

Proactive Advance Care Planning in Rural Primary Care

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Abstract

Relying on a family member to make medical decisions on behalf of a person who is unable to speak for themselves can cause unnecessary stress, cost, and dissatisfaction for both patients and their family. Making decisions without knowing a person's preference for care often leads to a poorer quality of life and discordant care. Without an advance directive to guide care, family members are left to assume the patient's wishes which can cause them to second guess a decision. Lack of knowledge and understanding are among the top reasons for not completing advance directives. As part of routine check-ups or well visits, primary care providers have the responsibility to introduce advance care planning to patients while patients are of sound mind and continue this discussion to include caregivers and/or family members. This quality improvement project helped facilitate a new process for beginning the advance care planning conversation in one rural Midwest primary care clinic. Current practices were identified to develop methods for change followed by an eight- week period where educational materials were offered to patients being seen for wellness visits which allowed the provider an opportunity to introduce advance care planning. Ancillary staff helped identify patients meeting inclusion criteria and facilitate a post-educational handout regarding patient satisfaction that was used to measure outcomes of implementing a standardized process.

Keywords: advance care planning, rural communities, primary care

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Proactive Advance Care Planning in Rural Primary Care

Advance care planning (ACP) is an on-going process of reflecting on values and preferences to formulate a plan to guide future healthcare treatment should a person become incapacitated and unable to speak for themselves (IHI, 2019). Advance care planning can lead to better symptom relief and lower treatment costs (Bond, et al., 2018). Not only has ACP been shown to improve quality of life, but it can also be beneficial in reducing caregiver stress (Bond, et al., 2018). Advance directives (ADs), which may result from ACP, include the appointment of a surrogate decision maker as well as written documents which identify the preferences verbalized in ACP (Center for Practical Bioethics, 2010). Advance directives have been shown to improve quality of life as well as prevent unnecessary suffering when carried out as the individual intended (CDC, 2012).

The Center for Practical Bioethics recommends advance directives be completed at the age of 18 and updated periodically to suit the changing dynamics of the person and their health (2010). To continually meet the patients where they are in terms of quality of life and what is most important to them, it is necessary for ACP to be an ongoing conversation that takes place over multiple visits and is readdressed as the trajectory of health changes (Michael, O'Callaghan, & Sayers, 2017).

Statement of Problem

Making medical decisions on behalf of a family member who is unable to can be stressful and emotionally taxing for surrogate decision makers (Weathers, et al., 2016). Among some of the top reasons for lack of AD completion is a lack of understanding and the assumption that an individual's family already knows their wishes for EOL care (Splendore & Grant, 2017). When EOL wishes have not been discussed in detail or written in a formal document, preference for

care can be misinterpreted causing family or non-familial decision makers to feel a sense of discomfort and insecurity regarding the healthcare decisions during the end of life (Michael, et al., 2017).

Due to the potential widespread impact and financial burden associated with end-of-life (EOL) care, the CDC recognizes advance care planning as a public health issue (CDC, 2012). Medical costs are greatest in the last year of life (Rao, et al., 2014). ACP decreases the overall cost of care at the EOL in many ways including decreasing overall inpatient days as well as preventing unwanted medical treatment (Rao, et al., 2014). Although many people have various concerns when it comes to EOL care, including cost and pain management, most people do not possess ADs (Rao, et al., 2014). Advance care planning can reverse this trend.

According to the IHI (2019), “most health care organizations do not have adequate systems in place to reliably support advance care planning for patients.” A rural family practice clinic needs assessment revealed there was no formal process for addressing ACP or the completion of ADs. The sole provider at the clinic in this project handled each case individually but reported that he feared patients were not getting the maximum benefit of ACP without a standardized process. Under the current informal process, there had been a reported low rate of recorded and completed ADs. The clinic recognized the importance of early ACP and identified a need for a process change to create consistency. When providers standardize the ACP process, it normalizes the conversation and decreases the overwhelming sense of emotion and burden for patients when individual circumstances change (Michael, et al., 2017).

Purpose

The purpose of this project was to improve the process of advance care planning through education, answering questions, and offering an informative resource guide to all adults (over

18) at each annual well visit in a rural primary care clinic. Broader dissemination of materials and iterative discussions increase the acceptance of ACP and thereby promote AD completion (Ashcraft & Owen, 2016). Advance directives are just one component of advance care planning. When a person is unable to speak for themselves during a serious illness, an AD can help guide care consistent with their preferences (Splendore & Grant, 2017). Patients receiving end-of-life care and their families have a higher satisfaction rate and overall quality of life when ADs are in place (Rao, et al., 2014). Despite the increasing demand to see more patients placed on healthcare providers, it is critical that practitioners recognize the importance of ACP and be diligent in promoting it (Splendore & Grant, 2017).

