Development and evaluation of A Self-Management WeChat Public Account for skin toxic reactions of immunotherapy patients with lung cancer

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Abstract

Background: The incidence and mortality of lung cancer are increasing year by year. Skin toxicity has become a common immune-related adverse event in patients with lung cancer immunotherapy. Mobile health devices have gradually developed, and electronic products are now available on the mobile medical platform to help lung cancer patients self-manage immune-related adverse events.

Objectives: The study is divided into four phases.   Phase 1: Evidence summary of skin toxicity self-management of lung cancer patients with immunotherapy and scale design and framework construction of WeChat Public Account. Phase 2: Assess the utilization of electronic devices for anti-tumor therapy in cancer patients. Phase 3: Develop the WeChat Public Account of skin toxicity in lung cancer patients with immunotherapy.Phase 4: Evaluate the usability of the Public Account.

Methods: We used the literature research method in the first phase. In the second phase, the purposive sampling method and group discussion were adopted. Then we used the brainstorming method in the third phase. In the fourth phase of the study, we used the focus group approach to conduct internal testing. A convenience sampling method was adopted to collect data.

Results: Through evidence extraction, the evidence was summarized from three aspects to form 32 best evidence. Based on this evidence, we constructed the framework and generated the preliminary image-text health education knowledge. Next, we found that the patients have self-management needs through the demand analysis and built the preliminary 3 modules and function design. Finally, we modified 6 problems through the focus group, PSSUQ data indicated that the median of usability was 4.67, information quality was 4.425, and interface quality was 4.4, which shows that the users were generally satisfied with the system as a whole. The results of the usability interviews also showed that most interviewees had a good user experience with our platform. However, the function design still needs improvement.

Conclusion: This study developed a WeChat Public Account which is called "FDUSCC-Nursing" based on the evidence summaries, framework construction, and demand analysis. It has been evaluated with good clinical usability and good user experiences, and it has excellent further clinical application.

Keywords: Mobile health, Lung cancer, Immunotherapy, Symptom management.

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1   Introduction

1.1   The incidence and mortality of lung cancer are increasing year by year

In 2020, there were 2.2 million newly diagnosed cases of lung cancer worldwide, accounting for 11.4% of all new cancer cases and ranking second in incidence [1]. Lung cancer also accounted for the most cancer-related deaths worldwide with 1.8 million deaths, representing 18.0% of all cancer deaths and ranking first in mortality [1]. Lung cancer was the most common cancer in China in 2022 (1,060,600 cases). It is the leading cause of cancer-related deaths in males and females [2]. Alarmingly, according to the World Health Organizationsprojections, China is expected to have over 1 million new lung cancer cases annually by 2025, making it the country with the highest incidence of lung cancer in the world [3].

1.2   Standard treatment of lung cancer

Standard treatments for lung cancer include surgery, radiotherapy, chemotherapy, targeted therapy, and immunotherapy. Since its clinical application and achievement of good therapeutic effect in the 21st century, immunotherapy has been increasingly used in patients with advanced tumors, particularly checkpoint inhibitors (ICIs), which are gradually being established. The mechanism of ICIs is to activate the human immune system, enabling the body to rely on its immune ability to kill tumor cells and thereby improve the survival rate of patients. According to the related articles [4], the immunotherapy methods commonly used at home and abroad include immune-monotherapy; immunotherapy combined with chemotherapy; dual immuno-suppressive therapy; immuno-combined anti-vascular therapy, and immunoadjuvant/adjuvant therapy.

1.3   Common immune-related adverse events

While immune checkpoint inhibitors activate the immune system in the body to play an anti-tumor role, excessive activation may disrupt the balance of T cells, leading to T cells attack against normal tissues or organs, which can cause local autoimmune inflammation and a series of toxic events, referred to as immune-related adverse events (irAEs)[5]. The occurrence of irAEs may be related to T cell activation against common antigens, increased levels of pre-existing autoantigens, and increased levels of pro-inflammatory cytokines [5].

1.4 Skin toxicity has become a common adverse reaction in lung cancer patients with immunotherapy

Non-small cell lung cancer (NSCLC) is the most common histological subtype of lung cancer, accounting for approximately 80% of all cases [6]. Currently, the standard of care for NSCLC patients involves comprehensive treatment primarily consisting of early surgical intervention, complemented by radiotherapy, chemotherapy, and targeted therapy. However, during this treatment process, patients may experience a range of adverse immune reactions [7]. In relevant clinical trials, nearly 40% of NSCLC patients receiving immunotherapy were diagnosed with skin-related adverse reactions [8,9,10], with 2% to 10% of patients experiencing severe (> grade 3) skin adverse reactions [11,12]. Additionally, studies have demonstrated that such skin symptoms significantly impact patients' comfort and quality of life [13].

1.5 The management of skin toxicity

The assessment of skin toxicity incorporates assessment by medical staff and self-reporting by patients. Based on the PRO-CTCAE tool, domestic scholar Peng Nana [14] formed a PRO-CTCAE subset of lung cancer immunotherapy, which can be used for symptom monitoring of adverse reactions during immunotherapy in lung cancer patients. This subset contains 13 symptoms associated with skin toxic reactions and can indicate whether each symptom occurs or how severe it is after the occurrence, improving the accuracy and convenience of skin symptoms assessment through patient self-reporting. Skin toxic reactions often occur when patients stay at home, and medical staff cannot obtain patients' situation dynamically promptly. As a result, the assessment of these skin toxic reactions by medical staff may lead to risks of low reliability and time sensitivity [15]. All in all, these patients had urgent demands to manage their skin toxicity symptoms after discharge in the form of self-management.

1.6 Mobile health devices could improve the self-management ability of lung cancer patients

Currently, the Internet has become an important source of health-related information for cancer patients [16]. Web-based e-health care can mitigate the stigma associated with cancer, enhance patients' treatment experience, and to some extent, increase patients' enthusiasm to participate in treatment [17]. Furthermore, it can address issues such as shortage of professionals, delayed information dissemination, and high treatment costs associated with traditional intervention modes [18]. While existing mobile health programs in China primarily

focus on managing patients at the treatment stage, there is still insufficient support for the self-management of patients after discharge [19]. In contrast, foreign studies place more emphasis on the use of mobile health devices to support the continuous care of cancer patients, including self-management support [20]. Nevertheless, the application of mobile health technologies based on WeChat in caring for cancer patients is increasing [21]. These technologies are used to provide authorization to patients mainly through information provision, interactive feedback, self-monitoring, and other forms, allowing patients to better understand their own health and improve their self-management capabilities, resulting in more cost-effective and sustainable care [22].

In summary, with the increasing incidence and mortality of lung cancer in China, the skin toxic reactions experienced by lung cancer patients during immunotherapy continue to negatively impact patients' quality of life. Therefore, it is essential to develop a medical service for patients with skin toxicity that empowers them to manage their own skin symptoms and improve their quality of life. This study aims to use the WeChat Public Account as a platform for patients to conduct self-management. Based on patients' needs for self-management of skin symptom, we will develop a WeChat public account based skin toxicity self-management module for lung cancer patients. In addition, we will conduct a usability evaluation and further improve the self-management ability and quality of life of lung cancer patients.

2   Literature review

2.1   Standard treatment of lung cancer

2.1.1 Surgical treatment

In the early stages of small cell lung cancer treatment, surgery was once the preferred treatment. Schreiber et al. [23] in the United States found that patients with limited-stage small cell lung cancer (LD-SCLC) whose tumor stage was T1N0M0 had a significantly better outcome after surgical treatment than radiotherapy and chemotherapy. Currently, the mainstream medical view is that detailed TNM staging is necessary, especially for accurate evaluation of lymph node metastasis. For patients with stage T1-2N0M0, surgical treatment is recommended as the first-line treatment, followed by postoperative adjuvant therapy[23].

2.1.2 Radiotherapy and chemotherapy

Chemotherapy and radiotherapy have always been critical therapeutic options for small cell lung cancer that are used throughout all stages of treatment[24]. Simultaneous chemoradiotherapy can also be used. According to a meta-analysis [24], the local recurrence rate was reduced by 25% to 30% and the 2-year survival rate was increased by 5% to 7% compared with chemotherapy alone.

2.1.3 Targeted therapy

Targeted therapy involves the use of drugs that can specifically bind to oncogenic gene loci to induce specific death of cancer cells in the body[25]. It is generally applied to advanced lung cancer patients. Compared with chemotherapy, targeted drugs have higher efficacy and fewer side effects, thus enabling precise treatment of lung cancer [25], which has greater clinical application value.

Targeted therapies have rapidly developed in the past few decades, starting with gefitinib, the first drug targeting epidermal growth factor receptor (EGFR), and EGFR tyrosine kinase inhibitor (TKI) drugs constantly being developed. Targeted therapies for other driver gene mutations have also made breakthroughs. Currently, the driver gene mutation targets of approved targeted therapies for lung cancer at home and abroad include EGFR mutation, anaplastic lymphoma kinase(ALK) fusion, ROS proto-oncogene 1(ROS1) rearrangement, BRAF-V600E mutation, neuro trophin receptor kinase (NTRK) fusion, Kristen rat sarcoma

viral oncogene(KRAS)-G12C mutation and human epidermal growth factor receptor-2 (HER2) mutation, among others.[26].

2.1.4 Immunotherapy

Since its clinical application and achievement of good therapeutic effect in the 21st century, immunotherapy has been increasingly used in patients with advanced tumors, particularly the lung cancer immunotherapy system based on immune checkpoint inhibitors (ICIs), which is gradually being established[4]. The mechanism of ICIs is to activate the human immune system, enabling the body to rely on its own immune ability to kill tumor cells and thereby improve the survival rate of patients[4.]

According to the related article [26], the immunotherapy methods commonly used at home and abroad include:

Immune monotherapy: The first indication of ICIs monotherapy is second-line treatment or more, and clinical trials of ICIs monotherapy first-line treatment have been carried out successively after the success of second-line and post-line treatment, and the beneficiaries are mainly people with high expression of PD-L1.

Immunotherapy combined with chemotherapy: Currently, chemotherapy combined with immunotherapy has become the standard first-line treatment for EGFR/ALK wild-type advanced NSCLC. Due to the limited treatment population of immunomonotherapy, combined therapy is an important strategy to expand the population suitable for immunotherapy.

Dual immunosuppressive therapy: Relevant studies have shown [27] that the combined application of some immunosuppressive agents can synergistically activate anti-tumor immune responses and improve the efficacy of immunotherapy.

Immunocombined anti-vascular therapy: anti-angiogenic drugs acting on the tumor microenvironment can transform the immunosuppressive microenvironment into a supportive microenvironment. At the same time, the use of anti-angiogenic drugs can reshape tumor blood vessels and enable immune effector cells to effectively infiltrate the tumor [28].

Immunoneoadjuvant/adjuvant therapy: The study results of IMpower010[29] showed that attillizumab adjuvant immunotherapy significantly improved the survival rate of patients compared with the best supportive therapy.

2.2   Common immune-related adverse events

While immune checkpoint inhibitors activate the immune system in the body to play an anti-tumor role, excessive activation may disrupt the balance of T cells, leading to T cells attack against normal tissues or organs, which can cause local autoimmune inflammation and a series of toxic events, referred to as immune-related adverse events (irAEs)[5]. The occurrence of irAEs may be related to T cell activation against common antigens, increased levels of pre-existing autoantigens, and increased levels of pro-inflammatory cytokines [30].

According to relevant studies, skin toxicity is the earliest and most common irAE. Women, patients with a history of allergy, chemotherapy, and advanced tumors, are particularly prone to immunotherapy-related skin toxic reactions [31]. These reactions are often clinically manifested as a measles-like rash (accompanied by pruritus), telangiectasia, pruritus, and vitiligo on the torso and limbs [32]. The median time of occurrence is about 1 month after immunotherapy, and most skin toxicity can be relieved, while some require remission after reducing or delaying immunotherapy. Additionally, irAEs can affect multiple systems in the body. Some examples are immune-related pneumonia, nephrotoxicity, endocrine adverse reactions, cardiac adverse reactions, and enteritis[30]. The types and characteristics of irAEs are related to the types of immune checkpoint inhibitors and the patient's own state. The severity of IRAES varies from an asymptomatic state to a life-threatening health situation[30] .

2.3   Application status of mobile health care in lung cancer patients

2.3.1 Application status of mobile medical care in lung cancer patients abroad

In developed countries, mobile medical care, using mobile health technology, has become a common way to provide remote nursing and health education to lung cancer patients. A randomized controlled trial by Denis et al. [33] on 49 patients with lung cancer showed that health education via smartphone applications extended the survival time of patients in the intervention group. Patients shifted from relying on the hospital to relying on themselves and their families for health management, from passive acceptance to active participation, which helped to change bad habits and promote healthy behaviors. Tamara[34] et al. used mobile

health devices to train cancer pain patients in pain management skills by using health education videos to provide some guidance to them and found that patients' self-efficacy was significantly improved after the intervention. Patients were more likely to accept mobile health technology for pain management guidance than traditional means.

Moreover, users can obtain medical information through smart mobile devices to receive medical care services, and medical personnel can monitor the symptoms of patients through reported symptoms, which can better manage symptoms for patients. Tang FWK[35] used tablet computers for 10 newly diagnosed lung cancer patients to self-reported common symptoms (dyspnea, fatigue, pain,anxiety). After reviewing the evaluation results, nurses provided targeted educational interventions and concluded that tablet-assisted symptom assessment could help assess patients' symptom burden in a busy clinical environment. This method can identify individual needs for a customized symptom management plan. The study by Maguire et al. [36] proposed the use of the symptom management system (ASyMS) developed based on Internet technology to monitor the conditions of chemotherapy patients after discharge when the time of hospitalization and outpatient treatment was shortened, and the symptoms of patients could be managed in a timely and effective manner.

2.3.2 Application status of other electronic medical treatment in lung cancer patients abroad

3D health game: The US Lung Cancer Mobile Health Tool (m-Health TLC) is the first interactive, immersive 3D iPad health game[37]. The m-Health TLC games are supported by information in the form of stories of lung cancer patients, who provide health literacy and self-management for the game's characters. Additionally, lung cancer patients can simulate outpatient visits with clinicians in the game, providing opportunities for therapeutic communication skills [37].

Internet-based Network Platforms and Websites: Christine L Paul et al. proposed an Internet-based intervention program to provide valuable information, emotion,practical support to lung cancer outpatients through real-time chat and email on the Internet, but it has not been formally carried out yet [38]. For example, Fabrice Denis et al. conducted routine follow-ups of lung cancer patients for 19 months based on their weekly symptom self-scores on the website. They found that follow-up based on online self-reported symptoms improved the overall survival rate of lung cancer patients and reduced their recurrence rate [39]. Dumang et al. [40] specially developed "OncoKompas" for cancer patients, which stored the basic information of

all patients. Cancer patients and their families could communicate and share through this platform. When patients raised questions on the platform, nurses could provide timely feedback to help them cope with the problems caused by the disease.

Computer-based customized health enhancement support system: Carter et al. [41]are currently developing a computer-tailored decision support tool to support shared decision-making in lung cancer screening decisions; The web-based Comprehensive Health Enhancement Support System (CHESS) improves caregivers' understanding and coping capacity, This website not only provides various cancer-related knowledge, including lung cancer, scientific and healthy lifestyle, and the latest progress in cancer research but also offers a cancer knowledge learning section for patients to learn on their own.

2.3.3 Application status of mobile medical care in lung cancer patients in China

In recent years, mobile medical technology has been widely used in the medical and health field due to its convenient, fast,easy-to-promote characteristics. Medical professionals use mobile phones, tablet computers, and other wireless devices to transmit health information to patients and provide medical services. Currently, there are various forms of mobile medical applications, including mobile phones, social media (such as QQ groups and WeChat), SMS or email follow-up, mobile apps, remote monitoring systems and network platforms, and patient management networks of hospitals, families, and communities [42]. However, as mobile health care is still in the initial stage of exploration in China, most studies focused on its application in the care of patients with other diseases, such as coronary heart disease [43], diabetes [44], hypertension [45] and chronic obstructive pulmonary disease [46]. There are relatively fewer studies on patients with lung cancer undergoing chemotherapy.

Application of continuous care in patients with lung cancer: In recent years, there have been increasing studies on the use of WeChat groups, WeChat platforms, and network platforms for continuous care in patients with lung cancer. He Li et al. [47] divided 120 patients with lung cancer into a control group and an observation group. The control group received routine care, while the observation group received health guidance follow-up, and question-answering based on WeChat, combined with pictures, text, and videos to improve doctor-patient interaction and transform patients from passive rehabilitation exercise to active exercise. The results showed that the quality of life and self-efficacy scores of the observation group were significantly higher than those of the control group. Wang Miao et al.[48] conducted continuous nursing intervention based on telephone return visits and WeChat network

platform communication for patients with advanced lung cancer who planned to receive chemotherapy. They found that this intervention could improve the overall quality of life and psychological status of patients, significantly reduce the unplanned re-visit rate of patients, and reduce the medical burden of patients.

Application in medical diagnosis and symptom management of lung cancer patients: Previous studies[49] have shown that image diagnostic tools developed based on artificial intelligence and deep learning technology are accurate in qualitative diagnosis and prediction of the malignant probability of pulmonary nodules. Clinicians can identify benign and malignant pulmonary nodules within about 1s through PC or smartphone access, with an accuracy rate of more than 90%. The ASyMS lung cancer symptom management system developed by KEARNEY et al. [50] records symptom changes, early detection, and reporting of chemotherapy toxicity and side effects, which helps healthcare professionals to intervene and manage in time, overcome geographical and time barriers, save clinicians' time, and reduce errors caused by incomplete information and human fatigue. China's mLCCare lung cancer management system is used to monitor and record patients' clinical progress, treatment history, and biomarker data, which can be linked to biobank databases to link patients' disease data for biological samples to enhance the application of medical research and clinical practice [51]. Domestic scholar Pang Yongli [52] reported that the extended nursing management mode of lung cancer chemotherapy complications based on a mobile management system is highly scientific and practical, which helps patients monitor the occurrence of chemotherapy complications in a timely manner.

