"Walk along, not alone"

Support the elderly immigrants with a Chinese background on the end-of-life preparation in the Dutch context



Master Thesis

Title: Support the elderly immigrants with a Chinese background on the end-of-life preparation in the Dutch context

Oct, 2020

Author

Peixin Wang

Delft University of Technology Industrial Design Engineering MSc. Integrated Product Design

Contact: peixinwangtud@gmail.com

Supervisory Team

Chair: Dr. ir. Sonneveld, M.H.

Department: Human-Centered Design (HCD) Section: Applied Ergonomics & Design

Mentor: Dr. ir. Boeijen, A.G.C. van

Department: Human-Centered Design (HCD)

Section: Design Aesthetics

Company mentor: Dr. Gudule Boland

Company: Pharos (Dutch Centre of Expertise on Health Disparities)

Preface

This project started with a discussion about an End Of Life (EOL) case with Dr. Sonneveld. As a volunteer in a Dutch hospice, Dr. Sonneveld met an immigrant family with a Chinese background. When the Chinese elderly spent the last phase in the hospice, the immigrant family was bothered by EOL-related issues. Meanwhile, they felt regret for not completing the last rituals according to the Chinese culture, which seemed impossible to be conducted entirely in the Dutch context. As an expert on EOL design, Dr. Sonneveld observed that disparities exist between the immigrants with a Chinese background and Dutch local at the EOL circumstance regarding practical aspects, rituals, and values concerning death. Without adequate preparation, coping with the EOL will be a challenge for the immigrant family. Based on the preliminary insights above, a qualitative research project was conducted to explore how the Chinese elderly regard EOL preparations in the Dutch context. Then it was furthered developed into a graduation project, in collaboration with Pharos, the Dutch Centre of Expertise on Health Disparities, aiming to find a way to make interventions on the EOL preparation of the elderly Chinese immigrants.

Table of contents

Chapter 1. General introduction

- 5 1.1. Background
- 5 1.2. Problem statement
- 6 1.3. Project approach

Chapter 2. Contextual research

- 9 2.1. Background
- 9 2.2. Method
- 13 2.3. Findings
- 15 2.4. Discussion
- 15 2.5. Conclusion

Chapter 3. Empathy understanding of the elderly Chiense immigrants

- 17 3.1. Background
- 17 3.2. Method
- 18 3.3. Procedure
- 19 3.4. Findings
- 23 3.5. Discussion
- 23 3.6. Conclusion

Chapter 4. End of life journey with professional support

- 25 4.1. Background
- 25 4.2. Method
- 26 4.3. Findings
- 30 4.3. Discussion

Chapter 5. Research synthesis

- 33 5.1. Review of research insights
- 34 5.2. Problem definition
- 34 5.3. Design direction
- 35 5.4. Design vision
- 36 5.5. Design requirements

Chapter 6. Design development

- 39 6.1. Ideation
- 43 6.2. Conceptualization
- 45 6.3. Iterations

Chapter 7. Final design

- 49 7.1. Concept overview
- 53 7.2. Game framework
- 57 7.3. User of the game
- 57 7.4. Description of the game

Chapter 8. Evaluation on final design

- 72 8.1. Goal of evaluation
- 72 8.2. Evaluation setup
- 73 8.3. Evaluation results

Chapter 9. Conclusion

- 79 9.1. Answer to the design question
- 79 9.2.Limitations of the design
- 80 9.3. Recommendations for the design

Chapter 10. Personal reflection

- 82 Personal reflection
- 83 Acknowledgement
- 85 Reference

Abbreviations and used terms

EOL - end of life

elderly Chinese immigrants - the elderly immigrants with a Chinese background residing in the Netherlands

GP - General practitioner

NVVE- the national right-to-die association (in the Netherlands)

KNMG - The Royal Netherlands Society for the Promotion of Medicine

RDMA - The Royal Dutch Medical Association

PSS - Product service system

Pharos - the name of the Dutch Centre of Expertise on Health Disparities

Exclusive summary

This thesis is about a design project which supports elderly immigrants with a Chinese background residing in the Netherlands on end-of-life (EOL) preparation. The focus of design research lies in looking into the social probe by design thinking. The qualitative research on the elderly Chinese immigrants and experience collected from EOL professionals together contributed to a holistic understanding of how the elderly Chinese immigrants cope with EOL preparation in the Dutch context.

The design aims to utilize design intervention to add value to the target group, in the way of introducing a tool for social workers to help the elderly better understand EOL topics, and consider their needs and preferences. The outcome of this project is a board game that triggers EOL discussions in a friendly manner.

Chapter 1. General introduction

This chapter starts with the background of this project, which maps out the holistic context of this project. The problem statement includes the design goal, the project scope, and the derived design questions. At the end of this chapter, the project approach is explained.

Chapter 1. General introduction

1.1. Background

End of life (EOL) is an inevitable part of everyone's life. It is hard to predict what the last stage of life will be. However, it is wise to navigate the possibilities of that stage when people are still capable of. In the Netherlands, the healthcare system and welfare system enable a broad solution space revolved around EOL, corresponding to medical service, care options, and personal values(Kroneman et al., 2016). By giving some thoughts to the wishes and boundaries, people can achieve a better-prepared trip towards the final stage of life (NVVE, 2016). However, this is not the case for all the residents in the Netherlands. Immigrants based in intercultural backgrounds are facing challenges in coping with EOL. For the elderly Chinese immigrants residing in the Netherlands, preparation on EOL is a challenge. Coming from a culture where death is a sensitive topic, the elderly Chinese immigrants are facing challenges while coping with EOL issues in the Dutch context (Liu et al., 2011).

To tackle the immigrants' EOL issues in the Netherlands, Pharos, the Dutch Centre of Expertise on Health Disparities has been working on various research and intervention projects over the years. As the client of this project, Pharos would like to explore a way to offer proper support to the elderly Chinese immigrants on EOL preparation.

1.2. Problem statement

This project is a pilot project that introduces design intervention into EOL preparation. The **design goal** of this project is: Support the elderly Chinese immigrants with EOL preparations in the Netherlands context.

As previously mentioned, the EOL preparation of immigrants is a complicated social problem that can not be well addressed all at once. Thus the project aims at promoting positive progress on EOL preparation among the elderly Chinese immigrants, to explore directions for professional intervention on immigrants' EOL preparation.

This project revolves around a social problem. For the designer, it is a new challenge to find an appropriate solution to fit both the context and the needs of stakeholders. It requires an in-depth understanding of the elderly Chinese immigrants, the key stakeholders, and the context. To correspond in Pharos' vision, the outcome of this project should be ready to test out with participants from the elderly Chinese immigrants. That is, fitting the current need and being practical to implement in the current context.

The **main design question** is: How to help the professionals to move one step further in supporting the elderly Chinese immigrants with EOL preparation?

1.3. Project approach

This project follows the double-diamond process (British Design Council, n.d.), including four phases, respectively discover, define, develop, and deliver.

Discover: The discover phase generates an understanding of how the elderly Chinese immigrants prepare for the end of life with the support of professionals in the Dutch context. In this phase, the context, the stakeholders, and the current professional interventions were investigated.

Define: In the define phase, the research results were reviewed and summarised. By synthesising the findings from the previous phase, the design vision and design direction were generated.

Develop: Based on the synthesis results from the previous phase, a tool helps with professional intervention on elderly Chinese immigrants' EOL preparation were developed. By conceptualising and iterating, the final design was made.

Develop: Based on the synthesis results from the previous phase, a tool helps with professional intervention on elderly Chinese immigrants' EOL preparation were developed. By conceptualising and iterating, the final design was made.

Deliver: In the deliver phase, the final design was evaluated with professionals. The final design was verified to be a feasible tool to support the EOL discussions in the current context. At the end of the deliver phase, recommendations and limitations were made.

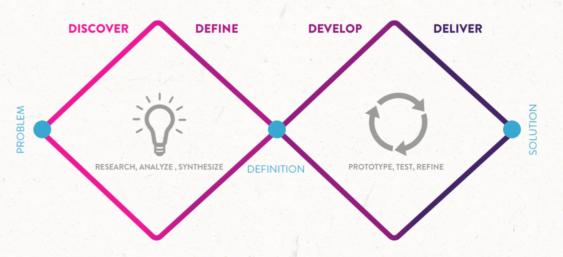


Figure 1.1. Double diamond framework

Chapter 2. Contextual research This chapter explains the disparities of the end of life (EOL) preparation in the Dutch and Chinese context, respectively. The stakeholders related to the elderly Chinese immigrant's EOL preparation were investigated. Together, these help with build an understanding of the current EOL preparation context for the elderly Chinese immigrants.

Contextual research

2.1. Background

People coping with the end of life (EOL) varies in different cultures, depending on the far- reaching influence of economic status, culture, and society (Blank, 2011). In the Dutch culture and Chinese culture, the perceptions and values of EOL are different. The majority of the Dutch public is open to EOL planning (Rietjens et al., 2006), which is not the case in Chinese culture (Mjelde-Mossey & Guo, 2005). The elderly Chinese immigrants originate from China and currently reside in the Netherlands. Both the originating context and acquired context influence their way of coping with the EOL. Consequently, living in an intercultural context, the immigrants' EOL preparation is way more different from people who originate in the Netherlands. Thus it is crucial to interpret the holistic context and corresponding influences.

The **main research question** answered in this chapter is:

What is the current context for the elderly Chinese immigrants to prepare for the EOL?

Four **sub research questions** in the context research are as below:

- 1. How to prepare for the EOL in the Dutch context generally?
- 2. How do Chinese people cope with EOL in general in a Chinese context?
- 3. What are the barriers and enablers for Chinese immigrants to prepare well for the EOL in the current context?
- 4. Who are the stakeholders in the EOL preparation of elderly Chinese immigrants in the Dutch context, and how do they contribute?

2.2. Method

The method used in this contextual research is a combination of 1) literature research and desktop research, and 2) interviews with professionals. The research results were viewed in a culture-sensitive way to conclude.

2.2.1. Literature research and desktop research

Preparing for the end of life (EOL) involves various considerations regarding medical, legal, ethical, and social-cultural aspects. The EOL preparations in the Dutch and Chinese

contexts were investigated representatively regarding these aspects. The results can be found in subchapter 2.3.2 and 2.3.2.

2.2.2. Interviews with professionals

The empirical knowledge known from the professionals' interviews served as a supplement to the literature research and desktop research. The interviewers include professionals from both Dutch and Chinese include three social workers, one Buddhism master, and one Christian pastor. These professionals have been served for Chinese immigrants over the years. Together, their input contributed to mapping out the status quo on the elderly Chinese immigrants' EOL preparation. Furthermore, one funeral practitioner based in China was interviewed to understand the EOL rituals in Chinese culture. His empirical knowledge also corroborated the findings from 1)literature research and desktop research.

2.2.3. Stakeholder analysis

After mapping out the "big picture," the stakeholder analysis was made to identify the stakeholders' roles in the elderly Chinese immigrants' EOL preparation. A value circle was made to show the relationships and connections between the stakeholders.

2.2.4. View the contexts through a culture- sensitive lens

The original and acquired cultures influence the target group on EOL preparation. The comprehensive effects were viewed from the cultural perspective and concluded in the subchapter 2.5 discussion and 2.6 conclusion.

Remark: Background of the interviewees

The interviewed social workers in the Netherlands all moved here at a young age, continued their education and careers in the Dutch context. Among them, two social workers originate from Chinese backgrounds. The other social worker came from Vietnam and worked for Chinese immigrants. The pastor also has a Chinese background. The Buddhism master moved from China to the Netherlands two years ago and worked on life and death education in Longquan Great Compassion Monastery. The Chinese funeral practitioner had been working in the funeral industry in China for 15 years.

2.3. Findings

2.3.1. End of life preparations in the Netherlands context

Medical and care aspect

In the Netherlands, most palliative care is covered by the regular Dutch healthcare system. The medical execution of the EOLrelated practices, including pain-relieving, symptoms distressing, and euthanasia, are maturely developed over the years. The terminally ill patients can get last care from the regional hospices and the palliative care centers (Kroneman et al., 2016). Suppose the elderly would like to spend the last phase at home. They can get district nurse services from the regional healthcare system, GP (general practitioner) visits, and home care services from local hospice (Kroneman et al., 2016; Government of the Netherlands, n.d.).

practices, with adoptions to the needs and wills of the dead and the family ("Ten things about death," 2015). The rituals including but not limited to: traditional customs, playing funeral music, offering coffee and cakes to funeral guests. Those with religion tend to follow the religious in the last rituals and funeral rituals (Goldade, 2020).

Legal and ethical aspect

In the EOL process, patient autonomy is supported by laws and regulations regarding the right to information and decision-making. By drawing up an AD (Advance Directive) and keeping it up to date, the patient can stipulate the decision making and the wishes in advance for being incapable in the last phase. The attorney appointed by the patient can also help with decision making on behalf of the unconscious patient.



Social-cultural aspect

Insurance plans can cover palliative care and hospice care costs to different degrees (Kroneman et al., 2016). 60% of Dutch households have funeral insurance. A Dutch funeral is often an invite-only event for the family members and friends to memorialize the dead one, and the rituals are usually inherited from traditional Dutch funeral



Figure 2.1. "A funeral scene in the Netherlands" (Rosalie Kuyvenhoven, 2017)



Figure 2.2. "A funeral scene in the Netherlands"

2.3.2. Cope with end of life in the Chinese context

Medical and care aspect

In late 1980, the concept of EOL came into Mainland China. As of 2014, there were more than 200 hospices located in China (Xie & Zhu, 2014). However, this is far more than enough in comparison with the vast population. In the ages where the elderly Chinese immigrants come from, the medical and care on EOL is a neglected healthcare dimension. In the last phase of life, people mostly rely on medical interventions and care from family members or external caregivers (Ning, 2018).



Legal and ethical aspect

In China, the last care services and medical interventions are under development in recent years but are not yet systemically promoted (Chung et al., 2020). For most Chinese, concepts as ACP (Advanced Care Plan) are novel (Liu et al., 2020). In Chinese culture, people often feel ambivalent about relaying patients' negative truth due to protectiveness (Pang, 1999). Sometimes, healthcare professionals, family members, and the patient share a different opinion on patient autonomy. The Farewell, a movie tells a story about a Chinese-American family who decides not to tell the grandmother about her terminal illness. It is a representative case for these related ethical concerns (Thomas, 2020).



