

A Three-Step Letter Advance Directive Procedure to Facilitate Patient-Proxy Alignment in Advance Care Planning

Muthuraman Alagappan, MD,¹ Michael T. Richardson, BA,² Matthew K. Schoen, BA,² Lori Muffly, MD,² Kathryn Tierney, RN,³ Patricia Jenkins, RN,³ Eric Neri, MS,² Helena C. Kraemer, PhD,² and Vyjeyanthi S. Periyakoil, MD^{2,4}

Abstract

Background: Little is known about the extent of alignment between hematopoietic stem cell transplant (HSCT) patients and their healthcare proxies with respect to advance care planning (ACP).

Aim: To determine if a structured three-step process using the letter advance directive (LAD) could (1) allow for the differences in opinion between patient-proxy dyads to surface and (2) help bridge preexisting discordance about specific treatment choices.

Design: Blinded to each other, the HSCT patient (LAD-1) and proxy (LAD-2) each completed the LAD (step 1). They unmasked, compared LAD-1 and LAD-2, and discussed their choices (step 2). They completed a final letter directive (LAD-3) by consensus (step 3).

Settings/Participants: Convenience sample of eighty dyads (patient and proxy) at a regional HSCT referral center.

Results: The mean patient-proxy concordance was 72.9% for the 12 questions in the LAD. Wanting to be pain free at the end of life was the statement with the most amount of agreement (88.75% in LAD-1, 91.25% in LAD-2, and 90% in LAD-3). Patient-proxy dyads had notable discordance related to specific treatments. The highest discordance was related to ventilator support (46.3% of patients refused it, while 58.8% of proxies refused on behalf of the patient). Overall, proxies were more likely than patients to opt in for dialyses and hospice care but more likely to opt out for cardiac resuscitation and sedation to palliate refractory symptoms. On open discussion, patient-proxy discordance mostly resolved in favor of the patient.

Conclusions: The ACP process should allow for patient-proxy differences to surface, facilitate a discussion about the granular details with the goal of reaching consensus. Our three-step approach using the LAD is an effective way to identify areas of patient-proxy concordance and discordance about specific treatment preferences. A structured patient-proxy discussion using the LAD helped reconcile discordance and most often in favor of a patient's original wishes.

Keywords: advance care planning; bone marrow transplant; end of life; hematopoietic stem cell transplant; letter project; proxy

Introduction

A MAJORITY OF PATIENTS DIE of one or more chronic illnesses. As patients become progressively sicker, many lose their ability to make health decisions.^{1,2} At that point, the

responsibility falls on the medical power of attorney (if appointed) or next of kin to serve as a decision-making surrogate or proxy.³ The proxy is asked to make medical decisions using substituted judgment (i.e., to decide as the patient would have decided if he/she had retained decision-making

¹Beth Israel Deaconess Medical Center, Harvard Medical School, Boston, Massachusetts.

²Stanford University School of Medicine, Stanford, California.

³Stanford Hospital and Clinics, Stanford, California.

⁴VA Palo Alto Health Care System, Palo Alto, California.

Accepted July 25, 2018.

capacity).⁴ However, substituted judgment is very challenging in these situations because many patients have not discussed their goals, values, and specific end-of-life preferences with their proxy decision makers.⁵ Armed with limited information and colored by their personal feelings for the patient, proxy decision makers may make decisions that are not consonant with the patient's preferences.

Rationale for choice of study population

Hematopoietic stem cell transplantation (HSCT) is an aggressive therapeutic procedure that is potentially curative but associated with high morbidity and mortality.^{6–9} Many HSCT patients are at risk of loss of decision-making capacity at any point in the treatment trajectory. These patients are also often faced with difficult end-of-life decisions, as more than half of HSCT patients admitted to the intensive care unit (ICU) after transplant require mechanical ventilation and the short-term mortality of allogeneic HSCT patients remains >50%.^{10–12} HSCT patients are also more likely to receive chemotherapy at the end of life, less likely to receive palliative care referrals, and more likely to die in the hospital compared with patients with solid malignancies.^{13–16} Thus, the HSCT population is a high-risk population in need of advance care planning (ACP). However, as patients seek HSCT with the goal of cure, they may be reluctant to engage in ACP. Clinicians caring for HSCT patients report barriers to initiating ACP discussions, including difficulty identifying the end-of-life phase due to continuing potential for cure and “unrealistic” patient expectations.⁷

