Acceptance of a community-based navigator program for cancer control among urban African Americans

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Abstract

Patient navigation is now a standard component of cancer care in many oncology facilities, but a fundamental question for navigator programs, especially in medically underserved populations, is whether or not individuals will use this service. In this study, we evaluated acceptance of a community-based navigator program for cancer control and identified factors having significant independent associations with navigation acceptance in an urban sample of African Americans. Participants were African American men and women ages 50–75 who were residents in an urban metropolitan city who were referred for navigation. Of 240 participants, 76% completed navigation. Age and perceived risk of developing cancer had a significant independent association with navigation acceptance. Participants who believed that they had a low risk for developing this disease. The likelihood of completing navigation increased with increases in age. None of the socioeconomic factors or health care variables had a significant association with navigation acceptance. There are few barriers to using community-based navigation for cancer control among urban African Americans. Continued efforts are needed to develop and implement community-based programs for cancer control that are easy to use and address the needs of medically underserved populations.

Introduction

Patient navigation involves providing targeted support that addresses individual-level barriers to obtaining cancer care and is becoming a standard component in many oncology settings [1–4]. Patient navigation has a long history in cancer care; the first patient navigation program was...
established by Freeman et al. [5] more than two decades ago to increase access to timely diagnosis and treatment among medically underserved women in a clinic setting. Since this first clinic-based navigation program, this practice has been conceptualized in many different ways and applied in several settings [4]. Navigation can target different domains in the cancer care continuum even though emphasis may be placed on resolving an abnormal finding through timely diagnosis and treatment in existing models [1]. But, navigation can also encompass prevention and early detection through community-based programs and outreach that are designed to address barriers such as fear and distrust and lack of understanding about risk factors for disease and screening guidelines. In prior studies, this type of navigation has been provided by lay health advisors (LHA) and peer educators in which community members provide informational (e.g. education about cancer screening), instrumental (e.g. transportation to screening services) and appraisal support (e.g. praise for obtaining cancer screening) [6–10]. Multi-component interventions that use a combination of LHAs, mass media and mobile mammography vans to provide education, support, and screening services to women in community and clinic settings have also been developed and evaluated [11–13]. These programs have been shown to be effective in terms of increasing access to and utilization of cancer screening and other services [14–17]. Empirical data are now emerging on the efficacy of clinic-based patient navigation on diagnostic and treatment outcomes for cancer and the process and procedures for developing and implementing navigation in diverse clinical settings [2, 4, 18–21]. This work has shown that navigation is likely to be provided by individuals with different types of educational and clinical backgrounds and considerable resources are invested to identify and train navigators [22, 23]. But, many individuals may decline to use navigation even though it is offered as part of standard care; only 56% of patients in a community hospital accepted navigator support for cancer care and clinical trial access [24]. Reasons for declining navigation may include a perceived lack of need for this type of program, having existing resources for support, and having a sufficient prior experience with the health care system [24]. Reports from the National Cancer Institute’s Patient Navigation Program show a similar trend in some settings; of 485 clinic patients who were randomized to receive navigation, 16% did not complete it [25]. The most likely reason for declining navigation was a perceived lack of need because 50% of those who declined navigation reported no barriers to obtaining cancer care. But, empirical data are not available on how specific characteristics of individuals may influence acceptance of navigation.

Reduced disparities in cancer outcomes among medically underserved populations is an anticipated outcome of patient navigation [26]; yet, many of these programs are delivered in medical centers that racial minorities and other underserved groups have difficulty accessing because of financial (e.g. lack of health insurance) and sociocultural barriers [27]. Community-based programs are being developed and implemented to fill this void; screening for diseases such as hypertension, diabetes and some forms of cancer is now frequently provided in community settings [28, 29]. At best, community-based programs should function as an adjunct to medical care that is provided in health care systems. Community-based programs should also target individuals who have reduced access to medical care and navigate these individuals to a more sustainable source of health care. Questions have been raised about the relative benefits, risks and costs of community-based programs [30]. These include concerns about the clinical impact of providing screening at health fairs and the qualifications of some groups that organize and provide services in community settings. Nevertheless, increased access to health care continues to be a priority among some racial minorities [31] and community-based programs are one way in which this priority is likely to be addressed.

