Patient-Reported Measures of a Breast Cancer Nurse Navigator Program in an Underserved, Rural, and Economically Disadvantaged Patient Population

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OBJECTIVES: To assess the efficacy of the University of New Mexico Comprehensive Cancer Center's (UNMCCC's) breast cancer nurse navigator (BCNN) program in addressing gaps in cancer care for an underserved, rural, and economically disadvantaged population.

SAMPLE & SETTING: 54 navigated patients under the care of the BCNN and 32 non-navigated patients whose care began prior to the start of the program.

METHODS & VARIABLES: Surveys were administered anonymously to patients during regularly scheduled appointments at UNMCCC.

RESULTS: Navigated patients more strongly agreed that they were prepared for the beginning of treatment and that calls were returned promptly, and showed a decreased desire for an after-treatment summary compared to non-navigated patients.

IMPLICATIONS FOR NURSING: Navigated patients report better understanding of and engagement with the healthcare system when assisted by a BCNN during breast cancer treatment with curative intent, as well as desire fewer services than non-navigated peers, indicating greater satisfaction.

KEYWORDS breast cancer; nurse navigator; patient satisfaction; utilization; socioeconomic status
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Nurse navigators are designated nurses who are specially trained to follow and support patients and families through cancer treatment (Freeman, 2012). One of the goals of a nurse navigator is to ensure that patients, particularly those with lower socioeconomic status, can move effectively through the system and receive the best care possible in a timely manner. Many programs designed to reduce racial and ethnic disparities in breast cancer care use nurse navigators to further that goal (Capitman et al., 2019; Freeman, 2006a, 2006b; Freeman et al., 1995).

The University of New Mexico Comprehensive Cancer Center's (UNMCCC's) patient population is socioeconomically diverse, with a population that is highly rural, of lower socioeconomic status, and largely comprised of people of color. In the 2020 census, New Mexico's population was 47.7% Hispanic, which was the highest percentage in the nation, and 8.9% Native American, second only to Alaska. The population was also 21% rural, a significantly higher percentage than in other southwestern states (U.S. Census Bureau, 2021a). UNMCCC's catchment area is the entire state of New Mexico, which measures 121,000 square miles and is the fifth largest and sixth least densely populated state in the United States (U.S. Census Bureau, 2021b). Were one to overlay the land mass of New Mexico over the Eastern Seaboard, half of it would include 20 National Cancer Institute–designated cancer centers (UNMCCC, n.d.).

People of color and rural patients face disadvantages in many areas of health, and breast cancer is

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no different. Although Hispanic women—a large population at UNMCCC—are less likely to develop breast cancer than non-Hispanic White women, they are more likely to be diagnosed at the regional stage rather than at the localized stage (Banegas & Li, 2012; Power et al., 2018). This trend of late diagnosis of breast cancer may also be true for some Native American women (Kaur et al., 2014). For example, despite an overall decrease in mortality from breast cancer in the U.S. general population, the rate for Native American women remained broadly flat from 1990 to 2009 (White et al., 2014). These disadvantages are also similar to the well-studied disparities faced by Black breast cancer survivors (Husain et al., 2019). Regarding socioeconomic status, New Mexico has the lowest percentage of employer-provided insurance coverage (36.6%) and the highest percentage of Medicaid coverage (32.7%) of the 50 states, excluding data from Puerto Rico. New Mexico is also one of only six states where more than half of births are financed by Medicaid (54%) (Gifford et al., 2017; Kaiser Family Foundation, 2019).

