THE PATIENT EXPERIENCE ON CANVAS

by

Anna Rain

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Anna Rain

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Approved by:

Dr. Kim Larson

East Carolina University College of Nursing

Introduction

Lung cancer is the leading cause of cancer mortality in the United States for both men and women (American Cancer Society, 2019). There is a wealth of research on lung cancer regarding risk factors, signs and symptoms, types of treatments, and trends; yet less is known about the personal experience faced by people with lung cancer. Specifically, among African Americans with lung cancer, the emotions they feel surrounding their diagnosis is largely ignored. The personal experience for persons of color related to a serious illness, like cancer, must consider the health disparities in the United States healthcare system. One author noted, "After 250 years of social segregation and discrimination, current health data confirm that African Americans are the least healthy ethnic group in the USA" (Noonan et al., 2016, pp.12).

African Americans aged 20 years or older with lung cancer in Eastern North Carolina have a higher mortality rate than the state average (Lea, 2014). Health disparities causing African Americans to have poorer health outcomes will require systematic change to eliminate, there are other steps that can be taken to give them a higher quality of care. Having a better understanding of the emotions that African Americans go through on their lung cancer journey is necessary to be able to provide holistic care. Cultural sensitivity and understanding are key concepts woven throughout nursing curricula to increase quality of care. In the discipline of nursing it is uncommon to find artwork that illustrates the emotions that individuals go through on their lung cancer journey. The purpose of this project is to expose the emotions of a lung cancer diagnosis through the arts.

Review of Literature

Lung cancer is the leading cause of cancer death in both male and female populations, estimating around 228,820 new cases and 135,720 deaths per year (American Cancer Society,

2020). Over half of the people who have been diagnosed with lung cancer die within one year of receiving their diagnosis. The 5-year survival rate is even less than that at 18% (Zappa & Mousa, 2016). In general, African American men tend to be around 15% more likely to develop lung cancer than white men, although White women are 14% more likely to develop lung cancer than black women (American Cancer Society, 2020). As of 2020, North Carolina (NC) has a significantly higher rate of new cancer cases at 69.0/100,000 than the national rate of 59.6/100,000 and ranks 40th among all states (American Lung Association, 2020). A study done comparing four different regions in North Carolina found that a 29-county area in Eastern North Carolina (ENC) had higher cancer mortality rates compare to the state's other 71 counties combined (Lea, 2014). The same study found that African Americans with lung cancer in ENC had a mortality rate of 77.2/100,000 residents aged 20 years or older, while the rest of the state had a mortality rate of 62.5/100,000 (Lea, 2014). It is theorized that the cancer mortality rates in ENC are higher than the rest of the state due to a combination of socioeconomic factors such as income, education, and other social determinants of health that could prevent a person from seeking treatment or preventative services (Lea, 2014).

There are several risk factors that research has found may increase someone's chances of developing lung cancer. The number one risk factor for developing lung cancer is cigarette smoking; linked to between 80% to 90% of lung cancer deaths in the United States (CDC, 2019; Zappa & Mousa, 2016). When compared to people who do not smoke, people who do smoke cigarettes are 15 to 30 times more likely to get lung cancer or die from lung cancer. In addition to smoking cigarettes, living around secondhand smoke is also harmful and can increase the likelihood of developing lung cancer by around 20-30% according to the U.S. Surgeon General (CDC, 2019; Zappa & Mousa, 2016). In an effort to reduce the health issues that tobacco is

known to cause, the Master Settlement Agreement was created. A study focusing on North

Carolina's involvement in the agreement describes it as:

> …a framework for tobacco industry payments to states totaling more than $200 billion
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> through 2025 in exchange for states dropping current and any future lawsuits seeking
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> remedy from the industry for health care costs related to tobacco-induced disease. In
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> addition to monetary payments, the MSA imposed restrictions on advertising, marketing,
>
> and promotion of tobacco products, particularly those aimed at youth (Jones, et al., 2007,
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> p. 37).

Another step has been taken across the country in December 2019 to reduce the rates of tobacco

use by raising the legal age allowed to buy tobacco from 18 years old to 21 years old. According

to the U.S. Environmental Protection Agency (EPA), there are about 20,000 cases of lung cancer

caused by radon each year (CDC, 2019). Radon is a natural gas commonly found in basements

with natural uranium deposits that cannot be easily detected and can be found in houses and

buildings (Zappa & Mousa, 2016). A family history of lung cancer may increase the risk of

developing lung cancer, as well as having a personal history of having lung cancer (CDC, 2019).

