

State Advisory Council on Quality Care at the End of Life  
Minutes from the September 13, 2019 Meeting

Meeting time and place: September 13, 2019, 10:00 a.m., Office of Health Care Quality, 7120 Samuel Morse Drive, Second Floor, Columbia, MD 21046-3422

Council members present: Paul Ballard (Attorney General's designee); Tiffany Callender; Karen Smith; Carol Eckerl; Christine Watts; Sister Lawrence Mary Pocock; Christopher Kearney; Shahid Aziz; Senator Ben Kramer.

On speakerphone: Elena Sallitto Boisvert; Henry Willner; Yvette Oquendo-Berruz.

Others present: Amanda Celentano; Michelle Ross, Emily Moncada; Sandra Dillon, Valoria Walker; Jack Schwartz; Sara Hufstader; Peggy Funk; Therese Hessler.

On speakerphone: Christine Boyd; Pamela Williams; Gail Mansell.

In Alan Eason's absence, Paul Ballard conducted the meeting. He welcomed Senator Ben Kramer and Shahid Aziz to the Council.

Christine Boyd, Health Policy Analyst, and Pamela Williams, Director, Maryland Department of Health, Center for Tobacco Prevention and Control, spoke with the Council to provide an update on the Maryland Department of Health's Advance Directive Program. Christine Boyd said the Department partnered with 13 organizations consisting of a broad reach of groups across 5 regions of the State to do outreach on advance care planning, as well as introducing the concept of electronic advance directives. These partner organizations received grants to conduct workshops and other special events. They held 250 events in 17 counties with an estimated 16,000 participants. They were able to collect about 5,000 surveys recording the participants' gains in their understanding of advance care planning as a result of those events. Over the previous couple of months, the Department had been analyzing the survey data. The Department was preparing a white paper to summarize the key findings, which white paper was soon be completed. The Department had earlier conducted a pilot community engagement project in 2017 and 2018 with 3 partner organizations in 3 parts of the State and wrote a white paper regarding the pilot project, which white paper had been distributed in November of 2018. The new report would expand on the former white paper.

Christine Boyd also said the Department is developing an advance directive information sheet to promote public awareness regarding the availability and accessibility of advance directives, including electronic advance directives in Maryland. As part of the community engagement series the Department had developed a one-page information sheet to hand out at events. The Attorney General's Office also had a robust information sheet available on its website. So, the Department began collaborating with the Attorney General's Office over the summer with the goal of creating one State advance directive information sheet written in clear language that captures all the statutorily required

information, including information on electronic advance directives. The draft given to the Council for their consideration had been carefully reviewed by the Attorney General's Office and the Maryland Health Care Commission. Next steps include professionally designing the information sheet with the support of the Attorney General's Office, translating it into different languages, and then disseminating it to multiple State agencies. Paul Ballard noted that Maryland law requires the Department to consult with the Council during the development of the information sheet.

Shahid Aziz noted that the goals and the values of the patient are mentioned in the advance directive information sheet only once. He said more discussion of the patient's goals and values is needed because not every potentially applicable treatment can be addressed in an advance directive. He suggested that the section under the heading "What is an advance directive?" be amended to say an advance directive is also a useful way to achieve the quality of life that you want. He also suggested that the section under the heading "What kind of information is in an advance directive?" be amended to add that an advance directive typically includes how you may or may not want to live with the help of artificially life-prolonging treatment at a minimum level that is meaningful to you.

Shahid Aziz also said it is important for people to start thinking about what a meaningful life at a minimum level is to them so that their health care providers can learn from them when artificially life-sustaining procedures would be harmful rather than helpful in carrying out their wishes. That way, the chosen treatments can automatically follow from their goals of care. He also suggested that the section under the heading "Are they expensive?" include that an advance directive may even be hand-written to emphasize how easy it is to complete one. Finally, he suggested that the section under the heading "How do I get started?" be amended to add "medical advisors" to the list of persons that an advance directive should be completed with, if desired.

Henry Willner suggested that a statement be added to the advance directive information sheet reminding people that input from palliative care physicians can be helpful.

Michelle Ross suggested that "family" be changed to "persons who matter the most." Tiffany Callender suggested that the term "loved ones" be used. She also said the advance directive information sheet was a wonderful resource if you are looking for such a resource. Otherwise, she said it scares some potential users and consequently you need to be aware of your audience.

