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Abigail M. Bohn

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Advance Directives: Do I need one?

Abigail Bohn

Department of Nursing

NURS 499: Senior Capstone

Dr. Cristan Sabio

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Abstract

Background: An advance directive is a document explaining the extent of medical treatment an individual wishes to receive in the event that they are no longer able to make decisions for themselves. Purpose: The purpose of this paper is to determine the impact of advance directives and to find ways to improve the advance care planning process. Methods: Twelve peer reviewed journal articles, containing both qualitative and quantitative data, discussing the use of advance directives in acute and primary care settings with amongst populations were referenced. Results: Results of these articles show that advance care planning should begin in the primary care setting while individuals are still capable of making their own decisions for future health care. Conclusion: Advance directives are not being utilized enough and when they are the documents are insufficient. More research is needed on measures to increase the use and effectiveness of advance directives.

Introduction

Do you have an advance directive? Do you even know what an advance directive is? I do, because I have researched what exactly it means to have a health care advance directive (AD) and how easily accessible they are to attain. I have put together a literature review compiling the information I found and took this research one step further. I don't want to know just what is being done now, I want to know what more we can do to ensure that the number of individuals with their own advance directive grows, as well as how we can improve the advance care plan (ACP) process.

Purpose

Only a quarter of people in the United States have an advance directive today (Anderson, Aldous, & Lupu, 2018). ADs enable clients to work with health care providers (HCP) and their loved ones to decide their end-of-life (EOL) wishes and the process to carry them out if they are one day no longer able to speak for themselves (Blackford & Street, 2011 as cited in Eunju Kim & Yoonju Lee, 2019). According to a study about advance directives, when patients are involved with their advance care plans they experience an increase in quality of life, fewer acute care admissions, and lower end-of-life health care costs (Detering, Hancock, Reade, & Sylvester, 2010; Denvir, Murray, & Boyd, 2015; Dixon, Matosevic, & Knapp, 2015; Zhang et al., 2009 as cited in Killackey, Peter, MacIver, & Mohammed, 2019). Plus, their caregivers experience lower rates of depression and anxiety since they don't have so much pressure placed upon them to follow their loved ones' wishes. Advance care plans are not only necessary for those with chronic and terminal illnesses. These documents are very helpful for anyone to have. Imagine you get hit by a bus tomorrow. Do you know what measures you'd want doctors to go to in order to save you? Does your family know? If you're the only one who knows your wishes, it might not be up to you to decide them in such cases.

Before I started the nursing program I didn't even know what an advance directive was and I bet there are a lot of others who haven't heard of them as well. This is part of the reason I am so passionate about finding out what more we can do to make advance directives more accessible and beneficial. Here's how I learned about ADs.

During my second semester in the nursing program I did my first medical-surgical clinical rotation at Northwestern Medicine Kishwaukee Hospital in DeKalb. One day there we had a presentation about advance care planning, explaining what they do and how to get one. I thought that I better get one after hearing this lecture. However, being a busy nursing student I

never made the time to do so and eventually forgot all about it. Fast forward a few semesters and I started my nurse internship the summer before my senior year at Advocate Sherman Hospital in Elgin where my real passion for improving advance directives began.

Day one of my internship I was in the intensive care unit (ICU) where I was super nervous and excited. I was assigned to one nurse and his two patients. These were pretty interesting cases and the morning had started out well. Although, there was another nursing student in the ICU who had an even more interesting case than me. She and her nurse had only one patient assignment that day because of how critical this patient was. The patient had a lot of comorbidities and was currently enduring respiratory distress. As I watched the doctor intubate her, I had no idea how important her story would eventually become.

By the end of day one we had to transfer this patient onto a special bed that is able to put the person in prone position, or to lie on one's abdomen. This is done to help relieve the pressure of the diaphragm from the chest, helping to ease the work of breathing, even when intubated with an artificial airway. The fact that this patient had to be intubated and placed in this special bed that day meant she was in pretty bad shape and I wasn't really sure if she would still be alive when we came back to clinical next.

Two days passed and we were back in the ICU. The patient was still there looking even worse than before. The other student with me in the ICU got assigned back to that patient and even the same nurse as before. Luckily for me, I became more involved with this case than with the patients I had been assigned to that day. This patient's nurse told me and the other student that things were not looking good and that this patient would most likely be crashing before lunch. She was right. Before noon that day, I was pressing the code blue button in the patient's room and starting CPR next. This was very scary but also exciting at the same time being a

nursing student and learning so much so early on in my nursing career. We coded the patient three separate times before she finally stopped fighting and passed away. Her death was sad, but unfortunately that wasn't the most traumatic part of this situation.

