Lay Navigator Model for Impacting Cancer Health Disparities

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Abstract This paper recounts experiences, challenges, and lessons learned when implementing a lay patient navigator program to improve cancer care among medically underserved patients who presented in a primary care clinic with a breast or colorectal cancer abnormality. The program employed five lay navigators to navigate 588 patients. Central programmatic elements were the following: (1) use of bilingual lay navigators with familiarity of communities they served; (2) provision of training, education, and supportive activities; (3) multidisciplinary clinical oversight that factored in caseload intensity; and (4) well-developed partnerships with community clinics and social service entities. Deconstruction of healthcare system information was fundamental to navigation processes. We conclude that a lay model of navigation is well suited to assist patients through complex healthcare systems; however, a stepped care model that includes both lay and professional navigation may be optimal to help patients across the entire continuum.

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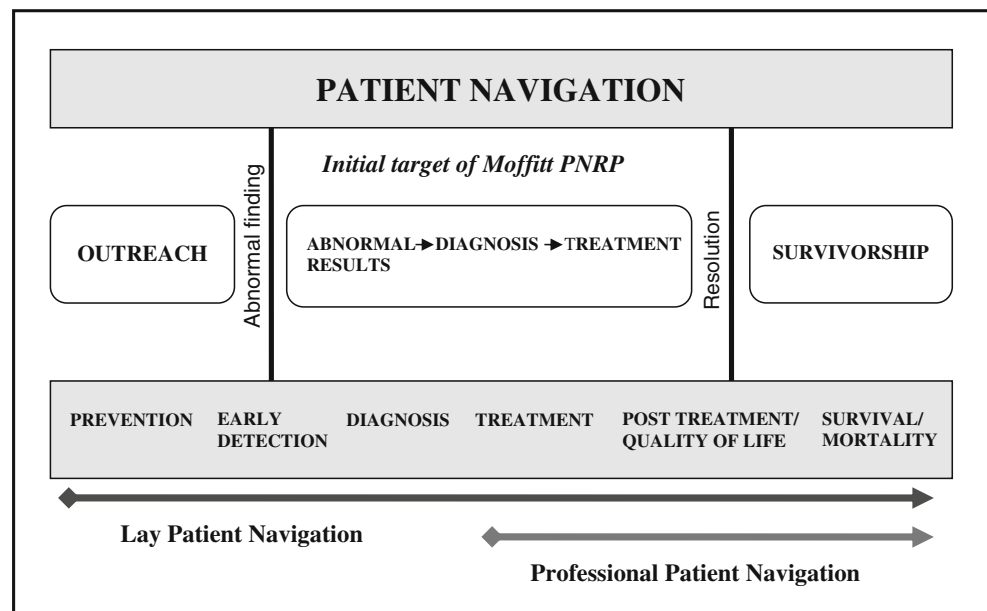K. J. Wells
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Introduction

There have been substantial advances in translating research findings into community health practices to reduce cancer risks over the past few decades. Yet, such advances are not always realized by all members of the society according to age, race, language, ethnic, and socioeconomic groups [1, 2]. The Tampa Bay region of west central Florida epitomizes this challenge, encompassing populations having low levels of education and high levels of poverty, substantial cultural diversity [3], and high cancer incidence. This combination translates to unacceptably high cancer mortality. As such, navigating through a fragmented and complex healthcare system is difficult, thereby decreasing the likelihood of favorable health outcomes and patient satisfaction. One potential solution is patient navigation, a model of healthcare coordination that focuses on reducing various barriers to achieve a particular health outcome [4–8].

At the core of patient navigation is the coordination of care achieved through individualized support and assistance in navigating required systems (e.g., financial, health, and social). Key components include promoting one-on-one contacts to aid patients, families, and caregivers to get through multifaceted health networks; providing education strategies to encourage a sense of empowerment; linking patients to community-based resources; trouble-shooting logistics to and from and within cancer treatment centers; and offering psychosocial support [4, 9]. As illustrated in Fig. 1, there are several phases in the cancer continuum in which navigation can take place, from early detection through survivorship.

