Refining the Patient Navigation Role in a Colorectal Cancer Screening Program: Results From an Intervention Study

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Abstract

Background: Oncology patient navigators help individuals overcome barriers to increase access to cancer screening, diagnosis, and timely treatment. This study, part of a randomized intervention trial investigating the efficacy of patient navigation in increasing colonoscopy completion, examined navigators’ activities to ameliorate barriers to colonoscopy screening in a medically disadvantaged population. Methods: This study was conducted from 2012 through 2014 at Boston Medical Center. We analyzed navigator service delivery and survey data collected on 420 participants who were navigated for colonoscopy screening after randomization to this intervention. Key variables under investigation included barriers to colonoscopy, activities navigators undertook to reduce barriers, time navigators spent on each activity and per contact, and patient satisfaction with navigation services. Descriptive analysis assessed how navigators spent their time and examined what aspects of patient navigation were most valued by patients. Results: Navigators spent the most time assessing patient barriers/needs; facilitating appointment scheduling; reminding patients of appointments; educating patients about colorectal cancer; the importance of screening, and the colonoscopy preparation and procedures; and arranging transportation. Navigators spent an average of 44 minutes per patient. Patients valued the navigators, especially for providing emotional/peer support and explaining screening procedures and bowel preparation clearly. Conclusions: Our findings help clarify the role of the navigator in colonoscopy screening within a medically disadvantaged community. These findings may help further refine the navigator role in cancer screening and treatment programs as facilities strive to effectively and efficiently integrate navigation into their services.

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Background
Oncology patient navigation (PN) is recognized as an important component of cancer care and, as of 2015, all Commission on Cancer (CoC)–accredited programs are required to provide PN services. Oncology PN, pioneered by Dr. Harold Freeman in 1990, is a process that provides “individualized assistance to patients, families, and caregivers to help overcome healthcare system barriers and facilitate timely access to quality health and psychosocial care from prediagnosis through all phases of the cancer experience.” Prediagnosis includes screening, which detects disease early when treatment is the most effective. Disparities in cancer screening persist and are based on race, ethnicity, and healthcare access and use, among other factors. Studies have shown the effectiveness of PN in increasing patient completion of cancer screening and reducing disparities among the medically underserved.

Generally, patient navigators (herein referred to as “navigators”) are either nonclinical members of the community or healthcare professionals (usually nurses or social workers). Many PN programs use navigators who are members of the population they serve, thus they are able to meaningfully address norms related to health beliefs, trust in the medical system, and language barriers. Navigators help patients overcome practical barriers to cancer screening, diagnosis, and treatment; provide culturally appropriate patient education; offer peer counseling; and provide linkages to financial and community resources. These activities align with the evidence-based strategies to increase early detection through screening as recommended by the Community Preventive Services Task Force, including offering client reminders and outreach, providing one-on-one education, and reducing structural (ie, practical) barriers.

As PN programs in cancer screening are increasingly being implemented in healthcare settings, it is crucial to understand navigator activities and to ascertain the value of PN interventions to patients. Such information will yield greater understanding of the navigator activities that are most critical to improved outcomes and enhance effective use of navigators within healthcare teams. Although some studies have systematically examined PN activities in cancer treatment settings, few have been conducted in cancer screening. Additionally, few PN studies include patient satisfaction measures in their design, and only one specifically examined the aspects of PN intervention that were valued by patients.

Our study was conducted as part of a larger examination of the efficacy of PN in increasing colorectal cancer (CRC) screening via colonoscopy in a medically disadvantaged population. This analysis was performed to characterize the activities of navigators, including time spent per activity and per patient, using the data collected by the navigators. Additionally, this study examined the extent to which patients valued and were satisfied with the PN intervention, including which aspects of the intervention patients considered most useful.

Methods
Data were obtained from the intervention arm of the Study of Patient Navigation for Colonoscopy, a randomized intervention study exploring the use of PN to increase screening colonoscopy in a medically disadvantaged population (E.A.R, unpublished data, 2016). The study was conducted at Boston Medical Center (BMC) and approved by Institutional Review Boards of the Centers for Disease Control and Prevention (CDC), BMC, and Westat.

