Improving Mammography Screening in the State of Nevada: Barriers and Solutions

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Abstract

Background: Breast cancer screening rates among women age 50 and older in Nevada are dramatically lower than the national average for breast cancer screening. Increasing these screening rates has become a priority for the Nevada Cancer Coalition and the State of Nevada Health Department.

Methods: Focus groups were held in five rural Nevada locations in order to ask women what barriers they face in seeking mammography screening. Focus groups were held in Carson City, Minden, Elko, Winnemucca, and Mesquite. Responses from focus group participants were recorded by one facilitator typing on a computer and another facilitator writing answers on a flip chart visible to all participants. The computer transcripts were uploaded to the NVIVO program, which was used to code for and create matrices of common themes discussed during the focus groups.

Results: The themes to appear most often were “Education and Knowledge,” followed by “Fear.” After looking back through the transcripts we determined that women in the rural areas of Nevada are confused about many aspects of mammography screening. This confusion feeds into the fear that they feel about being screened and being diagnosed with breast cancer. It is therefore recommended, that an educational program, combined with facilitator help and support, should be implemented in the rural areas of Nevada to increase breast cancer screening rates among women 50 years of age and older.

Background

Christine is a 58 year old mother of two girls and grandmother to four granddaughters. In December of 2008, Christine visited the doctor for a routine screening, where the staff discovered that Christine had an abnormal mammography. On the 22nd of December, Christine received her biopsy results, stating that she had invasive ductal carcinoma. Christine feared the worst at first, worrying that she might not survive until Christmas. After the initial fear had subsided, Christine began researching breast cancer and all the options that were available to someone in her position. In 2009, Christine underwent a lumpectomy, chemotherapy, radiation, and some breast reconstruction. She is now cancer-free (BreastLink, 2013).

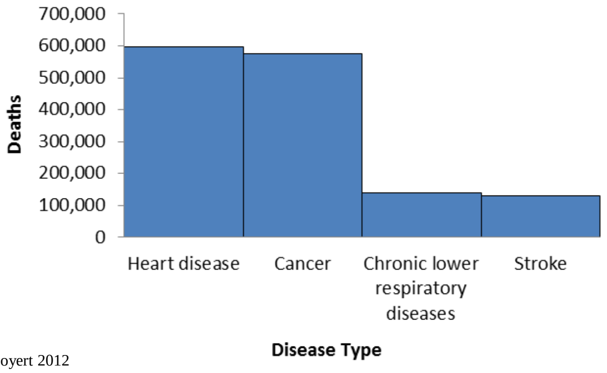
Christine reports that while 2009 was the worst year of her life, it was also filled with great blessings. Christine said that her family, co-workers, girlfriends and even some people she barely knew were there to help her through all the procedures and struggles. She reports having a greater appreciation for her immediate and extended family who have always supported her. Christine learned a lot about her character and the character of others during that year. She is determined to reach out to other women who are recently diagnosed and help them to see the "blessings amongst the struggles and fear" (BreastLink, 2013).

Christine's story is one example of how early cancer screening can help to find cancer cells before they spread and increase the individual's chances of survival with proper treatment. While this example of early cancer screening is specific to breast cancer, the same concept applies to all forms of early cancer screening services.

Why Cancer Matters

Cancer is the second leading cause of death in the United States. As can be seen in Figure 1 below, the leading cause of death in 2012 was heart disease, which was identified as the cause of death for 597,689 individuals. Cancer follows very closely behind with 574,743 recorded deaths (Hoyert, 2012).

Figure 1. Top Four Causes of Death in US, 2012



Hoyert 2012

In 1990, the National Cancer Institute reported the overall cost of cancer to be $104 billion, direct medical costs to be $35 billion, and lost productivity and mortality costs to be $69 billion (American Cancer Society, 2013). As seen in Figure 2, The National Institutes of Health report showed in 2008 that costs have risen to an estimated total cost of $201.5 billion, direct medical cost of $77.4 billion, and lost productivity and mortality cost of $124 billion (American Cancer Society, 2013).

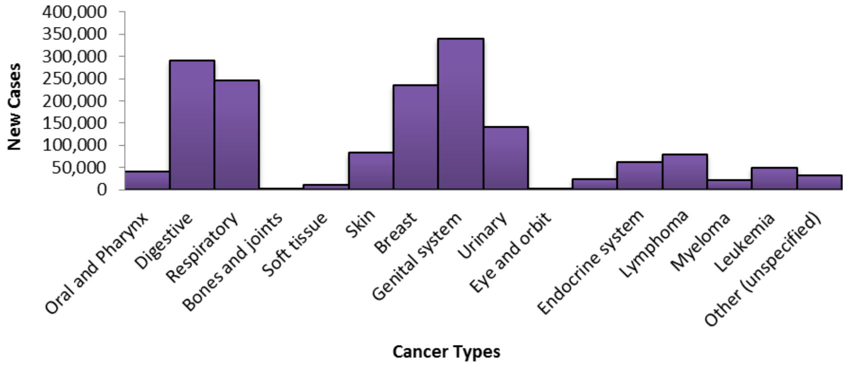
When a diagnosis of cancer is given to an individual and their family members, there is a ripple effect of impacts felt. Some of those impacts are physical and emotional changes, which can be due to both the cancer itself and cancer treatment. The emotional changes experienced most often are stress, depression and anxiety, anger, fear, and a sense of being disconnected or isolated from others (National Cancer Institute, 2012). The stress felt by a cancer patient is often related to the unknown experiences they are about to face in regards to surgery, treatment, and impacts on their family (National Cancer Institute, 2012). Depression and anxiety often emerge later, after the patient has undergone surgery and begun treatment. Often, this is a side effect of the treatment drugs themselves or a result of the physical changes brought by surgery. Many patients report that loss of hair, weight change, and disfigurement are hard to accept, often affecting how they see themselves and how others see them; patients often state feeling less integrity, wholeness, and normal functioning (Carver, 1998). These feelings can often get in the way of the patient's daily life and their relationships with family members and friends (National Cancer Institute, 2012). Anger can be felt by patients in regards to having been diagnosed with cancer or as a result of a bad experience with a healthcare provider, family member, or friend during cancer surgery and treatment (National Cancer Institute, 2012). A sense of being disconnected or isolated from others often stems from all the other emotions being experienced. Family members and friends may have a hard time relating to the patient's experiences and feelings, thus making the patient feel alone in their struggle (National Cancer Institute, 2012). The final emotion felt by most cancer patients is fear. Fear can stem from many different aspects of a cancer diagnosis, like the treatment and physical changes discussed above. However, fear can also steam from ideas that the cancer treatment will not work or cancer will return once treatment is complete (Melchior, 2013). Each cancer case is different and each individual handles a cancer diagnosis and its physical changes differently.

In addition to physical and emotional changes, there is a great psychosocial impact felt by the patient and family after a cancer diagnosis. For many individuals with cancer, the ability to perform selfcare is too difficult, and for many American families the ability to hire a professional caregiver is out of the question. For this reason, the typical caregiver is a family member or friend of the patient. Experience with cancer is often labeled a chronic stressor for both the patient and the caregiver. In most cases, both the patient and caregiver experience negative psychological, behavioral, and physiological impacts on their lives and health (Bevans, 2012). While the initial experience of being diagnosed with cancer is recognized as a significant stressor for the patient, family, and close friends, the resulting surgery and treatment creates even larger fears and challenges.

Common Cancers

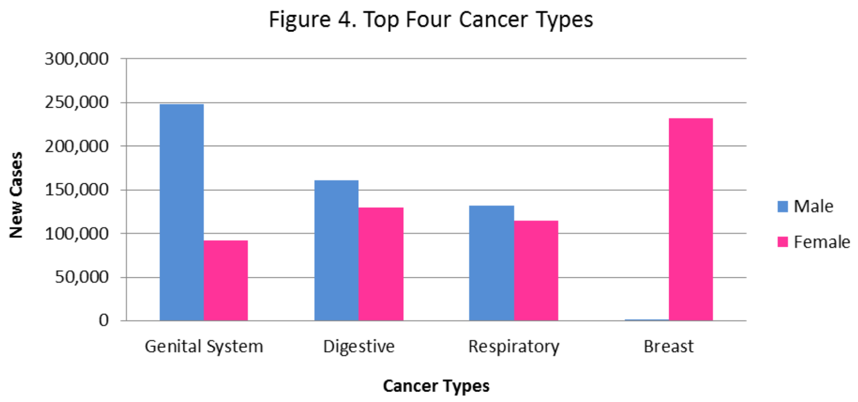
When considering the impact of cancer diagnosis and treatment on both families and the American society, we can look at how many individuals are diagnosed each year. (See Figure 3 showing the projected case numbers for 2013, based on 2012 reported data, of the top 15 most common types of cancer.)

Figure 3. Cancer Cases in 2013



Siegel, 2013

The top four types of cancers recorded in the United States are cancers of the genital system (cervical, vaginal, testicular, and prostate), digestive system, respiratory system, and breast. We can examine the incidence of these cancers further in Figure 4, by breaking them down into gender occurrence. In completing this breakdown for the top four most common cancers reported in August 2013, we can see that breast cancer has been determined to be the most common cancer among females worldwide, accounting for approximately 22.9% of all cancers in females (Siegel, 2013).



Siegel, 2013

Since breast cancer is the most common form of cancer for women and can have such detrimental effects, as Christine experienced, breast cancer detection and prevention has become a top priority for the Cancer Coalition in Nevada. The coalition is a statewide group of residents, doctors, nurses, surgeons, oncologists, legislators, and many others, who have a united goal to address the most common cancers plaguing the Nevada population and our nation.

Etiology of Breast Cancer

Before we can discuss the goals of the Nevada Cancer Coalition in relation to breast cancer occurrence in the Nevada population, it is important to understand breast cancer stages, surgery, and treatment.

Upon diagnosis, breast cancer is classified using a range of stage 0 to stage 4, indicating size, type, surgery option, and treatment options. The first classification is stage 0. This stage is characterized by cancer which is titled “carcinoma in situ,” this means that the cancer is non-invasive, or having remained within its “original place” (National Breast Cancer Foundation, 2012). This cancer can be found in two areas of the breast, the lobes and ducts. The first is lobular carcinoma in situ, which is generally not yet considered to be cancer. Some experts use the name “lobular neoplasia” in these cases, as it more accurately refers to the presence of abnormal cells, but does not yet label the cells as cancerous (National Breast Cancer Foundation, 2012). While doctors may not label these cells as cancerous, this diagnosis may indicate an increased risk of developing breast cancer in the future. The second area where these cells are found in the breast is ductal carcinoma in situ, or occurs within the milk producing ducts of the female breast. In this case, the abnormal cells have been found lining the milk duct(s) of the breast, but have not yet formed a tumor or solid form. This also means that the cells have not yet spread outside of the ducts into the surrounding tissue of the breast (National Breast Cancer Foundation, 2012). Cancer, if found at this stage, is highly treatable. If diagnosed in this stage and properly treated, the expected five year survival rate is 98.6% (National Cancer Institute, 2010). However, if the cancer is left untreated or undiagnosed, it has a chance of spreading into surrounding breast tissue and therefore progressing to another stage of classification.