The purpose of this paper is to describe patient navigation as an important asset and tool for removing impediments to

Fig. 1 Patient navigation model. This model describes the applicability of patient navigation from prevention and early detection, to survivorship efforts, and suitability of lay and professional patient navigators along the continuum. Adapted with permission from H.P. Freeman [13]

cancer care from screening abnormality to completion of cancer treatment. In the upcoming sections, we review models of patient navigation, illustrate key elements of our lay patient navigation model, and recount challenges, strengths, and lessons learned during the development of the Moffitt Patient Navigation Research Project (PNRP). Our discussions of the Moffitt PNRP draw on multiple sources of data, review of literature about patient navigation models, navigator feedback, direct observations, and patient encounter forms completed by the navigators.

Background

Description of Patient Navigation Models Several models of patient navigation have been implemented since the 1990s; each existing model varies considerably in regards to setting, approach, and integration in the healthcare system. Studies have been conducted and many are underway to determine the effectiveness of the various models of patient navigation for different settings and diseases [3, 5, 8]. Among the most common models, three have been widely identified in the literature.

Each navigation model is typically defined by the type of patient navigator who provides services. First, the professional model of patient navigation, usually located within a healthcare setting, employs professional patient navigators (e.g., social workers, nurses [usually advanced practice nurses], or health educators). Professional navigators focus on a wide variety of clinical and support services including, counseling, coordination of care, health education, communication between the patient and the healthcare team, and patient support and management services [6, 10, 11]. A second

model, lay patient navigation, utilizes lay persons from the community as patient navigators. Lay navigators receive training, tend to perform navigation in the community where the patients live and may be trained and supervised by a social worker or nurse with professional clinical supervision experience [3, 12]. The third model of navigation, advocated by Dr. Harold Freeman who created the concept of patient navigation, blends the two previously described navigation approaches [11, 13, 14]. The model is comprised of a team of lay and professional patient navigators that collaboratively assist patients from initial screening through diagnosis, treatment, and follow-up care [14]. This patient-centered model is illustrated by Ell (2009) [15] and is further supported by the Oncology Nursing Society which states that "patient outcomes are optimal when a social worker, nurse, and lay navigator function as a multidisciplinary team" [16]. Also, patient-centered navigated care is supported by the 2012 release of the American College of Surgeon's Cancer Program Standards, which calls for accredited institutions to have in place "a patient navigation process" to address healthcare disparities [17].

Methods

Characteristics of the Setting and Patients Receiving Navigation

The Moffitt PNRP represents one of nine sites, funded by the National Cancer Institute (NCI), to evaluate the efficacy of patient navigation. The evaluation of the Moffitt PNRP is published elsewhere [18]. Implemented in nine federally qualified health centers and two hospital-affiliated community

ambulatory clinics in West Central Florida, patient navigation was provided in 6 of the 11 sites. Patients who received navigation (*n*=588) were mostly from rural agricultural and urban areas. The majority were Hispanic (74 %) and Spanish speaking (69 %), and many migrated north during the summer months due to changes in the crop picking seasons (Table 1).

The description of the lay patient navigation component we recount here is part of a larger health disparities project

Table 1 Demographic characteristics of navigated patients

Characteristic	N (%)
Age range	18–89 years
Median age at detection of abnormality	42
Gender	
Female	567 (96.4)
Male	21 (3.6)
Race-ethnicity	
Black, non-Hispanic	39 (6.7)
White, non-Hispanic	109 (18.7)
Hispanic/Latina	430 (73.8)
Mixed/Other non Hispanic	5 (0.9)
Language	
English	184 (31.3)
Spanish	394 (67.0)
Haitian Creole	3 (0.5)
Indian	1 (0.2)
Portuguese	1 (0.2)
Unknown	5 (0.9)
Marital status	
Married	299 (57.2)
Education level of residence	
8th grade or less	175 (46.3)
Some high school	66 (17.5)
High school diploma (including equivalency)	92 (24.3)
Some college/vocational after high school or Associate degree or College graduate	45 (11.9)
Income	
Less than $10,000	176 (40.4)
$10,000 to $19,999	197 (45.2)
$20,000 to $29,999	54 (12.4)
$30,000 or more	9 (2.1)
Employment	
Not employed full time	332 (69.6)
Employed full time	
Insurance type	
Private insurance	21 (3.6)
Medicaid (no private or Medicare)	40 (6.9)
Medicare (no private)	21 (3.6)
Other government insurance	89 (15.4)
Uninsured	406 (70.2)