We developed a community-based navigation program for cancer control to address the needs and priorities of African American residents in an urban metropolitan area through an established academic-community partnership that includes primary care providers, behavioral scientists and
public health researchers, and representatives from community-based organizations [31, 32]. Our program uses community health workers to deliver navigation for cancer control, but has one critical distinction from existing programs: navigation is provided in a community setting by non-health care professionals who are community residents. We focused on navigation for these forms of cancer because this disease was a priority health condition among community residents [31] and African Americans continue to experience excess rates of morbidity and mortality from cancer [33]. Our navigation program recognizes the importance of working collaboratively with multiple stakeholders (e.g. primary care providers, community-based organizations, public health professionals); but importantly, avoids duplicating screening services that are best provided in a clinical setting. That is, we developed our program to be an adjunct to primary care; individuals without health insurance are navigated to primary care settings in which they can establish care, obtain assistance with getting health insurance, and receive cancer screening and other health care services. Those who have health insurance coverage and/or a primary care provider are assisted with maximizing the care they receive.

Efforts are now being made to identify metrics for evaluating the impact of patient navigation programs; many focus on measuring whether or not screening was received, time to diagnostic resolution, timeliness of care and clinical outcomes such as stage at diagnosis, survival, and recurrence rates [19, 34]. A more fundamental question, however, is whether or not individuals will use navigation, especially since substantial resources are needed to develop and implement navigator programs. Considerable investments are made to identify and train navigators, develop protocols for delivering navigation, and obtaining and/or creating resources to facilitate the navigation process. While one study evaluated uptake of patient navigation offered in a clinical setting [24] and other reports have described reasons for not completing navigation among those who were randomized to a patient navigation intervention group [25], empirical data are not available on the acceptance of navigation offered as part of a community-based program and even less is known about the characteristics of those who are likely to use this type of service. These issues are especially important to evaluate in medically underserved groups for whom targeted programs may be under-utilized even after considerable resources are invested to develop specialized services [35, 36]. As resources are invested to develop community-based strategies for health promotion and disease control, it is important to evaluate the reach and adoption of these approaches.

We evaluated uptake of our community-based navigator program in this report and also examined the association between navigation acceptance and socioeconomic, health care and sociocultural variables. In addition to evaluating the association between navigation acceptance and constructs from the theoretical frameworks that were used to develop the navigation protocol (e.g. perceived risk from the Health Belief Model), we were also interested in the association between navigation acceptance and social integration because previous research has shown that social factors are important when developing interventions to enhance utilization of cancer screening among African Americans. Social integration is an important component of social support; findings from qualitative studies demonstrate that African American men and women use a variety of social processes to make decisions about cancer screening; the opinions of significant others (e.g. community leaders, family members) were important to decisions about mammography among African American women [37]. Other work has shown that social ties (e.g. marital status, the number of relatives and friends in one’s social network, church participation) are important to mammography among African American women [38]. Relative to whites, the availability of social connections (e.g. being married, frequency of contact with friends and relatives) had a stronger effect on colon cancer screening behaviors among African American controls who were participating in a population-based case–control study of colon cancer screening [39]. Since research has also shown that future temporal orientation, or the extent to which one’s cognitive focus is on future
outcomes, is associated with beliefs about some forms of cancer screening and utilization of specific tests [40–44], we also examined the association between future temporal orientation and navigation acceptance in this study.

Materials and methods

Study population

Eligible participants were African American men and women who were ages 50–75. Individuals also had to be a current resident of the Philadelphia, PA metropolitan area in order to be eligible for participation. Men and women who had a personal history of breast, prostate, or colorectal cancer, and those who were experiencing symptoms of these diseases, were not eligible for study participation. A total of 240 participants were included in this analysis.

Procedures

All study procedures were approved by the Institutional Review Boards at the University of Pennsylvania and the Medical University of South Carolina. Participants were recruited by self-referrals from newspaper and radio advertisements and flyers at community organizations located in the Philadelphia, PA area that described the study as a research program that provides information on how to obtain screening for breast, prostate and colorectal cancer. Those who were interested in participating were directed to contact the study line. We used this approach to ensure that we were reaching a community-based sample of African American residents in the Philadelphia metropolitan area. Our previous research has shown that these strategies are effective at enrolling a study population that is demographically representative of the target community [32]. Following referral, a screening interview was completed to determine eligibility. Those who were eligible completed a structured baseline telephone interview to obtain socioeconomic characteristics, health care variables, and to measure sociocultural factors. At the end of the baseline telephone interview, participants were invited to participate in the navigation program and were given $20 at the first session for completing the interview and to cover transportation costs.

