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A Systematic Intervention To Improve Serious Illness Communication In Primary Care

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ABSTRACT Improving communication about goals and values for patients with advancing serious illness nearing the end of life is a key opportunity to improve the value of care. The Serious Illness Care Program, implemented at primary care clinics affiliated with Brigham and Women's Hospital in Boston, Massachusetts, is a multicomponent intervention designed to support best practices in communication by clinicians to increase conversations with patients with serious illness about their goals and values. We conducted a study of the program in fourteen primary care clinics participating in a high-risk care management program based in an accountable care organization. Patients in the clinics with the program implemented were more likely than those in comparison clinics to have serious illness conversations—including discussion of values and goals—documented in patients' medical records. Clinicians who participated also reported high satisfaction with training they received as part of the program, which they regarded as effective. This work suggests that the Serious Illness Care Program promotes more and better conversations among selected primary care patients, and it highlights the need for further research.

Evidence suggests that early conversations between clinicians and patients, begun before the final days and weeks of life, about end-of-life care are associated with enhanced care better aligned with patients' preferences.¹⁻⁴ The result is fewer nonbeneficial medical interventions, less distress for family, and lower costs. National organizations such as the Institute of Medicine have called for improvement in clinician-led discussions about goals, values, and care preferences for patients with serious illnesses.⁵ In this article we refer to these discussions as "serious illness conversations." The conversations constitute any discussion between a clinician and patient about prognosis, values, goals, or care preferences in the context of advancing serious illness and can, but do not necessarily, include recording of key patient

preferences in a legal document such as an advance directive. While there is no consensus on which clinicians should lead these conversations, primary care teams—which tend to have long-term relationships with their patients—may shoulder the responsibility for a large share of serious illness conversations.⁶⁻⁸

Patients and their caregivers in the primary care setting rely on their clinicians to initiate conversations about goals and preferences in serious illness.⁹⁻¹¹ However, primary care clinicians do not regularly address values and goals with their seriously ill patients.¹² Clinicians do not conduct these conversations at the appropriate time, often initiating them so late in a disease course that the trajectory of care cannot be significantly altered.¹³⁻¹⁵ Discussions in primary care tend to focus on biomedical and procedural issues rather than the psychosocial challenges

and human concerns that are more important to patients.¹⁶ Furthermore, the content of these conversations is often not accessible to other clinicians in current electronic health record (EHR) systems when transitions in care occur.¹⁷ These factors (frequency, timing, comprehensiveness, and accessibility) contribute to a gap that may generate low-value care in which seriously ill patients do not receive the kind of care they desire.

The reasons for this gap are diverse, stemming from system failures, including difficulty in identifying patients at high risk of death, and inadequate clinician training in communication.⁸ A number of policy efforts attempt to address these failures. For example, in October 2015 the Centers for Medicare and Medicaid Services, recognizing the value of advance care planning conversations, added specific billing codes to reimburse physicians for such conversations.¹⁸ These codes can be added to other levels of service and can be used multiple times, allowing for iterative discussions about patients' goals, values, and advance care plans. The aim of this policy change was to provide incentives to clinicians from any specialty to discuss patients' views on quality of life and care preferences.

To improve access to high-quality communication for patients with serious illness, our team developed the Serious Illness Care Program, designed to support best practices in serious illness communication by clinicians who lack specialty-level palliative care training in outpatient care settings.^{19,20} The program includes four core elements: a population approach to identifying patients, training and coaching for clinicians to use a structured Conversation Guide, reminders to conduct conversations, and a documentation system. The program is unique in that it is designed to promote conversations that focus on what is most important to patients living with serious illness and to explore factors that are key to maximizing quality of life. Abstracts presenting early work studying the program in outpatient oncology suggest that the program is feasible in oncology and has resulted in increased conversations that took place earlier, were more accessible and more effective in eliciting goals and values, and reduced anxiety and depression among patients in comparison to control groups.^{21,22}

We present a study designed, funded, and executed as a prospective implementation trial of the Serious Illness Care Program in a high-risk primary care population. In this article we describe the implementation of the program and our evaluation of the use of the program by clinicians and the intervention's impact on the prevalence, timing, accessibility, and com-

prehensiveness of documented serious illness conversations and hospice use among patients.