2.4   Framework

A holistic framework for the development of eHealth technologies: Holism posits that the properties of individual elements in a complex system are determined by the relations they bear to other elements [53,54]. A holistic perspective on eHealth technologies has been advocated elsewhere, as seen in the works of Dansky et al [55], Yusof et al [56], and Kukafka et al [57]. Without addressing the full range of factors, strategies to change behavior run the risk of being ineffective because they fail to recognize interdependencies between individual and organizational factors [57]. For us, this means that human characteristics, socioeconomic and cultural environments, and technology are closely interconnected.

The full development of the modules in this study follows the CeHRes roadmap in the holistic framework for e-health technology created by van Gemert-Pijnen et al. JE [58]. This roadmap

serves as a practical guideline to help plan, coordinate, and execute the participatory development process of eHealth technologies. The framework is intended for developers (such as technicians, designers, and health care professionals), researchers, policymakers, and students and health care providers for educational purposes). It also serves as an analytical instrument for decision-making about the use of eHealth technologies. The development process of an eHealth technology and the accompanying research activities can be divided into the following five parts (see Figure 1).

Contextual Inquiry: Information gathering from the intended users and the environment in which the technology will be implemented is conducted through field observations and interviews with intended users. This process provides insights into users' day-to-day rituals and habits and how technology can be matched to them.

Value Specification: This process elaborates on the outcomes of the contextual inquiry. Value specification involves the recognition and quantification of economic, medical, social, or behavioral values of key stakeholders.The most favorable solutions, along with user and organizational requirements, emerge from this process (such as user requirements and value drivers).

Design: Prototypes are built that fit with the values and user requirements. The design cycle involves the translation of functional requirements into technical requirements and prototypes, given the specified values and goals of the eHealth project. The project management team visualizes the translation into mock-ups keeping in mind the values, goals, and tasks that need to be fulfilled.

Operationalization: This step concerns the actual introduction, adoption, and employment of the technology in practice.

Summative Evaluation: Finally, summative evaluation refers to the actual uptake of a technology (its usage) and the assessment of the impact of eHealth technologies in terms of clinical, organizational, and behavioral terms.
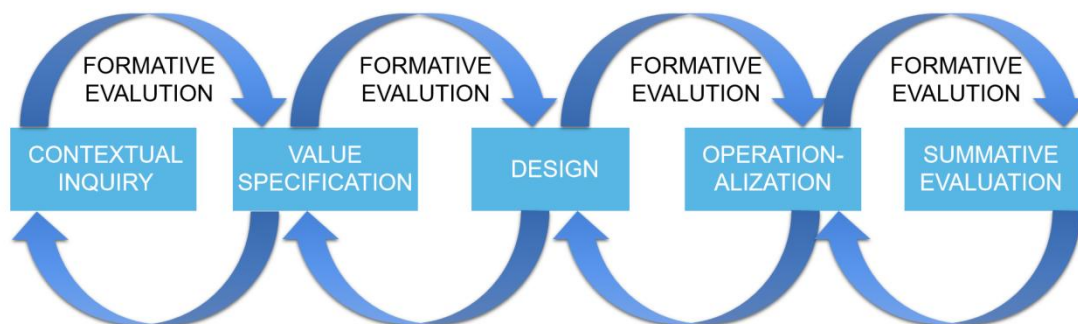
Figure 1：CeHRes Roadmap for the development of eHealth technologies

2.5   Definition

WeChat Public Account: An individual or organization can apply for a WeChat public account to promote all-around communication with a specific group, using various forms of media such as text, pictures, voice and video [59].

Lung Cancer Patient: In this study, lung cancer patients are defined as those who received relevant immunotherapy after being pathologically diagnosed with lung cancer [60].

Immunotherapy: Immunotherapy refers to the application of immunological principles and methods to overcome the state of immune tolerance or neglect of tumors by the body's immune system through passive or active means, and to enhance the body's anti-tumor immune response, with the aim of inhibiting tumor growth and eliminating tumor cells [61]. Commom immunotherapy drugs include cytotoxic T lymphocyte associated antigen-4, programmed death receptor-1/programmed death ligand-1(PD-1/PD-L1), Lymphocyte-activ-ationgene-3(LAG-3), among others [62].

 Self-management (SM): Self-management refers to a chronic disease management approach in which medical staff educate patients on the knowledge and skills necessary for disease management, give full play to their subjective initiative in disease management, empower them to take an active role in managing their condition, foster positive self-management attitudes and behaviors, and encourage patients to proactively achieve health goals and improve their quality of life [63]. In this study, the self-management group consists of lung cancer patients undergoing immunotherapy, who actively manage their skin toxicity symptoms through health information and nursing advice provided by medical staff.

Dermal toxic reaction (DTR): Drug-related skin toxicity is a common adverse effect [64]. Its clinical manifestations typically include a measles-like rash (accompanied by pruritus) on the trunk and limbs, dry skin, telangiectasia, pruritus and vitiligo, among other symptoms.

Mobile Health (MH): Telemedicine, also known as telehealth, refers to the use of mobile and wireless technologies (such as mobile phones, tablets, and satellite communications) to provide healthcare and information services from a distance. It represents a novel, patient-centered nursing model that is data-driven [65].

2.6   Summary

Immunotherapy is commonly used for lung cancer patients, and a series of immune-related adverse reactions caused by it require close attention by medical staff, especially immune-related skin adverse reactions, which are the earliest and most common immune-related adverse reactions[5,8] . Therefore, it is necessary for nursing staff to provide relevant nursing guidance. Furthermore, compared to the domestic development of mobile medical and electronic medical technology in foreign countries, the application of such technologies in lung cancer patients is more extensive and diverse. The information provided by relevant medical equipment is also more comprehensive and targeted. Currently, the application of mobile medical equipment in lung cancer patients in China mainly focuses on medical diagnosis and symptom management. However, there is a lack of substantive mobile medical equipment for follow-up care and self-management of lung cancer patients.

3   Research Purposes

Establish the framework and contents of self-management of skin toxic reactions in lung cancer patients with immunotherapy;

Assess the utilization of electronic devices for anti-tumor therapy in cancer patients;

Develop a WeChat Public Account of skin toxicity for lung cancer patients receiving immunotherapy;

Evaluate the usability of the WeChat Public Account.

4   Technology Roadmap
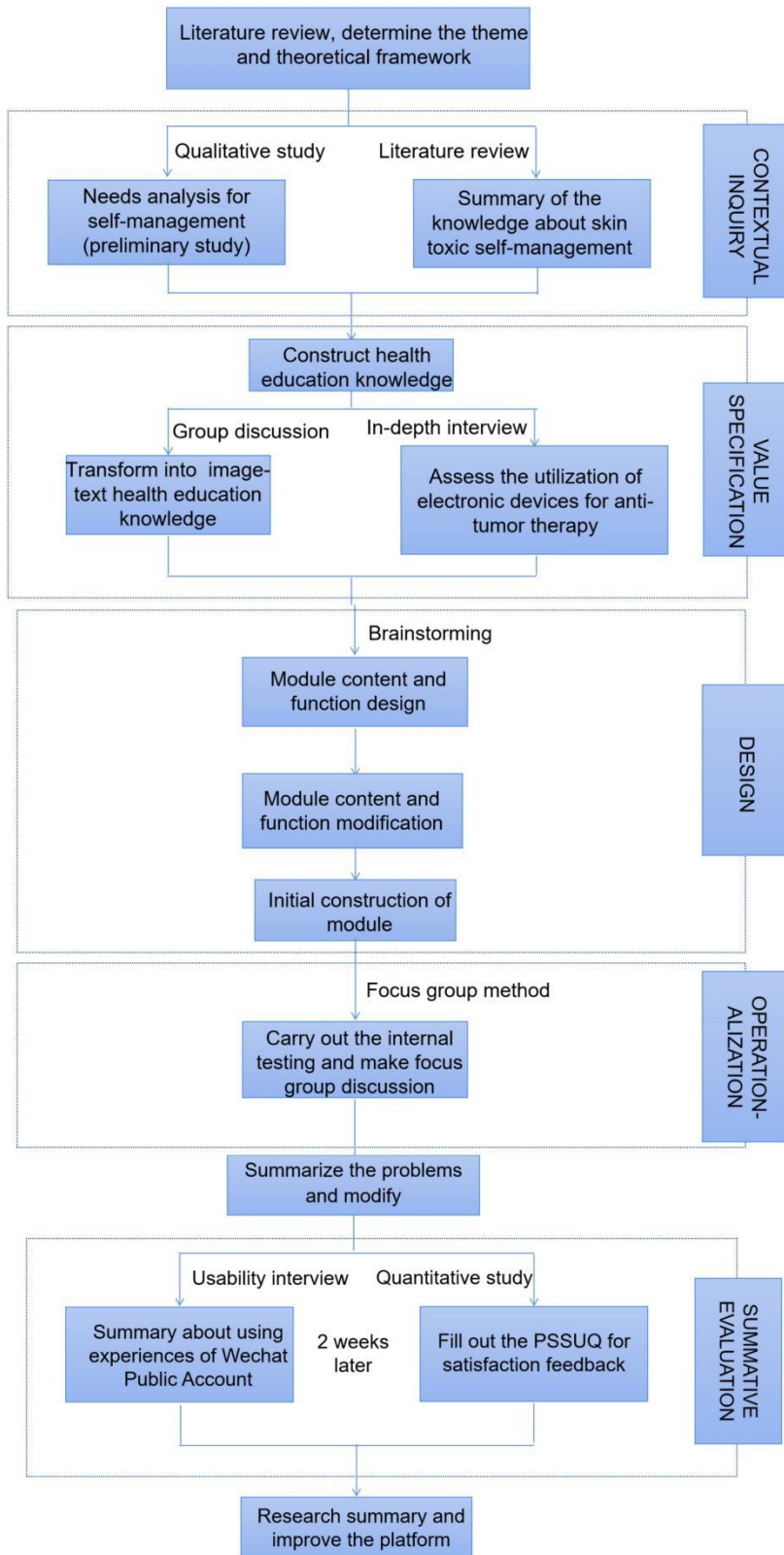
5   Phase 1: Evidence summary of skin toxicity self-management of lung cancer patients with immunotherapy and scale design and framework construction of WeChat Public Account

5.1   Identify the need for self-management of skin toxicity in immunotherapy patients with lung cancer (preliminary study)

A prior, qualitative study conducted interviews on the needs related to self-management of skin toxicity in lung cancer patients undergoing immunotherapy. Findings demonstrated that patients with lung cancer receiving immunotherapy had knowledge and information needs, symptomatic treatment needs, continuous service needs, and psychological counseling needs for self-management of skin toxicity symptoms. Certain challenges were also identified, including inadequate symptom recognition, insufficient self-management knowledge, ineffective self-response, and poor communication between healthcare providers and patients. These research results would provide the foundation for the development of the self-management module in the present study.

5.2   Evidence summary of skin toxicity self-management of lung cancer patients with immunotherapy

5.2.1 Research methods

Through a literature review approach, both domestic and international foreign guidelines, books, scientific literature, nursing practices pertaining to skin toxicity in immunotherapy were examined to establish the framework and content of the self-management knowledge required for the later development of the public account. The health education knowledge was then transformed into a visual image-text format based on professional discussions within the research team.

5.2.2 Search strategy

Database and networks were searched including CNKI, Pub Med, Cochrane Library, CINAHL, Web of Science, EMBASE, National Comprehensive Cancer Network Network (NCCN) , Joanna Briggs Institute (JBI). The search period would be extended up to July 2023.

Search terms used a combination of keywords and free words, including in English: "immunotherapy/chemotherapy/drug therapy/Molecular Targeted Therapy/immunological

therapy/Targeted Therapy/Drug Related Side Effects and Adverse Reactions/Drug Side Effect/skin toxicity/dermal toxicity/acute dermal toxicity/adverse skin reaction/skin lesions/self-management/Disease Management/Nursing, Practical/Practical Nursin /nursing intervention/nursing management/self-care."The Chinese search terms are"免疫治疗/化疗/靶向治疗""皮肤毒性/皮肤不良反应/皮肤毒性反应/皮肤损害/免疫相关不良事件""护理措施/应对策略/护理常规/自我管理/管理/自我护理"。

Search queries were conducted using CNKI and Pub Med as an example:

CNKI：(SU='免疫治疗'+'化疗'+'靶向治疗'）AND (SU= '皮肤毒性'+ '皮肤不良反应' + '皮肤毒性反应'+'皮肤损害'+ '免疫相关不良事件') AND (SU= '护理措施'+ '应对策略'+ '护理常规'+ '自我管理'+ '管理' + '自我护理')。

Pub Med:("immunotherap*y"[Mesh] OR "chemotherap*y"[Mesh] OR "drug therap*y"[Mesh] OR "Molecular Targeted Therap*y"[Mesh] OR "immunological therap*y"[Ti/Ab] OR "Targeted Therap*y"[Ti/Ab]) AND ("Drug-Related Side Effects and Adverse Reactions" [Mesh] OR "Drug Side Effect*" [Ti/Ab] OR " skin toxicit*y"[Ti/Ab] OR "dermal toxicit*y"[Ti/Ab]OR"acute dermal toxicit*y"[Ti/Ab] OR "adverse skin reaction*"[Ti/Ab] OR "skin lesions"[Ti/Ab]) AND ("self-management"[Mesh]OR "Disease Management"[Mesh]OR"Nursing, Practical"[Mesh] OR "Practical Nursing"[Ti/Ab] OR "nursing intervention*"[Ti/Ab] OR "nursing management"[Ti/Ab] OR "self-care"[Ti/Ab]).

5.2.3 Inclusion and exclusion criteria for references

Inclusion criteria are as follows:

- The study subjects must be cancer patients who have received or are receiving cancer-related treatment;

- The research must involve nursing management of skin toxicity;

- The literature types include clinical decision-making, guidelines, evidence summary, recommendations, best practices, expert consensus, systematic review and meta-analysis, and they should be published between January 1, 2015, to July 31, 2023, because the literature during this time may have timeliness and innovation.

- The literature must be written in Chinese or English.

Exclusion criteria are as follows:

- Incomplete information, inability to obtain the full text, and repeated publication of the study;

- Studies that do not pass the literature quality evaluation;

- Translated and interpreted versions of foreign guidelines, brief versions of guidelines, and non-latest versions(literature that was published earlier than 2015), which refers to the literature during the last ten years for the reason that this evidence could be more significant.

5.2.4 Literature Quality Evaluation

The guidelines were evaluated using the Appraisal of Guidelines for Research and Evaluation II, AGREEII [66], which includes 6 fields and 23 items, each scored on a scale of 1 to 7 points. Based on the standardized scores in each domain, the guidelines were divided into 3 levels of recommendation. Expert consensus and recommended practice were assessed using evaluation tools recommended by JBI Evidence-Based Health Care Center [67]. Critical appraisal for summaries of evidence (CASE) [68] was used to evaluate the quality of the included evidence summaries and clinical decisions. Clinical decision-making traced the source of evidence and evaluates the quality based on the type of original literature. The quality evaluation was independently performed by two researchers trained in evidence-based medicine according to the aforementioned criteria. In cases of differences in the evaluation opinions, a third researcher would be consulted for discussion and joint decision-making.

5.2.5 Evidence summary and polarization

Incorporate evidence-based complementary recommendations while preserving the original expression of independent evidence; when the evidence is the same, use concise and clear recommendations; when there are differences in the content of the evidence, prioritize high-quality, latest, or authoritative evidence. The level of evidence was pre-graded according to the JBI Evidence-based Health Care Center's Evidence Pre-Grading System (2014 edition), which is graded on a scale of 1 to 5 [69].

5.2.6 Research process

During this study phase, a senior dermatologist, an evidence-based senior researcher in related fields, and 4 medical staff from related departments of lung cancer immunotherapy were invited to review and provide feedback on the initial health education knowledge. Subsequently, the final image-text health education knowledge was established following revisions by the researcher, dermatologist, and researcher in turn after group discussion.

5.3   Results of the literature review and evidence summary

General features of the included literature: A total of 11 studies were included, comprising 4 guidelines, 3 evidence summaries, and 4 expert consensus documents. Figure 2 below illustrates the flow of literature inclusion and exclusion, while Table 1 provides an overview of the included studies.

Quality evaluation results of guidelines: Four guidelines [70,71,72,73] were included in this study. Among them, the overall quality evaluation results of 2 guidelines were grade A and the other 2 guidelines were grade B. The percentage of standardization in each field of the included guidelines and the results of two comprehensive evaluations are shown in Table 2.

Quality evaluation results of expert consensuses: Four expert consensuses [74,75,76,77] were included in this study. The evaluation results of all items were "Yes" and the research design was comprehensive, so the overall quality was high. Table 3 below illustrates the details.

 Quality evaluation results of evidence summaries: Three evidence summaries [78,79,80] were included in this study. The evaluation results of all items were "Yes" and the overall quality was good, so they were all included (Table 4) .7.3.2 Evidence summary and polarization:

The level of evidence was pre-graded according to the JBI Evidence-based Health Care Center's Evidence Pre-Grading System (2014 edition), which is graded on a scale of 1 to 5 [69]. Through evidence extraction and integration, finally, the evidence was summarized from three aspects (Self-assessment and proactive reporting, Daily protective measures, and common treatments) to form 32 best evidence. Table 5 below lists the 32 pieces of evidence in detail.

Preliminary search of the database(By Endnote,n=332):CNKI(n=42)、Pub Med(n=117)、Cochrane Library(n=99)、Web of Science(n=49)、NCCN(n=1)、JBI(n=20)、ESMO(n=2)、ASCO(n=1)、CSCO(n=1).

→ Exclude 38 duplicate literature

Read the title to get the literature(By Endnote,n=121):CNKI(n=30)、Pub Med(n=25)、Cochrane Library(n=5)、Web of Science(n=26)、NCCN(n=1)、JBI(n=10)、ESMO(n=2)、ASCO(n=1)、CSCO(n=1).

→ Exclude 109 inappropriate literature

Read the full text to get the literature(n=12)：CNKI(n=3)、Pub Med(n=2)、Cochrane Library(n=0)、Web of Science(n=0)、NCCN(n=1)、JBI(n=3)、ESMO(n=0)、ASCO(n=1)、CSCO(n=1).

