provided face-to-face, and the paper material will help a lot. Otherwise, I can't remember it."

Peer support by those who had the same experiences. During the treatment period, patients emphasize the importance of peer patient support, and they hope to communicate more with other patients to obtain information or increase confidence in treatment.

P3: "I used to ask other patients because they have been through it, and they know what is good or not. I trust them more..... Whenever I thought that someone survived for more than 10 years after surgery, I feel confident in the treatment. "

P13: "I have no experience in chemotherapy, and the doctor is too busy to answer me in detail. I usually asked other patients' experiences with side effects. "

Be treated like a normal person. Although most patients wanted much emotional attention, a few patients hoped to be treated like a normal person.

P7: "Many relatives and friends called to comfort me, I said I am fine, you do not have to comfort

me (haha). I think it's normal to be sick, and there is no difference between me and others. They make me feel uncomfortable and stressed as they comfort me and sympathize with me. "

Economic support needs. Because some treatments were not covered by medical insurance, some patients still had enormous financial pressure.

P11: "I'm old, and I don't have much income. It will reduce my financial burden if PICC can be reimbursed by health insurance. That is what I want."

P13: "I cannot work now. Some medicines also cannot be reimbursed by medical insurance, and my financial pressure is quite heavy."

6.3.1 Coping strategies

During the second cycle of chemotherapy, patients' coping style with chemotherapy mainly focuses on the following six aspects: 1) Minimizing adverse effects; 2) Seeking information from multiple sources; 3) Cognitive defense; 4) Cognitive reconstruction; 5) Seeking support; 6) Finding positive meanings. The theory of concepts and themes, sub-themes were in table 5.

Table 5 Themes, sub-themes and related coping theory concept for the second time of chemotherapy

Theory	Themes	Sub-themes
Problem-focused coping	● Minimizing adverse effects	- Changing lifestyle - Maintaining body image
	● Seeking information from multiple sources	- Collecting information about treatment and rehabilitation from the Internet, medical staffs and other patients
Emotion-focused coping	● Cognitive defense	- Passive acceptance - Distraction - Selective attention - Expressing emotion
	● Cognitive reconstruction	- Comparing with other BC patients to comfort self - Weakening the "patient" role - Establishing a belief in survival
	● Seeking support	- Relying on families - Sharing with other patients
Meaning-based coping	● Finding positive meanings	- The importance of health - Positive self-transformation

Theme 1 Minimizing adverse effects

Changing lifestyle. More than half of patients (mainly the elderly) changed their lifestyles to minimize the adverse impact on recovery. These behaviors included reducing activities to prevent edema in the surgical arms, changing the way of bathing to ensure wound healing and maintaining the function of infusion tools, changing eating habits, reducing smoking and increasing exercise to promote rehabilitation. Especially in terms of diet, most patients avoid dietary taboos to ensure safety, even if they were not sure whether the information is accurate. On the contrary, they forced themselves to eat more to strengthen their immunity to fight chemotherapy.

P5: *"I haven't imaged the operation impacted on the movement of my arm like now. I heard that if the arm is swollen, there will be no way to recover, I still dare not move my arm. "*

P8: *"I didn't remember what the nurse told me about the food. I checked it on the mobile phone when I am confused. I got the information that irritant food and "Fawu" shouldn't be eaten. I don't know whether it's right or not. The safest way is not to eat all. "*

P13: *"I didn't like meat before, but now I force myself to eat it! Eat more nutritious food so that I can have the power to undergo chemotherapy."*

Maintaining body image. Some patients experienced severe hair loss, and they maintain body image by cutting hair shorter, shaving, preparing wigs, or headscarves to reduce the visual impact of massive hair loss. However, a few patients cannot accept shaving their hair and ultimately losing their female image and letting it fall off.

P4: *"I lose my hair much, and it's too hard to look at myself. I felt better when my daughter buys me a flowered headscarf. At least I looked like a woman when I wear it. "*

P6: *"I'm afraid of losing it all, and I don't even dare to comb my hair. I can't accept shaving. It will not look like a woman! Argh!..... what else can I do?"*

Theme 2 Seeking information from multiple sources

Most patients gathered information actively by asking doctors, nurses, peer patients or searching online. They mainly focused on dietary taboos, reexamination methods, rehabilitation exercise, and side effects of radiotherapy. Although they already knew something at the first round of chemotherapy, collecting much information made them feel at ease.

P9: *"The online doctor said that PET-CT might check the whole body, and I want to do it. I didn't understand all these tests before, but now I feel more secure about knowing more. "*

P13: *"I worried whether I should delay radiotherapy or give it up because I have allergic history. I also want to ask the doctor in the radiotherapy department in advance."*

Theme 3 Cognitive defense

Passive acceptance. A few patients mentioned that they had no choice but to suffer chemotherapy because they care about their families or survival.

P5: *"If I want to live, I have to stand it (the tone is weak, with tears). I feel bad, and there are still six rounds of chemotherapy left. It is too long, but there is nothing I can do about it."*

P2: *"There's no way. My daughter said I must do the chemotherapy. I do this for her..... I don't want to suffer the pain at my old age. It's excruciating! "*

Distraction. Some patients reported that doing as much housework as they can or chatting with their families can divert their cancer attention and make them feel better.

P8: *"I think I can't stand being idle all the time..... If I do some housework or something..... I*

may not pay much attention to cancer. "

Selective attention. Some patients tried not to overthink how cancer and chemotherapy progress. Just pay attention to the present in how to solve difficulties and keep hope.

P11: "I had experience with chemotherapy, the hard feeling only continued for a few days, and it is not scared as others said..... I don't think about what will happen in the future when I feel bad. I just said to myself to get through today. "Get through today" can solve all the difficulties....."

P8: "I don't think much now..... Living well at present, and try to keep a good mood every day, maybe cancer can be cured! I must be in hope! Persistence is victory!"

Expressing emotion. Speaking out the worries relieved the pressure of some patients.

P3: "I'm afraid no one will pay any attention and listen to me. Speak out the worries and fears in my mind make me feel much more comfortable."

Theme 4 Cognitive reconstruction

Comparing with other BC patients to comfort self. Some patients comforted and encouraged themselves by comparing with other patients who were unfortunate or had a better prognosis, which made them more relaxed in dealing with stress.

P3: "Why my psychological state is good now? Because whenever I thought that someone survived for more than 10 years after surgery, I became confident in the treatment.....My cancer was not spread, I'll be fine!"

P9: "One patient divorced after diagnosed with breast cancer, and she is poor.....she also experienced severe nausea and vomiting..... Compared with her, my side effect is not severe, and I have a happy family. I'm luckier than her!"

Weakening the "patient" role. Some patients helped themselves to return to life and face treatment positively by weakening their patient role.

P1: "I went to the supermarket with my sister and tried to treat myself not as a patient gradually. Just do what I should do if I have a better physical condition. I think this gives me more power to face cancer. "

P7: "I am not treating myself as a patient..... Every time I come to the hospital, I think I get closer to health. Thus, I can be actively in treatment. "

Establish a belief in survival. Two patients mentioned that the one they loved and those who loved them gave them the motivation to strive after diagnosed with cancer.

P7: "I feel sorry sometimes for that I can't attend many activities of my son's school life I must actively cooperate with the treatment because I want to survive and stay with him longer. I will fight for the people I loved and those who loved me."

Theme 5 Seeking support

Relying on families. Patients with cancer were more dependent on their families physically and psychologically.

P11: "It's not convenient for me to move my hand. My daughter takes care of me in doing housework, cooking, and bathing. I feel relied on and at ease with her around me."

P1: "My sister and her husband are very kind to me. I stopped to think anything annoyed me when I stay with them. Now I am not anxious, and I can sleep well. "

Sharing with other patients. A few patients talked about the benefits of sharing with online peer patients.

P9: "When I am depressed, I watch other patients' videos or jokes that make me happy. I can share everything which I can't say to my husband or family in peer patient group.....they understand me much more than my family..... After listened to their stories, I felt much peace. I realized that regardless of the survival time or rate, I have to move on."

Theme 6 Finding positive meanings

The importance of health. Although most patients suffered a lot in chemotherapy, a few patients mentioned that they were deeply aware of the importance of health.

P7: "In fact, sometimes I think that being ill is not always bad, that is God warned me to take care of myself, so I pay more attention to health."

P13: "Nothing is as vital as health until I had cancer. Job position, money.... Without a good body, everything is useless."

Positive self-transformation. Some patients changed their attitude and mentality in dealing with things because of cancer.

P9: "I was easy to be angry before. After I was diagnosed with cancer, I heard that anger is a cause of breast cancer.... It's not good to be angry..... I realize that I can't change others, I will change myself (haha)."

P8: "In the past, I was anxious about little things, the cancer is a big shock for me, it made me let go of a lot of things and became less anxious."

7 Discussion

7.1 Assess the supportive care needs of patients with different contexts in different periods of Chemotherapy

Our results showed that individuals with different ages, education levels, surgical methods, and family support had different supportive care needs. For example, the elderly had low sexual needs, but they showed intense information needs; Patients with a low level of education wanted to be educated face-to-face by medical staff rather than printed material. Compared with patients who had conserving surgery, patients with mastectomy needed more information in functional exercise of the affected

limbs; the psychological burden of patients lacking family support was high.

Moreover, our study found that most of the patients coped "conservatively" when lacking knowledge under the influence of Chinese traditional culture. For instance, they did not perform self-rehabilitation exercises, consume "Fawu," or seek information about sex independently, which was disadvantageous to their life and physical and mental recovery. Regarding their diet, "Fawu" is a dietary term derived from traditional Chinese medicine widely spread among the population that may exacerbate surgical problems such as sores and tumors and causes allergic diseases or relapses. Most of the patients treated "Fawu" as taboos. Such as onions and leeks among vegetables, chicken, and mutton among meats, as well as fish and shrimp^[140]. The influence of different social, disease characteristics, and cultural backgrounds on patients' supportive care needs have been confirmed in many studies ^[46,49,117]. Also, we found that the focus of patients' needs also changed in different periods. For example, patients pay more attention to the information such as chemotherapeutic drugs and infusion tools before Chemotherapy, but they care more about alleviating the side effects and needing more emotional support after Chemotherapy began. In terms of coping strategies, some patients prepared wigs and artificial breasts before Chemotherapy, which help them maintain body image. Andrea et al. showed that patients who used anticipatory coping could regain a sense of control ^[141].

Therefore, before the supportive care intervention implements to meet such complex needs, it is crucial to assess patients' personal needs from different backgrounds over different periods of treatment and what they can do to anticipate the threat. Otherwise, the care provided may not be appropriate^[48,135,142]. We suggested that nurses should first comprehensively evaluate the patients' supportive care needs, understand the causes of their needs and what kinds of help they need, as well as their coping ability and resources. Then provide them with self-rehabilitation exercise, diet, sexual life, and other information education, as well as appropriate coping strategies.

7.2 Provide accurate and diverse information resources before the chemotherapy commenced

We found that patients reported strong needs for much information to be provided earlier to help them prepare for chemotherapy and make decisions even before the chemotherapy. Because of the initial diagnosis of breast cancer and the lack of coping experience, patients are worried about treatment^[46]. Thus, they need more information about the effects of chemotherapy, symptom control, and nutrition to understand the disease and reduce anxiety^[53,66], and make decisions^[143]. Although they searched on the Internet and talked to peer patients about treatment and rehabilitation, due to the inability to judge the accuracy of the information they found, they have cognitive misunderstandings in seeking and using information. The medical staff was the most reliable source, but many patients emphasize that the medical staff was too busy to answer their questions about daily life and treatment in detail, the information they obtained was not clear enough. Similar findings have been reported

before^[52]. Because of the late development of community nursing in China, high-quality medical resources are mostly concentrated in large hospitals, and local primary healthcare clinics are not the first choice for patients^[144]. The previous study found that oncology nurses were ideally placed to provide pre-chemotherapy nursing programs. Nevertheless, oncology nurses' health education in China is mostly carried out after the beginning of chemotherapy and is mainly based on routine postoperative care for the general cancer patient. The tailored information education on symptom management, functional exercise, diet, and nutrition for breast cancer patients is not enough.

Our patients reported that verbal information was easy to forget, and they hoped the medical staff could explain the relevant information not only once. For newly diagnosed patients, they need to hear the information many times to understand it fully^[145]. Besides, patients wanted diversified sources of information. They preferred face-to-face explanation, written material, and telephone follow-up. It is consistent with previous studies^[56,69]. Several studies^[146,147] have confirmed that information support through face-to-face and/or telephone counseling led by nurses effectively meets patients' changing information and support needs and improves their quality of life. On the other hand, written material might help the patient understand the health professionals' words when they speak fast, and patients could take it home to read it later or share it with their families^[51]. Therefore, we suggest that oncology nurses provide patients with accurate and diversified information resources early and repeatedly, to meet their changing information needs and improve their quality of life.

7.3 Strengthen psychological and emotional support

Patients experienced uncertainty and concern about the possible side effects of short-term chemotherapy and long-term recurrence and metastasis of breast cancer, which is consistent with the results of previous studies^[148,149]. Some patients were resistant to chemotherapy because of severe psychological pressure. Moreover, some patients reported shame and social disorders because of fear of hair loss. It may be related to the value of "saving face" in traditional Chinese culture^[150]. In addition, patients had a more significant psychological burden in terms of cancer's impact on their families. Under the influence of Chinese Confucianism, family culture has a significant social value^[151]. Patients cared about the impact of cancer on their families and not only themselves^[150], especially middle-aged women, who need to take care of their parents and raise their children.

Although patients tried to protect themselves from being hurt or protect their families by concealing their illness, it seems to increase their psychological distress. They affirmed the positive impact of the companionship of their families, the encouragement of nurses, and the sharing of peer patients on their emotions, but also said that the emotional support provided by doctors and/or nurses was insufficient. This finding is consistent with another study^[152] that explored the experience of coping behavior in dealing with a breast cancer diagnosis. Anu et al. ^[153] found that patient counseling,

discussion, and listening are the keys to maintaining mental balance and coping with cancer patients' treatment. Therefore, we suggest that nurses deeply understand the causes of patients' psychological distress and listen patiently to their feelings about treatment and cancer to provide supportive nursing intervention. At the same time, it is necessary to consider the traditional Chinese cultural background, carry out individual psychological counseling for patients with treatment and family concerns, and make effective use of social resources as their family and friends to alleviate psychological stress and negative emotions.

7.4 Promote the application of effective coping strategies

Our study found that individuals adopt different coping strategies to meet changing needs, and these strategies have different effects. Most patients tried to meet their information needs and manage discomfort symptoms by collecting the various information and minimizing adverse reactions. According to the stress and coping theory, these strategies belong to goal-oriented problem-centered strategies. Effectively problem-centered coping is most likely to contribute to a positive psychological state, as it makes participants experience personal control and a sense of achievement^[154]. Our patients encountered difficulties in gathering information and managing discomfort symptoms. It reduced the coping effectiveness significantly. Andrea and Ann Marie^[141] highlighted the importance of measuring not only concentrate on the strategies that women employed to cope with chemotherapy, but also the perceived effectiveness of these strategies. Therefore, it is necessary to know the forms and effectiveness of coping adopted by patients and redirect their coping strategies when needed^[155].

Some patients employed cognitive defense strategies like concealment, resistance, and passive acceptance. These seem to cause more stress and anxiety for them. Studies have shown that when breast cancer patients' avoidance and yield coping styles are dominant, the risk of depression is significantly increased^[156]. Moreover, this kind of defense even indicates poor psychological adaptation three years later^[157]. On the other hand, the patients who used the strategies of acceptance, diversion, selective attention, comparison with other patients, and expressing emotion, their psychological distress were alleviated. Many studies have shown that positive emotional expression enhances benefit finding, especially for women who presented avoidance-oriented coping^[158]; selective attention keeps anxiety within tolerable levels^[159]. Furthermore, refocusing attention helps the patient deal with the distress associated with chemotherapy effectively^[141]. When patients are unable to change the objective facts or external environment, these emotion-centered coping strategies could help them reduce emotional distress in the cognitive process and achieve better psychological adaptation^[135].

Besides, we found that some patients found positive significance after one chemotherapy cycle, which was slightly different from other studies^[141,152]. Previous studies mainly emphasized the

strategies of patients in dealing with negative emotions. We found that cancer triggered patients' attention to health and positive self-transformation. Women who experience positive meaning would have more positive emotions and better psychological adaptation^[160]. One study found that meaning-centered psychotherapy can effectively improve psychological distress and quality of life.

8 Conclusion

Based on understanding patients' personality characteristics, cultural background, and psychosocial environment, nurses should comprehensively assess patients' needs, what coping strategies they employed, and whether these strategies are effective. Then provide accurate information and sufficient emotional support to encourage them to use more effective coping strategies.

Study I-II Formulating a preliminary content draft of supportive care program

1 Literature review of supportive care intervention for breast cancer patients based on needs assessment

1.1 Background

After diagnosed with breast cancer, patients experienced varying degrees of physical and psychological damage due to the treatment. The supportive care intervention based on needs assessment for breast cancer patients has great significance in managing treatment-related symptoms, dealing with psychological problems, and improving their quality of life, which was focused on by many researchers in recent years^[103,161,162]. However, limited research reported the supportive care intervention tailored to Chinese breast cancer patients' needs^[113,163,164]. Therefore, developing a program to support Chinese breast cancer patients tailored to individual needs is necessary.

1.2 Aim

This review aimed to summarize the needs assessment tools, the delivery person, delivery format and dose, and deliver content for supportive care intervention, to provide a reference for the development of supportive care intervention for breast cancer patients based on needs assessment.

1.3 Method

Databases included Pubmed, and CNKI (China national knowledge infrastructure), targeted English or Chinese literature published from January 2009 to July 2020 using the keywords breast cancer, supportive care, needs, and intervention. Additional papers were included from reference lists. Literature review, study protocol, and supportive care interventions were not using an assessment tool to screen participants or not as intervention were excluded.

1.4 Result

1.4.1 Needs assessment tools used in supportive care intervention

1.4.1.1 Distress Thermometer (DT) and Problem List (PL)

The supportive care guideline^[165] developed by the national comprehensive cancer network (NCCN) recommends using DT and PL as screening tools to quickly identify cancer patients' psychological needs. DT is a single item with a scale from 0 (No distress) to 10 (extreme distress). If the score is less than 4, the distress can be managed through routine care. If the score is ≥ 4 , a member of the oncology team will browse the PL to identify the patient's key concerns and determine the best support resources (such as psychiatrists and social workers) to solve the patient's problems and concerns. PL is a list of 34 items with five dimensions: practical problems, family problems, emotional problems, physical problems, and spiritual/religious concerns. As initial assessment tools, DT and PL have good applicability in many countries^[165] and are widely used in the initial assessment of patients' needs in intervention studies^[166-170]. However, cancer patients in different countries have

different sensitivity to DT, and there are differences in the definition of DT critical value. A study in the Netherlands^[166] took 5 as the threshold for psychological pain intervention and intervened patients with $DT \geq 5$, while a study in Japan included intervention for patients with $DT \geq 3$ ^[167]. Danish scholars^[168] set the critical standard of DT to 7 and only intervened patients with $DT \geq 7$. For Chinese cancer patients, 4 is the best critical value^[171]. As far as the evaluation effect is concerned, the screening of DT and PL and referral to psychologists, social workers, and other professionals can effectively reduce patients' anxiety and depression^[169]. It is suggested that before providing supportive nursing intervention in the future, DT and PL can be used as assessment tools, and further individualized intervention can be provided for cancer patients with $DT \geq 4$.

1.4.1.2 Supportive care needs survey (SCNS)

SCNS is used to evaluate cancer patients' needs comprehensively and is generally applicable to all adult cancer patients. There were 59 items in the original scale, including the needs of health information, care and support, psychology, physiology and daily life, and sex, and the other needs of 4 additional items^[35]. The simplified SCNS34 entries retain the original 5 dimension names^[172]. The two versions of the scale were scored by the Likert 5, 1 as not applicable, 2 as Satisfied, 3, 4 and 5 as low, moderate and high need, respectively. Higher scores reflect greater unmet needs. At present, SCNS-SF34 is widely used to investigate breast cancer patients' needs and the evaluation of the effect before and after the intervention^[162,173]. Some scholars also use it as an index for initial screening of patients' needs. S.Aranda^[103] et al. used SCNS-59 to evaluate patient's needs, focusing on the items in which patients are rated as "high need", an intervention based on clarifying patients' problems and needs, and make referrals if necessary. The results showed that the intervention could effectively reduce the psychological and emotional needs of patients with high initial needs ($SCNS > 50$). Kanae et al. ^[167] paid attention to the content that patients rated as "high demand" in SCNS-SF34, applied problem-solving treatment, behavioral activation supervision combined with an information booklet provided psychological education to patients, they found that this method was feasible. Therefore, screening patients with high needs and giving priority intervention through needs assessment is critical in allocating nursing resources and resource utilization optimization.

1.4.1.3 Other assessment tools

Mertz et al.^[168] comprehensively assessed patients' needs through the content of physical and psychological self-report and subjective expression. The patient reported outcome (PRO) used DT, hospital anxiety and depression scale (HADS), quality of life questionnaire core (QLQ-C30). For $DT \geq 7$, anxiety and depression scores > 8 , and quality of life scores beyond the normal range were positive, requiring the supportive care intervention. Simultaneously, nurses designed detailed coping

plans for patients according to their specific problems, provided comments for overcoming obstacles and psychological education, and referred the patient to psychologists if necessary. This intervention could effectively reduce the stress, anxiety, and depression of patients. Therefore, the PRO could help the nurse to understand the patient's needs for health care services and find unidentifiable problems. Therefore, to promote the effective and efficient provision of supportive care services, patients' subjective and objective indicators as initial need assessment for breast cancer in supportive care intervention are suggested.

1.4.2 Delivery person for supportive care intervention

Several studies^[104,166,168] showed that nurses play an essential role in providing supportive care services, especially in improving patients' quality of life, nursing satisfaction, and meeting patients' needs. Compared with doctors, their simple and easy words are more popular with patients. Most studies trained the nurses to implement the supportive care services effectively^[95,103,104,167,170]. The training contents are mainly related to the content of the intervention, the methods of needs assessment, and communication skills. The time of the training varies from 1 to 2 days according to the intervention's content. Otherwise, the training is mainly provided by research designers, oncology psychologists, and multidisciplinary teams. Besides, nurses who were implementing intervention usually had more than 2 years of cancer nursing experience in most studies^[95,104,174], and some researchers chose nurses above undergraduate degree to conduct intervention^[104,174]. These nurse-led supportive care interventions have improved the prognosis of patients to varying degrees. It is suggested that when selecting nurses for conduct supportive care, the consideration of their work experience and standardized training before intervention are the cornerstones to ensure the smooth development of the intervention.

1.4.3 Delivery format and dose for supportive care intervention

For breast cancer patients, oral messages, telephone follow-up and written material, and website messages are acceptable forms, all of these depending on their age, educational level, and personal preferences^[175]. At present, several supportive care interventions were mainly carried out face-to-face and over the phone^[103,168,170,174], some of which are supplemented by an information booklet. Also, the intervention frequency of existing studies varies from 2 to 18 times. However, how many interventions are most effective is unclear. Therefore, in the design of future supportive care intervention, it is recommended to combine patients' personal preferences, as well as the results of previous surveys on the longitudinal changes of the needs of breast cancer patients and provide intervention before patient's needs reach a peak, to meet breast cancer patient's needs predictably.

1.4.4 Delivery content for supportive care intervention

A previous study^[1] showed that the highest unmet supportive care needs of breast cancer patients

were information needs, followed by psychological needs. Individualized information based on needs assessment, psychological or emotional support, and necessary referrals are important means of supportive care intervention^[48].

1.4.4.1 Information support

Due to the different treatment stages and duration of the intervention, information support includes cancer risk factors, treatment side effects, follow-up, sexual relationships, self-care strategies, available social resources^[103,104,167,168]. Aranda et al. ^[103] developed 25 information cards based on the best evidence, covering treatment side effects, communication strategies, family life problems, available service resources. Nurses provide patients with information cards specific to their individual information needs. Liao et al. ^[104] developed an information booklet on breast cancer treatment methods, treatment plans, side effects treatment, symptom management, self-care methods, dietary nutrition and other issues, and the experts evaluated the content validity of the booklet. Jolien et al. ^[176] designed a tailored network psychological education plan for patients based on literature and multidisciplinary teams. The educational materials are divided into 30 specific topics, including background information, problem-solving strategies, links to other websites or service resources, and other issues. Terry et al. ^[177] referred to the standard educational materials by the National Cancer Institute, the National Institute of Aging, and other authoritative institutions, and revised them appropriately according to patient's needs. These materials focus on normal breast health and breast cancer, routine examination techniques, side effect coping strategies, and other information distributed to patients before the intervention. Patients are encouraged to apply the contents of educational materials to their daily lives. Based on this, nurses should pay attention to two points when providing information support. First, the information materials most relevant to the patients should be formed by searching the best evidence, guidelines, and authoritative websites before the intervention. Also, experts reviewing the relevance of information content to ensure that the information is accurate and comprehensive is suggested. Secondly, during the intervention implementing process, targeted information support should be provided based on the patient's personal information needs.

