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Advancing Advance Care Planning in the Primary Care Setting

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ADVANCING ADVANCE CARE PLANNING IN THE PRIMARY CARE

by

William J. Bodnar

Antonette O. Sanderson

A RESEARCH PROJECT

Presented in Partial Fulfillment of Requirements for the
Degree of Master of Science
Department of Nursing
University of North Georgia

Dahlonega, Ga

Spring 2018

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We would like to thank our faculty advisor, Dr.Carolynn DeSandre, Phd, CNM, FNP-BC, for her enthusiastic guidance and research expertise throughout this project development. You have nurtured our research aptitude and we look forward to using the tools you have given us during future research projects.

DEDICATION

To our beloved spouses and children, we could not have completed this journey to becoming a nurse practitioner without you. You make us dream big and love even bigger. Thank you!

ABSTRACT

ADVANCING ADVANCE CARE PLANNING IN THE PRIMARY CARE

by

William J. Bodnar

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Despite providers agreeing that advance care planning counseling is within their scope of practice, many reported that they lack the time, education and resources needed to provide their patients with the counseling needed to make informed advance care planning decisions. In an effort to address the perceived time crunch described by many providers, we are seeking feedback on the accessibility and ease of utilization of the rapid assessment tool we created which should allow for PCP's to quickly identify patients who could benefit from advance care planning interventions. First, providers at all levels were surveyed about their personal implementation of an AD, they completed basic demographic information about their current practices, and then they assessed and provided feedback about the rapid assessment tool we created. A total of 21 providers participated over a 10-week period. 12 reported having their own documented advanced directive, 87.5% reported time was indicated as a major barrier to ACP discussions and 47.6% of participants indicated they would very likely use a rapid assessment tool (RAT) if one was available to prompt them to engage their patients in ACP. At the conclusion of this study, we are able to demonstrate that time continues to significant barrier to patient-provider engagement, modifications were made to the RAT and recommendations for future implementation studies for this tool were established based on the subjective feedback of the participants.

Advancing Advance Care Planning in the Primary Care Setting

Introduction

The utilization of advance directives allows patients to express wishes related to life-sustaining care in the event they are cognitively or physically unable to make decisions. Living Wills and Power of Attorney documentation are included in the umbrella utilization of advance directives (Advance directives & long-term care, n.d). Currently, it is encouraged that primary care providers (PCPs) and hospitalists address and document within the electronic health record what their patients wishes are in regard to their ACP choices (Advance Care Planning, 2016). The extent to which primary care providers are discussing advance care planning with clients is directly dependent on the PCP's ability to identify patient populations who will benefit from this discussion, their willingness to initiate this conversation, and their educational foundation and familiarity with advance directives.

The Centers for Disease Control and Prevention (CDC) lists coronary artery disease (CAD), diabetes mellitus (DM), chronic kidney disease (CKD) and chronic obstructive pulmonary disease (COPD) as contributors to the top ten leading causes of death in the US in 2014 (Heron, 2016). The prevalence and impact on death rates these chronic diseases have should encourage PCPs across the US to become proficient at managing and counseling about the progressive nature of these illnesses. Given the recommendation and the trustworthy relationship established between provider and patient, we feel that PCPs should be equipped with the appropriate education and tools to effectively initiate advance care planning discussions with their patients and families.

Background

A review of the literature revealed that providers perceived barriers to initiating advanced care planning for their patients. The barriers included too little time with their patient; perceived lack of education about advance care planning; lack of resources; unpredictability of disease progression; and lack of clarity about reimbursement for counseling (Ashurst et al., 2016; Bayea et al., 2013; Hayek et al., 2014, Howard, et al, 2017; Lesperance, 2014; Minto, 2011; Stephen, 2013). Research indicates that insufficient education about advance care planning options was discovered in both providers and patient populations (Ashurst, et al, 2016). When asked to define do not resuscitate (DNR) and do not intubate (DNI), respectively 35% and 39% of health care providers were unable to correctly define this terminology. Patients and families were only able to correctly define these terms 52% of the time. Research indicates that the implementation of a rapid assessment tool (RAT) could allow for at risk patients to be quickly screened and for PCPs to be prompted to address current wishes.

