A Quality Improvement Initiative to Implement the Serious Illness Care Program on Hospital Medical Wards: Impact on Patient and Clinician Experience

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Abstract

Background: The Serious Illness Care Program (SICP) is a communication intervention that builds clinician capacity to have earlier, more values-based conversations about goals of care with patients experiencing life-limiting illness. We report the impact of its implementation on hospital wards.

Methods: In this quality improvement initiative on the medical wards of two Canadian teaching hospitals, we trained physicians, nurse practitioners, and social workers in the use of the Serious Illness Conversation Guide. Between February 2017 and September 2020, we prompted trained clinicians to have serious illness conversations with hospitalized patients or their family member(s), for patients at high risk of dying. Outcomes were the number of clinicians trained, the number of conversations delivered, patient or family experience, including the extent to which they felt heard and understood, and clinician experience.

Results: We trained 57 (92%) of 62 eligible clinicians. We delivered conversations to 334 (29%) of 1158 eligible patients (or family members) and documented 274 (82%) of these in the medical record. After a serious illness conversation, 80% of patients or families rated the conversations as mostly or extremely worthwhile and felt more heard and understood (+0.2 on 5-point scale, P = 0.04). The majority (95%) of clinicians agreed (somewhat, mostly, or completely) that conversations could be done in an appropriate amount of time and 97% agreed (somewhat, mostly, or completely) that the Guide provided information that enhances clinical care.

Interpretation: The SICP can be implemented on medical wards of hospitals and can have a positive impact on patient and clinician experience.
Introduction

Improvements in serious illness communication are a key priority to improve the quality of serious illness care in Canada. In a multicenter survey of 363 patients experiencing life-limiting illness at 7 Canadian hospitals, participants stated that clear, honest communication with their physicians, feeling heard and understood as a person, receiving emotional support, and feelings of peace are the aspects of their care they were least satisfied with but that were most important to them. However, hospital-based clinicians often do not engage in these conversations: in a subsequent multicenter audit of communication practices with 233 seriously ill patients in the medical wards of 9 Canadian hospitals, we found that guideline-recommended elements of goals-of-care discussions (e.g., disclosing prognosis, eliciting values, fears or concerns, and preferences for care) were addressed infrequently by hospital-based clinicians (range 1–32%). Furthermore, addressing more elements was associated with both greater concordance between patients’ preferences and prescribed goals of care, and greater patient satisfaction. In this study, we define a serious illness conversation as a discussion between a practitioner and a patient with a life-limiting illness, or their substitute decision maker(s), regarding their understanding, prognosis, values, goals, fears, and sources of strength. Commonly cited barriers to these conversations include a need for patients to have a better illness understanding, lack of time, and clinicians’ uncertainty about their own skills, to the point where some clinicians actively avoid these discussions.

To address these barriers and the gaps in communication practice identified in our previous work, we undertook a quality improvement initiative to adapt and implement the Serious Illness Care Program (SICP) on the medical wards of several hospitals in Canada. The SICP is a system-based communication intervention designed to improve the timing, quality, and frequency of conversations about values and preferences in serious illness care.
and goals with patients facing life-limiting illness. In a cluster randomized controlled trial conducted in an outpatient oncology setting, the program resulted in earlier and more frequent conversations with patients and sustained reductions in patient anxiety and depression. We hypothesized that the program was well-suited to address the aforementioned barriers and could be adapted for use in an inpatient setting. In this study, we report the impact of the SICP on patient and clinician experience when adapted and implemented on the medical wards of two teaching hospitals in Canada.

Methods

Setting
Medical wards of two Canadian teaching hospitals: Hamilton General Hospital, Hamilton, Ontario and Foothills Medical Centre, Calgary, Alberta (Table 1).