Population
We recruited participants aged 50 to 75 years who were referred for screening colonoscopy from October 2012 to December 2014 at BMC’s Section of General Internal Medicine, BMC’s Family Medicine Department, and the East Boston Neighborhood Health Center. BMC is the largest...
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safety-net hospital in New England. Participants were prescreened based on eligibility criteria and were then recruited via telephone; those not reached by telephone were mailed an invitation letter. All participants had either private or public insurance that covered screening colonoscopy. Participants assigned to the control arm (n=423) received usual care, typically consisting of 1 informational call and 1 appointment reminder call.

Intervention
The intervention was conducted by 2 nonclinical navigators. Both navigators were recruited by BMC, were bilingual (English/Spanish), had experience in health care or community health settings, and were familiar with the local community. One navigator had significant PN experience and had previously received additional training in motivational interviewing from Boston University School of Medicine; the other navigator was trained for this study by the Harold P. Freeman Patient Navigation Institute and was mentored by the senior navigator. The junior navigator had a bachelor’s degree and the senior navigator was working toward earning a bachelor’s degree. Navigators were employed by BMC to work with study participants 20 hours per week for this study. A full-time research coordinator led participant recruitment through November 2013, after which the navigators served as part-time recruiters. Participants were not recruited and serviced by the same navigator (ie, the senior navigator provided navigation only to those recruited by the junior navigator and vice versa). Navigators worked with patients to identify, reduce, and eliminate personal, cultural, structural, and healthcare system barriers to screening colonoscopy and to support completion of the procedure.

Navigators first conducted an assessment of participants to identify relevant barriers to colonoscopy screening. Based on the assessment, they created a plan to facilitate the screening process. Navigators worked with participants primarily via phone, but also conducted some activities in person and by mail. Navigators used the PN Colonoscopy Tracking Form (a database in the medical records system) to track participants through the screening process and to document service completion for each contact (see supplemental eAppendix 1, available with this article at JNCCN.org).

Consistent with the intervention design, some activities were common among all navigated patients, such as assessment of barriers, patient tracking and follow-up, education about CRC screening and clearing the bowels in preparation for colonoscopy (hereafter referred to as bowel prep), and appointment reminders. Other activities were more individualized, such as addressing patient-specific barriers to colonoscopy screening. The PN intervention ended (1) when a patient completed their colonoscopy, received the results, and the referring primary care provider received the endoscopy report; or (2) if a patient had not undergone a colonoscopy within 6 months after study enrollment.

Data Collection
Data for this analysis were obtained from participant baseline and follow-up questionnaires and the PN Colonoscopy Tracking Form. Research coordinators conducted the 15-minute participant baseline survey primarily via telephone; this information was used for evaluation of the intervention and not shared with navigators. The baseline questionnaire assessed participant demographics and barriers to screening. All participants received a $25 gift card for completing the baseline survey. As soon as possible after colonoscopy was completed or if the participant was deemed nonadherent after 6 months, participants were called by a professional telephone interviewer (from Westat), who conducted a 10-minute follow-up survey. This survey included some of the same questions as the baseline questionnaire, but also included questions about patient satisfaction with navigation, including identifying which PN activities patients found most helpful. After completion of the follow-up survey, participants received another $25 gift card.

Navigators documented each patient contact (or activities conducted on behalf of the patient) in the electronic PN Colonoscopy Tracking Form, noting the type of activity (eg, phone, in person, mail, e-mail, no patient contact needed, flag provider, colonoscopy notes), patient barriers assessed (eg, lack of education about colonoscopy, language barriers, lack of transportation, securing an escort for the appointment), activities taken to address identified barriers, time spent on each activity, and overall time spent during that contact. All time fields used
15-minute increments. Data entry occurred in real time, while the PN was speaking with the patient, or immediately on completion of the phone call.

**Data Analysis**

This analysis discusses the findings on the 420 navigated patients. Although the study assigned 431 patients to receive the intervention, 11 were not included in the analysis (5 could not be reached and 6 were excluded because their spoken language was neither English nor Spanish). Summary statistics were generated for demographic variables (age, sex, race/ethnicity, language spoken at home, and income). We calculated frequency distributions for barriers reported in the baseline questionnaire, types of activities performed by the PN, and patient satisfaction questions. We calculated the average time PNs spent per patient and per activity for each patient by using the midpoint of each 15-minute time increment, omitting extreme outliers to more accurately represent mean time navigators spent with the patients. We conducted a content analysis on open-ended responses to questions about PN services that patients deemed were most helpful. Responses were coded by the second author (B.S.) and this coding was reviewed by the first (E.A.R.). We resolved differences through consensus, subsequently grouped codes into themes (education, emotional support, and practical support), and calculated the frequencies of responses for each code. All other analyses were performed with SAS version 9.3 (SAS Institute Inc., Cary, NC).

