

March 9, 2017

Testimony in support of HB 2031

Chairwoman Schmidt and members of the Committee:

My name is Janelle Williamson. I am a nurse practitioner with Lawrence Memorial Hospital's Pain and Palliative Care Service. I am certified in hospice and palliative medicine and have been practicing in the field for 9 years. I would like to thank you for the opportunity to discuss House Bill No. 2031.

We live in an instant gratification, entitled, consumerism world. The way in which healthcare services are requested and rendered is no different. Providers are trained to offer treatment and services and consumers are likely to accept proposed interventions. Patients and providers alike have become blinded by the idea that action implies hope. Over time this has resulted in a full-steam ahead approach to medical care and the unfortunate consequence of a transactional relationship between provider and patient. An expectation has been set to do everything possible, even when treatment may shorten life. Often times there is little discussion about whether or not to pursue a proposed medical intervention; rather informational scripts are given to patients so that we can mark a box indicating that we have provided informed consent. Part of the informed consent process is ensuring that the provider is full aware of the patient's preferences, wishes and goals in life. Unfortunately, training of providers has been woefully inadequate to equip them with the necessary tools to have these types of conversations. Furthermore, the idea of death has become seen as medical failure rather than as a natural part of the life process. As a result, patients may endure unwanted or undesirable medical intervention, particularly at the end of life.

Palliative care is the medical specialty that addresses the complex needs of a patient experiencing chronic, life-limiting illness. Unfortunately there is a nationwide shortage of palliative care providers and our state is no exclusion. Additionally, lack of knowledge from both healthcare consumers and providers about the difference between palliative care and hospice serve as a barrier to access.

House Bill No. 2031 aims to address these shortfalls by accomplishing 2 things:

- 1) Creates a palliative care consumer and professional education initiative through the Kansas Department of Health and Environment.
- 2) Establishes an interdisciplinary advisory council within the Department to advise on matters relating to the development, operation and outcomes monitoring of palliative care initiatives in the state.

It is critical as we face an aging population, with increasing medical co-morbidities, that providers of all levels are basically trained to initiate conversations with patients about their healthcare wishes. Similarly, increased awareness and knowledge of what palliative care is and is

capable of doing, is necessary to promote access for all. H.B. 2031 lays important groundwork for this process.

I would like to finish with the story of my patient, Mike. He is a 62-year-old gentleman who, up until last fall, was working full time in maintenance. He was active with his family and enjoyed his hobby of fishing. He noticed that he had been losing weight and suddenly developed some chest pain. After a series of doctor visits and diagnostic tests, he was diagnosed with stage IV lung cancer that was indeed terminal. However, treatment options were available that would potentially be life prolonging but palliative in their intent. Mike was hesitant to move forward with treatment as he was not certain he wanted to endure the potential side effects. He was already experiencing pain, shortness of breath, poor appetite, nausea and vomiting. I was able to visit with Mike and his family before he began treatment. I learned that what is most important to him is his family and particularly his 4 year old grandson. His goal is to live until next September so that he could be a part of a large family celebration. He was willing to proceed with treatment for this reason but made it very clear that if at any time it began to diminish his quality of life, he wanted to stop. He was able to describe an acceptable quality of life for me and his family. I prescribed something to boost his energy and to help with pain. Along the way I have helped facilitate various procedures to reduce his symptoms. He has been able to tolerate treatment with minimal side effects and is on his way to accomplishing his goal. We have already discussed hospice and the role this will eventually play in his care. His financial affairs and advanced directives have been completed. Most importantly, his family knows what his wishes are and he is receiving the care that he has chosen for himself. Palliative care is able to address the whole patient with this type of support – from pain and symptom management, to facilitating family discussions and advanced directive planning.

Thank you for your consideration of House Bill No. 2031. If I may be of any further assistance, don't hesitate to contact me at 785-554-8036.

Sincerely,

Janelle D. Williamson, NP-C, ACHPN

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