Disability and Health Journal xxx (2018) 1–7

Contents lists available at ScienceDirect

Disability and Health Journal

journal homepage: www.disabilityandhealthjnl.com

Breast cancer screening in women with cerebral palsy: Could care delivery be improved?

Neeharika Nandam [a], Deborah Gaebler-Spira [b, c, d], Rachel Byrne [e, f], Judith Wolfman [g, h], Judy Panko Reis [i], Chun Wai Hung [f], Allison Todd [d], Jordyn Durkin [j], Christina Marciniak [b, d, k, *]

[a] Northwestern University Feinberg School of Medicine, 420 E. Superior St., Chicago, IL 60611, USA
[b] Department of Physical Medicine and Rehabilitation, Northwestern University Feinberg School of Medicine, 710 North Lake Shore Drive, #1022, Chicago, IL 60611, USA
[c] Department of Pediatrics, Northwestern University Feinberg School of Medicine, 225 E. Chicago Avenue #86, Chicago, IL 606111, USA
[d] Shirley Ryan AbilityLab, 355 East Erie Street, Chicago, IL 60611, USA
[e] Cerebral Palsy Foundation, 3 Columbus Circle, 15th Floor, New York, NY 10019, USA
[f] Division of Pediatric Orthopedics, Columbia University Medical Center, New York-Presbyterian Morgan Stanley Children's Hospital, 3959 Broadway, Room 800N, New York, NY 10032, USA
[g] Department of Radiology, Northwestern University Feinberg School of Medicine, 676 N. St. Clair St., Suite 800, Chicago, IL 60611, USA
[h] Lynn Sage Breast Center, 250 E. Superior St., Chicago, IL 60611, USA
[i] Access Living, 115 West Chicago Avenue, Chicago, IL 60654, USA
[j] Division of Pulmonary and Critical Care Medicine, Northwestern University Feinberg School of Medicine, 676 N. St. Clair St., 14th Floor, Chicago, IL 60611, USA
[k] Department of Neurology, Northwestern University Feinberg School of Medicine, 303 East Chicago Avenue, Ward 12-140, Chicago, IL 60611, USA

ARTICLE INFO

Article history:
Received 3 August 2017
Received in revised form
9 February 2018
Accepted 14 February 2018

Keywords:
Breast cancer
Screening
Cerebral palsy
Mammography
Breast ultrasound

ABSTRACT

Background: Women with disabilities (WWD) have reported lower mammography rates than the general population, however rates for women with cerebral palsy (CP) have not been specifically studied.
Objective: To evaluate mammography rates in women with CP and to identify strengths and barriers with their screening experience.
Methods: Women with CP 40 years or older (n = 118) participating in a prospective cross-sectional survey were queried regarding screening status, imaging modality, and accommodation needs and availability. Categorical variables were summarized and Chi-square testing used to assess factors contributing to screening compliance. The effect of functional factors on screening was evaluated using logistic regression.
Results: 77 women (65.3%) had mammograms within the past two years; 56 (47.5%) were screening mammograms. Severity of fine motor deficits was associated with lack of screening (OR 0.559, p = 0.019). 85 (72.0%) experienced positive staff attitudes. Facilities most often met needs for ramps, elevators, and/or wide doorways (92.9%), exam explanations (84.4%), and accessible parking (82.5%). Needs least often met included accommodations for standing (59.3%) or for difficulties with arm/shoulder positioning (57.1%), and wheelchair-accessible mammogram machines (59.1%).
Conclusions: The screening compliance rate for women with CP is low, although the 2-year mammography rate is comparable to that reported for WWD and the general female U.S. population. Women were usually offered respectful care. Adequate physical accommodations during the procedure were reported less often than overall facility environmental accommodations. These findings demonstrate the need for improved screening rates in women with CP, and highlight areas for improving their screening experience.

Introduction

After skin cancer, breast cancer is the most commonly

* Corresponding author. Shirley Ryan AbilityLab, 355 E. Erie St., Chicago, IL 60611, USA.
E-mail address: cmarciniak@sralab.org (C. Marciniak).

https://doi.org/10.1016/j.dhjo.2018.02.002
1936-6574/

diagnosed cancer and the second leading cause of cancer-related deaths among women in the United States. In 2017 alone, the American Cancer Society estimated that breast cancer would make up about 30% of new cancer diagnoses in women, for a total of approximately 252,710 new cases, with 40,610 women dying from breast cancer.[1] Regular screening is recommended to facilitate early diagnosis and treatment, and thus decrease breast cancer mortality.