**Results**

Demographic data for the 420 patients who received navigation services are summarized in Table 1. Approximately half of the patients were aged 50 to 54 years (52.9%) and a similar proportion were female (55.5%). Most patients were either non-Hispanic black (40.5%) or Hispanic (39.0%), and slightly more than half spoke English as their primary language (55.7%). More than half of the patients

### Table 1. Demographics of Navigated Patients

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total navigated patients</td>
<td>420</td>
</tr>
<tr>
<td>Age, y</td>
<td></td>
</tr>
<tr>
<td>50–54</td>
<td>222 (52.9)</td>
</tr>
<tr>
<td>55–64</td>
<td>142 (33.8)</td>
</tr>
<tr>
<td>65–74</td>
<td>55 (13.1)</td>
</tr>
<tr>
<td>DK, refused, not ascertained</td>
<td>1 (&lt;1.0)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>187 (44.5)</td>
</tr>
<tr>
<td>Female</td>
<td>233 (55.5)</td>
</tr>
<tr>
<td>Race/Ethnicity</td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>164 (39.0)</td>
</tr>
<tr>
<td>Non-Hispanic black</td>
<td>170 (40.5)</td>
</tr>
<tr>
<td>Non-Hispanic white</td>
<td>64 (15.2)</td>
</tr>
<tr>
<td>Other</td>
<td>21 (5.0)</td>
</tr>
<tr>
<td>DK, refused, not ascertained</td>
<td>1 (&lt;1.0)</td>
</tr>
<tr>
<td>Language spoken at home</td>
<td></td>
</tr>
<tr>
<td>English</td>
<td>234 (55.7)</td>
</tr>
<tr>
<td>Other than English</td>
<td>185 (55.0)</td>
</tr>
<tr>
<td>DK, refused, not ascertained</td>
<td>1 (&lt;1.0)</td>
</tr>
<tr>
<td>Income (US dollars)</td>
<td></td>
</tr>
<tr>
<td>$0–$19,999</td>
<td>244 (58.1)</td>
</tr>
<tr>
<td>$20,000–$34,999</td>
<td>63 (15.0)</td>
</tr>
<tr>
<td>$35,000–$49,999</td>
<td>30 (7.1)</td>
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<tr>
<td>$50,000–$74,999</td>
<td>15 (3.6)</td>
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<tr>
<td>≥$75,000</td>
<td>23 (5.5)</td>
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<tr>
<td>DK, refused, not ascertained</td>
<td>45 (10.7)</td>
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<td>Private</td>
<td>87 (20.7)</td>
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<tr>
<td>Public</td>
<td>373 (88.8)</td>
</tr>
<tr>
<td>DK, refused, not ascertained</td>
<td>3 (&lt;1.0)</td>
</tr>
</tbody>
</table>

Abbreviation: DK, don’t know.

*Respondents could select more than one answer.

Figure 1. Barriers reported at baseline by patients randomized to receive navigation (N=420).
had incomes of less than $20,000 (58.1%); most patients reported incomes under $50,000 (80.2%). Most patients were publicly insured (88.8%).

At baseline, 98% of patients reported at least 1 barrier (data not shown); 57% of patients reported between 1 and 3 barriers, and 41% reported 4 or more barriers (data not shown). Patients faced challenges at multiple levels, including individual and interpersonal, cultural, environmental/structural, and healthcare system (Figure 1). The most commonly reported barrier was needing education about the colonoscopy procedure (59%), followed by scheduling the appointment (42%), out-of-pocket expenses related to the procedure (42%), and transportation (41%). One-third of patients (33%) anticipated the need for language translation. Slightly less than a quarter of patients reported time off work or identifying an escort home (required after sedation) as barriers to undergoing colonoscopy (24% and 21%, respectively). Navigators identified additional barriers through their assessment and over the course of navigation.

