Honoring Choices®
MINNESOTA

Phase II Report • Citizens League

Prepared by the Citizens League for Honoring Choices Minnesota.

September, 2011

tpt
SAINT PAUL | MINNEAPOLIS

Citizens League
Common ground. Common good.

Twin Cities
Medical Society

Overview

In the spring and summer of 2011, the Citizens League set out to learn how people experience and think about planning for end-of-life decision making. This effort is part of the broader, more comprehensive Honoring Choices Minnesota initiative being led by the Twin Cities Medical Society. The overarching goal of the project is to help people prepare for end-of-life decision making, by bringing awareness to the nature of the decisions and choices involved, by encouraging and enriching Minnesotans' proactive efforts in this regard, and above all, by supporting the self-reflection and family conversations that form the foundation of all meaningful end-of-life planning.

In this period, the Citizens League conducted eleven focus groups with a total of 49 people from differing backgrounds and perspectives. The purpose of these sessions was to learn:

- From what perspectives do people approach end-of-life decision making? Medical? Religious? Legal? Financial? Crises?
- What motivates people to plan and to have family conversations about end-of-life choices?
  What kinds of questions and concerns do they have?
- What is the appetite and capacity for conversations about death and dying – conversations that are intrinsically intimate in nature?
- How can the medical community support more deliberative end-of-life decision making?

Given a general societal aversion to talking about death and dying, the Citizens League approached the focus groups primarily as story-telling sessions: what experiences are participants willing to share and discuss? A discussion guide was developed and used to provide general direction for each session, but the specific questions and discussions followed the arc of the conversation that emerged as participants shared their experiences and reflections. The discussion guide was built the Citizens League's findings in an earlier phase of this project. The first phase also utilized discussion groups, but roughly half of the participants were professionals who routinely work with dying people, including medical, religious and social work professionals. This allowed the Citizens League to gather a broad picture, from both lay and professional perspectives, about how death and dying is handled in Minnesota. In contrast, only a few of the 49 participants in the second phase had professional experience with end-of-life decision making. (The Phase II discussion guide is found in Appendix B.)

The sessions were taped by Twin Cities Public Television, and excerpts can be found at www.honoringchoices.org. The Citizens League also organized online engagement at www.citizing.org/projects/choices. This report and the quotes it contains draw from both the online and in-person conversations.

Many, many lessons emerged from the sessions. Below we highlight the seven findings we believe are of greatest importance to the success of Honoring Choices Minnesota. Given the project's goal of encouraging and supporting Minnesotans to have family conversations about end-of-life decision making, these seven findings provide a powerful and effective base for expanding and refining Honoring Choices Minnesota over time.

Finding one: There is tremendous power in the simple act of sharing stories about end-of-life experiences.

Finding two: Sharing stories led to “aha” moments in every session.

Finding three: Participants emphasized the value of family conversations as the most important aspect of end-of-life planning.

Finding four: The availability of the advance directive as a legal document has led many to believe they are better prepared than they are.

Finding five: Participants held a mix of views and experiences about doctors and the medical establishment, ranging from hostility and resentment to deference and gratitude.

Finding six: Religious teachings and leadership are an important source of guidance for end-of-life decision making, but a number of participants sought increased involvement by faith-based leaders in organizing conversations and helping people reflect about death and related end-of-life choices.

Finding seven: One of the most powerful motivators, if not the most powerful motivator, for a myriad of end-of-life decisions and planning choices is the desire to protect one’s family.

Finding one:

There is tremendous power in the simple act of sharing stories about end-of-life experiences.

There was a kind of magic to the sessions, grounded in profoundness about what it means to be human. Such a statement may sound corny and far-fetched for public policy, but that’s the point. Without exception, the sessions were emotional, thought-provoking and revelatory. As one participant put it, “These discussions are a great equalizer.” Indeed, they were marked by extraordinary sincerity. Yet somehow participants didn’t seem to feel especially exposed or vulnerable. Instead, they felt reassured, affirmed, and motivated to have more conversations.

