

HHS Public Access

Author manuscript *Prev Med.* Author manuscript; available in PMC 2020 December 01.

Published in final edited form as:

Prev Med. 2019 December ; 129 Suppl: 105858. doi:10.1016/j.ypmed.2019.105858.

Patient navigator reported patient barriers and delivered activities in two large federally-funded cancer screening programs

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Abstract

Few data are available on patient navigators (PNs) across diverse roles and organizational settings that could inform optimization of patient navigation models for cancer prevention. The National Breast and Cervical Cancer Early Detection Program (NBCCEDP) and the Colorectal Cancer and Control Program (CRCCP) are two federally-funded screening programs that support clinical- and community-based PNs who serve low-income and un- or underinsured populations across the United States. An online survey assessing PN characteristics, delivered activities, and patient barriers to screening was completed by 437 of 1002 identified PNs (44%). Responding PNs were racially and ethnically diverse, had varied professional backgrounds and practice-settings, worked with diverse populations, and were located within rural and urban/suburban locations across the U.S. More PNs reported working to promote screening for breast/cervical cancers (BCC, 94%) compared to colorectal cancer (CRC, 39%). BCC and CRC PNs reported similar frequencies of individual- (e.g., knowledge, motivation, fear) and community-level patient barriers (e.g., beliefs about healthcare and screening). Despite reporting significant patient structural barriers (e.g., transportation, work and clinic hours), most BCC and CRC PNs delivered individual-level navigation activities (e.g., education, appointment reminders). PN training to identify and champion timely and patient-centered adjustments to organizational policies, practices, and norms of the NBCCEDP, CRCCP, and partner organizations may be beneficial. More research is needed to determine whether multilevel interventions that support this approach could reduce structural barriers and increase screening and diagnostic follow-up among the marginalized communities served by these two important cancer-screening programs.

Appendix A. Supplementary data

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Supplementary data to this article can be found online at https://doi.org/10.1016/j.ypmed.2019.105858.

Cancer; Navigation; Breast; Cervical; Colorectal; Screening

1. Introduction

Although overall cancer incidence rates continue to decline (Ward et al., 2019), cancer remains the second-leading cause of death in the United States (Ward et al., 2019) with 1,658,716 new cancer cases and 598,031 cancer deaths reported in 2016 (Centers for Disease Control and Prevention (CDC)). This burden continues to disproportionately affect low-income, minority, and geographically isolated communities (National Cancer Institute (NCI)). Of cancers with noted mortality disparities, breast, cervical, and colorectal are those with established population-level screening guidelines that reduce risk of cancer death (White et al., 2017). In 2015, after adjusting for age, 71.5% of women aged 50-74 years reported recent screening mammography, 83% of women aged 21-65 years reported recent cervical screening, and 62.4% of men and women aged 50-75 years reported recent colorectal cancer tests—all of which are below Healthy People 2020 screening targets of 81.1%, 93%, and 70.5%, respectively (White et al., 2017). Marginalized populations are even less likely to be screened (White et al., 2017). For example, screening mammography was lowest among American Indian/Alaska Native women (56.7%) as well as those lacking health insurance (35.3%) or a usual source of health care (32.9%) (White et al., 2017). Patterns of disparities among marginalized communities are similar for cervical and colorectal cancer screening (White et al., 2017).

The National Breast and Cervical Cancer Early Detection Program (NBCCEDP, www.cdc.gov/cancer/nbccedp) and the Colorectal Cancer Control Program (CRCCP, www.cdc.gov/cancer/crccp) are funded by the CDC to increase cancer screening in marginalized communities (Lantz and Mullen, 2015). NBCCEDP funds breast and cervical cancer prevention efforts in all 50 states, the District of Columbia, 6 U.S. territories, and 13 tribal entities while CRCCP funds colorectal cancer prevention efforts in 22 states, 7 universities, and one tribal entity. The primary focus of the NBCCEDP is: to deliver screening and diagnostic services through partnerships with primary care providers; to develop partnerships to promote outreach to communities; and recruitment among marginalized populations (Centers for Disease Control and Prevention (CDC) and Division of Cancer Prevention and Control, 2019). In contrast, the primary focus of the CRCCP is to partner with primary care clinics to implement evidence-based strategies to support and promote cancer screening (DeGroff et al., 2016 Joseph et al., 2016). Both programs support patient navigation as an evidence-based strategy to achieve programs goals.

Patient navigation has been instrumental in helping address individual, community, and structural barriers to cancer screening and treatment by providing connections to community resources, care coordination, patient education, and social support (Bernardo et al., 2019 Freeman, 2012 Sabatino et al., 2012). Delivery of patient navigation is complex given the diversity of sectors involved (e.g., healthcare, community organizations, workplaces) as well as fragmentation and cost reimbursement structures within the healthcare system (Freeman,

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2012). Models of patient navigation are further complicated by differences in how programs, organizations, and communities conceptualize the ultimate purpose of navigation (Wells et al., 2018). This difference directly translates to the skills or experiences preferred for the patient navigator (PN) role. Understanding differences in the conceptualization of patient navigation based on practice-setting, therefore, is informative. Wells and colleagues describe three main models of patient navigation based on these differences (Wells et al., 2018). The first model posits that PNs who provide navigation for screening, diagnostic follow-up, treatment, and survivorship have specific clinical training in order to understand and communicate complex healthcare processes to patients (Wells et al., 2018). The second model leverages PNs as "cultural brokers" who are members of marginalized communities that facilitate connections for improved access to health promotion programs or healthcare entities via trust-building and supportive relationships with patients (Wells et al., 2018). In this model, PNs are not required to have a clinical degree, but may have formal or informal training or experience in community health or health promotion (Wells et al., 2018). A third model suggests that navigation may be provided by a team of PNs with and without clinical training to more comprehensively address the individual, community, and structural barriers faced by patients when accessing health services (Wells et al., 2018).

