

63 Rural Primary Care and the Diagnostic Resolution of Abnormal Screening Mammograms: A Mixed Methods Study in Rural Missouri
Hunleth et al.



Journal of Health Disparities Research and Practice
Volume 12, Issue 6, Winter 2019, pp. 63-79
© 2011 Center for Health Disparities Research
School of Community Health Sciences
University of Nevada, Las Vegas

Rural Primary Care and the Diagnostic Resolution of Abnormal Screening Mammograms: A Mixed Methods Study in Rural Missouri

Jean Hunleth, Washington University School of Medicine in St. Louis
Julia Maki, Washington University School of Medicine in St. Louis
Amanda Lee, University of Arizona
Aimee James, Washington University School of Medicine in St. Louis
Rebecca Lobb, Family Reach Foundation

Corresponding Author: Jean Hunleth, jean.hunleth@wustl.edu

ABSTRACT

Rural health clinics (RHCs) and federally qualified health centers (FQHCs) play a vital role in initiating cancer screening in underserved, rural settings. Yet there is limited information about their involvement in diagnostic tests when a mammogram result is abnormal. Diagnostic resolution of abnormal mammograms varies widely by geographic location and resources, and timely resolution is important for addressing rural-urban cancer disparities. This mixed methods study in a rural region of Missouri with high rates of cancer mortality examined the roles of primary care providers during follow-up after an abnormal mammogram, the processes they used, and the clinic specific variations among these roles and processes. Our data show substantial involvement of primary care during follow-up, with differences in resources and formalized and informal strategies between FQHCs and RHCs. Elucidating roles and processes is a necessary step before evidence based strategies, often developed in urban settings, can be adapted for rural settings.

Keywords: Rural Healthcare Disparities, Mammography, Primary Health Care, Prevention and Control, Early Detection of Cancer, United States

INTRODUCTION

Rural areas often have higher cancer incidence and mortality compared to urban and suburban areas (James et al., 2017; Pruitt et al., 2015; Singh & Siahpush, 2014a, 2014b; Zahnd et al., 2018). In addition to greater travel distances to specialists and diagnostic and treatment

Journal of Health Disparities Research and Practice Volume 12, Issue 6, Winter 2019

<http://digitalscholarship.unlv.edu/jhdp/>

Follow on Facebook: [Health.Disparities.Journal](https://www.facebook.com/Health.Disparities.Journal)

Follow on Twitter: [@jhdp](https://twitter.com/jhdp)

facilities, rural residents tend to have higher rates of poverty and unemployment than residents in urban areas. In Missouri, where we carried out our research, rural residents are also more likely to be uninsured than urban residents (Robert Wood Johnson Foundation, 2018). Primary care providers play a critical role in health care, especially in underserved rural areas, where federally qualified health centers (FQHCs) and rural health clinics (RHCs) provide care to people who might not be able to otherwise access or afford care. With rural cancer disparities recently gaining national attention, it is critical to understand the roles that FQHCs and RHCs are already taking to prevent and control the impact of cancer in their patient populations.

In this article, we focus on one aspect of the cancer prevention and control continuum that can lead to disparities: diagnostic resolution of abnormal screening results. Screening efforts are only effective in preventing mortality when abnormal results are followed up adequately and treatment is available, and the National Academy of Medicine has identified incomplete diagnostic resolution of abnormal test results as a critical healthcare quality issue (*Crossing the Quality Chasm: A New Health System for the 21st Century*, 2001). Researchers have estimated that anywhere from 9% to 50% of US women do not complete follow-up after an abnormal mammogram (Taplin, Yabroff, & Zapka, 2012). For breast cancer, incomplete diagnostic resolution contributes to later stage at diagnosis (Taplin et al., 2004), and a systematic review and meta-analysis found significant rural-urban disparities in screening and diagnostic completion (Leung, McKenzie, Martin, & McLaughlin, 2014). Such findings offer compelling evidence for the promotion of mammographic screening and also necessitate attention to improving follow-up processes and reducing barriers, where needed (Lee et al., 2018). There are known effective strategies for improving rates of resolution of abnormal screening results. These include the reduction of out of pocket costs, removal of structural barriers, and the implementation of tracking systems (Baron et al., 2010; Wei, Ryan, Dietrich, & Colditz, 2005; J. M. Zapka, Edwards, Chollette, & Taplin, 2014). Further, patient navigator programs that help patients navigate the health system and psychosocial and structural barriers are shown to reduce time to diagnostic resolution for women who experience the greatest delays in care (Freund et al., 2014). However, such strategies must be adapted to specific settings and contexts in order to be feasible and effective (Bauman, Cabassa, & Stirman, 2018; Damschroder et al., 2009), and they must take into account the specificities of rural health care.

We carried out a mixed-method study to identify the role of rural primary care clinics in diagnostic resolution, and the organizational and setting contexts that shaped these processes and roles. Our research was set in the Missouri Bootheel, an area of the US Midwest that has a greater burden of mortality from breast cancer than other rural and urban areas in the region (Moore et al., 2018; U.S. Cancer Statistics Working Group, 2018). We focused on FQHCs and RHCs because these clinics serve the most underserved rural areas and populations and were the main providers of primary care in the Bootheel region (RHCs made up 87% of primary care in the region). FQHCs and RHCs also have different requirements, funding streams, and governance ("U.S. Department of Health and Human Services, Office of Rural Health Policy. Comparison of the Rural Health Clinic and Federally Qualified Health Center Programs," 2006), enabling a preliminary exploration of similarities and differences in their roles related to cancer prevention and control. Because rural areas are heterogenous, this study contributes to an emerging focus on rural cancer prevention in the Midwest (Charlton et al., 2014; Levy, Xu, Daly, & Ely, 2013; Muthukrishnan et

65 Rural Primary Care and the Diagnostic Resolution of Abnormal Screening Mammograms: A Mixed Methods Study in Rural Missouri
Hunleth et al.

al., 2018; Overholser et al., 2009; Rim et al., 2009; Zittleman et al., 2009), as well as an understanding of how researchers can approach adapting and implementing evidence-based strategies into under-resourced rural settings.

