The Design for a Regional Collaborative Care Model for Patients With Stoma Wound in China

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Abstract

The number of Chinese stoma patients is increasing (stoma refers to the artificial opening created through surgery in the abdomen of patient for treatment reason, and professional care for stoma wounds needs to be performed by professionally trained “enterostomal therapists (ET)”). However, due to the late start of China's stoma care business, the existing professional stoma therapists are far from meeting the needs of patients. Complications of stoma caused by the lack of effective care are seriously affecting the quality of life and physical and mental health of patients.

In response to this situation, a regional collaborative care model including central hospitals, community hospitals and families is being discussed in China.To provide patients with high-quality continuous care, not only the nursing process that includes these three elements needs to be addressed, but also the real needs of patients and the voices of their families, the training of professional stoma therapists and the career development path of community nurses, all need to be valued.

This thesis reports a design concept to implement in the stoma patient care. A service design methodology containing user research, insights development, preliminary design opportunities, case studies, concept model development, design, and prototype is adopted to map the area of investigation. Drawing from the latest technological advancements and considering both the physiological and psychological aspects of the issue, six aspects of volunteer, information, patient engagement, process of care, training and culture are identified and a concept model that intervenes in stoma patient care process is developed. In it, the aspect of information is preliminarily designed and a corresponding prototype plan is presented.

Il numero di pazienti con stomia è in crescita (Il termine stomia si riferisce all'incisione chirurgica operata sull'addome del paziente per necessità di trattamento, la cura professionale delle stomie deve essere condotta da personale specificamente qualificato' Terapista enterostomico (TE)).Tuttavia, a causa del tardo sviluppo di questa pratica nel comparto sanitario Cinese, il numero di specialisti è insufficiente a coprire il numero di pazienti coinvolti. Le complicazioni causate dallo scarso supporto medico si ripercuotono sulla qualità di vita e sulla salute fisica e psicofisica degli individui.

Per affrontare questo problema, la Cina sta recentemente sperimentando un modello di cura regionale e collaborativo che connette le maggiori strutture sanitarie, gli ospedali minori e le famiglie. Per offrire ai pazienti un'esperienza continua e di qualità, il processo infermieristico che include questi tre elementi deve altresì tenere conto dei bisogni reali dei pazienti, della voce delle loro famiglie, della professionalizzazione degli specialisti in stomia e dello sviluppo delle carriere degli infermieri coinvolti.

Il progetto contenuto in questa tesi si rivolge alla cura dei pazienti con stomia. Una metodologia tipica del design dei servizio contenente ricerca, sviluppo delle idee, identificazione delle opportunità, casi studio, sviluppo, progettazione e prototipazione è stato adottata. Tenendo conto della tecnologia e considerando sia gli aspetti fisici che psicologici del problema, sei aspetti sono stati identificati: volontari, informazione, partecipazione del paziente, processo di cura, formazione dei tecnici e cultura. Un concept con il relativo prototipo è poi stato sviluppato concentrandosi sull'aspetto dell'informazione.

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1 The stoma care

1.1What is stoma

Stoma refers to the artificial opening created through surgery in the abdomen of patient for treatment reason (National Center for Biotechnology Information, 2008). As consequence, postoperative urine or feces will be excreted by the stoma and collected by the stoma bag that is wore outside it. The stoma can be classified into a permanent stoma and a temporary one according to its nature, the former is permanent, and the latter will be re-locked by surgery after a period (Burch, 2008). There are three common types of stoma, namely colostomy, ileostomy, and urostomy (Burch, 2008). Colostomy and ileostomy are mainly employed to treat colorectal cancer or intestinal damage, and urostomy is mainly used for bladder or urinary system damage (Ding, 2008). Due to the change of the original defecation mode of the stoma patients, the patient' s self-image disorder is severely affecting the patient's physical and mental health (Sun et al., 2013; Smith, Spiers, Simpson and Nicholls, 2016).

The history of ostomy can be traced back to 500 years ago, and the planned ostomy has a history of about 300 years (Xu, 2009). The French surgeon Alexis Littre undertook an ostomy operation in 1710 on the body of a baby who died of congenital anal atresia (Xu, 2009). However, no matter how to improve the technique of ostomy surgery, the incidence of complications after ostomy remains high (Xu, 2009).

In developed countries, the proportion of stoma patients in the total population has reached 1% (Manderson, 2005). The number of patients with an intestinal stoma in China has exceeded 1 million, and it is growing at a rate of 100,000 per year (Yu, 2005).

1.2 The stoma care

1.2.1 The origin of stoma care

Professional care for stoma wounds needs to be performed by professionally trained “enterostomal therapists (ET)”, the word was created in 1961 and often developed by highly skilled nurses (Stelton, 2018).

According to Honglian Xu (2009), in 1917, the British surgeon Lockhart Mummery first proposed the concept of "stoma care". Moreover, Ruben Beach Turmbull, the physician from the United States proposed enterostomal therapy as “enterostomy treatment” to be a new discipline(Xu, 2009). He believed that in addition to basic surgical techniques, enterostomy should also pay attention to the stoma care of the patient, including the prevention and treatment of stoma complications, in addition to the psychological counseling of patient and their family, to provide rehabilitation care for the stoma (Xu, 2009).

For the first time in 1958, the stoma patient received more professional care provided by Norma N Gil, an anterior stoma patient (Burch, 2008). Ms. Gil received the ileostomy treatment from Dr. Turmbull for ulcerative colitis in 1954, her mother also received colostomy for rectal cancer, in the struggle with her and her mother's stoma care, Ms. Gil felt the physical and psychological pain of the stoma patient (Xu, 2009). Therefore, after her complete recovery, although she was not a professional caregiver, she began volunteering to help other patients with stoma care and assisted Dr. Turmbull (Burch, 2008). Later, Ms. Gil became the world's first stoma therapist under the training of Dr. Turmbull and assisted Dr. Turmbull to start the training of stoma care professionals (Burch, 2008). In 1961, they formed the world's first stoma therapist training program in the United States (Burch, 2008).

In 1971, a British-born ward sister Barbara Saunders became the UK's first stoma therapist, after she opened a stoma clinic with a surgeon, Ian Todd, in a hospital in London in 1969 (Black, 2000).

1.2.2 The stoma professional organizations

The worldwide stoma professional organizations are mainly the International Ostomy Association (IOA) and the World Council of Enterostomal Therapists (WCET). The IOA, established as a patient association, is committed to improving the quality of life of ostomates worldwide (International Ostomy Association (IOA), n.d.). Currently, there are three chapters, divided by European Ostomy Association (EOA), Ostomy Association of the Americas (OAA) and Asian Ostomy Association (AOA) (IOA, n.d.). As an international professional nursing association, WCET's Mission is “A unique Global Organization and leader in the specialty of Ostomy, Wound and Continence care” (World Council of Enterostomal Therapists (WCET), n.d.).

In 1958, the International Ostomy Association held a meeting in Toronto, Canada, where representatives of patients and therapists participated and discussed the establishment of other associations (Xu, 2009). Now the International Ostomy Association relies on its three regional chapters to carry out various activities to give professional support to patients with stoma.

In 1968, at the suggestion of Dr. Turmbull, the American Association of Enterostomal Therapists was established, and subsequently renamed the International Association of Enterostomal Therapists (IAET) (Stelton, 2018). In 1976, Ms. Gil organized a discussion at the IOA meeting about the establishment of an association which non-professionals who are keen on stoma care can also join, namely WCET and was established in Milan in 1978 (Brockmeier, 1997).

Since its inception in 1978, WCET has promoted ostomy treatment in most countries of the world. So far, 68 countries or regions have their own Enterostomal Therapists with professional stoma knowledge and qualification (WCET, 2018).

1.2.3 The stoma care state

In this chapter, the United Kingdom and the United States are used as examples to introduce the stoma care models in the world.

Enterostomal therapists in American serve inpatients and patients who require long-term care to provide counseling and technical services (Jiang, Zheng, Liu and Huo, 2013). The stoma care in American hospitals focuses on the complete process from hospitalization to discharge and connects with community care institutions. After discharge, patients can receive care from nursing programs in community hospitals developed by enterostomal therapists in surgical hospitals (Yang, Yan and Qin, 2016). This model not only shortens patient hospitalization time but also saves the medical costs of surgical hospitals (Yang et al., 2016).

Case management of stoma patients can achieve continuity care (Yang et al., 2016). According to the American Nursing Association, case managers are better at those with master's degree or advanced clinical management skills (Mateo, Matzke and Newton, 2002). The practice of stoma case management in the United States is performed by enterostomal therapists, or multidisciplinary teams are mainly composed of enterostomal therapists (Xue & Mei, 2014). Their work includes communicate and coordinate with the patient's medical team, caregivers to meet patient needs and develop for patients individualized care plans through patient needs assessment; and patients are regularly followed up to ensure that the desired goals are achieved (Xue & Mei, 2014).

In the United Kingdom, stoma care relies mainly on the National Health Service (NHS). After the patient leaves the surgical hospital, he or she will receive a visit from a local stoma nurse at home or by going to a local stoma care clinic to complete the connection between the surgical hospital and community care (National Health Service (NHS), 2017). Besides, patients with a stoma can also seek help from Colostomy UK, a British charity with an NHS endorsement, which provides assistance through the official website and a 24-hour telephone hotline (NHS, 2017). Stoma patients can also search through the website of Colostomy UK for local support team information and receive support (Colostomy UK, n.d.). In addition, there are also a number of stoma care products companies and stoma associations in the UK that provide similar support services. Similarly, the United Kingdom is also relying on the WCET system to develop enterostomal therapists (WCET, 2018).

1.3 The stoma care in China

1.3.1 The history of stoma care in China

Chinese stoma care started late. In 1988, Professor Yu Dehong from Changhai Hospital of Shanghai, visited the first stoma therapist school established by Dr. Turmbull in the United States (Xu, 2009). Then he brought back the concept of stoma care to mainland China.

In the popularization of stoma care, Professor Yu Dehong invited Ms. Gil to speak in China, Ms. Gil then funded two Chinese nurses to study therapist courses in Australia in 1993 (Xu, 2009). This initiative also filled the gap in Chinese enterostomal therapist area (Yang et al., 2016). Subsequently, mainland China sent nurses abroad to study stoma care courses, due to the high cost of overseas training and problems in language communication, it is difficult for nurses to learn the courses (Xu, 2009). This situation did not ease until 2001. In 2001, the Chinese mainland began to cooperate with WCET through Twinning Project with the help of Hong Kong (Stelton, 2018). China's first stoma therapist's school was jointly established by the Cancer Hospital of Sun Yat-sen University, the School of Nursing in Sun Yat-sen University, the Hong Kong University's Institute of Professional Continuing Education and the Hong Kong Institute of Osteotomy (Sun Yat-sen University, 2018). The stoma therapists School at Sun Yat-sen University has successfully held 16 sessions and trained 306 students (Sun Yat-sen University, 2018). There are more than 1,000 enterostomal therapists in China now (Liu et al., 2016).

1.3.2 The stoma care state in China

Chinese stoma care mainly focuses on inpatients and outpatients. Due to the disconnection between the care of the central hospital and the community hospital, the care received by the patient after discharge from the hospital is lack of continuity (Jiang et al., 2013). Although the continuous care received by patients includes telephone follow-up, family follow-up, stoma association, stoma clinic follow-up, network follow-up, and communication (Xu, Lu and Zhang, 2014), some of the contents lack operation procedures and implementation standards. For example, telephone follow-up is often lacking in continuity, and there is no clear number of requests for care interventions in the care system (Li & Fu, 2010).

However, as the relevant departments of the Chinese government have put forward new requirements for deepening quality nursing and improving nursing services (National Health Commission of the People's Republic of China, 2015), a series of domestic trials and studies on ensuring the continuity of nursing services and meeting the needs of patients have emerged.

Shanghai has started the long-term care insurance pilot project in the city since January 1st, 2018. It is expected to serve 3 million elderly people in Shanghai in 2018. Moreover, 42 specific service projects for community home care and old-age care institutions including stoma care, the costs incurred are assessed on a case-by-case basis and will be paid at least 85% by the long-term care insurance fund (Shanghai Municipal Human Resources and Social Security Bureau, 2017).

Xu Xiulian (2014) of Shandong University designed and developed a remote care system for stoma complications. Patients can choose online real-time video or offline consultation according to the actual situation, solve the stoma nursing problem under the remote guidance of the therapist, and solve some patients' long-distance problems.

Yang, Wang, Hou, and Nuan (2016) from Qilu Hospital of Shandong University reported a hospital-community-family tripartite information interactive platform developed by their hospital, which enables patients' information to be shared among the three parties and facilitates the continuous care outside the hospital, but the information cannot be shared between different hospitals.

Chu, Chen, and Liu from the Nursing Department of Jishou University Medical School and Wu from Xiangxi People' s Hospital (2012), with the Information Department of the university, built a remote wound treatment information platform based on mobile phone multimedia messaging. The effectiveness of this treatment platform for patients with chronic ulcers in the lower extremities was studied. The results showed that the wound treatment effect of the intervention group using the platform was better than that of the group without intervention.

Regarding the therapist talent training, in recent years, there was more emphasis on capable candidates, with college and undergraduate degrees in academic distribution, accounting for 45.98 % and 39. 08 %, but the master's degree still accounts for a small number, so the English level of the stoma therapist limits the improvement of the professional communication in international exchange and cooperation (Yang et al., 2016).

The stoma care in China develops rapidly in a short period. Compared with before, patients can receive more kinds of health education and continuous care. The incidence of complications after ostomy is reduced, and the patient's self-care ability is also improved (Yang et al., 2016). However, the problem still exists. Mainly for the following two aspects. First, from the perspective of patient care, there is still a lack of comprehensive care (Yang et al., 2016). The central hospital and community hospitals fail to achieve a seamless connection, the strength and role of community care are not exerted, the process of continuous care needs to be improved. Second, from the perspective of stoma therapist training, there is still room for improvement in the training of stoma therapists (Yang et al., 2016). The training of professional nursing people should be strengthened, and the application of multidisciplinary team service mode should be vigorously explored (Yang et al., 2016).

The projects stated by this thesis are focused on solving these two problems. First, how to make full use of the power of therapist and community care to achieve a full range of continuous care for patients by achieving a seamless connection between central hospitals and community hospitals. The second is how to improve the quality of stoma nursing staff and enhance their collaboration.

Service design, as a discipline with many practices in the field of public healthcare, has proved to be a significant role in the community context (Cottam & Leadbeater,2004). It is believed it will work well for achieving a seamless connection between central hospitals and community hospitals and solving continuous care issues. And experience-based co-design focuses on putting the user experience at the core, users and service providers are equal participants in the design process, which not only enhances the patient experience but also enhances the staff efficiency of stoma treatment.

2

Service design for healthcare

2.1The trend of service design for healthcare

Regarding the challenge that the healthcare field will face in the future, Tsekleves and Cooper (2017) proposed seven challenges based on a book, as well as five emerging trends generated by the challenge and seven opportunities which may deal with these challenges and trends.

Under the challenge group, seven themes have been defined, "*namely long-term healthcare, aging, social interaction and support, environment and lifestyle, non-communicable diseases, wellbeing and mental health, active Life/living*" (Tsekleves & Cooper, 2017, p. s2260). The emerging trends that are affected by the challenge are "*self-care/health Management, person-centric healthcare, holistic healthcare, community healthcare and preventative healthcare"* (Tsekleves & Cooper, 2017, p. s2261). The five opportunities that can deal with them are defined to be "*health communication, prototyping, co-design, evidence-based design, digital design, salutogenic design and holistic design*" (Tsekleves & Cooper, 2017, p. s2261).

In this model, service design will play an important role in putting people at the heart of design and development process (Tsekleves & Cooper, 2017). For example, the trend of self-management is a challenge and an opportunity for service design. To promote chronic disease self-management at the national level, how to organize and deliver this public health service requires a thorough reflection, including how to integrate technology into the healthcare system to advance and support chronic disease self-management (Tsekleves & Cooper, 2017). At the same time, due to the implementation of self-management, part of the service delivery will be transferred to the community and the patient's home (Tsekleves & Cooper, 2017). Community healthcare is also an opportunity for service design.

Besides this, a research by Lab4living and Head of Art and Design Research Centre at Sheffield Hallam University (2016) aimed to understand the current state and trends of design in the healthcare field, which were from other dimensions compared with the above points. There are five dimensions, namely clinical condition (the medical or health specialism that the design activities focused on), methods (the design forms), population (the different people group involved), setting (the place where the activities took place) and produced (the outcomes). As mentioned earlier, communities and networks are significant when facing the challenges of chronic diseases in the healthcare field (Cottam and Leadbeater, 2004). But the research showed that today' s design activities for healthcare are still concentrated in hospitals, and hospitals that invest heavily in funds still dominate the proportion of healthcare programs. Encouragingly, from the data point of view in the research, the location of healthcare projects tends to shift from the hospital to the community and daily life. It is believed that service design for healthcare, which focuses on public services in the industry (Sangiorgi, Prendiville and Ricketts, 2014), will also have a lot of room to play in this process.

2.2 Experience-based co-design for healthcare

Service design focuses on the realization of new value co-creation among actors (Wetter-Edman et al., 2014; Ostrom et al., 2015). It also pays attention to the participants' experience and uses it as the main source of inspiration (Meroni & Sangiorgi, 2011). Here I mainly introduces the development and application of experience-based co-design (EBCD) in the healthcare field.

Although patient involvement is not uncommon in the healthcare industry and has been going on for some time, it lacks vitality, and due to its overwork, some of the insights may be masked (Bate & Robert, 2006). Of course, this theory is not wrong in itself and is effective, but there is still a gap in its theory and practice (Bate & Robert, 2006). In the health field reform, new methods are needed, and EBCD has proven to be effective in improving the patient experience (Piper et al., 2012).

In the traditional concept, users are seen as passive recipients of products or services. As the concept changes, users begin to participate in the process of design and innovation as an indispensable factor (Bate & Robert, 2006). The user-centered approach has gradually turned to the user experience as the center, the user's true feelings and not only the user’ s medical goals are valued by the field (Bate & Robert, 2006). In this context, EBCD is developed by Bate and Robert (2006), based on understanding the feelings and experiences of users when they are in contact with services or processes, taking patients and employees' feelings to the core position, and promoting co-design by treating patients as equal participants in the practice of improving the experience (Piper et al., 2012). For the detailed process of EBCD, here are five steps mentioned in one of the studies of Piper et al. (2012). In this study, the project plan was first produced. Users and stakeholders were then gathered, and their experiences were collected through interviews and some other methods. Then the experience shared by discussing between the participants. After the step is the co-design part, all participants were considered equal in the design process. Finally, the solutions were being implemented and reviewed.

Figure 1. The process of experience-based co-design

After being proposed, EBCD has been used in England, Scotland and New Zealand, the application includes clinical head and neck cancer services, diabetes clinic services, and breast cancer screening services (Piper et al., 2012). According to Bate and Robert (2007), the use of the experience-based design method has proven that it can support the development of user-centered organizations in healthcare service. According to a research by Piper et al (2012), which is divided into two projects, focusing on improving the experience of the emergency department of a public hospital in New South Wales, two phases distance 24 months in Project 1 confirm the persistence of changes brought by EBCD; project 2, which delivered the upgraded experience to the participants, was also valid.

Learning

Whether From the perspective of future design opportunities in the healthcare field or based on the concept of EBCD, in the design and research process, the user experience should be placed at the center place, not just the treatment goal be looked as the core. This is especially important for stoma patients who have many psychological needs because of their low self-esteem. Understanding the experience of the stoma patients in the entire medical and nursing process, rather than just paying attention to the treatment results of the stoma, can help the stoma patients to return to their daily life better.

The EBCD process also inspires the design methodology. In the phases involving many stakeholders, such as the stoma positioning phase that patients, therapists, surgeons and even volunteers will be affected, how to explore the process and experience that everyone is satisfied with is very important. It is an effective way for everyone to participate in co-design as an equal role.

3 Research methodology

3.1 Project context

To explore the solutions to the existing problems in the field of Chinese stoma care mentioned above, the First Affiliated Hospital of University of South China (FAHUSC), Hengyang City, Hunan Province, China, as a comprehensive hospital integrating medical treatment, teaching, research, prevention, and rehabilitation, plans to organize the establishment of a regional collaborative care alliance for stoma patients.

There are two meanings about "region" here. One is to explore from the perspective of geographical location, starting from Hunan Province. The other is to explore the patient collaborative care model in the area consisting of central hospitals, community hospitals and families from the perspective of medical treatment.

The starting and ending time planned for this project has been from September 2017 to the end of 2019. The design and implementation of the project have been carried out by Hunan Lantern Medical care Technology Co., Ltd. I will participate in the project until the solution is implemented.

During my internship at a consulting company in February 2018, I met the Hunan Lantern Medical care Technology Co., Ltd. After the internship, I worked as a service designer, relying on the company, participating in the research and preliminary design of the project, helping to clarify the needs of stakeholders in the project system, using the service design methods to sort out the user journey and touchpoints, and delivering the design suggestions for the future design and development.

The First Affiliated Hospital of University of South China

As the project sponsor, FAHUSC has 2,626 formal employees, including 736 doctors and 1,322 nurses. There are 43 clinical departments in the hospital (the First Affiliated Hospital of University of South China, n.d.). The project was initiated by the Nursing Department in the hospital. Three inpatient departments included the Ward one in Department of Gastrointestinal Surgery, the Ward Two in Department of Gastrointestinal Surgery (Because the department is relatively large, it is divided into two ward areas according to the wards), and the Department of Urology participated in the project.

Figure 2. the First Affiliated Hospital of University of South China
(*http://www.nhfyyy.com/2018/jieshao_0504/352.html*)

Hunan Lantern Medical care Technology Co., Ltd.

Since 2013, the company has provided mobile smart care system services to some central hospitals in China. The company's business consists of four categories, a smart care section that assists nurses in intelligently managing the entire care process to improve efficiency; the doctor's section helps doctors to view doctor's orders, medical records of patients and track patients' situations at any time; the information section assists the head nurse in simplifying scheduling tasks; the patient service sector focuses on patient appeals to increase patient engagement (Hunan Lantern Medical care Technology Co., Ltd., n.d.). At present, the company' s services have benefited more than ten hospitals, 400 departments, 8,000 nurses and 100,000 patients (Hunan Lantern Medical care Technology Co., Ltd., n.d.).

3.2 Research methodology overview

During the three months from April to June 2018, I participated in the project. The research methodology included: understanding the project context based on the documents provided by the company, user research, insights development, preliminary design opportunities , case studies, concept model development, design, and prototype. The following figure shows the specific research methods and time arrangement of my involvement in the parts of the project.

