

# Muslim perspectives on advance care planning: a model for community engagement

Alya Abbas Heirali, Sidra Javed, Zaheed Damani, Rahim Kachra, Sabira Valiani, Al-Karim Walli, Philippe Couillard, Rose Geransar, Jessica Simon and Safiya Karim 

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## Abstract

**Background:** Advance care planning is the process of communicating and documenting a person's future health care preferences. Despite its importance, knowledge of advance care planning is limited, especially among the Islamic community. In addition, little is known about how the Islamic community views advance care planning in the context of their religious and cultural beliefs.

**Objectives:** We aimed to increase knowledge of the importance of advance care planning, to improve health care provider and public knowledge, and to encourage dialogue between the community and health care providers.

**Methods:** We organized a community event and assembled a multi-disciplinary panel. Through a moderated discussion, the panel members offered their perspectives of advance care planning within a Muslim context.

**Results:** Approximately 100 individuals attended the event including community members, health care providers, medical students, and faith leaders. More than 90% of respondents rated the event as very good or excellent, found the session useful and were encouraged to reflect further on advance care planning.

**Conclusion:** This event was successful in raising awareness about advance care planning within the Islamic community as well as educating health care providers on Islamic views. This model of community and health care provider engagement may also be beneficial for other faith groups wishing to discuss advance care planning within their respective religious and cultural contexts.

**Keywords:** advance care planning, community engagement, Muslim

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## Introduction

Community engagement is defined as “a process of working collaboratively with groups of people who are affiliated by geographic proximity, special interests, or similar situations, with respect to issues affecting their well-being.”<sup>1</sup> Potential benefits of community engagement in health care include: more informed decision-making, an increased sense of involvement and responsibility, an increased range of ideas and options for improvements in health, and increased credibility for health providers.<sup>2</sup>

The importance of community engagement in the promotion of advance care planning (ACP) has been emphasized by several organizations.<sup>3</sup> In November 2019, a group of medical students, post-graduate trainees, and physicians from Cumming School of Medicine at the University of Calgary organized community engagement session entitled: “Muslim Perspectives on Advance Care Planning.” The purpose of this session was to raise awareness around ACP in the context of religious and cultural beliefs of the Islamic community.

Correspondence to:  
**Safiya Karim**  
Tom Baker Cancer  
Centre, Division of Medical  
Oncology, Department of  
Oncology, University of  
Calgary, Calgary, AB T2N  
4N2, Canada  
[safiya.karim@albertahealthservices.ca](mailto:safiya.karim@albertahealthservices.ca)

**Alya Abbas Heirali**  
**Zaheed Damani**  
**Al-Karim Walli**  
Cumming School of  
Medicine, University of  
Calgary, Calgary, AB,  
Canada

**Sidra Javed**  
**Rahim Kachra**  
Department of Medicine,  
University of Calgary,  
Calgary, AB, Canada

**Sabira Valiani**  
Department of  
Medicine, University of  
Saskatchewan, Calgary,  
SK, Canada

**Philippe Couillard**  
Department of Critical  
Care Medicine, University  
of Calgary, Calgary, AB,  
Canada

**Rose Geransar**  
Faculty of Veterinary  
Medicine, University of  
Calgary, Calgary, AB,  
Canada

**Jessica Simon**  
Department of Oncology,  
University of Calgary,  
Calgary, AB, Canada

## Background

ACP is a process

that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of ACP is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness.<sup>4</sup>

ACP helps to ensure person's values are known if they lose capacity for communicating these themselves. A loss of capacity occurs commonly toward the end-of-life (EOL) when people are seriously unwell<sup>5</sup> and because of this ACP is often associated in people's minds with end-of-life (EOL) care. ACP and how people are cared for during serious illness are important aspects of quality medical care and have social, ethical, and economic implications.<sup>6-8</sup>

The international framework for ACP acknowledges the significance of integrating the aspects of spirituality and religious values and beliefs into planning practice.<sup>9-11</sup>

Therefore, it is important for health care providers to understand the views of different religious and cultural groups on ACP and EOL care.

The Islamic faith consists of two major schools of thought: the Shia and the Sunni.<sup>12</sup> Within these branches, there are similarities and differences in the approach to ACP and EOL care. Furthermore, ethnic and cultural factors can also influence how one views the topic of ACP.<sup>13</sup> For some Muslims, ACP is a foreign concept that is rarely discussed.<sup>14</sup> As a result, there may be a gap in understanding between a Muslim patient and their health care team when it comes to discussing ACP or EOL care.

Several studies have explored the views of the Islamic community with respect to ACP. In 2016, the WOOLF institute in the United Kingdom conducted a focus group of Muslim individuals greater than 50 years old and found that many families will put off uncomfortable conversations about care planning until a time when they become sick or are suddenly unable to communicate their wishes.<sup>15</sup> However, further research has also shown that individuals from the Muslim community were keen to learn about and were receptive to the concept of ACP.<sup>13</sup> Conclusions

from these and other studies have recommended community-based initiatives to raise awareness of ACP and how these concepts can be adapted and facilitated within their faith teachings.<sup>3,14,15</sup>

## Objectives

The overall aim of our project was to understand the current Islamic views on ACP and EOL care, in an urban, multi-ethnic, Canadian context and to encourage dialogue between health care professionals and the Islamic community. We sought to engage the Sunni and Shia communities including members from the Persian, Arabic, East-Asian communities among others.

