

COMMENTARY

Women With Cerebral Palsy and Breast Cancer Screening by Mammography

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ABSTRACT. Poulos AE, Balandin S, Llewellyn G, Dew AH. Women with cerebral palsy and breast cancer screening by mammography. *Arch Phys Med Rehabil* 2006;87:304-7.

We emphasize the need to identify specific barriers to participation in breast cancer screening by mammography experienced by women with cerebral palsy (CP). Mammography screening has been found to reduce mortality rates by 30%, but women with disabilities such as CP underuse this important preventive medicine facility, potentially leading to delay in diagnosis of breast cancer and a less favorable prognosis. Because equity in health care is compromised through underutilization by these women, barriers to participation and successful outcomes must be investigated. Barriers such as appropriate information, transport, and assistance prevent women with CP from getting to the facility. Once there, communication difficulties, physical limitations, psychologic barriers, and staff attitudes become barriers to a successful outcome. Education for health personnel as well as adaptation of the mammographic technique to suit the physical limitations of women with CP are critical to increasing participation and ensuring successful outcomes. Importantly, there is a need to identify women for whom having a mammogram is not an option and for whom alternative breast screening methods should be provided.

Key Words: Cerebral palsy; Communication; Mammography; Rehabilitation.

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BREAST CANCER IS THE SECOND most common cancer in the United States.¹ In Australia, breast cancer is the most common cause of death from cancer.² Breast cancer screening by mammography has been shown to reduce mortality rates by 30%³ and, despite recent methodologic debate, has been reaffirmed as an effective method for the early detection of breast cancer.⁴ This reduction is dependent on participation in initial screening and then rescreening, typically every 2 years. Research indicates that women with cerebral palsy (CP) have a 3 times higher mortality rate from breast cancer than the general population.⁵ Survey data from the U.S. Medical Expenditure Panel Survey and the U.S. National Health Interview Survey indicated a reduced uptake of mammography screening by women with disabilities.^{6,7} In a reanalysis of these

data sets, Legg et al⁸ found that 30% of women with self-reported cognitive limitations were less likely to use mammography services than women without a disability. Similar results were found for women with cognitive limitations in Western Australia. In this state, only one third of women with an intellectual disability were screened in the National Breast Cancer Screening Program.⁹ Thus, research indicates that many women with a disability are not participating in breast cancer screening. Therefore, in Australia alone, there are at least 400,000 women at risk of delayed diagnosis, costly late-stage cancer treatment, and potentially fatal malignancies.⁹⁻¹¹ Older women with a disability are at risk internationally. A report from the U.S. Centers for Disease Control and Prevention¹² indicated that older women with a disability and those with functional limitations were less likely to participate in breast cancer screening. A study by Caban et al¹³ found that women with a disability were less likely to undergo breast-conserving surgery, which suggests that diagnosis may occur at a later stage. In this commentary, we suggest that the range and extent of potential barriers to successful breast cancer screening by mammography experienced by women with CP provide a robust rationale for the reduced uptake of this service by women with disabilities that requires further investigation.

BARRIERS TO PARTICIPATION IN BREAST CANCER SCREENING BY MAMMOGRAPHY

Influences on uptake of health services have been shown in a model of health services utilization developed and expanded by Andersen¹⁴⁻¹⁶ and Aday¹⁷ and colleagues. After expansion, this conceptual model now includes environmental influences, population characteristics, health behaviors, and health outcomes.^{8,15} Successful participation in breast screening by mammography involves receiving and acting on appropriate information, getting to the breast cancer-screening facility, and having a mammogram that is of optimal quality for reporting. Barriers in any aspect of the model result in reduced uptake in health care services for women with CP. Consequently, women with CP who may experience not only motor disorders but also communication and literacy problems are confronted by a number of potential barriers to a successful screening.

Entry Barriers

Entry barriers include receiving appropriate information about breast cancer screening and how to make an appointment to attend. Also essential is facilitating the process of "getting there."

Appropriate information. Women require appropriate information about breast cancer screening including the benefits of mammography before they can make the decision to participate. Women with CP may have difficulty accessing information in appropriate formats.¹⁸ Research indicates that for women with CP acute illnesses were appropriately cared for by health services but that preventive medical care was lacking.¹⁹ Klingbeil et al²⁰ suggested that a possible explanation for the paucity of preventive care include limited education of patients and caregivers and perceived or real environmental barriers.