N=588

whereby it was hypothesized that a culturally appropriate patient navigator program would decrease delays in diagnostic services and the delivery of cancer treatment in an acceptable and cost-effective manner [18]. Although the Moffitt PNRP planned to evaluate the efficacy of patient navigation on the timeliness of cancer treatment, few study participants were diagnosed with cancer. As a result, the data collected to evaluate the timeliness of initiation of cancer care is being combined with other PNRP sites to evaluate this hypothesis. All study procedures were approved by the University of South Florida Institutional Review Board. Patients were navigated from time of abnormality to diagnostic resolution, and, for those diagnosed with cancer, to the end of primary cancer treatment as appropriate.

Selection and Implementation of the Moffitt PNRP Patient Navigation Model

Each patient navigation model previously described offers unique contributions in reducing cancer health disparities. After a careful consideration, our community-academic research team chose the second model of navigation, the lay patient navigation model, in which lay navigators were the centerpiece of the model, but whereby a supportive multidisciplinary team was in place [3, 18]. It was felt that lay navigators had high familiarity with the cultural background of the study populations, community resources, and key stakeholders and knew the local geography. This approach was also preferred by our community partners, participating primary care clinics, and our Community Advisory Board. In terms of day-to-day supervision, the navigators received individual and group supervision from a Masters level registered nurse, who served as their clinical supervisor and reviewed their patients' cases on an ongoing basis. Also, patient navigators were part of a multidisciplinary research team comprised of a family medicine physician, a doctorally prepared nurse, a psychologist, and a public health educator, all of whom provided the lay navigators with ongoing guidance, education, and support.

Characteristics of Navigators Drawing from Freeman's exemplar model program, [4] we sought to have patient navigators who were culturally attuned to the community; possessed strong problem solving abilities; had knowledge about community systems and resources; and most importantly, were able to connect people with required systems. Over the course of the project, four full-time and one part-time lay patient navigator were hired and trained to provide navigation. Four navigators were Spanish-English bilingual. In addition, the navigators, energized by community work, possessed important life experiences which helped them understand the culture and needs of the community. For example, all navigators were actively involved in various volunteer or civic activities within

their communities and had a strong desire to help others in need. Three navigators had previous experience being part of other health and social service teams. One navigator had experience as an outreach worker working in an urban setting and had been a missionary. Another navigator was a board member in a federally qualified health center and was also a member of a national migrant council. All navigators had completed high school, one had a bachelor's degree, and two were certified nursing assistants.

Description of Navigation Services Patient navigators worked closely with clinical staff at the community sites to identify eligible patients with breast and/or colorectal cancer abnormalities, using such methods as mammography or fecal occult blood test (FOBT) screening logs, information from referral coordinators and clinical staff, and computer searches of relevant diagnostic codes. Moreover, healthcare providers from the clinic completed a standardized referral form that was collected each week by patient navigators or faxed to PN program offices. More details on this process are found in a prior publication [18]. Once the clinic identified a patient in need of navigation, a navigator contacted and informed the patient about the program, obtained informed consent, screened for eligibility, and assessed the patient's needs and identified barriers to care. Once navigation commenced, the navigators worked with each patient to resolve barriers to care and to obtain resources required to achieve a specific health goal: (1) diagnostic resolution of the screening abnormality or (2) completion of treatment for patients diagnosed with breast or colorectal cancer. Navigators worked closely with the research team, community clinical sites, and community partners in the planning, coordination, and organization of the patient navigator program. Navigators remained in contact with the patients, the patients' family, and the patients' healthcare team throughout the course of their diagnostic and treatment care and became expert at being able to "break down" health information for patients utilizing patients' native language and familiar words. Through customized navigation strategies, guided by the nurse supervisor, it was anticipated that patients and their families would become empowered partners in their healthcare. The navigators became widely recognized as being a vibrant source of community information and support. Navigation concluded when patients had either achieved diagnostic resolution, completed recommended cancer treatment, or the patient was lost to follow-up despite multiple contact attempts.