As I had mentioned earlier, this patient had a lot of medical problems and was already in bad shape when she came to us. The outcome was starting to look poor, but her power of attorney (POA) was her husband and he wanted us to do everything we could to save her. How can you blame someone for wanting to keep their loved one alive? You can't blame them until it becomes an ethical issue, which this case definitely did. There was no way this woman was going to make it no matter what we did. We had her receiving the highest possible doses she could of not one, not two, but five different medications that work to increase blood pressure. Yet, her blood pressure was still not nearly high enough to adequately perfuse all the organs in the body. If a miracle happened and this woman survived she would never be the same again. Her blood pressure was so dangerously low that she was unable to have any pain or sedation medications. If she were to receive pain medication, her blood pressure would have dropped to the point of stopping her heart. Therefore, this woman was awake and aware of what was happening to her up until her heart gave out. If you asked her if she was in pain and to squeeze your hand indicating "yes," she would. This poor patient hardly looked human anymore by the time she passed away. She had become severely bruised and swollen around her face. She was bleeding out of random places. Her skin was coming off onto our gloves as we performed chest compressions on her. She was in pain and alone. None of her family came to see her that day. Her nurse had informed her husband that she most likely wasn't going to survive the day, and he had told her that he had things to get done and would be there when he got there. She died before he made it, after who knows how many fractured ribs and the amount of not only physical but

also emotional pain she must have endured that day. This happened because she could no longer speak for herself and chose the wrong person to be her POA, who put her through so much suffering when the end result was inevitable either way.

This was the day I realized how important it is to have an advance directive and POA that will be able to abide by my wishes if such a day ever comes where I can no longer make decisions for myself. This is so important for not only me but everyone, because no one deserves to go through what I witnessed this poor patient go through. Sadly, this is sometimes the case because even if you have an advance directive your POA or health care provider might not always follow your wishes. That is why I believe that there needs to be a better way to follow the patient's wishes in cases like these.

Methodology

I have compiled a systemic literature with twelve studies using the CINAHL (Cumulative Index to Nursing and Allied Health) Complete database, one of the most common databases used for nursing research. This was done by searching the key words advance directives or advance care plans, for full-text peer reviewed journals completed between 2010-2020 worldwide, with abstracts and references available. The data from these studies was summarized and analyzed for the current statistics about advance care plans, such as how many people have one, their accessibility, and efficiency. I have also included information including the current forms used in advance care planning from Northwestern Medicine Kishwaukee Hospital in DeKalb, Illinois; see Appendices A-J).

I found ways to improve accessibility such as offering them not only in acute inpatient care but also primary outpatient settings. I looked into improving efficiency as well, which can

be done by expanding on the scenarios listed on the advance care plan form rather than simply asking the individual if they prefer quality or quantity of life. I reviewed twelve professional sources for this paper and poster presentation, covering the importance of having and improving advance directives.

Review of Literature

A study done by Nassikas, Baird, & Duffy (2020) was done to determine ways to improve the number of advance directives being completed in the primary care setting. This is because Medicare began reimbursing providers for advance care planning in 2016, yet only one-third of chronically ill individuals have one, and only about 25% of all U.S. adults do (Nassikas et al., 2020). Part of this is due to physicians not feeling confident enough to have these much needed discussions. For this study physicians underwent a thirty minute advance care planning educational program before discussing ADs with the study participants (295 individuals age sixty-five and up being seen in the internal medicine primary care setting over a six-month period), leading to an increase in the mean number of documented ACP discussions from 2.24 (95% confidence interval [CI]: 1.0-4.9) to 8.94 (95% CI: 5.94-13.24) based on a Likert scale (Nassikas et al., 2020). This research shows that even with minimal intervention, physicians can be more confident in discussing advance care planning needs, enabling said discussions to begin much earlier in life when the patient is still young and healthy in the primary care setting at regular visits.

Lum, Jones, Matlock, Glasgow, Lobo, Levy, & Kutner (2016) discuss the need to improve ACP processes and conversations in the primary care setting. A pilot study was performed including nearly eighty participants age sixty-five and older meeting in a geriatrics clinic on two separate sessions each two hours long, one a regular visit and the other as a group

(Lum et al, 2016). In these meetings with a HCP and a social worker, discussions were had regarding ACPs through the RE-AIM framework. RE-AIM stands for Reach, Effectiveness, Adoption, Implementation, and Maintenance. The article gives further explanation for each “Reach: Will older adults participate in an advance care planning group visit? Effectiveness: Will older adults engage in advance care planning conversations? Adoption: Will providers refer patients? Implementation: Will patients come to both sessions? What aspects of advance care planning will older adults discuss in the GMV [group medical visits]?” (Lum et al., 2016). The maintenance portion of the RE-AIM framework was not assessed in this study. Lastly, it was found that these group sessions greatly increased patient engagement in ACP discussions (Lum et al., 2016).

A qualitative New Zealand study by Davidson, Banister, & de Vries (2013) was done to explain the importance of completing advance directives in the primary care setting. This is due to the growing aging population and the effectiveness of ACPs in facilitating quality end-of-life care. This study determined how nurses who are currently working in primary care feel regarding their role with advance care planning as well as their previous knowledge and experience with ACP. The nurses in this study claim that ADs give patients a "voice when they don't have a physical voice anymore" (Davidson et al., 2013). Thirteen senior nurses were interviewed and only one of them had previous experience with advance directives, yet they all agreed that ADs should be discussed in the primary care setting while the patient is still well and able enough to make one (Conroy, Fade, Fraser, & Schiff, 2009; Putman-Casdorph, Drenning, Richards, & Messenger, 2009, as cited in Davidson et al., 2013). This is because they have "seen too many people resuscitated that shouldn't have been" (Davidson et al, 2013). Despite not having much professional experience with ACPs, many of the nurses went through personal experiences with

family members where they had wished that an advance directive had been in place to make their loved ones more comfortable in their final days (Davidson et al., 2013). Having an AD gives the individual some control over the situation and allows for autonomy.

