

Maryland Health Care Commission

Hospice Education Initiative Work Group

July 29, 2013

Meeting Summary

Work Group members in attendance:

Danelle Buchman, Linda Cole, Arlee Gist, Larry Gourdine, Rev. M. Luther Hill, Terrie James-Taylor, G. I. Johnson, Steve Johnson, Bruce Kozlowski, Ted Meyerson, Maureen McNeill, Diane Owen, Paul Parker, Ingrid Redway, Mary Anne Rishebarger, Dr. Madeleine Shea, Caroline Silva, Nicole Stallings, Cathy Stasny, Jessica Talley.

Work Group members in attendance via teleconference:

Dr. Pat Fosarelli, Dr. Carlessia Hussein

Bruce Kozlowski, Maryland Health Care Commission (MHCC)

Mr. Kozlowski thanked the Work Group for providing their summaries following the April 29, 2013 meeting. There were several alternates attending this meeting, as well as new members joining the Work Group. The Work Group welcomed its new members and alternates.

The focus of the July Work Group meeting is to review with each participant their upcoming plans for outreach to minority and underserved populations in Maryland on issues related to transition at end of life, whether through aging or illness, with the goal of determining measures of success. New members are welcome to share their ideas during the meeting if they have not done so prior to the meeting. Mr. Kozlowski provided some background on the genesis of the Work Group, which was initiated at the request of Chairman Middleton and Senator Delores Kelley. Senator Kelley laid the ground work and established the focus. The underutilization of hospice services by the African-American community was of primary concern, with the belief that aggressive outreach and education would provide the necessary tools and information for the underserved to make informed decisions consistent with their beliefs regarding transition of life care and hospice.

Dr. Madeleine Shea, Delmarva Foundation for Medical Care, Inc.

The Delmarva Foundation has been working with CMS on looking at disparities in Medicare with end of life care. Dr. Shea is attending the Work Group to learn what the current best practices are and she is looking for direction in working with organizations across the country.

Jessica Talley, Hospice of the Chesapeake

Ms. Talley previously shared Hospice of the Chesapeake's liaison efforts working directly with patients and families to better understand the patient and family relationship; they also provide crisis intervention. Working directly with the community they assist with communication between patients and doctors, identify lack of access to care, and identify where need exists for other interventions to occur to facilitate better access to services and increase use of existing partnerships.

Hospice of the Chesapeake recently conducted a model of care focused on cancer care from the African-American perspective. CMS produced a video on communicating end of life care.

Maureen McNeill, Coastal Hospice and Palliative Care (Coastal Hospice)

Coastal Hospice is working on a measurable outcomes survey. It is an unscientific attitude survey that will be presented to African-American members of their community, collecting feedback, making revisions and then resurveying. They will share these results with the Work Group when complete.

Coastal Hospice is challenged by the CMS eligibility for coverage guidelines, particularly guidelines for hospice services and discharges for extended diagnoses. Medicare has become rigorous in scrutinizing hospice bills and has been denying coverage. Coastal Hospice is sensitive to not overselling services that they can't deliver on because of CMS oversight. They are ready to talk to patients and families about end of life care, what hospice has to offer families, but are concerned about being undermined by CMS when coverage is denied.

Reverend M. Luther Hill, Coastal Hospice

Reverend Hill has the access to the African-American church community. Prior to being a chaplain he was a part of Minority Outreach and Technical Assistance (MOTA). Dr. Hussein has a great model to reach out to any minority member of the community. Timing is key – it is important not to wait until a crisis to provide education. Most churches have health education conferences, which present an opportunity to provide hospice and end of life information. Some individuals don't want their pastors or reverends to know their health issues or to intervene for privacy reasons. Funeral homes provide another opportunity to get the hospice message out. Some people are more receptive in that environment to discussing what their end of life expectations or wishes are. Some pastors are also funeral home directors.

Bruce Kozlowski, MHCC

In a July 2013 meeting with Delegate Tarrant and Dr. Reverend Hathaway, the question did arise of who is responsible for payment of hospice services under Medicare and Medicaid. They have

since received current copies of reimbursement regulations for Medicare and Medicaid plus copies of the CDs “Reaching Out to the Underserved Populations” and “How Do I Pay for This?”

