Proceedings of UCLA Health
-VOLUME 23 (2019)-

ORIGINAL RESEARCH

Improving Patient and Surrogate Decision Maker Concordance by Defining Minimal Quality of Life

Haley Vertelney, BS[1], Jill Waalen, MD, MPH[2], Robert DeMonte, MD[3] and Lilian Hsu, MD[4]

[1]David Geffen School of Medicine at UCLA
[2]Scripps Research Translational Institute
[3]Scripps Dept. of Geriatric Medicine
[4]University of California Los Angeles Dept. of Medicine

Introduction

One of the main principles of medical ethics is patient autonomy—the patient's right to accept or refuse treatments according to their values. This is a cornerstone of self-determination that persists even when the patient is incapable of making decisions themselves. When patients lack capacity, clinicians rely on patient-designated or next-of-kin surrogate decision makers to accept or refuse treatments with the assumption that they will make the same decision as the patient would in each situation. Under the Patient Self-Determination Act, a patient can formally designate a surrogate. When the role is not assigned, many states have a defined legal hierarchy for determining who will serve as surrogate, which is typically the next-of-kin.[1]

Surrogates are involved in decision making with up to 40% of hospitalized patients and for 70% of patients over the age of 60.[2,3] A problem can arise, however, if a patient has become incapacitated without communicating their wishes beforehand, leaving physicians and family members without explicit instructions for how to best respect their wishes.

Patients value their autonomy. Fifty-seven percent of Californians say it is “extremely important” that their medical care wishes are followed.[4] Furthermore, they report that they expect that their chosen surrogate will accurately match the decisions they make for themselves in 87% to over 90% of circumstances.[4] However, Shalowitz et al. have shown that the actual participant-surrogate agreement in end-of-life choices can be as low as 68% (95% CI, 63-72).[1]

Many patients complete Advance Directives (ADs) to clarify their preferences for medical care when they are incapacitated, though it is clear that the current documents do not necessarily help surrogates honor patients’ wishes.[1] We hypothesized that the Minimum Quality of Life Form (MQLF) indicating specific capabilities necessary for achieving minimal acceptable outcome will improve agreement (Figure 1). This approach more clearly communicates the patient’s desired results rather than focusing on accepting or refusing specific interventions. The shift in focus to preferred outcomes may enable physicians and surrogates to better respect the patient’s end of life preferences in choosing treatment. The Life Support Preferences Questionnaire (LSPQ), a form created and validated by Beland and Froman after the Patient Self-Determination Act was enacted in 1991 was used to measure participant-surrogate agreement.[5]

Methods

Recruitment:

A convenience sample of ninety inpatients older than 18 years were recruited at a teaching hospital over a two week period. All patients admitted to the inpatient teaching service and hospice consult service, as well as hospital staff, residents, and medical faculty working on the service were included. Participants with pregnancy, delirium, and dementia, as well as those with existing documentation indicating end of life preferences were excluded. Participants meeting these criteria were approached over the two-week period of active recruitment. We did not maintain a log of the number of people approached who refused to participate and why they refused.

Randomization:

Envelopes were prepared to include the AD alone (control) or AD plus MQLF (intervention) (Figure 1).The allocation sequence was determined using a random number generator. Intervention envelopes were numbered according to the randomization sequence. Investigators were blinded to the sequence and enrolled participants were assigned envelopes sequentially.

Participant Instructions:

Participants were instructed to complete the forms included in the randomly assigned envelope and return them to the researchers. They indicated treatment preferences in the five scenarios on the Life Support Preferences/Predictions Questionnaire LSPQ and returned it in a separate sealed envelope. They did not communicate with surrogates during this process.

Researchers distributed a sealed envelope containing the completed AD (and MQLF for the intervention group) to a participant's corresponding surrogate along with a blank LSPQ. Surrogates were instructed to "Give the answer that you think the person who has designated you their Designated Power of Attorney (DPOA) would give, based on your prior discussions and the documents they have filled out." They completed this task in private and returned their LSPQ in a sealed envelope to the researchers.

