Oregon Health & Science University
School of Medicine

Scholarly Projects Final Report

Title *(Must match poster title; include key words in the title to improve electronic search capabilities.)*

Providing Goal-Concordant Care to Seriously Ill Patients: Patient Experiences of the Serious Illness Conversation Guide in a Primary Care Setting

Student Investigator's Name

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Graduation Year

2022

Project Course *(Indicate whether the project was conducted in the Scholarly Projects Curriculum; Physician Scientist Experience; Combined Degree Program [MD/MPH, MD/PhD]; or other course.)*

Scholarly Projects

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Scholarly Project Final Report

Concentration Lead's Name

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Project/Research Question

1) Understand patient attitudes/experiences with the Serious Illness Conversation
2) Assess how this conversation may have impacted the patient's relationship with their provider (strengthen, neutral, worsen)
3) Determine if patient's felt their care was meeting their goals/values after this conversation, and did they feel it would help their care in the future.

Type of Project *(Best description of your project; e.g., research study, quality improvement project, engineering project, etc.)*

Research Study

Key words *(4-10 words describing key aspects of your project)*

Serious Illness Conversation Guide, Advanced care planning, patient experience, therapeutic alliance

Meeting Presentations

If your project was presented at a meeting besides the OHSU Capstone, please provide the meeting(s) name, location, date, and presentation format below (poster vs. podium presentation or other).

Oregon Academy of Family Physicians, Virtual Annual Conference, April 24, 2021, poster

Publications *(Abstract, article, other)*

If your project was published, please provide reference(s) below in JAMA style.

None

Submission to Archive

Final reports will be archived in a central library to benefit other students and colleagues. Describe any restrictions below (e.g., hold until publication of article on a specific date).

Next Steps

What are possible next steps that would build upon the results of this project? Could any data or tools resulting from the project have the potential to be used to answer new research questions by future medical students?

The next steps will be continued analysis of quantitative chart review and case reports for patients who died within the duration of the study which will be conducted by me and the research team. Next steps could be understanding provider attitudes and experience with the SICG.

Please follow the link below and complete the archival process for your Project in addition to submitting your final report.

https://ohsu.ca1.qualtrics.com/jfe/form/SV_3Is2z8V0goKiHZP

Student's Signature/Date *(Electronic signatures on this form are acceptable.)*

This report describes work that I conducted in the Scholarly Projects Curriculum or alternative academic program at the OHSU School of Medicine. By typing my signature below, I attest to its authenticity and originality and agree to submit it to the Archive.

X ______________________________

Student's full name

Mentor's Approval *(Signature/date)*

Scholarly Project Final Report

Report: *Information in the report should be consistent with the poster, but could include additional material. Insert text in the following sections targeting 1500-3000 words overall; include key figures and tables. Use Calibri 11-point font, single spaced and 1-inch margin; follow JAMA style conventions as detailed in the full instructions.*

Introduction *(≥250 words)*

End-of-life discussions are necessary to ensure patients receive the care they want without undergoing unnecessary or harmful treatments[1-5]. Patients with serious illnesses are often faced with complex care decisions, which can be complicated by inadequate communication and physical and emotional distress[6]. This can lead to patients receiving interventions that do not align with their priorities and preferences[1,7]. While Advanced Directives can be useful, they have not shown efficacy in consistently ensuring patients receive the care they want at the end of life, perhaps because they focus solely on medical procedures and do not capture information on patient values, goals, and preferences for their care[8,9]. Further, early discussion of patient preferences and values has been shown to decrease anxiety and depression in patients at the end of life[8,9]. Thus, other tools are needed to evaluate beyond what medical procedures a patient would want and have those preferences adequately documented for entire care teams.

The Serious Illness Conversation Guide (SICG) was developed by a team of palliative care experts at Ariadne Labs to provide support for clinicians hoping to engage in these discussions with their patients[14,15]. Thus far, research has shown improvements in psychological symptoms such as anxiety and depression,[10] but has not evaluated how patients experience these conversations in a primary care setting or how it might impact their relationship with their provider. Our objectives were to: 1) Better understand patient experiences discussing end-of-life preferences using the Serious Illness Conversation (SIC) with their provider and 2) Understand how it may have impacted their relationship with their provider.

Methods *(≥250 words)*

This study was a qualitative research study using semi-structured patient interviews for descriptive analysis of the patient cohort. The participating clinic is part of a multi-institutional, cluster-randomized control trial assessing the utility of the SICG in the primary care setting. The intervention group of clinicians at the Oregon Health and Science University (OHSU) General Internal Medicine clinic received a 2.5-hour training to use the SICG to support having serious illness conversations with their patients.

