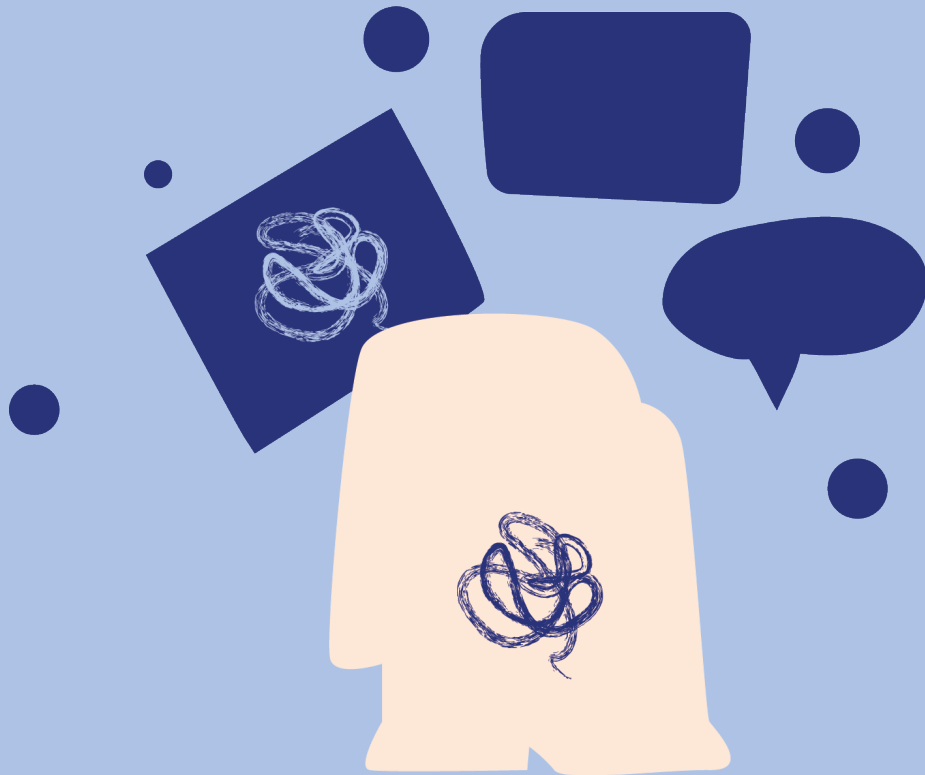


Echoes of Loss



exploring personal grief
through recognition

Master thesis by Layla de Blok

COLOPHON

Echoes of Loss: exploring personal grief through recognition

Master thesis

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Date and place

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Delft

***“We don’t see the world as
it is, we see it as we are.”***

Anaïs Nin
Famous diarist

PREFACE

Dear reader,

When I started this project I did not know how to answer the question: “What made you choose this project?” I have never lost a person close to me, so there was no clear answer, except for finding it an interesting topic. During this project, I realized I did have experience with loss and grief. Both my parents have been sick during my studies and for both of them, there was a significant chance they would die. Luckily they did not. However, I did get a glimpse of how disruptive and complex grief can be. I kind of pushed away these experiences, yet I do believe this (subconsciously) made me attracted to this project and chose the target group of parentally bereaved emerging adults.

I often wondered how I would have done if any of my parents had passed. After all, I knew nothing about ‘how to grieve’. Grief and loss looked so big, scary, dark and inevitable. Now, at the end of this project, I can say there is no general ‘how to’ for grief, and loss is still an inevitable part of life, but grief no longer feels as big, scary and dark. It is so much more nuanced and rich than I imagined. Perhaps in some ways even beautiful. I hope I have created something that reflects this lesson.

I could not have made this without support. First I like to thank my supervisors **Gert and Marieke** for guiding me through this project. The road was not without bumps, but I have always felt supported by you. Marieke, thank you for trusting this project to me and always having trust in me during this project, even if I did not always believe in myself. You were honest with me when my design was not good enough (yet). At the same time, you saw potential in my design direction. This helped me create something I am proud of. Gert, thank you for taking the time to review or think along. You often helped me zoom out and find perspective when I was lost in all the details. I also want to thank **Robin and Annelies** from Vereniging Leven met Dood. Your enthusiasm motivated me.

Many thanks to **all the people I have talked with who had lost a parent**.

Talking to you was inspiring for the project, but also on a personal level. You helped me get a rich understanding of what grief is. I could not have done this project without your openness to talk about something so personal.

Thanks to my **friends and family** who have helped in any way while writing this report. Thanks to my roommates **Lorena and Anne**, for putting up with my moods the last few months. But especially thanks for celebrating and reminding me of the small victories (and the hugs <3). Thank you **Deborah** for the Wednesdays at the Coffee Company, where you gave me knowledge on how to design online platforms. Lastly, many thanks to all **my graduation buddies** who have shared (a part of) this graduation journey with me. You made me feel less alone.

After thanking all these people, I would like to invite you to explore with me what grief is, and how we can support people experiencing it. I involuntarily dipped my toe in before, but please join me on this deep dive into the world of parental loss as an emerging adult.

Love,
Layla

GLOSSARY

Grieving, mourning and bereavement: In English, a distinction is made between mourning and grief. Unlike the Dutch language, which uses the word 'rouw' for both grieving and mourning, **grief** is the internal process of emotions and thoughts created by a loss. It is possible to keep this process hidden. **Mourning** is the outward expression of your grief. Mourning is greatly influenced by cultural beliefs, practices, and rituals. **Bereavement** is considered the period in which you experience your grief and express mourning (rouwperiode in Dutch). How long and if there is a designated period for this is also dependent on culture. (Lifespan Development, n.d).

Experience experts: the descriptor used in this thesis to describe a person who has lived through losing a parent as an emerging adult. They are seen as the experts of their own experience.

Off-time loss: refers to the death of a loved one that occurs outside of the expected or natural order. It is a term used to describe the loss experienced when a person dies before their time, such as the death of a child, a young person, or someone who dies unexpectedly.

Emerging Adulthood: A development phase, happening roughly between 18 and 30 years old (Arnett, 2000). It is a distinct period where young adults become more independent and explore various life possibilities. Characterized by delaying traditional markers for adulthood, like getting a job, buying a house, marrying, etc. It is mostly a Western phenomenon.

Professional grief support: Sometimes also referred to as formal support. It includes the services provided by professional, trained employees, typically paid for their work.

Informal grief support: This contains the help and support provided by friends, family and the community of the bereaved.

Blanket approach: Is the term for offering the same type of support and interventions to all grieving individuals, regardless of their unique needs and circumstances.

Website or platform: The key distinction between a website and a digital platform is on their approaches to user engagement. Websites offer one-way engagement, where users consume the content provided by the site. In contrast, platforms facilitate reciprocal engagement, with interactions between a platform and its users generating personalized experiences (Oomph, 2021).

VLmD: Vereniging Leven met Dood, the commissioner of this graduation project.

ABSTRACT

Grief is a complex experience without a specific end-point. It follows a unique path for each person. Many support sources are available, but finding support that fits is difficult. This inspired Verening Leven met Dood to develop the Rouw Wegwijzer, an online platform that provides personalised grief support. The focus of this thesis is to develop the platform from a user-centred perspective, specifically focusing on emerging adults who have lost a parent while not residing at home, a demographic for whom grief can wield a disruptive, life-altering impact.

The idea that grief has a set route and an end status of acceptance is a persistent, untrue belief in society. This shapes how bereaved think about their grief, how they are supported and what they expect from support. Contrary to this misconception, grief does not have a definitive end-point; rather, it involves a gradual and evolving understanding of the loss.

Effective grief support refrains from attempting to “fix” grief but rather acknowledges the bereaved and their experiences. Conversely, unhelpful support consists of offering unsolicited or paternalistic advice and attempting to solve the grief, approaches that contradict acknowledgement.

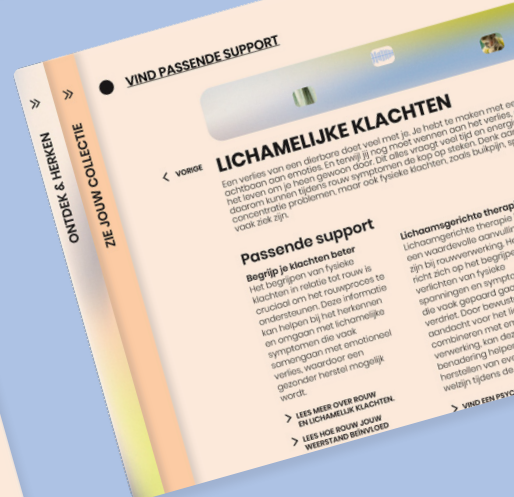
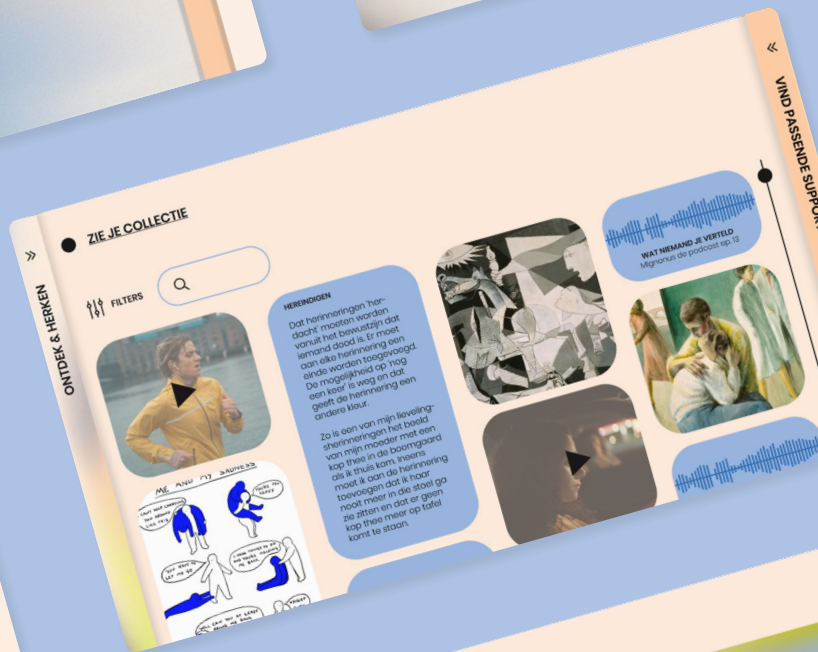
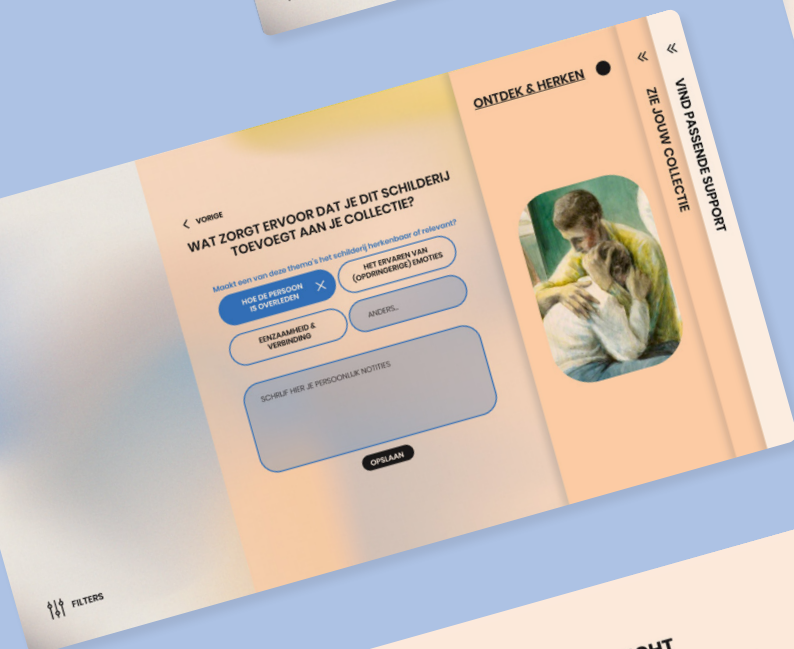
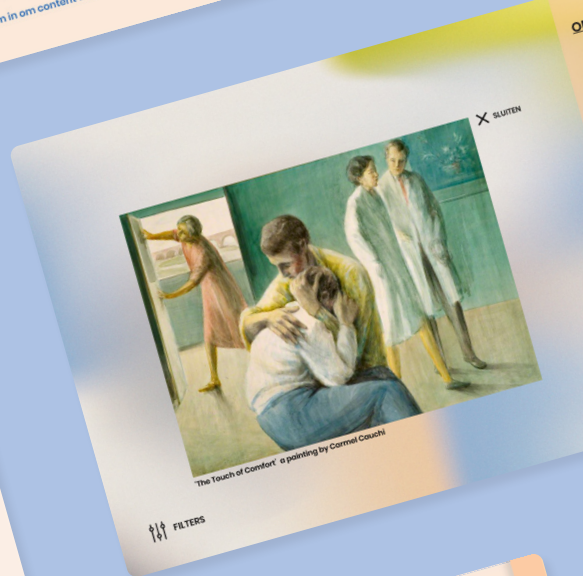
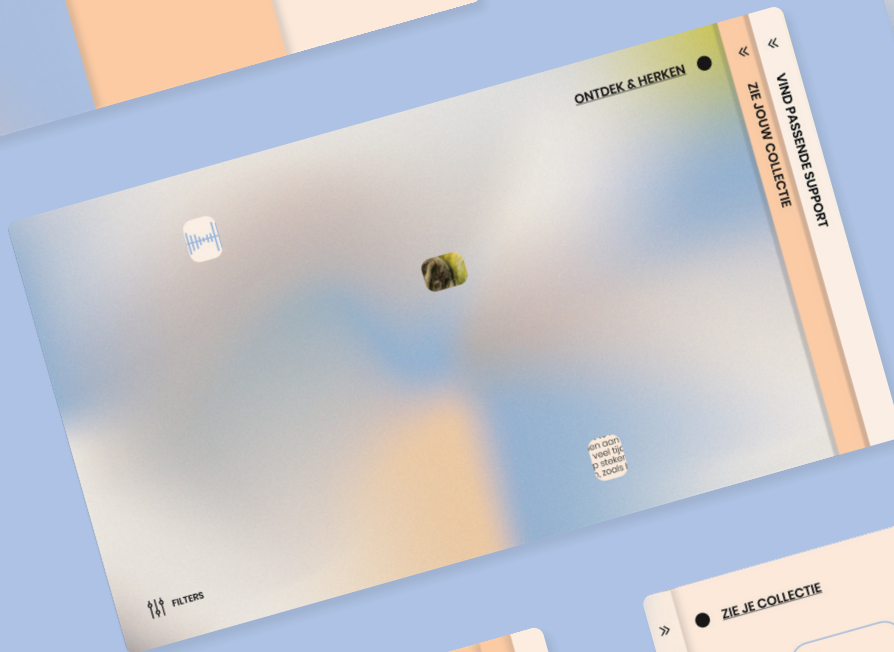
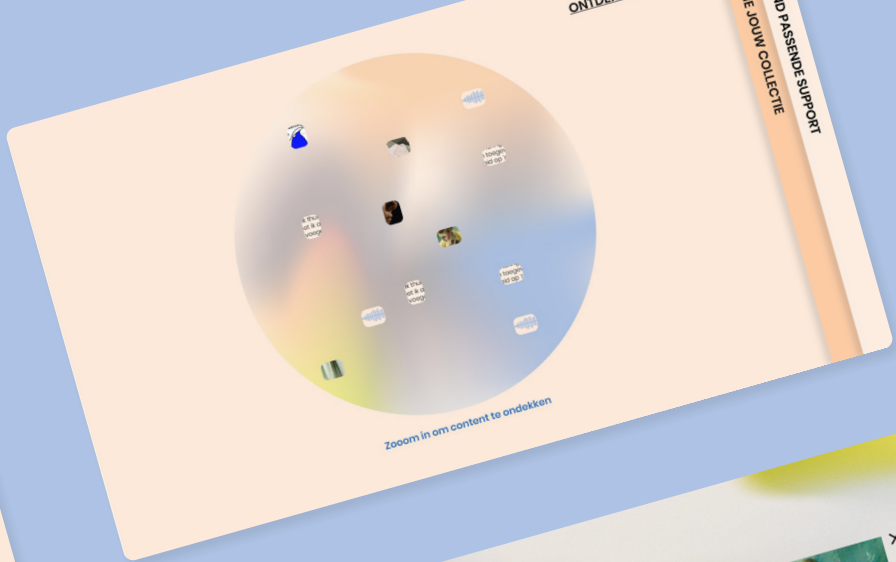
In this thesis, several research and design activities have been conducted to understand what grief is and what kind of support is considered supportive. Additionally, co-designing activities with the target group were conducted to find out what services are desirable for an online grief platform and how the interaction with the platform should be.

It was identified that grief support can have many forms, but usually is shaped as conversations or text. However, talking about grief can be difficult, due to the topic being taboo, making the bereaved untrained in expressing themselves and their needs. Generative sessions with the target group revealed “Recognition” as a promising design direction. Bereaved can expand their emotional

vocabulary, by recognizing their emotions and experiences in the expressions of others, ultimately leading to a deeper comprehension of their grief. This led to the following design goal: **“We want to offer bereaved emerging adults a place to explore their (understanding and expression of) grief, via recognition in others’ understanding and expressions.”**

The final design is a platform that leverages recognition to uncover and identify grief experiences that might be difficult to put into words. It allows users to explore what is important for them while exploring and collecting varied content about grief, captured in texts, audio, images and videos. Based on the collected content, and the themes discussed in it, an overview is created of which themes seem relevant for the user. Then, per theme, the user can access information and support.

The platform’s unique approach, transitioning from “exploring based on feelings” to a “structured and supportive” overview of relevant information and support, received positive feedback, with participants of the user test describing it as inspiring, clarifying and enlightening. However, usability issues hindered the user experience. Recommendations on how to improve the usability of the platform are made. Additionally, recommendations for further development of the Rouw Wegwijzer are given.



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Appendices

The appendices can be downloaded as a separate document from the TU Delft repository.

PART 0

Introduction

1/ PROJECT INTRODUCTION

1.1/ Context

Loss is an inevitable part of life, with 170,972 deaths recorded in the Netherlands in 2021 (Vereniging Leven met Dood, n.d.). On average, each person that passes leaves three next of kin behind. The death of a loved one can be a life- and identity-changing event (Porter & Claridge, 2021). The majority of individuals who undergo such loss experience grief, which is widely recognized as a natural response to the enduring stressor of losing someone important (Bonanno & Kaltman, 2001). Grief encompasses a range of short-term and long-term effects on an individual's life and well-being (more in chapter 3). Manu Keirse (Lectures 2022, 2023) compared grief to a fingerprint. Everyone can recognize what it is, yet for every person it is unique. This thesis explores ways to support individuals in their grief process, specifically emerging adults that suffered the loss of (a) parent(s).

support, VLmD wants to develop an online platform, called the Rouw We-gwijzer (Grief Signpost), that identifies bereaved individuals' unique needs, that provides appropriate resources or referrals to qualified professionals.

Acknowledging grief as a universal experience, the platform targets any bereaved individual in the Netherlands with internet access. VLmD envisions expanding the platform's support to include next of kin, strengthening the overall support network for those in grief.

VLmD clarified they will not assist in practical aspects post-loss, like funeral planning or insurance claims. Their focus is on providing and referring to fitting emotional and social support.

“Set up an innovative digital platform, that provides personalised information and support for bereaved people.”

Assignment by Vereniging Leven met Dood

1.2/ Project initiation

Vereniging Leven met Dood (VLmD), a non-profit, recognizes the need to improve the overview of support for bereaved individuals in the Netherlands. VLmD researches and provides grief support. Currently, grief support services in the Netherlands are plentiful yet fragmented, and the quality of care is often unclear (unpublished material VLmD, 2022). Personal fit is crucial; inadequate support may worsen suffering. To provide a guided way to find fitting

1.3/ Who is Vereniging Leven met dood?

Vereniging Leven met Dood describe their existence and history with saying they are a start-up, with hundred years of experience (Vereniging Leven met Dood, n.d., interview Anne-lies, see appendix 6). VLmD started in 1919 as Arbeidersvereniging voor lijkverbranding (AVVL), which became part of Yarden in 2001, a

funeral association. In 2022 Yarden became part of DELA another funeral association. VLmD did not join the merger and became independent.

In its current form, VLmD is a non-profit, with the credo 'samen verder' (continuing together). They have the mission to make death and grief less of a taboo in the Netherlands, however at the moment they are mostly focusing on offering support to the bereaved. They do this via multiple services where a bereaved can talk about their grief: a chat service, an email address, a phone call service or the option to meet face-to-face with a volunteer. All of these services are provided by volunteers. The Rouw Wegwijzer will be their next step in providing grief support.

1.4/ Scope of this thesis

My role in the research group

To investigate the viability, feasibility, desirability, content, and structure of the Rouw Wegwijzer, a research group has been established. Within the research group, my role is to propose a concept for the Rouw Wegwijzer, designed with the user's perspective in mind, as well as considering usability and desirability. Specifically, I will explore the interactive and experiential aspects of the platform. Meanwhile, other members of the research group are responsible for studying prevalent needs among bereaved individuals and developing corresponding content for the website.

Results from the research group will be used to attract investors. Consequently, the focus of this thesis will be on the conceptual development of the platform. UI prototyping will be

done to the level necessary for conveying the concept and user-testing. Also, the budget for the development of the platform is unknown.

Vereniging Leven met Dood already developed an idea direction for the Rouw Wegwijzer. This proposal is included in my analysis, however, it is not my role to redesign this proposal.

Having online 'conversations' about grief

One challenge is to go beyond digitizing offline grief support presently available. Digitization is the process of translating analogue information and data into digital form without changing anything distinct from the process itself (Accenture, n.d.). Therefore, the project should go beyond mimicking a conversation with a health professional through means such as chatbots or questionnaires. Added to this challenge is that discussions, contemplations, and emotional expressions regarding grief delve into deep reflections on life, representing profound "human" conversations (Seifu et al., 2022). However, in this context, such introspection will be facilitated by code, not an actual human being. Consequently, design challenges and ethical considerations arise, that need to be explored and addressed.

Target group

The Rouw Wegwijzer aims to welcome all kinds of users; however, considering the wide variation in experiences of grief based on the individual and context, a specific user context has been selected for this thesis. The target group consists of people between 18 – 35, who have experienced the loss of a parent while no longer living at home. This phase of life, known as emerging

adulthood (Arnett, 2000), is characterized by delayed traditional adulthood milestones (e.g., leaving home, getting married, having children). This phenomenon, and therefore the development phase, is mainly prevalent in the Western world. The life- and identity-changing nature grief can have, is even more relevant for emerging adults (Porter & Claridge, 2021). The intersection of emerging adulthood and grief is explored further in chapter 4.

Grief can also be experienced due to absence or disappearance of an individual in life not caused by death. This type of loss brings unique experiences (lectures Keirse, 2022, 2023). One might also experience anticipatory grief before a person dies, but is likely dying, for example due to illness (lectures Keirse, 2022, 2023), this can influence how grief is experienced also after the person

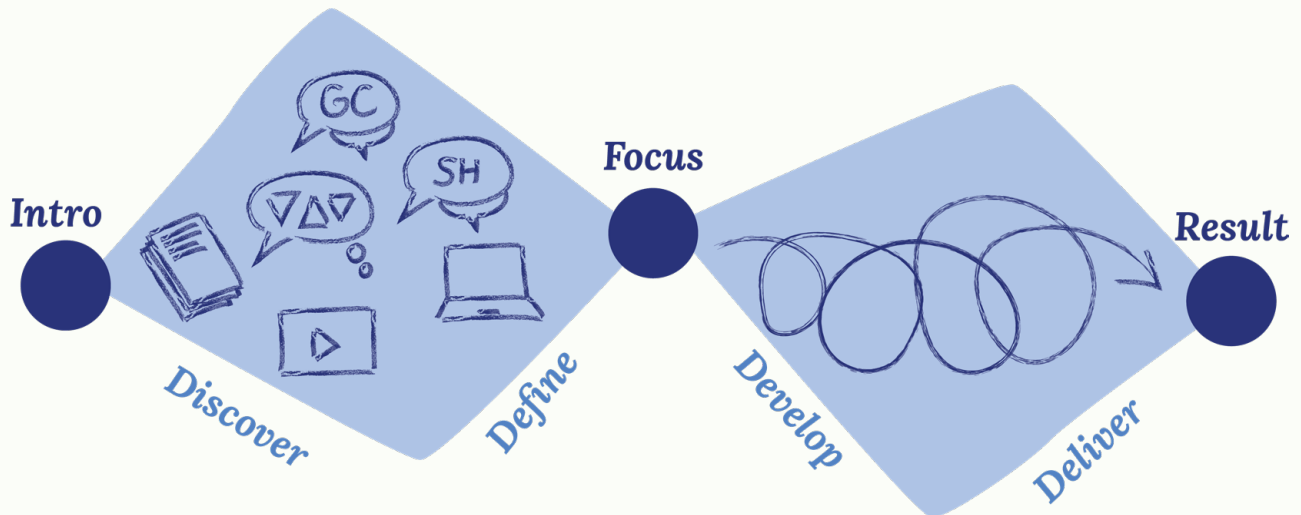
dies. For this thesis I will focus on people whose loved one has passed, in this case parent(s). In the final proposition of the Rouw Wegwijzer, people who experience grief from absence of a living person might also be part of the target group.

It is essential to consider that potential visitors to the website may be experiencing Prolonged Grief Disorder (PGD) (Appelbaum & Yousif, 2022). PGD is defined as a mental disorder in the DSM-5 (American Psychiatric Association 2013). VLmD want to research how to recognize the disorder and provide appropriate referrals to professional help through the platform. However, I am not trained on how to safely and ethically involve these people in research. Therefore, involving this target group and referral falls outside the scope of this graduation project.

IN SCOPE	OUT OF SCOPE
Focus on developing a concept for the online platform. The concept might be used to pitch to investors.	Content development for the platform.
Target group: Emerging adults who lost a parent(al figure), while not living at home.	Target group: Individuals suffering from PGD and how to refer them to professional care.
Grief due to the passing of a loved one, specifically a parent, or parental figure.	Grief due to the passing of an 'unloved' one, the absence/disappearance of a loved one or key person in life (e.g. a parent or previous best friend) and anticipatory grief.
Investigation and exploration of fitting interaction qualities for the Rouw Wegwijzer.	Mapping out specific needs (for support) grieving individuals might have.
Investigation and exploration of fitting user experience on the platform.	(Re)designing the concept of VLmD that they have in development themselves.
Focus on providing and referring to support and relevant third parties.	The Rouw Wegwijzer will not provide practical support.
Ethics considerations about designing personalised online grief support.	

Visual 01. Summary of what will be inside the scope and what not.

2/ PROJECT APPROACH



Visual 02. The double diamond

2.1/ Project approach

This project follows the Double Diamond framework (Design Council, n.d.). The framework consists of two diamonds, each representing a distinct phase in the design process.

Part 1: Discover

During the discover phase, research is conducted to understand the problem and context (Design Council, n.d.). The following research questions will be answered in this section:

1. What is grief and how do people experience this?
2. What bereavement experiences are specific for bereaved emerging adults?
3. What kind of grief support is considered supportive and currently available (online)?
4. What kind of resources and support do bereaved emerging adults expect, desire and imagine on an

(online) platform that offers support to the bereaved?