In an effort to increase the PCP's advance care planning knowledge-base and rates of engagement, providers at all levels have been offered education opportunities that seek to overcome their perceived barriers (Beyea et al., 2013). Both North Carolina and Florida engaged advanced practice providers in conference-like education opportunities, and both subsequently observed an increase in provider satisfaction and ACP rates. Rates of discussion increased from 7% to 31%, and in a post training survey 29% of participants stated they plan to take an active role in advanced care planning, while 25% of participants stated they feel better equipped to make a referral for palliative or hospice care (Beyea et al., 2013). Lesperance et al. (2013) discovered during post training sessions, providers and patients indicated increased rates of satisfaction after be-

ing provided the opportunity to have end-of-life and advance directive discussions. Training participants also indicated that their greatest gain was knowledge of community resources they could provide their patients in the future (Lesperance et al., 2013).

As an adjunct to training, prompts within the electronic health record have shown to increase rates of advance directive documentation to 76% (Hayek et al., 2014). When advanced training and prompts are paired together, it can be reasonably anticipated that rates of advanced care planning discussions will be enhanced between patient and provider (Beyea, 2013; Hayek et al., 2014; Lesperance, 2013). In addition to changing provider behavior and increasing their knowledge base, it is important to remember the patient and their potential gain from having more opportunities to participate in advanced care planning action. It was reported that high-risk patients who completed goals of care discussions in an intense outpatient management program were better able to direct their end of life care (Hummel et al., 2017). Findings revealed these patients spent about 50% more time in hospice leading up to their death, and 74% of them died while enrolled in hospice care. Patients and families reported high rates of satisfaction after being given the opportunity and time to express their wishes (Hummel et al., 2017). In comparison, in the absence of preparation, patients and families are forced to make these challenging end-of-life decisions based on the need to adapt to stressors such as decreased mobility, current or recent hospital admission, cultural beliefs and prognosis (Higginson et al., 2016; Zhang, 2013).

Haynes (2015), showed that education made patients more likely to want to complete an advance directive; however, it was lacking the perspective of the provider. Additionally, “The Conversation Project” demonstrated that educating their staff, starting a community group, and networking within the community infrastructure was integral to creating a culture of early ACP (University of Colorado Health, 2017 MAGNET Conference).

In an effort to address the perceived time crunch described by many providers, we seek to determine whether a RAT will improve the quality of ACP discussions between PCPs and their patients. Implementation of a RAT could allow for at risk patients to be quickly screened and for PCPs to be prompted to address current wishes. The tool will list identifiers that will screen a patient based on age and comorbid condition. Because the Centers for Disease Control and Prevention (CDC) lists coronary artery disease (CAD), diabetes mellitus (DM), chronic kidney disease (CKD) and chronic obstructive pulmonary disease (COPD) as contributors to the top ten leading causes of death in the US in 2014 (Heron, 2016), we have listed these comorbid conditions on the RAT and we are hopeful that this could allow PCPs to capture these high-risk patients in order to engage them in ACP counseling. The prevalence and impact on death rates these chronic diseases have should encourage PCPs across the US to become proficient at managing and counseling about the progressive nature of these illnesses. Given the Centers for Medicare and Medicaid Services (CMS) recommendation for documentation and the stewardship this has placed on PCP, we feel that this tool will assist with increasing rates of ACP documentation and potentially counseling as well.

Methods

Design

The RAT (Appendix D) was developed in order to capture adult patients in primary care with chronic illness. We feel focusing on chronic disease with high mortality rates would allow for the most number of patients to be captured in a primary care setting. We chose to list 4/10 leading causes of death in the US as reported by the CDC on the RAT: coronary artery disease, diabetes mellitus, chronic kidney disease and chronic obstructive pulmonary disease.

