

A Comparison of Advance Care Directive Attitudes and Completion Rates Amongst

Medicaid Population in Inland Empire Pre and Post-COVID-19 Pandemic

by

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Master of Public Health, California Baptist University, 2020

Thesis Submitted in Partial Fulfillment

of the Requirements for the Degree of

Master of Public Health

California Baptist University

December 2020

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Abstract

The passage of the Patient Self Determination Act in 1990 gave patients the legal right to express their wishes for future medical care and end of life treatment wishes. Yet, despite the benefits of executing an advance directive, most people do not have one executed. Few studies have been done that focus on the Medicaid population and their attitudes about completing an advance directive during a pandemic. This study aimed to determine if the COVID-19 pandemic was enough to influence attitudes and readiness in the Medicaid population about advance directives. A cross-sectional study was conducted using a modified version of Porter Novelli's HealthStyles end of life items and the four-item version of Measuring Advance Care Planning: Optimizing the Advance Care Planning Engagement Survey to obtain information about exposure to health information, health promotion, and communication about advance directives. The population sample consisted of 63 adult Medicaid recipients, 13 males and 49 females, living in San Bernardino and Riverside Counties in California. A paired samples *t*-test and a one-way analysis of variance (ANOVA) were performed. Based on these results, the COVID-19 pandemic was not a large enough motivator to influence advance directive completion in the Medicaid population.

Key Words: advance directives, Medicaid recipients, COVID-19 pandemic.

Acknowledgments

I am very grateful to my committee for their continued support and encouragement: Dr. Ashley Parks, my committee chair, and Dr. Melissa Wigginton and Dr. Lindsay Fahnestock. I also offer my sincerest appreciation to the rest of the MPH faculty for patiently guiding me throughout the MPH program for two years to prepare me to write this thesis.

The completion of this thesis project could not have been accomplished without the help and support from fellow team members at Inland Empire Health Plan—you know who you are.

A great thank you to my caring, loving, supportive husband Jim for your encouragement when things got tough.

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Overview of the Literature

One of the most challenging aspects of when a life-threatening accident or illness strikes you or a loved one is having to be faced with decisions about accepting or forgoing, initiating or withdrawing aggressive medical care (Rogne & McCune, 2014). An advance directive is a document that formally conveys an individual's wishes about medical decisions and names someone to make medical decisions when they lose the ability to make them (Rogne & McCune, 2014; Hickman et al., 2005). Two types of advance directives exist: the proxy directive and the Living Will. The proxy directive allows an individual to designate another person to make decisions for them in the event the individual is unable to do so (Rogne & McCune, 2014). This is a valuable form, especially in cases when an individual is estranged from their family, or have no immediate family to decide for them, and therefore, prefer to name a non-relative as their agent (Rogne & McCune, 2014). The second form, a Living Will, documents an individual's wishes about wanted or unwanted future medical care, including life-sustaining treatments (Rogne & McCune, 2014). Instructions can be detailed, general, or phrased in terms of the patient's personal values (Rogne & McCune, 2014). An informed patient exercises their right to express autonomy by completing an advance directive prior to a life-threatening accident or illness (Hunsaker & Mann, 2013).

Patient Self-Determination Act

Prior to the passage of the 1990 Patient Self-Determination Act (PSDA), physicians were not required to honor patients' expressed wishes for end of life care in a Living Will because the document was not a recognized legal document (Miller,

2017). Furthermore, next of kin had no legal grounds to discontinue life-sustaining measures because doing so was unacceptable by standards of medical practice at the time; if such a request was honored, it was considered homicide (Miller, 2017).

Two notable court cases that dealt with the care of patients were that of Karen Ann Quinlan and Nancy Beth Cruzan. Karen Ann Quinlan was 21 when she collapsed after a party after taking alcohol and sedatives on April 14, 1975 (In re Quinlan, 1976). She was taken to a hospital where doctors were able to save her life, but she suffered brain damage and lapsed into a “persisted vegetative state” (In re Quinlan, 1976). Her family then won a New Jersey Supreme Court legal battle to remove her from life support machines on March 31, 1976 (In re Quinlan, 1976). However, Quinlan was able to breathe on her own after she was removed from the respirator (In re Quinlan, 1976). She remained in a coma and was moved into a nursing home until she died nine years later in 1985 (In re Quinlan, 1976).

Nancy Cruzan was 25 in 1983 when she was involved in a car accident that left her in a “persistent vegetative state” (Cruzan v. Director, Missouri Department of Health, 1990). She was kept alive by a feeding tube and steady medical care (Cruzan v. Director, Missouri Department of Health, 1990). After it became clear that Cruzan would not improve, her parents waged a legal battle to have the feeding tube removed (Cruzan v. Director, Missouri Department of Health, 1990). The state hospital staff refused to honor this request without court approval, and case also went to the Supreme Court where it was ruled that the Cruzans had not provided “clear and convincing evidence” that Nancy did not want to have her life artificially preserved (Cruzan v. Director, Missouri Department of Health, 1990). Later in December 1990,

the Cruzans presented such evidence which ruled in their favor; Nancy died later that same month (*Cruzan v. Director, Missouri Department of Health*, 1990).

The families of both these women challenged the courts for the right to die when they were denied the ability to withdraw life support measures (Miller, 2017). In both cases, the young women involved were younger than 25 years old and suffered unfortunate series of events which left them in a “persistent vegetative state” with no hopes of recovery (Miller, 2017; *In re Quinlan*, 1976; *Cruzan v. Director, Missouri Department of Health*, 1990). Both families took their cases to the Supreme Court to have the ability to decide on their loved-one’s end of life care because physicians providing care refused to comply with their wishes (Miller, 2017).

The PSDA mandated that when patients are admitted into a federal facility that receives funding for Medicaid and Medicare recipients (therefore excluding private facilities), that they perform the following: (1) provide written information to the individual about their right to accept or refuse medical treatment following state law; (2) ask if an individual has an advance directive and if they do not, provide written information about advance directives; (3) offer an opportunity to execute an advance directive if they have not done so; (4) not discriminate in providing care on the basis of having an advance directive; (5) create a system to ensure compliance: and (6) educate institution staff and community about the patient’s rights pertaining to decision-making (Miller, 2017; Rogne & McCune, 2014; Hunsaker & Mann, 2013). States were also required to create written advance directive information to educate staff, caregivers, patients and communities in accordance with state law (Miller,

2017). Since the PSDA was passed, efforts have been made to inform and promote the use of advance directives (Ko, Lee, & Hong, 2016).

