**UNDERUTILIZATION OF REPRODUCTIVE HEALTH SCREENINGS BY WOMEN LIVING WITH DISABILITIES IN THE UNITED STATES**

by

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Submitted to the Graduate Faculty of

Behavioral and Community Health Sciences

Graduate School of Public Health in partial fulfillment

of the requirements for the degree of

Master of Public Health

University of Pittsburgh

2014

**ABSTRACT**

UNIVERSITY OF PITTSBURGH

GRADUATE SCHOOL OF PUBLIC HEALTH

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Ellyn Marie Cowan, MPH

University of Pittsburgh, 2014

In the United States, approximately 50.9 million adults under the age of 64 years live with some type of disability. In 2011 approximately 21.8% of men and 28.1% of women under the age of 64 years reported living with a disability, while 53.5% of men and 63.9% of women over the age of 65 years reported living with a disability. Disability is associated with many chronic conditions including obesity, cancer, diabetes, cardiovascular disease (heart disease), hypertension (high blood pressure), asthma, and mental illness. Living with disabilities has been associated with barriers to care and decreased utilization of preventive screenings. Women with disabilities report more issues with receiving reproductive health care when compared to women living without disabilities. Reproductive health screenings for women include clinical breast exams, mammograms, pelvic exams, pap smears, HPV tests, chlamydia tests, and testing for STIs. This problem is relevant to public health because women living with disability are an underserved population in the United States who experience barriers to receiving regular preventive care. In this paper, a literature review was conducted from December 2013 to January 2014. Twenty articles were reviewed to examine the current prevalence of breast cancer and cervical cancer screening behaviors and other preventive screenings for women living with disabilities. The literature review found that women living with disability underutilize breast cancer and cervical cancer screening more than women without disability. Women living with physical disabilities were more likely to be diagnosed with a sexually transmitted infection (STI) than men living with physical disabilities. Women with disabilities experience barriers to care including: environmental, physical, and individual. Women without disabilities reported having better experiences when receiving a mammogram compared to women with disabilities. Women living with multiple disabilities were more likely to need a mammogram machine accessible for persons sitting. Women with an intellectual disability have varying rates of mammogram utilization based on support and living environment. Women with disability who were young, African American, Hispanic, poor or married were more likely to have received a pap smear. In conclusion, women living with disabilities had lower rates of regular screening for both pap tests and mammographies when compared to women without disabilities. Future research is needed to better understand why women with disabilities underutilize preventive screenings. Future research studies should address access to health care issues and barriers to receiving care for women living with disabilities.

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preface

I would like to thank my essay committee advisor Dr. Martha Ann Terry and essay reader Dr. Wesley M Rohrer for assisting me in this new and exciting academic endeavor.

# Introduction

Approximately 50.9 million adults, under the age of 64 years, live with disability in the United States (National Center for Health Statistics, 2013). Disability is defined as a limitation or functional impairment that restricts a person’s ability to perform daily tasks (Erickson, Schrader, & Lee, 2012). In 2011, approximately 21.8 % of men and 28.1 % of women under the age of 64 years reported living with a basic activity limiting disability (National Center for Health Statistics, 2013). More individuals over the age of 65 years reported living with basic activity limiting disabilities, with 53.5% of men and 63.9% of women (National Center for Health Statistics, 2013).

Disability prevalence and severity increases with age (Erickson, Schrader, & Lee, 2012; Hosseinpoor et al., 2012; Karvonen-Gutierrez & Ylitalo, 2013). As a person ages, the severity of a disability may increase the prevalence and experience of chronic diseases (Reichard, Stolzle, & Fox, 2011; Wei, Findley, & Sambamoorthi, 2006). Many chronic conditions are associated with disability including cancer, diabetes, obesity, hypertension, cardiovascular disease, and asthma (Wei, Findley, & Sambamoorthi, 2006). Research suggests that persons living with disabilities have high rates of chronic disease because they underutilize regular preventive health care (Reichard, Stolzle, & Fox, 2011; Wei, Findley, & Sambamoorthi, 2006).

Disability has been associated with decreased utilization of preventive services (Reichard, Stolzle, & Fox, 2011; Suzuki et al., 2012). Research suggests that women living with disabilities, when compared to women without disabilities, not only underutilize general preventive screenings but reproductive health screenings including mammograms and pap smears (Wei, Findley, & Sambamoorthi, 2006). Women living with disabilities report more issues with receiving regular reproductive health care (Wei, Findley, & Sambamoorthi, 2006). Some issues women living with disabilities experience when receiving care include cost of preventive screening, inability to access a care center because of environmental obstacles, lack of accessible screening machines, and negative interactions with health care professionals (Todd & Stuifbergen, 2012).

This paper is based on a literature search and review that was conducted between December 2013 and April 2014. The overall purpose of this paper is to report findings from current literature on the utilization of preventive health services by women living with disabilities in the United States. The focus is on reproductive health services and women’s health care. Twenty articles were reviewed after meeting predetermined eligibility criteria. Specific questions were considered while reviewing the eligible literature:

1. Do women living with disabilities in the United States use preventive health services less than men living with disabilities?
2. Do women living with disabilities in the United States use preventive reproductive health services less than women without disabilities?
3. Are there barriers to receiving preventive reproductive health services for women living with disabilities?
4. Do women living with different types of disabilities experience preventive care differently?
5. Do women from different cultural backgrounds experience preventive care differently?

In this paper, there are five sections discussing disability in the United States and the findings from the reviewed literature. Chapter 2.0 describes the current background of the problem in the U.S. including current disability statistics, reproductive health screenings, and information on women living with disabilities. Chapter 3.0 presents the methods used to identify abstracts and articles reviewed. Chapter 4.0 discusses the findings from the articles reviewed, organized into five subsections. The five subchapters discuss the utilization of preventive health services as compared between men and women, preventive services between women with disabilities and women without disabilities, barriers to receiving preventive reproductive health screenings, differences in screening utilization by women living with disabilities, and experiences of women living with disabilities from different cultural backgrounds. Findings are also organized into a summary table at the end of the section. In Chapter 5.0, the findings from the literature review are discussed including limitations of the reviewed literature. And finally, Chapter 6.0 concludes the essay with a summary of findings, limitations of the paper, and recommendations for future research in disability health.

