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Strategies Used and Challenges Faced by a Breast Cancer Patient Navigator in an Urban Underserved Community

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Abstract

Patient navigation has been widely implemented by cancer care programs across the United States. While activities of navigators have been described elsewhere, little has been documented regarding specific strategies used or challenges experienced by navigators from their own perspectives. We describe the experience of an African American patient navigator who promoted breast cancer screening and facilitated diagnosis and treatment among inner-city mostly African American women in Newark, New Jersey. We conducted qualitative analysis of journal notes, log data, and in-depth interviews with the patient navigator. Strategies used by the patient navigator to develop trust and rapport included: (1) "meet patients where they are" (outreach is best performed in locations women frequent, such as hair salons); (2) being accessible (must be flexible and available by phone or in person to meet patient's needs); and (3) "bring it down, sista" (must have "street credibility" in dress and language). Key challenges included experiencing threats to safety, setting boundaries, and facing and overcoming burnout. The patient navigator responded to these obstacles by creating new community linkages and resources and reaching out for emotional support from her mother and supervisor. Areas that need to be addressed further for future patient navigator programs include promoting safety in potentially dangerous neighborhoods and helping navigators set boundaries and avoid burnout. Further research into experiences of patient navigators in different settings is needed to build upon this preliminary data, and to consider character traits and attributes best suited for a patient navigator, as well as the support needed for this new health care worker.

Keywords

breast cancer; minority health; urban population; health care

INTRODUCTION

Since Dr Harold Freeman first introduced the concept of a patient navigator at Harlem Hospital[1] in 1990, patient navigation has been widely implemented by cancer care programs across the United States to help eliminate disparities in cancer outcomes among underserved populations.[2,3] While the role of the patient navigator may vary in different clinical settings, it has generally been described as someone who provides education and emotional support to patients and assists them in overcoming barriers to cancer screening, diagnosis, and treatment.[2,3] Patient navigation has been associated with increased cancer screening and

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follow-up rates, improved timeliness in follow-up and diagnosis of abnormal screening tests, lower breast cancer stage at diagnosis, decreased anxiety, and higher patient satisfaction among vulnerable populations.[1,4–19]

Much has been described regarding services patient navigators provide to help patients overcome barriers to cancer screening, diagnosis, and treatment. Patient navigators address social, economic, cultural, behavioral, and systems barriers to receiving timely access to quality cancer care. They conduct an assessment of patient's individual needs, provide education, psychosocial support and advocacy, arrange financial assistance and social services, and coordinate medical appointments and cancer care.[2,3,20] While the role of patient navigator has been filled by nurses, social workers, health educators, or lay persons, critical attributes of a patient navigator have been defined as

> an individual who (1) facilitates access to care, (2) is a skilled communicator and listener, (3) is knowledgeable of the cancer system and resources in which they work, (4) acts as an empathic patient advocate, and (5) provides information and education.[21]

Despite the plethora of attention given to patient navigator programs, little has been documented regarding how patient navigators perform their duties, particularly the specific strategies they use in the field or challenges they face from their own perspective. We describe the personal account, barriers faced, and responses to challenges of a patient navigator in promoting breast cancer screening and facilitating diagnosis and treatment among urban mostly African American women. Findings from this paper will inform future patient navigator programs in underserved areas.

METHODS

This is a descriptive case study of 1 patient navigator serving mostly African American women in an inner-city, underserved community and university public safety-net hospital in Newark, New Jersey. The patient navigator was an African American female who provided breast cancer outreach and education in the community and navigated women with suspicious mammogram results through diagnosis and treatment. Qualifications and training of this patient navigator have been reported previously.[17] Briefly, this patient navigator has a bachelor degree in social relations and previous experience as a breast cancer support group volunteer, youth advocate, and habilitation counselor, but no prior experience as a patient navigator. Our previous randomized controlled trial found that among women with suspicious mammograms, this patient navigator program significantly improved timeliness to diagnosis, decreased anxiety levels, and increased patient satisfaction.[17] This current study is a retrospective analysis of data recorded by the patient navigator from April 2005 to September 2008 to better understand what led to the success of this program, particularly the strategies the patient navigator used and challenges she faced from her own perspective. This study was approved by the institutional review board of University of Medicine and Dentistry-Robert Wood Johnson Medical School.

Data Sources

The patient navigator maintained logs on patients she navigated, which included the number and types of contacts made; the barriers the women faced; the services she provided; whether or not the woman had been diagnosed with cancer; and basic demographic information, such as age, race, and insurance status. She wrote more detailed diaries on cases requiring more time and effort. These navigator logs and diaries were deidentified with no link to the subjects prior to analysis. In addition, 3 face-to-face in-depth interviews with the navigator were conducted to expand or clarify information in the logs and diaries.