The navigation program was developed using the principles of community-based participatory research [45] and was designed to address constructs from the Health Belief Model [46] and social support theory [47]. Specifically, we conceptualized navigation as a cue to action or support for cancer control; the navigation protocol focused on providing informational support to promote awareness about screening guidelines, increase knowledge about the availability of community-based resources for cancer screening and provide guidance on how to access these resources. The content of the navigation protocol and the tasks completed by the community navigators (CNs) were developed based on the priorities, concerns, and preferences that had been identified by community residents [31], the expertise and experience of academic and community investigators in health education and promotion and medical care, and the tasks that are typically completed by navigators across the cancer care continuum [20].

Navigation consisted of two individual sessions with a CN. The CN was a Philadelphia resident who had been trained in cancer prevention and control (e.g. cancer causes and risk factors, cancer facts and figures for African Americans, early detection strategies), case management, and was certified in patient navigation through formal training [48]. To facilitate payment for providing navigation, the initial CNs were hired as part-time employees at the University of Pennsylvania. There were a total of three CNs and there was at least one male navigator during the study period. When possible, navigation sessions with male participants were completed by the male CN. All CNs were African American. We used CN as opposed to nurse navigators or other health care professionals to facilitate the sustainability of the program. Sustainability is a primary principle of community-based participatory research (CBPR) [45].

At the first session, the CN completed an intake assessment to identify barriers to early detection (e.g. fear, lack of physician recommendation or...
health insurance, cannot afford co-payment, etc.) and to ascertain if and when cancer screening had been obtained. The CN also asked participants to indicate which type of cancer was their greatest concern. After completing the intake evaluation, CNs completed a barriers resolution worksheet to develop an individual action plan for each participant. For instance, if the participant had never been screened for any type of cancer and reported a family history of colorectal cancer, then navigation focused on obtaining colorectal cancer screening because family history is an important risk factor for this disease. Action plans included detailed strategies for addressing screening barriers in order to increase self-efficacy to address the barriers that had been identified. These plans were reviewed during a weekly case meeting that was attended by the study Principal Investigator (PI, CHH), a general internist, project manager, study coordinator, and the CNs. During the case meeting, the CN presented each participant and reviewed their access to and utilization of primary care (e.g. whether or not they had a primary care provider, date of last physical examination), cancer screening history, barriers to cancer screening, the subject’s primary area of concern and specific strategies that were recommended for navigation. Once consensus was reached, the action plan was finalized and reviewed with participants during the second navigation session.

The second navigation session focused on reviewing the action plan with participants and providing education about breast, prostate, or colorectal cancer in African Americans, risk factors for these diseases and strategies for early detection based on the American Cancer Society guidelines using a semi-structured protocol. Navigation was targeted to screening barriers for one type of cancer and was designed to equip participants with skills that they could use to address barriers to care. For instance, if participants indicated that their health care provider did not recommend screening, navigation focused on developing questions they could use to initiate a discussion about screening with their provider along with education about cancer and a review of screening guidelines. But, if the primary barrier was lack of health insurance, navigation consisted of cancer education and referral to a social or benefits worker in a federally qualified health care center who could assist them with obtaining coverage and medical care. Participants were contacted by telephone 2 months after the second navigation session to complete a post-navigation follow-up. During this follow-up, the CN reviewed the action plan, identified barriers to implementing the strategies included in the action plan and provided additional assistance with obtaining recommended services, if necessary. All navigation sessions were provided in a community setting (e.g. church, social service agency) during business hours on Monday through Friday.

