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Amanda Jennings

Honors Capstone Artifact – Dr. Meg Traci

Issue of Disparities Seen in Healthcare Among People with Disabilities

There are currently 61 million adults living in the United States living with a disability, that is approximately 1 out of every 4 adults (CDC, 2020). There is sufficient data to show that people with disabilities are at increased risk for health problems due to their inability to get adequate access to healthcare. Many factors influence this such as socioeconomic and physical reasons. This literature review will review thirteen articles, and how they pertain to the issue of differences in healthcare among people with disabilities. In this review I will begin broadly by addressing disparities in general healthcare among people with disabilities. This will help to lay a brief understanding of why people with disability are at decreased access to healthcare and how this affects their well-being. Then I will specifically address the difference in Breast and Cervical health for individuals with disabilities. It is known that a lower percentage of people with disabilities receive preventative breast and cervical healthcare compared to people without a disability (CDC, 2020). Women with disabilities, because of a decreased rate in prevention screenings, also suffer from higher mortality rates related to breast cancer (CDC, 2020). I will then end this literature review addressing the role medical providers play in this issue and areas for potential improvement in their field.

This issue deserves being addressed because it highlights an even more prominent issue of unequal healthcare access for individuals based on race, ethnicity, socioeconomic status. These factors ultimately limit access to healthcare based on unfair discriminations. Disability is just one of the areas that has been brought to the public's attention. If we as a society can understand why this disparity is seen, then it can begin to be addressed and hopefully actions can

HFD498 – Dr. Meg Traci

be taken to lessen the divide seen among individuals with disabilities and individuals without disabilities.

DISPARITIES IN GENERAL HEALTHCARE FOR PEOPLE WITH DISABILITIES

People with disabilities are at increased risk for certain health conditions including obesity, heart disease, diabetes (CDC, 2020). In fact, according to a survey done by the CDC (2020), adults aged 18-44 living with a disability are at higher percentages for all of the conditions listed above which are 38.2%, 11.5% and 16.3% respectively. When this is compared to adults aged 18-44 living without a disability, the percentages are 26.2% for obesity, 3.8% for heart disease, and 7.2% for diabetes. These differences can be accounted for by various barriers including structural-environmental barriers and process barriers (Hwang, 2009).

Structural-environmental barriers are described by Hwang (2009) as conditions in the physical and social environment of a facility. Examples of these include accessibility issues with ramps, parking spaces, examination rooms, equipment, and transportation to and from the location (Hwang, 2009). These can decrease access for a person with disabilities because they are not able to actually get to the facility, or they cannot get the necessary medical attention by physicians because the equipment available doesn't allow it. This is especially concerning because the largest percentage of people with disabilities is 13.7% with a mobility disability where they have difficulty walking or climbing stairs (CDC, 2020).

Process barriers differ from structural-environmental barriers because they are characterized as difficulties that people experience in the course of service delivery (Hwang, 2009). Examples of process barriers include difficulties experienced in convenience of care, receipt of preventive teaching, and patient-provider communications and interactions (Hwang,

HFD498 – Dr. Meg Traci

2009). Individuals with disabilities report problems with scheduling appointments as well as increased waiting times. Another often reported issue is individuals with disabilities experience higher levels of dissatisfaction with treatment and patient-provider communication (Hwang, 2009). This increased patient dissatisfaction leads to individuals not feeling comfortable attending follow-up appointments and often leads to decreased health-care appointments resulting in more health issues for people with disabilities. Data from the CDC (2020) shows that 1 in 4 adults aged 18-44 with a disability have not had a routine-check up in the past year.

Many alternative studies have been done to look at differences in healthcare among different types of disabilities. Havercamp et al. (2004) was interested in the differences between healthcare among adults with developmental disabilities, adults with other disabilities, and adults reporting no disability. Researchers compared status on health status, health risk behaviors, chronic health conditions, and medical care access across the three main trial groups. Results showed that adults with disabilities led more sedentary lifestyles and reported more inadequate emotional support compared to those without disabilities (Havercamp et al., 2004). Interestingly adults with developmental disabilities and other forms of disabilities were more likely to report being in fair or poor health and were at increased risk of suffering from multiple chronic health conditions (Havercamp et al., 2004).