Findings and Lessons Learned

Navigators started the navigation process by working closely and continuously with community health and social service organizations to act on the identified 10 barriers across the continuum of cancer care (Table 2). Three of the most

Table 2 Common barriers addressed in patient navigation

Barrier	Description of barrier	Patient with barrier	
		(*n*)	%
1	Insurance, being uninsured, underinsured, or dealing with co-pays	354	60.8 %
2	Fears about any aspect of medical care or their health	287	49.3 %
3	Language/interpretation	285	49.0 %
4	Location of healthcare facility	251	43.1 %
5	Perceptions/beliefs about tests/treatments	248	42.6 %
6	Communication-understanding the information given by provider	235	40.4 %
7	System problem with scheduling care	228	39.2 %
8	Transportation: Difficulty getting from home to obtain healthcare	200	34.4 %
9	Financial problems (i.e., housing, food, etc.): Dealing with financial problems that interfere with receiving healthcare	192	33.0 %
10	Social support	158	27.1 %
..13	Literacy-Difficulty understanding written communication from the healthcare setting	103	17.7 %

challenging and time-consuming barriers identified from patient encounter logs that the navigators tackled are noteworthy of discussion: (1) transportation; (2) healthcare system complexities; and (3) communication-health literacy demands (Table 2).

Transportation Five of the primary care clinics referring patients to the program were located in rural areas; however, most diagnostic and treatment services were located in urban areas. Although services were available in the community for transportation, often those services were limited to certain areas, making it difficult for patients living in homes located on rural dirt roads and trailer parks to access such transportation. Although several of the clinics in this study provided transportation to the cancer center, patient appointments did not always coincide with the van's schedule. Additionally, if the family did own a vehicle, a great deal of navigation time was spent in providing maps and explaining and writing directions, as many families were not familiar with roads and neighborhoods in urban areas. In some cases, this unfamiliarity resulted in the patient being late to their scheduled appointment. The navigators worked diligently with scheduling staff to keep them informed about the patients' transportation challenges, enabling the scheduling staff to better accommodate the patients' needs.

Health Care System Complexities One of the greatest challenges expressed by navigators was working within complex healthcare systems, which required keen understanding of how it worked, and then communicating the processes and

procedures to patients and their families. For example, the navigators spent large amounts of time explaining how to get an appointment, how to figure out the financial steps of applying for charity or low-income assistance programs, or where support resources were located. Detailed explanations were often needed (e.g., to describe how a payment plan could be negotiated and what terms on forms meant, such as "stocks and bonds").

Communication-Health Literacy Demands Another challenge identified by the navigators was the high information demands placed on patients by the healthcare system. This problem is not unique to patients with low literacy since the intricacies of the healthcare system are well known for getting in the way of clear communication [19, 20]. To remedy this, the navigators were guided closely by the doctoral level nurse investigator who had expertise in health literacy. They learned how to deconstruct information (i.e., broke information into smaller more manageable parts), made use of pictures and drawings, created glossaries of more simple terminology, and employed teach-back methods, a process that helps to gauge patient's understanding by repeating back the information learned. For example, the navigators would take a task such as getting a colonoscopy and reduce it to smaller parcels of information. So, to explain a colonoscopy, the steps would be "drilled down" to: purpose of the prep, where to get the prep; need to be close to a bathroom, need for transportation, and so on. In this manner, the information became more relatable, easier to understand, and more actionable.

Actions Taken by Patient Navigators to Address Barriers Of the 588 patients navigated by our program, 10 were diagnosed with cancer. Our experiences show that the navigators helped to close the gap for patients to reach diagnostic resolution by providing logistical, social, and/or emotional support. On average, the navigators performed 14 actions per patient (including referrals, scheduling appointments, preparing documents, providing education, and providing emotional support). Overall, patient navigators spent an average of 12.7 h (range 0.5–96 h) per non-cancer patient and 80 h (range 1.4–462 h) per cancer patient from the time of consent into the study to either the resolution of the screening abnormality or completion of cancer treatment.

Key Elements of Lay Navigation Model During the implementation of the Moffitt PNRP intervention, a number of elements were found to contribute to the effectiveness of the program.

