Introducing end-of-life group discussions in the primary care setting: Preliminary findings on patient engagement and satisfaction

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Mount Auburn Hospital and Harvard Medical School

Introduction

Patients have expressed an interest in learning more about end-of-life care, including exploring their own feelings and values around death and dying. However, in a California survey, only 23% of people reported having put their end-of-life wishes in writing and only 7% reported having had a doctor ask about their wishes for medical treatment at the end of their lives.

This project, supported by the 2013-2014 Harvard Medical School Innovation Fellows Program, explores the capacity of the primary care physician to initiate end-of-life planning among non-terminally ill patients age 65 and older through a structured peer group discussion.

Objectives

- Provide a safe space where patients and their loved ones can explore their preferences, values and goals related to end-of-life care
- Educate patients about end-of-life care planning and options
- Increase proportion of patients who have a signed health care proxy on file
- Expand end-of-life conversations outside of the small group discussion
- Help discussion participants recognize core values about end-of-life care
- Empower patients to take an active role in their health care

Methods

This is a pilot study using multiple semi-structured questionnaires in a prospective fashion. The questionnaires include knowledge surveys on end-of-life care, satisfaction survey and patient activation surveys. Patient activation and involvement in his/her own care was assessed using a validated questionnaire PAM (Patient Activation Measure). A total of 50 patients were recruited, and 39 were shortlisted and randomly assigned to control (n=19) and treatment group (n=20). The treatment group participated in group discussions on end-of-life care with a team consisting of the primary care physician, a medical resident, a nursing student, and a premedical student.

Surveys and Questionnaires

Results

Our study included 15 treatment patients, 7 family members, and 11 control patients. We held four group discussions.

- 100% of patients and family members reported feeling comfortable throughout the group discussion (n=22)
- 73% of treatment patients showed increased knowledge about end-of-life care planning issues, compared to 27% of control patients (n=26)
- The proportion of study patients with a health care proxy on file increased 40%, compared to a 0% increase among control patients (n=20)
- On average, participants reported sharing their discussion experience with four people outside of the study (n=15)
- 86% of patients and family members reported that the group discussion helped them recognize values and goals about end-of-life care (n=22)
- The PAM scores increased slightly from 68.6 to 69.1 in the treatment group and 63.5 to 66.3 in the control group (n=26). The majority of the participants in the treatment and control group entered the study at a PAM level 3 or 4 (93% of treatment patients and 91% of control patients)

Conclusions

- Patients are comfortable discussing end-of-life care planning in a small group setting with their primary care physicians
- Peer group discussions are an effective method for educating patients about end-of-life care planning
- Patients are more likely to fill out health care proxy forms if they have participated in a peer group discussion
- Patients and family members feel more comfortable having end-of-life care discussions with their loved ones after peer group discussions
- Peer group discussions helped patients identify core values regarding end-of-life care
- Patients who agreed to participate in the study had high activation levels, which may reflect their willingness to engage in a discussion about an uncomfortable topic

References

Surveys and Questionnaires

Surveys and Questionnaires for Data Collection

Baseline Questionnaire

PAM Questionnaire

Satisfaction Survey-Participant

Satisfaction Survey-Family Member

Discussion Resources

A Review: Having the Conversation

Resource List

Values Survey

Please indicate how much you agree or disagree with each statement as it applies to you.

Below are some statements that people sometimes make when they talk about their health.

1. I know how to prevent problems with my health.

2. Taking an active role in my own health care changes, like eating right and exercising, when new problems arise with my health.

