Advance Care Planning Conversations in Primary Care: a Quality Improvement Project Using the Serious Illness Care Program

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Research Article

Keywords: Family Practice, Advance Care Planning, Serious Illness Care Program, Quality Improvement

Posted Date: April 19th, 2021

DOI: <https://doi.org/10.21203/rs.3.rs-402429/v1>

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Version of Record: A version of this preprint was published at BMC Palliative Care on July 30th, 2021. See the published version at <https://doi.org/10.1186/s12904-021-00817-z>.

Abstract

Background: Advance care planning (ACP) conversations are associated with improved end-of-life healthcare outcomes and patients want to engage in ACP with their healthcare providers. Despite this, ACP conversations rarely occur in primary care settings. Therefore, the objective of this study was to implement ACP through adapted Serious Illness Care Program (SICP) training sessions, and to understand primary care provider perceptions of implementing ACP into practice.

Methods: We conducted a quality improvement project guided by the Normalization Process Theory (NPT). NPT is an explanatory model that delineates the processes by which organizations implement and integrate new work. The project was implemented in an interprofessional academic family medicine group in Hamilton, Ontario, Canada. Primary care providers (PCP), consisting of physicians, family medicine residents, and allied health care providers, completed Pre- and post-SICP training self-assessments, NoMAD surveys, and structured interviews.

Results: 30 PCPs participated in SICP training and completed self-assessments, 14 completed NoMAD surveys, and 7 were interviewed. Training self-assessments reported improvements in ACP confidence and skills. NoMAD surveys reported mixed opinions towards ACP implementation into primary care, raising concerns with their colleagues' abilities to conduct ACP and their patients' abilities to participate in ACP conversations. Interviews identified barriers to successful implementation including busy clinical schedules, patient preparedness, and provider discomfort or lack of confidence in having ACP conversations. Allied health identified discussing prognosis, scope of practice limitations and identification of appropriate patients as barriers.

Conclusions: Our findings complement existing literature regarding high PCP confidence and willingness to conduct ACP, but low participation which may be attributed to logistical challenges. Our findings identified areas of the SICP that were more difficult to implement (i.e., prognostication). Future iterations will require a more systematic process to support the implementation of ACP into regular practice and to address knowledge gaps identified with targeted training.

Background

Advance care planning (ACP) is a discussion of: care options; patient beliefs, values and preferences; mental and physical prognoses; and care decisions not restricted to goals of care and resuscitation directives.(1, 2) Physician-led discussions of ACP with older adults (> 65 years old) are associated with increased quality of life and mood, longer survival, decreased use of non-beneficial medical care near death, decreased expenditures, enhanced goal-consistent care, positive family outcomes, and improved physician work-life.(3, 4)

Canadians want more information about ACP from their healthcare providers.(5) A national survey of older patients from Canadian family practices reported that 68% of older patients have thought about their medical care preferences if they were sick and in hospital, but only 9% of them had engaged in

discussion with their primary care physicians about their end-of-life care preferences.(6) Despite patients wanting to engage in ACP, such conversations are infrequently had or recognized in primary care settings. A structured literature review determined that the prevalence of general practitioner-led ACP conversations with older adults is approximately 21% globally.(1)

Primary care providers have mixed perceptions of ACP and experience challenges in implementing this activity into practice. A national survey of Canadian primary care providers (PCPs) reported that PCPs are very confident and willing to have ACP conversations with their patients, yet reported low participation rates.(7) The same survey also identified key barriers to successful ACP implementation in primary care such as insufficient time and busy clinical schedules, lack of ACP knowledge or training, and patient end-of-life care literacy.(8) Despite these mixed perceptions, primary care is the ideal healthcare setting to initiate ACP conversations. PCPs share longitudinal relationships with their patients, making ACP conversations possible before critical illness or hospitalization, and free to span multiple encounters.

