MAKING FUTURE CARE VISIBLE:
APPLYING ANTHROPOLOGY TO DESIGN A FUTURE-FOCUSED CARE TOOL

A Project Report

Presented to

The Faculty of the Department of

Anthropology San José State University

In Partial Fulfillment

Of the Requirements for the Degree

Master of Arts in Applied Anthropology

By

Patrick Ryan Padiernos

May 2023

The Undersigned Graduate Committee Approves the Project Report Titled

Making Future Care Visible: Applying Anthropology
to Design a Future-Focused Care Tool

By

Patrick Ryan Padiernos

APPROVED FOR THE DEPARTMENT OF ANTHROPOLOGY

SAN JOSE STATE UNIVERSITY

May 2023

DocuSigned by:
Jan English-Lueck
9CDDDC475D2942E...
Jan English-Lueck, Ph.D. Department of Anthropology

DocuSigned by:
Roberto Gonzalez
337D5E307A8E416...
Roberto J. González, Ph.D. Department of Anthropology

DocuSigned by:
Rajiv Mehta
C4FA989770D141C...
Rajiv Mehta, M.S., MBA Atlas of Caregiving, CEO

Acknowledgments

I received so much care and support from others to help me design and create my project over the past few years. I would like to thank Dr. Jan English-Lueck, Rajiv Mehta, and Dr. Roberto González for inspiring and aiding me in my efforts. Thank you, Dr. Jan, for your patience, encouragement, and for introducing me to a world where I could engage with the complexities of the human experience through its visual forms and possibilities of the future. Rajiv, thank you for teaching me to see care in my everyday life and allowing me to explore its multiplicity. Dr. González, you inspired me to listen to the vibrant and sometimes overlooked sights, sounds, and colors of everyday life with Mariachi by Moonlight. Thank you.

Thank you to the medical anthropology students who offered me their experiences and for the conversations we shared learning the language of care. I hope you each excel beyond the futures you depicted in our activities and wish you the best. I want to thank the Rug Council for opening your doors to this lone anthropologist who landed on your virtual shore with nothing but a laptop, a journal, and curiosity about your ideas of the future. It was a pleasure to share our insights on care and I hope we can continue to re-visit our futures as the years pass, both in-person and online. Thank you Light for weathering the storms with me to complete my report. Thank you Devoid and RiverReeler for making me feel welcome and showing me the ropes. Thank you, Bluefin, for sharing your stories.

Finally, I want to thank the people in my life. Thank you to my cohort for the support we shared these past few years and special thanks to Graham, Dani, and Sean. The Covid kids who help keep me sane. To my family and friends, thank you for your unconditional love and support. Ash, thank you for all your help, support and patience. I promise I’ll finally be able to leave my room. Thank you to my nephews Leo and August, who inspired me to design a better future for you.

Table of Contents

Chapter One - Introducing My Project 6
Atlas of Caregiving 7
Addressing Atlas of Caregiving Needs by Applying Anthropology 8
Informing the Project: Care, Visualization, and Ethnographic Futures 10
    Documenting Care 11
    EFR and Integrating Futures to Inspire Agency 12
Applying Ethnographic Methods 15
    Participants 15
    Procedure 17
Crafting the Deliverables 19
Conclusion 22
Chapter Two - "Making Future Care Visible: Applying Anthropology to Desing a Future-Focused Care Tool" 23
Abstract 23
Addressing Organizational Needs 23
Integrating the Activity 26
Designing and Re-Authoring My Activity 28
Listening through Creating Videos 30
    From Complexity to Diversity 31
    "You Can't Cry Online" 34
Conclusion 36
Biography 37
Chapter Three - Re-Authroing your Care Future and Future Opportunities 38
Exploring Visual Data and Creating Videos 38
    Creating the Video Series 39
Challenges and Recommendations 41
    Stigma of Vulnerability in Caregiving 42
    Untangling the Complexity of Care: Insights and Recommendations 43
Appendix A 48
Appendix B 49
Cumulative Refrences 50

CHAPTER ONE

INTRODUCING MY PROJECT

In this project, I partnered with the non-profit organization Atlas of Caregiving to design a new activity that integrates methods of ethnographic futures research into their workshops around mapping personal care ecosystems[1]. Taking an ethnographic approach to design a new activity, I explored how we could provide more agency to participants and inspire them to make changes to their care ecosystems beyond the organization's current suite of pen-and-paper visual tools. As a result, I developed an activity called "Re-Authoring your Care Future," which guides participants in visualizing and depicting their futures in the context of care. I also created a “Care Futures” video series to teach my activity and demonstrate the application of the organization's tools in a virtual setting, using online platforms like Zoom and Discord. In this project, I illustrate how methods of applied anthropology can contribute to the design process by exploring the potential of combining visual ethnography, ethnographic futures research, and the anthropology of care to facilitate and co-create envisioning future care ecosystems.

This project report consists of three chapters. The first chapter introduces my project and the organization, problem statement, goals, the literature that informed my project, and an outline of my deliverables. In Chapter Two, organized as an article for *Practicing Anthropology*, I reflect on the process of designing my activity and video series, highlight major themes I found through the voices of my participants, and discuss my findings and the

---

[1] A care ecosystem refers to the interconnected network of individuals, organizations, and resources involved in caregiving. It emphasizes the complex relationships and collaborations among caregivers, care recipients, healthcare professionals, and support services to provide comprehensive care (Mehta 2019).

impacts of my research on the organization. In Chapter Three, I reflect on my project and conclude with recommendations for future research for the organization and the broader field of applied anthropology.

Atlas of Caregiving

Atlas of Caregiving is a non-profit organization that is dedicated to understanding and addressing the needs of family caregivers and utilizes innovative research methods to gain a deeper understanding of the caregiving experience. Their work is rooted in the broader "Quantified Self" movement, which aims to explore practices of self-tracking and the relationship between biosensing technologies and everyday life (Nafus 2016). By applying a "QS approach" to social and public health issues surrounding care, Atlas of Caregiving seeks to understand and teach practices related to personal science and has developed a set of six pen-and-paper “care tools” to guide individuals in observing, visualizing, and analyzing different aspects of care in their lives.

Inspired by data visualization, mindfulness, and self-care practices, the care tools developed by the organization support individuals as they collect and interpret their own data in the context of care. Individuals can use this data to visualize their care relationships, day-to-day activities, and even their connections to their bodies throughout the day. The organization’s flagship tool, the Atlas “CareMap,” is a pen-and-paper tool for visualizing and documenting one’s care ecosystem (Mehta and Williams 2021). Using a CareMap, individuals create a visual diagram of their care relationships, connections, and interactions in daily life, which can help them plan for potential difficulties, manage the many people involved, and identify missing people and services (Mehta and Williams 2021).

Atlas of Caregiving seeks to support individuals as everyday caregivers and foster a culture of care in communities. Their goal is to empower people to better care for themselves and others, and provide educational programs and resources to individuals and communities. The organization's work has the potential to inform broader care models and has important implications for social and public health issues. Their approach, rooted in personal science, self-tracking, and mindfulness, provides a valuable contribution to the understanding and improvement of caregiving practices.

Addressing Atlas of Caregiving Needs by Applying Anthropology

I began collaborating with Rajiv Mehta, the CEO and co-founder of Atlas of Caregiving, and my graduate advisor Dr. Jan English-Lueck in early 2021 to identify potential opportunities for applied research using the care tools developed by the organization. It was evident that the pandemic had brought about significant transformations in communication, learning, and care practices (Lerman Ginzburg and Schensul 2023), prompting us to explore how research could respond to these changing circumstances. As I further detail in Chapter Two, the organization had recently shifted in-person workshops to a virtual format during COVID-19. This shift brought to Mehta's attention a need to enhance the tools for users to take action, improve their care ecosystems, and further explore the organization's application in a virtual setting, where workshop participants could no longer share in-person connections.

English-Lueck and Mehta had been collaborating for several years to integrate the organization's CareMap and other visual tools into the medical anthropology curriculum on care at San José State University (SJSU). In our initial meetings, prior to the Fall 2021 semester, we discussed opportunities to introduce the tools to English-Lueck's medical anthropology class at SJSU. These students were beginning to return to in-person learning following COVID-19 lockdown restrictions. In our conversations, we reasoned that the tools offered by Atlas of Caregiving were particularly useful in not only allowing people to see the larger picture of their individual care ecosystems, but in fostering a community of practice around the topic of care. However, what often arose in our initial discussions around the organization's care tools, was a question of individual agency and self-efficacy.

In the context of care, one's ability to act and make choices (agency) and their own belief in their ability to reach a particular outcome (self-efficacy) can significantly influence their engagement with specific treatments and their ability to manage their health (Kleinman, 2019). High levels of agency and self-efficacy are associated with positive treatment outcomes and successful health management, whereas low levels of agency and self-efficacy may hinder a person's ability to engage with treatments and manage their health effectively (Poltorak 2013). Therefore, an understanding of a person's level of agency and self-efficacy is crucial for providing effective interventions and treatments for the study of care.

In the case of Atlas of Caregiving's tools, we had found that once participants are able to visualize care through the collection of their own personal data, the tools did not provide a specific means to help individuals make sense of their own care experiences. I wanted to help participants visualize the many layers of their care experiences and take the next step by visualizing how they might act to improve their care ecosystems. These research opportunities led me to question how I could make the organization's tools more actionable and inspire agency in participants after learning to visualize and depict different aspects of care in their lives. What could I learn from applying the tools in a virtual context, where participants no longer shared the same physical space?

My project aimed to answer three things: 1) How could we clarify the process of introspection for participants learning to visualize care? 2) How could the organization broaden its reach in a virtual context? And 3) were there any benefits to getting participants to not only work through the process of visualizing care, but help them work through the necessary changes that can benefit them after?

Informing the Project: Care, Visualization, and Ethnographic Futures

Informed by my research and the needs of the organization, I conducted an applied anthropological approach to user research to design a new activity around visualizing one's future in the context of care. In her work in the field of visual and sensory ethnography, Sarah Pink (2014) argues that anthropology can bring valuable insights and perspectives to the design process, including a focus on understanding the context and needs of end-users, as well as a commitment to ethical and sustainable design practices. She also emphasizes the importance of collaboration and co-creation in the design process, noting that involving end-users and stakeholders can lead to more effective and culturally sensitive design solutions.

To inform the design of my activity, care futures video series, and methodology, I drew on three fields: anthropology of care, ethnographic futures research, and visual anthropology. These fields provided me with theoretical frameworks to understand the diversity and logic of participants' care experiences, the cultural schemas they employed to plan for their future care needs, and strategies for unpacking and analyzing visual data to inform design changes.