Statistical Analysis:

The primary endpoint was percent agreement between participants and surrogates on the LSPQ. Agreement was scored as 1 point per scenario for both participant and surrogate choosing treatment or both choosing no treatment, for a total agreement score ranging from 0/5 (0%) to 5/5 (100%) for each pair. Mean percent agreement was compared between the groups using Student's t-test and percent agreement for individual scenarios on the LSPQ were compared between groups using the Fisher's exact test. As a secondary analysis, among participant-surrogate pairs that disagreed regarding treatment/no treatment, we determined whether the surrogate preferred treatment (i.e. was more aggressive) overall and according to whether they were a health care provider. The amount of time a person would tolerate being below their minimal quality of life was compared between medical personnel (those who interact with patients professionally) and others with a t-test.

Results

Of the 90 participant-surrogate pairs recruited, a total of 40 (20 per group) completed the study (Figure 2). We found no significant difference between the two groups with respect to baseline participant characteristics (Table 1). We found that most participants chose their spouse or significant other, and that relationship of surrogate to participant was also not different between the two groups.

We compared participant-surrogate agreement across all 5 scenarios as well as across each question individually by intervention group (Table 2). There was a significant difference between the two groups overall with a higher agreement in the group that received the MQLF (83% agreement) compared to those that did not (68% agreement) (p=0.02).

There was good agreement between participants and their surrogates in hypothetical scenarios of coma and persistent vegetative state, ranging from 80% to 100% in both control and intervention groups. For the intractable pain scenario agreement was lower but similar in both groups (70% and 65%). For the scenarios of chemotherapy or dementia, agreement was higher in the intervention group (80% for both scenarios) compared with the control (55% and 50% respectively), but the differences were not statistically significant.

We found that surrogates would make more aggressive treatment decisions than participants in all scenarios regardless of MQLF use except for intractable pain. One hundred percent of surrogates were more aggressive than participants for questions regarding coma and vegetative state for both MQLF and non-MQLF groups. Overall, 54% of surrogates were more aggressive than participants for hypothetical scenario regarding chemotherapy, and 77% were more aggressive for hypothetical scenario involving dementia. Forty-six percent of surrogates were more aggressive than participants for questions regarding intractable pain overall. We also found that medical personnel would on average tolerate being below their minimal quality of life for 1.0 months (SD 0.8 months), whereas non-medical personnel would tolerate for 4.7 months (SD 4.3 months) (p=0.05).

Discussion

Our results suggest that the Advance Directive does not adequately stand alone in maintaining patient autonomy, and that the MQLF improves surrogate-participant agreement when used concomitantly with the AD in five common end-of-life medical scenarios. We propose that the MQLF may be superior to the AD alone because it provides the context in which medical therapy, including life support, should be provided or withheld.

There are many barriers to effective communication between medical professional, surrogate, and patient. Prior discussions for end-of-life preferences are rarely held, and even if they do take place, they do not actually improve surrogate accuracy.[1] Shalowitz et al. demonstrated that surrogates are accurate 68% of the time when only the AD is used, yet this is a prevalent method of making treatment choices.[1]

The failure of the AD in maximizing patient-proxy concordance is consistent with our findings that demonstrate 68% participant-surrogate agreement when an AD alone is used. We found that the MQLF enhanced this agreement to 83%, a statistically significant improvement (p=0.02). There was better agreement between subjects and surrogates in hypothetical scenarios of coma, persistent vegetative state, and intractable pain than there was in scenarios involving chemotherapy and dementia, perhaps because surrogates consider the former to be more clearly permanent and therefore feel more comfortable refusing intervention. The hypothetical scenario regarding dementia showed a discordance between the MQLF (80%) and the non-MQLF group (50%) that approached statistical significance (p=0.10), possibly indicating that surrogates would be more challenged to make the correct decision in this situation without explicit documentation from the patient. The significant difference between the two groups when examining all five questions overall is promising for meaningful difference between the groups. It is possible that a larger sample size may have revealed statistical significance among individual questions.