The second classification is stage 1, in this stage the cancer is more evident, but is still contained in the area where the abnormal cells began to develop (National Breast Cancer Foundation, 2012). Stage 1 is broken down further, into two categories stage 1A and stage 1B. Stage 1A is a tumor, which measures smaller than the approximate size of a peanut, but has not spread to the lymph nodes near the breast. Stage 1B has a tumor the same size as stage 1A, however stage 1B also shows signs of cancer in the lymph nodes (National Breast Cancer Foundation, 2012). Stage 1 cancer is considered to be invasive, even though it has often not spread beyond its origination sight (National Breast Cancer Foundation, 2012). Individuals diagnosed with this classification of breast cancer have an approximate five year survival rate of 98.6% (National Cancer Institute, 2010).

The third classification is stage 2, in this stage the tumor is growing, but is still contained in the breast tissue. If the lymph nodes have been reached, it will only be the nearby lymph nodes affected (National Breast Cancer Foundation, 2012). This stage is broken down further, into two categories stages 2A and 2B. Stage 2A is a tumor which is less than two centimeters and has less than four axillary (armpit) lymph nodes affected by the cancer cells (National Breast Cancer Foundation, 2012). Stage 2 can also be classified by the presence of a tumor between two and five centimeters in size, with no spread to the lymph nodes. Stage 2B is a tumor whose size ranges from 2 and 5 centimeters and has less than four axillary lymph nodes affected by the cancer cells. Stage 2B can also be a tumor which is larger than five centimeters, with no spread of cancer cells to the lymph nodes (National Breast Cancer Foundation, 2012). This cancer is considered to be invasive and those diagnosed at this stage have a five year survival rate ranging from 98.6% to 84.4% (National Cancer Institute, 2010).

The fourth classification is stage 3, this stage is characterized by a tumor that has extended beyond the immediate region and typically has invaded nearby lymph nodes and muscles (National Breast Cancer Foundation, 2012). Stage 3 is broken down further into three categories, stages, 3A, 3B, and 3C. Stage 3A is a tumor whose approximate size is larger than that of a small lime. In addition to this tumor, small clusters of cancer cells are found in the lymph nodes. Stage 3B is a tumor of any size, with cancer cells invading the chest wall (National Breast Cancer Foundation, 2012). Stage 3B often exhibits evidence of swelling, inflammation, or ulcers in the breast tissue or chest wall. In this case, the cancer may also be found in nearby lymph nodes. Stage 3C is a tumor of any size, with cancer cells invading the chest wall, much like stage 3B. However, in stage 3C, the cancer has also invaded 10 or more lymph nodes (National Breast Cancer Foundation, 2012). Stage 3 of breast cancer is considered to be advanced, as the abnormal cells have moved through more than just breast tissue and has a five year survival rate of 84.4% (National Cancer Institute, 2010). While this cancer is considered advanced, there have been a growing number of effective treatment options discovered over the past years.

The final classification for breast cancer is stage 4, which is characterized by a tumor of any size and cancer cells that have spread to distant tissues and/or organs (National Breast Cancer Foundation, 2012), which indicates the cancer has spread to other areas of the body. This can include the brain, bones, lung and liver (National Breast Cancer Foundation, 2012). Diagnosis with stage 4 cancer has a five year survival rate of 24.3% (National Cancer Institute, 2010). Although, stage 4 breast cancer is considered invasive and incurable, current advances mean that more women are living longer, treating their breast cancer as a chronic condition. Therefore, the individual’s survival rate is affected by the stage at which the cancer is discovered and diagnosed.

As with any cancer, breast cancer patients experience many physical and emotional changes upon diagnosis and during treatment. Women diagnosed with breast cancer can undergo surgical procedures ranging from lumpectomy to double mastectomy. While a lumpectomy may not bring much physical distortion or disfigurement, mastectomy and double mastectomy bring large physical distortion and disfigurement. This change in physical appearance can lead women to feel depressed, less feminine, less attractive, less sexual, can cause feelings of loss of integrity and wholeness, etc. (Carver, 1998). While this physical change alone can be quite hard to handle, women who undergo chemotherapy in addition often experience hair loss, weight change, fatigue, appetite loss, and change in taste (Carver, 1998). These changes can greatly impact the patient’s daily life and relationships with family members and friends. The recognition of these changes before and during treatment often leads women to need additional care for stress, anger, and depression (National Cancer Institute, 2012).

Treatment Options

For most women diagnosed with cancer at stage I or II, lumpectomy surgery and radiation therapy is the chosen treatment method, as these are considered to be as effective as a mastectomy. Lumpectomy or partial mastectomy is a surgical procedure which removes the portion of the breast that contains a tumor or is affected in some way by the presence of cancer cells. The amount of tissue removed during the procedure is determined by the size and location of the tumor, as well as any hereditary or medical history factors (American Cancer Society, 2013). In some cases, small metallic clips are inserted into the breast tissue around the area where tissue is being removed. This is done to help specify a target area if radiation treatment will be completed in addition to surgery. After surgery, the removed tissue is analyzed to determine if any cancer cells lay close to the edges, the removed tissue is said to have "*positive margins*" if cancer cells are found within approximately two inches of the tissue edge (Morrow, 2012). If positive margins are found, the surgeon may choose to remove more breast tissue from the patient, this is called a *re-excision* (Morrow, 2012). When all cancer cells are found more than two inches from the edges of the tissue, it is said to have *negative* or *clear margins,* which means no further surgery will be need to remove cancer cells (Morrow, 2012).

For those women diagnosed with cancer in stages 3 or 4, lumpectomy is often not an option. In these cases, the best surgical option for removing the cancerous tissue is a mastectomy. Mastectomy is a surgery performed to remove all of the breast tissue, sometimes along with other nearby tissues if they have been determined to be affected by the cancer cells. While surgeons use the all-encompassing term mastectomy when talking with patients, there are in fact three different types of mastectomy (American Cancer Society, 2013). The first is a total mastectomy, in which the surgeon removes the entire breast, including the nipple, but does not remove any lymph nodes or muscle tissue. The total mastectomy is the most common type used to remove and treat breast cancer in advanced stages (American Cancer Society, 2013). Most patients can return home the following day, unless complications arise during or after surgery. The second type is the skin-sparing mastectomy, in which most of the skin over the breast, except the nipple and areola, is left intact rather than being removed with the other breast tissue (Nava, 2009). This surgery is slightly more complex than the total mastectomy as the surgeon must be careful not to damage the skin and try to cut in areas where the scaring will be hidden in a discrete manner. This surgery is used for women who plan immediate reconstruction of the affected breast(s). While this surgery can be used to remove smaller tumors, it is often not suitable for large tumors or tumors that were found close to the skin's surface (Nava, 2009). The final type is the radical mastectomy, which is a much more extensive operation, removing not only the entire breast, but also the axillary lymph nodes and pectoral muscles under the breast (American Cancer Society, 2013). Radical mastectomy is rarely completed today, unless the cancer is known to have spread to the chest wall.

Reconstructive surgery can be completed for women who have undergone either total or skin-sparing mastectomies (Nava, 2009). For patients who have undergone skin-sparing, most reconstruction is completed with the insertion of saline packs (salt water) or silicone implants, placed under the spared skin. For patients who have undergone total mastectomy, reconstruction is completed with the use of tissues from other parts of the body (American Cancer Society, 2013).

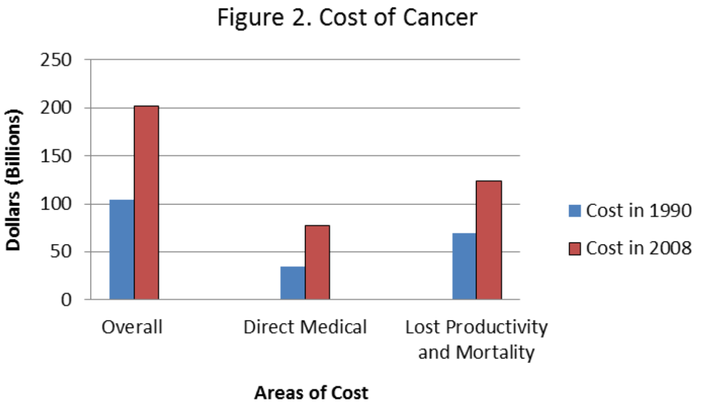
Radiation vs Chemotherapy

Radiation therapy is often completed in combination with lumpectomy surgery. There are two forms of radiation therapy, external and internal. External radiation therapy is where highenergy rays or particles are targeted at the area of the breast where the tumor was removed via a machine located outside the body. These rays destroy cancer cells (National Breast Cancer Foundation, 2012). This treatment is combined with the surgery to help reduce the chance that the cancer will return. This is the most common form of radiation therapy for women with breast cancer. If cancer was found in the lymph nodes in addition to the breast tissue, then the radiation may be targeted at this area as well. The second form of radiation therapy is internal radiation, in which radioactive seeds or pellets are placed into the breast tissue next to where the cancer is found. This is a very direct and concentrated form of radiation, and is used much less often (National Breast Cancer Foundation, 2012).

Chemotherapy is the administration of cancer-killing drugs, which can be given intravenously (injected into a vein) or by mouth. Chemotherapy is given in cycles, with periods of treatment followed by periods of recovery. Chemotherapy treatment usually lasts for several months, but may last longer in advanced stage cases (National Breast Cancer Foundation, 2012). There are two classifications of chemotherapy treatment: adjuvant and neo-adjuvant. Adjuvant chemotherapy is when chemotherapy is given to patients who have no evidence of cancer after their surgery is complete. Surgery was used to remove all the cancer that could be seen, and then adjuvant therapy is given to kill any cells that may have been left behind. Neo-adjuvant chemotherapy is given before surgery, typically in an attempt to shrink large cancer tumors so that they are small enough to be removed via surgery (National Breast Cancer Foundation, 2012). An additional advantage of this is that doctors can monitor how the cancer responds to specific chemotherapy drugs.

Cost of Cancer

Diagnosis with cancer often brings enormous changes for both the patient and patient’s family. One of the most debilitating impacts is the financial burden that a cancer diagnosis brings. It has been determined that no matter a family’s socioeconomic status, almost all those confronted with cancer treatment will deal with fiscal problems (Berkman, 1993).



