Would You Know What To Do?: A framework for thinking about ethics in design developed in response to the creation of a digital tool to facilitate end-of-life decision making.

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HEALTH AND WELLBEING

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Contents

Abstract

Well-adopted design process models notably lack ethics in their conceptions of the work that design practitioners complete. This thesis seeks to align ethical components of other disciplines with the seven-step design process codified by Kumar to better organize existing applied ethics tools available to design practitioners. The frameworks emerged from needs arising during a project to create and implement a digital facilitation tool called Canopy that helps support families better prepare for end-of-life Health Care decision making. It explores gaps in the existing ethics in design research, including identification of ethical interventions used within design process models. Using Canopy as an illustrative case, this thesis seeks to analyze ethically-bound challenges in the design process and their alignment to the challenges and remedies faced by other disciplines. It also proposes additional areas of research in design ethics worthy of further exploration.

Keywords

Design Ethics
Integration
End-of-Life
Health Care
Advance Care Planning
Design Research
Design Processes
Values

Glossary

Advance Care Planning: The process an individual undertakes to determine what decision-making and medical interventions they would like to receive in a situation where they are unable to speak for themselves.

Advance Care Directive/Living Will: Written or verbal instructions for a person's care if he/she is unable to make decisions. Often formalized into legal documents by the same name.

Caregiver: For this thesis, caregivers include family, friends, and loved ones who contribute to the care and well-being of a given patient.

Design Practitioner: Used in this thesis, this term refers to any person who utilizes design methodology or processes in their work. This term is used broadly to include those who may not identify as a designer, but nevertheless practice design.

Do Not Resuscitate (DNR): A physician's order not to attempt cardiopulmonary resuscitation (CPR) if a patient's heart or breathing stops. The order is written at the request of the patient or family, but it must be signed by a physician to be valid.

Durable Power of Attorney for Health Care (DPOA-H) or **Health Care Proxy/Surrogate:** An identified person legally designated to make decisions on someone's behalf.

End-of-life Care: Refers to health care, not only of a person in the final hours or days of their lives, but more broadly, the care of all those with a condition that has become advanced, progressive, and/or incurable.

Palliative Care: Care that "emphasizes the importance of considering psychosocial and spiritual aspects as well as the purely physical." Palliative care interventions aim to improve the control of symptoms (Finlay and Jones 1995) and to prevent and relieve suffering and improve quality of life (Pastrana et al. 2008).

Payer: This term is used to define organizations in the U.S. health care system ultimately responsible for paying for health care services, including public actors like Medicare and Medicaid and private insurance organizations.

POLST/MOST/POST/MOLST: Physician's Orders for Life-Sustaining Treatment (POLST), Medical Orders for Scope of Treatment (MOST), and Physician Orders for Scope of Treatment (POST) are one-page physician orders that help provide health care treatment instructions for seriously ill adults when nearing death. Sometimes they are also known as Medical Orders for Life-Sustaining Treatment (MOLST).

Provider/Clinician: These are the medical personnel who are part of the care team. Used more broadly, provider can also refer to the institution that staffs individual providers.

PREFACE

I must begin with the true story of a dear friend named Andréa. About a year ago, I spent the night in the emergency room with her as she cared for her Uncle Frank.[1] The events I witnessed that night inspired this project and continue to move me.

Frank had already spent nearly six months in this skilled nursing facility recovering from a surgical infection, but his health care journey began months before that. In 2016, he was diagnosed with throat cancer, the

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[1] Names have been changed to help protect privacy.

surgery for which caused his infection and the host of complications that followed.

Around noon, Andréa got a call from a care coordinator at the skilled nursing facility where Frank had been recovering. The coordinator told her they had transferred Frank to the Mount Sinai emergency department. Andréa sighed heavily when she heard it was a different hospital than had performed his surgery.

She called the emergency room and then her uncle's original surgeon. Then she called her sister. Then the doctors again. Then the rehab facility. Then the doctors once more. We were in her apartment. She was pacing back and forth across the room as she talked.

She had a small notebook where she was writing down names and phone numbers. She rustled through some papers that sat on her kitchen table until she found the do-not-resuscitate (DNR) order her uncle had signed. She clutched it and the notebook for most of the afternoon.

Frank was fine for the moment, but the doctor at the emergency room had questions for Andréa because Frank was moving in and out of consciousness. Can we do this or that? Have you talked about…? What about…? Questions were coming to her because she was his medical proxy, the legally-appointed decision maker authorized to speak on his behalf. Andréa and her uncle weren't particularly close, but before his throat surgery he asked, and she had said yes to becoming his proxy. So the decision fell to her.

Frank was somewhat estranged from the family—apparently, there was a falling out a long time ago. To make matters more complicated, Andréa's mother (Frank's sister) has early signs of dementia. Most days are fine, but stress or sudden events can cause her memory to worsen. Andréa spends a large amount of time carefully considering the information that reaches her mother—how it gets there and what gets said. That's why the third call was to her sister. Andréa was trying to figure out if she needed to get her mother to the hospital and how to break the news.

Later that evening, she got another call from the emergency room clerk. They put Frank's doctor on the line who told Andréa that Frank's blood pressure had dropped significantly and to stabilize him, they had injected him with medication. They asked her permission to put in a central line, a catheter that helps deliver medication directly into the bloodstream, so that they could continue to deliver this medication.

Andréa stood over her kitchen table and flipped through the DNR order. She said, "I don't know. I'm not sure what he would want." She read out loud the part of the DNR order that said Frank didn't want any excessive measures and she asked the doctor, "Does this count as excessive?"

He didn't answer. "It's not something I can answer for you." She pressed him for more, clearly shaken.

They talked for a couple more minutes, and finally, she revealed she was struggling because when she saw Frank just a few weeks ago in the hospital, he said, "I wish it were easier to die." Andréa asked how soon they needed an answer and if she had time to come up to the hospital—a 20-minute cab ride.

With a "yes" back from the doctor, we got in a cab. We sat silently on the way to the hospital. Andréa broke the silence only once to say to me, "Thank you for coming." I reassured her, and we continued in silence.

We got out on 101st and Madison Avenue in East Harlem, and when we approached the emergency entrance, Andréa stopped short of the door, made the sign of the cross, and said a short prayer. Then we walked in.

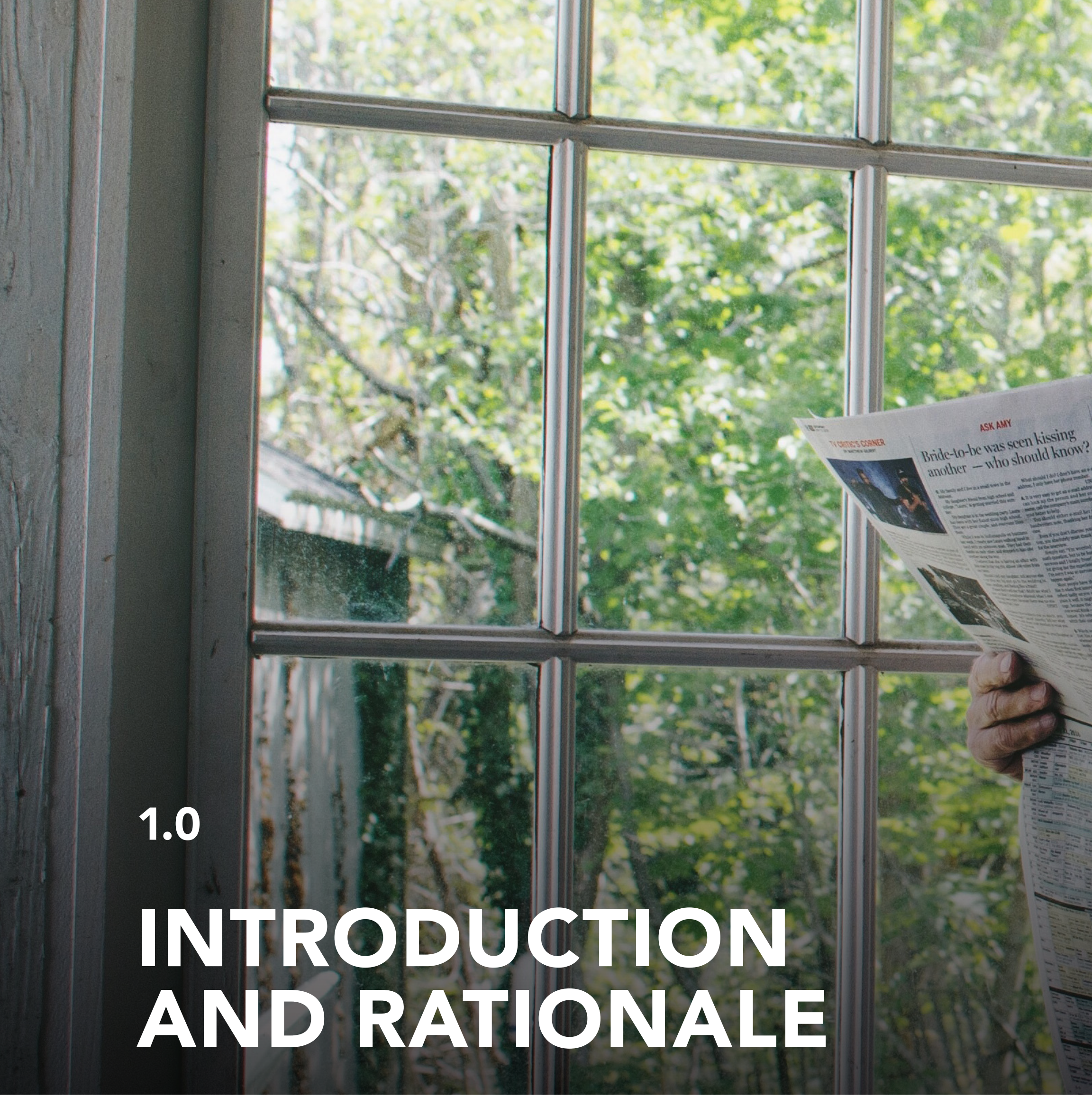
The receptionist helped us find the doctor, and Andréa walked back to speak with him. In the time it had taken us to get to the hospital, Frank had woken up and was responsive enough to talk about what was happening. In the end, he told the doctors he wanted the central line.

Frank's condition was touch-and-go the next day and the day after that. Andréa went back to the hospital, coordinated her parents' visit, and wrestled with tough medical decisions night after night.

I’ve since learned that situations like this happen at hospitals around the country. Right now, people and families are struggling with end-of-life decisions.

Frank died about a week later. Andréa called and told me that she was both sad and relieved. The whole process was incredibly stressful for her, and though she grieved, she was happy to know he wasn’t suffering anymore.

I walked away from my time with Andréa thinking there’s something here we’re not doing well. Losing a loved one is always going to be hard, but some parts of the situation felt unnecessarily so.



1.0

INTRODUCTION AND RATIONALE

Problems like those presented in Andréa’s story guide the actions of design practitioners, but beyond the surface of any problem, there are infinitely more questions that design practitioners must navigate to create interventions that positively change the given situation into a preferred one. To intervene well, design practitioners must understand the context surrounding them, the people involved in a given problem, the creative constraints present given available resources, time and environments, and the potential implications of their interventions.

Andréa's story and others like it prompted a project that evolved into a company called Canopy, which aims to provide tools to support families as they talk about and make difficult end-of-life health care decisions.

Planning for, facilitating, determining, and implementing end-of-life health care wishes is a particularly challenging problem to tackle. When considering the full scope of relationships and systems involved in the decision-making process, the challenge of designing an intervention to support end-of-life health care decision making is particularly wicked (Rittel and Webber 1973). Just the topic of end-of-life care often sparks wide debate. Attempts to define legislative guidelines and support for advance care planning within federal health care law have incited divisive language like "death panels" in debates about the topic (Frankford 2015; Tolle and Teno 2017).

Through the process of developing Canopy, some additional ethical questions arose due to the nature of the problem our interdisciplinary team was trying to solve. We were faced with ethical questions, which arose while constructing our tools, about the influence and potential consequences of our decisions in developing these tools to support end-of-life decision making: What if we inadvertently influence a family to make a decision that they regret later? How do you balance the power dynamics present in health care? How do you think about what is good and bad design when talking about literal life and death decisions?

Ethical questions often arise in the course of design activity, especially when designing for high-stakes outcomes—health, social justice, the environment. Common process models do not explicitly include moments of reflection or action geared toward supporting designers in the process of ethical evaluation and decision making (Kumar 2012b; Council 2005; Human Centered Design: Field Guide 2009). In addition, historical representations of creative problem solving and design process do not contain ethical considerations as part of the process (VanPatter and Pastor 2016).

In addition, applying ethics within the context of a design process can be challenging because of key issues, including how design practitioners 1) divide responsibility, leading to poor accountability that can lead to negative consequences; 2) make decisions implicitly leading to outcomes not initially intended but present because many small, implicit decisions led a team down an ultimately undesirable path; and 3) include or exclude stakeholders, leading to poor understanding of the potential outcomes of a designed intervention (Richard Devon and De Poel 2004).

As members of a young discipline, design practitioners still search for the boundaries of our practice and to identify the distinctive elements that make design, design. In addition, designers are being asked to participate in different and broader challenges, and more activities are being defined as design (Sanders 2008). Design methodologies are becoming more and more important to the functioning and thriving of modern organizations. As a result, other disciplines adopt and adapt design methodologies for use in the private and public sectors (Bason 2010; Carr et al. 2010). With design's expanding ambition and reach, its responsibility increases as well.

