UNIVERSITY OF TURKU

The development and usability evaluation of the symptom management module in the support system APP for parents of children with acute leukaemia

Department of Nursing Science

Master's thesis

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Abstract

Background

Childhood cancer is the second cause of death in children. Leukaemia is the most common childhood cancer, accounting for 31% of cancers in children under 14. It has become a global concern for children's health. During the treatment of children with acute leukaemia, symptom management is the most painful thing for children and their parents. The symptom brings pain to children, reduces their quality of life, and affects the disease's prognosis. Moreover, the symptom can lead to the termination of treatment, hospitalization prolongation, and treatment costs increase. Therefore, parents need to participate in the symptom management of their children. The parents of children with acute leukaemia bear the heavy blow of their children's condition and limited knowledge of leukaemia. They do not have sufficient knowledge for the treatment, care, symptom prevention, recognition, and management of the symptom. Hence, these facts result in an extreme lack of confidence in participating in symptom management of their children. Therefore, symptom management in children with acute leukaemia needs to be highly concerned. With the progress of mobile health technology, more and more information means are applied in chronic disease management. However, few studies focus on symptom management support for parents of children with acute leukaemia. Funded by the National Natural Science Foundation of China, our research team has constructed the framework of the support system APP for parents of children with acute leukaemia. The symptom management module of the support system APP was reserved—this study aimed at the pain points in the symptom management of children with acute leukaemia. By applying mobile health technology, this study constructed the symptom management module in the support system APP for parents of children with acute leukaemia, realized the function of the symptom management module, and finished the usability evaluation of the symptom management module. This study will help improve the effectiveness of symptom management of children with acute leukaemia, enhance parents' symptom management ability, and save medical resources.

Objectives

This research aims to develop the symptom management module in the support system APP for parents of children with acute leukaemia and evaluate the usability of the symptom management module.

Purpose one: To explore the parents' symptom management needs for children with acute leukaemia;

Purpose two: To construct the image-text knowledge base of the symptom management module in the support system APP;

Purpose three: To develop the symptom management module in the support system APP;

Purpose four: To evaluate the usability of the symptom management module in the support system APP.

Methods

The study was comprised of 4 parts：

Part1: The analysis of parents' symptom management needs for children with acute leukaemia

By the qualitative interview, six healthcare providers of the haematology-oncology department and 14 parents of children with acute leukaemia were interviewed, all from the Children's Hospital of Fudan University and the Children's Hospital of Suzhou University. This study also selected two WeChat groups of the haematology-oncology department of the Children's Hospital of Fudan University and the Children's Hospital of Suzhou University to collect and analyze the chat records of parents of children with acute leukaemia. The content analysis method was used to analyze the data of the interviews and the WeChat group chat records. Hence, the symptoms suitable for parents to manage, the symptom management needs of parents of children with acute leukaemia, and their needs for the symptom management module were deeply understood.

Part2: The construction of the image-text knowledge base

The clinical manuals, guidelines, scientific literature, and monographs on symptom management of children with acute leukaemia were searched. Combined with the preliminary analysis of symptom management needs in parents of children with acute leukaemia, the framework of the image-text knowledge base was constructed. Then, the symptom management module's preliminary image-text knowledge base was finished. Two researchers and two healthcare providers revised the preliminary image-text knowledge base. Finally, the researcher composed the final image-text knowledge base and reviewed it with two scientific researchers.

Part3: The development of the symptom management module in the support system APP

Based on the final image-text knowledge base and the analysis of the symptom management needs in parents of children with acute leukaemia, the brainstorming discussion with the multidisciplinary development team was organized to generate the function assumptions of the symptom management module. The multidisciplinary development team included three researchers, two healthcare providers, and two software engineers. By the human-centred concept and the agile development method, the researcher developed the symptom management module with software engineers through five steps: requirement confirmation, interface design, function realization, testing, and disclosure.

Part4: The usability evaluation of the symptom management module in the support system APP

The formative usability evaluation was implemented during the development of the symptom management module. The formative usability evaluation aimed to find the problems with the module's interface, font, and functions. Then the summarized usability evaluation was implemented when the module was completed. Five researchers, four healthcare providers, and ten parents of children with acute leukaemia were invited to evaluate the usability problems of the symptom management module by typical task analysis, Post-Study System Usability Questionnaire (PSSUQ), and semi-structured interviews.

Results

Part1: The analysis of symptom management needs in parents of children with acute leukaemia

The qualitative study of parents of children with acute leukaemia precipitated: 1) the symptoms that parents participated or wanted to participate in, the preliminary symptom list suitable for parents to participate in (36 physiological symptoms and 5 psychological symptoms); 2) parents' symptom management needs; 3) the functions of the symptom management module that parents needed. Moreover, the chat records of two WeChat groups were analyzed to supplement the parents' symptom management needs. The qualitative results of healthcare providers presented: 1) the final symptom list suitable for parents of children with acute leukaemia to participate in (41 physiological symptoms and 6 psychological symptoms); 2) the symptom management-related knowledge that parents need ed to know; 3) the healthcare providers' suggestion about the functions of the symptom management module. In conclusion, the final symptoms list suitable for parents to participate in (41 physiological symptoms and 6 psychological symptoms) was formed; Symptom management needs of parents of children with acute leukaemia (4 categories and 17 contents); Three main functions of the symptom management module (search function, symptom assessment and response function, and recommendation function).

Part2: The construction of the image-text knowledge base

The researcher constructed the framework of the image-text knowledge base, which included four categories and 17 contents. According to the framework, the preliminary image-text knowledge base was constructed. After the experts' review and revision, the final image-text knowledge base was generated, including 41 image-text knowledge articles of physiological symptoms and 6 image-text knowledge articles of psychological symptoms.

Part3: The development of symptom management module in the support system APP

The functions assumptions of the symptom management module in the support system APP included (1) Active browsing and searching function; (2) Symptom assessment-based recommendation function ; (3) Content-based recommendation function.

The functions of the developed symptom management module in support system APP included: (1) Active browsing and searching function: 1)Parents can directly browse the related image-text symptom management knowledge in the symptom management module; 2) Parents can search in the "Search" column, and the related image-text symptom management knowledge will emerge; (2) Symptom assessment-based recommendation function: After filling in the PROMIS (Patient-reported Outcomes Measurement Information System) pediatric self-reported / parent proxy-reported questionnaire in the APP, parents/children will be recommended the related symptom management knowledge according to the score of the PROMIS questionnaire; (3) Content-based recommendation function:1) If parents search for symptom-related information, the relevant image-text symptom management information will scroll in the "Recommended Articles" module in the APP home page; 2) When parents search for information related to chemotherapy drug, side effects related-symptoms of the chemotherapy drug will emerge in the search results; 3) There are physiological symptoms and psychological symptoms in the symptom management module, when it comes to a specific image-text symptom knowledge, the clickable related-symptom links (based on the symptom recommendation rule) are at the bottom of the image-text knowledge page. It will be linked to the other related symptom by clicking.

Part4: The usability evaluation of the symptom management module in the support system APP

In formative usability evaluation, six fundamental problems of the module interface were found and revised. After the development of the module, the summative usability evaluation was carried out. The scores of the PSSUQ after the test: researchers: 1)system usefulness is 5.2, information quality is 6.0, interface quality is 5.4, and overall evaluation is 6.0; 2) healthcare providers: system usefulness is 5.8, information quality is 6.0, interface quality is 5.9, and overall evaluation is 6.2; 3) parents: system usefulness is 5.8, information quality is 6.0, interface quality is 5.9, and overall evaluation is 6.2. The interview data with parents showed three topics related to usability: 1) " Awareness of symptoms management"; 2) " Advantages and benefits"; 3) " Disadvantages and obstacles."

Conclusions

Parents of children with acute leukaemia have various needs in symptom management. This study explored the suitable symptoms for parents to participate in (41 physiological and 6 psychological symptoms) and their needs in participation in their children's symptom management. Based on these findings, the researcher constructed the image-text knowledge base and developed the symptom management module in the support system APP. The usability evaluation showed that the module had good usability and met the symptom management needs of parents of children with acute leukaemia.

KEY WORDS： Symptom Management; Childhood Acute Leukemia; Support System; Knowledge Base Construction; Usability Evaluation

Abstrakti

Tausta

Lapsuusiän syöpä on lasten toiseksi yleisin kuolinsyy. Leukemia on yleisin lapsuusiän syöpä, jonka osuus alle 14-vuotiaiden lasten syövistä on 31%. Leukemiasta on tullut maailmanlaajuinen huolenaihe lasten terveyteen liittyen. Akuuttia leukemiaa sairastavien lasten oireiden hallinta on haastavin asia lapsille ja heidän vanhemmilleen. Oireet aiheuttavat kipua lapsille, heikentävät lasten elämänlaatua ja vaikuttavat taudin ennusteeseen. Lisäksi oireet voivat johtaa jopa hoidon lopettamiseen, sairaalahoidon pidentymiseen ja hoitokustannusten nousuun. Siksi vanhempien tulisi osallistua lastensa hoitoon ja oireiden hallintaan.

Akuuttia leukemiaa sairastavien lasten vanhemmat kantavat raskasta taakkaa lastensa sairauden ja heidän oman rajallisen tietonsa vuoksi. Vanhemmilla ei ole riittävästi tietoa leukemian oireiden hoidosta, ehkäisystä, tunnistamisesta ja hallinnasta. Sen vuoksi vanhemmat saattavat kokea, että heillä ei ole valmiuksia osallistua lastensa hoitoon ja oireiden hallintaan. Sen vuoksi olisikin tärkeää, että akuuttia leukemiaa sairastavien lasten oireiden hoitoon kiinnitetään huomiota.

Terveysteknologian kehityksen myötä kroonisten sairauksien hallinnassa käytetään yhä enemmän teknologiaa ja sen kautta kerättyä tietoa. Kuitenkin vain harvat tutkimukset keskittyvät akuuttia leukemiaa sairastavien lasten vanhempien oireiden hallinnan tukemiseen. Kiinan kansallisen luonnontieteellisen säätiön (*the National Natural Science Foundation of China*) rahoittama tutkimusryhmämme on suunnitellut APP-tukijärjestelmän akuuttia leukemiaa sairastavien lasten vanhemmille. Tämä tutkimus keskittyi akuuttia leukemiaa sairastavien lasten kipuoireiden hallintaan ja tässä tutkimuksessa rakennettiin kivun hallintaan liittyvä moduuli APP-tukijärjestelmään, ja testattiin osion käytettävyyttä. Tämä tutkimus auttaa parantamaan akuuttia leukemiaa sairastavien lasten oireiden hallintaa, tukee vanhempien oireiden hallintakykyä ja säästää lääketieteellisiä resursseja.

Tavoitteet

Tämän tutkimuksen tavoitteena on kehittää APP-tukijärjestelmän oireiden hallintamoduuli akuuttia leukemiaa sairastavien lasten vanhemmille ja arvioida oireiden hallintamoduulin käytettävyyttä. Osatavoitteet ovat:

1) Tutkia akuuttia leukemiaa sairastavien lasten vanhempien oireiden hallintatarpeita;

2) Rakentaa oireiden hallintamoduulin tietopohja APP-tukijärjestelmää varten;

3) Kehittää oireiden hallintamoduulia APP-tukijärjestelmässä;

4) Arvioida oireiden hallintamoduulin käytettävyyttä APP-tukijärjestelmässä

Metodit

Tutkimus koostui 4 osasta:

Osa 1: Akuuttia leukemiaa sairastavien lasten vanhempien oireiden hallintatarpeiden analysointi

Laadullisessa haastattelussa haastateltiin hematologian ja onkologian osaston terveydenhuollon asiantuntijoita (n=6) ja akuuttia leukemiaa sairastavien lasten vanhempia (n=14), kaikki Fudanin yliopiston lastensairaalasta ja Suzhoun yliopiston lastensairaalasta. Aineistoon valittiin mukaan myös kaksi WeChat-ryhmää Fudanin yliopiston lastensairaalan hematologian ja onkologian osastolta ja Suzhoun yliopiston lastensairaalasta, joista kerättiin ja analysoitiin akuuttia leukemiaa sairastavien lasten vanhempien chat-keskusteluita. Haastattelut ja WeChat-ryhmäkeskustelutietueet analysoitiin sisällönanalyysin avulla. Tulosten avulla ymmärrettiin, mitä oireita vanhemmat kokevat voivansa hallita ja millaisia tarpeita vanhemmilla on oireidenhallintaan ja APP-tukijärjestelmään liittyen.

Osa 2: Oireiden hallintamoduulin tietopohjan rakentaminen

Tutkimuksessa etsittiin kliinisiä käsikirjoja, suosituksia, tieteellistä kirjallisuutta ja monografioita akuuttia leukemiaa sairastavien lasten oireiden hallintaan liittyen. Yhdessä aiemman kirjallisuuden ja

tutkimuksen ensimmäisen osan tulosten perusteella rakennettiin viitekehys oireiden hallintamoduulin tietopohjalle, jonka pohjalta tietopohja luotiin. Kaksi tutkijaa ja kaksi terveydenhuollon asiantuntijaa tarkistivat alustavan tietopohjan. Lopuksi tutkija muodosti lopullisen tietopohjan ja tarkasteli sitä kahden tieteellisen tutkijan kanssa.

Osa 3: Oireiden hallintamoduulin kehittäminen APP-tukijärjestelmään

Lopullisen tietopohjan ja akuuttia leukemiaa sairastavien lasten vanhempien oireiden hallintatarpeiden analyysin perusteella järjestettiin aivoriihi monialaisen kehitystiimin kanssa oireiden hallintamoduulin kehittämiseksi. Monitieteiseen kehitystiimiin kuului kolme tutkijaa, kaksi terveydenhuollon asiantuntijaa ja kaksi ohjelmistoinsinööriä. Ihmiskeskeisellä lähestymistavalla ja ketterällä kehittämismenetelmällä tutkija kehitti oireenhallintamoduulin ohjelmistoinsinöörien kanssa viiden eri vaiheen kautta: vaatimusten vahvistaminen, rajapintasuunnittelu, toimintojen toteuttaminen, testaus ja julkistaminen.

Osa 4: App-tukijärjestelmän oireiden hallintamoduulin käytettävyyden arviointi

Formatiivinen käytettävyyden arviointi toteutettiin oireiden hallintamoduulin kehittämisen aikana. Formatiivisen käytettävyyden arvioinnin tarkoituksena oli löytää moduulin käyttöliittymän, fontin ja toimintojen ongelmat. Summatiivinen käytettävyysarviointi toteutettiin, kun moduuli oli kokonaan valmis. Viisi tutkijaa, neljä terveydenhuollon asiantuntijaa ja kymmenen akuuttia leukemiaa sairastavan lapsen vanhempaa kutsuttiin arvioimaan oireiden hallintamoduulin käytettävyysongelmia tyypillisen tehtäväanalyysin, PSSUQ-käytettävyyskyselyn (*Post-Study System Usability Questionnaire*) ja puolistrukturoitujen haastattelujen avulla.

Tulokset

Osa 1: Akuuttia leukemiaa sairastavien lasten vanhempien oireiden hallintatarpeiden analysointi

Akuuttia leukemiaa sairastavien lasten vanhempien haastatteluista tunnistettiin kolme eri kokonaisuutta: 1) oireet, joiden hallintaan vanhemmat osallistuivat tai halusivat osallistua, alustava oireluettelo, näistä oireista (36 fysiologista oiretta ja 5 psykologista oiretta); 2) vanhempien tarpeet lasten oireiden hallintaan liittyen; 3) vanhempien tarpeet APP-tukijärjestelmän oireiden hallintamoduuliin liittyen. Lisäksi kahden WeChat-ryhmän chat-tietueet analysoitiin. Terveydenhuollon asiantuntijoiden haastatteluista tunnistettiin kolme eri kokonaisuutta: 1) lopullinen oireluettelo, jossa on listattuna oireet, joiden hallintaan vanhemmat voivat osallistua (41 fysiologista oiretta ja 6 psykologista oiretta); 2) oireiden hallintaan liittyvä tieto, jota vanhemmat tarvitsevat; 3) terveydenhuollon asiantuntijoiden ehdotus APP-tukijärjestelmän oireiden hallintamoduulin toiminnoista. Tulosten perusteella muodostettiin: 1) lopullinen luettelo oireista, joiden hallintaan vanhemmat voivat osallistua (41 fysiologista oiretta ja 6 psykologista oiretta); 2) akuuttia leukemiaa sairastavien lasten vanhempien oireiden hallintatarpeet (4 kategoriaa, 17 alakategoriaa); 3) oireiden hallintamoduulin kolme päätoimintoa (hakutoiminto, oireiden arviointi- ja vastetoiminto sekä suositustoiminto).

