Care to feel it till the pain threshold

A project initiated to bring hope, months of feeling the opposite and a new way to design through the situation.

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Abstract

This thesis documents a personal journey of hope and exploration in the context of elderly living, undertaken by a designer who is also the granddaughter of an aging grandmother. The project takes place during a troubling time when reports of abuse and systemic problems in elderly care are being widely discussed. This context deeply influences the designer's research and personal life.

The journey involves investigating different ways of co-living with elder generations, using various research and design methods to find solutions that prioritize mutual care between older and younger generations. The designer's own experience of caring for her grandmother motivates this process. However, ethical concerns around the use of speculative design interventions arise when participants have to rely on the existing systems that are deemed problematic. This realization prompts a pause in the process to reflect on the consequences of design choices.

After reflecting on these ethical concerns, the designer embraces a relational approach that involves both herself and her grandmother facing the current situation and working together to improve their mutal inter-generational care.

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Introduction



"Family at Meilust", photography taken December 26th 2022 in Bergen-op-zoom

My parents and siblings traveled from France to the Netherlands to visit my grandmothers new appartment still empty at the time

May 1st 2023

I take the train to Bergen-op-zoom with a microphone I lend from school since I know this day will be important for us and could be for others at some point. At arrival I walk 25 minutes to my grandmother's flat. Since she broke her hip last summer, I don't want her to drive her car to pick me up anymore. I enter the building, walk on the thick red velvety carpet covering the floors and present myself to the hostess. The lady already told me many times during previous visits that that's not needed if I just come to visit an inhabitant. I still keep feeling the need to introduce myself each time as the lobby's architecture reminds me too much of a luxurious hotel I would consider out of my reach. That being if I ignore the parked scoot mobiles right after the first of three sets of sliding doors. The scoot mobile corner reminding me that the elevators of the service flat are too small for people to actually bring their priced vehicle and its contents to their apartment. I only spent one week at an architectural office as a 15-year-old intern however I still believe I would have thought of that when building a service flat catered to elderly people in The Netherlands. A flat land with the perfect features for scoot mobile use. Today I try to shut down all these observations and thoughts. Today is the day I stop visiting my grandmother and designing for elderly care in two separate bubbles of one story. The project I started a few months ago with the goal to gain new insights on how to care for my grandmother hasn't been successful in bringing me the hope I needed. Today I talk about how it has been a disservice to self-care and how I feel it prevented me to care for my grandmother. Today is the day to break the fourth wall of my design practice and not only facilitate an experience but live through it.

A practice of life

The moment you just read about marks a shift in my personal life but just as much in my design practice. It's a moment of firsts, a very uncomfortable moment that still feels right as I cared to feel the pain long enough until came the threshold that now pushes me to act on it. It feels right as I feel it will help my relationship with my grandmother and therefore my daily life. I would usually, in the past, avoid diving into personal feelings in my practice. The fact that I haven't changed my topic and kept exploring elderly care even if it hurt along the way due to my personal situation is a first. Having the courage to face my emotions led me to a point where the only reasonable reaction seemed to face them, share them and discuss them. If you keep reading this text you will embark on my hope seeking journey where I dealt with my responsibility as a granddaughter and as a designer. This journey may not have given me what I first looked for, a reassuring feeling that everything could be solved and taken cared of, but allowed me to question my design practice and will pave a new way. This new way will exist if I dare to stay in it, if I dare to explore my own discomfort.

The journey starts from my relationship with my grandmother. From living a problematic situation to seeking hope by researching alternatives, the story leads back to the moment of shift where my personal situation influenced my design methodology and decisions.

A relationship with my grandmother as situational context

This research project and thesis have a main storyline, my relationship with Ria, my paternal grandmother. The last few years have been hard for her and my family. Her partner passed away in November 2021 after battling cancer for only a few months, leaving her to live alone. Due to family circumstances, it felt like I was the only family member for my grandmother to depend on for support.

I am Dutch but my parents moved to France when I was four years old. I grew up in France and my parents still live there. At age nineteen, six years ago, I moved back to the Netherlands to pursue design studies. Since then, I have felt the responsibility of acting like a substitute for them when it comes to my family and especially my grandparents. I feel like I need to care for Ria as my father is not fully able due to geographical barriers. This comes with guilt as I often realize that due to my daily life, and choices, I also cannot give her the attention I feel she needs. In the summer of 2022, while still going through a difficult grieving process, she broke her hip and stayed in a rehabilitation center. That was the start of this design journey as I wanted to rely on my skills and practice to navigate the events.