However, few tools and frameworks exist to support practicing designers as they navigate ethical challenges—excepting research and participatory design practices (Petersen and Matheson 2017; Vistisen, Jensen, and Poulsen 2016). The ones that exist are largely focused on ethical interactions and inclusion or research participants and not on the process of decision-making within or consequences of the creation of an artifact (Davis and Janet 2009). Combined with design's relative youth, the lack of tools and frameworks adds an additional challenge for a design practitioner seeking to navigate the ethics of their work.

Other more mature disciplines (e.g., medicine, law, business) have more-developed, well-adopted applications of ethics in a professional context. However, because designers are fundamentally focused on "the conception and planning of the artificial," specific challenges arise that have not been well addressed by other disciplines (Buchanan 1992; Tonkinwise 2004). Designers create artifacts, which, broadly speaking, can include communications, products, services, and systems (Buchanan 1992). These artifacts exist beyond a specific moment in time and may have farther-reaching, more lasting, and more unexpected effects.

Yet design practitioners have much to explore about their own ethics. Though literature is emerging to help inform the ethical practice of design, in general, we lack widely accepted value systems, educational practices, professional guidelines, and systems of implementation and review for ethical actions. This thesis explores the potential alignment between existing theories, tools, and methods in ethics (both within and without design) into the design process, specifically the design process codified by Vijay Kumar in 101 Design Methods (Kumar 2012a). It explores the potential to utilize applied ethics components from other disciplines as a way to improve upon design practitioners' understanding of ethics in their work and to jumpstart the design field in thinking about how our ethical practices might be related and linked to the practices of other disciplines. Ideas about this alignment will be discussed both independently and through the lens of practical needs present during the course of creating Canopy.

2.0

PROJECT BACKGROUND AND CONTEXT

2.1. Overview

Canopy is a web application that helps families talk about and make plans for their eventual end-of-life health care concerns. The app was created by an interdisciplinary team composed of me and two other students at the University of Michigan. At a high level, Canopy provides enterprise-level software to health systems who then share a consumer-facing tool with patients. Patients complete a digitally-mediated advance care planning process, answering key questions about: their medical proxy; underlying values and belief systems; and medical decisions for commonly occurring situations. Canopy syncs their responses, returning documentation to the health system and sharing it with their loved ones.

Creating Canopy made clear the need for additional work to understand design ethics, research to support those questions, which was conducted in parallel to the activities described here. To provide context for the analysis and ethical framework proposed later in this thesis, this summary of Canopy discusses the challenges of advance care planning (ACP) and the end-of-life health care the application seeks to mitigate, the team and collaborators who have worked on Canopy, the process of research and product development, a description of the tool itself, and the implications of the project that necessitated ethical consideration.

2.2. Challenges in Advance Care Planning and End-of-Life (EOL) Health Care

Many questions arise during the course of end-of-life care and often few answers. In the moment where illness reaches a tipping point and critical decisions need to be made, families and patients ask much of their physicians and each other. What do you want? What do I want? What should I do? How do I decide? What are my options? What is most important? What does that mean?

In the most critical moments of health care emergencies and downturns, decisions are often made without much planning or consideration about personal preference—Ω Beyond the basic details of the situation, other factors can further complicate end-of-life decisions. Capacity deficits—people's awareness of the world around them and ability to make decisions—can cause confusion about how best to proceed on their behalf. Dementia and Alzheimer's patients comprise 3.4 million people in the U.S. alone ("Global Prevalence of Dementia: A Delphi Consensus Study" 2005). In addition to capacity, lack of consciousness may push decision making from an individual to their next of kin—also referred to as their medical proxy or durable power of attorney (DeMartino et al. 2017). Decision by proxy happen frequently: in approximately 40% of inpatients and 90% of those in an intensive care unit (DeMartino et al. 2017).

Emotional challenges and ambiguity placed on decision makers underlie the decision-making process (Detering et al. 2010). Decisions about life and death are intrinsically ethically-bound and morally arduous on many levels ("Ethics and End-of-Life Care for Adults in the Intensive Care Unit" 2010). An individual's core values may be in conflict with others'—their loved ones, providers, and systems that surround them. These conflicting values are difficult to navigate when the person is able to speak for themselves, but, in moments when they are unable to provide input, further burden falls to a loved one (Detering et al. 2010).

Advance Care Planning (ACP) is the formalized process that seeks to address these burdens (DeMartino et al. 2017). However, several barriers to ACP exist, including opportunity, subject matter, family dynamics, time, lack of awareness, denial, confusion, and cultural differences (Van Scoy et al. 2016; Rhee, Zwar, and Kemp 2013). Conversations about end-of-life included in ACP are complicated and may have multiple goals, including task completion, maintaining relationships, and presentation of one's own identity ("From Theory to Practice: Measuring End-of-Life Communication Quality Using Multiple Goals Theory" 2017). These barriers and complexities lead few to complete the process and to formalize documentation; best estimates suggest that only 37% of people have an Advance Care Directive (ACD), a legal document used to share end-of-life wishes with medical providers as part of ACP (Yadav et al. 2017).

Social disparities decrease the likelihood that planning occurs. In the United States, probability of completion for ACP decreases for minorities and other socially disadvantaged groups (Rao et al. 2014). For many populations, planning for end-of-life decisions is out of reach for a variety of reasons—logistical, economic, or accessibility (Rolnick, Asch, and Halpern 2017).

The system is searching for solutions. Modern health care technologies allow individuals to live longer but do not necessarily increase the quality of life, leading to soaring health care costs for patients in the last years of life. As of 2006, 25.1% percent of Medicare payments are attributable to patients in their last year of life (Greer Donley 2011). Studies show that putting ACDs in place can reduce EOL health care costs by up to 68% (Chambers et al. 1994). Estimates suggest that U.S. EOL expenditures will exceed $350 billion by 2020 (Dying in America 2015).

Existing tools to facilitate EOL conversations are resource intensive or ineffective at facilitating information sharing between patients and decisions makers. Health systems employ palliative care specialists who facilitate Advance Care Planning in hospital settings but face a shortage of qualified specialists ("Estimate of Current Hospice and Palliative Medicine Physician Workforce Shortage" 2010). And other resources (PDF guides, legal planning services) that exist do not align to best practices, which recommend surrogate (i.e., medical proxy) involvement in planning throughout the process to be better prepared for decision making in the moment (Sudore and Fried 2010). Establishing leeway in decision making can help decrease surrogate burden (Sudore and Fried 2010). Having an advance directive in place can make surrogates feel better prepared and more confident in making decisions (Ditto et al. 2001). The process of creating the ACD is seen as a way to improve family relationships, resolve conflicts, and improve trust (Rhee, Zwar, and Kemp 2013).

However, faults in ACD have led to calls from physicians and researchers to abandon the living will (an earlier name for advance directives) on the basis that the legal document itself does not help accurately plan and instead provides false promises (Fagerlin and Schneider 2004). Studies have shown that if an advance directive is unclear, providers tend to continue treatment by default (Teno et al. 1998). To support patients and their loved ones more effectively, clinicians have recommended that advance directives move away from legal documents and towards clinical documents, as there is no proof that their legality is a driving factor in helping reduce conflict (Rolnick, Asch, and Halpern 2017).

The logistics of delivering an advanced directive to appropriate medical personnel creates additional challenges in end-of-life care (Perkins 2007). Documents are often stored in inconvenient locations—a drawer or file cabinet in an individual's home or in a lawyer's office. Recent updates to electronic medical record (EMR) systems allow for more and varied documentation, but getting advance directives into an EMR system can be problematic (Bernacki et al. 2015). Delivery of ACDs in emergency situations is challenging, given that first responders and other personnel are often not in immediate contact with a person's medical proxy (Marco et al. 1997). So people are left without answers when they need them the most.

Ethical challenges exist throughout the decision-making process. Questions about a person's intentions, their life philosophy, or their core values can change the course of care dramatically. One person may want every possible opportunity to live, while another abhors the medical system and would rather not step foot in an emergency room. Many individuals lie somewhere in between—with nuanced beliefs to inform their journey through health care. Some people may have a clear picture of how their last days should transpire and others are perfectly happy to abdicate all responsibility to the person nearest to them. A key challenge to intervening on behalf of a patient is lack of knowledge among key advocates, including family members, providers, and, in contentious or extreme circumstances, government agencies and lawyers (Van Scoy et al. 2016; Rhee, Zwar, and Kemp 2013).

2.3. The Team and Collaborators

This project was conceived of and developed by an interdisciplinary team (hereafter referred to as "the team") comprised of me and two other then-graduate-students at the University of Michigan (one studying public health behavior and education and the other studying health informatics). During the course of the project's development, the team was supported by several people and groups, including on-campus entrepreneurs in residence, subject-matter experts from across the university, and student lawyers and designers from graduate-level clinics. Software engineers were employed to help move the tool from works-like prototype to functioning application. The team was also been mentored by several medical practitioners and health care industry experts from outside the University.

2.4. Process

Canopy progressed from an open collaboration to a registered corporation in less than one year. During that time, a wide range of design processes, including typical ethnographic research activities, concept exploration, and collaborative design methods were employed to create our core product and inform the creation of a business model and implementation strategy to support that product.

In recognition of the necessarily applied nature of the work to develop a new venture and real-world product, the research and activities described here apply a post-positivist lens (Howell 2013). Multiple methods of inquiry and evaluation were used to help triangulate the many contributing factors to advance care planning challenges. The challenges the team sought (and seek) to address are reflective of the real-world activities conducted by medical practitioners and individuals but are also influenced by the action the team takes. Thus, data were not gathered in a lab setting, but rather using research methods developed in social sciences, business, and design that we applied flexibly using design abductive reasoning, a process by which individuals and teams can create value without first identifying the underlying what and how that will lead to it (Dorst 2011). We utilized several problem frames to navigate through the problem we saw. We sought to understand the problem through the lens of an individual who may ultimately become a patient, a loved one who will be responsible for that patient’s care and decision making, the medical providers who will treat and intervene on that patient’s behalf, and the institutions that are responsible for structures that dictate those interactions. Below I have documented the activities we completed to better understand each of those frames and to learn more about the potential for and implications of possible interventions to improve the health care situation.

2.4.1. Context and Considerations

Overall, the team has conducted more than 600 hours of research to inform the development of Canopy. Universal to all activities described below, a few external factors and team decisions drove our process to engage with people during the course of this project.

Timeline. To date, the project has extended over one year, though work was not completed continuously during the process. Activities described above began in February 2017 and continued through March 2018 when documentation for this thesis began. During the months of May 2017–August 2018, work continued in a limited fashion, with more substantial activity resuming in September 2017.

Setting. Because the team is based in Michigan, many participants for Canopy-driven research were local experts or end-users. All participants were based in the United States and were able to speak English. Expert interviews were more widely distributed and sourced from the U.S. broadly. Interviews were conducted in-person when possible, in a convenient location for both the investigator and participant. When logistically necessary, interviews were conducted via phone or video-conferencing services.

Recruitment. Participants were recruited using convenience sampling, with initial recruitment recommendations sourced through existing contacts of the working team and then expanded using snowball sampling methods. In several instances, calls for participants and surveys were posted via social media and other digital channels to recruit participants. For each data collection method, only adults in good mental health were considered for inclusion. Children under the age of 18 were excluded, as well as those with permanent or temporary mental impairment.

2.4.2. Early Activity

The project began as an open collaboration among the team to participate in a social entrepreneurship program without a clear idea or problem defined. During the course of this collaboration, the team completed several interviews and observations in the hopes of identifying a problem to work on.

From here, the team developed an initial concept proposal in the form of a business pitch, which included key features, benefits, business model considerations, financial projects, and research to justify the potential need. Time was short to develop this pitch, so surveys were deployed quickly to gather initial information from potential end-users of advance care planning. An initial survey gathered information about the status of advance care planning in people's lives from 258 respondents gathered through snowball sampling. In addition, expert interviews were conducted with clinicians, palliative care specialists, elder law attorneys, social workers, insurance representatives, and others involved in or related to advance care planning.

2.3.3. Further Development

Following the initial concept pitch, the team conducted additional research to better understand the nuanced requirements of advance care planning through expert interviews and interviews with potential end-users with one or more of the following characteristics: 1) have no experience creating or dealing with end-of-life health care themselves or among their loved ones, 2) have created an advance care directive or living will, but have not used it, 3) have created an advance care plan (or had discussions) and needed to use it, 4) found themselves in a medical situation where they needed an advance care plan but had not previously completed one.

Over the course of Canopy's development to date, the team has conducted substantive interviews with 55 subject matter experts and engaged with more than 400 potential end users through one or more research methods (surveying, interviewing, observation). Members of the team have also conducted in-person shadowing of medical personnel, including the palliative care team at a large teaching hospital. I also completed a training course through Respecting Choices to become a certified advance care planning facilitator to better understand how medical personnel are being trained for advance care planning discussions with patient populations.

To support a systems-level understanding of the problem, the team also completed a detailed competitor analysis in which we identified existing interventions to support advance care planning that are already available either in the market or as materials distributed by institutions for patient or clients. Additionally, the team reviewed literature (summarized above) and more than 150 popular-media articles about end-of-life health care, death and dying, and related topics.

To understand the data gathered through these methods, several other analyses were conducted, outlining the needs, pain points, and desires of potential users of Canopy's advance care planning software. This process included creating an ecosystem map to understand how stakeholders in the space interact with each other (see Fig. 1); journey mapping (see Fig. 2) (Howard 2014) and affinity diagramming (Plain 2007) to analyze interview content; and examining existing best practices for advance care planning conducted without digital mediation. Other research and concept development exercises include: card sorting exercises to evaluate features; digital low- and high-fidelity prototyping in the form of paper prototypes, sketched storyboards, and clickable prototypes; community event booths with public prompts for attendees about their needs and desires to communicate their wishes (see Fig. 3); teaming activities and entity formation; and participation in industry events and conferences.

