Factors Affecting Long-Term-Care Residents' Decision-Making Processes as They Formulate Advance Directives

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Purpose: The purpose of this study was to describe factors contributing to the decision-making processes of elderly persons as they formulate advance directives in long-term care. **Design and Methods:** This study was qualitative, based on grounded theory. Recruitment was purposive and continued until saturation was reached. Nine residents of a long-term-care facility were interviewed by use of a semistructured format. Open and axial coding of interview transcripts were carried out and the factors contributing to the decision process were defined. **Results:** Elders based their decisions primarily on information gathered from personal experiences with death and illness. They obtained very little information from professionals or the media. Major factors considered by elders as they weighed information included spiritual, emotional, and social considerations. **Implications:** The factors considered during the decision-making process were oriented more toward the individual's experiences and less on contributions from objective sources than anticipated. Decision making for advance directives is a highly personalized process. The approach of health professionals when assisting with end-of-life decision making should be planned with these contributing factors in mind, so that the services offered to the individuals in this population best meet their needs.

Key Words: End of life, Advance care planning, Theoretical model, Grounded theory

Treating older residents with dignity and allowing them the opportunity for autonomous decisions is an essential part of quality medical care (Singer & MacDonald, 1998). This can be especially important if the individuals reside in a long-term-care facility, where many of the small decisions one takes for granted when living in the community are no longer possible. Participating in major medical decisions allows individuals control over their own health and survival (Cantor & Pearlman, 2003).

Advance directives are completed to document preferences for potentially life-saving medical treatment in case a person is rendered incapable of expressing his or her wishes in the face of catastrophic illness (Rocker & Dunbar, 2000). A lack of clear advance planning for health care may lead to conflict between physicians, patients, and family members; application of interventions that the patient would not have desired; or withdrawal of interventions that would have met patient wishes (Breen, Abernathy, Abbott, & Tulsky, 2001; Chambers, Diamond, Perkel, & Lasch, 1994). The ease with which advance directives can be completed in community and primary care settings (Betz Brown, Beck, Boles, & Barrett, 1999; Molloy, Guyatt, et al., 2000; Molloy, Russo, Pedlar, & Bedard, 2000) and their role in providing quality care (Singer, Martin, & Kelner, 1999) are well documented. Nevertheless, advance directives are seriously underutilized, particularly in long-term care; it is estimated that more than 50% of people entering nursing facilities do not have formal or informal directives in place at the time of admission (Porock, Oliver, Zweig, Rantz, & Petroski, 2003).

Efforts have been made to develop theoretical models of the decision-making process in health

care. The purpose of such theoretical models is to guide health care service delivery. Decision-making models seek to sensitize the user to the patient's decision process, in order to aid in planning intervention strategies and to assist in the development of policies and procedures that are responsive to patients' needs. Charles and associates (C. Charles, Gafni, & Whelan, 1999) defined the stages of decision making as information exchange, deliberation, and decision. This model was adopted and expanded by Heyland, Tranmer, and Feldman-Stewart (2000) in their discussion of decision making by dialysis patients. The physician imparts clinical information regarding the choices for the decision and the patient's medical condition in the information exchange stage. During the deliberation stage, the patient and physician take part in a discourse, weighing and evaluating options for treatment. In the decision stage, the decision is made and formalized. According to this model, the individual's satisfaction with the decision is determined by the thoroughness of the preceding stages. The Charles–Heyland model is primarily theoretically based and has not undergone testing to determine its applicability beyond acute and intensive care. The factors involved, particularly the information exchange and deliberation stages, have not been well described. Nevertheless, this model is probably the most thoroughly developed decision-making model for health care. Other models of decision making, including one specific to long-term care (Cantor & Pearlman, 2003), a consumer-oriented model (The Change Foundation, 2001), and one based on traditional decision theory (McCluskey, 2003), have similar weaknesses. These existing models fall short in their ability to describe the decision-making processes of elders in long-term care, particularly with reference to advance directives. Therefore, a greater understanding of factors that influence the decision-making process is required.

Goal

The goal of this study was to document the factors contributing to the decision-making process of competent elders as they formulate advance directives in a long-term-care facility.