Previous studies have found that in highly coordinated healthcare systems like UNMCCC—where providers, imaging services, and ancillary services are co-located—navigated patients receive significantly better care coordination, psychosocial care, and patient education than their non-navigated peers (Campbell et al., 2010; Wagner et al., 2014). In addition, patients who are navigated may experience a reduction in the time between diagnosis and start of treatment (Rohsig et al., 2019), although applicability to the current study's patient population and care setting is limited. The effect of navigation on patient understanding seems to be reproducible, as 90% of those who received information from a breast cancer nurse navigator (BCNN) felt satisfied and comfortable with their understanding of the disease (Trevillion et al., 2015). Similarly, prior research has shown that patient satisfaction is higher and distress is lower in navigated patients than in non-navigated patients (Dillon et al., 2021; Williams et al., 2004). According to Mertz et al. (2017), 42% of Australian people with breast cancer agreed that having a navigator-like contact would have improved their care experience. Many studies have attempted to measure the cost of healthcare usage with a BCNN, with some showing no difference in expenditure between navigated and non-navigated patients with breast cancer and others showing a significant increase after a telemedicine nurse navigator consult (Adler et al., 2019; Mertz et al., 2017). None have assessed whether a difference exists in patients' desires for service usage.

With the goal of improving care coordination, psychosocial care, patient education, and healthcare usage, UNMCCC instituted a BCNN program in 2017 to help guide patients within the organization. UNMCCC currently employs one full-time BCNN specifically for patients with breast cancer undergoing treatment with curative intent. This study aimed to evaluate usage of the BCNN program at UNMCCC by comparing the desire for services, use of services, and feelings of preparedness between navigated and non-navigated patients.

Methods

Sample and Setting

Surveys to assess patient satisfaction and services used were administered anonymously during regularly scheduled appointments at UNMCCC between April 29 and June 7, 2019, to patients with breast cancer who were either undergoing or had previously undergone treatment with curative intent. The survey was designed by the authors, with input from other stakeholders in the BCNN program at UNMCCC, including oncologists and the BCNN. This study was reviewed by the University of New Mexico Institutional Review Board, and consent was deemed not necessary because of the de-identified nature of the data collection.

Procedures and Data Analyses

Patients under the care of the BCNN (navigated patients) and those whose care began prior to the beginning of the program (non-navigated patients) were assessed. Patients were assessed at any point after completion of definitive treatment (surgery, chemotherapy, radiation therapy, or a combination thereof), but may have been receiving adjuvant endocrine therapy at the time that the surveys were completed. All patients with regularly scheduled appointments meeting the eligibility criteria were noted by the BCNN, clinic nurses, and physicians. Surveys were then administered to patients by the medical assistant who performed check-in and rooming of all patients. Patients were instructed to leave their completed survey in the room. The medical assistant collected the completed surveys while preparing the room for the next patient and placed them in a secure box in the nursing station. Surveys that were incomplete or not completed were securely discarded.

Overall, 32 non-navigated patients and 54 navigated patients completed the survey. Baseline patient

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demographics and questions regarding patients' specific point in their treatment journey were omitted in the hopes of shortening the survey and increasing the response rate, while also protecting patient confidentiality. The survey was written in English, but interpretation services were available from an in-person Spanish interpreter if needed. The first section of the survey focused on patients' experiences with the BCNN or office staff, such as whether they felt adequately prepared to start treatment, whether telephone calls were returned quickly, and how well patients perceived side effects to be controlled. Patients were asked to circle the degree to which they agreed with each statement on a Likert-type scale, and each response option was converted to a numeric score ranging from 1 to 5 (1 = strongly agree, 2 = agree, 3 = neutral, 4 = disagree, and 5 = strongly disagree). A Likert-type scale was used to standardize responses and allow for statistical comparison of highly subjective statements. For navigated patients, the statements referred to the BCNN as the source of support, whereas for non-navigated patients, "nurse navigator" was replaced with "office staff." The definition of "office staff" was left intentionally vague because patients interact with many different roles throughout treatment at UNMCCC, and the intent was to ensure that all staff were included. Physicians and advanced practice providers were intentionally and explicitly omitted.