Documenting Care

The study of care is a crucial area of inquiry that encompasses a broad range of practices that can shed light on some of the most pressing social and political issues in contemporary society, such as access to health care, social inequality, and the changing nature of everyday life. To guide my study, I took inspiration from Annemarie Mol's concept of the logic of care, because it emphasizes the importance of valuing and supporting the embodied experience of individuals within care systems (Mol 2008). According to Mol, it is important to consider that the tools, such as those designed by Atlas of Caregiving, are non-neutral "participatory devices" that have the ability to shape the experiences and practices of both those who create and provide them. She cautions that such "participatory devices" can obscure or simplify complex social and cultural factors that shape health outcomes. The way designers create and use these tools can influence how we perceive the roles and responsibilities of different actors in the care process, which can in turn shape the way care is delivered and received.

In studying the logic of care and patient choice, Mol (2008) suggests that healthcare practices should be oriented towards supporting the everyday care needs and experiences of individuals, rather than solely focusing on the technical aspects of treatment, which characterize the bio-medical model of care. I wanted the design of my activity and videos to highlight the embodied care experiences of participants by considering their individual everyday lived encounters with care. Talking about individuals within systems reveals that care is diverse. It shifts and reconfigures as the life experience of individuals changes over time (Mody 2020). In studying the complex factors necessary for the provisioning of effective care, anthropologist Arthur Kleinman (2019) emphasized the importance of engaging with patients and their families, in their everyday lives. Similarly, medical anthropologists, Perveez Mody, and Patrick McKearny highlight the importance of documenting individual experiences of care within larger systems as a means to uncover the dynamic processes whereby morality within care is established in practice (Mody 2020; McKearney 2020).

I placed the everyday care experiences of participants at the heart of my design approach. In doing so, I aimed to highlight the multiplicity of care and how care practices shift over time in response to individual experiences. To achieve this, I employed an ethnographic approach that focused on studying participants' user experiences within the context of their individual care practices and lived experience of care. This involved participating in the same activities as participants, recording meetings and discussions, taking detailed field notes, and collecting completed activities from participants. These methods allowed me to gain a deeper understanding of how participants operationalized their care ecosystems and provided valuable insights into the affective logic behind their decision-making. After establishing the care-focused nature of my project, the next step was to develop a prototype that would enable people to become active participants in shaping their care ecosystems.

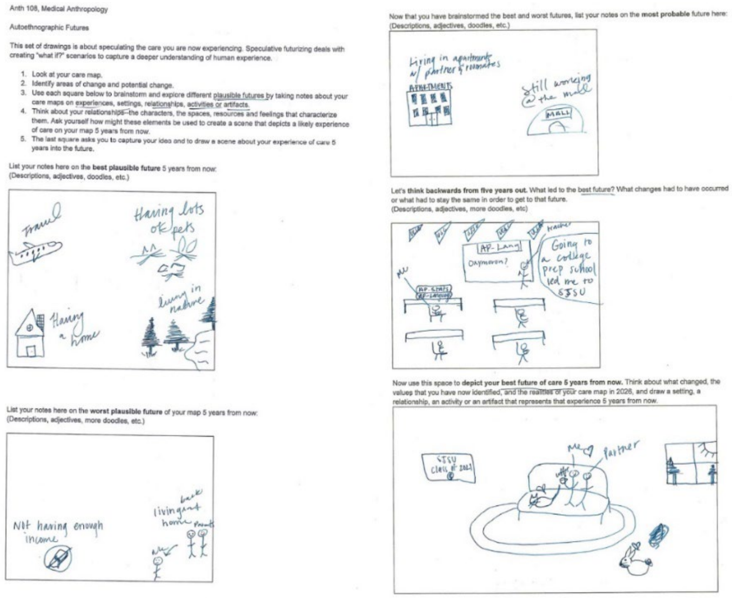
EFR and Integrating Futures to Inspire Agency

Anthropologists have long recognized the importance of the future as a site of cultural production, and have explored how future-oriented practices and discourses shape social and cultural phenomena. Appadurai (2013) argues that a greater focus on speculative approaches to ethnographic research can help us to understand the future-oriented practices and discourses that shape such phenomena. As suggested by English-Lueck et al. (2021) ethnographers can study the act of anticipating and shaping the future as an ethnographic practice to gain a deeper understanding of power dynamics and social practices.

For example, Mika and Venkataramani's (2021) ethnographic research on designing virtual primary care challenged the original assumption that rural, lower-socioeconomic populations would be best served by virtual primary care, given their greater geographic distance from clinicians and perceived barriers to access. Instead, they found that urban, higher-socioeconomic populations reported more favorable experiences with remote care and eagerly anticipated virtual primary care during COVID-19 due to the population's greater trust in, and agency with, institutionalized healthcare. Their research on designing remote primary care speaks to the importance of considering broader systemic influences when designing and implementing socially responsible and novel healthcare technologies by showing how structural forces shaped how individuals anticipated future care technologies.

Drawing inspiration from methods of anthropology that critically explore the social, cultural, and ethical dimensions of emerging technologies, I employed Robert Textor's (1995) qualitative interviewing methodology known as Ethnographic Futures Research (EFR) to develop prompts for my activity. EFR involves exploring people's ideas about the future to reveal the underlying affective logic behind them and is particularly useful for studying rapid societal changes driven by technology (Textor 1995).

According to Textor, individuals play an active role in shaping their own futures. In prototyping my activity, I focused on teaching participants to act as autoethnographers, interviewing themselves about their own future of care, where their existing cultural frameworks influenced their interpretations. I wanted participants to be able to use their care data to imagine future possibilities and build confidence in their ability to achieve their desired care future. To do this, I created five prompts inspired by EFR to guide participants in generating scenarios using visual or textual representations of what their future care ecosystems would look like. Future researchers can adapt these prompts to design and improve future activities and conduct similar research (See Appendix A). In Figure 1.1. below, I've provided an example from my original prototype completed by a medical anthropology student at SJSU.



Anth 108, Medical Anthropology

Autoethnographic Futures

This set of drawings is about speculating the care you are now experiencing. Speculative futurizing deals with creating "what if?" scenarios to capture a deeper understanding of human experience.

1. Look at your care map.
2. Identify areas of change and potential change.
3. Use each square below to brainstorm and explore different plausible futures by taking notes about your care maps on experiences, settings, relationships, activities or artifacts.
4. Think about your relationships–the characters, the spaces, resources and feelings that characterize them. Ask yourself how might these elements be used to create a scene that depicts a likely experience of care on your map 5 years from now.
5. The last square asks you to capture your idea and to draw a scene about your experience of care 5 years into the future.

List your notes here on the **best plausible future** 5 years from now:
(Descriptions, adjectives, doodles, etc.)

List your notes here on the **worst plausible future** of your map 5 years from now:
(Descriptions, adjectives, more doodles, etc.)

Now that you have brainstormed the best and worst futures, list your notes on the **most probable** future here:
(Descriptions, adjectives, doodles, etc.)

Let's **think backwards from five years out.** What led to the best future? What changes had to have occurred or what had to stay the same in order to get to that future.
(Descriptions, adjectives, more doodles, etc)

Now use this space to **depict your best future of care 5 years from now.** Think about what changed, the values that you have now identified, and the realities of your care map in 2026, and draw a setting, a relationship, an activity or an artifact that represents that experience 5 years from now.

Figure 1.1. Completed example of Autoethnographic Futures worksheet.

Building on the understanding that care practices are dynamic and responsive to individual experiences and changing circumstances, Ethnographic Futures Research (EFR) offers a unique approach to exploring the evolution of care practices over time by engaging participants in imagining and articulating possible futures for their care ecosystems (English-Lueck, Ladner, and Sherman 2021). As participants become conscious of their own values, they can become active participants in shaping their future (Textor 1995, Fox 2015). By identifying emerging trends and patterns, analyzing lived experiences, and understanding the social and cultural dynamics of care, I used EFR to provide valuable insights for developing an activity that incorporates individual agency into its design.

Applying Ethnographic Methods

Participants

To inform each iteration of my design, I worked with two groups I separated into an initial Alpha group and a Beta group. Introducing my prototype to the Alpha group, I would make changes and re-introduce it to the Beta participants. The participants of the initial Alpha group were composed of a preliminary sample, consisting of seventeen medical anthropology students at SJSU I introduced to an early version of my activity during their Fall 2021 semester. Due to in-person COVID-19 restrictions at the university during the semester, students completed the activities in a hybrid virtual setting, learning and completing activities both in-person in a classroom setting and online over Zoom. Participation in my care futures study for the Alpha group was non-mandatory and fourteen students chose to share their completed activities, six of which participated in exit interviews.

Employing network and community outreach as well as a demographic survey to determine prior experience in similar programs, I selected the Beta group due to their interest in my work, availability, and access to the resources required to complete our activities remotely. I selected the Beta group from a pool of 121 individuals from an online Discord community of Silicon Valley working professionals called the “Rug Council,” offering support to members from September to December 2022.

The Rug Council Discord channel was created in the early 2000s by fourteen members during their time in high school but has since grown into a larger online community. Despite its current function as a larger support network for working professionals, the Rug Council is a close-knit community of members who regularly communicate online. Describing what their community meant to them, Light, a founding member of the channel had this to say: "To me, it means my best friends are one instant message away. To me, it means we're gonna stay connected despite our ever-evolving world." Participation in my virtual sessions was non-mandatory and consent to participate was collected from seven members all of which completed the activities and exit interviews. Beta participants were all males who were aged 26-27 at the start of the activities[2].

---

[2] The Rug Council often supports members in online gaming and tech-related subjects/fields. Further, founding members were all males. These conditions may have contributed to the homogeneity of my Beta group which may speak to issues related to gender diversity in online gaming (Jenson and de Castell 2010), as well as tech-related fields (Miric, Yin, and Fehder 2023).