Michelle Ross showed the Council an information sheet she uses at Frederick Memorial Hospital that is written in both English and Spanish.

Christopher Kearney noted it is not good for a patient to provide detailed instructions in an advance directive without getting physician input. He said when a physician becomes aware of an advance directive's instructions after the fact, it makes it more difficult to get buy-in from the physician and have the advance directive honored. Shahid Aziz added that an advance directive is easy to do if the patient receives the right counsel from the physician in choosing what care to receive.

Carol Eckerl said health care providers are left with the responsibility to determine what the patient's wishes were when the expression of those wishes is inconsistent and doesn't make sense, and when families are telling the providers that what the advance directive states is not what the patient wanted. She said when a health care provider is confronted with an advance directive, the provider is honor-bound to comply with the directive's instructions.

Valoria Walker asked whether there was a standardized form on how to have the conversation with a patient during a Medicare wellness visit now that Medicare authorizes payment for that visit. Christopher Kearney replied there are different ways you have the conversation depending on whether the form is 5 Wishes or another form. Tiffany Callender said it is sometimes easier to engage people with electronic forms. Shahid Aziz said the conversation needs to include a discussion of the patient's treatment goals and you don't really need a form to do that. He said many physicians are not well versed in how to have such discussions. He said only 1% or 2% of advance directives have been completed with a physician starting the conversation with the patient.

Christopher Kearney said the advance care planning documentation in the medical record eventually takes the form of a MOLST form containing a health care provider's orders. Sara Hufstader said that not only the provider but also loved ones need to know who your agent is and what your wishes are.

Sandra Dillon said consumers are confused as to what the differences are between advance directives, living wills, and MOLST forms. Michelle Ross said it is very confusing for patients and they wonder why they are not seeing an attorney. Christine Watts said she works with the Medicaid population and that 95% of this population that she talks with have no idea what an advance directive means, that is, that it contains instructions regarding how you may want to live, with or without life-sustaining treatments. She said these documents need to be written at a 5<sup>th</sup> grade level.

Christine Boyd said she appreciated the Council members' thoughtful comments on the advance directive information sheet. Christopher Kearney asked if she could provide the Council with a brief summary of what the Department learned from the pilot program. She replied that the pilot program was conducted in 2017 and 2018 with 3 faith-based grantee partners who conducted 21 community engagement activities. The findings included that advance care planning is important to faith-based groups and that

faith leaders can serve as incredible messengers for advance care planning. They also found that advance care planning is a process and not a checklist of items. She said most organizations found there was a lot of groundwork they had to cover first before they could even talk about advance directives because there are a lot of terms and confusion regarding what an advance directive is. Their findings included that these groups were receptive to the concept of electronic advance directives. They found that advance care planning includes spiritual, medical, and legal considerations. They also found that it was an effective strategy to tack on advance care planning events to preexisting events that the faith-based groups were already holding, such as bible studies and seminars. These settings helped the participants learn about going through all the stages of advance care planning, such as starting conversations, talking about some of the terminology, and talking about their wishes. She said the second round of outreach activities included both faith-based groups and community-based groups, and thus had a broader reach.

Shahid Aziz asked how many participants had completed advance directives following the community engagement events. Christine Boyd replied they did not measure this. Instead, they asked the participants if they learned something and whether they intended to create an advance directive. She said 75% of participants responded that they intended to complete an advance directive. Shahid Aziz replied it may be good to look at how many participants completed an advance directive. Christine Boyd said they are making headway in getting people to think about these issues and that in the future it may be good to have data points regarding the participants' later completion of advance directives and conversations with their loved ones. She noted it is a process in which everyone is in a different stage. Shahid Aziz said that even a follow-up question about whether they had a conversation would be important. He said he believed the conversation was the more important part of advance care planning anyway.

Paul Ballard brought up the agenda item regarding the integration of advance directives into the State-designated health information exchange, that is, the Chesapeake Regional Information System for our Patients (CRISP). He said Jane Markley had asked the Council members to share their experiences in accessing advance directives on CRISP. Shahid Aziz said his staff could never find information on the computer at the hospital even for a patient who had been there before and for whom they had put their information in electronically. He felt it was a tall order to expect staff to find advance directives on CRISP but acknowledged he could be wrong. Jack Schwartz said if CRISP's press release is to be believed, then things have changed. He suggested that perhaps it would be good to ask physicians who are residents in hospitals working in intensive care units whether they are seeing advance directives pop up in CRISP when they are looking for something else, that is, whether there is a flag indicating the presence of an advance directive. He noted that without such a pop-up feature it is unlikely they are going to take the time to look for an advance directive in CRISP.