# BACKGROUND

In the United States, approximately 50.9 million adults under the age of 64 years live with some type of disability (National Center for Health Statistics, 2013). Disability has been defined as a limitation or functional impairment that limits a person’s ability to perform daily tasks (Erickson, Schrader, & Lee, 2012). Impairment of hearing, seeing, walking, thinking, and even talking can be defined as disability. Medical and self-reported disabilities are categorized as: visual, hearing, communicative, ambulatory or mobility issues, cognitive including developmental, and self-care disabilities (Brault, 2012; Erickson, Schrader, & Lee, 2012).

In 2011 approximately 21.8% of men and 28.1% of women under the age of 64 years reported living with a disability, while 53.5% of men and 63.9% of women over the age of 65 years reported living with a disability (National Center for Health Statistics, 2013). In the 2010 Census report, approximately 19 million adults over the age of 65 years reported living with a disability, and about 14 million out of the 19 million reported living with a severe disability (Brault, 2012). Brault (2012) defined severe disability as impairments or difficulties in performing one or more daily activities or tasks. About 30 million adults under the age of 65 reported living with a disability and 20 million out of the 30 million reported living with a severe disability (Brault, 2012).

Disability is common in individuals above the age of 65 years and the severity of the condition increases with age (CDC, 2011; Erickson, Schrader, & Lee, 2012; Hosseinpoor et al., 2012; Karvonen-Gutierrez & Ylitalo, 2013). For example, a person living with a physical impairment that requires her to use a wheelchair will be more likely to have issues with obesity and other chronic diseases when compared to a person without disability (Wei, Findley, & Sambamoorthi, 2006). As the individual ages the severity of the physical impairment may increase because of chronic diseases, limiting the person’s ability to perform daily tasks (Reichard, Stolzle, & Fox, 2011; Wei, Findley, & Sambamoorthi, 2006).

Disability is associated with many chronic conditions including obesity, cancer, diabetes, cardiovascular disease (heart disease), hypertension (high blood pressure), asthma, and mental illness (Wei, Findley, & Sambamoorthi, 2006). The prevalence of chronic disease in the disability population is high (Dixon-Ibarra & Horner-Johnson, 2014; Wei, Findley, & Sambamoorthi, 2006). Underutilization of preventive health care has been associated with the prevalence of chronic disease in the disability population (Reichard, Stolzle, & Fox, 2011; Wei, Findley, & Sambamoorthi, 2006).

## WOMEN LIVING WITH DISABILITIES

Women living with disabilities in the United States consistently report higher rates of disability when compared to men (Brault, 2012; Erickson, Shrader, & Lee, 2012; Hosseinpoor et al., 2012). Women with disabilities also report more issues with receiving care when compared to women living without disabilities (Wei, Findley, & Sambamoorthi, 2006). Issues with care include problems with accessing health insurance, accessing a primary care provider, and having regular visits with a primary care provider (Wei, Findley, & Sambamoorthi, 2006).

Living with disabilities has been associated with barriers to care and decreased utilization of preventive screenings (Reichard, Stolzle, & Fox, 2011; Suzuki et al., 2012). Historically, women living with disabilities underutilize preventive care (Reichard, Stolzle, & Fox, 2011; Suzuki et al., 2012). Most of the care received focuses on the primary condition, the disability, and not on possible secondary conditions like depression or breast cancer (Reichard, Stolzle, & Fox, 2011; Suzuki et al., 2012). Women living with disabilities may feel that the treatment and diagnosis of secondary conditions is not as important as treating disabilities.

Women may also experience barriers to receiving preventive services to decrease the likelihood of having a secondary condition (Todd & Stuifbergen, 2012). According to Todd and Stuifbergen (2012), women living with disabilities identify many barriers to receiving preventive screenings. Those barriers include the cost of preventive screening, location of clinic or hospital, and inability to access a care center because of environmental barriers (Todd & Stuifbergen, 2012). The cost of preventive screening depends on insurance type and coverage. Women living with disability who do not have insurance to cover the entire cost of a mammogram or do not qualify for social security disability insurance, may not be able to afford the test (Todd & Stuifbergen, 2012). Women who live far away from a testing location may have trouble obtaining accessible transportation to the clinic (Todd & Stuifbergen, 2012). Also, women may have trouble getting into the clinic because of physical barriers like stairs (Todd & Stuifbergen, 2012).

Other reasons why these women are not receiving routine preventive care include lack of accessible screening machines and negative interactions with health care professionals (Todd & Stuifbergen, 2012). There are very few accessible mammogram machines for persons living with disabilities that adjust so the screening can be performed comfortably (Todd & Stuifbergen, 2012). For example, a woman living with mobility disabilities may have trouble standing up to have a mammogram performed. If she cannot stand, health care professionals may react negatively and cause the woman physical pain and/or embarrassment while attempting to perform the screening (Todd & Stuifbergen, 2012). The woman may choose to not have the screening in the future to avoid the negative experience.

Women living with disability underutilize reproductive health screenings for breast cancer and cervical cancer prevention. Wei, Findley, and Sambamoorthi (2006) found that having a disability was associated with lower rates of mammograms 81% and pap smears 79% when compared to the rates of women without disability (87% and 88% respectively). They also found that women living with a disability were more likely to receive screenings for colorectal cancer and influenza immunizations than women without (Wei, Findley, & Sambamoorthi, 2006).

## REPRODUCTIVE HEALTH Screenings

The World Health Organization (WHO) (2014) defines reproductive health as the

right of men and women to be informed of and to have access to safe, effective, affordable and acceptable methods of fertility regulation of their choice, and the right of access to appropriate health care services that will enable women to go safely through pregnancy and childbirth and provide couples with the best chance of having a healthy infant.

Therefore, reproductive health screenings help to keep reproductive organs healthy and can help to diagnose issues with organs that are preventable. Reproductive health screenings for women include clinical breast exams, mammograms, pelvic exams, pap smears, HPV tests, chlamydia tests, and testing for STIs (National Women’s Health Resource Center, 2014). The reproductive health screenings can be separated into two categories: breast health and cervical health.