Not all participants came intending to share their own experiences – some thought they would just observe – but any initial reluctance quickly gave way to extraordinary moments of sincere and thoughtful sharing. People listened to one another intently and drew comfort, wisdom and inspiration from each other’s stories.

Finding two:

Sharing stories led to “aha” moments in every session.

It would be hyperbole to suggest that the discussions were life changing for the participants. But without exception, there was a least one participant in every session who exclaimed, “Oh, now I realize that…”, “Wow, I’ll have to go home and…” or “I never thought about it that way.”

What was most interesting about these revelations was that (for the most part) the participants were fairly sophisticated about the subject of end-of-life planning. Most had advance directives and/or had named health care proxies. Many had experiences making medical decisions or providing care for loved ones. This finding suggests that even people with a knowledge or experience lack opportunities and/or impetus for the deeper reflection and family conversations that Honoring Choices Minnesota espouses.

Finding three: Participants emphasized the value of family conversations as the most important aspect of end-of-life planning.

As noted above, most participants who took part in the listening sessions were experienced and relatively knowledgeable about end-of-life decisions and planning. The more experienced they were, the more likely they were to stress that family conversations are *the* key to end-of-life planning. As one participant noted, “You don’t just sit down and do a directive. You have to think and talk about it over many months.” Some participants noted that these conversations helped them learn new things about their loved ones and/or brought them closer together.

> *“Without intimate conversation and putting my father’s wishes on paper, I would have struggled with decisions at the end of his life. It was a mutual gift – he gave me directions, and I honored his wishes. Don’t wait; start the conversation with your loved one and think about your own, too.”*

In the Phase I report, we noted that clearly expressed wishes could ease family stress and enable more peaceful deaths. Family dynamics have a powerful influence over medical choices, and participants in Phase II described how this includes differing interpretations of a written directive. Family conversations help family members understand and accept their loved one’s wishes. They also ease the burden on the person who is entrusted with making medical decisions, by lifting guilt or uncertainty. Indeed, being well prepared can lead to a beautiful experience.

> *“When my father died, I felt so honored to have been able to do everything he wanted.”*

> *“As ironic as it may seem, the last year of our marriage was the best year.”*

Finding four: The availability of the advance directive as a legal document has led many to believe they are better prepared than they are.

This finding serves as an important corollary to the previous finding: the legal form of the advance directive takes on far greater value when it is prepared and shared though family conversations. In the listening sessions, participants often made statements about their health care directives, and through the course of the session, came to wonder about the utility of what they had prepared.

> *“I prepared my directive with my lawyer, and when I took it to my doctor he said he wouldn’t honor it, because it didn’t make sense for my stage of life.”*

> Husband: *“I don’t have an advance care directive.”*
> Wife: *“Yes you do.”*

> *“My parents both had directives, but when it came time, they were surprised how little guidance it actually gave them.”*

> *“I don’t really remember what’s in it.”*

> *"I suppose I should fetch it from the lawyer's safe."*
>
> *"I haven't told my health care agent that I have appointed him."*
>
> *"I have a directive, but I really didn't know what kind of questions to ask myself."*
>
> *"I am my mom's health care agent, but we haven't discussed her directive and I don't know what she wants."*
>
> *"What? A health care agent can't make decisions that override the directive?"*

Despite some reservations, most (but not all) participants still felt that it is important to have an advance care directive. This was especially true for same sex couples, who stated that without legal marriage it is incumbent upon them to be very intentional about such matters.

"Next of kin works for most people. For us, it could be a worst-case scenario. Because the laws are set up for hetero lifestyles, we have to be much smarter. That's a reason that we've dived into this."

Participants raised a number of concerns and questions about advance care directives, including:

- Under what circumstances will it be honored, or not?
- Does the health care agent have the authority to override instructions in an advance care directive?
- Can I change my instructions?
- What if I'm in a situation that I didn't properly anticipate in my directive? Could it hinder decision making?
- There are so many variables and possible situations. How do you complete a directive in a way that is useful?
- What does it mean to no longer have the ability to know who I am? Isn't this subject to a lot of interpretation?

Additional questions can be found in Appendix C.

