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Oregon Nurse Practitioners and Advance Care Planning

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Introduction: The Clinical Problem

The proportion of Americans entering old age is rapidly increasing. By 2050, the number of citizens age 65 or older is expected to increase to 83.7 million, more than double the age group population in the 2010 census (Ortman, Velkoff, & Hogan, 2014). The leading causes of death in people age 65 and greater are malignant neoplasm and chronic disease (Centers for Disease Control and Prevention [CDC], 2014), often requiring rigorous long-term treatment and close medical care. As the older population grows, the cost of healthcare during the last years of life falls heavily on Medicare. The incidence of admissions to the intensive care unit during the last month of life has continued to increase over time (Teno et al., 2013). Unfortunately, many of these hospital visits entail aggressive life supporting measures that function only to prolong the dying process at a large financial cost (Marik, 2015).

One method of improving the dying process, promoting patient autonomy, and controlling health care costs, is through advance care planning and the use of an advance directive. An advance directive is a legal document that can be utilized in the event a person becomes unable to make independent health care decisions. The document describes an individual's preferences for care at the end of life and appoints a surrogate decision maker (Lum, Sudore, & Beleman, 2015). The advance directive allows patients, family, and surrogates to feel less anxiety and more empowered at the end of life (Detering, Hancock, Reade, & Silvester, 2010).

Death is a natural and inevitable part of the human life cycle. However, communication and documentation of one's wishes at the end of life are frequently underperformed, leaving patients at risk for costly and possibly unwanted care. Rao, Anderson, Lin, and Laux (2014) evaluated 7,946 people of varied demographics in order to best represent the U.S. population, the researchers found that just 26% of individuals had an advance directive, however nearly 70%

reported concern over the care they would receive at the end of life. This study highlights the fact that medical providers are regularly missing the opportunity to speak with patients about their goals and preferences at the end of life.

Research done from the patient and the provider perspective demonstrate that it is desirable to begin discussing advance directives in the primary care setting early, when the patient is still healthy, with updates annually or as the patient's condition changes (Clayton, Butow, Psych, & Tattersall, 2005; Otte, Jung, Elger, & Bally, 2014). However, the literature shows that the barriers to end of life discussions are numerous and multifaceted. The most common barriers are related to policy and politics, healthcare systems, patient knowledge and preferences, and provider education and biases, all of which are compounded by the influence of race and ethnicity. The primary aim of this project was to focus on improving provider awareness and education related to the advance directives and the 2016 change in the Affordable Care Act that allows providers to bill Medicare for advance care planning. The secondary aim of this project was to determine the barriers advance practice registered nurses (APRNs) experience with advance care planning. Third, this project established how an APRN's experience as a registered nurse (RN) is related to their comfort with, and frequency of, end of life conversations.

Literature

Barriers Related to Policy and Politics

The United States Patient Self-Determination Act (PSDA) of 1990 was the first aggressive government effort in promoting the completion of advance directives. The PSDA is a federal law that requires all health care facilities that are associated with Medicare and Medicaid to inform patients of their right to make medical decisions, to provide the patient with information concerning advance directives, and requires documentation of whether the patient has an advance directive (Teno, Sabatino, Parisier, Rouse, & Lynn, 1993). The PSDA helped

bring the value of advance directives to light, however it was met with limited success (Carr & Khodyakov, 2007).

In another government effort to promote advance care planning, the original draft of the ACA included a plan to provide Medicare patients with billable services related to end of life planning. Unfortunately, during the political battles of 2009 these provisions became falsely referred to as “death panels.” This ignited the public’s fear of government seizing control of a patient’s right to life and access to medical care. The backlash became so intense that the legislation had to be removed from the Affordable Care Act (Oberlander, 2010; Frankford, 2015).

Fortunately, the provisions were resurrected, and as of January 1, 2016, providers can bill Medicare for advance care planning services using a Current Procedural Terminology (CPT) code 99497 for the first 30 minutes, and CPT code 99498 for each additional 30 minutes spent with the patient. There are no limits on the number of times these codes can be used and completion of an advance directive is not required when billing under these codes (Centers for Medicare and Medicaid Services [CMS], 2016). Providing clinicians with the ability to schedule and bill Medicare for appointments to exclusively discuss end of life planning, effectively decreases the barrier of reimbursement for services.

