



Lights, Camera, Action: Screenings of 'Being Mortal' Engage Californians in Advance Care Planning

Films can be provocative conversation-starters and can even motivate people to take action or change behaviors. What about behaviors concerning a sensitive topic like care at the end of life? Would a film screening and discussion be an effective way to move community members to take action for end-of-life care planning?

In February of 2015, the *FRONTLINE* documentary "Being Mortal," funded by the John and Wauna Harman Foundation, aired on public television stations nationwide. The program follows Harvard surgeon and writer Atul Gawande (pictured) — who, in 2014, published a book also called *Being Mortal* — as he shares the personal experiences of several patients and families at the end of life, including his own story about the death of his father.

This paper describes a 2015 advance care planning community engagement campaign centered on public screenings of "Being Mortal." It summarizes results of the project, including challenges and lessons learned from producing screening events in diverse communities around California.

Background

While 2.4 million people watched "Being Mortal" when it was broadcast via television, viewing by African Americans, Latinos, and Asian Americans was low, together making up only 16% of viewing households. The viewing audience also lacked diversity in terms of education level and age: The majority were white women age 50 and older, and more than two-thirds were college-educated. The Harman Foundation wanted to address this lack of diversity in viewership as part of its larger vision to extend the film's lifespan beyond the one-time PBS broadcast. In addition, the Harman Foundation wanted to test a hypothesis: that watching and discussing "Being Mortal" can move people to take concrete action around advance health care planning.

With this vision, the Harman Foundation teamed up with the California HealthCare Foundation in the summer of 2015 to promote community screenings of "Being Mortal" and assess their impact. The film would be followed by a guided discussion with audience members about end-of-life care choices. The discussion would aim to encourage participants to identify and communicate their wishes to loved ones and health care providers.

The Project

Sixty-five organizations — from small, grassroots groups like Grandmothers Who Help, to large institutions like Stanford Health Care — submitted proposals for one of 25 \$2,000 grants to host a community screening of “Being Mortal.” Applicant organizations were evaluated on the alignment of their goals with the purpose of the grant and on demonstrated ability to draw 50 to 100 people; to reach

an audience beyond the white, educated, middle- to upper-middle-class *FRONTLINE* demographic; and to engage participants in a well-planned after-film discussion encouraging personal action.

Many of the applicant organizations stated that helping people begin these vital end-of-life conversations ranked high among their top community

education objectives. One organization’s application stated, “We would like to be part of a movement to remove our culture’s stigma around aging and end-of-life care. By encouraging people to think about it and to talk about it, we hope to reduce our society’s ‘taboo.’ We believe that it is more healthy and in fact ‘normal’ to discuss the topic of end of life, and screening this important documentary would be an excellent vehicle to address this topic.”

Due to the diversity and strength of the proposals, project sponsors expanded the number of awards to 39 organizations to host at least one “Being Mortal” screening by the end of September 2015.

Representing communities from rural Mt. Shasta in the northern reaches of the state to urban San Diego in the south, the grantees fell into six primary categories: medical care networks, end-of-life coalitions, senior services agencies, hospices, universities, and churches. See the Appendix for a full list of grantees.



Anabel Kuykendall’s father got very sick very fast. He had diabetes and chronic liver disease, and when he contracted pneumonia in the spring of 2014, his organs started to shut down. He was 78 and had recently retired from his post with the San Diego County Quality Assurance Program. While he didn’t have an advance directive, Anabel’s father had shared his wishes on certain aspects of end-of-life care.

“He told me that he didn’t want a feeding tube,” Anabel said. “It wasn’t in writing, but he said it in front of his doctor. As he was getting worse, my aunts kept saying, ‘No matter what, we’ll keep him alive.’ I said, ‘It’s not your decision; he didn’t want that.’” Anabel made sure her father got the kind of treatment that he wanted, and didn’t get the kind of treatment that he didn’t want, at the end of his life. He died six weeks after his bout with pneumonia that spring.

Anabel said: “After that experience, I told my mom, ‘You have to get this [advance directive] taken care of.’”