5. What are desirable services and interactions on an online platform that provides personalised grief support?

The main activities conducted in this phase are interviews with different stakeholders and experts, generative interviews with experience experts, a literature research and analyses of multiple websites and platforms that offer grief support.

Part 2: Define

Based on input from earlier research activities and the generative sessions, choices are made about the function and interaction qualities for the platform. The design goal and interaction qualities for the platform will be defined. Lastly, the requirements for the Rouw Wegwijzer will be presented.

Part 3: Develop

In this phase, the focus is on formulating different ways to obtain the design goal (Design Council, n.d.). This phase is characterized by the co-evolution of the problem and solution (Dorst, 2019). By creating ideas, the multiple facets of the problem are explored. In this part the design will be presented and the evaluation with users will be discussed.

Part 4: Deliver

The delivery phases revolve around finalizing the design of the Rouw Wegwijzer. Insights from the user test will be written down into the recommendations. Recommendations will be made for further development

of the design. Finally, a reflection on the design and a personal reflection will be included.

2.2/ Project participants

To ensure the fit between the target group and the solution, the target group was involved in this thesis. In total 7 bereaved emerging adults participated in this process. Some experience experts also have relevant expertise from their involvement with peers, for example, due to their (volunteer) work. Experience experts and Rouw chat volunteers have pseudonyms to protect their privacy.

Experience experts

Laura

Elvira

David

Alex

Valeria

Stephan

Iris

Experts (grief)

Robin Zuidam

Rouwchat volunteer Tessa

Rouwchat volunteer Myriam

Experts (online platform)

Deborah Melado Cruz
(webdesigner)

Stakeholders

Annelies van der Ouw
(VLmD)

Visual 03. Project participants

PART 1

Discover

This part dives deeper into what grief is and what grief unique makes for bereaved emerging adults. It also creates an overview of (online) grief support and the desired services and interactions when receiving grief support. The following research questions are answered in this section:

1. What is grief and how do people experience this?
2. What bereavement experiences are specific for bereaved emerging adults?
3. What kind of grief support is considered supportive and currently available (online)?
4. What kind of resources and support do bereaved emerging adults expect, desire and imagine on an (online) platform that offers support to the bereaved?
5. What are desirable services and interactions on an online platform that provides personalised grief support?

Procedure

To answer the research question, multiple activities were conducted and are described under method. Then the themes found throughout the different activities were mapped out and clustered, to triangulate the findings. These (overlapping) themes are described in the results and used to make the conclusions.

Method

The research activities conducted where:



Literature research - Relevant theoretical and scientific information is found in articles, web pages and books. Scientific articles were searched via Google Scholar and found using relevant search words. Only articles published after 2018 were included unless an article described a theory deemed relevant in other articles. See appendix 2 for the research questions and search words.



Interviews with volunteers from the grief chat – To explore how current online conversations take place volunteers from the grief chat were interviewed. The grief chat provides the opportunity to talk (anonymously) about your grief online with a volunteer (see appendix 5 for interview guide).



Interview + session with stakeholders – To understand the stakeholders vision on grief and to incorporate their knowledge, Annelies van der Ouw and Robin Zuidam were interviewed (see appendix 6 and 7 for interview guides). A validation session with findings from the research was also held with Annelies and Robin (see appendix 12 for the set-up and results of the session).



Online videos –Watching documentaries and a talk show about grief to sensitize the author for the topic of grieving as an emerging adult (see the bibliographie for an overview).



Benchmarking online grief support providers– Multiple organisations have a platform or website that provides grief support, which are analysed. The current concept proposal done by VLmD is analysed too (see appendix 40 for an overview of all included websites and platforms, Appendix 8 for the analysis of Cruse.org.uk and the current proposal by VLmD).



Generative interviews - To understand and empathize with the target group, 1-on-1 generative sessions with five participants were conducted. Using the context mapping method (Sanders & Stappers, 2012), I invited them to share their grief process and co-design the platform's interactions and experience, see appendix 10 for the full set-up and appendix 14 for the results collected on Miro. The first part of the session consisted of a photo safari assignment and an open interview guided by the pictures of the photo safari and a timeline. In the second part the participants imagined a place for grief support and the employees volunteers via a co-designing assignment.

During the photo safari, participants were asked to capture images depicting the sources of solace for their grief they encountered the last few days. Additionally, they shared a favourite picture of their parent, serving as an icebreaker and introducing the 'third person' involved in the interview. After the introduction to the photo with the parent, the other photos were discussed. These images were then placed on a timeline, see visual 5. This timeline then functioned as a probe to understand the bereaved's experience with grief over time.

Next, the participants were invited to share their grief process and co-design the platform's interactions and experience. First the desired services on the platform were explored. As an invitation to imagine the support that should be provided on the platform, participants were asked to imagine a physical place for bereavement support. The leading question was: **What kind of support and information would the target group expect to find at a physical place for bereavement support?**

Participants could use an online white board (on Miro) to communicate their ideas, see visual 6. A deck of selected photos was used as inspiration material, see visual 7. Participants were also allowed to search for pictures online. Afterwards, we discussed what they made and what it signified.

After creating and envisioning the physical place for grief support, the participants were asked what kind of employees/volunteers they would expect. What would be the employees role? What would be their character? And how did the participant envision interaction with them? See visual 8 for an example of results. The leading question was: **What kind of interactions and experience does the target group desire?**

After this, the current proposal of VLmD for an online platform that provides personalized content was discussed. We also reflected if the participant's answers, expectations and wishes would change if the place and employee would be online instead of physical. We also discussed if and how they used online resources before for their grief.

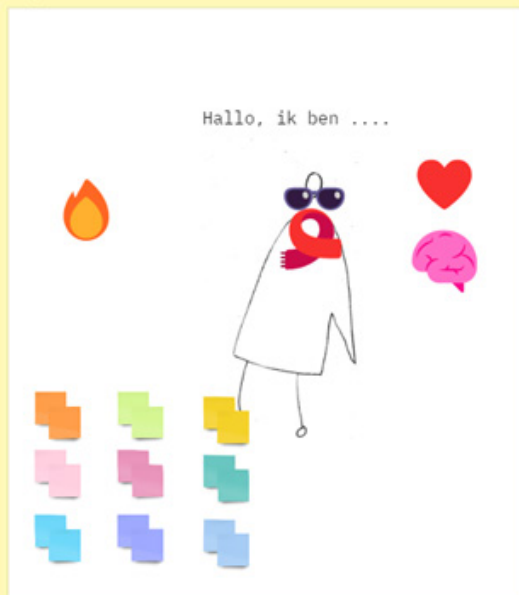
To finish the session we 'left' the physical place they created, see visual 9. What kind of goodbye would they expect? What kind of exit would their physical place for grief support have? And would the employee have a role in it?

The generative sessions were recorded and transcribed with the help of the online transcription programme Trint. Relevant quotes were put on quote cards, printed out and clustered to create themes and insights.

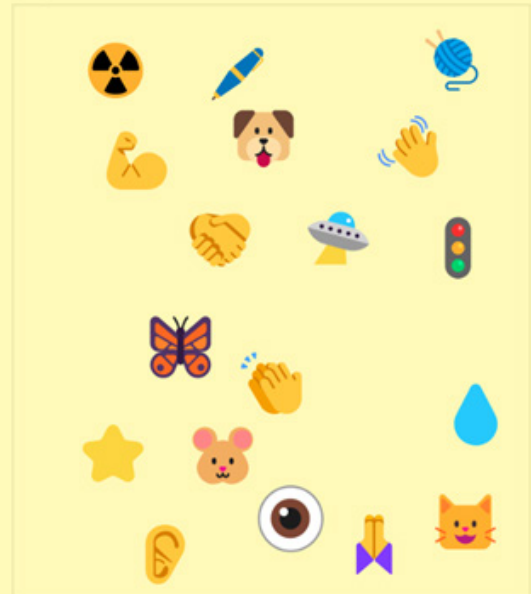
PARTICIPANT	LOCATION	RELATION TO GRIEF
Laura	Remotely	Laura suddenly lost her father a few years ago.
Iris	Remotely	Iris lost her mother after she had been sick for a while. Currently, she is working on a project about grief for young adults, as part of her work within the youth section of an employer's union.
Stehpan	Remotely	Stephan lost his father after he had been sick for a while. Experiencing how it is to grieve as a young person motivated him to start building a platform, Rouwnetwerk Jong. Among other things, rouwnetwerk Jong also provides peer meetings, which Stephan sometimes facilitates.
Elvira	Remotely	Elvira lost her mother after she had been sick for a while.
David	In-person	David lost his father after a long sick bed a few years ago.

Visual 04. Participants of the generative sessions

Stap 3. bouw een medewerker



Inspiratie materiaal



Visual 08. Who would you expect to work at your physical place? Build an employee and inspirational material.

Afsluiting: uitgang (en uitgang?)



Visual 09. How would they leave the centre they build, what would the exit (which might also be an entrance) provide? What would be the role of the employee at this point?

3/ UNDERSTANDING GRIEF

This chapter examines various grief models that describe how people go through grief. Although these models can aid in understanding grief, they should not be used for prediction. Nonetheless, understanding the essence of grief and having a brief overview of what to expect from it can significantly impact an individual's experience. Robin Zuidam, who was interviewed as an expert, provided the following analogy:

“Unfamiliarity with one’s grief is comparable to navigating through a bustling city centre without familiarity with the route or the driving styles of others – imagine Paris. It is a challenging, demanding, and stressful task to safely navigate through the chaotic traffic. Conversely, knowing what to expect from grief is like driving through the same city center, but with knowledge of the route, the city, and how others will drive. Despite the hectic traffic, one can engage in a relaxed conversation with a companion.”

Robin Zuidam

Co-founder Het Beziiningshuis and project coordinator of the Rouw Wegwijzer

describe four levels of human function that can be impacted by grief: emotional level, behavioural level, physiological level and thought level (see visual 10). The symptoms listed, clearly show that grief affects both mind and body, which are always interconnected (van der Kolk, 2014).

One well-known grief model that tries to create a process out of the different ‘symptoms’ of grief is the

phase model proposed by Elisabeth Kübler-Ross (1969). In her book “On Death and Dying,” based on her work in palliative care and conversations with the dying, Kübler-Ross identified five phases experienced by individuals facing death: denial, anger, bargaining, depression, and acceptance. Although these phases specifically

3.1/ Grief in phases

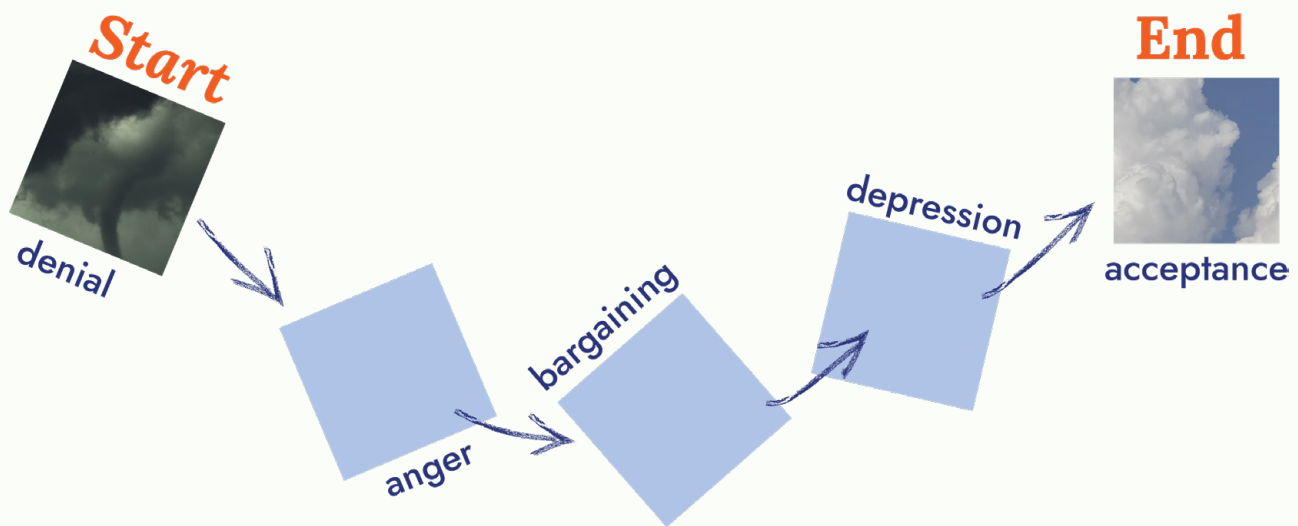


Grief is considered a normal reaction to an enduring stressor: the loss of someone important (Bonanno & Kaltman, 2001). As mentioned before, grief is unique per person. However, in general, people experience similar things. Skrozić & Kijamet (2022)

ly apply to the context of facing mortality, they have been widely popularized by the nickname “the five stages of grief.” However, there is limited empirical evidence supporting the model’s effectiveness (Corr, 2019). Over time it became apparent that the model is incorrect and outdated. In fact, relying on this model can potentially be harmful to both those



Visual 10. The 4 'symptoms' of grief (Skrozić & Kijamet, 2022) and some examples of how they manifest



Visual 11. The 5 stages of grief

grieving and those dealing with a terminal illness (Keirse; Corr, 2019), as it forces people into a mould of what a grief process should look like.

Despite Kübler-Ross (1969) herself describing that people can go back and forth or experience multiple phases at the same time, the model is often portrayed as linear. This suggests that people should go through all stages, following a prescribed sequence, leading to an eventual state of acceptance. However, the stages described are not stages, they are coping mechanisms, which people can experience, but do not necessarily do, especially not in a specific order. For example, Elvira, one of the experience experts that participated in the generative sessions, described one of the 5 stages, denial, as part of her grief process, but not the others.

The Kübler-Ross phase model remains the most popular and widely known model (Daniel, 2023). It has been applied in diverse areas such as management, healthcare technology acceptance, and feminist studies (Daniel, 2023). The model is actively taught in healthcare education and receives ongoing media coverage (Corr, 2020; Daniel, 2023).

Widespread acceptance and use of the model makes it relevant to date. It has greatly impacted cultural perceptions regarding how and to what intensity one must grieve to be able to adjust after a loss (McLean et al., 2022). It perpetuates the idea that grief has a specific timespan and an end state. As a result, even though the model is outdated, it still influences the experience of bereaved individuals via their expectations, how we mourn and how we support those who grieve.

“It started with a lot of incomprehension. I thought: ‘huh, how is this possible? What happened? This is not possible.’ And it felt to sudden, even though my mother was already sick for a long time, so I knew it would happen.”

Elvira

Experience expert

“Many people want a solution for their grief, they want to know how much longer it will take. There are no clearcut answers for that.”

Tessa

Volunteer at the Rouw Chat

3.2/ Active grieving

LR

GI

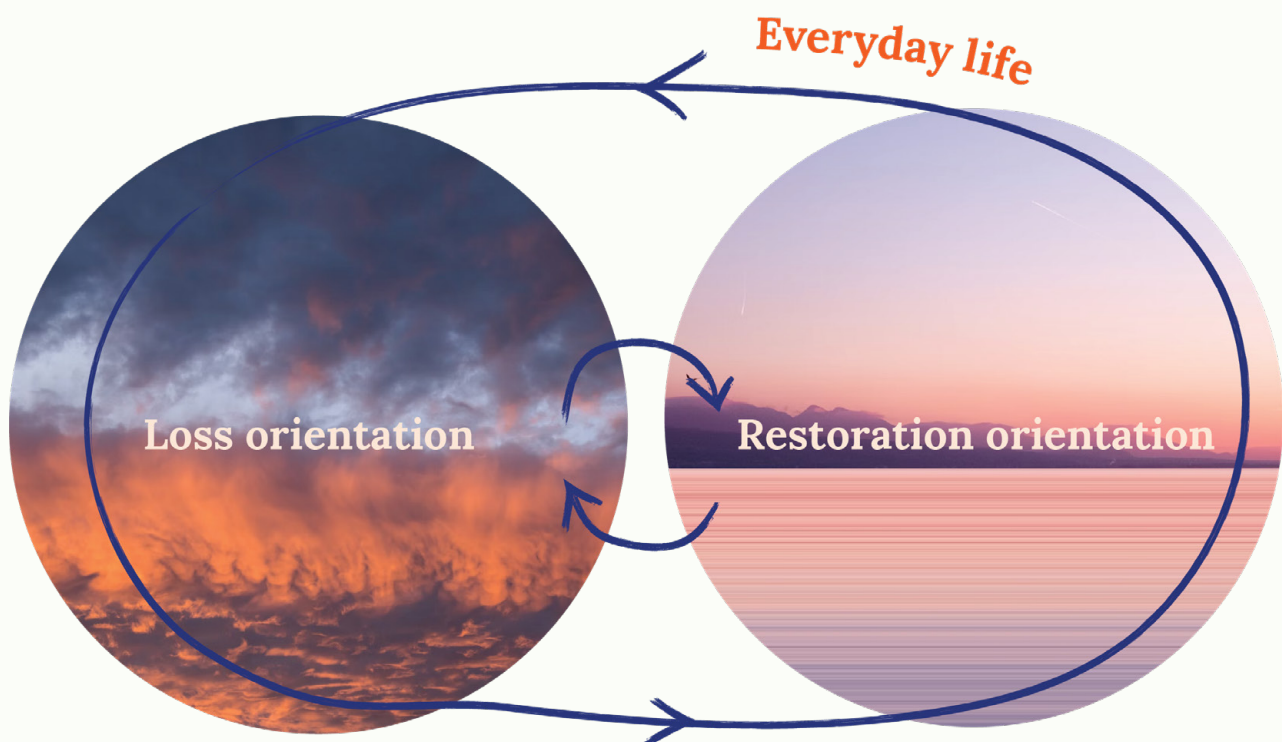
Next to implying an order and a set end, phase models also imply a passive nature. However, currently used grief models describe grief as an active process (Corr, 2019). Worden (1982) was the first to offer an active perspective on grief with four tasks to address: 1) accepting the loss, 2) experiencing the pain, 3) adjusting to a new environment, and 4) adapting to a new life. This model moves away from the passive nature of Kübler-Ross' model implies and gives grieving an active nature. Nevertheless, this model still suggests a chronological order and an end. After all, a task can be finished.

Stroebe and Schut (1999, 2010) propose a model that organizes similar tasks in a different framework, with two orientations. They introduce a loss-oriented track where the bereaved remembers the deceased

(comparable to tasks 1 and 2), addressing emotions and the loss of the specific person. Additionally, they incorporate the restoration-oriented track, which focuses on redefining life without the deceased (comparable to tasks 3 and 4), including the experience of secondary loss. The alternation between these orientations is called oscillation and is considered crucial for adaptive coping and adjustment (Stroebe & Schut, 1999).

Loss-oriented grief includes:

- Traditional 'grief work'. Like ruminating about the deceased and the life before the passing of the deceased.
- Experiencing expected and unexpected emotions related to bereavement.
- Having and shaping a continuous relationship with the deceased.
- Denial/avoidance of restoration changes.



Visual 12. Dual process model

Restoration-oriented grief includes:

- Attending to life changes due to the loss of a person.
- Doing new things without the deceased.
- Being distracted from grief.
- Denial/avoidance of grief.
- Exploring the new roles, identities and relationships without the deceased.

Stroebe and Schut (1999) deliberately incorporated the concept of taking a break from grief in the restoration orientation, recognizing its significance in coping. However, it is notable that this model positions grief as the central focus of an individual's life, as all non-grief activities are encompassed by taking a break from grief. Multiple interviewed bereaved emerging adults expressed the sentiment that life does not need to revolve around grief, yet the deceased parent still played a role in their life. For instance, David stated, "I consider my grief closed." Before sharing multiple rituals and objects he (had) used, when feeling the need to connect with his father.

3.3/ Growing around grief

LR

GI

Lois Tonking (1996) found a fitting metaphor for life-long grief and its place in life during a workshop with a bereaved mother. The mother drew how in the beginning her whole life was filled with grief, and how the expectation was that the grief would become smaller over time. In reality she observed that the grief stayed the same size, but her life grew around it.

This fits with empirical research about how people go through the two grief orientations (Fiore, 2019). Most bereaved individuals use more loss-oriented coping initially and experience more negative effect. Over time, affect becomes more positive and the bereaved used less loss-oriented coping strategies. In general, the first 6 months after the loss, bereaved people will be predominantly in the loss-orientation. Over time, they will spend less and less time in the loss-orientation (Fiore, 2019)

[Elvira about her timeline drawing that describes her grief journey]

"I noticed it was really hard to experience enjoyment in life. I truly could not enjoy small things anymore. I remember very vividly, one time my boyfriend asked: 'let's get an ice cream in the city.' The weather that day was beautiful. And all I thought was: 'Why for heaven's sake would he want to do that? What is fun about that?'. I also thought: 'If I cannot even experience one spark of joy, then this is really severe.' (...) At some point there are all these small steps towards what feels as a new life, a life without my mother in it. (...) It feels like those were really small steps towards finding back enjoyment in life. Not just enjoyment, but also fulfilment. Now it feels as if that line [representing her grief journey] is incredibly high."

Elvira

Experience expert

3.4/ Grief triggers

LR

GI

Grief can be experienced any time when there is a trigger (Keirse, 2022, 2023). A trigger can be anything that brings you back to that place of grief. Triggers might be a key



Visual 13. Growing around grief

moment in life, where the deceased cannot partake. Repeating ones, like Christmas or birthdays, or key transition moment in life like a graduation or having a first child. Bereaved people might have to negotiate their future without their lost one in it throughout their lives. For example, when a deceased father cannot walk his daughter down the aisle, the daughter might experience the loss-orientation by feeling longing for her father. Or she is forced back into a restoration-orientation, having to realize that her father will never know her as a married woman.

Another type of trigger, can be something that initiates the memories and emotions related to the person, for example a clothing piece that belonged to the deceased, a song that is associated with them or anything else that has an association with the deceased. During the generative sessions, it became clear that what triggers grief is dependent on the bereaved, their values, experiences and associations.

“The most difficult one is Christmas. Christmas... the most fucked up holiday imaginable. Because everyone is hyping each other with: ‘We are going to have such a good time together!’ And all I can think is that what we did no longer exists. Even if you are with everyone, the house won’t be full (...) and it will never be okay, because we are incomplete and that cannot be fixed.”

David
Experience expert

“I am not sure which flower, but the smell... when I smell it I return to that time. It makes me realize, yes, this also happened in my life. Or also: yes, this is [now], and that was and [still] is. It returns me every time to that, uhmm... solace is maybe a weird word... but yes, solace. It reminds me that: yes, it is not a nightmare, this is real.”

Elvira
Experience expert

3.5/ Grief as a positive experience



Participants of the generative sessions point out that others see their grief as a sad, negative experience. The assumption can be that grief will always be a negative experience because in general, that is the general view of what a grief experience is (Skrozić & Kijamet, 2022). Because of this association, life-long grief might sound like a constant, negative experience. However, grieving does not equal sad, some people might not even experience any sadness, (Skrozić & Kijamet, 2022). Not being sad is often seen as a sickness or abnormality, but it is not. The absence of sadness is not correlated with not grieving or unhealthy ways of coping (Skrozić & Kijamet, 2022). Even for those who do experience sadness and pain, grief can be more than that. Additionally, experiencing grief can be a positive experience too.

In literature, it is sometimes mentioned that people create a continued bond with the deceased by having that grief (Stroebe and Schut, 1999; Klass et al., 1996). Albeit painful, grief also represents the only place possible to have a feeling of still being with the deceased (Porter and Claridge, 2021, Gravesen & Birkelund, 2021).

Next to being a place for connection with the bereaved and other loved ones, grief also is a potential moment of personal growth, according to some participants of the generative session. In research too it is found that students who experience grief could experience personal growth (Tureluren et al., 2023), especially when given the opportunity to ruminate about their grief. For instance by

[About sharing one of her favourite pictures of her mother]
“I liked this exercise, because it makes you look at positive moments. Often people are inclined to... uhm... when you lose someone, often you talk about the sad moments. I noticed that there is discomfort in my surroundings to ask about fun memories.”

Iris

Experience expert

“I think grief is sad, it is painful, but for me it is so much more than that. In that period around the passing of my father and my mother, I experienced and received so much warmth from family and friends, the space to make jokes... It is so much more than just pain and the sadness.”

Ameline Ansu

Experience expert and author of ‘van harte gecondoleerd’, during the talkshow Crux

“I don’t think I am actively searching for it, but it’s more that there is something, a situation, that touches me and I notice: oh right, this is... this is the part of my mother in me. It’s like I tell myself in that moment: ‘Yes, I am allowed to feel this. This is.. this is beautiful to feel, because this is a little piece of my mother inside of me.’”

Elvira

Experience expert

“I enjoy talking about my father. Maybe you will get a difficult analysis out of me because of that. I think I talk differently about my father and the death of my father than others. More comfortably. So I like to talk about what kind of person my father was, and how his passing was, and maybe even how that had a positive influence on me. I think it is important to have that conversation, instead of only talking about the painful parts.”

Stephan

Experience expert

talking to a professional about what they are going through or receiving social support from friends.

3.6/ Acknowledgement and recognition

LR

GI

By its very nature, grief is intertwined with relationships, as it emerges in response to the absence or transformation of connections. How grief is experienced is therefore influenced by how others' witness, acknowledge and validate it (Peskins, 2019). Each society establishes distinct guidelines dictating who is entitled to mourn, the permissible extent and duration of mourning, and those who are excluded from grieving—yielding what Doka (2008) termed “disenfranchised grief”. This phenomenon, wherein an individual's grief is invalidated or unacknowledged, can be damaging for an individual (Peskins, 2019).

Disenfranchised grief is often characterised by a lack of social support (Pitman et al., 2018). This lack of support obstructs the bereaved from participating in the processes described in the restoration orientation. Some bereaved disenfranchise their own grief (Peskins, 2019). For instance, they might suppress their emotional responses when grappling with loss or choose to withhold their feelings when facing societal taboos like loss by suicide.

This underscores the significance of acknowledgement. Regardless of the nature of the loss or the identity of the bereaved individual, it is essential to recognizing that grief is there. This enables the bereaved to not stagnate in their grief (Peskins, 2019). The

next step would be to offer recognition, which validates further. It can also alleviate the feeling of being alone and create a better understanding of one's own grief (Doka, 2008; lectured Manu Keirse, 2022, 2023).

Discussion

It can be argued that many restoration-orientation activities can be performed outside of the scope of grief. Otherwise, someone's whole life is defined by grief, with everything outside of grief captured as ‘taking a break from grief’. Tonkin's (1996) description of how grief can be seen as lifelong is more respectful towards the life some can have outside of experiencing grief. A limitation of Tonkin's model (1996) is that grief is a static ‘shape’ in life. Whereas the dual process model describes how the experience of grief and what we grieve change over time. Therefore, in this project, a combination of these two models is used for the understanding of what grief is and could be.

A last note is that all models discussed primarily focus on the mind's level reaction to grief. It can be argued that it is impossible to have endurance in the mind without having any physical consequence, as the mind and body are interconnected via multiple physiological connections in the nervous system (van der Kolk, 2014; Stern, 2019). None of them includes the potential physical effects grief has on the bereaved, except for emotions, which can be considered bodily experiences (Stern, 2019). This could be a blind spot in the found literature and theories about grief.