Social-cultural aspect

The general value about death in Chinese culture can be interpreted as: Treat the dead ones as if they are still alive, reflecting a comprehensive effect from Confucianism, Taoism, and Buddhism. Contemporarily, people know death is a natural process that everyone will encounter in the end. However,

with traditional thoughts' long-term influence, people take an evasive attitude talking about death and value the last rituals (Ning, 2018). The funeral rituals are somehow related to traditional customs, depending on the local customs and personal needs. According to the funeral practitioner's practical experience, who had 15-years of experience in the Chinese funeral industry, the EOL preparations in China mostly lean towards property distribution, last rituals, and after-death rituals. The contemporary funerals were simplified in comparison with the ancient ones. Some ceremonies were retained and still complicated. The need for rituals derived funeral occupations and industries. When people die, the family members will conduct the last rituals with funeral practitioners and sometimes spiritual leaders.



scene in China" (Adobestock, 2020)



Figure 2.4. "Burning Chinese joss paper or ghost money"(Adobestock, 2020)

12

2.3. Findings

2.3.3. Stakeholders in the end of life preparation

The stakeholders involved in the EOL preparation of the elderly Chinese immigrants are mapped out in Figure 2.5.



Key stakeholders

All the EoL preparations revolve around the elderly. The inner-circle represents the key stakeholders who play essential roles in the EOL preparation, including:

The elderly and the family members are the core of the value circle. The family members including spouse and adult children, if any, support the elderly through the whole EOL journey. The adult children raised in the Netherlands are reliable support to the elderly in practical aspects. Besides, family value is vital in Chinese culture. The family members' opinions are valued by the elderly when they make important decisions.

The social worker supports both the elderly and the family member by giving suggestions based on their professionalism and profound experience. They know the Chinese immigrants well. Thus they can give concrete suggestions, even solutions to react upon their request.

Figure 2.5.
Stakeholders in the EOL preparation of the elderly Chinese immigrants

The GP (general practitioner) offers suggestions when the elderly have questions regarding the medical related issues in the EOL preparation. The GP contributes to the elderly's health literacy and EOL knowledge. GP is mostly involved in medical decision making and execution when it comes to the final stage of life.

The spiritual leader helps the elderly who has a religion to build understanding on life and death. They give last phase rituals and comfort if the elderly or family member has a religious belief.

The professionals mentioned above directly support the elderly and thier family on EOL preparation. Their suggestions matters, and influences the elderly's perception of EOL preparation.

Indirect stakeholders

The middle circle represents the indirect stakeholders.

When the elderly are diagnosed as terminally ill, the *medical staff* will advise the elderly and their family on the care plan. *The district nurse* will be involved in the last phase to offer care. *The local palliative center* and *the hospice* also provide care options for the elderly in the last phase of life. *Insurance companies* and *funeral parlors* are involved in EOL practice.

The elderly with a terminal illness may go to the *Chinese medicine practitioner* for help. They try to seek different medical interventions to try more treatment.

When the elderly make preparation for EOL, the medical suggestions, care options, and services offered by these stakeholders have an influence on their choice, but not desicive.

The elderly learn from the experience of *relatives and friends*. Their advice may also influence the elderly in EOL preparation.

Chinese organization is a channel that effectively brings the elderly, professionals, and related parties together.

From people around, the elderly get shared information, experience, and suggestions. These influence the elderly but not decisive.

Context setters:

The outer circle shows the stakeholders that relevant to this topic, but do not directly interact with the elderly.

The municipality supports the citizens with EOL service.

Organizations, such as Pharos, works for promoting health equity and disparities in health literacy, playing a promoting role in the EOL preparation of the immigrants.

Together, these stakeholders contribute to a better context for the elderly Chinese immigrants' EOL preparation.

2.4. Discussion

The EOL preparation is influenced by the cultural context in which people are raised and based in. For the elderly Chinese immigrants, the Chinese context and the Dutch context can be respectively regarded as their original context and acquired context. Disparities exist between these two contexts, including but not limited to: the available resources for EOL preparation, the understanding of EOL related issues, and the values towards life and death. In the Dutch context, medical interventions and care on EOL are built systematically. Life quality is the focus. However, in the Chinese context, more resources and supports lean towards the rituals and funerals. For the elderly Chinese immigrants:

They need more efforts to prepare well for EOL in the Dutch context

The acquired context introduces something new to them. Compared with the native Dutch people, elderly Chinese immigrants lack an understanding of the medical interventions and care options beforehand. To make use of the EOL preparation resources, the elderly immigrants first need to learn about them.

They need to deal with the disparities in the two cultures.

In Chinese culture, some resources are considered to be taken for granted. However, these may not be all available in the Netherlands. The elderly need to deal with the disparities in these two cultures. Also, EOL preparation is personal. The elderly need to define what matters for themselves, what they would like to accept, and what they would not.

Support is available in the current context.

The supports are available from family members, professionals, and various concerned parties. The peculiarity of EOL preparation requires both knowledge and experience. Therefore, the professionals are the best ones to help the elderly get familiar

with the current EOL preparation context. Get concrete support from the professionals will benefit EOL preparation.

2.5. Conclusion

In conclusion, for the elderly Chinese immigrants, both challenges and enablers exist on their way of EOL preparation. They need to explore a way that suits themselves, with supports from professionals. In order to explore the design opportunity, it is necessary to build an understanding of the elderly Chinese immigrants, and the professional support offered for them. In the following two chapters, these two topics are investigated representatively.

Chapter 3. Empathy understanding of the elderly Chinese immigrants

This chapter is to build an empathy understanding of elderly Chinese immigrants. The similarities, disparities among the Chinese elderly in EOL preparation were looked into.

Empathy understanding of the elderly Chinese immigrants

3.1. Background

In the previous chapter, a "big picture" on the EOL preparation in both original context (the Chinese context) and acquired context (the Dutch context) were demonstrated. Before offering support, it is vital to establish an empathy understanding of elderly Chinese immigrants. Based in an intercultural context, the immigrant group formulated its features and interaction dynamics over the years. By knowing how they cope with the context, the intervention can be further explored. The main research question of this chapter is:

What is the appropriate way of supporting elderly Chinese immigrants on EOL preparation?

The sub research questions are:

- 1. What are the elderly Chinese immigrants' needs and concerns on EOL preparation?
- 2. What should be considered explicitly while offering support to elderly Chinese immigrants?
- 3. How to trigger elderly Chinese immigrants to prepare for the EOL?

3.2. Methods

3.2.1. Literature research and desktop research

Literature research and desktop research were conducted to understand the target group as a collective from a macro perspective, on both historical and social aspects. The findings contribute to explaining the similarities and disparities within the target group.

3.2.2. Contextmapping

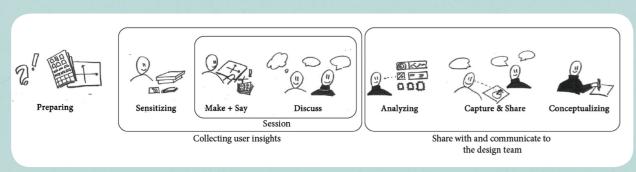


Figure 3.1. Procedure of contextmapping (Sleeswijk Visser et al, 2005)

The elderly immigrants are the best person to reflect on their own needs, concerns, wishes, and motivations. However, people are often unaware of what exactly these are. Therefore, the contextmapping method was applied in order to explore the potentials of supporting EOL preparation. The results are presented as the influential factors on EOL preparation and the four representative personas. The participants include five elderly Chinese immigrants and one middle-aged.

3.2.3. Interview with social workers

Interview with the social worker was conducted to gain more understanding of the elderly Chinese immigrant group. The interviewed social worker has 17-year experience serving for elderly Chinese immigrants. He is originated from a Chinese background, get educated and spend his whole career in the Netherlands.



Figure 3.2. Sensitizing booklet



Figure 3.3. Interview with one of the Chinese elderly



Figure 3.4. Clustered quotes

3.3. Procedure

Before the COVID crisis, interviews with Chinese elderly were conducted at Longquan Great Compassion Monastery, Utrecht; and the Stichting De Chinese Brug, the Hague.

3.3.1. Sensitize

A booklet with five small assignments was offered to the participants. By completing the assignments, the participants got prepared for the interview. See the booklet in appendices.

3.3.2. Interview

After filling the booklet, semi-structured interviews were conducted to get more information about sensitive topics, such as EOL issues.

3.3.3. Cluster and Analysis

Quotes from the interview transcripts were picked out and clustered. The clustered quotes were named regarding the topics.

3.3.4.Draw conclusions

Conclusions were drawn from the clustered quotes and translated into the influential factors on EOL preparation and the elderly personas.

3.4. Findings

3.4.1. Group image of the elderly Chinese immigrants

During the interview, the social worker described his working experience with the Chinese elderly. According to him, the elderly who come to social workers for help is usually at a relatively low integration level. Thus they need extra support on daily matters, including dealing with EOL issues. Coming from a collectivism culture, most of them are low key and hard-working. The Chinese elderly value the family and dignity. They tend to manage the difficulties alone or within the family, instead of speaking out loud. Their children generation are raised in the Netherlands. They have better language skills and follow Dutch values. For some of the elderly, the adult children are their connecting point with mainstream society. The elderly like to socialize with people from similar backgrounds. When they seek for advice, they tend to go to the social workers and volunteers whom they know for long.

3.4.2. Dynamic interactions with in the elderly Chinese immigrants group

Dynamic interaction exists among elderly Chinese immigrants. The group activities hosted by community centres, Chinese organizations and widely-known social workers are attractive for elderly immigrants. The elderly Chinese immigrants regard the activities as social opportunities where they can be together with peers from a similar background. Thus the theme activities and festival gatherings were attached with extra values. The community centre and Chinese organizations are their frequently visited places. For those with religion, the Buddhism temple and church are also their favourable places.

3.4.3. Influential factors in the EOL preparation

Based on literature research, the influential factors in the EOL preparation of older adults in intercultural context including spirituality, acceptance of death, the burden to the family, social support, distrust of doctors and healthcare settings, acculturation, and level of language fluency (Rahemi & Williams, 2020). Moreover, the disparities between different generation and personal value are found influential to the elderly Chinese immigrants during interviews. In the real-life, these factors will have a comprehensive effect on the elderly's decisions and actions.

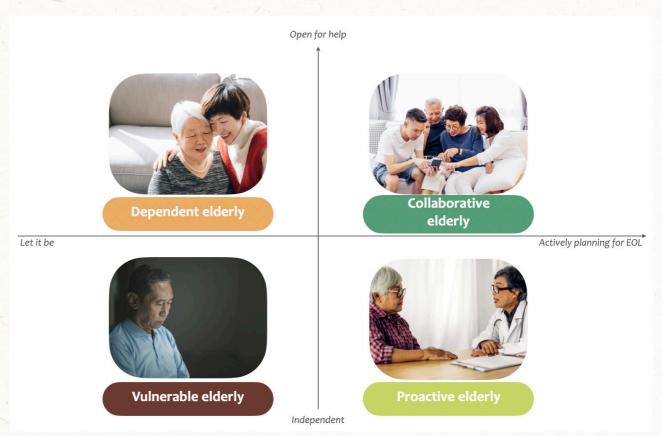


Figure 3.5. Elderly Chinese immigrants personas on EOL preparation

3) Personas

The data gathered from the elderly participants were analyzed. Four personas were drawn based on the analysis results. Two dimensions were identified to capture the differences between the elderly's attitude and dependence. See in Figure 3.5.

One dimension, represented by the horizontal framework axis, describes the elderly's attitude towards EOL preparation. On the other end of this axis, some elderly showed interest in exploring the EOL possibilities. They had roughly envisioned their EOL scenarios. Some even already communicated with professionals. Whereas some elderly took a relatively passive attitude towards EoL preparation. These elderly might not regard the EOL topic as taboo, but they think the EOL is not something that they can change, they will let it be.

The vertical axis of the framework and the other dimension that stood out between participants were their willingness for help and support. Some elderly highly valued family members' suggestions and support, whereas others would like to trouble others less.

With these axes, the participants were mapped out. It is found that three of the four quadrants can be represented with personas. The second quadrant, "Collaborative elderly," who proactively make use of existing resources, prepare for EOL preparation with the support from loved ones and professionals, remains empty because this elderly would likely not exist. For most elderly, the EOL preparation may still be at an initial level.

Persona 1) The dependent elderly



Figure 3.6. Persona - The dependent elderly

Quotes

"I would like to live together with my wife, we can take care of each other."

"I do not think too much about the unknown future."

"If I am ill, my children will help me and take care of me."

The integration level of dependent elderly is enough for daily life, but their values are more close to traditional values. The dependent elderly have a strong bonding with the family members. With the financial and emotional support from spouse and adult children, their lives are more manageable. When it comes to important decisions, they value the family members' opinions. Currently living a happy life, they seldom think about EOL. If they encounter that one day, they will rely on the arrangement of family members. Thus, they do not feel a strong need for exploring EOL. They have not realized the benefits of making EOL preparations.

Persona 2) The vulnerable elderly



Figure 3.7. Persona - The vulerable elderly government(municipality)."

Quotes

"I am not very fluent in Dutch. I can not explain everything clearly to the doctor."

"I felt very offended when I received the body donation inquiry letter."

"I don not know what to do for future life. I will follow the arrangement of the appearance of the app

Living alone in the Netherlands, without or faraway from the family and adult children, the vulnerable elderly need to rely on their own. For the vulnerable elderly, what people refer to as "normal," can be challenging. The integration level of the vulnerable elderly is relatively low, constrained by language skills and social isolation. They are not able to acquire enough information and effectively access to resources by themselves. Thus, they do not know about the available resources and care options. While referring to EOL and after-death, they tend to choose a way that requires fewer efforts. They are keen on better care and would like to know what will happen in the future life phase.

Persona 3) The proactive elderly



rigure 3.8. Persona - The proative elaerly

Quotes

- "I know about EOL topics from the seminars. I have visited the hospice before."
- "I know what happened around from newspaper."
- "I seldom talk about this with my kids. I don't know how to start such conversations."
- "I think my children's ideas are somehow different from Chinese."

The proactive elderly has a relatively high level of integration, and are open to accepting both Chinese values and the Dutch values. They are concerned about the ageing and EOL and would like to live in high quality in the future life. They are both capable and willing to prepare for the EOL. However, sometimes, they do not know how to start the discussion. Also, they need guidance on exploring the EOL topics. They are keen on reliable resources and professional suggestions. Also, they lack a channel to discuss and share with peers.

Persona 4) The collaborative elderly



Figure 3.9. Persona - The collaborative elderly

Quotes

- "I would like to make a concrete plan for myself." "I feel it is ok to discuss with family members."
- "I know medical treatments and care options in the Netherlands are different from China, I would like to explore more."
- "I want to keep tidy. If an unfamiliar friend comes to visit when I can no longer walk, it can be very embarrassing."

The collaborative elderly have a relatively high integration level and are open to different values. They think to prepare early on will reduce struggles and panic when the challenges occur. They like to discuss together with closed ones and make a concrete plan for future life. They would like to listen to the professional suggestions, take reference from peers, and think about their preference and need.