Methods

Design

This study was qualitative, developed in the grounded theory tradition (Strauss & Corbin, 1998). The aim of grounded theory is to inductively develop theory through the examination of data gathered from participants experiencing the process of interest (Strauss & Corbin). Theories are often expanded or confirmed in subsequent studies. For this study, we selected the Charles–Heyland model as a guide, as it was most closely related to the current research in its emphasis on the intellectual and emotional factors contributing to decision making, and it had proved robust within a different population. Furthermore, the Cantor–Pearlman model, which is most closely related to the population in question, was not published until the termination of the study.

Key informant interviews generated data regarding end-of-life decision making by a group of competent elderly residents of a long-term-care center.

Participants

All residents were recruited from a semiprivately funded, not-for-profit nursing facility in Kingston, Ontario, Canada. A nurse introduced each resident to the study and requested his or her permission to be referred to the principal investigator (H. Lambert), who then obtained consent. Inclusion criteria were (a) being competent to give informed consent, (b) having the ability to cooperate with the interview process, (c) experiencing no or mild cognitive impairment, and (d) having made an advance directive within the past 12 months. We judged competence to give consent to be adequate if the resident regularly made his or her own medical decisions. When introducing the resident to the study, the nurse assessed that the resident was able to understand goals and the nature of participation that was expected. The principal investigator was prepared to administer the Mini-Mental State Examination if there was a question regarding the resident's competence; this was not required for any of the participants. The nurse also was asked to estimate each resident's ability to participate in an in-depth interview requiring some introspection. Nurses depended on their experience with the residents to make this judgment; no participants had difficulty with the interviews, although there was variability in the expressiveness of the residents as would be expected in any sample.

Recruitment was purposive: We asked nurses to refer residents of both genders to represent a variety of ages, faiths, social backgrounds, health states, and care decisions. Once four residents had been recruited, we asked nurses to identify residents meeting specific criteria that had not yet been seen in the sample, most notably certain ages (under 85), religions (nonpracticing Catholic, atheist, and Protestant), and gender (male). Recruitment continued until the point of saturation, which is judged to occur when the information coming from new interviewees contributes no additional information to the model (Strauss & Corbin, 1998). We determined a priori that saturation would be met when all information from the interviews of the last two

residents fit into the codes developed in the analysis of previous interviewees.

The study was reviewed by ethics boards at the long-term-care facility and at Queen's University. There were 9 residents were referred to the study; all gave written informed consent to participate. The 7 women and 2 men were between 72 and 100 years of age. All were Caucasian; 7 were Catholic and 2 were from Protestant backgrounds. All had one or more chronic illnesses resulting in limitations in activities in daily living that were serious enough to require nursing care. One resident had mild dementia, characterized by occasional memory lapses for names and recent events. However, he was able to give consent and participate in the interviews without difficulty.

Data Collection and Analysis

We interviewed residents once or twice for a maximum total of 3 hr. Interviews were 1 hr in length on average (range 30–90 min). We developed a semistructured interview schedule (see the Appendix). We used the Charles–Heyland model of decision making as a guide because of its aforementioned applicability. Planned areas of questioning were related to (a) where residents obtained information about end-of-life decisions, (b) considerations in making the decision, and (c) how the decision itself was made. The purpose of a semistructured interview schedule is to provide the interviewer with a guide for obtaining information. However, there may be deviation from the guide, according to the information obtained and the quality of the interaction with the interviewee (Strauss & Corbin, 1998). Unscripted questions may be used to elicit more detailed information or to redirect residents to topics of interest. The interview schedule presented here serves as an example; the exact wording of the questions and the order of presentation differed among residents.

We audiotaped and transcribed the interviews. One resident declined taping, and one recording was lost as a result of a mechanical failure. We used field notes in the analysis for these cases. For the resident whose interview was lost, we verified the notes in the next interview, which was recorded. The resident who refused to be recorded was supplied with transcripts and invited to correct them until they were a fair representation of her statements. In those cases in which interviews had been recorded and there was a discrepancy between the transcript and the field notes, the transcript took precedence.