3. I know what a Health Care Proxy should be for me and not just what should be what is true for you and not just what.

4. I understand my health problems and what I should be doing to help myself.

5. I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself.

6. I have not thought about my values and goals around end of life.

7. I am confident that I can follow through on points I want medical care to stop if I can’t be comfortable.

8. I understand my health problems and what I should be what is true for you and not just what.

9. I know what an Advance Directive should be for me and not just what should be what is true for you and not just what.

10. I would be more likely to talk about it with family now, as opposed to in the future.

11. I know how to prevent problems with my health.

12. I understand my health problems and what I should be doing to help myself.

13. I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself.

14. I have not thought about my values and goals around end of life.

15. I am confident that I can follow through on points I want medical care to stop if I can’t be comfortable.

16. I would be more likely to talk about it with family now, as opposed to in the future.

Thank you for your time and participation!
Baseline Questionnaire

1. Which of the following statements best describes your current situation (please select one statement):

   ___ I have thought about what I would like if I become terminally ill, and have talked about it with my family.
   ___ I have thought about it briefly but have not discussed it with my family.
   ___ I do not like to think about it, and discussing it makes me feel uncomfortable.

2. Please select one of the following:

   ___ I know what a Health Care Proxy is, and I have one.
   ___ I know what a Health Care Proxy is, but I do not have one.
   ___ I do not know what a Health Care Proxy is.

3. Please select one of the following:

   ___ I know what an Advance Directive is, and I have one.
   ___ I know what an Advance Directive is, but I do not have one.
   ___ I do not know what an Advance Directive is.

4. Please select one of the following:

   ___ I understand what services hospice and palliative care provide.
   ___ I know the basics of hospice and palliative care, but would like to learn more.
   ___ I do not understand hospice and palliative care.

5. Please select one of the following:

   ___ I have a clear understanding of my values and goals around end-of-life care.
   ___ I am somewhat aware of my values and goals around end-of-life care.
   ___ I have not yet thought about my values and goals around end-of-life care.
Below are some statements that people sometimes make when they talk about their health. Please indicate how much you agree or disagree with each statement as it applies to you personally by circling your answer. Your answers should be what is true for you and not just what you think others want you to say.

If the statement does not apply to you, circle N/A.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Disagree Strongly</th>
<th>Disagree</th>
<th>Agree Strongly</th>
<th>Agree</th>
<th>N/A</th>
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</thead>
<tbody>
<tr>
<td>1. When all is said and done, I am the person who is responsible for taking care of my health</td>
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<td>2. Taking an active role in my own health care is the most important thing that affects my health</td>
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<td>3. I am confident I can help prevent or reduce problems associated with my health</td>
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<td>4. I know what each of my prescribed medications do</td>
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<td>5. I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself</td>
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<td>6. I am confident that I can tell a doctor concerns I have even when he or she does not ask</td>
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<tr>
<td>7. I am confident that I can follow through on medical treatments I may need to do at home</td>
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<tr>
<td>8. I understand my health problems and what causes them</td>
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<tr>
<td>9. I know what treatments are available for my health problems</td>
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<td>10. I have been able to maintain (keep up with) lifestyle changes, like eating right or exercising</td>
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<tr>
<td>11. I know how to prevent problems with my health</td>
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<tr>
<td>12. I am confident I can figure out solutions when new problems arise with my health</td>
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<tr>
<td>13. I am confident that I can maintain lifestyle changes, like eating right and exercising, even during times of stress</td>
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### Thinking about Values 
(Adapted from The Conversation Project)

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<thead>
<tr>
<th></th>
<th>Question</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I want my doctors to do what they think is best</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
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<td>2</td>
<td>I want all care possible to prolong my life, including tubes and wires</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3</td>
<td>I wouldn’t mind spending my last days in a hospital</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4</td>
<td>I wouldn’t mind being in a nursing facility</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5</td>
<td>My loved ones should do exactly what I’ve said</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6</td>
<td>I would still like all possible care</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

- **1)** I want to have a say in every decision
- **2)** Being comfortable and pain-free is more important than prolonging life
- **3)** I want to spend my last days at home
- **4)** Independence is very important to me
- **5)** My loved ones should do what brings them peace
- **6)** I wouldn’t want to prolong my life

If I can no longer recognize my loved ones and be aware of my surroundings...