The second group of questions was related to service usage and the desire for services. The instructions asked patients to rank the importance of their usage of or desire for use of services, such as educational information, appointment scheduling, emotional support, transportation assistance, and referral for financial and insurance assistance, on a scale from 1 to 9, with 1 being the most important, 2 being the second most important, and so on. However, only seven patients between both groups used the scale as intended. Instead, most patients ranked the items based on value (i.e., 9s on three items and 1s on two items, with the remainder left blank). This complicated the analysis of these data significantly, and, as such, two different analyses were performed. The first analysis was conducted based on the small number of patients who answered the questions as intended, which used the values as recorded by the patients. For the second analysis, which was intended to ensure that all responses were counted, responses were converted into binary responses, with any response counting as 1 and no response counting as 0. For both the ranked and binary analyses, results from each category, the desire for further services, and the strength of their importance to patients were summed to get an overall measurement of use of services.

For the intended Likert-type scale response analysis and the binary response analysis, statistical analyses included t tests with two tails and 95% confidence intervals. Analyses assumed unequal variation between groups because of the different numbers of responses in each group and an alpha of 0.05.

TABLE 1. Breast Cancer Nurse Navigator Patient Satisfaction Survey Scores

	Navigated Patients		Non-Navigated Patients		
Statement	N	$\bar{X}$	N	$\bar{X}$	p
I was adequately prepared to start cancer treatment.	52	1.56	29	2.1	0.02
At completion of your breast cancer treatment, would you find it helpful to receive an after-treatment summary?	49	0.92	29	1	0.044
My calls to the nurse navigator/office staff were returned quickly.	51	1.33	30	1.8	0.003
I felt that the nurse navigator/office staff was familiar with me and my treatment plan.	53	1.51	31	1.81	0.13
The nurse navigator/office staff helped me understand my treatment plan.	51	1.55	31	1.71	0.44
The nurse navigator/office staff took my concerns seriously.	53	1.43	31	1.52	0.58
The nurse navigator/office staff helped me manage side effects.	45	1.69	26	1.92	0.36

Note. Patients were asked the degree to which they agreed with each statement on a Likert-type scale ranging from 1 (strongly agree) to 5 (strongly disagree), with lower scores indicating greater satisfaction.

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Results

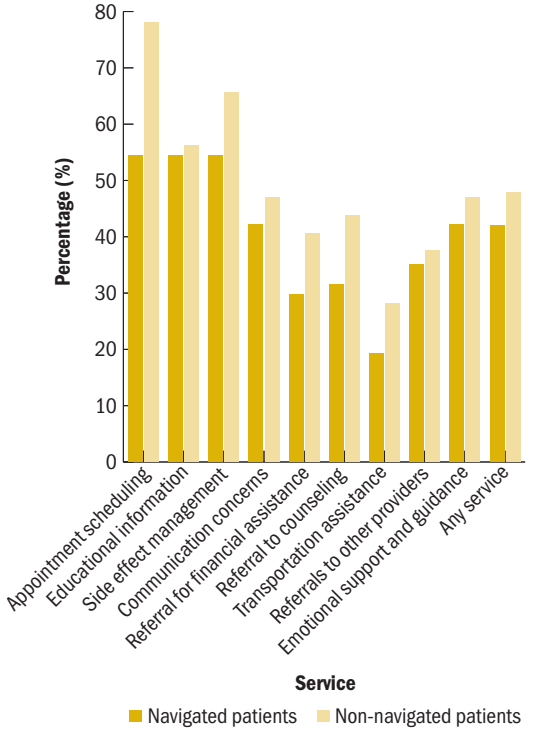
From April to May 2020, a total of 86 patients completed the surveys (n = 54 navigated patients and n = 32 non-navigated patients). Navigated patients more strongly agreed that they were prepared for the beginning of treatment as compared to non-navigated patients ($\bar{X}$ = 1.56 versus $\bar{X}$ = 2.1, p = 0.02) (see Table 1). Navigated patients also showed a decreased desire for an after-treatment summary ($\bar{X}$ = 0.92 versus $\bar{X}$ = 1, p = 0.044), and they more strongly felt that their calls were returned promptly when compared to non-navigated patients ($\bar{X}$ = 1.33 versus $\bar{X}$ = 1.8, p = 0.003). Navigated patients were more likely to agree that the BCNN was more knowledgeable about their treatment plan ($\bar{X}$ = 1.51 versus $\bar{X}$ = 1.81, p = 0.13), better helped them to understand their treatment plans ($\bar{X}$ = 1.55 versus $\bar{X}$ = 1.71, p = 0.44), took their concerns more seriously ($\bar{X}$ = 1.43 versus $\bar{X}$ = 1.52, p = 0.58), and better helped them to manage side effects ($\bar{X}$ = 1.69 versus $\bar{X}$ = 1.92, p = 0.36) as compared to office staff for non-navigated patients, but these results were not statistically significant.