1.4.4.2 Psychological/emotional support

Psychological or emotional support mainly includes listening to patients' concerns, providing decompression strategies, encouraging patients to express themselves, making goals and action plans^[103,104,167,168,170]. Jonathan et al.^[162] provided supportive emotional techniques, such as active listening, clarification, interpretation and education, and guidance on dealing with/managing side effects. Liao et al.^[104] provide a stress-free time and space for patients to clarify their uncertainties, express their thoughts and feelings, achieve psychological and emotional adaptation or modification, and receive a referral if necessary. Bigitte et al.^[168] use the strategy of listening to patient's thoughts,

feelings, and behaviors through the dialogue between nurses and patients, explore the experience of cooperation (patients' personal views and nurses' professional standards), and assess needs from PRO and conversations, and then provide psychological education, goal setting and intervention plans. They found one year after diagnosis, the patients' rehabilitation satisfaction increased significantly, and the levels of psychological distress, anxiety, and depression decreased significantly. Psychological support provides patients with the opportunity to share their feelings, and patients think that nurses can better understand their feelings than family and friends^[97]. Therefore, for patients with heavy psychological burdens, psychological support such as active listening, decompression strategies, and psychological education can alleviate their negative emotions.

1.4.4.3 Referral

The referral is one of the critical parts of supportive care services. For some patients with complex needs, satisfying their needs is beyond the primary health care team's capacity. Therefore, they need to be referred to other health care professionals. Such as psychologists, social workers, dietitians. Linda et al.^[169] referred the patients if their DT ≥ 4 , anxiety ≥ 10 , and depression ≥ 9 to psychosocial counseling institutions, referred patients with pain or fatigue ≥ 4 to doctors and nurses, referred patients with weight or food intake loss to nutrition departments. Another study^[166] discuss the situation of all patients with DT ≥ 5 or in need of additional support through multidisciplinary teams (oncologists, nurses, social workers, psychologists), develop treatment plans and refer patient if necessary. Therefore, teamwork among all health care professionals is essential to achieve comprehensive supportive care. It is suggested that future supportive care intervention should strengthen interdisciplinary cooperation, improve the referral norms and procedures, and make referrals according to patients' individual needs and conditions.

1.5 Summary and implication for nursing practice

Supportive care intervention based on a need assessment can reduce patient's needs, help them manage treatment-related symptoms, and improve their treatment compliance and quality of life. However, supportive care covers a wide range of areas, involving physiological, emotional, social, psychological, information, and other aspects. Systematic identification of patients' specific needs and clarifying the focus assessment stage is a crucial step in implementing supportive care intervention effectively. Evaluation can point out the direction for follow-up intervention and help nurses allocate resources effectively and efficiently in a busy medical environment.

The development of supportive care intervention for breast cancer patients should be based on the subjective and objective needs assessment and focus on the patients with a high level of needs and apparent physical and psychological damage. It is also suggested that the individual supportive care intervention program be designed based on the existing guidelines and patients' needs.

2 Supportive care program design

According to the primary needs and coping strategies of patients identified from the interview, and combined with previous literature review, a preliminary draft of the supportive care program was formulated based on the 'Tiered model of supportive care'.

2.1 Intervention goals

- (1) To reduce the supportive care needs and psychological distress of Chinese patients with newly diagnosed breast cancer undergoing chemotherapy.
- (2) To improve patients' information satisfaction and quality of life.

2.2 Intervention dose

Previous studies found that patients' psychological needs and information needs were highest at one month after diagnosis, whereas decreased at three months post-diagnosis^[37]. One month after diagnosis is the time when the patient was preparing for chemotherapy. Au et al.^[46] found that the patients awaiting initial chemotherapy have more information needs than those receiving chemotherapy, which may be related to the concerns of chemotherapy's side effects^[40]. Also, in the early stage and following chemotherapy, information about side effects management is the priority need for patients^[55,123]. Therefore, this intervention is started before patients receive chemotherapy and continue to 3 months after diagnosis, three sessions total (Figure 4).

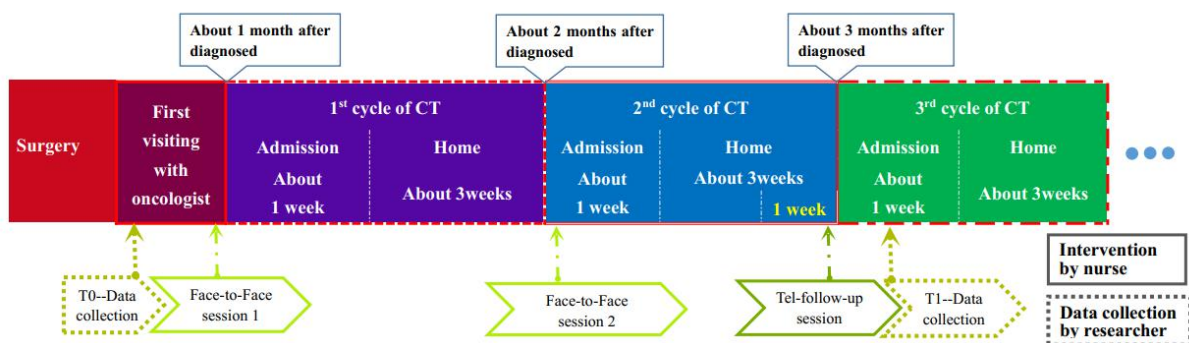


Figure 4. The time blueprint of the nurse-led supportive care program

2.3 Participants

Patients: Who is newly diagnosed with breast cancer and will receive chemotherapy for the first time.

Nurse: Oncology nurse and be trained on how to provide supportive care by the researcher.

2.4 The intervention mode of delivery

Many supportive care interventions were carried out face-to-face and over the phone^[103,168,170,174]. Some of them are supplemented by an information booklet. In this study, the intervention would be conducted through face-to-face and telephone consultation. The supplementation information booklet was designed based on study I (qualitative study) and relating

guidelines and textbooks.

2.5 Intervention components and activities

Based on the 'Tiered model of supportive care', we designed the intervention components as below (Details in table 6):

Face-to-face consultation session (Twice: before 1st and 2nd cycle chemotherapy, respectively)

Patients are encouraged to bring a significant other. This session comprises four components.

(a) Assessment: All patients use Distress Thermometer to assess their current distress, and Problem List will screen their needs, which includes practical, family, emotional, physical, social, and spiritual problems^[178]. Moreover, they will be provided the general information about chemotherapy and specific or common problems.

(b) Skilled Communication: Many patients may need additional information and education. The nurse will further clarify the problem, guide a positive approach to communicate supportive care issues, use the tool as a prompt, encourage patients to talk more about their main concerns, and offer additional information and support.

(c) Tailored responses: For some patients, they may require intervention for symptom management or psychosocial distress. The coping strategies provided will be tailored to the woman's individual top 3 concerns and needs from conversation and screening tools. (the coping strategies will be provided as a booklet, and the researcher will explain the method of how to use the booklet)

(d) Summary and referral: Few patients with complex needs may need intensive and ongoing complex interventions. The nurse will identify whether another health professional or service is needed, if it is, then referral to other specialist services. This nurse will summarize the main issue, then make an appointment time for the follow-up phone call.

Telephone follow-up session

The nurse will telephone the patient one week before the 3rd cycle of chemotherapy to:

- (a) Ask whether the suggested strategies have solved their concerns.
- (b) Prompt for further questions or new concerns after they finished the 2nd cycle of chemotherapy.
- (c) Provide more information and strategies if new concerns existed.

Table 6 The nurse-led supportive care program (Version 1)

① Intervention dose	Session one (Before CT start)	Session two (2 nd cycle of CT)	Session three (1 week before 3rd cycle of CT)
② Intervention nurse	Inclusion criteria: (a) Worked more than 5 years at oncological or breast department; (b) Has bachelor's degree or above; (c) Has good ability in communication; (d) Be willing to take part in this research; (e) Have finished the supportive care train course.		
③ Patient	Inclusion criteria: (a) Have a confirmed diagnosis of breast cancer and finished surgery; (b) Age: over 18 years old; (c) Newly diagnosed without metastasis; (d) The first time of receiving chemotherapy; (e) Aware of their cancer diagnosis; (f) Being available to be contacted by telephone. Exclusion criteria: (a) Cognitive impairment or severe mental illness; (b) History of other malignancy cancer.		
④ Intervention formats	Face-to-face consultation +booklet	Face-to-face consultation+booklet	Telephone follow-up
⑤ Intervention contents	<p>Informational Education to minimize the adverse effect and satisfied information needs:</p> <ul style="list-style-type: none"> ❖ Symptom management <ul style="list-style-type: none"> ■ Discomfort symptoms on the surgical side ■ Sleep disorder ■ Other symptoms ❖ Daily life <ul style="list-style-type: none"> ■ Diet taboo (Fawu) and nutrition ■ Self-rehabilitation exercise ■ Health sexual life ■ Body cleanliness ❖ Treatment and follow-up examination <ul style="list-style-type: none"> ■ Inducing factors and follow-up examination ■ Introduce of infusion devices ■ Benefit and side effects of chemotherapy drugs and how to alleviate side effects ■ Adjuvant endocrine, traditional Chinese medicine treatments <p>Emotional support to help patients to adapt to diseases and seek help:</p> <ul style="list-style-type: none"> ❖ Encouraging patients to express their concerns and feelings <ul style="list-style-type: none"> ■ Treatment effect and side effect, and recurrence and metastasis of cancer ■ Body image ■ Family and social relationships ❖ Guiding patients to adopt 	<p>Informational Education for what information patients still concerned:</p> <ul style="list-style-type: none"> ❖ Symptom management <ul style="list-style-type: none"> ■ Discomfort symptoms and functional recovery of surgical side ■ How to alleviate side effects ■ Rest and exercise ❖ Daily life <ul style="list-style-type: none"> ■ Diet taboo and nutrition(Mainly in how to alleviate white cell) ■ Body cleanliness ❖ Treatment and follow-up examination <ul style="list-style-type: none"> ■ Benefits and side effects of radiotherapy ■ Reexamination <p>Emotional support for what concerns still distressed patients:</p> <ul style="list-style-type: none"> ❖ Encouraging patients to express their concerns and feelings <ul style="list-style-type: none"> ■ Treatment effect and side effect, and recurrence and metastasis of cancer ■ Family and social relationships ❖ Guiding patients to adopt cancer and treatment <ul style="list-style-type: none"> ■ Distraction ■ Selective attention ■ Compare with other BC patients ■ Weaken the "patient" role ■ Establish a belief in survival 	<p>Follow-up: to understand the effectiveness of nurse support services and the ongoing needs of patients</p> <ul style="list-style-type: none"> ❖ Ask whether the suggested strategies have solved their concerns; ❖ Prompt for further questions or new concerns after they finished the 2nd cycle of chemotherapy; ❖ Providing information education, emotional support, or coping strategies based on the patient's specific situation

	<p>cancer and chemotherapy</p> <ul style="list-style-type: none"> ■ Anticipate preparation (wig, headscarf, artificial breast, mental preparation) ■ Acceptance ■ Distraction <p>❖ Understanding the patient's characteristic and possibly acquired resource to help them to seek support</p> <ul style="list-style-type: none"> ■ Peer patients ■ Families and friends' support ■ Medical staffs' support 	<p>❖ Understanding the patient's characteristic and possibly acquired resource to help them to seek support</p> <ul style="list-style-type: none"> ■ Peer patients ■ Families' support ■ Medical staffs' support <p>❖ Encouraging patients to find the positive meaning of cancer experience</p> <ul style="list-style-type: none"> ■ The importance of health ■ Positive self-transformation 	
⑥ Intervention procedure	<p>❖ Assessment and primary education (For all patient):</p> <ul style="list-style-type: none"> ■ Screening the needs/distress by Distress Thermometer (DT) and Problem List ■ Providing the general information education <p>❖ Skilled Communication (For many patients whose DT ≥ 4):</p> <ul style="list-style-type: none"> ■ Clarifying the cause of needs and/or distress ■ Using skilled communication to encourage patients to express ■ Understanding existed coping strategies and their effects <p>❖ Tailored responses:</p> <ul style="list-style-type: none"> ■ Providing coping strategies tailored to patients' individual top 3 concerns ■ According to the patient's characteristic and possibly acquired resource to help them to seek support <p>❖ Summary and record:</p> <ul style="list-style-type: none"> ■ Summarizing and recording the main issues ■ Making appointment for next intervention session 	<p>❖ Reappraisal and second education</p> <ul style="list-style-type: none"> ■ Evaluating the effectiveness of the strategies provided in session one. ■ Reassess the needs and distress currently by Distress Thermometer (DT) and Problem List, and providing information <p>❖ Skilled Communication:</p> <ul style="list-style-type: none"> ■ Clarifying the cause of current needs and/or distress ■ Using skilled communication to conduct a emotional support ■ Understanding existed coping strategies and their effects <p>❖ Tailored responses:</p> <ul style="list-style-type: none"> ■ Providing coping strategies tailored to patients' individual top 3 concerns <p>❖ Summary and record:</p> <ul style="list-style-type: none"> ■ Summarizing and recording the main issues ■ Making appointment for next follow-up session 	<p>❖ Final appraisal and education</p> <ul style="list-style-type: none"> ■ Evaluating the effectiveness of the strategies provided in the first 2 sessions. ■ Reassess the needs and distress currently by Distress Thermometer (DT) and Problem List, and providing information <p>❖ Skilled Communication:</p> <ul style="list-style-type: none"> ■ Clarifying the cause of current needs and/or distress ■ Using skilled communication to conduct a emotional support <p>❖ Tailored responses:</p> <ul style="list-style-type: none"> ■ Providing coping strategies tailored to patients' individual top 3 concerns <p>❖ Summary and referral:</p> <ul style="list-style-type: none"> ■ Summarizing and recording the main issues ■ Identifying the health professional or service ■ Referral few patients to other service
⑦ Record instrument for nurse	Nursing record audit data collection tool	Nursing record audit data collection tool (Part 4)	Nursing record audit data collection tool (Part 4)
⑧ Supplemental materials for patients	Booklet Symptom management; Diet and nutrition et al.)	Same booklet in session one	Same booklet in session one
⑨ Evaluation instrument for patient	Baseline: SCNS-34, EORTC QLQ-INFO25, FACT-B36		After intervention: SCNS-34, EORTC QLQ-INFO25, FACT-B

Chapter 4 Study II - Examining the content validity of the supportive care program

1 Purpose

To examine the content validity of the nurse-led supportive care program for Chinese breast cancer patients undergoing chemotherapy.

2 Design and Methods

An online focus group discussion with two rounds of questionnaire consultation by the Chinese expert panel was conducted. Each member of this focus group contributed their knowledge, skills, and experience to augment and support other participants' contributions and improve the value of feedback on the supportive care program.

2.1 Participant

The Chinese experts were invited through purposive sampling method who satisfy followed criteria:

- A. More than ten years of professional work experience in his/her field in China. (Clinical nurse or physician, or nursing manager, or nursing researcher, or a nursing educator),
- B. Has a professional understanding of breast cancer and chemotherapy,
- C. Has bachelor's degree or above,
- D. Has intermediate professional title or above,
- E. Be willing to take part in this research.

2.2 Sample size

Each focus group should consist of 4-12 participants^[179]. Six experts were invited to participate in this research.

2.3 The theme of the discussion

The discussion topics were as follows: (1) Is the intervention content and the nursing record sheet feasible for clinical nurses and patients? (2) Is the implementation process and instrument appropriate? (3) Is the booklet appropriate? (4) What are the further recommendations for the supportive care program? The specific questions were discussed according to the response of the first round of the consultation questionnaire.

2.4 The process of the focus group discussion

2.4.1 Preparation before the focus group discussion

To assess this program's content validity, the investigator designed a consultation questionnaire (Version 1) based on the supportive care program's preliminary draft. After the expert agreed to participate in this research, the consultation questionnaire with instructions, the booklet, and the nursing record sheet for the supportive program was sent to the experts by email. Each expert was

asked to rate the degree of relevance within the content domain. Space was provided to the experts to write down their opinion if they rate irrelevant. After the experts returned the questionnaires, the themes clarified through data analysis were discussed during the focus group. Furthermore, the researcher made an appointment with experts to discuss the specific themes through the online focus group, and these themes were sent to the experts by email three days before the focus group discussion.

2.4.2 During the focus group discussion

The focus group discussion was held online because of the influence of the COVID-19. After the researcher briefly introduces the aim, a summary of this supportive care program, and the discussion themes, experts were invited to discuss. The focus group discussion began at 8:00 AM and lasted two hours.

2.4.3 After the focus group discussion

After the focus group discussion, the researcher extracted the critical point of the discussion, consulted with the supervisor, and then revised the supportive care program as Version 2. After the experts returned the second round of the questionnaire, the supportive care program was formed.

2.5 Data collection

2.5.1 The quantitative data

Demographic data of the samples: A self-designed questionnaire that includes the sex, age, and other characteristics was employed to collect the samples' demographic data.

Content validity of the supportive care program: The content validity index (CVI) was calculated to validate this program's content. The CVI of the supportive care program was measured using a 4-point Likert scale from 1 (irrelevant) to 4 (extremely relevant)^[180]. Items met the content validity criterion if 80% of participants rated the item as 3 or 4^[180,181]. Item does not satisfy this criterion was discussed.

2.5.2 The qualitative data

The process of the group discussion was record-taped.

2.6 Data analysis

Frequencies and descriptive analyses were undertaken to analyze the quantitative data. Content validity analysis, a CVI value computed for each item on a scale (I-CVI) and the overall scale (S-CVI). For each item, the I-CVI is computed as the number of experts giving a rating of either 3 or 4, divided by the number of experts-that is, the proportion in agreement about relevance. When there are six experts, the I-CVI must be at least 0.83, reflecting one disagreement. As for scale-level content validity, it is to compute the I-CVI for each item on the scale, and then calculate the average I-CVI across items (refer to as S-CVI/Ave)^[182]. A criterion of 0.90 as the acceptability for an S-CVI/Ave^[183].

After the focus group discussion was held, the researcher conducted a verbatim transcription of the recorded discussion within 48 hours. Also, content analysis was used to analyze the qualitative data, and the critical comments were extracted.

3 Ethical considerations

This study was approved by the Ethics Committee institutions of Chiba University(No.R2-7). The purpose, possible risks, anonymity, and confidentiality were explained to the participants, who were aware of their right to withdraw from the study at any time.

3.1 Guarantee the voluntary nature of the formalities for obtaining research approval and consent

3.1.1 Formalities for obtaining permission from research cooperation facilities

After this study was approved by the Ethics Committee institutions of Chiba University, the researcher contacted the manager of the potential experts, and explained the aim, significance, and how the expert should cooperate with this study in verbal and written form. Also, the researcher obtained the manager's permission in introducing the potential expert who satisfied the selection criteria.

3.1.2 Formalities for obtaining consent from research subjects (the expert)

After obtaining the manager's permission to cooperate with this study, the researcher contacted the experts introduced by the manager, introduced the aim, significance, and how the expert should cooperate with this study in written and verbal form. The researcher promised the expert that his/her participation is entirely voluntary, and he/she may decline to withdraw from the study at any time. After obtained the expert's consent form, the researcher explained to the expert that considering the characteristic of the focus group discussion, if the expert hopes to withdraw from this study in the middle or after data was collected, the researcher contacted them to ask their permission to use their data which had been collected. If the expert disagreed with analyzing their data, the data would be deleted.

3.1.3 Possibility and details of external funds

There is no fund support for this research.

3.2 Guarantee of safety and reducing burdens when implementing the study

3.2.1 Countermeasures for disadvantages and risks associated with participation in the study

Physical and time burden: It is possible to increase the participant's physical and time burden when participating in this study. They might feel fatigued after 1 hour to 2 hours of discussion. Also, the expert can refuse to talk about any issues that make her/he feels uncomfortable. To decrease the expert's time burden, the researcher explained to the expert in the invitation cover letter that the focus group discussion may cost 1 hour to 2 hours preciously, and the consultation questionnaire may cost

them around 15-30 minutes each round. After the expert signed the consent form, the researcher contacted the expert to discuss their available timing for meeting. Besides, the expert was invited to answer each round of questionnaire consultation in one week, and two rounds of consultation were held at an interval of two months.

Mental burden: The participant might have a mental burden when they share their opinions with other peer experts. To reduce the expert's mental burden, the researcher explained to the expert that there are no right or wrong answers to the questionnaires, or the questions discussed in the focus group before the study. Moreover, the researcher suggested that they conduct the focus group discussion in a relatively quiet, comfortable, safe, and single room. Then the expert will have a comfortable space to express his/her opinions during the group discussion.

3.2.2 Guarantee of the applicant's ability to execute research and of the status of the research preparations

I obtained the qualification certificate of the nurse in China. Moreover, I had nearly two years of internship experience in a teaching hospital and two years of research data collection experience in the breast surgery department. Furthermore, before this study, I reviewed the studies related to this topic, and this program was developed based on the interview with breast cancer patients. I had the ability to conduct this study.

3.3 Protection of privacy, anonymity, and personal information during data collection and publication

3.3.1 Consideration of introducing the research and ask consent of the subjects (the expert)

The researcher (I) explained that all the data collected from them would only be used in this study. And the researcher (I) promised that the privacy, confidentiality, and security of the information collected from them would be protected during the study period. There is no impact on the expert's work, life, or interpersonal relationships even if she/he does not participant in or withdraw in the middle of this study. The researcher will seek the consent of the experts based on fully protecting their rights and interests.

3.3.2 Considerations for data collection and analysis

The researcher (I) explained that the data collected by questionnaires and the record of focus group discussion was only used for this study. In the process of data analysis, if the expert hopes to withdraw from the research, the researcher will discuss with the expert that the data collected from her/him can be use or not. To protect the expert's privacy, anonymity, and personal information, the researcher used a unique code to denote their names before the researcher sent the questionnaire to her/him. All the information only be available to members of the research team.

3.3.3 Considerations for data management

All electronic data (e.g., tap record or video tape, electric version of the consent form, withdrawal form, and consultation questionnaire) was stored on a secure computer with a personal password. All non-electronic data (e.g., written consent forms, hand-written notes, and the group or individual discussion transcripts) were stored in a locked research room. Data was brought to places other than schools, homes, or areas where the data are collected. Otherwise, the data would be kept for a maximum of ten years following the first publication resulting from the study, and then all electronic data would be deleted, all non-electronic data would be shredded.

3.3.4 Publication of research results and methods to remove subjects and relevant considerations

The researcher explained that the research results might be published in conferences or academic journals and obtained their permission to publish the result. Moreover, the researcher will share the result if the expert wants to know it. The expert's personal information would be protected when the paper is published.

4 Result

4.1 Characteristics of the participants

One male and five female experts whose ages ranged from 37 to 54 years old (46.00 ± 7.21) participated in this study. Three of them had a Ph.D. degree, and one had a master's degree. They worked in their professional field on average (22.83 ± 7.08) years. The details of their characteristics were listed in table 7.

Table 7 Characteristics of the experts (n=6)

Characteristics	No.	Characteristics	No.
Age (years old)		Educational level	
30-40	2	Ph.D.	3
41-50	1	Master	1
51-55	3	Bachelor	2
Present job title		Working experience (years)	
Physician	1	10-15	2
Professor	3	20-30	3
Head nurse	2	30-40	1
Department		Professions	
Breast surgical department	2	Medical	1
Nursing school	2	Nursing education	2
Oncology department	1	Nursing management	2
Nursing department	1		

4.2 The content validity of the two rounds of the consultation questionnaire

All the experts responded. With the two rounds of consultation questionnaire, each component's I-CVI is greater than or equal to 0.83, and the S-CVI is over 0.9. Indicating they agreed the content of this program is relevant to the construct of intervention. The details of the rating on the 9-components of version 1 and version 2 of the supportive care program were list in table 8.