Patients eligible for inclusion were 18 years of age or older, living with a serious illness, and assessed by a trained clinician that answered “No” to the question: “Would you be surprised if this patient died within the next year?” Patients with a diagnosis of dementia were excluded. Patients were recruited in the OHSU General Internal Medicine clinic by participating clinicians. There were 39 participants enrolled in this study, of which 18 were interviewed. Patients were asked the following five questions: 1) How did you feel about having the Serious Illness Conversation/Advanced Care Planning discussion with your provider? What was this conversation like for you? 2) Did having this conversation impact your relationship with your provider? If so, how? 3) Do you feel your treatment plans have been changed since having this discussion to meet your goals? 4) Do you feel your goals are currently being met for your treatment? 5) Do you feel confident your goals will be met in the future after having this discussion?

Interviews were audio recorded, transcribed, and coded using the “Human Connection Score” and “Serious Illness Conversation Guide” as validated tools to code the interviews. These codes were then analyzed for thematic analysis using Dedoose software by two independent coders. The goal of this qualitative analysis was to describe the therapeutic alliance of patients and providers following the serious illness conversation.

Results *(≥500 words)*

Eighteen patients were interviewed out of 39 enrolled in the randomized control trial. Thematic analysis revealed the following seven themes:

Necessity of Advanced Care Planning Discussion

Most patients expressed that discussing advanced care planning with their doctor was “necessary”. One participant said *“I think that it is something that your doctor must know. You know, how [I] feel about that...it’s [that] they must know!”* Some participants stated they valued the opportunity to share their wishes and preferences for their treatment should they be unable to express these wishes. One patient noted, *“I thought it was very important so that she knows my wishes before anything would happen to me.”* And another stated, *“I think it was nice because the thing is... that sometimes if I come in and... I’m out of it, at least he’ll know what to do. I mean, you know, what my wishes are.”*

Importantly, many participants conveyed that they expected their provider to discuss these conversations, *“I mean, it’s kind of like a part of her job, and I expect to have those conversations every so often if it’s unclear what she thinks my priorities are.”*

Clarity of Language

While many patients reported having positive to neutral reactions to these discussions with their provider, few noted their confusion and/or misunderstanding of the language used by the provider in the Serious Illness Conversation. One patient noted, *“I mean it’s silly to talk about goals [with] your doctor. We talked about it, and she did use the word goal. But, as far as I'm concerned, it’s just information.”* This same patient went on to explain that *“We talk about issues that… I wouldn’t call them goals. I would say I don’t go to the doctor to get goals. I go to the doctor because I have things to talk about. A medical issue.”*

When asked for further clarification, the participant did not understand what type of “goals” one might have, *“Well, as I said she mentioned goals and I didn’t have an argument with her, I just said yes, yes, yes. But, uh, I don’t know what goals. Could I have a goal of returning to age 50 instead of 80? You know?”* Additionally, another patient noted, *“I have no goals at my age. Obviously. My goals have been met and I'm in the backwaters of life, just enjoying the sunsets.”*

Trust/Security with Provider

Many participants reported feeling “secure” in their relationship with their provider. One stated*, “I guess I'm just secure. And we get along.”* Another participant shared that having the conversation even improved her feelings of secureness and trust, *“It just made me feel more secure that she was there to back me up and to know that what I was doing was right.”*

A few patients noted they did not experience any discomfort having this discussion with their provider, *“Because she is always there when I need her.”* In reference to their confidence in their provider for their future goals to be met, one participant said*, "I feel comfortable because I have complete confidence in her and I know everything she talks to me about is for my welfare."*

Many felt that their provider went above and beyond when listening to their concerns. Two participants articulated their relationship was strong due to these characteristics, *"Because she is a fabulous listener and really cares for her patients. I mean, I always feel very confident that she is proactive, and interested and really cares for her profession and for her patients."* Another noted, "*I think the thing is the fact that he is all [ready] to discuss almost anything, and he is really good at listening to what you really have to say. And he will verify that he's hearing it correctly."*

Valued Time Spent

Several participants reported they appreciated the amount of time their provider took to walk them through the conversation. One participant said, *"[It was] thought-provoking in that...she took the time to guide me through it. What all those questions really meant. As opposed to doing it on your own and just saying 'Oh, it's fine.'"* Another participant stated, *"Well, he doesn't seem to rush through things. You know when he's talking to me."* Others took note of the quality of the time their provider spent saying, "*She was very, very attentive on things. And was very concerned and spent her whole attention on me. There is nothing bothering her, there's no coffee time bothering her. There's no going away time bothering her. There's no other patients banging away inside her skull. She was right there with me all the way."*

