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The patient patient: The importance of knowing your navigator

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The patient patient: The importance of knowing your navigator

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Abstract

In Ontario, Diagnostic Assessment Programs (DAPs) have been implemented to improve the quality of care patients receive during the diagnostic phase of the cancer journey. Patient navigators play a critical role in this model by coordinating care and providing information and support to patients and their families. The objectives of this study were 1) to determine whether patient navigation in DAPs is associated with a better patient experience and 2) to examine whether patient navigation in DAPs modifies the effect of wait times and patient volumes on patient experience. Data reflecting patients' experience within the DAP were collected via survey and an average experience score was calculated for each region. To ascertain the relationship between patient experience, wait times and volumes, correlation coefficients were computed between regional patient experience scores and total regional patient volumes and between regional patient experience score and regional diagnostic wait times. To understand the impact of navigators on the patient experience, the sample was subdivided according to whether or not the respondent reported knowing their navigator. Patients who knew their navigator rated their experience significantly better than those who did not. For those who did not know their navigator, there was an inverse and significant correlation between patient experience scores and wait times; patients in regions with long waits had poorer experience scores overall. Patients who knew their navigator reported consistently good experience regardless of their diagnostic wait. The navigator appears to mitigate the negative impact of longer wait times on experience.

Keywords

Patient experience, lung cancer, diagnostic assessment, patient navigation

Introduction

The journey from suspicion of cancer to a definitive diagnosis or rule out can be a confusing and anxious time for patients. Patients with a suspicion of cancer will often require numerous tests and visit multiple healthcare professionals,^{1,2} often making transitions from one health care provider to another^{2,3}. To improve the quality of care during the diagnostic phase of the cancer journey, Cancer Care Ontario (CCO), an agency of the provincial government of Ontario and the province's principal adviser on cancer care, supports the development and implementation of Diagnostic Assessment Programs (DAPs) in all regions across Ontario^{1,2,3,4}. DAPs provide a single point of entry for patients to access centralized services that can include diagnostic tests, staging and comprehensive care. Multidisciplinary health-care teams in DAPs work in a collaborative setting to provide high-

quality, evidence-based, patient-centered care and aim to minimize system delays. DAP programs rely heavily on a model of patient navigation, where a trained professional coordinates the care for patients through the system of diagnostic testing^{2,5}. Patient Navigators also provide the necessary support and information about cancer to patients and their families and refer them to additional supportive services (e.g. social work) as required^{1,2,3}. Navigation support in each DAP currently ranges from 0.2 to 3.8 full time equivalents (FTE) of nursing staff. The majority (95%) of patient navigators working in Ontario DAPs are nurses.

The published literature suggests that one of the strongest known benefits of patient navigation during the diagnostic phase of care is in helping patients complete their cancer screening⁶. Researchers in the United States have even demonstrated cost savings associated with the improved diagnostic resolution achieved with patient navigation⁷.

There is also evidence to suggest that navigation has an impact on patient experience and quality of life ⁸. A retrospective cohort study of head and neck cancer patients with access to patient navigators reported that patients felt less stressed about their future, their body image, and communication or social issues arising from their cancer, and had greater satisfaction with the care they received during their cancer treatment ⁸. In a cross-sectional study of patient perceptions of navigation, 98% of patients who were assigned a navigator reported being grateful that the service was provided, and up to 95% agreed that navigation was an important addition to diagnostic care⁹. When the satisfaction levels of cancer patients with and without a navigator have been directly compared, multiple studies have reported higher levels of satisfaction in patients with a navigator compared to those receiving conventional care ^{10,2}. The evidence for a positive impact of patient navigation on satisfaction is not, however, undisputed. One study that looked at satisfaction measures before and after cancer care found no relationship between patient navigation and overall patient satisfaction ¹¹ but a possible role for navigation in addressing the barriers that are known to affect patient experience ¹¹.

