Designing with (Political) Complexity: Understanding Stakeholders, Emotion, Time, and Technology in the Case of Medical Aid-in-Dying

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Abstract

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In today's increasingly technological society, human activity cannot be properly understood without referencing computing artifacts. As we interact with and through these artifacts in everyday life, they affect our emotions and sensibilities, our thinking and decisions, and how we act individually and collectively. Designers of artifacts, on reflection, inevitably take part in shaping the sociopolitical fabric our society. With this dissertation my overarching goal is to support, or rather cultivate and transform, the ways people understand, communicate, and act upon sociopolitical issues through design. I conducted investigations on stakeholders, emotion, time, and technology in the case of medical aid-in-dying. Medical aid-in-dying invokes diverse (and often conflicting) perspectives among stakeholders, providing a rich context for investigating how to design technology vis-à-vis a complex, multi-faceted process of social change. Specifically, I conducted semi-structured and task-based interviews with 27 professionals (15 health care workers and 12 NGO volunteers), who worked with patients considering medical aid-in-dying. I examined communication media and challenges, sensitive keywords and terminology, and stakeholders.

Entangled in the web of complex social dynamics, my work raises methodological and ethical challenges, and calls for new design methods and frameworks. Methodologically, my dissertation contributes two new design methods—Stakeholder Tokens for eliciting diverse stakeholders and their interaction dynamics, and Meanings and Emotions for addressing participants' emotions and sensibilities around controversial topics. Theoretically, the findings from this dissertation broaden human-computer interaction (HCI)'s understanding of publics by conceptualizing publics as a sociopolitical process of evolving public consciousness rather than as embodied persons who are somehow parallel to the concept of users. In addition, the findings extend value sensitive design's conceptualization of stakeholders to include frameworks for excluded stakeholders, core and peripheral stakeholders, and difficult stakeholders. The findings also extend multi-lifepsan design by introducing a new category of multi-lifespan problem—which I call "slowly evolving public consciousness." At the broadest level, my dissertation contributes to a fuller understanding of and richer discussion around what it means to design with publics in complex sociopolitical contexts.

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Content

1. Introduction

Nearly three decades ago, Winograd and Flores (1986) wrote that “we encounter the deep question of design when we recognize that in designing tools we are designing ways of being” (p. xi). Their insight is strikingly relevant in today’s increasingly technological society. For the most part, human activity cannot be understood without referencing various computing artifacts. As we interact with and through these artifacts in everyday life, they affect our emotions and sensibilities, our thinking and decisions, and how we act individually and collectively. Designers of artifacts, on reflection, inevitably take part in shaping the sociopolitical fabric our society.

My research in human-computer interaction (HCI) focuses on the ethical and political implications of design at a societal level (e.g., publics) as well as at an individual level (e.g., private users). The notion of *human* in human-computer interaction has been shifting over time. Traditionally, HCI focused on the experience of individual users (e.g., ergonomics, cognitive science), which was extended to a group or community (e.g., groupware), and to a larger society (e.g., social computing). As interactive technologies become more pervasive, new opportunities arise for wider publics to leverage such technologies to emerge, communicate, and engage in social change. In the past several years, HCI and design researchers have begun to explore issues that arise from working with publics in highly complex and politically sensitive contexts. Such design research is still in its nascent stage. Little is known about who publics are and how to design technology for long-term social change. Open questions abound: How do people experience and engage with highly sensitive and controversial sociopolitical issues? How can we design systems to support political communication and social change as they unfold over very long periods of time? What design methods can we use? What frameworks would be helpful? What systems could be built?

With this dissertation my overarching goal is to support, or rather “cultivate and transform” (Bardzell & Bardzell, 2015), the ways people understand, communicate, and act upon sociopolitical issues through design. Entangled in the web of complex social dynamics, my work raises methodological and ethical challenges, and calls for new design methods and frameworks. To center my research focus, I conducted my investigations around the case of medical aid-in-dying. Medical aid-in-dying invokes diverse (and often conflicting) perspectives among stakeholders, providing a rich context for investigating how to design technology vis-à-vis a complex, multi-faceted process of social change.

The specific research questions follow:

Research Question #1 Communication. How do people communicate political issues and in what context? What media are used and for what purposes? What are the key communication challenges and opportunities?

Research Question #2 Issues. What is at stake? What are the critical and sensitive elements that underlie the political issue? What are the points of contention?

Research Question #3 Stakeholders. Who are the stakeholders? How do stakeholders interact with each other, in particular, in highly politicized contexts?

Research Question #4 Multi-lifespan. How can we design systems to support political communication and social change as they unfold over very long periods of time? What can we learn about sociopolitical issues by looking through the lens of multi-lifespan design? What are key attributes of a multi-lifespan design problem? What are key multi-lifespan design challenges and opportunities?

My work combines theoretical constructs from political theories, media studies, and social sciences with human-centered design practices from value sensitive design and multi-lifespan design.

My contributions are three-fold: theory, methods, and domain knowledge.

- Theoretical contribution to advance the (a) conceptual framing of publics and political communication; (b) understanding of stakeholders in a way that can provide HCI designers with a useful lens to for engaging diverse perspectives in highly complex settings; and (c) conceptual framing of multi-lifespan design problems.

- Methodological contribution to develop new design research methods for engaging with participants in highly complex and sensitive contexts.

- Domain contribution to broader end-of-life HCI and sociopolitical design.

2. Background

2.1. Defining Publics

Publics are queer creatures. You cannot point to them, count them, or look them in the eye. You also cannot easily avoid them. They have become an almost natural feature of the social landscape, like pavement.

—Michael Warner, 2002

In the past several years, human-computer interaction (HCI) and design researchers have begun to explore designing with "publics" (sometimes used interchangeably with "civics") in sociopolitical contexts. Contestational design (Hirsch 2006; Hirsch 2009), political design (DiSalvo, 2010), adversarial design (DiSalvo, 2012), public design (DiSalvo et al., 2014), agonistic participatory design (Björgvinsson, Ehn, & Hillgren, 2012), digital civics (Olivier & Wright, 2015), object-oriented publics (Jenkins et al., 2016), and speculative civics (DiSalvo, Jenkins, & Lodato, 2016) have all emerged in the last decade. Across such a variety of labels and design practices, one notable trend in these lines of research is to take pluralistic and emergent views on modern publics as opposed to a single undifferentiated public (DiSalvo et al., 2012; Lindtner et al., 2011). Concurring with this orientation, I distinguish "publics" from "the public" to highlight publics indefinite and pluralistic qualities. Yet there has been little attempt to explicitly address the fundamental mismatch between the emergent concepts of publics and the traditional notion of "users" that is understood in HCI as identifiable individuals or groups of individuals.

John Dewey (2008[1927]) made it clear in his seminal work *The Public and Its Problem* that publics must not be taken for a social community with shared interests and identity. As Noortje Marres (2005) noted, Dewey's publics are a community of strangers, "who are jointly implicated in an issue but who do not belong to the same social world." Michael Warner (2002) further argued that publics are a virtual social imaginary made up of indefinite strangers as opposed to particular persons in their singularity:

> The modern social imaginary does not make sense without strangers. …This constitutive and normative environment of strangerhood is more, too, than an objectively describable gesellschaft; it requires our constant imagining. (Ibid., p. 75–76)

Recognizing publics as a virtual social imaginary presents a new challenge for conventional user studies, where the foundational premise of user-centered-design is that we can meet, observe, and study users so that we can know them (see Table 1). In contrast, publics are made up of indefinite strangers, who, by definition, are unknown and unknowable to us. Yet we can still perceive, imagine, and talk about publics of their very being, in a quite casual way, which make publics so interesting. Warner (2002) wrote: “Publics are queer creatures. You cannot point to them, count them, or look them in the eye. You also cannot easily avoid them” (p. 7). A question arises: How can we engage such queer—amorphous and indefinite—publics in our design processes? Design research methods that rely on targeted, well-defined users will necessarily come up short. Consider personas for example. How can we build a persona that is representative of publics? What would that persona look like? Modern liberal democracy has become increasingly sensitive to the notion of diversity. Publics concern everyone from all walks of life, regardless of ethnic/racial identity, gender identity, sexual orientation, age, socioeconomic status, education level, religious beliefs, and differences in physical and cognitive ability. How do we elicit all of

Users	**Publics**
Targeted	Inclusive
Well-defined	Amourphou, Indefinite
Direct Stakeholders	Direct, Indirect, Excluded Stakeholders
Immediate	History, Past, and Future

Table 1. Key characteristics of users vs. publics.

these complexities and nuances and then synthesize them into a consolidated, operative image of the user? New approaches and methods are needed to engage publics in design.

I argue that publics can be more aptly conceptualized as a process rather than as people per se. To design for publics means to design in support of sociopolitical processes of issue formation and development of public consciousness rather than to design for certain "people" that are somehow parallel to the concept of users. Noortje Marres (2005, 2007) highlighted the process of issue formation (or "issue making") as a core mechanism for bringing publics into being. She defined issue formation as "the public-ization [sic] of an issue in a controversy" (Marres, 2007, p. 773). According to Marres, issues are made, or rather, *designed*, to become a controversy to provoke publics' attention. On a related note, Warner (2002) emphasized the notion of public attention as a constitutive aspect of publics:

> Publics, …lacking any institutional being, commence with the moment of attention, must continually predicate renewed attention, and cease to exist when attention is no longer predicated. (p. 87)

In other words, the existence and absence of publics depends on sociopolitical processes of issue formation and public attention. I further argue that such processes can take a very long time, in particular, for public consciousness to evolve around more progressive issues. From this perspective, my dissertation investigates sociotechnical processes of issue formation, i.e., focusing on political communication mediated by technology: What is the issue at stake? What roles do design and technology play in shaping issues? In turn, what roles do design and technology play in shaping public consciousness? These questions lay out critical considerations for my dissertation.

2.2. Characteristics of Political Issues

Public attention is difficult to attract and sustain; in Ben Berger’s word, “attention deficit democracy” (Berger, 2011). A question emerges: What makes certain issues important enough to warrant publics’ attention? Here, I highlight two key characteristics of political issues—(1) political issues are consequential; and (2) political issues are conflictive and provoke emotion.

(1) Political issues are consequential. Political issues are perceived to exert widespread impact and lasting consequences on the lives of people writ large (Dewey, 2008[1927]). In making a distinction between the sociocultural and the sociopolitical, Ron Eyerman (1992) emphasized that the ends of political action must aim at binding for the entire political community:

> Thus it is possible to make a distinction between sociocultural and sociopolitical movements. Sociocultural movements, for example, religious sects or countercultures, make use of legitimate and accepted forms of collective action—public demonstrations, recruitment, bloc voting, and so on—in their attempts to increase their numbers and secure the right to practice their beliefs. Yet they usually do not intend by these actions to make these beliefs or practices binding on the entire political community. When they do, as in the case of many contemporary Islamic movements, they are no longer sects or sociocultural movements but full-fledged sociopolitical movements. (p. 43)

Political issues bear certain yet unforeseeable binding consequences for the complex sociopolitical ecosystem of indefinite strangers we refer to as publics. As Walter Lippmann (1993[1927]) keenly observed, the modern society is immensely complex compared to a person’s “simple” political capacity. The scope of full consequences resulting from actions associated with political issues extends well beyond any individual’s ability to comprehend and control, no matter how expert she may be. As individuals we are far less informed than we would like; we have limited foresight into the future; and we have a limited attention span:

> The ramification of the issues before the public is so wide and intricate, the technical matters involved are so specialized, the details are so many and so shifting, that the public cannot for any length of time identify and hold itself. (Dewey, 2008[1927], p. 320)

Individuals are only "boundedly rational" to understand the relationship between specific means to an end when it comes to political issues, or in other words "politically-disabled," as Bruno Latour (2005) bluntly put it. Hence, political issues require attention of as many publics as possible to vigilantly monitor associated actions and consequences so as to recalibrate meanings of the issue as events unfold. As such, the United States employs a political and legal framework called "laboratories of democracy" (Galle & Leahy, 2009). The federalist system of government in the United States allows (and encourages) state and local governments to "test" new sociopolitical ideas without risk to the rest of the society. Based on the Tenth Amendment, state and local governments have the autonomy and political power to create their own laws and policies, thus acting as social laboratories. This framework has been one of the hallmarks of US federalism and was praised by the U.S. Supreme Court Justice Louis Brandeis (1932) in *New State Ice Co. v. Liebmann*, 285 U.S. 262, 311:

> To stay experimentation in things social and economic is a grave responsibility. Denial of the right to experiment may be fraught with serious consequences to the nation. It is one of the happy incidents of the federal system that a single courageous state may, if its citizens choose, serve as a laboratory; and try novel social and economic experiments without risk to the rest of the country.

The federal government, in turn, will select policies deemed most "successful," or rather politically attractive, to establish new policies at the national level. Such process can take a long time, which can only be sustained by continuous rekindling of publics' attention, which leads to my second point:

(2) Political issues are conflictive and provoke emotion. “A man is interested only when events have been melodramatized as a conflict,” wrote Walter Lippmann (1993[1927], p. 55). Although exaggerated, Lippmann keenly depicts the conflictive nature of political issues and publics’ emotion incited by the conflict and vice versa. Albeit in a different context, Chantal Mouffe (2007), who viewed irresolvable conflicts among publics as a constitutive aspect and a driving political force of democracy, similarly noted that proper political questions must *always* be presented as a point of contention. She wrote: “Properly political questions always involve decisions which requires us to make choice between conflicting alternatives” (Ibid., p. 2). Mouffe argued that such conflicts defy rationalistic solutions, highlighting the difference between political issues and “mere technical issues to be solved by experts” (Ibid.).

Furthermore, conflict extends not just to ideas or political questions but to the choice of different modes of communication—language, expressive style, medium, and so forth (Warner, 2002). In the following chapter I review two major political theories that describe democracy in contemporary society—the Habermassian public sphere (Habermas, 1991[1962]) and Mouffe’s agonistic pluralism (Mouffe, 2005)—focusing on how each theory characterizes political communication. Pointing to their limitations, I turn to the theory of affective publics (Papacharissi, 2015) as a fruitful lens that can help account for emotional and hybrid aspects of political communication.

2.3. Political Communication

2.3.1. Public Sphere

One of the most influential democratic theories is that of Jürgen Habermas (1991 [1962]). Habermas imagined publics to manifest in the form of public opinion derived from people’s “pubic use” of reason. Habermas described public opinion as articulating general interest on matters of common concern as opposed to expressing private interest on matters of personal concern. To generate such public opinion, Habermas argued that a person should effectively "bracket" one's private self—of their embodiment, identity, status, social relations, etc. A person should not let their own self-interest interfere with their public reasoning about the issues at stake—an idea related to what John Rawls (2009) called the "veil of ignorance."

In HCI we see evidence of a Habermasian view on publics in online deliberation forums (e.g., Kriplean et al., 2012). While the Habermasian public sphere is impartial and inclusive in theory, many feminist critics point out that in practice his idea of critical rational debate privileged a particular type of publics—that is, educated masculine bourgeois urbanity (Warner, 2002). By the same token, online deliberation forums endorsing Habermasian public sphere theory can be criticized for imposing a form of "discourse elitism," thus, excluding many "ordinary citizens" (Hindman, 2008).

2.3.2. Agonistic Pluralism

There is a growing body of work in the HCI and design community that draws from Chantal Mouffe's agonistic pluralism (2005)—contestational design (Hirsch, 2006), adversarial design (DiSalvo, 2012), and agonistic participatory design (Björgvinsson, Ehn, & Hillgren, 2012) to name a few. Agonistic pluralism gained interest as a critique of and a viable alternative to the deliberative models of democracy (i.e., Habermasian public sphere theory). Mouffe regarded the notion of social consensus, which is the core of deliberative democracy, as a "dangerously utopian idea" (Mouffe, 2005). In contrast, she argued that political problems are irresolvable at heart. More importantly, she saw conflicts as a driving political force of positive social change. In critique of the traditional consensual models of democracy (both deliberative and aggregative models), Mouffe envisaged a new model—namely, *agonistic pluralism*:

> This question, *pace* liberal theorists, is not how to negotiate a compromise among competing interests, nor is it how to reach a 'rational,' i.e. a fully inclusive, consensus,

> without any exclusion. Despite what many liberals want to believe, the specificity of democratic politics is not the overcoming of the we/they opposition but the different way in which it is established. What democracy requires is drawing the we/they distinction in a way which is compatible with the recognition of the pluralism which is constitutive of modern democracy (Mouffe, 2005, p.14).

According to Mouffe, publics are organized via collective identities of self and "legitimate others," which she called *adversaries* as opposed to illegitimate *enemies*. Criticizing the so-called "third way politics," she called for the multi-polarization of power. The notion of polarization is neither intrinsically evil nor can it be eradicated from society. Polarization is not just a human artifice of extremism but a commonly observed phenomenon in nature—it is observed in "birds of a feather," a flock of sheep, and a pack of wolves. Many sociological studies have explored the concept of *homophily*—the process by which "similarity breeds connection" (McPherson, Smith-Lovin, & Cook, 2001). Furthermore, on many occasions, polarization worked as a positive mechanism for giving voice to the marginalized (e.g., disability rights, feminism, LGBTQ rights) and as a driver for positive social change:

> When people shift from indifference to intense concern with local problems, such as poverty and crime, group polarization is an achievement, not a problem. Barry Goldwater was correct to say that "extremism in the defense of liberty is no vice." The American Revolution, the civil rights movement, and the fall of both communism and apartheid had everything to do with mechanisms of the sort sketched here. Once we acknowledge that extremism can be desirable, and that group polarization can move people toward engagement in solving serious problems, the analysis has to be modified. But how? (Sunstein, 2009, p. 149).

Key challenges of the political, then, are neither about depolarizing nor about removing conflicts. Mouffe noted: "the challenge for democratic politics consists in trying to keep the emergence of antagonism at bay by establishing the we/they in a different way" (Mouffe, 2005, p. 15). But how do we turn destructive antagonism into constructive agonism?

According to Mouffe, the key to creating a multi-polarized agonistic democratic space lies in the effort to keep the political terms as salient and as clearly separate as possible from the rest of the contentious areas such as ethics, morals, and religion. Ethics, morals, and religion are often essentialist or fundamentalist, therefore, leaving little room for acknowledging others:

> When politics is played out in the register of morality, antagonisms cannot take an agonistic form. Indeed, when opponents are defined not in political but in moral terms, they cannot be envisaged as an 'adversary' but only as an 'enemy.' With the 'evil them' no agonistic debate is possible, they must be eradicated. Moreover, they are often considered as the expression of some kind of 'moral disease', one should not even try to provide an explanation for their emergence and success (Ibid., p. 76).
>
> The danger arises that the democratic confrontation will …be replaced by a confrontation between essentialist forms of identification or non-negotiable moral values. When political frontiers become blurred, disaffection with political parties sets in and one witnesses the growth of other types of collective identities, around nationalist, religious or ethnic forms of identification. …This is why it is important to allow them an agonistic form of expression through the pluralist democratic system (Ibid., p. 30).

Mouffe was particularly sensitive about the use (or abuse) of moral vocabulary in politics. She saw that there was a direct link between the weakening of political frontiers (depolarization) and the moralization of politics. In particular, Mouffe warned of the danger of "uni-polarization" under the name of "humanity" when addressing political matters that is often disguised as "depolarizing." Here she strongly agrees with Carl Schmitt:

> Schmitt was very critical of liberal universalism with its pretense of offering the true and only legitimate political system. He criticized the liberals for using the concept of 'humanity' as an ideological weapon of imperialist expansion and he saw humanitarian ethics as a vehicle of economic imperialism (Ibid., p. 78).

> [T]hose parties could not be envisaged in political terms, i.e. as adversaries to be fought politically. So it was very convenient to draw the frontier at the moral level between 'the good democrats' and the 'evil extreme right'. …As I have stressed earlier, there is no consensus without exclusion, no 'we' without a 'they' and no politics is possible without the drawing of a frontier. …People were made to feel very good and very virtuous by simply participating in the denunciation of the 'evil forces.' Of course, this mobilization of passions was not acknowledged as such but perceived as the rational reaction of moral human beings wanting to defend universal values. In that way it was made congruent with the dominant rationalist perspective (Ibid., p. 73).

To summarize, Mouffe argued that we see political "others" as enemies when we see them through the lenses of morality, ethics, and religion. Thus, she claimed that we should practice separating political language from the contentious languages of morality, ethics, and religion as we engage in political communication. Then there would be no basis to define others as some kind of "moral disease" that needs to be eradicated, and we would be able to embrace each other as legitimate political adversaries. Therein lies my problem with Mouffe's theory of agonistic pluralism: I believe that such "clean" political language is neither possible nor desirable. How can we talk about crimes against humanity without talking about morals? How can we talk about the Syrian civil war without discussing religion? How can we talk about euthanasia without raising ethical questions? While attractive in many ways, after careful consideration, Mouffe's agonistic pluralism is no less idealistic than the Habermasian public sphere.

2.3.3. Affective Publics

Habermas and Mouffe both suggest that we should talk about political issues in a different way than informal "everyday" conversations (Fraser, 1990). Habermas, on the one hand, argued that we should talk about political issues in a critical, rational manner, believing that our judgment should not be distorted or swayed by emotion. Mouffe, on the other hand, argued that we should talk about political issues in strictly political terms—that we should not mix political language with morality, ethics, or religion. Yet, in lived life, people mix informed opinions with their feelings, and politics with their morals all the time. To address this gap between Habermas's and Mouffe's theories of political communication and everyday conversations, I turn to Zizi Papacharissi's theory of affective publics as a fruitful lens that can help account for emotional and hybrid aspects of the political. Papacharissi (2015) saw that the Internet not only reflects emotianal and hybrid aspects of the political but amplifies it, in particular, with the widespread use of social media. She characterized the Internet as a hybrid space where "social, cultural, political, and economic activities frequently converge [giving] rise to political expressions aligned with individual repertoires of self-expression, lifestyle politics, and personal reinterpretations of the political" (Ibid., p. 24–25):

> Everyday life lived through, in, and around media is energized by hybrid domains that blend the aesthetics of commercial and alternative, public and private, entertainment and politics, work and leisure, individuation and collectivism, and countless other dualisms around which we have organized our everyday routines in the past, including of course, rationality and affect. (Ibid., p.8)

On a related note, Warner (2002) argued that political communication should "remain open to affective and expressive dimensions of language," highlighting the importance of "the poetic functions of both language and corporeal expressivity in giving a particular shape to publics" (p. 115). Important to note here is that the role of affect (i.e., emotions and feelings) in politics is not secondary to rationality. Papacharissi argued that networked digital structures of expression and connection are “overwhelmingly” characterized by affect. Thus, she called for scholars to turn their focus to understanding “the role of affect in politics and the ways in which online media facilitate political formations of affect” (Papacharissi, 2015, p. 9).

2.4. Political Design in HCI

Carl Disalvo (2010) made a distinction between “design for politics” and “political design.” Design for politics focuses on improving the mechanisms of governance (e.g., e-Governance). Political design, in contrast, aims to reveal, question, and even subvert the conditions and structures of the status quo. My research is part of a growing body of work in HCI that engages the intersection between design research and sociopolitical issues. In particular, my work is inspired by three branches of political design: critical design, adversarial design, and contestational design. In this chapter, I will discuss the core theory of each in brief.

Critical Design. Emerging in the mid-1990s, critical design underscores the role of design to provide reflection and criticism against modern life dominated by technology. Anthony Dunne (2005[1999]) urged designers to be provocative—to question and challenge industrial agendas that percolate through and shape our everyday life.

> Critical design, or design that asks carefully crafted questions and makes us think, is just as difficult and just as important as design that solves problems or finds answers. Being provocative and challenging might seem like an obvious role for art, but art is far too removed from the world of mass consumption and electronic consumer products to be effective in this context, even though it is of course part of consumerist culture. There is a place for a form of design that pushes the cultural and aesthetic potential and role of electronic products and services to its limit. (Dunne & Raby, 2001, p. 58)

Dunne (2005[1999]) strongly criticized the widespread culture of functionalism and user-friendliness in the design community. He stated, “The easy communication and transparency striven for by champions of user-friendliness simply make our seduction by machines more comfortable” (Ibid., p. 30). Conversely, critical design focuses on creating “poetic experience,” sometimes to the extent that it generates “pathological discomfort.” This perspective is well illustrated in *design noir*, a specific tactic of critical design which focus on how the psychological dimensions of experiences offered through industrial products can be subverted and expanded to embody darker needs and desires.

> Like in Film Noir, the emphasis would be on existentialism. Imagine objects that generate ‘existential moments’—a dilemma, for instance—which they would stage or dramatize. These objects would not help people to adapt to existing social, cultural and political values. Instead, the product would force a decision onto the user, revealing how limited choices are usually hard-wired into products for us. (Dunne & Raby, 2001, p. 46)

On another level, design noir provides safe catharsis for people’s hidden lust for *vice*: “[W]e would simply enjoy the wickedness of the values embedded in these products and services. Their very existence is enough to create pleasure” (Ibid., p. 46). As such, critical design becomes more of a one-off art piece as opposed to what Donald Norman would call “everyday things,” in a similar vein that we indulge in the grim experience of film noir on condition that it happens on screen but not in our everyday life.

> Although I see them [critical design artifacts] as design proposals not artworks it seems that, to hold a design view where electronic objects function as criticism, one must move closer to the world of fine art because the design profession finds it difficult to accommodate such research. (Dunne, 2005, p. 63)

Despite Dunne’s concerns, critical design inspired, and continues to inspire many HCI design researchers, offering an innovative departure from rationalistic perspectives on design. At the same time, non-everydayness, which is essential for critical design, is often dismissed in HCI. Thus, much research seems to focus on how to apply critical design in designing artifacts for everyday use. Hassenzahl and colleagues' work on "pleasurable troublemakers" is one example (Hassenzahl & Laschke, 2015). Yet another example, Korn and Voida (2015), in review of Lefebvre (1991 [1947; 1961; 1981]) and de Certeau (1984)'s social theories of everyday life, advocated for devising "friction" in everyday life as an effective design strategy for infrastructuring civic engagement. But it seems rather countervailing to practice critical design in a way that attempts to move closer into the users' everyday life when critical design's core tactics (including user-*un*friendliness, defamiliarization, and functional estrangement) all point to the opposite direction—that is to say, to pull away from everydayness.

Adversarial Design and Contestational Design. Adversarial design draws on Mouffe's theory of agonistic pluralism, seeing democracy as an intrinsically contentious affair (see Chapter 2.3.2. Agonistic Pluralism). Adversarial design is particularly interested in attaining the quality of "visibility of dissensus" through which democracy is instantiated, expressed, and mobilized:

> In labeling an object as adversarial, I mean to call attention to the contestational relations and experiences aroused through the designed thing and the way it expresses dissensus. Labeling an object as adversarial also shifts the grounds for critique. It requires that the description and analysis of the object bring to the fore the way that its designed qualities enable or model the productive and ongoing questioning, challenging, and reframing that typifies agonism. (DiSalvo 2012, p. 7)

Adversarial design aims to investigate how computation is used for political ends and what political issues it brings forth. Specifically, DiSalvo (2012) introduced a tactic called *revealing hegemony*, which uses computational information visualization to expose and document "the forces of influence in society and the means by which social manipulation occurs" (p. 35). Drawing on Laclau and Mouffe (2001), adversarial design deliberately rejects the Marxist notion of hegemony as a class structure. Instead, adversarial design redefines hegemony as an open and flexible discursive strategy:

> From the perspective of a theory of an agonistic pluralism, hegemony is not a fixed and final state or an effort with a unidirectional vector (from powerful to subordinate). Rather, hegemony is a flexible and vigorous web of related factors, actions, intentions, and objects that are in constant flux, under pressure from and exerting pressure on a multiplicity of positions (DiSalvo, 2012, p. 35).

That said, adversarial design's notion of hegemony is not far from issue-oriented design's notion of issue-formation drawn from Marres (2005, 2007).

Contestational design like adversarial design draws on the notion of adversarial democracy with a bolder stance towards "partisanship." Tad Hirsch (2008) stated: "The implication is for designers to stake out positions not as facilitators or even as guardians of the public good, but rather as willing combatants who take sides in contentious social issues" (p. 27). Thus, contestational design not only acknowledges conflicts as a *de facto* condition of modern society, but also actively recruits designers to take part in the vanguard of sociopolitical change. Contestational designers work in close partnership with activist groups, who play a pivotal role in mobilizing publics. Claimed as an openly partisan affair, contestational design empowers designers to enjoy a greater degree of autonomy in their practice to use "their powers to advance agendas to which they are personally committed" (Hirsch, 2009). In this way, contestational designers can be freed from both the scientism notion of neutrality and so-called political correctness.

In Chapter 2.2, I noted that political issues are conflictive at the core. At times, political design may foreground, or even incite and "melodramatize," conflicts to provoke publics' attention and emotion. While such practices may seem counterintuitive to the "design as problem solving" perspective widespread in the HCI community, adversarial design and contestational design inspire designers to embrace conflicts as part of their design repertoire.

3. Analytical Framework

My research aims to design interactive systems and technology in highly complex settings, with diverse stakeholders around politically and emotionally sensitive issues, hoping to support long-term social change. *Stakeholders*, *emotion*, and *multi-lifespan* are the three important analytical frameworks through which I tackle my research problems.

3.1. Stakeholders

In Chapter 2.1, I argued that publics can be more aptly conceptualized as a process rather than as people. Yet, people—with human needs, desires, and values—should remain an important consideration. We need to engage people (i.e., stakeholders) in the design process. The question is how and to what extent should we engage stakeholders in the design process.

Value sensitive design (VSD) broadly defines stakeholders as "those who are or will be significantly implicated by the technology" (Friedman & Hendry, in press) similar to Dewey's definition of publics as those who are and will be significantly implicated by the consequences of the issue. Value sensitive design engages with both direct and indirect stakeholders. Direct stakeholders refer to those who interact directly with the technology, often characterized as users in HCI. Indirect stakeholders refer to those who although they never or rarely interact with the technology but are nonetheless affected by the technology. Importantly, these stakeholders are defined and understood by their "roles" as opposed to a "person" as an individual or other "entity":

> A "role" pertains to a stakeholder's duties, contextual identity, or particular circumstances. For example, the same person at one point in time might be a user of a technology (e.g., speaking on a cell phone or driving in an autonomous vehicle) and at another point in time a bystander in regard to the same technical system (e.g., sitting in a

> café near by someone else speaking on a cell phone or crossing the street in front of an autonomous car). Defining stakeholders in terms of roles positions designers to understand how the same "entity" could hold multiple relationships to the same technology as well as the potentially dynamic nature of an entity's relationship to a particular technology. (Ibid.)

This approach, however, could be rather techno-centric in that it puts technology in the center (e.g., a cell phone in the above example) and, in turn, identifies stakeholders in relation to that technology. Such an approach may fall short when designers attempt to intervene in a new design space where there is no established technology yet in place. Questions arise: Can we use the VSD stakeholder analysis method to identify stakeholders (i.e., direct and indirect stakeholders) in relation to sociopolitical issues as opposed to technology? While VSD's concept of stakeholders and Dewey's concept of publics share a similar tone, what is the relationship between stakeholders and publics? What will a stakeholder analysis tell us about publics? Taking up these questions, my thesis will contribute to extend applications and discussions of VSD.

3.2. Emotion

A central element of my work is political communication. On the one hand, I am particularly interested in the emotional dimension of politics and, relatedly, how intuitive thinking can also be used critically to further political thinking. On the other hand, I am interested in how technology may support or hinder/mute emotional expressions and intuitive thinking in varied sociopolitical contexts. Papacharissi (2015) argued that publics are shaped by the "structures of feeling," which are implicated by the structures of systems and technology that we build. Thus, she called for scholars to turn their focus to understanding "the role of affect in politics and the ways in which online media facilitate political formations of affect" (p. 9).

One of the key challenges for conducting research in emotionally sensitive settings entails (mis)use of language. Some expressions can invoke negative connotations, trigger trauma, or contribute to stigma. As researchers, we need to be careful and sensitive when communicating our research with others, in particular with participants in intimate or vulnerable situations. Yet it is often unclear how to do so. How can we ethically communicate about sensitive topics?

