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Adapting to a Shifting Healthcare Landscape: Illinois Breast and Cervical Cancer Program Lead Agencies' Perspectives

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Abstract

Understanding how safety net programs adapt to systemic health care changes is pivotal for creating feasible recommendations for policy implementation. This study characterizes perspectives of Lead Agency (LA) coordinators of the Illinois Breast and Cervical Cancer Program (IBCCP) in response to sociopolitical changes at state and national levels. Our cross-sectional study included 29 semi-structured telephone interviews between December 2015–January 2016. Respondents indicated some changes in the priority population served, changes in referrals and clinical services, and, a continued commitment to IBCCP. Our findings suggest that IBCCP and other safety net programs will need to be flexible to meet the ongoing needs of historically vulnerable populations in a complex, shifting environment. Implications for public health practice and policy include the need to ensure program personnel are aware of evidence-based strategies to reach different priority populations and are kept abreast of organizational and

Conflict of Interest

The authors have no conflicts of interest to disclose.

system changes that may impact referral patterns as well as the need to educate health care providers working with safety net programs about changes in the delivery and coordination of services.

Keywords

cervical cancer; breast cancer; healthcare reform; disparities

Introduction

Safety net programs do not exist in a vacuum – and act according to changes in science, emerging population needs, and shifting sociopolitical contexts (Angier et al., 2015; Bitler & Hoynes, 2016; Cristofalo, 2014; Hall, 2011a,b; Ku, Jones, Shin, Bryne, & Long, 2011; Redlener & Grant, 2009; Reiter, Jian, & Wang, 2014). Yet, little qualitative research has explored *how* these factors may influence programmatic capacity, needs, and efforts. Such data may be helpful for optimizing planning and implementation efforts as these types of factors continue to impact public health practice quantitatively (e.g., Angier et al., 2015; Ku et al., 2011; Reiter et al., 2014). To address this need, the current study characterizes how the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) site in the state of Illinois – the Illinois Breast and Cervical Cancer Program (IBCCP) – has responded to recent changes in state and national health care environments.

Background/Literature Review

The NBCCEDP is a safety net program that addresses a major public health priority. Racial/ethnic minority and socioeconomically disadvantaged women are diagnosed with breast and cervical cancer at later stages and experience poorer survival associated with these cancers relative to other groups of women (Daly & Olopade, 2015; Ooi, Martinez, & Li, 2011). Differences in cost and insurance coverage contribute significantly to disparities by affecting cancer screening uptake (Mukem, Meng, Sriplung, & Tangcharoensathien, 2015), and timing of detection (Kim, Chukwudozie, & Calhoun, 2013). The NBCCEDP was implemented to address these issues and ensure access for low-income, uninsured, and underserved women to breast and cervical cancer care (Eheman et al., 2014; Espey et al., 2014; Lantz & Mullen, 2015; Levano, 2014; Sanders et al., 2014; Yancy et al., 2014). NBCCEDP programs exhibit significant heterogeneity in implementation, including differences in which organizations participate/are engaged, staffing, and reimbursement processes (Lantz, Keeton, Romano, & DeGroff, 2004).

In addition to significant heterogeneity in program implementation, the NBCCEDP has had to be responsive to environmental shifts and evolve significantly throughout the >25 years since its inception (Lantz & Mullen, 2015). In most recent times, two major environmental changes have likely affected the NBCCEDP. First, the Patient Protection and Affordable Care Act (ACA) provided insurance coverage for 17 million previously uninsured individuals with coverage beginning in 2014 and preventive benefits for 47 million women <http://kff.org/uninsured/> (Carmen, Eibner, & Paddock, 2016; Cooper, Kou, Schluchter, Dor, & Koroukian, 2015; Nelson, Weerasinghe, Wang, & Grunkemeie, 2015; Simmons &

Skopec, 2012) – resulting in increased cancer screenings (Choi et al., 2015; Cooper et al., 2015; Fedewa et al., 2015; Hamman & Kapinos, 2015; Han, Yabroff, Guy, Zheng, & Jemal, 2015; Nelson et al., 2015). Second, changes in the health care environment have occurred after many states and local governments weathered years of budget-cutting due to the Great Recession, also potentially impacting the budgets of many public sector programs and initiatives (Gordon, 2012).