### Breast Health

Breast cancer is a common cause of cancer-related mortality in women in the United States (U.S.). Approximately 40,000 women will die from breast cancer in the year 2014, as estimated by the American Cancer Society (2013). The Cancer Society also estimates that about one in eight women or 12% of the women living in the United States will have breast cancer (American Cancer Society, 2013). Breast cancer related mortality has declined since the late 1980s, but is still high. Approximately one in 36 women will die because of breast cancer in the year 2014 (American Cancer Society, 2013).

Increases in breast cancer screening and preventive care have been associated with the decline in breast cancer related deaths (American Cancer Society, 2013). However, breast cancer screening has been identified as the most underutilized preventive health screening by women living with disabilities (Reichard, Stolzle, & Fox, 2011; Suzuki et al., 2012; Todd & Stuifbergen, 2012). Women with physical disability may choose not to receive this screening because there are few mammogram machines accessible to women with mobility issues (Angus et al., 2011). Also, healthcare providers may not be knowledgeable about the special needs of women living with disabilities (Angus et al., 2011). For example, a woman with physical impairments may not be able to stand up or hold herself up to go though the process of receiving a mammogram. Healthcare providers may not know how to assist the woman because they were not aware of her specific needs. The woman may not receive the test because the mammogram machine could not be adjusted.

### Cervical Health

Cervical cancer related mortality is not as common as breast cancer related mortality in women in the United States. Approximately 4,020 women will die from cervical cancer in the year 2014, as estimated by the American Cancer Society (2013). Most cases of cervical cancer are found in women who are younger than 50 years of age (American Cancer Society, 2013). If women receive regular pap tests and pelvic exams, they are less likely to have cervical cancer (American Cancer Society, 2013).

Women living with disabilities have lower rates of cervical cancer screening (79%) than women without disabilities (88%) (Wei, Findley, & Sambamoorthi, 2006). Women with disabilities may choose to not receive pap tests because of discomfort with the test and past negative experiences with healthcare providers (Bates, Carroll, & Potter, 2011). Women living with intellectual or developmental disabilities, who have a guardian, receive cervical cancer screening less when compared to women without intellectual or developmental disability (Bates, Carroll, & Potter, 2011).

The pelvic exam can be stressful and challenging for women living with disabilities and for health care professionals providing the test (Bates, Carroll, & Potter, 2011). Women with disabilities have reported increased comfort with the test if health care providers talk about each step of the exam, before performing the test (Bates, Carroll, & Potter, 2011). Depending on the type of impairment, health care providers can provide education that is appropriate for the woman receiving the test (Bates, Carroll, & Potter, 2011). This means that health care providers can talk through the procedure with the patient before performing the test (Bates, Carroll, & Potter, 2011). For example, the provider can show the woman the tools she will use and demonstrate how the tools will be used before performing the test (Bates, Carroll, & Potter, 2011).

## CURRENT SCREENING RECOMMENDATIONS

Current guidelines from the U.S. Preventive Services Task Force (USPSTF) act as prevention recommendations for breast health and cervical health. The preventive screenings for breast health are mammograms and clinical breast exams (National Women’s Health Resource Center, 2014). The USPSTF (2009) recommends biennial mammograms, screening every two years, for women ages 50 to 74 years. Women can choose to get the recommended biennial mammograms before the age of 50 years but it is based on personal choice and situation, not clinical recommendation (USPSTF, 2009). The USPSTF does not have a recommendation for clinical breast examination because of inadequate evidence (USPSF, 2009).

 Preventive screenings for cervical health are pelvic exams, pap smears, HPV tests, chlamydia tests, and testing for STIs (National Women’s Health Resource Center, 2014). Women should receive a pap smear every three years once they turn 21 years of age and until they are 65 years of age (USPSTF, 2012). If the pap smear results are abnormal, the screening intervals should be shorter in length (USPSTF, 2012). This means that if the test results are not normal, women should receive testing more often than every three years. If the pap test results are normal, at the age of 30 years women can decide to be tested every five years (USPSTF, 2012). During a pap smear a woman aged 30 years or younger should be screened or tested for HPV (USPSTF, 2012).

 Screening for chlamydial infection should be performed in women age 24 years and younger who are sexually active, non-pregnant and pregnant (USPSTF, 2007). Women over the age of 24 years should receive the test if they are at increased risk for chlamydial infection (USPSTF, 2007). Women over the age of 24 years old, who are not at increased for chlamydial infection, are not recommended to receive the screening (USPSTF, 2007). The USPSTF does not have general screening recommendations for Sexually Transmitted Infections (STI), the only recommendations were related to counseling (USPSTF, 2008).

## Public Health Relevance

Underutilization of preventive health services and screenings by women living with disabilities is a significant problem in the United States. As the population ages, the likelihood of being diagnosed with a disability and the severity of the condition intensifies (CDC, 2011; Erickson, Schrader, & Lee, 2012; Hosseinpoor et al., 2012; Karvonen-Gutierrez & Ylitalo, 2013). More women over 18 years of age report living with disabilities than men over 18 years of age in the United States (National Center for Health Statics, 2013). Women living with disabilities experience more barriers and issues when receiving regular preventive care than women without disabilities (Wei, Findley, & Sambamoorthi, 2006). It has been suggested that persons living with disabilities have high rates of chronic disease because they underutilize regular preventive health care ((Reichard, Stolzle, & Fox, 2011; Wei, Findley, & Sambamoorthi, 2006). This problem is relevant to public health because women living with disability are an underserved population in the United States who experience barriers to receiving regular preventive care.

# METHODS

The research process began by identifying articles for review through PubMed, an online research database. The process included searching the electronic database for relevant articles, reviewing article abstracts, accepting articles based on abstracts, and reviewing the full text of the accepted articles. Multiple searches were performed from December 13, 2013 to January 21, 2014. After review of initial research findings a second search was performed to include all reproductive health screenings. The final searches were performed from March 28, 2014 to April 3, 2014.

