

Maryland Health Care Commission
Hospice Education Initiative Work Group

September 24, 2013

Meeting Summary

Work Group members in attendance:

Ben Steffen, Paul Parker, Bruce Kozlowski, Linda Cole, Cathy Weiss, Philip Carpenter, Arnold Eppel, Dr. Pat Fosarelli, G.I. Johnson, Maureen McNeill, Ann Mitchell, Diane Owen, Ingrid Redway, Mary Ann Rishebarger, Christine Ruch, Madeline Shea, Jessica Talley.

Work Group members in attendance via teleconference:

Ted Meyerson and Nicole Stallings.

Paul Parker, Maryland Health Care Commission (MHCC)

Mr. Parker explained that due to the reorganization of the Maryland Health Care Commission (MHCC) staff, the work on long term care health planning and development is now part of the Center for Health Care Facilities Planning and Development. Bruce Kozlowski is Co-Director of the Center for Quality and Reporting.

Mr. Parker also discussed why the work group was convened and gave background information on when a Certificate of Need (CON) is required for hospice services. It is required for: 1) establishment of a new hospice; 2) expansion of an existing hospice into a new jurisdiction; and 3) a change in the bed capacity of a hospice

Mr. Parker informed the Work Group that the Commission has now taken final action to approve the new State Health Plan Chapter for hospices services, and that hospice education and outreach is an important component of the plan chapter.

Mr. Steffen stated that the importance of education does not diminish the total update of the State Health Plan. The 2014 budget has limited funding for outreach. However, Mr. Steffen indicated that the Commission serves as a facilitator; it does not launch educational initiatives.

Mr. Parker informed the work group that MHCC has published a schedule for CON review of projects for hospice services beginning in mid-2015. He stated that the MHCC will re-examine use rates as one measure of the success of education and outreach.

Linda Cole, Maryland Health Care Commission

Ms. Cole reviewed the themes that have emerged from previous meetings:

Hospice services:

- There is a need for education about hospice.
- There are religious, cultural, and ethnic barriers to the use of hospice.
- The use of minority staff for outreach helps to build trust and rapport.
- There is a need to overcome myths and erroneous cost perceptions.
- There is a need to intervene before there is a crisis.
- Patients need help, generally, in navigating the health care system.
- There is a need for education about program eligibility and resource availability.
- The role of the educator is to offer information, not to push for specific action or a particular choice by the patient.
- The audience needs to be carefully identified for educational efforts; what works with one audience might not work with others.
- There is a need to include the faith-based community in public education and outreach and to work with churches, particularly in the African American community.
- The educational message should be “life transitions” and not “end of life care.”

Staff training:

- There is a need for cultural competency training.
- There is a need to train doctors on how to share bad news and to ascertain that the patient/family has accurately received the information.
- Social workers should also be included in end-of-life training.

Resources:

- MedChi and Monumental can distribute materials, arrange CMEs, and do outreach to physicians.
- MHA has efforts underway in patient-centered care, staff education, palliative care, and partnering with hospitals.
- MOTA (Minority Outreach and Technical Assistance) is working to address health disparities.

At this point, meeting attendees were asked to share ideas and news of interest to the group.

Maureen McNeill, Coastal Hospice

Ms. McNeill presented the efforts of Coastal Hospice in outreach. She stated that Coastal Hospice will be producing TV ads, and evaluating their effectiveness by conducting surveys on the likelihood of using hospice services before and after the ads have run. She stated that the use of hospice services is lower for African Americans in Coastal Hospice's Eastern Shore service area. She discussed the possible reasons for this disparity and myths on why hospice services are not utilized by the African American community

Dr. Pat Fosarelli

Dr. Fosarelli also talked about the low use of hospice services by African Americans. She asked her seminary students what hospice means. They used phrases like "giving up", or "being disloyal to your loved one." The family should be the caregiver; that it is the family's responsibility.