Conclusion

Understanding one's grief process can help in being able to navigate it. A first step towards understanding are acknowledgement and recognition. Nevertheless, grief cannot be captured in a fixed process, like the 5 stages of grief. Yet, this debunked theory still has implications for current bereaved. It creates the notion that grief is passive and has a specific roadmap, with acceptance at the end. Current models acknowledge that grieving is active, does not follow a specific steps and is a life-long process of oscillating between experiencing loss and rebuilding life (Stroebe & Schutt, 1999). Yet, grief does not have to be the focal point of someone's life, or only be experienced as negative. Over time, what grief means and how it is experienced by the bereaved changes. In conclusion, grief does not necessarily have a definitive end-point; rather, it involves a gradual and evolving understanding of the loss.

4/ GRIEF AND EMERGING ADULTHOOD

In chapter 3 we have established an understanding of what grief is. This chapter describes the target group, the specific characteristics that come with the development phase of emerging adults and what specific and unique grief experiences the target group might experience.

4.1/ The characteristics of emerging adulthood

LR

Emerging adulthood, a developmental phase identified by Arnett (2000), describes a period in which traditional markers of adulthood are postponed, leading to a distinct set of characteristics:

1. **Identity exploration**, answering the question “who am I?” and trying out various options, especially in love and work.
2. **Instability**, in love, work, and place of residence.
3. **Self-Focus**, because obligations to others reach a lifespan low.
4. **Feeling “In-Between”**, in transition, neither adolescent nor adult.
5. **Possibilities/Optimism**, most emerging adults feel like they have time and unparalleled opportunities to transform and shape their lives.

Online developments prolong parental involvement in children’s lives after they leave home (Arnett, 2000). Simultaneously, the age of leaving

the parental home is increasing in the Netherlands (Gielen, CBS, 2022), hindering the development into full-fledged adulthood (University of Hampshire, n.d.).

4.2/ Off-time loss and life tasks

LR

GI

OV

Losing a parent in this phase is considered an off-time loss. This can create unique challenges for bereaved emerging adults and their families as it deviates from the natural progression of life and may disrupt the anticipated order of events. It can lead to heightened feelings of grief, shock, and a sense of injustice. Experiencing an off-time loss can complicate the grieving process. The off-time loss of a parent during this phase can create instability and delay or intensify the exploration of identity and other developmental topics. In a life phase where most people are focussed on building their identity and future, a bereaved emerging

“It’s very dependent on age how you grief, I think. And at my age life went so fast, which made it harder to keep up with a ritual or anything. (...) At some point it changes, you slow down. New things happen in life and you meet people with similar stories... Those are ways of mourning and grief too.”

Laura

Experience expert

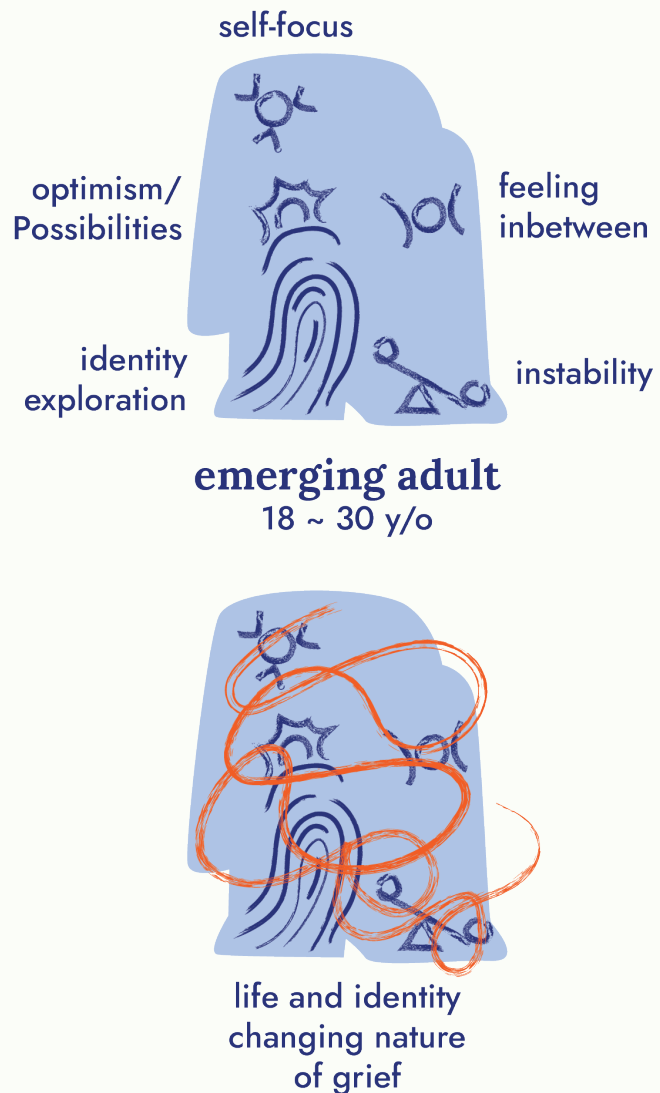
adult often find themselves having to slow down and renegotiating their priorities (Porter & Claridge, 2021; Cupit et al., 2022). Bereaved emerging adults report putting their lives on hold and delaying the typical tasks that characterize this life phase, such as education, career, financial independence, and self-discovery (Porter & Claridge, 2021). Consequently, they may experience long-term effects on their lives and careers. In both literature (Porter & Claridge, 2021; Cupit et al., 2022) and the generative sessions, bereaved emerging adults report they feel like there is no time for them to grieve.

4.3/ Thwarted connectedness

LR

GI

Compared to peers and older bereaved adults, bereaved emerging adults face an increased risk of developing mental health problems and experiencing loneliness following a loss (Porter & Claridge, 2021; Cupit et al., 2022). Loss and grief can lead to a crumbling social network, resulting in a secondary loss for the bereaved individual (Logan, Thornton & Breen, 2018). This can be even more impactful for emerging adults, not only because social connections play a big role in this life phase (Arnett, 2000), but most likely, the loss of a parent is an emerging adult's first time losing a close loved one (Porter & Claridge, 2022). They may not have peers who have gone through a similar loss, making it challenging for them to receive support and empathy from their social circle (Porter & Claridge, 2022). Consequently, bereaved emerging adults are more likely to feel lonely in their grief experience.



Visual 14. The impact of grief on the characteristics of emerging adulthood

“The moment my mother got sick, I felt like I was standing on a train platform and all my peers were in a train that speeded past me. And all I could do was wave them goodbye.”

Lisanne van Sadelhoff

Experience expert and author of ‘Je bent jong en je rouwt wat’, during the talkshow Crux

“I noticed that [grief] is complicated to relate to for some people. Yes, for sure. And luckily so, but it is um, that is something that made me feel very lonely at times.”

Elvira

Experience expert

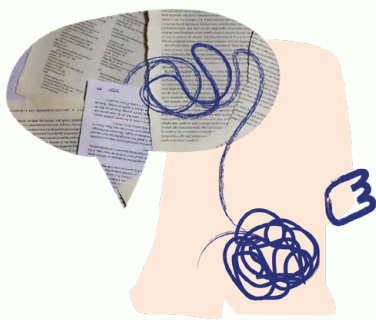
Discussion

In literature it is often discussed that grief 'halts' the normal development and progress expected. It is important to note that grief can also provide an opportunity for personal growth (Tureluren et al., 2023), which does not fit in the typical progress of emerging adulthood, yet can be valuable. As mentioned before grief can have a positive effect on life. Experiencing loss and reevaluating life can be seen as an opportunity to improve. Stein et al. (2018) found that for bereaved emerging adults positive changes in life, due to a loss, included behavioural changes and personal changes in outlook.

Conclusion

In conclusion, the loss of a parent during emerging adulthood can disrupt the exploration of identity and other developmental topics which are usually relevant at this age. This leads to a revaluation of priorities and potentially delayed progress in education, career, and self-discovery. Bereaved emerging adults face an increased risk of mental health issues and loneliness compared to their age peers or older bereaved adults. The loss of a parent often marks their first experience of losing a close loved one, and the lack of peers with similar experiences can further contribute to feelings of isolation. These challenges highlight the need for understanding and support for bereaved emerging adults as they navigate their grief and strive to build their lives.

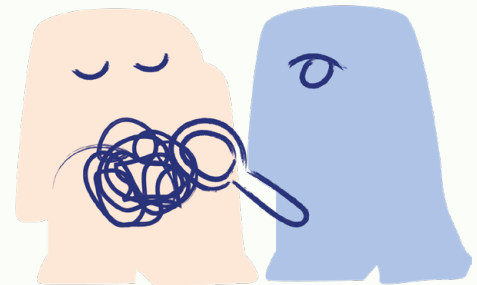
5/ AVAILABLE AND (UN)SUPPORTIVE GRIEF SUPPORT



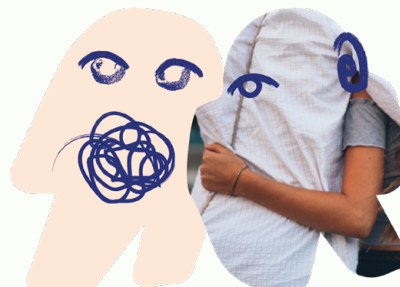
Informational support



Practical support



Appraisal support



Emotional support

The main goal of this chapter is to have an understanding of what support sources can be referred to by the Rouw Wegwijzer and how to create a helpful grief support platform. In the project description it is highlighted that the Rouw Wegwijzer should help users with finding fitting grief support. This support includes both informal help from friends, family, and the community, as well as professional support from trained individuals who are compensated for their services. This chapter aims to develop an understanding of the support available and what is seen as supportive or not.

Visual 15. The four support factors

5.1/ Overview of types of support available

5.1.1/ Support factors

LR

SH

In social support, 4 factors are distinguished that contribute to a sense of perceived and genuine connection to a caring social structure (House et al., 1988; Cacciato-re et al., 2021). These types of support can be described as follows.

Informational support may include logistical help on available services after death as well as advice, data, and information offered during a difficult or stressful time.

Instrumental support is things such as funeral planning, financial aid, trauma and crisis care and emotional experiences related to the loss.

Appraisal support can be seen as a passive means of self-evaluation often enacted for example, in peer-to-peer contact. It provides a means to assess one's self in a particular circumstance through like-others utilizing affirmation, feedback, and social equality.

Emotional support is provided through expressions of caring, compassion, trust building and mutuality.

The Rouw Wegwijzer will focus on providing emotional, appraisal and information support during times of loss, as VLmD does not offer instrumental support.

5.1.2/ Support sources

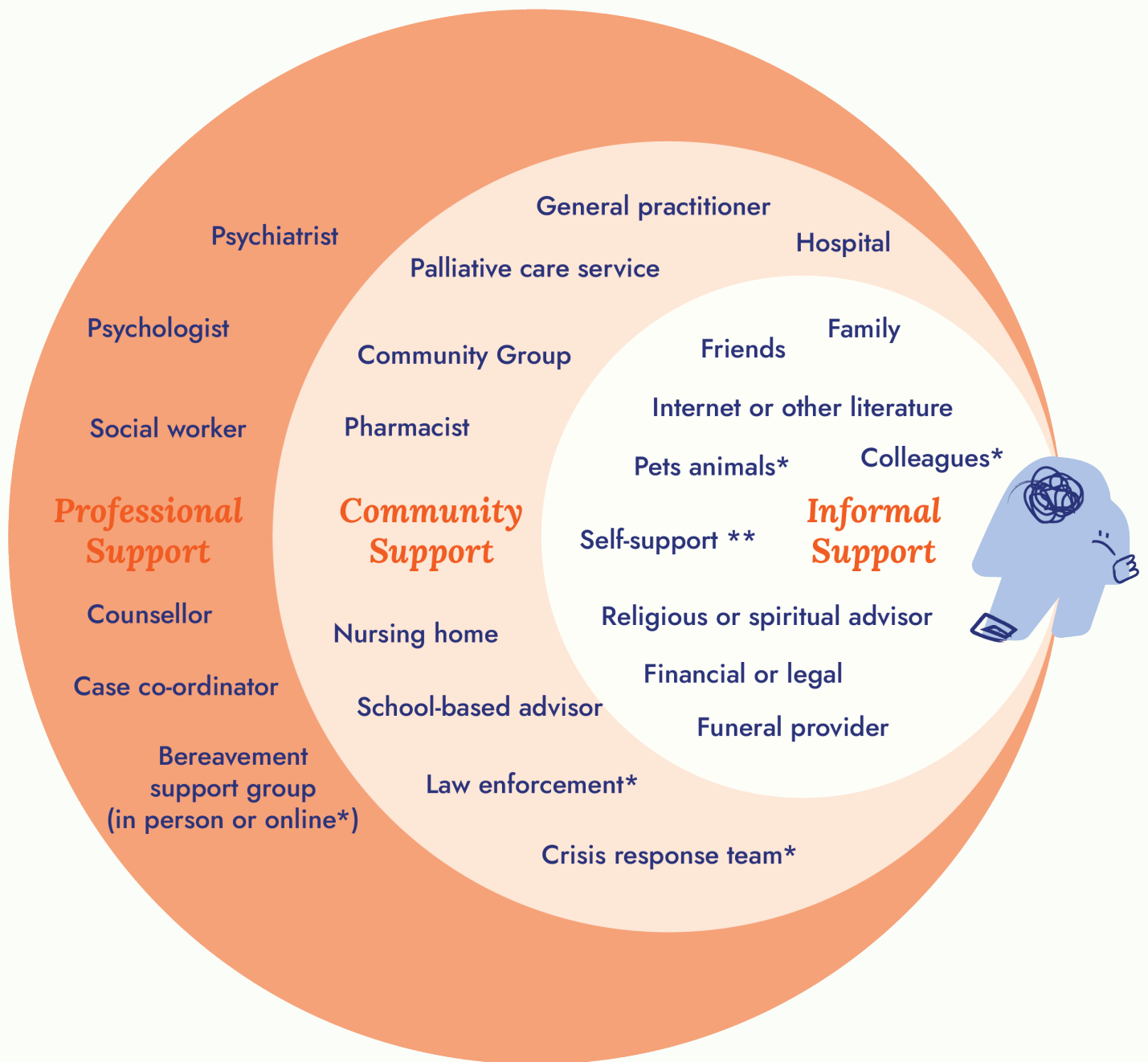
LR

SH

GI

Both Aoun et al. (2018) and Cacciato-re et al. (2021) present a list of distinct types of grief support sources. These can be divided in informal support, community support and professional support. Visual 16 provides an overview. By creating an overview of the different kinds of grief support sources we can know what the Rouw Wegwijzer can refer to.

In the generative interviews, people mentioned activities like meditating, writing or artistic expressions as supportive in their grief process. They are included in the overview as self-support. These activities address the combination of mind/body (van der Kolk, 2014) and acknowledge that the two are not two separate entities. These practices were not mentioned in the literature about grief support. Yet, they could be considered art therapy or body-oriented therapy, if guided by a specialized therapist. Arguably it is worthwhile to broaden the scope and include these types of support sources too, to see if the satisfaction of the bereaved will become higher. Online apps, like Grief Works and Grief Refugee already use a more holistic view of grief and include mindfulness exercises and guided meditations next to peer connections and articles providing informational support.



Visual 16. Aoun et al. (2018) divided support into three categories: professional, community and informal support. Community support is defined as paid professionals within the community, whose primary function is not directly related to providing grief support. This list is supplemented with sources mentioned by Cacciatore et al. (2021) and during the generative interviews.

*=from Cacciatore et al. (2021)

** = From interviews with bereaved emerging adults

5.2/ Online grief support

LR

OS

The Rouw Wegwijzer will function as an online grief support platform, therefore a deeper knowledge of online grief support is desired. The internet and literature are considered informal support sources (Aoun et al, 2018). An advantage of online support is that it makes informational support easily accessible and widely available.

It is important to understand that an online platform differs from a website. A website offers one-way engagement, where users consume the content provided by the site, but a platform allows for reciprocal engagement and interactions, creating a personalized experience for each user (Oomph, 2021). Websites that were analysed (see appendix 9 for a list) mainly provided informational support, often in the form of blog posts or informative articles on a variety of topics (Beaunoyer and colleagues, 2020). On platforms,

support is provided mainly via chats and forums (Cummins, Judson & Smith, 2021), on both specialised grief platforms (e.g., goodgrief.com) and non-specialized ones (e.g., Facebook groups). These places provide communication with peers, volunteers or professionals. Specialized platforms often act as a gateway to offline interactions with peers or professionals. A few platforms offer features that are less focused on social connections, like mood tracking, daily reflections (e.g., Grief Refuge) or peer-to-peer interactions (e.g., Good Grief).

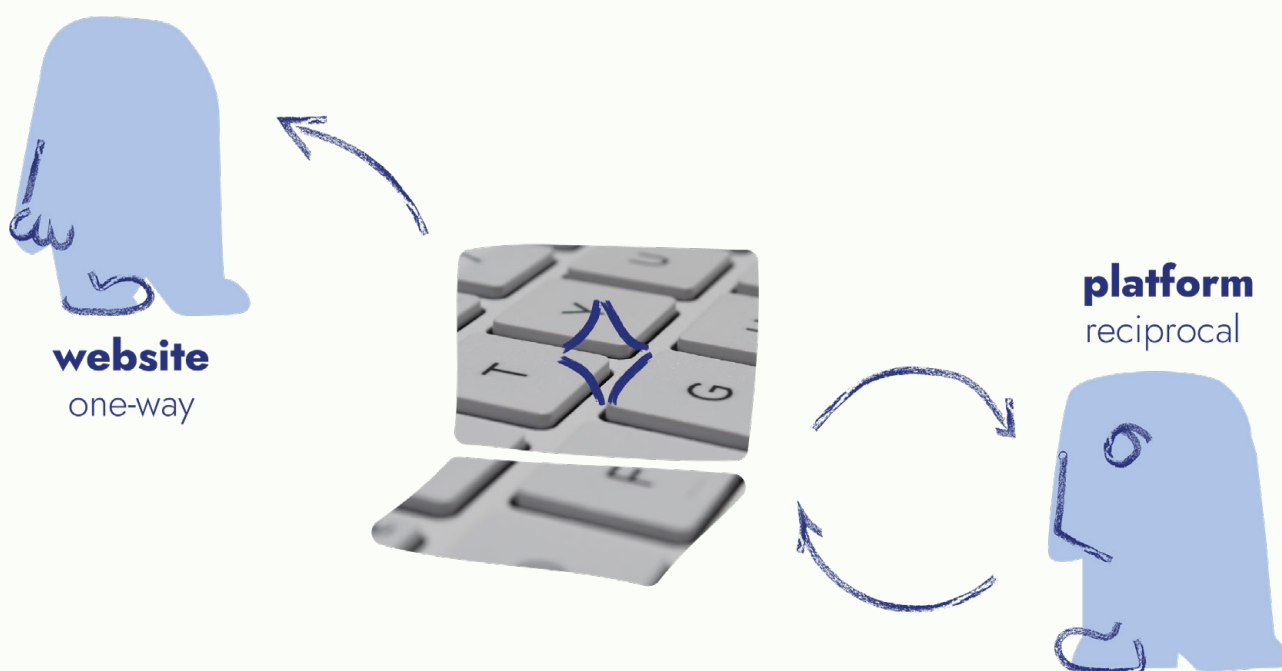
5.1.2/ (Un)helpful support

LR

GI

ICG

Cacciatore et al. (2021) highlight the lack of clarity regarding how grieving individuals interpret social support and identify it as helpful or not. One reason for this is the persistence of societal expectations stemming from Kübler-Ross's (1969) debunked



Visual 17. Website vs platform

phase theory; People and society still expect an end status of acceptance. As a result, bereaved individuals may seek or engage in (professional) grief support with the expectation that it will take away and solve their grief. This is an unrealistic expectation, but influences how helpful the support is experienced. Nevertheless, multiple researchers made an overview of which support was considered helpful and which not (Aoun et al., 2018; Cacciatore et al., 2021; Pitman et al., 2018).

Typically, most responsibility for grief support falls on family and friends (i.e. informal support). 88-92% of bereaved also experienced the support provided by these sources of grief support as very/quite helpful. Research about why family and friends are seen as most supportive is lacking, but most likely due to the myriad small contributions they make in a bereaved's daily life (Aoun et al., 2018). Nevertheless, informal support is not always sufficient (Cacciatore et al., 2021). One reason is that much of the informal support offered in the early grief, diminishes quickly, while the bereaved might not experience any less grief and need for support. Yet, professional grief support is only used by roughly 1/8 of all next of kin in the Netherlands (Vereniging Leven met Dood, n.d.) and it had the highest proportions of perceived unhelpfulness (Cacciatore et al., 2021; Aoun et al. 2018).

Interestingly, according to Cacciatore et al. (2021), emotional support and emotional acts of caring were both the most supportive and least supportive. What made the support helpful was creating an open space for expressing grief and value-free listening. Pets stand out as a consistent source of comfort, providing a

non-judgmental presence and unconditional acceptance (Cacciatore et al., 2021). Being non-judgemental and sincere in wanting to help the bereaved was also identified as important (Pitman et al., 2018). This reinforces the notion that sometimes 'just being there' is the most supportive act. Emotional support was considered unhelpful if the provider of support was focused on solving the grief or providing a solution (Cacciatore et al., 2021).

“We had a dog and I noticed that they gave me a lot of support and comfort. Because they are someone that comforts you, just by being there. They are someone that does not have any expectations for me.”

Iris
Experienceexpert

“Just keep showing up for me and listen. Don't try to fix it.” “... not trying to fix what can't be fixed. By accepting the new sad, grieving me as someone who is ok to be with and not expecting me to feel like I need to get over this or move on and become the happy person I was. Not making me feel like I have to wear a mask and pretend I am someone I am not.”

Quotes from research by Cacciatore et al. (2021)

The least helpful support, in general, was insensitive support, poor or unwanted advice, lack of empathy, systemic hindrance or support that was anticipated, but never provided (Aoun et al., 2018). A blanket approach, which involves offering the same type of support and interventions to all grieving individuals,

SUPPORTIVE	UNSUPPORTIVE
Creating an open space for expressing grief	Focus on solving the grief, providing solutions
Value-free listening, non-judgmental	Judgmental, insensitive or unwanted advice or support
Unconditional acceptance of the person and their grief	Dictating support, dictating advice
Just being there	Support that was anticipated, but never provided
Sincere intentions to help the bereaved	A blanket approach, generic support, lack of empathy, insincere interest

Visual 18. Overview of helpful and unhelpful support

regardless of their unique needs and circumstances, was experienced as generic and unhelpful (Cacciatore et al., 2021). Morbid or insincere interest was also not considered helpful (Pitman et al, 2018). From the generative interviews and the interviews with grief chat volunteers, it can be added that dictating support was also not helpful.

It can be concluded that the most helpful support does not try to resolve the grief but rather acknowledges the person’s right to grieve in their own way and time. This understanding is crucial in conceptualizing any form of grief support, whether informal, professional, or via platforms like the Rouw Wegwijzer.

5.5/ Support restricted by words



A discrepancy can be identified between how grief support is provided, in text and as conversations, and how skilled most people are

in having conversations about their grief. Talking about grief is hard since death and mourning are seen as taboo in Western cultures. Talking about death is not a common practice and many people avoid the topic (Allan & Burridge, 2006; Farberow, 2013). This lack of practice leads to an inability among people to express their feelings and experiences about death and loss. They lack a vocabulary that allows them to express what they are experiencing. However, most support for grief is available in conversations or written text, especially online. Exceptions of support that does not rely on conversations and text are practical help and acts of caring. However, these are not the focus of this thesis.

Additionally, reading and talking is not necessarily something that fits every bereaved. Some participants of the generative session underlined that they also felt the need to engage with their grief in other ways than having conversations

“What I hope is that people say: ‘I am looking for advice’ or ‘I want to share and express my feeling’ or ‘I need an outlet’ or ‘I am so sad’ or ‘I want to feel some hope and some solace.’ You hope that people can formulate something clear and concise, but in reality, that is surely not the case! People are so stuck in their emotions that brought them to the chat, they do not have an overview at all.”

Myriam

Volunteer at the Rouw Chat

“I know better what I do not need, if I make an comparison with others, and I talk to quite a lot of others [due to my job], I don’t necessarily need to talk about my own experiences.”

Iris

Experience expert

[About why art is important to him.]

“I think it is important for growing up healthy and dealing with negative feelings that you learn how to express it. You are not going to going to fix this alone, you have to be able to give it a place. You have to find ways to do that. As a species, we have evolved very far and we can write to each other, and have conversations. Still, it is inadequate for so many aspects of our life.”

David

Experience expert

Discussion

The results suggest that professional support is least satisfactory and informal support, especially from an animal, is most satisfactory. The big differences in satisfaction might be partially due to expectations for the source of the support, not necessarily the support provided. It can be hypothesised that professionals got lower satisfactory scores because the expectations of the bereaved are higher. Especially when the expectation from the bereaved is that the professional can make the grief go away, which is not possible. Pets being seen as most supportive strengthens the hypothesis. The expectations for animals are different from those for humans, as they cannot understand grief and act upon it like humans can.

Conclusion

In conclusion, support can be provided as informational support, instrumental support, appraisal support and emotional support, from varied sources. These sources can be categorized as professional support, community support and informal support. Online support is considered informal support and offers the advantage of easy accessibility to a wide range of topics. Grief support websites primarily provide informational support and online platforms the opportunity for connection with professionals and peers via chats and forums.

In general, support is considered helpful when it creates an open space for expression and listening without judgment, acknowledging the bereaved. Helpful support does not aim to fix grief; it simply respects the individual’s right to grieve on their

own terms and timeline. This understanding is key in shaping any type of grief support, whether informal, professional, or through platforms like Rouw Wegwijzer.

Additionally, whether support is considered helpful or not heavily relies on the bereaved's mindset towards grief and their expectations from the support they receive. If they hope for support to lead to a final stage of acceptance, they may be dissatisfied, as grief does not necessarily have an endpoint.

Most types of grief support, except instrumental support, rely on conversations or text. This can be challenging due to the taboo nature of death and grief in Western society. Most bereaved find it difficult to articulate their feelings and needs. For the development of Rouw Wegwijzer, it needs to be kept in mind that relying on text and conversations only will exclude users who do not have the vocabulary (yet) to express themselves or prefer to engage with their grief in other ways than only talking and reading.

6/ DESIRABLE SERVICES AND CHARACTERISTICS FOR AN ONLINE GRIEF SUPPORT PLATFORM

In the last chapter, we concluded that the content of the websites analysed was mainly informational support and that most platforms offered chats, forums or other social media services. However, VLmD does not have the ambition to become a social media platform or to provide only informational support. Therefore, in this chapter, we want to identify what services the platform should have and how to create a good experience for the user, by identifying desirable and undesirable characteristics of a platform.

6.1/ Desired services for an online support platform



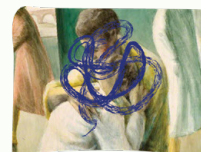
In this subchapter, we focus on identifying what kind of services the platform could provide to the user. During the generative interview, people mentioned activities and services they would like to be able to do or find at a place designed for grief support. They indicated that these were activities that they experienced as supportive in their grief journey. The activities fall into three categories: introspection, connection, and recognition, as depicted and described in visual 19.



