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Rituals.

Balanced Care Centre.

**The Design of a Support System for
Shanghainese Family Caregivers**

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ABSTRACT

L'aspettativa di vita si alza in tutto il mondo, il tasso di natalità diminuisce e nel frattempo i tassi delle malattie croniche e non trasmissibili aumentano drasticamente. C'è un crescente bisogno per pazienti di ricevere cure nell'ambito dei loro trattamenti. Di solito tale ruolo ricade sulle spalle dei familiari che si trovano in un ruolo totalmente nuovo, com'era prevedibile oppure no. Tuttavia, la figura di un badante implica molteplici responsabilità per cui la gente non è preparata. Inoltre tutta la situazione ha un impatto sulla loro vita privata perché gli ordini precedenti soffrono i cambiamenti imprevisti. E di conseguenza, i caregiver familiari sono sottoposti a grandi oneri fisici, emozionali e finanziari, diventano le vittime di circostanze e hanno bisogno di assistenza. In particolare i caregiver familiari cinesi tendono a immergere nel ruolo del badante totalmente a causa del confucianesimo e la pietà filiale. Oltre le responsabilità culturali, i badanti cinesi sono legalmente obbligati a prendersi cura dei loro familiari malati. Considerato questo il problema dei caregiver familiari debba essere affrontato con urgenza.

Il governo cinese riconosce il problema complesso del sistema sanitario come per

esempio i meccanismi disintegrati, mancanza della comunicazione fra gli operatori sanitari, scarsità di servizi, risorse umane certificate e tre classi degli ospedali. Molteplici obiettivi sono stati fissati nella strategia Healthy China 2030 e tra di loro il principio dell'orientamento all'utente. Nonostante la strategia non menziona gli interventi pianificati per i caregiver familiari, il governo identifica questa categoria della gente come un target. In tal modo occorre un'esigenza rigorosa dell'intervento per sostenere i caregiver familiari.

Nell'ambito di questo progetto sono state condotte vaste ricerche documentali e sul campo. La struttura di progettazione del sistema di servizi scelta ha facilitato la scoperta delle questioni intrinseche del sistema sanitario, i caregiver familiari e il nutrimento potenziale per l'intervento di design. Di conseguenza dopo lo sviluppo del progetto partecipativo che ha implicato i rappresentanti molteplici dei sistemi sanitari e i caregiver familiari, sono stati identificati molteplici problemi come la mancanza del sapere come fornire aiuto, il bisogno del sostegno reciproco e le attività, la vita sociale e il riconoscimento sociale. Come risultato nasce un progetto

del sistema di servizio L'idea mostra come i caregiver familiari shanghaiensi possono essere supportati tramite frequentare un'organizzazione che fornisce il sapere medico e le attività ed edifica la comunità. Il progetto nutre il potenziale della gente in quartieri come i volontari L'organizzazione crea uno spazio per la gente per incontrarsi e costruire le relazioni fiduciosi, rafforza la resilienza delle comunità. Queste azioni saranno il primo passo di un progetto a lungo termine grazie al quale la gente potrà supportare i badanti basandosi sui rapporti consolidati. Inoltre dato i prerequisiti cinesi del sacrificio e la pietà filiale il progetto mira ad aumentare la consapevolezza di importanza dell'equilibratura del ruolo di una persona come un badante e un individuo perché la qualità dell'assistenza prestata dipende direttamente sulla qualità di vita di un individuo. Riflessivamente i concetti dei rituali, equilibrio e umanità servono come dorsale del service idea. Inoltre essi rappresentano i valori confuciani. E come risultato viene proposto il "Rituals. Balanced Care centre" che potrebbe essere una delle cantene all'interno della stringa di interventi necessari nel sistema sanitario cinese.



ABSTRACT

Worldwide, people's life expectancy rises, the birth rate decreases, while the rate of chronic, non-communicable diseases dramatically boosts. There is an increasing need for patients to receive care within their treatments. Usually, this role falls on family members, who find themselves having a new role either predictably or not. They become family caregivers.

The caregivers' figure implies multiple duties, for which people are unprepared; besides, the entire situation impacts their personal lives because the previous orders suffer unforeseen changes. As a result, family caregivers undergo vast physical, emotional, financial burdens, become victims of circumstances, and need assistance. Specifically in China, given the Confucianist values such as filial piety, family caregivers tend to immerse into the caregiving role fully. Besides cultural duties, Chinese caregivers are legally obliged to care for their sick family members. Given this, the function of family caregivers needs to be urgently addressed.

Chinese Government points out the complex problems of its healthcare system. It suffers from disintegrated collaboration mechanisms, and lack of communication between diverse

health providers, scarcity of services and certified human resources. As the solution strategy to these problems, in the Healthy China 2030 policy multiple objectives were proposed among which, human-centeredness is prioritized. Despite that the policy does not mention planned interventions for family caregivers, the Government comprehends this category of people as a target. Thus, there is a stringent need for an intervention to support family caregivers.

Within this project, I have conducted extensive field methodology and desk research. The chosen service system design framework facilitated discovering the intrinsic issues of the healthcare system, family caregivers, and the potential areas for a design intervention. Consequently, after participatory project development and healthcare system representatives and family caregivers, multiple issues were identified, such as lack of knowledge of how to provide care, need for peer support and activities, social life, and social recognition. Accordingly, the author has conceived the service system proposal. The idea illustrates how Shanghainese family caregivers can be supported by being provided with medical knowledge, activities and being part of a

community. The proposed design intervention nurtures people's potential in neighborhoods as volunteers, organizing activities, and educating citizens as professional care-workers to facilitate caregivers' possibilities for respites. The organization creates space for people to meet and build trustful relationships, enhance community resilience, and it will be the first step of the long-term project, which could people support caregivers based on established relationships. Besides, considering that the Chinese culture prerequisites of sacrifice and filial piety, the project also aims to raise awareness of the importance of balancing a person's roles as a caregiver and an individual. The reasoning is that the quality of provided care directly depends on the quality of life of an individual. Reflectively, the Confucianist term of balance, and humaneness serve as a backbone of the service idea. As a result, the author proposed the "Rituals. Balanced Care Centre," which could be one of the key element of the intervention system within the Chinese healthcare system.

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Introduction

“Rituals. Balanced Care Centre. The Design of a Support System for Shanghainese Family Caregivers” is a master thesis project showing the development of a support system to tackle the multiple issues of family caregivers in Shanghai. The proposed concept includes offering knowledge, activities, and a community to family caregivers by nourishing the existing local human resources’ potential of volunteers and educated care-workers.

The thesis consists of nine chapters. After the first introductory chapter, the author described the research background. The chapter portrays the increasing problem of family caregivers worldwide, and specifically in China. The author emphasizes caregiving’s cultural implications, such as Confucianist filial piety, and points out changes implied by caregiving. Also, it contemplates the Chinese healthcare system, its issues, and development plans.

The third chapter described the potential of Service System Design to approach healthcare as a design space. The chapter also discusses how Service System Design methods can tackle the problem of vulnerable groups, as caregivers.

The fourth chapter flashed the light on the

chosen methodology to conduct the project. A depiction of concrete design tools for the different project phases has been made.

The fifth chapter dives into the desk research. It uncovers the successful case studies of interventions to caregivers worldwide. This chapter serves as a beacon and an inspiration for further work and unveils the current landscape of services. This chapter also portrays the existing practices to support family caregivers in China and Shanghai.

The sixth chapter explains the field research work. The author did multiple interviews in three different Shanghainese Hospitals, and spoke to multiple healthcare actors, including family caregivers for patients of different diseases. This chapter summarizes the insights that supports the ideation phase of the project.

The seventh chapter shows the ideation process, done through a co-design workshop with multiple invitees and the concepts’ validation sessions. The author describes the participants’s recruitment process, workshop tools’ development, workshop running, the analysis of the produced materials and gathered knowledge. The author proceeded in developing concepts for design interventions,

and organized validation sessions with medical experts and caregivers. The results of the validation session converged into the final service system idea.

The eighth chapter develops the service system intervention. The proposed organization “Rituals. Balanced Care Centre” is described through different design tools to efficiently develop and convey the main idea of the organization. Notably, Chinese culture, and, specifically, Confucianism values serve as a guide for the concept development and are mirrored in the design concept.

Lastly, the ninth chapter unveils the author’s final considerations regarding the project progress, the proposed solution and the project’s limitations.

RESEARCH background

Introduction

In the last decades, given the global trend of low mortality and birth rate, and the increase of chronic disease, it is projected that home care, provided by family members, is becoming the new normal (de Moor et al., 2017). However, caregivers' wide range of responsibilities, such as instrumental, physical and moral support, often lead to a caregiver's burden (Hu et al., 2018). A caregiver's burden, also called caregiver's strain, can manifest in caregivers' health detriment, both on physical and mental levels. However, in some cultures, e.g. Chinese culture, caregiving is perceived as a challenge and obligation of family members to provide the needed care to the sick family members. Moreover, the legislation obliges Chinese people to these responsibilities.

While many current health systems, including the Chinese one, seem to disregard caregivers' issues, many countries are exploring the concept of integrated care to distribute the caregiving burden better. According to researches, integrated care encompasses "services, providers, and organizations from across the continuum to work together jointly so that their services are complementary to one another, are coordinated with each other, and are a seamless unified system,

with continuity for the client" (Toscan et al., 2012: 2). According to this research, it is essential to build an integrated care system considering different actors' viewpoints, family caregivers included.

Since 1949, the establishment of the People Republic of China, the government has been investing tremendous resources to build the health system, and according to other countries is one of the fastest developing ones. However, after the latest cycle of reforms in 2009, in 2016, it was recognized the need to conduct a series of further reforms (World Bank Group et al., 2016). Thus in 2016, President Xi Jinping introduced the Healthy China 2030 policy (HC2030). In particular, the plan "gives due recognition and resources to both population-wide approaches and targeting of high-risk patients, focusing specifically on chronic diseases such as heart disease, diabetes, and cancer". This proposal aligned with an integrated care approach, presenting some challenges as the current multi-tiered arena, unevenness, and lack of unity in policy interpretation and implementation, representing obstacles in reforming the health system. The report "Deepening Health Reform in China" presents the considered steps in improving the current

health system in this direction.

The chapter aims to introduce the phenomenon of caregivers, with a focus on the Chinese context, to then reflect on the need for reform in the current Chinese healthcare system, based on caregivers' challenges, the prospect of the Healthy China 2030 and the attributes of the current welfare system: i.e. the multi-tiered health system with limited human resources and misaligned stakeholders. After describing the phenomenon of caregivers, the chapter will discuss the current state of the Chinese healthcare system, with proposed reforms and obstacles to implement them.

2.1 The phenomenon of caregivers

When studying caregivers' topic, studies condense about the gradual or abrupt changes which caregivers experience while becoming one, the implied responsibilities, the formed burdens, and their physiological manifestations or implications on life. Therefore, this chapter reveals the following topics:

- *The phenomenon of caregivers*
- *The concept of change happening to caregivers*
- *Implications of caregiving over family caregivers: health, family relationships, work*
- *Caregivers' coping ability with caregivers' burdens*
- *Caregivers in China*
- *Chinese cultural aspect in caregiving.*

2.1.1 Caregivers around the world

Given the worldwide aging population and the ongoing increase of patients with non-communicable diseases, such as dementia, cancer, Parkinson, stroke, the need for informal caregivers is rising (de Moor et al., 2017). Informal caregivers are "relatives or friends of an older person who provide, arrange, or oversee services that the older person needs because of functional disabilities or health needs", another definition refers to "interactions in which one family member is helping another on a regular (daily, or nearly so) basis with tasks that are necessary for independent living" (Liu, 2013: 12). Both definitions imply activities to help family members living independently, therefore, comprise provided help to live independently, meaning mitigate "economic, physical, and cognitive difficulties" (Liu, 2013: 15). The range of caregivers' responsibilities to assist family members include psychological, financial help and practical help, namely Activities of Daily Living (ADL), as washing, help administer medications, feeding; Instrumental Activities of Daily Living (IADL), as housework, meal preparation, money management, and shopping (Liu, 2013). About 42 percent of US workers have provided eldercare in the past five years (Liu, 2013).

Studies of caregivers show that around the globe, caregivers constitute a big percent of the population: as per 2017, in the US, 2% of people are unpaid caregivers, 20% in the EU, and in UK and Australia there are 10% each, the projections say that 49 % of the US workforce expects to be providing elder care for a family member or friend in the coming five years (Merck KGaA, 2017). There is noticed a disproportionate division of responsibilities: "eldercare responsibilities fall disproportionately not only on women but also on low-wage workers" (Williams et

al., n.d.: 2). Therefore low-wage female caregivers are facing substantial struggles to comply with the caregiving responsibilities. Financial capabilities, generally, play an important role in facing the caregiving challenge. Studies show that caregivers from the US, who live below the poverty level are “more than twice as likely as higher-income workers to provide more than 30 hours a week of unpaid assistance to parents or parents-in-law” (Williams et al., n.d.: 2). Given the amount of time and effort required to provide care, the phenomenon of caregiving is negatively impacting the quality of life of carers (de Moor et al., 2017).

Caregivers’ quality of life is one of the most prominent values threatened by the caregivers’ challenge’s complexity. The studies show that caregivers for patients of different diseases suffer from “functional, physical, social, psychological, and spiritual burdens” (Hu et al., 2018: 74), (for example, low self-esteem, anxiety), these implications constitute caregivers’ burdens (Guo & Liu, 2015) or called “caregivers strains” (Liu, 2013: 20). Studies classify caregivers’ strains on five levels (Liu, 2013):

- *sacrifice strain* - burden caused by selflessness in providing care.
- *exhaustion strain* - burden caused by physical and psychological tiredness.
- *capability strain* - burden caused by the capacity to provide physical, economical, psychological support.
- *expectation strain* - burden caused by feeling pressure to comply to expected caregivers’ behavior.
- *dependency strain* - burden caused by the dependency of a patient on a caregiver.

There are methods able to measure it, namely Zarit Burden Interview (Al-Rawashdeh et al., 2016; Hu et al., 2018). The method implies caregivers to respond to different questions which reflect “consequences of caregiving, patient’s dependence, exhaustion and uncertainty, guilt or self-criticism, embarrassment/ anger or frustration, psychological burden and emotional reactions, personal strain, and role strain (Al-Rawashdeh et al., 2016; Bachner, 2013; Tang et al., 2013). Other studies emphasize that in exploring caregiver experience, “it is necessary to consider two aspects of the caregiving context, caregivers’ status in structural context and care recipients’ needs for care.” The structural context encompasses “social stratification, social institutions, and interpersonal relationships”. More specifically, social stratification means socio-demographic status, social institutions - “a complex of roles and norms in an individual’s life”, and interpersonal relationships - the relationship between caregivers and care recipients examined in terms of kinship, space, and quality.

Caregiving harshly influences the previous life orders (Williams et al., n.d.) and family function (Guo & Liu, 2015). It pushes the caregivers to re-arrange their routine. Consequently, increasingly more researches are developed, increasingly more authorities and policy-makers draw their attention to the issue to mitigate it and achieve an inclusive welfare, where the uncertainties and difficulties of this population group are also met. Studies suggest that “caregiving in today’s economic climate and fragmented systems of health care and long-term services and supports (LTSS) can have a significant impact on the family members who are the caregivers” (Williams et al., n.d.: 3).

2.1.2 The concept of change and caregiving

Caregiving is one of the major changes in life, it influence caregivers’ common life roles and demands certain knowledge (Cui et al., 2014; Yiu et al., 2020), skills, and requires adaptation to this new role. Studies say that when “the changes are undesired, unscheduled, or uncontrolled, they usually give rise to stress” (Liu, 2013: 31). In their research about the impact of sudden, major changes, Karin Breu and Mary Benwell, claim that sudden changes unapologetically pull the rug from under employees “when environments change rapidly and discontinuously, plans for the future can no longer be based on the past” (Breu & Benwell, 1999: 497) These implications caused by a change implicate change of behavior, which is always a complicated procedure. This example can picture the complexity of adaptation not only in work environment, but also in private life, therefore are also characteristic for caregivers. In their new role, they also need to learn “building up the judgement of the rapidly changing context” (Breu & Benwell, 1999: 497). Breu and Benwell mention changes on two levels:

- *First-order change* - a change in one or a few dimensions, components, or aspects. This changes imply incremental alterations in previous orders and “do not change the world view, the paradigm.” (Breu & Benwell, 1999: 498)
- *Second-order change* - “a multidimensional, multicomponent, and multiaspectual change, resulting in new world view, new paradigm.” (Breu & Benwell, 1999: 498).

This frame can also be applied to the impact of a disease on a patient and implicitly the magnitude of change for the caregiver: either chronic or resolutional (first-order change) or acute (second-order change). Families,

who experience a family member being diagnosed with cancer, typically “lack time to anticipate and prepare, and feel little sense of control, and feel a great sense of shock, loss, and anger” (Rait, 2015: 14). For example, researches regarding the phases of cancer disease note three stages and their different impact over the family caregiver:

1. The acute stage is characterised by the high unfamiliarity of the new circumstances. (Rait, 2015) Families struggle with the new life routine, learn practical skills to provide care, and deal with medical devices at home.

2. Chronic stage. It differs itself by the possibility of the patient to play an active role in family. However the family members can never fully relax and “remain perpetually in a state of readiness for any emergency” (Rait, 2015: 5).

3. Resolution stage. This stage implies either a patient’s healing (characterized by re-arrangement of roles in the family) or death (characterized by loss of a family’s grief and sometimes denial) (Rait, 2015).

All of these stages can be characteristic for many diseases, therefore the categorization can be applicable for a wide range of caregivers.

In the beginning of a chronic disease, or when a diseases happens all of a sudden and are in a critical, acute phase (e.g. stroke), the caregivers are undergoing a significant distress, nurtured by unpreparedness of people. According to Breu and Brenwell, would constitute a major, “second-order change” (Breu & Benwell, 1999: 498). The researcher Pearlin classifies such sudden circumstances as “primary stressors: usually occurs first in a person’s experience. The stressor may be an event, such as an unexpected encounter; it

may also be a chronic strain that is enduring and repeated across a certain period of life” (Liu, 2013: 20). Within a sudden disease or an acute stage of chronic disease, family caregivers find themselves in an incredibly chaotic and unusual environment of change with little preparation and are pushed to make choices (Rait, 2015). Any of the cases mentioned above imply intense anxiety caused by the caregivers’ responsibilities and the new roles. They require getting used to “the series of both generic and idiosyncratic problems posed throughout the illness and its treatment” (Rait, 2015: 11) and deviance from normal family function (Guo & Liu, 2015; Rait, 2015).

After a certain period, chronic diseases or gradually evolving diseases, e.g. Parkinson’s, give caregivers space to accustom themselves emotionally and acquire practical skills (Rait, 2015). This case would constitute a first-order change, where caregivers face “secondary stressors” (Liu, 2013: 20) - which represent “consequences of the primary stressors” (Liu, 2013: 20). However, once established, secondary stressors may independently produce even more intense stress than the primary stressors “ (Liu, 2013).

2.1.3 Implications of caregiving over family caregivers

Becoming a caregiver can be gradual or thrusting while a family member suffers a catastrophic illness (Rait, 2015). Researches show that the relationship status with the caregiver plays a critical role in burdening caregivers. For example, spousal caregivers experience “higher levels of depressive symptoms, physical and financial burden, relationship strain, and lower levels of positive psychological well-being than do adult children caregivers” (Bouchard et al., 2019: 2). In any case, caregiving influences the caregivers’ lives drastically and changes the family dynamic and roles (Rait, 2015). Consequently, caregivers feel distressed on functional, physical, social, psychological, and spiritual levels as described below.

The influence of caregiving on caregivers’ health

The challenges mentioned above often result into the detriment of caregivers’ personal health. The researches show that family caregivers suffer mental or emotional illnesses. Anxiety (Zhang et al., 2014), low self-esteem (Rong et al., 2019), sleep disturbances (Geng et al., 2018; Zhang et al., 2014) ultimately root themselves into the lives of caregivers. For example, the likelihood of caregivers developing depression is “as much as 5-fold higher than that of the general population (Liu et al., 2011). The circumstances, where in the context, the lack of knowledge and time, caregivers are pressured to make possibly vital decisions, often on patients’ behalf (Williams et al., n.d.). It is one of the essential factors to cause emotional suffering.

Moreover, the stress can also manifest itself in physical health, e.g. caregivers can acquire cardiovascular diseases (Bouchard et

al., 2019), diabetes. A study of Shanghainese caregivers reveals that 70-80% of caregivers experience sleeping disorders, lack of appetite, breathing problems, and fatigue (Wang et al., 2018). Some of the caregivers might be psychologically overwhelmed by the number of roles they start having. Adult caregivers struggle to combine caregiving with either their spousal and parental role in their core family or with their roles at the workplace (Williams et al., n.d.). Efficient coping mechanisms are crucial in order to help caregivers preserve their health in such stressful circumstances.

Caregiving influence on family relationships

As mentioned earlier, when a family member is diagnosed with a malady, the wellbeing of entire family is shaken. Douglas S. Rait underlines in his studies about cancer patients and their families that there are “three premises that underlie the family-systems perspective to the patient” (Rait, 2015: 3):

1. Cancer of one family member affects all the family members individually and the family as a whole (e.g. “couple functioning and parent-child relationships, which reciprocally influence the patient’s experience”) (Rait, 2015: 3).
2. “The family with cancer is a family in transition” (Rait, 2015: 3), facing various challenges, “from practical to existential”. Families facing cancer must strive to maintain stability and, at the same time, reorganize their habitual patterns of functioning to meet the challenges produced by the illness.
3. “The goodness of fit” (Rait, 2015: 3) between the patient, family, and medical setting” are essential from a healthy

functioning of family-systems perspective.

The described premises may be applied to families caregiving for cancer patients and providing care for patients with other diseases. Douglas S. Rait suggests that the healthcare professionals shall “begin with a microscopic focus on the individual, his or her illness, and treatment, and then adds a wide-angle lens to perceive better the powerful social factors that influence, and are affected by, the patient’s experience” (Rait, 2015: 3). Such an approach will benefit the wellness of the caregivers and every family member and patients’ too. The critical factor is the extreme interdependence of family members and the fragility of family health.

Caregiving influence on finances and work

The circumstance when a family member needs treatment is implying a considerable financial hit. Some caregivers are leaving their jobs to fully dedicate themselves to the new caregiving responsibility. In this case, the study suggests that “family caregivers age 50 and older who leave the workforce to care for a parent lose, on average, nearly \$304,000 in wages and benefits over their lifetime” (Williams et al., n.d.: 3) Others report “lost wages and financial hardship” (de Moor et al., 2017: 2) and choose to continue working because of the need for economical stability. However, it is extremely hard to keep up with both of the huge responsibilities: caregiving and work, where performance might suffer. Studies show that “30% of women caring for an older relative with chronic care needs and functional limitations say they rarely or never feel their work and family responsibilities are aligned” (Williams et al., n.d.: 3).

When caregivers try to commit to both, usually work implies some changes: the working

hours might diminish - caregivers need to come later or leave earlier, periodical time off might be required (Williams et al., n.d.). For example, studies show that caregivers in the US need to take leave for two-six months (74%), and 16% took leave lasting from six months to one year (de Moor et al., 2017). Moreover, almost 40% of the caregivers made adjustments to their work schedule, workload, and job responsibilities (de Moor et al., 2017). These needs might be harshly met by the employers, who oppose needs of time off, or would complain about this, threatening the caregivers' comfort in leaving. Based on these behaviors there was coined the term "Family responsibilities discrimination (FRD), meaning the discrimination against workers caring for ill or disabled family members" (Williams et al., n.d.: 4). The limited work performing environment influences the career path, namely "12.2% of US caregivers experienced lost work opportunities" (de Moor et al., 2017: 6). In extreme cases, employers might even fire the employees. In US there exist some policies aiming to protect family caregivers, e.g. the federal Family and Medical Leave Act (FMLA), but the definition of 'family caregivers' might be limited to parental relationship only, e.g. in Oregon (Williams et al., n.d.: 4). Therefore, a big cluster of employees, who, for example, provide care for their spouse, are overlooked and disadvantaged. Another considerations for protection against FDR at work can be taken from United Kingdom, New Zealand, and Australia, where there is a right to request law, which "require employers to set up a process to negotiate workplace flexibility and allow employers to turn down flexible work arrangement requests only for certain business reasons" (Williams et al., n.d.: 10)

The studies suggest some interventions for company culture revision (Williams et al., n.d.: 15):

- 1) Adopt a model policy for preventing FRD: treating equally caregiving employees and non-caregiving employees,
- 2) Provide workplace flexibility: part-time and part-year work, telecommuting, compressed workweeks, flex-time;
- 3) Establish effective and predictable scheduling of hourly jobs;
- 4) Develop and provide education and training to supervisors and managers;
- 5) Offer eldercare support, resources, and referral services to employees: referral to caregiver resources in the community, on-site support groups for working caregivers, or discounted backup home care for emergency needs;
- 6) Implement recruitment practices for people with eldercare responsibilities.

As the globe ageing population is rising and caregiving is becoming the new normal, studies warn about the urgent need to adapt the "outdated workplace model" (Williams et al., n.d.: 6) to overcome the "mismatch between workplace and workforce" (Williams et al., n.d.: 6), giving space and including the new normal into an updated work model. Moreover, it is needed to create and/or refine laws aiming to protect family caregivers including different familial relationships and eliminate discrimination against them in an exhaustive way.

To conclude, caregiving negatively influences the entire life ecosystem and previous life orders of caregivers. They face detriment on the mental and physical health level, in work, in relationships.

2.1.4 Caregivers' coping ability with caregivers' burdens

As caregiving imposes a stressful burden, some studies suggest that individuals' coping mechanisms might vary based on caregiving's influence on their lives and individual characteristics. For example, two experts in stress studies, Lazarus and Folkman claim that "coping results from individuals' appraisals, the cognitive process, through which a person evaluates a particular situation concerning what is at stake and what coping resources and options are available" (Liu, 2013: 18). This suggests that assessing the influence of caregiving on caregivers' live perception of caregivers' strains. Hence, the coping mechanism results from caregivers' strains rather than origins. Moreover, Douglas S. Rait et al. writes about patients' coping mechanisms and agrees with the statement above. However, it also adds that "a patient's ability to manage the stresses associated with serious illness depends on his or her prior level of emotional adjustment, understanding of the illness, the threat posed to the patient's capacity to meet age-appropriate goals, the presence of social and emotional support, and variables determined by the disease" (Rait, 2015: 3).

In another theory called "self-concept discrepancy" (Liu, 2013: 18), Higgins suggests that caregivers' response to the challenge is culture-dependent. It "refers to the gap of self-state representations" (Liu, 2013: 18), meaning the mismatch about how people feel to accomplish their caregiving role and how society expects them to do it. For example, there is a central cultural concept of filial piety in China, which implies taking care of elderly parents. Moreover, Chinese law obliges society to provide care and stimulate care at home. In such a context, caregivers might face a conflict between their feelings and the responsibilities which are projected on them,

not taking into account their resources. Such situations escalate caregivers' burdens.

On the other hand the coping process also depends from an external factor, namely social support. In the stress theories, "social support refers to the access to and use of individuals, groups, or organizations in dealing with life's vicissitudes" (Liu, 2013: 33), but also studies subcategorise it as support from siblings, among which caregiving responsibilities are distributed, and therefore play a supportive role (Liu, 2013). Researcher Pearlin, in the Stress Process Model, identified the relationship between social networks and social support: "being part of a social network is necessary for a person to access social support, but, alone it is not a sufficient condition to receive social support. Instead, individuals can obtain social support only if they are involved in certain relationships in a social network" (Liu, 2013: 34). This highlights the importance of caregivers to be connected, eventually share their experiences (Youssef et al., 2019) or distracting themselves from the caregiving routine. In the US, Singapore, UK there are non-profit organizations "dedicated to meeting the needs of caregivers through education, support networks, crisis support, tailored services and self-care enablement" (Caregivers Alliance Limited (CAL), n.d.). For example, "Family Caregivers Alliance" organizes educational events, provides informational materials for caregivers, including online resources (Petrovic, 2013), regarding patients with different diseases, helps caregivers all around US to locate support organizations and be part of the big community (Family Caregivers Alliance, n.d.). However, there are no such developed social services for caregivers in China, where

it is culturally expected to receive support from the family (Liu, 2013).

2.2 Caregivers in China

China is suffering from an exponential amount of patients with noncommunicable diseases. According to the WHO report about the assessment of China on health and aging warns that “chronic noncommunicable disease prevalence will increase by at least 40% by 2030, almost 80% of all deaths in people aged 60 years or over are attributable to chronic noncommunicable disease” (World Health Organization, 2015: 1) This suggests the increasing percentage of the caregiving population both for these patients. WHO emphasises the need to create and/or adapt policies and services to support patients and their caregivers (World Health Organization, 2015).

Studies show that the availability of services for caregivers in China are scarce (Mao, 2010). The researches identified a support service in Beijing, it aims to stimulate the provision of care at home. Therefore it “distributes monthly voucher to older adults to purchase services in the community; provide supplemental coverage of out-of-pocket medical fees for old; promote traditional values that respect and care for older adults and the like” (Mao, 2010: 2). As of 2010, “6% of older adults receive care in the community agencies, and 4% of older adults receive care in institutionalized settings in Beijing” (Mao, 2010: 2). However, this care system scheme benefits caregivers only indirectly. In an interview of 2010, the vice-director of China Research Center on Aging explained that caregivers’ governmental support is evident (Mao, 2010).

At the policy dimensions, after the establishment of People’s Republic of China, the government regulated the duty of the core family to provide support for elder adults, stipulated in the fundamental state law, the Constitution of the People’s Republic of China. It says “that family care provided by spouses, adult children, and grandchildren to older adults is obligatory and if not fulfilled by them, penalization will take place” (Liu, 2013: 11). The law is especially reinforced in the parental relationship dimension. In article 49, the Constitution states: “Parents have the duty to rear and educate their children who are minors, and children who have come of age have the duty to support and assist their parents” (Liu, 2013: 11). Moreover, the Law for the Protection of Rights and Interests of the Aged detailed the responsibilities of family caregivers to support their elderly family members, for example (Liu, 2013: 11):

“Families are the chief support for the aged to live their lives. Family members should care for the aged” (Chapter II, Article 10);

“A supporter should perform the duty to pay the aged person’s living expenses, look after him and comfort him mentally and should give consideration to his special requirements. A supporter refers to a child of the aged person or a person having the duty to support him according to law. The spouse of a supporter should assist him in performing the duty to support the aged person” (Chapter II, Article 11);

“A supporter should provide medical expenses and nursing service for the aged person suffering from illness.” (Chapter II, Article 12)

Studies claim that the laws mentioned above have lingered for caregivers’ service to pop up,

(Liu, 2013). “Chinese government encourages informal caregiving to prevent the increasing cost of formal care, and it is afraid that the provision of formal care will make the Chinese traditional filial piety weaken” (Lin, 2019: 6). A resolution could be the recently claimed idea “to build a comprehensive care system and create a platform for family, government, private market, and society to work together” (Mao, 2010: 3). However, no specific initiatives were noticed. Despite the non-supportive infrastructure, conflictual roles of caregivers, and other challenges, family caregiving is mostly practiced and has a cultural connotation.

2.2.1 Chinese cultural aspect in caregiving

Generally, providing care within the family implies different kinds of relationships: assisting children, elderly parents, spouses, siblings, parents-in-law. This research has been focusing on providing care for adult people, independently of family relationships.

In China, the concept of family is solid. The family bonds represent one of the societal values. Therefore, when a family member suffers from a disease, the entire family is ready to help. Especially shouldered could be the adult children caregivers, whose obligation to provide care is connected to filial piety. Filial piety is the traditional value rooted in Confucianism as the guide for children’s behaviors and attitudes toward their parents (Liu, 2013). In China, there are many gender preference implications of filial culture. For example, “it expects eldest sons with particular privileges, such as inheritance rights and leadership in an

extended family, and expects that they will take primary responsibility for providing care for older parents” (Liu, 2013: 11). Besides, gender imbalance is also noted, for example “a daughter usually moves to her husband’s community after they marry and is traditionally expected to assist her husband in caring for his parents” (Liu, 2013: 11). Also, in their caregiving responsibilities, sons provide financial support, rather than daughters who provide physical assistance (Liu, 2013).

Caregiving, in many cases, is voluntary. Studies show that caregivers with higher income and education feel caregiving as a moral obligation (Liu, 2013). It is reported that such caregivers have a smaller caregivers’ burdens, namely “caregivers with higher educational degrees may feel their capability or value is not sufficiently exerted in providing instrumental care for their elderly relatives” (Liu, 2013: 25). However, caregiving can also be an imposed obligation by society to the patients’ families, especially children. Providing care to parents means giving credit to parents for efforts in bringing up children. Therefore children, who show filial piety in daily duties to their parents, are praised by society (Chiu et al., 2010; Liu, 2013).” Either voluntary care or compliant care providing, caregiving adult-children struggle either the challenges implied by caregiving or doing what they ought to do despite their wish or capabilities. This is another cultural component: endurance.

Despite the complexity of tasks that caregivers have to perform, Chinese caregivers might choose to endure the difficulties (Liu, 2013). In theories on stress, a strain usually involves relatively “enduring” problems, conflicts, and threats in people’s daily lives (Liu,

2013). A common practice in China could be the lack of wish to refer to a nursing home help due to a strong sense of practicing filial piety (Mao, 2010). Caregivers also endure the complications to balance caregiving with other roles: for example, being a parent for their children and pursuing a career (Mao, 2010; Sun et al., 2020).

Lastly, another cultural aspect is revealed in studies about possible support strategies. The studies about family bonds show that siblings are crucial in the help for patients (Mao, 2010). Another research shows that due to the “more collectivist nature of the culture” (Liu, 2013: 8), compared to Western cultures, Chinese caregivers note an outstanding efficiency of family therapy and family-based interventions (Liu, 2013). These cultural implications might be further researched.

2.3 Conclusion on phenomenon of caregivers and Chinese caregivers

The rate of chronic diseases arises worldwide, and in China, thus patients will need assistance within their treatment journey. However, caregiving can abruptly enter someone’s life, so the people are psychologically unprepared to deal with multiple responsibilities: providing instrumental, physical assistance, moral, and financial support. These extreme life events often result in caregivers’ burdens, physiological manifestations, and worsening caregivers’ personal life and health.

Caregivers in China have cultural differences, such as endurance to challenges, a high sense of filial piety, family members’ moral obligation to provide care to the family’s patient, supported by society’s expectations, and reinforced by Chinese law. Given this, Chinese caregivers might be limited in relieving their burdens. Therefore they need support strings provided by the government and the overall healthcare system. The next section will introduce and describe the Chinese healthcare system to show how it is currently operating the system through which caregivers and patients navigate.

2.4 Healthcare System in China

The Chinese healthcare system has an inevitably high complexity level in terms of governance, funding mechanisms, delivery, and provision system. This section provides an overview of these systems, highlighting the core aspects that have a direct or indirect impact on caregivers, which are: financial processes which stimulate over-prescription and insurance schemes covering patients’ treatment, limited medical resources, creating distrust through unneeded treatment procedures, lack of collaboration within the fragmented multi-tiered system.

Thanks to the governmental development strategies and vast amount of allocated financial resources, since the establishment of People’s Republic of China in 1949, economic, political and indispensably health system have undergone major improvements. Some of the results of these changes include enhancement of people’s life expectancy from 35 years in 1949 to 75 years in 2012 (Meng et al., 2015), moreover, 600 million of people were pulled out of poverty (World Bank Group et al., 2016). After proceeding through 3 phases of changes, in the last decade China has reached a universal health insurance coverage of 95% at a very high speed, compared to other countries (World Bank Group et al., 2016). For example, treatment reimbursement rates could reach up to 80%. Also the treatment of some diseases and the offer of basic medical services can be fully covered, significantly easing the burdens of the patients’ families (World Bank Group et al., 2016). The treatment is led by the three-tier healthcare delivery system: primary, secondary and tertiary healthcare institutions (Meng et al., 2015).

Despite the fact that the Chinese health system reached a position among medium-

high developed countries’ health systems, it started facing new challenges, namely the implications of decreased mortality, low birth rate, and enhanced urbanisation. The new life habits nurtured the evolvement of health risk factors, such as sedentary lifestyle, obesity, alcohol consumption, smoking, air pollution. Therefore, China’s new challenge consists of an increase of non-communicable, chronic diseases, which now represent 70% of the total burden of disease. Therefore, the situation ultimately implies the need to follow a new strategy in addressing healthcare (World Bank Group et al., 2016). The more the system is lingering, the more it will become complicated to face the challenge to reform due to the system gaps, lack of equity (Meng et al., 2015; World Bank Group et al., 2016), in the distribution of the resources and their usage, shortage of personnel and other weaknesses. The Chinese Government has realised that the health system resulted into a “hospital-centric, fragmented and volume-driven” (World Bank Group et al., 2016: 23) and would suggest to “Making the shift from a health care delivery system focused on production of treatments to one focused on value and producing health suggests a strategic agenda that aligns all stakeholders” (World Bank Group et al., 2016: xxx).

In 2015 the Chinese Government, therefore, endorsed the five-year visionary, long-term strategies put together in the “Healthy China” policy, where people’s health is the main system goal. Among all, the components of the healthcare delivery reform include the “people first principles” such as building harmonious relationships with patients, promoting greater care integration between hospitals and primary care facilities through tiered service delivery

and use of multidisciplinary teams and facility networks, shifting resources towards the primary level, linking curative and preventive care, reforming public hospital governance” (World Bank Group et al., 2016: xvii). The entire range of objectives, aimed by the Government, can be condensed to three goals (World Bank Group et al., 2016):

- *attaining better health for the population;*
- *providing better quality and care experience for individuals and families;*
- *achieving affordable costs.*

To understand how these objectives might be achieved, it is essential to understand the current healthcare “playground”, which consists of organizational structure, financing system, physical and human resources, and service delivery.

2.4.1 Organizational structure

In 2012, China had 34 provincial-level administrative regions, comprising four municipalities (Beijing, Shanghai, Tianjin, and Chongqing) directly under central government jurisdiction, 23 provinces (including Taiwan), five autonomous regions, and two Special Administrative Regions (SARs, Hong Kong and Macau); 333 municipal-level regional administrative units, 2852 county-level regional administrative units, and 40 446 township-level regional administrative units (National Bureau of Statistics, 2014) (Meng et al., 2015: 1). This vast territory and the number of people residing on it have benefited the tiered health system: primary, secondary, and tertiary level institutions, where primary providers deliver the narrowest range of services, while the

tertiary one represents the most modern, innovative healthcare centres. This system did not change since 1950-1960.

The Chinese healthcare macro-system consists of three “independent, yet interdependent systems: health financing system, a health-service delivery system, and a health supervision system” (Meng et al., 2015: 16).

Health supervision system

There are five principal tiers of public administration in China - central, provincial, prefectural or municipal, district or county, and township levels. Reforms and any major decisions shall be coordinated between these.

The highest central health administrative body of the Chinese healthcare system is the National People’s Congress. Its activity is empowered by other Governmental health structures and non-governmental organisations, which also play a huge role in health governance. All of these structures can be grouped as local government (Meng et al., 2015), who provide “personnel, infrastructure, equipment and other development projects for public health facilities, public township health centres, and community health service facilities” (Meng et al., 2015: 32), while the central government mainly provides the financing (Meng et al., 2015: 32).

China has a very hierarchical organizational, governance structure. Despite “policy directives mandating separation of functions in the health sector” (World Bank Group et al., 2016: xxxiii) and that such a structure has to imply unity of vision, China suffers from uneven perception and implementation of policies in healthcare (World Bank Group

et al., 2016). Moreover, the governing bodies, who plan the financing, write the new regulations and play the leading role in weaving the healthcare system, have poor strings to communicate directly and penetrate the essence of the local issue in healthcare. In such a set-up, the vast Chinese territory and the amount of provinces aggravate the problem (World Bank Group et al., 2016).

Health financing system

Both governmental and private resources ensure the financing of the health sector. The government invests in “direct fiscal contributions to health and social medical security funds” (Meng et al., 2015: 21). The direct fiscal contributions aim to support the activities of public health providers, the public health programs. Usually, the governmental financing constitutes only 10% (World Bank Group et al., 2016), this is not enough for many health providers. Therefore they seek financing from citizens, who, in their majority, pay for medical consultancies, procedures and drug procurement with out-of-pocket payments (OOT), besides, commercial insurance, workplace health financing schemes and non-profit-making organizations’ financing schemes” also constitute a revenue source (Meng et al., 2015).

The social medical security funds comprise three medical insurances - “the Urban Employee Basic Medical Insurance (UEBMI), Urban Residence Basic Medical Insurance (URBMI), and the NRCMS - as well as supplementary medical insurances, like catastrophic medical insurance” (Meng et al., 2015: 22). These insurance schemes have almost universal coverage. However, there is still space for improvement. The report

“Deepening Health Reform in China” claims that the health insurance agencies have a poor strategic envisioning, they “are yet to become strategic purchasers, they currently focus on fund management rather than creating strong incentives for providers of health services to transform inputs into cost-effective services” (World Bank Group et al., 2016: 10). An effective strategic purchasing mechanism powered by health insurance scheme can play a critical role in reforming the healthcare scheme by “incentivizing day-care and day-surgery, risk-adjusted capitation based financing of primary health care with special performance incentives for special high priority outcomes” (World Bank Group et al., 2016:10).

Health delivery system

The health delivery system consists of the ‘public health system’ and ‘medical service delivery system’. While the first one is responsible for “disease prevention and control institutions” (Meng et al., 2015: xvi), the former represents the totality of “hospitals at provincial, city and county levels, as well as grassroots institutions” (Meng et al., 2015: xx) both private, or public, the medical service delivery system were accounting 58% in 2012. The relationships and interconnections regarding subordination, business management, and business guidance of the hierarchical four-tiered system consisting of stakeholders on state, provincial, city, and county levels are represented in Figure 1 (Meng et al., 2015). The health department mainly oversees the Chinese Hospitals on provincial, city, district or county levels while the county health administration supervises the community hospitals. The entire system is exceptionally

inter-wired, and according to reports, the actors within it are not well-orchestrated (Meng et al., 2015; World Bank Group et al., 2016).

There are three major types of medical and health service institution in China: (1) *hospitals*; (2) *primary health care (PHC) institutions*; and (3) *specialized public health institutions*.

Each of the front-line health providers has its range of responsibilities. The rural healthcare services include a more narrow range of services, focusing mainly on basic first-aid services, from where the rural residents have to independently refer to higher-level urban institutions of a city or national hospitals. The urban institutions are more wide range: primary, secondary, and tertiary healthcare facilities. Because the hospitals can also provide primary healthcare services, people prefer to refer to tertiary level hospitals, even with non-severe health problems, which results in an unbalanced system in favour of secondary and tertiary institutions. The reason is the quantity and quality of human resources and equipment present in the tertiary and secondary hospitals. Besides, secondary hospitals have 100-499 ward beds, the tertiary ones have more than 500, while primary facilities 20-99 beds. Since 1989, Chinese hospitals have been classified into three levels according to their size and function. The comparative analysis of different tiered health centres is represented in Table 1. Despite the lower quality of professionals in primary institutions, they can still offer some of the services, which would redistribute overcrowded secondary and primary institutions' occupancy.

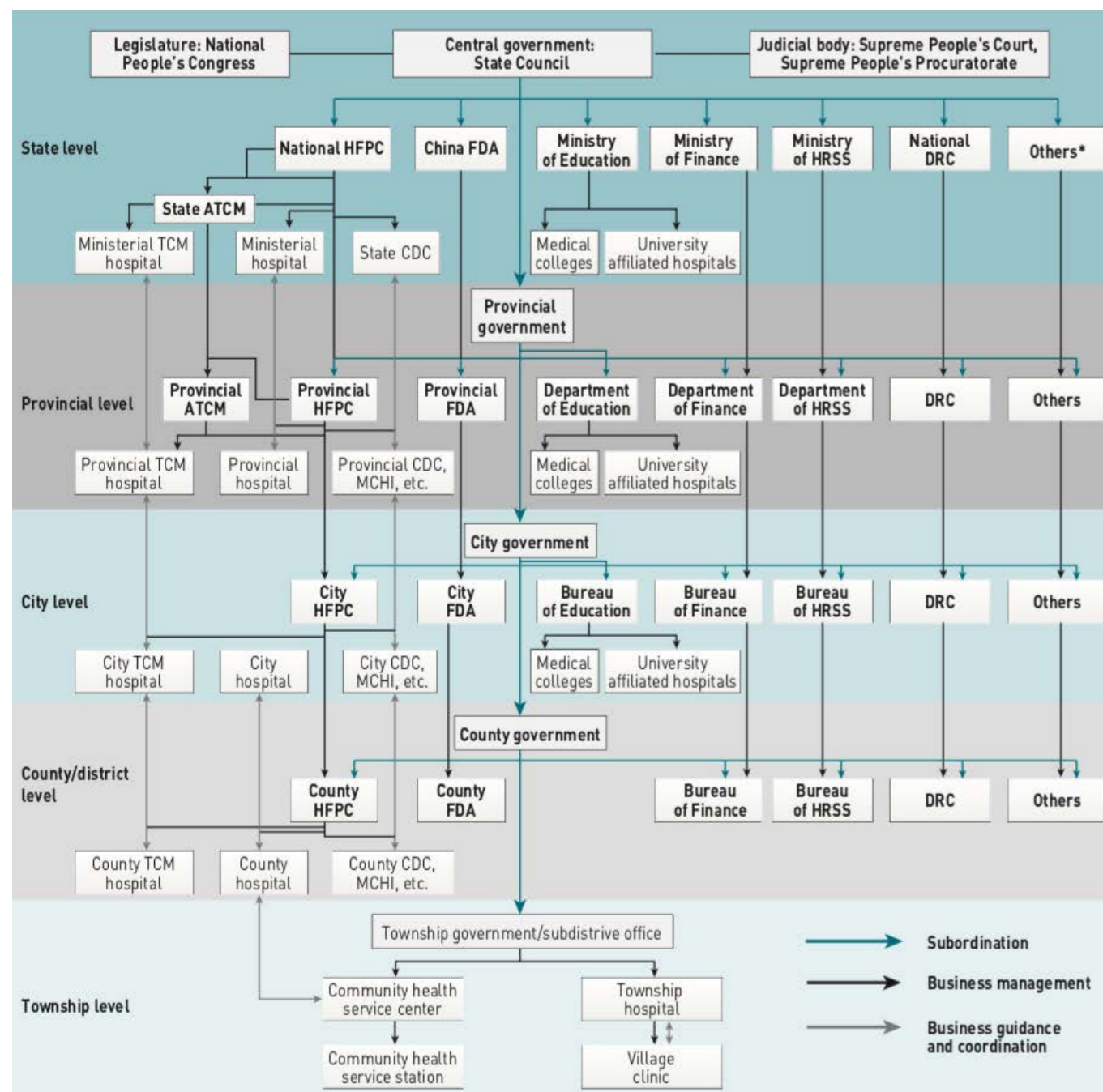
The number of healthcare institutions has been continuously growing: since 1978, it

has increased by 250% (Meng et al., 2015). Still, compared to other countries, the number of ward beds in Chinese hospitals is relatively low, especially in private hospitals, that focus mainly on curing outpatients. Compared to previous decades, in 2012, the general bed occupancy rate has increased by 30%, suggesting a more health-conscious population and higher hospitalisation rate, mainly with non-communicable diseases. The hospitalization rate differs drastically in the hospitals of different levels. For example, the tertiary hospitals are 104,5% full, while the PHC institutions' occupancy is only 60,4% (Meng et al., 2015), and the private hospitals have a minimal share of approximately 10%, as of 2011. The number of beds per 1000 people in rural areas constitutes 3.11, while in urban 8.11. The unbalanced system is one of the governmental focuses to be mitigated with future reforms.

As of 2011, 58% of healthcare providers are governmental, and there are 42% of private health providers that comprise "small clinics, with some hospitals, PHC centres, and township health centres" (Meng et al., 2015: 32). Currently, the government is stimulating private healthcare providers to thrive, however, in many provinces, the licensing regulations are unclear, and the processes are cumbersome. Despite the apparent unity of rules, in many regions, there is room for their interpretation. The government also supports "the enterprises, charities, foundations, and commercial insurance companies to invest in the health service industry by sponsoring, restructuring, hosting or purchasing healthcare facilities" (Meng et al., 2015: 32). The government recognizes the importance of the private sector in healthcare development and seeks strategies to empower it (World Bank Group et al., 2016).

Table 1. Different healthcare providers and their characteristics (World Bank Group et al., 2016)

Criteria	Tertiary hospitals	Secondary hospitals	Primary hospitals	Primary healthcare institutions (PHC)
Specialization	Serve multiple regions, offer high-level and specialized medical services and are responsible for higher education and scientific research	Regional hospitals offer comprehensive medical and health services to multiple communities and offer medical training and research.	Primary hospitals or health institutions offer preventive, clinical treatment, health care and rehabilitation service in a community	Community health service centres or stations in urban areas, township health centres and village clinics in rural areas. For example: centres for disease control and prevention, maternal and children health centres, prevention institutions for specific diseases.
Ward beds	>500	100-499	29-99	-
Insurance coverage rate for urban elderly patients	88%	90%		99%
Beneficiaries	residents of multiple regions			residents of geographic zone
Technical capacity	equipped with heavy medical tech		slow, yearly technical upgrade	
Human resources	high-level specialists including rare disease, who received bachelor/master/PhD education		village doctors, health professionals, who received higher medical education	



* Others include Ministry of Civil Affairs, Insurance Regulatory Commission, etc.
 HFPC: Health and Family Planning Commission;
 FDA: Food and Drug Administration;
 HRSS: Human Resource and Social Security;
 DRC: Development and Reform Commission;
 ATCM: Administration of Traditional Chinese Medicine;
 CDC: Center of Disease Control;
 MCHI: Maternal and Children Health Institution.

Figure 1. Organization of Chinese health system (Meng et al., 2015: 21)

Human resources

At the beginning of People's Republic of China declaration, there was a tremendous medical staff shortage. The term 'barefoot doctor', meaning "people who were both farmers and PHC personnel, who received a short-term training provided by primary healthcare institutions in rural areas" (Meng et al., 2015: 116), became very common. The barefoot doctors played a significant role in developing the rural healthcare system, and since 1985 China suspended this term and instead is calling this kind of practitioners village doctors. Since then, even though healthcare workers' quantity and quality increased, among medical staff in rural areas, only 6% have a bachelor's degree (Meng et al., 2015: 121), as the highly educated specialists are located in urban areas. The medical staff, who received comprehensive university training, are called general practitioners. Consequently they provide integrated services of figuring the diagnose, treating the common diseases and rehabilitating the patients and because of higher wages are motivated to work in urban areas and secondary or tertiary level hospitals.

Regarding the distribution of human medical resources, China has been struggling with both unbalance and a shortage of specialists. In the end of 2012, "the total number of health personnel in China was 9.12 million, including 6.68 million health professionals. There were 4.94 healthcare professionals per 1000 population including 1.58 licensed physicians and 1.85 registered nurses" (Meng et al., 2015: 119). In the past decades, the "ratio between doctors and nurses was 10:1, in 2012 it had reached 100:95" (Meng et al., 2015: 120). Even though compared to

neighboring and similar countries, China is has relatively good coverage with doctors, the shortage of nurses is drastic.

The further challenges regarding the human resources constitute recruiting and retaining healthcare workers both in urban and rural areas, mainly due to unattractive compensation packages, especially on rural and grassroots levels (World Bank Group et al., 2016). The lack of human resources implies the difficulty to extend health services, if caregivers would like to benefit from the help of a social worker or a psychologist, there might be not enough professionals. Besides, the additional revenue for healthcare workers was linked to the number of medical procedures, surgeries, admissions, prescribed drugs, there was noted a severe violation of these, which has been negatively affecting public health and seeding the distrust between specialists and patients, sometimes resulting in significant conflicts between patients' families and hospitals (World Bank Group et al., 2016). Such cases create distrust to medical professionals and, therefore, worsen both patients' and their families' treatment experience.

2.4.2 Challenges of the Health Service Delivery System

China recognizes the unbalanced usage and funding of hospitals, namely, “the number of outpatient visits to the hospitals was 1,7 times those to primary healthcare facilities, while actual bed occupancy of the former was four times that of the latter” (Meng et al., 2015: 28). To mitigate this problem, since 2006, China has started a “two-way referral regulation” (Meng et al., 2015: 141), which stimulates the collaboration between primary, secondary, and tertiary health institutions. The specialists are recommended to refer the patients to primary institutions for further treatment, e.g. “900 Urban Hospitals and 2000 County Hospitals Establish Long-Term Partner Assistance Programme” (Meng et al., 2015: 141).

On the other hand, the government was trying to mitigate unbalanced healthcare service usage through healthcare personnel training projects and special medical talent development programs in both urban and rural areas (Meng et al., 2015). This issue is on the agenda of China’s healthcare strategic development goals, stipulating enhancement of primary healthcare capacity as one of the major tasks (Meng et al., 2015).

However, the dual-referral system functions poorly and irregularly; the healthcare providers have a rather competitive relationship than a collaborative one. The reasons are multiple: partially due to the financing system, which implies the hospitals’ financial wellbeing depending on the number of treatments they provide. On the other hand, healthcare providers are not used to working in a cross-tiered way (World Bank Group et al., 2016). Moreover, the training projects aiming to improve human resources quality are also threatened by a lack of data analyzing institutions’ current state and the

lack of unified quality improvement strategy and scale (World Bank Group et al., 2016).

Consequently, after the policy functioning, results on the pilot projects mentioned above are lacking, and the unbalance is still present, despite that tertiary hospitals imply higher costs, as shown in Figure 2.

2.4.3 Reforms of Health System

Since the implementation of health reform of 2009, there have been noticed slight improvements on different levels, e.g. “establishing a universal medical insurance system and an equalized basic public health service system, strengthening the capacity of grassroots health institutions, establishing an essential medicines scheme and organizing public hospital reform pilots” (World Bank Group et al., 2016: xv). However, because of needed high expenditure in the last years, the experts project a four-fold expenditure soon if no reforms will occur and claim that healthcare reform needs to hasten (World Bank Group et al., 2016). “In 2015, the Central Committee of the Fifth Plenary Session of the CPC endorsed a national strategy, “Healthy China 2020”, which places the people health improvement as the main system goal” (World Bank Group et al., 2016: xxviii).

