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The Impact of the Affordable Care Act on North Carolinian Breast Cancer Patients Seeking Financial Support for Treatment

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Abstract

Background—The Affordable Care Act (ACA) was instated on 23 March 2010 to improve healthcare quality, reduce costs, and increase access. The Pretty in Pink Foundation (PIPF), a non-profit 501(C)(3) organization in North Carolina, provides financial assistance and in-kind support to individuals seeking help with breast cancer care. The objective of this study was to determine whether sociodemographic variables and treatment services varied among PIPF recipients since enactment of the ACA.

Methods—North Carolinians who received financial assistance from the PIPF between 1 January 2013 and 31 December 2014 were included in the study, and the cohort was divided into two groups based on receipt of assistance before or after the enactment of the ACA. Descriptive statistics were tabulated as frequencies. Comparative univariate analysis between both groups was conducted using the χ^2 and Mann–Whitney *U* tests. All tests were two-sided and a *p* value < 0.05 was considered statistically significant. All analyses were conducted using Stata.

Results—Overall, 1016 individuals fulfilled the inclusion criteria, and the median age of the cohort was 49 years (interquartile range 45–55). The ACA groups did not differ significantly by age, race, and sex; however, the groups varied with respect to income, employment, and clinical stage. In addition, the groups differed on the types of services for which they received financial assistance, but no difference was observed between groups with respect to insurance status.

Conclusion—Since the enactment of the health insurance market component of the ACA, there has been a reduction in subjects receiving assistance from the PIPF; however, no change in their insurance status has been observed.

The leading cause of mortality in the state of North Carolina is cancer, with breast cancer being the predominant organ site.¹ From 2009 to 2013, there were 45,146 new cases of breast cancer and 6491 deaths secondary to breast cancer in North Carolina.^{2,3} Studies report patients undergoing treatment for cancer are more likely to face financial hardship, with one study reporting bankruptcy rates among cancer patients 2.65-fold higher than non-cancer patients.^{4,5} Moreover, severe financial distress resulting in bankruptcy has been

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implicated as a risk factor for mortality from cancer.⁶ Concerns about financial burden among breast cancer patients are particularly troubling due to the costly multidisciplinary approach currently required to treat breast cancer.⁷ This multidisciplinary approach, regardless of insurance status, results in increased out-of-pocket expenses such as deductibles, and co-pays for hospitalizations and physician visits.^{8–10} The implementation of the Patient Protection and Affordable Care Act, referred to as the Affordable Care Act (ACA), aims to alleviate and address the sources of financial burden across the cancer continuum by increasing access to care and limiting out-of-pocket costs by reducing cost sharing.^{11–13}

To this end, the objective of this study was to gain a better understanding of the clinical factors, sociodemographic characteristics, and resource utilization by resource-poor individuals in the state of North Carolina with minimal to no insurance coverage. Using the database of the North Carolina state-based non-profit Pretty in Pink Foundation (PIPF), we sought to gain insight into how implementation of the ACA has affected financial resource seeking for breast cancer treatment by persons whose incomes do not exceed 250 % above the federal poverty line. We hypothesized that following enactment of the ACA, the number of breast cancer patients receiving financial assistance from the PIPF has decreased and that an increasing proportion of patients receiving assistance would be underinsured as opposed to uninsured.

METHODS

The PIPF is a 501(C)(3) non-profit organization based in Raleigh, NC, which provides financial assistance for office co-pays, ancillary services (prosthetic bras and cranial prosthesis), surgery, chemotherapy, and radiation therapy for North Carolinians with an adjusted gross income not exceeding 250 % of the federal poverty level (FPL). Other criteria for receipt of PIPF funding includes United States citizenship, North Carolina residency, and active treatment (surgery, radiation, or chemotherapy). Additionally, a letter of support from a physician documenting breast cancer diagnosis, current stage, and treatment plan is required. The PIPF serves as a primary payer for breast cancer-related services among the uninsured, and a supplemental payer for those with insurance.