There was no statistically significant difference in use of any service except for appointment scheduling, with navigated patients using scheduling services at a significantly lower rate than non-navigated patients (54% versus 78%, p = 0.017) (see Figure 1). Compared to non-navigated patients, there was a non–statistically significant decrease in use of educational information (54% versus 56%, p = 0.92), assistance with side effect management (54% versus 66%, p = 0.59), help with communication concerns (42% versus 47%, p = 0.83), referral for financial and insurance assistance (30% versus 41%, p = 0.4), referral to counseling (32% versus 44%, p = 0.724), referral for transportation assistance (19% versus 28%, p = 0.457), assistance with referrals to other providers (35% versus 38%, p = 0.97), and emotional support and guidance (42% versus 47%, p = 0.83) among navigated patients. There was not a significant difference when aggregating all services together, with 42% of navigated patients and 48% of non-navigated patients using the services measured (p = 0.11).

Overall, navigated patients wanted services significantly less than non-navigated patients (19% versus 30%, p = 0.00017), and navigated patients desired referral to counseling significantly less often (16% versus 27%, p = 0.048) (see Figure 2). There was also subjectively less desire for educational information (16% versus 30%, p = 0.24), assistance with side effect management (18% versus 36%, p = 0.097), assistance with communication concerns (20% versus 33%, p = 0.17), referral for financial and insurance assistance (20% versus 33%, p = 0.19), referral for transportation assistance (16% versus 27%, p = 0.26), assistance with referrals to other providers (18% versus 30%, p = 0.23), and emotional support and guidance (22% versus 33%, p = 0.22), but these differences were not significant. There was no difference in desire for help with appointment scheduling (24% versus 23%, p = 0.98).

When patients were asked to rank the importance of services rendered by the BCNN or the office staff, navigated patients were less likely to rank most services as very important, including assistance with appointment scheduling ($\bar{X}$ = 2.42 versus $\bar{X}$ = 2.05, p = 0.39), assistance with communication concerns ($\bar{X}$ = 2.88 versus $\bar{X}$ = 2.62, p = 0.41), referral to counseling and support groups ($\bar{X}$ = 5.64 versus $\bar{X}$ = 4.36, p = 0.34), assistance with the management of symptoms and side effects ($\bar{X}$ = 3.65 versus $\bar{X}$ = 1.76, p = 0.41), and educational information ($\bar{X}$ = 2.68 versus $\bar{X}$ = 1.75, p = 0.054) (see Figure 3). There was no difference between groups in ranking the importance of emotional support and guidance ($\bar{X}$ = 3.25 versus $\bar{X}$ = 3.17, p = 0.93), assistance with transportation ($\bar{X}$ = 5.86 versus $\bar{X}$ = 6.13, p = 0.88), and referrals for

FIGURE 1. Binary Analysis of Self-Reported Services Received (N = 82)