In 2014 the Chinese government, the World Bank Group, and the World Health Organization committed to working together on a joint health reform study to further improve the above-mentioned policy formulation and deepen the health reform. The report positions the “people-centered integrated care model” (PCIC) (World Bank Group et al., 2016: xviii) as the ultimate healthcare

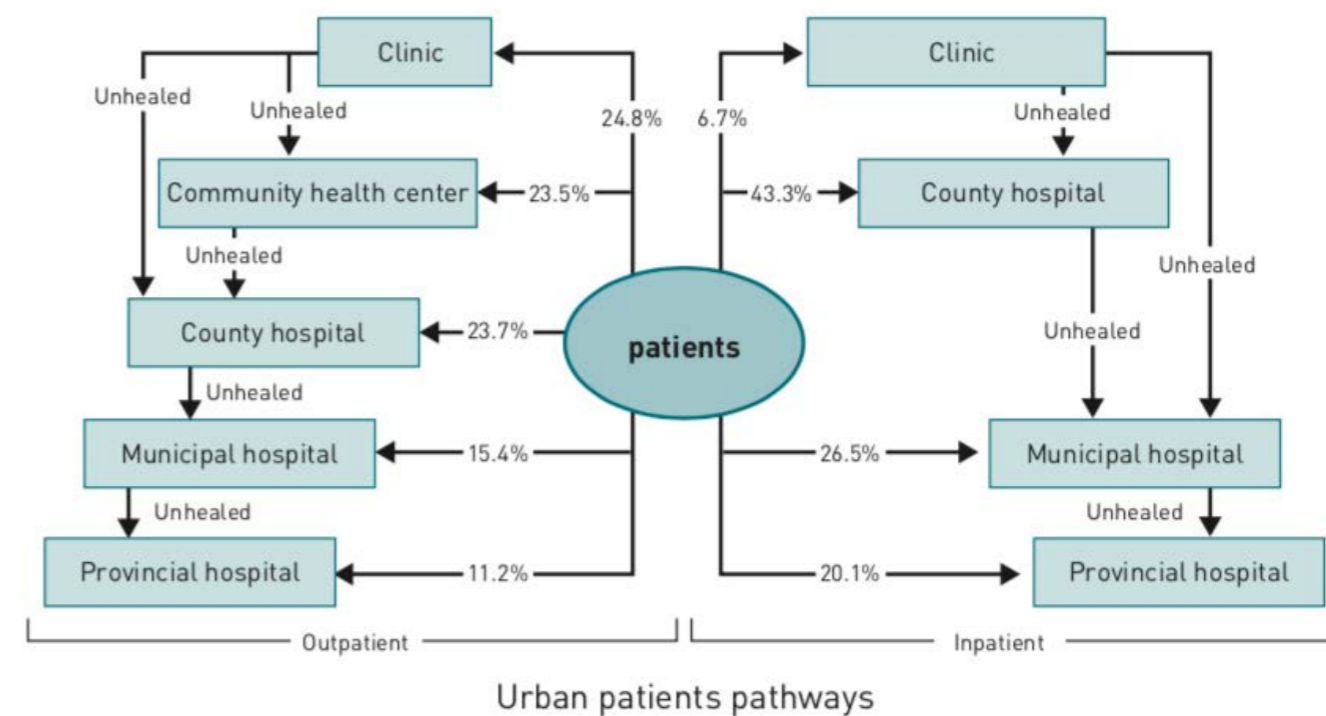


Figure 2. Urban patients' pathways through the healthcare system (Meng et al., 2015: 138)

system goal, the term used to refer to a health care delivery model that is organized around the health needs of individuals and families. Namely, the ‘people first principle’ means “building harmonious relationships with patients, promoting greater care integration between hospitals and primary care facilities through tiered service delivery and use of multidisciplinary teams and facility networks, shifting resources towards the primary level, linking curative and preventive care, reforming public hospital governance and strengthening regional service planning” (World Bank Group et al., 2016: xxix). At the core of these objectives, the change which the government aims to reach is “shift from a health care delivery system focused on production of treatments to one focused on value and producing health suggests a strategic agenda that aligns all stakeholders” (World Bank Group et al., 2016: xxx).

The report “Deepening Health Reform in China” highlights eight core objectives called “levers” grouped into “Service delivery levers” (numbers 1-4) and “Institutional and

financial environment levers” (numbers 5-8) (World Bank Group et al., 2016: 136):

1. *Shaping tiered health care delivery system in accordance with people-centered integrated care model (PCIC);*
2. *Improving quality of care in support of people-centered integrated care;*
3. *Engaging citizens in support of the people-centered integrated care model;*
4. *Reforming public hospitals and improving their performance;*
5. *Realigning incentives in purchasing and provider payment;*
6. *Strengthening health workforce for people-centered integrated care;*
7. *Strengthening private sector engagement in production and delivery of health services;*
8. *Modernizing health service planning to guide investment.*

The challenges and the proposed mechanism to overcome the barriers and implement the needed reform in China are described in

table 1 of the Annex 1 (World Bank Group et al., 2016: 136).

2.5 Conclusion on healthcare system in China

To conclude, the health system in China is exceptionally inter-wined, multiple structures on different levels make the system less flexible and agile. Families with patients have to navigate through the multiple health services independently, health providers and health insurance schemes, which have no connections. This creates a chaotic ambient for patients and caregivers. The help which families can benefit of, is empowered by the almost universal health insurance schemes, with high percentage of costs' coverage. The government understands the gaps and the need to make a tremendous step forward to obtain a people-centric health system, so that it benefits not only the patients but also the caregivers and aligns the players for smooth health delivery services.

The research “Deepening Health Reform In China. Building High-Quality And Value-Based Service Delivery,” claims that the implementation of all the reforms will take around ten years. It requires joining forces and engaging stakeholders of all levels to do the first step and complete the entire chain of improvements. First of all, it shall exhaustively define the actual health needs of the target population (World Bank Group et al., 2016) in order to “provide better quality and care experience for individuals and families” (World Bank Group et al., 2016: xvii). That is to say that caregivers have to be recognised as a target needing assistance and the patient and take an active voice in building the desired health system.

2.6 Final considerations on caregivers in China and the healthcare system

In China, non-communicable diseases rise tremendously in the last decades. As of 2010, the leading death causes have constituted chronic respiratory tract diseases 13.5%, heart diseases 20.8%, cerebro-vascular diseases 23.4%, and malignant tumors 26.5% (Meng et al., 2015). Such diseases imply patients' need for special care, which is usually provided by family caregivers. Despite overwhelming responsibilities and efforts in assistance, there is a tremendous scarcity of services dedicated to caregivers in China. The existing ones usually benefit caregivers indirectly through governmental financial help to patients. The governmental laws oblige all the family members to take care of the sick family member, especially children expected to comply to caregiving multiple responsibilities because of the Chinese cultural value of filial piety (Liu, 2013). Such a cultural set-up has not stimulated the creation of dedicated services, however in the current time-point, families mainly consist of the single child, who is likely to have his/her own one or two children and a spouse, and a career, caregiving becomes even obsolete. However, empowered by the Confucianist concept of endurance (Liu, 2013), most Chinese people comply with caregiving and prioritize the family member's well-being as the primary need. As a result of emotional, mental, and physical friction, caregiving may intervene in individuals' mental and physical health and menace personal and family growth (Rait, 2015). As the physical and emotional well-being of a caregiver impacts the quality of provided care, it is critically important to counterbalance the distress.

The chapter has illustrated how China has a hospital-centric, fragmented and volume-driven healthcare system that prevents this kind of support (Meng et al., 2015; World

Bank Group et al., 2016; World Health Organization, 2015). The recent healthcare policy “Healthy China 2030” has been emphasizing the importance to transit to a people-centered integrated care model, but the infrastructure serves as a multilayered barrier to transit, such as “institutional fragmentation, diffuse leadership and conflict of interests” (World Bank Group et al., 2016: 120). The policy summary “Deepening Health Reform In China. Building High-Quality And Value-Based Service Delivery” created by the Chinese government, the World Bank Group, and the World Health Organization describes the obstacles for the Chinese healthcare system. It proposes eight levers with detailed steps to leverage the challenges, for example, institutional collaboration. The conditions imply interventions “to be deep, comprehensive, and implemented in a coordinated and deliberate manner” (World Bank Group et al., 2016: 123).

This scenario offers a design opportunity for this thesis to follow some of the people-centered integrated care reform levers to explore how healthcare system actors' interplay and the inter-learning process could be enhanced (e.g. city hospitals, primary care facilities, and district hospitals) and better address the family caregivers' needs (World Bank Group et al., 2016). Moreover, integrated care calls for an open dialogue and direct involvement of patients, healthcare workers, administration of governmental institutions of different levels, private clinics and non-profit organisations, suggesting the need for collaborative approaches to healthcare innovation.

Given all these, the next chapter will investigate how PSSD is applied for healthcare reform with particular attention to integrated

care system design and existing collaborative health delivery services between different institutions. These findings will inform the methodology of the present research.

SERVICE SYSTEM DESIGN approaching healthcare and people in crisis

Introduction

Family caregivers' matter tackles two sensitive spheres: society, being represented by the family caregivers, and the healthcare system, as an environment where family caregivers navigate through and interact with throughout their experience. Therefore, it is essential to understand in which way design can help to tackle both of the complex systems: the vulnerable humans and the healthcare.

3.1 Family caregivers, the fragile and robust society.

"Contemporary societies are fragile" - points out Ezio Manzini in his paper about social resilience (Manzini & Thorpe, 2018). One of the contributors to this fragility is the catastrophic events, which deviate the usual course of events in people's lives and threaten the emotional integrity. Among social or economic crises on macro or micro scales, the situation of sudden disease or aggravation of family members' health state also manifests into a crisis period for the family caregivers. It puts people into a physically, emotionally, and financially vulnerable position. The researchers currently present various design

techniques to help people in crisis while minding their vulnerability and uncover the relation of the Service and System Design to fostering people's resilience in a situation, such as family caregivers. Specifically, Manzini refers to these designed outcomes as product-service systems "artifacts, events and activities", highlighting the mandatory cautiousness and consideration of people's vulnerability when designing for them (Cipolla, 2018; Manzini & Thorpe, 2018). Service System Design has the power to take a step up here. That is to say that service system designers can design the context while considering its prerequisites, which will influence the quality of these encounters and be the nourishment for the thriving environment to emerge and shape the socially desired resilience (Cipolla, 2018; Manzini & Thorpe, 2018).

As scholars claim, vulnerability shall be considered an ultimate leitmotif when designing. Interestingly, although while fragility is generally considered as a negative aspect or even a problem, Cipolla argues that it could be a positive and powerful "guideline for design" (Cipolla, 2018). She highlights four design enablers by virtues of their mechanisms and effects:

- *artifactual enabler*, designed to mediate collaboration and interpersonal relations relying on product design expertise;
- *attitudinal enabler*, designed to facilitate expression of personal attitudes or feelings to others depending on the open-ended design process;
- *processual enabler*, designed to foster interpersonal relations through a sequence of steps, relying on service design expertise;
- *narrative enabler*, designed to stimulate interpersonal relations via a personal interpretation of incidents or events, or an organized, assembled fictional narrative, relying on storytelling.

Based on people-to-people and people-to-objects relations, Cipolla also presents five findings to guide the design practice for vulnerability. I highlight the ones connected to people-to-people relationships:

- *relations have a "serendipitous nature"-relations can only be proposed as a possibility;*
- *relations shall not imply highly demanding interpersonal effort;*
- *if the state of vulnerability is shared among the participants, the relationships will be fostered, and greater openness, therefore robust resilience empowerment achieved;*
- *relations are concrete and demanding mutual presence in a specific time and place;*

Given this, when designing for a vulnerable society, such as family caregivers, designers shall consider designing enablers fitting the vulnerability implications so that it has the to transform into resilience. Lastly, the research

also shows that the actual designed practice for vulnerable groups requires designers to embrace the design process's unpredictability and results, and accept to have little control over the dynamic (Cipolla, 2018).

Besides proposing guidelines for design for vulnerability, the researchers also suggest approximate renderings of these frameworks. Manzini shows that the key to addressing crises and enabling people's resilience could be proximity to a place and collaboration, the power of a community, or "place related communities" (Manzini & Thorpe, 2018). However, for these communities to meet and eventually sprout into collaborative organizations, facilitation of encounters is required. The encounters are "relational" therefore, cannot be directly designed, unlike the conditions for these encounters, which, as noted above, shall consider the vulnerability and openness of people. Additionally, researchers stress that the vulnerable groups' participation implies disclosing oneself, which might feel risky and intimidating, and consequently be the barrier to forming communities and building meaningful relationships (Cipolla, 2018; Manzini & Thorpe, 2018). The encounters shall be facilitated by enablers and taking place in de-risked environments to enhance the sense of protection. Therefore, designers shall pay special attention when conducting design projects for vulnerable groups. However, they can also be well-equipped with empathic design tools to respond to these concerns (Freire & Sangiorgi, 2010; Manzini & Thorpe, 2018).

3.2 Innovation in healthcare

Healthcare systems worldwide represent complicated socio-technical mechanisms composed by multiple actors and networks with complex interactions (Ehrenfeld, 2019) in-between and “formalized institutional arrangements” (Vink et al., 2019: 21). Modern healthcare systems have been established in the previous century; now, their majority is patient-centric and were built to respond to the patients’ emerging needs back then. Currently, the healthcare system faces “two-folded challenges, either emerging from the demand side (the service receiving side) or from the supply side (the service delivering side)” (Decouttere & Vandaele, 2013: 14), or the “interplay itself between organizational design and staff-client interactions that co-produce care issues” (Hyde & Davies, 2004: 1408). The totality of healthcare problems is called by Norman and Stappers DesignX problems in DesignX socio-technical systems and emphasizes the three categories of issues, which are essential to consider when designing for healthcare. They are presented below (Norman & Stappers, 2015):

The Psychology of Human Behavior and Cognition:

1. System Design that Does Not Take into Account Human Psychology.
2. Human Cognition: The Human Tendency to Want Simple Answers, Decomposable Systems, and Straightforward Linear Causality.

The Social, Political, and Economic Framework of Complex Sociotechnical Systems:

3. Multiple Disciplines and Perspectives.
4. Mutually Incompatible Constraints.

The Technical Issues that Contribute to the Complexity of DesignX Problems:

5. Non-Independence of Elements
6. Non-Linear Causal Relations: Feedback
7. Long and Unpredictable Latencies
8. Multiple Scale Sizes
9. Dynamically Changing Operating Characteristics

Given these challenges, designers have to pay particular attention to human psychology, the social, political, and economic framework, and the system’s technical aspects. The local context of healthcare, the “social ecosystem, and organization” (Jones, 2014), shall be the nutrient to inform healthcare innovations.

Some public services, such as healthcare systems have failed, and many times due to the lack of human-factors and human-design (Norman & Stappers, 2015), lack of dialogue between the stakeholders and disconnections (Junginger, 2017). Given this, currently, the topic of healthcare has been questioned. A variety of topics has been raised accordingly, for example switching from the standard, disease-centered approach to a patient-centered (Decouttere & Vandaele, 2013) or even consider the entire environment of a patient, including the quality of interaction with their caregivers (Decouttere & Vandaele, 2013; Pfannstiel & Rasche, 2019), and target to reach a comprehensive, a family-centered approach (Jones, 2014). This response means observing the patient’s stakeholders and observing the family to be also the service user during the patients’ treatment. Therefore, it is crucial to move healthcare to a more inclusive system. However, it is challenging because the healthcare system is conceived as an inflexible and rather change-

resistant environment (Taysom & Crilly, 2017; Vink et al., 2019). Thus, there is a paradox of a need for change within an environment that can hardly change.

3.3 Service System Design tools

To understand the potential contribution of Service and System Design within the healthcare innovation, the definition of the disciplines should be made.

Service design is described as “a collaborative and creative approach focused on imagining and enabling new forms of value co-creation between actors” (Vink et al., 2019: 22). The collaboration empowers diverse actors to sit around the table and experience “novel ways of integrating resources enabling service innovation” with a different resolution of projects “across different levels of aggregation” (Vink et al., 2019).

According to Peter Jones, Systemic design is “an orientation, a next-generation practice developed by necessity to advance design practices in systemic problems. Approaching this magnitude of problems differs from other emergent design approaches through “scale, social complexity, and integration” (Jones, 2014: 2). Systemic design methodology can arrange and solve the issues and gaps of multilayered systems which “encompass multiple subsystems” (Jones, 2014: 2). By integrating systems thinking and its methods, systemic design “brings human-centered design to complex, multi-stakeholder service systems, such as industrial networks, transportation, medicine, and healthcare” (Jones, 2014).

Knowing the characteristics and the complexity of the healthcare system, Service

and System Design can respond to healthcare innovation by definition. The disciplines are well-equipped with a variety of tools that facilitates the healthcare innovation process. In their research Karine Freire and Daniela Sangiorgi point out the three design paradigms for the healthcare system (Freire & Sangiorgi, 2010):

- *Mass-production*, where the focus lies in “the application of expert knowledge to treat illnesses and on service efficiency” (2);
- *Mass-customisation*, where healthcare providers started applying customer research to tailor the service offering to specific needs of people “while keeping the sequential approach to value creation” (2)
- *Mass-collaboration*, where the healthcare system is led by the needs of the patients rather than path making without considering the multiple actors related to the healthcare, e.g. the ones receiving care or the ones who informally provide it. (3)

Also, Peter Jones highlights four domains for designers’ design process, namely “Design 1.0 to Design 4.0”. The division highlights interventions on different scales (Jones, 2014):

1. *Artifacts and communications*: design as making, or traditional design practice.
2. *Products and services*: design for value creation (including service design, product innovation, multichannel, and user experience), design as integrating.
3. *Organizational transformation* (complex, bounded by business or strategy): change-oriented, design of work practices, strategies, and organizational structures.
4. *Social transformation* (complex, unbounded): design for complex societal

situations, social systems, policy-making, and community design.

These stages represent the advancement “from simple to complex with a series of learning and skill stages necessary for negotiating increasing complexity”. It helps designers to navigate ambiguity and better see the horizon of interventions. Jones also claims that healthcare system design projects should be perceived as “Design 4.0”, implying the complexity of design interventions spaces: clinical practice but also policy, “the whole-system ecology that becomes the target of design” (Jones, 2014). This concept of the four domains of design process embodiment is inter-connected; every next stage includes the previous one. Therefore, design for healthcare implies changes on all the levels: “artifacts and communication; products and services; organizational transformation” (Jones, 2014) For example, an exhaustive design intervention for family cancer caregivers would include a D1.0 design solution, e.g., service advertisement. Next D2.0 could be rendered into a cancer information website. Moving to D3.0, a hospital might offer a specialized clinic unit for psychological support for family caregivers. Lastly, D4.0 might be the co-creation of a community organized for cancer caregivers staffed by caregivers and clinicians. These interventions convey different amounts of sense-making (consensual understanding of the functions of a problem area, becomes a critical requirement in situations of high complexity) (Jones, 2013) and strange-making (a process of differentiating form to capture attention) (Jones, 2013). The focus of sense-making, unlike strange-making, is directly proportional to the grade of the Design domain. It is represented in Figure 3. Therefore, navigating on higher levels of the

framework, designers focus on detangling the healthcare problems rather than differentiating the solution.

Peter Jones points out the framework listing five design methods for service designers in healthcare, the D4.0 domain:

- *Human-centeredness* - understanding of human activity and human concerns;
- *Iterative inquiry* - requiring the learning and re-integration of new thinking that occurs over successive explorations;
- *Convening stakeholders* - participants must have a personal stake in the outcome of the intervention;
- *Dialogic process* - enabling the connection of diverse stakeholders to the joint processes of inquiry and design;
- *Multiple design actions over time* - exploring the full dimensionality of a problem throughout the inquiry.

In what follows, there are presented multiple Design approaches, which empower Service and System Design to enable innovation in healthcare.

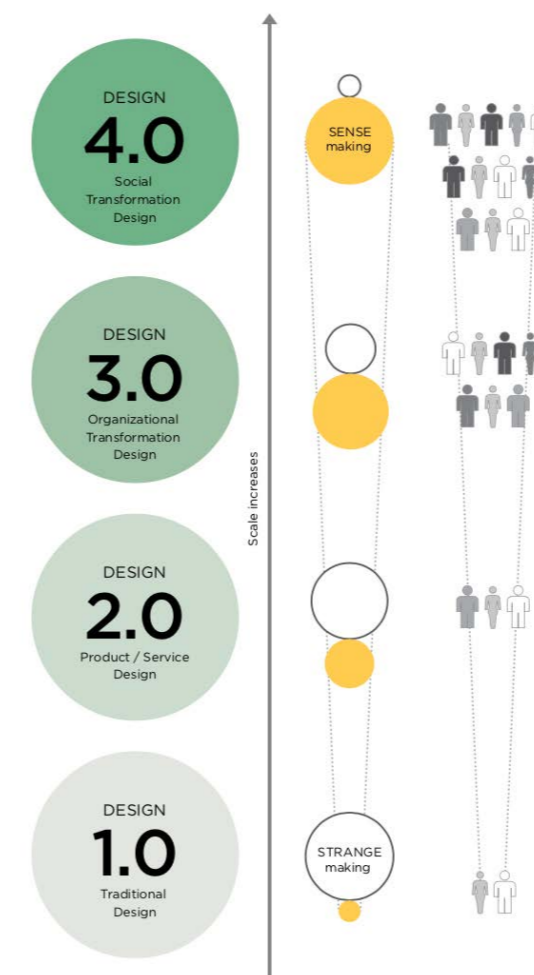


Figure 3. Design geographies and complexity scale (Jones, 2014: 8)

Framing the desired future

Service System Design is known to flourish a “pluralism of approaches” (Buchanan, 2019) and thanks to the “designerly thinking”, able to design a solution going backward: starting from the desired future can respond to the initial challenges of “what?” and “how?” (Dorst, 2015). As the designers widen their approach by discovering possible futures, and then condense the aspirations into ‘How’ questions to reach these futures, or, as Dorst points out, framing is “the act of proposing a new how” (Dorst, 2019). Framing naturally implies a highly contextual analysis, it provides

no clear identification of the problems that designers may address. Instead, the design turns away from the complexity of situations and surroundings and toward the obstacles and problems faced by human beings in concrete situations, creating environments (Dorst, 2019). That is to say that when approaching the matter of healthcare, designers might go broad in weaving the desired future and always nourish these visions based on the contextual analysis, which is especially crucial for projects in healthcare.

Multi-stakeholders dialogue. Co-design, co-creation, co-production

Innovating healthcare implies considering the variety of its components. It is claimed to be a “process of integrating resources in novel ways to enable new forms of value co-creation among actors” (Vink et al., 2019). Given this, the question is, who are the actors within healthcare systems and how to make them dialogue? Design studies claimed the current core actors to collaborate within designing a system are “academia, industry, government, and society” (Schütz et al., 2019). The challenge is to find incentives and practical ways to build “strategic coalitions”, which will be actively dialoguing throughout the design process” and finally build up a “roadmap for change” (Van Selm & Mulder, 2019).

Designers are invited to create of platforms to facilitate the co-creation of these newly designed offerings and enable the dialogue between actors. Moreover, besides implying various institutional actors, nowadays, the practices try to go away from the usual “monopoly of knowledge” (Freire & Sangiorgi, 2010). The users, in this context, are considered experts to contribute to building

the new paradigm. Multi stakeholders' active involvement has been a novel practice that disrupts the traditionally closed healthcare service delivery by giving the microphone to the citizens, the end-users of the system. What regards the collaborative design of the healthcare services, Sangiorgi and Freire (2010) point out three types of approaches:

- *co-design*, where there is a partnership between professionals, and individuals, as family, and patients;
- *co-production*, where users take an active role in delivering the services in an "equal and reciprocal relationship between the professionals and the family/neighbourhood/community";
- *co-creation*, where users "are central in the design, production and their continuous development".

Speaking particularly of the participation of the society in the healthcare design, Peter Jones claims that when the society takes an active role, "responsibility for the process is transferred to the stakeholders as a normative practice, following the principle that social and policy design is owned by the stakeholders who live with and benefit from the outcomes" (Jones, 2013: 28). Stakeholders' participation in healthcare projects is also connected to designers' probability to make poor design decisions. Jones also points to designers the importance of designing no harm, and despite the empathy design methods, there is a high risk of disregarding very important matters. Poor design decisions insignificantt ruin lives, therefore engaging multiple stakeholders on every stage of the process is crucial. Efficient participation of multiple stakeholders in, for example, mapping exercises might be

challenging (Van Selm & Mulder, 2019). However, multiple actors' contributions always help to obtain a clearer identification of design intervention possibility (Buchanan, 2019).

Given the different degrees of participation, there can be a multitude of outcomes. However, all will reflect responses to the users' actual needs in healthcare, as designers apply a human-centered design framework (Norman & Stappers, 2015). Therefore, implying the multitude of actors in Service and System Design practices in healthcare are crucial. Governments recognize they help to reach higher public engagement and therefore transparency, and ensure the start of the dialogue between stakeholders (Fry, n.d.) and reach "effective 'clinical pathways' and patients' experiences" (Freire & Sangiorgi, 2010: 2).

Mapping

Within framing and collaborative creation sessions with multiple stakeholders, designers will extensively use mapping tools. Namely, Gigamaps and Synthesis Maps are the "two types of system maps developed for working with socially complex problems" (Jones & Bowes, 2017: 230). The maps structure, organize the gathered contextual analysis and represent a "visual narrative" (Jones & Bowes, 2017: 230) aiming to help comprehend the complex "actor-relationships within a system of concern to stakeholders and informed audiences" (Jones & Bowes, 2017: 230). For example, the result of a synthesis map shapes the design challenges. It reveals design opportunities (Jones & Bowes, 2017) to "create environments that may support and improve the quality of human experience" (Buchanan, 2019: 85). These visualization

tools directly contribute to the design outcomes, and are particularly useful for complex Service and System Design projects.

3.4 Conclusion

Healthcare system is a complex, socio-technical mechanism that requires the ability to navigate through the multitude of stakeholders and complicated interactions between and the vulnerability of the end-users: patients and family members. Service System Design, however, can approach both sides of the coin and contribute to solving the matters with its variety of methodological tools, for example, 1) contextual research; 2) framing; 3) mapping; 4) co-creation; 5) human-centered and empathic design.

A fundamental challenge, within the application of the approaches mentioned above, is the "deeply rooted model of social interaction", which opposes healthcare services' "radical transformation" (Freire & Sangiorgi, 2010). It constitutes an inflexible system resisting changes. Even if ready for change, healthcare systems use to run incremental and limited transformations, "directed in a bottom-up way: adding more and more incremental improvements to the operational models under study" (Decouttere & Vandaele, 2013: 3) rather than holistic and radical changes, which are needed.

Researches show that design for healthcare a-priori requires a careful contextual analysis to discover all the existing components of the highly inter-wined and meticulous healthcare system, which will shape the newly designed system (Jones, 2014). Analyzing the context will inform the design process next step. Researchers suggest orchestrating multiple

actors of the complex socio-technical systems "to create their own value by co-producing offerings" (Freire & Sangiorgi, 2010: 2). The built "partnership between society, professionals, and community working together in the design development process" (Freire & Sangiorgi, 2010: 3). is considered co-creation of "ordinary people generating the content of services and shaping their nature" (Freire & Sangiorgi, 2010). These constellations of actors working together are essential to ensure meeting every actor's needs within this collective production of the new types of offerings. These activities need facilitation, and this is again where Service System Design is empowered. The design process has the competence "to challenge hierarchy and silo-mentality by facilitating co-creation" (Fry, n.d.) and, therefore, achieve a broader and inclusive engagement of users, starting from the patients to the family members. Moreover, within the work with a multitude of actors, mapping tools are extensively used by designers. They trigger visualizing opportunities and challenges, nurture coming up with novel design solutions for complex projects, requiring a systemic view, such as design for healthcare (Jones & Bowes, 2017)

Importantly, the practice and research highlight designers' need to consider the high-sensitivity of patients and their families. Therefore designers need "to develop news skills, sensitivity and attitudes" (Freire & Sangiorgi, 2010). Thus, the vulnerability of people plays a central role within the context for the design; designers need to apply empathy in the design process, and also consider features of design for resilience, where community building offers a significant contribution, to address the vulnerability (Manzini & Thorpe, 2018). Moreover, several

enablers are pointed out, which contribute to enhancing the resilience of groups. The attitudinal, processual, artifactual or narrative enablers empower people to facilitate interactions and build their strengths (Cipolla, 2018). These enablers constitute touchpoints of different design disciplines, including Service and System Design, which offers potential in redesigning services for caregivers and improving the healthcare landscape.

4

METHODOLOGY

4.1 Aim and objectives

The research aims to investigate *“how PSSD methods can build a system to alleviate the burdens of Shanghainese families”*, because according to the conducted research of the topic, caregivers in China and Shanghai are poorly supported. Therefore, designing an intervention for this topic will contribute to closing the gap both in research and practice. More precisely, the study will target caregivers in the critical stages of caregiving studying both the needs of experienced caregivers who have already overcome such phases in their experiences, and those who are experiencing them currently. The study will apply design research methods to firstly shape the pains and needs of caregivers and then discover and orchestrate the existent players.

To achieve this goal, this paper pursued six main objectives:

1. *Understanding the phenomenon of caregivers in general, and Chinese caregivers in particular;*
2. *Comprehending healthcare system and support organisations for caregivers in China and particularly Shanghai, and globally;*
3. *Analysing examples of Service Design*

contribution to address family caregivers’ needs;

4. *Understanding the actual experience of Shanghainese family members who are or who have been in acute periods of caregiving;*

5. *Developing a concept of a support system addressing the identified needs and existing resources.*

The particular methods to address these objectives are described below:

1. To address the first objective, desk research were conducted. The studied papers encompassed the following topics: challenges of becoming a caregivers, the concept of change, implications of caregiving, and Chinese cultural aspect of caregiving.
2. To reach the second and third objectives, I conducted desk research regarding the healthcare system in China, Chinese caregivers’ experiences, and their burdens, as well as exploring innovative healthcare services worldwide, design interventions in healthcare, services for caregivers in China and Shanghai.
3. To address the fourth objective, I conducted a field research in several

Shanghainese Hospitals, and interviews with medical workers: doctors, nurses, social workers, care-workers, and with caregivers in emergency, acute period of caregiving and those, who have overcome it;

4. As for the fifth objective, I conducted a co-design workshop and a validation session with medical workers and caregivers to review the data and ideate multiple scenarios: one concept has been then developed and elaborated using service design visualization tools.

The conducted activities and the action framework are described below in more details.

4.2 Methodology

Healthcare is a sociotechnical system of high complexity (Taysom & Crilly, 2017; Vink et al., 2019;), where there are implied multiple actors, on many levels, and there are raised very sensible topics. When targeting service innovation, such complex system requires a holistic approach, whose outcome need to tackle the four layers of practices of the whole-system ecology of services (Jones, 2014) and imply institutional changes on macro and micro levels (Vink et al., 2019). In order this to be achieved, need ‘enabling new forms of value co-creation among actors’ (Vink et al., 2019). Giving the floor to the different actors is considered as a indispensable innovation condition and duty of designers (Schütz et al., 2019). Service and System Design approach integrates knowledge “across the social-organization-service levels and defines new artifacts (for example, integrated products and services) that adapt to the market (social)

ecosystem and organization” (Jones, 2014). Therefore, it has been chosen as the fitting framework able to address these and allow beneficial changes and building strength, yet flexibility of organizations with “institutional arrangements that are resistant to change” (Taysom & Crilly, 2017; Vink et al., 2019).

In order to hit the thesis objectives within this healthcare project, Double Diamond Design Process is taken as a framework. Double Diamond is “a clear, comprehensive and visual description of the design process” where “the two diamonds represent a process of exploring an issue more widely or deeply (divergent thinking) and then taking focused action (convergent thinking)” (Design Council, 2020). The two diamonds consist of four phases: Discover, Define, Develop, Deliver and imply a non-linear approach, but rather iterative approach of work in loops of phases until the result is achieved. Moreover, the Double Diamond model suggests Design Principles, which perpetuate around people-centredness, visualisations, co-creation, and iterative loops. These principles served as a recurrent method within this thesis project, whose process is represented in figure 4.

Furthermore, the project involved different people in the research and design activities as detailed in the following table 2. Their roles and positions are described in the legend.

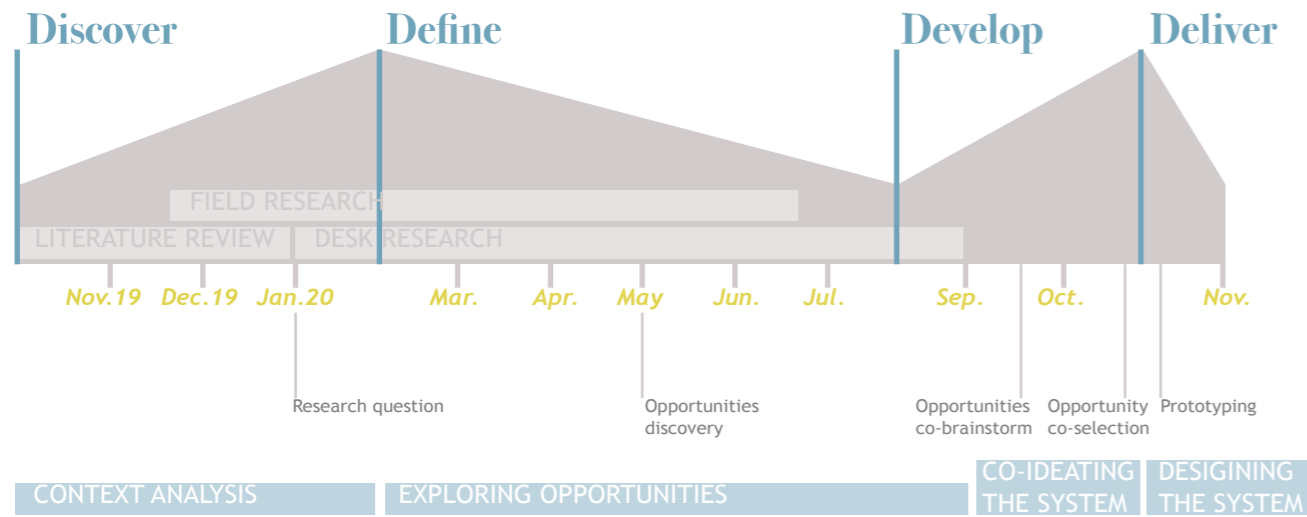


Figure 4. Project design process

Ninth People Hospital

- 1. Nurse 1 - ICU department, pulmonary section, Ninth People’s Hospital
- 2. Doctor 3 - Respiratory outpatient and inpatient departments.
- 3. Doctor 4 - Respiratory inpatient department.
- 4. Social work student 1 - Postgraduate student majoring in social work at Shanghai University, intern at Ninth People Hospital
- 5. Care-worker 1 - Respiratory inpatient department.
- 6. Caregiver 6 - caregiver for his wife who has an acute pancreatitis emergency
- 7. Caregiver 7 - caregiver for his mother with chronic intestine problems
- 8. Social work student 2 - Postgraduate student majoring in social work at Shanghai University, intern at Ninth People Hospital

Shanghai East Hospital

- 9. Doctor 2 - Professor in the Medicine Faculty Tongji University, and Head of stem cell department

Tongji Hospital

- 11. Caregiver 1 - caregiver for his mother multimorbidity illnesses, including heart disease
- 12. Caregiver 2, 3 - mother and daughter, caregiving for the husband/father, who has locomotory problems and chronic heart issues
- 13. Doctor 1 - surgeon at liver and pancreatic cancer department

Referrals

- 17. Nurse 3 - Chief Nurse, Inpatient Department, Pulmonary Hospital
- 18.. Caregiver 4 - caregiver for her father with prostate cancer
- 19. Caregiver 5 - periodically caregiver for her sister with untreatable respiratory disease

Shanghai Changzheng Hospital

- 10. Caregiver 8 - Caregiver for his mother with multimorbidity sicknesses

Fangsong Community Health Care Service Center

- 15. Doctor 5 - General Practitioner (Chinese Medicine) at Fangsong Community Health Care Service Center
- 16. Nurse 2 - nurse at Fangsong Community Health Care Service Center

Renji Hospital

- 20. Social worker 2- Medical social worker
- 21. Hospital admin - Assistant Researcher, Deputy Chief of Medical Department

Table 2. Information about all participants within the whole duration of the research (Nadejda Cervinscaia, 2020)

Activity	Description of the activity	Interaction	Participants
Field research	Preliminary, non-structured interviews were conducted in Tongji Hospital, emergency department. The participants responded to questions regarding caregivers reality and challenges. The majority of in-depth interviews were conducted in Ninth People Hospital. All the interviewees responded to questions regarding the healthcare system and caregivers’ challenges.	Face to face	Doctor 1 Caregiver 1 Caregiver 2 Caregiver 3
		Online call	NGO chairman Caregiver 4 Helen Caregiver 5
		Face to face	Caregiver 6 Caregiver 7 Doctor 2 Doctor 3 Doctor 4 Nurse 1 Social worker 1 Care-worker 1
Co-design workshop	Participants explored the context using persona and user journey map tools. Then, they defined multitude of issues, their cultural components and focused on one problem reflected by the ‘how might we?’ question. They envisioned solutions for the selected problem using ‘tomorrow’s narrative’ tool.	Collaborative session in an office	Doctor 2 Doctor 5 Nurse 2 Social worker 2 Hospital admin Social work student 1 Social work student 2 Caregiver 4 Chairman of Lymphoma Home NGO
Concept validation session	Participants familiarised themselves with 7 cards visualizing ideated service visions. Then, they assessed the prerequisites of each of the visions and marked their possibility to take place in the current reality. Then, they gave final feedback for each of the visions.	Face to face	Doctor 3 Doctor 5 Social worker 2
		Online call	Hospital admin Nurse 2 Nurse 3 Caregiver 1 Caregiver 4 Caregiver 8

Discover Phase (Oct.2019 - Feb.2020)

Discover phase is positioned in the first diamond, which helps people understand the topic, and frame the challenge. It involves speaking to and spending time with people who are affected by the issues (Design Council, 2020). Within this phase there was conducted a literature review, desktop research on the topic of caregivers in general, it helped to preliminary frame the challenge and to discover the first research findings, which consequently serve as pillars for the next activities of the thesis. The studied papers encompass the following topics:

- *challenges of caregivers in general and those in critical phases of caregiving;*
- *the concept of change, implications of caregiving;*
- *Chinese cultural aspect of caregiving.*

Moreover, there was taken a comprehensive overview on the organization of the healthcare system in China, services for caregivers in China and Shanghai. In order to assess the state of the services in China, there were also analysed the contrasting healthcare services for caregivers all over the world, created both by non-designers and expert designers. Lastly, within this phase, there were conducted preliminary, non-structured interviews with a doctor and four caregivers, based on the initial findings from the literature review. The interviews casted light on new topics, and also filtered or detailed and reinforced the findings from the literature review. The selection criteria was based on the acuteness of the disease, the caregivers were recruited in the emergency department in a Shanghainese Hospital, as well as the doctor, who daily deals severely ill cancer patients.

Define Phase (Mar. 2020 - Aug. 2020)

In the Define phase, the methodology proposes to articulate the insights gathered from the discovery phase and define the challenges in a distinct way (Design Council, 2020). Coherently, there were prepared qualitative semi-structured interview guides tailored to specific interviewees, lasting max 1 hour. These contributed in synthetizing the found data, and condensed the findings into solid topics. The interview questions and the interviewees were informed by the findings from the previous phase. Specifically, there were conducted interviews with four doctors from three Shanghainese Hospitals, one nurse, one social worker, one care-worker. All of the interviewees received either printed or verbal description of the research and have given their consent in using their interviews/pictures for the current research purposes. The primary selection criteria was based on the interaction with severely ill patients, and their caregivers. Also, there were conducted interviews with three caregivers, who are or have been in a critical phase of caregiving experience, also the demographic data such as sex, age, occupation aimed to be different in order to have an exhaustive overview

Semi-structured interviews

“Semi-structured interviews are in-depth interviews where the respondents have to answer preset open-ended questions and thus are widely employed by different healthcare professionals in their research.

Semi-structured interviews are based on semi-structured interview guide, which is a schematic presentation of questions or topics and need to be explored by the interviewer.” (Jamshed, 2014: 87).

on a different population. The majority of interviews was conducted in Chinese with the support of two Chinese native speakers, who were well informed in the area of the research. The interviews were recorded and transcribed in Chinese and/or English. Moreover, there were made observations within the visit of the Neighbourhood Committee, the neighbourhood authority organ. The selected Neighbourhood Committee operates in the partnership with the social work department of one of the explored Hospitals. The author gained informational materials, however they refused to participate to an in-depth interview.

Within this phase, the interviews were analysed using abductive sensemaking process (Kolko, 2010) on a digital canvas platform Miro. Within this process insights were identified. The findings converged into several personas, and initial topics/problematics which were to be explored later within the Develop phase.

Persona

Personas are fictional, conventional figures that encompass users’ needs, frustrations, and behaviors. These characteristics serve as a basis for a value proposition creation (“Interaction Design Foundation,” n.d.; West & Di Nardo, 2016).

Develop Phase (Sep. 2020 - Oct. 2020)

In the Develop phase, the Design Council Double Diamond methodology suggests that the second diamond “encourages people to give different answers to the clearly defined problem, seeking inspiration from elsewhere and co-designing with a range of different people” (Design Council, 2020). Speaking specifically of co-creation and people-centredness within complex systems, Service and System Design is claimed to be the enabler of diverse actors to come on one stage and to constructively dialogue, which contributes to aligning actors on a common ground and building a common future, nourishing the perspectives of the many participants (Vink et al., 2019). Design scholars claim that implication of the diverse and numerous actors might be challenging, there is a risk that the different “motivations and interests of participants might become a barrier to communication and lead to an unbalanced power dynamics, and mere verbal expression and conventional thought patterns may limit possible ways of envisioning desirable futures” (Schütz et al., 2019: 132). In order to address this, scholars suggest using the Service and System Design co-creation tools,

Co-design workshop

“Co-design workshops are a technique to explore and articulate actors’ needs and ideas, organizing joint creativity and co-creation of new solutions” (Vink et al., 2019: 28). They are seen “as part of the user activities leading to the stakeholder insights” (Decouttere & Vandaele, n.d.: 24)



Figure 5. Team B participants working on the problem definition tool within the workshop.

so that diverse participants can synchronously outer their point of views in a creative way, and co-build envisioned futures based on the identified context and its issues (figure 5 and figure 6). Given this methodological framework, a tight collaboration with diverse actors from the medical sector was the leitmotif of the current thesis project, the experts were implied in different stages of the project, but especially the Development phase, and served as a major resource in the creation of the final design concept.

Using the Product Service and System Design framework, there was planned and conducted a four hours co-design workshop. The recruited participants for the workshop were medical workers: two doctors, one social worker, two senior social work students, one nurse, one hospital administration staff and an experienced caregiver for a patient with a severe disease, who has participated in the previous Discover phase. Other participants were recruited according to the set criteria via social media or referencing. The workshop had three objectives: 1) exploring the topics and problems within the stories of the

ideated personas; 2) defining and prioritizing the identified problems, and 3) ideating a future vision of a support system in Shanghai. The workshop was conducted in two groups, being facilitated by the author in English and by a volunteering Designer, Chinese native speaker, with the group who was less confident in English. The workshop flow was designed by the author, being composed by series of design tools, and other tools designed and tailored specifically for the workshop. Within the first two objectives, there were identified initial problematics, factors opposing changes as well as design questions. Importantly, the workshop also tackled the Chinese cultural aspects in caregiving in terms of issues or situations regarding the caregivers' topics (Liu, 2013). As culture represents the ultimate context of solution, the findings of this domain served as a backbone for the next step, therefore this needs to be thoroughly explored to become a frame and facilitate non-conventional approach to problem solving (Dorst, 2015). Within the third objective, namely ideation of future solutions, the participants used a

PROBLEM DEFINITION					2
1 Let's think of the issues deeply. Why are things happening this way? What is missing? What is behind the issue?					2 Now let's define the 1-2 main problems to solve.
What contributes to the issue? How?					Problem 1
Issue1	why is it happening?		Does this issue have a cultural component? Which one?	Let's prioritize the issues:	Caregiver who _____
Issue2	why is it happening?				tries to _____
Issue3	why is it happening?				but _____
Issue4	why is it happening?				because _____
Issue5	why is it happening?				How might we _____
Issue6	why is it happening?				when/while _____?
Issue7	why is it happening?				Question 1
					Problem 2
					Caregiver who _____
					tries to _____
					but _____
					because _____
					Please, formulate the focusing question!
					How might we help caregivers to _____
					when/while _____?
					Question 2

Figure 6. The developed tool 'Problem Definition', aiming to identify the nature of issues and focalize on the main problem to ideate solutions on.

participatory prototyping tool, which implied an effective interaction (Schütz et al., 2019) to produce the magazine of the future featuring the desired support system being in place (Schütz et al., 2019). Finally, within the workshop, there was adopted a judgment-free approach, as Kies Dorst suggests, such a practice aims at stimulating a genuine opinion sharing, which is worth a deep think by itself, and insight creation (Dorst, 2015), besides having the produced artefact as the output of the workshop.

The generated materials were translated and analysed by the author on the Miro digital canvas platform and generated 'How might we?' questions, from which brainstorming process started. The generated visions and ideas generated by the participants within the workshop were also included. This process nourished the ideation of seven service design concepts, which were to be validated with different stakeholders (medical experts and caregivers).

The 30-45 minutes of individual validation was conducted according to the pre-prepared

validation guide and service concepts. The recruited participants were: three of the medical workers from the previous phase, one head nurse, who is novel to the visions and two caregivers, one novel, one from the previous phase. The recruitment criteria was selection of participants who have known the project and contributed to the ideation of the visions, and also external experts, who are not aware of the design process. Finally, based on the feedback gathered within the validation sessions, the author synthesized the findings into one solution.

Important to mention, within the entire process of interaction with the participants, video and photo materials have been taken. The participants whose faces are not blurred in this thesis, agreed for the author to use the pictures in the thesis without anonymizing the appearances.

Deliver Phase (Nov. 2020)

In the Deliver phase, according to the Design Council, there is thorough prototyping of different solutions at small-scale, rejecting those that will not work and improving the ones that will (Design Council, 2020).

Hence, the author visualized the system using diverse design tools. Specifically, the ideated organization “Rituals. Balanced Care Centre” were illustrated in an offering map tool. The solution implies the multi-stakeholder interactions within the complex sociotechnical system, mapping tools are extensively used. Within the proposed support system there are highlighted the newly established interactions of diverse nature, the required activities of the program and its touchpoints.

4.3 Conclusion

Product Service System Design framework effectively served to approach this research. Within the double diamond process, I could apply diverse design tools to reach the proposed objectives in discovering the context, defining the problem, developing opportunities and, finally, focusing on one concept to develop and deliver.

The major resource for this project was the tight collaboration with a multitude of actors with diverse roles: health professionals, hospital administration, family caregivers. Design tools facilitated communication and effective expression of actors’ viewpoints within all the stages of the research. Despite the fact that the participants were new to the proposed tools, they could effectively use them and, as they said, liked the creative approach of understanding the reality.

As a result, I could ideate the “Rituals. Balanced Care Centre” service solution, which benefited from being illustrated through other design tools within the deliver phase.

Finally, the Product Service System Design framework showed it’s potential to be applied for projects in healthcare.

DESK RESEARCH.

Services for caregivers worldwide and in China

5.1 Interventions for caregivers by non-designers

In many countries, there are interventions for caregivers. Policymakers and healthcare facilities create some of them, others are created within a design process framework. In what follows, there will be described initiatives developed within both of the approaches.

Policymakers and organizations have vastly developed the arena of services for diverse types of caregivers. The desk research reveals many supportive strings, existing mainly in the US, Scandinavian countries, Singapore. Usually, the help to caregivers fluctuates around the following domains:

- respite care
- informational support and training
- connection to the community of volunteers and peers
- care facilities navigation tools
- financial support

The above-mentioned supportive strings are described in the following examples: Agency for Integrated Care in Singapore, Family Caregivers' Alliance, and Caring Bridge in the US.

Agency for Integrated Care in Singapore

Healthcare in Singapore is one of the most innovative systems. Since 2018 in Singapore the Ministry of Health introduced the Caregiver Support Action Plan in order to strengthen the support of caregiving for seniors. It focuses on the following aspects:

- *Care navigation* (providing physical touchpoints for information and referral and one-stop information and resources by Agency for Integrated Care);
- *Financial support* (providing caregiver training grant or support to acquire nursing home services, or to pay to caregiving siblings);
- *Workplace support* (supporting caregiving jobseekers, encouraging employers to adopt flexible work arrangements);
- *Caregiver respite options* (freeing caregivers' time by enrolling patients to nursing homes, providing short-term day care, home-based respite)
- *Caregiver empowerment and training* (evolving community supportive teams to provide information, health and wellness, stress management activities, facilitating caregivers' training)

The government empowered the Agency for Integrated Care (Agency for Integrated Care - AIC Singapore, n.d.) as the reference actor for the above-mentioned categories of services. The agency was established in 1992, with the mission to coordinate seniors' placement to nursing homes, but in 2018 it was transformed "to coordinate the delivery of aged care services, and to enhance service development and capability-building across both the health and social domains" (Agency for Integrated Care - AIC Singapore, n.d.). The AIC's platform provides information for patients and families and includes both direct and indirect support for caregivers scattered within the following topics:

- preparing to care
- care at home
- caregivers' training
- looking after yourself
- end of caregiving
- information specific for the disease type (seniors with mobility aids, active seniors, bed-bound seniors, seniors with mental illnesses). In what follows, AIC strings to support caregivers will be presented.

Care planning and coordination

AIC's indirect support for caregivers aims to ease the caregiver's burden by creating a network of different services for patient care and making access to them more even (e.g. nursing, palliative care, care centres with activities for patients and meetings with peers, rehabilitation). For example, Integrated Home and Day Care (IHDC) provides a one-stop solution for families and patients. The IHDC is a single point of contact for families. The services include

nursing services, exercises for body and mind, and group activities for patients. The facility gets to know the patient and the family and coordinates the available range of services into a care plan called Advanced Care Planning (ADC). The care plan results from a discussion with caregivers and patients, assessment of their time resources and values. So it constitutes short or long-term support, in the nursing home or at the actual home of a family, with activities for elders that reflect their talents (music, drawing, exercise) and help to keep up the patients' mood. Consequently, caregivers' responsibilities decrease, they are shared with a dedicated facility and professionals.

Facilitation of activities between caregivers and patients

Besides, the AIC provides access and information about AIC Wellness Programm for seniors patients constituting "meaningful activities to enhance their wellbeing and quality of life". The programm focuses on creative recreational exercises and provides resources to run the activities for caregivers at home or for staff in community care facilities. Such activities help caregivers to reinforce the bond with the patients and obtain ground for pleasant interaction for both sides, not only practical help. By conducting these activities, caregivers would enhance the patient's well-being and reinforce the bond with the patient, spend a meaningful time together and therefore release stress. For example, The "Hand in Hand" Activity Guide encompasses a collection of games and cognitive, art, sensory, daily living, and nature appreciation activities.

Moreover, it also includes adaptations to patients with different impairments (e.g.

cognitive, visual, hearing, mobility). An example of an activity is the Button Tree Cushion Cover (see figure 7), asking patients to decorate a pillow cover with buttons. Notably, some of the activities from other activity guides include culturally relevant sceneries, e.g. stickers/puzzles/drawings with typical East Asian and South-East Asian scenes (Buddhist temples, characteristic plants etc.). Another similar guide “SPARK” is designed by “taking into consideration wellbeing principles adapted from the “Five Ways to Wellbeing” (New Economics Foundation, United Kingdom); the art activities provide Community Care participants opportunities for self-expression, learning, discovery and social experiences”(Sparks! Art for Wellness Toolkit for the Community Care Center, 2018). It highlights that anyone can facilitate the activities due to “step-by-step instructions, facilitation tips, and selected videos are also provided so that anyone, regardless of their previous art experiences” (Sparks! Art for Wellness Toolkit for the Community Care Center, 2018).

The direct help for caregivers provided by AIC, constitutes training, informational and moral support for every caregiving stage: beginning, emergency, end of caregiving. For example, the platform has a checklist of questions that will help caregivers understand if they have burnout, and it indicates a support hotline. It also gives some tips on balancing life with the caregiving role, e.g. getting informed about the condition to stay in control of the disease and spend time for personal care.

Respite care

Studies show the need for caregivers to take a break from their responsibilities, such temporary support and relief, easing the burden for the caregiver, is called respite care (van Exel et al., 2006). The AIC claims the importance of respite, therefore, AIC created a pilot Go Respite. The service helps to plan the break in advance, listing down all the details and needs about the patient, such as health conditions, special needs, preferences. Therefore, when caregivers need a respite, they can directly ask for it at AIC. The planning shortens the time to prepare the patient for the respite and move to the nursing home, taking away caregivers’ worries about the paperwork and security of a patient (see figure 8).

Caregivers Training

AIC provides training for caregivers to develop their caregiving skills for ambulant, bed-bound or wheelchair seniors. Such trainings help caregivers to eliminate ambiguities in their responsibilities, guide them in acquiring the needed skills. The trainings cover the fundamentals of caregiving for seniors: communicating with them, serving medications, developing clinical skills like tube feeding, facilitating exercises, and seniors’ nutrition. They also focus on teaching to care for seniors with different conditions, for example stroke. The trainings are available in both online and offline form, in many languages. The trainings are provided for a fee, however caregivers might apply for a training grant and receive Singaporean Governmental support to pursue the course.

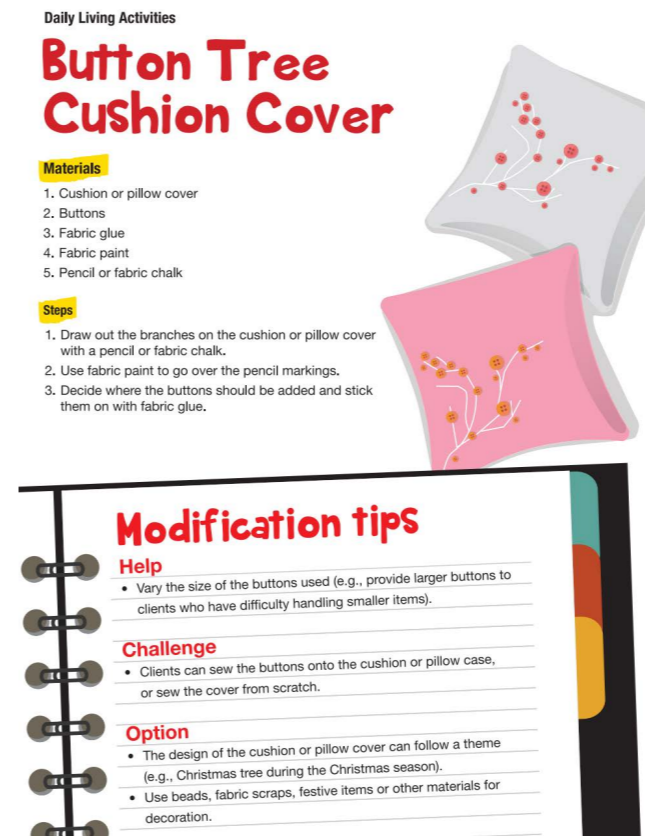


Figure 7. Example of an activity from the “Hand in Hand” activity guide (Agency for Integrated Care - AIC Singapore, n.d.)