Clinic-based settings have primarily adopted the first model of patient navigation and have employed nurses or other clinical staff as PNs (Freeman, 2012). Community-based settings, however, have tended to adopt the second model of patient navigation by activating lay health advisors or community health workers (CHWs) to perform navigation activities (Freeman, 2012 Paskett et al., 2011). In a systematic review of cancer-related patient navigation within federally qualified health centers (FQHCs), CHWs and clinical staff performed similar activities including providing education, assessing and addressing patient barriers, scheduling and attending appointments, as well as facilitating referrals to medical and social services (Roland et al., 2017). However, some navigation activities differed by setting of PNs; specifically, clinic-based PNs more commonly assessed and addressed barriers to care and/ or provided referrals for medical and social services, while communitybased PNs delivered activities focused on cancer education and awareness (Roland et al., 2017). Now, however, we are seeing a shift where clinics are adopting the second or third models of navigation to capitalize on the inherent cost-savings of employing CHWs (Johnson and Gunn, 2015) as well as growing evidence supporting the importance of cultural congruence between navigators and marginalized communities (Charlot et al., 2015).

Given this blending of patient navigation implementation over time, questions have emerged as to what navigation activities best map to what type of PN and in what setting. Identifying navigation activities performed and establishing and ensuring alignment with established competencies (Willis et al., 2016) for each model of navigation is needed to fully and equitably integrate this valuable service within the healthcare system (Byers, 2012). Furthermore, understanding the characteristics of PNs may help inform PN interventions as well as improve and/or clarify workflows. In sum, this information could be used to ensure systematic delivery of navigation services for screening completion to reduce cancer disparities (Byers, 2012 Freeman, 2012 Willis et al., 2016).

Currently, CDC's patient navigation policy requires that PNs deliver the following six activities: 1) assessment of patient's barriers to cancer screening, diagnostic services, or initiation of cancer treatment; 2) patient education and support; 3) resolution of patient barriers; 4) patient tracking and follow-up over at least two patient contacts to monitor completion of screening and diagnostic testing and treatment initiation; 5) collection of outcomes related to patient navigation (e.g., adherence to screening, diagnostic testing, and treatment); and 6) collection of patient-reported outcomes related to cancer screening, diagnosis, or treatment (Centers for Disease Control and Prevention (CDC); Centers for Disease Control and Prevention (CDC) and Division of Cancer Prevention and Control, 2019). While patient navigation is widely implemented by the NBCCEDP and CRCCP grantees (Centers for Disease Control and Prevention (CDC) and Division of Cancer Prevention and Control, 2019; Escoffery et al., 2015), a comprehensive assessment of navigation in these programs is lacking. The purpose of this study is to first characterize PNs within the NBCCEDP and CRCCP, focusing on reported PN characteristics and practicesettings, patient barriers, and navigation activities. Furthermore, this is the first study to collect data directly from PNs within the context of these two large, national cancerscreening programs.

2. Methods

2.1. Study design and online survey development

We conducted a cross-sectional survey among PNs affiliated with NBCCEDP and CRCCP in August–September of 2018. *Scope of practice* was assessed via items related to navigator job title/role, patient barriers reported, navigation activities provided, disease topics/ programs served, recruitment/outreach activities provided, and length of time in role. Survey items about *patient barriers* and *navigation activities* (see Appendices A and B, respectively) asked respondents to check all that applied to their navigation experience. Response options were based on those used in previously published studies (Roland et al., 2017 Wells et al., 2018). *Context of practice* was assessed via items related to organizational setting, service location, populations served, and mode of navigation. *Background experience/discipline* was assessed via items related to level of education, receipt of clinical training, and cancer history. *Demographic characteristics* assessed included gender identity and race/ethnicity while aspects of *training/technical assistance needs* assessed included training received and desired, mode of desired instruction for future trainings, and other resources/support. The study was reviewed by the University of Washington Institutional Review Board and determined to be exempt.

2.2. Sample and recruitment

Study personnel worked closely with NBCCEDP and CRCCP program directors and consultants as well as CDC program evaluators to ensure awareness and buy-in for PN assessment efforts. Names and email addresses of PNs within the NBCCEDP and the CRCCP were supplied by awardee program directors and/or their partner health systems and community-based organizations. An online survey link from the research team was sent to these PNs following an introductory email from their program director. On the survey introductory page, we defined PNs within the NBCCEDP/CRCCP as those who help

individuals access and complete cancer screening and diagnostic follow-up in clinical or community settings. Respondents were offered a \$25 online gift card for their time in completing the survey.

2.3. Data collection and calculated variables

Data were collected and stored using REDCap, a secure software application for electronic data capture (http://project-redcap.org/). PNs were categorized by cancer type navigated (i.e., breast and cervical cancer (BCC) and colorectal cancer (CRC); BCC PNs were grouped together as both cancers are addressed as part of NBCCEDP and over 90% of PNs who navigated for one cancer also navigated for the other. Geographic density was subjectively assigned by the PN based on the primary locations of populations served. Urban was defined as "in a large or very large city", suburban was defined as "in a town nearby a large city", and rural was defined as "in a town far away from a large city." PNs were also categorized by job type (i.e., healthcare practitioner and health professional). PNs with clinical job-titles (i.e., medical or nursing assistants, nurses, social workers, mental health counselors, or clinical providers) were defined as "healthcare practitioners." PNs without a clinical job-title were defined as "health professionals." Patient barriers were categorized as "personal or cultural" if related to individual or community characteristics of the patient or "structural" if related to policies, practices, or norms of healthcare programs or organizations (Freed et al., 2013).

