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A Community-based Participatory Research Project Exploring Skin Cancer Among Native Americans as presented in Cancer Education, Research and Outreach

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A Community-based Participatory Research Project Exploring Skin Cancer Among Native Americans as presented in Cancer Education, Research and Outreach

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May 2021

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UNO Native American Studies

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HONORS PROJECT PROPOSAL

Bobbie McWilliams

Honors, Thesis/Capstone/Practicum

December 14, 2020

Under the guidance of Dr. Regina Iodate (Robbins) for my Thesis/Capstone/Practicum honors course I would like to conduct qualitative arts-based research focused on the American Indian (AI) population and the second most common type of skin cancer, squamous cell carcinoma. I will conduct semi-structured interviews with Suzanne Walsh, a member of the Osage Nation tribe of Oklahoma, who has lived with squamous cell carcinoma. I will dive deeper into the causes of and cures for skin cancer among AIs, and develop educational curricula for Native Americans who want to learn about skin cancer or those who already have skin cancer. Ultimately, I will aim to answer the following research question: Why should Native Americans be interested in preventing squamous cell carcinoma?

Squamous cell carcinoma is the second most common form of skin cancer. It's usually found on areas of the body damaged by UV rays from the sun or tanning beds. It is an uncontrolled growth of abnormal cells arising from the squamous cells in the epidermis. Squamous cell carcinoma is a fairly slow – growing skin cancer, and unlike other types of skin cancer, it can spread to the tissues, bones, and nearby lymph nodes, where it may become hard to treat. When it is caught early, it is easier to treat.

Signs of Squamous Cell Carcinoma are:

- A dome-shaped bump that looks like a wart.
- A red, scaly patch of skin that's rough and crusty and bleeds easily.
- An open sore that doesn't heal completely.
- A growth with raised edges and a lower area in the middle that might bleed or itch.

Squamous – cell skin cancer is more likely to spread to distant areas than basal cell skin cancer. In some cases of squamous-cell carcinoma, you will notice a new growth on a pre-existing scar, mole, or birth mark. Existing lesions or sores that won't heal can also be an indicator of squamous cell carcinoma.

Early detection of squamous cell carcinoma is key, because if it is not detected in its early stages the cancer can spread to other areas of the body, which included lymph nodes and organs. Once this occurs the condition can be life-threatening. This is why it is so important to teach the Native American Youth about the dangers of skin cancer, what to look out for, and how to protect themselves.

Below is what I propose to complete as products that result from this capstone/practicum

1. Develop Curriculum – I will write Suzanne’s story about living with squamous cell carcinoma in a vignette to share with students.
2. Research – I will conduct a literature review specific to skin cancer and Native Americans.
3. Painting – I will create a Portrait of Suzanne Walsh and/or a Portrait of squamous cell carcinoma. The Portraits will be 10 by 14s, and the medium will be water color and/or oil paints.
4. Research Poster – I will create a research poster with photos and pictures of the paintings that will describe how squamous cell carcinoma can affect American Indians.
5. Research Presentation – For the YES Research Forum, I will design a plan of how to present my literature review to demonstrate my knowledge of skin cancer, I will present the vignette which shares Suzanne’s story and her battle with squamous cell carcinoma and highlight my research questions and findings. I will design a poster as a teaching aid to Present to the YES (Youth Enjoy Science) program. I will present to students in Omaha Public Schools Native Indigenous Centered Education program through the YES program. I will also present my painting and poster at the YES Research Forum (See attached YES Research Forum Description), and I will answer any questions that the audience may have.

HONORS PROJECT NARRATIVE

A Brief Introduction to Skin Cancer Education

No one is immune to skin cancer. According to the American Cancer Society (www.cancer.org/skin-cancer.html.) skin cancer is the most common type of cancer. It is important to distinguish different types of skin cancer because it diagnoses effect the type of treatment received and prognosis.

The different types of skin cancer are: squamous cell cancer which starts in the top layer of the skin, basal cell cancer which starts in the lowest layer of the skin, and melanoma the most serious type of skin cancer which develops from pigment containing cells known as melanocytes. Melanocyte cells are found in the innermost layer of the epidermis, (the top layer of the skin). Basal cell and squamous cell skin cancer are found in areas of our body that are exposed to the sun. These cancers are commonly found in the head, neck, and arms, but can occur elsewhere. These are common types of skin cancer and are likely treatable.

Basal cell and squamous cell skin cancer may look:

- Flat, firm, pale or perhaps they may have yellow areas appearing as scars.
- Raised reddish patches that can itch.
- Rough or scaly patches which can crust or bleed.
- Small pink or red shiny pearly bumps that may have blue, brown or black areas.
- Pink growths with raised edges and a lower center.
- Open sores which may ooze or crust and don't heal, or may heal and come back.
- Wart-like growths.

During a doctor's exam when checking for skin cancer, a physician may ask the patient many questions to assess the situation. They may ask if the patient has noticed any spots and if so, when those spots first started showing up. They will check the patient's entire skin for any type of growths or spots. Then, the doctor will check the size, shape, color and texture and they will check to see if there have been any skin changes. If the doctor thinks that the patient may have skin cancer, a biopsy will be performed. A biopsy is performed by taking a small sample of tissue from the patient. That sample is sent to a lab to be assessed.

The biopsy sample will be graded to help the doctor determine how fast the cancer should spread and grow. Cancer cells are graded against normal cells to tell how far your cancer has spread. Grades 1, 2, and 3 are given; grade 3 means that the cancer cells are tending to grow fast. In some cases, although not very common, basal and squamous cell skin cancer can spread to the lymph nodes. Lymph nodes are bean-size sacs of immune system cells. A patient's doctor will determine if their lymph nodes should be tested.

If it is determined that a patient does have skin cancer their doctor will want to find out how far it has spread. This process is called staging. This also helps the doctor determine what treatment types are best for you. Stages determine the growth or spread of cancer throughout the skin and it can tell if the cancer had spread to other parts of the body. Cancer can be stages, 0,1,2,3, or 4; the lower the number the less the cancer had spread. Stage 4 notes a more serious cancer that has spread beyond the skin.

There are many treatments for skin cancer. These include surgery, radiation, targeted therapy, and chemotherapy. Basal cell and squamous cell cancers can be cured with surgery or various types of treatment that affect just the spot on the skin. A patient's treatment plan will be determined on the stage and grade of the cancer. A patient's age, other health issues and

problems and how they feel about the types of treatment offered will help them decide on which treatment is the best. Surgery is the main type of treatment for skin cancer and the procedure is determined by each patient's individual needs.

Radiation is a type of treatment which uses high-energy rays to help kill cancer cells. Electron beam rays are a type of radiation that is used to treat cancer where the electrons go into the skin and only treat the cells that have the skin cancer in them. Radiation can also be used to treat skin cancer that has traveled to other parts of the body. Side effects of radiation are hair loss on the part of the body where the radiation was given and fatigue.

Ways of treating skin cancer without cutting into the skin are freezing, chemo directly on the skin and therapy to kill skin cancer cells. Another treatment is chemotherapy which uses drugs to fight skin cancer. The drugs can be directly inserted into a patient's veins or can be taken as a pill. These drugs get into the blood stream and travel to all parts of the body. Chemotherapy given this way can attack cancer that had already spread to the lymph nodes and other organs. Chemotherapy can make patients feel fatigue, cause them to feel sick to their stomach, and cause their hair to fall out. The good news is that these problems vanish after treatment ends.

Target therapy drugs can be used for treating basal cell and squamous cell skin cancers. These drugs attack cancer cells while causing very little harm to normal cells. Melanoma is less common than other types of skin cancers but is more likely to grow and spread. Melanoma skin cancer starts when melanocyte cells grow out of control and crowd out normal skin cells. The cancer can sometimes travel to the bone and grow there, this is called metastasis.

Cancer is named for the place in which it starts. Whether melanoma spreads to the bone or any other place in the body it is still called melanoma and is not called bone cancer unless it

started from cells in the bone. Melanocytes are cells in the skin that produce melanin which makes the skin brown or tan. Tests can be done to see if you have melanoma. A new spot on a person's skin or a spot that is changing in shape, size or color could be a sign of melanoma. A biopsy can be done if the doctor predicts that their patient may have melanoma. A chest x-ray can also be done to see if the melanoma has spread to the lungs.

CT or CAT scans can make detailed pictures of a person's insides. This test can be given to see if lymph nodes are swollen or if organs such as the lungs or liver have spots that could have been caused by the spread of melanoma. A CT scan can be used to guide a needle into the spots to perform a biopsy. An MRI scan uses radio waves and magnets rather than x-rays to create detailed pictures of your insides. This test can show if the cancer has spread. PET scans use a special kind of sugar that shows up inside the body with a specialized camera. If cancer is found the sugar will show up certain "hot spots" and it will indicate where cancer is found. This test can also show if and where the cancer had spread.

Grading melanoma skin cancer is very much the same as in grading basal cell and squamous cell skin cancers. Grade 3 is also the fastest growing cancer. The stages of melanoma are also similar to other types of skin cancer with stage 4 meaning that a more serious cancer has spread beyond the skin. Most of the treatments for melanoma are similar to those in basal cell and squamous cell skin cancers, but immunotherapy is also an option.

Immunotherapy is a treatment that can boost the immune system or that uses a man-made version of parts of the immune system that attack melanoma cells. There are many types of immunotherapy used to treat melanoma. They are drugs given into the vein as a shot or you can take them as pills. Side effects for immunotherapy are fatigue, feeling sick to the stomach, fever, chills, and rashes. Most side effects will go away when treatment is completed.

In an article written in Indian Country Today, *Skin Cancer, No One is Immune*, (Lee H., Tanya, October 21st, 2009, <https://indiancountrymedianetwork.com/news/skin-cancer-no-one-is-immune/>), Dr. Mona Gohara a skin care expert at Yale New Haven Hospital warned that people of color need to know three important facts.

1. No one is immune to skin cancer.
2. Ethnicity does not give any protection against skin cancer **melanin** does.
3. Everyone is vulnerable, everyone should use sunscreen every day and no-one is excluded.

