1. Introduction

The Patient Self-Determination Act (PSDA) passed by congress in 1991, requires that all health care institutions that receive Medicare or Medicaid funds provide patients with written information about their right to make their own health care decisions surrounding life-sustaining treatment including the right to formulate advance directives. The PSDA also requires facilities to document in each patient’s medical record whether an advance directive has been executed, to educate staff and the public about the right to forgo treatment, and to ensure institutional compliance with state law. Violation of the PSDA can lead to loss of federal funding (Markus, 1997). My GE-NMF PCLP project began in effort to increase the awareness surrounding advance directives among the USC-Eisner Family Medicine Clinic patient population. Although, advance directives are given to all new patients at the USC-Eisner Family Medicine Clinic and Eisner Pediatric & Family Medical Center sites, advance directives are rarely (if ever) returned to be placed in the patients’ medical record. Part one of this project included the development of a curricula that will educate patients and promote the use and completion of advance directives. Part two of the project was the piloting the educational workshop in both Spanish and English to the patients of USC-Eisner Family Medicine Clinic.

2. Background

The advance directive is composed of three parts. First component is selecting a health care proxy/health care agent also known as a durable power of attorney. This person will be responsible for making health care decisions when the patient is no longer able to do
so themselves. The second component is the living will. This is the written documentation expressing the individual’s prospective treatment and medical care choices if the patient were at the end-of-life and no longer able to communicate their wishes (Harris, 2013). Lastly, the form requires witnesses or notary signatures before the advance directive can be acknowledged as a legal document. However, despite patient, physician, social work, and ethicists support for advance directives, the completion of the form is still unpopular. Many people are hesitant to document end-of-life wishes using an advance directive. And to date, interventions have had little effect increasing completion of advance directives (Finnell et al 2011).

According to the California Healthcare Foundation, research shows that a majority of Californians prefer die at home instead of a hospital. Approximately 80% say that they definitely or probably would like to talk with a doctor about end-of-life wishes, but only 7% have had a doctor speak with them about it. In addition, while 60% of Californians say that making sure their family is not burden by tough decisions about their care is “extremely important”, the majority (56%) of Californians have not communicated their end-of-life wishes. Two-thirds of Californians say they would prefer a natural death if they were severely ill, while only 7% say they would want all possible care to prolong life (California Health Care Foundation 2012). Another important fact is that, 84% of physicians miss the opportunity to engage in end-of-life care planning with patients who have expressed concern or questions about their future (Ahluwalia et al. 2011).
Currently, there are no studies published on advance directive education taking place in a community based health center setting. However, there are few studies discussing outpatient education in skilled nursing facilities and VA clinics. Most publications mention advance directive education as either group education or one or more individual sessions with a social worker. However, group education was shown to be twice as effective as individual social work sessions, and as effective as multiple sessions with a social worker but less time consuming (Dipko et al 2004). As a result of high patient case load for the USC-Eisner Family Medicine Clinic Case Workers, and the published research on advance directive education, a group workshop on advance directives was chosen as our model. Our study aims to promote the understanding and use of advance directives amongst USC-Eisner Family Medicine Clinic adult patients.

3. Methodology

For two half days, I conducted interviews with the senior & persons with disabilities (SPD) patients and adult patients at USC-Eisner Family Medicine Clinic. Interviews were directed in either Spanish or English in effort to assess patient knowledge and sentiments of advance directives and education. (See Appendix: “Interview Questions: Sentiments Surrounding Advanced Directive Education”)

In addition, five different advance directives utilized within Eisner Pediatric & Family Medical Center (EPFMC) departments were studied (See Appendix: Advance Directive Tools).
o **Attorney General’s Advance Directive**
   This advance directive is a 6 page document written in an advance reading level with small font, without color or pictures. The form contains little instructions and no definitions. The form allows for power of attorney for health care designation, end-of-life treatment preferences, organ donation choices as well as a signature page. The Attorney General’s Advance Directive is the form most familiar with USC-Eisner Family Medicine Clinic providers.