American Cancer Society 2013

Statistics indicate that socioeconomic factors play a significant role in overall survival after cancer. The disadvantaged often have much lower survival rates compared to those who are advantaged (Brenner, 1991). Families with low socio-economic status must make extraordinary sacrifices to obtain and pay for cancer care. They frequently delay seeking help for symptoms. Therefore, those classified as falling below the poverty line are more likely to be diagnosed with cancer at an advanced stage and thus treatment options are significantly limited and much more costly (Berkman,1993). These limited treatment options are often out of reach for economically disadvantaged individuals and so often they choose to go without treatment. It is estimated that more than 37 million persons in the United States are uninsured, and no estimate of the number of underinsured exists (American Cancer Society, 2013). Some poor families, but not all, are eligible for Medicaid or Medicare coverage. However, those who are determined to be eligible know that these healthcare programs are not designed to deal with long-term care; instead, Medicaid and Medicare were meant for inpatient, acute care (Bried, 1992). While these families do have some medical coverage it will never be enough to cover the cost of cancer treatment.

Even for a typical middle-class family with insurance, treatment for cancer will still cause an increase in financial demands to cover medical costs. While insurance coverage could increase the patient's ability to receive cancer treatment, the financial costs from out-of-pocket expenses, such as deductibles and copayments, can be a financial burden. In addition to covering the cost of deductibles and copayments, some insured individuals are also required to pay out-of-pocket when gaps in coverage are discovered (Berkman, 1993). Some insurance companies have been shown to be slow in covering the extensive needs of cancer patients. When determining coverage of home care, long-term care, prosthetic devices, and restorative surgery, many policies will pay only if the patient has been hospitalized for at least 90 days (Berkman, 1993). Lack of coverage for these services can again increase the financial burden for the patient's family. Many insurance policies may not pay for complications that arise during treatment. Even for a middle-class family these unexpected additional costs, can force a family to choose between food and shelter and paying for the patient's cancer care (Berkman, 1993).

The average expenses for a family dealing with cancer fall into these areas: doctor visits, lab tests (blood tests, urine tests), clinic visits for treatments, room charges, equipment, doctors, pathologists, imaging tests (such as x-rays, CT scans, MRIs), radiation treatments (implants, external radiation, or both), drug costs (inpatient, outpatient, prescription, non-prescription, and procedure-related), hospital stays, surgery (surgeon, anesthesiologist, pathologist, operating room fees, equipment, medicines), and home care (equipment, drugs, visits from specially trained nurses) (American Cancer Society, 2013).

When considering the financial burden for cancer patients, we often think of the surgery and treatment, neglecting to consider the additional personal expenses that arise. These additional expenses include transportation, paying for parking, paying to stay in a nearby hotel during treatment, child care, housekeeping services, nonprescription medicines, orphan drugs (drugs developed specifically for a rare form of cancer), and even lost wages as a result of the disease and its treatment (Berkman, 1993 and Callanan, 2012). These lost wages may be due to taking time off work for daytime treatment, as many treatment services are offered only during business hours. This means that the patient must accept a reduction in pay for those hours not at work (Callanan, 2012). Another reason for lost wages can be linked to a family member having to stop work in order to care for the cancer patient if they are at an advanced stage (Macmillan, 2006). In fact, a 2010 survey reported that more than 57% of 1,000 cancer survivors who were working before their cancer diagnosis had to either give up their job or change roles after diagnosis, thus resulting in pay reduction or loss (Macmillan, 2006).

Macmillan (2006) found that the financial status of cancer patients and their households is negatively affected in 91% of recorded cases. These family’s average income levels fall approximately 50% after a member’s cancer diagnosis. These financial strains have a significant, negative impact on the family’s functioning and the family’s emotional status. These strains tend to be more dramatic in younger families and among patients with more advanced stages of the disease (Callanan, 2012).

Mammography Screening Controversy

According to data from the National Cancer Institute’s Surveillance Epidemiology and End Results (SEER) program, the death rate from breast cancer went down 30% from 1990 to 2005 due to mammography screenings (Kopans, 2010). Since then, multiple studies have shown that mammography decreases deaths in randomized controlled trials. If all women aged 40 and older participated in mammography screening, the studies estimate the potential benefit would be a decrease in deaths of approximately 50% (Kopans, 2010). In addition to lower death rates, both surgical and drug therapies for breast cancer have better results when cancer is found in early stages.

In the 1980s, a study was completed in two Swedish counties. Part of the population was randomly chosen and offered mammography screening, the other portion of the population was not invited to screen and thus acted as the unscreened controls (Kopans, 2010). In 1985, the preliminary results published showed a statistically significant 30% decrease in breast cancer deaths among the study participants. This decrease was in women ranging from 40 to 74 years in age. In addition to the study in 1980, another screening trial was held in Stockholm, Malmo, and Gothenburg (all Swedish); in addition to Edinburgh, Scotland (Kopans, 2010). In 1994, the data from these trials showed a 25% reduction in death for women aged 40 to 74 years who were screened (Kopans, 2010).

However, in 1993 a Canadian study called all previous study data into question when it showed no benefit for mammography (Begg, 2002). The Canadian National Breast Screening Study (CNBSS) showed a very low reduction in death rates due to screening, and stated that all previous mammography studies lacked uniformity in their guidelines. This made it difficult to draw definitive conclusions about the effectiveness of screening for breast cancer. The study authors stated that these difficulties stemmed from the fact that previous studies were conducted with healthy women, the majority of whom would not likely experience cancer (Begg, 2002). The claims from this study, along with the National Cancer Institute’s (NCI) decision to drop support for screening women ages 40 to 49 years, are the primary reasons for the mammogram controversy (Kopans, 2010). The controversy has continued to bring questions about the effectiveness of mammography screening in reducing breast cancer deaths, and has also brought forth questions about mammography's cost effectiveness (Kopans, 2010). In order for screening mammography to be viewed as cost effective by public health policymakers, the magnitude of its impact on mortality must be sufficient to offset the attendant costs and morbidities, which is the major reason why some organizations recommend screening for women over 50 years of age, but do not recommend it for younger women, since the study results show a much smaller risk reduction in younger women (Begg, 2002).

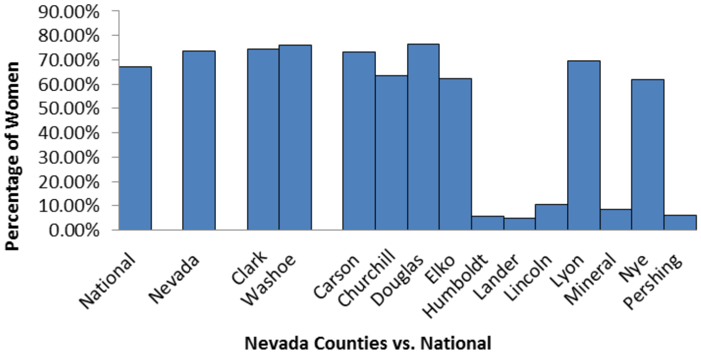
However, a careful review by the US Preventive Services Task Force shows that the Canadian study design and execution had major flaws (Kopans, 2010). The study was seriously underpowered, which means that the study did not recruit enough women to participate in the trial to have enough women who would be likely to develop breast cancer. These low numbers do not allow for data to show any statistically significant decrease in death among the screened women (Kopans, 2010). In addition to the low numbers, it was also determined that the quality of the mammography given to participants was poor. In fact, the Canadian's own reference physicist stated that the quality of the mammography during the trial was far from state-of-the-art, it was even poorer than the quality of screening being practiced in Canada (Kopans, 2010). Additionally, it was determined that the nurses and clerks who had assigned the women to each screening group knew which women had clinically evident breast lumps, as well as those who had palpable axillary lymph nodes, showing advanced incurable cancer. It is likely that the study had an excess of advanced cancers assigned, from the start, to the mammography group (Kopans, 2010). With these weaknesses having been brought forth, the mammography recommendations have returned to screening every one to two years for women 50 and older and their effectiveness is being questioned less and less.

More recently, the breast cancer controversy resurfaced when the U.S. Preventive Services Task Force changed the starting age for screening to 50 years of age from 40 years of age and changed the frequency recommendations from every year to every two years (Warner, 2011). The change of screening age was made due to the results of a randomized controlled study which showed a non-significant reduction in risk of death from breast cancer when screened. A significant reduction has been seen for those 50 years of age and older however. Thus, the recommendations were changed to 50 years of age and older. It should be noted that the study may have been limited by the mammography technique used, small sample size, and only a 70% compliance rate (Moss, 2006). The frequency of screening was altered due to observations suggesting that reduction in mortality from breast cancer was not more significant when the individual was screened every year verse every 18 to 33 months (Kerlikowske, 1995). It should be noted, however, that while this may be true for cancer cells with a slower growth rate, it is not accurate when looking at cancer cells that have a fast growth rate.

Mammography Screening Rates

Considering the large impact that cancer has, both on the nation and on the individual themselves, as well as the number of breast cancer cases and low screening rates in Nevada, the State Health Division has made breast cancer prevention a priority. Since we do not have effective means to cure or eradicate breast cancer, the state of Nevada, in partnership with the Nevada Cancer Coalition, felt that the best first step was to increase mammography screening rates so that breast cancer can be found in the earlier stages and thus require less surgery, less treatment, less death, and may reduce financial burden. The Nevada Health Division has prioritized breast cancer screenings as one of its strategic efforts to improve the health of Nevadans, more specifically, because of the low rate in the rural areas.

Figure 5. Mammography Screening Rates, 2012



Nevada State Health Division, 2013

Mammography Screening Locations

While completing the research for this project it was discovered that there was not a comprehensive source that listed mammography screening locations in the state of Nevada. The Nevada Cancer Coalition and myself felt that this resource should be made available as soon as possible in order to reduce this lack of knowledge about screening locations as a barrier. Thus, I researched mammography screening locations throughout the state and called each location to confirm that they did in fact offer mammography screenings. After creating a list of locations (including those visited by the Mammovan), I created an interactive Google map showing all available locations. For the locations that were permanent facilities, the name of the location, address, phone number, and hours of operation are listed when the curser is placed over the google “location marker”. For the Mammovan visited locations, a link to the Mammovan schedule appears when the curser is placed over the location. This way the individuals can see when the Mammovan will next be visiting their town. We hope that this will be a great resource for all women searching their town for a location to receive a mammography screening.

Relationship to the Ecological Model of Health

The Ecological Model of Health was introduced as a conceptual model in the 1970s by Urie Bronfenbrenner. Bronfenbrenner established the model to help further the understanding of dynamic interrelations among personal and environmental factors (Glanz, 2008). The conceptual model became a health theory in the 1980's, but was revised by Bronfenbrenner multiple times before his death in 2005 (Glanz, 2008). The theory looks at individual, interpersonal, community, and societal factors of health behaviors.

In the case of breast cancer, the individual factors can best be described as the ability to seek mammography screening and if the results should come back as positive, seek treatment. This may mean educating oneself and searching for resources and answers to help themselves receive mammography screening.

Interpersonal factors are elements within the closest relationships of the individual (peers, partners, family) that increase or decrease the individual's likelihood of seeking mammography screening. In this case, the interpersonal factors are a reminder system related to mammography screening. This reminder to have a mammography screening done can come from the spouse, children, parents, siblings, and close friends. This reminder from those whom the individual is close, can have a large impact of the individual's decision to seek screening or not.

