Acceptability of a Serious Illness Conversation Guide to Black Americans: Results from a focus group and oncology pilot study

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Abstract

Objectives. Serious illness conversations (SICs) can improve the experience and well-being of patients with advanced cancer. A structured Serious Illness Conversation Guide (SICG) has been shown to improve oncology patient outcomes but was developed and tested in a predominantly White population. To help address disparities in advanced cancer care, we aimed to assess the acceptability of the SICG among African Americans with advanced cancer and their clinicians.

Methods. A two-phase study conducted in Charleston, SC, included focus groups to gather perspectives on the SICG in Black Americans and a single-arm pilot study of a revised SICG with surveys and qualitative exit interviews to evaluate patient and clinician perspectives. We used descriptive analysis of survey results and thematic analysis of qualitative data.

Results. Community-based and patient focus group participants ($N = 20$) reported that a simulated conversation using an adapted SICG built connection, promoted control, and fostered consideration of religious faith and family. Black patients with advanced cancer ($N = 23$) reported that SICG-guided conversations were acceptable, helpful, and promoted conversations with loved ones. Oncologists found conversations feasible to implement and skill-building, and also identified opportunities for training and implementation that could support meeting the needs of their patients with low health literacy. An adapted SICG includes language to assess the strength and affirm the clinician–patient relationship.

Significance of results. An adapted structured communication tool to facilitate SIC, the SICG, appears acceptable to Black Americans with advanced cancer and seems feasible for use by oncology clinicians working with this population. Further testing in other marginalized populations may address disparities in advanced cancer care.

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Introduction

A growing body of evidence suggests that conversations about prognosis, goals, and values can improve the experience and well-being of patients with advanced cancer. These "serious illness conversations" (SICs) appear to improve rates of moderate to severe anxiety and depression, for example, an effect that may be mediated by improved information sharing and relationships with clinicians (Kumar et al. 2020; Paladino et al. 2019). Like other advance care planning (ACP) interventions, SIC may increase utilization of hospice and decrease hospitalization and intensive care utilization at the end of life (Ahluwalia et al. 2015; Brinkman-Stoppelenburg et al. 2014) ultimately improving quality "end-of-life" care (Teno et al. 2004, 2007, 2005).

Black Americans experience lower quality communication in health-care settings generally (Bullock 2006; Palmer et al. 2014; Shen et al. 2018) participate less in ACP (Harrison et al. 2016), advance directives (Bazargan et al. 2021), and enroll in hospice at lower rates than White Americans (Loggers et al. 2009; Mack et al. 2010a). Multiple factors contribute to lower engagement of Black Americans in ACP: patient factors include cultural and religious beliefs that may shape willingness to talk about dying, family consensus (as opposed to individual) decision-making, and poor access to care; clinician factors include implicit and explicit racial biases about willingness to participate in such discussions and challenges with cross-cultural communication (Periyakoil et al. 2015; Sanders et al. 2016). Varied interventions

to improve ACP among Black Americans include dyadic nursing interventions (Song et al. 2010) and engaging faith communities (Balboni et al. 2013; Bullock 2006).

The Serious Illness Conversation Guide (SICG) was developed to provide clinicians with a structured, patient-centered approach to SIC using tested language to communicate prognosis and elicit patients' goals, values, and priorities that inform decision-making. It has been implemented and studied as part of a multi-component systems-level approach to improve the frequency, timeliness, and quality of serious illness communication (Bernacki et al. 2019; Lakin et al. 2017). Its original version comprised 7 questions that help assess illness understanding and prognostic information preferences, and explores goals, fears and worries, important functional abilities, perceived preferences in light of possibly burdensome treatments, and family engagement.

The SICG was developed and tested with predominantly White patients and clinicians in a Northeastern cancer center, raising questions about its acceptability to geographically and ethnically or racially diverse groups (Bernacki et al. 2015, 2019). With the overall aim of informing adaptations to the SICG to better meet the needs of a population for whom disparities in end-of-life care are most evident, we conducted a two-phase study to understand SICG acceptability to Black patients affected by advanced cancer and their oncologists in a Southeastern US state.

Methods

Overview

This two-phase study included focus groups (Phase I) to gather perspectives on the SICG in Black Americans and a single-arm pilot study of a revised SICG (Phase II) with surveys and qualitative exit interviews to evaluate patient and clinician perspectives. Institutional Review Boards at the Medical University of South Carolina (MUSC) and Roper St. Francis Hospital (RSFH) in Charleston, SC, and the Dana-Farber Cancer Institute in Boston, MA, approved this study.