Procedure

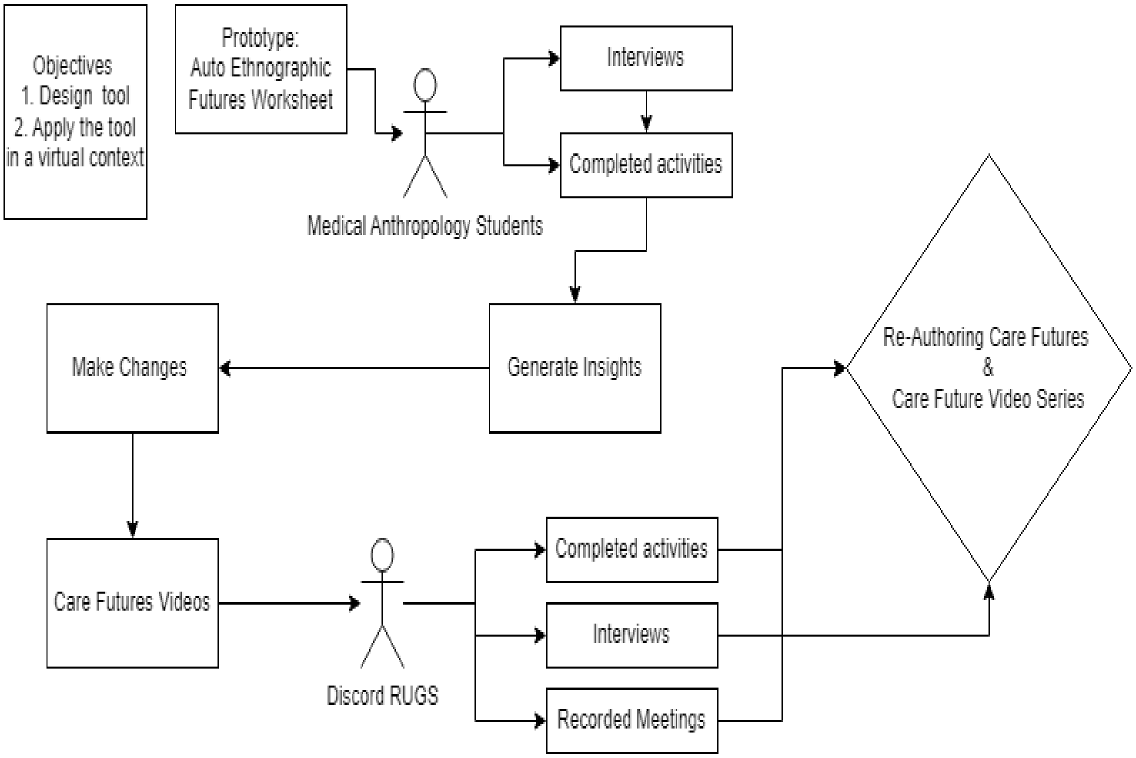


Figure 1.2. Flow chart of my process moving from initial prototype to completed deliverables.

In Figure 1.2. above, I outline my process working with both groups to complete the objectives, collect and analyze data and move from my initial prototype to the completed product of my project. Both Alpha and Beta participants were involved in a larger curriculum around care, which I further detail in Chapter Two. Including my activity in the larger curriculum, participants would create an initial CareMap 1.0, incorporate changes after activities, and end the program after completing and sharing their final CareMap 2.0. To provide context for both the visual data and participants' experience of the activities, I used a qualitative focus group approach to generate discussion around the topic of care among participants. Previous workshops from Atlas of Caregiving had supported the validity of focus groups among participants involved in learning about the original care tools in group settings (Mehta and Williams 2021). Based on the virtual workshop I hosted on Discord; I created a participant user journey map to illustrate this process (See Figure 1.3).

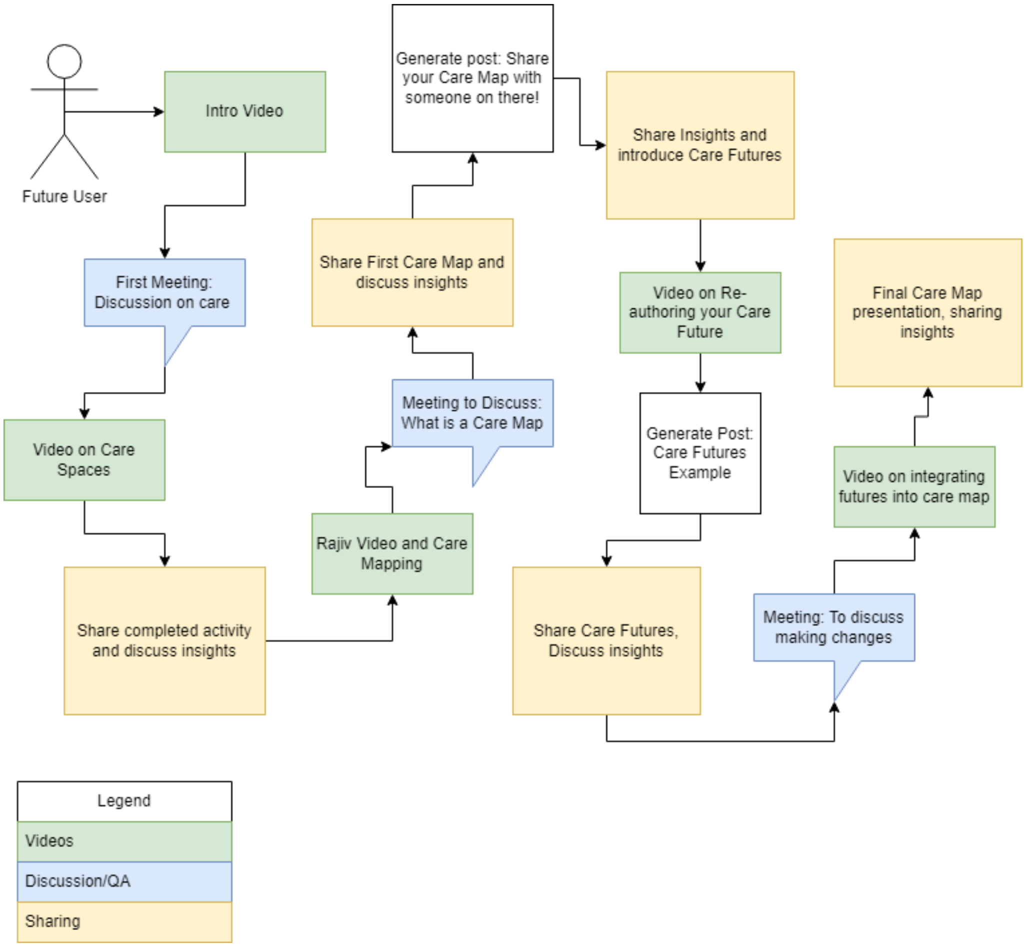


Figure 1.3. Participant journey map based on the virtual workshop I hosted guiding Rug Council participants.

Following final presentations of the CareMap 2.0, I asked participants to complete a semi-structured one-on-one exit interview with me to discuss their experiences during and after the completion of our activities. I conducted interviews both virtually and in person. I recorded in-person interviews using a handheld recorder and I collected virtual interviews recorded over Zoom and Discord. After completing a transcription, I sent copies to the interviewee for their records and asked if they wanted to omit any part of it. Each session lasted about 45 minutes.

My exit interviews were split into two parts to explore the overall reception of the activities around visualizing care and the experience of mapping their care futures. During each interview, I provided participants with a copy of their CareMap 1.0, Care Map 2.0, and care futures activity. I instructed them to reflect on their experience using the activities as visual guides. In my interviews, I explored participant's experiences with learning and visualizing care, the impacts of the activities on how they see and evaluate care, their values around care, and their experiences and opinions on my care futures exercise.

My interviews provided context for interpreting the visual elements of their care activities. They also provide insight into how participants operationalized making changes to their CareMaps. I added additional questions to the exit interview for the Beta group surrounding a specific channel in their Discord named "Serious Chat[3]." I did this to gain a better understanding of their virtual community and explore further opportunities to apply the care tools in online settings.

Crafting the Deliverables

Considering the fields that inspired my design process, I worked with both groups to prototype, test and re-design each aspect of my activity. I sought to utilize the potential of ethnographic futures research as a framework to inspire participants to become active agents

---

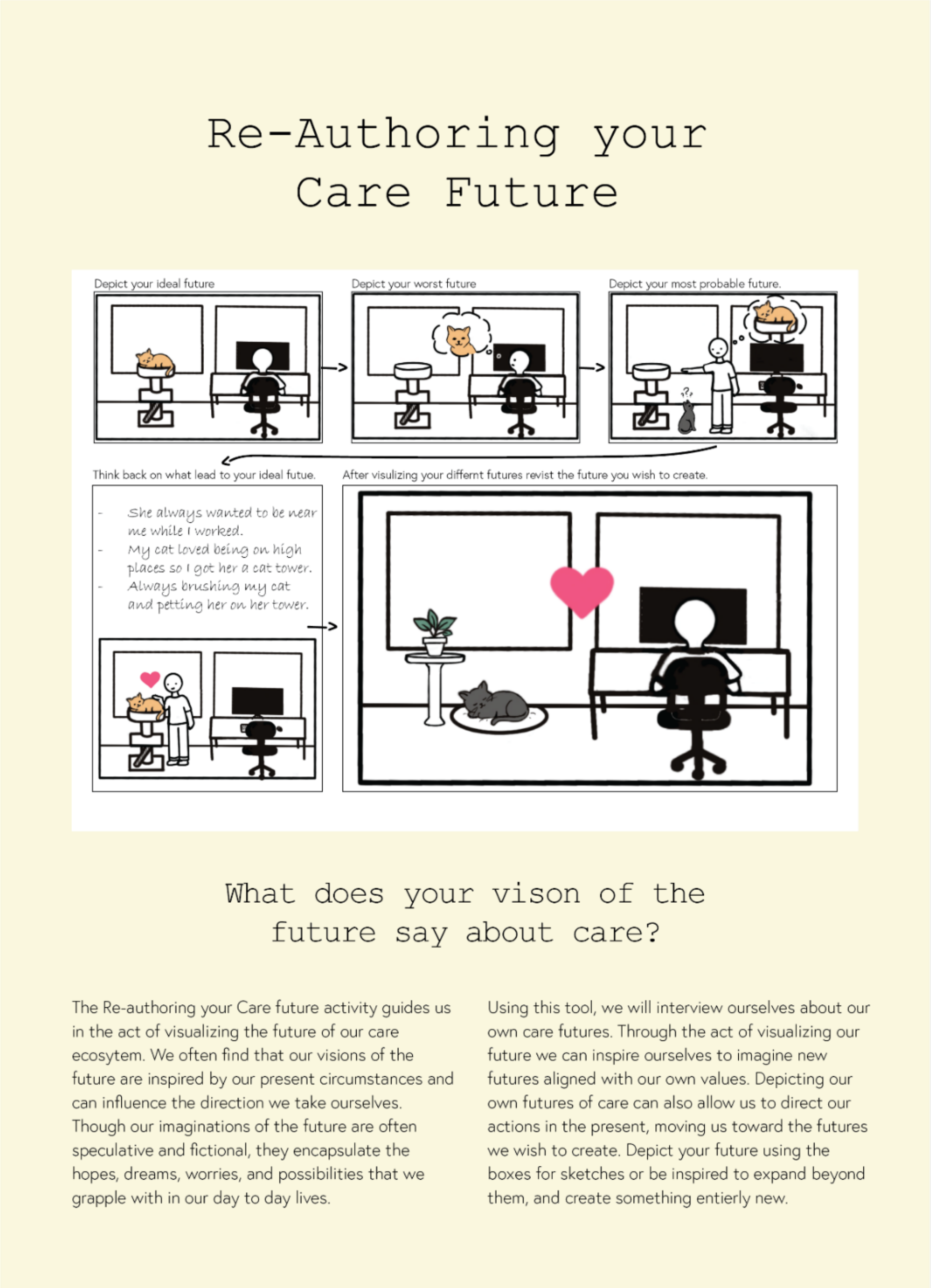
[3] "Serious Chat" is a separate channel on the Rug Council Discord server that I did not have access to. It was available to particular members of the community to post confidential more sensitive and personal messages that required more immediate attention from Admins.

in shaping their futures of care. Collecting care experiences, guiding participants in visualizing their care futures, and analyzing visual data to make changes to inform the design of my activity and videos, what I created resulted in the final deliverables I presented to Atlas of Caregiving. Table 1.1 provides a general breakdown of my deliverables, intended recipients, and the different mediums employed in my project.

