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Please Ask Gently: Using Culturally Targeted Communication Strategies to Initiate End-of-Life Care Discussions With Older Chinese Americans

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Abstract

Background: Health-care providers (HCPs) find facilitating end-of-life (EOL) care discussions challenging, especially with patients whose ethnicities differ from their own. Currently, there is little guidance on how to initiate and facilitate such discussions with older Chinese Americans (55 years) and their families. **Objective:** To explore communication strategies for HCPs to initiate EOL care discussions with older Chinese Americans in the San Francisco Bay Area. **Design:** This qualitative (focused) ethnographic study included field observations and individual semistructured interviews with 14 community-dwelling older Chinese Americans who lived independently at home, 9 adult children, and 7 HCPs. Responses were analyzed using open coding, memos, and comparison across participants. **Results:** The study participants emphasized the importance of assessing readiness for early EOL care discussions. All recommended using indirect communication approaches to determine older Chinese Americans' readiness. Indirect communication can be culturally targeted and applied at both system-wide (ie, health-care system) and individual (ie, HCP) levels. To institutionalize the practice, health-care facilities should implement EOL care discussion inquiries as part of routine during check-in or intake questionnaires. In individual practice, using depersonalized communication strategies to initiate the discussion was recommended to determine older Chinese Americans' readiness. **Conclusion:** Assessing readiness should be an essential and necessary action for early EOL care discussions. Culturally targeted assessment of older Chinese Americans includes using indirect communication approaches to initiate an EOL care discussion to determine their readiness. In addition to health-care system integration, providers should implement and evaluate proposed EOL discussion initiation prompts with their older Chinese American patients.

Keywords

end-of-life care, advance care planning, communication, Chinese Americans, palliative care, geriatrics

Introduction

Chinese Americans represented the largest group of Asians in the United States.[1,2] However, Asian patients accounted for only 1.2% of Medicare hospice patients in the United States in 2015.[3] Compared with other ethnicities, end-of-life (EOL) care discussion rates among Chinese patients, family members, and health-care providers (HCPs) have remained low.[4-7] With current changes in guidelines and legislation related to advance care planning,[8] the promotion of hospice and palliative care that includes effective and meaningful EOL care discussions may contribute to improved overall health care in the Chinese American community.

Due to lack of expertise and training in EOL care discussions, HCPs find such conversations challenging and this challenge is even greater with patients whose ethnicities are different from HCPs.[9,10] For HCPs to successfully engage older Chinese Americans and their families in early EOL care discussions, cultural accommodation and clinical practice concerns must be addressed. Cultural taboos of death and dying and an uncertainty about when and how to initiate EOL care discussions with older Chinese Americans are commonly reported as barriers.[11-13] Recent research exists on EOL care discussions with Chinese Americans and their families,[11-13] but

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little has focused on how to initiate and facilitate the conversation. This project's purpose was to explore HCP communication strategies to initiate EOL care discussions with older Chinese Americans and their families.

Methods

We conducted a focused ethnographic study[14] exploring preferences, communication, and strategies for EOL care discussions with older Chinese Americans, adult children of an older Chinese American, and HCPs. Unlike traditional ethnography that emphasizes participant observation, focused ethnography replaces long-term field observations with hypothetical scenarios and intermittent and purposeful participant observation.[14,15] This is particularly useful in eliciting participants' views on sensitive topics, which may be hard to elicit or observe in the field. Field observation at participants' homes and advance care planning outreach events were included to supplement interview data. As part of a larger study of EOL care discussions (reported elsewhere[16]), we focused on findings related to communication strategies to assess readiness or initiate EOL discussions with older Chinese Americans. The institutional review board of the authors' university approved the study protocol.

Study Participants and Setting

Three groups of participants were recruited from Chinese American community sites in the San Francisco Bay Area using purposive and snowball sampling including direct approach at Chinese American health fair events, flyers at Chinese American neighborhoods, e-mails, and social media posting at various Chinese American interest groups online. Eligible older Chinese Americans were English speaking, self-identified as Chinese or Chinese American, and aged ≥55 years. Eligible adult children were English speaking, self-identified as being of Chinese descent, aged ≥18 years, and expecting to care for a parent aged ≥55 years. Eligible HCPs were physicians, nurses, social workers, or chaplains who currently practice in geriatrics, primary care, or palliative care and were conducting EOL care discussions with older Chinese Americans at least monthly. Participant demographics are provided in Table 1.