Additional research found in an article by Bowman (2019) discusses the importance of understanding ethics in oncological nursing. Nurses play a key role in helping patients plan their EOL care, so it is important that nurses are supported in understanding ethics just as much as physicians. In the article “How to Have Ethical Discussions in your Practice,” the importance of advance care planning is explained through a patient story (Bowman, 2019). This young patient is fighting a losing battle with cancer. His wife doesn’t want him to give up, but she is willing to respect his wishes. He makes an advance directive for her to follow when the time comes. She claims it makes her feel stronger because she knows that she is making the decisions he would have wanted even if they’re not what she wants (Bowman, 2019). This article is a perfect example as to just how important it is to have an advance directive.

Discussing ethics when researching ACPs is very important. A study done by Saïoron, Ramos, Schneider, da Silveira, & Silveira (2017) explains how culture and religion are also very important factors to consider and can impact decision making when making advance care plans. Culture plays a very large role in an individual’s health care making decisions, especially when the decisions involve life and death. In some cultures, it isn’t common to discuss death. Both culture and religion can affect the emotions displayed when death occurs or is near. However, it is crucial to have an advance directive so health care providers will know what exactly the patient’s wishes are if they can no longer speak for themselves.

An article by Saralegui, De Ormijana, Delgado, Zabala, Gabilondo, & Melendez (2018) describes the Shared Care Planning (SCP) approach which focuses more on having EOL care

discussions rather than just filling out paperwork about said discussions. The importance of individuals being involved in these discussions with their families and health care providers is emphasized. SCP includes education for community members and training courses for health care workers (Saralegui et al., 2018). The focus of the study was chronically ill patients, the elderly, and others nearing the end of life, as well as anyone else considering their EOL wishes. SCP is continuing to grow today among the community it started in and is a great method that can be used to greatly improve the number of advance directives today.

A systemic review done by Pearse, Oprescu, Endacott, Goodman, Hyde, & O'Neill (2019) claims that about one-third of the study's participants (patients requiring the rapid response team [RRT] to respond to a rapid clinical deterioration while in the hospital out of a total of 47,850 patients) were patients nearing end-of-life. When patients are admitted to the hospital and don't have any advance care planning documents, they are considered a full code until stated otherwise. This means that at any time they begin to clinically deteriorate, interventions will be put into place including emergent interventions during rapid responses and cardiac arrests. This study was done to determine the prevalence of pre-existing ACPs and whether rapid clinical decline in the hospital setting prompts EOL care discussions and the potential referral to palliative care services. It was found that patients requiring an RRT had an increase in code status changes and medical treatment limitations but not in advance directives (Pearse et al., 2019). The patients in this study were found to have both high short and long-term mortality rates, yet there was minimal palliative care referrals (Pearse et al, 2019). If a patient may not want certain interventions performed, they need to have an AD before it is too late to make their own decisions which is why patients, their families, and their physicians need to start having advance care planning discussions much sooner than they are (Pearse et al., 2019).

Examining the use of advance directives with chronic kidney disease patients explains that these documents are very helpful but also very underutilized in the study by Anderson, Aldous, & Lupu (2018). This article focuses on an interview process which helps motivate clients to fill out an advance directive. This tool is known as Make Your Wishes About You, also called MY WAY (Anderson et al., 2018). The MY WAY approach works by utilizing health care coaches and providing information to explain that advance care planning is important for all persons, not just those who are seriously ill. It also emphasizes the importance of making these decisions preferably before a person is sick so that they don't make any decisions based on a flood of emotions (Anderson et al., 2018). MY WAY is used after providers have assessed an individual's readiness to have EOL care discussions because it is based around the Stages of Change Theory. This theory includes the stages: "Pre-contemplation: Patient is not ready to change, Contemplation: Patient is thinking about changing behavior, Preparation: Patient is planning to make changes in the future, Action: Patient is actively making, Changes, Maintenance: Change has happened, and patient is making efforts to maintain behavior" (Prochaska & Velicer, 1997, as cited in Anderson et al., 2018). The use of the MY WAY interview approach is just one technique that could increase the number of existing ADs.

Patients with heart failure (HF) are also under utilizing advance directives. Heart failure is the leading cause of hospitalization and the second leading cause of death in Canada, according to Killackey, Peter, MacIver, & Mohammed (2019). This review determined that the majority of HF patients do not have ACPs due to the uncertainty of life, fear and discomfort of discussing death, the lack of appropriate timing to discuss, and lack of trusting provider-patient relationships (Killackey et al., 2019). These barriers could be greatly reduced if HCPs took the

time to discuss advance directives during regular primary care visits, therefore increasing the number of ADs.