Study Data And Methods

STUDY SETTING We adapted and implemented the Serious Illness Care Program in primary care clinics affiliated with Brigham and Women's Hospital in Boston, Massachusetts, from January 1, 2014, to August 31, 2016. We focused on patients enrolled in the hospital's Integrated Care Management Program, a team-based, high-risk care management program in an accountable care organization. The Integrated Care Management Program is embedded in primary care practices and coordinates care for chronically ill, medically complex patients by assigning high-risk patients a nurse care coordinator to work closely with primary care physicians and social workers to help patients and their families develop and follow a customized care plan.²³ Qualification for the Integrated Care Management Program involves a two-step verification process: a claims-based algorithm, incorporating comorbidity and utilization, identifies potentially eligible patients, followed by validation of appropriateness for participation by each patient's primary care physician.

Out of a total of nineteen possible Brigham and Women's Hospital primary care clinics, we excluded five (one trainee clinic, one Spanish-speaking clinic, and three clinics in transition, such as those opening or closing). From the remaining fourteen clinics, we chose six to receive the Serious Illness Care Program (intervention); the remaining eight clinics served as comparison sites. Intervention clinics were a convenience sample chosen based on location and high volume of at-risk patients served, to maximize the efficiency of training for program implementation. Participating practices were both urban and suburban clinics from hospital- and community-based settings and served a diverse population of patients across the greater Boston area. Intervention clinics participated in each component of the Serious Illness Care Program,²⁰ while the comparison clinics participated in only one step of the program: identifying patients at high risk of death within two years. We obtained baseline patient characteristics from electronic health records. The study was approved by the Partners HealthCare Institutional Review Board and registered online with clinicaltrials.gov (Identifier NCT02879357).

IMPLEMENTATION We adapted key elements of the program for the primary care setting. In a structured training program lasting two and a half hours, palliative care experts trained intervention clinicians (physicians, nurse care coor-

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dinators, and social workers) on the use of the Conversation Guide. They made use of structured, learner-centered teaching methods, including demonstration and practice with trained medical actors. Palliative care specialists also provided coaching via monthly calls and as requested via phone, e-mail or in person. The process of selecting patients for a serious illness conversation after clinicians received training began when an electronic survey was e-mailed to all members of the clinical team. Clinicians each answered the Surprise Question: "Would you be surprised if this patient died in the next 2 years?" In previous work, clinicians' responding "no" to a Surprise Question asking about a one-year period has been shown to be associated with increased mortality in oncology and nephrology patients.^{24,25} Because the primary care population selected for this study had a lower expected mortality rate and less predictable illness trajectory compared to the oncology and nephrology patients in the earlier work, we used a two-year time frame, as requested by participating clinicians, to identify appropriate patients for conversations. Clinicians could also add patients to and remove them from their lists based on their clinical judgment. To prompt conversations, the implementation team distributed lists of each clinician's identified patients every other week via e-mail to the nurse care coordinator, who helped coordinate conversation timing and also notified program staff of challenges encountered and completed conversations. Clinicians completed structured documentation of each conversation in the advance care planning module in the EHR.²⁰ Clinicians in the intervention clinics were trained on the practical use of the EHR module during their training session.

EVALUATION OF IMPLEMENTATION We prospectively collected data about the implementation process in each clinic from January 1, 2014, to May 30, 2015, at which point our institution converted to a new EHR system. This conversion eliminated the previous EHR module and prevented further assessment of our primary outcomes, precluding ongoing comparable data collection. To assess the effectiveness of the training, we asked clinicians in the intervention clinics to complete a paper survey after the training ended. We measured the characteristics of clinician-patient conversations, such as which clinicians were involved and an estimate of time spent, via an electronic survey of clinicians after each conversation.

EVALUATION OF CONVERSATION DOCUMENTATION IN DECEASED PATIENTS The primary outcomes of this study were the prevalence, timing, accessibility, and comprehensiveness of serious illness conversations for patients who died dur-

ing the implementation period. To assess these outcomes, we used an intention-to-treat analysis. We chose death as an endpoint to account for the variation in disease states and stages of illness in this heterogeneous population. To assess the prevalence, timing, and accessibility of conversations, we conducted a retrospective chart review of outpatient records of all patients in intervention and comparison clinics who died during the implementation period. A reviewer used a codebook (see online Appendix A)²⁶ to abstract the first documented instance in the progress notes, which were blinded for the review, of a conversation that addressed at least one of the following domains: patient values and goals; prognosis or illness understanding; end-of-life care planning; or code status (that is, whether or not a patient has requested resuscitation in the event of a Code Blue) or desire for other life-sustaining treatments or procedures. The reviewer recorded the date, clinician's name, retrieval location, and content of the conversation. An expert panel reviewed every fifth coded chart to ensure consistency in abstracted notes.