Table 8. Ratings on the 9-components of version 1 and version 2 of the supportive care program by six experts

Component	Version	Expert A	Expert B	Expert C	Expert D	Expert E	Expert F	Experts in agreement	I-CVI
1. Intervention dose	1	4	4	4	4	4	4	6	1
	2	4	4	4	4	4	4	6	1
2. Eligible intervention nurse	1	4	4	4	4	4	4	6	1
	2	4	4	4	4	4	3	6	1
3. Eligible patient	1	4	4	3	4	4	4	6	1
	2	4	4	4	4	4	3	6	1
4. Intervention formats	1	4	4	4	4	4	4	6	1
	2	3	4	4	4	4	4	6	1
5. Intervention contents	1	4	4	3	4	4	3	6	1
	2	4	4	3	4	4	4	6	1
6. Intervention procedure	1	4	1	4	4	4	4	5	0.83
	2	-	-	-	-	-	-	-	-
7. Information booklet	1	4	4	4	4	4	4	6	1
	2	4	4	4	4	4	4	6	1
8. Nursing record sheet	1	4	4	4	4	2	4	5	0.83
	2	3	4	4	4	3	3	6	1
9. Evaluation instrument for patient	1	4	4	4	4	4	4	6	1
	2	4	4	4	4	4	3	6	1
Proportion relevant	1	1.00	0.89	1.00	1.00	0.89	1.00	<i>I-CVI/Ave = 0.96</i>	
	2	1.00	1.00	1.00	1.00	1.00	1.00	<i>I-CVI/Ave = 1</i>	

Note: I-CVI, item-level content validity index; S-CVI, scale-level content validity index, scale-level content validity index, averaging method (I-CVI/Ave)

'-': In the revised version 2 of this supportive care program, the intervention content and intervention procedure were merged, named as 'intervention content'.

4.3 Qualitative comments by experts

4.3.1 Resetting the intervention time during a period rather than a specific day

All the experts agreed that each session's intervention time should be set during a period rather than a specific day to improve participant's compliance. Considered patients' physical condition after they received infusion on the day of chemotherapy may affect patients' compliance with the intervention. The experts suggested that the intervention could be conducted one or two weeks before or after the chemotherapy.

A: "I suggest you advance the first intervention. About two weeks post-operation, the MDT team gave the patient a treatment plan... You can intervene once at that time (before the first chemotherapy)

and provide some information. It will be a great comfort to the patients."

D: "Either during one week before or 7-10 days after chemotherapy, telephone follow-up could be acceptable. The patient will feel uncomfortable for one week after chemotherapy. Intervention can be set during a period, not as a specific day."

4.3.2 Enriching the forms of intervention and increase follow-up after discharge

Two experts commented that the intervention could combine the booklet and WeChat to facilitate patients and increase the care continuity.

F: "The intervention can use the booklet, video, or published on WeChat. In this way, patients can save or re-reading the information at any time."

B: "The intervention setting should be consecutive, and patients can be followed up by WeChat, Internet, and telephone after they are discharged."

4.3.3 Resetting the participants' eligibility criteria according to the clinical situation

Most experts believed that it is not necessary to limit the educational level of the intervention nurse. There were two reasons. First, the nurse's clinical practice ability is vital for supportive care rather than the educational level. Second, the number of nurses with a bachelor's degree is not much in the current medical system. The experts also suggested that this study's target participants are breast cancer patients who are undergoing chemotherapy. It is unreasonable to exclude the patients undergoing neoadjuvant chemotherapy.

F: "Compared to the nurse who worked for three years with a master's degree, 15 years worked with a junior college, who has more working experience? Supportive care does not require nurses to have scientific research ability. It is a kind of clinical ability."

D: "There are few nurses who have a bachelor's degree with more than 5 years of working experience... It is not necessary to set a bachelor's degree or above."

F: "Neoadjuvant chemotherapy has become a standard treatment in Beijing. If you excluded the patients with recurrent cancer and the neoadjuvant chemotherapy, only a few patients are included."

A: "If the patients with neoadjuvant chemotherapy are excluded, the last patients who finished surgery might be diagnosed with early-stage cancer, and their prognosis will be better. There will be a selection bias in this study."

4.3.4 Highlighting the specific characters of the chemotherapy, revising the content based on previous guidelines

Four experts suggested revising this program's content specific to chemotherapy by removing the information related to other breast cancer treatments and following up with the information booklet. Moreover, enrich or revise the content related to chemotherapy based on guidelines or books.

F: "The content of the intervention should be clear. If you focus on the period of chemotherapy,

highlight it, and the contents related to disease or other else can be put in the booklet...Alopecia, leukopenia, leg pain, abdominal pain, and diarrhea should be included in the intervention...There is no evidence about seafood, and "Fawu" can affect cancer at present. Therefore, any uncertain content should not be written in the booklet. The contents of education should be found in guidelines or books."

E: "Exercise and rest, how to cope with changing body image, and other information during chemotherapy are also important to the patients. It should be considered in the intervention."

4.3.5 Making the intervention plan according to what patients should know and what they expect to know

Some experts suggested that it is unreasonable only to solve three concerns of the patient. Otherwise, even if the patient shows she does not need information, it does not mean what she has known is correct. Therefore, the intervention nurse should make a plan.

B: "Because patients are different, they may have various problems, so it is recommended to solve each problem, rather than just three issues."

F: "Even if the patient says she doesn't need it, we do not make sure that what she knows is correct. Therefore, it is necessary to list the contents that patients need to know and make a plan...We can educate the patient on what they are most concerned."

4.3.6 Revising the booklet with other side effects of chemotherapy and coping strategies for psychosocial problems

Three experts commented that the booklet's content was not comprehensive. The side effect of diarrhea, numbness of hand and foot, muscle pain, and the coping strategies of psychosocial problems were supposed to be added in the booklet.

A: "Diarrhea was not listed as the side effects of chemotherapy. Some patients use targeted drugs but withdraw in the middle because of serious diarrhea, so the information related to diarrhea is important. Also, the serious complications of taxol drugs are numbness of hand and foot and muscle pain."

B: "Lacking the psychological, emotional, and social function information in the booklet, which should be supplemented."

4.3.7 Revising the nursing record sheet much clear and appropriate to clinical practice

One expert suggested that the nursing record sheet should be clearer. Because some of the side effects of chemotherapy were not listed in this sheet, it will make the nurse feel hard to record.

5 Revising Version 1 of the supportive care program

According to the experts and the supervisor's recommendations, the revised Version 2 of the supportive care program (Table 9) was formed. Furthermore, to facilitate the nurse conducting this

program, a flowchart was developed (Table 10). Also, it was designed as a questionnaire being sent to the experts for the second round of consultation. The changes and reason for revising each component from version 1 to version 2 was explained in Table 11. In the second round of questionnaire consultation, the experts did not comment on the supportive care program content. Therefore, version 2 of the supportive care program would be used to guide the intervention in step 3.

Table 9 The nurse-led supportive care program (Version 2)

Intervention dose and format After the patient received their chemotherapy plan from their oncologists, they will be invited to participate in this study. The person who agrees to the participant will be asked to finish a baseline survey and be offered the booklet. Simultaneously, the nurse will make an appointment with the patient to provide individualized intervention when the patient is available. The intervention included three sessions of individualized counseling, lasts about 30-60 minutes/session. The tailored information and emotional support will be provided according to the most concerned patients at that time. Besides, patients can contact the nurse by phone or WeChat if they have any questions.

Intervention procedure	Description	Content									
1	Assessment and primary education Screening the needs/distress by Distress Thermometer (DT) and Problem List, and providing general information education.										
2	Skilled communication Using skilled communication (encourage patients to express, listen actively, clarify problems, etc.) to clarify the cause of needs and/or distress and understand the existing coping strategies and their effects.										
3	Tailored information and emotional support Based on fully considering the patient's age, education level, disease, treatment plan, personality traits, family context, and possible resources, tailored information and emotional support counseling according to what patients were most concerned about at that time will be provided.	<table border="0"> <tr> <td style="vertical-align: top;"> <p>Management of the common side effect of Chemotherapy</p> <hr/> <ul style="list-style-type: none"> -Chemotherapy-induced nausea and vomiting -Hair loss -Oral mucositis <p>Self-management during intermission of chemotherapy at home</p> <hr/> <ul style="list-style-type: none"> - Infusion devices - Diet and nutrition -Functional rehabilitation of upper limb on the affected side <p>Chemotherapy-related support and service resources</p> <hr/> <ul style="list-style-type: none"> -Resources of Internet </td> <td style="vertical-align: top;"> <ul style="list-style-type: none"> -Myelosuppression -Fatigue -Sleep disorder <hr/> <ul style="list-style-type: none"> -Self-image management <hr/> <ul style="list-style-type: none"> -Resources of peer patients </td> <td style="vertical-align: top;"> <ul style="list-style-type: none"> -Diarrhoea -Constipation -Skin and nail changes <hr/> <ul style="list-style-type: none"> -Exercise and weight management -Health sexual life <hr/> <ul style="list-style-type: none"> -Resources of books </td> </tr> <tr> <td style="vertical-align: top;"> <p>Information education</p> </td> <td style="vertical-align: top;"> <p>Emotional support</p> </td> <td style="vertical-align: top;"> <p>Encouraging patients to express their concerns and feelings</p> <hr/> <ul style="list-style-type: none"> -Effect and side effect of chemotherapy, and recurrence and metastasis of cancer -Body image -Family and social relationships <hr/> <p>Guiding patients to adopt cancer and chemotherapy gradually, to find the positive meaning of cancer experience</p> <hr/> <ul style="list-style-type: none"> -Anticipate preparation (wig, headscarf, artificial breast; mental preparation) -Accept the treatment -Distraction <hr/> <p>Helping patient to seek support</p> <hr/> <ul style="list-style-type: none"> -Families and friends' support </td> </tr> <tr> <td></td> <td></td> <td style="vertical-align: top;"> <ul style="list-style-type: none"> -Selective attention (focus on the positive) -Compare with patients who have a good prognosis and whose condition is more serious than themselves to get comfort. -Weaken the "patient" role -Establish a belief in survival <hr/> <ul style="list-style-type: none"> -The importance of health -Positive self-transformation <hr/> <ul style="list-style-type: none"> -Medical staffs' support -Peer patients' experience sharing </td> </tr> </table>	<p>Management of the common side effect of Chemotherapy</p> <hr/> <ul style="list-style-type: none"> -Chemotherapy-induced nausea and vomiting -Hair loss -Oral mucositis <p>Self-management during intermission of chemotherapy at home</p> <hr/> <ul style="list-style-type: none"> - Infusion devices - Diet and nutrition -Functional rehabilitation of upper limb on the affected side <p>Chemotherapy-related support and service resources</p> <hr/> <ul style="list-style-type: none"> -Resources of Internet 	<ul style="list-style-type: none"> -Myelosuppression -Fatigue -Sleep disorder <hr/> <ul style="list-style-type: none"> -Self-image management <hr/> <ul style="list-style-type: none"> -Resources of peer patients 	<ul style="list-style-type: none"> -Diarrhoea -Constipation -Skin and nail changes <hr/> <ul style="list-style-type: none"> -Exercise and weight management -Health sexual life <hr/> <ul style="list-style-type: none"> -Resources of books 	<p>Information education</p>	<p>Emotional support</p>	<p>Encouraging patients to express their concerns and feelings</p> <hr/> <ul style="list-style-type: none"> -Effect and side effect of chemotherapy, and recurrence and metastasis of cancer -Body image -Family and social relationships <hr/> <p>Guiding patients to adopt cancer and chemotherapy gradually, to find the positive meaning of cancer experience</p> <hr/> <ul style="list-style-type: none"> -Anticipate preparation (wig, headscarf, artificial breast; mental preparation) -Accept the treatment -Distraction <hr/> <p>Helping patient to seek support</p> <hr/> <ul style="list-style-type: none"> -Families and friends' support 			<ul style="list-style-type: none"> -Selective attention (focus on the positive) -Compare with patients who have a good prognosis and whose condition is more serious than themselves to get comfort. -Weaken the "patient" role -Establish a belief in survival <hr/> <ul style="list-style-type: none"> -The importance of health -Positive self-transformation <hr/> <ul style="list-style-type: none"> -Medical staffs' support -Peer patients' experience sharing
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4	Summary and referral Summarize and record the main problems and recommended strategies identified in this consultation, and make an appointment for the next consultation. At the end of all consultation, few patients will be referred to other experts (dietitian/psychiatrist, etc.) if their DT ≥ 4.										

Table 10 The flowchart and components of the nurse-led supportive care program

Overall objectives and outcomes of the intervention		<p>Objectives: After the intervention, ①patients will have the information about the effect and side effect of Chemotherapy, and the information on how to manage their physical and psychological problems related to cancer and chemotherapy; ②patients will have the information on how to acquire support resource;③patients' concerns will be improved by nurse's support.</p> <p>Outcomes: ①Patient will report her supportive care needs decreases after the intervention; ②Patient will report her psychological distress, information satisfaction and quality of life improves after the intervention.</p>				
Intervention dose	Intervention formats	Purpose and Focus	Content of the intervention		Remarks or examples	
<p>Session 1</p> <p>Before the first cycle of Chemotherapy (CT)</p> <p>(After the consultation meeting with the oncologist (The CT regimen has been determined))</p>	<p>Provide the information booklet, Face to face session (30-60 min)</p>	<p>Purpose: Guide patients to transition to chemotherapy smoothly.</p> <p>Focus: 1. Based on fully considering the patient's age, education level, disease, treatment plan, personality traits, family context, and possible resources, tailored information and emotional support counseling according to what patients were most concerned about at that time will be provided.</p> <p>2. Helping patients understand the chemotherapy regimen and provide coping strategies for possible side effects and preparatory in anticipation.</p>	Primary assessment		Screening the current needs/distress by Distress Thermometer(DT) and Problem List, and providing general information education.	
			Skilled communication		Using skilled communication to clarify the cause of needs and/or distress, understand the existing coping strategies and their effects.	E.g. encouraging patients to express, listen actively, clarify problems
			Information education	Learning about CT	1.The functions and cycles of CT	The explanation according to the chemotherapy regimen of the patient
					2. The cost, advantages and disadvantages, placement location, and duration of central intravenous infusion tools commonly used in CT	
					3. Introducing the common side effect of CT (Chemotherapy-induced nausea and vomiting, Hair loss, Sleep disorder) and coping strategies	
			Daily life	1.How to prevent upper limb edema and functional rehabilitation	Guidance should be given according to the surgical types and recovery level of surgery	
				2.Diet, nutritional, and recommended diet		
			Personal expectation information	Providing patients with other information that is not involved in the above information according to the needs assessment		
			Emotional support	Listening	Encouraging patients to express their concerns and feelings	Considering the surgical types, emotional problems, and family conditions of the patients assessed in the beginning
				Answering questions and coping	Answering patients' questions and provide positive coping strategies	E.g.Concerns for Body image: Anticipate preparation of wig, headscarf, artificial breast (Radical mastectomy) Concerns for CT: Helping patients understand chemotherapy and instructing them to accept reality, diverting attention.
Personal expectation support	Helping patient to seek support Providing emotional support to patients in other aspects not mentioned above, according to the assessment of the individual needs	E.g. Assist patients to contact their doctors, instruct them on how to communicate with their families, or introduce other patients with a good prognosis.				
Summary		Summarizing and recording the main problems and recommended strategies identified in this consultation	Making an appointment for the next consultation and her desired form (face-to-face or telephone)			

Continued

Intervention dose	Intervention formats	Purpose and Focus	Content of the intervention		Remarks or examples		
Session 2 A week before the second cycle of CT (Including the day of admission to hospital)	Refer to the booklet Face to face or telephone session (30-60min)	Purpose Understanding patients' physical and psychological reactions after the first chemotherapy and their current concerns. Focus Providing information and emotional strategies to deal with current problems to help patients receive and cope with chemotherapy.	Reappraisal Using Distress Thermometer (DT) and Problem List to assess patients' need for repeated education or emerging problems				
			Skilled communication Same with the first time				
			Information education	Cope with CT	1. Identifying the side effects that have occurred, review the side effect coping strategies provided, and enhance patients' understanding of knowledge.	Explanation combine with the regimen of chemotherapy and the occurrence of symptoms.	
					2. Introducing other side effects of CT (Myelosuppression, Fatigue, Diarrhoea) and coping strategies		
				Daily life	1. Related information on exercise and weight management during intermission of chemotherapy		
				Personal expectation information	Providing patients with other information that is not involved in the above information according to the needs assessment		
			Emotional support	Listening	Encouraging patients to express their psychological reactions after the first CT.		Considering the surgical types, emotional problems, and family conditions of the patients assessed in the beginning
				Answer questions and coping	Answering patients' questions and provide positive coping strategies		E.g. Guiding the patient to focus on the positive aspects of CT, weaken the "patient" role. By comparing with peer patients who have a good prognosis or whose condition is more serious than themselves to get comfort and hope
				Personal expectation support	Providing emotional support to patients in other aspects not mentioned above, according to the assessment of the individual needs		
			Summary		Summarize and record the main problems and recommended strategies identified in this consultation		Making an appointment for the next consultation and her desired form (face-to-face or telephone)

Continued

Intervention dose	Intervention formats	Purpose and Focus	Content of the intervention		Remarks or examples	
Session 3 A week before the third cycle of CT (Including the day of admission to hospital)	Refer to the booklet Face to face or telephone session (30-60min)	Purpose 1. Understanding patients' physical and psychological reactions after the first two rounds of chemotherapy (some of which may occur after the second chemotherapy) and their concerns about follow-up treatment. 2. Understanding the effectiveness of the first two individual counseling strategies and the other help patients hope to get. Focus Providing information and emotional strategies to deal with current problems, helping patients adapt to chemotherapy, and finding the positive significance of cancer treatment.	Final appraisal Using Distress Thermometer(DT) and Problem List to assess patients' need for repeated education or emerging problems			
			Skilled communication Same with the first time			
			Information education	Adapt to CT	Introducing other side effects of CT (Oral Mucositis, Constipation, Skin and nail changes) and coping strategies	Explanation in the basis of the occurrence of symptoms.
				Daily life	Focusing on introducing the coping strategies for the occurred side effects to enhance patients' understanding of knowledge.	
				Available resources	Introducing the WeChat groups, breast cancer websites and books where may access information	Explaining to patients who have partners and / or want to know about sexual health
				Personal expectation information	Providing patients with other information that is not involved in the above information according to the needs assessment	
			Emotional support	Listening	Encouraging patients to express their psychological reactions after the first two chemotherapy and their concerns about follow-up treatment.	
				Answer questions and coping	Understanding the effectiveness of the strategy provided by the first two consultations, answer their confusion, and understand the other help they hope to get.	
					Help patients find positive significance of cancer treatment	E.g. By understanding the people and things that patients care about most, to help them establish their belief in survival. Help patients understand the importance of health and explore their positive self-transformation in the process of cancer treatment.
			Personal expectation support	Providing emotional support to patients in other aspects not mentioned above, according to the assessment of the individual needs		
Summary and referral		Summarize and record the main problems and recommended strategies identified in this consultation	Few patients will be referred to other experts (Psychiatrist, etc.) if their DT ≥ 4.			

Table 11 The changes and reasons for revising each component from version 1 to version 2

According to comments of experts and the supervisor, the revised version 2 of the supportive care program was formed based on professional guidelines and books.				
Components	Version 1	Expert's comments	Version 2	The reason of revision
1. Intervention dose	Session one (Before CT start) Session two (2nd cycle of CT) Session three (1 week before 3rd cycle of CT)	1.The information booklet can be provided upon discharge after the operation. 2.The first session could be conducted after the treatment plan was determined two weeks after the operation. 3.The patient's physical condition is unwell on the day of chemotherapy and one week after chemotherapy, telephone intervention before chemotherapy or 7-10 days after chemotherapy is recommended.	After the patient received their chemotherapy plan from their oncologists, they will be invited to participate in this study. The person who agrees to the participant will be asked to finish a baseline survey and be offered the booklet. Simultaneously, the nurse will make an appointment with the patient to provide individualized intervention when the patient is available. The intervention included three sessions of individualized counseling, lasts about 30-60 minutes/session. Besides, patients can contact the nurse by phone or WeChat if they have any questions.	A flexible intervention time was reset to improve patient's compliance in participating in this supportive care program.
2. Eligible intervention nurse	Inclusion criteria: (a) Worked more than 5 years at oncological or breast department; (b) Has bachelor's degree or above; (c) Has good ability in communication; (d) Be willing to take part in this research; (e) Have finished the supportive care train course.	The clinical working experience is essential in implementing the program and considering the limited number of nurses with a bachelor's degree and more than five years of working experience. It is not recommended to set inclusion criteria for nurses. It can be expressed in the context of who will implement this program.	The researcher will train 2-3 nurses (who had more than five years of oncology nursing experience and consent to participate in this research). The training includes the definition of supportive care, screening and assessment process of supportive care needs, communication skills, the components of the nurse-led supportive care program, and how to implement the intervention.	Considered the situation of the Chinese medical system, the nurse's selection criteria were removed but stated as a context of this intervention.
3. Eligible patient	Inclusion criteria: (a) Have a confirmed diagnosis of breast cancer and finished surgery; (b) Age: over 18 years old; (c) Newly diagnosed without metastasis; (d) The first time of receiving chemotherapy; (e) Aware of their cancer diagnosis; (f) Being available to be contacted by telephone. Exclusion criteria: (a) Cognitive impairment or severe mental illness; (b) History of other malignancy cancer.	Considered the selection bias and sample size, it is not recommended to exclude patients with neoadjuvant chemotherapy.	The patient is newly diagnosed with breast cancer and is going the receive chemotherapy for the first time.	Considered the selection bias and sample size, specific selection criteria of patients were removed in program development. However, the selection criteria will be set in the pilot study.
4. Intervention formats	Face-to-face consultation + booklet + Telephone follow-up	1.Combining the booklet, telephone, WeChat, and face-to-face in implementing the intervention was recommended. Therefore, the patients may benefit from this program both hospitalization and discharge. 2.The peer patients group intervention was suggested.	Face-to-face consultation+booklet +Telephone or WeChat follow-up	The core of this study is nurse-led. Peer patients' support will not be involved in this study. However, the peer patients' resources will be shared with patients.
5. Intervention contents	Attachment	1. It is necessary to streamline the side effects and daily life care directly related to chemotherapy. 2. The intervention content is too much, which can be dispersed after the operation, during chemotherapy, and discharge. 3. Patients concerned more about diet "Fawu" the book of traditional Chinese Medicine was recommended. 4. Only solving three concerns of patients, which are not reasonable in clinical practice and ethical principle. 5. The characteristics of the patient's disease should be considered in individualization intervention.	Table 9 and 10	1.To make this program specific to chemotherapy, some common side effects were added after referencing related guidelines and books. Furthermore, the information not related to chemotherapy was noted in the booklet. 2.To facilitate the nurse implementing this program in practice, the intervention content and procedure were merged, and a flowchart was developed with specific objections and focus of this intervention in different sessions. The information about "Fawu" was listed in the booklet.
6. Intervention procedure	Attachment	No specific comments	Table 9 and 10	The intervention content and procedure were merged to facilitate the implementation of this program in practice by nurses.
7.Information booklet	Information booklet for patients	It is suggested that the coping information on diarrhea, psychology, emotion, and social function should be added to the information booklet.	Version 2 of information booklet for patients	After referencing related guidelines and books, the booklet was revised according to the expert's advice.
8. Nursing record sheet	Attachment	Some terms were not accurate.	Version 2 of nursing record sheet	After revising the content of this program, the nursing record sheet was revised accordingly.
9.Evaluation instrument for patient	SCNS-34, EORTC QLQ-INFO25, FACT-B36	No comments	SCNS-34, EORTC QLQ-INFO25, FACT-B36	Not revised

6 Discussion

The number of years of field experience confirms the panelists' expertise, and the sample might be considered heterogeneous, as nurses and a physician are working in clinical settings, and nursing professors are working in the school of nursing. Because nurses and a physician who works in the oncology area were included, they provided a perspective of "inside," and the academics provided a more "external" view.

This study aimed to evaluate the content validity of a nurse-led patient-centered intervention designed to improve the outcomes of Chinese breast cancer patients undergoing chemotherapy. Previous studies showed that face-to-face and written information were the most preferred format reported by the patient^[68,69], and nurse-led supportive care significantly improved cancer patient's emotional functioning, fatigue, and information needs^[161,162]. Our program was developed based on these results. Expert reviewers supported the supportive care program's content validity and agreed that each component had appropriate problem relevance. Furthermore, the two rounds of consultation questionnaires and one focus group provided essential comments and specific recommendations on revising the format and the supportive care program's content.

7 Limitation

The number of experts was small, as this evaluation was an initial assessment prior to the pilot study initiation. The nurses and patients interview to further assess feasibility and acceptability with the nurse-led supportive care program for Chinese breast cancer patients undergoing chemotherapy are included in the ongoing pilot study and would be used to shape future applications of the intervention.

8 Conclusion

The supportive care program is a nurse-led patient-centered intervention designed to improve the outcomes of Chinese breast cancer patients undergoing chemotherapy. This study demonstrates evidence supporting the supportive care program content validity, a critical first step before testing the feasibility and acceptability of an intervention in a pilot study. This research's overall significance is to increase understanding and further development of interventions to foster patient-centered supportive care.

9 Conflict of interest

There are no conflict of interest needs to be declared in this study.

Chapter 5 Study III - A pilot study to test the feasibility and acceptability of the nurse-led supportive care program for Chinese breast cancer patient undergoing chemotherapy

1 Purpose

To describe the use of nurse-led supportive care programs in the real-world context, assess the feasibility of the subject recruitment, measurement tools, and adherence to the intervention, and explore the acceptability and usefulness of this program in China.