An article by Block, Smith, & Sudore (2018) discusses how important ADs are while also explaining how they are not currently sufficient enough. It explains how the current advance care planning process isn't really a process, it's just the signing of some forms. However, it should be a process. A process would aid in the efficiency of advance directives much more than simply signing a document. For an individual to have their wishes followed advance care planning needs to be much more thorough. This could also help decrease the emotional toll that their POA will go through when making such difficult health-related decisions (Block et al., 2018).

Kestigian & London (2016) discuss what ACP is and why it is so important to have one. They discuss reasons why these documents are not always followed as directed, such as the patient's loved ones feeling like the individual would no longer want said wishes now that they are in said situation. However, it is also explained that following one's wishes is very important to prevent anyone from avoiding making these ADs or selecting certain medical treatments for fear that their loved ones won't follow their wishes (Kestigian & London, 2016). When a patient doesn't have an advance directive, their family may not know their wishes which could potentially lead to poor medical outcomes for the patient, as evidenced by the scenario discussed in the purpose section of this paper. This situation is a perfect example of what happens to individuals who do not have any advance care plans or their families do not know their wishes or wish to follow them.

The article by the 2019 Harvard Heart Letter discusses how to make decisions for yourself or your loved ones in order to plan for the future. It addresses one's current health state

as well as their health care goals, explaining that you don't have to be ill to make an advance directive. The number one cause of death in the U.S. is cardiovascular disease (Harvard Heart Letter, 2019). Cardiovascular disease doesn't always have a predictable progression and can result in sudden death, stressing the importance of having an advance directive (Harvard Heart Letter, 2019). Anyone can make an advance directive at any age and in any health state.

According to the Harvard Heart Letter (2019), these documents should be reviewed every few years as you age (or every few months depending on one's current health state) to maintain accuracy regarding an individual's wishes.

Results

The results of these studies explain the importance of making advance care plans, as well as the need for greatly expanding the usage of advance care planning. This is true for those nearing end-of-life but also for those who are ready to have these discussions. Several approaches have been developed to help improve this process, including RE-AIM, SCP, and MY WAY (Lum et al., 2018; Saralegui et al., 2018; & Anderson et al., 2018). As discussed in the qualitative New Zealand study, beginning ACP discussions in the primary care setting is another method to expand the number of existing ADs (Davidson et al., 2013). The overall results of this research show how simple interventions and tools can easily be implemented into our health care system to increase the number of existing advance directives. However, as helpful as ADs are, one article mentioned how insufficient current documents are and how they need to be much more descriptive (Block et al., 2018).

Discussion

After analyzing the results from my research, it was found that one way the advance care plan process can be improved is through beginning the implementation of discussions and documentation in the primary care setting. It is important to begin this process early while the patient is still able to make their own health care decisions. This practice is becoming more and more popular, helping to expand the number of ADs. This method can be utilized along with the other approaches previously discussed, including the RE-AIM framework, SCP, and the MY WAY approach to further increase the number of existing advance directives. These three approaches all increase the discussions of advance care plans. They make it easier to have those difficult discussions, which is often one of the biggest barriers to creating an AD as the research showed.

As helpful as advance care plans are, their efficiency could stand to be improved according to some of the research I found. This is how I came up with a possible improvement method after completing my research. That is for advance directives to include multiple scenarios that may potentially occur and make an individual unable to speak for themselves. With these scenarios the patient would select the extent of care they would wish to receive in said scenarios. This could be the method needed to increase the efficiency of advance directives that Block et al. (2018) was looking for. This method would allow for much easier decision making with less emotional distress for the individual's POA, as the research showed is very common. It would also be helpful in instances where an individual's POA or HCP choose not to abide by the patient's wishes, as is occasionally done. Although, more research regarding this method needs to be completed for any further evaluation.

Conclusion

The articles researched show just how essential it is to have an advance care plan for patients of all ages and conditions. This is because one of the most important aspects of nursing is advocating for the patient and their autonomy. The articles demonstrate how ADs provide patient autonomy in what may be the most important time to be autonomous, which is why they are so essential. By beginning these conversations early on in one's life in the primary care setting and utilizing RE-AIM, SCP, and MY WAY, the number of existing advance directives will go up. Lastly, I hope you decide to fill out your own advance directive and speak directly to whoever you assign to be your power of attorney about what your wishes are. This way you too can prevent enduring such a tragic patient outcome as previously discussed.