Burden of proxy decision making

Healthcare proxies have described an enormous emotional burden associated with surrogate decision making, as it often causes them to feel responsible for a loved one's death.^{17,18} Further, at least 40% of acutely ill medical inpatients have been estimated to lack decision-making capacity.¹⁹ Given the frequency of situations that require proxy decision making, it is important to characterize the alignment of patients and proxies with regard to end-of-life treatment preferences. A prior study has demonstrated that surrogate decision makers only predicted patient treatment preferences with ~70% accuracy.⁴ This low level of concordance raises questions about the ability of medical teams to rely on proxy decision makers to accurately reflect a patient's wishes related to specific treatments (e.g., dialysis, intubation, artificial nutrition and hydration, etc.). However, the variability in patient-proxy alignment related to individual treatment interventions in the HSCT population has not been well characterized. It also raises the question of whether a deliberate stepwise approach of guided ACP conversations between patient and proxy can help reveal specific points of disagreement, improve alignment between patients and healthcare proxies, and achieve consensus with regard to treatment preferences.

Goals of this study

The letter advance directive (LAD), a novel ACP tool written at a fifth-grade reading level and available in eight languages, is designed to help patients articulate their life goals, what matters most to them, and their wishes for care at the end of life.²⁰ We used the LAD to evaluate the concor-

dance between patient and healthcare proxy (i.e., a dyad) related to specific end-of-life decisions, and to identify the areas where discordance was most pronounced. The goals of this study were to explore (1) the extent of alignment or concordance between a patient's own choices and the proxy's choices on behalf of the patient, and (2) whether a three-step approach of engaging the patient and proxy (as described in the data collection section) could assist in creating a consensus advance directive to bridge any preexisting discordance.

Methods

Study design and recruitment

This is an interventional study examining whether the use of the LAD leads to more concordance between patient and proxy. Stanford Blood and Bone Marrow Transplant (BMT) Center is a HSCT regional referral center, serving patients from many health organizations, including Kaiser Permanente and others. All new patients referred for HSCT to Stanford Medicine were eligible to participate if they (1) began the process of undergoing HSCT at Stanford, (2) had been deemed to have capacity to make treatment-related decisions by their BMT care team, (3) had a designated proxy decision maker, and (4) both patient and proxy were willing to participate in the study. Patients pursuing either allogeneic or autologous HSCT were included in the study population, and all patients had an underlying hematologic malignancy. Patients were not excluded based on age, language, or gender. The study protocol was approved by the Stanford Institutional Review Board.

Data collection

Patients and their proxies were approached by one of the study coordinators either in the outpatient clinic or in the inpatient hospital room based on patient preference. The study was explained in detail, and if the dyad was willing to participate, written informed consent was obtained.

A three-step LAD procedure to facilitate patient-proxy consensus in ACP:

Step 1: The patient and proxy were each provided a blank copy of the LAD.²⁰ The patient completed the LAD (LAD-1) blinded to the proxy, while the proxy concurrently completed an LAD (LAD-2) *on behalf of the patient* and blinded to the patient.

Step 2: Next, the patient and proxy unmasked, reviewed each other's letters (LAD-1 and LAD-2), and discussed their differences question by question. A study coordinator was present in the room to answer any questions about the study but did not assist in the decision-making process.

Step 3: After the discussion, which was not time limited, the dyad (patient and proxy pair) was given a blank LAD, which they completed together (LAD-3) based on the joint discussion they had.

Data analysis

All responses were deidentified and recorded in a secure database. The statements about end-of-life care preferences were recorded as binary responses (agree or disagree).

Agreement, defined as the percentage of times that the patient (LAD-1), proxy (LAD-2), or dyad consensus (LAD-3) “Agreed” with a statement about a specific treatment, was calculated and reported as frequencies across the study cohort. Concordance, defined as the percentage of times for a given question when the patient and proxy both provided the same response, was calculated for LAD-1 and LAD-2 (e.g., LAD-1 and LAD-2 had 80% concordance for statement 2). The proportion of concordance between the dyad letter (LAD-3) and the patient’s initial preference (LAD-1) was also calculated.