3.3. Multi-lifespan

Multi-lifespan design focuses on the design and deployment of information systems to support long-term solutions to significant societal problems that are unlikely to be solved within a single human lifespan. In their launching of the multi-lifespan design research initiative, Batya Friedman and Lisa Nathan (2010) identified three categories of multi-lifespan problems as follows:

> Category 1: Limitations of the Human Psyche
>
> There are some harms that human beings commit against each other that are so profound that while one hopes for healing to occur within a single lifespan, given the human psyche that seems unrealistic. Consider the harms that result from civil war, genocide, and other forms of extreme conflict. When neighbors have killed neighbors, when parents have watched their children die, it may be impossible for persons who have survived to fully heal and forgive those whom they believe guilty of atrocities.
>
> Category 2: Tears in the Social Fabric
>
> Societies are comprised of complex social structures with deep, intertwined interdependencies – what one might refer to as the “social fabric” through which people care for themselves and each other, pass along generational knowledge, and sustain human life. Certain events – of either a natural or human origin – can cause severe tears in the social fabric. Rebuilding societal structures around such widespread changes in

> population distribution requires time for both the changes to stabilize and the population to regenerate itself.
>
> Category 3: Natural Time-scales that Move More Slowly Than a Single Human Lifespan
> Some natural processes can take hundreds of years, for instance the re-establishment of an old growth forest or the revival of an endangered species with long gestation periods and few young. Many environmental crises may benefit from information intensive tools (e.g., climate change simulations) as the solutions unfold over longer time frames.

My dissertation aims to understand how technology impacts the ways people understand, communicate, and act upon sociopolitical issues to make change. Change, however, takes time. Change is gradual, and revolutions, in the words of Raymond Williams (2001), are long. And they have to be long, Papacharissi (2015) argues, in order to attain meaning at the level of public consciousness. Over time a peculiar idea is developed into a more sophisticated discourse and, if successful, into an established hegemony. Such processes can take hundreds of years; consider for instance, the ongoing evolution of feminism since the terms “féminisme” and “féminist” first appeared in Europe in the 1870s. The HCI and design community, in contrast, is interested in technological innovation that is ever new. Here, change is rapid. Design life-cycles are short, calling for “lean” methods. Devices over five years old are regarded as legacy. Societal change and technological change demand two distinct rhythms that do not align. How, then, can we, as HCI researchers and designers committed to addressing larger societal issues, engage with different rhythms in our design processes? Multi-lifespan design provides a useful lens and tools for designing technology in support of longer-term, complex processes of issue formation and sociopolitical change.

4. Case Study: Designing Technology in the Highly Sensitive Context of Medical Aid-in-Dying

In my dissertation, I seek to explore sociopolitical design in the case of end-of-life medical decision-making law, policy and practice. In particular, I focus on the contemporary debates over the legalization of medical aid-in-dying in the United States. In the US, medical aid-in-dying was first legalized in 1994 via the Oregon Death with Dignity Act. As of this writing in 2018, seven out of 50 states have implemented laws that codify and allow access to medical aid-in-dying. Notably, in 2016, California, Colorado, District of Columbia, and the neighboring country Canada each passed their own versions of medical aid-in-dying legislation, creating a momentum among publics to engage in lively discussions around the topic. Medical aid-in-dying evokes diverse (and often conflicting) perspectives among publics, providing a rich context for investigating the roles of information and communication technology for shaping public consciousness around complex sociopolitical issues.

4.1. Medical Aid-in-Dying

Medical aid-in-dying is a nuanced and evolving concept. To date there is no succinct, agreed upon definition of what comprises medical aid-in-dying. In the United States, the term has emerged in recent years as a preferred alternative to the much-debated (and still commonly used) term “physician assisted suicide,” which carries negative connotations of “auto-killing” or “self-killing” (Stark, Dudzinski, & White, 2013). In contrast to physician assisted suicide, medical aid-in-dying is often used in a conservative manner to refer to a restricted practice in which a physician provides a terminally ill patient with a prescription for a lethal dose of medication, upon the patient's request and under certain conditions, for the patient to self-administer if she or he chooses to hasten her or his impending death. Yet, others argue that medical aid-in-dying could include other practices that reach beyond the narrow restriction above. For example, the

Canadian Medical Association (CMA), in their 2014 policy document, defined medical aid-in-dying as follows:

> Medical aid in dying refers to a situation whereby a physician intentionally participates in the death of a patient by directly administering the substance themselves, or by providing the means whereby a patient can self-administer a substance leading to their death. (Canadian Medical Association, 2014)

Under the above definition, medical aid-in-dying could include euthanasia as well as a broader category of patients who suffer from “a grievous and irremediable medical condition …without a prognosis necessarily having been made as to the specific length of time that they have remaining.” (C-14, 2016).

4.2. Complex Terminology

Political communication is further complicated as emergent publics “seek to put into circulation a new publicly available language” that embodies new ideas and intentions (Warner, 2002). For example, “sexism,” “sexual harassment,” and “marital, date, and acquaintance rape” were peculiar terms coined by emergent feminist publics decades ago. Today these terms can be found in everyday life circulating as common terminology, reflecting the change in the dominant public consciousness. As such, neologism plays an important role in social change, constantly formulating (re)interpretations of values, desires, and needs of emergent publics. However, the process of introducing new words and phrases into society can be perplexing because these terms are typically independent of their common meanings and often embody controversial meanings oppositional to the dominant social reality (Ibid.). Over time, some expressions end up fully accepted into mainstream. Others disappear. In order to support slowly evolving, long-term social

Key concept	**Related terms**
Advanced directives	Living will, DNR (do-not-resuscitate) order, health care proxy
Non-treatment decisions	Forgoing life-prolonging treatment, forgoing life-sustaining treatment, forgoing non-beneficial treatment, forgoing futile treatment
Palliative sedation	Terminal sedation, continuous deep sedation (until death), intensified alleviation of symptoms with possible life-shortening effect, sedating pharmacotherapy, "double effect"
Aid-in-dying	Assisted death, death with dignity, physician aid-in-dying, medical aid-in-dying
Assisted suicide	Physician assisted suicide
Hastened death	Voluntarily stopping eating and drinking
Euthanasia	Voluntary euthanasia, non-voluntary euthanasia, involuntary euthanasia, mercy death
"Winks and nods"	Acts to hasten death that are not sanctioned by the law
Suicide	Rational suicide, botched suicide
Killing	Mercy killing, murder

Table 2. Spectrum of end-of-life terminology.

change around medical aid-in-dying, the communication system should be sensitive and responsive to neologism and changes in terminology.

End-of-life options exist on a wide spectrum of ill-defined terms encompassing everything from advanced directives to aid-in-dying to suicide to killing as shown in Table 2. Here example terminology is categorized into a few key concepts and related terms. However, how each term is used, or should be used, in a given context is confusing and highly debatable. For example, while some right-to-die advocates insist that palliative sedation is covert medical aid-in-dying or euthanasia (Humphrey & Clement 2000), others argue that medical aid-in-dying should not be confused with palliative care (Herx 2015). While some use the term aid-in-dying interchangeably with, and as a substitute for, legalized physician-assisted suicide, others use that term to refer to "acts to hasten death that are not sanctioned by the law" (Smith, 2013). Each term is imbued with political and moral values. Furthermore, with a topic as sensitive as dying, some expressions can invoke negative emotions, trigger trauma, or contribute to the stigma attached to marginalized or vulnerable populations. Careful attention to nuances and intentions is needed.

4.3. Washington's Death with Dignity Act

In 1991, Initiative Measure No. 199 (I-119) was put on the Washington state ballot as an Initiative to the Legislature. It was the first significant attempt in Washington state to legalize medical aid-in-dying. I-199 defined medical aid-in-dying as follows:

> "Aid-in-dying" means aid in the form of a medical service provided in person by a physician that will end the life of a conscious and mentally competent qualified patient in a dignified, painless and humane manner, when requested voluntarily by the patient through a written directive in accordance with this chapter at the time medical service is to be provided. (Washington Secretary of State, 1991)

The language appeared on the ballot as follows:

> Shall adult patients who are in a medically terminal condition be permitted to request and receive from a physician aid-in-dying? (Washington Secretary of State, n.d.)

The measure was rejected by a margin of 46 to 54 percent.

After more than 15 years, in 2008, Initiative Measure No. 1000 (I-1000) was put on the ballot—this time, as an Initiative to the People. I-1000, modeled after Oregon's Death with Dignity Act of 1994, was more restrictive in that it explicitly prohibited lethal injections and voluntary euthanasia. The language appeared on the ballot as follows:

> Initiative Measure No. 1000 concerns allowing certain terminally ill competent adults to obtain lethal prescriptions. This measure would permit terminally ill, competent, adult Washington residents, who are medically predicted to have six months or less to live, to

> request and self-administer lethal medication prescribed by a physician. Should this measure be enacted into law?
>
> Yes [ ] No [ ] (Washington Secretary of State, n.d.)

The measure was approved by Washington voters by a margin of 58 to 42 percent. Washington became the second state in the United States to legalize medical aid-in-dying. I-1000 was codified as Chapter 70.245 RCW and Chapter 46-978 WAC, also known as the Washington Death with Dignity Act (DWDA). The DWDA has been in effect since March 2009.

The DWDA comes with very strict restrictions: (1) the patient must be determined by at least two physicians to be suffering from a terminal illness with less than six months to live; (2) the patient must be determined by a physician, or a state-licensed psychiatrist or psychologist to be free of any mental conditions impairing the patient's judgment; (3) the patient must make a voluntary request; and (4) the patient must self-administer the medication.

Terminal illness. The DWDA defines terminal illness as "an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment, produce death within six months." (70.245 RCW, 2008). The patient is incurably and irreversibly ill if the treatment or treatments in question will possibly prolong life but not restore health. Progressively debilitating and chronic conditions such as ALS (Lou Gehrig's disease) or multiple sclerosis qualify as incurable and irreversible illnesses. However, they do not qualify as terminal illnesses because the time of death cannot be predicted and hence are not covered by the DWDA. Paraplegics and stroke victims also do not qualify as terminally ill. Patients in the early stages of a disease are usually not eligible.

Mentally competent. The patient must have the decisional capacity to make an informed decision and the ability to carry out all other provisions of the act; to understand the prognosis, alternatives, risks, and consequences of her/his actions. The patient must fully understand the finality of the decision.

Voluntary choice: A patient's permission is not legally effective unless it is voluntary, freely given, without undue influence such as manipulation, duress, or coercion. Specifically, the DWDA requires two oral requests and one written request. First, the patient must make a formal oral request to her or his attending physician by asking, for example, 'Will you assist me in using Washington's Death with Dignity law?' The physician can say no. Participation by physicians, pharmacists, and other health care providers is totally voluntary, meaning that they are free to refuse a patient's request at any time. If the physician says yes, the patient can proceed to make a formal written request and reiterate the oral request to her or his attending physician. The written request shall be witnessed by at least two individuals. Under the DWDA, at least fifteen days shall elapse between the patient's initial oral request and the writing of a prescription.

Self-administer: The DWDA defines self-administer as "a qualified patient's act of ingesting medication to end his or her life in a humane and dignified manner." (70.245 RCW, 2008). The patient must have the physical capacity to ingest the medication. The DWDA specifically prohibits lethal injections and voluntary euthanasia.

5. Method

5.1. Participants

The overarching goal of this case study was to gain deeper insights into on-the-ground experiences with medical aid-in-dying and, in turn, identify potential design opportunities. To do so, I conducted a series of in-depth interviews with "professionals" who have direct contact with patients considering medical aid-in-dying. I felt that engaging with professionals was a good starting point for the research because they frequently deal with end-of-life issues in their work and they are well-experienced with having conversations about sensitive and nuanced aspects of medical aid-in-dying. There are two broad categories of such professionals: (a) those in the health field including physicians, psychiatrists, nurses, social workers, hospital chaplains, bioethicists, and health care administrators; and (b) those who volunteer for NGOs that offer end-of-life counseling and support services to patients. In general, the formal group interacts with the patient prior to and during the process of prescribing the lethal dose of medication, including determining a prognosis of six months or less; while the latter group interacts with the patient during and after the process of prescribing the lethal dose of medication, including being present at the moment of the patient's death. Participants were recruited in roughly equal numbers from these two communities—15 participants from health care institutions (10 females, 5 males; age 35–65, M=50) and 12 participants from volunteer organizations (7 females, 5 males; age 23–75, M=60). [1] Given the holistic, qualitative nature of the research and analyses, the data from both communities was examined together.

Participants were recruited from the state of Washington. Considering the taboo nature of the research topic, I used snowball sampling to gain access to potentially hidden populations (Goodman, 1961). All participants had experience in offering end-of-life counseling to dying patients, in particular, concerning the DWDA, thus, all qualified as expert informers or

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[1] Most of the volunteers had a background in health care including social workers, hospice workers, physicians, and nurses.

"experiential experts" (Young, Magassa, & Freedman, 2018).[2] All participants voluntarily took part in the study and had few qualms about discussing various issues of the DWDA. None of the participants actively opposed the DWDA. While all participants were deeply respectful and supportive of the patient's wish to access and use the DWDA, not all participants were necessarily "activist proponents" per se; not all favored medical aid-in-dying over other end-of-life options.

Depending on the results of this initial study focused on health care workers and NGO volunteers, in future work, I anticipate conducting additional studies with other populations whom I consider to be more vulnerable (e.g., patients, families) or less accessible (e.g., opponents).

5.2. Procedures

To create a comfortable environment, sessions were held individually. I met one-on-one with participants in a small meeting room on a university campus (see Figure 1) or in their place of work. On a few occasions, I met participants at cafes and libraries upon request. Each session lasted one to two hours. All sessions were recorded using a voice recorder (i.e., semistructured interviews and wrap-up interviews) and a digital camera (i.e., hands-on design activities).

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[2] During the semi-structured interviews, I asked participants when was the last time they had a conversation with someone about medical aid-in-dying. Participants' responses ranged from "half an hour ago" to "within the last two months." 18 participants (67%) responded that their last conversation happened within a week. Participants often described that having such conversations was a regular part of their work: *"...it is a part of my work, you know, on a weekly basis."*; *"I would say, in my day to day work, it comes up on a regular basis."*; *"I have those discussions all day long."*

Figure 1. I met one-on-one with participants in a small meeting room on a university campus.

5.2.1. Semi-structured Interview

During the 20-minute semi-structured interview, participants were asked to explain their organization's policy with regard to the DWDA and their roles within the organization. Next, I asked participants to share any aspects of their personal background which may have influenced their viewpoint on medical aid-in-dying. By reflecting on their personal life trajectory, it was hoped that participants would be better positioned to think about medical aid-in-dying from a wider perspective beyond the boundary of their current occupation:

> *Could you provide me a little bit of your background that might be helpful for me to understand your views on the issue? You prior work experience or volunteering experience, education or training?*

Participants were asked to describe their first encounters with medical aid-in-dying, including the first time they became aware of the concept "death with dignity" in general, and then Washington's Death with Dignity Act specifically:

> *Could you please tell me when you first became aware of the concept "death with dignity"?*
>
> *Could you please tell me when you first became aware of Washington's Death with Dignity Act?*

Next, participants were asked to recall the most recent conversation as well as the most memorable conversation that they have had related to medical aid-in-dying:

> *Could you please tell me when was the last time when you had a conversation with someone around the issue?*
>
> *Could you please tell me about a time when you had a particularly interesting or memorable conversation with someone around the issue?*

Participants were also asked to recall specific challenges as well as "feel good" moments that they have experienced when having conversations related to medical aid-in-dying:

> *Could you please tell me about a time when you tried to have a conversation and then encountered difficulty or challenges? What kind of information was difficult to communicate?*
>
> *Could you please tell me about a time when you felt like you had a really good conversation with someone around the issue? And, of course, "good conversation" can mean different things to different people, so how would you characterize what is a good conversation?*

Finally, participants were asked to reflect on their media use:

> *Recently, have you ever come across this topic in the media? Could you give me examples of the types of media where you get information?*

5.2.2. Meanings and Emotions

After the semi-structured interview, participants engaged in a series of hands-on design research activities exploring meanings and emotions around: (a) keywords associated with medical aid-in-dying, and (b) terminology used to refer to medical aid-in-dying.

First, participants were asked to enumerate any words, short phrases, or sentences that come to mind when they think about medical aid-in-dying. Each keyword was recorded on a 3x5 inch index card. After five minutes of brainstorming, participants were asked to select five keywords, which they would like to discuss further, and describe each keyword using the Sensual Evaluation Instruments (Isbister, Höök, Sharp, & Laaksolahti, 2006) (see Figure 2). I made it clear that the objects were creative props to help participants express emotions and feelings, and that they were not tools for a projective test:

> *I'd like to hear about each of these topics, but since we have limited time together, today I'm going to ask you to choose five keywords that you'd like to discuss further.*
>
> *We will talk about one topic at a time, and for each topic, could you please choose a shape that you think best represent how you feel about the topic that's on the table? To be clear, I am not*

Figure 2. A set of Sensual Evaluation Instruments.

> *a psychologist, and this is not a projective test. I am a design researcher, and these are just some props to help facilitate our conversation.*

Second, participants were asked to enumerate terms, both technical and colloquial, that they have used or heard others use to refer to medical aid-in-dying.

> *This time I want you to go through another round of brainstorming but a shorter version. A couple of minutes to think about all the different terminology—words and expressions people use to talk about what it is. As you may know, this issue exists on a spectrum. There are many different forms of medical aid-in-dying and sometimes people use different expressions to refer to the same thing. For example, death with dignity is one way to call it, but there could be other expressions too. Let's focus on the terminology—not just the formal terms but there could be some other expressions that people use to talk about it in more colloquial ways. So, could you write down anything that you hear.*

Each term was recorded on a 3x5 inch index card. After two minutes of brainstorming, participants were asked to select three terms which they would like to discuss further and to describe each term using the Sensual Evaluation Instruments.

5.2.3. Stakeholder Tokens

At this point, participants were sufficiently primed to articulate more nuanced aspects of medical aid-in-dying. Having surfaced keywords, terminology, and other issues, I asked participants to now turn their focus to stakeholders. A set of 12 wooden peg dolls was introduced as the tokens. Each wooden peg doll was about 2.5 inches tall and weighed 0.6 ounces (see Figure 3):

> *This time I want you to focus on people—the stakeholders and key players. It can be an individual, group, or entity. I have these [tokens] and they don't have names or labels. Please take a minute and use this painter's tape to create labels. Write down anyone you think has a stake, either those who are directly or indirectly involved in aid-in-dying, or those who are currently excluded but may be still interested or concerned.*

Figure 3. A set of tokens used in the case study.

Participants were given about five minutes to generate a list of stakeholders. Then they were asked to label the tokens (see Figure 4). I explained that the different colors of the tokens do not mean anything, that they are just a part of the fun:

> *Participant: Am I supposed to care about the color?*
>
> *Interviewer: No, it's just part of the fun. It doesn't have any ascribed meanings.*

Figure 4. Participants generating labels (left) and creating sketches (right).

If participants enumerated more than 12 stakeholders—that is, if participants ran out of tokens—I improvised by folding a blank index card to create more tokens (see Figure 5).

Once participants finished labeling the tokens, I asked them to visualize the relationships among those tokens on a large piece of paper (11x14 inches):

> *What I want to understand is the relationships and dynamics among these stakeholders. You can use these tokens, you can use all or some of them, place them on the paper and draw how they interact, how they communicate with each other or a lack of communication.*

Figure 5. Examples of sketches created during the Stakeholder Tokens activity.

Participants were given about ten minutes to sketch and explain their ideas. I avoided providing detailed instructions about what participants should do with the tokens. Instead, I created a situation in which participants could play around with what they could do with a handful of tokens on a piece of blank paper. Some participants thought aloud as they explored stakeholder relationships. Others took time to organize their thoughts first and then explained their ideas later.

5.2.4. Wrap-up Interview

In closing, I asked participants to reflect on the existing Washington's Death with Dignity Act of 2008 and then to identify areas for improvements:

Last question I'd like to ask is, in Washington we have the Death with Dignity Act, but the law is not set in stone. So, my question is, (1) what are some aspects you think are working well with the current law? And (2) what are some aspects where you see some room for improvements or changes?

5.3. Data Analyses

All sessions were recorded, which resulted in 18 hours of audio recordings of semi-structured interview and wrap-up interview and 20 hours of video recordings of Meanings and Emotions acvitity and Stakeholder Tokens activity. I listened to the recordings and transcribed participants' responses, resulting in 290 pages of transcripts.

5.3.1. Semi-structured Interview

I used open coding (Strauss & Corbin, 1990) and thematic coding (Gibbs, 2008) to analyze the semi-structured interview data. Three sets of codes/themes were developed: (a) means of communication, (b) communication challenges, and (c) characteristics of a "good conversation."

5.3.2. Meanings and Emotions

Keyword Analysis. Each participant enumerated 3 to 28 keywords (484 items in total, M=18). Paying attention to delicate nuances and details, each expression was treated as a unique keyword even if two or more expressions seemed to share very close meanings (e.g., *"complex"* is a distinct keyword from *"complicated"*). However, if the expressions only differed in terms of grammatical forms (e.g., singular and plural, noun and adjective) the expressions were considered as the same keyword (e.g., *"choice"* and *"choices," "conflict"* and *"conflicting"*). The video recordings of Meanings and Emotions activity were transcribed and reviewed alongside the keyword index cards for a more accurate understanding of participants' intentions.

Terminology Analysis. Each participant enumerated 4 to 15 terms—both technical and colloquial (206 items in total, M=8). Paying attention to delicate nuances and details, each expression was treated as a unique term even if the terms sounded very similar (e.g., *"end of life choices"* and *"end of life options"* were considered distinct as they were recorded on separate index cards by the same participant; in a similar vein, *"doctor assisted suicide"* and *"physician assisted suicide"* were considered distinct). However, there were two exceptions: First, *"Killing myself," "Killing myself or him/herself,"* and *"Kill myself / yourself / him/herself"* were all considered as the same term considering the colloquial nature of the expression—each participant was paraphrasing the same expression in a slightly different manner. Similarly, *"Kevorkian," "The Kevorkian Thing," "That Kevorkian Thing,"* and *"That Dr. Kevorkian Thing"* were all considered as the same term. The video recordings of the Meanings and Emotions activity were transcribed and reviewed alongside the terminology index cards for a more accurate understanding of participants' intentions.

5.3.3. Stakeholder Tokens

Label Analysis. Each participant enumerated 8 to 17 stakeholder labels (M=12). I used open coding (Strauss & Corbin, 1990) to generate a set of codes. Next, to measure coding consistency, Cohen's kappa was calculated for two coders based on the entire dataset (N=341). The primary coder conducted the data collection, while the secondary coder did not have any prior engagement with the study. The overall score was k=0.943, indicating very strong agreement.

Sketch Analysis. Qualitative analyses were used to look for themes and patterns across the sketches. Specifically, I examined the *sequence* of articulated tokens (e.g., the first and last tokens that participants called out when explaining their sketches) and the *position* of tokens laid out on the page (e.g., tokens that were placed in the center or near the edges of the page). I also paid attention to the relationships among tokens expressed through pictorial means such as symbols, lines, shapes, and annotations. The video recordings of the sketching activities were transcribed and reviewed alongside the drawings for a more accurate understanding of participants' intentions.

5.3.4. Anonymization

In the proceeding chapters, I report findings and discussions from 27 in-depth interviews with health care workers and volunteers. I refer to participants in terms of their background (H for health care worker and V for volunteer) followed by the participant number. Specific names (e.g., participant's affiliation) are anonymized. The terms "clients" and "patients" may be used interchangeably in the quotes by the volunteers. As one of the volunteers noted: *"We are not medical people, so we do not call them patients."*

6. Communication

I turn now to duscuss the findings, beginning with communication. Recall that communication is central to issue formation (see Chapter 2.2. Characteristics of Political Issues and Chapter 2.3. Political Communication). Here I explore diverse modes of communication and the ways in which media facilitate emotion. I asked participants about their on-the-ground experiences with medical aid-in-dying and how they communicated, focusing on (1) the use of communication media, (2) the problems of communication, and (3) descriptions of what a good conversation feels like.

6.1. Communication Media

Face-to-face interaction, phone calls, text messaging, and emails were identified as the primary means of communication in participants' work settings. In addition, written documents (e.g., the prescription of aid-in-dying medication, administratively required paperwork required by the Washington State Department of Health), video conferencing (e.g., Skype), and social media (e.g., Facebook, Twitter) surfaced as key communication media. I elaborate below on each of these communication media with illustrative quotes from the participants' responses.

Face-to-face Interaction

Face-to-face interaction is known to be the most fundamental and information rich way to communicate (Clark & Brennan, 1991). Nonverbal behaviors exchanged during face-to-face interaction can convey rich emotional information, and thereby give words contextually nuanced meanings (Roter et al., 2006). Moods and feelings can be revealed through eye contact, facial expressivity, postural positions, and gestures. Participants found the affective and nuanced qualities of face-to-face interaction essential to carefully navigating sensitive issues of medical aid-in-dying:

> It's a very emotional issue. So, face-to-face or verbal communication, you learn a lot more and you convey a lot more. And when you are dealing with someone in this kind of issue, there's a lot of judgement that's used in what to say and how to say it. And sometimes some things are appropriate and sometimes they are not appropriate. So, you judge that by direct interface with people. (V7)

Importantly, face-to-face interaction emerged as a profound and possibly irreplaceable means of communication during the last hour of medical aid-in-dying (cf. Foong, 2008). About an hour before ingesting the aid-in-dying medication, the patient usually takes anti-nausea medications and waits for the drugs to work. During this time, patients often have their last conversations with loved ones at the bedside:

> I've just had so many experiences with the families who-, it's like the family experiences something often unfamiliar to them, brand new, …where they are paying attention to finality, of the seeming finalities of relationships, and people become very reflective at these times …It's almost like people come to visit a shrine when they come to the bedside. And I think there's so much value to that, and sometimes I imagine that can happen in that aftermath of a death, where people are coming to funerals and doing their memorials, but I don't think it's quite as powerful as being at the bedside of the dying person and seeing (_____) what they teach you in that moment in life. (H2)

If present, volunteers allow the loved ones to focus on the dying patient by taking care of logistics (e.g., preparing the aid-in-dying medication, calling the medical examiner), answering questions (e.g., "Is it normal for the patient to react to the medication in certain ways?"), and as appropriate, facilitating dialogue between the patient and the loved ones (e.g., "Tell us about the great memory that you had.").

Interestingly, around the time California enacted their End of Life Option Act in 2016, a major national-level NGO changed their organizational policy to prohibit volunteers in California and

Oregon from engaging in face-to-face interaction with patients during the process of medical aid-in-dying, including providing in-person counseling, attending the death, and assisting in the preparation of aid-in-dying medication for the patient. Participants, particularly, the volunteers were deeply concerned about California and Oregon's decision to restrict face-to-face interaction between the patients and volunteers:

> Like [*anonymized national NGO*] in Oregon, those volunteers really don't have any hands-on contact with the clients anymore. Like it's done over the phone, and it's very kind of hands-off and not personal, because people are interpreting the law that in a way that says nobody should be involved in helping the patient. (V6)

> [T]hey believe that the primary transaction is between the physicians and the patients, and there should not be a third party involve. (V9)

Participants wondered what might happen should the policy in California and Oregon spillover into the policy in Washington, preventing volunteers from engaging in any unmediated, face-to-face interaction with patients. Without face-to-face interaction, alternative methods of communication are needed to provide reliable resources and the kind of support that are highly requested by patients and their families.

Phone Calls

Phone calls were commonly used by patients and families, particularly to make an initial inquiry about medical aid-in-dying:

> Usually we start by phone often times. (V5)

> [W]ith my job I do a lot of telephone job, so, when it comes up, it often comes up over the telephone …I would say 80%, it's on the telephone. (H14)

Phone calls were also identified as a preferred communication medium among elderly individuals:

> Originally there's phone contact, at which point we set up a meeting. The meeting is face-to-face. After that I typically ask the client what kind of communication they prefer. And the age group who's mostly using the act prefers telephone. …Probably more phone than anything else. (V2)

Phone calls allow people from remote places (sometimes from outside the state of Washington) to easily access information about medical aid-in-dying:

> Actually, I just got a phone call from a woman who is not a patient here, but has been recently diagnosed, I don't even know how old she was. She was recently diagnosed with metastatic ovarian cancer, was looking for somewhere she can-, she chose not to have any treatment, called, got my number somehow to request, to see palliative care with the intent of establishing care through the end of her disease, and also wanting the option to have death with dignity if that's the way she chose to go. (H13)

Interestingly, phone calls put a veil between people, not allowing them to see each other during the conversation, thereby providing a sense of anonymity and privacy. As such, phone calls seem to create a safe space for people to talk about taboo subjects, similar to a confession booth:

> I wonder sometimes having a telephone conversation might be easier for the patient inquiring, so it's not-, you know, that sort of that separation so that they are not necessarily seeing you. I don't know if that's true or not …but I always wondered, you know, even if they know what I look like, there's something more kind of anonymous about it, you know, kind of talking about it to make it safer in their own home—they are in a familiar kind of environment discussing it instead of medicalized clinic. I don't know but, you know, I wonder about it a lot. (H14)

At the same time, phone calls created a sense of uncertainty by blocking nonverbal behaviors that provide rich contextual cues for participants to adjust their conversation on the fly:

> I think there is, because [in face-to-face communication] I can read-, I can look and see what people's expressions are and read-, have more-, usually the-, that was different because I didn't know this person at all. Usually when I have them in person it's usually someone that I know, a little bit at least. And so, the conversation goes a little differently. (H13)

Text Messaging

While the telephone was widely used in a variety of contexts, participants pointed out that phone calls can feel "*dicey*" and "*problematic*" at times, particularly, if either the caller or the receiver is not "*in the right place at the right time*." Participants were cautious about potential bystanders overhearing the conversation. By comparison, text messaging felt more private and less intrusive. Therefore, some participants expressed a clear preference for text messaging over phone calls:

> Phone can be a little dicey sometimes because it could be, for example, a client's daughter, she could be at work, she has no idea, she picks up the phone, I say, 'I'm the volunteer from [*anonymized*],' it's like she could be sitting there with somebody else, you know. Sometimes the phone can be just problematic. Frankly I'd prefer to send an email or send a text to say, 'I'd love to set up an appointment to talk with you.' To make sure they are in the right place for it, for the discussion. (V5)

> I way prefer text to phone calls just because it's easier and I don't have to find a private place if I'm somewhere public. I don't have to go like make sure no one can hear me because it's very sensitive conversation sometimes. But text is just make sure no one is looking at my phone. Email's also great because I just do it from my phone. (V6)

Email

Email was particularly useful for delivering factual, descriptive information that would be kept for future reference (e.g., the checklist for the multi-step process of the DWDA, the list of up-to-date aid-in-dying medications). Individuals would briefly discuss general ideas over the phone and then follow up by email with detailed documents attached:

> Electronic communication is very helpful and written communication is very helpful because the process is very complex, and you have people that are very emotional, which makes it even more difficult for them to focus. So, if there's something they can reference, you know, like step one, step two, step three, that's very helpful. (V7)

> So yesterday, I can remember talking to a couple of physicians who needed information about writing prescriptions for death with dignity. So, they maybe didn't know the up-to-date or were worried they didn't know up-to-date prescribing options. So, they called and I told them I'd email them the handout that we have for doctors about our recommending death with dignity drugs. (V3)

At other times, participants found email to be "*too cold*" or "*distant*":

> Anytime I have relationship with a client, I do it over phone because I believe there's emotional component to it, and I don't want to-, I purposely don't communicate by email because it's too cold and distant. (V9)

In particular, one participant recalled a time when she learned about her patient's death via email. She felt that the way that email was written was very unusually *"neutral,"* and suspected that the patient may have taken aid-in-dying medication:

> I took one more look at my emails and there was a notification from the social workers saying this patient died this morning, and it was very neutral, no details. Just that notification to the care team that this patient had passed. And the significant thing about it is usually you don't get a notification that way. (H2)

Video Conferencing

Face-to-face interaction is a powerful communication method, but it can be expensive and effortful in distributed situations (Nardi & Whittaker, 2002). Outside of the Seattle metropolitan area, it is very difficult to find a physician who is willing to participate in the DWDA, thereby posing a significant challenge for patients in many areas of the state. Oftentimes the patient is too weak to travel to Seattle, and to get a physician to make a house call is costly and time consuming. In such cases, where face-to-face meetings are complicated to arrange, video conferencing can be a preferable alternative. Many participants were enthusiastic about the convenience and responsiveness of video conferencing that allowed patients in isolated areas to have better access to the DWDA:

> I've had clients who were actually so sick they weren't able to go and see their physician. And they were able to have their physicians consult over Skype, which I think is fantastic. You know, 10 years ago, 15 years ago, that never would have been possible. And had we had the law, these clients probably never could have gotten the approval that they need from physicians and got the prescriptions. Because Skype is a lot easier than getting someone to do a house call. …You know, some of these people that are in Kent, Edmonds, whatever, and trying to get a doctor up there to do a house call, that's a whole nother [sic] bugging. (V6)

> One of my first experiences was in [*anonymized location in Eastern Washington*], I went to see a gentleman with brain cancer, was diagnosed like six weeks before. And he was-, could hardly even speak. …They had no doctors that would cooperate. I went to see them at 10 o'clock in the morning, I left at about 11 o'clock. I made a call to our volunteer coordinator saying that 'We need to help them find doctors and get things going. He can hardly move.' I had lunch, I came out of lunch, the person I had talked to had called one of our volunteer doctors, who called another doctor, who had called the patient who was ready to Skype with them at 2 o'clock. That's responsive. (V7)

Video conferencing was also a useful tool for providing long-distance caregiving. In our increasingly mobile society, long-distance caregiving is a growing phenomenon (Braven & Sparks, 2011). Adult children move away from their home of origin for educational, career, and relationship purposes, while elderly patients move away from their family home for health care. During a period of protracted illness, long-distance family members often used video conferencing to stay connected with the patient and the primary caregivers. In this way, family members were able to engage in rich conversations about end-of-life issues, even from a long distance:

> So my husband’s grandmother recently died after a very long illness …She actually lived in the UK, and we Skyped regularly with his mother, the grandmother’s daughter. And his mother knows that I volunteer for [anonymized] and she knows what it is, and we’ve had a lot of conversations about how she wishes that it was an option there. …So I just, I did have some interesting conversations over Skype with her. (V6)

Administratively Required Documentation

Written documents are one of the most commonly used communication media. Under the DWDA Section 443.18., health care providers are required to document the following information in the patient’s medical record:

> (1) All oral requests by a patient for medication to end his or her life in a humane and dignified manner;
>
> (2) All written requests by a patient for medication to end his or her life in a humane and dignified manner;
>
> (3) The attending physician's diagnosis and prognosis, and determination that the patient is competent, is acting voluntarily, and has made an informed decision;
>
> (4) The consulting physician's diagnosis and prognosis, and verification that the patient is competent, is acting voluntarily, and has made an informed decision;
>
> (5) A report of the outcome and determinations made during counseling, if performed;
>
> (6) The attending physician's offer to the patient to rescind his or her request at the time of the patient's second oral request under RCW 70.245.090; and
>
> (7) A note by the attending physician indicating that all requirements under this chapter have been met and indicating the steps taken to carry out the request, including a notation of the medication prescribed.