- **6)** I wouldn’t want to prolong my life

theconversationproject.org
Satisfaction/Experience Questionnaire - Participant

1. Did you feel comfortable throughout the group discussion?
   □ Yes  □ No  □ I don’t know

2. Did the discussion change the way you think about your future care?
   □ Yes  □ No  □ I don’t know

3. Did the discussion help you recognize your values and goals about the way you wish to live the rest of your life?
   □ Yes  □ No  □ I don’t know

4. Do you think that it will be easier to communicate with your family about future care after this discussion?
   □ Yes  □ No  □ I don’t know

5. Do you have any suggestions for future conversations about this topic?
   ______________________________________________________________
   ______________________________________________________________
   ______________________________________________________________
   ______________________________________________________________

   Thank you for your time and participation!

Satisfaction/Experience Questionnaire - Family Member

1. Did you feel comfortable throughout the group discussion?
   □ Yes  □ No  □ I don’t know

2. Did the discussion change the way you think about your loved one’s future care?
   □ Yes  □ No  □ I don’t know

3. Did the discussion help you recognize your loved one’s values and goals about the way he/she wishes to live the rest of his/her life?
   □ Yes  □ No  □ I don’t know

4. Do you think that it will be easier to communicate with your loved one about future care after this discussion?
   □ Yes  □ No  □ I don’t know

5. Do you have any suggestions for future conversations about this topic?
   ______________________________________________________________
   ______________________________________________________________
   ______________________________________________________________
   ______________________________________________________________

   Thank you for your time and participation!
Today we discussed values and goals around your future health care plans. These are by no means set in stone, and they can change at any point in time. If you feel that your goals for your care have changed, please consult with Dr. Bloch who will support you through the process.

If you have not already completed your Health Care Proxy and Advanced Directive forms, please do so at your convenience and return them to Dr. Bloch’s office. Both of these forms are important in identifying goals for your future health care.

We encourage you to continue this conversation at home with family members and loved ones. The more you make your wishes known, the more likely they will be expressed and respected.

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**Important Reminders**

Today we discussed values and goals around your future health care plans. These are by no means set in stone, and they can change at any point in time. If you feel that your goals for your care have changed, please consult with Dr. Bloch who will support you through the process.

If you have not already completed your Health Care Proxy and Advanced Directive forms, please do so at your convenience and return them to Dr. Bloch’s office. Both of these forms are important in identifying goals for your future health care.

We encourage you to continue this conversation at home with family members and loved ones. The more you make your wishes known, the more likely they will be expressed and respected.

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**Resources for Future Planning**

- **Prepare For Your Care:** [https://www.prepareforyourcare.org](https://www.prepareforyourcare.org)
- **The Conversation Project:** [http://theconversationproject.org](http://theconversationproject.org)
- **The Conversation Project Starter Kit:** [http://theconversationproject.org/starter-kit/intro/](http://theconversationproject.org/starter-kit/intro/)
- **Health Care Proxy Form:** [http://molst-ma.org/sites/molst-ma.org/files/MA-Health-Care-Proxy-Form.pdf](http://molst-ma.org/sites/molst-ma.org/files/MA-Health-Care-Proxy-Form.pdf)
- **MOLST:** [http://molst-ma.org](http://molst-ma.org)
- **If you have questions about options regarding facilities or assisted living in the future, please contact Dr. Bloch who will refer you to a Case Manager.**
Results (click on each group for more detail)

Patient and Family Member Satisfaction Surveys

Treatment and Study Baseline Survey Trends

% of Participants with Health Care Proxy on File

Patient Activation Measure Results

Expanding the Conversation
Results from Satisfaction Questionnaire

**Patient Feedback**

- **Did you feel comfortable throughout the group discussion?**
  - Yes: 100%
  - No: 44%
  - I don’t know: 19%

- **Did the discussion change the way you think about your future care?**
  - Yes: 37%
  - No: 44%
  - I don’t know: 19%

- **Did the discussion help you recognize your values and goals about the way you wish to live the rest of your life?**
  - Yes: 88%
  - No: 6%
  - I don’t know: 6%