METHODS

Our study was carried out in 10 adjoining rural counties in the Bootheel region, located in Southeast Missouri. We chose these counties because they have among the highest rates of cancer mortality in the state (U.S. Cancer Statistics Working Group, 2018). Although there is variation, economic and health indicators are generally worse across the 10 counties than the national and state averages. All 10 counties have high rates of poverty: 17% to 31% of the residents in these counties live below the Federal Poverty Limit (compare to U.S. average of around 12%) (United States Census Bureau, 2019). The provider to patient ratio ranges between 1:910 and 1:12,180, and the percent of the population without health insurance is again higher than the national average, from 12%-18% (national average = 11%) (Robert Wood Johnson Foundation, 2018). Missouri did not expand Medicaid, leaving an estimated 352,000 people in the state uncovered who would have otherwise been covered under the expansion (Norris, 2018).

We used a two-stage, mixed methods, explanatory sequential design that began with a structured survey completed by key staff members in rural primary care clinics, followed by qualitative case studies of four clinics. Our study partners— Missouri Primary Care Association, Missouri Department of Health and Senior Services Office of Primary Care and Rural Health, Missouri Association of Rural Health Clinics—provided assistance at all stages of the research process. The study was approved by the Institutional Review Board at Washington University in St Louis. We provided letters to survey participants with the elements of informed consent, with completion of the survey considered consent to participate. Written informed consent was obtained from all participants in the qualitative interviews. All survey and interview participants were offered \$75 compensation for participation.

Survey Methods

Survey data collection occurred between April and July 2014 through a 30-minute, online or paper survey. All RHCs and FQHCs (RHCs=67; FQHCs= 10) in the 10 counties were eligible to participate. Our study partners provided us with the contact information for organizational leaders in the clinics, who were contacted via email or postal service, inviting them to participate in our survey. To encourage participation, our research partners contacted clinics that did not respond to our initial invitation by email, and we made follow-up calls.

This manuscript reports on a portion of the survey that included 21 items about organizational structure, electronic resources, relationships with referral organizations, and services provided to promote screening and diagnostic resolution of abnormal breast cancer results. We adapted items used in other organizational surveys of RHCs and FQHCs^{24, 25} by pretesting our survey iteratively in 21 primary care clinics (RHCs and FQHCs) in rural Missouri counties not included in the study, and obtaining input from our research partners. We report descriptive statistics for survey items stratified by RHC and FQHC.

Qualitative Case Study Methods

Eligibility to participate in the qualitative case study research included having participated in the survey. We stratified by RHC and FQHC because differing histories and regulations guide

Journal of Health Disparities Research and Practice Volume 12, Issue 6, Winter 2019

<http://digitalscholarship.unlv.edu/jhdrp/>

Follow on Facebook: Health.Disparities.Journal

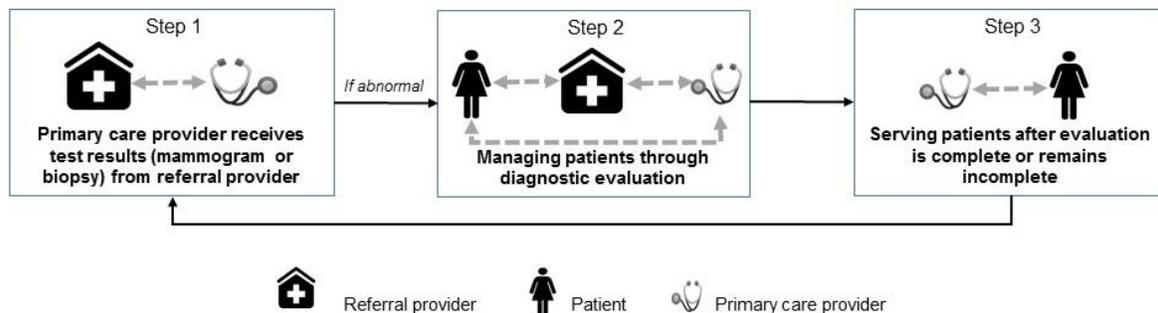
Follow on Twitter: @jhdrp

practices in RHCs and FQHCs (Office of Rural Health Policy, 2006) and because we identified differences in RHC and FQHC survey responses. We further purposefully selected case study sites that varied by size, geographic location, and hospital affiliation. We approached 4 RHCs and 2 FQHCs to invite them to participate in the case study. Of these, 2 RHCs and 2 FQHCs agreed to participate. Case studies were conducted between April and June 2015.

Case study procedures involved a full-day site visit to each clinic, which included qualitative one-on-one interviews of all staff involved in assisting women with diagnostic resolution of an abnormal screening mammogram (e.g., doctors, nurse practitioners, receptionists, case managers). We aimed to include representation from people who knew about the process and those who were part of administering the process. The interview guide consisted of open-ended questions about the processes the clinic used to promote diagnostic resolution of abnormal breast cancer screening and their specific roles in follow-up. We also included questions about the challenges they faced in their work. In addition to offering compensation for the interviews, we provided breakfast and lunch to the clinic staff. Providing refreshments promoted enthusiasm for the study, cultivated rapport, and acknowledged the effort that went into making our site visit possible.

Interviews were audio-recorded and transcribed verbatim. Our codebook included deductive codes based on the survey and inductive codes derived from transcript review. We also coded for the steps in the follow-up process, basing the steps on Taplin et al.'s care continuum to complete diagnostic resolution (Taplin et al., 2004; J. Zapka et al., 2010). Transcripts were double coded in NVivo 10. Once coding was complete, the team met to identify the process of follow-up in each clinic, and to explore variation among interviewees within each clinic. Such differences mostly related to differences in roles and level of involvement in the process, where some interviewees could offer much more information about different steps in the process than others. We included such variations in our analysis mostly as a means to examine different roles within the clinic. We then compared the general processes across clinics. This comparison led us to identify steps of the care continuum within the domain of primary care: (1) receiving test results from referral (mammography) provider, (2) managing patients through diagnostic evaluation, and (3) serving patients after evaluation is complete or remains incomplete (Figure 1).