Records of all patients who receive financial assistance are stored in a prospectively collected, secure electronic database. An Institutional Review Board (IRB) research exempt status (Pro00066844) was obtained from the Duke Medicine IRB for clinical investigations. To maintain the subject's confidentiality, all 18 Health Insurance Portability and Accountability Act (HIPAA) identifiers were removed from the dataset by PIPF administrators prior to transfer of the data to study researchers.

We queried the prospectively collected PIPF database for all individuals who received financial assistance from the PIPF from 1 January 2013 to 31 December 2014. Open enrollment for the ACA health insurance marketplace opened on 1 October 2013 and the health benefits took effect on 1 January 2014. Therefore, the cohort was divided into two groups: subjects in group 1 received assistance from the PIPF between 1 January 2013 and 31 December 2013 (designated the *before ACA enactment group*), and the second group was

comprised of individuals who received financial assistance from the PIPF between 1 January 2014 and 31 December 2014 (designated the *after ACA enactment group*). All subjects in each cohort were incident cases with no crossover between cohorts. Referral procedures to the PIPF did not change during the study interval.

Descriptive statistics were tabulated as frequencies. Comparative univariate analysis between both groups was conducted using the χ^2 test, Fishers exact test, and Mann–Whitney *U* test. All tests were two-sided and a *p* value <0.05 was considered statistically significant. All analyses were conducted using STATA (StataCorp LP, College Station, TX, USA).

RESULTS

Population Characteristics

Overall, 1016 patients fulfilled our inclusion criteria—554 before and 462 after ACA enactment. The referral process to the PIPF as well as the care providers did not change during the study interval. The median age of the sample was 49 years (interquartile range 45–55), and the sample was comprised of predominantly White (79.8 %) and single (56.9 %) women (Table 1). A majority of the sample was unemployed (76.6 %), with a reported mean income of US\$26,350. Most of the subjects had no insurance (76.7 %), but a small number of patients were insured under Blue Cross Blue Shield (14.3 %). Approximately 95 % of subjects had early-stage breast cancer (stage III or lower). The majority of patients received assistance with costs associated with radiation therapy (Fig. 1), and approximately 70 % of subjects needed financial assistance with two or more services (Fig. 2).

Univariate Analysis

Compared with 2013, there was a 17 % reduction in the number of people receiving financial assistance in 2014 ($n = 554$ and 462 ; $p = 0.0001$). The groups did not differ significantly by age, race, or sex (Table 1). Subjects who received financial assistance in 2014 were more likely to be employed (33.8 %) and single (66.7 %) compared with individuals from 2013 (14.5 % employed and 48.7 % single). There was an increase in the mean income of subjects in 2014 (US\$27,334) in contrast to 2013 (US\$25,529); however, the proportion of patients who were uninsured did not differ between groups. Of note, 2 % of subjects in 2014 indicated they had obtained insurance through the ACA (Table 2).

The groups differed significantly on the types of services (co-pay, COBRA, chemotherapy, radiation therapy, and surgery) for which they received financial assistance. Specifically, a higher percentage of individuals received financial assistance for co-pays, COBRA payments, and mastectomies in 2013 compared with subjects in 2014. Conversely, a greater percentage of persons received financial or in-kind assistance for radiation therapy, chemotherapy and surgery, particularly lumpectomy, in 2014 as opposed to 2013 (Fig. 1). No difference was observed between groups on the number of services requested ($p = 0.320$).

DISCUSSION

The findings in this paper indicate there remains a segment of North Carolinian breast cancer patients who are inadequately served by the current iteration of the ACA in this state. Overall, we observed a significant reduction in the number of patients requesting aid from the PIPF from 2103 to 2014; however, despite a 17 % reduction in the number of patients receiving PIPF assistance, we did not see a change in insurance status among PIPF recipients between 2013 and 2014. A significant portion of the cohort remained uninsured as opposed to underinsured, as we had anticipated. Moreover, a majority of subjects required assistance for multiple services secondary to the double burden of no insurance compounded by financial hardship.