Phase I: adaptation

Recruitment

To gather community-level perspectives, we recruited a convenience sample of African-American church members who met regularly to discuss community concerns to participate in a single in-person focus group. They comprised individuals from a group that met regularly in the church to discuss health-related issues. We used information in the electronic health record at MUSC specialty clinics, to identify Black Americans with Stage IV cancer, New York Heart Association Class III/IV heart failure, or Chronic Obstructive Lung Disease with >3 hospitalizations. We subsequently recruited them using letters and follow up phone calls. Those under 18 years of age were excluded. Patients and their nominated caregivers were invited to participate in 1 of 2 in-person focus groups at MUSC. We obtained verbal consent before the focus groups, provided refreshments, and compensated participants with a $25 gift card.

Data collection

Guidelines from the Consolidated Criteria for Reporting Qualitative Research checklist guided study methods and reporting (Tong et al. 2007). We developed a structured interview guide to gather feedback about the SICG after participants observed a live simulated demonstration of the SICG-led conversation between an oncology physician and a Black American woman with advanced breast cancer. The focus group interview solicited reactions to the SICG language, questions, content, and delivery. Participants were asked about a proposed new question in the guide: "What gives you strength as you think about the future with your illness?" This question was added for piloting based on research demonstrating the importance of family support and religious faith in ACP among Black Americans and input from researchers whose focus is health disparities (Sanders et al. 2018, 2016; Tay et al. 2017).

Focus groups and interviews were audio-recorded, lasted 60–90 min, and were co-facilitated by team members experienced in moderating focus groups (J.J.S., a White male palliative care clinician, and K.R.S., a White female doctoral-trained public health researcher) who did not know the participants.

Data analysis

Focus group recordings were transcribed verbatim and checked for accuracy. We used thematic analysis, an approach to identify themes through the classification, organization, and description of patterns within the data using both deductive and inductive approaches, with an initial codebook mapped to our interview guide and allowing additional themes to arise directly from the data (Braun and Clarke 2006; Clarke and Braun 2017). Using Microsoft Word, 2 investigators independently coded focus group data and reconciled differences by consensus. After coding data by group (church members and patients–caregivers), we combined data across groups to identify consistent themes and implications.

Phase II: acceptability

Recruitment

Clinicians. We recruited a convenience sample of oncologists from 2 health centers to complete training in the use of the SICG. Enrolled participants completed written informed consent procedures and then attended a 2.5-h in-person training with dinner and a $100 gift card. Using paper copies provided in advance of visits, oncologist participants then engaged in SICG-guided conversations with a sample of their seriously ill patients who enrolled in the study over a 16-week period in 2015.

Patients. A research assistant worked with clinic staff to review trained clinician clinic schedules and identify potentially eligible Black American patients with advanced-stage cancer. Oncologists identified potential participants with the application of the surprise question ["Would you be surprised if this patient died in the next year?" (Moss et al. 2010)]. Recruitment letters were followed by phone calls or in-person clinic visits to screen and enroll participants in a study about clinician communication. Patients provided written informed consent and received a $20 gift card.

Data collection and measures

At enrollment, patients completed a baseline survey either on paper or with the research assistant. Data were entered into REDCap. Participants then completed a SICG conversation with their trained clinician. Following conversation completion, study staff called patients at home 1 week later to complete a post-conversation survey. At the baseline, surveys assessed sociodemographic and clinical characteristics, trust and spirituality [validated Questionnaire on Beliefs and Preferences for End-of-Life Care (Johnson et al. 2008)], preferences for care and place of death, and a set of single

items about beliefs about dying, truth-telling, and ACP. Baseline and follow-up surveys also assessed the quality of communication and therapeutic alliance using measures validated in advanced-stage cancer populations (Engelberg et al. 2010; Mack et al. 2009). Finally, we assessed SICG acceptability with single-item ratings of the extent to which the conversation increased or decreased one's anxiety, hopefulness and sense of peacefulness, helpfulness of conversation elements, and perceived worth, timing, impact, and enjoyment of the conversation (Bernacki et al. 2015).