The Serious Illness Care Program (SICP), developed at Ariadne Labs in Boston, Massachusetts, is a communication intervention developed to identify oncology patients with a high risk of death in the next year and to train oncologists in having ACP conversations using the structured Serious Illness Conversation Guide (SICG).(9) The SICP has also been used in primary care settings with evidence of acceptance and benefit.(10) This training involved the use of standardized patients, observation and providing feedback to participants. Apart from quality improvement initiatives in two primary care clinics affiliated with the Brigham and Women's Hospital in Boston,(10) SICP implementation has not been evaluated in primary care settings extensively. As a result, there is an impetus to evaluate SICP implementation in Canadian primary care settings.

ACP conversations can sometimes feel difficult for providers and patients, and as a result, communication training must include comfortable language to initiate ACP conversations with patients. However, addressing the need for serious illness communication training among PCPs is only one of the strategies that will be needed to foster the implementation of ACP in primary care settings. Successfully implementing ACP in any healthcare setting involves steps such as the identification and preparation of appropriate patients and ensuring time is made available during appointments, that roles are clear, and that clear documentation of conversations occurs. The Normalization Process Theory (NPT) is an explanatory model that delineates the processes by which organizations implement and integrate new work.(11) The core constructs are coherence, cognitive participation, collective action and reflexive monitoring. When planning to implement a new process, NPT can be used to identify the issues to be considered in clinical settings.

As part of a quality improvement initiative, our goal was to explore the perceptions of clinicians in an interprofessional academic family practice regarding implementing ACP into routine care through using an adapted SICP and SICG, according to the constructs of NPT.

Methods

We conducted a quality improvement project in the McMaster Family Health Team; an academic interprofessional family medicine group consisting of two clinics and providing care to approximately 40,000 patients in Hamilton, Ontario, Canada.

Program implementation and evaluation

From March to May 2018, three training sessions were hosted for 34 PCPs consisting of physicians, residents, nurse practitioners, registered nurses, and social workers. Participants attended a 2.5-hour session consisting of group-based discussions about the principles of serious illness communication, followed by simulated conversations with standardized patients using an adapted version of the SICG, and receipt of real-time observation and feedback from trainers. Trainers had attended training themselves previously, from the team who developed SICP. Upon completion, participants were asked to complete pre-and post-training self-assessment surveys using Likert scale responses (1 = Not at all skilled, 5 = Extremely Skilled) to evaluate their perception of their skills (Additional File 1).

Evaluating the implementability of ACP in primary care

Over the next three months, PCPs who attended training agreed to use the adapted SICG to conduct conversations with two to three patients aged 65 or older with any diagnosis of a chronic, progressive illness or frailty that is expected to decrease life expectancy. Consenting patients and their substitute decision-makers were to be asked to complete surveys evaluating their conversation experience. Upon completion of conversations with three patients, PCPs were to complete surveys evaluating their conversation experiences.

Surveys and interviews were used to measure PCP perceptions of ACP and the SICP in primary care, as per the NPT framework. The NoMAD survey is a customizable 23-question survey based on the NPT constructs, used for gauging implementation processes from the viewpoint of healthcare professionals directly implementing new interventions.(12, 13) The survey was used to evaluate participants' perceptions of implementing ACP in their practice (Additional File 2). Surveys were administered three months following the final workshop. Structured interviews were completed with PCPs to identify perceived barriers and facilitators to successful implementation.

Analyses

Paired t-tests were conducted to examine pre-and post-workshop self-assessment scores. Means, frequencies, and proportions were calculated to describe NoMAD survey responses. Statistical significance was assessed by a two-tailed p-value of < 0.05. Analyses were completed using IBM SPSS Statistics for Windows, Version 26.0.

Interview recordings and notes were analyzed by a research assistant to identify themes (i.e., barriers and facilitators to implementation).

The Hamilton Integrated Research Ethics Board granted an ethics exemption to evaluate this training to improve the quality of ACP conversations in the clinics.

Results

Training evaluations

Thirty PCPs completed a pre-and post-training self-assessment evaluating their perception of the impact of the training session on their confidence and abilities to conduct ACP. Eighty-nine percent reported the training to be effective in improving their skills in conducting serious illness conversations, and 96% recommended the training to other healthcare providers. PCPs reported improvements in every assessment category following the intervention (Table 1).