Figure 1. Primary care specific roles after a woman receives an abnormal mammogram and through diagnostic evaluation



We report findings for each of these three steps. Because each step contains responses to the quantitative survey and qualitative interview, we use the term “respondents” to discuss the individuals who participated in the survey and “interviewees” to discuss those who participated in the qualitative interviews.

RESULTS

Characteristics of the Clinics and Participants.

Table 1 provides details on the survey and case study participants.

Table 1. Participant Characteristics

	Surveys	Interviews
	n=47	n = 20
Title, n (%)		
Manager/Administrator	27 (57%)	2 (10%)
Direct Care Provider (physician, physician assistant, nurse practitioner)	13 (28%)	6 (30%)
Clinical Staff (registered nurse, licensed practical nurse, medical assistant)	2 (4%)	9 (45%)
Administrative Staff (receptionist, referral coordinator)	5 (11%)	3 (15%)
Years of employment with clinic, n (%)		
1-3 years	11 (23%)	10 (50%)
4-10 years	14 (30%)	3 (15%)
> 10 years	22 (47%)	7 (35%)
Gender, n (%)		
Female	45 (96%)	18 (90%)
Male	2 (4%)	2 (10%)
Age, n (%)		
< 39	12 (26%)	7 (35%)
40-49	17 (36%)	4 (20%)
≥ 50	16 (34%)	9 (45%)
Missing	2 (4%)	—
Highest level of education, n (%)		
Associate's degree or less	23 (49%)	9 (45%)
Bachelor's degree	4 (8%)	3 (15%)
Master's degree or higher	15 (32%)	7 (35%)
Missing	5 (11%)	1 (20%)

Survey

Of the 77 clinics approached for the quantitative phase, 47 (61%) completed the survey. Clinic participation did not differ across the 10 counties but was higher among FQHCs (10/10=100%) than RHCs (37/67 = 55%). Respondents were usually clinic administrators or managers (57%), direct care providers and clinical staff (32%), and administrative staff (11%).

Journal of Health Disparities Research and Practice Volume 12, Issue 6, Winter 2019

<http://digitalscholarship.unlv.edu/jhdrp/>

Follow on Facebook: Health.Disparities.Journal

Follow on Twitter: @jhdrp

68 Rural Primary Care and the Diagnostic Resolution of Abnormal Screening Mammograms: A Mixed Methods Study in Rural Missouri
Hunleth et al.

Many respondents were long-time employees of the clinics (>10 years=47%; 4-10 years=30%), and most respondents were women.

Case Studies

Four clinics (2 FQHCs, 2 RHCs) participated in site visits, which resulted in 20 qualitative interviews (4-6 interviews per clinic). Each of the 4 clinics—referred to here as RHC1, RHC2, FQHC1, and FQHC2—was located in a different county. The population densities of these 4 counties ranged from roughly 20 to 100 persons per square mile, with RHC2 and FQHC1 located in the least dense counties. The counties had similar uninsured rates (around 15% at the time of the study). All had poverty rates higher than the national average. Of the 4 counties, the county in which RHC2 was located had the highest poverty rate and highest breast cancer mortality rate.

The 4 clinics differed in size and in affiliation. RHC1, the smallest of the clinics in physical size and patient population, was a stand-alone clinic with one primary care provider. RHC2, FQHC1, and FQHC2 each had two primary care providers and were affiliated with parent organizations. RHC2 had recently been acquired by a large hospital system and, as a result, was instituting many new procedures during the time of our site visit. The FQHCs were larger and employed more staff members than the RHCs. Both FQHCs employed case managers who assisted with diagnostic follow-up to abnormal breast cancer screening. All clinics were using electronic medical record (EMR) systems to varying degrees.

At each clinic, we interviewed a range of employees with varying roles. The distribution of employees interviewed was similar across the clinics with 2 exceptions: FQHC interviews included case managers, and we did not interview front desk staff at FQHC2. Most interviewees were women. Employees interviewed at RHC1 and FQHC1 tended to have worked at the clinics longer than those at RHC2 and FQHC2, where 80% and 100%, respectively, had worked for less than 3 years.

Step 1: Receiving test results from referral provider

Almost all survey respondents reported that their clinics regularly received the results of screening mammograms from referral sites and, with the exception of one missing response, all respondents identified that their clinics regularly received diagnostic mammography results. During our site visits, interviewees across the 4 clinics also reported regularly receiving screening and diagnostic mammogram results. Because referrals are not required for screening mammograms, they received results for both patients they referred for screening and those who screened without referrals. Most interviewees said that screening and diagnostic mammogram results were sent quickly. However, at FQHC2, interviewees reported having problems receiving results from some referral providers. They attempted to circumvent these issues by referring patients to specific diagnostic centers that they knew sent results reliably and quickly.

All clinics received screening and diagnostic mammogram results via fax, with referral providers only calling about results for the most “urgent,” abnormal, or “really abnormal” cases. Front desk staff scanned these results into the EMR system. However, the paper report of results played an important role in the follow-up process in three clinics [FQHC1, RHC1, RHC2]. The circulation of paper results among staff was due to physician preference [FQHC1, RHC2], insufficient training in EMR use [FQHC1, RHC1], and frequent Internet outages and EMR crashes. The EMR crashed so often in FQHC1 that one interviewee told us: “I have more pictures of crashed EMR systems than I do of my grandchildren on my [cell]phone.” While FQHC1 kept

the paper results so that they could continue working without the EMR, the RHCs used the paper results as a way to alert each other of the need to carry out specific actions during follow-up. Both RHCs had devised localized strategies, such as folding the paper in a particular way and using a post-it note system to flag the nurses and doctors, or setting results in specific places on one another's desks.

