Talk About Death: End of Life Planning with a Virtual Agent

Dina Utami,[1] Timothy Bickmore,[1(✉)] Asimina Nikolopoulou,[1] Michael Paasche-Orlow[2]

[1] Northeastern University, Boston, MA 02115, USA
[2]Boston Medical Center, Boston, MA 02118, USA
bickmore@ccs.neu.edu

Abstract. For those nearing the end of life, "wellness" must encompass reduction in suffering as well as the promotion of behaviors that mitigate stress and help people prepare for death. We discuss the design of a virtual conversational palliative care coach that works with individuals during their last year of life to help them manage symptoms, reduce stress, identify and address unmet spiritual needs, and support advance care planning. We present the results of an experiment that features the reactions of older adults in discussing these topics with a virtual agent, and note the importance of discussing spiritual needs in the context of end-of-life conversations. We find that all participants are comfortable discussing these topics with an agent, and that their discussion leads to reductions in state and death anxiety, as well as significant increase in intent to create a last will and testament.

Keywords: conversational agent, relational agent, spirituality, palliative care.

1   Introduction

Palliative care is a medical specialty that helps people with serious, typically life-limiting illnesses, and focuses on the alleviation of suffering, rather than on curing an underlying medical condition. Areas of care include the alleviation of pain, and other physical symptoms such as nausea, as well as the treatment of mental health conditions such as stress, anxiety, and depression. In the US, palliative care is distinct from hospice care, with the latter being explicitly concerned with end of life relief measures, although palliative services are offered during hospice care as well.

While palliative care has the potential to greatly improve quality of life in terminally-ill patients, in the US it is typically provided only during the last few days or weeks of a patient's life, even when patients could have benefitted from these services months earlier. Indeed, many patients have inadequate control of their symptoms and one third of hospice patients die within a week of initiating hospice services. Accordingly, identifying mechanisms to initiate palliative and hospice care earlier in a person's disease trajectory has become a strategic priority for quality improvement efforts [1].

To help address this need, we have been developing a virtual agent that plays the role of a palliative care coach, supporting patients directly and identifying opportunities for referral to human palliative care specialists or other resources. Our goal is to offer this agent to terminally-ill patients while they are in their last year of life, so that they can benefit from the alleviation of suffering that the agent may be able to provide.

One important aspect of palliative care that is frequently overlooked by medical professionals is a patient's spiritual needs. Spirituality is a complex construct, but is broadly recognized as a core dimension of palliative care [2]. For many patients, religion and spirituality can empower them by promoting broader perspectives on illness and mortality. This can help patients transcend anxiety relating to their immediate physical condition and provide support for coping with their advanced illness. One fundamental question in developing a virtual palliative care agent is whether patients would even accept spiritual counseling from an agent and, if they did, how should the agent relate to patients' religion, spiritual beliefs, and practices.

In this work we report the preliminary design of a virtual palliative care agent and results from an empirical study investigating how accepting older adults are of the concept. To specifically test acceptance of spiritual counseling by the agent, we created three versions of it with varying degrees of spiritual involvement, so as to determine whether there is a limit to how engaged older adults would want an agent to be in their religious and spiritual life.

2　Related Work

A number of virtual agents and robots have now been developed to counsel patients on health problems in general, and mental well-being in particular [3, 4]. Many researchers have also explored agents and robots as a social companion for older adults to address loneliness and isolation [5]. However, only one study to date describes a robotic companion that supports spiritual activities, including reading the bible [6]. For many people, religion and spirituality are private matters, and thus studies investigating self-disclosure with virtual agents are of relevance [7].