Advance Care Planning

Prior to documenting one's wishes for the medical care and designating an agent, an individual should journey through a planning process to contemplate, review, and discuss future health care and treatments with their agent, family, and personal physician (Kermel-Schiffman & Werner, 2017). This planning process is known as advance care planning. Advance care planning helps an individual formally communicate their values, beliefs, fears, wishes, quality of life, and care goals with their agent, loved ones, and personal physician (Rogne & McCune, 2014, p. 15) in the event that person becomes physically or mentally unable to make those decisions (Kermel-Schiffman & Werner, 2017). In the event of an emergency situation, when the patient is unable to decide treatment decisions and there is no surrogate or advance directive available, physicians will provide medically appropriate care to meet the patient's needs, which can later be withdrawn when their preferences become known (American Medical Association, 2020). When the patient's treatment goals are transferred to an advance directive, physicians and agents are given guidance to make good-faith efforts to respect the patient's wishes and implement care preferences (AMA, 2020).

Unfortunately, not all patients have an advance directive (Rogne & McCune, 2014). When an advance directive is absent, a patient may receive aggressive care that does not align with their wishes (Rogne & McCune, 2014). Moreover, family members may experience conflict and high levels of stress when deciding care as well

as depression and anxiety after the death of the individual (Kermel-Schiffman & Werner, 2017). In such instances, they also often experience higher end-of-life medical costs (Hunsaker & Mann, 2013).

Benefits for completing an advance directive include having increased autonomy (because values and treatment options will be respected) and improved quality of life and life satisfaction at the end of life (by reducing unwanted life-sustaining therapies) (Kermel-Schiffman & Werner, 2017; Kavalieratos et al., 2015). These meaningful conversations also benefit family left behind by reducing their decision-making burden, stress, anxiety, and depression experienced after the death of the individual (Kermel-Schiffman & Werner, 2017; Kavalieratos et al., 2015).

Rogne and McCune (2014) noted that advance care planning is a series of conversations that happen over a period of time, ideally when a person has no acute illness or chronic disease. When conversations do happen and an advance directive is completed, planning is typically considered finished and no longer continued (Hickman et al., 2005). Possible reasons for not restarting advance care planning discussions could be a person's fear of dying, lack of support from partners, and insufficient knowledge of the planning process (Kermel-Schiffman & Werner, 2017; Hunsaker & Mann, 2013). However, the National Institute on Aging (2018) recommended that adults review their advance directive every 10 years, or more often if their health status changes, if their living arrangements or life situation changes (ex. getting married, separated, or divorced), or their spouse or agent dies.

Young adults are an ideal target for healthcare practitioners to discuss advance directives with because they can learn about the process and document during the

course of their life and are most likely to care for an aging family member (Tripken & Elrod, 2017). Primary care physicians can play an important role in incorporating advance care planning conversations at routine annual visits and in subsequent patient care visits until the onset of frailty or the need for long-term care (Rogne & McCune, 2014; Spoelhof & Elliott, 2012).

However, this idyllic scenario is shattered by the reality that people have a difficult time talking or refuse to talk about planning for end of life care, including doctors (Rogne & McCune, 2014; Kermel-Schiffman & Werner, 2017). The primary care physician is in the best position to talk about advance directives since they know the patient best (Rogne & McCune, 2014). Research found that while patients do not want to talk about advance directives, they would rather have their physician bring up the topic (Genewick et al., 2018). However, physicians are frequently not trained or are uncomfortable in facilitating a conversation about advance care planning or end of life care (Rogne & McCune, 2014).

A federal mandate was passed in 2014 that required all public and private healthcare providers to adopt Electronic Health Records (EHRs) to improve care quality, but despite advancements in health information technology, many healthcare providers have not adopted EHRs (Odom & Willeumier, 2018). Use of EHRs varies across healthcare institutions and can be used to remind physicians to discuss advance care planning with patients or document advance directive completion (Dillon et al., 2017). An EHR has the potential to coordinate care across health settings, but unfortunately, a standard has not been established to collect or remind providers about advance care planning (Dillon et al., 2017).

State of California

Despite the benefits of planning, almost 75% of adults do not have an advance directive (Rao et al, 2014). Identified patient barriers are: fear of dying, complicated advance directive forms, lack of support, lack of interest, lack of knowledge, and the denial of having to complete one (Tripken & Elrod, 2017; Kermel-Schiffman & Werner, 2017; Spoelhof & Elliott, 2012; Rogne & McCune, 2014). Despite the requirement of the PSDA that every state provide written information about the forms, there is variability in forms from state to state (Hunsaker & Mann, 2013). The State of California combined both proxy and Living Will forms, which allows the patient to set the agent's limits of authority, express organ donation wishes, authorize autopsy, disposition of remains, and designate a primary physician in one advance directive form (California Probate Code, Section 4701). Although specific items must be included in an advance directive, the State of California does not promote the use of one specific standard form. The following agencies have advance directive forms available for public use: California Attorney General, California Hospital Association, California Coalition of Compassionate Care, UCLA Health Advance Directive, Caring Connections Advance Directive, and an easy to read form, PREPARE™ (UCLA School of Law, 2019). Advance directive forms are also publicly accessible through government sponsored sites (Mueller et al, 2010).

Physicians Orders for Life Sustaining Treatment (POLST)

It is important to clarify that an advance directive is not a medical order but rather a guide for desired care (Joyner, Palmer, & Hatchett, 2020). A tool that is commonly used to provide medical orders in medical emergencies is a Physicians

Orders for Life-Sustaining Treatment (POLST) form (Joyner et al., 2020; Rogne & McCune, 2014; POLST.org, 2020). Accessing this tool begins with conversations between the seriously ill individual, the healthcare professional, and significant other and/or family members (Joyner et al., 2020). This advance care planning tool was designed for individuals who are frail and/or seriously ill; it was not designed for healthy individuals (Joyner, Palmer, & Hatchett, 2020; POLST.org, 2020). Key differences between a POLST form and an advance directive form are: a POLST form is a medical order while a an advance directive is a legal document; a POLST form communicates specific medical orders while a an advance directive communicates general wishes about medical treatment; a POLST form travels with the patient across healthcare settings, while an advance directive does not, making a POLST form more accessible than an advance directive; emergency personnel are required to follow the orders written on a POLST, while they are not required to follow wishes stated on an advance directive; and a POLST does not appoint a healthcare proxy, while an advance directive does (POLST.org, 2020).