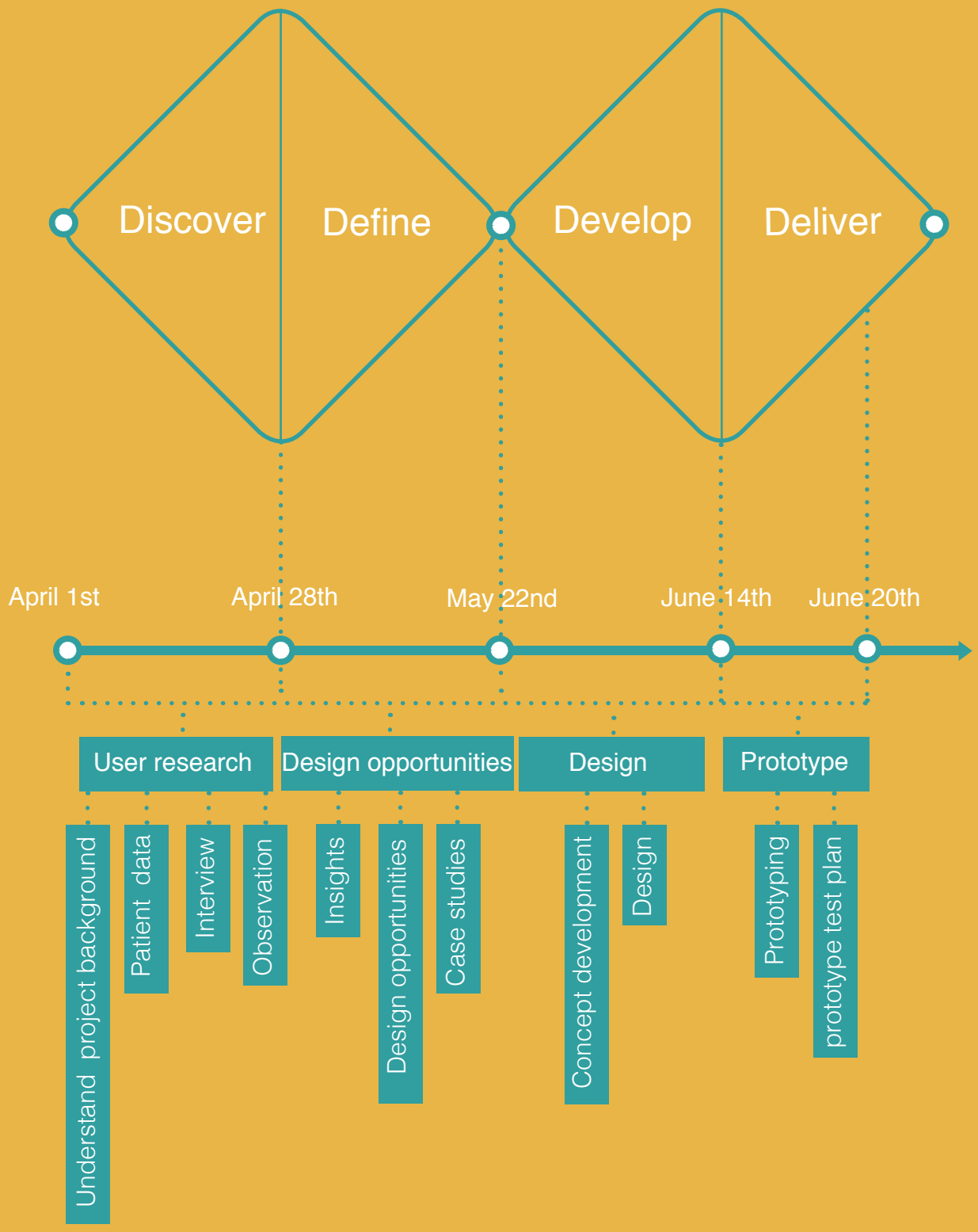


Figure 3. The research methodology overview

3.3 User research

When the participation began in April 2018, I learned about the project background through the materials provided by the company. The original intention of the hospital is to establish a medical alliance consisting of the central hospital, community hospital and family. It pays attention to the care problems after the discharge of the stoma patients, which want to solve the frequent complications of the stoma patients because of the lack of quality community care; and train more stoma professional nursing staff.

I wrote a preliminary research proposal and discussed the project content with the university supervisor. After that, I began to plan for the user research, for obtaining insights and clarifying the demands of stakeholders in the system.

There were three parts in these phase, patient data analysis, interview, and observation.

The period of this phase was from April 14th to April 28th, 2018, including the preparation of user interview outlines, user interviews, observation, and text collation and translation of the research content.

3.3.1 Patients data

During face-to-face communication with the therapists in the two wards of the Department of Gastrointestinal Surgery, the interviewees provided **two record books** of the stoma patient included basic patient information such as primary disease and address and so on, which was for telephone follow-up. There are subtle differences in the records used in the two wards, which can be found from the list. The record of Ward One includes the number, hospitalization number, name, gender, age, type of stoma (permanent or temporary stoma), date of surgery, surgical hospital, primary disease, address, contact information and review record. The record of the Ward Two includes the number, hospitalization number, name, gender, age, date of surgery, surgical hospital, primary disease, address, contact information, and review record.

According to the records, I separately counted the total number of patients in each book, the number of male patients, the number of female patients. And the number of patients in each segment after dividing the age of 40 to 90 by the age of ten. The number of patients living in an urban area and the number of patients in the township area also be counted. Moreover, I counted the number of patients with a temporary stoma and permanent stoma in Ward One record. So, the gender ratio, age distribution, proportion of urban and rural residents (according to the registered address), and the proportion of stoma type (permanent or temporary stoma) of patients were analyzed.

- Number
- Hospitalization number
- Patient name
- Gender
- Age
- Type of stoma (ward one)
- Data of surgery
- Surgical hospital
- Primary disease
- Address
- Contact information
- Review recored

3.3.2 Interview

The user interview period was from April 14th to April 20th, in which April 14th - April 17th was used to prepare the user interview outline. And from April 18th to April 20th, seven stoma patients in different stages, seven family members, three therapists of different departments, one gastrointestinal surgeon were interviewed through face-to-face, telephone and online chat tools. The arrangement is shown in table 1.

The different stages refer to one month after surgery, one month to three months after surgery, three months to six months after surgery, six months to one year after surgery, and more than one year after surgery. The different stages are required because the patients who are in different time periods after surgery are physically and psychologically faced with different problems and have different needs.

Some notes about the interviews:

1.The introduction section mainly included some simple warm-up issues to alleviate the possible tensions of the patient. For example, some basic information about the patient on the day of the interview, such as they came back the hospital for review by themselves or with their family together, whether they need an appointment for the review.

2. In the hospitalization section, the patient was guided to recall the physical and mental state before and after the surgery, and the support obtained when needed.

3.Regarding the part of daily life, it was about the progress, obstacle, and support of the patient returning to a healthy life.

4.The interview with the gastrointestinal surgeon was not in the original plan. After interviewing with the therapist, it was found that the stoma positioning was challenging to achieve in practice, which involved collaboration with the surgeon. Thus, I increased interview with gastrointestinal surgeon and focused on the process of ostomy surgery and the process of stoma positioning collaboration.

The related interview data will be described in the later chapter.

	Aim of interview	Structure of interview outline	Number of interviewee
Patient	To understand the physiological and mental status of the patient at different critical time points and the support they received when needed.	Introduction Hospitalization phase Daily life after leaving the hospital	7
Patient family	To understand the physiological status and psychological status of the patient's family at different critical time points, and the support they received when needed.	Introduction Hospitalization phase Daily life after leaving the hospital	7
Therapist	To understand their daily work processes, the problems they faced and their expectations and recommendations for the project.	Daily work of stoma care Career development of stoma therapist	3
Gastrointestinal surgeon	To understand the process of ostomy surgery and the process of stoma positioning collaboration.	Process of ostomy Collaboration of stoma positioning	1

Table 1. The interview plan

Interviewee category	Interviewee	Form/channel	Data
7 Patients	72 years old; one month after surgery; female	Face to face	April 20
	36 years old; 5 months after surgery; male	Face to face	April 20
	63 years old; in one month after surgery; male	Face to face	April 20
	59 years old; one month after surgery; male	Face to face	April 19
	47 years old; 7 months after surgery; female	Telephone	April 19
	68 years old; one month after surgery; male	Face to face	April 20
	56 years old; in one month after surgery; female	Face to face	April 19
7 Patient family members	The son of the patient, 40 years old The patient: 77 years old; in one month after surgery; male	Face to face	April 19
	The wife of the patient, 50 years old The patient: 50 years old; in one month after surgery; male	Face to face	April 19
	The husband of the patient, 59 years old The patient: 56 years old; in one month after surgery; female	Face to face	April 19
	The daughter of the patient, 30 years old The patient: 59 years old; in one month after surgery; female	Face to face	April 19
	The son of the patient The patient: 55 years old; in one month after surgery; female	Face to face	April 19
	The wife of the patient The patient: 57 years old; seven months after surgery; female	Telephone	April 19
	The husband of the patient The patient: 45 years old; ten months after surgery; female	Telephone	April 19
3 Therapists	Director of Nursing, Senior stoma Therapist in FAHUSC	Face to face	April 18
	Head nurse of the Ward One of Department of Gastrointestinal Surgery in FAHUSC, stoma therapist	Face to face	April 18
	Head nurse of the department of urology in FAHUSC, stoma therapist	Face to face	April 18
1 Surgeon	Surgeon of Ward One of Department of Gastrointestinal Surgery in FAHUSC	Online chat (WeChat)	May 9

Table 2. The interviewee information

3.3.3 Observation

The implementation time of the observation was concentrated on April 21st, while there were also scattered observations in the interview interval. The locations included central hospitals and community hospitals, which as shown in table 3.

Observation focused on the interaction between the patient and the therapist, the patient's appeal, and the support provided by the therapist.

I consulted in community hospitals on the grounds that there were needs for stoma patients, and whether the community hospitals provide related services. Moreover, if the services were not provided, what the reasons were. The service scope of the site and the number of residents were also found on the public signs of some community hospitals, which had reference value for the later design.

Later, from April 22nd to 28th, the Chinese records of the interviews were compiled by listening to the recordings and then translated into English records. Through the compilation and recording of the keywords, the Chinese records of the observations were compiled and translated into English records too.

Observation place	Observation time	Date
Stoma wound care clinic in FAHUSC	0.5h	April 18, 2018
Dressing room of Ward One in Department of Gastrointestinal Surgery of FAHNU	0.5h	April 20, 2018
Wards in Ward one and Ward two in Department of Gastrointestinal Surgery of FAHUSC	Free time between interviews	April 18 - April 20, 2018
Zhengxiang Community Health Service Center	0.5h	April 21, 2018
Zhengxiang lianhua community clinic	0.5h	April 21, 2018
Hengyang Xiecheng Minimally Invasive Hospital	0.5h	April 21, 2018
Hengyang Zhengshui Hospital	0.5h	April 21, 2018
Hengyang Zhengxiang Hospital	0.5h	April 21, 2018

Table 3. The observation plan

3.4 Persona

I summarized the persona consisting of three types of patients from the user research data.

Three types of persona, including active patients, general patients, and negative patients were summarized. They were not real patients, but each one was synthesized by data from several patients with similar behavioral patterns.

3.5 Journey map

Through interviews and observations, the original user journey map was summarized which was divided into six stages according to the user activities order.

The patient's behavior, touchpoint, emotion, frustration, and design opportunity were shown layer by layer.

Behavior represented several activities of the patient during the different phase. The touchpoint was corresponding to the activity. The emotion of the patient produced when the activity was performed. The frustration refered to the frustration point generated by the patient during the activity and can often be transformed. For the needs of patients, in response to these setbacks, new design opportunities had emerged.

On this basis, the behavior of the therapist was added, to avoid the missing of the design opportunity points from the perspective of the therapist.

3.6 Insights

The time for insights development was from April 28th to May 3rd. By extracting the points in the interview and observation records, the key points were classified, the insights themes were determined, and then the insights structure was organized according to the time sequence of the user journey.

Eleven themes were summarized, each of them was consists of the theme name, the quotes from interviewees and the insights content.

3.7 Preliminary design opportunities

There were two main steps in this process.

The first was to sort out the core problems from the perspectives of patients, patient families, therapists, and community nurses based on insights and journey map.

The second was to re-integrate these problems and develop design opportunities bases on them.

There was no direct division of opportunities according to these four categories of people because, considering the actual implementation of the project, it was best to execute some service modules first, and if only consider from a particular group of people, the remaining parties in the service may be ignored.

The design opportunities with six themes was produced then.

3.8 Case studies

After the design opportunity themes were acquired, I conducted case studies to develop a complete design concept based on them. The time for this phase was from May 8th to May 10th. Case study retrieval was mainly divided into two aspects, one was the great cases related to the six themes of the design opportunity, and the other was the excellent cases directly related to the stoma care. After getting the cases, I sorted them according to when, where, what, how, and the points I learned.

In the end, five cases involving user engagement, training, and technology were summarized.

3.9 Design concept

At this stage, from May 11th to May 20th, the complete design concept was developed. The six themes in the previous design opportunities were developed into six aspects of the design concept: volunteer, information, patient engagement, process of care, training, and culture. I first defined the whole design concept as well as each aspect; then, for each aspect, I did brainstorming and got some possible design ideas; eventually, I organized these ideas and produced design recommendations for each aspect.

3.10 Design for information

In the design phase, from May 21st to June 20th, two main parts were completed. One was to discuss with the company's project team for choosing one aspect and design it first. The other was to prepare the prototype for this design, and the complete prototype test plan was also summarized.

Design

The design of the information aspect continues from May 21st to June 13th. On May 21st, I conducted an online report to the company's project team, and then we decided to design the information aspect first. From May 22nd to June 6th, according to the different characteristics of different users, the user journey map with different user paths was completed. From June 7th to June 13th, by arranging the redesigned journey map, the touchpoints that (do not include staff) interact with the patient are summarized.

The touchpoints,includes digital outcomes such as smartphone-based software programs, and physical outcomes like stoma care kits, stoma wound care products, posters, and brochures. The stoma wound care product is professional medical appliance, and the stoma care kit is provided by the stoma care product supplier. The poster and the brochure have been partially tried by the hospital. Therefore, the software program was designed first. For posters and brochure, the relevant forms and styles will be tested in the prototype phase to help the hospital determine the direction for improvement.

Prototype

Prototype began on June 14 and ended on June 20. It mainly included prototyping and prototype test plan. An interactive patient digital interface prototype was created. To test the usability of the prototype, I designed different tasks for patients at different stages. For other information touchpoints, I made a test of the style preferences of paper materials such as posters, providing a basis for future improvements for the hospital.

4 Data analysis

This section focuses on the data analysis for the user research phase, includes the quantitative analysis of patient data and the quantitative analysis of interviews and observations, followed by learning from insights development.

4.1 Patient data

This section introduces the patient data analysis of the two wards of the Department of Gastrointestinal Surgery in FAHUSC, such as the gender ratio and age ratio of the patient. The specific results are shown in the figure 4.

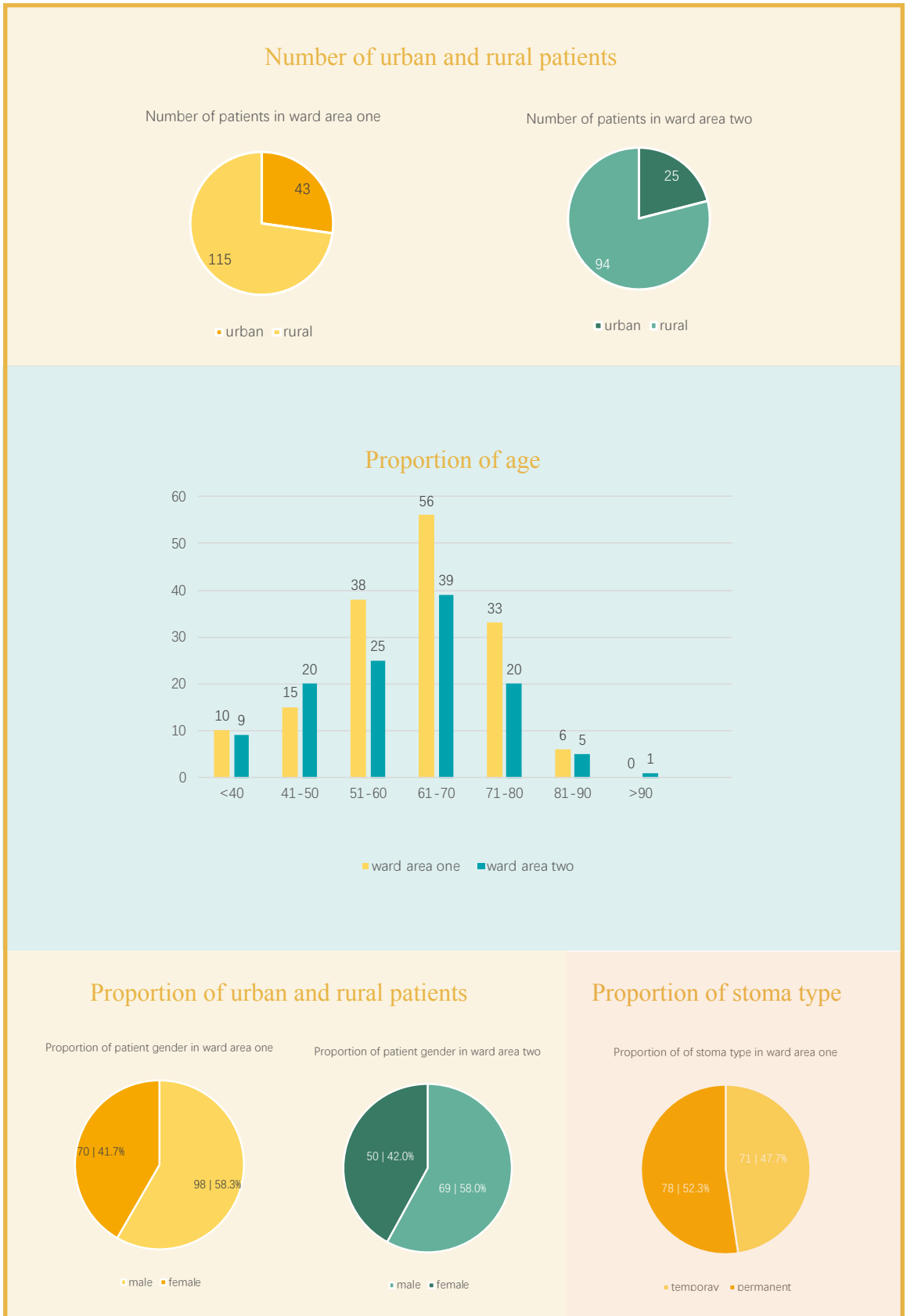


Figure 4. The data analysis of stoma patient in Gastrointestinal Surgery Department of FAHUSC

Since 2015, a total of 158 patients have been registered in the Ward One. Among them, male stoma patients account for 58.3%, and female patients account for 41.7%. In terms of age distribution, from the age of 40, a decade is divided into a region, and the number of 61-70 age group is the largest one which is 56. For urban and rural residents, 115 people live in the township area, 43 people live in the urban area. The number of patients with permanent stoma account for 52.3%, and the number of patients with temporary stoma account for 47.7%.

Since 2013, 119 patients have been registered in the Ward Two (only 4 cases were recorded in 2013 and 2014). In these patients, 58.0% are male stoma patients, and 42.0% are female patients. Regarding age distribution, the number of patients in the 61-70 age group is also the largest one which is 35. For the residential area, 94 people live in the township, and 25 people live in urban areas.

Learning

From the patient's data analysis, it can be found that most of the patients in the two wards are from the township area, which is far from the central hospital, it also showed the necessity of community hospitals and township hospital development.

The age group with the largest number of patients in both wards is 61-70. Therefore, in the subsequent design process, I considered the age ratio of the user, designed other paths that can replace the smartphone for the elderly users, and simplified the operation and set a larger font size when it is necessary to operate the system through the smartphone.

4.2 Interview

In this section, I will introduce what I found in interviews with different categories of interviewers, including patients, patient families, therapist, and surgeon. The discovery point for each category is followed by quotes to help it be better understood. The detailed data will be analyzed in the persona and insights chapters.

Finding from the patient interview

In the communication with patients, the patient's acceptance level of the stoma was found to be different, and the postoperative recovery was also different. There were roughly three categories (described in detail in subsequent chapter “persona”). Active patients would even develop small products to replace expensive foreign products in their daily life after surgery. A relatively intermediate patient could accept the presence of a stoma after a period of resistance, while negative patients rejected for the stoma in the whole postoperative life. It was also found that some patients develop rejection because they did not know the presence of the stoma before the surgery. Overall, the support received was not enough when patients need support.

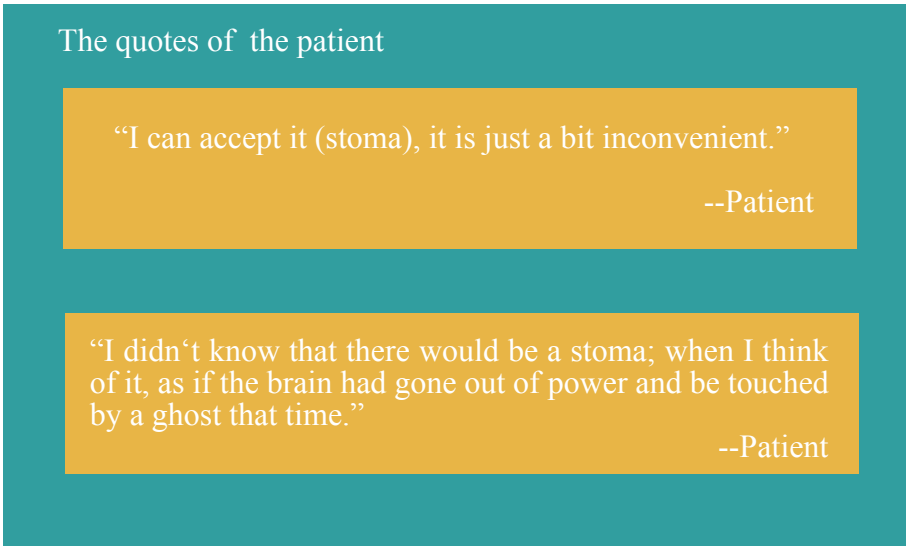


Figure 5. The quote of the patient

Finding from the patient family interview

The problems of the patient's family were mainly focused on stoma care and economic pressure. Most of the family members did not practice stoma care before the patient left the hospital. They all tried slowly after going home, and they were prone to errors and nervousness. Some family members said in the interview that the patient could not continue treatment as the economic pressure. Besides, the communication between the family and medical staff was also a problem, and some family members expressed doubts that they were not satisfied even after getting the reply.

