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Emily K. Songer  
*Grand Valley State University*

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Advance Care Planning Barriers for Young Adults

Emily K. Songer

Grand Valley State University

### Advance Care Planning Barriers for Young Adults

According to the CDC, 40.6% of young adult deaths occur from unintentional injuries, which is the leading cause of death for this age group (Heron, 2019). When accidents occur, they sometimes result in a loss of the ability to make medical decisions, and young adults most likely have never had the opportunity state their wishes regarding their medical care. This is why advance care planning is important, because it allows the opportunity to express those desires before it is too late. Many people often confuse advance care planning as a process that is only needed for the elderly and those who are critically ill, however as the statistic above shows that is not the case. In fact, advance care planning laws were implemented due to major court cases surrounding healthy young adults in their mid-twenties who suddenly became ill and needed life sustaining treatment (Miller, 2017). Despite the history of advance care planning originating from young adults, discussions often do not occur with young adults regarding advance care plans. Instead, health care professionals and researchers focus on providing information on advance care planning to older adults and patients who are critically ill. The purpose of this paper is to examine the history behind why advance directives are important, understand how they are obtained in Michigan, and look at the reasons why young adults should obtain them.

### History

The first time there ever became a need for an advance directive, the document created during advance care planning that states your medical wishes when you no longer can do so, was in 1975. At that time, a 21-year-old New Jersey woman named Karen Ann Quinlan suffered

brain damage after collapsing at a party that resulted in a diagnosis of her needing tube feedings and respiratory support for the rest of her life (Miller, 2017). Like most young adults, she probably thought something of this nature would never happen to her and had never documented her wishes. After her parents were informed of the tragic news, they asked the doctors to discontinue the measures that were keeping her body alive and were refused (Miller, 2017). Not giving up on their daughter, the Quinlan's put together a court case and won the decision to remove Karen from her feeding tube and ventilator, allowing them to put their daughter's body to rest (Miller, 2017). Resulting from this court case, California passed the first Natural Death Act in 1976, outlining a person's right to refuse medical treatments at the end of their life (Encyclopedia of Death and Dying, n.d.). In the years to come, each individual state followed with their own legislation regarding the Natural Death Acts (Encyclopedia of Death and Dying, n.d.).

Another important case occurred in 1983 when there was no advance directive created for the patient. A 23-year-old named Nancy Cruzan was in a motor vehicle accident that put her in a persistent vegetative state and resulted in her living in a rehabilitation hospital for seven years with no improvement (Miller, 2017). Her family was told by physicians she could live for 30 more years in this state, which they did not want for their daughter, so they made the decision to take her off from the tube feedings that were keeping her alive (Miller, 2017). The rehabilitation hospital refused to stop tube feedings because Nancy had not completed an advance directive, so the family had to go to court and supply evidence that this was what she would want (Miller,

2017). In 1990, the court ended up ruling in favor of removing the feeding tube and allowing Nancy to die (Miller, 2017). Due to this case, the Patient Self-Determination Act (PSDA) was passed which is a federal law that requires each federally funded medical institution to inform its patients of their right to complete an advance directive (Encyclopedia of Death and Dying, n.d.). This was a big step in making the knowledge of advance directives more readily available to patients to make their healthcare wishes known.

### **Advance Care Planning**

#### **Process**

Advance care planning (ACP) is not a single event of writing down information for future use, it is an entire process of conversations with a facilitator, your loved ones, and your healthcare providers. The importance of ACP being an entire process of documenting personal values regarding future end-of-life care, is that this will be used when the patient can no longer speak for themselves, so it is important to spend time getting correct information. The process often starts by speaking with a certified facilitator who is familiar with ACP and can help discuss the more difficult topics and answer questions regarding the process (Making Choices Michigan, 2018). There are organizations available that have certified facilitators ready to help specifically with ACP, in Michigan this organization is called Making Choices Michigan.

After identifying the personal values that would guide future healthcare decisions, it is important to choose a patient advocate. A patient advocate is someone who is chosen because they will carry through with the healthcare decisions that have been chosen for the advance

directive, even if they do not agree with them or if they will be hard decisions to follow through with (Making Choices Michigan, n.d.). When communicating with the patient advocate the end-of-life wishes that have been chosen, it is very important for them to not only be comfortable with being the chosen patient advocate, but also to be able to make those wishes known should they ever have to. Alternative patient advocates can be chosen, and it is often encouraged to choose more than one patient advocate to be prepared, but only one patient advocate can act on behalf of the patient at a time (Making Choices Michigan, 2018). This patient advocate may sometimes be referred to as a healthcare proxy or a designated power of attorney for health, but they all refer to the same thing and it is important to know that they are only able to make medical decisions, not financial decisions.