One of the possible explanations for our findings relates to how the ACA has been implemented in North Carolina. A key tenet of the ACA is creating near universal coverage by increasing insurance access through expansion of Medicaid, the use of premium tax credits, and the creation of an affordable health insurance marketplace.^{12,14,15} Under the ACA, Medicaid is expanded to include low-income persons with an adjusted gross income up to 138 % of the FPL.¹⁶ According to estimates from the North Carolina Division of Medical Assistance, this expansion was expected to cover 560,000 uninsured North Carolinians by 2019.¹⁷ However, the 2012 supreme court ruling making Medicaid expansion by states optional resulted in 20 states, mostly southern states, choosing not to expand Medicaid, with North Carolina being one of those states.¹⁶ Furthermore, some states, such as North Carolina, opted to not create a state health exchange, leaving the federally facilitated health exchange as the only avenue for North Carolinians participating in the ACA.¹⁸ The aforementioned decisions about how the ACA has been implemented in North Carolina are meaningful against the backdrop of a recent Gallup study showing North Carolina in the highest uninsured quartile for 2014, with 16.4 % of the population uninsured.¹⁹

For our study population in particular, the effect of the current iteration of the ACA in North Carolina is significant within the context of both their employment and marital status. The majority of patients in our study using the PIPF were unemployed, uninsured, and single. As a result, avenues for gaining insurance through employment or a spouse are not available to these patients. Additionally, one of the opportunities to capture low-income persons in the ACA was through the expansion of Medicaid, which is not available in North Carolina.¹⁶

Another component of the implementation of the ACA that could have contributed to our findings are the well-documented problems associated with the launch of the federal health insurance marketplace website, Healthcare.gov. According to a report by the United States Government Accountability Office (GAO), the key issues with the launch of the website were inadequate capacity planning, software coding errors, and lack of functionality, which might have prevented some potential PIPF enrollees from signing up.²⁰

A crucial element necessary for the successful enactment of the ACA is awareness. Our study looked at data very early in the inception of the health insurance marketplace, which could explain our failure to notice a difference in insurance status. Studies indicate that

individuals with incomes between 100 and 250 % of the FPL have a lower knowledge about health reform and insurance compared with those 400 % at or above the FPL.²¹ Since our entire population is below 250 % of the FPL, we can speculate that subjects in our study may not have been aware of the ACA, or have a low health insurance literacy. Further data on educational attainment and health literacy within our sample could help us to further understand this association.

The long-term implications of financial hardships imposed by no insurance coverage or being underinsured in cancer patients is well documented in the literature and makes the findings in this study population pertinent. In their evaluation of financial hardship among breast cancer survivors, Yabroff et al. noted uninsured survivors had the highest levels of psychological distress and financial hardship.²² Furthermore, increased financial burden, secondary to cancer treatment-related costs, are a strong predictor of poor quality of life, particularly in the areas of physical health, mental health, contentment with social activities and relationships.²³ One of the long-term consequences of financial hardship during cancer treatment is the extension of the effects of this hardship into the survivorship period. For example, studies indicate individuals experiencing financial hardship have an increased likelihood of poor compliance to treatment recommendations that provide a survival benefit, such as endocrine therapies.²⁴ Kent et al. reported that cancer survivors experiencing disease-related financial hardship were more likely to stop or postpone medical care after completing treatment for their index cancer. These post-treatment issues further highlight the importance of financial assistance and insurance during the treatment period.

A key limitation of our study was that the data were dependent on the patients who were referred to the PIPF. Although there were no significant changes in availability of PIPF funds between 2013 and 2014, there could have been unmeasured differences in how patients and providers became aware of or accessed these resources. Furthermore, the data accrual lends itself to selection bias and a possible lack of generalizability to a national population. In addition, we did not compare our sample with insured patients, nor did we perform multivariable analysis to control for confounding variables.

