

# Value Based Conversations in Diverse Communities

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## Introduction

There is well documented disparity in health care outcomes in minority groups, and this disparity extends to end of life. Your Voice, Your Values: The Conversation Project at Erie County Medical Center (ECMC) is a palliative care outreach team working on bridging the continuum of conversation around end of life care that is taking place in and around urban Buffalo, NY. This outreach team includes members of the community that reflect the diverse population that surrounds the medical center. Surveys that have measured the effectiveness of this team have challenged thinking re: the established belief that communities are not willing to engage in these conversations. Rather, outreach results show that the community not only wants to hear about this conversation, but is showing a readiness to action that needs to be translated into documentation by the health care community. The inclusion of these community members, as part of the palliative education team, increases community engagement that is respectful, culturally sensitive, and avoids stereotyping. These non-clinical team members work as “connectors”-connecting individuals to care in a manner that is respectful of each person, understanding the culture, beliefs and values that shape what matters most to each individual, and creating measurable change.

## Program Aims

(1) To open the dialog in populations where there is disparity in end of life. (2) To develop a training program for palliative care peer connectors who are of and from the community and trusted members of the community. (3) To start advance care planning in the community before bringing it into the doctor’s office. (4) To ensure individual’s wishes are known and respected when they can no longer speak for themselves. (5) To change the cultural norm from not talking about death and dying to talking about it. (6) To decrease the number of individuals that come into the hospital without ever having meaningful conversations with their loved ones centered on advance care planning.

### References

- 1.) Maureen Bisognano and Ellen Goodman. Engaging Patients And Their Loved Ones In The Ultimate Conversation. Health Affairs, 32, no.2 (2013):203-206
- 2.) Fulmer T, Gaines M. Partnering with Patients, Families , and Communities : An Urgent Imperative for Health Care: Josiah MacY, JR FOUNDATION;2104
- 3.) Lynn J, McKethan A . Value-Based Payments Require Valuing What Matters to Patients: JAMA October 13, 2015 Volume 314, Number 14
- 4.) Smith C, Brawley O. Disparities in Access to Palliative Care: Health Affairs Blog: <http://healthaffairs.org/blog>

**Your Voice, Your Values.**

Inspiring  
VOICE Awareness  
Community  
Love Understanding  
Conversation  
Compassion  
Faith Family Reliable  
Wishes Passionate  
Decision Connection  
Palliative  
Courage VALUES

Respect Care  
Loyal Love  
Trust Knowledge  
Comfort  
Meaningful  
Dependable  
Honest  
Committed

“I wish I knew about this project sooner. It would have really helped my family when my father passed.”  
—Patient’s family member

“Having these conversations with my mother made the process of letting her go a lot easier and I felt no guilt because I knew exactly what she wanted and what she valued.”  
—Community member

“Learning about this project changed my perspective on how healthcare should be carried out.”  
—Outreach team member

“This program is so important and valuable. Having the pastor preach about having the conversation is a wonderful way to reach members of the community.”  
—Presentation attendant

**The Conversation Project**

### Before and After: Self-Reported Changes in Thinking About the Conversation

Category	Percentage
Not ready at all	8%
Not ready, but thinking about it	15%
Ready, but not sure what to say	25%
Ready and certain of what I wanted to say	52%

Category	Percentage
Not ready at all	1%
Not ready, but thinking about it	5%
Ready, but not sure what to say	16%
Ready and certain of what I wanted to say	78%

Category	Percentage
A loved one	92%
A leader in my faith community	4%
My Doctor	1%
A nurse, or other healthcare professional	1%
Other	1%

## Potential Implications

Research has shown that if patients and their loved ones are approached by trusted members of the community to discuss end-of-life preferences, the rate at which they identify and talk with their designated healthcare proxy and the other important people in their life, increases greatly. Surveys also show that individuals want to have these conversations and would prefer to have them with a loved one. Furthermore, having these conversations has a large impact on healthcare costs. Studies have shown that in La Crosse, Wisconsin, where these discussions occur very regularly, the average cost savings for one individual in the last two years of their life is \$8,000. Further implication includes the growth of the program to include diverse populations where disparity in end of life care is known to occur. We have seen that many individuals want to have these discussions and once provided with the proper tools to begin the conversations, there will be an increase in the amount of people having the discussions. Therefore, healthcare systems must take the necessary steps to ensure they know how to have these conversations and translate the values of the individuals and families into the appropriate interventions.

## Preliminary Results

66% of people surveyed hadn’t had a detailed enough conversation with a loved one to ensure they know what their wishes are. (Prior to the presentation).

Prior to the presentation, 48% of the people were either not ready for the conversation or were uncertain of what to say during the conversation.

After the presentation, only 22% of the people were either not ready for the conversation or were uncertain of what to say during the conversation.

94% of people are likely to talk to a loved one within 30 days.

65% of the population would prefer to talk to a loved one if they have further questions or concerns.

Survey responses show that the community does respond to community outreach conversations.

Advance care planning is enriched by outreach teams that include non-clinical members that are of and from the community.

Palliative Care community education outreach is enhanced by the inclusion of palliative care community outreach teams that are non-clinical and are trained to facilitate conversations.

Faith-based leaders that are on our outreach team have provided a different avenue of reaching a large portion of the faith-based communities. So far we have attended roughly 20 events that were initiated through a faith-based organization or leader.

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