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Data Analysis

The analysis strategy used a grounded theory approach involving a series of immersion/crystallization cycles.[22] This approach involves immersing oneself in the data through cycles of readings and reflections, gaining emergent insights and themes, until reportable interpretations became apparent and crystallized. Initially, each research team member (J.F., J.W., B.D.) read and coded the logs and diaries independently. We then met in person to review initial coding schemes, agree on themes, and conduct preliminary interpretive comparative patient case analyses. To clarify or expand on the information and themes emerging from the logs and diaries, 3 in-depth interviews were conducted with the patient navigator. These interviews were audiotaped and transcribed verbatim, and transcripts were read and coded independently using the initial coding schemes. The team then met to discuss interpretations and to refine coding schemes as needed. Data within codes were reread and analyzed independently in a second immersion/crystallization cycle. Subsequent analysis meetings focused on new themes that emerged and on relationships among the themes as well as on differences in interpretation. Following these meetings, data segments were retrieved, sorted, and summarized using an editing style of data analysis, and emergent themes and interpretations were refined. The quotations included in this paper most represent the study’s key findings.

RESULTS

During April 2005 to September 2008, the patient navigator provided educational outreach to 5838 women through presentations at health fairs, churches, senior centers, beauty salons, drug stores, laundromats, homeless shelters, community centers, schools, and apartment buildings. The patient navigator provided navigation services to 343 women with suspicious mammogram results (American College of Radiology Breast Imaging and Reporting Data Systems) of 4 (suspicious abnormality) or 5 (highly suggestive of malignancy), guiding them to obtain diagnostic testing. For 86 women diagnosed with breast cancer, the patient navigator provided treatment support. Her main activities were similar to what has been described elsewhere[3,17,20] and included providing education and emotional support, arranging financial assistance and social services, improving communication between patients and health care providers, facilitating compliance with appointments, and linking patients to educational and community resources. Making home visits was key in the patient navigator’s ability to convince 32 out of 47 patients who were not compliant with breast cancer treatments to return to treatment.

We identified several themes that resonated throughout her experience as a first-time patient navigator in a new role. The following section describes the strategies she used to develop trust and rapport with these under-served women, followed by key challenges she faced and her responses to these obstacles.

Strategies Used by Patient Navigator to Develop Trust and Rapport

Meet the women where they are—The patient navigator initially performed educational presentations at churches and health fairs but quickly realized that “the women (at risk of) dying of breast cancer were not the women who are in attendance at health fairs.” She therefore began making presentations where women in this community tend to be: at beauty shops, nail salons, and laundromats within Newark. Most poignantly, the patient navigator described being welcomed into patients’ homes where she was able to witness and comfort patients during difficult, personal events. “Meeting women where they are” ultimately allowed the patient navigator to build rapport and trust with women in this underserved community and facilitated her assessment of their needs.

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> I go into the homes. I see sometimes it's not the healthiest living situation. I see the bare cabinets. I see them when they're upset because their child didn't come home, so I tend to get very close to some of the patients…I've gone over and the family was there and the patient's upset, it's the day before surgery, and I've sat down and spoke to their family and reassured their family. There's been times where I've been invited over for Sunday dinner.

"Meeting women where they are" also meant tackling women's most pressing social needs first prior to addressing compliance with breast cancer diagnostic testing or treatments.

> Sometimes it's like a crisis situation where, "I'm in the middle of chemotherapy and I'm being evicted…and I have no transportation." Of course they have no transportation, so then I will say, "I'll come and get you and we'll go to social services." She also needed food stamps…Her grandchild was coming to move back with her. So the food stamps that they gave her just weren't enough to cover it. So we went down (to social services) and it was very difficult. And we actually had to go down there about 3 times and then she was awarded additional monies for food stamps.

Be accessible—Being accessible was a key function of the patient navigator. She spent intensive time and energy accompanying patients to appointments and social service offices, as well as performing social services herself, such as bringing patients food from the food bank and driving them to buy wigs. Often, the patient navigator answered telephone calls during weekends or late at night.

> Patients will call many times on weekends, evenings, early mornings…Sometimes I have to be available on the weekends…Saturday mornings are the best days to find a patient who is noncompliant (with treatment)."

Bring it down, sista—The patient navigator learned early on that possessing "street credibility" was critical to establishing trust and rapport with women. She describes wearing traditional business attire and speaking formally during her first interactions with clients. Women quickly pointed out the need for her to "bring it down, sista," and speak "street" language and wear "street" clothes.