Results

Enrollment and baseline characteristics

Eighty patient-caregiver dyads were recruited between March 2016 and February 2017. The mean age of patients was 53.3 years (range 24–74 years). The majority of patients were male (60.0%), non-Hispanic white (63.75%), married (85.0%), had a college education or more (>80%), and born in the United States (73.75%) (see Table 1). The designated proxies were spouses (71.25%), adult daughters (8.25%), mothers (8.25%), or connected to the patient in other ways (12.25%). Thirty-four patients participated in this study a median of 4.5 days before the HSCT, 3 on the day of the HSCT, and forty-three patients a median of 11 days after the HSCT.

Agreement with specific treatment choices

Wanting to be pain free at the end of life was the statement with the most amount of agreement (88.75% patients agreed with the statement in LAD-1, 91.25% proxies agreed with the statement in LAD-2, and 90% patient-proxy dyads agreed in LAD-3). Conversely, wanting to spend the last days in the hospital was the statement with the least amount of agreement (6.25% agreed in LAD-1 and 3.75% agreed in LAD-2), although the concordance between the patient and proxy was the highest at 90% for this statement (Table 2).

Concordance between patient and proxy

Patients and their decision-making proxies had notable discordance in specific treatment areas. The major discordance in patient (LAD-1) and proxy (LAD-2) alignment was related to ventilator support (46.3% of patients did not want to be on a breathing machine, while 58.8% of proxies believed the patient would not want to be on a breathing machine). Other issues that elicited discordant views between patient and proxy included use of artificial feeding and use of hospice care (see Table 2). Of the individual treatment choices that resulted in patient-proxy discordance, proxies were more likely than patients to opt in for dialyses and hospice care, but more likely to opt out for cardiac resuscitation and sedation to palliate refractory symptoms. The mean concordance between patient and proxy was 72.9% for the 12 questions reported in Table 2.

Consensus LAD

Where there was disagreement between the patient (LAD-1) and proxy (LAD-2), the vast majority (see Table 2) resolved in favor of the patient in the consensus (LAD-3). Notably, 78.75% stated, “I am asking you to show this form

TABLE 1. DEMOGRAPHIC INFORMATION OF STUDY PARTICIPANTS

	Patient, n (%)	Proxy, n (%)
Age group, years		
20–29	5 (6.25)	6 (7.50)
30–39	11 (13.75)	11 (13.75)
40–49	13 (16.25)	12 (15.00)
50–59	18 (22.50)	20 (25.00)
60–69	28 (35.00)	20 (25.00)
70–79	5 (6.25)	9 (11.25)
80+	0 (0.00)	1 (1.25)
Refused	0 (0.00)	1 (1.25)
Gender		
Female	32 (40.00)	25 (31.25)
Male	48 (60.00)	53 (66.25)
Refused	0 (0.00)	2 (2.50)
Ethnicity		
Non-Hispanic white	51 (63.75)	47 (58.75)
Asian/Pacific Islander	16 (20.00)	15 (18.75)
Hispanic/Latino	7 (8.75)	11 (13.75)
Black/African American	2 (2.50)	1 (1.25)
Mixed/other	4 (5.00)	4 (5.00)
Refused	0 (0.00)	2 (2.50)
Marital status		
Married	68 (85.00)	67 (83.75)
Single	9 (11.25)	6 (7.50)
Divorced	2 (2.50)	0 (0.00)
Widowed	0 (0.00)	3 (3.75)
Refused	1 (1.25)	4 (5.00)
Education		
Elementary	0 (0.00)	1 (1.25)
High school	11 (13.75)	10 (12.50)
College	43 (53.75)	40 (50.00)
Graduate/professional	25 (31.25)	26 (32.50)
Refused	1 (1.25)	3 (3.75)
Birth country		
United States	59 (73.75)	55 (68.75)
Other	21 (26.25)	24 (30.00)
Refused	0 (0.00)	1 (1.25)
Language spoken at home		
English	63 (78.75)	56 (70.00)
Other	16 (20.00)	21 (26.25)
Refused	1 (1.25)	3 (3.75)

(LAD-3) and guide my family to follow my wishes” in event their family strayed away from the patient’s documented wishes.