Exploring the inner world, which can be seen as an **introspection**



Connecting the inner- and outer world, where the bereaved finds **connection** to peers and others



Finding **recognition**, where the bereaved recognizes themselves in expressions of others

Visual 19. Three categories of activities to engage with grief, found via the generative interviews

6.1.1/ Introspection

As discussed, grief for bereaved emerging adults can be complicated due to the perceived lack of time and space in this phase of life. Multiple interviewees suggested that the 'ideal grief support centre' should facilitate a sense of slowing down, which they do not experience in their day-to-day lives. Therefore, the first category found was introspection. Introspection refers to the process of examining and observing one's own internal thoughts, emotions, and mental states. It involves turning one's attention inward to gain self-awareness and insight into one's own cognitive and emotional processes (Schwitzgebel, 2019). During the generative session, multiple ways, activities, or places were mentioned, that allowed an individual to turn inward and explore their grief. Examples are: seeking out places and moments to be alone, by going on holiday alone, meditation, sitting and being with your grief, or actively searching for the loss orientation and confronting the emotions that can come with grief.

"I have to work pretty hard to get by and so much happens, so much social contact. When you are abroad, especially when there is no internet connection, then there is nothing (...). That helps to process some things and let it in because you are just there with yourself and your feelings."

Stephan

Experience expert

"For the cremation, I made one of those slideshows with lots of pictures of our life, but also of [my father's] life when he was younger. I used to play those slides a lot in the beginning. I would just look at those slides and cry, and that was kind of how I spend my Sunday evening."

Laura

Experience expert

"I am a fast thinker and I want to... well you have to... to process something like [the loss of a parent], you have to stand still. Take a moment to think about it. That was hard for me. I only managed to do that for 2 weeks, and then I went back to full speed ahead. (...) I think that slowing down and experiencing your grief can be really good for young people that go through this. (...) You can see it like some sort of rehab, where you will be set down. Coming from the idea 'you might not want this, but it is going to help you not to avoid [the grief]'"

David

Experience expert

6.1.2/ Connectedness

The second category of activities to cope with grief were activities that allowed one to connect with other people. The importance of experiencing connectedness, which can avoid loneliness, is already underlined in previous chapters. Connectedness is a fundamental need for human well-being, together with autonomy and competence (Deci & Ryan, 2012). Four out of five interviewees indicated that they imagined their ideal grief support place as a meeting place of some sort. It was underlined by participants that both sharing their stories and hearing others' stories was valuable. Participants of the generative sessions mentioned that ideally, they would connect with peers in age or type of loss, but the most important aspect was that they wanted to experience recognition and feel understood.

During the interviews with the Rouw chat volunteers, it was indicated that the most common visitors on the chat were people who experienced loneliness. Most did not have the infrastructure to find connectedness, peer contact or support. These people often expressed feeling suicidal and experiencing extreme loneliness and emotional duress. Alarming, this fits with the factors that indicate a significant risk for suicide attempts (Pitman et al., 2018). The factors were thwarted belongingness, withdrawal from others, lack of connection, and loneliness. This, together with the input collected from the generative sessions, underlines that VLmD should have a service that addresses and facilitates connectedness.

“For me, sharing creates that feeling of ‘oh, I am not the only one’. I think that we as people tend to live from our own perspective and to think ‘Oh all super intense and heavy for me.’ We kind of forget that [experiencing grief] is a really human thing.”

Elvira

Experience expert

“I envision it more as a place where people come together. And inside of that space, I would expect some um, triggering or nudging object, or questions, or something that initiates the conversation.”

Laura

Experience expert

From this sub-chapter it can be concluded that enabling connectedness is an important element of coping with grief and grief support, however, not every bereaved feels the need to converse with peers. Some might prefer other ways of feeling connected or do not feel the need to connect with peers at all.

“I think that at my centre there will be room for music. That is important to me. Making music together, to connect in another way than only talking.”

David

Experience expert

“My need is not really to talk. I notice with other people that I am very conscious of what they need and then I tend to not stay true to myself but to look at what the other might need. I also think I am very conscious of what others expect of me. And that is why I prefer to research [my grief] by myself.”

Iris

Experience expert

6.1.3/ Recognition

The third category consisted of activities that foster recognition. During the generative sessions, interviewees discussed various ways they sought recognition. Recognition was seen as a way to understand one's own emotions, by mirroring them to others' emotions. The participants of the generative sessions found recognition in conversations, but also via music, art, poetry, cinematography, gaming, and other mediums that contain an expression of grief. They also mentioned finding recognition in informational support sources, like a book.

Even if the experienced emotions were not obvious or conscious, recognition could occur. For instance, when someone identifies their sub-conscious feelings in a TV series, it signifies their ability to relate to and understand the emotions depicted on screen because they resonate with their own inner experiences. This can result in a sense of familiarity, empathy, or recognition of the characters' emotions, situations, or dilemmas. In turn, this can lead to a better understanding and expression of one's own emotions, situations, and dilemmas.

“I have been searching for [understanding of my grief] in expression. Um... expression as in: what kind of art do I like? But also, like I said, music: do I like this? And yes, I did this online, but I was not looking for information like: [uses a computerlike voice] Me sad, what to do?”

David

Experience expert

“[Recognition] can come from experiences, but also from theoretical sources. Like: ‘I read this book and they described that, and that was so recognizable for me.’ I think poetry is also really good to create that feeling because it might touch you briefly.”

Stephan

Experience expert

“I tried to use [art and artistic expression] to find out how I felt. A piece of art can sometimes name what you were not able to name. And then you can say: yes, this.”

David

Experience expert

6.2/ (Un)desired characteristics of an online support platform

Overall, a platform's design, characteristics and functionality directly impact the nature and quality of user interactions. Therefore it is explored what characteristics are desirable for the platform and which are not.

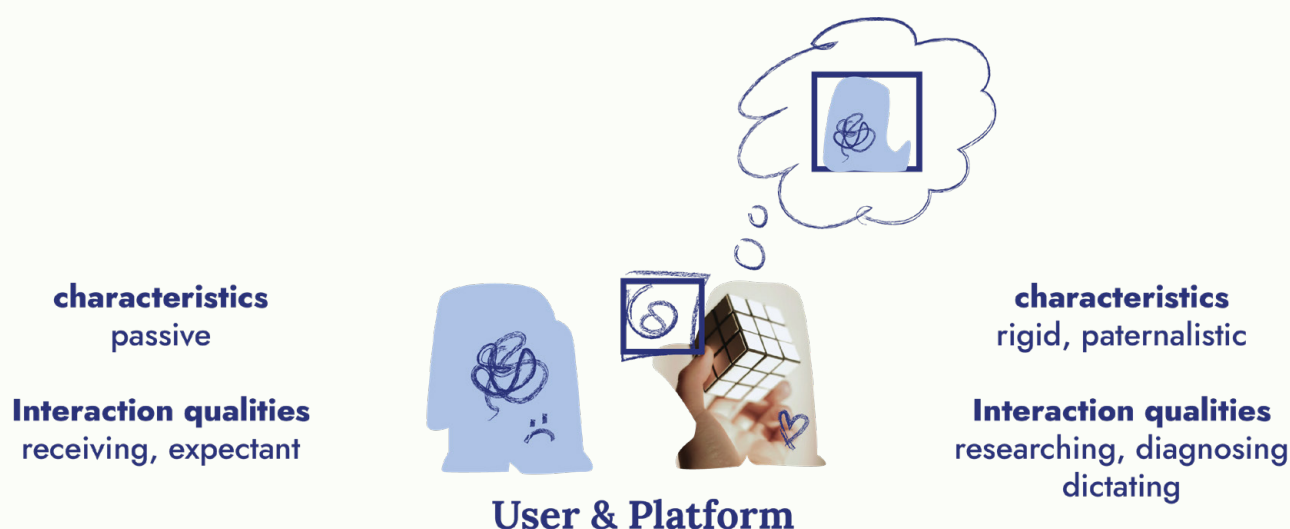
6.2.1/ Current characteristics

OS

Two platforms that provide personalised online grief support are analysed (see appendix 8). These platforms were Cruse.org.uk and a concept proposal by VLmD, which is under development. From the analysis, some current interactions provided by personalised grief support are identified. They are depicted in visual 20. The current interactions resemble a doctor's visit, with the platform diagnosing the user based on a questionnaire. The user does not have a big influence on what is asked or what

topics and factors are seen as relevant for them. Instead, both Cruse.org.uk and the proposal of VLmD take a top-down approach, which is not desirable from a user-centred design perspective (Gulliksen, 2003) and can be considered paternalistic. Next to that, the approach by VLmD is data-centric. Based on data about the demographic and contextual factors of the bereaved, support and advice are provided. However, this diminishes the bereaved to a statistic, which is also considered undesirable from a user-centred design perspective.

The top-down, data-centric approach creates a platform that can be characterized as **rigid and paternalistic**. Leading to the interaction qualities as depicted in visual 20. The platforms interact in a **researching, diagnosing and dictating** way with the user. The user does not have a say in how they are researched or diagnosed, making them **passive**. Their interaction qualities are **receiving and expectant**. This undermines the autonomy and competence of the user, which together with connectedness, are crucial for well-being (Deci & Ryan, 2012).



Visual 20. Current characteristics and interaction qualities of personalised grief platforms and their users.

6.2.2/ Desired characteristics of the platform



From the generative interviews, the following characteristics were identified as desirable: **Facilitating, non-judgmental and unassuming.** The platform should also be experienced as welcoming, by being characterized as **comforting, warm and soft.**

“Maybe my [librarian as a] grandpa is similar to my version of a dog [being present as a source of support] (...) I think they will say as it is, but there is no judgement behind what they say.”

Iris

Experience expert

During the generative interviews, participants indicated it was important to have someone (or in the case of an online platform: something) who could oversee all the information and possibilities, but remained non-judgmental in how and when they provided the information. Two participants likened this person to a librarian, as they are knowledgeable yet neutral. A librarian roughly knows how and where to find information. Yet, it is not their function to promote books by recommending or pitching random books, unless specifically asked for suggestions, their role is to facilitate. This coincides with the literature and which says dictating guidance is seen as unhelpful and judgment-free support is considered helpful (Cacciatore et al., 2021; Aoun et al. 2018).

During the generative sessions, it was emphasised that the support provider should know when to approach and be ready to provide support but

should not approach everyone indiscriminately. This could be described as unassuming. Again, a comparison was made with a librarian; they are there, ready to help and easy to approach, but they will not bother you if you are just browsing or searching.

Being facilitative, unassuming, and non-judgmental is not the same as being distant. It was stressed that the platform should be welcoming and empathetic to all types of bereaved people. One way of doing

this was to create a comfortable, warm, and soft environment and experience on the platform.

“No, [the employees] are not invisible. They are people, I think, that are more active in the background, just to wait and see. They do not walk towards you right away and yell: “Hey! How are you?!” They let you know with a smile that they are available for a chat if you want to.”

Laura

Experience expert

“I think it will be good if someone approaches you [when you enter]. Yes... but not for me, I think... No, I don’t want someone approaching me. But I would like the idea that I can calmly touch that person, just so to say. To be like: yes now it is necessary, join me for a bit. When I cannot find what I need, for example.”

Stephan

Experience expert

“I don’t know if I have a logical explanation as to why I have a preference for warm colours and soft pillows [at my centre], but perhaps it is the association I have of warmth with security, comfort and softness.”

Elvira

Experience expert

6.3.3/ Undesired characteristics

LR

GI

During the research activities, undesired behaviour and characteristics for the platform also arose. Logically, these undesired behaviours and interaction qualities are predominantly the opposite of the desired characteristics. They also overlapped insights found earlier about unhelpful grief support. It is undesirable to have a platform that is experienced as **judgemental or directive**. Next to that, the platform and grief support in general should not be experienced as **insincere, generic** (Cacciatore et al., 2021) **cold, medical or clinical**.

Discussion

Arguably, a good online grief support platform allows users to feel autonomous and competent. Which are, along with connectedness, fundamental human needs for a fulfilling life, according to the self-determination theory (Deci & Ryan, 2012). Arguably, the desired services for the platform allow users to fulfil these fundamental needs. The desired characteristics also describe a platform that enables the user to experience autonomy and competence in their interactions with it. On the other hand, the undesired characteristics describe a platform that undermines autonomy and competence.

“If someone starts to tell me how I should grieve, I think [blows raspberry]. So if someone says to me: ‘I think you have to do this’, especially if that is a digital person and not someone physical that I trust, I will be like: ‘I am a special snowflake and what you say is [negative sound].”

David

Experience expert

About what kind of employees he wants at his centre
“It definitely should not feel medical for me. (...) These two [points at an icon of a fireman helmet and a graduation beret]. You are not there for a counsellor or therapist.”

David

Experience expert

“If you want to create a space where people can open up, to share and be courageous enough to get vulnerable, for me it would be good if that would be somewhere where they feel at home and at ease. And yes, that would be hard for me in a white room with fluorescent lights. I would not feel safe there. I would not wish to go near.”

Elvira

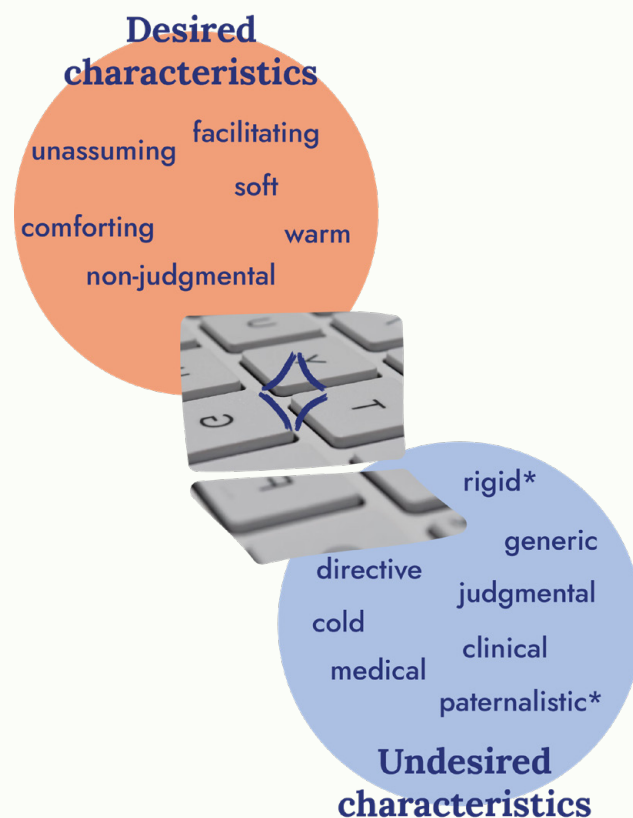
Experience expert

The current characteristics described in this chapter, rigid and paternalistic, undermine autonomy and competence too. It can be argued that they are therefore undesirable too.

Conclusion

In this chapter, the focus was on determining what are desirable services and (un)desirable behaviour for an online grief support platform. The desirable services identified can be categorized into three main categories of activities that allow coping with grief: introspection, connectedness, and recognition. These activities cater to the user's need for autonomy, competence, and connectedness, which align with the self-determination theory's fundamental human needs for well-being.

For the desired platform characteristics, three key qualities were highlighted: facilitation, neutrality, and unassuming behaviour. These characteristics emphasize the importance of the platform taking a background role, allowing users to make decisions and take actions autonomously. However, these key qualities did not mean that the platform should become distant. It was desirable for the platform to be welcoming and empathic towards the user, by providing a comfortable, warm and soft experience. In extension, it was undesirable for the platform to be experienced as cold, medical or clinical. This underline that a paternalistic relationship between the platform and the user is also not desirable. Other undesirable characteristics were pushiness, having ulterior motives, being judgmental, being insincere and being generic. These attributes would undermine users' autonomy, competence and uniqueness, making the



Visual 21. Desired and undesired characteristics for the platform. * Identified as undesired in the discussion.

platform less effective in providing grief support.

The chapter also examined two existing concepts for personalized grief support, Cruse.org.uk and VLmD. Both concepts unintentionally created paternalistic roles and interactions, which could hinder the user's autonomy and competence. This might be partially due to the interaction patterns mimicking that of a doctor's visit and using a data-centric perspective for providing the support.

The insights from this chapter will guide the design and development phase of the Rouw Wegwijzer. It showed the necessity of avoiding paternalistic roles and behaviours, and ensuring that users have the autonomy and competence to navigate their grief journey effectively.

PART 1 DISCOVER

Concluding

The idea that grief has an end-point of acceptance is a persistent, untrue belief in society. Grief is a complex experience that follows a unique path for each person. Yet, a generalisation that can be made is that most bereaved go back and forth between a loss orientation and a restoration orientation. Neither orientation is inherently sad and grief may even encompass positive aspects. Over time, how grief is experienced, how it manifests and what it means for the bereaved changes. Furthermore, while grief is an undeniable part of life and cannot be solved, it does not necessarily dominate a bereaved person's life.

The target group for this thesis are emerging adults who lost a parent, while not living at home. Emerging adulthood is a life phase for those between 18 and 30. Losing a loved one is not common at this age, especially since the loss of a parent is considered an off-time loss. Because of the less common occurrence of loss, experiencing loneliness and disconnection from peers is common. Next to that, encountering loss and grief in this life phase can significantly affect the typical characteristics and developmental milestones that characterise emerging adulthood.

Due to the aspects mentioned, grief as an emerging adult might create specific experiences. With this in mind an overview is created of the different facets of grief discovered, grouped as themes, see visual 22.

Grief support can be provided in many forms, but usually is shaped as conversations or text. Effective grief support ideally comes from loved ones who are available, understanding, and unconditional in their support, avoiding attempts to "fix" the grief, thereby acknowledging the bereaved. On the other hand, ineffective grief support involves trying to solve grief, offering unsolicited advice, lacking empathy, and imposing solutions on the bereaved. These efforts often contradict the understanding that there is no universal solution for grief. The Rouw Wegwijzer should prioritize acknowledging an individual's right to grieve in their own time and manner, rather than attempting to resolve their grief.

Three categories of activities were discovered that were experienced as supportive according to the participants of the generative sessions. These categories are introspection, connection with others, and recognition of one's emotions and

	Loss orientation	Restoration orientation	Both	Context factors
Grief and Me	Experiencing (obstrusive) emotions	Ignoring/avoiding grief	Thoughts influenced by grief	Influence of previous experiences
	Physical complains	Ignoring/avoiding restoration		
	Behaviour influenced by grief	Identity crisis		
	Meaningmaking			
Me and the Deceased	Loss of direct contact	Identity in relation to the deceased		Relationship to the deceased
	Continued bond with the deceased	Trying new things without the deceased		How the deceased past
		Shaping life without the deceased		
Grief and my Surroundings	Loneliness and connectedness	Attending to life changes due to loss	Connectedness with peers	Social/ historical/ religious/ cultural/ economical context
		(Re-)evaluation of lifegoals	Relation with close contacts (friends, family, etc)	Demographic bereaved
		Exploring new roles, identities and relationships without the deceased		

experiences in others. These can be used as a basis for developing the services on the platform. From various research activities it can be concluded that to ensure a positive user experience, the platform could be characterized as facilitating, non-judgemental, and unassuming while avoiding cold, paternalistic, directive or clinical characteristics. This approach empowers users to maintain a sense of autonomy and competence.

In conclusion, grief is an intricate journey with no fixed destination, unique for every person. A well-designed grief support platform should respect the unique paths of individuals and support them without becoming paternalistic.

Visual 22. Overview of grief themes.
The list was validated with Annelies van der Ouw and Robin Zuidam, see appendix 48 for the set-up and results of this validation session.

PART 2

Define

From the research conducted in part 1 we know what grief is, how it is unique for bereaved emerging adults, what kind of grief support is considered (un)supportive and what services and interactions are desirable for an online grief support platform. In this part of the report, we will define a focus for the design phase. A design goal for the platform is presented and the interaction qualities are defined. The interaction qualities are accompanied by requirements as to how to meet them. Lastly, two archetypes are developed. Their needs and motivations for using the platform inspired requirements for the content and support available on the platform.

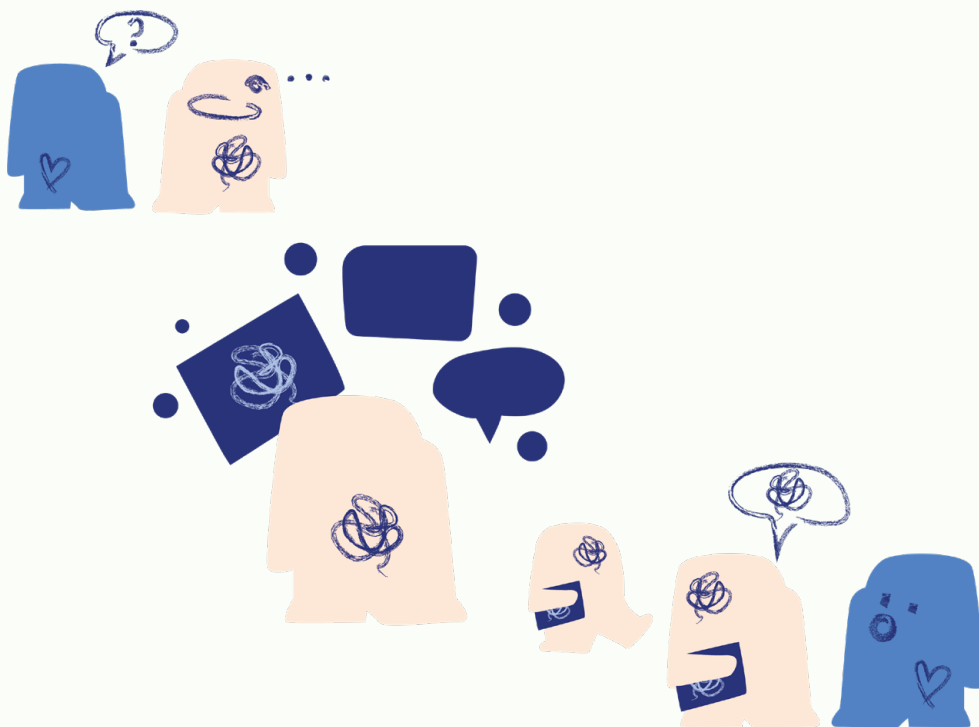
7/ CHOOSING A DIRECTION

7.1/ Design opportunity: Recognition

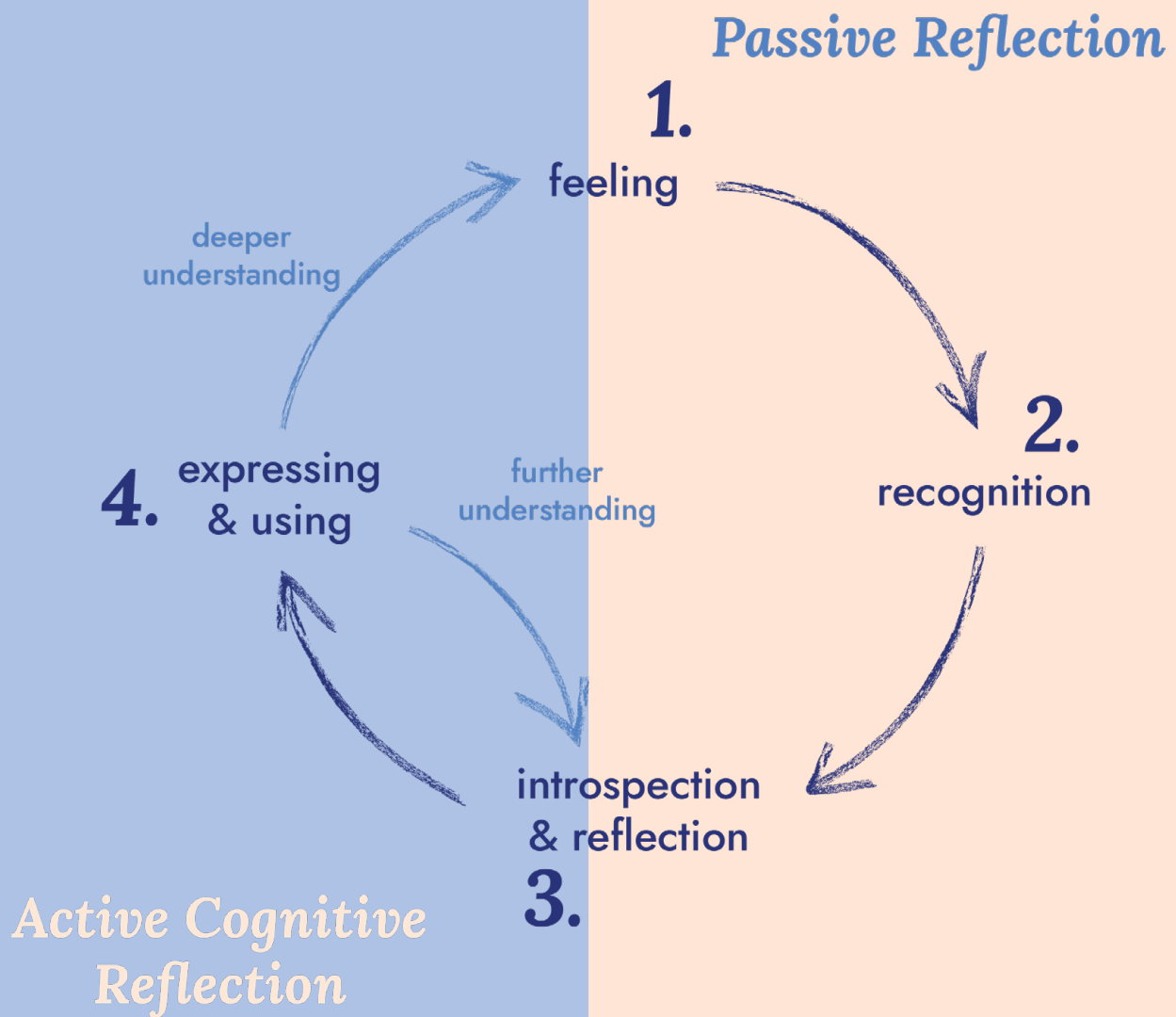
In Chapter 5.3, it was concluded that usually, when a bereaved person asks for help because they feel 'something' is off, they will need to be able to describe what they are experiencing (moving from step 1 to step 4 in visual 23). However, engaging in conversations about grief can be challenging amid a prolonged stressor like grief (Van der Kolk, 2014). Additionally, the bereaved's contribution to the conversation is restricted by the number of words and expressions they have to describe what they are experiencing. Due to the taboo nature of grief, this vo-

cabulary is limited (Farberow, 2013; Allan & Burridge, 2006). Yet, emotions can exist without corresponding words.

In Chapter 6 it was described that recognition was used as a method to find expression for what the participants were experiencing. Interestingly, participants mentioned that recognition did not only occur during conversations, but also many other moments. For example, while reading a book, or watching a movie. **Recognition can be found in any type of expression of feelings and experiences.** This is an opportunity that will be explored further in this thesis.



Visual 23. Finding expression via recognition



Visual 24. The model visualized describes how a bereaved can use recognition to find expression for what they are feeling.

A reflection on how recognition could allow a user to find expression for their grief led to the model visualised in visual 24. This visual lays out a step-by-step process on how recognition is used as a means to improve one's vocabulary and comprehension of their grief. The beginning state is that the bereaved individual experiences a feeling, whether consciously or subconsciously (1. Feeling). The next step involves discovering recognition in the expressions and insights of others regarding grief. Encountering these expressions can trigger a sense of comprehension, providing validation and insight into hidden

emotions (2. Recognition). The third step is introspection, which is also discussed as a potential service in Part 1. In this step, the bereaved appropriates and situates the new word/understanding within one's context via an active cognitive reflection (3. Introspection). Eventually, the bereaved has a new understanding of their grief, which has broadened their vocabulary for expressing (4. Expressing and using). They can now use the vocabulary to express or think about their grief, potentially discovering deeper emotions and meanings.