Although agent-based spiritual applications are rare, there are a very large number of commercial applications available that do not use agents, in addition to several research projects. Sterling and Zimmerman studied a Zen Buddhist community and noted that engagement in communal meditative sessions and other related practices via technology applications boosted users' sense of religiosity and their connectedness with their community [8]. Similarly, Hlubinka et al. developed AltarNation, an interactive environment using telepresence for meditation purposes, and noted positive outcomes in enhancing community engagement by minimizing physical distance [9]. Buie and Blythe studied meditation videos online and found that they are positively reviewed by users, in spite of the distraction of abrasive commentary and advertising [10]. Wyche et al. discussed the use of Podcasts, Powerpoint, email and other networked technologies in "spiritual formation," a deliberate process of spiritual life transformation via prayer, study and discussion with one's community in a Chris-

tian church, and noted varied efficacy of such technologies depending on the audience [11]. In another study, Buie and Blythe outlined the most prevalent instances of applications based on Bell's definition of "technospiritual practices," including Sonic Cradle by Vidyarthi, Riecke and Gromala, which aims to create a sense of immersion and mindfulness in meditative settings [12]. Finally, Wyche et al. discussed application design for faith-related purposes, and emphasized the importance of imagery integration in "Sun Dial," a prayer reminder tool that increased users' sense of connectivity with their communities of practice [13].

3   Design of a Virtual Palliative Care Agent

We have designed a touchscreen tablet-based virtual agent that counsels terminally-ill patients on topics related to palliative care (Figure 1). The agent is animated in a 3D game engine and speaks using synthetic speech driven by a hierarchical transition network-based dialogue engine. Conversational nonverbal behavior is generated using BEAT [14], animated in synchrony with speech, and includes hand gestures, posture shifts, head nods, and facial displays. User contributions to the conversation are made via a multiple- choice menu of utterances updated at each turn of the conversation.

Fig. 1. A Mobile Embodied Conversational Agent

To test the acceptability of our palliative care agent, we designed the initial system to discuss three death-related topics with users: last will and testament, healthcare proxy, and funeral preparations. A will or testament is a legal document in which someone describes their wishes regarding how their property is to be distributed after they die. A healthcare proxy designates another person who can make healthcare decisions for them if they are unable to make or communicate those decisions. In each topic, the agent describes the content, explains why it was important for anyone to address the topic, and then provides details and answers to frequently asked questions. These topics are related to end-of-life decision-making, and are relevant to everyone even if they are not terminally ill.

3.1 Spiritual Counseling

We also designed a spiritual counseling dialogue for initial evaluation and acceptance testing. The dialogue asks users about their spiritual orientation, specific religious beliefs, family religious background, religious practices, and beliefs regarding the meaning of death. The dialogue accounts for six major religions (Christianity, Judaism, Islam, Hinduism, Buddhism and Sikhism), as well as for atheism, spiritual humanism, and secular humanism.

AGENT:	*So, I am really interested in the relationship between religion and spirituality. Do you consider yourself spiritual, religious, both, or neither?*
USER:	*I would rather call myself religious, which I think is different from spiritual.*
AGENT:	*That's an interesting distinction to make. How would you identify your religion?*
USER:	*I'm Jewish.*
AGENT:	*I wish I knew more about Jewish traditions. Were you raised religiously?*
	Yes, I was.

Fig. 2. Excerpts from the PRO-SPIRITUAL Dialogue with a Jewish User

AGENT:	*So, I am really interested in the relationship between religion and spirituality. Do you consider yourself spiritual, religious, both, or neither?*
USER:	*I would say I'm spiritual, but not religious.*
AGENT:	*OK, great. Would you call yourself a Spiritual Humanist?*
USER:	*I don't know. What does that mean?*
AGENT:	*A Spiritual Humanist believes in some kind of spiritual life without subscribing to the beliefs or practices of a religious system, and above all, he or she believes in the innate value and dignity of human life.*
USER:	*I would say I'm a Spiritual Humanist.*
AGENT:	*OK, so were your family religious when you were growing up?*
USER:	*No, they were spiritual, but not conventionally religious.*

Fig. 3. Excerpts from the PRO-SPIRITUAL Dialogue with a Spiritual Humanist User

In order to support testing of our research question concerning the degree of religious involvement the agent should demonstrate, we created two versions of this dialogue. In the NEUTRAL version, the agent simply takes note of the user's responses, and adapts dialog as necessary to reflect utilitarian/functional use of the information in subsequent dialog, but otherwise no interest or follow-up. In the PRO-SPIRITUAL version the agent takes active interest in the user's spirituality, tailors dialog to the user's religious orientation, demonstrates knowledge of the user's religious beliefs and orientation, and acts supportive.