2.4. Statistical analysis

Descriptive statistics of PN characteristics and practice-settings were calculated by cancer type. Differences in distributions of patient barriers and navigation activities by cancer type were tested by *Z*-statistic. Differences among BCC and CRC PNs by PN job type were also tested by *Z*-statistic. Bonferroni adjusted *P*-values to account for multiple comparisons were calculated for each table and provided in table footnotes. All analyses were conducted using Stata SE version 13.0 (StataCorp, College Station, TX).

3. Results

Nearly all (66 of 67) NBCCEDP and (30 of 30) CRCCP program directors and/or their partners provided email addresses for a total of 1034 PNs across the U.S. as well as tribal and territorial entities. The number of PNs identified per awardee ranged between one and 227. Of the 1034 PN email addresses provided, 1002 were valid and sent survey invitations; 437 PNs (44%) completed the survey. Of the 437 responding PNs, 410 (94%) reported providing navigation for BCC and 172 (39%) reported providing navigation for CRC. There were 145 PNs (33%) who provided navigation for both BCC and CRC and provided data to both categories of PNs.

Table 1 presents descriptive statistics for PN characteristics and practice-settings, by cancer type. Most BCC and CRC PNs were female (96.6% and 93.0%, respectively).. No PNs identified their gender as transgender or non-binary. PNs were likely to navigate for other health conditions in addition to cancer (72.9% and 83.1%),. Relatively new to navigation (44.9% and 54.1% in role for <5 years), highly educated (55.9% and 55.3% college

degree), employed by government agencies (51.2% and 45.9%), and distributed across geographic regions and densities. Furthermore, a large fraction of BCC and CRC PNs were nonwhite (38.5% and 47.1%) and did not have a clinical job-title (30.5% and 36.1%).

Given differences in program establishment and design as well as populations served, patient barriers and navigation activities were compared for BCC and CRC PNs. Of the patient barriers assessed among both BCC and CRC PNs (Table 2), about 26% (6 of 23 barriers) were highly reported (i.e., by 75% of PNs) by both groups. Specifically, highly reported patient barriers among BCC and CRC PNs included lack of: knowledge about cancer; knowledge about cancer screening procedures; knowledge about the benefit of screening; motivation to get screened; transportation; and health insurance. About 13% (3 of 23) of assessed patient barriers were highly reported among BCC PNs only including: fears about the screening process; fears about receiving a cancer diagnosis; and inability to take time off work. Furthermore, BCC PNs reported about 30% (7 of 23) of patient barriers more frequently than CRC PNs including: difficulty scheduling appointments; fears about revealing immigration status; lack of same-gendered providers; lack of transportation; lack of childcare; inability to take time off work; and inaccessible clinic hours. Only one patient barrier was reported by < 25% of BCC PNs whereas six patient barriers were reported by < 25% of CRC PNs.

Of the navigation activities assessed among both BCC and CRC PNs (Table 3), 20% (3 of 15) were highly reported (i.e., by 75% of PNs) by both groups. Specifically, highly reported navigation activities among BCC and CRC PNs included: talking to patients in clinics about screening; providing one-on-one education; and assessing patient barriers to screening. About 53% (8 of 15) of assessed navigation activities were highly reported among BCC PNs only including: talking to patients in the community; referring/enrolling patients into cancer screening or health insurance programs; helping patients resolve barriers; providing emotional support; as well as patient reminders, follow-up, and tracking. Furthermore, BCC PNs reported 60% (9 of 15) of assessed navigation activities more frequently than CRC PNs including: assessing and resolving patient barriers, providing referrals to cancer screening and health insurance programs, providing emotional support, helping patients communicate with providers, as well as patient reminders, follow-up, and tracking. Only one navigation activity was reported by <25% of both BCC and CRC PNs (i.e., "Accompany patients to screening and/or diagnostic appointments"). Reported navigation activities among BCC PNs did not vary by PN job type (Table 4). Among CRC navigators, however, PNs with a clinical job-title were more likely to help patients understand the bowel prep process as well as access needed materials compared to PNs without a clinical job-title.

4. Discussion

This study is the first to examine patient barriers and navigation activities reported by a diverse sample of PNs within two large, federally-funded cancer screening programs. Overall, the majority of patient barriers and navigation activities delivered by BCC and CRC PNs were related to personal and cultural factors. Clearly, lack of awareness and education about cancer screening continue to be significant barriers among populations served by

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NBCCEDP and CRCCP. However, BCC PNs also reported more structural patient barriers including transportation and factors related to clinic hours, scheduling, and clinical workforce compared to CRC PNs. BCC PNs also reported more navigation activities to address all barrier types compared to CRC PNs and this did not vary by PN job type. Results suggest that CRC PNs can increase follow-up efforts (e.g., reminder calls) for both fecal screening testing and colonoscopy as well as activities to address structural barriers.

While CDC uses the same patient navigation policy for both programs, differences noted between BCC and CRC PNs in our study may reflect several factors. First, it is possible that more comprehensive navigation among BCC PNs is due to differences in program maturity and funding. Second, there are differences in the programmatic and structural characteristics of the two programs. It is plausible that BCC navigators are focused on delivering navigation directly to women screened through the program while the CRC PNs are focused on supporting implementation of evidence based strategies (e.g., patient and provider reminders, mailed FIT kits) at the health system-level. There may also be differences in patient barriers and delivery of navigation activities given that patients served by NBCCEDP are women and generally younger whereas patients served by CRCCP are older men and women. Greater frequency of barriers reported by BCC PNs like lack of childcare and inaccessible clinic hours are consistent with higher employment and child-rearing responsibilities among NBCCEDP patients. Finally, the growing adoption of at-home screening kits versus clinic-based screening procedures may also have a role in the differences in activities delivered by CRC versus BCC navigators. This may have future implications for navigation activities delivered by BCC PNs with advent of home-based cervical cancer screening (Winer et al., 2018).