3.5. Discussion

The findings demonstrate a lack of a holistic understanding of the EOL preparation. The current needs and concerns lean more on the practical aspect. The elderly immigrants are the best people to know themselves. However, deepend thinking on personal preference are in missing.

3.5.1. Barriers and enablers

The barriers for the elderly Chinese immigrants to make EOL preparations include:

- Language skill
- Health literacy
- Social integration level
- Different values between the old and young generation

The enablers are:

- Available support from professionals and concerned parties
- Family support
- The trust in professionals
- The strong interest in group activities.

3.5.2. How to support different types of elderly

The personas generated from the qualitative research indicated that looking into the personal aspect, the willingness and attitudes towards EOL preparation are various. To better

support, the elderly, professional intervention should be accessible for people with different needs. By showing the possibilities and available options in EOL, build a reliable channel for learning and have discussions, trigger motivation, the different needs can be covered. In this way, the intervention can trigger each persona to take further on proactive action. As indicated in Figure 3.10.

In conclusion, encouraging the elderly to discover their own needs, concerns, and values will benefit EOL preparation. With professional support, the feasibility will be taken to a higher level. While conducting professional interventions, the similarities and disparities in the elderly Chinese immigrants should be fully considered. Moreover, professional intervention can be introduced in a way that fits with their interest.

In the next chapter, the current professional support are investigated, and a suitable way of support are explored. These together contribute to find a way suitable for both the elderly Chinese immigrants and the professional side.

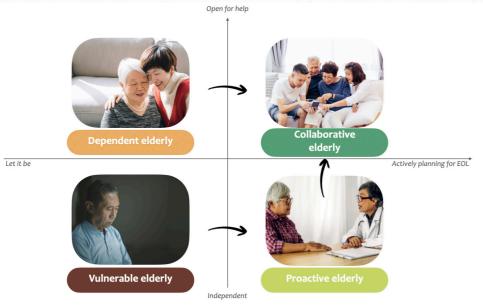


Figure 3.10. Envisioned transitions in different elderly personas

Chapter 4. End of life journey with professional support

After learning about the context and the elderly, this chapter will explore how the professionals support the elderly on their EOL preparation, to find opportunities for improving the current professional interventions.

End of life journey with professional support

4.1. Background

From the previous research (Chapter 2&3), a general understanding of the holistic context and the elderly Chinese immigrants was made. To answer the design question, how to help the professionals to move one step further in supporting EOL preparation, it is necessary to know about how the elderly cope with EOL preparation and EOL issues with professional supports. Thus, the **derived research questions** of this chapter were proposed as:

- 1. How do professionals support the EOL preparation and EOL related issues currently?
- 2. How do the elderly prepare for EOL and cope with EOL issues, with professional support?
- 3. What can be improved in the current workflow?
- 4. What are the new opportunities for professional intervention on EOL preparation?

4.2. Method

4.2.1. Interviews

Semi-structured interviews were conducted online with professionals from different disciplines. The interviewed professionals include three social workers, one general practitioner, two spiritual leaders (one Buddhism master, and one pastor). During the interview, the professionals shared their experience of working for elderly Chinese immigrants. The interview referred to five topics: Working experience as a professional, scenario of current support, problems encountered during work, evaluation of the current work, and culture related concerns. See the interview questions and results in appendices.

4.2.2. Journey map

A journey map was made to identify the potential opportunities for design intervention in the EOL preparation. By pooling professionals' experience and reflections, a general EOL journey of the elderly Chinese immigrants was generated. The journey map consists of three parts: the journey of a social worker (in green), the journey of the elderly and their family members (in red), the journey

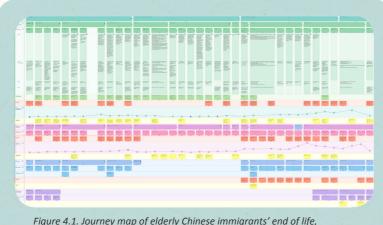


Figure 4.1. Journey map of elderly Chinese immigrants' end of life, with professional support. (See in the appendices)

of other professionals (in blue and purple). In this way, how different disciplines support the elderly on EOL preparation and the EOL phase were mapped out. The whole journey is narrative in chronological order. Both general activities and representative cases were merged into the journey map. The journey map indicated the main activities, needs, and insights in corresponding stages. The existing and potential problems were marked under related activities, as well as the derived opportunities. The challenge level of these moments was presented in a line chart. Limited by the space, the journey map was put into the appendices. In the subchapter 3.3.1 & 3.3.2, the takeaways from the journey map were summarized into wireframes and described.

4.3. Findings

4.3.1. Current end of life journey of the elderly Chinese immigrants

Prepare for EOL

Know about EOL Build own understanding Envision/prepare for the future Step into the last phase

Get diagnosed Get care and medical treatments Complete last wish Spend the last phase

Rest in peace

Get weak / unconsciou Receive last care Receive last rituals

Die Last rituals and funeral

Figure 4.2. Simplified end of life journey (regarding elderly)

The EOL journey consists of four stages: Prepare for EOL, approach the last phase, spend the last phase, rest in peace. In this section, these stages and the related problems were described.

Stage 1. Prepare for the end of life

Stage 1, prepare for the EOL, refers to the stage when the elderly are capable of planning and preparing for themselves. In this stage, the elderly are spending their elderly life. Based on own experience and understanding of ageing and EOL, the elderly envision or prepare for EOL, regarding the place to live, the people around, the care to receive, the rituals, and the funeral. The elderly learn about how to cope with EOL issues from the media, people around, own experience, and professionals. This is a stage of exploring. The challenge level is low because the elderly and their family members are not directly facing insurmountable difficulties. The problems in this stage were manifested as:

- In lacking a comprehensive and explicit understanding of end of life

People have different attitudes and understandings of ageing and EOL; Some elderly feel offended while receiving corpse donation inquiry in the mailbox; Some elderly get the wrong impression on euthanasia execution condition and regard it as a forced procedure for the last phase of life.

Limited discussion between the elderly and the family

Some elderly are sensitive about the EOL topic; they think talking about it will bring bad fortune and accelerate death.

For most elderly, talking about EOL is acceptable, but they had never discussed EOL in-depth with their loved ones.

Stage 2. Step into the last phase

With the natural ageing or terminal illness, the EOL is approaching. In the second stage, the EOL challenges gradually brought up to both the elderly and their family members. They have to cope with the practical EOL issues and deal with mental burdens. Apart from these problems that are caused by EOL, the problems resulted from the differences in Dutch and Chinese culture, regarding medical treatment, caregiving. Thus, the challenge level gradually increases. The problems in this stage are:

- Seeking for external support

Some people do not know about hospice and do not know they can get help from the regional healthcare system for home care support.

Chinese families regard taking care of the elderly as filial piety. However, taking care of the patient can be a long and tiring duration, requiring much effort from family members. Getting external help could release the burden.

Stage 3. Spend the last phase

In the third stage, the elderly got extremely weak and possibly incapable. If the problems raised in the former stages are settled, the challenge level will not increase too much. If not, the problems and struggles will remain until the end of the journey. The problems in this stage are:

- Different perception of medical treatment In some cases, the elderly patients seek to cure instead of easing. Such expectation may cause disappointment.

- Food and drink

Sometimes, family members offer food and drinks to the patient who is not able to take them.

Stage 4. Rest in peace

In the last stage, the elderly rest in peace. The last rituals and funeral were conducted, according to the elderly's wills, family preference, and economic status. The challenge level of this stage is relatively low. However, some of the wishes can be difficult to fulfil.

The problems in this stage are:

- The adult children do not know how to conduct traditional Chinese rituals and funerals;
- No guidance on rituals and funerals in the Chinese way.

These typical problems may cause worries from the elderly.

4.3.2. How professionals support

The closely involved professionals include the social worker, the GP (general practitioner), and the spiritual leader. They representatively contribute to different phases that are relevant to their professionalisms. Since the medical staffs and caregivers are mostly involved in the EOL stage instead of the preparation stage, their support is not elaborated in this chapter. As indicated in Figure 4.3, social workers offer long-term support to the elderly and their families during the whole EoL process. The GP is mostly involved in stage 2&3. For those with religious beliefs, spiritual leaders mainly help with rituals in the last stage(3&4).

How social workers support

Different from the other professionals, the social worker keeps a long term interaction with the elderly and their family. The experienced social worker has maintained long term connections with the Chinese elderly. They connect to the elderly, professional backing, and concerned parties. Every social worker has their working style. Different from the other professionals, they do not have a strict protocol to follow. Differently, the GP usually follows a standard procedure to give medical suggestions and conduct medical interventions.

In the preparation stage, the social worker helps the elderly to build an understanding of EOL by sharing knowledge, in the way of holding seminars and giving consultations. The essential EOL education is suitable for the elderly in the EOL preparation stage. During the seminar, the social worker talks through EOL topics and share how to cope with EOL issues. The common ways of essential EOL education include: Putting relevant information on general media and organizing EOL seminars. In 2019, the social workers hosted EOL seminars in the Hague, Netherlands. The social worker shared EOL knowledge and answered questions raised by the elderly Chinese participants after the seminar. When the elderly have a request, the social worker can give a consultation to help

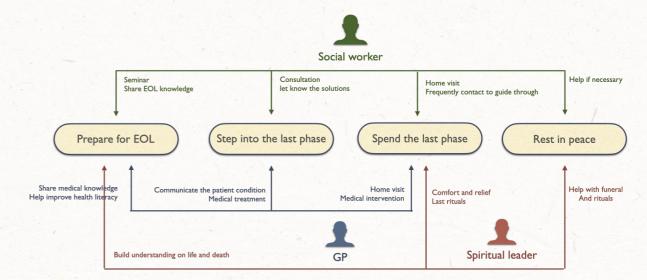


Figure 4.3. Professional support on the whole EOL journey

the elderly find a solution regarding their problems. This is not commonly conducted because the need is few. When the elderly go to the consultation, the problem they take is always tricky to tackle.

In most EOL cases, the elderly and their family contact the social worker for help when they meet difficulties. Most problems raised when the elderly were found terminally ill. At this stage, the social worker supports the elderly and their family by providing EOL consultation. Compared with general EOL education, the EOL consultation is more concrete. During the consultation, the social worker explains EOL knowledge, offers mental support, and mobilizes the client. The social worker gives advice based on the current circumstance of the help seeker. For the simple case, the social worker only needs to tell the right reaction to take at the corresponding stage. If the elderly are still capable or supported by family members, they can efficiently address the problem after learning the recommended solutions from the social worker. In very few cases, the Chinese elderly come to the social worker to seek an answer for their EOL concerns when they are still healthy. Depending on the understanding of EOL, the elderly may propose different views. The social worker will help them to access the current circumstance and tell them the recommended solution. If the case gets

worse, the social worker can also offer further support during the EOL phase of the elderly. To be noticed, supporting EOL related issues is not the only job for the social workers who serve for the elderly Chinese immigrants.



Figure 4.4. The social worker support the elderly by hosting EOL seminar and giving consultations

How other professionals support

Other professionals closely involved in the EOL journey are GP, spiritual leaders, and funeral practitioners. The GP visits the patient when they are not capable of going to the clinic. The spiritual leaders give comfort and the last rituals to the patients. The spiritual leaders interpret life and death from a religious perspective. The spiritual leaders also help the elderly to build an understanding of life and death from a religious perspective. Sometimes, the professionals refer other professionals to the elderly and their family, to make sure they get concrete help from the right person.

How Pharos support

By investigating the EOL issues in non-Dutch immigrant groups for years long, the needs and concerns from the different immigrant group were collected and looked into (Pharos, 2020). Based on the understanding of the immigrant groups, Pharos offered training to social workers, tell them how to communicate the EOL topics to the immigrants. The EOL simulation films and other materials made by Pharos also help to make these topics understandable for the elderly Chinese immigrants (Pharos, 2020). These materials matched with the immigrants' need and got positive feedback. However, the communications created by these materials remained one-way. The engagement of immigrants should be improved.

The vision of Pharos is to eliminate the disparities on health literacy in the immigrants. Pharos is tackling the immigrants' issues on a context setter level. Therefore, gaining a better understanding of the immigrants will add value to Pharos' work, and consequently benefiting back the immigrants.

How elderly react to professional support

According to the social workers' reflection on the past working experience, the elderly trust the social workers, spiritual leaders and other professionals they knew for long. The elderly have less contact with the GP in daily life. They need more time to build trust. Also, they need more time and effort to understand the medical suggestions offered by the GP, since the medical knowledge itself is difficult to understand, and the elderly's medical expectation is sometimes different from what the GP suggests.

The EOL seminars for Chinese immigrants started in 2019, which were new to the elderly. The elderly joined the seminar and got aware of EOL preparation. In addition to the EOL theme itself, the elderly regard the seminar as a socializing opportunity. They took friends or family members to join the seminar and enjoyed the atmosphere of the gathering.

The elderly gave positive feedback on the film made by Pharos since they learn about EOL knowledge from it, which is they had not heard about before. The elderly are willing to accept the supports offered by professionals, and especially the materials that adapt to them.



Figure 4.5. Demonstration film on EOL topics, specifically made for Chinese immigrants (Pharos, 2020)

4.4. Discussion

By looking into the professionals' working experience, the elderly Chinese immigrants' general preparation status and their reactions towards professional support were figured out. The EOL journey in real life can be divided into four phases: get prepared, encounter, go through, and approach the end. However, in most cases, the elderly and their family get into the "encounter" phase directly without adequate preparation. As death approaches, coping with EOL issues becomes more and more challenging. The limited understanding of EOL resulted in struggles and hard times. Therefore, it is vital to make interventions in the early stage. The ideal process is to prepare well before encountering the EOL challenges.

The research findings emphasized the gap existing between learning about EOL and encountering the EOL challenges. That is, the elderly seldom take proactive action towards EOL preparation. Knowing about EOL knowledge and resources from the seminar and other activities is not enough. Thus, there should be one more step between the seminar and the concrete consultation. Proper guidance from professionals and initiative from the elderly are both indispensables.

In the past EOL seminars, the elderly shared their opinions, raised questions, and had discussions, without feeling offended. This again demonstrated the potential of introducing EOL related interventions in the group activities, in line with the elderly's strong interest in group activities (See in 3.5.Discussion). Trigger proactive exploration from the elderly side in group activities can be a design direction.

The professionals also need input from the elderly. So that they can know the elderly better and improve the support they offer. Therefore, new interventions should trigger two-side communication between the professionals and the elderly.