Design decisions on the spiritual module have taken into consideration ethical concerns about the agent's engagement with spirituality and religion. We were specifically concerned with discussions that could be construed as blasphemous, deceitful, or indicative of misplaced trust. We also ensured adequate representation of all beliefs and provided pluralistic options for user responses in order to minimize any feelings of coercion, discomfort or unrest. The project team included representatives from six religious and spiritual backgrounds, who worked collaboratively throughout the length of the study to ensure that the dialogue was appropriate. In addition, the PRO-SPIRITUAL dialogue was reviewed by two different hospital chaplains to ensure that the content was thorough and respectful. Figures 2 and 3 shows excerpts of the PRO-SPIRITUAL dialogue.

4 Acceptance Study

We conducted an exploratory study to determine the reaction of older adults to discussing end-of-life topics with a virtual agent, and to examine the importance of spirituality within the context of this conversation. We recruited older adults (55 and up) for the study, since we felt that end-of-life planning would be more relevant to them than to a younger population. The study was conducted in a single session in a usability laboratory and was approved by our University Institutional Review Board.

All participants discussed the three end-of-life topics with the agent. To evaluate different levels of religious involvement by the agent, the study was conducted as a between-subjects randomized experiment with three arms:
1. CONTROL. The agent does not discuss spiritual needs at all.
2. NEUTRAL. The agent includes the NEUTRAL spiritual dialogue in the end-of-life discussion at the end of the interaction.
3. PRO-SPIRITUAL. The agent includes the PRO-SPIRITUAL dialogue in the end-of-life discussion at the end of the interaction.

4.1 Measures

In addition to sociodemographic measures, participants were asked to fill out the following self-report measures:

1. Death anxiety: Assessed at intake and after interacting with the agent using the Death Anxiety Scale (DAS) questionnaire. Representative questions include "I am very much afraid to die", and "I am often distressed by the way time flies so very rapidly" [15]. We used the version of DAS with 7-point Likert-scale, which has been shown to have higher internal consistency and discriminability [16].
2. State Anxiety: Assessed at intake and after interacting with agent using the State-Trait Anxiety Inventory (STAI) [17]. STAI has 20 items for assessing state anxiety. State anxiety items include: "I am tense; I am worried" and "I feel calm; I feel secure." All items are rated on a 4-point scale (e.g., from "Almost Never" to "Almost Always").

3. Death preparation stages of change: Assessed before and after interacting with the agent. We first asked participants whether they have already made a funeral plan, written their last will and testament, and filled out a health care proxy form. For each item, if a participant indicated that they had not, we asked them how likely they would be to complete these preparations in the following year.
4. Working Alliance: Working alliance is the trust that a patient has in working with a counselor or healthcare provider to achieve particular therapeutic goals. This was assessed after interacting with the agent using the bond items from the Working Alliance Inventory (WAI) [18].
5. Participant attitude towards agent: Assessed after interacting with agent using 12 single-item questions on a 7-point scale (Table 1).

4.2   Participants.

We recruited 44 older adults (24 males, 20 females, ages 55-82, mean 61.5) via an online advertisement, with 16 randomized to CONTROL, 11 to NEUTRAL, and 17 to PRO-SPIRITUAL. Of these 44 participants, 45% reported that they have at least one chronic health condition, 93% had spent time with someone who was dying, and 64% had some knowledge of advance directives (legal instructions on what medical care they should receive if they are incapacitated). Our participants had varying degrees of computer experience and educational backgrounds, ranging from not graduating high school to having an advanced degree. When the agent asked whether the participants were secular, spiritual, or religious, 22 answered religious, 15 answered spiritual, and 7 answered secular. Of the religious participants who volunteered their religious affiliations to the agent, 4 self-identified as Catholic, 3 as Christian, and 2 Jewish.