Dr. Fosarelli also stated that maybe a change in language may help. The word "transitioning" may help, but it is important to recognize that the word "dying" is part of the Judaeo-Christian tradition. She also stated that congregations in the African American community feel that they should care for their own, and that may be another reason for lack of using hospice services. Conveying the message that hospice care providers are responding to a "calling" may be perceived more positively.

Jessica Talley, Hospice of the Chesapeake

Ms. Talley stated that since hospice is a medically prescribed service, Hospice of the Chesapeake has begun to market its services directly to physicians, case managers, and nurses to encourage the use of hospice services. She stated that Hospice of the Chesapeake works at reaching the community by being present at health fairs. Ms. Talley stated that she felt access is not a problem, but a skill set to meet the needs of the African American community is needed.

Madeline Shea, Delmarva Foundation

Ms. Shea stated that she felt the term "end of life" is a big issue in choosing hospice services culturally. She felt that more skill building on cultural competency and health literacy may help increase hospice usage. She will be working with CMS on Quality Improvement for Disparities and will be happy to share the results of her research.

Diane Owens, Gilchrist Hospice

Ms. Owens informed the work group about the activities that Gilchrist Hospice has undertaken to increase use among the African American community. She stated that Gilchrist is conducting interviews for a diversity council to help guide Gilchrist in cultural competency and better ways to reach out to the community.

Mary Ann Rishebarger, Joseph Richey House

Ms. Rishebarger stated that hospices need to educate the public that hospice is a service that takes care of the family and not just the patient. She stated that Joseph Richey was doing outreach by visiting hospitals and talking to case managers and directors of nursing about hospice services. She also stated that she had a concern about the way in which some hospitals choose to have an exclusive relationship with a single hospice. Patients should be informed about the availability of all hospice options. She said she also offers tours of Joseph Richey House to members of the community.

Ann Mitchell, Montgomery Hospice

Ms. Mitchell stated that Montgomery Hospice has a long history of working to address the diverse needs of its community. She said that it has been working on outreach for many years with the goal of having the use of hospice services match the percentage of deaths by minorities. For Asians and Latinos, the use rates now match the percentage of deaths. For the African American community, the percentage of deaths is 14% but the use rate is 10%. She stated that a diverse staff helps in outreach to the African American community. She also stated that Montgomery Hospice is bringing diversity to the leadership of the hospice and this also helps bring patients to hospice services. She stated that Montgomery Hospice strives for a presence in the Latino and Asian communities.

Ingrid Redway, Seasons Hospice

Ms. Redway stated that Seasons' national office in Chicago has a formal process for outreach. They are trying to apply this at a local level to reach diverse segments of the market. She stated that building trust is an important aspect. Seasons hospice has been marketing at health fairs to get information out about hospice before hospice services are actually needed. She stated that information aimed at the family helps overcome cultural barriers to choosing hospice services among the African American population. Based on her experience with the Seasons inpatient unit at Northwest Hospital, she deals with families who say "we take care of our own", but then come to realize that they just cannot do it all.

Phil Carpenter, Washington Home and Community Hospices

Mr. Carpenter stated that he did not think outreach would significantly increase services in the African American community in the near future, and that it will take much more time. He also stated that he felt that diversity in the staff of the hospices was an important part in choosing hospice services in the African American community. Washington Home and Community Hospice participates in local health fairs. It also offers holiday grief workshops at no cost.

Christine Ruch, Washington Home and Community Hospice

Ms. Ruch stated the work of Community Hospice focuses on quality improvement. It plans to offer training in palliative care to nurses in the community free of charge. Their goal is to have nurse trainers in assisted living, nursing homes, and other settings.

G.I. Johnson, Baltimore City Health Department

Mr. Johnson stated that he feels that people, mainly pastors, in the African American community do not have information or firsthand knowledge of hospice services and what they provide. He stated that if pastors had a better understanding or more knowledge concerning hospice care that their advice in the community would be an important factor in encouraging their congregation's members to seek hospice services. When pastors use hospice themselves, they provide a great role model for the community.

Ted Meyerson,

Mr. Meyerson stated that he felt that even people who have been in hospice just don't understand hospice care. The physicians should take the first step in discussing hospice with patients. He stated that he felt that physicians were just as important as the church for getting information on hospice services out in the community. Mr. Meyerson felt that some palliative care legislation should be passed.