Our findings are consistent with one other examination of PN characteristics and activities within the CRCCP by Escoffery and colleagues using data collected from program directors, rather than directly from PNs (Escoffery et al., 2015). Interestingly, reported navigation activities were similar, however, frequencies of some navigation activities reported by PNs were slightly higher. Given that program directors complete annual surveys about elements of program administration including patient navigation, findings suggest their reports could provide an accurate and less burdensome assessment of patient navigation activities over time. Reported roles and education of PNs were also consistent with our findings; specifically, navigators tended to have clinical training and associate, nursing, or college degrees which is also reflected among current navigators in the NBCCEDP and CRCCP. However, a substantial proportion of PNs in our study reported practicing in a non-clinical job-title.

Our findings are also consistent with other studies describing delivered activities as reported by navigators overall as well as by cancer type (Escoffery et al., 2015 Rohan et al., 2018 Roland et al., 2017 Wells et al., 2018). Several studies indicate that clinical work experience is not a necessary component of successful navigation for breast (Roland et al., 2017 Viswanathan et al., 2009 Wells et al., 2011), cervical (Roland et al., 2017 Viswanathan et al., 2009), colorectal (Roland et al., 2017; Viswanathan et al., 2009), or overall cancer screening completion (Hou and Roberson, 2015). Furthermore, PNs without clinical work experience could be especially effective among low-resource medical settings (e.g., FQHCs), urban

settings, and with patients who are racially or ethnically concordant with the navigator (Wells et al., 2011). Yet, studies have found that navigation activities and modes of patient engagement are variable across PN models. One study found that community-based PNs provided more face-to-face education while clinic-based PNs provided more mail and telephone-based interventions (e.g., patient reminders) (Hou and Roberson, 2015). Another study not only found differences in navigation activities performed by practice-setting, but by the clinical work experience, education, and survivorship status of the PN (Roland et al., 2017).

However, few studies have examined possible differences in activities delivered by PN background, work experience, and training (Wells et al., 2018). While we note no differences in navigation activities by PN work experience, Wells and colleagues found that nurse PNs were more likely to provide treatment support and less likely to make arrangements and referrals to services (Wells et al., 2018). This lack of consistency may be attributed, in part, to the NBCCEDP patient navigation policy which requires that all women screened with abnormal screening results be navigated through diagnostic completion and, if diagnosed with cancer, through treatment initiation only. NBCCEDP PNs are then required to refer patients to others for support in treatment completion.

A significant study strength is that findings are based on data reported by a large nationallyrepresentative sample of navigators for breast, cervical, and colorectal cancer screening. Additionally, our study adds more dimensionality to the understanding of navigator experience by describing PN age, gender, race/ethnicity, languages spoken, and sexual orientation—characteristics that can be important for establishing trust with marginalized populations. Also, collaboration with program funders, directors, and navigators in our study design and implementation provided tremendous opportunities to increase the relevance and buy-in for future change efforts that might arise from these findings. Study limitations include a cross-sectional design as well as a moderate to low response rate for the online survey. Although our online survey response rate is higher than general population survey response rates (FluidSurveys University, 2014), our rate could still indicate that current study findings do not accurately represent the population of navigators within NBCCEDP and CRCCP. Finally, given high rates of turnover among clinic- and community-based staff, our findings may be less generalizable to PNs within the NBCCEDP and CRCCP. Despite these limitations, these findings provide a foundational understanding of navigation within these two large, federally-funded cancer screening programs.

Yet, questions remain as to *how* and *when* navigation activities should be delivered depending on background and work experience of PNs as well as the acceptability and effectiveness of these approaches among the patients and populations they serve. While Wells and colleagues have examined what combinations of navigation activities are delivered together for whom and by whom (Wells et al., 2018), we still do not know what combination of activities is most effective. Furthermore, patient navigation may not be useful for all patients thereby suggesting that targeting navigation efforts may also be more effective. Continued study of patient navigation models used, effectiveness of activities delivered, as well as associated costs is warranted, especially within NBCCEDP and CRCCP. Building capacity among PNs to systematically identify structural barriers and

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advocate for and/or initiate timely adjustments to program or organizational policies, practices, and norms could be one strategy to further optimize the effectiveness of patient navigation models within these programs. A recently reported navigator intervention to increase systems-level advocacy within two NCI-designated comprehensive cancer centers may provide such a change model (Cykert et al., 2019). Study is needed to determine whether multilevel interventions (i.e., targeting PNs and organizations) could further facilitate equitable access to cancer screening and diagnostic follow-up within NBCCEDP and CRCCP.

Careful examination of implementation approaches using an equity lens is also warranted to ensure that patient navigation models not only reduce cancer disparities for marginalized communities, but foster equity for PNs as well. For instance, although delivery of activities did not vary by job type among this racially and ethnically diverse sample of PNs, this factor may still influence a PN's effectiveness. Alternatively, if effectiveness of PNs does not vary by job type, it is possible that PNs without a clinical job-title could be paid less for doing the same work as PNs with a clinical job-title. This is of particular concern given the lack of racial/ethnic diversity of individuals within the clinical workforce, especially among nurses (Spetz, 2016). Both of these programs may well benefit from standardization of navigation activities across the continuum from screening to diagnostic resolution and treatment initiation with clearly and appropriately defined background and training expectations, as well as commensurate compensation and advancement opportunities for PNs. From a systems-level perspective, these processes may provide equal access to and improved quality of patient navigation for all patients as well as potentially foster capacity development among marginalized communities served by these programs.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

This paper is a product of the Alliance for Reducing Cancer, Northwest at the University of Washington Health Promotion Research Center (HPRC, cooperative agreement # U48DP005013) in collaboration with the University of Iowa (cooperative agreement # U48 DP005021) and Case Western Reserve University (cooperative agreement # U48 DP005030) as part of the Cancer Prevention and Control Research Network (CPCRN). CPCRN is a thematic network of the Prevention Research Centers (PRCs) Program that is co-funded by the Centers for Disease Control and Prevention (CDC) and the National Cancer Institute (NCI). The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the CDC or NCI. We would like to thank NBCCEDP and CRCCP directors, consultants, and PNs for their tremendous support of this study.