4.3   Quantitative Results

State Anxiety. There was a significant decrease in state anxiety during the interaction with the agent (PRE: 29.7 (8.7), POST: 27.8 (8.9), Wilcoxon signed rank, $p<.05$).

Death Anxiety. There was a trending decrease on death anxiety during the interaction with the agent (PRE: 3.82(1.04), POST: 3.71 (0.98), paired t, $p=0.096$).

Death Preparation Stages of Change. Of the 44 participants, 32 reported that they did not have a last will and testament, 33 had not shared their funeral plans with their family, and 20 had not filled out a health care proxy form. There was a significant increase in participants' intention to complete a last will and testament after talking to the agent (PRE:3.83(2.26), POST:4.27(2.43), Wilcoxon signed rank, $p=0.05$). We found no significant differences between pre and post intentions to write and share funeral plans or health care proxy forms.

Agent Rating. In general, participants were satisfied with the agent, wanted to continue working with the agent, and found it easy to talk to the agent. Participants also felt

that the agent was honest, trustworthy, and likable. We found significant differences between study arms in the agent's rating of repetitiveness, ease of use, and interestingness, with the PRO-SPIRITUAL agent rated the most interesting (Table 1).

Table 1. Agent's Rating by Study Group (Kruskal-Wallace H-tests)

Question (Anchors 1-7)	CONTROL Mean (SD)	NEUTRAL Mean (SD)	PRO-SPIRITUAL Mean (SD)	p-value
How close do you feel to the agent? (Not at all – Very close)	2.94 (1.95)	3.45 (1.69)	4.06 (2.33)	.39
How satisfied are you with the agent? (Not at all – Very satisfied)	4.88 (1.89)	5.82 (1.17)	4.82 (1.94)	.35
How much would you like to continue working with the agent? (Not at all – Very much)	4.56 (2.03)	5.91 (0.94)	4.71 (2.14)	.21
How much do you trust the agent? (Not at all – Very much)	4.81 (2.01)	6.09 (1.04)	5.53 (1.37)	.21
How much do you like the agent? (Not at all – Very much)	4.75 (1.81)	5.27 (1.74)	5.12 (1.76)	.76
Was the agent repetitive? (Not at all – Very repetitive)	4.56 (2.03)	2.94 (2.3)	1.73 (0.9)	.01
How easy was talking to the agent? (Easy – Difficult)	3.13 (2.00)	1.45 (1.51)	2.59 (2.06)	.02
How interesting was the agent? (Boring – Interesting)	3.56 (1.93)	4.55 (1.51)	5.12 (1.65)	.04
How would you characterize your relationship with the agent? (Complete stranger – Close friend)	3.44 (2.13)	3.00 (2.19)	3.41 (2.24)	.80
How much do you feel that the agent cares about you? (Not at all – Very much)	3.87 (2.33)	4.18 (2.32)	3.71 (2.44)	.82
How much do you feel that you and the agent understand each other? (Not at all – Very much)	4.73 (2.05)	5.36 (1.91)	4.47 (2.21)	.56
How much do you feel that the agent was honest about her feelings towards you? (Not honest – Very honest)	4.33 (2.41)	5.2 (1.87)	5.29 (1.69)	.56

Working Alliance. We found no significant differences between study groups on working alliance scores (all: 4.53 (1.24), CONTROL: 4.39 (1.39), NEUTRAL: 4.42 (1.12), PRO-SPIRITUAL: 4.73 (1.23)).

4.4 Qualitative Results

In general, we found that participants had positive impressions of the experience. The agent was positively evaluated as, "*very easy to work with*" [p4: 56 M Catholic], "*self-explanatory*" [p5: 57 M Spiritual Humanist], "*thorough, thoughtful and pleasant*" [p16: 56, F, Religious Unspecified], "*open, honest and able to speak with a great deal*

of clarity" [p6: 58 F Protestant]. Reflecting on the topic of the conversation, participants noted that, "*it was thought-provoking*" [p5: 57 M Spiritual Humanist] and "*it gave one an opportunity to think about these matters*" [p6: 58 F Protestant].