To assess the comprehensiveness of documented conversations, we conducted a second chart review on a randomly selected subset of forty-eight intervention and forty-eight comparison patients from the decedent population, compared at the group level to ensure similar duration of study involvement and clinic distribution. A reviewer abstracted and coded all instances of documented serious illness conversations (again blinded for the review) using methods described above, then used thematic analysis with a combined deductive and inductive approach to identify elements associated with comprehensive documentation. A second reviewer double-coded every fifth record (also blinded for review), and the results of the two reviewers were compared at regular intervals throughout the coding process.

EVALUATION OF HOSPICE USE IN DECEASED PATIENTS We analyzed patients' use of hospice, using claims data from January 1, 2014, to August 31, 2016, among a subset of deceased Integrated Care Management Program patients whom clinicians had identified as being at high risk of dying. We compared hospice use in the last six months of life among the subset of beneficiaries for whom we had complete Medicare claims data in their final month of life.

STATISTICAL ANALYSIS We present descriptive statistics for patients who died between January 1, 2014, and May 30, 2015. We calculated proportions for categorical variables and means and 95 percent confidence intervals for continuous variables. For descriptive and outcome variables, comparisons between the intervention

and comparison groups were done using the Rao-Scott chi-square test, clustering by primary care physicians, when the variables were categorical and using robust generalized estimated equations *t*-tests, clustering by primary care physicians, when the variables were continuous. All statistical analyses were performed using SAS software, version 9.4. We performed chart review analysis using NVivo v10.0 software (QSR International). For hospice analysis, we analyzed data from January 1, 2014, to August 31, 2016. We chose to analyze hospice use for a longer period of time than was the case with our primary study outcomes, to allow time for patients to enter hospice after the Serious Illness Care Program began.

LIMITATIONS This study had several important limitations. First, although prior data suggest that improved serious illness communication leads to enhanced patient outcomes, we do not know the extent to which documentation reflects actual discussions between patient and clinician. Second, because our study relied on available clinical data, it lacked data on direct patient outcomes, including information about whether patients received the type of care they desired. Third, clinicians in both the intervention and comparison clinics were asked the Surprise Question, which may have prompted clinicians in comparison clinics to initiate conversations with their patients, thereby attenuating differences between intervention and comparison clinics. Fourth, clinics included in this study were selected as a convenience sample, so the differences we found in communication outcomes could be due to unmeasured characteristics other than the program implementation. Fifth, the small sample size of this trial limited our power for analyzing our secondary utilization outcomes.

Study Results

We analyzed data from all fourteen participating clinics. Intervention clinics included fifty-two physicians, eleven nurse care coordinators, and seven social workers. Comparison clinics comprised seventy-three physicians, eleven nurse care-coordinators, and six social workers.

Clinicians in the intervention and comparison groups had similar amounts of time spent on clinical activities and similar years in practice. Populations in both intervention and comparison clinics had similar baseline characteristics (race, marital status, Charlson Comorbidity Index, and mortality rates).

IMPLEMENTATION OF THE SERIOUS ILLNESS CARE PROGRAM We trained forty-one of the fifty-two physicians and all of the nurse care coor-

dinators and social workers (84.3 percent of eligible clinicians) in communication and program procedures in the six intervention clinics during January–April 2014. Clinicians rated the training as highly effective (4.7 out of 5 on a Likert scale, where 5 was the most positive rating).

Clinicians in intervention clinics selected 230 patients for conversations using the two-year Surprise Question screening and clinical judgment. They screened a higher percentage of patients (72.7 percent compared to 39.6 percent in comparison clinics; $p = 0.0005$), but the proportion answering “no” to the Surprise Question was similar in both groups (35.7 percent in intervention clinics versus 39.3 percent in comparison clinics; $p = 0.5161$) (for a flow diagram describing study procedures and patient selection, see Appendix B).²⁶ These differences can be attributed to intervention clinicians’ training and engagement in the program and less screening completed in comparison clinics because patient selection was voluntary. At the time of transition to the new EHR, intervention clinicians had documented conversations in the advance care planning module for 111 patients (48.3 percent of those selected for conversation). The mean number of conversations conducted by primary care physician–led clinical teams was 2.1 (range: 0–9). Conversations were conducted by the physician alone 37.4 percent of the time, by the nurse alone 18.7 percent of the time, and by multiple team members 41.8 percent of the time. Physicians reported a median serious illness conversation time of 21.8 minutes (standard deviation: 16.3 minutes), while nurses reported the mean serious illness conversation time of 26.0 minutes (SD: 12.6 minutes).