Finding five:

Participants held a mix of views and experiences about physicians and the medical establishment, ranging from hostility and resentment to deference and gratitude.

In general, participants were appreciative of physicians' responsibilities and the medical and legal environments in which they work. Many, if not most, felt well-served by the medical community. A few stated that they would rely heavily on their physician's advice for end-of-life decision making. At the other end of the spectrum, some had become deeply distrustful of the medical community's willingness to do anything other than intervene to save lives, no matter how painful or fruitless. Pain management was the most frequently cited medical concern.

Participants were sympathetic to the difficult position in which the medical community is placed at the end of a patient's life. They understood that if the patient or family's wishes are unclear, physicians must err on the side of providing every treatment option possible, and they understood the legal consequences physicians can face for not doing so. "We need to protect medical personnel from relatives who are not prepared to let go," said one woman.

Participants had many suggestions for the medical community.

They expressed concern that medical training doesn't prepare physicians to help people die – their entire culture is one of "saving lives" which may involve aggressive treatments despite the fact that patients are dying. The medical default is to provide all possible care options, even if it doesn't make sense. If the family is not prepared to make alternative choices, this default will prevail.

> *As a woman's elderly mother aged, the medical situation was pretty clear for the mother and daughter, but doctors weren't always on the same page. The daughter took her mother to the audiologist, who suggested a new hearing aid that would last for seven years. She said, "We don't need that. Mom won't be here in seven years." The doctor's response was, "Don't say that!" Another doctor wanted her mother to get a mammogram. Why? She was in poor health; even if the scan discovered cancer, they wouldn't have done anything about it. Conversations that get family in agreement about priorities and the kind of care they will pursue are needed in order to be able to make these kinds of choices.*

Moreover, doctors treating people at end of life often don't know the patients. Participants asked that physicians:

- Be straightforward with patients and family about what they're facing and what doctors expect to happen. Don't be too pushy, but share information and analysis with patients and families.

  > *One woman said that a gift in her father's care was that one of her close friends from high school was his nurse, so she was able to be a little more candid than the other medical personnel. She told the family, "He's having a lot of seizures. In my experience, that usually means there's very little brain activity." Because the nurse said that, the woman's mother requested a neurological exam. The results made the family's decision easier.*
  >
  > *Another participant, who was herself a nurse, once performed CPR on a woman in her 90s – not because the medical personnel thought it was a good idea, but because the woman did not have a DNR so they felt they had to. The physician said to her, "We're going to crack all her ribs and puncture her lungs because we don't have permission not to." Her response to the physician was, "Can't you say that to the family?"*

- Welcome and work with loved ones.

  > *One man told a story of his father who had a defective heart valve from childhood scarlet fever and had lived long beyond what the doctors had*

> *expected. Both of the man's parents were reluctant to talk about this. Indeed, his father's cardiologist was unaware of this heart condition. Because the son was participating in his father's care, he was able to give the cardiologist this information, which informed the doctor's decisions.*

- Don't just see and treat the disease; comprehend the whole person.

> *Some participants were quite critical of the medical community's unwillingness to deal with, or insensitivity to, patients' and families' emotional states or other dynamics that are not strictly medical. One woman told the story of her husband, who while being treated for cancer said in front of his oncologist, "This is really heavy on my emotions." The doctor acted as if he hadn't heard the comment. Medicine as currently practiced, participants said, fails to recognize all aspects of health.*

- Help release family members from the feeling that they must do it all.

> *One woman was caring for her husband who had Alzheimer's at an early age. One day his doctor told her: "It's time for your husband to go into residential care." At first, she didn't understand. She was caring for him, and – she thought – doing a pretty good job. But the doctor told her: "It's time for you to be his wife again, not his caregiver." The woman said: "That was hugely helpful. I hadn't thought of that."*
>
> *Another young woman told of caring for her mother, who was dying of cancer. For a period, she, her sister, and their families cared for her mother in her home. Both daughters had young children and other responsibilities, and the mother was very worried about being a burden. In response, the daughters shielded their mother from what they were doing – they hid a lot from her. Eventually, they moved their mother into a residential hospice home. There, they were told: "You need time to be daughters." This was a relief both to the women and to their mother.*
>
> *"She was really happy she could be my mom," the woman told us, "that she could tell me I didn't have to come and care for her. I was her daughter; I didn't have to ask if she needed to go to the bathroom or needed medication." For the mother, not having her daughters in charge of her medical care helped release the anxiety of being a burden. She was cared for, and her daughters only provided medical support if they could and if they wanted to.*

In both of these stories, the medical community supported families in ways that were not strictly medical – they released them of some of their perceived duties, letting them know that their loved one's physical needs would be taken care of and that they needed to be there as family.