Design
Multisite quality improvement study.12

Intervention
Details of our adaptation and implementation of the SICP are reported elsewhere. The program consists of three main components: tools for clinicians, an educational component, and a system change component. Tools include a Previsit Letter for patients, the Serious Illness Conversation Guide and Clinician Reference Guide for clinicians, and a Family Communication Guide for patients and their families. The central communication tool is the Serious Illness Conversation Guide, hereafter referred to as the Guide, that is based on best practices in palliative care and provides patient-tested language for clinicians. The Guide addresses illness understanding, decision-making and information preferences, prognostic disclosure, patient goals, values and fears, views on acceptable function and trade-offs, and desires for family involvement. The educational component consists of a 2.5-h clinician training workshop that includes reflection, didactic teaching, skills practice using the Guide with standardized patients, and direct observation and feedback from expert faculty. Clinicians were eligible for training if they were attending physicians or social workers (or nurse practitioners, Hamilton site) on participating medical wards. System change refers to embedding processes in and making adjustments to existing workflow to enable these conversations in practice: identifying suitable patients, triggering clinicians to have serious illness conversations with eligible patients, delivering the conversation using the Guide, documenting the conversations in the medical record, giving participants the Family Communication Guide (Appendix 2) to support postconversation dialogue with family. The

Table 1. Characteristics of and implementation processes at participating sites

<table>
<thead>
<tr>
<th>Site characteristics</th>
<th>Hamilton General Hospital</th>
<th>Foothills Medical Center</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of participating medical wards</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Number of patient beds</td>
<td>100</td>
<td>28</td>
</tr>
<tr>
<td>Number of attending physicians working at a given time</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td><strong>Implementation processes</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinician training</td>
<td>2.5 h interactive skills practice session using the Serious Illness Conversation Guide (3:1 ratio of learners to expert facilitators; typically 6 learners per session)</td>
<td></td>
</tr>
<tr>
<td>Patient identification</td>
<td>InterRAI ED screener score of 5 or 6 and hospitalized for at least 48 h, or clinician selected</td>
<td></td>
</tr>
<tr>
<td>Age ≥ 65 years and hospitalized for ≥5 days, or clinician selected</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cueing clinicians for conversations</td>
<td>Unit Champion contacts clinicians via text message, phone, or in person</td>
<td></td>
</tr>
<tr>
<td>Preparing eligible patients or family members for conversations</td>
<td>Scripted or structured conversation</td>
<td></td>
</tr>
<tr>
<td>Delivering conversations*</td>
<td>Private meeting room</td>
<td></td>
</tr>
<tr>
<td>Documentation of conversations</td>
<td>Dictated structured notes transcribed into EMR</td>
<td></td>
</tr>
<tr>
<td>Advance Care Planning and Goals of Care Tracking Record in EMR</td>
<td></td>
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</tr>
</tbody>
</table>

EMR, electronic medical record.

*Residents or medical students were invited to attend serious illness conversations at the discretion of the attending physician. Occasionally, senior residents who had received skills practice training using the Serious Illness Conversation Guide (through separate training sessions offered through their residency training program) facilitated the conversation under the supervision of the attending physician.
program acknowledges that clinicians are busy, and therefore emphasizes the need for system change to create “protected time” for clinicians, that is, the frontline clinicians only need to focus on delivering and documenting the conversations. Table 1 summarizes the local adaptations of these processes at the two sites.

Patients were eligible if they were: (1) Hamilton site—hospitalized for at least 48 h with an interRAI Emergency Department Screener score of five or six (maximum score 6); (2) Calgary site—65 years or older and hospitalized for 5 days or more. Patients were also eligible if the attending physician believed that a serious illness conversation was a high priority. When patients did not have capacity to participate, substitute decision maker(s) were invited instead.

Quality improvement measures and data sources

Process measures
Unit champions collected real-time data on the number of eligible clinicians trained, number of eligible patients identified, number of eligible patients for whom we delivered a serious illness conversation, and number of conversations documented in the medical record.

Patient experience measures
We used the single-item measure “In the last 2 days, how much have you felt heard and understood by the doctors, nurses, and hospital staff?” that has been validated to evaluate palliative care quality improvement interventions. Response options were not at all, slightly, moderately, quite a bit, or completely. In addition, we used a seven-item questionnaire designed by the developers of the SICP to assess patient experience, in which patients (or family members) reported the impact of serious illness conversations on their understanding of what their health might be like in the future, sense of control over medical decisions, peacefulness, hopefulness about quality of life, sense of closeness with their clinician (response options were: decreased a lot, decreased somewhat, decreased a little, neither increased nor decreased, increased a little, increased somewhat, increased a lot). Patients also reported the extent to which the conversation was worthwhile (do not agree, somewhat agree, mostly agree, agree). Further, clinicians reported impact of the Guide on their anxiety in having these discussions, their patients’ emotional state (much worse, worse, slightly worse, neither worse nor better, slightly better, better, much better), and satisfaction with their role in patient care (greatly decreased, decreased, slightly decreased, neither increased nor decreased, slightly increased, increased, greatly increased). We collected clinician-reported measures by emailing trained clinicians an invitation to an online questionnaire, at least 6 months after they had completed their training (Appendix 4). We also conducted qualitative interviews with participating clinicians, the results of which are reported elsewhere.