SERIOUS ILLNESS CONVERSATION DOCUMENTATION IN DECEASED PATIENTS One hundred seventy-eight patients died during the study period. Deceased patients in intervention and compari-

EXHIBIT 1

Baseline characteristics of deceased patients in clinics that implemented the Serious Illness Care Program and in comparison clinics

Characteristic	Intervention (n = 101)	Comparison (n = 77)	p value
Male (number)	55	35	0.2772
Mean age (years)	79.5	78.5	0.6186
Percent white non-Hispanic	81.2%	79.2%	0.3278
Percent married/partnered	51.5%	42.9%	0.2692
Charlson Comorbidity Index (mean)	4.2	4.5	0.4542

SOURCE Authors’ analyses of electronic health record data retrieved from institutional databases generated from routine clinical care. **NOTE** For race/ethnicity and marital status, percentage calculations do not include missing data in the denominator (for race/ethnicity, missing $n = 7$; for marital status, missing $n = 4$).

son clinics appeared similar across a range of demographics and clinical variables at baseline (Exhibit 1), and there was no significant difference in mortality between groups at the end of the study period (8.3 percent in intervention clinics versus 7.3 percent in comparison clinics; $p = 0.4109$). For patients who died during the study period, more patients in the intervention group (62.4 percent) than in the comparison group (42.9 percent; $p = 0.0020$) had documentation of at least one serious illness conversation. For those who had documentation present, patients in intervention clinics were more likely (44.4 percent) than those in comparison clinics (3.0 percent; $p < 0.0001$) to have their conversations documented in the advance care planning module of the EHR; conversations for the comparison group were primarily documented within progress notes. The timing of conversations (133.7 days before death in intervention clinics, compared to 129.2 days in comparison clinics; $p = 0.8197$) was not significantly different between groups. Conversations for patients who died in the intervention clinics were more comprehensive, covering more elements related to values and goals (2.8 elements per patient, compared to 1.8 elements in comparison clinics; $p = 0.0301$); no statistically sig-

nificant differences in discussion of prognosis, code status/life-sustaining treatments, or end-of-life planning were seen (Exhibit 2).

HOSPICE UTILIZATION Of Integrated Care Management Program patients who died and who had been identified as being at high risk for dying by clinicians (a “no” answer to the Surprise Question), seventy-four (forty-seven from intervention clinics and twenty-seven from comparison clinics; the difference between the groups is due to lower rates of Surprise Question screening in comparison clinics) had claims data through their final month of life and were therefore included in the hospice utilization analysis. The percentage of patients who died who used hospice was not statistically significantly different in the intervention clinics versus in comparison clinics (55.3 percent versus 40.7 percent with at least one day on hospice; $p = 0.3342$). Length of hospice stay was not statistically significantly different (because of the low number of patients available for analysis) between intervention and comparison patients (51.0 versus 29.3 days; $p = 0.4300$).

Discussion

In this prospective implementation trial in a high-risk care management program in primary care, we examined the impact of a systematic multicomponent intervention to improve serious illness communication. We found that, compared to patients enrolled in comparison clinics, patients enrolled in clinics participating in the program who died had more serious illness conversations with their clinicians, and these conversations were both more comprehensive and more accessible in the medical record. The greater comprehensiveness of the documentation suggests that the Conversation Guide prompted more extensive exploration of key topics by clinicians—a desired outcome of the intervention. The intervention did not have an effect on the timing of conversations in relation to death. First conversations in both groups took place approximately four and a half months before a patient’s death, which is much earlier than previously reported in the oncology setting.¹⁵ To our knowledge, this is the first report of timing of serious illness conversations in relation to death in the primary care setting. There were no statistically significant differences in hospice use between the two groups, although numbers were small.