## initial search

The initial search began by entering key terms into the electronic database to identify abstracts and articles associated with preventive health services. All articles were identified using keywords related to the topic of interest (see Table 1). The initial searches generated 6, 555, 390 abstracts for review. Generated abstracts were reviewed for eligible content, and abstracts that did not meet eligibility criteria were excluded (see Figure 1). After evaluation of results and application of search restrictions 2, 206 abstracts were further examined for eligible content. Abstract eligibility criteria were the following: peer-reviewed, in English, sample population from the U.S., contain information on adult women (age 18 years and older) with confirmed or reported disability status (medically diagnosed or self-reported disability), and related to preventive health services.

|  |  |
| --- | --- |
| **Search Terms Used** | **Results Returned** |
| Disability | 150444 |
| Women | 67406 |
| Preventive | 141874 |
| Screening | 4901862 |
| Reproductive | 991312 |
| Reproductive Health | 41686 |
| Impairments | 35223 |
| Disability AND Women | 8511 |
| Screening AND Women | 211574 |
| Preventive AND Disability AND Women | 321 |
| Women AND Screening AND Disability | 2730 |
| Reproductive AND Women AND Screening AND Disability  | 279 |
| Reproductive Health AND Women AND Disability  | 196 |
| Reproductive Health AND Women AND Screening AND Disability  | 40 |
| Reproductive Health AND Women AND Disability AND United States | 47 |
| Women AND Disability AND United States | 1885 |
| **Total** | 6555390 |

Table : Terms and Results of the Initial Search

After abstract review and exclusions, 121 full text articles were examined for eligible criteria and content (see Figure 1). Article eligibility criteria were the following: contain information on adult women (age 18 years and older) with confirmed or reported disability status (medically diagnosed or self-reported disability), are related to preventive health services, review utilization of breast cancer screening, and review utilization of screening for cervical cancer. After exclusions, 17 articles were reviewed.

**Abstract Eligibility Criteria**

Articles excluded: published before 2009; not peer-reviewed; not in English; not in the U.S.

Articles identified using PubMed

n = 6, 555, 390

**Abstract Eligibility Criteria**

Articles excluded: published before 2009; not peer-reviewed; not in English; not in the U.S.; not preventive health services related; not women ages 18 years and older living with disability

Abstracts reviewed using PubMed

n = 2,206

**Article Eligibility Criteria**

Articles excluded: not preventive health services related; not women ages 18 years and older living with disability; not breast cancer related; not cervical cancer related

Full-text articles identified after Abstract review

n = 112

Articles included in literature review

 n = 17

Figure : Initial Search Article Review Process

## Final Search

The final search was performed to include all reproductive preventive health screenings, not just breast cancer and cervical cancer screenings. All articles found in the initial search were reviewed for other reproductive health screening results during the final search. The results from both searches will be combined and reported in the results section below.

The final search began by entering key terms into the electronic database to identify abstracts and articles associated with preventive health services. Articles were identified using keywords related to the topic of interest (see Table 2). The searches generated 7, 663,489 abstracts for review.

Table : Terms and Results of the Final Search

|  |  |
| --- | --- |
| **Search Terms Used** | **Results Returned** |
| Disability | 152721 |
| Women | 680029 |
| Preventive | 144645 |
| Screening | 4955534 |
| "screening" | 380270 |
| Reproductive | 999992 |
| Reproductive Health | 42769 |
| Impairments | 36753 |
| Disability AND Women | 8679 |
| "Screening" AND Women | 43353 |
| Screening AND Women | 214653 |
| Preventive AND Disability AND Women | 327 |
| Women AND Screening AND Disability  | 2783 |
| Women AND "Screening" AND Disability | 493 |
| Reproductive AND Women AND Screening AND Disability  | 284 |
| Reproductive AND Women AND "Screening" AND Disability  | 96 |
| Reproductive Health AND Women AND Screening AND Disability  | 42 |
| Reproductive Health AND Women AND "Screening" AND Disability  | 17 |
| Reproductive Health AND Women AND Disability AND United States | 49 |
| Total | 7663489 |

Generated abstracts were reviewed for eligible content and abstracts that did not meet eligibility criteria were excluded (see Figure 2). After initial review and application of search restrictions, 97 abstracts were further examined for eligible content. Abstract eligibility criteria were the following: peer-reviewed, in English, sample population from the U.S., contain information on adult women (age 18 years and older) with confirmed or reported disability status (medically diagnosed or self-reported disability), and related to preventive health services.

After abstract review and exclusions, 30 full text articles were examined for eligible criteria and content (see Figure 2). The articles were reviewed for information on mammogram and pap test utilization, barriers to receiving preventive screening, health inequities, and comparisons between women with and women without disabilities. After full text review for eligible content, three articles were included in the literature review and results reported in the section below.

**Abstract Eligibility Criteria**

Articles excluded: published before 2009; not peer-reviewed; not in English; not in the U.S.

Articles identified using PubMed

n = 7, 663,489

Abstracts identified using PubMed

n = 97

**Abstract Eligibility Criteria**

Articles excluded: published before 2009; not peer-reviewed; not in English; not in the U.S.; not preventive health services related; not women ages 18 years and older living with disability

Full-text articles identified after Abstract review

n = 30

**Article Eligibility Criteria**

Articles excluded: not preventive health services related; not in the U.S.; not women ages 18 years and older living with disability

Articles included in literature review

 n = 3

Figure : Final Search Article Review Process

# RESULTS

Twenty articles were reviewed after applying the eligibility criteria noted in the pervious section during the initial and final searches. The articles chosen were published between January 1, 2009, and January 15, 2014. Chosen articles had information on different disability types, barriers to care for women living with disability, and health disparities present depending on disability type. Findings are organized by five research questions (see Table 3). The 20 articles are organized at the end of the results section in a summary table (see Table 4).

Table : Research Questions and Associated Articles

|  |  |
| --- | --- |
| **Research Question** | **Number of Articles** |
| Do women living with disabilities in the United States use preventive health services less than men living with disabilities? | 2 |
| Do women living with disabilities in the United State use preventive reproductive health services less than women without disabilities? | 7 |
| Are there barriers to receiving preventive reproductive health services for women living with disabilities? | 5 |
| Do women living with different types of disabilities experience preventive care differently? | 4 |
| Do women from different cultural backgrounds experience preventive care differently?  | 4 |

##  Do women living with disabilities in the United States use preventive health services less than men living with disabilities?

