

***END OF LIFE:
What Society Should Do for Those Who are Dying?***

A Public Deliberation - April 11, 2016

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May 26, 2016

ACKNOWLEDGEMENTS

SUNY Broome would like to acknowledge the following individuals and organizations who contributed to the success of the April 11, 2016 End of Life Program:

- Laura M. Letson, Adjunct Instructor, Department of Psychology and Human Services
- Lisa Strahley, Coordinator, Civic Engagement Center; Chair, Teacher Education/Early Childhood Education
- Margherita Rossi, Chair, Department of Psychology and Human Services
- Jason Boring, Director, Student Activities
- Katherine Bacon, Chair, Performing Arts Program
- Sandra Stephens, Keyboard Specialist, Department of Continuing Education/Dean of Students Office
- Ashley Blackwell, Typist, Department of Athletics
- Helen DeVita, Catering Director, American Dining Creations
- John Richardson, Senior Maintenance Mechanic, Department of Maintenance
- Amanda Truin, Secretary, Department of Liberal Arts
- Debra Morello, Vice-President, Student & Economic Development/Executive Director
- Jennifer Micale, Staff Asst., Office of Marketing & Communications, Event Services
- Timothy Skinner, Coordinator, Full Time Adjunct, Department of Communications & Media Arts
- Chris Burger, Board Member, SUNY Broome Civic Engagement Center
- Eric Jensen, Board Member, SUNY Broome Civic Engagement Center
- Kathleen McKenna, Professor, History, Philosophy and Social Services, and Criminal Justice
- Laurel Goff, Adjunct Instructor, Department of History, Philosophy and Social Sciences
- Douglas Garnar, Founder, Civic Engagement Center, Distinguished Service Professor Emeritus
- Karryann Kohlbeck, Student
- Tom Flynn, Student
- Josh Doge, Student
- Kathryn Wills, Student
- Students in HMS 240 Class, Spring 2016
- Mark Jabaut, Playwright, The Bridge Club of Death
- Devon Goodman, Director, The Bridge Club of Death
- Marcy Gamzon, Actress, The Bridge Club of Death
- Roger Gans, Actor, The Bridge Club of Death
- Denise Bartolo, Actress, The Bridge Club of Death
- Tom Bohrer, Actor, The Bridge Club of Death
- Ian Von Fange, Actor, The Bridge Club of Death
- American Dining Creations, SUNY Broome
- MarCom, SUNY Broome
- Broome County Department of Health, Cancer Services Program, Binghamton, NY
- Broome County Department of Social Services, Binghamton, NY
- Broome County Office for the Aging, Binghamton, NY
- Broome County Veteran's Services Agency, Binghamton, NY
- Compassion and Choices, Denver, Colorado
- Lourdes at Home/Hospice, Vestal, NY
- Mercy House of the Southern Tier, Endicott, NY
- The Hearth at Castle Gardens, Vestal, NY

End of Life: What Should Society Do for Those Who are Dying?

INTRODUCTION

On Monday, April 11, 2016, from 6:00 to 9:00 p.m. the State University of New York at Broome's (SUNY Broome) Departments of Psychology and Human Services, Student Activities, and Civic Engagement, hosted a community event focused on end of life decisions by addressing the question, *End of Life: What Should Society Do for Those Who are Dying?* Participants included county residents and organizations, and SUNY Broome Community College administrators, faculty, staff, and students. SUNY Broome Instructor, Laura Letson, who teaches the course on death and dying, initiated the event.

PROGRAM OBJECTIVES

The objective of the evening program was to supplement and foster the learning outcomes for death and dying students, while providing an opportunity for community residents, organizations and others to participate in an open and non-judgmental forum designed to discuss end of life issues that individuals and society as a whole typically prefer to avoid. Another primary objective was to determine how attendees viewed the issue of physician assisted death (i.e. also known as "physician assisted suicide" or "right to die") in light of New York State's proposed legislation and in anticipation of the implementation of the recently approved right to die law within the state of California. At the time of the event, five of the 50 states had approved some form of right to die legislation, mirroring the State of Oregon's 1997 Death with Dignity Act.

BACKGROUND

In formulating the event, the program acknowledged that a considerable number of college students are either within 12 months of a family or a friend's death or comprise the one-third to nearly half of the college population who are within 24 months of bereavement. With regard to adverse life events, death loss was identified as the most common among undergraduates.¹ The realism of this research hit home immediately after the onset of the Spring 2016 semester, at which time SUNY Broome received the news that a former student had been killed in a car accident (the leading cause of death among college students). As the deceased was known among administrators, faculty and students, impacts were felt across the college community, including among students in Laura Letson's class.