Figure 8. Go Respite pilot project flyer from Singapore (Agency for Integrated Care - AIC Singapore, n.d.)

Family Caregiver Alliance in the USA

Family Caregiver Alliance (FCA), the organization of over 40 years aiming to improve the quality of life for family caregivers and the people who receive their care by intervening in the areas of policy, health and social system development, research, and public awareness, on the state, national and international levels. Within its long history, FCA conducted multitude of activities, research and established stable partnerships with other US organizations and the government.

FCA website has three main sections: *Caregiver Education*, *Policy&Advocacy* and *Caregiver Connect*. Each of them has a big repository of data, scattered in different services, presented below (Family Caregiver Alliance, n.d.):

- In-depth comprehensive caregiver assessment (in-person, by phone, FCA CareJourneyTM);
- Short and long range care planning;
- Training for caregivers, including managing dementia care behaviors, stress management, self-care for care-givers, problem solving and decision making skills;
- Respite care (in-home, adult day care, overnight, Camp for Caring);
- Legal/financial guidance;
- Counseling and caregiver support groups (in-person and online);
- Linkage to community-based services.

Family Care Navigator tool

The platform has a Family Care Navigator tool, which allows the public to access the information about caregiving facilities and support in every state of the USA. The website's section Caregiver Connect helps caregivers to find diverse supporting resources:

- connection to medical institutions (e.g. resource centres and medical trial research institutions in the US).
- online community of patients and caregivers (e.g. Smart Patients space to share stories);
- respite services.

Policy & Advocacy

Next, the Policy&Advocacy section is dedicated for the legal questions about caregiving and on the ongoing researches, policies which are under development. In 2001 within the FCA program there was developed National Center on Caregiving (NCC), it Works to advance the development of high-quality, cost-effective policies and programs for caregivers in every state of the USA. For example, this section includes a “Caregivers’ Policy Digest Newsletter”, where caregivers can access a totality of updated regulations.

Caregivers’ training

The section Caregivers Education section contains a very rich information for caregivers on many levels: legacy of caregiving actions, type and stage of a disease, geographical proximity to healthcare, age of patients, career within caregiving. The information includes “practical care strategies, stress relief, available community resources, how to handle family issues, as well as hands-

on care” (Family Caregiver Alliance., n.d.). They are put in different formats: webinars, scientific articles, brochures, texts (see Figure 9). For example, one of the webinars available on the FCA platform offers a free webinar “Tech Tools for Caregivers”. The webinar overviews technology e.g. smart phone apps, communication aids, in home sensors, and webcams can help make a home safer and reduce the caregiving workload based on determining the needs of a caregiver and keeping in mind the important aspects such as cost, privacy, ease of use.

Online Community

The online community of patients and caregivers, Smart Patients, was accessed by the author. It was witnessed that the forum is very popular, there are very many posts published by community members, where the other community members, and the Smart Patients experts comment, therefore provide emotional and informational support. For example, in Figure 10, a caregiver shares his emotions of being overwhelmed by the concrete disease and is seeking for advice, to which the Smart Patients administrator responds by inquiring more information about the disease, so that she can link to the right community of caregivers and give accurate advices.

Respite Care

FCA provides Camp for Caring option for patients with brain impairment where they can come from Friday to Sunday. During the camp they spend time in a community of similar patients and therefore give a chance for a break for caregivers (see Figure 11). Importantly, the FCA website shows testimonies of caregivers who have profited

of the Camp for Caring, and they claim to say about the great effect which respite had on both patients and themselves: “Awesome weekend! My mother remembered some of the activities they did [...] For me, it was the first time I slept in my own bed and slept late in a year and a half. I was nervous, but it was so very nice. If it wasn't for FCA this experience could not have happened—for both my mother and myself. Thank you from the bottom of my heart” (Family Caregiver Alliance ., n.d.).

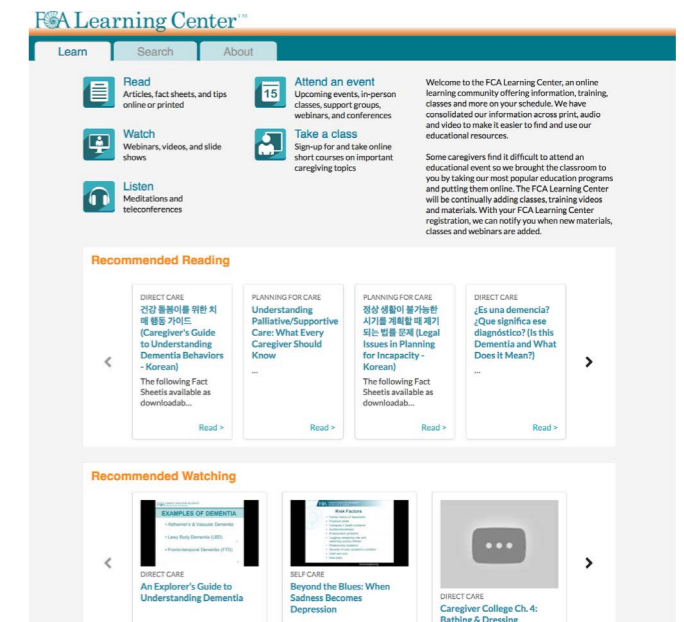


Figure 9. Caregivers’ Learning Center section of the Family Caregiver Alliance website (Family Caregiver Alliance ., n.d.)

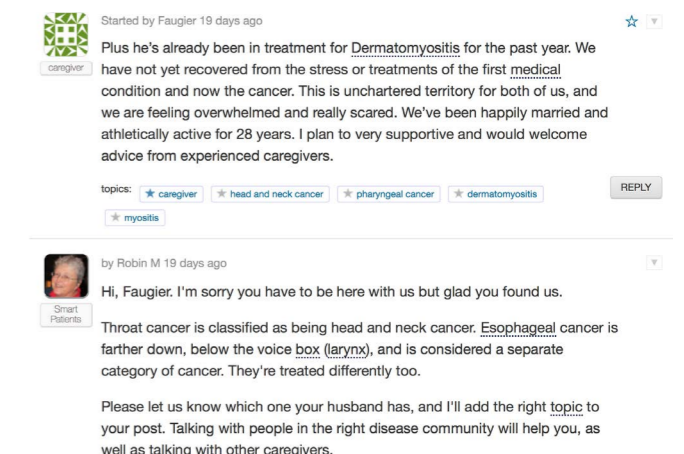


Figure 10. Smart Patients platform for online communication of patients and caregivers across the US (Smart Patients., n.d.)



Figure 11. Care Camp for patients with cognitive impairments aiming to provide caregivers a respite (Family Caregiver Alliance ., n.d.)

CaringBridge

The global non-profit social network CaringBridge was established in 1997, its mission is to “build bridges of care and communication providing love and support on a health journey” (CaringBridge, n.d.). CaringBridge has found that for caregivers it is emotionally difficult to update the entire friends and family circle regarding the patients’ healing process, and can be draining. Therefore, they assist various categories of caregivers to connect to family and friends and volunteers during a health journey. The concept of the service is to centralise and better coordinate the communication with the related people. So, the caregivers create their own website, where they share news, details about the healing process, interventions to undergo, and their needs. They can receive support from the private group of friends and family, with whom they interact on the platform.

Recently, the range of benefits provided by the organization has expanded. Since 2020, CaringBridge observed that 53% of the respondent caregivers and patients could require help with instrumental tasks, such as transportation, finances, chores, but they seldom asked. Therefore, the organisation expanded its touchpoints and created a tool “CaringBridge Planner” to delegate tasks to the community volunteers or friends and family (see figure 12).

Within the 23 years of service in 237 countries and territories around the globe, according to the CaringBridge data, there were created around 850 000 websites, among which 66% were created by caregivers. There has been also collected 1.4 million donations to Caring Bridge since 2002, allocated to families in need.

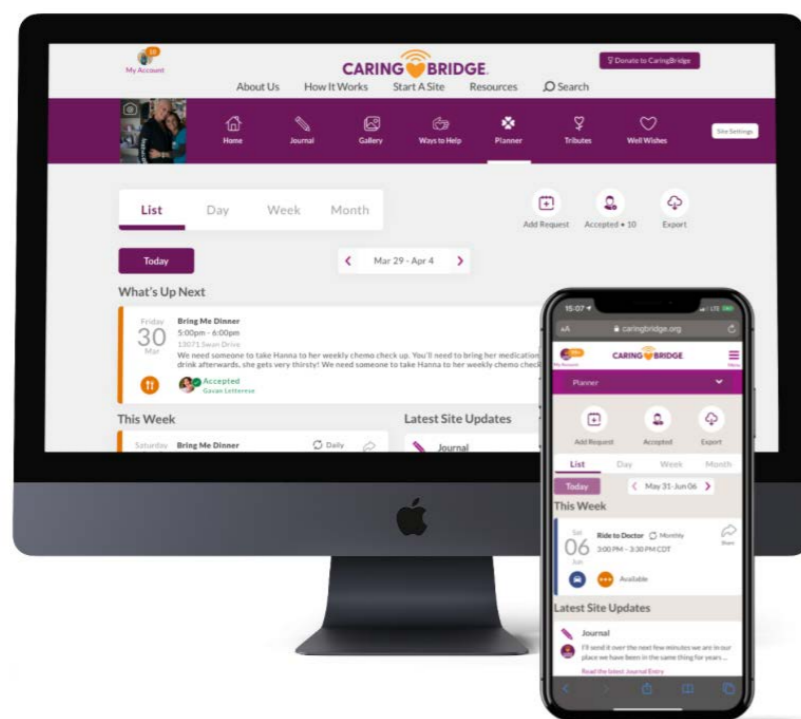


Figure 12. CaringBridge Planner for patients and caregivers to coordinate and share the tasks along the patients’ healing journeys (CaringBridge., n.d.)

Lotsa Helping Hands

Another approach of the health coordination process was discovered in the Lotsa Helping Hands platform and app. Unlike CaringBridge who helps caregivers connect with friends and family, this service creates links between volunteers and family caregivers through online communities. As Lotsa Helping Hands claim, they “empower online caring communities that help restore health and balance to caregivers’ lives” (Lotsa Helping Hands, n.d.). The platform is based on coordination, communication of support principles. It helps to “organize daily life during times of medical crisis or caregiver exhaustion in neighborhoods and communities worldwide” (Lotsa Helping Hands, n.d.). Consequently, caregivers benefit from assistance in tasks, emotional support and peace of mind, while the volunteers find meaning in giving back to those in need.

The platform and the app registers the user as a contributor to help someone by joining

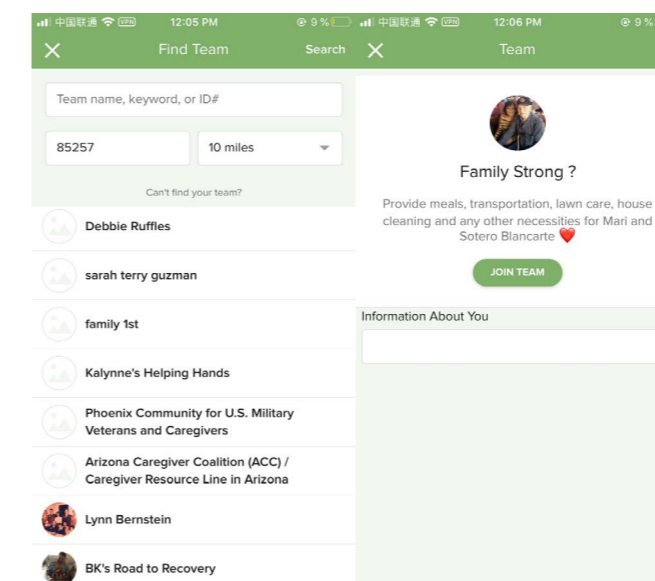


Figure 13. Community joining screens of the Lotsa Helping Hands app (Lotsa Helping Hands., n.d.)

someone’s caring team. The volunteer can look up teams by location, and send a request to to be part of it (figure 13). On the other side, there are users who have created the caring teams, and can post announcements, notes, tasks volunteers (figure 14). For example, tasks fall into categories as preparing meals, giving rides, shopping, visits. As a result, a volunteer takes a task listed by the caregiver and, therefore, eases caregiver’s burden from the amount of responsibilities. Also, caregivers can also chat with volunteers and receive encouragement, so they profit of emotional support. The reviews of the platform are very positive. Caregivers claim that the platform helps to coordinate help within the scattered caregiving family around the country, and also receive help from outside family circle. The statistics shows that there are more than 160 000 active users, more than 100 000 communities were registers, 2,1 million meals delivered and 580 000 rides given.

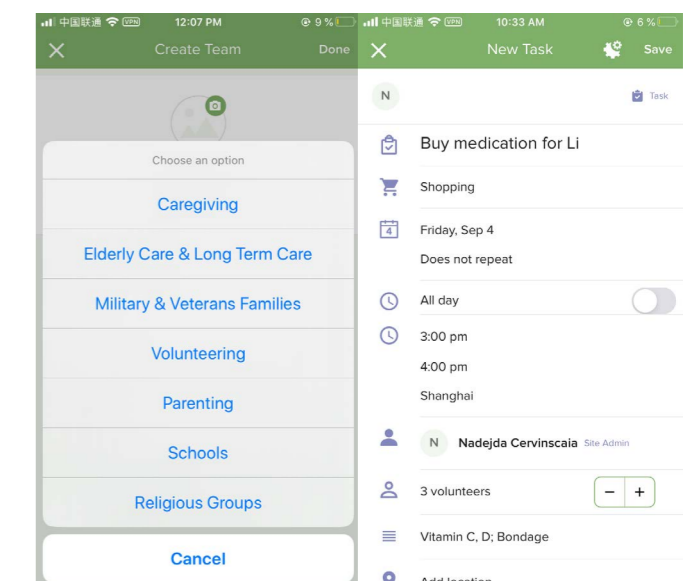


Figure 14. Registration of user’s own caring team and creation of the task to ask help for (Lotsa Helping Hands., n.d.)

5.2 Interventions for caregivers by Service and System Design

Healthcare is a vast and complex area, with multitude of actors: policymakers, healthcare professionals, insurance companies, pharmaceutical companies, medical institutions, patients and their families. Besides, the healthcare system is a “deeply rooted model of social interaction”, it opposes healthcare services’ radical transformation” (Freire & Sangiorgi, 2010). It is used to run incremental transformation, “directed in a bottom-up way: adding more and more incremental improvements to the operational models under study”(Decouttere & Vandaele, n.d.) rather than holistic and radical changes, which are actually needed. Innovating such a tremendous system (Vink et al., 2019) requires a totality of different expertise, participants in the innovation process and methods. Institutions acknowledge that the previous order of healthcare system is not responding to the new reality, so innovation becomes fundamental need, but is challenging. However, Service and System Design focuses on “a multidisciplinary, human-centered and iterative approach to service innovation” (Vink et al., 2019) and has the competence “to challenge hierarchy and silo-mentality by facilitating co-creation” (Kristine Rise Fry, n.d.), therefore is able to address the complex given problems.

In order to address this, Service and System design have been showing great results due to the efficiency of multitude of design thinking tools and methods to reach “effective ‘clinical pathways’ and patients’ experiences” (Freire & Sangiorgi, 2010). The resulting innovative healthcare systems step out of the disease-centred approach, achieving a patient-centered one, considering the entire environment of a patient and the quality of interaction with their caregivers (Decouttere & Vandaele, n.d.; Pfannstiel &

Rasche, 2019; Jones, 2013; Kristine Rise Fry, n.d.). Moreover, since design for healthcare, and especially projects for patients and caregivers require the acknowledgement of people’s high-sensitivity, designers need and can adapt to these conditions. They “develop new skills, sensitivity and attitudes” (Freire & Sangiorgi, 2010) to be able to engage the people in design thinking activities.

Various organizations dedicated themselves to contribute specifically to healthcare innovation by Design. For example, Experio Lab has developed projects for healthcare, with co-design as their core value. They see different health professionals and patients as an ultimate resource and believe that implying them into the design process, nurtures projects’ development (Experio Lab, n.d.). In what follows, there will be presented some of the design projects for caregivers developed by Experio Lab.

Experio Lab Sweden

Experio Lab Sweden is a collaborations of several country councils and regions around the country. It aims “to create healthcare service that make a difference in people’s everyday lives” (North Sea Blog, n.d.)

Among all the projects, Experio Lab has been working on design for caregivers, namely the In For Care project. The In for Care project targets to “explore how new forms of collaboration between the public sector, the private sector and civil society can provide answers to how increasing needs and demands can be met and how informal networks can be supported through new technology to develop public welfare services”. The project’s goal is to develop the informal sector in healthcare and will be implemented in close collaboration with

a wide range of stakeholders: municipalities, patients, family members and voluntary organisations in Värmland. It is a three year project in collaboration with municipalities and organizations in Denmark, Belgium, Scotland and Norway. In For Care is a large project, which bifurcated in multiple projects across the countries.

The project’s backbone is the Quadruple Helix Model, which implies active involvement of the four crucial pillars for successful service development: academia, citizens, industry, public authorities. The projects’ teams used a vast range of design thinking methods, such as brainstorming, personas, user journeys, open space meetings, workshops, scattered through a five-step design process: empathise, define, ideate, prototype, test. It helped the the multitude of involved actors to learn about caregivers and their challenges, and ideate ways of collaborations effective for all (figure 15) (North Sea Blog, n.d.; City of Aalst & Region Värmland, 2019). Finally, the project’s output is not only the developed specific services for different communities and neighbourhoods in the designated regions, but also the development of a Service Design Manual and other publications based on the adaptation of design methods according to stakeholders’ feedbacks (e.g. Figure 16).

Some of the developed projects include: Health Coordinator, Café De Palto, Vital Informal Care. They will be presented next.



Figure 15. Co-creation session for the project Café De Palto. (North Sea Blog., n.d.)

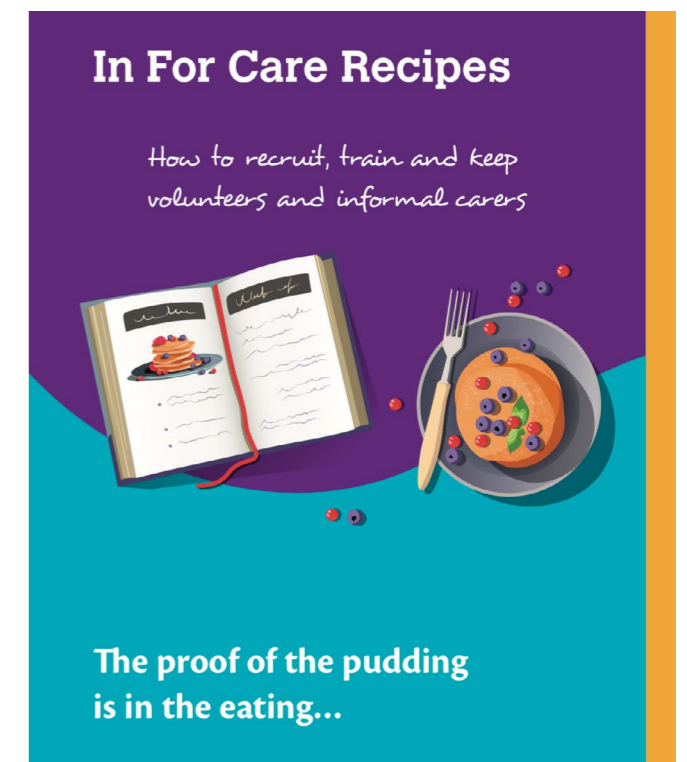


Figure 16. In For Care guidance for projects for family caregivers. (North Sea Blog., n.d.)

Health Coordinator

One of the interesting emerging pilot ideas was to create the figure of a health coordinator for a caregiver. The background have shown that some of the caregivers are overwhelmed by the amount of information received within the patients' treatment process and the need to update the entire family, meanwhile still having to fulfil the caregiving responsibilities. Within the research process and interviews, caregivers disclose that it could take hours a week to talk to everyone, who needed to be updated and the there will be less time to do personal matters. As a result, the figure of a 'health coordinator' was created to assist the caregiver and an app.

The health coordinator would retrieve information from healthcare providers and keep in touch with everyone, therefore facilitating the lives of caregivers. Moreover, caregivers reported a need to leave the patient alone to dedicate time for personal tasks, which would be very stressful, since some of the patients have unpredictable health needs. The health coordinator would assist the patient during this period, freeing caregiver from these worries.

This project was developed in a close collaboration between health institutions, volunteers, caregivers and tech companies. These participants collaboratively ideated and developed an app, allowing to receive new information about the patient. The medical staff could share details about the healing progress. These concepts were prototyped, and as a result, caregivers reported lower level of stress due to the patient being secured by another person and thanks to dedicating more time to themselves.

Café 'De Palto'

One of the sub-projects done within In For Care is the support group "De Palto" which was created by and for informal caregivers and consists of community meetings of caregivers. Within conceptualizing the service, the team has used various design thinking techniques, for example, co-creation sessions with caregivers and open space events to raise awareness (Figure 17). As a result, De Palto became "a travelling café that takes place monthly in one of the three local service centres" (Café De Palto, n.d.). Its goals are to raise awareness on caregiving, assist participant caregivers in informational support (e.g. on relevant services, specific diseases), and socialise in a relaxed atmosphere. The team has organized the cafés at different times and places in order to expand the community. After the successful meetings, the community also moved to an online space, where caregivers can communicate and receive informational support from a chatbot.

Keeping physical wellbeing

Within the In For Care there were also developed projects to ensure the physical and mental wellbeing. The project partnered with an various digital enterprises, in order to co-develop interventions to ease the life of caregivers. For example, the researches showed that caregivers' physical wellbeing are endangered. Therefore, this gap was seen as an opportunity to design an app to ensure the wellness of caregivers. So, collaboration with an IT company helped to adapt an existing exercising app to caregivers' needs, providing simple exercise at home (figure 18).

On the other hand, another project also focused on the physical wellbeing, exercise for caregivers, but in the offline space. Namely, the project Vital Informal Care in Hoogeveen, coordinated by the municipality, participating in the In For Care. The caregivers received free subscriptions to the gym, and possibilities to attend a series of entertaining activities with peers, such as bowling. The feedback of caregivers attending such activities was extremely positive, one of the participants said that the activities help her to relax and distract from the caregiving responsibilities (figure 19).

After finalization of the In For Care three year project, the team claims a great impact on raising awareness and enhancing collaboration between different experts and individuals. Moreover, three of the ideas have continued their development in Denmark: exhibition of volunteer opportunities, e-learning course for communication, communication training for volunteers and health professionals.



Figure 17. An open space event to raise awareness about caregivers within the Café De Palto project. source: (In For Care Recipes. How to Recruit, Train and Keep Volunteers and Informal Carers, 2019).

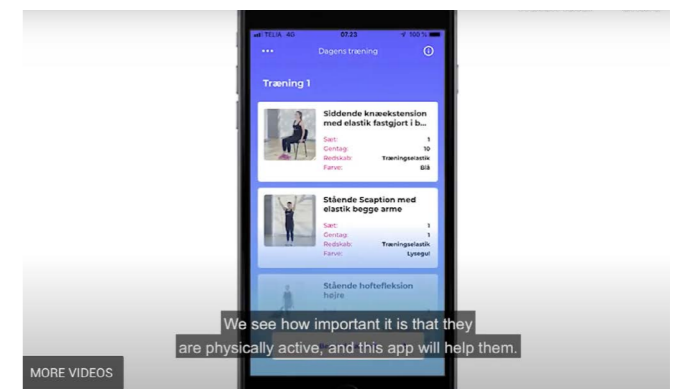


Figure 18. App developed for caregivers within the In For Care Projects. source: (North Sea Blog., n.d.)



Figure 19. Caregiver talking about the Vital Informal Care program. source: (North Sea Blog., n.d.)

5.3 Conclusion on services for caregivers worldwide

Different organizations dedicate themselves to caregivers' issues. The found initiatives fluctuate around the following typologies of help:

- *Health services coordination* - either through a digital tool, or a designated office, these services help to navigate within the healthcare system and access relevant services. Finally, it forms a care continuity landscape, which facilitates caregivers to understand the processes and take coherent actions and short-cuts.
- *Caregivers' tasks&info coordination* - using digital tools, e-calendars to coordinate caregivers' responsibilities through sharing them either with family and friends or volunteers. Moreover, other tools facilitate the medical workers to share updated health status of patients in the immediate mode.
- *Care planning* - caregivers are assisted to build a balanced long-term caregiving plan, taking into account personal needs and designing a caregiving schedule taking into account existent facilities.
- *Financial support* - governmental or private financial assistance to caregivers.
- *Community building* - online and offline, either in circles of peers or friends and family and volunteers.
- *Respite care* - service/program to facilitate caregivers to take a longer break, starting with two days off. It refreshes caregivers' minds and helps to restore the forces.
- *Caregivers's training and informational support* - caregivers can receive exhaustive information about the disease and an according care providing training, such advices cover, for example, house re-organization for patients, advices for stress relief. Moreover,

there are interactive tools for caregivers to interact with patients in a less common, but entertaining way, creating a stronger bond and relieving the sense of routine.

- *Emotional counselling* - either through direct professional help, or through linkages to online/offline communities of peers or volunteers.
- *Facilitating access to recreational activities* - as observed, this is the least developed category of assistance for caregivers. Some programs help caregivers to exercise at home, others provide individual vouchers or organize coordinated entertaining activities for groups of caregivers, e.g. sports.

To conclude, the arena of existing services worldwide is in an expansion process. Caregivers primal difficulty is dealing with daily tasks and navigating through the complexity of the healthcare system and required operations. In long term, it endangers their physical and emotional wellbeing. Platforms and organizations which help in coordination, therefore, relief, are acknowledged as useful and represent an asset for the healthcare system for its approachability and clarity.

Moreover, development of digital tools for caregivers is gaining more and more popularity. Even though caregivers may receive these kind of instrumental/informational assistance, it cannot fully contribute to emotional and mental wellbeing, for which the supportive strings still have space for development. Besides, what regards emergent situation, the resources for caregivers remain scarce, representing mainly trainings to prepare for emergency situation and assisting hotlines. Given this, the question of reinforcing emotional readiness, especially in emergency situation, still remains open on the world

scale. To understand the context of services for caregivers in China, in what follows, there will be analyzed the practices to support caregivers specifically on the Chinese arena.

5.4 Organizational support facilities for caregivers in Shanghai

China approached creation and delivery of services for caregivers relatively recently (Feng et al., 2020). Due to the exceptionally high and continuously increasing number of elderly people requiring care, the authorities understand the need to conceive services for the patients and their family members to better their physical and mental health. Legally and culturally, the family remains the main pillar for the patients and the other relatives, but because of the reduction in family size, the increased participation of women in the labour force and increased hours of work, the family-based support has become increasingly challenging (Du, 2015). Chinese caregivers report a lack of available formal care assistance or experience a lack of financial resources to pay for the help of professional caregivers (Lin, 2019). Therefore, different sort of support initiatives have been recently emerging trying to tackle different problems:

1) Residential care - daily services provided by specialised institutions (meals preparation, emergency assistance, transportation services, housekeeping, nursing care);

2) Community care - “key elements encompass day care centres, community care management centres, integrated community care centres, community health service centres and meal service for older persons” (Du, 2015: 10). The service content consists of direct care service as well as the economic subsidies;

3) Institutional care services - for example, charities and funds aiming to offer financial help to caregivers, or nursing homes.

Despite a number of support organizations, these services are mainly patient-centered and benefit caregivers only indirectly, and

most of them are in the megacities (Lin, 2019). Specifically in Shanghai, in order to qualify for assistance, families have to undergo a Standardised Assessment Mechanism for Elderly Services (Du, 2015). This pilot project successfully launched in 2006 and improved over time, aimed to assess the healthcare needs of an elderly population in Shanghai to regulate the healthcare provision of community care services. The plan evaluates the needs of the elderly population according to their daily living activities, cognitive capacity, emotional and other behavioural status, visual capabilities and social environment, as well as the presence of a critical illness (Du, 2015). The assessed people would be divided into three categories (mild, moderate and severe care needs) and will receive specific care subsidies and services. Such an assessment mechanism facilitates obtaining a focused offering of a service to a specifically identified target. Given this, even if the family is lucky to qualify for a practical or financial assistance, which, according to researches still remains of a poor quality (Sun et al., 2020), the psychological burden bared by the families still remains a unaddressed (Liu, 2011). The Government acknowledges these challenges and is working on policy design level to multiply the number of care providers (Du, 2015), however there would be still the need for tailored family caregivers range of services.

5.4.1 Residential Care

Residential care represents the biggest support service which the Chinese Government relies on. Besides the family care which is also considered as a component of residential care, it also extends on institutional support by diverse organizations directly benefiting the patients, and indirectly benefiting family caregivers. Specifically, such institutions provide:

- personal care
- meal service
- housekeeping
- nursing care
- transportation services
- home visits
- case management
- emergency assistance
- improvement of infrastructure
- economic subsidies;
- caregivers' training.

The direct residential support for family caregivers includes short-term training on care skills and economic subsidies. The target families are divided in several groups:

1. People with economic difficulties;
2. People with a moderate or severe level of impairment;
3. People aged 70 or older whose only child has died or is disabled;
4. People aged 100 or older.

Depending on the severity of seniors' conditions, the family can benefit of ¥ 300-400 (equivalent of circa EUR 40-55). Because of the amount of seniors in China, and especially in Shanghai, as the city with

Chinese oldest population, residential care services are in scarcity, and cannot respond to all the requests. Therefore, the Government aims to reinforce this string.

5.4.2 Community care services

Community care services are an important part of the healthcare system, they include direct care services provision and indirect ones (through the governmentally pre-purchased care services offered to the public). Despite the extensive governmental investment in constructing entities as community services, the demand drastically overpasses the offering. The key elements of the community services encompass:

- day care centres
- community care management centres
- integrated community care centres
- community health service centres
- meal service for older persons
- respite centres
- home assistance

The local governments are exploring diverse value propositions to different kind of elderly people. For example, the Hunan province government is exploring “a mutual support model for elders called “time banking”, in which a younger volunteer who provides services for an older person for an hour in the same community is credited with one hour that can be redeemed for an hour of service from another volunteer when that person needs elder care (Du, 2015). In Beixinqiao Street, the Beijing government is establishing a smart caring community for elders, where elders can access information

about household services, emergency assistance, health care, online counselling and others. (Du, 2015) Even though among the beneficiaries of such services there might be family caregivers too, the services are not specifically tailored for them, therefore can poorly address the caregivers' challenges.

Importantly, community support and community building are culturally specific to China. Therefore, they are taking up important roles in "combining nursing home service with health care, promoting the participation of social sectors in the provision of long term care, promoting mutual support among elders and building information networks of community-based long term care for elders." (Du., 2015: 13) The Government understands the potential of the communities and plans to fully unleash it. Moreover, the studies show that the citizens also prefer to receive care in their own communities (Sun et al., 2020). The crucial step to achieve this would be to enhance the visibility and the power of this assistance by expanding professional training and by recruiting volunteers to improve the provision of these communal services by family caregivers. (Du, 2015)

To conclude, the Government recognises the importance of community support and, sees it as the second main support service for patients, being preceded by family support, constituting 90% (Du, 2015; Sun et al., 2020). This mechanism was framed into the "9073" plan, where 90 stands for home-provided care, 7 for community support, and 3 for institutional care (Du, 2015). Even though we might consider that family members can support each other within the family circle, as the Government suggests, this is a considerable burden for the family. Families can currently benefit from external

institutional support, mainly on a practical level, not an emotional one (Wang et al., 2018), therefore not fully (Plöthner et al., 2019).

5.4.3 Institutional care

Another typology of support services for seniors include nursing homes in urban areas, homes for the aged in rural areas, hostels for older persons, hospices and nursing stations. They provide residential services, personal care, health care, mental health care, nursing care (especially 24-hour nursing care) and hospice care (Du, 2015). The institutional care also targets mainly the patient, and benefits the caregivers only indirectly by taking care of the patient, and therefore easing the pressure exerted on the caregiver.

Institutional care faces challenges on several aspects:

- *the shortage of professional service providers*
- *ensuring adequate standards*
- *limited human resources.*

The Government recognizes the importance of training the professional caregivers in order to ensure the quality of care for the patients. Currently, the majority of care-workers do not comply to the National Professional Standard of Nursing Caregivers. Therefore, there are special programs aiming to train care managers and care planners and care-workers for services at different levels, once the institutions respond to the set criteria, the problem of scarcity of services start diminishing.

Important to mention is the Governmental

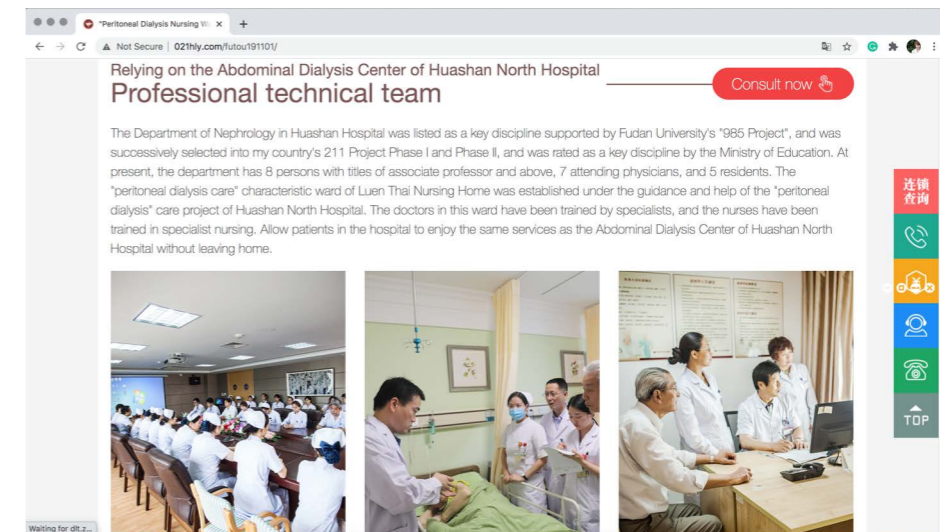


Figure 20. Riyuexing Nursing home landing page, explaining the service offering: care for patients with kidney failure, either at the hospital or at home (Riyuexing Rest Care Nursing Home in Shanghai, n.d.)

supports which such institutions receive. For example, nursing homes, or respite care organizations might be exempted from taxes and receive governmental support in its development: "nursing homes will be exempted from paying business tax, and non-profit institutions for older persons will be exempted from paying income tax; Government at all levels are also offering subsidies based on professional facilities, construction or reconstruction of infirmaries and physical facilities." (Du, 2015: 17) Such a vast contribution to the development of institutional care is also a major asset empowering different actors to finally respond to the increased service demand.

Nursing homes

Nursing homes are institutions, generally private sector operated, with professional carers for the patient, which contribute to the release of caregivers' duties. The potential of nursing homes as the supplementary part of the social care service system have yet to be explored fully. The nursing homes have a number of diverse professionals: nurses, psychologists, nutritionists, doctors, careworkers. The nursing homes focus on receiving patients for long term care and therefore provide a relief to the family by taking responsibility of practical and medical care to patients. However, there are also available the careworkers' visits to patients'

homes, if the family doesn't want to move the patient, but still needs assistance in daily instrumental activities.

One of the few elements of the institutional care in China represent the nursing homes. They are governed both privately and governmentally, and despite the considerate increase of the number of institutions, they can cover only 10% of the people in need for institutional care. Recently, several city governments in China are rethinking the institutional dynamic and develop new mechanisms of work, e.g. "combine nursing homes and health care, including cooperation between medical institutions and nursing homes, establishing medical departments within nursing homes, some have found ways to share resources or even general coordination, as in Ningbo city, where public and private sectors cooperate to operate nursing homes." (Du, 2015: 14) For example, the Riyuexing Rest Care nursing home in Shanghai (Figure 20), provides a totality of medical long-term care to patients of different diseases. Recently, the nursing home has cooperated with Huashan Hospital affiliated to Fudan University to establish a "peritoneal dialysis nursing" (Riyuexing Rest Care Nursing Home in Shanghai, n.d.) special ward focusing on peritoneal dialysis care and rehabilitation. The aim of the program was to reduce the burden of family caregivers to assist in treatment by providing experts to

conduct the required procedures. The staff is being regularly trained at the partnering hospital to be able to advance the medical care to patients either in the nursing home or at patients' homes.

Generally, studies show that nursing home care in China still has to undergo a series of changes and improvements. Besides, there is a social resistance towards nursing home care due to the Chinese values such as filial piety and culturally based beliefs venerating older adults emphasise the obligation to take care of older family members (Exel et al., 2007, Sun et al., 2020), using a nursing home service might be perceived as failure to comply to the traditional Chinese culture and might arise a social judgement to the family caregivers.

Respite care

Respite care is novel to China, the majority of them still being in the pilot phase (Du, 2015) and represent either governmental or non-governmental organizations, currently present in Beijing, Shanghai and Zhejiang (Du, 2015). The respite care service might be integrated into the Compound Community Support Service or the Neighborhood Committee, which is a local governmental organization, and among all can assist family caregivers by providing the help of professional caregivers or receiving elderly citizens to for day-activities (Zhang et al., 2015).

Respite care is positioned as “a promising method of sharing the responsibility of elder care between the government and family members” (Sun et al., 2020: 2). For example, in Beijing the first governmentally funded respite care pilot project was launched in 2018, which has been very successful and

serves as a base for other projects to emerge nationwide. In this particular instance, the respite care constitutes a day care service, where senior citizens can go to a nursing home where they can get all-round care and even attend creative classes, such as traditional Chinese painting or writing (Figure 21), or play developing games with other elderly people (Figure 22). Alternatively, nursing staff can be sent to such people's homes, while the family caregiver, who is the primary source of care for the senior patient, can take rest up to four days a month. In 2019 already, the program could assist 1,500 caregivers in families who care for disabled elderly people or the elderly people suffering from dementia (Coen, 2019; Wang for China Daily, 2020). Such initiatives are also emerging based on the partnerships between e.g. nursing homes and medical-service providers, based on the mode of government purchase of services. This particular pilot project extended to other Chinese cities, including Shanghai, where there have been existing community-based respite care to family caregivers since 2012.

Speaking particularly of Shanghai, according to the “13th Five-year Plan for the Development of Shanghai's Ageing Industry, it is expected that more than 500 elder-care homes and day-care centres will provide respite care services in 2020” (Sun et al., 2020: 2). These facilities could be used by families for either short term of several hours per day or up for three months. The costs range from ¥35 (EUR 8) for basic day care services, to ¥160/night for a bed and 3 meals a day (Zhou for China Daily, 2017). Such institutions also welcome patients for their recovery period, on average they have 10-40 beds. According to the China Daily interview of the deputy director of civil affairs of the Shanghainese district with the

highest percentage of elderly population, the services are fully booked (Zhou for China Daily, 2017). In order to qualify for a respite care program, the family caregiver needs to submit an application for respite care to their local neighborhood committees and the need for respite will be assessed according to a metric, after which the caregiver will be placed in the priority list of service provision. The priority is primary given to the families with lower income or patients with very severe health conditions.

Having an increasingly rising demand to the service, “the Shanghai authorities saw a solution in repurposing public-owned properties in or around residential communities to offer affordable respite care” (Zhou for China Daily, 2017). It is also considered beneficial that such services are provided in the local communities, in the neighborhoods which are familiar to families and patients. In the interview, the director of the home-based care services center in Shanghai cited a Chinese idiom “few dutiful children stand at the bedside of a parent with chronic diseases”, and added, “we want children who act as caregivers to be able to take a break, which we feel will ensure the devotion to their parents is sustainable” (Zhou for China Daily, 2017).

The articles about the respite care in China underline the need for further development and overcoming of the liability risks (Wei, 2019). Besides, there is described a negative stigma which governs over the idea of a day care/nursing home organization, which roots itself in the Chinese cultural values of filial piety and dedication.



Figure 21. Figure 1. Elderly residents take part in an art class at the day-care center in a citizen service station in Jiading sub-district, Shanghai's Hongkou district, on Aug 30 2020 (Wang / For China Daily, 2020)



Figure 22. The elderly enjoy an afternoon playing puzzles at the Jiangjiaqiao care center in Hongkou district, Shanghai. (Jiang Diwen / For China Daily)



Figure 23. Landing page of Shuidichou crowdfunding platform for patients with severe diseases (Shuidichou, n.d.)

5.5 Financial support

Caregivers' financial support in China is relatively strong, the Government invests in the wellbeing of the family caregivers through offering economical subsidies to families or offering low-cost services, as described in the subchapters above. However, there exist also other initiatives aiming to financially support caregivers, such as charities and crowdfunding platforms.

In China crowdfunding charities, helping families to collect funds, are increasingly popular. For example, the platform Shuidichou (Chinese: Drop of water) aims at collecting funds for their family members with serious illnesses (Figure 23). It has helped over 300 million caregivers to raise funds for their beloved ones (Shuidichou, n.d.) The platform provides a customer service support, where the citizens could request a 1 to 1 assistance in registering a crowdfunding case. Importantly, the platform has a very strict monitoring and checking system, and has an open blacklist of dishonest crowdfunding requests who "fabricate or exaggerate help-seeking information, conceal personal property

information, fabricate false medical records, and improperly embezzle medical funds" (Shuidichou, n.d.). A very strong security system helps donors to maintain trust to the platform be ensured in the transparency, openness and integrity being the true values of the platform, as it claims.

On the other hand, the Government also invests in the financial support of the family members, which up to know constitute the biggest support mechanism both legally and culturally. So, in some cities the children of elderly people could receive special allowance to be stimulated to live close to their parents, and therefore take care of them. The Government also tries to support these caregivers practically and assist the home-based care by establishing daily-care centres within communities (Du, 2015).

5.6 Conclusion

Chinese Government understands the implications of the increasing aging population and people in need of care. Also, the Government strongly relies on the assistance of the family caregivers within patients' treatments and, because of the Chinese cultural values, naturally sets them as a primary source of care for patients. However, it still recognizes the acute need to evolve policies and services benefiting patients and caregivers and stimulate the private sector to launch initiatives to benefit the people in need for care and their families. Nonetheless, the services are scarce and need both a boost in development but also to customize and tailor the services to the needs of caregivers, as now the available offerings target mainly the patients, and benefit the caregivers only indirectly, by alleviating their burdens from a practical point of view only.

The services are divided into 3 categories: residential care, community care, and institutional care. Based on the Chinese cultural habit, people are used to benefit of services in the neighborhood. Therefore, all the compounds and districts aim to have related services to improve patients' and their caregivers' lives. For example, neighborhood committees can offer care-workers to families in need to take a short rest from the daily care responsibilities. Also, there are nursing homes, which could either assist the senior patient at home or invite them to the centre's daily activities along with other patients. Some other organizations, namely the respite care pilot projects, can provide both short-term care almost free of charge, one day per week. Some of the respite care centres can sum the days and provide a long-term break to the family, while the seniors will be hosted and cared for by professionals in the centre.

From the financial point of view, the caregivers can receive allowances from the Government, or special, stimulating packages for family members who agree to reside in the proximity of their frail elderly family members. On the other hand, crowdfunding platforms, e.g. Shuidichou, assist caregivers in collecting funds for their family members struggling with severe disease.

When taking an overlook at the existing services, it is clear that the services' landscape is very young, poorly evolved, and not patient-centric. Compared to the world arena, China misses some aspects, for example the leisure activities for caregivers, or promotion of physical wellbeing. Besides addressing this aspect, the current services are scarce. Therefore, efforts in responding to the great need and demand should be enhanced to reach caregivers-tailored services while nourishing the existing prerequisites of the powerful and natural context of community and mutual support. The Government plays a crucial role and "should make policies for developing formal care services, and mobilize social resources to establish long-term care facilities and programs" (Lin, 2019).

FIELD RESEARCH

Introduction

This chapter shows the field research process, including the data collection and its analysis. The discovered topics regard caregivers' responsibilities, needs, challenges, and the attributes of the healthcare system arena to face the challenges.

6.1 Data collection

The data collection took place in two phases: Preliminary stage research conducted in December 2019 and second phase in-depth research conducted in February and May 2020.

The preliminary field research was conducted with a surgeon, whose working place will be anonymized, and 3 caregivers, met in Tongji Hospital in Shanghai. The preliminary field research aimed to validate initial desk research insights primary about acute stage caregiving and inform following in-depth studies. The initial desk research informed the author that the caregivers of different diseases might experience their burdens differently. Namely, caregivers providing help for patients with mental illnesses (Dahlrup et al., 2015) experience different challenges,

from the ones who provide care for patients with physical illnesses, because besides instrumental and help within daily living activities, they need to overcome the difficulty to dialogue with patients, due to patients' different grades of cognitive impairments. That is to say that caregivers providing care for patients with physical problems have a similarity between them, therefore for the purposed of this research, it was decided to focus on caregivers of patients with impairments other than mental. Moreover, the desk research informed the complexity and stressfulness of providing care, especially for patients with severe, long-term diseases. Such diseases are shocking news for patients and caregivers in the debut of the health issue, however through treatment, they might have periodical aggravations, when the caregiver is undergoing a change of circumstances again, a critical moment of a disease, when the caregivers' experience big stress again, regardless if the disease is a chronic disease or treatable, but severe.

Therefore, as anticipated in the methodology chapter, the criteria to choose caregivers were based on an emergency health issue, the acuteness of the disease and its severity. Consequently, the interviews were conducted

in the hospital's emergency hall, where caregivers for patients with different diseases in their acute stage could be met (figure 24, 25). The other criteria was differentiation: by age, gender, relationship, diseases which their family members have, financial status, and years of caregiving experience. The conducted desk research claimed that the age and relationship of caregivers to the patients have an essential role: usually, spouses perceive the health problem of the partner very problematically, the caregiving burdens are depriving, while in Chinese culture, due to the concept of filial piety, children feel the obligation to care for their parents; besides the challenge of younger caregivers (usually children of patients) struggle to combine caregiving with their other roles, job, and private family; also, the financial possibilities play an essential role in alleviating the burden, as well as social support, especially help from siblings, characteristic for Chinese culture, lastly the age of the caregiver also has importance as the older the caregiver is, the more fragile is his/her health. Given this, the secondary criteria was to meet caregivers representing different experiences. As a result, in the Tongji Hospital emergency hall, there were visually identified and differentiated by age, by the health condition of the patient, and by economic status, four caregivers (mother and daughter and a pair of siblings), among whom three caregivers gave interviews.

The criteria for choosing the doctor the gravity of diseases with which he/she operates. Namely, he/she should be working in a hospital department, which deals with severe health conditions of patients (e.g. cancer), so that the pathology can take unexpected turns and aggravate, be acute, therefore provide an augmented level of

stress for families. The doctor should have been mainly interacting with caregivers. The met surgeon responded to these criteria.

All of the interviewees were informed about the purposes of the research and agreed to the interviews. The preliminary research helped identify patterns of caregiving experiences considering different lengths, journeys, the received support and informed the further in-depth interviews.



Figure 24. Caregivers, patients and medical personnel in the emergency hall of Tongji Hospital in Shanghai (Nadejda Cervinscaia, 2019)



Figure 25. Interviewed Caregiver 1 with his sister at the bed of their mother who had a chest pain (on the left) (Nadejda Cervinscaia, 2019)

In the second phase of the field research, because of the similar research areas and facilitation of interviewing people, speaking mainly Chinese, the author was working together with a Chinese PSSD student. We used a qualitative design, one-hour in-depth interviews (IDI), informed by the previous phase's findings; for example, the interview guides got enriched with questions about the importance of religious practices to regain spiritual balance, or received governmental financial support.

Importantly, the goal of the second phase was to:

- *deepen the knowledge about caregiving experiences and the related emotional journey, focusing now not only on emergency period, but also the post-emergency experiences, always of severe diseases;*
- *discover the expert viewpoints of medical staff reflecting caregivers' situations, their interactions with caregivers and challenges faced from their professional perspective;*
- *understand existing services benefiting Chinese caregivers.*

In February 2020, two video call interviews with caregivers were therefore conducted: one with the caregiver previously met in the emergency hall of Tongji Hospital (Caregiver 2), who was now in a 'peaceful' stable period of the patient's disease and a referred caregiver because she responded to the criteria of the gravity of the disease (Caregiver 4), also being in a post-emergency period. In late May, there was conducted one more online interview (Caregiver 5) who was a referral from the interviewed doctor (Doctor 2) in early May. The caregiver has been in a post-emergency period for a severe, even a non-treatable disease patient. These interviews

were useful for comparing caregivers in a critical moment and caregivers who managed to go through it and be back to normal. Finally, the interview cycles with caregivers were finished with two more caregivers, both responding to the criteria of severe diseases and emergency period. Thus, caregiver 6 and 7 were met in the Intensive Care Unit (ICU) of Ninth People Hospital. The demographic data of all caregivers' are described in Table 1.

Also, in May 2020, the interviews were conducted with medical experts: a doctor from Shanghai East Hospital (Doctor 2), and a team of medical workers from Ninth People Hospital: two doctors (Doctors 3, 4), a nurse, a care-worker, and a medical social worker (Figure 26). The criteria of choosing these experts was their close interaction with caregivers and patients of different severe diseases and health states at the moment. Thus, the Doctor 2 was found online on the research centre of Tongji Hospital as an expert in organ regeneration, specifically the respiratory system. Therefore he treats patients in severe conditions. He agreed for a preliminary and an in-depth interview. Besides, interviews were conducted in a general ward, where patients with stable conditions are hospitalised, and an ICU. The care-worker, the nurse and one doctor (Doctor 4) are a team of the ICU. They treat patients in extremely dangerous, fragile conditions of different diseases, so family members are limited in visits, and care-workers provide the care. Doctor 3 is a medical worker in the general ward working with respiratory system problems, where patients are also hospitalised, but where the family can visit freely and provide the primary assistance, instead of hiring a care-worker.

In order to map the current facilities, it was

envisioned to talk also to the administration of the Ninth People Hospital, and the neighborhood committee situated in the same zone. However, after the introduction of the following research, none of these units agreed to give interviews. Lastly, there was implied a non-profit organization "Lymphoma Home" in Beijing, found during the desk research. The NGO is supporting patients and their families during online research. Consequently, the NGO was contacted and there an interview was conducted with its chairman. The interview aimed to discover the activities of the organization and their insights from interaction with caregivers.

The majority of the in-depth interviews (IDI) were conducted in Mandarin Chinese by the author and one of three collaborators: a student researching the same field, a design researcher, and a friend, all of them speaking Chinese. The majority of responses were recorded and transcribed by a native speaker, later translated by the author in English using online translators and finally checked by the native speaker if the translations comply with original written notes.

Caregivers IDIs encompassed their personal stories of becoming caregivers to a family member, how they learned about the disease, how they perceived it, and what were the new responsibilities. The IDI explored how the event impacted their personal lives, and how the new role impacted their previous life habits, what were the facilitating factors. The caregivers were asked to share their strategies of alleviating their states of mind and easing their duties.

The IDI of the medical staff tackled the general perceptions of challenges faced by caregivers as well as their duties along the caregiving journey, and finally doctors' and

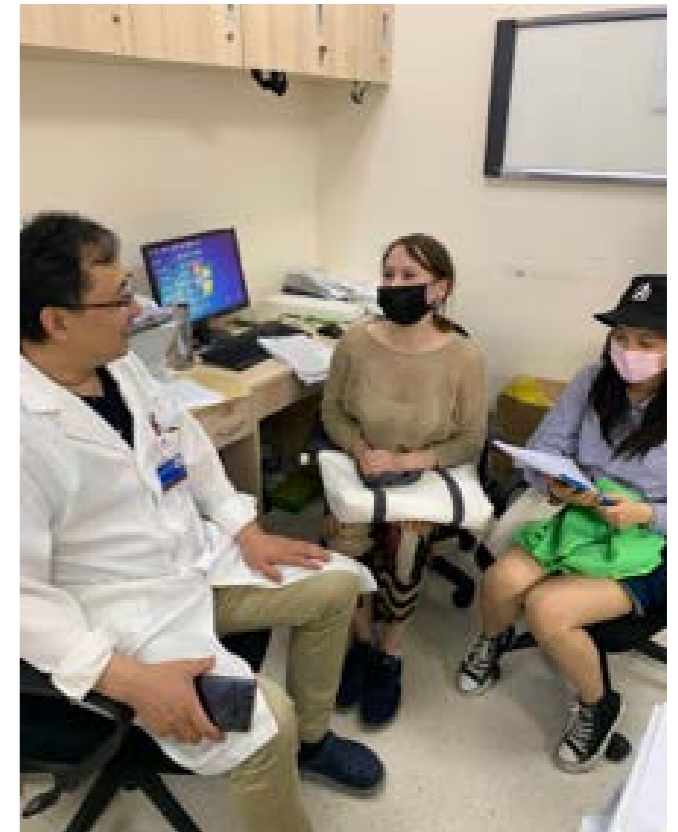


Figure 26. , May 2020 , interview with Doctor 3 in the general ward in Ninth People Hospital in Shanghai (from left to right: doctor, author, the Chinese colleague conducting a research in the same area)(Nadejda Cervinscaia, 2020)



Figure 27. Ninth People Hospital in Shanghai (Nadejda Cervinscaia, 2020)

health system's response to these. The IDI with NGO chairman revealed the activities of the organization and his insights from NGO's interaction with caregivers.

The IDI with the NGO Lymphoma Home addressed questions about the organization, interaction with caregivers, the partnerships and the envisioned future development.

Table 3. Demographic data of interviewed caregivers

<i>Interviewed caregivers</i>	<i>Caregiver 1 (Zhang)</i>	<i>Caregiver 2 (Lily)</i>	<i>Caregiver 3 (Lily's mom)</i>	<i>Caregiver 4 (Helen)</i>	<i>Caregiver 5 (Miao)</i>	<i>Caregiver 6 (Fu)</i>	<i>Caregiver 7 (Yin)</i>
Age	62	50	73	40	±50	±35	±35
Gender	male	female	female	female	female	male	male
Occupation	retired	accountant	retired	design researcher	no evidence	delivery man	no evidence
Patient	mother	father	husband and son	father	sister	wife	mother (±60)
Length of caregiving experience	8 years	13 years	13 years for husband and 5 years for the son	5 years	since childhood	1 day	very many years
Family members' disease	chronic heart problems	dad's/husband/s chronic heart problems: 2 strokes; locomotory problems; low immune system		prostate cancer	respiratory disease	acute pancreatitis	intestinal chronic disease
			chronic mental problems of the son				
Disease's phase at the interview moment	emergency aggravation of the chronic disease			stable health status		new to the disease, sudden aggravation of health	emergency aggravation of the chronic disease
Type support received	Governmental financial help; peer support; sister's support in emergency cases	Cleaning lady services and financial support from the government to hire a careworker 3h/week;		Psychological and governmental financial support; peer support	Psychological support; peer support	-	no evidence
			Daughter's financial and informational, operational support				
Main challenges	Financial and physical burden	Combining caregiving with other roles: work and parenting;	Physical, operational burden, financial challenge.	Regaining individual and family balance after patient's health crisis;	Combining caregiving with other roles: work and parenting;	Combining caregiving with other roles: work; Financial challenge.	Difficulty to navigate in a new city, hospital; Financial challenge.
Type of care provided (arranged by priority)	Physical care, mental support	Informational and financial support, mental support, physical care	Physical care, mental support	Informational support, mental support	Informational support	Hospital visits and material, financial support	Informational and financial support, assisting in visiting the hospital

6.2 Data analysis

The interviews' transcripts were analysed through an abductive sensemaking process (Kolko, 2010) and the core insights were clustered in Miro prioritizing, judging, and forging connections among them. All of these findings are reported in Table 2 of the Annex and the visual map illustrated in figure 28. More specifically, in order to navigate through the chaotic and impressive amount of the fifteen interviews and comprehend them, the author decided to visually organize, "map it all out" (Kolko, 2010: 16). The entire synthesis process can be considered a three-step one: 1) initial informational organization into rough topics; 2) re-mapping and re-denomination of clusters and sub-clusters; and 3) final refinement.