Larry Gourdine, Monumental City Medical Society

Monumental places messages and materials in physician offices so they can have conversations while taking care of patients and when they are in direct communication with family members. Physicians are in a good position to have these discussions. Monumental works with MedChi on educational materials, improving messaging materials and resources provided. Physicians are constrained by the “15 minute” rule per patient, yet end of life conversations take more time. Monumental seeks input to develop ways to provide more education to physicians.

Arlee Gist, Office of Minority Health and Health Disparities (OMHHD)

OMHHD works with all minorities and underserved populations in Maryland, not just African-Americans. Targeted groups include underserved Asian-Americans, Hispanics, and Native-Americans, all of whom have similar underutilization of these types of services.

The African-American mindset is “we take care of our own.” Hospitals who serve the African-American communities often have not verbalized to loved ones and caregivers that it is end of life. The African-American community is not receiving enough education about what is happening medically. Family members take a dying patient home without receiving end of life information and without knowing what services they are eligible for and what resources are available. The education process needs to start with the hospital staff at the onset of the patient entering the hospital. Physicians know the care and conditions of the individuals, and can provide information to hospices and families on who is likely to be eligible for hospice and/or end of life care. Training needs to be done for the front end staff (hospital, medical staff, chaplains at medical facilities) to provide information to patients and family upon entry, not just when close to end of life.

OMHHD staff goes into underserved communities and offers focus groups to minority populations. It is important to bring in people who look like the audience to provide services, and take recommendation from key leverage groups in a whole way. Messaging regarding death and dying should be the same for all; OMHHD does not want feedback saying that the messaging provided or what is offered to the African-American community is different than that provided to another community.

Dr. Carlessia Hussein, OMHHD

Dr. Hussein noted that her office is particularly interested in focusing on cultural competence. To her, this is a key word that means better identification of the provider of service (whatever

service that is) to the individual client. They focus on greater training to do that and how to relate to the client. There is legislation in Maryland that encourages all sectors of the healthcare delivery system to become more culturally competent. OMHHD is working with the MHA and others to provide support, training and technical assistance in promoting cultural competency. It is important to build greater trust in the healthcare system through cultural competency with end of life issues with all clients, not just minority clients.

Ted Meyerson, State Advisory Council on Quality Care at the End of Life

Mr. Meyerson suggested that the OMHHD include the frail and elderly among the other categories of minority populations. The average length of hospice stay in Maryland is at most 21 days. This lack of utilization indicates that either no one knows about hospice services or that no one is being referred to it. HB 30 (education regarding End of Life Services) was met with resistance by churches, the medical community and hospices, equating giving information about end of life as pushing people to make a decision about end of life. The Advisory Council sent out 30,000 cards to nursing home ombudsmen and physician offices across the state in an effort to bring attention to end of life rights. Everyone participating in this Work Group has outreach in place, but there is no coordination between the participants. Mr. Meyerson believes this Work Group could lead the way to make a coordinated, centralized effort to unify the message and get information out to people. Without coordination of effort there is no political power. He would like to see consensus from the group, and move one piece of legislation forward.

Mr. Meyerson noted that there is a sharp divide between the education of the healthcare providers and the education of the population being served. He sees the biggest opportunity in educating the population being served, as they are on the receiving end for end of life services. Patients need to know what their rights are and be able to pursue hospice or whatever service is available, without having to wait for the professional to tell them that they are at the end of life. Physicians are not prone to want to tell patients that they can no longer treat them.

Diane Owen, Gilchrist Hospice

Gilchrist has recently partnered their volunteer outreach program with churches in Baltimore City. Volunteers go into people's homes. This partnership has increased community and family awareness of hospice services. It is a grassroots effort, but as more volunteers make outreach with families, awareness is increasing.

Gilchrist believes that hospitals should be providing information on hospice and end of life care options. There is an enormous need to change the mindset of hospitals and physicians, beginning in medical school. Hospice education should be in the curriculum and part of the clinical rotation. Gilchrist has medical students who rotate in the hospice program. One obstacle is changing the "I am here to heal" mindset of physicians before they begin their training.