Despite the aforementioned biases, we believe our study is generally representative of the racial diversity, insurance status, and stage distribution of newly diagnosed breast cancer patients in North Carolina. For instance, African Americans comprise approximately 22 % of the state population and 20 % of newly diagnosed breast cancers, numbers that are reflected in our sample ^{2,25} (Table 1). The percentage uninsured among African Americans is 14 % compared with 11 % of Whites, thus African Americans are not considerably uninsured to skew our racial composition. With respect to stage distribution of recipients, the low numbers of patients with advanced breast cancer in our study can be attributed to the fact that the majority of breast cancers in the US are early stage (stage III or lower), and only 5 % are advanced stage (stage IV).²⁶ In addition, individuals with stage IV breast cancer qualify for supplemental income and insurance through the Office of Social Security and as a result may pursue those resources for financial assistance.²⁷

Finally, an important observation of this study was that we found significantly fewer patients seeking aid from the PIPF after, as opposed to before, enactment of the ACA. This finding

could be a reflection of the impact of the ACA on resource seeking among low-income breast cancer patients. However, studies over longer time periods since the enactment of the ACA, and with a larger state sample, are needed to confirm this effect.

CONCLUSIONS

This study provides important insight into the healthcare needs of uninsured and underinsured breast cancer patients in North Carolina. Longitudinal studies on state-wide databases, including the insured and uninsured, as well as additional follow-up on this cohort in future years, will allow greater insight into the true impact of the ACA on North Carolinian breast cancer patients. This study highlights the continued unmet need for patient assistance programs and organizations to help offset the cost of breast cancer treatment.

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References

1. North Carolina Central Cancer Registry. Cancer in North Carolina 2013 report. Raleigh: North Carolina Division of Public Health; 2013.
2. North Carolina Central Cancer Registry. [Accessed 12 Mar 2016] Cancer incidence rates. 2015. <http://www.schs.state.nc.us/schs/CCR/incidence/2013/5yearRates.pdf>
3. North Carolina Central Cancer Registry. [Accessed 12 Mar 2016] Cancer mortality rates. 2015. <http://www.schs.state.nc.us/schs/CCR/mort1014cnty.pdf>
4. Ramsey S, Blough D, Kirchhoff A, et al. Washington State cancer patients found to be at greater risk for bankruptcy than people without a cancer diagnosis. *Health Aff (Millwood)*. 2013; 32(6):1143–52. [PubMed: 23676531]
5. Jagsi R, Pottow JA, Griffith KA, et al. Long-term financial burden of breast cancer: experiences of a diverse cohort of survivors identified through population-based registries. *J Clin Oncol*. 2014; 32(12):1269–76. [PubMed: 24663041]
6. Ramsey SD, Bansal A, Fedorenko CR, et al. Financial insolvency as a risk factor for early mortality among patients with cancer. *J Clin Oncol*. 2016; 34(9):980–6. [PubMed: 26811521]
7. Meropol NJ, Schrag D, Smith TJ, et al. American Society of Clinical Oncology guidance statement: the cost of cancer care. *J Clin Oncol*. 2009; 27(23):3868–74. [PubMed: 19581533]
8. Arozullah AM, Calhoun EA, Wolf M, et al. The financial burden of cancer: estimates from a study of insured women with breast cancer. *J Support Oncol*. 2004; 2(3):271–8. [PubMed: 15328826]
9. Bernard DS, Farr SL, Fang Z. National estimates of out-of-pocket health care expenditure burdens among nonelderly adults with cancer: 2001 to 2008. *J Clin Oncol*. 2011; 29(20):2821–6. [PubMed: 21632508]
10. Zafar SY, Peppercorn JM, Schrag D, et al. The financial toxicity of cancer treatment: a pilot study assessing out-of-pocket expenses and the insured cancer patient's experience. *Oncologist*. 2013; 18(4):381–90. [PubMed: 23442307]
11. Moy B, Polite BN, Halpern MT, et al. American Society of Clinical Oncology policy statement: opportunities in the patient protection and affordable care act to reduce cancer care disparities. *J Clin Oncol*. 2011; 29(28):3816–24. [PubMed: 21810680]
12. Rosenbaum S. The Patient Protection and Affordable Care Act: implications for public health policy and practice. *Public Health Rep*. 2011; 126(1):130–5. [PubMed: 21337939]
13. Davidoff AJ, Hill SC, Bernard D, Yabroff KR. The Affordable Care Act and expanded insurance eligibility among nonelderly adult cancer survivors. *J Natl Cancer Inst*. 2015; 107(9):dju181. [PubMed: 26134034]