SUNY Broome is a community college, comprised of students of all ages and backgrounds. Coupled with the demographics of Broome County residents (where the college is located), the appropriateness of the forum seemed right on point. Simply, the program recognized that a significant portion of SUNY Broome's student base and the broader community had been touched by, or will face, end of life choices and decisions now or in the future. For these reasons, SUNY Broome was proud to open the event to community residents and to organizations servicing this population.

¹ Sara J. Tedrick Parikh and Heath L. Servaty-Seib, "College Students' Beliefs about Supporting a Grieving Peer," *Death Studies* 37 (2013): 653-669

INTERDEPARTMENTAL COOPERATION

To assure the End of Life Program (EOLP) would be appropriately designed for students, consultations were held with Margherita Rossi, Chair of the Psychology and Human Services Department, where the death and dying course is housed, as well as with Jason Boring, Director of Student Activities, to inquire about the possibility of a joint endeavor. Upon presenting the idea of an evening kicking off with a thought provoking, heartbreaking and humorous play focusing on end of life issues, that closes with a question related to a person's right to die with dignity, furnished the perfect pathway for launching a public deliberation (i.e. community dialogue) on the topic. This cooperative approach resulted in full financial support by the Student Activities Department, which enabled the event to be free to all participants.

Thereafter, the Coordinator of the Civic Engagement Center at SUNY Broome, Lisa Strahley, was approached for purposes of guiding the development of the deliberation given the program's framework. Further, the Chair of SUNY Broome's Performing Arts Program, Katherine Bacon, was contacted to assure the performance could be held at the Angelo Zuccolo Little Theater on campus. Ultimately, through the collective interest and planning of the departments noted above, the event took shape.

COMMUNITY AND ONCAMPUS OUTREACH

To raise awareness about the EOLP throughout Broome County, press releases were issued by SUNY Broome's media office, MarCom. In addition, Laura Letson prepared a "Guest Viewpoint" which appeared on April 7, 2016 in the *Press and Sun Bulletin* (covers the Greater Binghamton area and the Southern Tier of New York), outlining the purpose of the event and an invitation to residents and local organizations to participate. Organizations were also personally contacted by phone.

To broaden the audience further, Laura Letson and Douglas Garner, Founder of the College's Civic Engagement Center, appeared on Binghamton NOW, a popular radio talk show, hosted by Bob Joseph. The local television news station, WBNG, also sent a reporter to cover the event, which was highlighted on the evening news.

Beyond the external promotions, MarCom advertised the program several days in advance of the event on campus through the daily online BUZZ calendar. SUNY Broome's Department of Communications & Media Arts also agreed to video all aspects of the evening so a short video program could be prepared depicting various aspects of the end of life event, including the reactions by participants. Emails were also sent by the Psychology and Human Services Department, and the Center for Civic Engagement, to members within the administration, to chairs and faculty within the following courses or departments to promote the EOLP campus wide and among students:

- Chemical Dependency Counseling
- Communicating about Values
- Counseling Services
- EMT/Paramedic Program
- Ethics

- Health Sciences - Nursing and Medical Assistant
- Human Development
- Law
- Medical Ethics, Law and Economics
- Psychology and Human Services
- Public Policy
- Social and Political Philosophy
- Social Psychology

Since the Civic Engagement Center intended on using the National Issues Forum issues guide, entitled *End of Life: What Should Society Do for Those Who are Dying?*, participants were directed to an online version of the guide and encouraged to review it in advance of the event.

ORGANIZATIONAL REPRESENTATION

As a means of assuring representation by organizations that provide direct services, programs and/or assistance to the chronic or terminally ill, their families and other loved ones, or supply varying levels of supports to the general population, elders, veterans and/or social service recipients, six local government agencies, one independent/assisted living center, and one national nonprofit hosted informational tables at the event. (Note: Only a limited number of organizations were allowed to host tables given space limitations due to fire codes.)

The participating organizations included:

Lourdes at Home/Hospice

The certified Hospice program servicing the terminally ill of all ages (i.e. life expectancy of weeks up to six months) and their families in their homes, at Lourdes Hospital or in contracted hospitals (i.e. short term stays) and community nursing facilities (i.e. respite care) within Broome, Tioga and Delaware Counties, and parts of Chenango County.

Mercy House of the Southern Tier

A newly opened community care shelter located in Endicott, New York, that provides a home and a supportive family to people with terminal illnesses who can no longer remain at home. (All Mercy House residents are admitted via the Lourdes Hospice program.)

Broome County Office for the Aging

Assists seniors and caregivers by providing the services and benefits that elders need to live independently within the community and in their homes in Broome County.

Broome County Department of Health, Cancer Services Program

Provides free cancer screenings to residents of Broome, Chenango and Tioga Counties who do not have health insurance and furnishes free diagnostic testing when there is an abnormal screening result.

