Published in final edited form as:

Patient Educ Couns. 2010 August ; 80(2): 241–247. doi:10.1016/j.pec.2009.10.024.

Patients' Experiences with Navigation for Cancer Care

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Abstract

Objective—We examined how navigation, defined as the assessment and alleviation of barriers to adequate health care, influences patients' perspectives on the quality of their cancer care.

Methods—We conducted post-study patient interviews from a randomized controlled trial (usual care vs. patient navigation services) from cancer diagnosis through treatment completion. Patients were recruited from 11 primary care, hospital and community oncology practices in New York. We interviewed patients about their expectations and experience of patient navigation or, for non-navigated patients, other sources of assistance.

Results—Thirty-five patients newly diagnosed with breast or colorectal cancer. Valued aspects of navigation included emotional support, assistance with information needs and problem-solving, and logistical coordination of cancer care. Unmet cancer care needs expressed by patients randomized to usual care consisted of lack of assistance or support with childcare, household responsibilities, coordination of care, and emotional support.

Conclusion—Cancer patients value navigation. Instrumental benefits were the most important expectations for navigation from navigated and non-navigated patients. Navigated patients received emotional support and assistance with information needs, problem-solving, and logistical aspects of cancer care coordination.

Practice Implications—Navigation services may help improve cancer care outcomes important to patients by addressing fragmented, confusing, uncoordinated, or inefficient care.

Keywords

cancer treatment; navigation; disparities

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1. Introduction

Patient navigation – the assessment and alleviation of barriers to adequate health care by a trained lay-person¹ -- is a widely promoted approach to improve the likelihood that patients will complete recommended testing and treatment and reduce socio-economic, racial and ethnic disparities in care. Navigation programs most often focus on helping patients with positive screening tests complete the diagnostic workup expeditiously.^{2,3} Navigation has also targeted patients undergoing initial cancer treatment,⁴ and in palliative care.⁵

Navigation encompasses several potential forms of instrumental (defined as the provision of tangible aid and services that directly assist a person in need)⁶ and emotional support for individuals with cancer. Navigators assess patients' needs and, in collaboration with the patient, develop a plan to overcome barriers to high quality care.⁷ Instrumental navigation services help patients access the cancer care system and overcome barriers to care. Navigators provide assistance with insurance, finances, transportation, language barriers, communication with the doctor, securing childcare, obtaining relevant information, and coordination of cancer care.^{7,8} Because cancer is usually an emotionally charged and life-changing experience, navigators also may offer emotional support to patients and families by responding to emotional distress, expressing empathy, listening supportively, and providing comfort. Our program has also emphasized patient empowerment, encouraging patients to assume an active role in their care.¹

Recent studies have demonstrated an association between navigation services and improved breast cancer outcomes in African American women with breast cancer.^{4,9} However, little is known about what patients have found useful in navigation. Few studies have examined the components of navigation that patients consider important. This study explores patients' reports of cancer care experiences to address the following questions: (1) How do experiences of cancer care needs differ between navigated versus non-navigated patients? (i.e., intervention versus usual care/control groups) (2) What do navigated patients perceive as the most effective, meaningful and valuable aspects of navigation?

2. Methods

This study was conducted as part of a randomized controlled trial (RCT) of patient navigation-activation, designed to evaluate the effectiveness of patient navigators on cancer-related healthcare quality and outcomes.¹⁰ The navigator program was established for research purposes and was approved by the University of Rochester Research Subjects Review Board.

2.1 Description of navigator intervention and training

Navigators were trained lay community members, representative of the communities that they would be serving. We initially recruited the navigators by posting the position through our institution. The most effective method for hiring high quality patient navigators, however, was by gathering recommendations on potential candidates from our network of medical and service providers in the community. The National Cancer Institute, Center to Reduce Cancer Health Disparities, funded these full-time positions through a five-year grant. Navigator annual salaries ranged from US \$30,000-\$34,000. They assessed and ameliorated patient barriers to accessing healthcare with a goal of expediting the diagnostic workup and cancer treatment completion. Patient navigators participated in: (1) eight-week intensive training when first hired, (2) 80-hour family development course credentialed by New York State for community health workers and, (3) annual 2-3 day event sponsored by the American Cancer Society. Training covered the following topics: cancer health disparities, case management, breast and colorectal cancer education, interpersonal communication, community resources, motivational interviewing, end of life care, and working in health systems. Navigators were trained and

supervised by a social worker, and were encouraged to individualize their services according to patients' needs and to help patients take an active role in their care. Retention of navigators was facilitated by skillful, supportive supervision as well as collaboration and mutual support amongst the navigators.