Skin cancer shows up more in Whites than people of color including Native Americans and Alaskan Natives, African Americans, Hispanics, and Asian Indians. The center for disease control (CDC) finds that melanoma is the deadliest form of skin care and occurs in White Americans at a rate of 25.5 per 100,000 people, and in Native Americans and Alaskan Natives at the rate of 4.6 people per 100,000. The CDC also reports that in 2005, which is the most recent study available, 50,589 Whites, 1,122 Hispanics, 261 African Americans, 159 Asian/Pacific Islanders, and 95 American Indians/Alaskan Natives in the U.S. were diagnosed with melanoma. 21 percent of American Indian/Alaskan Natives died from the disease compared to 16 percent of Whites. There is a significantly higher percentage of American Indians/Alaskan Natives than Whites who have died from skin cancer.

Melanin exists in human skin and in a few other organs. Melanin predicts skin color and a person who has lots of melanin has dark skin. Melanin can offer some protection from U.V. radiation that causes skin cancer therefore darker skinned people get skin cancer at a lower rate than light skinned people. The degree of protection that the melanin provides is dependent on

how much melanin a person has. A lighter skinned Native American is just as much at risk for getting skin cancer as a White person is.

Morbidity rates depend on many factors other than just skin tone and ethnicity and other socioeconomic factors. Much of it depends on how much access Native Americans have to health care compared to Whites. People who are without access to regular medical care are more vulnerable to skin cancer than others. The morbidity rate among American Indian/Alaskan Natives is much higher than that of Whites, due to late diagnosis and treatment being irregular or not at all. Health screenings and both doctors and patients not being aware of skin cancer and/or not looking for symptoms of the disease factor in as well.

Everyone should wear sunscreen and protect themselves from the sun every day. Squamous Cell Carcinoma is linked to sun exposure in lighter skinned people. People with darker skin tend to have other kinds of damage caused by the sun such as scarring, chronic inflammation, discoid lupus, lesions and skin ulcerations that don't heal. Skin cancer that relates to these factors is more aggressive than those caused by direct sunlight. Melanoma which is the deadliest form of skin cancer in people of color is most likely to appear in the mouth, the palms of the hands, the soles of the feet, and under the nails.

Other risk factors for melanoma in minorities include albinism, burn scars, symptoms caused by radiation therapy, trauma, immunosuppression and preexisting moles, on the palms, soles of the feet or the mouth. According to an article written on *A Comparison of Quality of Life Between Native and Non-Native Cancer Survivors*, written by Linda Burhansstipanov in the *Journal of Cancer Education* (2012), the cancer burden continues to escalate among Natives. This burden includes multiple ways in which cancer impacts the entire family. There can be a loss of income as patients themselves may not be able to maintain a job. Other family members

have to give up their own life and dreams to serve as a caregiver to the patient. There are increased demands, which include the time and money spent for transportation to and from the cancer care facility, and depending on the family there are also child care expenses.

In an article written by Wendy Gifford named *Spirituality in Cancer Survivorship with First Nations People in Canada in Supportive Care in Cancer* (2019), researchers found that health-related recovery was significantly correlated to socioeconomic status. A higher socioeconomic status related to a higher quality of life and socioeconomic played a significant role in a person's life which impacts a cancer patient's ability to return to a normal life following the completion or treatment. For Native Americans, their quality of life was associated with their socioeconomic status and sociologic stress was one of the most important influencing factors.

The concept of cancer diagnosis within Native American communities is met with feeling of fatalism, fear, anxiety, and depression by most patients. The concept of fatalism is not superstition, but was based on the realities that many Natives saw in their family or their neighbors diagnosed with cancer pass away from the disease.

In the 1980s, and the first half of the 1990s, cancer as a word, much less a diagnoses, was rarely spoken about amongst Native American Communities, and avoidance of such a word was extended to spouses, and the children of the person with cancer. There are still some Native tribes that will not utter the word cancer but today such avoidance is no longer the norm. Today many cancer survivors (such as Suzanne) receive proactive support from their communities and few are ostracized as they were in the past. With programs like the YES and other outreach programs, there is a much more hopeful outcome for most Native American skin cancer patients.

Native American cultures, although very diverse, are strongly intertwined with spirituality of all living and non-living structures. This core of spirituality is why Native

American patients were inclined to report that there was no spiritual change in their quality of life following their diagnoses with cancer. The importance of spiritual activities was much higher in Native American than in Non Native American people. Native American patients are more hopeful, and reportedly have a stronger sense of a life purpose.

Spirituality, religion, and personal beliefs are relevant to health related and health care assessments. The inclusion of spirituality allows for a more holistic assessment and improves the case for a biopsychosocial-spiritual model of health. Long-term cancer survivors have frequently reported that cancer either positively or negatively influenced their lives, but others felt that the cancer had little long-term impact on their lives. Those that expressed negative feelings reported pain, physical deformities and social isolation.

According to an article written in the University of Cincinnati Science Daily, *Skin Cancer Rare – But More Deadly – In People with Darker Skin*” (27 July 2006), Native Americans were more likely to not answer spirituality questions, then they were to answer questions about physical, social, or mental and emotional items, primarily due to retaining the privacy of spiritual beliefs, and to avoid others from misusing Native spiritual practices. Tribal nations prohibit the sharing of spiritual information because of the abuse or misleading information shared in publication and elsewhere.

Many cancer survivors (including Suzanne) have viewed their skin cancer as an opportunity for emotional and spiritual growth that had enabled healing. Understanding the role of spirituality in cancer survivorship is so important in developing and delivering culturally safe health services that reduce the burden of cancer and ultimately improve cancer outreach and the facilities that Native American can go to for help with skin cancer diagnoses and skin cancer treatments. Advancements in cancer survivorship care have shown that holistic approaches

tailored to peoples with unique survivorship needs, can decrease the cancer burden and enhance the well-being and quality of life. The meaning of spirituality in Native American skin cancer survivors helped them become more interconnected with their self and with traditional roots & culture; they were able to merge thoughts and understanding through their body and their mind and gained the meaning of strength and faith throughout their cancer journey. They gave thanks and attended places of spiritual connectedness and enjoyed singing, praying, speaking to their creator and engaging with the sun and moon.

Findings, from the University of Cincinnati research study, showed that dark-skinned people commonly thought to be “immune” to most skin cancers - are more likely to die from skin cancer and its related complications. Researchers acknowledge that Native Americans develop fewer non-melanoma skins cancers compared with whites, but when the skin cancer does occur, it is typically more aggressive and most likely to have been diagnosed in its later stages, which leads to a disproportionately large number of deaths among Native Americans due to undiagnosed skin cancer issues. As the article states, “There’s a perception that people with darker skin don’t have to worry about skin cancer, but that is not true. Native Americans do get skin cancer, and because of this false perception most cases aren’t diagnosed until they are more advanced and more difficult to treat.”

Dark skinned people produce more melanin in the skin, and are suspect to severe “burn” and (UV) damage. Dark skin has increased epidermal melanin which provides a natural skin protection factor (SPF) of more than 13 in dark skinned individuals, and filters twice as much (UV) radiation as white skinned individuals, which has less melanin. Darker skinned individuals were 8.5 times more likely to develop squamous cell carcinoma which occurs in the upper layers of the skin and is the second most common type of skin cancer. Squamous skin cancer can occur

in areas of the body which are commonly protected from the sun which are the palms of the hands, feet and toes and mucous membranes. Squamous cell carcinoma can also develop on areas that are regularly exposed to the sun such as the nose, ears and the backs of the hands and the top part of the feet.

Physicians must teach behavior modifications such as the regular use of sunscreen, they must teach the importance of self-skin checks and utilize ways in which patients can obtain these, and they must teach patient how to recognize changes in their skin such as moles and changes in skin textures. Dermatologists are seeing an increasing number of skin cancer cases in women who are under the age of 30. This is because of the use of tanning beds and from the lack of the use of sunscreen and covering up while in the sun. Scholars argue that “we need to increase Public awareness of skin cancer among Native Americans if we are going to decrease skin cancer-related deaths. Prevention is key to fighting this disease.”

In the article *The Importance of Recognition of the Skin Cancer Risk of Native Americans: A Call to Action*, in *SKIN The Journal of Cutaneous Medicine* (2021), scholars note that Native American people are more likely to face lower survival rates from skin cancer and are more likely to be diagnosed in a later stage of skin cancer. Efforts to combat this reality have largely been focused on Asian, Hispanic, and African American patients; Native Americans have been unfortunately excluded from these studies. We need to raise awareness for Native Americans to be included in future skin cancer studies, so their skin cancer knowledge and risk can be better understood.

The term “skin of color” was created to be all-inclusive for those of ethnic origin who share similar characteristics and diseases related to skin pigmentation and scarring. Most skin of color articles related to skin cancer focus solely on African Americans, Hispanic, and Asian

populations. Native Americans are consistently excluded from these studies, as a result, details such as skin cancer knowledge, perceived risks, sunscreen use, and behavioral practices that are well known for other ethnicities are relatively unknown for Native Americans. Without this inclusion even the most basic information regarding Native Americans becomes difficult to ascertain.

Native Americans are an important United States demographic. An estimated 5.2 million Americans trace their heritage to Native American roots and the population is growing. It becomes increasingly important that dermatologists become more aware of the skin related needs of Native peoples. Native Americans have a lower 5 – year survival rate which is 69.8% versus 91% among Caucasians. This may be due to a lower order of suspicion among Native Americans leading to a delay in diagnosis which is particularly worrisome because current data suggest that the incidence of skin cancer is continually rising in Native Americans. The diagnoses for skin cancer in Native Americans is one of the lowest diagnostic age out of all of the races.

It is vital that Native Americans become aware of their skin cancer risks, that they use preventative measures such as sunscreen and extra clothing while out in the sun, that they are aware of early diagnoses, and that they are included in educational interventions to reduce their risk of skin cancer.

Education is the primary method for increasing skin cancer knowledge among ethnic groups. Research is also key. More data needs to be collected from Native Americans to assess the knowledge gaps related to skin cancer patients and providers. For this reason, we need more programs like the YES cancer research program to teach cancer education and promote prevention, treatment and research to help reduce the burden of skin cancer in Native Americans.