Publication of this supplement was supported by the Cancer Prevention and Control Network (CPCRN), University of North Carolina at Chapel Hill and the following co-funders: Case Western Reserve University, Oregon Health & Science University, University of South Carolina, University of Iowa, University of Kentucky, University of Pennsylvania and University of Washington.

References

Bernardo BM, Zhang X, Beverly Hery CM, Meadows RJ, Paskett ED, 2019 The efficacy and costeffectiveness of patient navigation programs across the cancer continuum: a systematic review. Cancer 125 (16), 2747–2761 8 15. [PubMed: 31034604]

- Byers T, 2012 Assessing the value of patient navigation for completing cancer screening. Cancer Epidemiol. Biomarkers Prevent 21, 1618–1619.
- Centers for Disease Control and Prevention (CDC), Division of Cancer Prevention and Control, 2019 National Breast and Cervical Cancer Early Detection Program: National Report for Program Years 2003–2014. U.S. Department of Health and Human Services, Atlanta.
- Chariot M, Santana MC, Chen CA, Bak S, Heeren TC, Battaglia TA, Egan AP, Kalish R, Freund KM, 2015 Impact of patient and navigator race and language concordance on care after cancer screening abnormalities. Cancer 121, 1477–1483. [PubMed: 25565151]
- Cykert S, Eng E, Manning MA, Robertson LB, Heron DE, Jones NS, Schaal JC, Lightfoot A, Zhou H, et al., 2019 A Multi-faceted Intervention Aimed at Black-White Disparities in the Treatment of Early Stage Cancers: The ACCURE Pragmatic Quality Improvement trial. 3 27 pii: S0027. J. Natl. Med. Assoc 9684 (18), 30191–30193. https://doi.Org/10.1016/j.jnma.2019.03.001. [Epub ahead of print].
- DeGroff A, Carter A, Kenney K, Myles Z, Melillo S, Royalty J, Rice K, Gressard L, Miller JW, 2016 Using evidence-based interventions to improve cancer screening in the National Breast and Cervical Cancer Early Detection Program. J. Public Health Manag. Practice 22, 442–449.
- Escoffery C, Fernandez ME, Vernon SW, Liang S, Maxwell AE, Allen JD, Dwyer A, Hannon PA, Kohn M, et al., 2015 Patient Navigation in a Colorectal Cancer Screening Program. J. Public Health Manag. Pract 21 (5), 433–440 Sep-Oct. [PubMed: 25140407]
- Escoffery C, Fernandez ME, Vernon SW, Liang S, Maxwell AE, Allen JD, Dwyer A, Hannon PA, Kohn M, et al., 2015 Patient navigation in a colorectal cancer screening program. J. Public Health Manag. Practice 21, 433–440.
- FluidSurveys University, 2014 Response Rate Statistics for Online Surveys—What Numbers Should You be Aiming for?.
- Freed CR, Hansberry ST, Arrieta MI, 2013 Structural and hidden barriers to a local primary health care infrastructure: autonomy, decisions about primary health care, and the centrality and significance of power. Res. Sociol. Health Care 31, 57–81. [PubMed: 24532864]
- Freeman HP, 2012 The origin, evolution, and principles of patient navigation. Cancer Epidemiol. Biomarkers Prevent 21, 1614–1617.
- Hou SI, Roberson K, 2015 A systematic review on US-based community health navigator (CHN) interventions for cancer screening promotion—comparing community-versus clinic-based navigator models. J. Cancer Education 30, 173–186.
- Johnson SL, Gunn VL, 2015 Community health workers as a component of the health care team. Pediatr. Clin. N. Am 62, 1313–1328.
- Joseph DA, Redwood D, DeGroff A, Butler EL, 2016 Use of evidence-based interventions to address disparities in colorectal cancer screening. MMWR Suppl 65, 21–28.
- Lantz PM, Mullen J, 2015 The National Breast and Cervical Cancer Early Detection Program: 25 years of public health service to low-income women. Cancer Causes Control 26, 653–656. [PubMed: 25837262]
- Paskett ED, McLaughlin JM, Lehman AM, Katz ML, Tatum CM, Oliveri JM, 2011 Evaluating the efficacy of lay health advisors for increasing risk-appropriate pap test screening: a randomized controlled trial among Ohio Appalachian women. Cancer Epidemiol. Biomarkers Prevent 20, 835– 843.
- Rohan EA, McDougall R, Townsend JS, 2018 An exploration of patient navigation and community health worker activities across national comprehensive cancer control programs. Health Equity 2, 366–374. [PubMed: 30569028]
- Roland KB, Milliken EL, Rohan EA, DeGroff A, White S, Melillo S, Rorie WE, Signes CC, Young PA, 2017 Use of community health workers and patient navigators to improve cancer outcomes among patients served by federally qualified health centers: a systematic literature review. Health Equity 1, 61–76. [PubMed: 28905047]
- Sabatino SA, Lawrence B, Elder R, Mercer SL, Wilson KM, DeVinney B, Melillo S, Carvalho M, Taplin S, et al., 2012 Effectiveness of interventions to increase screening for breast, cervical, and colorectal cancers: nine updated systematic reviews for the guide to community preventive services. Am. J. Prev. Med 43, 97–118. [PubMed: 22704754]