One explanation for the success of the MQLF could be its shift in focus from interventions to intended outcomes. In the MQLF, the patient describes the cognitive skills and emotional needs they require to achieve their minimal acceptable quality of life. Any treatment that would not achieve at least those needs in a patient-specified timeframe would not appropriate. The AD focuses on specific interventions, such as intubation or CPR. Marks et al. show that as few as 16% of patients discuss their CPR preferences with their family members, and even fewer (7%) do so with their physicians, even with the AD widely available. [6]

Most patients who fill out documentation do so with an attorney.[7] Bern-Klug et al. propose that this could be because critically ill patients typically have a team of doctors facilitating their care, which makes it difficult to know with whom to have the discussion.[7] It is more likely that a patient will have one lawyer, making them a clearer point person. A meeting with an attorney could be less rushed and held in an office setting more conducive to intimate talks than an interaction in a hospital setting. However, patients may not be able to make the informed decisions with a lawyer as they would with a medical professional because a lawyer is generally less versed in medical interventions and their typical outcomes.[7] When interventions outlined in ADs are not discussed with a medical professional, surrogates may make decisions without understanding the possible outcomes of life support. Shif et al. found this lack of awareness of outcomes to be true for cardiopulmonary resuscitation (CPR). The majority of surrogate decision makers interviewed in the ICU did not know the main indications for CPR.[8] Expectations of survival after CPR were greater than 75% though the actual survival rate has been shown to be between 0% and 16% depending on the time elapsed since arrest, presenting rhythm, early defibrillation, and other factors.[8,9] Clarification of the potential burdens of life support could impact surrogates' decisions for patients. Angelo et al. explored this idea by showing CPR videos to one group of patients with advanced cancer and simply describing what CPR entails to another. Twenty percent of those who watched the video opted for CPR vs 48% of those who just listened to the verbal description.[10] It is clearly important to comprehensively convey the risks and likely outcomes associated with medical interventions in order for a patient to make an informed choice about their end of life preferences. Lawyers are less equipped to educate patients on the interventions available than an experienced medical professional would be. Furthermore, we propose that the MQLF is superior to the AD because it may be easier for patients to make informed decisions about their minimal acceptable outcome than to accept or refuse specific interventions they may not entirely understand.

One of our endpoints was to investigate if medical personnel chose treatment preferences differently from those whose work does not involve patient care, and if they were more or less aggressive. We found that medical personnel would on average tolerate being below their minimal quality of life for as little as one fifth of the average time that non-medical personnel stated they would endure. Individuals more familiar with the course of treatment at the end of life could have more realistic expectations for outcomes, and therefore be less tolerant of prolonging life when its quality is below acceptable.

Another primary endpoint was to explore whether surrogates chose more aggressive care than patients would have wanted. We found that in nearly all circumstances when the participant and surrogate did not agree, the surrogate wanted more aggressive care than the participant. This is also found in other studies.[1,6,11] The default choice when they are unsure of patient preferences may be the more aggressive choice, reflecting a desire to do everything possible to prolong life.

We observed that many inpatients and patients who were terminally ill declined to participate, perhaps due to prioritizing time in ways other than participating in a study when at the end of life. Our convenience sample included residents and others who were not patients who were imminently dying, so our results could be biased towards people who are not currently facing these choices. Keeping a log of how many people were approached to participate could have helped us clarify selection bias like the one we observed for the terminally ill.

Notably, there were no Medicare billing codes for end of life discussions until 2013, and widespread use was not initiated until 2016.[12] This limited reimbursement for these important, often time-consuming conversations, which created an obvious financial incentive for doctors to have fewer or shorter discussions. We did not examine exactly how this impacted frequency or quality of discussions at the time, but our study was done shortly after billing capability was established. It is possible that the practice of having these discussions has changed now that some time has passed since billing codes were instated. Future studies could examine exactly how this has impacted the frequency and quality of end of life discussions between patient, surrogate, and practitioner.

Conclusion

Our results demonstrate that the MQLF improves agreement between patients and their surrogate decision makers in five common end-of-life scenarios. It significantly improves upon the current gold standard—the Advance Directive—when they are used together. It is a promising tool for bettering patient-surrogate agreement.

We found that when discordant with subject wishes, surrogates tend to choose more aggressive treatment than the patient would have wanted. This was true for both groups in our study. Healthcare professionals tended to choose less aggressive treatment and would tolerate being below their minimal acceptable quality of life for less time than people who did not work in healthcare.