Assessing contextual elements affecting implementation
We used the National Health Service Sustainability Model self-assessment tool to identify local factors that may influence the likelihood of continued project success at each site. The model consists of 10 factors related to process, staff, and organizational issues (Appendix 5). An overall score ≥ 55 suggests that a system intervention will have a high likelihood of sustained success, whereas a score <35 suggests that there are significant barriers to sustainability. To determine scores on the National Health Service Sustainability Model self-assessment tool, the implementation committees at each site led a face-to-face structured discussion, chaired by the site lead, to reach consensus on each item.

Statistical analysis
We used descriptive statistics to summarize patient and clinician characteristics. To assess change in responses to the “feeling heard and understood” question before and after a serious illness conversation, we used a paired t-test, as defined a priori, assigning the following values to the response options (1 = not at all, 2 = slightly, 3 = moderately, 4 = quite a bit, 5 = completely). We used counts and proportions to describe the distribution of responses to the questions on the patient and clinician experience questionnaires. In this study, we report data from two sites. We conducted exploratory subgroup analyses to examine differences in outcome measures between sites.
Although we implemented the program at four sites, one site ultimately developed different site-specific evaluation measures, which will be published elsewhere. The other site began work later and could not conduct formal evaluation because it first needed to channel resources into implementation and was then hampered by the global coronavirus pandemic.

**Ethics approval**

The Hamilton Integrated Research Ethics Board granted a formal written exemption from full review because the primary aim was deemed to be quality improvement. The initiative was fully reviewed and approved by Calgary’s Conjoint Health Research Ethics Board.

**Results**


**Implementation process measures**

Of 62 eligible clinicians (55 attending physicians, 4 nurse practitioners, 3 social workers), 57 (92%; 50 attending physicians, 4 nurse practitioners, and 3 social workers) completed clinician training. We delivered serious illness conversations for 334 (29%) of 1158 eligible patients. The following types of clinicians led the conversations: attending physicians 262 (78%), nurse practitioners 52 (16%), senior medical residents who had received training within their residency program and were supervised by trained attending physicians 16 (5%), social worker 1 (0.3%), unknown 3 (1%). Most conversations (n = 274, 82%) were documented in the medical record (Figure 1).

**Patient and family member experience**

The characteristics of the 334 eligible patients are reported in Table 2. In the majority of cases (n = 226, 68%), the patient was able to participate in the serious illness conversations, whereas 93 (28%) conversations were held with family member(s) alone (Table 3). Of the 334 conversations, a postconversation questionnaire was completed in 106 (32%) cases. Most of the respondents (80%) reported that conversations were worthwhile (mostly or extremely) and that they increased (a little, somewhat, a lot) their sense of control over their medical decisions (61%), peacefulness (60%), understanding of their life expectancy (65%), their sense of closeness to their clinician (62%), and understanding of what their health may be like in the future (75%). Approximately half (52%) of the respondents reported an increase in hopefulness, whereas 21% reported a decrease in hopefulness after the conversation (Figure 2).

The pre- and postconversation ratings of the heard and understood item were completed in 99 (30%) of 334 cases. Mean ratings before and after were 3.9 and 4.1, respectively (1 = not at all, 5 = completely), corresponding to a mean increase of 0.2 (95% CI 0.0 to +0.4, P = 0.04) after the serious illness conversation (Figure 3).

In exploratory subgroup analyses, we did not find appreciable differences in patient experience responses between sites (data not shown); however, we did find a significantly different effect of conversations on feeling heard and understood between sites; in Hamilton, mean scores before and after were 3.2 and 4.0, respectively (mean change +0.8, 95% CI +0.4 to +1.3, P = 0.002), versus in Calgary, mean scores before and after were 4.1 and 4.1, respectively (mean change 0.0, 95% CI –0.2 to +0.2, P = 0.90) (P = 0.001 for interaction).