2.2 Population, Interviewer Guide, Interview Process

Population—Inclusion criteria for the RCT were abnormal breast or colorectal cancer screening results or a diagnosis of breast or colorectal cancer. Patients were excluded from the RCT if they were cognitively impaired, institutionalized (i.e., residing in a nursing home or incarcerated), <18 years of age, pregnant, had a prior history of cancer or experience with navigation. Participants were randomized to receive either usual care or navigation.

From May 2007 to March 2008, we conducted individual in-depth semi-structured interviews with RCT participants who had a new diagnosis of cancer within two weeks of either of the following endpoints: 1) completion of all anti-cancer treatment, or 2) one year from the time of participant enrollment. The larger RCT was still ongoing. Participants who screened positive for cancer but ultimately did not have cancer were not interviewed. Figure 1 shows how this study's participants were chosen from the larger RCT.

Interview Guide—The interview questions were developed and refined by members of the research team, incorporating principles from the critical incident technique.^{11;12} Based on a literature review and preliminary observations of those involved in training and monitoring navigators, we identified key goals and challenges in cancer care, and questions about the navigation process (shown in Figure 2). We piloted and revised the questions prior to the actual interviews, and added questions after data collection had begun, when there was a need to gather additional data from the patients' perspective about their experience of care and the navigation program.

Conducting the interviews—The exit interview was explained during recruitment for the RCT. A research assistant contacted eligible participants to schedule a telephone interview and explain its purpose. Those who could not be contacted after at least three attempts were considered non-responders. Interviews were conducted in English or Spanish by trained health professionals on the research team (nurse, physician, and social worker). Interviewers introduced themselves by their first name and did not provide information about their professional training in order to minimize social desirability bias. Participants had previously provided written informed consent for the larger study and for the telephone interview; before conducting the exit interview, interviewers re-verified permission to audiorecord the phone interview. Interviews ranged from five to 60 minutes, audiorecorded and transcribed verbatim. All identifying information was deleted. Completed transcripts were stored on a password-protected database. Participants received \$25 remuneration. Our analysis began while data collection was still occurring.

2.3 Analysis

Our qualitative study team included three physicians, an epidemiologist, and a research assistant. We used an approach guided by grounded theory,¹³ a coding/editing approach to qualitative analysis. We began by formulating two inter-related questions to guide our analysis:

1. How do patients' experiences of cancer care needs differ between navigated (intervention group) versus non-navigated (usual care/control group) patients?
2. What aspects of navigation are the most effective (i.e., meaningful or valuable) aspects of navigation among patients who were navigated?

Development and refinement of codes and categories—To develop codes, each member of the team initially read the same five transcripts and independently generated codes. We combined and compared our codes and discussed discrepancies. We then grouped related sets of codes to form a set of categories, which we defined via group discussion. We used this code and category list when coding subsequent transcripts, which were coded by two team members. * As part of this process, new codes, categories, and over-arching themes were generated and discrepancies were resolved by team consensus. In the vast majority of cases (>90%), coders agreed on their coding. At the conclusion of this phase, we generated a total of 105 codes and nine categories, with a range of four to 19 codes per category.

Theme development—As coding progressed, we identified salient themes related to our guiding questions by sorting categories and their embedded codes and by identifying themes within and across categories that were most important to our guiding questions. We compared the relative importance of concepts as we formed explanatory statements (themes). For this paper, we focus on themes related to the comparisons of expectations of navigation services, comparing and contrasting expectations with helpful versus unhelpful navigation experiences. Throughout our theme development process, we tracked discrepancies or other sources of nonconforming data to guide future work.