Osa 2: Oireiden hallintamoduulin tietopohjan rakentaminen

Tutkija rakensi viitekehyksen tietopohjalle, joka sisälsi neljä kategoriaa ja 17 alakategoriaa. Kehyksen mukaan rakennettiin alustava tietopohja. Asiantuntijoiden palautteiden perusteella luotiin lopullinen tietopohja, joka sisälsi 41 artikkelia fysiologisista oireista ja 6 artikkelia psykologisista oireista.

Osa 3: Oireiden hallintamoduulin kehittäminen APP-tukijärjestelmään

APP-tukijärjestelmän oireiden hallintamoduulin toiminnot sisälsivät (1) aktiivisen selaus- ja hakutoiminnon; (2) oireiden arviointiin perustuvan suositustoiminnon; (3) sisältöpohjaisen suositustoiminnon.

APP-tukijärjestelmään kehitetyn oireiden hallintamoduulin toimintoihin kuuluivat: (1) Aktiivinen selaus- ja hakutoiminto: 1) Vanhemmat voivat vapaasti selata moduulista löytyvää tietoa oireiden hallintaan liittyen; 2) Vanhemmat voivat etsiä tietoa "Haku"-toiminnolla, (2) Oireiden arviointiin perustuva suositustoiminto: Täytettyään PROMIS (*Patient-reported Outcomes Measurement Information System*) -kyselyn joka on pediatrinen itseraportoitu / vanhempien raportoima

kyselylomake APP-tukijärjestelmässä, vanhemmille / lapsille suositellaan siihen liittyvää oireiden hallintatietoa PROMIS-kyselylomakkeen pisteiden mukaisesti; (3) Sisältöpohjainen suositustoiminto: 1) Jos vanhemmat etsivät oireisiin liittyviä tietoja, asiaankuuluvat kuvatekstin oireiden hallintatiedot vierivät APP-kotisivun "Suositellut artikkelit" -moduulissa; 2) Kun vanhemmat etsivät kemoterapialääkkeeseen liittyvää tietoa, hakutuloksissa ilmenee kemoterapialääkkeen sivuvaikutuksiin liittyviä oireita; 3) Oireiden hallintamoduulissa on fysiologisia oireita ja psykologisia oireita, kun on kyse tietystä oiretiedosta, napsautettavat liittyvät oirelinkit (oiresuositussäännön perusteella) ovat sivun alaosassa. Se linkitetään toiseen liittyvään oireeseen napsauttamalla.

Osa 4: App-tukijärjestelmän oireiden hallintamoduulin käytettävyyden arviointi

Formatiivisen käytettävyyden arvioinnissa havaittiin ja korjattiin kuusi moduulin käyttöliittymän perusongelmaa. Moduulin kehittämisen jälkeen suoritettiin summatiivinen käytettävyyden arviointi. PSSUQ:n pisteet testin jälkeen: tutkijat: 1) järjestelmän hyödyllisyys 5,2, tiedon laatu 6,0, käyttöliittymän laatu 5,4 ja kokonaisarviointi 6,0; 2) terveydenhuollon asiantuntijat: järjestelmän hyödyllisyys 5,8, tiedon laatu 6,0, käyttöliittymän laatu 5,9 ja kokonaisarviointi 6,2; 3) vanhemmat: järjestelmän hyödyllisyys 5,8, tietojen laatu 6,0, käyttöliittymän laatu 5,9 ja kokonaisarviointi 6,2. Vanhempien haastattelutiedot osoittivat kolme käytettävyyteen liittyvää asiaa: 1) " Tietoisuus oireiden hallinnasta"; 2) " Hyödyt ja edut"; 3) " Haitat ja esteet."

Johtopäätökset

Akuuttia leukemiaa sairastavien lasten vanhemmilla on erilaisia tarpeita lasten oireiden hallinnassa. Tässä tutkimuksessa tutkittiin oireita, joiden hallintaan vanhemmat voivat osallistua (41 fysiologista ja 6 psykologista oiretta), ja heidän tarpeitaan osallistua lastensa oireiden hallintaan. Näiden havaintojen perusteella tutkija rakensi tietopohjan ja kehitti oireiden hallintamoduulin APP-tukijärjestelmään. Käytettävyyden arviointi osoitti, että moduulilla oli hyvä käytettävyys ja se vastasi akuuttia leukemiaa sairastavien lasten vanhempien oireiden hallintatarpeisiin.

Asiasanat: Oireiden hallinta; lapsuuden akuutti leukemia; tukijärjestelmä; tietopohjan rakentaminen; käytettävyyden arviointi

Table of Content

List of Figures and Tables

Figures

Tables

Abbreviations

PP	Parent Participation
PROMIS	Patient-reported Outcomes Measurement Information System
ISO	International Organization for Standardization
PSSUQ	Post-study System Usability Questionnaire
ICT	Information and Communication Technology

Introduction

The high survival rate and symptom-related distress of childhood leukaemia

Childhood cancer is the second cause of death among children. Leukaemia is the most common childhood cancer, accounting for 31% of cancers in children under 14 years old, and has become a global concern for children's health care[1-2]. Acute Lymphoblastic Leukemia (ALL) and Acute Myeloid Leukemia (AML) are the most common Leukemia in children. It accounts for 80% and 15% of leukaemia in children under 14 years old. Nevertheless, childhood chronic leukaemia is rare[1]. Fortunately, the five-year survival rate of children with leukaemia has reached 70.5%. The five-year survival rate of children with ALL is as high as 90%, and that of children with AML is slightly lower, at about 64%[1,3]. Therefore, this study mainly focuses on these two types of acute childhood leukaemia, ALL and AML.

During the treatment of children with acute leukaemia, symptom management is the most painful thing for children and their parents. The symptom can be caused by leukaemia and the treatment. The common symptoms in children with acute leukaemia include fatigue, nausea, vomiting, anorexia, constipation, infection, pain, sweating, anger, and dysphoria[4-6]. Ideally, the health care practitioners would respond to different symptoms promptly and provide treatment and care. However, different types of leukaemia have different treatment schemes and phases, which enable the core symptoms of children with acute leukaemia to be various and difficult to predict.

Moreover, the symptom of children with acute leukaemia rarely exists in the form of single. Different symptoms often relate to and influence each other, showing the trend of the cluster. For children, it is multiple impacts rather than the simple sum of negative influences[7]. The symptom brings pain to children, reduces their quality of life, and affects the disease's prognosis. Moreover, the symptom can lead to the termination of treatment, hospitalization prolongation, and treatment costs increase. These side effects aggravate parents' care burden, mental pressure, and economic pressure[6,8]. Therefore, symptom management of children with acute leukaemia is in urgent need.

Low quality of parent participation in symptom management

Since the high incidence of childhood leukaemia is 0-4 years old[9], the children are young. Their expression, cognition, and self-care ability are limited, so parents need to participate in managing their symptoms. When the children cannot express symptom management needs,

parents often need to assume the identity of the children's spokesperson. However, parents of children with acute leukaemia are often under a heavy blow of their children's condition, combined with a weak awareness of the treatment and care of acute leukaemia. They do not own sufficient knowledge about the prevention, identification, and management of the symptoms. Their participation in symptom management extreme lack of confidence, often in a state of bewildered[10-11].

At the same time, the vast majority of children with acute leukaemia need chemotherapy, which lasts from induced remission, consolidation, and maintenance to home-based maintenance for an average of 2 to 3 years[1]—the long-term treatment results in two situations: in-hospital treatment and out-of-hospital family-centred care. Healthcare providers can promptly treat and control children's symptoms during in-hospital treatment. However, in out-of-hospital family-centred care, parents may easily ignore symptoms-inducing factors. They cannot recognize symptoms early; symptoms are not managed promptly and are mismanaged[10]. Hence, the symptom management effect of children is not ideal, and the parents have a poor experience with the participation in symptom management of their children[12]. Therefore, professional support and guidance should be provided to parents to promote their effective and efficient participation in symptom management. They are essential participants in the symptom management of children with acute leukaemia. It is very significant to improve the effectiveness of symptom management in children and enhance the experience of parents' participation in symptom management.

Application of mobile health technology to provide intervention

In <Health China 2030>, the chapter "the construction of health information service system." It promotes Internet+ health care and innovates the online health services model. Moreover, it puts forward establishing independent national health management and information services, promoting health big data applications, and meeting the individualized care service and precise medicine[13].

However, few intervention research projects are designed for parents of children with acute leukaemia, even for children with cancer. Some research mainly concentrated on parents' mental health via face-to-face or video phone; however, the traditional means of intervention are time-consuming and labour-consuming. Because of the long treatment cycle of leukaemia, there are family-centred care periods between the course of treatment. The in-hospital and out-of-hospital situations appear alternately. Limited by the human, healthcare resources and

other factors, the parents cannot continue to participate in the intervention. Thus, though the intervention provided for parents of children with disease is increased, the actual benefit is not ideal[14].

In recent years, mobile healthcare technology has been developing rapidly. Smartphones and applications (APPs) have been widely used due to their unparalleled advantages: convenience, real-time, accessibility, and interactivity. Third-party smartphone applications have become a necessary technical means for developing mobile health. They have been applied in health care and chronic disease management. Their feasibility and effectiveness in symptom management of cancer patients have also been fully proven[15-17]. Therefore, breaking through the traditional means of healthcare intervention, positively responding to the national health plan, and using mobile health technology to provide intervention for parents of children with acute leukaemia have become the trend.

This study is supported by the National Natural Science Foundation of China (Project ID: 71904195): The construction of a support system for parents' participation in symptom management of children with leukaemia: based on "User Profile". Our research team has constructed the framework of the support system APP for parents of children with acute leukaemia: "Leukaemia Treasure Box (Bai Bao Xiang in Chinese)." The support system has five modules: 1)health education module; 2)treatment process guidance module; 3)data collection module; 4)symptom management module; 5)diet recommendation module. The first three modules have been constructed in the previous work. This study developed the symptom management module of the support system APP to meet the symptom management needs of parents of children with acute leukaemia. Moreover, this study realized the function of the symptom management module and evaluated the usability of the symptom management module.

1 Research background

1.1 Definition

(1) Symptom management

"Care given to improve the quality of life of patients who have a serious or life-threatening disease. The goal of symptom management is to prevent or treat as early as possible the symptoms of a disease, side effects caused by treatment of a disease, and psychological, social, and spiritual problems related to a disease or its treatment. Also called comfort care, palliative care, and supportive care. "

(2) Parent participation

"Parent Participation (PP)" is a comprehensive multi-dimensional concept, which means that parents are involved or allowed to participate in the decision-making, implementation, or evaluation of measures, or directly become a consultant of a problem or event, so that parents can actively participate in and be responsible for the whole process of children's recovery[18]. The American Academy of Pediatrics points out that "parental participation" is the central principle of family-centred nursing practice and emphasizes that parent participation is beneficial to parents' physical and mental health and children's recovery[19].

(3) Mobile health

Mobile Health (mHealth) refers to the application of mobile phones, monitoring devices, personal digital devices, and other wireless devices in the field of medical treatment and health care. The mobile health (mHealth) field has emerged as a sub-segment of eHealth, using information and communication technology (ICT), such as computers, mobile phones, communications satellites, patient monitors, etc., for health services, Information, and data collection.

(4) Usability

The International Organization for Standardization (ISO) defines "usability" as "the extent to which specified users can use a product to achieve specified goals with effectiveness, efficiency, and satisfaction in a specified context of use" in the ISO9241-11[20].

(5) Usability evaluation

Usability evaluation is a technique used in user-centred interaction design to evaluate a product by testing it on users. It can be seen as an irreplaceable usability practice since it directly influences how real users use the system. It is more concerned with the design intuitiveness of the product and tested with users who have no prior exposure to it. Such testing is paramount to the success of an end product as a fully functioning application that creates confusion amongst its users will not last for long.

1.2 Literature review

1.2.1 The parents' symptom management needs for children with acute leukaemia

Parents have various needs during the care of children with acute leukaemia, such as information, social support, and symptom management. Healthcare providers should promptly discover and evaluate the importance and satisfaction of the needs of parents and provide extra help according to different families.

Kuan et al.[21] showed the needs of family caregivers of children with cancer in Hong Kong (49% of the samples were leukaemia). Their needs include obtaining information, accompanying children, communicating with health care professionals, promoting children's continued growth and development, maintaining caregivers' self-ability and facing family problems, and mobilizing community resources. They developed a questionnaire based on qualitative interviews with family caregivers of children with cancer, "Needs of Family Caregivers of Child Cancer in Hong Kong". It contained seven dimensions and 56 items, covering the following three questions: 1) the needs of the family caregivers in the care of the children; 2) the importance of the needs perceived by the family caregivers; 3) the satisfaction of the family caregivers with their needs. However, the questionnaire needs further verification if it can be used in mainland China.

Wang et al.[22] used the qualitative phenomenological methodology to understand the needs of parents of children with acute lymphoblastic leukaemia. They conducted in-depth semi-structured interviews with the parents of 14 children. The results showed that the needs of parents of children with acute lymphoblastic leukaemia could be summarized into five themes: information needs, symptom management needs, psychosocial needs, economic support needs, and high-quality care needs. Among these needs, parents have complex symptom management needs. The parents have little understanding of the basic information about acute lymphoblastic leukaemia and have a greater need for information related to

treatment and care. This led to poor parent participation in symptom management of their children. They should be given comprehensive intervention and support from multiple angles. The result indicated that the key is predictive prevention, early recognition, and timely treatment of symptoms. However, the symptoms that are suitable for parents to participate in are needed to explore.

Liu et al.[23] used phenomenological research methods to understand the symptom management needs and care experience of parents of children with cancer during chemotherapy. The study results showed that parents of children with cancer have multiple information needs for symptoms, adverse reactions, prevention, and care knowledge. The research showed that the information about symptoms and adverse reactions is the most concerning content for parents of children with cancer, especially in the early stage of diagnosis. The parents lack knowledge of symptoms and adverse reactions. This results in parents having terrible participation in symptom management, and their children's symptoms occur frequently.

"Wang et al.[24] identified unobserved subgroups of Chinese parents' caregiving ability for children with haematological malignancies and examined the associations of the latent class membership with individual characteristics. Three distinct latent classes of Chinese parents of children with haematological malignancies were identified with regard to caregiving ability: "high caregiving ability" class (n=131, 33.4%), "medium caregiving ability" class (n=170, 43.4%), and "low caregiving ability" class (n=91, 23.2%). The results showed that compared with parents of children with other kinds of haematological malignancies, parents of children with leukaemia were more probably to be in the "low caregiving ability" class than in the "high caregiving ability." Therefore, early and precise supportive intervention could be provided to the targeted parents to improve their caregiving ability, which improves the children's disease prognosis and quality of life. Moreover, the results of this study also reminded us that parents with high self-appraisal of caregiving ability might not have high ability in all the aspects of caregiving. Therefore, targeted support needs to be provided to parents based on their needs. "

In conclusion, few domestic and foreign studies on the need for parents' symptom management of children with acute leukaemia. Most of the studies explored the general needs of parents of children with acute leukaemia. Few studies focused on the needs of parents' when they participate in symptom management of children with acute leukaemia. Few studies

explored the needs of parents for symptom management in detail. No studies conducted interviews with healthcare providers to know the needs of parents and the suitable symptom for the parent to manage—these need to be further explored in future research. Therefore, it is necessary to pay attention to the long-term dynamic information and symptom management needs of the parents of children with acute leukaemia. It is necessary to provide them with scientific information and build a need-based management system for the symptoms of acute leukaemia throughout the disease. Furthermore, It is necessary to provide relevant information and psychological support for the family members of children with acute leukaemia to meet their symptom management needs. It also promotes improving the quality of care for children and disease recovery.

