

Palliative Care Council
January 27, 2016

Present: James VanKirk, Lauren Michalakes, Kandyce Powell, James(Greg)Burns, Debra O'Neil, Elizabeth Keene, Roland Joy, Jason Whitney, Bruce Condit, Kevin Lewis, Peggy Belanger, Kolawole Bankole Scribe: Alicia Mooney
Guests: Anna Graham, Hilary Schneider, Gordon Smith, Rick Erb, Dr. Tiffany Pierce, Adam Lacher, Liza Eager, Carol Francis,

Topic	Discussion	Follow up
Welcome and Introductions 8:00am		
Approval of minutes from last meeting	No comments	Minutes approved
Palliative Care Website	There has been discussion with Scott Fish. By mid Feb. he will have the web site up and running to publish documents and information.	
Upcoming Hearing	<p>An emergency rule was put into effect on January 1, 2017, as a result of the new law around opioid prescribing that passed last year. A public hearing on the rule will be held February 13 by DHHS to provide the public with an opportunity for comment. Jim will be attending and will represent anyone's comments from this committee. You can submit a written document ahead of time for discussion, but there is a deadline. Jim is concerned about the 6 month limit (Exclusion) for patients with cancer after treatment. He has recently seen patients over a year out after therapy who have been suffering with chronic pain that will never go away due to chemo/radiation and horrible scarring due to injury.</p> <p>The Code B exclusion, Jim would like clarification for patient with serious chronic illness. Does it have to be prescribed by a palliative care physician or the primary care physician?</p> <p>Greg was at a meeting with a different group earlier this week who also seek clarification on the above issue.</p>	

	<p>Kandyce stated she had received call from 2 lawyers asking what our definition of palliative care is. She was happy to be able to share it. She instructed that this meeting is public and invited them to attend. People do know that this committee exists as a resource. The committee's definition of palliative care and serious illness will share at the hearing.</p> <p>It was questioned if for hospice providers, does the code c exclusion exempt. Would it be reasonable to ask for total code c hospice exclusion? The only exclusion for hospice is the dosage limit and all other exclusions are enforced.</p> <p>Bruce shared our focus should be on the law and that we not move the pendulum back where it was before. The law was necessary to ensure that the momentum that has been made to push this effort forward is not lost. We can not go back to where we were with prescribing practices, but we need to pay attention to those who need end of life symptom relief. We should be focused on the individual that is in need of the care It is challenging for the primary care physician. We don't want to limit the scope of palliative care to just the specialist as to looking to expand to primary care physician. We should ensure there broad definition of palliative care. Care should be based on the patient and not the provider. The WHO stated there is a lack of care to palliative patients.</p>	
<p>Gordon Smith Maine Medical Association</p>	<p><u>Maine's New Opioid Prescribing Law and the Opioid Crisis</u> The MMA is providing education throughout medical practices. He provided their definition of palliative care. If a patient is on 200 morphine equivalent, the mortality rate is that 1:32 people will die each year. Our max dosage is 100 at this point based on CDC guideline. There are 16,000 people who are over the limit. 272 Mainer's died from heroin/opioid. Averages about 1 per day for 2016. Overdose rate in Maine increased 31% in 2014. Maine infant mortality 7.1/1000. 1:11 babies born in 2015 were drug affected in</p>	

