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Decision Making for Destination Therapy Left Ventricular Assist Devices: Implications for Caregivers

Colleen K. McIlvennan, DNP, ANP[1,2], **Jacqueline Jones, PhD, RN**[4], **Larry A. Allen, MD, MHS**[1,2], **JoAnn Lindenfeld, MD**[1], **Keith M. Swetz, MD, MA**[5], **Carolyn Nowels, MSPH**[3], and **Daniel D. Matlock, MD, MPH**[2,3]

[1]Section of Advanced Heart Failure and Transplantation, Division of Cardiology

[2]Colorado Cardiovascular Outcomes Research Consortium

[3]Division of General Internal Medicine, University of Colorado School of Medicine, Aurora, CO

[4]University of Colorado School of Nursing, Aurora, CO

[5]Division of General Internal Medicine, Mayo Clinic, Rochester, MN

Abstract

Background—Implanting centers often require the identification of a dedicated caregiver prior to destination therapy left ventricular assist device (DT LVAD) implantation; however, the caregiver experience surrounding this difficult decision is relatively unexplored.

Methods and Results—From October 2012 through July 2013, we conducted semi-structured, in-depth interviews with caregivers of patients considering DT LVAD. Data were analyzed using a mixed inductive and deductive approach. We interviewed 17 caregivers: 10 caregivers of patients living with DT LVAD, 6 caregivers of patients who had died with DT LVAD, and 1 caregiver of a patient who had declined DT LVAD. The themes identified, which could also be considered dialectical tensions, are broadly interpreted under three domains mapping to decision context, process, and outcome: 1) the stark decision context, with tension between hope and reality; 2) the challenging decision process, with tension between wanting loved ones to live and wanting to respect loved ones' wishes; and 3) the downstream decision outcome, with tension between gratitude and burden.

Conclusions—Decision making surrounding DT LVAD should incorporate decision support for patients and caregivers. This should include a focus on caregiver burden and the predictable tensions that caregivers experience.

Keywords

heart failure; left ventricular assist device; devices for heart failure; patient-centered care; destination therapy

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Corresponding Author: Colleen K. McIlvennan, DNP, ANP, University of Colorado, School of Medicine 12631 East 17th Avenue, B130 Aurora, CO, 80045 Phone: 920-540-0809 Fax: 303-724-2094, colleen.mcilvennan@ucdenver.edu.

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Destination therapy (DT) left ventricular assist devices (LVADs) are a relatively new treatment option for end-stage heart failure patients who are ineligible for heart transplantation. The most common reasons for heart transplant ineligibility, and consequently DT status, are advanced age and non-cardiac medical illness.[1] DT LVAD use is becoming increasingly common, with over 1,000 implanted in the United States in 2013 and an estimated 150,000-250,000 potentially eligible patients annually.[2, 3] Centers offering LVADs often require the identification of a caregiver prior to proceeding with the implant. A caregiver's requirements and responsibilities vary according to the center; however, at a minimum a caregiver is required to transport the patient and attend physician appointments, perform sterile driveline dressing changes, and learn the connections and mechanics of the LVAD equipment in order to troubleshoot in an emergency situation. The 2013 International Society for Heart and Lung Transplantation Guidelines for Mechanical Circulatory Support include recommendations that significant caregiver burden or lack of any caregiver is a relative contraindication to implantation of an LVAD.[1]

Several qualitative studies have detailed caregiver experiences of patients with LVADs.[4-9] Common themes in these studies include the “emotional rollercoaster” that caregivers describe prior to the LVAD and the need to adapt to a transformed life after the LVAD. The majority of these studies only included bridge to transplant patients and most of the interviews were performed after transplantation. Consequently, caregivers expressed the relief provided by the transplant as well as gratitude that their loved one was still alive. Only two studies have explored the unique perspectives of caregivers of patients with DT LVADs[10, 11] and no study has explored the perspectives of bereaved caregivers or caregivers of patients who declined an LVAD.