- Spetz J, 2016 The nursing profession, diversity, and wages. Health Serv. Res 51, 505–510. [PubMed: 26932595]
- Viswanathan M, Kraschnewski J, Nishikawa B, Morgan LC, Thieda P, Honeycutt A, Lohr KN, Jonas D, 2009 Outcomes of community health worker interventions. Evidence Report/technology assessment 1–144 (Al-2, B1-14, passim).
- Ward E, Sherman RL, Henley SJ, Jemal A, Siegel DA, Feuer EJ, Firth AU, Kohler BA, Scott S, et al., 2019 Annual report to the nation on the status of cancer, 1999–2015, featuring cancer in men and women ages 20–49. J. Natl. Cancer Inst 10.1093/jnci/djz106 5 30 pii: djz106.
- Wells KJ, Luque JS, Miladinovic B, Vargas N, Asvat Y, Roetzheim RG, Kumar A, 2011 Do community health worker interventions improve rates of screening mammography in the United States? A systematic review. Cancer Epidemiol. Biomarkers Prevent 20, 1580–1598.
- Wells KJ, Valverde P, Ustjanauskas AE, Calhoun EA, Risendal BC, 2018 What are patient navigators doing, for whom, and where? A national survey evaluating the types of services provided by patient navigators. Patient Educ. Couns 101, 285–294. [PubMed: 28935442]
- White A, Thompson TD, White MC, Sabatino SA, de Moor J, Doria-Rose PV, Geiger AM, Richardson LC, 2017 Cancer screening test use United States, 2015. MMWR Morb. Mortal. Wkly Rep 66, 201–206. [PubMed: 28253225]
- Willis AHE, Villalobos A, Pratt-Chapman M, 2016 Advancing the Field of Cancer Patient Navigation: A Toolkit for Comprehensive Cancer Control Professionals. The George Washington University Cancer Institute, Washington, DC.
- Winer RL, Tiro JA, Miglioretti DL, Thayer C, Beatty T, Lin J, Gao H, Kimbel K, Buist DSM, 2018 Rationale and design of the HOME trial: a pragmatic randomized controlled trial of home-based human papillomavirus (HPV) self-sampling for increasing cervical cancer screening uptake and effectiveness in a U.S. healthcare system. Contemp. Clin. Trials 64, 77–87. [PubMed: 29113956]

Demographic and professional characteristics reported by navigators within the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) and Colorectal Cancer Control Program (CRCCP).

	Breast & cervical (n = 410) N (%) ^{<i>a</i>}	Colorecta (<i>n</i> = 172) N (%) ^{<i>a</i>}
Navigator characteristics		
Age		
<40	134 (32.7)	67 (39.0)
40–49	79 (19.3)	33 (19.2)
50-64	173 (42.2)	62 (36.1)
65 +	17 (4.2)	6 (3.5)
Missing	7 (1.7)	4 (2.3)
Gender		
Male	8 (2.0)	10 (5.8)
Female	396 (96.6)	160 (93.0)
Missing	6 (1.5)	2(1.2)
Race		
African-American or African	38 (9.3)	21 (12.2)
American Indian/Alaska Native	15 (3.7)	12 (7.0)
Asian	23 (5.6)	13 (7.6)
Native Hawaiian/Pacific Islander	3 (0.7)	1 (0.6)
White	252 (61.5)	91 (52.9)
Multiracial	8 (2.0)	6 (3.5)
Missing	71 (17.3)	28 (16.3)
Hispanic ethnicity	73 (17.8)	29 (16.9)
Missing	7 (1.7)	3 (1.7)
Education		
< 12th grade	1 (0.2)	0 (0.0)
High school or general equivalency diploma (GED)	36 (8.8)	16 (9.3)
Two-year college degree (e.g. Associate's) or certification (e.g. LPN,)	142 (34.6)	60 (34.9)
Four-year college degree (e.g. Bachelor's)	166 (40.5)	61 (35.5)
Graduate (e.g. Master's, PhD) or professional (e.g. MD) degree	63 (15.4)	34 (19.8)
Missing	2 (0.5)	1 (0.6)
Languages spoken		
English	402 (98.1)	169 (98.3)
Spanish	84 (20.5)	33 (19.2)
Other	35 (8.5)	23 (13.4)
Sexual orientation		
Straight/heterosexual	384 (93.7)	162 (94.2)
Lesbian, gay, bisexual, queer	8 (2.0)	4 (2.3)
Other	2 (0.5)	1 (0.6)

	Breast & cervical (<i>n</i> = 410) N (%) ^{<i>a</i>}	Colorecta (<i>n</i> = 172) N (%) ^{<i>a</i>}
Missing	16 (3.9)	5 (2.9)
Cancer survivor	36 (8.8)	14 (8.1)
Missing	9 (2.2)	4 (2.3)
PN job type		
Health professional (e.g., community health worker, health educator)	125 (30.5)	62 (36.1)
Healthcare practitioner (e.g., nurse, social worker, provider)	249 (60.7)	96 (55.8)
Missing	36 (8.8)	14 (8.1)
Navigation experience, years		
<5	184 (44.9)	93 (54.1)
5–10	86 (21.0)	28 (16.3)
10+	138 (33.7)	49 (28.5)
Missing	2 (0.5)	2(1.2)
Organizational characteristics		
Employer type		
Government agency (e.g. health department, health district, health authority)	210 (51.2)	79 (45.9)
Tribal entity (e.g. sovereign nation or intertribal agency)	14 (3.4)	8 (4.7)
Community-based or non-profit health organization (no clinical service provision)	57 (13.9)	23 (13.4)
Federally-qualified health center (FQHC) or FQHC look-alike	57 (13.9)	39 (22.7)
Hospital or non-FQHC clinic	47 (11.5)	9 (5.2)
Academic/research institution	8 (2.0)	5 (2.9)
Other	0 (0.0)	6 (3.5)
Missing	4 (1.0)	3 (1.7)
Geographic region		
West	95 (23.2)	29 (16.9)
Midwest	117 (28.5)	70 (40.7)
South	132 (32.2)	48 (27.9)
Northeast	60 (14.6)	22 (12.8)
Missing	6(1.5)	3 (1.7)
Geographic density		
Rural	169 (41.2)	78 (43.4)
Urban or suburban	220 (53.7)	87 (50.6)
Missing	21 (5.1)	7 (4.1)
Other conditions navigated ^b		
Diabetes	213 (52.0)	116 (67.4
Hypertension	197 (48.1)	104 (60.5
HIV/AIDS	83 (20.2)	42 (24.4)
Other	228 (55.6)	102 (59.3
None	111 (27.1)	29 (16.9)
Missing	0 (0.0)	0 (0.0)
Navigation workflow established		