Additionally, a team of students studying human-computer interaction conducted research to evaluate Canopy's prototype software. The research was structured in two parts: 1) determining the topics necessary to a successful advance care planning process and building a holistic design team understanding about potential user pain points and needs around planning for health care decision making; and 2) determining the methods of capture and delivery most desired and feasible for individuals, caregivers (loved ones), and providers about inputs (what families and individuals provide) and outputs (what family members and medical providers receive) that we might use to best collect and share needed information.

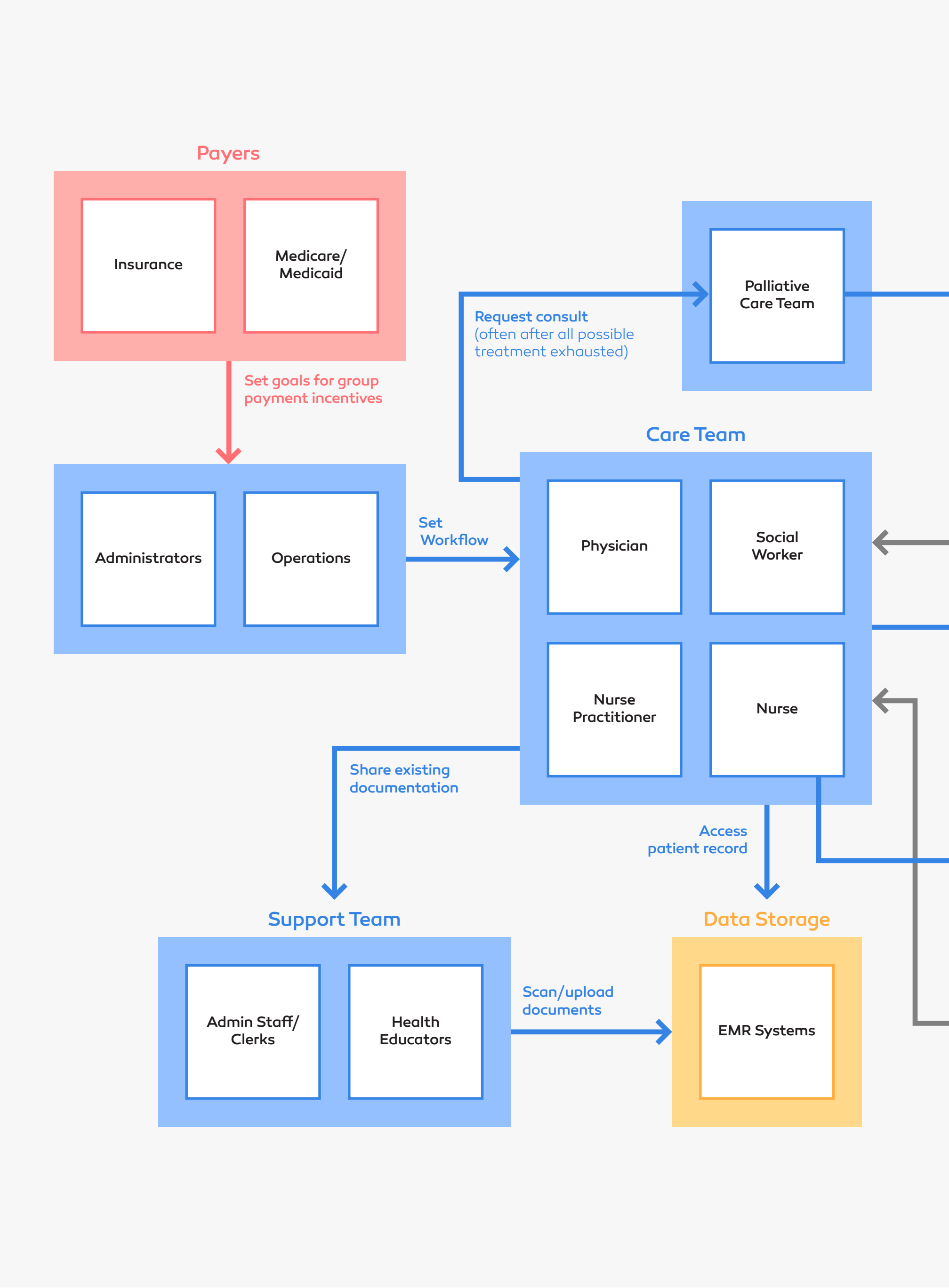
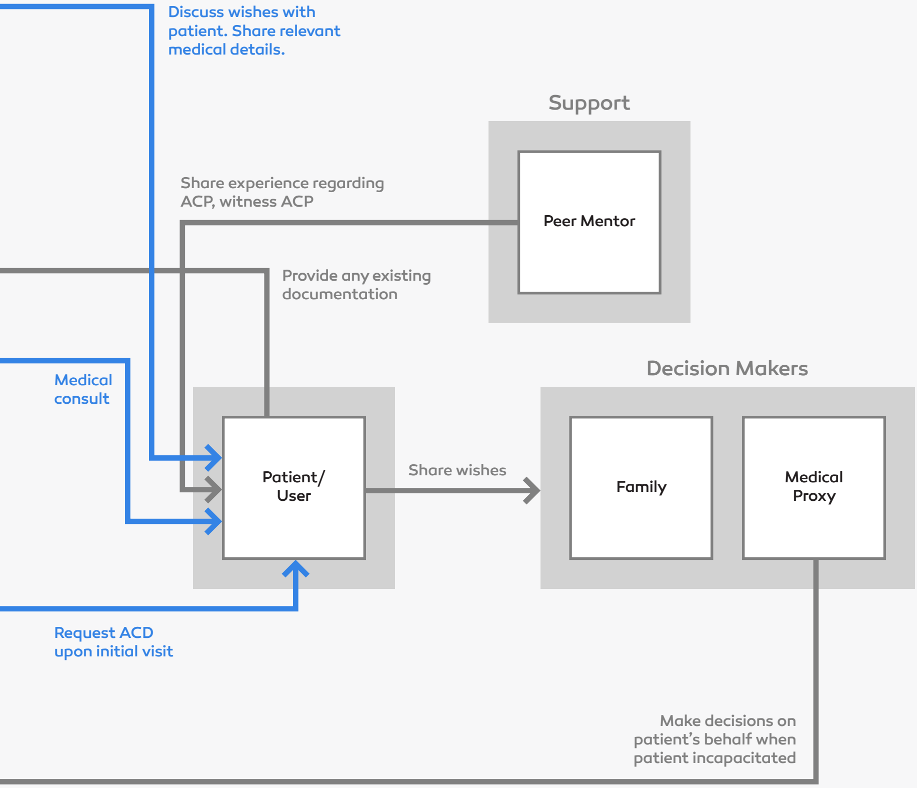


Figure 1. Ecosystem map developed to understand the relationships between participants in the advance care planning process.


Discuss wishes with patient. Share relevant medical details.
Support
Share experience regarding ACP, witness ACP
Peer Mentor
Provide any existing documentation
Decision Makers
Medical consult
Patient/ User
Share wishes
Family
Medical Proxy
Request ACD upon initial visit
Make decisions on patient's behalf when patient incapacitated

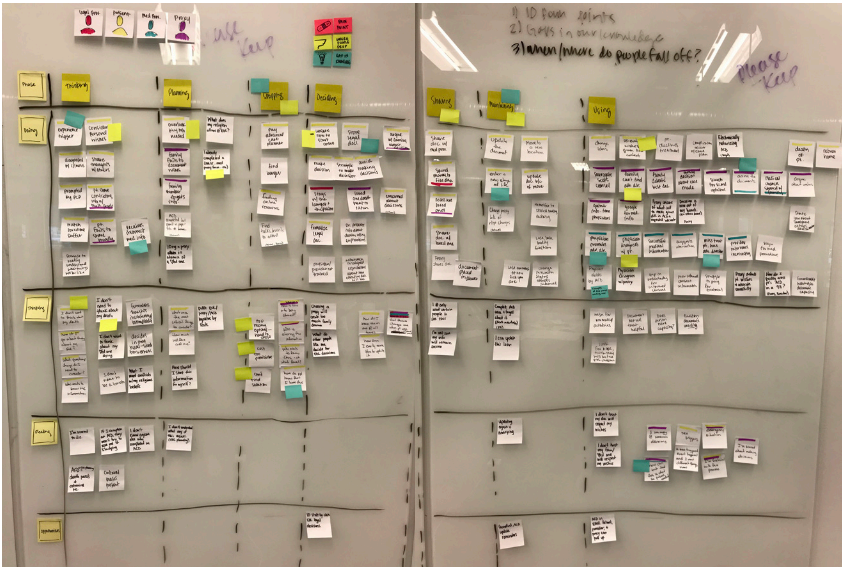


Figure 2. Journey map developed to show phases of advance care planning for individual users and specific interaction with legal providers, medical personnel, and a patient's medical proxy or family.

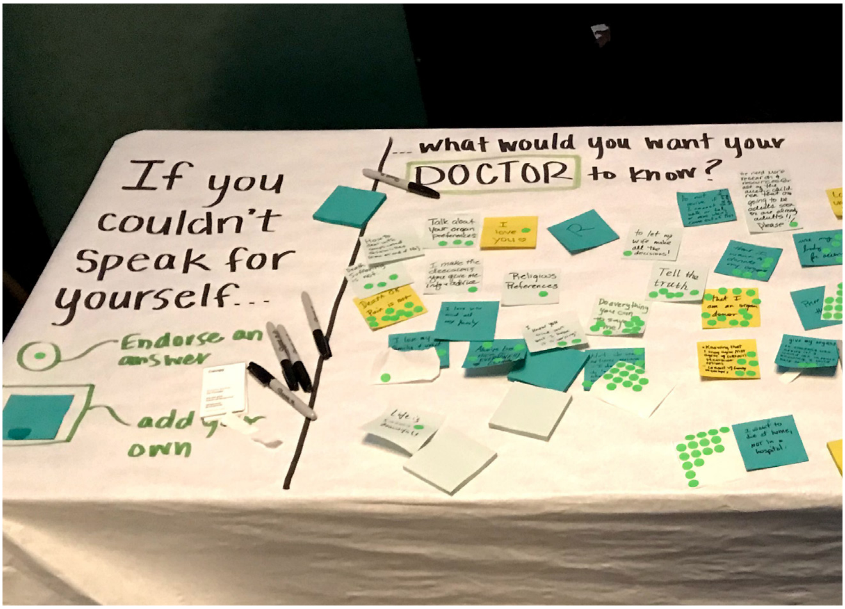


Figure 3. Image of table-top activity conducted at conference event. Participants wrote down important topics for doctors and family and upvoted existing responses that resonated with them.

2.4. Insights

As is typical in design processes focused on innovation, the team uncovered insights as a result of the research and analyses conducted. Though full documentation is too long for the constraints of this thesis, the following summary insights were gleaned and informed further research and product development:

Conversations Deferred. Physicians are not having end-of-life conversations or have them too late to be effective. Hospital systems need to better facilitate these conversations earlier and more often, but in general, clinicians are not well trained or prepared to have these conversations with their patients.

Values Underlie Decisions. Understanding values is paramount to getting a holistic picture of a person and being able to truly make an informed decision for them. It is impossible to prepare for every potential situation, but understanding values can help a medical proxy understand what a patient might want in a given situation. Patient-created video can provide an opportunity for a nuanced understanding of wishes that written text cannot.

Emergency Access Proves Difficult. Challenges accessing information in urgent situations contribute to poor proxy and provider knowledge of a patient’s wishes.

Reaching Everyone Takes Effort. Relying on diverse networks to distribute products/information has helped overcome population disparities. Hello (a card game for talking about death and dying) has been successful in getting lower socioeconomic status and people of color to participate. Hello facilitators have been trained from a wide variety of backgrounds, including representatives from religious institutions and community organizations.

Poor Onboarding Halts Progress. Many tools require too much up-front preparation to get started, leaving many people still struggling to engage with and complete goals-of-care and end-of-life conversations.

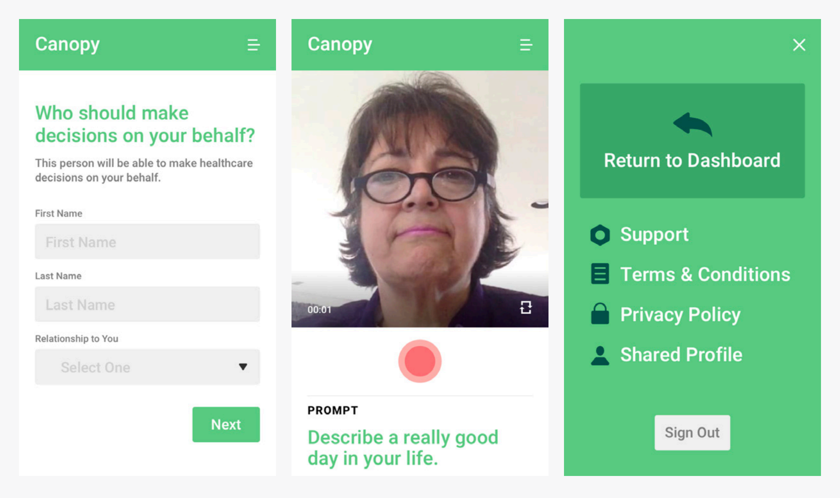
Technical Solutions Are Missing. Health systems and providers desire better integrations into their electronic medical records systems to reduce errors that occur due to lack of information.