1.2.2 The technology-based symptom management for parents of children with acute leukaemia

The development of information and communication technology (ICT) and the Internet has made it possible to provide convenient support for caregivers of children with cancer. The literature search results showed that related research included telemedicine and mobile health research. Among them, the intervention tools of telemedicine are video phones and online websites, and the intervention tools of mobile health are smartphone applications.

The video phone relies on the computer as the equipment. In the early stage, a dedicated person is required to install the computer and program. The caregivers, community nurses, and hospital medical staff must undergo pre-training. Since 2004, Bensink et al.[25] has carried out a series of caregiver support studies based on online video phones. They focused on caregivers of children with cancer who are receiving palliative care, caregivers of children with cancer who have been newly diagnosed, and caregivers of children with cancer who received the first intermittent family-centred care. Through remote information and psychological support, the cost of communication between caregivers and medical staff has been reduced. The convenience and efficiency of communication have been improved[26-27], and caregivers have promoted high-quality care for children during intermittent periods at home[28-29]. They have provided caregivers with psychological support. Wakefield et al[30-31] provided online video treatment for parents of children with cancer in three aspects: problem response, disease acceptance, and social interpersonal reconstruction, which effectively reduced the fear of disease recurrence and improved their psychological state.

The advantage of video-phone is that they can provide direct communication and emotional support. It is easier to implement and personalized, but medical staff must repeatedly answer the same questions from different caregivers. In this case, matching with standardized health education content can reduce medical staff's repeated health education work, such as online education websites[32], Apps' health education modules, and WeChat public platform[33-35]. With the continuous development of ICT, researchers have begun to pay attention to smartphone applications. The functions included information support, psychological support, appointments, and emergency calls. The health-related information can be directly stored in the application, reducing the number of medical staff consultation questions, and saving more medical resources[32-36]. Wang et al.[34] used smartphone applications and WeChat public account platforms to provide caregivers of children with home care, social support, knowledge education, and other services. The result significantly reduced the parents' anxiety and improved their children's social functions. The understanding of disease and care-related knowledge is improved, the need for knowledge is reduced, and the response to the entire intervention and the overall care satisfaction is exemplary.

Mehdizadeh et al.[37] developed a digital self-management system (CanSelfMan) to support children with acute lymphocytic leukaemia and their caregivers in Iran. The CanSelfMan includes five main modules (knowledge base, self-management tips, self-assessment report, ask a question, and reminders) that provide access to reliable information about acute lymphocytic leukaemia and the self-management skills required for side effects measurement and reporting. However, one limitation of this study was related to the content-based recommendation function, enabling the five main modules' functions not to have a great connection. Another limitation of this study was related to the readability of the knowledge base in the CanSelfMan. The knowledge base is text-only but still needs to be more vivid regarding parents' ability to understand cancer and symptom management information.

Some health application studies involve usability evaluation[25,31-32,37]. At the same time, the usability evaluation part of most studies included a small sample of non-experimental studies, for instance, trial feedback from target users, evaluation of medical staff, and inspection of technicians. The usability laboratory is currently one of the most critical places for usability testing. It is recommended that the carers, medical staff, and hospital stakeholders participate in the usability evaluation in conjunction with IT professionals and technical personnel. According to the ISO 9241 standard[20], the three usability indicators: "effectiveness, efficiency, and satisfaction," are followed by simple formative usability evaluations to

evaluate the user interface design wireframes to eliminate obvious usability problems; comprehensive formative usability evaluations to evaluate the true usability of functional modules; summarized usability evaluation to evaluate the time it takes for users to complete a specific task, the smoothness, and complexity of the input data. The usability evaluation results are summarized and fed back to the technical development team for tool modification and continuous optimization.

In conclusion, ICT-based symptom management support for parents is practical and convenient. However, few researchers applied the m-health application to satisfy the symptom management needs of children with acute leukaemia. No research focused on the health application of the symptom management needs of parents of children with acute leukaemia. No research applied the health application to improve the participation of parents of children with acute leukaemia in symptom management. No research constructed the symptom management smartphone application for parents of children with acute leukaemia. At the same time, usability evaluation of the symptom management smartphone application for parents of children with leukaemia needs to be checked.

This study relies on the prospect of the multi-disciplinary cross, targeting the "pain points" of symptom management in children with acute leukaemia and weak parent participation in symptom management. This study applied mobile health technology and constructed the symptom management module of the support system APP with a user-centred design for parents of children with acute leukaemia. This study would provide new ideas to children with acute leukaemia and their parents to participate in symptom management support.

1.3 Research content and roadmap

1.3.1 General research purpose

This research aims to develop the symptom management module in the support system APP for parents of children with acute leukaemia and evaluate the usability of the symptom management module.

1.3.2 Research questions

(1) What is the parents' symptom management needs of children with acute leukaemia?

(2) How to construct the image-text knowledge base of the symptom management module in the support system APP?

(3) How to develop the symptom management module in the support system APP?

(4) How to evaluate the usability of the symptom management module in the support system APP?

1.3.3 Research contents

The study was comprised of 4 parts：

Part1: The analysis of parents' symptom management needs for children with acute leukaemia

By the qualitative interview, six healthcare providers of the haematology-oncology department and 14 parents of children with acute leukaemia were interviewed, all from the Children's Hospital of Fudan University and the Children's Hospital of Suzhou University. This study also selected two WeChat groups of the haematology-oncology department of the Children's Hospital of Fudan University and the Children's Hospital of Suzhou University to collect and analyze the chat records of parents of children with acute leukaemia. The content analysis method was used to analyze the data of the interviews and the WeChat group chat records. Hence, the symptoms suitable for parents to manage, the symptom management needs of parents of children with acute leukaemia, and their needs for the symptom management module were deeply understood.

Part2: The construction of the image-text knowledge base

The clinical manuals, guidelines, scientific literature, and monographs on symptom management of children with acute leukaemia were searched. Combined with the preliminary analysis of symptom management needs in parents of children with acute leukaemia, the framework of the image-text knowledge base was constructed. Then the preliminary image-text knowledge base of the symptom management module was finished. Two researchers and two healthcare providers revised the preliminary image-text knowledge base. The researcher composed the final image-text knowledge base and reviewed it with two scientific researchers.

Part3: The development of the symptom management module in the support system APP

Based on the final image-text knowledge base and the analysis of the symptom management needs in parents of children with acute leukaemia, the brainstorming discussion with the multidisciplinary development team was organized to generate the function assumptions of

the symptom management module. The multidisciplinary development team included three researchers, two healthcare providers, and two software engineers. By the human-centred concept and the agile development method, the researcher developed the symptom management module with software engineers through five steps: requirement confirmation, interface design, function realization, testing, and disclosure.

Part4: The usability evaluation of the symptom management module in the support system APP

The formative usability evaluation was implemented during the development of the symptom management module. The formative usability evaluation aimed to find the problems with the module's interface, font, and functions. Then the summarized usability evaluation was implemented when the module was completed. Five researchers, four healthcare providers, and ten parents of children with acute leukaemia were invited to evaluate the usability problems of the symptom management module by typical task analysis, Post-Study System Usability Questionnaire (PSSUQ), and semi-structured interviews.

1.3.4 Roadmap

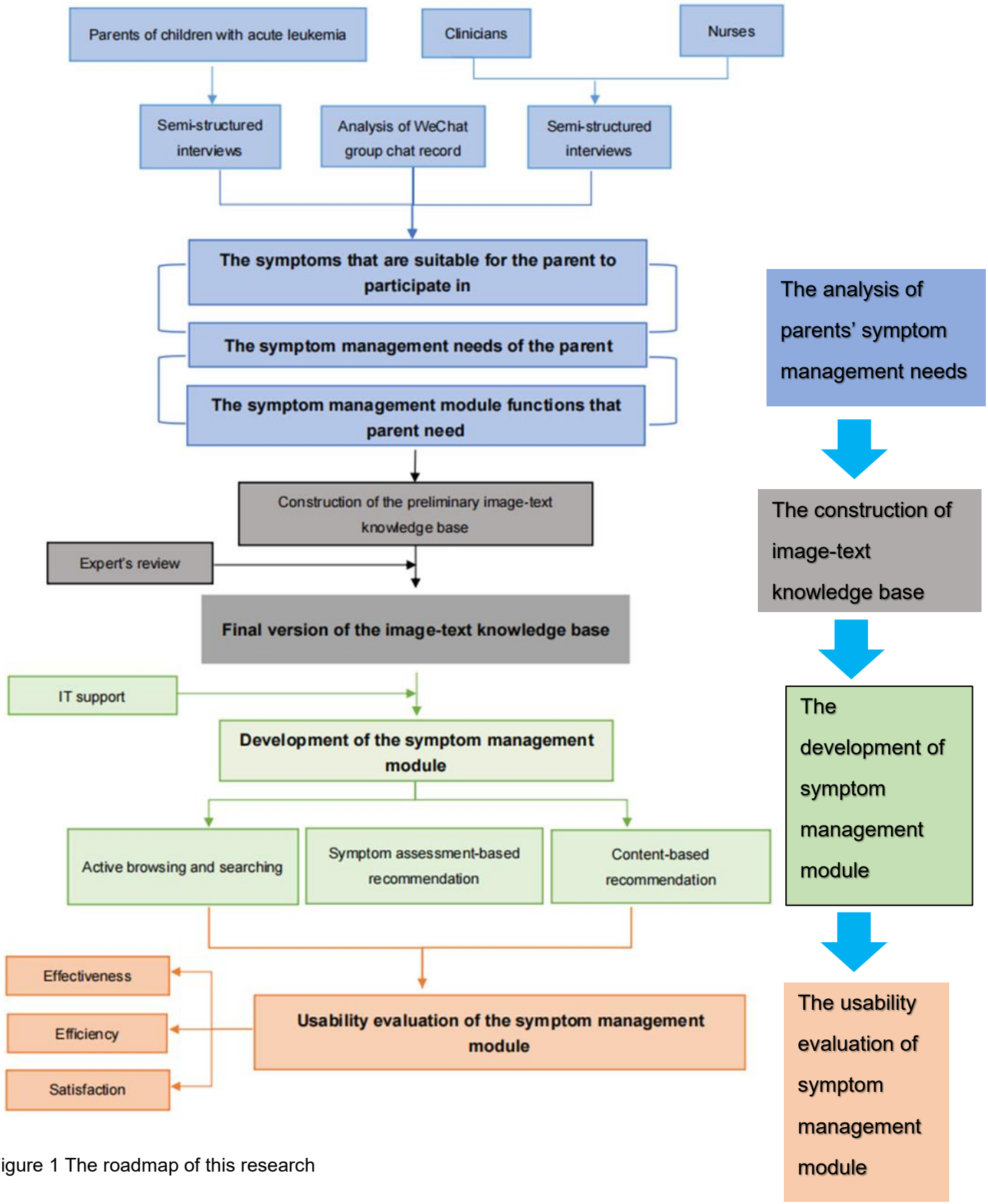

Figure 1 The roadmap of this research

2 The analysis of parents' symptom management needs for children with acute leukaemia

2.1 The Interview with the parents of children with acute leukaemia

2.1.1 Research purpose

To explore: 1) the symptoms that parents participated in or want to participate in; 2) parents' needs when they participate in symptom management for their children with acute leukaemia; 3) the functions that parents prefer to have in the symptom management module. Furthermore, the interview laid the foundation for developing the symptom management module to support the parent of children with acute leukaemia.

2.1.2 Participant

The researcher used the purposive sampling method to select the participants.

(1) Inclusion criteria for parents of children with acute leukaemia:

① The father or mother is mainly involved in the symptom management of the child with acute leukaemia.

② The child is diagnosed with leukaemia (ALL or AML), with no other severe or chronic diseases, aged <15 years.

③ The child is receiving treatment and has experienced symptoms caused by acute leukaemia or therapeutic schedule.

④ The parents are volunteers to participate in this study and are fluent in communication.

2.1.3 Research methods

The researcher followed the guidance of the qualitative research method and implemented the semi-structured interviews with the parents of children with acute leukaemia in the haematology-oncology department at the Children's Hospital of Fudan University and the Children's Hospital of Suzhou University. From September 2021 to December 2021, 14 parents of children with acute leukaemia were included in the one-on-one interviews.

(1) Interview outline

The researcher wrote the preliminary version of the interview outline and then sent it to the experts of the mentor group. Three experts revised it, and the final interview outline was decided. The final interview outline is shown as follows:

Interview outline for parents of children with acute leukaemia:

① What symptoms have you participated in or want to participate in?

② What were your symptom management needs when you participated in the care of children?

③ If there is a symptom management module in an APP, are there any functions you want?

(2) Data collection

"Before the interview, the researcher contacted the participants and briefly introduced the research purpose and methods. After receiving their consent, the researcher determined the interview date and place. The place was usually the department meeting room. The researcher interviewed according to the interview outline. If necessary, the researcher would adjust the outline and ask more questions related to their answers and meaningful to the result. Each one-on-one interview lasted for about 30 minutes, and the whole interview process was recorded with the participants' permission. The researcher observed the participants' facial expressions and body language and made interview notes carefully. The interview recording was transcribed into a written manuscript by the two people and sent to the participants. The participants read the written manuscript to make sure it was right. The researchers summarized the Information in the written manuscript and ensured that the data was saturated. "

(3) Data analysis

The researcher analyzed the interview data by the content analysis method[38]. NVivo qualitative data analysis software was used to collate and analyze the data. To ensure the accuracy of data analysis, the researcher used manual analysis to organize and analyze the data. The researcher set up the name and catalogue of the NVivo software research project. After each interview, the transcripts were imported into the software, and two researchers performed manual analysis.

2.1.4 Research results

(1) The characteristics of the 14 parents and children are shown in Table 1

Table 1 The characteristics of the parents and children (n=14)

No.	Parents					Children	
	Gender	Age	Education background	Average monthly earnings	Relationship with children	Age	Gender
P1	female	32	junior high school	2000-5000	mother	11	male
P2	female	26	junior college	2000-5000	mother	5	male
P3	female	31	senior high school	＞8000	mother	6	male
P4	female	46	bachelor	＞8000	mother	12	female
P5	female	42	junior college	5000-8000	mother	11	female
P6	female	31	bachelor	＞8000	mother	3	male
P7	male	25	junior high school	5000-8000	father	3	male
P8	female	38	bachelor	5000-8000	mother	7	male
P9	male	34	senior high school	2000-5000	father	8	female
P10	female	30	senior high school	2000-5000	mother	6	female
P11	female	27	associate bachelor	＞8000	mother	9	male
P12	female	37	junior high school	5000-8000	mother	12	female
P13	female	25	bachelor	5000-8000	mother	4	female

P14	female	35	senior high school	2000-5000	mother	10	female

(2) Interview results

1) Symptom list

①36 physiological symptoms:

Fatigue, sweating, fever, gingival abscess, perianal infection, urogenital infection, conjunctivitis, cough, pneumonia, nausea, vomiting, loss of appetite, constipation, diarrhoea, loss of weight, anaemia, headache, abdominal pain, bone and joint pain, other pains, dry mouth, lymphadenectasis, hepatosplenomegaly, skin eruption, pruritus, oral ulcer, skin ulcer, nosebleeds, bleeding spots in the skin, purpura, gums bleeding, taste changes, dizziness, lethargy, hair loss, sleep disorders.

②5 psychosocial symptoms:

Sadness, tension, anxiety, inattention, anger.

2) Symptom management needs

①Recognition of symptoms

Parents of children generally expressed a lack of early recognition of their children's symptoms. Their judgment based on common sense may cause delays in the condition of children. In the interview, five parents mentioned the need for guidance on symptom recognition.

P1: The child had a nosebleed at that time, but we did not pay much attention. We thought it might be accidentally knocked. After several days, we found that the nosebleed was constantly repeated and challenging to stop, so we came to the hospital for examination.

P2: After playing, my child complained of a stomachache, but I did not pay much attention. I think maybe he was kicked by other children while playing. He had a headache and a high fever; I thought he had flu.

P3: She (Child) said she was fatigued. She also did not want to go to the taekwondo class. I thought she was lazy without knowing what was wrong.