Air pollution has been identified as a risk factor for developing lung cancer and increases the risk

for lung cancer mortality by 8% (Zappa & Mousa, 2016). Radiation therapy to the chest also puts

other cancer survivors at a higher risk of developing lung cancer.

Lung cancer is treated differently depending on how far the cancer has spread, the type of

lung cancer the person has, the person's general health, whether there are signs and symptoms,

and whether or not the cancer has any mutations (National Cancer Institute, 2020; CDC, 2019).

Different options for lung cancer treatment include surgery, chemotherapy, immunotherapy,

radiation therapy, and targeted therapy. There are also many clinical trials being done that a

person with lung cancer may participate in, as current treatments for lung cancer are not curative. There are two categories of type of lung cancer, small cell lung cancer and non-small cell lung cancer (NSCLC). NSCLC is more common and accounts for around 80-85% of all lung cancer diagnosis (Huang et al., 2017). The standard treatment options for early stage lung NSCLC include surgery to remove the cancerous sections, adjuvant chemotherapy, immunotherapy and radiation therapy (National Cancer Institute, 2020; Huang et al., 2017). If the lung cancer is unresectable, the treatment of choice is radiation therapy and chemoradiation therapy (National Cancer Institute, 2020). People requiring palliative treatment can receive radiation therapy in order to relieve some of the symptoms from local involvement with NSCLS such as tracheal compression, vocal cord paralysis, or superior vena cava syndrome (National Cancer Institute, 2020). Immunotherapy has been identified as a breakthrough treatment in oncology and can be used in the treatment of non-small cell lung cancer (Zappa & Mousa, 2016). The standard treatment options for small cell lung cancer are chemotherapy and radiation. There has been an increased survival rate of 5% after three years when using chemotherapy and radiation together to treat small cell lung cancer when compared to using chemotherapy alone. No improvement exists in survival after the drug treatment duration is longer than 3-6 months, suggesting that for people with small cell lung cancer, maintenance chemotherapy does not prolong survival (National Cancer Institute, 2020).

Living with cancer is difficult; however, various coping strategies have improved quality of life. One suggested way to cope with having cancer is to use religion. A study done in Malaysia where the population primarily practices Islam found that a person's religious views strongly influence the way people looked at their cancer experience (Ahmadi, et al., 2018). The National Cancer Institute suggests keeping a daily routine, this might include going to work,

taking up a hobby, or doing mild physical activity (National Cancer Institute, 2019). As long as the person's doctor has approved it, physical activity has been proven to improve the chances of feeling better, control stress, increase appetite, speed healing, and help free your mind (National Cancer Institute, 2019).

Art has been used as a form of healing for centuries. It has been theorized that these paintings and drawing were used as a part of a ritual, decoration, entertainment, or to educate and keep a record of events (Owen, 2019). Most recently, it has been introduced as a form of therapy. A study done in 2008 placed a patient on an EEG monitor before, during, and after painting and drawing to observe their brain activity. The study showed that there was higher frequency brain activity in the occipital, parietal, and temporal lobes during and after painting and drawing when compared to the participant's baseline (Belkofer & Konopka, 2008). Although the study was unable to determine much more than that, it should encourage future researchers to conduct similar studies in order to determine the effect of art therapies on the brain. This study proved that an EEG can be used in the further observation of brain activity changes in patients participating in painting or drawing and will hopefully be conducted on more than one person in future studies (Belkofer & Konopka, 2008). With a shift towards holistic health care, art programs have demonstrated stress reduction and lowers anxiety (Beaulieu, 2016; Sonke et al., 2014). Art allows patients to express emotions that they may have been holding in or let out emotions that have been repressed. Allowing patients to express how they feel through art, could open up a new form of communication between nurses and person with lung cancer.

The use of art as therapy comes in various forms such as painting, drawing, music, and sculpting (Hart, 2017; Butcher, Dobson, Atkinson, Clayton & Couzins-Scott, 2016). In a program profile of the Arts and Medicine Institute at Cleveland Clinic, several studies are cited

as having improved patient outcomes (Gallagher, 2017; Hart, 2017). A study exploring the effects of looking at sculptures and analyzing them noted that the art challenged the participant's ways of thinking, allowed them to self-reflect, and left them with a sense of calm (Butcher et al., 2016). More research is needed on the effectiveness of these therapies on patient outcomes.