Table 1.1. Deliverables

	Re-Authoring your Care Future Activity	*Care Futures Video Series*
What is it?	*Activity that teaches participants how to visualize and depict their futures in the context of care.*	*Informational videos (3-5 minutes)* • *Intro to workshop* • *Video on care spaces* • *Re-Authoring your Care Future Activity* • *Integrating Futures into Care Map example*
Who is it for?	*Users of the Mapping Ourselves program.*	*Future users of the Mapping Ourselves Program.* *The creative team at Atlas of Caregiving.*
What is the medium?	*Digital and printable resource.*	*Video*

Incorporating the experiences of my participants, I created a final mockup of the Re-Authoring your Care Future activity based on the different textual and visual elements I pulled from my participants' activities and my own care future (See Figure 1.4). To make my work more accessible to future users and designers, I also posted the original “Care Futures” video series I created to supplement my virtual workshop (See Appendix B).



Re-Authoring your
Care Future

Depict your ideal future

Depict your worst future

Depict your most probable future.

Think back on what lead to your ideal futue.

- She always wanted to be near me while I worked.
- My cat loved being on high places so I got her a cat tower.
- Always brushing my cat and petting her on her tower.

After visulizing your differnt futures revist the future you wish to create.

What does your vison of the
future say about care?

The Re-authoring your Care future activity guides us in the act of visualizing the future of our care ecosytem. We often find that our visions of the future are inspired by our present circumstances and can influence the direction we take ourselves. Though our imaginations of the future are often speculative and fictional, they encapsulate the hopes, dreams, worries, and possibilities that we grapple with in our day to day lives.

Using this tool, we will interview ourselves about our own care futures. Through the act of visualizing our future we can inspire ourselves to imagine new futures aligned with our own values. Depicting our own futures of care can also allow us to direct our actions in the present, moving us toward the futures we wish to create. Depict your future using the boxes for sketches or be inspired to expand beyond them, and create something entierly new.

Figure 1.4. Final Activity Mockup presented to Atlas of Caregiving.

Conclusion

I created the Re-Authoring your Care Future activity and the supporting Care Futures video series to teach participants in a peer-to-peer setting to become better ethnographers of their care ecosystems. Using both in tandem, I intended to teach future users to act as anthropologists conducting an autoethnography on their CareMaps. Creating both the activity and videos, I provided Atlas of Caregiving and future users a more accessible and flexible way to engage with content in a virtual space. Moving from in-person to a virtual format where interactions between individuals shift, I paid careful attention to how physical presence, digital communication and accessibility influenced participants' experience and engagement. In the next chapter, I reflect on the process of designing the activity and video series, highlight major themes I found through the voices of participants, and discuss my findings and the impacts of the study on the organization.

CHAPTER TWO

"MAKING FUTURE CARE VISIBLE: APPLYING ANTHROPOLOGY TO DESIGN A FUTURE-FOCUSED CARE TOOL"

Abstract:

Working with the non-profit organization Atlas of Caregiving, I explored the feasibility of integrating methods of ethnographic futures research into a suite of pen-and-paper tools that guide individuals in the act of visualizing care in their everyday lives. As a result, I developed a visual activity called "Re-Authoring your Care Future," which guides participants in visualizing and depicting their futures in the context of care. I also created a video series to teach the activity and demonstrate the application of the organization's tools in a virtual context. In this article, I illustrate how methods of applied anthropology can contribute to the design process by exploring the potential of combining visual ethnography, ethnographic futures research, and the anthropology of care to facilitate envisioning and designing future care systems. Further, I reflect on the importance of understanding not only the current state of caregiving but also envisioning its possible futures.

Keywords: Care, Visualization, Ethnographic Futures Research, Visual Ethnography

Addressing Organizational Needs

Atlas of Caregiving is a non-profit organization that focuses on understanding the experiences and needs of family caregivers. They use innovative research methods to gain a deeper understanding of the caregiving experience and have created a set of six pen-and-paper "care tools" to guide people in visualizing and depicting different aspects of care in their lives (see Figure 2.1. Atlas "Care Tools"). The organization seeks to support individuals as everyday caregivers and foster a culture of care by providing tools, resources, and educational programs to individuals and communities, to empower people to better care for themselves and others. Their flagship tool, the Atlas "CareMap," is a tool for visualizing and documenting one's "care ecosystem" (Mehta and Williams 2021). Individuals use the CareMap to create a visual diagram of their interconnected network of care relationships, support systems, and interactions in daily life. Creating this diagram of their personal care ecosystem can help them plan for potential difficulties, manage the many people involved, and identify missing people and services (Mehta and Williams 2021).

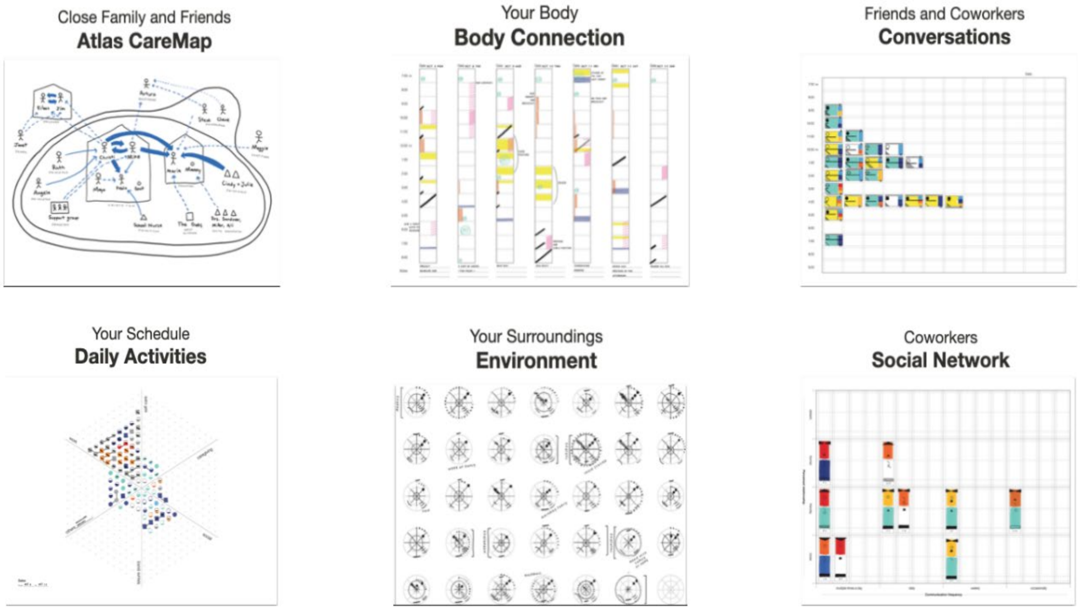


Figure 2.1. Atlas "Care Tools" (Courtesy of Atlas of Caregiving).

In February of 2020, Atlas of Caregiving began their yearlong We All Care Initiative (WACI). Collaborating with eleven organizations across Michigan, they hosted multiple in-person workshops through their Mapping Ourselves program to teach two hundred participants how to use each of their six tools centered around the CareMap. However, in response to COVID-19 lockdown restrictions, implemented in March 2020, Atlas of

Caregiving transitioned their workshops to a virtual format, hosting workshops online. Doing so enabled participants to complete the program from home safely.

I worked with Rajiv Mehta, co-creator of Atlas of Caregiving, after the completion of the virtual sessions in May of 2021. As a result of the (WACI) initiative, the organization found that their care tools have broad application to a diverse population of people in regular caretaking and caregiving environments (Mehta and Williams 2021, 41). One of the major benefits in-person workshop participants experienced was a sense of "collective self-reflection," where sharing and reflecting in a group setting deepened learning and strengthened community bonds (Mehta and Williams 2021, 39). Nevertheless, in a virtual context, participants' care experiences are no longer physically co-located. Transitioning their in-person workshops online during COVID-19 brought to Rajiv's attention a need to further explore the organization's application in a virtual environment and enhance the tools for users to take actionable steps to improve their care ecosystems beyond their workshops. To do this, Rajiv needed to reveal the thought processes of the CareMap creators.

Working with Rajiv to address Atlas of Caregiving's organizational needs, I proposed to develop and evaluate a new care tool for the organization that introduced methods of ethnographic futures research into the Mapping Ourselves program. The purpose of my study was to clarify the process of introspection for participants learning to visualize care and explore what we could learn from applying the tools in a virtual setting. I suggested that incorporating speculative and anticipatory methods into the visual tools developed by the organization might enhance participants' comprehension of the intricate nature of care, and facilitate the development of more comprehensive solutions that reflect the lived experiences and needs of the care recipients. Further, I offered to create informational videos to communicate activities and lessons online.

Integrating the Activity

I worked with a cohort of medical anthropology students at San José State University (SJSU) during the Fall 2021 semester to create and test my prototype, a pen-and-paper worksheet I called "Auto-ethnographic Futures." My experience with the students took place in a hybrid virtual context, with classes both in-person and online. Working with both Mehta and my graduate advisor Dr. Jan English-Lueck, I integrated my prototype into a larger curriculum focused on mapping and visualizing care using the CareMap. Both the Mapping Ourselves program and the anthropological theories surrounding the study of care informed our curriculum, which I later used to shape my virtual workshop with the next group I would work with.

In the curriculum, I guided participants through an iterative process where they created an initial CareMap 1.0, learned more about care through a biocultural perspective, made revisions to their CareMap, and created a final CareMap 2.0. This approach enabled us to better integrate my activity with other tools and methods used by the organization, enhancing its overall impact. Following this experience, I re-designed my activity using a flipped classroom model and began developing informational videos to support it. In Figure 2.2. I provide screenshots from my videos teaching the content and a participant user journey map of when I introduced each video, hosted a discussion, and when completed activities were shared in a virtual group setting.