Use of Atlas.Ti qualitative software program—We entered our final list of codes and categories into Atlas.Ti version 5.2 qualitative software to examine relationships among codes, categories and themes that addressed the guiding questions.

3. Results

During this project's study period, 42 transcripts of patient exit interviews were completed and transcribed. We reached data saturation after analysis of 35 interviews.

3.1 Participant characteristics

Nineteen of the 35 participants had been randomized to navigation. Twenty-eight individuals had completed treatment for breast cancer (all female), and seven had completed treatment for colorectal cancer (four female). Most participants were white (79%) and insured (74%; approximately half (38% of the insured patients had Medicare and/or Medicaid insurance). Reported annual income was similarly distributed between navigated and on-navigated participants and ranged from less than \$10,000 to \$60,000 (data not shown). Race, ethnicity, marital status, and employment status were similar between navigated and non-navigated participants, and also did not differ from the larger study population. Among navigated and non-navigated participants, 63% and 39%, respectively, had completed some college or beyond.

3.2 Participant expectations of patient navigation

3.2.1 Instrumental needs—The most common expectation of navigation described by participants was the addressing of instrumental needs, particularly information-giving (expressed by 24 participants -- 10 navigated, 14 standard care). Participants' expectations about receiving information about cancer-specific topics (e.g., how to arrange tests and appointments), addressing financial stressors, and managing insurance issues was a major concern (n=14), split fairly evenly between those randomized to navigation (n=8) and usual care (n=6). When first hearing about the navigation program, patients commonly hoped for concrete assistance with transportation in order to keep appointments (nine participants:six

*One member of the group (CS) served as primary coder; two interviews were independently double coded by each of the five remaining group members.

navigated, three non-navigated) and with finances or insurance coverage (14 participants: seven navigated, seven non-navigated). For example, a 57-year old navigated breast cancer patient described her need for help with insurance (see Table 2, Quotation 1). For some patients, instrumental needs included simply knowing what to expect, as one non-navigated breast cancer patient explained (see Table 2, Quotation 2):

3.2.2 Emotional support—Participants frequently discussed expectations regarding emotional support (14 participants: five navigated, nine non-navigated participants). Participants often described feeling overwhelmed at multiple occasions during their cancer care and, as a result, had the expectation that navigators would be a source of comfort and support to help them in times of distress. The support from an uninvolved person was often considered particularly salient, as a 72-year old navigated breast cancer patient reported (Table 2, Quotation 3). Some patients linked the apparently instrumental need for information with emotional needs, as an older non-navigated breast cancer patient commented (Table 2, Quotation 4):

3.2.3 Nonspecific expectations—In many instances (n=19, 10 navigated, nine non-navigated), participants were either unable to articulate specific expectations or provided general, nonspecific responses to questions about their expectations of navigation. In some instances, patients felt that they needed assistance with “*everything*” due to the overwhelming nature of a cancer diagnosis, as a younger navigated breast cancer patient described (Table 2, Quotation 5).

3.2.4 Miscellaneous—Other expectations for navigation included coordination of care (n=12, six navigated, six non-navigated), advocacy services (n=11, four navigated, seven non-navigated), having someone present or available throughout the cancer-care process, e.g. “being there” (n=9, five navigated, four non-navigated), and helping the participant to become activated in managing their care (n=8, two navigated, six non-navigated).

Comparisons: Among the participants with colorectal cancer (n=7, three navigated, four non-navigated), expectations were mostly for information. These participants less frequently discussed financial or transportation issues or becoming more involved in their care. Among our small number of male participants (n=3, all with colorectal cancer, one navigated), the expectations for navigation centered on information and emotional support -- similar to the overall sample. Also, male participants briefly mentioned expectations related to coordination of care, transportation, and availability to answer questions.