P7: At first, the child is a bit pale. Later the gum and the eyelid all turned pale. At the time, I realized that is something wrong.

P11: At that time, the child's vision decreased rapidly. I think it may be that the child reads too many books at night. After the hospital, the doctor told me that the tumour cells had affected the retinal nerve.

②Causes of symptoms and related knowledge

The parents' cognition of disease, treatment, and symptoms directly affects their attitude and practice of child care. Children's symptoms may not be alleviated in time based on incorrect knowledge or judgment.

P1: At first, I was not quite sure why the child had nosebleeds because I did not know about the disease, and I did not know why the child had uncontrollable nosebleeds.

P2: I do not know the reason why the child vomits. I would not have been so unprepared if I could have known some relevant knowledge and the reason in advance.

P4: When medicine has been stopped, (symptoms) is ok, but do not know it was caused by which drug, child applied both the cytarabine and the homoharringtonine.

P5: When secondary therapy ended, the platelet suddenly became very low, the skin appeared haemorrhaged, but I do not know the specific reason. I thought it might be related to the drug.

P6: My child had gingival bleeding at that time, but I did not quite understand the specific reason. I asked the doctor, and he said it was a side effect of chemotherapy, but he did not tell me which chemotherapy drugs caused it.

P7: The cognition of chemotherapy is a double-edged sword, killing bad cells and killing good cells. Some discomfort is normal. I think I do not need to deal with it.

P8: We are not clear if the more significant the response (fever) is, the treatment effect better?

P10: I usually check the instructions of drugs by myself, mainly to see the adverse reactions of drugs.

③Treatment and care of symptoms

Their parents need specific, personalized symptoms management guidance for children's chemotherapy symptoms.

P1: I did not know how to deal with my child's nosebleed. I asked him to look up at first, but later I realized it was wrong.

P2: I felt caught off guard. The child had a heavy vomit. I was very nervous, I did not know how to handle it, but I could only go to the doctor.

P3: Our child's grades were excellent. She held on until she finished the exam, and then we went to the hospital, so we did not deal with it initially.

P4: When the child gets cold, I only know I can rub him with my hands, especially the bottom of his feet.

P5: I took my child to the hospital as soon as he had a bleeding spot on his skin because I did not know how to deal with it, and I was afraid of making a mistake. At that time, the child received the platelet transfusion, and then he gradually recovered.

P6: I was mainly looking for a doctor because I did not understand it very well.

P7: I need to know how to release the child’s anxiety, especially in the bone marrow aspiration, my child is very nervous and anxious.

P9: We do not know children should have a what diet when nausea and vomiting, or when the platelet was low, they should eat what kind of food.

P12: The child has a destructive appetite, we cannot do anything about it, so we respect his opinion.

P13: Parents need to know how to deal with fever, diarrhoea, constipation, and stomatitis.

④Prevention of symptoms

Parents are in great need of relevant prevention and guidance knowledge. During chemotherapy, the adverse reactions of children are diverse, and the parents of children lack symptoms knowledge of predictive. Six parents mentioned the need for guidance on symptom prevention.

P1: If I had asked the doctor what we could and could not eat initially, the child might not have developed intestinal infections and pancreatitis.

P5: I do not think there is any way to change the situation because it was caused by chemotherapy drugs, which should be unavoidable. Hence, it just appeared and let the medical staff deal with it.

P6: I do not think I can do anything. I will just listen to the doctors and nurses.

P7: The hospital gave much guidance on (symptoms). The child entered PICU this time because of the nosebleed caused by thrombocytopenia. If I had heard Doc Zhou's lesson earlier (notes for bone marrow suppression period), we would not have entered ICU...

P8: It is best to know some possible adverse reactions and symptoms in advance. We can be prepared.

P14: The yellow portion (methotrexate) is the most prone to oral ulcer, which we do not understand at the beginning...

3) Module functions

①Search function

P1: If I had some questions about leukaemia or the symptom, I only searched for it in Baidu.

P3: I think the function of searching information is very significant.

P6: The healthcare providers are very busy daily; they do not have sufficient spare time to answer our questions. We need to find leukaemia knowledge by ourselves.

P12: I learn a lot from the other parents in the hospital, but I need a scientific way to learn more. The searching function is essential.

P14: It is best if this module has the function of searching.

②Recommendation function

P1:I hope the module can give me some simple knowledge, like image-text content. I do not need profound knowledge.

P2: If this module can give us some suggestion content, it is best.

P5: Sometimes, I do not know what I need to know, especially when the child just gets leukaemia, so I need a recommendation function.

P6:Too much text content is tedious. I wish it could have a function to give me some exciting multimedia content.

P8: I want to know the correlation between the different symptoms. Maybe a recommendation is a good choice.

P11:When my child gets the fever, I would like to do if other symptoms occur because of fever.

P13: It is best if this module has a function of recommendation.

③Symptom assessment and response function

P4: My child is always in a mindset of anger. I do not know why. I am afraid that anger may be a harmful factor for my child's body, so I need an assessment function.

P7: How to the degree of pain? I want to have an assessment function that can assess the pain degree.

P9: It is best if this module is intelligent, which means it has a response function.

P10: After chemotherapy, my children often said she was fatigued. I needed to know the degree of her fatigue.

2.2 WeChat group chat record analysis

2.2.1 Research purpose

To further explore parents' needs when they participate in symptom management for their children with acute leukaemia. Furthermore, the analysis laid the foundation for providing support for the parent of children with acute leukaemia.

2.2.2 Participants

(1) Inclusion criteria for the WeChat group chat record:

① Chat record of the parent of children with acute leukaemia in the WeChat group.

② The chat content about the symptom management sent by the parent of children with acute leukaemia.

2.2.3 Research methods

The researcher followed the content analysis method's guidance and selected the chat record of parents of children with acute leukaemia from the WeChat group in the haematology-oncology department at the Children's Hospital of Fudan University and the Children's Hospital of Suzhou University. Then the researcher analyzed the parents' WeChat group chat records. From September to December 2021, 137 requests for symptom management were collected from parents of children with acute leukaemia in the WeChat group.

(1) Data collection

This study selected the chat record of parents of children with acute leukaemia from the WeChat group in the haematology-oncology department of Children's Hospital of Fudan University and Children's Hospital of Soochow University. Two groups include 287 and 499 parents, respectively. The two group members mainly consist of parents of acute leukaemia children. Their group nicknames: 1) child's name; 2) parents(father/mother); 3) the ward; 4)the disease; 5)the stage of treatment. Therefore, the participants of this study were parents of children with acute leukaemia who could be identified according to their nicknames and asked questions in the WeChat groups. By WeChat group manager agreed, two researchers became the group of members. The group manager released an announcement to inform the group members of the identity of the researchers and the purpose of the research (through WeChat group chats, collecting parents' needs of symptoms management). After the group members' consent, from September to December 2021, The researchers recorded questions from parents of children with acute leukaemia daily. They did not send information in WeChat groups.

(2) Data analysis

The researcher sorted out the original data and established an Excel database, applying the content analysis method[38] to analyze the WeChat chat records. Two researchers coded the data, counted the symptom needs (frequency $\geqslant$2), separated them into different themes, and presented them in frequency.

2.2.4 Research results

(1) Types and proportions of the symptom management needs

One hundred thirty-seven requests for symptom management were collected from parents of children with acute leukaemia. The symptom management need types and proportions are shown in the table below.

Table 2 The symptom management need types and proportions

Need types	Proportion (%)
The care of symptoms	82(59.85%)
The cause of symptoms	29(21.17%)
The effect of symptoms on the course of treatment	13(9.49%)
The prevention of symptoms	8(5.84%)
The Identification and management of high-risk symptoms	5(3.65)

(2) Record analysis results

Through the analysis of WeChat chat records, it can be concluded that parents of children with acute leukaemia have guidance needs in each link of symptom management.

①The care of symptoms

Both the disease itself and the treatment of acute leukaemia may cause some symptoms. The results show that some parents have the care knowledge about diet. Symptom care was the category most asked by parents in symptom management (137 times) (82, 59.85%), indicating that parents generally require symptom nursing guidance.

②The cause of symptoms

Parents were concerned about the causes of symptoms (29, 21.17%), such as whether food or drugs caused the symptoms. ″Why does my child get pancreatitis? Does it because of diet?″

"Is it normal for children to have sore feet after injecting pegaspargase? " "After injecting pegaspargase, why does the children's pouch turn purple?" "Yesterday child used vindesine, and he feels fatigued this morning, is it normal?" Once it is known that similar conditions have occurred in other children, parents are somewhat reassured and focus on symptom care.

③The effect of symptoms on the course of treatment

The treatment cycle of acute leukaemia is long. Each course is gradually advanced, so parents are more concerned about whether the occurrence of symptoms will affect the treatment process of the children (13, 9.49%). Parents do not want the symptoms to lead to treatment interruption or changes, so providing psychological support and information about children's symptoms and treatment progress is essential.

④The prevention of symptoms

Symptom prevention (8, 5.84%) was rarely mentioned. Parents mainly asked about diet prevention and preventing infection-related symptoms, such as fever, oral ulcer, anal redness and swelling, and urinary tract infection.

⑤The identification and treatment of high-risk symptoms

Parents rarely mentioned identifying and treating high-risk symptoms (5, 3.65%). Among the high-risk symptoms, parents attach great importance to the bleeding symptoms of children. The low frequency of asking these kinds of questions reflects that parents have a better grasp of these contents, which may be related to the attention and education of health providers.

2.3 The Interview with the healthcare providers

2.3.1 Research purpose

To explore: 1) the symptoms that are suitable for the parents to participate in; 2) parents' symptom management needs under the perspective of the healthcare providers; 3) the functions that the healthcare provider thinks it is necessary for the symptom management module. Furthermore, the interview laid the foundation for developing the symptom management module to support the parent of children with acute leukaemia.

2.3.2 Participants

The researcher used the purposive sampling method to select the participants.

(1) Inclusion criteria for clinicians of the haematology-oncology department:

① Clinicians who have been treating children with acute leukaemia for more than five years.

② Clinicians who have a master's degree or above.

③ Clinicians are volunteered to participate in this study.

(2) Inclusion criteria for nurses of the haematology-oncology department:

① Nurses who have been caring for children with acute leukaemia for more than five years.

② Nurses who have a bachelor's degree or above.

③ Nurses are volunteered to participate in this study.

2.3.3 Research methods

The researcher followed the guidance of the qualitative research method and implemented the semi-structured interviews with healthcare providers of the haematology-oncology department from the Children's Hospital of Fudan University and the Children's Hospital of Suzhou University. From September 2021 to December 2021, 6 healthcare providers were included in the one-on-one interviews.

(1) Interview outline

The researcher wrote the preliminary version of the interview outline and then sent it to the experts of the mentor group. Three experts revised it, and the final interview outline was decided. The final interview outline is shown as follows:

Interview outline for healthcare providers of the haematology-oncology department:

① What symptoms do you think are suitable for parents to participate in?

② What symptom management knowledge do you think is necessary for parents to know?

③ If there is a symptom management module in an APP, are there any functions you think the APP should have?

(2) Data collection

"Before the interview, the researcher contacted the participants and briefly introduced the research purpose and methods. After receiving their content, the researcher determined the interview date and place. The place was usually the department meeting room. The researcher interviewed according to the interview outline. If necessary, the researcher would adjust the outline and ask more questions related to their answers and meaningful to the result. Each one-on-one interview lasted for about 30 minutes, and the whole interview process was recorded with the participants' permission. The researcher observed the participants' facial expressions and body language and made interview notes carefully. The interview recording was transcribed into a written manuscript by the two people and sent to the participants. The participants read the written manuscript to make sure it was right. The researchers summarized the Information in the written manuscript and ensured that the data was saturated. "

(3) Data analysis

The researcher analyzed the interview data by content analysis method[38]. NVivo qualitative data analysis software was used to collate and analyze the data. To ensure the accuracy of data analysis, the researcher used manual analysis to organize and analyze the data. The researcher set up the name and catalogue of the Nvivo software research project. After each interview, the transcripts were imported into the software, and two researchers performed manual analysis.

2.3.4 Research results

(1) The characteristics of the six healthcare providers are shown in Table 3

Table 3 The characteristics of the healthcare providers (n=6)

No.	Gender	Age	Education background	Professional title	Work experience
C1	female	37	master	head nurse	16 years

C2	female	36	bachelor	nurse-in-charge	16 years
C3	male	33	master	attending doctor	12 years
C4	female	47	bachelor	head nurse	27 years
C5	female	37	master	nurse-in-charge	17 years
C6	male	45	doctor	professor	25 years

(2) Interview results

1) Symptom list

①Physiological symptoms

C1: Children who experience fatigue are often shown to decrease physical activity.

C2: Tachypnea is also a common symptom among children with acute leukaemia, but we need to rule out the tachypnea caused by non-medical reasons, such as crying and playing.

C3: Some chemotherapy drugs can affect children's intestinal function, so abdominal bloating occurs. The child can increase in fart and belch because of the bloating.

C4: Some chemotherapy drugs can cause skin darkening, including cyclophosphamide, adriamycin, epirubicin, and fluorouracil.

C5：Not only does the child have nosebleeds, but other areas may also bleed. Some chemotherapy drugs can directly stimulate the bladder mucosa epithelium. Such as ifosfamide can cause hemorrhagic cystitis.

C6：Pneumonia is not a symptom; it is a diagnosis or disease. Urinary tract infection mainly manifests as urgent urination, frequent urination, and painful urination. Most platinum drugs have peripheral neurotoxicity, among which cisplatin and oxaliplatin are the most significant.

②Psychological symptoms

C2: Children suddenly out of their familiar environment and hospitalized, it is easy to have a lonely mind.

C3: Inattention is not a psychological symptom and can be caused by various causes.

C4: Children in the ward, surrounded by more children. Peer relationship is not a big problem because most hospitalization is not long-term but intermittent.

C5: After receiving chemotherapy, many children lose their hair and are afraid to meet people.

The research refined and formed the final version of the symptom management needs list according to the interview results of healthcare providers and parents of children with acute leukaemia.

①41 physical symptoms:

Fatigue, sweating, fever, gingival abscess, perianal infection, conjunctivitis, cough, polypnea, nausea and vomiting, loss of appetite, abdominal bloating, increase in fart, increase in hiccup, constipation, diarrhoea, loss of weight, anaemia, headache, abdominal pain, bone and joint pain, dry mouth, lymphadenectasis, hepatosplenomegaly, skin eruption, skin itching, dry skin, abnormal skin colour, oral ulcer, skin ulcer, nosebleeds, subcutaneous bleeding, pruritus, gums bleeding, abnormal urine colour, urinary irritation, taste changes, dizziness, lethargy, hair loss, sleep disorders, acro-anesthesia.

②6 Psychosocial symptoms:

Sadness, tension, anxiety, anger, self-image disorder, loneliness.

2) Symptom management knowledge

①Causes of symptom

C1: Many parents think the symptom was caused by one single factor; however, the drug, the emotion, and the environment all can influence the symptom.

C2: Diet is a significant factor for children with acute leukaemia. Children who accept pegaspargase should have a low-fat diet. They will get digestive symptoms otherwise.

C5: Some symptoms are not caused by leukaemia, but the parents do not know. We need to let them know that other factors, like pancreatitis, can cause many digestive symptoms.

②Care of symptom

C3: Many parents do not know much about drug therapy. We need to give them some care knowledge about medicine.

C4: Non-medicine care is critical, too, such as physical therapy, music therapy, etc. We need to give them a whole picture about care.

3) Symptom management module

①Recommendation function

C1: The symptom does not exist separately but shows a cluster trend.

C5: I think giving parents some recommendation knowledge is quite essential. Many symptoms can emerge at the same time. The parents need more guidance at that time.

②Symptom assessment and response function

C2: Some parents sometimes do not know how to assess symptoms; they do not know how to judge the severity of symptoms.

C3: The symptom management module needs to be wise, which means it can be a responder for parents and help them assess the symptom of the children.

C4: The symptom scale is a good way for parents to assess their children's condition. I think we can insert some scale in the module.