2 Method

A pilot study with mixed methods and pretest-posttest design was conducted.

2.1 Participant

Pilot data are often a prerequisite for determining adequate sample sizes for the intervention. Generally, 10 to 20 participants are needed to obtain estimates of variance in the primary outcome measures needed to determine intervention effect size^[137]. Therefore, I plan to recruitment 10 patients.

Purposive sampling was used to select participants:

Patient inclusion criteria: (1) were newly diagnosed with stages I to III breast cancer and after surgery, (2) were over 18 years old, (3) were going to receive chemotherapy for the first time, (4) were aware of their cancer diagnosis. (5) Being available to be contacted by telephone in Chinese. Exclusion criteria: (1) Had a history of other malignancies, and (2) be diagnosed with a cognitive or psychological disorder.

Oncology ward nurse inclusion criteria: (1) had more than five years of oncology nursing experience, (2) had a bachelor's degree, (3) consent to participate in this research, and (4) having time to participate in the training course by the researcher.

Before the patients' recruitment, two nurses who consented to participate in this study were trained by the researcher once. The training course last 30min, and it includes the definition of supportive care, screening and assessment process of supportive care needs, communication skills, the components of the nurse-led supportive care program, and how to implement the intervention. During the intervention, the researcher (me) followed the nurse up with the whole process in patient's recruitment, questionnaire assessment, and intervention implementation. Before each session, the researcher (me) helped the nurse recall the patient's situation and what the nurse had done last time. Furthermore, to keep the intervention smoothly conducted, the researcher answered the nurse's questions about the intervention after each session.

2.2 The nurse-led supportive care program setting

The primary object of this program is to reduce the supportive care needs of patients with newly diagnosed breast cancer in the early stage of chemotherapy. And the secondary object is to reduce

patients' psychological distress, improve their information satisfaction and quality of life. There are three sessions, and all sessions are led by an oncology/breast ward nurse. The nurse follows four steps to conduct the intervention in each session. However, the purpose and focus for each session is different. Patients are encouraged to bring a significant other to participate. [Details are listed in Appendix 9, to help the nurse better understand the intervention process, we set an example of this program's flowchart (Appendix 10).]

First, the nurse uses Distress Thermometer and Problem List to assess the patient's current distress and needs.

Second, the nurse further clarifies the problem and uses a positive approach to guide the patients to express their supportive care issues, use the Distress Thermometer and Problem List as a prompt, and encourage patients to talk more about their main concerns.

Third, the nurse provides the information and emotional support tailored to the patient's concerns and needs. (The information and coping strategies were provided as a booklet also)

Finally, the nurse ends the session by summarizing the main issue. After all the three sessions finished, for a few patients who have complex needs, the nurse identifies whether another health professional or service is needed, if it is, then referral to other specialist services.

2.3 Outcome measures

2.3.1 Primary outcomes

The primary outcomes include the acceptability of the proposed intervention, the feasibility of recruitment and measurement, and the adherence to the intervention.

Feasibility		
Recruitment process	Feasibility of measurement tools	Feasibility of intervention procedure
<ul style="list-style-type: none"> ■ Number of people interested in this program from eligible people. 	<ul style="list-style-type: none"> ■ Time taken to fill in questionnaires. 	<ul style="list-style-type: none"> ■ Intervention adherence.
<ul style="list-style-type: none"> ■ Number of people attending interview with researcher. 	<ul style="list-style-type: none"> ■ Missing data from questionnaires. 	<ul style="list-style-type: none"> ■ Number of sessions attended.
Acceptability: Experience of the interventionist(s) and patients (qualitative interview by the researcher)		
<ul style="list-style-type: none"> ■ Patients' and interventionists' views after the intervention implementation. 		
<ul style="list-style-type: none"> ■ Interventionists' report of challenges and issues in, as well as the ease of, the delivery of the intervention. 		
<ul style="list-style-type: none"> ■ Patients' and interventionists' perspectives on the intervention elements that are useful in achieving the outcomes, suitable for application in day-to-day life, and/or need refinement. 		
<ul style="list-style-type: none"> ■ Patients' and interventionists' reports on how the intervention affects the outcomes and on experience of unanticipated effects. 		

The interview outline for the patient:	The interview outline for the ward nurse:
<ol style="list-style-type: none"> 1. How do you think the intervention dose and duration for each session of this program? (Is it easy (or) difficult to understand? Which parts?) 2. Which part of the intervention is useful in addressing your needs? 3. How do you think about the information booklet? 4. What benefits you have gained from this program? 5. Which part of the intervention need to be refined? 	<ol style="list-style-type: none"> 1. How do you think the intervention dose and duration for each session of this program? (Is it easy (or) difficult to understand? Which parts?) 2. What are the challenges and issues in, as well as the ease of, the delivery of the intervention? 3. What benefits have you gained, or how could the patient be benefited from this program in your opinion? 4. How do you think about the information booklet? 5. Which part of the intervention need to be refined?

2.3.2 Secondary outcomes (The secondary outcomes were used to evaluate the usefulness of the intervention before and after the program delivery.)

(1) Supportive care needs-short form (SCNS-34)

SCNS-34 measures patients' perceived need strength on 34 needs classified into five domains^[172]: Physical and daily living (5 items), Psychological (10 items), Patient care and support (5 items), Health system and information (11 items), and Sexuality (3 items) needs. Patients rated each of these 34 needs for the previous month using a 5-point Likert scale ("need strength"): 1—No need: not applicable; 2—No need: satisfied; 3—Low need; 4—Moderate need; and 5—High need. The Chinese version maintained a good internal consistency, with Cronbach' s alpha > 0.70 for the whole scale. Therefore, the questionnaire is suitable for Chinese cancer patients. And the Chinese version maintained a good internal consistency^[184].

(2) Functional assessment of cancer therapy—breast (FACT-B Version 4.0)

The FACT-B version 4 was used to assess health-related QOL. The FACT-B is a 36-item questionnaire consists of 5 subscales: physical well-being, emotional well-being, functional well-beings, social/family wellbeing, and breast cancer subscale. The participants were asked to rate how true each statement is for the last seven days, and each item is rated on a 5-point Likert scale^[185]. Wan translated it into Chinese, and the Cronbach' s alpha for the FACT-B total score was 0.61 ~ 0.84 among 5 subscales^[186].

(3) The European organization for research and treatment of cancer quality of life group information questionnaire (EORTC QLQ-INFO 25)

The EORTC INFO (25 items) is to assess the perception of cancer patients regarding the information received at different areas and phases of the disease and care, and it has four multi-item scales—information about the disease (INFODIS, 4 items), medical tests (INFOMEDT, 3 items), treatment (INFOTREAT, 6 items) and other services (INFOTHSE, 4 items)—and eight single items (INFODIFP, INFOHELP, INFOWRIN, INFOCD, SATINFO, RECMORE, RECLESS, OVERHELP).

The response format is a 4-point Likert scale (1—not at all, 2—a little, 3—quite a bit, 4—very much), except four items with a dichotomous response (yes/no). All scores are linearly transformed to a scale of 0 to 100, a higher score indicates better-perceived information. The Internal consistency for all scales was good (Cronbach's alpha > 0.70)^[187,188]. The global score was calculation method according to Singer et al.'s study^[189].

2.4 Data analysis

2.4.1 Quantitative data analysis

Frequencies and descriptive analysis were undertaken on the data by SPSS 24.0, to provide percentages of questionnaires or the sample's characteristics. Nonparametric statistics were used because of the small sample size. The Wilcoxon signed-rank test was adopted to compare the SCNS, QOL, and QLQ-INFO pre and post-intervention.

2.4.2 Qualitative data analysis

A verbatim transcription of the recorded interviews was conducted by the researcher within 48 hours after each interview. The inductive qualitative data analysis was used to identify patients' and nurses' feedback of participating this intervention. Firstly, the researcher read and re-read the interview transcription to gain a general understanding of what the participants was talking about. During the analysis process, these four steps we followed^[138]: 1) paraphrasing all relevant parts of the material; 2) “streamlining” each paraphrase by deleting anything that distracts from the main statement; 3) comparing paraphrases and creating a more general paraphrase based on similarity; and 4) creating a category name.

3 Ethical considerations

This study was approved by the Ethics Committee in institutions of Chiba University (No. R2-28) and the first affiliated hospital of Dalian Medical University (No. PJ-KS-KY-2020-123). The purpose, possible risks, anonymity, and confidentiality were explained to the participants. They were also aware of their right to withdraw from the study at any time.

3.1 Guarantee the voluntary nature of the formalities for obtaining research approval and consent

3.1.1 Formalities for obtaining permission from research cooperation facilities

After this study was approved by the Ethics Committee in Chiba university institutions, the snowball sampling method was used to find the potential hospital to recruit the participants. An invitation cover letter and Summary of the research proposal were sent to the hospital nursing manager. This study started after the approval of the Research Ethics Committee of the hospital was acquired.

3.1.2 Formalities for obtaining consent from research subjects

After the eligible participants were selected, the researcher invited them by sending an invitation

cover letter and Summary of the research proposal, and consent form, to briefly introduce the aim, significance, method, and how they may cooperate with this study, privacy, and confidentiality, benefit, and possible risks of participating in the study, and the situation of withdrawal in written and verbal explanation.

3.2 Guarantee of safety and reducing burdens when implementing the study

3.2.1 Countermeasures for disadvantages and risks associated with participation in the study

(1) Possible risks of participating in the study

The only foreseeable risks involved in the study are time burden. (About half to one hour in participating in the program training (nurse), about half to one hour of participating each session of the intervention (totally three sessions), and about half to one hour's interview after the intervention. Also, this program might refer to some sensitive problem (e.g., Sexual problem) or recall the hard diagnosis and treatment experience of breast cancer, and patients have the right to decline to discuss any issues that they feel uncomfortable or refuse to continue. During this process, the nurse will control the situation and minimize the discomfort to ensure the patients' safety.

(2) How to ensure safety and reduce the burden of the nurse and patient

a. To reduce the participant's mental burden, I suggested the nurse conduct the intervention in a relatively quiet, comfortable, and safe room. Then the nurse will have enough time and space to implement the intervention.

b. To protect patients, the nurse will check the patient's physical and mental condition again to ensure the patient's safety to participate in the intervention at any time.

c. The information and data are used only for this study, and I will keep it on my personal computer with a password to protect it safely.

3.2.2 Guarantee of the applicant's ability to execute research and of the status of the research preparations

I obtained the qualification certificate of a nurse in China. Furthermore, I had nearly two years of internship experience in a teaching hospital and two years of research data collection experience in the breast surgery department. This study would be conducted under the guidance of a doctoral supervisor.

3.3 Countermeasures for adverse events that may occur during the study

If the adverse events (AE) occurred, the researcher would report all Serious Adverse Events to the nurse or head nurse or superior leaders immediately. In the event of a death, the researcher will supply the IRB with any additional requested information. Otherwise, the researcher will followed-up the AEs until they have resolved or stabilized or until 30 days after the participant's involvement in the study has ended, whichever occurs sooner. Otherwise, to prevent me from getting hurt or any incidents during the research or intervention, I have bought medical insurance in China.

3.4 Protection of privacy, anonymity, and personal information during data collection and publication

3.4.1 Consideration of introducing the research and ask consent of the subjects (the nurse/patient)

The researcher explained to the participants that all the data collected from them would only be used in this study and promised that the privacy, confidentiality, and security of the information collected would be protected during the study period. There is no impact on the participant's treatment or care, even if she does not participate in or withdraw in the middle of this study. The researcher would seek the participants' consent based on fully protecting their rights and interests.

3.4.2 Considerations for data collection and analysis

Before the study, the researcher explains to the participants that she promises to keep all data safe. Voice Recorder would be used under the participant's permission. To protect the privacy of the participants, the researcher would use English letters to denote their names. Furthermore, in data analysis, if the participant hopes to withdraw from the research, their data would not be taken as the analysis object. All information from the interview would not be shared with others except the researcher's supervisor and the research team.

3.4.3 Considerations for data management

All electronic data was stored on my personal computer, and the password will be set. All non-electronic data will be stored in my locked research room. Data will not be brought to places other than schools, homes, or areas where the data are collected. To be kept for a maximum of ten years following the first publication resulting from the study, all electronic data will be deleted, and all non-electronic data will be shredded.

3.4.4 Publication of research results and methods to remove subjects and relevant considerations

- (1) I will explain to the nurse/patient that the research results may be published in conferences or academic journals.
- (2) To protect the nurse/patient's privacy, I will use English letters to denote their names when the paper is published.
- (3) If the nurse/patient wants to know the results, I will conveniently share the results with them.

4 Result

4.1 Participants' characteristics

The mean age for the patient group was 46.13 years (SD=11.09). All of them married, and four of them received middle school education, and five were cared for by their spouse. There were two nurses consent to participate in this study, both of them have bachelor degree, they had 5 and 8 years of oncology/breast nursing experience, respectively. Table 12-1 and 12-2 summarizes participants'

social-demographic and clinical factors at baseline.

Table 12-1 Nurses' characteristics (n=2)

No.	Age	Education level	Nursing experience	Oncology/breast nursing experience
N1	20s	Bachelor's degree	5 years	5 years
N2	40s	Bachelor's degree	31 years	8 years

Table 12-2 Participants' characteristics (n=8)

Variable	n (%)	Variable	n (%)
Age (years)		TNM stages	
<40	3(37.5)	I	4(50)
40-60	5(62.5)	II	2(25)
Occupation		III	2(25)
Employed	4(50)	Surgical type	
Unemployed	2(25)	Modified radical mastectomy+SLNB	4(50)
Retired	1(12.5)	Breast-conserving surgery+SLNB	2(25)
Farmer	1(12.5)	Breast reconstruction+SLNB	2(25)
Education level		Chemotherapy regimen	
Master's degree	2(25)	TC (Four cycles)	1(12.5)
Bachelor's degree	1(12.5)	EC (Four cycles)	1(12.5)
High school	1(12.5)	AC-T (Eight cycles)	3(37.5)
Middle school	4(50)	EC-T (Eight cycles)	1(12.5)
Household income (Monthly)		TAC (Six cycles)	1(12.5)
<1000 RMB	1(12.5)	TCbH (Six cycles)	1(12.5)
3001—5000 RMB	4(50)	Caregiver	
>5000 RMB	3(37.5)	Spouse	5(62.5)
Marital status		Child	1(12.5)
Married	8(100)	Friend	1(12.5)

Note.TNM: Tumor, node, metastasis; SLNB: Sentinel lymph node biopsy.

AC-T: Doxorubicin and Cyclophosphamide, four cycles, then Docetaxe, four cycles; EC: Epirubicin and cyclophosphamide, four cycles;

TC: Docetaxel and cyclophosphamide, four cycles; EC-T: Epirubicin and cyclophosphamide, four cycles; then Docetaxe, four cycles;

TCbH: Docetaxe, carboplatin, and herceptin, six cycles; TAC: Docetaxe, doxorubicin and cyclophosphamide, six cycles.

4.2 Feasibility

From November 2020 to March 2021, twelve patients met the inclusion criteria, and nine patients consented to participate in the intervention, three patients refused participation due to lack of interest and poor physical condition (Figure 5). The participation rate in the intervention was 75% (9/12). Among the nine patients, eight finished all the intervention sessions, one patient dropped out because she gave up the treatment at the 2nd round of chemotherapy, and the rate of adherence to the intervention program was 89% (8/9). The average times taken for the questionnaires collection were 11.25 min, 36.5 min, 23.38 min, and 22.38 min for the intervention implementation session 1, 2, 3,

respectively.

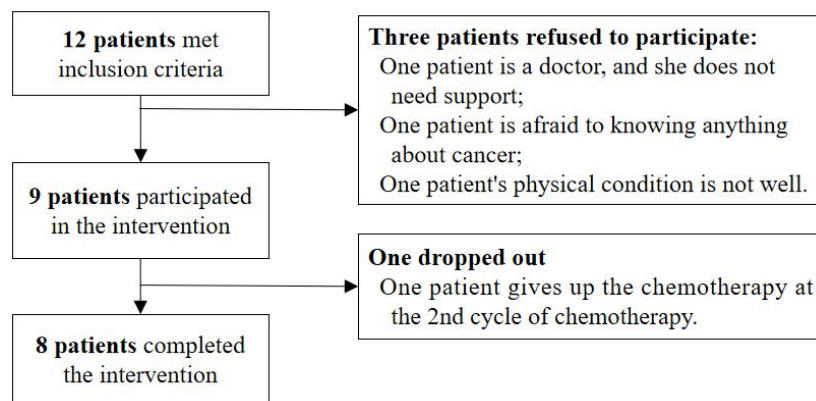


Figure 5 Flow chart of the intervention sample

4.3 Acceptability (Qualitative results)

Finally, six patients and two nurses accepted the interview, two patients refused because of poor physical condition. The average interview time with patients and nurses were 15.92 min and 14.33 min, respectively. According to the interviews, all six patients thought they could accept the intervention dose and duration for each session of this program, and the nurse's words were easy to understand. In addition, two nurses reported that around 20 min of intervention could be accepted when their clinical work was not much heavy. Moreover, three themes emerged from the interview: (1) Benefits of participating in this supportive care program (Patients' and nurses' view); (2) Challenges of this supportive care program (nurses' view), and (3) suggestions for further intervention revision (patients' view). Themes and example quote from the interviews were listed in Table 13.

Table 13 Themes and example quotes from the interviews with patients and nurses

1. Benefits of participating in this supportive care program (Patients' and nurses' view)	
(1) From knowing nothing to knowing a lot, and prepare in advance	
Patient's quotes	Nurse's quotes
<i>P3: "I think I benefit a lot from this program, from knowing nothing to knowing a lot about chemotherapy. Now I know how to face and handle the problems after chemotherapy starts. It is good for me."</i>	<i>N2: "I used to help the patient to solve their problem after it emerged in routine care, the patients have no time to prepare psychologically... After I explained to her in advance, patients could foreknow and prejudge their situations... and they can handle some issues by themselves in advance."</i>
<i>P5: "I think the first session is the most useful one...because I don't know anything and feel scared...After the nursing consultation, I know what kinds of side effects I may experience after chemotherapy, and prepare myself in advance... I am not scared anymore".</i>	
<i>P7: "The nurse's consultation gave me a plan when I had a problem, and she also provided me several methods to deal with it..... I can choose the one that made me feel comfortable and appropriate, that's very nice."</i>	

Table 13 Themes and example quotes from the interviews with patients and nurses (Continued)

(2) Changing life behavior to prompt rehabilitation (Patient's quotes)

P1: "The nurse told me the side effects and the nutrition information, I look for patterns and adjust my eating time when I have a gastrointestinal reaction, which makes me feel less uncomfortable."

P6: "I feel nausea and vomiting after the first cycle of chemotherapy, I remember that nurse suggested to eat a piece of ginger...I don't use to eat ginger, but the nausea is exactly relieved after I eat it...I believe that the information providing in advance helps me a lot".

P7: "Some of my behavior changed because of this program. Eating habits, living habits... I gained knowledge, and then I re-planned my future life."

(3) Becoming optimistic and the fear decreased

Patient's quotes

P5: "The nurse gave me much help psychologically. When I know I needed chemotherapy, I feel...despairing...but now I have changed a little bit...at least my attitude is optimistic."

P1: "I think this program is helpful to me in many aspects, significantly improved my psychological state and mood... After the consultation, I feel much more cheerful and not concern a lot... I think this program is very good and effective."

Nurse's quotes

N1: "Before the chemotherapy, the patients were confused, anxious, and fear. After I explained these things (about chemotherapy) to her, she looks calm down.... She feel fear because she has no idea about the future. After the consultation, unknown turned to known, she would not be scared as the beginning."

(4) Expressing the feelings safely (Patient's quotes)

P1: "I have two sisters...even they know my disease, they cannot help a lot...In contrast, they may worry about me... I need to speak out my feelings, but there are a few people I can talk...the nurse has done well in the communication...I willing to talk to her."

P7: "I think the listener is crucial.... nurse acts as a listener...First, I feel safe.....Second, she can provide me some professional suggestions... I would like to express myself to her."

(5) Information booklet helps a lot

Patient's quotes

P3: "The information booklet is very useful because I have many problems that I don't know how to deal with. I can find the solution in the booklet.... It's convenient and easy to understand... Nurse's words are easy to forget, the booklet can help me review, and I can take notes on it."

Nurse's quotes

N1: "When the patient was interested in some issues, she can look up the booklet first...If she still has questions, then come to ask us.... she learned the knowledge, and it might shorten the nursing hours."
N2: "Patients could read the booklet if there were some issues that the nurse not mentioned."

(6) Self-learning (Nurse's quotes)

N2: "When I educate the patients, it is also a process of self-learning. I can teach the patients though my own study.....I learn a lot professional knowledge and some relevant knowledge (from this program)... "

(7) Understand patients more (Nurse's quotes)

N1: "Generally... I have less time for each patient. This time I spend specific time to know one patient, to understand this patient's situation, how she thinks, what she is concerned about a lot... some issues I did not notice even I worked for many years... For example, Patient 7 pays more attention to her self-image, she is worried about the eyebrows and hair will lose or not, her skin will not grow spots... Different people focus on different problems, and we should know more about the patients' thinking in routine care in the future..."

N2: "In routine care, like communication, I provide less guidance to the patients. Through the assessment, I can understand more about the patient's psychological status and her family issues..."

Table 13 Themes and example quotes from the interviews with patients and nurses (Continued)

2. Challenges of this supportive care program (Nurse's view)

(1) Too busy to spend much time with one patient in the practice

N2: "when we were busy, it is difficult to sit down as a consultant and discuss patient's specific needs in detail...However, this program is essential for patients and nurses...It is better to arrange a nurse specialist to do this job."

(2) Have difficulties responding to patient's complex needs

N1: "The most awkward thing is when P7 mentioned about her family concerns like she could not coordinate the relationship with her husband or child...I cannot do anything but only comfort her...Also, if the patients ask me some questions about medical, e.g., how about my prognosis? I comfort her because I do not know what it will be ..."

3. Suggestions for further intervention revision (Patient's view)

P7: "I think the information booklet is helpful. Nevertheless, I hope you can add more real cases in this booklet, e.g., from previous patients' experience, there are some good strategies for recovery, you can separate as suggestion 1 or 2, like this.... Another suggestion, when I have needs, it is well if the nurse can solve them. If the nurse could not solve it (problems related to treatment), asking a doctor to join us will be better. Alternatively, the nurse reports my question to the doctor, and the doctor helps me to solve it."

4.3.1 Benefits of participating in this supportive care program**(1) From knowing nothing to knowing a lot, and prepare in advance**

For newly diagnosed patients, this is their first-time receiving chemotherapy. Therefore, most of them know nothing about chemotherapy, which made them feel scared and anxious. The detailed information support of this supportive care program raised their understanding of chemotherapy, let them know what may happen after chemotherapy, and how to handle these problems in advance, patients were not scared like before (P1, P3, P5, P6, P7, P8).

From the nurse's view, she used to help the patient solve the problem when it emerged in routine care, and the patients have no time to prepare psychologically. After this program was conducted, patients could foreknow and prejudge their situations and handle some issues by themselves in advance (N2).

(2) Changing life behavior to prompt rehabilitation

Five patients reported that they changed their life behavior (especially on surgical side arm exercise and nutrition) after they received the information support to prompt rehabilitation. They also stated that some changes relieved their physical discomfort symptoms (P1, P5, P6, P7, P8).

(3) Becoming optimistic and fear decreased

Three patients thought that one of the most significant benefits of this program was emotional support, and it changed their psychological status. It helped them becoming positive and reduced their concerns about chemotherapy. They can face their friends and future life with confidence (P1, P5, P7).

One nurse found that patients were feared because they have no idea about the future. After the consultation, the unknown turned to known, and some patients would not be scared like before (N1).

(4) Expressing the feelings safely

After being diagnosed with breast cancer, patients were unwilling to talk about their feelings to the close person because they worried it would make others concerned. Also, someone did not want to talk about the disease with their colleagues to protect themselves from gossiping. This program offered them more space to express themselves to the nurse, making them feel safe and released (P1, P5, P7).

(5) Information booklet helps a lot

Five patients thought that the content of the information booklet was comprehensive and straightforward. When they were not feeling well, they would look through the booklet to find the solutions. The contents of the nurse's explanation are easy to forget, the booklet can help them memorize, and they can also take notes on the booklet (P1, P3, P6, P7, P8).

Two nurses perceived the importance of the information booklet. They thought the booklet helped the patients to learn more, and patients could read the booklet if there were some issues that the nurse not mentioned. Moreover, the booklet might shorten the nursing hours (N1, N2).

(6) Self-learning

One nurse reported that she benefited a lot from this supportive care program. Before conducting the consultation, she learned professional information, nutritional knowledge, and the needs assessment process. She treated the intervention procedure as a self-learning process (N1).