We used Strauss' constant comparative method of analysis (Strauss & Corbin, 1998). Analysis continued throughout the data-collection process. We initially open-coded the data line by line; that is, we broke down the interviewees' comments into precise concepts. We created more than 200 loosely
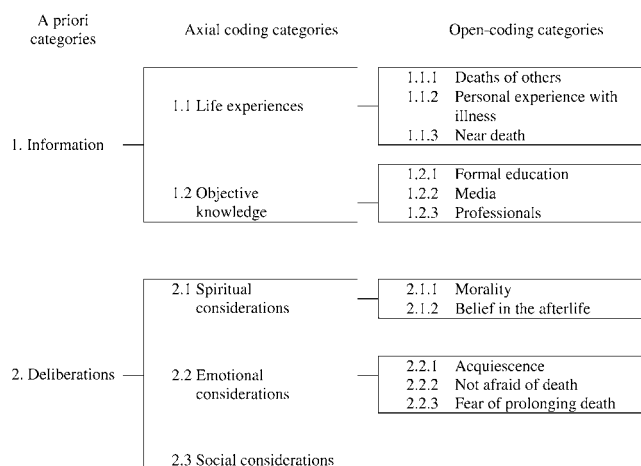

Figure 1. Coding diagram.

worded codes, and then we refined them into the 12 rightmost categories in the coding diagram (Figure 1). Next, we used axial coding to group these into broader conceptual categories, according to the common features between the concepts, creating the 5 axial categories found in the center column of Figure 1. We then explored relationships between categories by comparing them with each other and with the literature. We found that the axial categories fit into the classification and definition of information exchange and deliberation provided by the Charles–Heyland model, so we retained this categorization.

We carried out all data analyses with the assistance of the NVivo (version 1.0) software package, which is a qualitative analysis and data-management package that facilitates the creation, combination, linking, and retrieval of text within coding categories. The coding diagram is found in the Figure 1.

We used several methods to verify the trustworthiness of the analysis. We reviewed the coding process as it progressed. We verified observations regarding the emerging results with the interviewees for accuracy, and we compared them on an ongoing basis with the Charles–Heyland model.

Results

The factors influencing the formulation of advance directives fell into two broad categories: sources of information and gathered facts, and ideas and emotions that influenced the weighing of information during the decision-making process.

Information

The broad category of information concerned where and how the residents obtained information about end of life, advance directives, and death. The

information used in making the decision came from two sources: life experiences and objective knowledge. These factors were associated with the Charles–Heyland information exchange stage of decision making.

Life Experiences

The effect of life experiences on one's feelings about death centered on two types of experience—the deaths of others and one's own experience with illness, including near-death experiences.

Deaths of others.—One of the most universal and influential events in the lives of the residents was the death of a family member or close friend. This influence was attributed to grief, and by facts about end-of-life decisions and death learned from the experience. In many cases, the situation of the loved one was not comparable with the resident's current situation. Nevertheless, many residents applied the experience of the deceased as if it were identical to their own situation. The opinions generated by these experiences were so strong that they were not overridden by factual information about the residents' own health.

This group of elders has the unique generational characteristic of having memories of both world wars, and 3 of the participants were veterans. Witnessing the deaths of others in this context imbued a sense of futility about resuscitation in our sample. There also appeared to be an inability or unwillingness of the participants to accept the differences between their own current situation (living in a facility with health professionals on hand, where life-saving techniques could be applied) and the wartime situation (where mortal wounds could be inflicted without warning, and advanced life support was not available). One male veteran said, "I don't want nothing. I was overseas. We didn't have a chance to have CPR."

Personal Experience With Illness.—Most residents considered themselves to be in good health. This was associated with acceptance of noninvasive or minor interventions such as antibiotics, transfer to hospital, and intravenous medication and hydration. However, there appeared to be no relationship between the perception of one's health and choosing to receive invasive interventions such as tube feeding, ventilation, and CPR. Some residents had recently come close to death as a result of infection, heart ailments, or stroke. This reportedly had little effect on these residents' thoughts about end-of-life care. They did not feel that they needed to reconsider their decision in light of the deterioration in their health. One said, "at that point it could have gone either way. You know, I didn't know if I'd requested CPR or what. . . . At the hospital there I came and faced

the hole. There's no such thing as talking about it then."

Objective Knowledge

We coded any discussion of information gathered from authoritative sources as objective knowledge. This information is less subject to influence by emotions than the information gathered from personal experiences.