Lay Navigators Being Culturally Attuned to the Communities Served The delivery of culturally, linguistically, and literacy relevant care is critical for addressing health disparities. Such care needs to exhibit sensitivity to the differences in individuals, which may be due to variations in cultural backgrounds,

socioeconomic status, ethnicity, sexual orientation, or education. Being culturally attuned includes understanding how marginalization increases health risks for individuals and feeling energized versus drained by cultural differences [21]. The underlying principle to being culturally attuned, consistent with the Office of Minority Health's Enhanced CLAS (2010), is to "provide effective, equitable, understandable, and respectful quality care and services that are responsive to diverse cultural health beliefs and practices, preferred languages, health literacy, and other communication needs"—see https://www.thinkculturalhealth.hhs.gov/Content/clas.asp [22]. As such the navigators in our program were highly familiar with the everyday situational realities of the population they served and placed high value on the development of trusting relationships that promoted healing [1]. They took time to get know the patients, listened to their concerns, identified ways to deconstruct and simplify health information in language specific terms, and setup a course of realistic actionable steps to achieve a healthcare goal. In short, they were the "front line" personnel who helped to broker information and were effective in this role because of their high sensitivity to community members' everyday situations. Thus, we believe being culturally attuned represented a positive step toward the repair of a "broken" healthcare system for eliminating myriad barriers to cancer diagnosis and treatment.

Navigator Training and Support Navigator training and education were vital to the PNRP; it entailed national [23] and ongoing local bi-weekly training sessions, often provided by the nurse supervisor and doctoral level nurse investigator. As examples, topics included Cancer 101; Navigation Strategies; Patient Advocacy; Effective and Clear Communications; Financial Resources; and so on. Training also included updates on HIPAA and an annual human subjects' research ethics class. Moreover, the navigators attended cancer center lectures, toured various hospital screening and diagnostic facilities, and became familiar with multiple community resources, such as the ACS Hope Lodge, support groups, and social service agencies. As new learning needs emerged, training sessions were offered, e.g., Boundaries in Healthcare, Domestic Violence, and Cancer Terminology Refreshers. Additional details on the trainings and other programmatic information are available in the literature [3].

Sustainable Community-Moffitt Provider Partnerships Sustainable partnerships with community clinics and other community organizations were essential to keep aligned with available resources and linkages to critical community resources [24]. Based on the extensive partnerships already developed through the cancer center's outreach and research efforts, the navigation program was received quite favorably. The primary care community clinics and hospitals participating in the study established a system in which the navigators were

integrated as part of the clinic team. These arrangements helped patients view the navigators as an extension of the local clinic system. This also helped community providers gain access to navigation services more readily and conveniently for assisting their patients. Also, vital to the development of the lay navigation model was the formation of professional relationships within the cancer center. The navigators essentially served as a "vital link" between the patients' providers, schedulers, social services department, and the patients' community.

Community-based relationship building and resource identification was crucial in providing successful lay navigation. The navigators built an array of relationships including church and social systems, social service staff at the participating primary care clinics, and clinic van/shuttle drivers to further assist each patient. Regarding funding options, this was a critical underpinning of our program. For uninsured patients, a resource specialist worked closely with them to identify how they could qualify for a funding option, e.g., Medicaid, county resources, or cancer center charity care. In short, extensive efforts were made to assiduously link patients to an appropriate follow-up resource. For example, through these resources, the PNRP staff was able to "negotiate" with community providers to offer diagnostic services, such as a colonoscopy, for a fraction of the cost.

Attention to Caseload Distribution During the course of the project, we found that we needed to create an informal system

that allowed us to rate patients based on predicted acuity and resource intensity. The nursing supervisor began to informally rate patients based on resource intensity on a scale that ranged from Level 1 (least resource intensive) to Level IV (most complex and resource intensive). For example, a high acuity caseload might involve patients whom had multiple barriers, few resources, and complex health issues—See Table 3. This did not necessarily mean that all patients with cancer were categorized as high acuity, but rather patients who had complex situations required more navigation time. This system contributed to more effective use of financial and personnel resources, overall navigator morale and satisfaction through distribution of cases, and ultimately enhanced patient care. We are currently working on further developing and refining this tool, but view this as a fertile area of future patient navigation research and practice in which nurses can be instrumental in establishing the categories that would assist administratively in the process of managing caseloads.