Community factors are those within extended relationships (school, workplace, neighborhood) that increase or decrease the individual's likelihood of seeking mammography screening. In the case of community this refers to an extended reminder system. The extended reminder system can be the individual's doctor, advertising for breast cancer awareness events, and reminder cards/letters sent by clinics and local coalitions. This level also includes the availability of screening services. This includes free services such as the Mammovan and informational services provided by community health workers and Nevada Health Services.

Societal factors are norms and laws that either sustain or do not sustain resources to create a healthy environment. In relation to breast cancer screening, this means creating societal norms that encourage women to seek screening and discourage feelings of fear and helplessness. This can also mean establishing laws and policies that make it possible for all women to be screened for breast cancer and reduce the barriers Nevadan women face.

Research Question

After observing the low screening rates in the rural areas of Nevada, this question emerges: What barriers have women in rural Nevada faced in seeking and receiving mammography screenings, now and in the past?

Methods

In order to determine the barriers that Nevadan women face in receiving mammography screening, we decided to hold focus groups in rural Nevada and ask women what barriers they faced or had overcome in seeking mammography screening.

Why Focus Groups?

Focus groups were chosen as a method of data gathering as they are considered to be relatively low-cost, less time consuming, and offer high face-to-face validity. The researcher can know that the answers provided are likely to be valid and true as they are face-to-face with each participant (Kitzinger,1995). Focus groups are particularly useful in exploring the participants' knowledge, impressions, and experiences which can be used to gather information about what people think, how they think, and why they think that way. Focus group data are particularly sensitive to cultural variables and experiences (Kitzinger,1995). The format of focus groups also allows for the moderator to probe participants' answers, gathering more clarification and detail as needed. This format is useful when participants raise unanticipated issues or answers, and is especially appropriate when the data are gathered via a series of open-ended questions allowing participants to express what is of importance to them, in their own vocabulary, showing their own priorities and interpretations (Kitzinger, 1995). Thus, the main reason for using a focus group format is to allow the researcher to investigate topics where opinions and attitudes are conditional or uncertain.

In addition to focus groups, an online survey was created as a second method of data collection. An online survey was developed and distributed as they are inexpensive to carry out and make it much easier to recruit large numbers of participants from across the state (Evans, 2005). In addition to the low cost and statewide reach, online surveys allow for a fast and organized manner of gathering data, which in turn makes the data analysis faster and cheaper (Evans, 2005). While the amount of data gathered via online survey is much larger than focus groups, the electronic format with which the data are organized and stored makes the analysis easier to complete (Evans, 2005).

Procedures, Participants & Locations

Funding, provided by the Nevada Cancer Coalition, allowed for five focus groups to be held. The Nevada Cancer Coalition staff and I determined that all focus groups should be held in rural areas, as the rural areas have the lowest screening rates. We decided to hold two focus groups in areas with higher recorded rates, one in an area with an average recorded rate, and two in areas with low recorded rates. We felt that by talking with women from each of these areas we could determine which barriers were specific to rural areas and which were statewide barriers. The areas chosen for higher recorded rates were Carson City and Minden (Douglas), both of which had recorded percentages above 70. The area chosen for average recorded rate was Elko (Elko), which had a recorded percentage around 60. The areas chosen for lower recorded rates were Winnemucca (Humboldt), and Mesquite (outside Clark), both of which had recorded percentages around 10. Focus groups were held at the following locations: Partnership Carson City (Carson), Virgin Valley High School (Clark), Partnership of Community Resources (Douglas), Northeastern Nevada Regional Hospital (Elko), and Humboldt General Hospital (Humboldt). While Clark county itself is considered urban, the town of Mesquite, where the focus group was held, is an hour from Las Vegas and is considered rural. Focus group locations were determined by looking at mammography screening rates based on each Nevada county. Each county reported mammography screening rates to the Nevada State Health Division, as seen in Figure 5 on page 21.

The five focus group and survey questions were first drafted by myself and Cari Harrington of the Nevada Cancer Coalition, biased on the information we were looking for regarding barriers for women in the rural areas of Nevada. After drafting these questions, I completed online research of focus group development and question writing, as well as read *The Focus Group Kit (1997)* book series published by Sage publishing. In addition to these readings, guidance was also given via phone interview with Jo Anne Earp, author of *Increasing Use of Mammography Among Older, Rural African American Women: Results from a Community Trial,* a journal article based on focus group results obtained in North Carolina, which I had found during my research. Examples of questions were provided by Jo Anne Earp via focus group materials. After completing this research and reading Cari and I re-evaluated and made a few changes to the five focus group questions based on the new information we had learned. Emails were exchanged between coalition representatives in the chosen areas to determine dates, times, and locations for each focus group.

Participants were recruited using the flyers shown in Appendices A through E. Coalition representatives and staff posted the recruitment flyers in local area hospitals, clinics, community centers, and senior centers. The flyers told potential participants the date, time, and location for the focus group, as well as the fact that they would be provided refreshments and a $20 WalMart gift card. Women who wished to participate were asked to RSVP to the University's Center for Program Evaluation, in order to ensure that the facilitators would have enough food and gift cards.

At each focus group, participants were welcomed by the facilitators and offered refreshments as they arrived, signed in, filled out the short demographic questionnaire (Appendix F). Participants were given a short introduction explaining the purpose of the focus group and the procedure that would be followed. It was explained to the participants that one facilitator would lead the group discussion, asking one question at time, allowing time for each of participant to respond. Each response would be recorded on the flip chart by the lead facilitator as well as on the computer by the other facilitator. If the participants gave a response or answer that was unclear, the facilitator asked them to expand on or explain their answer. Participants were asked to respect other participants' responses and informed that each recorded response would remain anonymous. Once all questions had been asked and all participants had had a chance to respond, the focus group was ended by the lead facilitator, who thanked the participants for attending and for answering each question openly. The lead facilitator then gave each participant a $20 Wal-Mart gift card as a thank you for their time. Focus groups were completed between September and October 2013.

The five focus groups were composed of 32 female participants, ranging in age from 40 to 83 years old, all residents of Nevada. There were two focus groups held in Carson City as we had enough participants for one English speaking group and one Spanish speaking group. The English speaking group was made up of 10 participants, while the Spanish speaking group was made up of 6 participants. We conducted two separate focus groups here due to the number of participants and the fact that we had six participants that were primarily Spanish speaking. The Spanish speaking group was conducted entirely in Spanish and the transcripts were later converted to English for analysis. The focus group in Minden was made up of eight participants, all of whom were English speaking. The focus groups in the more rural areas of Nevada were quite a bit smaller in size; Elko had four participants, while Winnemucca and Mesquite had only two participants each. All participants in these areas were English speaking. The majority of participants were 40 to 60 years of age, spoke English, had earned a four-year college degree or had taken a few college level courses, were either working-full time or not looking for work, and had an annual household income of $40,000 or less. When comparing focus group participants' education levels and annual incomes to the data reported in 2013 to the US Census Bureau, our participants appear to be a good representation of the Nevada population's education. However, the annual household income for our participants was lower than normal. The Census Bureau report states that the average Nevadan citizen (84.4%) has a high school degree or higher and that the average annual household income is around $49,760 (US Census Bureau, 2013 and Department of Numbers, 2013). A table of the focus group demographics can be found in Appendix H.

In addition to focus groups, an online survey was developed to reach areas covered by the focus group areas as well as other rural areas in Nevada. The survey was composed on Survey

Monkey and was open to all women in Nevada from September 2013 to December 2013. Nevada Cancer Coalition posted the Survey Monkey link to the Nevada Cancer Coalition website, Nevada Cancer Coalition Facebook page, local newspapers, and had Wendy Demonte promote the link on her "Health Spot," during the evening news.

Analysis

The computer program NVIVO was used to assist in the analysis of the focus group data. NVIVO is a qualitative data analysis software package. It was designed for qualitative researchers working with very rich text-based information. The program is predominantly used by academic, government, health researchers, and commercial researchers. NVIVO is intended to help users organize and analyze non-numerical or unstructured data. The program allows users to classify, sort and arrange information in order to examine relationships in the data.

The focus group transcripts for each focus group were imported into the NVIVO computer program to begin analysis. A word frequency count was run via NVIVO to begin looking for common themes which could appear as the transcripts were coded. These possible themes were entered as nodes into the NVIVO program for easy coding access. The transcripts were then read through individually, coding for common themes as they occurred. If a new theme was discovered, which had not been found via the word count, a new node was created and the new theme was coded. Each transcript was looked over three times by myself, to verify that all possible codes had been identified and recorded into the NVIVO system. Once all transcripts had been coded by theme, we completed queries (matrix coding) via NVIVO to identify patterns. Matrices were run for each question and its nodes (themes), for all questions and node (theme) occurrence, and for each location and its nodes (themes). The NVIVO data/results were used to summarize the themes discussed in the focus groups and therefore identify barriers to screening for focus group participants.

After reviewing the methods by which the online survey was developed, and the data which had been collected, it was determined that the online survey data would not be included in the analysis and results. The data gathered through the online survey may not be accurate (participants could provide dishonest answers) and did not come from the desired population.

Limitations

While the focus groups were extremely helpful in identifying possible barriers that rural Nevada women face in receiving mammography screening, there were some limitations determined after the focus groups were complete. The largest limitation for the focus groups was the recruitment process used to obtain participants. As previously stated, participants were recruited by placing flyers in community centers, senior centers, hospitals, and doctor’s offices. While we did get participants in the desired age group from these locations, we realize now that placement of flyers in places such as grocery stores, WalMart stores, churches, and libraries, may have reached a wider portion of the desired population. In addition to increasing flyer locations, a second limitation was having the incentives of refreshments and a $20 gift card advertised on the flyers. This may have cause some women to participate purely to receive a gift card and not because they were really interested in sharing their barriers. Had this been the case the women may not have been as talkative or open to sharing their experiences, making their participation less useful in determining barriers to mammography screening.

Another limitation, the wording used on the recruitment flyers stated that we were looking for female participants who were willing to share their “experience with breast cancer screening or the reasons” they had “not been screened”. We had meant for this statement to encourage women who had been screened in the past, but who were not be screened now, to share the barriers that were currently facing in seeking screening. We realized afterwards, however, that this wording appeared to encourage participants who had always been screened and did not really have any barriers to screening. Thus, this wording on the flyers is a limitation in that it encouraged participation from a few women who were not part of our target audience and who could not really help us to identify current barriers to mammography screening.