Twenty-five PCPs agreed to use the adapted SICG to conduct ACP conversations with their patients and subsequently refer them to study researchers, however, only 3 patients were referred to researchers by December 2018. As a result, patient ACP conversation experiences were not evaluated.

Table 1

Participant's self-assessment of skill pre-and post-Serious Illness Conversation training (n = 30).

Self-assessment category	Pre-Workshop Score	Post-Workshop Score	P-Value*
	Mean (SD)	Mean (SD)	
1. Set up a serious illness conversation	2.7 (0.9)	3.8 (0.7)	.001
2. Assess patient understanding of their illness	3.3 (1.0)	3.9 (0.7)	< .001
3. Ask patients about their preferences for information about the future	3.0 (1.0)	3.9 (0.8)	< .001
4. Share prognosis	2.1 (1.0)	3.1 (0.8)	< .001
5. Acknowledge and respond to patient emotion	3.8 (1.1)	4.0 (0.9)	< .001
6. Allow silence	3.2 (1.2)	3.9 (1.0)	< .001
7. Explore goals for future care	3.1 (0.9)	3.9 (0.9)	< .001
8. Inquire about fears and worries	3.1 (1.1)	3.9 (0.8)	< .001
9. Ask about sources of strength	2.8 (1.1)	3.8 (0.8)	.001
10. Explore views on trade-offs	2.3 (0.9)	3.4 (0.9)	< .001
11. Inquire about views on critical abilities†	2.4 (0.9)	3.6 (0.8)	.011
12. Explore views on family involvement†	3.3 (0.8)	3.9 (0.7)	.002
13. Speak < 50% of time	3.1 (1.2)	3.7 (1.1)	< .001
14. Overall confidence in having serious illness conversations	2.5 (0.9)	3.6 (0.9)	< .001
<i>Notes: Likert Scale Responses: 1 = Not at all skilled, 5 = Extremely Skilled; * Paired Samples T Test, $\alpha = 0.05$;</i>			
<i>† N = 29 due to incomplete assessment.</i>			

NoMAD survey and interview findings

Fourteen PCPs completed surveys evaluating their perceptions of implementing ACP into practice. Seventy-one percent of respondents were female, 50% were physicians and 50% had more than 6 years of clinical experience. When asked to rate how familiar they felt about conducting ACP in primary care, respondents reported a mean score of 6.8 (0 = Feels very new, 10 = Feels completely familiar). Respondents reported mean scores of 5.9 and 8.0 (0 = Not at all, 10 = Completely) when asked if ACP is currently part of their work and if they feel that ACP can become part of their work.

Respondents reported mixed opinions towards ACP in primary care (Table 2). All participants agreed on the potential value of conducting ACP in their professional role and the belief that participating in ACP is a legitimate part of the PCP role. All respondents agreed or strongly agreed that they are open to working with colleagues in new ways to make ACP possible in primary care and will continue to support ACP implementation in primary care. However, 58% did not agree that they can easily make ACP part of their clinical routine. Fifty-four percent lacked confidence in their colleagues' abilities in conducting ACP, and 57% lacked confidence in their patients' abilities to engage with them when discussing ACP. While 86% of respondents believed that enough training can be provided to staff to implement ACP, 50% believed that available resources are not adequate to support implementation.

Table 2

Responses to the survey on implementation of Advance Care Planning (ACP) in primary care (n = 14).