7.2/ Design Goal

Based on the design opportunity of recognition the following design goal is formulated. For the Rouw Wegwijzer, an online platform in development by Vereniging Leven met Dood which aims to provide personalised grief support.



“We want to offer bereaved emerging adults a place to explore their (understanding and expression of) grief, via recognition in others’ understanding and expressions.”

Bereaved emerging adults: the target group of the design proposal of this thesis.

A place to explore: This place to explore will be the Rouw Wegwijzer. Encouraging a user to explore, can be done through the way the platform is designed.

Recognition: The Rouw Wegwijzer is providing appraisal support. It allows a self-evaluation, by mirroring one’s feelings to others’ feelings and experiences.

Others’ understanding and expression of grief: expression in the broad sense, for example: podcasts, illustrations, grief theories, books, music, cabaret, dance, cinematography, anywhere any way where someone expresses their experience.

Their (understanding and expression of) grief: By finding expressions of grief (experiences) that fit the user, they build up a vocabulary for their own experience, enabling them to reflect and find understanding and expression.

7.3/ Interaction qualities and how to achieve them

Based on the insights from part 1, it is decided to use supportive, facilitating and explorative interaction qualities. For each interaction quality, it is also defined how the platform should be characterized, to achieve the interaction quality.

Explorative

The user should be encouraged to explore the expressions of others which are captured in the content on the platform. The design should reflect the **nuanced and dynamic** nature of grief in its design and content. By providing varied content that highlights the many facets of grief, the platform can give the user a **researching** role in finding out what expression and grief support fits them.

Facilitating

The platform assists and facilitates, so the user can figure out what is important to them, staying **humble and unassuming**. Which was identified as desirable characteristics in chapter 6. The platform does not try to resolve the grief but acknowledges the bereaved's right to grieve in their

own way and time. Therefore, the platform is not presented as an expert and does not impose solutions or predetermined directions for the user, nor is it judgemental. It should help the user in selecting what is relevant to them and what not, while simultaneously avoiding providing unsolicited advice, for example by determining what would be 'good' for the user, based on statistics. It embraces the complexity and uniqueness of each bereaved(s' grief).

Supportive

The platform should be considered supportive, by creating an user-centered and acknowledging experience. The supportive character of the platform is embodied by a design that is **warm and soft** in its interactions and visual design. Both were identified as desirable ways to characterize the platform in chapter 6.

In conclusion, while designing and shaping the platform a balance is to be sought between providing autonomy and competence to the user by allowing them to explore freely and find their path and expressions, without getting lost or overwhelmed by too many options and directions.



Explorative
nuanced, dynamic
& researching



Facilitating
humble & unassuming



Supportive
warm & soft

7.4/ Archetypes: understanding the needs and motivations of users

To create a broad understanding of what kind of content and support should be offered on the platform, two archetypes of potential users are developed. The archetypes have specific needs, expectations and motivations for engaging with the platform. The archetypes are inspired by the research done in part 1 of the thesis and based on the two grief orientations of the dual process model (Stroebe & Schut, 1999). A bereaved can move between the two archetypes or recognize themselves in different aspects of the archetypes.

The Solace Seeker

This archetype is focused on what they feel and are considered with their grief experiences in the current moment. For this archetype grief is predominantly a negative or overwhelming experience, making them more focused on finding relief and solace. They hope to find validation and acknowledgement for their feelings and experiences through the platform.

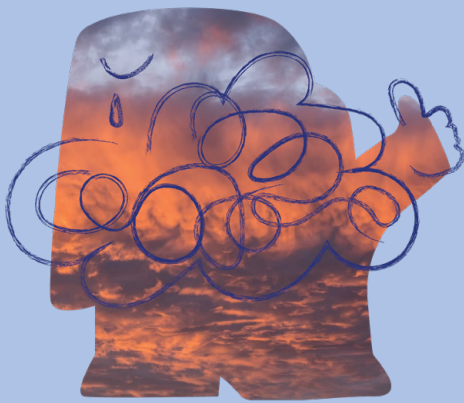
Some people who fit this archetype believe that grief is ending, due to the ongoing influence of the phase-model by Kübler-Ross, as explained in chapter 3. This means that Solace Seekers, especially when their loss has not been recent, might feel ashamed or annoyed, for not having reached the expected endpoint of acceptance. If the grief is not recent, the care and involvement of those around them most likely have decreased too. As a result,

the Solace Seeker might have trouble finding people to talk about their grief or places to express their grief.

Their grief related emotions are often experienced as intrusive and undesired. They therefore experience resistance to consciously and actively engage with their grief and emotions. Some might mask their grief. Especially for these people, it is important to normalize that every person grieves in their own way and time. This archetype is driven by a search for relief and consolation.

The Grief Inquirer

The Grief Inquirer represents individuals who approach their grief journey with a quest for understanding. They are motivated by the search for insight and inspiration. Next to painful and negative aspects of grief, the Grief Inquirer is also able to see the positive sides and outcomes of their grief. They can find consolation in the bittersweet emotions that grief can trigger. As a result, they are more kind towards their grief and experience less resistance to engage with it, compared to the Solace seeker. They understand that each bereaved has their own unique path that does not necessarily end with acceptance. Therefore, they are driven by the desire to comprehend the implications of their grief on their life now and in the future. They would not engage with the Rouw Wegwijzer to find specific support, but because they want to be engaged with and be informed about this part of their life and identity. They are driven by interest.



Solace Seeker

“When I feel overwhelmed by my grief, I want to find recognition and acknowledgment, so I can feel solace.”

“When I am engaging with my grief, I want to find insights and inspiration, so I can understand what grief means to me and my life.”



Grief Enquirer

Visual 26. The two grief archetypes

7.5/ List of requirements

Based on the research done in part 1, the interaction qualities and archetypes, requirements are formulated for the platform, its content and the support it should refer to.

General requirements for the platform

- The platform should acknowledge that all grief experiences are unique.
- The platform should acknowledge that grief can encompass many types of emotions and experiences, including positive ones.
- The platform does not try to resolve the grief but acknowledges the bereaved's right to grieve in their own way and time.
- The platform should avoid mimick-

ing the interactions of professional grief support.

- The platform should not be experienced as cold, clinical, medical, judgemental, directive, rigid, generic, insincere or paternalistic.

Requirements for platform content

- The platform should include content discussing topics and experiences unique and relevant for bereaved emerging adults.
- The platform(s content) should provide recognition, acknowledgement and insight into the wide variety of (negative and positive) emotions and experiences due to bereavement.
- The platform(s content) should

acknowledge and normalise that every person grieves in their own way and time.

- To meet users who experience resistance to engaging with their emotions (e.g. the Solace Seeker), the platform contains light-hearted content.
- To meet users who want to explore and research their grief (e.g. the Grief Inquirer), the platform has content that goes in-depth and provides refreshing and new perspectives.

Requirements for the support provided or referred to

- The platform should refer to or contain support that facilitates connection in general and with peers.
- For users who are high in emotion and/or have difficulty finding a place to express their grief (e.g. the Solace Seeker), an accessible place to express their grief should be added.
- To meet users who do not have a place to express their grief, but desire to (e.g. the Solace Seeker), the Rouw Wegwijzer should be able to refer to a place where they can go or provide this place.

PART 2 DEFINE

Concluding

“Recognition,” emerged as a promising design direction. Bereaved can expand their emotional vocabulary, by recognizing their emotions and experiences in the expressions of others, ultimately leading to a deeper comprehension of their grief. This approach recognizes that grief goes beyond words and conversations. Consequently, the following design goal was formulated for the Rouw Wegwijzer: “We want to offer bereaved emerging adults a place to explore their (understanding and expression of) grief, via recognition in others’ understanding and expressions.”

The chosen interaction qualities—explorative, facilitating, and supportive—will guide the design phase. The platform aims to facilitate an exploration of their and other’s grief while maintaining a supportive atmosphere. With this approach we aim to empower bereaved emerging adults to navigate their unique grief journey, fostering recognition, understanding, and self-discovery.

Two archetypes, the Solace Seeker and the Grief Inquirer, guide the content and features of the platform to cater to different needs and motivations. The Solace Seeker

seeks recognition and acknowledgment for their overwhelming grief, while the Grief Inquirer aims for insight and inspiration in understanding their grief. Based on the research done in part 1, the interaction qualities and archetypes, multiple requirements are developed, which will be applied when developing the design for the Rouw Wegwijzer.

In summary, Part 2 sets the stage for designing an online grief support platform that empowers bereaved emerging adults to explore, express, and understand their grief through recognition, ensuring the platform is explorative, facilitating, and supportive to meet diverse user needs.

PART 3

Develop

In part 1 we created an overview and general understanding of grief, the target group and grief support (online). In part 2 it is described in what direction the Rouw Wegwijzer will be developed for this thesis. In this part, the design proposal is introduced. This design proposal is then tested with users, discussed in this part too.

Method

During the design process there was a back and forth between the definition of the problem and a proposal for a solution. "In design, this process is described as co-evolution of problem and solution (Dorst, 2019). The solution allows us to understand the problems better and to discover new facets of the problem, giving insights for new solutions. As a result, the user journey and platform design have been repeatedly iterated. During this process, multiple design activities were conducted: initial ideation, benchmarking, conceptualisation and validation with users. This creates a process as pictured in visual 27.

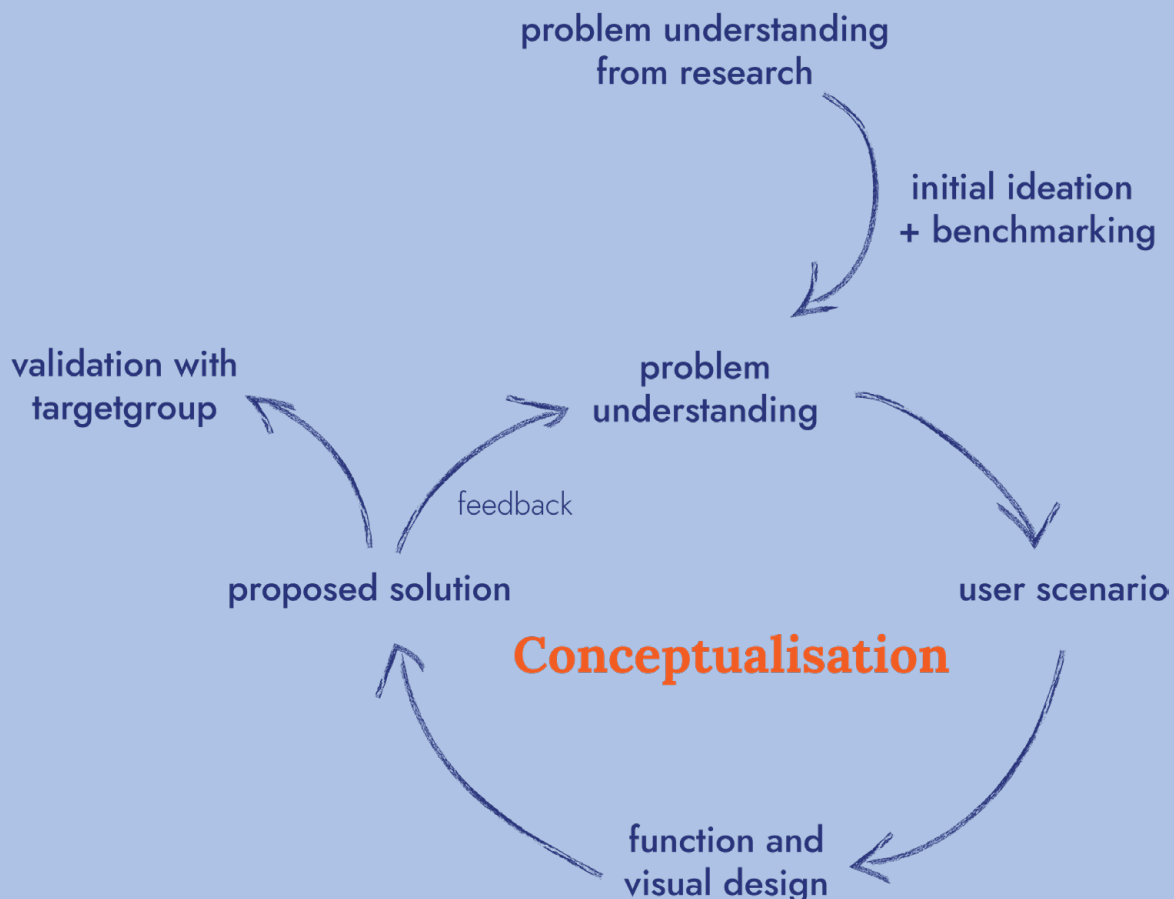
Activities

Initial Ideation: an ideation session with fellow designers was organised, individual ideation was conducted and a paper prototype was created and filmed to collect ideas and feedback from fellow designers.

Benchmarking: 1) analyse interesting websites and platforms. Find out how they encourage exploration and arrange their content (appendix 41). 2) Visual style inspiration (appendix 11).

Conceptualisation: Multiple mock-ups were created throughout the iterative cycles. Visual 31 gives an impression of the various mock-ups. The mock-ups were discussed with fellow designers, professional (web)designers, the graduation team and VLmD, to collect feedback for the next mock-up.

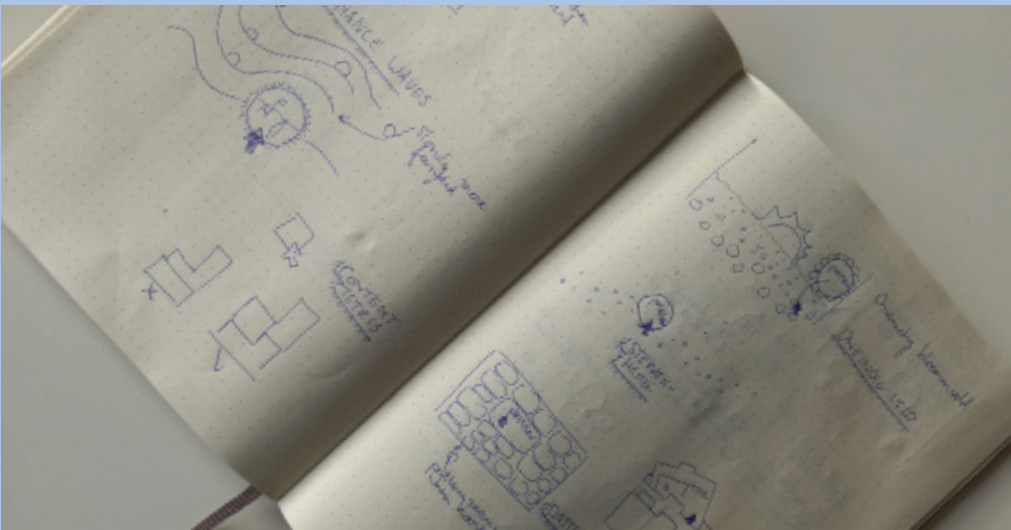
Validation with users: A visual and a functional prototype was created. These prototypes were used to do a user test with the target group. The goal for the user test was to validate the intended use, and if the design sufficiently addressed the interaction qualities. A more detailed description will be provided in chapter 9.



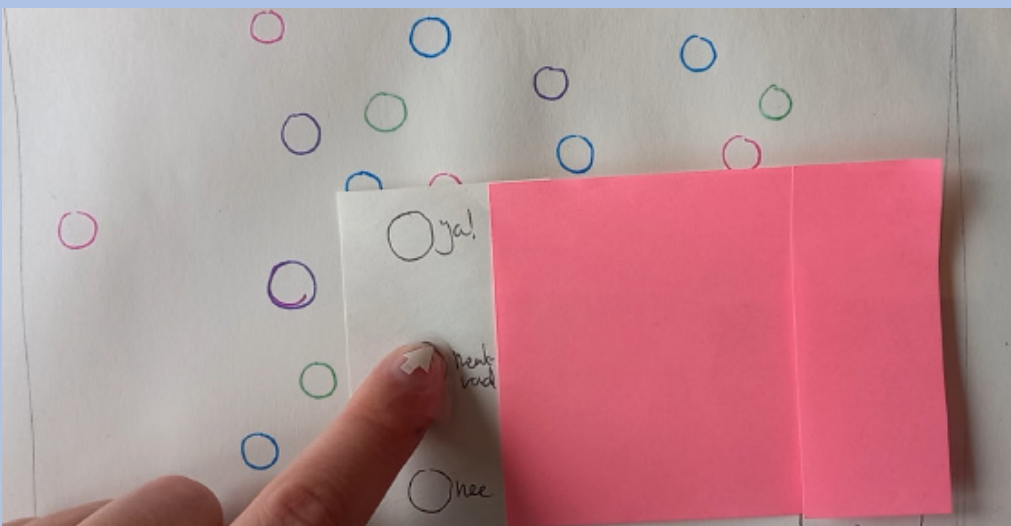
Visual 27. Process of the deliver phase.



Visual 29. Creative session with two professional designers.



Visual 30. Individual ideation

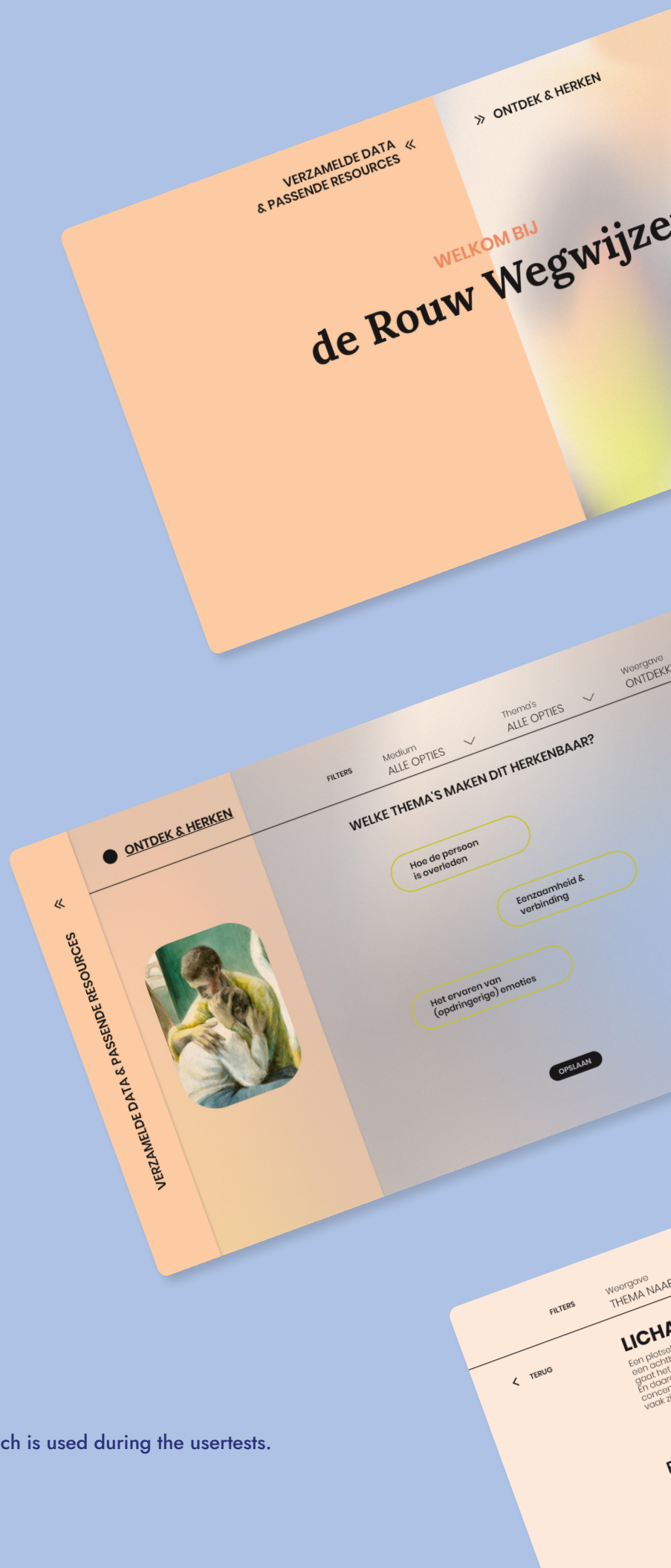


Visual 28. Paper prototype






Visual 31. Impression of the various mock-ups.



Visual 32. Impression of the final design, which is used during the usertests.

ONTDEK & HERKEN

VERZAMELDE DATA & PASSENDE RESOURCES



het meest
toewijzen

PASSENDE RESOURCES

ONTDEK & HERKEN

VERZAMELDE DATA

FILTERS

Woergave
THEMA NAAR RESOURCE

HET ERVAREN VAN
(OPDRINGERIGE) EMOTIES

EENZAAMHEID &
VERBINDING

IDENTITEIT

CONNECTIE
MET PEERS

CONNECTIE MET LOTGENOTEN

LICHAAMELIJK
KLACHTEN

= THEMA MET OPGESLAGEN MATERIAAL

= OPGESLAGEN MATERIAAL

= THEMA ZONDER OPGESLAGEN MATERIAAL

ROUW CHAT
Vind iemand om mee te
kijken naar je resultaten

PASSENDE RESOURCES

ONTDEK & HERKEN

VERZAMELDE DATA

RESOURCE

LIJCHAMELIJKE KLACHTEN

JE HEBT 2X
IETS OPGESLAGEN
MET DIT THEMA

PASSENDE resources

Begrijp je klachten beter
Het begrijpen van fysieke
klachten in relatie tot rouw is
cruciaal om het rouwproces te
ondersteunen. Deze informatie
kan helpen bij het lichamelijke
en omgaan met emotioneel
symptomen met emotioneel
symptomen door een
mogelijk

Lichaamsgerichte therapie
Lichaamsgerichte therapie kan
een waardevolle aanvulling
zijn bij rouwverwerking. Het
richt zich op het begrijpen en
verlichten van fysieke
spanningen en symptomen
die vaak gepaard gaan met
verdriet. Door bewuste
aandacht voor het lichaam te
combineren met emotionele
verwerking, kan deze
benadering helpen bij het
herstellen van evenwicht en
herstellen van de rouwperiode.

Ademen
Ademhalingsoefeningen zijn
waardevol bij rouwverwerking.
Ze helpen bij het kalmeren van
de geest, verminderen van
stress en bevorderen van
emotioneel herstel, waardoor
men beter om kan gaan met
verlies.

> DOWNLOAD 'THE BREATHING' APP
> VIND YOGALESSEN

8/ THE DESIGN

The Rouw Wegwijzer is intended to become an online platform that provides personalised support. On the platform bereaved emerging adults can explore their grief and intuitively find fitting grief support. The platform is not presented as an expert, but an equal that explores together with the user. The focus is on the journey and less on the result.

On the Rouw Wegwijzer, we want to leverage recognition to uncover and identify grief experiences that are difficult to put into words. It allows users to explore what is important for them and what is not, without asking them to be able to verbalize what they are experiencing.

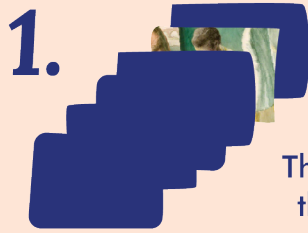
8.1/ From finding recognition to getting fitting grief support

Before we discuss the design, it is relevant to know how the platform uses recognition in expressions of grief to create a personalised grief support overview for the user. A method was developed through the mock-ups. This method is visualised in visual 33, on the next page. The journey described in the visual goes from exploration and 'feeling what fits' to specific grief support, from abstract and experiential to specific.

Two important elements can be identified in visual 33 that play a role in the design of the Rouw Wegwijzer: the 'pieces of content' and the 'themes'.

The pieces of content: Pieces of content are other's expressions and understandings of grief. Expression can be made in many forms. This means that the user can find paintings, podcasts, poetry, articles, books, music, cabaret, dance, cinematography and more on the platform. To enable these expressions on a digital platform, we will only include expressions that are captured in image, video, audio, and text. The aim is to offer a wide variety of pieces of content. They differ in themes discussed, tone of voice, background, type of medium etc, this way we ensure that the user is exposed to many perspectives, allowing them to collect and find what seems relevant to them.

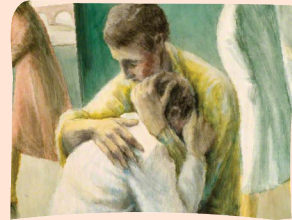
Themes: The themes used for the Rouw Wegwijzer are the themes that we concluded part 1 with, as depicted in visual 22 on page 50.



1.

The user in can go through multiple pieces of content

2.



The user indicates if a piece of content is recognizable to them.

3.



The piece of content is labelled with themes. The users can correct how the piece of content is labelled.

4.



Multiple pieces of content are saved and labelled this way. Creating some sort of database.

5.



Based on this database and overview can be created of recurring themes. The overview is presented to the user.



6.

Via this overview the user can access the corresponding support.

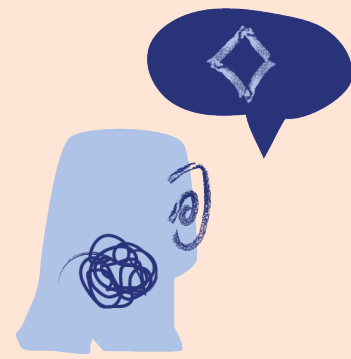
Visual 33. The method how the platform personalises the platform

8.2/ User Scenario

The method described in visual 34 is translated to a user scenario which describes 8 touchpoints. For this thesis, we will focus on conceptualizing touchpoints 4 to 7. Each touchpoint indicates an interaction between the Rouw Wegwijzer and the user. As can be seen in the user scenario, there are moments when a user can take the insights or inspiration provided by the platform and leave the platform with this new knowledge. In this thesis, step 8 is considered the end-point for the Rouw Wegwijzer, where the user gets a personalised overview of relevant themes and support. Yet, for the user, it can be a starting point to start engaging with grief support offered by VLmD and third parties.

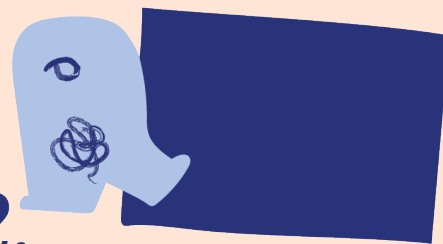
Visual 34. The user scenerio depicting the various touchpoint and exitpoints on the platform

1.



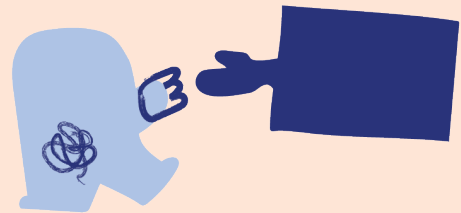
The user hears about VLmD and the Rouw Wegwijzer, via some campaign or a friend. They decide to take a look.

2.