As a designer I have always been interested in biopolitics and how systems influence individual human lives. Biopolitics is a concept proposed by French philosopher Michel Foucault and pertains the study of rules and systems of power that govern the bodies in modern society. (Foucault et al., 2004) I engaged with this concept in my bachelor studies when I focused on prenatal care and disability rights when to design a speculative archive of discussion points around Nipt in the Netherlands as my Transformation Design graduation project. The project was called Ethical Maze. (van Stratum, 2021) This experience brought me to first approach this research process by engaging in a series of design methods such as system mapping and investigating different aspects of elderly care at large. A process that gradually changed to a field exploration, which I will detail later in this thesis. The design exploration will then end up shaped by the situation I'm living with my grandmother

Elderly care was a main subject in French news in 2022 as Victor Castanet published his book Les Fossoyeurs (2022) exposing corruption and abuse inside the multinational company ORPEA. Reading this book while my grandmother was experiencing abusive treatment during her stay at a revalidation center made me angry and powerless. So, while I continued investigating the problems of the system within my design process, I increasingly felt the need to seek for hopeful stories and solutions. In establishing that need and positioning within my research process as a designer, I changed my work approach and sought a specific context to carry out research where I could engage with the field and find solutions to care for my grandmother. I remembered a building located in my street, Bergweg in Rotterdam, a few blocks away from my apartment. Located above my neighbourhood Dirk supermarket, there is a Humanitas flat for elderly living. Humanitas is a non-profit organization created in Rotterdam after world war II. It has numerous facilities in and around Rotterdam, most are catered towards elderly care, but some are focused on community work at large. (Stichting Humanitas, 2023)



Close to home



"Op bezoek bij Oma", photography taken September 2nd 2022 in Bergen-op-zoom

I visited my grandmother during her stay at revalidation center Tante Louise after she broke her hip.

A grandmother in need

Should I call Oma?

No she's gonna cry again ...
I should do more!

But I already have so much going on!
I could pass by on Wednesday

But then I'm yet again not eating home

The text above shows a sneak peek into the thought processes I have had about caring for my grandmother the past year. Previously I had already experienced feelings of guilt for not visiting enough but that really accentuated when she broke her hip and suddenly needed more care. This happened in the summer 2022, right when I started a new full time work position and was starting the graduation phase of my master. Next to my job and studies I am also a dancer, a partner, a friend and feeling the responsibility to take care of her engaged a lot of my mental capacity. Whether needing to sacrifice other things to visit or choosing to not visit and having to feel the guilt of that decision took a tool on my mental health. My grandmother is a loving person and she cares for me but her emotional fragility is sometimes hard to carry. When on a Sunday, I have a few hours at home and decide to call her to just chat a little bit and she answers in tears of emotion because I thought about calling her it suddenly makes the call really heavy. The next week I then might not call if I am not able to handle that pressure because of a tiring week. The decision to not call is then something I will keep thinking about the next days, feeling like I was too weak and let her down. The design process I engaged in relieved some of this tension but also fed right into it. By researching the topic I still felt like I was contributing to improving the situation for both of us but on another hand, the content I encountered made me only more worried and guilty.

A troubling symptom

After her hip operation, my grandmother stayed at revalidation center Tante Louise in Bergen-op-zoom. (Tante Louise, 2023) This stay became an important moment in my involvement to the topic as a designer as I not only was concerned for her well-being but discovered problems I saw as design challenges. Her hip wasn't replaced but fixed with pins, that is a procedure leading to more recovery time than a full replacement. The fact that she previously suffered from multiple hernias and had a fragile knee on the same right leg would not facilitate her recovery. This is something that was not considered at first when giving her a timeline of her stay based on standards for hip operations. Her progress did not follow the standard. I remember her telling me she felt pressure to recover fast or they would send her back home even if she could not move independently yet.