Additionally, in an attempt to reduce any chances of having identifiable data, especially in the focus groups with only two or three participants, we did not use any identifying markers to monitor each woman's answers. While this was effective in keeping all answers from being linked to any particular individual, it also meant that we were unable to monitor how many times each woman mentioned a theme. Thus, the data collected was analyzed by frequency of theme and not by how many women mentioned the theme. This is a limitation in that we could not control for any particular woman who may have mentioned one particular theme many different times during the course of the focus group. This could mean that one woman's focus on a particular theme caused the theme to appear very high on the list, when in fact it was only important to one or two woman rather than the whole group. Furthermore, this lack of identifying markers made it impossible to link the answers each woman gave with the demographic data she had provided at the beginning of the focus group session.

A final limitation for this research was the online survey, which was ideally completed to gather large amounts of data, but which in the end was excluded from this paper. While surveys can be good for reaching a vast population, they also have many limitations. First, online surveys are only accessible to those who own a computer and know how to operate the computer itself, the internet, and a survey online. Completing surveys online also makes it hard to keep participants from completing the survey more than once, which would alter the survey findings. Second, online surveys often experience “nonresponse”; this means that there is often a low response for online surveys and/or the survey is answered by individuals who have a heavy interest in the topic. This can easily sway or skew the data that is gathered from the survey. While research for writing survey questions was completed prior to the survey’s development, a lack of formal training in conducting surveys ultimately lead to error and poor survey development.

In addition to possible internet access limitations, multiple submissions, nonresponse, and measurement error; there were also some limitations in the survey itself, which were discovered after the survey had been released. Upon reading Dillman’s principles for constructing web surveys, it was discovered that there were many principles which were not addressed in our online survey (Dillman, 1986). The first example of this is principle number five: “provide specific instructions on how to take each necessary computer action for responding to the questionnaire.” This idea was not considered and not included in the online survey for this research. Should the participants not have had knowledge about how to complete a survey online, they may have opted to not complete the survey at all. Had the participants been provided with these instructions, we may have received more online survey submissions (Dillman, 1986). Another principle not previously considered was principle ten: “use graphical symbols to convey a sense of where the respondent is in the completion progress.” The use of a graphical symbol was not included in our online survey, this may have affected the number of participants who took the survey as they could not see how far along they were in the survey. Not knowing this may have deterred some women from participating in the online survey. Finally, Dillman’s eleventh principle says that one should “be cautious” about the use of “check-all-that-apply and open-ended questions” in an online survey (Dillman, 1986). Both of these were used in our survey for breast cancer screening. Thus, this could create a possible limitation in the data that was gathered.

Results

Focus group participants were asked five open-ended questions. Below is a list of each question, a graph showing the responses based on category, and some examples of answers given for the most common category.

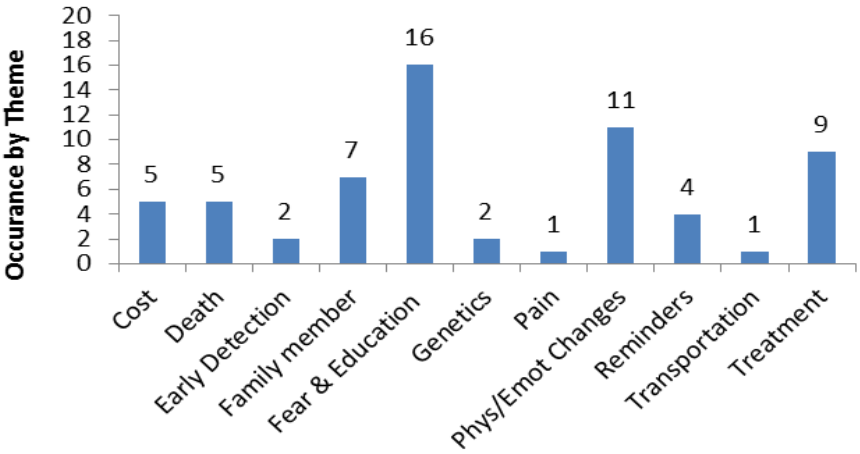
Themes by Question for Focus Groups

The first question asked was “What comes to your mind when I say breast cancer screening?” This question was asked in order to gauge the positive, negative, or neutral opinion that women held about mammography screening overall. The participants provided answers regarding the high cost of cancer and its treatment, the role of insurance coverage or lack thereof, mammography screening and its impact on cancer diagnosis (early detection), fear of cancer and its possible outcomes and treatments, pain or discomfort experienced during the screening, as well as fears of breast tissue damage or rupture of tumor or breast implants, and lack of transportation to screening locations – especially in rural areas. Figure 6, below, shows the number of times each theme was mentioned in response to the question. The most common theme was “Fear & Education” in relation to positive test results. Participants made statements such as:

> *“It was frightening the first time.”*
> *“Fear of if you get screened and they find something you’ll have to go to Reno for treatment.”*
> *“Afraid of what they are going to find out….fear of finding out that they are the next ones in the genetic chain”*
> *“Worried about radiation”*

> *"If there is any tumor in there they will squish it and it will pop."*
> *"You hear it hurts like crazy, listening to other peoples' nightmare stories."*
> *"Some women can afford it (screening) but they are afraid of the radiation, they say I don't want that in my body."*
> *"What's the point if you can't treat – you just know you are dying."*

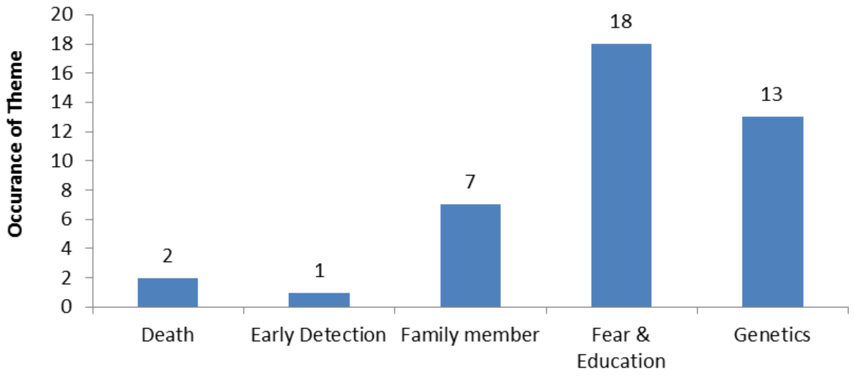
Figure 6: Question 1: What Comes to Your Mind When I Say "Breast Cancer"?



Next, participants asked if they felt women like them (age 40 and older with no personal history of cancer) were at risk for breast cancer. This question was asked to see if participants were facing barriers to seeking the screening itself or if the main barrier was not understanding their risk of developing breast cancer. The focus group participants responded yes and provided statements regarding family or friend's deaths due to cancer, family or friends who had been diagnosed with cancer, some statements about high risk of cancer or information they had heard about high cancer incidence, and genetically altered foods which may increase cancer risk. Figure 7, below, shows the number of times each theme was mentioned in response to the question. The most common theme was "Education & Knowledge." Participants made statements such as:

> *"1 in 11 women will get breast cancer."*
> *"Odds are 1 in 9 and there are 9 of us here."*
> *"All the chemicals that they are enhancing our food supply with has a lot to do with it, the genetically altered seeds, hormone injected beef."*
> *"The region stresses eating healthy, growing your own food, I think all of that tends to help."*
> *"We're pretty healthy and conscious, educated on what's helpful and what's good."*
> *"I do it because I'm supposed to. I know that's what you need to do."*

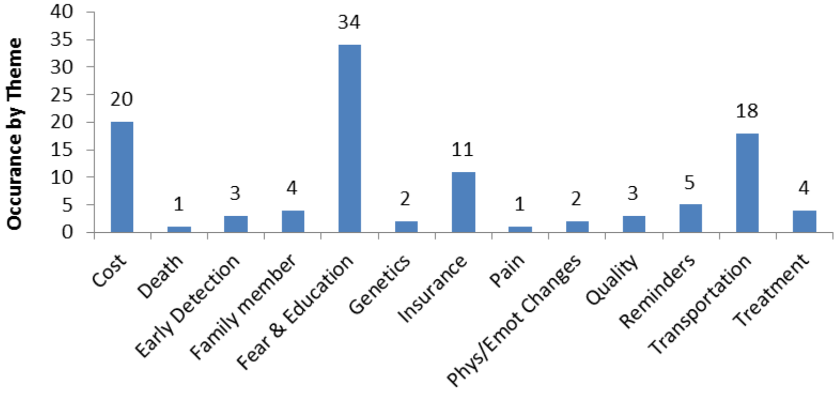
Figure 7: Question 2: Do You Think That Women Like You are at Risk for Getting Breast Cancer?



Question three asked why they thought some women choose not to get screened for breast cancer. This question was asked to see if the barriers the women faced themselves was the same as the barriers they felt other woman faced, or if they felt that the barriers they faced were unique to themselves. The woman answered this question based on what barriers they felt other woman were facing. Participants responded with answers about the high cost of screening and treatment which can be hard to afford, lack of insurance to cover screening cost, and lack of support and encouragement from family and friends; therefore they do not see the need for screening. Some women feel they are not at risk because there is no family history of cancer. Some mentioned fear of discovering that one does have breast cancer and the possible physical changes in regards to surgery and treatment, lack of knowledge about the importance of being screened and how treatment costs can be reduced, pain experienced during the mammogram itself, lack of reminders from doctors, friends, or family; issues with transportation to the screening location, inability to get time off from work and/or find a babysitter for children, and fear of treatment or death should a tumor or cancer cells be found, some women would rather not know. Figure 8, below, shows the number of times each theme was mentioned in response to the question. The most common theme was "Cost" followed closely by "Transportation/Childcare." Participants made statements such as:

> Cost:
> *"The cost of the mammogram"*
> *"1-2% of women who can afford to do it"*
> *"Some women have no insurance and money."*
> *"I think more people would use it if it was free or low cost. A lot of people don't have insurance."*
> *"Requiring a doctor's referral"*
> *"They can screen, but they can't help you with treatment afterward."*
>
> Transportation/Childcare:
> *"Transportation or they don't have a car"*
> *"Location and travel; in rural location you have to travel to find a place."*
> *"Many of the women's husbands work in the mines and they may not have transportation while their husbands are working."*
> *"They are working and they can't take time off and the schedule isn't convenient."*
> *"I don't have the time. I'm busy. Taking care of parents, taking care of family"*

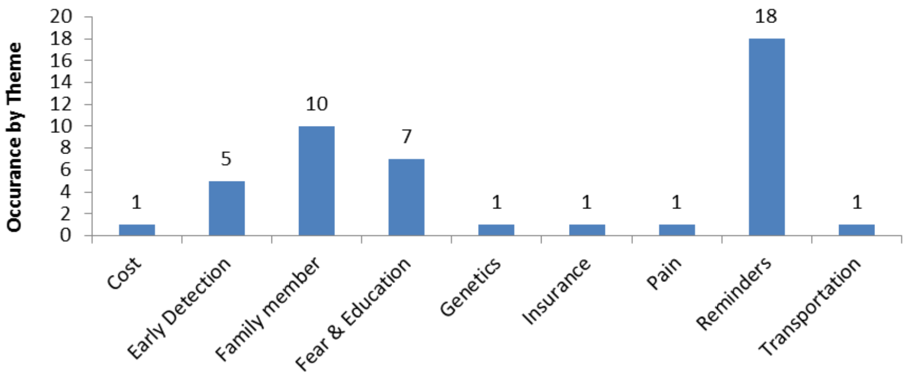
Figure 8: Question 3: Why Do You Think That Some Women Choose Not to Get Screened for Breast Cancer?



