

Addressing Breast Health Inequalities Among Women with Disabilities

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Introduction

- Breast cancer is one of the leading causes of cancer deaths among women.
- According to the CDC's National Center on Birth Defects and Developmental Disabilities the number of women with disability in the United States ranges from 19.9 to 28.6 million depending on how disability is defined.
- As many as 1 in 5 women has some type of limitation in physical and/or mental functioning.

Breast Health Disparities

- Women with disabilities continue to experience inequalities in accessing their breast health screening, educational, and treatment services.
- Research has indicated that women with disabilities are less likely to have a clinical breast exam, screening mammogram, and diagnostic mammogram compared to women without disabilities.

Factors Affecting Breast Health Care

- There are numerous factors that contribute to women with disabilities being able or not able to access breast health care and services.
- Some common factors include physical accessibility, knowledge and attitudes among providers, financial and insurance issues.
- These factors may serve as either barriers or facilitators to obtaining proper breast care.

Common Examples of Barriers

- Inaccessible facilities and equipment
- Lack of health insurance coverage/low income
- Negative attitudes of breast health providers
- Lack of disability knowledge among providers
- No assistance available (professional/personal)
- Lack of accessible transportation
- No alternative formats of educational materials
- Difficulty remembering (lack of reminders)

Educational Materials

- As part of an earlier project, three specialized educational materials have been developed and distributed to address breast health inequalities among women with disabilities.
 - A Consumer's Guide to Breast Health for Women with Disability
 - A Provider's Guide to Breast Health for Women with Disabilities
 - A Directory of Missouri Breast Health Care Centers for Women with Disabilities

Need for an Accessibility Instrument

- Although these materials have addressed the importance of accessible breast health facilities and equipment (e.g. mammography and exam tables), feedback from women with disabilities have indicated the need for a user-friendly tool that could be used to determine the level of accessibility or inaccessibility of breast health facilities and provide specific ways to address a feature that is not accessible within a facility.

Breast Health Accessibility Project

- The current three-year grant project funded by Susan G. Komen for the Cure (May 2006-April 2009) addresses recommendations made by consumers (women with disabilities), family members, and breast health providers.
- The project is currently developing and pilot testing an accessibility checklist and associated resource guidebook specifically designed for breast health facilities of all types (hospitals, community centers, radiological facilities, etc.).

Breast Health Accessibility Project

- Additionally, the project will track how the accessibility of breast health facilities impacts consumer use (women with disabilities).
- Finally, the project will evaluate the impact of the accessibility checklist and resource guidebook on breast health provider awareness, attitudes, and behaviors as well as consumer use of breast health facilities.

Overall Project Objectives

- To increase consumer awareness and knowledge of accessible breast health facilities and services among women with disabilities
- To increase the understanding of accessibility features and accommodation among breast health providers
- To provide resource information on improving accessibility of breast health facilities
- To improve overall access to breast health services and care for women with disabilities

Project Methodology

- Both quantitative and qualitative methods are being used to develop, evaluate, and test the content and format of the instrument prototypes.
- Methods include a literature and internet search, initial and follow-up focus groups comprised of consumers and providers, and actual facility site checks by both consumers and providers using the initial and revised instrument prototypes.

Literature and Internet Search

- A detailed literature and internet search has been conducted to identify and compile various types of accessibility instruments that have been developed.
- These tools have been reviewed and grouped into categories (e.g. too detailed/not detailed; user friendly/not user friendly).
- Based on these findings and other ideas proposed by the P.I. and project participants, several instrument prototypes were developed.

Focus Groups

- Focus groups have been conducted – one of women with disabilities and another of breast health providers - to provide initial feedback of the drafted instrument prototypes.
- Based on this input, the accessibility checklist and resource guidebook have been modified and they are now being pilot-tested by both consumers and providers on a small sample of breast health facilities in the St. Louis area.

Instrument Prototypes

- The accessibility checklist provides a list of key accessibility aspects that should be provided in any breast health facility including specialized equipment and alternatives to traditional features (printed materials, regular scheduling and intake procedures, etc.)
- The resource guidebook provides information on how to use the checklist and specific ways to improve the overall accessibility of facilities.

Next Steps

- Preliminary data will continue to be collected from the initial pilot test of five facilities.
- Data will be compared between testers for each facility as well as between facilities among all testers (consumers and providers).
- Feedback on the format, content, and ease of use of the checklist and guidebook at actual facilities will be compiled and analyzed.
- The findings will be used to modify the current prototype instrument versions.

Next Steps Continued

- The modified version will be modified and then tested across multiple facilities throughout Missouri enabling comparison of the instruments across different types of facilities and in varying geographical areas (larger city versus small rural community).
- The number of testers will be expanded to include a greater number of women with disabilities and breast health providers.

Concluding Remarks

- The presented project uses a participatory approach to addressing an identified breast health need by involving both women with disabilities and breast health professionals.
- Social workers have a role to advocate on behalf of those that are marginalized in terms of taking measures to alleviate and/or eliminate health disparities that may exist.

Contact Information

- For further information or to obtain copies of project materials, please contact:

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