One of the key mechanisms by which patient navigators appear to improve patient satisfaction is through patient education. Navigators routinely play an education role, in which they enable patients to better understand their medical condition and help them manage their anxiety ¹. Those cancer patients who understand information relating to their own health have been found to have less stress and to be more confident and knowledgeable, allowing them to more easily participate in the processes of care and recovery ¹². In a retrospective cohort study of breast cancer patients, navigators were seen to increase patient appreciation as well as knowledge of their personal health and the importance of post-operative or post-treatment practices ¹³. In this study, the use of a navigator increased adherence to a set of pre-determined quality indicators by 27%, significantly improving the rate of follow-up mammograms, systemic therapy use and survivorship quality of life ¹³. Interestingly, patient navigation has been found to continue to enhance patient self-care and health practices beyond the termination of the patient-navigator relationship as a result of increased patient knowledge ¹³.

Waiting for diagnostic results is difficult and a patient's healthcare experience can be affected by the length of time that they have to wait throughout their cancer journey ^{14,15,16,17}. Patient navigation programs in cancer care have been found to provide immediate improvements in both wait time and access to care ². A Multidisciplinary Lung Cancer Clinic (MLCC) in the United States that implemented nurse navigators managed to decrease the time from diagnosis to treatment or therapy from 1 to 3

months, down to 14 days in 92% of lung cancer patients ¹⁰. The same MLCC reported a large increase in patient satisfaction after the introduction of nurse navigators, regardless of diagnosis or disease outcome ¹⁰. Similarly, a study of the effectiveness of patient navigators found that among patients who were randomly assigned to a navigator, only 6% of those with an abnormal mammogram did not have a definitive diagnosis after 60 days, compared to 22% among those randomly assigned to the group without access to a navigator ¹⁸. This decrease in wait time was found to be associated with lower anxiety and greater patient satisfaction, regardless of the result of the diagnosis ¹⁸. A study of wait times for breast cancer care in Canadian regional cancer centers found that the utilization of nurse navigators to streamline care and provide information and support to patients significantly decreased wait time for surgery and increased patient satisfaction through enhanced care and communication ¹⁹.

Research to date suggests that patient navigation may enhance a program's capacity to meet demands for care and several studies have focused on the role of navigation in managing high volumes of patients in a clinical program ^{1,10}. Navigators have been described as particularly helpful for managing complex cases in high volume situations, especially in organizing multidisciplinary work ¹. It has also been found that navigators allow programs to provide care to more patients. For instance, a study of lung cancer patients found that following the introduction of a navigator to coordinate services for patients, 48% more patients could be seen and treated at the cancer center ¹⁰. It is appreciated that this greater capacity may result in higher patient volumes, which may negatively affect the amount of navigation time per patient. However there is a dearth of research assessing the impact of patient volume on experience or satisfaction with care during the diagnostic phase of the cancer journey.

Given the extant literature that demonstrates the link between navigation and greater patient satisfaction, decreased wait times, and an ability to manage greater patient volumes, this study aimed to determine the relationship between patient experience and navigation, wait times and patient volumes for patients undergoing diagnostic assessment for suspected lung cancer in DAPs in Ontario. The objectives of this study were 1) to determine whether patient navigation in DAPs is associated with a better patient experience and 2) to examine whether patient navigation in DAPs modifies the effect of wait times and patient volumes on patient experience.

Methodology

One year of data from the DAP provincial Patient Experience Survey (PES), collected from July 1, 2012 to June 30, 2013 was used for this study. The survey targets

patients undergoing diagnostic testing for suspicion of thoracic/lung cancer in DAPs across the Province of Ontario. Administrative data regarding patient wait time from referral to diagnosis was collected from all thoracic/lung DAPs for the same time period. The unit of analysis was the Regional Cancer Program (or 'region'), of which there are 14 in Ontario.