Anabel heard about a screening of “Being Mortal,” the *FRONTLINE* documentary about patients’ experiences with end-of-life issues, through her work. “I wanted to . . . get my mother to go with me,” she explained, “I had been telling her about the importance of an advance directive. I figured that the movie would be a good way to encourage her to do this.”

Anabel and her mother attended the Being Mortal screening in their community on a Wednesday. That Saturday, Anabel gathered her family members at her house, where they witnessed her mother’s signing of her advance directive. “We took care of the advance directive for mom,” Anabel said. “We had enough people in the house to have two people witness it. We were all there, so everyone knows the language in the document. This is a family effort. Everyone understands the importance. After we did mom’s, I asked my brother and sister-in-law if they have one. Her mom just had surgery, so all of this is making her think that they should have this done, too. Because of all this, they all started thinking.”

Table 1. “Being Mortal” Host Organizations by Type

Medical Care Network	10
End-of-Life Coalition	8
Senior Services Agency	6
Hospice	4
University	3
Church	3
Other	5



Asale Kimaada (pictured, at left, with GWH board member Gwen Cowans), a 65-year-old mother of two adult daughters, is founder of the East Bay advocacy group Grandmothers Who Help (GWH). Her motivation for organizing a screening of “Being Mortal” was deeply personal.

“My mother had a heart attack and stroke while she was visiting her sister,” Asale said. Her mother, who had a history of heart disease, lived in Colorado. Asale, 28 at the time, and her older brother lived in California. “When we got to her, she was on a respirator, with tubes down her throat. The hospital staff suggested we take the tubes out. But they told us that she’ll probably pass away because she wasn’t breathing on her own. My brother and I said, no. We were young.

We knew nothing about respirators or life support. If the hospital had explained the meaning of vegetative state before they presented us with the option to remove her from the respirator, we would have been able to make a more educated decision.”

Eventually, her mother began to breathe on her own. Asale moved to Denver and became her mother’s caregiver for the next two years. “She recognized us, but that’s about it,” Asale said. Her mother couldn’t speak, walk, or turn over by herself. Asale had to change her diaper and “carry her everywhere.” “When it comes to me, I don’t want to live like that,” she said. “I tell my daughters, I don’t want to do that to you, and you don’t do that to me.”

“Being Mortal” prompted candid conversations about end-of-life care with her family. “I asked my brother, ‘When you pass, have you made plans? What about your wife, have you talked about this?’ He tells me, don’t worry. He’s still not opening up, but we’re starting those conversations. And for all those people at the screenings, they are going to talk about it — now that they know about it.”

Dooley underscores the importance of advance care planning and encourages viewers to take its goals to heart. After the screening at the California State Capitol building in mid-September, Secretary Dooley helped facilitate a lively discussion, which she peppered with her own personal stories about end-of-life care for various family members.¹

To support their event-planning efforts, grantee groups were provided with the following resources:

- ▶ An informational webinar for applicants to learn about the goals of the project
- ▶ A mid-course conference call for grantees who had completed their screenings to share what they learned with groups who had not held their screenings yet
- ▶ Support from a project manager with deep knowledge of community engagement around advance care planning
- ▶ A screening toolkit containing event-planning and promotional materials, a film discussion guide, and an advance care planning checklist to encourage people to leave with a personal action plan²

Event organizers were encouraged to structure the after-film discussion in whatever way worked best for their particular audience. Most chose to either facilitate a large- or small-group discussion or a question-and-answer session, and some invited end-of-life experts from the community to address the audience.

The majority of host organizations had experience providing community education related to aging or end-of-life planning, and two-thirds partnered with at least one other community organization with such experience. Common community partners included libraries, senior residences, palliative care programs, and hospitals. Furthermore, several applicants had strong relationships with Asian American, African American, and Latino community organizations and centered their event plans around outreach to those groups.