14. Kaiser Family Foundation. [Accessed 11 Mar 2016] Summary of The Affordable Care Act. 2013. <http://kff.org/health-reform/fact-sheet/summary-of-the-affordable-care-act/>
15. Rosenbaum S. The ACA: implications for the accessibility and quality of breast and cervical cancer prevention and treatment services. Public Health Rep. 2012; 127(3):340–4. [PubMed: 22547867]
16. Garfield, R., Damico, A. [Accessed 13 Mar 2016] The coverage gap: uninsured poor adults in states that do not expand Medicaid: an update. 2015. <http://kff.org/health-reform/issue-brief/the-coverage-gap-uninsured-poor-adults-in-states-that-do-not-expand-medicaid-an-update/>
17. Silberman P, Cansler LM, Goodwin W, Yorkery B, Alexander-Bratcher K, Schiro S. Implementation of the Affordable Care Act in North Carolina. N C Med J. 2011; 72(2):155–9. [PubMed: 21721506]
18. Oberlander J, Perreira K. Implementing Obamacare in a red state: dispatch from North Carolina. N Engl J Med. 2013; 369(26):2469–71. [PubMed: 24328441]
19. Witters, D. [Accessed 12 Mar 2016] Arkansas, Kentucky see most improvement in uninsured rates. 2015. http://www.gallup.com/poll/181664/arkansas-kentucky-improvement-uninsured-rates.aspx?utm_source=tagrss&utm_medium=rss&utm_campaign=syndication
20. United States Government Accountability Office. CMS has taken steps to address problems, but needs to further implement systems development best practices. Washington, DC: United States Government Accountability Office; 2015.
21. Barcellos SH, Wuppermann AC, Carman KG, et al. Preparedness of Americans for the Affordable Care Act. Proc Natl Acad Sci USA. 2014; 111(15):5497–502. [PubMed: 24706843]
22. Yabroff KR, Dowling EC, Guy GP Jr, et al. Financial hardship associated with cancer in the United States: findings from a population-based sample of adult cancer survivors. J Clin Oncol. 2016; 34(3):259–67. [PubMed: 26644532]
23. Fenn KM, Evans SB, McCorkle R, et al. Impact of financial burden of cancer on survivors' quality of life. J Oncol Pract. 2014; 10(5):332–38. [PubMed: 24865220]
24. Neugut AI, Subar M, Wilde ET, et al. Association between prescription co-payment amount and compliance with adjuvant hormonal therapy in women with early-stage breast cancer. J Clin Oncol. 2011; 29(18):2534–42. [PubMed: 21606426]
25. United States Census Bureau. [Accessed 8 Apr 2016] QuickFacts North Carolina. 2015. <http://www.census.gov/quickfacts/table/PST045215/37>
26. Iqbal J, Ginsburg O, Rochon PA, Sun P, Narod SA. Differences in breast cancer stage at diagnosis and cancer-specific survival by race and ethnicity in the United States. JAMA. 2015; 313(2):165–73. [PubMed: 25585328]
27. Society AC. [Accessed 8 Apr 2016] Health insurance and financial assistance for the cancer patient. 2015. <http://www.cancer.org/treatment/findingandpayingfortreatment/understandinghealthinsurance/healthinsuranceandfinancialassistanceforthecancerpatient/health-insurance-and-financial-assistance-disability-ssi>

FIG. 1. Distribution of PIPF-funded services in the study population pre-and post-ACA. *PIPF* Pretty in Pink Foundation, *ACA* Affordable Care Act

FIG. 2.