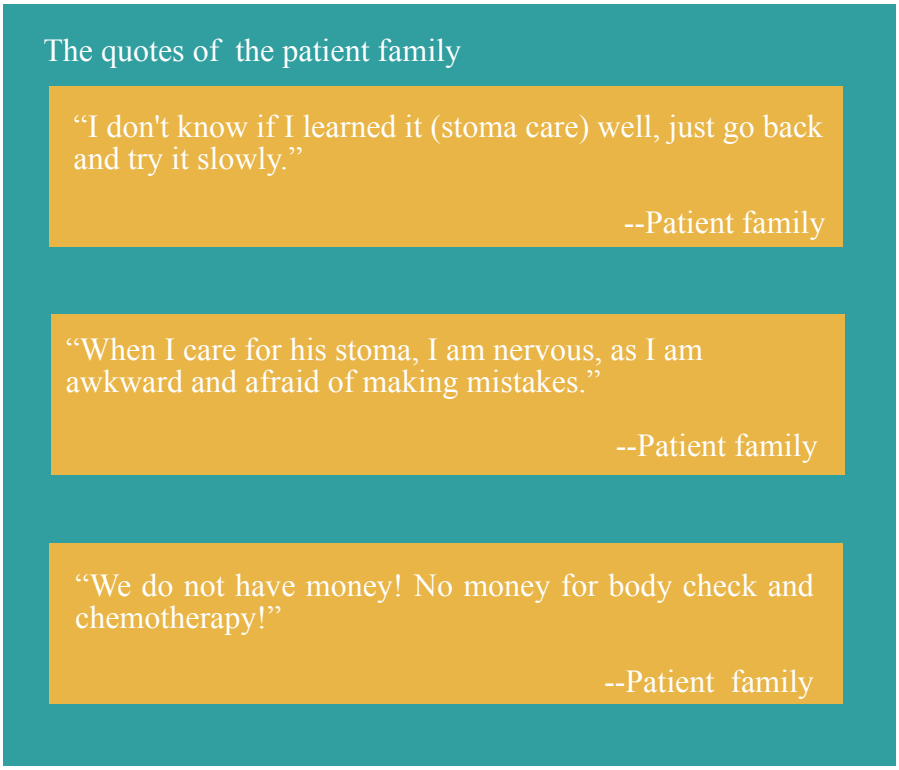


Figure 6. The quote of the patient family

Finding from the stoma therapist interview

In the communication with the therapists, it was found that the stoma positioning and stoma introduction before surgery were two hard points. Stoma positioning was essential for stoma care. For example, whether the patient can clearly see the stoma will directly determine whether the patient can take care of himself. However, in practice, stoma positioning was awkward. First, because the problem of collaboration with the surgeon, the therapist being interviewed had hardly been collaborated with the doctor. Second, because the emotional problems of the patient, the patient was unwilling to know the details, so it was impossible to locate the stoma. Similarly, because of emotional problems, some patients did not know that there would be a stoma before surgery.

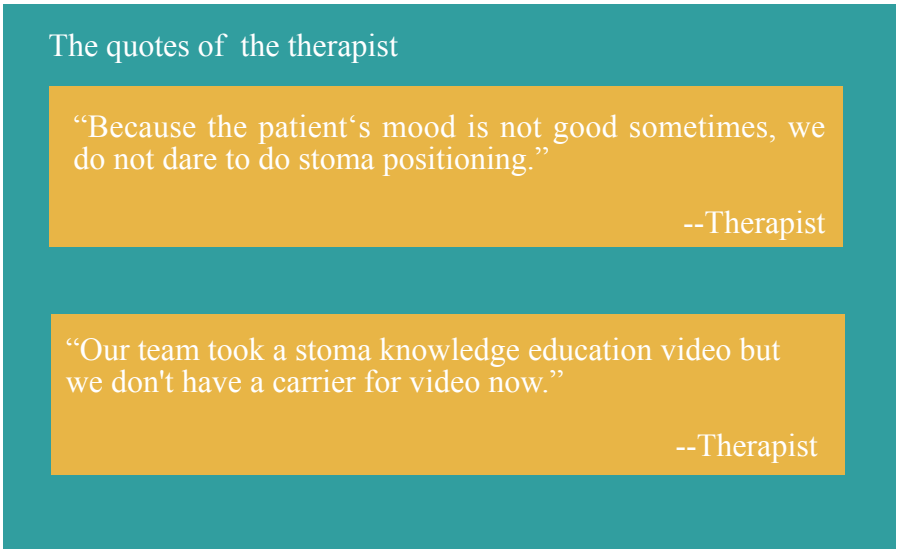


Figure 7. The quote of the therapist

Finding from the surgeon interview

In the interview with the surgeon, the situation described by the therapist was confirmed, and the interviewed surgeon had never communicated with a therapist. In the education he received, the stoma positioning was entirely a business of surgeon. They mainly consider the treatment factors when positioning, and less consider the nursing factors.

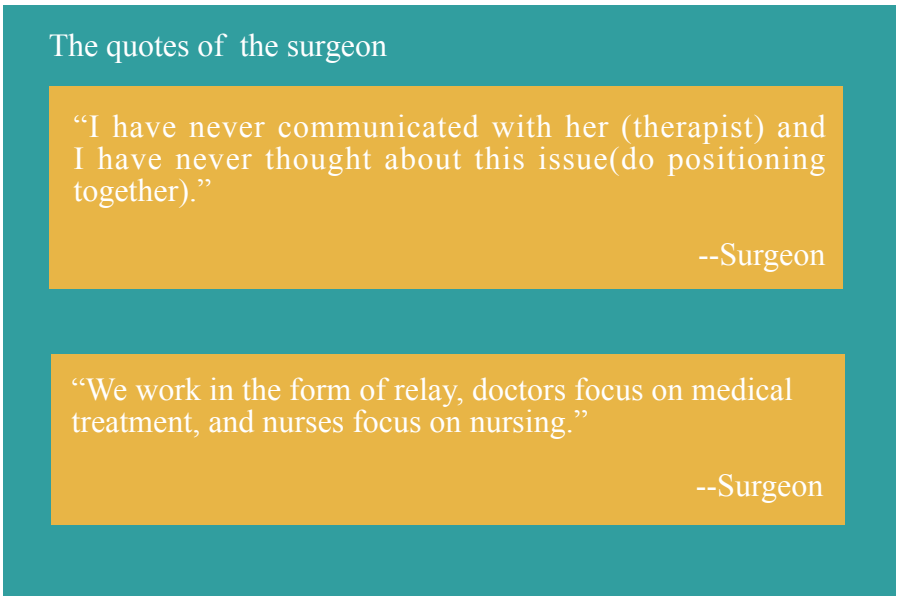


Figure 8. The quote of the surgeon

Learning

In summary, I found that the problems of this project was not entirely concentrated in the community nursing field after the patient was discharged from the hospital. Many problems had been exposed before the patient's surgery. For example, stoma positioning, medical staff collaboration, doctor-patient communication, family members' learning of stoma care. The output at this stage was beneficial in clarifying the patient's overall journey and identify the problems.

4.3 Observation

I observed the stoma wound clinic and the gastrointestinal surgery ward in FAHUSC and visited 5 community hospitals. The observation content of the 5 community hospital is shown in the table 4, followed by the content of other places' observation.

Hospital name	Focus of observation	Key information
Zhengxiang Community Health Service Center	Staff	There are total 15 doctors and 14 nurses according to the public sign. I found one frond desk staff sit behind the desk, two doctors were chatting in one clinic room.
	Stoma care	The staff said they could not take care of the stoma because there was no disinfection equipment; even if the patient came with stoma care materials, they could not do it.
	Other information	According to the public sign, the center's service covers 7 neighborhood communities and 31,069 residents. There are two floors in this center. It seemed that only a few clinic rooms close outside on the first floor are commonly used. As there was no sound and no people went in and out the other clinic rooms.
Zhengxiang lianhua community clinic	Staff	There was only one doctor. No one received me after I entered the clinic. I walked to the dispensing room inside to find the doctor who was preparing the medicine.
	Stoma care	The doctor said he cannot care the stoma wound and let the patient go to FAHUSC.
	Other information	There was no room sign inside the clinic; It looked like there was one clinic room, one dispensing room and one dressing room. The overall environment was like a home environment as there were home sofas, as well as some home furnishings
Hengyang Xiecheng Minimally Invasive Hospital	Staff	Unknown
	Stoma care	The doctors can care the stoma, and the patient do not need to make an appointment; The patient can go there directly. The price is unknown and will be decided according to the condition.
	Other information	I entered from the back door, and there were several clinic rooms on the way to the lobby. Only doctors and no patients in the clinic room.
Hengyang Zhengshui Hospital	Staff	Unknown
	Stoma care	The doctors can care the stoma, and the patient needs to register (no registration fee) first, the total cost is less than 100 RMB (around 12 EUR).
	Other information	The hospital is good at rehabilitating severed limbs according to their promotion.
Hengyang Zhengxiang Hospital	Staff	Unknown
	Stoma care	Unknown
	Other information	The front desk staff did not know what stoma was. Let me go to the inpatient department on the sixth floor. But the inpatient department said that the floor is the wards for baby. The front desk staff then called the surgeon, and no one responded.

Table 4. The observation content

The stoma wound care clinic

In the stoma wound care clinic, I observed that some patients came for stoma care, but did not pay the registration fee in advance. Although they were familiar with the medical staff, they still have to pay the fee first. And the clinic was divided into two parts, one for diagnosis and one for the medicine change. If the doctor was changing the medicine for other patients and there was no medical staff in the diagnosis space, the outside patient did not know what was going on, and they needed to wait.

The dressing room of gastrointestinal surgery

In the dressing room of gastrointestinal surgery, it was observed that the stoma bag of the patient could not be glued because the skin was not cleaned. They turned back to FAHUSC and thought it was a stoma problem. After knowing the real reason, the family members thought that the nursing staff did not explain it clearly. Also, the small dressing room was crowded with three beds, but there was no barrier between them. When the nurse changed the medicine for the patient, someone came in and asked the nurse to sign the document.

The gastrointestinal surgery ward

In the gastrointestinal surgery ward, the nursing staff introduced the stoma to the postoperative patients and usually used the questioning form. For example, "Do you know what it is on your stomach? Do you know what this means?", and the patient usually expressed stunned.

Learning

Although the outpatient and inpatient departments of the central hospital can provide stoma care and a series of services, the entire nursing service lacks a complete process and is prone to omissions. Also, there is a large workload for the nursing staff. All of these means that a complete stoma care process is required within the central hospital to standardize the work of caregivers, improve work efficiency and reduce their burden.

The healthcare workers in most community hospitals are relatively relaxed in the period I have observed. A small number of community hospitals seem to be relatively standardized but still have room for improvement in this area, while the small clinic looks very informal. Almost all community hospital nurses have little knowledge of stoma, and only doctors know part of it. In fact, the primary stoma care can be mastered through simple training and practice. Therefore, it is essential to increase the standardization of the process of community hospitals and to conduct training related to the stoma.

4.4 Persona

Reviewing the data of the user research, I first determined different kind of patients. From the data, they can be divided into three types of patients.

The first category is patients with higher enthusiasm. Not only can they return to daily life quickly after discharge, but according to interviews, patients also actively develop nursing products, or help other patients online.

The second category is patients who are in general level. They are usually able to accept the condition and stoma after being persuaded. They can slowly return to daily life after the resistance period. For example, during the interview and observation process, some middle-aged and elderly patients were found to be able to slowly accept the presence of the stoma and slowly return to daily life.

The third category is negative patients. They usually cannot accept the condition and the existence of the stoma. They are more likely to refuse treatment and care and have a tendency to stop treatment. For example, during a telephone interview, it was discovered that after the surgery, the patient could not accept the fact, she had never worn the stoma bag by herself within one year after the operation and stayed in bed all day. And there were also patients give up treatment because of the financial issue or chemotherapy was too painful.

Corresponding to the above three categories, these three personas are not real people, but the data are from the user research stage, and each persona is a combination of some patients.

"These products are expensive and difficult to buy. So try to do it myself."

Name: Zhi Liu
Age: 37
Work: Software developer
Location: Hunan, China
Family: Single
Disease: Rectal cancer

Needs

- Develop alternatives to foreign care products that are more expensive and inconvenient to purchase.
- There is an efficient source of information enables sharing his experience with others.
- Hope that the products he has developed will be known by more people and help more patients.

Frustration

- Lack of efficient sources of information.
- It's difficult to promote the products he developed.
- Be sad occasionally, there are still negative emotions.

Preferred channels

Wechat

QQ

Phone call

Personality

Introvert — Extrovert

Passive — Activity

Figure 9. Persona A

"I will be happy if the illness can be cured; stoma is just not convenient in everyday life."

Name: Pingying Zhang
Age: 72
Work: Retire
Location: Hunan, China
Family: Married
Disease: Rectal cancer

Needs

- Maintain efficient communication with therapist.
- Understand some "abnormalities" about stoma are really serious or not.
- A community hospital can solve the problem of stoma care nearby.

Frustration

- Can't contact therapist and hospitals in a timely way.
- Fear of stoma symptoms.
- Community hospital cannot solve the problem, still need go to a distant central hospital for easily solved problem.

Preferred channels

Phone call

Wechat

Personality

Introvert Extrovert

Passive Activity

Figure 10. Persona B

"I can't accept the stoma, my head was like be touched by the ghost when I am in hospital."

Name: Jing Li
Age: 54
Work: Rest at home
Location: Hunan, China
Family: Married
Disease: Rectal cancer

Needs

- Return the stoma back.
- Someone can help care the stoma and change the stoma bag.

Frustration

- Can't accept the stoma at all.
- Stoma care is too difficult to do on my own.
- Don't want go out and just lying at home everyday.

Preferred channels

Wechat

Phone call

Personality

Introvert Extrovert

Passive Activity

Figure 11. Persona C

4.5 Journey map

For the journey map, it was divided into six stages according to the user activities order, namely surgical preparation, surgery, recovery, chemotherapy, daily life, and referral.

The below figure shows the details of the journey map, and the description follows the figure.

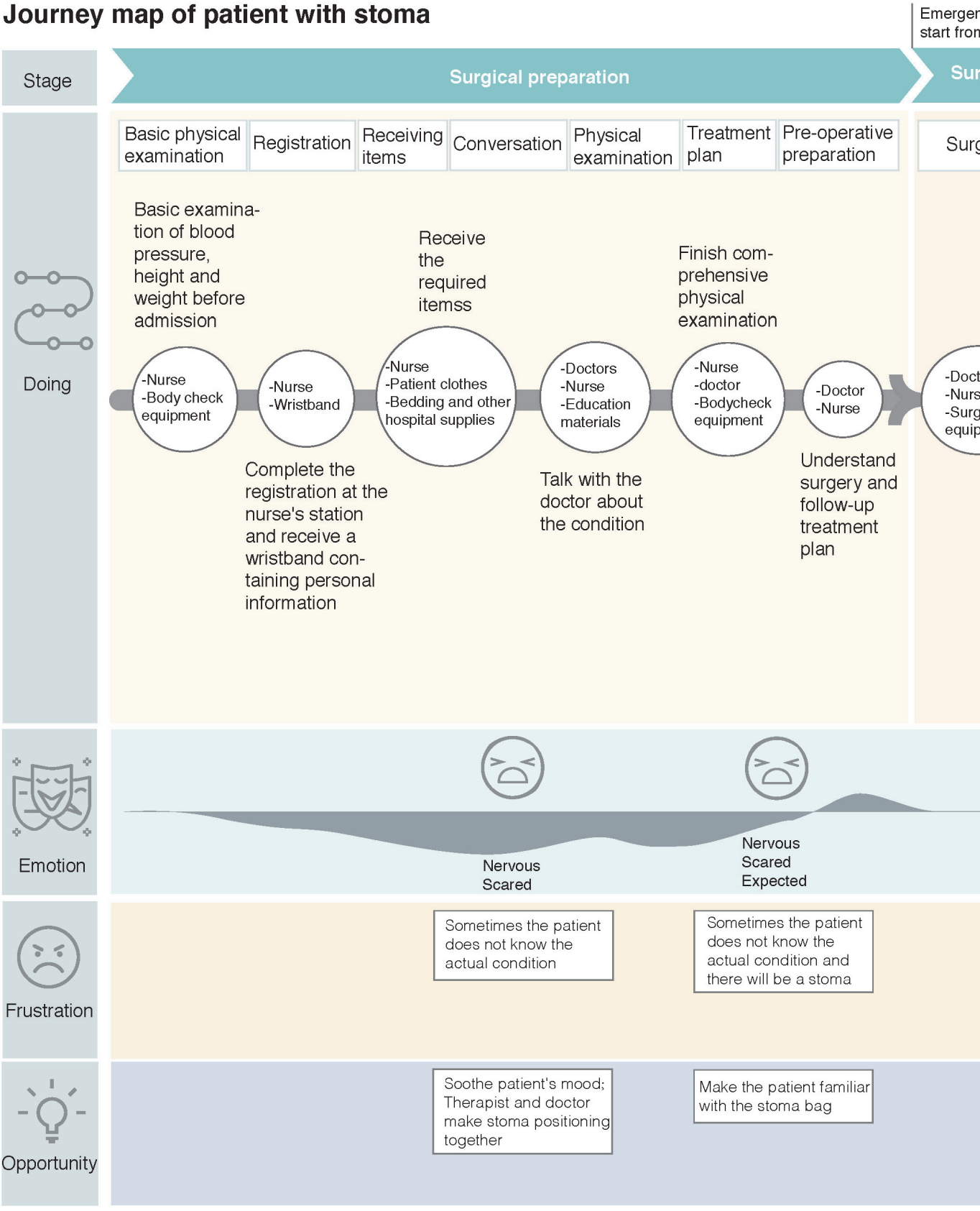
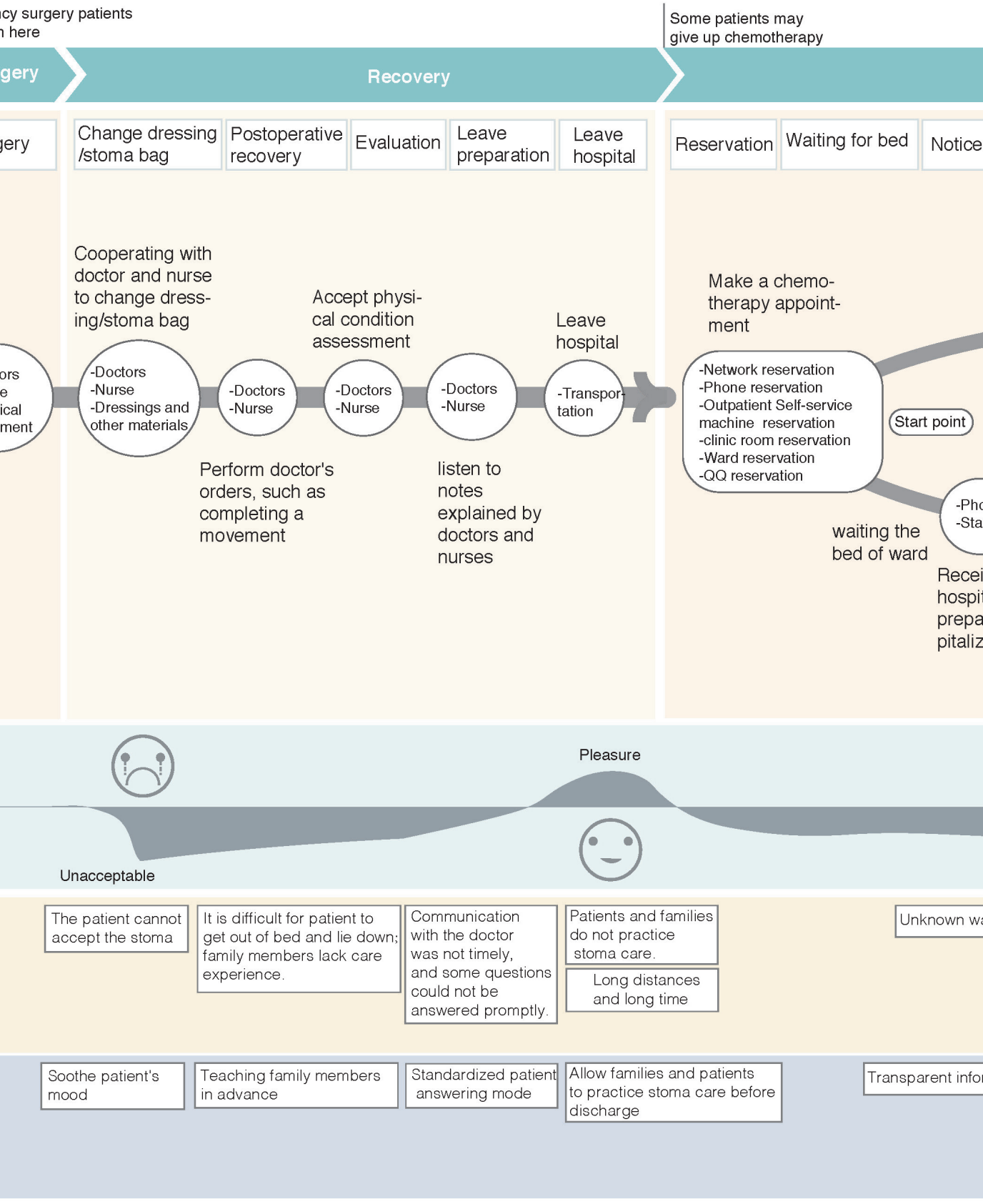
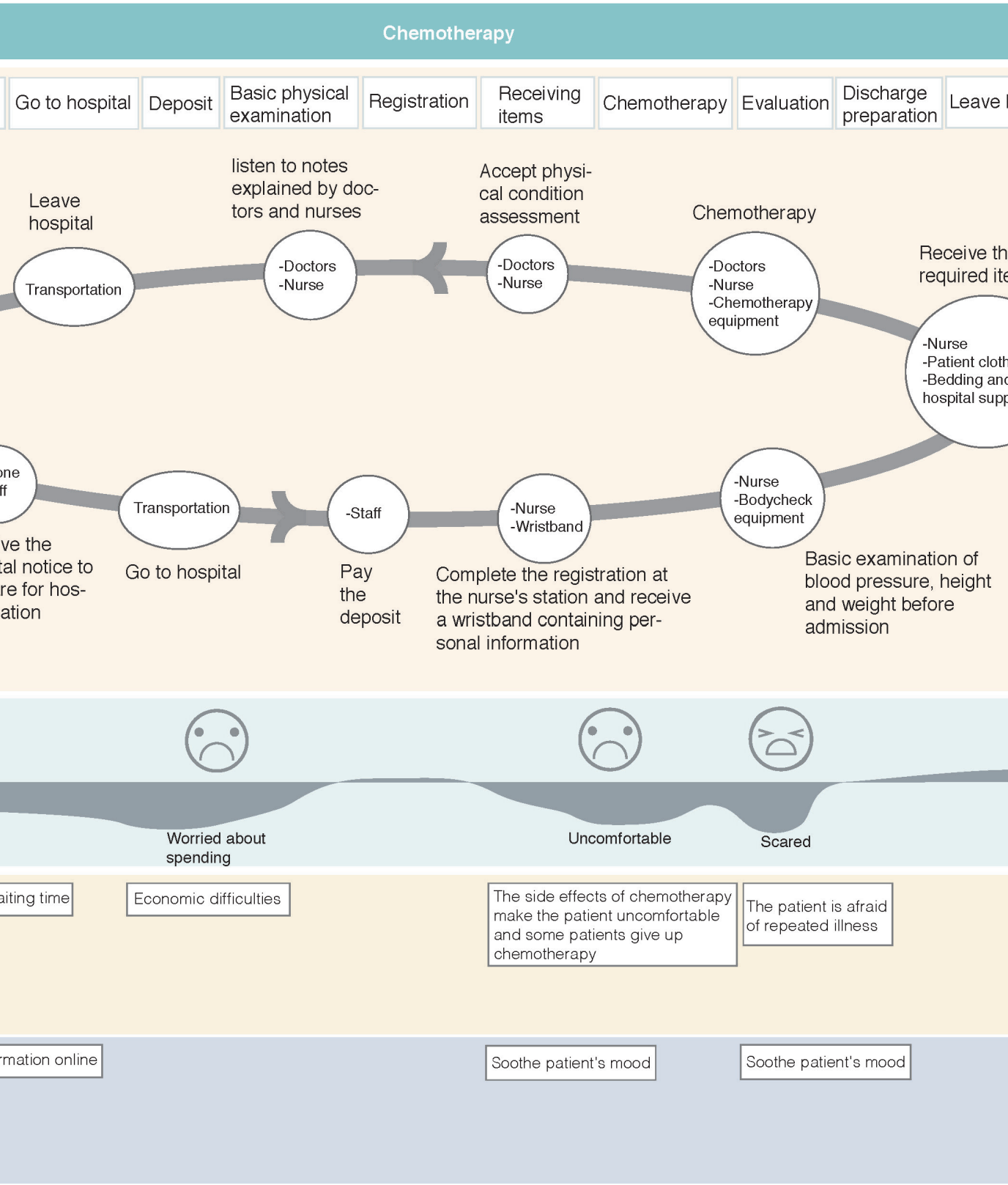
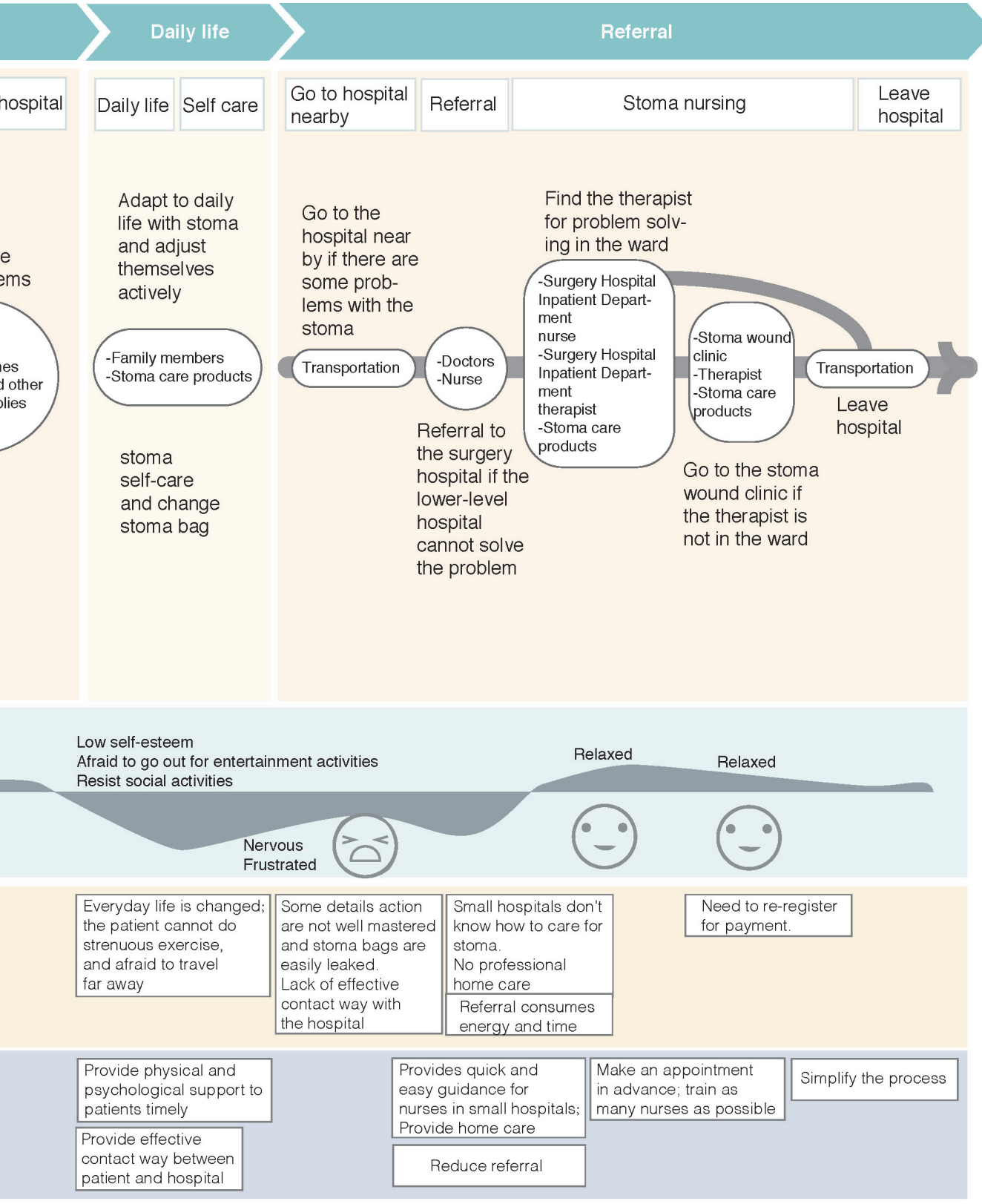