Tiffany Callender said her understanding from CRISP's press release is that the notice of the existence of an advance directive would be embedded in the care alerts. Christopher Kearney said he could ask palliative care physicians if anyone is using it and whether they are finding advance directives to be accessible on CRISP. He would then report back to the Council. Tiffany Callender said the functionality depends on the hospital. She said that if you're not seeing it, it might just mean your hospital has to take the information into its particular electronic health record and get it in-context to make it work. She said just because it does not work does not mean it is not able to work. Shahid Aziz said he could also ask the fellows he teaches at Johns Hopkins what their experience had been. Jack Schwartz asked if in fact the only smooth route to find advance directives in CRISP is to have them created in MyDirectives, and if so, why that would be the case, because if true it would be a while before there are enough advance directives in CRISP. Christopher Kearney said the use of CRISP in hospitals is very intensive and if advance directives are in CRISP, the staff will find them. Christine Watts said she uses CRISP every day at the hospital and has yet to see a pop-up about advance directives.

Tiffany Callender suggested that Paul Ballard ask Brandon Neiswender and Paul Gleichauf to come back to a Council meeting and demonstrate how this works. Jack Schwartz said he used MyDirectives after being inspired by the press release. Michelle Ross said she likes the format of MyDirectives but noted it can be a challenge if the user does not have both their email address and the health care agent's email address.

Christopher Kearney provided an update about the Coalition to Improve Serious Illness Care in Maryland. He said California created a coalition of different groups, including providers, payors, patients, and interest groups. Senator Kramer asked if California's coalition was formalized by their State's legislature and Christopher Kearney replied that it was.

Christopher Kearney said when you are diagnosed with a serious illness, everything in your life changes, not just the medical care you receive. He said in California there are 13 million Medi-Cal patients who have been allowed access to palliative care services, which extends palliative care services to non-hospice patients with serious illnesses, who don't have to give up curative treatments. He said Oregon, Massachusetts, and Arizona also have coalitions. He said the idea remains strong. He attributed the success in other states to the fact that their coalitions have been payor-supported.

Senator Kramer asked what the motivation is for payors to sponsor a coalition and whether there were any savings to be had. Christopher Kearney replied there were savings to be had as well as the improved ability to provide the best care for seriously ill patients in accordance with their wishes, which may not include hospital-based, expensive, unwanted, and aggressive care. He said he is optimistic that CareFirst will

support Maryland's coalition. Senator Kramer asked if the Massachusetts legislature formalized their coalition and Jack Schwartz replied that Massachusetts has no statute.

Christopher Kearney said this could take a while in Maryland and noted it took 10 years to develop California's program, but he said that Maryland's coalition already has good partners. He said California has shown that this focus on palliative care will help patients, which should help Maryland's efforts to eventually get legislation enacted. He said if you can keep people out of the emergency department and out of the hospital, then you save money.

Senator Kramer noted that California is good with their legislative analysis. Christopher Kearney stated California's program was only initiated as recently as January, 2018, and thus they haven't published much research about its results. But he stated that Sharp's managed care organization in Southern California brags that no patient of theirs with advanced cancer gets admitted to the hospital. Senator Kramer said he would welcome the opportunity to engage in a conversation about the coalition.

Sara Hufstader asked if there was anything the group could do to support Christopher Kearney in this endeavor. He replied that the coalition still does not have a physical headquarters. Peggy Funk said concurrent curative care and palliative care benefits are now provided for children and veterans, and that it would be good to also allow other seriously ill patients to obtain such concurrent care.