Navigation workflow established

	Breast & cervical (<i>n</i> = 410) N (%) ^{<i>a</i>}	Colorectal ($n = 172$) N (%) ^{a}
Yes	348 (84.9)	145 (84.3)
No	53 (12.9)	22 (12.8)
Missing	9 (2.2)	5 (2.9)
Role of navigator supervisor		
Clinical staff (e.g. nurse or social worker)	143 (34.9)	53 (30.8)
Clinical provider (e.g. physician, physician assistant, nurse practitioner)	12 (2.9)	7 (4.1)
Clinic manager or executive leadership	119 (29.0)	55 (32.0)
Program or health department staff	54 (13.2)	21 (12.2)
Other/undefined	70 (17.1)	30 (17.4)
Missing	12 (2.9)	6 (3.5)
Opportunities to collaborate with other navigators or outreach workers		
Yes	364 (88.8)	156 (90.7)
No	38 (9.3)	12 (7.0)
Missing	8 (2.0)	4 (2.3)

^aMay sum to >100% due to rounding error.

^bResponses are not mutually exclusive.

Patient barriers reported by navigators within the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) and Colorectal Cancer Control Program (CRCCP).

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	Barrier Type ^a	Breast & cervical (n = 410) N (%)	Colorectal ($n = 172$) N (%)	P value ^b
1. Lack of knowledge about cancer	Personal or cultural	368 (89.8)	155 (90.1)	06.0
2. Lack of motivation to get screened	Personal or cultural	328 (80.0)	142 (82.6)	0.48
3. Belief that won't get cancer	Personal or cultural	253 (61.7)	115 (66.9)	0.24
4. Lack of awareness that screening prevents or controls cancer	Personal or cultural	321 (78.3)	139 (80.8)	0.50
5. Lack of knowledge about screening process	Personal or cultural	331 (80.7)	140 (81.4)	0.86
6. Lack of knowledge about completing bowel prep	Personal or cultural	ı	106 (61.6)	,
7. Embarrassment or personal modesty	Personal or cultural	263 (64.2)	125 (72.7)	0.05
8. Fears about being diagnosed with cancer	Personal or cultural	335 (81.7)	123 (71.5)	0.006
9. Fears about the screening procedure	Personal or cultural	324 (79.0)	126 (73.3)	0.13
10. Difficulty with scheduling appointments	Structural	287 (70.0)	77 (44.8)	<0.0001
11. Fears about immigration status	Structural	183 (44.6)	47 (27.3)	0.001
12. Lack of family support to receive screening	Personal or cultural	106 (25.9)	41 (23.8)	0.61
13. Community beliefs or attitudes about screening procedures	Personal or cultural	148 (36.1)	53 (30.8)	0.06
14. Community beliefs or attitudes about accepting healthcare	Personal or cultural	122 (29.8)	38 (22.1)	0.06
15. Lack of providers who are the same gender as client	Structural	127 (31.0)	21 (12.2)	< 0.0001
16. Mistrust or negative past experience with healthcare system	Personal or cultural	175 (42.7)	60 (34.9)	0.08
17. Language barriers	Structural	253 (61.7)	85 (49.4)	0.006
18. Lack of transportation	Structural	355 (86.6)	130 (75.6)	0.001
19. Lack of escort to and from colonoscopy	Structural	ı	90 (52.3)	ı
20. Lack of childcare	Structural	193 (47.1)	38 (22.1)	<0.0001
21. Lack of adult care	Structural	81 (19.8)	20 (11.6)	0.02
22. Inability to take time off work	Structural	344 (83.9)	112 (65.1)	<0.0001
23. Lack of health insurance or concerns about cost	Structural	358 (87.3)	134 (77.9)	0.004
24. Long distance to screening facility	Structural	162 (39.5)	51 (29.7)	0.02
25. Clinic hours of operation do not fit schedule	Structural	213 (52.0)	58 (33.7)	0.001
26. No access to mobile mammography	Structural	123 (30.0)		·

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B	Barrier Type ^a	$\begin{array}{c c} \mbox{Breast \& cervical} & \mbox{Colorectal} & \mbox{I} \\ (n=410) & (n=172) \\ N \ (\%) & N \ (\%) \end{array}$	Colorectal (n = 172) N (%)	P value ^{b}
27. No access to test options (e.g. pap tests, fecal test kits, endoscopy sites, etc.) St	Structural	1	12 (7.0)	1

^aClient barriers categorized as "personal or cultural" if related to individual or community characteristics of client or "structural" if related to policies, practices, or norms of healthcare programs or organizations.

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 ^{b}P value from comparison of proportions using a large-sample Z-test statistic; Bonferroni adjusted value given 23 tests = 0.002

Cancer screening navigation activities reported by navigators within the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) and Colorectal Cancer Control Program (CRCCP).