Proving Accuracy Is Necessary. Among elderly populations, the legal burden to prove capacity during the creation of legal documents causes deep questioning in case of disputes. Recordings of a person at the time of document creation may help mitigate these concerns.

2.5. Intervention Description

In its current form, engaging with Canopy works like this: Canopy partners with a health system and gets a program set up, which includes technical integrations with EMR systems and supporting the onboarding of staff through marketing materials and on-the-ground training programs. Then, triggered by a patient's diagnosis or age, providers, including physicians, nurses, social workers, health navigators, or other key staff, "prescribe" Canopy to their patients. Patients and families use the digital tool at home through a web application available on any device with an internet browser, clarifying their wishes in three important ways. Using a mix of text input and multimedia recording, individuals answer basic questions to 1) identify their desired medical proxy, 2) share values and information to clarify how they might make major life decisions, and 3) answer commonly-occurring medical questions.

This information is stored securely by Canopy as well as transferred directly to the patient's EMR at their medical provider's office. Through the web application, individuals can share their wishes widely with their loved ones by sharing their Canopy profile. This profile contains identifying information for their medical proxy, all recordings and information collected during the process of answering questions about values and medical information, and a signed advance directive (which effectively contains the same information in an executed legal document). When an individual enters a new life stage, Canopy can easily be updated directly from the web application to reflect their new situation. Those updates are synced automatically to both medical providers and loved ones who may have received notice of patient's advance directive, keeping everyone up to date.



Who should make decisions on your behalf?

This person will be able to make healthcare decisions on your behalf.

PROMPT

Describe a really good day in your life.

Figure 4. Sample screens from a prototype of the Canopy web application. From left: Text input for medical proxy identification, video recording screen of values-based questions, primary navigation menu.

2.6. Implications

Canopy's development will continue well after the completion of this thesis, but in the time between its initial conception and now, there are key moments that spurred the need for a deep dive into design ethics. While developing Canopy, a few specific ethical challenges arose for the team that necessitated further inquiry.

Balancing Layers of Decision Making. As the team began to understand the ecosystem of end-of-life decision making, we realized the tool we were making would influence much more than just a single person's wishes and would involve the belief systems of families, medical providers, and supporting medical systems. The tool formalizes documentation for an individual, but to be effective, it needs to support the family who is making decisions and speak to their underlying values as well. For some families, decisions are made quite easily, but for others the entire conversation stirs deep-seeded disagreement. How do we help them navigate this difficult conversation with full transparency? Layered onto that are medical providers' own belief systems. In a situation where the medical provider and the family disagree, whose authority is ultimately respected? How do you ensure that the systems in place, which include Canopy, best protect the individual's pre-determined wishes, but also ensure flexibility for all actors in the ecosystem to navigate the situation given new information not known to the individual patient when their wishes were codified?

Content Presentation. Some of the core content necessary to help inform decisions for families and providers alike is challenging to present holistically and with minimal bias. For example, statistics about the effectiveness of cardiopulmonary resuscitation (CPR) indicate poor outcomes for the majority of patients. For adults in the hospital, 24.8% survive in-hospital CPR ("Cardiac Arrest Statistics" 2012). For those over the age of 64, chances of survival decrease to 18.3% (Ehlenbach et al. 2009). However, personal expectations of CPR effectiveness are much higher, which has been attributed to mainstream media representations of the procedure (Van den Bulck 2002). How do we represent both positive and negative outcomes of the treatment fairly and accurately to minimize the influence we have on the patient and their family? (Especially given a topic with expectations so misaligned from reality.)

Representation and Cultural Considerations. As a culturally diverse team ourselves, we spoke often about the need to ensure health equity and outcomes for individuals who, because of their socioeconomic status, ethnic background, gender or sexual orientation, are excluded from advance care planning processes (Rao et al. 2014; Harding, Epiphaniou, and Chidgey-Clark 2012; Lowers 2017; Perkins et al. 2002). We aim to increase access for these individuals. However, for some, the process of advance care planning itself runs counter to cultural values. In the U.S., our decision-making processes around health care are largely centered on the patient and align with Protestant beliefs about death and dying established by the elite (Ballou and Landreneau 2010). And existing biases by health care providers have called for additional work to increase self-awareness (White et al. 2018). How might we create an experience that can be tailored to the needs of all people and yet still protect their values within a system that may not share them?

3.0

LITERATURE REVIEW

3.1. Purpose and Justification

This review is intended to provide a systematic review of existing literature about design ethics, adjacent ethical topics, and identify current research gaps in ethics integration into design processes. It is organized into the following thematic areas: 1) definitions, 2) design ethics, 3) professional codes of design ethics, 4) existing interventions/tools to support ethical practice in design, 5) educational tools for design ethics, and 6) other disciplinary approaches to ethics.

Key gaps identified from this review include: 1) No strong alignment of ethics to well-tested and utilized design processes practiced in professional settings. Many papers focus on specific parts of the design process but fail to provide a holistic overview. 2) Few published cases that can be used as discussion tools to educate and practice ethics. 3) Few papers acknowledge the many practical roles that designers play (beyond creators of things).

3.2. Methodology

3.2.1. Parameters/Rules for Inclusion

This literature review includes papers published in English in peer-reviewed journals or publications, specifically prioritizing those that use both qualitative or quantitative methodologies containing primary research. The review also includes papers or essays that propose focused tools or techniques. Included publications feature at least one of the following: 1) a philosophical view of design that seeks to align ethical or moral thought with unique characteristics of design, 2) frameworks for ethical alignment and evaluation as it relates to design or adjacent disciplines, and 3) research about practical applications of ethics in creation or decision-making contexts, including research conducted in the context of other disciplines.

3.2.2. Process

To conduct this literature review, I took three key steps. First, I conducted a keyword search of relevant publication databases, including Google Scholar, ACM, Design & Applied Arts Index (DAAI) Database, Design Studies, Design Issues, International Journal of Design, Design Journal, Journal of Design History, CoDesign, and Design Philosophy Papers.

The following keywords were used in various combinations to search: “Design,” “Ethics,” “Processes,” “Values,” “Codes of Conduct,” “Governance,” “Decision Making,” “Tools,” “Law,” “Business,” “Public Health,” “Medicine,” “Journalism,” “Media,” “Economics,” “Engineering,” and “Human-computer Interaction.”

Second, I reviewed the reference sections of the resulting publications for related or additional literature that met selection criteria. Third, I reviewed existing literature reviews on related topics to search their references section for additional publications.

3.3 Review

3.3.1 Definitions

Design Defined

The definition of design is often debated as the usage of the term design does not yet denote a clear set of activities or field of study with defined boundaries (Dilnot 1982). In fact, so many definitions of design exist that it becomes challenging to settle on one cohesive definition (Love 2000). To ground the reader, this thesis considers both the discipline of Design, as well as the practice of design activities as included in the definition of the term design. Though the primary audience for this thesis is those who self-identify as part of the discipline of Design or one of its many sub-disciplines, the practices of those who do not identify as designers but complete similar or identical activities may also find relevance in this thesis. Thus, I prefer Herbert Simon's definition: "Everyone designs who devises courses of action aimed at changing existing situations into preferred ones" (H. A. Simon 1996). In acting, design practitioners create artifacts, which broadly speaking can include communications, products, services, and systems, but they are fundamentally focused on the "conception and planning of the artificial," which can create impact well beyond these artifacts (Buchanan 1992; Willis 2013). This activity includes a broad range of processes and methods, including but not limited to critical design, user-centered design, contextual inquiry, human factors and ergonomics, usability testing, generative design research, co-design, and participatory design (L. Sanders 2008).

Design has been applied in broad contexts, including discursive, commercial, responsible, and experimental (Tharp and Tharp 2009) and provides benefits to an organization when integratively applied across the functions of an organization (Stevens, Moultrie, and Crilly 2009). However, design often exists informally or incompletely, as in the case of silent design, when participants act as designers without realizing it, partial design when design is applied superficially or in a limited manner, and disparate design when design activities are not coordinated (Stevens, Moultrie, and Crilly 2009). These less formal conceptions of design are often not recognized for what they are by the actors but identified only after they occur. Though they are, nonetheless, design activities. However, because these activities are not formalized, they are beyond the realm of what we will consider to as design for the purposes of this thesis.

Ethics Defined

In philosophy, three common areas of ethical study include meta-ethics (the nature of right and wrong), normative ethics (standards and principles used to evaluate right and wrong), and applied ethics (using standards and principles in specific situations) (Bonde and Firenze 2013). Overlaying each of these areas of study are ethical theories that fall broadly into these categories: 1) consequentialist theories that consider outcomes as a course of action, 2) non-consequentialist or duty theories that consider external, broader rules and norms that should guide actions, and 3) virtue-based theories that put emphasis on the development of one's character and making decisions based on what a "virtuous" person would do (Bonde and Firenze 2013). The terms ethics and morals are often used interchangeably, though there are some specific uses of the term ethics that reach beyond solely speaking to the moral nature of an action or actor (Downie 1980). These include: 1) professional ethics, which are codified standards and practices used to establish norms of practice, and 2) ethics may refer to the specific procedures codified (Downie 1980).

3.3.2 Design Ethics

Though design ethics comprises a relatively small body of knowledge, several design ethics writings exist, ranging from specific interventions in design research practices to broader theories about the implications of design and how to consider ethics in the process of planning and creation. As design has shifted between “a means of ordering the world” and “shaping commodities,” the need for additional work not only to define design, but to define the ethics of the activity of design has become necessary (Dilnot 1982).

Scholars have identified a general lack of design ethics literature and knowledge among practitioners. Becker et al. suggest that the discipline of design has ignored the explicit knowledge coming from philosophy (Becker and Leslie 2012). To remedy this ignorance of how to use ethics in design, they suggest a combination of casuistry, defined as case-based analysis, and communicative ethics, where good can be determined based on communication between rational actors (Becker and Leslie 2012). However, their suggestion for case-based analysis of ethics is not possible given the current lack of design-led ethics case studies for use in understanding the given circumstances and positing possible implications among design practitioners. To utilize their recommendation in practice, much work needs to be done to support discipline-wide documentation and distribution of cases.

In addition to methods of applied ethics, other scholars have suggested underlying philosophical theories that may closely align to design activity. Tonkinwise writes about embodied ethics, combining Bruno Latour’s concept of delegated morality with materialized ethical arguments to provide an alternative to the Aristotelian concept of akrasia, which means “knowing the right thing to do and yet not doing it” (Tonkinwise 2004). He suggests that design is already intrinsically ethical and identifies two key problems with Aristotelian concepts that materialized ethics better addresses: 1) akrasia does not include things but rather assumes people-to-people conduct and 2) ethics is intrinsically human and not possible to automate (Tonkinwise 2004). Stewart and Lorber-Kasunic similarly suggest that akrasia happens as a result of multitasking in which the here-and-now takes precedence over what will be best in the long-term. They provide a “conception of design as disburdening, of design things as actors within a network of ethical relations,” suggesting that designers are responsible, in part, for the “nature of things” (Stewart and Lorber-Kasunic 2006). To mitigate this, they propose that designers consider broader pains of the user, not only those directly and presently identified (Stewart and Lorber-Kasunic 2006).

Beyond the concept of akrasia, D'Anjou proposes a model of design ethics based in Sartrean existentialism that includes "reflective process" and not objective decision-making process, which he argues would allow "decision-makers to flee freedom of choice and responsibility" (d'Anjou 2011). His proposed process includes five phases: 1) accept complete freedom and responsibility in design practice, 2) reflect on prior design choices, 3) reflect on external demands, 4) reflect on practical limitations, and 5) enact design choices that reveal an awareness of freedom and acceptance of personal responsibility (d'Anjou 2011). However, neither this proposed process or the philosophical underpinnings of akrasia are widely understood or accepted by the design community. And though they may help to inform the academic understanding of design ethics, they do not provide a structure useful for the real-world application of ethics in the practice of design. Though valuable in academia, D'Anjou's framework is less valuable to practitioners because too much prerequisite knowledge is required to engage with it.

Designers have historically pointed to the intersection of design activities and social challenges facing the world, which can be seen as a type of ethics. In Design for the Real World, Papanek calls upon designers to recognize their role in social and moral outcomes in the areas of safety, security, waste, environmental harm, pollution, health, and others (Papanek 1972). Victor Margolin outlines a culture of sustainability that rejects historical alignment of design activity to consumer culture, and instead, he repositions design among a set of values that prioritize the sustainable creation of the future (Margolin 1998). These alignments to modern social issues have merit in that they call attention to the potential spheres of influence design practitioners may affect during the course of their work. But this overlap alone does not provide guiding ethics useful in the application of multiple types of social challenge or fully address the range of activities that design practitioners complete. Merely considering the potential social impacts of one's work does not necessarily address how or why the work should be completed in the first place.