Figure 2The inclusion and exclusion flow of literature

Table 1 The basic information of the included literature

Literature	Year	Source	Type	Title
中国抗癌协会肿瘤护理专业委[70]	2019	CNKI	Guideline	中国癌症症状管理实践指南——皮肤反应
American Society of Clinical Oncology[71]	2021	ASCO	Guideline	Management of Immune-Related Adverse Events in Patients Treated With Immune Checkpoint Inhibitor Therapy: ASCO Guideline Update
John A. Thompson[72]	2023	NCCN	Guideline	Management of Immunotherapy-RelatedToxicities
CSCO[73]	2023	CSCO	Guideline	免疫检查点抑制剂相关的毒性管理指南
王刚等[74]	2021	CNKI	Expert consensus	抗 EGFR 单抗治疗相关皮肤不良反应临床处理专家共识
中国抗癌协会[75]	2019	CNKI	Expert consensus	EGFR-TKI 不良反应管理专家共识
Califano[76]	2015	PUBMEND	Expert consensus	Expert Consensus on the Management of Adverse Events from EGFR Tyrosine Kinase Inhibitors in the UK
Gravalos[77]	2019	PUBMEND	Expert consensus	Clinical management of cutaneous adverse events in patients on targeted anticancer therapies and immunotherapies: a national consensus statement by the Spanish Academy of Dermatology and Venereology and the Spanish Society of Medical Oncology
Jolyn[78]	2022	JBI	Evidence	EGFRI: Management of Skin Toxicity

Literature	Year	Source	Type	Title
			summary	
Sophie[79]	2021	JBI	Evidence summary	Targeted Therapy: Epidermal Growth Factor Receptor Inhibitor Associated Skin Rash Prevention and Treatment
Tania[80]	2021	JBI	Evidence summary	Epidermal Growth Factor Receptor Inhibitor (EGFRI): Management of Cutaneous Adverse reactions

Table 2 Quality evaluation results of 4 guidelines

Literature included	Percentage of standardization by field (%)						Score	Level
	Scope and purpose	Stakeholder involvement	Rigour of development	Clarity of presentation	Applicability	Editorial independence		
中国抗癌[70]	80.57%	88.89%	77.08%	69.44%	35.41%	70.83%	5	B
American Society of Clinical Oncology[71]	75.56%	71.67%	83.29%	86.11%	62.5%	45.83%	5	B
John A. Thompson[72]	95.67%	78.8%	90.48%	98.9%	79%	78.42%	7	A
中国临床肿瘤学会指南工作委员[73]	96.88%	70.57%	62.34%	67.89%	80.26%	70.34%	6	A

Table 3 Quality evaluation results of 4 expert consensus

Annotation:C1: Is the source of opinion clearly identified?C2: Does the source of opinion have standing in the field of expertise? C3: Are the interests of patients/clients the central focus of the opinion? C4:Is the opinion's basis in logic/experience clearly argued? C5:Is the argument that has been developed analytical? Is the opinion the result of an analytical process drawing on experience or the literature? C6:Is there reference to the extant literature/evidence and any incongruence with it logically defended?

Literature included	C1	C2	C3	C4	C5	C6
王刚等[74]	yes	yes	yes	yes	yes	no
中国抗癌协会[75]	yes	yes	yes	yes	yes	no
Califano[76]	yes	yes	yes	yes	yes	no
Gravalos[77]	yes	yes	yes	yes	yes	no

Table 4 Quality evaluation results of 3 evidence summaries

Annotation: C1:Specific in scope and application; C2:Authorship is transparent; C3:Reviewers/ editors is transparent; C4:Search methods are transparent and comprehensive; C5:Evidence grading system is transparent and ttranslatable; C6:Recommendations are clear; C7:Recommedations are appropriately cited; C8: Recommendations are current; C9:Unbiased; C10:Can apply it to my patients.

Literature included	C1	C2	C3	C4	C5	C6	C7	C8	C9	C10
Jolyn[78]	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes
Sophie[79]	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes
Tania[80]	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes

Table 5 Evidence Summary

Category of evidence	Content of evidence	Level of evidence
Self-assessment and proactive reporting	1.Instruct patients to report suspicious symptoms to the treatment team (medical staff) in a timely manner when toxicity occurs [73].	2
	2.The severity of adverse skin events should be assessed as early as possible and refine whether specialist advice or referral is needed [72,78].	3
	3.Patients should be encouraged to report any changes in their health status to their medical staff [71].	4
	4.Patients should report the appearance or worsening of new symptoms immediately, and they also should avoid self-management without coordination with the oncology treatment team[72,79].	3
	5.The PRO-CTCAE self-report scale is recommended for self-assessment[71,72].	4
	6.Dry skin: Grade1:Covering <10% BSA and no associated erythema or pruritus. Grade2:Covering 10 - 30% BSA and associated with erythema or pruritus; limiting instrumental ADL. Grade3:Covering >30% BSA and associated with pruritus; limiting self care ADL[77].	1
	7.Bullous dermatitis: Grade1:Asymptomatic; blisters covering <10% BSA .Grade2:Blisters covering 10 - 30% BSA; painful blisters; limiting instrumental ADL.Grade3:Blisters covering >30% BSA; limiting self care ADL. Grade4:Blisters covering >30% BSA; associated with fluid or electrolyte abnormalities; ICU care or burn unit indicated[71,72,73].	1
	8.Palmar-plantar erythrodysesthesia syndrome: Grade1:Minimal skin changes or dermatitis (e.g., erythema, edema, or hyperkeratosis) without pain. Grade2:Skin changes (e.g., peeling, blisters, bleeding, fissures, edema, or hyperkeratosis) with pain; limiting instrumental ADL. Grade3:Severe skin changes (e.g., peeling, blisters, bleeding, fissures, edema, or hyperkeratosis) with pain; limiting self care ADL[77].	1
	9.Photosensitivity: Grade1:Painless erythema and erythema covering <10% BSA. Grade2:Tender erythema covering 10 - 30% BSA. Grade3:Erythema covering >30% BSA and erythema with blistering; photosensitivity; oral corticosteroid therapy indicated; pain control indicated (e.g., narcotics or NSAIDs)[77].	1
	10.Pruritus: Grade1: Mild or localized; topical intervention indicated. Grade2: Widespread and intermittent; skin changes from scratching (e.g., edema, papulation, excoriations, lichenification, oozing/crusts); oral intervention indicated; limiting instrumental ADL. Grade3:Widespread and constant; limiting self care ADL or sleep; systemic corticosteroid or immunosuppressive therapy indicated[71,72,73,77].	1
	11.Rash maculo-papular: Grade1:Macules/papules covering <10% BSA with or without symptoms (e.g., pruritus, burning, tightness) Grade2: Macules/ papules covering 10-30% BSA with or without symptoms (e.g., pruritus, burning,tightness); limiting instrumental ADL;Grade3:Macules/papules covering >30% BSA with moderate or severe symptoms; limiting self care ADL[72,73,74,77].	1
	12.Skin hyperpigmentation Grade1: Hyperpigmentation covering <10% BSA; no psychosocial Impact. Grade2:Hyperpigmentation covering >10% BSA; associated psychosocial impact[77].	1
Daily protective measures	13.Avoid direct sunlight without protection (e.g. using sunscreen)[70,74,75,78,80].	1
	14.Avoid products that can cause skin dryness (e.g. alcohol-based cosmetics, hot water)[70,75,78,80].	1
	15.Avoid beard growth and use correct shaving methods (e.g. trim facial hair before shaving, avoid electric shavers) and protective or moisturizing products that are less likely to damage or dry the skin[76,78,80].	2
	16.Avoid hair removal wax and plucking[76,78,80].	1

Category of evidence	Content of evidence	Level of evidence
	17.Regularly moisturizing with gentle chemical-free and oil-based products[70,74,75,78,80].	1
	18.Limit cosmetic use and use gentle products for make-up removal[78,80].	3
	19.Keep finger and toe nails trimmed[76,70,78,80].	2
	20.Vitamin K1cream has shown some benefit and is well-tolerated[70,80].	1
	21.For patients with depigmented skin in light-exposed areas, light protective measures are recommended to avoid sunburn[70,80].	2
	22.Patients should be informed of the necessity of sun protection before treatment, and the following sun protection measures should be taken every day: (1) Pay attention to physical cover when going out, such as sunshade, sun hat and sunglasses. (2) It is recommended to apply broad-spectrum sunscreen 30 minutes before going out after moisturizing cream[70,75,80].	3
	23.Timely moisturizing skin care after cleaning: (1) Choose light emulsion for the areas that secrete more oil, such as face, neck and back, twice a day; (2) Where the skin is prone to dry, such as the extremities and hands and feet, choose a thick cream or cream twice a day; (3) It is recommended to choose medical skin care products that do not contain ethanol, contain ceramides or other physiological lipids, and have the effect of skin barrier repair[70,75,80].	3
Common treatments	24.For grade 1-2skin toxicity: topical corticosteroids, emollients and oral antihistamines can be used when ICI treatment continues, and corticosteroids can be used twice a day until the condition improves[76,79].	2
	25.For≥grade 3 or intolerable grade 2 skin toxicity: Patients with more severe skin toxicity who do not respond to external drug treatment should be given systemic corticosteroid therapy, and ICI treatment may need to be interrupted or even stopped[76,79].	2
	26.The targeted treatment of pruritus includes oral antihistamines and topical medications[74].	3
	27.In those who have developed grade 1 to 3 acneform rash, topical corticosteroids and oral antibiotics in addition to usual skin care is suggested, as compared to usual skin care alone[74].	4
	28.Pruritus: Topical (medium-to high-potency steroids) or systemic (antihistamines or gabapentin/pregabalin or doxepin)[71,72,73,77].	4
	29.Xerosis: Topical for mild/moderate xerosis (emollient creams packaged in jar/tub that lack potential irritants,occlusive emollients containing urea, colloidal oatmeal and petroleum-based creams) topical for severe xerosis (medium to high-potency steroid creams[78,77].	4
	30.Radiation dermatitis: Topical (maintain hygiene and gently clean and dry skin in the radiation feld) or systemic (antibiotics (doxycycline))[72].	4
	31.Rash: Topical (alclometasone 0.05% cream, fuocinonide 0.05% cream twice daily, or clindamycin 1%) or systemic (doxycycline 100 mg twice daily, minocycline 100mg daily, or isotretinoin at low doses of 20 to 30 mg/day)[73,74,77].	4
	32.For paronychia: Preventative measures to avoid pressure and friction (loose footwear and correct nail trimming) is recommended[74,78].	4

5.4   Scale design and framework construction of WeChat Public Account

5.4.1 Design of the scale and logic of the WeChat public account

The development of this initial self-report scale is rooted in the framework of the lung cancer immunotherapy PRO-CTCAE subset (Appendix 1). It facilitates patients to initiate the self-report process, and if the report indicates the presence of skin toxicity, they will be directed to complete the subsequent standardized questionnaire.

Subsequently, participants would be asked to complete a standardized questionnaire, which is based on the NCI-CTCAE 5.0 grading standard for skin adverse reactions. This questionnaire would provide a more comprehensive assessment of the severity of skin toxicity. To develop the questionnaire, we identified 9 common symptoms (including dry skin, pruritus, palmar-plantar erythrodysesthesia syndrome, reactive cutaneous capillary endothelial proliferation, rash macular-papular, photosensitivity, skin hypopigmentation, vitiligo, bullous dermatitis) of skin toxicity associated with immunotherapy through a thorough review of the existing literature (Appendix 2).

5.4.2 Generate the preliminary image-text health education knowledge

Based on the "daily protective measures" and "common treatments" parts of the evidence summary, we generated the preliminary image-text health education knowledge. It contained 7 essays and they can be divided into 4 major themes, they were "basic knowledge of skin toxicity of Immunotherapy", "skin protection", "life care of skin", and "medication guide"(Appendix 3). What's more, our team filmed and edited three of its own small health education videos about skin protection in this process (Appendix 4).

5.4.3 Generate the final image-text health education knowledge

We refined the preliminary image-text health education knowledge into the final image-text health education knowledge through collaborative discussions with 4 engineers (Appendix 5).

5.5   Discusion

5.5.1 Abundant evidence sources, with good timeliness and practicability

The evidence summarised derived from 4 guidelines, 4 expert consensus papers and 3 evidence summaries. The overall quality of the literature was high, and all of them were

published or updated in 2019 or later, with strong timeliness. The evidence items included all involved self-management of skin toxic reactions in immunotherapy, which was consistent with the subject of evidence, and the evidence was supported by both foreign and domestic literature, which had certain reference values for the practice of self-management of skin toxic reactions in immunotherapy.

5.5.2 Patient-reported outcomes are necessary for self-management of cancer patients

Patient-reported outcomes (PROs) are essential for the self-management of cancer patients. PROs, which concentrate on patient self-reported health-related outcomes and emphasize capturing a patient's genuine experiences, can offer more reliable information about the patient compared to conventional clinical indicators [81]. The included guidelines [71,73] propose that by utilizing self-reported outcome information from cancer patients, healthcare professionals can gain a more comprehensive understanding of the issues and requirements of patients during the treatment or self-management process. It is important to acknowledge that during the self-management of patients experiencing skin toxicity, the reported outcomes may vary due to differences in individual symptoms. Therefore, healthcare professionals should advise patients to conduct a rational analysis of the reported outcomes and implement tailored self-symptom management measures based on the specific symptoms observed.

5.5.3 Self-symptom management should be carried out when the patient is discharged

Post-discharge self-symptom management should be implemented as part of the patient's care plan. Irrespective of the underlying condition, patients should engage in self-symptom management activities following discharge. Findings from a foreign randomized controlled trial demonstrated that post-discharge self-management interventions are safe and effective, leading to a significant reduction in patient readmissions within a 30-day timeframe [82]. Therefore, for cancer patients experiencing skin toxicity, healthcare professionals can encourage regular self-assessment and self-management activities post-discharge, aiming to maintain symptom stability and enhance their quality of life.

5.6   Conclusion

The evidence summaries systematically synthesized the most robust evidence regarding the self-management of cancer patients experiencing skin toxicity, encompassing three key aspects: "Self-assessment and proactive reporting", "daily protective measures" and "common treatments"."Self-assessment and proactive reporting" plays a crucial role in the self-management process, enabling patients to gauge the presence and severity of skin toxicity."Daily protective measures" empowers patients with appropriate medical knowledge to effectively safeguard their skin health. "Common treatments" entails the utilization of numerous medical guidelines. Hence, healthcare professionals should provide guidance to patients in implementing specific self-symptom management interventions tailored to their individual symptoms, as identified through patient-reported outcomes (PROs).

6 Phase 2: Assess the utilization of electronic devices for anti-tumor therapy in cancer patients

6.1 Qualitative interview

6.1.1 Research methods

By conducting qualitative interviews with patients currently using or who have used electronic products related to anti-tumor therapy, we could gain a deep understanding of the demand and usage situation of existing electronic products for anti-tumor therapy in cancer patients. This information provided a basis for the design of the skin toxic reaction module and product design that will follow.

6.1.2 Research setting and subjects

The purposive sampling method was used to select tumor patients from the Fudan University Shanghai Cancer Center(FDUSCC)for semi-structured one-on-one in-depth interview.

Inclusion criteria:

- Pathological diagnosis of tumor;

- Age ≥18 years old and having received relevant anti-tumor therapy;

- Experiencing treatment-related adverse reactions, and using or having used electronic products related to anti-tumor therapy;

- Being willing to participate in the interview and physically able to do it during the interview.

Exclusion criteria:

- Patients who are having a combination of other serious life-threatening diseases;

- Having cognitive impairment or mental illness.

The sample size is determined based on data saturation, which was reached when no new and important topics emerged.

6.1.3 Interview outline

Have you received anti-tumor therapy, and if so, are you aware of any related adverse reactions or preventive measures that may occur as a result of the therapy? If yes, through what channels did you learn about them?

What types of electronic products related to anti-tumor therapy (such as WeChat mini-programs, WeChat public accounts, or mobile applications) have you used in the past or currently?

Do you find the module design of the electronic products helpful for managing your symptoms? Which module design is your favorite, and why? In what ways has it helped you?

Do you find the content of the electronic product attractive and engaging enough for you to use regularly? How often do you use it, and do you find it easy to use?

What do you think are the advantages and disadvantages of this electronic product? What improvements do you think could be made for similar electronic products in the future?

6.1.4 Data Collection

Prior to the formal interview, the researcher(Jutao Hu) introduced herself, explained the purpose, content and process of the study to the participants, ensured the confidentiality of the interview content, and guaranteed the anonymity of the study. The researcher obtained the participants' consent and signed the informed consent form (details are provided in Appendix 6). The interview process was recorded and lasted between 15 to 25 minutes. The interviews were conducted in a quiet, private room to minimize interruptions. During the interview, the researcher listened carefully, explored specific questions in depth, paid attention to the participants' expressions, movements, and emotional responses, and took notes throughout the interview. The recordings were transcribed into written transcripts and returned to the participants for verification.

6.1.5 Data Analysis

Within 24 hours after the interview, the recordings were transcribed into a written transcript, and the transcribed contents were time-stamped according to the interview situation, and a label was created. All recordings were imported into NVivo 11.0 software for data management and analysis. Conventional content analysis was used to systematically analyze,

summarize and encode all transcribed data. It was a kind of research method to describe the communication content objectively, systematically and quantitatively. Its essence was the analysis of the information contained in the communication content and its changes. Two research team members independently read and analyzed the data.

6.1.6 Quality control

Participants were encouraged to prepare fully for the formal interview and became familiar with the interview process. The interview data was transcribed by two researchers and checked verbatim to minimize research bias.

6.2 Results of qualitative interview

6.2.1 The demographic characteristics of the participants in the interview

A total of 12 patients were included in this study, and their demographic information is presented in Table 6.