**Clinician experience**

Of the 57 clinicians who received training, 39 (68%) completed the clinician experience questionnaire (33 attending
Clinicians perceived that, in general, discussions using the Guide improved their patients’ emotional state (73%). Overall, 82% of clinicians reported that their satisfaction of their role in their patients’ care increased (Figure 4). There were no appreciable differences in clinician experience by site (data not shown).

National Health Service Sustainability Model

Figure 5 and Appendix 5 show site scores on the National Health Service Sustainability Model. Total sustainability scores were 46.4 in Hamilton and 59.4 in Calgary (an overall score $\geq 55$ suggests that a system intervention will have a high likelihood of sustained success, whereas a score $<35$ suggests that there are significant barriers to sustainability). At both sites, the factors with the lowest scores indicating the greatest opportunity for improvement were senior leadership engagement and support, and infrastructure for sustainability.

Discussion

We found that the SICP can be adapted and implemented on medical wards of hospitals. Clinicians found the Guide was easy to use, feasible to complete in an appropriate amount of time and had a positive impact on clinical care. Patients and families who responded to study questionnaires found the conversations worthwhile, with increase in illness understanding, peacefulness, sense of control over medical decisions, closeness with their clinician and, in some cases, feeling more heard and understood.

In contrast to most other communication tools in the field of advance care planning, the SICP has high quality evidence to support its effectiveness, with a cluster randomized controlled trial in outpatient oncology demonstrating more frequent, higher quality and earlier conversations, and sustained reductions in patient anxiety and depression compared to usual care. Further analyses also found the intervention was acceptable and useful to clinicians and improved patient experience. However, the hospital differs in important ways from the outpatient clinic. For instance, most hospital clinicians do not have a longitudinal relationship with their patients, requiring rapid rapport-building to engage in serious illness conversations. Also, because of acute symptoms, hospitalized patients may be less able to participate in these conversations, and families’ attention may be more focused on treatment of the acute problem. Therefore, the

<table>
<thead>
<tr>
<th>Table 2. Characteristics of 334 eligible patients for whom the patient and/or family member received a serious illness conversation</th>
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<tbody>
<tr>
<td><strong>Eligible patients</strong> (N = 334)</td>
</tr>
<tr>
<td>Age, years, Mean (SD), (n = 334)</td>
</tr>
<tr>
<td>Gender, n (%)</td>
</tr>
<tr>
<td>Male</td>
</tr>
<tr>
<td>Female</td>
</tr>
<tr>
<td>Missing</td>
</tr>
<tr>
<td>Frailty score*, median (IQR), (n = 269)</td>
</tr>
<tr>
<td>English speaking, n (%)</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>Missing</td>
</tr>
<tr>
<td>Cognition, n (%)</td>
</tr>
<tr>
<td>Oriented</td>
</tr>
<tr>
<td>Not oriented**</td>
</tr>
<tr>
<td>Missing</td>
</tr>
<tr>
<td>Patient living alone, n (%)</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>Missing</td>
</tr>
<tr>
<td>Marital status, n (%)</td>
</tr>
<tr>
<td>Never married</td>
</tr>
<tr>
<td>Married or living as married or common-law</td>
</tr>
<tr>
<td>Widowed</td>
</tr>
<tr>
<td>Divorced, separated, or never married</td>
</tr>
<tr>
<td>Missing</td>
</tr>
</tbody>
</table>

*Clinical Frailty Score by Rockwood et al. $1 = $very fit$, 2 = fit$, 3 = managing well$, 4 = living with very mild frailty$, 5 = living with mild frailty$, 6 = living with moderate frailty$, 7 = living with severe frailty$, 8 = living with very severe frailty$, 9 = terminally ill$.**Substitute decision makers participated in conversations if the patient lacked capacity.

<table>
<thead>
<tr>
<th>Table 3. Participants in serious illness conversations</th>
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</thead>
<tbody>
<tr>
<td>Conversations (N = 334)</td>
</tr>
<tr>
<td>Patient alone</td>
</tr>
<tr>
<td>Patient and family member(s)</td>
</tr>
<tr>
<td>Family member(s) alone</td>
</tr>
<tr>
<td>Missing information</td>
</tr>
</tbody>
</table>

All data are reported as numbers (%).

physicians, 3 nurse practitioners, and 3 social workers). All clinicians agreed that the Guide was easy to use, with 95% agreeing (somewhat, mostly, fully) that the Guide can be used in an appropriate amount of time. Clinicians also agreed that the Guide allowed them to gather important information (100%), helped them understand patients’ values and goals of care (100%), helped build a trusting clinician–patient relationship (100%), and provided information that enhanced clinical care of their patients (97%).
benefits of the SICP cannot be assumed to generalize to the inpatient setting.