While she stayed in the center, I discovered multiple problems I felt concerned about as a granddaughter but also as a designer fascinated by systems and biopolitics. And that was the case even if at the time I did not know the extent of what she really had to go through. A few months after her stay there, she revealed information about ways she was treated that I deemed as abusive. I do not develop those experiences in this thesis for privacy reasons and because I do not have any investigation nor do I have proof. I will only speak of events I witnessed or got familiar with during her stay. During one of my visits to the center, and while she was recovering after surgery, I noticed she had no compression stockings on. From my previous experience in special need care, I knew that she should wear these after an operation that immobilized her, especially given her age. She explained that she indeed had a thick leg and that the staff had noticed this with three different

people inserting the information in their tablets. I was shocked that this situation had not been addressed even if I could see the stockings in the closet of her room. My brain had a hard time comprehending that writing information in files for others to see later and act on it had priority over actually caring for the patient right in front of them.

A nurse working at the center and taking care of my grandmother told her that if 20 years ago she knew nursing would be as administrative as it has to be she would have chosen an office job with easy hours instead. The nurse reported that she missed a lot of what made her want to become a nurse in first place. These facts and patterns resonate with a lot of what I learned from the scandals at ORPEA where healthcare workers were left in mental distress due to management decisions impacting their work. (Castanet, 2022)

A troubled ecosystem

The experiences I went through with my grandmother fed into my design process as I was already mapping out and researching how to make sense of victor Castanet's book Les Fossoyeurs (2022). I had already bought the book as it was becoming a best seller in France, and because I have always been interested in the care industry.

This interest led me to work at a non-profit organization that facilitated leisure activities and vacation for special need people from 2015 to 2018. During my time there I experienced multiple occurrences that made me question care institutions and made me angry at my country's system. Just to name a few examples, I saw people with only two pants and three tee-shirts in their closet even during winter months. I've had people, on vacation with us, thank me as I changed their protection during the day as at home in the institution they would usually need to wait for after dinner to get a new one. These experiences took place while I was living in France, which I believe of being one of the western countries with the strongest welfare system.

Through my experiences in France and my grandmothers stay in the rehabilitation center in The Netherlands I became familiar with what seemed to be problematic symptoms of a failing care system. But even knowing that, Castanet's investigation still shook me as it revealed how systemic the problem was and how many victims were hurt in the process. His investigation lasted three years and he managed to talk to more than 250 witnesses. I personally was really touched by the testimonies of children that had their parents in ORPEA facilities and how powerless they felt even once they discovered abusive behavior and took action. With the story of one son not even being able to move his mother out of the facility as he signed a contract. (Castanet, 2022) Castanet not only exposed abusive care but linked this to global corruption and public fund embezzlement. (France Culture, 2022) ORPEA's abusive treatment came from management decisions cutting funds on important pillars of care such as hygiene products. Examples of them embezzling public funds meant for the purchase of incontinence products made me really angry. They were committing a double crime, taking part of my capital for personal gain and thereby leaving vulnerable people in distress. The fact that ORPEA, unofficially, offered Castanet 15 million euros as an incentive for him to not publish his book made me feel like they still planned on keeping the power in hands and continue their unethical behavior without any problem if it wasn't for one journalist's courage. (Le Parisien, 2022) It reinforced my impression of a whole social-political system failing in holding people accountable. This power play made me tick as a designer and pushed me to seek an understanding of the full system and expose it further so that it would bring challenges of possible interventions. But it mostly made me feel really anxious about my grandmother's future, as while she is losing autonomy she might have to rely on facilities similar to ORPEA's. I felt like I could not trust our society and its structures to take care of her.



Greener grass next door



"Humanitas Bergweg", photography taken from Humanitas's website (Stichting Humanitas, 2023)

A building

The desktop research I was doing about elderly care and the experiences with my grandmother felt quite grim. This was giving me anxiety but it also did not feel that relevant as a design practice as it wasn't bringing in a new perspective. Castanet's book already was a mapping of the problem and at this point I felt like I wasn't adding to it.

Moving on, I decided to seek hope by researching other care and living systems for elders. I also needed to have a more active approach, as a way for me to fight the powerlessness I felt with my grandmother. If I couldn't really change her experience, I needed to feel like I was acting on something and moving towards a goal. That is the start of my research at the Humanitas building on the Bergweg in Rotterdam.

