Galveston Alliance of Island Neighborhoods (GAIN) and Galveston Citizens Police Academy Alumni Association (GCPAAA)

Community Bioethics Dialogue: Mental Health and Seniors

Final Report March 28, 2016

A Partnership between the Galveston Alliance of Island Neighborhoods (GAIN) and the Galveston Citizens Police Academy Alumni Association (GCPAAA), Galveston, and the Institute for the Medical Humanities, University of Texas Medical Branch, Galveston

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Introduction

To carry out the project, an Academic Support Team from University of Texas Medical Branch-Galveston (UTMB) formed a partnership with participants from the Galveston Alliance of Island Neighborhoods (GAIN) and Galveston Citizens Police Academy Alumni Association (GCPAAA). Most of the participants had previously participated in Community Bioethics Dialogues on Patient-Centered Outcomes Research (PCOR) and Comparative Effectiveness Research (CER) in January and February of 2014. During the second round of dialogues, the participants elected to discuss mental health, a topic of critical interest to the community, with the goal of learning more about various issues and the implications surrounding aging, as well as considering actions needed to address the identified problems. The ethical questions addressed by the group include the following:

- What are the critical issues in mental health for seniors?
- What is the role of health care system in supporting mental health for seniors?
- What is the role for various constituencies (patients, families, caregivers, and government) in managing mental health?

Our Process

In 2015, the Academic Support Team met with representatives from GAIN and GCPAAA four times to plan the second round of dialogues. A number of topics were considered,
but after extensive discussions, the topic of “Mental Health and Aging” was selected as being most important to participants due to its impact on the community. A number of us have faced issues with friends and family experiencing mental health issues. In addition, we are concerned with various social issues, such as the increase in mental health problems for those in jails and prisons. Once the main topic was selected, more discussions ensued to identify the details within mental health that we wanted to consider. From these discussions, we selected five areas as being the most interesting and representative of the most difficult issues facing the elderly regarding their mental health: general mental health and seniors; brain decline; caregiver issues; medications; and downstream issues (implications for the community).

The executive leadership for both GAIN and GCPAAA oversaw the recruitment of participants from the organizations and provided the meeting facilities. A few participants from the first round in 2014 were unable to attend the sessions on mental health, so several additional members of the organizations were invited to join. Of the fifteen group members, eleven belonged to GCPAAA and four to GAIN. As awarded in the original Patient-Centered Outcomes Research (PCOR) grant, the project was overseen by the Sealy Center on Aging at UTMB and participants were 65 years of age or older. The group asked the co-investigator and graduate assistant to serve as the facilitator for the group.

Prior to the beginning of the dialogues, the Academic Support Team compiled a list of articles from medical journals and the lay press related to ethical issues in mental health and seniors (Appendix 1). The original round of dialogues covering PCOR and CER held in 2014 occurred for two hours each week for five (5) weeks. In the planning sessions for the round on Mental Health and Seniors, participants requested that guest speakers, knowledgeable on the various topics, would present to them for an additional hour each week. Accordingly, the
dialogues occurred for three hours each week, for five weeks, during January and February 2016. Case studies formed the major basis for discussion during each session (Appendix 2). We were also encouraged to conduct independent research and to discuss our deliberations with friends and family at home in between sessions. The Academic Support Team provided a recorder, attended the sessions, and took notes during sessions.

Before the final dialogue session, the Academic Support Team compiled a list of ethical values taken from notes during Sessions 1-5. The list was provided to us prior to Session 6 and we were asked to agree or disagree with each ethical value statement, and if we agreed, to rank the statement as having high, medium, or low priority. We discussed the list extensively during Session 6, and the results formed the basis for the draft report, which was presented to us prior to the discussion on March 16, 2016, and any further disagreements resolved at that time. This report is the result of that final meeting.

**Major Ethical Conclusions**

We discussed a number of issues with critical ethical issues and values. The discussions were lively, and we were not unanimous on any key values that we identified during the proceedings. As a result, we have prioritized our values into three categories: those on which we mostly agree that the characteristic is of highest importance; those on which more than half of us agree that it is important; and those for which some of us consider the value to be of high importance.