However, in a chart review of early data from our hospital-based implementation, we found that serious illness conversations during the intervention phase were of higher quality than among historical controls. Our current findings suggest that the SICP is adaptable to hospital medical wards without compromising known benefits to patient and clinician experience. Our study also extends previous studies by showing that serious illness conversations delivered by hospital teams (not palliative care consultants) can result in an improvement in patients feeling heard and understood, a validated quality measure for palliative care.

Clinicians often cite lack of time and training, a fear of destroying patients’ hope and increasing their anxiety as barriers to serious illness conversations. However, our findings suggest that the Guide can be completed in an appropriate amount of time. Although we did not measure conversation duration, others reported a median duration of 14 min (from audio-recorded conversations in the original trial), and clinician-reported durations of 22 min (physician-led) to 26 min (nurse-led) in primary care, which is anecdotally similar to our experience. In addition, more important than the absolute duration of the conversations is their acceptability to clinicians. In our study, a majority (95%) of clinicians agreed (somewhat, mostly, or completely) that conversations could be done in an appropriate amount of time. Importantly, in our study, most patients reported feeling more hopeful, more...
Figure 4. Responses to clinician experience questionnaire.

Figure 5. Summary of scores on the National Health System Sustainability Model at the (a) Hamilton site and (b) Calgary site.
peaceful and, in some cases, more heard and understood after having serious illness conversations with their hospital clinician. While the majority reported positive experiences, 21% did report a decrease in hopefulness, consistent with the implementation of this program in the oncology setting; however, the oncology trial also found sustained, statistically significant, and clinically meaningful reductions in patient anxiety and depression at 6-months follow-up, suggesting that initial reports of decreased hopefulness are either transient, are outweighed by other benefits of the conversation, or that there may still be an opportunity to further enhance the positive impact of these conversations (e.g., by providing longitudinal communication skills coaching to clinicians after initial training). Nevertheless, the overall positive impact we observed demonstrates that clinicians who do not have a prior relationship with patients can nonetheless develop rapport rapidly using the tool and that this is not a barrier to meaningful conversations.7

At a health system level, the RE-AIM framework offers one approach to assess our efforts to translate research into action. The framework delineates five domains: reach, effectiveness, adoption, implementation, and maintenance.25 We were able to generate high rates of clinician participation in training and adoption of the Guide in practice. When used, we observed more accessible documentation of conversations in the medical record, and, among survey responders, positive experiences on clinicians, patients, and families. Yet, conversations reached only one-third of the eligible population. Very few eligible patients declined to engage in a serious illness conversation when invited. Therefore, there were other reasons for the limited participation of all eligible patients. First, although we found personal “nudges” from Unit Champions were effective in prompting conversations, we needed to balance this with alert fatigue and a need to maintain collaborative relationships with frontline clinicians. Second, although clinicians rated the Guide as feasible to complete, the full process of identifying an eligible patient, prompting the clinician, scheduling, and delivering the conversation still take time, and sometimes were interrupted by patient discharge, transfer to another unit, attending physician leaving the service or, rarely, death of the eligible patient. Finally, despite excellent uptake of clinician training (92%), once on the ward, clinicians ranged from high adopters to avoidant which limited our reach to all eligible patients. Although we did approach our initial goal of clinicians having one conversation per week, our reach to 30% of eligible patients highlights that the number of patients who could potentially benefit may outstrip the capacity to have these conversations in a hospital setting. It may be more useful to view these conversations as part of an ongoing process, requiring additional engagement of primary care and outpatient practitioners. Finally, to maximize sustainability, we found that both sites need to focus on senior leadership engagement and support, and infrastructure for sustainability. There are considerable resources needed for training and identification of patients which need leadership support. For instance, our implementation relied on external funding of a Unit Champion (0.5 to 1.0 full-time equivalent of a ward nurse’s salary) to facilitate various key processes, including identifying eligible patients, nudging clinicians to have serious illness conversations, and scheduling a time for the conversations to occur. Our experience so far suggests that senior leadership is very willing to voice moral support and affirmation about the importance of this work; however, ongoing commitment of organizational resources to ensure sustainability is less clear. Although one conceptually attractive option is to embed processes and roles into the existing envelope of funding for medical programs, it is unclear whether the impacts we observed could be achieved without some minimum amount of funding. Future work could examine strategies to maximize the feasibility and efficiency of implementation to create opportunity for larger scale spread and impact of this intervention.

