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Impact of Culturally Based Medicine on Patient Decision Making

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** Pre-print Version**

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I. Summary

This is a case of a Ms. C, a 37 year-old woman originally from Zambia, Africa, with an unremarkable medical history prior to the unfortunate diagnosis of cervical cancer in 2014. Ms. C, was diagnosed with cervical cancer at an early stage with many treatment options available at the time of her diagnosis to potentially limit disease progression including: conventional surgery, chemotherapy and radiation therapy, all commonly recognized treatment approaches and medical management utilizing "westernized" medicine theory. Based upon the ideology of the patient's family and her own personal beliefs of healing and western medical practices, she instead opted for a culturally-based complementary and alternative medicine (CAM) management of her cervical cancer and declined surgery, chemotherapy and radiation therapy. After 2 years of CAM management, her cervical cancer metastasized to her lungs and brain. After numerous hospitalizations for cancer-related illnesses and increasing symptom burden, she sought typical western medical interventions including chemotherapy, external beam radiation, along with a

nephrostomy tube for renal failure and uterine artery embolization for chronic uterine bleeding. Within 6 months of such interventional techniques failing to improve her prognosis, the patient died under hospice home care. This case highlights the importance of elucidating how a patient understands their own medical condition and reconcile their belief system and cultural practices early in the management and treatment process. This is possible through emphasizing and practicing a thorough cross-cultural interview and is especially important when dealing with potentially life limiting pathologies like cancer, and when making key decisions such as choosing between CAM vs. western medicinal practices, or a holistic approach utilizing both. Physicians and patients must focus on removing cultural barriers to medical care.

Keywords: Cancer, Cervical Cancer, Gynecology, Obstetrics, Palliative, Cultural Barrier

II. Case

Ms. C. was a 37 year-old Zambian woman who was diagnosed with early stage cervical cancer two years previously. She was presented with options for local treatment, which could have been potentially curative. She elected, however, to pursue complementary and alternative medicine (CAM) treatments, which she thought would be curative. Treatment consisted of herbal medicines, commonly used in her native country. Unfortunately, after two years, her disease progressed and metastasized widely, to her lungs, brain, gastrointestinal tract and kidney. At that point, she did accept treatment, including external beam radiation therapy and chemotherapy. She also required treatment for renal failure, which was due to obstructive uropathy and arterial embolization to control uterine bleeding. Her symptoms, however, were unremitting and she required multiple visits to emergency rooms, as well as hospital admission, for severe cough, abdominal pain, nausea and vomiting. She became malnourished and suffered from recurrent genitourinary and gastrointestinal infections. It became clear that symptom management should be the main focus of

her care. As a result, palliative care consultation was requested. The patient's main concern was management of her pain. Efforts were made to educate the patient about the unremitting course of her disease, but she was unable to engage in discussions of prognosis and advance care planning. She did not have a living will, nor did she have a health care surrogate.

The patient was born and raised in Zambia and had resided in the United States for the past seven years. Her mother immigrated to the United States when the patient was quite young and was a practicing nurse. She lived in close proximity to her daughter and was often at the bedside during hospitalizations. The patient eventually named her mother as the health care surrogate. Ms. C also had a sixteen year old son, who was in high school. Ms. C. was employed, and continued to work, with increasing difficulty, despite her treatment and symptoms, in order to maintain her health insurance.

Ms. C., remained in palliative care during her hospitalizations as well as at home, following her discharges. Her pain worsened, and she eventually required opioids for pain control. She did not take her medications as prescribed, despite repeated attempts by her caregivers to explain the importance of taking her medications regularly on schedule. She was offered twenty-four hour access to her caregivers, but often called only when she had an emergency. She had significant psychosocial and economic issues requiring intervention by social work and chaplains. Although she eventually became hospice eligible, she continued to be unable to discuss her prognosis and end of life wishes, other than to express her desire to remain at home with her son. In addition, she refused additional support from her mother. During hospitalizations, she became very controlling regarding specifics of her care, regarding such issues as temperature of her drinks and arrangement of her pillows. She eventually was able to accept the recommendation of hospice care and she died at home, according to her wishes.

III. Discussion

Early stage squamous carcinoma of the cervix, when properly treated, is associated with a generally good prognosis. Patients who have Stage I disease have a five year life expectancy between 76 (Stage IB2) and 98% (Stage IA1) [1]. As the disease progresses, survival expectations decrease. Patients who have disease which has metastasized beyond the pelvis (Stage IVB) have a five year life expectancy of 9%. It is clear that effective screening and treatment of early stage cervical carcinoma results in significant improvement of survival. There are, however, other variables which have the potential of detracting from the benefit of early detection and/or early treatment. A major set of variables relates to availability and acceptance of screening and early detection, as well as availability and acceptance of effective, potentially curable treatment.

Availability of services is often a function of geography and socioeconomic state. Acceptance of treatment options, once recommendations are made, can be a much more ambiguous and depend on an extremely complex array of patient and physician (care giver) variables. When a caregiver presents medical recommendations to a patient, it must be done with the assurance that the patient is able to not only comprehend the nature of their illness, but also when establishing reasonable goals and potential risks of treatment, alternatives to the proposed treatments, including none at all.

Information, as noted, must be delivered to the patient in an objective fashion, and in a way which allows the patient to understand. It requires overcoming potential language barriers, problems with intellectual capacity and individual defense mechanisms, such as denial. It also requires an understanding of potential cultural factors, which may interfere with the willingness of

a patient to accept medical recommendations. Patients should never be stereotyped, based on their cultural origin, but the possibility that cultural differences could influence a patient's acceptance of a treatment recommendation, should always be considered and effectively explored. Firstly, it is important to understand the patient as an individual, and then, understand the patient's relationship to his/her community.