Sampling occurred by word of mouth, snowballing and utilizing offices of providers affiliated with an established list of a university's clinical rotation sites. Participants were able to ask additional questions about the purpose of the study and development of the tool. Participants completed the surveys and separated their responses from the consents by placing them in two large envelopes: one for their signed consent and the other for their completed surveys. This allowed for protection of the surveys and consents.

Primary care providers across rural north Georgia were given a packet that consisted of the consent (Appendix A), pre and post surveys (Appendix B, Appendix C) and a copy of the RAT and asked to provide feedback on additions that could be made to better capture the patient population we are seeking. Provider is defined as: Medical Doctor (MD), Doctor of Osteopathic Medicine (DO), Nurse Practitioner (NP) or Physician Assistant (PA). After consent was obtained, participants were asked to disclose basic demographics about their degree level, personal implementation of an advanced directive (AD) and their current practices to engage patients for ACP.

In total, 50 copies of pre and post surveys were distributed, 23 were returned and 21 were used to complete data statistics. At the conclusion of the study and after all statistics have been completed, the consents and responses were shredded to maintain confidentiality.

Statistical Analysis

IBM SPSS statistics was used for data analysis. Survey data was coded, descriptive statistics were calculated, and these statistics were used to analyze data comparing pre and post survey responses. The returned surveys were numbered so that the researchers could independently verify that the data was entered appropriately. Additional qualitative data was obtained from handwritten recommendations from the participants.

Providers current willingness of ACP engagement without an actively implemented RAT was compared to their willingness of engagement after evaluating the developed tool. The analytic cohort consisted of the responses gathered from the providers over a 10-week period. We compared rates of reported engagement between provider groups, identified the number of providers with their own AD and modified the RAT for future implementation based on subjective feedback from the participants.

Results

Out of 21 survey responses, eight participants are MDs, twelve participants are NPs and one participant identified as a PA of surveyed providers indicated that they have their own AD in place. The single surveyed PA reported having an AD in place, 100% implementation. In comparison to MDs, NPs represented the provider group with the higher rate of personal implementation at 47.6%. Only 1 of 8 of MDs, 4.8%, reported having an AD in place. When asked about current ACP discussions, 66% of NPs report being somewhat likely or likely to engage patients in ACP in their current practice. Eighty-seven percent of MDs report their engagement as very likely or extremely likely in their current practice, and the response received from a PA indicated he/she was likely to ask patients about their ACP decisions. Given the future implementation potential, providers were asked to indicate their willingness to utilize the RAT in future practice. Response rates indicated MDs and NPs would likely use a similar tool 62% and 8% of the time respectively. Twelve percent of MDs compared to 66.7% of NPs reported willingness as very likely, and at 25%, MDs and NPs reported their willingness as extremely likely to utilize a RAT

to engage patients in ACP. A PA indicated their willingness as being likely to utilize a RAT if one was provided to them for future implementation.

The literature review revealed many barriers perceived by providers. The most common barriers were assessed on the surveys, and time was a major concern, with 85.7% of participants indicating it was a barrier to their practice. Only three of twenty-one participants, 14.3%, indicated that time was not a barrier. Seventy percent of providers indicated that communication is not a barrier, eighty-five percent of providers indicated that family dynamics is a barrier, and sixty percent of providers indicate that having an interdisciplinary approach would be beneficial to ACP. Some additional reported barriers by participants included: limited time to provide the in depth conversation needed to adequately address ACP, concerns on the providers ability to remember to utilize the tool, lack of engagement for “stable” patients and the patient’s perception of their chronic illness. Additionally, trust was cited as major contributor for the provider to have in depth conversations, costs associated for a notary and reimbursement were also listed.