In addition to “Being Mortal,” audiences were shown two other film clips: The first was a personal message from Dr. Gawande taped specifically for the California screenings. In it, he thanks people for coming to watch and discuss his film, and he encourages audience members to “talk about your wishes, about what your priorities are — what really matters to you most — and be willing to ask others those same questions.” The second film clip was a message from Diana Dooley, Secretary of the California Health and Human Services Agency. In it, Secretary

Impact and Outcomes

Public Response

Just as the statewide response to the request for proposals far exceeded expectations, so did the public response to the local screenings. While the project goal was to hold 25 events statewide, the total number of screenings exceeded 65, reaching more than 3,000 community members. Due to the level of public interest, many hosts decided to hold more than one screening, sometimes to accommodate waiting lists, and some held as many as six screenings. At the time of the writing of this report, additional events are still being planned.

A few of the events attracted media attention. In Orange County, a local newspaper reporter and a TV reporter attended the screening at the Nhan Hoa Health Care Clinic. Coverage by these reporters provided excellent publicity for the subsequent screenings held by the host agency, whose focus was on reaching the county's Vietnamese American community members.

Sparkling Conversations

What was the impact of the "Being Mortal" screenings on participant attitudes and beliefs about advance care planning? A simple survey assessed whether and to what extent viewing and discussing the film changed people's perceptions of the importance of talking to loved ones and care providers about end-of-life care wishes and of putting those wishes in writing. It also helped determine if the film has broad appeal, or if it only resonates with certain demographics.

A questionnaire given to participants before and after the film included questions such as, "Have you ever talked with a loved one, a doctor, or someone else about the kind of care you would want if you were seriously ill or dying?" and, "How important is it to have your end-of-life care wishes in writing?"

These questionnaires revealed that participants were engaged in this topic and found the film and discussions to be valuable. They felt that participating in the screenings helped them to think through their own end-of-life wishes, and, by the end of the screening event, many seemed motivated to talk to their loved ones about the issue.

However, the surveys showed that there was little shift in opinion during the community screenings themselves. This is because most participants came into the events already feeling that this topic is important. For example, even before seeing "Being Mortal," 96% of participants indicated that they felt it was important to put their end-of-life wishes in writing.

The effects of participating in the screenings were revealed in the results of an email survey sent one to three months after the screening. It included questions such as, "Since watching and discussing Being Mortal, have you talked with a loved one, a doctor, or someone else about the kind of care you would want if you were seriously ill or dying?" This follow-up questionnaire, which was completed by 381 respondents, suggested that participants were greatly impacted by the film and discussions.³ Since participating in the community screenings:

- ▶ 91% said that they are now more comfortable discussing end-of-life wishes.

- ▶ 91% said they have spent time thinking about the kind of care they want if they become ill.
- ▶ 81% have talked to someone about the kind of care they would want if they were dying.
- ▶ 60% of those who do not have an advance directive said that they are now likely to put their end-of-life wishes into an advance directive in the next three months.
- ▶ 55% of those who have not yet talked with a doctor about this issue said they are likely to bring up their end-of-life wishes at their next routine doctor visit.

On a number of other measures, the follow-up survey showed that participants took meaningful actions to plan for their end-of-life care after attending a screening event. For example, 28% of respondents said that they selected someone to make end-of-life care decisions for them if they become ill and cannot speak for themselves. Also, 17% completed an advance directive after seeing the film and participating in the discussions. Finally, 6% spoke to a doctor about their end-of-life wishes. These are key steps in end-of-life planning, and the community screenings may have played an important role in these actions.⁴

Host organizations were asked about their goals for community engagement and how well the "Being Mortal" screening helped them achieve those goals. "To spark new conversations about end-of-life care planning between audience members and their loved ones" was the top desired outcome, named by 82% of grantees, with the second-most common outcome being "to increase general interest in end-of-life planning in our community." The vast majority

(95%) of the grantees indicated that “Being Mortal” helped them meet these goals “very well.”

Providers Inspired

One unanticipated outcome was the impact on care providers who attended the screenings. While the screening campaign was focused primarily on reaching general community audiences, in some cases, a number of medical professionals attended. Many of these providers shared how much they benefited professionally from watching the video. At a screening event in Fresno, for example, physicians in the audience shared that they felt inadequately prepared to have conversations with patients about difficult end-of-life care decisions. They said that Dr. Gawande’s honesty and humility in relating his own discomfort and sense of inadequacy allowed them to be more candid about their own need for training and support to have these critical conversations with patients.