2.4 Conclusion

The summation of the analysis of parents' symptom management needs for children with acute leukaemia is shown in Table 4:

Table 4 The summation of parents' symptom management needs research

	Interview for parents	WeChat record analysis	Interview for healthcare providers	Summation
Symptom list	36+5	/	41+6	**41+6**
Symptom management needs	Recognition (Clinical feature of symptom)； Cause (Drug factor)； Care (Daily life care)； Prevention (Drug-use, symptom knowledge)	Cause (Dietary factor); Care (Diet care, method of symptom care); Prevention (Daily life, diet prevention)	Cause (Environment, emotional, other factors)； Care (Medication, mental, other care).	**Recognition** (Clinical feature of symptom)； **Cause** (Drug, environment, emotional, other factors)； **Care** (Daily life, medication, mental, other care, method of symptom care)； **Prevention** (Daily life, diet prevention, Drug-use, symptom knowledge).
Symptom management module functions	Search; Recommendation; Assessment and response.	/	Recommendation; Assessment and response.	**Search;** **Recommendation;** **Assessment and response.**

(1) Symptom suitable for parents to participate in

①41 physical symptoms:

Fatigue, sweating, fever, gingival abscess, perianal infection, conjunctivitis, cough, polypnea, nausea and vomiting, loss of appetite, abdominal bloating, increase in fart, increase in hiccup, constipation, diarrhoea, loss of weight, anaemia, headache, abdominal pain, bone and joint pain, dry mouth, lymphadenectasis, hepatosplenomegaly, skin eruption, skin itching, dry skin, abnormal skin colour, oral ulcer, skin ulcer, nosebleeds, subcutaneous bleeding, pruritus, gums bleeding, abnormal urine colour, urinary irritation, taste changes, dizziness, lethargy, hair loss, sleep disorders, acro-anesthesia.

②6 Psychosocial symptoms:

Sadness, tension, anxiety, anger, self-image disorder, loneliness.

(2) Symptom management needs

①Recognition of symptoms

②Causes of symptoms and related knowledge

③Treatment and care of symptoms

④Prevention of symptoms

(3) Functions of symptom management module

①Search function

②Recommendation function

③Symptom assessment and response function

2.5 Discussion

(1) The results show that the symptom needs of parents of children with acute leukaemia are diverse and detailed. Some of these needs are the contents of health education that hospitals routinely carry out. At the same time, some are not covered by health education. Moreover, it is difficult for medical staff to provide timely and personalized guidance to parents of children with acute leukaemia in out-of-hospital periods. Parents often cannot fully grasp the guidance of medical staff in a short period. Many symptoms needs of parents are too detailed for the healthcare provider. Therefore, carefully collecting parents' needs is the key to making health

education as comprehensive as possible to provide practical support for parents. Parents cannot master symptom management knowledge at one time. It is necessary to provide multiple forms of materials to meet their needs, such as e-resources.

(2) Effective symptom management is significant for reducing parents' physical and mental pressure and improving symptom control effect and related physical functions of children. The incidence of acute leukaemia-related symptoms is related to the time of diagnosis, the severity of the disease, and the symptom measurement method. Failure to communicate with professionals may also affect symptom management effect. Parents of ALL children also expressed that their needs for long-term symptom management have not been well met. An effective symptom management system is urgently needed to assist the symptom management of ALL children. Therefore, predictive prevention, early recognition, and timely treatment of complex symptoms in children with ALL are the keys to symptom management.

(3) This study collected parents' symptom needs through qualitative interviews and spontaneously analyzed the WeChat group chat records. The WeChat group chat analysis provided multiple angles for the study to collect the needs of parents for ALL children. However, it is worth pointing out that the in-group parents rarely updated the treatment course information in time, which made the researcher unable to rank the collected needs according to the treatment course. It is one of the limitations of this study. In addition, this study mainly adopts manually collecting information in the WeChat group. In the future, we can also consider adding AI intelligent information collection robots in the group to collect and classify group chat information.

3 The construction of the image-text knowledge base

3.1 The literature study of the image-text knowledge base

3.1.1 Research purpose

To construct the framework of the image-text knowledge base of the symptom management module of the support system APP.

3.1.2 Research methods

The researcher collected the clinical manuals and guidelines of the haematology-oncology department of the Children's Hospital of Fudan University and the Children's Hospital of Soochow University. The researcher also searched the scientific literature, official textbook, and monographs on symptom management of children with acute leukaemia.

3.1.3 Research results

Based on the clinical manuals, guidelines, scientific literature, and monographs on symptom management of children with acute leukaemia. Combined with the analysis of symptom management needs, the researcher built the framework of the image-text knowledge base, including four second-level and 17 contents. The framework of the image-text knowledge base is shown in Table 5 as below:

Table 5 The framework of the image-text knowledge base

First Level	Second Level	Content
Specific symptoms	Identification of symptom	①The introduction of symptom
		②The clinical feature of symptom
	Cause of symptom	①Drug factors
		②Environmental factor
		③Dietary factor
		④Emotional factor
		⑤Other factors
	Care of symptom	①Daily life care
		②Diet care
		③Symptom management
		④Medication care
		⑤Mental health care
		⑥Other care
	Prevention of symptom	①Daily life prevention
		②Diet prevention
		③Drug-use knowledge
		④Symptom knowledge

3.2 The preliminary construction of the image-text knowledge base

3.2.1 Research purpose

This part of the study was implemented to design the preliminary image-text knowledge base construction of the symptom management module.

3.2.2 Participants

Following voluntariness and informed consent principles, the researcher included two experts in acute childhood leukaemia research and two experts in acute childhood leukaemia clinical practice.

Experts need to meet one of the following requirements:

①The researcher who has rich experience in acute childhood leukaemia research.

②The healthcare provider who has rich experience in acute childhood leukaemia clinical practice.

3.2.3 Research methods

The researcher constructed the preliminary image-text knowledge base based on the image-text knowledge base, including 41 physiological symptoms and six psychological symptoms. Two senior researchers and two healthcare providers were included to revise the preliminary image-text knowledge base.

3.2.4 Research results

(1) The characteristics of experts

Four experts were participating in the review, including two senior researchers and two healthcare providers. The details of the experts are shown in Table 6:

Table 6 The characteristics of experts (n=4)

No.	Gender	Age	Education background	Research field	Technical Title	Work experience
1	female	51	doctor	nursing research	professor	26 years
2	female	32	doctor	nursing research	associate professor	7 years
3	female	36	master	clinical practice	head nurse	16 years
4	female	33	bachelor	clinical practice	nurse-in-charge	12 years

(2) The preliminary image-text knowledge base

The preliminary image-text knowledge base was viewed by experts and shown in Figures 2 and 3 (take “headache” as an example). It includes 41 physiological symptoms and 6 psychosocial symptoms.

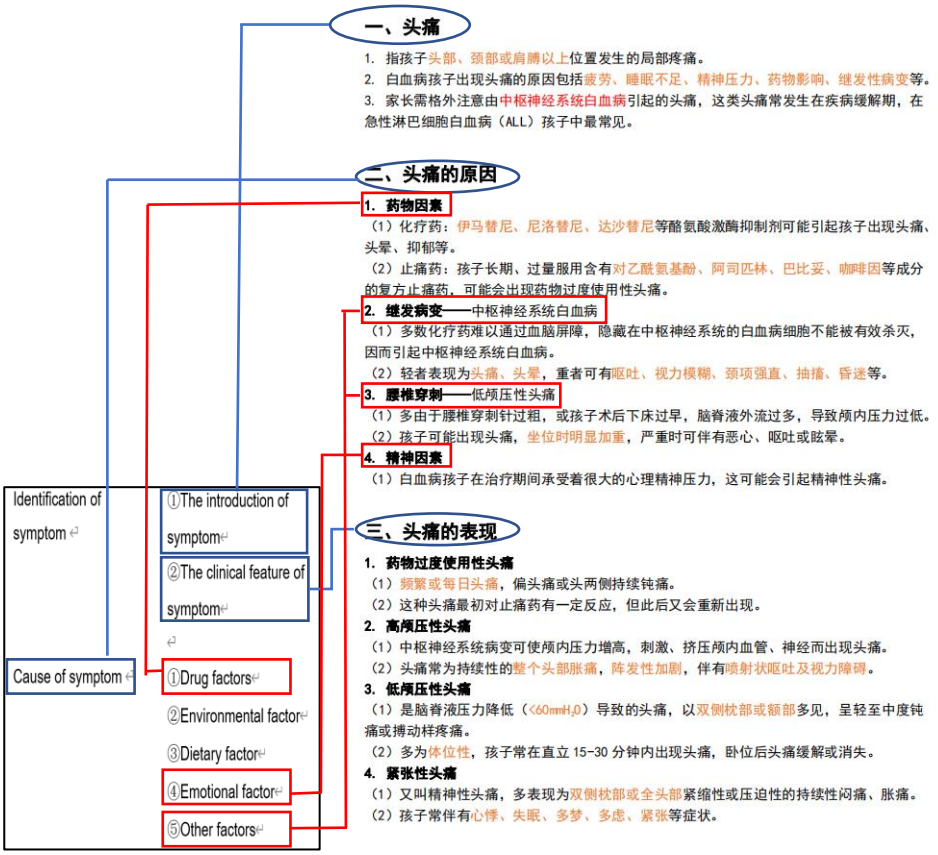

Figure 2 The preliminary image-text knowledge base (headache)

Figure 3 The preliminary image-text knowledge base (headache)

3.3 The final construction of the image-text knowledge base

3.3.1 Research purpose

This part of the study was implemented to design the symptom management module's final image-text knowledge base construction.

3.3.2 Participants

Following the principles of voluntariness and informed consent, the researcher included two experts in the fields of acute childhood leukaemia.

Experts need to meet the following requirements:

①Expert who has rich experience in acute childhood leukaemia.

②Expert who has engaged in any layout design program and has rich experience in this field.

3.3.3 Research methods

(1) Preliminary Image-text knowledge base to final Image-text knowledge base

According to the preliminary image-text knowledge base, the researcher applied the XIUMI platform to compose the preliminary image-text knowledge base into the final knowledge base, including 41 physiological symptoms and 6 psychological symptoms.

(2) Expert review

The researcher invited two senior researchers to review and proofread the final knowledge base, including 41 physiological and 6 psychological symptoms.

3.3.4 Research results

(1) The characteristics of experts

Two experts were participating in the review. The details of the experts are shown in Table 7:

Table 7 The characteristics of experts (n=2)

No.	Gender	Age	Education background	Research field	Technical Title	Work experience
1	female	51	doctor	nursing research	professor	25 years
2	female	32	doctor	nursing research	associate professor	7 years

(2) The final image-text knowledge base

The final image-text knowledge base was viewed by experts and shown in Figure 4 to 8 (take “headache” as an example). It consists of 1) description of headache; 2) clinical manifestation of headache; 3) causes of headache; 4) care of headache; 5) prevention of headache.

Figure 4 The final image-text knowledge base (introduction of headache)

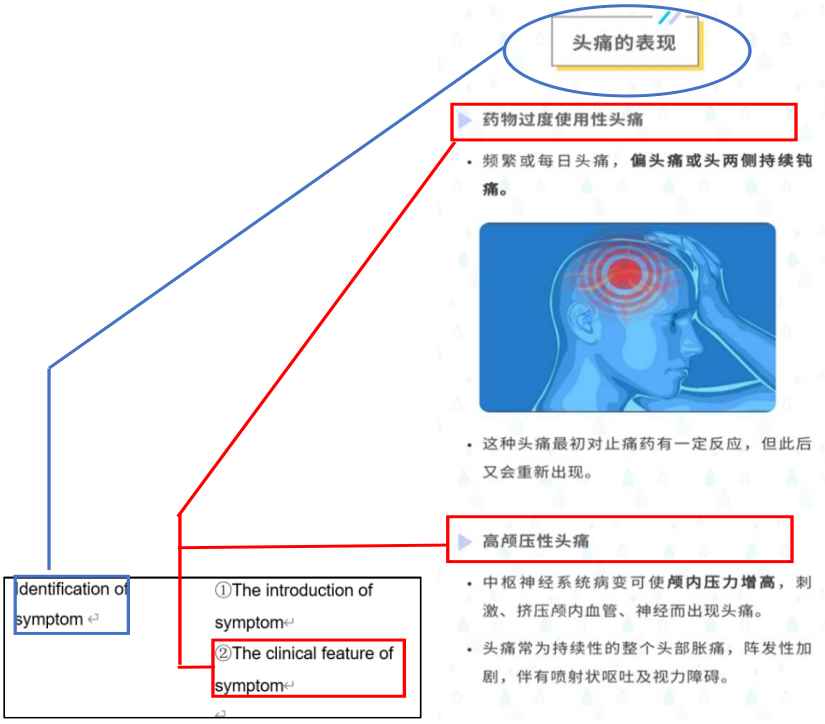

Figure 5 The final image-text knowledge base (clinical feature of headache)

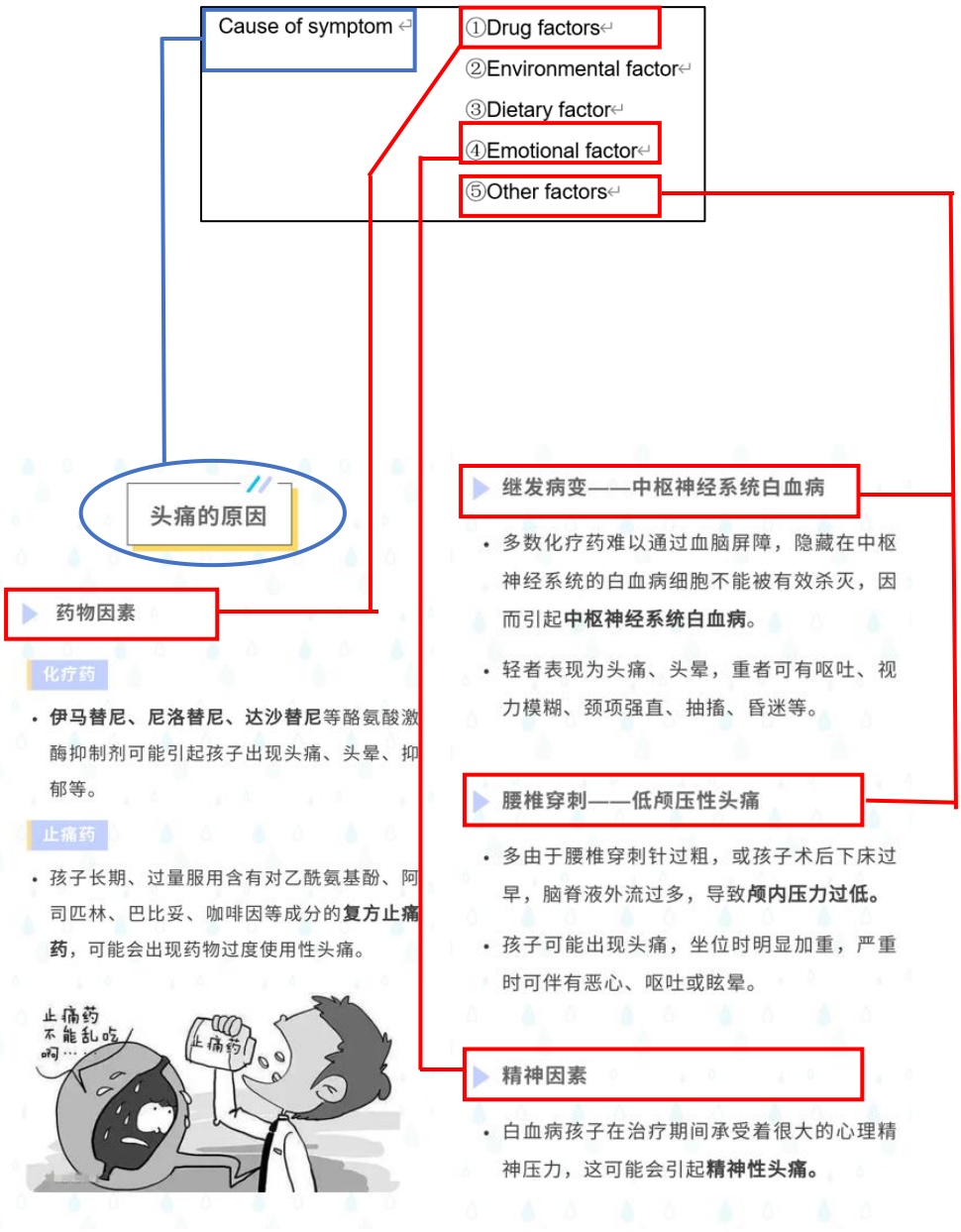

Figure 6 The final image-text knowledge base (cause of headache)