Chapter 5. Research synthesis This chapter is a synthesis of multiple research insights. In the former chapters, the context, people involved, and the current professional supports on elderly Chinese immigrants' EOL preparation were investigated and analyzed. In this chapter, these insights were synthesized and transited into a problem definition. The design direction and design vision were then derived from the problem definition. In the end, design requirements were proposed to guide the development phase.

5.1. Review of research insights

5.1.1. Regarding the context

The elderly Chinese immigrants come from a context where abundant resources skewed on rituals, whereas medical intervention and life quality improvement are not systematized yet. In the Netherlands, medical and caring systems are way more developed. The disparities in the context-setting lead to a lack of awareness and understanding of EOL preparation. For elderly Chinese immigrants, the first step for EOL preparation is to build an understanding. To go across the boundary between the EOL cultures, elderly Chinese immigrants need a channel to get adequate explanations and guidance.

5.1.2. Regarding the elderly Chinese immigrants

According to the research on the elderly Chinese immigrants, they showed similarities in needs, concerns, and values. Targeting them as a group is a promising approach. Besides, the particularity in elderly Chinese immigrants should be fully considered. The professional intervention should enable the different types of elderly to connect to and benefit from it. EOL of the immigrants is not only a social probe but also a personal matter. Helping the elderly Chinese immigrants to prepare well is not a one-size-fit-all assignment. To achieve a satisfying preparation, the professionals should guide the elderly to think about their needs, preferences, and wishes to find a way that fits their circumstances. To cope with EOL preparation in the Dutch context, proactive exploration from the elderly themselves is decisive.

5.1.3. Regarding professional support

The current interventions benefit the elderly but not enough. Professional supports that suits the elderly Chinese immigrants will add significant value to their EOL preparation. Current ways of professional intervention are mainly in two ways: Sharing EOL knowledge in the seminars and offering consultations to help with the EOL issues. In recent years, the

seminars were carried out, received positive from the elderly, and showed its potential. However, the seminars focus on share information and knowledge. The communication, discussion, and further considerations are not enough. As for the consultation, it only happens when the request is proposed. It helps the elderly to solve the concrete problems they encounter. However, it is not an effective way of support for the elderly in the EOL preparation stage. Among the professionals, the social worker is the best one to carry out early-on interventions. Since their connections with the elderly and the concerned parties enable them to offer support to fit the current context. Their professionalism and rich experience help the elderly to get comprehensive support on the EOL preparations.

5.2. Problem definition

The research insights demonstrated the importance of early intervention from the professional side. Based in the Netherlands context, the elderly Chinese immigrants can prepare for EOL, no matter the capability. However, some barriers exist on the way of approaching that.



For the elderly:

- They need support to find and overcome the limitations caused by culture background
- Some are fear of EOL because of the uncertainty or taboo
- They do not realize the benefits of EOL preparation and in lacking the motivation to prepare.
- They need to learn about EOL, but accessible, reliable resources are not enough.
- Have not seriously considered how to make a personal preparation to fit their circumstances and preferences.



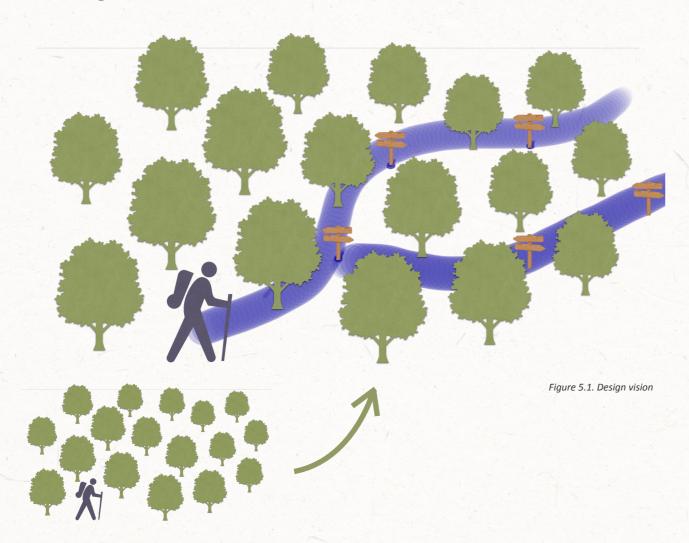
For the social worker:

- Their limited time and energy make it impossible to support every elderly with concrete consultation.
- The current interventions on EOL preparation are one-way communication. The discussion, communication, and deepen thinking are not enough.
- The way they offer support is not specific enough for elderly Chinese immigrants.
- In lack of transition professional interventions between the seminar and the concrete consultation.

5.3. Design direction

Therefore, the design directon is derived: Design a tool for social workers to offer early intervention on EOL preparation, which suits the elderly Chinese immigrants, and feasible to implement in the current context.

5.4. Design vision



Going through the EOL journey is a once in a lifetime experience, which is full of uncertainties. For the elderly Chinese immigrants who have few experiences on coping with EOL in the Dutch context, it is like walking in a jungle. In the jungle, people may encounter challenges and struggles, may lose direction and feel hopeless.

Thus, the design vision was proposed as:

" Set signposts for the elderly Chinese immigrants to their road to the EOL, to mobilize them proactively exploring the EOL preparations together with social workers, in the way of early intervention."

The signposts are created in order to show the possibilities in the EOL to the elderly. Even if this is a challenging road to walk through, the elderly can always get instructions and know how to react on specific points. With knowing there is always a direction, the elderly get encouraged and feel mobilized to make more explorations towards EOL preparation. The support from social workers helps them to learn about the EOL and make preparations early on. The road might be full of challenges. However, with the guidance and accompany, it is manageable.

5.4. Design requirements

1) Reduce fear

- The game should build the sense that EOL is something people can talk about, give the ECI the courage to talk about it, and face it.
- The game should create a comfortable atmosphere, reduce anxiety and fear towards EOL.
- The game should let the ECI know that the EOL challenges are solvable. No matter what situation they are in, they can always achieve a better end by using available care options, medical interventions, and professional supports.

2) Build understanding and eliminate misunderstanding

- The game should help the elderly to build a clear and holistic understanding of EOL.
- The game should offer knowledge to the elderly in a clear, structured way;
- The game should inform the elderly well about the resources related to EOL;
- The game let the elderly know how to react in each step;
- The game should demonstrate the foreseeable possibilities in future life in a clear and structured way.
- The game should tell the elderly how to cope with possible challenges.
- The game should let the elderly know how to better prepare for EOL and why it is recommended.
- The game should help to find out the existed misunderstandings caused by unfamiliar and incomprehension. For example, some elderly regard euthanasia as a coercive way for the last stage. This is not the case.
- During the game, the existed misunderstanding and questions raised by the elderly should be eliminated.

3) Help the elderly to find their way

- The game should enable the elderly to try out different options and see the possibilities;
- The game should guide the elderly to think about their own needs, concerns, preferences, and personal values.

- The game should inspire the elderly to think about what is essential for them, consequently helping the elderly find their way of coping with EOL.
- The game should trigger discussion on EOL topics among the elderly.
- The game should encourage the elderly to explore their preference in EOL issues.

4) Empower and motivate the elderly

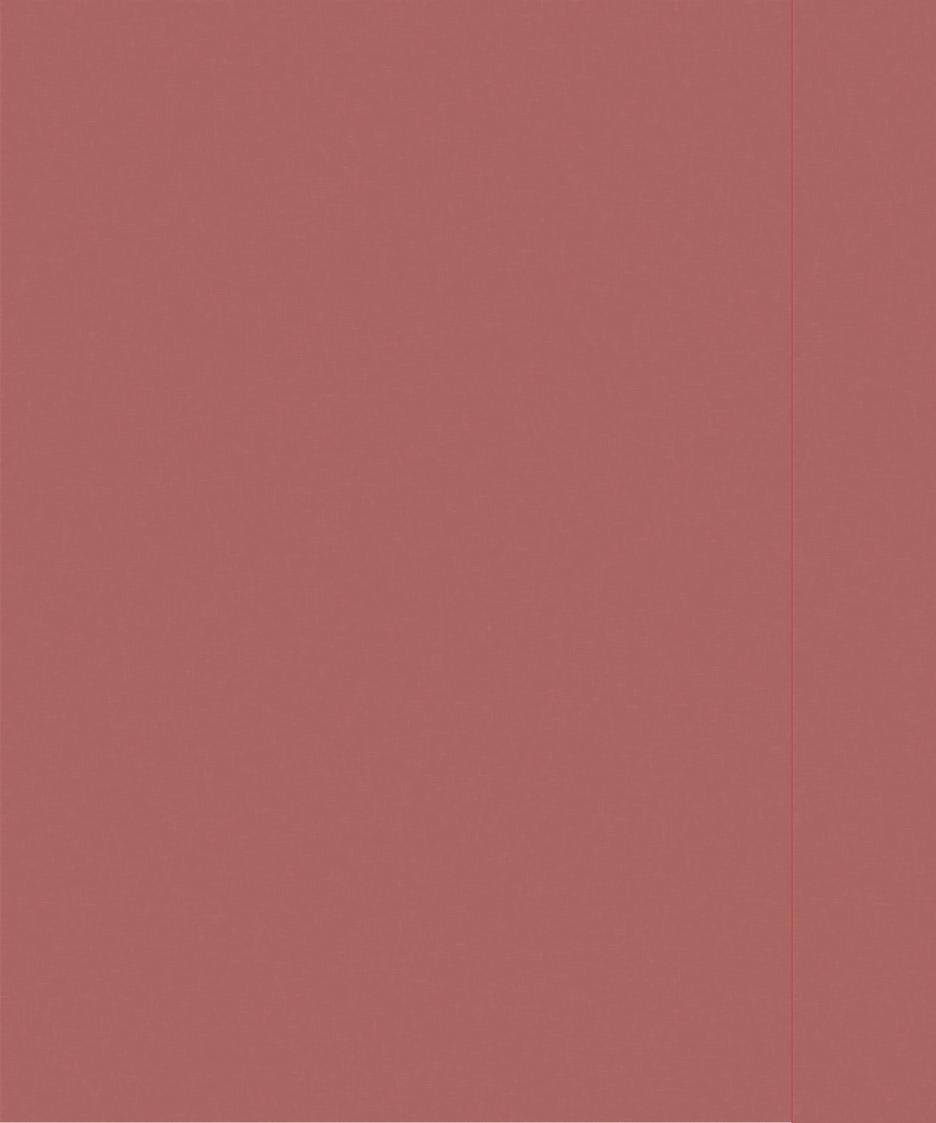
- The game should let the elderly feel less vulnerable and more supported.
- The game should guide the elderly to participate in the discussion and better express themselves.
- The game should help the elderly to build confidence in talking about EOL.
- The game can serve as a trigger, provoke some further considerations about EOL, and trigger discussions among the elderly and their family members.

5) Help the social worker

- The game should be easy to host;
- The game should avoid distractions, misleading, and overloading;
- The game should be easy to carry out;
- The game should be easy to maintenance;
- The game should trigger discussion among the elderly participants and their peers;

6) Ideally, the game can also meet the wishes below:

- The game should inspire the elderly to think about an ideal preparation for themselves;
- The game can trigger the elderly to take action towards EOL preparation;
- The game can be liked and spread among the elderly and their peers.



Chapter 6. Design development

This chapter narrates how a feasible tool for the elderly and the social worker came into being. Firstly, ideations were conducted based on the design direction and design vision proposed in the synthesis chapter. Three preliminary concepts were generated from the ideas. Among these concepts, the EOL preparation package was selected and developed into an EOL theme board game. After tests and iterations, the concept was conceptualized into the final design.

6.1. Ideation

6.1.1. Introduction

Individual ideations and co-creation sessions were conducted to generate ideas on tackling the problems. The individual ideation used sketches to present and document the ideas. Online cocreation sessions were conducted to further explore the design opportunity and generate more ideas. In each session, four designers from IDE faculty and one facilitator participated. Each session lasted for about two hours. See the descriptions on co-creation session in appendices.

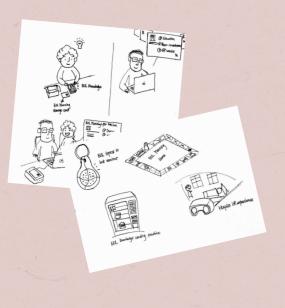


Figure 6.1. Individual ideation results

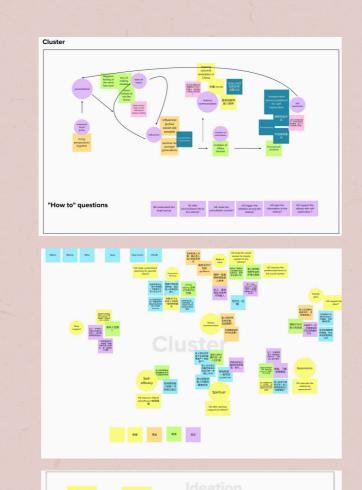


Figure 6.2. Co-creation results

6.1.2. Results

Ideas collected from individual ideation and co-creation sessions were selected and developed into three concepts.

Concept 1- the EOL preparation package

The EOL preparation package includes a series of materials related to EOL preparation. The package contains a guidebook, a voice notebook, and a template. With this package, the social workers can talk through the EOL topics with the elderly, in face-to-face consultations, or group sessions.

- The guidebook of EOL preparation uses graphics and words to explain EOL related topics. With the embedded voice IC, the elderly can listen to the voice introductions made pre-recorded by the social workers.
- The template is a small assignment for the elderly. The theme is to design a "good death" for character Mr.X. The elderly will use given stickers and make drawings to make a complete plan for Mr.X on his path towards the last phase of life.
- The voice notebook is offered to record the elderly's voice message. The voice notebook is offered to record the elderly's voice message.

Concept 2 - Semi-EOL VR game

The semi-EOL VR game shows the EOL journey to the elderly with a series of VR scenarios. During the game, the elderly go through the whole procedure of EOL preparation, including visit the hospice, create last wishes, and plan for rituals. The social work stands by and guides the elderly through the game. The participants can save their play records and use them in the next game. With the VR game, the elderly will get into the simulated scenario and understand the topics better. The VR game simulates the real case scenario. It is make the EOL topics less abstract. The novel gamification way will impress the participants.

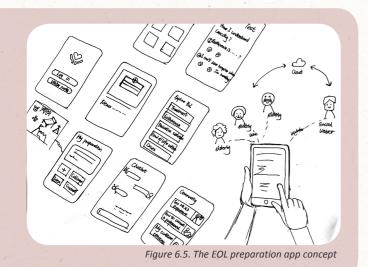


Figure 6.3. The EOL preparation package concept

The guidebook helps the elderly to learn about EOL topics. For those with a lower literacy level or poor eyesight, the voice IC will benefit. The template creates a sense of preparing the EOL for "someone else". When the elderly take the package back home, they use the voice notebook to record follow-up questions and further thoughts orally.