Some event organizers stressed the importance of taking “Being Mortal” to health care provider audiences in a more focused way, including suggestions to engage the medical education system. One agency representative shared, “I am going to be presenting this to community health clinic staff and hospital staff. I suggest a clear involvement with them playing a role in this going forward. If they are not prepared for the discussions, it is not helpful to be referring people to them. We encountered many people who thought having a legal document settled the issue, and it was not necessary to talk to anyone, [not] even the physician.”

When **Luz Salazar Garcia** (pictured at left with daughter, Luz Solis) was diagnosed with diabetes in the 1980s, she refused her physician’s advice and take insulin to control her blood sugar. Her father, a train conductor in Mexico, had died in 1958 of an insulin overdose prescribed by a railroad doctor, and she swore she would never take the drug. By 2003, she was going blind, her blood pressure was too high, her legs affected by neuropathy, and she suffered internal bleeding in her eye from advanced glaucoma. Luz Garcia was afraid to be left alone and her husband and her only child became round-the-clock caregivers.



Two years later, Garcia lay in a Whittier hospital. The chart told a grim tale: breast cancer, congestive heart failure, blindness, kidney failure, neuropathy, hypertension, glaucoma, depression.

Garcia’s daughter, Luz Solis, 52, ruefully remembers how different physicians offered contradictory advice. “One doctor told me: If your mom was my mom, I would let her go,” Solis said. But the attending physician gave Garcia’s husband a different prescription — immediate kidney dialysis. “Don’t you love your wife?” the doctor badgered him. “Don’t you know this is something she needs?” Emilio Garcia authorized bedside dialysis.

Solis argued with him. How could he square his decision to continue the treatments with her mother’s clear wish to die in peace? “He was unwilling to listen. My dad wanted my mom to live, whatever it took,” she said.

Luz Garcia resisted the dialysis preparations, shouting in Spanish, “I don’t want this — why are you doing this to me?” Solis’s father and her husband walked away from the commotion, but Solis sat outside the room, sobbing. Finally the room grew quiet, the dialysis commenced, and the patient was asleep.

Before dawn Luz Garcia was gone. “I carry the remorse, and I wish my mom would have not died this way. It was very emotional. It was horrible what we three went through.”

On September 9, Solis participated in a community screening of Being Mortal at Cal State LA’s College of Health and Human Services. At the conclusion of the movie, she moderated one of many small discussion groups intended to educate participants about choices they might make if they had a serious illness and to encourage them to identify and communicate their wishes to those who matter, a far different fate from that of her mother.



Husband and wife **Bernie Lichtenstein** and **Rose Ly** volunteer at the Vietnamese American Community Center of the East Bay in Oakland, site of a community screening of “Being Mortal.”

“Dying is an important event,” said Bernie, a transplant from New York, who completed an advance directive ten years ago following the death of his mother. “My mother was 89 when she died. For the last two years she was confined to bed and tube fed. She was not aware and couldn’t make known what she was feeling. That second stroke wiped out whatever ability she had to communicate.”

Bernie’s brother, five years older, moved into her apartment to care for her. “It was his decision that she be kept on whatever medical means to stay alive,” Bernie said. “I didn’t feel that way, but he was her main caretaker. I didn’t want to interfere with him, but I thought maybe that was not a good way for these things to happen.”

By contrast, Rose, an immigrant from Vietnam, hasn’t formalized her end-of-life wishes. “We Asians think that if you don’t close your eyes completely when you die, it means there’s something you haven’t done,” she said. “Completing the form might be one way to ensure that your eyes are closed before you die.”

Watching the film did prompt Rose to talk with her 82-year-old mother who also lives in Oakland. “She doesn’t want to think about it. She thinks, ‘When it happens, it happens.’ Her will is that if anything happens send her to her sister in Vietnam.” Ultimately, Rose knows that she will be responsible for her mother’s end-of-life care, whether or not she clearly communicates her preferences. “She trusts that I’ll take care of her and make decisions for her,” Rose said. “She’s healthy now, but if someday something happens, she trusts that I’ll do what’s best for her.”

