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A healthcare provider perspective in overcoming the psychological and emotional barriers of advance care planning: The need to normalize the conversation

South Burlington, VT

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Advance care directives: Uses and Barriers to use

- There is an increasing desire in public to have some control over the course of the last phase of life, including medical decisions and goals (1-4)
- Advance care planning is a means of “extending the autonomy” of the patient when the patient is otherwise unable. (5)
- ACD are both written documentation aspect and a social process. (6)
- Barriers: ACD are stressful for patients and may lead to suboptimal implementation. (7)

The impact of advance care planning on public health

- ACD are able to improve compliance with patients' wishes and reduce family stress, anxiety and depression. (8,9)
- 22 recent studies show an association between ACD and withdrawal of life sustaining treatment per patient preference.(5)
- 10 studies showed decrease in life sustaining treatments, 5 showed decreased tube feeding. While 11 studies showed no change.(5)
- Increased use of hospice and palliative care and an increase in the use of comfort plans have been associated with ACD.(5)
- Six studies showed association between ACD and patient and family: satisfaction, quality of life or quality of death and dying, while five other did not.(5)
- At the UVM South Burlington family practice site currently has an advance care directive or a health care proxy (HCP) form for ~ 38.5% of its patient population.
- At the same site the >65 y.o. population 60% have an ACD/HCP on file

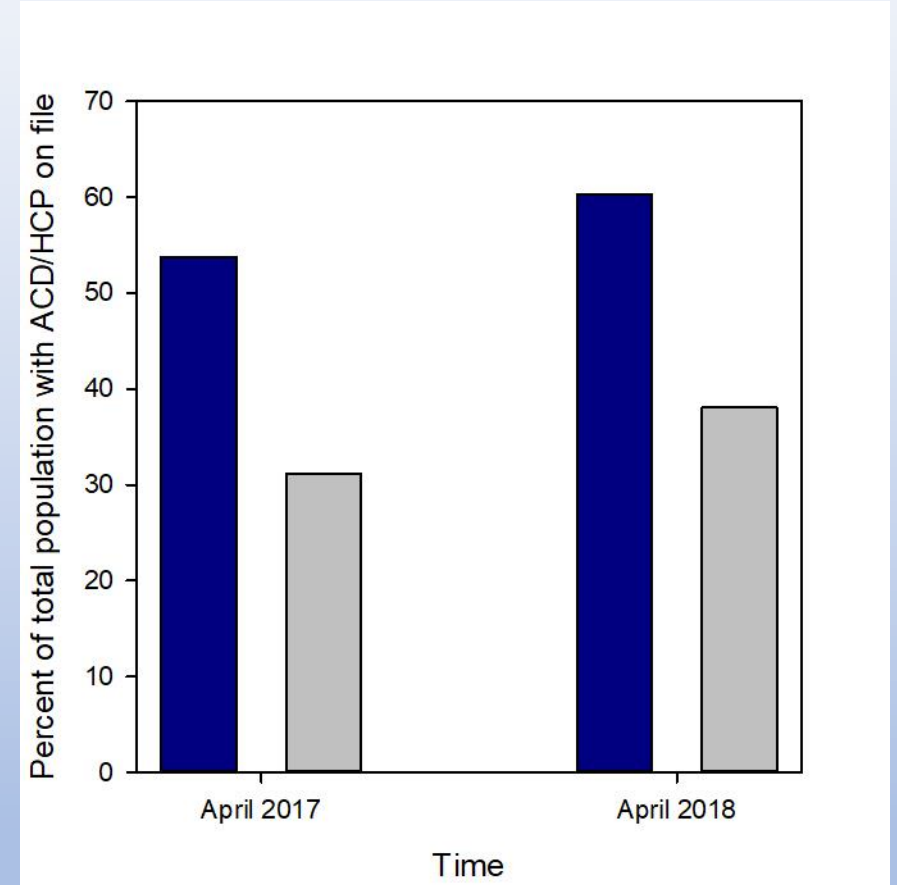


Figure: Percent of patient population >65 y.o. with ACD/HCP on file (Blue) vs. the entire patient population of UVM-South Burlington with ACD/HCP on file (grey) over the course of 1 year.

Community perspective

- Interviews conducted with the following groups: Physicians, community health team (social worker), medical assistant, and a representative from Vermont ethics network.
- **When speaking of the effects of ACD on personal, family and community health**
 - ACD gives guidance to people for later in life situations and it also helps to alleviate their fear of what is to come. It gives the family confidence about the healthcare of their loved one. They feel more comfortable asking for the patient's wishes. Community wide, I feel that both healthcare and emotional cost is the concern. (Whitney Calkins MD)
 - The patients that want to do it, do so for their children. So that their loved ones may not have to make these tough decisions. We also see people who had either good experiences with the passing of a loved one and want the same thing for themselves or bad experiences and want to make sure no one else experiences similar hardship. (Kelly Walters Community Health Improvement Supervisor)
- **When highlighting the greatest difficulty in having the ACD filled out**
 - It is harder to gauge how a patient might be feeling sometimes, especially when they have a terminal diagnosis. Initiating the conversation on the subject is the most difficult part in such cases. I feel that it is also harder for physicians to broach the subject because we are so hard wired to want to save and extend a patients healthy life as much as we can. (Kate Lamancuso MD)
 - By the time the patients come to us, they have decided that filling out the document is necessary. It is a difficult thing to do however, since it forces the patient to think about their mortality and end of life. (Kelly Walters Community Health Improvement Supervisor)
 - Initiating the conversation might not be as difficult, but ensuring that the complete document is returned is difficult. Many responses we get are "I'm too young for this" or "my family knows what I want. Not everyone takes the document seriously. (Michelle Degree Clinical Care assistant and Stephanie Marceau LPN)