Unlike screening and diagnostic mammograms, which almost all respondents reported receiving, only two-thirds of respondents reported routinely receiving biopsy results from specialists (Table 2, 1c). The interviews offer a possible interpretation of this finding. Interviewees identified that, by the point in diagnostic evaluation when a woman receives a biopsy, the “system takes over” [FQHC1] and patients are more fully under the specialists' care. Despite this transfer of care, all interviewees still wanted biopsy results. When the FQHCs identified that results were missing or delayed, they contacted the specialists to either give them a “gentle reminder” (one week later) [FQHC2] or a firm request (within a day or two) [FQHC1]. This contact also alerted the FQHCs to whether a patient had missed their biopsy appointment.

Table 2. Survey Results – Reported by Steps in Care

Survey Items	Rural Health Clinics (n=37) n (%)	Federally Qualified Health Centers (n = 10) n (%)
Responsibility for managing patients through diagnostic resolution		
When screening mammograms show abnormal results, responsibility for managing patients through to diagnostic resolution belongs to: ^{3,4}		
The service provider	17 (46%)	4 (40%)
The referring provider (primary care)	33 (89%)	9 (90%)
The patient	29 (78%)	7 (70%)
Step 1. Primary care provider receives test results from referral provider		
1a. Clinic receives referral report from radiologist after a screening mammogram ²		
Yes, routinely	35 (94%)	10 (100%)
Yes, sometimes	1 (3%)	
Missing	1 (3%)	
1b. Clinic receives referral report from radiologist after a diagnostic mammogram ¹		
Yes, routinely	36 (97%)	10 (100%)
Missing	1 (3%)	
1c. Clinic receives referral report from specialist after a breast biopsy ²		
Yes, routinely	25 (67%)	7 (70%)
Yes, sometimes	10 (27%)	3 (30%)
I don't know	1 (3%)	
Missing	1 (3%)	

Step 2. Primary care provider management of patients through diagnostic evaluation		
2a. When the results of a mammogram are abnormal mammogram, we: ⁴		
Recommend that patients make an appointment with a primary care provider	17 (46%)	8 (80%)
Other (please specify): Make a referral for follow-up appointments ⁵	19 (51%)	4 (100%)
2b. Total number of methods for contacting patients after an abnormal mammogram (phone, mail, email, other):		
1 method	23 (62%)	3 (30%)
2 methods	10 (27%)	4 (40%)
3 or more methods	3 (8%)	3 (30%)
Missing	1 (3%)	
2c. Total number of attempts to contact patients after an abnormal mammogram:		
1-4 times	6 (16%)	5 (50%)
Until patient is reached	30 (81%)	5 (50%)
Missing	1 (3%)	
2d. When my organization contacts patients after an abnormal mammogram, we have procedures in place to assist patient with: ^{3,4}		
Scheduling a diagnostic mammogram	32 (86%)	10 (100%)
Scheduling a breast biopsy	31 (84%)	10 (100%)
2e. When my organization contacts patients after an abnormal mammogram, we have procedures in place to assist patient with: ^{3,4}		
Understanding what to expect and how to prepare for follow-up appointments	30 (81%)	9 (90%)
Managing psychosocial challenges	24 (65%)	8 (80%)
Managing access to care challenges	22 (59%)	9 (90%)
Step 3. Patient Completes Diagnostic Evaluation		
3a. When patients are diagnosed with breast cancer, my organization: ³		
Assists them enroll in a treatment program	26 (70%)	9 (90%)

1. No respondents reported: Yes sometimes, No, or I don't know
2. No respondents reported: No
3. Percent that reported: strongly agree or agree.
4. Responses are not mutually exclusive.

Step 2. Managing patients through diagnostic evaluation

Most survey respondents strongly agreed or agreed that it was their responsibility, as primary care providers, to manage patients through diagnostic resolution (Table 2). More than two-thirds of respondents reported that it was also the responsibility of the patient, but less than half agreed that it was the referral service provider's responsibility. During our site visits,

Journal of Health Disparities Research and Practice Volume 12, Issue 6, Winter 2019

<http://digitalscholarship.unlv.edu/jhdrp/>

Follow on Facebook: Health.Disparities.Journal

Follow on Twitter: @jhdrp

interviewees discussed what the management of responsibilities meant to their day-to-day practice. We divide their comments into 3 overlapping categories: discussing results with patients, scheduling and tracking diagnostic appointments, and managing access.

Discussing screening and diagnostic results with patients. Both respondents and interviewees expressed a sense of responsibility for contacting patients after their clinic received abnormal mammogram results. Interviewees viewed this contact varyingly as: ensuring that the woman had actually received a call or letter with the results from the mammography site; “checking in” with the woman to explain results, answer questions, and encourage follow-up; and letting the woman know the next steps needed to reach diagnostic resolution.

All interviewees assumed that referral sites had already contacted the women about their results. However, the receptionist at RHC1 emphasized that the population they served was difficult to reach by phone, and may not have received results. She said, “People change their phone numbers a lot. I think a lot of it is money issues... they haven’t paid their bill or they’re out of minutes.” She called to make sure that women did not fall through the “cracks.” The case manager in FQHC1 expressed a similar concern, and she sent certified letters to women with their mammography results when she could not reach them by phone.

All respondents from FQHCs and about half from RHCs reported that they scheduled in-office appointments to discuss abnormal screening results with patients (Table 2, 2a). Interviewees from FQHC1, FQHC2, and RHC2, however, did not describe in-office appointments as standard practice. They said that most conversations about abnormal mammogram happened over the phone. Calling patients, rather than having them come in to the clinic, was aimed at minimizing the time between abnormal result receipt and resolution, as well as reducing the expense to the patient (copay, transportation, time off work). While interviewees in RHC1 reported having all patients with abnormal results come in to their clinic to receive results, those in the other 3 clinics said that they made judgment calls, typically only asking women whose mammogram results were “urgent” [FQHC1] or “really abnormal” [RHC2] to come into the clinic to go over the results.