Figure 12. The journey map


cy surgery patients
n here
Some patients may
give up chemotherapy
gery
Recovery
gery
Change dressing /stoma bag
Postoperative recovery
Evaluation
Leave preparation
Leave hospital
Reservation
Waiting for bed
Notice
Cooperating with doctor and nurse to change dress-ing/stoma bag
Accept physi-cal condition assessment
Leave hospital
Make a chemo-therapy appoint-ment
ors
e
ical
ment
-Doctors
-Nurse
-Dressings and other materials
-Doctors
-Nurse
-Doctors
-Nurse
-Doctors
-Nurse
-Transpor-tation
-Network reservation
-Phone reservation
-Outpatient Self-service machine reservation
-clinic room reservation
-Ward reservation
-QQ reservation
Start point
-Pho
-Sta
Perform doctor's orders, such as completing a movement
listen to notes explained by doctors and nurses
waiting the bed of ward
Recei
hospit
prepa
pitaliz
Pleasure
Unacceptable
The patient cannot accept the stoma
It is difficult for patient to get out of bed and lie down; family members lack care experience.
Communication with the doctor was not timely, and some questions could not be answered promptly.
Patients and families do not practice stoma care.
Long distances and long time
Unknown wa
Soothe patient's mood
Teaching family members in advance
Standardized patient answering mode
Allow families and patients to practice stoma care before discharge
Transparent infor


Chemotherapy
Go to hospital
Deposit
Basic physical examination
Registration
Receiving items
Chemotherapy
Evaluation
Discharge preparation
Leave
Leave hospital
Transportation
listen to notes explained by doctors and nurses
-Doctors
-Nurse
Accept physical condition assessment
-Doctors
-Nurse
Chemotherapy
-Doctors
-Nurse
-Chemotherapy equipment
Receive th
required ite
-Nurse
-Patient cloth
-Bedding and
hospital supp
-Nurse
-Bodycheck equipment
Basic examination of blood pressure, height and weight before admission
-Nurse
-Wristband
Complete the registration at the nurse's station and receive a wristband containing personal information
-Staff
Pay the deposit
Transportation
Go to hospital
ve the
tal notice to
re for hos-
ation
Worried about spending
Uncomfortable
Scared
aiting time
Economic difficulties
The side effects of chemotherapy make the patient uncomfortable and some patients give up chemotherapy
The patient is afraid of repeated illness
rmation online
Soothe patient's mood
Soothe patient's mood


Daily life
Referral
hospital
Daily life
Self care
Go to hospital nearby
Referral
Stoma nursing
Leave hospital
Adapt to daily life with stoma and adjust themselves actively
-Family members
-Stoma care products
stoma self-care and change stoma bag
Go to the hospital near by if there are some prob-lems with the stoma
Transportation
-Doctors
-Nurse
Referral to the surgery hospital if the lower-level hospital cannot solve the problem
Find the therapist for problem solv-ing in the ward
-Surgery Hospital Inpatient Depart-ment nurse
-Surgery Hospital Inpatient Depart-ment therapist
-Stoma care products
-Stoma wound clinic
-Therapist
-Stoma care products
Go to the stoma wound clinic if the therapist is not in the ward
Transportation
Leave hospital
Low self-esteem
Afraid to go out for entertainment activities
Resist social activities
Nervous
Frustrated
Relaxed
Relaxed
Everyday life is changed; the patient cannot do strenuous exercise, and afraid to travel far away
Some details action are not well mastered and stoma bags are easily leaked.
Lack of effective contact way with the hospital
Small hospitals don't know how to care for stoma.
No professional home care
Referral consumes energy and time
Need to re-register for payment.
Provide physical and psychological support to patients timely
Provide effective contact way between patient and hospital
Provides quick and easy guidance for nurses in small hospitals; Provide home care
Reduce referral
Make an appointment in advance; train as many nurses as possible
Simplify the process

Surgical preparation

In the first stage, surgical preparation, the patient undergoes a basic physical examination then receives the basic items required for hospitalization, such as the patient's cloth. After the patient entering the hospital, he or she will complete the examination according to the situation, discuss the treatment plan with the doctor and prepare for the surgery. At this stage, the typical emotional depression of patients is the discussion of treatment options, they usually dominated by emotions such as nervousness, rejection, and fear, especially when they know there will be a stoma. There are also a few patients who expect to recover after surgery.

Surgery

The second stage is surgery, which requires little patient initiative.

Recovery

The third stage is the recovery phase, in which the patient is helped by the therapist for medication. What the patient needs to do is to follow the doctor's advice to ensure proper exercise and to be evaluated until the discharge criterias are met. At the time of discharge, the patient will receive a therapist's business card about the online stoma community. However, some patients said they did not know about it. The common problem at this stage is that many patients know the existence of the stoma after surgery, which is difficult to accept. Moreover, concerning stoma care, the patient has hardly studied it.

Chemotherapy

The fourth phase is the chemotherapy phase, where patients need to make an appointment, wait for a bed and notification, and then follow a procedure similar to hospitalization. Not all patients need chemotherapy, and some patients give up chemotherapy because of the economy problem or the side effect of chemotherapy. The main negative emotion of patients at this stage is the pressure brought by economic problems. The side effects of chemotherapy are harrowing, and some of the patients are afraid of disease recurrence.

Daily life

The fifth stage is daily life, and the sixth stage is referral. There is no mandatory temporal order between the two stages. In the daily life after discharge, the patient began to adapt to life with a stoma. Everyday habits, such as diet, dress, exercise, have been changed. The most important thing is that patients need to start trying stoma care by themselves. Many patients stop here. There are also other obstacles, such as repel the stoma, and it is easy to suffer from self-esteem, then be away from the outside world.

Referral

When there is a problem with the stoma, the patient needs to be referred due to the limited care level of community hospitals; many patients return to the surgical hospital after multiple referrals. The main problem in the referral process is that patients are prone to fear because they do not know whether the problem is serious or not, and it is challenging to travel long distances.

Learning

Looking through the whole journey, the main emotional depression of the patients lies in preoperative conversation, stoma acceptance, postoperative care, economic pressure of chemotherapy, side effects of chemotherapy, low self-esteem of daily life, difficulty in self-care, and referral. Clearing out these setbacks provides the basis for the next phase of design opportunity transformation.

4.6 Insights

The findings of the user research phase were summarized as insights included eleven themes.

The eleven themes are choice of hospital, stoma positioning, stoma acceptance, stoma care learning, nursing process record, daily life after leaving the hospital, community hospitals, communication, financial issues, care products, career development of therapist. Among them, the career development of therapist is the basis, communication, financial issues and care products run through the whole process, and other themes are sorted in chronological order.

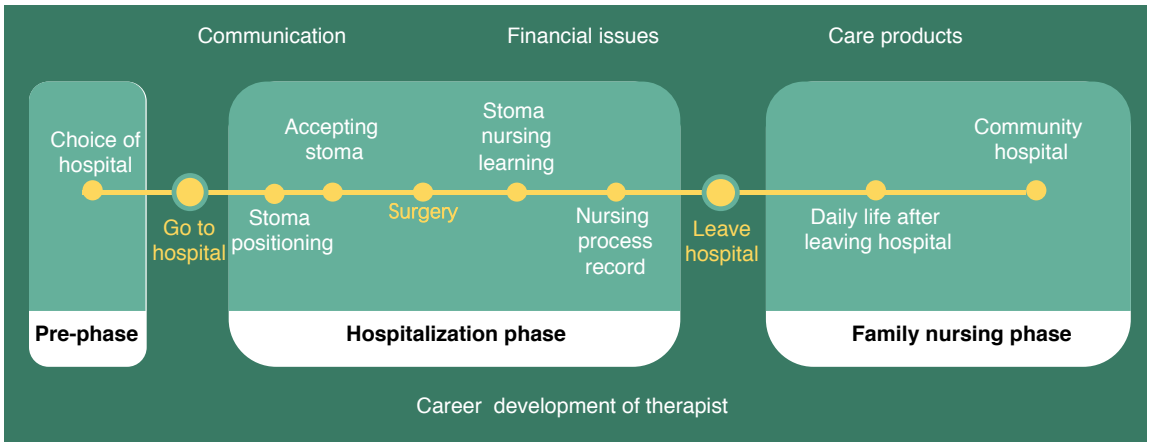


Figure 13. The insights map

The chapter then introduces each insight below separately; each theme begins with the interviewee's quotes, followed by the specific content.

Theme	Choice of hospital
Quote	Therapist: “Someone said that our hospital is a farmer hospital.
Insights	1. The patient usually chooses a central hospital for surgery near home. 2. County residents believe in FAHUSC (The best one in the city) more.
Theme	Stoma positioning
Quote	Doctor: “We work in relay form, doctors focus on medical treatment, and nurses focus on nursing.” Therapist: “Because the patient’s mood is not good sometimes, we do not dare to do stoma positioning.” Doctor: “I have never communicated with her(therapist), and I have never thought about this issue (do positioning together).”
Insights	1. If the positioning of the stoma is not accurate, there will be a great side effect on follow-up care. 2. The positioning of the stoma should be done by the therapist, but it is usually done by a doctor. 3. The Nursing Department did not take the initiative to participate in the stoma positioning of the inpatient department because of insufficient staff and low remuneration. 4. The patient's mood is unstable, and it is difficult to communicate the stoma positioning, which can delay the operation and affect the condition. 5. Doctors consider the treatment more when positioning stoma, without considering the difficulty of patient care. 6. There is no communication about positioning between doctors and therapist. 7. The doctor did not know if there would be a stoma before the operation sometimes. 8. The doctor thinks the positioning is the work of the doctor, the nurse focus on nursing.
Theme	Stoma acceptance
Quote	Patient: “I didn’t know that there would be a stoma; when I think of it as if the brain had gone out of power and be touched by a ghost that time.” Patient: “I can accept it, it is just a bit inconvenient.” Patient: “I don’t want to know the details.”

Table 5. The insights content

Insights	1. Some patients do not know there will be a stoma and can only accept it passively. 2. Some patients reject to know the details of the condition. 3. Successful story videos recorded by volunteers can encourage patients. 4. The patient had insufficient cognition of the stoma before surgery and was more concerned with the cancer condition.
Theme	Stoma care learning
Quote	Patient family: “I don't know if I learned it well, just go back and try it slowly.” Therapist: “Our team took a video, but we don't have a carrier for playing .”
Insights	1. The patient did not learn how to take care of the stoma before leaving the hospital which actually will affect their daily life. 2. Some family members are reluctant to learn stoma care. 3. Family members who are willing to learn stoma care lack the chance of stoma nursing practice before leaving the hospital. 4. Family members lack portable nursing education materials (intellectual property problem). 5. The hospital’s existing education video has no carrier.
Theme	Nursing process record
Quote	Therapist: “When I had no time to record, I did not record it perfectly.”
Insights	1. Nurses register stoma patient care information manually, which is a heavy workload and lack of digital records..
Theme	Communication
Quote	Patient family: “I asked the doctor, but I still cannot understand.”
Insights	1. Doctor’ s answers cannot solve the doubts of patients and their families during hospitalization. 2. There is lack of efficient and convenient online contact methods between patient and hospital. 3. Patient has a strong desire to stay in contact with the hospital.
Theme	Daily life after leaving hospital

Quote	Patient: “I mainly go out with my family.”
Insights	1. Patient's family lacks nursing knowledge. 2. Patients reduce contact with the outside world, reduce activities with a heavy workload and travel far away. 3. Many problems in daily life can be avoided by teaching patient care carefully.
Theme	Community hospital
Quote	Community hospital staff: “We don't have disinfection equipment here. You go somewhere else.”
Insights	1. Township hospital doctors and nurses lack knowledge about stoma. 2. Township hospital doctors and nurses lack a convenient and a quick way to learn knowledge about stoma.
Theme	Financial issues
Quote	Patient family: “I asked the hospital for subsidy policy. The hospital let me to ask the county (related department). But I can't go back.” Patient family: “We do not have money! No money for body check and chemotherapy!”
Insights	1. Patients lack the way to understand the subsidy policy. 2. Patients face economic problems.
Theme	Care products
Quote	Therapist: “This kit is sent to the patient when they are discharged from the hospital.”
Insights	The utilization rate of stoma care education materials provided to the hospital by the existing professional companies among patients is not high.
Theme	Career development of therapist
Quote	Therapist: “The one who can do this must be interested in this topic.”
Insights	1. Interest and the realization of personal value has a positive impact on becoming a therapist. 2. Experiences in special departments such as burns, surgery, and operating room help the development of therapists.

Learning

Based on the Insights on these eleven topics, all of the patient's medical procedures from pre-hospital to hospitalization and after leaving the hospital were discovered. These themes were not limited to the community hospitals in the early stages thinking of the project. Many of the problems in the hospitalization period, such as the stoma positioning, were beyond the imagination. Moreover, issues related to the cultural concept such as medical staff collaboration have also been found, and the problems with therapist career development have begun to be noticed. Only by truly solving these problems can the user experience be improved, and the stakeholders of the entire system can benefit from the system. This phase provided a new perspective for the subsequent design concept, making me not limited to the patient perspective and the community care field.

5

Preliminary design opportunities

This section first introduces the main problems from the perspective of four types of users based on the previous data.

Then, to allow a part of the project can be implemented first, the above four groups of problems were reclassified into six categories of design opportunities, which avoided neglecting other users if only one type of user was considered. For example, if all of the problems of the patient were discussed first, in some cases, the experience of therapists who provide the service may be ignored; but if the design opportunity theme was changed to focus on different field, like information transmission, the experience of all users in this process could be considered more comprehensively.

So, then introduces the preliminary design opportunities with six themes developed from the four groups of problems.

Perspective	Main problems
Patient	How might we let patients accept and learn preoperative stoma knowledge? How might we effectively solve the patient's doubts during hospitalization? How might we reduce the financial burden of patients? How might we psychologically appease patients when they are suffering the side effects of chemotherapy? How might we support patients return to normal life as soon as possible? How might we support the patients when they need medical resource after they leaving the hospital?
Patient family	How might we teach patients' families learn stoma care quickly? How might we reduce the financial burden of patient family? How might we address the psychological needs of patient family?
Therapist	How might we achieve collaboration between therapist and surgeon? How might we make the therapist achieve efficient stoma positioning? How might we help the therapist to successfully complete the stoma education? How might we establish an effective connection between the therapist and the patient? How might we improve the occupational status of the therapist?
Community hospital nurse	How might we design the career development path of community hospital nurses? How might we develop the stoma learning platform for community hospital nurses?

Table 6. The problems

By reorganizing the above four groups of problems, the design opportunities with the six themes, **namely volunteer, information, patient engagement, process of care, training, and culture**, were summarized as below.

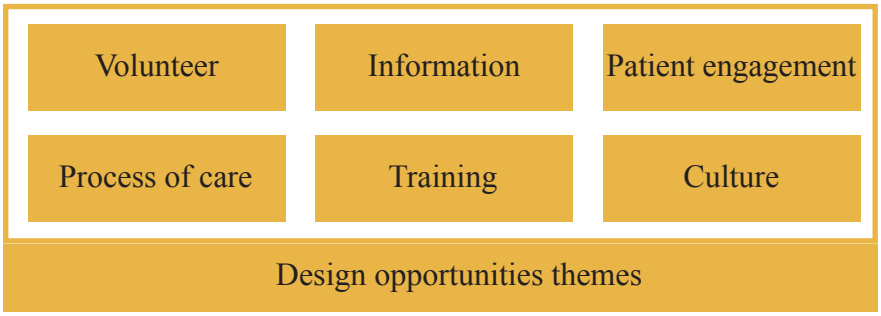


Figure 14. The opportunities themes

For the volunteer, give full play to the advantages of volunteers, such as share their experiences, help patients accepte the stoma and connect doctors and patients, and can also help the therapist to solve the problem of stoma positioning and stoma education.

Regarding information, it means the condition, the financial subsidy policy, the insurance policy, the doctor-patient communication, and the different support information at different stages are appropriately transmitted to the patient at the required time.

From the perspective of patient engagement, patients and their families are actively engaged in the whole process, which will make better health outcomes.

From the perspective of process of care, the standardized nursing process at all levels of hospitals, the nursing process for patients and their families, and the referral process are identified.

For the perspective of training, it is about training on the stoma care workers at all levels and communication between doctors and patients.

Culture, this part focuses on the collaboration of doctors and nurses, doctor-patient communication and medical triage system.

6 Case studies

In the case study session, exceptional cases related to the six aspects of the design opportunities were focused.

The case studies phase aims to understand existing solutions to similar problems, to learn their strengths, and to avoid limitations in future project development.

There are five cases be summarized. The first two are cases through self-management and patient engagement to produce better health outcomes, they are the online mental health community Big White Wall that focuses on the user's mental problems, and mCheck project based on the paper list that focuses on the safety of newborn babies and new mothers. The third is a case from Beth Israel Deaconess Medical Center that promotes patient and family engagement by involving patients in hospital management. The fourth is the case of the stoma care product company Coloplast which using the stoma care kit to transmit information in China. The last one is the online virtual training platform for the physician from the Alibaba Group Artificial Intelligence Health Laboratory, which enhances physician expertise through advanced technology.