Terrie James-Taylor, Montgomery Hospice

Montgomery Hospice offers one on one educational conferences for doctors in the hospitals to share all the concepts about hospice. Doctors have a difficult time telling patients that they are at the end of life. Doctors need to be educated about the procedures for following a hospice patient.

Steve Johnson, MedChi

MedChi is the largest physician organization in the state, so they are well situated to communicate with the physicians. MedChi looks forward to an opportunity to partner with the hospices, and is willing to distribute articles on the topic of hospice education. They have a very large continuing medical education (CME) department that has the means to electronically reach out to a wide audience. Every Monday MedChi sends out a lengthy newsletter to members via electronic ListServ, as well as sending Twitter feeds. Each county and Baltimore City has a local medical society. The largest counties meet monthly or quarterly. The small counties have more localized information, and do not meet as frequently. Primary contact is made through the State MedChi office, which holds two annual meetings as well as specialty meetings.

Ingrid Redway, Seasons Hospice

The medical director at Seasons Hospice reaches out to the medical and physician community, particularly in July when the new medical residents begin. Seasons Hospice physicians hold education sessions for the medical residents and attend grand rounds in order to meet large groups of physicians. Ms. Redway is also a community member of the Sinai Ethics Committee, in which capacity she can provide education and outreach to the hospital staff.

Mary Anne Rishebarger, Dr. Bob's Place and Joseph Richey Hospice

Dr. Bob's Place and Joseph Richey Hospice serve a unique population, primarily the underserved in Baltimore City (Joseph Richey) and children (Dr. Bob's Place). They accept anyone into their hospice regardless of ability to pay for services. They also provide home-based services.

Danelle Buchman, Hospice and Palliative Care Network of Maryland (Hospice Network)

Ms. Buchman thanked the members of the Hospice Network who are attending the Work Group meeting and for their tremendous work in Maryland providing direct hospice services. She expressed concern about the bigger goal of the Work Group. Ms. Buchman sees the need for better coordination of efforts by the various organizations and hospices in the Work Group in order to promote the work currently being done and to identify best practices already in place.

The annual Hospice Network conference has been moved to November 2013 to coincide with National Hospice Month. In addition, Hospice Network has smaller educational programs throughout the year. They have monthly webinars and in the past have shared hospice best practices. Education and advocacy is the primary focus of the Hospice Network, and they are willing to tailor a webinar with an outreach specific to diverse populations.

Nicole Stallings, Maryland Hospital Association (MHA)

Ms. Stallings previously provided an overview of how the MHA has the ability to communicate with their 66 members across the state. She is very experienced with getting messages and best practices communicated; she does not have as much experience with core messaging around hospice and particularly how to reach underserved individuals. Ms. Stallings wants to help push these resources out, but is not sure that these resources are yet available. If there is consensus about what specific materials (best practices, standards, etc.) are to be distributed, she can help the MHA members get the information distributed, and offers her assistance to other members of the Work Group. The MHA will produce a hospice related webinar within six months.

Ms. Stallings expressed concerned about what kind of training currently exists in hospitals, and how comfortable staff is talking with patients and families about hospice and palliative care. Many hospitals have strong relationships with community hospices and others are looking to grow relationships. From the MHA standpoint, they look toward creating purposeful partnerships; for example, the day after the November Hospice Network annual meeting, the MHA is holding a meeting in the same location to market together the work that the MHA does with the work of the Hospice Network.

The MHA has a steering committee that is focused on care transitions, which is comprised of many of the groups on the Work Group.

Maureen McNeill, Coastal Hospice

Addressing the broader issue of getting physicians to make referrals to end of life care, Coastal Hospice subscribes to a national newsletter publication that they customize for their hospice and distribute to physicians. They are launching an end of life education program for nurses, in collaboration with Peninsula Regional Medical Center, and invite nurses from medical practices to participate. Coastal Hospice's ongoing outreach with the healthcare community includes participation in physicians' meetings, and meeting with physicians and staff in their offices. When working with the faith based community, it is important to have a presenter who looks like the audience.