Literature has explored how these significant environmental changes affected different stakeholders overall, including patients (Hom et al., 2016; Kamimura et al., 2016), employers (Boubacar & Foster, 2014), and high-ranking healthcare system administrators (Sommers, Arntson, Kenney, & Epstein, 2013). What is not known is *how* such changes have influenced on the ground program delivery and coordination, particularly in safety net programs. Specifically, how do changes in priority populations affect patient enrollment and organizations' ability to meet their caseloads, depending on demographics in their catchment areas (e.g., urban versus rural settings)? How might relationships between local sites implementing the safety net program and referring providers/healthcare systems change, potentially due to beliefs/awareness about safety net programs continuation in a changing healthcare environment? How might a changing healthcare system impact agencies' perceptions and commitment about the safety net program and its mission? These are questions that have not been answered by previous literature.

The Current Study

To address the questions described above, we focus on the perceptions of individuals directly responsible on a day to day basis for carrying out the NBCCEDP throughout Illinois and their interactions with the multiple forces and players that affect program implementation. In Illinois, the state grantee of the NBCCEDP, the Illinois Department of Public Health (IDPH), initiates contracts with different organizations (Lead Agencies – LA) to implement the program throughout the state. These organizations can be local health departments (LHD), federally qualified health centers (FQHC), or community-based organizations (CBO). Each LA has a program coordinator who is responsible for overseeing: 1) patient identification/enrollment; 2) patient referral processes (e.g., to screening or diagnostic care); and, 3) communication with IDPH as well as local providers/healthcare organizations.

Our findings on the unique perspectives of these stakeholders may help to inform acceptable and feasible approaches to enhance the flexibility of public health practice programs and optimize policy implementation. This study thus aligns with *Health Promotion Practice's* mission to characterize the “development and application of public policy conducive to the promotion of health and prevention of disease” and how sociopolitical factors (e.g., ACA, Great Recession-influenced state budgets) have potentially affected the application of cancer health promotion programs across different settings in Illinois State (e.g., urban/rural).

Methods

Procedures

Between December 2015–January 2016, thirty-one IBCCP LA coordinators were invited to participate in the study first by e-mail (3–4 attempts) and, if no response was made by e-mail, up to 4 attempts were made by telephone. Table 1 depicts the characteristics of the LAs. Twenty-nine LA coordinators were interviewed by four team members. Audio-recorded interviews were generally 45–60 minutes in length. The study protocol and all materials were reviewed and approved by the Institutional Review Board at the University of Illinois at Chicago. All participants provided informed consent.

Qualitative data collection and analysis

We engaged in iterative, concurrent data collection and analysis partially aligned with grounded theory convention and the principle of constant comparison (Glaser, Strauss, & Strutzel, 1968; Morse, 2015). Specifically, our concurrent analyses informed data collection and vice versa. First, we used a semi-structured guide that included open-ended questions to assess how LA staff perceived that the changing health care environment brought about by the ACA and other sociopolitical factors (e.g., state budget, consolidation of health systems) affected their relationships with key program stakeholders, service delivery and programs, and program operations services. Sample questions are provided in Table 2. Most original questions were framed in the context of the ACA. However, LA coordinators often specified changes resulting from other forces including the state budget versus changes related to the ACA. After each interview, staff debriefed and uploaded comments for other team members to review prior to subsequent interviews. One team member summarized these comments on a weekly basis which resulted in a live codebook. The team regularly discussed comments and summaries throughout the data collection process to review emerging codes, discuss areas of agreement, and arrive at consensus. This discussion resulted in a data-driven codebook for analysis of verbatim transcriptions of interviews, which were checked for accuracy and uploaded into Atlas.ti, version 7 (Berlin, Germany).

This second phase of data analysis was in line with multi-faceted content analysis approaches (Bernard & Ryan, 2009; Hsieh & Shannon, 2005). Three team members independently coded these data while collectively discussing interpretations, creating corresponding codes, and categorizing codes into larger representative groups. Thematic saturation was assessed by monitoring how codebooks and how text was coded across analytic iterations and increasing sample size.

Results

Below, we discuss the themes that emerged: 1) Changes in Demographics of the Priority Population Served; 2) Changes in Referrals and Clinical Services; and, 3) Continued Commitment to IBCCP in a New Healthcare Environment.