October 11th 2022

After I got a coffee at the Brasserie a few days ago I decide to go back to Humanitas alone with Castanet's book so that I can read situated in that particular context. The book addresses a lot of senses and mostly smells, I deem it interesting to read from inside Humanitas as the start of a practice of connecting to that place. I walk with my book in a tote bag. When arriving at the entrance of the building, I expect the Brasserie's menu panel but it isn't there. I wonder if they are open or if they just forgot to put it out. I enter through the gliding glass doors. Right next to me, on the right I see the menu from yesterday still written on the black bord leaning against the wall. I don't know what to make out of it. I engage on the escalator to leave the lobby and access the main space on the first floor. While doing this I rethink of the elevator in the ORPEA building "Les Bords de scene". How each floor takes you further from humanity. While arriving upstairs, I can immediately see that the Brasserie is closed.

The entire plaza feels quiet but there are some people here and there. After turning on myself a few times, clearly looking lost to the outsider's eye, I make eye contact with two women. One of them asks me if they can help. I introduce myself as a student living in the neighborhood looking for a place to read and study as I'm tired of having to go to the library or a café in the city center and get crazy in my student room. This is true so I'm okay with saying this even if I already have a research motive to be in this specific space. I feel I need to be there but I don't have a clear objective or plan yet so I first want to encounter the environment as openly and freely as possible therefore decide to not say anything about what I study or research. I immediately get invited to the library corner that is open. A group of four people are sitting around two round tables. The lady that welcomed me is the volunteer that runs the library. She explains that it's open every morning and every afternoon and that everyone is welcome, inhabitants and visitors. She asks if I want coffee and leads me to the table. I ask if I can join and sit down, everyone at the table immediately allow me so I join them at the table. The coffee gets here. I do take my book out but instead of really reading I kind

of just sit there and let conversations happen. I learn that the group consists of three inhabitants and two volunteers, one is just there for company at that time and the other rules the library, makes the coffee, thee and distributes biscuits. After a few coffees and too many biscuits it's 12.00 and the library closes for the morning, it will be open again at 14.00.

A vision

In order to research the nature of the Humanitas building and understand its history I decide to look at the Stadsarchief Rotterdam to find archival documents. After some desktop research I make a few trips to the archives to listen to recordings from 1997 and 1998. The building was inaugurated in 1997 and the recordings are therefore relevant as they showcase the concept behind the building and how it was innovative. Dr. Hans Marcel Becker was the director of Humanitas at the time of inauguration of this building and wrote a book about his vision a few years later. (Becker, 2004)

The Humanitas building is a flat full of "levensloopbestendige woningen"- life-resistant homes. To be a life-resistant home sixty criteria are taken into account, thirty for the exterior environment, thirty for inside each apartment. With these homes, the goal is to dissociate living and care by focusing on privacy and autonomy. One of the ground rules is based on the right of someone to fill in their live following their own insights.

Thanks to the archival documents I discovered important concepts valued by Humanitas as the "Yes" culture and the "Use it or lose it" mantra. (Stadsarchief Rotterdam, 1996)

A hopeful designer

I visited the Humanitas building multiple times a week or once every few weeks for three months, from October to December 2022. I would always just enter as a neighborhood visitor and join the library coffee sessions or just sit at one of the tables. I took part of conversations, listened, journaled but also drew illustrations of specific anecdotes or moments I witnessed. It was okay for me to just do this as a student living in the neighbourhood.

As my archival research evolved and I worked on video translations of the concepts found in the audio pieces I felt the need to connect it with the present. Putting the research about the Humanitas concept in perspective with the life in the building in 2023. The goal being to see how the theory applied itself and what has positive outcomes 25 years later. (Becker, 2004)

The first design intervention I created focuses on the "use it or lose it" mentality. The main question is if people living at Humanitas keep more skills than if they would live in another system.

What are things that we do daily? What are things that we are able to do but in fact never do? What are things we used to do but aren't able anymore? What are the things we've always dreamt of doing?

I designed multiple iterations of this concept. A conversation piece, a more workshop based experience, a game but ended up deciding not to use any of them in the Humanitas building.



The pain treshold



"A fresh start", photography taken May 1st 2023 in Bergen-op-zoom

Photography taken on the day I shared my design process with my grandmother.