Across all activities, navigators spent an average of 44 minutes per patient (Table 2), and 75% received less than 1 hour of navigation services. Figure 2 illustrates the percentage of patients receiving each navigator activity and the average number of minutes spent on that activity per patient for the activity reported. Aside from assessment and planning, navigator activities corresponded closely to patient-reported barriers (as reported in Figure 1). Navigators spent more time overall on the most frequently reported activities. On average, navigators spent the greatest amount of time conducting assessment and planning (mean, 27.2 minutes per patient), which was also their most frequently reported activity (89%). Other frequently reported navigator activities included delivering education about colonoscopy (78%; 14.4 minutes), reviewing bowel prep instructions (73%; 13.6 minutes), scheduling or rescheduling colonoscopy appointments (71%; 15.1 minutes), arranging transportation (71%; 13.4 minutes), arranging for an escort (71%; 13.3 minutes), and providing peer support (63%; 15.0 minutes).

Patients completing the follow-up questionnaire (n=287) were highly satisfied with the PN services (Figure 3). Nearly all (96%) would recommend PN services to others, valued working with their navigator (95%), and rated their experience good, very good, or excellent (95%).

Table 3 summarizes navigation services patients identified as most helpful in the follow-up survey. Their responses largely related to education, emotional support, and practical support services. Nearly half of the patients valued the explanation of the colonoscopy procedure and bowel prep procedures (47.1% and 46.7%, respectively), followed by providing encouragement/social support (40.5%). Several patients reported their fear of the colonoscopy and that the navigator was able to alleviate their fears and anxiety, thereby convincing them to complete their colonoscopy. Many patients reported that they were thankful to have someone to listen to their concerns and answer questions. Education about the importance of completing the colonoscopy (12.8%) was also identified as helpful, as were arrangement of transportation or escort after the procedure (7.5%), appointment scheduling/rescheduling (7.0%), and language concordance between patient and navigator (3.1%).
Discussion

These study data provide insight into how the PN role can be further refined. In our study, PN activities corresponded closely to patient-reported barriers, although a lower percentage of patients anticipated having each barrier. Our findings show that navigators in our study spent the most time assessing needs/planning, educating participants about the procedure, reviewing bowel prep instructions, arranging escorts and transportation, scheduling appointments, and providing peer support. Some activities (eg, arranging escorts and reviewing bowel prep) are specific to colonoscopy, but overall, these activities correspond with findings from other examinations of PN activities in screening and treatment.23,31,32 In our study, despite patients’ anticipating needing assistance with out-of-pocket expenses for colonoscopy, navigators did not need to spend time addressing these concerns as other studies have reported,23 because all screening colonoscopies are covered by health insurance in Massachusetts.38 Given the recent increase of PN programs in healthcare settings, it is necessary to better understand the activities navigators conduct, including how much time they spend engaging in these activities.

Navigators in our study spent an average of 44 minutes per patient, which is less than other studies have reported; one study in cancer screening found that navigators spent an average of 107 minutes with each patient.14 Navigators in that study helped patients decide between colonoscopy and fecal occult blood test, which could account for the longer time reported. Similarly, a study of navigators in cancer treatment reported that navigators spent 2.5 hours per patient.23 This difference is not surprising, because it is expected that patient navigators working in a cancer treatment setting versus a cancer screening setting would work with patients over a longer period of time and address more complicated concerns.

Most patients in our study are from disadvantaged socioeconomic backgrounds. This is notable because disparities in healthcare access and treatment persist for those who are economically disadvantaged and/or members of racial and ethnic minority groups.5–8,39 Interestingly, a recent multicenter, randomized control trial found that PN intervention decreased

| Table 3. Patient Navigation Services Patients Found Most Helpful (n=227) |
|-----------------|-----------------|-----------------|
| **Type of Support** | **N (%)** | **Illustrative Quote** |
| **Education** | | |
| Explanation of colonoscopy procedure | 107 (47.1) | “They explained everything and followed up with any questions that I had.” |
| Bowel preparation | 106 (46.7) | “[The navigator] made sure that I was clear when to start taking medication, how to mix, and when to mix everything...made sure I did not eat.” |
| Importance of procedure | 29 (12.8) | “[The navigator] explained...the reason for having the procedure done and risks if you don’t get it done.” |
| **Emotional support** | | |
| Encouragement | 92 (40.5) | “[The navigator] never gave up on me.” |
| ** Practical support** | | |
| Transportation/Escort | 17 (7.5) | “Kept in contact with me; made sure I had a ride to and from.” |
| Appointment scheduling | 16 (7.0) | “I missed my appointment and [the navigator] gave me a call back to reschedule.” |
| Language concordance | 7 (3.1) | “Explained everything in detail in Spanish.” |