Our study has limitations. First, the patient or family member response rate to questionnaires was approximately 30%. Although missing responses were often due to factors unlikely to correlate with patient experience measures (e.g., discharge, transfer to another service, death), it remains possible that nonresponders were systematically different from responders. Second, we observed a ceiling effect on the feeling heard and understood measure, suggesting that other outcome measures may be required to determine the impact on patient experience. Third, we did not measure the impact of the program on behavioral outcomes such as greater engagement in advance care planning activities. This could be an area for future research. Fourth, we did not measure impact of the conversations on subsequent system outcomes, such as readmission rates and emergency room use.26 Finally, we conducted our implementation at Canadian teaching hospitals, so our experience may not be generalizable to other hospitals or settings.

In conclusion, the SICP, originally designed for outpatient oncology setting, can be adapted and implemented on medical wards of hospitals and can have a positive impact on patient and clinician experience. Further work is warranted.
to determine how to efficiently implement, spread, and sustain this intervention in other hospitals.

**Acknowledgments**

The authors would like to thank Shelley Weniger and Jocelyn Semenchuk for all the time and energy they devoted to the implementation of the Serious Illness Care Program as Unit Champions on their respective medical wards.

**Author Contributions**

You, Simon, Swinton, Ma, Dunne, Jayaraman, Kobewka, and Munene contributed to the conception or design of the work. Singh, Swinton, Lagrotteria, Paladino, and Bernacki contributed to acquisition, analysis, and interpretation of data. You and Singh were involved in the drafting of the work, and Simon, Swinton, Ma, Dunne, Jayaraman, Kobewka, Munene, Lagrotteria, Paladino, and Bernacki contributed to the critical revision for important intellectual content. All authors gave final approval of the version submitted for publication.

**Disclosures**

None of the authors have conflicts of interest to disclose.

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**References**


Appendix 1. Serious Illness Conversation Guide

Serious Illness Conversation Guide

CONVERSATION FLOW

1. **Set up the conversation**
   - Introduce purpose
   - Prepare for future decisions
   - Ask permission

2. **Assess understanding and preferences**

3. **Share prognosis**
   - Share prognosis
   - Frame as a “wish...worry”, “hope...worry” statement
   - Allow silence, explore emotion

4. **Explore key topics**
   - Goals
   - Fears and worries
   - Sources of strength
   - Critical abilities
   - Tradeoffs
   - Family

5. **Close the conversation**
   - Summarize
   - Make a recommendation
   - Check in with patient
   - Affirm commitment

6. **Document your conversation**

7. **Communicate with key clinicians**
Serious Illness Conversation Guide

PATIENT-TESTED LANGUAGE

SET UP

“I’d like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want — is this okay?”

“What is your understanding now of where you are with your illness?”

“How much information about what is likely to be ahead with your illness would you like from me?”

“I want to share with you my understanding of where things are with your illness…”

Uncertain: “It can be difficult to predict what will happen with your illness. I hope you will continue to live well for a long time but I’m worried that you could get sick quickly, and I think it is important to prepare for that possibility.”

OR

Time: “I wish we were not in this situation, but I am worried that time may be as short as ___ (express as a range, e.g. days to weeks, weeks to months, months to a year).”

OR

Function: “I hope that this is not the case, but I’m worried that this may be as strong as you will feel, and things are likely to get more difficult.”

EXPLORE

“What are your most important goals if your health situation worsens?”

“What are your biggest fears and worries about the future with your health?”

“What gives you strength as you think about the future with your illness?”

“What abilities are so critical to your life that you can’t imagine living without them?”

“If you become sicker, how much are you willing to go through for the possibility of gaining more time?”

“How much does your family know about your priorities and wishes?”

CLOSE

“I’ve heard you say that ___ is really important to you. Keeping that in mind, and what we know about your illness, I recommend that we ___. This will help us make sure that your treatment plans reflect what’s important to you.”