Although there are strong beliefs in the effectiveness of art therapy, as well as improving the patient's lives, art therapy could be encouraged and implemented throughout the care team, allowing them to achieve the same or similar positive effects as have been seen in the patient population. Many studies and articles reviewed for this project had a minimal number of participants, with only one having more than 50 people, suggesting that more research needs to be done on the topic of art in healing.

Purpose

The purpose of this project is to expose the emotions of a lung cancer diagnosis through the arts.

Research question

The research question in this study is: How does an African American in Eastern North Carolina experience the daily emotions of living with a cancer diagnosis?

Method

This study used art as a basis of healing expression (Hart, 2017). This project was conducted under the guidance of the East Carolina College of Nursing's resident artist, a lung cancer researcher, and a nurse scientist with expertise in qualitative analysis. During the painting process I consulted with the East Carolina University resident artist for guidance and clarification. This professor/artist has received awards in oils, watercolor, & acrylics, and has had her paintings within and on the covers of several nursing textbooks and other publications.

This project is a series of three acrylic paintings on canvas with the use of other materials such as ribbon and cigarettes. The first painting, titled *Method Behind Madness*, was a process completed in the City Art Gallery in Greenville, NC which involved learning the principles and elements of design. This painting was chosen to highlight tobacco as the number one risk factor of lung cancer. The second painting, titled *He will Guide Me*, was inspired by a conversation with an African American woman and depicts daily coping strategies. The third painting, titled *Survivor's Desk*, also inspired by this conversation, depicts the importance of a life's work.

Method Behind Madness was made to depict the number one known risk factor of developing lung cancer. The paint used was acrylic in a deep purple to compliment the green of the tobacco leaf and to show the dark nature of the disease. The background that the purple is painted over is printed out research about the risk factors of lung cancer and prevalence of the disease specifically in the African American community. The goal of using research as the background painted over was to exemplify that although there is ample evidence available about the use and danger of tobacco, many people continue to use it as it has addictive properties. This was intended to prompt the viewer to look more closely at what the paper is saying about the risk factors of lung cancer in the African American community.

The tobacco leaf was put in the center because it is the basis of all tobacco products. Cigarettes are the most commonly used tobacco product linked to the development of lung cancer, therefore they are pictured next to the tobacco leaf. The cigarette box is open to give the viewer the chance to smell the tobacco and stimulate another sense other than sight. The white ribbon is the symbol for lung cancer, so it was used to depict what the tobacco use leads to. The painting reads from left to right in order to show that the tobacco use is the cause of the lung cancer. The white ribbon was made out of ribbon material which gives the painting another type of media.


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Bible
Bed
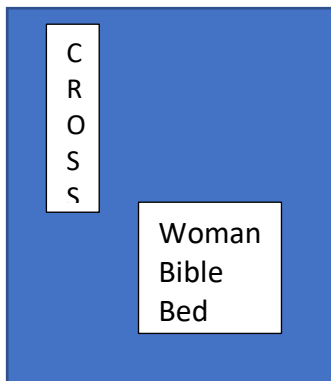
(Draft)

He will Guide Me depicts the importance of faith in a cancer survivor's journey. There were three objects used in order to keep the painting interesting to the viewer, as people are most interested in groups of three. The painting and objects have been placed on the canvas so that it adds a smooth balance and rhythm to the painting. In the painting, various shades of green paint were rolled onto the background to provide dimension. The color connects this painting to the first painting as it is a similar green to the one used on the tobacco leaf in the first painting. A darker forest green surrounds the woman in a gown sitting on the edge of the bed. A lighter green was used in the background around the cross to reflect a source of light.

The woman in the painting represents a patient battling with cancer. Her posture suggests fatigue and sadness, common symptoms of patients with cancer. I chose to paint her skin literally black to emphasize the African American's plight when dealing with illness or disease, as they have a higher mortality rate when diagnosed with lung cancer. Using black paint also increases the contrast between the woman and the background, in order to draw the viewer's eyes to her. The bed cover was painted a light gray in order to keep a somber mood without drawing too much attention to the bed itself, as the woman is the main focus of the painting. There is a bible on the bed next to the woman as an important symbol of religion and coping.