	<p>2015. We only have 13,000 births in the stated. He gave over prescribing examples like wisdom tooth extraction. The law is not blaming prescribers but attempting to assure patient safety He handed out and discussed the Maine Opioid Collaborative recommendations. There are 57 bills attached to this issue in the legislature. The legislation will form a work group to look at the bill to sort out the issues with the bill. It will not be just legislators. It will not have any authority but will have 4 legislators, community members and physicians. An overview of chapter 488 was discussed. The prescription monitoring program was discussed which includes all prescribers. Without a mandate, compliance would not be adhered to. There are exceptions for cancer pain, after treatment of cancer pain, hospice, and end of life care. They are not exempt from the PMP at this time. There were individual patients that came forward with specific circumstances i.e. a burn patient. A medical necessity exemption was given a time to get through to the 2017 implementation when the emergency rule took affect. The law facilitates pharmacist and physician communication. There is a grace period with the PMP due to a vendor change on December 20th, 2016 not allowing enough time to register. An issue arose with the PMP delegates. New delegates had to re- register. There is a grace period in March and October but the law is the law. On July 1, 2017 the dosing for the 300mg exemption will cease and Schedule 2 opioids are to be ordered electronically. By the end of year, all prescribers need to have 3 hours of education for CME's. Opioids for treatment i.e. suboxone are exempt. Partial fill law allows the patient the right to not fill the entire script but the remainder of the script may not be filled at a later time. The patient can not come back in because it alters the original script. The pharmacist has to notify the prescribing provider within 7 days that</p>	See attached handouts
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	<p>the script was altered, but does not have to notify the prescribing provider that the script was not picked up at all.</p> <p>The definition of palliative care that the council created is shared in the presentation given to providers. There is no limitation that primary care physician can not use the palliative care exemptions per discussion at this time.</p> <p><u>Slide 21 and 22 refer to the exemptions.</u></p> <p>There is NO exemption for PMP check in any venue. You are exempt from max daily dose and allowable doses and still questioning the ICD 10 coding.</p> <p>The post cancer treatment period of 6 months was discussed. This is a rule that will be discussed at the legislative level. All exemptions fall under the same category. Cancer care is A, palliative care is B and Hospice care is C. Total categories are A through G.</p> <p>When a physician delegates, the prescriber (provider) must review the dosage, if there are multiple scripts being written by another physician, or being filled at another pharmacy to have ownership. It was asked if physician education going to be given about replacement of medications to manage pain effectively and coverage for alternative therapies by insurance companies? The MMA needs assistance in completing the above question. They need the assistance of palliative care committee to deliver proper education.</p> <p>There are pharmacists that are not filling prescriptions. This needs to be addressed with the provider and pharmacist when it occurs. If assistance is needed, please contact Gordon for intervention. An exemption for failed taper for patients who have a failed taper. A podiatrist was asking for this exemption. This is a real situation that will be addressed at the next legislative session.</p>	<p>Max daily dose, allowable doses and ICD 10 coding are questions that do not have concrete answers that will be discussed and posted when resolved.</p> <p>The pain symposium is on May 5th at point look out to educate on the opioid prescribing.</p> <p>The MMA is willing to do more education and any time. Please contact Gordon if you would like education.</p>
<p>Maine Healthcare Association Rick Erb</p>	<p><u>Maine Long Term Care: (LTC)</u> Some long term care facilities have been forced to close due to regulation changes and funding. There are vintage facilities that have</p>	

many capital needs that do not have the money to address the needs. The only way to add beds to an existing facility is to reallocate them from another existing facility. Beds can not be created. The average age in LTC is 85 and it is increasing. Length of stay has dropped by 8 months in Maine Care. Medicare rehab stays have increased by 9 days raising discussion about Medicare spending and reflect shorter acute care stays. The major pressure for LTC providers is staffing levels due to shortages. Residents have been turned away for this reason. Staffing levels are not dropping at this time. The average hours of care per patient per day are about the same. There 200 open nursing positions 600 open CNA positions in the state. There is a spike in agency staffing due these shortages and it affects quality and cost. There is pressure to background check nurses including finger printing. It is a big problem in rural areas. There is a shortage of nursing home administrators. All above will lead to quality issues. Participation in hospice is not always possible due to the requirements related to RN coverage due to contracts Maine is 28th out of 50 states providing hospice care to residents in LTC. There has been a burst of regulatory and CMS requirements stressing the existing LTC. They feel under siege. The requirements of participation have not been updated for 20 years. They have been updated to be introduced over the next 3 years. The individually owned LTC are beginning to close due to regulations. The regulations causing the most challenges are payroll based journal and daily assessments of staffing to resident numbers generating more paperwork and too frequent assessments. The major population of residents is dementia diagnosis at 59%. Music therapy is a positive intervention for this population. The DHHS relationship is strong at this time. CMS is attempting to standardize the survey process that is helping the facilities of well.