Men and women living with disabilities are more likely to receive preventive services than men and women living without disabilities. Miller et al. (2013) examined the relationship between gender and disability for receiving preventive health services using 2001 – 2007 Medical Expenditure Panel Survey data. They found that older adults used regular preventive services more often when compared to adults less than 64 years of age. Older adults, men and women, received approximately 75.7% of preventive care while adults younger than 64 years of age received 60% of services. They also found that women in the study, living with and without disability, were older and had a higher age range when compared to men. Little information was available about differences between men and women (Miller et al., 2013).

Women living with physical disabilities were more likely to be diagnosed with a sexually transmitted infection (STI) than men living with physical disabilities. McRee, Haydon and Halpern (2010) looked at the National Longitudinal Study of Adolescent health from 1994 to 1995 and 2001 to 2002. They looked at reproductive health data for individuals aged 18 to 26 years. They found that 13.9 % of women and 6% of men living with physical disability were diagnosed with a STI. They also found that 9.3% of women and 8% of men tested positive for having a STI (McRee, Haydon, & Halpern, 2010).

## Do women living with disabilities in the United States use preventive reproductive health services less than women without disabilities?

Women living with disabilities had lower rates of regular screening for both pap tests and mammographies when compared to women without disabilities. Armour, Thierry, and Wolf (2009) conducted secondary data analysis on state-level surveillance data from 2008. They found that women ages 40 and older living with disabilities reported lower rates of mammography screenings in the past two years when compared to women without disabilities. They also found that women with disabilities were less likely to have received a pap test within the last three years when compared to women without disability (Armour, Thierry, & Wolf, 2009).

Women without disabilities reported having better experiences when receiving a mammogram compared to women with disabilities. Clark et al. (2009) conducted a matched cohort study to compare healthcare experiences of women with disability to those without. Women with disabilities reported better experiences if the mammogram clinic was not far away, if a trusted healthcare provider recommended the clinic, and if they had positive and safe experiences while being screened. Women without disabilities were getting screened more than women living with disabilities (Clark et al., 2009).

Drew and Short (2010) looked at the relationship between living with a disability and receiving a pap smear using the National Health Interview Surveys from 2000 and 2005. They found that women living with disabilities had 41% less odds of receiving a pap smear than women without disabilities. Women living with mobility limitations had 35% less odds of receiving a pap smear than women without mobility limitations. If the woman had both mobility and sensory limitations, she had even lower odds of receiving a pap smear than women without limitations (Drew & Short, 2010).

Women utilized mammograms more regularly if they had complex activity limitations than women without limitations. Miller et al., (2013) examined the relationship between gender and disability in receiving preventive health services using 2001 – 2007 Medical Expenditure Panel Survey data. They defined basic activity limitations as sensory, physical, cognitive, and mental limitations. Complex activity limitations were classified as functional and work related limitations. They found that women with both basic and complex activity limitations were more likely to receive blood pressure and cholesterol screening than women without limitations. Women living with basic and complex limitations received cervical cancer screening at lower rates than women without limitations (Miller et al., 2013).

Andresen et al. (2013) conducted a systematic literature review to look at the utilization of pap smears, mammograms, and clinical breast examinations by women with disabilities. They found that women with severe disabilities were less likely to receive a mammogram when compared to women without disabilities. They found varying rates and findings for pap smear testing (Andresen et al, 2013).

Wisdom et al. (2010) reviewed 16 years of research from 1990 to 2005 to examine health disparities between women with and women without disability. They found that women with disabilities were less likely to have received a pap smear when compared to women without disabilities. They also found that women with disabilities were less likely to have received a mammogram when compared to women without (Wisdom et al., 2010).

Horner-Johnson et al. (2014) conducted a study to examine the differences in breast and cervical cancer screening rates by women living with different disability severity levels. Using Medical Expenditure Panel Survey data from 2002 – 2008, they found that women with disabilities were not as likely to be up-to-date with current screening recommendations when compared to women without disabilities (Horner-Johnson et al., 2014).

## Are there barriers to receiving preventive reproductive health services for women living with disabilities?

Jarman et al. (2013) conducted surveys with women living with disability to identify barriers to accessing breast cancer screening. They found that women living with multiple disabilities were more likely to need a mammogram machine accessible for persons sitting. This means that more sitting mammogram machines are needed. They also found that women with only physical disabilities were more likely to report needing to sit down during a mammogram (Jarman et al., 2013).

Suzuki et al. (2013) conducted an educational workshop to understand the barriers to receiving mammograms by women living with mobility limitations. They found that individual barriers to receiving care include other health conditions, family, self-care, and little knowledge about testing with the mammogram machine. They also found that information about screening techniques were unclear and that past negative experience with providers act as barriers to care (Suzuki et al., 2013).

Physical access barriers to breast cancer screening include hard-to-grip or absent handle bars on mammogram machines (Jarman et al., 2013; Lezzoni, Kilbridge, & Park, 2010), inability to grip the handle bars or stand (Lezzoni, Kilbridge, & Park, 2010), inaccessible mammogram equipment and inaccessible exam tables (Jarman et al., 2013; Lezzoni, Kilbridge, & Park, 2010), difficulty when attempting to position while standing and difficulty when attempting to position while lying down (Lezzoni, Kilbridge, & Park, 2010), unavailable accessible equipment (Jarman et al., 2013; Lezzoni, Kilbridge, & Park, 2010), and injuries from maneuvering (Lezzoni, Kilbridge, & Park, 2010).

Environmental barriers include difficulty locating a doctor with accessible equipment and knowledge of disability care, difficulty with appointment scheduling, providers too far away in distance, insurance coverage and deductibles, transportation problems, and financial issues (Suzuki et al., 2013). Mobley et al. (2009) found similar results when looking at Surveillance Epidemiology and End Results (SEER) Medicare data from California. They found that women with disabilities who lived in a more urban area, with better transportation, were 40% more likely to receive a mammogram than women without disabilities (Mobley et al., 2009).

## Do women living with different types of disabilities experience preventive care differently?

Women with severe disability were less likely to receive mammograms than women with moderate disability. Caban et al. (2011) looked at the results from the Medicare beneficiary survey from 2004-2005 to examine relationships between mammography utilization and disability status in the Medicare beneficiary population. They found that women with moderate disability were 24% less likely to get mammograms than women without disability. They also found that women with severe disability were 54% less likely to receive mammograms than women with moderate disability (Caban el al., 2011).