Discussion

This study evaluated whether participants felt a RAT could be utilized in practice to help engage chronically ill patients in ACP discussion. Sixty-seven percent of NPs reported willingness to use a RAT as very likely and the only surveyed PA and 62% of MDs reported willingness to use a RAT as likely suggests that NPs have a greater willingness to the Rapid Appraisal tool in its current form. Additionally, 66% of NPs report being somewhat likely or likely to engage patients in ACP in their current practice, 87.5% of MDs report their engagement as very likely or

extremely likely in their current practice and the PA reported being likely to engage patients in current practice. This data indicates that MDs seem more willing to have ACP discussions.

We found that participants agree ACP is a necessary and holistic healthcare need; however, the participants felt: (1) the tool was not all inclusive; (2) providers are unsure where to refer their patients if they desire to learn more about ADs; (3) time would continue to be the primary barrier to engagement; (4) cost to the patient for a notary if one was needed, and (5) reimbursement rates for the provider.

Additional findings included: (1) 57% of participants report having an AD in place even though they all reported varying rates of engagement with their own patients, suggests there isn't a strong correlation between having an AD and having a conversation with a patient about ADs; (2) one participant felt that the tool did not specially address the amount of time it would take to have conversations with patient/family, which might be better addressed by implementing an approach, process or tool that limits the discussion time, for example, and (3) another participant reported that identifying the at-risk patient was not the problem, instead interpersonal barriers will keep the provider from engaging patients in ACP discussions. These barriers can vary from personality to social factors and from educational to cultural considerations. Neither participants provided a recommendation for these concerns, however the researchers felt both responses could be important considerations during future implementation studies.

For future implementation we recommend the following changes (1) add "cancer" to the RAT without age inclusion criteria; (2) include a list of resources about AD for the provider; (3) develop a list of resources for patients to learn about ADs.

Recommendations

Recommendations to improve the RAT included: having a quick reference handout that providers could give to patients outlining AD's and any affiliated electronic resources (28.6%); adding additional criteria identifying patients with indolent cancers and criteria for patients <50 years old with a diagnosis of cancer (19%); adding additional examples of chronic illness (14.3%). One participant felt that patients who experience trauma or sudden loss of motor or cognitive ability due to stroke would not be captured on the RAT because there wasn't any criteria listed on the current tool. Another participant suggested that the patient fill out an AD questionnaire, and if they denied need for further discussion, then the provider would not need to broach the topic of ACP. Additional recommendations included creating a pocket reference tool for providers; embedding the tool into the electronic medical record (EMR); and providing resources on how to initiate ACP conversations.

Conclusion

Based on this study, time was identified as a major barrier to providing ACP counseling and that having a rapid assessment tool to help identify at-risk patients would be an effective prompt to initiate these discussions. Additional research that includes a large-scale implementation plan would be helpful in order to determine rates of ACP engagement, and whether the rapid assessment tool and accompanying resources helps to alleviate the providers' time constraints.

The ongoing consideration of how and when ACP discussions occur in primary care, hospitals, and in communities will lead to better methods of creating a continuous link between these contexts of care. As we approach the variety of settings, providers, and patients involved, it

is important that we collaborate with other disciplines in order to find common themes and communication pathways that will easily bridge gaps that were once thought of as distant. In the end, the benefit will come to the patient and their family as they move through the ACP process, which we hope will lead to improved end of life care.

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APPENDICES

Appendix A

UNG UNIVERSITY of
NORTH GEORGIA
Institutional Review Board (IRB)

IRB Exempt Waiver
IRB Protocol Code: 2018-003
Decision Date: 01/16/2018

Antonette Sanderson
Department of Nursing

Project Title: Advancing Advance Care Planning in the Primary Care Setting

Dear A. Sanderson

Your IRB application 2018-003 entitled "Advancing Advance Care Planning in the Primary Care Setting" has been evaluated in light of the federal, state and institutional guidelines that govern the protection of human subjects. Based on the review, the proposed research has been deemed **EXEMPT** under Category 2: 45 CFR 46.101(b)(2).