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Appendix A

HIPAA PERMITS DISCLOSURE OF POLST TO HEALTH CARE PROFESSIONALS AS NECESSARY FOR TREATMENT			
 State of Illinois Illinois Department of Public Health		IDPH UNIFORM PRACTITIONER ORDER FOR LIFE-SUSTAINING TREATMENT (POLST) FORM	
<p>For patients, use of this form is completely voluntary. Follow these orders until changed. These medical orders are based on the patient's medical condition and preferences. Any section not completed does not invalidate the form and implies initiating all treatment for that section. With significant change of condition new orders may need to be written.</p>			
Patient Last Name		Patient First Name	MI
Date of Birth (mm/dd/yy)		Gender <input type="checkbox"/> M <input type="checkbox"/> F	
Address (street/city/state/ZIP code)			
A	CARDIOPULMONARY RESUSCITATION (CPR) If patient has no pulse and is not breathing.		
Check One	<input type="checkbox"/> Attempt Resuscitation/CPR <input type="checkbox"/> Do Not Attempt Resuscitation/DNR <i>(Selecting CPR means Full Treatment in Section B is selected)</i>		
When not in cardiopulmonary arrest, follow orders B and C.			
B	MEDICAL INTERVENTIONS If patient is found with a pulse and/or is breathing.		
Check One (optional)	<input type="checkbox"/> Full Treatment: Primary goal of sustaining life by medically indicated means. In addition to treatment described in Selective Treatment and Comfort-Focused Treatment, use intubation, mechanical ventilation and cardioversion as indicated. <i>Transfer to hospital and/or intensive care unit if indicated.</i> <input type="checkbox"/> Selective Treatment: Primary goal of treating medical conditions with selected medical measures. In addition to treatment described in Comfort-Focused Treatment, use medical treatment, IV fluids and IV medications (may include antibiotics and vasopressors), as medically appropriate and consistent with patient preference. Do Not Intubate. May consider less invasive airway support (e.g. CPAP, BiPAP). <i>Transfer to hospital, if indicated. Generally avoid the intensive care unit.</i> <input type="checkbox"/> Comfort-Focused Treatment: Primary goal of maximizing comfort. Relieve pain and suffering through the use of medication by any route as needed; use oxygen, suctioning and manual treatment of airway obstruction. Do not use treatments listed in Full and Selective Treatment unless consistent with comfort goal. Request transfer to hospital only if comfort needs cannot be met in current location. Optional Additional Orders _____		
C	MEDICALLY ADMINISTERED NUTRITION (if medically indicated) Offer food by mouth, if feasible and as desired.		
Check One (optional)	<input type="checkbox"/> Long-term medically administered nutrition, including feeding tubes. Additional Instructions (e.g., length of trial period) <input type="checkbox"/> Trial period of medically administered nutrition, including feeding tubes. _____ <input type="checkbox"/> No medically administered means of nutrition, including feeding tubes. _____		
D	DOCUMENTATION OF DISCUSSION (Check all appropriate boxes below)		
	<input type="checkbox"/> Patient <input type="checkbox"/> Agent under health care power of attorney <input type="checkbox"/> Parent of minor <input type="checkbox"/> Health care surrogate decision maker (See Page 2 for priority list)		
Signature of Patient or Legal Representative			
Signature (required)		Name (print)	Date
Signature of Witness to Consent (Witness required for a valid form) I am 18 years of age or older and acknowledge the above person has had an opportunity to read this form and have witnessed the giving of consent by the above person or the above person has acknowledged his/her signature or mark on this form in my presence.			
Signature (required)		Name (print)	Date
E	Signature of Authorized Practitioner (physician, licensed resident (second year or higher), advanced practice nurse or physician assistant) My signature below indicates to the best of my knowledge and belief that these orders are consistent with the patient's medical condition and preferences.		
Print Authorized Practitioner Name (required)		Phone	
Authorized Practitioner Signature (required)		Date (required)	 Page 1

Form Revision Date - May 2017 (Prior form versions are also valid.)

SEND A COPY OF FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED • COPY ON ANY COLOR OF PAPER IS ACCEPTABLE • 2017

Appendix B

HIPAA PERMITS DISCLOSURE OF POLST TO HEALTH CARE PROFESSIONALS AS NECESSARY FOR TREATMENT

****THIS SIDE FOR INFORMATIONAL PURPOSES ONLY****

Patient Last Name	Patient First Name	MI
<p>Use of the Illinois Department of Public Health (IDPH) Practitioner Orders for Life-Sustaining Treatment (POLST) Form is always voluntary. This order records your wishes for medical treatment in your current state of health. Once initial medical treatment is begun and the risks and benefits of further therapy are clear, your treatment wishes may change. Your medical care and this form can be changed to reflect your new wishes at any time. However, no form can address all the medical treatment decisions that may need to be made. The Power of Attorney for Health Care Advance Directive (POAHC) is recommended for all capable adults, regardless of their health status. A POAHC allows you to document, in detail, your future health care instructions and name a Legal Representative to speak for you if you are unable to speak for yourself.</p>		
Advance Directive Information		
I also have the following advance directives (OPTIONAL)		
<input type="checkbox"/> Health Care Power of Attorney <input type="checkbox"/> Living Will Declaration <input type="checkbox"/> Mental Health Treatment Preference Declaration		
Contact Person Name	Contact Phone Number	
Health Care Professional Information		
Preparer Name	Phone Number	
Preparer Title	Date Prepared	

Completing the IDPH POLST Form

- The completion of a POLST form is always voluntary, cannot be mandated and may be changed at any time.
- A POLST should reflect current preferences of persons completing the POLST Form; encourage completion of a POAHC.
- Verbal/phone orders are acceptable with follow-up signature by authorized practitioner in accordance with facility/community policy.
- Use of original form is encouraged. Photocopies and faxes on any color of paper also are legal and valid forms.