Formal Education.—Three residents had formal health care training. This education, even if outdated, appeared to take precedence over information that was given by the physician at the time of the decision. It did not make the residents any more or less likely to select or reject treatments, and it did not appear to help the residents clarify any misunderstandings about medical procedures when they were compared with individuals without such training.

Media.—Despite the prevalence of scenes of medical care, life-saving interventions, and death on television, most residents did not refer to these as sources of information in their decision making. Even when a resident remembered such information, it was discounted. One resident said of television medical dramas: "Well, it looks interesting, but it doesn't really happen that way."

Professionals.—According to the procedures in place at the facility, information was given to each resident regarding the nature of the intervention on which he or she was expected to render a decision. However, residents stated that professionals did not provide them with any details regarding treatments or their conditions. Statements reflecting a lack of information were asked of the interviewer by many of the residents:

> [about treatment in general]: "I don't know all of the extreme measures you can take nowadays. . ."
> [about CPR]: "Well, they press on your chest and I don't know too much about it. . ."
> [about tube feeding]: "What is it where they take the food away and they starve or something? What is that?"

The repetitious questions and the apparent misunderstandings suggest that the information presented by professionals is not being retained or is not understood. Whatever the reason, the residents are evidently not depending on information from professionals to make their decisions.

Deliberations

Residents also referred to a number of factors that corresponded to the deliberation stage of the Charles–Heyland decision-making process. These

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factors were used to determine the relative importance of the information gathered in the previous stage. They reflect intangible, value-laden concepts that residents use to bring meaning to the events of their lives.

Spiritual Considerations

All of the residents spoke of their spiritual beliefs as important factors as they were considering the care they would want to receive at the end of life. Most spoke of involvement in an organized Christian religion, either presently or in the past. Some also spoke of having developed nontraditional beliefs. Regardless of what the resident's current spiritual beliefs were, these thoughts were a source of comfort.

Morality.—Residents with strong religious beliefs felt their faith provided them with a definitive moral code to follow. Those who were no longer following their religious upbringing relied more on dispassionate reasoning, often still reflecting Judeo-Christian values about the common good. It was not possible for us to predict what residents' choices for end-of-life care would be from their moral base. Rather, their own interpretation of community duty, fairness, and faith dictated how they would weigh the information they had gathered.

Belief in the Afterlife.—The majority of respondents believed that there was "something" beyond death. Most were unable to indicate what they imagined this afterlife would be like, although they looked toward it as a positive experience. Among those with strong religious beliefs, most thought there was a heaven. Others did not believe in a spiritual afterlife; they believed either in reincarnation or in the end of subjective experience. Regardless of belief, none of the respondents appeared to be afraid of death, and most reported being accepting of whatever awaited them. The feeling that death would be a release from the travails of earthly life was a common one, and, in general, residents looked forward to some aspect of their current existence—pain, the task of existing, or awareness of deteriorating health—ending. Sentiments such as these weighted residents' deliberations toward rejecting medical intervention at the end of life. In the words of a Catholic resident, "When you're going to go, you want to be ready. Nobody wants to end up in Hell, that's for sure."

Emotional Considerations

Emotions brought forth on the approaching end of life reflected lessons learned from the events of a lifetime. All of these categories were closely related and had a strong influence on decisions for care.

Acquiescence.—Some residents spoke about having led a "good" or "full" life, or a sense of completion. Many residents also spoke about the changes in their thinking as they aged. Their ability to accept death, their level of devotion to a religion or faith, a desire to rejoin loved ones, and the wisdom they gained through their experiences were common thoughts. Generally, statements of this kind were associated with refusal of life-saving interventions.

Another common perception was that the world had changed beyond the resident's ability to cope. These thoughts were best expressed by a 100-year-old female resident, who said this: "I've lived too long. I've seen too many faces, and I've been through the world wars, and it makes quite a difference. I've lived too long and I don't like what I see now."

The sense of having seen or done enough increased a resident's willingness to reject potentially life-saving treatments and was generally associated with feelings of satisfaction.

Not Afraid of Death.—Residents made statements regarding what they expected death to be like, and how they would prefer to die. Most residents stated that they did not dwell on thoughts of death and that this was not a topic of immediate importance to them.