To comply with the act, health care providers are also required to file the following documents to the Washington State Department of Health[3]:

(1) Written Request for Medication to End My Life in a Humane and Dignified Manner form, DOH 422-063
(2) Attending Physician's Compliance form, DOH 422-064
(3) Consulting Physician's Compliance form, DOH 422-065
(4) Psychiatric/Psychological Consultant's Compliance form, DOH 422-066, if an evaluation was performed.
(5) Attending Physician's After Death Reporting form, DOH 422-068
(6) Pharmacy Dispensing Record form, DOH 422-067

The above forms are downloadable from the Washington State Department of Health website in PDF form. All forms must be printed, completed, signed, and physically mailed (as opposed to transmitted electronically) to the department of health. In addition, some health care institutions require their employees to process additional paperwork for their internal records:

> So, they are not only the Washington State Health Department forms that, you know, they need to fill out with the patient, but there are some [*anonymized health care institution*] forms in addition to that. …in terms of [*anonymized health care institution*] forms they are hard copies. And after they are completed, they are stored in a secure location with our director of Supportive Care Services. (H8)

In short, the DWDA involves a lot of paperwork and logistics management, which can be confusing and frustrating for participating health care providers. They must figure out what information needs to be recorded, what specific forms are required, who is responsible for completing which forms, and where to find the forms:

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[3] Washington State Department of Health is mandated to collect and review all administratively required documentation about the patient's death using the DWDA. The information collected is not a public record and may not be made available for inspection by the public. However, the department of health is responsible for generating and making available to the public an annual statistical report of information collected under the act.

> Documentation, you know, was a big question. …Who can provide the documentation, does it have to be a physician, or can it be a nurse practitioner or physician assistant, or you know, things like that. …[S]o, I had to kind of search a little to find the required documentation that was required by psychiatry because there is a specific form for psychiatry to fill out. So, I think I had to search for a little bit, get online, look for it. (H12, psychiatrist)

Among the various documents, the after-death report was seen as particularly problematic. The Department of Health holds the attending physician responsible for completing the Attending Physician's After Death Reporting form (DOH 422-068), which asks a number of questions about the specific context of the patient's death, including, but not limited to:

> *Where did the patient ingest the medication?*
> *Did the patient take the lethal dose of medication according to the prescription directions?*
> *Were there any complications after the ingestion of the lethal dose of medication?*
> *What was the time between ingestion of the lethal dose of medication and unconsciousness?*
> *What was the time between ingestion of the lethal dose of medication and death?*
> *At the time of ingestion of the lethal dose of medication, was the patient receiving hospice care?*

However, the attending physician often does not have the necessary information at hand because the attending physician rarely *attends* the patient's death. Therefore, in order to fill out the form, the attending physician needs to solicit information from those who were actually present when the patient ingested the aid-in-dying medication, whether it be the primary caregivers, the hospice staff, or the volunteers:

> [T]here's like after-death paperwork, right? So, the state wants to know like did they take the medication, how long was it between the taking of the medication and the time they went unconscious or the time between they died, wanted to die, and were there any complication. And this is information the main medical team might not have, but the hospice might have or the [volunteers] might have. So

> then trying to get information to the state so they can kind of understand more—what's happening, who's asking for it, are these things working the way they envisioned, what adjustments need to be made that sort of stuff. (H1)

Witten Prescription

Another critical document is the prescription for aid-in-dying medication. Washington's DWDA specifies three distinct methods for delivery: the written prescription can be delivered personally, by mail, or by facsimile to the pharmacist. Because of this provision, the prescription cannot be transmitted electronically, which causes a lot of inconvenience for the attending physician as well as the patient:

> Right now it has to be hand delivered, mailed, or faxed. And so sometimes the prescription can't get there very easily, and people have to wait longer. (V12)

It can be particularly problematic if the designated pharmacy is located in a remote area:

> Once the requests are made, when can a prescription be written, where can the prescription go because where the prescription can go varies depending on the prescription. Some have to go to certain pharmacies that are compounding pharmacies and actually put together a mixture, versus dispensing a medication which any pharmacy can do. (V2)

> And I have done all this driving because I had to go to his doctor and get the prescription, and take it to the pharmacy, and then bring it back, and it was Friday afternoon, which I hate driving, especially in the East side. (V8)

V6 reasoned that the intention behind this provision may be to have a secure chain of custody. The law was drafted in 2008, which was heavily modeled after Oregon's Death with Dignity Act, which was drafted in 1994. However, with current advanced technology, V6 believed that it would be possible to securely transmit the prescription electronically to the pharmacist:[4]

> [W]hen the physician writes the prescription, the prescription has to be actually like mailed in an envelope or like hand carried to the pharmacy. It cannot be transmitted electronically. And I understand, I mean, I kind of theoretically understand why because you want to maintain a chain of custody, but I also think we probably have the technology to be able to send a secure email from a physician to a pharmacy without that actually being an issue. And actually, I'm not sure why that is specifically in the law, …I think that's something that's just, we can probably do better. (V6)

Social Media

According to a recent Pew Research Center report, two-thirds (67%) of Americans get their news on social media (Pew Research Center, 2013). Consistent with the statistics, Facebook was frequently identified as a key source of news:

> I'm on Facebook and sometimes [*anonymized NGO*] will make posting on Facebook, and there's the [*anonymized NGO*], they are national, I think, and they post things. I see that. So, I see things there. I don't subscribe to the papers, I don't have TV reception, so I don't watch the news on TV. I don't listen to radio because I listen to recorded books when I drive around. So, no other than Facebook. (V4)

Furthermore, Facebook provided a space for people to engage in political dialogue with their friends and acquaintances around trending topics:

> I think the last time was actually on Facebook with California doing the death with dignity. And so, I think that was even in the last few months that it sort of bubbled up in the media towards me. …So, I

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[4] This issue has been improved in California's End of Life Option Act of 2015. In California, with the patient's written consent, the attending physician can transmit the written prescriptions electronically to the pharmacist.

> have a lot of friends in California debating it and discussing it being very political, and kind of high energy, high emotional energy surrounding it. (H14)

Interestingly, one participant shared an experience in which the participant simply updated his status on Facebook that sparked a conversation about medical aid-in-dying:

> [T]he last time I encountered the issue on social media was my own posting on Facebook of what I did in conjunction with my 50th high school reunion and several people getting in touch. …There was a list of simple things you fill out—are you still working, what do you do. And I said, 'I work with [*anonymized NGO*].' That's all I said. And I got some 'Hmmm, that sounds interesting. What is that?' And so, I would tell people. And I would get back the 'Good for you' response or 'I really wish that were somewhere where I lived.' And I was curious to see how it would go because my high school is in a very conservative part of the country and so. [Interviewer: And may I ask in which state?] Well, it's in Pennsylvania, but in an area that is, it's a lot of Amish, a lot of (_____), it's extremely politically, essentially conservative. So, that was the reason I put it out so gently in the first place. And I was curious if somebody would bring it up in a disagreeing way. But no one did, and I don't know what that means. (V2)

That said, none of the participants reported that they actively post things about medical aid-in-dying on social media. Furthermore, a few participants were explicitly against using social media as a platform to talk about medical aid-in-dying. Conventional design of social media forces users to generate micro statements and punchlines, which seemed problematic and inappropriate for having nuanced, in-depth conversations:

> I personally have some biases away from Twitter, I'm a bit of an introvert, …That's too much for me! (*laughs*). So, I may not be as in the know like of colleagues who are tweeting or putting things on Facebook, that sort of stuff. …I think one of the challenges with the topics that are potentially controversial, or (_____) emotionally, or culture you are socially charged, is the nuances. And the individual sort of experience related to them are very hard to communicate in whatever Twitter will—one hundred and something characters. And so, a lot of sort of punchlines and sort of micro statements

> that one might spit out through various media, it's just so underwhelming. And to some degree—what's the word, not insulting—but it doesn't get to the depth and complexity of what's going on. …So, I mean, that's the gap. And I think the proportion of the content is not meant to allow for uncertainty. People like a punchline story to finish. (H11)

Other Media

Many participants reported that they get at least some of their news through traditional mass media such as newspapers, radios, and television. However, participants remembered very few specific details. Life is busy, and participants could recall only vaguely (if at all) hearing about something related to medical aid-in-dying while they were commuting or having breakfast:

> There's Oregon and Washington and then there was another-, was that California? Yeah. So that's where I've heard. [Facilitator: Do you remember what-] Nothing! (*laughs out loud*) (H8)

> I really haven't heard about it for a long time. The media seems like kind of-, seems like it's completely flying under the radar. But I will say that I'm not a big media person. I mean I listen to public radio in the morning, you know, I'm getting my breakfast, and that's about my-, and then I do read, you know, I do read media either on paper or online, but much of that is international then local. (H9)

> I'm not nearly as watching this closely as I'd like to because life is busy. But anytime I hear it being discussed, my ears are opened. …But again, I wasn't able to pay the same amount of attention as I'd like to, but knowing that, or recognizing that it's kind of a spreading change in policy. (H2)

Participants reported that they used online search engines to get information. In addition, participants reported getting news through various types of online professional network, including listservs, webinars, and scholarly literature (e.g., medical website).

The Internet created a rich environment where multiple communication media can emerge. At the same time, it created a sense of information overload:

> You know, I get all sorts of emails, you know, and mostly junk mail (*laugh out loud*). And once in a while, you know, I'll have the time to look at the title of the article and if it catches my eyes I'll try to read it and see if I can learn something. (H12)

> And there's a lot of information out there, but you gotta search for it really hard. (V7)

In this section, I reviewed key media that are being used to communicate medical aid-in-dying in various contexts and discussed the unique quality of communication each medium affords. Next, I turn to examine challenges specific to communicating medical aid-in-dying.

6.2. Communication Challenges

Thinking about communication challenges around controversial political issues, it is easy to imagine a scene in which two individuals with conflicting perspectives are having a heated debate. By contrast, participants reported that they rarely encountered any *"pushback"* from those who disagree. When asked to recall particular communication challenges or difficulties that they have encountered, participants usually began their answers by saying that talking about medical aid-in-dying was *"not difficult,"* that it was part of their day-to-day work:

> I don't know if I'd characterize any of these as difficult, only because I've been doing it for a long time. (H10)

> I have those discussions all day long. (V12)

Yet, the empirical data of this study revealed multiple communication challenges that emerged from within and outside participants' work settings, including: sociocultural taboos concerning death, hidden practice of medical aid-in-dying (stemming from concerns around coercion, privacy, and politicization), uninformed patients and physicians, confusing terminology, management of roles and expectations, and sensitivity to nuance. I elaborate below on each of these communication challenges.

6.2.1. Sociocultural Taboos Concerning Death

Death is taboo to discuss in many cultures, particularly, in the United States. There is a widespread reluctance to talk about death and dying, which makes it difficult to discuss medical aid-in-dying. Instead of confronting their own mortality, many Americans tend to label such talk as "morbid" and try to stave it off as long as they can. According to 2013 Pew Research Center survey, over a quarter of U.S. adults (27%) reported that they have not given very much thought or have given no thought at all to their own wishes for end-of-life medical treatment, even those aged 75 or older (25%) (Pew Research Center, 2013). Consistent with the literature, participants reflected on situations where dying was an avoided topic:

> [I]t's also part of society that even my closest friends, you know, they ask what I'm doing and when I mention what I'm doing they just change subject like that. People just don't want to discuss death, and obviously to younger people even more—it's not an issue for them they don't want to discuss it. (V7)

> [M]y father doesn't even want to hear about my experiences working here in Washington, just of this volunteer thing that I do. He doesn't have interest in hearing about it or listening to me talk about it, much less engaging in a conversation about like what he wants at end of life. And they don't live here, they live in Tennessee, which is probably gonna be the 49th state to ever legalize this law. But even just trying to have a conversation about what kind of treatment he would want or when in the point he would want to go hospice or even what he wants as quality of life to be, it's just-, it's not something he is willing to engage in. (V6)

In a society where death is not the most welcome topic, initiating a conversation about death is a big challenge. Participants reported that having conversations with patients was *"not difficult"* in part because those conversations were always initiated by the patient. Participants joined the conversation knowing that their interlocutors (i.e., the patient) were willing to talk about medical aid-in-dying. Common ground was immediately established:

> Most of them [conversations] go pretty smoothly, people are interested at the very least, some of them are clearly-, they clearly want to pursue it— 'That's exactly what I'd like to have available.' So, again,

> because they are initiating the request in a sense, there is very little pushback. I mean there is no pushback. And sometimes very eager interest to learn more about it. (H7)
>
> [P]eople call me wanting this right [the DWDA], and so, the challenge usually is trying to help them access it. Not that I'm talking about it and people don't want to hear. (V12)
>
> I think when I'm there, you know, the subject [medical aid-in-dying] and the format [the DWDA] have already been established. That's why I'm there. So, talking about death is the reason for being there, and they [patients] expect it. And also, even though there will always be conflicting issues, by the time a person gets to this point, they want the information, and they want to proceed. So, if you are in a normal social situation, the questions we ask and the information we need to get will be incredibly awkward. But given the format, it just is part of the process. (V11)

In contrast, participants were far less comfortable discussing medical aid-in-dying outside their work setting—that is, to engage in informal dialogue with their family, friends, and acquaintances. Participants described that they would very *"carefully"* and *"gently"* introduce the topic if deemed appropriate:

> [I]t's a very very sensitive, very delicate issue that it needs to be addressed with care, and tenderly. (H6)
>
> [H]ow you really have to enter really really carefully. So, I'm not somebody who right away will say that I'm a volunteer for [*anonymized NGO*], you sort of tip toe and venture into the territory a little bit before you know you can go into full disclosure, or at least that's how I feel. (V5)
>
> But you know, I don't talk about it just openly with everybody that I meet. But sometimes with friends, when things come up and people are talking about death or talking about, you know, their sick grandma, how much she is suffering and that they wish there is another option, I'll kind of bring this up and let them know about it, and I have a couple of friends who just didn't even realize it [medical aid-in-dying] was a thing. (V6)

However, to their surprise, participants were often met with positive comments when disclosing their work, or at least without visible affront:

> I think with a colleague, a retired—well, she's not retired—but, a person who I worked with was a Catholic in the mental health system. And thinking that I would tell her what I was doing, and expecting her to be quite shocked and maybe not think so highly of me, and I got the opposite response, which was surprising. [Interviewer: Could you tell me a little bit more about what was her reaction?] Well, it was that she thought it was a really good idea. And while she—like sort of everybody I know—thinks that this is very difficult work and sort of surprised that anybody in the world would do it, they encouraged it, and said they would never want to do it, but that was something they can that see needed to be done. (V11)

> Everyone with whom I had contact is aware of what I'm doing, is very supportive, or else they haven't indicated to me (____). So, I've had no debates with people around the issue. (V2)

> I guess all the people that I had conversations with agreed. I mean, they didn't agree, they may have disagreed, but it was never a difficulty, it was just another opinions [sic] that were respected. (H5)

V8, like many participants, used to not tell people about her volunteer work. However, V8 recently began to feel the need to discuss medical aid-in-dying more openly. V8 did not want people to think of medical aid-in-dying as *"weird"* or mischaracterize it as *"Kevorkian sort of stuff."* V8 wanted to talk to others about her volunteer work so that people could have a better understanding of medical aid-in-dying, and yet, it wasn't clear how to do so effectively:

> I used to not really tell people about what I did, you know. I've just started telling people because I wanted to not be thought of as weird or just like Kevorkian sort of stuff. And I want people to know about, 'Oh, I do this,' you know. So, I've changed in that way, and I don't really know what we need to do. (V8)

Illness and death—these are difficult experiences that all human beings go through, but I suggest that these topics are much harder to discuss than they need to be. Death is not necessarily as unfortunate as most people think. As participants explained, *"dying is not the worst thing that can happen to people":*

> And yet, there are outcomes that are worse than dying. Dying is not the worst thing that can happen to people, and people who are dying understand that, and that's what I think this is about. (H10)
>
> I think what really informs me in my work is that I really don't I think that death is, again, not the worst thing that can happen to a person. …We all have our life is all. I mean, it's trite and I would never say it to patients, but we all will die eventually, and so it's just not the worst thing. And so, that's what informs me as I work through people. It's tremendously sad and it can be really painful, but it just isn't' the worst thing. (H13)

Dying is not the opposite of living but a part of living. As V3 described, to talk about dying is *"just another way of saying the way that I live":*

> "You die the way you lived"—I think everybody in hospice care has heard that phrase a million times, that people come at their death the same way they came at everything else in their life. …When people call and they are happy and they are making jokes, I get the feeling that it's not just when they'd been dying that they have a good sense of humor. People who can make a really funny interesting joke probably have had some practice doing it, and I see that they probably for the most part carry it through as they die. So, I think this because being around people who are dying, I think, has taught me a lot about how I'd live my life, and then it has help me reflect on maybe the way that I'll die, which is just another way of saying the way that I live. (V3)

6.2.2. Hidden Practice of Medical Aid-in-Dying

Washington's DWDA has been in effect for almost a decade, and yet, relatively little has been done to normalize it into mainstream medicine. On-the-ground experiences with medical aid-in-dying remain mostly hidden and unspoken. As H10 remarked, *"It's all so hush-hush":*

> Sure, it does feel like after seven years [doing the volunteer work], this is something I say sometimes, it's like the underground railroad. After seven years, this is-, people are choosing this option all the time, and it still feels like you are the only one if you decide you want this, you know. It's like you are knocking on somebody's door in the middle of the night hoping they'll help—it's an underground railroad. And it's-, it actually has not had a good platform for people to get together to have conversations, find each other, and get support. It's like the community it exists, but they don't know where they are. So, there's a lot of good work to be done. (V12)

> Personally, there is nothing being done to really monitor implementation of this law, and as far as I can tell, very little research going on actually looking at how this works on-the-ground. …and the truth is we don't really know because we are not really looking. And it's all so hush-hush. (H10)

Through the analysis, I identified three underlying concerns that posed significant challenges to openly practicing medical aid-in-dying: coercion, privacy, and politicization.

Coercion. First, participants expressed a deep concern about potential coercion. Participants were very careful about discussing medical aid-in-dying with their patients because "*it is a fine line*" between legitimate influence (e.g., providing information) and undue influence (e.g., coercion). Seattle Cancer Care Alliance, for example, like many health care institutions in Washington, does not allow posting information pertaining to Washington's DWDA or the hospital's medical aid-in-dying program in public spaces, thereby effectively requiring that patients decide for themselves to initiate requests (Loggers et al., 2013). As H1 commented, "*It's not something that's advertised. It's not something that's openly discussed*" in hospitals. Health care workers and volunteers withhold information until patients explicitly communicate their interest in medical aid-in-dying:

> [S]o, one other thing is that it's not something that is necessarily-, you wouldn't necessarily offer it to a patient. It's more if a patient is inquiring about it, and then you'd provide information. So that can sometimes pose complications in terms of, you know, making sure people are aware and know their

> options. Because they're thinking of something, but if they are not really asking for it, they might not get that information. (H1)

The problem is that the request often comes too late because the patient does not understand how much time it takes to go through the process of the DWDA:

> So, things that would come up is, patients won't necessarily ask for this till very very end. And the law requires that there's, you know, there's a timeframe. Things have to happen in certain order and certain amount of time has to go by. So where there can be complication is that you have a patient who is, you know, rapidly dying or really struggling in a lot of pain, and they're asking for this [medical aid-in-dying] and then you come into this conversation saying, 'Okay, actually we have to make sure we have a physician who is willing to prescribe, and you taking the first oral request, and then you have these other steps you have to complete, and it's gonna be over two weeks before anything-, you could even get a prescription if everything happens in a timely manner.' So, sometimes those conversations can be very difficult because, you know, it could have been something like the patient has been thinking about it and they just didn't ask for it, they didn't realize that there was a waiting process. So sometimes suddenly they're in a spot where they're actually ready to take the medication and they can't have it right away because there is this delay. So sometimes these conversations can get complicated just because, you know, you feel for the patients because they're in a, they're suffering, and they want something. But we have to go by the law, and yeah. (H1)

> [T]he law says 15 days if you can get through it, if they [the patients] can get through it. But in reality, you are looking at a month at least to find doctors, get appointments. And their will to live is so strong, that people will just hold on and hold on until they are really suffering, and then it's too late. They don't have the capability to see the doctors or get through the process, and that's kind of sad. (V7)

Timing is essential, particularly when someone is actively approaching death. Sometimes participants would sense that their patient might be contemplating medical aid-in-dying, and they know that if the patient wants to use the DWDA that they should act quickly. However, participants were not able to say anything until the patient spoke out, and even after the patient raised the topic, participants would very carefully follow up the conversation, to make sure that the patient was not coerced into thinking about medical aid-in-dying:

> [A]nd what was really hard for me was to hold back and not just tell her what I thought, you know, immediately, because you want people to come to that themselves, but you are also actively approaching death. …because with this population you don't always have one more conversation (H8)

Privacy. Another concern was tied to the patient's privacy:

> [People are] so concerned about privacy, which is a really important concern in this whole thing—balancing act between integrity of the practice and privacy of the individual. (H10)

In the United States, Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule sets a national standard for the protection of individually identifiable health information (45 CFR Parts 160 and 164, 2002). Physician-patient medical discussions should generally occur in private, and health care workers should take reasonable precautions to ensure that their communications with the patient are confidential. In a similar vein, volunteers are generally under a confidentially agreement, which prevents them from discussing specific cases of medical aid-in-dying outside their organizations:

> I am also under confidentiality agreement. It's not that I feel uncomfortable [to talk about my volunteer experience], but I know that we are not supposed to take stories outside. (V8)

Both health care workers and volunteers are bound to protect the patient's privacy unless the patient gives permission for disclosure. And in the case of medical aid-in-dying, the patients tend to keep the matter as private as possible. Patients are often worried about the stigma of suicide associated with medical aid-in-dying and how it may impact, or rather damage, their legacy. Patients, therefore, tend to carefully select a small number of people whom they trust and only communicate within that group. Even intimate family members are not necessarily allowed to be informed about the patient's choice to pursue medical aid-in-dying:

> [Patients] have to choose wisely because sometimes they can have negative, you know, impacts on-, so you don't tell everyone. …you have to think about what that [pursuing medical aid-in-dying] means and what that means for your legacy left behind. (H13)

> What we heard a lot and what I see is, because of worries about stigma and because of worries about legacy, people don't tell and trust. They don't tell everybody. It's not public in many ways. …Trust is fundamental here because this is the final act, and if it's not done well, it can really mess things up for not only the person in the situation but their legacy. …But this fear of somehow skewing up the legacy or turning it into a suicide, or separating family dynamics and adding to it and making it worse instead of being able to come together and forgive—that [fear] keeps people separated and apart. And a lot of the family members spoke about those dynamics and what happened to them as they were both trying to support the person who was dying and maintain relationships with the rest of the families. (H10)

Politicization. As a part of end-of-life care, medical aid-in-dying calls for clinical research within the medical community. At the same time, it is a highly controversial political topic—case studies and publications can be easily sensationalized.

Many participants recalled participating in information sessions and having a lot of open conversations (sometimes heated debates) about medical aid-in-dying when I-1000 was on the ballot in 2008:

> When it was on the ballot, when it was being discussed for a vote. [Interviewer: Do you remember what the context was like? What people were talking about?] It was, you know, very heatedly debated. You know, people were probably more openly at work discussing their thoughts and feelings about it actually because it wasn't a done deal. It was still in debate. (H6)

Soon after the vote, however, the topic quickly disappeared from public view as well as from participants' workplace:

> Less now. I mean just after-, when was the vote? [Interviewer: 2008]. Yeah, so, not as much recently. (H8)

> [O]nce these laws get passed you hardly hear a peep anymore. There aren't harsh stories on the news, there aren't protests on the streets, no one's threatening to shoot doctors or burn down their offices, the issue kind of goes away once the law is in place. (V2)

> [T]here was a lot of education initially when it [the DWDA] came out, but then I don't see much about it anymore. (H12)

While I-1000 was approved and the DWDA has been successfully implemented, participants still had ongoing concerns about the law being challenged and revoked:

> [T]here's constant ongoing push back by folks who don't support these measures to rescind the laws. And that's what I'm calling the politics of this. (V9)

Indeed, there have been many attempts to overturn medical aid-in-dying legislation in neighboring states, including the George W. Bush administration's attempt to block Oregon's law in *Gonzales v. Oregon* and an ongoing litigation challenging California's law in *Ahn v. Hestrin*. Therefore, those who support and practice medical aid-in-dying tend to operate *"in a deep defensive mode,"* not wanting to *"poke the bear"* and jeopardize hardly-won rights:

> First of all, I think we are sort of always operating in a deep defensive mode here in Washington because we feel like compared to the rest of the United States we are lucky, and that we are continually being sort of attacked, to take away those rights. So that to actually trying to gain more rights would be presumptuous or may not succeed. …I mean, we are very, very careful group not to do anything illegal because, yeah, everything will be in jeopardy. (V8)

> [H]ow to get the information out because there's a-, I won't say appalling but alarming amount of misinformation or lack of information both in the medical field and with the public, is astonishing. So, you want to get the information out, but you don't want to "poke the bear." You don't want to get the opposition fired up, so there's a lot of challenges there. (V7)

Overall, there was a strong concern about opponents misinterpreting and abusing stories, which prevented the practitioners from openly discussing on-the-ground experiences.