Please note that – unlike projects that involve expedited and full reviews which are approved for one year – exempt research does not have an expiry date. However, while your project is exempt from continued IRB review, the research must adhere to the proposal submitted to the IRB. If changes to protocol/s become necessary during research project, you will need to submit *IRB Form 1.4* to the IRB. Please note that any changes to existing research protocols may prevent the research from qualifying for exempt review and thus may necessitate the submission of addition other documents/materials. Important, any changes to your research and research protocols will require prior IRB approval before implementation.

Once you complete the study (or if you decide to terminate your project prematurely) please submit *IRB Form 1.3* to inform the IRB about the status of the project. The IRB will send courtesy reminders but it is the responsibility of the principal investigator to complete the research process by submitting the form.


One of the primary goals of the IRB is to prevent negative incidences during research. Despite our best efforts, however, unforeseen circumstances or events may arise over the course of a project. If an unanticipated problem and/or adverse event happens during your study, please immediately notify the IRB and submit *IRB Form 4.1* to the IRB Chair. Other actions also may be required depending on the nature of the incidence.

Finally, please include the IRB protocol code denoted above in all your communication or correspondence related to your application and this letter. Should you have additional questions or require clarification of the contents of this letter, please contact me.

Good luck with the project!

Best,

Lisa Jones-Moore, PhD
UNG IRB Chair
irbchair@ung.edu

	<p>IRB Form 3.1 Informed Consent Form</p>
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Title of the Study: Advancing Advance Care Planning in the Primary Care Setting

Researcher: William Bodnar BSN, RN and Antonette O. Sanderson BSN, RN. Master of Science Family Nurse Practitioner candidates, class of 2018 at the University of North Georgia, 82 College Circle, Dahlonega, GA.

Introduction:

You are being asked to take part in a research study being conducted by William Bodnar and Antonette Sanderson for a Graduate Project under the supervision of Dr Carolynn DeSandre in the Department of Nursing at the University of North Georgia.

You have been approached because you serve as a medical provider to adult populations with chronic illness. We are requesting feedback about a rapid assessment tool (RAT) we have created and whether you believe it could be implemented in a busy primary care practice. We also seek recommendations on how the RAT could be improved.

Purpose:

The goal of this project is to determine whether providers feel that their ability to engage patients in advance care planning would be encouraged through the implementation of a rapid assessment tool. We feel that primary care providers have the opportunity to engage in early coaching about the progressive nature of chronic illness and we are hopeful that if given the right tools, PCPs will have the time needed to educate their patients about the necessity and benefits of having an advanced directive. At this time, we are seeking feedback on the rapid assessment tool we have created and whether you feel it would change your behavior and the frequency you ask your patient about implementing an advance directive

Procedures:

The survey will take approximately 20 mins. We will provide you with a pre and posttest that will assess your current advance care planning engagement and how you will rate the ease of implementation of the rapid assessment tool. We will leave the materials with you and make an individualized plan to collect your responses at your convenience. We would like to have the responses within two weeks of providing you the materials.

Risks/Benefits:

There are no direct benefits to you from participation, but your willingness to share your knowledge and experiences will contribute to the development of a tool we feel has the potential to increase provider and patient interaction and ultimately increase patients understanding of the progressive nature of their illness and their willingness to implement an advance directive. We feel this survey will lay the groundwork for a future study that will be able to evaluate the effectiveness of the tool after being fully integrated within a practice.

The risks associated with participation in this study are minimal. There will not be any financial compensation for completing this survey.

Confidentiality:

Your study data will be handled as confidentially as possible. If results of this study are published or presented, individual names and other personally identifiable information will not be used. To minimize the risks to confidentiality, we will only be collected data that identifies the provider level-MD, DO, NP or PA- and any recommendations for improving the RAT. The researchers will be the only clinicians assessing the data and all responses will be shredded after they are transcribed into an electronic file that, again, will not have any identifying information. Lastly, the report will only describe the data as being collected by geographic region.

Your participation in this study is voluntary. Even if you decide to participate, you may withdraw from the study without penalty at any time during or after the study. You may have the results of your participation, to the extent that the can be identified, returned to you, removed from the research records or destroyed.