The agent managed to evoke conversations that the participants have had with human interlocutors in the past and to instigate new ones, thus informing a more holistic mindset towards death and death preparation. Most participants indicated that the conversation was a reminder of something that was "*in the back of [their] mind*" [p15: 56 M Religious/ Unspecified]. A participant also stated: "*I already knew about health proxy but the two other things, I've never thought about those things. The funeral and the will I haven't thought about those because I'm all about living my life, I didn't think about those arrangements.*" [p13: 63 M Spiritual Humanist]

Participants noted the benefits of including spirituality in end of life discussions, especially on the preparation front: "*Well it's important especially when you have to take into context the funerals, arrangements that must be made, different religions have different aspects you know. Jewish religion has to be buried right away while Catholics can wait you know with the funerals homes and everything and um, it all has to be taken into account.*"[p43: 61 F Catholic]; *"Yes. Because you are given a certain level of peace of mind.* [p6: 58 F Protestant]; *"Oh yes, I know God has more plans for me and I'll never be shy about talking about that. He ain't done with me yet." [p20: 62 F Christian];"Huge yeah, whatever that spirituality means for the person." [p36: 55 M Catholic]*

The reactions to the spirituality discussion with the agent were mixed. Some participants said that they didn't mind discussing spirituality with an agent but thought that it might be intrusive or too personal for other people. Some participants said that the level of detail was just enough for it not to be intrusive, while others suggested that we add more depth to it. This finding brings to light the importance of tailoring the inclusion and/or the depth of the spirituality discussion to users' specific need. One user suggested that we add the options "*can we change the topic?*" or "*I don't even want to talk about that subject.*" for users who find spirituality to be a very personal subject [p6: 58 F Religious].

When we asked whether they would rather talk about spirituality with a person than an agent, twelve participants indicated that they would prefer to talk to a person: "*Like I said it was nice talking to Tanya about it, but as for specifics in the end I need someone who [is] like the person who's going to be doing this for me. I guess what I liked best was what she made me think about spirituality and religion*" [p29: 55 M Secular humanist]. Eight participants said they have no preference: "*Doesn't matter. She was very friendly though and I liked talking to her a lot, I could trust her like she was a real person sitting in front of me*" [p20: 62 F Christian]. And, seven participants said they would prefer talking to an agent: "[...] *easier to talk to a computer agent about it. People tend to be pretty opinionated about that stuff, especially when they get to be around my age*" [p40: 57 M Spiritual].

5 Discussion

This study demonstrates that older adults react positively to an agent talking about end of life preparation. Older adults are comfortable discussing these topics with an agent and the discussion leads to significant reduction in state anxiety and a significant increase in intent to create a last will and testament. We also found that, regardless of their religious or spiritual background, participants thought that an agent discussing their spiritual orientation and demonstrating knowledge of and interest in their spirituality was significantly more interesting, less repetitive, and easier to talk to than an equivalent agent that did not discuss their spirituality at all.

5.1 Future Work

There are many interesting areas of research related to palliative care and spiritual counseling delivered by virtual agents. Rather than feeling uncomfortable with more religious involvement by the agent, our users indicated they wanted even more spiritual involvement in these conversations. Whether users will actually want significantly more involvement—in activities such as prayer with or by the agent—remains to be seen.

We have expanded the palliative care agent into a longitudinal palliative care support system encompassing the following topics: (1) physical activity promotion, (2) symptom tracking and medication promotion (3) stress reduction, (4) spiritual needs assessment and counseling, and (5) advanced care planning. The system tracks user progress on behaviors of interest (e.g., exercise) and also tracks user symptoms and quality of life ratings to provide comparative feedback and recommendations (e.g., "Sorry to hear your pain is worse. Do you have medication for that?"). The spiritual counseling module supports a range of religious activities, such as praying, fasting, studying sacred verse/ scripture, and reflecting on past holidays. The system is designed to interact with patients at home for six months, as well as to provide communication channels to a nurse monitoring the system and a family caregiver. A clinical trial is underway.

Acknowledgments

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