Barriers

Patient health literacy was addressed by Sudore et al. (2014) and Spoelhof and Elliott (2012) as a potential barrier to completing advance directives because the majority of the advance directive forms available are complex and difficult to understand. Health literacy is the degree to which an individual can understand and process health information to make an appropriate health decision (Health Resources and Services Administration, 2019). Nouri et al. (2019) recognized that health literacy is an important predictor of advance care planning knowledge and advance directive

completion among older adults. Low health literacy was shown to be more prevalent in older adults, minority populations, those who have low socioeconomic status, and the medically underserved, all of which constitute a group of adults who have higher rates of advance directive completion (HRSA, 2019; Hunsaker & Mann, 2013).

Unfortunately, the majority of state-sponsored advance directive forms read at the Flesch-Kincaid Grade Level (FKGL) scale of 11.9 (Mueller et al., 2010). The FKGL is a tool that has been widely used in assessing patient education materials where the scale result represents the grade level of the reading material analyzed (Williams, Muir, & Rosdahl, 2016). However, since the Mueller et al. (2010) study was published, Regents of the University of California have developed an easy-to-read form that has been proven to increase advance care planning engagement in older adults (Sudore et al., 2017).

Income level has also been identified as a barrier to complete an advance directive (Saeed et al., 2019). Saeed et al. (2019) noted that even among individuals of lower socioeconomic status (self-reported lower annual incomes < US\$20,000), their disparities are so formidable, such as poor access to healthcare in general, that they are deprived of an opportunity to complete an advance directive.

Community Interventions

Since the passage of the PSDA, a number of intervention programs to increase advance directive completion have been developed for patients and clinical staff (Jezewski et al., 2007). Interventions include pamphlets, booklets, site-specific forms, training videos, educational videos, seminars, and workshops (Jezewski et al., 2007). Despite these efforts, the majority of adults do not have a completed advance

directive (Rao et al., 2014). However, palliative care and hospice facilities often offer advance care planning discussions and advance directive completion services, which helps to explain the higher advance directive completion rates of older adults with serious illnesses (Tai-Seale et al., 2017). The Coalition for Compassionate Care of California (CCCC, 2020) offers consulting services to healthcare organizations and community agencies that help them design an effective, patient-focused advance care planning solutions program for their diverse populations and also addresses the organizations' unique culture. The Centers for Disease Control and Prevention (CDC, 2015) and the California State University Shirley Institute for Palliative Care (2020) offer Advance Care Planning Courses to health service professionals where they can earn continuing education hours.

Community interventions offer information sessions to patients of cancer treatment centers that utilize nurses or lay health worker-led staff (Patel et al., 2019; Rabow et al., 2019). The community programs or pilot studies that were conducted in California were facilitated in the San Francisco area (Nouri et al., 2019; Sudore et al., 2012; Sudore et al., 2018), while one study was facilitated in San Diego among low income older adults (Ko et al., 2016). The PREPARE online program was developed in California and is offered online for free to the public. This easy-to-use site teaches patients communication and decision-making skills, helps incorporate patients' values, and empowers patients to communicate their values to others (Sudore et al., 2012). In Southern California, Kaiser Permanente medical centers offer their version of advance care planning classes, Life Care Planning, but only to its patient members (Kanter et al., 2013). Inland Empire Health Plan (IEHP) offers an advance care

planning in-person class called My Life My Choice to the community. The program teaches adults about the benefits of advance directive completion, communicating patient wishes with family and physician, and how to complete the easy-to-read PREPARE advance directive form (IEHP, 2020). Jezewski et al. (2007) found that one-on-one and group advance care planning interventions with older adults, significantly increased advance directive completion rates. Despite these findings, healthy adults under the age of 50 with one or no comorbidities have limited in-person options to learn more about advance care planning in Riverside and San Bernardino Counties.

Conclusion

Since the passage of the PSDA, healthcare organizations have been mandated to provide advance directive information, including providing forms to patients, but patients are not obligated to complete them (Hunsaker & Mann, 2013). Adults are at different stages in their readiness to complete an advance directive, but certain triggers can influence a person to engage in advance care planning conversations, such as pressures from family and personal physician, witnessing a family member's end of life care gone wrong, recognizing their own susceptibility (Fried et al., 2009; Levi et al., 2010), and being nudged by an estate planner (Saeed et al., 2019).

Since its arrival in the United States in early February 2020, COVID-19 has raised public awareness of becoming seriously ill (CCCC, 2020). Preliminary evidence suggested that anxiety, depression, and stress are common reactions to the COVID-19 pandemic (Rajkumar, 2020). However, only two articles mention the importance of advance directive completion during the pandemic outside of palliative

care and intensive care settings as determined through a PubMed search with the key words “covid-19,” “advance,” “care,” and “planning” (Block, Smith, & Sudore, 2020; Curtis, Kross, & Stapleton, 2020). In these uncertain times, planning for the possibility of the inability to communicate is important because of strict visitor restrictions currently implemented in hospitals to reduce spread of COVID-19. These stricter restrictions can leave a patient without a healthcare proxy to speak at bedside on their behalf if clinicians are forced to provide care quickly (Block et al., 2020). Documentation of an advance directive is crucial given that the current physical distancing policies can also impede access to completed advance directives (Block et al., 2020). This demonstrates why it is important that all adults should, at a minimum, identify a healthcare proxy because the risk for morbidity and mortality is universal (Block et al., 2020).

Purpose

The purpose of this study was to examine an individual’s self-reported readiness to complete an advance directive during the COVID-19 pandemic. This study also explored differences in completion of an advance directive across self-reported readiness and health levels. Participants were Medi-Cal enrollees in San Bernardino and Riverside Counties.

Research Questions

The aim for this study was to answer the following research questions:

1. Are there differences in self-reported readiness to complete an advance directive before and after the COVID-19 pandemic?

2. Are there differences in post-COVID-19 pandemic self-reported readiness to complete an advance directive across self-reported health levels?
3. Is there a difference in self-reported readiness to complete an advance directive pre-COVID across self-reported age ranges?
4. Is there a difference in self-reported readiness to complete an advance directive post-COVID across self-reported age ranges?