Participatory Design and Co-Design

With roots in Scandinavia, Participatory Design was born out of Marxist ideals and initially used to empower labor unions and workers to shape the technology they used in their work (Spinuzzi 2005). Since its conception, participatory design has been adapted to new contexts, but as a methodology, it is concerned with “exploration of tacit knowledge, invisible work, and unstated individual and organizational goals” (Spinuzzi 2005). Within participatory design (PD) practices, values are both implicitly and explicitly identified to help support positive outcomes better aligned to the needs of a specific population. In PD applications of virtue ethics, three key virtues are most important: cooperation, curiosity, and creativity. These are defined as such: 1) cooperation: seeking to “find an appropriate middle” and establish a space to do so. 2) curiosity: openness toward other people and their experiences. 3) creativity: openness to other ideas and a desire to productively combine them (Steen and Marc 2011). Co-design is a subset of participatory design, as both terms refer to collective creativity. However, the two terms developed separately--participatory design in Europe and co-design more commonly in the United States. Co-design, similar to participatory design, refers to “the creativity of designers and people not trained in design working together in the design development process” (E. B.-N. Sanders and Stappers 2008). Though co-design shares similar intent to collaboratively create with end-users, it is not framed with the same Marxist and democratic underpinnings as participatory design (Spinuzzi 2005; E. B.-N. Sanders and Stappers 2008).

PD practices have been recognized in other contexts, including persuasive computing, as a method to engage stakeholders in ensuring that vulnerable people are included in the values of design outcomes (Davis and Janet 2009). Participatory design has been identified as an application of dialogic ethics in which “meaningful communication between users and designers [...] can guide the development of effective and humane technological design methods” (Salvo 2001). This definition seems to rely on similar principles as defined by Becker et al. when describing communicative ethics (Becker and Leslie 2012), though Salvo describes dialogic ethics in the context of engaging with users rather than considering the implications of design interventions (Salvo 2001).

Human-Computer Interaction

Within the field of human-computer interaction (HCI), value sensitive design (VSD) prevails as the technique most used to consider ethics. Defined by Friedman et al., it identifies twelve "specific human values with ethical import:" human welfare; ownership and property; privacy; freedom from bias; universal usability; trust; autonomy; informed consent; accountability; identity; calmness; and environmental sustainability (Friedman and Jr 2002). Friedman et al. make three key ethical contributions: 1) they explicitly acknowledge that technology systems are hard to modify after they have been established, which necessitates early inclusion of ethics, 2) they suggest that multidisciplinary collaboration is required to support ethical engagement, and 3) they propose that there is a need to add human values to the list of criteria used to evaluate success in HCI (Friedman and Jr 2002). Since the original publication, VSD has been applied in other disciplines, including software engineering (Barn and Barn 2015).

Several HCI practitioners have analyzed the ethics of their work to understand applied ethics in HCI. Vandenberghe et al. reviewed two HCI projects that suggest the need for "explicit transparency," especially in regards to funding sources and "critical reflection" about the accuracy and intention behind methods used in HCI work. They were concerned that HCI methods are being used to mask malpractices due to underlying values and influences (Vandenberghe and Slegers 2016). As a result of analysis, Lööv et al. proposed a process of HCI completion in gate reviews, steps that must be completed before moving on in the technology development process to ensure ethical outcomes (Lööv and Joakim 2008).

Research practices in HCI also have well-documented ethical literature. Included in the discussion are evaluations of data privacy, informed consent, power structures, and ethical review boards. In research, evaluation of HCI ethics discuss informed consent, researcher-participant power differential, presentation of data in publications, the role of ethical review boards, and corporate-facilitated projects (Brown et al. 2016). Challenges specific to the field include: the creation of social environments, the power of research subjects to influence outcomes given their predisposition, and influencing information (Brown et al. 2016).

Challenges of modern technology capabilities have led to additional research tools and methods focused on maintaining anonymity, including one called un-googling, which entails removing identifying information from a publication like names, contextual details, and research location (Shklovski and Vertesi 2013). Privacy concerns in the era of big data fall under a theory called contextual integrity, defined as “sharing information according to the expectations under which it was originally offered” (Goodman and Elizabeth 2014). Additional research identified current ethical challenges in sensor ubiquity, the commodification of data, the opacity of information exchange, and scale of data capture (Goodman and Elizabeth 2014). One case reviews issues of data security and privacy given the use of data gathered from the Apple App Store. The case notes that there are conflicts intrinsic in ethics and that research and design are “enmeshed” (Rooksby et al. 2016). Another paper investigates how research in information technologies can bring values to light and provides a tool to analyze strengths and weaknesses of each method to reveal values (Shilton, Koepfler, and Fleischmann 2014). Yet another explores ethical issues intrinsic in collaborative storytelling mediated by technology (Mu et al. 2015). Despite all of the approaches outlined in the literature, a conflict of content and approach still exists for ethics, and though in many instances problems have been identified, interventions to help mitigate potential negative consequences are relatively nascent across the board.

3.3.3 Professional Codes of Design Ethics

Existing codes and frameworks for professional conduct in design are largely focused on the practice of design as a consultant and primarily consider the business ethics of work as a designer—not the outputs or process of design itself. Key topics include transparency, confidentiality, and a general belief that designers should do good. These codes of ethics are primarily delivered through professional associations, including the Industrial Design Association of America, AIGA | The Professional Association for Design, and the Association for Computing Machinery.[2] The effectiveness of these professional codes has not been explicitly studied, but since they provide only a cursory understanding of the ethical challenges confronting design practitioners, on their face, they seem marginally effective in supporting design practitioners in their work.

3.3.4 Existing Interventions/Tools to Support Design Ethics

Some interventions created in academic and professional contexts already support designers in ethical practice. For example, In "Design for Worldview," Kolawole developed a methodology to combine design thinking and the principles of unconscious bias training (Kolawole 2016). Microsoft developed a toolkit to improve the inclusiveness of products for people of all abilities (Microsoft 20162016). "Design for Agency" is a paper and associated materials about how to protect individual user agency in digital products ("Design for Agency"). However, these materials are often either narrow in their focus or not widely written about or evaluated beyond the initial proposal.

Designers have developed their own manifestos, including the "Ethical By Design Manifesto" (Mulvenna, Boger, and Bond 2017), intended for a broad audience, which looks to move beyond "autonomy, beneficence, non-maleficence, and justice" and codify a list of values for design. Further, practitioners have developed the "Designer's Oath," which was created by design practitioners in the Mayo Clinic's innovation group at the Mayo Clinic in response to a practical need ("Designer's Oath"). The "Ethical Design Manifesto" provides a framework for ethical design that is based on Maslov's hierarchy of needs that places delightful at the top, human effort in the middle, and human rights at the base (Kalbag and Balkan).

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[2] A more complete list of organization that provide ethical codes of conducts for their members includes: Academy of Design Professionals, Association for Computing Machinery, American Institute of Graphic Artists (AIGA), Industrial Designers Society of America, Australian Graphic Design Association (AGDA), International Game Developers Association, Interior Designers of Canada.

Frameworks have been developed to respond to designers' need to consider the ethics of their own designs. Triple Font Theory includes an ethics screen for the design of objects, which combines a conventional, principle-based, and ethical tests approach to determine if a course of action is morally acceptable (Arjoon 2007). In its evaluation, a "morally good object" must meet three criteria: the object, motivation for selection, and circumstances must each be morally good (Arjoon 2007). Considering the implications of designing for human sexuality, especially as related to "arrangements of responsibility and control," Goodman and Vertesi developed a series of "sensitizing questions" for designers to better consider how system-level decisions can change "capacities for action" among individual users (Goodman and Vertesi 2012). Designers have also explored techniques that use fiction to unpack and address the long-term effects of a designer's work in the context of HCI (Linehan et al. 2014).

3.3.5. Ethical Training/Education for Designers

Limited writings and tools exist to support the education of designers. However, numerous academics and professionals have pointed to the need for ethical training in design (de Waal Malefyt and Morais 2017, 87–103). In one study, a design educator used film, current events, and reflective writing to help students reflect on ethics–an approach students found helpful to begin thinking about ethical issues even though they recognized that the films provided extreme examples (Applin et al. 2006). In another, an educator integrated ethics into education through a writing process aimed at helping students identify their audience and ethical code (or nomos) (Trim and Michelle 2017).

3.3.6 Other Disciplinary Approaches to Ethics

What follows are brief summaries of the ethical frameworks of other disciplines. These are by no means exhaustive, but, in the context of this literature review, are intended to briefly introduce key concepts in order to identify overlap and gaps with existing design ethics literature and to establish a context for later sections.

Biomedical Ethics

Most modern concepts of biomedical ethics revolve around Beauchamp and Childress' Principles of Biomedical Ethics, which establishes a group of four values: autonomy, beneficence, nonmaleficence, and justice, held in tension with one another (Beauchamp and Childress 2009). In addition to this framework, the Belmont Report established key principles used in research. It discusses "(i) the boundaries between biomedical and behavioral research and the accepted and routine practice of medicine, (ii) the role of assessment of risk-benefit criteria in the determination of the appropriateness of research involving human subjects, (iii) appropriate guidelines for the selection of human subjects for participation in such research, and (iv) the nature and definition of informed consent in various research settings" (United States. National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research and United States. Dept. of Health, Education, and Welfare 1978).

Economic Ethics

In economics, especially behavioral economics, important discussions about the ethical implications of nudges used in behavioral economics include analysis of light paternalism tactics and issues of power and authority (Loewenstein and Haisley 2007). Though often associated with utilitarian ideas, the field of economics has also explored the application of multiple theories to economics to support better policy that is more tailored to the human experience (Wight 2015).

Engineering Ethics

Engineering ethics faces challenges because of its focus on individual ethics (Gunes 2012). Devon et al. suggest that design (in engineering) is an intrinsically ethical process and that a "social ethics paradigm" is an important method to uncover and make ethical decisions in design. Based in the thinking of John Dewey, the social ethics paradigm suggests that we must intelligently examine institutional customs and their consequences to determine how best to modify them (R. Devon and van de Poel 2004). It focuses on the design process, suggesting that improvements in process will lead to better outcomes, but recognizes the importance of acknowledging individual behavior (R. Devon and van de Poel 2004). Within the realm of computer science and computational engineering, discussions of disclosive computer ethics are "concerned with the moral deciphering of embedded values and norms in computer systems, applications and practices," meaning they seek to understand and structure methods for making the activities invisible to a user in computing to ensure ethical actions are being taken (Brey 2000). Suggested values in disclosive computer ethics include justice, autonomy, democracy, and privacy (Brey 2000).

Public Health Ethics

In public health, there are often challenges that ask public health professionals to break or prioritize existing bioethics principles, forcing a balance between individual ethics and societal ethics (Kass 2001). Practitioners are forced to prioritize either individuals or a broader community (often choosing the broader community) in the context of public health crises (Kass 2001). Kass proposes a "code of restraint" and "positive rights" as potential courses of action, which would allow public health practitioners to ensure individual rights whenever possible, but also affirm the need for improvement of the community that an individual is a part of (Kass 2001). Kass proposes a six-part framework for addressing ethical challenges to align with this "code of restraint" and "positive rights" combination. Additional frameworks in public health have been published by professional organizations like the Public Health Leadership Society, which include general principles that can guide practitioners as they work (Thomas et al. 2002).

Business Ethics

In entrepreneurship, business leaders face challenges of fairness, relationship management, distribution and other challenges, which can actively "complicate moral thinking and behavior" (Hannafey 2003). Dynamics in business are changing, and poor definitions make ethics challenging to navigate more generally (Lewis 1985). Businesses operate through contracts and are often established with the express purpose to improve shareholder value, a fiduciary duty between a company’s management and its shareholders (Boatright 1994). This relationship creates tension between the short- and long-term decision making of a company. However, triple bottom line theory says that to be sustainable, business must meet standards of economic prosperity, environmental quality, and social justice (Elkington and Rowlands 1999). New corporate forms are emerging to formalize the relationship between profit and social mission within a company’s bylaws, allowing for a more explicit ability to balance the financial needs of a company with a broader social purpose (Kerlin 2006).

On the whole, business ethics is not well adopted by practitioners. However, studies have been completed to measure the uptake of business ethics principles by employees, showing that only slight improvements have been made in recent years (Longenecker et al. 2006). However, studies have found that the existence of key factors can lead to ethical activity: immediate job context, organizational culture, and characteristics of work (Chau and Siu 2000) In business ethics, challenges with existing frameworks include their ability to be top-of-mind in “critical moments” (Mitchell and Yordy 2009). One example of an ethical framework for ethical decision making is called COVER It, which includes two key phases. The first is a due diligence phase in which relevant facts, issues, alternatives, and stakeholders are identified, and the second is a philosophical analysis phase that looks at the ethical challenge through a variety of lenses to more objectively evaluate outcomes (Mitchell and Yordy 2009).

Legal Ethics

The first list of ethics rules in law was documented in 1863 (Hoffman 1836). Identified standards for professional practice include: respect of client confidences, candor toward the tribunal, truthfulness in statements to others, and professional independence (Pirsig 1949). Codified in the United States by the American Bar Association, legal professionals have strict guidelines that govern their participation in and entry into the legal field, which include procedural requirements for their position, enforcement procedures, and guidance for attorney’s facing personal and professional dilemmas (Aba Center For and Center for Professional Responsibility (American Bar Association) 2009). Important debates about values in the legal profession, though well established, are still debated given new contexts, including the continued democratization of legal processes. Wendel calls for a continued alignment of the legal profession to historical calls to act in the public interest as an officer of the court, in addition to well-ratified confidentiality and loyal client service activities (Wendel 2013).

Journalism/Media Ethics

As is true for many disciplines, values in journalism and media are much debated, but substantial agreement about between professional codes of conduct are well documented (Roberts 2012). Institutions like the Poynter Institute have codified a set of principles and values to share widely with journalist audiences and provide training, writing, and other resources to professionals and help guide their thinking (“The Poynter Institute Code of Ethics”). Guiding principles include “seek truth and report it as fully as possible, act independently, minimize harm, and be accountable and transparent” (Poynter).