The specific objectives of this project were:

1. To improve knowledge of clinically relevant Islamic teachings regarding end-of-life care.
2. To encourage dialogue between the Islamic community and health care providers regarding important aspects of ACP and EOL care.
3. To explore the perceptions and ideas of the Muslim community to successfully initiate ACP conversations within their families as well as with health care providers.

## Methods

### *Design of the event*

*Content and format.* The concept of this project was initiated by a group of interested physicians, residents, post-doctoral, and undergraduate medical students from the Cumming School of Medicine at the University of Calgary, most of whom identified as Muslim. We were motivated by our personal and professional experiences of ACP and a desire to improve Islamic community members' and health care providers' dialogue on the synergies and tensions inherent in ACP. Initial planning began in October 2018 and monthly meetings were subsequently held. After several meetings, we determined that the best format for this event would be to present a personal patient and family-centered story of ACP followed by a moderated panel discussion. We selected a panel that consisted of:

1. A patient-family member.
2. Two Islamic scholars (one from the Sunni faith and one from the Shia faith)
3. A health care professional (a Medical Oncologist).
4. A clinical ethicist.

We chose the patient representative to be a Muslim woman who had personal experience with the benefits of ACP. She shared her experience with her mother who was diagnosed with metastatic breast cancer, and how having ACP discussions over time helped her and her family to better understand her mother's wishes and to communicate these to their health care team.

We chose a moderator for the event who had experience with public events (local TEDX organizer) but limited knowledge of ACP and therefore approached the topic with curiosity and with a similar approach as would a Muslim community member. The moderator was provided with the following four questions to ask the panelists, with the ability to add follow-up questions based on the responses:

1. What is ACP?
2. Why is ACP important?
3. Why do we find ACP so difficult to talk about and are there any teachings from Islam to guide us on how to approach ACP?
4. How can we start thinking/talking about ACP?

#### *Description of the event*

**Venue.** This symposium was held at the Genesis Center, a large recreational, community center in Northeast Calgary with a large immigrant population. The center often holds community programs and is a familiar location for members of the Islamic community. We held the event on a Sunday afternoon from 2 to 4 pm in early November 2019. We ensured that the event did not conflict with any religious holidays or events.

**Marketing and advertising.** Our target audience for the event was members of the Muslim community as well as health care professionals who would benefit from understanding views toward ACP within a Muslim context. Two posters were designed that included a brief description of the event, panel members, date and time, and venue. These were widely distributed to various health care providers, hospitals, Islamic community groups, and mosques through the use of print advertising, email, and social media. An Eventbrite page was created with a link for free registration for the event. Press releases were sent to various television and radio news channels. On the morning of the event, a local news channel

interviewed Dr. Safiya Karim, one of the organizers as well as the health care provider panelist.

**Cost of the event.** The event was sponsored by one-time donations from the Departments of Oncology and Critical Care Medicine at the University of Calgary, Calgary Zone Advance Care Planning Goals of Care Designation Program and the O'Brien Institute for Public Health at the University of Calgary. The total cost was approximately dollars \$1400 for food, venue, and materials.

#### **Results**

The event took place on November 03, 2019. There were approximately 100 individuals in attendance. Before the program started, samosas and chai were served. Attendees were sat at tables set up for about 6 to 8 people, one facilitator (medical student or organizing committee) at each table and encouraged discussions using "Conversation Starters" (Box 1). Cards and pens for writing their questions about ACP and feedback forms were also on each table. A children's activity table was set-up in the room but only one child attended and sat with her family. No ethics board review was requested for this community event.

The program began with the recitation of a few Quranic verses followed by Indigenous land acknowledgment. This was followed by the story from the patient representative and the moderated panel discussion. The last 20 minutes of the event was dedicated to a brief question/answer period from the audience. In addition, a booth was set up at the back of the room by the local health region ACP team to provide and offer attendees handouts on ACP, personal directives, and goals of care.

#### **Box 1.** Conversation starters.

- What activities do you do that give you joy? (eg. Hobbies, being with family, eating, etc.)
- What does it mean to "live well and die well"?
- If you were diagnosed with a terminal disease, who would you like to be there for you?
- Do you know what your family or close friends would want in a medical emergency?
- What abilities would you be willing to give up to spend more time with your family?