- Understand that the average person sees things much differently from the medical profession and experiences the death of a loved one in the context of a life that may be turned upside down. The typical person sees their illness and death in terms of its impact on other aspects of their life – mourning, financial considerations, who gets the china, where their cousin will move to, etc. It is never simply a medical issue. A loved one's illness can have far-reaching repercussions in other areas of a persons life.

> *"My husband is dying right now and I have been making all the decisions alone with no support and 2 small kids to support. It got so bad I complained they were not turning him. The next day the cops came out and took my kids. The hospital complained about me, but all I needed was help getting home. Now I have to move all alone and get secure before they can come home. I want a DNR but his family is arguing with me. He doesn't want be a vegetable!*

Participants also described a medical system so complicated, with an increasing need for medical literacy, that one cannot negotiate it well on one's own. An advocate is needed. Although hospitals sometimes provide this service, it's not always sufficient. For example, one participant described a patient who was in excruciating continuous pain but was unable to access pain medication until a hospice worker interceded with doctors in her behalf.

People who have had such an advocate among their families or friends recognize how valuable it is.

> "The best thing in care is to have one point person, regardless of the disease state or the diagnosis; one person should be the point of contact for everything. This is the way that it is in customer service organizations and in other areas of business. There is no way for any layperson to know which specialist deals with which area or who they should call if they are having trouble with pain, or drug management, or a new problem, who they should call. If hospitals want to evolve, they should have each patient have one case manager, and each case manager should have no more than 10-20 'cases' per month. If one patient/case dies, another should be added."

Finding six:

Religious teachings and leadership are an important source of guidance for end-of-life decision making, but a number of participants sought greater faith-based leadership in organizing conversations and helping people reflect about death and related end-of-life choices.

People search for a framework within which to make end-of-life decisions. For some, this framework is their faith. Adath Jeshurun Congregation, for example, has developed practices, teachings and rituals that make the process of death and dying a responsibility of the broader faith community. Participants expressed how much wisdom this type of experience builds in faith communities:

Our families and broader church [congregation] communities are repositories of wisdom about how we care for each other. We have countless stories of people caring and dying well (or not well). We need to start sharing that wisdom. Eliciting that discussion is the role of a pastor, but even before we get to ethics and church teachings, that's what needs to be brought forward.

A few participants sought greater clarification from religious leaders about the types of end-of-life choices that are permitted by their faith. The more common desire, however, was for greater leadership in organizing and supporting conversation about death and dying. As one religious leader said, “As religious people, if we’re not preparing people for death, what are we doing?”

Finding seven:

One of the most powerful motivators, if not the most powerful motivator, for a myriad of end-of-life decisions and planning choices is the desire to protect one’s family.

This finding was also a finding from Phase I discussions, but it’s worth repeating because it is perhaps the foundational element for motivating families to discuss their wishes with one another.

Over and over in these conversations, people told stories in which decisions were driven by the desire to protect loved ones. This most human urge plays out in all sorts of ways – the mother who continued treatment even though she didn’t want it because her son wasn’t ready to let her go; the wife who doesn’t talk about death because she doesn’t want to agitate her husband; the father who tells no one of his condition because he doesn’t want his family to worry; the daughter who fights doctors to secure pain medication for her mother.

This was captured beautifully by two different stories from the discussion groups.