Challenges Faced by the Lay Patient Navigators Two particular challenges came to light when the navigators provided assistance for patients who were diagnosed with cancer: (1) a steep learning curve to become familiar with medical treatment terminology; and (2) difficulty coping with their own emotional stress. These challenges have nursing implications and support the vital role of the

Table 3 Case examples for acuity levels

Case example: Level 1-Low acuity navigation actions	Case example: Level IV-High acuity navigation actions
Ms. A is a 76-year-old Caucasian with a high school diploma. She was able to understand written documents with minimal assistance at times. She had worked in the school system her whole life as a teacher's aide. Although widowed a few years before, her daughter who was an RN was very involved in her mother's healthcare. Ms. A had her own transportation and drove herself to her appointments. Her daughter accompanied her to most clinic visits, and they consulted with the doctors directly about Ms. A's need for a breast biopsy and discussed her options in English. She had Medicare and a supplemental health insurance to cover her health care.	Ms. G a 50-year-old immigrant from Mexico residing in the USA for 5 years. Ms. G states that she has three years of schooling in Mexico. Her limited literacy was noted by her not being able sign her own name (used an X)—she did not understand the words in most documents that were given to her, even in her native language, *Spanish*. Yet, she was very dedicated to field work and to being a housewife living in a rural area of our county and was open to learning. She was married with several adult children but could not depend on them for support. Her husband did not get involved in her health matters and her adult children were not involved, either by choice or because they did not know of her health situation. She had low understanding of the severity of her diagnosis at first and was unable to seek resources for treatment on her own as she was unfamiliar with the health system. She was uninsured and undocumented in the USA. She was very quiet and inhibited.
The patient navigator served to make the initial linkages to a clinic for a breast biopsy and supported the family in their navigation of the health system. The patient was well versed on breast biopsy procedure and was accompanied by her daughter. The breast biopsy outcome was negative.	The bilingual patient navigator was a significant resource in linking Ms. G to the nurse for education on her cancer diagnosis and needed treatment. Also, the navigator was able to link Ms. G to a social worker for processing of the charity application for care at the cancer center. The navigator accompanied Ms. G to her appointments, explained processes, and arranged local transportation through the local community health center van. Most importantly, the navigator was able to establish a strong relationship with Ms. G whereby she trusted the navigator enough to follow through with her treatments of chemotherapy and subsequently breast surgery, a mastectomy which saved her life. Due to the complexity of the situation, the nurse supervisor also assisted in navigation and education.

professional navigation (e.g., nurses) in future navigation models of care.

Steep Learning Curve for Medical/Clinical Terminology
Although the lay navigators were familiar with basic cancer treatment terms, they faced difficulties when attempting to break down medical jargon from the treating oncologist to the patient. Therefore, the navigators worked very closely with the project's nurse supervisor to discuss commonly used terminology related to the treatment and medications and to develop a plan of action. The navigators would consult with the nurse supervisor prior to responding to a cancer patient's question, and were instructed to work closely with the patient's primary oncology and nursing team members. Sometimes, patients did not feel comfortable asking questions to their health providers and instead funneled questions through the navigators. As new learning needs surfaced, we provided additional training (e.g., navigators observed the chemotherapy unit). Additionally, the entire multidisciplinary research team met regularly to discuss active cancer cases to strategize on navigation actions.

Emotional Stress A second major challenge that faced by the navigators was working with patients who were diagnosed with cancer. The navigators reported experiencing emotional stress upon seeing their patients go through cancer treatment. This stress was at times personally difficult for the navigators. During the long time that the navigators provided services to the cancer patients, the navigators often became very involved in the patients' lives (e.g., home visits, interactions with family members). Many cancer patients disclosed highly personal information to the patient navigators. Ongoing team discussions about appropriate methods for establishing professional boundaries were needed in some cases.

When patients died, the navigators experienced significant grief, visited the family, and attended the funeral. One navigator expressed *"It's hard to explain to people and to my family what's going on inside me. I know that it's not family, but I feel that I just lost a family member. It hurts that much!"* Reflecting on this experience, we feel that lay navigators were not fully prepared for the stress related to caring for patients with cancer. Nurses and other health providers, on the other hand, are often exposed to bereavement and end-of-life content in their academic programs, which may be especially helpful in guiding cancer patients through the cancer experience. As time went on, the navigators became better at coping with these experiences through increased training, emotional support, and discussions with our multidisciplinary research team (physician, nurses, and psychologist). This points to a need to place continued attention on relational roles and relational boundaries as recently reported by Philips et al. 2014 [25].