“How does this plan seem to you?”

“I will do everything I can to help you through this.”
Appendix 2. Family Communication Guide

Talking about your illness with loved ones and caregivers

This booklet can help you talk with your loved ones about your illness and the future. It is based on what you have already talked about with your clinician.

Talking about your illness with friends and family may not be easy, but it will help them understand what is important to you. It will also help them support you and your decisions.

Before you talk to your loved ones, think about when and where you want to talk. Choose a time and place when you feel relaxed. Be sure you have time to talk for a while. You can use the words in this guide, or use your own words — whatever is easier for you.
I am doing OK right now, and even though there is no rush, my doctors think we need to begin talking about my future care.

They believe in being prepared and want to know my goals and wishes for medical care.

Since you are important to me, I'd also like you to be part of the conversation.

If at some point I can’t speak for myself, I want you to be able to make decisions for me.

Start the conversation

Check in with your loved one

UNDERSTANDING
What is your understanding now of where I am with my illness?

INFORMATION
I know that it may not be easy, but I would like to share information about my illness with you. Is that okay?

How much information about what is likely to be ahead would you like from me?

My doctor and I talked about the outlook for my illness—can I share that with you?
Share what is important to you

**GOALS & WISHES**
I'd like to share some of my goals that might affect my healthcare decisions. Some things I’m looking forward to are...

**EXAMPLES:** Meet my new grandchild, celebrate my next birthday, etc.

**FEARS & WORRIES**
My biggest fears and worries about my future with this illness are...

**EXAMPLES:** Not being able to make decisions for myself, or having to ask others for help with basic needs.

**ABILITIES**
I can’t imagine not being able to do certain things...

**EXAMPLES:** Not being able to recognize or interact with people, not being able to care for myself, etc.

**TOUGH CHOICES**
I know that we may have to choose between treatments that are hard to go through and more time.

**EXAMPLES:** Being in the hospital, having a feeding tube, living in a nursing home, being on a breathing machine, more chemotherapy, etc.

*Here’s how I think about those choices...*

Plan to talk again

Do you have any questions about what we have discussed?

I would like to talk with you about my illness and medical care as my treatment continues. Is that okay?

I know this was probably not an easy conversation. How do you feel now that we have talked?

Are there other people we should talk with?

*Remember to talk again with your loved ones / caregivers as your situation or wishes change*
NOTES
You can use this page to write down ideas from your talk, questions for your clinician, or any other thoughts.
Serious Illness Care Program Patient Experience Survey Form: Pre-Conversation

Over the past two days, how much have you felt heard and understood by the doctors, nurses, and hospital staff?

☐ Completely
☐ Quite a bit
☐ Moderately
☐ Slightly
☐ Not at all

SICP ID: ________
Serious Illness Care Program Patient Experience Survey Form

Yesterday you had a conversation with your doctor/Nurse Practitioner about your wishes for your future care. Think about that conversation and answer the following questions. Please select the response that best matches your answer.

<table>
<thead>
<tr>
<th>To what extent did this conversation increase or decrease...</th>
<th>Decreased a lot</th>
<th>Decreased somewhat</th>
<th>Decreased a little</th>
<th>Neither increased nor decreased</th>
<th>Increased a little</th>
<th>Increased somewhat</th>
<th>Increased a lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>your understanding of what your health may be like in the future</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>your sense of control over your medical decisions</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>the closeness you have with your clinician</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>your hopefulness about your quality of life</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>your understanding about your life expectancy</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>your sense of peacefulness</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
</tbody>
</table>

Over the past two days, how much have you felt heard and understood by the doctors, nurses, and hospital staff?

☐ Completely
☐ Quite a bit
☐ Moderately
☐ Slightly
☐ Not at all

Overall, how worthwhile was it to talk about these issues with your doctor (or Nurse Practitioner)?

☐ Not at all
☐ Somewhat
☐ Mostly
☐ Extremely
What, if anything, do you think you might do differently as a result of this conversation?