Limitations:

Though the five scenarios we chose are common and representative of what a patient might face in end-of-life care, it is impossible to examine all possible situations. The scenarios we chose may not accurately reflect actual decision making, especially given our binary yes/no options to treatment. Additionally, surrogate decision makers usually have the input of other individuals familiar with the patient when making these important decisions.

Beland and Froman validated the Life Support Preferences Questionnaire.[5] However, the version of the LSPQ they validated included six scenarios. We removed the sixth scenario of the form because it did not apply to the situation we were studying. By doing so, the validity of the form was lost in this preliminary study. Moving forward, our MQLF could be validated and examined for its impact when used on its own.

Additionally, the currently available documents are static. A patient filling out an Advance Directive lists their preferences for the moment in which they filled it out. In reality, patients' values can change over time, and the documentation for their end of life preferences should reflect that development. The MQLF could be improved to be dynamic, prompting patients to revisit the document over time to update it.

Future Considerations:

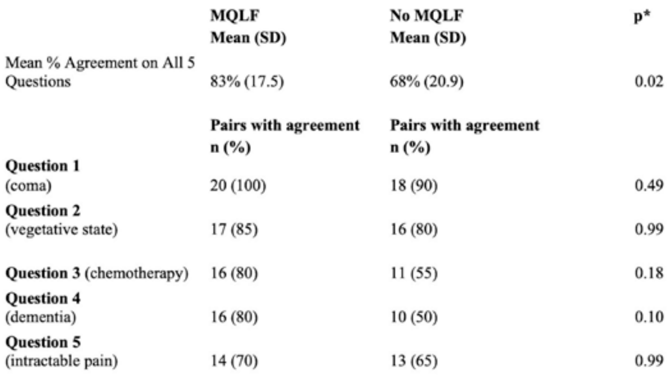
Further investigation is necessary to determine if encountering these scenarios at an older age would change a patient's treatment preferences and acceptable minimal quality of life. The MQLF is a snapshot of a patient's preferences at a point in time, and they may not be static. Interestingly, Zweibel et al. found that surrogates chose no treatment more often than not when the patient is an older relative.[11] The patient's age might impact their personal preferences as well as the surrogate's perception of their preferences. Repeating our study with a participant population that is imminently facing end-of-life decisions would be worthwhile.

The MQLF could be improved to allow patients to prioritize certain qualities over others. The scenarios are currently weighted equally, and the same time frame is applied unequivocally to all. The MQLF could be modified to allow patients to quantify the amount of pain or discomfort that makes life not worth living. The MQLF should be compared to the AD alone to determine if it improves participant-surrogate agreement independent of the AD. Additionally, current documentation of end of life preferences could be improved not only to provide minimal quality of life, but to help patients understand available life-sustaining interventions and their outcomes.

The authors have no financial disclosures to declare and no conflicts of interest to report.

Table 1. Baseline Participant Characteristics by Intervention Group.

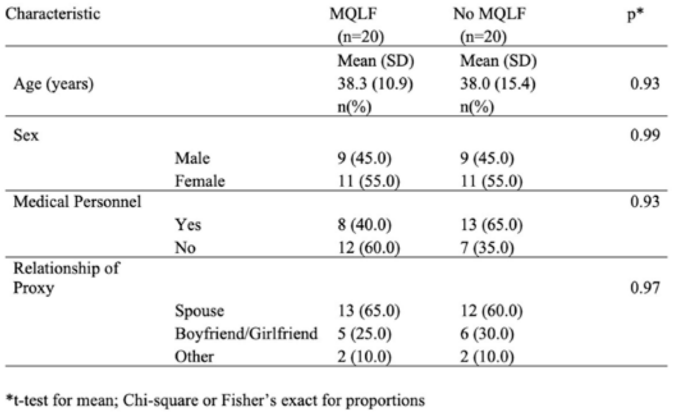
Minimal Quality of Life Form (MQLF)



	MQLF **Mean (SD)**	**No MQLF** **Mean (SD)**	**p***
Mean % Agreement on All 5 Questions	83% (17.5)	68% (20.9)	0.02
	Pairs with agreement **n (%)**	**Pairs with agreement** **n (%)**	
Question 1 (coma)	20 (100)	18 (90)	0.49
Question 2 (vegetative state)	17 (85)	16 (80)	0.99
Question 3 (chemotherapy)	16 (80)	11 (55)	0.18
Question 4 (dementia)	16 (80)	10 (50)	0.10
Question 5 (intractable pain)	14 (70)	13 (65)	0.99

Table 2. Percent Participant-Proxy Agreement on Scenario Questions by Intervention Group.