Women with an intellectual disability have varying rates of mammogram utilization based on support and living environment. Wilkinson et al. (2011) analyzed data to examine mammogram utilization rates by women with intellectual disability. They found that women who have higher needs for support were less likely to get mammograms than women with no need for support. They also found that women who have other health conditions and diagnoses were more likely to receive a mammogram than those without comorbidities. Women with Downs Syndrome were less likely to receive a mammogram (Wilkinson et al., 2011).

Women living with intellectual disability who depend on caregivers were less likely to receive reproductive screening than those without caregivers. Swaine et al. (2013) conducted interviews with women living with intellectual disability and their caregivers to identify barriers to receiving cervical and breast cancer screening. They found that 75% of the women interviewed received a mammogram and 77% received a pap test. They also found that some caregivers did not believe that the women they cared for needed the screenings. Some caregivers reported that past experiences of sexual abuse and lack of sexual activity were reasons for screenings not to be performed (Swaine et al., 2013).

Women living with cognitive and physical disabilities receive pap smears and mammograms at different rates. Reichard and Fox (2013) conducted secondary data analysis on 2000 to 2008 Medical Expenditure Panel Survey data. They found that women living with cognitive disability were 70% more likely to receive a pap smear and 55% more likely to receive a mammogram if they did not also have a physical disability. Women living with physical disability were 45% more likely to receive a pap smear and 47% more likely to receive a mammogram if they did not also have a cognitive disability. Women living with both cognitive and physical disabilities were the least likely to receive routine pap smears and mammograms (Reichard & Fox, 2013).

## Do women from different cultural backgrounds experience preventive care differently?

Women with disability who identify as Black or African American were more likely to receive a pap smear than White women. Drew and Short (2010) looked at the relationship between living with a disability and receiving a pap smear using National Health Interview Surveys from 2000 and 2005. They found that women with disabilities were more likely to be 40 to 64 years of age, African American/Black, have a high school education or less, and live at the 299% federal poverty level. They also found that women with disabilities who identified as Hispanic were more likely to receive a pap smear than White women (Drew & Short, 2010).

Women with disability who were young, African American, Hispanic, poor or married were more likely to have received a pap smear. Reichard and Fox (2013) conducted secondary data analysis on 2000 to 2008 Medical Expenditure Panel Survey data. They looked at data for women eligible for Medicare and Medicaid. They found that women living with cognitive and physical disabilities were for more likely to be young, African American or Hispanic. They also found that African American women over the age of 40 years were more likely to receive a mammogram if they did not have a cognitive disability (Reichard & Fox, 2013).

Women who identified as White were more likely to have received cervical cancer screening than other women with disabilities. Martin, Orlowski, and Ellison (2013) looked at statewide Patient Eligibility Assessment Tool (PEAT) data from a home care waiver program in Ohio. They found that White women living with disability were more likely to be screened than African American women living with disability (Martin, Orlowski, & Ellison, 2013). Parish et al. (2013) also found similar results for breast cancer screening. They reported that African American women with intellectual disability were less likely to receive mammography when compared to White women with intellectual disability (Parish et al., 2013).

African American women living with intellectual disability were less likely to report accurate information during an interview about breast and cervical cancer screenings than white women. Son et al. (2013) performed face-to-face interviews with women living with intellectual disability and compared interview results with retrospective medical data. They found that women who lived in urban areas were less likely to accurately report when they received their last mammogram or Pap test than women who lived in rural areas. They also found that African American women and older women were less likely to report accurate information during the interview (Son et. al., 2013).

Table : Literature Results

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Research Article | Methodology | Participants | Type of Disability | Screening Tests Reviewed | Summary of Results |
| Andresen et al., 2013 | Systematic Review Methods |   | Disability severity  | Pap smear, mammography, and clinical breast examination | Found five studies; No standard definition of disability; Pap smear utilization by disability severity, varying results; three studies concluded that mammography utilization rates were lower for women with more severe disability; inconsistent utilization of clinical breast exam; Overall, screening utilization rates were lower as disability severity increased |
| Armour, Thierry, & Wolf, 2009 | Data analysis, 2008 BRFSS | Women ages 18 years or older | Self-reported Disability | Pap smears and mammography | Lowest self-reported disability in Iowa and Hawaii. Highest self-reported disability in West Virginia. Fewer WWD (Women With Disability) reported receiving a mammogram in the past 2 years than WWOD (Women Without Disability). Fewer WWD reported receiving a pap test in the past 3 years than WWOD. WWD had lower rates of all reproductive screenings when compared to WWOD.  |
| Caban et al., 2011 | Medicare Current Beneficiary Survey (MCBS) 2004-2005 | Women ages 65 or older, Medicare beneficiaries | Moderate Disability and Severe Disability | Mammography | n = 4,610; 29% had moderate disability, 21% had severe disability. Women with moderate: 24% lower odds of having mammogram. Women with severe: 54% lower odds of having mammogram |

Table 4 Continued

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Research Article | Methodology | Participants | Type of Disability | Screening Tests Reviewed | Summary of Results |
| Clark et al., 2009 | Data analysis, 2003-2005 Cancer Screening Project for Women Survey, Matched Cohort Study (WWD match with WWOD) |   | Disability status, severity, and type | Mammography | WWD reported poorer health and higher BMI. WWD had significantly lower screening rates than WWOD. WWOD were more likely than WWD to report better patient experiences while receiving a mammogram |
| Drew & Short, 2010 | Data analysis, NHIS adult household survey 2000 and 2005 | Women ages 21 to 64 years | Mobility, sensory, cognitive, social, and mental limitations.  | Pap smear | 68% of WWD had received pap smear in the previous year. 75% of WWOD received pap smear in the previous year. WWD visited the doctor more regularly than WWOD. WWD had 41% lower odds of having pap smear than WWOD. As disability severity increased, odds of receiving pap smear decreased.  |
| Horner-Johnson, et al., 2014 | Data analysis, Medical Expenditures Panel Survey (MEPS) 2002-2008 | Women ages 18 to 64 years | Disability severity, basic action difficulties, complex activity limitations | Pap smears and mammography | As women aged, disability severity increased; as disability severity and limitations increased, rates of screening decreased; WWOD utilized preventive screenings more than WWD |