Hypothesis

The research hypothesis for the first research question was that there would be a statistically significant difference in readiness to complete an advance directive due to the COVID-19 pandemic. The null hypothesis for the first research question was there would not be a statistically significant difference in readiness to complete an advance directive due to COVID-19 pandemic. The second research hypothesis was that there would be a statistically significant difference in readiness to complete an advance directive across self-reported health levels. The null hypothesis for the second research question was there would not be a statistically significant difference in readiness to complete an advance directive across self-reported health levels. The research hypothesis for the third research question was there would be a statistically significant difference in self-reported readiness to complete an advance directive pre-COVID across self-reported age ranges. The null hypothesis for the third research question was there would not be a statistically significant difference in self-reported readiness to complete an advance directive pre-COVID across self-reported age ranges. The research hypothesis for the fourth research question was there would be a statistically significant difference in self-reported readiness to complete an advance

directive post-COVID across self-reported age ranges. The null hypothesis for the fourth research question was there would not be a statistically significant difference in self-reported readiness to complete an advance directive post-COVID across self-reported age ranges.

Methods

Design

This study used a cross-sectional design. Data were collected from randomly selected members of a not-for-profit Medicare-Medicaid healthcare plan in Southern California to examine participant readiness to complete an advance directive after the arrival of COVID-19 in the United States. This study was approved by the California Baptist University Institutional Review Board and the healthcare plan's legal counsel. Informed consent was obtained from all participants (see Appendix A). The survey questionnaire was available in English and Spanish. Consent and questionnaires were completed online by participants.

Participants and Procedures

A sample of health plan members was randomly selected by the plan's Healthcare Informatics (HCI) Department. The HCI team is responsible for supporting compliance and audit reporting needs, Medicare reporting, Quality Systems WorkFront requests, and quality systems technical training for Analysts. According to the health plan's 2020 Annual Member Profile report, the majority of Plan Members have Medi-Cal, are female, Hispanic, and prefer English. Medi-Cal is California's version of Medicaid, a health coverage program that offers free or low-cost services for low-income adults, children, seniors, and select indigent groups who live in California (Covered California, 2020).

Members eligible for the study were active with the health plan from January 1, 2020 to July 1, 2020, aged 18 and older, enrolled in Medi-Cal only, and opted into the plan's texting program. Members in active status have been recognized by the

State of California's Medicaid healthcare program and have been assigned to a managed health plan for continuity of care. Members who did not meet the specified criteria were not included in the recruitment.

The health plan routinely sends text reminders to members about the Member Portal, nurse advice line, Community Resource Center (CRC) promotions, flu, urgent care, Connect IE, and Healthcare Effectiveness Data and Information Set (HEDIS) campaigns related to cervical cancer screenings, asthma, colorectal, prenatal, and others. In order to avoid texting fatigue, 10,000 (5,000 from each of the two counties the Plan serves in Southern California) plan members were randomly selected to receive a text message to participate in the study (Baseman et al., 2013).

Selected participants were sent a text message with a link to the study questionnaire. Responses were administered and collected using the Qualtrics online system CoreXM5 (Qualtrics, 2020). Qualtrics is a technology platform that organizations use to collect and manage data. Participant consent was obtained by clicking on the survey link and agreeing to participate in the study. Participants who completed the questionnaire were assured their information would be kept confidential. The survey questionnaire (see Appendix B) consisted of questions regarding demographics, future health care plans and treatment wishes (written and discussed), advance directive completion, and readiness to complete an advance directive. Identifying information, such as first or last name, date of birth, social security number, or Plan ID number, were not collected. The questionnaire had 16 questions with member respondents taking an average of approximately five minutes to complete. Incentives were not offered to participants who completed the survey.

Measures and Instruments

The questionnaire developed for the purpose of this study was derived from Porter Novelli's HealthStyles end of life items (Rao et al., 2014) and the four-item version of Measuring Advance Care Planning: Optimizing the Advance Care Planning Engagement Survey (Sudore et al., 2017) to obtain information about exposure to health information, health promotion, and communication about advance directives. To capture the specific needs of the health plan, The Porter Novelli survey question, "Have you discussed your future healthcare plans and treatment wishes with anyone?," was rephrased into two separate, more specific questions: (1) "Have you ever discussed your future healthcare plans and treatment wishes with your doctor or other healthcare professional?" and (2) "Have you ever discussed your future healthcare plans and treatment wishes with family?" For the question, "Besides your doctor, who do you trust to provide information on advance care directives and/or end of life issues?" one of the answer choices was changed from "Nonprofit organizations (AARP, American Cancer, Society)" to "Your health plan (name of Health Plan)" to reflect the logical options for the target audience.

To measure participant readiness level, two of the questions on the four-item version of Measuring Advance Care Planning: Optimizing the Advance Care Planning Engagement Survey were changed from, "How ready are you to sign official papers naming a person or group of people to make medical decisions for you?," to "Thinking back to before COVID-19 arrived in the United States (in February), how ready were you to complete an advance care directive?" and "Since the arrival of COVID-19 in the United States (as of today), how ready are you to

complete an advance care directive?” To measure level of readiness retrospectively, the original response options were used, which included the following options: “I have never thought about it,” “I have thought about it, but I was not ready to do it,” “I was thinking about doing it in the next 6 months,” “I was definitely planning to do it in the next 30 days,” and “I have already done it.”

The minimum required sample size required to answer the research questions was calculated using G*Power software, version 3.1 (Faul et al., 2007), for two statistical tests including a paired samples *t*-test and an analysis of variance (ANOVA). An effect size of 0.5, an alpha level of 0.05, and a power of 0.80 was used to determine the required sample size of 34 for the paired samples *t*-test. An effect size of 0.5, an alpha level of 0.05, and a power of 0.80 was used to determine the required sample size of 200 for the ANOVA.

Independent Variables and Dependent Variables

The independent variable for the first research question was the difference in the timeframes between self-reported readiness to complete an advance directive pre COVID-19 pandemic and post COVID-19 pandemic. Self-reported readiness to complete an advance directive before COVID-19 was measured using the following question: “Thinking back to before COVID-19 arrived in the United States (in February), how ready were you to complete an advance care directive? (choose one).” Self-reported readiness to complete an advance directive after COVID-19 was measured using the following question: “Since the arrival of COVID-19 in the United States (as of today), how ready are you to complete an advance care directive? (choose one).” The response options for both questions were: “I have never thought

about it,” “I have thought about it, but I was not ready to do it,” “I was thinking about doing it in the next 6 months,” “I was definitely planning to do it in the next 30 days,” and “I have already done it,” To compare means, the response options were coded numerically on a 1-5 scale as follows: 1 = “I have never thought about it,” 2 = “I have thought about it, but I was not ready to do it,” 3 = “I was thinking about doing it in the next 6 months,” 4 = “I was definitely planning to do it in the next 30 days,” and 5 = “I have already done it” to create a ranked scale.