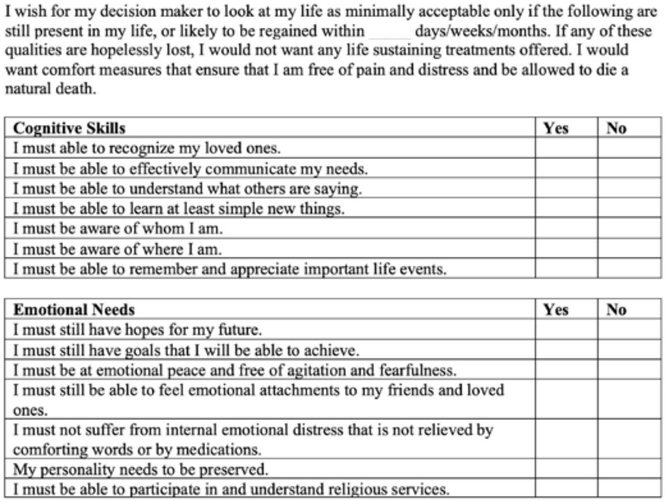
Minimal Quality of Life Form (MQLF)



Characteristic		MQLF (n=20)	No MQLF (n=20)	p*
Age (years)		Mean (SD) 38.3 (10.9)	Mean (SD) 38.0 (15.4)	0.93
		n(%)	n(%)	
Sex				0.99
	Male	9 (45.0)	9 (45.0)	
	Female	11 (55.0)	11 (55.0)	
Medical Personnel				0.93
	Yes	8 (40.0)	13 (65.0)	
	No	12 (60.0)	7 (35.0)	
Relationship of Proxy				0.97
	Spouse	13 (65.0)	12 (60.0)	
	Boyfriend/Girlfriend	5 (25.0)	6 (30.0)	
	Other	2 (10.0)	2 (10.0)	

*t-test for mean; Chi-square or Fisher's exact for proportions

Figure 1. Minimal Quality of Life Form (MQLF). The MQLF lists different abilities the patient can indicate as necessary to prolong their life.

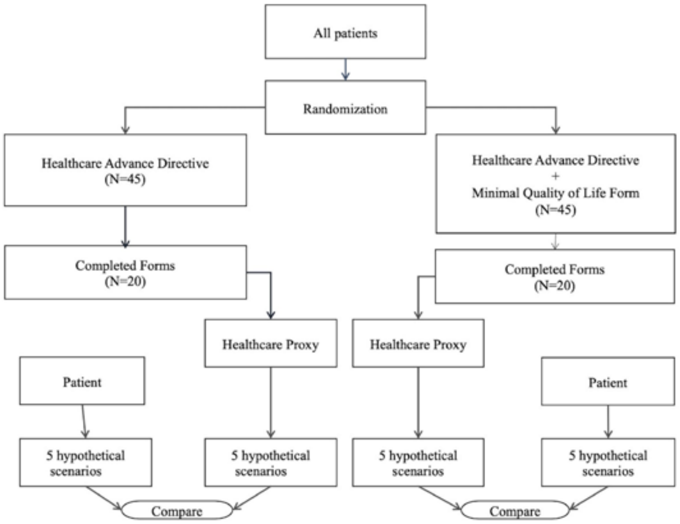


I wish for my decision maker to look at my life as minimally acceptable only if the following are still present in my life, or likely to be regained within ______ days/weeks/months. If any of these qualities are hopelessly lost, I would not want any life sustaining treatments offered. I would want comfort measures that ensure that I am free of pain and distress and be allowed to die a natural death.

Cognitive Skills	**Yes**	**No**
I must able to recognize my loved ones.		
I must be able to effectively communicate my needs.		
I must be able to understand what others are saying.		
I must be able to learn at least simple new things.		
I must be aware of whom I am.		
I must be aware of where I am.		
I must be able to remember and appreciate important life events.		