Provider Barriers

Physicians tend to regard discussions related to end of life as uncomfortable, but necessary (Braun, Ford, Beyth, & McCullough, 2010; Wissow et al., 2004). When determining who should be responsible for completing the advanced directive, hospital-based physicians feel that the primary care provider should be accountable for discussing code status and appointment of surrogate decision makers (Anselm et al., 2005; Tung & North, 2009). Discussing death and dying can be a deeply personal endeavor for the patient and deserves dedicated time in clinic; as

such many providers report a lack of time as a barrier to initiating and completing these conversations (Anselm et al., 2005; Snyder, Hazelett, Allen, & Radwany, 2013; Wissow et al., 2004; Tung & North, 2009).

Numerous studies found that providers felt there was a lack of training to prepare them for leading conversations about death and dying (Anselm et al., 2005; Braun et al., 2010; Wissow et al., 2004; Barnes et al., 2012; Gigon, Merlani, & Ricou, 2015). While some of the older physicians expressed that their education had inadequately prepared them for discussing death with their patients, newer providers reported their training was enhanced by a curriculum that included end of life issues. The physicians agreed that their comfort level with these difficult conversations increased with time and experience (Braun et al., 2010).

In addition to the barriers related to training and time for advance care planning, physicians reported cultural ignorance as a barrier for discussing end of life with some patients. The providers cited a fear of offending the patient and family by committing a cultural faux pas that would irreversibly damage the relationship (Periyakoil, Neri, & Kraemer, 2015; Anselm et al., 2005). Not surprisingly, disparities in end of life planning and care among minority groups have been highlighted in many studies (Pollack, Morhaim, & Williams, 2010; Periyakoil, Neri & Kraemer, 2016; Evans & Ume, 2012; Kwak & Haley, 2005; Hopp & Duffy, 2000).

A small number of physicians report less interest in completing an advance directive claiming they do not believe it is effective in protecting the patient's wishes (Snyder et al., 2013). The barriers that lead to ineffective advance directives include incomplete or missing documentation in the electronic medical record (EMR) (Wilson et al., 2013), legalistic language that is too vague to prepare patients and families for the complexities of end of life decisions (McMahan, Knight, Fried, & Sudore, 2013; Nauk et al., 2014), and discordant requests for care

from the surrogate decision maker (Anselm et al., 2005; McMahan et al., 2013; Nauk et al., 2014).

Gap in the Literature

The literature review was aimed to investigate the barriers to end of life discussions and completion of advance directives from the perspective of nurse practitioners, in addition to physicians. However, only one study was found that was specific to nurse practitioners and their skill in performing end of life discussions. The authors concluded that, similar to their physician counterparts, nurse practitioners generally had positive attitudes towards advanced care planning, however few regularly included it in their practice (Schlegel & Shannon, 2000).

There remains a gap in knowledge as to how the APRN functions in leading end of life conversations and in the completion of advance directives. In an effort to meet the projected deficit of 20,400 primary care providers by the year 2020 (Health Resources and Services Administration, 2013), the number of nurse practitioners entering primary care is increasing, especially in rural and underserved locations (U.S. Department of Health and Human Services, 2013). These providers will undoubtedly be tasked with advance care planning. However, there is a dearth of literature to show that the barriers experienced by physicians are the same for all healthcare providers.

Purpose

The quality improvement portion of this project focused on improving provider awareness and education related to advance care planning and the January 1, 2016 change in the ACA that allows providers to bill Medicare for these services. This project also engaged in data collection in an attempt to fill a gap in the literature. APRNs across the state of Oregon were surveyed to elucidate the barriers they face with advance care planning. Last, the project aimed

to determine how an APRN's experience as an RN is related to their comfort with, and frequency of, advance care planning.

Approach to the Conduct of the Project

Participants/Population

Participants were limited to the state of Oregon. In an effort to capture clinicians that provide ongoing, direct, and holistic patient care, the inclusion criteria was limited to nurse practitioners. As such, certified register nurse anesthetists and clinical nurse specialists were excluded. In order to reach the broadest audience, the Oregon State Board of Nursing's (OSBN's) list serve of APRNs, composed of 2,608 nurse practitioners, was used to distribute a link to the survey via email. The certified nurse midwives, pediatric nurse practitioners, and psychiatric-mental health nurse practitioners on the mailing list could not be separated from the family nurse practitioners prior to distribution without compromising participant protection, therefore the participants were asked to select their specialty within the survey.