Table 1. Key Characteristics of Participants.

Characteristics (N = 30)	Older Chinese Americans (n = 14)	Adult Children (n = 9)	Health-Care Providers (n = 7)
Age (years)			
Mean	66.64	41.8	45.1
Range	57-77	31-57	31-57
Gender			
Female	10	5	6
Male	4	4	1
Marital status			N/A
Married	10	5	
Divorced	2	4	
Single	2	0	
Birth place			N/A
United States	5	4	
Non-United States	9	5	
Years in United States			N/A
Mean	51.14	34.9	
Range	30-76	16-57	
Primary language			N/A
English	8	6	
Cantonese	1	2	
Mandarin	5	0	
Chiu Chow	0	1	
Education			N/A
Some college	2	0	
Bachelor's	6	5	
Some master's	1	1	
Master's	5	2	
PhD		1	
Discipline			
Advanced practice nurse			2
Physician			3
Social worker			2
Specialty			
Palliative care			4
Internal medicine			2
Geriatrics			1
Years of work with older Chinese Americans			
Mean			15
Range			5-26
Frequency of EOL discussions with older Chinese Americans			
At least once a month			5
At least once a week			1
Daily			1
Ethnicity			
Chinese			6
Caucasian			1

Abbreviation: EOL, end of life; N/A, not applicable.

Data Collection

The first author conducted face-to-face, individual in-depth interviews in English and recorded informal field observations with 14 older Chinese Americans, 9 adult children, and 7 HCPs. Written informed consent was obtained after study purposes and procedures were explained. Interviews lasted approximately 45 to 90 minutes (average 60 minutes); separate interview guides were used to capture each group's perspectives. Sample interview questions are provided in Table 2. For older Chinese Americans who were aged ≥58 years and reported caring for very old parents (>80 years old), additional interview questions were added to enrich the data. For instance, they were asked to express how they would prefer EOL care discussions to be conducted with themselves as well as with their parents. The interview guides were modified based on the responses of the participants during the data collection process. Field notes and memos were written following each interview. The interviews were audio-recorded and professionally transcribed.

Table 2. Sample Interview Questions.

1. Tell me a little bit about your Chinese background. (older Chinese Americans and adult children)
2. Tell me a little bit about your background with caring for older Chinese American patients. (Health-care providers)
3. Tell me if talking about the end of a person's life is something that you have ever experienced. Any example? (Older Chinese Americans and adult children)
4. Tell me about any experiences that you have had with people at EOL. What do you think of these experiences? (Older Chinese Americans)
5. Tell me about any EOL care discussion experiences that you have had with older Chinese American patients and their families. (Health-care providers)
6. What are methods that you think may be helpful to initiate or facilitate the conversation with older Chinese Americans/your parents? (Older Chinese Americans, adult children, and health-care providers)
7. What are the suggestions that you would give to health-care providers who do not have much experiences with discussing EOL care with older Chinese American patients? (Older Chinese Americans, adult children, and health-care providers)
8. How would you like to initiate an EOL care discussion with your older Chinese American patients and family? (health-care providers)
9. Would you like health-care providers to initiate an EOL care discussion with you/your parents? If yes, how would you like the health-care provider to initiate the EOL care discussion with you/your parents? (Older Chinese Americans and adult children)

Abbreviation: EOL, end of life.

Data Analysis

Interview transcripts and field notes were analyzed in an iterative, multistep process, starting with open coding. Open codes were examined and sorted to identify focused codes[17] related to assessment, readiness, and communication strategies. Constant comparative analysis[17] was performed within data from each group and among the 3 groups. The first and last author (both nursing qualitative researchers) collated and refined or discarded potential categories and focused codes, and 2 major categories (ie, health-care system integration and HCP practice) were defined and identified. The data set was then reviewed by the first author to confirm the 2 categories and checked for additional missing codes from the early analytical stage. The research team, which consisted of 2 qualitative research experts, 1 geriatric research expert, and 1 EOL nursing professional, discussed major categories and preliminary analysis results. The last 13 participants were given the preliminary analysis results to verify whether the findings were appropriate and reflected their responses. At the 13th participant, no new data emerged, so verification ended. Triangulation was used to strengthen the study's rigor by including multiple methods (eg, interviews and informal field observation), investigators, and categories of participants.[14,18]