People with disabilities often suffer from long-term chronic conditions due to the inability and inconvenience for them to attend regular appointments, as well as not having a regular health-care provider (Hwang, 2009). In fact, 1 in 3 adults with disabilities 18-44 years old do not have a usual primary care physician. Another important limiting factor in regular health care for people with disabilities is the cost associated with service. A large proportion of facilities fail to help patients with disabilities with financial burdens and may not offer any

HFD498 – Dr. Meg Traci

financial counseling. The CDC (2020) reported that 1 in 3 adults with disabilities have an unmet health care need because they cannot afford to get the appropriate care required.

DISPARITIES IN WOMEN’S HEALTH AMONG WOMEN WITH DISABILITIES

Prevention screening is recommended for many forms of cancer including breast, cervical, and colorectal cancers in order to prevent late detection and increases the likelihood of a positive outcome (Merten et al.,2012). In terms of breast cancer, regular screening by a provider can increase the chance of early detection, when breast cancer is easier to treat (CDC, 2020). According to the U.S. preventative task force (2016), women should begin mammography annual screenings between age 40-49 based on provider recommendation and should continue annual screening from age 50-74. However, among women with disabilities the percentage that actually received an annual mammogram is 61% compared to 75% of women without a disability (CDC, 2020). This is especially concerning because the less chance there is of early detection, leading to increased rates of death related to breast cancer for women with disabilities (CDC, 2020).

Barriers that women with disabilities experience include those similar to the ones described above, however may be more specified due to the nature of mammograms and preventative women’s health. For example, women with intellectual disabilities are often overlooked in outreach efforts and are not targeted by education breast and cervical health programs (Merten et al., 2012). Additionally, women with mobility disabilities experience difficulties with breast self-examinations and accessibility of equipment in mammography facilities (Merten et al., 2012). Both of these examples lead to increased rates of breast cancer for women with disabilities as opposed to those who aren’t (CDC, 2020).

HFD498 – Dr. Meg Traci

The data surrounding decreased breast and cervical screening rates among women with disabilities has interested many researchers since this problem began to be recognized. A study was conducted by Nosek and Howland (2004) to look at the difference in breast and cervical screening rates among women who had physical disabilities. This study concluded that these women were at a higher risk for a delayed diagnosis of breast and cervical cancer (Nosek and Howland, 2004). A written questionnaire was conducted and asked a total of 843 women aged 18-65; 450 women with disabilities and 393 without disabilities (Nosek and Howland, 2004). Among the 450 women with disabilities the breakdown of physical disabilities is as follows: 26% spinal cord injury, 18% polio, 12% neuromuscular disorders, 10% multiple sclerosis, and 8% had connective tissue disorders (Nosek and Howland, 2004). Nosek and Howland (2004) found that based on their data women with disabilities were less likely to receive regular pelvic exams and mammograms. Regularity of pelvic examination was also influenced by the severity of the functional limitation. 22% of the women with disabilities in this study had severe functional limitation and this significantly decreased the likelihood of them receiving pelvic exams when comparing to other women with disabilities and women without disabilities (Nosek and Howland, 2004). However, having a severe functional limitation did not show any statistical significance for receiving a biennial mammogram when compared to other women with disabilities and women without disabilities. Since women with disabilities are less likely to receive preventative care, leading to higher incidences of late-stage breast and cervical cancers.

Another study was done by Iezzoni et al. (2010) to assess the physical barriers in diagnosis and treatment of breast cancer among women with mobility impairments. This study concluded that women with mobility impairments face numerous physical barriers during their course of diagnosis and treatment (Iezzoni et al., 2010). Iezzoni et al. (2010) conducted a study

HFD498 – Dr. Meg Traci

consisting of individual interviews with 20 women with chronic mobility impairments who were diagnosed with early-stage breast cancer. In these interviews, most women reported inaccessible equipment, other accessibility difficulties, and facility policies/procedures as their main concerns (Iezzoni et al., 2010). Examples of inaccessible equipment consist of mammography machines, examination tables, radiation therapy equipment, and weight scales (Iezzoni, 2010). The inaccessibility of equipment doesn't allow for women with disabilities to receive the care they need to treat or diagnose breast cancer. Other examples of inaccessibility reported by women were that they had difficulty standing or lying down during their mammography, and some reported inaccessible office doors (Iezzoni, 2010). Also, due to inaccessible equipment some women reported unanticipated events that resulted in the patient feeling unsafe and even injured (Iezzoni, 2010). It was also alarming to read about some of the quotes included from women regarding the communication and interactions with their providers. This study emphasizes the need to reform the accessibility standards associated with mammography facilities as well as provider guidelines.