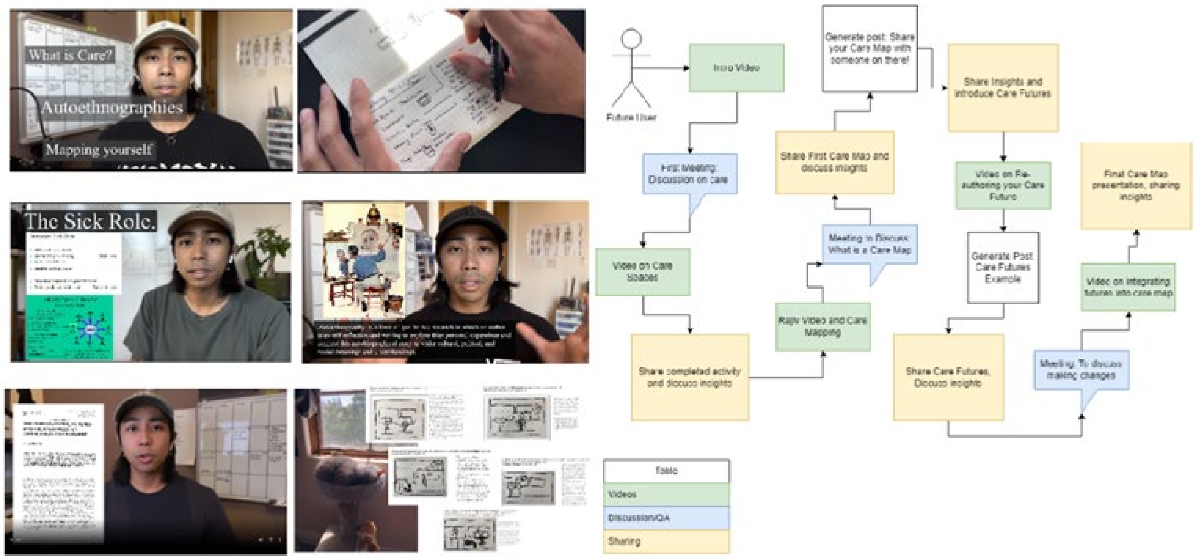


Figure 2.2. Screen capture of instructional videos (left) and future user journey map based on my virtual workshop with the Rug Council (right).

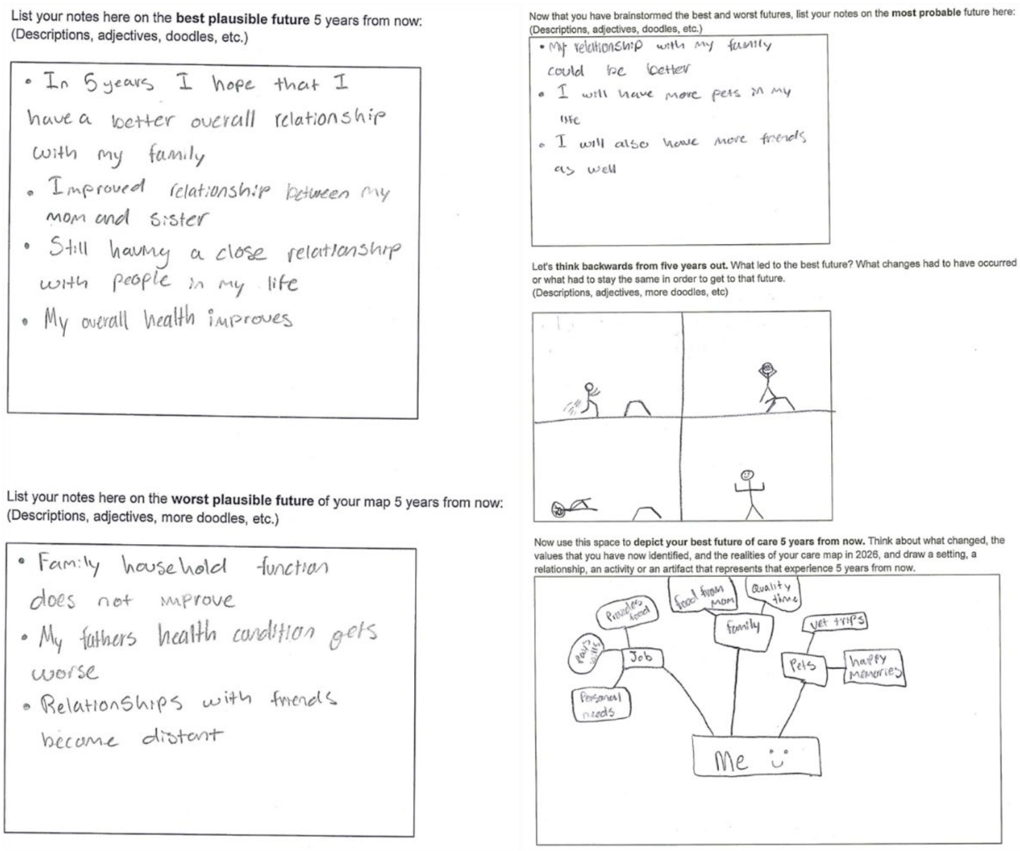
I re-introduced my activity as a virtual workshop to an online Discord community of Silicon Valley working professionals and their ancillary networks, known as the "Rug Council." A name shortened by members referring to themselves as the "Rugs." In September of 2022, the Rugs and I organized a regular meeting schedule to learn about the organization's care tools, my future tool, and share our experiences.

Collaborating with members of the Rugs community using Discord, I used videos to communicate lessons. Sharing videos over the Discord platform, I condensed and contextualized our curriculum to provide participants with more flexibility and more time to engage in virtual discussions. In December 2022, my virtual workshop was completed and I presented my findings to Mehta in early 2023. Over the course of my work, I created a condensed virtual curriculum using the videos and developed a mockup of my activity in-line with the organization's style guide.

Designing and Re-Authoring My activity

To design my prototype, I used the anthropological theories surrounding care systems and the potential for visualization and ethnographic futures to deepen our understanding of them. According to Mol (2008), visualizing our futures in the context of care can help us move away from crisis-oriented approaches to social and environmental challenges. To this end, I drew inspiration from Robert B. Textor's Ethnographic Futures Research (EFR) methodology to develop the prompts in my activity. EFR is an interviewing methodology that aims to elicit from interviewees their perceptions and preferences among possible and probable alternative futures for society and culture (Textor 1995).

Teaching participants to act as autoethnographers collecting data on their CareMaps, I adapted this methodology into my activity to help them elicit personal insights on their care ecosystems. The activity I created guides participants, using a CareMap, to develop a set of future scenarios based on their best, worst, and most plausible care future. Further, it instructs participants in the act of self-reflecting on what led to their best future. After developing these scenarios, I instructed participants to re-depict their best future. In Figure 2.3. I provide a student’s completed worksheet from my initial prototype.



List your notes here on the **best plausible future** 5 years from now:
(Descriptions, adjectives, doodles, etc.)

- In 5 years I hope that I have a better overall relationship with my family
- Improved relationship between my mom and sister
- Still having a close relationship with people in my life
- My overall health improves

List your notes here on the **worst plausible future** of your map 5 years from now:
(Descriptions, adjectives, more doodles, etc.)

- Family household function does not improve
- My fathers health condition gets worse
- Relationships with friends become distant

Now that you have brainstormed the best and worst futures, list your notes on the **most probable** future here:
(Descriptions, adjectives, doodles, etc.)

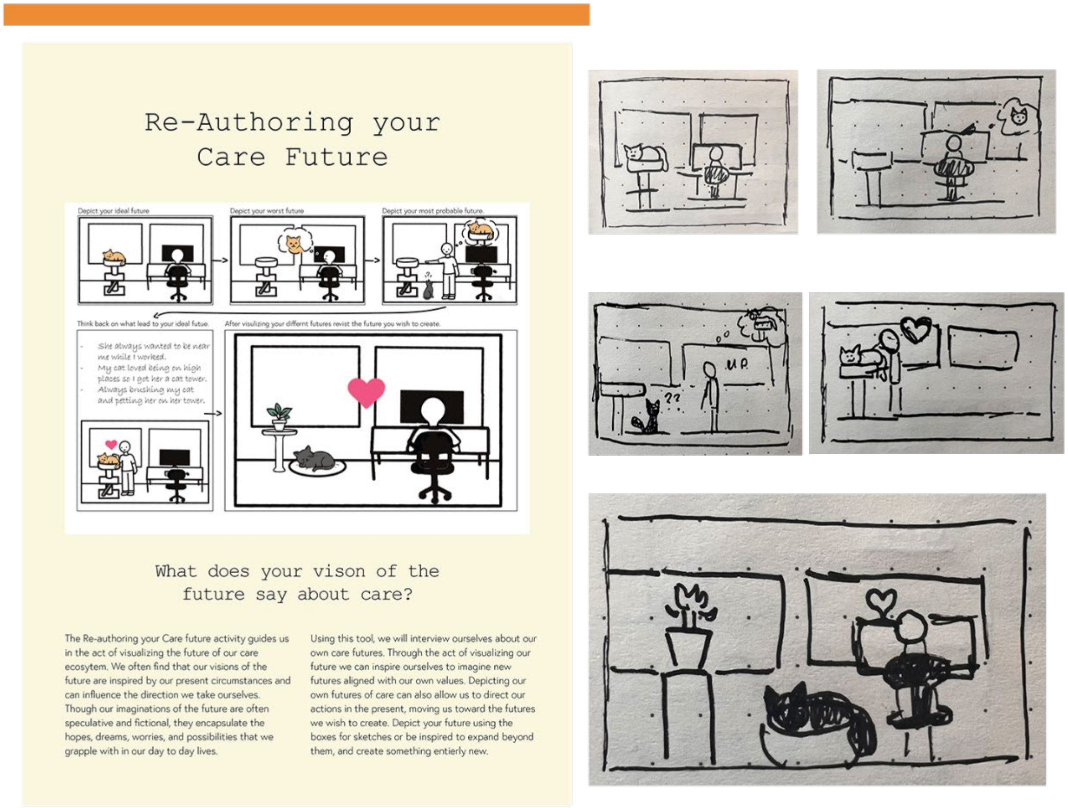
- My relationship with my family could be better
- I will have more pets in my life
- I will also have more friends as well

Let's **think backwards from five years out.** What led to the best future? What changes had to have occurred or what had to stay the same in order to get to that future.
(Descriptions, adjectives, more doodles, etc)

Now use this space to **depict your best future of care 5 years from now.** Think about what changed, the values that you have now identified, and the realities of your care map in 2026, and draw a setting, a relationship, an activity or an artifact that represents that experience 5 years from now.