The cross in the top left corner was made a lighter brown than the bed in an effort to make it less eye-catching so that the viewer sees the woman and the bed first and then their eyes will go to the cross. Using the cross as the source of light is symbolism of how it was being used as a source of strength and hope for the cancer survivor. The placement of the cross and the bed is to create balance and rhythm throughout the painting, as well as to drive your eyes to those spots.
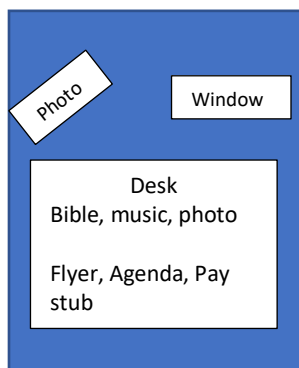
The third painting, *Survivor's Desk* was created to show a survivor's treasure chest in a more modern sense. This painting depicts what the desk of a cancer survivor might look like. It is made to look like an office as to suggest that work was part of the journey, and to continue to work would be one coping mechanism for a cancer patient. Another ode to using work to deal

with the illness is a pay stub on the desk, indicating that the patient has been working throughout their cancer journey. I included two family pictures in this painting to depict the importance of a social support system as a coping mechanism. One family picture is on the desk, while the other is only partially seen on the wall. I wanted to include two different family photos in two separate places to emphasize how important family is during this time. Another device I included was a bible. This connects to the cross in the previous painting by continuing to show the importance of religion to cancer survivors. I also included a day planner in the center of the desk. This is in the center to emphasize how important it is to keep a routine and to try and continue to live life as much as possible with cancer. There is also a flyer for a group for people that have cancer in order to provide support for each other. The last thing on the desk is headphones, to symbolize music as a coping mechanism.

The desk is a dark brown in order to draw the viewer's eyes to it. It is stretched across two points on the canvas that would draw a viewer to look there first. The background is a plain tan in order to exemplify an office setting as well as to not take away from the desk. There is a window on the wall with a blue sky seen out of it. As this painting in the timeline of the series is once the patient no longer has cancer, the scene outside is bright and hopeful and an example of the joy one might feel after beating cancer. The painting shows that the desk is at the corner of the room to add dimension to the painting.

Findings

The major finding in this project was the representation of a life of a cancer survivor. Despite the risk factors, treatment options, and coping mechanisms, the life of a person with lung cancer is retained. Religion and family support played major roles in the ability to cope with a cancer diagnosis. Religion specifically was found to change the way that people viewed their

cancer diagnosis and was a useful source of strength (Ahmadi, et al., 2018). It was also found that staying active and involved in everyday life was an effective coping mechanism. Overall, I found that throughout the cancer journey an African American with lung cancer might feel shocked, frightened, hopeful, and strong.

Discussion

The nursing profession can learn how to better care for the emotions of the African American person with lung cancer. With a better understanding of the risk factors, treatments, and coping mechanisms surrounding lung cancer, the nursing profession will be better prepared to give patient education around a lung cancer diagnosis. In this project we found that African Americans experience multiple emotions day-to-day when given a cancer diagnosis, which is important to take into consideration as a nurse. Caring for a person emotionally should be considered as important as taking care of them physically and knowing what emotions they may be feeling will improve their quality of care. Knowing the effects of art in healing could also be important to be aware of in the nursing profession, as art can be used as a tool for both patients and healthcare workers.

Conclusion

In conclusion, there were many emotions that an African American with lung cancer in ENC go through. First, shock at the diagnosis, then strength and perseverance persisted. African Americans in Eastern North Carolina are more likely to be diagnosed with lung cancer than other ethnic groups in the same region. Risk factors, treatment options, and coping mechanisms are all important to consider when providing holistic nursing care. Art can be added to the toolkit of nursing care to better understand the patient experience.

Clinical relevance

These findings are relevant in the clinical setting as they pertain to the mental health of the African American person with lung cancer in ENC. In order to provide the best holistic care to this population, it is necessary to understand the daily experience with a serious illness. It would also be helpful to understand the effects of art in the healing process of the person with lung cancer. There is a need for further research into the subject of the emotions of going through lung cancer, especially for this population. There is also a need for further research into the effect of art in healing.

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