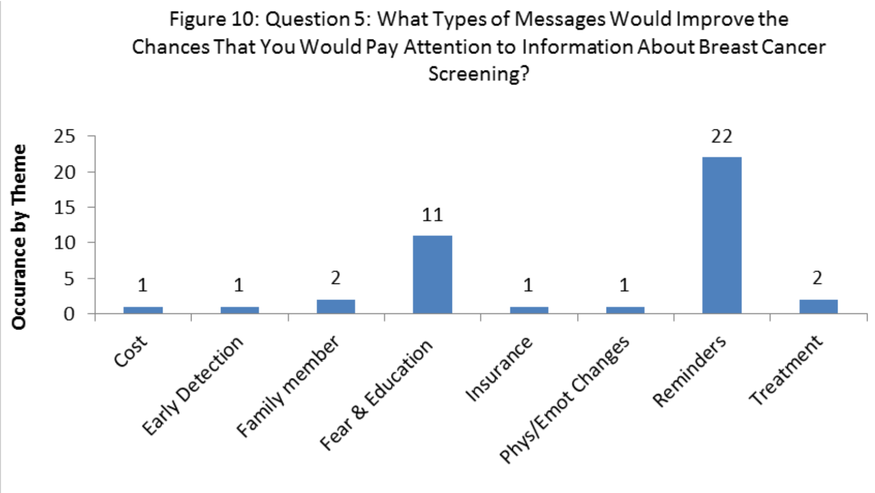
Participants were then asked what has or has not influenced or motivated them to get screened for breast cancer in the past two years. This question was asked to determine what motivation(s) women had felt increased or would increase their willingness to seek a mammography screening. Participants responded with answers about encouragement from family members or friends to get screened, history of family or friends who had been diagnosed creating a desire to be screened, fear of not finding breast cancer early enough, knowledge of statistics about breast cancer risk; reminders from physicians, cards in the mail, reminders during breast cancer awareness month, insurance coverage allowing the screening to be free or low cost, and feeling a lump or symptom that may mean cancer is present. Figure 9, below, shows the number of times each theme was mentioned in response to the question. The most common theme was "Reminders." Participants made statements such as:

> *"Reminder postcard"*
> *"I always get a reminder letter."*
> *"Advertising during the month of October"*
> *"In the clinics, there are flyers."*
> *"The rodeo had a huge thing—wear pink night."*
> *"My doctor schedules the screening for me."*
> *"Wendy Damonte, personal stories, like the tv news caster"*
> *"Media attention that Angelina Jolie got, not relatable, but it got people talking about it"*

Figure 9: Question 4: If You Have Been Screened, What Influenced or Motivated You to Get Screened for Breast Cancer in the Past 2 Years?

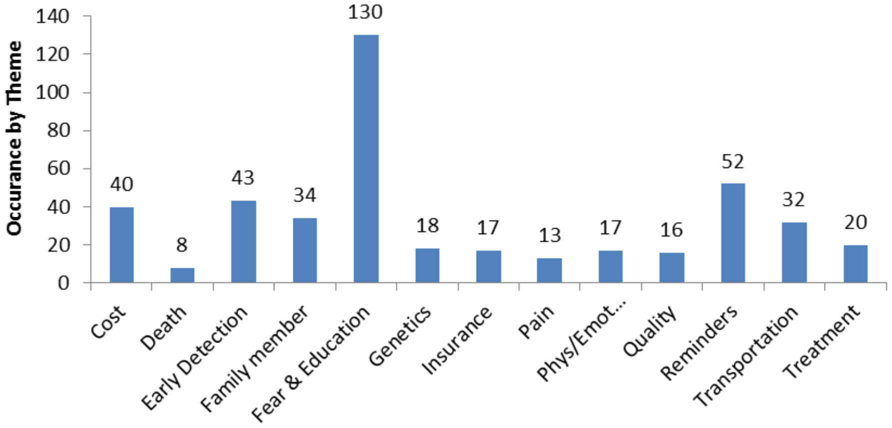


The fifth and last question asked what types of messages would improve the chances that they would pay attention to information about breast cancer screening. This last question was asked in an attempt to determine what methods could be incorporated into a program to help increase the women's' willingness to participate in mammography screenings. Participants responded discussing messages with information about where to get screened, phone numbers, cost or cost exemption; messages about uniting together, supporting each other so that all women feel empowered to be screened; messages with facts and figures regarding breast cancer risk and survival; participants also liked reminder cards sent via mail or reminders from their physician. Figure 10, below, shows the number of times each theme was mentioned in response to the question. The most common theme was "Reminders," as can be seen from the quotes listed for the previous question.



Each individual focus group question had a different "top" theme that rose to the surface. However, when we look at all the questions together, Figure 11, the most prominent theme was lack of "Education & Knowledge" regarding breast cancer and mammography screening. The least prominent theme when looking at all the focus group questions combined was "Death" or fear of death in regards to a diagnosis with breast cancer.

Figure 11: Total Occurance of Themes During Focus Group



In addition to looking at the themes that arose for each question asked, we looked at how often each theme was mentioned in each focus group location. When looking at the occurrence of each theme for each focus group location, we determined that the most commonly mentioned theme in every location was "Education and Knowledge." Participants' statements included:

> *"Dense tissue: When do we have to repeat the screening?"*
> *"Do women who have gone through infertility treatment and have had hormone shots have higher risk of breast cancer?"*
> *"Susan G Komen said that they would help get free mammograms and then I went and they knew nothing about it at the center."*
> *"Does all the chemicals that they are enhancing our food supply with have a lot to do with it, the genetically altered seeds, hormone injected beef?"*
> *"I think for a person going in for their first time. I think they'd want to know how soon they'll get the initial results back and how the test is done." "and when to start getting tested"*
> *"Some women can afford it but they are maybe afraid of the radiation, they say I don't want that in my body; it may be lack of information or inconsistent information"*
> *"Do they do anything different for women with breast implants?"*
> *"If you get screened free then is it considered a pre-existing condition if you need treatment?"*
> *"What is the survival rate if found early?"*

Thus, the findings would appear to show that the biggest barrier for all locations in regard to theme mentioned most is lack of knowledge or confusion about when screening should be completed, how helpful it really is in treatment and survival, and how safe the mammogram is itself (if it does more damage than good).

While the most common theme mentioned for each focus group location was the same, the second highest and least commonly mentioned themes did differ by focus group location, see Figure 3.

Figure 3: Themes by Location of Focus Groups

Location	Top Theme Mentioned	2nd Highest Theme Mentioned	Themes Least Mentioned
Carson City (Spanish)	Education & Knowledge	Early Detection	Genetics, Physical & Emotional Changes, and Treatment
Carson City (English)	Education & Knowledge	Quality and Reminders	None
Elko	Education & Knowledge	Reminders	Pain and Treatment
Winnemucca	Education & Knowledge	Fear and Transportation	Pain and Physical & Emotional

			Changes
Gardnerville/Minden	Education & Knowledge	Fear	Death, Pain, and Treatment
Mesquite	Education & Knowledge	Fear	Death, Physical & Emotional Changes, and Treatment

Based on these themes it would appear as though the barriers of least concern are "Treatment," "Pain," "Physical & Emotional Change," and "Death."

Discussion

Based on the findings for the focus groups discussed above, we can see that the barriers which should be addressed as soon as possible are "Education & Knowledge" followed by "Fear." Women appear to need more education regarding the necessity of mammography screening, the screening's effectiveness, the screening's safety, and how often screening should be completed. In educating women about these components of breast cancer screening, we will also likely reduce fear as well. Based on additional findings, it would appear that one method for completing this would be the use of information provided along with screening reminders.

The data would appear to suggest that the largest barrier to mammography screening is a lack of education and knowledge about the necessity of mammography screening, the screening's effectiveness, the screening's safety, and how often screening should be completed. It would seem as though women are knowledgeable enough to know that screening does in fact reduce risk of death from breast cancer, reduces the need for extensive treatment, does not pose excessive pain, and does not need to have a negative impact on a woman's physical appearance and emotions. Thus, while we cannot say these themes do not pose any barrier to screening, they would appear to be less of a barrier to screening at this point in time.

A positive discovery would appear to be that fear of death is not a barrier to screening. It would seem as though women have been educated enough to know that screening does in fact reduce risk of death from breast cancer and thus it is not a barrier. By educating women about the benefits of early screening, we can increase their knowledge about safety of screening and options available should a positive diagnosis be made. This increase in knowledge should reduce any questions of screening safety and options, thus reducing the fear that women feel.

Elimination of Barriers

Glanz's research indicates lack of education and knowledge among people could best be addressed using the Health Belief Model as a health behavior change model. The Health Belief Model was developed in the 1950's by social psychologists at the U.S. Public Health Service. This model suggests that people's beliefs about health problems, perceived benefits, and self-efficacy explain engagement in health-promoting behavior (Glanz, 2008). The Health Belief Model has five constructs which are used to address a health issue. These five constructs are perceived susceptibility, perceived benefits, perceived barriers, self-efficacy, and cues to action (Glanz, 2008). Perceived susceptibility can best be described as a subjective assessment by the individual of their risk for developing a health problem. Basically, those who perceive they are susceptible will be more likely to engage in the preventive health behavior. Perceived benefits can best be explained as the individual's belief of the value of engaging in the preventative health behavior to decrease risk. If the individual believes the action will reduce susceptibility or seriousness they are more likely to engage in the preventive measure(s). Perceived barriers are the individual's assessment of obstacles they face in engaging in the preventive health behaviors (Glanz, 2008). The benefits of the health behaviors must outweigh the barriers that the individual faces. Self-efficacy is described as the individual's perception of their competence to successfully preform the health behavior. If the individual does not believe they are capable of preforming or maintaining the health behavior, then they are not likely to start the behavior at all. Finally, cues to action are something that prompts engagement in health promoting behavior, such as some sort of reminder which helps the individual begin and maintain the health behavior (Glanz, 2008).

For this specific case, the suggested program intervention(s) combine an educational program along with facilitated help in scheduling mammography screenings. The recommended program was developed using ideas gathered from two journal articles, titled, *Increasing Mammography Screening among African American Women in Rural Areas* (Powell, 2005) and *Multi-strategy Health Education Program To Increase Mammography Use Among Women Ages 65 and Older* (Rimer, 1992). In both cases, the developed programs were implemented and did show an increase in mammography screenings for the target areas and populations. The recommended program would be implemented at senior centers, churches, and community groups and would focus on breast cancer screening education. The program would begin with a letter mailed to all women members of the senior center, church, or community center, announcing an upcoming educational sessions and a visit from the Mammovan (Rimer,1992). The women will be invited to attend an educational program consisting of a video, supporting print materials, and group discussion. The invitation will also let the women know that refreshments and a tote bag filled with incentives will be supplied at the program. An opportunity to schedule an appointment with the Mammovan will be offered at the end of the program (Rimer,1992 and Powell, 2005).