Discussion

It is not entirely clear in the literature which model of navigation is most effective for improving health outcomes for different settings, diseases, or populations. Based on our experiences, the Moffitt PNRP provided useful insights into the strengths of a lay model of navigation that outreaches to medically and historically underserved populations receiving care in the community. The importance of having lay navigators involved in navigation across the continuum of cancer care is underscored based on a number of factors. First, navigators from the community who are familiar with cultural values and community resources are tremendous assets to cancer outreach programs—they can bridge communications and offer important insider perspectives [3]. Therefore, a vital aspect of our navigation program was the development of trusting and therapeutic relationships for improved well-being. This function is effectively carried out through one-on-one relationships between the navigator and the patient [13, 25]. The ability of the navigators to facilitate communication also built a level of trust that made patients comfortable to speak openly about their health, feelings, and even their family/personal situations.

Second, lay navigators were very effective at breaking down healthcare system and communication barriers. For the patients served by our navigators, the importance of easy-to-understand communications was vital, and deconstructing health information into simple parcels was paramount. For the providers at the primary care settings, having a navigator meant being able to track the status of their patient at any given time. For the cancer center and other clinical facilities, having navigators meant the ability to reach patients who may have been lost to follow-up. This, in part, can be attributed to the personal characteristics of the navigators (language spoken, commitment to community, knowledge of cultural values and beliefs, and relationships with community and stakeholders) [13]. Overall, the role of the navigators as communication brokers is highly consistent with other navigation studies [12, 26–30] that view them as valuable assets for helping patients access information, problem-solve, and sift through the myriad logistics of cancer care. Further, we ascribe that patient navigators often work within a number of functional area domains as cogently identified by Willis et al. 2013 [31]: professional roles and responsibilities, community resources, patient empowerment, communication, barriers to care/health disparities, education/prevention and health promotion, ethics and professional conduct, cultural competency, outreach, care coordination, psychosocial support services/assessment, and advocacy. As such, continued efforts to define and refine these roles are fertile areas of future scientific and clinical inquiry.

In reviewing challenges faced by our lay navigators, it became clear that a difficult aspect of their role was dealing with their emotions when navigating patients in the cancer

treatment phase. Furthermore, the need to set boundaries of the navigator's roles was an important lesson learned. In these instances, the nurses and other team members played vital roles to assist the navigators in care coordination and coping with their emotions. Nurses and other health providers may be especially helpful with debriefing sessions to support and develop the role of lay navigators in the field.

One limitation about this project should be considered. That is, patient navigation occurred within the framework of a research study. Researchers were involved in the development of the navigation program as well as the hiring and training of navigators, and may have influenced linkages to care. However, we believe that any possible influence was outweighed by careful reflection and discussion about the practicalities of navigation within community-based settings. Further, institutionalization of the navigators within community-based settings was the desired outcome. As this project was an endeavor funded as a research investigation, the patient navigator positions ended when the study concluded. However, as a direct result from the patient navigation project, the clinics started to invest more time in navigation activities after the study was completed. As the program neared completion, we prepared each community clinic by having them identify some key people for the navigators to transfer navigation-related activities, compile navigation resources into guides for the participating clinics, and solidify strong linkages between the clinics and the cancer center [3].

Conclusions

The Moffitt PNRP model consisted of a unique set of elements designed to reduce the number of patients lost to follow-up following an abnormal cancer screening result and improve timely initiation of cancer treatment [3]. Our experiences reinforced that the use of both lay navigators and professional navigators may be an optimal way to outreach to medically underserved communities. What this means is that who should navigate is often best determined by the level of skills required at a given phase of navigation. These observations are consistent with the Principles of Navigation as outlined by Freeman and Rodriguez [13]. Based on our experiences, we conclude that the lay model of patient navigation is appropriate for navigating medically underserved patients who are in the stage of the continuum of cancer care that starts at the prevention/outreach phase to the point of diagnosis. Navigation from the point of cancer diagnosis through the phases of treatment requires closer supervision of lay navigators by professionals, such as nurses, or requires nurses to perform navigation. Research is needed to add to our understanding about the efficacy of each type of patient navigation model in reducing cancer health disparities.

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