DT LVAD patients are often older with significant comorbidities that preclude heart transplantation.[12] As such, the decision to get a DT LVAD is arguably more complicated than the decision to receive a temporary LVAD in anticipation of a transplant. Additionally caregivers are commonly female spouses of DT LVAD patients, who are also older with co-morbidities[10, 11]; understanding their perspective in DT LVAD decision making is extremely important as they are at particular risk for experiencing stress and caregiver burden due to the increased demands on caregiving with DT LVAD. There is a paucity of literature exploring the decision-making process of caregivers of patients considering DT LVAD. The Ottawa Decision Support Framework is a prescriptive framework that guides the development and evaluation of decision support interventions. This framework states that participants' decisional needs (e.g. knowledge, values, support) will affect decisional quality (e.g. informed, values concordant decisions).[13] The decisional needs and decisional quality impact subsequent outcomes such as emotions, regret, blame, and behavior. The framework asserts that decision support can improve decision quality by addressing unresolved decisional needs. Therefore, as part of a larger agenda to help both patients and caregivers navigate this complicated decision, we aimed to understand the caregivers' experiences and identify their needs related to decision making surrounding DT LVAD.

Methods

Study Design

We conducted a qualitative, descriptive study[14] utilizing in-depth, semi-structured interviews with caregivers of patients currently living with a DT LVAD, caregivers of patients who had died with a DT LVAD, and caregivers of patients who had refused a DT LVAD. A qualitative study design was chosen in order to gain a comprehensive understanding of a caregiver's experience with decision making surrounding DT LVAD and was especially appropriate given the lack of existing data on the topic. The study was approved by the institutional review board at the University of Colorado. Written or verbal informed consent was obtained from all study participants. Participants were compensated $25 for their time.

Sampling and Recruitment

Caregivers of patients who were currently or had previously been cared for at the University of Colorado were eligible for the study. We interviewed a convenience sample of caregivers of both living and deceased DT LVAD patients who were willing to participate in the study. We also included caregivers of patients who had declined DT LVAD. Interviews were conducted until no new themes emerged.[15-19] The principal investigator directly recruited caregivers using her established clinical relationships with both the patients and the caregivers. To identify caregivers, patients were asked to name a primary caregiver who had provided support during their decision and who assisted with their ongoing care. If more than one person was identified, the patient was asked to choose one caregiver who was functioning as the primary caregiver. Caregivers were excluded if the patient's DT LVAD implant had occurred greater than 5 years prior.

Data Collection

In-depth, semi-structured interviews were conducted either in person or by phone by two trained research staff without a clinical relationship with the patients between October 2012 and July 2013. Given the potential for intense emotional response, a member of the study team with a social work background and expertise in qualitative research performed the interviews of bereaved caregivers. All caregivers were interviewed alone in order to allow them to speak as freely as possible regarding their experience. Consistent with study goals and established qualitative research methods,[17-19] these in-depth, semi-structured interviews utilized broad, open-ended questions to elicit personal thoughts and experiences regarding decision making surrounding DT LVADs. Three interview guides were developed: 1) for caregivers of patients living with a DT LVAD, 2) for caregivers of patients who had died with a DT LVAD, and 3) for caregivers of patients who had refused DT LVAD (**Appendix**). The interview guides were based on the Ottawa Decision Support Framework.[13] Domains addressed in all three interview guides included factors involved in the decision-making process, assessment of clinician interaction, future decisions, consideration of alternatives, as well as degree of satisfaction with the decision. The interview guides of patients who chose to pursue a DT LVAD included questions regarding the expectations of living with a DT LVAD and unexpected outcomes. The interviews were digitally recorded, professionally transcribed, and reviewed for accuracy. Caregivers also completed a short survey including demographic questions in order to characterize the sample.

Qualitative Analysis

Transcripts were entered into ATLAS.ti 7.0[20] software and data were analyzed using a mixed inductive and deductive approach.[15, 21, 22] We began with a process of exploring each transcript for language and phrases used by participants to describe their decision-making experiences. Three members of the study team each reviewed a subset of interviews separately, meeting regularly to reach consensus on our codebook as well as emerging themes. Through an iterative, multidisciplinary team-based process, codes were reviewed and discussed to ensure their completeness and contextual authenticity. A multi-disciplinary team-based approach was used to add depth to interpretation. Further, by using a multi-disciplinary team representing the various facets of the decision-making process, we were able to ensure that one point of view did not dominate theme interpretation. We developed the final codebook incorporating both data-derived codes and formal domain codes defined a priori from the Ottawa Decision Support Framework, consistent with our mixed inductive and deductive approach.[13, 22, 23] A process of open coding was applied to the remainder of the interviews, concomitant with team discussion and data re-immersion, followed by axial coding in which we established links between the a priori and in vivo codes to provide a conceptual and thematic description.[23] Confirming and disconfirming cases were discussed until consensus was reached. The entire study team determined thematic saturation was reached when additional interview data created little or no change to the codebook and no new patterns or themes emerged.[14-17]