Figure 7 The final image-text knowledge base (care of headache)

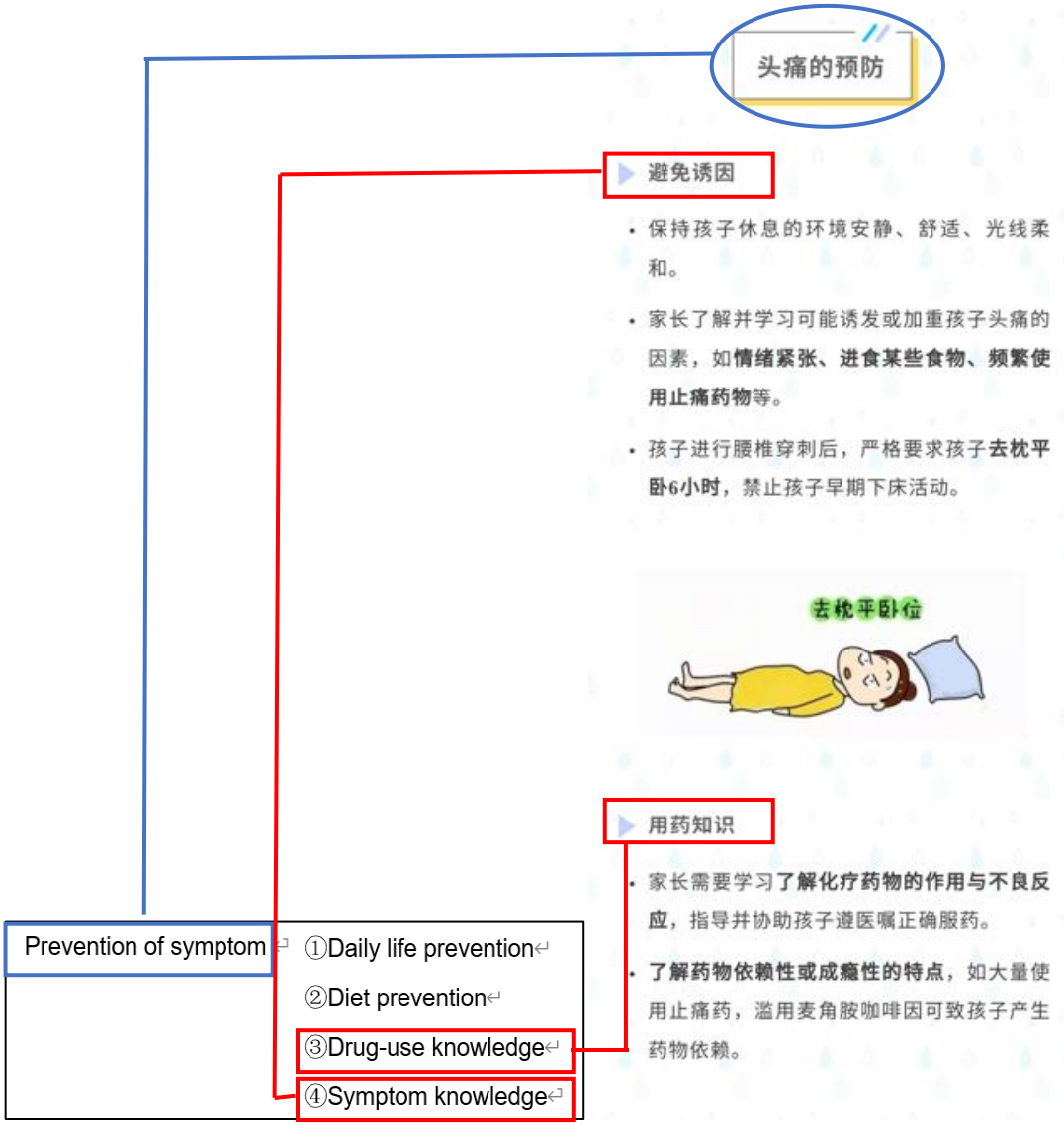

Figure 8 The final image-text knowledge base (prevention of headache)

3.4 Discussion

(1) This part of the study is based on the clinical manuals, guidelines, scientific literature, and monographs on symptom management of children with acute leukaemia. Combined with the symptom management needs analysis research in the early stage. It is clear what kind of image-text knowledge base needs to be constructed for parents of children with acute leukaemia. The framework of the image-text knowledge base was mined through literature research, and the initial symptom needs analysis. The researcher constructed the preliminary image-text knowledge base and invited stakeholders such as researchers and healthcare providers were included to review it. These ensure the scientific nature of the knowledge base in the design stage.

(2) The experts from the research institute and clinical setting offered a lot of constructive suggestions about the preliminary image-text knowledge base constructed by the researcher. The researcher decided on the final image-text knowledge base by following the recommendation of experts. Based on the network graphic resources and the suggestions of stakeholders, the researcher applied the XIUMI platform to construct the final image-text symptom management knowledge base. The final image-text symptom knowledge base is illustrated, easy to use, and highly acceptable. It is more affluent in content and more suitable to the need of the parents. In addition, the information of symptom management knowledge base should be authentic and readable. It involves symptom introduction, clinical symptom feature, symptom cause, symptom care, and symptom prevention.

4 The development of the symptom management module in the support system APP

4.1 The function assumptions of the symptom management module

4.1.1 Research purpose

This part of the study aims to put forward the function assumptions of the symptom management module in the support system APP.

4.1.2 Participants

The researcher used the purposive sampling method to select the participants.

(1) Inclusion criteria:

Participants need to meet one of the following requirements:

① Healthcare provider who has rich experience in symptom management of acute childhood leukaemia;

② Researcher who understands the module functions development methodologies;

③ Engineer who has rich experience in health management APP development.

4.1.3 Research methods

Based on the final image-text knowledge base and the analysis results of the symptom management needs. The multidisciplinary development team includes three researchers, two healthcare providers, and two software engineers. The researcher organized the brainstorming[39] discussion among experts to form the primary module functions. People who participated in the group discussion could ask questions and develop some ideas in a free and open atmosphere, stimulating creativity and bringing more constructive inspirations to module functions. Furthermore, the function assumptions can be the basis for developing the symptom management module.

(1) Brainstorming outline

① Combined with the primary symptom management module function needs analysis, what functions do you think need to be developed to meet the needs?

②What other functions do you think are necessary for the symptom management module?

③Given the correlation between the symptoms of children with acute leukaemia, how to implement the content-based recommendation function of the symptom management module?

(2) Data collection

"The brainstorming was held in the meeting room to ensure the discussion took place in a quiet environment with no distractions. Everyone had pens, paper, or a computer to write down whatever came to mind. Before the discussion, the researcher introduced the theme of discussion and the primary analysis results of the symptom management module function. The brainstorming lasted for about 90 minutes. During the meeting, the researcher presented the brainstorming outline, recorded the discussion with the participants' permission, and made the discussion notes. The recording of brainstorming was transcribed into a written manuscript. "

(3) Data analysis

The researcher analyzed the manuscript and summarized the creative, practical, and beneficial ideas. Then the researcher combined the ideas and drew the results.

4.1.4 Research results

(1) The characteristics of the participants are shown in Table 8

Table 8 The characteristics of the brainstorming participants (n=7)

No.	Gender	Age	Education background	Professional title	Work experience
B1	female	25	master	/	2 years
B2	female	32	doctor	associate professor	7 years
B3	female	51	doctor	professor	26 years
B4	female	37	master	head nurse	17 years
B5	female	36	bachelor	nurse in charge	16 years
B6	male	32	bachelor	/	10 years

B7	male	29	bachelor	/	8 years

(2) The function assumptions of the symptom management module in the support system APP

1) Active browsing and searching functions

①Parents can directly browse the related symptom management knowledge in the symptom management module.

②Parents can search in the "Search" column, and the corresponding image-text symptom management knowledge will emerge.

2) Symptom assessment-based recommendation function

After filling in the PROMIS[40] (Patient-reported Outcomes Measurement Information System) pediatric self-reported / parent proxy-reported scale in the APP, The related symptom management knowledge will be recommended according to the score of the PROMIS scale.

3) Content-based recommendation function

①Parents search for symptom-related information. The relevant image-text symptom management information will scroll in the "Recommended Articles" module of the APP home page.

②When parents search for information about a chemotherapy drug, this drug's side effects related-symptoms will emerge in the search results.

③There are physiological symptoms and psychological symptoms in the module. When parents read the specific image-text symptom knowledge, clickable related-symptom links (based on the symptom recommendation rule) are at the bottom of the image-text knowledge. It can automatically link to the other related symptom by clicking. The symptom recommendation rule (take “Gastrointestinal symptom” as an example, The full version is in the APPENDIX) is reviewed by two healthcare providers and shown in Table 9:

Table 9 The symptom recommendation rule (Gastrointestinal symptom)

Symptom types	**Specific symptom**	**Related symptoms**
Gastrointestinal symptom	Nausea and vomiting	①Fatigue
		②Loss of weight
		③Taste changes
		④Dizziness
	Loss of appetite	①Loss of weight
		②Fever
		③Fatigue
		④Nausea and vomiting
		⑤Abdominal bloating
		⑥Gingival abscess
		⑦Oral ulcer
	Constipation	①Increase in fart
		②Abdominal bloating
	Diarrhoea	①Fatigue
		②Loss of weight
		③Perianal infection
	Abdominal bloating	①Constipation
		②Taste changes
	Increase in hiccup	①Constipation
		②Increase in fart
		③Abdominal bloating

Increase in fart	①Constipation ②Increase in hiccup ③Abdominal bloating

4.2 The function realization of the symptom management module

4.2.1 Research purpose

To develop the symptom management module based on the human-centred concept and agile development method.

4.2.2 Research methods

(1) Requirement clarification: The researcher communicated with software engineers over the support system APP framework and ensured that the engineers understood the requirement.

(2) Design: The interface designer designed the symptom management module's human-computer interaction, operation logic, and interface aesthetics.

(3) Development: According to the design for the symptom management module, the software engineers wrote and modified the module's front-end and back-end codes.

(4) Testing: After developing the symptom management module, the engineer submitted the source code. Then, the researcher tested it repeatedly and feedbacked the deficiencies. The engineer amended it depending on feedback.

(5) Release: With engineers' assistance, the symptom management module will be accessible to the public.

4.2.3 Research results

(1) Technological points of development

Table 10 Technological points of development (Android)

	front-end	back-end
development language	React-Naive, java	PHP
development environment	Android8+	Linux
development tools	VScode, Android Studio	PHPStorm
coding mode	Utf-8	Utf-8

Table 11 Technological points of development (iOS)

	front-end	back-end
development language	React-Naive, object-c	PHP
development environment	iOS9+	Linux
development tools	VScode, XCode	PHPStorm
coding mode	Utf-8	Utf-8

(2) The user interface and functions

1) Active browsing and searching functions

①Active browsing: Parents can directly browse the related information in the symptom management module.

Figure 9

②Active searching

Parents can search in the "Search" column, and the related image-text symptom management knowledge will emerge.

Figure 10

(2) Symptom assessment-based recommendation function

After filling in the PROMIS (Patient-reported Outcomes Measurement Information System) pediatric self-reported / parent proxy-reported questionnaire in the APP, parents/children will be recommended the corresponding symptom management knowledge according to the score of the PROMIS questionnaire.

The questionnaire is a five-point Likert scale in which scale 1 indicates “totally disagree”, and scale 5 indicates “totally agree”. No knowledge will be recommended if all answers are “totally disagree”; otherwise, the corresponding symptom management knowledge will be recommended.

Figure 11

(3) Content-based recommendation function

1) Parents search for symptom-related information. The relevant image-text symptom management information will scroll in the "Recommended Articles" module of the APP home page.

Figure 12

2) When parents search for information about chemotherapy drugs, side effects related to symptoms of this drug will emerge in the search results.

Figure 13

3) There are physiological symptoms and psychological symptoms in the module. There are clickable related-symptom links at the bottom of the image-text knowledge for a specific image-text symptom knowledge. It can automatically link to the other related symptom by clicking (Based on the symptom recommendation rule).

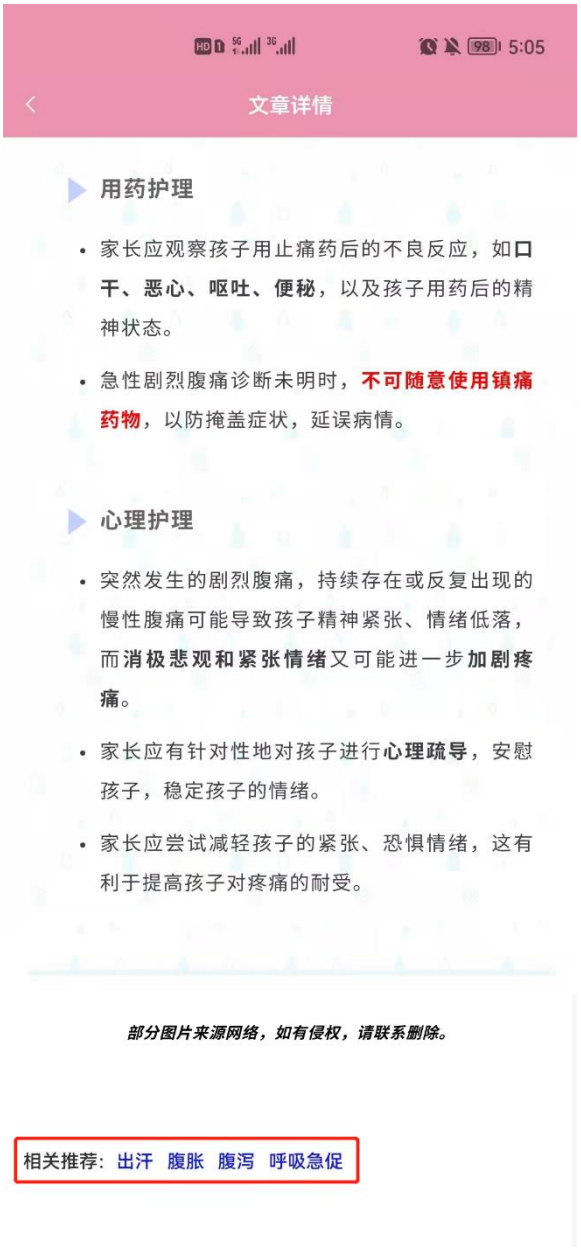

Figure 14

(4) Back-end

1) User Management: The page is used to manage the basic information of all participants, including parents' information, children's information, and information management.

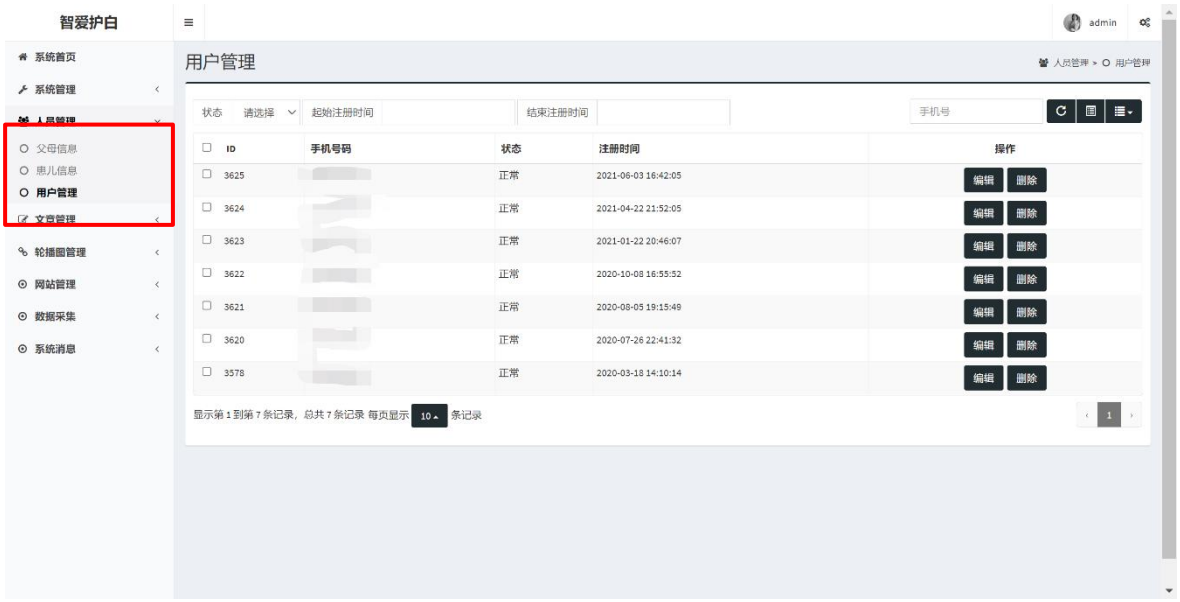

Figure 15

2) Knowledge base management: The page manages the knowledge base information. The manager can delete, modify, and adjust the knowledge base's information.