Current breast cancer screening guidelines vary among different professional groups. The American College of Obstetrics and Gynecology (ACOG)'s updated guidelines as of July 2017 recommend that average risk women start annual or biennial screening by no later than age 50, but to also offer the option of screening to interested women ages 40–50. Prior to this update, ACOG recommended that women undergo annual screening starting at age 40.[2] The American Cancer Society (ACS) recommends annual screening from age 45–55 with the option to transition to screening every two years after age 55.[3] The United States Preventive Services Task Force (USPSTF) recommends that average-risk women be screened every two years from ages 50–74.[4] A recent national survey of primary care physicians and gynecologists showed that in current practice the majority of providers are recommending annual screening starting at age 40 to their patients.[5]

Mammography is presently the recommended breast cancer screening modality. While there is debate on the effectiveness of mammography and possible over diagnosis, studies have shown that mammography may reduce breast cancer mortality rates by up to 40% for women ages 50–69.[6,7] Although alternative modalities are available, none have sufficient evidence for use in screening. Breast ultrasound may be used to further characterize lesions found on screening mammograms or to aid in evaluating women with dense breast tissue. However, ultrasonography is not currently recommended alone or in conjunction with mammography for the routine screening of average-risk women. Imaging using breast MRI and digital breast tomosynthesis (DBT) have similar insufficient evidence to recommend as a primary screening modality. Finally, regular clinical breast examination (CBE) is also not recommended alone or alongside mammography for routine screening, with some concern for CBEs increasing false positive results.[8]

As of 2015, 65.3% of women ages 40 and older had mammography within the past two years for either diagnostic or screening purposes according to the Centers for Disease Control (CDC).[9] Unfortunately, the mammography prevalence among women with disabilities (WWD) appears to be lower. The 2010 National Health Interview Survey found that the 2-year mammography prevalence among WWD was only 61.4%, compared to a rate of 75.0% in women without reported disabilities at the time.[10] Additionally, comparisons between this and prior surveys identified worsening of these disparities in rates over time for those with movement disabilities.[11] Significant differences in self-reported mammography prevalence were similarly found in the 2008 Behavior Risk Factor Surveillance System.[12] Women with more severe mobility impairments, and limitations in activities of daily living may receive less imaging, with even lower rates found in rural areas.[13,14] Qualitative studies of WWD have identified several barriers to regular mammography exams including difficulty getting to appointments, difficulties with physical positioning, and a lack of adequate test explanations.[15,16] Furthermore, primary care physicians may overly focus on disability-related care with WWD and not spend sufficient time discussing preventive care services such as mammography.[17] This disparity may also extend to breast cancer treatment and outcomes as WWD are less likely to receive breast conserving surgery or radiation therapy when they develop early stage breast cancer.[18,19] In addition, breast cancers may be diagnosed at a later stage and cancer-specific mortality rates may be higher for WWD.[18,20]

Although such issues are likely to be especially problematic for women with cerebral palsy (CP) due to the range of possible motor and sensory impairments, studies of this specific disability group have not been previously performed. An estimated 764,000 children and adults in the United States have CP.[21] Unlike many other disabilities, CP is present from birth and primarily characterized by motor-related impairments including weakness, balance deficits, spasticity, dystonia and ataxia. Individuals with CP frequently also have additional speech, hearing, or cognitive deficits.[22] Previous studies of mammography in WWD have usually grouped women with a variety of diagnoses, including acquired disabilities such as stroke and spinal cord injury. These study results may not be reflective of the multiple challenges encountered by women with CP, who often have more varied functional impairments. Thus, it is likely that women with CP have even lower mammography rates and access to appropriate gynecological care than other WWD. Focus groups with women with CP have identified some of the barriers to breast cancer screening, which are, in part, similar to those identified in other studies of WWD. These include lack of information from primary care providers, difficulties interacting with technologists due to speech impairments, and physical pain during positioning.[23]

While specific imaging rates for women with CP are not known, outcomes following a breast cancer diagnosis appear to be less favorable. Day et al. found that breast cancer specific mortality rates for women with CP in California were almost twice that of the overall population.[24] Generalizability of this study's results is limited due to the young average age of the participants and the majority having non-severe CP. The markedly higher number of breast cancer-related deaths however emphasizes the need for further research on screening and treatment on a larger scale in women with CP.

The objectives of the present study were to determine overall mammography prevalence and screening guideline compliance in women with CP, as well as to identify which accommodation needs are most commonly met or unmet at the time of imaging. Our aims were to highlight the current state of breast cancer screening in women with CP, including both strengths in care and areas that could be targeted for further improvement.

Methods

Source study

This study was conducted as part of the *Transforming the Healthcare of Women with Disabilities* (THWD) project. THWD was a prospective cross-sectional survey study conducted from 2015 to 2016 across four academic medical centers, and was approved through each institution's local research review board. The overall study sought to define and examine obstacles to optimal healthcare for women with CP. English-speaking women ages 18–89 years with a diagnosis of cerebral palsy were eligible to participate ($n = 375$). Recruitment was performed in-person or by posting flyers at outpatient CP clinics, through outreach to women participating in community-based programs, and by contacting past research registry participants with CP through email, mail, or phone.

The survey could be completed in-person, by phone, or online. Depending on the site, participants' ability to respond to survey questions was determined by direct assessment for in-person or phone surveys, or subjects comfortable with completing an online survey could request that a link be emailed to them. Legal guardians provided this information if they were registered as the primary phone or email contact in records. Subjects had the option of completing the survey with the help of an assistant of their choice.

Please cite this article in press as: Nandam N, et al., Breast cancer screening in women with cerebral palsy: Could care delivery be improved?, Disability and Health Journal (2018), https://doi.org/10.1016/j.dhjo.2018.02.002