STUDY DATA

Supplemental Interview With Suzanne

Bobbie Leesley (McWilliams) - Interviewer

YES, Program Typed Interview #8

Suzanne Walsh – Interviewee

Dr. Regina Iodate (Robbins)

April 7th, 2021 – Telephone Interview

Bobbie – Good morning Suzanne, how are you today?

Suzanne – I’m just fine thank you Bobbie, how are you doing?

Bobbie – I’m doing good, I guess because of the circumstances it just didn’t work out to do the recording in Kansas City so today were doing the recording over the telephone, um and it’s just so great to talk to you Suzanne.

Suzanne – Thank you Bobbie, it’s great to talk to you too!

Bobbie – Today is April the 7th, 2021, and I would like to ask you Suzanne, do I have your permission to tape you today, to record you?

Suzanne – Absolutely, absolutely, Bobbie

Bobbie – Thank you so very much, Suzanne I just want to thank you for your contribution to the YES program, and to the honors program on my behalf. You have helped so many YES youth members and Native American students to realize through your story the dangers associated with getting skin cancer, and some of the ways of acknowledging what skin cancer looks like, and

how you can prevent it. I am now in my Honors, Thesis, Practicum class at the University of Nebraska at Omaha, and I feel as though we have come full circle with the Suzanne Story. The research started four years ago, in March of 2017 with an honors class which revolved around your shared story with skin cancer that you have had, and since then I have been working for the YES program, and telling the youth about your story. We want to thank you for all of your knowledge about skin cancer Suzanne, and for sharing it with us and with the YES program. We also wanted to thank you for your contributions, and your interviews that were published in the June 2020 issue of the Suzanne Story in the American Cancer Society Journal of Ethics. Thank you for everything Suzanne.

Suzanne - Well thank you and I have enjoyed it! Every bit of it, thank you so much for interviewing me!

Bobbie – Oh Suzanne, we appreciate you, we want to thank you, you were an endless amount of help, you don't know how much you have helped the youth, and helped them realize that they have to protect themselves, wear sunscreen, and make sure that they are covered when they go out in the sun. A lot of the research was based upon specifically Native Americans, and a lot of them think that they can't even get skin cancer because their skin is already dark and that is just not true because they can get skin cancer just as much as any body can.

Suzanne – Your right about that, anybody can get skin cancer.

Bobbie – Yes, so Suzanne can you please tell us a little bit about the cancers that you have had in the past?

Suzanne – Well, I have had a lot of cancer in the past, all three kinds, basal cell, squamous cell and melanoma, and not too long ago I had a squamous cancer on my foot. The doctor took what he thought all of it out and it wouldn't heal, and it wouldn't heal, and then I went back to the

doctor and he hadn't gotten of the cancer so and they had to redo my foot, and it was very, very painful, and you wouldn't think that cancer would be on the top of your foot, but it was with me, and it was painful, and they finally got finished with that, and now my foot is still healing, and it still looks a little bit black and blue from all of the trauma that it has had. So I'm pretty cured now from my foot, so I am very happy about it!

Bobbie – Oh, I'm happy about it too! How would you say that having the squamous skin cancer in your foot was different than some of your other skin cancers that you have had?

Suzanne – Evidently it was very deep, and that was probably the reason that they didn't get it all the first time, so when the doctor finally got it all, I was very happy about it. I guess that in a spot like that on the top of your foot, and all of the veins you have there, just seem to hurt a lot more than other places.

Bobbie – Sorry to hear that Suzanne, that's awful, and that was kind of what brought me to the next question that I was going to ask you which was did you find the healing process of having that squamous on the top of your foot kind of different this time? Was it harder to heal? Did it not heal fast? Was it harder to walk on? What kind of things did you experience with it?

Suzanne – It was hard to walk for a while, and I think that was I was experiencing was the lower you get in your body from your heart, the longer it takes to heal. It just took so long to heal that I just couldn't believe it, it was months before it was completely healed, and I had to go back and they finally got all of it.

Bobbie – You did have to go twice didn't you, and the first time was very painful, and then you had to go back again?

Suzanne – Yes I did, yes because it wouldn't heal, wouldn't heal, and they had to do it all over again and take more cancer out.

Bobbie – Oh my gosh, um how do think having the squamous cell carcinoma has affected you in your life? The things that you like to do and everything.

Suzanne – Well, it was quite a while before I could where the shoes that I wanted to wear, I couldn't walk and I couldn't wear shoes and sox, it wasn't good for what I would like to wear. Everything was just too hard on it, it was too sore, for too long, so everything was harder.

Bobbie – Oh yes, and I remember seeing you in August when you had the bandage on at my son's wedding and I remember you having a rather hard time with your foot, and a hard time getting around on it.

Suzanne – Yes I did, I really did. It was very hard so I would say if the children go out in the sun, or any body that goes out in the sun to be sure and put sunscreen on all over, even on your feet. Because you wouldn't think so, but that's where it was with me, its been a lot of places with me but I would say that the top of my foot is where it burned the hardest.

Bobbie – Yes, and that's interesting because I read a lot of articles about skin cancer and a lot of people even get skin cancer underneath their feet, and so for you to have skin cancer right on the top of your feet, the sun must of really beat down on your feet during your life, may be with your diving.

Suzanne – May be so, I think that you are probably right, I think that that's what happened.

Bobbie – Oh my goodness! Which foot is in, in the right or the left one?

Suzanne – The right.

Bobbie – The right one.

Suzanne – It took a while to heal, and it just affected my life.

Bobbie – Oh Suzanne, I am so sorry to hear that.

Suzanne – Thank you, Bobbie

Bobbie – Suzanne, as a Native American woman what would you like to tell other Native Americans about your experiences that you have had with skin cancer in general.

Suzanne – Well in general I would like to tell them that they can get skin cancer, and they don't think that they would because they have darker skin and actually they don't get as burned as most people do, so they don't even realize that they can get skin cancer. My advice to them is to be careful out in the sun and to use the lotion on top of their feet, and all over, especially their shoulders and face, and your cheeks, and be careful while your out there.

Bobbie – Well, I know that all the interviews that I have conducted with you, this is actually the eighth interview now, and you've always told them and taught the youth to be careful about their skin, and to where lotion. We did a lot of experiments with the Youth at the science fare, and we conducted experiments with the kids and everything, and they learned how the sun could get through lotion, and it could get through cloths, but especially bare skin. Through the experiments they learned how the sun really is and how it can negatively effect their skin.

Suzanne – Yes, it certainly does!

Bobbie – Yes, it does!

Suzanne – But it is also a lot of fun to be out in the sun! I wouldn't say to not go out it the sun. I would say go out there and cover up, and have fun!

Bobbie – Yes, and then this is the last question that I have for you, but what would you tell your peers about growing up in the sun and experiencing what you have been through it in your life.

What would you tell your peers about how you grew up in the sun and what you experienced?

Suzanne – Well, I would tell them to be out in the sun and the air and the water because it's wonderful, absolutely wonderful, you couldn't have more fun in your life then being outside and having a good time! I would also tell them that if they burn easily, and even if they're Native

American they could possibly burn, and that should cover their shoulders and their chins, and their cheeks, and well now, their feet too!

Bobbie – Absolutely, absolutely! The research that I am working on now is somewhat specifically going towards squamous skin cancer, which that's a little more dangerous than the pre-skin cancers that you have had. So I am learning a lot about it and doing a lot of research so is there anything else that you can add about the squamous skin cancer?

Suzanne – Well, that kind of skin cancer can be very, very painful, and then not only painful but it forms a crust, wherever it is. The crusty thing is hard and if you touch it, it hurts. It won't really come out, if you have it, you really have to get it taken out by a dermatologist, you should go if you have squamous skin cancer, and you will know that it is squamous because it will hurt a little when you touch it.

Bobbie – Thank you for sharing that because that is so important that the youth check that, and check their whole body to see if there is any unusual raising or raising of the skin, or irritation or discoloration or any of that, especially if they touch it and its painful that means that they need to get to a dermatologist right away.

Suzanne – You're certainly right, Bobbie, you're certainly right!

Bobbie – You know no matter how hard it is for them to get to a dermatologist they must go.

Suzanne – They should absolutely go.

Bobbie – O.K., well Suzanne we just want to thank you a million times, thank you again, you've been wonderful in sharing your story, and I'm sure that it has gone a long, long way, and so many youths have learned from this, and I have experienced this myself, because I have sat with the Native American Youth. We have spoken about it and they have said that they have learned from the Suzanne Story and that they are going to take care of their skins. I've shared your story

with a lot of people, and you have helped a lot of people through your story and we want to thank you.

Suzanne – Well thank you Bobbie, thank you, and I am very happy about it. Thank you so much!

Bobbie – Thank you Suzanne, and you have a wonderful day!

Suzanne – Oh, you too, you too!

Bobbie – O.k., good-bye now.

Suzanne – Bye-bye.