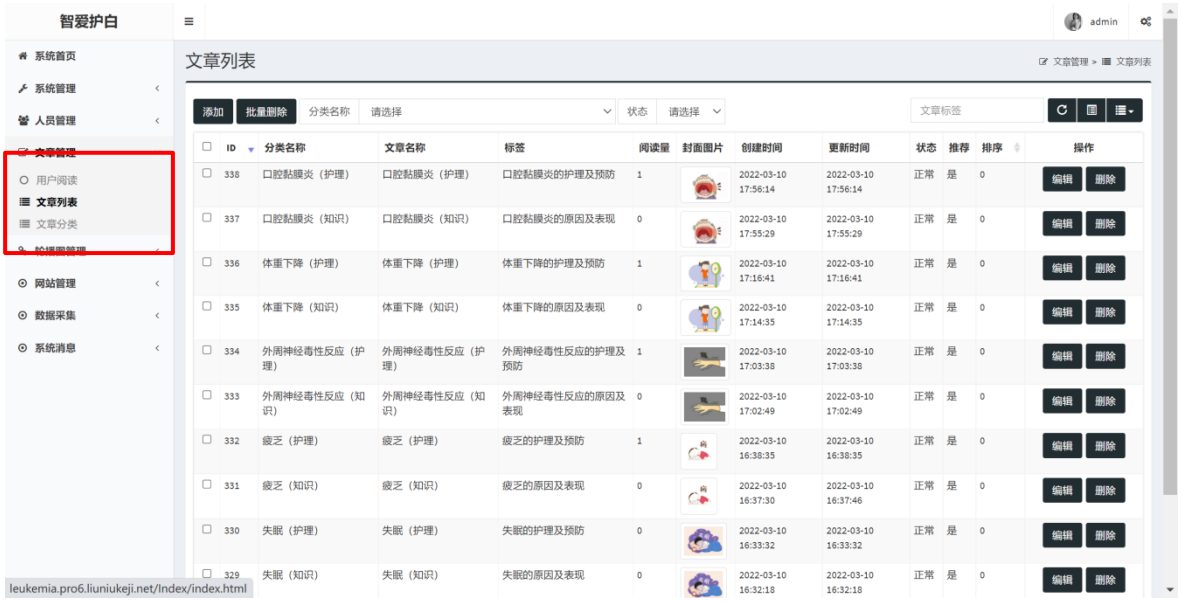

Figure 16

3) Data Collection: The manager can view and export the specific content filled in by the user, and search for parents' mobile phone numbers or the number of times they have filled in the questionnaire. The page displays the results of the questionnaire in detail.

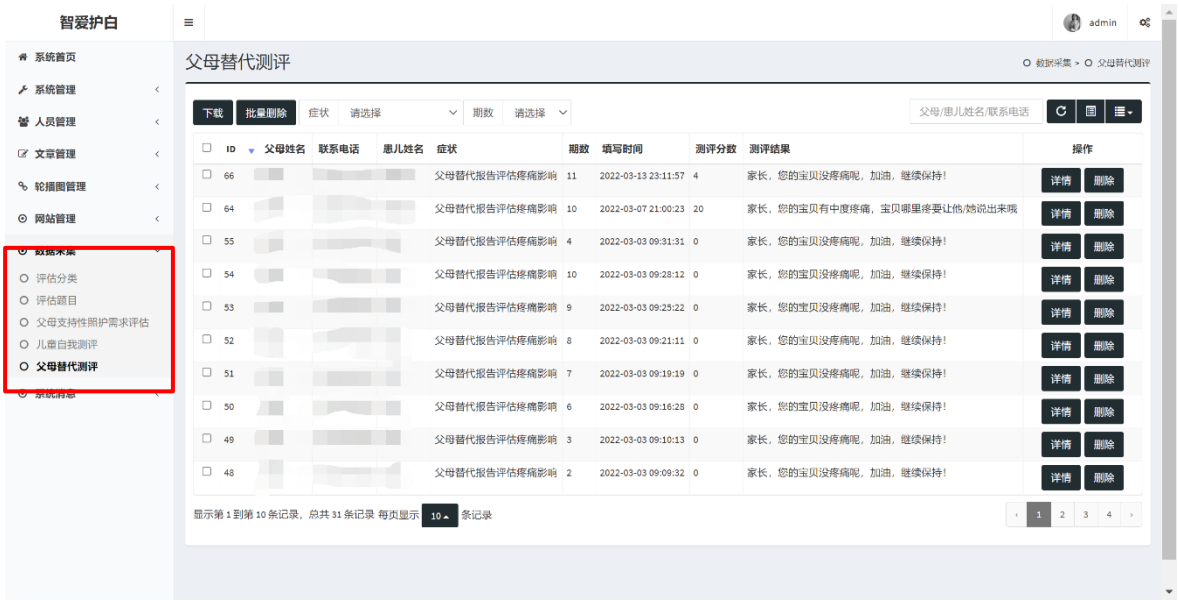

Figure 17

5 The usability evaluation of the symptom management module in the support system APP

5.1 The formative usability evaluation of the symptom management module

5.1.1 Research purpose

Implement the formative usability evaluation to evaluate the user interface, module functions, and module designs during development.

5.1.2 Research methods

The researchers conducted functional tests on the accomplished module and recorded the testing process of the symptom management module entirely. The researcher wrote down the shortcomings and problems and feedbacked them to the software engineers. This process was repeated until all the problems were fully solved.

5.1.3 Research results

Take the results of formative usability on January 12th,2022, for example.

Table 12 the results of formative usability on January 12th, 2022

The usability problem	Results
1) Too much spacing at the top of the title of the symptom management module.	solved
2) The function is not implemented: After parents fill in the PROMIS scale, the module will recommend related symptoms management knowledge according to the scale score.	solved
3) The function is not implemented: The module will scroll "related tweets of symptom management when parents search-relevant symptoms information."	solved
4) Add the function of adjusting the sequence of the symptom items for the back-end.	solved
5) When parents search for information about chemotherapy drugs, there are no side effects related to the drug in the search results.	solved
6) Garbled characters appear in the module.	solved

5.2 The summarized usability evaluation of the symptom management module

5.2.1 Research purpose

Implement the summarized usability evaluation to evaluate the usability problems and the suggestions when the user is using the module.

5.2.2 Participants

The participants were included by purposive sampling method：

①The researchers (management staff) of the symptom management support system were selected. In February 2022, 5 researchers (management staff) were included.

②The healthcare providers of the haematology-oncology department of the Children's Hospital of Fudan University were selected as the participants. In February 2022, a total of 4 healthcare providers were included.

③The parents of children with acute leukaemia in the Children's Hospital of Fudan University were selected as the participants. In February 2022, a total of 10 participants were included.

5.2.3 Research methods

"The usability testing and semi-structured interview are implemented to understand the usability problems. The usability testing is reported with the time duration of the task completion, the task's completion rate, and the score of the PSSUQ. The user interview is conducted to let users report their experiences and give their opinions to guide the symptom management module's optimization. "

(1) Evaluation Criteria：

To examine the quality of the users' task completion, the researcher adopted the ISO 9241-11 framework[20]. There are three components in the framework:

① "Effectiveness: examine the users' ability to complete the given tasks. Participants are asked to complete six tasks. Completing each task's success or failure rate is measured to

evaluate the symptom management module's effectiveness. Task completion is considered successful when the user completes the task without error or asking for assistance. "

② "Efficiency: examine the required user resources to complete the tasks. To evaluate the efficiency of the symptom management module, the researcher records the time (in seconds) that participants took to complete each task. Each task is initiated by expressing the word "start" and finished when the user mentions the end. "

③"Satisfaction: record the users' opinions and feedback. It is used to evaluate the system's overall usability through the Chinese version Post-study system usability questionnaire (PSSUQ)[41], a usability assessment questionnaire which has been used in many Chinese studies[42-44] and with high reliability[44] and validity[45]. The questionnaire is a seven-point Likert scale in which scale 1 indicates "totally disagree," and scale 7 indicates "totally agree." PSSUQ contains three evaluation dimensions: system usefulness, information quality, and interface quality. "

(2) Process of implementation：

① "Tasks construction: based on the symptom management module's core functions and the typical and necessary operations of management staff, the researcher designed the core evaluation tasks. The tasks were viewed by experts and shown in Table 13 (back-end testing for management staff) and Table 14 (front-end testing for healthcare providers and parents of children with acute leukaemia). "

Table 13 tasks for usability testing from the back-end

Task	Name
1	Open the back-end of the symptom management module
2	Add a physical symptom label
3	Delete a psychological symptom label
4	Release a physical symptom image-text knowledge base
5	Upload a physical symptom image-text knowledge base
6	Check the reading user ratio

Table 14 tasks for usability testing from the front-end

Task	Name
1	Open the symptom management module
2	Register an account
3	Find and read the content of the symptom management module
4	Search the symptom in the search column
5	Find the related information recommendation at the bottom of the graphic symptom management information
6	Fill in the PROMIS scale, and get the recommended symptom management knowledge.

② "Equipment and environment preparation: For the convenience of testing, the testing room was the current office room of the children's hospital of Fudan University. The videotape recorder and the computer were set in advance. Besides, testing in this room could provide the staff with the feeling of working in a natural scene. "

③ "Preparation of researcher, recorder, and participants: The researcher informed the participants about the aim of the testing and its process. The researcher practised saying instructions several times. The recorder recorded the participants' facial expressions, words, and gestures. "

④ "Start the testing: The researcher read the task instructions for the participants. After the participants began the operation, the recorder recorded each task's time duration, the participants' mistakes, and participants' expressions or actions. The researcher was silent and was not allowed to send participants any signals about the mistakes. If the participants cannot complete the task, it is suitable to skip to the next task. "

⑤ "After the testing: Participants finished the PSSUQ. Then, the researcher conducted an interview. The Interview outline: How do you feel about using the symptom management module? How does this symptom management module help you understand symptom management knowledge? Do you gain any good experience from the symptom management module? Does this symptom management module have any shortcomings or drawbacks? How to improve it? Do you have any other feedback? "

(3) Data collection

① "Observation: pay close attention to the participant's action but not interfere with the operation and record the usability problems. "

② "Audio and video recording: record the screen operation and words said by participants. "

⑤ "Time record: the whole process will be recorded manually. "

(4) Data analysis

Analyzed the interview data by the Colaizzi method[46] with two different researchers. By descriptive statistics, the researchers analyzed user action indicators. By mean, count and percentage, the categorical data and the continuous data were presented.

5.2.4 Research results

(1) results from the researchers (back-end)

Table 15 The characteristics of the participants (n=5)

No.	Gender	Age	Education background	Professional title	Management experience
P1	female	29	master	research assistant	6 months
P2	female	32	doctor	post-doctoral	2 years
P3	female	51	doctor	professor	2 years
P4	female	27	master	research assistant	10 months
P5	male	25	master	research assistant	20 months

① Effectiveness

Table 16 Effectiveness from researchers data

	Task1	Task2	Task3	Task4	Task5	Task6
Complete number	5	5	5	5	5	4

Complete rate	100%	100%	100%	100%	100%	80%

② Efficiency

Table 17 Efficiency from researchers data

	Task1	Task2	Task3	Task4	Task5	Task6
Mean Time	3.12	31.90	24.16	36.95	29.80	13.15
Maximum Duration	3.70	40.90	22.30	40.34	35.54	15.80
Minimum Duration	2.71	21.70	18.20	30.53	23.54	10.23

③ Satisfaction

PSSUQ results show: System usefulness is 5.2, Information Quality

is 6.0, Interface Quality is 5.4, Overall Evaluation is 6.0.

(2) Results from the healthcare providers (front-end)

Table 18 The characteristics of the healthcare providers (n=4)

No.	Gender	Age	Work duration
M1	female	37	16 years
M2	female	36	16 years
M3	female	33	12 year
M4	female	37	17 year

① Effectiveness

Table 19 Effectiveness from the healthcare providers

	Task1	Task2	Task3	Task4	Task5	Task6
Complete number	10	10	10	10	10	10

Complete rate	100%	100%	100%	100%	100%	100%

② Efficiency

Table 20 Efficiency from the healthcare providers

	Task1	Task2	Task3	Task4	Task5	Task6
MT	3.01	33.41	13.25	11.74	13.33	63.37
Max D	3.50	40.45	23.35	15.21	20.32	89.32
Min D	2.43	30.45	7.53	8.98	9.73	47.73

③ Satisfaction

PSSUQ results show: Module usefulness is 5.8, Information Quality

is 6.0, Interface Quality is 5.9, Overall Evaluation is 6.2.

(3) Results from the parents of children with acute leukaemia (front-end)

Table 21 The characteristics of the parents (n=10)

No.	Gender	Age	The age of children
N1	female	32	11
N2	female	26	5
N3	female	31	6
N4	female	42	11
N5	male	35	7
N6	male	28	6
N7	female	34	13
N8	female	30	6
N9	female	25	4
N10	female	25	4

① Effectiveness

Table 22 Effectiveness from the parents

	Task1	Task2	Task3	Task4	Task5	Task6
Complete number	10	10	10	10	10	10
Complete rate	100%	100%	100%	100%	100%	100%

② Efficiency

Table 23 Efficiency from the parents

	Task1	Task2	Task3	Task4	Task5	Task6
MT	3.02	43.90	15.25	9.31	14.34	60.55
Max D	3.65	50.88	24.55	15.21	22.32	90.64
Min D	2.34	35.55	8.53	6.98	9.73	45.31

③ Satisfaction

PSSUQ results show: Module usefulness is 5.8, Information Quality

is 6.0, Interface Quality is 5.9, Overall Evaluation is 6.2.

(4) interview results

The results are summarized as follows:

1) Awareness of symptoms management

Some parents of children with acute leukaemia said that they had paid less attention to their children's symptoms and feelings in the interview. Using the symptoms management module, they realized that children also have a lot of physiological and psychological feelings that need to be concerned.

N1: “I do not have a sound cognition of the symptom of my child. I only know some common symptoms, like fever. By using the module, I have learned a lot about the symptom. It improved my awareness of symptom management.”

N4: “Before I used the module, I learned everything about the symptom from the healthcare provider. It offered me a great chance to self-learn about symptom management."

N7: "After using the module, I know that symptom management is quite important. Many symptoms can be prevented if I have sufficient about the causes, the care, and the other factors of the symptom.”

2) Advantages and benefits

① The Module makes symptom management more efficient, and it is generally easy to use.

N1: I think it is easy to operate, and the contents are obvious.

N7: The information can help me effectively to learn knowledge.

N8: This information is very useful in helping me to manage the symptoms.

N9: I'm able to observe every symptom knowledge, like the cause of vomiting. I do not need to ask a question to healthcare providers.

②The module's content and function are scientific, convenient, and simple to understand.

N2: It is helpful. Sometimes, we also want to pay more attention to symptom management, but we don't know exactly what content is scientific. The module offers us a way to learn that.

N3: It's helpful, mainly for parents who are not familiar with the symptom of acute leukaemia. It's beneficial to learn some crucial things and very simple to understand.