Figure 6.4. The semi-EOL VR game concept



Concept 3 - EOL preparation app

The app helps the elderly to learn about and explore EOL preparation. The elderly can click the icons to get an explanation of the EOL topics. They can use this app to chat with peers and EOL experts online.

The social workers collect news and resources about EOL and update it to the app. The app connects the elderly with similar interests, builds an online community and trigger discussions. The elderly can get timely news about EOL.

6.1.3. Concept evaluation

Based on the design requirements in chapter 5, the discussion with the social worker and the requests proposed by Pharos, a Harris profile was made to evaluate the concepts. See in Figure 6. Via the five criteria, the EOL preparation package was rated higher.

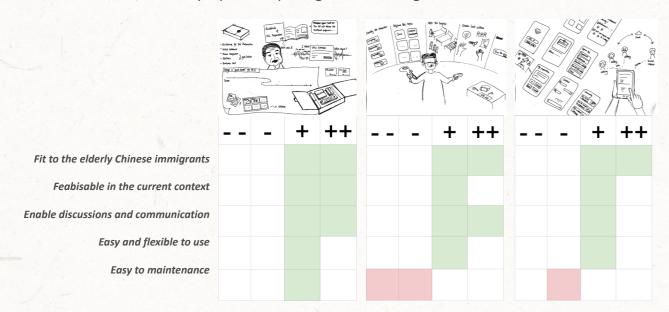


Figure 6.6. Harris profile

6.1.4. Further develop the concept

The EOL package includes a set of tools for the elderly to use. Among them, the timeline is selected to be further developed.

The reasons are:

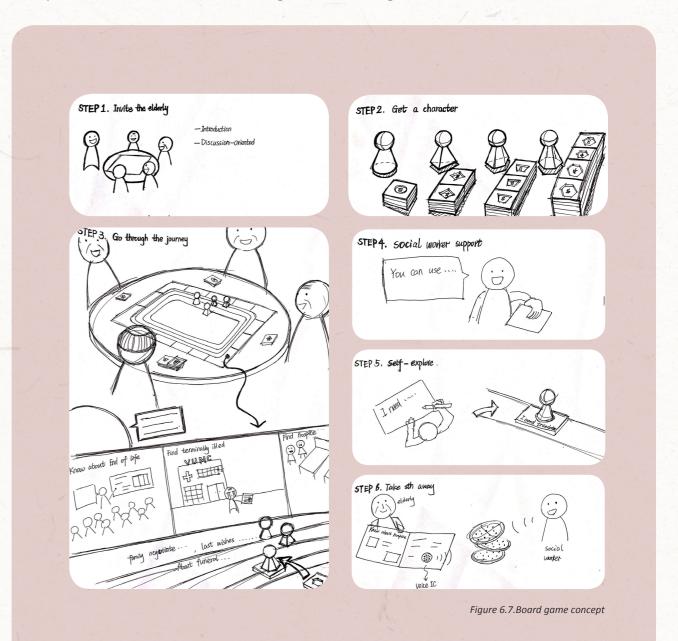
It enables the elderly to work together with social workers and peers.

It asks the elderly to design a "good end" for a virtual character. While filling the timeline for the character, the elderly can make use of his / her own preferences. They can also relate the character to the circumstance of their own.

The game-like format is less offensive. It is a friendly way of making EOL discussions.

At the end of the ideation phase, the new design decision was made: Design a physical game, in which the EOL topics are well-integrated. The social worker can use it to help the elderly Chinese immigrants to better understand EOL.

Based on the previous results, a board game concept was made. The participants go through an EOL journey with pawns. During the game, the possiblities for pawns with different capabilities will be explored. The social worker hosts the game and offere guidance.



6.2. Conceptualization

6.2.1. Define game content

To conceptualize the board game, the involved topics are firstly defined. During the game, the elderly participants should learn about:

Medical and care options:

What are the available medical interventions and care options for the EOL phase From who and where the elderly can get medical treatment and care Where to spend the last phase

Typical challenges elderly Chinese immigrants may encounter in EOL:

Stay at home or go to hospice
Get care from family members or get external support
How to apply for home care
How to make use of insurance

Topics regarding personal preference:

What is valuable in ones life What medical treatment people would like to receive or refuse

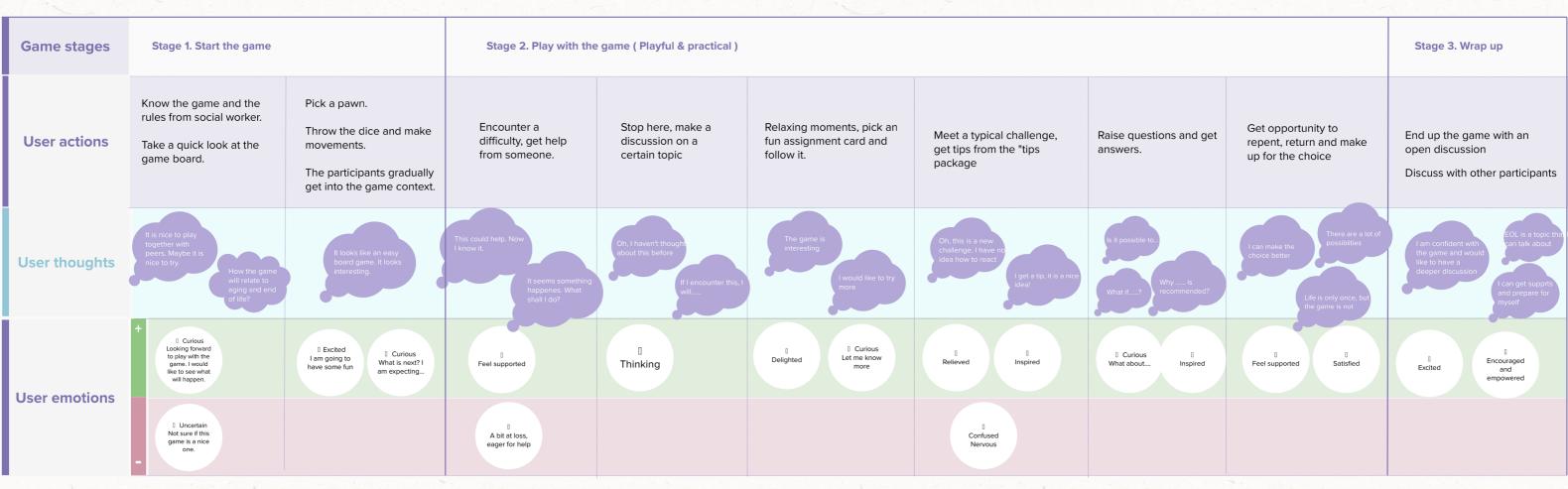
6.2.2. User experience design

To define the desired user experience in the game, a user experience map was created. The interactions that need to take place in the game was described in simple language.

In the user experience map, the game was divided into three parts: Start the game, play with the game, and wrap up the game. The desired user actions, user thoughts, and user emotions were defined.

By integrating the topics and desired experience, the content of the game board was enriched.

Figure 6.8. User experience design



6.3. Iterations

6.3.1. Methods

During the conceptualization, multiple tests with the single participant (for three times) and group participants (for two times, the first time with two participants, the second time with four participants) were conducted. The participants are all TU Delft students from China. None of them have EOL experience in the Dutch context before. The aim of the test is to check if the game works in a smooth flow and find out problems from the current game version. During the test, the author acted as a social worker, guided the participants through the game and answered their questions. The interactions during the game were observed. After running through the game, the participants were asked to give feedback on the content and the experience. Insights from observations were evaluated. Together, the test results were implemented into iterations.

6.3.2. Results

Iteration on the character

[Original version] A fixed character with simple description on age and gender [Iterated version] Enrich the biography with personality, family setting, insurance and property holdings, hobbies, and religious; Creat relationships between two of the characters

Iteration on game mechanism

[Original version] A one-way journey enable multiple routines [Iterated version] One-way journey with rich action points

Iteration on the gameboard

[Original version] Everything on the gameboard
[Iterated version] Make use of game cards, add interactions;
Develop tips capsule, move the solutions out from the game board;
Use a combination of description, pictures, and icons in the blocks;
The tone of game description and instructions are made more and more gentle, less offensive

Iteration on game content

[Original version] Only focus on EOL topics, some discussion topics are hard to understand. [Iterated version] Add fun elements and easy topic; For discussion topics: first, describe a scenario, then ask the discussion question.

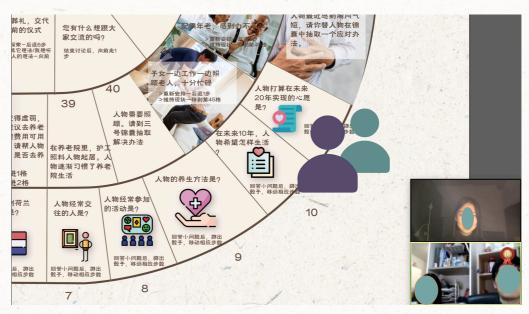


Figure 6.9. Online testing with group participants of two

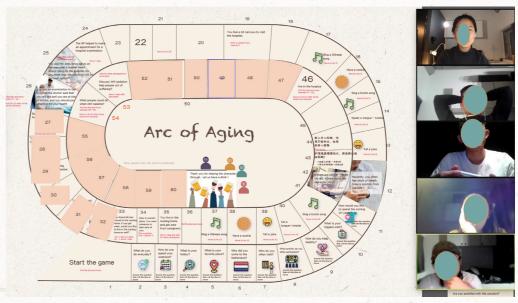


Figure 6.10. Online testing with group participants of four

46

Chapter 7. Final design

This chapter introduces the final design outcome - "Walk along, not alone," a board game that enables the elderly to explore EOL preparation with the guidance from the social worker, in a gamification way. The chapter starts with an overview of the board game. Then the game stucture was explained, followed by the users of the game. In the end, the game description ellborates the different stages in the game. In the report, the English version of the game is used for explanation use. The version designed for elderly Chinese immigrants is in Chinese.

7.1. Concept overview

荷你同行 "Walk along, not alone"

"Walk along, not alone" is a board game specifically designed for elderly Chinese immigrants residing in the Netherlands. As immigrants originated from a different culture, the elderly Chinese immigrants can use this game as a playful tool, to gain a better understanding of how to cope with ageing and end of life (EOL) in the Dutch context.

With rich interaction game mechanisms, the game helps the elderly learn about the possibilities, challenges, and solutions in the EOL journey. This game enables people to discuss sensitive topics in a comfortable atmosphere. Medical and care options, typical challenges that Chinese immigrants may encounter are integrated into the game. Besides, the role-play, the action mechanism and the fun assignments make the game easy to follow and playful. In this way, the game is made both practical and playful.

Four tips capsules are prepared, in corresponding to four typical challenges in Chinese immigrants' EOL journey. When the pawns encounter the pre-setted challenges in the gameboard, the participant can choose solutions from the Tip Capsules.

In the game board, three zones are covered by flip over cards. Each colour represents a topic. The covered blocks are the possibilities in the mentioned topic. For example, blocks covered by blue cards each tells a piece of information about hospice.

Tips Capsules

Start here

Characters with biography

Four pawns with biography are used in the game. Each participant role-plays a character during the game.

The game board

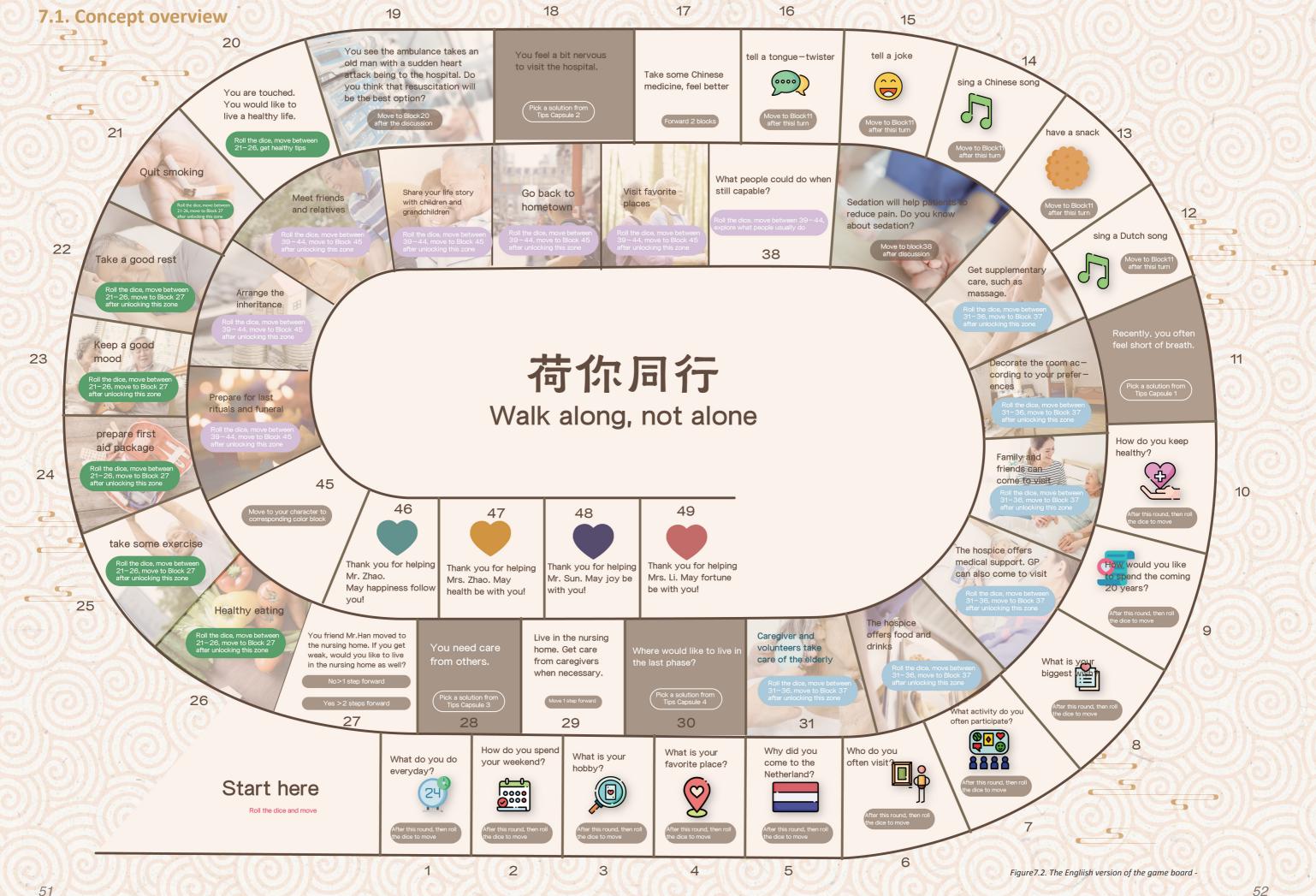
The game board is a groud for the pawns to move. It includes 49 blocks in total. By rolling the dice and following the instructions in the blocks, the participants take the pawn to move forward.

