Using Navigators to Improve Care of Underserved Patients

Current Practices and Approaches

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BACKGROUND. Logistic, cultural, educational, and other barriers can impede the delivery of high-quality cancer care to underserved patients. Patient navigation services represent one innovation for addressing perceived barriers to care encountered by disadvantaged patients. In this report, the authors have 1) defined patient navigation, distinguishing it from other cancer support services; 2) described how programs are organized; and 3) discussed the need for research on program effectiveness.

METHODS. Information was examined on navigation programs published in the scientific literature and online. Qualitative research also was conducted, consisting of direct observation of patient care in cancer clinics with and without navigators in northern California, in-person interviews with personnel and patients in the clinics observed, and telephone interviews with navigators at four sites across the United States.

RESULTS. The authors found that navigation services have been implemented at all stages of cancer care: prevention, screening, treatment, and survival. Navigators differ from other cancer support personnel in their orientation toward flexible problem solving to overcome perceived barriers to care rather than the provision of a predefined set of services. There are no rigorous demonstrations of the effects and effectiveness of navigation, although such studies are underway.

CONCLUSIONS. Currently, patient navigation is understudied, and literature documenting its effects and effectiveness is scant. Rigorous studies are needed of the navigator role and program costs and benefits. Such studies will facilitate an assessment of program effectiveness, feasibility across a range of health care settings, and performance relative to alternative approaches for addressing barriers to care among the underserved. Cancer 2005;104:848–55.

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In the United States, the burden of cancer is distributed unequally with respect to race and ethnicity, socioeconomic status (SES), and nativity. 1,2 These social factors shape cancer morbidity and mortality in complex ways through effects on incidence, disease stage at diagnosis, prognosis, and outcome. 3–7 In terms of disease stage at presentation and 5-year survival rates, a disproportionate burden of disease falls on members of racial and ethnic minority groups, those of lower SES, and recent immigrants—groups that, together, may be considered medically underserved or disadvantaged. 2 These disparities fuel dissatisfaction among patients and raise concerns that the health care system perpetuates, perhaps even exacerbates, social inequity. 8
Although no single or simple reason explains these disparities, research to date suggests that a variety of barriers impede prevention, screening and early detection, follow-up of suspicious findings, and aggressive treatment of disease among the disadvantaged. These barriers include being uninsured or insured insufficiently through Medicaid or other public insurance programs\(^1,^5,^8–^14\); lower levels of health literacy or education that may contribute to fears of cancer screening and/or diagnosis\(^2,^10,^12,14,17\); cultural orientations that contribute to lack of trust in medical institutions or fatalism regarding cancer\(^2,^5,12–17\); logistic barriers due to lack of transportation, child-care commitments, clinic schedules, and rural residence\(^1,^2,^5,^8,12,15,16,18\); and difficulties negotiating relationships with providers or healthcare organizations arising from language or cultural differences\(^1,^2,9,18\).

Patient navigator programs seek to reduce disparities by addressing these barriers. The first navigation program was established in New York in the early 1990s with support from the American Cancer Society (ACS). After its reported success,\(^19\) additional programs were established with support from private foundations and through local initiatives. In 2003, 2 bills in the United States Congress, House Resolution 918 and Senate Resolution 453, proposed support for patient navigators as part of “model programs to provide...prevention, early detection, treatment, and appropriate follow-up care services” for medically underserved patients and populations. A report by the Trans-Health and Human Services Cancer Health Disparities Progress Review Group identified patient navigation programs as an important resource for eliminating cancer health disparities.\(^18\) To date, navigator programs have focused on helping patients overcome barriers to care through a variety of means.\(^18,19\) In 2002–2003, the National Cancer Institute (NCI) funded 6 patient navigator programs as part of its Cancer Disparities Research Partnership Program. In 2005, the National Institutes of Health plan to commit an additional $55 million to support research on the effectiveness and cost effectiveness of patient navigator programs.\(^20\)

Amid this increasing interest in patient navigation lead by both the federal government and major cancer organizations such as the ACS, we sought to assemble the relevant literature to address three basic questions about patient navigation: 1) What is patient navigation? 2) How are navigator programs organized? 3) What is known about the effects and effectiveness of navigator programs? By defining terms, describing how navigation programs are organized and operate, and documenting current understanding of their effects and effectiveness, our objective is to help establish a framework for future analyses and initiatives. We also suggest methods and metrics for future research.