Building a Community Network

An additional outcome of the “Being Mortal” campaign was the building and strengthening of partnerships among community groups interested in advance care planning education. Two-thirds of grantees partnered with other community organizations for their screening events, and of these grantees, all indicated that they plan to work with the partnering organizations again on future events.

The event organizer from Grandmothers Who Help described her partnership with local churches and a local HIV education foundation: “This was such a wonderful learning experience for our community partners and for us as well. I was able to reach out to organizations doing community outreach that we had no idea were functioning in our community. We were able to develop resources for our community in a more genuine way, working together knowing

we were all there to help one another. It’s hard to put into words how eager people were to come out and help.”

Reaching Diverse Audiences

The diversity of the community screening audiences indicated that the attention to reaching out beyond the typical *FRONTLINE* demographic paid off, with a higher percentage of total viewers being from communities of color. Specifically, the campaign succeeded in bringing the film to a higher percentage of Asian American and Latino audiences; however, it could have benefited from a stronger focus on reaching African American audiences.

Table 2. “Being Mortal” Viewership, by Race/Ethnicity

	FRONTLINE TV SCREENING	COMMUNITY SCREENINGS
White	85%	59%
Asian American	2%	19%
Latino	4%	10%
African American	11%	5%
Other	0%	2%
No Response	0%	5%

Note: Numbers may not add up to 100% due to rounding.

Source: Nielsen viewership data and participant questionnaires from the community screenings.

While the screening events were largely very successful, throughout the campaign, organizations serving immigrant communities and communities of color expressed concern about the lack of cultural and socioeconomic diversity among the families

featured in the film. One event organizer in Oakland said, “We have previewed the film and have some concerns with respect to the community in which we are hosting the event. Except for Dr. Gawande and his family, all participants are white. Furthermore, they seem to be relatively affluent. It is hard to believe that there were no people of color represented in the *FRONTLINE* video. While well done, perhaps a different program would be more appropriate for reaching minority populations.”

Others pointed out that understanding the bulk of the film’s content required a relatively high health literacy level, with a fair amount of the film’s dialogue taking place between physicians who are discussing approaches to tough patient care decisions. Other event organizers expressed concern that the film was only available in English.

Even with these limitations, the grantee organizations remained committed to targeting diverse communities and to making the film relevant to their audiences. Event hosts brought expert knowledge of the cultural sensitivities of their audiences to the planning process and framed the screening and discussion in ways that were culturally appropriate. One event organizer shared, “There are cultural sensitivities within the community regarding mortality — that is, a general sense that if you speak about death, you will invite death. We approach the subject in a culturally sensitive manner and focus less on the mortality issue and more on providing the next generation with instructions on how to handle their older generation’s critical health choices. The focus is on how to execute the choices made by their elders and helping the elders to be clear.”

An event organizer in Oakland decided to address concerns about the film’s lack of cultural diversity by mentioning it directly when introducing the film to their largely African American audience, and then engaging African American facilitators and using stories of African American patients to augment the film scenarios.

Many of the organizations expressed interest in showing the film in other languages, and two went to great lengths to make this possible by translating the entire transcript of the film. The Caregiver Resource Center in Orange County added Vietnamese subtitles to the film, and Stanford Health Care added a Spanish voice-over. The translated materials had a far-reaching impact: The Vietnamese subtitled version was shared with another grantee organization, and the Spanish-language version was shared with eight other organizations, resulting so far in at least two additional events targeting Spanish-speaking audiences.

Conclusion

The results of this project leave little doubt that the themes addressed in “Being Mortal” struck a chord with many participants of varying backgrounds and ethnicities — grantees, audiences, and medical personnel, to name a few. While the project sponsors had hoped that the campaign was well-timed and would benefit from increasing media attention to the topic of end-of-life care, they could not have anticipated the community demand for an opportunity to explore the topic face-to-face. Community organizations eager for a new advance care planning engagement tool were met with larger-than-expected community audiences eager to engage. And, based on the success of the screening campaign in California, the Harman Foundation has engaged a national partner to spread the screenings nationwide in 2016.