N10: It is convenient to use the module to review the course of chemotherapy and the symptoms. It is like an electronic notebook, I can open it and learn something everywhere.

3) Disadvantages and obstacles

①The interface and the layout of the module need to be further optimized.

N1: The module is not beautiful enough, I think.

N4: We need to design the interface about the front or other things to make it look more advanced.

N9: The interface of this module was not pleasant enough, I think.

N10: The picture on the screen is stretched out.

②Lack of communication channels with healthcare providers

N3: We cannot have direct access to communicate with the healthcare professionals through the module.

N9: I think there is still a lack of interaction with the real world, such as doctors and nurses. We hope to have some functions of professional feedback in the module.

5.3 Discussion

(1) The limitations and optimization strategies of the module

According to the results of qualitative research, we find some problems with this module. Especially in the aspects of the design of the interface and the functions of the module. We need to beautify the module and realize the more practical functions in the future.

6 Conclusion

6.1 Conclusion

(1) Analyzed symptoms that were suitable for parents to participate in and parents' needs in symptom management

The researcher conducted the semi-structured interviews and analyzed WeChat group chat records. The results included: 1) the symptoms that were suitable for the parent to participate in; 2) parents' symptom management needs when they participated in the care of their children; 3) the symptom management module functions that parents needed.

(2) Constructed the image-text knowledge base of the symptom management module

Based on the literature analysis and the preliminary needs analysis results, the researcher constructed the framework of the symptom image-text knowledge base of the symptom management module. Then, the researcher finished the final construction of the image-text knowledge base after verification and revision by experts. It included 41 image-text knowledge articles of physiological symptoms and 6 image-text knowledge articles of psychological symptoms.

(3) Constructed the symptom management module

The researcher held a brainstorming discussion to put forward the function assumption of the module. Then, the researcher coordinated with software engineers and completed the development of the symptom management module in the support system APP.

(4) Evaluated the usability of the symptom management module

The researcher implemented the formative usability evaluation and summarized usability evaluation, and solved the usability problems. The usability evaluation results showed that the module had great effectiveness and efficiency. The information in the symptom management module is of high quality. The symptom management module can bring the parents many good benefits and have the potential to improve parent participation in symptom management of children with acute leukaemia.

6.2 Innovation

(1) Explored symptoms that were suitable for parents to participate in and parents' needs in symptom management

This study obtained the symptoms that were suitable for parents to participate in. Moreover, this study analysed the parent's needs in symptom management through semi-structured interviews and WeChat group chat record analysis.

(2) Constructed the symptom management module in the support system APP

This study focused on the parent participation in symptom management of children with acute leukaemia. Moreover, according to the parents' needs in symptom management, the researcher constructed the image-text knowledge base and the symptom management module with three core functions through multidisciplinary team collaboration.

(3) Conducted the comprehensive usability evaluation for the symptom management module

This study conducted a comprehensive usability evaluation, including survey with PSSUQ, typical task analysis, and semi-structured interviews. Moreover, the researcher conducted the usability evaluation among multiple groups (management staff, healthcare providers, and parents).

6.3 Research deficiencies and future prospects

(1) The effect of the symptom management module

Due to the time limits, the researcher has not evaluated the effect of the symptom management module in the support system APP among the parents of children with acute leukaemia. The group-controlled trial could be carried out in the future

(2) The recommendation rules of symptom

The recommendation rules of the symptom management module need to be further improved, such as the relationship between the chemotherapy drug and the symptom. To make symptom management support fit parents' symptom management needs.

References

[1] WARD E, DESANTIS C, ROBBINS A, et al. Childhood and adolescent cancer statistics, 2014 [J]. CA Cancer J Clin, 2014, 64:83-103.

[2] BHAKTA N, FORCE LM, ALLEMANI C, et al. Childhood cancer burden: a review of global estimates [J]. Lancet Oncol, 2019, 20(1):e42-e53.

[3] ZHENG R, PENG X, ZENG H, et al. Incidence, mortality and survival of childhood cancer in China during 2000-2010 period: A population-based study [J]. Cancer Lett, 2015, 363(2):176-180.

[4] OLSON K, AMARI A. Self-reported Pain in Adolescents With Leukemia or a Brain Tumor: A Systematic Review [J]. Cancer Nurs, 2015, 38(5):E43-53.

[5] Zheng Y, Liu K, Pu XQ, et al. Survey and analysis of symptom clusters in children with acute leukemia during chemotherapy [J]. Chinese Journal of Nursing, 2016, 51(11):1320-1324. (Chinese)

[6] Li RR, Chan YY, Ma JL, et al. Research progress on the influencing factors of symptom clusters in children with leukemia during chemotherapy [J]. Chinese Journal of Modern Nursing, 2018, 24(28):3465-3468. (Chinese)

[7] Xu YH, Shen NP, Yuan CR, et al. Identifying typologies of symptoms in children with leukemia employing latent class analysis [J]. Journal of Nursing Science, 2018, 33(19):22-25. (Chinese)

[8] TAICZ M, PÉREZ MG, REIJTMAN V, et al. Epidemiology and risk factors for prolonged hospital length of stay in children with leukemia and bacteremia. Cohort study [J]. Rev Chilena Infectol, 2018, 35(3):233-238.

[9] STELIAROVA-FOUCHER E, COLOMBET M, RIES LAG, et al. International incidence of childhood cancer, 2001-10: a population-based registry study [J]. Lancet Oncol, 2017, 18(6):719-731.

[10] Wang YY, Wang JT, Yu SY, et al. Parents' Needs of Early Diagnosed Children with Acute Lymphoblastic Leukemia:A Qualitative Study [J]. Nursing Journal of Chinese People's Liberation Army, 2016, 33(4):6-10. (Chinese)

[11] Xie AW, Shan YY, Yao WY, et al. Qualitative research on real experience of parents of children with acute leukemia in children undergoing first chemotherapy [J]. Chinese Journal of Modern Nursing, 2017, 23(11):1536-1538. (Chinese)

[12] LIU Z, ZHU YY, LI XH. Phenomenological study on the psychological course of parents of children with leukemia [J]. Chinese Journal of Practical Nursing, 2014, 30(9):41-45. (Chinese)

[13] Issuance of the CPC Central Committee and the State Council <an outline for the "Healthy China 2030" initiative> [EB/OL]. [2018-10-1]. http://www.gov.cn/xinwen/2016-10/25/content_5124174.htm

[14] APPLEBAUM AJ, BREITBART W. Care for the cancer caregiver: A systematic review [J]. Palliat Support Care, 2013, 11:231-252.

[15] WANG J, WANG Y, WEI C, et al. Smartphone interventions for long-term health management of chronic diseases: an integrative review [J]. Telemed J E Health, 2014, 20(6): 570-583.

[16] Wang JT, Wang YY, Liu YY, et al. Application and prospect of smartphone apps in health management of patients with chronic diseases [J]. Chinese Journal of Nursing, 2014, 49(8):994-996. (Chinese)

[17] HERNANDEZ SILVA E, LAWLER S, LANGBECKER D. The effectiveness of mHealth for self-management in improving pain, psychological distress, fatigue, and sleep in cancer survivors: a systematic review [J]. J Cancer Surviv. 2019 Jan 11.

[18] COYNE IT. Parent participation: a concept analysis [J]. J Adv Nurs, 1996, 23(4):733-740.

[19] JONES J, NOWACKI AS, GREENE A, et al. Investigating parent needs, participation, and psychological distress in the children's hospital [J]. Hosp Pediatr, 2017, 7(7):385-394.

[20] SPEICHER M. What is usability? a characterization based on ISO 9241-11 and ISO/IEC 25010 [J]. arXiv preprint arXiv:150206792, 2015.

[21] KUAN HY. Identifying the needs of Chinese family caregivers of children with cancer in Hong Kong Dissertatio [D]. Hong Kong: Hong Kong Polytechnic(People's Republic of China), 2000:631.

[22] Wang YY, Wang JT, Yu SY, et al. Parents' Needs of Early Diagnosed Children with Acute Lymphoblastic Leukemia:A Qualitative Study [J]. Nursing Journal of Chinese People's Liberation Army, 2016, 33(4):6-10. (Chinese)

[23] Liu YY, Sun J, Ruan HS, et al. Qualitative study on symptom management care experience and needs of parents of children with cancer during chemotherapy [J]. Chinese Journal of Modern Nursing,2020,26(35):4914-4918. (Chinese)

[24] WANG J, BI X, WANG J, et al. Chinese parents' caregiving ability for children with haematological malignancies: A latent class analysis. [J]. Nurs Open. 2022 Apr 18.

[25] BENSINK M, ARMFIELD N, RUSSELL TG, et al. Paediatric palliative home care with Internet-based video-phones: lessons learnt [J]. Telemed Telecare. 2004;10 Suppl 1:10-3.

[26] BENSINK M, ARMFIELD N, IRVING H, et al. A pilot study of videotelephone-based support for newly diagnosed paediatric oncology patients and their families [J]. Telemed Telecare. 2008;14(6):315-21.

[27] BRADFORD N, YOUNG J, ARMFIELD NR, et al. A pilot study of the effectiveness of home teleconsultations in paediatric palliative care [J]. Telemed Telecare. 2012 Dec;18(8):438-42.

[28] BENSINK M, WOOTTON R, IRVING H, et al. Investigating the cost-effectiveness of videotelephone based support for newly diagnosed paediatric oncology patients and their families: design of a randomised controlled trial [J]. BMC Health Serv Res. 2007 Mar 5;7:38.

[29] BENSINK ME, ARMFIELD NR, PINKERTON R, et al. Using videotelephony to support paediatric oncology-related palliative care in the home: from abandoned RCT to acceptability study [J]. Palliat Med. 2009 Apr;23(3):228-37.

[30] WAKEFIELD CE, SANSOM-DALY UM, MCGILL BC, et al. Online parent-targeted cognitive-behavioural therapy intervention to improve quality of life in families of young cancer survivors: study protocol for a randomised controlled trial [J]. Trials. 2015 Apr 11;16:153.

[31] WAKEFIELD CE, SANSOM-DALY UM, MCGILL BC, et al. Acceptability and feasibility of an e-mental health intervention for parents of childhood cancer survivors: "Cascade" [J]. Support Care Cancer. 2016 Jun;24(6):2685-94.

[32] MAYER DK, RATICHEK S, BERHE H, et al. Development of a health-related website for parents of children receiving hematopoietic stem cell transplant: HSCT-CHESS [J]. Cancer Surviv. 2010 Mar;4(1):67-73.

[33] WANG J, YAO N, SHEN M, et al. Supporting caregivers of children with acute lymphoblastic leukemia via a smartphone app: a pilot study of usability and effectiveness [J]. Comput Inform Nurs, 2016, 34(11):520-527.

[34] WANG J, YAO N, WANG Y, et al. Developing "Care Assistant": A smartphone application to support caregivers of children with acute lymphoblastic leukemia [J]. J Telemed Telecare, 2016, 22(3):163-171.

[35] WANG J, HOWELL D, SHEN N, et al. mHealth supportive care intervention for parents of children with acute lymphoblastic leukemia: Quasi-experimental pre- and postdesign study [J]. JMIR Mhealth Uhealth, 2018, 6(11):e195.

[36] YAGER PH, CLARK M, CUMMINGS BM, et al. Parent participation in pediatric intensive care unit rounds via telemedicine: Feasibility and impact [J]. J Pediatr, 2017, 185:181-186.

[37] MEHDIZADEH H, ASADI F, EMAMI H, et al. An mHealth Self-management System for Support Children With Acute Lymphocytic Leukemia and Their Caregivers: Qualitative Co-design Study [J]. JMIR Form Res. 2022 Apr 15;6(4):e36721.

[38] VAISMORADI M, TURUNEN H, BONDAS T. Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study [J]. Nursing & health sciences, 2013, 15(3): 398-405.

[39] Xue L. Brainstorming [J]. Business Research, 2005, 05): 61-62. (Chinese)

[40] PROMIS HEALTH ORGANIZATION. Home [EB/OL].[2021-03-20] https://www.promishealth.org/.

[41] LEWIS J R. IBM computer usability satisfaction questionnaires: psychometric evaluation and instructions for use [J]. International Journal of Human‐Computer Interaction, 1995, 7(1): 57-78.

[42] Zhang Y. Construction and empirical study of self-management intervention program for breast cancer patients based on mobile health application [D]. The Second Military Medical University,2019. (Chinese)

[43] Geng Z. Study on mobile health intervention based on pattern of physical activity of breast cancer patients during chemotherapy [D]. The Second Military Medical University,2018. (Chinese)

[44] Zhang R. The design research of an intelligent auxiliary system of home care for disabled elderly [D]. Southwest JiaoTong University,2019. (Chinese)

[45] An L, Long J, Yang G, et al. Evaluation of Yunnan information management system of HIV/AIDS antiretroviral therapy based on user experience [J]. Chinese Journal of AIDS & STD,2020,26(02):155-159. (Chinese)

[46] COLAIZZI P F. Psychological research as the phenomenologist views it [J]. 1978.

Appendix

Post-study System Usability Questionnaire

Dear users,

After using the platform, please evaluate the platform for the following questions. Each item has 7 options, ranging from strongly disagree -- strongly agree is marked as 1-7, and please tick "√" on the corresponding score.

You are：☐researcher ☐healthcare provider ☐parent

		Totally disagree			Agree		Totally agree	
System Usefulness	Overall, I am satisfied with how easy it is to use this module.	1	2	3	4	5	6	7
	It was simple to use this module.	1	2	3	4	5	6	7
	I was able to complete the tasks and scenarios quickly using this module.	1	2	3	4	5	6	7
	I felt comfortable using this module.	1	2	3	4	5	6	7
	It was easy to learn to use this module.	1	2	3	4	5	6	7
	I believe I could become productive quickly using this module.	1	2	3	4	5	6	7
Information Quality	The module gave error messages that clearly told me how to fix problems.	1	2	3	4	5	6	7
	Whenever I made a mistake using the module, I could recover easily and quickly.	1	2	3	4	5	6	7
	The information (such as online help, on-screen messages, and other documentation) provided with this module was clear.	1	2	3	4	5	6	7
	It was easy to find the information I needed.	1	2	3	4	5	6	7
	This information is very useful in helping me to complete the corresponding tasks	1	2	3	4	5	6	7
	The organization of information on the module screens was clear.	1	2	3	4	5	6	7
Interface Quality	The interface of this module was pleasant.	1	2	3	4	5	6	7
	I liked using the interface of this module.	1	2	3	4	5	6	7
	This module has all the functions and capabilities I expect it to have.	1	2	3	4	5	6	7

		Totally disagree			Agree		Totally agree	
	The word display on the module is easy to read	1	2	3	4	5	6	7
	The color contrast of the module is well designed	1	2	3	4	5	6	7
	The picture on the screen is very clear	1	2	3	4	5	6	7
	I will still remember how to operate the module next week	1	2	3	4	5	6	7
Overall Evaluation	Overall, I am satisfied with this module.	1	2	3	4	5	6	7

Original publications and academic conferences

[1] **Yue P**, Wang JT, Yuan CR, et al. Research and prospect on the application status of intelligent nursing in health management of children [J/OL]. Journal of Nurses Training. (in Chinese, Revised Manuscript)

[2] **Yue P**, Wang JT, Yuan CR, et al. Research and prospect on the application status of natural language processing in health care [J/OL]. Journal of Medical Informatics. (in Chinese, Revised Manuscript)

[3] Wang JT, **Yue P**, Yuan CR. Application and prospect on the electronic application of patient-reported outcomes measurement information system [J/OL]. Journal of Nurses Training: 1-4[2021-12-13] (in Chinese)

Academic Conferences

1. Jingting Wang, Wen Zhang, **Peng Yue**, Xiaolan Dong, Changrong Yuan. The development of a smartphone application to support parents of children with leukemia. Poster, 2021 Nursing Informatics International Congress.

2. Wen Zhang, Jingting Wang, **Peng Yue**, Xiaolan Dong, Changrong Yuan. Development and usability test of a supportive care App for caregivers of children and adolescents with acute lymphoblastic leukemia. Poster, 2022 ISOQOL 29th Annual Conference. (Revised Manuscript)

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