Broome County Veteran's Services Agency

Furnishes an array of services to an estimated 18,000 veterans and their families, as well as to active duty servicemen/women and their families; offers professional assistance and advice in the filing of applications for benefits; and familiarizes veterans and their families regarding available benefits.

Broome County Department of Social Services

Promotes self-sufficiency through the delivery of temporary and transitional assistance, disability assistance, and the collection of child support, and assures the protections of vulnerable individuals.

The Hearth at Castle Gardens

Offers independent living, assisted living, and memory care services for those requiring additional support.

Compassion and Choices

This national nonprofit is an advocate for improving patient rights and individual choice at the end of life, including access to medical aid in dying.

EXPRESSION OF SUPPORT

In light of the opening of Mercy House of the Southern Tier, on February 28, 2016, which is fully funded by grants and donations, SUNY Broome requested EOLP attendees bring one roll of paper towels or a box of tissues as a donation to the organization.

THE BRIDGE CLUB OF DEATH

The Bridge Club of Death was the selected performance to launch the evening program because of the playwright's ability to address the serious topic of end of life decisions in a thought provoking and humorous way. It also created an inroad to begin a communitywide conversation on a topic that is generally avoided or primarily addressed during times of crisis.

The Bridge Club of Death is a funny and heartbreaking play that highlights four residents in a nursing home who routinely meet to play bridge while taking on the law and their own consciences by scheduling appointments to provide death with dignity to residents within the facility. As the health of one of their own bridge club members is on a downward spiral, and the nursing home director is on to their escapades, the remaining three are left confronting the question of whether or not they should assist in ending their friend's life. Written by Rochester based playwright Mark Jabaut and directed by Devin Goodman, the performance addresses the issues of aging, death, morality, euthanasia and

murder, all within a matter of 50 minutes running time. As the play ends with a presenting dilemma, the audience is left pondering what one bridge club member will ultimately do. This presented as the perfect opportunity to take a brief break, grab something to eat, and proceed right into the community deliberation.

PUBLIC DELIBERATIONS AND PARTICIPANT QUESTIONNAIRES

Public or community deliberations are an opportunity for citizens to join together to thoughtfully consider a morally charged topic or problem about things they value, to make choices with others about ways to approach difficult issues, and to work toward creating reasoned public judgment. Generally, deliberations serve to inform participants about an issue, furnish a chance to consider different approaches and perspectives, to address strengths and weaknesses, and to identify trade-offs.

Webster's Dictionary defines a trade-off as a situation in which a person must choose between or balance two things that are opposing or cannot be had at the same time. It's something a person doesn't want to accept in order to have something else.

Since 2006, SUNY Broome has been conducting public deliberations on difficult issues, including but not limited to substance abuse, economic inequality, health care, racial injustice, bullying, obesity, purpose of higher education, and mental illness. These forums help to model a collegial platform for community dialogue and participants often self-report on the questionnaires that there should be more opportunities to deliberate.

According to the National Issues Forum, a nonpartisan, nationwide network of locally sponsored public forums for the consideration of public policy issues, the deliberation forums provide a way for people of diverse views and experiences to seek a shared understanding of the problem and to search for common ground for action. Typically, forums are small gatherings where people convene for a few hours to deliberate about an important and difficult public problem (or issue), led by trained, neutral moderators, and use an issue discussion guide that frames the issue by presenting the overall problem and then three or four broad approaches to the problem. Forum participants work through the issue by considering each approach; examining what appeals to them or concerns them, and also what the costs, consequences, and trade-offs may be that would be incurred in following that approach.

Deliberating on tough issues provides everyday citizens and the community as a whole with a chance to gain insights, express opinions and to hear how the views of others may differ from their own. The deliberative process underscores respectful honest dialogue and well-reasoned decision making. This type of community dialogue is based on citizen perspectives rather than expert politics. Therefore, attempts to foster an inclusive welcoming environment for all stakeholders to join in the conversation are made practical without the usual pressures typically associated with open-ended discussions or debates.

Due to the projected number of participants and in recognition that public deliberations are usually held among small groups, the Civic Engagement Center made a determination to hold multiple forums, each facilitated by a trained moderator, accompanied by a note-taker.

Generally, public deliberations require participants to review an issues guide or some other material in advance of the forum, assuring that attendees have access to the same information. However, in the case of the EOLP, it was anticipated that a fair number of participants would attend without having reviewed the information. For this reason, the Civic Engagement Center developed and furnished each participant with a placemat that framed the issue and portrayed each of the three options, including possible actions and trade-offs. This option worked well.