The survey results suggest that there is great potential to use “Being Mortal” to spur discussion — and action — around end-of-life issues. The greatest impact may simply be increasing comfort around the topic and helping individuals explore their feelings about their own end of life.

About the Author

Julie Boudreau is an outreach specialist and advance care planning community engagement consultant. She acted as project manager for the “Being Mortal” campaign.

Acknowledgments

Sahar Driver served as film strategist for the project, providing guidance to the team for using film to create social change.

PerryUndem conducted and analyzed the pre- and post-screening evaluations.

About the Harman Foundation

The John and Wauna Harman Foundation is a family foundation focused on improving end-of-life care in the US. Our mission is to encourage Americans to have meaningful conversations about their end-of-life care wishes with the important people in their lives before serious illness occurs, thereby improving quality of life as death is near. For more information, visit www.jwhfoundation.org.

About CHCF

The California HealthCare Foundation (CHCF) is leading the way to better health care for all Californians, particularly those whose needs are not well served by the status quo. We work to ensure that people have access to the care they need, when they need it, at a price they can afford.

CHCF informs policymakers and industry leaders, invests in ideas and innovations, and connects with changemakers to create a more responsive, patient-centered health care system.

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Endnotes

1. Secretary Dooley wrote about the screening at the California State Capitol building in the October 12, 2015, article, “Living Well, Dying Well,” The CHCF Blog, www.chcf.org.
2. “‘Being Mortal’ Community Screening Toolkit,” California HealthCare Foundation, www.chcf.org (PDF).
3. Because event attendance far exceeded the project’s official survey capacity, the online follow-up survey was administered to a sampling of participants.
4. The full report on findings from the participant follow-up surveys by PerryUndem, “Measuring Impacts of Community Screenings of ‘Being Mortal’ in California,” is available at www.chcf.org.

Appendix. “Being Mortal” Community Screenings Campaign Grantees in California

ORGANIZATION	LOCATION
Ashby Village	Berkeley
California State University, Los Angeles, College of Health and Human Services	Los Angeles
California Central Valley Coalition for Compassionate Care	Fresno
Caregiver Resource Center – Orange County	Fullerton
Catholic Charities of Santa Clara County	San Jose
Chinese American Coalition for Compassionate Care	Shingle Springs
Community Wellness Services, Inc.	Pasadena
Compassionate Care Alliance	Monterey
East Bay Conversation Project c/o ACCMA Community Health Foundation	Oakland
Elmhurst United Methodist Church	Oakland
Fresno Healthy Communities Access Partners	Fresno
Golden Castle Adult Day Health Center	Palo Alto
Government Action and Communication Institute	Fair Oaks
Grandmothers Who Help	Livermore
Hospice of the Foothills	Grass Valley
Humboldt Advance Care Planning Coalition: Live Well, Die Well	Eureka
Institute on Aging	San Francisco
John Muir Health (John Muir Medical Center)	Concord
Loma Linda University Health Institute for Health Policy & Leadership and Loma Linda University Center for Christian Bioethics	Loma Linda

ORGANIZATION	LOCATION
Los Angeles LGBT Center	Los Angeles
Marin County Aging and Adult Services	San Rafael
Mercy Foundation North	Redding
Mercy Hospice	Redding
My Care, My Plan — Speak Up Sonoma County	Santa Rosa
North and South of Market Adult Day Health (SteppingStone)	San Francisco
Orange County Aging Services Collaborative	Irvine
Our Lady of Guadalupe Church (Hammel St.)	Los Angeles
PIH Health	Whittier
Saddleback Laguna Hills/SCAN	San Clemente
San Diego County Coalition for Improving End-of-Life Care	San Diego
San Mateo Medical Center, Senior Care Center	San Mateo
Snowline Hospice	Sacramento
Stanford Health Care	Stanford
UCSF Osher Center for Integrative Medicine	San Francisco
University of California, San Diego	San Diego
Venice Arts	Venice
Vietnamese American Community Center of the East Bay	Oakland
Visiting Nurse & Hospice Care of Santa Barbara	Santa Barbara
Washington Hospital Healthcare System	Fremont