o **Advdir.org**
   This advance directive is a 16 page document written in size 14point font, without color or pictures. The form contains a long question and answer, instruction and advance directive purpose section. There is also an area covering patients’ rights. The form allows for power of attorney for health care designation, end-of-life treatment preferences, pain relief decisions, organ donation choices as well as a signature page. This booklet is provided to all new patients at USC-Eisner Family Medicine Clinic and the Adult Department at EPFMC.

o **California Standard Advance Directive**
   This advance directive is a 19 page document written in a 12th grade reading level (Sudore 2007) with size 12point font, without color or pictures. The form contains instructions, purpose, power of attorney designation, end-of-life treatment preferences, organ donation and execution of advance directive. The Standard Advance Directive is utilized by providers of the EPFMC Mental Health Department.

o **Five Wishes**
   The Five Wishes advance directive is a 12 page document written in an advance reading level with small font with color and no pictures. The form contains reasons for use, and many options for wishes 1-5. Wishes cover health care agent designation, broad end-of-life treatments, comfort care, environment, patient values as well as, words to remember. Signatures are also required. This form is utilized at many neighboring clinics as well as, the Los Angeles County Hospital. This form is a favorite of the geriatrics clinic provider at USC-Eisner Family Medicine Clinic; however there is a financial cost of $5 per booklet.

o **The Institute of Health Care Advancement Advance Directive**
   This redesigned advance directive is a 12 page document written at a 5th grade reading level, in 14point font, in color and with culturally diverse pictures (Sudore 2007). This advance directive contains definitions, broader end-of-life treatment choices, values as well as instructions, purpose, power of attorney designation, organ donation and execution of advance directive.
Studies have shown that providing non-intimidating, appropriate reading level language and discussing patient values for treatment have increased rates of completion of advance directives. After studying user-friendliness, literacy level and cost of the form, in addition to patient preference, the Institute of Health Care Advancement Advance Directive was chosen as the designated form for our workshop.

A one-hour workshop was created (See Appendix: AD workshop English), to cover needs and instructions to completing the advance directive. Over the course of two weeks, 3 workshops (2 Spanish 1, English) were conducted. A total of fourteen participants took part. Patients provided feedback on Patient Satisfaction Surveys (See Appendix; Patient Satisfaction Surveys).

4. Results

17 initial interviews were conducted with adult patients ages 29-74 years old in effort to evaluate their understanding of advance directives and their attitudes towards advance directive education. Of these 17, only 13 interviews were completed in full. Findings from the interviews were consistent with publish studies surrounding advance directive education. Despite all new patients receiving an advance directive when they first registered and became patients of EPFMC, most were unaware of the term “advance directive” and most stated not having communicated their end-of-life wishes with their families (California Health Care Foundation 2012).
After the interview, patients were provided with a definition, and purpose of an advance directive. Patients stated that education about the form was essential to improve their comfort completing an advance directive. Speaking to their family and medical provider about their end-of-life care was also something they identified as important.

Recruitment for the advance directive workshops took place over the course of three weeks via referrals from medical providers, case managers and one-on-one invitations while the patients were in the waiting lobby or exam room. Although
evidence showed that the use of passive information such as posters and leaflets (Tamayo-Velazquez et al. 2010) does not increase the advance directive completion rates by themselves, when interactive information such as workshops are employed the completion rate does increase. Therefore, flyers (See Appendix: Flyers) promoting the workshops were placed in each exam room, as well as the waiting lobby, clinic hallways and bathrooms. In addition, reminder notices and phone calls were also conducted for patients who expressed interest in attending a session. The workshops were conducted at various times throughout the week with Saturday morning being the most favorable time. A total of 14 participants took part in the advance directive educational workshops, and provided feedback via a satisfaction surveys. Patients were given a $5 Starbucks Gift Card for their participation. Feedback given from satisfaction surveys (See Appendix: Patient Satisfaction Survey) were incorporated to the curricula.
5. Discussion

Advance directives are given to all new patients at USC-Eisner Family Medicine Clinic (USC-EFMC), however only one advance directive had ever been completed and returned as of July 2013. Nonetheless, after weeks of patient interaction, workshop publicity and participation, several improvements surrounding advance directive awareness could be observed. Patients and medical providers described an increase in knowledge on advance directives and increase dialogues on end-of-life treatment preferences. There is a positive correlation, with patient’s level of knowledge and positive attitude, and predicted completion rate of advance directives (Ko, et. al 2013). In addition, studies show that patients with advance directives are less likely to receive life-sustaining treatment or die in the hospital, as well as burden their families with difficult decisions (Silveira et. al 2010). Patients were most interested in avoiding unwanted suffering as well as improving relationships with their medical provider and families. Lastly, advance directive education workshops empowered participants. Patients sought out advance directives for their families, and one female patient brought in their completed advance directive to be placed in her medical record.