**MATERIALS AND METHODS**

We reviewed published literature on patient navigation. However, after initial search efforts, it became clear that the literature was not developed sufficiently to address our research questions. There appeared to be two primary reasons for this deficiency. First, systematic evaluations of navigation only recently have begun and have yet to appear in the literature. Second, many navigation programs have been oriented toward local quality-improvement initiatives rather than scientific research, evaluation, and publication. Accordingly, we approached this review using two simultaneous approaches. First, we conducted a systematic literature review. Second, one of us (D.D.) collected original data on patient navigation programs through a variety of qualitative research methods.

**Literature Review**

We searched the PubMed data base between December 2003 through March 2004 using the terms “patient navigator,” “patient navigators,” “navigator,” “navigators,” and “patient navigation.” We combined these terms with the Medical Subject Headings (MeSH) terms “lay health aides,” “medically underserved areas,” and “neoplasms” as well as the non-MeSH terms “cancer” (in place of “neoplasms”) and “poverty” (in place of “medically underserved areas”). Using non-MeSH terms did not improve our results, so the results reported here are those that were obtained using MeSH terms. Overall, 5461 references were retrieved, including 4580 articles that did not refer to cancer and were eliminated, leaving a total of 881 references. We examined the titles of these references and eliminated 601, because they used the term navigation in a manner different than that intended here (for example, studies of cancer among Air Force navigators and reports of surgical technologies for navigation within the body). We examined the abstracts of the remaining 280 articles and found 76 articles that addressed patient navigation per se. Twenty articles were duplicates, leaving a total of 56 unique references from the PubMed searches.

To identify other published materials, we examined the bibliographies of retrieved references, searched the Social Science Citation Index using the terms and authors from the PubMed references, and searched the Internet, including websites of organizations that have funded navigator programs, including the ACS, the NCI, the Avon Foundation, and the Susan...
G. Komen Foundation. An additional 6 references were identified, yielding a total of 62 references.

Qualitative Research
The first author collected qualitative data by 1) direct observation of patient care in clinics with and without navigators; 2) in-person, semistructured interviews with navigators, other providers, and patients from the clinics where observations were conducted; and 3) semistructured telephone interviews with navigators from federally funded programs across the United States. To obtain in-depth information on how navigator programs operate, the first author directly observed patient care in an outpatient oncology clinic in northern California that served low-income patients and was the site of a locally funded navigator program from October 2002 to December 2003. To supplement data gathered through observation, in-person, semistructured interviews (60–90 minutes in length, tape-recorded) were conducted with navigators, other providers, and patients at the clinic. To provide context for the results from the navigator-equipped clinic, observational and interview data also were collected in two outpatient clinics without navigator programs, one that served a low-income population and another that served a higher SES population.

To gain a broader perspective on the experiences of navigators outside northern California, in June–July 2004, we contacted the 6 patient navigator programs funded by the NCI Cancer Disparities Research Partnership Program and conducted telephone interviews (25–45 minutes in length, tape-recorded) with navigators in 4 of these programs. Building on the information we collected in California, we asked about barriers addressed and services provided, navigator background and training, patient and clinician responses to the program, and for an assessment of program success.

Standard anthropologic research methods were used during observation and interview research in all settings.21 Data analysis was conducted with Folio Views computer software following the precepts of analytic ethnography, including study site immersion, simultaneous data collection and analysis, and detailed and iterative concept development.22 All research protocols were reviewed and approved by appropriate Institutional Review Boards. Appropriate consents were obtained from research participants. In accordance with our approved protocols, we do not identify any specific individuals, programs, or clinics that participated in this research.