In an effort to secure the opinions of participants regarding approaches discussed, and to confirm various trade-offs, a questionnaire was devised and disseminated upon completion of the evening program that asked whether people ***strongly agreed, somewhat agreed, somewhat disagreed, strongly disagreed*** or were ***not sure*** about various statements. This questionnaire sought input as to how attendees thought the state and federal governments, the American Medical Association, health care professionals, the Supreme Court, and others should proceed in various areas such as living wills and advanced directives, the definition of a “quality of life”, peer consultations, state laws, and physician assisted death. Statements on the questionnaire were presented in the *End of Life* guide and also discussed to varying degrees during the deliberation.

END OF LIFE PROGRAM OVERVIEW

Given the evening program started at 6:00 p.m. and would not be finished until 9:00 p.m., doors opened at 5:00 p.m. so participants would have approximately one hour to visit with representatives from eight different organizations (descriptions above), so they could gain an understanding of service offerings and programs available within the community.

Lourdes at Home/Hospice
Mercy House of the Southern Tier
Broome County Office for the Aging
Broome County Department of Health, Cancer Services Program
Broome County Veteran’s Services Agency
Broome County Department of Social Services
The Hearth at Castle Gardens
Compassion and Choices

The second portion of the event offered attendees the opportunity to view *The Bridge Club of Death*, which was the first time that the college’s Center for Civic Engagement had an opportunity to utilize the Arts in collaboration with community dialogue and public deliberation. The hope was to provide participants with a collective experience that could elicit an emotional connection to the issue prior to engaging in the topic with their fellow citizens.

Prior to introducing the performance, Laura Letson set the tone of the evening by sharing some societal perceptions and challenges related to death, dying and associated decisions. She further explained that SUNY Broome’s role in the EOLP was to solely provide a framework for a facilitated, non-judgmental and balanced forum, with no preconceived agenda, allowing for the open sharing of participant views and opinions.

Following *The Bridge Club of Death* performance, Lisa Strahley explained the purpose of a community deliberation and invited all attendees to participate in one on end of life decisions. As the deliberations were located in another building, close in proximity, participants transitioned to engage in the community dialogue.

Using a deliberative format, participants openly addressed what society should allow and support at the end of life, while exploring possible options that could be adopted by NYS policymakers and citizens. The deliberations examined three different options, ranging from preserving life at all costs, to keeping patients comfortable and pain free, to allowing the terminally ill to have the right to control how and when they die. It also provided for the discussion related to trade-offs.

End of life choices, under most circumstances, are difficult and uncomfortable, so the overall objective was to address the availability of options, as well as associated challenges and therapeutic value. Given the advances in medical treatments and technology, the population is living longer and confronting decisions regarding end of life care. Illnesses that were once death sentences are now often treatable. Yet, we often prolong the lives of the chronically ill who, if given the choice, would opt to end their suffering and have the right to die peacefully. Related decisions also raise many questions, including but not limited to philosophical, ethical, religious, and legal considerations. As more and more states, including New York, consider passing right to die laws, SUNY Broome spearheaded the event with the intent to provide sufficient time for community members to explore possible options with fellow citizens.

Today, more than 100 million Americans have chronic diseases and deciding what is best has become both a personal and a public decision. Many chronically ill people can be kept alive through extremely painful and debilitating terminal stages. As a result, a growing number are asking for the right to take their lives in an effort to end their suffering.

However, on average, the end of life is the most expensive period of all, with Americans spending five times the money on health care in their last 12 months of life than in any previous one year period. Even those who will never face these choices will pay for them through tax dollars and costly insurance premiums. So the question of *What Should Society Do for Those Who are Dying?* is an important one for everyone to consider.

END OF LIFE PROGRAM OUTCOMES

Market reach: Exposure relating to the event garnered from MarCom's efforts, the Guest Viewpoint, radio talk show, television coverage, and related activities, had a potential market reach in excess of 300,000.

In general: The event successfully brought citizens together to participate in a dialogue focused on a difficult community issue. Nearly 40% reported that they were thinking differently about the issue following the completion of the forum. All acknowledged that the deliberative process brought out different points of view and opinions, which helped participants to be better informed. One of the moderators further reported that all of the participants in her group agreed about the value of these types of conversations, in the community and within families. There was resounding support to

increase public deliberation opportunities in that participants stressed the need for respectful civic dialogue and problem solving. It was also determined that many of the attendees were made aware of the event via the Guest Viewpoint appearing in the newspaper.

Informational Tables: A total of eight organizations hosted informational tables prior to the onset of the event, which seemed to have a steady flow of participants who were picking up materials and engaging in conversation.

Donations: More than 50 rolls of paper towels and 15 boxes of tissues were collected and donated to Mercy House.