Contacts and Questions:

If you have any questions about this research project or interview, feel free to contact William Bodnar at wjbodn8942@ung.edu or Antonette Sanderson at aosand6682@ung.edu or the faculty advisor Dr Carolyn DeSandre at carolynn.desandre@ung.edu

Statement of Consent:

I agree to participate in this project / study / interview, and to the use of this project / study / interview as described above. The signature below indicates that you have read the information in this document and have had a chance to ask any questions you have about the study.

Participant's Signature		Date
Researcher's Signature		Date

Questions or problems regarding your rights as a participant should be addressed to Dr. Lisa Jones-Moore, Chair of the Institutional Review Board, University of North Georgia, Middle Grade Education, 82 College Circle, Dahlonega, GA, (706) 867-2969, IRBchair@ung.edu

Appendix B

Advancing Advance Care Planning in the Primary Care Setting

Pre Survey

I am a:

- MD
- DO
- NP
- PA

Likert scale

1= not at all 2= somewhat 3 = likely 4 = very likely 5= extremely likely

1) Have you completed your own Advance Directive? Yes No

2) How likely are you to have a conversation about advance directives with your patient?

1= not at all 2= somewhat 3 = likely 4 = very likely 5= extremely likely

3) How many patients do you have advance directive conversation with on a weekly basis?

1= none 2= 1 - 5 patients 3=greater than five (5) patients

4) If you were provided with a tool to prompt a conversation about advance directives, would you be willing to use it?

1= not at all 2= somewhat 3 = likely 4 = very likely 5= extremely likely

5) If you were provided with a tool, do you think it could be implemented quickly?

1= not at all 2= somewhat 3 = likely 4 = very likely 5= extremely likely

6) Do you feel it would address the time constraints of a busy clinical practice?

1= not at all 2= somewhat 3 = likely 4 = very likely 5= extremely likely

7) What do you perceive as barriers to having a conversation about advance directives?

- | | | |
|--|-----|----|
| a. time | Yes | No |
| b. communication skill | Yes | No |
| c. complex family dynamics | Yes | No |
| d. lack of interdisciplinary coordination | Yes | No |
| e. other: (Please explain using the free space below:) | | |

Appendix C**Advancing Advance Care Planning in the Primary Care Setting****Post Survey**

Likert scale

1= not at all 2= somewhat 3 = likely 4 = very likely 5= extremely likely

1) Would the Rapid Assessment Tool prompt you to have a conversation about advance directives with your patient?

1= not at all 2= somewhat 3 = likely 4 = very likely 5= extremely likely

2) Was the tool effective at identifying patients who need to have a conversation about advance directives?

1= not at all 2= somewhat 3 = likely 4 = very likely 5= extremely likely

3) After having been provided with a tool to prompt a conversation about advance directives, would you willing to use it?

1= not at all 2= somewhat 3 = likely 4 = very likely 5= extremely likely

4) Could the tool implemented easily and quickly?

1= not at all 2= somewhat 3 = likely 4 = very likely 5= extremely likely

5) Do you feel the tool addressed the time constraints of a busy clinical practice?

1= not at all 2= somewhat 3 = likely 4 = very likely 5= extremely likely

6) What do you perceive as barriers of the quality of the tool? Please explain:

7) What do you perceive as problems to its implementation? Please explain:

8) What improvements would you make to the tool for future studies?

Appendix D

Utilize tool for all patients over age 50. If time permits, providers can provide counseling on advance care planning during this visit or may schedule patient to return to the clinic for a more lengthy discussion.

Rapid Appraisal Tool

Offer Advance Care Planning counseling if (1) over 50yrs plus one comorbidity OR (2) over 65yrs regardless of presence of chronic illness. Indicate at bottom of tool what steps were taken next

1) Patient is >50 yrs and at least **one (1)**

- CAD
- COPD
- DM
- CKD

2) Patients >65 yrs. Provide resources for all patients in this age range regardless of comorbidities.

- Patient declined need at this time
- Resources provided or counseling scheduled