Flip over cards



The dice

Roll the dice to decide how many steps to move.



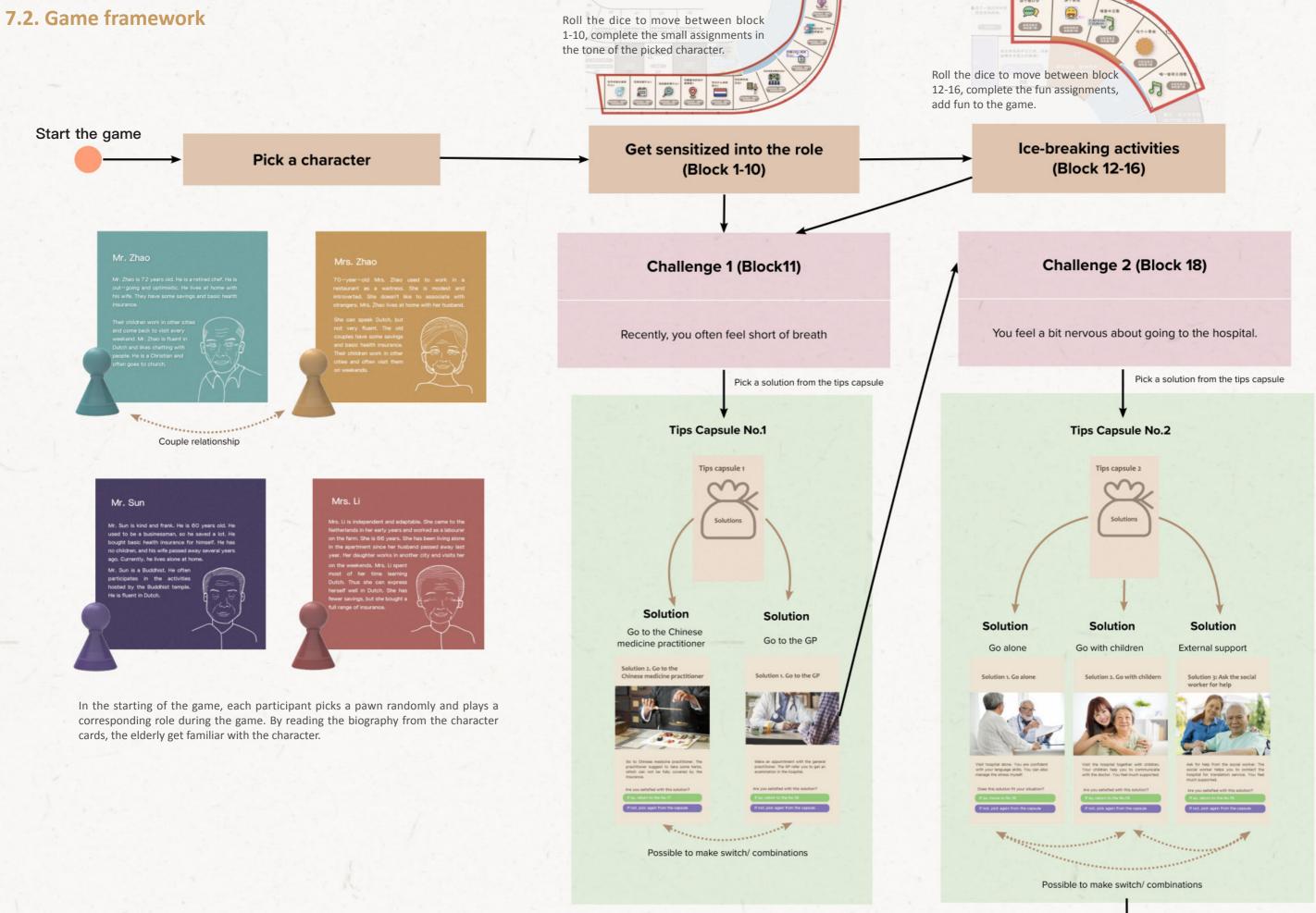


Figure 7.3. Game frame work - part 1

7.2. Game framework Healthy tips Discussion 1 (Block 19): (Block 20-26) Certain treatment or not? Continue here Nursing Challenge 3 (Block 28) Challenge 4 (Block 30) home (Block 29) Life will come to an end. If you are in the last phase, where Sometimes, you need people to take care of you. would you like to live? Pick a solution from the tips capsule Pick a solution from the tips capsule Roll the dice to move Tips Capsule No.4 **Tips Capsule No.3** between block 20-26, explore the available services from the hospice Tips capsule 4 Tips capsule 3 Know about the Discussion 2 (Block hospice (Block 20-37): Know about 26) the sedation Roll the dice to move Solution Solution Solution Solution Solution Solution between block 38-44, Get care from the family External support Go to the hospice explore and discuss, what Get care from the children Get care from the spouse External support are the valuable things to Solution 2. Stay at the current place, get care Solution 2. Taken care of by Valuable things to do before the last phase(Block 38-44) Move between block 45-49, get the thanks Wrap up the game and blessings from the (Block 45-49) characters. Possible to make switch/ combinations Possible to make switch/ combinations Figure 7.4. Game frame work - part 2 End of the game

7.3. User of the game



1) Participants

This game allows two to four elderly Chinese immigrants to participate. The knowledge level and experience of EOL does not influence participating in the game. For the elderly who are curious about the EOL preparation, they can use this game to learn about the EOL topics. For those who are eager to make EOL preparations, they can experience the EOL journey in the tongue of the character. For those merely would like to try it as a game, they can also get fun from the game, and get to know the EOL topics. The participants should use the same language or dialect in the game.



2) Game host

The game is suggested to host by the social worker or volunteer who gets trained on end of life knowledge and know the elderly Chinese immigrants well. Their language skill should match with the participants. Usually, the elderly prefer Cantonese, Mandarin. Some would like to use other dialects. The host guides the participants through the game, facilitate the game, lead the discussion, provide further explanations on the topics, and answer the questions from the participants.

7.4. Description of the game

1) Stage 1: Set up the game

Recruit elderly participants by flyers or through Chinese community. Find a place that the elderly familiar with. Prepare table, seats, snacks and drinks. Before starting the game, ask the language preference and literacy level in a friendly manner. If any of the participants are illiterate, the host should offer more support during the game, and encourage all the participants to read out loud during the game.



2) Stage 2: Start the game

The host introduce the game and give a self-introduction, then ask the elderly to each pick a pawn randomly. Send out the corresponding character cards. The host ask the participants to read out loud and get familiar with the biography. During the game, the participants will role-play these characters.

Relationship between the characters: Mr. Zhao and Mrs. Zhao are old couples. The other characters do not know each other The biography of the characters are:

[Mr. Zhao]

Mr. Zhao is 72 years old. He is a retired chef. He is out-going and optimistic. He lives at home with his wife. The old couples have some savings and basic health insurance. Their children work in other cities and come back to visit every weekend. Mr. Zhao is fluent in Dutch and likes chatting with people. He believes in Christianity and often goes to the church.

[Mrs. Zhao]

70-year-old Mrs. Zhao used to work in a restaurant as a waitress. She is modest and introverted. She doesn't like to associate with strangers. Mrs. Zhao lives at home with her husband. She can speak Dutch, but not very proficient. The old couples have some savings and basic health insurance. Their children work in other cities and often visit on weekends.

[Mr. Sun]

Mr. Sun is kind and frank. He is 60 years old. He used to be a businessman, so he saved a lot. He bought basic health insurance for himself. He has no children, and his wife passed away several years ago. Currently, he lives alone at home. Mr. Sun is a Buddhist. He often participates in the activities hosted by the Buddhist temple. He is fluent in Dutch.



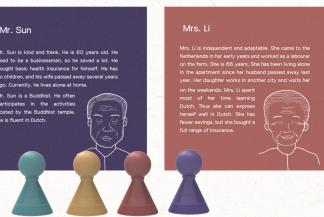


Figure 7.5. Pawns and character cards

[Mrs. Li]

Mrs. Li is independent and adaptable. She came to the Netherlands in her early years and worked as a laborer in the farm. She is 66 years. She has been living alone in the apartment since her husband passed away last year. Her daughter works in another city and visits her on the weekends. Mrs.Li spent most of her time learning Dutch. Thus she can express herself well in Dutch. She has fewer savings, but she bought a full range of insurance.

With the role-play mechanism, the elderly experience this journey in the perspective of the character. This way is less offensive for talking about EOL. Also, the participant plays a character whose circumstance is not the same with themselves. This will help them realize the things they have not considered or encountered by themselves before. With the biography and the relationships in the characters, the game is made full of fun.

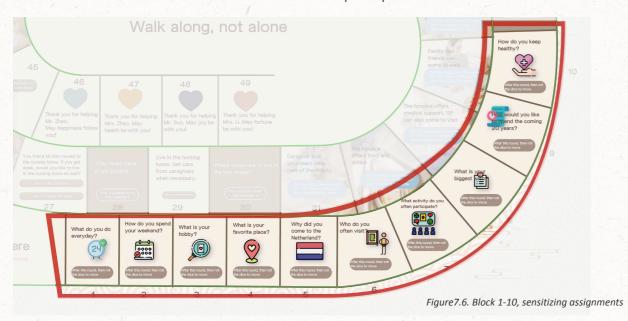
3) Stage 3: Sensitizing stage

Start the game. The elderly take turns to roll the dice and move. In the tongue of the characters, the elderly participants complete the sensitizing assignments in Block 1-10. These blocks help the elderly participants get familiar with the characters. The sensitizing assignments are:

- 1. What do you usually do every day?
- 2. How do you spend the weekend?
- 3. What is your hobby?

- 4. What is your favourite place?
- 5. Why did you come to the Netherlands?
- 6. Who do you often visit?
- 7. What activities do you often participate?
- 8. What is your biggest wish?
- 9. How would you like to spend the coming 20 vears?
- 10. Could you please share your tips for keeping healthy?

Afte complete the assignments in each round, the participants roll the dice to move.



The action instructions in block 1-10 are: Answer the questions in the tongue of your character. After this round, then roll the dice to move.

That is, each participant will go through at least one block from block 1-10. After several rounds in this stage, the pawns are going to end up between block 11- 16. Since the block 10 is the last block in this stage, and the dice indicates between 1-6. Therefore the block 16 will be the furthest end after leaving block 1-10.

4) Stage 4: Relaxing stage

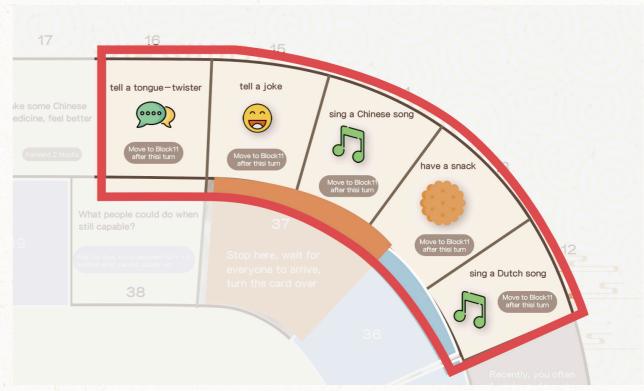


Figure 7.7. Block 12-16, relaxing moments

When the pawns move between block 12-16, the participants complete relaxing assignments to relax. The "Relaxing moments" add fun to the game, in order to create easy atmosphere, increase fun, and enhance the confidence in playing the game.

The action instruction in these blocks are: Complete the relaxing assignment, then move to Block 11 after this turn. That is, all the pawns will end up in block 11 after the "Relaxing moments" round.

The relaxing assignments are:

- 1. Sing a song in Dutch
- 2. Have a cookie
- 3. Sing a song in Chinese
- 4. Tell a joke
- 5. Tell a tongue-twister

5) Stage 5: Encounter challenges

The brown blocks are in corresponding to the tips capsules, aim to let the elderly participants explore the solutions. There are four typical challenges located in block 11, 18, 28, 30, respectively.

The challenges are:

Block 11. Recently, you often feel short of breath.

Block 18. You feel a bit nervous about going to the hospital.

Block 28. Sometimes, you need people to take care of you.

Block 30. Life will come to an end. If you are in the last phase, where would you like to live?

The action instruction in these blocks are: Check the description in the block, then draw a solution from the corresponding tips capsule.

Block 11 and 30 are challenges that all pawns will encounter. The other ones will be encountered depending on different choices made in former blocks. The challenges are typical challenges that the elderly may encounter in real life. These challenges are introduced in a neutral tone. There are always solutions offered by tips capsules, which prevent the elderly participants from feeling helpless while facing the challenges.

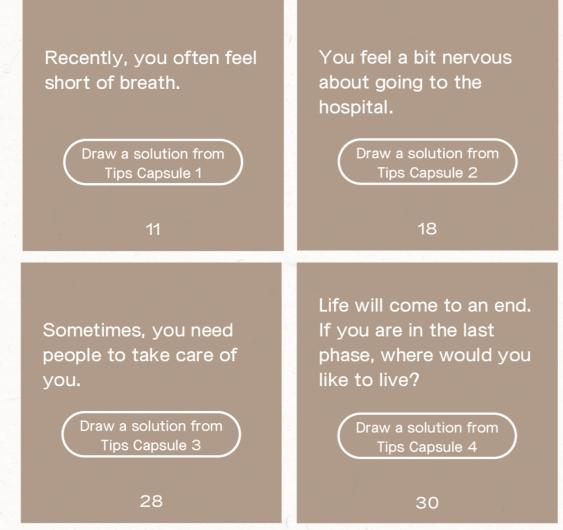


Figure 7.8. Blocks with challenges to react towards

6) Stage 6: Find solutions from the tips capsules

The tips capsule cards are prepared in corresponding to the typical challenges. When the pawn encounters the challenges in the game board, the participants will follow the action instruction and turn to the tips capsules for a solution. By flip over the tips capsule cards, the participants check the solutions on the other side. In these cards, pictures and descriptions demonstrate the solutions. The participants follow the prompts to move forward if they are satisfied with the solution they draw. If they are not satisfied or the solution does not fie the circumstances of their characters, the participants can draw again until they can move on.

The action instruction in these blocks are:

Check the description in the block, then draw a solution from the corresponding tips capsule. To be noticed, real life is usually more complicated than the described scenarios. Thus the solutions serve as a reference for the elderly participants. They can make combinations of the solutions they draw from the tips capsules. It does not mean the character can only continue with only one solution.