Attendance: Over 75 people attended *The Bridge Club of Death* performance and of these, nearly 60 stayed to join in the public deliberation. Some who did not attend the community forum indicated that while they had planned to stay, when they learned that the deliberation rooms were in a different building (in very close proximity), they opted not to attend. A few also commented that they were unable to walk due to physical limitations. Another significant deterrent may have been the weather, which was a combination of cold and rainy, making the second location even less desirable.

Two-thirds of participants were community members whereas one-third was comprised of administrators, staff and students from SUNY Broome.

Deliberation Forums: Of the participants who attended the play and deliberation, 44 of the approximate 60 people completed and submitted the questionnaire. Results revealed that respondents were overwhelmingly female (75%) and primarily between the ages of 46 to 65+. Only 20% were ages 18-30 years.

Option 1: Maintain Quality of Life

Medical advances make it possible to keep people alive long after they might otherwise have died naturally. People should be able to opt for discontinuing treatment when prolonging life promises only further pain and suffering. Doctors should focus on the quality of the lives of the terminally ill patients in their care.

Option 1 contends that our focus should be on maintaining quality of life, which means when continued efforts to keep terminally ill patients alive a few more days or weeks resulting in needless pain and suffering, life-support treatment should be discontinued. At that point, caregiving efforts should be devoted to **keeping patients comfortable and pain free.**

Participants were asked if they agree or disagree with the following statement:

- a. *The American Medical Association and other governing boards should standardize a definition of “quality of life” in a way that is universally understood. The criteria for determining the “quality of life” should be critical in determining whether or not a procedure will be used.*

59% of all 44 respondents disagreed with this statement on account that “quality of life” is a subjective term that varies from person to person and situation to situation presenting difficulties in the establishment of a definition. Moreover, there was discussion that choices along the continuum of end of life care could hinder life quality.

A primary weakness identified was that by having government mandate certain standards would result in too much oversight in end of life decisions when people have a general mistrust of these public bodies. Other identified weaknesses included the fact that some people change their minds regarding their choices at the end of life, inequity of insurance, a one size fits all approach which is not viable here, and potential implications resulting from some individuals being valued more than others, not to mention associated costs.

Several potential trade-offs were not fully considered as participants were uncomfortable giving government the right to define what “quality of life” means and seemed to feel that the only viable trade-off was promoting the use of wills and advance directives to assure that patient wishes would be established and known. (See action b. below)

Participants were asked if they agree or disagree with the following statement:

- b. Hospitals, health insurance firms, and employers should require people to develop living wills and/or advanced directives.*

As it was agreed that it is often tough to make decisions for loved ones when there isn’t a pre-determined plan in place, two-thirds of all 44 respondents, or **66%**, agreed that hospitals, health insurance firms and employers should require people to develop living wills and/or advanced directives.

One noted strength in favor of having some sort of advance directive was that these documents allow individuals to focus on how and when they wish to die and that patients have the right to define such terms and not medical professionals.

While the group agreed with action b. for Option 1, the trade-off was that over time and in crisis, individuals may change their minds regarding their healthcare wishes, which may lock them into agreements that may or may not reflect their true intentions. The pressure may also influence the terms. Therefore, the group consensus was that these documents needed to be revisited periodically. (Note: This is the standard recommendation for advance directives, in that they should be reviewed at least every two to three years.)

Some participants also identified the importance of loved ones being aware of such wishes, which ultimately relieves the burden on family members and others in making end of life decisions, and highlighted the need to identify a trusted individual with this information.

Participants were asked if they agree or disagree with the following statement:

- c. *We should hold people accountable for their own quality of life. Doctors should be able to withhold costly treatment and resources from those who make lifestyle and dietary choices that foster chronic illnesses.*

Of the 42 participants responding to action c., **57%** disagreed that people should be accountable for their own quality of life if that meant that doctors would be able to withhold treatment and resources. Participants commented that health and life choices are not cookie-cutter one-size fits all scenarios and that there are many factors, such as addiction and genetic composition variables, which could impact upon one's lifestyle and dietary choices that lead to chronic health problems.

The majority of respondents felt that people inflicted with these types of challenges should not be denied treatments based on such factors. Some attendees discussed the notion that 'an ounce of prevention is worth a pound of cure', meaning that citizens, when possible, should respect their bodies in an effort to reduce costly healthcare treatment.

Option 1 Synopsis:

Overall, while the a. b. and c. action statements under Option 1 inquired about matters relating to the American Medical Association and other governing boards, as well as hospitals, health insurance companies, employers, doctors and patients, the deliberation results identified a consistent sense of discomfort and mistrust among participants regarding government and other public bodies. Simply, participants felt that government should not define "quality of life" or intervene with health care decisions in that these choices should be left up to individuals versus medical professionals.