The first step was to transcribe and preliminary map the interviews' findings. Therefore, each interviewee was assigned a colour of a digital post-it (see legend of figure 29), and then the author started extracting the primary quotes by prioritising and judging. Kolko claims that this process is Starting from the quotes of the very first interviewee, the some of the post-its with the quotes started mapping out clusters of specific themes, such as "impact on caregivers", "hospital environment". Consequent pieces of information from interviews might be adding value directly to the existing clusters. Sometimes, when adding post-its into an existing cluster, a new subtopic might be shaped. Otherwise, some of the information were taking an arbitrary space. Such post-its, being influenced by the interviews yet to be analysed, would open the topic later, or support other topics yet-to-come. On the go of this process, clusters with clear topics where preliminary named. Many times, the initial names of the clusters were renamed in order to illustrate their contents better, other times the initial topic

was disappearing by being split. For example, "hospital environment" was diluted, some of its post-its were repositioned, the remaining ones were roofed under "material and informational help". Interestingly, at the middle-end of this process, some of the quotes where fitting into two clusters, therefore they were duplicated and included accordingly. Other post-its were difficult to fit and they were left aside. This step aimed to position the quotes by topics, so at the end, different categories were shaped, and the most fruitful topics could be noticed, for example, the financial cluster and the impact on caregiver, caregivers' roles were huge clusters, where absolutely all interviewees contributed. Thus, ideas of the problematics and opportunities was present already on this stage. However, they were rough, as the post-its inside each category were not carefully arranged.

Secondly, every cluster was analysed. Each cluster of the significant topic contained different aspects of the theme. Therefore, the post-its were rearranged into a sub-cluster, and each of them was also given a name, for example, the cluster "impact on caregivers" bifurcated into "stress" and "positive attitude". The post-its left aside in the previous step could find their perfectly fitting place. At the end of this stage, all the topics and sub-topics were clear, though the cluster's critical learning was not well-written yet. This was the next step.

Thirdly, all the key-words portraying the clusters and sub-clusters' names were written into comprehensive sentences, which would be the core insights from the conducted field research, such as in figure 5. For example, "Many of debuting caregivers trust doctors, because perceive them as experts, however

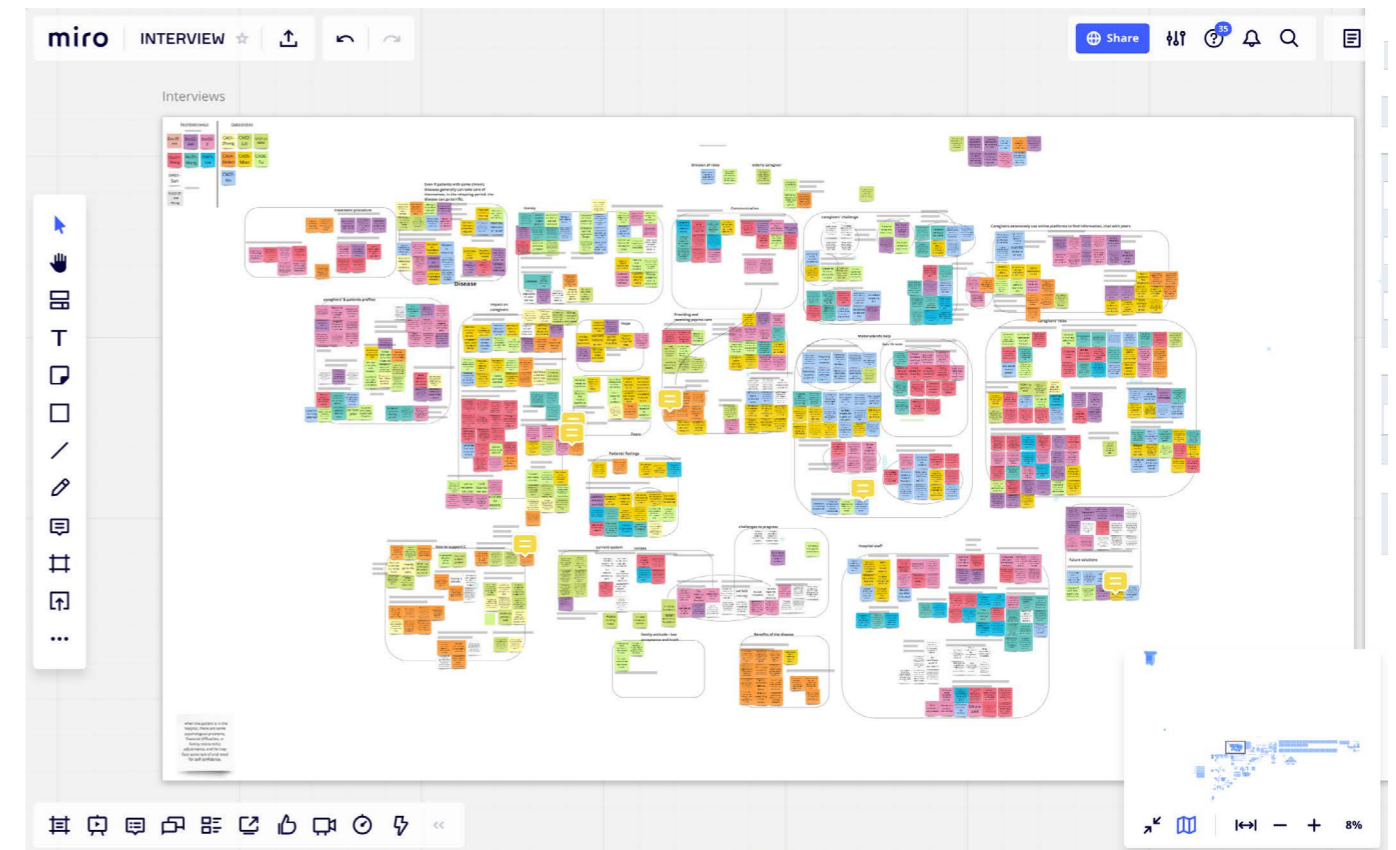


Figure 28. Abductive sensemaking process from the conducted interviews, done on the online programme Miro (Nadejda Cervinscaia 2020)

some undergo a distrust, doubt and denial period. It takes time to comprehend and accept the situation, especially if the treatment gives no progress." All the sentences were later arranged in a table containing the insight, the topic/major insight, and quotes from interviewees who contributed to the insight. At the end of the arrangement, it got clear that some of the insights, which initially represented different clusters, were actually building together another major insight. So, they were rearranged accordingly into the top rows of the table as "primary" learnings and the major insight, which they were building, was formulated in the first column of the Table 2 of the Annex 2. As Kolko mentions, "synthesis often results in several high-level themes that help shape future design activities" (Kolko, 2010: 17). These major insights help to nurture the design stage of the project.

Following this data analysis, I summarised significant themes and challenges related to

caregiving and compared these insights with desk research about caregivers' experiences. They are presented next.



Figure 29. Four areas of insights (impact on caregivers, hope, fears) with topics' sub-clusters inside each of them, generated through the abductive sensemaking process from the conducted interviews, done on the online programme Miro (Nadejda Cervinscaia, 2020)

6.3 Discussion on findings regarding caregivers

The interviews' results consist of findings about caregivers and about the healthcare system, benefits which caregivers can nourish. More specifically, the insights comprise highlights about:

- Caregiving crises
- Caregivers's responsibilities
- Caregivers' challenges
- Implications of caregiving
- Relief methods for caregivers
- Structures of supportive strings for caregivers
- Network and collaborations of current supportive structures for caregivers
- Current challenges of and aspirations for desired health system

Some of findings also supported the literature review, for example the concept of endurance (Mao, 2010), sharing caregiving roles within a family, the complexity of the debut of caregiving accompanied by extra level of anxiety (Pérez-Cruz et al., 2019), sharing sessions are efficient for a caregiver's relief (Guo & Liu, 2015), the fragmentation of the healthcare system, scarcity of collaborations. We present the following topics below, with supporting statements per each.

Caregiving crises

Concerning the interviews with caregivers particularly, the seven interviewed caregivers represented different caregiving experiences, however, the interviews with all of them referred to particularly difficult, chaotic and stressful periods: the debut of caregiving and the moments of the aggravation of patients' states. This finding was consistent for both caregivers with longer experience, and was

also noticed in the caregiver who is new to this role. This shows, that despite the fact that through time caregivers get used to the disease, acquire needed skills to provide care, get informed about the disease, the illness is still unpredictable and, unfortunately can aggravate/relapse, or new diseases may appear. According to both interviews and literature review, such circumstances constitute major stresses, and place the caregiver in almost a new environment again, just like in the beginning of the disease (Pérez-Cruz et al., 2019). This insights is the common point between caregivers with long experience and the debuting ones.

"This experience is a rollercoaster, there are some panic stages when you don't know what to do, and after you find a solution, you have the calm period again." (Caregiver 4)

"My biggest fear is mother to have unexpected, sudden health issues. It is very tiring because his mother has multiple illnesses, she is getting sick over and over and one week we can visit a hospital with one problem, while next week with something else." (Caregiver 1)

What regards particularly the caregivers in the debut of the journey, according to some of the medical workers observations, families need some time to accepted the disease, might be resistant to clinicians' advices.

"For elderly patients or patients with chronic diseases, the family may be psychologically prepared and prepared for the patient's death at any time. However, some patients came in through the emergency department. Their family members did not make a mental preparation[...]the most common thing is that family members don't understand why the disease happened and refuse the reality" (Doctor 4)

“When finding out about the disease most of caregivers understand and cry, they accept it and start to cooperate. The educated caregivers always cooperate well and get less depressed. Some others cannot accept the truth and some are even resistant to clinician’s suggestions.” (Doctor 1)

Caregivers’ responsibilities

As interviewees mentioned, caregivers’ duties consist of physical assistance, informational, mental, and financial support. Physical work, including consistent house chores, were mentioned as the most challenging parts; they imply daily tiredness and directly impact health. Interestingly, caring for a family member who maintains physical independence, alleviates caregivers’ burdens both from a physical and emotional perspective. Moreover, such caregivers do not fully perceive themselves as caregivers (mentioned by caregivers 2, 4 and 5). Also, it is noted that older caregivers experience challenges in providing physical care. Besides, they manifest the need to be accompanied by someone in emergency situations, so they get support in the multiplicity of tasks that caregivers need to perform.

“I am a lucky caregiver since I do not have real commitment. My dad is even sometimes cooking for me!” (Caregiver 4)

The medical workers mentioned that the caregivers provide basic medical assistance to patients, such as measuring blood pressure. Moreover, patient’s rehabilitation progress highly depends on the quality of care provided, therefore it is important for the caregivers to have the skills.

“The job of a caregivers is usually to remind to take pills, physical help and

support, measuring blood pressure/sugar level, accompany to the hospital. The bad thing right now is that caregivers don’t get training.” (Doctor 2)

“One responsibility is to take care of daily life, and the other is to discover some changes in the patient’s condition in time.” (Doctor 4)

Another role of caregivers includes informational and financial supports. Caregivers explained that they are the main communication channel with the doctors and are the ones who hold the full information about the disease and treatment. It regards especially elderly patients or older caregivers, for whom it is challenging for the elderly to perceive complex information. Therefore the caregivers inform themselves about the disease, many times under the pressure of time and decision making.

“I also accompany our sick dad and mother to the hospital because it is difficult for my mother to follow everything that doctors say.” (Caregiver 2 about caregiver 3)

Interestingly, many caregivers did not refer to financial support as one of their responsibilities, but agreed when they were asked directly. This might be due to the family’s primary role and filial piety in Chinese culture, which univocally implies financial support.

“On a daily basis, my mother takes care of the father, but if something suddenly happens, she always calls me to look for information about symptoms or treatment. Besides, I also accompany them to the hospital because it is difficult for my mother to follow everything that doctors say and to navigate through the hospital, pulling the wheelchair in front... And economic support, of course.” (Caregiver

2 about caregiver 3)

“Lastly, I provide economic support for them, it is very important! All the help I provide is my responsibility as their daughter.” (Caregiver 2)

Besides, caregivers carry the role of conducting communication with the doctor and providing moral support to the patient. Caregivers are also entitled to make decisions for the treatment and sign required documents if the patient cannot do it.

“Coordinate the relationship between doctors and patients. The second point is to ease patients’ mood, which is very important.”(Caregiver 6)

“These are the three typical situations to inform family members, one is to go out for an examination, the other is to make the patient’s condition change worse, and the other is to do some invasive operations that require informed consent which they have to sign.” (Nurse)

Sometimes, decision-making can be even more difficult since some caregivers are making treatment decisions without patients’ full participation. In China, it is quite widespread to hide the true diagnosis from the patient. So the family has the entire responsibility and complexity of deciding about the treatment and liberating the patients from this task, who usually only know that the disease is benign. Finally, as a Chinese cultural trait, all the above-mentioned responsibilities and the entire caregiving experience is mainly perceived as given and needed to be endured.

“They don’t share their emotions to other people, maybe very close relatives, but normally they take it as something which they need to endure, it is very cultural. They hide the truth from their sick relative, and

tell them that it is a benign disease, needing to have an operation. The doctors support hiding the truth, it is a Chinese culture trait.” (Doctor 1)

Caregivers’ challenges

Combining caregiving with other roles is challenging. All middle-aged caregivers reported the challenge to balance caregiving with their other roles (mentioned by caregivers 1, 2, 4, 5, 6) - middle-aged caregivers are likely to have children to take care of and a job. Namely, five out of six experienced or expected a negative impact on their career, e.g., refusing an overseas job offer, limiting business trips, asking for leave. The caregivers have to prioritise, and, as supported by the literature review, feel a challenge to combine multiple roles.

“Shortly before the diagnose, I was in the middle growth of my career. I was looking for overseas opportunities and got a job in a company’s regional office, which would imply changing the city. However, as my father was diagnosed, I decided to resign.” (Caregiver 4)

“Actually, I don’t have time anymore to take care of her now[...]I have to go to work and take care of my children.”(Caregiver 5)

“Caregiving affects work; for example, I can’t work today anymore.”(Caregiver 6)

It was noted that the elder caregivers are especially burdened by the physical assistance. One of them benefits of professional care-worker assistance, and the other one wishes he had financial resources to afford a place in a nursing house.

“Our compound caregiver comes 3 times a week, for 1h. I am anyway very tired because it is not enough help.”(Caregiver 3)

“I wish I could pay a nursing home care.”
(Caregiver 1)

All the caregivers mentioned experiencing financial challenges for surgeries and further treatment; they are usually asking for financial help within their prominent families or economize on other spendings. However, Governmental support is consistent: all of the families had the support of up to 90% for different medical procedures. Moreover, many organizations can provide financial support through crowdfunding. Notably, one of the doctors mentioned the possibility for patients to be treated with experimental medicine. Such treatment would be fully sponsored, so many families are willing to follow it because they have hope for innovative medicine.

“We got financial governmental support: a discount for surgery, and some of the medicines are 100% free and then you need to pay, and afterwards you get 70% off again.”(Caregiver 4)

“Caregivers will tell us that the family is in a difficult financial situation, so they hope to save a little money on medicine.” (Doctor 4)

Moreover, some of the supportive findings are strongly interlinked with cultural traits. Namely, caregivers univocally feel the duty to provide care. They choose to seek support inside the family, endure and not uncover their feelings in public, and hide the patient’s actual diagnosis. These characteristics may contribute to condensing pressure because of not sharing it because of cultural constraints. Decision making is another challenge in caregiving. The doctor also stated that when the diagnosis is not very obvious and potentially fatal in Chinese culture, it is widespread to hide the actual diagnosis from the patient.

“Caregivers hide the truth from their sick relative and tell them that it is a benign disease, needing to have an operation. If the family considers that the patient should not know, doctors support in hiding the truth; it is a Chinese culture trait.” (Doctor 1)

“My caregiving mother and sick father were attending gatherings organized by a volunteer or the Buddhist community, they enjoyed it.” (Caregiver 4)

Implications of caregiving

A mentioned consequence of caregiving is the deprivation of caregivers’ physical health. This finding illustrates the insights from the literature review. Specifically, the two elder interviewed caregivers mentioned the deprivation of their health once caregiving became the new routine. The caregivers use to place the sick family member’s needs before their own needs and might disregard consistent rest.

“Last year I was diagnosed with diabetes, and low immune system. I didn’t have to get that tired as I was always getting. Before my diagnosis, if I urgently needed to come to the hospital with my mother, I was trying to still finish all the planned tasks. But now I try to split up the remained tasks for that day within the next days. Otherwise, I tire myself too much.” (Caregiver 1)

“My mom is also not very well, she has heart issues, high blood pressure. However, she is doing all the housework and is the first person to provide care for my dad.” (Caregiver 2 about caregiver 3)

However, as some caregivers claim, caregiving can be caregivers’ chance to learn about themselves and their family, rethink their values, and the lives they lived. They

felt empowered to become better, show a good example to their children, and build the family relationships they are aspiring to. Some of the caregivers mentioned that they have changed their approaches within family relationships and became kinder and closer.

“Within this crisis, there is a lot of opportunity space for everyone in the family to rethink their lives and become more united in solving the new life circumstances. You are to reflect on life, death, and health.”(Caregiver 4)

“I am trying to adapt and adjust to this situation, be the role model for my kids.”(Caregiver 1)

“My caregiving mom became also more outspoken, she tells him how much she loves him and we all understand that together is better than one. My mom started practising Tai Chi in the park every morning.” (Caregiver 2 about Caregiver 3)

Interestingly, medical workers mentioned that caregivers generally trust doctors and follow their suggestions, however in the critical moments, they might start feeling distrust to the treatment process, because the patients don’t get better. In such critical moments caregivers might also start conflicts with medical workers and be short-tempered.

“Patients sometimes are short-tempered, but Lee would adjust herself and wouldn’t take it seriously.” (Care-worker)

“The worries about patients may make caregivers anxious and quarrel with medical staff.” (Nurse)

“The family has not yet made an objective assessment of the patient’s condition so it mistrusts the doctors.” (Doctor 4)

Relief methods of caregivers

A crucial role in gaining the balance is to get external support: either family or society. The two caregivers (4, 5) who claimed to be feel balanced about the health challenge of their family member, highlighted the importance of finding and the difficulty of preserving the balance. Regaining balance is very challenging and requires constant work to be kept and has a direct impact on the entire family. As noted, these two caregivers have been benefiting of psychological counselling.

“Once a family member gains balance, the whole family dynamic changes.”(Caregiver 4)

“Balance is very fragile; it is a tough and constant job to keep it. Any external situation can destroy this equilibrium. Within dad’s disease, there are no predictions; anything can change.”(Caregiver 4)

“Belief, meditation, and social support are factors facilitating regaining emotional equilibrium.”(Caregiver 4)

It was noticed that the longer a caregiver is providing care, the better and more efficient strategies for gaining both information about the disease and balance he/she has. The interviewed caregivers practice traditional sports, religious practices or sharing with family. As discovered within interviews, Chinese caregivers also share with very close friends or peers, but full externalisation of emotions happens mainly within the family circle. It is described as a Chinese cultural trait.

“I go to the park for a walk, I do Tai Chi.”(Caregiver 3)

“I seek support from my relatives: sister, and 4 brothers, the family union is very powerful. I also go for holidays” (Caregiver 2)

“To gain peace, my mother is going to a buddhist temple every year. She prays.”(Caregiver 2 about caregiver 3)

“They don’t share their emotions to other people, maybe very close relatives.” (Doctor 1)

“I was feeling worried, very anxious, and was looking for support from my colleagues and friends in a similar situation. For example, my ex-colleague could support me by sharing her personal stories about her dad. We would write encouraging emails to each other.” (Caregiver 5)

“One of my friends in the same situation gave a tip: to make an excel file with all the medical tests. Such kind of visualization makes it easier for a doctor to understand the progress.”(Caregiver 4)

6.4 Discussion on findings regarding healthcare system and organizations related to caregivers

The interviews also revealed some details about the current supportive strings and structures for caregivers. They are presented below.

Structures of supportive strings for caregivers

An important finding mentioned by both doctors and caregivers is that in China, psychological help may be stigmatised as obsolete, and often people skeptically

perceive it and instead need a nudge to go for it (Exel et al., 2007). Moreover, one of the doctors confessed that he does not think that caregivers would think of support organizations. However, the two caregivers (caregivers 4, 5), who benefited from professional moral assistance, recognized its importance and recommended it to others. As another doctor mentioned, this kind of support is just starting to gain recognition.

“I found out about counselling sessions and inquired my friend’s opinion on this. She said it might be a good idea, so I had some 4-5 sessions. My dad refused to go[...]One year after the surgery my father together with my mother, despite their initial skepticism, participated in some workshops, some of 1 week, some of 1 day. They were doing meditation to calm down and regain balance, the methodology includes Food Brain Field Meditation.” (Caregiver 4)

“Caregivers encounter the disease suddenly, they get very depressed. Sometimes they might become angry at other relatives, for no reason, because they are depressed but they don’t accept even this. People think depression means being crazy, they don’t think psychological support is important. They don’t share their emotions to other people, maybe very close relatives, but normally they take it as something which they need to endure, it is very cultural.”(Doctor 1)

“It is important to give patients psychological counselling and spiritual encouragement. It is also very important for the caregiver, because the caregiver sees no hope.” (Caregiver 5)

More specifically about social support, most medical workers and caregivers mentioned

the importance of peer support in overcoming anxiety, getting informed, and finding practical pieces of advice, doing it offline and online. In China, the online chatting is very popular. Accessing online forums and resources is also common among elderly people. Therefore many caregivers look for support online. However, sometimes these groups also have pessimistic comments, which may negatively influence patients and caregivers.

“I was looking for additional information about the disease and treatments in online communities, I did not want to rely on doctors entirely. Besides, I needed some inspiration and confidence. In the online communities, I can always find stories of the same diseases and related suggestions, some people are like “models,” they share a lot, and it is hard to ignore them.”(Caregiver 4)

“We launched an Online community where current and former patients can chat and comfort each other.” (chairman of Lymphoma Home NGO)

What regards support specific organizations, only one caregiver could name an assisting institution. The caregivers mentioned a compound community unit with professional caregivers who can provide physical assistance for patients, therefore indirectly benefiting the caregiver by relieving physical assistance difficulties. However, the demand for this service is much more than the available specialists. The assignment of specialists is done according to the patient’s financial need and emergency of health state. The families can benefit from discounts, even 85%. Another caregiver mentioned an individual volunteer-based initiative, where her parents, including the patient, participated together. This finding also supports the claim from the

literature review about the efficiency of family therapy in support.

“Getting a compound caregiver is very difficult; the chances are very low. But the price is excellent 6 ¥/h versus the market price of 40 ¥/h” (Caregiver 2)

Lastly, doctors mentioned that some of the patients don’t have insurance, some, despite life savings and family help, don’t have enough money for surgery, some of older patients refuse the treatment and prefer to leave their life savings to their children, as an element of Chinese culture. In these cases, doctors might suggest online platforms, charity organizations, who might facilitate caregivers to collect funds for surgery.

“The money can be collected from society by NGOs, it was working well until when the money started being stolen. There could be collected even some 200000 - 300000 ¥. Now collecting is difficult, media is saying bad things. There is no real trust anymore. The government will regulate these NGOs transparency. The info is spread through wechat. People would still donate if they trust/ somehow know the people requiring money. Anyway the money goes to the NGO first. The patient is the priority for the family, so the entire family will collect money too.” (Doctor 1)

Social work department in a hospital

When healthcare professionals were asked about supportive mechanisms for caregivers, some mentioned careworker services, online chat communities with patients and caregivers for similar diseases, or platforms for economic help. However, the majority could not name a dedicated support organisation for caregivers, providing, for example, moral

support. Besides, doctors explained that they never thought of caregivers as people needing help and highlighted that the current system is highly patient-centric.

“I never thought of caregivers, I even didn’t notice that problem[...]Everything now is patients’-centered and we perceive caregivers as individuals. This is so new to me. We know that they tired and stressed, they have double-worries: for the patient and for themselves.” (Doctor 2)

One of the doctors (Doctor 3) referred us to the social work department. After the medical social worker interview, it is clear that the range of their possible interventions is vast. Moreover, the literature review finding underlined the efficiency of family therapies due to the Chinese cultural aspect and the importance of the social work department. Due to the complexity of decision making and the overall stress, families might develop internal conflicts. The social worker revealed that they have tools to facilitate a balanced discussion and resolve misunderstandings.

“The social worker can arrange a volunteer for you. The social worker can also raise money for you. The social worker can provide you with psychological aspects. Social workers can also help you better family relationships.”

“Maybe for some cancer patients, when they are struggling between different treatment plans, and family members cannot determine the good one. For example, some family members recommend surgery, and some family members do not recommend surgery, then there may be family conflicts. Social workers can organize them and initiate a family meeting. So social workers can organize and promote and coordinate family

relationships.”

Notably, the interviews with the social worker of Ninth People Hospital mentioned the definite need for caregivers to participate in the social work department’s activities. Inspired by social work departments’ success in Western hospitals, he mentioned the high potential of this starting practice in China. However, so far the financing and human resources are limited. Namely, the Ninth People Hospital operates with thousands of patients and caregivers daily and has more than 50 departments. However the social work department consists of only two people, so the scarcity is apparent. Moreover, caregivers’ knowledge about the possibility to benefit of dedicated educational and stress-relieving programs is limited. The social workers are the ones to take the initiative to find and assist caregivers. But often, caregivers cannot participate because they cannot leave the patient alone.

“So social workers in developed countries do a lot of things, because they have a lot of resources in the first place, and basically caregivers will find social workers when they have problems. However, in the mainland, because social workers have just started, they are not yet known to many people.[...] Some patients may have only one caregiver, so he may not be able to participate. Maybe after the patient has surgery, he must take care of the patient.”

However, it is noted that the caregivers who managed to participate, are very satisfied. The social worker expressed the efficiency of the workshops with caregivers.

“They can share some of the stress, distress, and emotions they encountered in the care of patients, also the current state, or some

of their current care experience, their optimism. Maybe some family members are very optimistic, some family members are very negative. After hearing the feedback of other caregivers, the family members of the negative patients will share with the patient some confidence and support.”

“We wrote an article about our team’s model, and found that it was effective, and then wrote a paper. This article will introduce the effective factors of this group, such as the sharing just mentioned.”

Network and collaborations of current supportive structures for caregivers

Network and collaborations of current supportive structures for caregivers

Another insightful mentioning by the social worker is the collaborations: e.g., a Shanghai University and have access to student volunteers, street residents volunteers, children of medical staff volunteers, and medical volunteers, companies. He explained that many Chinese companies want to be socially responsible. Therefore some find charities or contact the social work department and donate money to be later distributed to families in need. However, this practice has low visibility and is not optimised: the social work department does not have a resource list, with companies eventually open for collaboration. Therefore it may be challenging to come back to these companies later for eventual common projects. So, the potential of collaborations is unfolded due to the lack of resources and a project pathway.

“We don’t have a list of resources. But having a list is better, there may be a list in hospitals from other countries. In China it all

just started.”

“I certainly will feel as if there is insufficient support from the outside.”

Regarding networking, the interview with the chairman of the NGO “Lymphoma Home” was fruitful. It flashed light on their contribution to patients and, indirectly/passively, their families. The NGO guides for families to connect to such clinics and medicine companies, research centres, it has strong governmental support. The NGO has been allocated a dedicated room in a hospital in Beijing. The volunteer, former lymphoma cancer patient, provides moral support to lymphoma cancer families and proposes the eventual possibility to pursue a sponsored treatment in exchange for patients’ health data. Besides, the “Lymphoma Home” has a web platform and an app, where caregivers communicate, exchange information and support each other. This platform is very popular.

“It is difficult because caregivers are on their own. With “Lymphoma Home” they get connected to the existing system of medicine research institutions and famous doctors.”

Notably, the chairman of the NGO mentioned the tight collaborations of the Hospital in Beijing with medicine national and foreign development companies and expressed the willingness to expand their network due to the well-functioning pattern: the hospital refers patients to the NGO, which shares the data with medicine companies, famous doctors and clinics, and provide finance, though experimental treatment to the patient. As the model is successful, they want to extend to more diseases and more potential partners. Similarly, such a model was mentioned by the Doctor 2, who is also the chairman of a stem

cell medicine development company. This suggests that there are grassroots initiatives of building networks and referral system between medical institutions and workers.

“Now we want to focus not only lymphoma tumour, but also leukaemia, lung, breast cancer, ophthalmoneuromyelitis. The pattern works well, but there is not enough funding.” (chairman of Lymphoma Home NGO)

“There is no treatment for them now, so they come to us to use stem cells therapy. We have to screen, not everyone can join because of our criteria. Sometimes people can join, for example a control group and a normal group with stem cells treatment. [...] We have collaboration with major hospital in Beijing, Guagnzhong, very famous scientists, they recruit patients from all over China.” (Doctor 2)

Current challenges of and aspirations for desired health system

Regarding the caregivers' journeys, many caregivers mentioned poor guidance through the treatment process, and the healthcare improvement aspirations were connected to this problem. It was noted that even though nurses and doctors might provide information regarding places where to buy materials, such initiatives are not standardized or centralised. Therefore the system has some gaps of information and guidance support. As Doctor 3 mentioned, some doctors guide through the treatment procedures; however, he aspired that volunteers could take this responsibility so that doctors can focus on medical research.

“The most unclear moment is when we just moved in to the Ninth People Hospital, without a doctor or a nurse, I just sat

there without knowing what to do next. I hope to add some guidance[...]I once had an idea: When I go to a new city, whether it is traveling or seeing a doctor, there is a consulting agency that I can consult in advance. In this way, if we come after having checked the information clearly, it will later be less mess.” (Caregiver 7)

“We will tell them what patients need, including daily necessities and medical supplies (for example, paper towels, urine pads, and even our medical auxiliary tapes and auxiliary materials). Then tell the family where to buy and when it is needed.[...] If an institution is willing to provide this kind of help, it may be beneficial to the non-local family members of patients.” (Nurse)

“In addition, we hope that volunteers can help caregivers, such as social workers. For example, if the family members do not understand the condition, the volunteers can introduce the caregivers to other caregivers for the same diseases and processes, e.g., surgery, rehabilitation, etc. These things are all done by doctors now, so we have no time left for more important things. This is a very basic but important thing, so if there are volunteers who can help caregivers and doctors.” (Doctor 3)

When questioned about the envisioned healthcare system, besides the institutional, top-down intervention, the medical workers underlined the community's power in building it.

“It depends how you want to innovate: top down or bottom up. Realistically you can try do some practical thing: organize some patients. Start maybe with wechat app group.” (Doctor 2)

6.5 Conclusion

Analysis of IDIs shaped several caregivers' related themes encompassing:

- *The critical points within the caregivers' journey happen at the beginning of the disease and anytime when the disease takes a new turn, and the treatment path has to be rediscovered before surgery or similarly crucial interventions.*
- *Denial of the situation, doubt, and distrust to doctors* - There is a denial period for some caregivers filled with distrust and doubt to doctors and their processes, especially if the disease is sudden or is persisting, it takes time to comprehend and accept the situation.
- *Lack of stability and unpredictability are typical in caregiving for severe diseases, and this uncertainty grows fear;*
- *Caregivers have emotional blocks and mood fluctuations due to high pressure* - The pressure which caregivers' experience can cause conflicts, aggravates comprehension, and perception of information. The most stressful periods is the surgery and the diagnosis of the disease;
- *Caregiving implies multiple responsibilities, which contribute to forming a caregiver's burden and can result in the aggravation of personal health, especially the caregivers who provide constant physical assistance, and the older caregivers feel the burden.*
- *Personal vs. patient's interests' tradeoff, biased for patients' needs* - Caregiving is a tradeoff between different habitudes work/ practical help/ emotional help/ habits, it implies sacrifice which impacts significant life roles and areas, this is an implication especially for young and middle-aged caregivers;
- *Need for guidance though the treatment*

process - Guidance in the hospital and throughout the treatment process (on practical, informational levels) eliminates ambiguities and gives a feeling of security;

- *Caregivers do not know which kind of help is available and where to get it* - Caregivers do not know what they can be assisted with and how to get this help, sometimes healthcare professionals suggest and guide them to obtain it.

- *Treatment implies financial spendings; therefore financial support is crucial.*

- *Sharing and absorbing information is a way to relieve the burden and feel in control* - Getting informed by communication with doctors, peers, reading multimedia materials and online portals helps caregivers to feel aware and empowered.

- *Importance of finding balance in the new circumstances* - The health crisis is an good opportunity to rediscover yourself and rethink family relationships, your life and priorities. Often, regaining balance comes through being close to nature, practicing tai chi, visiting religious places, peer groups, psychological counseling.

- *Chinese culture has an implication on caregiving: hiding the truth from patients and relatives, enduring the severe disease together with the family members and the importance of support from relatives, presence of filial piety and therefore duty to provide care* - Hiding a patient's real health status is common for Chinese culture (either caregivers do not fully tell the situation to relatives, or patients hide their pains or doctors and family hides from the patient). Also, caregivers and doctors referred to perceiving the challenge to overcome the disease as a given challenge, aimed to be endured as it

is often not seeking help, but enduring the difficulty independently. The endurance habit also might influence caregivers to accept professional psychological help; however, it can be partially relieved due to moral support from the family members. Finally, caregivers in a parent-child relationship with patients demonstrate a high level of filial piety and care for parents.

Regarding the healthcare system:

- *Healthcare system fragmentation* - The current healthcare system is highly patient-centered, and the practical help which caregivers can get is often fragmented and implies a high economic burden, despite the widespread governmental help;

- *The system is not emphasising enough the importance of psychological help* - The current healthcare system is highly patient-centered. The importance of psychological help for caregivers is often overlooked in favor of patients' needs;

- *Unexplored potential of the system, despite the existing attributes due to lack of support* - The Hospitals collaborate with different organizations/institutions, but the partnerships could be nurtured more if there were support and tools. Moreover, the social work department and the Lymphoma Home NGO, which are very prospective, is not empowered enough with human and financial resources.

The insights point at of caregivers' need to be guided through the treatment process, both on practical, informational and psychological support levels. However, the healthcare system is not optimised to deliver it.

It was found out that the experienced caregivers who found balance in their

circumstances might be easily shaken when the situation goes of out of track. Similarly to the debuting caregivers, they become fragile and lost. Therefore, especially debuting caregivers and the ones in emergencies need help to readjust spiritual equilibrium.

The psychological help was recognized as crucial; however, caregivers might feel reluctant to it and might need a nudge. However, they are willing to receive social support both from the family and peers. Therefore, facilitating sharing practices in different groups might be considered in the design of services for caregivers' support.

The presence of grassroots initiatives was also noted, for example:

- the Lymphoma Home NGO was first created to build a community of lymphoma patients and the caregivers transformed itself into an NGO that bridges patients and families to medical resources;

- a former lymphoma cancer patient became a volunteer to be the trustee for patients and provide guidance on behalf of NGO Lymphoma Home;

- volunteers are collaborating with the social work department in the Ninth People Hospital.

Such initiatives denote the presence of needs, resources of these activities and underline the high power of collaboration. On the other hand they serve as an inspiration for the improvement of healthcare. As such phenomenons also follow some of the proposed healthcare reform policies for building a people-centered integrated care model, they should be empowered.

Lastly, as in China, the Government plays a central role and actively influences the

course of events. Within the field research process, it was noted the importance of official authorization to support interviewing. Therefore, it is essential to consider governmental support in conducting such projects.

7 CONCEPT DESIGN ideation

Introduction

Within this chapter, there is described the four-step ideation process:

1. Co-design ideation workshop;
2. Analysis of the workshop results and formulation of service visions;
3. Validation session;
4. Formulation of the final service solution.

After an extensive field and desk research, there were gathered multiple insights previously described. Even though the accumulated data gave a good overview of the current system, it was decided to conduct a service system ideation workshop to diverge into the development phase. Co-design workshops are extensively used in the service design field. Researchers claim that workshops are the technique “to be used to explore and articulate actors’ needs and ideas, organizing joint creativity and the co-creation of new solutions” (Vink et al., 2019). Specifically, research highlights the importance of implementing co-design workshops in projects connected to healthcare, where the multitude of actors and users is extraordinarily complex, and where design has the power to “cultivate and enable institutional work” (Pfannstiel &

Rasche, 2019). The multiple invited actors are dialoguing and evaluating divergent propositions (Pfannstiel & Rasche, 2019). Within the co-design workshop, participants use visualization tools to simulate and explore service scenarios through experience maps (Vink et al., 2019). Consequently, in this chapter, there is described the ideation and validation process of the service solutions. The validation is a useful tool to “identify most relevant aspects to focus on and improve” (Pfannstiel & Rasche, 2019). As a result, there was developed a service design solution, encompassing multiple potential elements to respond to the needs of caregivers and be able to integrate into the context.

7.1 Preparation for the workshop

To tailor the workshop, there were listed known and unknown information which would be crucial within the design of the system:

The knowns:

- *The functioning, weak and strong points of the healthcare system regarding caregivers.*
- *Six types of Shanghainese caregivers’*

problems and existing interventions to mitigate them in China and worldwide (problems: financial, dealing with practical tasks, acquiring information, poor social life, emotional, navigation through the system).

- *The importance of the Chinese cultural aspect within the matter of caregivers.*

The unknowns:

- *How might we help caregivers in the short term?*
- *What could be the roadmap of the service system for the caregivers? What are the resources currently available?*
- *How do hospital staff and caregivers envision the solution to the most critical problem?*
- *What are all the Chinese cultural aspects to consider when approaching caregivers?*

Given this, the workshop’s goal was to understand the potential of the current system set-up for the intervention on caregivers’ emotional well-being in the acute stage. To ensure that different perspectives are not overlooked but rather nurtured (Pfannstiel & Rasche, 2019), the author wanted to reach the workshop goal by considering the contribution of different groups: medical workers, administration workers, caregivers.

The next step within the workshop preparation was the simultaneous the tools’ development and recruitment processes.

Workshop’s agenda

The workshop was ideated to have three stages:

0. **Introduction - 20 min.**
 - Project introduction;
 - Icebreaker;
1. **Explore the context - 1hrs.**
 - Discovery of the two personas;
 - Formulating two experience maps;

Break - 15 min.
2. **Problem definition - 45 min.**
 - Definition of issues
 - Prioritisation of issues
 - From issues to design questions

Break - 15 minutes;
3. **Envisioning the future - 45min.**
 - Inspiration from case studies
 - Envisioning the desired future
 - Final presentations

Tools’ development

Part 0. Break the ice

As different professionals and people who might never meet each other within the workshop were invited to the workshop, breaking the ice at the beginning of the workshop stands crucial. The set atmosphere will reign through the entire workshop and affect the work process and the results.

Breaking the ice within this workshop had two stages: welcoming the participants with drinks to a spacey place with music asking them to write their names on the tape, followed by a short presentation about the research, and an ice-breaker.

In order to align the participants on the topic, the author prepared a presentation. The contents of the presentation were:

1. General data about the caregivers' issues in China: the increasing amount of caregivers, the impact of caregiving on the physical and mental health, interdependence of quality of care, and caregivers' quality of life.

2. Healthy China 2030 Policy and Chinese Government views: shifting resources towards primary care facilities, strengthening the link between different healthcare actors, building harmonious relationships with patients and families.

3. About the author's master thesis project: research phases and work conducted up to now; scales of change implied by the caregiving (predictable alternation in patients' health status versus unpredicted changes); the discovered responsibilities of caregivers.

4. Chinese cultural aspect in caregiving: the concept of filial piety, sacrifice, Confucianist values of the Chinese society.

5. The project goal: Supporting family caregivers while nourishing their cultural values of filial piety and endurance.

After the presentation, there was planned an icebreaker game (Figure 30). It included inquiring about different information from the other participants and presenting the curious findings to everyone.

GET TO KNOW EACH OTHER

What he/she likes doing?	Where is he/she from?
1	1
2	2
3	3
Where did he/she study?	What is his/her main professional interest?
1	1
2	2
3	3
Ask about whatever you want:	What is his/her favourite food?
1	1
2	2
3	3


Figure 30. Icebreaker tool (Nadejda Cervinscaia, 2020)

Part 1. Explore the context

Aligning on the stories

When implying the participatory approach within the system design, the first step is to align the multiple participants on the same ground (Stroh, 2015). The ultimate alignment for the ideation of the service would be synchronizing ideas with the target audience. Therefore, the first exercise was to get familiar with the two pre-designed personas (Beihu and Lenji), caregivers with different experiences, and caregiving length (Figure 31). The personas were designed based on the findings from the field and desk research,

focusing on the caregivers' needs, aspirations, and frustrations, which were infused in the narratives. The personas captured different archetypes also by personal characteristics and Chinese cultural values. The activity emerging from the persona tool was to highlight the important parts of the story. The two personas' narratives are useful for the participants to "understand experiences" (Pfannstiel & Rasche, 2019). Therefore, the exercise aims to align and immerse all the participants into the story of their Persona to design the service for persona archetype later.



Beihu, 75
caregiving for his wife, who has heart disease and diabetes
Caregiving experience 2 years

"I WAS ALWAYS HOPING THAT WHEN RETIRED, I CAN FINALLY REST AND ENJOY, BUT AGING BROUGHT SO MANY NEW WORRIES, AND I HAD TO LEARN TO GO ON."

Story 2 years ago, his wife was diagnosed with diabetes and since then she cannot do many things which she used to do her entire life: grocery, cooking, cleaning. These responsibilities are mainly on Beihu's shoulders now. Beihu has to give injections to his wife to balance her sugar level and control it. However, 2 weeks ago, Beihu's wife had a sudden stroke and she was just discharged from the hospital. She is very fragile and once she gets home he will have to take special care of her and remind to rest and to take pills.

When the wife was diagnosed with diabetes, Beihu learned how to cook to keep his wife's low sugar diet and even enjoys it. Now he also will need to adapt the care considering her heart issues. Learning to do all these take Beihu much energy. Moreover, if he does not rest properly, he starts being nervous and forgetful.


Beihu perceives these changes in a problematic way. When the diseases happened, his friends saw his struggles and advised him to go to Buddhist temples and pray. Even though he was first very stubborn and skeptical, after 4 years ago, he tried it and partially regained his balance. However, now there is a sudden new problem.

Beihu's son helps his parents financially but has his own family and cannot help practically.

Hopes He can afford to hire the cleaning lady for more days per week and even a careworker. He hopes to get external help.

Fears Beihu is very afraid that his wife will have repetitive strokes, or other diseases will appear. He is thinking of it constantly.

Needs Practicing tai chi every morning and playing mahjong with his friends. Preserve the course of life before his wife's diseases.



Lenji, 50
caregiving for her dad, who has lung cancer
Caregiving experience 1 month

"I CANNOT SEE HIM SO WEAK, FILLED WITH TUBES, NOT KNOWING IF WE CAN AFFORD TO TREAT HIM IF THE DISEASE DOES NOT STEP BACK."

Story A few months ago her retired and windowed dad started feeling a strange discomfort when breathing. He was always a smoker, and coughing has been a common thing, so he didn't pay attention, and told none about his feelings.

Then he went to the doctor by himself and found out the health risks. So the dad informed Lenji that he needs to undergo many health checks. Lenji assisted the dad in passing the health tests and found out the diagnosis of lung cancer, but the doctor informed only Lenji about it.

Lenji and the doctor told the father that the tumor is benign and decided to hospitalize him for the surgery. She has been visiting her father daily, he is not that cheerful as he used to be and motivate her. Next week father will be at home, Lenji will take a 3 weeks break from work to take care of her dad. She feels burdened to hide the truth and suddenly finds herself in such a situation.

Fears They got financial help from the Government, covering 80% of the costs, even though it was very complicated from the bureaucratic point of view. Even though her dad has savings, Lenji is afraid not to pay for the full cycle of treatment, including eventual chemotherapy, as she also has to save to pay for her daughter's English classes. After losing her mom one year ago, dad moved to Shanghai to live together, she is afraid to lose him. He is the only close living relative and to whom she is very connected.

Also, she is afraid that her dad will find out that he has lung cancer and will lose his will to live.

Needs A trusted and structured information to comprehend the illness and understand the alternative treatments. Reconnecting to nature and spending time with her friends and family members. Be the role model for her daughter and provide her excellent education.

Hopes To find a treatment which will negatively affect dad's body the least. Therefore, Lenji entered many online communities to seek advice from peers, which hopefully say the truth.

Figure 31. The two developed personas: Beihu (for team A) and Lenji (for team B) (Nadejda Cervinscaia, 2020)

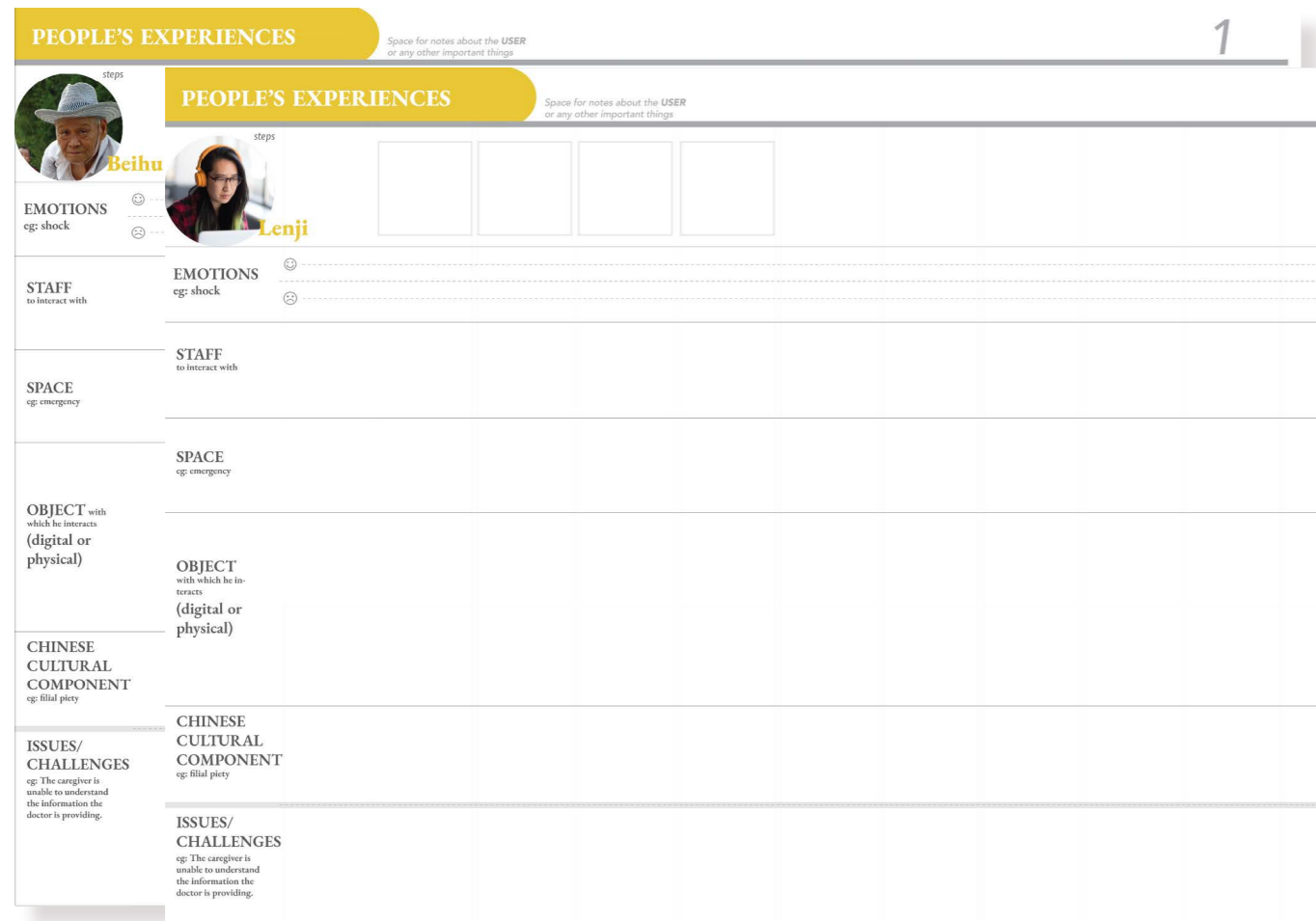


Figure 32. The customized user journey maps for the two personas: Beihu (for team A) and Lenji (for team B) (Nadejda Cervinscaia, 2020)

Creating the user journey

Next, starting from the particular stories of the personas under the radar, the participants are to build the Journey Map for a chosen time (Figure 32). The formulated journey map is the tool to list the user's activities, mapping the emotions related to each step, the touchpoints, and the Chinese culture aspect component of a step. Researches of Service Design for Healthcare show that when the different healthcare actors are implied into mapping the experiences, the actors tend to shift their perspective onto the provided services and overall experience of the healthcare user, and "challenge their own assumptions about the effectiveness of the current roles and norms" (Vink et al. 2019). Moreover, user journeys are useful to help experts emphasize with the user and "observe them in their own contexts" (Pfannstiel & Rasche, 2019). Therefore, the

Journey Map aimed to immerse even more in-depth into caregivers' experiences and formulate doubts about specific timepoints within these experiences. So, the participants would list down issues or challenges related to certain steps to later dig deeper into the nature of the issues.

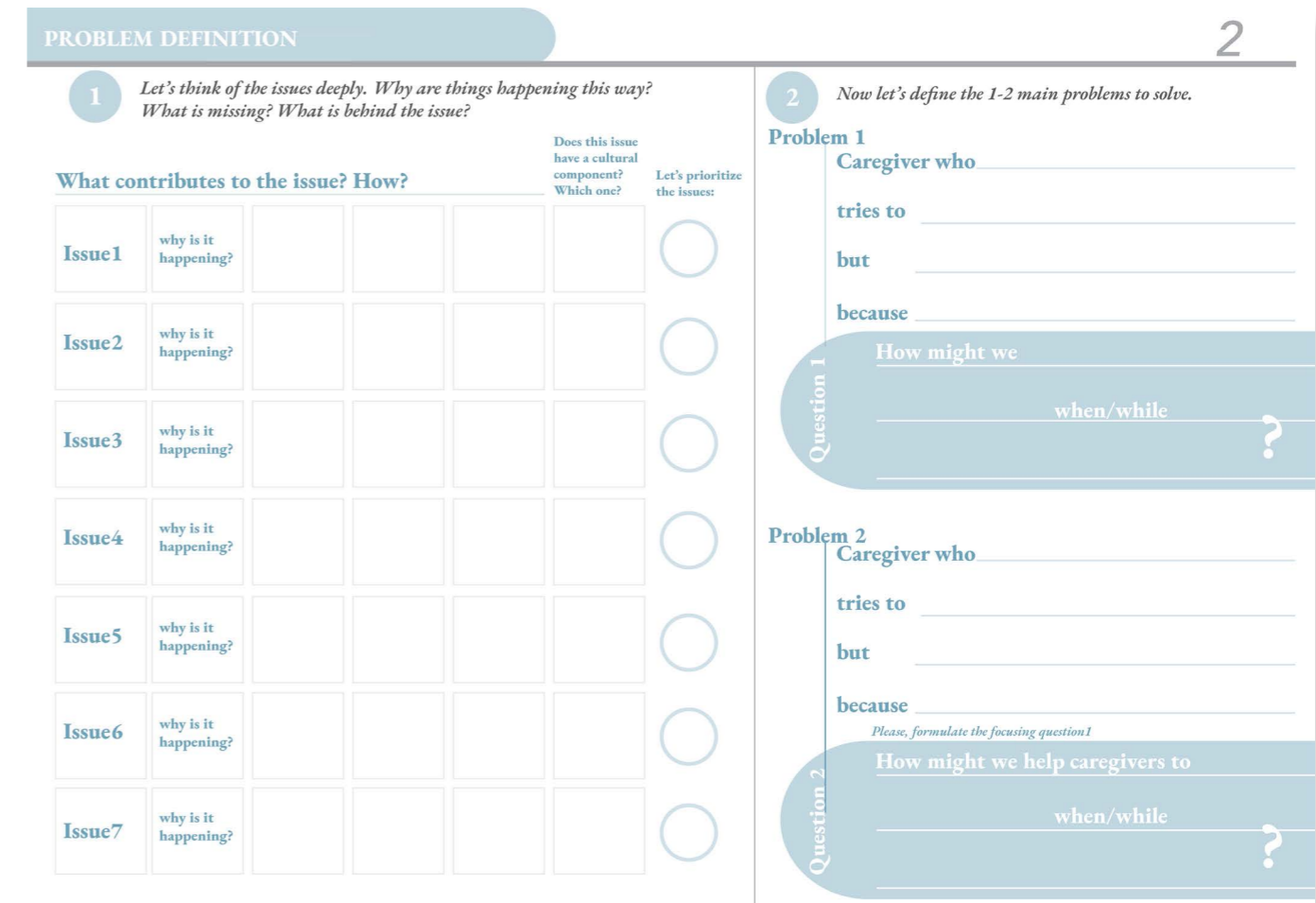


Figure 33. The customized user journey maps for the two personas: Beihu (for team A) and Lenji (for team B) (Nadejda Cervinscaia, 2020)

Part 2. Problem definition

"5 Whys" and prioritizing

The next part of the workshop consisted of multiple tools following the previously designed Journey map. The three tools of this workshop part are represented in Figure 33. First of all, the issues and challenges identified in the Journey map's bottom row were now placed into the "5 Whys" tool. The participants had to find root causes of the issues. Moreover, the author included one more graph, "Chinese cultural component," for the arguments rooting themselves in the Chinese culture. Consequently, the participants had to determine what are the most critical issues, and to prioritize the issues to focus on.

"Focused" user story

Next, the participants had to frame the

chosen critical problems into 1-2 user story sentences, focusing on the prioritized problems.