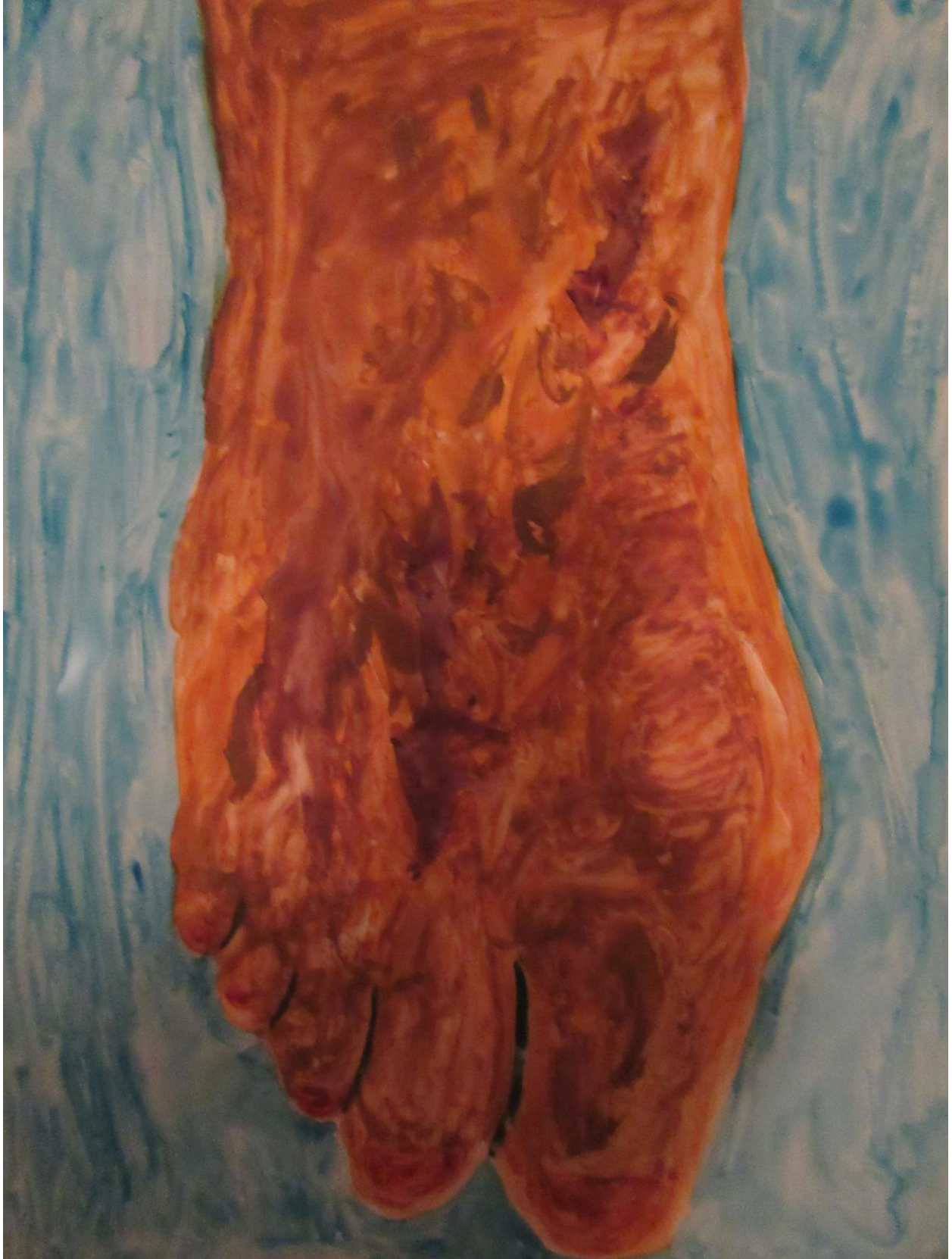
Portraits of Suzanne











Photographs of Suzanne









ABSTRACT FOR INTERNATIONAL CANCER EDUCATION CONFERENCE

A Community Academic Partnership's Evaluation of Art Exhibitions to Increase Community Readiness to Address Cancer in an Urban American Indian Northern Plains Community

Background: American Indians in the Indian Health Service Northern Plains region experience higher death rates for multiple cancers compared to American Indians in other regions. One community in this region participated in a community readiness assessment that found a low level of readiness to address cancer and little knowledge about community efforts and resources to address cancer. We evaluate this community's strategic approach to share visuals and stories that present information about cancer to improve readiness. **Description:** We describe a unique partnership between a cancer research education program, a university library, a public school's Title VI Indian Education program, and local artists that facilitated co-curation of four public art exhibitions that promoted awareness of community resources and efforts to address cancer in this American Indian community. Field notes, observations and surveys associated with these exhibitions were triangulated to evaluate how the arts can be employed to promote community readiness to address cancer. **Evaluation:** Four art exhibitions, *Portraits of Care*, *Buckskin Buddies*, *Suzanne's Story* and *The Body and Mind of Cancer*, engaged students, educators and local community in cancer education. The arts provided culturally relevant ways to weave western and traditional beliefs and values together to address cancer at different points across the cancer control continuum. Creating and exhibiting art proved to be an effective strategy to develop community-academic partnerships and increase knowledge of resources and awareness of efforts to address cancer in this Urban American Indian Northern Plains community. **Impact:**

Community-academic partnerships that employ culturally relevant approaches to share cancer information have potential to improve community readiness to address cancer in diverse communities. Engaging community in the creation and exhibition is a promising practice for raising urban American Indian communities' knowledge of cancer and awareness of cancer resources and efforts.

SUZANNE'S STORY

Bobbie McWilliams
University of Nebraska at Omaha, Omaha, NE
Regina Robbins, PhD, University of Nebraska Medical Center

ABSTRACT



Suzanne Walsh, a member of the Osage Nation who resides in Tulsa, OK, was first diagnosed with skin cancer in her 50's; Suzanne was interviewed to chronicle her reflections on living with cancer from a holistic perspective and shared her story both verbally and visually, collaborating with YES! scholar artist/researcher to create a series of photographs, drawings and paintings that present a visual narrative. Interview transcriptions and images collected were analyzed to explore the lived experience of cancer and to gather data that can contribute to cancer education within the Native American population.

VISUAL DATA



The social sciences have taken a 'narrative' and 'visual' turn from recognizing images as merely illustrations to seeing images as 'texts' that can be read, studied and interpreted in innumerable ways.

PRELIMINARY FINDINGS

"I love the sun, and I'm a swimmer and I trained for diving for the Olympics and I was in the sun all of my life."

"I have had pre-skin cancer, basal cell carcinoma, squamous cell carcinoma, which is second stage skin cancer, it appears white and crusty (figure 1) and melanoma on my arms, (figure 2)."

"I go to the doctor quite often."



Figure 1

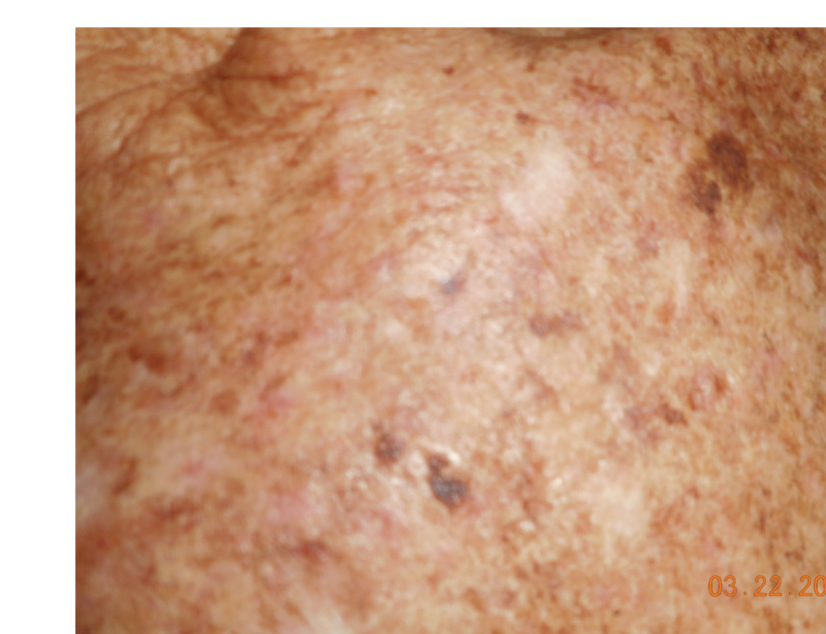
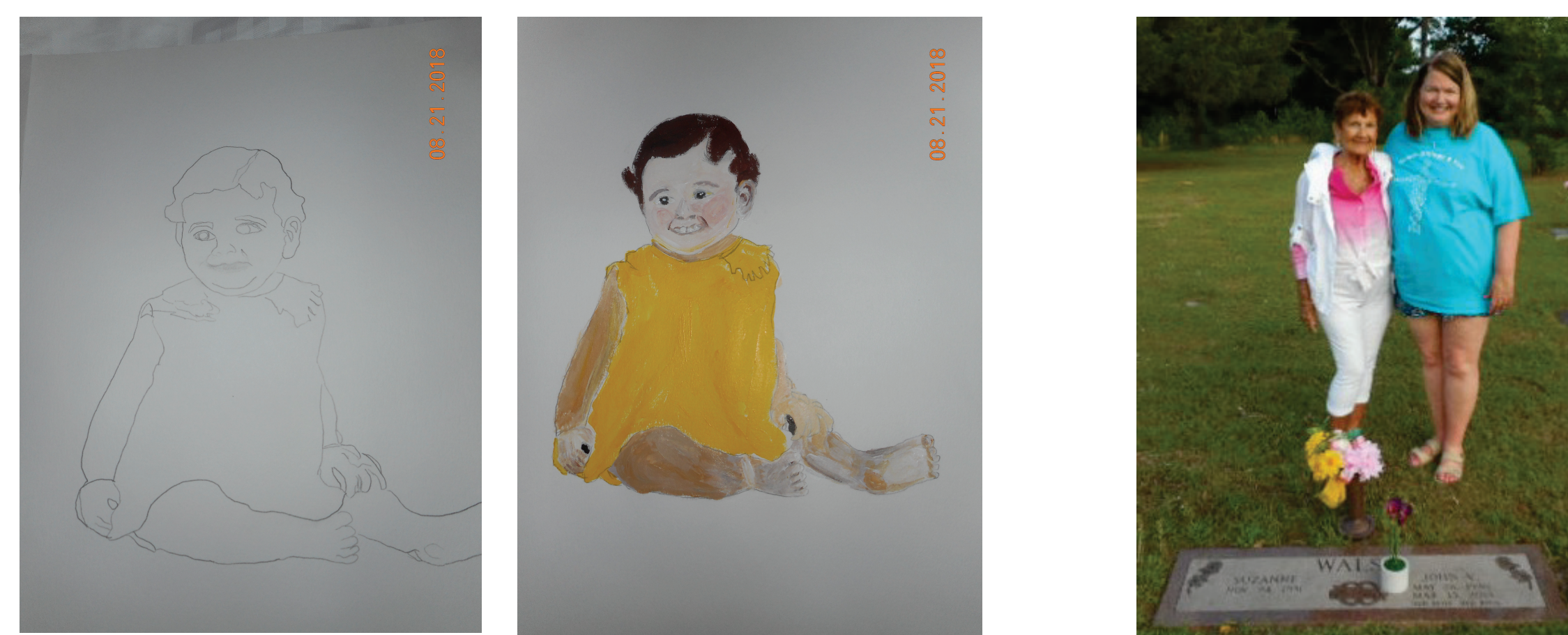


Figure 2

INTRODUCTION



This case study used art-based research methods to qualitatively examine drawings of Suzanne Walsh along with the associated transcripts from interviews she conducted about her lived experience of cancer. This data was analyzed to explore reflections on life with cancer and to contribute toward cancer education.