The last part of the ACP process is to document the decisions that have been made throughout all the discussions in an advance directive (AD) and register the document. An advance directive is a document that reflects the healthcare values and medical preferences of the patient for circumstances when the patient is unable to make their own medical decisions (Making Choices Michigan, n.d.). This document can be updated at any time, as well as the patient advocates. Once the patient advocate signs and the patient signs the AD in front of two witnesses, the document is legally bound and no further action is required for the document to be used in the future (Making Choices Michigan, n.d.). The best place to store the completed AD is to upload the document into the Great Lakes Health Connect system's Virtual Integrated Patient Record (VIPR), which is a secure community health record that allows hospitals state-wide to

view the document if needed (Great Lakes Health Connect, n.d.). Having the document uploaded into the VIPR allows a future healthcare team to access the document quickly and implement treatment preference into the medical care plan. It is also important to keep a personal copy in a convenient location, as well as provide a copy with a personal medical provider and inform them of the decisions that have been made.

### **Young adult perspectives**

When young adults turn 18, they are often just starting out their lives and gaining independence, so they are not thinking about what might end their life and what their wishes would be if something tragic occurred. The reality behind death and incapacitating events is they are unpredictable, and these events can occur to anybody no matter how young they are. A common misconception of young adults is that family members will know what medical wishes they would prefer if they were not able to speak for themselves and that their family would perfectly carry out those wishes (Mizzi, 2017). This does not typically occur and there is often a lot of controversy and stress trying to decide what a patient would choose if they could make the decision themselves.

When college students were given the opportunity to think about their healthcare beliefs and create ADs, many had positive experiences. In fact, despite the common belief that young adults do not want to think about death, one research article found that 88% of healthy young adults had a desire to engage in the end-of-life decision making process (Sanders & Robinson, 2017). This demonstrates that ACP discussions should be occurring more often with younger

generations of adults instead of avoiding the conversation because of a belief that they are not interested in the conversation. A study was conducted in which college students were asked to fill out an AD and discuss their wishes with their key family members and friends, then afterwards they were asked about their feelings during the process. There were a multitude of responses to the study, but one of the students reflected, “I felt so empowered by going through this process... it also encouraged me to talk to some of the people who matter most to me about what they want as well” (Sanders & Robinson, 2017, p. 338). Educating students about ADs and helping them complete their own document not only gives them autonomy for their future care but also gives them the opportunity to start conversations with their family members regarding their healthcare wishes before it is too late. Hopefully having the opportunity to complete their own AD encourages students to help their family members with getting an AD completed as well, but even if they don’t complete an AD, having conversations regarding medical values and beliefs is a huge first step if something ever occurs. Another student that participated in this study expressed, “my mom and dad have always told me the way life was going to be; however, through this legal document, I have the ability to, for the first time, articulate the way I want my life to be and how I want to die” (Sanders & Robinson, 2017, p. 339). The first 18 years of a person’s life, if not longer, is often dictated by a parent’s decisions. If an AD is not created, with a patient advocate chosen, then medical decisions are often made by the parents if a young adult is not able to make medical decisions for themselves. The AD creates a voice for patients to express their wishes when they are no longer able to speak.



**Patient advocate perspectives**

The patient advocates of young adults have a very important responsibility in honoring their medical wishes, and young adults often put a lot of thought behind who they want to be their chosen advocate. In the Sanders and Robinson's study (2017), some students reflected on the burden they felt at choosing a patient advocate because they were worried about choosing the wrong family member, and in turn upsetting other members of the family. Therefore, it is important for young adults to know that they can have alternative patient advocates so that multiple people can know their wishes and be available if needed. Another valuable thing to remember is that the patient advocate can be changed at any time. The patient advocate is supposed to be the person who is going to make the medical choices that have been chosen by the patient, not necessarily the person that the rest of the family wants the patient advocate to be.