To ensure protection of the participants, the researchers were blinded to the names on the list serve and no specific identifying information was solicited from the participants. Data was stored in the password-protected REDCap data warehouse, and accessed only by the researchers and the REDCap support team.

Implementation

Project approval was obtained from Oregon Health and Science University's internal review board. The project was conducted with a survey using REDCap software that is supported by Oregon Health and Science University's Research Services department. The survey was distributed via email to the OSBN's list serve of nurse practitioners, a total of 2,608 providers, on February 27th, 2017. The invitation email included a short description of the survey, expected time commitment, link to the consent, and was followed by a link to the survey.

The participants had the option to complete or ignore the survey request. One reminder email was sent on March 13th, 2017. The survey was closed on April 4th, 2017.

To meet the unique goals of this study, the survey and the educational module were developed by the researcher, and piloted by two School of Nursing faculty, three doctoral students, and two specialists from the REDCap research team prior to distribution. The survey began by gathering general demographic data. Information was then elicited about the APRN's experience as an RN, such as work setting, experience with respiratory and cardiac resuscitation, number of years worked, and size of community served. This was followed by questions related to the APRN's current specialty, approximate size of community served, and number of years in practice. Next, the survey inquired about the provider's current practices and comfort with advance care planning. This section concluded with a list of barriers to advance care planning, which were a composite of issues experienced by physicians from the literature. The participants were asked to use a Likert scale to evaluate how much each barrier influenced their practice, options included "never," "rarely," "sometimes," "often," and "always." The section ended with an open answer question to provide the participants with the opportunity to detail other barriers they had experienced to advance care planning.

After completing the pretest portion, the participants moved on to an educational module. The educational module was a 6-minute video on advance care planning for the Medicare population that was created by the researcher. It began with benefits of discussing end of life and then provided information related to the 2016 amendments to the ACA and Medicare that allow providers to bill for advance care planning. The CPT codes, reimbursement rates, documentation requirements, and limitations were presented. The video concluded with a list of resources for those that wanted more information.

A brief post-test followed the educational module. In this section, the participants were asked if they had used the Medicare CPT codes in the past, and how likely they were to use the codes with eligible patients in the future. The survey closed by asking the APRNs if the information presented in the module changed their comfort level with discussions related to advance care planning.

Results

Demographics

The survey was delivered to 2,608 nurse practitioners. A total of 174 (6.7%) responded, but only 143 (5.5%) completed the entire survey. There were 20 (14%) males and 123 (86%) females. The breakdown of nurse practitioners by current work setting is as follows: acute care (13, 9.1%), urgent care (11, 7.7%), primary care (48, 33.6%), pediatric (2, 1.4%), midwife (11, 7.7%), hospice (3, 2.1%), long term care (6, 4.2%), specialty care (31, 21.7%), and other (18, 12.6%). Most, 105 (73.4%), reported working as an RN for 10 or more years, and 84 (58.7%) reported working as an APRN for 10 or more years. Of the primary care providers, 48 completed the entire survey, while an additional 5 only completed the pretest section and stopped at the point of starting the educational module. There were 6 (11.3%) males and 47 (88.7%) females that selected primary care as their current work setting.

Barriers

Primary care providers reported seeing Medicare patients every day (62.3%) and several times per week (24.5%). The vast majority felt moderately (34%) to very (58.5%) comfortable initiating discussions related to advance care planning, advance directives, or end of life care with their patients. To evaluate each barrier from the Likert scale, the number of participants that selected “sometimes,” “often,” or “always” were totaled and divided by the sum of people that had responded. The barriers faced by primary care providers, from greatest to smallest, are

as follows: lack of time (81.1%), patient unwilling to discuss end of life (64.7%), electronic medical record does not generate reminders (58.5%), difficulty navigating patient and family dynamics (54.7%), lack of training/education (42.3%), fear of being culturally insensitive (42.3%), lack of clarity in documentation requirements (41.5%), lack of reimbursement (26%), lack of clarity on who should initiate the conversation (provider versus patient initiation) (19.3%), feeling that advance care planning is not effective in protecting the patient's wishes (18.9%), personal discomfort with end of life conversations (17%), and feeling that it is not your responsibility to discuss end of life with your patients (9.4%) (see appendix A for barriers to advance care planning).