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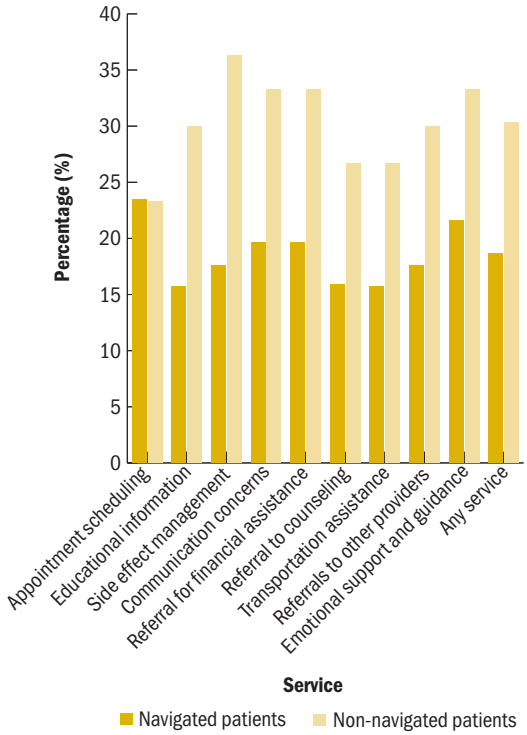
financial assistance ($\bar{X}$ = 4 for both groups, p = 1). With all data points combined, navigated patients ranked services used as slightly less important to them than non-navigated patients ($\bar{X}$ = 3.34 versus $\bar{X}$ = 3.09, p = 0.21), without a statistically significant difference.

When measuring the number of patients with a primary care provider, 50 navigated patients and 29 non-navigated patients reported having a primary care provider (p = 0.53).

Discussion

Patients under the care of the BCNN wanted services significantly less frequently than their non-navigated peers while showing similar use, suggesting that navigated patients were able to access all the services they wanted through the BCNN. These results support prior research from the United States and other countries that found that patients reported overall higher satisfaction with care received and increased feelings of control over their care when under the care of a BCNN (Berezowska et al., 2021; Dillon et al., 2021; Hook et al., 2012; Loiselle et al., 2020; Mertz et al., 2017).

FIGURE 2. Wanted Services Among Total Respondents (N = 82)



KNOWLEDGE TRANSLATION

- Patients who received care from a breast cancer nurse navigator (BCNN) wanted services significantly less frequently than non-navigated patients, despite showing similar use.
- Navigated patients desired referral to counseling significantly less often and had a decreased desire for emotional support, suggesting an underlying emotional support mechanism when a BCNN assists patients.
- Patients under the care of a BCNN felt that their telephone calls were answered quickly, showed a decreased desire for an after-treatment summary, and felt more prepared to begin treatment, all of which suggest better engagement with the healthcare system.

Further supporting the belief that navigated patients are more satisfied with the care they received was the stronger agreement that they were prepared for the beginning of treatment (1.56 versus 2.1, p = 0.02) and the perception that their telephone calls were returned more quickly (1.33 versus 1.8, p = 0.003), all while showing a decreased desire for an after-treatment summary (0.92 versus 1, p = 0.044). Considering the retrospective nature of the survey questions, the study results also indicate that patients under the care of a BCNN felt more knowledgeable overall about their care, which supports the findings of a previous study in a similar system (Wagner et al., 2014). Patients' satisfaction and feelings of control, combined with the decrease in use of services, are similar to the findings of a randomized controlled trial conducted in the Netherlands (Berezowska et al., 2021), which has a healthcare system with significantly different barriers to care and a very different patient population.

The decrease in use of assistance with scheduling appointments between patients receiving care from the BCNN and patients receiving care from office staff (54% versus 78%, p = 0.017) indicated that the BCNN acted prior to the patient needing intervention. This supports previous research showing that the use of a BCNN decreased the time between diagnosis and treatment by scheduling appointments more quickly, which may have led to meaningful differences in outcomes, particularly for patients of lower socioeconomic status and underrepresented patients, who often experience delays in care (Battaglia et al., 2007; Husain et al., 2019). The BCNN may have also served as a proxy for other services, such as psychiatric care and nutrition, by counseling patients, thereby eliminating the desire for formal consultation with these

