Published in final edited form as:

Pract Radiat Oncol. 2018 ; 8(6): 351–353. doi:10.1016/j.prro.2017.09.004.

Walking Forward: A Narrative from South Dakota

Daniel G Petereit, MD, FASTRO

Avera Cancer Care Institute – Sioux Falls, SD, Rapid City Regional Cancer Care Institute, 353 Fairmont Blvd, Rapid City, SD 57701, dpetereit@regionalhealth.org

People might have thought that South Dakota was near Death Valley for a career. Perhaps it seemed so to many of the American Indians (AIs) when they heard the word “cancer” but for me as an opportunity to make a difference for the people and being part of a community with solid family values, it was anything but. What turned out has stunned me and a number of supporters and sceptics as to what we have done and what we can accomplish. Imagine, for a moment, that we are leaders in concepts in global health from the state known for Mount Rushmore and buffalo roundups.

Narrative is a key component of the AI culture and also of other indigenous populations in general making experience and lessons learned broadly applicable. I am grateful for the opportunity to contribute this narrative to convey how I as a radiation oncologist went from an academic practice specializing in gynecologic oncology to my current location of 18 years in Rapid City, SD, where I have had the opportunity to work with the Northern Plains American Indians as part of a NCI funded cancer disparity project called *Walking Forward*. The aim was to bring the plight of indigenous populations off the sidelines into the middle of the *Jim Thorpian* type playing field where stakes are huge.

Narratives begin from where one’s life starts and mine was strongly influenced by my father Dr. Frank Petereit. His story is relevant to mine as it motivated me to become a physician and to help the underserved. It is remarkable on several levels. He had a very rough start, not uncommon to many in my “SD neighborhood” as he was born in poverty, saw his dad drown at the age of 5, was placed in a boys’ home, gritted his way to medical school, rotated as a medical student with the same surgeon who saved his life years earlier, and ultimately became a successful radiologist.

When we who are privileged make it up the ladder of success, it is a mere fraction of what many under-privileged must accomplish. The seeds of working with the AI culture were probably sown as I fished on the banks of the Missouri River with my father on the Crow Creek Indian Reservation. The same moonlight that reflected on the river gave me much to ponder as my father did decades earlier as he mourned the loss of his father.

Publisher's Disclaimer: This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

My motivations for becoming a physician and radiation oncologist are most likely similar to anyone reading this. I was fortunate to have performed my residency at the University of Wisconsin-Madison and even more fortunate to have led the radiation therapy portion of the gynecologic oncology service for 5 years.

When I decided to re-locate back to my home state in South Dakota in 1999, several of my colleagues questioned this decision including one of my mentors Dr. Ted Lawrence who wrote me the following in a very nice letter that I have kept: “Dan, I was, indeed, stunned to get your recent letter that you are leaving the University of Wisconsin... It sounds like you have given this a lot of thought and that it is the right thing for you”. It was one of those letters that you save in your permanent file. So, thank you Dr. Lawrence for your feedback and support 18 years ago. Indeed, I had given it great thought with the idea of returning home to help build and sustain excellence in cancer care and to be part of life in a community that had strong values of self-reliance and helping one another when the need arose. But, the culture of science and service in which I was immersed was going with me.

While family was a key motivating factor for relocating back to my home state, another one was the potential to work with the AI community who suffer tremendous health disparities. In 2002, the “stars aligned” as the NCI announced the Cancer Disparity Research Partnership (CDRP) Program for community cancer centers. We were well positioned to compete for this RFA and soon were the recipient of a multi-million dollar grant. We were one of the two grants funded the first time in leaders...pioneers... until I woke up the next morning anxious about how we were going to implement this herculean project. This proposal was pioneering in providing resources to the “little guy” with help from mentors at UW, Mayo and the NCI. It was a reversed paradigm- from little up to big. It was serious NCI science.

The initial hypothesis for the first five years of Walking Forward was to address cancer disparities through patient navigation, clinical trial access, and identification of barriers to early detection and successful treatment for American Indians. There are many lessons learned and published but the most important was the need to listen, listen, listen and then listen some more.[1–3] It took 2 years to gain the confidence of a community that saw nothing but suspicion in government programs. To simply be trusted was a high point in my life. We were successful in understanding the epidemiology of the cancers, the reason for gaps in care, the benefits to patient navigation and demonstrating the AIs and their resource-limited neighbors would, indeed, join clinical trials. They only needed to understand and be given a chance.

The second 5 year grant cycle was a continuation of similar themes, but with a much more in depth patient navigation program. We recently completed a smoking cessation project for 256 AIs through a RCT using nicotine replacement, counseling and text messaging to mitigate the high rates of tobacco use (40–50%) and tobacco induced cancers – a bit removed from radiation oncology, perhaps, but not really as we are complete doctors! In June of 2017, we submitted an RO1 with the goal of increasing low dose CTs (LDCT) rates for screen eligible smokers for the entire western part of South Dakota by targeting 135

primary care providers and 1,000 high-risk individuals through two interventions. The objective is, of course, to reduce lung cancer mortality rates.