Scheduling and tracking diagnostic appointments. Most survey respondents at RHCs and all at FQHCs reported that they assisted patients with scheduling diagnostic mammograms. When discussing scheduling follow-up appointments, the interviewees mentioned the issue of where to send the patient. Most interviewees said that they preferred that patients went back for a second mammogram at the same site, but they also reported “matching” patients to referral providers for follow-up based on what they knew about the patients’ insurance, proximity, personality, and the reputation of the provider (including reputation for reporting results; see Step 1). Their options varied by the connections they had and the availability in the region, as well as their own resources to assist patients through follow-up. For example, the nurse practitioner in RHC1 preferred her patients to go to a certain hospital that had follow-up and assistance services, given her clinic’s lack of other resources. Interviewees from RHC2 felt pressure to send patients to the hospital with which they were affiliated, but they also knew that this “didn’t always work” for patients.

In FQHC1 and RHC2, interviewees said that they scheduled appointments prior to reaching out to the patient and gave patients “the phone number in case that [appointment] ends up not working for them” [RHC2]. In contrast, interviewees at FQHC2 recommended providers, and had patients schedule their own appointments. In RHC1, where all women with abnormal mammograms were asked to come in, the receptionist took a more hands-on approach to

scheduling patients' follow-up during their in-office appointment to "encourage them" to go to their appointment. All clinics said that they "could help" patients with scheduling [FQHC2] or rescheduling [FQHC1 and RHC2] if the patient asked, but the main responsibility fell on the patient once they had the appointment, including in RHC1.

All clinics [except FQHC2] relied on referral sites to give reminder calls for scheduled appointments unless they felt they needed the extra call [FQHC1]. Interviewees reported that it was common to see patients outside the clinic and some interviewees informally reminded patients when they saw them [RHC2]. In contrast, the social worker at FQHC2 referred to herself as the appointment "police," giving reminder calls to patients before appointments and checking in after appointments.

Both FQHCs generated reports on open referrals and called patients to reschedule missed or cancelled appointments. In RHC1, the receptionist kept a list of patients who had been referred for screening mammograms and diagnostic evaluation. However, the day-to-day operations generally restricted her from actively checking if the patients attended their appointments: "You look back [at the list] and you're usually two months out, and then you realize that the patient never did go for a diagnostic exam."

Managing challenges to follow-up care. Most FQHC respondents reported that their clinics had procedures in place to assist patients with psychosocial (80%) and access (90%) challenges during follow-up. These numbers were lower in the RHCs, with 65% and 59% of respondents reporting procedures in place to assist with psychosocial and access challenges, respectively. Such differences were also evident in the interviews. For example, FQHC2 used standardized tools to identify financial, transportation, and psychosocial needs, and both FQHCs mentioned employing staff explicitly dedicated to addressing patient barriers to care (e.g., transportation).

While interviewees from the other clinics did not specify such tools, they and interviewees from FQHC2 emphasized other ways of listening to and identifying their patients' needs. These were based on time spent with patients [all clinics], as well as on experiential knowledge that staff had gained from living in a rural area [FQHC1, RHC2, RHC1]. In the FQHCs and in RHC2, interviewees faced constraints on time during clinical encounters due to regulatory pressures, the large number of patients they served, and the multiple and complex health needs of their patient population, and (in FQHC1) the EMR crashing frequently. Staff attempted to circumvent these constraints by reaching out to patients when they ran into them in the halls and outside of the clinic [FQHC1, RHC2]. In FQHC2, the physician routinely frustrated "higher ups" in the organization with how long he spent with patients, something other interviewees in FQHC2 praised him for. They said that this time spent shows patients that "he cares, he listens."

Interviewees in each clinic mentioned that their patient populations faced economic and other health issues that affected how they and their patients managed follow-up. These included opioid abuse [FQHC1, RHC2], comorbidities [RHC1], and mental illness [FQHC2]. When specific needs were identified, the RHCs had the least resources to help patients through follow-up. The nurse practitioner at RHC1 expressed it like this: "How do you tell somebody, 'You have something wrong, but I'm sorry, we can't do anything for you; you don't have money'?" She helped patients prioritize where to "allocate funds" when they could not afford to pay for all of their health needs. She also attempted to send patients to places where she knew there were

supportive services. Sometimes she gave women money for transportation out of her own pocket to help them get to these diagnostic appointments.

Step 3. Serving patients after evaluation is complete or remains incomplete.

Incomplete diagnostic evaluation. Across the case studies, interviewees identified a number of constraints that patients faced that led them to not complete follow-up. Interviewees focused especially on the constraints due to poverty, the “financial part” of follow-up, and they identified that people had to prioritize expenses for themselves and their families. As an interviewee in RHC2 told us, a copay of \$2.00 could be a “pretty significant” expense for the people they serve. The financial aspect of follow-up was also gendered, and women patients, according to one interviewee, at times felt that “they shouldn’t use [money] or waste [money] on themselves” [FQHC1]. All interviewees conveyed the constraints they faced in serving their patients financial and psychosocial needs, including concerns that patients would not reveal to them the extent of their needs [RHC2], and that this affected whether a patient completed diagnostic evaluation.

Both RHCs also expressed concerns that their patients might “fall through the cracks” because of their (lack of) tracking systems for missed appointments. Interviewees at RHC2 said that they often did not find out that a patient did not have a diagnostic appointment until the patient came in for their next visit. While they said that they had talked amongst themselves (prior to our site visit) about the need for a tracking system, they doubted that they had the “man power” to implement one more thing in addition to what they were already doing.

Because there were limits to the amount of assistance all sites could offer, they needed patients to take responsibility, something reinforced by the number of survey respondents who identified patients as responsible for managing themselves through diagnostic evaluation (FQHC 70%, RHC 78%). While we are wary of giving too much weight to the differences between FQHC and RHC survey response, our qualitative research would suggest that RHCs relied on respondents to take greater responsibility, given the limits on their resources.