Some participants voiced that they felt doctors don't typically have enough time to have in-depth conversations on a regular basis. One participant said, "*There just simply doesn't seem to be enough time overall. There was time during that visit because it was, you know, planned for, but generally doctors every doctor now have such a patient load that it's hard to cover, you know, these concerns as well as attention to the medical end of it."* And another mused, *"I wonder if every doctor has time to do that kind of thing."*

Deepened Patient-Provider Relationship

While many participants noted they had a good relationship with their provider, many noted that they had a prior positive relationship. *"We've had a good relationship and been open with one another and, yeah, it just added another piece to it,"* said one participant. Another noted that while they felt their relationship with their provider was already strong prior to the SIC, the conversation strengthened that impression, *"I have really positive feelings about Dr. X. So, if anything, it just reinforced those feelings."*

When asked about the relationship with provider prior to discussion many reported having a strong relationship at baseline. *"Yeah, I've always had that feeling with her. I don't see this as being a new thing,"* and another noted, *"We have a very close relationship."* When asked about their feelings having the advanced care planning discussion, one participant said, *"Well, I love (my provider) so I could discuss anything with her."*

Ability to be Open and Honest

Patients expressed that their relationship allowed them to be open with their doctor regarding their preferences, *"I mean... I'm not going to doctor to hold back information, or not talk about certain issues. I have been very happy with her. I told her how I felt. She is quite open and honest to me. And that's one of the reasons why I like her*."

Another noted that their relationship allowed them to feel comfortable discussing the topics of the SIC, *"And I don't mind sharing with her what I feel like...to me [it] was more of a friend, friendly conversation we would have at any time."* Others noted that their longstanding relationship made it more comfortable having the discussion with their provider, *"I said we've known each other a long time. And I'm not always just real quiet about my answers."*

Others reported they felt the honesty worked both ways, that they could expect their provider to be honest with them in the future, *"I realize that my circumstances will change. And I also think that... I trust Dr. X to be realistic with me...when that changes and that if I ask for things that aren't realistic anymore."* The same participant further explained, *"If the kids, if they had more information than I did, I'm not sure they would be honest with me. Dr. X, on the other hand, will be very honest with me."*

A few patients also noted they appreciate their doctor being non-judgmental about their values which in turn helped them feel they could be honest about their preferences. One patient said, *"I'm not interested so much in extending my life. Like I'm not fearful of death. I appreciate her for taking my comment that I'm not clinging to life… I'm not going to change my life in any big way just because I think it's going to extend the number of years that I live."* And another patient, *"And I, you know, even though I have the tattoo, you know, 'Do not resuscitate' and I believe have discussed with her and other doctors what that means to me."*

Confidence in Provider to Respect End-of-Life Wishes

When asked if patients were confident that their goals would be met in the future after having this discussion with their provider, many remarked they felt confident in their provider in having their goals met. Per one patient's experience, *"And I'm comfortable and I am absolutely confident that when the time comes to deal with the end-of-life stuff the plan is in place and will be carried out."*

However, not all patients were absolutely certain their wishes would be respected if their provider was not present to advocate for them, one patient said, *"I think when the times comes if [my doctor] is around I know she'll see that I'm well taken care of and what is done is going to be right and, you know, so I feel perfectly confident about that."* Another patient noted that despite filling out a POLST, they still did not feel fully confident their wishes would be respected, *"My POLST is hanging on the back of my front door. Now, whether anybody pays attention to it in the moment of crisis. I don't know. "*

A few patients noted that having their preferences documented in the electronic health record increased their confidence in their wishes being followed. One patient noted, *"It's in my file that I don't want to be resuscitated under certain conditions, so I think everybody will honor that."* And another noted, *"He's [the provider] really good at documenting what our conversations are so they're in the record and so that even if he's not there...there is somebody who can read it you know and that kind of thing."*

A few felt they could trust their doctor both with treatment plans in the future, and with providing the honest information, *"I feel that I can trust him to try to do what I want. You know, when I finally have to say, 'I'm tired. I don't want to do this anymore.'"* When asked about future treatment, the same patient responded, *"I realize that my circumstances will change. And I also think that... I trust Dr. X to be realistic with me…when that changes and that if I ask for things that aren't realistic anymore."*

Most patients (83.3%) shared a positive experience regarding these discussions (Fig. 1). Eight patients reported feeling a strengthened relationship with their provider (Fig. 1). While 10 respondents indicated no change in their patient-provider relationship, six reported already feeling a strong therapeutic alliance (Fig. 1). Most interviewees did not indicate a change in their treatment plans following the SIC, but 88.9% felt their goals were currently met (Figure 2). Patients expressed confidence that their end-of-life wishes would be followed and respected.