- **Do you think that it will be easier to communicate with your family about future care after this discussion?**
  - Yes: 87%
  - No: 7%
  - I don’t know: 6%

**Family Member Feedback**

- **Did you feel comfortable throughout the group discussion?**
  - Yes: 100%

- **Did the discussion change the way you think about your loved one’s future care?**
  - Yes: 88%
  - No: 14%
  - I don’t know: 7%

- **Did the discussion help you recognize your loved one’s values and goals about the way he/she wishes to live the rest of his/her life?**
  - Yes: 100%

- **Do you think that it will be easier to communicate with your loved one about future care after this discussion?**
  - Yes: 100%
Results from Baseline Questionnaire

### Treatment Participants Baseline Score Trends
- 73% *Baseline scores improved over time*
- 19% *Baseline scores improved then regressed*
- 7% *Baseline scores declined over time*
- 7% *Baseline scores stayed the same*

### Control Participants Baseline Score Trends
- 27% *Baseline scores improved over time*
- 27% *Baseline scores improved then regressed*
- 27% *Baseline scores declined over time*
- 19% *Baseline scores stayed the same*
% of Participants with Health Care Proxy on File

- Treatment: 60% before study, 70% after study
- Control: 20% before study, 20% after study
Patient Activation Measure (PAM) Results

Mean PAM 0-100 Score by Administration by Group

- Control
- Treatment

View Patient Activation Measure
We asked patients, “How many people have you spoken to about the group discussion?”

On average, each patient spoke to four people about their experience in the group discussion.
View module slides with narration and video

View module slides only (no narration or video)
THE CONVERSATION

Dr. Nathalie Bloch
Dr. Aftab Iqbal
Alyse Krantz
Abigail Frydryk
Discussion Set-Up
Team Member Introduction

Nathalie Bloch MD MPA:

Primary Care Physician and an Internist. An asst. medical director and a board member at MACIPA and a fellow for Innovation at the Harvard Medical School. Moved to Boston in 2003- finished here her residency at Mount Auburn Hospital and completed a master degree in public administration at the Harvard Kennedy School.
Aftab Iqbal MD MPH:

Aftab Iqbal is a third year internal medicine resident at Mount Auburn Hospital with a passion for access to primary care, healthcare delivery mechanisms, global health and geriatrics. Aftab got his medical degree from Rawalpindi Medical College, Pakistan ('08) and went on to complete a masters degree in epidemiology as a Fulbright scholar at the Harvard School of Public Health ('10). He has served as an Associate Director at a healthcare startup, Naya Jeevan, which works on providing micro-health insurance to people who earn less than 200 dollars/month in Pakistan.
Alyse Krantz BA MS:

Alyse Krantz is a pre-medical student at the Harvard Extension School. Before pursuing medicine, Alyse taught elementary school in New York City and Bogotá, Colombia. She holds a B.A. from the University of California at Santa Cruz and an M.S. from Brooklyn College. Alyse hopes to practice family medicine in underserved/immigrant communities.
Team Member Introduction

Abby Frydryk BS:

Abby Frydryk is an acute care nurse practitioner student at the MGH Institute of Health Professions. She completed her undergraduate degree at Indiana University and received a B.S. in Public Health. Her interests lie in internal medicine and geriatrics.
Introduction

• Individual and family member introduction
  • Study purpose
  • Confidentiality
• Questions before we begin?
Preferred Location of Death

- Home: 70%
- Hospital: 16%
- Hospice: 4%
- Other: 7%
- Don't know: 2%
- Refused: 2%

Actual Location of Death

- Facility: 70%
- Home: 16%
- Other: 4%

Discussed End-of-Life Wishes with a Doctor

- Yes: 7%
- Refused: 1%
- No: 92%

Discussed End-of-Life Wishes with a Loved One

- Yes: 42%
- Refused: 2%
- No: 56%

Lake Research Partners and the Coalition for Compassionate Care of California. (February, 2012) Final Chapter: Californians’ Attitudes and Experiences with Death and Dying. Retrieved at: [https://www.chcf.org/publications/2012/02/final-chapter-death-dying#ixzz365ceRwwI]
Video

Responses?