6.2.3. Uninformed Patients and Physicians

Because people tend not to talk about medical aid-in-dying, many people do not know about what medical aid-in-dying is:

> It's amazing to us, we still find people who have lived in the state for years but don't know that we have the Death with Dignity law. Some people know we have the law but don't know how to go about find out about it. (V1)

> And it's a little interesting to me that there are a number of patients, who don't aren't aware of the law, and don't realize that it's available. (H7)

There is no standardized practice to educate and inform patients and physicians about the DWDA. Both patients and physicians, who were interested in medical aid-in-dying, were left without guidance to find necessary information on their own, either through word of mouth (although *"it's all so hush-hush"*), general publicity (although *"it's not something that's advertised"*), or by *"googling"* (although *"you gotta search for it really hard."*):

> These people eventually find our organizations through hospice or by googling. (V10)

> We have no legal or structural relationship with the law. But most physicians who are prescribing under the law are aware of us or the individuals are aware of us just through general publicity. (V2)

Both patients and physicians relied heavily on a particular local NGO to get information about the DWDA, which raised some concerns among physicians:

> The only clearing house of information about it is a partisan political group, which is [*anonymized local NGO*], they are a patient advocacy group, they have an agenda. And over the last several years, I've gotten-, I have sort of spearheaded some meetings, discussions among doctors who are-, who have participated in one way or another. So, they are not against it, but they have been looking for more-, for non-partisan support. …I would like Washington State Medical Association to provide a platform for us to take this out of the partisan world and into the kind of neutral-, on to neutral territory. …we

> need a place for doctors to get information and talk about what-, about the burden, and how it feels in way-, we don't have anywhere to go. (H15, physician)

For some physicians, lack of access to information led to their unwillingness to participate in the DWDA. Physicians hesitated, not necessarily because they were philosophically opposed to medical aid-in-dying, but because they did not know enough about what medical aid-in-dying entailed:

> It's not uncommon to hear from a doctor, 'Well, I kind of support you but I have no-, what to do, I don't know what my responsibilities are.' You know, they kind of don't want to do it because they don't know enough about it. (V1)

> The other reason is doctors are so busy, and if they are not familiar with it they will not do it. They at least have to fill out the form, that's another thing. If they are not familiar with it, they just, you know, 'I'd rather not.' And the other reason is that even those who are philosophically more progressive and supportive, they are just not familiar with the law. They are not familiar with what drugs to use. So, you know, unless it's something that they are doing repeatedly-, the oncologists, they are dealing with cancer patients and death on a daily basis, so they have more information about it. (V7)

That said, many patients struggle to find attending and consulting physicians:

> [I]t's very very difficult because they are in a situation finding two doctors and for the law, and to have people come to you that say-, I mean they are just at total odds—they are dying, they are not in any position to go doctor shopping. And so, if we can help them by finding two doctors for them they are eternally grateful. (V10)

> The challenge usually looks like "I am in the hospital, I feel like I should have the right to access this law, none of my providers will help me, everybody tells me they don't do this. What should I do now?" That's the challenge, usually. (V12)

While it may be difficult to change a person's political or philosophical position, it is possible to provide education for physicians who would otherwise be supportive to increase their confidence in practicing in medical aid-in-dying. Accordingly, many participants felt the need for formal training and education (e.g., continuous medical education [CME] requirement, part of the coursework in the medical schools) to inform physicians about medical aid-in-dying:

> I also think that there should be a CME requirement, continuing medical education requirement. I think that we require doctors to have certain number of hours of CME if they are going to prescribe more than a 120 mg of morphine a day for chronic pain, but we don't require anything, anything of them [the attending and consulting physicians]. We don't require any ethics, we don't require any discussion, we don't require anything other than to have a license to practice. And I think that's wrong. (H15)

> These, you know, physicians, all the physicians have to learn somehow. You know, it shocked me that we still occasionally will have clients who come and say, 'My physician didn't say no, but just don't know anything about the law.' And I don't know how you can be a physician in Washington state and not know anything about the law. I just think if I was a doctor here and the law passed that I can write a legal prescription for someone, then I would figure out what that meant. I'd say obviously most doctors that are doctors now were doctors before the law passed didn't have the chance to learn in the medical school, but now that we have the law, we teach them about pretty much every other law involving healthcare—we teach them about HIPAA and every other stuff. So, why don't we teach about this law. (V6)

H14, in particular, emphasized the need to train physicians how to *communicate* with their patients about medical aid-in-dying:

> I'm not sure, or I haven't heard of any formal training on, you know, how they do this with the patients, you know. So, are there things, you know, certain questions that should be asked and explored? Are they doing it-, sort of asking these questions, versus sort of saying 'Okay.' You know, like how much time they are actually in the room, setting time up discussing this issue, especially when you get that second physician who may not know that. So, I guess if there's anything, it would be to make sure physicians who do this has the type of training in communication and, you know, talking

> about issues in a very comfortable, really sort of getting into maybe deep existential issues with the patients, if that sort of arises. (H14)

> Those conversations that a medical doctor have with these patients are intimate conversations, they are talking about end-of-life issues. Ninety-nine percent of the time there's a caregiver there who's usually the spouse. Sometimes kids come, too, to those conversations. And the whole emotional component of this transaction is not part of the personality of the medical doctor. Medical doctors are scientists. And if you look at the characteristics of these scientists, they are interested in facts, research, data, chemicals—you know, things like that—physiological uptake issues, not the transaction between human beings. And the last thing these patients need is that kind of characters in their lives. So that's why I say they are personal. (V9)

For patients, on the other hand, lack of access to information has led to exclusion (the issues of exclusion will be discussed in further detail in Chapter 8.3. Excluded Stakeholders):

> I mean, like the general statistics, I think, show that it's primarily educated people who are asking for this. So, if somebody isn't aware of something like this [the DWDA] exists and is available to them, then they wouldn't necessarily ask for it even though they might want something. (H1)

For the patients who were vaguely aware of medical aid-in-dying, they often had an oversimplified understanding of how it worked—that they could just ask for *"a pill"* (when in reality, it may involve opening up and mixing hundreds of capsules of pills) which the doctor would immediately prescribe (when in reality, the law required multiple documents and waiting periods). The patients were often surprised (and frustrated) to find out how complicated and time consuming the actual process was:

> I think it's difficult, these are difficult conversations when somebody doesn't understand kind of how much the law requires people to do and sort of enter the process with the expectation that 'I just need to talk to my doctor about this, and then they'll prescribe a pill.' And that people, particularly, if they feel that they are very close to the end of life, that their time is very short, people can get very anxious and frustrated, and sometimes angry about the fact that the process has to go in a certain order, has a

> certain wait time, and so on. And that can be really hard to convey to people. I mean, it is what it is, and I have to let people know, but sometimes people come in with misconceptions, and then are really surprised and sometimes devastated if they feel like they can't pursue the thing that they want to pursue. … I think that the media doesn't necessarily provide an accurate picture of how specific the law is, that it's not, like I was mentioning before, that it's not that you have a conversation with the doctor and they write you a prescription, that it's really a very specific legal process that requires multiple steps. (H4)

> [B]ecause people always think that this is going to be about a magic pill under enchanted bush. Because realistically no one needs to read about the law or learn about it until they're in this situation. And when they're in that situation there isn't the (____) with all the patients, the concentration to literally read the law that is so confusing. So, the "Misinterpretation" is what I chose to describe the anxiety that people feel by the time they've met us. (V10)

Such misconception was especially problematic because it prevented patients from initiating the process in a timely manner, especially in cases where patients are degrading so quickly that they are unable to get out of bed to go see a doctor and get the medications in time:

> Not infrequently because they come to us a little later than is optimal. And their decline is a bit too precipitous at that point, and they are trying to get [through the] hurdles in the most efficient way possible. So logistics are big. (V2)

> [W]here I experience frustrations are usually around getting notified and getting pulled in a timely manner just to make sure that things are going as smoothly as possible. (H1)

Therefore, one of the communication challenges was to clarify misconceptions about the multi-step process of the DWDA, including waiting periods:

> So, if the patient shows interest of-, requests death with dignity access, I may give them a brief overview. The first thing I let them know is that it's a process and that it takes some time, so if they are even thinking about it, they should initiate the process sooner than later. (H7)

> But one of the problems with when I said patients not getting into it quickly enough, part of it is because they can’t get the information, and they will get misinformation from the doctors. They’ll talk to their doctor and the doctor will say, ‘Well, you are not ready to die yet, it’s too early for you.’ When in fact if you have six months to live, I always tell people that if you are in hospice, if you qualify, if you are even thinking about it as a possibility, go through the process. So, there’s the lack of information, some of the information they get is not correct. (V7)

6.2.4. Confusing Terminology

Another communication challenge stemmed from the lack of clear terminology around medical aid-in-dying. Health care providers had to carefully pay attention to subtle cues, which may or may not imply the patient’s interest in medical aid-in-dying, and then follow up as appropriate:

> Mostly I wait for patient cues on that. I don’t bring it up. I mean, I don’t know I’ve ever initiated a conversation. But sometimes patients will drop cues, and I’ll pursue that and say-, well, I had a patient, for example, not long ago, say something to the effect that ‘Maybe I need a Dr. Kevorkian,’ or something like that. And so, then I’ll just pursue that and say, you know, ‘Tell me more about that,’ you know. (H7)

> I’m thinking about how patients might refer to it. It’s maybe the more common way, if they don’t use one of the formal terms. It’s usually this [*“Help in the Dying Process”*] or some paraphrase of that, you know, that they may say something like, you know, ‘I wish there were medication that, you know, help me die comfortably or peacefully or without pain.’ (H7)

The issues of terminology will be discussed in further detail in Chapter 7.2. Terminology.

6.2.5. Managing Roles and Expectations

The DWDA entails a complicated multi-step process that requires multiple stakeholders to communicate and collaborate. Managing expectations among diverse stakeholders is a big challenge. Moreover, miscommunication and false expectations create tension among stakeholders. Here I describe the roles of the *palliative care team*, *social workers*, and *attending physicians* to illustrate the difficulties of managing expectations.

Palliative Care Team. While the DWDA has been in effect for almost a decade, relatively little has been done to normalize its practice into mainstream medicine. Few patients have used the law; most physicians are inexperienced:

> There's a very small number of people that use death with dignity compared to the population of dying people. It's a drop in the bucket. And so, certainly general practitioners rarely see it. (V7)

That said, when a physician receives a DWDA request from their patient, they usually seek advice from their colleagues who they expect to have expert knowledge in this area. Physicians may call the palliative care team, expecting that they know best how to communicate various end of life options with the patients, including medical aid-in-dying:

> I usually ask them [patients and families] to consider talking to a palliative care team, because to me they really are the communication experts about these very difficult topics and to have the conversation once the patient starts to explore what they want to do—to appoint a durable medical power of attorney so that that individual can be the voice to help the health care team. …I think this team [palliative care team] is what helps people get a better handle on all of this because these are all things that get verbalized out loud during these conversations (H9)

Interestingly, however, the palliative care team did not necessarily consider themselves as experts to handle DWDA requests. For example, H11, a participant from the palliative care team, explained that if physicians called the palliative care team, the physicians were redirected to the social work team. *"Interprofessional tensions"* arose across different specialties:

> Yeah, we are in a bit niche and a bit of a (____) position where palliative care specifically we are-, we do deal with a lot with end of life care—we are trying to broaden the scope of what we do. And I think

> one of the tensions that comes up with death with dignity being in health care system is they-, the patients may request it, other doctors will [say,] 'Oh I'm gonna call that palliative care to talk about it.' And for us, we don't want to be the Death with Dignity team necessarily. So, I think there's sort of an interprofessional tension there, where it's like this is-, we are not the only ones who can have this conversation, and sometimes the real delivery and (____) around death with dignity comes from the social worker—we have two in the hospital who are trained very well to do this. And so, we are often just telling things like 'Call them [social workers] first, have them come meet. If there's additional contact or questions, we can help.' So, expectations about what's the world think we should be doing, expectations about what we think we should be doing, and that operations of how you-, this actually should be operationalized for patients and families. (H11)

The few physicians who were more open about their positive stance on medical aid-in-dying became known as "the person"—the designee to whom everyone turned to ask for prognostications and prescriptions. Participants talked about the pressure they have felt being in this position, overwhelmed by the expectations placed on an individual physician:

> I mean, I guess another difficult conversation was, none of the other psychiatry consultants really want to do these evaluations. (H3, psychiatrist)

> And kind of by default I've become this like this [one person] clearing house for a lot of this stuff, and that's not, you know, that's not my job. …maybe I'm qualified to do it, but certainly I'm not mandated to do it. And maybe we need to institutionalize this a little more. (H15, physician)

Social Workers. Another tension emerged around the role of social workers. V6, one of the volunteers, reflected on her experience working with social workers assigned to handle DWDA cases in a local health care institution. In V6's view, the social workers seemed *"like they are just doing their job"* and perhaps not caring enough. V6 expected them to be more involved and dedicated:

> My experience here working with social workers with the end of life law has been not great. So, like [*anonymized health care institution*] has a specific social worker assigned to Death with Dignity cases

> and she's lovely. I've never met her in person, but I've communicated with her in various means, and she seems like a wonderful, nice person and everything. But she just isn't-, I kind of-, I don't know, I kind of expect people that are involved in this to be really involved in it and really interested in it and really wanting to advocate it and do what they can for the people involved. And a lot of my experiences with social workers here around the law was kind of like they are just doing their job, and they'll just do what they have to do because it's their job, but they are not gonna stay 10 minutes late to answer your phone call, they are not gonna write an email on a Saturday, they are not gonna do anything outside of just what isn't base required for their job. (V6)

However, H8, who worked at the health care institution mentioned by V6, had a very different account. In H8's experience as a coworker, the social workers were very much dedicated to the patients to the point that they were emotionally *"parched"*:

> [B]ut I feel like the designee, there's a designee who's MSW, and she's parched. I've talked to one of them and it's heartbreaking sometimes. She thought it would really be like good advocacy and then just like, 'No, these are real stories,' and it's sometimes really hard, you know. And so, I think palliative care as well and chaplains too and social workers too—we have real patients. …You know, anytime you're working with patients it's-, you're gonna have some heartbreak too. (H8)

Attending Physician. Yet another tension arose from the gap between the legal responsibility of the attending physician and the patient's general expectation about the attending physician's role. Washington's DWDA defines the attending physician as follows:

> "Attending physician" means the physician, as defined in chapter 18.71 or 18.57 RCW, who has primary responsibility for the care of the patient and treatment of the patient's terminal disease.

The specific responsibilities noted in the provisions include: (a) determining the 6-month prognosis and (b) writing the prescription. That said, the law does not necessarily require an attending physician to have any established relationship with the patient or to attend the death:

> I think, instead of calling the doctor who writes the prescription the "attending physician" they should call him the "prescribing physician" so that it makes more sense to the client and their family. (V4)
>
> A lot of times with our clients—I don't necessarily know if this is true with everybody that's choosing the law—but especially for people that are contacting [*anonymized NGO*], a lot of times it's because their family physician, their general practitioner, their oncologist, the doctors that they already have relationships with have declined to participate—they don't want to participate. So, they are reaching out to us because they need help in finding somebody. And we kind of have a short list of physicians that we use over and over again who we know are willing to participate to see the clients, who will do assessments and write the prescriptions. That said, kind of the history of the term "attending physician," you know, attending is-, was somebody who attended to, who was there, who was overseeing all of your care, who was kind of your beacon in your sickness, who was the one that you could turn to for your answers, the ones that you could turn to for, to kind of have all the information, kind of sailing the ship. And I think that, unfortunately, because of time constraints and life constraints, a lot of times our attending physicians see our clients for one appointment …And that's the end of relationship. I don't necessarily think we need to change the terminology and to call it something else, like somebody will say "prescribing physician," but I just think we do use the term "attending physician" a lot and I think that it is misused. (V6)

Patients may feel lost and disappointed if those whom they expect to be their attending physicians—who have been involved in treatment across the trajectory of their illness, who they have a good, long-term relationship with (e.g., family doctor)— refuse to prescribe the medication:

> [P]eople have been going to their same doctors who they have a good relationship with, but don't know and don't realize that their doctors will not be able to involve themselves in aid-in-dying because they belong, work for religious medical organizations that have a conscious clause. (V10)
>
> I think of a couple of gentlemen who really wanted death with dignity, and they weren't able to have it, and just real-, you know, real frustration, real disappointment, and just some anger on the part of one

> gentleman. Just he didn't understand, he was just confused like, 'I don't know why, I don't understand why they say I can't have this.' (H6)

Another tension between patients and attending physicians can arise from prognostication. The eligibility for hospice and medical aid-in-dying both depend on a 6-month prognosis:

> The big thing is this conflict about the six-month thing. (H15)

> [I]f you qualify for the hospice you can qualify for death with dignity in terms of that six months or less. (H1)

Patients who have been given a 6-month prognosis for the hospice benefit may expect that their physician will provide the same prognosis if they ask for the DWDA. But to the patient's surprise, the physician might say, 'No, I cannot say that you have 6 months or less to live.' The patient might be confused about what appears to be a mixed message. The patient might think that the physician is acting inconsistently, changing their words, *"trying to get in the way of the patient access."* Prognostication, however, is complicated, and physicians must consider different consequences of using hospice and medical aid-in-dying as they carefully make each prognosis:

> [S]ometimes, two laws, the hospice eligibility rules, I should say there's two sets of rules come in conflict. Under hospice, the medical director is responsible for certifying that it's more likely than not that a patient has a prognosis of six months or less. We all know that the prognostication is very, very difficult in certain diseases. And the policy has been to for the purpose of the hospice benefit, when it's really unclear to err on the side of allowing the patient to come on to hospice to say, 'Yes they meet these general guidelines.' And then to see how they do. Because built into hospice benefit is, into the hospice structure is this allowance for decertification from hospice. …The language for qualification for the Death with Dignity Act is almost identical—prognosis of six months or less. However, the consequences are completely different. We had a number of situations in which a hospice medical director said, 'Yes for the purpose of hospice eligibility, I think this patient qualifies. But I do not feel comfortable with my level of certainty, of prognosis, is not sufficient for me to agree to sign as a consulting physician.' And that created a lot of conflict because-, it created conflict because the patient

> really wanted this. They wanted those two doctors' signatures. Suddenly this team that's suppose to support the patient is now giving what they would interpret as mixed messages. The patient advocacy organization, *[anonymized NGO]*, sometimes interpreted that as the hospice medical directors are trying to get in the way of the patient access. That created a lot of hard feeling. And then, and so we took our job very seriously. Very seriously. And I think we are sometimes regarded as we should just sign off. (H15, physician)

> [Y]ou have to have a prognosis of six months or less, theoretically, but COPD which is the condition he had, chronic obstructive pulmonary disease, is pretty unpredictable, I would not be surprised if he died in six months but he can also live for years—that sort of grey area. Unpredictable condition. …truthfully as a provider, to err on giving someone hospice, if I'm wrong then the hospice signs off. To err on death with dignity, if I'm wrong and he dies, that's not a reversible event. So sort of this prognostication being an imprecise science in decisions and care opportunities that relate to prognostication, how as a physician we wrestle with these things and try to grapple around making the right decisions. So I, along with a number of colleagues, felt like 'Yeah, we don't think we can quite endorse death with dignity request at this point, but certainly his interest in hospice,' you know, to err there is a less of a malady than it would have been with death with dignity. (H11, physician)

6.2.6. Sensitivity to Nuance

Many participants highlighted the importance and the difficulties of communicating nuances:

> I pick nuance because it's something that I've been aching for in this whole discussion and which seems to be very elusive. I think again a nuance exists at many different levels both internally within the patient, within the physician, within the culture, I think, or it *can* exist. I think nuance is-, I tend to be pro-nuance. I find nuance interesting and beautiful. (H15)

Nuances and emotions often get lost when the topics are politically debated at the public level, simplified into a question of yea or nay:

> [W]ith the woman in Oregon, the young woman who—and I can't remember her name—who was a very strong advocate for it, and you know, I wasn't particularly influenced in one way or another. …I think that it lacked some nuance, and I think that's been frustrating to me in general, is that it does seem to fall into you are either for it or against it. (H15)

> A lot of people …they don't really, they haven't been up close and personal to experience it [a death]. So a lot of these individuals have a lot to say about what's happening here, but they don't have it at that micro-level of having experience, so they talk in broad general strokes, or they want to make-, they feel they have the right to make decisions about choices that they don't even understand the context or circumstances in which this immediate group [indicating the "patient," "family" and "friend" tokens] is living with. (H9)

Over time, as they gained more on-the-ground experience in medical aid-in-dying, participants became more sensitive to nuances and details:

> I didn't understand any of these wrinkles and nuances at the time [the 2008 vote]. I was like a lot of the-, I mean …at the time it wasn't anything like I had a huge amount of experience with it, and I voted for it as a sort of basic matter of freedom of choice. (H15)

> So, I think I read all of these things really differently as somebody who is a researcher and somebody who have spent enormous amount of time thinking about this and really getting into the details of this. At the higher level, I don't know how much people engage with the facts of the case and what they actually see. So, I'm not sure if I am helpful to you. I'm too into this to be man on the street kind of person to give you a sensibility about it. (H10)

Participants described that in their experiences, medical aid-in-dying felt rather *"grey," "blurry,"* and *"amorphous"* at many different levels that could not be simplified into a matter of black and white, pro/anti dichotomy:

> And it was a particular friend who was kind of saying like, not understanding why people would have a problem with it and sort of "this is a no-brainer." And kind of discussing with her, you know, as a

provider and somebody who talks to people about this, this is really-, it's really not-, it seems like it's black and white but once you are actually in it, doing it, it really feels very grey. (H14)

Doctors themselves get I think probably pretty mixed up, so I often think about what it's like for a doctor to decide to participate or not. I assume that it's easier for some people and maybe involves a lot of soul searching for others. And it's something I never had to do and will never have to do. But it's something I think about. …I guess this shape (*see Figure 6*) is-, sort of reminds me of a grey beach like a rock on a grey beach, and I think this question with doctor participation probably leads people to a lot of tough decisions to make and feels like being on a grey day on grey beach. (V3)

Figure 6. ***"I guess this shape is, sort of reminds me of a grey beach like a rock on a grey beach."*** **(V3)**

What is natural? …what is a natural death? Some people might say it involves a breathing machine. Some people might say that a natural death is one with no medicine involved from the beginning. Death with dignity is not considered a natural death. Although when a person dies, their underlying illness is what's reported on the death certificate, so in a way they didn't die because they used death with dignity, they were going to die imminently. So really the person died of liver cancer or whatever, so I guess it speaks of what is natural and what does comfort mean. …general idea of the question, it's maybe more amorphous than the question with a rigid belief. (V3)

Then this is where I feel like my values, you know, their [the patients'] values trump mine, and because I just would always want to be someone who stood by their values, but what that means in this situation is a little blurry. (H2)

> So, the law is very clear that the medication has to be self-administered. That said, it doesn't really define what self-administer is. …And I think that probably every volunteer has a slightly different definition of what self-administer is. …But I think that that's a very grey area, and you start walking this fine line on when are you helping too much and when are you not helpful. (V6)

Unfortunately, the way most social media is currently designed does not support communicating rich nuance, emotion, and details that are essential *"to get to the depth and complexity of what's going on":*

> I think one of the challenges with the topics that are potentially controversial, or (_____) emotionally, or culture you are socially charged, is the nuances, and the individual sort of experience related to them are very hard to communicate in whatever Twitter will—100 and something characters, and so a lot of sort of punchlines and sort of micro statements that one might spit out through various media, it's just so underwhelming and to some degree, what's the word, not insulting but it doesn't get to the depth and complexity what's going on. (H11)

6.3. Characteristics of a "Good Conversation"

Ultimately, my goal is to build a better communication system that allows people to engage in more meaningful conversations around medical aid-in-dying. But what is a good conversation? How does a good conversation feel? Analyzing the empirical data, I have identified three key characteristics of a good conversation. Good conversations feel *open, reflective,* and *respectful.*

Open. In a good conversation, people feel open to talk about death and dying:

> I think the real opportunity is that death cannot be a taboo subject that we can't talk about. We need to talk about it. And families need to talk about it, sooner than later. And I think in America, people need to think about the whole thing before they get sick, before they are so vulnerable and stressed out and having these difficulties. (H9)

> So, I wrote "Death is easier when people talk about it." I guess this could mean death after the fact is easier for the loved ones when they talk about it, but it could also mean dying is easier for the person when they talk about it before they die. And it's probably easier for the family if they talk about it before they die. …I think that allowing that conversation to stay open and happen often is probably a great gift they can give to their loved ones. (V3)

> The benefit, partly, it puts dying in the spotlight. That's one of the benefits. (H2)

In a good conversation, it may feel natural for people to think and talk about dying. People may feel safe and encouraged to talk about *"anything that's on their mind, whatever it is":*

> [A] lot of what I'm doing is educating clinicians about how to have these conversations—so helping them to also diffuse their own anxiety around this topic, and about how they are gonna engage with people who bring it up. And to realize that the people who talk about it—we are all thinking about it, we all think about dying at some point. And if you have terminal illness, you think about dying, period. But nobody will talk to you. Then you have to hold all of that anxiety inside. So, I'm trying to make space for people to speak freely and be okay with that. (H10)

> Many good conversations, and mostly what comes to mind are the patients. Because …[if] this is something that they want to have as an option, and when they understand that you will support them and that you will talk to them directly about anything that's on their mind, whatever it is, and look at it objectively as you can—I can—then that gives them a sense of peace. You can see it in their eyes, and they tell you about it. (V11)

People may feel free to ask any questions and expect to get their questions answered. There would a good exchange of ideas and respect on both sides:

> I think in the public sphere, a good conversation is when people feel free to ask questions and I can answer their questions. When there's a good back and forth and respect on both sides, those are good, and I feel good about those presentations. On a personal level, the good conversations, again, it tend to be when a client feels free to ask questions and gets their questions answered and understands, and

> when I'm able to answer all those questions and when I'm able to reassure them that whatever the choice they make will be the choice that gets respected. (V1)

At the end of the conversation, people may feel calm and relieved of anxiety. People may feel happy—smiling and perhaps even making jokes:

> A good conversation is the one that reduces anxiety. That creates a space where people can be heard and express what really worries …because everybody's worried, everybody has concerns. So, I think a good conversation is when, at the end of that conversation people feel relieved and calm. (H10)

> And I remember leaving that conversation with everybody feeling kind of happy. People were smiling and joking and glowing a little bit. (V3)

Reflective. In a good conversation, people may be encouraged to ask *why*—to dive deep into their inner thoughts, get to the roots of their desire to consider medical aid-in-dying:

> [W]hat matters is people have worries and we engage with those worries very seriously and listen to them, and not only listen to them so that we can dismiss them at the end but actually hear what's behind the concern. So pushing to understand more about, in qualitative interviews and other, ask *why* five times, right? So just keep peeling the layers back until we get to what the real issues are. (H10)

> [W]hen someone says they are thinking about death with dignity, I want to really know what's behind that. And one of things that we know is that-, to find out if there's anything they particularly fear about this process that they would go through naturally. (H13)

> And also, I know that, that some physicians—not all—do a really good job of really talking with the patients to learn about *why* this is something that they want to pursue and what alternatives they might have to pursuing this process. So really drawing out what it is for the patients, what is bringing up this desire to pursue this—fears, hopes, values, et cetera. So, I think that that's a big part of it. …the communication that happens—that we hope happens—between the patients and the people who are important to them, and so that everybody understands what is happening in this situation, and that people have the opportunity to come together in a really meaningful way around a really profound act,

> or profound potential act. Because so often people pursue the process and then don't take the medication, but that pursuit of the process can lead to an interesting conversation itself. (H4)

Sometimes, medical aid-in-dying is not what people necessarily desire as an end, but it is what people use as a means to explore broader issues of life and death:

> I try to let people know that when this issue [medical aid-in-dying] comes up, more often than not it's a proxy for a bigger issue. …what I see over and over and over again is that people use this topic of death with dignity as a litmus test to find out if they can talk about dying. Because nobody wants to talk about dying. (H10)

> [A] great conversation is really just having more of the open conversation of what does the end of life mean to you—what are, you know, we can have a conversation about going into legacy and goals, and what are their hopes and fears, you know, finding out why a person would even want a death with dignity, because there are variety of factors and then often times there are things that can be done to kinda alleviate some of those fears. And a lot of patients just want to know that they have the option. So sometimes, a good conversation is making sure, letting them know how they can have that option, but then also letting them know that they also have other options whether (___) through palliative care or hospice or other things that can alleviate symptoms or minimize some emotional distress through counseling, you know, there's a variety of things. (H1)

To engage in reflective conversations, it is important to be patient, allowing enough time and space for individuals to explore their values and beliefs (*"soul-searching"* as some participants put it) and to come to their own conclusions:

> Yeah, I think, you know, as a professional, a good conversation is really one in which you are gathering information and helping that person understand what their feelings are around it. …I think to me a good conversation is when the person that-, the patient is really leading the discussion. And that's tricky because I always want to give more information and so it's really waiting to see what information do they really want and when to stop the conversation. So, to me a good conversation

> when I leave the room is when I feel like we've sort of explored what they want to do with that time. (H13)

> [W]hat was really hard for me was to hold back and not just tell [the patient] what I thought, you know, immediately, because you want people to come to that themselves. But you are also actively approaching death. …I wondered at the end should I have just go ahead and proclaimed that just saying 'I think it's okay,' you know, because with this population you don't always have one more conversation. (H8)

Respectful. In a good conversation, people respect each other, regardless of their differences in positions, values, opinions, intentions, and actions. A sense of respect is key in order to bring together people who may deeply disagree to nonetheless collaborate on the same issue:

> I would say this conversation that I've had with the leadership of [*anonymized NGO*] when we met a few weeks ago, it was good! It was hard but it was good, and I felt like we respected each other. And I think that's an answer to your question what constitutes a good conversation. It's where we can really see each other, where we can really have a difference of opinion, understand why-, understand to a degree our roles influence, as professionals our roles influence our positions. (H15)

> [I]t requires this kind of leap of 'I don't agree with this, but I respect and love you and I want to support you in whatever you choose to do.' (H4)

V2 juxtaposed the idea of respect with other qualities such as trust, truthfulness, confidence, and faith. These are key elements for establishing a good conversation, and in turn, providing an ideal context for collaboration:

> I would characterize a good conversation where the client and I both respect each other's intentions and actions. We have a level of trust that each of us is telling the other one the truth. I mean it's more like a felt sense that the conversation is working. …Let me get back to your question what is a good conversation. Where we both leave it feeling like we have confidence and faith in each other and look forward to working further on the same issue. …If you don't have trust, it's game over. (V2)

Relatedly, H3 identified honesty and compassion as key characteristics for a good conversation:

> I thought it was an honest interchange about the decision that was emotionally difficult for everybody, and I think the process was kind of honest and compassionate and it worked out well. (H3)

To be respectful, it is important to learn how to listen:

> [B]eing respectful about the difference of opinions when they aren't my personal views, and so working really hard to listen and hear what the kernels of the arguments are on the other side so that we can be very respectful and not just dismiss that it's wrong. Because they are not my view doesn't make them wrong. (H10)

> I would hope these guys are doing a lot of listening and not all the talking so that if we are at end of life that we are listening what's important and what do they need. (H9)

Such conversations can be constructive without being persuasive:

> [T]he real good conversation or conversations is when you have a constructive dialogue and not necessarily change people's minds but at least make people think in a different way than they were previously. (V7)

Good Conversation is to Have No Conversation at All. Interestingly, V8 pointed out how the idea of "having a good conversation" can become a burden. At times, a good conversation is to have no conversation at all:

> [O]ne of the things I appreciate about this job, this role is that as opposed to being a chaplain for example, is that there is no expectation about what is a good conversation. …then I don't feel like there's an expectation that we've also sort of put the burden of having another good conversation with me if they [patients] don't need to. So that to me is freeing because I am providing a service anyway with a medicine if that's all they [patients] need, then I can feel in good conscience if that's all I'm giving. (V8)

7. Issue

In order to build a communication system that cultivates meaningful political communication, it is important to understand the issue at stake. What makes medical aid-in-dying political? What are the critical and sensitive elements that underlie the issue of medical aid-in-dying? What are the points of contention? Furthermore, as noted in Chapter 4.2. Complex Terminology, in order to support slowly evolving, long-term social change around medical aid-in-dying, the communication system should be sensitive and responsive to neologism and changes in terminology. What are the key terms being used to describe medical aid-in-dying?

Importantly, I aimed to understand people's feelings and sensibilities toward specific keywords and terms. In multiple instances, participants used the word *"feelings"* (rather than rationales) to describe how people approached and understood the issue:

> I think this sort of goes to, I guess, my own *feelings* about this. (H15)
>
> I think for me, I tend to have conversations about it with very intimate people and close friends and my husband, to try to explore my *feelings* about it. (H6)
>
> Well, there were a lot of discussions, there were a lot of meetings about it [medical aid-in-dying] to get people's *feelings* and thoughts about it. (H12)
>
> I always acknowledge everyone has their personal views about this difficult subject, and there's room for all of those *feelings*. (V1)
>
> It seems like in the health care industry there's a lot of ambivalence about the law and who-, even though it is a law, it is patient's right, I think different people *feel* differently about participating. (H9)
>
> [I]n [*anonymized health care institution*] there's a strong respect for physicians and staff regarding their personal *feelings* about how to participate in this process, and that nobody is asked to participate in this process who *feels* uncomfortable with it, that it contradicts their ethics or their morals and I appreciate that. (H4)

> [F]aith groups which have their own *feelings* about these rights. (V12)

Feelings and emotions play important roles for people to understand and make sense of complex issues. Earlier in Chapter 2.3.3. Affective Publics, drawing from Papacharissi's theory I noted that the role of affect in politics is not secondary to rationality. By contrast, affect (i.e., feelings an emotions) may trump rationality in the case of medical aid-in-dying. Consider H2's reflection:

> You know, I almost feel like the conversations get trumped by my experiences—that's what bubbles to the top. Because I do find a profound experience every time I interact with situations where death with dignity is being considered or, you know, performed, I suppose. …So, that's the emotional experience that doesn't get factored in enough, I think, into those more logical conversations. And I can't-, you know, that logical side of me actually performs well enough until I come up closely. (H2)

In what follows, I report keywords and key terms of medical aid-in-dying. I do so by focusing on participants' feelings and sensibilities toward those keywords and terms.

7.1. Keywords

In the Meanings and Emotions activity, participants provided 345 distinct expressions of ideas related to medical aid-in-dying (see Appendix A for the full list). Most of the ideas were expressed in the form of a short keyword (284 keywords, 82%). Other ideas were expressed in longer phrases (21 phrases, 6%) or sentences (33 sentences, 10%). In four cases, ideas were expressed in the form of a question reflecting the philosophical nature of the issue: "*Am I giving up?*"; "*What does God think?*"; "*What is natural?*"; "*Changing the Law?*" In three cases, ideas were expressed in the form of a contrast. Interestingly, contrasts were used to draw attention to delicate nuances of the issue rather than to foreground conflicts between two concepts: "*Depression vs. Grief*"; "*Wellness vs. Health*"; "*Ethics vs. Law.*"

Here, I focus on the five most frequently identified keywords: CHOICE, FAMILY, PAIN, COMPASSION, and DIGNITY.