Changes in Demographics of the Priority Population Served

In response to questions about the changing health care environment, changes in the demographics of the IBCCP priority population and the impact on LA caseload, outreach, and enrollment were often mentioned. Urban-rural differences emerged. For example, many LA coordinators in urban areas, particularly Chicago, noted they were still on “priority” (a designation given to assure that LAs who are close to reaching caseload do not overspend their grant funds and are always able to serve high-risk [e.g., symptomatic] women) or were likely to achieve their target caseload. Respondent #4 remarked, “Well, [ACA] has had a huge impact...but we are exactly where we need to be to meet caseload for this year.”

In contrast, LA coordinators in rural areas more often highlighted a dramatic decrease in their caseloads. While a decrease in assigned caseloads was in some cases due to state budget cuts, LA coordinators often discussed the decrease in caseloads in the context of the health benefits ACA provided former clients, as exemplified below:

With ACA, it’s wonderful that everyone is getting their health coverage and stuff. It has really hurt the program. For breast and cervical, we used to have a lot of people coming in. Now that they have the medical [insurance] card...with breast and cervical [programs], the caseload is extremely lower than it has been for years. #23

By definition, most of our women qualify for the Affordable Care Act, which is wonderful for them...I’ve seen a huge impact on my program, but at the same time these are women who are now having insurance who can still get those services. They’re just not getting them through me, which, the main thing is that the women have access to healthcare. But definitely for the program, [ACA] has negatively impacted the [LA] program. #28

Respondents, typically from rural counties such as respondent #18, perceived and explicitly identified rural-urban differences in challenges with caseloads: “The Lead Agencies in Chicago – they’re in need to help women, whereas we rural areas don’t have as much need, because they (the women) are getting insurance.” Rural-urban differences in caseload partially intersected with the ethnic composition of the geographic region. Urban areas and rural areas with greater immigrant populations appeared to perceive less of an ACA impact on their caseload. Chicago-based Respondent #25 noted: “We definitely have seen an impact from ACA, but we have patients here who just won’t be eligible...So, we haven’t seen a huge drop in our enrollment.” Conversely, non-Chicago respondent #23 stated: “[Outreach] is a little more difficult... as opposed to what’s going on up in Chicago...I’ve been working with the local [Nationality #2 community]. They’re difficult to reach.”

LA coordinators with decreased caseloads often emphasized new challenges in identifying and enrolling eligible women. One challenge concerned the need to focus more aggressively to reach populations for which LAs often had limited resources and knowledge of effective strategies. Respondent #9 stressed:

We’re doing more outreach than I’ve ever seen them do in the past ten years of the program here...and yet we still don’t have people calling in and looking to register. We’re going to health fairs for refugees. We’re going to health fairs for Nationality

#1. We're going to health fairs for Nationality #2 ...we do it at least once a month. Sometimes it's five times a month. We're going to all the free clinics. We have several monthly free clinics at churches. We show up there. We're not getting any referrals and we can't figure out why.

Changes in Referrals and Clinical Services

For the most part, respondents did not indicate that changes in the health system were having an impact on their referral processes and the clinical services to which women are referred. Most informants perceived that referral processes and the availability of clinical services were not significantly altered during this time of change. As noted by Respondent #29: "Luckily we've had a relationship with most of our facilities and there's been no change there. They've been pretty agreeable in working with us." On the other hand, there were some concerns about perceived clustering of clinical services into larger healthcare systems, by rural respondents in particular, as exemplified by these quotes:

I don't think any [changes in referrals] so far, but I do have some concerns in our area...I'm a little worried about the future of medical care and private physicians....many of the physicians are joining big conglomerate groups or corporations...some of our private physicians have closed private practices and they become hospitalists...[In response to "*Has that impacted how many contracts or providers you do have for referrals?*"] Not at this time...we have contracts with a surgeon but we also have a contract with the hospital that he goes to. Even if the individual contracts would go away, we would have the hospital contract. I don't think we've lost any contracts. #8

So far, services offered and even the billing procedures have not changed. Now I don't know what will hold in the future, especially for a lot of these rural hospitals...I was just informed like a week ago, two weeks ago, that some small clinic is now going to be part of a BLINDED clinic system. -#21