3.3 What are the most effective (i.e., meaningful or valuable) aspects of navigation?

3.3.1 Emotional support—Among the 19 navigated participants, the most commonly expressed, highly valued navigator functions encompassed themes of emotional support (n=17), “being there” (n=14), and information-giving (n=13). Although few navigated participants mentioned emotional support as an initial expectation of navigation, emotional support was mentioned as a strongly valued aspect of navigation by nearly all navigated participants. A younger breast cancer patient (Table 3, Quotation 6) illustrates the importance of emotional support. Emotional support was important even for patients who had other forms of social support or family involvement in their care, as a 37-year-old breast cancer patient described (Table 3, Quotation 7).

3.3.2 Being there—Having the navigator “be there” for patients was infrequently mentioned as an expectation (five navigated patients) but was commonly mentioned as a valued aspect of navigation (14 of 19 or 74% of navigated participants). “Being there” was variously described as a form of emotional support provided by having the navigator as a comforting presence, a

source of social support, or as a buffer against isolation or loneliness. The presence of the navigator as a source of comfort and emotional support was highly valued, especially when confronting the shock of the initial diagnosis, having to process information and understand treatment options, and having to coordinate complex treatment plans. An example of “being there” is discussed by an older breast cancer patient (see Table 3, Quotation 8).

In other instances of “being there,” navigated participants described the theme of meaningful navigation as embodying personalized, comprehensive, accessible continuity of care for them throughout the cancer care process. Examples of this form of “being there” consisted of having the navigator attend office appointments, visit them in the hospital, link them to community resources, and represent a preferred alternative to family members in discussions about their cancer or treatment plan.

3.3.3 The navigator as an “insider.”—Having a navigator as someone with personal knowledge of the participant's overall life situation, while also having direct linkages as an “insider” to the health-care system, helping them through administrative challenges, offering security, comfort, or peace of mind by simply knowing that the navigator was there as a resource, “checking in” with calls or informal visits, were all described by participants as examples of “being there.” These examples, while certainly related to feeling emotionally supported, also encompassed activities, roles, or relationships that the participants highly valued in their navigators, as illustrated by a middle-aged breast cancer patient (Table 3, Quotation 9). “Being there” allows the navigator to be well integrated into the cancer care process, exemplifying how navigation was meaningful throughout the cancer treatment course (see Table 3, Quotation 10).

3.4 Negative experiences with navigation

Five participants mentioned negative experiences with navigation. (Each of these same five participants also provided in-depth examples of positive experiences, represented in the sixteen above.) The negative experiences were related to gender (specifically, discomfort with having a male navigator assigned to a female breast cancer patient mentioned by three patients), interruptions in continuity of the navigator-patient relationship (in one instance, due to reassignment of a navigator), the experience of distance (actual and relational) between the navigator and a patient, and lack of accessibility (specifically, a failure of the navigator to call a patient back promptly). These negative experiences all made it difficult for these patients to articulate their cancer needs, have an emotional connection with the navigator, and have the navigator present in their care. Thus, these negative experiences also provide indirect support for the most highly valued elements of navigation we discovered: instrumental services, emotional support, “being there”, and being an “insider.”

3.5 Barriers and cancer care needs that were not addressed

In general, cancer-care needs not addressed or met were described much less frequently (n=17, eight navigated, nine non-navigated). The unmet needs related to cancer care for navigated patients consisted of transportation (cited by three participants living outside the city), financial burdens (n=2), more extensive sources of social support (n=1), and the wish that the navigator had been involved sooner in cancer care (n=1). In many instances, the navigated participants initially reported examples of unmet needs that eventually resolved through the process of navigation or through other sources of support.

Commonly expressed unmet cancer-care needs for non-navigated participants included themes of feeling isolated, lacking in social or emotional support, and not having someone to talk to or help process information (n= 5). These unmet needs tended to persist throughout the cancer-care period.

Three non-navigated participants felt they did not get the information they needed about aspects of their cancer care or treatment plan—specifically, on side effects, treatment options, or treatment course. Two non-navigated participants had unmet needs related to financial assistance, and another described inadequate home nursing visits. One non-navigated participant extensively and vividly described several unmet needs related to coordination, activation, and advocacy for her cancer care.