Attendees further purported that having hospitals, health insurance companies and employers to require that people develop living wills and/or advance directives would assure that a patient's wishes would be known and could be adhered to.

Option 2: Preserve Life

Those drawn to this option feel it is the obligation of society to preserve life at all costs, regardless of a patient's wishes and those of their families. All life is valuable and worth saving. We have a collective moral responsibility to do everything possible to prevent death. As long as there is the ability to maintain life, our skills should be employed in sustaining it.

Option 2 maintains that **we must preserve life at all costs** and do everything we can to prevent death. This means sparing no expense to extend the lives of those who are sick. It should be difficult for doctors to give up on patients, and the end must not be brought about by deliberate medical neglect or intervention. Right to die laws must be repealed.

Participants were asked if they agree or disagree with the following statement:

- d. *We should educate families and patients regarding their legal rights to demand treatment and to require doctors to sustain their lives at all costs.*

Action d. was supported by the group for Option 2 in that **57%** of the respondents felt that families and patients should receive such education. Yet, this sentiment was due in part to patients lacking trust in the motives of some health care professionals. One contingent felt a trade-off was that doctors may make decisions at times based on kickbacks and incentives offered to them by insurance companies, while others questioned a rush to judgment for other reasons. Therefore, patients need to be informed and willing to ask the tough questions.

Participants were asked if they agree or disagree with the following statement:

- e. *We should force doctors to participate in peer consultations with health care professionals not directly involved with their patients.*

Action e. was also supported by the group in that of the 43 responses to the statement, **53%** of participants agreed that we should force doctors to participate in peer consultations, given a lack of trust in the current medical system; outside influences in the health care industry, namely insurance and pharmaceutical companies; fear of malpractice suits by physicians; and rash decisions made due to insufficient numbers of medical providers, all of which hinder quality healthcare.

For these reasons, it was determined that medical peer-to-peer consultations may improve healthcare diagnoses and treatment plans. The potential drawback or trade-off was that this would consume time, especially when medical decisions may need to be made promptly, resulting in increased patient costs.

Participants were asked if they agree or disagree with the following statement:

- f. *We could appeal to the Supreme Court to roll back all state laws that have legalized physician-assisted death.*

82% of the respondents disagreed (75% strongly disagreed) and felt we should not make such an appeal to roll back laws legalizing physician assisted death. Participants felt most impassioned that citizens should have the right to make end of life decisions. The group did not identify any trade-offs or drawbacks relating to this action.

Option 2 Synopsis:

There was recognition that people do not want to die alone, that life-extending technology can result in emotional turmoil among loved ones, that the medical profession and health care system are not utilizing/practicing protocols based upon the same standards, and that when we preserve life at all costs, we also sacrifice and impact upon a person's quality of life. Such life-extending options can intrude upon what a person wants, can result in an individual's loss of personal choices, as well as high medical costs, and can ultimately eliminate choices among more needy populations within society (e.g. financial struggles among an aging society). Additionally, such treatment could prevent quality of life being re-reached.

More than half of the respondents felt that families and patients should receive education regarding their legal rights. However, this was partly due to the lack of trust in health care professionals given the potential of incentives and outside pressures. Yet, slightly more than half agreed that peer-to-peer consultations may improve healthcare diagnoses and treatment plans, even though the trade-off was that this would consume time, be challenging during instances when medical decisions must be made promptly, and result in increased patient costs.

Overall, the group overwhelmingly supported the existence of laws on physician assisted death in other states and felt they should be upheld versus rolled back and consistently advocated for citizens to have the right to make their own decisions.

Option 3: My Choice, My Right

The freedom to choose for oneself, as long as it does not directly infringe upon the rights of others, is a deeply held American value. People should all have the right to decide whether they want to live to die. We should expand the options available to all of us at the end of our lives to include the right to seek help from our physicians in ending our lives when death is inevitable, and suffering makes life unendurable.

Option 3 maintains that **people should have the right to control how and when they die**. The freedoms we value so highly in choosing how we live should not be taken away from us at the end of our lives. People should have the right to end their own lives and to enlist their doctors in helping them to die when a terminal illness leaves nothing to look forward to but higher levels of pain and suffering.

Participants were asked if they agree or disagree with the following statement:

g. The federal government should legalize physician assisted death in all 50 states and the District of Columbia.

Of the 43 responses to this statement, **63%** of participants felt that the federal government should legalize physician-assisted death in all 50 states and the District of Columbia. This statement further reflects the collective position that citizens should have the right to make end of life decisions and the importance of lobbying in favor of compassionate choices.

The one drawback or trade-off is that this could burden families and encourage an increase in impulsive acts.

It is important to point out that 18% of the respondents strongly disagreed with this statement. Comments against such legislation included a lack of sensitivity toward cultural and religious beliefs on death and dying, and a distrust in political systems legislating such issues.