Figure 3. Patients’ satisfaction with patient navigators.
the time from abnormal screening result to diagnostic resolution, but only after a 90-day lag time. This finding led the authors to conclude that PN may be most effective for participants who are in the most need, such as those at higher risk of being lost to follow-up.40

Finally, our study found that patients were highly satisfied with the PN intervention and most valued the navigators for providing emotional support and education. This builds on conclusions drawn from qualitative studies of navigators in cancer care, which found that PN processes are based on relationship-building and instrumental assistance.12,35 These findings support the premise that healthcare professionals need to respect patients as individuals whose social circumstances affect their health and health behaviors—a central element of patient-centered care.41,42

One limitation of our study was that the PN tracking database only allowed navigators to record time spent in 15-minute intervals, rather than allowing them to add actual time spent, which limited variation needed for some analyses. Additionally, because just more than half (55%–57%) of navigated patients completed the follow-up questions related to satisfaction with PN and which activities/services were most helpful, this limited our assessments of those constructs. A major strength of this study is its large sample size, particularly compared with similar studies of the PN intervention itself23,26,31 and patient satisfaction with PN services.12,35 Another strength is this study’s use of the data generated by the navigators during the course of their interactions with patients, rather than the report of others either observing or supervising their work. Finally, this study examined 3 important domains: navigator activities, time spent per activity and per patient, and patient satisfaction.

Conclusions

Although this study pertains to CRC screening via colonoscopy, these findings may inform other cancer screening and treatment programs, including public health programs funded by the CDC that support PN, such as the National Breast and Cervical Cancer Early Detection Program, the CRC Control Program, and the National Comprehensive Cancer Control Program.41 Given both the requirement to incorporate PN services into CoC-accredited cancer programs and the promise patient navigators hold in helping to reduce health disparities, further research of existing PN programs is needed to refine the nonclinical navigator role to avoid duplicating services already provided, especially by nurses or social workers.18 Additionally, future research may explore the relationship between PN services and outcomes, including whether concordance between self-reported barriers and barriers assessed and addressed by navigators influences outcomes.

References

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Posttest Questions

1. True or False: Oncology PN is a process that provides individualized assistance to patients, families, and caregivers to help overcome healthcare system barriers and facilitate timely access to quality health and psychosocial care from prediagnosis through all phases of the cancer experience.

2. In this study, the most commonly reported barrier to colonoscopy screening for the participants was ______.
   a. Time off work
   b. Transportation
   c. Out-of-pocket expenses
   d. Elder or child care
   e. Lack of education about the colonoscopy procedure

3. In this study, the navigator interventions that patients identified as most helpful were the provision(s) of ______.
   a. Encouragement/social support
   b. An explanation of the colonoscopy procedure and bowel prep
   c. Education about the importance of completing the colonoscopy
   d. Transportation or escort after the procedure
   e. Appointment scheduling
   f. Language concordance between patient and navigator

4. Lack of education about the colonoscopy procedure


16. Appointment scheduling

17. Elder or child care

18. Out-of-pocket expenses

19. Time off work

20. Transportation

21. Education about the importance of completing the colonoscopy

22. Scheduling the appointment

23. Language concordance between patient and navigator

24. Encouragement/social support

25. An explanation of the colonoscopy procedure and bowel prep

26. Education about the importance of completing the colonoscopy

27. Transportation or escort after the procedure

28. Appointment scheduling

29. Language concordance between patient and navigator

30. A need for language translation

31. Scheduling the appointment

32. Encouragement/social support

33. An explanation of the colonoscopy procedure and bowel prep

34. Education about the importance of completing the colonoscopy

35. Transportation or escort after the procedure

36. Appointment scheduling

37. Language concordance between patient and navigator

38. A need for language translation

39. Scheduling the appointment

40. Encouragement/social support

41. An explanation of the colonoscopy procedure and bowel prep

42. Education about the importance of completing the colonoscopy

43. Transportation or escort after the procedure

44. Appointment scheduling

45. Language concordance between patient and navigator

46. A need for language translation

47. Scheduling the appointment

48. Encouragement/social support

49. An explanation of the colonoscopy procedure and bowel prep

50. Education about the importance of completing the colonoscopy

51. Transportation or escort after the procedure

52. Appointment scheduling

53. Language concordance between patient and navigator