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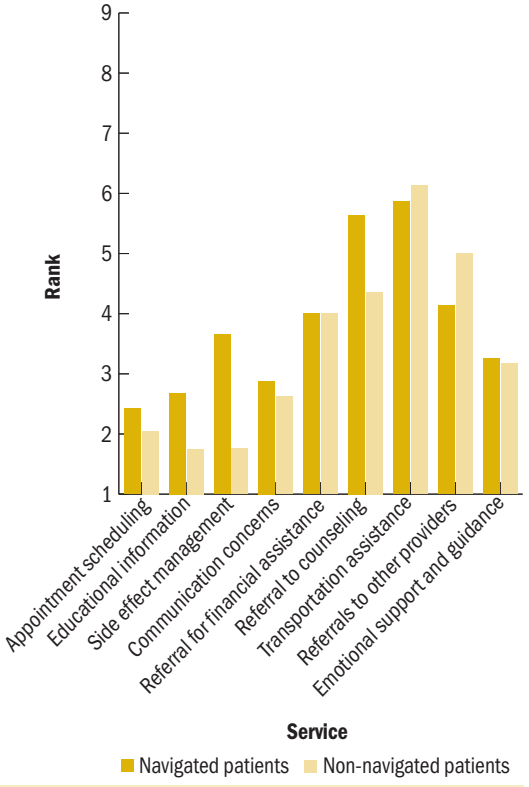
services. Navigated patients desired referral to counseling significantly less often than non-navigated patients (16% versus 27%, p = 0.048) which, in conjunction with the subjective decrease in desire for emotional support (22% versus 33%, p = 0.22), suggests that there is an underlying emotional support mechanism when a BCNN assists patients. This is an area shown to be of significant importance to women aged younger than 50 years (Pedersen et al., 2014).

Limitations

This study has several limitations. Although the survey was conducted in a prospective manner, patients were asked to recall their past experience with cancer treatment after definitive therapy, which may introduce recall bias. The surveys were not validated either psychometrically or via a process for face validation in this population, potentially allowing bias to be introduced in the questions. This was a small study, which likely limited the power of the analysis to detect meaningful differences and may have limited the results. The different styles of responses to the ranking in the second section of the survey presented another challenge, further limiting the sample size and intended analysis, and possibly masking statistically significant effects. The instructions were likely the source of confusion, which asked patients to do the following: "Rank all those you thought were important, with 1 being the most important, 2 being the second most important, etc. You do not have to rank all options." Further clarity, such as "Rank only one option as 1," would have likely prevented this.

Nurse navigation programs vary broadly from system to system, reflecting local needs as intended, so the generalizability of this work may be limited (Paskett et al., 2011). The integrated nature of UNMCCC, where all oncology services outside of major surgical care and inpatient management are co-located in one building, could potentially show different results than would be seen in a more fragmented care system. However, in a more fragmented system, the effects of a BCNN may be even more pronounced. Lastly, treatments may change over time, practices can vary among oncology providers, and disease stage differs among patients. Therefore, it is unlikely that patients received the exact same care, resulting in both inter- and intragroup variations.

FIGURE 3. Importance of Services Received or Rendered Among Total Respondents (N = 82)



Note. Patients were asked to rank the importance of services rendered from 1 (most important) to 9 (least important).

Implications for Nursing and Conclusion

The results of this study showed that patients in a diverse, underrepresented, rural, and economically disadvantaged population report better understanding of and engagement with the healthcare system when assisted by a BCNN during the treatment of breast cancer with curative intent. Patients who received care from a BCNN desired fewer services than their non-navigated peers, indicating greater overall satisfaction with their cancer care. Understanding of and engagement with health care, as well as patient satisfaction, are all important aspects of patient care, particularly because underserved populations are at increased risk of poor outcomes. Therefore, these areas merit future research to mitigate health disparities and ensure equitable care for all patients.

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Williams and Dayao completed the data collection. Williams and Tawfik provided statistical support. Williams, Dayao, Brown-Glaberman, and Tawfik provided the analysis. Williams and Tawfik contributed to the manuscript preparation. All authors contributed to the conceptualization and design.

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