CHOICE. Ten out of 27 participants identified CHOICE as a keyword (5 health care workers, 5 volunteers). Participants elaborated on CHOICE from two perspectives: either in terms of a fundamental value or in terms of specific decision-making options involved in the process of DWDA. Approaching from a value perspective, many participants described CHOICE as *"one of the most important things about this law"* that they understood medical aid-in-dying as "*sort of basic matter of freedom of choice.":*

> I think people are entitled to their own choices what they are going to do to their body in their lives as long as there isn't harm to somebody else in the process …and I think that's the prime thing, that people have their choices. …I believe people are entitled to choose what to do with their bodies, whether it's an abortion, birth control, ending your lives (V4)
>
> A patient's right to choose. I really think that this is why I love this Death with Dignity and why I'm happy to live in a state that allows that because I believe in people's right to choose if that's what they want to choose, and that's what this whole thing is based on. (H13)
>
> I think it's the keyword in any discussion about death with dignity because it is a matter of choice by the dying person. (V1)
>
> Who am I to decide that for other people. And so that's why the choice is. (H5)
>
> People have a choice legally, I think that's the main thing that it's a legal choice. (V4)

As such, some participants associated CHOICE in medical aid-in-dying with the issues of abortion rights and gay rights. While CHOICE was generally perceived as a positive value among participants, it also evoked uneasy feelings, in particular, when asserted in a *"righteous"* manner:

> [W]e tend to think of choice as a good thing although it can also be an overwhelming thing. … I think we praise it really highly, and I think it's-, there's also something jagged about it. …'I want this. Don't take away my choice. I should be able to have…' It feels like a right, and there's something righteous about articulating choice. (H15)

Other participants discussed CHOICE in the context of various decision-making options that the patient needs to consider as they follow through the process of DWDA including with whom to share their decision to pursue the DWDA, and with whom not to share, and if not, what alternative stories to tell about their death, what will be their legacy, which specific medications to take, where, and when:

> There's so many levels of decisions, not just yes or no. (H8)

> [I]t comes into play in numerus categories. And one of the main ones is what drug do they want to take, with various options that vary significantly in price. … And then another main option is if I'm taking medicine when do I take and who will be present. (V2)

> So advocates often see the answer to the modern problem of dying as solved by helping facilitate, focusing on patient choice. If we have patients more able to make choices consistent with their values then we've improved the dying situation. Other people have said facilitating patient's choice in dying hasn't helped. …For example, everybody assumed that giving people in the Intensive Care Unit more choice about what would happen would improve their experience. But it turned out a lot of families didn't know when choice was relevant or possible, that there are a lot of default options that just kind of happen automatically that it's not like people even know you have a choice. And that things are often more driven by health care context like how many hospice beds are available in this city versus intensive care unit beds? And, you know, does hospice take this kind of patient? And who's paying for what? And what kind of mistakes are physicians worried about making? And what are they sanctioned for as opposed to ones that they are not? So choice seems like a great thing, everybody's in favor of choice but it may not be that relevant. …Choice isn't compelling as it seems to be a lot of times. (H3)

> It’s their choice. And they don’t have to take the meds they choose to do it. In fact, when we hand it to them to self-administer, I say, ‘Once you take this you will die, and do you still want to do it.’ So, giving them the choice all the way long. They are in charge of that whatever direction they want to go. (V4)

FAMILY. Nine out of 27 participants identified FAMILY as a keyword (5 health care workers, 4 volunteers). FAMILY was one of the core stakeholders (see Chapter 8.2. Core and Peripheral Stakeholders) that impact patients’ decisions and actions and vice versa:

> So, family wishes is really interesting and important because it really affects sometimes what the patients are asking for or not asking for, or how they go about things. (H1)

> I choose “family” because I think Death with Dignity Act impacts the entire family. You know, there’s actually, you know, it is a patient’s decision but it is also a family decision because it impacts the family. (H14)

Participants often associated FAMILY with the idea of support, invoking positive feelings of love and comfort. However, in reality, family dynamics are tricky and complicated. Not all family members are always supportive of the patient’s decision to pursue the DWDA:

> [T]hough in reality there’s some luxury to the “everyone at the bedside death.” There are so many deaths that don’t happen that way anyway. (H2)

> A challenging moment have been when you are with the family, and half of the family is with the patient who is requesting to go through the process, and the other half of the family is very much opposed to it. And they-, everyone is quite verbal. (V11)

> And then my role switches to help them [the clients] with the actual process of dying. So, I help them talk to their families about the implications of this, who is on board, who is not on board, who wants to be present at the death. (V9)

> [S]ometimes I got patients who would ask that we [social workers] do not talk with their family members and that they don't bring this up with their family. And other times they do bring this up with their family. And sometimes family is very supportive and they say, 'I really wish they didn't do this but I'm gonna support them because I love them.' So, there can be a lot of conflicting emotion and things can get pulled in very different directions. So, it's often times not everybody's on the same page. (H1)

Family's values, wishes, and goals may not align with the patient's, and may evoke "*a lot of conflicting emotion*"—disagreement, distrust, and division—creating "*all kinds of issues for the family members":*

> [S]ome sort of schism, where people are not experiencing it together (H2)

> [T]his fear of somehow screwing up the legacy or turning it into a suicide, or separating family dynamics and adding to it and making it worse instead of being able to come together and forgive—that keeps people separated and apart. And a lot of the family members spoke about those dynamics and what happened to them as they were both trying to support the person who was dying and maintain relationships with the rest of the families. Really complicated stuff. (H10)

That said, a number of participants clarified that FAMILY is defined by the degree of involvement rather than the biological relationship:

> [I]t's not only like my biological family but the family …include[s] my coworkers and friends. (H5)

> [I]t could be that their friends are way more supportive then their family and their family, there can be a dysfunctional relationship that didn't, doesn't get healed. (H9)

PAIN. Nine out of 27 participants identified PAIN as a keyword (6 health care workers, 3 volunteers). While Washington State Department of Health's annual reports indicate that bodily pain is not the primary concern for choosing the DWDA (DOH 422-109, 2017),[5] many participants recognized the excruciating, unbearable pain that many patients suffer:

> I don't know how to say this, I'm struggling. But I think of all of my blood and marrow transplant patients who-, their disease progresses but more importantly they develop a condition called graft-versus-host disease, where all their skin sloughs off. And it's pain, and it's definitely suffering, but it's more than that …So I don't know how to put that. I don't know how to explain it. It is the most excruciating. I've seen a lot, but that is like the-, it's hell on earth—that's the only way I know how to say it. I mean, it's like you're living-, if you believe in heaven and hell then that's hell. (H9)

> But there was an experience with a patient when I was a pain clinician saying, 'If you can't improve my pain without leading to inability to walk, then I'm gonna use the [aid-in-dying] medicine.' (H2)

> So, this is probably if I'm thinking about how patients might refer to it, it's maybe the more common way. …they may say something like, you know, 'I wish there were medications that, you know, help me die comfortably or peacefully or without pain.' So, this encompasses a wider universe than the death with dignity statute—that it could include sedation in which, you know, the patient is sedated free from pain, but which may hasten death. …so, a lot of patients are simply wanting that. They're not necessarily wanting to time their death. They just want to be free from suffering at the time of death. (H7)

Participants, particularly the health care workers, often associated PAIN with the issues of pain management, including the dilemma of *"double effect"* in which administering high-dose opioids to treat a terminally ill patient's pain may hasten the patient's death:

> Because I think medication, typically at the end of life, you know, cuts both ways. It can relieve suffering, but it's not always straightforward that it's gonna relieve suffering. We often see people given too many symptom relief medications, get all confused and in worse shape than they were before

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[5] These annual reports are based on the after-death forms filled out by medical providers. Thus, the findings are based on medical providers' perception of their patients' motivation for Death with Dignity; it is not based on the patients' first-hand accounts.

> they got them. …So the other way, there's the classic notion of "double effect," which has to do with intended versus unintended consequences of symptom relieving medications, and even back in the 50s, Catholic church said hastening dying is okay if it's not the intended effect of the medication. So, if you're trying to relieve suffering and people end up dying as a result, that's okay. So, that's another duality about medications. (H3)

> [W]e might be able to control the pain, but we may not be able to take the pain away. So, this group [indicating the "patient" and "family" tokens] might have an expectation "no pain," and this group [the medical team] needs to help this group [the patient and the family] understand that we can control the pain better, but we may not get rid of all the pain. And, because if we gave you so much medication that you have no pain, we would have sedated you and you won't be walking, talking, communicating, living some quality of life. (H9)

COMPASSION. Eight out of 27 participants identified COMPASSION as a keyword (1 health care worker, 7 volunteers). Participants, particularly the volunteers, noted COMPASSION as a primary aspect of care that they can provide for the patient:

> [I]n our role, we are providing information, we are helping them get through the process, but we are also showing compassion and care even with people that you may not be possibly able to help to where they want to be in terms of their death, you can provide compassion. And that again is very rewarding, and you can always do that in every situation no matter what and who that person is. You can provide that. (V7)

> [T]he important part of that to me is what we bring to the process as volunteers is that ability to be fully open and to be present to whatever unfolds and to meet it with kindness and warm compassion. And just to really be present and aware. (V5)

> I mean it's tough and hard conversations to have, but patients and families appreciate it because not everyone can do that, or not everyone can do it with kindness and compassion. (H11)

COMPASSION was closely tied to the concept of PAIN:

> I can see how when it's continuously interfered with by nausea or anxiety or pain, whatever it is, just the reality is, that's a terrible-, to subject somebody to have to have days, weeks, and months of that when they're having no positive experience to compensate for it. It seems as incompassionate [sic], non-compassionate as, you know, almost, you know, having the dogs in the cages where you perform experiments on them or something. It just seems uncompassionate to be black and white in your thinking. (H2)

> [T]hey could see the compassion side of this …they get the compassion part of deep pain. They've seen the suffering of deep pain and they get that. (H8)

While CHOICE is a fundamental value that underpins the concept of medical aid-in-dying, there are at least two distinct arguments that can lead to different interpretations of what medical aid-in-dying entails. The CHOICE-autonomy argument, which is the dominant argument in the United States, focuses on a person's right to control their own bodies, thus, it is critical that the patient self-administers the medication to end their own lives. The CHOICE-COMPASSION argument, on the other hand, takes the approach that every person is entitled to live free from pain and suffering, *"That people should not have to suffer until they die. That they should be able to choose their exit, and there's freedom in that"* (V12). From the CHOICE-COMPASSION perspective, it is less relevant whether or not a person self-administers the medication; euthanasia may be allowed. Furthermore, medical aid-in-dying may be allowed for nonterminal patients, whether the cause of the patient's suffering is psychological or somatic. Indeed, in Europe, The Netherlands, Belgium, and Switzerland allow medical aid-in-dying for psychiatric patients without an underlying somatic disorder (Player, 2018):

> Americans argued that assisted dying is appropriate because, on an autonomy argument that it's your life, you get to decide about whether or not you end it because you know better than anyone else. Plus, it's your life. As opposed to the Dutch context, where really the Dutch talk about the right of a citizen to not have to endure unbearable suffering. So that is more of a compassion argument. …[Self-

> administration criterion] that's consistent with the whole autonomy argument that that's why we are allowing them [eligible patients] to do it because they are in control—they are controlling the process and the action as well as the decision. So, I don't think I have things to suggest. I think I agree that moving toward psychiatric euthanasia would be problematic and the stakes are much more costly in that situation, although I believe suffering can be truly overwhelming, which is I think (____) Dutch went for it, they are not denying that people are suffering terribly, but I don't think the US is ready for it. (H3)

DIGNITY. Seven out of 27 participants identified DIGNITY as a keyword (4 health care workers, 3 volunteers). Participants described DIGNITY in terms of the *"loss of sense of dignity"* or *"undignities"* which they saw as one of the most critical issues for dying patients:

> Dignity is something that is very important to patients as they approach the end of life and typically loss of dignity is, or loss of their sense of dignity is something that tend to-, that plays into their decision to request death with dignity. …I think that …when they feel like life isn't predictable and they don't have any control over it anymore, then they do often feel like they lose dignity. (H12)

> Dignity, I chose because it's so key when someone's dying—they have no control, they lose their physical dignity, they often lose their psychological dignity, they lose so much. And dignity to me is just so important for everybody, but particularly when the person is dying, because they are losing so much. (V1)

DIGNITY was closely tied to the concept of *"sense of self":*

> [Y]our world shrinks, it gets smaller, and your capacities to do the things that used to define who you are go away, so trying to understand your own dignity and sense of self as it gets smaller is really hard for many people. And for some people it's not hard at all. (H10)

> So, it's kind of loss of predictability or kind of sense of self. (H12)

While many patients experience severe loss of DIGNITY in advanced stages of their illness, DIGNITY can be restored at the time of death:

> When a person takes their last breath in that state of peace without all that undignities [sic], it's common for family members to feel a little-, where there's that last out-breath where there's no following in-breath that they feel perhaps a little bit deflated that they've just lost their loved one but in a very sometimes comfortable way. (H7)

7.2. Terminology

Also in the Meanings and Emotions activity, participants provided 111 distinct expressions to talk about medical aid-in-dying (see Appendix B for the full list). As one of participants clarified, *"these are different ways of kind of talking about the same thing."* The five most frequently identified terms included: DEATH WITH DIGNITY, EUTHANASIA, PHYSICIAN ASSISTED SUICIDE, PHYSICIAN AID-IN-DYING, and ASSISTED SUICIDE. I provide a sense for how participants viewed each of these terms below.

DEATH WITH DIGNITY. Given that the official title of the Washington's law is "Death with Dignity Act," unsurprisingly, the most frequently identified term was DEATH WITH DIGNITY. Seventeen out of 27 participants identified DEATH WITH DIGNITY, describing the term as a *"standard," "staple"* or *"shorthand":*

> "Death with Dignity," it's on the table because that's how we usually refer to the law here. (V12)

> "Death with dignity," it's kind of standard …I would refer to this all the time as death with dignity, and because it's kind of the way the law is and the law's called. So, that's how I usually refer to it. So, it's kind of the staple. (H1)

> "Death with dignity," I chose because it's the most common phrase and most often known. When you say "death with dignity," it's recognizable. (V1)

While most participants agreed that DEATH WITH DIGNITY was perhaps the most commonly used term, their feelings were mixed about the term. About half of the participants expressed positive feelings, explaining that the term well-reflects the spirit of the law:

> "Death with dignity," I like that title. I mean comparatively. …Because I think it brings out the best hope of this act and that's what I've seen. (H8)
>
> So "death with dignity," this is the terminology that is used here in Washington. I find that this is the terminology that most people will understand and they resonate to. It's like a good vision statement—it's simple, it's memorable, people get it. (V9)
>
> When they framed the law, you know, I think they did a great job of choosing a name that fits the intention of the law. And I can't think of very many people that would say they didn't want to be dignified at the end of death. …[I]n talking about the death with dignity statute, I think this is a perfect terminology for the people for whom the law was developed because it is-, if you choose, if that is your choice, then you are pretty assured to be able to die with dignity at a time of your choosing with, in a situation of your choosing, and with whom you'd like to be. (H7)
>
> "Death with dignity" has implications of something that is gentle and respectful, and allowing somebody to maintain their dignity, their wholeness. …it's a gentler supportive phrase of I-1000. (H6)

Some participants liked the fact that the term did not involve the word "physician," thereby putting the patient and their dignity in the spotlight:

> [I]t's really the patient than, you know, it's more focused on the patient. …It does give the patient, I think, at least the term gives the patient more control. (H12)
>
> [When] somebody is dying, we don't really talk about physician or not physician, and they're just dying with dignity. I mean, because they are dying consciously at the time that they've decided to die, and in the way they want to die, with people around them they want around them. (V8)

> I like the idea that there's some dignity in the death process—it opens up the conversation because we don't talk about death very much. And then there's also a choice implied the terminology "death with dignity"—it's about your choice not somebody else's choice, physicians, palliative care team or somebody like that. (V9)

By contrast, other patients expressed negative feelings about the term. There are many ways to die with dignity, and different people may have very different ideas about what it means to die with dignity. It may feel inappropriate (and even *"insulting"*) to use the term DEATH WITH DIGNITY exclusively to specify medical aid-in-dying, which may inadvertently imply that other deaths are *"undignified":*

> So, "death with dignity" is what I am just in the habit of using as shorthand for physician aid-in-dying. But it's a really problematic term and it's problematic because I think it inherently suggests that other kinds of deaths aren't dignified. …So, even though it's something that I have a habit of using quite a bit as shorthand, I really feel like it's a language that hopefully we will start to move away from because again it suggests other types of deaths might not have their own kind of dignity too. I mean, death is always—not always but most of the time—it's a natural process that has its own integrity and its own inherent dignity. And I just, for that reason find this phrase sort of problematic. (H4)

> I don't think it's the best phrase because there are many ways to die with dignity, and death with dignity law is just one of those. And I think sometimes this can be offensive to hospice providers because they feel that they also provide death with dignity, and they do. (V1)

> "Death with dignity" is a murky, ambiguous term, …it almost implies that, say, a natural death from a lousy disease is not dignified, and I think that's ridiculous. But it's usually harder to change the labels than to just go with what's there. …I chose this form (*see Figure 7*) because it's just completely amorphous. You cannot describe this form to someone in a way that it can be reproduced much as they cannot define death with dignity in a way that was consistent from person to person. (V2)

Figure 7. ***"I chose this form because it's just completely amorphous."*** **(V2)**

> It's also somewhat controversial as all of this topic is because people who don't support the law see this as not dignified. …They don't believe there's actual dignity in drinking a pharmaceutical that ends your life. I argue back and forth about that because I don't think there's a lot of dignity in a respirator or in a breathing tube or a stomach pump or a feeding tube, diapers for the last year of your life, inability to articulate your ideas. (V9)

A few participants described DEATH WITH DIGNITY as a *"euphemism":*

> "Death with dignity" can sometimes be more of a euphemism for what's happening than the actual process. (V3)

> This is the ultimate euphemism for me. …It's a horrendous euphemism. …it's a euphemism covering up ugliness of our social situation, you know. If we had life with dignity then death with dignity would be okay, but it-, it's very weird to me—it's a very pretty picture trying to cover up a lot of the ugliness of our society. …So to me, the reason behind using this language is 100 % political and social in terms of saying that the dignified part is control, the dignified part is being able to maintain your autonomy and self-determination. …So, it's really trying to smooth over the unpleasant details of what actually

> happens. And you know, who wouldn't want to die with dignity? Of course, we all want to die with dignity. (H10)

EUTHANASIA. Fifteen out of 27 participants identified EUTHANASIA. For most participants, the term invoked negative feelings; the term felt *"disturbing"* and *"incendiary"*:

> "Euthanasia," which I, is not-, that's something you-, that's disturbing to me. (H8)

> And I therefore think this is a very hot button topic that when we use that word ["euthanasia"] in this context of our own history of people with authority killing people without their permission, there's no way we're ever going to find peace with this term in this country [the United States]. …So this is a really—I'm trying to think the right word—incendiary word because it kind of automatically opens up distrust and invites it to come in, and then it subjects all the other work that people who tried to build trust on and worked diligently to have trust in relationships goes right out the window. So it's a very packed term. (H10)

H4 noted that it may be *"the worst word"* one can use to talk about medical aid-in-dying:

> This is really the-, I almost say the worst word. And I don't hear this used very often any more, I think, but that some people still think of physician aid-in-dying as euthanasia, as a physician actively putting a medication in a person that will end their lives. (H4)

Participants associated the term with opponents:

> You know, I had some patients who were, I remember, vehemently opposed. A doctor who was my patient, who was very-, he was a pretty high-powered doctor and was very public, and did interviews and opposing death with dignity or whatever they call it—they call it euthanasia or whatever. (H6)

> Yeah, that's more-, I think that's when they're kind of against it. They might say, 'Yeah, that's what they do out in Oregon and Washington.' (H8)

While opponents often referred to medical aid-in-dying as EUTHANASIA, participants felt that it was "*so inappropriate for the circumstances*" to do so. Participants distinguished medical aid-in-dying from EUTHANASIA based on the self-administration criterion. Participants pointed out that the term EUTHANASIA undermined the *"power," "agency,"* and *"autonomy"* of the patient who self-administers the medication to die on their own term:

> [I]t suggests something unnatural is happening, something that is one person in power acting against a person not in power. And my whole take on physician aid-in-dying is that it is the patient who's in power. Ultimately, they are the ones driving the process according to the law, and they are the ones choosing whether or not to take the medication, and then to self-administering the medication. And euthanasia suggests nothing about that. (H4)

> Who is the one delivering the medications? [T]here's the very fine line between medical death or natural death and a murder, and that line is where euthanasia is—right there, because of the agency involved here, and it resides entirely on trust. And as soon as you say this word ["euthanasia"] in the United States, trust is gone. Because we can't imagine empowering medical professionals with this authority. So, this is a very scary word. It also has a very ugly history where people have been put to death by people and without consent so another concept underneath this is consent. (H10)

> [P]eople get confused—euthanasia confused with aid-in-dying. Euthanasia is completely separate in that euthanasia is that someone can make you die, which is usually a doctor with sedative or by needle etc., but it isn't self-administered. And when people talk about aid-in-dying and euthanasia, they kind of mix those terms where is that they are completely different. Well, they are completely—the administration of it and often the decision-making and the autonomy are different. Aid-in-dying at least (_____) our lives. It's based on autonomy and self-determination. And you are the one who is administering and making the decision. Euthanasia could be either a doctor administering by your choice—a shot or giving too much morphine which is a "double effect," it's 'Oh, I would relieve them from their pain but oh my gosh they died.' At that point, it's not you making the decision—it's the doctor making the decision. (V10)

Some participants reflected on the difference between animal euthanasia and medical aid-in-dying:

> So, we euthanize animals, and because we [humans] are the ones making a decision on their [animals'] part. But this is not what physician aid-in-dying is. It's people making their own decisions. (H4)

> I think for animals people associate with that ["euthanasia"] as a okay thing, like a "good death." But I don' think they associate the Greek with-, the Greek words of this word with that for humans. (H8)

While most participants felt strongly against EUTHANASIA, there were a few participants who felt rather neutral about the concept of EUTHANASIA. H15, for instance, noted that the distinction between EUTHANASIA and medical aid-in-dying may be artificial:

> I think if we are going to say that this [medical aid-in-dying] is okay, that then splitting hair isn't fair. It isn't fair for a person who can't swallow or who didn't get a peg tube to, you know, or who doesn't have the hand coordination. So, I think if we are going to say it's okay to allow a partnership between the doctor and the patient to end the patient's life, then I don't think that we should determine the means. I think that's artificial nonsense. (H15)

> [I]t sort of feels like mutual language to me. So, there's just sort of nothing there that's really coming to mind on-, yeah, there's no sort of, at least within me, there's no emotional language either way in it. (H14)

PHYSICIAN ASSISTED SUICIDE. Twelve out of 27 participants identified PHYSICIAN ASSISTED SUICIDE. Many participants pointed out that PHYSICIAN ASSISTED SUICIDE is the term commonly used by patients as well as the media:

> I'd say physician assisted suicide is the most common thing I hear from people who don't work in the area and I think that's the case because that's the terminology the media uses and it's the one which everyone relates back to Dr. Kevorkian and understands what is being talked about. (V2)

> I guess for me the term is used a lot. So, people do not ask for death with dignity, they usually ask for physician assisted suicide. (H1)

Participants expressed negative feelings, noting that PHYSICIAN ASSISTED SUICIDE was an *"inappropriate," "poorly used,"* and "*terrible term.*" Many participants felt it misleading to include the word "suicide" in the term. Participants distinguished medical aid-in-dying from suicide based on the six-month or less prognosis criterion. Participants pointed out that the word suicide failed to acknowledge the fact that the patients who are eligible for the DWDA are facing an imminent death. Therefore, the choice being made is not about whether to live or die but how to die, given that they are already actively dying:

> Physician assisted suicide is a very commonly used when people talk about death with dignity, and it's hard to believe that it's not suicide. …but the person is already dying and I always use that if the person's in a burning building and they jump from the burning building that's not suicide. …you are already dying and you are choosing to lessen your pain. (V7)

> [I]t fundamentally comes down to the cultural provisions against the suicide and the implications of the mental instability and that this isn't a rational choice. And so, to move away from suicide is definitely to distance-, to do two things—to take seriously that premature suicide is a tragic thing, and that we are trying to locate this [medical aid-in-dying] very differently as dying and not as suicide with the implication that you are already dying, and this is help with how that dying goes as opposed to you are mentally instable, you are vindictive, you are going against god, all of these social provisions about how one ends one's life in one's own hands. (H10)

Suicide may be socially acceptable in certain contexts. But in the United States, suicide is generally seen as a *"bad thing"* that people *"frown upon,"* carrying negative connotations:

> You know, a suicide is, you know, almost universally-, well, there's certainly cultural practices that condone and sometimes even celebrate suicide but, you know, generally in our culture suicide is frowned upon, thought of as a very bad thing. (H6)

> I think that the word suicide has a lot of negative connotations in our society, I don't think that's true for all cultures everywhere always. We should maybe think about that and not just automatically jump on the word suicide as like a bad bad phrase that shouldn't ever be used. (V6)

Some participants had very strong emotional responses. To hear the term PHYSICIAN ASSISTED SUICIDE felt *"very frustrating," "painful,"* and *"jagged."* One of the participants noted, *"This drives me nuts":*

> [T]his is the term that comes up that I don't use, but people would refer to it often as physician-assisted suicide, which to me is like—it's a little more heavier connotation, just the fact that it's using suicide in the statement. So, for me it brings up more of a stronger response, just for me personally. …So, in terms of a shape, it's probably, it's definitely *(see Figure 8)* more sharper, more jagged, I would say more kind of a inflammatory kind of phrase. (H1)

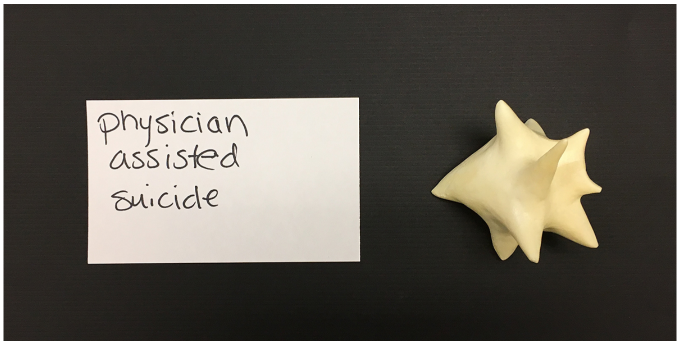


Figure 8. *"It's definitely more sharper, more jagged."* (H1)

> And so, it's usually used by the opponents of I-1000 to say, 'You know what this is. This is people helping you commit suicide.' So, it's a painful, jagged image to convey the—what does it convey? I guess, there's a lot of judgment, and there's anger and passion and intensity behind this phrasing in this [opposing] side of the argument, and the people who are opponents of this says very very strongly. (H6)

> [T]his drives me nuts, this term, physician assisted suicide, because in no way is it suicide in my mind. …I think calling the death with dignity process physician assisted suicide is, you know, it's attempted to sort of undermine the integrity and the wholeness and the thoughtfulness for which everyone in my experience approaches the process. …it's a term that's used and, I think, poorly used. And it

> undermines those people who have chosen to take part in a death with dignity—it undermines their intention and their thought, it's a terrible term. (H7)

Other participants problematized the notion of "physician assistance." This phrase could be misleading, implying a more active role played by the physicians in performing medical aid-in-dying than how it actually works (e.g., helping the patients to ingest the medication, when in reality, most attending physicians are not even present at the time of their patient's death):

> [P]hysician assistance is entirely murky too, like it implies to me a degree of action that I don't think is what actually occurs. A physician may make a tool available to a client but that to me is much more passive kind of assistance than what we might assume by just looking at the term. I mean if I looked at this term I would interpret it as meaning euthanasia (V2)

> [I]t doesn't describe what the assistance is. And the only assistance is helping people qualify and supporting them through that. There's no physical assistance and that could be misleading, so. (V1)

> And the word "assisted" implies—I don't know why it's different from "aid" for me—but it implies more active role for the physician like the physician is actually there. And what we know is that the patient has to self-administer the medication so it's not again it suggests a lot more I guess participation by the physician when it is not actually the case, and it is potentially pejorative for the person who is completing it. …"Assisted," again I think is just misleading term that suggest that some that a physician or a medical person is, is more involved in the process than they really are. (H4)

That said, H8 noted that the term PHYSICIAN ASSISTED SUICIDE was "*doubly troubling*" because it is a combination of two problematic words—"physician assistance" and "suicide":

> Physician assisted suicide, that again puts it on the physicians and not on the autonomy of the person making the decision. …I don't know if that's the right word. It's not the proper focus, it puts it on the physician. And the word suicide too. …People have started saying "somebody suicided [sic]" instead of "committed suicide," but there's a lot of, what do I want to say, negative thoughts around suicide. So "physician assisted suicide" is just is doubly-, I think doubly troubling and I think provocative. (H8)

Interestingly, V6 noted that there could be a kind of gentleness to the term despite all its spikiness:

> [I] chose this shape *(see Figure 9)* because there's spiky bits—because it's a spikey situation. But I think there is also some beauty and a different way of looking at the term "physician assisted suicide" that isn't so spikey—that is kind of a gentler approach to it. (V6)

Figure 9. ***"There's a spiky bits—because it's a spiky situation. But I think there is also some beauty …kind of a gentler approach to it."*** **(V6)**

PHYSICIAN AID-IN-DYING. Eleven out of 27 participants identified PHYSICIAN AID-IN-DYING as a term. Overall, participants characterized the term as "*fairly neutral,*" "*balanced,*" and relatively "*accurate*" term compared to alternatives:

> [M]any other terms that people use are not correct characterization of physician aid-in-dying (H11)

> I would say this is almost exactly the same as "physician assisted death"—that's the term that I use …and I think it's kind of accepted as fairly neutral. …it's sort of balanced. It doesn't have the word "suicide" in it, it is clear, it requires a physician, it has the word "death" in it, it doesn't have the word "dignity" in it because I think that that is, you know, death with dignity implies all kinds of things that it is by definition dignified, which I don't think it necessarily is and that other kinds of deaths aren't dignified. (H15)

> I guess I think of it here as a spectrum with death with dignity on the one end and something like euthanasia on the other end, and physician aid-in-dying seems to be somewhere in the middle, where the role is clearly defined in the term, a physician is helping you die. And dying is also clear, but it

> lacks maybe polarized piece that assisted suicide might have, and it also lacks almost the jargon that death with dignity is—that since it's the law, it's maybe sometimes strange for people to use [death with dignity] as a colloquial thing. So, I think physician aid-in-dying is a, something near the middle of the spectrum. (V3)

> [T]his is kind of what I know to be the most preferred term for, and accurate term for this process, is that physicians are aiding patients in having some control over process that is already happening, you know. But ultimately it is the person who is making the choice and that the physician is helping and facilitating that. And that it is help-, it's not a—what should I say, ugh, I'm struggling—it's not a negative thing. I'm trying to think of the right word. It's not forcing them to do something, it's not coercing or encouraging. It's offering somebody an option and really that's what physicians should do I think. (H4)

That said, many participants raised questions about the notion of "physician aid," which is *"ambiguous"* and potentially misleading, just as some participants problematized the notion of physician assistance in PHYSICIAN ASSISTED SUICIDE:

> The downside that I see in this term is that "aid" is still pretty unclear—how active is the physician in your death. I guess the idea with the death with dignity is that the physician helps you, but you are the person who is actively doing it. Whereas in euthanasia you are maybe being injected by a doctor so that there's less activity on the dying person's part. So, the drawback, maybe being closer to the middle, is it's hard to tell what exactly the role is. (V3)

> It can be like misinterpreted because it-, this looks like it's about the physician not the patient. …you kind of don't know who the driving force is in here. (H5)

Thus, V8 suggested to *"just take the [word] physician out of the terminology all together":*

> I feel that people are autonomous in their own lives. I don't know why the physician has to come into it really, you know. So, in a way it's sort of-, potentially we are holding the physician responsible regardless of the law, and we should just take the physician out of the terminology all together. Yeah. So even though there is nothing offensive about it, it doesn't seem necessary to me. (V8)

Other participants, however, saw the value in keeping the word "physician" in the term—that it grants *"authority"* and *"legitimacy"* by implying that it is neither a random kind of "*car mechanic aid-in-dying*" nor "*a do-it-yourself kind of job*":

> It's interesting to me that when we talk about physician aid-in-dying or physician assisted suicide, we are, you know, the first word is the "physician" so once again this is the healthcare system worried about itself. At the same time, it also wins some authority and support so that you have "physician aid" in dying as opposed to aid-in-dying suggests to me, or physician assisted suicide, that there is somebody with medical knowledge that is engaged in the process. So, you are not hanging out by yourself, but you actually got a companion who is there, and hopefully, one who is managing your dying. Also, it's somebody who is authoritative, potentially comforting, knowledgeable, expert. So, it's not a do-it-yourself kind of job, which is more true for the aid-in-dying. (H10)

> It also certainly has a medical piece to it, so it falls within the legal confines of the death with dignity. You know, it doesn't have-, it's not "aid-in-dying," it's "physician aid-in-dying," so that you know that there's a doctor involved, which I think for some people maybe legitimizes the medical piece to it. So, it may help put some people's mind at ease, knowing that the there's a doctor involved versus "car mechanic aid-in-dying." (V3)

ASSISTED SUICIDE. Ten out of 27 participants identified ASSISTED SUICIDE. At a glance, the term may seem very similar, and almost equivalent, to PHYSICIAN ASSISTED SUICIDE. However, participants identified ASSISTED SUICIDE and PHYSICIAN ASSISTED SUICIDE as distinct terms evoking different emotions. Lacking the notion of "physician," ASSISTED SUICIDE evoked "*starker*" and "*deeply negative*" feelings. Participants described the term as biased and judging:

> That seems even starker than "physician assisted suicide" because when you see physician connected to it you think of some sort of compassionate care. Assisted suicides sounds almost like a criminal act, you know, there's accomplices—suicide with accomplices. So that's a really deeply negative term, deeply negative way to use. And anytime I see that in print just there like that, I'm thinking bias. (H2)