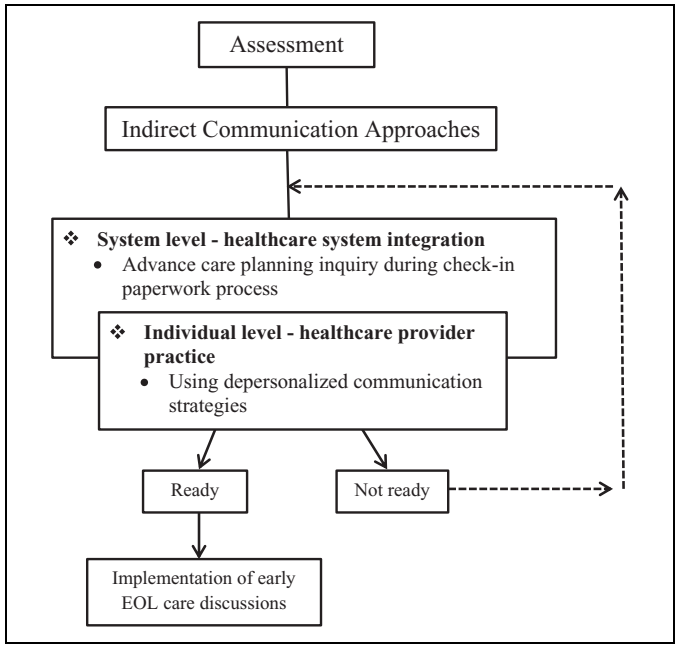

Figure 1. Culturally targeted end-of-life care discussion initiation.

Results

Data indicate a need to assess older Chinese Americans' readiness to engage in EOL care discussions *prior* to a serious or terminal illness. All participants recommended the use of indirect communication approaches, rather than direct questioning, to initiate discussions with older Chinese Americans to determine their readiness. Moreover, they recommended that these approaches should be culturally targeted, meaning that they try to take a group or population's lived experiences, values, and beliefs into consideration. We identified 2 major prerequisites that were instrumental to determine older Chinese Americans' readiness for EOL care discussions: (1) health-care system integration of advance care planning and (2) HCP practice (see Figure 1).

System Level: Health-Care System Integration

Health-care system-level integration includes integrating EOL care discussion inquiries during all patient appointment check-in processes in addition to HCPs' practices, which are implemented at an individual patient level. Integrating a question or 2 about advance care planning in check-in paperwork during health-care visits (eg, hospitals, emergency departments) and outpatient settings was strongly recommended by both older Chinese Americans and adult children to increase older Chinese Americans' awareness of advance care planning and help to engage them in EOL care discussions.

> Maybe put it in writing and just say, when you come in for a general physical, just include that in the general information that, a question…would you be willing to talk about end of life? If they (older Chinese Americans) check no, then of course, and the doctor will know not to ask or let the patient indicate whether or not they

> would be willing to discuss it…The patient can indicate yes or no, or indicate they don't want to respond to the question period. (67-year-old male, older Chinese American)

Although completing an advance directive was not mandatory at all health-care facilities, some require patients with no advance directive to indicate whether they are interested in completing one and/or have an EOL care discussion. For example, a 76-year-old Chinese American, whose 99-year-old father had not previously discussed EOL care, received a routine advance directive inquiry (written question) during an emergency department visit check-in process. The daughter felt the routine inquiry was a nonthreatening and acceptable way to initiate an EOL care discussion with her father who was being checked in to the emergency department. She stated, "This is the best opportunity, as if it's part of the intake that has to be done in the hospital, because there were a lot of other questions that had to be answered."

Individual Level: HCP Practice

At an individual level, HCPs can determine older Chinese Americans' readiness by using depersonalized communication strategies to initiate an EOL care discussion. All older Chinese Americans expressed that they were or would be receptive to EOL care discussion assessment provided by HCPs. A 51-year-old adult child stated, "you can ask them (older Chinese Americans) first, and then the newer generation that's like me, they will talk about it. This is okay…You just bring this question up."