Overall, 46% (n=16, five navigated and 11 non-navigated) participants described a negative cancer-care experience related to communication difficulties, lack of understanding or agreement with the treatment plan, lack of coordination of cancer care, loss of trust, or negative attitudes of health-care professionals. Examples of negative experiences encompassed themes of frustration with being unable to readily contact offices for appointments or questions, delays, difficulties with transportation, feeling as if “everything was coming way to fast”, inefficiencies with coordination of care, and communication problems with physicians or other cancer-care health professionals. In four-out-of-five instances in which navigated participants discussed negative cancer-care experiences, they also described how the navigator helped them in the situation. In the fifth case, the participant did not feel she could relate to the navigator as a person. That participant also described several instances of negative experiences in her cancer care. In contrast, for non-navigated participants, the aforementioned negative experiences with cancer care remained unresolved in the majority of instances.

4. Discussion and Conclusion

4.1 Discussion

Previous studies of navigation for cancer care have focused primarily on needs assessments and problem-solving to guide navigation tasks.^{2;14;15} The most compelling finding of our study was the extent to which participants valued navigation for both emotional support and as a personalized, comprehensive, accessible means of facilitating care throughout the cancer treatment period. In this study, navigated patients cherished both the emotional benefits from navigation and the presence of the navigator as an “insider”. This new and important finding has implications for the design of cancer navigation programs: in addition to providing help with instrumental needs, navigators should be trained to recognize, acknowledge, and respond to emotions.

If the most meaningful benefits of navigation are aligned with emotional support, accessibility, and personalized knowledge of them as individuals, then navigator's presence and availability offsets some of the difficulty patients experience accessing the health care system and dealing with impersonal care from health care staff. When navigators understand patients as persons, they tend to be more flexible and offer more approaches adapted to individual needs rather than standardized protocols that work for some but not all patients.

Because patients perceive navigators both as “insiders” to the system, “witnesses”, and/or “someone on my team”, the navigator helps patients distinguish between expected (but non-threatening) variation in cancer care processes and problematic differences in the quality or type of care a patient might receive. Our participants described several examples in which this dual role of the navigator helped avoid errors, address miscommunication, resolve inefficiencies, and improve poorly coordinated care. Non-navigated patients' complaints about negative aspects of cancer care that could have or might have been helped through navigation also provided evidence to support this assertion.

Since navigation was first conceptualized and implemented as a strategy to improve cancer care outcomes, several studies have reported a positive association between navigation and improvements for breast cancer such as access to mammography screening, follow-up, and

patient satisfaction.^{14;16-18} However, very limited information is available on why or how navigation might work to improve cancer care, especially from the perspective of the patients themselves. A qualitative study of older women with breast cancer explored their experiences with nursing case managers and showed that patients valued their nurse case managers for their medical skills, assistance with activities of daily living, emotional support, and education. These findings overlap considerably with our results on navigated patients.¹⁹ Other national programs, such as the American Cancer Society's national navigation program, are designed to assist individuals negotiate the healthcare system and train navigators to systematically address financial, emotional, and logistical aspects of patients' cancer care needs.²⁰ Most work on navigation has focused on the development of needs assessment tools for use in the initial identification and prioritization of navigation tasks (e.g. "Distress Thermometer" developed and endorsed by the National Comprehensive Cancer Network),²¹ with less attention devoted to continuity of navigation tasks throughout the cancer care period.

Patients value the navigator's role as distinct from other health professionals (such as a case manager or a nurse educator) because of the navigator's relative independence from the healthcare system, status as having both an in-depth knowledge of the system, but also a strong alliance to the patient, emphasis on getting to know the patient as a person and explicitly offering to be present in his or her life in a personalized way, and paraprofessional-level of training. The navigator acts as a bridge between two worlds--the fragmented, poorly coordinated health care system and the complex biopsychosocial needs of cancer patients, especially those who are socially disadvantaged.