> [T]his is a negative one. So, for a long time you used to hear about it as assisted suicide because it had a judgment about it (H9)

In contrast to PHYSICIAN ASSISTED SUICIDE, which implied a clinical practice, ASSISTED SUICIDE implied an accomplice of suicide, which is a criminal act in the United State. As such, this term seemed to cause deep emotional harm, in particular, for the loved ones caring for the patient—the term is "*hurtful*," and *"it can really have an impact on survivors,"* leaving people "*in a state of a total shock*":

> "Assisted Suicide," I chose because people still use that terminology and it's difficult for them to see how that's hurtful for people who are choosing it. …And it's hard to hear. (V12)

> "Assisted suicide" does not necessarily reflect a situation in which someone is going to die. And also leaves the family, the friends, anyone close in a state of total shock. Usually messy, usually bereaving over the fact that they committed suicide. And leaving the family and friends to (_____) over that verses the loss of the person as much as confusion. So, and there is no warning about it. So, this comes up a lot. (V10)

Interestingly, participants did not associate the term with opponents (cf. see EUTHANASIA). While the term was deeply negative, participants reported that in most cases it was just a benign mistake made out of ignorance as opposed to someone intentionally trying to cause harm:

> [T]o varying degrees, many people have used that word ["assisted suicide"] without, you know, who haven't spent a lot of time thinking about this, very innocently. And if then when you say, 'Oh suicide' and actually suicide isn't legal and, you know, they adopt the term "physician aid-in-dying" very easily. (H15)

> I think "assisted suicide" is often used by people who actually want it to be-, to look at it in a more balanced way, even though it's not a term that we like. (V11)

Therefore, a number of participants reported that they have actually engaged in conversations with others to raise awareness about the term ASSISTED SUICIDE when they hear it:

> So, when somebody says, ‘Oh they’re doing assisted suicide,’ I’ll say, ‘Words are actually really important. This is a legal, you know. This is what distinguishes it as something under-, within a legal foundation.’ So, yeah—that’s what I mean by that. (H15)

> They [people] still see it as suicide and that needs education. …So, we try to help people understand terms that would be more respectful of others making this choice. (V12)

That said, ASSISTED SUICIDE is one of the shortest, simplest terms, and participants were concerned about the media often using ASSISTED SUICIDE as a shorthand, particularly in headlines:

> I think the gaps come primarily from the language that’s used by the media. Again, assisted suicide is still a very common phrase that’s used, and I think that that language is just inaccurate. …[W]e still see in a lot of the news coverage around, even around the laws that are trying to be passed—‘This is an assisted suicide law.’ And you know, I think because the word “suicide” carries such a stigma, it’s really-, this is a problematic term. (H4)

> [M]aybe the headlines is ‘How California is implementing their assisted suicide law’ and it’s a little bit frustrating because assisted suicide is maybe not the best term to use. …Suicide has a lot of mental health connotations, and so when media will call it assisted suicide, I think it shapes a public view of what the law means or who might use the law. …I think that assisted suicide paints a more bleak picture than what I see. (V3)

COLLOQUIAL EXPRESSIONS. In addition to formal terms, participants identified a number of colloquial expressions that are being used in everyday life. The most frequently identified expressions included: THE KEVORKIAN THING and MURDER. Four participants identified THE KEVORKIAN THING as a slang term that they often hear:

> The Kevorkian thing or like, “You know, that stuff with the Kevorkian.” Yeah, I mean just something with his name in it. Because they can’t-, they don’t know what it’s supposed to be called or whatever. Yeah. (H8)

While most participants expressed rather negative feelings towards Jack Kevorkian (e.g*., “weird,” “controversial,” “a sort of rogue individual”),* H9 expressed sympathy for him:

> Oh poor Dr. Kevorkian. I hate that they [people] use his name like that. …But I do hear people talk about Kevorkian events so they’re kind of putting judgment on individuals who are doing this assisted death. (H9)

Four participants identified MURDER as a slang term, but without providing any further explanation. Only one participant, H11, made a brief remark about MURDER:

> Yeah, it seems to have negative connotations, that it seems like it’s pointy, not a really comfortable shape *(see Figure 10)*. Negative balance to it. So. (H11)

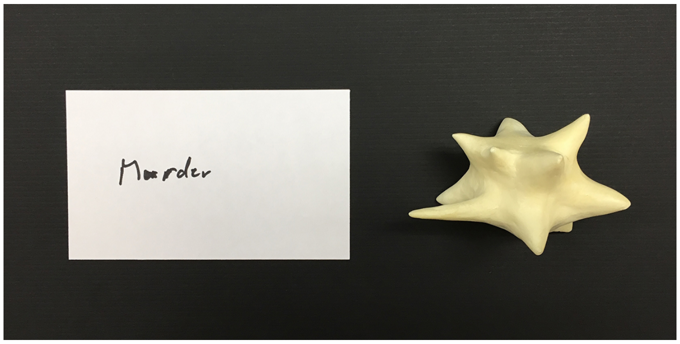


Figure 10. ***“It’s pointy, not a really comfortable shape. Negative balance to it.”*** **(H11)**

8. Stakeholders

In the context of medical aid-in-dying there are a wide range of stakeholders, many of whom sit in complex and sensitive relations with each other. This case study aimed (a) to identify different types of stakeholders and (b) to understand stakeholder dynamics, particularly, in highly politicized contexts. In what follows, I describe key findings with selected examples that illustrate who the stakeholders are and how they interact in the case of medical aid-in-dying.

8.1. Inclusive List of Stakeholders

To gain a holistic picture of the widespread stakeholder network, a set of grounded coding categories was developed from the participant-generated stakeholder labels. Table 3 provides a brief summary of diverse stakeholders involved in medical aid-in-dying, including 21 top-level categories and examples.

This label analysis advanced my understanding of stakeholders in at least in two ways. First, I was able to identify and distinguish more nuanced roles. Second, I was able to uncover and highlight underrepresented stakeholders who are typically overlooked.

Distinguishing Nuances. The word “physician” often modifies medical aid-in-dying terminology (e.g., physician aid-in-dying, physician assisted suicide) and is used indiscriminately to refer to MDs in general. However, most (if not all) medical aid-in-dying legislation requires participation of more than one physician, with each physician playing a distinct role in the process of delivering medical aid-in-dying:

1.	**Patients** (e.g., terminally ill patient, people who are ill)
2.	**Family** (e.g., partner, children, parents)
3.	**Community Members** (e.g., friends, neighbors)
4.	**Caregivers** (e.g., paid caregivers, volunteers)
5.	**Health Care Providers** (e.g., physicians, nurses, social workers, pharmacists, palliative care, hospice care)
6.	**Medical Institutions** (e.g., hospitals, medical associations)
7.	**Pharmaceutical Industry** (e.g., drug makers, drug suppliers, pharmacy)
8.	**Insurance** (e.g., insurers, insurance company, Medicaid)
9.	**Religious Communities** (e.g., chaplains, churches)
10.	**Law Communities** (e.g., lawyers, legal system)
11.	**Politicians** (e.g., legislators, policy makers)
12.	**Government** (e.g., federal government, state government, public health officials, law enforcement)
13.	**Publics** (e.g., citizens, voters, uninformed publics)
14.	**Political Stance** (e.g., advocates, opponents, bystanders)
15.	**Media** (e.g., mass media, news, press)
16.	**Those Who Don't Qualify** (e.g., minors, non-residents, neuro patients, mentally ill)
17.	**Those Who Are Marginalized** (e.g., minorities, lower socio-economic status patients)
18.	**Geographic Distinctions** (e.g., other states, Canada, Europe)
19.	**Generational Distinctions** (e.g., Baby Boomers, generations, legacy)
20.	**Personality Types** (e.g., those who value individual freedom, control freaks)
21.	**Other** (e.g., authors, ethicists, funeral services, morticians, philosophers, schools)

Table 3. Top-level categories from the label analysis

> Probably doctors actually, they don’t always agree. There are many different doctors usually involved with these patients. (V8)

Reflecting on Washington’s DWDA, participants further distinguished the role of physicians into attending physicians, prescribing physicians, consulting physicians, and psychiatrists. Attending physician refers to a state-licensed physician who has completed residency and is practicing independently in their chosen specialty. Washington’s DWDA is activated when a patient makes an oral request to her or his physician. Upon the patient’s request, the physician can choose to either opt-in or opt-out. If opting-in, the physician has a further choice either to participate as an attending physician or a consulting physician. The difference between the two roles may be subtle yet profound in terms of decisional responsibility. An attending physician, on the one hand, has the primary responsibility to determine a terminal illness, which will lead to death within six months. A consulting physician, on the other hand, supports the attending physician by confirming her or his prognosis. If either physician believes the patient's decisional capacity is impaired by a psychiatric or psychological disorder, they must refer the patient for a psychological examination by a state-licensed psychiatrist. Finally, the attending physician writes a prescription for lethal medication to be self-administered by the patient. That said, participants reflected on the nuanced difference between an attending physician and a prescribing physician (see section 6.1.2. Communication Challenges for details). Participants also reflected on the difference between choosing to participate as an attending physician or a consulting physician. Consider H1's comment:

> Participating providers, you know, can opt-in or out depending on situations and circumstances. And sometimes that they do participate, they might only be willing to consult or sometimes they will be willing to prescribe. Or …depending on who the patient is and what their circumstance is, one time they might prescribe and one time they might refuse to and only consult. So, it's also one of those changing-, not really clear. (H1)

H15, who is a physician, further elaborated on the implications of taking the role of an attending physician versus a consulting physician:

> [W]e thought long and hard about whether a hospice employed physician like me would be able to serve as a prescribing physician. And we decided not to allow that by policy. …[W]e didn't want [*anonymized health care institution*] to become the go-to hospice for the purpose of receiving prescriptions. And I personally didn't want to become that magnet. On the other hand, we thought about the responsibilities of a physician whose expertise is in end-of-life medicine. …For many years, we offered the service if the patient was enrolled in [*anonymized health care institution*] and [already] had a prescribing physician, that one of the hospice staff would serve as a consulting-, in the role of consulting physician. And I have done that a number of times. Over the years, a number of issues have come up that has made it so that we do not routinely offer that service. (H15)

On that note, H11, who is also a physician, described the difference between positioning oneself as an attending physician and as a citizen, and how it may change one's perspective on the issue:

> At personal level, especially as someone who can operationalize and provide the medications and lead to someone hastening their death, that has a different implication as opposed to saying as a society I agree with the opportunity that I think it should be available, but I may not want to be the person that's providing it. (H11)

Participants also distinguished physicians from their support staff. While physicians work closely with nurses, social workers, and other support staff to commonly appear as a unified medical team, participants pointed out the importance to recognize their individuality:

> And so this is really the clinical team that is often represented as the physician as the forward face …because it's physician aid-in-dying, they [physicians] are the ones empowered to do the work. But they have the support team who also supports the patient. (H10)

> So this is social workers, physicians, and nurses. And they are each their own entity but they are also kind of within a group or facility. So you know that they interact individually …and there can be disagreement within all of them. But they also kind of act almost as a unifier to the outside people. (H14)

> I think it's important to separate, you know, the doctor's value and the nurse's value [because they] may be at odds. …So it could be the whole, all of the medical providers but I think it's important to separate doctors and nurses. (V3)

> You know, the nurse in the doctor's office who's known the patient for a long time, who is facilitating, you know, or I should say, or any ancillary staff who are involved, who may feel funny about, you know, getting the prescription to the pharmacy. (H15)

Moreover, participants perceived physicians*,* who are individuals, as distinct from hospitals or medical associations, which are institutions. While these institutions are comprised of physicians, participants pointed out that the institution's interests and values may not be aligned with those of the physicians:

> I would distinguish, so the professional organizations like the American Medical Association, people usually call them AMA, and I see them as different than individual doctors. (V9)

> I think they [medical associations] are kind of, they are sort of somewhat removed from this process. The AMA [American Medical Association], they are a really powerful group and as well is the Washington State Medical Association. …It is also frustrating to us because the AMA does not represent the majority of physicians, but the public doesn't know that maybe. 'AMA says this, well they gotta be right.' That's how AMA comes in. (V1)

Particularly, in the case of religiously affiliated hospitals, the hospital's values may be more closely aligned with those of the religious organization that is running the hospital rather than the values of the physicians who work for the hospital:

> [A] lot of the hospices in Seattle are Catholic-based organizations, and they kind of have very firm rules against participating in the Death with Dignity law. (V6)

> Catholic hospitals within our state not only do not support the law but are very restrictive on how any physicians who work for them can interact with the law. …Now I'm trying to think if or how I should put hospitals in here as a stakeholder. And on top of my head I'm not sure to what extent they are actual stakeholders in the process [of Washington's DWDA] as it exists at the present other than trying to assure the physician who works with them do not violate the law. And of course they [the hospital] may have to work with the religious organization that owns them. (V2)

> Also here is the 'religious right,' …as a stakeholder they have quite a bit of opposition to Death with Dignity and in Washington, runs a lot of medical systems. So this impacts nurses and doctors, who I have separate [tokens] on the board. …The religious right can tell the doctor that they can't participate and the doctor has to opt-out because of that. (V3)

Collectively, the label analysis expanded my understanding of physicians in at least three ways: (a) the role of physicians was further subdivided into more nuanced responsibilities (e.g., prescribing physician vs. consulting physician); (b) the distinction between physicians and their affiliated medical teams (e.g., nurses, social workers) was further clarified; and (c) the distinction between physicians and institutions (e.g., hospitals, medical associations) was further clarified.

Highlighting Underrepresented Stakeholders. Participants also identified a number of unique stakeholders who are often underrepresented in mainstream end-of-life discourses. For example, while mainstream discourses have been mostly concerned with the well-being of the patient's family caregivers, participants identified paid caregivers as a distinct stakeholder. In the US context, paid caregivers are often immigrants with diverse cultural backgrounds, who may have widely different (if not opposing) beliefs about living and dying than those of the patient. H13 reflected on how such cultural diversity can complicate the experience of medical aid-in-dying in residential care facilities, making it difficult for both the patient and the paid caregivers:

> [If] you are in the nursing home, this decision is harder because these paid caregivers often are from different cultures that may not really believe [in medical aid-in-dying], …and so they might have a really hard time dealing with this as to withhold food or give pain meds that are, that looks like hastening someone's death. So they are definitely part of stakeholders in this because they have to witness this. So I would put two eyes here (*see Figure 11*) that they are witnesses and they hear the discussion. But they don't really have part in the decision making. (H13)

Figure 11. A pair of eyes implies witnessing.

In addition, participants identified *death workers* (Moncur et al., 2012; Walter, 2005), who conduct specialized work after death, as necessarily involved but often overlooked stakeholders. For example, V6 reflected on her interaction with the local medical examiners:

> Most of the medical examiners in the Seattle area are really good …but if you get out to the boondocks of eastern Washington and kind of other places and you suddenly call the medical examiner's office and say, 'Hey, we have a client that used death with dignity' …They kind of freak out and don't know how to react to that. (V6)

Dying and death involves a series of collaborative processes comprised of sets of discrete, complex, and sensitive tasks (Moncur et al., 2012). These tasks are carried out by remarkably diverse stakeholders, each playing a distinct role. As shown in the above examples, non-medical workers such as paid caregivers and medical examiners have clear roles in the collaborative processes of dying and death. They are part of the holistic end-of-life experience, both influencing and influenced by the choice of the patient. Yet, these non-medical workers' roles are under addressed in the mainstream end-of-life discourses. This label analysis allowed me to broaden the scope of the stakeholders by highlighting the roles of typically overlooked stakeholders, providing detailed accounts of their experiences.

8.2. Core and Peripheral Stakeholders

Having surfaced a broader and more nuanced array of stakeholders, my next step was to narrow the focus to identify direct and indirect stakeholders. Value sensitive design (VSD) distinguishes stakeholder roles as direct or indirect in relation to how people interact with the technology (Friedman & Hendry, in press). Direct stakeholders are those who interact directly with the technology, often characterized as users in HCI. Indirect stakeholders are those who although they never or rarely interact with the technology but are nonetheless affected by the technology. Leveraging the value sensitive design terms, I asked participants to think about direct and indirect stakeholders around the topic of medical aid-in-dying:

> *Write down anyone you think has a stake, either those who are directly or indirectly involved in medical aid-in-dying.*

I analyzed the transcripts and sketches to identify direct and indirect stakeholders. Interestingly, participants often distinguished their stakeholders in terms of *core* and *peripheral* stakeholders (priority) rather than in terms of direct and indirect stakeholders (proximity).

Core Stakeholders. In order to understand key stakeholders, I started by examining the sequence of articulated tokens. My hunch was that participants would identify and talk about more important stakeholders first, and then gradually move on to talk about less important (or more peripheral) stakeholders. Perhaps unsurprisingly, most participants (74%) began their conversation by referring to the patient: *"It starts with the patient"* (H1); *"Okay. So I'm gonna start by taking the patient and put that person in the center"* (H3); *"So the patient is in the middle."* (V10). Other stakeholders that participants first-identified included: family, physicians, social workers, the religious community, politicians, and the mentally ill.

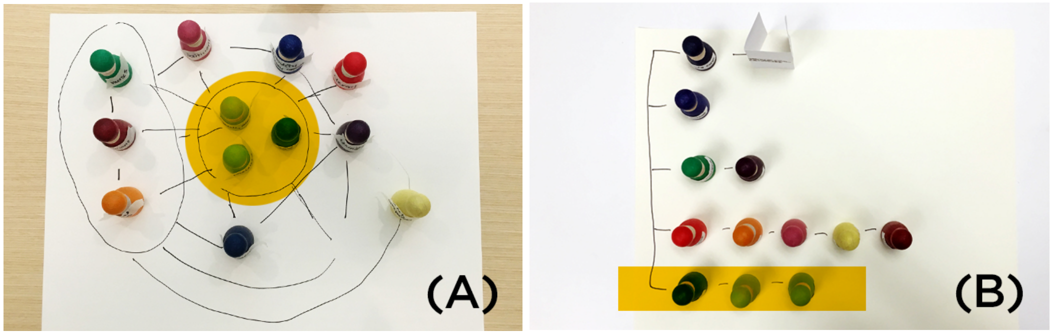


Figure 12. Examples of core stakeholders. Core stakeholders were typically positioned in the middle section (A) or in the front row (B) (yellow highlights were added for emphasis).

In addition to their first-identified stakeholder, participants often grouped a small set of tokens as the *core* or the *center* (21 cases, 78%). Participants tended to place the core group in the middle of the page: "*I think I'll kind of put those guys in the middle. ...So I see these guys as kind of a core"* (H9). Sometimes participants drew a circle around the core group to emphasize the cluster (see Figure 12A). In a few cases where participants organized tokens into a linear style, the core groups were typically lined up in the front row (see Figure 12B). Most frequently included in the core group were the patient (19 out of 21 cases) and family (16 out of 21 cases). Other stakeholders that were identified as the core included: friends, physicians, physicians' support staff (e.g., nurses, social workers), hospice, pharmacists, caregivers (e.g., volunteers), medical institutions (e.g., hospitals), insurance, the pharmaceutical industry (e.g., drug suppliers), the religious community (e.g., religious leaders), politicians, political supporters (e.g., advocates), and political opponents.

Peripheral Stakeholders. In contrast to core stakeholders, I was also interested to understand who the less important stakeholders may be—that is, who may be on the periphery. As with the core stakeholders, I started by examining the sequence of articulated tokens, but this time focusing on the last token to be brought up in the conversation. While there was a strong consensus on which token participants chose to begin their conversations (i.e., the patient), there was little agreement on which token to end on. The stakeholders that were most frequently identified last were the pharmaceutical industry (4 times) and the religious community (3 times). Interestingly, the religious community was included in both sets of the first- and last-identified stakeholders. Other stakeholders that participants last-identified included: physicians, patient's community members (e.g., friends, neighbors, colleagues), those who are marginalized (e.g., illegal, people without access to $ [sic] or language), pharmacists, social workers, medical institutions (e.g., hospitals), insurance, law enforcement, public health officials, lawyers, legislators, the media, schools, philosophers, celebrators, and Europe.

Occasionally, participants explicitly called out specific tokens as *"peripheral"* (8 cases, 30%) that are seen as "*not important*" or more "*distant*": *"And now we are getting into people who are*

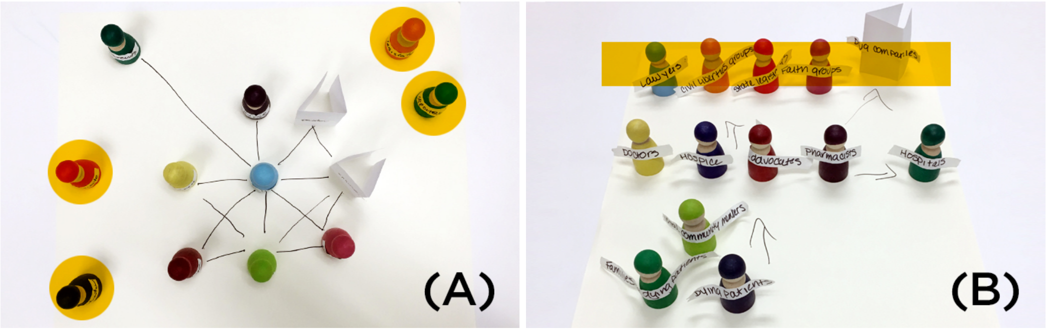


Figure 14. Examples of peripheral stakeholders. Peripheral stakeholders were typically positioned towards the edges (A) or in the back row (B) (yellow highlights were added for emphasis).

more peripherally involved. So yeah, I would tend to put these people around on the outside" (H3). Participants tend to place peripheral tokens towards the edges of the page (Figure 13A). In a few cases where participants organized tokens into a linear style, the peripheral stakeholders were typically lined up in the back row (Figure 13B). Most frequently identified as peripheral stakeholders were: the religious community (4 out of 8 cases) and legislators (3 out of 8 cases). Other stakeholders that were identified as peripheral include: patients' colleagues, medical institutions (e.g., hospitals), [medical] administrators, the pharmaceutical industry (e.g., drug suppliers), political supporters (e.g., advocates), political opponents, political bystanders, civil liberty groups, disability advocates, the media, lawyers, the federal government, the military, public health officials, morticians, and uninformed publics. Interestingly, the religious community, the pharmaceutical industry, political supporters (e.g., advocates), and political opponents were included in both sets of the core and peripheral stakeholders.

8.3. Excluded Stakeholders

In addition to core and peripheral stakeholders, I wanted to understand if there were any excluded stakeholders. And if so, who are they? I examined the transcripts to identify excluded stakeholders, which emerged from participants' verbal description of their tokens. I found that there are different ways that exclusion can happen. I categorized excluded stakeholders into four distinct types:

A. Categorical Exclusion. This type of exclusion refers to the stakeholders who are excluded at a public level by law or policy. In this case study, several participants identified stakeholders who do not qualify to use the current version of Washington's DWDA. The law defines *terminal illness* as an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment, lead to death within six months. The law is not available to patients who suffer from nonterminal illnesses, even progressively debilitating and irreversible conditions such as ALS (Lou Gehrig's disease), nor is anyone whose predicted time of death is incalculable. Participants noted:

> I haven't talked about very much is that this excludes a lot of people—it excludes people with neurodegenerative diseases, it excludes-, and that's a whole other question. Should you allow people who have a different prognosis? I think if we are gonna stick with this six months thing then I think that it has to be, there has to be clarity. (H15)

> You have to have a six months or less prognosis to use the [Washington's Death with Dignity] law. Parkinson's disease, multiple sclerosis, …there are couple of others, so those people don't qualify for the law and it's a problem because they are obviously suffering greatly but the doctors cannot say 'You are mostly likely to die in six months.' (V1)

> Death with Dignity Act requires that the individual self-administer. So, if they cannot hold a cup to their lips and pour it in their mouth, or push it through the feeding tube, they don't qualify for the law. (V2)

However, this does not mean that categorical exclusions do not have impact at an individual level. The experience of categorical exclusion can be quite personal and emotional:

> I decided to add mentally ill because …sometimes there are people who have mental illness and you don't want to live anymore, and it sounds like, maybe feel excluded and maybe feel like their suffering isn't recognized. (V3)

> I think I agree that moving toward psychiatric euthanasia would be problematic and the stakes are much more costly in that situation, although I believe suffering can be truly overwhelming, which is I think [why the] Dutch went for it, they are not denying that people are suffering terribly, but I don't think the US is ready for it. (H3)

B. Sociocultural Exclusion. A second type of exclusion refers to the stakeholders who are excluded at a community level due to low socio-economic status or cultural differences. In this case study, several participants surfaced stakeholders who do qualify and yet choose (or rather, were made) not to use the law because of their sociocultural background:

> I also think people, and particularly people who has certain privilege—again racial privilege, gender privilege, class privilege—are probably more used to saying 'I get to control this situation,' and also know, may have more faith that the medical system will act on their behalf than people who historically have been discriminated against or not been able to trust the medical system as much, so I think that there's a piece of this that is just uncomfortable for me, and part of that piece is that, that not everybody has equal access for range of reasons. (H4)

> And depending on whether you lived in a society as someone who has been able to express autonomy and self-determination and whether you are *not* someone who has been able to do that makes a big difference on how you view this. One of the things I think is most interesting is, I think one of the reasons why we see most of the people who pursue this law are coming from the place of privilege or experience with getting their way, and that's why that this is so threatening to them, I've said the last minute they can't do that it really threatens their sense of self. But for people who've really never been allowed to make choices like this, it's not really an issue. So, it really does happen to your life story about what expectations you have had for yourself and your capacity to choose. So, if you've been able to choose and then you're denied choice at the last day of your life, that feels like an affront and that you lost. But for people who don't have that experience, they don't really care. (H10)

In another instance, H4 reflected on those who are prohibited because of a language barrier:

> And then left out of this process are people who aren't included in the conversation because they are poor or because they have language barriers and they are not really counted into any of these. …I feel like there is a potential that people-, their voices are not only not heard but they aren't even potentially aware of the conversation. (H4)

According to Washington's DWDA, the patient must make two separate oral requests to the attending physician in order to invoke the law, and it is critical that these requests are made based on informed and voluntary decision. That said, a few participants talked about the challenges of bringing translators into the process for non-English speaking patients, which may increase the possibility of coercion or undue influence.

C. Self-exclusion. This type of exclusion refers to the stakeholders who deliberately choose to exclude themselves. Consider V1's reflection:

> They are not excluded. They exclude themselves. We have had no African Americans use the law, we've had several Hispanics and Asians, but we do certainly would like to include everybody. …I think that certainly African Americans have a well-justified suspicion of medical community because of the Tuskegee and all of the stuff that's been done to them. So I think it's natural for them to be skeptical. But I think also that there are people in that community who would like to know more about the law and have that option available. …There are all kinds of cultural issues. (V1)

Self-exclusion is different from disapproval, in which stakeholders actively engage by raising oppositional voices. Self-exclusion is a form of withdrawal, in which stakeholders pull away from the issue by turning a blind eye:

> Health care system and state medical association, they don't even know they should be involved. I'm gonna call this the 'Blind Man' because they should be involved but they are turning the blind eye right now. (H15)

> I think they [AMA and WSMA] are kind of, they are all sort of somewhat removed from this process. The AMA, they are really powerful group and as well is the Washington State Medical Association, I should have written. (V1)

> I personally believe that medicine [motioning to the "medical professionals" and "Medicaid" tokens] abdicated its role and they are way out here at the corner trying not to, wishing that it would go away. … Okay, so they are over here wishing the subject should never come up. …In my opinion they should be in here [motioning toward the center] but they never were. (V11)

<u>D. Selective Exclusion.</u> This type of exclusion refers to the stakeholders who are excluded at an individual level based on personalized selection criteria. In this case study, many participants described a situation where some family members or friends are deliberately uninformed or misinformed:

> You have to choose wisely …you don't tell everyone. (H13)

> And some might not even, like their parents might not even know about it, they might be totally clueless …for whatever reasons they've chosen to just, the patients chose to block them out a little bit, but keep them in relationship. (H8)

Individual choices may be idiosyncratic, yet selective exclusion was one of the most commonly discussed themes across participants. Some participants reflected on how family relationships are gradually built over time and that the choices for selective exclusion would often depend on individuals' past relationships:

> At the most micro it's the patient and the patient's family taking care for them over the course of the illness. So it doesn't just happen over night, there's a trajectory. And this relationship exists, and ideally it does but not always, is the two-way street back and forth. (H10)

8.4. “Difficult” Stakeholders

Through a qualitative analysis, I was able to identify specific stakeholders who are particularly difficult or challenging to have conversations with. Perhaps unsurprisingly, participants noted that it can be difficult to communicate with opponents—that there could be “*a lot of misinformation thrown around and accusations and so forth*”:

> [D]uring the campaign especially, opponents were very vocal. And sometimes they were somewhat disruptive when we were trying to speak. Other times, we had debates and there would be an opponent. And those discussions were sometimes very difficult with opponents misrepresenting the law—scare tactics that kind of thing. …I think there were lot of instances where, particularly in the presentations and the debates, there was a lot of misinformation thrown around and accusations and so forth. …There was one occasion where an opponent accused our organization of being funded by the funeral industry, which is false, but, you know, what can you do? All you can do is tell the audience that’s not true. (V1)

Participants reported that they have observed many heated debates in the community as well as in the media during the 2008 political campaign. Interestingly, however, most participants reported that they rarely had to deal with strong opponents in real life:

> When I’m talking to general public, …the people who turns out at these events more often than not tend to be pro. Not too many people come who are hecklers or who are, you know, trying to say this [medical aid-in-dying] is a bad thing. I think those folks just don’t listen or don’t show up or don’t come whatever. That’s not anything to say about them—I’m just saying that tends to be who’s in the audience. (H10)

> Everyone with whom I had contact is aware of what I’m doing is very supportive, or else they haven’t indicated to me (____). So, I’ve had no debates with people around the issue. (V2)

Participants saw little point in trying to confront and persuade opponents: “*By the way I have a lot of respect for that position and I never saw to change their minds about that.*” (V9). Thus, rather than engaging in political debates, people chose not to communicate at all if they disagreed: "[*T]here is not much to talk about with them.*" (H15); "*[P]erhaps dis-communication or whatever, you know."* (H7)

That said, H15 described that her most difficult conversations had been with supporters (as opposed to opponents) of medical aid-in-dying:

> And yet, my most difficult conversations have been with supporters of it. I mean, I considered myself as a supporter of it. …You know, I've had-, I mean, I haven't had that many conversations with people who, you know, deeply oppose it … I haven't had any difficult conversations with people who are opposed to it because I respect-, because there is not much to talk about with them. I'm not in a position to try to convince them. …my really tough—and in some ways I'd say devastating—conversations have been with the proponents because I feel like I-, just because of the position I've been in, have been misunderstood. And that's been-, those have been incredibly painful conversations, much more so than I would have expected. (H15)

H15's reflection shows that political conflicts are more than a binary debate between "pros" and "antis." Political conflicts may arise within an alliance and such conflicts can be emotionally intense, posing significant challenges to communicating and practicing medical aid-in-dying.

In addition, many participants reflected on the difficulties that they felt when they tried to have conversations with young people. While Americans tend to avoid talking about death and dying in general (see Chapter 6.2.1. Sociocultural Taboos Concerning Death), participants felt greater reluctance among young people:

> People just don't want to discuss death, and obviously to younger people even more—it's not an issue for them, they don't want to discuss it. (V7)

Most young people these days, particularly in the US context, have little, if any, experience with death. Young people are either not interested in discussing the topic because it is not their concern, or they are interested in a rather *"abstract way*"—young people tend to talk in "*broad general strokes*" because "*they don't really know what words to use*":

> I'm older—so, I remember my grandparents being at home, and I remember dying. But I think many young people today have not lived in a multi-generational setting in America. They've never seen people die. …because I think as Americans have moved further away from their homes, and they don't come home and help with dying parents always. A lot of people just pay money to have-, they don't really-, they haven't been up close and personal to experience it. So, a lot of these individuals have a lot to say about what's happening here, but they don't have it at that micro-level of having experience. So, they talk in broad general strokes, or they want to make-, they feel they have the right to make decisions about choices that they don't even understand the context or circumstances in which this immediate group [indicating the "patient," "family" and "friend" tokens] is living with. (H9)

> Sometimes it's uncomfortable to bring it up with younger people. I think older people have had more people die in their lives, maybe some people die of painful illnesses. And I think young people are interested in more abstract way. So, it's hard for them to maybe feel comfortable asking questions, which then makes having a conversation difficult because they are interested but they don't really know what words to use. Or they never thought about their values as far as even just to end-of-life planning let alone making the decision to hasten your death. So maybe there's a barrier when it comes to people who don't have experience with death. (V3)

8.5. Stakeholder Interrelationships

As I began to better understand who the stakeholders are, about their remarkable diversity, I also wanted to better understand their interrelationships and dynamics. Thus, I examined the visual languages used in participants' drawings. Using Aaron Marcus' classification of visual language (Marcus, 1992; Marcus 2003), I identified three types of visual language participants used to express relationships: pictogram, ideogram, and diagrammatic elements.