She stated that she needed me to "keep it real, and take it down." She did not want a person who acted like a member of the staff; she wanted a "sista" who acted like a friend from the neighborhood. It is not enough that I am a black woman. To connect with these women, I must be black and on their level…[This patient] *calls me from time to time and still teases me about how I spoke "white" when we first met.*

Challenges Faced by Patient Navigator

Experiencing threats to safety—Working in the field in this urban community posed several dangers. The patient navigator knew how to evade gang-related activity, such as by avoiding wearing certain colors, speaking back when spoken to, and not asking for directions. However, she was attacked by a stray dog once and also robbed at gunpoint in broad daylight. Another time, when she and some volunteers went to an apartment building to pass out literature about mammograms, they were told by management not to go up to the apartments due to a string of robberies.

> Men or women were blocking the staircases with carts or junk…forcing you to take the elevator…When the elevator doors opened, you were being robbed at knifepoint.

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Additionally, the patient navigator was sometimes threatened when dealing with patient's family members.

> She has breast cancer and her husband doesn't want her to get a lumpectomy or a mastectomy, nothing… She had snuck and called me a couple of times and she said, "Well I want to live so I want a mastectomy but my husband is totally against it." He found out that she was speaking to me and he actually called me and told me to never speak to his wife again, that I'm sabotaging his relationship and he really really just exploded.

Setting boundaries—Due to the intensive time and energy needed to develop trust and rapport, the patient navigator struggled at times with setting boundaries with patients while promoting compliance.

> They do call (on weekends), they are upset. I know if they have a Monday or Tuesday appointment, if they had a bad weekend, or if they had a bad night, they're not gonna go…And it's harder to get them back into another appointment, vs just calling them back that night and trying to calm them down and talk to them.

She soon realized that making call backs at the end of the day or calling women regularly on a weekly basis helped to set boundaries.

> Women who are going through breast cancer, the majority of them really don't have any support. A lot of women are single women. They don't have a husband. Many of them don't have kids or are raising their grandkids and so I'm their source of support. And so if I don't call them for a week, they'll be calling me.

Facing and overcoming burnout—Given the emotional and physical demands of her job, the patient navigator described occasional feelings of discouragement, frustration, and futility.

> Sometimes I just feel like I just can't do everything…it just seems like you're helping the same people over and over again. You're not getting anywhere, just new issues. Not necessarily just with breast cancer, but this community that I work for has so many other things that they're dealing with, that sometimes it just feels like you're running on a treadmill and not getting anywhere.

Furthermore, she admonishes that a patient navigator must have resilience in order to perform her duties.

> You have to be resilient. There's people that's gonna work the system and they're gonna work you too. And sometimes it's hard, you need tough skin. I've been cussed out many many times. I've been through a lot and you have to be able to take your hits.

Patient Navigator's Responses to Challenges

Creating new linkages—The patient navigator not only linked women to preexisting services, she was resourceful and creative in forming new linkages to assist her in meeting patients' needs. For example, when a patient was sleeping on the floor without sheets, the patient navigator contacted a linen store, who donated linens, towels, rugs, and pillows. For another homeless breast cancer patient who she assisted in obtaining subsidized housing, the patient navigator organized a furniture drive with a breast cancer support group to donate furniture. She also "signed her up for Toys for Tots so that her children would have a good Christmas." For another 41-year-old woman, with stage 4 breast cancer, she obtained help through a church:

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> I contacted a local church that I went to for health fairs and spoke with the assistant pastor about her condition and what the church could do to help. Women from the church cooked dinner twice a week and went to clean the home and wash clothes once a week. She died in her home alone. Her husband called me. I went over to grieve with the family. Her husband and mother requested for me to speak at the funeral.

Forming a volunteer network—The patient navigator established a peer network of approximately 24 volunteers consisting of other breast cancer patients and women from the community. These volunteers helped relieve some of the time that would be required of the patient navigator in providing education and emotional support to patients.

> A lady diagnosed with breast cancer went through her first, second bout of chemotherapy and then all her hair came out. And so she was very, very upset. And so I asked her permission to call another patient who's going through the same thing, whose hair just started growing back. It started off as her being very, very sad, the next thing I know, her and the volunteer was laughing and "you're hair's gonna grow back" and the lady was saying "I didn't realize, I knew my hair on my head would go away but I didn't realize all bodily hair was gonna come out." So they were joking about that…and the volunteer went with her to the wig supply store…and they still call each other to this day.

Other volunteers assisted her in feeling safe in the field. For example, before performing outreach at an apartment building in the "projects," she recruited a volunteer from that building.

> Someone that lived in that building that was called "grandma" was actually a volunteer with me. And so because they knew her, they were receptive…She was a well-known older lady, she's lived there for something like 20 years, she said she's seen it all so she wasn't very frightened.