Oncologists completed online surveys to assess their confidence using single items for a set of serious illness communication elements at the baseline and after study completion. Follow-up surveys also assessed experiences using the guide with an instrument adapted from a previous trial (Bernacki et al. 2015). Participants rated single items about the extent to which they gained useful information about patient goals, fears and worries, and sharing information with family and additional items about experiences using the SICG. Oncologists also participated in 20–30-min debriefing interviews by phone at study completion to explore SICG experiences.

Data analysis

In the current study, we present baseline characteristics and beliefs to describe patients and their illness context. We then present patient perceptions of communication quality, therapeutic alliance, and ratings of the SICG conversation at the follow-up to examine acceptability. We present clinician confidence at the baseline and follow-up and ratings of their experience using the SICG at the follow-up. We used descriptive statistics to summarize oncologist and patient demographic factors and patient clinical factors. We mapped data graphically (e.g., figures and bar charts) to illustrate patterns in beliefs and perceptions of acceptability. We deferred the use of statistical tests due to the small sample size. Finally, we analyzed clinician qualitative interviews using the thematic analysis methods described earlier. After completing clinician qualitative and quantitative acceptability data independently, we used a joint display to integrate findings.

Results

Phase 1: adaptation

Participants

Community and patient–caregiver focus group participant demographic data have previously been reported (Sanders et al. 2018). The "community" group included 9 members of an African-American church (mean age = 50; range 25–66). The majority (*n* = 8) were female, had experience as caregivers for a loved one with serious illness (*n* = 8), and had at least some college education (*n* = 7). The patient–caregiver group included 11 participants, 7 with serious illness and 4 family caregivers (mean age = 58.5; range 49–73). Years of education and self-rated health varied in the patient–caregiver group with 4 participants having a high school degree or less and the majority rating their health as fair (*n* = 6) or poor (*n* = 2).

Qualitative data

Focus group participants generally described positive reactions to the SICG conversation, noting that the approach (1) builds connection between patients and their clinicians, (2) supports shared decision-making and offers a sense of control, and (3) fosters inclusion of religion, spirituality, and family, as desired (Supplementary Table S1). Results also highlighted practical suggestions regarding the timing and context of the conversation.

Building connection. Participants described an appreciation for the conversation framing and reflected that the guide-directed communication was unique in its emphasis on making a connection with one's clinician and approaching the illness together. For example, one community member noted that "The doctor talked like he is a human being. And he acts concerned, you know" (Patient #4). Unfortunately, participants also reflected that this type of communication was atypical in their experience with doctors. As one community member with experience as a caregiver stated, "I think [the conversation guide] will be good, because some doctors don't know how to really talk to us. But if we, seriously ill or not, if we consider these questions we will have something on our side besides having nothing" (Community member #1).

Promoting control. Focus groups also highlighted that the communication appeared to promote patients' control over their care and decision-making. As stated by one community member, "I believe what [the conversation is] trying to do is to help the patient have more control over his or her situation. The questions give the patients control" (Community member #2). Another caregiver noted appreciation for the doctor being "candid…you can't make an informed decision if you haven't been informed" (Caregiver #9).

Faith and family. Participants specifically noted that the question about strengths was important because it opened up the opportunity to share the role of one's faith and family in coping with illness: "You know, everybody's faith is different…it's about the patient's issue and what works for her…that I worship, it makes me feel better" (Caregiver #10); "You need two things…for me the two are faith and family" (Patient #2). Furthermore, one community participant reflected that "[The strengths question] brought a smile to my face when I heard it…because the first thing that crosses my mind is my God, my faith, and my peace" (Community member #6), indicating that this was important to one's care.

Despite the evident importance of family in decision-making, some felt it was important to have this conversation alone with their clinician first. As one said, "Some people don't want their family to know, so maybe a good question to add in with that one does, 'do you want them to know anything about it?' Some people really don't want their family. They just want to do it themselves" (Community member #8).

Practical issues. Finally, in thinking about when the conversation should occur and with whom, participants offered different perspectives. One community participant "would like to see this come from my primary care doctor" (Community member #6), while a patient noted that "I want to talk to the expert…the one who was treating the cancer" (Patient #4). Another expressed the importance of expressing ongoing commitment to patients after difficult conversations.

Guide adaptations

Figure 1 provides an image of the modified SICG, with 2 main adaptations based on focus group findings. Results affirmed our inclusion of a new question to inquire about what brings individuals strength as they think about the future with their illness and informed addition of a closing statement emphasizing non-abandonment: "I will do everything I can to help you through this."

Fig. 1. Updated Serious Illness Conversation Guide.
Note: Updates to the guide based on focus group findings appear in boxes lined in red.