The educational program would address perceived susceptibility and perceived benefits. In addition to the education program, home visits would be completed by community health workers or members of RSVP (senior volunteers providing peer-to-peer education) trained to review contents of the educational video, answer any questions, provide self-exam training, provide any lost print materials, and assist the women in scheduling a screening if they have not already done so. The community health workers or members of RSVP would be trained to schedule screenings with both the Mammovan and other clinics or hospitals in the area. If needed, the community health workers or members of RSVP will help the women obtain a referral for the screening (Powell, 2005). Community health workers or members of RSVP would also be provided $40 vouchers which would require only a $10 copayment by the women for screening at the Mammovan and at approved clinics. These vouchers would be provided only to women who greatly need the financial assistance (Rimer,1992). While these vouchers would be available, we expect that the implementation of free screening under the Affordable Care Act will ultimately eliminate the need for these vouchers over time. The home visit and vouchers, in addition to the educational program, would address perceived barriers and self-efficacy. Reminder cards would be sent to the women a week before their appointment as a cue to action. Additionally, the women would be contacted by the community health workers or members of RSVP after their appointment time to verify their attendance and to provide support and materials should test results have confirmed a positive breast cancer diagnosis. (Rimer,1992 and Powell, 2005). The effectiveness of the program will be measured via pre and post-tests. The pre-test given to test the women's knowledge before the program begins and the post-test after the program's implementation to measure change in the level of knowledge for each woman.

The recommended program addresses the lack of knowledge & education barrier, fear, reminders, cost, and transportation. The fact that this program addresses four of the ten barriers in addition to the most common barrier of knowledge & education, means that the program should be provided as much funding as is necessary to start and sustain the program. Policymakers and legislators should write a law stating that this program will be guaranteed funding for a minimum of five years, in order to allow the program to really take effect and reduce the target barriers. This may mean pulling funding from other cancer programs which are not showing positive progress/change. Additionally, a law should be established to ensure that all approved clinics accept the $40 vouchers provided, thus requiring a $10 copayment for women to be screened. If the approved clinics do not accept the vouchers than some sort of penalty, potentially financial, should be executed, thus ensuring that clinics accept the vouchers and the cost barrier can be addressed.

Future Research

Future research should conduct another set of focus groups in addition to monitoring the mammography rates to determine if in fact, the program is being implemented properly and is properly reducing the barriers that Nevadan women currently face. As stated previously, while demographic data were collected for all the focus group participants, none of the information was used during this research. This was due to the inability to connect the demographic data with the specific answers given by each participant. Future research in this area should look at the relationship(s) that the demographic data plays or does not play in the barriers faced in receiving Mammography screening. It may be helpful to see if educational level, employment status, occupation, or income level play a role in the types of barriers women in rural Nevada face in seeking screening.

Conclusion

After analyzing the data that were gathered during each of the five focus groups, we have determined the answer to the research question, what barriers do women in rural Nevada face in seeking and receiving mammography screenings each year? The answer is that the greatest barrier faced by women in rural Nevada is lack of education & knowledge about breast cancer screening. In order to reduce this barrier and increase screening rates we need to educate women in rural Nevada about the necessity and benefits of early detection through mammography screening, the screening's effectiveness in finding breast cancer at an early stage, the safety level of mammography screening, and how often screening should be completed. The above recommended program should be an effective way to bring education to women in rural Nevada and increase breast cancer screening rates in Nevada.

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Appendix A. Recruitment Flyer for Carson City Focus Group

Come talk about breast cancer screening and earn a $20 gift card!

Share your experience with breast cancer screening or the reasons you have not been screened. The Center for Program Evaluation at the University of Nevada, Reno and Partnership Carson City are looking for <u>*women over the age of 40, with no personal history of cancer*</u>, to participate in a focus group to discuss breast cancer screening.

Participants will receive a gift card for $20 and refreshments. It will take about 2 hours to complete the short survey and talk in the focus group.

Focus Group Location: Partnership Carson City
1711 N Roop St, Carson City

Date: September 10th, 2013
Time: 11:30am to 1:30pm

Please contact to RSVP:
Elizabeth Christiansen, Ph.D.
Center for Program Evaluation
University of Nevada, Reno
Phone: (775) 682-6853
Email: elizabethc@unr.edu

Appendix B. Recruitment Flyer for Douglas Focus Group

Come talk about breast cancer screening and earn a $20 gift card!

Share your experience with breast cancer screening or the reasons you have not been screened. The Center for Program Evaluation at the University of Nevada, Reno and Partnership Carson City are looking for *women over the age of 40, with no personal history of cancer*, to participate in a focus group to discuss breast cancer screening.

Participants will receive a gift card for $20 and refreshments. It will take about 2 hours to complete the short survey and talk in the focus group.

Focus Group Location: Partnership of Community Resources
1517 Church Street Gardnerville, NV 89410

Date: September 10th, 2013
Time: 5:30pm to 7:30pm

Please contact to RSVP:
Elizabeth Christiansen, Ph.D.
Center for Program Evaluation
University of Nevada, Reno
Phone: (775) 682-6853
Email: elizabethc@unr.edu

Appendix C. Recruitment Flyer for Elko Focus Group

Come talk about breast cancer screening and earn a $20 gift card!

Share your experience with breast cancer screening or the reasons you have not been screened. The Center for Program Evaluation at the University of Nevada, Reno and Partnership Carson City are looking for *women over the age of 40, with no personal history of cancer*, to participate in a focus group to discuss breast cancer screening.

Participants will receive a gift card for $20 and refreshments. It will take about 2 hours to complete the short survey and talk in the focus group.

Focus Group Location: Northeastern Nevada Regional Hospital
2001 Errecart Bolvd., Elko, NV 89801

Date: September 17, 2013
Time: 5:30pm to 7:30pm

Please contact to RSVP:
Elizabeth Christiansen, Ph.D.
Center for Program Evaluation
University of Nevada, Reno
Phone: (775) 682-6853
Email: elizabethc@unr.edu

Appendix D. Recruitment Flyer for Mesquite Focus Group

Come talk about breast cancer screening and earn a $20 gift card!

Share your experience with breast cancer screening or the reasons you have not been screened. The Center for Program Evaluation at the University of Nevada, Reno and Partnership Carson City are looking for *women over the age of 40, with no personal history of cancer*, to participate in a focus group to discuss breast cancer screening.

Participants will receive a gift card for $20 and refreshments. It will take about 2 hours to complete the short survey and talk in the focus group.

Focus Group Location: Virgin Valley High School
820 Valley View Dr Mesquite, NV 89027

Date: September 24th, 2013
Time: 5:30pm to 7:30pm

Please contact to RSVP:
Elizabeth Christiansen, Ph.D.
Center for Program Evaluation
University of Nevada, Reno
Phone: (775) 682-6853
Email: elizabethc@unr.edu

Appendix E. Recruitment Flyer for Winnemucca Focus Group

Come talk about breast cancer screening and earn a $20 gift card!

Share your experience with breast cancer screening or the reasons you have not been screened. The Center for Program Evaluation at the University of Nevada, Reno and Partnership Carson City are looking for *women over the age of 40, with no personal history of cancer*, to participate in a focus group to discuss breast cancer screening.

Participants will receive a gift card for $20 and refreshments. It will take about 2 hours to complete the short survey and talk in the focus group.

Focus Group Location: Humboldt General Hospital
118 E. Haskell St., Winnemucca, NV 89445

Date: October 2, 2013
Time: 11:30am to 1:30pm

Please contact to RSVP:
Elizabeth Christiansen, Ph.D.
Center for Program Evaluation
University of Nevada, Reno
Phone: (775) 682-6853
Email: elizabethc@unr.edu

Appendix F. Pre-Focus Group Questionnaire

PRE-DISCUSSION INFORMATION SHEET

We appreciate your taking the time to give us some background information about you for the group. We will not report any of your answers by name, so please do not write your name on this piece of paper. If you would like one of our team members to read this to you and record your responses, please let us know. We will collect this from you before you enter the group.

THANK YOU.

1. What is your date of birth? (Month/Day/Year)

____

2. In which Nevada county do you live?

☐ Carson
☐ Churchill
☐ Clark
☐ Douglas
☐ Elko
☐ Esmeralda
☐ Eureka
☐ Humboldt
☐ Lander
☐ Lincoln
☐ Lyon
☐ Mineral
☐ Nye
☐ Pershing
☐ Storey
☐ Washoe
☐ White Pine

3. What is your highest education level completed?

☐ 6th Grade or less
☐ 7th –8th Grade
☐ 9th –11th Grade
☐ 12th Grade without a High School diploma
☐ 12th Grade with a High School diploma
☐ GED
☐ Some college
☐ Associate degree
☐ Completed college (4 year degree)

4. What is your employment status? (check all that apply)

☐ Full-time
☐ Part-time
☐ Presently not employed outside the home, looking for work
☐ Presently not employed outside the home, not looking for work
☐ Student
☐ Laid Off
☐ On Strike
☐ Disabled

5. What do you do for a living? What is your occupation/profession?

____

____

6. What is your approximate household income?

- ☐ $0-$19,999
- ☐ $20,000-$39,999
- ☐ $40,000-$59,999
- ☐ $60,000-$79,999
- ☐ $80,000-$99,999
- ☐ $100,000-$119,999
- ☐ $120,000-$139,999
- ☐ $140,000-$159,999
- ☐ $160,000-$169,999
- ☐ $170,000-$179,999
- ☐ $180,000-$189,999
- ☐ $190,000-$199,999
- ☐ $200,000 and up

7. Is there a history of cancer in your family?

- ☐ Yes
- ☐ No

8. If yes, what types of cancer?

- ☐ Bladder Cancer
- ☐ Breast Cancer
- ☐ Colon Cancer
- ☐ Endometrial Cancer
- ☐ Kidney (Renal Cell) Cancer
- ☐ Lung Cancer
- ☐ Melanoma
- ☐ Non-Hodgkin Lymphoma
- ☐ Pancreatic Cancer
- ☐ Prostate Cancer
- ☐ Rectal Cancer
- ☐ Thyroid Cancer

9. During what time of the day do you most often listen to the radio?

- ☐ 5a-11a
- ☐ 12p-5p
- ☐ 6p-12a

10. How often do you listen to the radio?

- ☐ Every day
- ☐ 5-6 days a week
- ☐ 3-4 days a week
- ☐ 1-2 days a week
- ☐ Never or rarely