**Measures**

We used validated items from national surveys to evaluate socioeconomic characteristics (e.g. income, marital status, education and employment status) [49]. Health care variables included health insurance status and the participant’s usual source of medical care (doctor’s office versus other settings). Sociocultural factors included perceived risk of developing cancer, future temporal orientation and perceptions of social integration. To measure perceived risk, participants were asked how likely it was they would develop cancer at some point in the future (1=very low to 5=very high) using an item from the Health Interview National Trends Study (HINTS) [50]. We re-coded this item into low (very low, somewhat low, moderate) and high (somewhat high, very high) perceived risk of developing cancer. We used the future temporal orientation scale developed by Lukwago et al. [51] to evaluate the extent to which subjects focused their attention and action based on future plans and expectancies. This scale had acceptable internal consistency in our sample (Cronbach’s alpha = 0.65). Social integration was measured in terms of actual and perceived levels of social cohesion. Specifically, participants were asked to indicate the number of community organizations to which they belonged to measure social involvement. This item has been used previously in the HINTS. We used the collective efficacy scale to measure...
perceptions of social cohesion [52, 53]. The collective efficacy scale asks participants how much they agree or disagree that their neighborhood is close knit and if people where they live can be trusted, share the same values, get along, and are willing to help each other. The collective efficacy scale had good internal consistency in our sample (Cronbach’s alpha = 0.81).

Our outcome measure was based on the RE-AIM model and defined as acceptance of community-based navigation [54]. Participants who completed both sessions were categorized as acceptors. Those who actively refused to complete navigation or could not be reached to schedule one or both sessions were categorized as decliners. Participants who completed the first navigation session, but declined the second session, were also categorized as decliners. Similar methods have been used to characterize acceptance rates for cancer prevention and control services among African Americans in previous reports [32, 35, 36].

Data analysis
First, descriptive statistics were generated to characterize participants in terms of socioeconomic characteristics, health care variables and navigation acceptance. Next, we used Chi Square Tests of Association and t-tests to evaluate the bivariate relationship between navigation acceptance and socioeconomic status, health care, and sociocultural factors. We then used logistic regression analysis to identify factors having significant independent associations with navigation acceptance. Factors that had a bivariate association of $P < 0.10$ with navigation acceptance were included in the regression model.

Results
Of the 240 participants who were offered navigation, 76% accepted and 24% declined. Table I shows the characteristics of our sample and the bivariate analyses of navigation acceptance based on socioeconomic factors. There were significant age differences in navigation acceptance; acceptors were older (mean = 57.5, SD = 5.3) compared with decliners (mean = 55.9, SD = 4.3) ($t = -2.13$, $P = 0.03$). Navigation acceptance rates were also higher among women compared with men, but this difference was only marginally significant.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Level</th>
<th>n (%)</th>
<th>% Navigator acceptors</th>
<th>$\chi^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>Male</td>
<td>110 (46)</td>
<td>71</td>
<td>2.69$^\dagger$</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>130 (54)</td>
<td>80</td>
<td></td>
</tr>
<tr>
<td>Marital status</td>
<td>Married</td>
<td>37 (16)</td>
<td>76</td>
<td>0.002</td>
</tr>
<tr>
<td></td>
<td>Not married</td>
<td>199 (84)</td>
<td>75</td>
<td></td>
</tr>
<tr>
<td>Education level</td>
<td>$\geq$ Some college</td>
<td>124 (52)</td>
<td>75</td>
<td>0.08</td>
</tr>
<tr>
<td></td>
<td>$\leq$ High school</td>
<td>115 (48)</td>
<td>76</td>
<td></td>
</tr>
<tr>
<td>Employment status</td>
<td>Employed</td>
<td>74 (31)</td>
<td>76</td>
<td>0.0001</td>
</tr>
<tr>
<td></td>
<td>Not employed</td>
<td>164 (69)</td>
<td>76</td>
<td></td>
</tr>
<tr>
<td>Income level</td>
<td>$&gt;$ $20,000</td>
<td>109 (48)</td>
<td>75</td>
<td>0.06</td>
</tr>
<tr>
<td></td>
<td>$&lt;$ $20,000</td>
<td>120 (52)</td>
<td>77</td>
<td></td>
</tr>
<tr>
<td>Health insurance</td>
<td>Yes</td>
<td>164 (68)</td>
<td>74</td>
<td>1.19</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>76 (32)</td>
<td>80</td>
<td></td>
</tr>
<tr>
<td>Perceived risk of cancer</td>
<td>Higher/much higher risk</td>
<td>24 (10)</td>
<td>58</td>
<td>4.34$^*$</td>
</tr>
<tr>
<td></td>
<td>Same/lower risk</td>
<td>210 (90)</td>
<td>78</td>
<td></td>
</tr>
</tbody>
</table>

$^aP < 0.05$; $^\dagger P < 0.10$. $^*$Some subjects were missing data for these variables: marital status, $n = 4$; education, $n = 1$; employment status, $n = 2$; income, $n = 11$. 