Definition

Advance Care Planning

Conceptually, advance care planning is defined as a process of discussing values and goals of treatment to create directives for use in situations of incapacitation. Operationally, advance care planning is defined as on-going discussion with primary care providers or via use of educational materials that leads to defining what is most important to the patient in terms of their healthcare at a given time. Often this may include the completion of an outside the hospital do not resuscitate (OHDNR) or another advance directive.

Background and Significance

The following literature review addresses the history of advance care planning, overall impact on patient satisfaction and outcomes, barriers to ACP among patients and providers, strategies to promote ACP as well as AD completion, and benefits of ACP. PubMed and Google Scholar were searched using the terms “advance care planning”, “rural communities”, and “primary care”. A total of twenty-five articles were reviewed; those kept for inclusion looked at

associations between ACP and AD completion, effect on patient satisfaction, and ACP specifically in rural communities. Several articles were excluded that were older than ten years, looked at other aspects of rural health not related to ACP, or studied ACP in specific populations that could not be easily generalized to the rural population.

History of Advance Care Planning

Over the past twenty years, the need for action around ACP has been recognized by multiple stakeholders, professional organizations, the government, communities, and even the courts (Tulsky, Fischer, Rose, & Arnold, 1998). Increased recognition has encouraged organizations to promote ACP as a standardized process. In 1991, the U.S. Congress passed the Patient Self-Determination Act (PSDA) which required facilities receiving reimbursement by the Centers for Medicare and Medicaid Services (CMS) to ask about advance directives, inform patients of their right to ACP, and offer educational material (Ramsaroop, et al., 2007). The Joint Commission on Accreditation of Healthcare Organizations (JCHAO) has similar requirements for documentation and education regarding ADs for hospitalized patients (Ramsaroop, et al., 2007). In 2014, the Institute of Medicine (IOM) published the report *Dying in America* which called for, among other things, an expansion of ACP services throughout the healthcare system in the United States (IOM, 2014). Then in 2016, CMS took another step forward in reducing one of the barriers contributing to lack of ACP in outpatient or primary care settings by creating specific billing codes which allowed providers to be reimbursed for ACP discussions (Bond, et al., 2018). Despite the implementation of such mandates and the public education efforts like the National Healthcare Day, on April 16th, there has yet to be a significant change in the number of persons with an AD (Splendore & Grant, 2016).

Impact of Advance Care Planning on Patient Satisfaction and Outcomes

Advance care planning has the potential to influence quality in all phases of life. Patients in rural communities have their own unique perspectives that impact satisfaction and perception of quality of life especially during the end of life (Splendore & Grant, 2016). Being able to stay in their own home for as long as possible and maintaining independence are two examples of QOL measures valued by rural dwellers that are supported by ACP (Ashcraft & Owen, 2016). A decrease in hospital admissions and overall hospital days and the increase in usage of hospice services suggests that this wish is being honored effectively when ACP is happening (Weathers, et al., 2016). Patients in rural areas take pride in a strong sense of family so staying involved and engaged in the healthcare of the familial unit is often a top priority that can be prepared for through proper ACP (Ashcraft & Owen, 2016).

In general, patients who have actively participated in ACP are overall more satisfied with their provider and the care they receive (Bond, et al., 2018). Engaging in ACP creates a more trustworthy environment and helps to build the patient-provider relationship (Bond, et al., 2018). Additionally, families and caregivers also benefit from ACP as it has been shown to decrease caregiver burden and lead to better coping during the bereavement period (Bond, et al., 2018). When a loved one's wishes have been clearly communicated ahead of time, it reduces the anxiety and sense of pressure to make a healthcare decision in the way that he/she may have wanted done (Bond, et al., 2018). Family and providers can feel confident in implementing or discontinuing certain treatments on the patient's behalf (Bond, et al., 2018).

Patients and healthcare systems alike benefit from improved outcomes with ACP. First, ACP is shown to positively impact AD completion (Bond, et al., 2018). When done well, ACP offers a structured setting for good communication between patient, provider, and family and gives everyone an opportunity to ask questions. The provider should facilitate the conversation

by offering the facts regarding the overall health of the patient and allow the patient to speak freely regarding their wishes in a place of support and understanding (Tulsky, Fischer, Rose, and Arnold, 1998). Patients treated this way often feel a greater sense of their basic principles, particularly autonomy, beneficence, and justice for self (Bond, et al., 2018).