Decision-making comfort

After completing the dyad letter (LAD-3), all patients and proxies were asked to respond to how comfortable they feel with surrogate decision making *before* and *after* this exercise on a scale of 1 (least comfortable) to 10 (most comfortable). The response rate for these questions was 92.5% (148/160). For patients, the median comfort level with their proxy’s decision making was 9 *before* the exercise and 10 *after* the exercise on a 0–10 scale. For proxies, their median comfort level with making decisions on behalf of the patient was 9 *before* the exercise and 10 *after* the exercise.

TABLE 2. COMPARING PATIENT (LETTER ADVANCE DIRECTIVE-1) AND PROXY (LETTER ADVANCE DIRECTIVE-2) INITIAL ALIGNMENT RELATED TO SPECIFIC END-OF-LIFE WISHES

<i>End-of-life preferences</i>	<i>Percentage of patients who agreed with this statement</i>	<i>Percentage of caregivers who agreed with this statement</i>	<i>Percentage of concordance between patient and caregiver (i.e., both agreed or both disagreed with the statement)</i>	<i>Percentage of concordance between consensus letter and patient's original preferences</i>
What I DO NOT want at the end of my life				
I do not want any attempts to restart my heart (to be resuscitated) if it stops beating	20.00	23.75	78.75	95.00
I do not want to be on a breathing machine	46.25	58.75	57.50	90.00
I do not want artificial liquid feeding	45.00	35.00	67.50	92.50
I do not want dialysis	30.00	23.75	73.75	92.50
I do not want to spend my last days in a hospital	66.25	62.50	63.75	91.25
I do not want to die at home	11.25	5.00	86.25	96.25
What I DO want at the end of my life				
I want to be pain free	88.75	91.25	87.50	96.25
I want to spend my last days in the hospital	6.25	3.75	90.00	100.00
I want you to help me die gently and naturally	75.00	77.50	65.00	92.50
I want to die at home	63.75	61.25	62.50	95.00
I want hospice care	50.00	60.00	65.00	90.00
If my pain and distress are difficult to control, please sedate me even if this means that I may die sooner	80.00	85.00	77.50	93.75

Column 5 shows how the patient-proxy discussion of the patient's end-of-life wishes impacted the consensus (letter advance directive-3) in favor of the patients' wishes.

There were 37 patients who completed the LAD on or before the BMT and 43 after the BMT procedure. The concordance between the patterns of responses between the two cohorts was very similar (Spearman's correlation was 0.95).

Discussion

Main findings

Most Americans bear the burden of declining functional status in the last few years of life.²¹⁻²³ Seriously ill patients often lose their ability to make decisions about their healthcare, necessitating their proxies to take over medical decision making.¹ Proxy medical decision making has been shown to be associated with poor accuracy of only ~70%.^{4,24,25} While advance directives are helpful in knowing a patient's preferences, standard state-approved documents do not always ask for patient input about specific treatment choices. When our study participants (patient-proxy dyads) completed the LADs (LAD-1 and LAD-2) blinded to each other, individual treatment choices reflected significant disagreement that varied by the specific treatment choice, most notably with respect to mechanical ventilation at the end of life.

Fortunately, in every single instance, the patient-proxy dyad was able to reconcile their differences and collaboratively complete a LAD (LAD-3). It is also remarkable that in cases where the patient (LAD-1) and proxy choices (LAD-2) were not congruent, the proxies were willing to defer to the patient and document the patient's decisions in LAD-3. Also, on completing the dyad letter (LAD-3), both patient and proxy indicated a high level of comfort with the healthcare decision-making process.

The exercise of completing the LAD blinded to each other allowed the "patient-proxy" differences in opinion to sur-

face, which they were then able to resolve amicably by discussion. We believe that this process is extremely valuable as it allows the patients to reflect on their values and preferences. It also allows the proxy to gain a specific understanding of the patient's wishes related to individual treatments and discuss these with them. This consensus-building exercise can help empower patient-centered decision making, and decrease the stress and uncertainty borne by proxies when making end-of-life decisions on behalf of the patient.