We employed several strategies to assure trustworthiness of the findings.[24-26] To assure dependability, the primary coder kept an audit trail during the analytic phase of the project. To assure transferability, we have attempted to describe our sample in adequate detail so that others can determine how different populations compare. To assure credibility and confirmability, we triangulated our findings using a multi-disciplinary study team[26] consisting of two advanced heart failure and transplant cardiologists, a heart failure and transplant nurse practitioner, two palliative care physicians, and two qualitative experts. Throughout the data analysis, this team met to discuss the analytic process and emergent themes. Additionally, themes were presented to a cardiac health services research group to seek input regarding trustworthiness.

Results

Between October 2012 and July 2013, we interviewed a total of 17 caregivers: 16 caregivers of patients who had received a DT LVAD and 1 caregiver of a patient who had declined a DT LVAD. Duration of interviews ranged from 21 to 72 minutes. At the time of interview, 10 were caregivers of patients currently living with a DT LVAD and 7 were caregivers of patients who were deceased. The majority (n=12) were spouses or widows of the patients; in addition, there were 2 daughters, a mother, a sister, and a friend. One caregiver was male, and was a friend of the patient. The age of caregivers ranged from 35 to 79. Nearly all caregivers spent more than 8 hours per week caring for their loved one (n=13), and the majority attended almost all medical appointments (n=14). Additional summary statistics are provided in Table 1.

Throughout the interviews, the overarching theme was that considering a DT LVAD is a complex decision-making process. The complexity and tensions coalesced around three domains: 1) the decision context, 2) the decision process, and 3) the decision outcome (Table 2).

Decision Context

Caregivers described a complicated decision context, in which being offered a DT was often preceded by years of poor health. The decision was then frequently marked by a sense of urgency and, for some, dashed hopes, as a result of being declined for heart transplantation.

Tension: hope and reality—In this stark decision context, caregivers experienced an underlying tension between hope and reality. Within the same interview, some caregivers expressed both hope for a future as well as the reality of their loved ones' prognosis; however, they rarely verbalized the incongruity or tension between these two lenses. At the time of decision making, most caregivers reported feeling the DT LVAD would offer the patient more time and improved quality of life. Less often articulated was the fear that the patient would not survive surgery or would experience persistent complications.

Years of poor health—Patients being considered for DT LVAD implantation often experienced an extended period of deteriorating health prior to their decision-making period. Caregivers reported that loved ones had struggled with heart failure and other comorbidities for lengthy periods of time, arriving at the DT LVAD decision point exhausted, physically and emotionally compromised, and often desperate for a chance to improve their quality of life.

- “…it [heart failure] was killing him. He had no strength. He had no quality of life. He was just existing.” [Living]

A sense of urgency—Caregivers spoke of the need to make a decision quickly before their loved one became ineligible for a DT LVAD or died. Those who felt pressure to make a decision quickly due to the patient's deteriorating health recalled the subtheme of a “narrow window”. Several caregivers expressed that the DT LVAD should be offered earlier to patients. These caregivers felt the DT LVAD discussions had occurred at a point when their loved ones were almost too sick to survive the major surgery.

- “He had gotten really sick…and they were like ‘This needs to be done like this week.’ Like ‘If you are going to choose to do it, he needs to do it like right now.’” [Bereaved]

Ineligibility for transplant—Several patients (n=4) whose caregivers were interviewed had been considered for a heart transplant prior to the DT LVAD evaluation. In these situations, the decision to proceed with a DT LVAD was strongly influenced by the inability to proceed with heart transplantation. Caregivers expressed that once the patient was deemed ineligible for a transplant, both the patients and caregivers realized the DT LVAD had become their only option.