Table 4 Continued

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Research Article | Methodology | Participants | Type of Disability | Screening Tests Reviewed | Summary of Results |
| Jarman et al., 2013 | Data analysis, Carolina Mammogram Registry |   | Multiple Disabilities: hearing, vision, and physical | Mammography | Women with multiple disabilities were more likely to need staff assistance during procedure. Barriers identified: need for handrails next to changing bench, room to turn wheelchair, printed materials not available in other formats, and more accessible parking.  |
| Lezzoni, Kilbridge, & Park, 2010 | In-person or telephone interviews | Women ages 30 to 59 years | Mobility Limitation | Mammography | n=20; Barriers to screening: inaccessible equipment, examination tables, and interactions with radiology technicians. As women age, they are at greater risk of having disability.  |
| Martin, Orlowski, & Ellison, 2013 | Data analysis, Patient Eligibility Assessment Tool (PEAT) | Women ages 20 to 80 years | Medically diagnosed disability | Pap smears | Mean age 49.6 years, 45.4% received pap smear within last 3 years, 70.4% of women screened were White, women with more difficulties with ADLs they were less likely to be screened |
| McRee, Haydon, & Halpern, 2010 | Data analysis, National Longitudinal Study of Adolescent Health 1994-1995 and 2001-2002 | Women ages 18 to 26 years | Physical Disability | STI testing and pap smear | 69.7% received gynecological exam in the past 12 months; 61.8% received a pap smear; 13.9% diagnosed with STI; 9.3% tested positive for STI; WWD had lower odd of receiving a pap smear when compared to WWOD; Men with disability (MWD) reported 6% diagnosis of STI and 8% tested positive for having a STI |

Table 4 Continued

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Research Article | Methodology | Participants | Type of Disability | Screening Tests Reviewed | Summary of Results |
| Miller et al., 2013 | Data analysis, Medical Expenditure Panel Survey (MEPS) 2001-2007, Andersen's Behavioral Model of Health Care | Women ages 18 -64 and 65 older, Men ages 18-64 and 65 older | **Basic Activity Limitation**: sensory, physical, cognitive, and mental. **Complex Activity Limitation**: functional and work-related.  | Pap smear, mammography, colonoscopy, sigmoidoscopy, cholesterol, and blood pressure | Cervical cancer screening rates are lower in women with basic activity limitations (ages 18-64 years), Mammogram rates are higher in women with complex activity limitations (ages 18 - 64 years), for both men and women - having a usual source of care increased the likelihood of utilizing/receiving preventive care, adults aged 65 and older receive preventive screening more often than younger adults. |
| Mobley et al., 2009 | Data analysis, Surveillance Epidemiology and End Results (SEER) - Medicare Data | Women from California n= 70, 129 | Reported Disability  | Mammography | WWD were 5% less likely than WWOD to get a mammogram; WWD living in community with greater intensity were 40% more likely to get a mammogram |
| Parish et al., 2013 | Data analysis, retrospective 2008-2009, medical records and in-person interviews | Women ages 40 or older, African American and White | Intellectual Disability (ID) | Mammography | African American women are much less likely to receive screening when compared to White women with ID |

Table 4 Continued

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Research Article | Methodology | Participants | Type of Disability | Screening Tests Reviewed | Summary of Results |
| Parish et al., 2012 | Computer-assisted interviews, face-to-face interviews  | Women with developmental disability, n=202 | Developmental Disability | Pap smears and mammography | Health literacy/knowledge of women with DD: 31% knew the definition of cancer, 39% knew the definition of mammography, 18% knew mammogram frequency, 88% knew who should do breast exams, 35% knew the definition of a pap test, 19% knew pap test frequency, and 41% knew how to decrease exam related anxiety.  |
| Son et al., 2013 | Face-to-face interviews and retrospective medical data from 2006-2010 | Women with intellectual disability, n=155 | Intellectual Disability (ID) | Pap smears and mammography | Women over estimated how often they received pap smears and mammograms; 46% accurately reported when they had their last pap smear; 43% accurately reported when they had their last mammogram; Older WWD and African American WWD were less likely to accurately report information about screening; WWD living in rural areas, when compared to WWD living in urban area, were more likely to get a pap smear |
| Reichard & Fox, 2013 | Data analysis, Medical Expenditures Panel Survey (MEPS) 2000-2008,  | Dual eligible (Medicare and Medicaid) adults ages 18 or older | Cognitive limitations, physical disabilities, double diagnosis (cognitive and physical), or neither cognitive nor physical | Pap smear, mammography, dental visit, and flu shot | Health status varies by disability type, if person had more chronic conditions they were more likely to receive preventive services. Being dual eligible, young, African American or Hispanic, low income, or married increased likelihood of having a pap smear. Being 40 years or older and African American increased likelihood of having had a mammogram. |

Table 4 Continued

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Research Article | Methodology | Participants | Type of Disability | Screening Tests Reviewed | Summary of Results |
| Suzuki et al., 2013 | Promoting Access to Health Service (PATHS) Intervention/Educational Workshop 2007 - 2009 | Women ages 40 to 64 years  | Mobility Limitation | Mammography | Barriers: interference by other health conditions, self care limitations, family and home responsibilities, little knowledge about mammograms, information from health care provider is unclear, past negative experiences with providers and testing |
| Swaine et al., 2013 | Women Be Healthy Randomized Controlled Trial, a psycho-educational program | Family caregivers of women with ID, n=32 | Intellectual Disability (ID) | Pap smear, mammography, and clinical breast exam | 83% of caregivers report that women with ID received clinical breast exams from health care provider, 80% received breast exam in the past year, 75% of women received a mammogram, 77% received pap/pelvic exam |
| Wilkinson et al., 2011 | Data analysis, Massachusetts Department of Developmental Services Electronic Health Records | Women ages 42 – 74 years old | Intellectual Disability (ID) | Mammography | Average age: 54.7 years, 53% overall mammography rate, as the number of diagnoses increased so did the odds of receiving a mammogram, women living in residential settings were more likely to receive mammograms, women with RN acting as health coordinators were more likely to receive mammograms. Women who did not receive mammograms had higher ADL needs, Down Syndrome, and had a guardian.  |
| Wisdom et al., 2010 | Literature review articles from 1990 to 2005 |   | Physical, sensory, intellectual, developmental and psychiatric | Pap smear, mammography, clinical breast exam, and flu shot | WWD are less likely to receive pap tests and mammograms when compared to WWOD |

# DISCUSSION

This review of the literature looked at all disability types, disability severity, and barriers to preventive care for women with disability. The results suggest that women with disability are underutilizing care and that there are disparities when receiving preventive services. All 20 articles discussed the prevalence of current screening behaviors in women living with disabilities. Two of the articles compared utilization of preventive services by men and women and seven articles compared women with and women without disabilities. Four articles provided information on barriers to receiving care and four articles compared experiences between different cultural backgrounds.