"How might we?" Questions

Lastly, within this part of the workshop, the participants were asked to formulate "How might we?" questions in order for the rhetorical questions to prompt their minds for the next part of the workshop: envisioning the future. According to Vink et al., bringing questions about the desired institutional aspects of a problem or opportunity will help not get stuck in the ordinary thinking about the desired institutional arrangements. Therefore this exercise aimed at bringing up open-ended questions, which will nourish creative thinking.

Part 3. Envision the future

Tomorrow's narrative

Within this part of the workshop, the participants were given nine inspiration cards describing diverse interventions for caregivers' good. The cards included solutions for different problems: financial, emotional, practical help (Figures 34, 35). The participants would receive three cards and highlight the most intriguing parts, and then share in the group their findings. This exercise was meant to stimulate thinking outside the box and nourish ideation, implied in the next exercise.

Next, there was designed a "Tomorrow's narratives of 2025" tool (Figure 36). The tomorrow's narratives is an envisioning technique based on the idea of writing fictional articles that simulate the moment in which the product or service will be launched in the market (IDEO, 2005). The tool included spaces to fill:

- Interview
- Quotes
- Sidebars
- Big headline
- Magazine name
- Visualization of the concept idea

Each of these topics included prompting questions to stimulate participants' thinking. For example, the Interview part included the questions:

- What is the support system about?
- What kind of help caregivers benefit from?
- Who are the people/organizations are involved in the support system, on which role?

- How is the project happening?

The last part of the 'Envisioning the future' part was to step back from the vision of 2025 and, given the current healthcare and infrastructure circumstances, to indicate what would be the short-term milestone to achieve already in 2021.

The last part of the workshop was the presentation of concepts.

Agency for Integrated Care (AIC)
Singapore

RESPITE CARE

What is the support?

Agency for Integrated Care is a Non Profit Organization which helps caregivers with multiple projects. Its mission is "to coordinate the delivery of aged care services, and to enhance service development and capability-building across both the health and social domains". One of the services AIC provides is Respite Care. Studies show the need for caregivers to take a break from their responsibilities, such temporary support and relief, easing the burden for the caregiver, is called respite care. The AIC

claims the importance of respite, therefore, AIC created a pilot Go Respite. The service helps to plan the break in advance, listing down all the details and needs about the patient, such as health conditions, special needs, preferences. Therefore, when caregivers need a respite, they can directly ask for it at AIC. The planning shortens the time to prepare the patient for the respite and move to the nursing home, taking away caregivers' worries about the paperwork and security of a patient

Lots a helping hands
USA

PLATFORM to ASK FOR HELP

What is the support?

Lotsa Helping Hands is a Non Profit offering visibility to caregivers through a platform and app. This service creates links between volunteers and family caregivers through online communities. As Lotsa Helping Hands claim, they "empower online caring communities that help restore health and balance to caregivers' lives". The platform is based on coordination, communication of support principles. It helps to "organize daily life during times of medical crisis or caregiver exhaustion in neighborhoods

and communities worldwide". Consequently, caregivers benefit from assistance in tasks, emotional support and peace of mind, while the volunteers find meaning in giving back to those in need.

Figure 34. Inspiration card with a repite care case study from the Agency for Integrated Care in Singapore (Nadejda Cervinscaia, 2020)

Figure 35. Inspiration card with a navigator tool case study from the Family Caregivers' Alliance in the USA (Nadejda Cervinscaia, 2020)

DESIRED Future
Team _____

Magazine name:

Oct. 2025

Picture - visualize your concept

5) Magazine
What is the name of the magazine?

4) Big Headline
What are the big news? How are caregivers now supported?

1) Interview
WHAT:
What is the support system project about? What kind of help can caregivers benefit from? How do caregivers find about this support system? What has happened for the community as a result of the project?
WHO & WHY:
Which people/what organizations are involved in the support system, on which role? What is the value for these people/organizations to participate? Who is managing the support system? Who is helping with this project?
HOW:
How did the project got to be possible? Where is the project happening?

2) Quote
Who is cited? What is being quoted? Who and what reposts on weibo?

3) Sidebars
What are the interesting facets of the cover story? Is there a criticism? What are the things to improve?

Figure 36. 'Tomorrow's narrative of 2025' tool (Nadejda Cervinscaia, 2020)

Recruiting

The ideal team for the ideation workshop includes actors with different expertise, namely medical workers and caregivers. According to the researches of Service Design's contribution to healthcare, when inviting multidisciplinary practitioners to a co-design workshop, "the participants can better leverage the tensions and opportunities amid institutional complexity to catalyse innovations" (Vink et al. 2019). Bitterman argues that within designing for healthcare, all the users (families and medical workers) shall be involved (Pfannstiel & Rasche, 2019). Based on these suggestions, the author aimed to find:

- social workers or psychology experts;
- doctors from both outpatient and inpatient department;
- administrative worker;
- caregivers.

The participants' recruitment was done via social media and direct inviting the participants of the previous research phases. The author designed posters for online and offline use, mentioning the workshop's aim, the phases of the workshop, and the roles who are to be involved.

The online poster in Chinese and English (Figure 37) was distributed through WeChat social media. The interested people could scan the QR code and contact the author. Also, the author wrote emails to the different Universities in Shanghai that teach social work students. In China, personal contacts are very important, therefore the author also asked her social circle to share the news about the co-design workshop.

Table 4. Information about the ideation workshop participants (Nadejda Cervinscaia, 2020)

N.	Name	Gender	Position	Working place
1.	Social worker 2	female	Medical social worker	Renji Hospital
2.	Doctor 2	male	Professor in the Medicine Faculty, Doctor in Head of stem cell department	Shanghai East Hospital; Tongji University
3.	Doctor 5	female	General Practitioner (Chinese Medicine)	Fangsong Community Health Care Service Center
4.	Nurse 2	female	Nurse	
5.	Hospital admin	male	Assistant Researcher, Deputy Chief of Medical Department	Renji Hospital
6.	Caregiver 4	female	Caregiver for her father, a cancer patient	Freelance design researcher
7.	Social work student 1	female	Postgraduate students majoring in social work	Shanghai University
8.	Social work student 2	female		

Lastly, the author also went to an inpatient area of the Changzheng Hospital and invited caregivers to attend the workshop. The author used the printed invitation letters (Figure 38).

All the recruiting activities helped to establish contacts that were useful in the next phase of the project. As a result, there were recruited 15 people, among whom eight could attend the workshop. The demographic data of the participants is described in Table 4.



Figure 38. Print invitation letter to the workshop(Nadejda Cervinscaia, 2020)

IMPROVING CAREGIVERS' EXPERIENCES IN SHANGHAI

Hello,

I am Nadia, a student of Politecnico di Milano (Italy) also have been studying at Tongji University.

The caregivers' wellbeing topic is sensitive for me, this is why I decided to conduct my research on it.

Now I am conducting a thesis for the master degree, called "Design of a Support Service System for Shanghai Families in the Acute Stage of Caregiving". And I'm inviting medical workers and caregivers to take part in the **CREATIVE WORKSHOP**.

My goal
The thesis project aims to propose and design a solution to support Shanghai family caregivers. Particularly, I am interested to find ways to sustain caregivers when caring for patients with complex and multiple conditions, in their acute and emergency stages.

About

Now the Master Thesis is in the second stage of development. In the first phase I have conducted interviews at Ninth People's Hospital and Shanghai East Hospital with medical workers. Thanks to the discovered challenges that caregivers experience, I developed insights for the organization and potential the current healthcare system offers.



The second stage of the project wants to use this data to inform a collaborative design session with **5-7 participants** (doctor, nurse, psychologist, social worker, nursing home manager and care-givers), to discuss findings and develop ideas. This workshop will consist of 3 parts aiming at:

Workshop plan



1 Context analysis and issue definition

Discussing the current experiences of caregivers and the existing healthcare system issues and potentials.

2 Envisioning the desired future

Envisioning the desired change in the current healthcare system to help caregivers to cope and endure their experience.

3 Bridging the gap

Imagining how to reduce the gap between the current situation and the desired future.

Details:

Taking part in this workshop implies participating in a **3h creative session with simple exercises which stimulate creative thinking**. Your participation will help me to improve my current understanding and inform my design for Master thesis.

English + Chinese

上海市黄浦区南京路751号4号楼201室

According to your availability within 09/26-10/11

A visual report from the session will be shared for your knowledge.

Why participating?

You will have a chance to **engage in a constructive discussion** with medical experts and caregivers and together build a vision for a caregivers-friendly system.

This vision will be the basis for a service for caregivers. **Your knowledge could inspire other researches and later come true.**

Also, **we will have a great tea and snacks** to stimulate the creative thinking :)



If you are interested, please, send me a message.

Figure 37. WeChat social media invitation letter post (Nadejda Cervinscaia, 2020)

7.2 Ideation workshop

Before the workshop

The participants were divided into two groups according to their positions and knowledge of English. The groups were facilitated in English by the author (Team A), and another group was facilitated in Chinese by a native speaker designer who volunteered to help within this workshop (Team B). In case that Team A encountered difficulties in understanding, there was assisted by a native speaker design researcher, who was implied in the project also in the field research phase. The groups were planned to be working simultaneously. The author met the volunteer several times to get to know each other, understand if the collaboration is possible, explain the aim of the project, present the designed tools, and align on the course of the workshop. The meetings were beneficial to establish trust between the two facilitators and build the facilitators' team.

Importantly, the author created a common WeChat group of all the participants, where there the agenda was posted, where the participants could address questions and e-meet each other before the workshop and eventually, get connected. It helped to create a friendly atmosphere and enhance enthusiasm among the participants (Figure 39). The author also posted persona cards, which was the workshop's first tool and contained much information. The participants were kindly asked to read the cards before the workshop in order to facilitate information comprehension.

On the workshop day, the author posted triggering pictures of delights waiting for the participants. Also, as the workshop space was appointed in an office buildings area, where it might be challenging to navigate, the author attached direction signs, which were

also posted in the WeChat group. It created a friendly atmosphere and stimulated online interaction.

Within the workshop day, the participants were using this WeChat social media group to post pictures of the process and later directly chat with each other. It facilitated the formation of relationships.

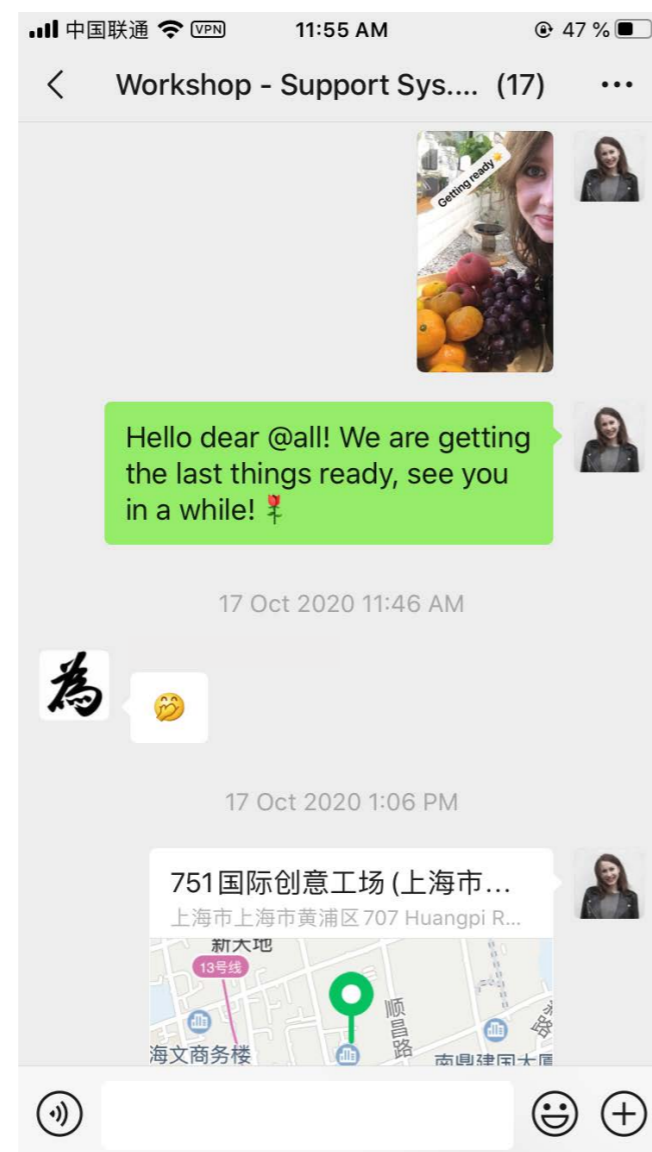


Figure 39. WeChat social media group of all the workshop participants (Nadejda Cervinscaia, 2020)

The Workshop

Part 0. Break the ice

After a short project introduction (Figure 40), the author decided to facilitate people's interaction through the previously described icebreaker table. The participants had to inquire from multiple people about multiple pieces of information and then share one of their findings (Figure 41).

The activity was done outside, with good weather, and the participants enjoyed the activity. It set the start for relationships by getting to know interesting information about each other, including professional interests.

Part 1. Explore the context

Each of the participants expressed what considers essential within the caregiver's persona card (Team A - persona Beihu; Team B - persona Lenji). Then the team proceeded with building the user journeys of the personas. The results of the Journey Maps are presented in the Figure 42. The teams immersed in the stories successfully related to the persona cards when proposing an action to add to the journey map. The participants also understood how the journey map tool could cast doubt on the current flow of happenings and guide to formulating the problem based on the multitude of issues and challenges.

Results Team A:

Within the exercise Team A formulated the story of Beihu being overwhelmed with duties, arguing with his wife about daily household matters, who, besides diabetes, recently had a heart attack. Beihu wants to have practical help from his son, who cannot provide it, and the rare time when Beihu can



Figure 40. The research project introduction (Nadejda Cervinscaia, 2020)



Figure 41. The icebreaker exercise (Nadejda Cervinscaia, 2020)

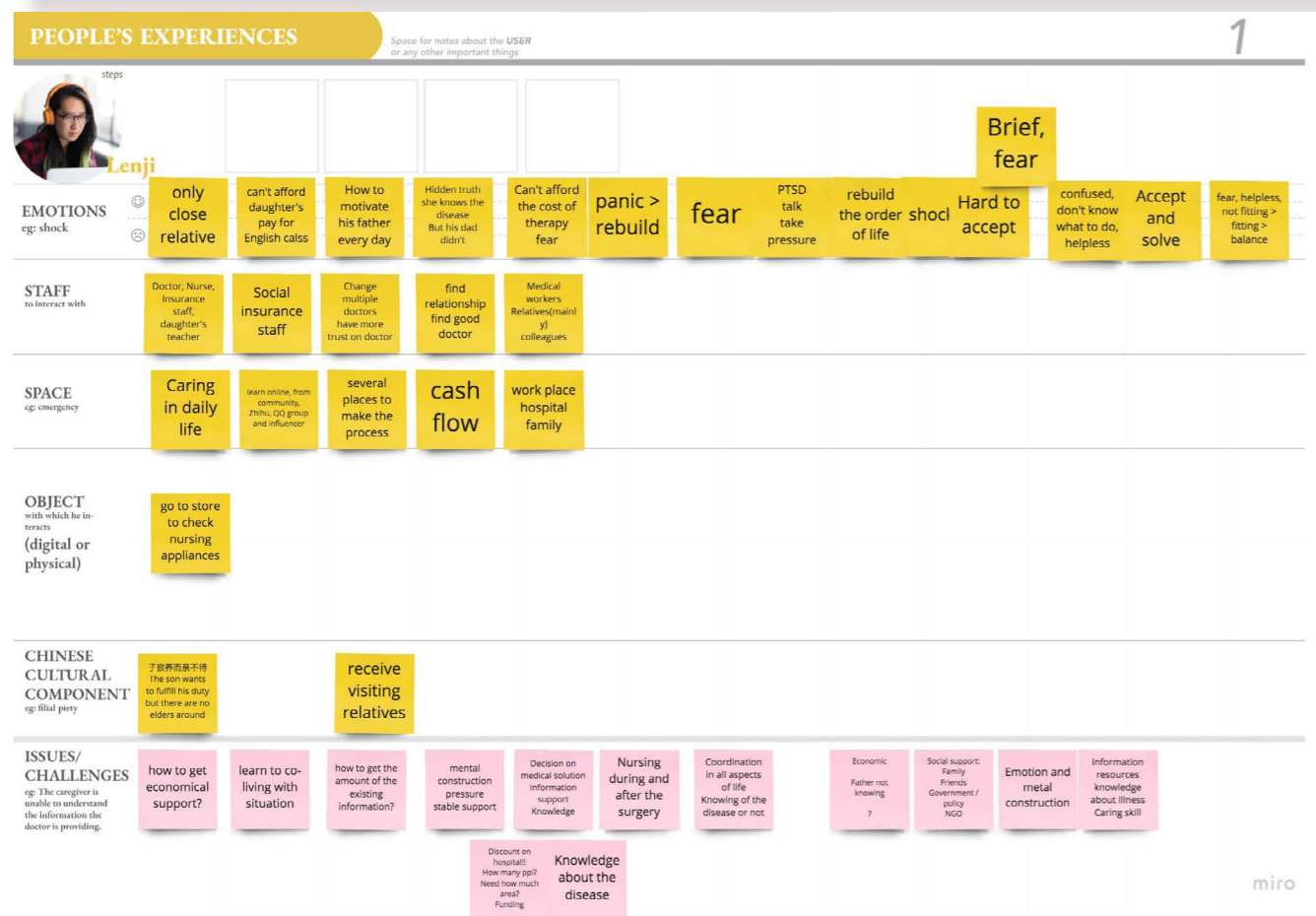
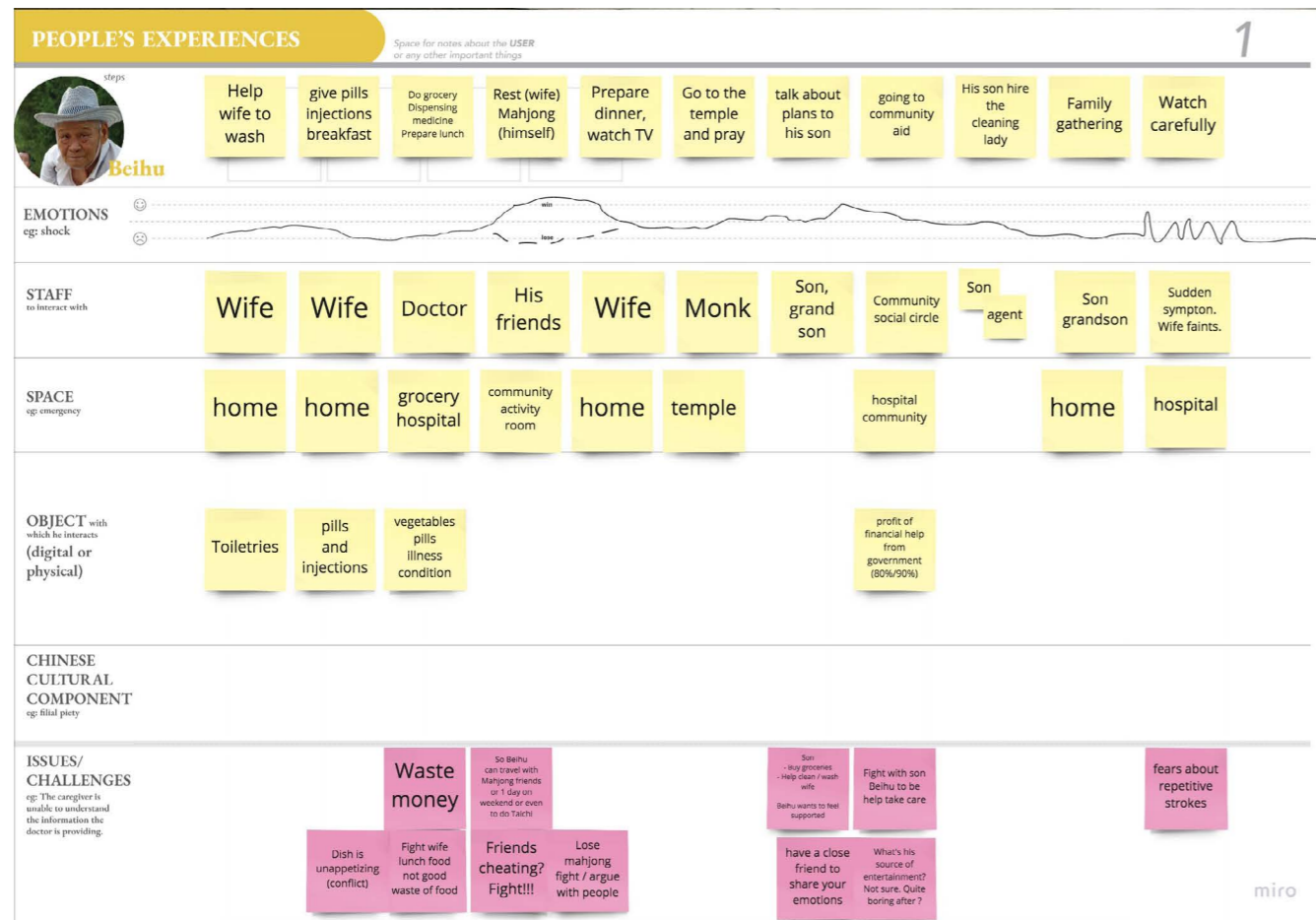


Figure 42. The formulated user journeys of Team A (top) and Team B (bottom) (Nadejda Cervinscaia, 2020)

take a rest is playing the Chinese board game Mahjong. Within the game, he sometimes loses money, arguing with his friends, and it all brings again to arguments with the wife. Then, there was appointed a family dinner, where the wife suddenly fainted, and it the entire family, including Beihu got very anxious and felt helpless again.

Once the journey map was finished, Team A noticed that Beihu does not have time for himself, and being overwhelmed by the number of responsibilities makes him irritated, impatient, feeling misunderstood. The user journey mapping process of the Team A is represented in the Figures 43, 44.

Results Team B:

Team B did not build a journey map but reflect upon the specific story described in the persona card. So, the journey, limited by the persona card, included topics of Lenji feeling pressure of hiding the malignity of the disease from her father, pressure of distrusting doctors and feeling immense economic pressure despite the insurance. The emotional line built by the team includes a broad range of feelings: helplessness, confusion, fear, lack of balance.

Team B realized that the key reason for the insecurity is Lenji's non-acceptance of circumstances, lack of information to understand the course of the treatment. These also prevent her from ability to make effective decisions. Lastly, finances are another problem of hers.

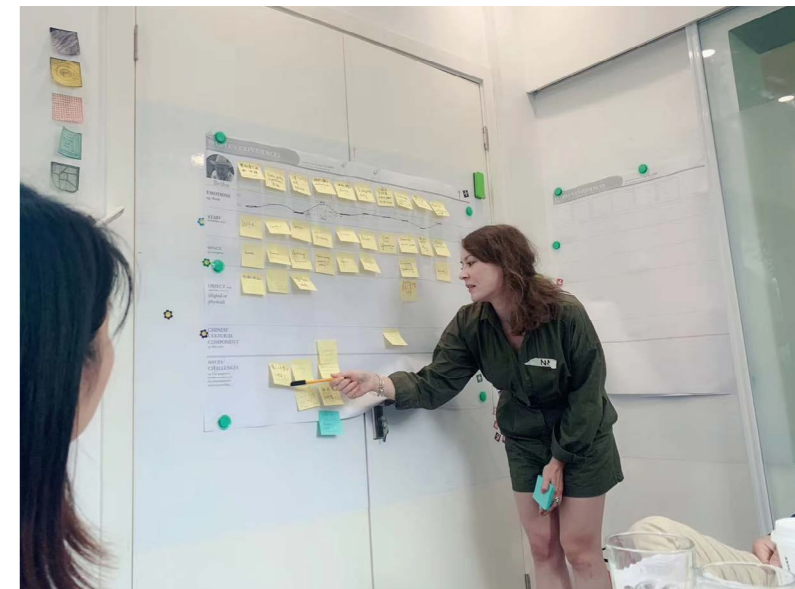


Figure 44. The author discussing with the Team A on the issues within the mapped user journey (Nadejda Cervinscaia, 2020)



Figure 44. The Team A mapping the user journey (Nadejda Cervinscaia, 2020)

PROBLEM DEFINITION 2

1 *Let's think of the issues deeply. Why are things happening this way? What is missing? What is behind the issue?*

What contributes to the issue? How?	Does this issue have a cultural component? Which one?	Let's prioritize the issues
Friends cheating in marriage? Fight! His wife perceives mahjong as waste of money Fight with wife or in lunch room not good work Lose mahjong light / argue with people this is his way to release emotions Indirect way to express negative feeling Cannot express feeling to wife not to provoke her heart attack Direct express to neighbor seems to become gossip or someone sees it as a confrontational event that needs to be prevent		6
have a close friend to share your emotions will share facts but not emotion make keep emotion in heart		5
Dish is unappetizing (conflict) maybe wife still can't accept "why am I having this?" internal struggle Feel guilty husband sacrifice taste 2 people are affected by illness Husband looks light care mention but also not to his taste = wife doesn't appreciate his cooking or sacrificing of his taste Sacrifice husband's taste		3
What's his source of entertainment? Not turn. Quite boring after retiring Have no time to arrange his own activities guilty about his wife disease go worse worry social judgment if he goes for himself. It will look like he is selfish		4
fears about repetitive strokes lack of knowledge about how to care his wife properly low education fears to annoy doctors with many detailed questions The bad influence on his future economic live alone He will love only person he can emotionally talk to the disease is out of control		1
Spin - Big problem - Help claim / assist wife Beihu wants to feel supported So Beihu can travel with Mahjong friends or 1 day on weekend or even to go Taichi Fight with son Son should also take care of his mum to help him to relieve pressure have something he wants entertainment Only in Wu V.D. "hospitals" to go nursing home It's hard work "nurse" of age - maybe too mental trouble / reception		2
why is it happening?		

2 *Now let's define the 1-2 main problems to solve.*

Problem 1
Caregiver who Beihu
tries to take good care of his wife
but he's unable to get knowledge about it
because he has low education and is embarrassed to ask too many questions to doctors, despite that he needs precisions.

How might we
provide systemic knowledge by doctors and social workers to inform caregivers?

Problem 2
Caregiver who Beihu Wife is first, himself is second
tries to have his son involved in the care
but his son can not do so
because he has his own work & family to worry

Please, formulate the focusing question!

How might we help caregivers to
involve children to share responsibility when/while
Beihu feels tired or wants to travel? micro

PROBLEM DEFINITION 2

1 *Let's think of the issues deeply. Why are things happening this way? What is missing? What is behind the issue?*

What contributes to the issue? How?	Does this issue have a cultural component? Which one?	Let's prioritize the issues
Issue 1 Issue the emotion of anger... caregivers don't know where to look for trustworthy information there are lots of resources		6
Issue 2 the pressure from patient and other aspects of life... for raising pressure, family, friends or other... let me to understand... Even though she is raising money, but still feel the heat or stress. Because there is always something happening in life.		1
Issue 3 Seeing doctor, surgery arrangements, and all the other process are troublesome, every time it consumes lots of time and effort		7
Issue 4 Patient doesn't obey or patient's emotion is changing according to the price Communication with doctor and nurse... difficult, because medical terms.		5
Issue 5 Knowledge about how to care his wife... let me to understand... Even though she is raising money, but still feel the heat or stress. Because there is always something happening in life.		3
Issue 6 Knowledge about how to care his wife... Even though caregiver has followed from the government, but still couldn't afford the medical fee, living and education. let me to understand... Even though she is raising money, but still feel the heat or stress. Because there is always something happening in life.		2
Issue 7 why is it happening? How to balance work and life? Family and care giving? Working pressure. Boss? Leader?		4

2 *Now let's define the 1-2 main problems to solve.*

Problem 1
Caregiver who _____
tries to _____
but _____
because _____

How might we
entire family support for emotional support
Emotion: Social worker intervention for emotional support
Cafe outside of the hospital
pressure release tool kit
online talking platform
family member communicating handbook tool kit

Group support emotional support
look for professional books emotional support
arrange some lectures, educating knowledge
group activities, volunteer club
psychological counseling look for mental support, others support
professional resources > psychological counseling

Problem 2
Caregiver who _____
tries to _____
but _____
because _____

Please, formulate the focusing question!

Question 2
For financial help: Mutual aid association
For financial help: Funds, Red Cross, society
Hometown? hometown association financial support
For financial help: Policy counseling, government allowance
For financial help: Discount of medical fee
Public info service, Wechat account
Child's career guidance
Fundation Non-profit organization Fund raising
connect resources, charity department in company
For financial help: Non-profit organization, fundation micro

Figure 45. The Problem Definition tools developed by the Team A (top) and Team B (bottom) (Nadejda Cervinscaia, 2020)

Part 2. Problem definition

The participants took the post-its with previously generated issues and challenges in the journey map and placed them into the 5 Why's tool. The participants discussed the reasoning of every issue, and it helped to see the challenges from a more rooted perspective. The two formulated Problem Definition canvases are presented in the Figure 45. The teams' processes are pictured in Figures 46, 47.

Results Team A:

Team A pointed out very many reasons for each issue, and the majority of them had a connection to the Chinese cultural aspect. For example, Team A pointed out that men in China (mostly mid-aged and older ones) are not used to express their emotions, fearing criticism and social judgment "Beihu has no entertainment because he is worried that will be judged if he cares about himself, which will look selfish of him". Another point is the importance of the sacrifice and the prominent feeling of guilt. As Beihu cooks special food for his wife with diabetes, he sacrifices his own taste in order to please his wife; however, they still conflict because the food is unappetizing.

The most critical issue chosen by Team A was Beihu's fear of repetitive strokes, which reasons in the lack of knowledge about the wife's disease. Despite that Beihu feels uninformed, he fears to annoy doctors with multiple questions and complicated comprehension process. He is pushed to navigate through unclear information, being unable to forecast the other happenings, where he would be left alone in the case of his wife's death.

The second most critical issue was the

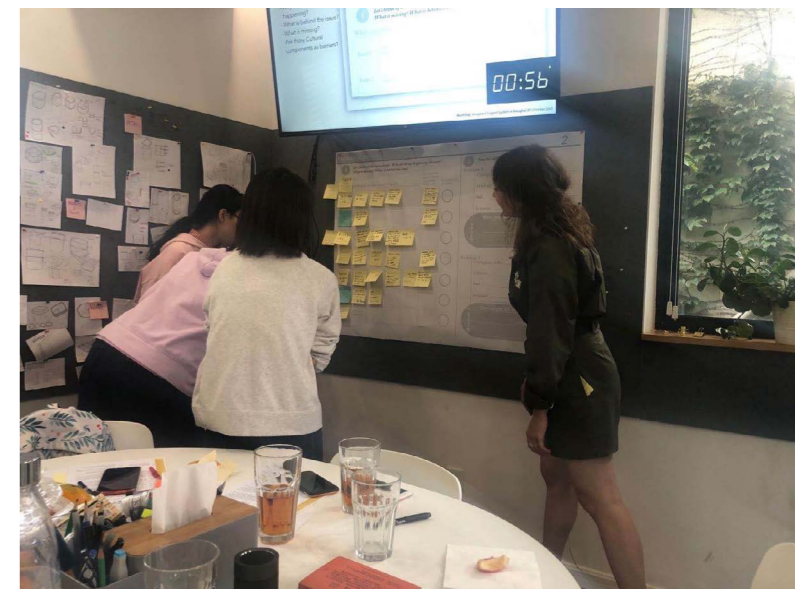


Figure 46. Team A in the process of prioritizing the defined issues from the user journey map (Nadejda Cervinscaia, 2020)



Figure 47. Team B in the process of prioritizing the defined issues from the user journey map (Nadejda Cervinscaia, 2020)

Table 5. The results of the problem definition part of the workshop

Team	User story	Generated 'How might we?' question
Team A	Caregiver Beihu tries to take good care of his wife, but he's unable to get knowledge about it because he has low education and is embarrassed to ask too many questions to doctors, despite that he needs precisions.	How might we provide systemic knowledge by doctors and social workers to inform caregivers?
	Caregiver Beihu tried to have his son involved in caregiving, but his son can not do so, because he has his own work and family to worry.	How might we involve children to share the responsibility when Beihu feels tired or wants to travel?
Team B	-	*How might we provide psychological counselling to support caregivers?
	-	*How might we financially support caregivers?

* questioned formulated by the author based on teams' materials

previously appointed problem of Beihu not having time for his interests by having his son's assistance in caregiving duties. The reason for Beihu not having assistance from external services is the bad image that he could gain because in China it is not socially acceptable to request nursing home services for patients younger than 80 years old.

Consequently, Team A formulated two problem definitions in the form of a user story and the reflecting 'how might we' questions. They are presented in table 5.

Results Team B:

The team B reflected on the issues anchored around the topic of 1) insufficient financial support and caregivers' allowance, reasoning in the fact that Lenji has to also pay for her daughter studies, and the treatment is a time-undefined process; and 2) inability to accept the disease reasoning in lack of guidance to get rid of depression, and release emotions.

Team B did not fill in the user story tool, nor

did it fill the 'how might we?' question in the right way. Instead, the team proposed many solutions connected to the two most critical issues. The author included the proposed ideas in the individual ideation session after the workshop.

The generated user stories based on the top prioritized issues and the produced 'How might we?' questions are presented in the Table 5.

Part 3. Envision the future

The teams received inspirational cards with case studies on services for caregivers from different countries. The teams read the cards with curiosity (Figure 48) and were enthusiastic about the solutions. Notably, Team A almost got influenced to switch the previously set direction to one of the problems tackled in the inspiration card. Therefore, it is essential to make teams understand that inspiration cards are meant to look at the matter from a different perspective; however, still keep in mind the identified main focus. The cards also prompted some discussions between participants, and despite that everyone had time to read only three cards, the participants were curious to read all the other cards.

Results Team A:

Starting from the identified problem of lack of time for entertainment and personal interests, Team A envisioned a "Daytime Caring Centre" with the headline of "Daytime service gives caregivers a rest. This is not a dream" (Figure 49). The organization would provide different activities for caregivers: music therapy, drawing therapy, social workers and volunteers', compounds' assistance. The organization would be positioned on every street. Importantly, the volunteers who would assist family caregivers would prioritize the waiting list to be part of service users. The generated quote regards a family caregiver saying, "I can finally go on a vacation". The organization would be sponsored by private and governmental funding, companies' support, as well as a small contribution from families. This service's concern was the high service demand, which would require evaluation of the family caregivers' urgency to benefit from this service. Another concern

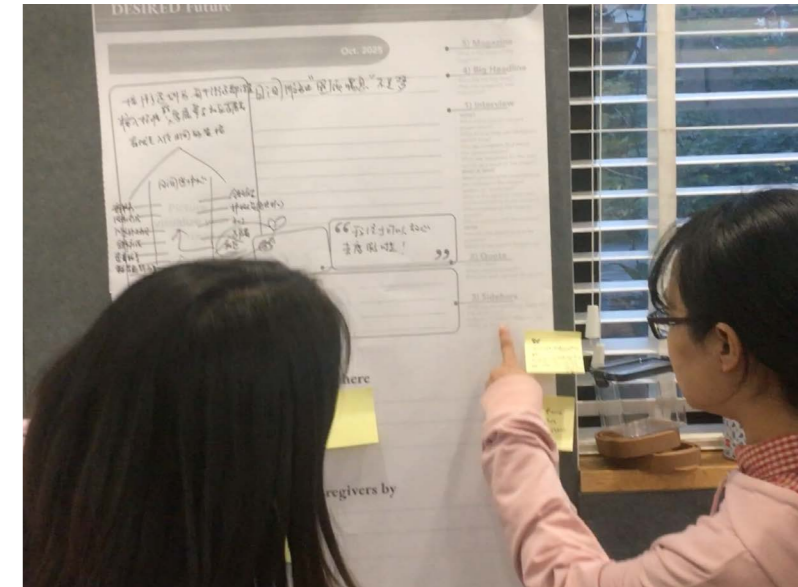


Figure 49. Team A in the process of building tomorrow's narrative canvas, ideated the "Daytime Caring Centre" (Nadejda Cervinscaia, 2020)



Figure 48. Team B reading the inspiration cards with case studies (Nadejda Cervinscaia, 2020)

regarded the need of more funds in order to run the activities of the center. The team mentioned that the short-term milestone to achieve would be to provide the family caregivers with the support of social workers, volunteers, compound, and other caregivers.

Results Team B:

Starting from the identified problem to deal with emotional pressure, Team B ideated two visions: a “Caregiver Club” service and “Caregivers’ Guardian”.

Within the Caregiver Club service, caregivers can speak up, and receive support from doctors and peers. The written quote was of a caregiver “since I joined the Group’s activity, I feel much more relaxed with support from a medical worker and other friends. I don’t feel nervous and painful anymore.” The team thought by 2025, service has to include all the Hospitals in the network and function in every Shanghai district. As a short term plan for 2021, the service had to reduce caregivers’ pressures, provide knowledge and skills, and establish harmonious communication with doctors.

The Caregivers’ Guardian service is an online platform, which can be accessed by any caregiver in order to obtain psychological support. The breaking news quote was “Caregivers’ mental platform is officially launched!”. Within this platform, the caregivers would connect to volunteers, social workers, psychologists, doctors and informational resources about diseases, and the community of caregivers. The AI would also empower the platform to assist caregivers on psychological matters. The short-term goal is to launch in China, and in the long-term, to extend the platform globally. The presentations of the Teams’ concepts are presented in the Figures 50, 51.

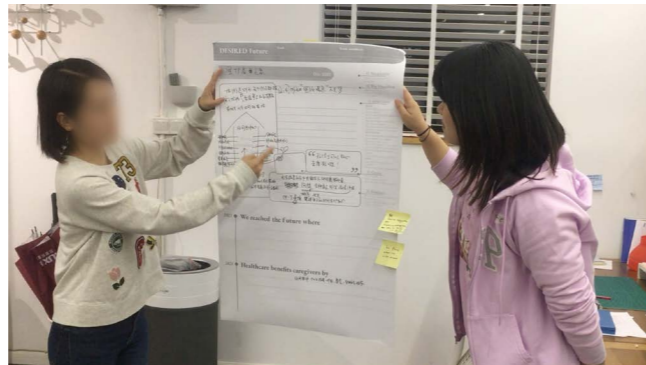


Figure 50. Presentations of the envisioned service solutions by Team A (Nadejda Cervinscaia, 2020)



Figure 51. Presentations of the envisioned service solutions by Team B (Nadejda Cervinscaia, 2020)

7.3 Workshop analysis

After the workshop, the author translated into English all the workshop materials with a Chinese native speaker’s help. The digitalized results were visualized on the Miro platform. The process of analysis was as follows:

1. Reviewing all the produced materials
2. Identifying the workshop’s highlights - making notes with interpretations and picking certain materials’ excerpts.
3. Exploring the entire range of intervention possibilities - analyzing the ‘How might we?’ questions generated within the workshop and producing new ones.
4. Finding patterns and areas within intervention possibilities - clustering ‘How might we?’ questions.

Within the process of highlighting the key findings of the workshop, there were pointed out the following key elements:

- Emotional relief and massive pressure on caregivers;
- Popularizing the emotional support;
- Need of caregivers’ education,
- Empowering connections of actors and entities. Namely, 1) legal entities (hospitals and compounds), and 2) different actors (caregivers, different medical workers experts, volunteers);
- The importance of Chinese cultural activities for caregivers: music, painting, Mahijang boardgame;
- Importance of preserving the face by showing dedication and endurance, sacrifice;
- Importance of being recognized for the multiple sacrifices which caregivers willingly do due to their cultural values;

- Omitting social judgment;
- Possibility of getting funding from the Government, companies, family.

These findings nourished the development of ‘How might we?’ questions. It is important to generate guiding questions because they will inspire for solutions. Formulating the right questions to open up one’s mind to ideate multiple solutions is not an easy task, especially for non-designers who have never experienced this tool before. One of the common mistakes in using the ‘How might we?’ question is to propose the solution within the question. Therefore, the author aimed to review the questions generated in the workshop.

One of the questions created by Team A was “HMW involve children to share responsibility when a caregiver feels tired and wants to travel?”. The author reflected on this question and realized that involving children and travelling is the proposed solution for the actual need to take a break by sharing responsibility with another figure. Therefore, the author reformulated the question generated by the team into “HMW assist the caregiver to share caregiving duties when a caregiver feels tired and wants to take a break”. Similarly, the question “HMW provide systemic knowledge by doctors (with whom caregivers always interact) and social workers (as specialists) to provide a quality care to patients?” included a solution of actors (doctor and social worker), reflecting the actual need to gain practical and emotional knowledge in dealing with caregiving. This question was reformulated into “HMW equip caregivers with systemic practical and emotional knowledge to provide quality care to patients?”.

Table 5. The results of the problem definition part of the workshop

Cluster topic	Generated ‘How might we?’ questions
Building confidence	HMW help caregivers overcome embarrassment connected to going with their own needs?
	HMW assist the caregiver to share caregiving duties when a caregiver feels tired and wants to take a break?
	HMW get caregivers build resilience and control of events within many scenarios?
	HMW help caregivers to feel confident to prioritize their own interests without losing face in front of society?
Funding	HMW help enhance funds for caregivers?
Pressure release	HMW improve the network of caregivers for mutual assistance aiming to enhance their psychological endurance?
	HMW help caregivers communicate with their family members and patients and express their feelings?
	HMW assist caregivers in pressure release?
Education	HMW equip caregivers with systemic practical and emotional knowledge to provide a quality care to patients?

Moreover, based on the workshop materials, the author generated more ‘How might we?’ questions. Clustered by area of intervention, the ‘How might we?’ questions and the newly formulated ones are presented in the Table 6, including those generated within the workshop (highlighted in bold).

Further in the process, the author aimed to narrow down the area of intervention. Because funding has not been representing the author’s interest, the author decided to focus on the three areas of design interventions, which had a connection in-between: building confidence, pressure release, and education of caregivers. Despite that, funding and economical help for caregivers are critical and must be considered as a topic for future research. The final list of the ‘How might we?’ questions, from which service brainstorming started, is presented below:

- **How might we help caregivers overcome the embarrassment connected to eliminating ambiguities within the caregiving experience?**

- **How might we share caregiving responsibilities while a caregiver feels tired and wants a break/ to travel?**
- **How might we get caregivers to build resilience and own control over the various disease as much as possible?**
- **How might we help caregivers to feel confident to prioritize their own interests without losing face in front of society?**
- **How might we assist caregivers in pressure release?**
- **HMW equip caregivers with systemic practical and emotional knowledge to provide quality care to patients?**

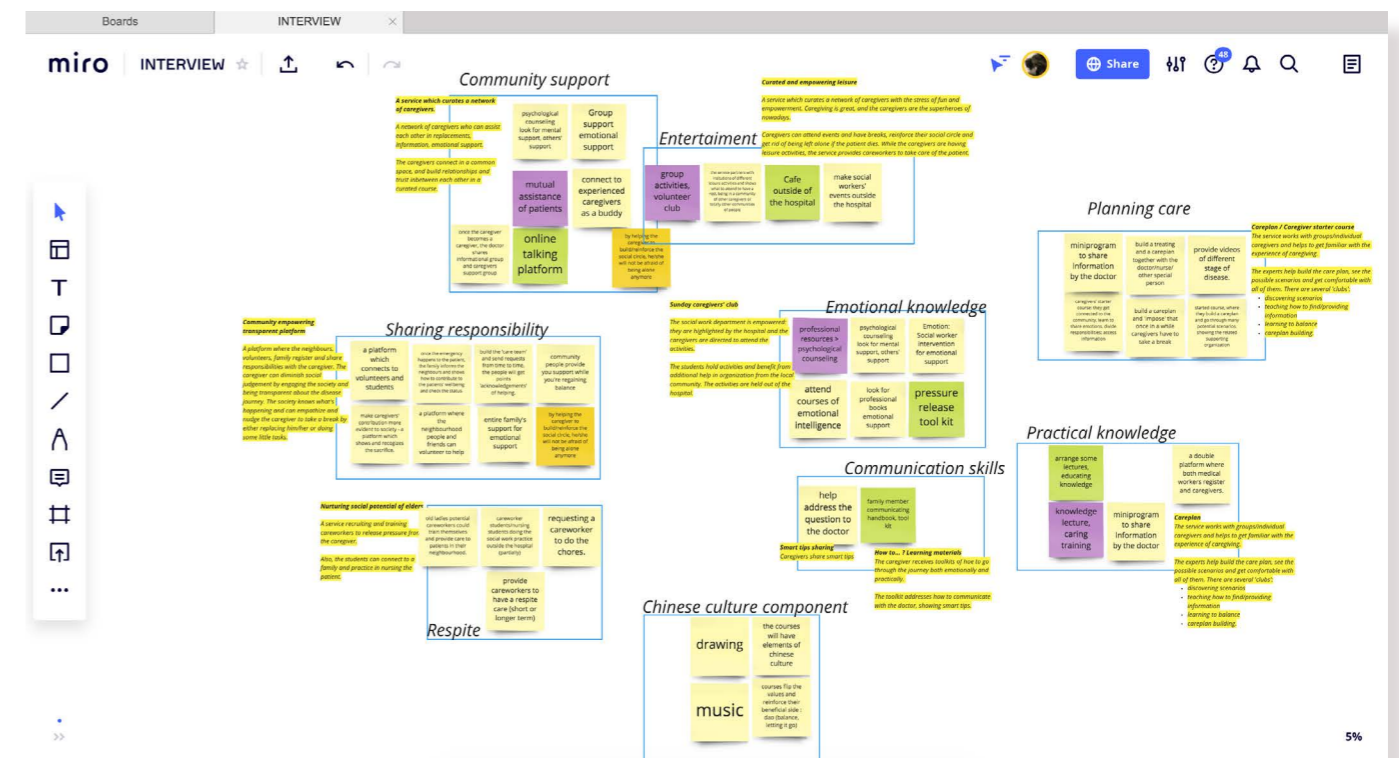


Figure 52. The brainstormed elements of the solutions clustered into service solutions/visions, with keywords. (Nadejda Cervinscaia, 2020)

Development of the concept visions

Starting from the refined six ‘How might we?’ questions, the author brainstormed on possible service solutions or the service elements to respond to each of the questions. Later, the solutions’ elements were recategorized into “higher-level themes related to thematic frames” (Pfannstiel & Rasche, 2019). There came up nine topics, visualized in the Figure 52:

- Practical knowledge
- Emotional knowledge
- Communication skills
- Planning care
- Entertainment
- Community support
- Sharing responsibility
- Respite Care
- Chinese culture

Once clustered, the author analyzed the cluster within and formulated the first draft-

service description (highlighted in yellow in the Figure 52). For example, in the cluster Respite, which included four brainstormed solutions:

- provide care-workers to have respite care for caregivers (short or long term)
- requesting care-workers to do the chores;
- old ladies from the neighborhood could be potential care-workers and train to provide care to the patient, while the caregiver will have a break;
- nursing students and social work students could pursue internship within this organization to be able to train also outside the hospital.

These ideas shaped the first draft-service concept/-vision: “Nurturing the social potential of elders and other people” A service recruiting and training care-workers to release pressure from the caregiver. Also, the students can connect to a family and practice in nursing the patient.

As shown next in Figure 53, the draft

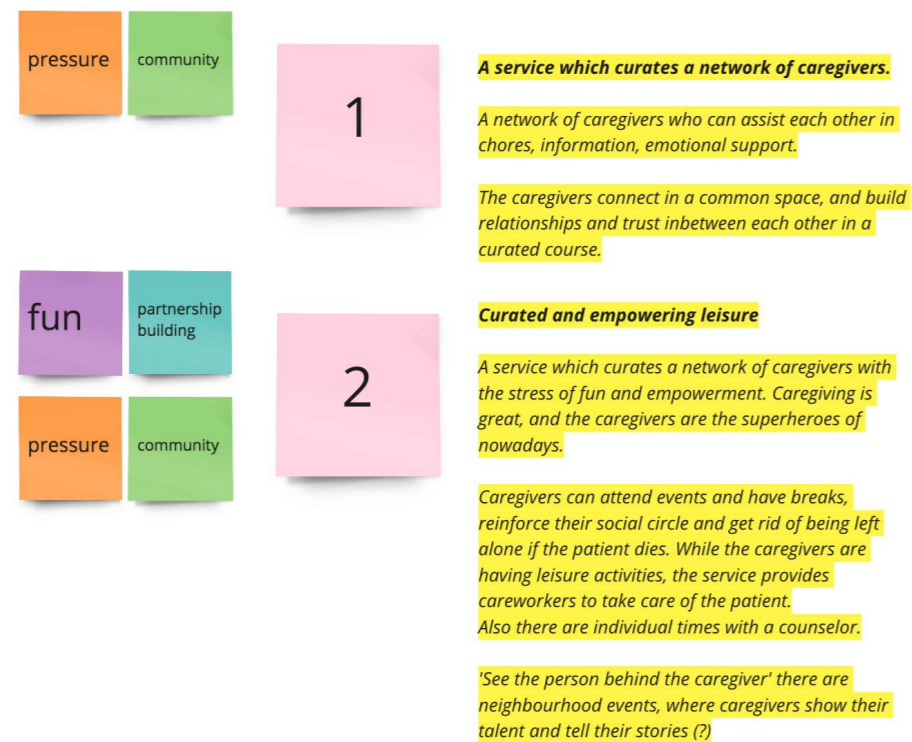


Figure 53. Example of service solution refinement, including tagging the solution with key words (Nadejda Cervinscaia, 2020)

descriptions were organized in another Miro platform board, where the author reformulated and detailed the service proposals. To understand the previously identified problems that the services solve, the author tagged different solutions by keywords. The keywords were useful to briefly define the service intervention and have a general overview of the impacts of all the visions and their similarity and differences. They are listed below:

- pressure release
- community building
- partnership building
- empowering different categories of people
- providing information
- overcoming social judgment.

All the refined draft-visions are presented next.

Vision 1 - A service curating a network of caregivers for practical and emotional help.

The service consists of a network of caregivers who can assist each other in chores, information, emotional support. The caregivers connect in a shared space and build relationships and trust in-between each other in a curated course.

Vision 2 - A service which curates caregivers' leisure

The service consists of curating a network of caregivers with the stress of fun and empowerment. Caregiving is a unique duty, and the caregivers are considered the superheroes of nowadays. Caregivers can attend events and have breaks, reinforce their social circle, and get rid of being left alone if the patient dies. While the caregivers have leisure activities, the service provides care-workers to take care of the patient. Also, there are individual times with a counselor. 'See the person behind the caregiver' there are neighborhood events where caregivers show their talent and tell their stories.

Vision 3 - Caregivers' starter course

The service works with groups/individual caregivers and helps to get familiar with the experience of caregiving. The experts help build the care plan, see the possible scenarios, and get comfortable with all of them. There are several 'clubs':

- discovering scenarios
- teaching how to find/providing information
- learning to emotionally and practically balance
- care-plan building.

Vision 4 - Nurturing the social potential of elders, students, and people with free time to assist caregivers

The service consists of recruiting people to become care-workers to release pressure from the caregiver. Also, the students can connect to a family and practice in nursing the patient.

Vision 5 - Transparent platform to engage the community in assisting patients

A platform where the neighbors, volunteers, family register and share responsibilities with the caregiver. The caregiver can diminish social judgment by engaging society and being transparent about the disease journey. Society knows what is happening and can empathize and nudge the caregiver to take a break by either replacing him/her or doing some little tasks.

Vision 6 - "How to...?" Learning materials and neighborhood facilitators to explain the information and gain necessary medical skills

The service consists of a curated community where caregivers are empowered to share tips for different stages of different diseases. The caregiver receives toolkits of how to go through the journey both emotionally and practically. The toolkit addresses how to communicate with the doctor, showing smart tips.

Vision 7 - Sunday caregivers' activity club

The social work department is empowered: the hospital highlights them, and the caregivers are directed to attend the activities. The students hold activities and benefit from additional help in the organization from the local community. The activities are held out of the hospital.

7.4 Visions' validation session

The next step was to validate the visions and visions' elements with the audience. The validation session aimed to:

1. Discover the possibilities of the services to take place given the implied actors and roles, dynamics of relationships.
2. Discover the obstacles which might come on the way to making a vision happen.
3. Prioritize the most visions according to their impact on the caregivers' wellbeing and likelihood to happen.
4. Explore suggestions for visions' refinements.

In order to respond to these objectives, the service descriptions were organized on separate cards and translated into Chinese (Figure 54). Each of the cards was divided into different blocks of information:

1. Name and description of the vision.
2. The caregivers'/contextual needs which lead to the development of the vision
3. Checkbox with assumptions that have to be true in order for the vision to happen.
4. Storyboard visualizing the vision
5. Stakeholders' map
6. Implied touchpoints

Validation activity

The validation sessions aimed to run in two or three groups of people in order for the participants to speak up their minds. Three of the participants have a poor command of English. Therefore the author requested two native Chinese speakers, which were familiarised with all the visions and the validation process beforehand. The validation cards were translated into Chinese, and the translations' accuracy was reviewed two

times. The validation session with the other participants was planned to be conducted in English by the author. Each session was planned to take around 1-1,5 hours of either physical or online meeting. Within the online meetings, the solution cards were sent to the participant beforehand, and during the phone or video call, the facilitator would follow the planned process consisted of the following steps:

1. Explanation of the activity flow and the goal of the validation session.
2. Reading the visions cards carefully.
3. Marking the checkbox of the assumptions per each vision: what can indeed happen, what cannot happen, what could happen.
4. Commenting on each of the assessments of each vision's assumptions.
5. Giving a general opinion about each vision.
6. Selecting a few visions or visions' components that inspire hope to the participants.

The cards are fully illustrated in the Figures 91-97 of the Annex 3.

Participants' recruitment

As the workshop's ideas nourish the visions, the author aimed to minimize the bias that the validation invitees could have once met a vision that reminds them of the workshop's ideas. Therefore, the criteria for the participants' recruitment included:

- people who do not know the project;
- people who participated within one or more of the previous steps;

VISION 3

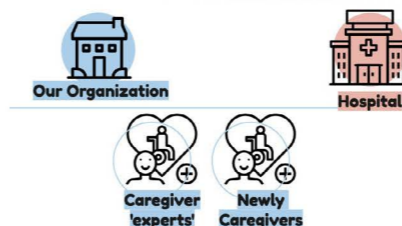
Caregiver starter course

The service works with caregivers and helps to get familiar with the experience of caregiving. The service is also a reference point to address questions and sick for support in critical moments.

The experts help build the care plan, see the possible scenarios of the disease, predict needs and get comfortable with all the experience. There are several 'classes' which caregivers can join:

- discovering scenarios of caregiving (which are also presented with real cases of 'role model' caregivers);
- teaching how to find trustworthy information you might need;
- learning how to regain emotional balance in group, according to interests/one's self;
- care-plan building in partnership with a hospital.