- “…when we first started out…we had hopes of a transplant…but once the lung function was done, and the kidneys…there was pretty much nothing. There was no hope other than the LVAD.” [Living]

Decision Process

The actual decision process was a time when caregivers felt mixed emotions, including uncertainty, and a desire to support their loved ones. Some caregivers acknowledged voicing their own preferences regarding DT LVAD to their loved one, with all but one caregiver in favor of implantation. Additionally, many caregivers noted that their relationship with the doctors was very important in their decision making.

Tension: wanting loved one to live and wanting to respect their wishes—Caregivers' narratives revealed an internal tension between wanting their loved one to live and wishing to respect their loved one's decision regardless of his or her choice. As they recalled the decision process, many caregivers talked about a fear of losing their loved one or an intense desire for them to survive. Factors included apprehension about being widowed, a need for help with responsibilities such as raising grandchildren, or the perceived inability of a family with other recent trauma to cope with further loss. In contrast, a few caregivers focused heavily on their belief that this was an extremely personal decision and the patient should not be influenced by others' opinions.

Influence of relationships with the clinicians—Several caregivers recalled their experiences with the clinical personnel when going through the DT LVAD decision-making process. Some were relieved to have their clinicians' support, while others expressed frustration with the urgency of the decision and the pressure to pursue a DT LVAD.

- “And it takes a big doctor to be able to let a patient go. To be able to say, you know, this is their wish and this is what they want…When you go through so much, I think it gets to a point where you need to listen to the patient, when he's had enough.” [Declined]
- “Well, we both really loved Dr. X and really respected him. So I'm sure just feeling that he had suggested this, that you know, it was probably a good decision.” [Bereaved]

Making the decision—Several caregivers saw the DT LVAD as their loved one's only option. For this reason, many did not seriously consider factors such as the risks of surgery, complications, or burdens of living with a DT LVAD. Others stated they viewed it as a life or death decision.

- “We really didn't want to look at the negative side.” [Bereaved]
- “I felt that the decision we had to make was life and death. Not whether or not we were going to talk about whether or not we were going to have the implant you know?” [Bereaved]

Decision Outcome

Decision outcome encompasses how caregivers felt about the decision after the fact and largely included satisfaction and regret. Notably, some caregivers expressed ongoing uneasiness with the decision. Caregivers whose loved one chose to pursue DT LVAD experienced both gratitude for extended life and a sense of burden. Some caregivers reflected on the decision itself with regret or feelings of unfulfilled expectations, while others had never given the decision a second thought.

Tension: gratitude and a feeling of burden—As they reflected on the experience of their loved ones living with a DT LVAD, the caregivers spoke of tension between gratitude for the additional life afforded by the DT LVAD, but also a sense of burden related to caregiving, such as frequent hospitalizations. The subtheme of “you do what you gotta do” was common. The few who acknowledged a sense of burden were hesitant to express any misgivings, and emphasized that, in spite of the onus, they would not wish for anything different. This balancing act between gratitude and sense of burden was dynamic, fluctuating between both the negative (e.g. a new hospitalization) as well as the positive (e.g. activities previously not possible).

Reflecting on the decision—Living with a loved one with a DT LVAD for a period of time resulted in increased reflection about the decision-making process among caregivers. While some expressed disappointment about what life was like with the DT LVAD, others focused on the life-prolonging benefit and improved quality of life afforded by a DT LVAD.

- “Now that we've experienced it, I've thought ‘Was that the right decision?’” [Living]
- “I mean, if he would have told me he was going to still be sick [after the surgery]… then we'd have probably had a lot different way of thinking.” [Living]

Discussion

For patients and their caregivers, decisions about whether or not to pursue invasive technologies in the setting of chronic progressive illness are arguably some of the most complicated in medicine. Although caregivers form a critical component of the care for patients with chronic disease, their role is particularly central to and formalized in the setting of DT LVADs. Lack of caregiver support is considered a relative contraindication for implanting an LVAD according to the current mechanical circulatory support guidelines.[1] Most LVAD programs go so far as having a mandatory requirement for a dedicated and capable caregiver in order for a patient to be eligible for a DT LVAD. Therefore, it is critically important that we understand the caregiver's perspective as patients consider this invasive technology. By utilizing a multi-disciplinary team-based approach for analysis and interpretation, the many facets of the decision-making process were represented. Multiple disciplinary perspectives allowed various possibilities to be explored in the interpretation of data, and also assisted when informing possible solutions for the DT LVAD decision-making process. We consider the nuances of disciplines and practice as we offer potential solutions and implications. This continues to move the needs of the caregiver from the previous silos to interdisciplinary care.