5 Drawings

YES! scholar and artist/researcher Bobbie McWilliams carried out a series of drawings, *Images of Suzanne*, that depict Suzanne in everyday life, living with skin cancer and sharing her story.

5 Interviews

YES! scholar artist/researcher Bobbie McWilliams recorded 5 interviews conducted to complement *Images of Suzanne* and chronicle her story in visual form.

"I feel like I survived very well the cancer that I've had."
– Suzanne Walsh, Skin Cancer Survivor

VISUAL & VERBAL DATA



"I was in the sun from the time I was six months old.... I loved to swim and I loved to be outdoors I don't remember any suntan lotion....we used baby oil and iodine and we would actually almost fry in the sun, but that's how much we loved it!"



"They may not notice right away, but normally I can notice it myself, the melanoma was a black spot, extremely shiny, and very small, like a pencil head, and it just didn't look right, so I told the doctor, I said, 'what is this?' He said, 'We have to get that diagnosed' so that's when they found the melanoma."

"I've been very fortunate, extremely fortunate!"
– Suzanne Walsh, Skin Cancer Survivor

FUTURE DIRECTIONS

Cancer is so often considered fatal and Suzanne's story can serve as a testament to life with cancer. When we are confronted with images depicting illness, suffering and care we are invited to consider what we embrace and what we resist in ways that can transform our understandings of cancer into something educational and possibly even inspiring. As Suzanne explained, "we try not to talk about illness when we're together, we just want to have a good time." These images along with Suzanne's story in written form can serve to open up dialogue around this topic and promote greater understanding of cancer by engaging public and academic audiences in stories that can inform those who are facing cancer as patients, caregivers, educators and scholars. Dr. Mona Gohara, a skin care expert at Yale New Haven Hospital, warns that people of color need to know three important facts.

1. No one is immune to skin cancer.
2. Ethnicity does not give any protection against skin cancer melanin does.
3. Everyone is vulnerable, everyone should use sunscreen every day and no-one is excluded.

REFERENCES

- Hodge, D. R., Limb, G. E., & Cross, T. L. (2009). Moving from colonization toward balance and harmony: A Native American perspective on wellness. *Social Work, 54*(3), 211-219.
- Lee, T. H. (2009, Oct 21). Skin cancer: No one is immune. Retrieved from <https://newsmaven.io/indiancountrytoday/archive/skin-cancer-no-one-is-immune-6QE1PJHGyU2wb2Wz9QCKBQ/?full=1>.

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PERSONAL NARRATIVE

Portraits of Suzanne, an Osage Woman's Story of Loving the Sun and Living With Skin Cancer

Bobbie McWilliams and Regina Idoate, PhD

Abstract

Suzanne, an elder of The Osage Nation, has been diagnosed with basal cell carcinoma, squamous cell carcinoma, and melanoma skin cancer. Her daughter, Bobbie, a cancer researcher working for the Youth Enjoy Science Research Education Program, conducted a case study to share Suzanne's story through written narrative and a series of images that present Suzanne's reflections on cancer prevention and treatment from a holistic perspective. Seven interview transcripts, as well as photographs, drawings, and paintings of Suzanne, were created and analyzed to explore Suzanne's lived experience of cancer. In her story of living with cancer, Suzanne shares an elder's love and wisdom that can inform cancer education and prevention efforts to help address Native American cancer disparities.

Native Americans Do Get Skin Cancer

Nearly 1 of 10 Native Americans (NAs) believe that Native peoples do not develop skin cancer, and nearly 9 of 10 have been sunburned at least once.¹ Melanoma skin cancer among NAs is less common than among whites²; however, only 1 of 10 NAs report using sunscreen regularly on their bodies,¹ and skin cancer among NAs often goes underdiagnosed until more advanced stages.² NAs' perceptions of their low risk of skin cancer, coupled with limited access to health care services, could contribute to the finding that, historically, NAs have made significantly fewer office visits to a dermatologist than whites.³ Scholars and practitioners recommend increasing public awareness and public health education and improving **screening and early detection** to prevent cancer.⁴ In an effort to raise the NA index of suspicion and increase efforts to prevent skin cancer among NAs, we share Suzanne's story through written narrative and portraits as a case study exploring one NA woman's lived experience of skin cancer.

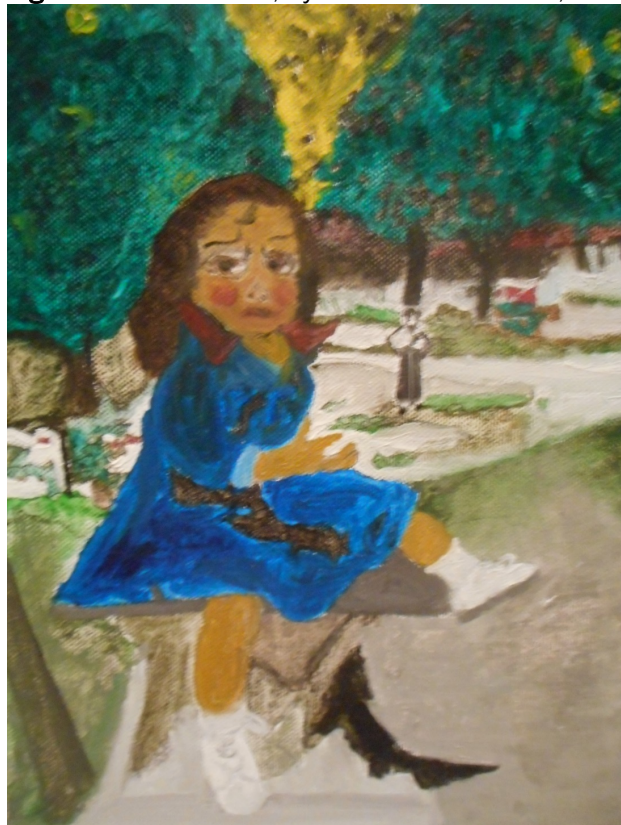
Suzanne, an elder of The Osage Nation who resides in Tulsa, Oklahoma, has spent the majority of her life outdoors, in the water and under the sun. Suzanne grew up in the Great Plains near the Osage ancestral lands, surrounded by rivers and lakes. She loved to swim and embodied the Osage sacred name "children of the middle waters." Suzanne's daughter, Bobbie McWilliams, citizen of The Osage Nation, an undergraduate fine arts major/Native American studies minor and a Youth Enjoy

Science (YES!) Research Education Program cancer research intern at the University of Nebraska Medical Center, and Regina Idoate, citizen of the Cherokee Nation of Oklahoma, conducted a case study to share Suzanne's story through written narrative and a series of images that can promote awareness of and reflection on cancer prevention and treatment from a holistic perspective. This article shares Suzanne's story, both verbally and visually, as analyzed through arts-based narrative inquiry. Bobbie conducted and transcribed 7 interviews and created several drawings and 5 portrait paintings of Suzanne that were qualitatively analyzed by the authors of this manuscript to share her story as an aesthetic whole.

Suzanne's Story

Suzanne tells stories of being exposed to the sun even as a baby: "My mother had me in a buggy and ... my legs would turn black, just black." Growing up, Suzanne had a special relationship with the sun. She loved to swim and loved to be outdoors. Bobbie illustrated Suzanne's description of her childhood in a portrait that reflects her youthful unprotected exposure to the sun (See Figure 1). She swam outdoors so much as a child that she recalls wearing out the bottom of her bathing suit. When Suzanne was a teenager, she and her friends, wanting to be tan, "used baby oil and iodine and ... would actually almost fry in the sun." In college, too, Suzanne regularly sunbathed and spent hours in the pool performing synchronized swimming routines with her sisters. Suzanne says that, throughout her youth, she was never told to wear sunscreen and doesn't recall being aware that sunscreen lotion even existed. She's convinced that her family, teachers, and health care professionals didn't even know about skin cancer.

Figure 1. *Curious Sue*, by Bobbie McWilliams, 2018



© 2020 B. McWilliams.

Media

Acrylic on canvas.

As a child, Suzanne does not remember ever thinking about protecting her skin from sun exposure. Although her mother's understanding of life and nature recognized dangers of the sun—and if her mother “happened to be in the sun, she'd have a great big hat on her head to cover up”—Suzanne never thought about the possibility of developing skin cancer. She spent most of her youth at the pool, training to be in the Olympics for diving, working as a lifeguard, and teaching swimming and lifesaving to both elders in her community and children at orphanages. She remembers “just like it was yesterday” teaching swim strokes under the sun on a grassy hill beside the pool.

After marrying and growing a family, Suzanne taught all 9 of her children how to swim and took them to the pool all summer long, every year. She describes swimming with her kids and living life at the pool as “a lot of fun!” Suzanne continued lifeguarding well into her 50s and is still swimming today.

In the summer of 1988, at age 56, Suzanne was diagnosed with skin cancer. She states, “It's just something that I got.” She explains, “I went to a skin doctor because I had different things on my arms and legs.” The doctor, however, found something on her back. Suzanne was shocked and “didn't know what it was.” She vividly recounts the doctor saying, “you have skin cancer.” She “was just flabbergasted, and ... just couldn't believe it!” Suzanne's first thought was that she would no longer be able to swim or be in the sun. She is happy to say, however, that she still visits the pool regularly and enjoys the sun in small amounts, wearing clothes, hats, and sunscreen to reduce her risk of skin cancer. She also visits the dermatologist regularly for screening.

Suzanne has had as many as 33 precancerous spots on her face and body treated and, according to her, she has been diagnosed with “every kind of skin cancer possible.” She calculates that, for her, “the cancer usually grows an inch apart from one another.” She describes a precancerous lesion as “a skin lesion that's formed before cancer.” She explains that screening is important because “the skin doctors can tell that it's a precancer ... and they treat them so they won't turn into cancer.” She has been diagnosed with basal cell carcinoma, which she describes as “more of a topical skin cancer,” squamous cell carcinoma, which she says “forms kind of a crust on your body,” and **melanoma**, which she refers to as “the bad one.” In Suzanne's words, “basal cell skin cancer is ... on top of your skin and it normally bleeds, and it is usually scraped off or burned off, preferably, rather than having it cut out.” She describes how basal cell carcinoma “won't stop bleeding until you have something done about it.” She says that squamous cell carcinoma “forms a very crusty top, and it's a bit painful, if you touch it ... and they have to get that out because that could spread, and get bigger and bigger, the crust part on top.” She warns, “what's ever on top of your skin is also underneath, so you have to be careful with that and be sure that you have it taken out.”