ACP provides improved patient outcomes associated with lower healthcare costs and decreased hospital length of stay (Rao, et al., 2018). Successful ACP and the completion of an AD can have an impact on reducing those costs to not only the patient but also to insurers, the healthcare organization itself, and the public (Bond, et al., 2018). The U.S. Department of Veteran's Affairs (VA) views ACP as a return investment (2017). When carried out respectfully, ACP can be a time-consuming conversation however the potential to decrease costs of unwanted healthcare treatment and unnecessary hospital admissions is significant (VA, 2017).

Barriers to Advanced Care Planning Among Patients and Providers

Time. Despite the recent support and advocacy for ACP, estimates of completion rates of advance directives only range from 8-30% (Ashcraft & Owen, 2016). There are many barriers that are attributable to the trend in low completion rates. Providers don't have time to adequately address ACP (Splendore & Grant, 2016). Providers are being called on to take on the role of actively engaging in ACP without waiting for serious illness, which may cause visits to take longer (IHI, 2019). In the culture of today's healthcare environment, providers are constantly asked to be more productive. Reimbursement and financial gains are directly related to the number of patients seen. When patients are scheduled into a fifteen-minute slot, it is not feasible to address multiple complex health issues as well as give adequate time to ACP (Ramsaroop, Reid, Adelman, 2007).

Discomfort. Another provider barrier includes discomfort with facilitating such a conversation. ACP is an advanced communication skill and is equal in importance to the skill required in managing diabetes or other chronic illness (IHI, 2019). Providers should understand the patient's goals of care in order to best direct the conversation to plan for future healthcare. Without adequate training in both ACP and EOL discussions, providers do not feel prepared to facilitate these conversations (Splendore & Grant, 2016).

Accessibility. A barrier specific to individuals residing in rural communities is a reported challenge in accessing adequate healthcare services (Ashcraft & Owen, 2016). Often these patients are older, have difficulty with transportation to urban areas, and have a lack of key resources (Ashcraft & Owen, 2016). Rural communities often lack access to specialists, social workers, or other personnel trained in ACP making the PCP responsible for covering a broad range of healthcare topics including ACP (Ashcraft & Owen, 2016).

Lack of awareness. A common barrier for patients is lack of awareness of ACP (Weathers, et al., 2016). Patients are not engaging in ACP and thereby not completing ADs simply because they do not know what ACP is or how to go about the process (Weathers, et al., 2016).

Other. Other barriers reported by patients include worry about being a burden to their family and friends, fear and apprehension, and assumption their family already knows their wishes for EOL care (Splendore & Grant, 2016). Additionally, low health literacy and difficulty with communication can affect ACP (Michael, et al. 2017). Health illiteracy is a broader issue which includes a lack of knowledge of disease progression and realistic goal setting (VA, 2017).

Strategies for Promoting Advance Care Planning

One strategy is for ACP to take its place along a continuum lifestyle model which means the process should occur at strategic intervals as the trajectory of health, illness, and circumstances fluctuate (Michael, et al., 2017). ACP will likely not look the same for any two patients as everyone differs in where they are in their health journey and in what they hold in highest regard for EOL care (Michael, et al., 2017). It is important for healthcare providers to recognize that ACP may eventually lead to AD completion but meeting the patient where they are at through communication, active listening, and follow-up is all a part of ACP (Weathers, et al., 2016).

Direct communication is another strategy to promote ACP. Patients report that they prefer to engage in and are more likely to participate in such conversations, when the provider uses direct communication methods (Rao, et al., 2014). Using a combination of resources to include visual, written, and verbal means is valuable to patients as well (Splendore & Grant, 2017). Patients can take written materials with them to develop more questions or share with loved ones not present at the visit.

Another key strategy of successful ACP is the provider developing a solid foundation of trust with patients. Longevity of patient-provider relationships, where the relationship has had time to mature, helps to set the stage for effective ACP (Rao, et al., 2018). Particularly in rural America where healthcare providers are held in high regard, patients would prefer ACP conversation to happen with their PCP whom they know and trust (Rao, et al., 2018). Building on the foundation of confidence, providers are better equipped to individualize treatment plans and goals for care. Primary care providers in these areas often know their clients on a personal level and have cared for several generations within a family (Rao, et al., 2018). Continuity in provider care and consistency in communication allow patients to continue to build on their

knowledge and understanding of ACP and their current state of health (VA, 2017). Though time is a factor, providers need to remain flexible to changing health and treatment goals.