Pictogram

Pictogram refers to an icon that has clear pictorial similarities with some physical object. Pictograms were found to be particularly effective in describing a stakeholder's demeanor or attitude. Most commonly used pictograms were a simplified drawing of a facial feature. For instance, H9 drew many ears around the patient's support group to emphasize the importance of listening when they communicate with the patient (see Figure 14):

> I would hope these guys are doing a lot of listening and not all the talking so that, if we are at end of life, that we are listening what's important and what they [the patients] need. (H9)

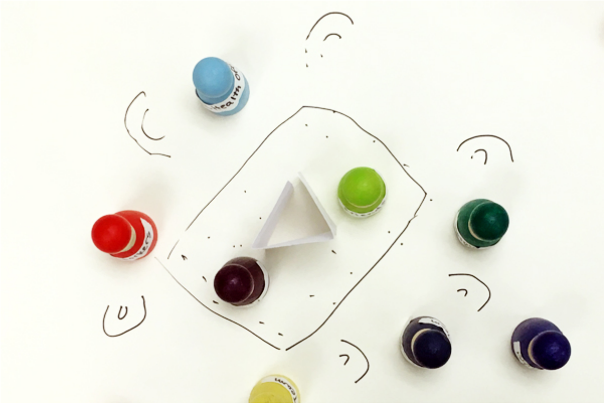


Figure 14. An example pictogram. Ears implies listening.

Ideogram

Ideogram refers to a symbol that stands for ideas or concepts. Participants commonly used question marks and heart symbols to illustrate a stakeholder's mental states. For instance, V11 drew a question mark to express uncertainty and confusion (see Figure 15):

> [T]he nursing facilities and retirement communities also, they don't know what to do about it either. (V11)

Figure 15. An example ideogram. A question mark implies uncertainty and confusion.

In another instance, V6 drew a heart to describe an intimate relationship between the patient and his partner. And then in contrast, V6 used pictograms of multiple facial expressions to convey more multi-faceted relationships between the patient and his children (see Figure 16):

> This is the client that works, and he has his spouse or his partner who is close and involved in everything so they are like in love. And they have children who are maybe happy about it or maybe not happy about it, or maybe don't know how they feel about it. (V6)

Figure 16. An example ideogram. Heart implies an intimate relationship.

Diagrammatic elements

Participants integrated an array of diagrammatic elements in their drawings such as lines, ovals, and rectangles. Here I present five major elements that participants used in their drawings:

(1) *Solid lines*. Participants often used solid lines to indicate close social ties and direct relationships (see Figure 17):

> So the solid lines are more direct relationships, and the dotted lines are more kind of, you know, as needed relationships. (H12)

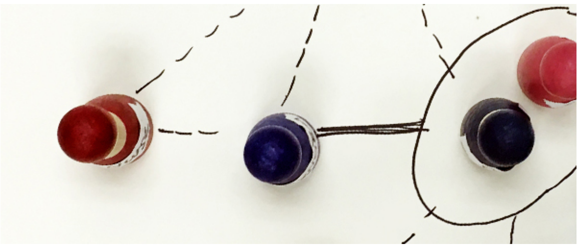


Figure 17. Solid lines indicate close social ties and direct relationships.

(2) *Dotted lines*. Participants often used dotted lines to indicate weak social ties and indirect relationships (see Figure 18):

> And actually bystanders, I'll put a dotted line. They aren't really related. (V4)

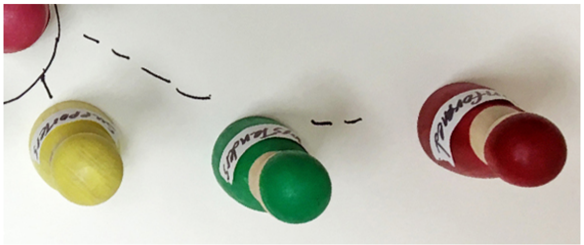


Figure 18. Dotted lines indicate weak social ties and indirect relationships.

A compelling and unusual example emerged in H10's discussion of a temporal relationship, where one stakeholder becomes another stakeholder at a later point in time as a person moves along her trajectories of life (see Figure 19):

> [T]here's a dotted line between citizens and patients because right now we may not be a patient but at some point we will be a patient. (H10)

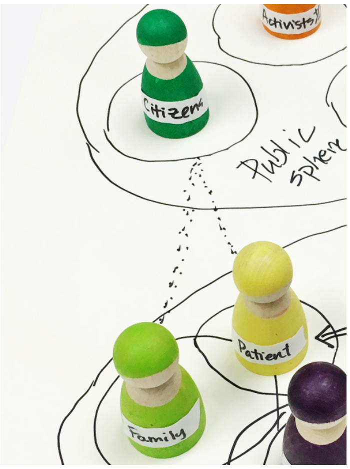


Figure 19. Dotted lines indicate temporal relationships.

(3) *Jagged lines*. Participants often used jagged lines to indicate conflict or breakdown (see Figure 20):

> The faith-based opponents and those who value individual freedom and who are supporters are most at odds—so, jagged line. (H6)

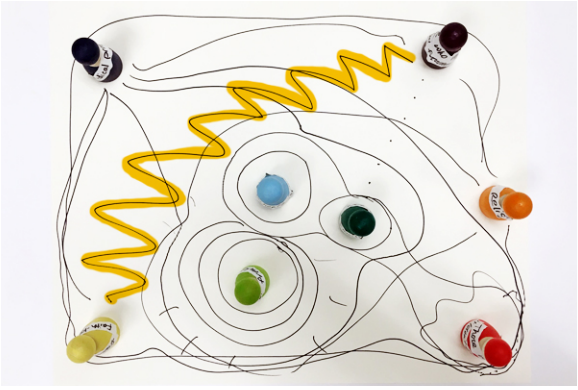


Figure 20. Jagged lines indicate conflict or breakdown (yellow highlights were added for emphasis).

(4) *Ovals*. Participants commonly used oval shapes to group together a set of closely related stakeholders (see Figure 21):

> So, at the heart of it is the patient and his or her physician and the family—is really an overlapping circle, I'll do that first. And these are really—with nurses, social workers, and pharmacists—is really all part of the clinical team. (H10).

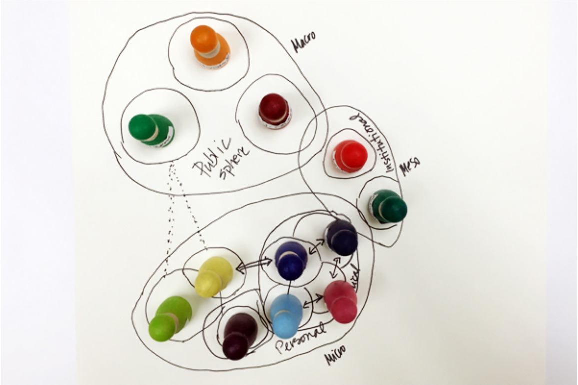


Figure 21. Ovals indicate groups and teams.

(5) *Rectangles*. Participants commonly used rectangular shapes to indicate isolation and exclusion (see Figure 22):

> They [medical aid-in-dying laws] only got passed because the Washington voters voted on it. But once they voted on the law and it was passed, then they [the voters] got shunned and they got put over there in the little box. And no one cares about them anymore. (V6)

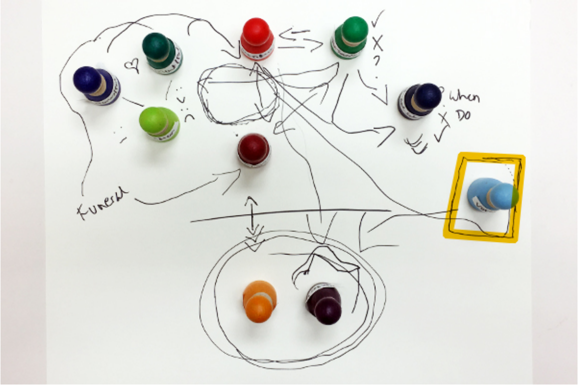


Figure 22. Ovals indicate groups and teams (yellow highlights were added for emphasis).

Enactment language

In addition to visual language, participants sometimes used enactment language to express dynamic aspects of the relationship. For instance, H8 used the direction the peg dolls were facing to convey supportive (e.g., facing in) or conflicting (e.g., facing out) relationships:

> And right around the patients, I feel like, is all their community. And some of them are facing out like ‘I don’t even want to see it.’ Some are like ‘I’m with you for goodness sake, I want the best for you and I want relief for you.’ And some might not even-, like their parents might not even know about it, they might be totally clueless. So, I should just put like in the dark (*filling-in with black color*). (H8)

> Sometimes (*knocking off the “family” and “friends” tokens*) they don’t get along and don’t communicate very well. It’s optimal (*letting the tokens stand up again*) when we can promote good communication with them, and that they are all singing from the same sheet of music, if you will, about what we are trying to do. (H9)

Interestingly, V5 and V9 did not use any visual language at all in their sketching (see Figure 23). Instead, these participants carefully arranged their tokens on a blank sheet of paper and continued to readjust the tokens’ positions as they told their stories. In particular, using subtle motions, both participants expressed a type of delicately oscillating relationship, where stakeholders may deviate “a little bit” from their presumed positions:

> So the client, they are right in the center. Actually, they are a little separated from their family, a little separated, there. (V9)

> And then *[anonymized advocacy organization]* is actually the national level group …and I see them essentially over here in this camp *(motioning towards a group of tokens that the participant identified as “the patient-centered camp”),* although you know, actually maybe a little bit over here *(motioning towards a group of tokens that the participant identified as “the resistance camp”)*. They challenged us in some ways. (V5)

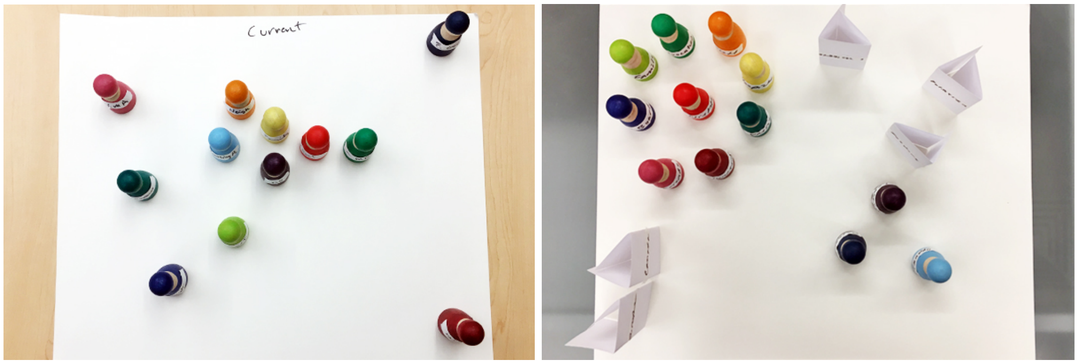


Figure 23. Two participants did not use any visual language at all in their sketching.

9. Multi-lifespan

As stated in Chapter 3.3. Multi-lifespan, my dissertation aims to understand how to design systems to support political communication and social change as they unfold over long periods of time—10 years, 50 years, 100 years and more. Using the lens of multi-lifespan design, I focused on (a) identifying multi-generational stakeholders and (b) understanding the process of slowly evolving public consciousness. I elaborate below on each of these multi-lifespan design foci with illustrative quotes from the participants' responses.

9.1. Multi-generational Stakeholders

Traditionally value sensitive design (VSD) defined stakeholders by their roles in relation to "the technology at hand" (Friedman, Kahn, & Borning, 2006). In contrast, using a multi-lifespan design lens, Yoo et al. (2013; 2016) raised questions about how to consider the concept of multi-generational stakeholders when envisioning future technology that does not yet exist. Here I report on interesting examples of multi-generational stakeholders and generational tensions that emerged from the empirical data.

What we experience in childhood shapes our worldview, but society keeps changing over time. Long standing values and norms can shift, replaced by others. Tensions may arise between older and younger generations with different upbringings and worldviews. Accordingly, younger participants reflected on generational tensions that they have experienced when they tried to have conversations with their parents about medical aid-in-dying:

> So, this has been an interesting job for me to have from my dad's point of view because sometimes we'll talk about death with dignity and I think it challenges some of his beliefs. I don't think he has ever been necessarily opposed to it, but it's-, he'd make comments like 'That's not something that was around when I was a kid.' I think it's just kind of a new territory for him. So, it's been interesting for me to hear how he contextualizes it. (V3)

> [M]y father doesn't even want to hear about my experiences working here in Washington just of this volunteer thing that I do, he don't have interest in hearing about it or listening to me talk about it, much less engaging in a conversation about like what he wants at end of life, and they don't live here, they live in Tennessee, which is probably gonna be the 49th state to ever legalizes this law, but even just trying to have a conversation about what kind of treatment he would want or when in the point he would want to go hospice or even what he wants as quality of life to be, it's just-, it's not something he is willing to engage in. (V6)

What I found particularly interesting is the generational tension caused by the older generation of physicians, who were trained and licensed before medical aid-in-dying was legal:

> You know, it shocked me that we still occasionally will have clients who come and say, 'My physician didn't say no but just don't know anything about the law.' And I don't know how you can be a physician in Washington state and not know about the law. …I'd say obviously most doctors that are doctors now were doctors before the law passed [that they] didn't have the chance to learn [about the Death with Dignity law] in the medical school. But now that we have the law, we teach them about pretty much every other law involving healthcare, we teach them about HIPAA and every other stuff, so why don't we teach about this law? (V6)

Important to note here is that older generations should not be simply regarded as a legacy from the past; they may play important roles in the future. V3 specifically identified the Baby Boom generation as *"the next important stakeholder"* that may emerge as a key stakeholder in the near future:

> I think they are also linked to Baby Boomers. There's gonna be a lot of people dying soon as Baby Boomers get older. And the way that Baby Boomers are part of the progressive death industry is gonna change how these laws get implemented and in effect how people die. So, you know, the Baby Boomers' mindset on these issues is-, they're probably the next important stakeholder because they are the ones who are gonna be dying. (V3)

Collectively, these examples point to a set of multi-generational stakeholders, who may not be considered as key stakeholders at the present but may be in some other timeframe either in the past or in the future.

9.2. Slowly Evolving Public Consciousness

One of the Internet's most-read stories in 2014 was the *People Magazine* interview with Brittany Maynard, a 29 year old terminally ill patient who announced to the world that she will die on November 1, 2014 on her own terms with dignity (Eagan, 2014). Diagnosed with terminal brain cancer and a prognosis of less than six months to live, Maynard decided to move from California, where she was born and raised, to Oregon, which was one of few states in the United States that allowed patients to request medical aid-in-dying. During her last days, Maynard launched an online campaign to make medical aid-in-dying legal and accessible nationwide in the United States. Specifically, she urged legal reform in her home state of California. Maynard's story went viral online, creating a momentum among publics to engage in lively discussions around the issues of medical aid-in-dying. Given the strong public demand, California policymakers passed a medical aid-in-dying legislation under Senate Bill No. 128 End of Life Option Act in October 2015 (SB 128, 2015).

During interviews, some participants reflected on the Brittany Maynard case—how her story was portrayed in the media and how it may have impacted public consciousness. Some participants felt that little has been changed—that things seem to *"just [go] around in circles,"* and *"It just waxes and wanes in terms of how present it is on people's minds.":*

> So, the Brittany Maynard case—obviously the latest poster child. So, I'd say, you know, when there's any kind of case when somebody goes public, it feels like it's just another turn of the conversation. And I don't really think like the conversation has really changed. It just waxes and wanes in terms of how present it is on people's minds. (H10)

> It seems like you're just going around in circles. (V1)

Participants who made a comment on the Brittany Maynard case criticized how the media sensationalized her story, framing it into a matter of black and white, pro/anti dichotomy. Lacking important nuance and details (recall Chapter 6.2.6. Sensitivity to Nuance), the Brittany Maynard story seemed to have little to contribute to advancing public consciousness about medical aid-in-dying:

> [W]ith the woman in Oregon, the young woman who—and I can't remember her name—who was a very strong advocate for it, and you know, I wasn't particularly influenced in one way or another. …I think what-, and to a certain extent she was that-, it was—I wouldn't say she was used, I think she was a willing sort of spokesperson for the pro side—I think that it lacked some nuance, and I think that's been frustrating to me in general, is that it does seem to fall into you are either for it or against it. (H15)

> The whole argument about whether this is a good thing or not a good thing, the whole argument about whether this made sense for a young woman who seem to be doing really well. (H10)

Many participants felt that little has changed—things seemed to *"just [go] around in circles,"* and *"It just waxes and wanes in terms of how present it is on people's minds":*

> So, the Brittany Maynard case—obviously the latest poster child. So, I'd say, you know, when there's any kind of case when somebody goes public, it feels like it's just another turn of the conversation. And I don't really think like the conversation has really changed. It just waxes and wanes in terms of how present it is on people's minds. (H10)

> It seems like you're just going around in circles. (V1)

H9, like many participants, criticized the media sensationalism. But she also felt *"just a tiny shift maybe in public sentimentality and how they wanted to think about this case":*

> I'm thinking about a young girl, I think she was in the late twenties who had a brain tumor. It wasn't that long ago—seems like it was a year ago maybe. She was very young, just married, and I know

> there was quite a—I think probably her youth, her announcing a date, and I think she very quickly realized 'Okay, that was not the right thing to do,' that it should be kept more private. But that was a very sensationalized, I thought, in the media. But I also thought she was able to put-, to express herself. I don't remember if it was on Facebook, but some social media she published sort of a letter, and I don't know, I felt just a tiny shift maybe in public sentimentality and how they wanted to think about this case instead of just outrage and being, you know, 'Oh my gosh, she can't possibly know with that age that that's what she needs to do.' But I felt like maybe people after her-, I think it was like a letter that she wrote about her decision and why she did what she did and things. I think also her husband did was verbal about or communicated his thoughts about it. So, I thought maybe, I felt a small shift in from being totally negative and against it to maybe more understanding. Maybe not acceptance but maybe a little understanding. (H9, emphasis added)

On a related note, H11 reflected on the role that Jack Kevorkian played in changing public consciousness, *"pushing a cultural norm":*

> I think some of that was about him more than I would guess that it was about sort of the endeavor, but at the end of the day that's an example of, sort of where documentary film makers can take a sort of rogue individual who wants to push a cultural norm. …And I think having people talk about that led to some discussion, which allowed people to talk about heavy and weighted content in a-, to allow I think change. (H11)

Dr. Jack Kevorkian was a highly polarizing figure and perhaps a *"rogue individual,"* but nonetheless he was pivotal to the medical aid-in-dying movement in the United States. His story raised people's consciousness about patients who are suffering with terminal illness and the need for an alternative end-of-life care. That said, some participants reported that they became first aware of the concept of medical aid-in-dying through the Kevorkian controversy in the 80s:

> [T]hat's when we first started hearing about this sort of thing, and he [Dr. Kevorkian] was trying to educate the universe in that matter. I mean, he was kind of helping people. Very controversial obviously—he was controversial. …I mean he was doing what he thought was right, but he was raising

> a lot of ire and disturbing a lot of ways of thought. It was in the 90s or the 80s, it could be in the 80s even, I think I was still at home, yeah. (H8)

> [Y]ou know, he [Dr. Kevorkian] went to jail. What he was doing back in the—I think it was in the 80s, early 80s. …I lived in the mid-west then. Mid-west was highly Christian and religious about-, and felt that he was basically murdering people and, or even though he said, 'Well, I didn't touch the drug, I just set it up, they did it,' I think people felt like he was promoting suicide and that that was in their judgment he's not God and therefore he can't do that. (H9)

While participants were against media sensationalism and polarization, they acknowledged that in order to make change and to *"move the needle about what [is] acceptable in the society,"* at times someone has to come out to be intentionally aggressive and *"push the limits,"* rather than striving for balance:

> *(Pointing to the index card that says, "Progressive Ideas")* We want people to have choice in this. So that's why that's important. Pushing the limits. (V9, see Figure 24)

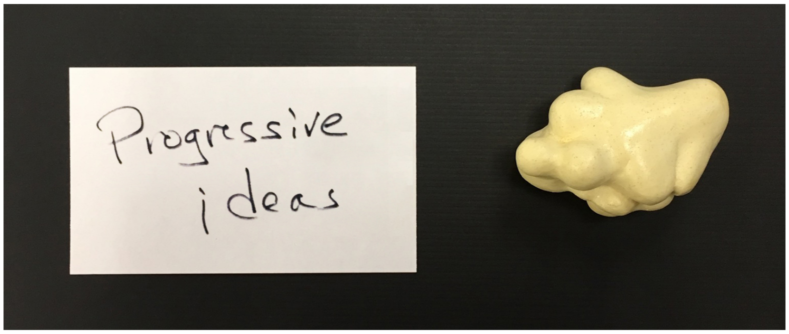


Figure 24. *"Pushing the limits."* (V9)

> [Hemlock Society] it was an advocacy group that was, you know, interested in one side and relatively aggressive about promoting that, …so they weren't striving for balance—they were kind of trying to move the needle about what was acceptable in the society. (H15)

Interestingly, in Washington, the issue has mostly disappeared from public view since the DWDA went into effect in 2009. Recall that in Chapter 6.2.2. Hidden Practice of Medical Aid-in-Dying I identified politicization as one of the key concerns, which prevented people from openly engaging in the practice of medical aid-in-dying. Concerned with potential political backfire, people tended to operate in a defensive mode rather than in a progressive mode. The issue has disappeared from public view. Little has changed—as V1 noted, *"at this point, we're kind of stuck":*

> The difficulty is that with the initiatives, if you open up the law to change, then anybody can come in and monkey with the law. So, we know that if we open it up to try to expand the access, our opponents will come in and try to change the law in ways that we'll feel would be detrimental. So, at this point, we're kind of stuck on that. I don't think our society is quite ready for that. (V1)
>
> The problem is that once you kind of open the door to change, you might open the door to a change in ways that you don't want—you want to open a door to a change in ways that you do want. Which is why I picked this shape *(see Figure 25)* because then you have these spiky sides you are like 'Oh bad things can happen, rights can be taken away, the law can get more complicated, they can put more restriction on it.' (V6)

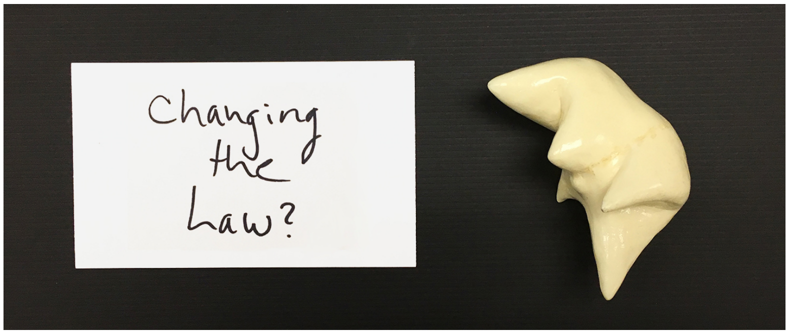
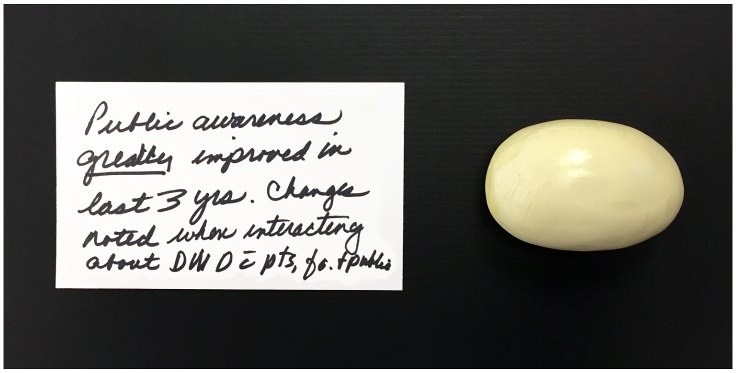


Figure 25. ***"then you have these spiky sides you are like 'Oh bad things can happen, rights can be taken away, the law can get more complicated, they can put more restriction on it.'"*** **(V6)**

V11 suggested that bringing in new generations that are unharmed and less biased, passing the baton for them to lead the movement can be a solution to this problem:

> *(Picking up an index card that says, "Public awareness greatly improved in about 3 years. Change noted when interacting about DwD with pts, dr. & publics")* One thing we have to avoid as an organization is thinking that there are too many people who are opposed to us because having been through all the previous battles people I think are bruised and they kind of anticipate that there's gonna be a trouble but maybe there isn't so much. So, maybe if you brought in a brand new group of people to run the organization so to speak, they would start at a different [place] because they are more optimistic, and I think we should be now. And I do think we are at a time right now where things can really move forward. (V11, see Figure 26)



Public awareness
greatly improved in
last 3 yrs. Changes
noted when interacting
about DWD c̄ pts, dr. & publics

Figure 26. ***"maybe if you brought in a brand new group of people to run the organization so to speak, they would start at a different [place] because they are more optimistic."*** **(V11)**

Despite many challenges, participants felt hopeful for the future, reporting that they have observed positive changes in society over the years:

> I noticed that over time the [media] coverage has seemed to become more positive. It seems like, where there just seems to be more openness around this being something that is a value, and that notably doesn't seem to be being abused in the way that many people feared when the laws were initially passed. So. (H4)

> [M]y husband is a medical oncologist and they are kind of known for not being enthusiastic about the law because of their fear that patients may think that they don't want the treatments of medical oncologists, or the medical oncologists who they go to for help are going to not help them and in fact help them die, which they do not. Medical oncology particularly opposed as a medical group to death with dignity. So, I have seen over the years that particular group evolved enormously as the public has

> evolved. And when, I mean the differences between now and when I first thought about this or, even as a concept or, even the idea that I have never conceived of before, is gigantic because of the public changing its mind and because of people are having positive experiences with it. (V11)

Participants understood that social change is a slow, gradual, multi-lifespan process. As V9 put it, *"this is an evolution so I'm not holding my breath. …we're not gonna see those in my lifetime. Some point in the future we may":*

> From a progressive standpoint, I really wish that we could be forward thinking. The rate of Alzheimer's is increasing, Baby Boomers are also increasing, (_____) increasing, so we are gonna have a bunch of people who should be [interested in medical aid in dying that do not currently qualify under the DWDA of 2008]. So, I wish we can get past that, but this is an evolution so I'm not holding my breath. …That's-, so we're not gonna see those in my lifetime. Some point in the future we may. (V9)

10. Reflections on the Methods

In the field of human computer interaction (HCI), researchers are increasingly engaging with sensitive topics and vulnerable populations. A question arises: How can we communicate ethically about sensitive topics such as death and dying with research participants? While the semi-structured interview is an established method long used in social science, as Hanington and Bella (2012) point out, "When prompted by traditional research methods such as questionnaires and interviews, people often find it challenging or uncomfortable to articulate and express their innermost feelings, thoughts, and desires" (p. 33). We need better research methods and more nuanced communication tools to engage with participants in intimate or vulnerable situations.

I developed two new design research methods—Stakeholder Tokens and Meanings and Emotions —to help navigate emotionally sensitive topics with participants. Here I provide a brief reflection on each method, including its benefits and limitations.

10.1. Stakeholder Tokens

Benefits. The Stakeholder Tokens activity largely consists of two parts—first, generating labels to attach to physical tokens who represented stakeholder groups, and next, sketching relationships among those stakeholder groups. Interestingly, ten out of 27 participants (five health care workers, five volunteers) added new tokens while they were sketching, realizing that they had forgotten about some important stakeholders. Participants would ask, *"Can I have a couple more people?"* Fifteen additional stakeholders were identified in this way.

Sometimes, it was the most central stakeholder (i.e., the patient) that participants missed, which they immediately realized right at the beginning of the sketch:

> You know what? I'm missing a really important person. I'm missing the patient! The person, I want the person! We gotta make one more. How did I miss the person? (H9)

> I just forgot the patient so, oh, so I should put them in here! *(adding the "patient" at the center of the paper)* (H8)

Other missing stakeholders were identified in the middle of sketching. As the sketches became more developed, gaps were revealed. Participants seemed surprised that they had completely forgotten about important stakeholders:

> I do need one more—I forgot the most important—if you have one more figure. …I need to put activists in here for death with dignity. (V11)
>
> I didn't even think of the legal folks too. …Yup, got it. Okay. I don't know how I forgot them. (H8)
>
> Oh, "pharmaceuticals," how can I forget about you! (H5)

Interestingly, sometimes it was the participant's own stakeholder group that they had forgotten:

> Oh, it's interesting! I didn't put any religious leadership. (H6, chaplain)

In addition to identifying missing stakeholders, participants also identified a number of communication gaps by examining their sketches:

> This *(indicating the "hospital" token)* is sort of odd, they're on their own. Yeah. (V12)
>
> *(Curiously pointing out that there is no line attached to the "minorities" token)* …so the minorities are the only ones that don't talk to anybody. And that's one thing that we are trying to do, and so hopefully we can talk with the minority communities and educate them better. (V1)

Taken together, sketches worked as a reflective tool that allowed participants to identify interesting gaps that they perhaps did not see before, and to tell a richer and more holistic story about an issue that is so complex and difficult to explain. Sketches prompted participants to step back, reflect on, and make sense of the issue that they had been deeply immersed in.

> I'm trying to work my things in my head, I'm trying to problem solve. (H11)

Limitations. Value tensions may not only arise between the stakeholders but also internally within the stakeholder (Friedman & Hendry, in press). The method provided rich language for expressing the value tensions that arise between different stakeholders (e.g., visual language such as jagged lines and roadblocks, enactment language such as facing away, placing tokens far way in the opposite directions). However, the method was less effective in expressing the internal value tensions that arise within a single stakeholder group with mixed values and beliefs:

> So, these can be either supportive or unsupportive, so there might be—I don't know how to draw that relationship (H7)
>
> Well, probably *(indicating the "mourners" token)* there should be a slash and "celebrators" because it's-, mourning by itself doesn't capture the whole thing, there is celebration, I think. [Interviewer: So should we (add another token?)] …I was gonna put it ["/celebrators" label] on the mourner. No. I think they [the mourners and celebrators] go together. (V4)
>
> So, I don't know how to draw the relationship when there's a conflicting agenda. (V7)

The complexity and diversity could not be fully expressed. A number of participants pointed out that the sketches that they made were *"just a snapshot"* of changing relationships:

> [T]his is just one way it can play out, I don't know. I mean in the best world that's what I think. (H9)
>
> So that's how I would organize this. I mean, it's one of the million ways to do it. (H15)

That said, participants were less interested in making an objective portrayal of the existing situation, but more interested in making a self-expression of what they would hope to see:

> [T]he people who are as individual struggling with end of life illness and their family members *(drawing a circle in the middle of the paper)*, maybe it's a wishful thinking that they are sort of in the center, but. (H4)

> There’s a real kind of right-brained way I’d like to demonstrate it—something more tree-oriented. At the risk of not really responding correctly, I’m gonna do it kind of more right-brained way. (see *Figure 27*) (H2)

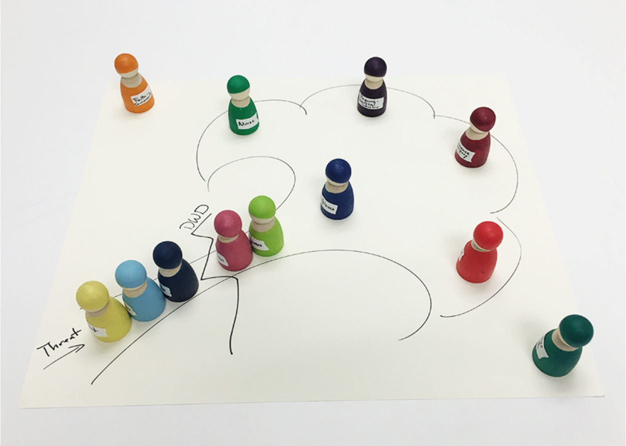


Figure 27. ***“There’s a real kind of right-brained way I’d like to demonstrate it—something more tree-oriented.”***

While most participants found it easy and fun to work with the tokens (e.g., *“I love playing with these guys! …Those were really fun!”*), a few participants were rather shy, feeling uncomfortable and hesitant about using peg dolls and making sketches:

> So let’s—I can’t draw. How can I draw this. I’m terrible at this. (H14)

> I’m not the neatest person on that kind of stuff, so. (V4)

> Okay, so let’s—what’s going on? I don’t know. This exercise is a little bit harder for me. (H6)

> This is like a kindergarten (V10).