11. During the past 30 days, which of the following have you listened to at least 3 times a week? (check all that apply)

☐ Alternative
☐ Ambient
☐ African
☐ Bluegrass
☐ Blues
☐ Caribbean
☐ Classical
☐ Christian
☐ Country
☐ Disco
☐ Folk
☐ Gospel
☐ Hip Hop
☐ Heavy Metal
☐ Hard Rock
☐ Instrumental
☐ Jazz
☐ Latin
☐ Musical
☐ New Age
☐ Oldies
☐ Opera
☐ Pop
☐ Punk
☐ Rap
☐ Reggae
☐ R & B
☐ Rock
☐ Salsa
☐ Trance

12. During what time of the day do you most often watch television?

☐ 5a-11a
☐ 12p-5p
☐ 6p-12a

13. Do you subscribe to a newspaper? If yes, which?

☐ Ahora Latino Journal
☐ Ahora News Reno
☐ Battle Mountain Bugle
☐ Bonanza
☐ Boulder City News
☐ Comstock Chronicle
☐ Daily Sparks Tribune
☐ Dayton Courier
☐ Desert Valley Times
☐ Downtown Las Vegas View
☐ El Mundo Las Vegas
☐ Elko Daily Free Press
☐ Elko Independent
☐ Ely Daily Times
☐ Eureka Sentinel
☐ Fallon Eagle Standard
☐ Fernley Leader
☐ Goldfield News
☐ Henderson Home News
☐ High Desert Advocate
☐ Humboldt Sun
☐ Lahontan Valley News
☐ Las Vegas Business Press
☐ Las Vegas City Life
☐ Las Vegas Inc
☐ Las Vegas Mercury
☐ Las Vegas Review Journal
☐ Las Vegas Sun
☐ Las Vegas View
☐ Las Vegas Weekly
☐ Laughlin Entertainer
☐ Laughlin Nevada Times
☐ Lincoln County Record
☐ Lovelock Review Miner
☐ Mason Valley News
☐ Mineral County Independent News
☐ Moapa Valley Progress
☐ Nevada Appeal
☐ Nevada Business Journal
☐ Nevada Press Association
☐ Nevada Rancher
☐ North Lake Tahoe Bonanza
☐ Northern Las Vegas/Alliante View
☐ Northern Nevada Business Weekly
☐ Pahrump Valley Times
☐ Record Courier
☐ Reno Gazette Journal
☐ Reno News & Review
☐ Tonopah Times-Bonanza and Goldfield News

14. **Please indicate** how often **you normally get your local news from the sources below.**

Television	☐ Always	☐ Sometimes	☐ Rarely	☐ Never
Radio	☐ Always	☐ Sometimes	☐ Rarely	☐ Never
Newspapers	☐ Always	☐ Sometimes	☐ Rarely	☐ Never
Magazines	☐ Always	☐ Sometimes	☐ Rarely	☐ Never
Doctor Visits	☐ Always	☐ Sometimes	☐ Rarely	☐ Never
Church or religious organization	☐ Always	☐ Sometimes	☐ Rarely	☐ Never
Friends	☐ Always	☐ Sometimes	☐ Rarely	☐ Never
Family members	☐ Always	☐ Sometimes	☐ Rarely	☐ Never
Facebook	☐ Always	☐ Sometimes	☐ Rarely	☐ Never
Other:__________	☐ Always	☐ Sometimes	☐ Rarely	☐ Never

15. **Please indicate** how often **you usually get information about health services in your community from the sources below.**

Television	☐ Always	☐ Sometimes	☐ Rarely	☐ Never
Radio	☐ Always	☐ Sometimes	☐ Rarely	☐ Never
Newspapers	☐ Always	☐ Sometimes	☐ Rarely	☐ Never
Magazines	☐ Always	☐ Sometimes	☐ Rarely	☐ Never
Doctor Visits	☐ Always	☐ Sometimes	☐ Rarely	☐ Never
Church or religious organization	☐ Always	☐ Sometimes	☐ Rarely	☐ Never
Friends	☐ Always	☐ Sometimes	☐ Rarely	☐ Never
Family members	☐ Always	☐ Sometimes	☐ Rarely	☐ Never
Facebook	☐ Always	☐ Sometimes	☐ Rarely	☐ Never
Other:__________	☐ Always	☐ Sometimes	☐ Rarely	☐ Never

This is the end of our questions.
Thank you for your time.

Appendix G. Focus Group Introduction and Questions Provided to Facilitator

Focus Group Questions

We have invited you here to share your thoughts about breast cancer screening. The Nevada Cancer Coalition is exploring why there are lower rates of breast cancer screening in parts of Nevada. Your participation in this group today will help us understand what barriers women might face in receiving screening as well as possible ideas to help increase women's participation in screening. We are taking notes of your responses; however, we will not report anyone's names in any our report.

We have some guidelines to help make this focus group process a positive experience for everyone.

- I will ask a question and give everyone a turn to answer the question. If you do not have anything to say, you may say "pass." I will come back to you after others have responded to see if you have thought of an answer.
- Share one idea at a time. While someone else is talking, please wait until your turn to share your ideas.
- No ideas are bad ideas. We are trying to generate as many ideas as possible.
- No one should judge or criticize another's answer.

Let's get started.

Opening: Please tell us your name

Introduction: What comes to your mind when I say "breast cancer?"
Probe: Why do you say that?
Probe: What concerns, thoughts, or feelings come to your mind?

Key: Do you think that women like you are at risk for getting breast cancer? Why or why not?

Transition: So what comes to your mind when I say breast cancer screening?
Probe: What do you know about screening?
Probe: Tell me what is involved in screening?

Key: Do you think that breast cancer screening increases a woman's chance of surviving breast cancer? Why or why not?

*Key: Why do you think that some women choose not to get screened for breast cancer?
Probe: Do you think women are afraid? If so, what are they afraid of?
Probe: Are there other barriers to getting screened (e.g., service location, transportation issues, other challenges or issues)?

Key: What are your thoughts about free or low-cost breast cancer screening (mammograms)?
Probe: Do you think women worry that the quality of free screening might not be very good?

Probe: Do you trust that free screening services are as good quality as services that cost money or require insurance coverage?

*Key: If you have been screened, what influenced (or motivated) you to get screened for breast cancer in the past 2 years?

Probe: Did a family member, friend, or doctor encourage you to get screened, did you see a media story or read something online, did you receive a remind card in the mail, did someone you know get cancer, do you have a family history of cancer?

*Key: What types of messages would improve the chances that you would pay attention to information about breast cancer screening?

Probe: How would you respond to messages that use <u>humor</u>? Why?
Probe: How would you respond to <u>serious</u> messages? Why?
Probe: How would you respond to messages that try to <u>scare</u> you? Why?
Probe: How would you respond to messages that give you information about your risk of getting breast cancer? Why?

Closing: Is there anything that you do not know about screening that you would like to know?

Appendix H. Demographic Table for Focus Groups

Table: Demographics for focus groups by location

	Carson	**Clark**	**Douglas**	**Elko**	**Humboldt**
Demographics					
Age	40s: 3 50s: 6 60s: 3 70s: 2 80s: 1	40s: 1 50s: 1 60s: 0 70s: 0 80s: 0	40s: 2 50s: 4 60s: 1 70s: 1 80s: 0	40s: 1 50s: 3 60s: 0 70s: 0 80s: 0	40s: 0 50s: 1 60s: 0 70s: 1 80s: 0
Language	English: 10 Spanish: 6	English: 2 Spanish: 0	English: 8 Spanish: 0	English: 4 Spanish: 0	English: 2 Spanish: 0
Education	6th Grade or less: 4 High School Diploma: 2 GED: 1 Associate Degree: 0 Some college: 3 4 year degree: 5 No answer: 1	6th Grade or less: 0 High School Diploma: 0 GED: 0 Associate Degree: 0 Some college: 0 4 year degree: 2 No answer: 0	6th Grade or less: 0 High School Diploma: 1 GED: 0 Associate Degree: 2 Some college: 2 4 year degree: 2 No answer: 0	6th Grade or less: 0 High School Diploma: 2 GED: 0 Associate Degree: 0 Some college: 1 4 year degree: 1 No answer: 0	6th Grade or less: 0 High School Diploma: 0 GED: 0 Associate Degree: 0 Some college: 1 4 year degree: 1 No answer: 0
Work	Full-Time: 3 Part-time: 3 Looking: 3 Not looking: 3 Disabled: 1 No Answer: 3	Full-Time: 1 Part-time: 0 Looking: 0 Not looking: 1 Disabled: 0 No Answer: 0	Full-Time: 4 Part-time: 2 Looking: 0 Not looking: 2 Disabled: 0 No Answer: 0	Full-Time: 1 Part-time: 0 Looking: 0 Not looking: 1 Disabled: 2 No Answer: 0	Full-Time: 0 Part-time: 0 Looking: 1 Not looking: 1 Disabled: 0 No Answer: 0
Occupation	Retired: 4 Nurse: 1 Breastfeeding peer counselor: 1 Office Manager: 1 Housewife: 1 Property Management Admin.: 1 AmeriCorp VISTA: 1 Accountant/Housewife: 1 No answer: 3	Teacher: 1 Mother/Housewife: 1	Retired: 1 Prevention Specialist: 1 School Aide: 1 Substitute Teacher: 1 DUI Case Manager: 1 Probation: 1 School Secretary: 1	Office Manager: 1 Physical therapist: 1 Practice Manager (EDI*): 1 Housewife: 1	Social Work: 1 No Answer: 1
Income	$0-$19,999: 4 $20,000-$39,999: 5 $40,000-59,999: 0 $60,000-$79,999: 2 $80,000-$99,999: 1 $100,000-$119,999: 0 $120,000-$139,999: 0 $140,000-$159,999: 1 $180,000-$189,999: 1	$0-$19,999: 0 $20,000-$39,999: 0 $40,000-59,999: 0 $60,000-$79,999: 0 $80,000-$99,999: 1 $100,000-$119,999: 0 $120,000-$139,999: 1 $140,000-$159,999: 0 $180,000-$189,999: 0	$0-$19,999: 0 $20,000-$39,999: 2 $40,000-59,999: 0 $60,000-$79,999: 1 $80,000-$99,999: 0 $100,000-$119,999: 3 $120,000-$139,999: 1 $140,000-$159,999: 1 $180,000-$189,999: 0	$0-$19,999: 2 $20,000-$39,999: 0 $40,000-59,999: 0 $60,000-$79,999: 0 $80,000-$99,999: 0 $100,000-$119,999: 1 $120,000-$139,999: 1 $140,000-$159,999: 0 $180,000-$189,999: 0	$0-$19,999: 1 $20,000-$39,999: 1 $40,000-59,999: 0 $60,000-$79,999: 0 $80,000-$99,999: 0 $100,000-$119,999: 0 $120,000-$139,999: 0 $140,000-$159,999: 0 $180,000-$189,999: 0