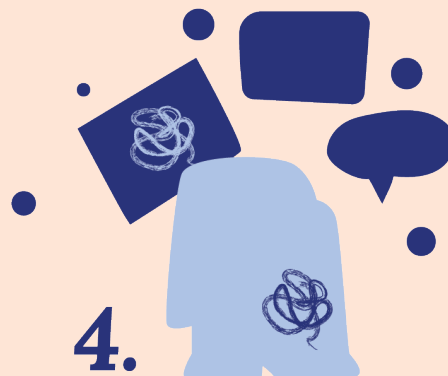
The user enters the platform.

3.



If it is a first-time user, an onboarding is provided. In this onboarding, it is explained what the user can expect from the Rouw Wegwijzer and how to use it.

4.



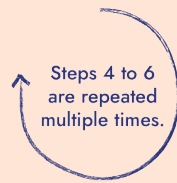
The user goes into an online surroundings where they can explore and find a variety of pieces of content.

5.



Exit.

When the user finds a piece of content that seems recognizable, relevant or interesting to them, they can save this piece of content.

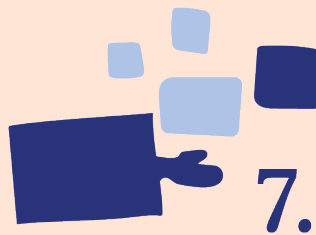


6.



The user can indicate why something was noteworthy for them. This is to prevent the system of the platform from making assumptions about why something is saved.

Exit.

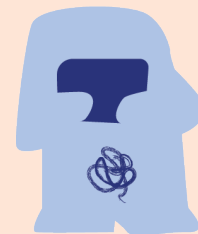


7.

Based on the data collected the platform shows an overview of which themes seem important to the user and offers fitting support

Exit.

per theme.

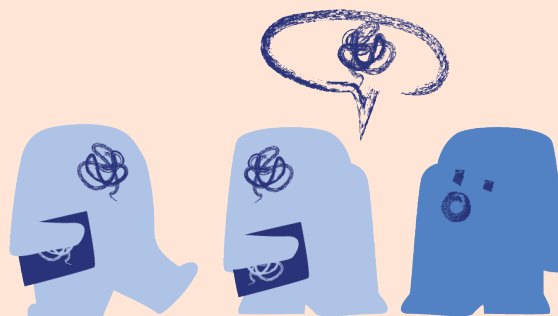


8.

Using the personalised overview of themes and corresponding support the user continues to explore the different information and services offered by VLmD and third parties.

Exit.

Some users leave the platform at this point and take the insights and vocabulary they found with them. They can use this in their further exploration and conversations outside of the Rouw Wegwijzer.



8.3/ The design per touchpoint

Based on the user scenario touchpoints 2, 4, 5, 6 and 7 are contextualized further into a prototype, which will be discussed here.

Touchpoint 2: The user enters the platform

When the user enters the platform, they will see a first screen, which is divided into two sections. When the user enters the right part of the screen, they will find the 'explore and discover' section. Here they can find and collect content. On the left, the user can find the collected content and the personalised overview of topics with corresponding support.

Touchpoint 4. Finding the 'explore and recognize' section

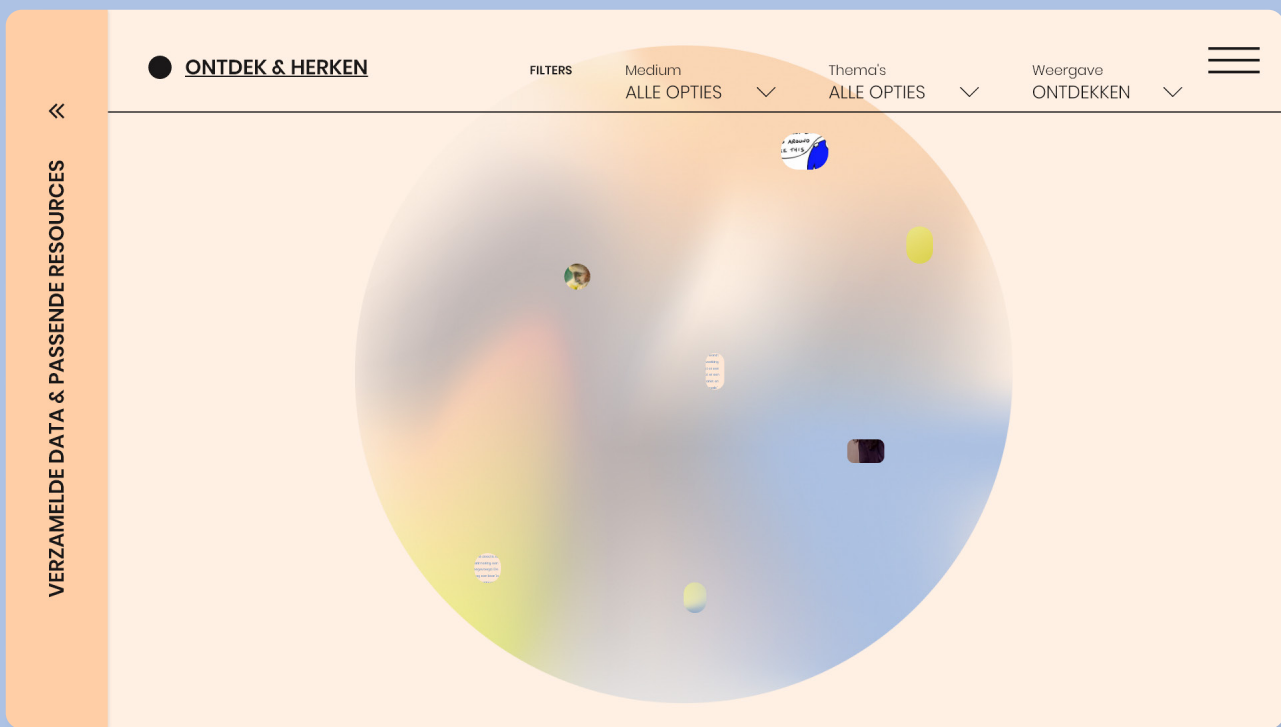
When the user enters the 'explore and recognize' section, they will see an interactive environment in which multiple pieces of content are randomly placed, see visual 36. From here the

user can freely move around the environment, zoom in and zoom out, similar to how one moves around in Google Maps. If the user navigates closer to a piece of content, it will become bigger (see visual 37). If the user clicks a piece of content or has navigated close enough, it will fully open, see visual 38 and 39. Pieces of content containing audio and video will also start playing automatically if the user comes close enough. This is to make the user curious and invite them to continue navigating closer till they can view the full piece of content.

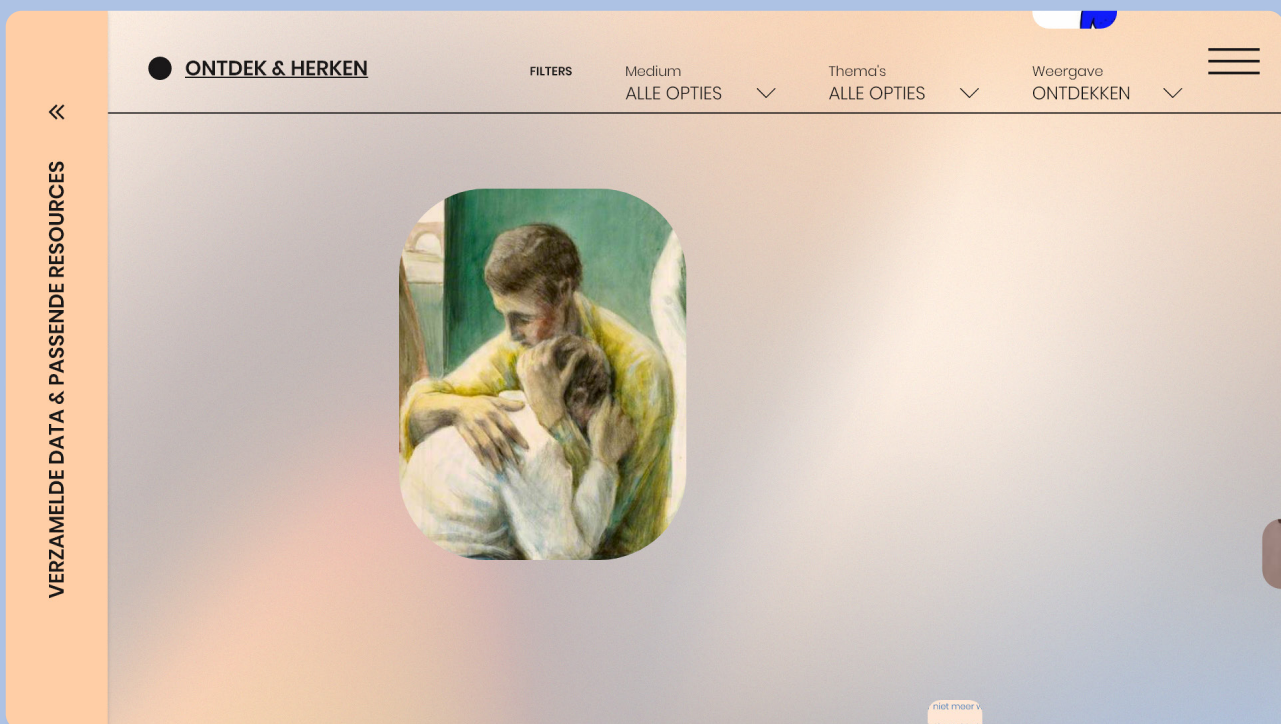
The 'explore & recognize' section will not update based on user interests to avoid an echo chamber (Ge et al., 2020). An echo chamber, a (digital) setting where algorithms provide content based on past activities, can narrow and hinder exposure to alternative viewpoints. By not personalizing this section's content, users can explore diverse themes, and expressions, and discover new perspectives.



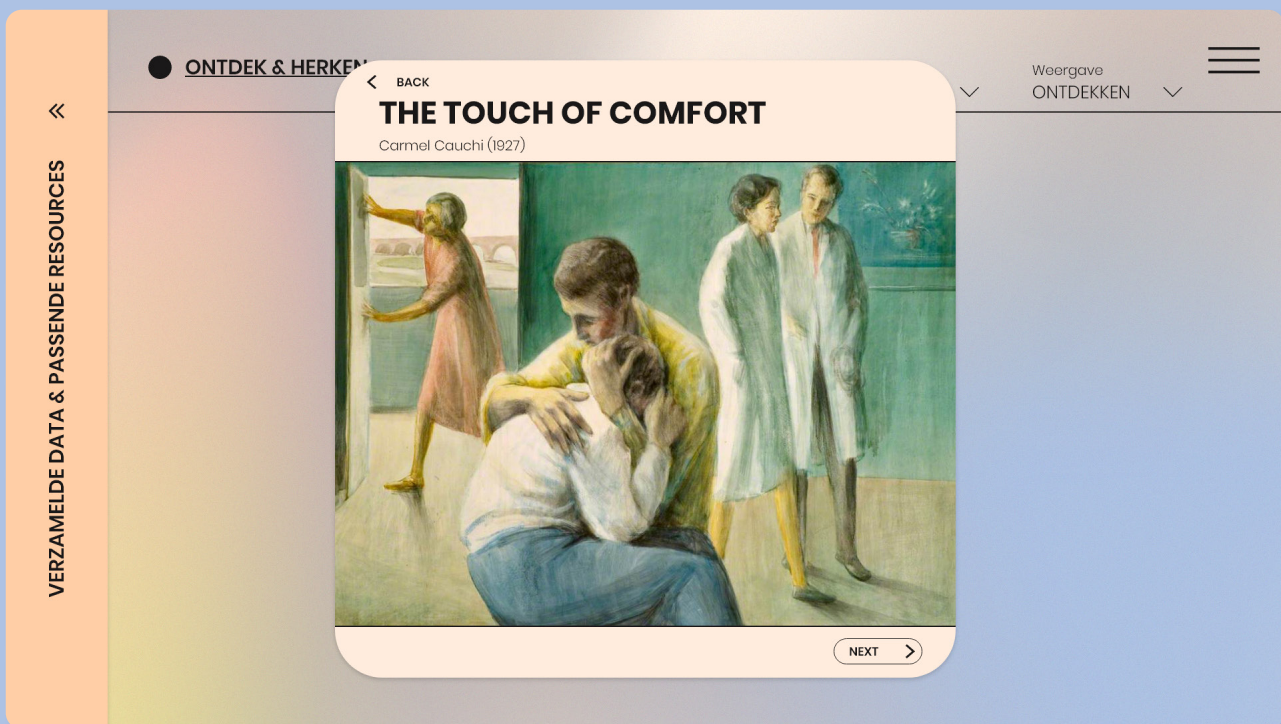
Visual 35. This visual shows the landing page of the Rouw Wegwijzer. It provides two directions.



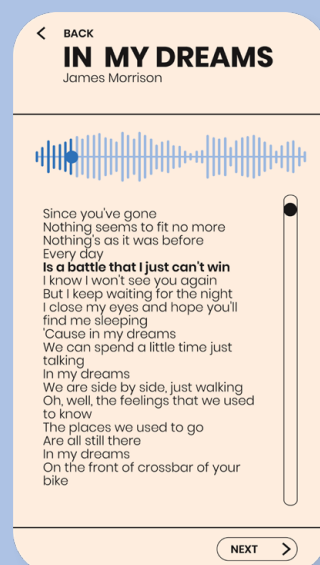
Visual 36. The user has navigated closer to a piece of content in the interactive environment of the 'explore and recognize' section. The piece of content becomes bigger, the closer the user navigates.



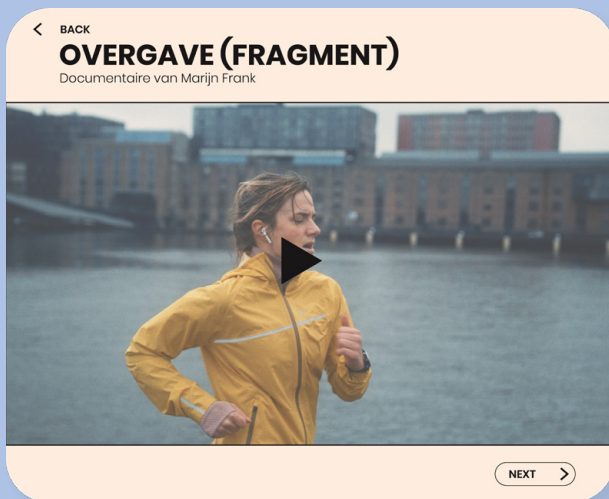
Visual 37. The interactive environment of the 'explore and recognize' section, is completely zoomed out. In this environment, the pieces of content can be found.



Visual 38. When the user clicks the piece of content it will fully open.



Visual 39. The design for a fully opened text and audio based piece of content.



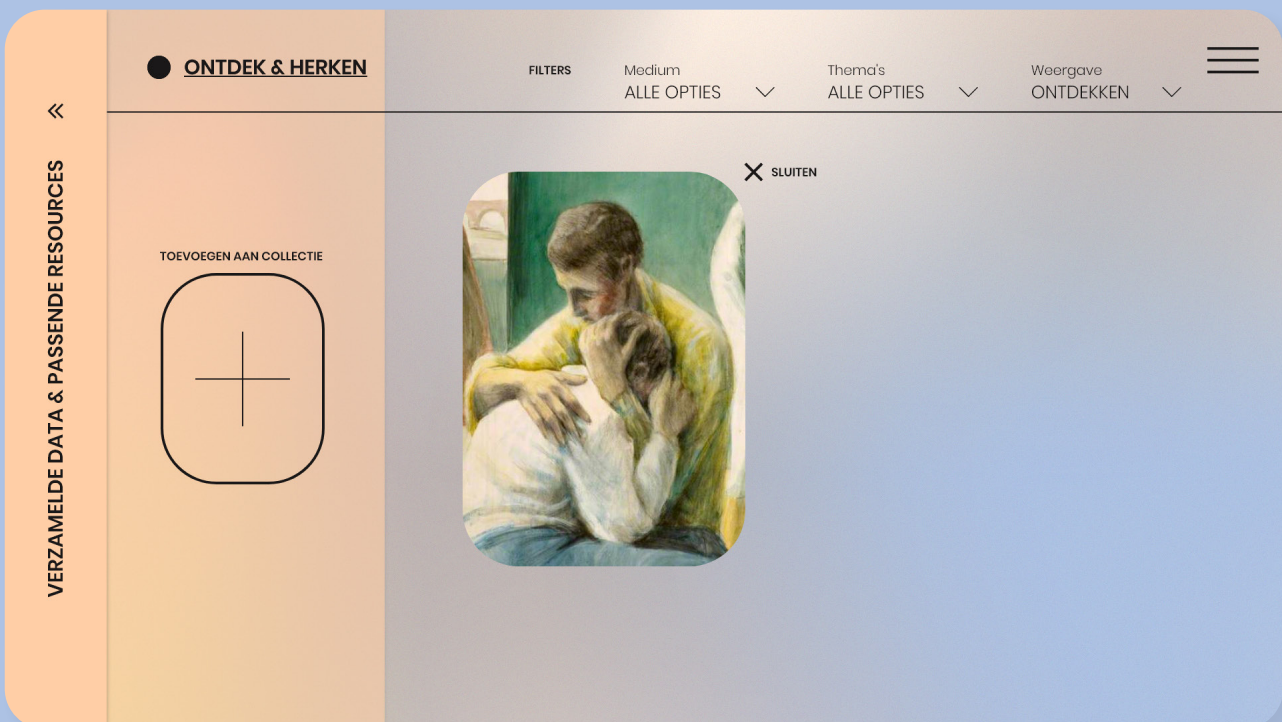
Visual 40. The design a fully opened video-based piece of content.

Touchpoint 5. Recognizing a piece of content

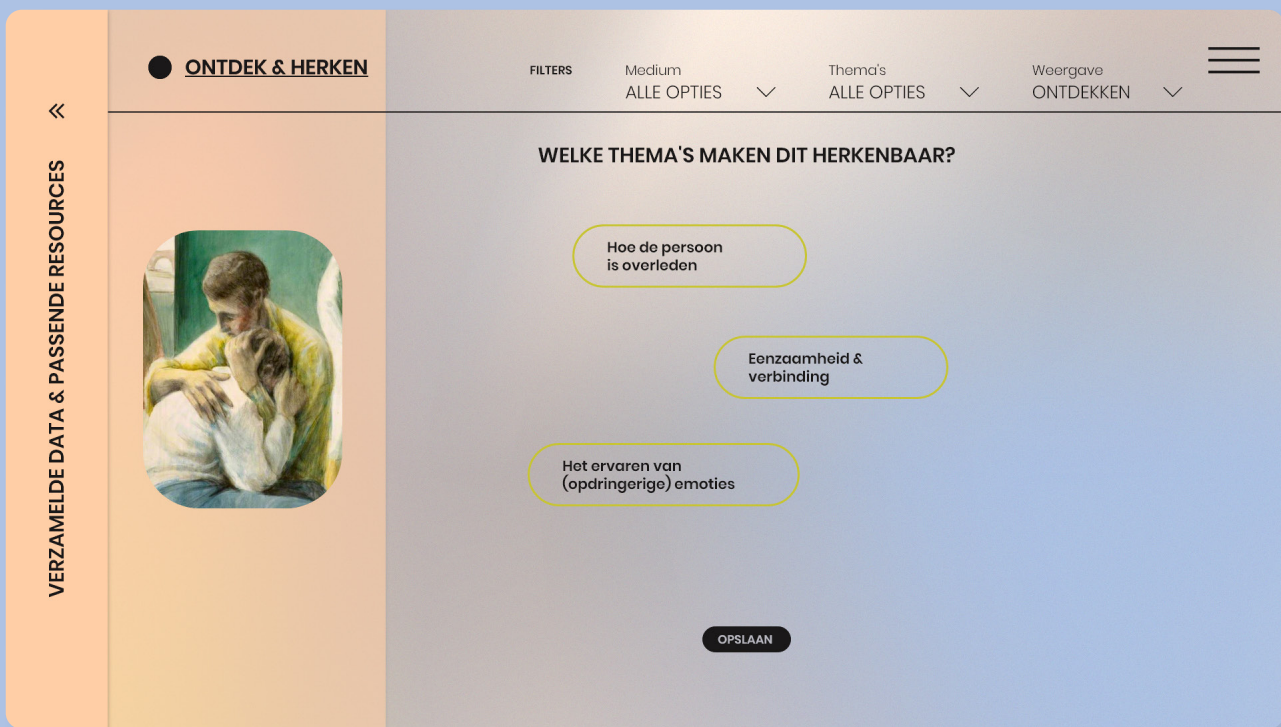
Once the user has interacted with the piece of content by viewing, reading or listening to it, they can indicate if it is recognisable for them or not. They can indicate this by clicking 'add to collection' (toevoegen aan collectie), as depicted in visual 41.

Touchpoint 6. Indicating why something is saved

One piece of content most likely touches upon multiple themes, however, the piece of content might be relevant or recognised due to only a selection of those themes. Therefore, the user can indicate which themes seem relevant to them while saving the piece of content (see visual 42). This is to ensure that the data saved fits the user and is not based on assumptions.



Visual 41. The user can indicate that a piece of content seems relevant, by adding it to their collection.



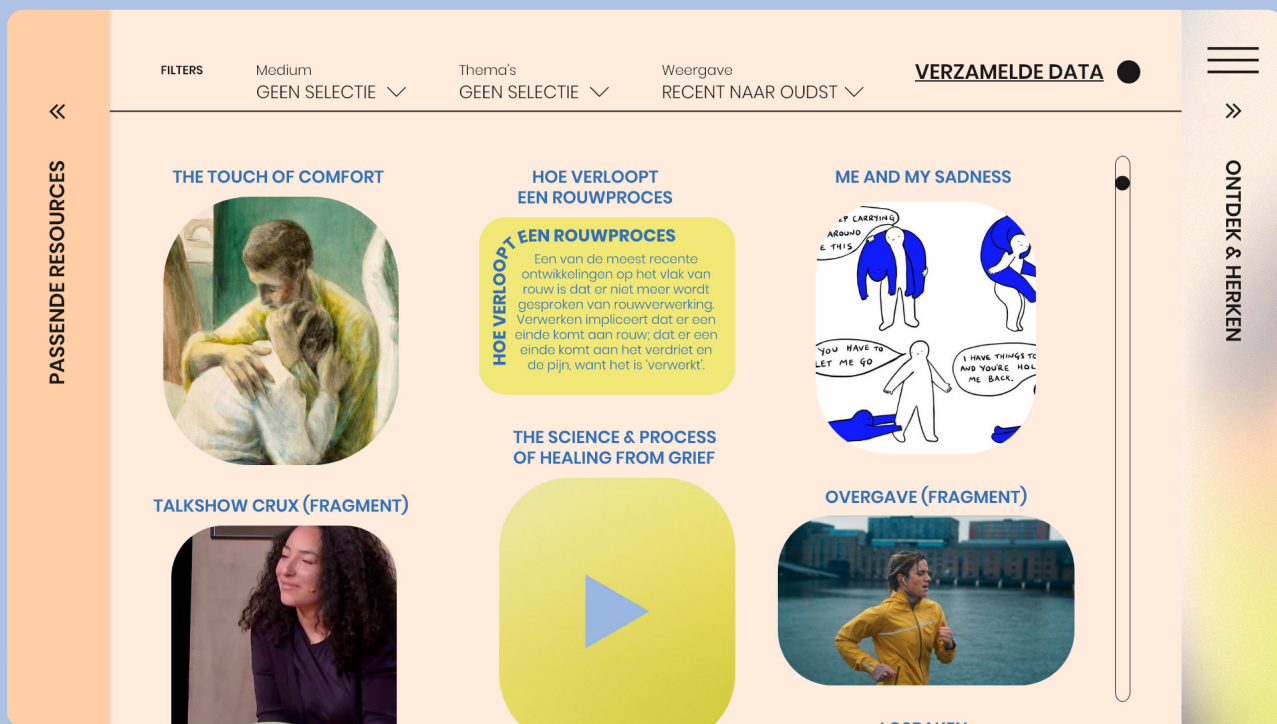
Visual 42. The user can select which themes make the saved piece of content recognisable before it is saved to the collection.

Touchpoint 7. Getting personalised support

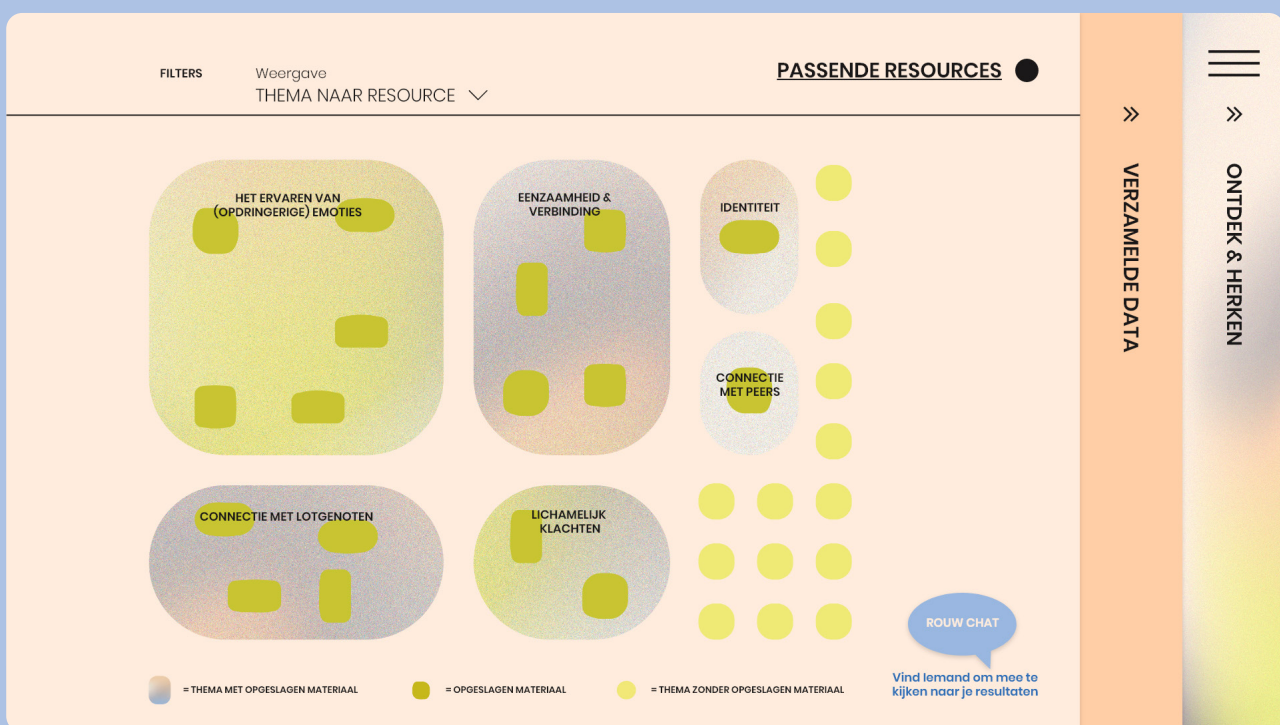
The personalized support page is not presented as a solution or endpoint but as a beginning point for further exploration. Based on the data themes collected together with the pieces of content, a personalised overview of relevant themes is created, see visual 43. The size of a tile becomes larger, when the theme is recurring more often among the saved pieces of content. This is how the grief support provided person-

alises. If the user clicks one of the tiles, they will go to a page which provides specific information and support about that theme, see visual 45. This part of the platform is titled the 'fitting resources' section (passende resources).