> *A man’s mother was diagnosed with a fatal condition. She lived in a small town in North Dakota, and while visiting her, he learned that she wanted to die at home. However, she was unable (emotionally) to have this conversation with her husband, despite the fact that he would ultimately make medical decisions on her behalf. An acute episode occurred and the doctor first recommended a transfer to a local facility and then to a hospital many miles distant. The son knew that this was not what his mother wanted, but his father did not. Although the son discussed the decision with his father, he deferred respectfully to his father’s decision to transfer his mother to the hospital. She died there; neither the son nor the father was with her when she died.*
>
> *During a separate conversation, one participant, a young mother, started tearing up. She has two young children and parents in good health. She has never been in situations requiring life or death medical decisions. Her emotions were simply her response to the stories of others in the group who have dealt with the death of a loved one. “Oh, I’m crying and I’ve never even had anyone die,” she said. She had been named her mother’s health care agent. The stories of others helped her realize the nature of this responsibility – the immense honor, the profoundness of the trust being placed in her, and the awesomeness of making life and death decisions for a loved one. She left the discussion determined to talk to her mother to better understand the choices she may someday have to make.*

As the stories show, respect and concern for loved ones can motivate people in different ways. Some people plan for end-of-life decisions because they want to honor their loved ones. Others refrain from discussions out of respect. Many other motivations that spring from the desire to protect family were described – those that compel planning and conversations, and those that act as barriers to planning and conversations.

Planning was often triggered by a family event – perhaps the birth of a child or the diagnosis of a parent's illness. Participants gave reasons for planning such as the desire to keep loved ones from difficult decisions, guilt over those decisions, or family dissension. The conversation is seen as a gift to those who may care for you, or make medical decisions for you some day.

On the other hand, we fear talking about death because we hate to confront the fact that we'll lose people we love. We don't want to raise the possibility of death with a loved one who's dying. One person said, "My only regret is that I didn't ask my (dying) husband if he was afraid."

Finally, there was a solid subset of participants who were motivated by a much larger vision of "protection" – that is, they felt a responsibility not to unnecessarily consume resources. A number of participants talked about the high cost of end-of-life medical treatment. They expressed concern that as a society, we cannot afford expensive questionable treatments for dying patients. Their personal sense of duty includes foregoing such treatments for themselves so they do not pose an added financial burden on society.

Implications for future efforts

This modest foray into end-of-life conversations – ten discussion groups and limited online conversations – underscored the enormous potential of Honoring Choices Minnesota. Ironically, the very thing that keeps people from sharing their stories – that is, death being such an intensely personal issue – is the same thing that makes the stories so ultimately sharable: people who have experiences with death seek meaning, and this meaning can be gleaned from other people's stories.[1] More than a few participants joined the discussion group because they had recently experienced a death or have a life-threatening health situation. We learned that once people share their experiences with others, their eagerness for further conversations and self-reflection grows.

Moreover, people found motivation to become socially active about end-of-life decision making. We made contacts with dozens of active citizens who are interested in contributing to social change around this topic, having already volunteered their time and shared their very personal experiences. They form a potentially strong base from which to engage communities, promote family conversations, and develop tools that support family conversations.

Based on what we learned from the discussions, we believe the following types of efforts could be very effective in advancing the Honoring Choices Minnesota project goals.

Use "trigger points" – diagnoses, medical examinations, births or deaths in the family – to introduce information or opportunities to think about and/or plan for end-of-life decision making.

Many participants said that their interest in the conversations sprang from a life event or situation, such as an illness, the birth of a child, or the death of a parent. In such moments, people become more reflective, and appear to be especially open to thinking about end-of-life planning. In other cases, the event is a powerful eye-

---

[1] Research shows that "narrative learning" is quite powerful, because it is a primary way to satisfy people's search for context and meaning. See for example…

opener. When asked whether it's possible to imagine what it's like to make end-of-life medical decisions in crisis situations, an entire group of panelists emphatically shook their head "NO!" In our society we try not to think about death, much less plan for it. Naturally occurring but momentous events provide powerful opportunities to engage people in thinking about end-of-life planning. This could be done as unobtrusively as providing a small booklet of stories – much like those we heard during our conversations.