According to the Institute for Healthcare Improvement, there are several key recommendations to consider when implementing ACP into practice. First, people respond to real-life story sharing (IHI, 2019). Whether they are popular cases seen in the media or situations closer to home, people can relate to examples. Second, respectful care, which is in concordance with patient wishes, leads to improved quality of life and satisfaction (IHI, 2019). And third, when considering internal change for ACP practice, organizations need to look at the functionality and feasibility within the community and develop a process improvement accordingly (IHI, 2019).

Additionally, the IHI talks about “Conversation Ready” facilities. They acknowledge five key principles for identifying readiness: exemplify, connect, engage, steward, and respect (IHI, 2019). The first two require providers to think of their own values and recognize personal bias and discomfort with such discussions (IHI, 2019). Once the provider is confident in their own convictions, they are better prepared to actively engage with their patients and truly hear and understand individual preferences (IHI, 2019). When addressing sensitive topics, patients may feel vulnerable, which is why the principle of respect is of the utmost importance throughout the care process (IHI, 2019).

Benefits of Advance Care Planning

The ACP process has a positive impact on increasing advance directive completion rates (Bond, et al., 2018). Patients who have ADs in place report an increased sense of fulfillment and an overall better quality of life during the end of life (EOL) transition (Bond, et al., 2018). ACP and completed ADs have been shown to have a direct correlation with decreased rates of dying

in the hospital as well as an increased use of hospice services (Weathers, et al., 2016). Around three fourths of individuals require decision making regarding their EOL treatment; however, most lack the ability or capacity to speak on their own behalf at the time and require a surrogate decision maker to be their voice (Splendore & Grant, 2017). Additionally, only about one quarter of patients had advance directives though about two thirds had concerns about their EOL care (Rao, et al., 2014).

Patients' are often more comfortable with having a trusting relationship with the primary care provider (PCP) than other members of their healthcare team, so it makes sense that decisions regarding end of life care should include the PCP (Rao, et al, 2014). The United States Preventative Services Task Force (USPSTF) recommends the annual screenings that typically make up the annual wellness exam performed by the PCP (USPSTF, 2018). The well person visits are commonly performed by the PCP which affords a unique and timely opportunity to educate, answer questions, and provide resources for advance care planning. Additionally, ACP is a requirement of the annual Medicare wellness visit and CMS recognizes it as billable time during other routine visits (Bond, et al., 2018). Broader dissemination of materials and iterative discussions increase the acceptance of ACP and thereby promote AD completion (Rao, et al., 2014).

Project Aims

The purpose of this project was to improve the process of advance care planning through education, answering questions, and offering an informative resource guide to all adults (over 18) at each annual well visit in a rural primary care clinic. The project consisted of four aims: (1) determine current practices for advance care planning in one rural Midwest primary care clinic; (2) identify strategies that promote early and progressive advance care planning; (3)

implement a standardized process for initiating advance care planning and disseminating educational information; and (4) qualitatively evaluate the implementation of a standardized process.

Methods

Design

This quality improvement project created a standardized process for education and advance care planning in a rural primary care clinic using the Plan- Do- Study- Act framework (The Deming Institute, 2019). The first step in the PDSA model, Plan, included performing a needs assessment and collaborating with the clinic staff to determine realistic goals for change. Next, an eight-week quality improvement project was implemented as the Do phase. All patients over the age of eighteen who were seen for an annual well person visit were asked if they had an advance directive while being checked in by the ancillary staff. Regardless of pre-existing AD, all patients meeting inclusion criteria were offered an educational guide that discussed advance directives and the different forms of ADs (Appendix A). Patients had anywhere from 5-15 minutes to read the brochure before the provider arrived. Additionally, the packet provided the patient with educational information that they could review and/or share with their loved ones prior to their next visit. The staff assisting the patient to the exam room were also provided a handout with check boxes to mark whether the patient accepted or refused the material and why (Appendix C). After the nurse completed her portion, she placed the handout back on the paper chart of the physician to review and complete. The portion the physician completed was based on what he and the patient discussed for follow-up action. He checked options according to patient response. At the conclusion of the eight-week implementation, data collected in the form of patient surveys, interview guides, and field notes and was studied and evaluated to determine project success. Finally, the Act step was conducted by taking the results from the

project and presenting them to the hosting facility with recommendations for making an effective and sustainable practice change at the clinic. At the end of the eight weeks, there were follow-up discussions with the provider and other staff members which determined that actively using the educational guide improved practice by encouraging more patient- provider communication. The project manager was on site to engage with staff, communicate about how the process was going.