Caregivers tend to place the needs of loved ones above their own and the level of caregiver responsibility required for DT LVAD has the potential to intensify caregiver burdens.[5,27]Several studies have focused on the difficulties of the post-LVAD caregiver experience,[5, 11, 27] emphasizing the importance of a quality decision about whether or not to pursue DT LVAD in the first place. Our results and those of prior studies highlight the importance of the caregivers' perspective in this decision process. As one of only a few studies to include caregivers of patients who have died, caregivers provided a unique perspective that comes with reflection on past experiences in a patient's absence. Due to the dire nature of the DT LVAD decision, it may not even be possible to fully explore a caregiver's perspectives when patients are still alive. A “do or die” mentality means caregivers may be unable to reflect on the decision process while still caring for their loved one. Additionally, unlike most other studies our interviewers had no prior relationship with any of the caregivers.

We described tensions within each domain, though the word “tension” may oversimplify the state of the emotion. Each of these tensions could be described as dialectical tensions, or two ideas being equally valid when considered alone but contradictory when paired.[28] End-of-life of life care has been shown to produce dialectical tensions, where caregivers utilize relational history as knowledge.[29] These tensions demonstrate not just than a duality in choices but a situation steeped in uncertainty, doubt, ambivalence, uneasiness, and ambiguity.[28,29]

There continues to be a need to improve the framing around the decision process for all high-stakes, medically complex decisions, including DT LVAD. Interviews with patients have demonstrated that the complexity and related emotion surrounding chronic progressive illness contribute to patients' fear of discussing alternatives or hearing about complications and burdens.[30] Caregivers not only viewed DT LVAD as their loved ones' only hope, but they also felt pressured to make a decision quickly—negating the chance for full and open consideration of risks, benefits, and burdens. Therefore, decision support in this context must be timely but also responsive to the emotions and coping strategies of patients and caregivers. Reframing DT LVAD as a “potentially life-prolonging” therapy rather than a “life saving” one better captures the ongoing medical issues as well as the greater than 50% death rate over the next 4 years[2]. This could facilitate caregivers' understanding of DT LVAD as one option, not the only option.

A large amount of information is provided to patients and caregivers during the decision-making process. While informed consent is essential, the current process and practices are not sufficient. Given the complex tradeoffs of DT LVAD, necessary components of shared decision making must include optimal patient selection; extensive informed consent' adequate time to review expected risks, benefits, and burdens; and a strong grounding in patients' and caregivers' goals and values.[31]

Involving caregivers throughout the entire decision process can help manage expectations for life with or without a DT LVAD. Several interventions should be considered for caregivers of patients considering DT LVAD. First, in order to better prepare caregivers for the burdens of DT LVAD, LVAD programs should continue to invite caregivers to participate in the decision-making process. This helps to address caregivers' concerns and works to further engage them as active participants. Second, DT LVAD caregiver-specific tools and resources should be developed to outline responsibilities and the impact on the caregiver's life. Third, providing caregivers with tools such as a decision aid may help to manage expectations and relieve the potential for post-decision caregiver burden. It is important for programs to normalize the ambivalence felt by caregivers by informing them that others have experienced this as a very complex decision. Fourth, ongoing caregiver support groups, separate from patient support groups, can assist in empowering caregivers as well as validating feelings and concerns.[32]

Deciding whether or not to pursue a DT LVAD is just one decision, of many, that patients and caregivers face. Future work surrounding caregivers of patients considering DT LVAD could explore the decision process prospectively. Additionally, future studies should investigate the potential correlations between caregivers and their propensity toward certain tensions (e.g. which characteristics make caregivers more likely to have decision regret). This would lend itself to identifying caregivers who would benefit from tailored caregiver support or interventions, with some caregivers potentially needing no interventions at all.

Limitations

There are several limitations to our study that should be considered when interpreting our data. First, this study was performed at a single academic center with a relatively homogenous convenience sample, including only 1 male caregiver; however, this is one of the first studies to focus on the unique DT LVAD caregiver population. Second, the sample of bereaved caregivers was small and we included only 1 caregiver of a patient who declined a DT LVAD. Currently, this is the only study that includes bereaved caregivers of DT LVAD patients and our team intends to explore this population in future research. Lastly, caregivers were interviewed following the decision about DT LVAD. This could bias the results as the caregivers would be influenced by the outcomes; however, we chose this strategy deliberately so as not to influence the DT LVAD decision-making process with our interviews.