(7) Understand patients more

Moreover, this program offers nurses a specific time to understand patients' individual needs, psychological and family issues, which they might neglect due to the heavy clinical nursing workload. The nurses recognized the importance of understanding the patient's situation in routine work (N1, N2).

4.3.2 Challenges of this supportive care program (Nurse' view)

(1) Too busy to spend much time with one patient in the practice

Even though two nurses identify the particular significance of this supportive care program, they stated that it is challenging to sit down as a consultant and discuss patient's specific needs in detail because the routine workload was heavy. They suggested arranging a nurse specialist to provide this service or trained one to two nurses to conduct the intervention when their workload was not much heavy (N1, N2).

(2) Have difficulties responding to patient's complex needs

In addition, one nurse mentioned two points of the most challenging part of this program. First, when the patient shared some concerns about family issues which she could not coordinate, anything the nurse can do but comfort her. Moreover, she could not answer the questions related to treatment prognosis because she also does not what it will be (N1).

4.3.3 Suggestions for further intervention revision (patient's view)

One patient suggested adding more real cases in the information booklet; sharing some good strategies that other patients used in that cases would be helpful. Otherwise, she found some questions related to treatment that the nurse could not answer, and she hoped there would be a doctor join in this program (P7).

4.4 Usefulness of supportive care needs, psychological distress, QOL, and Patients' perception of information

The mean DT score and total SCNS-SF34 score showed a significant decrease post-intervention from pre-intervention, respectively (pre 3.63 ± 2.88 vs. post 1 ± 1.41 , $Z=-2.21$, $P= 0.027$; pre 2.49 ± 0.73 vs. post 2.08 ± 0.59 , $Z=-2.52$, $P= 0.012$). For the SCNS-SF34 subscales, Health system and information needs were significantly improved after the intervention (pre 3.65 ± 0.89 vs. post 2.41 ± 0.98 , $Z= -2.52$, $P = 0.012$), whereas other needs decreased but showed no statistically significant change. Moreover, there were no statistically significant changes FACT-B scores after the intervention. However, there were statistically significant increases in the QLQ-INFO25 Global score (pre 39.67 ± 10.36 vs. post 66.00 ± 15.51 , $Z=-2.52$, $P=0.012$), and the subscales of treatment, other services, and INFOHELP showed statistically significant improvement.

The changes in SCNS-SF34, FACT-B, and QLQ-INFO25 for those patients who completed the intervention are shown in Table 14.

Table 14 Pre and post-scores for all study outcomes (n=8)

Outcome	Pre-intervention	Post-intervention	Z	1P
	Mean \pm SD	Mean \pm SD		
DT Score	3.63 ± 2.88	1.00 ± 1.41	-2.21	0.027
SCNS (1-5 range)	2.49 ± 0.73	2.08 ± 0.59	-2.52	0.012
Physical and daily living	1.90 ± 0.70	1.88 ± 0.49	-0.21	0.833
Psychological	2.35 ± 1.25	2.08 ± 0.68	-0.85	0.395
Patient care and support	2.20 ± 0.51	1.88 ± 0.32	-1.38	0.167
Health system and information	3.65 ± 0.89	2.41 ± 0.98	-2.52	0.012
Sexuality	1.92 ± 1.12	1.50 ± 0.76	-1.86	0.063
FACT-B (0-4 range)	2.75 ± 0.62	2.68 ± 0.36	-0.17	0.866
Physical Well-Being	3.34 ± 0.71	3.14 ± 0.64	-0.68	0.497
Social/Family Well-Being	3.14 ± 0.45	2.66 ± 0.50	-1.61	0.108
Emotional Well-Being	2.54 ± 1.16	2.75 ± 0.56	-0.33	0.735
Functional Well-Being	2.29 ± 0.95	2.09 ± 0.72	-0.85	0.397
Additional concerns	2.47 ± 0.71	2.75 ± 0.34	-1.27	0.205

Table 14 Pre and post-scores for all study outcomes (n=8) (Continued)

Outcome	Pre-intervention	Post-intervention	Z	¹ P
	Mean ± SD	Mean ± SD		
QLQ-INFO25 Global score	39.19 ± 13.79	64.63 ± 19.43	-2.52	0.012
Disease	54.17 ± 27.82	71.88 ± 23.12	-1.56	0.12
Medical tests	68.06 ± 28.13	83.33 ± 23.76	-1.16	0.246
Treatment	25.69 ± 19.46	65.97 ± 17.17	-2.52	0.012
Other services	3.13 ± 8.84	37.50 ± 27.09	-2.37	0.018
INFODIFP	41.67 ± 15.43	54.17 ± 17.26	-1.73	0.083
INFOHELP	16.67 ± 35.63	50.00 ± 30.86	-2.27	0.023
SATINFO	41.67 ± 23.57	75.00 ± 23.57	-1.84	0.066
OVERHELP	45.83 ± 30.54	83.33 ± 17.82	-1.98	0.047

¹Wilcoxon Signed-rank test; Z = Z score

INFODIFP: Information about different places of care; INFOHELP: Information about things you can do to help yourself; SATINFO: Satisfaction with the information received; OVERHELP: Overall the information has been helpful.

5 Discussion

This nurse-led supportive care program was feasible and acceptable in Chinese patients with newly diagnosed breast cancer undergoing chemotherapy. In this feasibility study, the participation rate was 75% (9/12), and 89% (8/9) patients finished all three sessions of this program. The participation rate was higher than a Japanese intervention for reliving breast cancer women's perceived needs^[167], and the adherence rate was higher than Kotronoulas's study^[190], which conducted supportive care to lung cancer patients. The possible reason for the good participate rate and adherence rate of this nurse-led supportive care program was that Chinese breast cancer patient had high level of supportive care needs^[114], and most patients hope to have one medical staff to talk about their conditions, treatment, and follow up^[46], while this nurse-led program provided patients sufficient time to asking their concerns and solving their needs.

In addition, patients and nurses reported well acceptability of this program and expressed their views and feeling on the significance of this program in the interview. Overall, patients appreciated the information and emotional supports that enriched their knowledge, prepared them for the chemotherapy process in advance, changed their life behavior, and reduced their fear and anxiety, which is consistent with Chow et al. conducted the intervention program for gynecological cancer patients in Hong Kong^[191]. Furthermore, patients found this program offered them space to safely speak out their concerns and feelings without worrying about stressing their closed person or being gossiped. Influenced by Chinese culture, breast cancer women had barriers to expressing emotions, and someone felt a stigma about cancer^[150]. A previous study found that nurses were considered the appropriate person to make cancer patients feel safe and secure^[94]. Therefore, nurse-led information and emotional support are necessary and acceptable for breast cancer patients.

Nurses reported that this program allows them to spend a specific time understanding patients' needs and concerns, which might be neglected in routine care. It helps to strengthen the relationship between nurses and patients^[190]. Even though nurses clearly stated the significance of this program, their daily work is too busy to spend much time consulting with every patient. It is a little bit difficult to implement this program in the clinical context, and they suggested arranging a specific nurse to provide this service. Breast cancer case managers have developed in China in recent years^[192], some researchers found these case managers play a crucial role in breast cancer patients' rehabilitation and health education. However, this position was not common set in most hospitals, and breast cancer case managers usually offer the consultation service for free, because they do not have the prescription right^[193]. It may influence their working enthusiasm. Therefore, a great effort is needed to develop a nursing service system to train more breast cancer case managers and offer them sufficient rights.

Moreover, one nurse reported that was difficult to response to patients' family issues. The possible reason is that the young nurse does not have sufficient family living experience, may have not been able to deal with the full spectrum of patient needs^[190]. Hence, more training course in discussing the coping strategies for complex needs is required. Also, one patient and one nurse mentioned that the nurse could not response to patient's questions related to treatment well. And the patient hoped one doctor can join the program. As Dr. Fitch stated^[48] in the supportive care framework, 'to provide comprehensive supportive care, much expertise is needed.' One Australian study^[194] found that most breast cancer survivors were satisfied with the care provided by the cancer support team (e.g., breast surgeon, medical oncologist, breast care nurse, family). Therefore, when revising supportive care service programs in the future, strengthening multidisciplinary cooperation, and inviting experts from multiple fields should be considered essential aspects of service improvement.

Our findings supported the preliminary usefulness of the nurse-led supportive care program, in which nurses provide information and emotional support and coping strategies to meet patient's comprehensive needs. This intervention program decreased patient's psychological distress and improved their total supportive care needs and perception of the information they received significantly. This result is consistent with previous nurse navigator supportive care interventions^[167,170]. However, changes in sub-scales of SCNS did not show a statistical significance except for health and system information needs, it may be due to the small sample size, but we found patients' needs decreased in these sub-scales. Future studies should increase the number of samples to test the effectiveness of this nurse-led supportive care program.

Besides, we did not find significant changes in quality of life, and it is similar to other studies' results^[103,162,168]. Some researchers questioned whether the questionnaire was sensitive enough to measure differences of QOL^[166,170], and they also provide a possible explanation that patients had a

good global QOL at baseline, which makes it hard to establish a clinical improvement^[166]. In contrast to previous studies^[103,162], we found a decrease in patients' physical wellbeing, social/family wellbeing, and functional wellbeing from baseline to post-intervention. The possible reason is that the patient had good QOL at baseline because she did not experience any side effects of chemotherapy. With the side effects and some symptoms emerged, and patients' physical wellbeing and functional wellbeing decreased, these symptoms and side effects undoubtedly affect their family and social relationships even though we provided some strategies to alleviate their symptoms. Nevertheless, patients' emotional wellbeing and additional concerns improved. We are not sure this change happened because of our supportive program or the influence of time. In future studies, a control group should be set to clarify the reason for the improvement change.

6 Conclusion

Our result suggested that it is a feasible and acceptable intervention program which include information and emotional support led by nurses. Our program may be effectively in meeting newly diagnosed breast cancer patient's needs, improving their perceptions of information. The effectiveness of this nurse-led supportive care program should be confirmed in a future well-designed randomized control trial with bigger samples.

7 Conflict of interest

No conflict of interest needs to be declared in this study.

Chapter 6 General discussion and conclusion

1 Characteristic of this nurse-led supportive care program

Supportive care is an essential service for helping cancer patients manage treatment-related symptoms and cope with psychological problems^[97,162]. Many researchers highlighted that supportive care interventions are effective in cancer patients^[161,162]. However, the effect of nurse-led supportive care tailored to Chinese patients' needs during chemotherapy has not been shown so far. In China, nurses provide supportive care just as routine care for chronic disease, not be specifically customized for breast cancer patients^[114]. There is a pressing need to identify the effectiveness of delivering timely and quality supportive care to the growing population of breast cancer survivors^[104]. Our program has contributed to the advancement of existing knowledge on the role of nurse-led supportive care for newly diagnosed breast cancer women during chemotherapy. Key innovative elements of this nurse-led supportive care program are as follows:

First, this program was developed based on comprehensive consideration of Chinese cultural background. It is well known that supportive care has been conducted in many developed countries^[103,162], but due to the different cultural contexts, Chinese breast cancer women had different needs compared to women living in western countries^[39]. Therefore, we have sufficient considerations of the characteristics of Chinese breast cancer women when we design this program: (1) 31.3% of newly diagnosed Chinese women had health and system information needs^[1]. They do not have sufficient information about the disease or its treatment^[195]. In addition, under the influence of traditional Chinese culture, most women coped conservatively when they lack knowledge (e.g., did not perform self-rehabilitation exercises, did not intake any food they thought was *fawu*, or did not actively seek information about sexual activity). Therefore, one of the major intervention contents of this program is information support. The nurse provided professional and necessary information to solve patient's concerns. Some sensitive issues that patients may feel awkward for asking (like sexual life) can be found in the information booklet. (2) Moreover, based on the influence of Chinese Confucianism, family culture has a significant social value^[196]. Therefore, we invited one of the patient's close people to participate in this program to make her feel supported. (3) Compared with European Americans, Chinese tend to suppress emotions to maintain a harmonious social relationship^[197]. Hence, Chinese breast cancer women had barriers to expressing their emotions to their families, because they believed their bad emotional status would burden their families^[150]. Moreover, someone felt a stigma about cancer and refuse to talk with surrounding people. With these issues, nurses as the professional and secure person that patients trust, provided patients safety time and space to express their emotions, and offered many emotional supports to the patients.

Second, this program is dynamic and flexible. On the one hand, we knew that breast cancer patients experienced dynamic changes in supportive care needs with the proceeding of treatment^[2,173]. Even though some researchers provided supportive care many times in their interventions, they did not focus enough on individuals' needs changes^[103,104]. To provide supportive care tailored to individual needs at different time points, we assess patients' needs before each session of the intervention program. Besides, the breast care nurse reported that 1-week between face-to-face and telephone follow-up sessions was too short^[103]. In this program, we set up the interval time between intervention sessions based on the trends of supportive care needs changing from previous longitudinal studies^[2,36]. This intervention design is more scientifically supported. On the other hand, to be effective, supportive care must be based on tailoring specific intervention approaches^[48]. In our program, we provide the intervention flexible. (1) The patients could select the intervention format (face-to-face, telephone) follow their preference. (2) Considering the real clinical context, some patients can clearly express their individual needs, but other patients may not notice what they need. We designed the intervention by combining the fixed and flexible content. Previous studies and literature review clarified what breast cancer patients need, and we set up that part as fixed content. We also provide flexible content through assessing individual needs, to ensure that most patients can benefit from this program.

Third, this program provides support to help patients anticipating what may happen and review what did happen. Usually, patients did not receive information from a nurse until the day they start chemotherapy^[198]. Before the chemotherapy, anticipatory emotional distress and physical symptoms significantly influence the patient's prognosis^[199,200]. Piombo et al. evaluated a nurse-delivered pre-chemotherapy educational intervention to diverse patients, and they found that the intervention improved patients' self-reported knowledge and decreased treatment-related anxiety^[201]. However, this intervention is not tailored to individual needs. In our program, we set up different goals and focus on different sessions, provide information and emotional support before chemotherapy treatment starts, and help patients understand what may happen and how they can cope. Besides, the nurse assists patients reviewed the problems they experienced after the chemotherapy, strengthening the patient's memory of the information and knowledge the nurse offered.

2 Consideration of the cultural adaptation when using 'Tiered model of supportive care'

Cultural adaptation was considered when we select the framework related to supportive care. First, the 'Tiered model of supportive care' adapts the 'supportive care framework' described by Fitch^[48]. As we know, the 'supportive care framework' was guided many studies with a different culture^[81,202,203]. Three Chinese studies^[204-206] used the 'supportive care framework' to formulate the intervention for Chinese cancer patients and cancer caregivers, and they reported that the intervention under the guidance of the 'supportive care framework' would provide more targeted care. Therefore,

the 'supportive care framework' is an appropriate framework for Chinese cultural interventions. From what has been discussed above, we believed that the 'Tiered model of supportive care' developed by adapting the 'supportive care framework' could guide Chinese intervention.

Second, the 'Tiered model of supportive care' was developed by Supportive Cancer Care Victoria, Australia^[90]. It is well known that Australians come from various cultural and ethnic contexts. Over 7.6 million migrants come from about 200 countries living in Australia, and Chinese (650,600) were the third group of overseas-born in 2019-2020^[207,208]. In addition, there were more than 176,000 Chinese born in Victoria. 'Tiered model of supportive care' as an element of supportive care policy and EdCaN learning resource published by Victoria government and the Australian government^[78,90], which has been widely implemented for Australians including Chinese-Australian. We think it can be used for Chinese cancer patients.

Third, when we used the 'Tiered model of supportive care' as the research framework, we adjusted it according to the Chinese culture. In this model, as the complexity of patients' needs increases, the strategy to address needs must change. Hence, we conduct a qualitative interview to understand the complexity of Chinese breast cancer women's needs. We found that Chinese women's physical needs, psychological needs, information needs and emotional needs, social needs were influenced by Chinese culture (conservatively thinking, Chinese Confucianism, family-centered, emotional suppression). Therefore, we designed the intervention content under the consideration of these characteristics. For example, nurses provide professional knowledge to help patients managing physical symptoms and changing their conservative thinking, which may lead to unhealthy behavior. Also, nurses instruct patients on communicating with families when they think the cancer diagnosis burdened their families. In addition, we asked for feedback from nursing and medical experts about the feasibility of conducting the intervention in the Chinese cultural environment. All the Chinese experts agreed that this program would be helpful in the practice.

3 Methodological considerations of designing this nurse-led supportive care program

This dissertation offers crucial methodological contributions. First, our study I-I is the first known qualitative study that described the supportive care needs of Chinese women newly diagnosed with breast cancer prior to adjuvant chemotherapy. Many quantitative studies investigated the supportive care needs of Chinese women with breast cancer^[46,114]. Wang et al.^[114] found that 60% of Chinese breast cancer patients had a moderate to high need following diagnosis. However, quantitative studies are unable to understand more profound the patients' needs and concerns. Klungrit et al.^[142] explored the supportive care needs of Thai women with breast cancer undergoing chemotherapy, and they found patients had the need for physical comfort and health safety, the need for encouragement, the need for solution of financial problems, and the need for communication and useful information. Compared to

Thai women's shyness and not bothering anyone characteristic, Chinese women have conservative thinking. Besides, given China's unique public health insurance system, understanding the supportive care needs of Chinese women with newly diagnosed breast cancer is necessary to inform the improvement of supportive care service. Therefore, our qualitative study I-I offers a good foundation for developing a nurse-led supportive care program.

Second, we followed a systematic and rigorous process and method to develop this program. The main steps for developing intervention protocols^[209] include (1) to establish a conceptual framework for interventions with the regard to the identified research problem; (2) to develop evidence-based intervention protocols along with careful consideration of the intervention target, delivery methods, intervention property, intervention dose. We reviewed previous guidelines and original studies to determine the intervention target, delivery methods, intervention content and dose. Also, we provided straightforward intervention procedures and examples of strategies that nurses may easily understand and conduct. These procedures and strategies can enhance intervention methodological rigor and improve the acceptability in regular consultation.

Third, to examine the content validity of our nurse-led supportive care program, we invited six experts who majored in nursing practice, nursing education, nursing management and clinical medicine, and held an online focus group meeting. Using a focus group facilitates interactions among people, and it can help them express and clarify their views in ways^[210]. We gathered professional comments and revised our program accordingly. This method improved the creditability of our intervention program.

Four, our study III evaluated the feasibility of the intervention by implementing both quantitative and qualitative methods. It provides further evidence of the importance of using the mixed method to achieve a complete understanding of the implementation and use of nurse-led supportive care intervention. Conducting a mixed method, the researcher could collect the two types of data simultaneously during a single data collection phase. In addition, by using the two different methods in this fashion, the researcher can gain perspectives from different data types or different levels within the study^[211]. Numerous researchers supported the advantages of collecting both quantitative and qualitative data. They used the mixed method to evaluate the feasibility or effectiveness of the supportive care intervention^[190,212-214]. We collected quantitative data to analyze the statistical significance of implementing this intervention for patients, and we also analyzed qualitative data through interviews to evaluate the cultural appropriateness and participants' experience of this intervention. Therefore, we gained different perspectives from the mixed method for further modification of this intervention program.

4 Implications for nursing practice

4.1 Nurses should raise their awareness of providing supportive care tailored to breast cancer women's needs

Due to China's large population based and limited healthcare resources, breast cancer patient's specific needs and concerns might not be met in routine care^[114]. However, patients with high supportive care needs reported more physical symptom distress and poor quality of life^[36,47,215]. Nurses should raise their awareness of the importance of supportive care to break this vicious cycle. Also, nurses provide routine care not specific for breast cancer patients^[114]. Breasts are a secondary sexual feature for women, and women who lose breast(s) may experience more complex needs. Therefore, the provision of tailored supportive care is vital for improving patients' physical and psychological wellbeing and nurses' high quality of care. We recommend the nurses raise their awareness of providing supportive care tailored to breast cancer women's needs.

4.2 Nurses should implement the supportive care through a standardized intervention

Supportive care is yet to be well established in mainland China, and there is a large gap between cancer supportive care services and the needs of Chinese patients with cancer^[215]. Our nurse-led supportive care program offered a clear intervention procedure by assessing patient's needs, clarifying needs by skilled communication, providing tailored information and emotional support, and summarizing and referral. When implementing this program in practice, training nurses about supportive care is necessary, and the nurse with at least five years of oncology or breast care experience will be the proper person. Yet, current training was not adequate in enhancing nurse's ability to solving patient's complex needs. We suggest the nurse practitioners developing more standardized training courses. According to Fitch's supportive care framework, with the complexity of patient's needs increases, nurse's strategies to address needs should change^[48]. Considering the limited healthcare resources, effective and efficient allocate nursing resource is important for the nursing system. Nurses should implement supportive care through a standardized intervention to save time and resources.

4.3 Organizations should develop the nurse's role in providing supportive care service and held more standardized training courses

With the increasing survival rate and consciousness of health, breast cancer women focus not only on the survival of cancer, but also the well quality of life. Most breast cancer patients stated that nurses' crucial role in meeting their needs and improving their quality of life^[96,99,101]. However, we found that influenced by the heavy workload and limited supportive care knowledge and skill, nurses did not have sufficient time and ability to provide high-quality supportive care. Some junior nurses may not have been able to deal with patient's complex needs^[190]. Cancer Australia has developed a

two-hours cancer supportive care educational resources to enable cancer health professionals to develop knowledge and skills in supportive care screening, assessment, and referral^[216]. Also, Cancer Australia developed 'The national cancer nursing education project' (EdCaN) to improve nurses' professional ability to provide high-quality supportive care^[88]. More than fifty publications have cited EdCaN and the EdCaN Framework in guiding local professional development^[89]. NCCN Clinical Practice Guidelines in Oncology published many guidelines to instruct professionals conducting the supportive care^[217].

Therefore, to achieve high-quality supportive care, we suggest that organizations like hospitals and communities should notice the nurse's role in providing supportive care service and hold more standardized training courses to enhance nurses' knowledge and skill of supportive care. Besides, nursing managers should allocate nurse resources appropriately, offer nurses more time to support patients

5 General limitations and future research directions

This study has four limitations.

First, this research is designed for Chinese breast cancer patients undergoing chemotherapy, and the conclusion may not be suitable for other countries or at another treatment period.

Second, influenced by the COVID-19, we only included a small number of participants in the pilot study. Moreover, this research was mainly conducted in one large teaching hospital in northeastern China. We tried our best to decrease bias by reviewing many international and Chinese papers related to supportive care needs and carefully considering Chinese culture when designing this nurse-led supportive care program. Nevertheless, that may lead to bias and limit the generalization of the findings. Therefore, large sample multicenter trials are needed to test the effectiveness of the nurse-led supportive care program for most breast cancer patients.

Third, due to the limited time of the doctoral course, we did not investigate the long-term effectiveness of this program. Mertz et al. found that an individual, nurse-led intervention has effectively improved breast cancer patients' satisfaction with treatment and rehabilitation, decreased their distress, anxiety, and depression at one year after the intervention compared to the control group^[168]. Also, our study III found that the nurse-led supportive care intervention changed patients' unhealthy life behavior. However, it is unknown whether the nurse's information and emotional support will still positively affect patients' cognitive statuses, eating habits, life behaviors at 3 months, 6 months, or even 1 year after the intervention. Thus, we suggest the researchers evaluate the long-term effectiveness of nurse-led supportive care programs on patients' cognitive statuses, eating habits, and life behaviors in future studies.

Fourth, considered most breast cancer patients have no religious beliefs, and their life meaning

perception is above average^[218], we did not design the spiritual support as the key component of this program. Nevertheless, in the third session's emotional support of this program, nurses help patients find the positive meaning of treatment, establish belief in survival, and explore positive self-transformation. Future studies should include spiritual support into the comprehensive supportive care to help breast cancer patients to find renewed meaning and aim in their lives.

6 Conclusion

To achieve high-quality, patient-centered care, new programs of service provision are needed, particularly those nurse-led supportive care based on a comprehensive assessment of patient's individual needs. This dissertation shows that nurse-led supportive care has the potential to fill gaps in health care services by addressing the supportive care needs of Chinese women with newly diagnosed breast cancer undergoing chemotherapy. It also serves to underscore the increasingly important role that nurses could play as providers of supportive care. However, influenced by the heavy workload and limited supportive care knowledge and skill, nurses did not have sufficient time and ability to provide high-quality supportive care. Future research should focus on overcoming these barriers to improve the supportive care service.

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Study I

Appendix 1—Interview outline

The same participant will be interviewed twice.