The patient could have been influenced by many individual factors when she declined early treatment – financial, intellectual, social, language and emotional factors. All of these factors should be understood, as well as possible, by the care giver. In this particular case, an understanding of the attitude of Zambian culture toward "Western" medical care, could certainly have influenced her decision making process. This possibility underlies the concept of cultural competence, which all caregivers should make an earnest attempt to achieve. It is unknown if her initial encounters with her original medical team at diagnosis utilized a cross-cultural interview method to develop a mutually acceptable plan of care for her and her family.

It is estimated that by 2050, minorities will make up 47% of the U.S. Population [2]. This highlights the importance of recognizing and understanding the cultural influence in medical decision making as the population demographics shift to increasing numbers of ethnic minorities. Thus, it becomes a priority for physicians to be educated in practicing culturally sensitive medicine aimed at developing a plan of care that is amenable to different groups of patients who may share unique cultural perspectives pertaining to disease, to illness, and to healing [3,4]. This can positively affect management of various chronic, psychiatric, and potentially lethal conditions like that of Ms. C. Inevitably, practicing culturally based medicine will optimize patient care, outcomes, and undoubtedly improve the patient-physician relationship as well as adherence to plan of care. As such, focusing on the development and implementation of a solid cross-cultural

interview would be an ideal first step in developing foundational cross-cultural patient-physician relationships essential to quality healthcare.

Gregory Juckett, M.D. of the American Association of Family Physicians provides a detailed outline to conduct a cross-cultural interview, which can be simplified to 4 essential steps [2]:

Steps of conducting a cross-cultural interview:

Step 1: Small talk

Step 2: Speech and body language

Step 3: Interpreter if necessary

Step 4: Checking for understanding

Before engaging in a cross-cultural interview, the physician and patient should ensure that they have adequate time as the interview is a slow process if done correctly. It is vital to not rush any step as it may appear that the physician is 'disinterested' in the patient's story and values. In Step 1, the "small talk" establishes trust between the patient, their family and the physician. During this initial phase of the interview, the physician should be as formal as possible. This demonstrates respect and is the best way to address the patient. It is important to note that some cultures do not speak very much, nor express their feelings to strangers. Some patients avoid eye contact out of respect [2]. Do not interpret this as a meaning of "Defiance" or "Disrespect", as doing so will alter the dynamic in the relationship thereby creating a judgment about a person who you are getting to know. It also helps to echo the behavior of the patient to initially gain their trust and to help them be more open during the interview. For example, if they are sitting with their arms crossed, mimicking their behavior would help create a neutral and more equitable form of communication.

Perhaps Step 2 - Language is the most important step of this process. Language, word diction, connotation, and body language are an easily misinterpreted form of nonverbal communication. Thus, as a physician providing cross-cultural care, it is important to use universally neutral acceptable gestures like a smile - which demonstrates friendliness and is often perceived as being 'welcoming' to patients. Additionally, using simple words with reduced syllables helps to further reduce such miscommunication, especially for people who speak English as a second language. Soft toned voices are preferred, as opposed to loud harsher tones that can easily be confused for overbearing dominance. Softer toned, more introverted patients may not want to communicate with louder speaking medical providers because of intimidation [5]. Head movements are not universal gestures. For example, South Asians utilize a head nod/shake to mean "I understand" whereas the same head nod in different cultures means "No" [6].

Step 3, using an interpreter may still be needed even if the above steps are implemented. In the ideal case, it is best to utilize a professionally trained medical interpreter or a staff member to act as the interpreter [7]. Using a family member or friend may be more convenient; however, the technicalities of the translation may not be adequate enough for medical history and diagnosis purposes. Additionally, the family/friend may add their own personal interpretation of what is being asked.

Step 4, the patient's understanding of the condition/illness is equally as important as Step 2. This will allow the physician to gather what the patient knows, but equally importantly how they feel and what they believe about their condition [8]. This will help to reveal cultural barriers that may exist when developing a plan of care. For example, if the patient firmly believes in herbal based CAM or holistic approaches to healing/medicine, a discussion about the potential impact of their beliefs to their medical condition is vital to their overall prognosis as in the case of Ms. C.

Allowing the patient to explain their beliefs, even if the physician may disagree, demonstrates a respect of their views and offers a chance to create a mutually agreeable plan of care that the patient will more likely adhere to, allowing for a more favorable prognosis. After counseling a patient, it is imperative to include early follow-up to ensure patient understanding, adherence to the collaborative treatment plan, and answer any questions that may have developed since the initial visit.

Inevitably, these steps are not concrete methods to have the "perfect" physician-patient relationship. Rather, they are steps to help create the most healthy cross-cultural patient-physician relationship that can greatly impact the medical management, adherence, and outcomes of care possible by elucidating the patient's personal beliefs about medicine, healing, and their own illness. In the case of Ms. C, a properly conducted cross-culture interview and early interview may have altered the medical management of her condition, and perhaps improved her outcome, including delaying or preventing her untimely death.

IV. Acknowledgements

The research team would like to dedicate this work to medical students, researchers, clinicians, and especially those affected by and lost to cancer.

V. Conflicts of Interest

The authors declare that there is no conflict of interest regarding the publication of this paper.

VI. Author Contributions

All authors contributed equally to the authorship of this manuscript.

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