> They (HCPs) probably should initiate an EOL care discussion and see whether the patient wants to respond to it or not. If they (older Chinese Americans) say no, then you just honor them and just annotate it if the patient doesn't want to discuss that. (A 67-year-old older Chinese American)

Adult children stated that HCPs should assess older Chinese Americans' willingness to engage in EOL care discussions during annual examinations and health-care visits, but the assessment with their parents must be done in a way that is indirect, impersonal, and culturally and age appropriate. All participants consistently recommended the use of indirect, culturally targeted communication approaches. As a 72-year-old older Chinese American stated, "It's not straight forward. It's got to be you go around in circles until you finally get to the target." Similarly, a 59-year-old older Chinese American expressed, "If you're too direct, sometimes it's a turnoff. I think you have to bring it up gently." Both older Chinese Americans and adult children explicitly stated that direct communication was not preferred for EOL care topics. As 1 older Chinese American explained, "It [a direct approach] is just like giving them [older Chinese Americans] a shot without any kind of mental preparation."

In the application of the indirect communication approaches at an individual level, our participants suggested that HCPs could perform the assessment by initiating a discussion using depersonalized communication strategies. Depersonalized communication strategies refer to a form of indirect communication that minimizes discussions of an individual's own death and include the following 5 strategies.

Use another person's EOL care experience. All participants most frequently recommended the use of another person's EOL care experience as an example to initiate an EOL discussion. It is important to note that asking older Chinese Americans to imagine themselves in a declined health condition was explicitly discouraged because it may provoke unnecessary anxiety and lead to bad luck, as some Chinese believe that talking about their own death was like inviting death and death will come sooner. Exploring older Chinese Americans' perspectives on another person's EOL care experiences can minimize the sensitivity related to death and dying.

Frame the discussion as a standard question by policy. All participants emphasized EOL care discussions should be framed as a standard question to reduce the sensitivity of the topics regardless of whether or not there was an official policy in place. For example, a primary care physician tried to remove sensitivity of EOL care discussions by using a visualized and generalized technique, by claiming that she completed the physician order for life-sustaining treatment form with all her patients.

Acknowledge cultural taboos and ask for permission. Both older Chinese Americans and adult children suggested that HCPs need to be aware of cultural taboos surrounding EOL topics among older Chinese Americans and should query them about this. Strikingly, no HCPs reported using this strategy to initiate the discussion, instead they emphasized the importance of not stereotyping a specific population with certain cultural characteristics.

Provide a Chinese longevity blessing statement as a prompt or describe a longevity scenario. Both HCPs and adult children recommended integrating a cultural longevity element into assessment inquiries; however, no older Chinese American mentioned this strategy.

Use the provider's own experience as an example. The HCP participants reported that they successfully engaged their patients in EOL care discussions using their own experiences as examples. The HCP participants believed that self-disclosure helps diminish sensitivity related to EOL care discussions by modeling and aligning themselves with patients.

In summary, indirect communication approaches were strongly recommended by all participants and can be delivered by various methods. It is worth noting that during the interview, the first author asked the older Chinese Americans about their Chinese background and then transitioned to discussing their EOL care experiences with others. All the older Chinese American participants were able to engage in the EOL care discussions and none reported distress during the interviews. Supporting quotes for depersonalized communication strategies and proposed initiation prompts are listed in Table 3.

Table 3. Representative Quotes Related to Depersonalized Communication Strategies and Initiation Prompts.