 Women living with disabilities underutilized both breast cancer screening and cervical cancer screening. They also had lower rates of getting screened when compared to women without disability. Women without disabilities had more positive experiences while getting mammograms and pap tests. Women with mobility limitations had the most difficulty getting mammograms because of physical barriers and environmental barriers. Those barriers included mammogram machines that cannot be adjusted to accommodate a sitting woman.

 Few articles compared the screening differences between men and women living with disabilities. Most articles compared the different screening utilization rates and experiences between women with and women without disabilities. The articles had reported similar results, stating that women without disability utilized screenings more regularly than women with disability. One finding did not follow this trend. Andresen et al. (2013) found that women with severe disabilities were more likely to receive pap testing when compared to women without disabilities. This result is interesting because it compares disability severity in levels, not just with or without disability.

 Women with different types and severity of disability experience care and utilize preventive screenings at various rates. Overall, as disability severity increased the likelihood of being screened decreased, for both breast cancer and cervical cancer screening. Also, as support decreased for persons living with intellectual disability, screening utilization decreased. Women living with intellectual disability depend on caregivers to guide care. For example, if a caregiver did not believe the woman was or could be sexually active, cervical cancer screening was not performed.

 African American women and Hispanic women received preventive screenings more often than White women. This finding was surprising in light of Martin, Orlowski, and Ellison’s (2013) work which found that White women were more likely to receive cervical cancer screening than other women with disabilities. And according to Parish, Swaine, Son, and Luken (2013), African American women with intellectual disability were not as likely to receive a mammogram when compared to White women with intellectual disability. It was surprising to see such different results and differences in screening behaviors over time.

As African American women aged and if they did not have a cognitive disability, they were more likely to receive a mammogram (Reichard & Fox, 2013). This could be because the screening recommendations do not begin until women are about the age of 40. It was interesting because the comparison group for this study was women living with physical disability. This result does not agree with other results about barriers to mammograms and inaccessible machines. Why are African American women living with physical disabilities in this study still more likely to receive mammograms?

The most surprising finding from this literature review was the lack of articles discussing or reviewing all aspects of reproductive health screenings. Only a few articles discussed STIs testing and clinical breast exams, most articles focused on mammograms and pap tests. This was surprising because the final search was performed to include all types of preventive health screenings, and very few articles could be found. More information is needed on different preventive health screenings to be able to address health issues within the population.

There are many limitations of the research reviewed. First, there was no standard definition for disability. Many research conducted focused on creating a definition of disability that worked with the study. Other research used definitions defined by disability organizations and leaders in the disability field. Without a standard definition for disability the external validity and generalizability of these studies are low. A standard definition is needed to be able to improve the care of persons living with disability and to be able to compare groups of individuals living with disability.

Second, many of the surveys were not created to determine disability status or do not ask specific questions about living with a disability. The data are from general behavioral surveys, asking questions about health practices and attitudes. More data collection is needed to be able to assist the priority population in increasing preventive screening practice. More questions need to be asked to properly address current health disparities in women living with disability.

# CONCLUSION

Disability limits personal ability to perform daily tasks and can interfere with preventive health practices. As people age, the likelihood of being diagnosed with a disability increases. In the United States, more women reported confirmed or diagnosed disability than men. Women living with disabilities underutilize reproductive health screenings more than women without disabilities. A literature search and review was conducted from December 2013 to April 2014 to look at current research about preventive health screenings and disability health.

The purpose of this paper was to report findings from current literature on utilization of preventive health services by women living with disabilities in the United States. Twenty articles were reviewed and the results were discussed. The literature review found that women living with disabilities had lower rates of regular screening for both pap tests and mammographies when compared to women without disabilities. As disability severity intensified, utilization of preventive health screenings decreased. The review also found that rates of screening utilization varied depending on disability type. For example, women living with intellectual disabilities who had a caregiver were less likely to receive reproductive screening than those without caregivers. Women living with physical disabilities were less likely to receive screenings when compared to women with cognitive disability.

Rates of screening utilization also varied depending on cultural background. Women who identified as Black or African American had varying rates of pap smears, but most studies reported that African American women living with disability received screening more often than White women living disability. African American women living with intellectual disability were less likely to receive mammography when compared to White women.

This literature review has limitations. First, the reviewed literature only contains articles written in English, with sample populations from the United States. This means that the findings from this paper are not generalizable to populations in other countries. There are many articles on PubMed from other countries that would have added more information about different populations and preventive services. Future literature reviews should contain articles from other countries to make findings more generalizable.

Second, the findings in this review were from existing peer-reviewed data from published articles. This is a limitation of this paper because original research was not performed. No new data were collected from this review and therefore no new data were added to the disability research field. New data are needed to be able to understand current issues within a population, to be able to create programs or interventions to address issues.

## Recommendations For Future Research

Future research is needed to better understand why women with disabilities underutilize preventive screenings. More information is required to properly address the reproductive health concerns for the population in order to improve health outcomes and increase the utilization of health screenings. Future research studies should address access to health care issues and barriers to receiving care for women living with disabilities. For example, hospitals can adjust policies to improve experiences during screenings, improve provider education on disability health, and improve the physical layout of clinics to reduce possible physical environmental barriers to care.

 More qualitative studies are needed to properly understand why women living with disabilities are receiving preventive screenings less. Researchers could work with disability advocacy groups and committees to be able to get a better understanding of this issue. Researchers could also work with hospitals and clinic staff to understand current screening techniques and perspectives of the practitioners who perform screening procedures with persons living with disabilities. There are many opportunities for future research in the field of disability health and these recommendations only scratch the surface.

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