1. For breast cancer patients who are awaiting initial chemotherapy:
 - (1) What are your current experiences and feelings about the upcoming chemotherapy?
 - (2) What kind of problems do you need help now?
 - 1) Please talk more in physical aspects;
 - 2) Please talk more in psychological aspects;
 - 3) Please talk more in sexuality aspects;
 - (3) How do you cope with these needs by yourself?
 - (4) What are your expectations for the upcoming chemotherapy?
 - (5) What kind of information do you want to be provided to help you coping with upcoming chemotherapy?
 - (6) What kind of information format do you prefer? Why is that?
 - (7) What are your suggestions or comments on current nursing services?
 - (8) How do you think nurses can best assist you to cope with chemotherapy?
2. For breast cancer patients at the beginning of 2nd cycle of chemotherapy
 - (1) What are your current experiences and feelings about chemotherapy?
 - (2) What kind of change do chemotherapy have on your health and life?
 - 1) Please talk more in physical aspects;
 - 2) Please talk more in psychological aspects;
 - 3) Please talk more in sexuality aspects;
 - (3) What are the advantages and disadvantages of chemotherapy?
 - (4) What kind of information do you want to be provided to help you coping with chemotherapy?
 - (5) What kind of information format do you prefer? Why is that?
 - (6) What are your suggestions or comments on current nursing services?
 - (7) How do you think nurses can best assist you to cope with chemotherapy?

Appendix 2—Summary of research proposal

The supportive care needs of Chinese women with breast cancer at the early stage of chemotherapy— A qualitative study.

1 Purpose

The aim of this study is to understand the supportive care needs of Chinese women with breast cancer at early stage of chemotherapy in China.

2 The significance of this research

The incidence of breast cancer in China is increasing year by year, how to support them has been a big social issue. Through this qualitative study, patient's specific needs will be identified, and their desired nursing assistance will be clear, it will provide reference for better supportive care, finally improve patients' QOL and satisfaction of care.

3 Method

A semi-structured, face-to-face interview will be applied to conduct this study. The interview outline was built based on the categories of supportive care needs by Fitch ^[24] and literature review, to explore the details of patients' needs further (Appendix 1 interview outline). All the participants will be interviewed at two time points (1: awaiting initial chemotherapy, 2: in the beginning the 2nd cycle of chemotherapy).

3.1 Participants

(1) Inclusion criteria: (a) Have a confirmed diagnosis of breast cancer and finished surgery; (b) Age: over 18 years old; (c) Newly diagnosed and the cancer stage is from I to III; (d) Receiving chemotherapy for the first time; (e) Known the cancer diagnosis.

(2) Exclusion criteria: (a) Cognitive impairment or severe mental illness; (b) History of other malignancy cancer; (c) Physical condition is not adequate to finish this study (Judged by responsible doctor or nurse).

Facility

Inclusion criteria: a) Third-grade hospital; b) Over one thousand women receive breast cancer treatment to ensure the sample size) Patients who treated in the hospital are not confined to one area to ensure the diversity of sample; d) Agree to assist this research.

3.2 Sampling method

Purposive sampling method will be used in this research, and the number of participants is adequate when saturation of information is achieved.

3.3 Data collection

3.3.1 Data collection method

Each eligible participant will be explained of the study at the oncology clinic or ward by the researcher. Only patients who give their informed consent will be recruited. They will be assured of anonymity and confidentiality of any information collected from interview. Each participant will be interviewed 30~60 minutes by researcher under interview outline at two time points (1: awaiting initial chemotherapy, 2: in the beginning the 2nd cycle of chemotherapy).

3.3.2 Place and time of data collection

Interview will be conducted in a quiet place at hospital, the researcher will try to create a comfortable environment for participants to talk.

3.4 Data analysis

Content analysis with an inductive approach will be chosen. Data analysis process will be conducted under the supervision of the supervisor to ensure the validity and credibility of the data analysis. The Chinese data will be translated into English for analysis.

3.5 Ethical considerations

This study was approved by the Ethics Committee in institutions of Chiba university in Japan (No.31-49).

3.5.1 Benefits of participating in the study

The expected benefits are that the supportive care needs of participants will be identified, they may get better supportive care by nurse in the future. (Appendix 5 Letter of invitation to Participate in the research)

3.5.2 Possible risks of participating in the study

The only foreseeable risks involved in the study are fatigue caused by 30-60 minutes of the interview, as well as sensitive issues that might arise during the interview process. Some participants may find it is hard to discuss all aspects of their disease. Interviewees will be informed that they had the choice to decline discussing issues that they found uncomfortable. They can refuse to be recorded their interviews or part of the interviews and to stop the conversation at any time without affecting their treatment or care. (Appendix 5 Letter of invitation to Participate in the research)

3.5.3 How to ensure the safety of the study and how to reduce the burden of the participants

- (1) Before the study, the researcher will discuss with the responsible doctor or nurse, whether the physical and psychological status of the participants could participate in the study. Also, the researcher will ask participants if they can start, if they are uncomfortable because of the side effects, the study will be postponed. After the participant is stable, the willing of participants will be confirmed again.
- (2) If participants have large emotional fluctuations during the study, pause and comfort the participants. After the participant is stable, the willing of participants will be confirmed again. if the participant feels uncomfortable during the interview, the researcher can ask help from doctor or nurse.
- (3) To decrease the time burden of the participants, the researcher will complete the interview within 30 to 60 minutes.
- (4) To reduce the mental burden of the participants, the researcher will conduct this interview in a relatively quiet, comfortable, and single room, giving the participants enough time and space to express their needs during interviewing.
- (5) In the process of the study, if the participants ask questions other than the outline of the interview, and the researcher couldn't answer or respond to them, the researcher will turn to the medical staff in time.
- (6) The researcher will observe the state of the participant during the interview. If they show fatigue, discomfort, or other conditions, the researcher will slow down or stop the interview to reduce the physical burden of the participant. The willing of participants will be confirmed again.

3.5.5 Privacy and confidentiality

Participants will be informed of the measures that would be taken to protect their privacy and to ensure the confidentiality of the information collected from them.

- (1) Before the study, the researcher will explain to participants that the interview content collected

from them will be used in this study only.

- (2) To have a comprehensive understanding of the participants' condition, the researcher will look up their medical records. (Appendix 5 Letter of invitation to Participate in the research)
- (3) To make the participants understand the research well, the researcher will explain in easy words.
- (4) When participants are invited to participate in the study, they will be told that it is voluntary to take part in this study, they can withdraw at any time. Even if they do not attend, their treatment and care will not be affected.
- (5) The researcher will promise to keep the security of the content of interview during the study period.
- (6) To protect the privacy of the participants, the researcher will use English letters to denote their names.
- (7) In the process of data analysis, if the participant hopes to withdraw from the research, the data of them will not be taken as the analysis object.
- (8) All electronic data (e.g., record) will be stored on a secure computer, and the password will be set. All non-electronic data (e.g., consent forms, hand-written notes, and interview transcripts) will be stored in a locked room.
- (9) Data will not be brought to places other than the researcher's school and home, or hospital where the data are collected.
- (10) To be kept for a maximum of ten years following the first publication resulting from the study, and then all electronic data will be deleted, all non-electronic data will be shredded.

3.5.6 Consideration of publication

- (1) The researcher will explain to director of nursing department and participants that the analysis result of the study may be published in conferences or academic journals.
- (2) To protect the privacy of the participants, the researcher will use English letters to denote their names when the paper published.
- (3) The results are used for this study only, and they will be kept by the researcher in a locked room.
- (4) If director of nursing department or participants want to know the analysis results of the study, the researcher will share the analysis results in a convenient way for them.

3.5.8 External funding

This study was founded by the Guangzhou Taihe Medical Humanities Research and Education Foundation in 2019. The aim of this found is to improve people's health, encourage medical humanistic research based on the detailed data, and fund students and young researchers with potential academic ability to carry out medical humanistic research in universities across China.

3.5.9 Conflict of interest (COI)

There is no conflict interest.

Appendix 3—Letter of invitation to assist in the research-for the director of nursing department
___Year___Month___Day

Dear [name of the director of nursing department],

Thanks for your time to read my letter.

My name is Cai Yingjie, a Ph.D. student from Chiba University, Japan. I obtained the qualification certificate of specialty and technology of nurse in China. Also, I had nearly two years of internship experience in clinical and two years of experience of research data collection in the breast surgery department

At present, I am going to do research to understand the supportive care needs of Chinese women with breast cancer at the early stage of chemotherapy. Therefore, I hope to have your permission to collect the data of breast cancer women' supportive care needs in this hospital. And please reply me in one week (___Year___Month___Day).

The details of my research documented in the Appendix 2 Summary of research proposal.

The study was approved by the ethics committee of Chiba University (No.31-49). During the research process, if method of the research adjusted or any ethical problems occurred, I will report to you immediately.

[Consideration of assistance in this research]

- This research is part of my doctoral dissertation. I would be happy to share the analysis result in a convenient way for you (if you hope).
- The analysis results of this study may be published in conferences or academic journals, and to protect the privacy of the participants, I will use English letters to denote participant's names when the paper published.

[External funding]

This study was founded by a non-profit foundation named Guangzhou Taihe Medical Humanities Research and Education Foundation in 2019. There is no conflict interest.

Patient-centered care is unlikely to occur without a good understanding of patient's needs and factors that influence them. To provide better supportive care, it is essential to identify patient's supportive care needs. Therefore, your assistance is very importance to improve the quality of care.

And if there is anything not clear about this study, please contact me.

The researcher: CAI YINGJIE
Graduate School of Nursing, Chiba University
Department of Frontier Practice Nursing
Division of Modern Gerontological nursing
Telephone: Email:
Supervisor: Prof. Harue MASAKI
Email address:

Appendix 4—Letter of invitation to assist in the research-for the responsible doctor or nurse

___Year___Month___Day

Dear [the name of the responsible doctor or nurse],

Thanks for your time to read my letter.

My name is Cai Yingjie, a Ph.D. student from Chiba University, Japan. I obtained the qualification certificate of speciality and technology of nurse in China. Also, I had nearly two years of internship experience in clinical and two years of experience of research data collection in the breast surgery department

At present, I am going to do research to understand the supportive care needs of Chinese women with breast cancer at the early stage of chemotherapy. Therefore, I hope to have your assistance.

The details of my research documented in the Appendix 2 Summary of research proposal.

The study was approved by the ethics committee of Chiba University (No.31-49).

[Method of this study]

In this study, I will interview the breast cancer women at the early stage of chemotherapy twice (before the initial chemotherapy, and at the beginning the 2nd cycle of chemotherapy), to ask their supportive care needs about chemotherapy. The interview will cost 30-60 minutes each time, and it will start without affecting the patient's treatment and care.

[Which part I expect to have your assistance]

1. I hope you to introduce patients who meet the select criteria to me. (I listed the select criteria in Appendix 2 Summary of research proposal)
2. It will be very meaningful to collect the participant's medical information (e.g., their age, time of cancer diagnosis and surgery, cancer stage, medical history) as my research data. After I get the permission of the participants to use these data, please allow me to look up the participant's medical and nursing records to collect these data only in the hospital.
3. I hope to have a privacy room when I interview participant, to give the participants enough time and space to express their needs. Please arrange a privacy room for me to collect data.
4. Before the interview start, I will confirm with you whether the physical and psychological status of the participants could participate in the study.
5. If the participant feels uncomfortable during the interview, I will inform you immediately, please help me to deal with.
6. In the process of the study, if the participants ask questions other than the outline of the interview, and I couldn't answer or respond to them, please help me to deal with.

[Consideration of assistance in this research]

- This research is part of my doctoral dissertation. I would be happy to share the analysis result in a convenient way for you (if you hope).
- The analysis results of this study may be published in conferences or academic journals, and to protect the privacy of the participants, I will use English letters to denote participant's names when the paper published.

[External funding]

This study was founded by a non-profit foundation named Guangzhou Taihe Medical Humanities

Research and Education Foundation in 2019. There is no conflict interest.

Patient-centered care is unlikely to occur without a good understanding of patient's needs and factors that influence them. To provide better supportive care, it is essential to identify patient's supportive care needs. Therefore, your assistance is very importance to improve the quality of care.

And if there is anything not clear about this study, please contact me.

The researcher: CAI YINGJIE
Graduate School of Nursing, Chiba University
Department of Frontier Practice Nursing
Division of Modern Gerontological nursing
Telephone: Email:
Supervisor: Prof. Harue MASAKI
Email address:

Appendix 5—Letter of invitation to Participate in the research-for patients

Dear [Participant name],

My name is Cai Yingjie, a Ph.D. student from Chiba University, Japan. I obtained the qualification certificate of specialty and technology of nurse in China. I had nearly two years of internship experience in clinical and two years of experience in research data collection in the breast surgery department.

Now I am going to do research to understand the supportive care needs of Chinese women with breast cancer at the early stage of chemotherapy.

The following information is provided for you to decide whether you wish to participate in the present study. You should be aware that you are free to choose not to participate without affecting your treatment or care.

You are free to express your willingness of withdraw at any time (e.g., before or after you signed the consent form; before or after you finished interview).

[Introduce of research and how to cooperate]

- I will conduct 30-60 min interviews with you at two points-before the initial chemotherapy, and at the beginning of 2nd cycle of chemotherapy. To talk about your supportive care needs about chemotherapy.
- It will be very meaningful to collect your medical information (e.g., your age, time of cancer diagnosis and surgery, cancer stage, medical history) as my research data, please allow me to look up your medical and nursing records, to use your medical information in this research.
- To understand your word well during the interview, please allow me to record your voice and note your words.
- After the first or second interview, if I have any ambiguity about the interview content, please allow me to contact with you in a convenient way.

[Considerations of participation in this research]

Benefits of participating in the study

- The expected benefits are that the supportive care needs of yours will be identified, you may get better supportive care by nurse in the future.

Possible risks of participating in the study

- The only foreseeable risks involved in the study are fatigue caused by 30-60 minutes of the interview, as well as sensitive issues that might arise during the interview process. You may find it is hard to discuss all aspects of their disease. You had the choice to decline discussing issues that you found uncomfortable. You can refuse to be recorded your interviews or part of the interviews and to stop the conversation at any time without affecting your treatment or care. If you withdraw to participate in this interview at any time, your data will be deleted and not be used to analyze.

How to ensure your privacy and confidentiality

- All electronic data (e.g., record) will be stored in a secure computer, and the password will be set.
- All non-electronic data (e.g., consent forms, hand-written notes, and interview transcripts) will be stored in a locked research room.
- The analysis result of the study may be published in conferences or academic journals, I will use English letters to denote your names when the paper published.

➤ I would be happy to share the analysis result in a convenient way for you (if you hope).

[External funding]

This study was founded by a non-profit foundation named Guangzhou Taihe Medical Humanities Research and Education Foundation in 2019. There is no conflict interest.

[Thanks for your cooperation]

After the interview finished, I will give a rehabilitation training grip ball to promote the recovery of your upper limb function.

Thanks for your time to read this letter, and it will be my pleasure to interview you, your cooperation will provide good foundation for better supportive care in the future.

If you need time to consider whether to take part, please reply me 2-3 days later, and you need to sign a consent form if you agree to join this interview. To be clear, the consent form and your medical information are only used in this study.

Do not hesitate to ask any questions about the study either before participating or during the time that you are attending, and I will be happy to help.

Explanation Date: ___Year___Month___Day

The researcher: CAI YINGJIE
Graduate School of Nursing, Chiba University
Department of Frontier Practice Nursing
Division of Modern Gerontological nursing

Telephone: Email:
Supervisor: Prof. Harue MASAKI
Email address:

Appendix 6—Consent form

Consent of participating in “The supportive care needs of Chinese women with breast cancer at the early stage of chemotherapy— A qualitative study.”

- Aim
- Method
- How to cooperate
- Considerations of participation in this research
- External funding
- Thanks for cooperation

The above content of this study has been explained to me by the researcher both in oral and written form, and any questions I had have been answered.

I know that I may withdraw the study at any time. I voluntarily agree to take part in this study.

Signature of Participant: _____

Date: _____

Signature of participant' family member: _____

(When participant is unable to sign)

Thanks for your cooperation, if you have any question, please contact the researcher.

The researcher: CAI YINGJIE
Graduate School of Nursing, Chiba University
Department of Frontier Practice Nursing
Division of Modern Gerontological nursing

Telephone:

Email:

Supervisor: Prof. Harue MASAKI

Email address:

Appendix 7—Withdrawal form

Research title:

The supportive care needs of Chinese women with breast cancer at the early stage of chemotherapy—
A qualitative study.

Signature by the participant:

I agreed to participate in the above study, but now I want to withdraw from the study and withdraw my
previous consent.

Date of withdrawal: Year Month Day

Signature of participant:

Signature of participant' family member:

(When participant is unable to sign)

I have confirmed the withdrawal application of the above participant.

Date of withdrawal: Year Month Day

Signature of researcher:

Study II

Appendix 1 Summary of the research proposal

Research topic:

Online focus group discussion for further revising the nurse-led supportive care program for Chinese breast cancer patients at the early stage of chemotherapy

1. Aim and significance of this study

To identify the individual supportive care needs of breast cancer patients at the early stage of chemotherapy, and provide support service tailored to these needs, help patient transferring and adjusting to chemotherapy well. We developed a nurse-led supportive care program. This study aims to collect the experts' perspectives and determine the appropriateness and content validity of the supportive care program's draft in China.

2. Method of this study

2.1 Participant selection

This inclusion criteria for the Chinese expert are as follows:

A. More than ten years of professional work experience in his/her field in China. (Clinical nurse or physician, or nursing manager, or nursing researcher, or nursing educator); B. Has a professional understanding of breast cancer and chemotherapy; C. Has a bachelor's degree or above; D. Has intermediate professional title or above; E. Be willing to participate in this research.

2.2 The process of this study

This research includes three rounds, two rounds of questionnaire consultation, and one round of online focus group discussion. And 4-6 experts will be invited to take part in this study.

First, after the expert agreed to participant in this research, a consultation questionnaire (Version 1) with instructions and supplemental materials will be sent to the experts by email. The experts are invited to rate the questionnaire first. After the experts returned the questionnaire, the researcher will analyze the questionnaire and clarify the themes that need to be discussed based on the analysis result. These themes will be sent to the experts by email.

Second, the researcher will arrange the time for the online focus group discussion with the expert. The themes clarified based on the analysis result will be discussed among the focus group.

Third, the experts are invited to rate a modified consultation questionnaire (Version 2) according to the expert's opinions on the focus group discussion.

Finally, the final version of the supportive care program will be finished.

The amount of time necessary for the completion of the questionnaires will vary with each panelist but should range from approximately 15–30 minutes. And it will cost 1 or 2 hours for the online focus group. There are no right or wrong answers to the questions. This study is seeking expert opinion. And the discussion process of the group meeting will be videotaped or record-taped after we got the permission of the experts. Besides, if the meeting time is difficult for a few experts, the researcher will try to obtain permission to interview the expert individually.

3. How the expert will cooperate with this study

We invite the expert to give their professional opinions on the questionnaire consultation and online focus group discussion. The focus group discussion will be held online because of the influence of the

COVID-19. The expert will be suggested to find a quiet, comfortable, safe, and single room with available Internet to conduct this online focus group discussion, and the internet fee should be paid by him/herself.

4. Consideration of the voluntary

It is important that the expert's participation in this study is entirely voluntary. Even if she/he does not wish to take part in this study, there is no impact on his/her work, life, or interpersonal relationships. Also, she/he can withdraw from this study at any time with no reason. If the expert withdraws in the middle, the researcher will discuss with the expert that the data collected from her/him can be use or not.

5. Protection of privacy, anonymity, and personal information

Besides, any information the expert provides will be confidential. When the results of the study are reported (the result may be public in academic conferences or journals), the expert will not be identifiable in the findings. His/her name will not be recorded on any rounds; instead, the expert will be allocated a unique code that can only be identifiable to the researcher. She/he will remain anonymous to the other experts throughout this consultation questionnaires, and only the researchers will be able to identify his/her specific answers. The return of the completed consultation questionnaire implies consent to participate. The data of this study will be kept for a maximum of ten years following the first publication. Then all electronic data will be deleted. All non-electronic data will be shredded.

6. Benefits of participating in the study

We cannot promise the study will help the expert as an individual, but the information we obtain might help improve the future research direction for breast cancer nursing. The patients might benefit from this program due to the expert's knowledge sharing.

7 Possible risks of participating in the study

The only foreseeable risks involved in the study are fatigue caused by 1 hour to 2 hours of discussion. Also, the expert has the choice to decline discussing issues that she/he feels uncomfortable.

8 Possibility and details of external funds

There is no fund support for this research.

9 Conflict of interest

No conflict of interest needs to be declared in this study.

10 Who has reviewed the study?

This study has been approved by Chiba University of Research Ethics Committee and date of approval.

Appendix 2 Invitation cover letter—for the expert's manager

Dear Sir/ Madam,

Re: <Online focus group discussion for further revising the nurse-led supportive care program for Chinese breast cancer patients at the early stage of chemotherapy>

My name is Cai Yingjie, a doctoral course student from Chiba University, Japan.

To identify the individual supportive care needs of breast cancer patients at the early stage of chemotherapy and provide support service tailored to these needs, help patient transferring and adjusting to chemotherapy well. We developed a nurse-led supportive care program. This study aims to collect the experts' perspectives and determine the appropriateness and content validity of the draft of the supportive care program.

We invite you to introduce the expert who may improve the future research direction for breast cancer nursing. Please review the aim, significance, method, and other details about this study in the attachment files.

You should understand that the expert's participation in this study is entirely voluntary. Even if she/he does not wish to take part in this study, there is no impact on his/her work, life, or interpersonal relationships.

If you are willing to assist us in the study, please send the expert's email address to us. We would be very grateful if you introduce the expert to us. We sincerely hope you will agree with the expert to participate. If you have any questions, please, email the researcher's e-mail address or call the researcher's WeChat number.

Thank you for your time and any help you may be able to offer to this study.

Yours sincerely

Cai Yingjie.

Supervisor: Prof. Harue MASAKI

【Please contact us as follow】

Mailing address: Chiba University Inohana Campus. Department of Gerontological nursing. The 2nd year of doctoral course student Cai Yingjie. 1-8-1 Inohana, Chuo-ku, Chiba 260-8675 JAPAN

Email address:_____wechat ID:_____

Supervisor: Prof. Harue MASAKI

Email address:_____

Appendix 3 Invitation cover letter—for the expert

Dear Sir/ Madam,

Re: <Online focus group discussion for further revising the nurse-led supportive care program for Chinese breast cancer patients at early stage of chemotherapy>

My name is Cai Yingjie, a doctoral course student from Chiba University, Japan. To identify the individual supportive care needs of breast cancer patients at the early stage of chemotherapy and provide support service tailored to these needs, help patient transferring and adjusting to chemotherapy well. We developed a nurse-led supportive care program. We sincerely invite you to participate in this study because you have been identified as an expert in this area.

This study aims to collect the experts' perspectives and determine the appropriateness and content validity of the draft of the supportive care program.

Before you decide, it is important to understand why the research is being done and what it will involve. Please review the aim, significance, method, and other details about this study in the attachment files carefully. We think you will find the process interesting, and the results will be made available at the conclusion of this study if you want.

If you are willing to participate in the study, we would be very grateful if you could complete the consent form and return it before <insert return date>.

We sincerely hope you will agree to participate. Please ask us if there is anything that is not clear or if you would like more information, and please take your time to decide whether you wish to join this study.

Thank you for your time and any help you may be able to offer to this study.

Yours sincerely

Cai Yingjie.

Supervisor: Prof. Harue MASAKI

【Please contact us as follow】

Mailing address: Chiba University Inohana Campus. Department of Gerontological nursing. The 2nd year of doctoral course student Cai Yingjie. 1-8-1 Inohana, Chuo-ku, Chiba 260-8675 JAPAN

Email address: _____ Wechat ID: _____

Supervisor: Prof. Harue MASAKI

Email address: _____

Appendix 4 Consent form

Participant identification number: _____

Research topic:

Online focus group discussion for further revising the nurse-led supportive care program for Chinese breast cancer patients at the early stage of chemotherapy.

I confirm that I have read and understood the summary of the research proposal dated for the above study. I have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily. **I am willing** to participate in two rounds of questionnaire consultation and one round of online focus group discussion and the follow-up stage.

I understood these items listed in the summary of the research proposal (*Please tick*)

- | | |
|---|--------------------------|
| 1. Aim and significance of this study | <input type="checkbox"/> |
| 2. Method of this study | <input type="checkbox"/> |
| 3. How the expert will cooperate with this study | <input type="checkbox"/> |
| 4. Consideration of the voluntary | <input type="checkbox"/> |
| 5. Protection of privacy, anonymity, and personal information | <input type="checkbox"/> |
| 6. Benefits of participating in the study | <input type="checkbox"/> |
| 7. Possible risks of participating in the study | <input type="checkbox"/> |
| 8. Possibility and details of external funds | <input type="checkbox"/> |
| 9. Conflict of interest | <input type="checkbox"/> |
| 10. Who has reviewed the study? | <input type="checkbox"/> |

Name of the participant

Date

Signature

Email address

Appendix 5 Withdrawal form

Research topic:

Online focus group discussion for further revising the nurse-led supportive care program for Chinese breast cancer patients at the early stage of chemotherapy.

I withdraw my consent from the participant in the above study.

Please tick the items you agreed below:

- I agree the researcher_____ use and manage my data in this study.
- I need the researcher to delete my data in this study.