The independent variable for the second research question was self-reported health levels. Self-reported health levels were measured by the following survey question, “Would you say that in general your physical health is ___?” The response options were: “Poor,” “Fair,” “Good,” “Very Good,” and “Excellent.” Health level responses were coded: 1 = “Poor,” 2 = “Fair,” 3 = “Good,” 4 = “Very Good,” and 5 = “Excellent,” Health level responses for “Don’t know/not sure” were not coded.

The dependent variable for the first and second question was the participants’ readiness to complete an advance directive post COVID-19. This dependent variable was measured by the following question: “Since the arrival of COVID-19 in the United States (as of today), how ready are you to complete an advance care directive? (choose one).” To compare means, the response options were coded numerically on a 1-5 scale as follows: “I have never thought about it,” “I have thought about it, but I was not ready to do it,” “I was thinking about doing it in the next 6 months,” “I was definitely planning to do it in the next 30 days,” and “I have already done it.” The response options were coded: 1 = “I have never thought about it,” 2 = “I have thought about it, but I was not ready to do it,” 3 = “I was thinking about doing it in the next 6

months,” 4 = “I was definitely planning to do it in the next 30 days,” and 5 = “I have already done it.”

The independent variable for the third question was the self-reported readiness to complete an advance directive pre COVID-19 pandemic. Self-reported readiness to complete an advance directive before COVID-19 was measured using the following question: “Thinking back to before COVID-19 arrived in the United States (in February), how ready were you to complete an advance care directive? (choose one).” The response options for the question were: “I have never thought about it,” “I have thought about it, but I was not ready to do it,” “I was thinking about doing it in the next 6 months,” “I was definitely planning to do it in the next 30 days,” and “I have already done it.” To compare means, the response options were coded numerically on a 1-5 scale as follows: 1 = “I have never thought about it,” 2 = “I have thought about it, but I was not ready to do it,” 3 = “I was thinking about doing it in the next 6 months,” 4 = “I was definitely planning to do it in the next 30 days,” and 5 = “I have already done it” to create a ranked scale.

The independent variable for the fourth question was the self-reported readiness to complete an advance directive post-COVID-19 pandemic. Self-reported readiness to complete an advance directive post COVID-19 was measured using the following question: “Since the arrival of COVID-19 in the United States (as of today), how ready are you to complete an advance care directive? (choose one),” To compare means, the response options were coded numerically on a 1-5 scale as follows: “I have never thought about it,” “I have thought about it, but I was not ready to do it,” “I was thinking about doing it in the next 6 months,” “I was definitely

planning to do it in the next 30 days,” and “I have already done it.” The response options were coded: 1 = “I have never thought about it,” 2 = “I have thought about it, but I was not ready to do it,” 3 = “I was thinking about doing it in the next 6 months,” 4 = “I was definitely planning to do it in the next 30 days,” and 5 = “I have already done it.”

The dependent variables for the third and fourth questions were self-reported age ranges. To compare means, the response options were coded numerically on a 1-4 scale as follows: 1 = “18-24,” 2 = “25-44,” 3 = “45-64,” and 4 = “65+.”

Data Analysis

Data in this study were analyzed using the IBM Statistical Package for Social Sciences (SPSS) software, version 27. To answer research question one, a paired samples *t*-test was utilized to compare self-reported mean differences in readiness to complete an advance directive pre and post COVID-19 pandemic’s arrival to the United States. To answer research questions two, three, and four, ANOVAs were utilized to compare readiness to complete an advance directive pre COVID and post-COVID-19 across self-reported health level categories and self-reported age ranges.

Results

Demographics

The total number of participants who consented to participate in this study was 63 (0.63% of the 10,000 sampled). Table 1 illustrates the demographic details of the sample. The majority of the participants described themselves as being of Hispanic, Latino, or Spanish Origin (57.6%). The next largest majority was White/Caucasian at 21.2% of the sample. Female participants accounted for the majority of the sample at 79.3%. Adults in the 45-64 group accounted for 61.9% of the sample. English was the preferred language of the sample at 68.3%. The majority of the respondents resided in San Bernardino County (63%), and the rest resided in Riverside County at 36%. Nearly 64% of respondents reported that they had never discussed future healthcare plans and treatment wishes with their family, and 80% of respondents indicated they did not have an advance directive (see Table 3).

Table 1

Demographic Table for Survey Responses

Variable	<i>n</i>	%
Gender		
Male	13	20.97
Female	49	79.03
Preferred Language		
English	43	68.25
Spanish	20	31.75
Age Groups		
18-24	1	1.59
25-44	19	30.16

	45-64	39	61.90
	65+	4	6.35
County of Residence			
	Los Angeles	1	1
	Riverside	21	36
	San Bernardino	37	63
Race/Ethnicity			
	American Indian or Alaska Native	2	3.03
	Asian or Asian-American	2	3.03
	Black or African American	7	10.61
	Hispanic, Latino, or Spanish Origin	38	57.58
	Middle Eastern or North African	1	1.52
	Native Hawaiian or Other Pacific	0	0
	Islander		
	White/Caucasian	14	21.21
	Some other race, ethnicity, or	2	3.03
	origin		