Training and engagement of 100 percent of nurses and social workers and 79 percent of physicians at their clinic sites demonstrates that a two-and-a-half-hour on-site training program is feasible for busy clinicians; the high satisfac-

EXHIBIT 2

Frequency, timing, comprehensiveness, and accessibility of documented clinician-patient serious illness conversations among deceased patients in clinics that implemented the Serious Illness Care Program and in comparison clinics

	Intervention (n = 101)	Comparison (n = 77)	p value
FREQUENCY: AT LEAST ONE CONVERSATION DOCUMENTED BEFORE DEATH			
At least one conversation documented	62.4%	42.9%	0.0020
Conversation documented in EHR module	44.4%	3.0%	<0.0001
TIMING: FIRST DOCUMENTED CONVERSATION, DAYS BEFORE DEATH			
Days (mean)	133.7	129.2	0.8197
COMPREHENSIVENESS OF DOCUMENTED CONVERSATIONS BEFORE DEATH			
Number of patients reviewed	48	48	
Number of patients with at least one conversation	28	24	
Code status or life sustaining treatment (domain contains 2 components)			
Mean number of components	0.8	0.8	0.8449
Prognosis and illness understanding (domain contains 4 components)			
Mean number of components	1.6	1.0	0.1777
Values and goals (domain contains 7 components)			
Mean number of components	2.8	1.8	0.0301
End-of-life planning (domain contains 4 components)			
Mean number of components	1.8	1.5	0.2865

SOURCE Authors’ analyses of electronic health record data retrieved from institutional databases generated from routine clinical care.

tion ratings demonstrate that clinicians found the training effective. The time required for clinicians to conduct a serious illness conversation appeared to be feasible within a primary care clinician's workflow. Reimbursement for time spent on advance care planning, which was not available during the time of this program, may enhance physicians' engagement with these conversations in the future.

In addition to clinician training, this intervention included several systems-change components, including a strategy to identify the population of patients who could benefit from serious illness conversations. While we used the Surprise Question to identify "at-risk" patients in this study, this method misses as many as 79 percent of at-risk patients.²⁷ This indicates the need for improved identification strategies for early palliative care interventions, such as nonproprietary, EHR-based algorithms that can be readily integrated into the clinical workflow.

The active engagement of nonphysician team members in this program appeared to contribute to the feasibility of this approach. Since clinics tailored the intervention to their own practice styles, the engagement of nonphysicians varied. However, the finding that a majority of conversations involved more than one type of clinician suggests that the team approach was viewed as effective by the clinicians involved and that it expanded access to serious illness conversations in the population we studied. We believe that this finding supports that value of team engagement in improving access to serious illness care conversations in primary care, deserves future study, and is an important consideration in generalization of this work.

Overall, this intervention was feasible, was endorsed by clinicians, increased discussions about patients' goals and values for those who died, and contributes to a new model for improving care for seriously ill patients in the primary care setting. Funding for such improvement efforts will be needed. The Palliative Care and Hospice Education and Training Act (H.R. 3119), now currently in Congress, proposes to fund research, education, and training in caring for patients with serious illness for both specialty palliative care clinicians and nonspecialists

and would facilitate this type of work.

Another element that would enhance the communication with and quality of care for patients with advancing serious illness would be the formulation of national standards and incentives that could help assure uniformity and completeness in collection of patient-reported outcomes relevant to the care of such patients.²⁸ As an implementation trial, our study relied on available clinical data and could not collect extensive data on patient outcomes, including information about whether the care received was the care desired. However, the routine collection of information about patients' and families' experiences, through administration of standard questionnaires, holds potential as a source of this critical information.²⁸

Conclusion

Our study suggests that the Serious Illness Care Program, implemented at Boston's Brigham and Women's Hospital is a practical intervention that improves access to high-quality serious illness conversations for primary care patients in a high-risk care management program. This work highlights the impact of a program that uses brief clinician training, a structured approach to focus serious illness conversations on what matters most to patients, a process for identifying patients, and reminders to conduct and document these conversations in an accessible location in the medical record. However, the multicomponent nature of the intervention prevents an assessment of which components contributed to outcomes, and more research needs to be done to shed light on what facilitates health care providers' adoption of the program. The limitations to our study that we identified above point to the ongoing need for development and execution of pragmatic trials of communication interventions for seriously ill patients. Furthermore, our program highlights the need for better systematic measurement of outcomes that are important to patients, along with increased training and coaching for clinicians in conducting serious illness conversations. Further research on the outcomes and cost implications of such interventions is urgently needed. ■

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