Table 6 The demographic information of interviewees

No.	Gender	Year	Education	Diagnosis	Treatment
1	Male	55	Junior high school	Prostate cancer	Radiotherapy
2	Male	66	Junior high school	Prostate cancer	Chemotherapy
3	Male	56	Senior high school	Prostate cancer	Radiotherapy
4	Male	47	Primary school	Prostate cancer	Chemotherapy
5	Male	60	Junior high school	Bladder cancer	Radiotherapy and chemotherapy
6	Male	58	Senior high school	Prostate cancer	Radiotherapy
7	Male	62	Junior high school	Bladder cancer	Radiotherapy
8	Female	48	Senior high school	Renal cancer	Targeted therapy
9	Female	56	Junior high school	Renal cancer	Targeted therapy

No.	Gender	Year	Education	Diagnosis	Treatment
10	Male	65	Junior high school	Bladder cancer	Chemotherapy
11	Male	60	Primary school	Bladder cancer	Chemotherapy
12	Male	59	Senior high school	Bladder cancer	Radiotherapy and chemotherapy

6.2.2 The topics were refined after the interview analysis

Topic1:The demand for self-management information

The demand for post-discharge anti-tumor knowledge: Certain patients express a requirement for ongoing medical consultation regarding their knowledge of anti-tumor measures after being discharged, as quoted below

> "*There will inevitably be some adverse reactions after discharge, and it is impractical to visit the hospital for consultation every time, as it would be time-consuming and costly*." (P 10)

> "*While being in the hospital, I could readily contact doctors and nurses for immediate assistance, which was very convenient. However, I also desire guidance and support from healthcare professionals once I am at home*." (P5)

Limited access to self-management information: Certain patients may seek information from various online platforms; however, these sources often require financial resources, and the information provided is not tailored to their specific needs.

> "*I also consult some medical platforms, but I can only ask two or three questions each time, and we cannot obtain professional guidance." P8 stated, "I usually rely on Zhihu App or other medical platforms to gather medical information, but the amount of information obtained is limited.*"(P9)

Topic2:The WeChat public account of the department facilitates effective self-management for patients

The health consultation module offered by the department's WeChat Public Account facilitates effective self-management for patients post-treatment.

"Through the health consultation module, I can regularly share pictures of my ostomy with the doctor for real-time consultations."(P1)

"I regularly access the health consultation module to acquire the medical knowledge I require, which enhances my understanding of my condition."(P7)

The health education module offered by the WeChat platform delivers a wealth of medical knowledge.

"The WeChat public account regularly provides me with health education tips, and I read them when I have free time." (P7)

"I find the medical knowledge in these posts to be more comprehensive and specific compared to what I can find on the internet, and I make sure to click on them every time."(P12)

Topic3:The demand for enhanced self-management capabilities of electronic devices

Electronic products should feature user-friendly interfaces: Numerous electronic products are designed for the elderly population, necessitating more convenient and simplified operating systems.

"I don't use smartphones much because they are too complex to operate." (P8)

"Of course, I prefer using devices that are more convenient and easy to operate."(P9)

"If I find a device difficult to use, I won't continue using it."(P2)

The content design of the health education model should be more personalized and tailored.

"The medical advice provided by the department is quite general, lacking specific guidance for different patient conditions." (P3)

"I hope to see more targeted health education materials in the future that cater to different types of patients, enabling me to have a clearer understanding of what actions I should take."(P6)

The functional design of modules should be more diverse.

"The WeChat public account of our department has a check-in function, which I believe is a good design for promoting health behavior management. However, I often forget to check-in."(P4)

"I wish to have an app with interactive games that can enhance my interest in learning about health knowledge."(P5)

Regarding content format, patients exhibit varying preferences, with a majority expressing a preference for content that combines graphics and text.

"Due to my limited memory, I find it easier to remember knowledge when it is presented through a combination of pictures and words." (P1)

"Personally, I prefer content in the form of text, pictures, voice, or video."(P3)

6.3 Discussion

6.3.1 The cognitive and self-management capacity of cancer patients in response to cancer therapy is inadequate

Foreign studies on supporting the self-management of cancer patients have a long history, encompassing various intervention modalities, often incorporating online approaches such as telephone follow-up and internet-based interventions. In contrast, domestic research on the self-management of cancer patients began relatively late, with limited implementation and a narrow focus, primarily centered around enhancing health education post-discharge [83]. The survey subject of this study is limited to Fudan University Shanghai Cancer Center, and the sample size is small, which reduces its representativeness to some extent. Consequently, it is imperative to proactively conduct prospective randomized controlled clinical trials to offer evidence-based, scientifically valid self-management skills training and enhance the patients' self-management capabilities.

6.3.2 The diversified functions of mobile health were conducive to improving patients' self-management ability

Some existing studies have shown that mobile health devices can help improve lung function symptoms and psychological functions of lung cancer patients[84], improve the quality life of

lung cancer patients[85], and save medical costs in medical institutions[86]. Therefore, in the future, medical personnel should develop high-quality and diversified mobile medical devices integrating symptom assessment, symptom management, health information provision, and interactive feedback. After that, they should carry out relevant application studies in lung cancer patients to explore its feasibility, so as to establish a sound application system for mobile medical self-management of lung cancer patients.

6.3.3 The functionality and content of electronic products utilized in anti-tumor therapy should be diverse and comprehensive.

Currently, numerous anti-tumor electronic products in China manifest common challenges, limited formats, and the prevalence of standardized templates. Consequently, patients often perceive these platforms as lacking attractiveness and usability[87]. Therefore, when designing new anti-tumor electronic products, considerations should be made regarding their ease of use for all individuals, the need for personalized and targeted content design catering to diverse populations, and the incorporation of diverse and comprehensive functional module designs.

6.4   Conclusion

The in-depth interview reveals that certain patients express a demand for continuous medical knowledge consultation and self-management electronic products. Consequently, clinical medical personnel should conduct comprehensive evaluations of the medical requirements of tumor patients, gain a thorough understanding of their attitudes and cognitive status regarding post-discharge self-management, and develop electronic products for anti-tumor treatment that integrate information with medical interventions. Furthermore, there is a need to continuously enhance the functionality and content design of these products to better align with the specific needs of patients.

7 Phase 3:The preliminary module content and function design of WeChat Public Account

7.1 Module content and function design

The researcher herself formed a multidisciplinary team consisting of four medical staff from related clinical departments and two software developers. Based on the preliminary demand analysis results and image-text health education knowledge, the researcher was responsible for the framework and the overall scale design of the platform, then the brainstorming method was adopted to discuss with the professors and finalize the function and content design details of the WeChat Public Account.

7.2 The preliminary modules and functions design include:

The name of the WeChat Public Account was called "FDUSCC-Nursing".The function and content design of the public account decided by the multidisciplinary team were as follows:

"Symptom-assessment module": This module had two parts: the first part was the scale which was adapted from the lung cancer immunotherapy PRO-CTCAE subset, and the second part was the standard questionnaire (It was based on NCI-CTCAE 5.0 skin adverse reaction grading standard), through doing these scales they can evaluate their skin symptoms and obtain their skin toxicity severity rating.

"Symptom-management module": It contained three main functions: health education, follow-up management, and health consultation. They included skin medication, diet guidance, life care, medical and treatment guidance, health education, severity warning, and more.

7.3 Workflow of WeChat public account

Patients can access FDUSCC-Nursing by scanning the QR code or other methods (such as direct referral from medical staff), and the system will dynamically recommend relevant scales based on the patient's condition. Upon completion of the questionnaire, if the patient exhibits skin toxicity, the system will provide corresponding medication guidelines and pertinent skin prevention knowledge tailored to the severity of the evaluated outcomes. If no skin toxicity is detected, the system will deliver general skin prevention knowledge to the patient. Additionally, after one week, the "clock" module will automatically remind the

patient to participate in another evaluation. The workflow of the WeChat Public Account is illustrated in Figure 3.

7.4 An example (Dry skin) of patient manual

Step1:Scan the QR code (Figure3)

Patients can access FDUSCC-Nursing by scanning the QR code or other methods. This QR code will be given to them after discharge or during the process of discharge health education.

Figure 3. QR code

Step2: User registration (Figure4)

During this step,after following WeChat Public Account,the patients will be asked to make the user registration of their personal information.
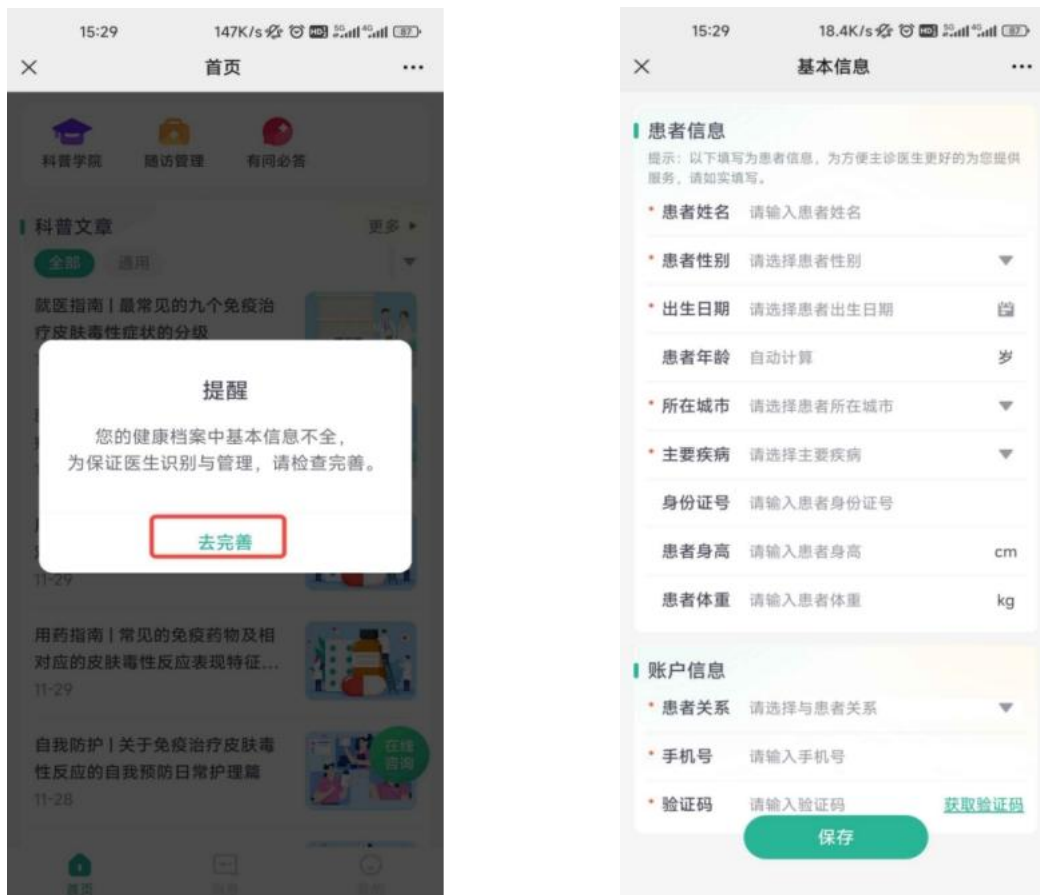
Figure 4 User registration

Step3: Filling in the preliminary Pro-CTCAE questionaire (Figure5)

The patients can have access to the preliminary Pro-CTCAE questionnaire after registration. It facilitates patients to initiate the self-report process, and if the report indicates the presence of dry skin, they will be directed to complete the subsequent standardized questionnaire, if not, they will be asked to move on to the next question in the preliminary Pro-CTCAE questionnaire for the assessment.
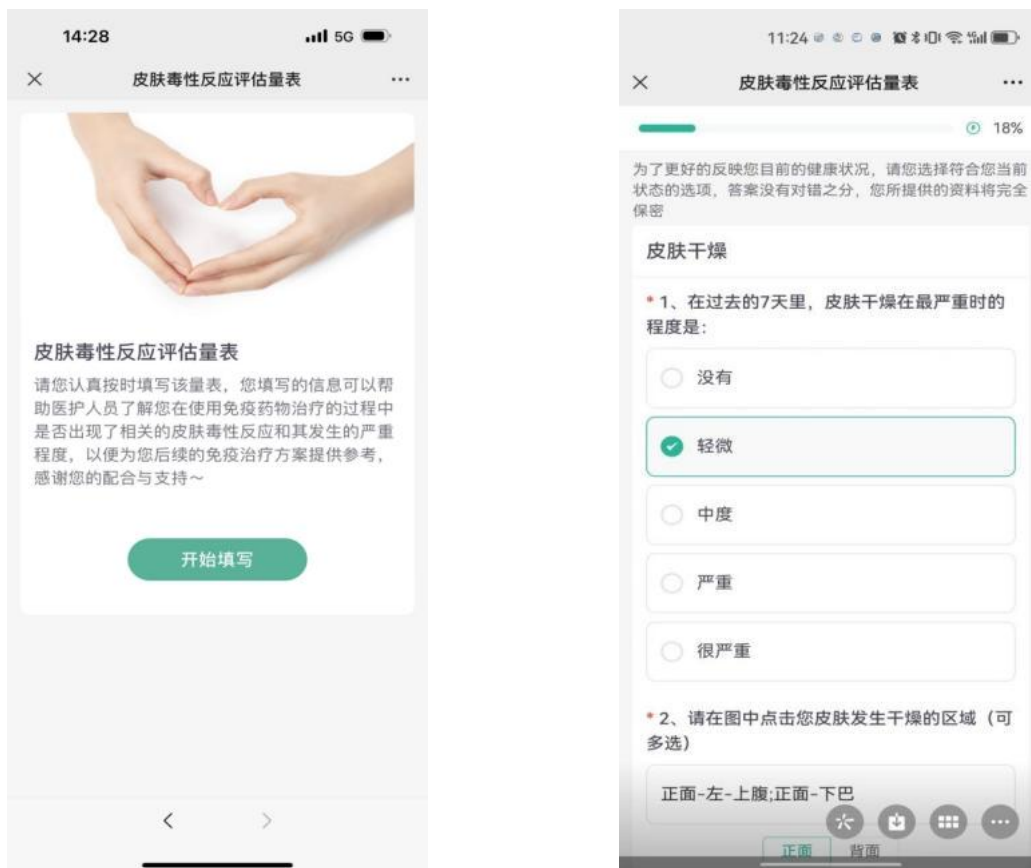
Figure 5 Filling in the preliminary Pro-CTCAE questionaire

Step 4: Filling in the standardized questionnaire (Figure6)

Subsequently, participants will be asked to complete a standardized questionnaire, which is based on the NCI-CTCAE 5.0 grading standard for skin adverse reactions. This questionnaire will provide a more comprehensive assessment of the severity of skin toxicity. This system will calculate the area and grade the severity of skin toxicity. After that, they will fill in the next question in the preliminary Pro-CTCAE questionnaire and enter the next cycle.

Figure 6 Filling in the standardized questionaire

Step5: Evaluation results and corresponding self-protection recommendations (Figure7)

After the patients complete all the questions, the system will have a comprehensive evaluation result and push corresponding self-protection recommendations to the patients according to their self-assessment symptoms. If the condition of the patient is worse (reaches the warning value), the system will automatically alarm the doctor, and the medical staff will carry out further intervention.
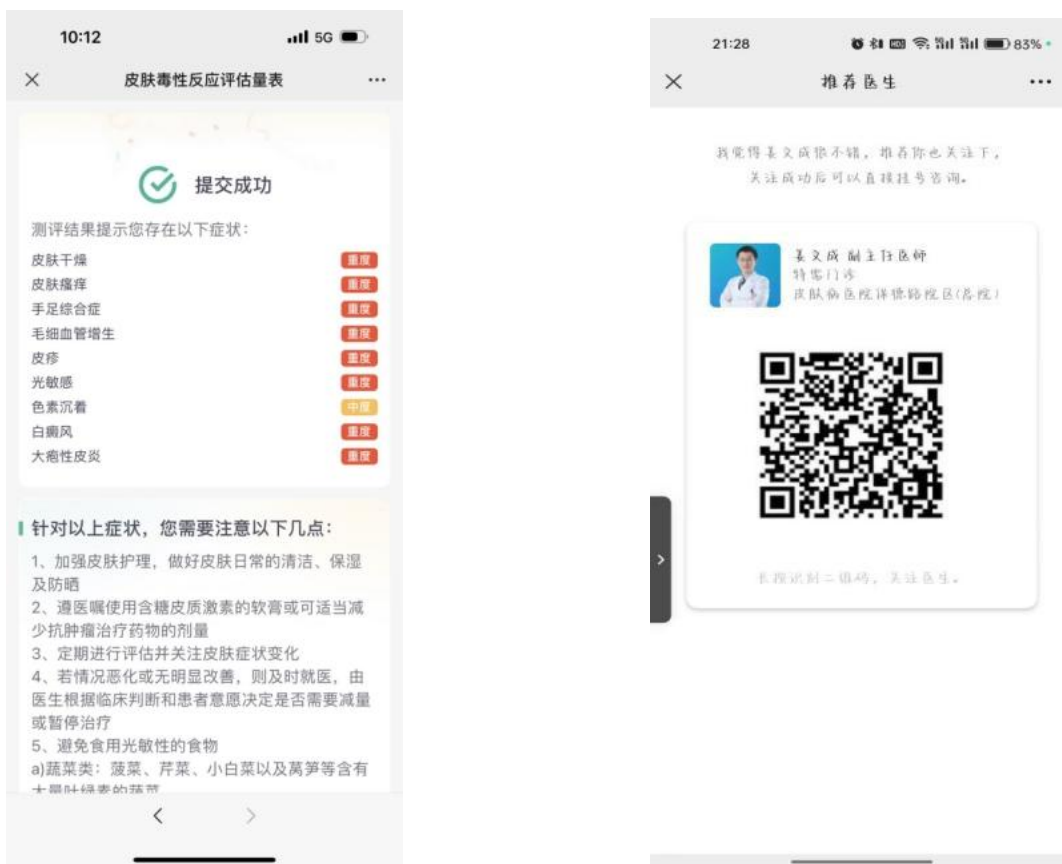
Figure 7 Evaluation results and corresponding self-protection recommendations

Step 6:Browse the health education knowledge (Figure8)