Depersonalized Communication Strategies (Suggested by Whom)	Quotes	Initiation Prompts
Use another person's EOL care experience as an example (suggested by HCPs, older Chinese Americans, and adult children)	"We know that someone in their family has passed away. We asked what the circumstances were. What did they learn from those things? I think it's asking them what their experiences were helps them to take away the stigma from themselves. If imagining themselves in that situation. That's just too much for them." (A social worker, HCP) If there is an incident happened on the news or things happened among their friends or family members, relatives, and then, happens to be brought in the conversation and then, you can observe their attitude and see if they are willing to talk about it." (62-year-old older Chinese American) In thinking about your aunt (she passed away) and what's going on I thought I'd ask you how you feel about that and would you like this (EOL treatments) or not…(41-year-old adult child)	"What do you think about the EOL care experience that you had with ___ (eg, father, mother, a relative)?"
Frame the discussion as a standard question by policy (suggested by HCPs, older Chinese Americans, and an adult child)	What I'm trying to do now is I use the POLST as the trigger for it so I pull out the bright pink piece of paper, and I say, "We're all doing this bright pink piece of paper for all my patients," so they don't feel like they're picked up because they're going to die…I say "you're doing well now…Here's just an opportunity for us to know, we have to fill this form. I'm trying to do this with everybody, it's an opportunity for us to discuss some things that are uncomfortable but I'd like to know what you think about this or if you'd thought about them before." (A primary care physician, HCP) The doctor can say, "…we just want to have this in our record. Would you mind filling this (an advance directive) out, so we will know how to take care of you according to your wish? "So there's no harm, no hard feeling. (64-year-old older Chinese American) The physician can ask, "Starting this year, this is a topic that we ask our patients…" Is the patient ready to talk about it now, or prefer later? If the patient says later…the physician can put a note on the record. (51-year-old adult child)	"If you prefer not to have this discussion, we don't have to talk about it. However, it is our policy that we ask all of our patients."
Acknowledge cultural taboos and ask for permission (suggested by older Chinese Americans and adult children)	Just to be sensitive about what may be superstitious to somebody else…anytime you're dealing with an older Chinese, ask them "Are you superstitious about talking about preparing for death?" (67-year-old older Chinese American) The easiest way to raise up this topic is to make sure the HCP show they understand Chinese culture. You can say, "I know in Chinese culture, we are supposed not to talk about that…" (46-year-old adult child)	"Some of my patients prefer not to discuss EOL care topics. I wonder how you feel about talking about this?"

(continued)

Table 3. (continued)

Depersonalized Communication Strategies (Suggested by Whom)	Quotes	Initiation Prompts
Provide a Chinese longevity blessing statement as a prompt or describe a longevity scenario (suggested by a HCP and an adult child)	After you have reassured them that they're really healthy, just say, "You're healthy… Hopefully I'll be as healthy as you when I get to that age. I wish you live to 100. Do you want to live to 100?" Maybe that's one way to open it. To start off with something positive and move on to seeing whether they have given any thought to this. (A primary care physician, HCP)	"I wish for you longevity that you live to 100 years old (長命百歲). Do you want to live to 100 years old or older?"
	You can talk about, "when you get older, you have this kind of problem, 80 years old, you need to have your cane with you and 90 years old maybe you need to have somebody take care of you. Maybe 100, you die."…If you want to just step in the topic directly, that's not a good idea. (46-year-old adult child)	
Use the provider's own experience as an example (suggested by HCPs and an adult child)	Another technique I use with my older patients who are still quite healthy, especially if they're approaching their late 80s, I would tell them the story of my mother, who lived until 92. When she was in her late 80s, she told me…(A primary care physician, HCP)	"My mother/father told me what she/he would want at the end of his/her life."
	I tell them I also have one (an advance directive) done, so that they can see I'm younger and that there is a value. (A social worker, HCP)	"I completed an advance directive as well."
	Maybe if you're trying to bring it up to someone, you can talk about your own personal plan first and say, "I've been thinking about what might happen to me when I pass away, and this is what I would like. What would you like?" (34-year-old adult child)	

Abbreviation: HCP, health-care provider; EOL, end of life; POLST, physician order for life-sustaining treatment.

Readiness for EOL Care Discussions

All participants suggested readiness could be determined by observing older Chinese Americans' attitudes, verbal and nonverbal responses to the initiation prompts, and the HCPs' clinical judgment. As a palliative care social worker stated, "we throw a little bit out there and you see what is their response. Sometimes people don't want to talk about it, they'll just like [no facial expression]…If they want to talk about it, they will ask you." Similarly, a 67-year-old older Chinese American stated, "you feel it [the HCP]…you can say a word or two that will lead you, whether you can lead it on or not."

Implementation of EOL Care Discussions

Older Chinese Americans and adult children perceived that health-care encounters could serve as a good opportunity to discuss EOL care with the approval of the older Chinese Americans. The HCPs should assess the readiness of older adults using advance care planning inquiries during the check-in process and/or by initiating the discussion using the proposed prompts. Based on HCPs' clinical judgment, if HCPs sense that older Chinese Americans are ready and willing to have the discussion, they can then proceed to discuss EOL care planning. If the older Chinese American is not ready for the discussion, HCPs should note this and reassess at a later time.