The optional open answer question about additional barriers received 67 comments from APRNs across all work settings. 29 comments, all from those outside of primary care, stated that they do not consider advance care planning a part of their role. 8 participants stated specifically that advance care planning should be done by the primary care provider. 6 providers mentioned difficulty discussing end of life with patients suffering from decreased cognitive functioning or dementia.

Primary Care Provider's Experience as a Registered Nurse

A total of 53 primary care providers that completed the pretest section, 36 (67.9%) had worked in acute or critical care as an RN, 17 (32.1%) had not. Of those that had worked in acute or critical care, 29 (80.6%) had spent 10 or more years in working as an RN, 32 (88.9%) had experience with resuscitation of cardiac or respiratory arrest, 23 (63.9%) reported feeling very comfortable with advance care planning, and 20 (55.6%) discussed advance care planning at least several times per week. Of the primary care providers that did not have experience in acute or critical care as an RN, 12 (70.6%) had spent 10 or more years in working as an RN, 10 (58.8%) had experience with resuscitation of cardiac or respiratory arrest, 8 (47.1%) reported

feeling very comfortable with advance care planning, and 8 (47.1%) discussed advance care planning at least several times per week (see Appendix B for the Primary Care Provider's Experience as a Registered Nurse). While the raw data appears to support the hypothesis that APRNs with experience in acute or critical care as an RN are more comfortable with advance care planning and perform it more frequently, the data was not found to be statistically significant with a p-value of 0.15.

Educational Module

Focusing on primary care providers, the pretest illustrated that the majority (92.5%) already felt moderately to very comfortable with discussions related to advance care planning. After the educational video, 95.9% stated that they were moderately to very comfortable with discussions related to advance care planning. 73.5% reported that they had not used the Medicare CPT codes for advance care planning within the last year. After the educational module, 87.8% stated that they were moderately or much more likely to use the Medicare CPT codes for eligible patients.

Discussion and Practice-Related Implications

Barrier Themes

When asked to describe any barriers that were not available in the Likert scale section, those outside of primary care made it abundantly clear that advance care planning was not part of their role, and that it should be the responsibility of the primary care provider. In addition, 90.6% of primary care providers acknowledged that discussing end of life with patients is their responsibility. These results indicate that primary care providers need to own the task of advance care planning and highlight the importance of future initiatives that address barriers to advance care planning in the primary care setting.

The top seven barriers reported by primary care providers, can be broken down into three general categories. First, system barriers, which are lack of time and an electronic medical record that does not generate reminders. Second, barriers related to education, including a lack of training/education, a lack of clarity in documentation requirements, and fear of being culturally insensitive. Third, barriers that are outside of the provider's control, such as having a patient that is unwilling to discuss end of life and difficulty navigating patient and family dynamics.

Addressing lack of time will likely entail modifications in billing practices and a shift in culture. As it currently stands, outside of the Medicare CPT codes, there is not a system to reimburse providers for their time spent performing advance care planning. Without changing the culture to prioritize end of life planning, and appropriately reimbursing providers for their efforts, lack of time will continue to be one of the largest barriers faced by primary care providers.

Another system issue reported was electronic medical records that do not generate reminders. Solving this issue will require a monetary commitment from healthcare systems and clinics, and a time commitment from those working in medical informatics. Followed by staff training to acknowledge these reminders and respond appropriately.

The solution to educational barriers, including lack of training/education, lack of clarity in documentation requirements, and fear of being culturally insensitive, could be addressed in the nurse practitioner curriculum. Given the results of this survey, universities may want to consider increasing instruction related to end of life care and documentation of patient's wishes in a culturally appropriate manner, via lecture or simulated patient experiences. Those already working as a primary care provider may benefit from continuing education opportunities.