Conclusion

Caregivers of patients considering DT LVAD face many complex issues, including interpreting the decision to implant a DT LVAD in the context of risks and benefits, balancing their needs and the needs of their loved one, and managing feelings of caregiver burden. Interventions to improve caregiver experiences of decision making with DT LVAD should focus on the involvement of the caregiver. Further, expectations of caregivers need to be honest and managed carefully, and LVAD programs should recognize caregiver involvement and provide ongoing support and skills training.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1
Caregiver Characteristics at Time of Interview

	n=17
Relationship to Patient	
Spouse	12(70%)
Daughter	2(12%)
Mother	1(6%)
Sister	1(6%)
Friend	1(6%)
Demographics	
Age in years, median (range)	63(35-79)
Female, n	16(94%)
Non-Caucasian, n	1(6%)
Family Income, n	
$15,000-$30,000	3(18%)
$30,000-$60,000	11(64%)
$60,000-$100,000	3(18%)
Education Level, n	
Some high school	2(12%)
High school graduate/GED	3(18%)
Some college	7(41%)
4-year college graduate	4(23%)
more than a 4-year degree	1(6%)
Time from Declination/Implant to Interview	
Declined: in days	248
Living: in days, median (range)	1042(416-1877)
Bereaved: in days, median (range)	548(90-1847)
Caregiver Responsibilities	
Hours Per Week Spent Caring for the Patient	
<1 hour per week	2(12%)
1-2 hours per week	2(12%)
3-5 hours per week	-
6-8 hours per week	-
>8 hours per week	13(76%)
Frequency of Attending Medical Appointments with Patient	
Never	-

	n=17
Occasionally	3(18%)
Often	-
Almost all of time	14(82%)

Table 2

Tension with Illustrative Quotes

	Living	**Bereaved**	**Declined**
Tension Between Hope and Reality			
Hope	*And all of a sudden there was this little ray of hope you know? You could just see it change his life…because he had pretty much given up.*	*It was hope. A new future. A life again.*	[Both hope and reality addressed together]: *You'd hear him get his hopes up once in a while and think about things and think he would get better. And then he would realize he didn't want to put all the work into it of getting better.*
Reality	*…it [heart failure] was killing him. He had no strength…and one day I went to pick him up and I saw him, he could just barely walk to the car…he couldn't climb the stairs. He had no quality of life. He was just existing.*	*…but definitely we thought through, 'Do you think dad can make it through this? Do you think he can mentally do this? Do you think his wife could be the caregiver for the next 10 years?'*	
Tension Between Wanting Their Loved One to Live and Respecting Their Loved One's Wishes			
Wanting Their Loved One to Live	*…anything to make my dad still be here. We were 100% willing. Even the side effects didn't bother us…'cause they told us about the machine and we were like 'Of course. Yes. We want it.'*	*I just figured this was it…we are going to finally push death away and we were going to really go for this, because he would have a better blood flow. He would have a chance to do things.*	Not Applicable
Respecting Their Loved Ones Wishes	*My thoughts were this was his life and it was his choice. I said 'I don't want you doing it for me. You are doing this for you. Is this what you really, truly want? So I really made sure the decision was his choice.*	Interviewer: *What do you think was THE most important thing in the decision?* Caregiver: *That [patient] made up his mind what he wanted.*	*Cause whatever he wanted I would agree with…no matter what I felt about it, I wanted him to be happy with the decision. And I thought I didn't want to be able to influence him in that decision. Cause to me it was a very personal decision.*
Tension Between Gratitude and a Feeling of Burden			
Gratitude	*We have to thank God for the LVAD because otherwise we wouldn't have him now.*	*…it was some of the most blessed time we had together. It really was. It ended up being such a blessing.*	Not Applicable
Burden	*I've never felt caregiving was my gift…I tend to feel like I'm being imposed upon at times…that you are being called upon.*	*I think it was a little scary. So worried that you are not going to do something quite right…those last couple months, I just was worn out.*	Not Applicable