Statement based on NoMAD survey adaptation	Agree or Strongly Agree,
	N (%)
1. I can see how ACP differs from previous management of patients.	10 (71.4%)
2. Staff in my organisation share understanding of the purpose of conducting ACP in primary care.	7 (50.0%)
3. I understand how conducting ACP affects (changes) the nature or way I work.	13 (92.8%)
4. I can see the potential value of conducting ACP in my professional role.	14 (100.0%)
5. There are key people driving ACP in primary care settings.	9 (64.3%)
6. I believe that participating in ACP is a legitimate part of my role.	14 (100.0%)
7. I am open to working with colleagues in a new way to make ACP work in primary care settings.	14 (100.0%)
8. I will continue to support the implementation of ACP in primary care.	14 (100.0%)
9. I can easily make ACP (identify, invite, discuss & discuss) part of my daily work.	6 (42.9%)
10. Conducting ACP can be disruptive to my previous working relationships.	2 (14.3%)
11. I have confidence in my colleagues' ability to conduct ACP.*	5 (35.7%)
12. I have confidence in patients' ability to engage in ACP discussions with me.	6 (42.9%)
13. ACP can be carried out by people with appropriate skills.	14 (100.0%)
14. Sufficient training can be provided to staff to implement ACP in primary care.	12 (85.7%)
15. Sufficient resources are available to support ACP implementation in primary care.	5 (35.7%)
16. I have received feedback about the effects of conducting ACP in primary care settings.	2 (14.3%)
17. The staff I work with agree that conducting ACP in primary care settings is worthwhile.	12 (85.7%)
18. I value the effects that incorporating ACP has had on my daily work.	12 (85.7%)
19. I think feedback about conducting ACP could be used to improve it in the future.	12 (85.7%)
20. I can modify how I conduct ACP in primary care.	11 (78.6%)
* N = 13 due to incomplete survey.	

Seven PCPs (3 physicians and 4 allied health professionals) were interviewed and identified different barriers to implementation. All physicians identified busy clinical schedules as a barrier, noting the difficulty in having opportunistic ACP conversations with their patients. Other barriers identified by physicians included patient preparedness to engage in ACP conversations and discomfort or lack of confidence in having ACP conversations. All allied health professionals (i.e., nurse practitioners, registered nurses, and social workers) identified discussing prognosis with patients as a barrier, emphasizing that prognostication is outside their scope of practice. Other barriers identified by allied health professionals included scope of practice limitations and identifying appropriate patients for ACP conversations.

Interviewees identified the following suggestions to increase the quantity and quality of ACP conversations in primary care: conducting conversations over multiple appointments, increased collaboration between physicians and allied health professionals, and more training to normalize conversations as a standard of care for health care providers regardless of clinical role or specialty.

Discussion

Key findings

In this quality improvement project where 30 PCPs were trained to have serious illness conversations through an adapted SICP and SICG, we examined training assessments and perceptions of the implementability of ACP in primary care. Overall, PCPs rated the SICP training workshops as highly effective in improving their skills and confidence in having ACP conversations in primary care. Our findings complement existing literature on PCP perceptions of SICP training workshops for primary care. (10) We also found high PCP confidence and willingness to conduct ACP, but low completion and/or reporting rates, which resonates with other research.(14) This may be attributed to logistical challenges raised by physicians such as busy clinical schedules, which may result in lower ACP conversation rates despite high PCP confidence. Our findings that busy clinical schedules are perceived to be a barrier for physicians complements existing literature on ACP implementation.(14–16)

Our results identified differences between physicians and allied health professionals. Physicians reported high self-confidence in conducting ACP with patients themselves, but less confidence in their colleagues conducting ACP conversations. Allied health professionals reporting greater difficulty with discussing prognosis compared to physicians is also found in other studies.(14) This is further compounded by the scope of practice limitations, another barrier specific to allied health professionals. Allied health professionals' hesitancy to conduct ACP conversations due to limited scope of practice is a barrier identified in other studies as well.(14)

Our results suggest that training will not lead to increased rates of ACP conversations in clinical practice, despite positive reception to the training and using broad patient eligibility criteria. Physician doubts about ACP implementation were largely explained as logistical challenges, and assumptions made about

patient preparedness. Our results suggest difficulty in knowing how to arrange conversations with busy clinical workflows, and how to broach a sensitive subject effectively and comfortably. Despite the training being evidence-based and incorporating both simulated patients and feedback, the training may not be real-world case-based enough to have a positive impact on confidence and workflow challenges. Although the SICP recognizes the need for process changes in clinics such as mechanisms to identify patients, trigger the conversation and prepare patients,(9) it is important to confirm the relevance of these approaches locally in quality improvement initiatives.