RESULTS
Defining Patient Navigation
A striking finding from the literature review was the lack of a standard definition of patient navigation. Such a designation is requisite for practitioners and researchers who seek to distinguish navigation from other cancer support services, such as advocacy, outreach, education, case management, and social work. Although some published sources defined navigation as the provision of particular services or a set of services to patients, others defined a navigator as someone who specifically addressed barriers to care. In practice, as reflected in the qualitative data, the barrier-focused definition was more common. We argue here for a barrier-focused definition because it offers practical and conceptual advantages over a service-focused definition.

In separate literature reviews, the United States Center for Medicare and Medicaid Services (CMS) and the Canadian Breast Cancer Initiative attempted to define navigation according to services provided. The CMS review identified three types of navigation services: connecting individuals to screening, following patients postscreening, and assisting patients through the course of treatment.23 The Canadian Breast Cancer Initiative focused on treatment services, finding that some navigators proactively direct patients through treatment by scheduling appointments, for instance, whereas others facilitate treatment more subtly by providing information, support, and encouragement.24

These service-focused definitions lack specificity, however, because a variety of workers also coordinate patient care, provide cancer education, assist with administrative arrangements, or provide social or emotional support.25 Inside clinics, these services may be provided by case managers, advance practice nurses, and physicians.24,26 In the community, lay or peer advisors and counselors, promotoras de salud, community health workers, and community health advisors also provide navigation-like services.27,28

Because of this, the more useful definition emphasizes the navigator’s focus on perceived barriers to care. The particular services provided by navigators depend on the barriers they identify and the strategies they adopt to eliminate or reduce those barriers.18,19,29,30 This barrier-focused approach emerged clearly in the qualitative data. In the clinic we studied, navigators provided a variety of services, such as locating misplaced charts, interpreting for non-English-speaking patients, and providing emotional or educational support for patients and families. Providers and patients often welcomed their intervention, although
providers occasionally expressed concern that navigators might provide information and advice that was beyond their area of expertise.

For example, at one outpatient clinic, a Chinese-American Cantonese-speaking navigator reviewed the schedule days in advance, placed reminder phone calls to patients considered at risk to miss their appointment, highlighted patients with new diagnoses so that providers would allow extra time for these appointments, and pulled "shadow" charts for all patients. When clinic began, the navigator escorted patients to examination rooms and briefly reviewed the reason for their visit to ensure that the chart was current. Later, when it became clear that test results for many patients had been misplaced, the navigator spent an hour in the file room locating the misfiled documents. When she returned to clinic, she spent considerable time with one monolingual, Cantonese-speaking patient who was eligible for a clinical trial. First, the navigator interpreted for the trials coordinator who was introducing the study, a task that included clarifying that both arms of the trial involved drugs known to be safe and effective. When the patient continued to express misgivings about the trial treatments, the navigator asked the study investigator, a senior physician, to provide further explanation and reassurance. Ultimately, the patient declined to enroll, and the navigator and study investigator then discussed possible ways to revise the study consent protocol to address cultural issues relevant for Chinese immigrant patients.

In telephone interviews, navigators reported a similarly wide range of activities. Depending on their perception of local need, programs coordinated patient transportation, provided screening outreach and education, arranged clinic appointments, and facilitated payment through Medicaid or other sources. Programs also reported that they attempted to bridge language and cultural differences between providers and patients and that they provided patients with emotional and social support. Clinic observations and navigator interviews suggest that contemporary navigation services reflect local perceptions of patient needs and barriers to care.

Navigators Compared with Other Support Workers

Building on the barriers-focused definition, we sought to distinguish navigators from other cancer support workers (Fig. 1).

Navigators primarily play a reactive role by trouble-shooting a patient’s problems as they arise. Navigators may be inserted into a health care setting to facilitate adherence to a particular component of care, such as mammography or colon cancer screening. The barriers to be addressed often are not specified in advance but emerge during interactions with patients. Like navigators, patient advocates play a reactive role by trouble-shooting a patient’s problems as they arise. However, unlike navigators, advocates are concerned with the healthcare system as a whole rather than delivery of care to individual patients. Community outreach workers, such as lay health educators, typically focus on informing patients about the importance of adherence to a particular healthy behavior, such as colon cancer screening. Compared with navigators, educators are more proactive in addressing specific barriers, such as lack of knowledge of the benefits of the screening. Social workers and case managers also play a more proactive role than navigators in delivering services to individual patients. Clearly, there is overlap between the work of navigators and other cancer support workers, and our literature review suggests that different investigators use these terms inconsistently.