Number of services¹ for which PIPF funding was obtained pre- and post-ACA. ¹ Services include co-pays, chemotherapy, radiation therapy, surgery, and COBRA. *PIPF* Pretty in Pink Foundation, *ACA* Affordable Care Act

TABLE 1

Characteristics of subjects seeking support from the PIPF from 2013 to 2014

Variable	Total	Pre-ACA (2013) (N = 554)	Post-ACA (N = 462)	p value
Age, years				
Median (IQR)	49 (45–55)	50 (45–55)	49 (45–55)	0.28
Mean (SD)	50.1 (±7.4)	50.4 (±7.5)	49.7 (±7.1)	
Race				
White	811 (79.8)	437 (78.9)	374 (81)	0.26
African American	194 (19.1)	113 (20.4)	81 (17.5)	
Other	11 (1.08)	4 (0.7)	7 (1.5)	
Sex				
Female	1001 (99.5)	550 (99.3)	461 (99.8)	0.25
Male	5 (0.49)	4 (0.7)	1 (0.2)	
Employment				
Unemployed	778 (76.6)	472 (85.2)	306 (66.2)	0.0001
Employed	236 (23.3)	80 (14.4)	156 (33.8)	
Unknown	2 (0.20)	2 (0.4)	0	
Income (mean) [US\$]	26,350 (±9792)	25,530 (±9271)	27,335 (±10,307)	0.008
Marital status				
Single	578 (56.9)	270 (48.7)	308 (66.7)	
Married	432 (42.5)	279 (50.4)	153 (33.1)	0.0001
Unknown	6 (0.59)	5 (0.9)	1 (0.2)	
Clinical stage				
I	621 (61.1)	368 (66.4)	253 (54.8)	0.0001
II	267 (26.3)	127 (23)	140 (30.3)	
III	81 (8.0)	31 (5.6)	50 (10.8)	
IV	18 (3.7)	23 (4.2)	15 (3.3)	
Unknown	9 (0.9)	5 (0.9)	4 (0.9)	

PIPF Pretty in Pink Foundation, *ACA* Affordable Care Act, *IQR* interquartile range, *SD* standard deviationData are expressed as *n* (%) unless otherwise specified

TABLE 2

Insurance status and insurance type pre- and post-ACA

Variable	Total	Pre-ACA (2013) (N = 554)	Post-ACA (2014) (N = 462)	p value
Insurance status				
Uninsured	779 (76.7)	413 (74.6)	366 (79.2)	0.080
Insured	237 (23.3)	141 (25.5)	96 (20.8)	
Insurance type				
No insurance	779 (76.7)	413 (74.6)	366 (79.2)	0.0001
Blue cross/blue shield	145 (14.3)	78 (14.1)	67 (14.5)	
Medicare	27 (2.7)	18 (3.3)	9 (1.95)	
United	16 (1.6)	12 (2.2)	4 (0.9)	
Atena	12 (1.2)	9 (1.6)	4 (0.7)	
Coventry	16 (1.6)	13 (2.4)	3 (0.7)	
Medcost	9 (0.9)	5 (1)	1 (0.2)	
Cigna	6 (0.6)	6 (1.1)	0	
ACA	6 (0.6)	NA	9 (2.0)	

ACA Affordable Care Act, NA not available

Data are expressed as *n* (%)