Published critical outcomes include establishment of trust within tribal communities, identification of barriers to cancer screenings, creation of research infrastructure, and clinicaltrial enrollment of 4,000 AIs as well as higher completion-of-treatment and patient-satisfaction rates for patients undergoing cancer therapies. Recent Walking Forward data analysis suggests American Indian cancer patients with screen-detectable cancers are now presenting with earlier stages of disease and subsequently higher cure rates. [1–8]

To accomplish those results required, on a quarterly basis-and sometimes more-since 2002, 300-mile round-trips totaling thousands of “on the road” miles were conducted visiting staff and community members residing on the reservations of Pine Ridge, Rosebud, and Cheyenne River. For the first few years, the journeys were weekly or monthly. The road time has given me hundreds of hours to meet and listen to countless, fascinating individuals. I truly have learned much more from the AI population than they have from me.

One invaluable exchange, for example, provided us with key direction. KILI radio is situated on a butte within the Pine Ridge Indian reservation, five miles from the site of the Wounded Knee Massacre (a story that, I believe, should be required American history reading). Hour-long interviews on KILI continue to be an especially effective method of communicating our messages. While driving back from conducting one such interview, I stopped for gas. A Native fellow asked if I were “that cancer doctor” he’d just heard on the radio. I responded yes, and he replied, “Well, if you get cancer, it doesn’t matter; everyone dies.”

From that brief exchange, a realization surfaced: that man and his family are not going to seek cancer screening. Our staff began conveying to the community essential messages about early detection leading to successful treatment.

Continuing that message over the years, several cancer survivors have participated in our interviews. Today, terms commonly heard in the community include “IMRT,” “prostate and breast brachytherapy,” and “SBRT”. Who’d have thought!

I can’t ignore the call to help people who are marginalized and suffer tremendous historic trauma from events including Wounded Knee in 1890, not when there are opportunities to make a difference. My father was able to rise above his disadvantaged beginnings. I hope that the American Indian population will rise above their current dilemma. I see evidence of progress happening. What is now becoming appreciated is that the AI issue is not merely one of poverty but it is a much more complex issue of how indigenous people in resource rich countries relate to their society at large. Indeed, in the last 2 UICC meetings, indigenous populations in higher income countries are recognized to have similar issues to people in low resource countries with severe cancer care disparities. So, the work we are now doing is considered a key component of global health, being addressed by the UICC and also the International Cancer Expert Corps of which I am a contributing member.

Radiation oncologists working to address cancer disparities in our communities and abroad are well poised to do so.[9] We are physicians who care for patients with a dire illness. We

use our marvelous tools to relieve suffering. We can do so much more than sit behind our computers and work on DVHs all day. We can reach out to understand why patients present as they do and to remove barriers. And we can produce cure, relieve suffering and provide hope. The work challenges and rewards on many levels.

Nowadays, life as a doctor is more and more full of paper work, forms, data, billings, credentialing and re-credentialing. But the essence is still in helping humanity and taking on challenges. It has been “the road less traveled”, but one that is most fulfilling. It remains a huge opportunity to make a difference, to demonstrate that unique research can be conducted in the community, and that in our technological world of radiation oncology there is room for ongoing narrative and fantastic opportunities guided by the courage and wisdom of my father and the leaders in the community that simply do not give up.

Finally, as I have the luxury of chasing walleyes on a local reservoir, I continue to ponder the many life lessons learned from my father, my community and my family as the reflection of the moon and our creator continue to give back to me. To quote my father, “life has been a miracle” - a miracle to which we contribute!

References

1. Petereit DG, et al. Increasing access to clinical cancer trials and emerging technologies for minority populations: The Native American project. *Journal of Clinical Oncology*. 2004; 22(22):4452–4455. [PubMed: 15542797]
2. Rogers D, Petereit DG. Cancer Disparities Research Partnership in Lakota Country: Clinical Trials, Patient Services and Community Education for the Oglala, Rosebud and Cheyenne River Sioux Tribes. *American Journal of Public Health*. 2005; 95(12):1–4.
3. Petereit DG, Burhansstipanov L. Establishing Trusting Partnerships for Successful Recruitment of American Indians to Clinical Trials. *Cancer Control Journal of the Moffitt Cancer Center*. 2008; 15(3):260–268. [PubMed: 18596679]
4. Petereit DG, et al. Addressing cancer disparities among American Indians through innovative technologies and patient navigation: The Walking Forward experience. *Frontiers in Oncology*. 2011; 1(11):1–9. [PubMed: 22655224]
5. Petereit DG, et al. Prevalence of ATM Sequence Variants in Northern Plains American Indian Cancer Patients. *Frontiers in Oncology*. 2013; 3(319):1–5. [PubMed: 23373009]
6. Guadagnolo BA, et al. Patient navigation for American Indians undergoing cancer treatment. *Cancer*. 2011; 117(12):2754–2761. [PubMed: 21656754]
7. Guadagnolo BA, et al. Medical Mistrust and Less Satisfaction with Health Care among Native Americans Presenting for Cancer Treatment. *J Health Care for Poor and Underserved*. 2009; 20(1): 210–226.
8. Guadagnolo BA, D P, Coleman CN. Cancer Care Access and Outcomes for American Indian Populations in the United States: Challenges and Models for Progress. *Semin Radiat Oncol*. 2017; 27(2):143–149. [PubMed: 28325240]
9. Petereit DG, Coleman CN. Global Challenges in Radiation Oncology. *Frontiers in Oncology*. 2015; 5:5–8. [PubMed: 25688333]