Among the few individuals that did report changes, there was a perception that some health care providers and clients were misinformed or did not have adequate knowledge about IBCCP in an era of changes brought about by the ACA as well as state budget difficulties. Specifically, due to the ACA and changes in the state budget, some LA coordinators reported that some providers and clients believed that the IBCCP LAs were closed. For example, Respondent #20 noted:

To be honest, with all this budget information and the stuff on the news about different health departments closing, there have been rumors that we're no longer open for service. We've heard this from different clients...I don't know if the doctors are associating that particular problem with all the programs in the Health Department or what. There's a lot of misinformation out there. We're trying to provide outreach to say – we're still here.

Continued Commitment to IBCCP in a New Healthcare Environment

Despite shifts in the landscape, LA coordinators repeatedly emphasized their steadfast commitment to IBCCP, as exemplified by these respondents:

[I have] concerns obviously with continual changes with the budget, but I want to remain positive and look at the importance of what we do as a whole... this program could be very effective and continue to contribute to women of our county or of our state to continue to receive services. We may not look like what we look like now but I still think there's room in this state for us to continue to do what we need to do to have our women reach the optimum health. - #7

[Despite] overall concerns, we hope that the IBCCP stays around. It is a very valuable program for communities of Illinois – especially here in metro Chicago... where we have an increased number of patients...and the high-deductible population group...this program has benefited many clients who may not have been able to get diagnostic testing done before and were able to get the diagnostic testing done...this is a very valuable program out there. -#14

Similarly, Respondent #11 emphasized her commitment to providing services to uninsured clients. In her community, she noted she will always be likely to find those who are not insured, either because of citizenship issues or because of patients' decisions in light of high premiums for insurance programs. She emphasized that in this new era, IBCCP's availability was very important in order to provide screening services for these women as well as to support women in general who needed help navigating a shifting healthcare environment.

Discussion

We used qualitative interviews to understand the perceptions of IBCCP LA coordinators with respect to the changing health care environment and their understanding of the shifting role and value of the IBCCP. As described above, multiple major sociopolitical shifts have occurred that may have impacted this program, including the ACA and the effects of the Great Recession on state budgets (Carmen et al., 2015; Gordon et al., 2012; Nelson et al., 2015; Simmons & Skopec, 2012). Understanding these perceptions is of particular interest, given that public health practitioners – especially those serving traditionally marginalized populations -- must be flexible and responsive to an increasingly dynamic health care environment to achieve our country's public health goals. This work thus contributes to a growing body of work that is characterizing the impacts of shifts in healthcare through the lens of different affected stakeholders (Boubacar & Foster, 2014; Hom et al., 2016; Kamimura et al., 2016; Sommers et al., 2013) and quantifying impacts of sociopolitical factors on public health programs (e.g., Angier et al., 2015; Ku et al., 2011; Reiter et al., 2014). Further, our findings provide insight as to what is needed to plan and implement adaptations that reflect current needs and the environment at hand.

Changes in the IBCCP priority population and the impact on caseload, outreach, and enrollment were identified. Such work aligns with recent predictions that NBCCEDP programs throughout the nation may become particularly important for immigrants (Levy, Bruen, & Leighton, 2012). Nonetheless, there were urban-rural differences. While Chicago-based LAs generally did not struggle to meet caseload, the opposite was true for rural-based LAs. This may have been because urban LAs have historically served more immigrant women, who still need IBCCP services due to their inability to qualify for most health insurance. Rural LAs sometimes expressed frustrations about their limited success with

reaching these populations, perhaps due to their limited experience with these specific communities. The importance of additional training for the LA staff and sharing of best practices was emphasized as key to assuring programmatic success as target client populations change.