Paul Ballard next brought up an item that Jack Schwartz had brought to the attention of the Council, that is, the fact that the American Cancer Society had given Maryland one of the 7 worst rankings for its pain policies related to cancer patients. Paul Ballard said he did some preliminary research and found that the poor ranking seemed to be based primarily on Maryland's lack of a formal policy or law related to pain management other than statutes that apply to health care facilities, which statutes require that adequate pain management be included as a patient right. Instead, Maryland seems to be reactive in its policies rather than having a proactive law or policy. He provided the Council with a copy of the Maryland Board of Physicians' regulation about the Centers for Disease Control's opioid guidelines. He said the regulation allowed the Board or one of its disciplinary panels to consider these guidelines for prescribing opioids for chronic pain but that the guidelines are not binding on the Board or one of its disciplinary panels. In contrast, he said that the Virginia Board of Medicine issued a policy statement regarding what it expects as the standard of care for physicians in the prescribing of opioids.

Shahid Aziz noted the ranking is not about whether a patient is in fact getting good pain treatment and wondered whether a policy is needed to say you must give a patient good pain treatment. Jack Schwartz stated it seems evident that the American Cancer Society seemed to think it matters to have an affirmative policy to encourage better

practice. He noted that the opioid crisis has led to an atmosphere of fear among practitioners regarding the use of aggressive pain management. He said he does not know whether having a policy matters but thought the issue was worth raising with the Council so the Council can figure out whether it makes a difference to have a policy. He said if patients are not getting adequate pain management, and if the lack of a policy may be contributing to fear among practitioners such as oncologists, then it is up to the Council to raise the issue.

Sister Lawrence Mary Pocock said her facility has been able to obtain adequate pain medications at the end of life. But she said their younger Sisters have been unable to get adequate pain medicine because they have been told by hospitals that the law prohibits prescribers from giving them these medications.

Christopher Kearney said this is not a unique story. He noted that relieving pain had been a priority back in the 1990's but now the opioid crisis has made practitioners afraid to prescribe pain medications. So, now things have swung back in the direction of not providing enough pain relief. He said even in the hospice world it is a challenge. He said physicians are not good at pain medication prescribing anywhere but now they are even more concerned about it.

Peggy Funk said she would talk to the Maryland Cancer Collaborative about the issue.

Christine Watts said MedStar Family Choice has a policy on effective pain management where chronic pain patients are required to be seen by a pain specialist. She said patients are required to sign a contract with the pain specialist, which is why a lot of patients are being referred to pain specialists by their primary care providers. She said 3 groups are excluded from this requirement, that is, cancer, hospice, and sickle cell patients, because the assumption is their pain is being managed by their specialist. She noted that for chronic pain patients, a 30-day limitation on pain medications is causing problems.

Christopher Kearney said many pharmacies are not stocking opioids. A Council member said hospices have contracts with pharmacies. Jack Schwartz said that if patients are suffering at the end of life, then the Council owes it to those patients to act even it means pushing back on the current social and political wave regarding opioids.

Michelle Ross said you have to look at the total cost of care provisions. She said that for a year or two Frederick Memorial Hospital has stopped seeing pain patients without life-limiting illnesses and that these patients end up landing in the emergency room to manage their pain.

Paul Ballard suggested the Council form a subcommittee to study the issue. Christopher Kearney volunteered to follow up with him. Paul Ballard said they would report back to the committee at the next Council meeting.

Senator Kramer asked whether Maryland needs legislation because the pendulum may have swung too far away from ensuring that adequate pain medication is provided to patients. He suggested the legislature could possibly create a pain management council to study the issue. He said he would be happy to work on legislation and noted that he sits on the Senate Finance Committee, which committee would be charged with looking at the issue.

Shahid Aziz asked whether having a policy is going to improve pain management. Paul Ballard asked whether the Council's clinician members knew anecdotally what physicians are afraid of, that is, whether it is being disciplined by their licensing board, being sued, or being prosecuted criminally. Christopher Kearney replied that all of those possibilities are driving their fears but he believed the prescribing part of the issue was now under control, although probably it is now too restricted in favor of not writing pain medication prescriptions. He thought a policy would be helpful to counter the perception of physicians that they should not write pain medication prescriptions. Paul Ballard said knowing the cause of the physicians' fear would be helpful in designing an appropriate remedy, whether it be at the board level to modify the standards of care from a disciplinary standpoint, or whether it be at the legislative level to modify the civil liability of prescribers in this area of practice.

Sara Hufstader stated that providers not in palliative care do not necessarily have the skill set to assess and manage pain. Thus, she said it is not just fear but also a lack of skill sets to appropriately assess and manage pain. She noted that the Center to Advance Palliative Care's State Report Card on palliative care would be published soon and the Council will be able to see how well Maryland is doing with regard to the treatment of palliative care patients. Paul Ballard wondered whether there was any research on lack of good pain management in Maryland or nationwide and what is driving the fear of prescribers regarding the issue of prescribing pain medication.