Discussion

The EOL care discussions are culturally appropriate to conduct with older Chinese Americans as long as they are ready to do so. Our findings suggested that it is important for health-care facilities and HCPs to take the initiative to assess older Chinese Americans' readiness by using indirect communication approaches to initiate the discussion. Moreover, our study extends the current literature by demonstrating how indirect communication approaches can be culturally targeted and applied at both system-wide and individual levels.

All participants suggested that the assessment is an essential and necessary step, which is consistent with the literature.[19,20] Furthermore, our findings supported the use of indirect communication approaches to determine older Chinese Americans' readiness for early EOL care discussions, and our HCP participants have successfully used this approach as an icebreaker to

engage older Chinese Americans in the discussion. A superstition held by some Chinese people is that talking about EOL may invite death to come sooner. This increases the sensitivity of discussing EOL care with older Chinese Americans. Consequently, it is considered disrespectful by some to raise such discussion to Chinese seniors.[21-23] Therefore, it is important to initiate an EOL care discussion "gently" with Chinese seniors. Indirect communication approaches also have been found to be the preferred EOL care discussion strategy among various ethnic groups, such as Southeast Asians.[13,24,25] In a systematic review of indirect patient communication about EOL, the authors found that this approach was a "gentle way of 'pushing at the door' of the topics—which some patients take up and some deflect."[26]

Building advance care planning inquiry into the check-in procedures builds indirect communication into health-care systems. The participants' responses indicated that for Chinese Americans, this approach aligns with the essential principle of indirect communication since it diminishes the pressure of face-to-face, verbal communication with HCPs. This approach also offers the patient the opportunity to decline EOL care discussions nonverbally or outside the presence of HCPs. Standardizing the EOL care discussion by policy may minimize the taboo. For those Chinese Americans who indicate they do not want to have EOL care discussions in an intake query, HCPs can use their clinical judgment to determine whether there is an urgent need to address EOL care or use the initiation prompts to reassess their patient's readiness if appropriate.

The HCPs using depersonalized communication strategies to initiate the EOL care discussions can help providers to determine Chinese Americans' readiness. The 2 strategies that are consistently recommended by all 3 groups are using another person's EOL care experience as an example and framing the discussion as a standard question by policy. Uniquely, acknowledging the cultural taboo and asking for permission were only mentioned by older Chinese Americans and adult children, not by HCPs. Our interpretation is that, on one hand, HCPs in the San Francisco Bay Area have learned about Chinese American cultural characteristics. On the other hand, these HCPs are educated about the importance of not stereotyping patients based on their ethnicity. As a result, HCPs avoid verifying their own preexisting cultural assumptions with their patients. Nonetheless, older Chinese Americans and adult children recommended that HCPs' preexisting cultural knowledge can be tailored and used as an initiation prompt with their patients. The 2 strategies supported by HCPs and adult children (but not older Chinese Americans) were integrating a cultural longevity blessing to the assessment inquiry and using the provider's own experience as an example. Thus, further research is needed to explore whether older Chinese Americans would appreciate these 2 strategies.

Limitations and Strengths

This was a qualitative focused ethnography, so findings may not be generalizable to a broader population. The older Chinese Americans were English speaking, educated, physically active, and living without a terminal illness, so our results do not apply to all Chinese Americans. However, this was the first study that focused on communication strategies to initiate early EOL care discussions with older Chinese Americans. We emphasize the voices of older Chinese Americans, adult children, and experienced HCPs who care for this population because they are key informants who can help less experienced HCPs facilitate EOL care discussions with older Chinese Americans.

Practice Implications and Conclusions

Indirect communication approaches can be applied at both system-wide and individual levels to assess older Chinese Americans' readiness for early EOL care discussions. The use of culturally targeted communication strategies to initiate EOL care discussions can promote engagement of this group. Thus, health-care facilities should consider implementing the EOL care discussion inquires in their check-in routine intake paperwork. The HCPs can implement and evaluate the suggested initiation prompts provided here with their older Chinese American patients to see whether they are helpful. Future studies are needed to further investigate the effectiveness of the proposed communication strategies.

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Declaration of Conflicting Interests

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