The barriers experienced to advance directive education should also be addressed. When this project began recruitment and lack of patient participation were not anticipated. Thus a protocol for educational workshop recruitment should have been established. Providers had a difficult time remembering to recruit patients and while initially SPD patients were a target population, many factors (transportation, severity of their health etc) hindered their
participation. Although, USC-Eisner Family Medicine Clinic hours were 8-5pm Monday-Friday, the morning workshop had low attendance. The afternoon and Saturday workshop had the best patient participation. Attendance could have also been affected due to short recruitment time. Lastly, provider recruitment was also affected because end-of-life care conversations are not part of medical providers’ or USC-Eisner culture. Nonetheless, avoidance of end-of-life conversations is not uncommon. Research has shown that physicians often miss the opportunity to engage in end-of-life treatment discussions despite patient prompting such concerns (Ahluwalia et. al 2011).

Conclusion

Our findings cannot be generalized to all patients of community based health centers. As noted, recruitment and participation was difficult to achieve. Workshop participants, were patients, who regularly visit USC-Eisner Family Medicine Clinic and who were pro-active about their health care. Most of these patients were able to attend with less than a 2 week notice. In addition, participants enjoyed working in a group setting and expressed comfort sharing personal experiences. It would be recommended that social worker support be available in case patients need emotional support. Additionally a standard, user-friendly advance directive such as the Institute for Health Care Advancement’s advance directive, will need to be implemented among all EPFMC sites and the advance directive educational workshop should be offered all new adult patients. Furthermore, medical providers and the medical care team who is responsible for advance directive distribution and referrals should also receive information about the standard advance directive form contents.
Although, advance directive group workshops are not a financially compensated service, education provides a service aligned with EPFMC’s mission to provide comprehensive healthcare. Early preparation and planning ensures patients receive care that is in agreement with their wishes. Patient-provider dialogues after completion of advance directives are opportunities to solidify the patient centered care model highlighted at EPFMC. Nonetheless, provider knowledge and understanding about advance directives was not evaluated in this study. Therefore, lack of attention to advance directives from the providers could be multi-factorial such as lack of knowledge about the form and its components, or inability to identify opportunities to discuss end-of-life treatments.

In summary, we found that advance directives are a valuable resource if one knows they exist, has the understanding to complete it, and discussion of ones preferences is encouraged. This project found, advance directive barriers experience by patients included a lack of knowledge about the form and the unwillingness to initiate end-of-life discussions with their family and medical providers. After taking part in the advance directive workshop, the purpose of this project was met. A successful Spanish and English educational workshop was created, and patients expressed increase comfort surrounding advance directives. In addition, the majority of participants asked for additional forms for family members and friends and medical providers were reminded of the need to include end-of-life discussions as part of their regular treatment plan.
References


2. California HealthCare Foundation, “Final Chapter: Californians’ Attitudes and Experiences with Death and Dying” February 2012.


6. Ko Eunjeoung, Lee Jaehoon. “Completion of Advance Directives Among Low-Income Older Adults: Does Race/Ethnicity Matter?” American Journal of Hospice & Palliative Medicine 00(0) 1-7 2013


Appendix


July 24, 2013

Eisner Pediatric Family Medical Center & GE-NMF PCLP

Interview Questions: Sentiments Surrounding Advanced Directive Education

Prescreening:
A. Introduction (myself, Jenny and program project)
B. Assure information is confidential and will not be shared with anyone other than my Faculty Advisor and Faculty Mentor.

1. Patient Demographics
   a. Sex:
   b. Age:
   c. Ethnicity:
   d. Primary Language:
   e. Health visit reason (e.g., chronic conditions? Yearly physical? Follow-up):
   f. Who helps you with your health decisions/concerns? How do they participate?