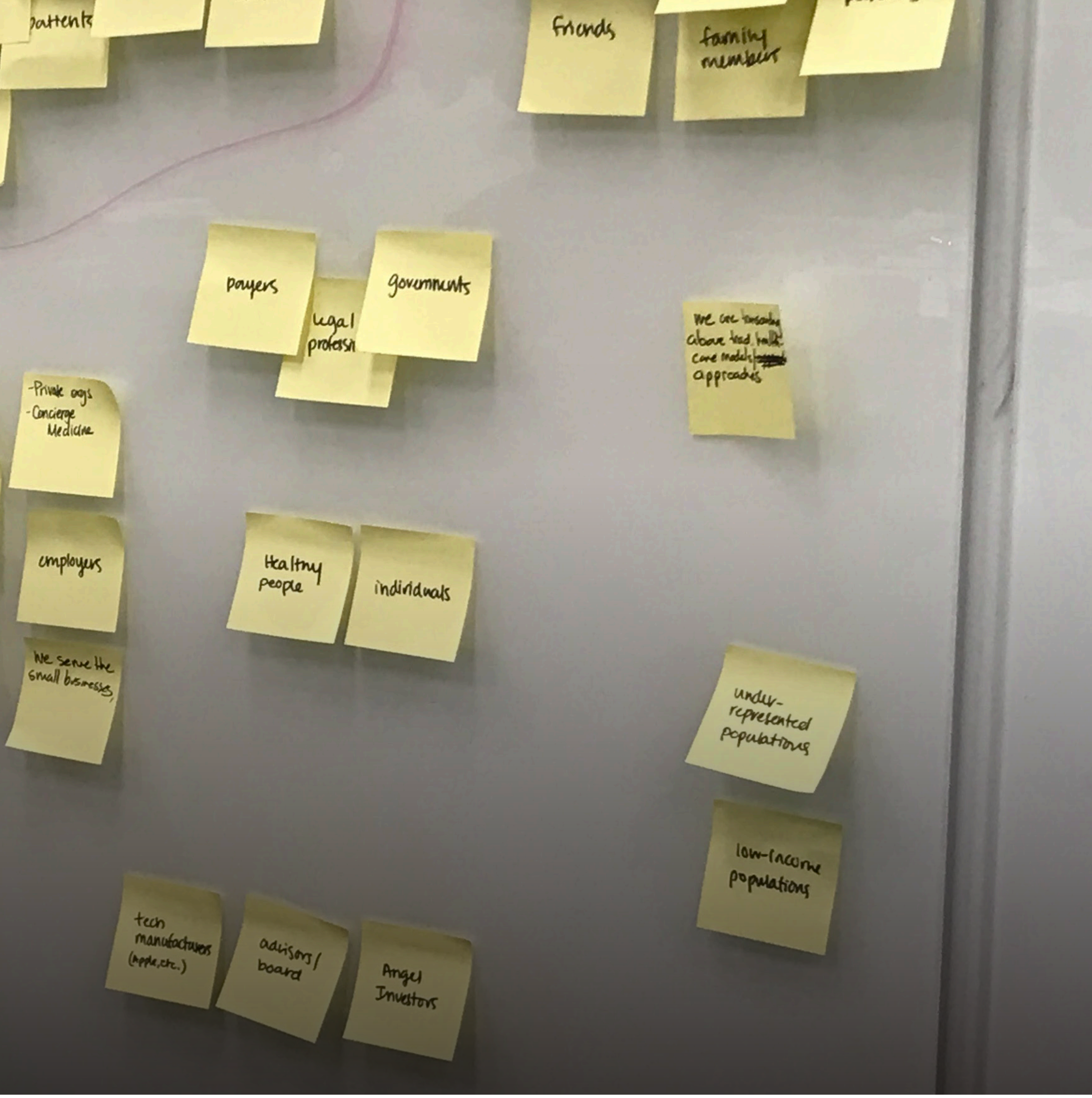
Identified problems for journalists and media professionals include: accuracy and verification, independence and allegiances, deception and fabrication, graphic images and image manipulation, sources and confidentiality, special situations like breaking news, and ethics in the age of the internet and citizen journalism (Ward 2009). In addition, literature points to ethics as a distinguishing factor between professional actors and amateurs (Craft 2017). And in situations where clear ethical standards have not been set by the field, structures are in place within news media institutions to allow, and in some cases require, individual actors to share the thinking present in their ethical decision making. However, these same structures do not extend to bloggers and other “participatory journalists” present in online journalism (Friend and Singer 2015).

3.4. Summary Thoughts

Free from the constraints of the real world, design in academia can occupy an ideal space. Thinking about design ethics in these ideal spaces, therefore, moves from truly applied ethics to applied in idealistic and unrealistic scenarios, which takes existing thinking about design ethics from being highly practical and useful to muddled concepts that bear little resemblance to the challenges designers face. In the practice of design in professional contexts, new power dynamics, environments, and social challenges make acting ethically difficult. Given the content of the current literature and gaps in the areas of practical tools, educational tools and resources, and sample applications of theory to practice, we have much work to do to better understand how ethics truly interacts with the practice of design.

4.0

METHODOLOGY



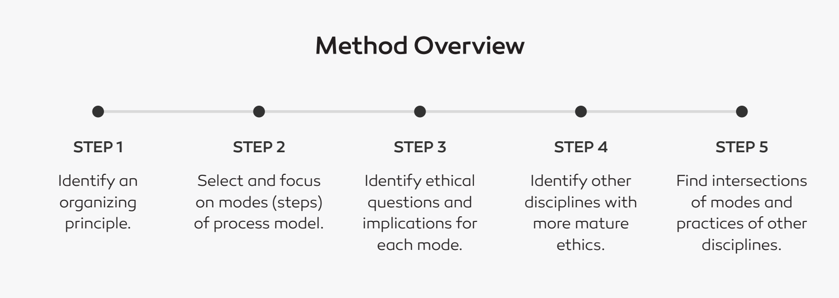
4.1. Purpose

This work seeks to understand ethics and its placement in design to organize existing approaches to applied ethics in the context of design practice. It aims to draft the beginnings of an analytical framework to incorporate ethics into the digital product and innovation work process.

4.2. Method

This work most closely aligns with a combination of research for design and research through design (Godin and Zahedi 2014; Frayling 1993). As described previously, the need for this research arose from Canopy, a project aimed to address advance care planning gaps, creating a digital tool to support families as they attempt to better clarify their wishes. Like the project that inspired it, this research also applies a post-positivist lens (Howell 2013). Rather than separate the ethics component of this research from the project that inspired it, naturalistic inquiry in combination with supporting primary and secondary research from the field of design ethics was used to inform the resulting proposed framework (Ritzer 2007). As the context of this research naturally shifted from within the Canopy project to a parallel track outside of Canopy, methods were chosen to both make sense of the large amount of data gathered through literature review and to organize information against processes utilized in the creation of Canopy.

In general, the ethical evaluation conducted as part of this thesis was grounded in the project work occurring in parallel for Canopy. During the course of design and development of the Canopy software, many ethical questions surfaced for the team. Inspired and spurred by these questions, I conducted additional research, analysis, and synthesis to understand how to fill identified gaps in ethical literature for the practice of design. The steps taken to conduct this parallel activity are outlined below.



Method Overview

STEP 1 Identify an organizing principle.

STEP 2 Select and focus on modes (steps) of process model.

STEP 3 Identify ethical questions and implications for each mode.

STEP 4 Identify other disciplines with more mature ethics.

STEP 5 Find intersections of modes and practices of other disciplines.

Figure 5.

Step 1: Identifying an Organizing Principle

To approach the topic of ethics, which is a rather large undertaking, I needed to identify a lens or organizing principle with which to view the challenges of design ethics. In addition to the gap analysis conducted during literature review, I also generated and reviewed potential ways to understand and improve the way ethics is integrated with design. In service of both project needs and broader applicability concerns, for the purposes of this research, I compared ethical texts and real-world situations facing the team in Canopy with a well-known process model developed by Vijay Kumar and published in 101 Design Methods (Kumar 2012a). This particular process model contains rich and layered information to help designers plan, execute, and evaluate their own processes. The model is organized around seven modes of design practice, which are steps design practitioners might take during the course of developing interventions. The model is concrete in its descriptions of these seven modes, pairing each mode with a list of mindsets and methods that can be utilized depending on where in the design process a practitioner finds themselves.

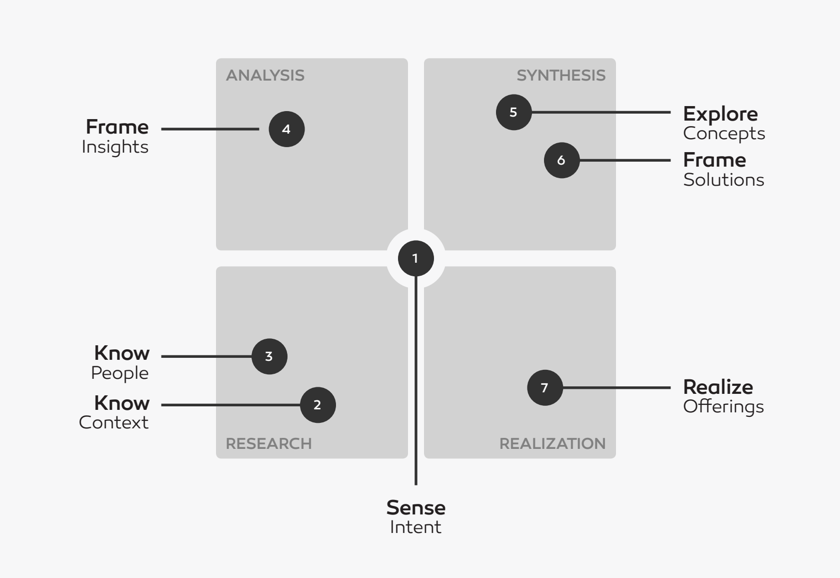


Figure 6. Process model for design innovation adapted from Kumar

Step 2: Select Process Model

To begin the analysis, I first focused on the seven modes outlined by Kumar. In the organization of the model, these seven modes are part of four broader phases and contain mindsets and methods within them. The modes are 1) Sense Intent, 2) Know Context, 3) Know People, 4) Frame Insights, 5) Explore Concepts, 6) Frame Solutions, and 7) Realize Offerings. (See *Fig. 6* above for a diagram outlining the Kumar process model.)

Step 3: Identifying Ethical Questions and Implications

Utilizing the summary description included in Kumar and practical experience gained during the course of developing Canopy and other software projects, I listed key questions and ethical implications at each step/mode of the process model in response to both the underlying project needs ex-post facto and prior project work in other contexts. Identifying these high-level questions help promote understanding of the types of situations a designer may find themselves in given the stage of the process.

Step 4: Identify Other Disciplines

To determine potential mediation of the ethical challenges faced in the design process, I identified and reviewed key literature, case studies, and characteristics of other disciplines with more mature approaches to ethics. The process of identifying the disciplines for inclusion was not based on highly-rigorous inclusion criteria, but rather on the existing literature review (described in section 2). Those selected include one or more of the following traits: 1) had established processes for ethical evaluation, 2) ethics played a substantial role in the practice of the discipline, and 3) cases of prior ethical decisionmaking are present in the disciplinary literature. The included list of disciplines described in the Results section is only a start; there are likely other relevant disciplines I was unaware of during the course of this analysis that would also apply usefully to design practices.

Step 5: Find Intersections

I looked at the literature from other disciplines, and in some instances, I talked to experts about their processes to find overlaps. I aligned the intersections between the process in design and the processes from these other disciplines to formalize where the needs of design practitioners intersect with other disciplines. Factors for alignment include similar activities or needs during the course of that disciplines' work, often derived from existing case studies or other examples of application that align with key challenges in each design mode.

4.3. Limitations and Risks

The methodology followed was conceived in response to real-world project needs and largely subjective evaluations of contextual information. Thus, the process will be difficult to fully replicate; however, every effort was made to detail the process to allow for thorough evaluation by other practitioners and researchers of the methods described in this section.

4.4. Ethics Statement

As defined in the HRPP Operations Manual (OM) Part 4, section V, subsection A, specifically outlined in table 6, this project is classified as a Quality Assurance and Quality Improvement Activity, and thus, falls outside of the Common Rule and FDA definitions of human subjects research and does not require IRB approval. However, all activity conducted as part of this project was conducted in a manner aligned to IRB best practices. Written or verbal consent was obtained from all participants to document or otherwise record the interaction and steps taken to both secure and maintain the privacy of all participants. When conducting observations or other activities in a medical context, Health Insurance Portability and Accountability Act (HIPAA) standards were followed.[3]

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[3] See a copy of relevant sections of the University of Michigan's operations manual: http://research-compliance.umich.edu/operations-manual-part-4

5.0

RESULTS

As a result of the analysis described above, I propose the following structures as useful to better understand the types of ethical considerations that design as a discipline may need to consider when developing a set of standard methods and principles for ethical action. Those findings are two-fold. First, I will outline consistent components that are true of matured ethical disciplines worthy of emulation by design practitioners. Second, I will outline how these components can be used in the design process by capitalizing on the overlap between design activities and the activities of other disciplines. Of note, the findings presented here were generated following the majority of the activity to create Canopy described in Section 2. Thus, many of the sample applications of the proposed framework were generated retroactively.

5.1. Components of Mature Ethical Disciplines and Status in Design

What follows is a list of the common components present in mature ethical disciplines (see *Fig. 7*) synthesized during the literature review detailed in section 3.0. *Component* here is defined as a characteristic, activity, or other descriptor of the practices or knowledge in a discipline that contributes to the successful application of ethics in the practice of that discipline. The titles for these components were generated to be useful, not necessarily based on an external, widely-accepted taxonomy. Other disciplines may call components something different, but to normalize the variation, I have named each component for the purposes of this thesis. Disciplines vary in the degree to which the components are present, and some disciplines have applied components to better success than others. Below, I will describe each component and describe where the discipline of design stands in relation to it.

