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Initiating healthcare agent education in time-limited settings

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Rotation Month: Aug 19 – Sep 27, 2019
Location: Swanton, VT
Problem Identification

– Of Medicare beneficiaries, <1% of study participants had patient physician end of life discussions during routine care\(^1\). Identifying a proxy for health care opens the door for continued advanced care planning between patients, families, and their clinicians. Furthermore, ACP discussions can be used to further build rapport between physicians and patients.

– Several barriers were identified:
  – **Time and Money:** Clinicians are unable to help patients advance care planning due to time and cost constraints.\(^2\)
  – **Late Onset:** Advanced planning is often initiated when the patients are elderly or seriously ill \(^3\)\(^4\), even if young adults may be interested in advanced care planning\(^5\).
  – **Stigma:** Most patients are willing to discuss advanced care planning, but they are waiting for their physicians to begin the conversation and to raise the necessary questions\(^6\). The reluctance of PCPs to initiate these conversations is considered “a primary reason that most Americans do not have an advance directive.” \(^7\)
  – **Education Level:** Completion among disadvantaged populations tend to be low, particularly among lower educational status\(^8\). While half of American adults read at or below an 8\(^{th}\) grade level, Advance Directive forms are written at a 12\(^{th}\) grade level\(^9\).
Cost and Benefit

– Advanced care planning (ACP) leads to reductions in overall health care costs and inpatient utilization.
  – ACP cases had fewer inpatient admissions and inpatient days, with adjusted costs $9,500 lower compared to controls. \(^{[10]}\)
  – Patients who reported end of life discussions with their medical team reported a $1041 reduction in the cost of care or 35.7% cost compared to those who did not report end of life discussions. Patients with higher costs had worse quality of death in their final week. \(^{[11]}\)

– Increases likelihood of honoring a patient’s preferences for less intensive treatments \(^{[12]}\)
– Increases incidence of patients dying in their preferred location \(^{[13]}\)
– Reduces stress, anxiety, and depression in surviving family members \(^{[14]}\)
“Everyone should have a health care advocate. Primary care providers have the responsibility to guide patients and their family members on advanced care planning, similarly to conversations about organ donation. Age and health should not be a limiting factor for having advanced care discussions. This is particularly true in rural Vermont where farm workers, skiers, and those operating heavy machinery may be prone to life-threatening accidents.”

– Kellie Uzell, Certified Clinical Medical Assistant

“I worked in this office for 17 years. And from my experience, I think patients will require assistance with advance care documentations given that the process may be difficult to comprehend and intimidating to fill out. Furthermore, some patients do not have the education level to understand the documentation well enough to fill it out themselves. I feel comfortable having these discussions with patients and am open to raising awareness about health care proxies.”

– Jodie Gagne, Administrative Assistant
Intervention/Methodology

A. Conversations about health care agents can be started as part of a routine social HPI. For the purposes of this project, the following questions were asked in sequence:

1. Who would you say is your main support system?
2. Is this someone you talk about medical decisions with?
3. In the event where you are not able to make medical decisions for yourself, is this someone you would be comfortable handling your medical decisions and/or finances?
4. Would you be willing to fill out documentation to ensure that this person be designated as your health proxy?

B. A brief summary was provided of the following:

- HIPAA authorization: “This gives the agent access to your medical information.”
- Medical power of attorney: “This gives the agent the ability to make medical decisions when you are not able to.”
- Durable financial power of attorney: “This gives the agent the ability to manage your finances when you are not able to.”

C. Follow up for documentation was scheduled after patients touch base with their designated proxy.
Intervention/Methodology

A brief pamphlet was prepared for the medical team to be engaged in HCA discussions regardless of one’s medical educational background.

The pamphlet offers a way to engage in HCA conversations in a simple and time-efficient manner by providing step-wise instructions, structured questions, and definitions for HCA terminology.

This pamphlet may not be appropriate for distribution to patients at or below the 8th grade reading level and is not to serve as a replacement for a medical-team provided education. According to the SMOG readability index, this pamphlet was rated as a 10.5 which correlates to an 11th grade reading level.
Community Response

Of 10 patients that verbally designated a health care proxy following a 5 minute intervention:

– **Respondents widely varied in age**: From 24-75 years old

– **Medical conditions ranged from non-terminal to terminal**: included anxiety, agoraphobia, major depressive disorder, PTSD, chronic pain syndrome, drug use disorder, end stage lung cancer.

– **Designated individuals also vary**: Proxies include friends, fiancé/husband, siblings, parents, and children. *Health care professionals were not mentioned as preferred proxies.*

“Unfortunately, I was knowledgeable about death from a young age. Conversations about death should be carried out between parents and their children, even if their child is under the age of 18 and/or healthy. You could get into a car accident at any age. My husband works in security and he oversaw the funeral of a young person who just committed suicide. You never know what could happen. As for me, I see my husband as my health care agent and power of attorney.” – Parent of 18 mo for a wellchild visit

“I have never had a doctor talk to me about this. While I am closer to my cousin, I am more comfortable with my mom making medical decisions and handling my finances. We talked about these things in the past, but I didn’t know it needed to be in writing. Do YOU even have a health care agent?” – 33 yo with a history of panic disorder with follow up for STEMI

“I have never heard about health care agents until today. My mother is my best friend and we share everything together. I think it’s important to talk about this given that I have had so many things happening to me at such a young age. I will have to talk with my mother first and I will want documentation in the future visit.” – 55 yo survivor of a MVA now with complex pain syndrome
Effectiveness and Limitations

– Assessing Effectiveness:
  – Chart review to include pre and post-intervention proxy designation rates may be employed
  – Retrospective studies can be done to assess proxy designation rates compared to the national average following the intervention

– Assessing Limitations:
  – Results can not be generalized without further sampling, which is complicated by the limited time frame of this project.
  – Patients who do not have a support system could not be assessed, and it is unclear who would be the proxy in that case.
  – Initiating the conversation is often the first step to having advanced care discussions, but it does not change the fact that the literacy level required for documentation may not be adequately addressed.
Future recommendations

- Forms for designating health care advocates or providing an advanced directive may be further refined to allow those of varying educational backgrounds to fill them out. Given that current forms are not written to accommodate the <8th grade education level, it is likely that many patients will require coaching/prompting when filling out the documentation. The Institute for Healthcare Advancement (IHCA) redesigned California’s advanced directive documentation to suit the 5th grade educational level and was found to be more accessible to patients[15]. Efforts can be made to adapt the IHCA advanced directive for Vermonters.
Future recommendations

− Both health care providers and support staff may be educated on how best to initiate ACP conversations as part of a routine visit. Proxy designation can be a steppingstone to continue refining advanced care conversations in future visits.

− Given that young adults are interested in being educated about ACP, health care designation can be extended to high schools and college campuses in the form of workshops.

− Conversations about health care proxies can be initiated with new parents as part of a comprehensive health education for their children, regardless of the children’s age.

− Given the high rate of motor vehicle accidents among minors, designating health care advocates can be a part of a comprehensive driver’s education course.
References