2. Knowledge on Advance Directives
   a. Do you know how decisions about your medical care are made if you were unable to speak for yourself? (¿Sabe usted cómo se deciden sus decisiones médicas en una emergencia si usted no pudiera comunicarse?)

   b. If a moment when you are too sick to express yourself comes, how would you communicate the kind of medical treatment you want or don’t want? (¿Cómo expresaría sus deseos de tratamiento médico si llega el momento en que usted está tan enfermo que no puede expresarse?)

   c. What can you do now that you are not sick regarding the medical treatment choices you want when you are so sick to communicate them yourself? (¿Qué puede hacer usted ahora que no está enfermo, acerca de sus deseos médicos en el futuro?)

   d. What do you know about Advanced Directives? (¿Sabe usted acerca de las Disposiciones de Última Voluntad Para La Atención Médica, a veces también conocida como un Testamento en Viene a)}
   a. If you were too sick to speak/write, what kind of medical treatment would you want or not want? (Qué hace cuando esté tan enfermo que no pueda expresarse, qué tipo de tratamiento médico quisiera o no quisiera?)

   b. Would you ever want to receive medical interventions such as, blood transfusions, major surgeries, life-support, CPR, mechanical ventilation, and tube feeding? How about if you had an incurable condition? Does anyone know these wishes? (¿Quieres recibir intervenciones médicas como transfusión de sangre, cirugías, ventilación mecánica o alimentación artificial por tubo? ¿Alguien sabe estos deseos?)

   c. Is there someone you trust to make health care decisions for you? Do they know? (Tiene usted una persona de confianza que pueda designar como su representante para que tome decisiones relacionadas con su atención médica? ¿Los sabe?)

4. Show patient an AD form and Discuss
   a. After seeing this form, would you feel more confident in making decisions about your medical care? (Después de ver esta forma, ¿se siente más confiado en tomar decisiones sobre su tratamiento médico?)

   b. What concerns do you still have? (¿Tenía preocupaciones hoy todavía?)

5. Sentiments on Education Regarding Advance Directives
   a. Who would you think is the most appropriate to address Advanced Directives with you? (¿Alguien es la persona más indicada para discutir Disposiciones de Última Voluntad contigo?)

   b. How do you feel if you were referred to a case manager or social worker for your AD education? (¿Cómo se sentía si la información sobre Disposiciones de Última Voluntad fue dada por un trabajador social, o asesor de salud?)

   c. How would you feel if you were in a group receiving AD education/information? (¿Cómo se sentiría en un grupo recibiendo información sobre Disposiciones de Última Voluntad?)
July 24, 2013

d. How likely are you to sign an AD and POLST form after receiving information on it? (¿Cuál es la probabilidad de que firmes una AD y un formularios POLST después de haber recibido información sobre ellos?)

e. What can we do to encourage you to sign and return the AD to your provider and discuss it with your family? (qué podemos hacer para motivar a firmar, entregar la AD y discutirla con su familia?)

f. Why do you think most people do not have an AD or have not shared their wishes with their PCP? (¿Por qué crees que la mayoría de las personas no tienen una AD y no comparten sus deseos con su médico?)

6. Preference of AD form
   a. Which form do you prefer to read?
      - Attorney General’s AD for California
      - CA AD—planning for important Decisions
      - 5 Wishes AD
      - CA Advance Care Directive (pictures)

   b. Which form would you most likely fill out?
2. Advance Directive Tools

   a. Attorney General’s Advance Directive


   b. Advdir.org
c. California Standard Advance Directive


4. Five Wishes

http://www.agingwithdignity.org/five-wishes.php
5. The Institute of Health Care Advancement Advance Directive

http://iha4health.org/default.aspx/MenuItemID/266/MenuGroup/_Home.htm

3. AD workshop English

Introduction

› Who am I?

› Why do we speak about his subject here?
The facts....

› 60% of people say that making sure their family is not burdened by tough decisions is “extremely important” to them.

› But 56% have never communicated their end-of-life wishes

› Nearly 80% of Californians said they would want to speak with their doctor about end-of-life care, if they were seriously ill.

› But only 7% have actually reported having such a conversation.