Reaching Out for Support

The patient navigator received energy and support from her mother and her supervisor. Her mother was a breast cancer survivor and activist who founded an affiliate chapter of a national African American breast cancer support network. It was through her mother and this organization that the patient navigator was socialized as a helper, learned to deal with pain, and received encouragement and emotional support. The patient navigator's supervisor allowed her to be creative and defended her activities to other hospital personnel, who commented that the patient navigator rarely showed up in the office and was not professionally dressed. Her supervisor responded that she would not be doing her job properly if she was in the office and dressed in professional clothing. Since this was a new role, the patient navigator was not limited by previous institutionalized structures.

> When I first got here, I think everyone has in mind what the community is like. But it's a lot different when you're out there, and (my supervisor's) allowed me to hit the pavements and really go out there and see firsthand what the community needs…You definitely need good support from your superior, someone who's gonna fight for you.

Her supervisor also helped her in setting limits, such as returning phone calls at the end of the day or directing patients to other social services.

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DISCUSSION

This is the first description of experiences and specific strategies used by a patient navigator from her own perspective. While most patient navigator literature focus on patient barriers and describe general functions related to the patient navigator role, our account is navigator focused and details specific challenges the patient navigator faced. We are also the first to report the issue of vulnerability and safety in the field for these workers. Although this case study is limited by the perspective of a single patient navigator, the richness of the data provides in-depth insight into what navigators experience on a day-to-day basis. Case studies are also useful for "developing context-specific predictions, plans, and decisions."[23]

Patient navigation is being widely implemented to help decrease disparities in cancer outcomes in vulnerable populations.[2,3] While there is controversy on whether the patient navigator should be a nurse,[21] social worker,[24] or lay person,[25] we argue that the patient navigator's background is not as important as the attributes needed to be a successful navigator in this setting: being accessible, nonjudgmental, resilient, dedicated, creative, patient, and knowledgeable of the community. While a national standardized training program for patient navigators was recently created,[26] accounts like ours, with documentation of specific navigator strategies and challenges, will help guide the evolution of this new health care worker.

There are several issues revealed from this research that should be addressed further when implementing patient navigator programs in urban, underserved areas. Of utmost importance is preventing violence and promoting safety. Like other home care workers, patient navigators who visit patients' homes are at risk of violence from patients or household members, community crime, and hostile animals. Patient navigators typically work alone and do not have the traditional safety protections present in hospital and other institutional settings (eg, security guards, alarm systems, video surveillance, controlled entry).[27] In a recent study, up to 61% of home care workers experienced verbal abuse, while almost 11% had been physically assaulted.[28] These exposures to violence are associated with physical injuries and significant psychological distress.[29–31] Employer safety policies and specific strategies promoting safety may decrease risks of verbal and physical violence in home care workers.[28] These include: having a written safety policy and providing safety training on violence prevention (eg, risk factors for assault, how to handle hostile patients and family members, ways to de-escalate verbal abuse, how to shorten or abandon the visit, visiting during a safer time of day); assessing home visit risks; providing cell phones, security escorts or paired visits for high-risk visits; collecting statistics on threatening and unsafe situations; having mandatory periodic check-ins with the office; and having staff and management jointly involved in developing safety management systems.[28,32]

Another issue to address proactively when implementing patient navigator programs is helping patient navigators set boundaries. The fact that our patient navigator was not working within a formalized workspace or time schedule gave her the flexibility to be in the field, responding spontaneously to patients' needs. However, this also enabled her to perform activities that were outside the scope of navigation activities. Other home care workers have also experienced demands for services that were outside of their job descriptions, such as requests for cooking, cleaning, lifting furniture, or performing laundry services.[31] While being accessible, developing relationships, and meeting patients' immediate needs were paramount to her success, the patient navigator recognized the need for creating a better separation between her work life and her personal life. Having a team of patient navigators to share the burden may be needed, but this greater expense may be prohibitive for some programs. Supervisors have important roles in guiding the patient navigators to set boundaries by limiting activities to those supporting the goals of patient

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navigation and referring patients to other community resources (ie, social workers) when needed. Prospectively planning for the optimal activities of the patient navigator in the local environment would more clearly define the patient navigator's role.

Finally, helping patient navigators avoid burnout is needed to sustain these roles and programs. Many centers may only have 1 person as a patient navigator in a new role, which puts the patient navigator at risk for isolation. Forming formal networks with other patient navigators to create a social support system for debriefing and sharing challenges, as well as promoting safety policies and guidelines for setting boundaries, may help to decrease negative effects from the emotional demands of this work.[31]

Being accessible, resilient, and resourceful are key attributes for success as a patient navigator in this urban underserved community. Areas that need to be addressed for future patient navigator programs in this setting include ensuring safety when working in potentially dangerous neighborhoods and helping navigators set boundaries and avoid burnout. Further research into experiences of patient navigators in different settings is needed to build upon this preliminary data and to consider character traits and attributes best suited for a patient navigator, as well as the professional, organizational, and social support required for this new health care worker.

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