Phase II: pilot testing

Participant characteristics

Thirty-two patients were approached about the study. Six patients did not complete the study, 2 withdrew, and 1 was determined by their clinician to no longer be eligible. Twenty-three patients enrolled and completed a SICG conversation and all surveys. Table 1 includes patient demographic and health data. Participant characteristics varied widely: the average age was 71 and the majority were women, had a high school education or less, and reported an income of less than $10,000 annually. Over half rated their health status as good or better, although most had one or more emergency room and hospital stays in the past 12 months. Almost all patients identified as somewhat or very religious; about a third had a living will. Patients reported low mistrust in the health-care system [average 12/50 (higher scores indicate greater distrust); SD: 5.0].

Table 1. Pilot study participant characteristics ($N = 23$)

Characteristic	N (%)
Male gender	6 (26)
Age, average (range)	71 (50–88)
Marital status	
Married	6 (26)
Widowed	6 (26)
Divorced	2 (9)
Single, never married	9 (39)
Highest education	
Less than high school	9 (39)
High school graduate	6 (26)
Some college or technical school	4 (17)
College graduate	4 (17)
Income	
<$10,000	15 (65)
$10,000–$20,000	3 (13)
$20,000–$40,000	1 (4)
$40,000–$60,000	2 (9)
$60,000–$70,000	1 (4)
>$75,000	1 (4)
Self-rated health	
Poor health	4 (17)
Fair health	5 (22)
Good health	11 (48)
Very good health	2 (9)
Excellent health	1 (4)
ER visits in last 12 months, average (range)	1.5 (0–6)
Hospital stays in last 12 months, average (range)	2.6 (0–21)
Self-reported cancer diagnosis	21 (91)
Primary cancer diagnosis	
Lung	2 (9)
Genitourinary (prostate/bladder)	3 (13)
Gynecologic (uterine, cervix, and ovary)	7 (30)
Gastrointestinal (gastric, pancreas, and colon)	5 (22)
Glioblastoma	1 (4)
Other	5 (22)
Living will in place	7 (30)
Durable power of attorney for health care in place	5 (22)

Oncology clinicians represented 2 institutions with 4 in an academic setting – gynecologic ($n = 1$), gastrointestinal ($n = 1$) and neuro-oncology ($n = 2$) – and 2 community-based general medical oncologists. Five of the 6 were male; all identified as White. The number of conversations completed per clinician ranged from 2 to 10.

Patient beliefs

Figure 2 describes participants' end-of-life care preferences and beliefs about dying and ACP (*Questionnaire of Beliefs and Preferences for End-of-Life Care*) (Johnson et al. 2008) at the baseline. Many participants believed that being comfortable ($n = 11$) or out of pain ($n = 13$) was more important than longevity. Of the 23 participants, only 4 preferred to live as long as possible even on life support. Most ($n = 17$) patients preferred to be at home rather than in a hospital, although many ($n = 13$) would still want hospital or Emergency Room visits. Most patients indicated they were comfortable talking about death ($n = 18$), would want doctors to disclose prognosis if they were dying ($n = 19$), and would tell their family if they were dying ($n = 19$). All believed death to be a normal part of life, and half had thought about or talked to family about medical care. Few ($n = 4$) agreed that death should be avoided at all costs.

Patient experiences

After the conversation, most patients rated communication quality very high (avg: 9.3/10, SD: 1.6) and reported strong therapeutic alliance (avg: 3.80/4, SD: 0.5). Over half reported increased hopefulness about quality of life ($n = 11$; $n = 8$ reported that hopefulness neither increased nor decreased) and prognosis ($n = 10$; $n = 8$ reported hopefulness to neither increase nor decrease). Most patients also reported the conversation increased their sense of peacefulness ($n = 15$), but approximately 1/3 ($n = 7$) reported increased anxiety – the rest reported no change ($n = 9$) or a decrease ($n = 7$) in anxiety about their illness.

As highlighted in Figure 3, the majority of patients rated the content of the SICG conversation as helpful with the highest endorsement for the discussion about one's understanding of their illness, personal goals, fears and worries, and asking about family. Also, some patients reported that they did not discuss some of the conversation domains. The least frequently discussed (or, alternatively, unrecollected) content included: (1) abilities so critical to one's life that they would not want to live without them ($n = 9$), (2) how much one would be willing to go through for the possibility of gaining more time ($n = 7$), and (3) how much one's family knew of their priorities and wishes ($n = 7$).