	<p>There is an effort to reduce the use of antipsychotic medications in the LTC. We are down to 16% use in the state. It was asked if hospice patients are included in the numbers and he believe they are excluded.</p> <p>Medicare changes: cost sharing responsibilities, the shared savings programs and the IMPACT act are impacting partnerships with facilities. It may affect other facilities. If facilities end up with higher Medicare population versus Maine Care it may upset the balance of reimbursement is helping to sustain facilities. The ACO use of partnerships brings concern as well. There were no major issues in the ACA for LTC.</p> <p>MCHA can be a resource. Almost all facilities in Maine belong to Association.</p> <p>It was asked if there is there any sense in facilities how readily available palliative care consults are available to residents. An answer was not available at this time. Jim shared that he has reached out to the facilities in the area and some have been in agreement but a few have refused.</p> <p>A question was posed about salaries of staff in LTC in relation to the shortage. Rick shared they can not compete with acute care pay and is concerned about the increased minimum wage rule. CNA is 11.73/hr state wide. CNA retention is a large issue and LPN schools have closed in the state affecting staffing as well. Northern Maine Community College is going to offer an LPN program. Discussion was held about LPN use and the continuous care hospice benefit. The difficulty in placing young patients with neurological disorders is becoming prevalent. The Ombudsman is pushing forward with this issues and it is recommended that 16 beds be allocated for this population.</p> <p>They are partnering with home care for staffing as to the competition of staff is in retail and fast food. It was asked if there is thought that</p>	<p>Rick will send out a survey to facilities and share the results with the council.</p> <p>Kandyce shared a resource about retention of CNA's in LTC dealing with support of grief and loss in the setting brought satisfaction. It important to acknowledge to emotional support and they patient in the midst of a loss.</p>
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	<p>the staff could follow patients from the LTC to home health or hospice. Homecare has multiple part-time employees. The LTC could help to absorb those hours and provide full time for the staff. There are not enough young people in Maine to meet the demands of the industry. They are trying to attract new American workers to the industry. Kandyce shared that people want to stay in the community. It is difficult to do so when the resources are not available. The community of Jackman is considering running a CNA program in their adult education program. A curriculum is being developed for nurse manager training. Rick will see if the grief component may be added to the education.</p> <p>It was asked if there has there been discussion around the older workers in the LTC venue considering the expense it may incur. There are caregivers that have had to leave employment to care for loved ones at home. Could these people be employed? There are many families in Maine that have this experience. Rick shared that some facilities are open to this suggestion. It was shared that a resource center was created by the governor in Portland to help physicians transfer their licenses from other countries. It is now being opened to others such as engineers. It sometimes comes down to English as a second language and being able to translate the exams to become licensed in the states and liability insurance to obtain clinical practice.</p>	
<p>Carol Francis Health Director of Passamaquoddy Health Center</p>	<p>Carol started by speaking about the obituary of a tribal member David Moses Bridges. She has experience with 4 of the 5 tribal communities in Maine. The Passamaquoddy tribe is in Washington county. There are 2 reservations with separate health centers. Each tribe has a comprehensive health clinic. The clinic offers, MD, FNP services, chiropractor, massage therapist, podiatrist, and full time pharmacist. There is an attempt to bring services to community as patients don't want to leave home or have transportation. The elders</p>	

are very reluctant to leave the reservation. Home visits have increased with the elderly patients which are well received. The clinics offer WIC, dental and substance abuse. There is a large gap with elders and young generation's related to substance abuse. They have had 5 overdoses in the last months at the clinic. Suboxone is being sold in the community and misused. It is being traded to get their next fix. There are about 30 members who go to Portland for suboxone treatment and bring it back to sell. Carol wanted to make sure to pass this along so the awareness is heightened. The members who are in the monitored programs are doing well due to increased monitoring.

A survey was done in 2012 to identify health issues on the reservations. The leading health risk identified was substance abuse followed by, diabetes, alcoholism, cancer then obesity. Members do not fully sign on to preventative screening. Most funding comes through Indian Health Services. They do not have a large amount of money. They are reimbursed about \$3900 per member and the cost is \$8000 per member. Most members are underinsured. They can not afford co-payments.