G.I. Johnson, Baltimore City Health Department, Office of Aging and CARE Services

Mr. Johnson provided an overview of the efforts of the Baltimore City Health Department (BCHD) to provide hospice outreach to the black community. Experience has found that in the black communities there is a lack of knowledge about hospice. In previous years his office attempted a hospice outreach program with the black church community in Baltimore City that failed, primarily due to starting at the “bottom” i.e., they started at the individual (congregant) level and tried to work their way up. BCHD learned from their mistake that they have to start at the top, establishing contact with the pastor of the church, in recognition that the pastor is the leader of the community. Mr. Johnson’s office is hosting a conference on November 6th that will bring together all the faith based leaders.

The churches are well positioned to identify elderly people who are at risk or in need of assistance, as elderly people form the largest body of the church community. Many of these elderly members do not know what assistance is available or where to turn for help. BCHD is putting together materials for the churches, and will meet with church leaders to develop dialogue to communicate a clear understanding of what hospice is, to help their seniors utilize the programs. Church leaders essentially want to know if and how the hospice materials will benefit their congregation. A pastor who has a personal connection with hospice can increase the exposure in the black community. Most congregants rely on their pastors or ministers to provide guidance, so it is important to teach the pastors and ministers a better way to talk about end of life options and provide accurate information. Most churches need a program because so many senior members need an opportunity to be informed of and discuss end of life options. Arnold Eppel has a very good relationship with the churches and Mr. Johnson bridges the connection between a hospice professional and the churches. Two major issues in the black community are trust and attitude.

Terrie James-Taylor, Montgomery Hospice

Montgomery Hospice has found it is effective to get buy in from the church community, beginning with the pastors, elders, deacons and deaconesses. Then you can utilize the different ministries within the church, such as those who deal with death and dying, those who visit the sick and shut-ins, and the health and wellness ministries. Everyone in the church has experienced a loss, but someone might not necessarily want to go to the church leader, yet is comfortable seeking assistance from within one of the ministries. Ms. James-Taylor recommends checking the calendar of events at the churches, to see what programs are scheduled where you can target education to seniors, on topics such as Caring for the Caregiver or Alzheimer and Dementia issues.

Ms. James-Taylor said that she does not start off conversations by talking about death and dying; rather, she discusses Hospice 101 in broader terms of what services they offer, explaining their

different programs, sharing what the volunteers do, and explaining how care is provided, such as by a nurse or home health aide.

Caroline Silva, University of Maryland School of Medicine

Ms. Silva noted that there are many factors that play into any patient or family's decision to choose hospice. A patient or family member might be resistant to using hospice. It might be a lack of knowledge about hospice services, lack of trust in the medical community, lack of strong family support, worry about the economic cost (will Medicare/Medicaid pay for it?), as well as personal, cultural or religious reasons. Many physicians are resistant to suggesting hospice care.

Dr. Pat Fosarelli, Central Maryland Ecumenical Council

“Best Practices” for hospice are continually evolving, particularly with pediatrics and special needs patients. For those for whom faith is important, it is important to link to that community, as no faith tradition says you have to “go it alone.”

Bruce Kozlowski, MHCC

It is important to note that we want to educate the underserved about their transition of life choices, not convince people what to do.

The African-American faith based community in Baltimore City is now well represented on the Work Group, but we still lack representation from the African-American faith based community in Prince George's County. Mr. Kozlowski requests Ms. Stasny's assistance in finding a representative from that county.

Summary

The Work Group is intended to be a short-term commitment; to document what is currently being done with outreach and education of the underserved, and what the member organizations plan to do prospectively; to learn from each other; to recognize the diversity of the underserved and the differences in the approach necessary to have a conversation about transition in life and hospice; and to recognize that while there is value in some unity of approach, there is also value in diversity since not all providers or audiences respond the same.

It is important to:

- educate the underserved about their transition of life choices, not convince them as to what they should do
- educate the community about transition of life issues and hospice services before a crisis occurs

- bring in the faith-based community leaders to assist in outreach efforts
- provide education to the healthcare providers about how to have a discussion on transition of life choices
- provide resources and educational materials to the healthcare community and churches
- identify the audience before you get the message out; what works in one setting might not work as well in another; what works with one audience may not work with another
- utilize the outreach and education opportunities that already exist to the fullest