Date of withdrawal: ___Year___Month___Day

Signature of participant:_____

Do you hope the researcher to contact you (through the way kept in the consent form) when the data is deleted?

- Yes
- No

【Please contact us as follow】

Mailing address: Chiba University Inohana Campus. Department of Gerontological nursing. The 2nd year of doctoral course student Cai Yingjie. 1-8-1 Inohana, Chuo-ku, Chiba 260-8675 JAPAN

Email address:_____Wechat ID: _____

Appendix 6 Consultation questionnaire

Instructions on how to complete consultation Round 1

There are two parts of this questionnaire.

Part 1: please fill the characteristic sheet about your general information.

Part 2: Consultation questionnaire

There are nine components of this supportive care program. The content validation of the supportive care program is measured using a 4-point Likert scale from 1 (irrelevant), 2(Somewhat relevant), 3(Quite relevant) to 4 (extremely relevant). Please rate the content relevance and clarity according to your professional judgement. If you marked as irrelevant, please write down your opinion on the space.

Please complete the questionnaire as fully as you can. It is important that the researcher can identify your responses as the consultation process has individual feedback to every panel member built into the process. Once you have completed the questionnaire, please return it to the researcher by <return date>. Thank you for agreeing to participate in this study.

Part 1 characteristic sheet

Background details

1. Code number:	2. Age:		
3. Educational level:	<input type="checkbox"/> Bachelor's degree <input type="checkbox"/> Master degree <input type="checkbox"/> Doctor degree		
4. Are you...	<input type="checkbox"/> Male	<input type="checkbox"/> Female	

Current employment

5. Present job title:	6. Department:		
7. Employing organization:			
8. Please tick, which professions you work in:			
<input type="checkbox"/> Clinical nursing	<input type="checkbox"/> Nursing theory	<input type="checkbox"/> Nursing management	<input type="checkbox"/> Nursing education
<input type="checkbox"/> Clinician	<input type="checkbox"/> None of the above (Please state.....)		
9. Working experience in the profession (Years):			

Part 2: Consultation questionnaire

Component	Content			Content relevance				Opinions
				Irrelevant	Somewhat relevant	Quite relevant	Extremely relevant	
① Intervention dose	Session one (Before CT start)	Session two (2 nd cycle of CT)	Session three (1 week before 3 rd cycle of CT)	1	2	3	4	
② Intervention nurse	Inclusion criteria: (a) Worked more than 5 years at oncological or breast department; (b) Has bachelor's degree or above; (c) Has good ability in communication; (d) Be willing to take part in this research; (e) Have finished the supportive care train course.			1	2	3	4	
③ Patient	Inclusion criteria: (a) Have a confirmed diagnosis of breast cancer and finished surgery; (b) Age: over 18 years old; (c) Newly diagnosed without metastasis; (d) The first time of receiving chemotherapy; (e) Aware of their cancer diagnosis; (f) Being available to be contacted by telephone. Exclusion criteria: (a) Cognitive impairment or severe mental illness; (b) History of other malignancy cancer.			1	2	3	4	
④ Intervention formats	Face-to-face consultation +booklet	Face-to-face consultation+booklet	Telephone follow-up	1	2	3	4	

Please rate (1 (irrelevant), 2(Somewhat relevant), 3(Quite relevant), 4 (extremely relevant). If you marked as 1(irrelevant), please write down your opinion on the space.)

Component	Session one (Before CT start)	Session two (2 nd cycle of CT)	Session three (1 week before 3rd cycle of CT)	Content relevance				Opinions
				Irrelevant	Somewhat relevant	Quite relevant	Extremely relevant	
⑤ Intervention contents	<p>Informational Education to minimize the adverse effect and satisfied information needs:</p> <ul style="list-style-type: none"> ❖ Symptom management <ul style="list-style-type: none"> ■ Discomfort symptoms on the surgical side ■ Sleep disorder ■ Other symptoms ❖ Daily life <ul style="list-style-type: none"> ■ Diet taboo (Fawu) and nutrition ■ Self-rehabilitation exercise ■ Health sexual life ■ Body cleanliness ❖ Treatment and follow-up examination <ul style="list-style-type: none"> ■ Inducing factors and follow-up examination ■ Introduce of infusion devices ■ Benefit and side effects of chemotherapy drugs and how to alleviate side effects ■ Adjuvant endocrine, traditional Chinese medicine treatments 	<p>Informational Education for what information patients still concerned:</p> <ul style="list-style-type: none"> ❖ Symptom management <ul style="list-style-type: none"> ■ Discomfort symptoms and functional recovery of surgical side ■ How to alleviate side effects ■ Rest and exercise ❖ Daily life <ul style="list-style-type: none"> ■ Diet taboo and nutrition(Mainly in how to alleviate white cell ■ Body cleanliness ❖ Treatment and follow-up examination <ul style="list-style-type: none"> ■ Benefits and side effects of radiotherapy ■ Reexamination ■ 	<p>Follow-up: to understand the effectiveness of nurse support services and the ongoing needs of patients</p> <ul style="list-style-type: none"> ❖ Ask whether the suggested strategies have solved their concerns; ❖ Prompt for further questions or new concerns after they finished the 2nd cycle of chemotherapy; ❖ Providing information education, emotional support, or coping strategies based on the patient's specific situation 	1	2	3	4	

Please rate (1 (irrelevant), 2(Somewhat relevant), 3(Quite relevant), 4 (extremely relevant). If you marked as 1(irrelevant), please write down your opinion on the space.)

Component	Session one (Before CT start)	Session two (2 nd cycle of CT)	Session three (1 week before 3rd cycle of CT)	Content relevance				Opinions
				Irrelevant	Somewhat relevant	Quite relevant	Extremely relevant	
⑤ Intervention contents	<p>Emotional support to help patients to adapt to diseases and seek help:</p> <ul style="list-style-type: none"> ❖ Encouraging patients to express their concerns and feelings <ul style="list-style-type: none"> ■ Treatment effect and side effect, and recurrence and metastasis of cancer ■ Body image ■ Family and social relationships ❖ Guiding patients to adopt cancer and chemotherapy <ul style="list-style-type: none"> ■ Anticipate preparation (wig, headscarf, artificial breast; mental preparation) ■ Acceptance ■ Distraction ❖ Understanding the patient's characteristic and possibly acquired resource to help them to seek support <ul style="list-style-type: none"> ■ Peer patients ■ Families and friends' support ■ Medical staffs' support 	<p>Emotional support for what concerns still distressed patients:</p> <ul style="list-style-type: none"> ❖ Encouraging patients to express their concerns and feelings <ul style="list-style-type: none"> ■ Treatment effect and side effect, and recurrence and metastasis of cancer ■ Family and social relationships ❖ Guiding patients to adopt cancer and treatment <ul style="list-style-type: none"> ■ Distraction ■ Selective attention ■ Compare with other BC patients ■ Weaken the "patient" role ■ Establish a belief in survival ❖ Understanding the patient's characteristic and possibly acquired resource to help them to seek support <ul style="list-style-type: none"> ■ Peer patients ■ Families' support ■ Medical staffs' support ❖ Encouraging patients to find the positive meaning of cancer experience <ul style="list-style-type: none"> ■ The importance of health <p>Positive self-transformation</p>		1	2	3	4	

Please rate (1 (irrelevant), 2(Somewhat relevant), 3(Quite relevant), 4 (extremely relevant). If you marked as 1(irrelevant), please write down your opinion on the space.)

Component	Session one (Before CT start)	Session two (2 nd cycle of CT)	Session three (1 week before 3rd cycle of CT)	Content relevance				Opinions
				Irrelevant	Somewhat relevant	Quite relevant	Extremely relevant	
⑥ Intervention procedure	<ul style="list-style-type: none"> ❖ Assessment and primary education (For all patient): <ul style="list-style-type: none"> ▪ Screening the needs/distress by Distress Thermometer(DT) and Problem List ▪ Providing the general information education ❖ Skilled Communication (For many patient whose DT ≥4): <ul style="list-style-type: none"> ▪ Clarifying the cause of needs and/or distress ▪ Using skilled communication to encourage patients to express ▪ Understanding existed coping strategies and their effects ❖ Tailored responses: <ul style="list-style-type: none"> ▪ Providing coping strategies tailored to patients' individual top 3 concerns ▪ According to the patient's characteristic and possibly acquired resource to help them to seek support ❖ Summary and record: <ul style="list-style-type: none"> ▪ Summarizing and recording the main issues ▪ Making appointment for next intervention session 	<ul style="list-style-type: none"> ❖ Reappraisal and second education <ul style="list-style-type: none"> ▪ Evaluating the effectiveness of the strategies provided in session one. ▪ Reassess the needs and distress currently by Distress Thermometer(DT) and Problem List, and providing information ❖ Skilled Communication: <ul style="list-style-type: none"> ▪ Clarifying the cause of current needs and/or distress ▪ Using skilled communication to conduct a emotional support ▪ Understanding existed coping strategies and their effects ❖ Tailored responses: <ul style="list-style-type: none"> ▪ Providing coping strategies tailored to patients' individual top 3 concerns ❖ Summary and record: <ul style="list-style-type: none"> ▪ Summarizing and recording the main issues ▪ Making appointment for next follow-up session 	<ul style="list-style-type: none"> ❖ Final appraisal and education <ul style="list-style-type: none"> ▪ Evaluating the effectiveness of the strategies provided in the first 2 sessions. ▪ Reassess the needs and distress currently by Distress Thermometer(DT) and Problem List, and providing information ❖ Skilled Communication: <ul style="list-style-type: none"> ▪ Clarifying the cause of current needs and/or distress ▪ Using skilled communication to conduct a emotional support ❖ Tailored responses: <ul style="list-style-type: none"> ▪ Providing coping strategies tailored to patients' individual top 3 concerns ❖ Summary and referral: <ul style="list-style-type: none"> ▪ Summarizing and recording the main issues ▪ Identifying the health professional or service ▪ Referral few patients to other service 	1	2	3	4	
⑦ Nursing record sheet	Nursing record audit data collection tool	Nursing record audit data collection tool (Part 4)	Nursing record audit data collection tool (Part 4)	1	2	3	4	
⑧ Supplemental materials	Booklet for patients			1	2	3	4	
⑨ Evaluation instrument for patient	Baseline: SCNS-34, EORTC QLQ-INFO25, FACT-B36		After intervention: SCNS-34, EORTC QLQ-INFO25, FACT-B	1	2	3	4	

Instructions on how to complete consultation Round 2

There are eight components of this supportive care program. The content validation of the supportive care program is measured using a 4-point Likert scale from 1 (irrelevant), 2(Somewhat relevant), 3(Quite relevant) to 4 (extremely relevant). Please rate the content relevance and clarity according to your professional judgement. If you marked as irrelevant, please write down your opinion on the space.

Once you have completed the questionnaire, please return it to the researcher by <return date>. Thank you for agreeing to participate in this study.

According to comments of experts and the supervisor, the revised version 2 of the supportive care program was formed based on professional guidelines and books.				Content relevance				Opinions
Components	Expert's comments	Version 2	The reason of revision	Irrelevant	Somewhat relevant	Quite relevant	Extremely relevant	
1. Intervention dose	1.The information booklet can be provided upon discharge after the operation. 2.The first session could be conducted after the treatment plan was determined two weeks after the operation. 3.The patient's physical condition is unwell on the day of chemotherapy and one week after chemotherapy, telephone intervention before chemotherapy or 7-10 days after chemotherapy is recommended.	After the patient received their chemotherapy plan from their oncologists, they will be invited to participate in this study. The person who agrees to the participant will be asked to finish a baseline survey and be offered the booklet. Simultaneously, the nurse will make an appointment with the patient to provide individualized intervention when the patient is available. The intervention included three sessions of individualized counseling, lasts about 30-60 minutes/session. Besides, patients can contact the nurse by phone or WeChat if they have any questions.	A flexible intervention time was reset to improve patient's compliance in participating in this supportive care program.	1	2	3	4	
2. Eligible intervention nurse	The clinical working experience is essential in implementing the program and considering the limited number of nurses with a bachelor degree and more than five years of working experience. It is not recommended to set inclusion criteria for nurses. It can be expressed in the context of who will implement this program.	The researcher will train 2-3 nurses (who had more than five years of oncology nursing experience and consent to participate in this research). The training includes the definition of supportive care, screening and assessment process of supportive care needs, communication skills, the components of the nurse-led supportive care program, and how to implement the intervention.	Considering the situation of the Chinese medical system, the nurse's selection criteria was removed but stated as a context of this intervention.	1	2	3	4	
3. Eligible patient	Considering the selection bias and sample size, it is not recommended to exclude patients with neoadjuvant chemotherapy.	The patient who is newly diagnosed with breast cancer and be going to receive chemotherapy for the first time.	Considering the selection bias and sample size, specific selection criteria of patients was removed in program developing. However, it will be set in the case study.	1	2	3	4	
4. Intervention formats	1.Combining the booklet, telephone, WeChat, and face to face in implementing the intervention was recommended. Therefore, the patients may benefit from this program both hospitalization and discharge. 2.The peer patients group intervention was suggested.	Face-to-face consultation+booklet +Telephone or WeChat follow-up	The core of this study is nurse-led, peer patients' support will not be involved in this study. However, the peer patients resources will be shared with patients.	1	2	3	4	
5. Intervention contents	1. It is necessary to streamline the side effects and daily life care directly related to chemotherapy. 2. The intervention content is too much, which can be dispersed to after operation, during chemotherapy, and discharged. 3. Patients concerned more about diet "Fawu" the book of traditional Chinese Medicine was recommended. 4. Only solving three concerns of patients, which are not reasonable in clinical practice and ethical principle. 5. The characteristics of the patient's disease should be considered in individualization intervention.	Table 9 and 10	1. To make this program specific to chemotherapy, some common side effects were added after referencing related guidelines and books. Furthermore, the information not related to chemotherapy was removed to the booklet. 2. To facilitate the nurse implementing this program in practice, the intervention content and procedure were merged, and a flowchart was developed with specific objection and focus of this intervention in different sessions. The information about "Fawu" was listed in the booklet. To facilitate to nurse implementing this program in practice, the intervention content and procedure were merged	1	2	3	4	
6. Information booklet	It is suggested that the coping information on diarrhea, psychology, emotion, and social function should be added to the information booklet.	Version 2 of information booklet for patients	After referencing related guidelines and books, the booklet was revised according to expert's advice.	1	2	3	4	
7. Nursing record sheet	Some terms were not accurate.	Version 2 of nursing record sheet	After revising the content of this program, the nursing record sheet was revised accordingly.	1	2	3	4	
8. Evaluation instrument for patient	No comments	SCNS-34, EORTC QLQ-INFO25, FACT-B36	Not revised	1	2	3	4	

Study III

Appendix 1 Summary of the research proposal-ward nurse version

Research topic:

A pilot study to test the feasibility and acceptability of the nurse-led supportive care program for Chinese breast cancer patient at the early stage of chemotherapy

1 Aim and significance of this study

To provide support service tailored to breast cancer patient's needs at the early stage of chemotherapy, help patient transferring and adjusting to chemotherapy well. We developed a nurse-led supportive care program. This study aims to describe the use of nurse-led supportive care program in the real-world context, and assess the feasibility of the subject recruitment, measurement tools and adherence to the intervention, and to explore the acceptability of this program.

2 Method

A pilot study with mixed methods and pretest-posttest design will be conducted.

2.1 Participant

Patient selection

Inclusion criteria: (1) Be newly diagnosed with stages I to III breast cancer and finished surgery, (2) Be over 18 years old, (3) Be going to receive chemotherapy for the first time, (4) Be aware of their cancer diagnosis. (5) Being available to be contacted by telephone.

Exclusion criteria: (1) Had a history of other malignancies, and (2) be diagnosed with a cognitive or psychological disorder.

Interventionist

2-3 ward nurse who had more than 5 years of oncology nursing experience and be willing to take part in this research will be invited to participant to this study.

2.2 The nurse-led supportive care program setting

The primary object of this program is to reduce the supportive care needs of patients with newly diagnosed breast cancer in the early stage of chemotherapy. And secondary outcome is to reduce patients' psychological distress, improve their information satisfaction and quality of life. There are three sessions led by a oncology ward nurse. The nurse will follow four steps to conduct the intervention in each session. However, the purpose and focus for each session is different. Patients are encouraged to bring a significant other to participant. (**Details is listed in Appendix 8**, to help the nurse better understand the intervention process, we set an example of this program's flowchart.)

First, the nurse will use Distress Thermometer and Problem List to assess patient's current distress and needs.

Second, the nurse will further clarify the problem and guide a positive approach to communicate of supportive care issues, use the tool as a prompt, and encourage patients to talk more about their main concerns.

Third, the information and emotional support tailored to the patient's concerns and needs will be provided by the nurse. (The coping strategies will be provided as a booklet also)

Finally, nurse will end by summarizing the main issue. For few patients have complex needs, nurse will identify whether other health professional or service is needed, if it is, then referral to other specialist services.

2.3 Outcome measures

The primary outcomes include the acceptability of the proposed intervention, the feasibility of recruitment and measurement and the adherence to the intervention. The patient will be asked to fill the questionnaires before and after the intervention. And both of the patient and nurse will be interviewed by the researcher. Also, the researcher will calculate the feasibility. (Please review the table 1 Timing of proposed data collection and instruments)

Table 1 Timing of proposed data collection and instruments

Subjects	Pre-Intervention	Post-Intervention	
	SCNS-34, FACT-B Version 4.0, EORTC QLQ-INFO 25	SCNS-34, FACT-B Version 4.0, EORTC QLQ-INFO 25 Qualitative Interview (By the researcher)	Feasibility Recruitment process <ul style="list-style-type: none"> • Number of people interested in this program from eligible people. • Number of people attending interview with researcher. Measurement tools <ul style="list-style-type: none"> • Time taken to fill in questionnaires. • Missing data from questionnaires. Intervention procedure <ul style="list-style-type: none"> • Intervention adherence. • Number of sessions attended.
Patients		1. How do you think the intervention dose and duration for each session of this program? (Is it easy (or) difficult to understand? Which parts?) 2. Which part of the intervention is useful in addressing your needs? 3. How do you think about the information booklet? 4. What benefits you have gained from this program? 5. Which part of the intervention need to be refined?	
Oncology ward nurse		Qualitative Interview (By the researcher) 1. How do you think the intervention dose and duration for each session of this program? (Is it easy (or) difficult to understand? Which parts?) 2. What is the challenges and issues in, as well as the ease of, the delivery of the intervention? 3. What benefits have you gained, or how could the patient be benefited from this program in your opinion? 4. How do you think about the information booklet? 5. Which part of the intervention need to be refined?	

3 How the ward nurse will cooperate with this study

(1) Take part in the program training: The training includes the definition of supportive care, screening and assessment process of supportive care needs, communication skills, the components of the nurse-led supportive care program, and how to implement the intervention. It will be conducted by the researcher.

(2) Help the researcher to select the eligible patient: After the patient finished the consultation meeting with doctor and determined her chemotherapy plan, please introduce the eligible patient to the researcher, and we (me and you) will introduce the study to the patient and her family (If her family accompany them or she needs her family's opinions to participate or not), including the study purpose, significance, methods, how to cooperate, privacy and confidentiality, and the situation of withdrawal of the study. After the patient who signed the consent form, the researcher will ask the patient to fill questionnaires at baseline. Then, the researcher, patient and the ward nurse will negotiate the time of intervention (Both available for patient and ward nurse).

(3) Implement the supportive care program: Please check the patient's physical and mental condition again, to ensure her safety to participant the intervention (Before, during, after each session of the

intervention). Then the nurse will conduct the supportive care program to the patient who signed the consent form. (The patient has the right to withdraw of this study at any time with no reason)

(4) Share experience of implementing the intervention: After the intervention finished, the researcher will interview the nurse who implement the intervention. Interviewing the nurse to share his/her experience of implementing the intervention based the interview outlines.

4 Consideration of the voluntary

It is important that the nurse's participation in this study is entirely voluntary. The nurse has the right to take a rest if she/he feels exhausted or withdraw from this study at any time with no reason, and it would not have any negative consequences to her routine work or her relationships with the nursing managers, or patients.

5 Protection of privacy, anonymity, and personal information

Besides, any information the nurse provides will be confidential. When the results of the study are reported (the result may be public in academic conferences or journals), the nurse will not be identifiable in the findings. His/her name will not be recorded except the consent form and Withdraw form; instead, the nurse will be allocated a unique code that can only be identifiable to the researcher.

The data of this study will be kept for a maximum of ten years following the first publication by the researcher in personal computer or a locked room. Then all electronic data will be deleted. All non-electronic data will be shredded.

6 Benefits of participating in the study

We cannot promise the study will help the nurse as an individual, but this program may increase the nurse's understanding of supportive care and provide the care support specific to patient's needs better. And the information we obtain from this study might help improve the quality of nursing for future breast cancer nursing, and the patients might benefit in this program due to the nurse's knowledge and time sharing.

7 Possible risks of participating in the study

The only foreseeable risks involved in the study are time burden. (About half to one hours in participating in the program training, about half to one hour of participating each session of the intervention (totally three sessions), and about half to one hour's interview of her/his experience after the intervention) and may makes the nurse feel exhausted (If the intervention session continued in a long time). (Might cost their day work time or the rest time).

8 Possibility and details of external funds

There is no fund support for this research.

9 Conflict of interest

No conflict of interest needs to be declared in this study.

10 Who has reviewed the study?

This study has been approved by Chiba University of Research Ethics Committee and date of approval.

Appendix 2 Summary of the research proposal-patient version

Research topic:

A pilot study to test the feasibility and acceptability of the nurse-led supportive care program for Chinese breast cancer patient at the early stage of chemotherapy

1 Aim and significance of this study

To provide support service tailored to breast cancer patient's needs at the early stage of chemotherapy, help patient transferring and adjusting to chemotherapy well. We developed a nurse-led supportive care program. This study aims to describe the use of nurse-led supportive care program in the real-world context, and assess the feasibility of the subject recruitment, measurement tools and adherence to the intervention, and to explore the acceptability of this program.

2 Method

A pilot study with mixed methods and pretest-posttest design will be conducted.

2.1 Participant

6-10 patients will be recruited representing the target population in this pilot study.

Inclusion criteria: (1) Be newly diagnosed with stages I to III breast cancer and finished surgery, (2) Be over 18 years old, (3) Be going to receive chemotherapy for the first time, (4) Be aware of their cancer diagnosis. (5) Being available to be contacted by telephone.

Exclusion criteria: (1) Had a history of other malignancies, and (2) be diagnosed with a cognitive or psychological disorder.

2.2 The nurse-led supportive care program setting

The primary object of this program is to reduce the supportive care needs of patients with newly diagnosed breast cancer in the early stage of chemotherapy. And secondary outcome is to reduce patients' psychological distress, improve their information satisfaction and quality of life. There are three sessions, and all sessions are led by an oncology ward nurse who was trained by the researcher. The nurse will follow four steps to conduct the intervention in each session. However, the purpose and focus for each session is different. Patients are encouraged to bring a significant other to participant in this study. (Details is listed in the Appendix 8.)

First, the nurse will use Distress Thermometer and Problem List to assess patient's current distress and needs.

Second, the nurse will further clarify the problem and guide a positive approach to communicate of supportive care issues, use the tool as a prompt, and encourage patients to talk more about their main concerns.

Third, the information and emotional support tailored to the patient's concerns and needs will be provided by the nurse. (The coping strategies will be provided as a booklet also)

Finally, nurse will end by summarizing the main issue. For few patients have complex needs, nurse will identify whether other health professional or service is needed, if it is, then referral to other specialist services.

2.3 Outcome measures

The primary outcomes include the acceptability of the proposed intervention, the feasibility of recruitment and measurement and the adherence to the intervention. The patient will be asked to fill the questionnaires before and after the intervention. And both patient and nurse will be interviewed by the researcher. Also, the researcher will calculate the feasibility. (Please review the Table 1 Timing of

proposed data collection and instruments)

Table 1 Timing of proposed data collection and instruments

Subjects	Pre-Intervention	Post-Intervention	
	SCNS-34, FACT-B Version 4.0, EORTC QLQ-INFO 25	SCNS-34, FACT-B Version 4.0, EORTC QLQ-INFO 25 Qualitative Interview (By the researcher) 1. How do you think the intervention dose and duration for each session of this program? (Is it easy (or) difficult to understand? Which parts?) 2. Which part of the intervention is useful in addressing your needs? 3. How do you think about the information booklet? 4. What benefits you have gained from this program? 5. Which part of the intervention need to be refined?	Feasibility Recruitment process Number of people interested in this program from eligible people. Number of people attending interview with researcher. Feasibility of measurement tools Time taken to fill in questionnaires. Missing data from questionnaires. Feasibility of intervention procedure Intervention adherence; Number of sessions attended.
Patients			

3 How the patient will cooperate with this study

(1) **Sign the consent form:** If the patient is willing to participate this supportive care program, she needs to sign the written consent form and reply to it to the researcher.