There is a large need for skilled care in community. It is lacking at this time. Local agencies do not have the staffing to send the supports to our families. Have had 2 referral hospice services that went well and remained at home until end of line. Carol helps with the transition of members to outside services to help them allow outsiders in the home. It is important that outside agencies understand that the patient usually had a large family network involved in their care. Training should be provided to skilled nurses programs that the patients on the reservations do want you to come in and alleviate the barriers.

The have received funding to be able to perform home visits to help with relief for staffing. It is hard to have a native provider return

	<p>back to reservation to provide services. There is much historical trauma with the tribes due to people being taken from the reservations and it has been difficult to over come the trust issues. The lack of personal skills in understanding the cultures in history can inhibit relationships necessary to provide care. It is important to understand individuals and what the background is to understand personhood and provide quality care. The use of trauma informed care. The book Coyote Medicine was offered as a resource dealing with cultural differences and palliative care.</p> <p>Hospitalization charges are not to exceed the Medicare rates. The local hospitals have accepted the Medicare rate from tribal reimbursement. The challenges are in the outpatient arena with the costs. Bruce offered to help Carol with reimbursement issues and challenges if needed.</p>	
<p>Discussion: Morning session</p>	<p>Anne Graham introduced herself and her role at the American Cancer Society.</p> <p>Hilary shared information about the opioid prescribing rulemaking hearing. The public hearing on February 13th in Augusta is to provide comments on the 6 month post remission for cancer patient. She also encouraged people to ensure that conversations around opioid addiction are balanced and recognize the need for cancer patients to manage pain and the evidence-based use of opioids for relief of pain for cancer. The American Cancer Society has patient-facing materials for pain and cancer. One publication is almost 80 pages long and another is 25 pages due to complexity of issue and many options for pain managementThe ACS advocates for discussions with provider, caregiver and patient. There are other issues like co-payments that may prohibit patients from obtaining their medications. It was fortunate that this committee was formed prior to the opioid reform was passed to ensure that patients in need receive</p>	

	<p>services as the HHS Committee was aware of issues in discussions on palliative care.</p> <p>Lauren described a practice in NY that when patient dies, the RN was responsible to dispose of medication in the home. This is not the practice in Maine. There was a symposium about disposal issues in which no one could agree on a method to dispose of medications. It should be a conversation in the home at throughout care. Patient families know how to dispose of medications. Is drug disposal state based or facility policy? It was recommended to be placed on the pain symposium agenda for discussion. Some communities have a take back program. There was a send back program that was in place for 2 years that was not further funded. There is a lack of consistency of disposal and there are more drugs in the house than there used to be as well.</p>	<p>Kandyce will add it to the agenda for the pain symposium.</p>
<p>Cigna Dr Tiffany Pierce Elizabeth Hoffman</p>	<p>Cigna had 80,000 customers in Maine. They are located throughout Maine with dense populations in urban areas as well. They have not had challenges obtaining palliative care and hospice in the state as of today. It was discussed that there is an area the size of Rhode Island in the state that lacks access to services. There are pilots being conducted in the northeast region of the US regarding end of life services but they are not available in rural areas. The pilots are internal for Cigna. The results will be shared with value based partners and published in the literature.</p> <p>Advanced Illness Care: There are work groups in Connecticut discussing on how to facilitate hospice discussions with consumers and providers.</p> <p>Palliative and Hospice Services: The coverage mirrors Medicare plan. The respite services may differ but the other levels of care are pretty similar (i.e. home based, inpatient, crisis care, education on advanced illness and medications). There is the ability to carve out services attributing to the quality of life. Radiation and transfusions may be</p>	<p>Dr Pierce will take it back and see if the information could be released to the council.</p>

provided for a set period of time. The case manager can work with hospices without respite care to help provide alternatives. The case manager will reach out to patients with a cancer diagnosis and help facilitate hospice conversations. The discussions are tracked by feedback from the providers in the contractual relationships. Identification of diagnosis including cancer, CHF, cardiovascular disease, end stage liver and kidney disease, COPD, and neuromuscular diseases are detected by the case manager positions, claims and proprietary algorithms. Services are benefit plan driven. The majority of Cigna's customers in Maine are self insured and employer driven. Medicare is studying concurrent care related to early hospice referrals while receiving treatments.