Due to the suddenness surrounding many young individual's deaths, discussing their end-of-life wishes or regrets about not being able to document their wishes is not an option. However, there is an opportunity to examine how these young individual's patient advocates felt when they were first asked to take on the patient advocate role, as well as when they were tasked with implementing their loved one's medical decisions at the end of their life. During the Sanders and Robinson's study (2017), one student reflected on a discussion with their father and said, "I was so scared that he was going to be mad at me, but he ended up being relieved he could just be my dad if something happened to me" (p. 339). Having documents in place and discussions about healthcare wishes ahead of time alleviates the pressure of a patient advocate

becoming a decision-maker should a tragedy occur, instead they become an executioner of the patient's wishes. There is also valuable insight gained from people who have lost a loved one who had already completed an AD. One family member remarked that they are not sure they would have been able to focus on making end-of-life decisions due to the overwhelming amount of grief they felt by the knowledge of their loved one's circumstances (Sellars et. al, 2017). By having the AD in place, the decision-making pressure was taken off from the family and they were given time to grieve their loss in that moment and allow the medical professionals to follow through with the patient's wishes. Had the patient not documented their wishes, that time in the hospital would have been filled with stress and tension in order to figure out what the patient would want had they been able to talk.

## **Education**

### **Patients**

Research has shown that young adults are willing to participate in ACP when they are presented with the knowledge of them, however, very seldom is information brought to them regarding ACP. This is why more effort needs to be made in ensuring that information is not only shared with young adults, but that the individuals that will be educating them are prepared to do so. Health care providers need to be educated on how to help a patient complete an AD in order to be comfortable with offering to help a patient complete their documents (Pirinea, Simunich, Wehner & Ashurst, 2016). The terminology and material found within an AD can be

confusing and difficult to work through, which is why it is important for health care providers to be prepared to help their patients with completing their AD.

### **Patient advocates**

Not only is it important for the healthcare providers to become educated on the ACP process, but they should also facilitate discussions between the patient and their chosen patient advocates. This is because it is often difficult to start a discussion surrounding ACP with others because the subject matter is often considered “taboo” (Sellars et. al, 2018, p. 219). The discussion guided by the health care provider should allow the patient to express their healthcare views and beliefs without judgement. In this setting, the patient can speak comfortably without worrying about the conversation being avoided by their patient advocate due to its difficult material. The goal surrounding healthcare providers and ACP should be to help educate the patient and assist them and their patient advocates through the process.

### **Students**

There should also be more actions taken to try and promote spreading the knowledge of ACP to young adults to increase the number of ADs completed by young adults. One important step to take is to host educational sessions at universities. Universities are home to a many young adults that are working to educate themselves daily. Holding information sessions allows students to become aware of what ACP is and why they should consider starting the process themselves. Another area within the university setting that should be adjusted to incorporate more information regarding ACP is curriculum for health care programs. Studies show that more

education and training is needed for healthcare professionals to assist with ACP, and the best place for this education and training to begin is while they are in school (Blackwood, Walker, Mythen, Taylor, & Vindrola-Padros, 2019). Not only does this training allow these future health care professionals to assist their future patients with ACP, it educates themselves as young adults on the importance of ACP and gives them the resources on how to start the process themselves.

Lastly, it is important to provide young adults with as many tools and resources as possible to help them with their ACP process. As mentioned before, some young adults may feel burdened by decisions such as choosing a patient advocate, or they may feel overwhelmed by thinking of dying someday (Sanders & Robinson, 2017). Due to this, it is important to have certified consultants available to discuss these difficult topics. Even if the topic does not seem difficult to handle to begin with, it may become so later, which is why it is important to have people to discuss these feelings and beliefs with, whether that be the consultant or a campus counselor. Another tool that can be used to help young adults make messages clearer to patient advocates is video recordings. In a recent study with college students using video recordings with ADs, results showed that the recordings made the students think more deeply about their own definition of quality of life (Kiersch & Potter, 2019). Using video-recordings with ADs would add an even more personal touch for the young adults and might influence more people. Not every student may want to use this resource, but having the option to use it to share a message out loud rather than just put words to paper may be more effective for some young

adults. Using different tools and resources to assist young adults with ACP may help encourage more young adults to consider starting the process.

### **Conclusion**

The history surrounding advance care planning involves young adults, yet the focus on who is completing this process and creating an advance directive does not include young adults. This is why it is important to educate young adults on what advance directives are, how they can obtain one, and reasons why they should obtain one. Understanding how to complete the ACP can be made easier by talking with a licensed facilitator, who can help understand personal medical values and beliefs and facilitate conversations with a patient advocate. When young adults have been introduced to ACP, they have felt empowered and desired to share the information with loved ones. Patient advocates, who play an important role in honoring the wishes within an AD, have shared that the process reduces the decision-making pressure in a crisis. Now is the time to educate young adults in ACP before it is too late, and they are not able to use their voices in the future.

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