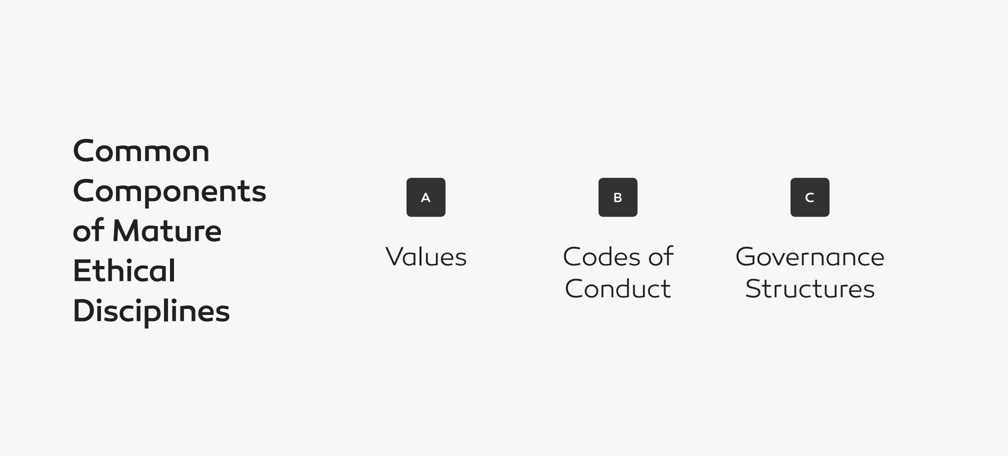

Figure 7.

5.1.1. Values (Component A)

Description. Values are often defined as an overarching framework by which to evaluate the morality of an action or set of actions. They are commonly used in tension with each other, allowing for competing values to exist at the same time. This often forces practitioners to engage in the hard work of evaluating their actions and making a choice given the evidence they have in hand.

Status for Design. As a discipline, design has not fully defined its values. Practitioners often pride themselves on being human-centered and showing respect for the populations they design with and for. Through manifestos, practitioners have formalized those values to share (Mulvenna, Boger, and Bond 2017; "Designer's Oath"). However, the values proposed are often debated and not yet consistent.

5.1.2. Codes of Conduct (Component B)

Description. Codes of Conduct are ratified rules or guidelines often set forth by a professional organization or governing body of a specific discipline. They are often intended to provide guidance for practitioners as well as frame the standards used to evaluate conduct in a given case.

D Public Discourse

E Evaluation Frameworks

F Educational Tools

G Best Practices

Status for Design. Design organizations have established codes of conduct for professionalism. Nearly every professional design organization has guidelines about what it means to be a design professional and the ethical standards one should uphold when conducting the business of design.

5.1.3. Governance Structures (Component C)

Description. This broadly includes process requirements, institutional support, and entities present in a discipline that define how ethics is considered, evaluated, and built within an organization or discipline.

Status for Design. Disciplines like journalism have established independent centers to research and inform professionals about the ethics of their work. In hospitals, specific protocols and committees guide medical professionals in reviewing and evaluating their actions against well-established value systems. Designers have yet to develop formal systems for the discipline or within organizations in similar ways.

5.1.4. Public Discourse (Component D)

Description. This includes the broad set of activities where professionals and scholars publicly discuss and debate ethics for the benefit of practitioners.

Status for Design. Discourse within the discipline is not well structured. Only one journal exists for the publication of design and philosophy. While canvassing available tools and resources, I read, watched, and listened to many lectures, talks, and speeches about design ethics. Though these conversations do occur frequently, they tend to only conduct surface-level evaluations of design ethics, providing broad calls to action in support of sustainability or “design for good.” Few examples discuss specific instances of ethical challenge or decision-making, resorting instead to well-known and understood examples of accessibility or sustainability in application for designers like plastic bag recycling and image overlays on the web.

5.1.5. Evaluation Frameworks (Component E)

Description. This includes tools, methods, and techniques that can be used to evaluate either pre-, during-, or post-implementation of an intervention or course of action.

Status for Design. Some of these exist in design, but on the whole, the discipline does not have many methods to evaluate the ethical implications of our work, especially in the context of large collaborations or systems-level interventions. And what does exist is not well-integrated into the practice models that design professionals use to organize their work.

5.1.6. Educational Tools (Component F)

Description. This includes the creation and utilization of teaching tools, lesson plans, case studies, and resources that can be utilized in an educational context (in academia or professionally) to teach designers about ethics and help them wrestle with, understand, and apply key ethical concepts.

Status for Design. To date, design has not built cases to help teach ethics. In other professional disciplines like law, medicine, and business, cases of past situations are presented as a way to learn from issues of the past and to explore personal and professional belief systems that guide our actions. Developing case studies falls beyond the scope of the work I completed this year, but is essential for the future of our discipline. We must think about ways to document ethical challenges we face as designers and centralize that information for educational use.

5.1.7. Best Practices (Component G)

Description. This includes situated, contextual instructions for design practitioners that, if well-followed, are likely to lead to positive outcomes based on prior experience and contexts where they have been applied.

Status for Design. Especially in the area of privacy, accessibility, and sustainability, best practices are emerging, but they are not yet centralized or easy to find.

5.2. Framework for Intervention

What follows are the various elements and formation of a framework for ethical alignment of design process and the ethical practices of other disciplines. This framework may be used to support design practitioners in organizing the many approaches to ethical practice that intersect the design process and to provide initial direction and support to design practitioners in the context of communication, products, service, and systems creation and implementation. The framework's aim is to support the maturity of design ethics and to help inform and organize additional dialogue about the future of design ethics and a more ratified and structured ethical practice in design.

5.2.1. Structure

The framework builds on the initial structures present in the process model developed by Kumar but aligns the modes contained in that model to useful components of ethical practice found in other disciplines. To do this, the framework aligns four key elements 1) the existing process mode from Kumar's model, 2) key ethical questions and implications for each mode, 3) aligned disciplines for each mode, and 4) for each aligned discipline, a summary description of the seven components outlined in section 5.1. The following diagram outlines the alignment for all seven of the modes present in Kumar's process model. It outlines the key ethical implications present in each mode and the disciplines that most closely intersect with those key questions. (See *Fig. 8* for visual depiction.)

5.2.2. Navigation and Use

As presented, this framework's navigation works similarly to Kumar's model. It is intended to be flexibly applied to a given context or situation. In Kumar's model, practitioners are free to navigate the various modes out of order, in different orders, and without all modes if a given situation calls for it. (See *Fig. 9* for a visual representation of pathways through Kumar's model.)

Designers can identify where they are in the process and navigate where they are going next.

Based on the activities completed and intended purpose of each mode, these are high-level guiding questions that designers can use to identify potential ethical implications.

Based on intersecting needs, these are disciplines that face similar ethical challenges.

These are the various elements that make up a given discipline's ethical practice and may be utilized by design practitioners.

MODE	ETHICAL IMPLICATION	ALIGNED DISCIPLINES	ETHICS COMPONENTS
1 **Sense** Intent	What is worthy of our attention?	Social Sciences, Business	For each discipline, all relevant and available components may be utilized to help support design practitioners. A Values B Codes of Conduct C Governance Structures D Public Discourse E Evaluation Frameworks F Educational Tools G Best Practices
2 **Know** Context	How do we source and find information? Where do we look? What do we include?	Journalism, History/Archive	
3 **Know** People	How do we engage people to understand their experience? Who do we reach? How do we do it?	Bioethics	
4 **Frame** Insights	How do we make sense of what we have uncovered? What do we keep? How do we frame it? What do we prioritize?	Law, Public Policy, Journalism	
5 **Explore** Concepts	What do we create? With whom?	Human-Computer Interaction, Participatory Design	
6 **Frame** Solutions	How do we craft and build an intervention? How do we ensure the right things are created?	Engineering, Public Health, Business, Medicine	
7 **Realize** Offerings	How do we deliver an intervention? Where do we start? Where should we go?	Business, Medicine, Law	

Figure 8. Framework overview and structure.

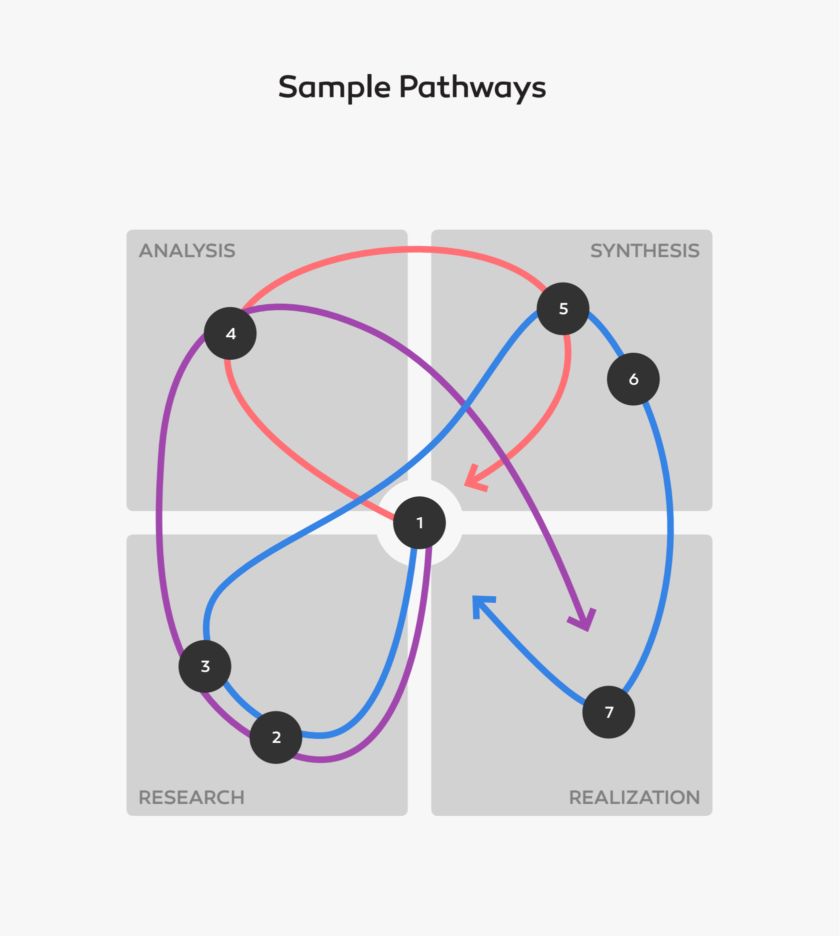

Figure 9. Adapted from Kumar.

Because the core components of the ethical framework are built on top of these modes, similar flexibility is afforded to design practitioners in navigating ethical components from other disciplines. Practitioners can use existing knowledge of the situation and of design to navigate to the logical step of the process in which they find themselves. In addition to the methods and mindsets set forth by Kumar, they can utilize the ethical support of other disciplines to improve decision making, explore long-term implications for implementation, and learn about the moral challenges present in their work. Once the design practitioners have identified a discipline most closely aligned to their situation, the various components of that discipline's ethics can support them through the key activities they will conduct. (See *Fig. 10* for a chart of how the various ethical components may be utilized.)

MODE	**POTENTIAL UTILIZATION** (Not Exclusive)
A **Values**	Used to form guiding principles and evaluate work
B **Codes of Conduct**	Used to shape rules of operation
C **Governance Structures**	Used to codify long-term implementation
D **Public Discourse**	Used to clarify contextual application and nuance
E **Evaluation Frameworks**	Used to aid decision making
F **Educational Tools**	Used to inform design practitioners and explore personal and professional ethics
G **Best Practices**	Used to aid in decision making, especially given constraints on time or resources

Figure 10. Utilization of ethical components.

Illustration of Navigation *(See Fig. 11)*

Mode 6 of Kumar's model is Frame Solutions. In this mode, design practitioners detail a concept and ask: how do we build it? Several disciplines

MODE	ETHICAL IMPLICATION	ALIGNED DISCIPLINES	ETHICS COMPONENTS
6 **Frame** Solutions	How do we craft and build an intervention? How do we ensure the right things are created?	Medicine	A Values C Governance Structures

Figure 11. Sample application of framework.

think about interventions and how they should happen, including medicine, which has all of the ethical components of a mature discipline. As design practitioners clarify their interventions, especially those involving the care or health of individuals, they can utilize medicine's values framework as a means of understanding how to think through their design decisions. In bioethics and medicine, four values (autonomy, non-maleficence, beneficence, and justice) are held in tension as a way to ensure measured and balanced interventions that serve the patient as well as possible. Replace patient with user, and the same works pretty well in a broader design process. These four values often contradict each other. For example, in a situation where limited medication is available, you may prioritize justice as a value to ensure fairness in the distribution of that medication rather than the autonomy of the patient. But the values allow practitioners to speak about the situation with clarity and navigate through decision making with a shared understanding of the ethics involved. Depending on the situation and their need for long-term process improvement, design practitioners can also look to governance models from health care institutions as a model to emulate in their own practice. Design practitioners need not utilize all seven components in a given situation, but rather, given their understanding of their current situation can select components of a discipline's (or disciplines') ethics that best apply to their situation. In the example provided here (see *Fig. 11*), only the component's (A) values and (C) governance structures were included, but in another situation, the chosen component may be (F) educational tools. My hope is that this framework may provide an initial starting point to support designers and prompt academic discussion about ethical design implications at various stages.