Cigna may be seen as a long term insurer as to some consumers have been on service for 70 years. According the contract, it may be a per diem rate or per visit. Most often is a per diem rate. All inpatient hospice stays must reviewed by their medical director. Lauren asked if the case manager attempts to link the patients to palliative care providers as necessary. Cigna does initiate referrals to palliative care physicians or providers. In New Hampshire they are trying to avoid the term hospice and use advanced illness care. Cigna has pain management programs that are case managed. It was asked what is being done for Community Outreach for benefit education. Cigna had different modalities. They have value based partnerships Cigna Accountable Care organizations. They fund nurse case managers in physician practices to help educate about the benefits. They do benefit fairs to help educate as well. They have worked with physician office to find homecare agencies that have a type of bridge program to be able to transition to care. Dr. Pierce stated that they do education directly with employers and their staff about the benefits provided. It was asked if Cigna have any specific criteria that trigger a palliative care consult. Dr. Pierce stated yes that they have algorithms that they

	<p>follow but the details could not be shared at this time. Elizabeth stated that it is at the discretion of the case managers. Lauren suggested it may be worthwhile to have some standardization of criteria for palliative care.</p> <p>Kandyce shared her perspective about the term of hospice and its use and the fear of end of life. She had noticed over the years with the introduction of the Medicare benefit that hospice is associated with the very last moments of life. Jim stated the same thing is happening with the term palliative care and its equivalence to immanent death.</p>	
<p>Maine Alzheimer Association Adam Lacher</p>	<p>Adam shared a presentation he prepared for the council. Alzheimer's is the most expensive disease in the United States. It is the 6th leading cause of death with no treatment options available. 85% of dementia is Alzheimer's It is not a normal part of aging. Kandyce asked if there were any incident of pediatric dementia related reported. Adam was not aware of this at this time. The MAA serves multiple people every day via a 24 hour hot line. There are 26,000 people in Maine living with Alzheimer's. There are about 70,000 people who are providing care for Alzheimer's patients without reimbursement. (953 million dollar in care at 12 dollars an hour.) Caregivers may be going hungry due to increase cost of providing care. (28%) The disease has a cost similar to the defense budget. The statement went onto support hospice/palliative care support for Alzheimer's disease. Mainecare will pay out 180 million dollars for Alzheimer's disease patient. There are better outcomes, less ED and hospitalizations were less when palliative care was involved. Long term care residents with palliative care had better outcomes and increased quality of care. A national plan was placed by the government in 2010 that is reported annually. In 2011, an Alzheimer's report was created. It is the driving force behind Alzheimer's care. The report has 100 recommendations for care. One is increased education for providers in best practice in all services and settings nationally. The PCHETA</p>	

bill, under consideration in the last Congressional session, was co-sponsored by all of our Maine's Congressional delegation in 2016 and will be re-introduced this year. The bill largely focuses on research and education.

Adam presented a personal story written by a co-board member who's aunt had dementia and experience end of life care in a LTC with hospice. It was asked if there are funds available for people who have to stay home and care for family. There are few options at this time. There is a tax credit is available to help with care. They are trying to pass paid caregiver leave to care for persons with Alzheimer's. There are many hidden costs that arise due to impaired judgment that are not captured as part of the cost of providing care. It was discussed that people are outliving their pensions due to longevity. It is thought that appropriate transitional care for patients with Alzheimer's eases the disease. Palliative care is the best concept for these transitions.

Kandyce shared that we have been trying to deliver care in a seamless manner and the difficulties that it brings.

The G0505 Medicare code maybe to help with transitions of care. The VA has a dementia unit. There is a homemaker/Home health aide program available for use. The hours available are 4-20 hours per week that vary. Hospice services are available in contracted nursing homes to help provide care as well. If you have a veteran that needs something, the service organizations may assist them.