Although the patients have completed the questionnaire, they still have more or less relevant questions about their symptom management, at this time they can click on the "health education" module to browse the relevant health education articles, in fact, after they complete the form, the system will also push some articles for them.
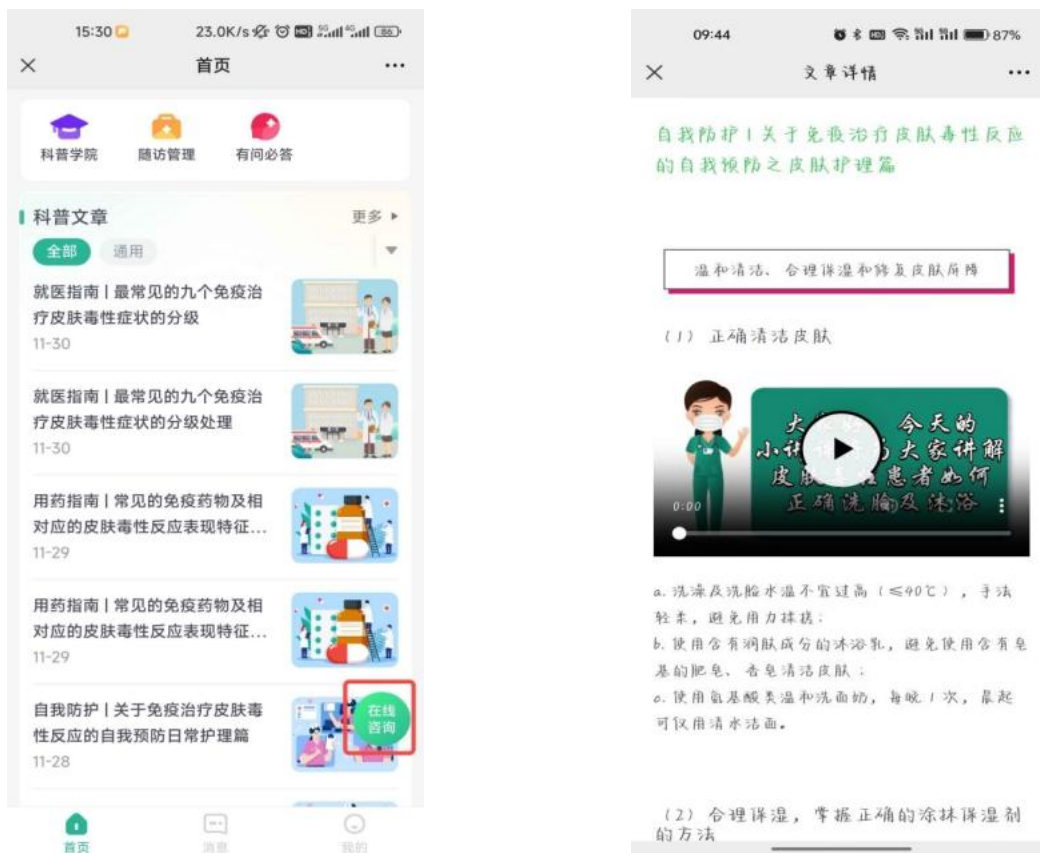
Figure 8 Browse the health education knowledge

Step7: Consult about correlative information (Figure 9)

As the knowledge content of the health education articles produced by the system is limited and universal, some patients may still have questions after reading the relevant science articles, so they can go to the "health consultation" module for further consultation. If the machine answers still cannot solve their problems, they can further transfer to the manual to consult the doctors online.
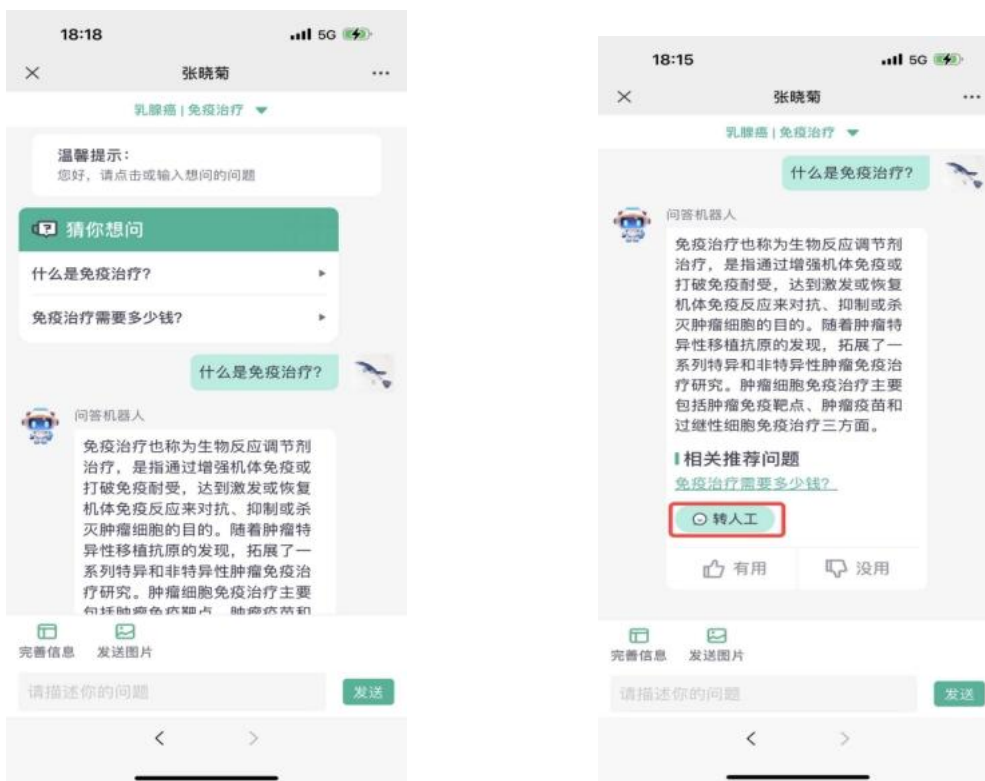
Figure 9 Consulation on the correlative information

8   Phase 4: Usability evaluation of the WeChat Public Account

8.1   Research methods

This study used two methods to collect data for the usability evaluation. The first method used focus group discussion to obtain opinions and further modifications. The second method used convenience sampling to select 20 lung cancer immunotherapy patients from Fudan University Shanghai Cancer Center to use WeChat named "FDUSCC-Nursing" and follow up for two weeks. The patients' experience was summarized through usability interviews, and the Post-Study System Usability Questionnaire (PSSUQ) was distributed to collect patients' satisfaction with its use.

8.2   Focus group for internal test discussions

8.2.1 Focus Group Discussion

The focus group method was commonly used for usability evaluation and it was utilized in this study. After constructing the WeChat Public Account, internal testing was conducted, followed by focus group discussions. The participants in the focus group discussions included medical staff of the researcher team and technical team. All participants possessed the necessary experience and information required by the institute, and they were able to communicate effectively with each other.

8.2.2 The characteristics of the participants (Table7)

Table 7 The characteristics of the participants

No.	Gender	Profession	Education background	Professional title	Work experience
1	Female	Nursing	Master	Chief superintendent nurse	29years
2	Female	Nursing	Doctor	Chief superintendent nurse	18years
3	Female	Nursing	Master	Co-chief superintendent nurse	10years
4	Female	Nursing	Bachelor	Nurse-in-charge	11years
5	Female	Nursing	Master	Nurse	2years
6	Female	Informatics	Master	Engineer	10years
7	Male	Informatics	Master	Engineer	6years

10.2.3 Discussion Process

The researcher herself took charge of the discussion process,firstly her reported to the focus group on the specific design and process of using the WeChat public account "FDUSCC-Nursing", and the participants discussed and commented on the structure and functionality of the public website, content saturation, ease of use, port connectivity, and display of operations. The researcher recorded the discussion and summarized the modifications, and submitted them to the technical team(two engineers) for modification.

8.3   Results of the focus group discussion

Here listed 6 problems identified by the research team, which were subsequently addressed by the researchers and engineers.

Table 8The problems and the solutions

No.	The problems	Solutions
1	The differences betwween "limiting instrumental ADL "and "limiting self care ADL"in the scale are obscure.	Using some examples to help the patients have a better understanding of the Terminology (Figure10).
2	The Cutoff values of 9 symptoms need to be defined to alarm the healthcare personnel the severity of the patients.	Set the Cutoff values to ≥grade 3 due to the patient's condition has deteriorated beyond self-management in that time(Figure 11).
3	The pictures and videos which are searched in the internet have copyright disputes.	Making the videos by ourselves and noting the source of the pictures(Figure12).
4	Patients fill in the scale once a week,such frequence results in inconvenience.	A new overall assessment question is added at the beginning of the scale to reduce the burden of patients,if the patients have no skin problems during this week,they don't need to fill out the next scale.(Figure13).
5	Some of the symptoms mentioned in the question are difficult to understand.Such as photosensitivity, vitiligo, bullous dermatitis ect.	Adding pictures of symptoms after each question(Figure14).
6	The calucation of the body surface area including front and back,but it lacks a reminder for patients to flip the picture,so they may leave out it.	Making a reminder animation in the picture of the body surface area,which patients can click on the "back"button to flip the picture(Figure15).

Figure 10 Some examples

Figure 11 Set the Cutoff values
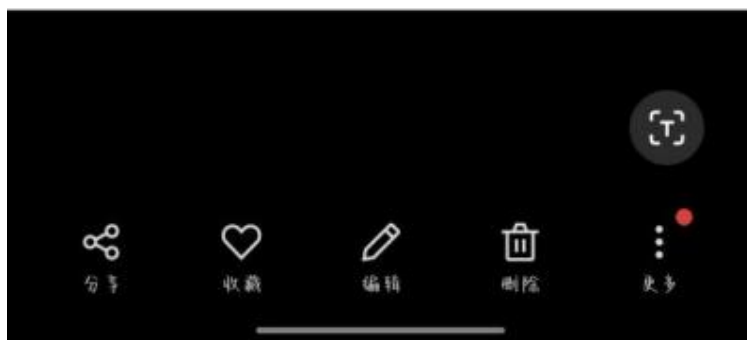
Figure 12 Making the videos by ourselves and noting the source of the pictures

Figure 13 A new overall assessment question is added

Figure 14 Adding pictures of symptoms after each question
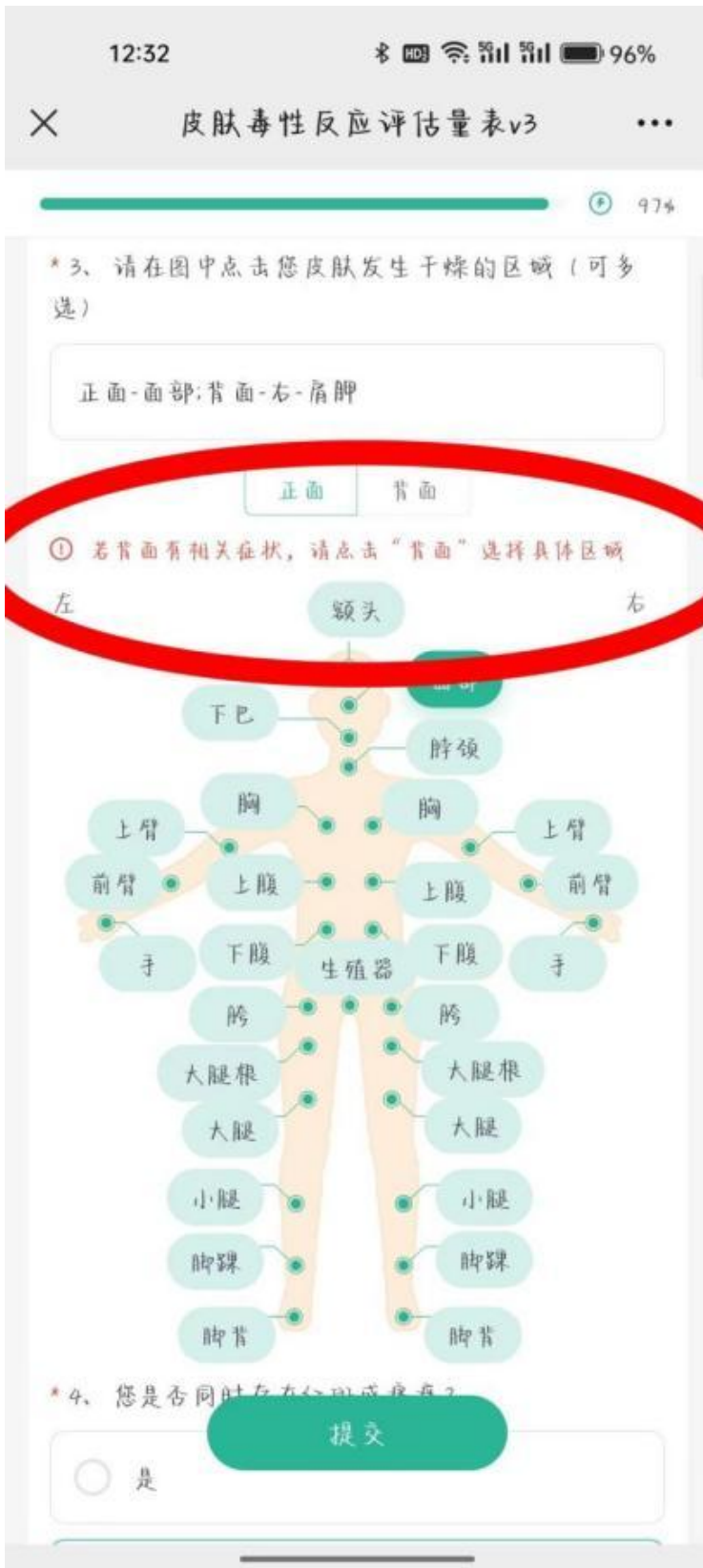
Figure 15 A reminder animation in the picture of the body surface

8.4 User satisfaction and user experience evaluation of "FDUSCC-Nursing"WeChat

8.4.1 Research methods

A convenience sampling method was used to select 20 lung cancer immunotherapy patients from FDUSCC，and a two-week follow-up of skin toxicity reactions in these patients was conducted using "FDUSCC-Nursing" WeChat.

Inclusion criteria:

- Pathological diagnosis of lung cancer;

- Age ≥18 years old and having received immunotherapy;

- There are physical side-effects related to drug treatment of skin toxicity;

- Being willing to participate in the interview and physically able to do it during the interview.

Exclusion criteria:

Patients who are having a combination of other serious life-threatening diseases;

Having cognitive impairment or mental illness.

8.4.2 Evaluation indicators of user satisfaction

Post-Study System Usability Questionnaire (see Appendix 7 for details): Fill out the Post-Study System Usability Questionnaire (PSSUQ) for satisfaction feedback [88], including four dimensions of usability, information quality, interface quality and overall evaluation of each functional module, with a total of 20 items and 5 options for each item: 1 is very poor, 2 is poor, 3 is average, 4 is good, 5 is very good. The overall Cronbach's α of the original scale is 0.94, and the Cronbach's α of the three dimensions of usefulness, information quality, and interface quality are 0.9, 0.91, and 0.83, respectively.

8.4.3 The outline of the usability interview

Do you think this WeChat Public Account is well-designed to meet your skin management needs during immunotherapy?In your opinion, if it helps you, what specific benefits might it offer to you?

Do you find the design and the presentation of the health education essay appealing?

What other additional functions or content do you expect or look forward to?

8.4.4 Research process

After obtaining informed consent from the patients (see Appendix 8 for details), the researcher explained the module and the process of using WeChat to the patients on a one-to-one basis and collected information face-to-face after the patients had used it for two weeks. In addition, during the two-week follow-up period, the researcher contacted the subjects once by phone. At the end of the two-week study, the researchers collected data from subjects who used WeChat during this period. On the day of the follow-up, the researcher distributed questionnaires to collect and analyze user satisfaction and conducted usability interviews about the user experience. If there were any questions or concerns, the researchers provided explanations but did not advise or guide patients in any way.

8.4.5 Statistical Methods

The SPSS software was used to create a database for statistical processing of the collected quantitative data. Continuous variables were described using the mean and standard deviation, while categorical variables were analyzed using frequency and percentage. The data from the interviews were imported into NVivo 11.0 software for data management and analysis. Conventional content analysis was used to analyze all transcribed data.

8.4.6 Quality control

Before using the WeChat Public Account, the research subjects were provided with one-to-one explanations of the process of using the public account, as well as an introduction to the specific module functions. The module of "registration" in the background of the public account is designed to include complete information verification and to obtain contact information from the users.

During the process of using the WeChat Public Account, the researchers would conduct telephone follow-ups to urge the patients who had not completed the use task.

After the use of the WeChat Public Account, data collection and analysis would be conducted by the researcher herself.

8.5   The results of the Post-Study System Usability Questionnaire (PSSUQ)

8.5.1 The characteristic of the patients

This study included a total of 21 patients,one patient withdraw from the study because he didn't go to our hospital for immunotherapy.

Table 9 The characteristic of the patients

No.	Gender	Age	Diagnosis	Treatment
1	Male	64	Lung cancer	Immunotherapy and targeted therapy
2	Female	58	Lung cancer	Immunotherapy and chemotherapy
3	Female	52	Lung cancer	Immunotherapy
4	Male	51	Lung cancer	Immunotherapy
5	Male	55	Lung cancer	Immunotherapy and chemotherapy
6	Female	56	Lung cancer	Immunotherapy and targeted therapy
7	Male	60	Lung cancer	Immunotherapy and chemotherapy
8	Male	64	Lung cancer	Immunotherapy
9	Male	66	Lung cancer	Immunotherapy and targeted therapy
10	Male	67	Lung cancer	Immunotherapy
11	Male	65	Lung cancer	Immunotherapy and chemotherapy
12	Female	66	Lung cancer	Immunotherapy and targeted therapy
13	Male	54	Lung cancer	Immunotherapy and targeted therapy
14	Male	53	Lung cancer	Immunotherapy and chemotherapy
15	Male	54	Lung cancer	Immunotherapy and targeted therapy
16	Male	56	Lung cancer	Immunotherapy
17	Male	66	Lung cancer	Immunotherapy and chemotherapy
18	Male	51	Lung cancer	Immunotherapy and targeted therapy
19	Male	50	Lung cancer	Immunotherapy
20	Male	56	Lung cancer	Immunotherapy and targeted therapy

8.5.2 User satisfaction of the patients with PSSUQ

The Post-Study System Usability Questionnaire (PSSUQ) has a total of 20 items and four dimensions for each item.The average of the responses to all statements was shown by Mean Score,Maximun Score and Minnmun Score in the Table10;the average of the responses to all statements of the same dimension was shown by Mean Score(MS)in the Table11.