“I want mine to be...”

“I want mine to be... surrounded by loved ones and alert enough to acknowledge the special presence of those in my home with me”.

“I want mine to be at home... relaxed and planned out (as much as it can be) so that folks can focus on laughing and healing”.

“I want mine to be... put off as long as possible. I would like to be pain-free and receive all possible care until the very end”.

“I want mine to be... in a facility, with great nurses providing comfort care”.
A questionnaire to help you explore your feelings, values, and goals around future care.

- Please complete the Values Questionnaire with a family member
- Discussion
- Personal experiences
### Thinking about Values (Adapted from The Conversation Project)

1. I want my doctors to do what they think is best
   - Rating: 1 2 3 4 5
   - I want to have a say in every decision

2. I want all care possible to prolong my life, including tubes and wires
   - Rating: 1 2 3 4 5
   - Being comfortable and pain-free is more important than prolonging life

3. I wouldn’t mind spending my last days in a hospital
   - Rating: 1 2 3 4 5
   - I want to spend my last days at home

4. I wouldn’t mind being in a nursing facility
   - Rating: 1 2 3 4 5
   - Independence is very important to me

5. My loved ones should do exactly what I’ve said
   - Rating: 1 2 3 4 5
   - My loved ones should do what brings them peace

If I can no longer recognize my loved ones and be aware of my surroundings...

6. I would still like all possible care
   - Rating: 1 2 3 4 5
   - I wouldn’t want to prolong my life
Advance Directive

*Advance directives* are legal documents that allow you to spell out your decisions about end-of-life ahead of time.

Today we will discuss two types of *advance directives*:

1. Health Care Proxy Form
2. Do Not Resuscitate/ Do Not Intubate
Health Care Proxy Form

The form identifies your health care agent (often called a “proxy”), the person you trust to act on your behalf if you are unable to make health care decisions or communicate your wishes.

This is probably the most important document to sign.
Choosing a Health Care Proxy

Your Health Care Proxy should be someone who:

- You trust to honor and respect your wishes
- Is comfortable with carrying out difficult decisions
- Someone you feel comfortable sharing health information with
DNR/DNI

**Do Not Resuscitate/Intubate orders** are medical orders signed by a physician that instruct health care providers not to attempt cardio-pulmonary resuscitation (CPR) or intubation in the event of cardiac and respiratory arrest.
CPR

Cardiopulmonary resuscitation (CPR) is a set of medical procedures that attempt to restart the heartbeat and breathing of a person who has no heartbeat and has stopped breathing.

CPR can be life-saving in certain cases for otherwise healthy people but is much less effective when a person has a serious chronic illness.
Cardiopulmonary Resuscitation (CPR)
Intubation & Mechanical Ventilation

Intubation and mechanical ventilation is the use of a tube and a machine to help get air into and out of your lungs.
Additional Resources for Planning

Your Conversation Starter Kit

The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care. We know that no guide and no single conversation can cover all the decisions that you and your family may face. What a conversation can do is provide a shared understanding of what matters most to you and your loved ones. This can make it easier to make decisions when the time comes.

A Review: Having the Conversation

Resources for Future Planning

- Prepare For Your Care:
  https://www.preparedforacare.org
- The Conversation Project:
  http://thecommunicationproject.org
- The Conversation Project Starter Kit:
  http://thecommunicationproject.org/starter-kit/sitemap
- Health Care Proxy Form:
- MOLST:
  http://molst-ma.org
- Advanced Directive/Comfort Care/ENBR:
- If you have questions about options regarding facilities or assisted living in the future, please contact Dr. Bloch who will refer you to a Case Manager.
Closing

- Thank you for your time
- Reiterate confidentiality
  - Planning is ongoing
  - Satisfaction survey

Thank you for your participation!