Limitations—Certain limitations should be acknowledged when interpreting these results. First, we had small numbers of male and colorectal cancer patients in this sample. Although we found that codes and themes were similar for these patients and the overall sample, certain navigation experiences may be specific to gender or cancer type that go beyond what we have reported here. The majority of our participants and all interviewers were female, which may have facilitated the discussion of emotionally-oriented themes. Secondly, the vast majority of our participants had insurance and spoke English, which may have influenced their expectations and experiences regarding navigation. In a sample of lower socioeconomic status or lower educational attainment, we might have observed different themes related to navigation. Thirdly, our navigators received intensive training in communication. Whether similar results would be seen in the absence of such training is not known. Fourth, our results may not apply to programs in which navigators are employed by health systems, as we found that the navigators' independence freed them to consider multiple options and avoid role conflicts. Fifth, although we used the perspectives of those involved in training and supervising navigators in creating our initial interview protocol, there was no explicit involvement of patients and their families in this phase; rather, their perspectives informed further iterations of the protocol during the data collection process. Finally, several of our participants commented on cognitive difficulty or memory problems either as a side effect of the chemotherapy or because of feeling shocked, numb, or overwhelmed at the early stages of their cancer care. Since the interviews were conducted at the end of the study, participants may have had difficulty remembering specific details about navigation expectations or experiences early in their care, especially if they had cognitive difficulties or other memory problems due to their illness or its treatment.

4.2 Conclusion

Cancer patients value navigation. Patients report that navigation offers emotional support, assistance with information needs and problem-solving, help with logistics, and "being there" as a continuous, accessible presence during cancer care. The navigator's independence, status as both an insider to the system and a strong ally to the patient, and paraprofessional-level of

training all contributed to meaningful and effective navigation for patients undergoing breast and colorectal cancer treatment.

4.3 Practice Implications

Our findings, taken together with the work of others, suggest several directions for improving clinical care. Our results support the role of navigation to address fragmented, confusing, uncoordinated, or inefficient care. Our study shows ways in which navigation can help improve cancer care outcomes important to patients such as facilitating access to appointments, providing emotional support to help patients continue with their treatments and remain involved in their care, and helping patients identify their needs proactively in order to assist with problem-solving. Our results are consistent with a recent qualitative study of experts' opinions on barriers and facilitators to high quality cancer care.²² Further research is needed to examine these effects in other cancer patient populations.

“The authors confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the quotations.”

Acknowledgments

We extend our thanks to the patients who participated in our patient navigation research program for sharing their insights, thoughts, and reflections with us. We also deeply appreciate the dedication, commitment, and hard work of the entire navigation staff in our program. This project was financially supported by grants from National Cancer Institute: U01CA116924 (Dr. Fiscella, Principal Investigator) and minority supplements 03S1 and 03S2 (Dr. Jean-Pierre, Principal Investigator).

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Figure 1. Flow diagram of patient participants in study

For cancer patients randomized to navigation (intervention group)

- Was there any specific way that you felt a patient navigator could help you?
- Try to recall a time when the navigator did something particularly helpful.
Please tell me about that time. What did the navigator do, specifically? How was it helpful?
- Try to recall a time when you needed something and the navigator was not able to help out. What was it that you had hoped for? What actually happened?

For cancer patients randomized to usual care (control group)

- Did you receive any help from a patient navigator or social worker – either from this program or the American Cancer Society or any other organization?
- Was there any specific way that you felt a patient navigator could help you?
- As you went through your cancer care, tell me about a specific time when you wished you had help getting the care you needed?

Figure 2. Interview questions

Table 1

Participant socio-demographic and health information

	Overall	
	N	%
Cancer Type		
Breast	28	80%
Colorectal	7	20%
Duration in Study		
Until cancer treatment complete (less than one year)	13	37%
Navigated	8	
Non-navigated controls	5	
One year*	22	63%
Navigated	11	
Non-navigated controls	11	
Gender		
Female	32	91%
Male	3	9%
Age		
Mean (SD)	54.2 (12.7)	
Minimum / Median / Maximum	30 / 55 / 83	
Race & Ethnicity		
White	24	69%
Black\African American	7	20%
Hispanic	2	6%
Choose not to answer	1	3%
Other	1	3%
Place of Birth		
US	31	89%
Outside US	4	11%
Marital Status		
Married/Living as married	13	37%
Other	22	63%
Education		
Less than 12 years	8	23%
12 years or more	27	77%
Household Status		
Homeowner	23	66%
Other	12	33%
Household Size		
Mean (SD)	2.9 (1.9)	
Minimum / Median / Maximum	1 / 2 / 9	
Annual Income		