LA coordinators largely did not indicate changes in referral processes and the clinical services to which women were referred. A few rural LA coordinators expressed concern about the potential of private health providers becoming absorbed into larger healthcare systems. LA coordinators also expressed uncertainty regarding how or if clinical and referral processes may change in the future. One potential notable change in the referral relationship with providers was that some clients and providers, particularly in rural areas, assumed that IBCCP was terminated given state budget issues and changes in the healthcare landscape due to the ACA. These findings speak to the need for continued vigilance to educate providers about the role and services provided by IBCCP and potentially other and similar safety net programs in the changing health care environment. This was especially true in 2017, as the shifting fortunes of the Affordable Care Act in Congress and the instability of the insurance markets were continually in the headlines, likely producing uncertainty on the ground for many health care related programs. Commitment by IBCCP LA coordinators to the program and its mission is one of the cornerstones of this public sector safety net program. Although LA coordinators expressed some difficulties implementing the program in these changing times, their commitment to reducing breast and cervical cancer remained clear. Respondents were clear that IBCCP is still needed in their communities to serve those not served or insured through other means, and as a safety net to help insured women navigate and receive critical services given the difficulties women face in navigating both the health care delivery and insurance systems, particularly women with limited experiences with these systems.

This study has several limitations. Although we interviewed the majority of IBCCP LA coordinators, we were not able to interview all. Further, given that states vary in NBCCEDP implementation processes, our findings may not be generalizable to other state breast and cervical cancer screening programs (Albright et al., 2011; Rittenhouse, Shotell, & Fisher, 2009). Our study also was not able to characterize in depth the rich diversity and nuanced differences among respondents, who varied in their history with IBCCP and their roles, nor characterize completely the variation resulting from differences in LAs' size and context (e.g., geographic region).

Conclusion and Implications

Categorical safety net programs such as IBCCP may be called on to reassess their missions, to change their service portfolios and product lines, and to serve new populations and/or serve their traditional populations in new ways, depending on significant shifts in the health care environment (Angier et al., 2015; Bitler & Hoynes, 2016; Cristofalo, 2014; Hall, 2011a,b; Ku, Jones, Shin, Bryne, & Long, 2011; Redlener & Grant, 2009; Reiter, Jian, & Wang, 2014). To do so effectively will require that these programs remain flexible, be willing to continue to educate themselves on new approaches and the needs of new and different populations, and be willing to engage in the ongoing education of their partners and

stakeholders. Our study offers one example of how research that addresses programmatic responses and evolution may further public health practice. Study findings indicates at for that IBCCP needs to: 1) monitor success in outreach and enrollment, as the definition of un/underinsured – and thus the program’s priority population - is changing; 2) work closely with clinical providers to keep them informed about existing and new services; and, 3) ensure that IBCCP personnel are aware of organizational and system changes that may impact referral patterns (e.g., clustering into larger healthcare systems).

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Table 1

Characteristics of 31 IBCCP Lead Agencies (LA) for which Coordinators were involved in Key Informant interviews.

	% (n)
LAs that participated	93.6 (29)
LA Type	
LHD	58.1 (18)
FQHC	32.3 (10)
Hospital/CBO	9.7 (3)
Geography	
Chicago	29.0 (9)
Suburban	25.8 (8)
Small/Medium Metro	19.4 (6)
Rural	25.8 (8)
Caseload	
Small	31.0 (9)
Medium	51.7 (15)
Large	17.2 (5)
Percent abnormal breast screens	
0.0 – 33.3	71.0 (22)
33.4 – 66.6	25.8 (8)
66.7 – 100.0	3.2 (1)
Percent non-English speaking clients	
0.0 – 33.3	45.2 (14)
33.4 – 66.6	16.1 (5)
66.7 – 100.0	38.7 (12)

LHD: Local Health Department. *FQHC*: Federally Qualified Health Center. *CBO* = Community-based organization.

Table 2

Semi-structured questions for LA coordinator interviews.

Major Domain	Sample Questions
General	Broadly speaking, how do you believe the ACA has affected the Illinois Breast and Cervical Cancer Program?
Changes in Demographics of the Priority Population Served	Please describe how women enter the IBCCP program at your site. Have there been any changes in the last several years? Since the ACA? How have changes brought about by the ACA influenced the populations IBCCP is trying to reach and enroll?
Changes in Referrals and Clinical Services	What are the changes/challenges to making referrals to providers through the IBCCP program? Particular changes because of the ACA? What have been persistent barriers? What have been useful strategies to overcome new and continued challenges to making referrals?
Continued Commitment to IBCCP in a New Healthcare Environment	Given the current environment, both budget issues and the ACA, what are your overall questions, concerns, or ideas for the future of the IBCCP program?