In our study, 46.3% of patients indicated that they did not want ventilator support at end of life. However, more than half of HSCT patients admitted to the ICU require mechanical ventilation after transplant.²¹⁻²³ We acknowledge that a time-limited trial of mechanical ventilation may be necessary to support patients through the post-BMT complications. Some patients may want mechanical ventilation or other treatments for only a short time-limited trial and not for long-term situations. The LAD provides areas for free text responses, where patients can provide more clarification about their wishes related to each treatment, including time-limited trials and stopping criteria. Nuanced early discussions between patient and proxies before transplant related to these issues may result in better understanding of the patient values, and reduce the prevalence of patients receiving unwanted and nonbeneficial treatments at the end of life and alleviate proxy distress-related decision making.

Implications

Our study has both practical and policy implications that are valuable in both a national and international context. Advance directive documentation is one way for patients to

provide anticipatory guidance for their future care. The simple decision-making exercise of building patient-proxy consensus as described in our study allows for their opinion differences to surface and gives them an opportunity to resolve them while the patient still has decision-making capacity. In situations when the patient and proxy have irreconcilable differences, the patient has the choice of persuading the proxy to their views or assenting to the proxy's choices. In some cases, the patient may instead choose to appoint another person who is willing to carry out his/her will as the designated proxy. We also highlight that the patient-proxy consensus-building process led to increased patient and proxy comfort in decision making. It could also potentially lead to preference-sensitive care at the end of life. In terms of policy, we posit that the ACP process must involve steps that allow for patient-proxy differences to surface and then enable consensus building by discussion. Such an approach will potentially decrease the likelihood of proxies making medical decisions without prior knowledge of the patient's stated preferences.

Limitations

Our study has several limitations. This study was conducted at a specific point during the patient's disease, and it is likely that a patient's choices will change over time as they traverse through the illness process. Further, the patients in this study were all approached at different points in their transplant process, and patient and family perspectives on end-of-life choices likely evolve through the transplant process and illness trajectory. The lack of standardization of when in the transplant process that patients were approached likely introduces heterogeneity into the data. However, including patients at various points in the transplant trajectory provides a more general overview on end-of-life decision making, regardless of timing. Further, the heterogeneity in timing allows global assessment of the feasibility of the LAD as an intervention at various stages during the HSCT process, such as before transplant or even weeks after. A second limitation is that this study used a convenience sampling approach: dyads were recruited into this study based on their availability and willingness to participate, which conveys a selection bias. This is a cross-sectional study. It does not address the question of whether in the future, the proxies will implement the choices indicated in the consensus LAD-3. In the longitudinal follow-up phase of this study, we are currently tracing if and how the choices indicated in the dyad directive (LAD-3) change over time, and whether these choices translate into goal-concordant care. At the very least, the three-step LAD procedure to deliberately identify patient-proxy differences and allow for a discussion while the patient still has decision-making ability will give the proxy an opportunity to learn about the patient's goals and wishes firsthand and directly from the patient. This will limit the problem of proxies blindly making future health decisions on behalf of the patient with no prior knowledge of the patient's preferences. This three-step LAD procedure can be utilized in patients with any chronic or serious illness as a structured and simple way of eliciting what matters most to patients and allowing them an opportunity to discuss their choices with their proxies.

Conclusion

We have shown that in a high-risk (HSCT) population, patients and their proxies can successfully collaborate to

build consensus in ACP documentation using a three-step procedure. While the process of ACP is complex and challenging, a simple act of identifying the patient-proxy differences in opinion and allowing them an opportunity to discuss each specific choice and have an opportunity to reconcile them is a crucial step in moving toward patient-centered end-of-life decision making.

Acknowledgments

Dr. Periyakoil's time is supported by Grants R25MD006857, U54MD010724, VA: 1P1HX001980-01, and 5P50AG047366. Dr. Alagappan and Mr. Schoen were supported by the Stanford School of Medicine's Medical Scholars Research Program. The Stanford Letter Project is supported by a grant from the Feigenbaum Nii Foundation.

The study protocol was approved by the Stanford Institutional Review Board.

Author Disclosure Statement

The authors declare that there is no conflict of interest.

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Address correspondence to:
Vyjeyanthi S. Periyakoil, MD
Stanford University School of Medicine
1265 Welch Road
Stanford, CA 94305

E-mail: periyakoil@stanford.edu