Human Subject Protection

The project proposal was reviewed by the Institutional Review Board (IRB) at the University of Kansas Medical Center (KUMC) and was determined to be a quality improvement project (Appendix D). In this project, it was not necessary to obtain informed consent as consisted of providing educational material. If patients chose to pursue completion of one or more of these documents, it was a voluntary act. There were no patient identifiers used during data collection as it was primarily collection of practice habits and provider surveys rather than patient data.

Setting

This project took place at a rural family practice clinic (FPC) located in a town with a population less than 200 people. Located about 45 miles from a tertiary hospital, the facility was physician owned and employed four other people. There were two licensed practical nurses (LPN), one who serves as the office manager, back-up nurse, and radiology technician and another who is responsible for rooming patients, obtaining vital signs, and a variety of other nursing skills. The other two employees were secretaries with roles that included checking patients in, appointment scheduling, answering phone calls, ordering supplies and preparing

paper charts for upcoming appointments. This clinic served patients from newborn to geriatric with a majority of clients being 65 and older.

Providers in rural communities have unique opportunities for patient engagement and relationship building. At one primary care practice in the rural Midwest, family was of the utmost importance. The physician at the rural clinic project site often treated multiple generations of the same family which provided him the ability to get to know familial structures and appreciate their dynamics. In most cases, this familiarity created a stronger patient-provider bond and thus trust. As the only provider in the community, he had a sense of pride and a responsibility to promote health and wellness. By implementing a practice change that made ACP a standard part of a wellness visit, much like drawing a lab, it started to normalize and encouraged a whole community to begin the process of ACP.

Sample

This project used a convenience sample of patients seen within the eight-week implementation phase. We anticipated between forty and fifty patients. Inclusion criteria for this project was any patient over the age of eighteen being seen at the participating clinic for an annual wellness physical. This project excluded anyone over eighteen being seen for acute or follow-up visits. It was not necessary to recruit any patients for this project.

Data Collection

Evaluation was a multi-part process. Initially, there were conversations with the provider and clinic staff to better understand current processes and recognize where there were shortcomings. Key processes and insights were recorded in field notes. At bi-weekly intervals, the project manager used interview guides to direct questions to the clinic staff (Appendix B). The qualitative data from these interviews was compared through the progression of the project.

During this project, we asked clinic staff, when rooming a patient, to inquire about the presence of advance directives and to offer all patients meeting inclusion criteria the educational ACP guide (Appendix A). This gave the patient time to review the material and develop questions prior to being seen by the provider. The educational guide provided the reader information on advance directives which included living wills, durable power of attorney for healthcare, and outside the hospital do not resuscitate order (OHDNR). The process of disseminating materials and collecting data had several steps. First, if a patient acknowledged having an AD, they were asked to provide a copy for the clinic if it was not already on file. Second, regardless of a preexisting AD, the nurse offered the patient the material and simply checked a box on an attached handout as to whether the patient accepted or refused the material and why. Third, after filling out their portion, nurses placed the check sheet on the front of the chart for the provider. The 'for provider use' section asked about patient engagement and the plan for follow-up. ACP is an on-going process, therefore if the patient requested more information or expressed desire to move forward with completing an AD, they were encouraged to discuss options for an individualized plan with the provider. He would then mark whether the patient planned a follow-up, requested more information, or refused any further ACP discussions. The check sheets were then kept for the project manager to collect and use for data analysis.

The project manager was present at the facility weekly to facilitate the implementation of this practice change. During these visits, the project manager also had the opportunity to make first-hand observations by watching how staff members fulfilled their role and helped to facilitate any unforeseen obstacles. At bi-weekly intervals, there were short interviews with each

clinic staff member (Appendix B). Interview questions were used to measure process improvement throughout the eight weeks.

Results

During the eight-week implementation, a total of six patients met inclusion criteria; however, one of those was missed in the process and not offered materials ($n = 5$). Of the five patients remaining, three of them (60%) were sixty-five or older, one aged 50-64 (20%), and one aged 18-29 (20%). Only one of the five (10%) accepted the material. The one that accepted the material was of the 50-64 age group. Of the four that refused the material, three of them (75%) reported already completing an advance directive. One of the patients who reported already having an AD had a DNR while the other two had a combination living will/DPOA-HC. None of the completed AD documents were currently filed in the patient charts. One patient declined the information and was not interested. Only one patient brought up questions regarding advance directives to the provider. There were varying results for a follow-up plan. One patient refused any further discussion, two reported they would return their AD paperwork to the clinic, and one was willing to discuss at a future time and age.