The nature of the trigger events varies somewhat with age. The most common trigger event, regardless of age, seems to be a death or serious illness in the family. Yet, the experiences of younger adults don't necessarily translate to planning for themselves; more likely it encourages them to think of other elderly relatives. More elderly people plan for themselves as part of an overall package of preparation, including wills and estate planning. As a result, this planning tends to more be legalistic. See further discussion of this below.

Encourage places of worship and other communities to organize end-of-life conversations.

The people who participated in our workshops were brave, highly motivated for personal, professional or social reasons and/or responded to a personal request to participate. If Honoring Choices is to succeed on a wide scale, the fear or stigma associated with talking about death must be removed. The best way to do this is to organize the conversations in places that people naturally associate with, who are trusted, and have credibility on this issue. As one participant put it: "How the information is presented is as important as what the information is. Community gatherings where people can share with one another are very valuable – not being lectured to but being able to share with others. Cool media (internet, TV) also don't work as well; you need the warmth of conversation."

Places of worship are a natural fit. People look to their faith and religious leaders to help them make meaning from difficult life challenges. Other possibilities might include certain civic organizations, social service agencies, community groups, or even book clubs. The point is to locate the opportunity for conversations in a comfortable environment where people feel at ease and there is ample opportunity for sharing and reflection.

Websites can perform an effective outreach function—especially one that provides an accessible format (e.g., blog) to help people think about the issues and find information.

Matters of death and dying are highly personal, but we experimented with online discussion and information to get a feel for whether online interaction would be effective. Two sites were launched; one by the Citizens League featuring discussion and information and another by Twin Cities Public Television featuring videos clips from the discussion sessions. Regarding the Citizens League website, over slightly less than four months, there were approximately:

- 750 visits,
- 370 unique visitors,
- 52 project members (who signed up with name and personal information),
- 510 visits to the blog, and
- 170 visits to the library (which housed resources and factual information).

This is not a great deal of people. Yet the level of activity surprised us in a good way because the website was not well publicized and the initial phase of most websites are typically very slow on the takeup. It is also interesting that the blog was the most visited feature: two-thirds of the visits included visits to the blog. Finally, the Citizens League originally planned to include film clips from the discussion groups on its website. This more dynamic content was plaved on the TPT website instead. Usage of TPT's website also shows that websites can be an effective outreach vehicle. From July 26th to August 25, this website had:

- 1,399 visits,
- 938 unique visitors, and
- 3.48 page views per visit.

Provide attorneys with simple materials that can encourage their clients to think beyond the legal questions, to contemplate the more humanistic questions with their loved ones.

To the extent that advance care directives have become more common, it is largely as a legal document. As described above, this has backfired in the sense that people see it more as a perfunctory, legal device rather than the contemplative document with the power to unite loved ones in challenging times and ensure that people end their lives consistent with the narrative in which they lived it. It is also fair to say that many directives are being completed without a full understanding of its implications.

Attorneys could encourage their clients to consider the directive more broadly if they had some simple materials to distribute. Three sets of information would be invaluable: (1) some basic legal questions answered (although people are consulting their attorneys there seems to be a significant amount of misunderstanding about some of the basic ways that advance care directives work), (2) some basic medical facts about common end-of-life procedures, and most importantly (3) stories. Stories help people reflect in ways that factual information cannot.

Provide basic facts that improve people's medical literacy – for example, about the likelihood of an elderly frail person surviving CPR and under what conditions.

A simple fact sheet (which should be tested with a variety of people) could be distributed through any of the means discussed above.

How group conversations are facilitated is important, but it's not a technical matter; rather it's a question of making people feel at ease and willing to share.

The Citizens League held the discussion groups to learn about how people think about and prepare for end-of-life decision making. We found out that people learn: (1) through experience and (2) by sharing those experiences and listening to others' experiences. Therefore, the goal of any discussion session should be first and foremost to get people to share their own stories. While the Citizens League prepared and used a discussion guide, we allowed the stories that participants shared to be the real guide.