The framework specified in Figure 1 may facilitate research and evaluation of navigation programs by distinguishing the navigator’s role analytically from other cancer care providers, but it is not a rigid description of each position. In practice, these roles share elements. Individuals in each role seek to respond and adapt to the needs of individual patients, and members of health care teams often share and exchange roles while providing care. The overlapping circles in Figure 1 represent this reality. For example, several navigators we interviewed proactively provided outreach and education to individuals and groups. In clinic, we commonly observed that social workers adopt the reactive, problem-focused approach associated with the navigator role—an aspect of their work they acknowledged freely in interviews. Analysts who adopt a barriers-focused definition of
navigation must be aware of and sensitive to the overlap between navigation and other cancer support services in practice.

How Navigator Programs are Organized

Navigator programs have been established throughout the United States with support from private foundations, in conjunction with grants from federal, state, and local government, and through local initiatives by cancer centers, community-based clinics, and philanthropy. Freeman et al.’s program in Harlem targeting “high incidence of late-stage cancer and poor prognostic outcomes of low-income and medically underserved minorities” has served as a paradigm for other navigation programs. That program seeks to address perceived barriers stemming from mistrust and system complexity by training and employing lay individuals to provide one-on-one follow-up and case management. Other programs also report addressing cultural, educational, and language impediments to screening and treatment through outreach and education conducted by community health workers. Many programs report matching patients with navigators of similar ethnic and racial background.

Table 1 summarizes the characteristics of 11 navigation programs we found described in the limited published literature and does not represent an exhaustive list of extant navigation programs. For each, we show the focus of the program, the types of cancer and cancer care addressed, characteristics of navigators employed by the program, the funding source, and the extent to which there has been a formal evaluation of the program’s effectiveness or cost effectiveness.

Table 1: Characteristics of 11 Navigator Programs Documented in the Literature

<table>
<thead>
<tr>
<th>Focus/program</th>
<th>Disease site</th>
<th>Personnel</th>
<th>Sponsor</th>
<th>Evaluation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Seattle Indian Health Board Breast and Cervical Cancer</td>
<td>Breast and cervical</td>
<td>Professional</td>
<td>Avon</td>
<td>Yes</td>
</tr>
<tr>
<td>Health Program (Seattle, WA)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Breast and Cervical Cancer Program; Grace Hill Health Center (St. Louis, MO)</td>
<td>Breast and cervical</td>
<td>Lay/peer</td>
<td>ACS</td>
<td>Unknown</td>
</tr>
<tr>
<td>Language and cultural barriers across spectrum</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Juntos Contra El Cancer; University of Arizona/Mariposa Community Health Center (AZ)</td>
<td>Breast and cervical</td>
<td>Lay/peer</td>
<td>Komen</td>
<td>No</td>
</tr>
<tr>
<td>4. Avon Breast Cancer Project; Massachusetts General Hospital/Chelsea Health Center (Boston, MA)</td>
<td>Breast</td>
<td>Lay/peer</td>
<td>Avon</td>
<td>Yes</td>
</tr>
<tr>
<td>5. Patient Navigator Program; Department of Public Health (San Francisco, CA)</td>
<td>Breast and cervical</td>
<td>Lay/peer</td>
<td>NCI</td>
<td>Yes</td>
</tr>
<tr>
<td>Into screening, follow-up of suspicious findings; into treatment</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Harlem Cancer Education and Demonstration Program; Harlem Hospital Center (New York, NY)</td>
<td>All</td>
<td>Professional</td>
<td>ACS</td>
<td>Yes</td>
</tr>
<tr>
<td>7. Community Health Advocates Program; Emory University (Atlanta, GA)</td>
<td>Breast and cervical</td>
<td>Lay/peer</td>
<td>Avon</td>
<td>Planned</td>
</tr>
<tr>
<td>8. Northwest Native American Navigator Program Pilot Study (WA and OR)</td>
<td>All</td>
<td>Professional</td>
<td>NCI</td>
<td>Planned</td>
</tr>
<tr>
<td>9. Heartland Division Navigator Program; Truman Medical Center (Kansas City, MO)</td>
<td>Breast</td>
<td>Professional</td>
<td>ACS</td>
<td>Yes</td>
</tr>
<tr>
<td>Support during treatment</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Bayhealth Advocacy Navigator Breast Cancer Program (Dover, DE)</td>
<td>Breast</td>
<td>Lay/peer</td>
<td>Komen</td>
<td>Unknown</td>
</tr>
<tr>
<td>11. Navigator Services (Campbell and Salinas, CA)</td>
<td>All</td>
<td>Lay/peer</td>
<td>ACS</td>
<td>Unknown</td>
</tr>
</tbody>
</table>