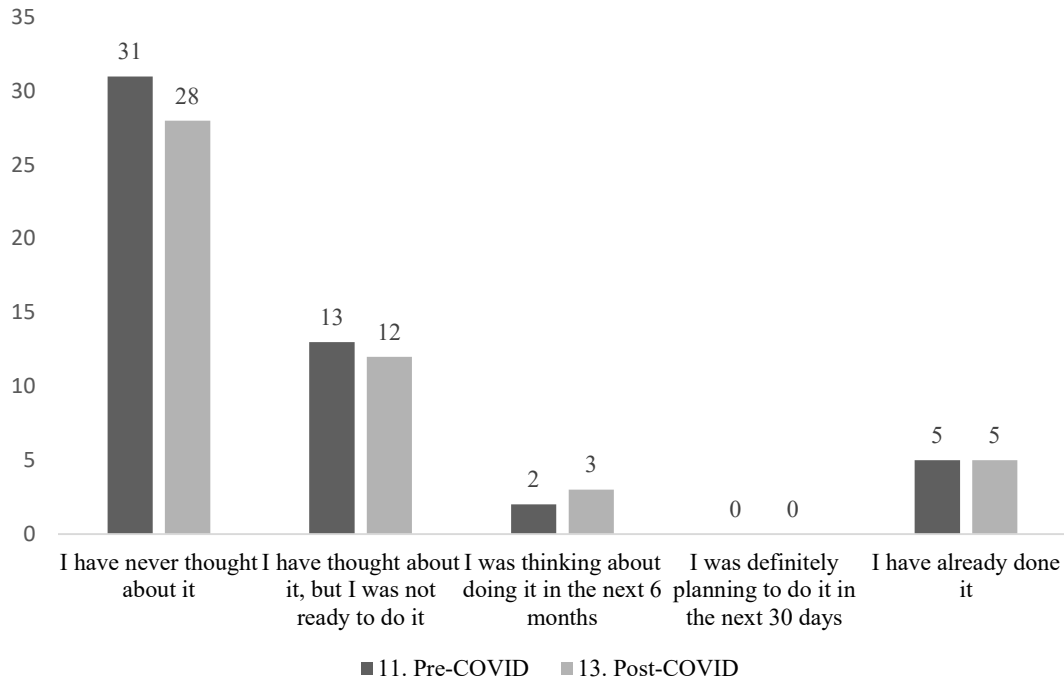
Note. n = 63

Major Findings

To answer research question one: “Are there differences in self-reported readiness to complete an advance directive before and after the COVID-19 Pandemic?” a paired samples *t*-test was calculated to compare self-reported readiness to complete an advance directive before and after the COVID-19 pandemic. The mean readiness to complete an advance directive at pre-COVID-19 was 1.68 (*SD* =1.16) and the mean at post COVID-19 was 1.81 (*SD* =1.26). No significant change was found from pre COVID to post COVID ($t(46) = -1.52, p = 0.135$). The COVID-19 pandemic did not appear to increase readiness to complete an advance directive amongst respondents (see Figure 1).

Figure 1

How ready are you to complete an advance directive?



To answer research question two, “Are there differences in post-COVID-19 Pandemic self-reported readiness to complete an advance directive across self-reported health levels?” a one-way ANOVA was calculated to compare post-COVID self-reported readiness across self-reported health levels. A significant difference was found in post-COVID-19 self-reported readiness to complete an advance directive across self-reported health levels ($F(4,12) = 2.69, p = 0.044$). Individuals with a self-reported health level of “Excellent” ($M = 3.50$) reported a higher level of readiness to complete an advance directive, whereas individuals with a self-reported “Poor” health level ($M = 1.22$) reported a lower level of readiness to complete an advance directive (see Table 2).

Table 2*Means across self-reported health levels*

Response	Mean	Std. Deviation
Poor	1.22	.441
Fair	2.33	1.589
Good	1.55	.945
Very good	1.00	0.000
Excellent	3.50	2.121

To answer research question three, “Is there a difference in self-reported readiness to complete an advance directive pre-COVID across self-reported age ranges?” No significant differences were found in the readiness to complete an advance directive pre-COVID across different age groups ($F(3, 47) = 1.59, p = .205$). Age did not appear to influence readiness to complete an advance directive before the COVID-19 pandemic. To answer research question four, “Is there a difference in self-reported readiness to complete an advance directive post-COVID across self-reported age ranges?” There was also no significant difference found in the readiness to complete an advance directive post-COVID across age group categories ($F(2, 45) = 2.45, p = .098$). Age did not appear to influence readiness to complete an advance directive after the arrival of the COVID-19 pandemic.

This study asked respondents to indicate if they had an advance directive with the following question: “*Do you have written instructions about the type of medical treatment you would want to receive if you were unconscious or somehow not able to communicate? (This is sometimes known as a living will or an advance care directive).*” Responses to this question are reported in Table 3.

Table 3*Number and percent of respondents who do and do not have an advance directive.*

Answer	<i>n</i>	%
Yes	9	15.79
No	46	80.70
I don't know	2	3.51

Note. n = 57

This study also asked respondents to indicate reasons for not having an advance directive with the following question: “*An advance care directive is designed to help others make medical or treatment decisions for your care in situations where you are not able to make decisions for yourself. Common forms of advance directives include living wills, and durable healthcare power of attorney. If you do not have an advance care directive, please tell us why? (choose one)*”. Responses to this question are reported in Table 4.

Table 4*Number and Percent of Respondents Reasons for Not Having an Advance Directive.*

Answer	<i>n</i>	%
Does not apply; I have an advance care directive.	6	10.71
I don't know what advance care directives are.	16	28.57
Never thought about signing one.	19	33.93
Do not need it because I am in good health.	0	0.00

Do not need it because my family knows my wishes.	7	12.50
Do not need it because my doctor knows my wishes.	1	1.79
Some other reason.	7	12.50

Note. n = 56

Discussion

Summary of Major Findings

Despite benefits of having an advance directive being well-documented (Kermel-Schiffman & Werner, 2017), physicians do not routinely mention advance care planning with their patients in an office setting (Rogne & McCune, 2014). Nurses often lack knowledge of advance directives and confidence to address advance directives with their patients (Miller, 2018), thus leaving the patient to initiate advance care planning conversations. The current results found that during the 2020 COVID-19 pandemic, individuals are at varied levels of readiness to complete an advance directive (see Figure 1) and a pandemic was not enough to increase the influence an individual's preparedness ($p = .135$).

This study found that 28.5% of respondents self-reported a lack of knowledge regarding advance directives by indicating, "Didn't know what advance directives are." Of the respondents, 33.9% indicated they have "Never thought about signing one." Both responses would place the participants in the pre-contemplation stage of the Transtheoretical Model (Prochaska & Velicer, 1997). However, it should be noted the latter response is not an indication the individual does not know what advance directives are. Our study also found that 83.3% respondents indicated they trust a family member or partner to provide advance care planning and end-of-life information; the second largest source respondents trust to provide information on advance directives or end-of-life issues is their health plan (see Table 5).

Table 5

Besides your doctor who do you trust to provide information on advance directives and end of life issues?

Answer	<i>n</i>	%
Family members or my partner	40	83.33
Lawyer	1	2.08
Clergy (minister, rabbi, priest, etc.)	2	4.17
Internet	0	0.00
Federal government (CDC, National Cancer Institute, etc.)	0	0.00
Media (newspaper, magazine, news)	1	2.08
Your health plan	3	6.25
Some other person or organization	1	2.08

Note. n = 48

Ko et al. (2016) showed that older adults were more willing to complete an advance directive because of their declining health. Our study had opposite findings in that individuals' health status post COVID-19 is enough to affect readiness to complete an advance directive ($p = 0.044$). The mean of the participants who reported "Excellent" health was the highest across all other responses.