All but one patient rated the discussion as worthwhile, and most ($n = 20$) thought that this was the right time for the conversation (1 preferred earlier, and 2 preferred later). Most patients ($n = 19$) were not considering making changes in their treatment plan, although many had plans for the follow-up: a few planned to think more about the issues ($n = 3$), and several planned to talk more with the health-care team ($n = 9$) and loved ones ($n = 14$). Issues that patients wished to discuss further ($n = 5$) surrounded prognosis and time frame, treatment, and changing physicians. Most patients reported liking the conversation a little ($n = 2$) or a lot ($n = 15$).

Clinician experiences

Clinicians rated their confidence high after completing conversations with patients over the study period (Table 2), especially in demonstrating empathy, responding to patients' emotions, discussing end-of-life issues, discussing palliative care, and determining timing of hospice referral. Clinicians reported the greatest increase in confidence from the baseline for discussing end-of-life issues, inquiring about fears/worries, and eliciting patient goals.

At the follow-up, clinicians reported high acceptability with the SICG conversation and positive implications concerning its
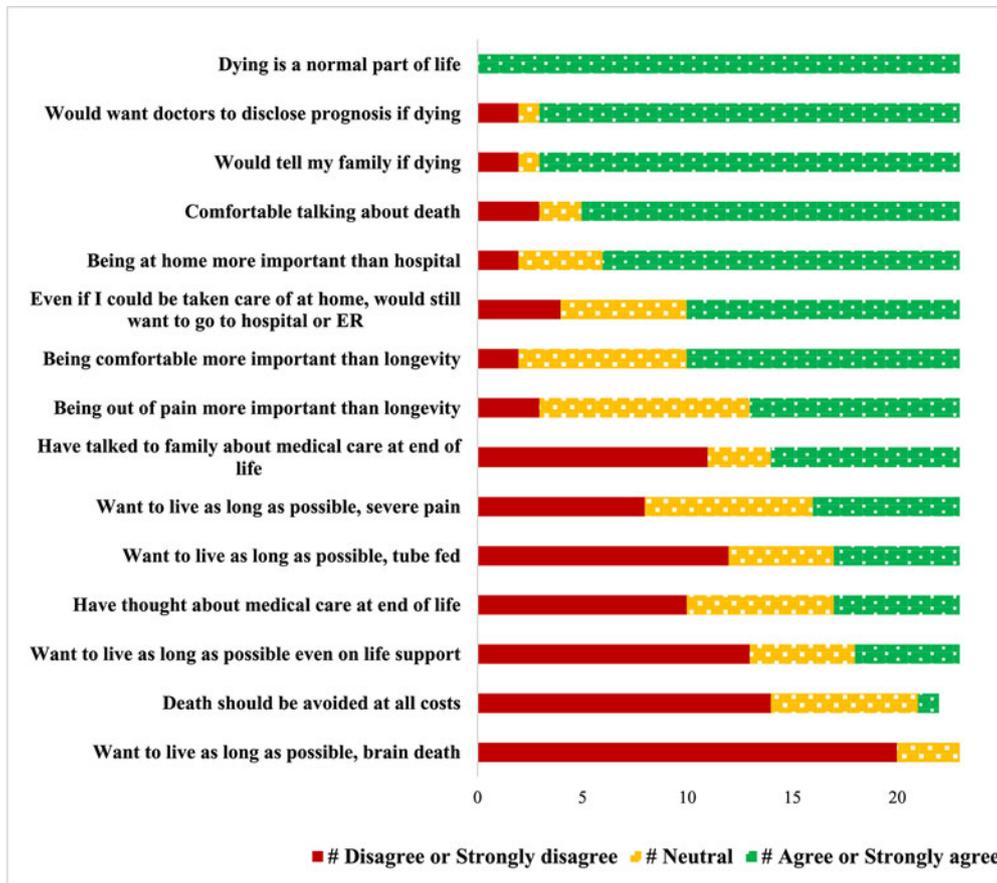
Fig. 2. Patient end-of-life care preferences and beliefs about dying and ACP (baseline).