Reviewing a POLST Form

This POLST form should be reviewed periodically and in light of the patient's ongoing needs and desires. These include:

- transfers from one care setting or care level to another;
- changes in the patient's health status or use of implantable devices (e.g. ICDs/cerebral stimulators);
- the patient's ongoing treatment and preferences; and
- a change in the patient's primary care professional.

Voiding or revoking a POLST Form

- A patient with capacity can void or revoke the form, and/or request alternative treatment.
- Changing, modifying or revising a POLST form requires completion of a new POLST form.
- Draw line through sections A through E and write "VOID" across page if any POLST form is replaced or becomes invalid. Beneath the written "VOID" write in the date of change and re-sign.
- If included in an electronic medical record, follow all voiding procedures of facility.

Illinois Health Care Surrogate Act (755 ILCS 40/25) Priority Order

- | | |
|--|---|
| 1. Patient's guardian of person | 5. Adult sibling |
| 2. Patient's spouse or partner of a registered civil union | 6. Adult grandchild |
| 3. Adult child | 7. A close friend of the patient |
| 4. Parent | 8. The patient's guardian of the estate |

For more information, visit the IDPH Statement of Illinois law at
<http://dph.illinois.gov/topics-services/health-care-regulation/nursing-homes/advance-directives>

HIPAA (HEALTH INSURANCE PORTABILITY AND ACCOUNTABILITY ACT of 1996) PERMITS DISCLOSURE TO HEALTH CARE PROFESSIONALS AS NECESSARY FOR TREATMENT

Appendix C

Living Will

DECLARATION

This declaration is made this _____ day of _____ (month, year).

I, _____, being of sound mind, willfully and voluntarily make known my desires that my moment of death shall not be artificially postponed.

If at any time I should have an incurable and irreversible injury, disease, or illness judged to be a terminal condition by my attending physician who has personally examined me and has determined that my death is imminent except for death delaying procedures, I direct that such procedures which would only prolong the dying process be withheld or withdrawn, and that I be permitted to die naturally with only the administration of medication, sustenance, or the performance of any medical procedure deemed necessary by my attending physician to provide me with comfort care.

In the absence of my ability to give directions regarding the use of such death delaying procedures, it is my intention that this declaration shall be honored by my family and physician as the final expression of my legal right to refuse medical or surgical treatment and accept the consequences from such refusal.

Signed _____

City, County and State of Residence _____

The declarant is personally known to me and I believe him or her to be of sound mind. I saw the declarant sign the declaration in my presence (or the declarant acknowledged in my presence that he or she had signed the declaration) and I signed the declaration as a witness in the presence of the declarant. I did not sign the declarant's signature above for or at the direction of the declarant. At the date of this instrument, I am not entitled to any portion of the estate of the declarant according to the laws of intestate succession or, to the best of my knowledge and belief, under any will of declarant or other instrument taking effect at declarant's death, or directly financially responsible for declarant's medical care.

Witness _____

Witness _____

Appendix D

ILLINOIS STATUTORY SHORT FORM POWER OF ATTORNEY FOR HEALTH CARE**NOTICE TO THE INDIVIDUAL SIGNING THE
POWER OF ATTORNEY FOR HEALTH CARE**

No one can predict when a serious illness or accident might occur. When it does, you may need someone else to speak or make health care decisions for you. If you plan now, you can increase the chances that the medical treatment you get will be the treatment you want.

In Illinois, you can choose someone to be your "health care agent." Your agent is the person you trust to make health care decisions for you if you are unable or do not want to make them yourself. These decisions should be based on your personal values and wishes.

It is important to put your choice of agent in writing. The written form is often called an "advance directive." You may use this form or another form, as long as it meets the legal requirements of Illinois. There are many written and on-line resources to guide you and your loved ones in having a conversation about these issues. You may find it helpful to look at these resources while thinking about and discussing your advance directive.

WHAT ARE THE THINGS I WANT MY HEALTH CARE AGENT TO KNOW?

The selection of your agent should be considered carefully, as your agent will have the ultimate decision-making authority once this document goes into effect, in most instances after you are no longer able to make your own decisions. While the goal is for your agent to make decisions in keeping with your preferences and in the majority of circumstances that is what happens, please know that the law does allow your agent to make decisions to direct or refuse health care interventions or withdraw treatment. Your agent will need to think about conversations you have had, your personality, and how you handled important health care issues in the past. Therefore, it is important to talk with your agent and your family about such things as:

- (i) What is most important to you in your life?
- (ii) How important is it to you to avoid pain and suffering?
- (iii) If you had to choose, is it more important to you to live as long as possible, or to avoid prolonged suffering or disability?
- (iv) Would you rather be at home or in a hospital for the last days or weeks of your life?
- (v) Do you have religious, spiritual, or cultural beliefs that you want your agent and others to consider?
- (vi) Do you wish to make a significant contribution to medical science after your death through organ or whole body donation?
- (vii) Do you have an existing advance directive, such as a living will, that contains your specific wishes about health care that is only delaying your death? If you have another advance directive, make sure to discuss with your agent the directive and the treatment decisions contained within that outline your preferences. Make sure that your agent agrees to honor the wishes expressed in your advance directive.