ACS: American Cancer Society; NCI: National Cancer Institute; Komen: Susan G. Komen Foundation.
Programs 6–9, including Freeman et al.’s Harlem program, focus on barriers to follow-up and treatment, such as mistrust of the health care system and the complexity of modern cancer care. Programs in Atlanta, Washington, Oregon, and Kansas City have modeled themselves after the Harlem program. All of these programs are predicated on the belief that a divide between patients and clinics impedes access to care, and they seek to bridge this perceived divide by recruiting navigators directly from underserved communities or by training navigators.

Programs 10 and 11 address barriers to care that are believed to reflect a lack of social support for already diagnosed patients. The Dover and California programs target patients who currently are in care or recently have completed treatment. In the course of addressing social, emotional, and practical barriers to continued treatment and surveillance, navigators in these programs also may provide outreach to new patients or may provide referrals for further services to existing patients.

Do Programs Address Barriers?

We have no definite knowledge of how or whether programs address barriers to care. Available data (from the literature and from our qualitative research) only report experiences of currently operating programs and reflect a self-selected sample. Navigator programs have developed in response to local barriers to care, and few published studies of navigation include prersearch/postresearch designs or other systematic evaluations of program effects. Some studies reviewed the services provided by emerging programs or presented limited comparative data on outcomes. A number of studies provided detailed descriptions of the design and implementation issues addressed during program development or research study.

In our qualitative data, navigators and program administrators reported that they addressed barriers by anticipating and resolving patients’ problems, often by brokering patient relationships with service providers rather than by providing those services directly. For example, several programs reported helping transport patients to clinics. At one program with a history of providing transportation, providers became concerned that patients requested rides even when other options were available. Rather than confront patients about this over-utilization, this program considered terminating this service altogether and referring patients to organizations like the ACS that specialize in arranging patient transport. Workers at programs believed that familiarity with particular patient communities helped them recognize and address barriers to care. Some programs hired bilingual and bicultural navigators from the communities they served to help foster linguistic and cultural competence. Other programs conducted needs assessment, outreach, and in-depth training to encourage relationships between navigators and patient communities.

The literature suggests that navigation is associated with improved rates of screening and follow-up, lower clinical stage of presentation, and higher patient satisfaction. Process evaluations and program descriptions suggest that navigation services improve the clinic’s ability to engage, track, and support patients and to develop communication and trust between clinicians and disadvantaged populations. However, these results are interpreted best as suggestive of opportunities for future research. Studies to date have not employed sufficiently rigorous research designs to allow for any conclusions about the true effects of navigation programs.

DISCUSSION

From their origin at a single site in New York City a decade ago, navigator programs have expanded to hospitals and clinics across the country. Continued interest, support, and expansion of navigator programs appear likely. Published evidence from randomized trials demonstrating that navigation is effective in reducing health disparities does not exist; however, intensified interest and dedicated funding from the NCI will make this an active area of research. We suggest key measures and hypotheses that should be addressed in future research evaluating navigation services.