Big White Wall

https://www.bigwhitewall.com/v2/Home.aspx

What

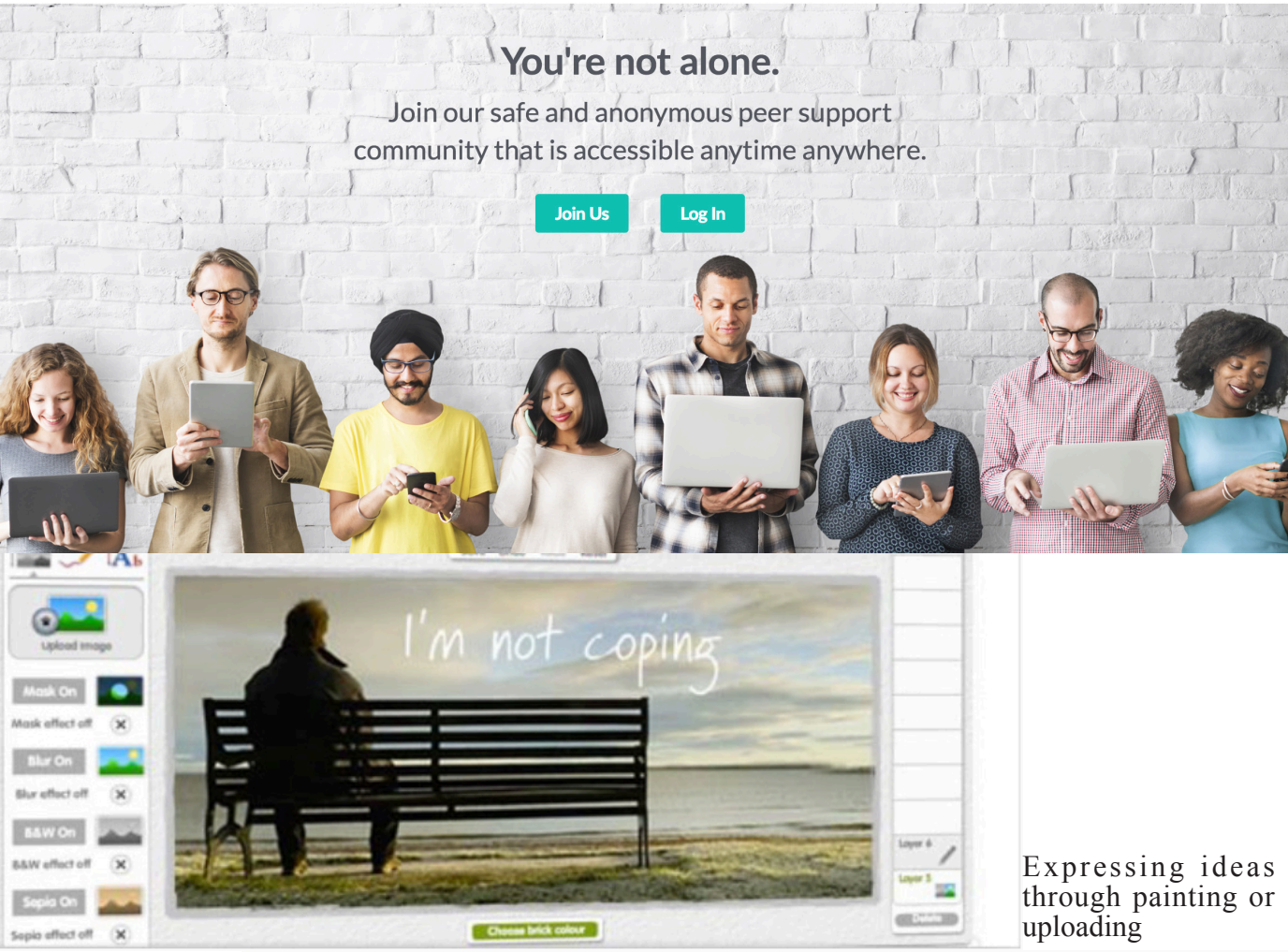
"Big White Wall is a digital mental health support service which is available online, 24/7, and is completely anonymous so you can express yourself freely and openly. Professionally trained Wall Guides monitor the community to ensure the safety and anonymity of all members. In addition to BWW's online community, you will have access to a wealth of useful information and can work through tailored self-help programmes covering topics such as anxiety, sleep, weight management, depression and many more."(Big White Wall, n.d.)

How it works

Big White Wall enables users to join the mentoring support program through testing, surveys, and access assistance. Users can anonymously post ideas, express their ideas through painting or uploading images, promote themselves in useful information, make anonymous friends, and participate in instructional support courses on the official website. Users can get services through a computer, tablet or mobile phone. Regarding fees, the NHS has agreed to pay fees, in addition to private or public sector organizations paying for employees. So the service is free for this group of members, and users can also choose to register for a six-month subscription at a price of £9.99 per month.

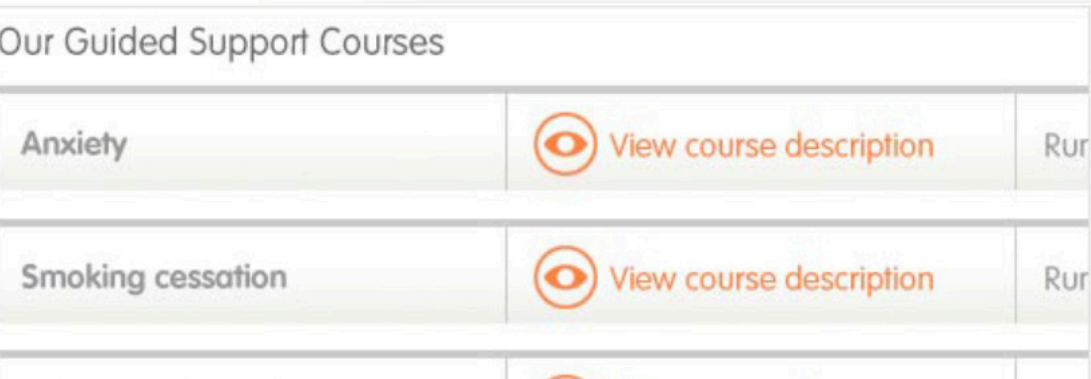
2007

United Kingdom



Expressing ideas through painting or uploading

Promoting in useful information



Participaing in instructional support courses

Figure 15. The website of Big White Wall

Learning

In this case, when the psychological problem is relatively mild, the patient can get help in a simple form, which can avoid patients go to psychological counseling clinics with serious psychological problems and save much money. This practice of enhancing patient engagement in a self-management manner through an online platform to support patients is worth learning.

The Seven-Day Mother And Baby Health Checklist: mCheck

http://www.who.int/patientsafety/patients_for_patient/resources/en/
Laurance et al. (2014)

What

To save lives (babies and mothers), the World Health Organization has developed a simple, paper-based list called the mCheck system to help mothers identify vital signs of danger during the first week of baby birth. The service was pilot tested in parts of Indonesia in 2013. It is also one part of Patients for Patient Safety projects of World Health Organization.

How it works

Within seven days of birth, the mCheck system automatically sends a text or audio message to the mother's mobile phone to remind her to check the baby and herself for signs of danger.

The problems on the paper list are divided into two parts, six of which are for babies, such as "Is my baby breathing faster and harder, or slower, or grunting?" “Does my baby have a fever?” “Are the whites of baby’s eyes yellow?” There are also six questions for mom, like “Do I have a fever?” “Do I have a bad headache?” “Am I bleeding a lot?”

If the answer to any of the questions on the list is yes, then the mother is advised to seek medical help immediately. When the mother asks for help, her phone automatically triggers a text message to remind the health care provider to bring the mother and her baby to the health center or hospital.

2013

United Kingdom

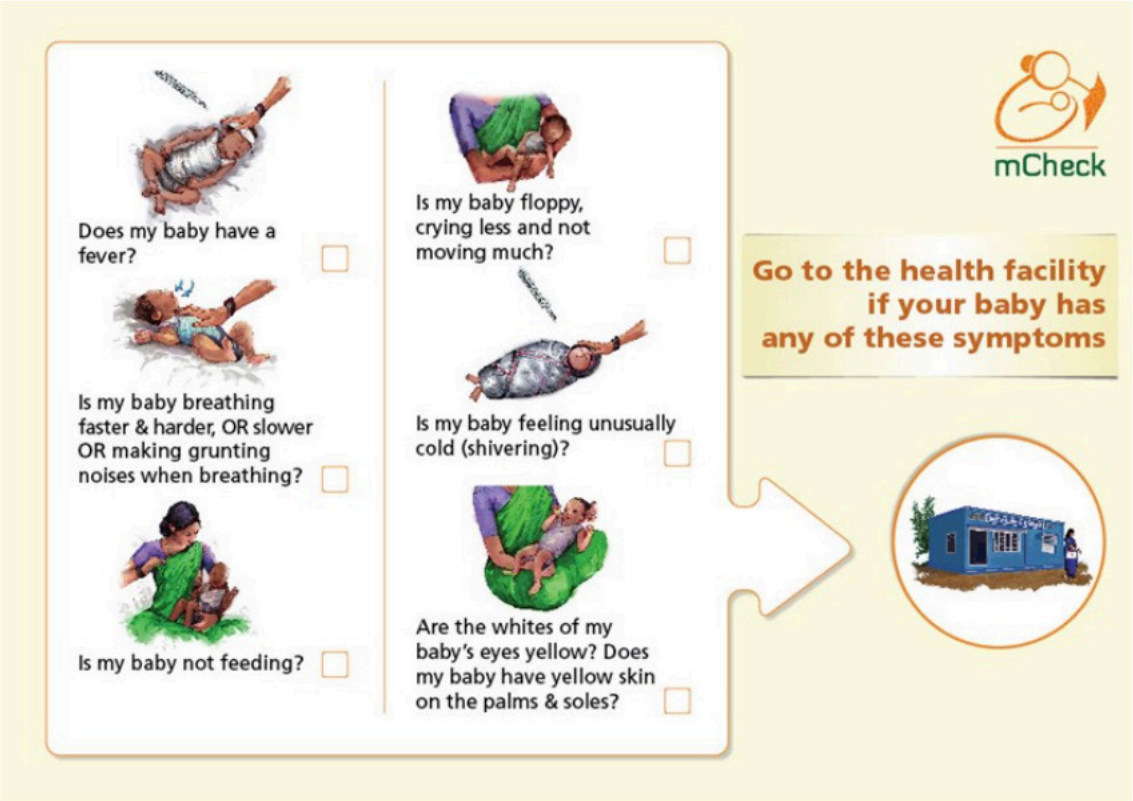


Figure 16. The mCheck

Learning

The case improves the survival rate of newborns and new mothers through the self-manage of the new mothers. The paper list used in this case has low technical requirements, which is simple and straightforward but effective. It is worth learning to choose the appropriate carrier to transmit information and enhance patient engagement according to the actual environment and technical conditions, .

Beth Israel Deaconess Medical Center (BIDMC)

https://www.bidmc.org/about-bidmc/quality-and-safety/patient-and-family-engagement-at-bidmc

What

Beth Israel Deaconess Medical Center (BIDMC), in Boston, USA, in order to improve the experience of patients in the medical center, the service is redesigned with the medical staff by allowing the patient or family to serve as a advisor in BIDMC.

How it works

Patients and families are mainly involved in hospital service improvement in three ways: participating in Advisory Councils, becoming advisors on Hospital Committees and participating in Focus Group and Project. Among the Advisory Councils, there are the Hospital-Wide Council, the Universal Access Council, the Newborn Intensive Care Unit Council, as well as the Intensive Care Unit Council; each Council meets 3-6 times one year and for a two-year term. Advisors on Hospital Committees include the Patient Care Committee, the Patient Education Committee, and the Ethics Advisory Committee. Focus Group and Project Opportunities include Impatient portals, Food Services, End of life planning, Open Notes, and Revising the BIDMC website and more.

Unknown

Boston, USA

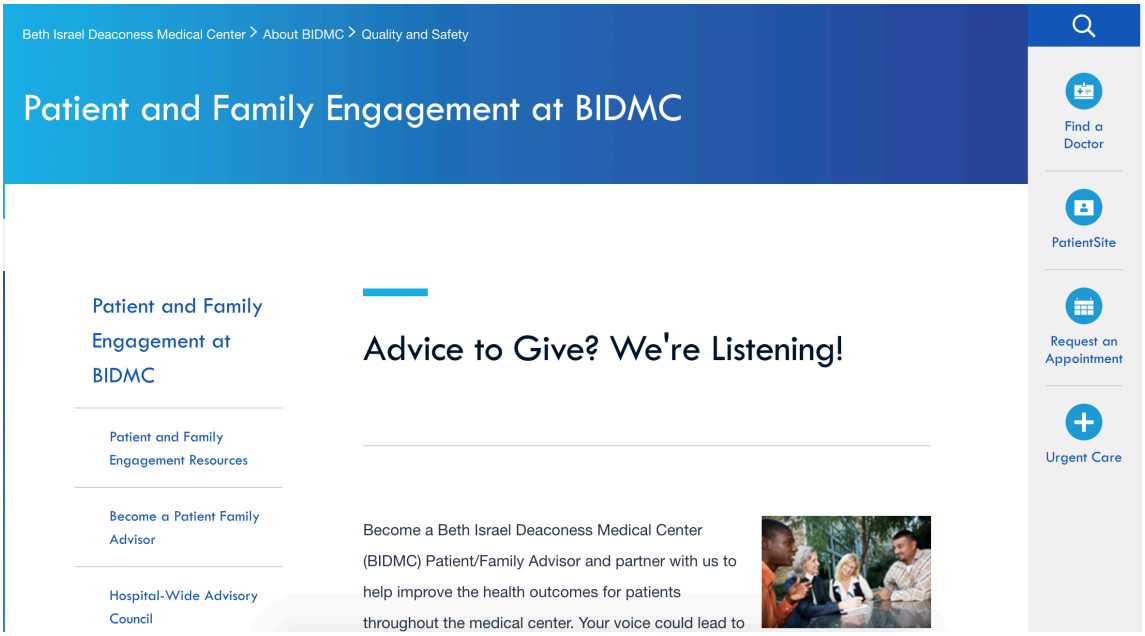


Figure 17. The website of BIDMC

Learning

This case allows patients and families to participate in the council and committee, which not only enhance patient engagement, but also benefit patients with better health outcomes. It can be referred when developing patient engagement project at the organizational and institutional levels.

Coloplast kit for stoma patient in China area

Coloplast stoma care kit

What

As a company engaged in the development, production, and sales of medical care products, Coloplast provides free services for stoma patients who are registered as company members in the Chinese region, the service including the video about the stoma bag wearing process, expert lectures and more.

How it works

Coloplast has access to stoma patients through hospitals that use the company's products. The hospital gives patients the free stoma care kit from Coloplast when they leave the hospital, and there is a guide about how to become the member of Coloplast and some useful tool and material for patient inside the kit.

In order to attract the patient to register as a member, once the registration successful, the Coloplast will give the patient a free curved scissors for stoma care. If the patient uses the product of Coloplast, they can always get the support free.

The support includs: video about stoma bag wearing process, expert lectures, consult online with nursing staff in the form of uploading pictures, nursing information, patient inspirational stories and case sharing, and patient club.

Unknown

China

Figure 18. The Coloplast stoma care kit

Learning

Coloplast spreads useful nursing knowledge through a practical stoma care kit that not only helps the patient but is also an example of the perspective shifting from the company perspective to a user perspective. It can be referred when developing a project related to information spread.

Clinician competence training platform from Artificial Intelligence(AI) lab of Alihealth

https://you.alihealth.cn/?tbpm=1

What

The Clinician competence training platform is developed by AI lab of Alihealth of Alibaba group in China.

The immersive physician training system can automatically builds virtual patients. Physician users can diagnose and treat virtual patients in a simulated scenario. They can acquire medical knowledge, standardize diagnosis and treatment, and improve clinical thinking through the system.

How it works

The physician training system mines the clinical path of disease from past desensitization cases and automatically constructs virtual patients. When the system simulates the patient's visit, the doctor needs to check the body condition, assist in the examination, make a final diagnosis, and perform the diagnosis and treatment. At the same time, the system will guide doctors to make appropriate treatment measures according to the patient's different condition. The virtual patient will follow the doctor's diagnosis and treatment measures, give the corresponding physical state changes, result reports, post-execution status.

2018

China

Figure 19. The website of Alihealth

Learning

In this case, the virtual platform can train doctors through expose doctors to a large number of real cases in a short period, and there is no risk of misdiagnosis. It is an example in which advanced technology is very successful in professional training. From this case, it can be found that advanced technology can provide a new perspective for the design of the system, so it is necessary to pay attention to the technology in related fields in the process of project development.

Conclusion

Through these five cases, I learned how to take advantage of patient engagement from different perspectives in the field of healthcare, like the application in patients' psychological and physical health and the application from personal and organizational aspects. I also learned how to transmit information through appropriate carriers, and the benefits of advanced technology for the system. These knowledge points have been used in the development of the design opportunities mentioned above, making it a preliminary design concept.

7

Concept model development

Through case studies and further desk research, the preliminary design opportunities have been further developed. In this chapter, I first introduce the overall definition of this design concept, then the six aspects in the design model and relevant design suggestions are followed which the project team can refer to in the subsequent design process.

About the development of the design concept model. I developed the six themes of design opportunities into six aspects of design concepts, and then learned the importance of focusing on advanced technologies, the physical and mental health of patients from case studies and further literature studies. Finally, it was decided to use advanced technology as the basis for the entire design concept model, focusing on these six aspects from both physiological and psychological perspectives in the model. The process of development is shown in figure 20.

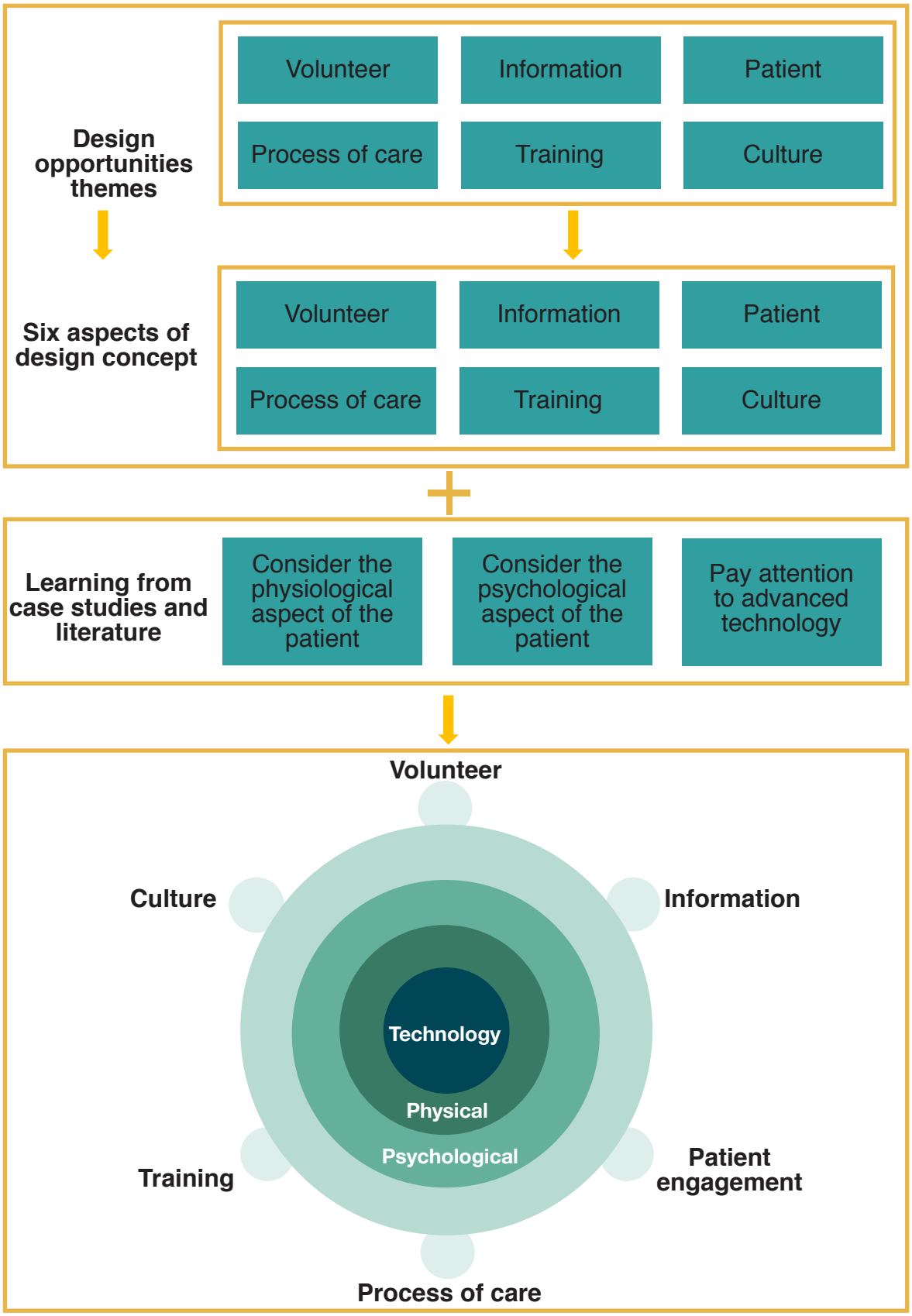


Figure 20. The process of concept model development

Considering the feasibility, this concept model uses advanced technology as a support point. On this basis, support is given to both the physiological and psychological needs of patients with a stoma. In the actual implementation process, the support mainly covers six aspects include volunteer, information, patient engagement, the process of care, training and culture. Volunteer, giving full play to the strength of volunteer to eliminate the patient's psychological burden on stoma and help the therapist to perform stoma positioning better. In terms of information, the service provider is assisted to deliver the required information to the patient at the appropriate time with the appropriate carrier. Patient engagement encourages patients and their families to increase their participation and achieve better health outcomes. The process of care creates a standard care process in both central hospitals and community hospitals. Training, from the perspective of service providers, assisting therapist and surgeons for better collaboration and providing training for community hospital nurses. Culture, solving the problem of collaboration between healthcare staff and improving the relationship between doctors and patients. It can be seen that not only the patient's needs are taken into consideration, but other users in the system are also covered. Specific introduction of the aspects will be introduced below.