All residents openly talked about the inevitability and unpredictability of death. Most residents stated that they were not afraid of death, and some stated that they looked forward to it. One man said this:

> If I'm dead, I'm not going to suffer. It's like when you're having an operation and they put you under so you won't feel it when they're chopping you up . . . so when you die, you're not going to feel anything. . . . There's no pain, no suffering, there's no regrets. I'm like most people, I have my regrets, I think we all do at this stage, but when we die there's none of that.

Fear of Prolonging Death.—All of the residents expressed concern that some treatments would merely prolong an inevitable death. These expressions were independent of whether or not a resident agreed to receive life-saving treatment. This appeared to represent a "prevailing wisdom," and the interviewees seemed to feel that everyone did, or should, feel the same way. The overwhelming sentiment expressed by residents was that, at a certain age and physical condition, it is better to die than to maintain life by artificial means.

> I've seen a number of a people they tried to keep living a longer time. . . . It's no use anyway. They're not going to get better. All they're doing is prolonging it. I had a sister who took an aneurysm . . . and they had her on the tubes, they had artificial respiration, . . . I said pull it out. . . . I know people here in the hospital they live for months and I said, no . . . I don't want that part at all.

The value a resident placed on his or her life was clearly related to judgments regarding the physical and cognitive condition of other residents in the facility. Loss of continence and the inability to recognize familiar people were cited by almost all interviewees as reasons that would make one's life not worth preserving. It is evident from the agreement among the residents that fear of being in a severely impaired state has a profound impact on thoughts about end-of-life care. The presence of others in frail health is a daily reminder of what could be if life is prolonged beyond what is perceived to be worthwhile: "I see people in here. . . . I think we should all when we get to the stage when we have to be fed and diapered and bathed, I think we should be given a needle and put to sleep."

Concern about physical suffering during the dying process was mentioned by several interviewees. The thought of being kept alive and in pain was particularly distasteful. Residents who expressed the most apprehension about pain were those who desired the least intervention.

Social Considerations

Residents spoke of their thoughts about the impact of their health care decisions on others. Few used the word *burden*, but the implication of these statements was that they did not want to make other peoples' lives more difficult by prolonging the death process: "I said [on the advance directive] that I didn't want my life extended, because what's the point? . . . I'm alone in the world. It would be a lot easier on everyone if I went."

Statements regarding dependence reflected residents' thoughts about accepting help from another person in order to carry out activities of daily living, or making decisions about finances and health care. The residents stated they did not want to be taken care of, and they perceived a great loss in quality of life should they fall into a state requiring a high level of assistance with self-care activities.

Some of the respondents indicated their children and other loved ones should have no say in their affairs. The majority expressed concerns that their illnesses would be an inconvenience to their families. In those cases, residents thought that health professionals were best equipped to provide assistance. These thoughts had a strong influence on the residents' rejection of life-saving measures.

Discussion

This research has added to our understanding of the decision-making process of elderly individuals as they formulate advance directives for care. The collecting and weighing of information occur over the course of a lifetime, with very little contribution from professionals or other authoritative sources.

The information is weighed on the basis of a complex mix of emotional, social, and spiritual considerations. Although the relative importance of each of the factors described herein cannot be predicted for individual elders, it was evident that life experience was the most important source of information regarding end-of-life care, and that spiritual considerations were, for most participants, the primary factor in deliberation. The descriptions of decision making indicate a rich and highly personal process for all participants.

Certain factors found in this sample deserve further examination. The experience of veterans is especially worthy of closer study. In consideration of the veterans' reluctance to accept interventions, the existence of the psychological phenomenon of "survivor guilt" is possible (Kaplan & Sadock, 1991, p. 59). Although an exploration of this question was beyond the scope of this project, it would be interesting to discover to what degree this played a part in residents' decisions. This knowledge will be important as veterans of more recent conflicts reach late adulthood and face end-of-life care choices.

The low level of contribution by the media to the decision-making process was not expected. The media has been recognized to influence thoughts and behaviors regarding health care choices among adults (Kahn, 2001; Passalacqua et al., 2004; Peyrot, Alperstein, Van Doren, & Poli, 1998). However, previous findings have indicated that an educational video has little effect on the formulation of advance directives (Betz Brown et al., 1999). Most participants had televisions and radios, and so were assumed to be media consumers, yet the media played no role in their decision making. This aspect of the results bears closer examination.