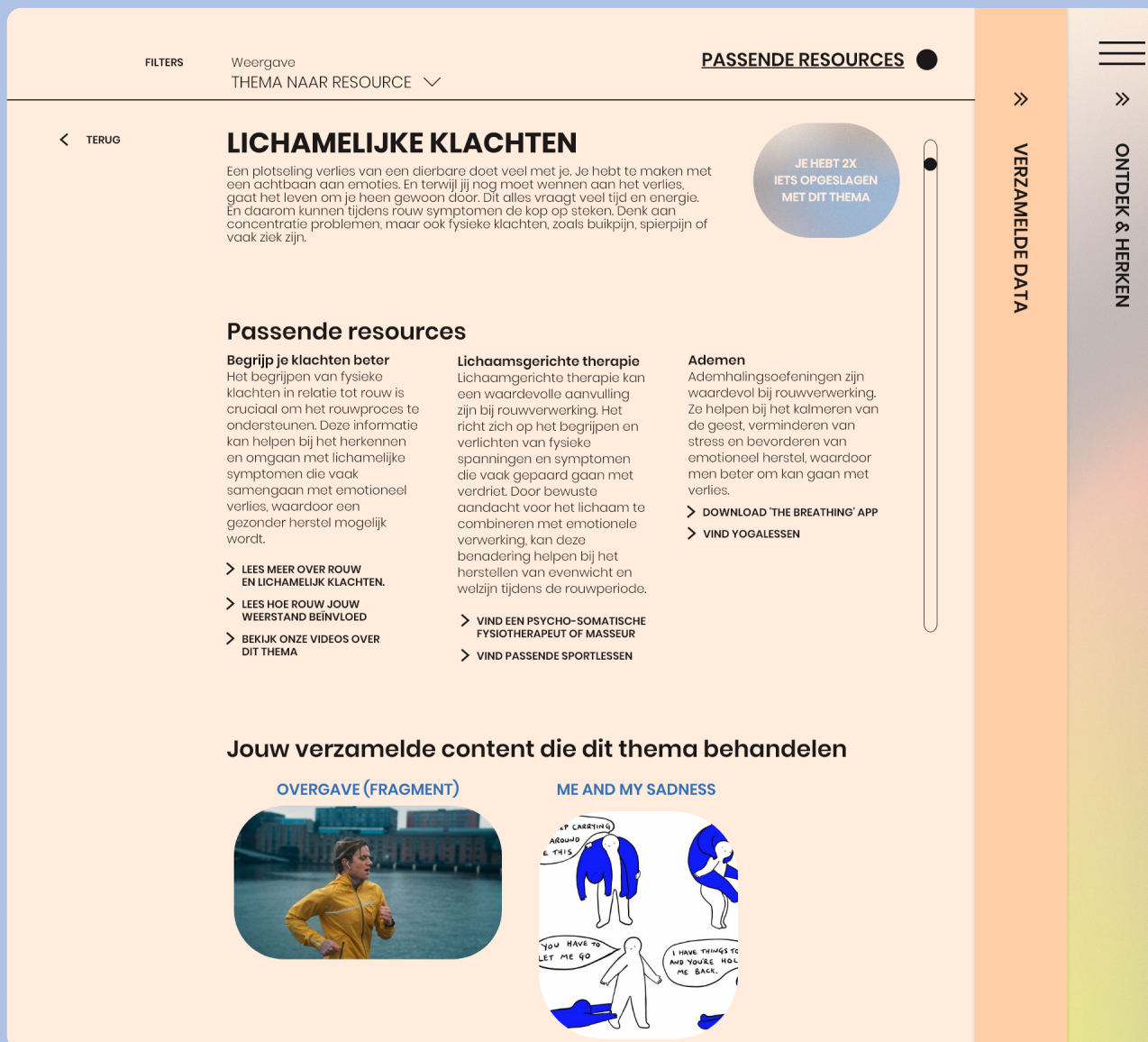
The user can also access their collected pieces of content, see visual 44. This section is titled the 'collected data' section (verzamelde data).



Visual 44. The visual shows the 'collected data' section of the platform. Here the user can see the pieces of content they have collected and access them if they want to view, listen or read them again.



Visual 43. The user can select which themes make the saved piece of content recognisable before it is saved to the collection.



Visual 45. Per theme, a page is created where the user can find support and information relevant to this theme. The user can also see which for which pieces of content they indicated this theme was relevant.

Conclusion

In summary, the Rouw Wegwijzer is a user-focused online platform designed to provide personalized grief support for bereaved emerging adults. It aims to help users navigate their grief journey without requiring them to articulate their feelings. The design includes two key components: “pieces of content” and “themes.” Pieces of content encompass a variety of expressions, captured in text, images, audio, and video, that offer diverse perspectives on grief. The user can explore these pieces of content and collect the ones that allow them to feel recognised or relevant. When they collect a piece of content, the user is asked which themes make the piece of content recognizable for them. The themes are derived from research findings in part 1. Based on the data gathered via the collected pieces of content and their themes, an overview is created of themes that are recurring as relevant to the user. Per theme information and support sources can be found.

In conclusion, the Rouw Wegwijzer’s user-centric design enables users to find recognition and fitting support as they navigate the complex journey of grief.

9/ VALIDATION WITH USERS

In this chapter, the user test will be discussed. The purpose of the test is to validate that the designed platform allows users to find support for their grief in a way that is appropriate to the interaction qualities.

5 research questions have been set up to guide the user test:

1. What kind of experience does the design afford according to the user?
 - 1.A. What experience does the 'explore and recognise' section of the platform afford?
 - 1.B. What experience do the 'collected data' and 'fitting resources' sections of the platform afford?

2. In what way does this experience fit the intended interaction qualities?
3. In what way does the user want to indicate why something is saved?

9.1/ Method

Participants & setting

To validate the set-up of the performance of the prototype, a pilot was conducted with one user outside the target group. Once the performance was adequate, a user test was conducted with 5 participants and now from the assigned target group. See the table.

PARTICIPANT	LOCATION	PARTICIPATED IN GENERATIVE SESSION	RELATION TO GRIEF
Laura	Remotely	Yes	Suddenly lost her father a few years ago.
Iris	Remotely	Yes	Lost her mother after a long sick-bed, has contact with bereaved youth and emerging adults for her work.
Valeria	Remotely	No	Lost her father a few years ago.
Alex	In-person	No	Has lost multiple loved ones, most recently his father after a long sick bed
David	In-person	Yes	Lost his father after a long sick bed a few years ago.

Visual 46. Participants in the usertest.



Visual 47. Online set-up for user test



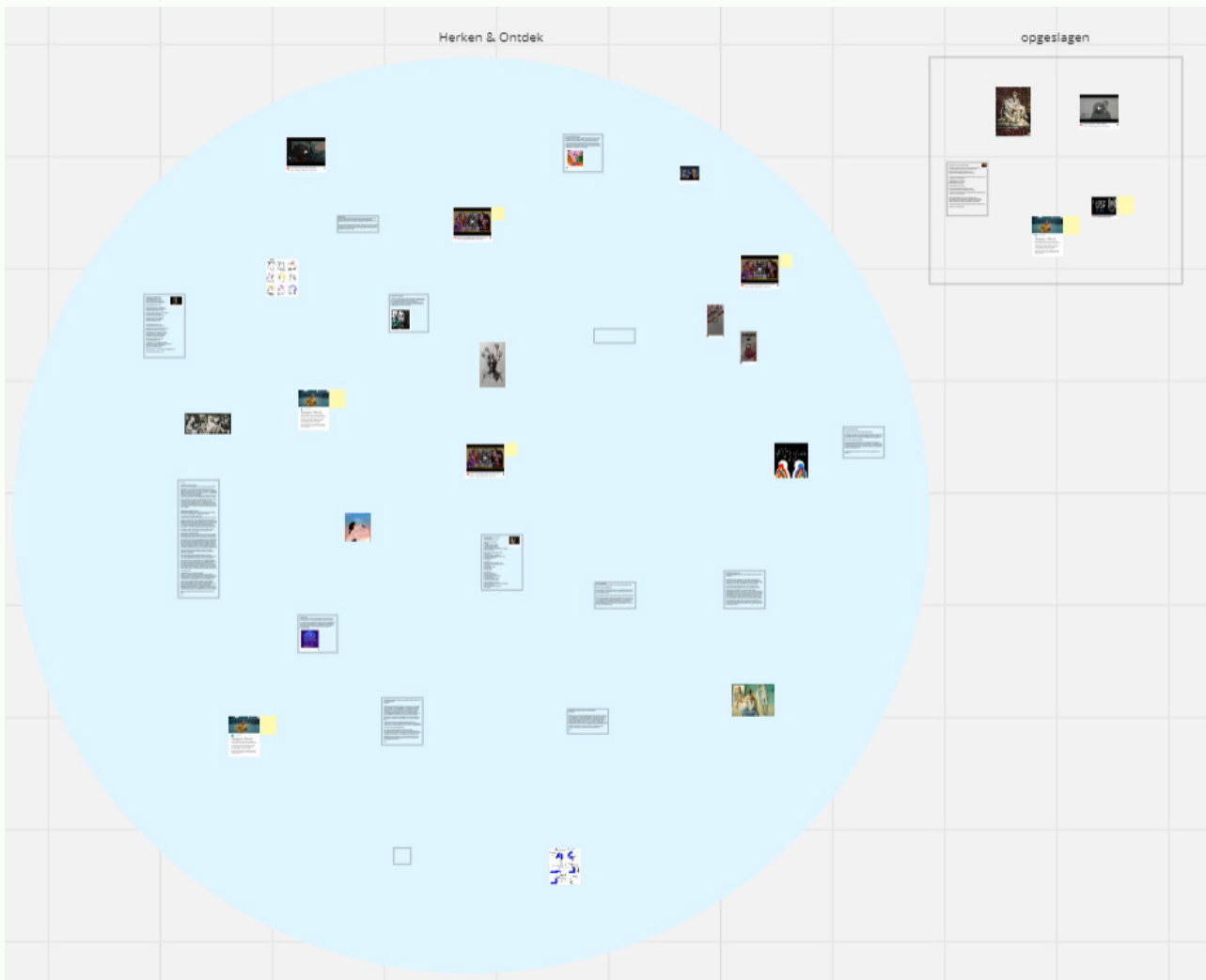
Visual 48. In-person set-up for user test

Prototypes

Two prototypes of the Rouw Wegwijzer design were developed. One prototype was a working visual prototype created in Adobe XD, using only 5 pieces of content. This is the prototype described in Chapter 8. The 'Explore and Recognise' section was not fully responsive in this prototype. Therefore, it was decided to create screen recordings of different steps for the user test.

The second prototype created in Miro, was a fully functional one to

illustrate again the 'Explore and recognize' section, see visual 49. In this prototype, 36 pieces of content were included (see appendix 13 for all included pieces). These content pieces were collected throughout the project and are partially crowd-sourced, to ensure a varied range of content. To complete the test, we returned to the prototype in Adobe XD, as the last two parts of the platform, the 'collected data' and 'fitting resources' sections were responsive in this prototype.



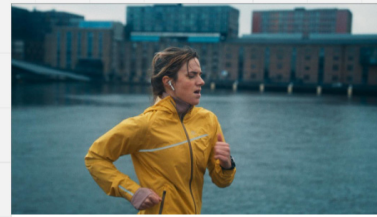
Visual 49. The visual shows the prototype in Miro, completely zoomed out. In the prototype 36 different pieces of content can be found, all placed on the blue circle. The participants could move the content that seemed interesting or recognizable to the square on the canvas. This square represented their collection.

Mignonnus de podcast

In het eerste seizoen van de podcast van Mignon Nusteling leest zij voor uit haar nooit uitgegeven manuscript 'Wat niemand je vertelt wanneer je vader doodgaat'. Hierbij bespreekt ze de ongemakkelijkheden van rouw en verlies. Deze autobiografische verhalen roepen al snel herkenning op en brengen op een lichte manier zware onderwerpen naar boven.



#1 Wat niemand je vertelt: Proloog
Spotify | Updated 15-09-2023 @ 10:54 GMT+02:00

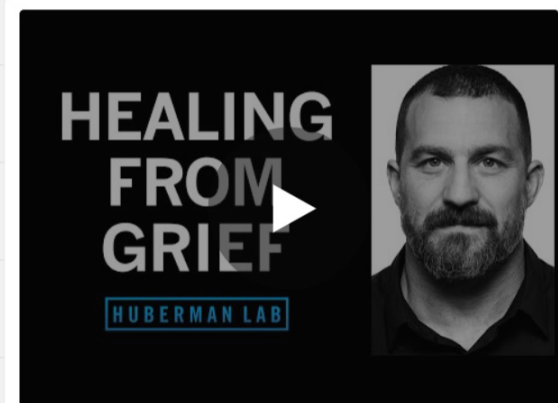


Kijk 37:58
- 41:44

www.2doc.nl

Overgave - 2Doc.nl

Documentaire over hoe ingrijpend het verlies van een dierbare vriend of vriendin kan zijn. Regisseur Marijn Frank verloor haar hartsvriendin Annemarie en toont in deze documentaire hoe moeilijk het was daarna de draad van het leven weer op te pakken.



The Science & Process of Healing from Grief | Huber...
YouTube | Updated 15-09-2023 @ 11:38 GMT+02:00



@WHERY... LINES

Dodemoederclub

Het speciale gevoel dat uitgaat van mensen die ook hun moeder zijn verloren.

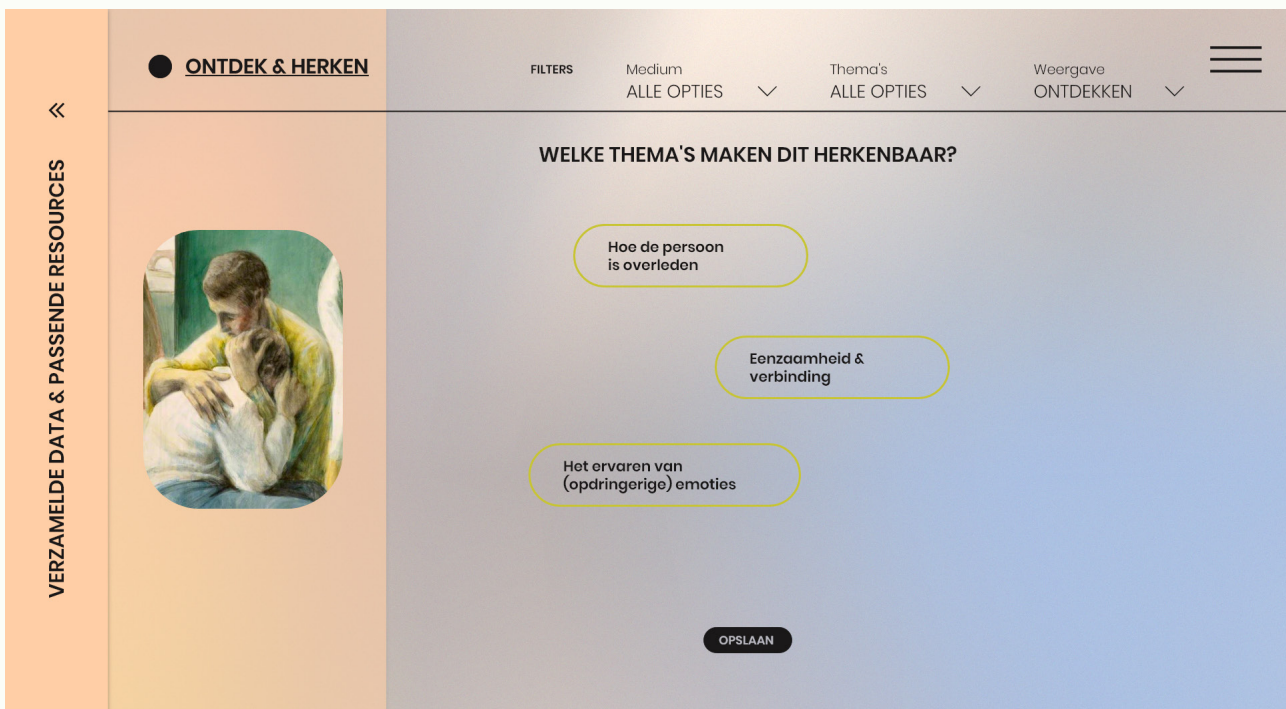
Een geheim genootschap waar je liever geen lid van bent, maar als je dan toch je moeder kwijt bent, je blij bent dat we er zijn. Hoewel de feitelijke omstandigheden van ieder lid anders zijn, resonanceert op een diepe laag een verlies dat het persoonlijke overstijgt.

James Morrison - In My Dreams

Since you've gone
Nothing seems to fit no more
Nothing's as it was before
Every day
Is a battle that I just can't win
I know I won't see you again
But I keep waiting for the night
I close my eyes and hope you'll find me sleeping
'Cause in my dreams
We can spend a little time just talking
In my dreams
We are side by side, just walking
Oh, well, the feelings that we used to know
The places we used to go
Are all still there
In my dreams
On the front of crossbar of your bike
We can go any place, anywhere you like
In my dreams
And as hard as it seems
Till then I'll wait
To see you again
In my dreams
Don't you wake me up
I don't wanna go nowhere
I could wait here for a zillion years
You're gone too soon
I know I'll never get the chance
To say the things I never said
But I keep waiting for the night
I close my eyes and hope you'll find me sleeping
'Cause in my dreams
We can spend a little time together
In my dreams



Visual 50. Some examples of how the content was presented to the participants in miro, see appendix 13 for the full list of included pieces of content



Visual 51. This screen capture was used as a probe for a discussion about how the platform should allow the user to indicate why they saved a piece of content.

Data collection

The user test was recorded on Zoom. What was taken from the recordings for analysis were quotes from the participants and descriptors used by the participants to describe their experience on the platform. Lastly, the participants were given the intended interaction qualities and asked if they recognized these in the design. Their (dis)agreement per interaction quality was noted down by the researcher.

Procedure

The user test followed guidelines, which can be found in Appendix 14. In the guidelines the procedure is described and specific questions per step. The user test then consisted of roughly two parts, with the first part covering the 'explore and recognize' section of the platform, and the second part covering the section of the platform providing personalised support (the 'collected data' and 'fitting resources' section). The first part consisted of the screen captures of the Adobe XD prototype and the

Miro prototype. These included the touchpoints from entering the platform till having indicated why something is recognisable. While going through the screen captures of the Adobe XD, the user was asked what they saw and what they expected to happen in the next capture. A small discussion was held at the end. Using the screen capture as depicted in visual 51 as a probe, the user was then asked if they felt the available themes were sufficient. They were also asked what other ways they would like to indicate why a piece of content was relevant

Next, the working prototype in Miro was introduced. The participant was asked to go through the pieces of content in the prototype for circa 5 minutes and see if they found something of interest or relevancy. The participant was then asked to describe their experience of Miro in 3-5 words while imagining the design of the visual prototype. This was followed by a short interview to gather feedback

For the second part of the user test the participant returned to the prototype in Adobe XD. They were asked to look for their collected pieces of content and then search for support fitting for them according to the platform.

At each step, the user was asked what they saw and what they expected to happen. They were then asked to describe their experience in 3-5 words. Again some follow-up questions were asked.

The intended qualities of the interaction were then discussed and the participant was asked to reflect on whether they recognised them in the design of the platform. Finally, some concluding questions were asked.

Analysis

Notes were taken during the test and these notes were used to get an initial overview of the user feedback. The interviews were then reviewed and quotes and missed insights were noted and included in the results. The quotes were clustered and the overview was improved. The descriptors for the user experience collected were analysed in collaboration with ChatGPT. ChatGPT categorised the words used to describe the experience as positive, neutral/ambivalent or negative. Then the researcher would correct if the classification used by ChatGPT did not correspond with how the word was described in the interview.

9.2/ Results

Different sections cater to different kinds of users

As discussed before, the platform has different sections, that offer different, but connected services. Different participants were interested in different sections. David indicated that he enjoyed searching based on feeling, what is offered in the 'explore and recognize' section of the platform. Laura was interested in the same section because it enabled them to find new inspiring types of support and content. Alex indicated he preferred a more goal-oriented exploration, based on the themes, making the 'fitting resources' section of the platform more suitable for them. Lastly, Valeria highlighted that for them the platform seemed most interesting, due to the option to create your own collection of pieces of content.

"I think I search more based on feeling. Less on information."

David

Experience expert

"I find it a nice way to place things in a [digital] space. It makes it inspiring. I can imagine that if everything were to work, you could discover things you had no idea about. For example, that podcast seems interesting to listen to. I had never thought of that before. This way, you come across new forms of content."

Laura

Experience expert

“I’m not very in touch with my emotions, so when I see artwork or something more distant from me that belongs to someone else, it affects me less. [...] I find [the section that offers support] more interesting; it would suit me better. If I could look at it by theme earlier [in the last section], that would have been more useful for me.”

Alex

Experience expert

“Saving and being able to search for things later, that’s what makes this design unique for me.”

Valeria

Experience expert

Exploring and saving pieces of content

Varied interests

4/5 participants (David, Laura, Iris and Valeria) were able to find pieces of content that seemed interesting to them in the ‘explore and recognize’ section. The saved content did not overlap much between the participants. Participants saved content because it was recognisable, felt interesting to the participant, evoked a feeling, or triggered some association related to the (loss of the) parent. Lastly, pieces of content were also saved if they seemed long, yet interesting, like a podcast or a book, and the participant wanted to come back to them later. Two participants (Valeria and Alex) also mentioned they would like to add their own material to their collection too. For example a song that reminded them of their deceased parent.

“I started to associate a lot, and I remembered: oh, I also know these [other things], those are beautiful too and touched me. It would be nice if you could add your own things and associations to your collection. After all, it’s your collection.”

Valeria

Experience expert

Motivated to explore

The four participants that were able to collect material, seemed motivated to explore and collect pieces of content and were reluctant to stop when the researcher indicated it was time to continue to the next part of the test. Multiple participants mentioned they were curious to find out what else could be found on the platform. Valeria mentioned that she would like it if the platform would refresh its content.

Indicating why content is relevant

Participants indicated that it was nice to have a few pre-defined options to indicate why they wanted to add a piece of content to their collection. However, the description of the labels was difficult to understand, and having only three labels was seen as limiting. All participants indicated that they would like to be able to add their own descriptions or labels.

David after he has been told that we will continue to the next part of the test

“Oh Art! Wait... I quickly add this one too!”

David

Experience expert

“I would like it if the things I haven’t chosen would go away at some point. And also that I can see new things from time to time.”

Valeria

Experience expert

“How the person passed away is a very brief moment for me, so I would immediately dismiss that option. But if you had something like ‘how the person said goodbye.’ Yes, then I immediately see the last hug with my father.”

David

Experience expert

“I like that a few pre-determined options are provided. It gives a bit of guidance. It would also be nice to write down a few keywords yourself, but I do find it difficult to fit entirely into one of those options. [...] I would also like to be able to add my own notes with my associations.”

Valeria

Experience expert

Getting personalised support: Theme Overview

After testing the 'explore and recognize' section of the platform, the part of the platform that personalises was tested. All the participants initially seemed confused when entering the 'fitting resources' section of the platform. They needed some time to understand the visual overview depicted on the first page. The visual overview was accompanied by a legend. After their initial confusion, 4/5 participants (David, Iris, Valeria, Laura) seemed to read the legend and then understand the overview. Alex still wondered why some themes were shown bigger than others.

Recurring usability issues

Some recurring usability issues were identified that influenced the overall experience and use of the platform.

Navigation menu

The first usability issue was the design of the navigation menu. In the use flow for the user test, the participant starts at the right side of the menu (collecting pieces of content) and moves to the left (accessing themes around grief and related support). Multiple participants indicated that this direction felt counterintuitive and made it more difficult to understand the relation between the sections.

“My initial impression was, ‘Wow, this looks schematic and complex,’ even though it wasn’t, but the first impression was that it was very different from the playground earlier [at the explore and recognize section].”

David

Experience expert

“It took a while for me to grasp the [last section with personalised content]. It partly had to do with the order, from right to left. If it were from left to right, then I would understand that step-by-step you’re delving into the material in more detail.”

Laura

Experience expert

Titles and descriptions

A second recurring usability issue was the use of inconsistent and ambiguous titles and descriptions throughout the platform. The titles 'saved data' and 'fitting resources' used for the section that personalises were indicated as ambiguous and unclear. The 'saved data' page was predominantly referred to as 'collection' or 'library'. Text and instructions on various pages were also pointed out as unclear or inconsistent. Visual 52 provides an example.

Lack of feedforward and introductions

Another recurring usability issue is the lack of feedforward and introductions that provide context for the different sections of the platform. The titles were the only hint as to what to expect in a section and as discussed, they were considered unclear. Next to not having feedforward and an introduction per section a general introduction was missing too, as the onboarding was not designed or included in the user test.

“Collected data (verzamelde data) feels rather technical, collection might be better.”

Alex

Experience expert

“On this page, it says ‘which themes make this recognizable’ (welke thema’s maken dit herkenbaar). What is meant by ‘this’ (dit)? I don’t understand what ‘this’ is referring to.”

Laura

Experience expert

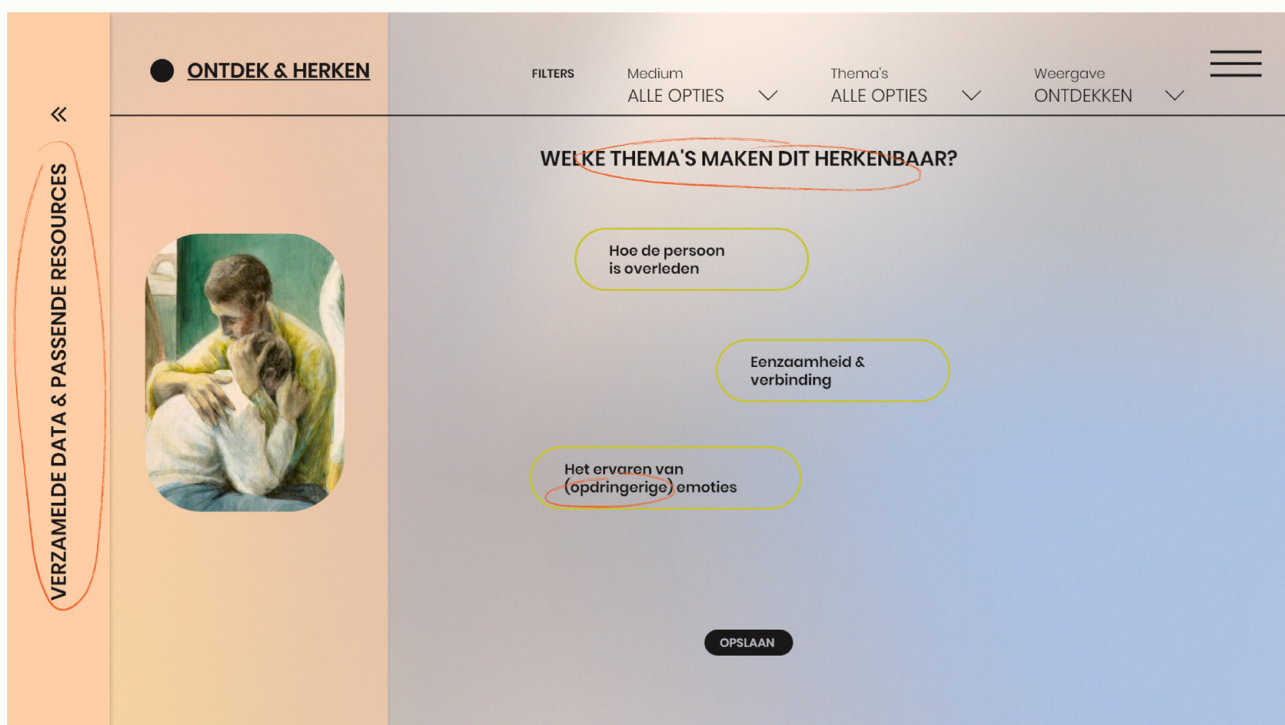
“When I clicked on collected data, I was not sure what to expect.”