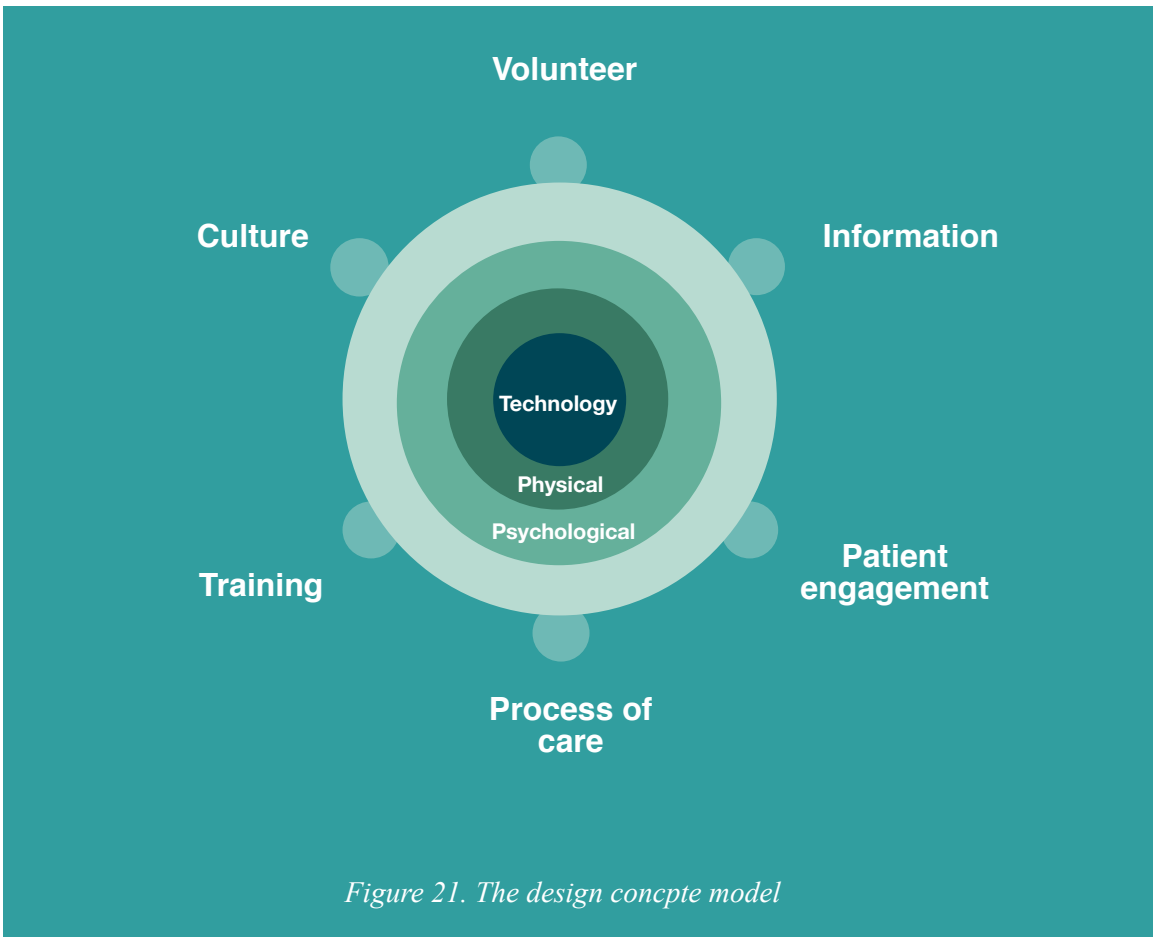


Figure 21. The design concpte model

7.1 Volunteer

This topic focuses on leveraging the power of volunteers, by sharing their experiences, providing support to help patients alleviate psychological anxiety and fear.

There are no organized volunteer teams in the FAHUSC's stoma-related departments now. In the interview with the therapist, it was found that success stories from other patients can encourage negative patients. In the case study, it was also found that letting other patients participate in the public affairs of the hospital is beneficial for better health outcomes. Therefore, other patients and families can be considered as volunteers.

For the content, it is divided into three levels. The first level is to provide supplementary assistance, such as providing transportation support like car sharing for patients living far away; and providing accommodation for patients' families, exchanged at low prices or organic products. The second level is direct communication with patients, such as encouraging patients who resist stoma, giving their confidence from their own stories; sharing useful information, nursing tips, and introducing appropriate job opportunities. The third level is about the organization and planning, such as organize the activities. These three levels increase the requirement of volunteer step by step. At the same time, the volunteer training methods can be diversified for different levels, and the same volunteer can participate in one or more levels according to the condition.

Related forms can be online information sharing, one-on-one exchanges, workshops, and so on.

7.2 Information

The focus of this topic is to transmit the condition, financial subsidy policy, insurance policy, doctor-patient communication, and different support information at different stages to the patient in the appropriate form and carrier at the required time.

For example, in the early stages of hospitalization, information such as policies, financial subsidies, and insurance claims are transmitted to patients through posters and some other materials, to alleviate the pain of patients who want to give up treatment because of the financial burden. For each publicity and education session, the therapist or nurse leads the patient study section by using the front bed screen or the care kit, which are more vivid than the general paper materials. However, it is still necessary to retain paper material for the patient or family member for review, as the bedside screen is not controlled by the patient. Patients who can use a smartphone can also review the knowledge through a smartphone-related application.

7.3 Patient engagement

Regarding the concept of patient engagement, different institutions and scholars have proposed different concepts at different times. The concept proposed by Carman et al. in 2013 is cited here.

"We define patient and family engagement as patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system—direct care, organizational design and governance, and policy making—to improve health and health care. Although
we use the term patient engagement for simplicity's sake, we recognize that those who engage and are engaged include patients, families, caregivers, and other consumers and citizens." (Carman et al., 2013).

The patient engagement framework summarized by Carman et al. (2013) was mainly discovered and studied, the details can be checked in figure 22.

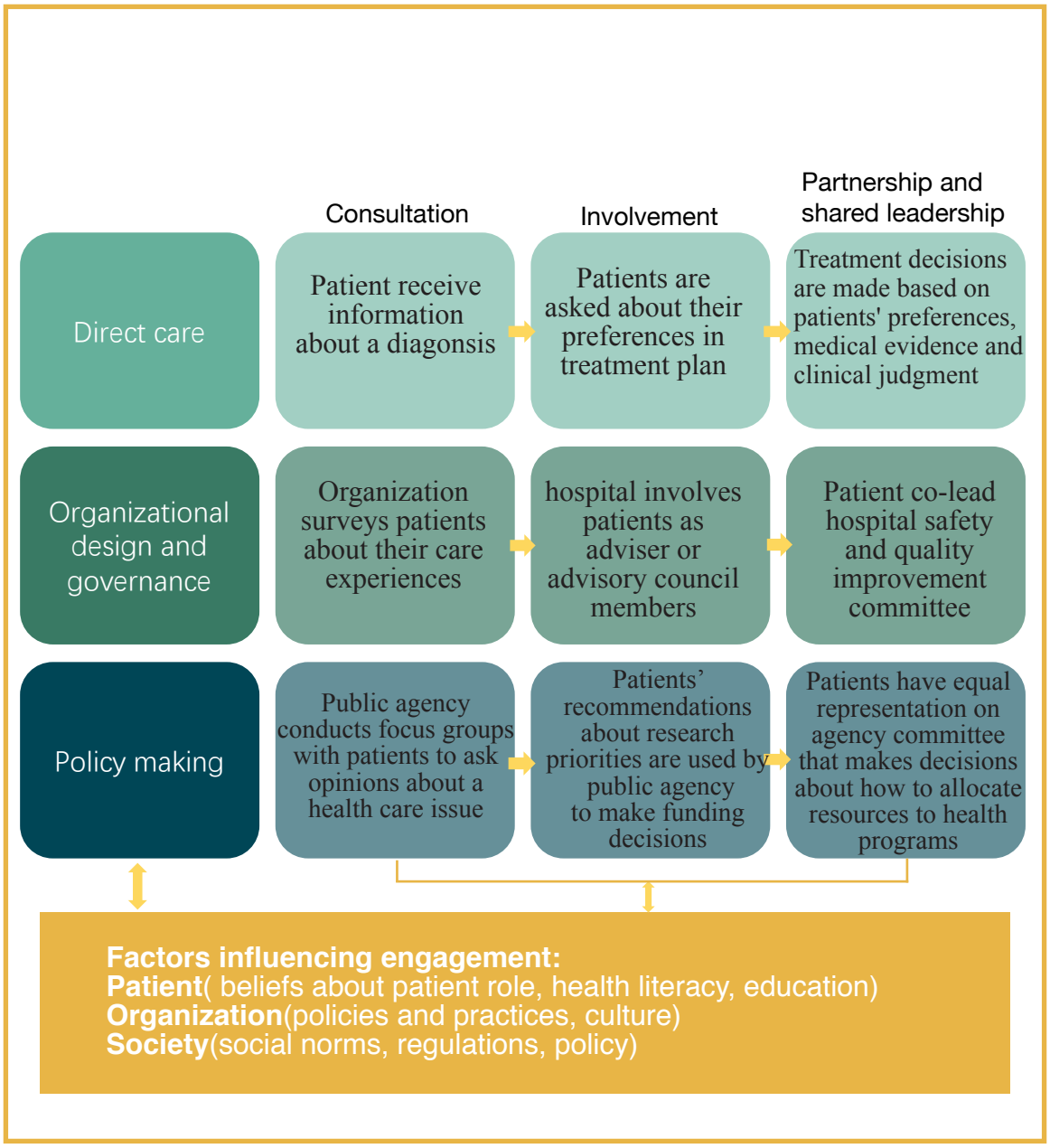


Figure 22. The patient engagement framework by Carman et al., 2013 (redraw by the author of this thesis)

They divided the levels of patient engagement into three, namely direct care, organizational design and governance, and policy making. In each level, three progressive relationships with the continuum of engagement as a clue were defined to be consultation, involvement, and partnership and shared leadership. It also summarized the three main factors that affect patient engagement, they were the patient's own beliefs about the patient's role, and health knowledge and education; the practice and culture at the organizational level; the norms laws and policy at the social level.

After understanding the concept and the basic framework, there was a preliminary search on how to measure patient engagement. It is recommended that the research team of Graffigna in Italy. They proposed the PHE model to measure patient engagement in 2015 (Graffigna, Barello, Bonanomi and Lozza, 2015). I chose it because, in 2017, a joint study between Hunan Xiangya Hospital and the Italy team showed that the model is equally applicable in China (Zhang et al., 2017). So, it can be used as a theoretical basis in subsequent project practice.

The design of this section is based on the patient engagement framework mentioned above. The purpose is to allow patients and their families to engaged in the healthcare process. Before the participation, the patient's engagement level can be measured first, and then the plan is based on the actual situation of the patient.

The contents summarized according to the patient engagement framework of Carman et al. are as followed figure 23. According to the factors affecting patient engagement in the framework, the basis of patient engagement in China is not well-developed, from the research in China (Hou, Xu, Zhou, Lu and Pang, 2014), for some patients, the family's excessive participation is not what the patient wants. So, the patient engagement here is more focused on direct care and organizational levels, while higher level needs to be developed gradually.

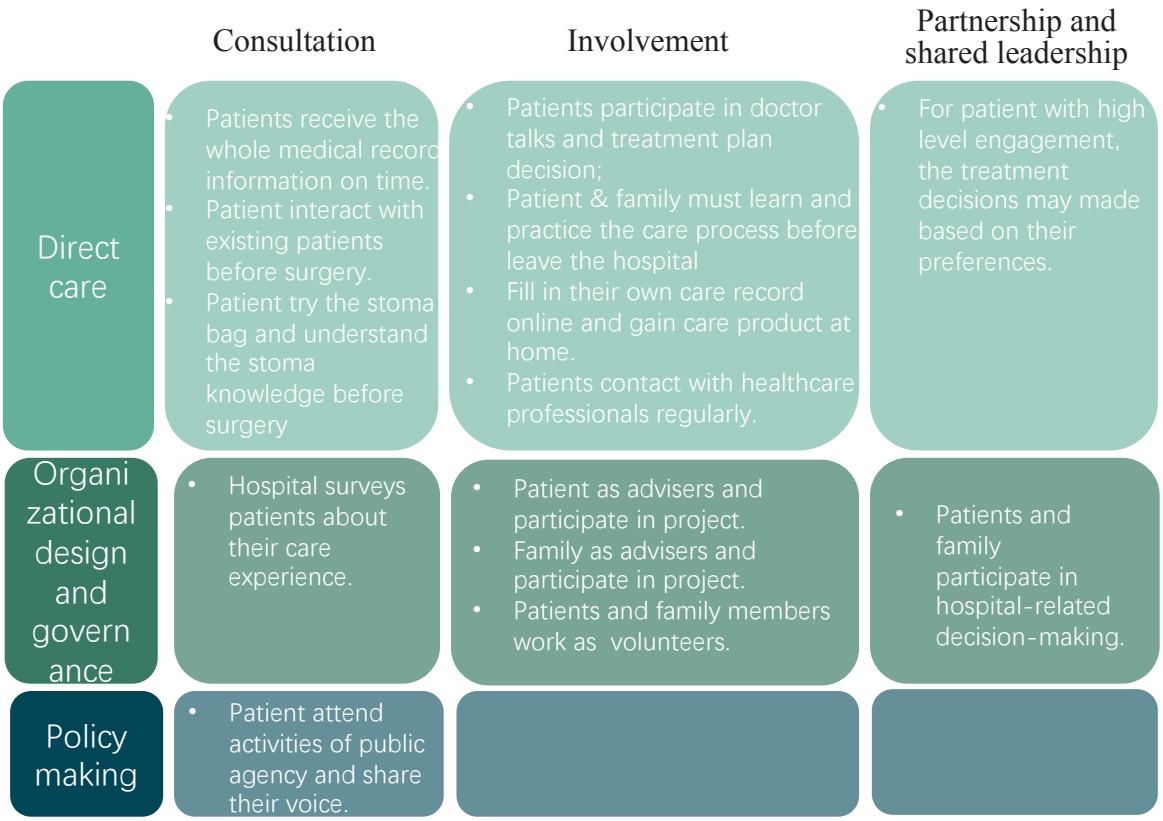


Figure 23. The develpment suggestion based on patient engagement framework

At the level of direct care, depending on the degree of patient engagement, it is possible to understand the condition and try to learn stoma knowledge in the consulting stage. Patients who engaged in second stage will participate in various doctors' conversations to discuss treatment options. At the highest stage, patients can determine their own treatment preferences.

At the organizational design and management method level, the first stage is the hospital's research of the patient's medical experience, the second stage is the involved stage, the patient and the family can participate as relevant consultants or volunteers, and the third stage is the patient and family can participate in hospital-related decisions.

Regarding policy development, I suggest that patients and their families do not have to participate in too many parts as it is need time to make the transition. Therefore, the first stage is the main stage, that is, patients and their families can participate in the activities of public institutions and share their suggestions.

7.4 Process of care

From the perspective of care process, it is hoped to establish a standardized stoma care process within hospitals at all levels, optimize the process of patient and family nursing learning and the referral process between different hospitals.

The topic is also divided into two parts: central hospitals and community hospitals.

For central hospital

Within the central hospital, first of all, strengthen the standard process of stoma care in the hospital, and then provide the nursing teaching video for the patient and the family on the online platform. It is better to assess the patient and family care level according to the actual situation, for example, the care knowledge and practice of the patient and the family may be successfully demonstrated before being discharged from the hospital. For the outside, the central hospital leads the practice in the regional collaborative care alliance, by establishing a standard process for receiving referrals from lower-level hospitals, and managing the therapists go to community hospitals regularly for consultation, lectures, and online Q&A.

For community hospital

For the community hospitals, the standard process for community hospital stoma care should be established. Outside the community hospital, the hospital should actively participate in regional collaborative care alliance, organizing community care activities, and establishing a comprehensive referral process with higher-level hospitals.

7.5 Training

This topic focuses on the training of stoma nursing staff at all levels of hospitals, as well as doctor-patient communication training.

It is divided into two parts: central hospital and community hospital.

For central hospital

In the central hospital, in addition to training therapist, nurses who know more about stoma care should be trained in relevant departments such as gastrointestinal surgery and urology; it is also important to improve communication between surgeon and therapist and find ways to collaborate on stoma positioning. The forms can be workshops, role-playing, presentations, group discussions, case study sharing and so on.

For community hospital

In community hospitals, helping community nurses to define the path of career development, and allowing nurses who are willing to do stoma care to learn stoma nursing courses through practice ways online and offline. For example, in addition to basic course materials, there are online Q&A sessions every week and the therapist regularly goes to the community for guidance. When a community nurse reaches a certain level, he or she can receive a medal or certificate reward.

7.6 Culture

This aspect is mainly about the malformed relationship between doctors and nurses, in the doctor-patient communication and medical triage system caused by cultural concepts. For example, some doctors do not pay attention to the work of nurses and there is also central hospital superstition among some patients.

On the issue of healthcare collaboration, these ways can be tried to provide opportunities for nurses and doctors to communicate: organize medical staff collaboration seminars regularly, and record work videos and play them in the workshop (Grant & Colello, 2007).

As for the doctor-patient communication, doctors and nurses can experience the daily life of the patient; it is also can be improved through the exchange of the patient diary - Doctor Diary - Nurse Diary.

On the issue of the triage system, it is still necessary to rely on the implementation of policies at the national level. Before there is any substantial change, it can be considered providing the patient with subsidies who is willing to transfer to other hospitals that can also solve the problem.

7.7 Design output recommendations

Based on this design concept model, the possible form and content of the final design output are introduced below.The output was divided into four parts.

Online platform

First, the online platform based on the company's existing software and hardware, including mobile phone applications as a patient touchpoint, nurse-side handheld pad application, stoma wound online community.

Implementation manual

The second part, various types of implementation manuals, such as standard process manuals for different levels of hospitals, process manuals for referrals.

Guidebook and kit

The third part is a guidebook and supporting kits for designing various activities mentioned in the concept model such as workshops and community activities.

New organization

The fourth part, new organizations, such as patient advisory organizations, patient family advisory organizations, patient volunteer organizations, patient committees and medical care research groups.

8

Design for information aspect

8.1 Design content

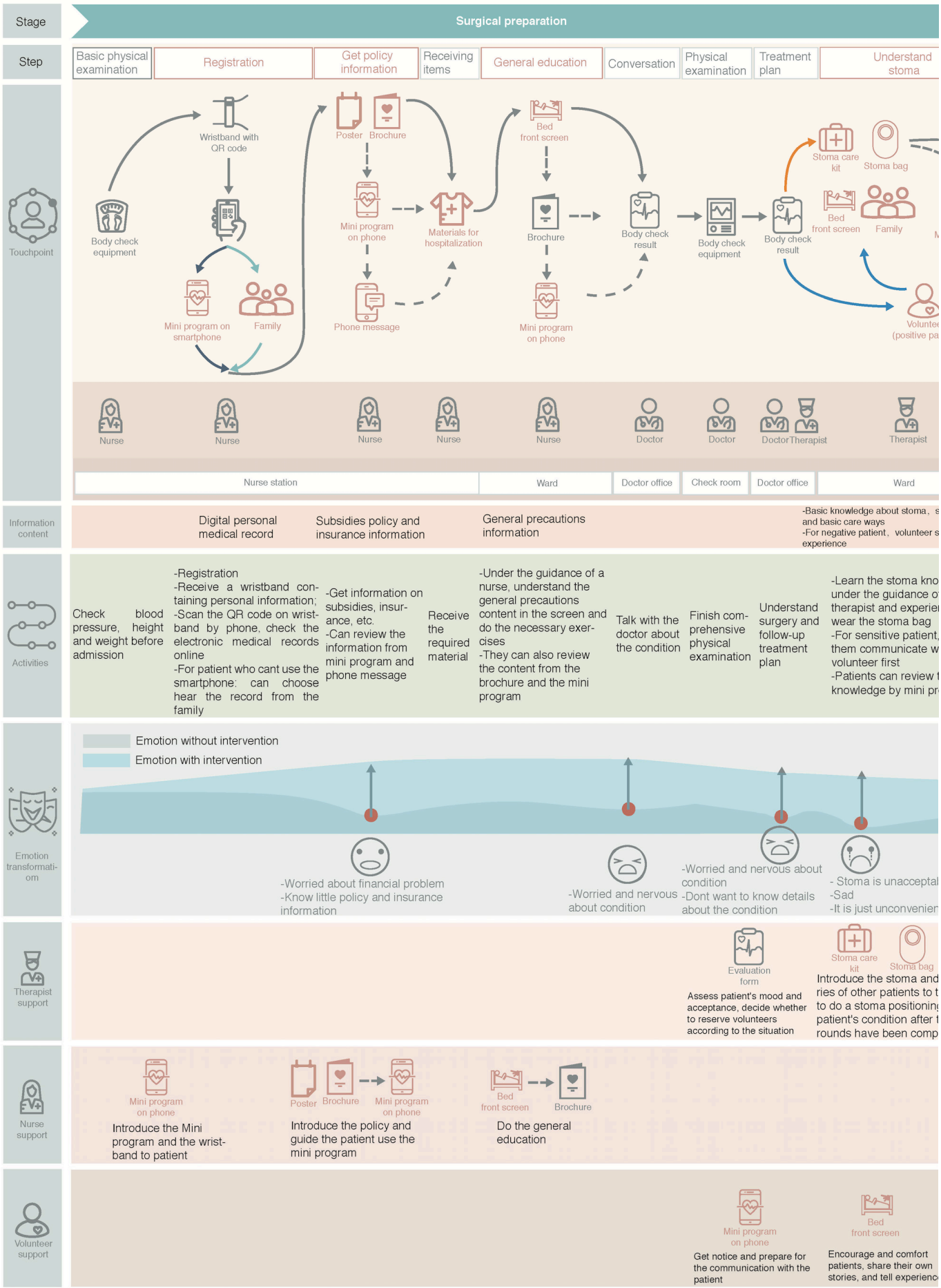
After completing the design concept model, I communicated with the company's project team and selected the priority direction based on feasibility and overall project schedule together. Finally, the design direction of the information is selected, that is, the information required by the patient and the family is intervened and transmitted in the correct form at an appropriate period.

The design content of this stage includes the user journey map redesign, the system map design, the touchpoint analysis, and the touchpoint design.

8.1.1 Journey map redesign

Based on the user classification, I redesigned the journey map for different types of patients, because different types of patients behave the same in some parts in the journey, so put them in the same map.