The type of skin cancer that Suzanne fears the most is the one she calls “the bad one,” melanoma. She learned from her dermatologist that melanoma “could spread through your entire body.” Suzanne describes noticing the melanoma on her body as “one very black spot.” She says, “it was extremely shiny, and very small, like a pencil head, and it just didn't look right.” The Skin Cancer Foundation urges people to examine their skin from head to toe on a monthly basis.⁵ Suzanne saved her own life by doing just that,

noticing the melanoma on her body and going to the doctor to ask, “What is this?” Suzanne says “I thought it might travel and I wouldn’t be alive today. I had to go to the hospital and they had to cut it out, I guess they did a good job because there’s only a dent in my arm from where they cut—that’s all, it’s fine.”

When discussing her experience with melanoma, she says, “I was glad that it hadn’t spread any further than my arm, very glad.... I’ve been very fortunate praying, and I have been very fortunate with cancer that it hasn’t gone any further.” Her joy, contentment, and gratitude are evident in her smile, her bare and relaxed arms, and the YES! t-shirt that she proudly wears in *Smiling Sue* (See Figure 2). At age 84, Suzanne lost her beloved husband, John, in 2015, but she still enjoys precious time with her 9 wonderful children and loves to make time for friends: “We try not to talk about illness when we’re together, we just want to have a good time.” She asserts, “I’m very happy that I’m able to do the things I like to do.... I feel like I survived very well the cancer that I’ve had, and I’m still getting it, and hopefully it won’t be the bad one.”

Figure 2. *Smiling Sue*, by Bobbie McWilliams, 2019



© 2020 B. McWilliams.

Media
Oil on canvas.

If you talk to Suzanne, she will tell you, “I still love the sun!” Observing the portraits, a viewer might notice not only Suzanne’s love for the sun but also her gratitude to be alive to share her story. Reflecting on one of her own portraits, Suzanne states, “It shows how my skin really is ... and I don’t think that my skin looks very good, and the truth is that it shows in the portrait what it really is!” (See Figure 2). She admits, “I know that I have a lot of skin cancer, my whole body is full of skin cancer.” Suzanne has new cancers and spots forming all the time. Every time she goes to the dermatologist, more cancers are removed. Suzanne affirms that “to survive all this, I’ve been very fortunate, extremely fortunate.... There are many people who have had cancer way worse.” In fact, she adds, “My sister had melanoma in her leg and it just wouldn’t heal, they tried and tried, and then it got infected and then it got worse, it was a contributing factor to her death at age 86 years old.” Ultimately, she says, “I hope others don’t get it” and “if it [Suzanne’s portraits and story] could help just one child or one person to be careful in the sun, it would be all worth it!” Suzanne is very proud of the cancer research and prevention work that her daughter, Bobbie, is doing with the YES! program, noting, “I feel very good about sharing my story, very good about it.” Suzanne wants to tell the youth “not to go to tanning beds and to be very careful.” She emphasizes, “I would like them to know that they should go out and have a good time, stay healthy, and be happy, but wear some sunscreen or a shirt or something over their skin so that they won’t get the skin cancer that I have had.”

Learning From Suzanne’s Story

Suzanne’s story can help promote cancer awareness, prevention, and control within Bobbie’s local urban NA community in the Northern Plains region of the Indian Health Service, as cancer is a leading cause of premature death among NAs, and NAs experience severe **health disparities** specific to cancer.⁶ Bobbie presented Suzanne’s story as a case study in a research poster at the 2019 Nebraska Science Festival in Omaha, Nebraska⁷; at the 2018 American Indian Health Research Conference in Grand Forks, North Dakota⁸; and at both the 2018 and 2019 Cancer Biology and You (CBY) workshop for NA students in South Sioux City, Nebraska.^{9,10,11} Participants in the 2019 CBY workshop reported that viewing and discussing the portraits of Suzanne was their favorite activity at the event. In this activity, the authors asked students entry-point questions to encourage them to observe and reflect on the portraits of Suzanne.¹² This approach can open up a dialogue around cancer, a topic often considered taboo in NA populations.¹³ Bobbie stresses that anyone can get skin cancer, even a citizen from The Osage Nation with a dark complexion. Suzanne reaffirms this fact, noting, “I do look very Indian, and I don’t think there’s a whole lot of us that really do have skin cancer, but I certainly do.”

CBY participants said that, in viewing Suzanne’s portraits, they hear Suzanne saying, “protect yourself,” and they see “joy” and an encouraging message to enjoy life and “live long” in her image. Wrapped in a quilt, Suzanne embodies a powerful message, reminding us all to cover up and protect our skin (see Figure 3).

Figure 3. *Suzanne's Wisdom*, by Bobbie McWilliams, 2019



© 2020 B. McWilliams.

Media

Oil on canvas.

References

1. Maarouf M, Zullo SW, DeCapite T, Shi VY. Skin cancer epidemiology and sun protection behaviors among Native Americans. *J Drugs Dermatol*. 2019;18(5):420-423.
2. Kryatova MS, Okoye GA. Dermatology in the North American Indian/Alaska Native population. *Int J Dermatol*. 2016;55(2):125-134.

3. Fleischer AB Jr, Feldman SR, Bradham DD. Office-based physician services provided by dermatologists in the United States in 1990. *J Invest Dermatol*. 1994;102(1):93-97.
4. Warne D, Kaur J, Perdue D. American Indian/Alaska Native cancer policy: systemic approaches to reducing cancer disparities. *J Cancer Educ*. 2012;27(1)(suppl):S18-S23.
5. Skin Cancer Foundation. Self-exams save lives: early detection starts with you. <https://www.skincancer.org/early-detection/self-exams/>. Accessed November 26, 2019.
6. White MC, Espey DK, Swan J, Wiggins CL, Ehemann C, Kaur JS. Disparities in cancer mortality and incidence among American Indians and Alaska Natives in the United States. *Am J Public Health*. 2014;104(suppl 3):S377-S387.
7. McWilliams B, Robbins R. Suzanne's story. Poster presented at: Nebraska Science Festival; April 27, 2019; Omaha, NE. <https://sciencefestivals.org/festival/nebraska-science-festival/>. Accessed February 18, 2020.
8. McWilliams B, Robbins R. Suzanne's story. Poster presented at: 16th Annual American Indian Health Research Conference; October 20, 2018; Grand Forks, ND. <https://ruralhealth.und.edu/assets/1917-8100/aihrc-agenda.pdf>. Accessed February 18, 2020.
9. University of Nebraska Medical Center. *Interprofessional Education at UNMC: 2018 Annual Report*. https://www.unmc.edu/academicaffairs/educational/ipe/UNMC_IPE_AnnualReport.pdf. Accessed February 25, 2020.
10. Herek TA, Branick C, Pawloski RW, et al. Cancer biology and you: an interactive learning event for Native American high school students to increase their understanding of cancer causes, prevention, and treatment, and to foster an interest in cancer-related careers. *J STEM Outreach*. 2019;2:1-14.
11. McWilliams B, Idoate R. Exploring skin cancer through portraiture inquiry. Poster presented at: Cancer Biology and You Day; October 29, 2019; South Sioux City, NE.
12. Simon D. The Entry Point QUESTs: constructing understanding in the visual arts. In: Hetland L, Veenema S, eds. *The Project Zero Classroom: Views on Understanding*. Boston, MA: Harvard Graduate School of Education; 1999.
13. Idoate R, Gilbert M, King KM, et al. Urban American Indian community health beliefs associated with addressing cancer in the Northern Plains region [published online ahead of print March 11, 2020]. *J Cancer Educ*.

Bobbie McWilliams, a citizen of The Osage Nation, is an undergraduate student at the University of Nebraska at Omaha who is studying fine arts and Native American Studies with a specific focus on Native American health and wellness. She also works as a cancer research intern at the University of Nebraska Medical Center for the Youth Enjoy Science Research Education Program.

Regina Idoate, PhD is a citizen of the Cherokee Nation of Oklahoma and an assistant professor of health promotion in the College of Public Health at the University of Nebraska Medical Center in Omaha. She is also a coinvestigator in the Youth Enjoy Science Research Education Program, which aims to increase diversity in cancer-related careers. Idoate's primary areas of specialization include medical humanities, preventive and societal medicine, spiritual wellness, and Native American health.

The Editor's Note

This human subjects research was reviewed by the University of Nebraska Medical Center Institutional Review Board in 2020

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All artists and subjects who participated in creating the Indigenous content analyzed herein contributed their perspectives and voices to all aspects of the research and the research analysis processes. Following Indigenous style, we formally use the names of Indigenous Peoples, and we recognize relationship and trust as the source of truthfulness, accuracy, and mindfulness about community impacts and continuity with history and heritage. This work is an expression of the individuals' and communities' rights and ownership of the research process and data. This project was sponsored by a Youth Enjoy Science Research Education Program grant (R25 CA221777) from the National Cancer Institute of the National Institutes of Health.

Conflict of Interest Disclosure

The author(s) had no conflicts of interest to disclose.

The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.



The image above includes various YES Research Interns. Front row from left to right is Tada Vargas, Audrey Bavari, and Bobbie McWilliams Leesley. Back row from left to right is Alex Nelson, Alec Ferreira, and Erica Lafferty.

YES Overview

The Youth Enjoy Science (YES) program aims to increase the number of Native American cancer research and health care professionals. This research education program encourages partnerships between biomedical scientists, science educators, and community leaders for cancer education and prevention. High school and undergraduate college students with Native American ancestry can participate in cancer research experiences at the Fred & Pamela Buffett Cancer Center or College of Public Health at the University of Nebraska Medical Center.