Table 10 The data of 20 items

Item	Mean Score	Maximum Score	Minnmun Score
1	4.45	5	4
2	4.3	5	3
3	4.7	5	4
4	4.75	5	4
5	4.65	5	4
6	4.8	5	4
7	2.4	4	2
8	2.55	4	2
9	4.55	5	4
10	4.65	5	3
11	4.35	5	3
12	4.5	5	4
13	4.3	5	3
14	4.25	5	3
15	3.0	4	2
16	4.6	5	4
17	4.4	5	4
18	4.75	5	4
19	4.7	5	4
20	4.5	5	4

Table 11 The data of 3 dimensions

Dimension	Item	Mean Score	Median
Usability	1-6	4.61	4.67
Information quality	7-12	3.83	4.425
Interface quality	13-19	4.26	4.4
Overall evaluation	20	4.5	4.68

PSSUQ results showed the average score of usability was 4.61, information quality was 3.83, interface quality was 4.26, and overall evaluation was 4.5. The median of usability was 4.67, information quality was 4.425, and interface quality was 4.4. According to the supplementary in this questionnaire [88], the closer the average to 5, the higher the usability of the WeChat Public Account.

However, in this study, due to most of the data being skewed rather than normally distributed, and the median of the responses to all statements in the usability dimension and overall evaluation dimension should be significant, they demonstrated the patients have a good satisfaction of our Public Account, with a high score(4.67) in usability and overall evaluation(4.68). However, the information quality dimension was 4.425 and the interface quality dimension was 4.4, appeared that users found some parts of the WeChat Public Account to be relatively dissatisfied, these can be shown in the mean score of item7(2.4),item8(2.55) and item15(3.0).

8.6   The results of usability interview

The overall feedback on the usability of the WeChat Public Account is positive, the patients believed that the WeChat could meet the demands of self-management, including scientific and easy-to-understand health education information; reasonable function design; as well as convenient and practical features.

The WeChat Public Account was believed capable of providing scientific and easy-to-understand health education information for skin toxicity patients. For example, one of the participants described the created WeChat public account as useful and easy to understand.

 "*It turned out that I find myself did not know much about skin toxicity, however,some health education information in this WeChat Public Account is easy to understand,made me learn a lot of new and useful knowledge*".(P13)

Another participant trusted the WeChat account as scientific when he or she compared it with another previously used app for the same purpose.

 "*I think the health education information in this WeChat Public Account is pretty scientific,Before,I used to look for the information on the Xiaohongshu APP,but I didn't know whether the knowledge on Xiaohongshu APP was scientfic or not.*"(P10)

Some patients perceived that the function design of WeChat Public Account was reasonable,making them mange their skin toxicity better.

 "*It should meet my needs,sometimes when I didn't know how to handle the skin toxicity,I can come here to evaluate and learn some health education information*".(P7)

"This WeChat Public Account provides the evalution scales for me to make the assessment of the haelth condition of my skin,so I can always know if my skin was having the skin toxicity".(P16)

Some patients thought the management module in this WeChat Public Account was convenient and practical.

"Actually,I think the most favourable function is the self-assessement module,it could send me the evalution scales every week to track the changes of my skin condition,I think it is so convenient ".(P3)

"When I completed the scales,it could make some recommendations for me according to the severity of my skin toxicity,I think it is quite practical ".(P10)

The patients believed that health education articles of theWeChat Public Account was useful,such as the videos and pictures were well-designed; the typesetting of articles was clear and the content was comprehensive.

Some patients perceived that the videos and pictures in health education articles were well-designed,making it easier to accept and interesting to read.

"When I browse the health education articles,some videos in the articles should catch my eyes,and I find them interesting and helpful".(P11)

"Sometimes I may feel cofused when I learned some knew knowledge,but the pictures could make the knowledge easier for me to accept. "(P5)

Another part of patients perceived that the typesetting of health education articles was clear and reasonable.

"I feel quite amazing when the medical guidelines appear acccording to the severity of the self-assessment results".(P7)

"I think it make me easier to understand the professional knowledge by the combination of the videos,pictures and text".(P9)

Another patient believed that the content of the health education articles was rich,including the knowledge they want.

"The content of the health education articles included the daily skin protective measures and some medication duidelines,I think they are quite comprehensive".(P1)

Patients believed that the content and the functions of the WeChat Public Account should be improved in the future.

Some patients hoped the quantity and the content of health education articles should improved.

"I like browsing the health education articles in my free time,but it only have 7 articles,I hope the quantity of the articles should be more large".(P2)

"I think the content of the articles should be more rich and comprehensive".(P14)

Some patients wanted to operate the WeChat Public Account more smoothly.

"When I click it,I find the Public Account may respond slowly sometiomes" .(P6)

"I do not know whether it is the reason of the network, sometimes there is a delay when entering the module."(P19)

Other patients hoped that there should be more functions in the WeChat Public Account.

"I hope there should be more functions,such as when I do something wrong, it can warn me".(P20)

"Actually,I think it can be more convenient to use after adding some new functions".(P15)

8.7 Disscusion

8.7.1 Evaluation about the usability of mHealth should comprehensive

There are numerous methods to evaluate the usability of mHealth, and the Post-Study System Usability Questionnaire (PSSUQ) was the most commonly used questionnaire [88]. The selection of the PSSUQ in this study represents an innovative approach to questionnaire selection for assessing usability. The PSSUQ in this study indicates that the median of usability was 4.67, information quality was 4.425, and interface quality was 4.4, which shows that the users were generally satisfied with the system as a whole. However, the function design still needs improvement. The results of the usability interviews also showed that most interviewees had a good user experience with WeChat. However, some suggested that

WeChat needed improvement in function and content design. Therefore, we should consider adding new functions and upgrading the content to make further modifications in the future. It is worth noting that many reviews highlight the limited adoption of automated methods such as eye tracking in evaluating mHealth [89]. The research methods used in this study had some limitations, such as simple qualitative interviews, and questionnaires may lack representativeness to a certain extent. Therefore, after we improved our WeChat Public Account, further research is needed to incorporate eye tracking and other wearable devices into the research process to enhance the objectivity of the results.

8.7.2 Problems that should be paid attention to when developing mobile health medical products for lung cancer patients

In the era of artificial intelligence, there is a certain contradiction between data sharing and privacy protection [90]. Medical personnel and information developers should maintain a balance between data sharing and privacy protection when developing mobile medical software, data encryption and access control can be set to protect users' privacy[90]. At the same time, because the age of lung cancer patients are generally older, it is necessary to inform them in advance in a more understandable way and carry out relevant network security education to enhance the privacy protection awareness of the elderly. In addition, the elderly often have difficulties in "digital integration"[91], so the use habits of the elderly should be fully considered in the design process of mobile devices, such as using voice arousal function, operation interface is simple and clear, and using large fonts, so as to meet the demands of the elderly and improve the effectiveness of mobile medical applications in the elderly group. In the platform we designed in this study, we only did some routine data protection and user privacy protection, but we did not include some details of patient data in the scope of protection, therefore, in the future development of our Public Account, we needed to appropriately expand the scope of data protection.

8.8   Conclusion

Firstly, we conducted six essential modifications through the focus group. Subsequently, we administered the PSSUQ to patients and conducted a usability interview. The results showed positive user satisfaction and user experience evaluation of WeChat Public Account but also identified areas for potential future improvement. The template was utilized to enhance the

self-management of other common symptoms, which was further extended and implemented for the purpose of post-treatment follow-up and adverse reaction monitoring in tumor patients.

9 Innovations and Limitations

9.1 Innovations

Aligned with the "Internet + nursing" development trend in China, this study focuses on the development and evaluation of a self-management module for skin toxic reactions in lung cancer patients undergoing immunotherapy. The topic selection is precise, and the intention is clear. The content and functions of the WeChat public account module are developed based on demand analysis and knowledge base construction. This provides a novel and convenient way for patients to self-manage their condition, thereby improving their quality of life.

9.2 Limitations

(1) The survey subject of this study is limited to Fudan University Shanghai Cancer Center, and the sample size is small, which reduces its representativeness to some extent.

(2) The WeChat public account developed in this study is only for patients with skin toxic reactions of lung cancer immunotherapy. The content and functional design of the module is only one aspect of adverse immune reactions, therefore the public account requires further improvement in the future.

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Appendices

Appendix 1 Preliminary self-report scale

题号	题干	选项				
1	在过去的7天里，皮肤干燥在最严重时的程度是：	**没有**，自动跳转至下一题	**轻微**，跳转至分级评估量表1	**中度**，跳转至分级评估量表1	**严重**，跳转至分级评估量表1	**很严重**，跳转至分级评估量表1
2	在过去的7天里，皮肤瘙痒在最严重时的程度：	**没有**，自动跳转至下一题	**轻微**，跳转至分级评估量表2	**中度**，跳转至分级评估量表2	**严重**，跳转至分级评估量表2	**很严重**，跳转至分级评估量表2
3	在过去的7天里，手足综合征（手或脚上的皮肤红疹，可能会导致开裂、脱皮、发红或疼痛）在最严重时的程度： （插入图片1）	**没有**，自动跳转至下一题	**轻微**，跳转至分级评估量表3	**中度**，跳转至分级评估量表3	**严重**，跳转至分级评估量表3	**很严重**，跳转至分级评估量表3
4	在过去的7天里，你是否有任何凸起于皮肤的红色血管痣（瘤）： （插入图片2）	**是**，跳转至分级评估量表4		**否**，自动跳转至下一题		
5	在过去的7天里，你是否有任何皮疹（不伴瘙痒）： （插入图片3）	**是**，跳转至分级评估量表5		**否**，自动跳转至下一题		
6	在过去的7天里，你是否有任何皮肤上发痒的红疙瘩： （插入图片3）	**是**，跳转至分级评估量表5		**是**，跳转至分级评估量表5		
7	在过去的7天里，你的皮肤对阳光的敏感度是否有增加：	**是**，跳转至分级评估量表6		**否**，自动跳转至下一题		
8	在过去的7天里，你是否有任何不寻常的皮肤变黑：	**是**，跳转至分级评估量表7		**否**，自动跳转至下一题		
9	在过去的7天里，你是否有皮肤白斑（白癜风）： （插入图片4）	**是**，跳转至分级评估量表8		**否**，自动跳转至下一题		
10	在过去的7天里，你是否有出现充满液体的大水疱： （插入图片5）	**是**，跳转至分级评估量表9		**否**，评估结束		

Appendix2 Further assessment scale

症状	题号	题干	选项	跳转逻辑	分级判断标准 (标红色为触发预警)	干预措施 （除毛细血管增生和白癜风，其余干预措施需合并同类项）
Symptom 1 皮肤干燥	Q1	在过去的7天里，皮肤干燥在最严重时的程度是：	没有	转Q6	该套题逻辑判断：Q2的结果直接决定最终分级 轻度（1级）：<10%的体表面积 中度（2级）：10%-30%的体表面积 重度（3级）：>30%的体表面积	轻度： Tip1：加强皮肤护理，做好皮肤日常的清洁、保湿及防晒 Tip3：定期进行评估并关注皮肤症状变化 中度： Tip1：加强皮肤护理，做好皮肤日常的清洁、保湿及防晒 Tip2：遵医嘱使用含糖皮质激素的软膏或可适当减少抗肿瘤治疗药物的剂量， Tip3：定期进行评估并关注皮肤症状变化 重度： Tip1：加强皮肤护理，做好皮肤日常的清洁、保湿及防晒 Tip2：遵医嘱使用含糖皮质激素的软膏或可适当减少抗肿瘤治疗药物的剂量 Tip3：定期进行评估并关注皮肤症状变化 Tip10：若情况恶化或无明显改善，则及时就医，由医生根据临床判断和患者意愿决定是否需要减量或暂停治疗
			轻微	转Q2		
			中度			
			严重			
			很严重			
	Q2	请在图中点击您皮肤发生干燥的区域：	累计体表面积的划分区间 ① 累计体表面	转Q3		
	Q3	您是否同时存在红斑或瘙痒？	是	转Q4		
			否			
	Q4	该症状是否影响您日常使用工具（例如打电话、购物、开车）？	是	转Q5		
			否			
	Q5	该症状是否影响您日常生活自理能力（例如穿衣、吃饭、洗浴）？	是	转Q6		
			否			
Symptom 2 皮肤瘙痒	Q6	在过去的7天里，皮肤瘙痒在最严重时的程度为：	没有	转Q11	该套题逻辑判断：Q7的结果直接决定最终分级 轻度（1级）：轻度或局部瘙痒 中度（2级）：广泛伴强烈的瘙痒，断断续续 重度（3级）：广泛伴强烈的瘙痒，持续不断	轻度： Tip1：加强皮肤护理，做好皮肤日常的清洁、保湿及防晒 Tip3：定期进行评估并关注皮肤症状变化 中度： Tip1：加强皮肤护理，做好皮肤日常的清洁、保湿及防晒 Tip2：遵医嘱使用含糖皮质激素的软膏或可适当减少抗肿瘤治疗药物的剂量， Tip3：定期进行评估并关注皮肤症状变化 重度： Tip1：加强皮肤护理，做好皮肤日常的清洁、保湿及防晒 Tip2：遵医嘱使用含糖皮质激素的软膏或可适当减少抗肿瘤治疗药物的剂量 Tip3：定期进行评估并关注皮肤症状变化 Tip10：若情况恶化或无明显改善，则及时就医，由医生根据临床判断和患者意愿决定是否需要减量或暂停治疗
			轻微	转Q7		
			中度			
			严重			
			很严重			
	Q7	您皮肤瘙痒的严重程度为：	轻度或局部瘙痒	转Q8		
			广泛伴强烈的瘙痒，断断续续			
			广泛伴强烈的瘙痒，持续不断			
	Q8	您是否存在瘙痒后搔抓引起的皮肤改变（如水肿，丘疹，抓痕，渗出/痂皮）等？	是	转Q9		
			否			
	Q9	该症状是否影响您日常使用工具（例如打电话、购物、开车）？	是	转Q10		
			否			
	Q10	该症状是否影响您日常生活自理能力和睡眠（例如穿衣、吃饭、洗浴）？	是	转Q11		
			否			
Symptom 3 手足综合征	Q11	在过去的7天里，手足综合征（手或脚上的皮肤红疹，可能会导致开裂、脱皮、发红或疼痛）在最严重时的程度：（有插图）	没有	转Q15	该套题逻辑判断：Q12的结果直接决定最终分级 轻度（1级）：无痛性轻微皮肤改变或皮肤炎症（红斑、水肿、角化过度） 中度（2级）：痛性皮肤改变（剥落、水疱、出血、水肿、角化过度）	轻度： Tip1：加强皮肤护理，做好皮肤日常的清洁、保湿及防晒 Tip3：定期进行评估并关注皮肤症状变化 中度： Tip1：加强皮肤护理，做好皮肤日常的清洁、保湿及防晒 Tip2：遵医嘱使用含糖皮质激素的软膏或可适当减少抗肿瘤治疗药物的剂量， Tip3：定期进行评估并关注皮肤症状变化 重度： Tip1：加强皮肤护理，做好皮肤日常的清洁、保湿及防晒 Tip2：遵医嘱使用含糖皮质激素的软膏或可适当减少抗肿瘤治疗药物的剂量 Tip3：定期进行评估并关注皮肤症状变化 Tip10：若情况恶化或无明显改善，则及时就医，由医生根据临床判断和患者意愿决定是否需要减量或暂停治疗
			轻微	转Q12		
			中度			
			严重			
			很严重			
	Q12	您手足综合征的严重程度为：	无痛性轻微皮肤改变或皮肤炎症	转Q13		
			痛性皮肤改变（剥落、水疱、			
			重度皮肤改变（剥落、水疱、			