People often think they "don't know anything" or have nothing to contribute. But nearly everyone has some experience with death, even very young children. One young mother told the story of her five-year old son, who accompanied her on visits to the nursing home to see her dying mother. People asked her, “Why are you bringing your son along? Don’t you think it’s too much for him?” She replied, “He’ll tell me when it is.” One day upon leaving the nursing home, she asked her son, “Would you like to kiss your grandmother goodbye?” “No” he replied, “Too scary.”

Participants are so in interested in one another’s stories that the facilitator’s main job is to help these stories flower. Once people start sharing their experiences, the questions, concerns, fears and triumphs come tumbling out. Beginning with a simple question such as “Have any of you had to make end-of-life medical decisions or care for someone who was dying?” will elicit a number of responses. From there, the facilitator should listen intently, not be afraid to probe in a way that causes people to reflect a bit, and suspend all judgment.

Appendix A: Methodology

The Citizens League conducted ten focus groups with a total of 49 people from differing backgrounds and perspectives. The purpose of these sessions was to learn:

- From what perspectives do people approach end-of-life decision making? Medical? Religious? Legal? Financial? Crises?
- What motivates people to plan and to have family conversations about end-of-life choices?
- What kinds of questions and concerns do they have?
- What is the appetite and capacity for conversations about death and dying – conversations that are intrinsically intimate in nature?
- How can the medical community support more deliberative end-of-life decision making?

Approach

The Citizens League approached the focus groups primarily as story-telling sessions: what experiences are participants willing to share and discuss? We wanted to know this for two reasons: 1) to better understand how Minnesotans approach end of life decision making; and 2) to test people's willingness to share their stories. Brain research and adult learning theory are beginning to show the importance of narrative, and story-telling more specifically, in learning. For example, Clark (2008) states "The stories of significant transitions throughout life, such as landing a first job, losing a parent, coping with major illness, or retiring from a career, when considered collectively express the meaning one makes of developmental growth throughout one's life…In narrative learning theory, we argue that there is an even closer connection between learners and experience. The nature of experience is always prelinguistic; it is "languaged"after the fact, and the process of narrating it is how learners give meaning to experience."

Focus Group Structure and Process

Focus groups were kept small (four to eight participants) to ensure that each participant had ample opportunity to contribute to the discussion. A discussion guide (Appendix B) was developed and used to provide general direction for each session, but the specific questions and discussions followed the arc of the conversation that emerged as participants shared their experiences and reflections. The focus groups were facilitated by a professional facilitator and discussion sessions lasted 1 ½ to 2 hours. At least one observer took notes each session, in addition to the taping of the session by TPT.

Participant Selection

With the Twin Cities Medical Society, the Citizens League determined the number of focus groups (eleven) and the diversity that would be sought among participants to ensure representation by different cultures and faiths. The Twin Cities Medical Society took responsibility for convening some of the racial/ethnic groups; those are not reported here. The Citizens League convened the following groups: Catholic, Jewish; GLBT; under 40; mainline Protestant; African American; and 5 mixed groups. The demographic-specific groups were convened by identifying an organizer from within the group who then recruited additional participants. Participants in the non-specific groups responded to a general call for participants in pre-scheduled sessions. These participants were recruited via the Citizens League website, newsletter and online discussion forum "CitiZing." Participants were not compensated in any manner.

While some participants were personally recruited, most participants were self-selected. Self-selection bias was presumably offset by the mix of perspectives across groups. However, it not possible to know how people who have no interest in participating might have responded.

Review of Draft Findings

Participants in and observers of the focus groups were allowed to review and comment on the draft findings. This was done to ensure that the findings accurately represented the discussions and the intent of the discussions. Commenters asked for a few clarifications and additions, but suggested no changes to the main body of findings presented here.

Validity of Findings

The validity of the findings is generally commensurate with that of most qualitative research. Even though participants were self-selected, collectively they represented a variety of perspectives. The findings presented in this report are based on themes repeated across the various focus groups. As the meetings progressed, the themes became clear, that is, despite the different backgrounds and experiences of participants, the themes from their stories were similar from focus group to focus group. The findings converged over time—a feature of qualitative research.