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(P < 0.10). None of the health care variables had a significant association with navigation acceptance, but perceived risk of developing cancer had a statistically significant association with navigation acceptance. Fifty-eight percent of participants who believed that they were at high risk for developing cancer accepted navigation compared with 78% of those who believed that they were at low risk for developing this disease ($\chi^2 = 4.35, P = 0.04$).

Table II shows the results of the bivariate analysis of navigation acceptance based on sociocultural characteristics. Navigation acceptors had higher scores for future temporal orientation compared with those who declined. Navigation acceptors also belonged to a greater number of community organizations compared with decliners. However, the associations between navigation acceptance and future temporal orientation and membership in community organizations were marginally significant.

The results of the logistic regression analysis of navigation acceptance are shown in Table III. Age and perceived risk had significant independent associations with navigation acceptance. The likelihood of accepting navigation increased as participant’s ages increased. But, participants who believed that they were at high risk for developing cancer had a lower likelihood of completing navigation compared with those who believed that they had a low risk for developing this disease. As in the bivariate analysis, the association between navigation acceptance and community involvement was also marginally significant in the regression model. The likelihood of accepting navigation increased with greater community involvement with marginal significance.

### Discussion

To our knowledge, this is the first study to evaluate acceptance of a community-based navigator program in a medically underserved population that continues to experience disproportionate rates of morbidity and mortality from cancer. Overall, 76% of participants were navigation acceptors and 26% declined navigation. Our acceptance rates were higher than those reported for clinic-based patient navigation in one study [24] and the acceptance rates found in other programs that were developed specifically for African Americans. Only 50% of African American women participated in a genetic counseling program that was developed specifically for women at increased risk for hereditary breast cancer [35], whereas more than two-thirds of participants in this study completed navigation. An important distinction between our program and others is that we offered navigation in community settings and focused our services on addressing barriers to cancer screening as opposed to delivering genetic counseling and testing in a health care system. Recent research has shown that African Americans have greater levels of distrust in health...
care providers [55] and systems [56, 57] than whites, but there is more trust in informal networks that provide health information [58]. We also offered navigation in a community setting where socioeconomic characteristics and health insurance coverage are less likely to influence one’s ability to access the program. Close to 70% of our sample was unemployed, 50% had a low annual household income, and 32% did not have health insurance. Individuals with few economic resources may have an interest in and need for community-based programs. Offering navigation in a community setting to individuals with limited economic resources, and who have greater availability because of unemployment, may have translated into high acceptance rates. By offering navigation in a community setting, we removed the influence of health care variables and economic factors; this may explain why none of these factors had a significant association with navigation acceptance.

Our findings also show that navigation acceptance is not likely to differ based on many demographic factors that are usually important to health care behaviors and outcomes. That is, whereas the likelihood of navigation acceptance increased with age, education level was not associated with navigation acceptance and our acceptance rates did not differ between men and women. Importantly, men composed about 50% of our sample and this gender distribution is consistent with the proportion of males and females who are residents in Philadelphia, PA. We used community-based strategies that were developed collaboratively by the partnership to recruit participants and we matched male participants with a male navigator when possible. These aspects of our program may explain the relatively equal gender distribution in our sample. However, the rates at which participants did not complete navigation were higher than those observed in recent patient navigator programs implemented in clinic settings [25, 59]. Twelve percent of patients in the Ohio Patient Navigator Program who were randomized to the navigation group did not complete navigation and only 16% of those in the Boston, MA program did not complete navigation during the intervention period. There are important differences between our study and these navigation programs. Both the Ohio and Boston programs were implemented in clinic settings and targeted individuals who had an abnormal screening result. These factors may reduce the likelihood that patients will decline navigation. In contrast, our participants did not have an abnormal screening result and were not experiencing a symptom of disease. This may have contributed to less interest in and urgency for navigation among some participants. Another important difference between our program and others is that we only enrolled African Americans whereas all ethnic and racial groups were enrolled in other patient navigation programs. There may be racial differences in acceptance of patient navigation that is offered in clinic settings; future studies are needed to determine if racial minorities are more or less likely to decline or not complete clinic-based navigation programs. Continued research is needed to characterize the types of needs that community residents have for navigation and to understand how these needs vary.