Community perspective

- **Successful approaches**

- Telling them that the document is a fluid living document and that they can update it anytime they want. Highlight the fact that if they change their mind at any point, their wishes on the spot will supersede the document on file. *(Whitney Calkins MD)*
- Breaking the document down into smaller pieces helps make it less overwhelming for the patients. A patient may come in thinking that they are about to setup strict guidelines. Helping them understand that the ACD only provides guidance for their loved ones regarding their wishes and is not scenario specific eases their apprehension. I also see that as they are trying to fill out the document, they are also afraid of forgetting something, a multiseession approach is helpful for them as well. *(Kelly Walters Community Health Improvement Supervisor)*
- With younger patients highlighting the need for ACD of HCP in case of catastrophic events is key. Sometimes they don't want their parents (de-facto decision makers for children and young adults) to be making their decisions. It helps to tailor the conversation towards the specific person. *(Michelle Degree Clinical Care assistant and Stephanie Marceau LPN)*
- **When speaking of the subgroups of populations that struggle the most in filling out ACD**
- I think there has been a stigma associated with the document in our society. Our conversations about it haven't normalized yet. It needs to become normalized and we need to restore the image of ACD's as a principally good idea. *(Kelly Walters Community Health Improvement Supervisor)*
- I find that older patients take the topic more seriously. Perhaps it is more real to them than the younger patients. I also believe that we might benefit from having an online version of the healthcare proxy form like we do for the PHQ-2, especially when it comes to the younger population. *(Kaitlyn Barton LPN)*
- In our practice, focusing on the HCP document has received overall a good response. I believe it to be a conversation starter that will help to direct the conversations in the future towards the right direction. *(Whitney Calkins MD)*

Intervention and methodology

- When asked for any advice
 - Normalize the information. Make it the norm. Inform people. Talk about it long before it's a problem. *(Kelly Walters Community Health Improvement Supervisor)*
 - Let's remove the taboo from the conversation. Make it a normal everyday conversation to be had. *(Kate Lamancuso MD)*
 - Normalizing the conversation would be helpful. Maybe not at acute visits, but definitely make it a normal part of all other visits at the doctor's office. *(Michelle Degree Clinical Care assistant and Stephanie Marceau LPN)*
 - Normalizing the conversation maybe helpful, but it needs to be done with care because overexposure may alienate the patients. *(Kaitlyn Barton LPN)*
- Based on this response, a more approachable, attention grabbing pamphlet was designed

Intervention and methodology



Advance Care Directives

- Are documents that declare your desires for the handling of your healthcare when you have become unable to communicate your wishes
- They provide a framework of your wishes to your family, loved ones, and physicians about your decisions for your medical care that highlight your personal values
- Remember, there is **NO** law in Vermont that automatically allows your loved ones or family to make decisions for you in your time of need
- Anyone but your health care provider/doctor can be your agent
- Rest assured. The advance care directives are fluid documents. Change them as much as you feel is necessary to make sure they reflect your current wishes
- The advance care directives are for you, if you are older than 18.

Advance Care Directives

- Extend your autonomy
- Improve compliance with your wishes
- Guide your loved ones in decisions about your healthcare
- Decrease the anxiety and improve both your comfort and the comfort of your loved ones

What can you do?

- Make your own document **OR**
- Use one of the several templates from Vermont Department of Health at

www.healthvermont.gov/vadr/register.aspx

What can we do for you?

- Provide templates for you to fill out
- Fax them to the registry for you
- Answer your questions. We, the physicians, the medical care staff, and the community health team, are here to help.

Results

- Is a repackaging of the narrative of choice necessary?
 - I think we are already trying to position it as choices that you are making for and with your family. It is important to continue to frame it in that context. This is so your choices are taken into account when you are hospitalized. *(Whitney Calkins MD)*
 - I think it is already presented as a choice. The key is to reach the younger generation. I use the retirement plan as a representative argument. As we grow up and realize its importance, we invest in it. We need to convince our patient population that thinking about ACP is like having a great retirement plan. *(Kelly Walters Community Health Improvement Supervisor)*
 - Feels like we are already doing that. Many times it seems that the patient already has their mind made up about whether they are going to fill out the document or not. *(Michelle Degree Clinical Care assistant and Stephanie Marceau LPN)*

Evaluation of effectiveness and limitations

- Handouts give patients a chance to evaluate and understand the information at their individual pace
- They decrease office visit time discussing the information and make for a more informed conversation between the provider and the patient
- The pitfalls of normalization
 - Normalizing the conversation maybe helpful, but it needs to be done with care because overexposure may alienate the patients. *(Kaitlyn Barton LPN)*
 - Oversaturation of information was a concern among most of the interviewees
- Simultaneous need for normalization and care and respect for the patient and the topic was also stressed

Recommendations for future interventions/projects

- Based on the multiple interviews, the following suggestions and recommendations for future projects are being made
- While among the >65 y.o. population at the south Burlington office the completion rate is ~60%, the overall rate of completion is 38.5%.
- This implies that there may be a specific subgroup of population that is not filling out the document and needs to be identified.
 - Time is the difficulty. Because of it the conversation about ACD is often pushed to the end of the interaction with the medical staff. As such, especially targeted towards the younger patients, an online version of the document may be able to generate more of a response.
 - I also believe that we might benefit from having an online version of the healthcare proxy form like we do for the PHQ-2, especially when it comes to the younger population.
- Based on the suggestions above, a future intervention could employ an online version of the healthcare proxy form with built in system reminders.

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