Another way to judge the validity of the findings is the extent to which they hold up against academic research. For example, findings one and two about the sharing of stories as a learning experience is backed up by a host of published writing, including Clark (2008), mentioned above. Finding five, which spoke to the reluctance of doctors to allow patients to die, is supported by Drough and Koenig (2002) . Finding seven, protecting one's family from burdens, is consistent with the research reported in Moorman (2011).

Sources

Clark, M.C., and Rossiter, M. (2008). "Narrative learning in adulthood." New Directions for Adult and Continuing Education, 119.

Drought, T and Koenig, B. (2002). "'Choice' in End-of-Life Decision Making: Researching Fact or Fiction?" The Gerontologist, Vol. 22, Special Issue III.

Moorman SM. (2011). "Older adults' preferences for independent or delegated end-of-life medical decision making." Journal of Aging Health, (23)1.

Appendix B: Discussion Guide

Introduction (5 minutes)

Facilitator: Today we're going to talk about your experiences or viewpoints on end-of-life planning. First we'll do introductions. Next, we'd really like to hear your stories about your experiences.

We are doing this work on behalf of the Twin Cities Medical Society, which is conducting a multi-year project called Honoring Choices. The goal of the project is to help people's end-of-life is consistent with their wishes. End-of-life planning in a key part of making this happen, and our conversations today will help improve how end-of-life planning is done.

If taped: TPT is taping this and may use segments from this conversation on their website or in a series of three programs they are producing for the Twin Cities Medical Society on this topic.

Do you have questions about why we're here today or how the information will be used?

Group Introductions (5 minutes)

Please tell us your name and why you were interested in being here today.

Stories (30-45 minutes)

1. Have any of you been involved in caring for someone who is dying or making medical choices on their behalf? What were your experiences? (Is there anything you wish doctors had done differently?)
2. Have any of you expressed your own wishes for end-of-life care, either in conversation or more formally through an advance care directive? What was this experience like for you? Do you feel confident that your wishes will be followed?

Health Care Decision Discussion

Now we're going to talk about the types of decisions you may need to make in a medical situation.

1. **General understanding.** Have you had conversations with loved ones about the types of end-of-life choices you or they would want? Do you have a health care directive? Why or why not? What have you heard about them? What are your concerns about them?
2. **Health care agent.** In Minnesota, there is no "presumed" agent if one is not specified. Who gets to make the decisions is the biggest reason for end-of-life cases that go to court.
    - α. Do you have a designated agent? Does that person know?
    - β. How did you decide who it should be?
    - χ. Were there sensitive family issues to consider? How did you handle them?
3. **Medical treatments.** Generally speaking, the status quo is that all treatment will be given unless there is an agent or directive specifying not to give treatment.
    - α. How would you describe the circumstances, if any, in which you would not want treatment?
4. **Decision-making process.**
    - α. What would encourage you to either talk with loved ones about your end-of-life wishes?
    - β. Who would you talk to? What sorts of things would you want to talk about?
    - χ. How did/would you go about making the decisions for end-of-life choices and/or an advance care directive? Is there professional help you would want? Of what type and from whom?
    - δ. What role, if any, does faith play in your decision making?

Appendix C: Frequently Asked Questions

Questions we heard frequently in in-person and online conversations include:

- If more than one agent is named in an advance care directive, whom does the law recognize? How are conflicts between agents resolved? What if all agents cannot be reached; can that delay treatment?
- Do doctors really pay attention to written advance care directives or just listen to the family? Under what circumstances will directives be honored or not honored?
- What if a family member disagrees with the decision of the appointed agent?
- Is an advance care directives an obligation or a guide for the agent?
- Will EMTs honor a do not resuscitate order or other instructions from an advance care directive in emergency situations?
- Who makes the decisions if no agent has been appointed and a person is unable to make or communicate his or her own decisions?
- What happens if an appointed agent disagrees with a written directive?
- Does the health care agent have the authority to override instructions in an advance care directive?
- Can I change my instructions?
- What if I'm in a situation that I didn't properly anticipate in my directive? Could it hinder decision making?
- There are so many variables and possible situations. How do you complete a directive in a way that is useful?
- What does it mean to no longer have the ability to know who I am? Isn't this subject to a lot of interpretation?