Fig. 3. Patient ratings of Serious Illness Conversation Guide conversation acceptability by content domain.

utility. Qualitative exit interview results paralleled these findings, and results are synthesized in Table 3. Quantitative findings highlighted that the guide was considered easy to use, allowed for timely discussions, and allowed clinicians to evaluate and gain useful information about patients' understanding, fears, and worries. Qualitative data supported these findings, emphasizing the positive

Table 2. Clinician confidence in communication topics with seriously ill patients at the baseline and follow-up

Communication topic[a]	Clinician confidence		
	Baseline average (range; *n* = 6)	Follow-up average (range; *n* = 4)	Average change over time, *n* = 4
Discussing end-of-life issues	5.00 (4–6)	5.83 (5–6)	1.00
Demonstrating empathy	5.5 (5–6)	6.00 (5–7)	0.25
Estimating prognosis	4.5 (4–5)	5.17 (4–6)	0.50
Assessing patient understanding of prognosis	4.5 (4–5)	5.17 (4–6)	0.75
Determining information preferences	4.75 (4–6)	5.5 (4–7)	0.50
Inquiring about fears/worries	3.75 (3–5)	5.67 (5–7)	1.75
Eliciting patient goals	3.75 (3–5)	5.17 (3–7)	1.25
Assessing views on functional impairment	4.25 (3–6)	5.17 (3–7)	0.75
Assessing trade-offs	4.75 (4–6)	4.83 (3–7)	−0.25
Telling a patient he/she has a poor prognosis	5.25 (5–6)	5.50 (4–6)	0.50
Using therapeutic silence	5.25 (4–6)	5.50 (4–7)	0.00
Responding to patients' emotions	5.00 (4–6)	6.00 (5–7)	0.50
Discussing discontinuing disease-modifying therapy	5.25 (4–7)	5.67 (5–7)	0.25
Discussing palliative care	5.25 (4–6)	5.83 (5–7)	0.25
Determining timing of hospice care	5.00 (4–6)	5.83 (5–7)	0.50

[a]Clinicians self-rated self-efficacy on a scale of 1: very unskilled to 7: very skilled. Baseline data missing for 2 clinicians.

aspects of the structure of the conversation (i.e., introduction, framing, and timing), its ease of use, its impact on promoting a better understanding of where the patients were with their illness, and its effect on accelerating decision-making. Finally, clinicians highlighted that the guide supported connecting with patients, ensured coverage of a comprehensive set of important topics, and supported a better understanding of patients' goals and values, including those related to religion and spirituality.

Clinicians also reported challenges related to time constraints and certain guide questions that required additional explanation (e.g., discussions of prognosis and trade-offs). For example, one clinician noted that it was challenging to feasibly complete the SICG conversation within a routine appointment, while another described that some of his patients required follow-up conversations related to their disease. Other challenges reported by individual clinicians included that one patient required some questions rephrased for additional simplicity, and one clinician cited age-related health literacy as a barrier.

Discussion

With the goal of understanding the acceptability of a structured guide to support SIC and proposing adaptations to support dissemination in diverse communities, we conducted a two-phase study. Focus groups with community-dwelling and seriously ill Black Americans and their caregivers elicited support for language included in the SICG and affirmed additions of a question focused on strengths and language to support the clinician–patient relationship. Subsequent pilot testing of an adapted guide with Black Americans with advanced cancer and their oncologists support the acceptability of the adapted SICG.

Specifically, focus group participants agreed that the SICG supported rapport-building and shared decision-making and that a question focused on strengths gave space to incorporate discussion about faith and spirituality. Some have written about the benefit of strengths-based assessment in clinical care (Rashid and Ostermann 2009), and this is common practice for many palliative care clinicians. Given the risk of perceived abandonment after this type of conversation, they described the importance of language to reaffirm the clinician–patient relationship. In pilot testing of the adapted guide, while nearly one-third of the 23 participants reported increased anxiety as a result of the conversation, a majority reported enjoying the conversation and indicated that it increased their sense of peace. They also reported high levels of trust and therapeutic alliance after the SICG conversation, and the majority indicated they were planning to talk more with their loved ones after the conversation. These findings may suggest the importance of ensuring that systems have adequate resources in place to support the follow-up after an SIC (e.g., counseling and connecting to family members).

These acceptability findings resonate with previous studies of the SICG. In a randomized trial in oncology, nearly 80% of 163 patients reported a SICG-facilitated conversation as worthwhile (Paladino et al. 2020b). Most (64%), but fewer than in our sample, reported the conversation happened at the right time. A majority reported no change in sense of control (46%→46%), but improvements in hopefulness (47%→33%), peacefulness (51%→36%), and anxiety (57%→28%). Surveys and interviews with a more diverse sample of oncology patients (16% Black, 3% other) exposed to the SICG at a mid-Atlantic cancer center showed similar perceptions of the worthwhileness (90%), with majorities reporting increases in understanding of their health (55%) and their closeness with clinicians (58%) (Kumar et al. 2020).