In addition to the surveys completed by the staff, bi-weekly interviews were held with the staff at the clinic. Prior to the project, the provider was trying to incorporate ACP into his visits. The physician reported a perceived slight increase in ACP being done at wellness visits from the months leading up to implementation of the project. Although this wasn't measured, the physician felt the material provided in the project helped to create a concrete plan with patients and to improve their understanding. As the project carried on, there was a reported upward trend in the number of patient's engaging in ACP conversation even outside of the patients who met our inclusion criteria per physician response.

The nurse who engaged in patient care and in this project, was asked bi-weekly questions. She recalls that patients typically responded that they were not interested, or they already had an AD. She felt that she had a well-established relationship with the patient population at the clinic, so she was not uncomfortable in the role of offering the material to patients. Additionally, she felt that the process was easy to follow for both staff and patients. She felt that her role was straightforward and in the event patients had questions that she did not feel equipped to answer, she was prepared to refer questions to the physician.

The secretary involved in recognizing patients meeting inclusion criteria and preparing the charts prior to patient visits was also interviewed at biweekly intervals. She reported that she did not have any difficulty but did recall there was one patient who met inclusion criteria who staff simply missed in offering the information. The secretary did not perceive any barriers, but she did mention that she noticed a lack of scheduled wellness visits which she attributes to the low volume of participants. During this time of year, there was an increase in well child visits as this project took place in the weeks leading up to children returning to school for the year which impacted the numbers of well-adult visits.

Discussion

Prior to hosting this project, this facility did not have a formal process for discussing ACP with patients. There was no dissemination of information and the ACP conversation was intended only if the provider felt compelled to bring it up based on recent hospitalization or recognition of an overall decline in patient health. With lack of a formal process, the provider at this clinic worried that while high risk patients were reasonably being reached, there were patients who could potentially benefit from ACP who were overlooked. This could include

patients with chronic illness who were not at the end-of-life. After acknowledging a need for change, the decision to move forward with implementation of a standardized process was made.

The sole provider in a rural community is often held in high regard. By making annual ACP a standardized process where patients are hearing it repeatedly, it may normalize the process. Patients hear about it when they come for their wellness visit and again when they return with their spouse for theirs and begin to realize that ACP isn't just a conversation reserved for the end of life, but rather a part of on-going wellness and ideally it will promote conversation outside of the clinic. Beginning to reach out to patients earlier, in this case, at the age of 18 and annually thereafter, provides more repetition and opportunity for education. Additionally, implementation of educational resources, gives patients more time to read about ACP when it's suitable to them. By having material to take home, patients can take ample time to read the material or share it with loved ones and were encouraged to return to the clinic with follow up questions or concerns.

When considering the strategies for promoting ACP, this project took advantage of several of them. The project encouraged direct communication between provider and patient. Practicing in the community for nearly twenty years, the provider has built trusting relationships with his patients. Identification of feasibility was addressed both prior to and at the culmination of the project. It is limited in evaluating the continuum lifestyle model as this was confined to eight weeks and therefore did not assess how people may react in a year at their next annual visit. Broader dissemination of information may help to spread awareness. Hanging posters in public venues, offering material to patients being seen for visits other than wellness physicals, and hosting a town hall meeting that offers Q&A would all be ways to increase community

education. Additionally, when asked at the final interview, the physician recommended using material that was bolder and more eye catching.

Initially, there was some resistance to the process change of incorporating ACP into wellness exams. Based on staff interviews and field notes, patients were reluctant to accept the material stating that they weren't interested right now. The complexity of the patient's health and where they fall on the healthcare continuum, helps to determine how ACP will progress for that patient. An eight-week project did not provide enough time to evaluate whether patient resistance was improving within this clinic.

In the bi-weekly interviews, there were several trends that emerged. First was the perceived ease of implementing material that provoked conversation on advance care planning. Based on feedback from interviews with staff, the level of difficulty for any one person involved in this process was minimal. Second, the provider at this clinic was affirmed throughout the process that this material did in fact promote the discussion of advance care planning and helped to guide conversation with patients. He confirmed that it was useful in introducing the concept and supplementing conversation. Based on discussion and interviews with staff, providing ACP material did not cause adverse effects. Participation was voluntary, and although in some cases patients refused the material, it did not cause poorer outcomes. Instead, it served as a prompt for the provider and encouraged conversation.