Symptom	Q	问题	选项	转向	逻辑判断/分级	建议
	Q13	该症状是否影响您日常使用工具（例如打电话	是	转Q14		
			否			
	Q14	该症状是否影响您日常生活自理能力（例如穿衣、吃饭	是	转Q15	重度（3级）：重度皮肤改变(剥落、水疱、出血、水肿、角化过度)伴疼痛	
			否			
Symptom 4 毛细血管增生	Q15	在过去的7天中，您皮肤是否出现毛细血管增生？（有插图）	是	转Q16	该套题逻辑判断：Q16的结果直接决定最终分级	轻度： Tip4：易摩擦部位可用纱布保护，避免出血 Tip5：若出现破溃出血可采用局部压迫止血处理，必要时及时就医
			否	转Q17	轻度（1级）：单个或多个结节最大直径≤10mm，伴或不伴破溃出血	中度： Tip4：用纱布保护易摩擦部位，避免出血 Tip5：若出现破溃出血可采用局部压迫止血处理，必要时及时就医 Tip6：可以采取局部治疗措施，如激光或外科切除等，若出现感染需进行抗感染治疗
	Q16	您发生毛细血管增生的严重程度为：	单个或多个结节最大直径≤		中度（2级）：单个或多个结节最大直径>10mm，伴或不伴破溃出血	重度： Tip4：用纱布保护易摩擦部位，避免出血 Tip5：若出现破溃出血可采用局部压迫止血处理，必要时及时就医 Tip6：可以采取局部治疗措施，如激光或外科切除等，若出现感染需进行抗感染治疗 Tip10：若情况恶化或无明显改善，则及时就医，由医生根据临床判断和患者意愿决定是否需要减量或暂停治疗
			单个或多个结节最大直径	转Q17		
			呈泛发性，可能有感染（出现红肿热痛等症状）		重度（3级）：呈泛发性，可能有感染（出现红肿热痛等症状）	
Symptom 5 皮疹	Q17	在过去的7天里，你是否有皮疹或者任何发痒的红疙瘩？（有插图）	是	转Q18	该套题逻辑判断：Q18的结果直接决定最终分级	轻度： Tip1：加强皮肤护理，做好皮肤日常的清洁、保湿及防晒 Tip3：定期进行评估并关注皮肤症状变化
			否	转Q22		中度： Tip1：加强皮肤护理，做好皮肤日常的清洁、保湿及防晒 Tip2：遵医嘱使用含糖皮质激素的软膏或可适当减少抗肿瘤治疗药物的剂量， Tip3：定期进行评估并关注皮肤症状变化
	Q18	请在图中点击您皮肤发生皮疹的区域：	累计体表面积的	转Q19	轻度（1级）：<10%的体表面积	
	Q19	您是否同时存在其它相关伴随症状（如：瘙痒，灼烧感，紧绷感和红斑等）？	是	转Q20	中度（2级）：10%-30%的体表面积	重度： Tip1：加强皮肤护理，做好皮肤日常的清洁、保湿及防晒 Tip2：遵医嘱使用含糖皮质激素的软膏或可适当减少抗肿瘤治疗药物的剂量 Tip3：定期进行评估并关注皮肤症状变化 Tip10：若情况恶化或无明显改善，则及时就医，由医生根据临床判断和患者意愿决定是否需要减量或暂停治疗
			否		重度（3级）：>30%的体表面积	
	Q20	该症状是否影响您日常使用工具（例如打电话、购物、开车）？	是	转Q21		
			否			
	Q21	该症状是否影响您日常生活自理能力（例如穿衣、吃饭、洗浴）？	是	转Q22		
			否			
	Q22	在过去的7天里，你的皮肤对阳光的敏感是否有增加？	是	转Q23		
			否	转Q27		
Symptom 6 光敏感	Q23	请在图中点击您皮肤对阳光敏感的区域：	累计体表面积的	转Q24	该套题逻辑判断：Q23的结果直接决定最终分级	轻度（1级）—— 重度（3级） Tip1：加强皮肤护理，做好皮肤日常的清洁、保湿及防晒 Tip7：避免食用光敏性的食物 a)蔬菜类：菠菜、芹菜、小白菜以及莴笋等含有大量叶绿素的蔬菜 b)水果类：橘子、柠檬、芒果、菠萝等 c)海鲜类：生蚝、海虾、河虾以及大闸蟹等
	Q24	请问您的光敏性皮炎是否伴有触痛？	是	转Q25	轻度（1级）：<10%的体表面积	
			否		中度（2级）：10%-30%的体表面积	
	Q25	您是否同时存在水泡和光敏感等伴随症状？	是	转Q26		
			否		重度（3级）：>30%的体表面积	
	Q26	您是否感觉该症状已经危及到您的生命？	是	转Q27		
			否			
Symptom 7 色素沉着	Q27	在过去的7天里，你是否有任何不寻常的皮肤变黑？	是	转Q28	因症状整体较轻，该症状不设置预警值	轻度—— 中重度 Tip1：加强皮肤护理，做好皮肤日常的清洁、保湿及防晒 Tip7：避免食用光敏性的食物 a)蔬菜类：菠菜、芹菜、小白菜以及莴笋等含有大量叶绿素的蔬菜
			否	转Q30		
	Q28	请在图中点击您皮肤发生色素沉着的区域：	累计体表面积的	转Q29	轻度：累计体表面积＜10%	

	Q29	该症状是否影响到您的心理健康（感到抑郁、心情低落等）？	是	转Q30	中重度：累计体表面积 ≥ 10%	b)水果类：橘子、柠檬、芒果、波罗等 c) 海鲜类：生蚝、海虾、河虾以及大闸蟹等
			否			
Symptom 8 白癜风	Q30	在过去的7天里，你是否出现皮肤白斑（白癜风）？（有插图）	是	转Q31	该套题逻辑判断：Q2的结果直接决定最终分级 轻度（1级）：<1%的体表面积 中度（2级）：1%≤累计体表面积≤5%	轻度-中度： Tip8: 按医嘱局部使用皮质类固醇药物，如钙调神经磷酸酶抑制剂（他克莫司软膏及吡美莫司乳膏） 重度-极重度： Tip9: 按医嘱系统使用皮质类固醇药物，如钙调神经磷酸酶抑制剂（他克莫司软膏及吡美莫司乳膏），若情况出现恶化，则及时去皮肤病医院就医
			否	转Q32		
	Q31	请在图中点击您皮肤出现白斑的区域：	累计体表面积的	转Q32		
Symptom 9	Q32	在过去的7天里，你皮肤是否出现充满液体的大水疱（大疱性皮炎）？（有插图）	是	转Q33	该套题逻辑判断：Q2的结果直接决定最终分级 轻度（1级）：<10%的体表面积	轻度： Tip1: 加强皮肤护理，做好皮肤日常的清洁、保湿及防晒 Tip3: 定期进行评估并关注皮肤症状变化 中度： Tip1: 加强皮肤护理，做好皮肤日常的清洁、保湿及防晒 Tip2: 遵医嘱使用含糖皮质激素的软膏或可适当减少抗肿瘤治疗药物的剂量，
			否	结束作答		
	Q33	请在图中点击您皮肤出现大疱性皮炎的区域：	累计体表面积的	转Q34		
大疱性皮炎	Q34	该症状是否影响您日常使用工具（例如打电话、购物、开车）？	是	转Q35	中度（2级）：10%-30%的体表面积	重度： Tip1: 加强皮肤护理，做好皮肤日常的清洁、保湿及防晒 Tip2: 遵医嘱使用含糖皮质激素的软膏或可适当减少抗肿瘤治疗药物的剂量 Tip3: 定期进行评估并关注皮肤症状变化 Tip10: 若情况恶化或无明显改善，则及时就医，由医生根据临床判断和患者意愿决定是否需要减量或暂停治疗
			否		重度（3级）：>30%的体表面积	
	Q35	该症状是否影响您日常生活自理能力（例如穿衣、吃饭、洗浴）？	是	结束作答		
			否			

Appendix3-1 Basic knowledge of skin toxicity

主题一：关于免疫治疗及皮肤毒性，你知道多少？

1.1 什么是免疫治疗？

免疫治疗是指运用免疫学原理和方法，通过主动或被动的方式，打破机体免疫系统对肿瘤的免疫耐受或忽视的状态，增强机体抗肿瘤的免疫应答，从而达到抑制肿瘤生长、清除肿瘤细胞的目的。通过免疫检查点抑制剂阻断机体免疫系统的负性调节机制是免疫治疗的重要策略之一。

1.2为什么会出现免疫相关的不良反应？

免疫检查点抑制剂在通过阻断免疫检查点、解除免疫抑制、增强肿瘤特异性免疫应答的同时，也会非特异性地激活免疫系统，打破了 T 细胞激活过程的平衡状态，过度激活的 T 细胞攻击人体正常的器官或组织，引发局部炎症，产生与免疫治疗相关的特殊不良反应，即为免疫相关不良反应。

1.3 为什么用药之后会出现皮肤毒性反应？

免疫药物在杀伤肿瘤细胞的同时，也会伤及正常细胞，从而导致相应器官出现副作用。其中，皮肤作为人体最大的器官，更是"重灾区"。

1.4 最常见的免疫治疗皮肤毒性症状及主要表现有哪些？

1.4.1 斑丘疹

（1）症状表现：斑丘疹以斑疹（扁平）和丘疹（突起）为特征，也称为麻疹样皮疹；

（2）部位：常累及躯干上部，向心扩散。

1.4.2 皮肤干燥

部位：为身体任何部位的皮肤干燥，发生部位以四肢为主，最容易出现在下肢，其次背部、上肢、手的发生率也在40%以上，可伴鳞屑和瘙痒，少数患者会出现阴道和会阴部干燥。 皮肤干燥可使皲裂，皲裂最常见于指尖、脚跟、指骨周围皮肤和指间关节背侧表面，并伴明显疼痛。

1.4.3 皮肤瘙痒

表现：可能伴有干燥或脱屑，好发于躯干和四肢。

1.4.4 大疱性皮炎

症状表现：特征为皮肤炎症和出现充满液体的大疱，严重或泛发、间歇性；皮肤因抓挠而变化（如水肿、丘疹、脱皮、苔藓样变、渗出/结痂）

1.4.5 手足综合征

部位：易出现在受压力或摩擦的区域（手掌、脚跟、趾骨头或由鞋子或体力劳动引起的摩擦区域）。

表现：双侧掌跖受压部位出现过度角化、红斑和脱屑，伴疼痛和感觉迟钝，有刺痛、烧灼或疼痛感，对接触物体的耐受性降低。

1.4.6 白癜风

部位：白癜风常出现在面部、颈部、手背、手指、腕部、前臂、腹部及腰骶部等暴露的部位。

表现：患者通常表现为一片或几片大小不一的白色斑片，斑片中心通常白色显著，而其周围皮肤呈淡白色。如果皮肤下有血管，斑片可能略呈粉红色。斑片可能是圆形、椭圆形、不规则形或线状。

Appendix3-2 Skin protection

主题二：关于免疫治疗皮肤毒性反应的自我预防之皮肤护理篇

1.温和清洁、合理保湿和修复皮肤屏障。
（1）正确清洁皮肤-具体操作 详见视频 1
a. 洗澡及洗脸**水温不宜过高（≤40℃）**，手法轻柔，避免用力揉搓；
b. 使用**含有润肤成分的沐浴乳**，避免使用含有皂基的肥皂、香皂清洁皮肤 ；
c. 使用氨基酸类温和洗面奶，**每晚 1 次**，晨起可仅用清水洁面。
（2）合理保湿，掌握正确的涂抹保湿剂的方法-具体操作 详见视频 2
a. 面部、颈前和后背等**相对油脂分泌多**的区域选择**质地轻薄**的乳液每天 2 次；
b. 四肢伸侧和手足等**皮肤易干燥**的部位，选择**质地厚重**的霜或乳膏，每天 2 次；
c. 建议选择不含乙醇、含有神经酰胺或其他生理性脂质以及具有皮肤屏障修复功效的医学护肤品。
d. 避免使用会导致皮肤干燥的产品（如：热水、含酒精的化妆品、香水、果酸产品、PH>7 的肥皂、表面活性剂、清洁剂、去角质产品等）。

2.做好物理及化学防晒以预防皮疹的出现和加重
（1）外出时注意物理遮挡，如**避阳伞、遮阳帽和墨镜**等，尽量避免在正午时段（上午 10：00˜下午 15：00）长时间的户外活动 ；
（2）建议出门前 30 min 在保湿霜后涂抹广谱防晒霜，要求选择防晒系数 **SPF≥30 和 PA≥++**（分别预防紫外线 UVB 和 UVA）的产品，避免在无任何防护的情况下直接接触阳光。

附：关于一些防晒霜的小知识

SPF 指数： SPF 是指日光防护因子，表示防晒霜能够抵御 UVB 辐射的能力。SPF 值越高，防晒霜的防晒效果就越好。

PA 指数： PA 是指紫外线 A 波的防护指数，表示防晒霜能够抵御 UVA 辐射的能力。PA 值越高，防晒霜对 UVA 的防护效果就越好。PA 指数是从+到++++的四个级别，+表示最低级别，++++表示最高级别。
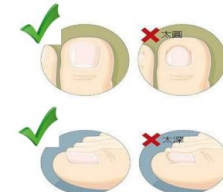UVB 容易使表层皮肤晒伤，而 UVA 则可以直达皮肤真皮层，破坏弹性纤维和胶原蛋白纤维，从而使皮肤老化、松弛以及变黑。相比起 UVB，UVA 的杀伤力更大，会直接伤害到真皮层。基于此，防晒霜上不仅有防止晒伤、晒红表皮层的 SPF 指标，还多了防 UVA 的 PA 指标。

3.注意个人卫生，避免皮肤摩擦和皮肤破损
（1）避免穿过紧、粗糙衣物、羊毛、尼龙等材质的衣服，勤换衣裤，保持衣物清洁干燥，尽量选用**棉质、宽松的服装和鞋袜**。

（2）不留指甲和趾甲，并正确修剪，减少甲缘的磨损和创伤，避免过短，尽量保证甲缘圆钝，避免可能造成手足损伤的工作或运动。

如何正确修剪指甲？（详见视频 3）

Appendix3-3 Life care of skin

主题三：关于免疫治疗皮肤毒性反应的自我预防日常护理篇

1.增加机体抵抗力

（1）睡眠充足：首先，入睡的时间不超过 **30 分钟** ；其次，夜间醒来的次数 **少于 3 次** ；睡眠时间在 **8 小时左右**，最关键的是，在第二天醒来的时候，主观的感受是一种精力恢复良好，情绪稳定，注意力集中的状态。

一入睡小技巧：
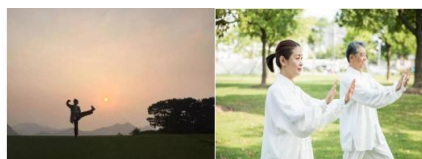

2.适当参加体育锻炼

——什么是适度锻炼？

在保证日常营养均衡摄入的前提下，以运动后精力充沛、**微微出汗**即可。**切忌不能过度劳累。**

——选择什么锻炼方式呢？

建议选择低强度的有氧训练，诸如快走、慢跑、骑自行车、瑜伽、爬楼梯和一些低强度的健身操、中式的太极拳、八段锦、五禽戏等。

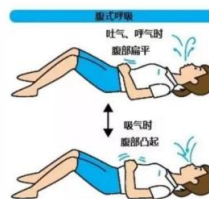**——建议在一天中什么时候运动最好呢？**

可在每日清晨或傍晚锻炼半个小时。

3.自我心态调整

（1）尝试接受治疗发生皮肤毒性带来的外貌上的改变。

（2）控制不良的情绪，向身边其他人**倾诉、和亲戚朋友聊天、听听音乐、腹式呼吸转移**注意力。

附：怎么样做腹式呼吸？

双手分别置于胸部和腹部，闭口，用鼻深吸气；

感觉腹部隆起、膈肌自然下移，吸气默数 3 秒；

缩唇（吹口哨样），缓慢呼气达默数 6-9 秒；

腹部尽量回收，双手一步向腹部加压，促进膈肌上移的方式；

维持呼气时间是吸气时间的 2-3 倍。

（3）积极与医护人员沟通，了解皮肤毒性相关知识。

（4）适当参加些集体活动，与其他病友分享皮肤毒性相关知识。

（5）乐观心态，积极配合治疗。

4.饮食注意点

（1）饮食清淡、避免油腻、辛辣刺激食物。

（2）忌饮浓茶、咖啡、酒类等饮料。

（3）尽量经口进食高热量、高蛋白、高维生素易消化饮食。

（4）避免日间进食感光性食物-**尤其是光敏性皮炎患者**（芥菜、油菜、莴苣、芹菜、荠菜、萝卜叶、菠菜、香菜、红豆、柠檬、土豆、橘子、紫菜、白葡萄、柑橘、芒果、菠萝、螃蟹、花蛤)。

Appendix3-3 Medication guide

主题二：最常见的九个免疫治疗皮肤毒性症状的分级处理

1. 皮肤干燥分级处理

分级	治疗指南
1 级	加强皮肤护理，做好皮肤日常的清洁、保湿及防晒 定期进行评估并关注皮肤症状变化
2 级	加强皮肤护理，做好皮肤日常的清洁、保湿及防晒 遵医嘱使用含糖皮质激素的软膏或可适当减少抗肿瘤治疗药物的剂量 定期进行评估并关注皮肤症状变化
3 级	加强皮肤护理，做好皮肤日常的清洁、保湿及防晒 遵医嘱使用含糖皮质激素的软膏或可适当减少抗肿瘤治疗药物的剂量 定期进行评估并关注皮肤症状变化 若情况恶化或无明显改善，则及时就医，由医生根据临床判断和患者意愿决定是否需要减量或暂停治疗

2.皮肤瘙痒分级处理

分级	治疗指南
1 级	加强皮肤护理，做好皮肤日常的清洁、保湿及防晒 定期进行评估并关注皮肤症状变化
2 级	加强皮肤护理，做好皮肤日常的清洁、保湿及防晒 遵医嘱使用含糖皮质激素的软膏或可适当减少抗肿瘤治疗药物的剂量， 定期进行评估并关注皮肤症状变化
3 级	加强皮肤护理，做好皮肤日常的清洁、保湿及防晒 遵医嘱使用含糖皮质激素的软膏或可适当减少抗肿瘤治疗药物的剂量 定期进行评估并关注皮肤症状变化 若情况恶化或无明显改善，则及时就医，由医生根据临床判断和患者意愿决定是否需要减量或暂停治疗

3.手足综合征的分级处理

分级	治疗指南
1 级	加强皮肤护理，做好皮肤日常的清洁、保湿及防晒 定期进行评估并关注皮肤症状变化
2 级	加强皮肤护理，做好皮肤日常的清洁、保湿及防晒 遵医嘱使用含糖皮质激素的软膏或可适当减少抗肿瘤治疗药物的剂量，
3 级	定期进行评估并关注皮肤症状变化定期进行评估并关注皮肤症状变化 加强皮肤护理，做好皮肤日常的清洁、保湿及防晒 遵医嘱使用含糖皮质激素的软膏或可适当减少抗肿瘤治疗药物的剂量 定期进行评估并关注皮肤症状变化 若情况恶化或无明显改善，则及时就医，由医生根据临床判断和患者意愿决定是否需要减量或暂停治疗

4. 毛细血管增生的分级处理

分级	治疗指南
1 级	易摩擦部位可用纱布保护，避免出血 若出现破溃出血可采用局部压迫止血处理，必要时及时就医
2 级	用纱布保护易摩擦部位，避免出血 若出现破溃出血可采用局部压迫止血处理，必要时及时就医 可以采取局部治疗措施，如激光或外科切除等，若出现感染需进行抗感染治疗
3 级	用纱布保护易摩擦部位，避免出血 若出现破溃出血可采用局部压迫止血处理，必要时及时就医 可以采取局部治疗措施，如激光或外科切除等，若出现感染需进行抗感染治疗 若情况恶化或无明显改善，则及时就医，由医生根据临床判断和患者意愿决定是否需要减量或暂停治疗