We found that perceived risk of developing cancer had a significant independent association with navigation acceptance; perceived risk was the only variable whose association was statistically significant in the multivariate regression model. Even though heightened perceived risk is generally associated with a greater likelihood of compliance with cancer screening guidelines [60, 61], participants in this study who believed that they were at high risk for developing cancer had a decreased likelihood of accepting navigation compared with those who had a low perceived risk. Previous research has shown that that perceived risk of developing cancer is positively associated with fatalistic beliefs about the disease and avoiding information about cancer [62]. Cancer fatalism is also association with having less positive expectations about early detection [63]. It could be that participants who had a high perceived risk of developing cancer were less likely to accept navigation because they have fatalistic beliefs about this disease. Declining navigation for cancer control and screening could be one way of avoiding information about this disease. Recent estimates from the American Cancer Society show that African
American men have a one in two chance of developing any type of cancer and African American women have a one in three chance [33]. Despite these statistics, many African Americans do not believe that they are at risk for developing cancer despite the presence of established risk factors [64, 65] and only 10% of participants in this study reported that they were at risk for developing cancer. Navigator programs may need to provide individualized risk information in addition to education about risk factors for disease to enhance risk comprehension in this population.

Social factors are an important component of many health behavior theories. For instance, according to social support theory [47], social integration reflects the number and types of interpersonal relationships, whereas social systems are an important element in the diffusion of innovations theory [66, 67]. But, we found non-significant differences in navigation acceptance based on the extent to which participants were socially integrated. It could be that the number and types of interpersonal relationships are less important to the acceptance of a new community program relative to the position that participants in our study had in their social system or network. That is, according to the diffusion of innovations theory [66, 67], those who were navigator acceptors may be considered innovators or early adopters; innovators and early adopters tend to be individuals who use programs that appear to be interesting, are very social and are likely to be opinion leaders in their communities. This may be why participants who were members of a greater number of community organizations were more likely to accept navigation compared with those who belonged to fewer groups. This finding should be interpreted with caution because the association between navigation acceptance and membership in community organizations was marginally significant in the bivariate and regression analyses. Nevertheless, additional studies are needed to determine if navigator acceptors shared information about our program with other individuals in their social networks.

In considering the results of this study, some limitations should be noted. First, we evaluated acceptance of our community-based navigation program in one geographic area in a single medically underserved population. There may be different acceptance rates and predictors of acceptance in other geographic areas and populations. Another possible limitation is that we recruited participants using self-referrals from newspaper advertisements; this may have resulted in some selection bias. We used self-referral strategies to recruit participants for this study because of the importance of voluntariness in decisions to participate in research [68] and our goal was to enroll a community-based sample that was demographically representative of African Americans in the Philadelphia, PA metropolitan area. Our previous research has shown that the recruitment methods we used are effective at enrolling a sample that is demographically representative of African Americans in Philadelphia [32]. Additional research is needed to characterize acceptance rates in other populations and areas. It is also important for future studies to evaluate the effects of community-based navigation, and the decision to accept or decline this type of program, on cancer screening behaviors.

Our study is the first to show that acceptance of a cancer control program is high in a population that may be slow to use evidence-based innovations. This may be because our program met an identified need and was easy to use. It is important for diverse stakeholders (e.g. physicians, behavioral scientists, public health researchers, community-based organizations) to be actively involved in the development and implementation of community-based programs for cancer control so that the appropriate level of care can be provided while meeting the needs of the medically underserved population. Future studies are needed to determine if this type of partnership model can be used to develop clinical programs and other types of community-based initiatives for cancer control in medically underserved populations.

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None declared.

References

Acceptance of a community-based navigator program