In contrast to common perceptions held by clinicians (Sanders et al. 2018), Black American participants in this study expressed openness to these conversations and believed them to be important and even necessary. This accords with other research that

Table 3. Joint display of quantitative and qualitative results for clinician acceptability: experiences using the guide

Domain	Quantitative[a]	Qualitative
Allows for discussion about the end of life in a timely manner	Scale (Strongly disagree – Somewhat disagree – Neither agree nor disagree – Somewhat agree – Strongly agree): 1 at "Neither agree nor disagree", 5 at "Strongly agree" (star at Somewhat agree/Strongly agree)	"I think I enter the conversation earlier and a little more gently. Just in general in practice. I tend to bring it up at any fork in the road, not just when things take a turn for the worse." (Clinician 4) "I think it escalated – it accelerated treatment decisions, goal decision-making. The ability to get into important elements of care. To get there quicker." (Clinician 2) "I feel like this is a great introductory conversation…But for the patient who is in the throws of the decision …toward the end of the conversation, the questions weren't specific enough." (Clinician 4)
Easy to use	Scale (Strongly disagree – Somewhat disagree – Neither agree nor disagree – Somewhat agree – Strongly agree): 1 at "Somewhat agree", 5 at "Strongly agree" (star at Strongly agree)	"It covers a lot of detail with very focused questions. And yes, you still manage to get a lot out of the patients in a short period of time." (Clinician 3) "Time constraints could make it difficult to get all the questions in." (Clinician 3)
Degree to which increased or decreased one's role in patients' care	Scale (Greatly decreased – Slightly decreased – Neither increased nor decreased – Slightly increased – Greatly increased): 1 at "Slightly decreased", 3 at "Neither increased nor decreased", 2 at "Slightly increased" (star at Slightly increased)	"My overall feelings were that I found it helpful, in fact very helpful, for a number of tough cases allowed for an opportunity to bring up a tough conversation in a structured way…allowed a deeper conversation that they hadn't gone through." (Clinician 2) "Overall experience was very positive. I think it helped open up a conversation regarding patient beliefs and understanding." (Clinician 5) "On the one hand it was a great way to initiate the conversation but I don't think had enough meat at the end to really guide the patient through some critical decision-making steps." (Clinician 4) "Helps me understand my [patients'] religious convictions better and focus on their goals more." (Clinician 5)
Ability to evaluate the patient understanding of prognosis	Scale (Not at all – A medium amount – A great deal): 4 and 2 near "A great deal" (star before "A great deal")	"I think it helped open up a conversation regarding patient beliefs and understanding. Where patients were." (Clinician 5) "Mainly opened up my understanding of what their understanding was of their disease and what they thought was good." (Clinician 5)
Gain useful information from asking about the patient's fears and worries	Scale (Not at all – A medium amount – A great deal): 2 and 4 near "A great deal" (star before "A great deal")	"What I really liked is that what I didn't ask patients about – fear, goals – I realize that there were a lot of things I didn't ask [previously]. I thought that it was productive to ask those – if anything it improved the relationship. Did with one patient and his wife and it was a really nice conversation and it opened up him talking about some things. There was more depth to our doctor–patient relationships." (Clinician 1) "You get to the loss of abilities is the one thing that you fear. Everybody wants to be as able as possible for as long as possible." (Clinician 4)
Overall effectiveness of this discussion in understanding patients' values and goals about end-of-life care	Scale (Not at all – A medium amount – A great deal): 1 near "A medium amount", 5 near "A great deal" (star before "A great deal")	"It has just helped me focus more as a clinician on those things. I'd like to think I was focused on that before. But it has helped me focus on their goals more. Which direction we're going and why we're going there." (Clinician 6) "I think with African American patients, you kind of…it helps you understand their religious convictions/understanding better. Faith to some degree. That's where it helped out." (Clinician 5) "I think it helped refine and sharpen the goals of care." (Clinician 6)

[a]Numbers on each scale indicate the number of clinicians endorsing each response.

demonstrates the belief among those from multiple ethnic and racial groups that doctors should engage patients in end-of-life conversations (Blackhall et al. 1999; Clark et al. 2018). Patient's end-of-life preferences and beliefs about ACP varied, although most indicated a preference for comfort-focused care.