Most of the participants (38.3%) self-reported their health status to be "Good," which would explain why they had never considered signing an advanced directive. However, no significant relationship was found between age and readiness to complete an advance directive pre ($p = .205$) or post ($p = .098$) COVID-19.

Public Health Implications

As mentioned above, the results of this study show that Medi-Cal recipients do not know what advance directives are and reasons why they don't have one. This

clearly shows a gap in knowledge and an opportunity for healthcare providers and facilities to better meet advance care planning needs. The reality of the COVID-19 pandemic has hospitals and clinicians working on multiple fronts to keep people from getting sick and caring for those who fall ill (Block et al., 2020). Although planning for an unforeseen COVID infection is ideal, strict hospital visitor policies to reduce the spread of COVID have compounded the urgency of having an advance directive (Block et al., 2020) since anyone can become infected with COVID, including an individual's healthcare proxy.

Although clinicians are a good first line to begin advance care planning conversations, the reality is that providers do not often have the training needed to start this discussion (Chan et al., 2019). However, with appropriate training, providers can be effective advocates for their patients (Tully, 2018). Office visits typically only allow time to respond to illness or injury issues as opposed to preventive care (Shaw et al., 2014). Therefore, community education programs that focus on advance care planning can help educate and inform patients, while saving time for providers during office visits. When physicians do not have the time or the training to discuss advance care planning in an office visit, they can refer the patient to a community education program (Rogne & McCune, 2014; CCCC, 2020; Tully, 2018).

For example, Kaiser Permanente has developed a Complete Care program to which physicians refer patients for additional education on a variety of problem areas including diabetes, hypertension, and advance directives called Life Care Planning (Kanter et al., 2013). Additionally, physicians in Riverside and San Bernardino Counties can refer their patients to IEHP's advance care planning classes called My

Life My Choice in which participants can learn the basics of completing an advance directive form through a virtual platform (IEHP, 2020).

Group education has been found to be more effective in completion of advance directives because of interaction and active discussions with an individual who is knowledgeable about them (Jezewski et al., 2007). Healthcare institutions must stress the value of an advance directive to all adults, especially before a patient is hospitalized (Tully, 2018). Repeated exposure to advance directives especially prior to hospitalization, have resulted in increased advance directive completion compared to receiving the information only at the time of admission as required by the PSDA of 1990 (Jezewski et al., 2007).

Healthcare organizations can consider using reminders in the EHRs to increase advance care directive discussions between healthcare providers and patients. The Palo Alto Medical Foundation (PAMF) has a universal “health maintenance reminder” in their electronic medical record system that is set up to remind physicians to have an “advance directive discussion” with all their patients when they turn 65 (Tai-Seale et al., 2017). The reminder appears until the discussion has been satisfied, which has resulted in higher rates of advance directive completion (Tai-Seale et al., 2017). Training targeted for physicians and nurses about advance directives are also available through workshops and specialized curricula, like *Let Me Decide*, and *Respecting Choices* (Jezewski et al., 2007) and state-specific training programs (CCCC, 2020).

Study Limitations

One of the major limitations of this study was the small number of responses received. We were not able to determine differences found within health levels due to low sample sizes; a post hoc test was not performed because at least one group had fewer than two cases. Low response rates could have been attributed to the following factors: Federal Communications Commission (FCC) limitations, omission of Medicare recipients, hesitancy or fear of clicking on links, or ignoring the text message.

Historically, the highest number of responses received from any text message campaign for the health plan are within the first three days the text message is sent out. Additional attempts were scheduled in order to obtain a greater number of responses. However, the FCC passed two rulings starting June 25, 2020 that limited the applicability of autodialer restrictions in the Telephone Consumer Protection Act (TCPA), which resulted in the ceasing of scheduled texting messages (TCPA, 2020).

Another factor that could have possibly contributed to low response rate was the omission of Medicare recipients. Medicare recipients are older (usually over age 65) and have higher rates of health decline which are both triggers for advance directive completion. Cautiousness, hesitancy, or fear of clicking on a link may have also influenced the decision to participate or not. Due to a high number of scams and viruses, potential respondents could just be “erring on the side of caution” by reading the text but not clicking on a link because they don’t want their phones to be “infected” with a virus or have their phones hacked. Because this survey was initiated in July after many people were working from home, schools were closed, supplies

were running low, there were long lines at various stores, and many individuals were worried about not being able to work, the text message could have taken as a low priority for the individual at that time and was unintentionally ignored.

Another limitation was the COVID-19 pandemic. Due to the social distancing rules and at-home orders issued by local and state health departments, we were unable to have in-person contact with the community to provide information about advance directives and advance care planning. Timing of the survey in relation to the pandemic may have also limited respondents' ability and readiness to respond to the survey questionnaire. The survey was administered only five months into the pandemic, which may not have been enough time to perceive the seriousness of the pandemic.

Additional limitations were homogeneous sample for age, which could have been contributed by omission of Medicare recipients or the categorization of age groups in the survey question. Many of responses were received from the same age group. The way the age was collected was also a limitation. Age data were collected as a range instead of a continuous variable, which limited the availability of options to analyze the data received.

Self-report bias was noted as a limitation because respondents may have answered some or all the questions according how they think they should answer rather than how they would normally answer. Voluntary response bias was also noted as a limitation. Participants with a strong interest in the topic were more likely to respond, and people who didn't have an interest in the topic may not have responded.

Recommendations for Future Study

The novel coronavirus has opened the door to countless opportunities for future research in the area of advance care directives and advance care planning. As COVID-19 continues to impact minorities, people of color, and older adults disproportionately (Chokhi, 2020; Farrell et al, 2020), the true impact of COVID-19 on advance directive completion has yet to be seen. A pandemic has the potential to change future attitudes and completion rates, especially if an individual contracts the virus or personally knows someone who contracted the virus (Block et al., 2020; Funk, Moss, & Speis, 2020). Conducting this study again when the COVID-19 pandemic is truly gone (no more new cases and a vaccine is available) will add knowledge to this area of research.