Actors:



NEEDS:

- Caregivers need to learn how to provide care.
- Caregivers are unfamiliar with what caregiving experience might imply and demand.
- Caregivers need to attend activities to regain their emotional balance.
- Caregivers need to have the support of other caregivers, and be in the community.

ASSUMPTIONS:

YES/NO/MAYBE

✓ ✗ ±

- The caregivers are willing/ready to get to know the both sides of caregiving: the rewarding and the demanding one.
- Caregivers would like to attend 'caregiving classes'.
- 'Expert caregivers' would like to join the 'classes' and share their experience, be 'role models'.

STORYBOARD



POINTS OF INTERACTION:



愿景3

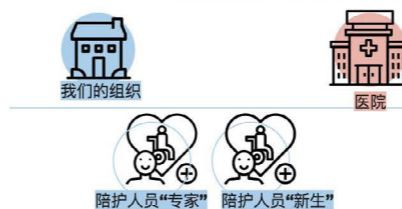
陪护人员的入门课程

该服务与陪护人员一起使用,有助于熟悉护理经验。该服务还是在关键时刻作为解决问题和生病的人的参考点。

专家帮助制定护理计划,查看疾病的可能情况,预测需求并熟悉所有经验。陪护人员可以加入以下“班级”:

- 专业陪护人员分享会(也与“角色模型”护理人员的真实案例一起呈现);
- 传授如何找到您可能需要的可靠信息;
- 学习如何根据兴趣/个人来恢复小组的情绪平衡;
- 与医院合作制定护理计划。

角色:



需求:

- 陪护人员需要学习如何提供护理。
- 陪护人员对某些潜藏的/要求的护理经验不熟悉。
- 陪护人员需要参加一些活动以恢复情绪平衡。
- 陪护人员需要得到其他陪护人员的支持,并融入社区中。

猜想:

是/不是/可能

✓ ✗ ±

- 陪护人员愿意并准备了解陪护的各方面知识,例如陪护所带来的好处以及陪护背后的艰辛。
- 陪护人员想参加“护理课程”。
- 有经验的“陪护人员”想加入“班级”并分享他们的经验,成为“案例”。

故事板



接触点:



Figure 54. The developed validation cards with service vision 3 in English and Chinese (Nadejda Cervinscaia, 2020)

• people with different professional roles and perspectives: social workers, inpatient and outpatient doctors, nurses, administrative workers, caregivers.

The author contacted the research participants of previous phases were contacted and invited to the validation

session. The two invitees, who were new to the project, were previously encountered within the workshop's recruitment phase but could not attend the workshop for personal reasons and were looking forward to the next occasion to collaborate. The participants' data are presented in the Table 6.

Table 6. Participants' data of the validation session

N.	Name	Occupation	Participated in the field research	Participated in the workshop	Participated in both field research and workshop	New to the project
1.	Doctor 3	Inpatient Doctor Respiratory Department, Ninth people Hospital	+			
2.	Caregiver 1	Caregiver for his mother with multimorbidity sicknesses	+			
3.	Doctor 5	General Practitioner (Chinese Medicine) in the Fangsong Community Health Care Service Center		+		
4.	Nurse 2	Nurse in the Fangsong Community Health Care Service Center		+		
5.	Social worker 2	Medical social worker, Renji Hospital		+		
6.	Hospital admin	Assistant Researcher, Deputy Chief of Medical Department, Renji Hospital		+		
7.	Caregiver 4	Caregiver for her father, a cancer patient			+	
8.	Caregiver 8	Caregiver for his mother with multimorbidity sicknesses				+
9.	Nurse 3	Chief Nurse, Inpatient Department, Pulmonary Hospital				+

Validation session results

The pictures of the validation process are shown in the Figures 55, 56, 57. The summaries of the feedbacks for every vision are presented below.

Vision 1 - A service that curates a network of caregivers for practical help and emotional support.

Within this vision, the participants agreed that the social worker is an important actor to imply and organize the neighborhood committee's activities. Moreover, most participants agreed that the hospital would be interested in providing caregivers' support, the participant who did not agree claimed that municipal hospitals could be rival with the ideated Service Provider. There must be found a way to collaborate.

The participants highlighted the emotional

support and communication because caregivers might have arguments with patients considering the service offering. Caregivers must have strings to share and learn how to deal with these.

Lastly, the neighborhood people do want to volunteer. Besides, companies stimulate employees to volunteer; they can accumulate points and trade points to goods. Sometimes, companies even require volunteering activities in order to promote employees.

Vision 2 - A service which curates caregivers' leisure

Maybe not all the caregivers would like to have entertainment, but it is necessary for their mental health. In the traditional Chinese mindset, the idea of leisure for caregivers is not shared and even not allowed, could be accused. Therefore, this mindset of caregivers taking a break and doing diverse leisure activities must be taught and promoted as a social campaign. The participants said that this idea could be implemented in the long-term and could start as physical group activities targeting emotional and physical relief (e.g. traditional square dancing). This findings is also supported by the research, claiming the need to promote physical wellbeing to caregivers and day program activities (Marks, 1996; Rha et al., 2015). Generally, Chinese people would not think to attend activities. They would need a nudge.

Maybe the service provider can give multiple tickets to activities, so caregivers invite their friends. Lastly, it is essential to consider that there will be different kinds of caregivers; some could be too tired to attend activities, and that caregivers might prefer different activities.

Importantly, companies in China would like to organize/offer leisure activities; such humanitarian activities determine their success.

Last but not least, the participants mentioned that privacy is an important matter. Therefore caregivers in China might not want to disclose their personal life situations, especially bad ones, with foreign people. Sometimes caregivers would not trust care-workers of volunteers, how could trust be built first?

Vision 3 - Caregivers' starter course

This vision was selected as the favorite one by 8/9 of the participants. The reason is the lack of knowledge of how to provide care to patients.

It is important to familiarize caregivers with the entire caregiving experience beforehand. This would diminish the number of questions and clear up ambiguities and help to release pressure from the nurse, who now have to explain to caregivers individually the basics of medical assistance. Moreover, caregivers would know how to perceive and behave in emergencies. They are used to go to the hospital directly, even though when the problem does not require this approach.

Vision 4 - Nurturing the social potential of elders, students, and people with free time to assist caregivers

Dividing people in groups of people to assist caregivers in different duties is a good idea. The neighborhood people would be interested in specializing in care-work and working as care-workers. However, the caregivers might need facilitation to understand that the neighborhood people have been certified to provide care and can be trusted. Having actively engaged volunteers would help to infiltrate the volunteering mindset in the young generation.

Vision 5 - Transparent platform to engage the community in assisting patients

Neighborhood people represent a potential for help to caregivers but cannot run independently. If there are volunteers to assist caregivers, there should also be a mechanism to train them according to the disease and supervise their work quality. So the organization has to be a top-down nature. Besides having non-professional assistance, the service provider also has to provide professional assistance: psychological help and care-workers' assistance.

The difficulty could be in motivating volunteers. They could gain points and exchange them for goods.

Lastly, the concept of sharing knowledge already exists in the hospitals, where inpatients share tips with other inpatients.

Participants said that creating the Figure of a role-model expert caregiver, who is sharing know-how, is a great idea. Younger caregivers would probably even pay for such meetings, unlike the older ones, expecting free coaching. Scholars also highlight the importance of creating occasions for caregivers to be recognized (Kent et al., 2016).

Hospitals could have the capacity and availability to teach medical skills.

The senior medical students are enthusiastic about diving into practicing the skills in the field. So, they would be interested in teaching care but are very busy with studies. Participants suggested proposing this activity as an internship opportunity to be recognized by their schools.

Generally, this scenario requires high openness and trust; it is very idealistic. The majority of participants said that despite that in compounds, there are friendly relationships between people. To make this vision come true, there must be more occasions to communicate and build trust with each other. Caregivers would need time to accept help from the neighborhood. Lastly, the matter of disclosing personal information to other people is very sensible in Chinese culture.

Vision 6 - "How to... ?" Learning materials and neighborhood facilitators to explain the information and gain basic medical skills

The participants' opinions were divided, the majority claiming that the hospital would be interested in partnering, and one participant from the hospital's administrative position claimed that there would instead be rivalry relationships. Additionally, some collaborative strings exist between third-class hospitals

and first-class ones, and their collaboration with the service provider could be divided according to their resources' availability. The caregivers would benefit from being divided into groups according to the disease types.

Lastly, the learning component of this vision was appreciated by the participants.

Vision 7 - Sunday caregivers' activity club

This vision took the place of the second most liked vision, being selected by 4/9 participants.

The participants claimed that the university and the students would be interested in partnering to ensure exercising students' knowledge in the field. However, the students are busy with the studies, so maybe it could only happen in an internship.

It is essential to understand the club's different activities outside the hospital. The participants suggested having light sports activities, e.g., table tennis, exercise, mahjong board game, or picnic.

The participants appreciated the idea of linking different people and empowering social workers who have professional skills to work with vulnerable people.



Figure 55. The validation process with the Social Worker 2 and the Hospital admin (Nadejda Cervinscaia, 2020)



Figure 56. The validation process with the Doctor 3 and the translator at Ninth People's Hospital (Nadejda Cervinscaia, 2020)

7.5 Development of the final vision

The main learnings after the validation session include the following insights:

- Caregivers need to acquire information and basic medical knowledge about the type. By being equipped with information, their insecurity feeling will decrease.
- Caregivers need leisure, entertaining activities; however, activities as going to a concert will not be socially accepted in the short-term, unlike group physical activities for relief. Nonetheless, it is essential to promote the importance of activities for caregivers, through promotional campaigns.
- Neighborhood people are keen to volunteer and provide support; however, they must be trained to provide medical assistance and be trusted by caregivers, even in assisting for tasks as chores.
- The Chinese culture has to preserve the family's privacy, and the caregivers would not want to disclose their fragility and the state of health of the patient, which are seen as negative things.
- Hospitals (third class) and community hospitals (first-class) would be interested in the partner and provide training for caregivers and/or citizens who want to become care workers.
- Some retired people in neighborhoods might have free time and could want to learn to be a care-worker.
- The volunteers and care-workers who assist caregivers shall be acknowledged with volunteer points and monetarily, respectively.
- The volunteer points system is standard in Shanghai, and companies incentivize the citizens to volunteer to get a promotion.
- Companies in China are willing to donate

goods or funds for humanitarian projects.

Given these insights and keeping in mind the field and desk research information acquired before, the author ideated the following service proposal:

A chain of organizations in neighborhoods which partner with Hospitals and Shanghai Universities to:

- train caregivers to acquire medical skills related to the disease type;
- train neighborhood people to become care-workers;
- release burdens from caregivers by connecting them to the care-workers and volunteers, facilitate their collaboration;
- build the community of caregivers and local volunteers;
- organize stress-relieving activities: 1) provide individual counseling to caregivers, and 2) provide relieving physical activities to caregivers;
- organize motivational events: motivate caregivers by expert caregivers (caregivers with long caregiving experience), who become role models.

Importantly, in the long-term, the organization has to facilitate caregivers to benefit from leisure activities. The development of the service solution is described in the next chapter.

7.6 Conclusion

The co-design workshop was a great approach to shape the problems and brainstorm on envisioning the future solutions to mitigate them. Thanks to the workshop, the participants were prompted into discussions, argued on different topics through their perspectives, and, in the end, constructively dialogued as teams to reach the proposed goals.

The participants proved to be very engaged. They enjoyed the creative approach to identify the problems starting from particular persona stories, dig deeper into the nature of the problem, ideate solutions, and later present them to the other team. The entire workshop process was enjoyable; the participants particularly appreciated the designed tools they never encountered before, but which were able to prompt and guide their thinking process and discover other actors' different perspectives. Additionally, it was very useful to create the common wechat social media group and post informations there so that the participants can familiarize with the workshop agenda and some materials (in this instance, persona cards).

Within this workshop, the team with the English facilitator had a good command of English, however, sometimes participants still encountered difficulties in expression, and the author had to appeal for the help of a native speaker. Moreover, despite that the two facilitators agreed on using the tools, the teams slightly differed in completing the tasks. For example, Team B did not complete the user journey and the user story tools in the proposed template, as also the team used another template to visualize the ideated service intervention. Therefore, there was organized a debriefing session to clarify some aspects of team B's materials. For the

workshop's preparation, it is recommended for the facilitators to try out filling in the tools together or ensure the accurate alignment.

Despite the challenges mentioned above, the groups produced excellent materials, which nourished the seven service solutions/visions.

The ideated service solutions' validation session was a powerful tool to prompt discussion on the ideated visions. The exercise requiring the participants to mark the possibility of the assumptions facilitated a good understanding of service implications and feasibility. The storyboard was also useful to exemplify certain scenes within the service solutions. Lastly, the actors' map's visualization facilitated an instant overview of the actors implied in the service organization and stimulated the participants to comment easier.

The difficulty within the validation session consisted of the logistical organization. The face to face sessions implied multiple papers with printed service solutions, and as the validations were appointed in different places in Shanghai: coffee shops, doctor's office in the hospital, it was challenging to have an overview of all the solutions because there was little space to arrange the papers. Notably, three validation sessions were conducted online because of the participants' unavailability to meet face to face. To the author's surprise, the quality of the validation session did not decrease. So, online means of validation can be recommended, especially video call validation.

To conclude, the participants constructively expressed their points of view within the validation sessions, which were not considered by the author before, or were unknown to the author. The participants' opinions converged

in many aspects, e.g., the importance and urgency for the caregivers to acquire medical care knowledge. Consequently, the insights and opinions gathered within the validation session were helpful to formulate the final service idea.

8

DEVELOPMENT of caregivers' support system in Shanghai

Introduction

The developed organization “Rituals. Balanced Care Centre” is a space of knowledge, rest, and community support. *At Rituals, caregivers can learn disease-specific medical skills, attend activities as social and physical wellbeing activities, and be part of the community of volunteers and caregivers. To ensure caregivers' availability to attend the centre, the center will connect them to care-workers, who would assist patients.* Being aligned with the governmental plan of enhancing the number and quality of care-workers, the centre will provide education to citizens to become care-workers. The care-workers will be certified and ensured by collaborating with partnering hospitals and community hospitals, and students, who would conduct official internships. The activities will be organized by the local volunteers in collaboration with Rituals' staff. The organization of activities and their attendance by caregivers will be rewarded with points later exchanged for goods.

In the following chapter, the ideated service is described using different design tools. The previous work, done within the field, desk research, as well as ideation workshop and concept validation, served as a basis for the proposed service system.

8.1 System definition and service offering

Within the service development process, there emerged several questions. Responding to them lead to the ideated service. The service offering is formulated below and represented in the offering map (figure 57):

Service that organizes activities provides medical knowledge and builds up the community of local caregivers, volunteers and care-workers.

The leading service offering consists of medical knowledge delivery. Rituals will organize two types of courses: beginner caregivers and another one for citizens who want to become care-workers. The secondary service offerings consist of activities organized by local volunteers with the help of Rituals' staff. The activities will include physical well-being exercises, communication activities, possibly traditional Chinese writing. As discovered within the validation phase, the activities are crucial for caregivers. However, if the activities have a vivid entertainment character, they will not be appealing to caregivers, who will instead feel guilty to attend. Therefore, in the short-term, the activities must have primordial character, physical well-being and socializing, or culture related occupations.

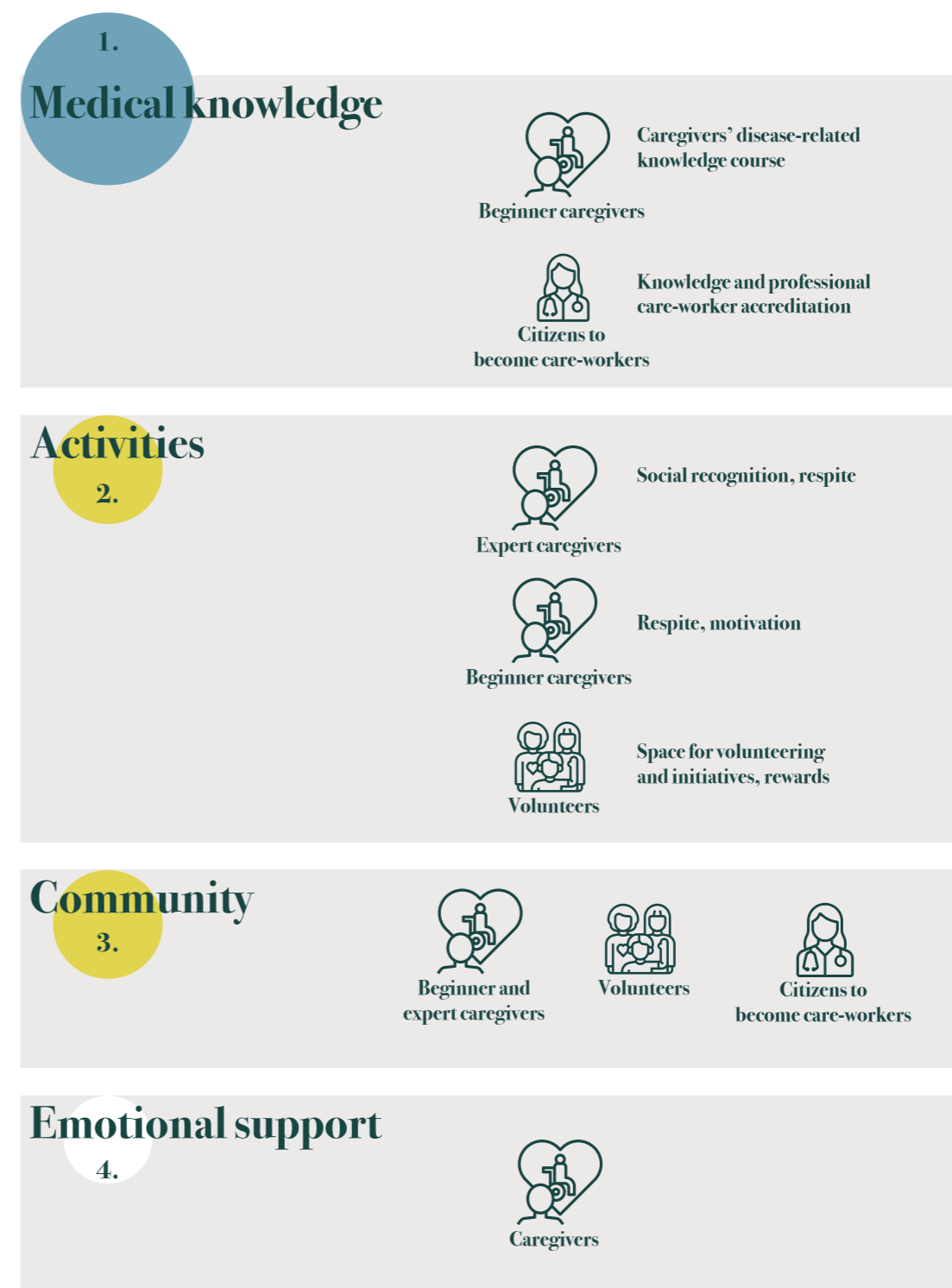


Figure 57. Offering map of the Rituals. Balanced Care Centre (Nadejda Cervinscaia, 2020)

Moreover, the expert caregivers, who have a long experience, will also be stimulated to volunteer and organize motivational sessions for beginner caregivers.

Within Rituals' events, there will be a strong emphasis on building the community of local caregivers (expert and beginners), volunteers,

and accredited care-workers, who would later professionally assist caregivers in their duties.

The tertiary service offering consists of an emotional support point. Caregivers will be able to access psychological help if needed. During the previous project phases, there

was found out that emotional help in China is currently considered extremist. Therefore its accessibility at Rituals aims to raise awareness of mental health's importance and make it perceived as normal.

Chinese cultural aspect

In the Confucianist writings, the idea of parents and sacrifice are tightly interwoven: "While parents are alive, serve them according to ritual. When they die, bury them according to ritual, and sacrifice to them in accord with ritual" (Confucius & Watson, 2007). From these excerpt, one can understand how necessary sacrifice is once an individual wants to manifest filial piety.

Moreover, the filial piety notion also constitutes the concept of humaneness "Filial and brotherly conduct, these are the root of humaneness" (Confucius & Watson, 2007). Consequently, the concept of humanness implies sacrifices, "The man of high ideals, the humane person, never tries to go on living if it is harmful to humaneness", from here one can understand that acting in discordance with filial piety equals to losing humaneness. Additionally, the fundamentality of humaneness, or filial piety, are positioned as a worth reason for sacrifice: "there are times when he sacrifices his life to preserve humaneness" (Confucius & Watson, 2007).

Finally, the concept of filial piety also includes ritual, or rites. The power of rituals are highly valued, they are keys essential in gaining balance, "what ritual values most is harmony". Notably, rituals are highlighted as the key to obtain harmony "you may understand the ideal of harmony and work for it, but if you do not employ ritual to regulate the proceedings, things will not go well," and even more, lack of rituals can be destructive.

Rituals are described as the core of actions, which when followed "could summon forth in mind the emotions and attitudes appropriate to the occasion". This passage classifies the empowerment which rituals have, to regulate the inner self according to the outer world.

To sum up, in Chinese culture, the terms of filial piety, humaneness, sacrifice, and rituals are strongly interconnected. Therefore, when designing an intervention into this topic, these fundamental cultural aspects are essential to consider.

Branding

As mentioned previously, the organization will help caregivers gain harmony and balance by rethinking their routinal duties, infiltrating respites, external help, social life, and personal well-being. These changes imply a reorganization of daily rituals. Rituals play a major role in gaining harmony in the both sacral space of caregiving, as pointed out in Chinese culture, but also sacral personal space. Therefore, the choice of organizations' name is 'Rituals. Balanced Care Centre'.

From the etymological point of view, the word Ritual, in Chinese 仪式 (Yíshì), means:

- 1) *ceremony, rite, worship*
- 2) *culture.*

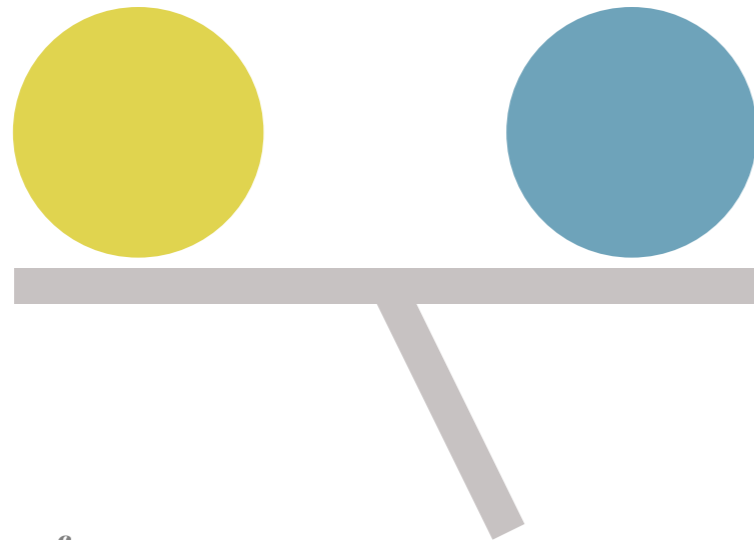
Notably, the second meaning of the word 'rituals' in Chinese is 'culture'. This implies the notion of art, knowledge, and awareness, something which one shall learn and transmit. The four characters of 仪式 (Yíshì) also have a separate meaning, word: 人 (rén) person, 义 (yí) righteousness, 弋 (yí) to shoot, and 工 (gōng) work. So, in Chinese, when a person, righteousness, and targeted work are put together, they build up together the ritual.

The developed logo of the Rituals translate the idea of harmony with two circles on a scale, balance. Besides the balance element that naturally means equilibrium and harmony, the circle in Chinese culture symbolizes "unity, fullness". The organization's concept is for the caregivers to strive for fullness in both individual life and caregiving, balancing the two. The two circles symbolize the two spaces for the two roles: individual and caregiver. The balance holds the two circles. Notably, the color choice is also symbolic; the yellow color in Chinese culture represents "the center of everything" (St. Clair, 2016). To give credit to the patient's centrality in caregivers' priorities, all the graphical elements related to the patient will be represented through the yellow circle. The blue color in the Chinese culture represents "health, prosperity and harmony", and within the branding of the Rituals organization stands for the personal space of the individual. The Harmonious blue and the 'core yellow' represent the primary colors. The secondary colors convey the feeling of calmness and security: 'wood green', 'calm grey' and 'chalk grey'. The brand logo and colors are represented in the Figure 58.

All the touchpoints will include the major graphical element is the circle on the weight, which is either balanced or not showing wither the caregivers' issues brought by lack of balance, or the harmony of the two circles, implying the efficiency of the solutions proposed by the Rituals Centre.

Rituals. 仪式

Balanced Care Center



Primary font

This font style is used in the logo, in titles, subtitles and textual highlights.

Bodoni 72 Book
Bodoni 72 Bold

Secondary font

This font style is used as the main textual font.

Trebuchet MS Regular

Font for the Chinese characters

Heiti SC Light
Heiti SC Medium



Vision

We envision caregiving as be a positive, thriving experience for any individual.

Mission

Our mission is to support caregivers by educating them on medical skills, balancing their routine with activities, and empowering by community power.

Beliefs

We believe that the quality of care depends on the quality of life of a caregiver. Quality care and quality life lie in gaining balance in caregiving rituals through knowledge, activities, and community.

Communication message

The service wants to emphasize the importance of the balance between the duties of caregivers and individuals. The organizations flashes light on the interdependence between a caregiver's quality of life and the quality of provided care. The communication message on the touchpoints is the following:

"Quality of care depends on caregiver's quality of life."

Figure 58. Branding components of Rituals. Balanced Care Centre: logo, fonts, colors (Nadejda Cervinscaia, 2020)

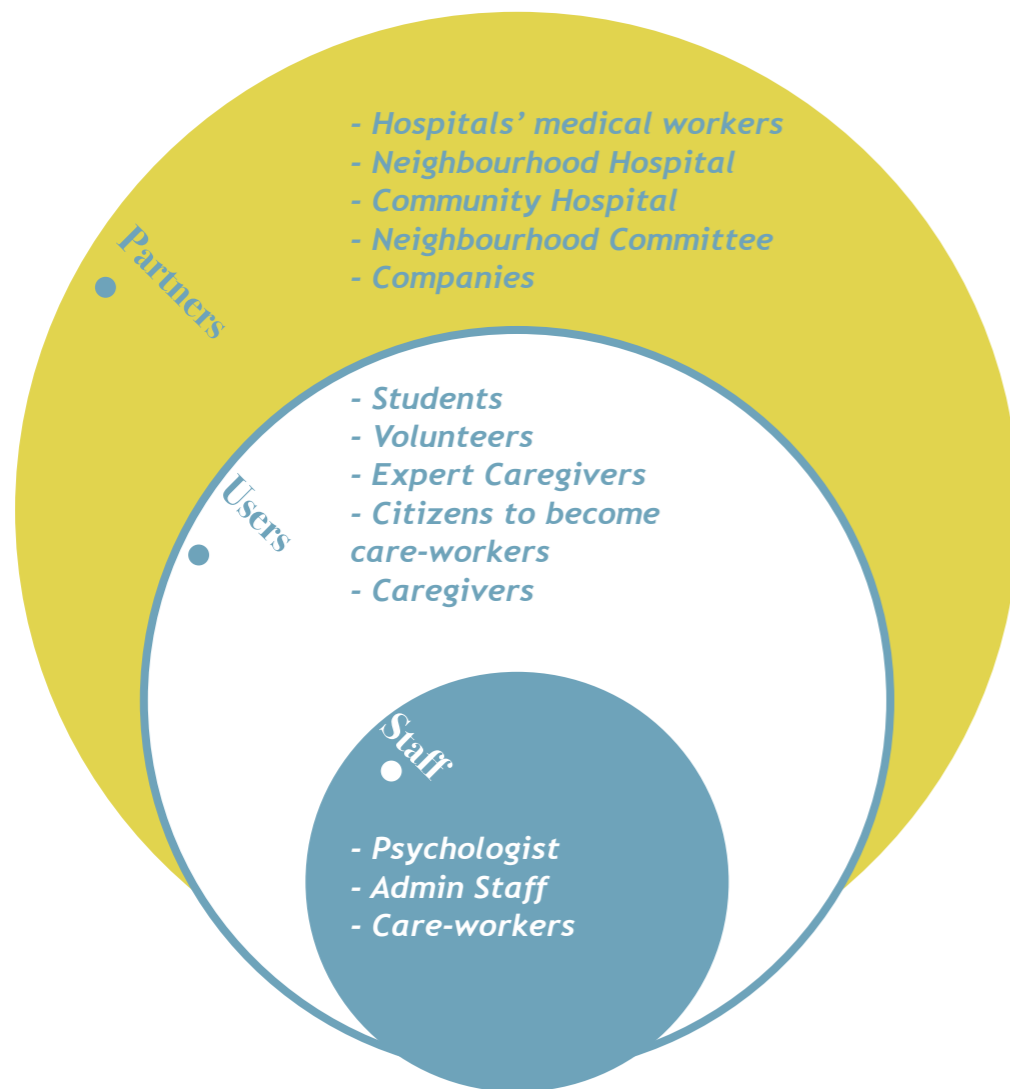


Figure 59. Stakeholders' map of Rituals. Balanced Care Centre (Nadejda Cervinscaia, 2020)

Stakeholders' map

The system of actors implied by the proposed service concepts includes a multitude of individuals and organizations. The actors are structured by roles into Partners (Hospital, Community Hospital, University, Neighbourhood Committee), Users (caregivers: beginner caregivers and experts caregivers, citizens to become care-workers), and Staff (care-workers, service administration, social worker/psychologist) (see Figure 59). Importantly, the volunteers and the students act as both partners and users of the service.

To better understand the proximity of interactions, the stakeholders were divided into three groups:

- Direct: family caregivers. The direct target is the primary beneficiary of the service.
- Secondary: volunteers and citizens, expert caregivers;
- Tertiary: students, medical social workers.

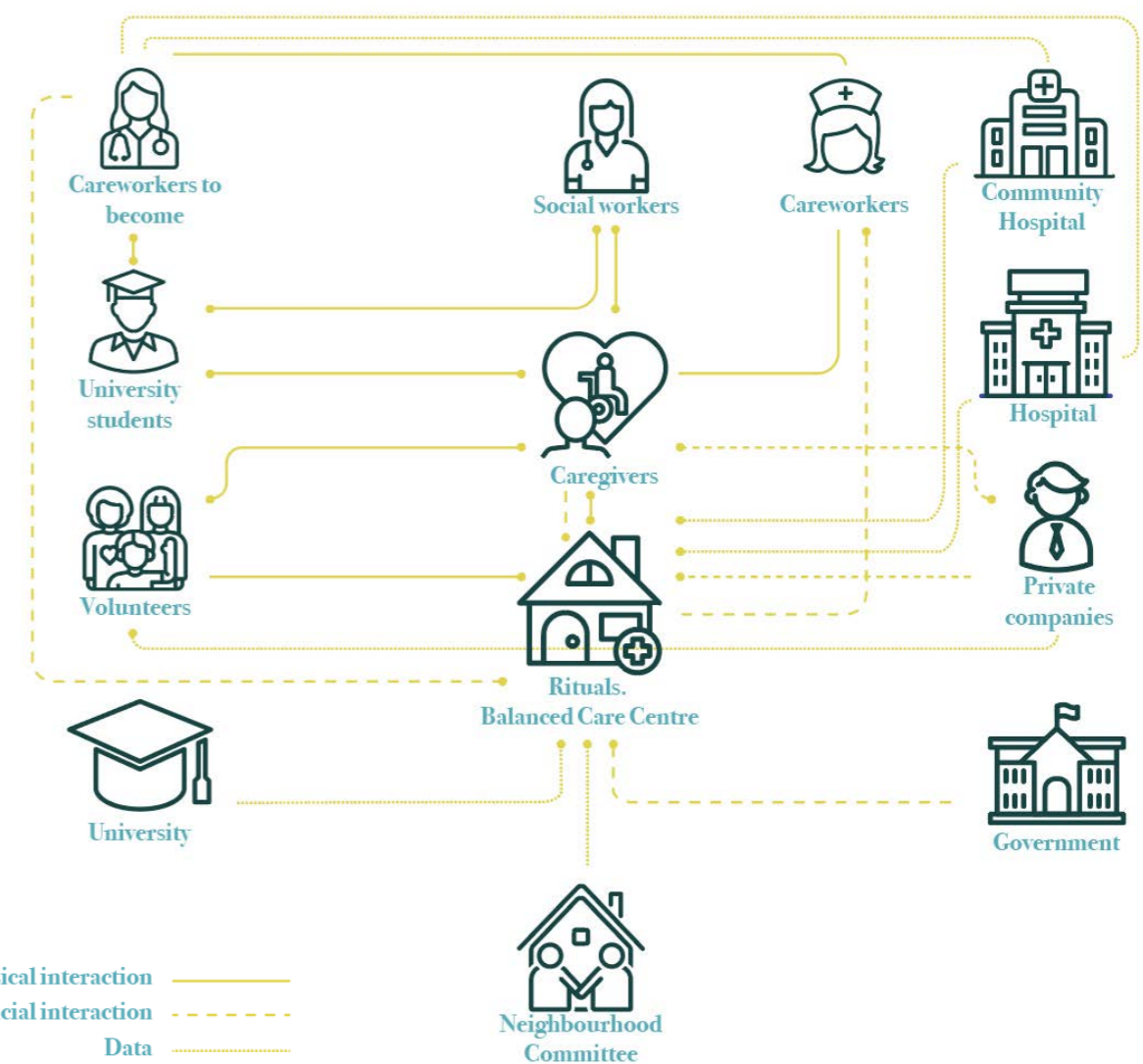


Figure 60. Rituals. Balanced Care Centre's System map (Nadejda Cervinscaia, 2020)

System map and stakeholders' interaction

In order to understand what are the interactions between the actors, there was created the system map, visualized in Figure 60. The system map is "a synthetic representation that shows in one single frame all the different actors involved in a service delivery, and their mutual links" (Morelli, 2010). It helps to visualize and understand the nature of connections between the actors.

The detailed interactions of the different actors are represented in the stakeholders' interaction map. There was created a stakeholders' interaction map (figure 61). As discovered during the desk and field research, currently in China and Shanghai, healthcare facilities have a high disintegration. The third

class hospitals, which own the highest quality of technological and human resources and funding, captivate the majority of patients for treatment, even when treatment can be pursued in the community hospitals. The Chinese government has created the Healthy China 2030 policy, where they plan to strengthen the communication and exchange of resources, reinforce the interaction of experts from the two entities. Considering this, and considering the participants' suggestions during the validation phase, the two entities can collaborate with the ideated service to deliver the courses for caregivers and care-workers. The hospitals and the community hospitals will represent

the knowledge and the human resource repository to deliver medical skills. The hospitals would have a more supervising role and quality control, while the community hospitals' are better equipped with time and human resources.

Notably, as the governmental structure governing every Shanghainese neighborhood, the neighborhood committee has all the neighborhood's inhabitants and their health status. Also, the neighbourhood committee is the organization that has information about the local volunteers. The validation session's participants explained that the neighbourhood committee is a neighbourhood governmental office, rather than an organization taking the lead on volunteers' community. Therefore, there is a lack of an organization which would systematically organize volunteers, to where the volunteers refer to and can rely on. The neighborhood committee will promote the service to the neighbourhood and connects the organization to the government, ensuring its transparency and activities. Lastly, the organizational environment in China is hierarchical and top-down driven. Therefore, it is crucial to ensure a strong connection to the government, starting with collaboration with the local structures. Besides, this link proves the organization's trustworthiness and transparency in the eyes of local people.

Another element within the actors' chain is the Universities and the senior medical students. As discovered during the validation phase, the students are keen to translate their theoretical knowledge into practical activities. However, due to the business, the students might have difficulty to include working at the organization. During the validation session, multiple participants suggested proposing the internship

opportunity to students. Hence, collaboration with the Universities is essential to promote the service to the students and officialize students' work after finalizing the internship. The medical students could be gaining experience in preparing and teaching the

medical course, while the social work students could practice in organizing diverse events at the centre. In both of the cases, they will be working closely with the proficient medical workers from the hospitals and community centers; therefore their continuous learning

will be also ensured.

On the other hand, the vital pillar of the service represents the companies. Importantly, in China, the companies consider donating goods and funds to social organizations recognized

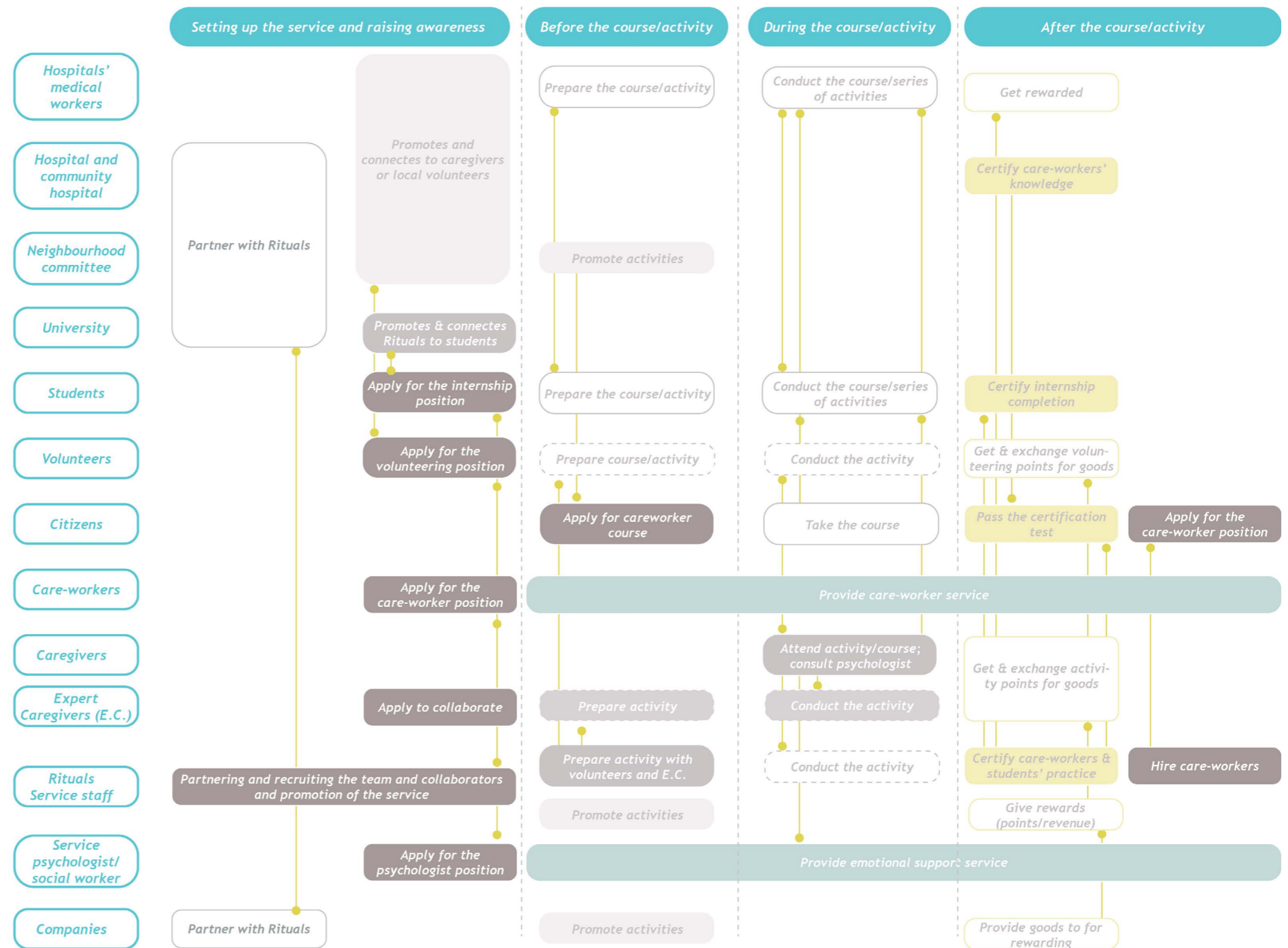


Figure 61. Stakeholders' interaction map of the Rituals. Balanced Care Centre (Nadejda Cervinscaia, 2020)

by Civil Affairs Bureau. Donation activities ensure enhancing their image and have a tax reduction mechanism. Besides, the practice of donating goods by companies is expected. For example, there are vending machines, where volunteers could procure goods with their volunteer points. Considering that this practice is common, the companies are included as partners, who can donate either fund to the organization or goods for volunteers and caregivers.

Another important actor is the neighbourhood volunteer. Within the field research, when the social worker of a hospital mentioned that he has a connection to the local community of volunteers who volunteer in the hospital, also during the validation session, it was confirmed that volunteering is widespread. Importantly, as mentioned by some participants during the validation session, many companies encourage their employees to volunteer to get a promotion. Therefore, there is a huge potential of local volunteers, who feel potent to contribute to the social good, this potential can be flourished to ensure caregivers' support. The volunteers' primary role would be to organize activities for caregivers and the organizations' staff or assist students and medical workers in delivering their mission at the organization. Besides, during the validation session, in some of the visions, the volunteers' roles included helping caregivers with practical tasks. Even though the participants said that it is unlikely to happen in the short-term because of caregivers' trust issues and concern to disclose their privacy to volunteers, the participants mentioned that it could be possible in the long-term. Therefore, first, the organization will contribute to building trust between volunteers and caregivers by giving the occasion of encounters, and

next, the organization would facilitate the practical help of volunteers to caregivers.

As one of the leading service proposition includes teaching medical knowledge, another target besides caregivers could be the neighbourhood inhabitants. The separate course would train the citizens to be care-workers, which would benefit their individual knowledge, and also build up the capacity as a potentially professional care-worker. Such a decision is rooted in two reasons: during the validation session, it was discovered that the citizens could be interested in learning to provide professional care. Moreover, in the desk research, it was discovered that currently, the majority of care-workers are not accredited and do not have the required medical knowledge. The Chinese government considers educating care-workers and promoting the spreading of medical knowledge. This will enhance social well-being and strengthen social capacity to respond to diseases with less assistance of the over-demanded medical workers at the hospital.

Finally, the primary actor within the system is the caregiver. The neighbourhood caregivers would benefit from the medical knowledge course, activities, the peers' and volunteers' community, and emotional support. As mentioned by medical workers and caregivers from the validation session, caregivers would benefit from activities, however, due to the Chinese culture, they might feel guilty and fear social judgment of attending leisure activities. As pointed by participants, in China, caregiving implies filial piety and, sometimes, excessive sacrifice. Therefore, the service will propose physical well-being activities, such as group exercises or communication activities. These primary

activities would less likely seed a dissonance of a caregiver attending activities. Within the validation session it was discovered that there must be organized an advertisement campaign, which slowly infuses the concept of caregivers' wellbeing. Therefore, in long-term, the organization could propose leisure to caregivers and would become socially accepted.

On the other hand, the caregiver figure bifurcates in caregivers with no experience, and the experienced caregivers. As discovered before, the figure of the expert caregiver already exists in social media, such a caregiver gives advices to freshmen and motivates them. Within the proposed organization, this relationship will be moved to offline. Specifically, expert caregivers will hold motivational speeches with know-hows and empower and get acquainted the newly caregivers with the journey that expects them. Lastly, such an interaction will also facilitate recognition of caregivers' efforts and sacrifices, which was another previously-discovered aspiration.

Value proposition:

In order to provoke interest in participating in the service either as a partner or as a user, the service has to provide triggering offerings to each of the stakeholders. The offerings can constitute tangible or intangible benefits, both are important when deciding to use the product or service. The value proposition map is presented in the figure 62.

Speaking specifically of the value proposition for the primary target, the caregivers, it reflects the service offering of knowledge, activities, and community:

Gain balance in your caregiving rituals through knowledge, activities, and community.

The core concept lies in counterbalancing the current multitude of tasks and ambiguities about the disease. Specifically, the poor social life, overwhelmingness by caregiving duties, and emotional pressure could turn positive through related education, socializing, activities and space for personal interests. The change-makers are the organized human resources, which make all these to come true. Moreover, the idea of counterbalancing should persist in caregivers' experience and bring caregiving to the new level of being: habit, or, said in another way, ritual.

Value proposition

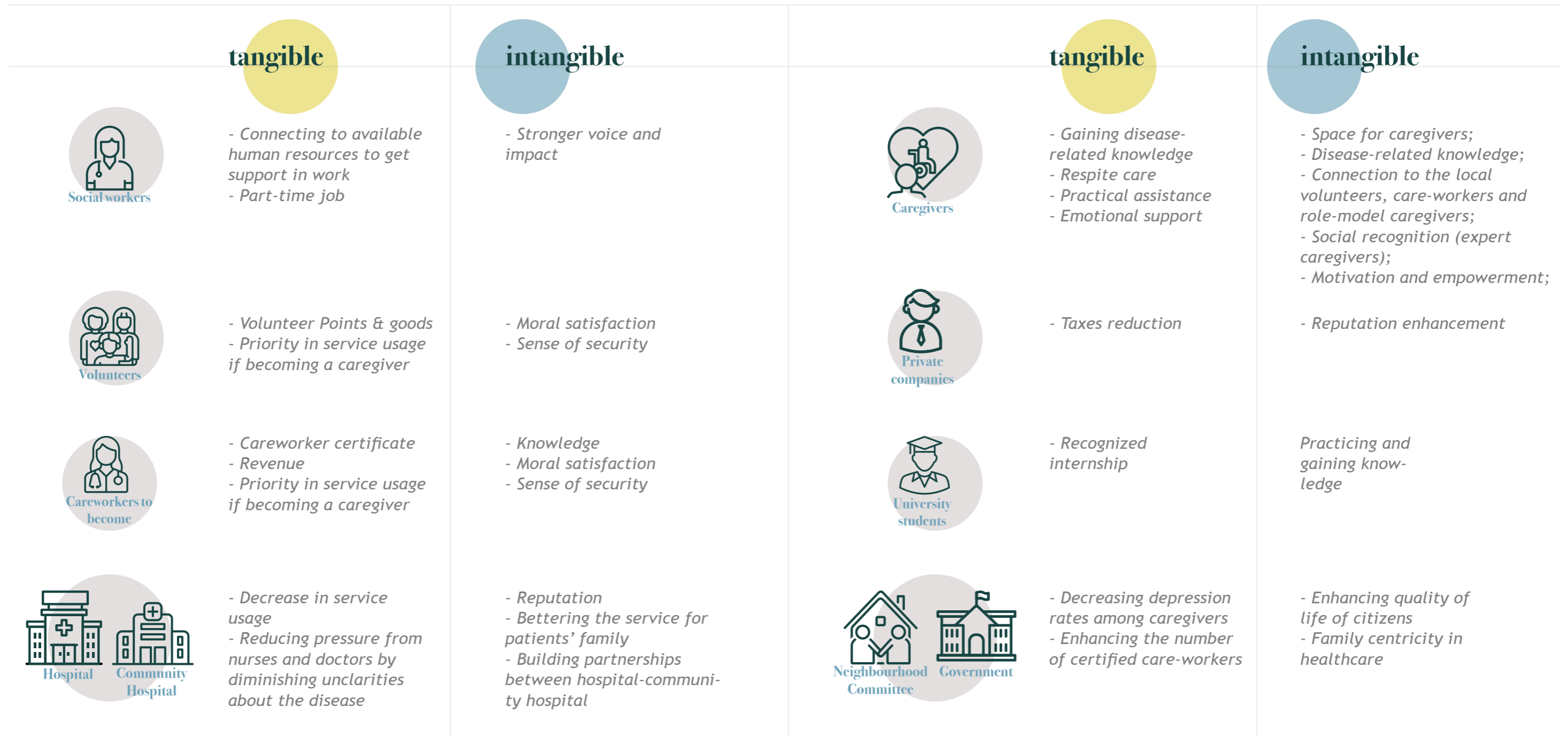


Figure 62. Value proposition map of the Rituals. Balanced Care Centre (Nadejda Cervinscaia, 2020)

8.2 Business Model Canvas

To understand the organizational functioning, there was developed a business model canvas. The business model is a tool “to describe the rationale of how an organization creates, delivers, and captures value” (Osterwalder & Pigneur, 2010: 25) The tool is constituted of nine blocks. In what follows, the business model will represent how Rituals works (figure 63).

As previously mentioned in the offering map, the key offerings for the primary target will constitute medical knowledge course, activities, community building and emotional support. Besides, the secondary service target (students, volunteers, citizens and community as a whole) will benefit from space where they can better their skills and enhance resilience through collaboration. Speaking specifically of the business aspect of the organization, Rituals will partner with Hospitals, community hospitals, universities and neighbourhood committees. These entities will support Rituals outsourced human resources. Namely, the medical experts of the healthcare facilities will deliver the medical knowledge to family caregivers and citizens enrolled in the care-worker's course. They will be supported by the senior medical students, recruited with the help of their universities, who, in their turn will profit of strengthening their skills. Partnering with accredited healthcare facilities will ensure the quality of the delivered knowledge and certify the care-workers. The healthcare partners will be motivated to partner because having knowledgeable caregivers is a long-term investment. It will contribute to releasing the occupancy of the medical workers, who, besides treating patients, currently have to instruct caregivers to provide care in a decentralised manner. Besides, Rituals will partner with companies,

who will donate goods and stimulate their employees to volunteer for the service. All these partners will also serve as channels to promote the service. The other distribution means will be diverse Chinese social media channels.

From the financial point of view, Rituals will be funded by the government and private donors. However, following the care-workers' course will imply a cost for citizens and bring revenue to the organization. It is projected that caregivers' knowledge course will be free of charge. The revenue will facilitate for the organization to reward the partnering medical workers, and the internal staff, maintain the space and organize fundraising campaigns.

Business Model Canvas

<p>Key partners</p> <p>Community Hospital and Neighbourhood Hospital</p> <ul style="list-style-type: none"> - providing part-time personnel to organize and teach the medical training course; - promoting the service to caregivers; <p>Shanghai University - connecting to the senior medical students;</p> <p>Neighbourhood Committee</p> <ul style="list-style-type: none"> - connecting to the local caregivers and promoting <p>Companies - providing goods to acknowledge volunteers.</p>	<p>Key activities</p> <p>Teaching & giving space for practicing medical knowledge:</p> <ul style="list-style-type: none"> - Teaching disease-related medical knowledge to caregivers; - Teaching neighbourhood inhabitants to become care-workers; <p>Emotional support and relief:</p> <ul style="list-style-type: none"> - Conducting relieving physical activities to caregivers; - Providing emotional counselling point to caregivers; - Organizing events with role-models caregivers; <p>Community building and community support:</p> <ul style="list-style-type: none"> - Recruiting and training volunteers; - Connecting caregivers to the local volunteers, care-workers and role-model caregivers; - Connecting caregivers and care-workers. - Organizing volunteers to conduct events and relieving physical activities to caregivers;. 	<p>Value proposition</p> <p>Caregivers:</p> <ul style="list-style-type: none"> - Respite possibility and space for caregivers; - Knowledge and preparation for caregiving to caregivers; - Connection to the local volunteers, care-workers and role-model caregivers; - Social recognition to expert caregivers; - Motivation and empowerment; <p>For volunteers:</p> <ul style="list-style-type: none"> - Priority to access the service for volunteers if they become caregivers in future; - Volunteering points and goods to volunteers; 	<p>Students:</p> <ul style="list-style-type: none"> - Providing internship opportunity to medical students; <p>Hospitals:</p> <ul style="list-style-type: none"> - Decrease of amount of inquiries from Hospital medical workers; <p>Citizens who became careworkers:</p> <ul style="list-style-type: none"> - Certified courses to become care-workers; - Revenue; <p>For the community:</p> <ul style="list-style-type: none"> - Building trust in the neighbourhood; - Building local community resilience. 	<p>Relations</p> <ul style="list-style-type: none"> - Maintenance of community and trustworthy relationships between volunteers-caregivers; and caregivers-care-workers; - Promotion relationships with care-workers; - Coaching relationships with students; - Emotional and respite assistance with caregivers; - Points system rewards. 	<p>Customer segments</p> <ul style="list-style-type: none"> - Caregivers; - Citizens who become care-workers; - Students; - Volunteers; - Community as a whole.
<p>Cost structure</p> <ul style="list-style-type: none"> - Organizing and maintaining the space; - Teaching the caregivers and care-workers; - Fundraising campaigns; 	<p>Revenue streams</p> <ul style="list-style-type: none"> - Payments for the care-worker course; - Fundraising campaigns; - Governmental support; - Donations from companies and private donors; - Selling medical data to medical research companies. 	<p>Key resources</p> <p>Teaching & practicing medical knowledge:</p> <ul style="list-style-type: none"> - Medical experts of several, most common diseases in Shanghai; - Medical students; - Citizens to be willing to become careworkers <p>Emotional support and relief:</p> <ul style="list-style-type: none"> - Psychologist/ in-house social worker; - Providing emotional counselling point to caregivers; 	<p>Channels</p> <p>Hospital:</p> <ul style="list-style-type: none"> - Empowering the local community to be care-workers; - Providing knowledge and preparation for caregiving to caregivers <p>Universities:</p> <ul style="list-style-type: none"> - Medical faculties distributing information to their students; 	<p>Compounds:</p> <ul style="list-style-type: none"> - Distributing information to the inhabitants of a district; <p>Companies:</p> <ul style="list-style-type: none"> - Distributing information for the employees to volunteer locally; <p>Social media: weibo, Rituals WeChat, Rituals website</p>	<p>Logistics:</p> <ul style="list-style-type: none"> - Space

Figure 63. Business Model Canvas of the Rituals. Balanced Care Centre (Nadejda Cervinscaia, 2020)

8.3 Storyboards

In order to visualize the actors' interactions, there were also produced storyboards. Storyboards "are valuable aids for designers to visualize aspects of their solutions which users might appreciate most in their contexts of use and with their unique needs and motivations" ("Interaction Design Foundation," n.d.). So, storyboards are illustrated scenarios, based on the defined personas (figure 64), depicting touchpoints and users' interactions with them (figure 65).

The personas supported and empowered the developed storyboards of the two caregivers (figures 66, 67), a volunteer (figure 68), a student (figure 69), and a Rituals social worker (figure 70).

Rebecca
Casual audiophile

Age 26
Gender Female
Occupation Frontend developer
Marital status Single
Location Mountain View

Online locations Work and mobile
Computer(s) iPhone and MacBook Pro
Internet usage 8-9 hours

TECHNOPHOBIC ————— TECH WIZ
CDs ————— MUSIC STREAMING
CASUAL LISTENER ————— HARDCORE GEEK

How will Rebecca interact with Spotify?

Questions Rebecca will ask:

- How do I keep updated on new releases by artists I follow?
- How do I learn of new artists I haven't heard of?
- Can I listen to music in a data-efficient manner?
- How can I listen on both my MacBook and my iPhone?

Who influences Rebecca?