It is known that women with disabilities experience higher rates of breast-cancer related death as compared to women without due to decreased screening measures. A study done by McCarthy et al. (2006) examined the association among breast cancer treatment differences and survival for women with disabilities. The study considered women with disabilities to be those who qualified for social security disability insurance (SSDI) and Medicare. Researchers looked into if patients received breast-conserving surgery versus mastectomy, and if the former they collected data on whether the women then received radiotherapy and/or axillary lymph node dissection (McCarthy et al., 2006). The results showed that women with a disability had lower rates of breast-conserving surgery, 43.2% compared to 49.2% of women without a disability, and

HFD498 – Dr. Meg Traci

if a woman with disability did have breast-conserving surgery she was less likely to receive radiotherapy and axillary lymph node dissection (McCarthy et al., 2006). Another interesting result that McCarthy et al. (2006) found was that women with a disability had lower survival rates compared to women without disabilities. If women are receiving the same quality of care, then we should likely see similar mortality rates associated with breast cancer for women with and without disabilities. Since this is clearly not seen, this issue should be addressed by the public and medical providers.

ROLE OF MEDICAL PROVIDERS IN TREATING PEOPLE WITH DISABILITIES

Getting medical providers aware of this gap in access to healthcare for people with disabilities is crucial. The attitude and guidelines for treating people with disabilities should be readdressed in order to help alleviate the negative effects on patients with disabilities.

Paris (1993) addressed this issue by conducting a study focusing on the attitude of medical students and medical providers on treating patients with disabilities. A questionnaire was sent out to medical students and health-care professionals to determine if any significant differences existed. The results showed that fourth year medical students and health-care professionals had significantly more positive attitudes towards people with disabilities (Paris, 1993). Demographic differences existed as well; females compared to males were found to hold significantly more positive attitudes (Paris, 1993). This study was one of the first conducted looking into the issue of provider differences for individuals with disabilities, so it highlighted the need for health and educational fields to integrate people with disabilities into the standards associated with healthcare.

HFD498 – Dr. Meg Traci

This push for medical providers to improve health care for people with disabilities was recognized within the medical community and in 2005 the US Surgeon general released *Call to Action to Improve the Health and Wellness of Persons With Disabilities* (Kirschner and Curry, 2009). The goal of this was to increase the professional education among health-care providers when caring for people with disabilities, while addressing previous gaps in knowledge or standard of care that previously existed (Kirschner and Curry, 2009). This was to be implemented in medical schools and in furthering educational settings for health-care providers (Kirschner and Curry, 2009). This is positive to see that there continues to be a push towards narrowing that gap for people with disabilities, however I believe there is still a lot more that can be done.

In this literature review I sought out the answer the question why there are differences in healthcare for individuals with disabilities and what is currently being done to address this. It is clear that individuals with disabilities suffer from a decreased access to adequate healthcare and are suffering from more serious, long-term conditions because of this. Physical barriers and process barriers exist for people with disabilities that ultimately are the cause of this. I was then interested in specifically how this affects women with disability in terms of breast and cervical health. Similar to more generalized findings, women with disabilities suffer from decreased preventative care and therefore increased breast and cervical cancer related deaths as compared to women without disabilities. As far as what is currently being done, I believe this is where the gaps truly exist. We know that data has existed for years to support these disparities, however it seems as though this is not being talked about enough in the general public. In a further literature review, I would hope that it would address questions related to specific programs aimed at lessening the divide in healthcare for people with disabilities. I would also hope that it would

HFD498 – Dr. Meg Traci

incorporate data to show the effect of these programs on long-term data surrounding care for people with disabilities.

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HFD498 – Dr. Meg Traci

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HFD498 – Dr. Meg Traci

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