10.2. Meanings and Emotions

Benefits. The Meanings and Emotions activity allows participants to creatively express their thoughts, feelings, and other aspects of their life that are otherwise difficult to articulate. Sensual Evaluation Instrument (SEI) objects (Isbister, Höök, Sharp, & Laaksolahti, 2006) provided alternative ways for individuals to project their abstract thoughts and feelings onto externalized, embodied objects, and then use these objects as a tangible reference point for conversation (Hanington & Bella, 2012).

That said, one question I had about the SEI objects was: Would each shape evoke a particular kind of feeling (e.g., Shape A evokes feelings of X, Shape B evokes feelings of Y)? I observed no relationship between a specific shape and a specific kind of feeling. Participants interpreted the shapes in their own unique ways. For example, V3 and H15 chose the same shape (see Figure 28), both describing that they can almost feel this shape inside their hearts. Interestingly, however, they were experiencing different emotions:

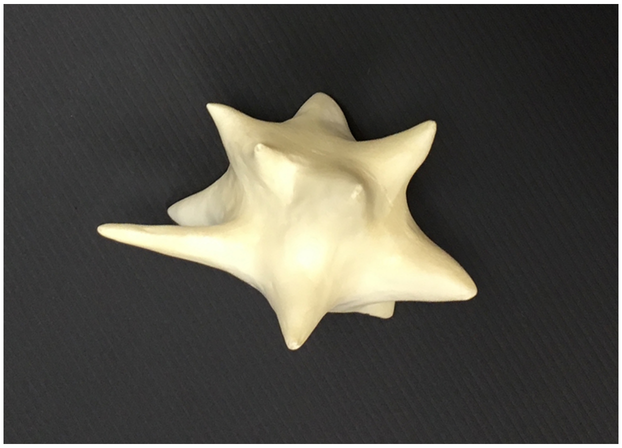


Figure 28. a bright glowing star vs. an aggressive weapon

> I think that allowing that conversation [about medical aid-in-dying] to stay open and happen often is probably a great gift they can give to their loved ones. I'll pick this shape …because the shape to me looks like the star and so I can almost imagine someone pulling the shape out of their heart and giving it to someone else. It's bright and glowing, and I think that's maybe the best metaphor I can say for talking to someone else about death, being able to pull a star out of your heart and give it to them. (V3)

> This shape sort of seems aggressive—seems like it can be used as a weapon. And I think that's how people feel a lot, even internally conflicted. I think that that's how I f-, I can imagine this shape being in my heart. When I think about how I felt in many conflicts that I've been a part of, sometimes I felt like this internally. Sometimes I wanted to throw this at the wall. Yeah. (H15)

Yet in another example, V1 and V9 pointed to the same shape (see Figure 29), both describing that the shape reminded them of a hand gesture, but reading completely different signs:

Figure 29. Thumb-up vs. up raised middle finger.

> I chose this because it reminds me of thumbs-up. (V1)

> Well, this reminds me of the—and I don't need to tell you why, do I? [Interviewer: Could you please?] This is the up raised middle finger. *(laughs out loud)* (V9)

The ways participant engaged with the SEI objects were widely diverse and creative. Yet, participants often seemed to think that they were choosing the most *"obvious"* shape, that they did not need to explain why they chose the shape and what it meant. I had to keep reminding participants to provide explanations:

> I feel like I'm choosing the most obvious shapes for these things. (H4)

Limitations. While most participants found it interesting to work with the SEI objects (e.g., *"Well, how fun to articulate all this stuff!"*), a few participants felt uncomfortable, hesitant to use them. Those participants reported that the shapes felt *"strange"* and irrelevant:

> Well I just find those strange. I mean I felt like I had to force myself to choose one, I don't think they were, they were not relevant to me. (V10)

10.3. Designing Methods for Sensitive Contexts

Together the methods elicited rich and nuanced discussions and emotions. Participants appreciated how the hands-on design activities allowed them to explore the issue *"from very many different ways, not just asking questions."* The method allowed participants to *"[get] in touch with [their] feelings about this whole thing,"* encouraging them to engage with *"other side of [their] brain":*

> I really like the way there's lots of-, you're really looking at it from very many different ways, not just asking questions. I liked all the playing around, so thank you. (H13)

> I guess what I'm getting in touch with is my feelings about this whole thing and how valuable it is. (V4)

> These are really fun! …They're really interesting, yeah. You're making me engage with other side of my brain. (H9)

As H2 noted, the method did not necessarily lead to a new conclusion, but it made H2 process her inner thoughts and feelings about the issue. H2 reported that the experience of the whole interview had been cathartic:

> Well, just the catharsis and the pleasure and the clarity of having this conversation kind of makes me wish that it was a everyday thing, that we look at difficult issues this way. It doesn't lead me to a new conclusion, but it makes me process it. (H2)

As stated above, an overarching question which motivated me to develop these methods was: How can we communicate ethically about sensitive topics such as death and dying with research participants? Ethics are difficult measure, but sometimes you know it when you see it. A compelling example emerged during an interview when H6 emphasized the sensitive and delicate nature of the topic and added, *"I want to do a lot of like what you are doing,"* providing a sign that I was able to communicate about the topic with care:

[I]t’s a very very sensitive, very delicate issue that it needs to be addressed with care, and tenderly, and I want to do a lot of like what you are doing—understanding why the person is considering that, where is it coming from. (H6)

11. Key Insights and Design Opportunities

Here I highlight four key insights and design opportunities each insight affords.

Insight 1. Stakeholders Matter.

Bill Buxton (2010) emphasized the importance of exploring multiple design ideas before committing to build one thing because so much is at stake in getting the right design. In a similar vein, I argue that much is at stake when we decide who will be our users. Exploring with multiple stakeholders using a robust stakeholder analysis method will help us identify the most interesting and promising users.

Value sensitive design methods rely on designers and researchers generating a robust list of stakeholders and then carefully identifying key stakeholders whose values will be explicitly supported through design. As technology becomes more pervasive, its implications become increasingly widespread and complex. In turn, more extensive conceptual and empirical work is needed for understanding a broad range of stakeholders. Without a robust stakeholder analysis method, designers may leave out many interesting stakeholders, in particular, peripheral and excluded stakeholders. Peripheral and excluded stakeholders are not necessarily trivial nor dispensable. Consider "uninformed publics," for example, who were identified as a peripheral stakeholder. Publics play a critical role in legalizing medical aid-in-dying. In liberal democratic societies, publics are "the ultimate foundation of all legitimate law" (Näsström & Kalm, 2014, p. 4). As V6 pointed out, *"[Washington's Death with Dignity Act] only got passed because the Washington voters voted on it."* However, once the law was passed, the issue quickly disappeared from public view. Publics were left uninformed about how the law was working, presenting a concrete design problem:

> [B]ut I think that we could do a better job of keeping them [publics] informed about how is this law that you voted for working? How is it playing out? Is it working well, is it not working well? Would you care if it's working well? Would you be interested in voting on changes? Would you not be

> interested in voting on changes? And I think there are ways to do that that we just didn't explored it all (V6).

Furthermore, the work reported here suggests that core stakeholders are not always the best users to interact with. The ultimate goal of medical aid-in-dying is to improve the patient experience at the end of life and, unsurprisingly, patients were the most frequently identified core stakeholders (see Chapter 8.2. Core and Peripheral Stakeholders). Accordingly, I consider patients to be the primary stakeholders, and their values (e.g., choice, dignity) will be prioritized and explicitly supported throughout the design process. However, to design for patients does not necessarily mean to design a system to be used by patients who are struggling with their complex medical conditions. Designing a communication system intended for use by physicians, social workers, and volunteers, for example, may be more appropriate and effective—alleviating interprofessional tensions (see Chapter 6.2.5. Managing Roles and Expectations) so as to result in better end-of-life care for patients.

Design opportunities for stakeholders matter. In this research, using the Stakeholder Tokens method I identified a wide range of stakeholders and illustrated unique communication challenges and design opportunities each stakeholder affords. In particular, I identified interesting design opportunities to engage with at least three different cateogies of stakeholders. First, excluded stakeholders, such as non-English-speaking patients and the challenge of bringing translators into the process of making informed and voluntary requests (as described in Chapter 8.3. Excluded Stakeholders). Second, "difficult" stakeholders, such as young people who have little experience with death and who *"don't really know what words to use"* (as described in Chapter 8.4. "Difficult" Stakeholders). And third, other underexplored stakeholders such as hospice physicians who face a dilemma around the six-month prognosis (as described in Chapter 6.2.5. Managing Roles and Expectations).

Insight 2. Social Change Takes a Long Time.

We may have romantic ideas about revolutions—a big wave that sweeps the world, turning everything upside down overnight. However, public consciousness evolves over long periods of times (see Chapter 9.2. Slowly Evolving Public Consciousness). Social change is a slow, gradual process marked by intermittent milestones (e.g., votes, elections, revolutions) that accelerate the evolution. While most political design focuses on milestone moments, my work draws attention to the in-between periods, in which people feel *"stuck"* and things seem to be going nowhere. As Jos Boys (2014) suggested, designing for social change is less about being the vanguard of a revolution but more about "working persistently within a pattern of three steps forward and two steps back; of staying hopeful, knowing that what we have to do is accumulate many such small acts, that we can make an impact down the line." (p. 58). Specifically, I suggest that reimagining such in-between periods as "laying fallow"(Friedman & Yoo, 2017) opens up new design opportunities. Laying fallow is a form of pause that primarily serves the purpose of refreshing people, resources, or other aspects of the project. Such fallow periods aid with project sustainability and can act as a counterpoint to what might be experienced as relentless workflow leading to social and political burnout.

Design opportunities for social change takes a long time. Multi-lifespan design provides a set of heuristics for using pause intentionally and strategically in the design process (Friedman & Yoo, 2017). These heuristics include articulatig a aationale and rhythm for pause, initiating pause, documentation, managing expectations and maintaining relationships, monitoring for restart conditions, and restarting. Leveraging these heuristics, a system can be built to help stakeholders better plan for and manage lapses in their political projects (e.g., smooth transition in and out of pause, managing expectations across multiple stakeholders, monitoring and documenting the implementation of laws and policies, passing the baton to a new generation).

Insight 3. Political Communication Is More Than Debate.

Political communication is often characterized as a debate between the political proponents and opponents. Yet, in the interviews reported on here, participants repeatedly expressed that they were rarely confronted with an opponent in real life. Rather, everyday conversations often involved a complex internal political negotiation among diverse partners in an alliance. Tensions arose not just from difference in roles and responsibilities, but also in feelings (e.g., a sense of respect or lack thereof) and underlying values (e.g., choice-autonomy approach vs. choice-compassion approach). Such political communication is nuanced, emotional, and explorative, departing from the conventional understanding of political debate that is dichotomized, rational, and conclusive.

Design opportunities for political communication more than debate. I suggest that there is a rich design opportunity to turn our focus from macro- to micro-politics. In my research, I illustrated some unique micro-political communication challenges, including complicated family dynamics (see Chapter 7.1. Keywords); interprofessional tensions across attending physicians, palliative care team, and social work team (see Chapter 6.2.5. Managing Roles and Expectations); and some deep misunderstandings between physicians and volunteers (see Chapter 8.4. "Difficult" Stakeholders). Miscommunication lead to false expectations, distrust, and hard feelings. Designing a communication system to alleviate micro-political tensions and increase mutual affection (e.g., by visualizing collaborations and clarifying roles) may be of helpful.

Insight 4. Methods Matter.

Using a well-designed method creates a good conversation between the researcher and participants. In my dissertation, I asked participants to define a good conversation in the context of their work on medical-aid-in-dying, especially, to describe how it feels. I identified three key characteristics of a good conversation. Good conversations feel *open, reflective,* and *respectful* (see Chapter 6.3. Characteristics of a "Good Conversation"). Interestingly, participants were able to identify these same three characteristics when they reflected on their experience engaging with the interview process (see Chapter 10.3. Designing Methods for Sensitive Contexts). Participants were *open* to talk about their experience with death and dying to the extent that it did not breach patient confidentiality. Participants found the methods to be *reflective*, allowing enough space and tangible tools for them to explore their values, feelings, and thoughts. Finally, there was a sense of *respect* on both sides between the researcher and participants. That said, I argue that designing a good research method is not so different from designing a good communication system. Well-designed research methods, in turn, can directly inform how to design better communication systems and tools.

Design opportunities for methods matter. Several participants showed interest in using the Stakeholder Tokens method and the Meanings and Emotions method in their own work settings. Given such interests, these methods could be adapted to build communication toolkits for professionals. For example, the Stakeholder Tokens method can be adapted to visualize points of interprofessional tension and to clarify roles and expectations. The Meanings and Emotions method, on the other hand, can be repurposed to help professionals engage in more reflective conversations about medical aid-in-dying with their patients, providing a safe runway for patients to voice their inner thoughts and feelings.

12. Conclusion (Contributions and Future Work)

I turn now to briefly highlight key contributions of my dissertation—theory, methods, and domain knowledge—and then conclude with open questions and future work.

12.1. Theoretical Contributions

My theoretical contributions are three-fold. First, I provided conceptual framings for understanding publics and political communication that are different from the conventional understandings of users and political debate in the field of HCI. In addition, the empirical findings of my case study provide evidence for the usefulness of these conceptual framings. In Chapter 2.1 Defining Publics, drawing from Warner (2002) I argued that publics can be more aptly conceptualized as a process rather than "people" per se. I argued that to design for publics means to engage in a slow, complicated sociopolitical process of evolving public consciousness rather than to design for certain people who are somehow parallel to the concept of users. Taking this perspective, in Chapter 9.2. Slowly Evolving Public Consciousness, I analyzed how participants perceived of and conceptualized publics. Consistent with Warner's writings, participants characterized publics in terms of the degree of attention (*"waxes and wanes"*). Participants also talked about the holistic, sociopolitical process of evolving public consciousness (*"move the needle about what [is] acceptable in the society"*) rather than addressing publics as specific stakeholders with unique needs and desires. Furthermore, in Chapter 2.3.3. Affective Publics, I introduced Papacharissi's theory of affective publics (2015) as a fruitful lens that can help account for affective and hybrid aspects of political communication. Using this lens, I paid special attention to expressions of feelings in my analyses. Consistent with Papacharissi's writings, the empirical data reported in Chapter 6, 7, 8, and 9 demonstrates the importance of communicating emotional, ethical, and philosophical aspects of medical aid-in-dying in a nuanced manner. The goal in such political communication is less about persuading others but more about co-constructing an understanding of what is the issue at stake.

Second, my dissertation contributes to value sensitive design theory by extending the understanding of stakeholders. Previously, value sensitive design has considered stakeholders primarily in terms of being direct or indirect, with some attention to other categories such as by-stander or datapoint. With this work, I introduce several other important ways to consider stakeholders including the concept of core stakeholders, peripheral stakeholders, and difficult stakeholders. Particularly, in Chapter 8.3, I provided a conceptual framing for understanding excluded stakeholders in nuanced ways. I identified four types of exclusion: categorical exclusion, sociocultural exclusion, self-exclusion, and selective exclusion. This framing of exclusion is not specific to medical aid-in-dying but applies more broadly in various sociotechnical contexts. Understanding exclusion is important if we want to design systems that are more inclusive. As we deal with data and computing in increasingly large scale and in public settings, issues of representation, bias, and accountability will continue to be in question. We need to continue to make efforts to gain more accurate understandings of whose values we represent through our systems and whose values we don't, and to find ways to support diversity. Using this framing of exclusion can help designers and researchers to better conceptualize and engage with excluded stakeholders in their projects.

Third, my dissertation contributes to the multi-lifespan design theory by introducing a new category of multi-lifespan problem—which I call *slowly evolving public consciousness*. Multi-lifespan design focuses on the design and deployment of information systems in order to support long-term solutions to significant societal problems that are unlikely to be solved within a single human lifespan. Recall that in their launching of the multi-lifespan design research initiative, Friedman and Nathan (2010) identified three categories of multi-lifespan problems: limitations of the human psyche, tears in the social fabric, and natural time-scales that move more slowly than a single human lifespan. Extending these categories, in Chapter 9 Multi-lifespan, I showed compelling evidence of multi-lifespan thinking about generational stakeholders and the slow process of evolving public consciousness around the issue of medical aid-in-dying. The empirical data demonstrates that social change inevitably takes time, that it requires a long-term, multi-lifespan approach to allow publics to slowly evolve their consciousness on the matter at stake to *"move the needle about what [is] acceptable in the society."*

12.2. Methodological Contributions

Methodologically, my dissertation contributes two new design research methods—the Stakeholder Tokens method and the Meanings and Emotions method. Stakeholder issues often emerge from the complex social dynamics and defy straightforward explanations. Stakeholder analyses, to do it justice, may require extensive conceptual and empirical work. Yet, it is often unclear how to effectively do so. Most studies provide a conclusive statement of the key stakeholders without necessarily providing a detailed explanation about the method through which they were identified or selected. Addressing this gap, Stakeholder Tokens advance value sensitive design by providing a concrete method for conducting more robust stakeholder analyses. The Meanings and Emotions method, on the other hand, focuses on creating a safe space and providing tangible tools for participants to express their ideas and feelings, in particular, around highly sensitive and politicized topics. In addition, I provide a set of heuristics for evaluating the quality of researcher-participant communication—openness, reflectiveness, and respect—derived from participants' ideas about what constitutes a good conversation.

12.3. Empirical Contributions

Empirically, my dissertation contributes to two different domains of human-computer interaction (HCI). First, my dissertation adds a case study to the domain of end-of-life HCI. The end-of-life is a relatively recent domain for exploring technology use and design in the HCI. Less than a decade ago, Massimi and and Charise (2009) proposed an approach called *thanatosensitive design*, calling attention to ethical and methodological issues for designing technology in end-of-life contexts. To date, mostly focusing issues following a person's death such as bereavement (Odom, Harper, Sellen, Kirk, & Banks, 2010) and post-mortem arrangements (Moncur, Bikker, Kasket, & Troyer, 2012). While there is much potential in understanding the roles of technology for supporting *the dying,* for people who are approaching imminent death (Massimi, Odom, Banks, & Kirk, 2011), only a very few studies have explored this design space (Foong 2008; Ferguson, Massimi, Crist, & Moffatt, 2014). My dissertation provides insights into the experiences of the dying, describing the multi-faceted process of medical aid-in-dying which has rarely been articulated in the HCI. Second, my dissertation adds a case study to the domain of sociopolitical HCI. While many have thoughtfully engaged in a wide range of sociopolitical issues, no one has attempted to investigate the issue of medical aid-in-dying with respect to the use of communication technologies. Through this case study, I highlight the importance of taking a long-term, multi-lifespan design approach to conducting sociopolitical HCI research.

12.4. Open Questions and Future Research Direction

The work reported here, while making progress on advancing sociopolitical HCI, leaves many questions unanswered and raises other new ones. Here are a few. How do online publics communicate political issues, in particular, via social computing? How is online communication different (if at all) from how stakeholders communicate issues on the ground? What draws publics' attention? Public attention is difficult to attract and sustain. There are many important issues with extensive and serious consequences that do not necessarily warrant publics' attention. As Ben Berger (2011) wrote, "Democracy means, and in practice has always meant, citizens struggling to pay attention and invest energy politically" (p. 8); he called such democracy an "attention deficit democracy."

This one key question entails: What roles can design and technology play in formulating public attention? To gain traction, I aim to conduct cross-media content analyses on selected conversation threads that gained a lot of public attention. I will examine informal, free-flowing communication (e.g., brief responses and comments) exchanged on social networking platforms (e.g., Reddit, YouTube) and news media platforms with a focus on “structures of feelings” (Williams, 2001; Papacharissi, 2015) being shaped by the medium.

Furthermore, I aim to conduct a proof of concept design study to build a communication system that enables nuanced conversations around medical aid-in-dying in the United States. Here my goals are two-fold: (a) to demonstrate the viability of specific theories and insights developed from my dissertation, and (b) to gain new knowledge and insights by engaging in practice of research through design. I may borrow insights and tools from the established methods of affective computing (Boehner, 2005). In turn, designing for affective publics may contribute to discourses on affective computing by introducing the political lens on affect. The concept of affect is relatively undertheorized in relation to the political. More work is needed.

APPENDIX A. MEDICAL AID-IN-DYING KEYWORDS (FULL LIST)

	Keyword
1	1st Oral Request
2	2nd Oral Request
3	Acceptance
4	Access
5	Administrivia
6	Adult
7	Advocacy / Advocating
8	Agency
9	Anger
10	Anticipation
11	Appreciation
12	Assistance
13	Anxiety
14	Attending Physician
15	Autonomy
16	Awareness
17	Barbiturates
18	Beautiful
19	Being Outside
20	Bitter Taste
21	Body
22	Bravery
23	Boundaries
24	Burden
25	Burden on Family
26	Bureaucracy
27	Catholics
28	Cats
29	Celebration of Life <final rituals>
30	Choice / Choices
31	Closeness
32	Closure
33	Collegiality
34	Comfort / Comfortable
35	Communication
36	Communication Breakdown
37	Community
38	Community Education
39	Community Support / Community Supported
40	Compassion / Compassionate
41	Compassion & Choices / End of Life WA
42	Competence
43	Complete
44	Complex (many variables / stakeholders + options)

45	Complicated
46	Complicated Death
47	Compounding Pharmacies
48	Conflict / Conflicting
49	Inner Conflict
50	Confidentiality
51	Confusion
52	Connection
53	Consistency
54	Consulting Physician
55	Contentment
56	Control
57	Controversy
58	Crude
59	Culture
60	Day Zero
61	Death
62	"Death Panels"
63	Decisional Capacity
64	Decision Making
65	Deep
66	Delirium
67	Demographic Variation
68	Dependency
69	Depression
70	Despair
71	Difficult
72	Dignity
73	Dignity in Death
74	Discernment
75	Disease
76	Disfunction
77	Disparity
78	Doctors
79	Double Effect
80	DNAR (Do Not Attempt Resuscitation) Decision
81	DPOA (Durable Power of Attorney)
82	DWD (Death with Dignity)
83	Dying
84	Dying Process
85	Ease
86	Education
87	Embarrassment
88	Embrace
89	Empathy
90	End of Life
91	End of Life WA

92	Ethics
93	Euthanasia
94	Existential Conundrum
95	Existential Suffering
96	Expanding
97	Expense of DX
98	Faith
99	Family
100	Family Division
101	Family Dynamics
102	Family Support
103	Family Wishes
104	Far-reaching
105	Fear
106	Fear about Illness, Decline, Dying
107	Fear of unknown
108	Finances
109	Financial Resources
110	Freedom
111	Freedom from Suffering
112	Friends
113	Friendly Folks
114	Frustration
115	Funding
116	Generosity
117	Goal Achievement
118	Goals at End of Life
119	God
120	Good Death
121	Grace
122	Gratitude
123	Gratitude for My Life
124	Grey
125	Grief
126	Happy
127	Hastening Death
128	Healing
129	Heart Warming
130	Hell on Earth
131	Help
132	Helplessness
133	Hemlock Society
134	Holistic
135	Home
136	Hope
137	Hopelessness
138	False Hope

139	Hospice
140	Hospital
141	Humanity
142	Humane Option
143	Humor
144	Impact on Family / Community
145	Impaired Functional Abilities
146	Important
147	Income Inequality
148	Information
149	Informed Decision
150	Independence
151	Individual Rights
152	Inner / Outer Circle
153	In Person Visits
154	Integrity
155	Intimate
156	Isolation
157	Joy
158	Judgment
159	Kindness
160	Learning
161	Legal / Legalities
162	Legacy / Legacies
163	Legislation
164	Lifespan
165	Logistics
166	Loneliness
167	Long Hours
168	Loopholes
169	Loss
170	Love
171	Magical
172	Male
173	Marital Dynamics
174	MD's Personalities
175	Meaning
176	Medication
177	Medicine
178	Memories
179	Mercy
180	Mindfulness
181	Misinterpretation
182	Misunderstandings
183	Money
184	Mourners
185	Non-English Speakers

186	"Normal"
187	Nuance
188	Opioids
189	Options
190	Other Agencies
191	Outreach
192	Pain
193	Pain Management
194	Palliative Care
195	Parents
196	Participating Providers
197	Patient Initiation
198	Client Directed
199	A Patient's Right to Choose
200	Peace
201	Personal
202	Pharmaceutical Companies
203	Philosophy of Life
204	Phone Consults
205	Physician Assisted Suicide
206	Physician Burnout
207	Physician Power
208	Places to Take Medication
209	Politics
210	Political
211	POLST (Physician Order of Life Sustaining Treatment)
212	Power
213	Precise
214	Prescribing Physician
215	Presence
216	Private
217	Privilege
218	Progressive Ideas
219	Profound
220	Publicity
221	Quality of Life
222	Race
223	Readiness
224	Reasons to Live
225	Reclaiming Control
226	Reconciliation
227	Red Tape
228	Regional Difference
229	Release / Releasing
230	Relief
231	Religion
232	Religious Barriers

233	Religious Beliefs
234	Religious Differences
235	Residency Requirements
236	Resources
237	Respect / Respectful
238	Responsibility
239	Restricted Access
240	Reunion
241	Rewarding
242	Rite of Passage
243	Sad / Sadness
244	Search for MD's
245	Seattle-Centric
246	Secrecy
247	Sedatives
248	Self-determination
249	Sense of Self
250	Shame
251	Sharing
252	Sickness
253	Social / Societal
254	Social Workers
255	Sorrow
256	Spirituality
257	Spiritual Distress
258	State Law
259	Stigma / Discrimination
260	Struggle
261	Suffering
262	Suicide
263	Support
264	Supporting Loved Ones
265	Support of MD's
266	Supportive helpers
267	Surrender (letting go)
268	Symptoms - Shortness of Breath - Pain - Cognitive Changes
269	Symptom Management
270	Taxing
271	Terminal Illness
272	Timeliness
273	Timing of The Law
274	Touching
275	Tranquility
276	Treatment
277	Treatment Refusal
278	Trust
279	Uncomfortable

280	Understanding
281	Values
282	Weird Relationships
283	White
284	Written Request
285	"Am I giving up?" failing / losing
286	"What does God think?"
287	What is natural?
288	Changing the Law?
289	Depression vs. Grief
290	Ethics vs. Law
291	Wellness vs. Health
292	"I am concerned about people who are excluded from the bedside of dying pts due to moral conflict"
293	"I am enchanted by the healing that happens to families at the bedside of dying pts."
294	"I love my patients who choose DWD - they impress me almost every time, and that makes the experience easier."
295	"I worry that there is a net negative impact in this new right for DWD"
296	"Realistically, some people are tired of illness & decline"
297	"We are not one person; we are a collective consciousness."
298	"Who am I to impose my values and moral dilemmas on others?"
299	Not My Choice - personal - role
300	"I've lived a good life, I'm done."
301	"I just want it to be over"
302	"Death is not the worst thing that can happen to a person"
303	"Dignity can be preserved with choice"
304	"Glad I can facilitate discussion"
305	"It takes time to empty capsules - make slurry ..."
306	"I want to make sure fears are also addressed"
307	"I want to make sure pain control is addressed"
308	"I would support a loved one"
309	"I would want the choice myself"
310	"Sometimes surprising to be asked"
311	"Takes time for families to understand, agree with"
312	"What must it feel like to know the day of your death"
313	Death is easier when people talk about it.
314	"I'm not sure if I'm asking the right question."
315	"I've never done this before."
316	"I want to do it right."
317	"My doctor won't participate."
318	You die the way you lived.
319	Need It Everywhere
320	Law Is Not Perfect But Is Generally Well Designed
321	Medication Costs Out of Reach for Some Patients
322	Process Can Be Frustrating for Some Patients

323	Need more MDs and RNs and SWs involved. Need more funding. Need more public awareness.
324	Public awareness greatly improved in about 3 years. Change noted when interacting about DwD with pts, dr. & publics
325	"Conflict with desire to nurture"
326	Dying in Exactly the Way One Chooses
327	Honoring Another's Wishes
328	Making Creative Choices until the End of Life
329	"Often not acted upon"
330	Starring into Void
331	Follow Up with Client's Family
332	Relief From Talking About Options
333	Outreach and Education to Medical Providers
334	Wanting to be with family
335	Unexpected Bodily Changes
336	Great Opportunity To Learn - for Volunteers
337	Lack of Information in Medical Field
338	Reluctance to Discuss Death
339	Responsiveness EOLWA extremely responsive
340	Evolved with people when don't know what circumstances will be found.
341	Help with life biggest problems - one of
342	Open minded liberal but something bias in liberal direction
343	Public distrust uncertainty fear of euthanasia
344	Public fears that end of life will be (___) about due to monetary reasons
345	Public fear that family will encourage DwD where it should not be used or that pt will use it when don't want to.

APPENDIX B. MEDICAL AID-IN-DYING TERMINOLOGY (FULL LIST)

	Term
1	"Against my religious beliefs"
2	Aid in Dying
3	Alert and Oriented x4
4	Assisted Death
5	Assisted Dying
6	Assisted Suicide
7	Attending Physician
8	Bought The Farm
9	"Can I get an injection to end my life?"
10	Choice
11	Choice at End of Life
12	Compassion & Choices
13	Compassion and Choice Law
14	Competent
15	Consulting Physician
16	Control of Death Process
17	Crossing Over
18	Death
19	Death by Opioids
20	Death inappropriate too early
21	The Death Medicine
22	Death Panel
23	Death Squads
24	Death with Dignity (DWD)
25	The Deep Sleep
26	Dementia
27	Dignity
28	"Die My Way"
29	"The Drugs To Off Me"
30	Doctor Assisted Dying
31	Doctor Assisted Suicide
32	End of Life
33	End of Life Choices
34	End of Life Options
35	End of Life Washington
36	Ending Life
37	Ending It All
38	Ending Pain
39	Euthanasia
40	Exit
41	Exploitation
42	Final Exit
43	Freeing One's Shackles
44	God's Will

45	Going against God and his will
46	Going for Another Life
47	Going to Next Level
48	Going Home
49	"Go Juice"
50	Good Death
51	Granny Death Panels
52	Hemlock Solution
53	Hastened Death
54	Hastening Death
55	Hastening Death Taking Own Life
56	Hastening
57	The Helium Method
58	"Help in the Dying Process"
59	"Help with Ending It"
60	"Help... to Avoid Suffering"
61	"How can anyone predict someone will die when?"
62	I1000
63	"Is there a way to prevent anymore suffering?"
64	"I wish our state had a law like Oregon"
65	"I wish there were a legal way to end my life"
66	"Just Taking a Pill and Going To Sleep"
67	"Kevorkian" / The "Kevorkian Thing" / That Kevorkian Thing / That Dr. Kevorkian Thing
68	"Kill myself / yourself / him/herself"
69	The "Little Black Pill"
70	Medical Suicide
71	Missing the suffering that should provide meaning
72	Moving On
73	Most loving act possible - wife supports husband
74	Murder
75	My Life My Choice
76	Palliative Sedation
77	Passed
78	Passing
79	Patient Autonomy
80	Patient Dignity
81	Patient-directed Death
82	Patient Directed Dying
83	Patient Freedom
84	Patient Suicide
85	Physician Aid-in-Dying
86	Physician Aided Death
87	Physician Aided Suicide
88	Physician Assisted Death
89	Physician Assisted Suicide (PAS)
90	Planned Death
91	Planned Suicide

92	"A pill to end my life"
93	Providers
94	Pushing Myself Over
95	Release
96	Relief
97	Right to Die
98	Self Administer
99	Self Murder
100	Sin
101	Slippery Slope
102	Soul Voyage
103	Stopping Treatment
104	Suicide
105	"That's All Folks"
106	Timed Death
107	Transition
108	Voluntary Stopping Eating and Drinking
109	"Weeding out those who are vulnerable"
110	"What's the difference between self administered and say, IV push if that's what 'I' want?"
111	"Why can't we follow through on someone's wishes i.e. - dementia, coma"

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