Many of the factors important to end-of-life decisions cited by the residents had a definitely negative emotional context. Memory is known to be stronger for emotionally charged events than for neutral ones (Charles, Mather, & Carstensen, 2003; Denburg, Buchanan, Tranel, & Adolphs, 2003), and, over the long term, appears to be stronger for negative events than for neutral or positive ones (Kensinger & Corkin, 2003; Quevedo et al., 2003). People of all ages appear to be most able to remember the gist of negative memories (Denburg et al.), which is what appeared to be more important during decision making than the precise details. Other information or memories may not have carried the same emotional impact, and so would not have had a comparable effect on the process. It is likely the information most easily remembered by elders when making the decision was of sad or traumatic events. Negative information also has been shown to influence decision making more than positive information (Tversky & Kahneman, 1991). Health professionals assisting in the decision should be aware of the possibility that elders might be unduly influenced by negative memories, and they

should be prepared to provide support and reinforce positive information when possible.

Our study involved residents of Caucasian and Christian backgrounds. This is typical of the southeastern Ontario population. The definition of saturation that we set a priori was met: the last two interviewees did not contribute further information to the model. Although the addition of individuals of different belief systems or demographic attributes might have added additional information to the model, these characteristics were not represented in the population from which we drew. Residents in our sample referred to life experiences and decision factors common to all races and creeds, and very seldom to factors specific to their own racial or religious background. The study bears replicating in a region with a more varied demographic. However, until results of such a study are available, the factors in decision making described in this article may provide a starting point for discussions with individuals of any nationality. The factors affecting decision making described here are not intended to be an exclusive representation of the factors involved in this decision-making process. Rather, this study is intended as a new framework on which clinicians may base their interactions with clients, leaving room for individualization.

The implicit and protracted decision-making process runs contrary to findings about decision making that suggest an organized and time-limited process (Rosenfeld, Wenger, & Kagawa-Singer, 2000; Wurzbach, 2002), and it suggests professionals may need to approach patients accordingly. An acknowledgment of patients' beliefs and concerns has been found to be lacking in physicians' approaches to advance directives, even though these values are recognized as important predictors of treatment preferences (Crawley, Marshall, Lo, & Koenig, 2002; Doukas & McCullough, 1991; Steinhauser et al., 2000).

This study provides a guide for clinicians who wish to provide assistance to their clients, in order to maximize older adults' understanding of advance directives and the choices they are being asked to make. This research, specific to long-term care, addresses a growing sector of the population that has been infrequently addressed in the literature.

Most worrisome is the difficulty that residents experience in remembering the advance directive. In another study, 8 of 12 competent elderly clients were unable to remember enough information to give informed consent for an advance directive, and 2 were unable to remember formalizing the document (Sayers, Schofield, & Aziz, 1997). There is an urgent need to improve how directives are sought. Complete disclosure of information pertaining to medical procedures must be provided, likely to a level of detail that is not necessary for younger adults. In addition, an explanation of the purpose and implication of an advance directive should also be provided to improve elders' comprehension of these documents. We suggest that professionals should interview residents to find out exactly what their values and beliefs are, and what experiences in their lives are likely to influence the decision for or against various treatments. Medical information could be supplied at the same time, in a form that will be salient for the individual, for example by written documentation (Betz Brown et al., 1999; Brandenburg & Gifford, 1997) or improved verbal communication (Aronson & Kirby, 2002). In addition, supporting residents throughout the time necessary to complete their deliberations would lend a level of quality and compassion to care that currently may not be present. As there is no consensus among experts regarding the amount of assistance that should be given by a professional (Ford, Schofield, & Hope, 2003; Inman, 2002), the needs of individual clients should be respected, instead of expecting everyone to make their advance directives with the same assistance from staff within the same restrictive time frame. There is a need for professionals to pay closer attention to each individual's decision-making process. Increased vigilance to the factors influencing the decision-making process will enable us to provide the best care possible to elderly residents of long-term-care facilities as these difficult decisions are made.

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Appendix

Interview Schedule

How did you find out about the advance directive?

What factors did you consider when you were making your decision?

What do your beliefs tell you about what kind of care you would like to receive?

What was the single greatest influence on your decision?

Tell me about any conflict you experienced as you were making your decision.

Is there anything else we should know about how you made your decision?