Lessons learned from this quality improvement project include, a practice change is not likely to be perfected in eight weeks, simple yet eye catching materials are preferred, and a change that is relatively easy and efficient is more likely to flourish. Giving each staff member specific, realistic roles seemed to work well and did not overwhelm them. Qualitative interviewing allowed staff members to openly express their opinions on how the project was

going. It is also important to understand the comfort level of staff in carrying out their role as well as their attitude towards ACP. Educating staff up front on the need for the practice change may help to encourage involvement. Additionally, had this project been hosted at a different time of the year when adolescent exams weren't as prevalent, there may have been a larger sample size.

Limitations

Eight weeks was not ample time to fully assess the effectiveness of a practice change. This is a relatively short amount of time for staff to become familiar with the new process and become efficient at it. Additionally, it did not provide enough time to pinpoint the inadvertent omissions and make necessary adjustments. Likewise, a sample size of five patients is very small making it impossible to draw conclusions about the clinic population as a whole. Another limitation was the time of year this project was conducted. This project took place in July and August just as the local children were returning to school which lead to an increased number of well child visits and impacted the number of well adult visits. Lastly, fitting additional time in for ACP in visits that can already be lengthy proved to be an issue.

Recommendations

Given the low volume of patients that met inclusion criteria and of those the small number interested in ACP education compared to the projected number of participants, it would seem that it is not an issue isolated to ACP alone. Maybe there is a greater need for encouraging well patients to be seen annually, or maybe there is a misconception regarding ACP. Continuing to educate staff on recognizing those meeting inclusion criteria, prioritizing its importance, and providing them with the tools to successfully engage in meaningful ACP could yield an increased number of participants. Additionally, there could be benefit in following up in one

year and again at two years. This would allow for the project manager to look at the evolution of the practice change and how patients react when being offered the resources for a second and third time.

It is possible that offering the material to patients at other visits, such as appointments for chronic disease management would increase the overall sample size as well. Using acute and chronic visits to inform patients that this will be addressed at each annual visit would give patients time to reflect and perhaps not be caught off guard when they return for the wellness visit. Additionally, for those patients already possessing an AD, the clinic could ask that they bring in a copy at their next visit which would help in drawing conclusions about the patients at this clinic.

It may be worthy to explore the insurance coverages of the patients at the clinic as well. Advance care planning is a requirement of the initial and subsequent Medicare wellness visits. Ensuring that ACP is at minimum being addressed at those visits could potentially increase the overall number. The clinic staff could also emphasize to all patients that Medicare encourages ACP at their wellness visits which may help to prove its importance.

Lastly, getting the community involved in this change could change outcomes. Promoting the practice change at various community events might make patients feel like they are choosing to partake in ACP rather than being put on the spot at their visit. Having educational resources available at high traffic areas within the community would give patients an opportunity to read about ACP and come to their visits with questions already in mind.

Conclusion

This quality improvement project offered educational materials on advance care planning at adult wellness visits and by doing so, promoted a standardized process and encouraged conversation. While the overall sample size was small, the qualitative data reflects that the implementation of ACP material was both easy and effective. By emphasizing the importance of ACP on a community level and continuing to host these conversations on a regular basis the process may normalize. For future quality improvement, greater staff education, greater community education and involvement, consideration of ACP at acute/chronic visits, and future follow-up beyond eight weeks could all be considered. It is reasonable to conclude based on this quality improvement project that asking staff to fulfil relatively simple roles might lead to a sustainable change and using eye catching, reader friendly printed material to compliment ACP for annual wellness visits offers at least some benefits without any negative effects.

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Appendix A



CONVERSATION STARTER KIT SUMMARY SHEET

NAME _____

DATE _____

The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care. We developed the Conversation Starter Kit to help you talk with your loved ones about your—or their—wishes for end-of-life care. After you have the conversation, you can use this Conversation Starter Kit Summary Sheet to record your wishes, and share them with your doctor or others as you wish. And you can return to it over several conversations.

When should you have the conversation?

Even if you're in good health, it's still important to make sure your loved ones, and your health care team, know your wishes, since anyone's health status can change suddenly. It's particularly important to have the conversation if you or a loved one has a chronic or serious illness. Every conversation will help your loved ones and your care team understand what matters to you.