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Activities of PN	Activity Type ^a	Breast & cervical (n = 410) N (%)	Colorectal (<i>n</i> = 172) N (%)	<i>P</i> value ^{<i>b</i>}
1. Talk to the clients in the community about screening	Personal or cultural	329 (80.2)	121 (70.4)	0.009
2. Talk to the clients within clinics about screening	Personal or cultural	309 (75.4)	130 (75.6)	0.96
3. Provide one-on-one education about screening	Personal or cultural	348 (84.9)	147 (85.5)	0.86
4. Provide group education about screening	Personal or cultural	194 (47.3)	71 (41.3)	0.18
5. Assess client barriers to screening	Structural	364 (88.8)	134 (77.9)	0.0007
6. Make referrals or enroll clients into cancer screening programs	Structural	357 (87.1)	120 (69.8)	<0.0001
7. Make referrals or enroll clients in financial assistance or health insurance programs (e.g. Medicaid)	Structural	323 (78.8)	94 (54.7)	<0.0001
8. Help clients resolve barriers to screening (e.g. transportation, translation services)	Structural	356 (86.8)	113 (65.7)	<0.0001
9. Provide emotional support	Personal or cultural	324 (79.0)	104 (60.5)	<0.0001
10. Mail out FIT kits	Structural		82 (47.7)	
11. Call clients to remind them of screening and/or diagnostic follow-up appointments	Personal or cultural	312 (76.1)	110 (64.0)	0.003
12. Help clients prepare for screening appointments (e.g. prepare list of questions for provider)	Personal or cultural	226 (55.1)	82 (47.7)	0.11
13. Help clients access bowel preparation materials	Structural	I	79 (45.9)	ı
14. Help clients understand the bowel preparation process	Personal or cultural	I	100 (58.1)	ı
15. Help clients communicate with health care providers	Personal or cultural	288 (70.2)	98 (57.0)	0.002
16. Re-contact clients to see if they completed cancer screening	Structural	308 (75.1)	107 (62.2)	0.002
17. Reminder calls to clients to encourage they complete FIT/FoBT tests	Personal or cultural	ı	111 (64.5)	ı
18. Track clients through the screening and/or diagnostic follow-up process	Structural	357 (87.1)	116 (67.4)	<0.0001
19. Accompany clients to screening and/or diagnostic appointments	Personal or cultural/structural	90 (22.0)	20 (11.6)	0.004

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 ^{b}P value from comparison of proportions using a large-sample Z-test statistic; Bonferroni adjusted value given 15 tests=0.003.

healthcare programs or organizations.

Cancer screening navigation activities by type of navigator within the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) and Colorectal Cancer Control Program (CRCCP).

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Activities of PN	Breast & cervical				Colorectal		
	Activity type ^a	Without clinical training $(n = 125)$ N (%)	With clinical training (<i>n</i> = 249) N (%)	P value ^b	Without clinical training $(n = 62)$ N (%)	With clinical training (n = 96) N (%)	P value ^c
1. Talk to the clients in the community	Personal or cultural	106 (84.8)	194 (77.9)	0.11	50 (80.7)	60 (62.5)	0.02
2. Talk to the clients within clinics about screening	Personal or cultural	97 (77.6)	185 (74.3)	0.48	45 (72.6)	75 (78.1)	0.43
3. Provide one-on-one education about screening	Personal or cultural	113 (90.4)	206 (82.7)	0.05	53 (85.5)	83 (86.5)	0.86
4. Provide group education about screening	Personal or cultural	72 (57.6)	105 (42.2)	0.005	33 (53.2)	33 (34.4)	0.02
5. Assess client barriers to screening	Structural	117 (93.6)	217 (87.2)	0.06	48 (77.4)	76 (79.2)	0.79
Make referrals or enroll clients into cancer screening programs	Structural	115 (92.0)	213 (85.5)	0.07	46 (74.2)	65 (67.7)	0.38
7. Make referrals or enroll clients in financial assistance or health insurance programs (e.g. Medicaid)	Structural	98 (78.4)	199 (79.9)	0.73	35 (56.5)	51 (53.1)	0.68
 Help clients resolve barriers to screening (e.g. transportation, translation services) 	Structural	116 (92.8)	210 (84.3)	0.02	41 (66.1)	64 (66.7)	0.94
9. Provide emotional support	Personal or cultural	100(80.0)	203 (81.5)	0.72	31 (50.0)	66 (68.8)	0.02
10. Mail out FIT kits	Structural	ı	ı	,	30 (48.4)	46 (47.9)	0.95
11. Call clients to remind them of screening and/or diagnostic follow-up appointments	Personal or cultural	92 (73.6)	190 (76.3)	0.57	38 (61.3)	61 (63.5)	0.78
12. Help clients prepare for screening appointments (e.g. prepare list of questions for provider)	Personal or cultural	71 (56.8)	133 (53.4)	0.54	28 (45.2)	48 (50.0)	0.55
13. Help clients access bowel preparation materials	Structural	ı	ı		18 (29.0)	54 (56.3)	0.0008
14. Help clients understand the bowel preparation process	Personal or cultural	ı	ı		25 (40.3)	66 (68.8)	0.0004
15. Help clients communicate with health care providers	Personal or cultural	89 (71.2)	177 (71.1)	0.98	34 (54.8)	57 (59.4)	0.57
16. Re-contact clients to see if they completed cancer screening	Structural	96 (76.8)	185 (74.3)	0.60	35 (56.5)	63 (65.6)	0.25
17. Reminder calls to clients to encourage they complete FIT/FoBT tests	Personal or cultural				38 (61.3)	62 (64.6)	0.68
18. Track clients through the screening and/or diagnostic follow-up process	Structural	103 (82.4)	223 (89.6)	0.05	36 (58.1)	71 (74.0)	0.04
19. Accompany clients to screening and/or diagnostic appointments	Personal or cultural/ structural	35 (28.0)	50 (20.1)	0.09	11 (17.7)	8 (8.3)	0.08

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^aClient barriers categorized as "personal or cultural" if related to individual or community characteristics of client or "structural" if related to policies, practices, or norms of healthcare programs or organizations.

 b_{P} value from comparison of proportions using a large-sample Z-test statistic; Bonferroni adjusted value given 16 tests=0.003.

 ^{c}P value from comparison of proportions using a large-sample Z-test statistic; Bonferroni adjusted value given 20 tests=0.003.

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