Journey map of patient with stoma

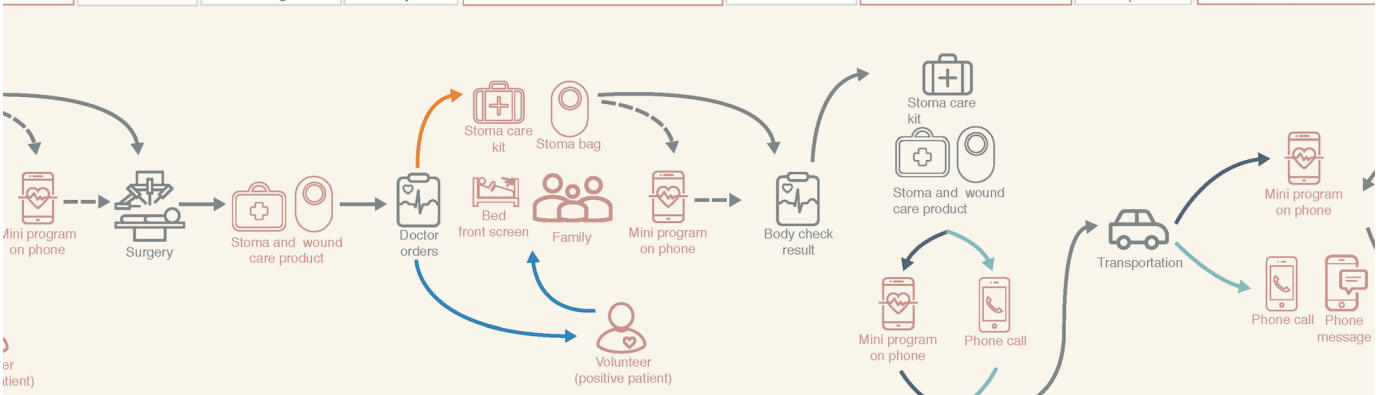


Emergency surgery patients start from here

Some patients may give up chemotherapy

Surgery | **Recovery**

	Surgery	Change dressing /stoma bag	Postoperative recovery	Learn stoma care	Evaluation	Leave preparation	Leave hospital	Reservation reminder



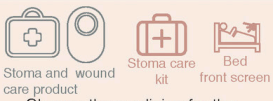
	Doctor Nurse	Therapist	Therapist	DoctorTherapist	DoctorTherapist
	Surgery room	Ward			
such as what is stoma successful stories and		Stoma care knowledge and how to use related products	Stoma care knowledge and how to use related products		Review and Chemotherpy geestion and reminde info
wledge f the nce to let ith the ogram	Surgery	Cooperate with therapist to care the wound and stoma	Perform doctor's orders, such as completing a movement	-Learn the stoma care knowledge under the guidance of the therapist, the one who with better state can try to change the stoma bag by himself -They can review the knowledge from mini program or kit -For sensitve patient, let them communicate with volunteer first	Accept physical condition assessment	-Get different notes for different phases and listen to notes explained by therapist -Choose different contact way(mini program or phone call) according to the patient	Leave hospital	Get review/chemotherapy reservation reminder and appointment options

- Stoma is unacceptable
-Sad
-It is just unconvenient

- Stoma is unacceptable
-There is no opportunity to practice stoma care
-Just family learn the care knowledge

- Scared
- There is no enoug

Bed front screen
successful stoe patient, and try based on the e doctor's eted.



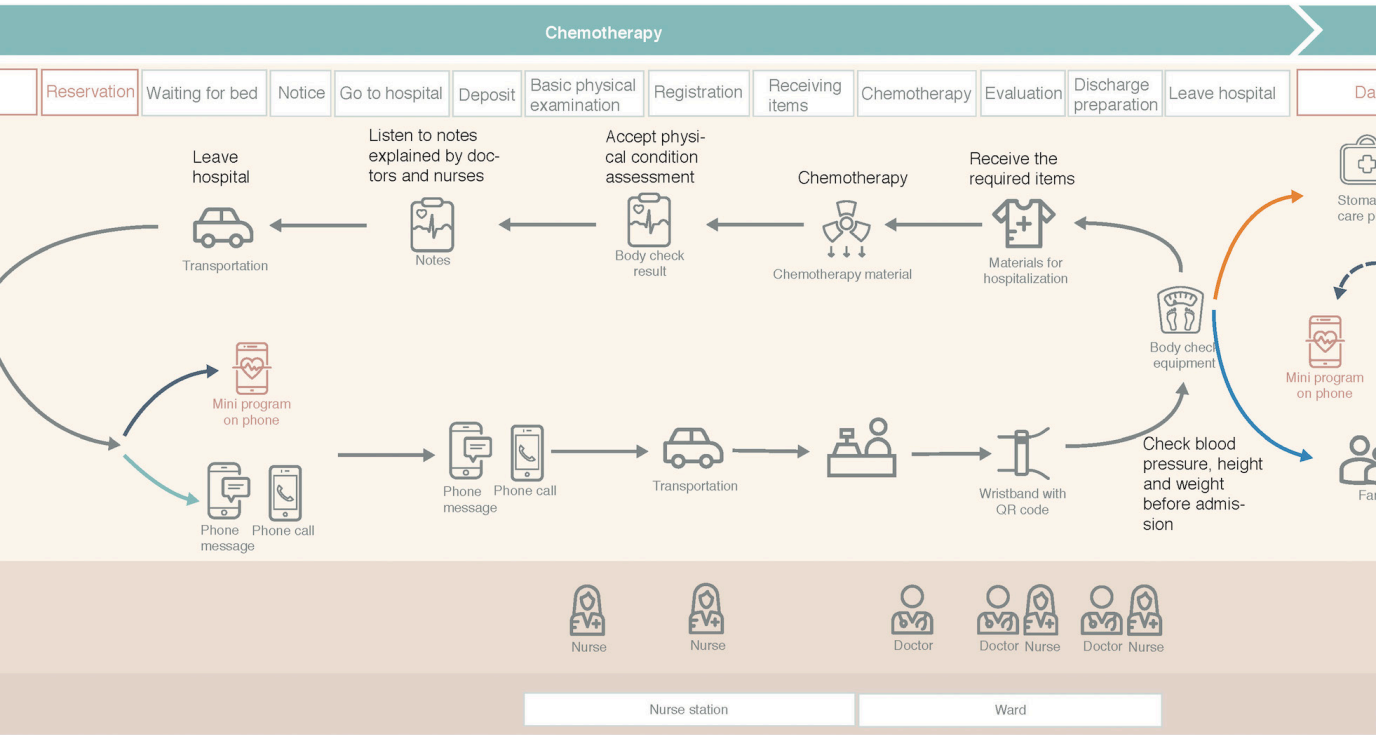
Change the medicine for the patient, take care of the stoma, replace the stoma bag, and teach the patient care method.

Explain the post-discharge considerations; guide the patient contact with therapist online

Bed front screen

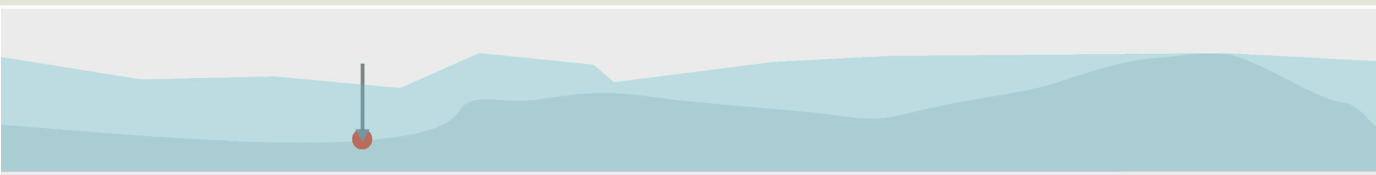
Encourage and comfort patients, share their own stories, and tell experiences.

s.



sug- Reservation aviliable choice
rmation information

er-	Make a chemotherapy appointment through different ways	Wait the bed of ward	Receive the hospital notice to prepare for hospitalization	Go to hospital	Pay the deposit	Complete the registration at the nurse's station and receive a wristband containing personal information	-Stoma care and bag -For positive pat practice do it by can review the k mini program, t learn it from thei cant use smartp -For some negat guide them by th



h money

- Is there any bed or how many days I need wait for

- Dont know ho stoma
-Nervous

Care the stoma of patients;
solve the stoma related problems

Explain the post-discharge considerations

Prepare docu project,such a education vide cles.

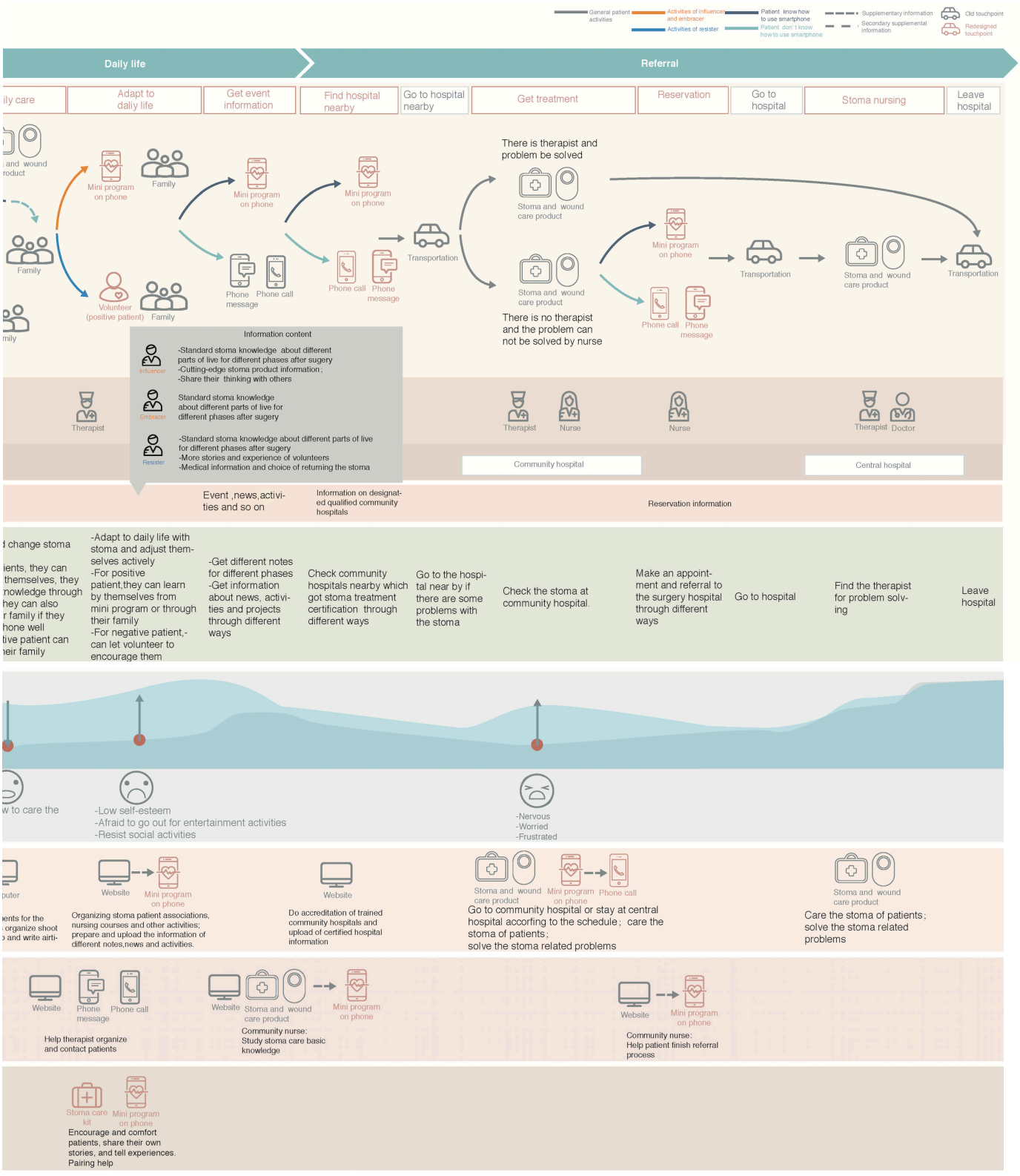


Figure 24. The redesigned journey map

The journey is also divided into six stages: surgical preparation, surgery, postoperative recovery, chemotherapy, daily life, and referral. Some of the emergency surgery patients start to enter the service from the surgery, some patients do not need chemotherapy, and there is no strict temporal relationship between daily life and referrals.

Then each row goes down to the patient's activity, the corresponding touchpoint, the information content transmitted, the space where the activity occurs, and then the patient's emotional changes, including comparison before and after design intervention, it is followed by the activities of the therapists, nurses and community nurses who provide services.

In the touchpoint phase, different arrows are used to indicate different paths. Gray arrows indicate general paths. The gray small gap dotted arrows indicate the way to supplement the information in the activity. For example, after the patient has learned the relevant knowledge through the therapist, the patients still want to review it, then the user can do it by reading the brochure. The gray large gap dotted arrows indicate the secondary information supplement in the activity. For example, after the patient reviews knowledge through the brochure, he or she also wants to expand the learning, so the patient can learn according to the database in the mobile application. The orange arrows represent the path of the active and generally level patients in the patient category mentioned above, and the blue arrows represent the path of the negative patient. According to the data in the user research, the age of the stoma patients is concentrated in the 61-70 age group, and there are also older patients. In the interview, some patients mentioned that they would not use a smartphone. So, the dark green arrows represent the path of a patient who is using a smartphone or related electronic device, and the light green arrows represent the path of a patient who cannot use a smartphone or related electronic device.

Next, the contents of the journey map are introduced in chronological order.

Surgical preparation

The first stage is the surgical preparation period. This phase mainly includes the following changes. First, the patient will receive a wristband containing personal information when they are admitted to the hospital. The patient can scan the QR code on the wristband through WeChat to log in the Mini program (It is Similar to the form of smartphone software and used as the information carrier of the patient in this design. The specific content will be introduced in the subsequent touchpoint design phase) for viewing their medical records, or to learn about financial subsidies and insurance. Second, when the patient talks with the doctor, the doctor will evaluate the patient's mental state. If the patient is optimistic, he or she will directly receive the stoma therapist's education on the basic knowledge of stoma; If the patient is negative, the doctor will contact the volunteer, and the volunteer will psychologically appease the patient by sharing the experiences and telling own inspirational stories. Third, a new bedside screen has been added to broadcast volunteers' motivational stories and basic knowledge of stoma, and the intervention of stoma care kits has been moved to the preoperative preparation stage, which will help patients to accept the stoma better.

Surgery

The second stage is surgery, which requires little patient initiative.

Recovery

The third stage is the postoperative recovery period. Changes at this stage have focused on post-operative stoma care, including patient self-learning and family learning. The stoma therapist will teach stoma care through practice, and patients and their families can also choose the way they like to learn more in the bed video, mobile phone software, brochures and other ways. For more negative patients and their families, volunteers will also intervene in the process. When the patient is discharged from the hospital, the stoma therapist will confirm the future contact method with the patient according to the patient's acceptance of the electronic product. The options are mobile communication software, mobile phone/telephone call, and mobile phone message.

Chemotherapy

The fourth stage is the chemotherapy stage. When the scheduled chemotherapy date is approaching, the patient will receive a chemotherapy reminder sent by the hospital through a specific channel according to the previous selection as mentioned above. The patient then makes a chemotherapy appointment and can obtain a specific bed waiting time to reduce the negative emotions caused by unknown waiting.

Daily life

The fifth stage is the daily life of the patient. At this stage, patients are encouraged to perform stoma care by themselves. Patients who can use electronic products can consolidate their stoma care knowledge through mobile phone software and other channels. Patients who are not familiar with electronic products can operate through their families. The main difference at this stage is the daily information that the patient receives, which are differentiated according to the three types of patients. For active patients, provide them more information on advanced products, help them to research some care tips, and provide a platform for them to share the experience. For patients in general mental level, provide standardized nursing knowledge, as well as activities such as stoma patient social meeting to help them become more active in social life. For passive patients, increase the frequency of sending volunteer stories and experiences; and provide them more medical possibilities for stoma return, such as advanced treatment techniques in more advanced hospitals for their reference. All patients will receive standard stoma care knowledge.

Referral

The sixth stage is referral. When there is a problem with the patient's stoma, the patient can go to the community hospital with the stoma care qualification and nearest to their home. If it is not an emergency, the patient can also wait for the therapist to go to the community for treatment. The appointment can be made in the way that the patient can use skillfully as above. If the community hospital cannot solve the problem and the patient needs to be referred, the community hospital will also assist the patient to make an appointment for the hospital that will receive the patient.

For the redesign of this journey map, the corresponding system map was also defined. The system map with the flows of fund, information and materials, including the patient, the patient's family, the therapist, the doctor, the community nurse, and the stoma product company, is shown in the following figure.

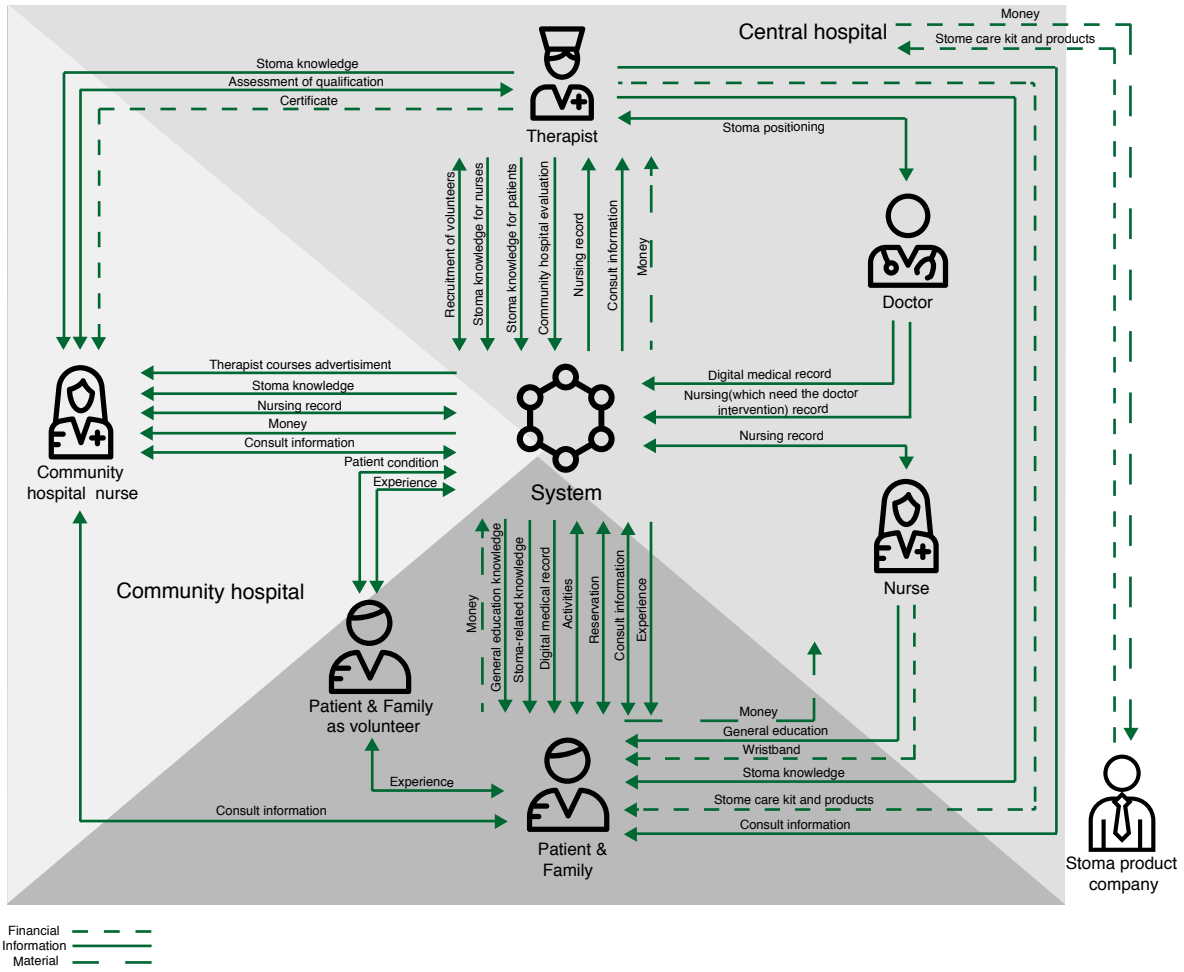


Figure 25. The system map

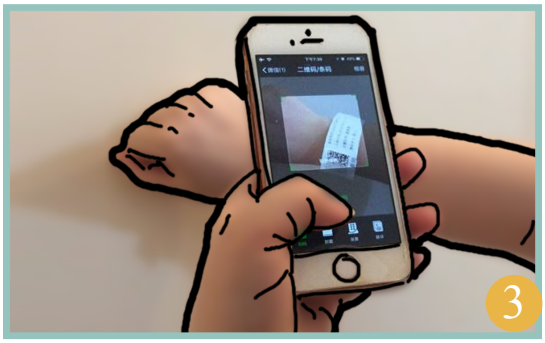
8.1.2 Touchpoint design

This section describes the design of the software program for the patient.

Regarding software program, WeChat, an online chat platform with more than 1 billion users in China is used as a carrier (WeChat, n.d.). Because WeChat's newly developed Mini Program in the system can work as a software application, opened by scanning the QR code without downloading software, which saving patients' time and reducing the cost of use. The specific scenario is shown in the figure 26. When the patient starts the hospitalization period, the patient will get a special wristband with a QR code. Using WeChat to scan the QR code, the patient can open the Mini Program directly without downloading. This technology has been widely used in China.

Finish the basic body exam and get wristband with personal information and QR code.

Open Wechat on smartphone and find the scan function.If the patient can not use smartphone, can be helped by the family.



Use the scan function of Wechat scan the QR code on wristband, then the patient can use the Mini program without log in again.

Check the information on Mini program, such as medical record and insurance information.

Figure 26. The storyboard

The Mini program is divided into five modules, namely today's reminder, reservation, community, database and personal page.

Figure 27. The Mini program interface - the introduction of five modules

Today's reminder is based on the postoperative time of the patient to determine the appropriate and unsuitable behavior of the patient on the day, and whether there is a need to replace the stoma bag on the day, there is also a link to the video for teaching stoma bag replacement. Patients do not have to worry about forgetting something which helps them reduce their psychological burden. Patients can also choose to delve into the reasons behind these recommended behaviors if they want to understand.

Figure 28. The Mini program interface - today's reminder

Reservation is divided into four categories, namely community hospital care reservation, central hospital review reservation, chemotherapy reservation, and online consultation reservation.