5.3 Application of Framework

What follows is a series of usage examples concerning various disciplinary ethics applied to Canopy's key design and implementation challenges. In some instances, the framework was applied retroactively due to the timeline of the two work tracks completed for this thesis. However, the examples provided here might allow design practitioners to understand ways to embed the ethical framework in their own processes as a way to plan their actions, navigate a challenging situation, or evaluate past actions.

5.3.1. Balancing Hierarchy and Power Dynamics in Health Care

Situation. In addition to developing the product intervention for Canopy, the team also developed a viable business model for the product. In the business model, we have multiple stakeholders, each with different value propositions and needs (See *Fig. 12*). We are crafting tools for

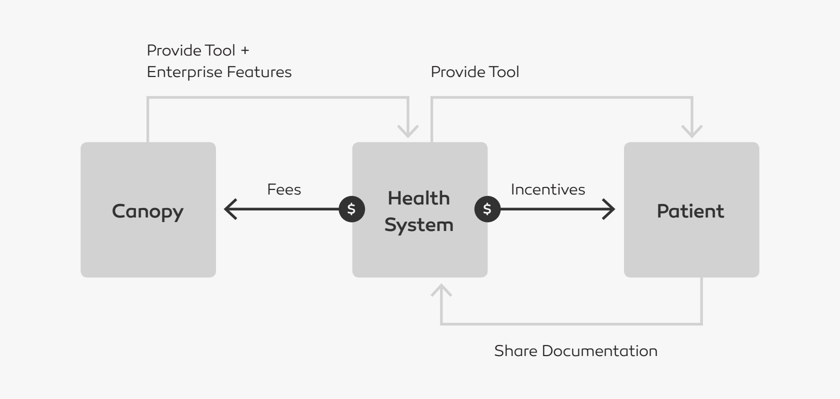

Figure 12. Diagram of Canopy business model.

individuals and their families, but our customers are the health systems and hospitals that serve them. And our value proposition for each of those audiences is different. For families, we provide peace of mind as they navigate the complexity of modern medicine. For health systems, we help reduce costs. Studies have shown that advance care planning can substantially reduce the cost of end-of-life care, mainly through the reduction of unwanted interventions would not have actually wanted.

Ethical Implication. Each audience has different perceived and actual power, especially in medical emergencies. In times of uncertainty, the default in the U.S. medical system is to act in order to keep patients alive or make them healthier. But for some people, those actions are not the right or desired move. In the course of developing Canopy, many of the individual providers we spoke with have affirmed their intention to support patient-centered care. However, health systems are businesses that have to make money to survive, which leads to the potential for abuse, especially in the context of a third-party service like Canopy. And Canopy's customer differs from its end-user. Based on our interviews and literature review, we determined that the incentives for families and the incentives for the health system to use Canopy are, in the aggregate, aligned. But ensuring that alignment continues is essential to protect the people who use our tool.

Applying the Framework. Detailing the business model and feature set of a product falls in Mode 6 of Kumar's model. One of the other disciplines aligned with that mode of activity is Medicine, which has put governance structures in place to ensure positive health outcomes. Medicine thinks deeply about interventions and how they should happen. For Canopy, we have used medicine's values and governance structures as a way to analyze some of the tactics we used to distribute and structure Canopy. In general, this allowed us to understand situations in a medical hospital that test the limits of reasonable decision making and put providers in precarious situations. This, in turn, allowed us to understand the types of situations we might need to account for and build structures to support in Canopy itself. For example, in situations where a patient has Alzheimer's or dementia, rules and regulations built upon a need to ensure autonomy (one of medicine's values) create confusing decision-making challenges when an earlier conversation with a loved one during a moment of clarity contradict the patient's expressed wishes during a moment of diminished mental capacity. We have built video and multimedia capture experiences into Canopy to support decisions and ensure patient autonomy, as well as building simpler sharing features to help families better advocate for the patient in emergency situations, emphasizing patient authority over the health care process.

MODE	❻ Frame Solutions
DISCIPLINE	Medicine
ETHICS COMPONENTS	A Values, C Governance Structures

5.3.2. Implementing interventions that Contain Nudges

Situation. During the process of creating Canopy, we faced tough choices about curating topics of conversation that can change the course of someone's life drastically. Existing advance care planning training and techniques emphasize the need for neutrality, but content and framing presented in Canopy is inherently biased. How we ask questions of families and the content of those questions will change how families move forward in their lives. As we developed Canopy, we brainstormed and curated topics from existing advance care planning practices and content captured during the course of interviews. (See *Fig. 13*).

Ethical Implication. An inherent tension exists in any intervention between ease of use and comprehensiveness. For Canopy, existing barriers to entry already make it hard to speak about and make end-of-

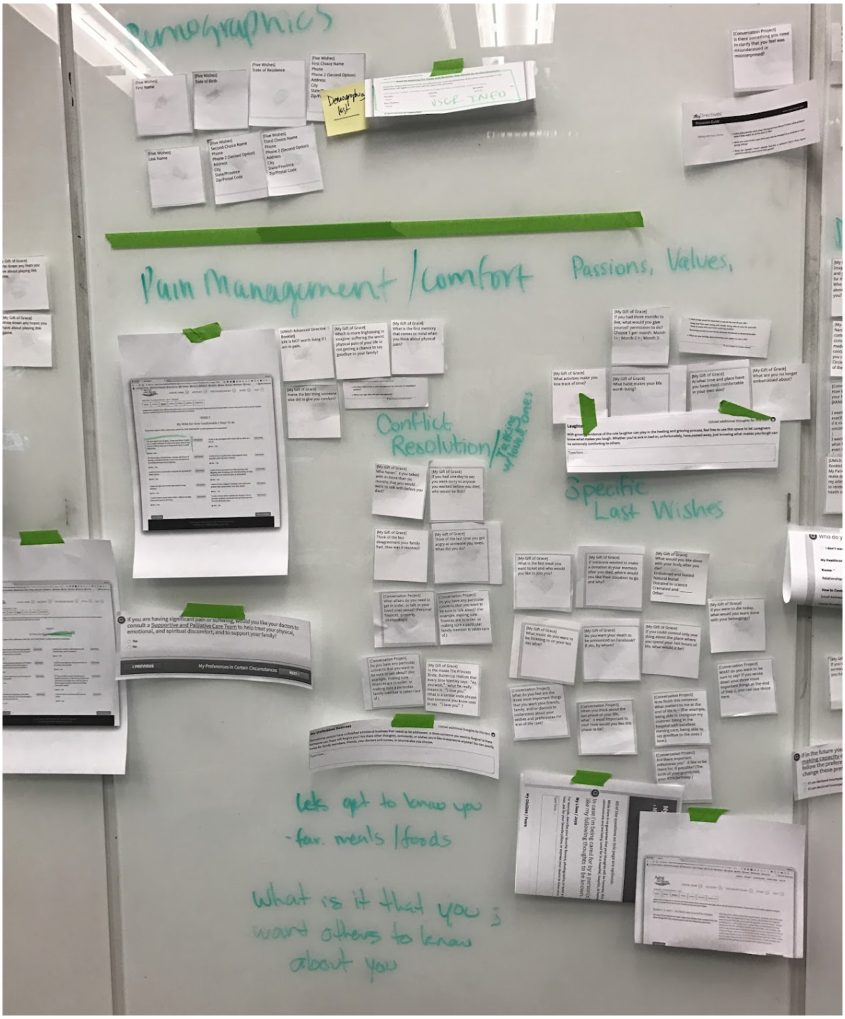

Figure 13. Image of affinity diagramming exercise while determining topics of conversation to include in Canopy.

life health care decisions. Currently, families do not complete advance care planning because talking about death is hard and, in our society, families lack proper support and incentives to get started. However, to holistically support individuals, we curated and developed nearly 50 topics of conversation in the initial phases of Canopy's development. They ranged from talking about organ donation to what does a good day looks like. Grouping these topics worked just fine, but prioritizing them was a challenging exercise given the ethical implications of leaving wishes incomplete. Making decisions about what to include or not to include was paralyzing. And further, sharing that information with people in a transparent and informed way proved a design hurdle to overcome. Key questions included: How do you realistically remain neutral? To what extent is that important? Is it possible? What should the people you are speaking with know about you before you begin? What does the process look like?

Applying the Framework. Against mode 5, explore concepts, we were able to utilize human-computer interaction (HCI) tools and frameworks to think about digital autonomy and how to safeguard information and privacy. Value Sensitive Design, though not perfect, was a useful framework to clarify how to prioritize user autonomy and transparency tactics. In addition, digital patterns created by industry practitioners helped support more effective and rapid implementation of good principles into our design prototypes, including disclosure of data usage and privacy terms and conditions ("Data Permissions Catalogue").

MODE	⑤ Explore Concepts
DISCIPLINE	Human-computer Interaction
ETHICS COMPONENTS	A Values, G Best Practices

5.3.3. Including Underserved Voices

Situation. From the early days of our collaboration, as a team and now as a company, we have espoused the value and need for health equity. We believe everyone should have access to advance care planning. As a team, we've included structures in our business model and crafted values statements that emphasize the need for diversity, equity, and inclusion in the work that we do. To include those most marginalized, we offer Canopy for free to people who qualify for income-based social services, waiving the fees charged to a health system for any of their beneficiaries who cannot pay for it.

Ethical Implication. To deliver on our promise of inclusivity, we needed to capture and document the cultural differences present in early research about Canopy. And though Canopy's team is by percentage majority woman and minority, there were (and are and will be) gaps in our knowledge regarding how broad audiences approach and discuss advance care planning topics. In addition, logistical and geographic constraints mean that access to a diversity of research participants and experts is not always possible. In addition, the challenge of representing that information successfully in documentation and in shared materials, especially when considering the understanding and perspective of a wider team and broader audience, also proved were also difficult.

Applying the Framework. While framing insights (mode 4), the team utilized journalism's values systems and public discourse about the presentation of information. Journalists uphold key principles about the accurate and fair representation of information that is well sourced and researched ("SPJ Code of Ethics"). We struggled throughout the development of Canopy to source and gather participant data from a wide range of potential end users. During the course of development, we needed to share the insights gleaned from interviews, observations, and survey data with other team members and collaborators along the way. To ensure that individuals were accurately represented, care was taken to generate user personas that accurately reflect the real people we interviewed. In the process of sharing information, we did our best to accurately recreate the situation our subjects found themselves in by using audio recordings, photography, and accurate transcripts to ensure information is not lost in translation or intentionally misrepresented to fit a desired set of facts.

MODE	④ Frame Insights
DISCIPLINE	Journalism
ETHICS COMPONENTS	B Codes of Conduct, G Best Practices

6.0

CONCLUSION AND FUTURE WORK

In this thesis, I have outlined a proposed framework for organizing ethical frameworks from a broad array of disciplines against a well-established process model for design to help support practitioners as they navigate their design work. This framework was developed in response to and in dialogue with Canopy, a digital tool to support individuals in their completion of advance care planning processes. As discussed, the framework was developed because of the need to wrestle with deeply ingrained ethical challenges during the creation of Canopy.

For design to reach ethical maturity (at least to the level of other disciplines), we have much work to do. But I hope that by organizing against our process, we might be able to accelerate the journey to get there. Other disciplines have developed and documented additional tools, structures, and thinking around ethics that are presented herein as the component of ethical practice.

Ethics can be deeply known and understood by an individual, but sharing one's ethics in a team or group setting requires language and structure to thinking, especially when it comes to teams and groups with differing amounts of experience and knowledge. Without these language and structured thinking, the time it takes to evaluate and think through good practice and the expense of that process, means design practitioners are disincentivized to carefully consider the consequences of their actions. Design as a discipline has borrowed from other disciplines to establish its own methodology. (Design research practices are largely borrowed from marketing and the social sciences.) A similar approach in ethics, therefore, seems appropriate.

The framework presented here is intended to support the further development of ethical scholarship and practice within the design discipline. It is my hope that others may find it valuable and useful in their own work as they seek to conceive, plan, and implement interventions using design methodology. I offer it to the field as a starting point only, and hope that others build upon, adopt, change, and evaluate it to better suit their needs with the ultimate aim of building better habits and practices within the discipline of design and among design practitioners as we navigate increasingly complex and wicked challenges.

Future Work

There are several areas of research into design and ethics this thesis does not address due to time and logistical constraints. The following items are worthy of further research or action:

- Developing a bank of case studies developed to help educate and inform design practitioners through casuistry, similar to cases presented in law, business, or medicine that help professionals practice. Aimed to help better prepare designers and students to enter new situations with a philosophical and moral grounding.

- Creation of additional tools and methods to help designers and design practitioners cope with ethical challenges. The framework presented herein is a step in the right direction, but is not complete and further perspectives would help fill in gaps and provide changes that could help support in new ways.
- Thorough evaluation with design practitioners to understand how they might utilize the model in their work are not yet complete. More formal analysis and evaluation will be needed to understand the efficacy of the proposed framework.
- Determining requirements for and developing a design ethics institute dedicated to research and inquiry with the goal of discovering, developing, and promoting design ethics and other ethical frameworks in the context of design.

Final Thoughts

Ethics is challenging in any context. During the course of my thesis work, I often questioned my ability to answer even basic questions about how to act ethically in design. I recognize that the framework here is imperfect, but by proposing it, I hope designers, design educators, students, and those interested in applying design to their work can better approach our work and wrestle with ethical decisions more effectively. Like any prototype, now that it exists, it can be better evaluated and tested in additional contexts beyond the scope of one project.

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