Clinicians in the current study found that the SICG training gave them confidence in elements of SIC, including responding to emotions and eliciting patients' goals and values. These findings are consistent with a prior SICG study, where a large majority of the 54 clinicians (90) reported that SICG conversations were

effective and timely (Paladino et al. 2020b). In this study, clinicians also identified challenges, including having sufficient time for conversations and the needed follow-up, comprehensibility to a low literacy population, and remembering questions on the guide. These findings add more depth to our understanding of clinician SICG experiences in a new population of Black oncology patients, highlighting its acceptability and also offering insight for future research. In response to this and other discussions with those who care for underserved and marginalized populations, Ariadne Labs, the health systems innovation center in which the SICG was developed, has undertaken a revision of the guide to improve comprehension and ease of use.

While our study focused primarily on clinician acceptability, we also captured clinician reports of post-intervention confidence in surveys and perceptions of the impact of the conversation in interviews. Findings echo those from an evaluation of SICG training by clinicians from multiple specialities (over 1/3 oncologists or radiation oncologists) from 3 health systems. In that study, clinicians reported improvement across a range of skills (e.g., assessing information preferences, allowing silence, and speaking less than 50% of the time) and improved self-ratings in skills (Paladino et al. 2020a).

One important consideration is that patient recollection of conversation content was low for some SICG elements. This suggests that some parts of the SICG were either less memorable or less utilized by clinicians. This may reflect perceived time pressures reported by clinicians (given that the 3 least remembered questions come near the end of the SICG) or discomfort with asking about important abilities, perceived treatment trade-offs, or family involvement. Anecdotal experiences from other SICG studies suggest that clinicians often struggle with questions about abilities and trade-offs, perhaps because they represent a paradigm shift in this type of communication. In this study, clinicians reported sometimes needing to clarify these questions or provide examples.

Our findings suggest that SICG-guided conversations were acceptable to a regionally homogenous sample of African-American community members and patients with advanced cancer and feasible for use by their oncologists. As such, it may help overcome barriers that currently drive disparities in SIC and care for Black Americans and other people of color. In addition to what is known about inequities in pain and symptom management and utilization of hospice, evidence (Gardner et al. 2018; Johnson 2013) shows Black cancer patients in one study were less likely to receive goal-concordant care, even when they wanted comfort-focused care (Mack et al. 2010b). Clinician communication has been identified as a contributor to racial disparities in care broadly (Penner et al. 2014). Research exploring communication experiences has identified themes that include disrespect and disregard for patient perspectives, both of which exacerbate mistrust (Cuevas et al. 2016). Current research seeks to promote ACP as a means to combat inequities in serious illness care (Ejem et al. 2019). Our findings suggest that the SICG provides one acceptable approach to improving ACP in this population, and perhaps others who experience similar marginalization in and by health-care systems.

Limitations

This study has limitations. Our focus groups were conducted by 2 White investigators, which may have inhibited discussion around the lived experience of illness that may have informed further SICG adaptations. However, our collection of frank and emotional accounts of low-quality communication and care, and racial

discrimination, suggests a level of comfort among participants. Though intentionally exploratory, we only conducted one focus group of community-dwelling adults in Phase I and cannot assess data saturation. More participants and perspectives may have led to more or different proposals for SICG adaptation. For Phase II, the lack of control group limits the comparison to those patients who did not have the conversation; those who agreed to participate may not be representative of Black cancer patients; and the small number of participants may limit the generalizability of their perspectives. Furthermore, 5 of 6 clinicians were men and most patients were female, which may have influenced results by way of unmeasured gender dynamics. Future larger-scale research is needed to test the effects of the SICG conversation on patient and family-centered outcomes in diverse patients and clinicians.

Conclusion

An adapted structured communication tool to facilitate SIC, the SICG, appears acceptable to Black Americans with advanced cancer and seems feasible for use by oncology clinicians working with this population. The addition of a question focused on strengths elicited positive reflections about religious faith and family. Areas identified for further improvement by clinicians may inform training approaches for the guide, as well as further guide adaptations to enhance future use in the setting of low health literacy. Patients' perceptions that the SICG builds rapport, promotes respectful communication, and helps communicate prognosis in ways that are timely and worthwhile suggest that this may help drive equity in serious illness communication and care and may have applicability for those from other underserved and marginalized communities.

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