Patient Experience Survey

DAP patient experience scores were derived from the PES, an anonymous, 18 item, retrospective survey routinely used in all 15 lung/thoracic DAPs across the 14 regional cancer programs in Ontario. The survey asks a variety of questions about DAP patients' experience, including information, communication, and emotional support, as well as their relationship with the DAP patient navigator. Thirteen questions relate specifically to the patient's experience in the Diagnostic Assessment Program. The remainder includes 2 demographic questions, 2 questions about the patient's levels of anxiety and fear and 1 question asking whether the patient knew their navigator. The DAP PES was adapted from the Ambulatory Oncology Patient Satisfaction Survey (AOPSS), a survey developed and validated in Canada by the National Research Corporation²⁰ and used in at least two provinces across the country. Ten of the 18 PES items were derived from the AOPSS, although slightly modified after face validity testing for the purpose of using them with the DAP patient population. A list of the survey questions can be found in Appendix 1.

The PES is routinely administered by DAP Navigators or nurses to each patient visiting a DAP. There is no systematic follow-up for compliance except for the encouragement of the Navigator or nurse to complete the survey at the end of their diagnostic testing. Completed surveys are returned directly to Cancer Care Ontario online or by mail. This work reflects the data from surveys received between July 1, 2012 and June 30, 2013.

A composite patient experience rating was calculated for each patient by scoring the responses from each of the 13 questions that addressed aspects of patient experience on a 4-point scale and adjusting for the number of patient experience questions answered. A regional score was then derived based on the average composite score among patients in each region for the entire time period in question.

The survey also contains one question asking patients to identify whether or not they knew their Navigator and two demographic questions regarding the patient's level of education and age. The question of whether the patient knew their Navigator was used as a stratifying variable and in this study was considered a proxy for whether the patient used the services of the Navigator. The demographic variables were used to determine the

comparability between those who knew their Navigator and those who did not.

Administrative Data

Time points for wait time calculations and patient volumes from July 1, 2012 to June 30, 2013 were obtained from administrative datasets held by Cancer Care Ontario. The diagnostic wait time interval (from referral to diagnosis) was calculated as the time from referral to a DAP to the date on which a pathology or imaging report confirmed a patient's diagnosis or rule out of cancer²¹. For each region, the 50th, 75th and 90th percentiles of the wait time interval were studied to understand regional variation in diagnostic wait times. Patient volumes were also calculated, reflecting the total number of patients in each region who received care from a DAP during the year of interest.

Analyses

In order to investigate the representativeness of the survey respondents with respect to the overall DAP population of patients, patient age from the DAP administrative data was compared to self-reported demographic information from the patient experience survey. A between-group comparison was also performed to look at differences between the group who knew their Navigator and those who did not, focusing on age and level of education. These demographic analyses were undertaken utilizing chi square tests to determine if there were significant differences in the distribution of the data between the groups.

It was not possible to link survey data to administrative data at the patient level because the survey was anonymous and no patient identifiers were available. However, survey and administrative data were aggregated and linked at the regional level. As a result, all analysis involving survey data and other DAP data (i.e. volumes, wait times) were performed with the region as the unit of analysis (n=14).

In order to ascertain the relationship between patient experience, wait times and volumes, Pearson correlation coefficients were computed between regional patient experience scores and total regional patient volumes and between regional patient experience score and the 50th, 75th and 90th percentile of regional diagnostic wait time.

To understand the impact of navigation on the patient experience, the sample was subdivided according to whether or not the respondent reported knowing their Navigator. The navigation and non-navigation groups were analyzed separately using Pearson correlations to explore the relationship between wait times or volumes and patient experience ratings. These two groups were also compared using a Student's t-test to determine the overall effect of navigation on patient experience rating.

Results

Patient Experience Survey Response Rate

The Patient Experience Survey (PES) had an overall response rate of 20.9% (1,325 PES responses received out of a total of 6,327 DAP patients in that time period) and response rates varied by region from 5 to 44%. Among those surveys received, the completion rate was 97.5%. The proportion of respondents who reported knowing their Navigator was 75.8% (1,005) while 24.3% reported that they did not. The rate of respondents indicating they knew their Navigator varied by region between 58% and 91%. In the PES, patient age was captured as an ordinal variable and 60.9% of respondents were in the 55-74 age category (Table 1). PES respondents, whether they reported knowing their Navigator or not, had the same age distribution as the overall DAP population. There were also no significant differences in education between those who knew their Navigator and those who did not. The most prevalent education category was ‘high school’, accounting for 38.8% of those who knew their Navigator and 31.8% of those who did not.