Figure 2.3. Protoype of original worksheet completed by a student.

I used a range of methods to gather data, including conducting semi-structured interviews with participants, analyzing their completed care activities, and comparing experiences between hybrid and virtual contexts to inform the design of my activity. I also reflected on the study results to identify areas for improvement and inform future iterations of my activity. Throughout my study, I conducted a total of 11 exit interviews with participants (6: medical anthropology students, 5: Discord "Rugs"), analyzed the data collected from completed activities to reveal their distinct experiences with the tools, and presented my video series to Atlas of Caregiving and the completed design of the Re-Authoring your Care Future activity (see Figure 2.4. Re-Authoring your Care Future Mockup).



Re-Authoring your
Care Future

Depict your ideal future

Depict your worst future

Depict your most probable future.

Think back on what lead to your ideal futue.

- She always wanted to be near me while I worked.
- My cat loved being on high places so I got her a cat tower.
- Always brushing my cat and petting her on her tower.

After visulizing your differnt futures revist the future you wish to create.

What does your vison of the
future say about care?

The Re-authoring your Care future activity guides us in the act of visualizing the future of our care ecosytem. We often find that our visions of the future are inspired by our present circumstances and can influence the direction we take ourselves. Though our imaginations of the future are often speculative and fictional, they encapsulate the hopes, dreams, worries, and possibilities that we grapple with in our day to day lives.

Using this tool, we will interview ourselves about our own care futures. Through the act of visualizing our future we can inspire ourselves to imagine new futures aligned with our own values. Depicting our own futures of care can also allow us to direct our actions in the present, moving us toward the futures we wish to create. Depict your future using the boxes for sketches or be inspired to expand beyond them, and create something entierly new.

Figure 2.4. Re-Authoring your Care Future Mockup (left) and original sketches from my field journal (right).

Listening through Creating Videos

Listening to the experiences of the participants involved in my study informed each iteration in designing my activity. As an applied anthropologist, I have found that utilizing both ethnographic and design thinking approaches are an effective way to address complex user needs. According to prominent medical anthropologist Arthur Kleinman (2019), actively engaging with patients and their families in their everyday lives is essential for providing effective care. Further, Johnston (2002) asserts that by engaging with the complexities of user needs through visual methods, researchers and designers can develop more complete pictures of user-centered design, customer-focused products and services, and customer behavioral patterns. By considering the role of individual reflection in the existing tools created by Atlas of Caregiving, I aimed to empower participants to better understand the complexities of care practices and plan for more responsive and inclusive care systems.

Following my experience with the medical anthropology students and consideration to make the care curriculum more engaging and accessible in a virtual format for the Rugs and future stakeholders interested in learning about Atlas of Caregiving's tools, my original worksheet expanded into a video series. I used the videos to help demystify my research methods and worked closely with the organization and participants to create my activity. The videos I created and the visual data I collected not only contextualize the care tools for others; they also highlight the evolution of the design process behind Re-Authoring your Care Future. I used hours of recorded interviews, meetings, and voices from our interactions to learn how participants articulated their language of care. The following section details the major challenges and insights gained from my experience collaborating with individuals to rewrite their personal narratives focusing on their care futures.

From Complexity to Diversity

In my interviews, I asked participants to reflect on the changes between their first and final CareMaps. Participants often commented on their initial struggles to identify the essential elements of their care experiences. As a result, participants shared that their initial CareMaps were incomplete and insufficient portrayals of their care ecosystems. For example, Ethan, a medical anthropology student, and public health major, explained that with his first CareMap, he wished he had included more descriptive details about his relationships and goals with the people in his care ecosystem. Ethan explained that "I think it would have been better if I added something more. Just in a descriptive kind of way, like a sentence or a part describing how this person affects my life or a goal that I have with this person." In a subsequent interview, I spoke with Rug Council member RiverReeler, who expressed dissatisfaction with his first CareMap, saying, "...it was quick, as you could see. It was a quicker CareMap compared to the final one, and it was just more direct routes of connections that I have. There were just people; there weren't any activities or anything like that." Many participants shared similar viewpoints, emphasizing the need for a deeper understanding of care to develop a comprehensive and meaningful visual representation of their care ecosystem.

By the time participants had created their final CareMaps, they had found a new language with which to think about and communicate care with others. Participants found my future-focused activity an essential part of the care curriculum that allowed them to reflect on their care experiences and unravel the complexity of their care networks. Devoid, a founding member of the Rug Council, stated that the future prompts helped him untangle the complexity of care through "getting everything off [his] mind" and focusing on what he "actually" cares about. He explained:

> "So much of this is just getting everything off of your mind. Because you start off and you have like a million kinds of thoughts bouncing around and then you're like, 'Okay,' you write one down at a time until eventually you're like this is literally everything I can think of…it kind of forced me to ask myself what's all the stuff I actually...like I actually care about. What's all the stuff that [matters], when I think of what a good future looks like."

Much like Devoid, participants used my futures activity in conjunction with their CareMaps to gain clarity on their personal values and priorities. By encouraging participants to consider not only their current relationships but also the potential impacts of these relationships on their future aspirations and goals, my activity helped them discover important care connections they wanted to depict, maintain or strengthen. For example, Chris, a medical anthropology student and anthropology major, found that the activity helped him uncover deeper layers to his care relationships and see important details he might have otherwise overlooked, stating:

> "I think it does help you see some of those, like, think about those details. So, when you go back and forth between the CareMap and the futures activity, you can start to see more layers of like, oh, maybe I need to make this relationship better because this mentorship might help me with this thing in my future or whatnot."

Interviewing participants about their experience in our activities, I found that the Re-Authoring your Care Future activity helped participants untangle what care meant to them and gain a more nuanced understanding of their own care needs and values. Participants began envisioning a future where their care ecosystems met their individual needs and they had access to the support they desired. From creating their initial CareMaps to the time of our interviews, participants began to take concrete steps towards achieving the futures they depicted in their activities. My participants' experiences demonstrate the potential for my future-focused activity to facilitate a more reflective and user-friendly approach to visualizing and depicting care relationships. The prompts in my activity allowed participants to express gratitude for what they had depicted, feeling more comfortable in their abilities to anticipate and adapt to changes.

RiverReeler later expressed satisfaction with his second CareMap, explaining how visualizing his care future allowed him to “dig deeper into [his] connections” and “expand” on his ideas more:

> "And then when I swapped over to the newer one [CareMap 2.0] I started to expand on that idea more and just like...what people and activities matter to me, and how far that web can go, if you allow it to, and how... maybe these might have come up first on the first draft if I would nurture these more than I have been doing in the past. So, the second revision just definitely felt better…just trying to dig deeper into the connections that I have."

Like others, RiverReeler expressed enthusiasm with mapping and visualizing his care system and a desire for personal growth. Based on the experiences of my participants, these statements encapsulate the major themes that I extracted from participants' feedback on my activity. Overall, participants found my future-focused activity to be a valuable addition to the program, helping them to expand their initial CareMap, reflect on their values surrounding care, and see more layers of their social and emotional networks. Yet, the future isn't always expansive, and we must take careful consideration of how new designs and technologies can influence how humans communicate. Although my participants had access to the tools and technologies that allowed them to interact in digital environments, I quickly learned that there are still new hurdles to consider.

"You Can't Cry Online"

From our conversations and completed activities, it was clear that the participants in my study were well acquainted with a variety of digital communication technologies. They often commented on how digital communication allowed them to cultivate and maintain important care relationships in their lives. Further, many depicted the use of a variety of digital technologies to strengthen or maintain their care relationships. For example, when I interviewed Maya, a sophomore and medical anthropology student, she expressed how the music streaming app Spotify had been something she had included on both her CareMaps. She commented on how students like her really "value music" and often use digital technologies like Spotify playlists and TikTok “to tell a story.” Similarly, when I asked Manny, a sophomore and medical anthropology student, about an important care relationship he depicted on both his CareMaps, Manny explained that although they “couldn't even see each other's faces or really get a feel for each other's person,” communicating through Zoom and Snapchat had allowed his “friend [to remain] on [their] second CareMap.”

Conversely, I also found that digital communication posed constraints different from face-to-face encounters. In my interviews and virtual workshop, participants noted that expressing and receiving emotional support through virtual settings presented a unique set of challenges to consider. Asking Devoid about why the Rug Council had a separate channel called “Serious Chat” commented on the necessity of conveying a shared sense of seriousness online, stating that:

> “Yeah, it's...it's hard like, you can't...I mean, to say it simply, you know, you can't, you can't cry online, right? Like, there's just ...there's so much that goes into real-life communication that is just cut off. And so like, not everyone has the ability to eloquently express, like, difficult emotions, especially while you're feeling them. It's even harder.”

As Devoid insightfully observed, 'you can't cry online'. Devoid’s words brought to my attention the difficulty of fully conveying emotions virtual context. While participants used digital communication technologies to build and maintain caring relationships, the limits of virtual communication can also lead to a sense of frustration and disconnection, as the full depth of one's feelings cannot always be effectively communicated or received online. What this issue requires is better attention paid to not only how we communicate over virtual space, but how we design new technologies to do so.

Conclusion

As demand for care services continues to increase, it is crucial to design future care systems with creativity and foresight. My work with Atlas of Caregiving demonstrated the importance of engaging with stakeholders to co-create tools and approaches tailored to their specific contexts and concerns. The findings of my study presented herein demonstrates the significance of Re-Authoring Your Care Future, which Mehta found to be a valuable asset to Atlas of Caregiving. The positive reception of my activity has led to its inclusion in the organization's larger curriculum, indicating its potential as an effective tool for facilitating the envisioning and designing of new and diverse care experiences. Furthermore, the incorporation of flipped content videos in my study prompted the organization to reevaluate its approach to communicating its tools in a virtual setting.

The task of mapping and visualizing care is complex, yet essential for understanding the intricate networks of relationships, responsibilities, and emotions that shape the experience of care. In my study, I highlighted the importance of engaging with stakeholders, employing novel approaches, and co-creating tailored solutions to foster diverse and inclusive care experiences. Conducting an applied anthropological approach to user research provided me with the flexibility to engage with the diversity of participants' individual care needs and values, offering me key insights into their everyday lived experiences. Designing Re-authoring your Care Future and the accompanying videos demonstrated the potential of combining visual ethnography and ethnographic futures research to facilitate more inclusive and empathetic future care systems. This approach highlights the importance of employing innovative methods to address the challenges of caregiving in a constantly evolving technological landscape.