High School and Undergraduate Internship

Through the YES program, high school students (16 and older) and undergraduate students with Native American ancestry can participate in varied research experiences in the summer and, for students located in the Omaha metropolitan area, in part-time research projects during the school year. Research experiences are tailored to students' interests, and students may receive payment for their participation.

“Virtual” Research Forum Overview

The YES Research Education Program 2nd Biennial Research Forum will be offered online and welcomes all students, their families, and the greater community. There will be guest presentations regarding topics across the cancer control continuum with a specific focus on how cancer impacts American Indian communities.

Location and Time

The live research forum will be on Friday, April 23rd from 2:00 pm – 5:00 pm CST via Zoom:

- Zoom link: <https://unmc.zoom.us/j/92017794158?pwd=UWtEbWxQN2Q5VXM5QjUzMVVPeIBPZz09>
- Meeting ID: 920 1779 4158
- Password: 241977

This program is funded by the NIH/NCI Grant # R25CA221777



Agenda

- 2:00 – 2:15 pm CST **“Welcome & Prayer” presented by Steve Tamayo**
We will begin in a culturally relevant way by welcoming our guests and beginning with a land acknowledgement and prayer. ***No recording is allowed during this session***
- 2:15 - 2:30 pm CST **“National Cancer Institute’s Center to Reduce Cancer Health Disparities Overview” presented by Dr. Alison Lin**
A brief overview of the National Cancer Institute’s Center to Reduce Cancer Health Disparities and her role as the Deputy Chief of the Diversity Training Branch.
- 2:30 - 3:00 pm CST **“Program Overview” presented by Drs. Joyce Solheim and Maurice Godfrey**
A brief overview of the YES program and its activities will be presented during this session.
- 3:00 - 4:30 pm CST **Student Cancer Research Projects presented by YES Scholars**
Live zoom power point or poster presentations and pre-recorded presentations by YES scholars.
- 3:00 – 3:15 pm CST **“Pancreatic Cancer Research Strategies” by Ms. Audrey Bavari**
Pancreatic cancer is a deadly disease for which new treatments are needed, and in this study a laboratory research approach was optimized to assess the effectiveness of a novel therapy for this illness.
- 3:15 – 3:30 pm CST **“Suzanne: Lived Experience with Squamous Cell Skin Cancer” presented by Ms. Bobbie McWilliams Leesley**
This case study shares portraits of Suzanne, an elder of the Osage Nation, through a written narrative and a series of drawings and paintings that Portray Suzanne's reflections on living with skin cancer from a holistic perspective.
- 3:30 – 3:45 pm CST **“The Role of CTDP1 in Breast Cancer Development and DNA Damage Response” presented by Ms. Mira Norman**
In order to order to establish the role of CTDP1 in breast cancer development and DNA damage response, the Woods Lab generated CDTp1 knockout mice and observed the effect this had on embryonic development.
- 3:45 – 4:00 pm CST **“Arts-based research to promote cancer education amongst Indigenous peoples” presented by Ms. Hannah Butler-Robbins & Ms. Mariah Abney**
This scoping review was conducted to identify studies that have utilized arts-based research methods with Indigenous peoples to address cancer across the cancer control continuum.
- 4:00 – 4:15 pm CST **“Development and characterization of a non-alcoholic steatohepatitis-induced hepatocellular carcinoma mouse model” presented by Ms. Erica Lafferty**
This study was conducted to further understand the molecular signaling pathways associated with non-alcoholic steatohepatitis and hepatocellular carcinoma.
- 4:15 – 4:30 pm CST **“HDAC Inhibitors for Pancreatic Cancer Treatment” by Ms. Cecilia Barbosa**
In this project, new pancreatic cancer treatments were investigated and demonstrated to have promise as effective therapies.
- 4:30 - 4:45 pm CST **“Buffalo Facing a Storm: Understanding Native American Students’ Barriers and Facilitators in the Pursuit of Health Professions Careers” presented by Dr. Regina Idoate & Dr. Keyonna King**
This presentation will review a study that examined the barriers and facilitators to pursuing health professions careers and offer recommendations for increasing Native American representation in the health professions workforce in Nebraska.
- 4:45 – 5:00 pm CST **“Thank you & Encouragement Song” presented by Steve Tamayo**
This session will send all forum guests in a culturally relevant way thanking them for their time and participation. ***No recording is allowed during this session***



Presenter Biographies



Dr. Alison Lin is Deputy Chief of the Diversity Training Branch (DTB) of the National Cancer Institute's (NCI's) Center to Reduce Cancer Health Disparities (CRCHD) since 2019. In this capacity, she plays a central role in the strategic planning of the branch and program implementation to enhance workforce diversity in cancer research. Dr. Lin oversees the management of the NCI's diversity-focused training programs, including both the extramural Continuing Umbrella of Research Experiences ([CURE](#)) program and the Intramural CURE ([iCURE](#)) program. Previously, Dr. Lin served as Program Director in DTB since 2012, and led the development, implementation and management of the Youth Enjoy Science (YES) Research Education Program ([R25](#)) and the [iCURE](#) program. She also led the management of the [NCI Research Supplements to Promote Diversity in Health-Related Research](#) and the [NCI Supplements to Promote Reentry into Biomedical and Behavioral Research Careers](#). Prior to joining NCI, Dr. Lin served as an Instructor in Medicine at Harvard Medical School in Boston, MA. While at Harvard Medical School, she conducted interdisciplinary research focused on understanding the molecular interactions of membrane proteins and their signaling mechanisms, particularly those that modulate the cytoskeleton. Dr. Lin received her Ph.D. in physics/biophysics from the University of California, Santa Barbara for work on the optimization of non-viral cationic lipid DNA carriers in gene delivery. She received her B.S. in physics, summa cum laude, from the University of Minnesota, Twin Cities.



Dr. Maurice Godfrey is a Graduate Faculty Fellow and Professor at the Munroe-Meyer Institute of the University of Nebraska Medical Center in Omaha for more than twenty years. He spent a year as a Visiting Professor in the Department of Human Genetics of the University of Ghent, Belgium. With his late mentor he pioneered immunohistochemical and molecular studies in the Marfan syndrome. Among his awards, Dr. Godfrey has been recognized as a Basil O'Connor Scholar of the March of Dimes and Established Investigator of the American Heart Association. He also received the Antoine Marfan Award of the National Marfan Foundation; the Chief Standing Bear Organizational Award from the Nebraska Commission on Indian Affairs; the UNeMed Corporation Research Innovation Award from the University of Nebraska; Friend of American Indian Education from the Nebraska Department of Education, and the Friend of Science Award from the Nebraska

Academy of Sciences. Since 2005, he has led two National Institutes of Health programs, SEPA and YES, to bring science to schools and communities on Indian reservations in Nebraska and South Dakota.



Dr. Joyce Solheim is a Professor in the Eppley Institute for Research in Cancer & Allied Diseases and serves on the Senior Leadership Council of the Cancer Center as the Associate Director for Training and Education. At UNMC, Dr. Solheim has also assisted in the National Cancer Institute (NCI)-funded Pancreas Cancer Specialized Program of Research Excellence (SPORE) by serving as the Co-Director of the Career Enhancement Program for junior faculty and as the Co-Director of the Developmental Research Program for pilot research projects. As the Director of the Cancer Research Doctoral Program and as the Associate Director of the NCI-sponsored T32 Cancer Biology Training Program, Dr. Solheim leads cancer education programs for graduate students at UNMC. Dr. Solheim is also the Co-Principal Investigator of the NCI R25

Youth Enjoy Science Research Education Grant for educational outreach to Native American middle school students, high school students, undergraduates, and community members in the area of cancer-related education. In her research laboratory at the Cancer Center, much of the work has focused on the assembly and functions of proteins that play vital roles in the immune defense against tumors



Presenter Biographies



Dr. Regina Idoate, enrolled member of the Cherokee Nation of Oklahoma, is the great-granddaughter of a teacher, the granddaughter of an artist, and the daughter of a nurse. She studied at Arizona State University, University of Arizona, Creighton University, University of Nebraska Omaha, and University of Nebraska Medical Center (UNMC). She holds degrees in Psychology, Spanish Language & Culture, Native American Studies, Maternal and Child Health, and Preventive and Societal Medicine. Dr. Idoate is a governing board member at the Center for Great Plains Studies and serves as assistant professor in the Department of Health Promotion in the College of Public Health at UNMC. Her active research falls into three broad areas: (1) Medical Humanities, (2) Healthcare Workforce Development, and (3) Preventive and Societal Medicine. Dr. Idoate loves to collaborate across disciplines, colleges, and cultures. She specializes in community-based participatory research and works in partnership with public schools, non-profit organizations, campus institutions, and tribes to promote health and wellness.



Dr. Keyonna King has a doctorate in public health with a concentration in preventive care from Loma Linda University, and a Masters in Psychology with a clinical emphasis from Pepperdine University. Dr. King is one of the first recipients of the prestigious Bill & Melinda Gates Millennium Scholarship. She has worked closely with one of her mentors, Dr. Susanne Montgomery, on mixed methods research designs and has extensive experience utilizing the Community-Based Participatory Research (CBPR) approach with minority communities. Dr. King is an assistant professor at University of Nebraska Medical Center in the College of Public Health, Department of Health Promotion. She practices the CBPR approach to engage community in projects to address health disparities through UNMC's Center for Reducing Health Disparities. Specifically, she partners with the North Omaha community to address priority health needs identified by the community such as mental health, chronic disease intervention and prevention, violence, and improving the diversity of the healthcare workforce. Dr. King also teaches the Applications of CBPR to doctoral students in the PhD Health Promotion and Disease Prevention Research. Dr. King focuses her personal research efforts on using CBPR to understand and address depression in African American men; and improving mental and physical health outcomes for African Americans and American Indians/Native Americans.