1.4 Billion dollars in funding for research. Jackson lab has part in a grant by NIH for Alzheimer's research. Prevention efforts are being pursued and almost ready to be published. The Mediterranean diet, adequate sleep and regular exercise may be part of risk reduction data.

<p>Portland Public Health and HHS Department Kolakole Bankole, MD</p>	<p>Palliative Care and Quality of Life: Disparities in Care We should focus on cultural competence and the new issues that arising in proving care. Over every 10-15 years, the proportion of minorities has increased. In 2010, minorities comprised it 35% of the US population. Maine is about 95% white. The further north in Maine, the less diversity is present in populations. Portland has a greater diversity and foreign born representation. A definition of palliative care was aimed at relieving suffering and having the best quality of life. Access to care, the way the care is received and the quality of the care being provided are important aspects to explore. Cultural preferences come to life especially at the end of life. They need to be incorporated in the care. 63% of the US hospitals have a palliative care team. Only 50% of the safety net hospitals have a palliative care team contributing the underutilization of palliative care. Palliative care in Britain was compared. Minorities want to be taken care of and want to extend their lives but may receive less. Physicians may give less information as compared to white people. Providers who do not share the same ethnicity tend to not share the information and explain palliative care. The facts are presented versus full information. There may be poor communication, lack in emotional support and misunderstand care options. A study was performed in 2012 with 5 parameters of quality of life: dyspnea, pressure sore in LTC, emotional and spiritual report, communication and plan of care consistent with patient wishes. It was compared to African Americans, white and Hispanic. It validated the lack access to care if the lack of funding was present. There is a WHO study as discussed that speaks to training of providers in palliative care and how it will improve longevity.</p>	<p>Dr. Bankole will send the presentation out to the members for review.</p>
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	<p>Culture is the way of life of a particular group. It is a determinate of health if it is considered appropriately. Cultural competence was defined.</p> <p>2013 there are 15 standards that must be adhered to in providing care. Some of the standards include the use of Interpreters and literacy.</p> <p>Cultural destructiveness, blindness, and humility were discussed. Cultural competency includes mandates, laws, policies, standards practices and attitudes. These qualities will increase the quality of care. It was asked if there are enough interpreters to meet the needs of consumers. Portland area has about 60 interpreters. There are Skype services available for translation.</p> <p>Cultural humility is a lifelong commitment to self evaluation and self critique and developing beneficial and non-paternalistic relationships. The values are openness appreciation, acceptance and flexibility An IHI clip on cultural humility was shared.</p> <p>Recommendations to improve palliative care for minority patients were discussed including increased research, public awareness, professional workplace capacity, palliative care education, and create new care delivery models. Kandyce shared that the prison community has multiple religions and the ability of the caregivers in the system and how they adopt cultural humility to provide support to another. The Health Equity Prescription was shared: Platinum rule, 3A's Principle, and Cultural Humility Values.</p> <p>Jim asked if studies had been performed about the cultural humility of the people that you work with versus patients. There have not been official studies.</p>	
Palliative Care Report	<p>The CAPC palliative care report was published and Maine received a B. Per the study, there are 10 of 14 hospitals that have palliative care programs to equal 70%. It surveyed hospitals with only 50 beds. Maine secured its own report for hospital based palliative care</p>	<p>Maine Hospital Association has already grabbed the report to share the information.</p>

	document for final discharge there is a box for palliative concepts that is missed at times. It is part of the 8 P's for assessment and the 8 th P is palliative care. It may be placed at the beginning versus the end.	
AAHPM	The annual meeting is in February in Phoenix. There is an invitation for the clinicians who were involved in these meetings to gather and meet while there.	A report back from this event was encouraged.
Updated list	A new committee list was distributed to the committee. A typo was discovered in the report. Corrections will be made and the list will be redistributed.	Kandyce will redistribute a corrected list.
Next meeting	April 21, 2017	
Meeting adjourned- 4:30pm	4	Respectfully submitted Alicia Mooney, MSN, CHPN