Patient Experience Ratings

On the whole, the group of patients who knew their Navigator had significantly higher average ratings of patient experience compared with the group of patients who did not (91.7 compared to 81.5, $t(11)=8.520$, $p<0.0001$).

At the regional level, there was no significant correlation overall between average patient experience rating scores and diagnostic wait times, whether at the 50th, 75th or 90th percentile (Table 2). However, for the group of patients who did not know their Navigator, there was an inverse and statistically significant correlation between patient experience scores and wait times, measured at the 75th and 90th percentiles ($r=-0.580$, $p=0.04$ and $r=-0.590$, $p=0.04$), implying that for those patients in regions with very long waits, there was poorer experience overall. This relationship did not hold true among the group of patients who knew their Navigator ($r=-0.430$, $p>0.158$ at the 75th percentile and $r=-0.389$, $p=0.206$ at the 90th percentile) (see Figures 1 and 2).

Table 1. Survey Response and Demographic Characteristics

	RESPONDENTS TO THE QUESTION: “DID YOU KNOW WHO THE NAVIGATOR WAS?”		TOTAL SURVEY RESPONDENTS	OVERALL DAP POPULATION
	“Yes” N (%)	“No” N (%)		
TOTAL	1,005 (75.8)	320 (24.2)	1,325 (20.9)	6,327 (100)
AGE				
18 - 34	1 (0.1)	1 (0.4)	2 (0.2)	69 (1.1)
35 - 54	76 (7.5)	25 (10.2)	101 (8.1)	724 (12.0)
55 - 74	623 (61.7)	141 (57.6)	764 (60.9)	3446 (57.2)
75 or older	309 (30.6)	78 (31.8)	387 (30.9)	1790 (29.7)
EDUCATION				
Elementary	160 (16.1)	48 (20.1)	208 (16.9)	Not collected
High School	385 (38.8)	76 (31.8)	461 (37.5)	Not collected
Technical	274 (27.6)	65 (27.2)	339 (27.6)	Not collected
Undergraduate	75 (7.6)	21 (8.8)	96 (7.8)	Not collected
Graduate	97 (9.8)	29 (12.1)	126 (7.8)	Not collected
Average Patient Experience Score	91.7%	81.5%		n/a

Table 2. Relationship Between Regional Diagnostic Wait Times and Patient Experience Scores, by Navigation Status

	Navigation Status	Association with Pt. Experience	
		R*	p-value
Diagnostic Wait Times Measured at the 50 th Percentile	Navigation	0.185	0.563
	No Navigation	0.288	0.360
	All	0.007	0.982
Diagnostic Wait Times Measured at the 75 th Percentile	Navigation	0.430	0.158
	No Navigation	0.580	0.044
	All	0.268	0.396
Diagnostic Wait Times Measured at the 90 th Percentile	Navigation	0.389	0.206
	No Navigation	0.590	0.040
	All	0.216	0.497
DAP Patient Volumes	Navigation	0.009	0.979
	No Navigation	0.100	0.755
	All	0.390	0.205

*These values are the square roots of R² values as generated using the RSQ function using median Wait Times by region and average question score by region.

*Note: Two regions - South East and Erie St. Clair - did not have any PES data entries available in the specified time period

There were no significant relationships between regional DAP patient volumes and regional patient experience ratings, either overall ($r=0.390$, $p=0.205$), for groups of respondents who knew their Navigator or for groups who did not ($r=-0.009$, $p=0.979$ and $r=0.100$, $p=0.755$) (see Figure 3).

Discussion

This study demonstrates that patient navigation offered during the diagnostic phase of the cancer journey may be associated with improved patient experience, especially in the face of long waits for diagnostic answers. In general, patients who report knowing their Navigator tend to report higher experience scores. These results are aligned with the literature, where studies demonstrate a robust increase in patient experience ratings and satisfaction when they have patient navigation support^{2,10}.