Participants were asked if they agree or disagree with the following statement:

h. The American Medical Association should work to standardize protocols for physician assisted deaths, making it unnecessary for people to come up with their own innovative ways of taking their own lives.

71% of the respondents agreed with this statement, reflecting the group's overall position that citizens should have the right to make end of life decisions. One person commented that citizens, working together, could lobby for compassionate choices legislation and advocate for change.

Participants were asked if they agree or disagree with the following statement:

i. Health care professionals should be absolved of all legal penalties for assisting patients to die.

66% (of 41 responses) of participants agreed that health care professionals should be absolved of all legal penalties in these instances. This gives healthcare professionals more protection against malpractice and places more responsibility on citizens to be informed, prepared and responsible for their end of life decisions. At the same time, this was also viewed as a potential trade-off in that it may lead to higher instances of malpractice because healthcare professionals may no longer fear being punished.

Option 3 Synopsis:

The majority of participants supported actions g-i which related to the right to control how and when we die. There was strong support for physician assisted death laws across the United States and in the District of Columbia; for the establishment of standardized protocols for physician assisted death; and for absolving health care professionals of legal penalties for assisting patients to die.

Trade-offs or potential drawbacks identified by those in opposition of right to die laws felt they failed to take cultural and religious beliefs on death and dying into consideration. Here again, the issue of distrust among political systems legislating such issues also surfaced reluctance on the part of participants.

At the same time, there was concern that absolving physicians could actually result in increased mistakes and instances of malpractice in the event doctors were not attentive to individual nuances or circumstances. It could also present challenges for those physicians whose faith conflict with right to die choices, not to mention create issues among a changing cast of hospitalists who are unequipped to work with family members on end of life issues, placing the burden of these decisions solely on patients and/or their families.

ADDITIONAL FEEDBACK

Some comments made by participants on the questionnaire as to whether they were thinking differently about the issue included, but were not limited to:

- "Discussion on the topics was so valuable."
- "Better informed."

- “The forum has caused me to think more acutely about these issues and these options.”
- “Generally, I take the same stand, but I have things to re-evaluate.”
- “A broader understanding of legislation and the idea that no one of the three options is an absolute solution.”
- “I need to focus on what my plan will be, not enough time is spent on this topic as it is so hard.”
- “I heard different opinions, which opened my mind.”
- “I learned about the different views of life.”

As for respondent feedback as to aspects of the issue they hadn’t considered before included some of the following:

- “Questions of quality of life versus just preserving life.”
- “Issues with DNRs, and compassion and choices with assisted ending of life.”
- “Others opinions were very interesting, especially the personal stories.”
- “Viewing other’s wishes than your own.”
- “Exploration of other cultures’ views on death and dying.”
- “Different experiences of others.”
- “The various opinions about the right to choose when to die.”

In response to what citizens, working together, could do to address this problem within their community, the following was shared:

- “Continue forums such as this one.”
- “Have more forums like this within the community – talk in high schools, churches, etc.”
- “More open dialogue and community informational opportunities.”
- “Educate, educate, educate; these forum discussions are fantastic.”
- “Educate people on the choices we discussed.”
- “Lobby for compassionate choices’ legislation.”

- “Advocate for legal change.”
- “Talking more is the most important thing; we all need to talk more.”
- “Just open up venues for people to actually talk about death and dying.”
- “Educate about the different cultural practices and beliefs, as well as the best options medically and scientifically, which can be pursued with the best interest and benefit of the people.”
- “Talk to their healthcare providers strongly about end of life choices, have additional forums and periodicals available.”

In general, participants expressed support for future deliberations and recognized the importance of these community gatherings in addressing issues related to end of life and death and dying.

LESSONS LEARNED

Location and convenience matters:

In planning future events, we will make every effort possible to secure one central location conducive to all aspects of the agenda. The loss of 15 or more people between the performance and the deliberation was the result of a second location in combination with cold and rainy weather.

Art and Public Deliberations

Blending the Arts with a public deliberation seems to have had a positive impact on attendance. *The Bridge Club of Death* performance prompted participants to begin thinking about end of life decisions and related issues, which served as the perfect foundation for a deliberation forum. In addition to the program’s academic, educational and therapeutic values, it was entertaining, which presented as a win-win in every respect.

Audience Reached

This event attracted many more individuals between the ages of 46-65+ than younger. Moving forward, efforts will be made to determine how we can best secure participation by younger people to join in the conversation. For starters, we can begin the advertising on campus weeks prior to the event. Additional outreach efforts will be made to include the use of flyers and other materials promoting the event in areas where younger people congregate and in locations servicing the elder, veteran and general populations.