Appendix E

**WHAT KIND OF DECISIONS CAN MY AGENT MAKE?**

If there is ever a period of time when your physician determines that you cannot make your own health care decisions, or if you do not want to make your own decisions, some of the decisions your agent could make are to:

- (i) Talk with physicians and other health care providers about your condition.
- (ii) See medical records and approve who else can see them.
- (iii) Give permission for medical tests, medicines, surgery, or other treatments.
- (iv) Choose where you receive care and which physicians and others provide it.
- (v) Decide to accept, withdraw, or decline treatments designed to keep you alive if you are near death or not likely to recover. You may choose to include guidelines and/or restrictions to your agent's authority.
- (vi) Agree or decline to donate your organs or your whole body if you have not already made this decision yourself. This could include donation for transplant, research, and/or education. You should let your agent know whether you are registered as a donor in the First Person Consent registry maintained by the Illinois Secretary of State or whether you have agreed to donate your whole body for medical research and/or education.
- (vii) Decide what to do with your remains after you have died, if you have not already made plans.
- (viii) Talk with your other loved ones to help come to a decision (but your designated agent will have the final say over your other loved ones).

Your agent is not automatically responsible for your health care expenses.

WHOM SHOULD I CHOOSE TO BE MY HEALTH CARE AGENT?

You can pick a family member, but you do not have to. Your agent will have the responsibility to make medical treatment decisions, even if other people close to you might urge a different decision. The selection of your agent should be done carefully, as he or she will have ultimate decision-making authority for your treatment decisions once you are no longer able to voice your preferences. Choose a family member, friend, or other person who:

- (i) is at least 18 years old;
- (ii) knows you well;
- (iii) you trust to do what is best for you and is willing to carry out your wishes, even if he or she may not agree with your wishes;
- (iv) would be comfortable talking with and questioning your physicians and other health care providers;
- (v) would not be too upset to carry out your wishes if you became very sick; and
- (vi) can be there for you when you need it and is willing to accept this important role.

Appendix F

WHAT IF MY AGENT IS NOT AVAILABLE OR IS UNWILLING TO MAKE DECISIONS FOR ME?

If the person who is your first choice is unable to carry out this role, then the second agent you chose will make the decisions; if your second agent is not available, then the third agent you chose will make the decisions. The second and third agents are called your successor agents and they function as back-up agents to your first choice agent and may act only one at a time and in the order you list them.

WHAT WILL HAPPEN IF I DO NOT CHOOSE A HEALTH CARE AGENT?

If you become unable to make your own health care decisions and have not named an agent in writing, your physician and other health care providers will ask a family member, friend, or guardian to make decisions for you. In Illinois, a law directs which of these individuals will be consulted. In that law, each of these individuals is called a "surrogate."

There are reasons why you may want to name an agent rather than rely on a surrogate:

- (i) The person or people listed by this law may not be who you would want to make decisions for you.
- (ii) Some family members or friends might not be able or willing to make decisions as you would want them to.
- (iii) Family members and friends may disagree with one another about the best decisions.
- (iv) Under some circumstances, a surrogate may not be able to make the same kinds of decisions that an agent can make.

WHAT IF THERE IS NO ONE AVAILABLE WHOM I TRUST TO BE MY AGENT?

In this situation, it is especially important to talk to your physician and other health care providers and create written guidance about what you want or do not want, in case you are ever critically ill and cannot express your own wishes. You can complete a living will. You can also write your wishes down and/or discuss them with your physician or other health care provider and ask him or her to write it down in your chart. You might also want to use written or online resources to guide you through this process.

WHAT DO I DO WITH THIS FORM ONCE I COMPLETE IT?

Follow these instructions after you have completed the form:

- (i) Sign the form in front of a witness. See the form for a list of who can and cannot witness it.
- (ii) Ask the witness to sign it, too.
- (iii) There is no need to have the form notarized.
- (iv) Give a copy to your agent and to each of your successor agents.
- (v) Give another copy to your physician.
- (vi) Take a copy with you when you go to the hospital.
- (vii) Show it to your family and friends and others who care for you.

Appendix G

**WHAT IF I CHANGE MY MIND?**

You may change your mind at any time. If you do, tell someone who is at least 18 years old that you have changed your mind, and/or destroy your document and any copies. If you wish, fill out a new form and make sure everyone you gave the old form to has a copy of the new one, including, but not limited to, your agents and your physicians.

WHAT IF I DO NOT WANT TO USE THIS FORM?

In the event you do not want to use the Illinois statutory form provided here, any document you complete must be executed by you, designate an agent who is over 18 years of age and not prohibited from serving as your agent, and state the agent's powers, but it need not be witnessed or conform in any other respect to the statutory health care power.

If you have questions about the use of any form, you may want to consult your physician, other health care provider, and/or an attorney.