Medicare recipients typically have higher advance directive completion rates because of their declining health (Tai-Seale et al., 2017). Including Medicare recipients in future studies could allow researchers to compare Medicaid and Medicare groups' attitudes and completion rates for advance directives. Future studies can also explore which advance directive form Medicaid and Medicare populations prefer. There are currently a handful of advance directive forms available for patient use in the State of California such as the California Advance Directive (AARP), PREPARE for Your Care form, California Hospital Association Advance Health Care Directive Form 3-1, Kaiser Permanente Life Care Planning Form, and online fillable forms. Studies could also be performed on healthcare provider satisfaction on reimbursement rates for the advance care planning conversations for which Medicare pays.

Conclusion

The COVID-19 pandemic has changed how people live their lives day-to-day. Unfortunately, it is not a big enough motivator to increase a person's readiness level to complete an advance directive as demonstrated by this study's findings. Although most people don't like to discuss advance directives, they often count on family to make medical treatment decisions for them when the time comes. This puts a form of responsibility on family to be well-informed about advance directives. More efforts should be focused in educating minority and lower income communities and healthcare providers about advance directives so that advance care planning conversations are a more common occurrence and socially accepted. These community education sessions could help clear up any misconceptions about advance directives, such as being a tool to plan for death, funerals and/or distribute property, so people are less afraid to talk about them and more likely to use them.

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Appendix A: Consent Form

What is this study about? The purpose of the study is to figure out if the COVID-19 pandemic may motivate adult health plan members to complete an advance care directive.

Principal Investigator Information: If you have any questions about this study, please call the principal investigator Ethel P. Manley at (909) 890-2000 or email at HealthEd@iehp.org

Participation & Privacy: If you agree to be in the study, we will ask you to fill out a short survey about advance care planning and advance care directives which will take about 7 minutes to complete. Answer as honestly as you can. **Your participation is 100% voluntary and you can exit the question form at any time.** Your IEHP Member benefits will not be affected in any way if you choose to participate or not. We will not ask for any information that will identify you like date of birth or SSN. Your answers will be kept private and used to help us improve programs available to IEHP Members.

Risks & Benefits: There minimal risks to participate in this study. Participants may experience feelings of worry, stress, or anxiety thinking about the current pandemic, things they have done, things they have not done or thought about. If the questions bring up any discomfort or worry, you can contact the National Institute of Mental Health (NIMH) at (866) 615-6464 or text HOME to 741741 to connect with a Crisis Counselor (crisistextline.org). Benefits of this study will help improve the programs available to IEHP Members.

By clicking “Agree”, you are telling us that you:

- ✓ Have read the above information
- ✓ Voluntarily agree to participate
- ✓ Are at least 18 years of age
- ✓ Are an IEHP Member

Choose one:

- AGREE
- DISAGREE

Appendix B: Survey Questions

1. **Which language do you prefer?**
 - a. English
 - b. Spanish

2. **What is your age group?**
 - a. 18-24
 - b. 25-44
 - c. 45-64
 - d. 65+

3. **What is your home zip code?** _____

4. **What sex were you assigned at birth?**
 - a. Male
 - b. Female
 - c. Do not want to answer

5. **Which categories best describe you?** (choose all that apply)
 - a. American Indian or Alaska Native
 - b. Asian or Asian-American
 - c. Black or African-American
 - d. Hispanic, Latino, or Spanish Origin
 - e. Middle Eastern or North African
 - f. Native Hawaiian or Other Pacific Islander
 - g. White/Caucasian
 - h. Some other race, ethnicity, or origin

6. **Would you say that in general your physical health is _____?**
 - a. Excellent
 - b. Very Good
 - c. Good
 - d. Fair
 - e. Poor
 - f. Don't know/not sure

7. **Future healthcare plans are plans about the types of medical treatment you want or don't want to receive if you become seriously ill in the future. **Have you ever discussed your future healthcare plans and treatment wishes with family?****

- a. Yes
 - b. No
 - c. I don't know
8. **Have you ever discussed your future healthcare plans and treatment wishes with your Doctor or other healthcare professional?**
- a. Yes
 - b. No
 - c. I don't know
9. **Do you have written instructions about the type of medical treatment you would want to receive if you were unconscious or somehow not able to communicate?** This is sometimes known as a living will or an advance care directive.
- a. Yes
 - b. No
 - c. I don't know
10. An advance care directive is designed to help others make medical or treatment decisions for your care in situations where you are not able to make decisions yourself. Common forms of advance directives include living wills and durable healthcare power of attorney. **If you do not have an advance care directive, please tell us why?** (choose one)
- a. Does not apply; I have an advance care directive
 - b. Don't know what advance care directives are
 - c. Never thought about signing one
 - d. Do not need it because I'm in good health
 - e. Do not need it because my family knows my wishes
 - f. Do not need it because my doctor knows my wishes
 - g. Some other reason _____
11. **Thinking back to before** COVID-19 arrived in the United States (in February), how ready were you to complete an advance care directive? (choose one)
- a. I have never thought about it
 - b. I have thought about it, but I was not ready to do it
 - c. I was thinking about doing it in the next 6 months
 - d. I was definitely planning to do it in the next 30 days
 - e. I have already done it

12. **Which of the following is your biggest concern about end-of-life care?**

(choose one)

- a. Where I will receive care
- b. The cost of care
- c. My comfort and dignity
- d. The pain I might experience
- e. I don't have any concerns
- f. Some other concern _____
- g. I don't know

13. **Since the arrival of COVID-19 in the United States (as of today), how ready are you to complete an advance care directive?** (choose one)

- a. I have never thought about it
- b. I have thought about it, but I was not ready to do it
- c. I was thinking about doing it in the next 6 months
- d. I was definitely planning to do it in the next 30 days
- e. I have already done it

14. **Besides your doctor, who do you trust to provide information on advance care directives and/or end-of-life issues?** (choose one)

- a. Family members or my partner
- b. Lawyer
- c. Clergy (minister, rabbi, priest, etc.)
- d. Internet
- e. Federal government (CDC, National Cancer Institute, etc.)
- f. Media (newspaper, magazine, news)
- g. Your health plan (Health Plan Name)
- h. Some other person or organization

15. **How likely are to attend an in-person class that explains what an advance care directive is, why you should have one, and how to complete the form?**

- a. Not at all likely
- b. Somewhat likely
- c. Extremely likely

16. **If you are not able to attend an in-person class that explains about advance care directives, which of the options below do you prefer?**

- a. Written information on IEHP website
- b. Video
- c. Podcast

- d. Virtual meeting
- e. Phone call
- f. Other: _____