Biography

Patrick R. Padiernos (padiernospatrick@gmail.com). MA in Applied Anthropology from San José State University. He is a visual anthropologist who specializes in creating ethnographic films and uses mixed media to document different cultural contexts. Focusing on exploring how individuals and communities imagine and plan for the future, his primary areas of interest are the study of care systems, including how individuals navigate and envision complex healthcare and caregiving environments.

CHAPTER THREE

RE-AUTHORING YOUR CARE FUTURE AND THE FUTURE OPPORTUNITIES

The Re-Authoring your Care Future activity began as a pen-and-paper worksheet, but through each iteration transformed into a collaborative space for participants to imagine and share their diverse experiences of care with others. In my study, I learned that participants view services, such as the programs offered by Atlas of Caregiving, as more than their material embodiment, and involve the experience of both providers and recipients. As Blomberg and Darrah (2015) reason, it is not the service itself that I designed, but instead, I worked on improving the conditions for reflection. In designing activities like Re-Authoring your Care Future, the focus is not solely on the service as a standalone entity. Instead, the focus is on the broader context in which the service will operate.

Design researchers need to consider the desires, constraints, and experiences of users, as well as the organizational and social structures that support a service. Additionally, they need to take into account the cultural, economic, and political factors that shape the service and its outcomes. By considering these various factors, the design process can better ensure that a service is well-suited to the specific context in which it will operate and it will effectively meet the needs of its users.

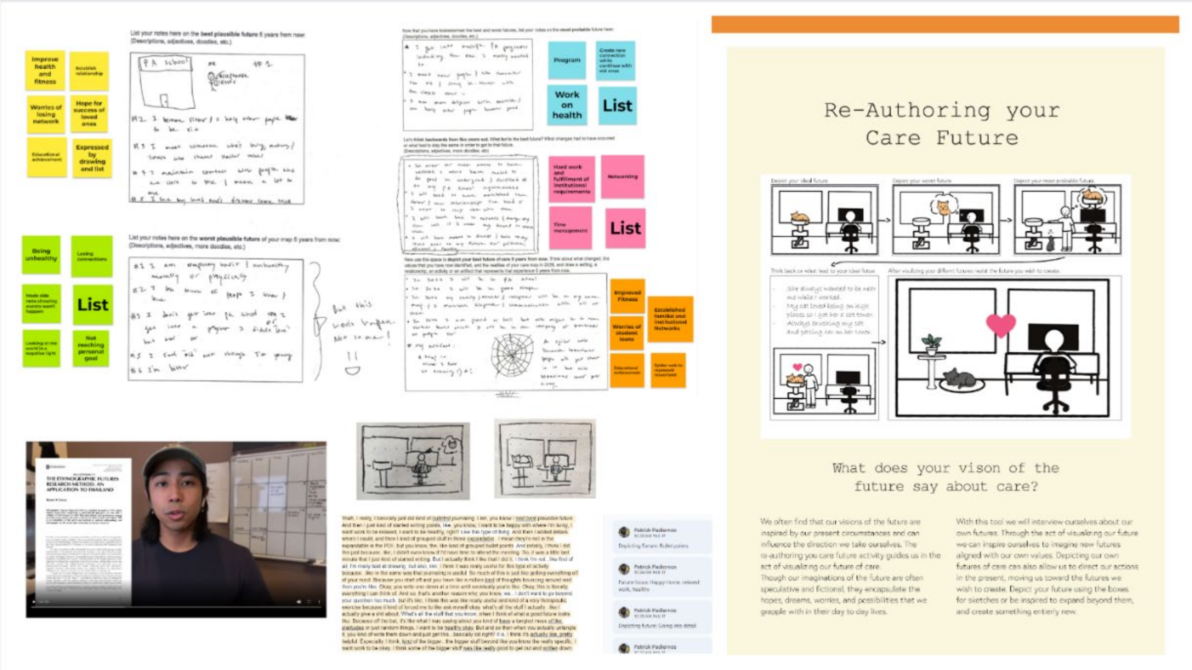
Exploring Visual Data and Creating Videos

As Pink (2007) argues in her overview of visual ethnography as a research methodology, visual methods can capture embodied aspects of lived experience that are often challenging to articulate in words alone. Graphics, that is, drawings and images, are a different form of expressive culture that can communicate emotions and values. Words are not the only medium that can be analyzed (Kimball 2009). I integrated visual depictions into my activity to enhance Textor's approach, enabling participants to envision complex sociocultural futures related to care. Doing so led to a more nuanced and comprehensive understanding of the topic. Additionally, using visual data and thematic analysis in my project provided a valuable tool for generating new insights, promoting collaboration, and enhancing virtual communication in my study.

Creating the Video Series

As part of my final design, I created four instructional videos to communicate information in a virtual workshop. Following the completion of my virtual workshop, I created a separate video highlighting my own inspirations behind this project to generate further interest in my work as well as the work of Atlas of Caregiving (see Appendix B). I decided to create my videos for Atlas of Caregiving because they offered my research a few particularly useful things. The first was to provide a tangible product for the organization to use to communicate content more effectively over virtual space. The other two benefits I gained was a secondary tool to analyze the data I collected and a tool for reflecting on my own involvement in the project.

I used the act of creating the video content as a secondary form of visual analysis. This deeper analysis allowed me to better understand the key concepts and themes being conveyed in my videos and develop a more nuanced and effective approach to using the videos in a virtual setting. Additionally, I was able to tailor the content to my participants' specific needs and interests, creating a more personalized and engaging learning experience. Later in the chapter, I go into more detail on how creating the videos allowed me to engage in the process of reflexivity and outline my recommendations to ensure responsible and respectful use of visual data. In Figure 3.1. below I provide some examples of the various visual and textual elements that informed my project. This collage shows only a fraction of the visual and textual data I collected and analyzed during my project and serves to showcase the diversity in which both types can be used to inform the design process.



We often find that our visions of the future are inspired by our present circumstances and can influence the direction we take ourselves. The re-authoring you care future activity guides us in the act of visualizing our future of care. Though our imaginations of the future are often speculative and fictional, they encapsulate the hopes, dreams, worries, and possibilities that we grapple with in their day to day lives.

With this tool we will interview ourselves about our own futures. Through the act of visualizing our future we can inspire ourselves to imagine new futures aligned with our own values. Depicting our own futures of care can also allow us to direct our actions in the present, moving us toward the futures we wish to create. Depict your future using the boxes for sketches or be inspired to expand beyond them, and create something entirely new.

Figure 3.1. Collage of visual and textual elements involved in my design process.

The visual data I collected played a significant role in my project, encompassing visual depictions in participants' activities, recorded meetings, and the video content I created. To analyze my data, I used a thematic analysis approach to identify recurring themes and patterns from completed activities, recorded meetings, and transcribed interviews (Harding 2013). The visual data ultimately served a dual purpose as both a catalyst for generating insights and as a mediator for facilitating communication and collaboration between myself and the study participants. Using the insights I gained from my analysis, I made modifications to my research tool and developed my videos. Further, by using a visual language, both myself and the participants were able to share and communicate our experiences through a more diverse medium, fostering a community of practice and a deeper level of engagement.

The design process, in this sense, is not only concerned with creating a functional service but also with creating an environment that fosters desired outcomes. As such, the activity I designed entails an active and intentional process of reimagining and reshaping the possibilities and meanings of care through the lens of personal narratives and social relationships, challenging dominant discourses and power structures that often constrain and marginalize caregivers, and forging new paths of care that are grounded in empowerment, resilience, and community support. In the next section, I reflect on key challenges my study uncovered and provide recommendations for future research for the organization

Challenges and Recommendations

By applying an anthropological approach to design Re-Authoring your Care Future, I gained the flexibility to address the complex and diverse needs of both individual and organizational stakeholders. I highlighted the potential of incorporating ethnographic futures research methods into the organization's toolkit by utilizing the unique experiences of the individuals involved. Not only did I realize the need for designing new interventions and tools to address the broader challenges of caregiving, but I also learned about the importance of listening to and documenting individual care needs to inform these interventions. In the following section, I will outline some of the challenges faced by those I worked with regarding the stigmas surrounding care, as well as the opportunities for the organization to address them to inform future interventions and tool design. I end with my reflection on creating videos as form of visual analysis and provide my recommendations for responsible and respectful use of visual methods.

Stigma of Vulnerability in Caregiving

> "You know, you just take it right? And you don't mention anything to anyone. But I think for me, personally, what ended up happening was you hunker down, and you just keep getting beat by work, by your parents, by COVID. By this and that, and what happened was like, I started going through depression, like real diagnosable depression, not just like, low-grade mild depression that goes away after a bit. But chronic, like, depression that I ended up going to a psychiatrist for. I think for me, that's different, like really different. I think it sounds a little weird when I say it out loud. But inwardly, I had this attitude, like I don't really need my friends to pour on, because I don't want to be weak. But it turns out, I was the weak one. Not able to take care of myself."

This description comes from Bluefin, a 27-year-old programmer and former Twitch streamer from the Rug Council Discord community. I had asked Bluefin what his experience visualizing and mapping care was like, and to think about some of the insights he gained. While conducting our care activities virtually presented its own set of challenges and barriers, as I stated in Chapter Two, these challenges and barriers reflected the larger everyday social, environmental, and individual challenges faced by participants within the context of care. Bluefin's description provided me with a reflection on the multiple barriers that can impede one's ability to cope with everyday care experiences. His statement highlights the tendency to internalize stress and prioritize stoicism, often to the detriment of one's mental health. Bluefin's experience of depression is indicative of a broader issue of the emotional toll of caregiving, particularly in the context of a global pandemic. Moreover, his reluctance to seek social support underscores the stigma surrounding vulnerability and the societal expectation of self-reliance.

It’s important to note that Bluefin's experience is one narrative. However, his testimony offered me a poignant reminder of the human toll of navigating these complex systems and the need for greater social support for those who provide and receive care. Although our activities provided participants with the space and tools to share their experiences, Bluefin's experience highlighted the emotional toll of caregiving and the stigma surrounding vulnerability, as well as the societal expectation of self-reliance. His testimony reminds us of the need for greater social support for those who provide and receive care in the context of complex systems, particularly during and after a global pandemic. As Atlas of Caregiving continues their research on providing beneficial and accessible care tools, it is important for future anthropologist and designers in the field of care to work towards destigmatizing vulnerability. Researchers and service providers can achieve this objective through continued inquiry and collaborations that actively considers the emotional toll of caregiving and the stigma surrounding vulnerability, as well as the societal expectation of self-reliance.