? As you think about how you want to live at the end of your life, what's most important to you?

Now finish this sentence: What matters to me at the end of life is...

(For example, being able to recognize my children; being in the hospital with excellent nursing care; being able to say goodbye to the ones I love.)

Where I Stand Scales

Select the number that best represents your wishes. (You can write on the dotted line below each scale if you'd like to explain or add notes about your answer.)

As a patient, I'd like to know...

1 2 3 4 5

Only the basics about my condition and my treatment

All the details about my condition and my treatment

If I had a terminal illness, I would prefer to...

1 2 3 4 5

Not know how quickly it is progressing

Know my doctor's best estimation for how long I have to live

As doctors treat me, I would like...

1 2 3 4 5

My doctors to do what they think is best

To have a say in every decision

How long do you want to receive medical care?

1 2 3 4 5

Indefinitely, no matter how uncomfortable treatments are

Quality of life is more important to me than quantity

What are your concerns about treatment?

1 2 3 4 5

I'm worried that I won't get enough care

I'm worried that I'll get overly aggressive care

How involved do you want your loved ones to be?

1 2 3 4 5

I want my loved ones to do exactly what I've said, even if it makes them a little uncomfortable

I want my loved ones to do what brings them peace, even if it goes against what I've said

What are your preferences about where you want to be?

1 2 3 4 5

I wouldn't mind spending my last days in a health care facility

I want to spend my last days at home

When it comes to sharing information...

1 2 3 4 5

I don't want my loved ones to know everything about my health

I am comfortable with those close to me knowing everything about my health

- 7 Who would you want to make decisions on your behalf if you're not able to? (This person is often called a "health care proxy." Check with your state about how to grant this person the legal authority to make medical decisions for you.)

- 8 Do you have any particular concerns (questions, fears) about your health? About the last phase of your life?

- 9 What do you feel are the three most important things that you want your friends, family, and/or doctors to understand about your wishes and preferences for end-of-life care?

1.

2.

3.

Appendix B

Bi-Weekly Interviews

Physician

1. Since the start of this project, have you noticed an increase in ACP at your wellness visits?
2. How many times in the past 2 weeks would you say you have engaged in ACP?
3. Do you feel that the written material helped you to begin the ACP conversation?
4. What barriers are you seeing or do you have suggestions that would help this process be more effective?

LPN's

1. What are the most common reactions you are seeing from patients when you bring up ACP/ADs and offer them The Conversation Project materials?
2. Tell me about your comfort level with introducing ACP and offering The Conversation Project materials?
3. Are you encountering questions from patients that you are not able to answer? (give examples.)
4. What suggestions do you have for making your role in disseminating the information easier?

Secretaries

1. Do you feel that your role in preparing charts and placing The Conversation Project material on the front is too difficult?
2. Have you noticed, since beginning this project, an increased amount of patient either scheduling follow-up visits for further ACP or are returning completed directives?
3. What barriers are you encountering regarding your role in the ACP process? Do you have suggestions for improvement?

Appendix C

Proactive Advanced Care Planning in Rural Primary Care

1. Age Range:
 18-29 _____ 30-49 _____ 50-64 _____ 65+ _____
2. Does the patient have an existing directive?
 - Yes (mark all that apply) _____
 - Living Will _____
 - Durable Power of Attorney for Healthcare (DPOA-HC) _____
 - Do Not Resuscitate (DNR) _____
 - If yes, do we have a copy on file? Yes _____ No _____
 - If yes, still offer material and proceed to #2
 - If no, request copies, offer patient the material and proceed to #2
 - No _____
 - If no, offer patient the educational material and proceed to #2
3. How did the patient respond when given the advanced direction material?
 - Accepted material _____
 - Was eager and curious about the information _____
 - Reaction was indifferent (not curious/didn't refuse) _____
 - Clear reluctance _____
 - Refused material _____
 - Not interested _____
 - Prefers to wait until family is present/talk it over with family first _____
 - I don't want to think about it _____
 - Feels they are too young/ too healthy _____
 - Already has one and doesn't want more info _____

For Physician Use:

1. Did the patient have questions/ bring up ACP discussion during today's visit?
 Yes _____ No _____
2. Plan for follow- up (mark all that apply):
 - Schedule follow-up individual visit to discuss ACP _____
 - Schedule a family visit _____
 - Requested more detailed workbook _____
 - Is planning to complete an AD prior to next visit _____
 - Refused any further discussion _____