Illinois Statutory Short Form Power of Attorney for Health Care

Appendix H

MY POWER OF ATTORNEY FOR HEALTH CARE

THIS POWER OF ATTORNEY REVOKES ALL PREVIOUS POWERS OF ATTORNEY FOR HEALTH CARE.

(You must sign this form and a witness must also sign it before it is valid.)

My name (print your full name): _____

My address: _____

I WANT THE FOLLOWING PERSON TO BE MY HEALTH CARE AGENT

(An agent is your personal representative under state and federal law):

(Agent name) _____

(Agent address) _____

(Agent phone number) _____

(Please check box if applicable) ☐ If a guardian of my person is to be appointed, I nominate the agent acting under this power of attorney as guardian.

SUCCESSOR HEALTH CARE AGENT(S) (optional):

If the agent I selected is unable or does not want to make health care decisions for me, then I request the person(s) I name below to be my successor health care agent(s). Only one person at a time can serve as my agent (add another page if you want to add more successor agent names):

(Successor agent #1 name, address and phone number)

(Successor agent #2 name, address and phone number)

MY AGENT CAN MAKE HEALTH CARE DECISIONS FOR ME, INCLUDING:

- (i) Deciding to accept, withdraw, or decline treatment for any physical or mental condition of mine, including life-and-death decisions.
- (ii) Agreeing to admit me to or discharge me from any hospital, home, or other institution, including a mental health facility.
- (iii) Having complete access to my medical and mental health records, and sharing them with others as needed, including after I die.
- (iv) Carrying out the plans I have already made, or, if I have not done so, making decisions about my body or remains, including organ, tissue or whole body donation, autopsy, cremation, and burial.

Appendix I



The above grant of power is intended to be as broad as possible so that my agent will have the authority to make any decision I could make to obtain or terminate any type of health care, including withdrawal of nutrition and hydration and other life-sustaining measures.

I AUTHORIZE MY AGENT TO (please check any one box):

- ☐ Make decisions for me only when I cannot make them for myself. The physician(s) taking care of me will determine when I lack this ability.

(If no box is checked, then the box above shall be implemented.) OR

- ☐ Make decisions for me only when I cannot make them for myself. The physician(s) taking care of me will determine when I lack this ability. Starting now, for the purpose of assisting me with my health care plans and decisions, my agent shall have complete access to my medical and mental health records, the authority to share them with others as needed, and the complete ability to communicate with my personal physician(s) and other health care providers, including the ability to require an opinion of my physician as to whether I lack the ability to make decisions for myself. **OR**

- ☐ Make decisions for me starting now and continuing after I am no longer able to make them for myself. While I am still able to make my own decisions, I can still do so if I want to.

The subject of life-sustaining treatment is of particular importance. Life-sustaining treatments may include tube feedings or fluids through a tube, breathing machines, and CPR. In general, in making decisions concerning life-sustaining treatment, your agent is instructed to consider the relief of suffering, the quality as well as the possible extension of your life, and your previously expressed wishes. Your agent will weigh the burdens versus benefits of proposed treatments in making decisions on your behalf.

Additional statements concerning the withholding or removal of life-sustaining treatment are described below. These can serve as a guide for your agent when making decisions for you. Ask your physician or health care provider if you have any questions about these statements.

SELECT ONLY ONE STATEMENT BELOW THAT BEST EXPRESSES YOUR WISHES (optional):

- ☐ The quality of my life is more important than the length of my life. If I am unconscious and my attending physician believes, in accordance with reasonable medical standards, that I will not wake up or recover my ability to think, communicate with my family and friends, and experience my surroundings, I do not want treatments to prolong my life or delay my death, but I do want treatment or care to make me comfortable and to relieve me of pain.
- ☐ Staying alive is more important to me, no matter how sick I am, how much I am suffering, the cost of the procedures, or how unlikely my chances for recovery are. I want my life to be prolonged to the greatest extent possible in accordance with reasonable medical standards.

Appendix J

SPECIFIC LIMITATIONS TO MY AGENT'S DECISION-MAKING AUTHORITY:

The above grant of power is intended to be as broad as possible so that your agent will have the authority to make any decision you could make to obtain or terminate any type of health care. If you wish to limit the scope of your agent's powers or prescribe special rules or limit the power to authorize autopsy or dispose of remains, you may do so specifically in this form.

My signature: _____

Today's date: _____

HAVE YOUR WITNESS AGREE TO WHAT IS WRITTEN BELOW, AND THEN COMPLETE THE SIGNATURE PORTION:

I am at least 18 years old. *(Check one of the options below):*

☐ I saw the principal sign this document, **OR**

☐ The principal told me that the signature or mark on the principal signature line is his or hers.

I am not the agent or successor agent(s) named in this document. I am not related to the principal, the agent, or the successor agent(s) by blood, marriage, or adoption. I am not the principal's physician, advanced practice nurse, dentist, podiatric physician, optometrist, psychologist or a relative of one of those individuals. I am not an owner or operator (or the relative of an owner or operator) of the health care facility where the principal is a patient or resident.

Witness printed name: _____

Witness address: _____

Witness signature: _____

Today's date: _____