In this way, the elderly participants can get aware of the challenges that they may encounter in future life. They can get inspirations on solving the challenges. The action mechanism makes the game more interactive. The elderly will be engaged in the game and follow the game easily. With the different solutions picked out, the discussion can be triggered among the participants. Besides, the tips capsule is a metaphor that Chinese elderly are familiar with. This also created pleasant perceptions among the elderly.

In next page, the tips capsules and challenges are described together.

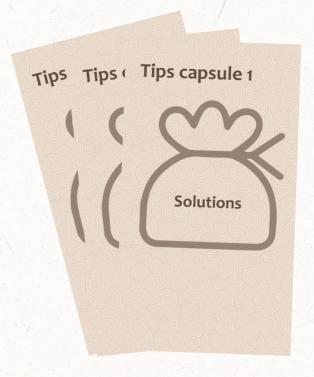


Figure 7.9. Back side of the tip capsules cards

Tips capsule in Chinese culture

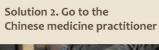
In ancient China, tips capsule were commonly used during the war and problematic cases. People get a brocade bag from a wise man. The prepared solutions are sealed in the brocade. When emergency or challenges happens, the one opens the brocade can be dismantled and act upon. Contemporarily, this metaphor describes a smart solution to relieve distress in time. Block 11 and 30 are the challenges that all pawns will encounter. The other ones will be encountered depending on different choices made when drawing solutions from the tips capsules. Here the solutions in tips capsules are described together with the corresponding challenges.

6) Stage 6: Find solutions from the tips capsules











practitioner suggest to take some herbs, which can not be fully covered by the

Are you satisfied with this solution?

Challenge 1

Recently, you feel short of breath.

Solutions in tips capsule 1

1. Go to the GP

Make an appointment with the general practitioner. The GP refer you to get an examination in the hospital.

2. Go to the Chinese medicine practitioner

Go to Chinese medicine practitioner. The practitioner suggest to take some herbs, which can not be fully covered by the insurance.

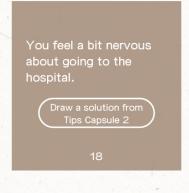
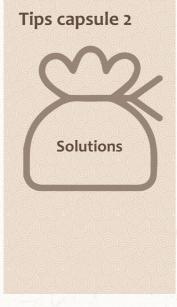


Figure 7.10. Challenge 1 & Tips capsule 1









Challenge 2

Recently, you feel short of breath.

Solutions in tips capsule 2:

1. Go to the hospital alone

Visit hospital alone. You are confident with your language skills. You can also manage the stress myself.

2. Go with children

Visit the hospital together with children. Your children help you to communicate with the doctor. You feel much supported.

3. Ask the social worker for help

Ask for help from the social worker. The social worker helps you to contact the hospital for translation service. You feel much supported.

Figure 7.11. Challenge 2 & Tips capsule 2

6) Stage 6: Find solutions from the tips capsules

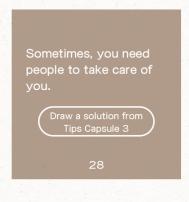


Figure 7.12. Challenge 3 & Tips capsule 3











Are you satisfied with this solution?

Solution 2. Stay at the

Solution 3. Ask for external help



district nurse comes to your place and takes care of you. The cost can be

Are you satisfied with this solution?

3. Ask for external help

care of you.

Challenge 3

Solutions in tips capsule 3

1. Taken care of by children

2. Taken care of by spouse

Sometimes, you need people to take care of you.

However, the spouse is also aged. He/she often feels tired.

Your spouse knows your living habits well. He/She takes good care of you.

The children travel between the two cities. They try theis best to take

After applying from the municipality, the district nurse comes to your place and takes care of you. The cost can be covered by insurance.

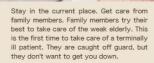
Life will come to an end. If you are in the last

Figure 7.13. Challenge 4 & Tips capsule 4









Are you satisfied with this solution?





district nursing service or ask for palliative care service from a local hospice. The professional caregiver comes to help, creating a great relief for both patient and

Are you satisfied with this solution?

Challenge 4

Life will come to an end. If you are in the last phase, where would you like

Solutions in tips capsule 4

1. Go to the hospice

Go to the hospice. Get care from the caregivers and volunteers based on your personal needs and wills.

2. Stay at the current place, get care from family members

Stay in the current place. Get care from family members. Family members try their best to take care of the weak elderly. This is the first time to take care of a terminally ill patient. They are caught off guard, but they don't want to get you down.

3. Stay at the current place, ask for external help

Stay in the current place. Apply for district nursing service or ask for palliative care service from a local hospice. The professional caregiver comes to help, creating a great relief for both patient and the family.

7) Stage 7: Exploration on specific topics

In the game board, three zones are covered by the flip over cards. The blocks covered by the same colour are related to a specific exploration topic. The action mechanism is: The participants roll the dice to move. When the pawn arrives at a block, flip over the card on that block and check information in the block. When the pawn enters the zone, the moving mechanism changes into: move in the same colour blocks until the participants unlock all the blocks in that zone. If there are other participants going through the same zone, together, the participants "unlock" this zone and learn about a specific topic. The exploration topics are:



You are troubled.
You are troubled.
You are troubled.
You would like to be the troubled of tro

Figure 7.15. Explore the healthy tips

Block 21-26 You are touched. You would like to live a healthy life.

Block 21 - Quit smoking

Block 22 - Take a good rest

Block 23 - Keep a good mood

Block 24 - Prepare first aid package

Block 25 - Take some exercise

Block 26 - Healthy eating

Block 32-36 Discover what is available in the hospice

Block 31 - Caregiver and volunteers take care of the elderly

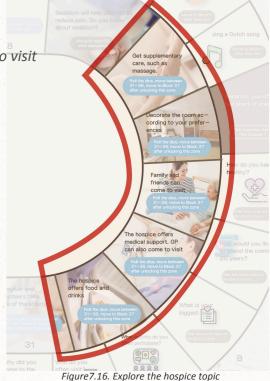
Block 32 - The hospice offers food and drinks

Block 33 - The hospice offers medical support. GP can also come to visit

Block 34 - Family and friends can come to visit

Block 35 - Decorate the room according to your preferences

Block 36 -Get supplementary care, such as massage



Block 39 - 44 What people could do when still capable?

Block 39 - Visit favorite places

Block 40 - Go back to hometown

Block 41 - Share your life story with children and grandchildren

Block 42 - Meet friends and relatives

Block 43 - Arrange the inheritance

Block 44 - Prepare for last rituals and funeral



Figure 7.17. Explore the "things to complete" topic

8) Stage 8: Discussion stage

Two discussion blocks locate in the game board. The **action instruction** in these blocks are:

The pawn stops at the "discussion blocks", wait for everyone to arrive, and then start the discussion with peers and the host.

When all the pawns arrive the discussion block, the host will lead the discussion. Firstly, the host repeats the description of the discussion topic and provides some further explanation on it. Then listen to the elderly's opinions. To be noticed, these topics may involve ethical concerns. The host should help the elderly build a clear and adequate understanding of the discussion topics, and make sure they perceive it. There are no right or wrong opinions.

The discussion topics are:

Block 19: Discussion regarding resuscitation

You see the ambulance takes an old man with a sudden heart attack being to the hospital. Do you think that resuscitation will be the best option?

Example conversations:

"I would like to live the longer the better. So I think people should pay all effort to get medical treatment."

"Heart attack seems not too painful, I know some people regard it as a nice way to leave the world. They don not want rescitation."

"I prefer to suffer less pain. Moreover, I do not want to be over treated. Then what will be a nice choice for me?

Block 37: Discussion regarding sedation

Sedation will help patients to reduce pain. Do you know about sedation?
Example conversations:

"It is my first time to hear about the sedation. It is so nice to have sedation to reduce pain in the tough stage."

"If I need sedation, who is going to help with that?"

"The GP will help."

"I think being conscious is also important. If I am in that stage, I would carefully consider to what degree I am going to use the sedation."

"This is a concern indeed. It is nice to think about it when still capable. If you encounter that, you can discuss with GP."

"My religion claims that pain is a suffer to prepare for a better afterlife. This is conflict with my wish. Maybe I should......"

"Yes, this is something to further considerate. You can discuss with spiritual leaders and think about what do you value, and what is your preference."

To be noticed

The euthanasia topic is not included in the game board to avoid negative impressions from the elderly. But this can be a derived topic in the discussion. The host can lead participants to learn about this topic.

9) Stage 9: Wrap up stage

In the end blocks, the thankyou notes from characters are given to the elderly.

The action instruction in these blocks are:

Move to the block matches with your pawn. Read the thankyou notes from your character.

The thankyou notes:

Block 46 - Thank you for helping Mr. Zhao. May happiness follow you!

Block 47 - Thank you for helping Mrs. Zhao. May health be with you!

Block 48 - Thank you for helping Mr. Sun. May joy be with you!

Block 49 - Thank you for helping Mrs. Li. May fortune be with you!



Figure 7.18. Wrap up stage - Thankyou notes from the character

In this way, the game ends up in a pleasant atmosphere.

Chapter 8. Evaluation on final design

This chapter introduces the evaluation of the final concept made with social workers. The evaluation setup includes the materials, participants, and procedures of the final evaluation. The evaluation results include scores given towards evaluation questions and qualitative feedback for further improvements.

Evaluation on final design

8.1. Goal of evaluation

The goals of the evaluation are:

To verify if the final design achieves the design goal;

To identify if the final design fits the current context;

To assess the usability and desirability of the final design;

To get insights on if the final design will match the elderly Chinese immigrants;

To collect feedback from professionals to further improve the design.

8.2. Evaluation setup

Constrained by the corona measurements, all the evaluations were conducted online with participants who had experience with the Chinese elderly on the EOL topic.

8.2.1. Participants

As claimed in the scope of the project, the project mainly focuses on the professional intervention side. Thus, the evaluation leans towards collecting feedback from the professionals. Besides, the corona crisis made getting access to the elderly infeasible. Therefore, the participants of the evaluation session included: Two social workers and one experienced volunteer. One of the social workers works as an advisor to support Chinese elderly immigrants in solving daily life difficulties. He helps with EOL related matters and hosts EOL seminars for elderly Chinese immigrants, the scale of which is usually one to two hundred participants. The experienced volunteer used to host several EOL seminars together with the social worker. She does not offer support on the practical matters but often answers EOL-related questions proposed by the Chinese elderly. Working for EOL related issues is also part of her job, not all. As for the second social worker, she has no experience helping with practical EOL matters but with rich experience serving elderly Chinese immigrants.

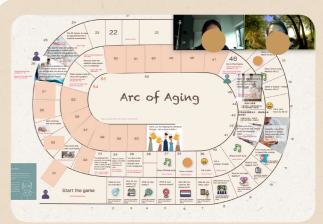


Figure 8.1. Online evaluation with the social worker

8.2.2. Materials

The digital version of the board game was used to demonstrate the game. Character cards, pawns, dices, game board, reversible cards, and tips capsule cards were shown to the participants remotely, all in the digital version.

Two online forms were designed to help the participants to evaluate the final design. The form used a ten-point Likert scale. The first form asked the participants how elderly Chinese immigrants may perceive and experience the game as a game participant. Since the participants are only professionals instead of any Chinese elderly, the first form only asked for overall feedback. The second form asked the professionals to evaluate how they perceive and experience the game as a game facilitator. This form includes concrete questions regarding usability and desirability.

8.2.3. Procedures

1) Brief introduction

Welcome and briefly introduced the evaluation.

Described using context to the participant.

2) Demonstrated the game

Picked a character randomly and went through the game.

The participant followed, meanwhile, thought out loud.

During the game, the participant's actions and thoughts were observed and recorded. Explanations were provided when necessary.

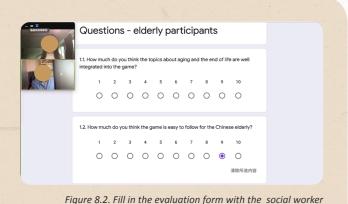
3) Evaluate the game

After going through the game, the participant filled in two evaluation forms and told the reason for the scores he/she gives.

4) Ask for feedback

In the end, the participant was interviewed, shared their overall experience, asked further questions, and gave suggestions. These are recorded and summarized.

5) Repeated step 1 to 4 for the next participant



8.3. Evaluation results

The evaluation results include two parts:

- 1) Results of the evaluation form
- 2) Feedback on the game

8.3.1. Results of the evaluation form

All three participants gave positive feedback on the game format and the game experience. The social workers attached importance to the working experience and the context. They all proposed that for social workers with much experience working with the elderly and rich knowledge on EOL topics, the game will be easy to use. For less experienced ones, more practice will be required. The collected reviews are relatively close, except for question 2.3. One of the participants suggested the game itself will benefit social work, but improving professionalism is overused.

See the evaluation questions and given scores in Figure 8.3.



2.6 How much do you think the design will help you improve •

2.7 How would you rate your experience with this game? (Average

professionalism in social work? (Average score: 7.33)

score: 8)

Figure 8.3. Evaluation questions and given scores

8.3. Evaluation results

8.3.2. Feedbacks on the game

The overall design is perceived as a good tool to make EOL discussions. It creates engagements of the elderly side. Change giving information to the elderly to let them participate.

- "It is nice to merge the EOL-related topics in a board game."
- "The game puts a sensitive topic in a relaxing manner. It breaks the taboo of talking about death."
- "Engagement is the new thing I can envision from this design. In the past, we used flip overs, posters, and films to tell the elderly about EOL. Those are one-sided communication. This game will make the elderly more involved and create more interactions."

The board game format is new to some Chinese elderly. Some elderly may feel it is fresh and grow interested; some may feel it less attractive.

- "The board game is possibly a new thing for some of the Chinese elderly. The elderly who have no experience playing board games will perceive it as a new game and grow interests in the game. For those who love board games, they will actively react towards it and efficiently manage the game."
- "The board game is not a very popular activity among the Chinese elderly. Instead, the Chinese elderly are more interested in playing Mahjong and shopping in the market. To attract the elderly to join the game, social workers need to put it nicely."

The involved topics match with the need of the Chinese elderly. It is possible to present the content in different ways.

- "Having explanations about the hospice is very nice. Based on my experience in end of life seminars with the Chinese elderly, most of them, at least 90%, do not know the hospice. They raised questions about the hospice. The most frequently asked one is, are there any Chinese-speaking caregivers or volunteers in the hospice?"
- "The scenarios in the solution capsules can be slightly adjusted to fit real life. If you show this to the elderly participants during the game, they can get more aware of the challenge. For example, you can show a case in which the family members are exhausted from taking care of the dying elderly, but they do not know how to speak to the elderly.