Important insights from the panel included that ACP is in keeping with the teachings of Islam, in that our physical life on this earth is limited, and it is important to consider and plan for our death, just as we would plan in others domains of our life, for example, our finances. The Imam shared how he asks people to reflect when they say they are “leaving it to God” whether they also left it to God when they chose what work to do or for purchasing car insurance. The health care provider anecdotally told stories of various patients who did and did not have an ACP and how this could affect family dynamics at the EOL. The clinical ethicist provided guidance on the dilemmas families face when they are making decisions uncertain of what their loved one would want. He also drew on his personal experiences with the death of a family member and how this prompted him to have conversations with his sisters about their own values and wishes for their health care.

The audience questions touched on concerns about Islamic perspectives on medical treatment decisions like “Is it ever appropriate to forgo attempted Cardio-pulmonary resuscitation.” There were 13 questions submitted but time for only two to be answered by the panel.

At the end of the event, participants were invited to chat informally with the panel members and were asked to complete an anonymous survey that evaluated their overall experience with the event; its usefulness in their health care; and any improvement suggestions for similar future events.

Forty four evaluation forms were completed. Formal demographics were not collected; however, attendees ranged in age from young adults to senior citizens. More than 90% of the respondents rated the event as very good or excellent and found the information useful. More than 90% of respondents stated that the session encouraged them to reflect on ACP. Attendees appreciated the panel format, sharing of personal experiences, and the multiple perspectives on the panel. One community member commented “I enjoyed learning about how advanced care planning fits into my faith and responsibility as a Muslim.” Feedback from a non-Muslim physician included that he “learned practical language to use while having such type of discussions with a Muslim family.” Community members and health care professionals expressed interest in continuing these discussions within a smaller, focused audience. Networking connections were formed, for example, between the health

## Box 2. Lessons learned.

### Would do again:

1. Hold the event in the community with no cost to participants.
2. Assemble a diverse panel of speakers.
3. Start with a patient story.

### Would change for next time:

1. Providing more time for questions or scheduling time for small group Q&A at the tables after panel discussion might have allowed more dialogue between attendees.

region ACP team and a local volunteer coordinator for Islamic seniors programs. Attendee’s suggestions for future events and lessons learned are summarized in Box 2.

## Discussion

We aimed to organize a community-based event on ACP to better understand the Islamic views on ACP and EOL care and to encourage dialogue between health care professionals and the Islamic community.

There have been several initiatives on engaging and educating the public on ACP. The British Columbia Center for Palliative Care (BCCPC) conducted a project using peer-facilitated group activities to improve public engagement in ACP.<sup>16</sup> Rather than using health professionals, this study investigated the role of the public in providing support and education as peers. They concluded that peer-facilitated workshops on ACP were effective in increasing participants’ knowledge of ACP and encouraging them to participate in ACP activities. Other studies have also explored using community volunteers as a method to introduce ACP.<sup>17,18</sup>

Projects examining specific religious and cultural groups’ views on ACP have also been conducted. For example, the BCCPC is currently exploring promoting ACP in the South Asian community.<sup>16</sup> Trained volunteers will conduct educational ACP sessions in Punjabi and address cultural and societal issues related to ACP. Other groups have also explored views on ACP within the South Asian<sup>14,19</sup> and other major religious communities.<sup>20,21</sup>

To our knowledge, there have not been any published engagement activities that have aimed to

educate a cultural/religious group on ACP as well as health care professionals on the views of that community toward ACP. In this setting, community and academic stakeholders were able to foster meaningful engagement driven by curiosity and a genuine desire to understand and be understood. The symposium was organized with community partners, and took a culturally sensitive approach in creating a safe space for conversation. It highlights the tremendous utility of community engagement events, and the role of inclusive, bi-directional dialogue in transcending barriers. This type of community engagement session also aligns with the recent Canadian framework for ACP that encourages health care providers be included in community education sessions, so that they may also learn from stories.<sup>22</sup>

### Conclusion

This community engagement event was well attended and achieved our aim to understand the current Islamic views on ACP and EOL care and to encourage dialogue between health care professionals and the Islamic community. The positive feedback highlights the ability of this model to serve as a means for better community and health care provider engagement. This type of model could be used to advance public participation and knowledge of ACP in different faith or community groups. It may also be considered as a model to share knowledge on other important health care topics.

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### Conflict of interest statement

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

### Ethics

This activity was conceived as a community forum with the primary purpose of enhancing dialogue. Guided by Articles 2.1, 2.4, and 2.5 of Canada's Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans, 2nd

edition (TCPS 2),<sup>23</sup> and the use of the Alberta Research Ethics Community Consensus Initiative (ARECCI) Ethics Screening Tool,<sup>24</sup> review by the University of Calgary Conjoint Health Research Ethics Board was deemed unnecessary. All written comments and surveys were captured anonymously. Participants were informed with the invitation to complete the survey that their responses would be analyzed and used to create a final report from the activity (which did not stipulate nor preclude publication as a research article). Informed consent was not obtained from participants verbally or in writing, but was implied from their participation in the survey (as is allowable under Article 3.12 of the TCPS 2 policy). Participants were also free to abstain from leaving written comments.

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### ORCID iD

Safiya Karim  <https://orcid.org/0000-0002-2527-074X>

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