Ads, Music charts, Her own tastes, Friends, Co-workers

Rebecca's situation

Goals, motivations:

- Listen to great music to keep her productive at work
- Relax and unwind at the end of the day
- Superior music quality for full enjoyment of tracks
- Expand the circle of music artists she listens to

Key words
music, jazz, r&b, pop, artists, new releases, top charts, background music

Rebecca's story

Music is a big part of my life; I like to think that I always have a "background music" running in each scene of my life. I love working while listening to music; somehow, it gives me a lot of focus on my task.

I regularly talk to my co-workers about music and singers — that's what we like to talk about over lunch. We're constantly looking for new artists to inspire us and to expand our music library, but lately it seems a little tough to do that. Everything seems to have a "filter bubble" effect, and we keep listening to the same genres and artists.

I really enjoy finding new artists that match my subjective taste, and most of the times I get those from my close friends. I wish there were a way to find more music and artists without having to rely on the serendipity of life!

Example of a persona that shows the six main elements you should include. Name, age, gender, tag line, experience and skills are placed on the left-hand side. The middle column focuses on the context to indicate how they would interact with a product or service. Finally, on the right-hand side some goals and concerns are shared, as well as a short scenario to indicate the persona's attitude.

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Figure 64. Example of a persona (Interaction Design Foundation, 2020)

Mary works in an office where she spends most of her day sitting still behind her computer.

She often gets back pain and she wishes she could exercise more, but at the end of her workday she has to pick up the kids and cook dinner, so when she has free time she just wants to lie on her couch

Mary isn't the only one in her office who would like to exercise more, so her team have decided to download the app "team move" to motivate each other to exercise

"Team Move" was recommended to Mary by one of her friends. The app let's her and her co-workers give each other exercise challenges.

Work created with Scenes™ by SAP AppHaus (<https://experience.sap.com/designservices/scenes>)

Figure 65. Example of a user story (Interaction Design Foundation, 2020)



Lenji (50)

caregiving for her dad, who has lung cancer and doesn't know about the malignancy of it

“I don't know what to do, what to trust and where to find strength to fight the cancer”

Experience 1 month
 Occupation Shop assistant
 Financial status Middle-low
 Martial status Married, 1 kid

Social ●●○○○

Emotional ●●●●●

Creative ●●●●○

Needs

Learning how to take care of her father, who is about to undergo chemo. Finding strength to fight with the disease, without her father finding out the diagnose.

Frustrations

Excess of different information confuses her. She doesn't know how to take care of the father, moreover, combining it with educating her kid makes her feel overwhelmed and lost.

Hobby

Practicing tai chi every morning and playing mahjong with his friends.

Storyboard 1

The caregiver Lenji has recently become a caregiver for her father. She is overwhelmed by the tragic disease, the amount of information she needs to understand, and her duties as a teenager's mother. She scans the QR code of the poster in the block of flats, then accesses information about Rituals activities online. She decides to consult the emotional

support point and disclose her feelings. In the centre she meets another caregiver who recommends her to also take the medical knowledge course. She decides to enrol. After some time of attending the course and timely accessing the psychological support she feels relieved and can better deal with her daily caregiving routine and personal life.



Figure 66. Illustrated storyboard of the caregiver Lenji (Nadejda Cervinscaia, 2020)



Beihu (75) caregiving for his wife with diabetes and a recent heart attack

“In this 2 years I got to know everything about diabetes, and now I need to get acquainted to my wife’s heart disease. All new again.”

Experience 2 years
 Occupation Former guard
 Financial status Middle
 Martial status Married, 1 son

Social ●●●●○
 Emotional ●○○○○
 Creative ●○○○○

Needs

The freshly diagnosed heart disease implies new care skills, which Beihu doesn’t have. Also, he wants his efforts in care to be recognized.

Frustrations

Within the constant care which he provides to his wife, he feels bad not to have a single pause. Lack of breaks makes him nervous and he is tending to argue with his wife. He’d like to live his social life in a fuller way, as it was before his wife’s diseases.

Hobby

Practicing tai chi every morning and playing mahjong with his friends.

Storyboard 2

The caregiver Beihu visits his wife, who has recently had a heart attack. He has been caregiving for her as a diabetes patient for two years now, but the sudden heart attack has implied new difficulties. The nurse sees that his fragility and shares the leaflet of Rituals. He registers in the app and browses the activities, where he finds out the yoga class is coming soon. However, as his wife has been just discharged, he needs to ensure constant supervision for her and would not be able to attend the activity unless a care-worker substitutes him for a while. Later, he finds out that the medical knowledge course for caregivers for heart diseases will start soon; he attends it to get equipped with this new knowledge. Soon he sees that at Rituals, he can share his knowledge about caring for a diabetes patient, and he decides to do so. The other participating caregivers appreciate his sharing, and he feels acknowledged. After some time of combining his full-time caregiving with Rituals he feels balanced, and has a more harmonious relationship with the wife.

finds out that the medical knowledge course for caregivers for heart diseases will start soon; he attends it to get equipped with this new knowledge. Soon he sees that at Rituals, he can share his knowledge about caring for a diabetes patient, and he decides to do so. The other participating caregivers appreciate his sharing, and he feels acknowledged. After some time of combining his full-time caregiving with Rituals he feels balanced, and has a more harmonious relationship with the wife.



Figure 67. Illustrated storyboard of the caregiver Beihu (Nadejda Cervinscaia, 2020)



Aina (57) experienced neighbourhood volunteer

“My father taught me to be useful to the society. The goodness is the fundament of strength!”

Experience 7 Years
Occupation Housewife
Financial status High

Social ●●●●●
Emotional ●●●●○
Creative ●●●●●

Needs

She feel empowered when she can help people around her and express her creativity, make use of her former vocation of a yoga teacher.

Frustrations

Many times volunteering doesn't imply creative tasks, but rather practical duties. She wishes that within her activities she could build relationships as she recently moved to the new district.

Hobby

Healthy lifestyle, sports, yoga.

Storyboard 3

Two neighbours see the notice of the Rituals centre in their block of flats. The volunteer Aina inquires information on the website and then visits the centre to volunteer. She is requested to make an activity plan for the activity which she would like to conduct. Aina presents her idea to the staff and later conducts the activity with caregivers. She

receives volunteer points and exchanges it for goods at the vending machine. After several months of volunteering, Aina decides to get certified as a care-worker. She pursues the course and enjoys it. As the neighbours caregivers have seen her at Rituals and know her volunteering yoga activities, they trust her and hire as a part-time care-worker.



Figure 68. Illustrated storyboard of the volunteer Aina (Nadejda Cervinscaia, 2020)



Linna (24) a passionate nursing student, not knowing in which field to specialize

“I cannot wait to graduate and work in a hospital, but before that I need to still learn and practice!”

Experience 0 years
 Occupation Senior student
 Specialization Nursing

Needs

Practicing the acquired knowledge and deciding which medical field to focus on.

Frustrations

Since she is not Shanghainese, finding a job in a good hospital in Shanghai, with no connection, is very difficult. She needs to prove competitive skills and experience.

Social ●●●●●
 Emotional ●●●○○
 Creative ●●●○○

Storyboard 4

Linna saw a recruiting poster for interns of the medical school at Jiaotong University, where she studies. She applied for the internship and was invited to an interview. After a competitive students' selection, the nursing student Linna undergoes an internship of 4 months at Rituals. She is guided by an experienced nurse of the Ninth People Hospital, respiratory inpatient department. Her internship consisted in curating the

medical course for beginner caregivers, specifically for patients with heart issues. She browsed a lot of materials in order to prepare it. She is so knowledgeable, that sometimes was delivering the course to caregivers mainly independently. Her efforts were highly appreciated by Rituals. She will use the gained certificate to proof her experience and start the career.

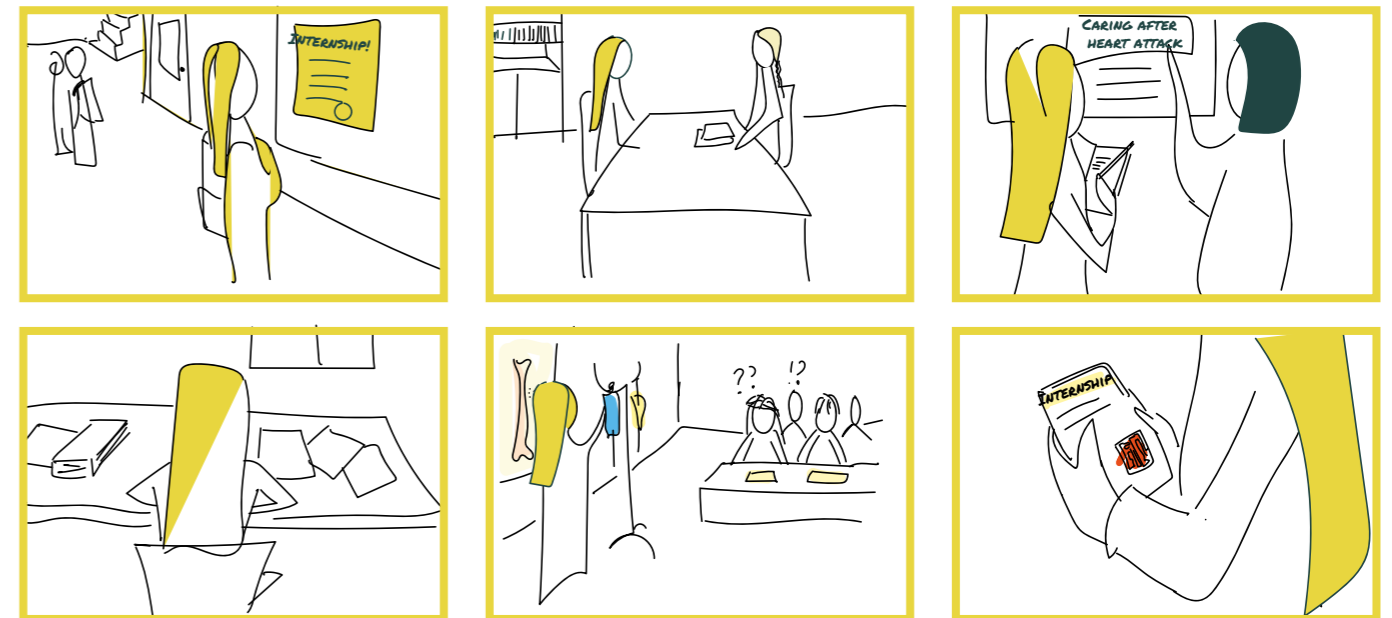


Figure 69. Illustrated storyboard of the student Linna (Nadejda Cervinscaia, 2020)



Yue (33) social worker at Rituals

“Social workers have so much work in China, and very few resources!”

Experience 8 years
Occupation Social worker
Financial status Middle

Social ●●●●●
Emotional ●●○○○
Creative ●●●●○

Needs

Yue loves social work, she specializes in vulnerable groups, but she needs a more flexible workplace than a hospital, since she became a mother.

Frustrations

When she worked in the hospital, her social work projects were too big for the resources she could have.

Storyboard 5

Yue, the social worker, was overwhelmed by the hospital's bureaucracy where she was working. She couldn't get enough funding of her ideas, nor the social work team was enough to accomplish her ideas for projects with caregivers. Also, the work at the hospital badly impacted her time to be spent with her little daughter. She applied for the social worker position at Rituals and got employed. She was assigned an intern, who helps her with the events which she has in mind to organize for caregivers. She enjoys a less stressful work environment at Rituals, where she can even take her daughter sometimes.



Figure 70. Illustrated storyboard of the social worker Yue (Nadejda Cervinscaia, 2020)

8.4 Service touchpoints

The Rituals' touchpoints will be spread across digital and physical spaces. The touchpoint map is presented in the figure . The touchpoints constitute:

Online:

- website
- app
- online courses and activities
- WeChat account
- Reward' points

Offline:

- Rituals' space
- courses' and activities' contents
- courses and activities
- personnel delivering the activity/course
- posters/leaflets (distributed by the partners: neighbourhood committee, hospital, community hospital, university);
- vending machine for points' exchange.

Each of the touchpoints are described below.

App

To facilitate the service idea in helping caregivers obtain balance by reconsidering their daily rituals, there was conceptualized an app. The aim of the app is to:

- 1) acknowledge the caregivers with the activities and resources available at the Rituals
- 2) nudge them to participate in the happenings by providing assistance of a volunteer or a care-worker to help them and triggering with a point system.

Overall, the app's idea reflects the concept of "Space for caregiving" and "Space for

me". Specifically, the app gives users space to write notes, 'to do' lists for two different roles of theirs: as a caregiver and as an individual with personal interests. The clear separation of spaces would make evident the need to ensure that the caregiver focuses on both of his/her roles and balances them. This idea emerged within all the phases of this research when it was discovered that caregivers tend to disregard their personal life and place the patient's interests first. The line between the individual as a caregiver and the individual as a person becomes blurred. Even though the patient's good can be clearly projected to the caregiver's well-being, it is still essential for the caregivers to consider their personal matters. Also, considering the specifics of the Chinese culture, the app respects the individual decision about the level of dedication in caregiving. However, still gives a nudge and food for thought by showing the ratios of duties and activities for each of the roles.

The architecture of the app is represented in figure 71. The app is divided into four sections: 'At Rituals', 'My learnings', 'My rituals' and 'My profile'. Each of these sections is described below.

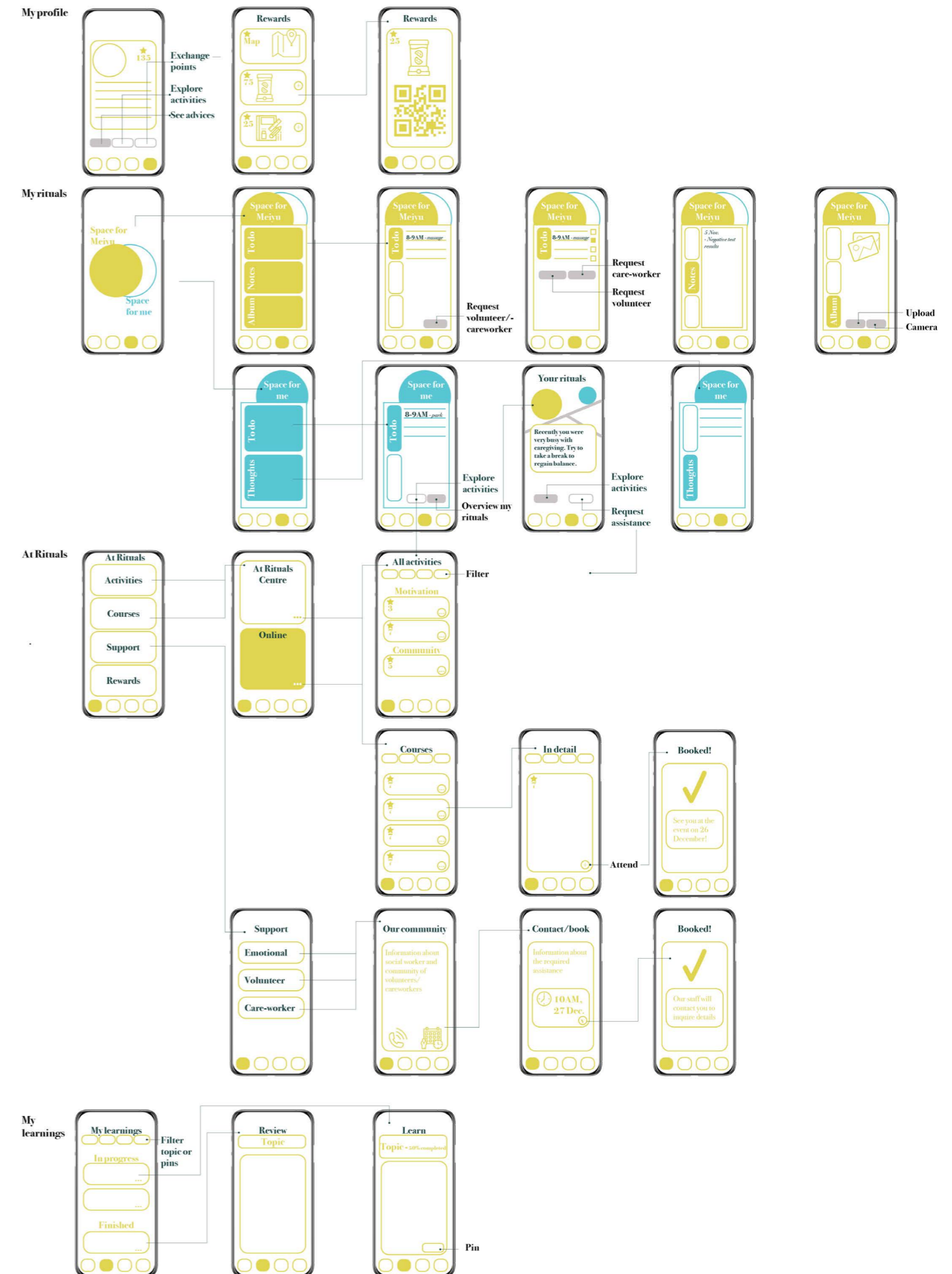


Figure 71. Architecture of the Rituals' app. (Nadejda Cervinscaia, 2020)

Registration process

To start using the app, or also registering on the website, upon registration, users will have to respond to several questions reflecting details about their caregiving experience (about the patient, about the duties, about the challenges), and about their personality (their hobbies, their time to rest) (see figure 72). The app will later use this information in order to give related advices in the registration letter (figure 73). For example, when the individual responded that in order to have a full energetic recharge, he/she needs 2 hours of personal time per day, the app will notice that the duties are not giving space for the caregiver to accomplish this and will suggest asking for care-worker's assistance to have a respite.

On the other hand, the app also asks about caregiving experience and could later suggest holding a motivational speech for expert caregivers, who have vast caregiving experience and knowledge. This information will be accessed through "My profile", "see advices" shown next.

From the given advices in the registration letter, the user can be directed either request support, or go to the full range of Rituals' facilities shown next in the section 'At Rituals'.

About you as a caregiver

To whom are you providing care? For how long?

How much time do you dedicate to caregiving?

2h/day 4h/day 6h/day Full-time

What is the disease?

Gastrol Heart disease Respiratory disease

What are your caregiving duties?

Medical procedures Chores Cooking
 Financial matters All Emotional support

What is your challenge in caregiving?

Medical procedures Chores Learning about the disease
 Financial matters All Emotional resilience

Do you have some help with caregiving now? Whose?

Care-worker Family None
 Cleaning lady Friends

System's response

Proposing to share experience as a role-model (min. 2 years experience)

Highlight the importance of a break

Proposing - heart related medical materials

Proposing - medical course

Proposing - volunteers' help

Proposing - careworkers' help

Proposing - psychological counselling

About you as an individual

Are you an introverted or extroverted person?

Introverted Extroverted

What do you like doing?

Reading Socializing Sports Mahjong

What would you add to your routine?

More time for myself Meeting people
 Creative activities Exercising

How much more time/day would you need for a good rest or your interests?

1h 2h 3h 4h _____

When do you have more time during the day?

Early morning Early afternoon
 Late morning Late afternoon

System's response

Proposing - group activity

Proposing - volunteers' help
 - careworkers' help

Proposing - suitable time

Your Rituals. Your Balanced Care

Hello Beihu!

Welcome to Rituals. You're a dedicated caregiver, it is admirable!

Within your caregiving duties, it would be great if you could indeed spend more time for your own comfort. It will boost your energy and empower you to provide quality care to your wife, you might consider adding some rituals to your routine for balance. Here is what we propose:

- join our group activities at rituals (e.g. communication club on Wednesday at 11AM);
- space for meeting other caregivers, you could play Mahjong together;
- get to know our great careworkers and volunteers for eventual help;

Also, as you requested, here is more link with information about the **medical skills course** and what you should primary know about **heart diseases**.

At Rituals we have a big community of caregivers, some are new, others are experienced like you. We'd be happy if you could **share your experience and knowledge**. The beginning caregivers need to know about your know-hows!

Last, but not least, remember about **Rituals App**. You would stay updated about all the activities at Rituals and **get points by balancing your caregiving time with daily space for yourself**. Make it a ritual!

Meanwhile, discover all the activities.

Figure 73. Letter received upon users' registration on the website or app, containing tailored advices and links. (Nadejda Cervinscaia, 2020)

Figure 72. Registration questionnaire discovering the information about the user as a caregiver and the user as an individual (Nadejda Cervinscaia, 2020)

'At Rituals' section of the app

The app's section 'At Rituals' contains all the offerings of the service: activities, courses, support and rewards, its architecture is represented in the figure 74 (0). First of all, by clicking either 'courses' or 'activities', the user will be directed to choose the space: online or physical events at the Rituals office (1). Then, the user can filter the activities (2) or courses (3) by their category (e.g. communication, motivation, physical activities, heart-related courses) and select the preferred activity, read the information about it. To stimulate caregivers attending activities, courses, and get support, each of these will have a point system (4). Once the caregiver attends the activities, the points will be collected in his profile. The users can access the repository of available goods to exchange the points in section 'Rewards' (5). Another factor in stimulating caregivers to attend is to display information about the organizers of the activity (6). As discovered during the workshop and validation session, in China, people feel uneasy about disclosing information about their private matters, especially the fragile topic on the health status. So, by attending activities that might raise these topics could be sensible. Therefore it is important to build trust and ensure a non-judgemental environment. This feature of the app will help get familiar to the organizers team (medical workers, volunteers, students, expert caregivers) and build trust. Once the user clicks attend, the activity will be booked (7) and transferred to "My rituals" section of the app. This section is presented in the next spread.

Lastly, another subsection of the 'At Rituals' includes 'Support'. The caregivers can select what kind of support they need (8),

read about the community or experts who provide this help on behalf of Rituals service (9) and request it (10). The Rituals staff will later contact them in order to set down the appointment and find out details about the situation (11).

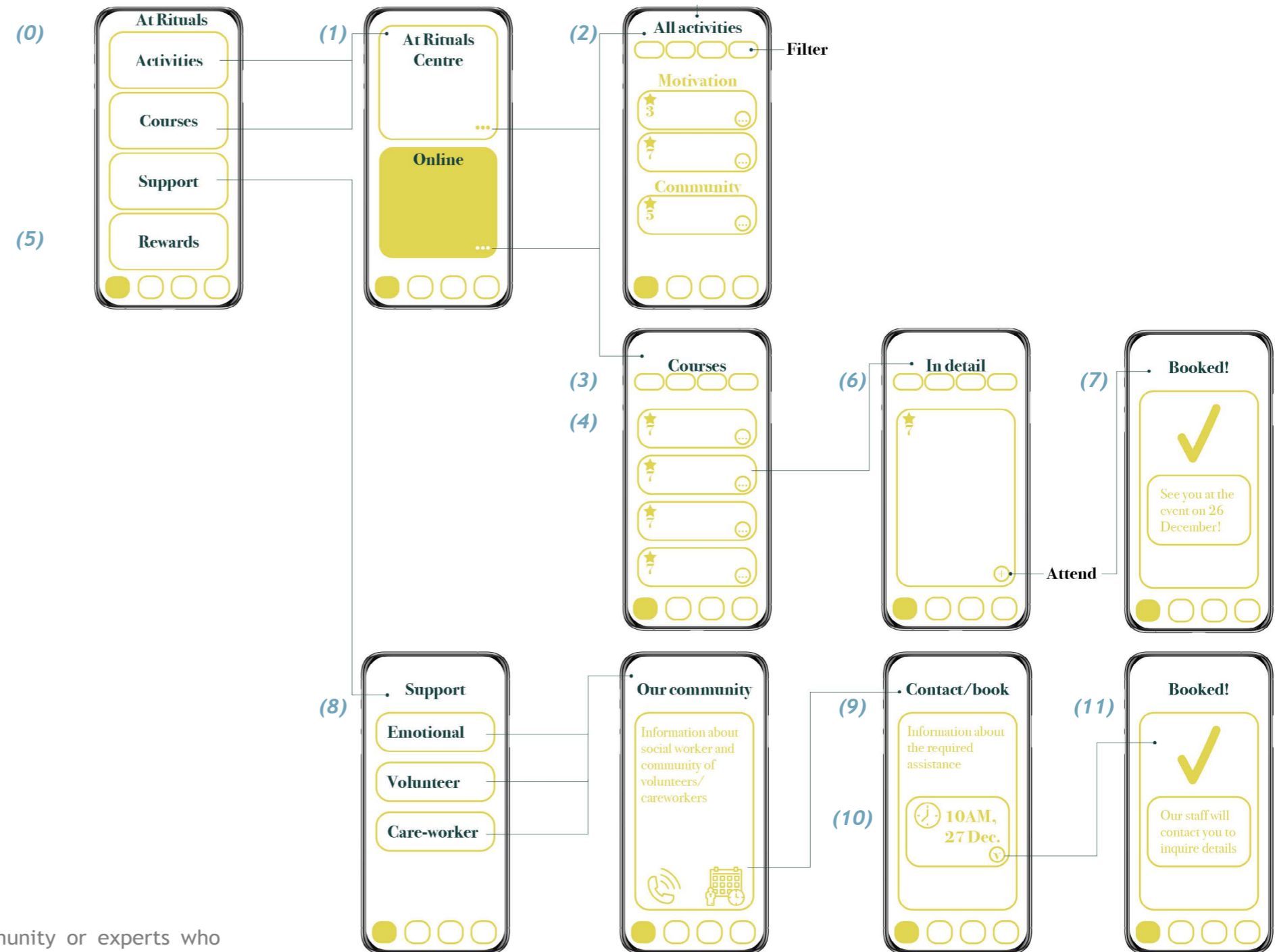


Figure 74. The section 'At Rituals' of the proposed app (Nadejda Cervinscaia, 2020).

'My rituals' section of the app

The "My rituals" section's architecture is visualized in figure 75. It is divided in two: "Space for (patient's name)" and "Space for me" (1). In the "Space for Meiyu" (2) there are three possibilities: to plan the 'to do' list (3), write notes (4) or take pictures (5). In order to release the burden from caregivers, upon planning the 'to do' list, the app will suggest to the caregiver to ask for assistance (6). This is how the caregiver can request a care-worker's or volunteer's help. The caregiver can mark specific tasks which he/she would like to be assisted on (7). Besides, 'Space for Meiyu' will have a function to write notes (8) and collect pictures to the patient (9). This functions aim to store patient's information securely, being easy to access anytime.

The section "Space for me" (10) includes a 'to do' list too (11), and 'thoughts' (12). Within planning the personal 'to do' list (13), the caregiver will be proposed to either explore and add Rituals' activities, or have the general overview of 'my rituals' (14). The 'my rituals' page shows the conclusion on the ratio of the caregiver's activities as a caregiver and as an individual. The interface will include the visual identity of the Rituals', showing the balance and the focus where the caregiver stresses on. From here, the caregiver can select to discover activities and be directed to 'at rituals' space (15), or request assistance (16).

Within the 'thoughts' section (17), the caregiver can make any sort of notes. This section would nudge the caregiver to take a moment to reflect on the thoughts and better comprehend the moment of life which they are facing. According to researches, this practice can bring mindfulness and flourishing (Ehrenfeld, 2019).

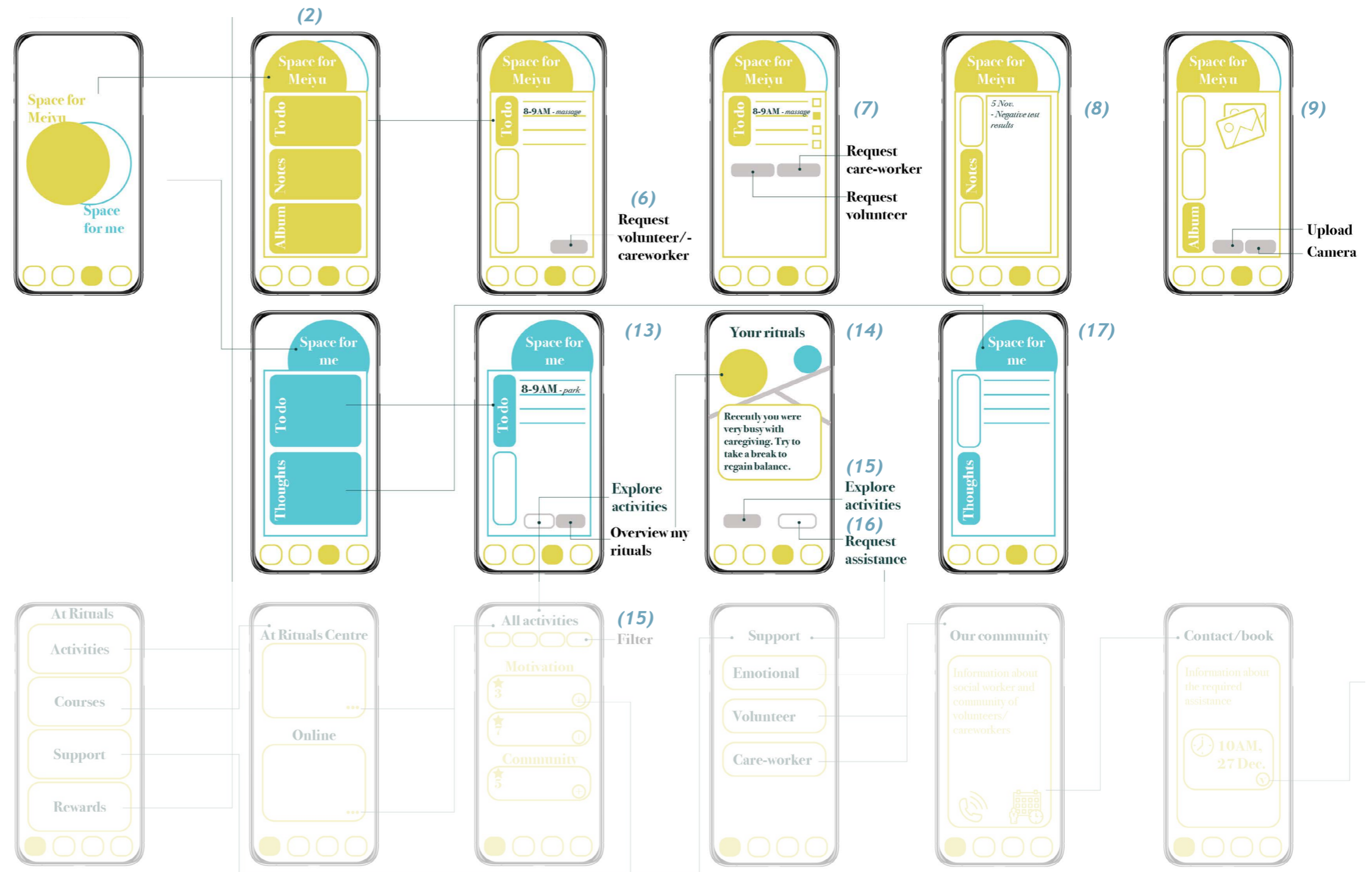


Figure 75. The section 'My Rituals' of the proposed app (Nadejda Cervinscaia, 2020).

'My learnings' section of the app

Next, the section 'My learnings' contains the knowledge repository, with courses already attended by the caregivers. Its architecture is represented in the figure 76. The caregiver can access his/her library (1), filter the courses by topic (2). The user will discover and the courses in progress (3) or the finished courses (4). By accessing the course, the user can review the information (5). When accessing a new course, the user can see the progress bar (6), learn the information and pin the highlights (7), which later can be also be found by filtering the topics and pinned courses (2).

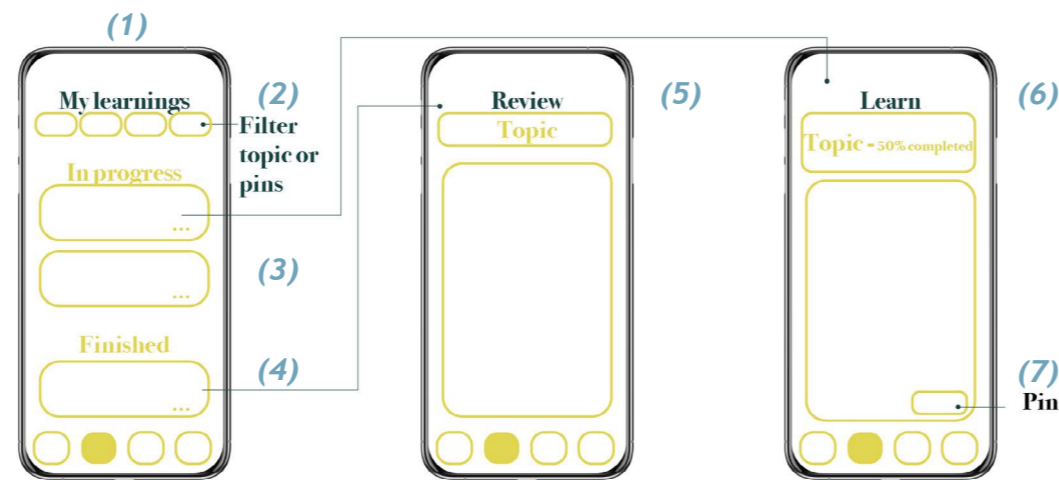


Figure 76. The section 'My Learnings' of the proposed Rituals app (Nadejda Cervinscaia, 2020).

'My Profile' section of the app

Within 'My Profile' section of the app the user can discover tailored advices, see personal collected points, and access the rewards shop. The architecture of this section is presented in figure 77.

In the profile section, the user can read about his/her caregiving patterns based on the data collected in 'My Rituals' section presented above (figure 74, (14)). Besides, as mentioned before, when attending activities, courses, and requesting help for Rituals support, the caregiver will collect points. These points rewards can be exchanged for goods in special vending machines, popular in Shanghai, or exchanged for medical knowledge courses. The whole range of goods will be visualised in the rewards shop (3), indicating also the places where the caregivers can pick the good (4). The caregiver can pick the desired good and scan the generated QR code in order for the machine to give the good (5).

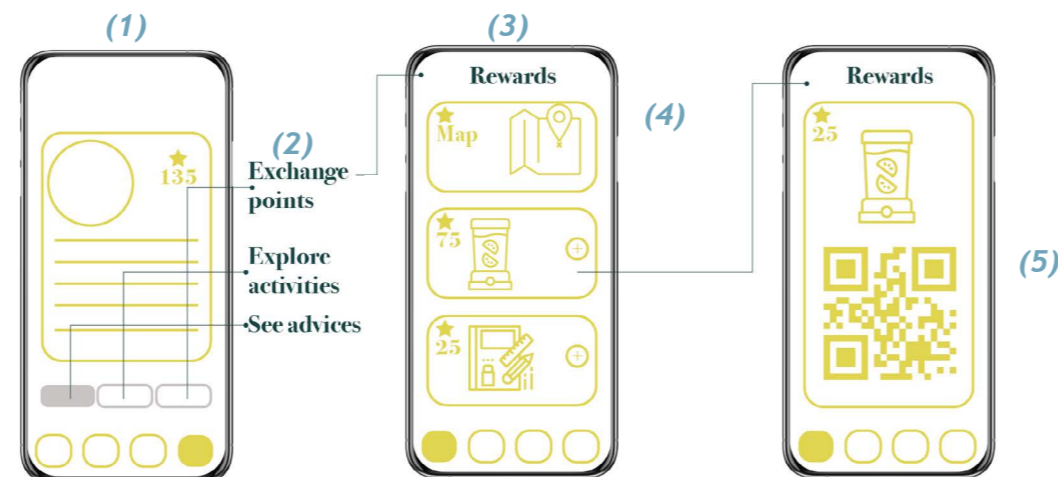


Figure 76. The section 'My Profile' of the proposed Rituals app (Nadejda Cervinscaia, 2020).

App renderings

In order to visualize the possible rendering of the app, there were developed several screens presented next.

'My profile' screen (figure 77) depicts the user persona Beihu, who is caregiving for his wife Meiyu. He has attended one Rituals activity and has collected some points. He can see related advices for him to balance the caregiving rituals, discover activities or exchange points.

The user Beihu can access his learnings 'My learnings', presented in the figure 78). The user can discover the courses which he has taken, and the ones in progress. The learnings are organized by folders, which are reflecting his wife's diseases: diabetes and heart disease.

Lastly, the 'At Rituals' section illustrates the multitude of activities at Rituals is also visualized (figure 79).

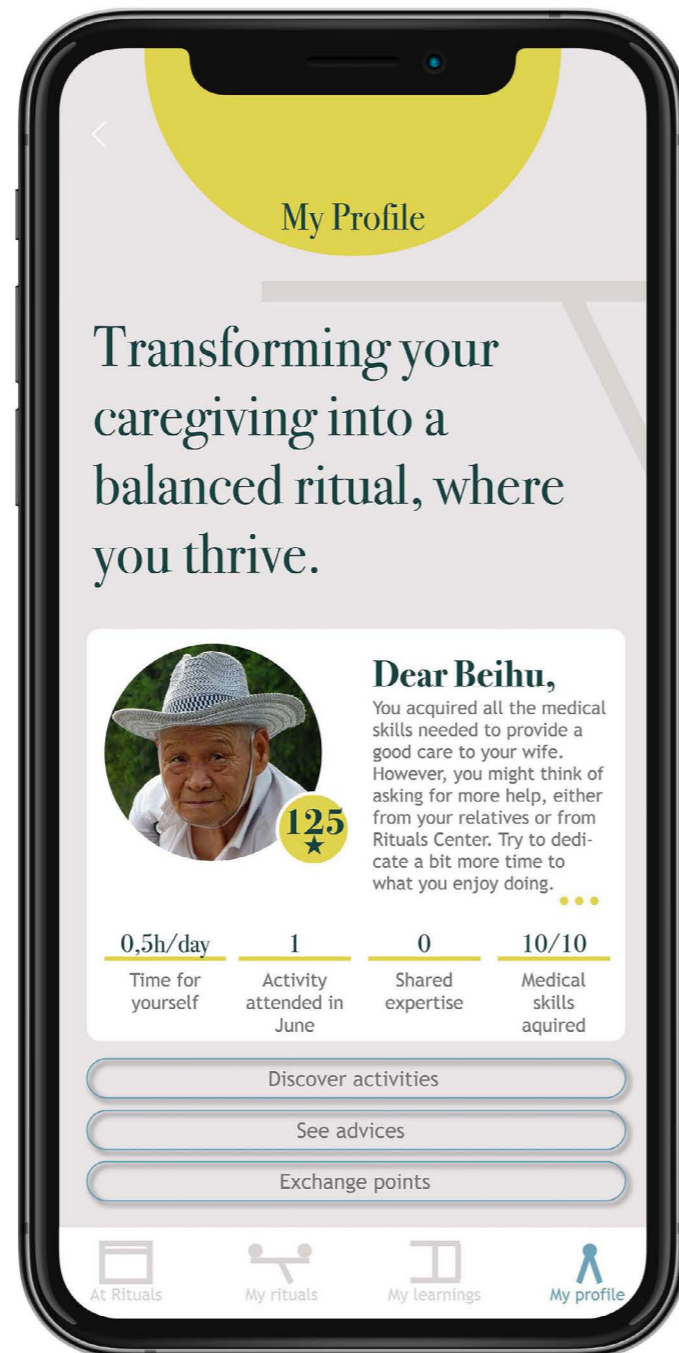


Figure 77. Rendering of the Rituals' app, 'My Profile' section (Nadejda Cervinscaia, 2020).



Figure 78. Rendering of the Rituals' app, 'My Learnings' section (Nadejda Cervinscaia, 2020).



Figure 79. Rendering of the Rituals' app, 'At Rituals' section (Nadejda Cervinscaia, 2020).

App renderings

Lastly, 'My rituals' section is visualized in figures 80, 81. We can observe how the user can switch spaces by tapping in the top of the screen ('space for me' and 'space for Meiyu'). Then, there are shown the two different schedules and to do lists for the caregiver as a caregiver and as an individual. Such a layout will be the nudge for the person to remember to dedicate some time to personal space. There can be also seen the points, which the user can gain by requesting help, or securing some time for personal well-being. The information in the 'space for me' is based on the data set by the user upon registration. It contains the information about the user's hobbies and the desired time for leisure, therefore can suggest related advices, such as practicing taichi for the user Beihu.

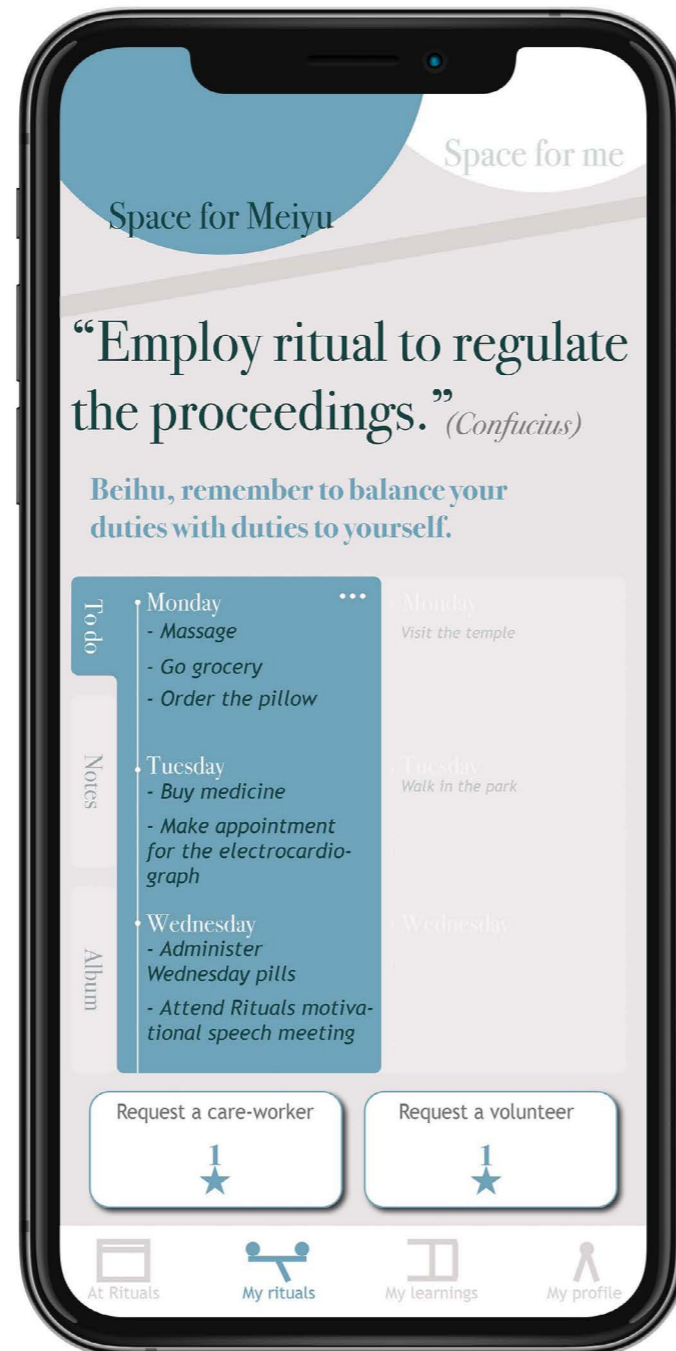


Figure 80. Rendering of the Rituals' app, 'My rituals' section 'Space for Meiyu' (the patient) (Nadejda Cervinscaia, 2020).



Figure 81. Rendering of the Rituals' app, 'My rituals' section 'Space for me' (the caregiver) (Nadejda Cervinscaia, 2020).

Website - Landing Page and About sections

The website will represent the primary touchpoint for the public to get to know about Rituals. The website will display information for a diverse target:

- primary service users (caregivers);
- partners (volunteers and citizens, students, medical institutions).

The website consists of the following sections:

- *About*: presenting the vision and mission of the Rituals centre;
- *Activities*: presenting the ongoing activities in the online and physical Rituals space;
- *Partners*: the page for the potential students, companies, hospitals to partner with Rituals;
- *Contacts*;
- *Personal profile*, where the caregiver can access his calendar of activities to attend.

The landing page (figure 82) of the website will incorporate the core information about the service, showing the offerings, the organization's beliefs, mission and vision (figure 83).

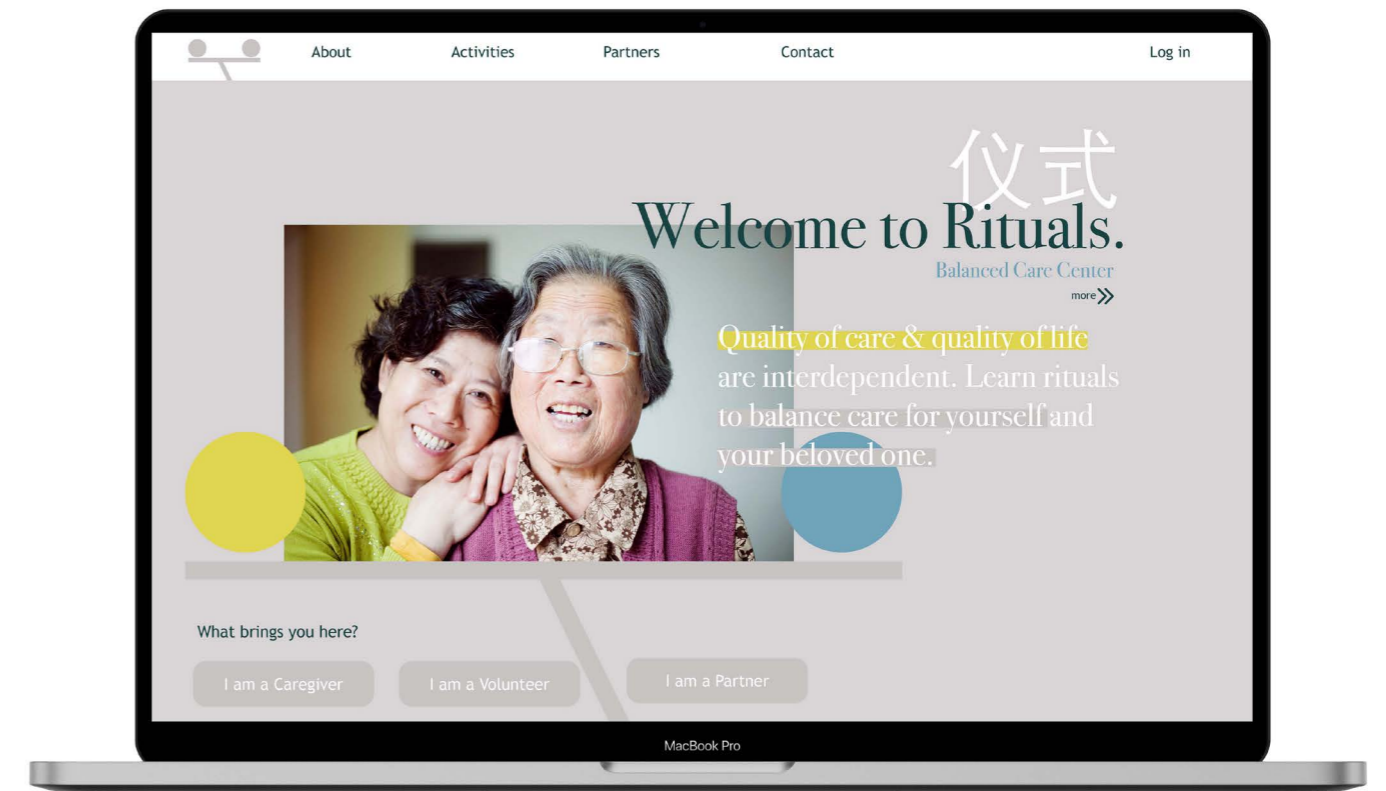


Figure 82. Rendering of the Rituals' website, landing page (Nadejda Cervinscaia, 2020).

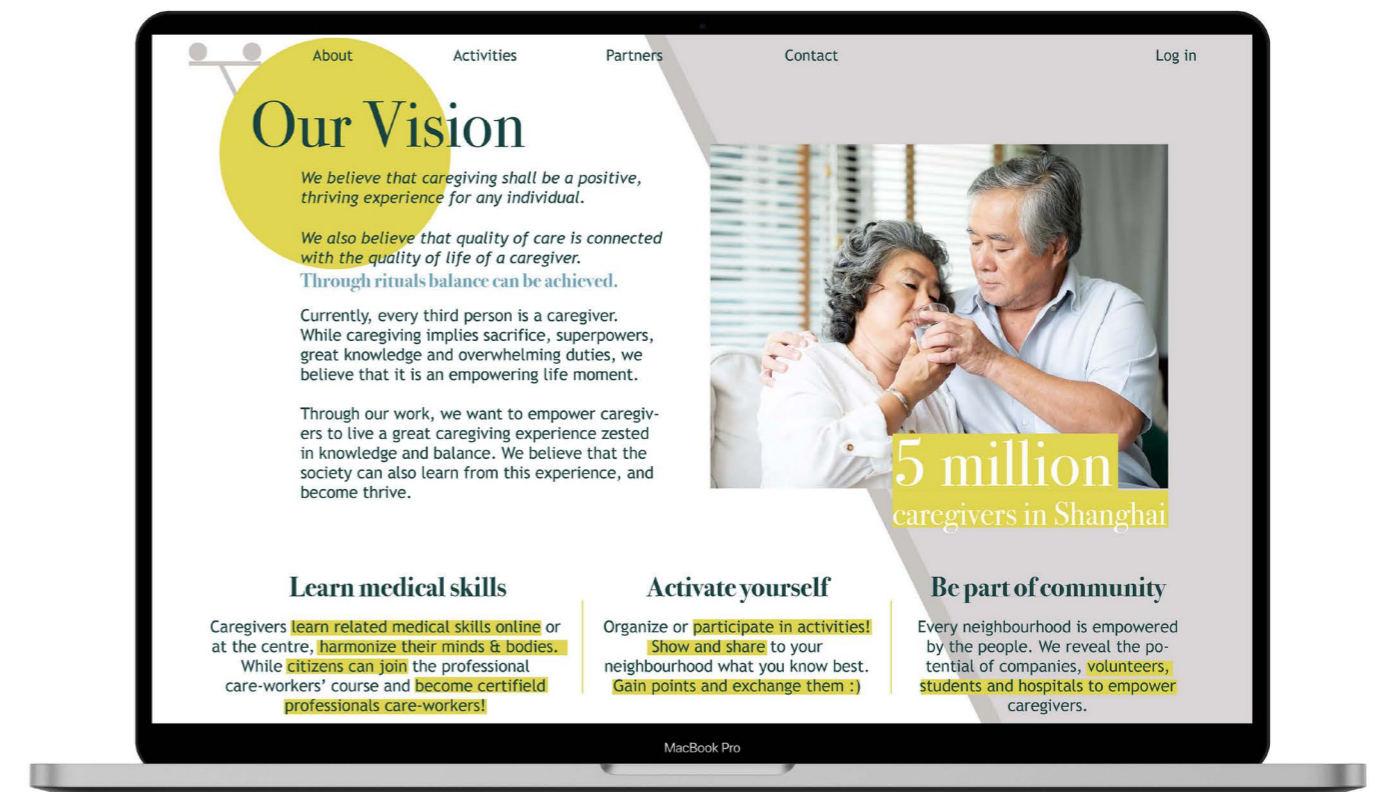


Figure 83. Rendering of the Rituals' website, landing page presenting the About section with vision, mission and service offering (Nadejda Cervinscaia, 2020).

Website - Partners' section

The partners' page includes a collaboration program for each of the partners, visualized in figure 84, based on the section 'Volunteer' or Student. The partner can click on the related space (1). The viewers can access the information and get to know the required commitment, the benefits, and partners' testimonials. For example, the students' page is visualized in figure 85.

Informationally, the pages is divided into:

- *your profile, where partners can find out about the set requirements for a collaboration;*
- *your contribution, where partners can see what they can contribute with;*
- *your result, where partners can find out their potential benefits from a potential collaboration.*

Below, the viewer can discover a student's testimonial about conducting the internship at Rituals (2).

Navigation: About, Activities, **Partners**, Contact, My profile

仪式

From 1-time input to Rituals. to Balance.

Not sure how could you contribute?

(1)

Volunteer or Student | Hospital | Neighbourhood Committee | Company

Your profile	Your contribution	Your result
You're a Master student of a Medical School in Shanghai or you're a local volunteer, with a great skill who can curate a learning/recreational activity.	Organize an activity for the local community. Don't worry, you will have a team, and the Rituals organizational support.	Have the chance to practice your leadership and skillfulness, get connected to the local community and build relationships.

Stories

(2)

“The internship cleared up my focus in nursing. After graduation I want to work in a social organization!”

Lisa Ping conducted her 6 months internship at Rituals. Along with other 3 students of nursing she was responsible for curating the basic medical course for family caregivers. Under the supervision of the senior medical worker she first formed a program for family caregivers of lung cancer and heart disease. Afterwards, she was conducting the 1 week course. Overall she taught 87 family caregivers, who were delighted by her kindness and energy.

more >>

6 months intern | 87 caregivers | 2 medical programs

Figure 84. Rendering of the Rituals' website, partners' section (Nadejda Cervinscaia, 2020).

Website - Activities section

The activities section, includes information about the medical knowledge courses, online and offline activities at Rituals. It is visualized in figure 85.

The user can search activities, events or courses by location or by category of event and discover details about the activities. The user can find out the points that every activity implies for volunteers and caregivers.

If the person is interested in the course to become a care-worker, the page will present the information about the course as shown in figure 86, and likewise, the partners' page shown previously in figure 84, it will have a testimonial section.

Lastly, the web design of the site has to follow the idea of the balance, therefore, the central graphical element is the circle on the weight, which is either balanced or not.



Figure 85. Rendering of the Rituals' website, activities' section (Nadejda Cervinscaia, 2020).



Figure 86. Rendering of the Rituals' website, activities' section regarding the care-workers' course (Nadejda Cervinscaia, 2020).

Space

The Rituals space is a crucial touchpoint. The organization will be located in governmentally owned buildings with unused spaces, which, according to the recent Shanghai Government policy, will be refurbished for the social good, and there will be organized respite care centres (Sun et al., 2020). Besides, the Shanghai Government highlights the importance of making respite care accessible for caregivers, and stimulates initiatives to meet the inhabitants of every district of Shanghai.

The following spaces are projected to be needed at Rituals:

- *the open space with reading, communication, private and playing areas.* This space will be situated in the organization's very entrance, and the glass facade will give an overview of the happenings there: people socializing, playing traditional Chinese Mahjong game, reading, or resting.
- *the reception area is the first information point.* The personnel would assist visitors and respond to their questions.
- *the classrooms.* These are the spaces where caregivers and citizens will follow the medical knowledge courses. As the courses will be divided by disease type, these classrooms will have a turnover of different caregivers. The care-workers will follow their separate, certified program to become care-workers.
- *the psychological assistance room.* It is the space where the social worker or the psychologist would provide private counselling sessions to caregivers.
- *office room.* It is the space for the Rituals' admin staff.

- *all-purpose room.* It is the space where students, volunteers and the staff could organize activities for caregivers.

Notably, the spatial design will respect the branding philosophy of the Rituals. Specifically, the spaces will incorporate the idea of the circle, which is also vastly used in traditional Chinese architecture.