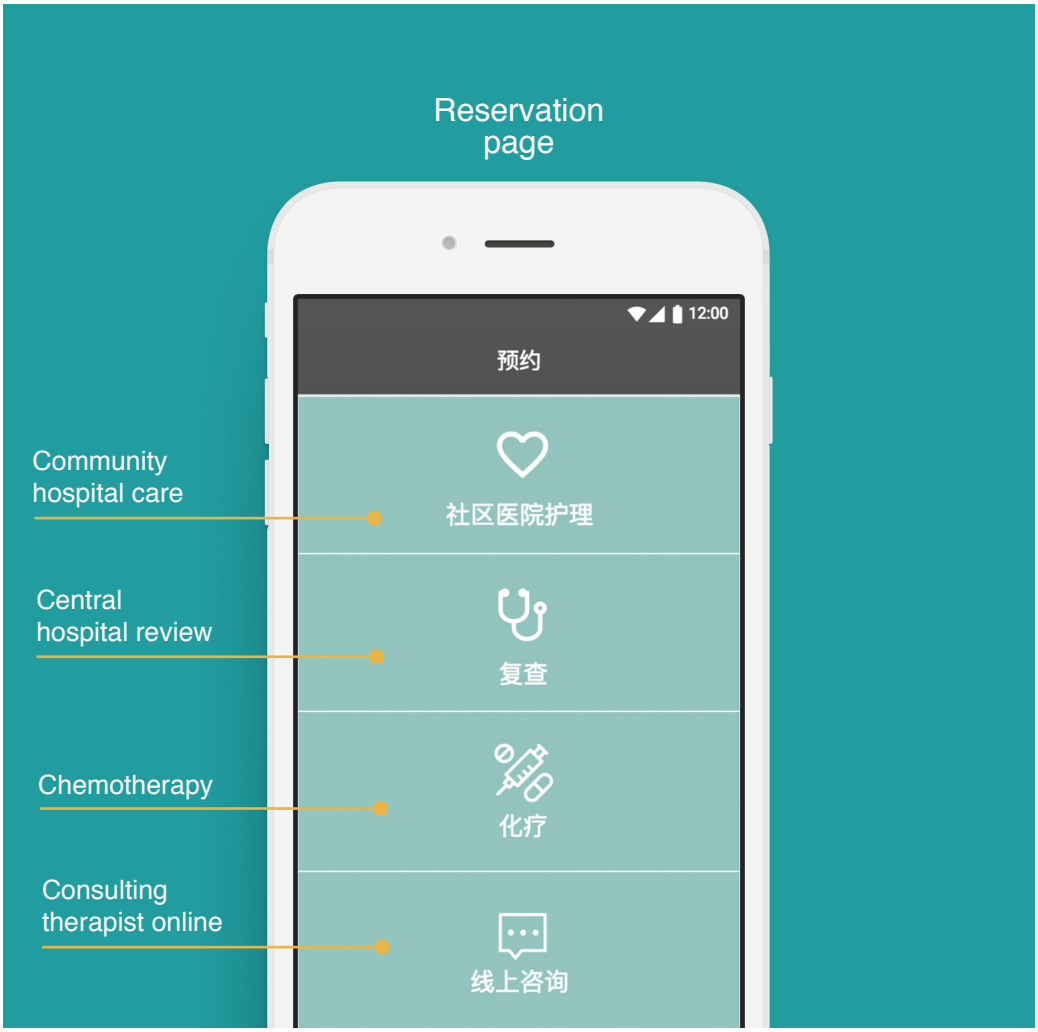
The community hospital reservation will display the qualified designated hospital nearest to the patient and the patient can make an appointment based on the time period.

The central hospital review reservation gives priority to the patient's surgical hospital, while patients can also search for other hospitals, and the patient can make an appointment based on the choice of time or doctor.

Because chemotherapy involves hospitalization, it can't immediately show that the reservation is successful. However, it helps the patient to send a reservation request, and it will show the expected waiting time, which can reduce the patient's waiting anxiety.

Online consultation is also divided into live chat and message, support for voice and send video or picture.

Figure 29. The Mini program interface - reservation



The community page mainly sends information such as social activities, volunteer stories sharing, articles from doctor and therapist. Patients can sign up directly to participate in activities or collect favorite articles and communicate with authors.

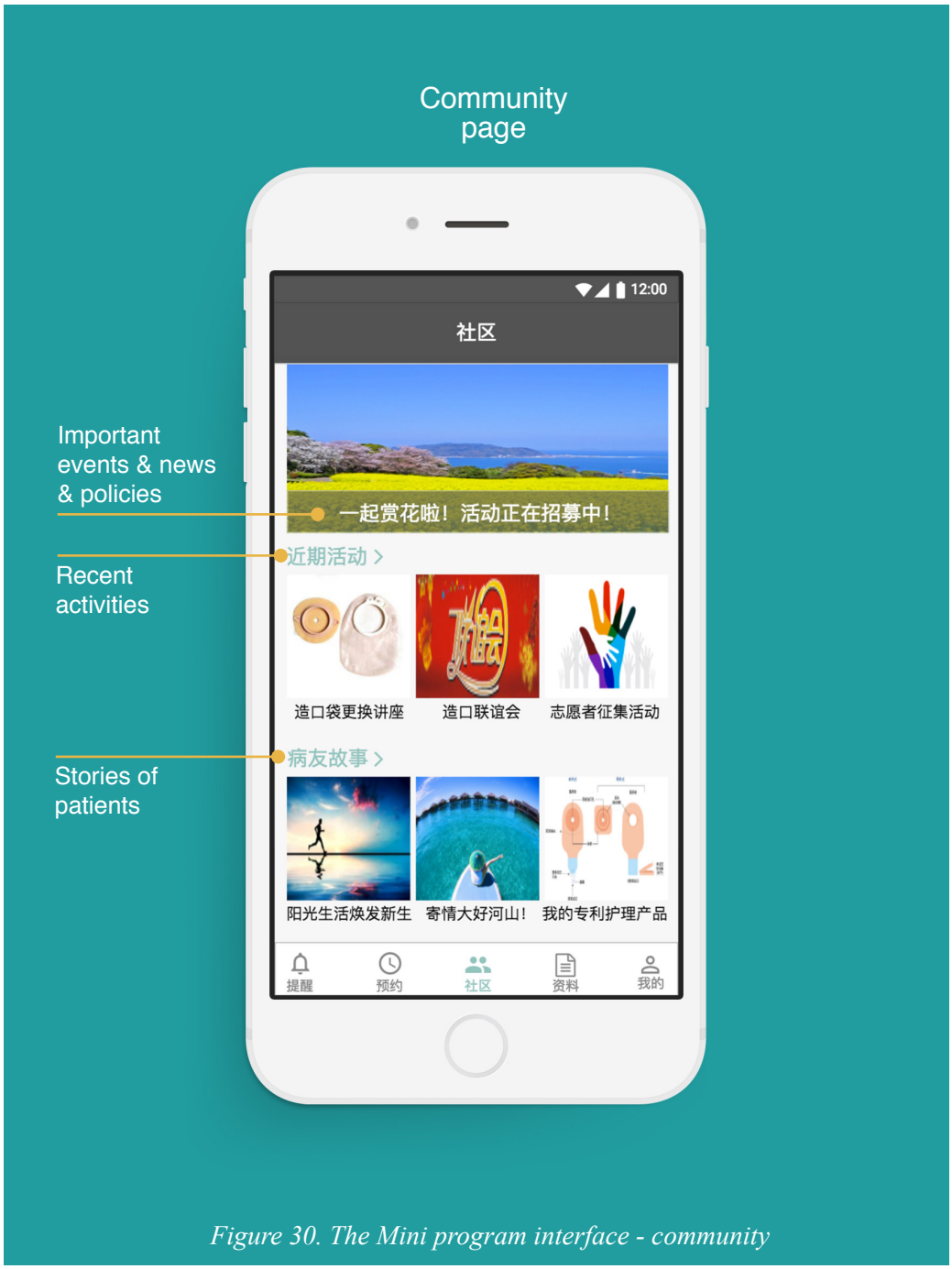


Figure 30. The Mini program interface - community

The database includes all stoma knowledge and financial-related policies for patients who want to know.

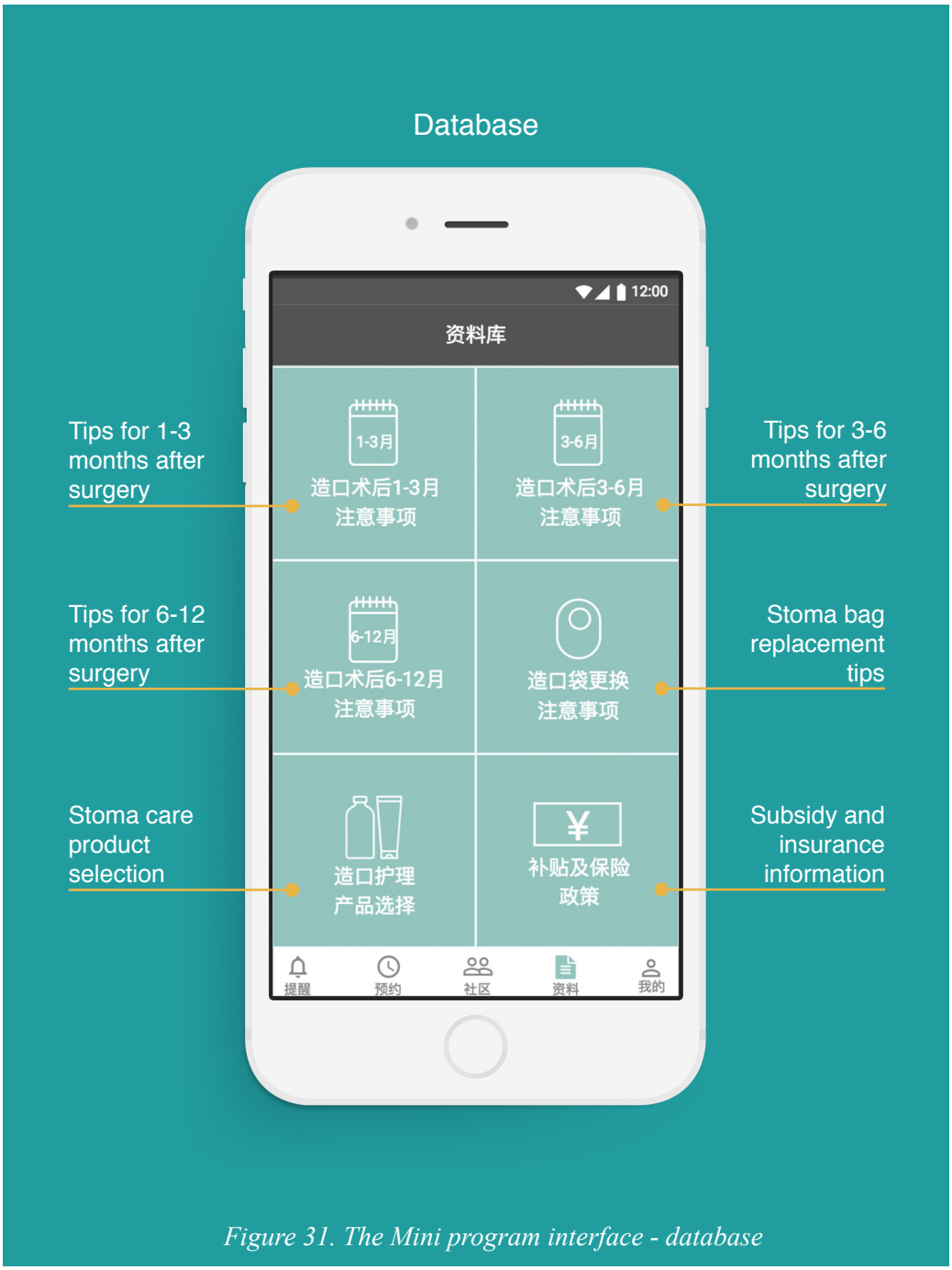


Figure 31. The Mini program interface - database

There are patient's medical records, collections, and volunteers and healthcare workers followed by the patient in personal page. The medical record is convenient for medical treatment and online consultation. Following users in the profile can make it easier for patients to communicate with other users online.

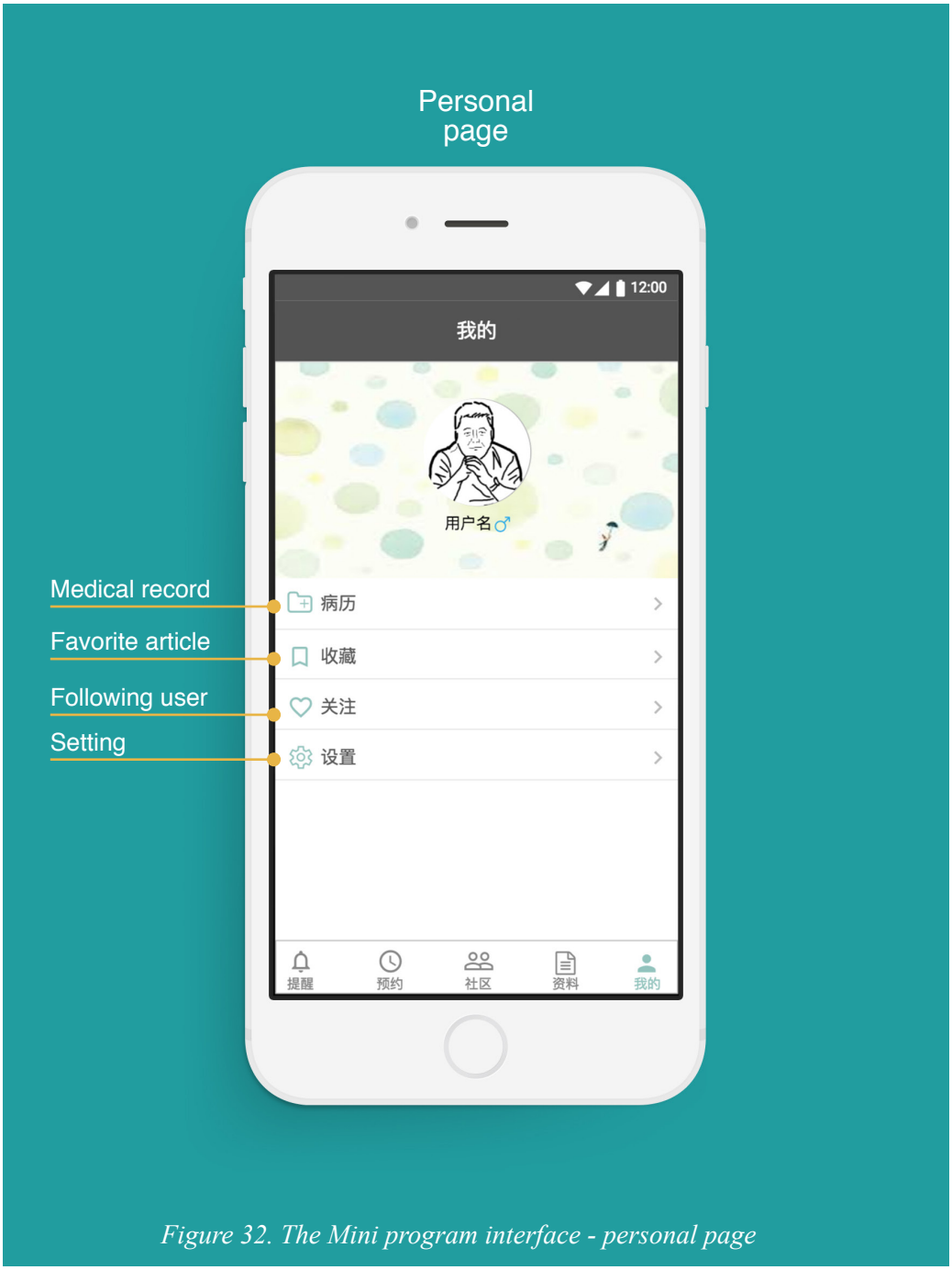


Figure 32. The Mini program interface - personal page

For the payment function, the payment system that comes with WeChat will be used. Regarding the color, the soothing green is selected; the font size is also large, which is convenient for the elderly people.

Considering some elderly people are unable to complete the above operations, the operation can be completed with the help of their families, or they can use alternatives such as WeChat, mobile phone calls, and mobile phone messages which are expressed in the redesigned journey map.

8.2 Prototype

In the prototype stage, an interactive prototype based on the Mini program interface was created, and the card for obtaining the style preference of the paper materials such as posters will send to the central hospital for testing. By the time of the thesis finished, the prototype and test methods have been produced, and the company had no time to implement the field tests, but it is on the agenda.

8.2.1 Prototype making

Based on the Mini program interface, some pages that can be clicked and interacted are created. Since click once can reflect the function, only one clickable place created for the different content of one single function, for example, in a list containing multiple articles, only the first article can be clicked.

About obtaining styles preferences for paper materials such as posters, different styles pictures such as comics, text descriptions, photos, and line drawings, were selected to allow patients understand the meaning of the problem visually.

The questions inside the card are these two:

1. Now the nurse is going to provide you with surgery education, in the following forms, what is your preference order? Please sort the following according to your preference (1 is favorite, 4 means least liked).

Comic; text; physical picture; description of painting; other (if any, please add)

2. Now the nurse is going to provide you with surgery education. In the following carriers, what is your preference order? Please sort the following according to your preference (1 favorite, 4 least liked).

Paper brochure; static picture on tablet; video on tablet; oral presentation by nurse; other (if any, please add)

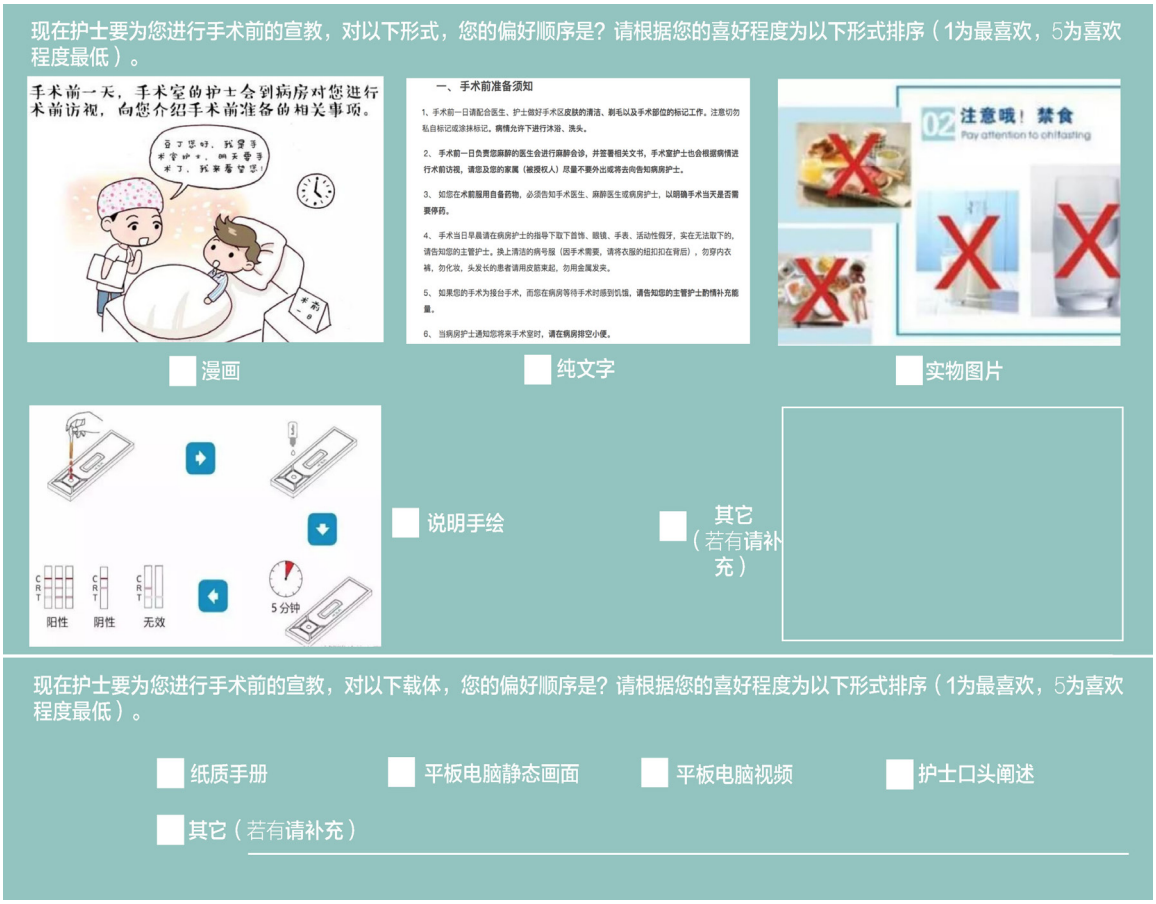


Figure 33. The prototype test card

8.2.2 Prototype test plan

For Mini program test, I set different tasks according to different test objects, for understanding the usability of the Mini program.

Tasks settings are based on the different phases of the patient, simulating the scenarios in which they need to use the Mini program, and recording the time and difficulty they need to complete the task. For example, for patients before surgery, patients can be asked to find the financial subsidy knowledge in the Mini program.

Through the time of finishing task, performance and questions of the patient, the usability can be understood.

For the testing of material styles and carrier preferences, face-to-face interviews will be used to present the cards to the patient.

Note：There are different tasks for different stage users. If there is any doubt or difficulty in understanding the prototype, don't tell the answer first but ask the user's thoughts first. After the users completes the task, we can let them explore the prototype and give suggestions.

User	Task
Patient before surgery	1. Find and read the article written by other patient and follow the patient. 2. Find the subsidy policy and insurance section. 3. Find the video of the stoma bag replacement.
Patients who have not been discharged after surgery	1. Find and read the article written by other patient and follow the patient. 2. Find the video of the stoma bag replacement.
Chemotherapy patient	1. Fina and read today's reminder. 2. Make an appointment for chemotherapy; review; community hospital care; online consultation. 3. Find the corresponding stoma knowledge section according to their postoperative time period (such as 1-3 months, 3 months-6 months). 4. Sign up for one offline activity. 5, Find and read the medical records.

Table 7. The prototype test task

9 Conclusion

I participated in this project for three months, completed user research, insights development, preliminary design opportunities, case studies, design concept development, and design development.

Through the understanding and analysis of the development of stoma care in the world and in China, the development and trend analysis of service design in the healthcare field, and the user data obtained in the user research, the importance of community hospitals in the whole nursing process is understood.

The needs of stoma patients in continuous care from different levels was clarified, and a design model that gives patients physiological and psychological support from the six aspects of volunteer, information, patient engagement, process of care, training, and culture was established. Moreover, the information aspect in it was designed, the patient's journey was redesigned during the design process, prototype included two parts was also sent to the company waiting for implementation.

9.1 Strengths

The project combines the central hospital in the southern part of Hunan Province, China and a company with the foundation in the field of smart care. There is a rich practical foundation and technical support. The theory and practice of service design have been employed for the design of the regional collaborative care for stoma patients, in which the patient's medical treatment and follow-up care experience will be regarded as a complete process, from the pre-hospital preparation to the daily life after discharging. It is conducive for providing patients with a full range of continuous care, solving the patient problems and improving patient experience.

9.2 Limitations

The limitations of this project are mainly reflected in the following aspects.

First, the selection of interview patients during the user research. Patient interviews have not been exposed to patients who have been treated for one year or more due to patient fit and physical reasons. Although patients at this stage are theoretically accustomed to postoperative life, the types of needs may be reduced, but still, limited the understanding of patients.

Second, the backstage design of the user's new journey in the design phase. There is no specific design for the backstage operation that support the user journey, such as business processes within the hospital, evaluation criteria, and employee manuals.

Third, the psychological support for the patient during the design phase is slightly weak.

9.3 Future research

About future research, the team can continue to develop the model of the design concept, deepen the design of the information aspect, and carry out the design of the other five aspects according to the actual situation. The intervention in psychological support can also be strengthened.

LIST OF FIGURES

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