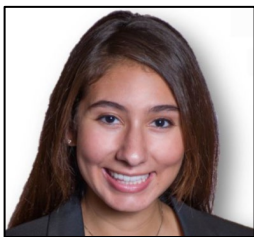
Mr. Steve Tamayo is a traditional Sicangu Lakota artist whose family originates from the Rosebud Reservation in South Dakota. After graduating from High School in 1984, Tamayo enlisted in the US Army, serving in the 101st Airborne Division. After returning to Omaha in 1987, he studied the traditional arts of the Umonhon people under Howard Wolf. As a mentor, Wolf instilled in Tamayo a deep appreciation and knowledge of Umonhon art and culture. He learned the importance of traditional materials, construction and the history surrounding native artifacts and regalia. In 2000, Tamayo moved to the Rosebud Reservation, where he augmented his understanding of Northern Plains art; he earned his BFA from Sinte Gleska University in 2011 where he developed and taught the traditional arts program. Tamayo currently leads study groups on his Reservation and travels to schools and museums throughout the country to study and teach historic methods of artifact construction and preservation. He is a regular consultant to the curatorial and conservation staff at the Smithsonian's National Museum of the American Indian; his most recent work there is the current exhibition, "As We Grow," focused on traditional native games and toys. He has been an artist-in-residence and cultural consultant with OPS and teaches Native American Art History at Metropolitan Community College. Tamayo's honors include the 2014 NAC Governor's Heritage Art Award for excellence in cultural artistic expression. In 2015, he and Paul High Horse won the Omaha Entertainment and Arts Award for best two-person exhibition and were again nominated in 2016. Tamayo has exhibited at The National Museum of the American Indian, in Washington, DC, The Kaneko in Omaha, The Great Plains Museum in Lincoln, NE, the John G. Neihardt Center, and RNG Gallery in Council Bluffs, IA. Some of his most recent work includes buffalo robes for Willie Nelson and Neil Young and a tipi offered to President Obama from Bold Nebraska.

Presenter Biographies



Ms. Aislinn Rookwood is the Program Manager for the National Cancer Institute-funded Youth Enjoy Science (YES!) Research Education program at the University of Nebraska Medical Center (UNMC), which aims to increase the number of Native American students pursuing a cancer research and/or healthcare profession. She graduated with an AS from Phoenix College in Phoenix, Arizona and a BS and MPH from the Mel and Enid Zuckerman College of Public Health (MEZCOPH) at the University of Arizona in Tucson, Arizona. She is currently a doctoral student in the Department of Health Promotion in the College of Public Health at the UNMC researching how to better address environmental justice topics through community-engaged research and workforce development. As the YES! program manager, Aislinn collaborates with an

interdisciplinary team to develop culturally relevant programming, mentors Native American youth interested in research, and facilitates educational programs that support students' pursuits in becoming public health and biomedical researchers.



Ms. Audrey Bavari is a pre-medicine student at the University of Nebraska at Omaha. She is Oglala Lakota, and the daughter of Yvonne Bavari, who has been featured by the Science Education Partnership Award Program as a role model for her contributions in the health profession. Audrey participated in the YES! Program for 2 years conducting research in a laboratory in the Buffett Cancer Center. She has presented her pancreatic cancer research to UNO/UNMC faculty and Native American community members, and she is a co-author on a manuscript submitted for publication.



Ms. Bobbie McWilliams Leesley, Osage Nation, is a Studio Art & Art History major at the University of Nebraska at Omaha, she is an honor student, and she adores her minor in Native American Studies. She has been a YES intern for three years, and her experiences with the YES program include presenting at the Nebraska Science Festival, 16th Annual American Indian Health Research Conference, and Cancer Biology and You Day.



Ms. Mira Norman, Santee Sioux, is a high school student at Duchesne Academy and is currently in her junior year. She has been exploring her Native American ancestry and has been a YES! intern for about one year. At school, she is a top honors student. Not to mention, she is the president of the Sustainability Club. Through the program, she has been exploring her future career paths and using this opportunity to gain insight and experience into life as a cancer researcher. While her in-person activity within a laboratory at the Buffett Cancer center has been put on hold due to COVID-19 restrictions, she is excited to continue on within YES!



Ms. Hanna Butler Robbins is a senior at Arizona State University studying microbiology and a member of the Cherokee Nation, and the daughter of teachers, and a descendant of Nanyehi Ward, a beloved woman among the Cherokee who acted as an ambassador to European settlers. She completed an internship at the University of Arizona assisting with research in immunology focusing on γ -IFN-inducible lysosomal thiolreductase expression's impact on melanoma survival. She currently serves as an intern at the University of Nebraska Medical Center focusing on public health research and outreach specific to cancer prevention, treatment and research in Indigenous communities.



Presenter Biographies



Ms. Mariah Abney, member of the Eastern Band Cherokee tribe, is a media communications student at the University of Nebraska-Omaha and Metropolitan Community College. She is an intern in the Youth Enjoy Science program working with Dr. Regina Idoate to raise awareness of cancer within Native American communities through art and community exhibition. Prior to working with Dr. Idoate, Mariah worked with Dr. Youri Palov's lab investigating the antitumor activities of *Staphylococcus epidermidis* strain MO34 on skin neoplasia (e.g., cancer). Mariah has participated in the YES! Program for 3 years.



Ms. Erica Lafferty, member of the Cheyenne River Sioux, currently attends Oglala Lakota College and South Dakota School of Mines & Technology where she is working on a pre-health degree. She has worked on various research projects such as the National Science Foundation-funded OSSPEEC and the Engineering/Science Projects in Community Service (EPICS) program at South Dakota School of Mines & Technology. She participated in the YES! program the past 2 summers in various capacities. After graduation, she plans to pursue graduate school in public health.



Ms. Cecilia (Cece) Barbosa is currently a freshman pre-health profession student at the University of Nebraska at Lincoln. Her Native American heritage comes principally from her mother's side of the family; she was born into the Omaha Tribe and the Bird Clan. While Cece was a student at Omaha North Magnet High School, she undertook research in a Buffett Cancer Center laboratory. Based on her efforts, she is a co-author on a manuscript submitted to a cancer research journal. In addition to her research, she participated in the YES! Program through attending a variety of presentations on many facets of cancer investigation and therapy at the University of Nebraska Medical Center.



REFERENCES

1. Burhansstipanov, Linda et al. "A Comparison of Quality of Life Between Native and Non-Native Cancer Survivors: Native and Non-Native Cancer Survivors' QOL." *Journal of cancer education* 27.S1 (2012): 106–113. Web.
2. Fleischer AB Jr, Feldman SR, Bradham DD. Office-based physician services provided by dermatologists in the United States in 1990. *J Invest Dermatol.* 1994;102(1):93-97.
3. Gifford, Wendy et al. "Spirituality in Cancer Survivorship with First Nations People in Canada." *Supportive care in cancer* 27.8 (2019): 2969–2976. Web.
4. Herek TA, Branick C, Pawloski RW, et al. Cancer biology and you: an interactive learning event for Native American high school students to increase their understanding of cancer causes, prevention, and treatment, and to foster an interest in cancer-related careers. *J STEM Outreach.* 2019;2:1-14.
5. Hodge, DR, Gordon EL, Cross T. "Moving from colonization toward balance and harmony: A Native American perspective on wellness." *Social Work* 54, no. 3 (2009): 211-219.
6. Idoate R, Gilbert M, King KM, et al. Urban American Indian community health beliefs associated with addressing cancer in the Northern Plains region [published online ahead of print March 11, 2020]. *J Cancer Educ.*
7. Kailas, A., Solomon, J. A., Rigel, D. S., Mostow, E., McMichael, A. J., Pritchett, E. N., Jackson-Richards, D., Desai, S. R., & Taylor, S. C. (2017). The Importance of Recognition of the Skin Cancer Risk of Native Americans: A Call to Action. *SKIN The Journal of Cutaneous Medicine*, 1(2), 107–108. <https://doi.org/10.25251/skin.1.2.10>
8. Kryatova MS, Okoye GA. Dermatology in the North American Indian/Alaska Native population. *Int J Dermatol.* 2016;55(2):125-134.
9. Lee, T. H. (2009, Oct 21). Skin cancer: No one is immune. Retrieved from <https://newsmaven.io/indiancountrytoday/archive/skin-cancer-no-one-is-immune->
10. Maarouf M, Zullo SW, DeCapite T, Shi VY. Skin cancer epidemiology and sun protection behaviors among Native Americans. *J Drugs Dermatol.* 2019;18(5):420-423.
11. McWilliams B, Idoate R. Exploring skin cancer through portraiture inquiry. Poster presented at: Cancer Biology and You Day; October 29, 2019; South Sioux City, NE.
12. McWilliams B, Robbins R. Suzanne's story. Poster presented at: 16th Annual American Indian Health Research Conference; October 20, 2018; Grand Forks, ND. <https://ruralhealth.und.edu/assets/1917-8100/aihrc-agenda.pdf>. Accessed February 18, 2020.
13. McWilliams B, Robbins R. Suzanne's story. Poster presented at: Nebraska Science Festival; April 27, 2019; Omaha, NE. <https://sciencefestivals.org/festival/nebraska-science-festival/>. Accessed February 18, 2020.
14. McWilliams, B., & Idoate, R. (2020). Portraits of Suzanne, an Osage Woman's Story of Loving the Sun and Living With Skin Cancer. *AMA Journal of Ethics*, 22(6), 557-564.
15. Simon D. The Entry Point QUESTs: constructing understanding in the visual arts. In: Hetland L, Veenema S, eds. *The Project Zero Classroom: Views on Understanding*. Boston, MA: Harvard Graduate School of Education; 1999.
16. Skin Cancer Foundation. Self-exams save lives: early detection starts with you. <https://www.skincancer.org/early-detection/self-exams/>. Accessed November 26, 2019.

17. University of Cincinnati. "Skin Cancer Rare -- But More Deadly -- In People With Darker Skin." ScienceDaily. ScienceDaily, 27 July 2006.
<www.sciencedaily.com/releases/2006/07/060727100422.htm>.
18. University of Nebraska Medical Center. Interprofessional Education at UNMC: 2018 Annual Report.
https://www.unmc.edu/academicaffairs/educational/ipe/UNMC_IPE_AnnualReport.pdf.
Accessed February 25, 2020.
19. Warne D, Kaur J, Perdue D. American Indian/Alaska Native cancer policy: systemic approaches to reducing cancer disparities. J Cancer Educ. 2012;27(1)(suppl):S18-S23.
20. White MC, Espey DK, Swan J, Wiggins CL, Ehemann C, Kaur JS. Disparities in cancer mortality and incidence among American Indians and Alaska Natives in the United States. Am J Public Health. 2014;104(suppl 3):S377-S387.