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Primary care doctors may focus on underlying conditions rather than preventive health care.⁷ In a study²¹ that focused on reasons for not having a mammogram, 25% of women with physical disability such as CP were not told by their doctor they should have one. This is a cause for concern because Balandin and Morgan²² noted that many adults with CP have poor literacy skills and never read to gain information but rely on family members, carers, or health professionals to provide health information. This is not always a reflection of cognitive status. Indeed, Koppenhaver et al²³ noted that adults with CP and no cognitive impairment frequently have limited literacy skills because they were never expected or taught to read. In addition, the physical problems associated with CP can make holding written information and turning pages an impossible task. An additional concern is that women with CP may receive no information at all or be given incorrect information concerning the requirement to stand for a mammogram.⁷ Providing information offers choices and provides a perception of being in control for people and may act as an enhancement factor for breast cancer screening.²¹ Appropriate information may be provided by breast cancer-screening promotion personnel who target women with disabilities such as CP to ensure the dissemination of appropriate information by providing talks and presentations. Although this is an effective way of providing information about the service,²⁴ difficulty in making an appointment and transportation to the facility may preclude participation.

Getting there. Women with CP experience similar barriers to getting to the facility as reported by most women, including cost, access to facility, and transportation.^{25,26} Women with CP may experience barriers to preventive health care that are specific to having a severe physical disability. These include problems with physical access to services and difficulties in obtaining appropriate personal assistance.¹⁸ Women with CP who use a wheelchair may experience difficulty with limited space and access in the screening facility itself, in the mammography room, and in the toilets. Women who are not independently mobile may need to rely on having a person to transport them and/or accompany them to the breast cancer-screening site. This reliance impacts on the resources of support staff and on family members or carers who must accompany them.²² Any one of these entry barriers can result in an inability to participate in the service.²⁷

Outcome Barriers

Once entry barriers are overcome, women with CP may experience outcome barriers that involve difficulties with the mammography procedure itself. Many women experience some physical and psychologic discomfort during the procedure that they typically find embarrassing, threatening, uncomfortable, and physically demanding.^{28,29} The potential for the exacerbation of these categories of discomfort for women with CP is increased because of communication difficulties, physical limitations, and negative staff attitudes.^{7,21,30-33} An unsuccessful outcome of the mammography procedure has the potential to become an additional entry barrier for women with CP and may deter them from participating in rescreening.

Communication. Physical and psychologic discomfort experienced during mammography can be relieved by appropriate communication about the procedure.²⁸ However, this important aspect of the interaction between the technologist and woman undergoing mammography may be difficult or impossible for many women with CP who also experience severe communication difficulties or have little or no functional speech. Technologists typically have little experience or training in communication with women with CP, particularly those women whose

communication is augmented or difficult to understand. Communication difficulties are expressed in the following quotation:

"I just tell them straight up, 'I've got cerebral palsy' and you usually have to break the ice because they don't know anything about you and you don't know anything about them . . . if you lay down your history, if you tell them up front that you have cerebral palsy, perhaps they look at you a bit weirdly to start off with, unable to comprehend or whatever, I just tell them 'I'm perfectly capable of understanding what you are saying and I want to know exactly what is in store for me'" (Carol, a woman with CP).^{34(p8)}

In mammography, effective communication is essential for gaining a successful outcome.^{28,35} Effective communication facilitates gaining the confidence and compliance of the woman and also helps ensure that the breast compression is tolerated at an appropriate level. Without effective communication, the woman is unlikely to relax sufficiently to ensure optimal positioning, and this has the potential to compromise a successful outcome.³⁵ The need to relax is particularly pertinent for women with CP who are likely to experience increased involuntary movement or spasms if they are uncomfortable or anxious. Most important, for women with physical disabilities such as CP, direct and honest communication is highly valued.³⁰

Physical Limitations and Psychologic Barriers

The positioning required for mammography is difficult for women with CP and has been identified as a barrier to participation.²¹ The mammography procedure requires women to remain motionless for a few seconds during exposure. It also requires the woman to raise her arm to steady herself by holding on to the mammography machine.³⁶ The physical limitations experienced by women with CP may result in them being unable to comply with these requirements.^{19,37} Women with CP experience similar psychologic barriers to the procedure as unimpaired women (eg, having a stranger touch their breasts).²¹ However, physical limitations exacerbate the psychologic barriers to mammography. A woman with CP described balancing precariously on a stool or needing support from nurses or technologists to undergo mammography. She noted that this magnified the pain and indignity of the mammography procedure.¹⁹ Consequently, both the woman and the technologist may experience feelings of frustration and failure. It may not be possible to produce any images or the images may be blurred because of involuntary movements. Positioning difficulties may mean that not all the breast tissue is adequately visualized, and therefore an optimal report may not be possible.

Staff Attitudes

Personnel in breast cancer screening may show negative attitudes^{21,30,34} toward women with CP. These attitudes may be encouraged by the perceived need for extra resources such as additional health personnel, an increase in time taken to complete the procedure, and the likelihood of a less than optimal outcome.²⁴ Negative attitudes related to the "usefulness" of screening women with disabilities have the potential to influence the success or otherwise of the mammography procedure.⁷ Such attitudes of staff toward women with CP clearly deter women from making an initial appointment as well as attending for rescreening.

Future Directions

Despite the barriers discussed previously, some women with CP do undergo regular mammograms. There is a need to identify appropriate strategies that will ensure an optimal pro-

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