5.斑丘疹分级处理

分级	治疗指南
1 级	加强皮肤护理，做好皮肤日常的清洁、保湿及防晒 定期进行评估并关注皮肤症状变化
2 级	加强皮肤护理，做好皮肤日常的清洁、保湿及防晒 遵医嘱使用含糖皮质激素的软膏或可适当减少抗肿瘤治疗药物的剂量， 定期进行评估并关注皮肤症状变化
3 级	加强皮肤护理，做好皮肤日常的清洁、保湿及防晒 遵医嘱使用含糖皮质激素的软膏或可适当减少抗肿瘤治疗药物的剂量 定期进行评估并关注皮肤症状变化 若情况恶化或无明显改善，则及时就医，由医生根据临床判断和患者意愿决定是否需要减量或暂停治疗

6.光敏性皮炎分级处理

分级	治疗指南
1-3 级	加强皮肤护理，做好皮肤日常的清洁、保湿及防晒 避免食用光敏性的食物 a)蔬菜类：菠菜、芹菜、小白菜以及莴笋等含有大量叶绿素的蔬菜

Appendix4 The health education videos about skin protection

⊘ 1　　　⊘ 2　　　⊘ 视频二：涂抹保湿剂和药膏　　　⊘ 视频三：剪指甲　　　⊘ 视频一：如何正确洗脸及沐浴

Appendix5-1 Basic knowledge of skin toxicity

什么是免疫治疗？

免疫治疗是指运用免疫学原理和方法，通过主动或被动的方式，打破机体免疫系统对肿瘤的免疫耐受或忽视的状态，增强机体抗肿瘤的免疫应答，从而达到抑制肿瘤生长、清除肿瘤细胞的目的。通过免疫检查点抑制剂阻断机体免疫系统的负性调节机制是免疫治疗的重要策略之一。

为什么会出现免疫相关的不良反应？

免疫检查点抑制剂在通过阻断免疫检查点、解除免疫抑制、增强肿瘤特异性免疫应答的同时，也会非特异性地激活免疫系统，打破了 T 细胞激活过程的平衡状态，过度激活的 T 细胞攻击人

3.皮肤瘙痒

表现：可能伴有干燥或脱屑，好发于躯干和四肢。

皮肤瘙痒

4.大疱性皮炎

症状表现：特征为皮肤炎症和出现充满液体的大疱，严重或泛发、间歇性；皮肤因抓挠而变化（如水肿、丘疹、脱皮、苔藓样变、渗出/结

最常见的免疫治疗皮肤毒性症状及主要表现有哪些？

1.斑丘疹

（1）症状表现：斑丘疹以斑疹（扁平）和丘疹（突起）为特征，也称为麻疹样皮疹；
（2）部位：常累及躯干上部，向心扩散。

斑丘疹

2.皮肤干燥

5.手足综合征

部位：易出现在受压力或摩擦的区域（手掌、脚跟、趾骨头或由鞋子或体力劳动引起的摩擦区域）。
表现：双侧掌跖受压部位出现过度角化、红斑和脱屑，伴疼痛和感觉迟钝，有刺痛、烧灼或疼痛感，对接触物体的耐受性降低。

手足综合征

6.白癜风

部位：白癜风常出现在面部、颈部、手背、手

Appendix5-2 Skin protection

自我防护 | 关于免疫治疗皮肤毒性反应
的自我预防之皮肤护理篇

温和清洁、合理保湿和修复皮肤屏障

（1）正确清洁皮肤

a.洗澡及洗脸水温不宜过高（≤40℃），手法
轻柔，避免用力搓揉；

做好物理及化学防晒以
预防皮疹的出现和加重

（1）外出时注意物理遮挡，如遮阳伞、遮阳帽
和墨镜等，尽量避免在正午时段（上午10：00~
下午15：00）长时间的户外活动；

（2）建议出门前30 min在保湿霜后涂抹广谱防
晒霜，要求选择防晒系数 SPF≥30 和 PA≥++
（分别预防紫外线 UVB 和 UVA）的产品,避免在
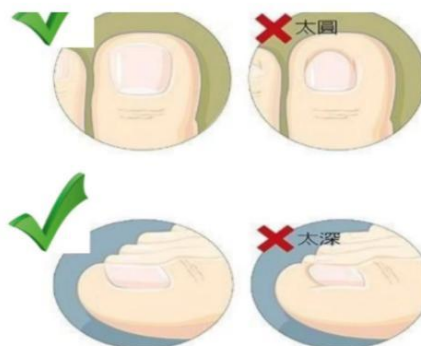无任何防护的情况下直接接触阳光。

记得防晒！

（2）合理保湿，掌握正确的涂抹保湿剂
的方法

a.面部、颈前和后背等相对油脂分泌多的区域选
择质地轻薄的乳液每天 2 次；

b.四肢伸侧和手足等皮肤易干燥的部位，选择质
地厚重的霜或乳膏，每天 2 次；

c.建议选择不含乙醇、含有神经酰胺或其他生理
性脂质以及具有皮肤屏障修复功效的医学护肤
品。

如何正确修剪指甲？

Appendix5-3 Life care of skin
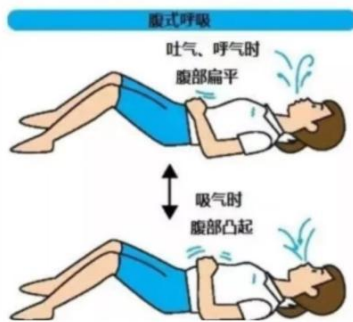
附：怎么样做腹式呼吸？

双手分别置于胸部和腹部，闭口，用鼻深吸气；

感觉腹部隆起、膈肌自然下移，吸气默数3秒；

缩唇（吹口哨样），缓慢呼气达默数6-9秒；

腹部尽量回收，双手一步向腹部加压，促进膈肌上移的方式；

维持呼气时间是吸气时间的2-3倍。

首先，入睡的时间不超过30分钟；其次，夜间醒来的次数少于3次；睡眠时间在8小时左右，最关键的是，在第二天醒来的时候，主观的感觉是一种精力恢复良好，情绪稳定，注意力集中的状态。

一入睡小技巧：

·什么是适度锻炼？

在保证日常营养均衡摄入的前提下，以运动后精力充沛、微微出汗即可。切忌不能过度劳累。

·选择什么锻炼方式呢？

建议选择低强度的有氧训练，诸如快走、慢跑、骑自行车、瑜伽、爬楼梯和一些低强度的健身操、中式的太极拳、八段锦、五禽戏等。

（1）饮食清淡、避免油腻、辛辣刺激食物。

（2）忌饮浓茶、咖啡、酒类等饮料。

（3）尽量经口进食高热量、高蛋白、高维生素易消化饮食。

（4）避免日间进食感光性食物-尤其是光敏性皮炎患者（芥菜、油菜、莴苣、芹菜、荠菜、萝卜叶、菠菜、香菜、红豆、柠檬、土豆、橘子、紫菜、白葡萄、柑橘、芒果、菠萝、螃蟹、花蛤）。

Appendix5-4 Medication guide

1·皮肤干燥分级处理

分级	治疗指南
1级	·加强皮肤护理,做好皮肤日常的清洁、保湿及防晒 ·定期进行评估并关注皮肤症状变化
2级	·加强皮肤护理,做好皮肤日常的清洁、保湿及防晒 ·遵医嘱使用含糖皮质激素的软膏或可适当减少抗肿瘤治疗药物的剂量 ·定期进行评估并关注皮肤症状变化
3级	·加强皮肤护理,做好皮肤日常的清洁、保湿及防晒 ·遵医嘱使用含糖皮质激素的软膏或可适当减少抗肿瘤治疗药物的剂量 ·定期进行评估并关注皮肤症状变化 ·若病况恶化或无明显改善,则及时就医,由医生根据临床判断和患者意愿决定是否需要减量或暂停治疗

2·皮肤瘙痒分级处理

分级	治疗指南
1级	·加强皮肤护理,做好皮肤日常的清洁、保湿及防晒 ·定期进行评估并关注皮肤症状变化
2级	·加强皮肤护理,做好皮肤日常的清洁、保湿及防晒 ·遵医嘱使用含糖皮质激素的软膏或可适当减少抗肿瘤治疗药物的剂量 ·定期进行评估并关注皮肤症状变化
3级	·加强皮肤护理,做好皮肤日常的清洁、保湿及防晒 ·遵医嘱使用含糖皮质激素的软膏或可适当减少抗肿瘤治疗药物的剂量 ·定期进行评估并关注皮肤症状变化 ·若病况恶化或无明显改善,则及时就医,由医生根据临床判断和患者意愿决定是否需要减量或暂停治疗

1·皮肤干燥分级

分级	描述
1级	<10%的体表面积,无红斑和瘙痒
2级	10%-30%的体表面积,伴有红斑和瘙痒,日常使用工具受限
3级	>30%的体表面积,伴有瘙痒,日常生活自理受限

2·皮肤瘙痒评估

分级	描述
1级	轻度或局部瘙痒
2级	广泛伴强烈的瘙痒,断断续续;搔抓引起皮肤改变(如水肿,丘疹,抓痕,渗出/痂皮);影响工具性日常生活活动
3级	广泛伴强烈的瘙痒,持续性发作;影响自理性日常生活活动或睡眠;

7·色素沉着的分级处理

分级	治疗指南
1-2级	·加强皮肤护理,做好皮肤日常的清洁、保湿及防晒 ·避免食用光敏性的食物 a)蔬菜类:菠菜、芹菜、小白菜以及莴笋等含有大量叶绿素的蔬菜 b)水果类:橘子、柠檬、芒果、菠萝等 c)海鲜类:生蚝、海虾、河虾以及大闸蟹等

8·白癜风的分级处理

分级	治疗指南
1-2级	按医嘱局部使用皮质类固醇药物,如钙调神经磷酸酶抑制剂(他克莫司软膏及吡美莫司乳膏)
2-3级	按医嘱系统使用皮质类固醇药物,如钙调神经磷酸酶抑制剂(他克莫司软膏及吡美莫司乳膏),若情况出现恶化,则及时去皮肤病医院就医

3·手足综合征的分级

分级	描述
1级	无痛性轻微皮肤改变或皮肤炎症(红斑、水肿、角化过度)
2级	痛性皮肤改变(剥落、水疱、出血、水肿、角化过度),影响工具性日常生活活动
3级	重度皮肤改变(剥落、水疱、出血、水肿、角化过度)伴疼痛,影响自理性日常生活活动

4·毛细血管增生的分级

分级	描述
1级	单个或多个结节最大直径≤10mm,伴或不伴破溃出血
2级	单个或多个结节最大直径>10mm,伴或不伴破溃出血
3级	呈泛发性,可能有感染(出现红肿热痛等症状)

Appendix 6 Informed consent for interview

Dear patient,Hello! I am a researcher from the Nursing School of Fudan University. I sincerely invite you to participate in this study. Please read the following carefully and consider whether to participate in this interview.

We are conducting a study on "Development and evaluation of self-management module of skin toxic reactions of immunotherapy for lung cancer patients based on WeChat public account". This study aims to understand the utilization of electronic devices for anti-tumor therapy in cancer patients, summarize the evidence according to the interview research results, establish relevant knowledge base, develop a patient self-management module based on WeChat public account, and carry out follow-up usability evaluation. The main purpose of this interview is to understand the utilization of electronic devices for anti-tumor therapy in cancer patients.

You participate in the study by being interviewed and collecting data in the form of notes or audio recordings. In the interview, you can express your own opinion.

Participation in this interview is completely voluntary and you can withdraw from the study at any time. At the same time, your identity and what you say during the interview will be kept strictly confidential, and your personal interview answers and research data will not be fed back to any other person or organization except the researcher. Your name will only appear on this consent form (only your participant number will appear on the interview materials), and the consent form will be kept separate from the interview materials, and any information that may personally identify you will be hidden. What appears in the results is only an anonymous set of data. In any written or oral report of the interview, the names and identifiable information of the persons interviewed will not be mentioned.

I agreed to participate in the interview and I know that I could withdraw from the study at any time. In addition, I understand that all information will be kept strictly confidential by the researchers.

Interviewee：

Researcher：

Date:

Appendix 7 Post-Study System Usability Questionnaire （PSSUQ）

Table 12

Score：1 is very poor, 2 is poor, 3 is average, 4 is good, 5 is very good.

Dimensions	Items	Score（√）
Usability	1.The account is easy to use	1 2 3 4 5
	2.I feel simple applying the account	1 2 3 4 5
	3.I can quickly complete the assigned task by using this account	1 2 3 4 5
	4.I feel comfortable using the account	1 2 3 4 5
	5.I feel easy learning to use the account	1 2 3 4 5
	6.I believe I can manage myself more efficiently if I use this account	1 2 3 4 5
Information quality	7.If the account has errors,it can tell me how to handle them	1 2 3 4 5
	8.Whenever I make a mistake using the account, I can recover quickly and find the correct way	1 2 3 4 5
	9.The information provided by the account is very clear	1 2 3 4 5
	10.It is easy to find the information I need on the account	1 2 3 4 5
	11.The information provided by the account is helpful for my healthy self-management	1 2 3 4 5
	12.The information arrangement of this public account is very reasonable	1 2 3 4 5
Interface quality	13.The interface is clear and friendly	1 2 3 4 5
	14.I like to use the account interface	1 2 3 4 5
	15.The account contains the functions I expect	1 2 3 4 5
	16.The display of the account is easy to read	1 2 3 4 5
	17.The color design of the account interface is beautiful	1 2 3 4 5
	18.The pictures displayed on the account are clear	1 2 3 4 5
	19.I can still remember how to operate the account next week	1 2 3 4 5
Overall evaluation	20.On the whole, I am satisfied with this account	1 2 3 4 5

Appendix 8 Informed consent for usability evalution

Dear patient,Hello! I am a researcher from the Nursing School of Fudan University. I sincerely invite you to participate in this study. Please read the following carefully and consider whether to participate in this interview.

We are conducting a study on "Development and evaluation of self-management module of skin toxic reactions of immunotherapy for lung cancer patients based on WeChat public account". This study aims to understand the utilization of electronic devices for anti-tumor therapy in cancer patients, summarize the evidence according to the interview research results, establish relevant knowledge base, develop a patient self-management module based on WeChat public account, and carry out follow-up usability evaluation. The main purpose of this interview is to understand your feelings about the use of our public account.

You will participate in this study by completing a Post-Study System Usability Questionnaire.

Participation in this interview is completely voluntary and you can withdraw from the study at any time. At the same time, your identity and what you say during the interview will be kept strictly confidential, and your personal interview answers and research data will not be fed back to any other person or organization except the researcher. Your name will only appear on this consent form (only your participant number will appear on the interview materials), and the consent form will be kept separate from the interview materials, and any information that may personally identify you will be hidden. What appears in the results is only an anonymous set of data. In any written or oral report of the interview, the names and identifiable information of the persons interviewed will not be mentioned.

I agreed to participate in the interview and I know that I could withdraw from the study at any time. In addition, I understand that all information will be kept strictly confidential by the researchers.

Interviewee：

Researcher：

Date:

Appendix 9 Ethics Committee Grant Letter

复旦大学附属肿瘤医院医学伦理委员会（SCCIRB）

B-1（3.0版）-2018.10.1

复旦大学附属肿瘤医院医学伦理委员会
批准函

伦理编号：2001213-37-NSFC

审查日期	2020.3.18、2020.3.30
审查会议地点	NA
研究项目名称	基于患者报告结局的肺癌免疫治疗不良反应症状纵向变化机制及精准应对策略研究
审查文件	相关资料（每单项必须填写，提交资料标记为 √，未提交资料的标记为 ✕，如无版本号标记为 一） ☒ 国家食品药品监督管理局批件，批件文号：___ ☒ 方案，版本号：___ ☒ 项目，编号：___ ☒ 药品生产许可证及检测报告/医疗器械注册证及检验报告 ☑ 知情同意书样本，版本号：纵向研究知情同意书1.0版（2020.3.11）；随机对照知情同意书1.0版（2020.3.11） ☒ 研究者履历、临床研究经历 ☑ 其他（请说明）：2020年度国家自然基金标书正文部分
研究科室	护理部
主要研究者	张晓菊
申办者	研究者发起-国家自然基金项目（2020年度）
伦理审查方式	□ 会议审查 ☑ 快速审查
评审委员	朱骥、李小秋
审查意见	研究者的伦理审查申请于2020年3月13日递交，根据SOP规定，经两名主审委员快速审查，分别于2020年3月18日、30日反馈，意见均为：同意申报。 　　该批准函仅限于研究者申请2020年度国家自然基金时使用，一旦立项，该方案须经伦理委员会再次审核、完善后方能正式开展，如此次申报不成功，该批准函不生效。 　　　　　　　　　　　主任或副主任委员签字： 　　　　　　　　复旦大学附属肿瘤医院医学伦理委员会（盖章） 　　　　　　　　　　　日期：2020年3月31日

注意：（请仔细阅读）
1. 该研究进行过程中将接受伦理委员会的持续审查，持续审查方式为：**NA（本研究不需要持续审查）。**
　持续审查频率为：研究批准之日起NA。（伦理委员会有权根据实际进展情况改变持续审查频度）
2. 本批件将在各中心机构及其伦理委员会备案。
3. 已批准项目须遵循 本伦理委员会批准的方案执行，须符合 CFDA/GCP 和《赫尔辛基宣言》的原则。
4. 暂停/提前终止临床研究，请及时通知伦理委员会。
5. 发生严重不良事件及影响研究风险受益比的非预期事件，须及时报告本伦理委员会。
6. 对已批准的临床研究方案、知情同意书等材料的任何修改及主要研究者更换等，须及时通知本伦理委员会重新审查，获得批准后执行。
7. 发现违反方案情况须及时报告伦理委员会。
8. 请根据伦理委员会对持续审查频度的意见，无论试验开始与否，请在持续审查日到期前 1 个月提出持续审查的申请。
9. 本批件有效期为壹年，研究者应在批件有效期内提交年度/定期报告，审查后续发"伦理审查意见通知"。
10. 完成临床研究，须提交结题报告供伦理委员会审查。
11. 所有伦理委员会审查的内容都已经涵盖在批件上。