A paradox

After her time in the revalidation center my grandmother went back to her apartment but her now being alone and less mobile she couldn't properly stay there anymore. She moved to a service flat. A lot of hardship went through the decision making process and the moving period itself. This was accentuated as I was researching elderly care and the numerous problems it entails. The more I learned, the more guilt I felt for not being able to properly take care of my grandmother by myself. But this also felt like an impossible sacrifice to make at the moment. I took this project on to gain understanding and hope. During the process, it became hard to distinguish how I felt as a granddaughter and what I thought as a designer. The more I recognized problems, the harder it was to feel at ease with her new living situation.

My design eye tends to look for problems to solve but some problems are not immediately fixable and that affects my relationship with her as I then cannot just be a supporting granddaughter. On the other hand, my personal situation motivates me to study this context and design for it. This is the paradox I felt stuck in.

The situation I'm in at the moment will happen more and more as the population is ageing and the inter-generational gap is growing in the Netherlands. This will lead to full generations of working people that need to be productive to society having a problem taking care of their elders. They will have to work to pay the care of their elders. But how the system is at the moment, it's quite questionable if they should trust it to properly care for them.

A shifting moment

In this chapter, I'm addressing how I for the first time have a practice that immediately affects my personal life. When looking at my past design experiences and studies, I can state that I have always treated subjects I care about and learned from my projects. But I feel like even if the results of my projects helped me grow as a designer but also a person they never directly affected my personal life. Treating a subject really close to my daily life is a scary step out of my comfort zone but is probably necessary to experience the impact of design. The emotional entanglements make it hard to take action as I feel a pressure to not design anything that could hurt my grandmother.

As a facilitator, I put others through an experience that I now for the first time get to feel for myself. During my design process at Humanitas, I wanted to facilitate a workshop for elders to speculate about their perfect living situation. I was really enthusiastic but when came the question to do it with my grandmother I realized what it would do with her after the workshop. She would be looking at her current life with a similar eye to mine, a critical eye, comparing everything to what could be. This would not help her settle in her new life and would only cause distress. By not feeling ok to have the experience with my grandmother, I decided to also not have it with other elders. Speculation is something I believe in as a design practice as it allows me to stay critical about current situations and work towards something else but if you are not in a position to change anything it just feels a bit cruel. The moment itself would have been beautiful, hopeful, I would be a sign of promise for a better future but as soon as I'm not there anymore, which would have happened they would stay with their unattainable dreams that I would have made more realistic.

This does make me question my practice at large. I would define my practice in this few words:

"I want to help people understand their surroundings and current situation.

I believe that the understanding of one own's context and behavior is key to make informed and relevant decisions.

I believe that when given the right experience everyone can gain new insights on their situation and role and make a stronger impact on their surroundings and on society at large.

My practice, Discursive Gamification, aims to provide this experience by facilitating personal reflection and collective discourse."

I questioned if the age was a factor of me not believing in the beneficial aspects of new insights. The answer to that is that I actually believe their life experiences give them even more ground to explore and will bring more fertile insights. But the problem is that I feel like they will not be able to act on their insights to make impact on their life and the one of others. I'm not sure if this is a shortcoming I have or if this is a symptom of how society makes elderly people dependent. In the past months, my grandmother was put in positions of abuse where she felt powerless to take basic care of herself. The fact that I saw that and also felt powerless broke my hope. But it might be unfair to not even try.

I arrived at a moment where what I ethically should do as a granddaughter and as a designer need to merge. I have to expose these questions to my grandmother in a transparent way and give her a say. I need to shift from keeping creative control, designer power to a more relational practice where I acknowledge that as both entities will hold the consequences, both need to way in the decision process. A shift from being facilitator to being co-practitioner.

A new way

Where I first explored different research methods to develop a participatory speculative approach I now want to have a more transparent approach to the relationship with my grandmother. Discussing how we feel so that we can together build a situation where we care about each other. Our relationship will then serve as a raw catalyzer for others from our generations to reflect. I want to focus on the creation of intimacy to allow an audience to replace us with their own loved ones.

It's a new decision making process in my practice. Instead of having my emotions decide if something is right or not and if I should do it, it's about acknowledging the emotions themselves and their relevance.

This is what brings me to that day in May 2023, sitting with my grandmother and exposing what I just wrote here.