**Highest Importance**

Since we did not achieve unanimity on the various values, we have placed the highest emphasis on those tenets considered by at least ten of us to have the highest priority. We have attributed these to two categories: the health care system and the individual’s role.

*Health Care System.* In general, we believe that mental health is as important as physical health
for seniors. A community benefits when its citizens have access to good mental health care. As we age, we believe that the stability of remaining in our own homes is important, and government/community programs should promote that goal. Within the health care system, there are a few specific areas that require additional attention:

- We are aware that as a country, seniors comprise a growing percentage of the population. Accordingly, the health care system needs to support that trend by assuring that all health care providers have core curriculum training in geriatrics. We believe that mental health should be monitored as closely as physical health for seniors. Accordingly, we believe that society has a responsibility for improving mental health services to everyone in the U.S.

- We are concerned with the quality of care facilities for the aging populace, and believe that individuals providing direct health care in facilities should be trained, licensed, and paid fairly for their work.

- We are alarmed at the increases in drug prices, and believe that Medicare should place common drugs on competitive bids in order to help manage prices.

- We note the alarming rate of jail and prison inhabitants with mental health issues, and believe that correctional facilities are not appropriate repositories.

**Community/Individual Role.** All of us are aging, and we believe that friends and family members have an obligation to look after each other and to speak up and/or seek help when someone’s behavior changes.

- Given the difficulty of making plans when their wishes are not known, we acknowledge that more community education is needed on the importance of medical directives, their purpose, and importance.
• With the increase in seniors in our society, we believe that Medicare and Medicaid should be expanded to widen coverage for aging people who have no one to care for them, or whose care needs to be supported.

• We recognize the role of churches and community groups in serving our populace, and believe that those providing social services, such as feeding the homeless, should have access to mental health training.

Moderate Importance

In this category, we have placed characteristics that were considered to have the highest priority by at least half of us.

Health Care System. Within the health care system, we have noted the importance of mental health care, and many of us consider this to be a societal issue that calls for protecting the elderly in general and improving mental health services to all people. Specific concerns include the following:

• As noted above, most of us believe in the value of educating all professional health care providers in geriatrics. Some of us would extend that value to establish policies to encourage physicians to train as geriatricians to care for aging populations.

• We note the value of the US free enterprise system, and several of us consider that the expanding role of lobbyists in insurance, pharmaceutical, and health industries should be curtailed. Some of us would expand this to disallow those benefiting from health care policies from making contributions to political campaigns.

• Some of us are concerned that those entering care facilities have limited rights when problems arise, and do not have a sufficient grievance process that allows us to address problems – we feel arbitration is insufficient. We are also concerned that complaints for
facilities receiving Medicare and Medicaid funding are not publicized in a clear and understandable manner. We think the complainer’s language should be included as written, and people given an opportunity to understand specific issues associated with a facility.

Other Areas. We believe that these issues deserve discussion in the press, and believe that news outlets have a responsibility for providing balanced information about mental health in order to dispel myths. We believe that groups sponsoring health fairs should include mental health information and screenings in this activity. In addition, many of us believe that governmental agencies should work with private organizations like the Salvation Army to improve services to those with mental health issues.

Lowest Importance

A number of other discussion topics did not reach consensus on their importance, but were still considered to be of sufficient significance to include in this report. Many of these issues fell in the area of the role of government in supporting programs for the elderly and mental health. Some of us are very concerned about the reduced responsibility of families in caring for their elderly members. This translates into a need for more care facilities. In the area of expanding care facilities, some of us believe that the Federal government should establish national incentives for communities to set up senior centers to serve local populations. As an expansion of access to care, some of us do not believe that people should have to be living below the poverty line in order to qualify for Medicaid-supported nursing home care. We believe that Social Security rules need to be expanded to widen the safety net for individuals with mental health issues. Others believe that resources, such as senior centers to serve the local populace, should be funded by the business or volunteer sector.
Comments on the Community Bioethics Dialogues

These sessions provided a unique opportunity to learn more about mental health issues in our community and in broader society. Going forward, we would like to see more attention paid to the issue of mental health and aging, knowing that many of us may experience problems or will need to care for family members.