› 70% of people say they prefer to die at home

› But 70% will die in a hospital or a long-term care facility.

Outline for today's presentation

› 1. Introduction

› 2. What are Advance Directives and what is their purpose?

› 3. Uses of Advance Directives

› 4. Thoughts from the group

› 5. Completing the form and communicating your wishes

› 6. Question & Answer
What is an Advance Directive and what is its purpose.

- This is a legal document that allows you to state how you wish to be treated if you were to become seriously ill and at end-of-life.
- Helps your family, doctor, and friends prevent guessing what you would want.
- You will be able to learn the wishes of your loved ones, and be able to give them the support needed when they need it most.

Examples of Advance Directives in Use.

http://wn.com/advance_directive

http://www.youtube.com/watch?v=vSwY5pA4cGc	first 3:39min

Thoughts?

Advance Directive Form

- It has 3 parts:
  - Part 1: Choosing a health care agent
  - Part 2: Making your own health care choices
  - Part 3: Signing the form

PART 2 Make your own health care choices

Choose one

Choose one

Choose only one

Choose only one

If you are sick, your doctors and nurses will always try to keep you comfortable and free from pain.
ADVANCE DIRECTIVES EDUCATION FOR PATIENTS
Zulma Pérez-Estrella MD Candidate 2016, KUMC
Eisner Family Medicine Clinic & EPFMC

Are You Ready... Or is there something more???

Question & Answer

[Diagram of healthcare options and decision-making process]
4. Patient Satisfaction Surveys

<table>
<thead>
<tr>
<th>Satisfaction Survey—August 13, 2013</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. How helpful was this workshop?</strong></td>
</tr>
<tr>
<td>1</td>
</tr>
<tr>
<td>Very Poor</td>
</tr>
<tr>
<td><strong>2. How important was the information received in this workshop?</strong></td>
</tr>
<tr>
<td>1</td>
</tr>
<tr>
<td>Very Poor</td>
</tr>
<tr>
<td><strong>3. How clear was the Information delivered to you in this workshop?</strong></td>
</tr>
<tr>
<td>1</td>
</tr>
<tr>
<td>Very Poor</td>
</tr>
<tr>
<td><strong>4. After this workshop how likely are you to complete an Advance Directive?</strong></td>
</tr>
<tr>
<td>1</td>
</tr>
<tr>
<td>Definitely Not</td>
</tr>
</tbody>
</table>

**Additional Suggestions:**
5. Flyers

Living Wills & Advance Directives

IT’s TIME FOR A CONVERSATION

Helping make difficult decisions easier.

Advance Health Care Directives give you the right to give instructions about your own health care and also have the right to name someone to make health care decisions for you if you are too sick to make them yourself.

This workshop is for all adults, especially seniors, those with chronic conditions and those with aging parents.

Date: Monday August 5, 2013 (Español) 9-10am
Tuesday August 13, 2013 (English) 1:30-2:30pm

Location: 1400 South Grand Ave, Suite 101 Los Angeles CA 90015
Questions: contact Zulma Perez-Estrella (213) 744-0801 ext. 2262

FREE Event

EISNER PEDIATRIC & FAMILY MEDICAL CENTER

Instrucciones Anticipadas de Atención de Salud y Testamentos en Vida

ES TIEMPO DE TENER UNA CONVERSACIÓN

Haciendo las decisiones difíciles más fáciles

Las Instrucciones Anticipadas de Atención de Salud le da a usted el derecho de dar instrucciones sobre el tipo de tratamiento médico que desea o no desea recibir. También le da el derecho de designar una persona que tome decisiones en su nombre cuando no lo pueda hacer usted mismo.

Este taller es para todas personas adultas, especialmente si es mayor de 65 años, tiene padres mayores de edad o tiene condiciones crónicas.

Fecha: Lunes 5 de Agosto de 2013 (Español) 9-10am
Martes 13 de Agosto de 2013 (English) 1:30-2:30pm

Dónde: 1400 South Grand Ave, Suite 101 Los Angeles CA 90015
Si tiene preguntas llame a Zulma Pérez-Estrella (213) 744-0801 ext. 2262

Evento GRATIS

EISNER PEDIATRIC & FAMILY MEDICAL CENTER