Elena Sallitto Boisvert stated that practitioners might get spooked by legislation because it might affect their standard of care. She stated that HIPAA was an example where practitioners overreacted with their fear of liability. Gail Mansell agreed.

Valoria Walker said that when she was on the patient family advisory board at Johns Hopkins Bayview Hospital, they talked about the opioid epidemic in Baltimore City and that she saw reports she could email to Paul Ballard. Christopher Kearney noted that a hospital's patient/family council is very good forum for this issue. He said there may be other groups that are also concerned about this issue of inadequate pain management.

Shahid Aziz said there is no harm in having a policy on pain management but wondered how much good would result from all the effort in creating a policy. Jack Schwartz noted there are likely to be very few double-blinded research studies regarding the effectiveness of pain management policies. Paul Ballard stated that the Council's statutory mission is concerned with care given at the end of life as opposed to the care of chronic pain for other patients.

Sandra Dillon, who is with the Hospice Alliance representing hospice and palliative care providers in the Delmarva, advocated for a statewide coordination of advance care planning campaigns modeled after the Horizon Foundation's SpeakEasy campaign. She said this would help to prevent duplication of efforts.

Tiffany Callendar said the Horizon Foundation would be happy to work with others to coordinate efforts and for different groups to learn from each other about what is effective in promoting advance care planning and the honoring of patient's wishes. Sandra Dillon said that a State toolkit developed by the Maryland Department of Health or the Maryland Department of Aging would be helpful to describe what has been shown to work, which could then be tweaked to fit local demographics. Sara Hufstader said she was supportive of this idea of having a State-coordinated effort. Peggy Funk said this is a fabulous idea and the Hospice and Palliative Network would support this statewide coordination in any way they can. Sandra Dillon said the hospice and palliative care community is on the same page. She said they are looking for a way to engage with the Department of Aging and the Department of Health. Sara Hufstader said the best practices nationwide should be examined. Paul Ballard noted that Christine Boyd said that the Department was going to issue a white paper, which might be beneficial to those efforts.

Tiffany Callender asked whether this effort could take the form of a workgroup of the Coalition to Improve Serious Illness in Maryland. Christopher Kearney noted there is a distinct advance care planning program or serious illness coalition in every California county and said it would be appropriate to include such a workgroup within Maryland's coalition too.

Valoria Walker said they are speaking about 5 Wishes in Anne Arundel County, that in Howard County they have MyDirectives through the Horizon Foundation, that Baltimore City and Baltimore County have no advance directive form that they are focused on using, and that in Montgomery County they use 5 Wishes and MyDirectives. Thus, she said she will make 5 different presentations based on what each county is using.

Christopher Kearney noted that the ultimate goal is to be like LaCrosse, Wisconsin, where most everyone has an advance directive because it is now part of their cultural expectations.

Sara Hufstader said that there is a need for marketing and messaging in a common language, for example choosing “proxy” or “health care agent” so that people understand what terms mean when advance care planning is discussed.

Shahid Aziz asked what kind of response these campaigns are getting. Tiffany Callender replied that Horizon Foundation’s SpeakEasy program is tracking who is completing advance directives. She said thousands of advance directives have been completed through the program. She said they tend to be completed by older, educated, white people who were already thinking they needed to complete one. She said younger, healthier people could not care less, so thus the challenge is how to engage these people. Christopher Kearney noted that lots of communities don’t trust the medical community to do these things, and thus there is a lot to overcome.

Valoria Walker said she speaks to college students at UMBC and said that young students are definitely engaged at her presentations but need to learn visually with videos.

Christopher Kearney said that Massachusetts has done the most advanced research on this issue regarding what is most effective in persuading people to complete an advance directive. Shahid Aziz asked whether it would make sense to target high risk folks at hospitals and through their insurance companies. Christopher Kearney said the research has broken the groups studied into quartiles with certain shared characteristics.

Paul Ballard briefly discussed the new national POLST form. He said Maryland law requires that out-of-state orders regarding life-sustaining treatments be honored. Thus, if the national POLST form is recognized by the state in which it was completed, he said that Maryland health care providers would be required to honor the national POLST form.