Emotional Needs	**Yes**	**No**
I must still have hopes for my future.		
I must still have goals that I will be able to achieve.		
I must be at emotional peace and free of agitation and fearfulness.		
I must still be able to feel emotional attachments to my friends and loved ones.		
I must not suffer from internal emotional distress that is not relieved by comforting words or by medications.		
My personality needs to be preserved.		
I must be able to participate in and understand religious services.		

Figure 2. Schematic representation of study design and how many subjects in each group responded. Forty-five participant-proxy pairs were recruited and randomized into each group. Twenty in each group completed the forms.



REFERENCES

1. **Shalowitz DI, Garrett-Mayer E, Wendler D**. The accuracy of surrogate decision makers: a systematic review. *Arch Intern Med*. 2006 Mar 13;166(5):493-7. Review. PubMed PMID: 16534034.
2. **Raymont V, Bingley W, Buchanan A, David AS, Hayward P, Wessely S, Hotopf M**. Prevalence of mental incapacity in medical inpatients and associated risk factors: cross-sectional study. *Lancet*. 2004 Oct 16-22;364(9443):1421-7. PubMed PMID: 15488217.
3. **Silveira MJ, Kim SY, Langa KM**. Advance directives and outcomes of surrogate decision making before death. *N Engl J Med*. 2010 Apr 1;362(13):1211-8. doi: 10.1056/NEJMsa0907901. PubMed PMID: 20357283; PubMed Central PMCID: PMC2880881.
4. **Brownlee S**. End-of-Life Care in California: You Don't Always Get What You Want. *California Healthcare Foundation*. 2013.
5. **Beland DK, Froman RD**. Preliminary validation of a measure of life support preferences. *Image J Nurs Sch*. 1995 Winter;27(4):307-10. PubMed PMID: 8530120.
6. **Marks MA, Arkes HR**. Patient and surrogate disagreement in end-of-life decisions: can surrogates accurately predict patients' preferences? *Med Decis Making*. 2008 Jul-Aug;28(4):524-31. doi: 10.1177/0272989X08315244. Epub 2008 Jun 19. PubMed PMID: 18566485.
7. **Bern-Klug M, Byram EA**. Older Adults More Likely to Discuss Advance Care Plans With an Attorney Than With a Physician. *Gerontol Geriatr Med*. 2017 Nov 17;3:2333721417741978. doi: 10.1177/2333721417741978. eCollection 2017 Jan-Dec. PubMed PMID: 29201947; PubMed Central PMCID: PMC5697586.
8. **Shif Y, Doshi P, Almoosa KF**. What CPR means to surrogate decision makers of ICU patients. *Resuscitation*. 2015 May;90:73-8. doi: 10.1016/j.resuscitation.2015.02.014. Epub 2015 Feb 21. PubMed PMID: 25711518.
9. **Marco CA**. Ethical issues of resuscitation: an American perspective. *Postgrad Med J*. 2005 Sep;81(959):608-12. Review. PubMed PMID: 16143694; PubMed Central PMCID: PMC1743345.
10. **Volandes AE, Paasche-Orlow MK, Mitchell SL, El-Jawahri A, Davis AD, Barry MJ, Hartshorn KL, Jackson VA, Gillick MR, Walker-Corkery ES, Chang Y, López L, Kemeny M, Bulone L, Mann E, Misra S, Peachey M, Abbo ED, Eichler AF, Epstein AS, Noy A, Levin TT, Temel JS**. Randomized controlled trial of a video decision support tool for cardiopulmonary resuscitation decision making in advanced cancer. *J Clin Oncol*. 2013 Jan 20;31(3):380-6. doi: 10.1200/JCO.2012.43.9570. Epub 2012 Dec 10. PubMed PMID: 23233708; PubMed Central PMCID: PMC4090424.
11. **Zweibel NR, Cassel CK**. Treatment choices at the end of life: a comparison of decisions by older patients and their physician-selected proxies. *Gerontologist*. 1989 Oct;29(5):615-21. PubMed PMID: 2599421.
12. **Carlson T, Marshall L**. Advance Care Planning. ACP Frequently Asked Questions. https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/PhysicianFeeSched/Downloads/FAQ-Advance-Care-Planning.pdf. [CMS web site]. June 2018. Accessed September 2018.