Untangling the Complexity of Care: Insights and Recommendations

I found that the Re-authoring your Care Futures activity provided participants with a means to untangle the complexity of care in their lives. Nevertheless, I also learned that with the diversity of individual care experiences comes a greater diversity of care needs. Although I found success applying the tools created by Atlas of Caregiving and received a positive reception on my own tools, convenience and voluntary participation limited the diversity of my groups. It's important to note that the experiences of the two groups I worked with only represent a fraction of the complex and diverse care experiences of individuals. Researchers need to do more work to document the diverse care needs and experiences of people in different contexts.

As an anthropologist, I found that creating videos featuring myself allowed me to engage in a process of reflexivity. Through the creation and analysis of my videos, I was able to reflect on my own biases, assumptions, and positionality as a researcher, which ultimately led to a deeper understanding of the research process and the experiences of my participants. By critically examining my own role in the research process, I was able to develop a more nuanced and self-aware approach to my work, which allowed me to better account for my own perspectives and biases and to more effectively engage with my participants. This process of reflexivity was essential to my research, as it allowed me to approach my work in a more thoughtful and critical way, ultimately leading to more meaningful and insightful research outcomes.

I wanted to carry this process of reflexivity over into my activity and the videos I created. My aim was to provide the necessary tools to help individuals better articulate their own experiences of care, so that they could have a deeper grasp of their own care needs. To achieve this, I emphasized teaching participants to act as autoethnographers of their own care ecosystems. In doing so, I instructed individuals to critically reflect on their personal experiences within a larger care system, explore the cultural and social factors that shape these experiences, and document their observations through the use of autoethnographic methods. Incorporating autoethnography into my videos and activity provided participants with a space to share their own stories and perspectives on care.

Though the data I collected came from two unique groups, I witnessed an observable diversity and depth of experiences represented. In a recorded discussion following the medical anthropology student's final presentations on their completed CareMaps, Rajiv reflected on and expressed admiration for the diversity participants had depicted saying, "I'm impressed and pleased to see the kind of creativity that people showed in their CareMaps and really changing them to the things that were important to them. I loved many of those ideas. Someday there should be a booklet of: Different ways that you can share your CareMap."

By teaching participants to approach their care systems from an anthropological perspective and reflect on their own positionality within these systems, we can gain a more nuanced understanding of the challenges and opportunities involved in caregiving. More importantly, teaching participants to be reflexive of their own personal care ecosystem can help to increase the diversity and depth of experiences represented and build a sense of community and solidarity among participants. As researchers continue to apply visual methods in their work, I developed a series of steps based on my experience for adapting traditional research methods to ensure responsible and respectful use of visual methods for both anthropologist as well as anyone interested in conducting similar work (see Table 3.1).

Table 3.1. Steps for Adapting Traditional Research Methods to ensure Responsible and Respectful use of Visual Methods

Obtain informed consent from participants	• Explain the purpose of the research • Explain the methods involved • Explain how the data will be used • Inform participants of their right to withdraw from the study at any time
Protect anonymity and confidentiality of participants	• Remove any identifying information from data • Ensure data is stored securely
Be reflexive in approach	• Acknowledge positionality, biases, and potential power dynamics in research process • Reflect on own identity and how it may affect research • Reflect on how presence and actions may affect participants
Adopt a collaborative approach	• Involve participants in research process • Co-create research questions, methods, and outputs • Provide feedback to participants on research findings
Be sensitive to cultural differences	• Avoid imposing own cultural values or assumptions on participants • Acknowledge diversity of experiences and perspectives • Ensure research is conducted in culturally appropriate and respectful manner

As seen in Table 3.1. above, as Atlas of Caregiving continues to work with diverse groups of people in a variety of caregiving environments, it is crucial that the organization continues to recognize the diversity of individual care experiences and the complexity of care needs in order to provide more comprehensive support and resources. I recommend that Atlas of Caregiving prioritizes the documentation of underrepresented individuals and communities' experiences, while also incorporating goals and descriptions that are more detailed in their CareMaps to capture the complexity of care ecosystems. This will help create a more comprehensive understanding of care experiences and provide the necessary support and resources to those who provide and receive care. We can create more inclusive and meaningful approaches to caregiving that serve the diverse needs of individuals and communities by centering the voices of care recipients and providers, engaging with them reflexively and collaboratively.

APPENDIX A

Below I provide the set-up questions and prompts I used in my activity design inspired by Robert Textor's (1995) Ethnographic Futures Research (EFR) methodology. This format can be used by future researchers and designers interested in conducting similar work.

Set-up	Prompts/Procedure
1. Look at your care map. 2. Identify areas of change and potential change. 3. Use each square below to brainstorm and explore different plausible futures by taking notes about your care maps on experiences, settings, relationships, activities or artifacts. 4. Think about your relationships--the characters, the spaces, resources and feelings that characterize them. Ask yourself how these elements might be used to create a scene that depicts a likely experience of care on your map 5 years from now. 5. The last square asks you to capture your idea and to draw a scene about your experience of care 5 years into the future.	Use drawings, descriptions, adjectives, doodles, stories etc. to… • List or depict your thoughts on the **best plausible future** 5 years from now. • List or depict the **worst plausible future** of your map 5 years from now. • Now that you have brainstormed the best and worst futures, list or depict your notes on the **most probable** future. • Let's **think backwards from five years out.** What led to the best future? What changes had to have occurred or what had to stay the same in order to get to that future. List or depict your retrospective. • Now use this space to **depict your best future of care 5 years from now.** Think about what changed, the values that you have now identified, and the realities of your care map in 2026, and draw a setting, a relationship, an activity or an artifact that represents that experience 5 years from now.

APPENDIX B

Project Links

Care Futures Video series:

https://youtube.com/playlist?list=PLpTG__YvE2OYvduo-3umDjgmsf8EBALaS

Atlas of Caregiving Links

Atlas of Caregiving Website:

https://atlasofcaregiving.com/

We All Care Initiative Final Report:

http://bit.ly/WACI_Report

Mapping Ourselves Workbook:

https://atlasofcaregiving.com/wp-content/uploads/2015/05/Mapping-Ourselves-book.pdf

CUMULATIVE REFERENCES

Appadurai, Arjun. 2013. *The Future as Cultural Fact: Essays on the Global Condition*. New York: Verso Books.

Blomberg, Jeanette and Chuck Darrah. 2015. *An Anthropology of Services: Toward a Practice Approach to Designing Services*. San Rafael: Morgan and Claypool.

English-Lueck, J. A., Sam Ladner, and Jamie Sherman. 2021. "Little Dramas Everywhere: Using Ethnography to Anticipate the Future." *Ethnographic Praxis in Industry Conference Proceedings* 2021(1):7-14. https://doi.org/10.1111/epic.12051

Fox, Elizabeth. 2015. “Making Cashmere, Making Futures: The Work of Hope and the Materialization of Dreams in a Mongolian Cashmere Factory.” *Inner Asia* 17(1):77-99. https://doi.org/10.1163/22105018-12340034

Harding, Jamie. 2013. *Qualitative data analysis from start to finish*. London: Sage.

Jenson, Jennifer, and Suzanne de Castell. 2010. “Gender, Simulation, and Gaming: Research Review and Redirections.” *Simulation & Gaming* 41(1):51-71. https://doi.org/10.1177/1046878109353473

Johnston, Gavin. 2002. “Video, Ethnography, and the Corporate Environment: Adapting Methods of Data Collection and Presentation (or Convincing the Corporate Monster Not to Eat You).” *Practicing Anthropology* 24(4):40–42. https://doi.org/10.17730/praa.24.4.j75421x487362887

Kimball, Lucy. 2009. “Reassembling the visual.” *Ethnographic Praxis in Industry Conference Proceedings* 2008(1):316-324. https://doi-org.libaccess.sjlibrary.org/10.1111/j.1559-8918.2008.tb00115.x

Kleinman, Arthur. 2019. *The Soul of Care: The Moral Education of a Husband and a Doctor*. New York: Viking.

Lerman Ginzburg, Shir and Stephen Schensul. 2023. “Problems Faced During the Beginning of the COVID-19 Pandemic.” *Practicing Anthropology* 45(1):23–27. https://doi.org/10.17730/0888-4552.45.1.23

McKearney, Patrick. 2020. “Challenging Care: Professionally Not Knowing What Good Care Is.” *Anthropology and Humanism* 45(2):223-232. https://doi-org.libaccess.sjlibrary.org/10.1111/anhu.12302.

Mehta, Rajiv. 2019. *Seeing the Invisible: Strengthening Your Care Ecosystem with Atlas CareMaps*. Palo Alto: Atlas of Caregiving. Accessed October 28, 2021. https://atlasofcaregiving.com/wp-content/uploads/2015/05/Seeing-the-Invisible-v1.pdf

Mehta, Rajiv, and Susan Williams. 2021. *Tools for Life: An Exploration on the Value of Personal Science for Care, Wellbeing, and Community in Michigan.* Palo Alto: Atlas of Caregiving. Accessed October 28, 2021. http://bit.ly/WACI_Report

Mika, Marie and Arvind Venkataramani. 2021. "Designing Virtual Primary Care: Desire or Dread? How Structural Forces Shape the Anticipation of Futures." *Ethnographic Praxis in Industry Conference Proceedings* 2021(1):91-107. https://doi.org/10.1111/epic.12059

Miric, Milan, Pai-Ling Yin, and Daniel C. Fehder. 2023. "Population-Level Evidence of the Gender Gap in Technology Entrepreneurship." *Strategy Scien*ce 8(1):62-84. https://doi.org/10.1287/stsc.2022.0170.

Mody, Perveez. 2020. "Care and Resistance." *Anthropology and Humanism* 45(2):194-201. https://doi-org.libaccess.sjlibrary.org/10.1111/anhu.12301.

Mol, Annemarie. 2008. *The Logic of Care: Health and the Problem of Patient Choice.* New York: Routledge.

Nafus, Dawn. 2016. *Quantified: Biosensing Technologies in Everyday Life.* Massachusetts: MIT Press.

Pink, Sarah. 2007. *Doing Visual Ethnography*. London: Sage.

--- 2014. "Digital-visual-sensory design anthropology: Ethnography, imagination and intervention." *Arts & Humanities in Higher Education* 13(4):412-427. https://doi.org/10.1177/1474022214542353

Poltorak, Mike. 2013. "The Efficacy and Self-Efficacy of Treatment." *Medical Anthropology Quarterly* 27(2):272-291. https://doi.org/10.1111/maq.12027

Textor, Robert B. 1995. "The Ethnographic Futures Research Method: An Application to Thailand." *Anthropological Perspectives on the Future of Culture and Society* 27(4):461-447. https://doi.org/10.1016/0016-3287(95)00011-K.