- Several participants have mentioned that there was too much reading material. I do not agree. I actually felt it gave me an insight into how much thought, collaboration, study and research has gone into mental health issues. Both medical and lay people have delved into the past, present and future. While we are not making Elephant-size strides, media communication has definitely stepped up the pace. These issues have brought about a clearer understanding of mental illness, its ramifications on society in general and families in particular, and has evoked a sense of compassion for what our fellow human beings are dealing with on a daily basis. We should all count our blessings.

- It was very helpful to me, because any time you sit with a group of people and pass around information, you end up learning, and that is what I have gotten out of it. What I would like to see happen is not just to talk about it in our community, but also send to legislators who can do something about it.

- To add to what has been said, I think that one of the benefits of the discussions is that we have become aware of some of the resources that are available and contacts when we have need and to share with the community.

- I am becoming more and more convinced that topics of importance in our lives (like mental health, aging, dementia, housing, and workforce issues) are a great deal larger and more complicated than one person can really understand. There is always something
being left out. This experience has frightened me, because I realize that anyone can be a victim of dementia, and then you can be at the mercy of the system that is more interested in efficiency and income than taking care. I find that while it would be nice to have the legislature do something, they don’t do anything until everyone agrees, and I don’t know that everyone on this island would agree. They might not understand the issues as we all grow older. I don’t know how we get from there to here.

- I was raised by my grandparents, whom I was pretty sure were the oldest people on the planet (in their early 60s). I came here aware of what we were going to discuss. What I rediscovered is that while we are all in this together, in a real sense, we have to walk that valley together, and the society will applaud if we do well and stand back if we don’t. I don’t know how you get a society that is interested in income and productivity to pay attention to those that don’t. Social Security was brought along to help aging widows and has, from the onset, perverted to see the needs of youngsters with single parents, people injured on the job, and many other worthy causes, but less and less attention to the original purpose, which was an aging society with no visible means of support. In Mexico, aging widows dressed in black sell flowers. I hope that people with no real axe to grind will find a way to translate this to be useful. How do you turn a society around? I don’t know. Sometimes I think it is just hopeless.

- I think what I have been able to get out of this group is that we have created something that is going to tell whoever it goes to how we feel about what we have talked about and give them some tools to understand how we feel about those issues. I don’t think we can do any more than that, but I am glad that I had the chance to participate. Some of us will do a little more than we have done before to help people out.
• What I found to be interesting is that someone said, “my name is Jim and I am suffering from dementia.” It made me realize that we are all in the game together. This environment allowed me to listen to other people’s experiences. Moving on from there, I have low expectations of anything changes, but being human, we have hope of being bettered through government. I increased my knowledge base and what is going on in the world of the elderly, and I will be equally a victim as others. What it has told me, is that I must prepare, and I fear that the general society is not doing that.

• I agree that as a whole, we realize we share we are facing aging and possibility, and this has helped us to prepare wills and advance directives, and I would like to see this go to OLLI so that they have plans and understand about home care and housing. The play was very good, and showed problems that people can face in nursing homes, and groups need to understand what they might do to prepare themselves.

• I thoroughly enjoyed this, and learned a lot. The main thing that concerned me is that I didn’t have advance directives and am looking into that. I have already told my family to let me go if I can’t get better, but I need to put it in writing. I need to care for myself as much as possible.

• I am very naïve, and have been naïve all my life. I refused the GI bill because I already had a job. I have accepted Social Security, but both my wife and I have led a sheltered life. I have heard stories in here have quickened me – I don’t know of ways we can change things, but we see people in the news that make changes. I am not one of those people. We made wills that we have updated. You quickened my understanding of the need for advance directives. We need to write that out and within six weeks, everyone will have originals. You guys did that. What I have enjoyed is our ability to quietly
disagree or explain things that are difficult to understand. I’m sorry this is our last session.

- We found out that even though we are different backgrounds and have different experiences, we can discuss our values.