	Overall	
	N	%
<\$30,000	15	43%
\$30,000 - \$59,000	10	29%
Unknown	10	29%
Employment		
Employed	14	40%
Not employed	21	60%
Health Insurance Status		
Private health insurance	26	74%
Public or no health insurance	9	26%
Total	35	100%

* Most of the 22 participants who ended formal involvement as study participants at one year were continuing on hormonal treatments for five years.

Table 2
Expectations of Navigation

3.2.1 Instrumental Needs

Quotation 1. *The insurance is changing so quickly you can't keep up with all the changes. Even if you have insurance-- your own policy. And you never know all the different places that you can go and ask for assistance or information. [It would be] very helpful to have someone who thinks, 'Well let's just ask this person about this because if it exists, they know where it is.'*

Quotation 2. *What would have been helpful was -- would have been to have someone who I felt I could go to who... would tell me really, you know be realistic with me and say, 'Okay well you know we say its going to take four hours but it's really going to take eight hours,' or something like that...And also to present options.*

3.2.2 Emotional support

Quotation 3. *I really needed to...talk to someone that is not part of the family and friend and this and that, that I can convey some of my feelings*

Quotation 4. *[I expected the navigator would] Help me better understand what was happening...That put me at ease....[I had] a lot of different -- mixed feelings, you know. Some of the things that I was feeling...nerves, a lot of things...[Having a navigator] put my mind at ease.*

3.2.3 Nonspecific Expectations

Quotation 5. *I didn't know how I was gonna do and find everything out that I needed to know. I was excited that I got a navigator. It would be another person to turn to if I had questions or something...I had concerns about understanding treatments, and understanding what was involved with having cancer. I didn't have a car so I was worried about transportation, and I was worried about who's gonna watch my kids...I had many, many concerns...every area of my life I guess. Everything.*

Table 3
What are the most effective (i.e., meaningful or valuable) aspects of navigation?

3.3.1 Emotional support
<p><i>Quotation 6. My navigator was always... there for me, calling me, you know. Physically and emotional support. [To] see how I'm doing -- if there's anything... she can do for me... it's somebody that ... I can talk to. Really like have that connection.</i></p> <p><i>Quotation 7. I definitely felt like it was another person who was involved in my... appointments and knew what was going on in my life, and... if I had something on my mind... I could talk to her about it.</i></p>
3.3.2 Being there
<p><i>Quotation 8. To be able to know that there was somebody that I could have called if things were really desperate was immeasurable.</i></p>
3.3.3 The navigator as an insider
<p><i>Quotation 9. It was really nice to know that when I was going up for a treatment that my navigator was gonna be there. It's not that I needed her to sit with me the whole time, and she usually couldn't, [but] she would have if I'd asked her to. But it was just nice to see her face and touch base with her, and it gave some real continuity to the whole process. Especially through chemo. You have a different nurse every time, you never know who it's gonna be. They [the nurses] are wonderful and they're friendly and so forth but it's "Ok, who's it gonna be this week, who's it gonna be next week" whereas your navigator is sort of that constant through it.</i></p> <p><i>Quotation 10. If it hadn't been for [my navigator]...I went almost three months without my [medication insurance coverage] and she got it all straightened out for me so I didn't have to pay for prescriptions. She got a lot of help- we got the paperwork worked out. I had to make phone calls and stuff, but I got the paperwork and it was made out properly. And she got me information, pamphlets, got a hold of the cancer people because we knew that my breast was going to be removed. Oh goodness, she helped me so much. Just being able to talk to me, but she definitely got a lot of information because I knew nothing about cancer... I just knew that they were going to remove my breast. That was my option and that's what I went for. I didn't want to do chemo because I knew I was already sick, so...She came and visited me when I went through the emergency room and that was nice. I didn't have anybody, you know. She was there...supportive..and...just made me feel better.</i></p>