___________________________________________________________________________________________
___________________________________________________________________________________________
___________________________________________________________________________________________
___________________________________________________________________________________________
___________________________________________________________________________________________
___________________________________________________________________________________________
___________________________________________________________________________________________
___________________________________________________________________________________________
___________________________________________________________________________________________
Appendix 4. Clinician survey instrument

Clinician Experience

Clinician discipline (circle one): MD / NP / PA / RN / SW / Other: _____________ Date: __ /__ /__
Clinician Name: ___________________________________________________________
Clinician Specialty: _______________________________________________________
Clinic name: ______________________________________________________________

Are you using the Serious Illness Conversation Guide? Yes/No

If No, rate from 1 to 3 your top 3 reasons for not having serious illness conversations (1 is the most important reason, 3 is the least important reason):

- Insufficient time
- I don’t feel prepared to have the conversation
- I don’t want my patient to be anxious or depressed
- I don’t have a copy of the Guide when I need it
- I don’t want to take away my patient’s hope
- I’m unsure about the right time to have this conversation
- Other: _______________________

If Yes →

To what extent you agree with the statement.

<table>
<thead>
<tr>
<th>The Serious Illness Conversation Guide...</th>
<th>Do not Agree</th>
<th>Somewhat Agree</th>
<th>Mostly Agree</th>
<th>Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Allows me to gather important information.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Is easy to use.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Helps me understand my patient’s values and goals of care.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Provides information that enhances my clinical care of this patient</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Helps build a trusting clinician-patient relationship</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Can be done in an appropriate amount of time</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

In general, when I finish the discussion using the Serious Illness Conversation Guide, I think the conversations result in the patients’ emotional state being:

- Much better
- Better
- Slightly better
- Neither worse nor better
- Slightly worse
- Worse
- Much worse

Overall, how much did your discussion of these issues with your patients increase or decrease your satisfaction with your role in your patients’ care?

- Greatly decreased
- Decreased
☐ Slightly decreased
☐ Neither increased nor decreased
☐ Slightly increased
☐ Increased
☐ Greatly increased

In general, The Serious Illness Conversation Guide has made my anxiety about having these discussions:
☐ Much better
☐ Better
☐ Slightly better
☐ Neither worse nor better
☐ Slightly worse
☐ Worse
☐ Much worse
☐ I do not have anxiety about these discussions
Appendix 5. National Health Service Sustainability Model scores for each site

<table>
<thead>
<tr>
<th>Domain</th>
<th>Factor</th>
<th>Calgary</th>
<th>Hamilton</th>
<th>Maximum score</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Process</strong></td>
<td>Benefits beyond helping patients</td>
<td>4.0</td>
<td>4.7</td>
<td>8.5</td>
</tr>
<tr>
<td></td>
<td>Credibility of the evidence</td>
<td>6.3</td>
<td>6.3</td>
<td>9.1</td>
</tr>
<tr>
<td></td>
<td>Adaptability of improved process</td>
<td>3.4</td>
<td>2.4</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Effectiveness of the system to monitor progress</td>
<td>3.3</td>
<td>2.4</td>
<td>6.5</td>
</tr>
<tr>
<td></td>
<td><strong>Overall Process Domain Score</strong></td>
<td>17</td>
<td>15.8</td>
<td>31.1</td>
</tr>
<tr>
<td><strong>Staff</strong></td>
<td>Staff involvement and training to sustain the process</td>
<td>6.3</td>
<td>6.3</td>
<td>11.4</td>
</tr>
<tr>
<td></td>
<td>Staff behaviours towards sustaining the change</td>
<td>5.1</td>
<td>5.1</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>Senior leadership engagement and support</td>
<td>5.7</td>
<td>5.7</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>Clinical leadership engagement and support</td>
<td>15</td>
<td>6.7</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td><strong>Overall Staff Domain Score</strong></td>
<td>32.1</td>
<td>23.8</td>
<td>52.4</td>
</tr>
<tr>
<td><strong>Organization</strong></td>
<td>Fit with the organization’s strategic aims and culture</td>
<td>7</td>
<td>3.5</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Infrastructure for sustainability</td>
<td>3.3</td>
<td>3.3</td>
<td>9.5</td>
</tr>
<tr>
<td></td>
<td><strong>Overall Organizational Domain Score</strong></td>
<td>10.3</td>
<td>6.8</td>
<td>16.5</td>
</tr>
<tr>
<td></td>
<td><strong>Total Sustainability Score</strong></td>
<td>59.4</td>
<td>46.4</td>
<td>100</td>
</tr>
</tbody>
</table>