- Not that many years ago, you didn’t hear depression and bipolar discussed openly, and the media has now made a big deal, and it is a surprise to see how many people are suffering with these disorders, and I think it puts us in a different place. I think if I knew I had a mental disorder, I could talk openly to most people about it. I’m not shy about talking to health professionals, but now I can talk to others.

- What we are realizing is that more people live with mental illness, but many don’t acknowledge they have a problem, but still function.

- We need youth and their vitality to take what we have done and push it out to the public.

- This dialogue was a valuable opportunity for a small group of folks to learn and discuss mental health and its impacts on communities and families. I think it opened some very important ideas to some of the participants who hadn’t been presented with this information before. As someone who has been a part of the mental health profession in this state I was heartened to hear people realize that there are needs that aren’t being addressed and wrestle with how to meet them. This is just one type of discussion I feel need to be held in all our communities to improve awareness of the dearth of services that are available to us all. Thank you for the opportunity to participate.

- Mental Health for Seniors leaves me somewhat concerned as to where I would be headed if I had mental health. It appears to me, with the abundance of information available to the public, many solutions and congressional involvement should have been present
today. With the information received from the mental health dialogue presentations, I will become more involved and discuss these issues with my Congressman and Senators with hopes of stirring more interest in Mental Health.

- I really enjoyed the bioethics discussions. Learning more about mental health and the issues related was very informative. I hope that more can be done in the near future to solve some of the problems for people with those health concerns. Putting people in prison is not the solution. Mental health facilities are needed as well as professionals that can solve mental health concerns.
Participants:
Amelia Collins
J.D. Roberts
Claudean Smith
Linda Strevell
Bob Hern
Sheila Kern
Phillip Trittel
Judy Trittel
Fran Card
Terry Card
Frances Ryan
Dan Cote
Jim Sweeney
J. Bangle
Curtiss Brown

Facilitator:
Peggy Determeyer

Academic Support Team:
Jerome Crowder
Peggy Determeyer
Appendix 1.

List of Background Readings and Session Topics
Community Bioethics Dialogues

Mental Health Issues – Topic List and Readings

Week 1 Overview of Mental Health Issues

**Guest Speaker:** Dr. Mukaila Raji, Professor & Director, Division of Geriatric Medicine, UTMB

**Readings**


Week 2 Brain Decline

**Guest Speaker:** Dr. Oma Morey, Sr. Medical Educator – Educational Development, Internal Medicine

**Case Study**

The research-based reader’s theater, *The Long Journey Home: Caring for a Loved One with Dementia,* is based on the 2-Act play of the same name, both written by Dr. Oma Morey. The play depicts true stories of 10 caregivers in the Houston/Galveston area who have taken care of parents, children, and spouses with dementia/Alzheimer's, and who participated in a qualitative study conducted by Dr. Morey. The dialogue comes directly from comments made in the interviews in order to keep true to the stories. The reader’s theater was developed by excerpting eight scenes from the original play. A narrator was added to explain what was happening in the scenes so the listener can follow the movement that was performed in the stage production. Members of the University of Texas Medical Branch and the local acting community read the eight roles in the reader’s theater, expressing both the words and emotions portrayed in the play. The play is currently performed for incoming medical students and has been part of a course for the past 6 years.
Readings

*Causes of Brain Decline*, matrix developed by Peggy Determeyer, PhD Candidate at the Institute for the Medical Humanities