The event attracted three times the number of females than males. Though it is true that females comprise the largest percentage of caregivers in the United States, ranging from 53-68%, the event seemed to attract a disproportionate number of females (75%). While the reasons for this disparity are unknown, efforts will be made to include more males in future endeavors. Moreover, steps will be

taken to compile information that will identify the reason(s) for this disparity in hopes that future events continue to meet the needs of the campus and the greater community.

Informational Tables

The inclusion of informational tables hosted by six countywide organizations, one facility which provides independent and assisted living services, as well as memory care for those requiring additional help, and one national nonprofit dedicated to compassionate choices at the end of life, was informative. Organizational representatives, including several agency directors, provided information about their agency's programs and services. Materials were also furnished as were answers to presenting questions.

Providing one hour's time prior to the beginning of the event for informational table visits was insufficient in that it did not provide ample opportunity for attendees to visit with these organizations during each phase of the program as questions arose.

In the future, in addition to hosting the program in one location from beginning to end, more time will be allocated for the sharing of information by organizations by retaining the table set-ups throughout the course of the event.

Issues Guide

While participants of public deliberations are to review an issues guide in advance of attending the community forum to assure they are provided with a framework for the topic, including options and approaches for consideration, the Civic Engagement Center anticipated that a significant number of event attendees would not have read the material prior to the program date.

It appeared that participants learned about the event in diverse but anticipated ways, which impacted upon their awareness about the online guide. For example, while one person may have read about the program offered in an online post, with a ready link to the issues guide, others may have become aware upon listening to a radio talk show where reference to reading material was not made.

In the future, given the array of outreach methods, various approaches will be used to promote deliberations and will seek to determine whether a condensed version of an issues guide, less than 20 pages, is feasible for use. Though the NFI guides are well recognized and valued, it presents as a point of information since the scope of the reading material, in this case, may have dissuaded a fair number of people from reading and/or participating.

SUMMARY

SUNY Broome's event, entitled *End of Life: What Should Society Do for Those Who are Dying?*, held on April 11, 2016, was a success, attracted upwards of 75 people from the community and campus wide, and featured a professional performance followed by a public deliberation that provided meaningful information about a range of end of life options and choices to program attendees.

The event's audience was comprised of individuals ranging in ages from 18-65+ and were primarily women. Approximately one-third of the participants were SUNY Broome administrators, faculty and students, whereas the remaining two-thirds were members of the broader community.

Using an art form in collaboration with a public deliberation (i.e. facilitated community dialogue) proved to be extremely beneficial in that it enabled the program to offer academic, educational, and therapeutic value, while providing insight about a serious and much avoided topic in a safe, engaging and entertaining way. It also was the first time these two concepts were used in combination as a means of launching a National Issues Forum deliberation, resulting in very positive feedback from attendees.

The End of Life Program (EOLP) explored the questions of what society should allow and support at the end of life and suggested possible options, ranging from preserving life at all costs, to keeping patients comfortable and pain free, to allowing the terminally ill to have the right to control how and when they die. It further reviewed the related psychological, philosophical, ethical, religious and legal aspects, and provided the opportunity for attendees to gain information and insight about programs and services within the community via tables hosted by eight organizations.

The EOLP outcomes revealed that participants overwhelmingly supported a person's right to make their own end of life decisions versus medical professionals and favored right to die legislation being established by the federal government in all 50 states. Along these same lines, the group consensus supported the upholding of existing laws in the five states where right to die options are in effect and opposed having them rolled back.

Participants expressed distrust in government and other public governing bodies, resulting in a lack of support for having the American Medical Association (AMA) or others standardize a definition for the term "quality of life," so that it could be universally understood. In addition to feeling the term is subjective, in that its meaning can vary from person to person and case by case, the lack of trust among those within these institutions was largely due to a perception that incentives and pressures placed upon physicians and others in the health care field by insurance companies, pharmaceutical firms, and others, compromise patient care.

The group supported the action that hospitals, insurers and employers should require people to develop living wills and/or advance directives, and asserted these documents could assure that a patient's wishes would be known and adhered to. It was also determined that the AMA should be allowed to standardize protocols for physician assisted deaths, so people would not have to identify their own innovative ways to end their own lives, and affirmed that people would be accountable for their own quality of life.

Trade-offs or potential drawbacks identified by those in opposition of right to die laws felt they failed to take cultural and religious beliefs on death and dying into consideration and noted they could present challenges for physicians whose faith conflict with right to die choices. There was also concern that absolving physicians could potentially result in increased mistakes and instances of malpractice.

Ultimately, the deliberation revealed that the majority of participants consistently supported citizen rights that allow people to control how and when they die. It further confirmed support for future deliberations and recognized the important role of these community gatherings in addressing issues related to end of life and death and dying.