In terms of measures, the navigator role must be defined more fully, and appropriate metrics need to be developed to measure the services provided by navigators. We have suggested one definitional approach here. This approach and others should be operationally defined and compared in future research. If the barriers-focused conceptualization of the navigator role is accepted, then better measures are needed of barriers to care in specific localities. Even if barriers to care have been shown to exist using aggregate data, tools are needed to assess which barriers affect specific patient populations in particular clinics.

The key hypotheses to be addressed regarding navigation are, first, is it effective; and, second, if it is effective, then is it cost effective? Consistent definitions need to be used as a prerequisite for answering this question, and comparisons need to be made across settings of reasonable similarity. For example, comparison of navigation to promote adherence to cancer screening in two underserved populations with...
very different cultural orientations (e.g., Vietnamese and Hispanic) would be problematic.

There are two possible research designs that may be considered. One is to randomize patients within a particular clinic to receive navigator services and to then compare outcomes for patients assigned and not assigned to navigation. Drawbacks of this approach are that the very existence of a navigator in a health care setting may influence the way in which other members of the health care team provide care. Moreover, to the extent to which patients are aware of the navigator service, they may perceive it as “unfair” that they are denied access to a potentially useful resource. The alternative design is to randomize health care settings themselves to implement navigation and then compare outcomes across sites. Using this design, the outcome is the adherence rate for each particular clinic. The first challenge to implementing this design is that it is necessary to identify clinics that have underserved populations who are reasonably similar. Next, it is necessary to identify clinics willing to be randomized to navigation or lack thereof. The health care settings that have championed this strategy for health care improvement have dedicated substantial efforts to training navigators to serve as part of their teams. For those centers that already have committed to the navigation concept, assignment to the control arm would be problematic. For centers with no prior experience, hiring and training navigators is an obstacle. Nevertheless, this is the research design that ultimately will be required to determine the effectiveness of such programs. Navigator programs may achieve their objectives by promoting adherence to recommended health care by individual patients; or, alternatively, their presence may change the culture of the health care setting itself and influence the way the health care team as a whole delivers care. To specify the mechanism of success, studies that evaluate navigation will need to 1) evaluate individual patients to determine the extent to which navigators influenced their ability to adhere to necessary care and 2) evaluate clinics to determine the extent to which the presence of navigators changes the clinic culture.

If it can be demonstrated that these mechanisms are effective, then researchers must examine their cost-effectiveness. To date, there have been no such demonstrations, although some authors have made the case that navigation does not need to be costly. Cost-effectiveness studies will be exceedingly complex and will require detailed information about local conditions and the training, credentialing, and particular services provided by navigators. These analyses will need to be conducted in parallel to randomized trials evaluating navigators’ effectiveness and will need to include experienced economists. Because our qualitative research and the published literature show that navigators often receive extensive training, the level of training of navigators and other health care personnel in a particular setting must be factored into these analyses. Some sources suggest that reducing training, using less experienced peer navigators, or asking navigators to take on social work or education/outreach tasks reduces costs but also reduces a program’s efficacy. Reliable measurement of services and barriers would facilitate appropriate analyses of program costs, benefits, and cost effectiveness. Such measures also would facilitate comparisons between navigation programs with alternative approaches for addressing barriers to care among the disadvantaged. Conducting studies to evaluate the effectiveness and cost effectiveness of navigation will be challenging and will require time.

Although most clinics do not have navigators, many health care teams already are familiar with the concept of navigation. Distributed or team navigation already has been adopted in some clinical environments, although with even less formal research and evaluation than has been the case for navigator programs. By focusing on the concept of navigation and fostering teamwork among existing multidisciplinary team members, navigation may lead to improved outcomes. Receptionists, existing computer systems, case managers, technicians, nurses, and physicians all may incorporate the concepts of navigation into their work without the presence of any actual navigators. To ensure that patients receive the services necessary to achieve desired outcomes, team members jointly assume responsibility for coordinating patients’ care by stepping outside strictly defined roles. It will be important in research to distinguish between approaches that integrate the concept of navigation into health care delivery and those that charge specific individuals with this role.

REFERENCES