Cancer and noncancerous findings. Our survey did not ask about primary care roles after diagnostic resolution, but the interviewees identified how they saw their roles after resolution. All clinics wanted to know the outcome to keep in their charts for future visits. These results informed how they approached follow-up when women had repeat abnormal screening mammograms. For example, one interviewee said that women who had a previous abnormal screening mammogram, but who were not diagnosed with cancer, were easier for her to talk to about follow-up testing because these women were less concerned.

Cases in which cancer was found made an impression on interviewees, even though primary care sites were not involved directly in treatment. As one interviewee put it, “By the time they reach oncology, they’re sort of out of our grasp” [FQHC2]. Still, all interviewees emphasized that they and their clinics wanted to stay informed about their patients’ treatment. In FQHC1, this was partially because they wished to advise patients about their treatment options and the providers and procedures to seek out or avoid. Interviewees also wanted to keep apprised of their patients’ treatment “to know what our patients are going through” [FQHC2]. They expressed this desire because knowing their patients’ treatment helped them provide better health care and also because they cared about them. In a small town atmosphere, a patient undergoing treatment might stop by

just to talk and, during these times, the staff and clinicians' role was to "cheer her up" when she was having a "bad day" [FQHC1].

DISCUSSION

Our research examined the roles that primary care providers in rural areas played in breast cancer prevention and control. We synthesized our quantitative and qualitative research and compared and contrasted the findings to (1) identify the types of roles that rural primary care sites took in follow-up and (2) describe these roles. As our data show, clinic staff identify themselves as responsible for ensuring that women receive follow-up. They are involved throughout the process, from receipt of the abnormal screening mammogram to care for the patient after diagnostic completion (or when it is not completed). We divided their expressed responsibilities into three categories of involvement based on our results: (1) receiving test results from referral (mammography) provider, (2) managing patients through diagnostic evaluation, and (3) serving patients after evaluation is complete or remains incomplete. The receipt of screening mammogram results initiated their role in follow-up, something all interviewees identified as a call to action.

This study has several important implications for rural cancer prevention and control. First, there is strong evidence to suggest that effective tracking systems increase the likelihood of resolving abnormal test results (Baron et al., 2010; Wei et al., 2005; J. M. Zapka et al., 2014). Our case studies affirmed that having adaptable tracking and follow-up systems assisted clinics in identifying the women who had missed appointments or for whom referral sites did not send reports, and also that a lack of systems made identification difficult. The RHCs both expressed a desire to implement or improve tracking systems and also worries that the women they served were at risk of falling through the cracks or having delays in their diagnoses. This was partially why the nurse practitioner at RHC1 tried to shift women into specialist care more fully after an abnormal cancer finding and why the receptionist took so much time with patients to find an appointment that she thought they would be able to keep. In effect, even in the absence of formalized tracking systems, the RHCs were devising solutions. An adaptable tracking intervention could build on these solutions. Rather than disregarding the existing solutions and variation, we might acknowledge that all tracking systems must be adaptable to the context and setting (Bauman et al., 2018; Chambers & Norton, 2016). For example, interviewees at FQHC2 made evident that even the best EMR system could present problems where there was no steady Internet connection.

Second, there were some differences between how rural FQHCs and RHCs approached follow-up after receiving an abnormal mammogram result. These differences cut across the three categories we presented. The rural FQHCs had more formalized staff (e.g., case managers) and processes (e.g., tracking systems) to assist women in navigating or overcoming barriers to completing diagnostic resolution. The Health Resources and Services Administration requires FQHCs to provide preventative health, case management services, and to maintain quality assurance programs (Health Resources and Services Administration, 2016), and FQHCs qualify for federal grants that cover costs to support services (e.g., transportation) that RHCs do not (Committee on the Future of Rural Health Care, 2005). The case managers in the FQHCs described taking on roles similar to those of patient navigators (Dohan & Schrag, 2005; Freund et al., 2014; Krok-Schoen et al., 2015; Lobb, Allen, Emmons, & Ayanian, 2010). Given the extreme lengths to

which it seemed that the interviewees at the RHCs were going and the burdens they faced, it would be difficult to expect RHCs to implement formalized processes or become more fully involved in follow-up processes without resources similar to the FQHCs. However, our research suggests that the formalized systems in the FQHCs and the access to more resources did not solve the problems. For some interviewees, it opened up a new set of problems when the systems fit uneasily in the rural context.

Third, while there were apparent differences between FQHCs and RHCs, there were also similarities. For example, all clinics were serving women who were dealing with extensive health and financial needs. All clinics faced limits to what they could do and the resources they could identify to assist women. The additional resources and personnel in FQHCs were beneficial, but all clinics could still identify women who did not complete diagnostic follow-up. All sites described locally-developed strategies to assist women achieve diagnostic completion, such as reminding women of appointments when they ran into them in the community, giving money out of their own pocket, strategically referring women to sites connected to assistance programs, and helping women decide what health care they needed and what health care they could delay. They did so with very few resources, and it often fell to clinical staff and front desk staff, who were already overworked, to try to deal with a range of needs. Though we have no way of knowing due to the constraints of this research project, certain locally-developed solutions likely did assist some women receive care.

Finally, the qualitative interviews suggest a lack of trust that women would receive their results and other information they needed from some referral providers. This may be due to the level of poverty in the region, where people are difficult to reach by phone or by mail (Muthukrishnan et al., 2018). Further, the interviews led us to expand the category of ‘completion’ to go beyond diagnostic resolution. Interviewees expressed a desire to remain knowledgeable about the women’s experiences with hospitals and specialists. They said that it helped them care for patients’ multiple health needs, including, but not limited to those related to cancer prevention. Having such knowledge also enabled them to care for the woman in other ways, such as through giving her comfort or cheering her up.

There are limitations to our study. First, we focused exclusively on primary care clinic providers and staff, and we do not know whether the women found the navigation and communication strategies used in each clinic to be helpful. Likewise, we did not interview staff in referral sites, who may have had different perspectives of their own roles and the roles of primary care providers. Second, we were unable to assess patient records and, therefore, do not know the actual rates of diagnostic completion at each clinic. Finally, while we had a high response rate for our survey in general, there was a much lower response rate among the RHCs than among FQHCs, something that may further demonstrate the work burdens RHCs face in the region, which leave staff with little time for external activities that take them away from their daily duties.