Vending machine

The goods' vending machine for points exchange represents another important touchpoint. Besides the fact that these machines are currently scattered in Shanghai (figure 87), the centre will also include one.



Figure 87. Vending machine for volunteers in Shanghai (Source: https://3g.163.com/news/article_so/FD243R9Q0514A0P8.html)

Volunteer points

The goods' vending machine for points exchange represents another important touchpoint. They were visualized above in the app. Lastly, volunteers' activities and caregivers' attendance of activities and medical knowledge courses will be rewarded

with points. The points will be collected in the Rituals app, in the personal profile of the caregiver. The volunteers' points will be collected on the special digital card, currently existing on a dedicating platform in China, visualized in figure 88.

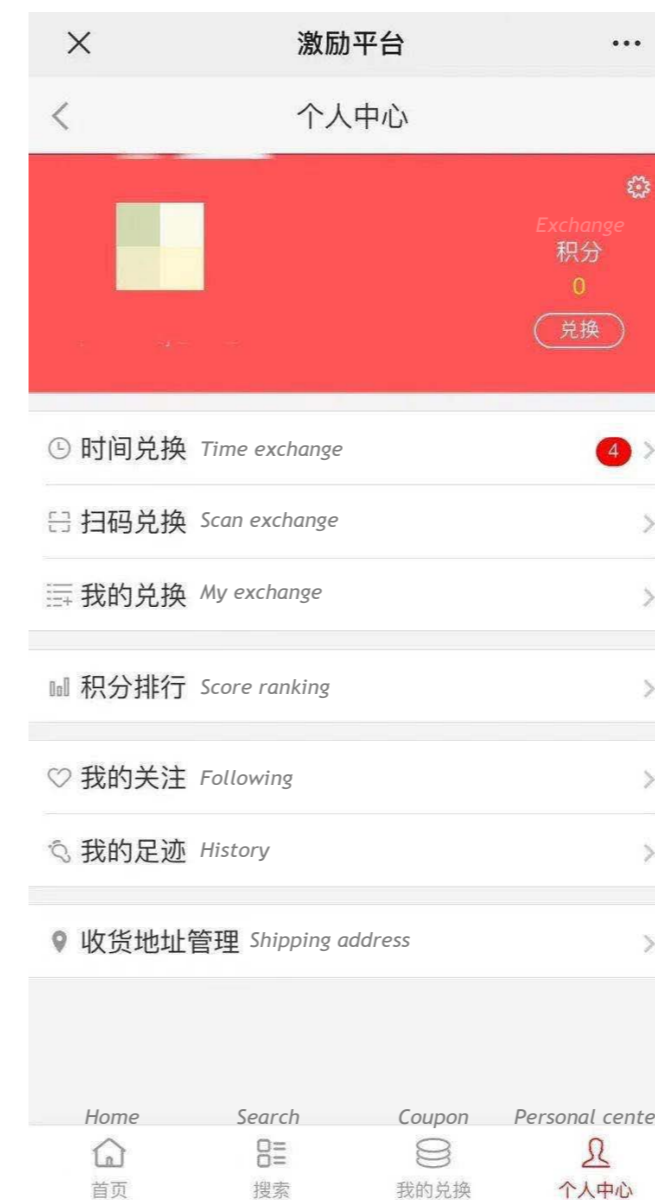


Figure 88. Chinese platform for volunteers to collect social points and exchange them in vending machines (Source: https://3g.163.com/news/article_so/FD243R9Q0514A0P8.html)

Leaflets

Notably, the range of designed leaflets (figures 89, 90) will be diffused through several channels. First, the hospitals' medical personnel will share the leaflets with the Rituals service (figure 89). In the hospitals and community hospitals, there will also be displayed posters with service details. Besides, the information will be shared by the neighborhood committee in the neighbourhood. The posters will be attached in compounds and blocks of flats. Importantly, as the neighborhood committee knows all the information about the vulnerable families, chronic patients, the neighbourhood committee personnel could suggest the service directly to families.



Figure 89. Medical staff promoting the service to caregivers (Nadejda Cervinscaia, 2020)

Figure 90. Promotion leaflet for caregivers and the community (Nadejda Cervinscaia, 2020)

8.5 Conclusion

The service system “Rituals. Balanced Care Centre” was designed to tackle the problem of caregivers to:

1. Receive disease-related knowledge and eliminate ambiguities of how to provide care;
2. Have occasions to meet people and enhance the social circle and emotional wellbeing of caregivers, who feel left alone or do not have opportunities to meet people
3. Perceive emotional support accessible;
4. Perceive community as a resource and build trust to it by creating occasions for people to meet, interact and support each other;
5. Have an opportunity for a break by having access to care-workers' and volunteers' support in caregiving duties.

The service also benefits volunteers who want to activate for social good and citizens who can become certified care-workers and activate as professionals. To develop and visualize the service mechanism there were used multiple design tools, such as service offering map, system map, stakeholder's map, stakeholders' interaction map, storyboards, touchpoint map, and business model canvas. Besides, some of the touchpoints were exemplified in concrete examples (website, app, leaflets).

Importantly, within the whole duration of the research and concept design, the author explored the Chinese culture. It helped to understand the mentality behind specific actions and desires of caregivers. For example, filial piety and indispensable sacrifice are related to it as a tribute to the family. Notably, the filial piety and sacrifice mechanisms, described as rites, or rituals in the Confucianist texts, are considered to prove humaneness and the harmony of things,

where Chinese people find rest “the humane person rests in humaneness” (Confucius & Watson, 2007). It points out the natural course of things for Chinese culture: caregivers who fully dedicate themselves to caregiving. To address this mindset, it is crucial to set Chinese cultural notions and specifically Confucianism as fundamental for the service system design. Consequently, to give credit to the Chinese cultural values and to propose a harmonious solution to this context, the author implied the Rituals and Harmony, or Balance as a leitmotif of the support centre. The balance is to be reached by serving for the good of the patient and, simultaneously, for the good of the individual.

Additionally, when designing organizations in China, the government plays a central, facilitating role. It is important for designers to consider the top-down environment and align the service with the policy plans.

Lastly, the current service concept does not tackle caregivers' financial burden, which was also discovered as significant. Therefore, it is recommended for further research to take the financial aspect of caregiving as an intervention opportunity.

FINAL considerations

The research focused on creating a service system support to enhance the quality of life, and therefore, quality of care of family caregivers to Shanghainese patients. The project was divided into four phases: 1) preliminary field research, 2) desk and field research, 3) ideation of the service solution using participatory design tools, and 4) development of the proposed solution.

The research encountered few obstacles. To officially access the medical sphere in Shanghai, and, presumably, entire China, the author needed to obtain official permissions to access the hospitals for research. Obtaining permissions is not stipulated but can be facilitated by reference letters from University, preferably a Chinese one. The documents take time to undergo screening by healthcare administrative personnel, but there is no guarantee of collaboration acceptance. In this setup, one reason for the author to encounter refusals for research in hospitals was the COVID-19 pandemic, which transformed all the Chinese organizations into very sensible entities, especially healthcare facilities. Another reason is the disinterest and, possibly, distrust or concern to a foreigner's research with no personal reference. To tackle this, the author spread

the news about the research online, as the online space in China is very visualized by people. Also, personal referencing played a crucial role in the success of this research. For a successful collaboration in China, it is recommended to establish and develop personal relationships powered by referencing.

Notably, within the preliminary field research in December 2019, when there was no outbreak yet, the encountered caregivers were very keen to share their research experiences. They also agreed to befriend in WeChat and stay in touch for further eventual inquiries. Later, preserving relationships proved to be very important, as the author repeatedly addressed other questions and invited for participatory sessions within the subsequent research phases.

Within the duration of the project, the author was tightly collaborating with Shanghainese medical experts, as they represent the prominent reference people for family caregivers and family caregivers themselves. Despite the COVID-19 pandemic outbreak at the end of the first phase of the project, the collaboration was very successful. The interviewees, participants of co-design and

concept sessions, were extremely excited to tackle the critical problem of family caregivers in Shanghai and use a design framework as a facilitator to outer their voices.

The language barrier played a significant role in communication; therefore, collaborating with Chinese native speakers was essential. Besides, within the translations, the author needed to comprehend concepts specifically for Chinese culture. Hence, when conducting design projects for such a radically new culture, it is essential for researchers to dive into understanding people's cultural background. The author leaned on Confucius's cultural pillars and could better understand people and their actions and expectations from the support system to be designed.

Within the ideation and development processes, the design tools played the central role. A co-design workshop was conducted, followed by a concept validation session. The designed tools facilitated the participants to express their perspectives and think creatively. Notably, the fact that along the whole project, experts were representing different structures of healthcare, holding different positions, and overall could represent the realities of different healthcare areas: administration, inpatient, outpatients departments, first and third-class hospitals, as well as a non-governmental organization and medical research company.

The proposed design intervention encompasses an organization that provides medical knowledge to caregivers, holds activities, and builds the community. The "Rituals. Balanced Care Centre" aims to be a resource of knowledge for caregivers and a resource for emotional support, rest, leisure, and communication for caregivers individually. The concept pivots on the idea

of balancing the two roles: caregiver and individual. Rituals. Balanced Care Centre foresees punctual interventions in the numerous Shanghainese districts, as the idea of the created organization has the local community as the backbone of the service system. As discovered during the design process, the local community manifests a strong volunteering will and can be used as a resource. Prominently, the concept highlights volunteers to assist caregivers in daily duties. However, as discovered, Chinese culture limits Chinese people from opening up their privacy and matters regarding their family member's health status.

Nonetheless, this proposal has significant potential in the case of the local volunteers and caregivers will build trust to each other. Therefore, in the short-term, their interaction will consist of activities curated by volunteers. Besides, as the significant capable Rituals' and teaching medical knowledge, this offering will also be proposed in a separate course for local inhabitants to become certified care-workers. This will enhance people's knowledge of providing care and multiply the number of professional care-workers, which is currently drastically low and unqualified. Besides, the care-workers will be an important way for the caregivers to take a respite and participate in the center's activities. Finally, inviting local people to a shared space, meeting, building trust, and establishing relationships will strengthen their unity and resilience as a community and individual caregivers. The proposed concept is one of the necessary interventions in improving Chinese healthcare and does not respond to other identified and presented issues, such as financial support.

Lastly, China is a fast-changing and a very

dynamic environment, where the Government invests massively in development, and speaking, particularly about healthcare, in enhancing respite care centers. Besides, the Government plays the central and most authoritative role in decision-making; therefore, collaboration with the Government and alignment to the planned development and policies are crucial. Thus, such a context can play a restrictive role in solutions' development or implementation; however, it can be vitally supportive and accelerating.

Research limitations

One of the major limitations within this project has been the language. As the author does not speak Chinese, there was a need for Chinese native speakers to take part within some of the activities of this project. Their participation was crucial, and has been facilitating the project, but could also serve as a bias within the interpretation of the results. For future projects in China, it is recommended to hold workshops fully in Chinese language, or ensure participants' great English command. This will facilitate a smooth communication and excellent understanding of the participants.

Another limitation connected to the language has been the usage of tools translated into Chinese. Compared to using design tools in English only, translating the tools into Chinese helped the participants to better understand the exercise, however, there is no guarantee of an accurate understanding of the translation and comprehension of the materials.

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ANNEX 1

Table 1. Healthcare reform levers in China, their challenges and implementation strategies (World Bank Group et al., 2016)

N. Reform lever	Challenges	Implementation strategies
<p>1. Full adoption of a reformed service delivery model, referred to as people-centered integrated care (PCIC), in order to accelerate progress toward China’s vision of health service delivery reform and improve value for money.</p>	<ol style="list-style-type: none"> 1. Poor experience in gatekeeping to refer to primary healthcare services 2. Downward referral systems function irregularly 3. Hospitals have few incentives to shift care to lower levels or to integrate care with lower levels . 4. Health care workforce lacks the knowledge, skills and culture to work collaboratively 5. Higher income opportunities at upper levels encourage migration of health workers to large hospitals and create shortages on lower tier healthcare facilities 6. Insufficient integrated care practices to serve as a basis for further development. 7. There are only minimal differences among copayments charged at hospital outpatient departments and primary care facilities to deter “hospital first” care seeking behaviors. 8. In the existing integrated projects “hospital alliances”, there is a domination of power, where larger hospitals become channels to capture patients at higher levels of care . 9. Lack of interoperability despite few eHealth innovations. 10. Lack of a unified and standardized local and national systems to measure and improve the quality of primary health care service delivery, chronic disease management and patient satisfaction. 	<ol style="list-style-type: none"> 1: Primary health care is the first point of contact 2: Multidisciplinary teams 3: Vertical Integration, including new roles for hospitals 4: Horizontal Integration 5: Development of eHealth and interoperability 6: Integrated clinical pathways and dual referral systems 7: Measurement and feedback 8: Unified certification criteria for healthcare facilities
<p>2. Continuous quality improvement is a foundational element of PCIC and creating a high value system, and is essential for gaining citizen trust</p>	<ol style="list-style-type: none"> 1. Insufficient institutional support for sustained quality improvement; 2. Poor information on quality of care for a improvement strategy, namely evidence on secondary hospitals and primary facilities is little. 3. Quality management practices at the facility level targeted to reward the volume of healthcare service rather than quality 	<ol style="list-style-type: none"> 1. Promote an organizational structure to lead to the creation of an information base and development of strategies for quality improvement 2. Systematically measure data on quality of care and use it continuously to support quality improvement 3. Develop and promote use of tools to improve quality of care in health facilities
<p>3. Recognizing the key role of patient trust for the success of the PCIC model, the report recommends that patients are empowered with knowledge and understanding of the health system and be actively engaged in the process of seeking care.</p>	<ol style="list-style-type: none"> 1. A comprehensive, system-wide approach to engage citizens in health, with well-defined roles for patients and providers, is still missing. 	<ol style="list-style-type: none"> 1. Building Health literacy; 2. Creating a supportive environment for citizen engagement 3. Shared decision-making
<p>4. The reformed service delivery model requires new roles for hospitals .</p>	<ol style="list-style-type: none"> 1. Most public hospitals are unaccountable to public authorities and act in their own interests, because usually governmental investments account cca. 10% only. 2. Influencing managers’ behaviors may be difficult because they appear more accountable to higher-level leaders who appointed them than to the government agencies responsible for reform implementation or on-the-ground performance. 	<ol style="list-style-type: none"> 1: Develop sound organizational arrangements for public hospital governance; 2: Gradually increase the delegation of decision rights to hospitals; 3: Establish strong accountability mechanisms for autonomous public hospitals to strengthen performance ; 4: Align Incentives with public objectives and accountabilities; 5: Strengthen and professionalize managerial capacity.

Table 1. Continuation. Healthcare reform levers in China, their challenges and implementation strategies (World Bank Group et al., 2016)

N. Reform lever	Challenges	Implementation strategies
5. Service delivery reform will entail realigning incentives and strengthening purchasing.	<ol style="list-style-type: none"> 1. Perverse supply-side incentives: Hospitals tend to provide more services, even if they are not mandatory for the treatment, because services are their biggest share of financing and therefore, Hospitals are volume driven, rather than quality driven 2. Perverse incentives among public hospitals for capital-intensive investment: high contrast between hospitals and primary healthcare facilities to invest in technology to attract patients and gain more profit from procedures. 3. Perverse demand-side incentives: patients prefer Hospitals' services because of the perceived higher quality of technics and medical staff. 	<ol style="list-style-type: none"> 1: Switch from fee-for-service as a dominant method of paying providers to capitation, case-mix, and global budgets 2: Correct and realign incentives within a single, uniform and network-wide design in support of population health, quality and cost containment; 3: Correct and realign incentives to reverse the current irrational distribution of service by level of facilities; 4: Consolidate and strengthen the capacity of insurance agencies so as to equip them to become strategic purchasers
6. Strengthening Health Workforce for PCIC - Medical human resources will need to reflect the new shape of service delivery	<ol style="list-style-type: none"> 1. Imbalances in workforce composition primary and tertiary healthcare facilities 2. Unattractive compensation levels and perverse financial incentives: healthcare staff is differently payed in rural&urban areas, and across facility levels, also as prescriptions imply bonuses, medics are incentivised to do so, even if unnecessary. 3. Restrictive headcount quota system, creating rigidities in recruitment and little autonomy in building own team 4. Limited mobility across healthcare facilities, especially of medical practitioners 5. Lack of managerial and decision-making autonomy in hiring health workers on Hospital level, as this is controlled by the government. 	<ol style="list-style-type: none"> 1: Build a strong enabling environment for the development of primary health care workforce to implement the PCIC mode; 2: Reform the compensation system to provide strong incentives for good performance; 3: Reform the headcount quota system so as to enable a vibrant labor market and efficient health workforce management.
7. Private sector engagement should be aligned with the new shape of the delivery system.	<ol style="list-style-type: none"> 1. Across government agencies there is no unified and unclear role of private providers to contribute to national objectives: if they shall be complementary, supplementary or integral to the public delivery system. 2. Decentralized nature of regulation: licensing a private facility varies significantly, and in many localities remains cumbersome, unpredictable and costly, and criteria governing eligibility for social health insurance are vague. 3. Overcome people's stigma for bad reputation due to practices of over-treatment, fake advertisement etc. 4. Limited capacity to engage public sector in policy-co-design, since this practice has never been exercised. 5. Difficult market entry due to public sector hegemony, especially if foreign investors are involved. 6. Inconsistent tax policies 7. Uneven implementation of reforms allowing doctors to practice in multiple facilities 8. Uneven implementation of latest reforms lifting restrictions on reimbursements of social health insurance to private hospitals 	<ol style="list-style-type: none"> 1. Develop a clear and shared vision on the private sector's potential contribution to health system goals 2. Strengthen key regulations and enforcement capacity to steer the production and delivery of health services toward social goals 3. Establish a level playing field across public and private providers so as to promote active private sector engagement

Table 1. Continuation. Healthcare reform levers in China, their challenges and implementation strategies (World Bank Group et al., 2016)

N. Reform lever	Challenges	Implementation strategies
<p>8. Modernization in ways that capital investment decisions are made in the health sector in China, and moving away from the traditional input-based planning towards capital investments based upon region-specific epidemiological and demographic profiles.</p>	<ol style="list-style-type: none"> 1. Lack of investment planning, which contributes to super scaling of investments particularly at the hospital level; 2. Limited knowledge of capital investment planning techniques, the current ones don't reflect population health needs 3. Absence of clear procedures to assess value- for-money of investments for potential profitability and sustainability assessment 4. Mismatch in procedures for administrative reporting and planning clearances 	<ol style="list-style-type: none"> 1. Move away from the traditional input-based planning towards capital investments based upon region-specific epidemiological and demographic profiles 2. Engage with all relevant stakeholders and local communities in the planning process 3. Empower and enable regions and provinces to develop their own capital investment plans 4. Introduce a Certificate of Need program to evaluate and approve new capital investments in the health sector 5. Prioritize community health projects

ANNEX 2

Table 2. Summary of primary and secondary topics from the conducted interviews (Nadejda Cervinscaia, 2020)

N.	Insight	Primary Topics
1.	Denial Doubt Distrust Lack of stability Uncertainty	There is a denial period for caregivers filled with distrust and doubt to doctors and their processes especially if the disease is sudden or is persisting, it takes time to comprehend and accept the situation. Uncertainty, unpredictability and the risk of Death grows fear in the patient and caregivers. Lack of stability, chaos of the situation and also practical life, tires caregivers very much, they regain calmness through being close to the 'roots'.
2.	Emotional block // crisis moments	The pressure which caregivers' experience can cause conflicts, the stress which caregivers experience, aggravates comprehension and perception of information. The most stressful periods is the surgery and the diagnosis of the disease
3.	Tradeoff = sacrifice	Caregiving is a tradeoff between different habitudes work/ practical help/ emotional help/ habits, it implies sacrifice which impacts a lot the success of life areas.
4.	Tradeoff = sacrifice Being informed helps to relieve and make decisions	Caregivers' help is fundamental in the treatment process, but the amount of responsibilities is overwhelming, so receiving practical assistance, is making the difference. Caregivers appreciate practical advices while sharing their worries and chatting with peers inside or outside the hospital. Guidance in the hospital and throughout the treatment process (on practical, informational levels) eliminates ambiguities and gives a feeling of security. Getting informed by communication with doctors, peers, reading multimedia materials helps caregivers to feel aware and empowered. Doctors feel they spend too much time on communication and wish that someone would assist caregivers. When caregivers are sharing online their progresses, there might be a mood fluctuation caused by other people and it can be tricky to regain hope and balance. Caregivers feel it meaningful to share with peer, learn from role models, and aspire to be role models when going through this experience.

N.	Insight	Primary Topics
5.	Financial support	Caregivers need financial support throughout treatment to get practical or emotional assistance, but might need a help to find it out.
6.	Health system not placing enough emphasis on psychological help	The current healthcare system is highly patient centered, the importance of psychological help is often overlooked in favour of patients' needs, and the practical help which caregivers can get, is often fragmented and pricy. Caregivers don't know about some help and how to access them, they would eventually appreciate the help of an organization, even for a fee.
7.	Potential of partnerships	The Hospitals collaborate with different organizations/institutions but the partnerships could be flourished more if there was a support and tools.
8.	Crisis = opportunity to rethink	The health crisis is a good opportunity to rediscover yourself and rethink family relationships, your life and priorities.
9.	Hiding the truth or enduring by yourself as a Chinese culture implication	Hiding the real situation is common for Chinese culture, either caregivers don't fully tell the situation to relatives, or patients hide their pains or doctors and family hide from the patient.

Table 2. Summary of primary and secondary topics from the conducted interviews (Nadejda Cervinscaia, 2020)

N.	Topic	Insight	Interviewee	Quote	N.	Topic	Insight	Interviewee	Quote
1.	Caregivers go through a vast range of negative emotions, and react with fear, doubt, insecurity, distrust, denial.	There is a denial period for caregivers filled with distrust and doubt to doctors and their processes especially if the disease is sudden, it takes time to comprehend and accept the situation.	Doctor 4	<i>Distrust is mainly seen in the family members of patients who have stayed long in the ICU.</i>	2.	Caregivers need external help to go through the caregiving experience, both on practical and emotional levels.	All the caregivers seek for moral support from their relatives, ideally the family has to be there.	5/7 caregivers	<i>I have none in Shanghai to talk to relieve my pressure.</i>
			3/7 caregivers speaking about doubt, fear the patient to be overseen or not have an tailored medical help	<i>Doctors usually have typical prescriptions</i>			Doctor 4	<i>Non-locals may have a call with the family gives to gain confidence and strengthens psychological care.</i>	
		Uncertainty, unpredictability and the risk of Death grows fear in the patient and caregivers.	4/7 caregivers	<i>So now my biggest fear is to have unexpected, sudden health issues.</i>			2 medical workers	<i>Counseling is very convenient in situations for newly diagnosed patients</i>	
		Surgery and the beginning of the disease is a critical point making the caregivers to be very nervous. Then they get used to the idea.	Doctor 3	<i>Caregivers were very nervous and anxious before the operation, but after it, they'll be relieved.</i>			1 caregiver who benefited of psychological class	<i>It is important for caregivers to receive spiritual counseling</i>	
2.	Caregivers need external help to go through the caregiving experience, both on practical and emotional levels.	Caregiving is a tradeoff between different habitudes work/ practical help/ emotional help/ habits, it implies sacrifice which impacts a lot the success of the parts of life.	6/7 caregivers	<i>Caregiving hugely impacts the caregivers' and patients' career.</i>	3.	Guidance in the hospital and throughout the treatment process (on practical, informational levels) eliminates ambiguities and gives a feeling of security. It is important especially when the situation or environment are new to caregivers.	Because of the messy/stressful environment, caregivers appreciate guidance in the hospital from a dedicated person to help with navigation, instruction for what to do and where to go.	2/7 caregivers	<i>With comparison, Yin feels service of hospital in Nanjing is better that he was told everything timely and volunteers would help.</i>
		Caregivers are under huge pressure and their' mental and physical wellbeing is influenced by the patients' conditions and might affect them longterm.	all medical staff	<i>I shouldn't tire myself too much. I thought i had good health, but then was diagnosed with this diabetes.</i>			the secondary caregiver supporting the primary caregiver	<i>Sometimes mom complains to me and then I tell her that I am with her, we are together.</i>	
		Caregivers are nervous and come to the hospital early to be closer to the situation.	Nurse	<i>When caregivers are very anxious, they could break the rules and rush into the ward without protection cloth.</i>			Nurse 1	<i>We tell C. to buy items in our hospital/ bring from home/ or recommend pharmacies</i>	
		Caregivers appreciate practical advices while sharing their worries and chatting with peers inside or outside the hospital.	3/7 experienced caregivers	<i>"She could support me by sharing her personal stories about her dad, who actually later died."</i> <i>"My friend gave a a tip: to make an excel file with all the medical tests."</i>			the secondary caregiver supporting the primary caregiver	<i>I hops for a convenient life during hospization, she hopes she can buy goods easily</i>	
	Good news about patients' conditions or a chat with the medical staff gives caregivers confidence and relief.	3 medical workers	<i>For caregivers to relax we confirm that the patient is good after the operation.</i>						

Table 2. Continuation. Summary of primary and secondary topics from the conducted interviews (Nadejda Cervinscaia, 2020)

N.	Topic	Insight	Interviewee	Quote	N.	Topic	Insight	Interviewee	Quote
3.	Guidance in the hospital and throughout the treatment process (on practical, informational levels) eliminates ambiguities and gives a feeling of security. It is important especially when the situation or environment are new to caregivers.	The city (accommodation/transport/food) is unfamiliar for non-local caregivers, older people. The ones who are young or travel can orient relatively well, but mostly guidance is needed.	2 doctors	<p>“An old caregiver may not be familiar with the surroundings of the hospital, and will have a problem with finding food, a cheaper hotel.”</p> <p>“Young caregivers may still be able to adapt to Shanghai, using mobile phone”</p>	4.	Hiding the truth or enduring by yourself as a Chinese culture implication	Hiding the real situation is common for Chinese culture, either caregivers don't fully tell the situation to relatives, or patients hide their pains or doctors and family hide from the patient.	2 caregivers; 1 patient	<p>“She thought it was a minor problem, she did not tell me that she wanted to see the doctor”</p> <p>“We decided to be transparent with the father, because he could participate in decision making according to how he feels his body.”</p>
			2 non local caregivers	Non local caregiver feel unfamiliar about Shanghai when come to find the treatment	5.	Getting informed by communication with doctors, peers, reading multimedia materials helps caregivers to feel aware and empowered.	In their communication with medical staff, caregivers respect the hierarchy and timing to talk about the medical workers specialization (treatment/ nursing)	4 medical workers	Family members will go to ask help from nurses first, then ask doctors for treatment information.
		The hospital can provide practical or info support about food and hygiene products	2 doctors	We can order meals for family members, and it is very cheap.			Getting informed by communication with doctors, peers, reading multimedia materials helps caregivers to feel aware and empowered.	1 caregiver	I interact with nurses but with no high expectations
			2 caregivers who have never been to the Ninth people hospital before	Careworkers are extremely irresponsible			Doctors talk briefly and truthfully about the critical condition to caregivers because don't want them to get too emotional.	3 medical workers	I just talk with the patient and also with very short words, they get too emotional.
		Caregivers needs a good rest and can overnight in the general ward, but not in the ICU. So the non-locals have to rent a room, but sometimes they sleep in the hall to save money or to respond to the doctors immediately in case the patient needs assistance.	3 medical workers	Sitting purposeless outside ICU is bad for a caregiver			Low & high tech informational support helps caregivers to understand informations	1 caregiver	Fu's mood is affected by what doctor says about his wife.
		Caregiving can be novel for some people and the activities unclear because there is none to train/inform.	1 doctor	They shall have basic medical knowledge and take charge of those patients, their daily life, to take pills, to exercise.				1 doctor	We can provide videos and manuals to help families understand diseases and operations in a variety of ways.
			1 caregiver (emergency department)	I have no caregiving experience.			The caregivers' role is to communicate with the doctor about patients' conditions, caregivers with better education do it more efficiently.	2 doctors	Caregivers' role is to communicate
		Some of the rules and legal procedures are not clear in the very beginning, because caregivers don't know what to do next.	1 nurse	Caregivers sometimes want to enter the ICU earlier, after nurses' explanation, they will understand.				3 caregivers	if the family is not accompanying, the patient's condition will not be clear
			2 caregivers (novel to Shanghai)	I felt unclear when they sat in the ward without knowing what to do next.			Caregivers use a lot the media channels to get information about doctors' reputation, the treatment suggestions, chat with peers, it makes them feel relieved and updated.	3 caregivers	We were checking treatment possibilities online and then asking doctors' opinions on some other treatment ideas

Table 2. Continuation. Summary of primary and secondary topics from the conducted interviews (Nadejda Cervinscaia, 2020)

N.	Topic	Insight	Interviewee	Quote	N.	Topic	Insight	Interviewee	Quote
6.	Doctors feel they spend too much time on communication and wish someone to assist caregivers.	Because doctors prefer to focus on treatment and research activities, don't have much time to communicate online/offline with families. They wish there were some volunteers	3 doctors	<i>All the discussions are done by doctors now, so we have no time left for more important things.</i>	8.	Caregivers' help is fundamental in the treatment process, but the amount of responsibilities is overwhelming, so receiving practical assistance, is making the difference.	Caregivers' role is complex: nurse, 'mother', psychologist, some are good at it and some are not. Caregivers' role is to provide mental support, they influence patients mood and can enlighten patients' moods with good news. The hospital can provide practical or info support about food and hygiene products	1 doctor 2/6 medical workers 4/6 medical workers	<i>Ideally, an angel caregiver should be half doctor, half nurse, half mother. Patients know they are very ill and lying here every day, so the family needs to give the patient confidence. The caregivers' responsibility is generally responsible for helping the patient decide how to be treated, helping the patient to sign and make a decision.</i>
7.	When caregivers are sharing online their progresses, there might be a mood fluctuation caused by other people and it can be tricky to regain hope and balance.	Caregivers and patients find independent disease groups, the atmosphere is mainly positive, but there is also plenty of depressed attitude and distrust. Doctors stimulate their group of patients to use wechat and discuss conditions there, but are busy to always reply.	1 doctor 1 doctor 2 doctors	<i>Sometimes patient A would write: "oh i feel so good" and patient B would say "oh, I feel bad" or "I feel no changes". Members of online comm. share a lot and it is hard to ignore them, there are people who are like "models" Doctors will share information/ advices and discuss common health issues in the group.</i>			Caregivers provide economical help, many of them don't even mention it.	5/7 caregivers 1 caregiver	<i>We chose the surgery because we believe that it directly fights the root of the problem. Lastly, I provide economic support for my caregiving mom and sick dad.</i>
8.	Caregivers' help is fundamental in the treatment process, but the amount of responsibilities is overwhelming, so receiving practical assistance, is making the difference.	Because the efficiency of treatment implies materials, caregivers are in charge to provide the medical workers with supplies. Caregivers tend to provide routine care, which might be very challenging and tiring because of enhanced physical effort and unexperience. Caregivers need help with practical daily tasks because the amount of work is overwhelming and gives the feeling that all the responsibilities are on their shoulders. Caregivers' help is fundamental in the rehabilitation process, so they communicate with doctors and get an unformal training by medical staff.	1 caregiver 2 medical workers 2 medical workers 6 caregivers 4 caregivers (3 elderly caregivers + emergency) 5/6 medical workers 2 caregivers	<i>Who would buy the goods? We need to tell the family where to buy daily products Some of careworker responsibility is to change urine pad/ shave I go to the market, I clean, I am doing all the physical work My mom has a cleaning lady coming once per week. She helps with the household, but she is anyway tired. I suppose with great caregivers, the patients would recover better and we would be happier She will rehabilitate in Jianxi because someone will take care of her</i>			Caregivers recognise the need for external help in caregiving, however, some of them cannot afford and would decide to spend on it depending on the cost. Caregiving can be novel for some people and the activities unclear because there is none to train/inform. When patients can take care of themselves, caregivers are relieved significantly and the quality of life of everyone enhances.	6/7 caregivers (the 7th person was not asked) 1 doctor 3 caregivers	<i>My decision to ask for help depends if help from support org. is free or not. They shall have basic medical knowledge and take charge of those patients, their daily life, to take pills, to exercise. "I am not a typical caregiver, I am a lucky caregiver since I don't have physical commitment."</i>
					9.	The importance of psychological help is underestimated	Caregivers scale down the role of the caregiver, that it is mainly about physical help. So, the ones who don't really provide it, don't fully perceive themselves as caregivers.	3 caregivers	<i>"I am not a typical caregiver, I am a lucky caregiver since I don't have physical commitment."</i>

Table 2. Continuation. Summary of primary and secondary topics from the conducted interviews (Nadejda Cervinscaia, 2020)

N.	Topic	Insight	Interviewee	Quote	N.	Topic	Insight	Interviewee	Quote
10.	Caregivers need financial support throughout treatment to get practical or emotional support, but might need a help to find it out.	Because of poor economic reasons, caregivers need/want to cut practical costs: materials/ medicine/ housing.	2 caregivers	<i>We cannot afford the cost of hiring a care worker, so, after work I will accompany my wife by myself.</i>	11. The pressure which caregivers' experience can cause conflicts, it is important that others understand this.	Mostly, Patients are pessimistic and worried, fewer are positive. The level of cooperation depends on their mood: when they lose their temper they would not cooperate with medical staff and their caregivers. But when they feel hopeful they follow advices.	3 medical workers	<i>Sometimes patients will be particularly irritated, pulling out the tubes front their bodies and not cooperating with us.</i>	
			3 doctors	<i>C. will tell us that the family is in a difficult financial situation, so they hope to save a little money on medicine.</i>			3 caregivers	<i>My sister patient is sometimes very pessimistic</i>	
		Often the cost of the treatment is blurry and families might not be prepared for it, only some non-local patients (who come dedicatedly to the hospital and have a longer experience in caregiving) expect the costs.	2 medical workers	<i>Caregivers from out of Shanghai are mostly prepared for money, they know they would spend money in Shanghai.</i>			1 social worker	<i>The main reasons for participation rejection are mainly because of the patients' needs.</i>	
			2 caregivers (1 non-local & 1 emergency caregiver)	<i>I don't know what will be the rehabilitation costs</i>			3 caregivers	<i>Other participants in counseling workshops might also be cancer patients.</i>	
			4 doctors	<i>Social workers' department can help to find some charities, but we have a long waiting list and need to have an economic situation assessment for each family.</i>			1 experienced caregiver	<i>I found out about counselling sessions and inquired my friend's opinion on this.</i>	
			Caregivers have ways to seek financial support (online/SW from the hospital), their initial financial potential plays a big role in getting help from SW.	3 caregivers			<i>We got financial governmental support: a discount for surgery, and some of the medicines are 100% free</i>	1 doctor	<i>We definitely hope that he can participate, but we need to respect the patient's own wishes, just like the informed consent,</i>
Some caregivers don't know about some help and how to access them, they would eventually appreciate the help of an organization, even for a fee; others may get advises from medical staff.	4 doctors	<i>Nurses will privately tell family members to use donation platform like "shuidichou".</i>		social worker 1	<i>We introduce the time and purpose of our workshop, e.g. hoping to provide a chance for caregivers to share care experience, and then provide care support.</i>				
	5 caregivers	<i>I know no channel to get the news to hire a care worker.</i>							
11.	The pressure which caregivers' experience can cause conflicts, it is important that others understand this.	The timing is very important for caregivers, being late can be fatal, therefore hurry imposes an extra level of stress	1 caregiver	<i>Traffic jam almost made us loose appointment.</i>	13. Lack of stability, chaos of the situation and also practical life, tires caregivers very much, they regain calmness through being close to nature.	Commuting is tiring for lack of stable place and the unknown, people who commute short, appreciate it.	4 caregivers	<i>Commuting to the hospital is troublesome.</i>	
			4 medical workers	<i>Caregivers and nurses have different focus on caregiving. Sometimes it makes conflicts.</i>			4 medical workers	<i>"Now she is going to a buddhist temple every year. But dad believes less in this."</i>	
			1 caregiver (emergency case)	<i>I had a bad experience with security, they gave me a wrong, long direction!</i>				<i>"I go to the park for a walk, I do Tai Chi."</i>	

Table 2. Continuation. Summary of primary and secondary topics from the conducted interviews (Nadejda Cervinscaia, 2020)

N.	Topic	Insight	Interviewee	Quote
14.	The current healthcare system is highly patient centered, the importance of psychological help is often overlooked in favour of patients' needs, and the practical help which caregivers can get, is often fragmented and pricy.	Despite the increasing importance of psychological care, social medical workers' unit is very weak and the workers aspire for more resources and visibility.	2 medical workers	"Other countries have a social worker per department..."
		The Hospitals collaborate with different organizations/institutions but the partnerships could be nourished more if there was a support and tools.	3 medical workers	"The critical issue is that system's improvement requires financial support from the government." "The list of resources, including financial ones is useful."
		Caregivers request a lot of physical care help, and don't put enough emphasis on psychological assistance.	1 experienced caregiver	
15.	The health crisis is a good opportunity to rediscover yourself and rethink family relationships, your life and priorities.	There are bounded services who train people to provide physical care to patients, because there is a high demand and need.	2 medical workers	All Shanghai hospitals have a bundled service in the ICU and an independent choice for the need of careworker in the general ward.
		The current healthcare system is patient centered, because the majority of actors are focused on curing the disease of patients.	2 medical workers	We generally focus on patients, so the assistance and help we provide are usually patient-centric,
		The disease and caregiving can be a nice opportunity to rediscover yourself and rethink the bond between the caregiver and the patient and better them, but not everyone can achieve it.	1 experienced caregiver	"Dad became more open, emotional and gentle, he is listening to the others more."
		The crisis, the disease and caregiving might reshape the personalities.	1 experienced caregiver 3 caregivers	This compound community organizations with professional caregivers who can provide physical assistance.

ANNEX 3 - ideated visions for the validation session

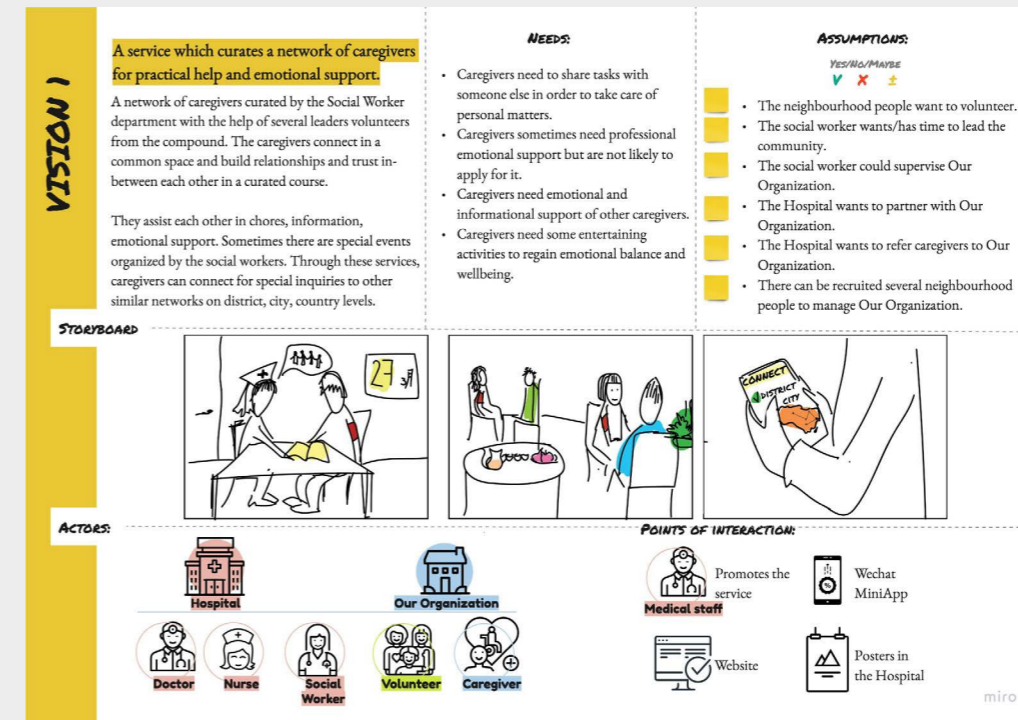


Figure 91. Vision 1 generated for the validation session with participants (Nadejda Cervinscaia, 2020)

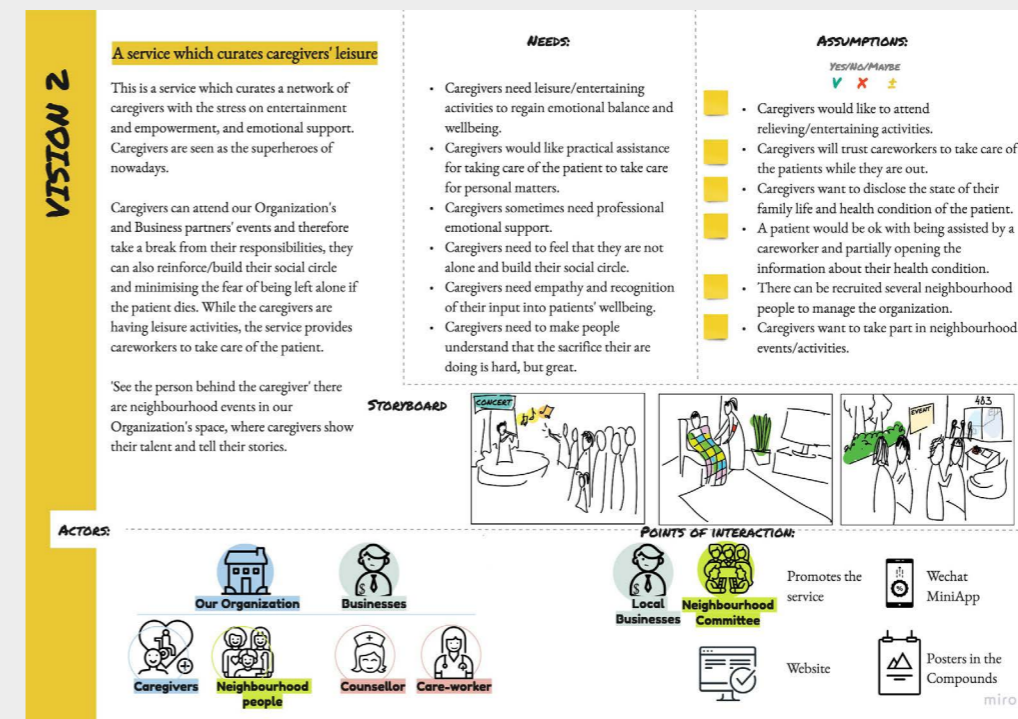


Figure 92. Vision 2 generated for the validation session with participants (Nadejda Cervinscaia, 2020)

ANNEX 3 - ideated visions for the validation session

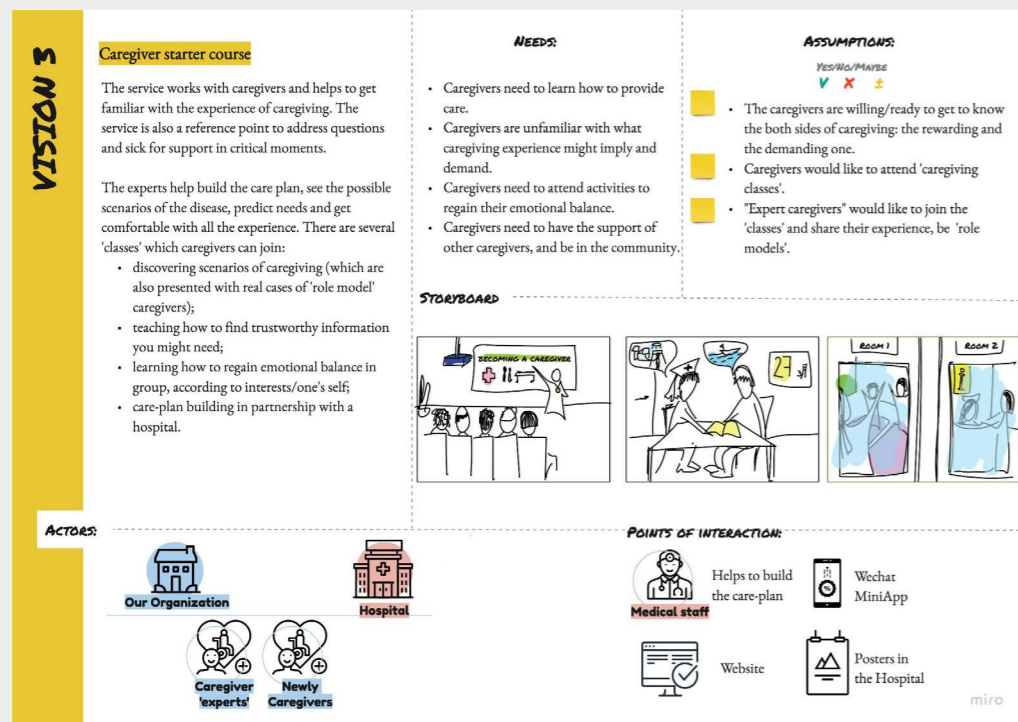


Figure 93. Vision 3 generated for the validation session with participants (Nadejda Cervinscaia, 2020)

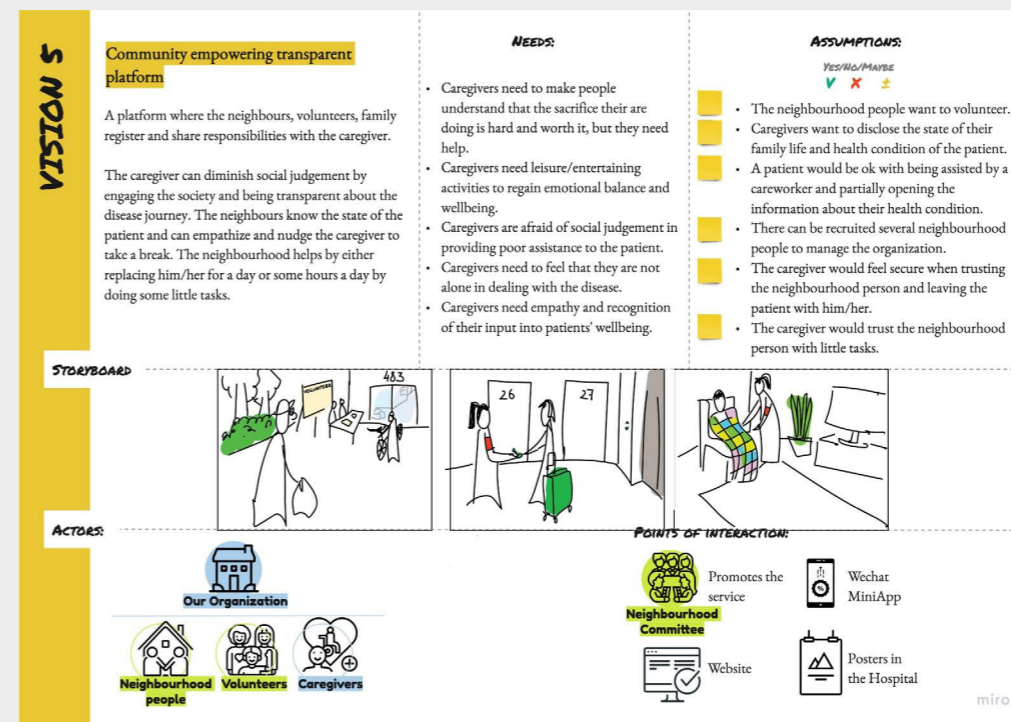


Figure 95. Vision 5 generated for the validation session with participants (Nadejda Cervinscaia, 2020)

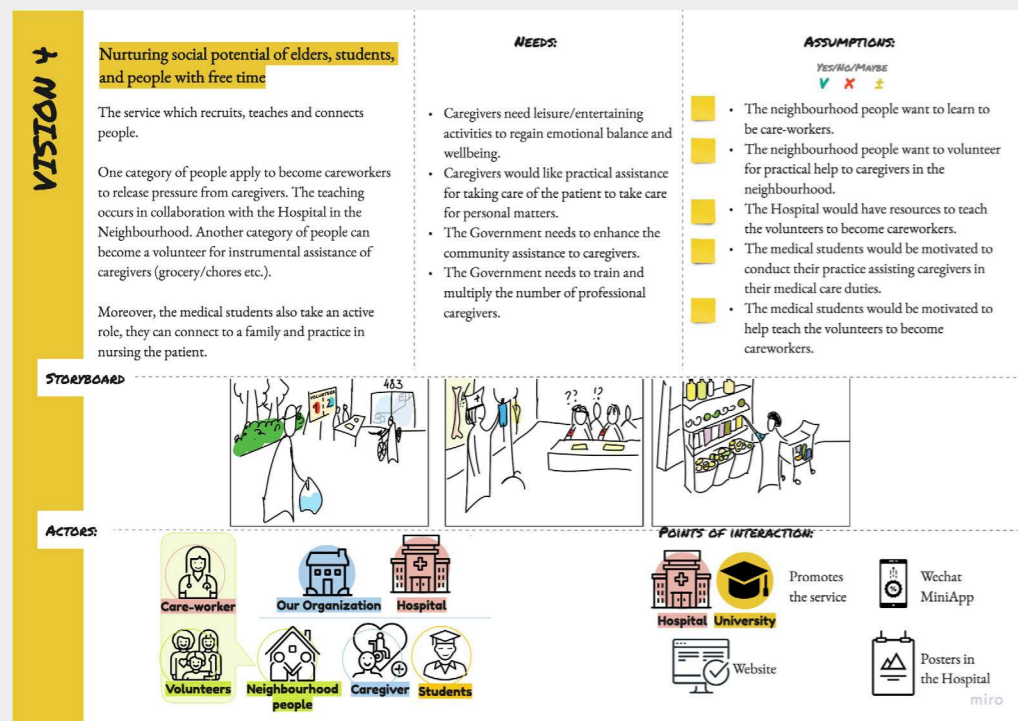


Figure 94. Vision 4 generated for the validation session with participants (Nadejda Cervinscaia, 2020)

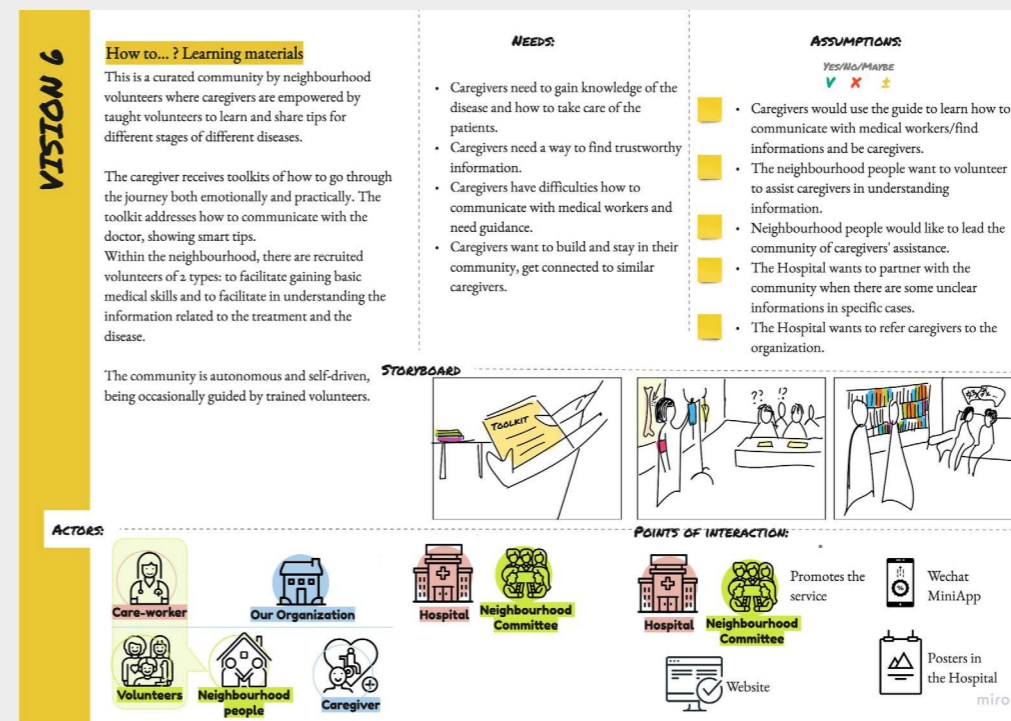


Figure 96. Vision 6 generated for the validation session with participants (Nadejda Cervinscaia, 2020)

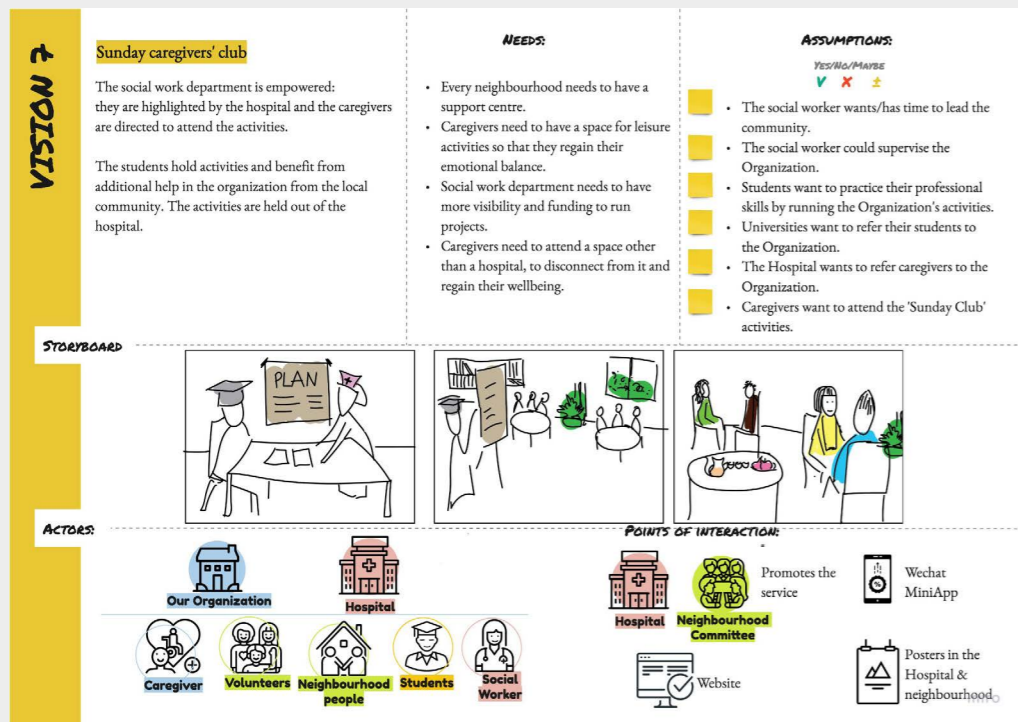


Figure 97. Vision 7 generated for the validation session with participants (Nadejda Cervinscaia, 2020)



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Rituals.
Balanced Care Centre.