(2) **Finish the baseline assessment:** SCNS-34, FACT-B Version 4.0, EORTC QLQ-INFO 25

(3) **Participate in the supportive care program:** First, the patient will be asked to assess their main problems by the distress thermometer (DT) and problem list at the beginning of each session, speak out the reasons of her concerns, existed coping strategies and effects. Then the nurse will provide the information and emotional support tailored to the patient's needs. After three sessions of intervention, the patient will be asked to fill the questionnaires.

(4) **Share experience of implementing the intervention:** After the intervention finished, the researcher will interview the patient who participated in the intervention. Interviewing the patient to share her experience of participating the intervention based the interview outlines.

(5) Allow the researcher to review her medical and nursing record and use her medical information in this research.

4 Consideration of the voluntary

It is important that the patient's participation in this study is entirely voluntary. There is no influence if she does not wish to take part in this study. Also, she can withdraw from this study at any time with no reason. Even the patient withdraws, it would not have any negative consequences to her treatment or care. If the patient withdraws in the middle, the researcher will discuss with the patient that the data collected from her can be use or not.

5 Protection of privacy, anonymity, and personal information

Besides, any information the patient provides will be confidential. When the results of the study are reported (the result may be public in academic conferences or journals), the patient will not be identifiable in the findings. Her name will not be recorded on anywhere (Except the consent form and

Withdraw Form). The patient will be allocated a unique code that can only be identifiable to the researcher. The data of this study will be kept for a maximum of ten years following the first publication by the researcher in personal computer or a locked room. Then all electronic data will be deleted. All non-electronic data will be shredded.

6 Benefits of participating in this study

This program may increase patient's knowledge in coping with physical, psychological, informational, and other problems related to chemotherapy.

7 Possible risks of participating in this study

The foreseeable risks involved in the study are time burden in participating this program (for participating in the program: Each session may cost 30-60 minutes (Totally three sessions), and the questionnaire assessment may cost about 10-15 minutes before and after the intervention. The interview will cost 30-60 minutes.), and the patient may feel exhausted (If the intervention session continued in a long time). The patient has the right to take a rest if she feels exhausted or withdraw at any time if she thinks hard to continue.

This program might refer to some sensitive problem (e.g., Sexual problem) or recall the hard diagnosis and treatment experience of breast cancer during the intervention process. Some patients may find it is hard to discuss all aspects of their disease. They had the right to decline discussing any issues that they feel uncomfortable. They can refuse to continue the intervention at any time without affecting their treatment or care. At the same time, the nurse will control the situation, minimize the discomfort to ensure the safety of the patients.

8 Possibility and details of external funds

There is no fund support for this research.

9 Conflict of interest

No conflict of interest needs to be declared in this study.

10 Who has reviewed the study?

This study has been approved by Chiba University of Research Ethics Committee and date of approval.

Appendix 3 Invitation cover letter—to the nursing manager

Dear Sir/ Madam,

Re: <A pilot study to test the feasibility and acceptability of the nurse-led supportive care program for Chinese breast cancer patient at the early stage of chemotherapy>

My name is Cai Yingjie, a doctoral course student from Chiba University, Japan. To identify the individual supportive care needs of breast cancer patients at the early stage of chemotherapy and provide support service tailored to these needs, help patient transferring and adjusting to chemotherapy smoothly. We developed a nurse-led supportive care program. This study aims to describe the use of nurse-led supportive care program in the real-world context, and assess the feasibility of the subject recruitment, measurement tools and adherence to the intervention, and to explore the acceptability of this program.

To have a better understanding of why the research is being done and what it will involve, please review the aim, significance, method, and other details about this study in the attachment files. We will be very grateful if we could have your cooperation to facilitate the implementation of this program.

If you are willing to assist us in the study, please helping us as follow:

1. **Please helping us to recruit the nurses:** we hope to have your assistance in sending the invitation cover letter to all oncology ward nurses and announcing them that who are interested in the supportive care program can contact the researcher to ask for detail information. Their implementation experience is essential in helping us for further revising this program and possibly benefiting breast cancer nursing.

2. **Please helping us to coordinate the time and routine nursing work of the intervention nurse:** Due to the intervention nurses will cost additional time to conduct this program, it might influence their routine care work to some extent. We will be grateful if we could have your understanding and be acknowledged by other colleagues during the intervention process. We will try our best to answer nurses' confusion about this study and explain the significance and benefits of this study. In addition, during the process of intervention, the researcher will try her best to assist nurses to implement intervention to minimize the care burden on nurses.

You should understand that the nurse's participation in this study is entirely voluntary. Even if she/he does not wish to take part in this study, it will not have any impact on his/her work, life, or interpersonal relationships.

We would be very grateful if you introduce the nurse to us. We sincerely hope you will agree with the nurse to participate. If you have any questions, please, email the researcher or call the researcher's WeChat number.

Thank you for your time and any help you may be able to offer to this study.

Sincerely,

Cai Yingjie.

【Please contact us as follow】

Mailing address: Chiba University Inohana Campus. Department of Gerontological nursing. The 2nd year of doctoral course student Cai Yingjie. 1-8-1 Inohana, Chuo-ku, Chiba 260-8675 JAPAN

Email address: _____ wechat ID: _____

Supervisor: Prof. Harue MASAKI

Email address: _____

Appendix 4 Invitation cover letter—to the patient

Dear Madam,

Re: <A pilot study to test the feasibility and acceptability of the nurse-led supportive care program for Chinese breast cancer patient at the early stage of chemotherapy>

My name is Cai Yingjie, a doctoral course student from Chiba University, Japan. To identify the individual supportive care needs of breast cancer patients at the early stage of chemotherapy and provide support service tailored to these needs, help patient transferring and adjusting to chemotherapy well. We developed a nurse-led supportive care program. This study aims to describe the use of nurse-led supportive care program in the real-world context, and assess the feasibility of the subject recruitment, measurement tools and adherence to the intervention, and to explore the acceptability of this program.

We sincerely invite you to participate in this study to test the feasibility and acceptability of this study. Your opinions is essential for further revision of this program.

Before you decide, it is important to understand why the research is being done and what it will involve. Please review the aim, significance, method, and other details about this study in the attachment files carefully. We think you will find the process interesting, and the results will be made available at the conclusion of this study if you want.

If you are willing to participate in the study, we would be very grateful if you could complete the consent form and return it before <insert return date>.

We sincerely hope you will agree to participate. Please ask us if there is anything that is not clear or if you would like more information, and please take your time to decide whether you wish to join this study.

Thank you for your time and any help you may be able to offer to this study.

Sincerely,

Cai Yingjie.

【Please contact us as follow】

Mailing address: Chiba University Inohana Campus. Department of Gerontological nursing. The 2nd year of doctoral course student Cai Yingjie. 1-8-1 Inohana, Chuo-ku, Chiba 260-8675 JAPAN

Email address: _____ Wechat ID: _____

Supervisor: Prof. Harue MASAKI

Email address: _____

Appendix 5 Invitation cover letter—to the ward nurse

Dear Sir/ Madam,

Re: <A pilot study to test the feasibility and acceptability of the nurse-led supportive care program for Chinese breast cancer patient at the early stage of chemotherapy>

My name is Cai Yingjie, a doctoral course student from Chiba University, Japan. To identify the individual supportive care needs of breast cancer patients at the early stage of chemotherapy and provide support service tailored to these needs, help patient transferring and adjusting to chemotherapy well. We developed a nurse-led supportive care program. This study aims to describe the use of nurse-led supportive care program in the real-world context, and assess the feasibility of the subject recruitment, measurement tools and adherence to the intervention, and to explore the acceptability of this program.

We sincerely invite you to participate in this study to test the feasibility and acceptability of this study. Your opinions is essential for further revision of this program.

Before you decide, it is important to understand why the research is being done and what it will involve. Please review the aim, significance, method, and other details about this study in the attachment files carefully. We think you will find the process interesting, and the results will be made available at the conclusion of this study if you want.

If you are willing to participate in the study, we would be very grateful if you could complete the consent form and return it before <insert return date>.

We sincerely hope you will agree to participate. Please ask us if there is anything that is not clear or if you would like more information, and please take your time to decide whether you wish to join this study.

Thank you for your time and any help you may be able to offer to this study.

Sincerely,

Cai Yingjie.

【Please contact us as follow】

Mailing address: Chiba University Inohana Campus. Department of Gerontological nursing. The 3rd year of doctoral course student Cai Yingjie. 1-8-1 Inohana, Chuo-ku, Chiba 260-8675 JAPAN

Email address: _____ Wechat ID: _____

Supervisor: Prof. Harue MASAKI

Email address: _____

Appendix 6 Consent form

Participant identification number: _____

Research topic:

A pilot study to test the feasibility and acceptability of the nurse-led supportive care program for Chinese breast cancer patient at the early stage of chemotherapy

I confirm that I have read and understood the summary of the research proposal dated for the above study. I have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily. **I am willing to** participate in this program, fill the questionnaires and(or) join the interview, and the follow-up stage.

I understood these items listed in the summary of the research proposal (*Please tick*)

- | | |
|---|--------------------------|
| 1. Aim and significance of this study | <input type="checkbox"/> |
| 2. Method of this study | <input type="checkbox"/> |
| 3. How to cooperate with this study | <input type="checkbox"/> |
| 4. Consideration of the voluntary | <input type="checkbox"/> |
| 5. Protection of privacy, anonymity, and personal information | <input type="checkbox"/> |
| 6. Benefits of participating in the study | <input type="checkbox"/> |
| 7 Possible risks of participating in the study | <input type="checkbox"/> |
| 8 Possibility and details of external funds | <input type="checkbox"/> |
| 9 Conflict of interest | <input type="checkbox"/> |
| 10 Who has reviewed the study? | <input type="checkbox"/> |

Name of the participant

Date

Signature

Email address

Appendix 7 Withdrawal form

Research topic:

A pilot study to test the feasibility and acceptability of the nurse-led supportive care program for Chinese breast cancer patient at the early stage of chemotherapy

I withdraw my consent from the participant in the above study.

Please tick the items you agreed below:

- I agree the researcher_____ use and manage my data in this study
- I need the researcher to delete my data in this study

Date of withdrawal: ___Year___Month___Day

Signature of participant:_____

Do you hope the researcher to contact you (thought the way kept in the consent form) when the data is deleted?

- Yes
- No

【Please contact us as follow】

Mailing address: Chiba University Inohana Campus. Department of Gerontological nursing. The 3rd year of doctoral course student Cai Yingjie. 1-8-1 Inohana, Chuo-ku, Chiba 260-8675 JAPAN

Email address:_____wechat ID:_____

Appendix 8 The nurse-led supportive care program (Version 2)

Attachment 8 The nurse-led supportive care program

Intervention time and format	<p>After the patient received their chemotherapy plan by their oncologists, they will be invited to participant to this study. The person who are agree to participant will be asked to finish a baseline survey, and be offered the booklet.</p> <p>At the same time, the nurse will make an appointment with the patient to provide individualized intervention when the patient is available. The intervention included three sessions of individualized counseling, lasts about 30-60 minutes/session. The tailored information and emotional support will be provided according to the what patients were most concerned at that time. In addition, patients can contact the nurse by phone or Wechat if they have any questions.</p>																																				
Intervention procedure	Description	Content																																			
1	Assessment and primary education	Screening the needs/distress by Distress Thermometer(DT) and Problem List																																			
2	Skilled Communication	Using skilled communication (encourage patients to express,listen actively, clarify problems, etc.) to clarify the cause of needs and/or distress, understand the existed coping strategies and their effects.																																			
3	Tailored information and emotional support	<p>On the basis of fully considering the patient's age, education level, disease, treatment plan, personality traits, family context and possible resources, tailored information and emotional supportive counseling according to what patients were most concerned at that time will be provided.</p> <table border="0" style="width: 100%;"> <tr> <td style="width: 50%; vertical-align: top;"> <p>Management of the common side effect of Chemotherapy</p> <hr/> <table border="0"> <tr> <td>-Chemotherapy-induced nausea and vomiting</td> <td>-Myelosuppression</td> <td>-Diarrhoea</td> </tr> <tr> <td>-Hair loss</td> <td>-Fatigue</td> <td>-Constipation</td> </tr> <tr> <td>-Oral Mucositis</td> <td>-Sleep disorder</td> <td>-Skin and nail changes</td> </tr> </table> <hr/> <p>Self-management during intermission of chemotherapy at home</p> <hr/> <table border="0"> <tr> <td>- Infusion devices</td> <td>-Self-image management</td> <td>-Exercise and weight management</td> </tr> <tr> <td>- Diet and nutrition</td> <td></td> <td>-Health sexual life</td> </tr> <tr> <td>-Functional rehabilitation of upper limb on the affected side</td> <td></td> <td></td> </tr> </table> <hr/> <p>Chemotherapy-related support and service resources</p> <hr/> <table border="0"> <tr> <td>-Resources of internet</td> <td>-Resources of peer patients</td> <td>-Resources of books</td> </tr> </table> </td> <td style="width: 50%; 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4	Summary and referral	Summarizing and recording the main problems and recommended strategies identified in this consultation, and make an appointment for the next consultation. At the end of all consultation, few patients will be referred to other experts (dietitian/psychiatrist, etc.) if their DT ≥ 4.																																			

Appendix 9—Nursing record sheet

Date of Survey: DD/MM/YYYY

The signature of the recording nurse: _____

Part 1: Patient Profile Note: The marked items in first and third parts need to be obtained by patients, others could be obtained from medical records.

<p>1. Date of birth: DD/MM/YYYY (Age: _____ years old)</p> <p>2. Marital status</p> <p><input type="checkbox"/> Single</p> <p><input type="checkbox"/> Married</p> <p><input type="checkbox"/> Divorced</p> <p><input type="checkbox"/> Widowed</p> <p>5. Education background</p> <p><input type="checkbox"/> No education</p> <p><input type="checkbox"/> Elementary school</p> <p><input type="checkbox"/> Middle school</p> <p><input type="checkbox"/> High school</p> <p><input type="checkbox"/> College</p> <p><input type="checkbox"/> Graduate school</p>	<p>3. Employment</p> <p><input type="checkbox"/> Employment</p> <p><input type="checkbox"/> Sick leave</p> <p><input type="checkbox"/> No employment</p> <p><input type="checkbox"/> Retired</p> <p>6. Religion</p> <p><input type="checkbox"/> None</p> <p><input type="checkbox"/> Buddhist</p> <p><input type="checkbox"/> Christian</p> <p><input type="checkbox"/> Taoist</p> <p><input type="checkbox"/> Others</p>
<p>4. Payment of drug expenses</p> <p><input type="checkbox"/> Self-financed</p> <p><input type="checkbox"/> Medical insurance</p> <p><input type="checkbox"/> Commercial insurance</p>	

Part 2: Cancer Diagnosis and Treatment

7. Date of diagnosis: DD/MM/YYYY

<p>8. TNM stage</p> <p><input type="checkbox"/> I</p> <p><input type="checkbox"/> II</p> <p><input type="checkbox"/> III</p>	<p>9. Surgery type</p> <p><input type="checkbox"/> Breast-conserving surgery</p> <p><input type="checkbox"/> Mastectomy with reconstruction</p> <p><input type="checkbox"/> Mastectomy without reconstruction</p>	<p>10. Regional lymph node surgery type</p> <p><input type="checkbox"/> ALND</p> <p><input type="checkbox"/> SLNB</p> <p><input type="checkbox"/> IBALND</p>
<p>11. Chemotherapy regimen</p> <p><input type="checkbox"/> AC-T <input type="checkbox"/> EC-T</p> <p><input type="checkbox"/> AC-D <input type="checkbox"/> EC-D</p> <p><input type="checkbox"/> AC-P <input type="checkbox"/> EC-P</p>	<p><input type="checkbox"/> TC</p> <p><input type="checkbox"/> EC</p> <p><input type="checkbox"/> AC</p> <p><input type="checkbox"/> others ()</p>	<p>12. Chemotherapy cycles</p> <p><input type="checkbox"/> Four rounds</p> <p><input type="checkbox"/> Six rounds</p> <p><input type="checkbox"/> Eight rounds</p>

Part 3: Family conditions

<p>13. Monthly family income</p> <p><input type="checkbox"/> <1000 RMB</p> <p><input type="checkbox"/> 1000—3000 RMB</p> <p><input type="checkbox"/> 3001—5000 RMB</p> <p><input type="checkbox"/> >5000 RMB</p>	<p>14. Number of children</p> <p>_____ Son(s)</p> <p>_____ Daughter(s)</p>
---	---

15. Other family concerns mentioned in the conversation:

16. Telephone number of the patient:

17. Telephone number of the family:

Part 4: Supportive care intervention record

1. Distress Thermometer score: _____ **2. The sessions of the intervention:**
 Session one Session two Session three

3. Needs and/or distress and cause

4. Existed coping strategies and effect Valid
 Invalid
 Unsure

5. Possibly acquired resource
 Internet resource (Please state.....)
 Family support (Please state.....)
 Social support (peer patients, other medical staffs, relatives and friends) (Please state.....)

6. Please check the specific intervention support you provide, and if it is not listed in the following table, please briefly describe the strategy you provide in the option "other"

Informational Education	Session			Emotional support	Session			
	1	2	3		1	2	3	
◇ Nausea and vomiting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Encouraging patients to express their concerns and feelings	◇ Treatment effect and side effect	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
◇ Hair loss	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		◇ Recurrence and metastasis of cancer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
◇ Fatigue	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		◇ Body image	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Management of the common side effect of Chemotherapy ◇ Sleep disorder	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		◇ Family and social relationships	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
◇ Myelosuppression	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		◇ Others (Please state...)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
◇ Diarrhoea	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Guiding patients to accept cancer and treatment	◇ Anticipate preparation (wig, headscarf, artificial breast; mental preparation)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
◇ Constipation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		◇ Acceptance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
◇ Oral Mucositis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		◇ Distraction	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
◇ Skin and nail changes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		◇ Selective attention	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
◇ Other symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		◇ Compare with other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	◇ (Please state)					BC patients			
Self-man agement during intermiss ion of chemothe rapy at home	◇ Diet and nutrition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		◇ Weaken the "patient" role	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	◇ Functional rehabilitation of upper limb on the affected side	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		◇ Establish a belief in survival	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Chemoth erapy-rel ated support and service resources	◇ Self-image management	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Helping patient to seek support	◇ Others (Please state...)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	◇ Exercise and weight management	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		◇ The importance of health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	◇ Health sexual life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		◇ Positive self-transformation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	◇ Others (Please state.....)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		◇ Others (Please state.....)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
◇ Resources of internet	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	◇ Peer patients		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
◇ Resources of peer patients	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	◇ Families and friends' support					
◇ Resources of books	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	◇ Medical staffs' support					
◇ Others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>						
◇ (Please state.....)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>						
Other information							Others (Please state.....)		
9. Does she need to be referred to other services <input type="checkbox"/> Yes (Please write down what kind of service) <input type="checkbox"/> No									
10. The appointment time for the next intervention session:									

Appendix 10—Information booklet for breast cancer patients undergoing adjuvant chemotherapy (excerpts)

乳腺癌患者化疗知识手册



即将踏上化疗的征程

您准备好了吗?

注：疾病变化复杂，治疗方法繁多，请相信临床医护人员会为您安排适合您的治疗及护理方案。

此知识手册不能替代专业的判断。此外，本手册建议的对策适用于一般患者，如果您希望具体了解相关内容、或您存在糖尿病、高血压等其他基础疾病，请咨询您的主治医生及护士。

祝您顺利完成化疗，早日康复!



前言

乳腺肿瘤是女性最常见的肿瘤，其新发病人位居女性肿瘤之首。但是，随着早期诊断和治疗技术的不断创新和改进，患者的预后相对较好，生存时间也相对较长。

肿瘤的诊断或许令您有些措手不及，尤其是对于初次接受化疗的您来说，可能会有担心和不安，迫切的想要了解更多有关化疗及康复的信息，但可能会在繁杂的信息中不知所措。此知识手册列举了一些常见的化疗副作用，并提供应对副作用及化疗间歇期居家自我管理、促进康复的对策及建议。旨在以通俗易懂的语言，帮助您和家人更好的了解化疗，并为其做准备。您还可以利用手册最后的空白部分随时记录下您的疑问或感悟，方便您与医生、护士沟通，助您更从容的应对化疗!

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一、认识化疗

1.化疗是什么

化疗是化学治疗的简称，是一种应用特殊化学药物杀灭恶性肿瘤细胞或组织的治疗方法^[1]。



2.化疗的作用

因治疗目的不同，化疗也有不同的作用。化疗可以在手术前或放疗前缩小肿瘤；清除手术或放疗后可能残留的微小癌细胞；消灭复发或转移的癌细胞；在无法治愈的情况下控制肿瘤的生长；



缓解癌症相关症状，如缩小引起疼痛的肿瘤；有助于放疗和生物治疗更好地发挥作用^[2]。

3.化疗的疗程^[3]

您的主治医生会根据您的病情为您制定合理的治疗方案。一般来说，化疗频率和时间取决于：

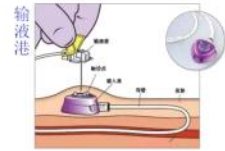
- ❖ 癌症的类型和分期；
- ❖ 治疗目标；
- ❖ 化疗的类型；
- ❖ 您的身体对化疗的反应。

1

化疗是呈周期性进行的，较为常见的是以 21 天为一个周期（但治疗方案不同，周期时间也不同，具体请咨询您的主治医生）。在每个周期中，您可能需要 1~3 天接受治疗。治疗结束后会有一段休息期，让您的健康细胞新生。

4.化疗常用中心静脉通路的选择^[3,4]

选择适当的静脉通路是预防因药物造成局部皮肤、肌肉组织及血管破坏的重要措施。首选中心静脉，包括中心静脉置管（CVC）；经外周静脉置入中心静脉导管（PICC）；输液港（Port），示意图如下（注：下图仅为示意图，请参考临床实用物）。



2

表 1 化疗常用的中心静脉通路的比较

（注：下表仅供参考，具体请以临床医护人员指导为主）

装置	中心静脉置管 (CVC)	经外周静脉置入中心静脉导管 (PICC)	输液港 (Port)
定义	经锁骨下静脉、颈内静脉、股静脉置入，尖端位于上腔静脉或下腔静脉的导管	经贵要静脉、肘正中静脉、头静脉、肘静脉、颈外静脉置入，尖端位于上腔静脉或下腔静脉的导管	完全置入人体内的闭合输液装置，包括尖端位于上腔静脉的导管部分及埋植于皮下的注射座。
使用期限	1~2 周	数月~1 年，或遵照产品说明书	4~5 年，或遵照产品说明书
维护周期	每周维护 1~2 次	至少每 7 天维护一次	非治疗期间应每 4 周到医院进行 1 次维护
优势	费用较低	置管步骤相对简单，损伤较小，留置时间长，并发症发生率相对较低。	完全植入体内，感染风险低，减少反复穿刺，减少每周换药及冲管，携带方便、美观。
劣势	操作较复杂，损伤较大，易引起并发症，感染率高，不适合长期静脉输液	价格较高，患者难以自我护理	置管和拔管都需要手术，费用也较 CVC 和 PICC 高
日常生活中的维护	1.防止导管扭曲、打折、滑脱。严禁自行移动导管。 2.穿开襟宽松衣物，避免穿紧身或高领衣服。	1.日常活动：可从事一般家务劳动、日常工作 and 体育锻炼，应避免置管侧手臂提拿、托举重物，以及剧烈运动； 2.置管期间沐浴：避免盆浴，淋浴前用塑料薄膜包裹保护置管部位，范围包括穿刺点上下 10 cm，层数≥2 层；淋浴后尽快用毛巾擦干局部并检查贴膜，一旦潮湿应及时更换。 3.穿衣：穿脱衣物动作轻柔，防止导管脱出，可剪取长 20 cm 的清洁丝袜罩于置管处手臂，保护导管； 4.睡眠：在治疗和睡眠时应避免长时间压迫置管侧肢体，以避免血液流动减缓，形成静脉血栓。	1.保持输液港周围皮肤清洁干燥，不可用力擦洗，避免局部皮肤损伤，避免置入部位受到撞击。 2.注意观察有无胸痛、胸闷、肢体麻木及发热等症状，如有请及时到医院就诊。

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5.化疗的副作用

化疗的目的是杀死快速生长的癌细胞，但它也会影响健康细胞。这些细胞包括口腔和肠道中的细胞，骨髓中负责造血的细胞，以及让您的头发生长的细胞。当化疗损害这些健康细胞时，可能会引起相应的副作用。



常见的有乏力、恶心呕吐、口腔溃疡、血细胞计数下降、脱发等。

化疗以不同的方式影响着人们，虽然这些药物有一些常见的副作用，但并不是每个人都会经历这些副作用。而且大多数副作用是暂时的，治疗结束后会逐渐消失^[4]。

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