Limitations

Our study has three important limitations to consider. First, our findings are reflective of one academic family health team. As a result, these findings may not apply to other primary care teams and organizations, or other health care settings. Second, only 14 out of 25 consenting PCPs completed NoMAD surveys, resulting in a 56% response rate. A higher response rate would have further strengthened the validity of our findings. Third, our objective was to evaluate whether there was a role for SICP in implementing ACP in primary care, and we did not undertake the study to increase the frequency of ACP conversations. However, a separate chart review of patients who died from January 2017 to December 2017 from the McMaster Family Health Team, found that 42% of decedents had a goals of care conversation, 32% discussed their illness understanding, 26% discussed patient values, beliefs and priorities going forward, and only 11% discussed prognosis.(17) A repeat chart review may be able to report on the potential impacts of SICP implementation on the frequency of ACP conversations. Despite these limitations, our findings complement existing literature and findings.

Considerations for future implementation & research

Successful implementation of ACP in primary care will require systematic processes and logistical supports beyond training sessions only. Specifically, PCPs may benefit from systematically identifying patients who could benefit from ACP, for example through electronic medical record queries of patients with life-limiting chronic illnesses, or by inviting all older patients for conversations regardless of their health status. Both approaches address concerns related to identifying appropriate patients for ACP. Additionally, administrative support can facilitate conversations by sending ACP resources, such as the Speak Up! workbook,(18) to patients ahead of their scheduled appointments with PCPs and by having resources readily available during appointments. PCPs may also benefit from training curated to address specific knowledge gaps identified to their clinical roles. Specifically, ACP training for allied health professionals should focus on discussing disease prognosis or natural history of progressive illnesses. Furthermore, future ACP implementations may benefit from a community-of-practice approach, that aims for gradual change over one to two years with ongoing knowledge sharing. Lastly, future research is needed to evaluate patient and substitute decision-maker experiences of ACP conversations and the effectiveness of conversations in primary care.

Conclusions

Overall, our findings suggest physicians and allied health professionals working in primary care are very receptive to the idea of ACP but are less optimistic about the feasibility of implementing ACP into clinical practice. Attention to specific implementation concerns may help identify improvements for future iterations of ACP implementation.

Abbreviations

ACP – Advance care planning

SICP – Serious Illness Care Program

SICG – Serious Illness Conversation Guide

NPT – Normalization Process Theory

PCP – Primary care provider

Declarations

Ethics

The Hamilton Integrated Research Ethics Board granted an ethics exemption to evaluate this training on the basis of quality improvement, as per Canada's Tri-Council Policy Statement 2 (TCPS2), Section 2.5. HiREB waived the need for consent for clinician participants and allied health professionals, including social workers. Informed consent was obtained from participating patients and substitute decision makers. All methods were carried out in accordance with TCPS2.

Consent for publication

Not applicable.

Availability of data and materials

The datasets analyzed during the current study are available from the corresponding author upon reasonable request.

Competing interests

The authors declare that they have no competing interests.

Funding

This study was partially funded by McMaster University's Department of Family Medicine and the Canadian Frailty Networks' 2015 Transformative Grant.

Authors' contributions

DG conceived the study, and all authors designed the study. AH was responsible for data collection, analysis, and writing the manuscript. All authors revised the manuscript critically for important intellectual content, gave final approval of the version to be published, and agreed to be accountable for all aspects of the work.

Acknowledgements

The authors would like to thank our colleagues John You and Marilyn Swinton for their valuable comments and suggestions. Additionally, we would like to thank all our clinician participants who made this project possible.

Funding Statement

This study was partially funded by McMaster University's Department of Family Medicine and research grant TG2015-03 funded by the Canadian Frailty Network (Technology Evaluation in the Elderly Network), which is supported by the Government of Canada through the Networks of Centres of Excellence (NCE) program.

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