CONCLUSION

Our research has shown that both FQHCs and RHCs are involved in follow-up to abnormal mammography, and we identified three categories in which they discussed the most involvement: receiving tests results from referral providers, managing patients through diagnostic resolution, and serving patients after evaluation is completed or remains incomplete. The roles and strategies

taken by staff at primary care sites, and the settings and contexts in which such roles and strategies arise, clearly must be considered when introducing policy and programmatic changes to promote diagnostic completion. While there is a substantial evidence base for certain interventions (e.g., tracking systems, navigation), these are not and should not be treated as one-size-fits-all approaches. Further, many interventions have been developed and tested much more frequently in urban environments. Partnering with rural primary clinics to understand the reality of their system and the formal and informal strategies they have developed to assist their specific patient populations is a vital first step.

ACKNOWLEDGEMENTS

We are grateful to all of the clinics that participated in this study and to the Missouri Primary Care Association, Missouri Department of Health and Senior Services Office of Primary Care and Rural Health, the Missouri Association of Rural Health Clinics, and the American Cancer Society Primary Care Health Systems and Hospitals Divisions for advising us on the project. The research was supported by a grant from the American Cancer Society (MRSO-13-153-01-CPPB). Drs. Hunleth and James also received support from the Siteman Cancer Center and Foundation for Barnes Jewish Hospital.

REFERENCES

- Baron, R. C., Melillo, S., Rimer, B. K., Coates, R. J., Kerner, J., Habarta, N., . . . Task Force on Community Preventive, S. (2010). Intervention to increase recommendation and delivery of screening for breast, cervical, and colorectal cancers by healthcare providers a systematic review of provider reminders. *Am J Prev Med*, 38(1), 110-117. doi:10.1016/j.amepre.2009.09.031
- Bauman, A. A., Cabassa, L. J., & Stirman, S. W. (2018). Adaptation in dissemination and implementation science. In R. C. Brownson, G. A. Colditz, & E. K. Proctor (Eds.), *Dissemination and Implementation Research in Health* (Second ed., pp. 285-300). New York: Oxford University Press.
- Chambers, D. A., & Norton, W. E. (2016). The adaptome: advancing the science of intervention adaptation. *Am J Prev Med*, 51(4 Suppl 2), S124-131. doi:10.1016/j.amepre.2016.05.011
- Charlton, M. E., Mengeling, M. A., Halfdanarson, T. R., Makki, N. M., Malhotra, A., Klutts, J. S., . . . Kaboli, P. J. (2014). Evaluation of a home-based colorectal cancer screening intervention in a rural state. *J Rural Health*, 30(3), 322-332. doi:10.1111/jrh.12052
- Committee on the Future of Rural Health Care. (2005). Quality Through Collaboration: The Future of Rural Health Care. *Institute of Medicine Report*.
- Crossing the Quality Chasm: A New Health System for the 21st Century*. (2001). United States of America: Committee on Quality of Health Care in America. Institute of Medicine. National Academy of Sciences.
- Damschroder, L. J., Aron, D. C., Keith, R. E., Kirsh, S. R., Alexander, J. A., & Lowery, J. C. (2009). Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. *Implement Sci*, 4, 50. doi:10.1186/1748-5908-4-50

77 Rural Primary Care and the Diagnostic Resolution of Abnormal Screening Mammograms: A Mixed Methods Study in Rural Missouri
Hunleth et al.

- Dohan, D., & Schrag, D. (2005). Using navigators to improve care of underserved patients: current practices and approaches. *Cancer, 104*(4), 848-855. doi:10.1002/cncr.21214 [doi]
- Freund, K. M., Battaglia, T. A., Calhoun, E., Darnell, J. S., Dudley, D. J., Fiscella, K., . . . Paskett, E. D. (2014). Impact of patient navigation on timely cancer care: the Patient Navigation Research Program. *Journal of the National Cancer Institute, 106*(6). doi:10.1093/jnci/dju115
- Health Resources and Services Administration. (2016). Summary of Program Requirements. Retrieved from <http://bphc.hrsa.gov/programrequirements/summary.html>
- James, C. V., Moonesinghe, R., Wilson-Frederick, S. M., Hall, J. E., Penman-Aguilar, A., & Bouye, K. (2017). Racial/ethnic health disparities among rural adults - United States, 2012-2015. *MMWR: Surveillance Summaries, 66*(23), 1-9. doi:10.15585/mmwr.ss6623a1
- Krok-Schoen, J. L., Brewer, B. M., Young, G. S., Weier, R. C., Tatum, C. M., DeGraffinreid, C. R., & Paskett, E. D. (2015). Participants' barriers to diagnostic resolution and factors associated with needing patient navigation. *Cancer*. doi:10.1002/cncr.29414
- Lee, S. C., Higashi, R. T., Sanders, J. M., Zhu, H., Inrig, S. J., Mejias, C., . . . Tiro, J. A. (2018). Effects of program scale-up on time to resolution for patients with abnormal screening mammography results. *Cancer Causes Control, 29*(10), 995-1005. doi:10.1007/s10552-018-1074-4
- Leung, J., McKenzie, S., Martin, J., & McLaughlin, D. (2014). Effect of rurality on screening for breast cancer: a systematic review and meta-analysis comparing mammography. *Rural Remote Health, 14*(2), 2730.
- Levy, B. T., Xu, Y., Daly, J. M., & Ely, J. W. (2013). A randomized controlled trial to improve colon cancer screening in rural family medicine: an Iowa Research Network (IRENE) study. *J Am Board Fam Med, 26*(5), 486-497. doi:10.3122/jabfm.2013.05.130041
- Lobb, R., Allen, J. D., Emmons, K. M., & Ayanian, J. Z. (2010). Timely care after an abnormal mammogram among low-income women in a public breast cancer screening program. *Archives of Internal Medicine, 170*(6), 521-528. doi:2010.22 [pii] 10.1001/archinternmed.2010.22 [doi]
- Moore, J. X., Royston, K. J., Langston, M. E., Griffin, R., Hidalgo, B., Wang, H. E., . . . Akinyemiju, T. (2018). Mapping hot spots of breast cancer mortality in the United States: place matters for Blacks and Hispanics. *Cancer Causes Control*. doi:10.1007/s10552-018-1051-y
- Muthukrishnan, M., Sutcliffe, S., Hunleth, J. M., Wang, J. S., Colditz, G. A., & James, A. S. (2018). Conducting a randomized trial in rural and urban safety-net health centers: added value of community-based participatory research. *Contemp Clin Trials Commun, 10*, 29-35. doi:10.1016/j.conctc.2018.02.005
- Norris, L. (2018). Missouri and the ACA's Medicaid expansion. *Healthinsurance.org*, (October 25, 2018). Retrieved from
- Office of Rural Health Policy. (2006). *Comparison of the Rural Health Clinic and Federally Qualified Health Center Programs*. Retrieved from Available from URL: <http://www.hrsa.gov/ruralhealth/policy/confcall/comparisonguide.pdf>:

78 Rural Primary Care and the Diagnostic Resolution of Abnormal Screening Mammograms: A Mixed Methods Study in Rural Missouri
Hunleth et al.

- Overholser, L., Zittleman, L., Kempe, A., Bublitz Emsermann, C., Froshaug, D. B., Main, D. S., . . . Westfall, J. M. (2009). Use of colon cancer testing in rural Colorado primary care practices. *J Gen Intern Med*, *24*(10), 1095-1100. doi:10.1007/s11606-009-1063-0
- Pruitt, S. L., Eberth, J. M., Morris, E. S., Grinsfelder, D. B., & Cuate, E. L. (2015). Rural-urban differences in late-stage breast cancer: do associations differ by rural-urban classification system? *Tex Public Health J*, *67*(2), 19-27.
- Rim, S. H., Zittleman, L., Westfall, J. M., Overholser, L., Froshaug, D., & Coughlin, S. S. (2009). Knowledge, attitudes, beliefs, and personal practices regarding colorectal cancer screening among health care professionals in rural Colorado: a pilot survey. *J Rural Health*, *25*(3), 303-308. doi:10.1111/j.1748-0361.2009.00234.x
- Robert Wood Johnson Foundation. (2018, October 25, 2018). County health rankings and roadmap.
- Singh, G. K., & Siahpush, M. (2014a). Widening rural-urban disparities in all-cause mortality and mortality from major causes of death in the USA, 1969-2009. *J Urban Health*, *91*(2), 272-292. doi:10.1007/s11524-013-9847-2
- Singh, G. K., & Siahpush, M. (2014b). Widening rural-urban disparities in life expectancy, U.S., 1969-2009. *Am J Prev Med*, *46*(2), e19-29. doi:10.1016/j.amepre.2013.10.017
- Taplin, S. H., Ichikawa, L., Yood, M. U., Manos, M. M., Geiger, A. M., Weinmann, S., . . . Barlow, W. E. (2004). Reason for late-stage breast cancer: absence of screening or detection, or breakdown in follow-up? *Journal of the National Cancer Institute*, *96*(20), 1518-1527.
- Taplin, S. H., Yabroff, K. R., & Zapka, J. (2012). A multilevel research perspective on cancer care delivery: the example of follow-up to an abnormal mammogram. *Cancer Epidemiology, Biomarkers and Prevention*, *21*(10), 1709-1715. doi:10.1158/1055-9965.epi-12-0265
- U.S. Cancer Statistics Working Group. (2018). U.S. Cancer Statistics Data Visualizations Tool, based on November 2017 submission data (1999-2015). Retrieved from www.cdc.gov/cancer/dataviz website:
- U.S. Department of Health and Human Services, Office of Rural Health Policy. Comparison of the Rural Health Clinic and Federally Qualified Health Center Programs. (2006). Retrieved from <http://www.hrsa.gov/ruralhealth/policy/confcall/comparisonguide.pdf>
- United States Census Bureau. (2019). QuickFacts. Retrieved April 15, 2019
- Wei, E. K., Ryan, C. T., Dietrich, A. J., & Colditz, G. A. (2005). Improving colorectal cancer screening by targeting office systems in primary care practices: disseminating research results into clinical practice. *Archives of Internal Medicine*, *165*(6), 661-666. doi:10.1001/archinte.165.6.661
- Zahnd, W. E., Jenkins, W. D., James, A. S., Izadi, S. R., Steward, D. E., Fogleman, A. J., . . . Brard, L. (2018). Utility and generalizability of multi-state, population-based cancer registry data for rural cancer surveillance research in the United States. *Cancer Epidemiol Biomarkers Prev*. doi:10.1158/1055-9965.EPI-17-1087
- Zapka, J., Taplin, S. H., Anhang Price, R., Cranos, C., & Yabroff, R. (2010). Factors in quality care—the case of follow-up to abnormal cancer screening tests—problems in the steps and interfaces of care. *Journal of the National Cancer Institute. Monographs*, *2010*(40), 58.

79 Rural Primary Care and the Diagnostic Resolution of Abnormal Screening Mammograms: A Mixed Methods Study in Rural Missouri
Hunleth et al.

Zapka, J. M., Edwards, H. M., Chollette, V., & Taplin, S. H. (2014). Follow-up to abnormal cancer screening tests: considering the multilevel context of care. *Cancer Epidemiology, Biomarkers and Prevention*, 23(10), 1965-1973.

Zittleman, L., Emsermann, C., Dickinson, M., Norman, N., Winkelman, K., Linn, G., & Westfall, J. M. (2009). Increasing colon cancer testing in rural Colorado: evaluation of the exposure to a community-based awareness campaign. *BMC Public Health*, 9, 288. doi:1471-2458-9-288 [pii] 10.1186/1471-2458-9-288 [doi]