Finally, barriers that are outside of the primary care provider's control, specifically a patient that is unwilling to discuss end of life and difficulty navigating patient and family dynamics. While these factors are outside of the provider's control, they may not always be outside of the provider's influence. Breaking down these barriers will require time, dedication, understanding, and the cultivation of a therapeutic relationship.

The barriers experienced by nurse practitioners appear akin to those experienced by physicians as reported in the literature. However, it is not possible to make an accurate and direct comparison without using this same tool/survey for physicians practicing in Oregon.

Primary Care Provider's Experience as a Registered Nurse

The researcher hypothesized that NPs that had worked in acute or critical care as an RN may be more likely prioritize discussing end of life. The results of this survey show that the primary care NP's experience as a registered nurse, specifically working in acute or critical care, does not appear related to their comfort with, and frequency of, advance care planning.

Educational Module

The primary care provider's comfort with discussions related to advance care planning improved only slightly with the educational module, from 92.5% to 95.9%. However, the survey indicated that 73.5% of providers had not used the Medicare CPT codes within the last year, and 87.8% reported that they were moderately to much more likely to use the codes after completing the educational module. It is unclear why providers had not used the CPT codes in the past, however it may be at least partially related to lack of awareness, emphasizing the need for continuing education. Using the Medicare CPT codes for eligible patients should help decrease reimbursement and lack of time as barriers to advance care planning.

Limitations

Given the design of this study, one of the largest limitations is the voluntary sampling method, which risks that those already interested in the topic may be more likely to participate in the study, thereby skewing the results. As described above, most of the participants had worked as an RN for more than 10 years and as a NP for more than 10 years. The responses and conclusions drawn from this seasoned workforce may not be generalizable to the larger population. Finally, the survey was created by the researcher to meet the unique needs of this study, risking reliability and bias when using a tool that has not been previously validated.

Conclusion

The results of this study clearly illustrate that clinicians believe that advance care planning should take place in the primary care setting. Unfortunately, nurse practitioners, similar to their physician counterparts, continue to experience significant barriers. Upcoming initiatives should focus on improving or implementing educational support for current and future APRNs to aid in successful, culturally sensitive, end of life discussions, advance care planning, and the completion of advance directives. Lack of time, a barrier that was represented strongly in the literature and within this study, will need to be addressed with a culture change to prioritize advance care planning and improving the dying process. This culture change is unlikely to occur in the absence of the provider's ability to bill and be reimbursed for time spent having these conversations. The amendments to the ACA, and the resulting Medicare CPT codes, are a step in the right direction, however increasing awareness and providing education on this benefit is integral to increasing the occurrence of advance care planning in the primary care setting. Primary care providers are tasked with guiding patients throughout the life span, planning for death is a part of quality and holistic care that will allow the patient continue to enjoy life without the anxiety of unspoken wishes.

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Appendix A
 Barriers to Advance Care Planning Experienced by Primary Care Providers

Barriers	Selected: Sometimes, Often, or Always	
Lack of time *	43/53	81.1%
Patient unwilling to discuss end of life	33/51	64.7%
Electronic medical record does not generate reminders *	31/53	58.5%
Difficulty navigating patient and family dynamics	29/53	54.7%
Lack of training/education	22/52	42.3%
Fear of being culturally insensitive	22/52	42.3%
Lack of clarity in documentation requirements *	22/53	41.5%
Lack of reimbursement	14/53	26%
Lack of clarity on who should initiate the conversation (provider versus patient initiation)	10/52	19.3%
Feeling that advance care planning is not effective in protecting the patient’s wishes	10/53	18.9%
Personal discomfort with end of life conversations	9/53	17%
Feeling that it is not your responsibility to discuss end of life with your patients	5/53	9.4%

* Categories in which “always” was selected at least once

Appendix B
 Primary Care Provider’s Experience as Registered Nurse

	Primary Care Providers	
	RN Experienced in Acute/Critical Care	Without RN Experience in Acute/Critical Care
Number	36	17
10+ Years Working as a Registered Nurse	29 (80.6%)	12 (70.6%)
Experience in Resuscitation of Cardiac or Respiratory Arrest	32 (88.9%)	10 (58.8%)
Feel Very Comfortable with Advance Care Planning	23 (63.9%)	8 (47.1%)
Discuss Advance Care Planning at Least Several Times per Week	20 (55.6%)	8 (47.1%)