Week 3 Caregiver Issues

**Guest Speaker:** Alice Williams, MS, LBSW, Executive Director, Libbie’s Place Senior Day Program

Readings


Week 4 Medication Issues

**Guest Speaker:** Andrea Wirt, Nurse Practitioner, UTMB

Readings


Week 5 Downstream Issues

**Guest Speaker:** Dr. Jason Glenn and Captain Byron Frankland
**Readings**


**Week 6 Discussion of Values**
Appendix 2.

Case Studies
Week 1 Case Study – Mental Health Decline

Your best friend comes to you with a problem. Her 83-year-old mother has been living alone and doing well. Recently, your friend was reviewing her mother’s accounts and noticed that there were several bills that had been paid in duplicate, and a few checks were written to organizations that your friend did not recognize. When she questioned her mom, your friend did not hear satisfactory answers, especially for the checks written to organizations, saying that she has been watching “those nice people” on television, and they were asking for money to help children on the other side of the globe. Her mom did not remember paying the bills in duplicate at all, and does not remember seeing a positive balance on some bills. In addition, your friend has learned that her mom has stopped going to her friends’ weekly canasta game, and knows that this is unusual since this has brought her a lot of pleasure. Finally, your friend notices that her mom’s house is not as neat as it used to be. Your friend works full time and is not able to follow her mom every day, and asks for your advice.

- What are the priorities for your friend to consider? Why?
- How would you help her to identify solutions?
- What are the values to be considered in your friend’s predicament?
- What are the policy issues, if any?
Week 2 Case Study: Reader’s Theater, Dr. Oma Morey, UTMB

The research-based reader’s theater, The Long Journey Home: Caring for a loved one with dementia, is based on the 2-Act play of the same name, both written by Dr. Oma Morey. The play depicts true stories of 10 caregivers in the Houston/Galveston area who have taken care of parents, children, and spouses with dementia/Alzheimer's, and who participated in a qualitative study conducted by Dr. Morey. The dialogue comes directly from comments they made in the interviews in order to keep true to the stories. The reader’s theater was developed by excerpting eight scenes from the original play. A narrator was added to explain what was happening in the scenes so the listener can follow the movement that was performed in the stage production. Members of the University of Texas Medical Branch and the local acting community read the eight roles in the reader’s theater, expressing both the words and emotions portrayed in the play. The play is currently performed for incoming medical students and has been part of a course for the past 6 years.
Week 3 Case Study – Caregiver Issues

Sam has been taking care of his wife ever since she was diagnosed with Alzheimer’s two years ago. Until now, he has been coping with the day-to-day issues, although his four children are concerned that he is not taking care of himself. This is evidenced when Sam develops a heart condition and is hospitalized for several days. Upon returning home, his children insist that he arrange for help around his house, but Sam is concerned about finances, and does not take their advice. Three of the four children live in other cities. Sam has been your friend for several years, and one day at lunch, he unloads on you about his situation, not knowing what to do

- What are the priorities for your friend to consider? Why?
- How would you help him to identify solutions?
- What are the values to be considered in your friend’s predicament?
- What are the policy issues, if any?
Week 4 Case Study – Medication Issues

You and Mary Ellen have been friends for over 20 years. One day at lunch, you notice that she is not as alert as usual. You ask how she has been doing, and Mary Ellen confides that she has been having some health issues and seeing several doctors, one of which has prescribed blood pressure medicine. Recently you read an article noting that seniors are at risk for having medicines over-prescribed to them by doctors. You ask Mary Ellen about the other medications she is taking, and learn that there are several that are listed in the article that may cause problems when taken at the same time. Mary Ellen becomes defensive, and says that she trusts her physicians.

- What are the priorities for your friend to consider? Why?
- How would you help him to identify solutions?
- What are the values to be considered in your friend’s predicament?
- What are the policy issues, if any?
Week 5 Case Study – Downstream Issues

Your church has recently established a ministry to homeless people. One of the services is providing a warm lunch for them on three days out of the week. You begin volunteering, and when you are serving food one day, you notice that several of the clients are acting out by shouting at the wall and not responding well to questions. Your church has not prepared well enough to address people with such problems – you thought you were just doing a good deed by providing meals, and instead you find your church committed to much more than that.

- What are the priorities for your congregation to consider? Why?
- How would you help them to identify solutions?
- What are the values to be considered in providing services to the homeless?
- What are the policy issues, if any?
Participant Signatures

Amelia Collins
Claudean Smith
J.D. Roberts
Bob Hern
Sheila Kern
Judy Tittel
Phillip Tittel
Frances Davis Ryan
Fran Card
Jim Sweeny
J. Bangle
Dan Cote
Terry Card
Linda Strevell
Curtis Brown