Arnold Eppel, Baltimore City Health Department

Mr. Eppel stated that more education on hospice can increase the use of the services in the African American community. He said that he thinks we can make a significant difference in two years. He stated that he felt assisted living managers should be required to learn about hospice services as part of the training required by OHCQ. He also stated that more education is needed with case managers about the availability of hospice care. He is working with the bullet points that Dr. Pat Fosarelli drafted for pastors; he likes the phrase "hospice can be a gift." He mentioned the November 6th program at Morgan State University for religious leaders.

Nicole Stallings

Ms. Stallings stated that the Health Delivery Reform Subcommittee of the Health Care Reform Coordinating Council has a focus on hospitals' partnerships with long term care, and end of life and hospices issues should be discussed. She stated that the Subcommittee was not aware of this Work Group. The work group should connect with Dr. Herrera in DHMH. Ms. Stallings discussed relevant data and the reasons that hospice patients are readmitted to hospitals. Ms. Stallings also questioned the targeting of marketing efforts about hospice, based on reported experience with mailings received. She feels that more mail marketing may need to be targeted to less affluent households, which are probably the households with the least familiarity and receptivity to hospice.

Other Comments

Ms. Rishebarger stated that one reason for readmission of hospice patients to hospitals may be that loved ones call "911" when they can't handle the changing condition of the patient, because that is what they are used to doing. "Panic" is a cause for the "911" calls.

Ms. McNeill questioned the purpose of the Work Group. Ms. Cole stated that the work group was for sharing information so everyone can benefit.

Dr. Fosarelli stated that education is important for increasing the use of hospice services. She felt that the heads of dioceses should encourage hospice education for pastors, etc. She said that the Central Maryland Ecumenical Council needs speakers on hospice services. She also stated that Med Chi should see that hospice is discussed at any of its meetings with physicians. She stated that people whom the family trusts, which are often pastors or doctors, but could be other persons, should be able to discuss hospice services with them.

Ms. Talley stated that she felt there was a physician bias against hospice (mainly older physicians) because of lack of information and that more education to physicians may help in increasing the use of services.

Dr. Fosarelli stated that she felt medical schools should require hospice education for medical students and residents. She also stated that seminaries and religious schools should require hospice education.

Ms. Stalling asked the work group if there were models outside of Maryland for hospice education.

Meeting Summary:

Ms. Cole summarized the meeting discussion:

- Hospice is a “calling”; hospice is a gift;
- Need to educate front-line health care workers;
- Need to address and dispel myths about hospice;
- Need to look for tools and share information;
- Hospice team needs to work with the family unit;
- Need to get physicians as well as church leaders educated.

Next Steps:

Mr. Parker discussed what should be done in the future regarding hospice education. He said that he did not think that additional meetings of this type were necessary, given the three that had already occurred. He discussed ideas on how to proceed and asked the work group what they would like from the MHCC.

Ms. McNeill asked about how to measure attitudes and what measures to use. She stressed the need for focus groups.

Ms. Mitchell asked about other areas in the US that are similar, demographically, to Prince George’s County and Baltimore City and what measures may be working or not working in these areas. Ms. Cole said that we can look at use rates in other states. Mr. Parker talked about tracking use rates by race or ethnicity and whether the hospices are currently tracking this. There was discussion about push-back on

collecting racial data. However, Ms. Ruch indicated that the new Hospice Item Data Set has race as a mandatory variable. Nicole Stallings asked for a report to summarize the ideas submitted.

Mr. Parker suggested that we might need another group to determine how best to measure progress in education and outreach. Mr. Parker stated that the Work Group would not hold another meeting next month. He recommended that the Work Group would gather information on a quarterly basis from the hospices on what they have done and post it on the Commission's website, which would include a Hospice Education and Outreach page. He suggested that the Work Group reconvene in the spring of 2014 to discuss progress and share information about the education and outreach activities they engage in over the next six months.