Final words



"First reactions", still from video recorded May 1st 2023 in Bergen-op-zoom

Image from the discussion I had with my grandmother after reading my thesis to her for the first time.

On May 1st 2023, I visited my grandmother with an in-Dutch-translated version of this thesis. We sat down in her living room. She made tea, I installed a camera and sound recorder in the room. I read the text and let her react. From there on we discussed the content and how we could move forward.

Ria's first reaction

In the next paragraph, Ria's words are in italic where mine aren't.

Well, can I respond now?

You can certainly respond

Oh because there is so much to say, I'm totally impressed Fleur, very much. And I want to say first that you have not fallen short at all, not at all. I never had that feeling. I did recognize, I felt... when you just said "I thought I was my father's deputy" I understood that, I never thought of it so literally. I have never felt that you have fallen short, not at all, I am very happy with you, really very happy. And you once said to me "I call a little less because there are so many things that keep me busy" and I thought that was very realistic.

Yes

And I am very impressed by the analysis you make, how, following that French study, you also see your own experience with your holiday work. So much goes wrong and I'm glad I shared some things with you when I was in rehabilitation because my eyes have been opened there too. Unbelievably so ! And I'm still in touch with two people from that rehabilitation period. We occasionally eat together and then we share things. And I think very often about people who are still staying there because there is no place for them anywhere. I think that's really very important.

[...]

If I understood correctly, you also wanted to do a certain investigation and you didn't do it because you thought it would burden me. I know I was larmoyant for a long time, I'm still easily tearful now but I really wish you would do that with me, I want to get that insight.

It was mainly an idea to build into what the perfect lifestyle would be like for you. Also starting with the Humanitas building and the people who live there. But it was at a time, I'm talking about 2 months ago, where you had a lot of trouble living here. And then my point was that I already saw a lot of things, the first time I came in I immediately mentioned things that were kind of problematic in my eyes.

The kitchen

Yes, and if you are going to do research about your perfect world then you are going to sketch out a dream, but in what way will that dream come true in the next few years. This is something I do very often with other designers or with young people because then you can work on making that new reality or dream come true for the next 10 years, for example. Only suddenly I thought about how you here now, you could say that you want to live somewhere else and in a different way, but you will likely have to stay here. So that's kind of what I meant by burdening you with a negative view of your current living situation. So I decided not to do it with the residents of Humanitas either because the same situation could arise with them. Then there's also a point where it didn't feel right not to do it at all because it's still something that bothers me. I feel that together we need to find a better way to live together. From there I also decided to do this today, just read everything, explain. Giving you the choice or at least looking together to see how far we can gain new insight while getting something positive out of it.

That doesn't feel burdensome to me when you say I think it's a good thing to do. I'm now to the point where I would find it interesting. I know that coming to live here was the right choice and I'm glad I made that choice.

[...]

Then I am curious because you now say that you would be ready and it seems fun to you. If you were to look back, what would that have done to you in January or February? To then think about everything you would actually want but have to miss out on.

I couldn't have done it then, I didn't even dare to go downstairs to the happy hour with the neighbors. I then always talked too much or I started crying. If you had talked to me about this house, It wouldn't have been helpful in anyway. I was still completely knotted.

Yes, I noticed then that you had a lot of trouble accepting that you lived here and it is from that feeling that I built up the way of thinking expressed in my thesis.

[...]

I think I am now at a point where there is nothing, if you were to list all kinds of negative things that would make me go crazy or that I would think "see, I have to get out of here".

On my side I realized it's not something I have to do on my own side, it's something I have to open up. That's why I expose the question to you with my entire thinking pattern. If you say I am open to it right now and I want to take steps, then that seems interesting to me to do. That is something we both have to find a balance in. That I don't feel guilty about hurting you through the process. That we both take care of each other, that it works on both sides.

[...]

I suddenly have the feeling that I can also do something useful and that's the worst thing about getting old, that you think who am I going to sit here for. And your explanation of how you got here, the logic, I see it very clearly now and I hope you continue in this.

[...]

I have completely given up the resistance to live here now and want to make the best of it.

My concluding words

I believe that this project is important as it talks about hope in a social system where we might often feel powerless. It explores how generations can live together in a capitalistic society. And it puts the role of social designers up front, the impact a workshop, a design piece can have on someone else. But it is important to end on my grand-mother's words.

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