The social workers proposed several topics to add into the game. However, too much content can make the game duration longer and make the discussion more complicated. A balance is required.

- "Regarding the last topic, how to spend the rest of life. The game could assign them a "satisfying end". The game could ask them to leave a memorial to the loved ones, do something nice for others, and evaluate life's value. I want to give the elderly a sense that even the physical strength is decreasing, there are still potentials in other aspects."
- "There is still a long way to go before losing physical capability and relying on others' care. This is in missing in the game. The game involves the nursing home and the hospice. In the Netherlands, the elderly can get care from aanleunwoning(care home), bejaardeultuis(retire home), verpleegtehuis(nursing home), and hospice, depending on their health condition and physical capability. If the elderly would like to know more care options. It is crucial to make a clear distinction between the different places. The game itself, or the social worker should make a clear explanation."

The visual style fits the elderly's preference. The icons are too modern style. This can be improved.

- "Make sure the size of the fonts is big enough for the elderly.
- "It is nice to use traditional symbols in the background. This will remind the elderly of their familiar Chinese elements. The Chinese elderly will love it if they find it recognizable."
- "The icons in the "sensitize section" and the "Ice-breaking activities" are in modern style. I am not sure if the elderly will love them."

The user experience is nice overall. The game is interactive and interesting.

- It significantly depends on the context and the social worker's experience.
- The game is interesting and interactive. It reminds me of the monopoly game.
- The game puts the end of life topics in an easy-to-follow way.

8.3.3. Suggestion for improving the design

More characters can be created for the game.

- "I would like to see more characters. I believe this will create resonate in participants with different life stories. Also, I would like to see more content that reminds people of real-life cases."

Test the game out with elderly participants. This will also help enrich the biography and the game content.

- "I am looking forward to seeing the game being tested out with the elderly. They can also help to enrich the character biography and the topic."

Online interactive version can be deloped

- "It would be nice to combine new technology with this game."

 The elderly wear a VR glass and go through the game."
- "The game can be adjusted to help Dutch elderly, elderly immigrants with other backgrounds residing in the Netherlands, and elderly living in other countries."
- "It can be developed into a computer game, enable youth and middle-aged to play with it."

Other Questions

- Q: "Is this design suitable for the elderly with dementia?"
 A: "No, the current version is designed for the Chinese elderly who are still capable of making preparations, aiming to create awareness, trigger discussion, and ideally promote proactive action towards end-of-life preparations. Pitifully, due to this project scope, the elderly with dementia are not included in the target user."
- Q: "I would suggest using the game in the "Meet each other" activity. It is going to be hosted by the Hague municipality."

Chapter 9. Conclusion This chapter ellborates how the design question is answered. The limitations of the design is discussed. The recommendations for implementation and further development are proposed.

9.1. Answer to the design question

The **design question** is: How to help the professionals to move one step further in supporting the elderly Chinese immigrants with EOL preparation?

To answer this question, the project first started broad research on the context and the stakeholder. For the elderly living in an acquired culture background, both barriers and enablers exist in their EOL preparation context. By building empathy understanding on the elderly Chinese immigrants, the way to support was found. That is, introduce the sensitive topic with an engaging activity, enable elderly with different needs to participate and benefit from it.

By looking into the existing interventions, the limitations of the current professional support were found. The current interventions are all one-side communication, which can be improved into: let the elderly engage more and speak out their needs, questions and considerations.

The way professionals work were investigated. Based on this, the social worker was found out to be the best professional to support the elderly. Till here, the research is narrowed down and lead to a clear direction: Design a game to help social worker facilitate the discussions on EOL topics.

To reach the final design, multiple tests and iterations were conducted. This made the game structure and action mechanism solid. It is highly feasible to update the game when new knowledge and new solutions need to be introduced to the elderly.

In the evaluation, the design received positive feedback. It is perceived as a useful tool to make EOL discussions easier. The current version is ready to test out with the elderly participants.

9.2.Limitations of the design

Not all EOL topics are included in this game

There are various EOL-related topics worth discussing. Constrained by the game duration, it has not covered all of the topics.

High requirements for the game hosts

To conduct this game, a high familiarity on EOL knowledge is required from the game facilitator. Also, the game host should know the elderly Chinese immigrants well.

Test and evaluate

The final design has been only evaluated with professionals. No elderly participants have tested the game out. The game should be examined regarding related ethical concerns. This is not achievable within the scope of this project.

Ethical concerns

Due to time limitation, the final design has not been reviewed with strict ethical standards.

9.3.Recommendations for the design

Steps before introducing the game to elderly participants

Step 1. It is recommended to first play the game between social workers, experienced volunteers, Pharos educators and other EOL experts. It is a vital step to be highly familiar with the game before introducing it to the elderly.

Step 2. The pilot tests with elderly participants are recommended to conduct with the accompany of more than one expert.

Several pilot tests with the construction of Pharos educators is needed.

Step 3. With the practice in former steps, the host will get enough experience and be capable of facilitating the game independently with a group of elderly participants.

For further iterations

This design can be iterated periodically by Pharos or social workers after carried out with the elderly Chinese immigrants. During the tests with young Chinese participants, it is already found that new proposals and ideas came out during playing and discussions. During the game with elderly Chinese immigrants in future, the experience and opinions shared by the elderly will help to enrich and adjust the game content.

Adapt the game to other target groups

This game can be adjusted to adapt to other target groups. For example, immigrants from different cultural backgrounds, Chinese immigrants residing in other countries. The Dutch elderly may also use it. Based on concrete research and understanding of a specific target group, the content, visual style, typical challenges, and the key moments in the game can be adjusted to fit different culture and context.

Develop an online version

Develop an online version, enable people from different age groups to access to the game.

Merge with other technology—for example, VR game.

As a reference for other ussage

The game puts the sensitive EOL topic in an easy way. This design can be adjusted to fit other topics or needs. For example, tough topics.

Chapter 10. Personal reflection

In this project, I have achieved my goal of design for a social probe and design for EOL topic. At the beginning of this project, I doubt a lot, is it possible to tackle or make any intervention on such a topic with design. Magically, it is achieved in the end. At this moment, I think reliable design methods and design intuition make it happened. Also, the strong support from my supervisory team and the on-point feedback from the social workers are solid backings. This is a forgettable individual project, in which I faced a mass of challenges and finally found a way to cope with them. As a designer, I have learned the importance of designer intuition again in this project. Also, I have learned that initiative could take people anywhere, no matter how tough the road seems to be. The topic itself taught me a lot, about life, about people. I am impressed by the stories, the passion, and the vision people share to me.

The COVID accompanied the whole project. It makes people think more about the end of life topic. Working in the COVID is a memorable experience. It feels like doing a "spacewalk". The surrounding environment becomes a vacuum. The inspiring conversations and pleasant moments from daily life suddenly disappear. When I got aware of the influence on my life, work, and mood, it is a bit late. From this experience, I have learned that reviewing my own daily life and work is very important.

In the project, there are pities, of course. I can not leave the last-minute-person club, even in the last project of the master career. Hope I can get rid of the procrastination one day! If there is a second chance to conduct this project, I will pay more attention to time management. Also, I will try more resources to get feedback, to listen to people from different expertises.

Acknowledgement

At the end of the project, I would like to thank my supervisory team. Without their help, I am not able to go this far. I would like to thank my chair, Dr. ir. Sonneveld, who started coaching me since the beginning of the former research project. At the moment when I doubted whether a designer could make something for this topic, her inspiring suggestions, warm encouragement took me out from the struggles. Her passion on the end of life topic, empowered me a lot. I would like to thank my mentor Dr. ir. Boeijen, A.G.C. van. She is open-minded, considerate, and always open for help. Her knowledge about culture and design inspired me a lot. Her help on report I would like to thank my company mentor, Dr. Gudule Boland. She took a lot of time from her busy schedule and offered insightful input to the project. With the remote meetings, we had a lot of discussions, which push the project forward.

Special thanks to Mr Lau, Xiaofei, Miss Leung, Mr Wai, master Xianchang, and the pastor who would like to keep anonymous. They kindly took time from the extremely busy schedule and joined the interviews. I have learned a lot from their rich experience and wisdom. Also, I would like to thank the elderly participants who kindly shared their life story and opinions with me.

A lot of thanks to my peer students who actively participated in my co-creation sessions and contributed so many excellent ideas. It is my great honour to work together with so many talented designers-to-be. Thanks must be given to Chengtian, Xiaochen, Yuxin for taking time to discuss the design. A big thanks to Yiling for her last-minute support. And special thanks to Hosana and Xuexue, their words cheered me up again when I almost give up.

Moreover, I would like to thank Dr. Ir. Hao, C for her inspiring talk at the beginning of the graduation project, which helped me to narrow down the broad topic in time and defined what I would like to achieve in this project.

Last but not least, I would like to give a big big thanks to my dear mom and dad for their unconditionally love and support. In Chinese, 谢谢爸爸妈妈无条件地爱我、支持我去做我想做的任何事情。

Reference

- 1. A funeral scene in the Netherlands. (2017, May 3). [Photograph]. The Future of Funerals: What the UK Funeral Industry Can Learn from the Dutch. https://www.ritualstoday.co.uk/the-future-of-funerals-what-the-uk-funeral-industry-can-learn-from-the-dutch/
- 2. AFP. (2017, May 25). Dutch funeral [Photograph]. Dutch Funeral Expo Digs up the Latest in Death Trends. https://www.todayonline.com/world/europe/dutch-funeral-expo-digs-latest-death-trends Blank, R. H. (2011). End-of-life decision making across cultures. The Journal of Law, Medicine & Ethics, 39(2), 201-214.
- 3. Chung, H., Harding, R., & Guo, P. (2020). Palliative Care in the Greater China Region: A Systematic Review of Needs, Models, and Outcomes. Journal of Pain and Symptom Management, 1–28. https://doi.org/10.1016/j.jpainsymman.2020.08.040
- 4. Contextmapping. (n.d.). Retrieved from http://contextmapping.com/about/
- 5. Design Council. (n.d.). What is the framework for innovation? Design Council's evolved Double Diamond. Retrieved September 29, 2020, from https://www.designcouncil.org.uk/news-opinion/what-framework-innovation-design-councils-evolved-double-diamond
- 6. Funeral Customs China culture. (n.d.). WaybackMachine. https://web.archive.org/web/20160718180034/http://traditions.cultural-china.com/en/14Traditions986.html
- 7. Goldade, J. (2020, August 17). Cultural Spotlight: Dutch Funeral Traditions. Frazer Consultants. https://frazerconsultants.com/2019/06/cultural-spotlight-dutch-funeral-traditions/
- 8. Government of the Netherlands. (n.d.-a). Care and support at home. Retrieved September 29, 2020, from https://www.government.nl/topics/care-and-support-at-home/living-independently-for-longer
- 9. How to talk about life and death: In gesprek over leven en dood in Kantonees (met ondertitels in het Mandarijn). (2019, March 19). Pharos. https://www.pharos.nl/kennisbank/papia-tocante-bida-y-morto-in-gesprek-over-leven-en-dood-in-kantonees-met-ondertitels-in-het-mandarijn/
- 10. Kennisbank. (2020, June 24). Pharos. https://www.pharos.nl/kennisbank/?thema=palliatieve-zorg
- 11. Koopmans, R. T., Pellegrom, M., & van der Geer, E. R. (2017). The Dutch move beyond the concept of nursing home physician specialists. Journal of the American Medical Directors Association, 18(9), 746-749.
- 12. Kroneman, M., Boerma, W., van den Berg, M., Groenewegen, P., de Jong, J., & van Ginneken, E. (2016). Netherlands: health system review.
- 13. Liu, C. H., Ingleby, D., & Meeuwesen, L. (2011). Barriers to health care for Chinese in the Netherlands. International journal of family medicine, 2011.
- 14. Liu, L., Zhao, Y.-Y., Zhang, L.-H., & Chan, H. Y.-L. (2020). Measuring Self-Efficacy and Readiness for Advance Care Planning in Chinese Older Adults. Journal of Pain and Symptom Management, 60(3), 622–629. https://doi.org/10.1016/j.jpainsymman.2020.06.013
- 15. Mjelde-Mossey, L. A., & Chan, C. L. (2007). Survey on death and dying in Hong Kong: Attitudes, beliefs, and preferred end-of-life care. Social work in health care, 45(1), 49-65.
- 16. Morhaim, D., & Morhaim, S. (2020). Preparing for a Better End: Expert Lessons on Death and Dying for You and Your Loved Ones (1st ed.). Johns Hopkins University Press.

- 17. Ning, X. (2019). Hospice and palliative care research in mainland China: Current status and future direction. Palliative Medicine, 33(9), 1127–1128. https://doi.org/10.1177/0269216319857495
- 18. Pang, M. C. (1999). Protective truthfulness: the Chinese way of safeguarding patients in informed treatment decisions. Journal of Medical Ethics, 25(3), 247–253. https://doi.org/10.1136/jme.25.3.247
- 19. Pieke, F. N., & Benton, G. (1998). The Chinese in the Netherlands. The Chinese in Europe (pp. 125-167). Palgrave Macmillan, London.
- 20. Pharos. (n.d.). In gesprek over de laatste levensfase met Chinese migranten. Retrieved March 4, 2020, from https://ingesprek.pharos.nl/
- 21. Rahemi, Z., & Williams, C. L. (2020). Does ethnicity matter—Cultural factors underlying older adults' end-of-life care preferences: A systematic review. Geriatric Nursing, 41(2), 89–97. https://doi.org/10.1016/j.gerinurse.2019.07.001
- 22. Rietjens, J. A., van der Heide, A., Onwuteaka-Philipsen, B. D., van der Maas, P. J., & van der Wal, G. (2006). Preferences of the Dutch general public for a good death and associations with attitudes towards end-of-life decision-making. Palliative Medicine, 20(7), 685-692.
- 23. Sørensen, K., Van den Broucke, S., Fullam, J., Doyle, G., Pelikan, J., Slonska, Z., & Brand, H. (2012). Health literacy and public health: a systematic review and integration of definitions and models. BMC public health, 12(1), 80.
- 24. Ten things about death in the Netherlands. (2015, October 6). DutchNews.Nl. https://www.dutchnews.nl/features/2015/10/10-things-about-death-in-the-netherlands/
- 25. The Final Stages of Life. (2013–2016) (Fifth edition, Vols. 1–8). Amsterdam, the Netherlands: NVVE.
- 26. Thomas, L. (2020). One wedding and no funeral: The Farewell. The Lancet Psychiatry, 7(8), 672. https://doi.org/10.1016/s2215-0366(20)30303-5
- 27. Xie.Y, & Zhu.H.L. (2014). Difficulties and solutions for the localization of hospice care. Chinese Medical Ethics, 27(3), 367-368.