Valeria

Experience expert

Viewing and adding pieces of content

Participants indicated that showing the title of a piece of content prominently in the full view did not add value. They also added navigating to a new page to add a piece to the collection felt redundant.



Visual 52. An example of a page with multiple descriptions and titles that were unclear to the participants.

“I’ve had quite a few conversations with [grieving] young people [for my work], and in those, you can hear a search for recognition and information, and a positive way to engage with their grief, and I think this [platform] could be a great way to do so.”

Iris

Experience expert

Experience on the platform

In general, the platform was experienced as positive. The negative experiences were mostly related to ambiguity and unclarity, see visual 53 on the next page. Iris notes how she thinks that this design offers a positive way to find recognition and information.

Other participants described the platform as inspiring, clarifying, enlightening and deepening, due to it first focusing on exploring and feeling and then becoming more structured and supportive. Participants indicated that this movement from abstract to clear and specified grief support was surprising to them and was indicated as valuable and inspiring.

All participants stated that they recognised the interaction qualities in the design when the interaction qualities were presented to them. Some descriptors used by the participants before seeing the interaction qualities are even the same or similar to the interaction qualities.

“[It is] clarifying, because you haven’t just saved things for fun. I have the impression that you have [designed] something that systematically leads to advice, without immediately resorting to some sort of magic AI personalization tool.”

David

Experience expert

“The first part was more like an expedition, and here, I feel it’s more focused on supporting.”

Iris

Experience expert

“For me, the experience was quite enlightening, as you’re not just searching based on feelings [in the first part] but also learning more [in the second part].”

Valeria

Experience expert



Visual 53. The words used to describe the experience on the platform

Discussion

The results of the user test are relatively cohesive. Four out of five participants were enthusiastic about the platform and similar (usability) issues were raised. The experience on the platform was predominantly positive. When asking clarification for on the descriptors, it became clear that the negative experiences were mainly related to usability issues. Therefore, it can be argued that improving the design based

on usability issues will improve the experience of the platform.

Participants seemed motivated to explore and collect pieces of content. One participant, Alex, was not enthusiastic about the platform and did not find pieces of content that interested him. He expressed he already explored what grief meant to him, due to earlier losses and the multiple times he had to say goodbye to different aspects of his father, who

had Alzheimer's. He indicated that he was more interested in the section of the platform, where the themes and corresponding grief support could be accessed. This shows that some users might prefer to search more goal-oriented and specific. This is offered in the 'fitting resources' section of the platform. However, this section is difficult to find, due to the design of the navigation menu and the titles of the sections. By improving the accessibility of the support offered per theme, the platform could cater to a wider range of users.

The user test also highlights some opportunities for personalisation for the collection they were building. Participants indicated they liked adding personal notes, next to adding the pre-determined themes. They showed further interest in personalising their collection by adding their own material as well. It needs to be researched what the implications would be for the function and experience on the platform if these functions were added.

Conclusion

The majority of participants appreciated the platform's unique approach to finding grief support, which they described as moving from 'exploring based on feelings' to getting support in a 'structured and supportive' way. This movement was described as clarifying, enlightening and deepening.

The participant's motivation to continue exploring pieces of content in the 'explore and recognize section' and their positive experience while doing so indicates it is a promising feature on the platform. Participants appreciated the freedom of movement when

collecting pieces of content and the variety of it.

However, the results also highlighted some recurring usability issues, such as unclear or redundant titles, inconsistent descriptions, unnecessary extra steps, and a confusing navigation menu. These issues affected the overall user experience and need to be addressed to make the platform more user-friendly.

The participants' varied interests in different sections of the platform suggest that it has the potential to cater to a wide range of users. Currently, the section that contains the collection and the section that offers grief support per theme is difficult to find and understand, due to the mentioned usability issues. By improving these issues, the platform can better serve users with distinct preferences. Additionally, the collection section can become more personal, by allowing users to add personal notes to pieces of content and perhaps even upload their own content.

Overall, the platform's alignment with the intended interaction qualities and the positive user feedback indicates its potential to provide a supportive and exploratory experience for individuals dealing with grief. Addressing the identified usability issues and making the platform more intuitive will be crucial in optimizing its effectiveness and ensuring it meets the varied needs of its target audience.

PART 3 DEVELOP

Concluding

In summary, the Rouw Wegwijzer is a user-focused online platform providing personalized grief support for bereaved emerging adults. Two main elements are “pieces of content” and “themes.” Pieces of content are expressions of grief, captured in image, video, text or audio. Users collect pieces of content that are recognizable or relevant for them, and indicate due to which themes the content seemed relevant. Based on this collected data, an overview is created that shows which themes are recurring. Per theme, the user can then find information and support. The platform’s unique approach, transitioning from “exploring based on feelings” to a “structured and supportive” overview of relevant themes and support, received positive feedback, with users describing it as inspiring, clarifying and enlightening.

However, usability issues such as unclear titles and navigation problems hinder the user experience. The function of different section is unclear and some sections are difficult to find. These issues must be addressed for the platform to become more user-friendly. Furthermore, how

the user indicates why they saved a piece of content needs to be developed further, providing room for personal associations.

In conclusion, the Rouw Wegwijzer’s user-centric design offers recognition and tailored support for the complex grief journey. With refinements to resolve usability issues, the platform can provide invaluable support to bereaved emerging adults.

PART 4

Deliver

In the last part, we introduced the design and conducted a user test. The platform was received with mostly positive feedback but also contained multiple usability issues. In this part recommendations to improve usability for the design are made and visualized. Then recommendations are made for further development and implementation of the platform.

10/ RECOMMENDATIONS AND FURTHER DEVELOPMENT

10.1/ Recommended design changes

The results of the user test gave insight into the usability issues of the design. In this chapter, we will discuss the recommended improvements for the design to solve these issues and to improve the general use of the platform.

Sections of the platform

In the user tests it became clear navigating through the platform was difficult due to the design of the

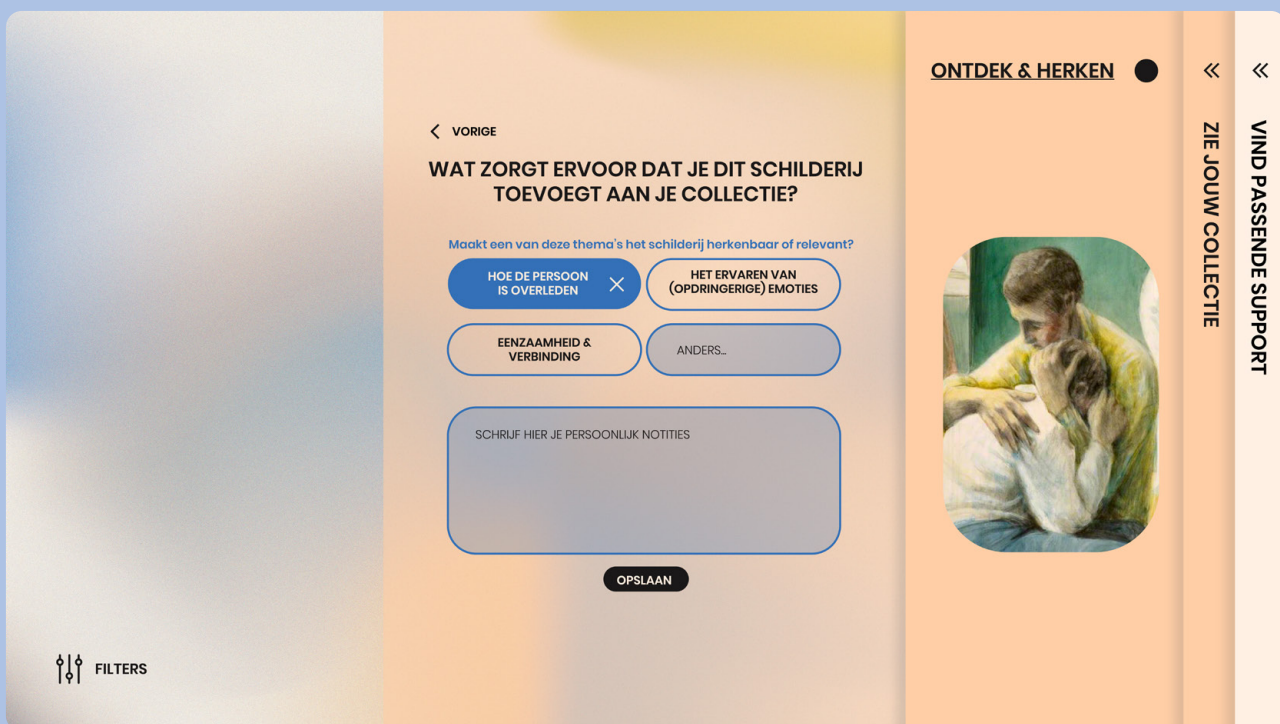
navigation menu and the titles of the sections. By creating less ambiguous, technical names for the 'collected data' and 'fitting resources' sections the user could have a better understanding of what the function of each section is. On visual 54 it can be seen that the section containing the collected pieces of content will be renamed to 'Zie jouw collectie' (see your collection) and the section containing the support will be renamed to 'Vind passende support'. The 'Ontdek & Herken' section will not be renamed.



Visual 54. The redesign for the landing page of the platform, which divides the platform into three distinct sections.



Visual 55. The redesign for how the full piece of content is shown. As can be seen, the piece of content can directly be added to the collection.



Visual 56. Redesign for how the user can indicate why they added a specific piece of content to their collection. Next to tagging themes, the user can also add notes.

Navigating through the platform

In the new navigation menu, the user moves from left to right, from broad and abstract to specific and personalised. The 'explore and recognize' is on the left of the menu, 'see your collection' is in the middle and the 'find fitting support' section is on the right.

Seeing a full piece of content and adding it to the collection

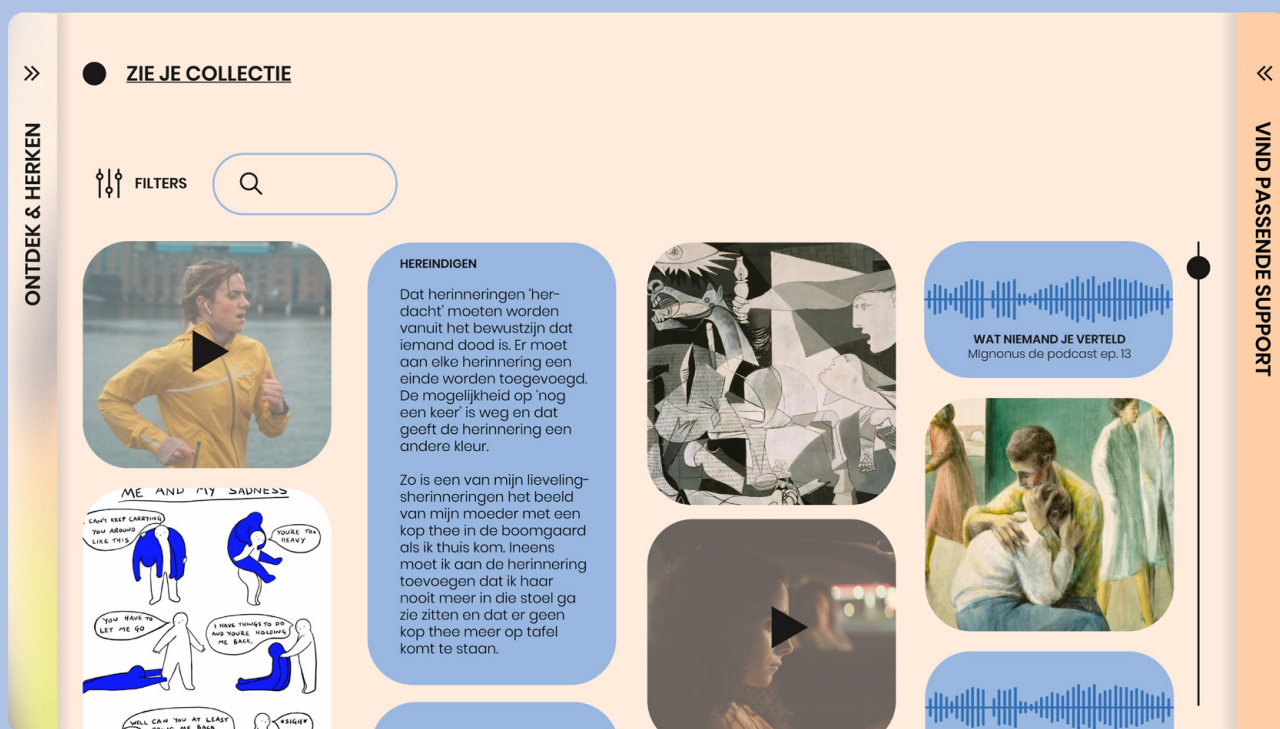
The flow from seeing a full piece of content to adding it to the collection is streamlined. When a piece of content is opened, the option to add it to the collection is provided on the same page, see visual 55. As a result less actions are needed to add a piece of content to the collection, compared to the previous design.

Adding notes

After adding a piece of content to their collection the user has the opportunity to add their associations and notes, next to tagging the themes. This can be seen in visual 56. These notes can also be found back in the collection when a user opens a saved piece of content. Visual 57 shows the collection.

Providing context for the visual overview

From the user test, it was concluded that the visual overview of themes was difficult to understand. In visual 58 it can be seen that more context is provided by adding titles and an introductory text. Per theme, a tiny preview of the pieces of content containing that theme is shown. This is also done on the page providing information and support per theme, see visual 59.



Visual 57. Redesign for the collection of pieces of content.



Visual 58. The redesign for the page providing a visual overview of all grief themes.



Visual 59. The redesign for the page providing information and support per theme.

10.2/ Further development

Throughout the platform, improvements can be made. To structure the improvements and recommendations for further development, we will discuss the recommendations per touchpoint of the user scenario (see visual 34 in chapter 8).

Touchpoint 1: Finding out about the Rouw Wegwijzer

Getting to know about the Rouw Wegwijzer

It is important to create a communication and marketing strategy to familiarize potential users with VLmD and the Rouw Wegwijzer. 4/5 participants in the user test indicated they were interested in using the platform if it existed, but they also mentioned that they would now know how they would find out about it, as they did not actively search for support online.

Touchpoint 2: Entering the platform

Cookie and privacy consent

A cookie and privacy consent form will be needed on the website per European law (EU, 2016). From meetings and feedback from VLmD, it was gathered that they wished to use the input from users on the Rouw Wegwijzer as a method to collect data and insight for (academic) research. The design of the consent form is an opportunity to transparently communicate what data will be used to the user and create a trustworthy, equal relationship between the platform and the user. It is recommended to inform the graduation thesis of Aniek Hegemans (2021), which can be found in the bibliography of this thesis. She researched the ethics around consent and data

harvesting for online platforms. Her thesis includes strategies to create a more fair and understandable way for the user to consent to data collection on online platforms.

Touchpoint 3: Onboarding

An onboarding needs to be created that informs users about what to expect on the platform and how to use it.

Touchpoint 4+5: Exploring and finding relevant content

Design of the 'explore and recognize' section

Sound design

The design of the 'explore and recognize' section needs to be developed. Sound is already a part of the platform via the pieces of content that contain audio. However, for people to find and engage with the audio pieces, they need to have their sound on. Perhaps creating a (background) sound design for the whole 'explore and recognize' section can encourage users to engage with the platform with the sound on? Would sound design make the platform more immersive? What sounds would create the right atmosphere on the platform?

Moving between the pieces of content

The intended way of moving through the interactive environment of the 'explore and recognize' section needs to be tested further. What kind of use-cues are needed to ensure that the user can easily navigate in the environment?

Refreshing content and making an account on the platform

Research needs to be done into how much content is a desirable amount

on the 'explore and recognize' section to encourage exploring, without overwhelming. An option is that the content refreshes. Vereniging Leven met Dood indicated that they prefer if users make an account, or even become paying members of the association. Perhaps some content can be accessed for free once the user has explored all content, they are invited to make an account and explore more pieces of content afterwards. Research needs to be done into how this would influence the interactions and relationship between the platform and user.

Content of the 'explore and recognize' section

Developing and selecting pieces of content

An important part of the development of the platform will be the content for the 'explore and recognize' section of the platform. To ensure a user-centred platform, involving the target group throughout the development of content is recommended. It is also recommended to include content from external parties, next to content produced by VLmD, to ensure a wide range of viewpoints and expressions is included.

A potential challenge for collecting pieces of content is IP rights that exist on music, videos and other potential sources. An opportunity could be to collaborate with different art schools and ask students to create their illustrations, comics, choreographies etc for the platform.

Length of pieces of content

Research should be done about the length of content pieces that are audio, video or long texts, e.g. a book. Would using fragments of

longer pieces create a good user experience? What would be a good length to engage the user, but also encourage them to explore multiple pieces of content?

Content disclaimers

Ideally, the Rouw Wegwijzer has content with a wide variety of themes. Maladaptive coping, suicide, suicidal thoughts and other sensitive themes can be part of the grieving experience, thereby it makes sense to represent them on the platform. Research is indecisive about if exposure to suicide and suicide ideation done by a fictitious character or unknown person, predicts suicidal ideation and behaviour in an individual (Ferguson, 2019). Yet, it might be desirable to indicate that the piece of content can be triggering, or that the coping mechanism discussed or shown in the piece of content can be harmful. A choice has to be made to perhaps exclude specific types of expressions and themes, which could mean that some users might not find acknowledgement and/or recognition. Research and prototyping should be done to find the right balance between excluding and warning without becoming judgemental and still acknowledging those who do experience maladaptive coping and/or suicidal ideation.

Touchpoint 7: Indicating why content is saved

Developing a list of themes

The pieces of content need to be labelled with relevant themes. In this thesis, a list of themes is identified in part 1. This list is used for the prototypes. Further development of the themes is needed with experts and the target group, to ensure that the list is comprehensive and the

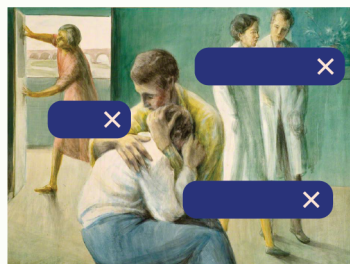
words used to describe a theme are clear for the user. Further research is also needed about how specific the themes need to be for easy use and comprehension. Then the pieces of content need to be labelled. It is recommended take the list of topics and to label the pieces of content in collaboration with the targetgroup.

Other parameters for personalizing
Another topic for further research is if other parameters can be used to personalise the support page. For example, if the user mostly saves pieces of content that are video-based, would it make sense to also provide them with more video-based information when they look at the support and information per theme?

Large Language Models and Identifying Themes
During the user test, it became clear that it was desirable to allow users to add their notes to a saved piece of content. These notes that users leave, can potentially function as the input for a Large Language Model (LLM). Integrating a LLM into the design provides three opportunities for further development, see visual 60.

The first opportunity is that the LLM can identify additional themes that are relevant for the user, from the list of themes already created for the Rouw Wegwijzer. A second opportunity is that the LLM can assist in updating the themes already labelled to a piece of content, if a theme is not labelled, but often appears in the notes by users. A last opportunity is that an LLM can help identify unknown themes, so new information and support pages can be created. Further research is needed to find out how this exactly could work, and how to create a fair AI system and maintain a good user experience.

Current design



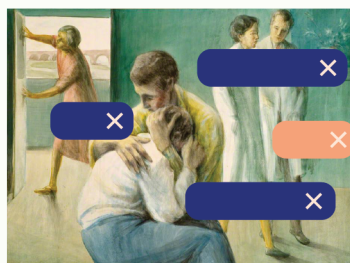
type your personal notes here...

1th opportunity



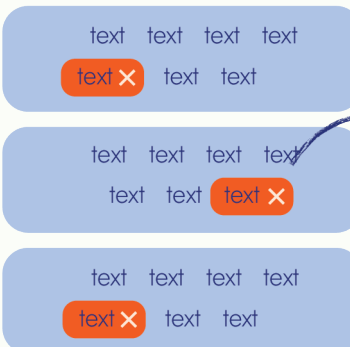
text text X text text
text text text X

2nd opportunity



text text X text text X
text text text X

3d opportunity



new theme identified

Visual 60. The visual depicts potential developments, using a LLM model.

Touchpoint 8: Finding resources

Content development for support pages

As mentioned earlier a comprehensive list of themes needs to be developed. Per theme, fitting grief support needs to be identified. This grief support can be offered by VLmD or third parties. As argued earlier in this thesis, most grief support focuses on text and conversations, neglecting the mind/body connection. Therefore it is highly recommended to research which grief support can address both mind and body and include these too.

Other recommendations

Target group for further development

As mentioned in the introduction of this thesis, VLmD wants to include all bereaved on its platform. They also want to be able to welcome the next of kin of the bereaved. However, the author recommends making a selection of intended users. One of the first lessons of good design is that “if you design for everyone you design for no one”. Making a fitting and comprehensive list of themes and content will not be possible, if no choices are made about who will use the platform. Per newly introduced target group, it is advised to research what themes are relevant and what kind of content should be included to appeal to this target group.

Finding investors

The latest update from VLmD mentioned that they are still looking for investors for the platform. To make

investors interested in the platform and what it can do, a demo was created. In the demo, the various functions of the platform are shown. This demo also functions as the showcase for the design accompanying this thesis.

Change the title to Rouw Kompas

The last recommendation is to change the name of the Rouw Wegwijzer (Grief Signpost) to Rouw Kompas (Grief Compass). Arguably, a signpost does not fit the intended interaction qualities of the platform, whereas a compass does. A signpost signs to a destination, an end-point, giving it a directive and rigid character, both identified as undesired character traits for the platform. A compass can be used at any point, during any journey. It assists the user in finding their orientation and general wayfinding. Arguably, this makes a compass explorative, facilitating and supportive, and therefore a more fitting analogy for the platform.



Visual 61. From Rouw Wegwijzer to Rouw Kompas

PERSONAL REFLECTION

Beginning this project, my excitement mixed with a touch of fear. I had burned myself before on a graduation project and I really wanted to ace this one. Reflecting, it did not go as planned — no dazzling process, no on-time finish. Yet, when I look through my hyperfocus on these two aspects, I can see it did go well in other ways. I learned a lot, particularly about my mindset about designing and loss. Wrapping up, here is a reflection on what I have learned.

Communication

Conveying ideas posed a challenge. In my mind, I can see connections between different subjects and things. Everything always seems to be connected in some interesting way. This can be amazing for creativity. After all, creative ideas are often combinations and connections that were not there before. However, for communicating a big, complex, solo project it was less helpful. There was a lot of information that needed to be ordered and detangled. I know that if I externalize all the seemingly related ideas and topics, I can take some distance and pinpoint the main insights. However, for this solo project, most of the ideating and thinking happened in my (creative, yet chaotic) head, making it challenging to write down the main points from the get-go. This can be illustrated by how my writing process went. What I wrote often missed logic. When I would return to the text at a later point, I saw many little pieces of information that in my mind were connected to the main point, but when written down

drowned the main insight. Editing became my saviour, unravelling my tangled thoughts, but also my most time-consuming activity.

This reinforced my love for teamwork because thinking out loud is inherently part of collaboration. After this graduation, I will therefore actively look for jobs within organizations that work in teams. Another lesson for me was that writing and editing help with organising my thoughts. Luckily, I have become faster with brain dumping and editing, thanks to the practice I have had writing this monster report. So I could use it for (smaller) solo projects in the future if sparring partners are not available.

Focusing on end-results

I struggled to embrace the iterative nature of designing, due to a stiffening fear of doing something wrong. I was very focused on doing everything right, right away. In previous projects, I experienced this less. I think that this fear of mistakes stems from not being able to finish my previous graduation project. I decided to quit that project because my mental and physical health were not up to par. During this new graduation project, I felt anxious when I did not have the answers (yet). It made me fear that I would never have them and eventually fail again.

I know from earlier projects that designing is easier and more fun, if I do not focus solely on results, but also on making the road towards it enjoyable. This project had many

aspects I enjoyed, but that fear had a voice that told me what I did would probably go wrong, that I was too slow, or that what I did was not good/academic/prepared enough. I first needed to streamline everything, before I discussed it, but as mentioned above, discussing ideas helps detangle my thoughts.

Funnily, I think that I can get inspiration for a more healthy mindset from my design for the Rouw Wegwijzer. The initial project brief was to create a platform that would provide personalised grief support, making it very result-focused. The design I made in the end is more about the process and enjoying it, less about the destination. Taking that teaching, I think there is a nice challenge for me in the future: doing more of what I usually enjoy while designing. I know that some things I enjoy are learning about new things and people, doing small experiments, and sharing and discussing ideas. Unsurprisingly, the moments I enjoyed most during this thesis were learning about grief, doing the generative interviews and the user test. The second part of my future challenge is noticing and reminding myself that I (can) enjoy these things and am capable of doing them too, silencing my inner critic.

Challenging my Solace Seeker mindset

It was inspiring to hear from different people how they experienced their grief and how open they were to talk about it with me. I always enjoy learning about life, society and people, especially if it (positively) influences how I see and treat myself. Everyone I spoke to dealt with loss differently and I learned something from each of them. Before this project, I think I would identify as a Solace Seeker who believes grief has

an endpoint. I can be very unkind to myself if I linger 'too long' on loss and the emotions that come with it. Finding a point of view on loss, that is more kind towards grief and treats it less as something that needs to be fixed, is a valuable insight I will take with me. These lessons have already helped me with my own loss experiences and with being a better supporter of others.

This project might be the most challenging project I have done so far. I had difficulties with communicating ideas and accepting the iterative nature of design. I am especially happy to be done with writing. Yet, looking back I am grateful for the lessons learned from the project and everyone involved. Silencing my inner critic for a bit, I can say I am also proud of the final design I made. It turned out pretty cool and I hope it helps VLmD further. I am proud of the contribution I could make to making bereaved people feel more supported while going through their unique grief journey.

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- Unpublished conversations and literature within research group.
- Unpublished reports from Vereniging Leven met Dood, about the project proposition (2022)
- Unpublished reports from Vereniging Leven met Dood, about their concept proposition (2023)
- Lecture series by Manu Keirse, 17 December 2022 and 7 January 2023. Organized by de Academie van Geesteswetenschappen.

Photo material in illustrations

- Unsplash.com
- shopify.com/stock-photos

Sensitizing material for the author

- Trinkets (Netflix series)
- Eternal Sunshine of the Spotless Mind (Movie)
- Overgave (documentary)
- Moeders Springen Niet van Flats (documentary)
- Wat je niet moet zeggen tegen jonge mensen in rouw - CRUX (online talkshow) <https://www.youtube.com/watch?v=46R4oN40-MQ>
- Het einde van de Eenzaamheid – Benedict Wells (fiction book)
- Dromer – Benedict Wells (fiction book)