Figure 1. Patient-Provider Therapeutic Alliance

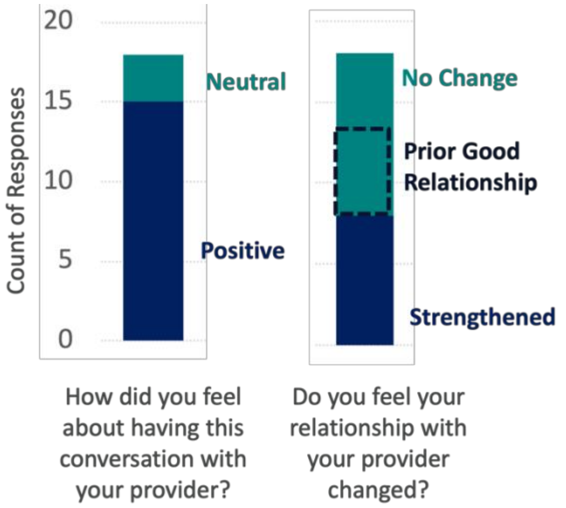
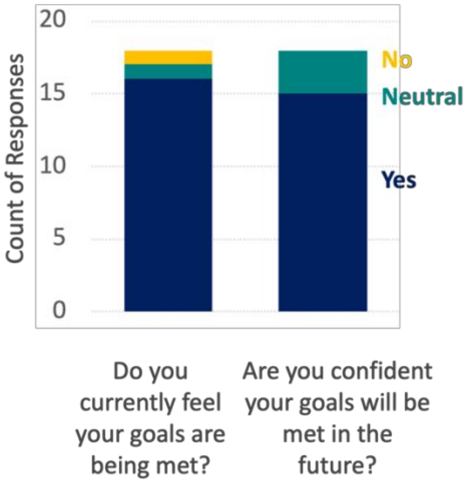


Figure 2. Patient-reported goal concordant care



Discussion *(≥500 words)*

Descriptive analysis of qualitative interviews indicated that patients felt positive overall about having the Serious Illness Conversation with their provider. These results indicate that most patients in this cohort felt it was a necessary conversation to have, and most even expected to have it with their provider. Many felt that the SIC gave them an opportunity to express their wishes and preferences for their treatment, which also may be related to many patients feeling trust in their provider and confidence in their wishes being followed in the future after having this discussion. Notably, some even mentioned feeling more confident knowing their wishes were recorded in the electronic health record. However, not all patients felt the same level of confidence, as one patient noted that even after filling out a POLST, they did not express full confidence it would be followed if their provider was not present/available.

Of note, some patients did have some confusion surrounding the use of the term “goal” when discussing advanced care planning, preferences, and values for their care. Many reported that at their age they “did not have any goals” remaining, and that raised confusion. One participant even noted that they just went along with their provider when using the term “goal” in this discussion. These results may indicate there is some disparity and incongruence of language used by patients and providers and may require further inquiry on the use of these terms in the SIC.

This patient cohort indicated they felt an overall positive interaction with their provider when having this discussion. Many patients noted that prior to this conversation that they already had a strong relationship with their provider, and they felt they could discuss any topic with their provider. Some noted this was due to a longstanding good relationship with their doctor, others noted their attentiveness and listening skills made them feel comfortable and acknowledged during this interaction. These results may indicate the importance and strength of using the SICG in a primary setting, as prior strong relationships may improve patient’s experience with these conversations and enrich the quality of these discussions.

This study has some notable limitations. It was a small sample without a control group so these findings can only be used as a descriptive analysis. We had a small, homogenous study sample and results may not be widely generalizable. Self-selection bias may be occurring in this cohort of patients as they volunteered for this qualitative study and may not be representative of all patients receiving the SIC. Next steps for this research will be to correlate the use of the SICG with reception of "goal-concordant care" using quantitative analysis to assess if patients receive care in line with the goals they express in the SIC, and if it is improved from patients who have not had this SIC with their providers. Further analysis of the cases in this study for patients who died during the duration of this study period to assess if the care they received at their end of life was concordant with the goals and values they expressed in the SIC is also needed.

Conclusions *(2-3 summary sentences)*

Overall, patients expressed a positive attitude about end-of-life discussions with their providers using the SICG protocol. Conversations are well-received by patients, allow patients to express their wishes, and strengthen patient-provider relationships. These results support the utility of the SICG in the primary care setting to improve and guide advanced care planning discussions.

References *(JAMA style format)*

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