Interestingly, the results from the current study also demonstrate that not only are patients more satisfied and have a better experience when they know their Navigator, but factors that can negatively impact their experience may be allayed by the Navigator. Specifically, patient navigation appears to mitigate the impact that longer wait times have on lowering patient experience ratings such that among the groups of patients who knew their Navigator, consistently good patient experience was seen,

regardless of wait. These findings are consistent with prior evidence suggesting that the most marked effects of navigation on diagnostic wait times are among patients with the greatest delays in their care^{22, 23, 24}.

One other factor hypothesized to impact patient experience in DAPs is patient volumes. However in the current study, regional patient volumes had no significant relationship with patient experience, either overall or when the groups were divided based on whether or not the patient knew their Navigator. This suggests that the volume of patients in a DAP does not directly influence their patient experience, at least at the regional level. Further study is needed to determine if this result is indeed accurate or whether such a relationship does exist at the individual level but is masked by other factors not measured in this study. For example, regional differences in the administration of DAPs and resourcing may have a larger impact on patient experience than overall volume. Additionally, since navigation has been shown to increase the volume of patients that a cancer center can serve while concurrently improving patient experience¹⁰, the true impact of increased patient volumes on experience may be obfuscated. It is possible that once a navigation model is implemented and the associated improvement in patient experience is realized in a center, further increases to patient volume could begin to compromise patient experience at that center, particularly if no additional

Figure 1. Relationship between Patient Experience and Diagnostic Wait Time Across Regions - 75th Percentile

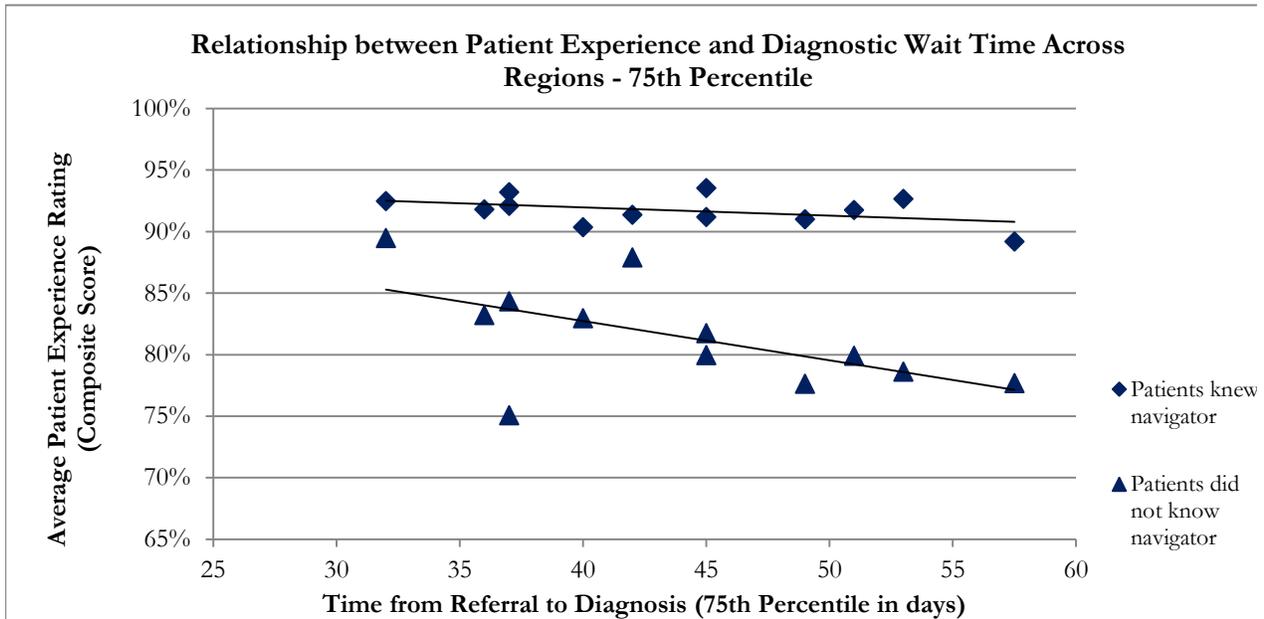
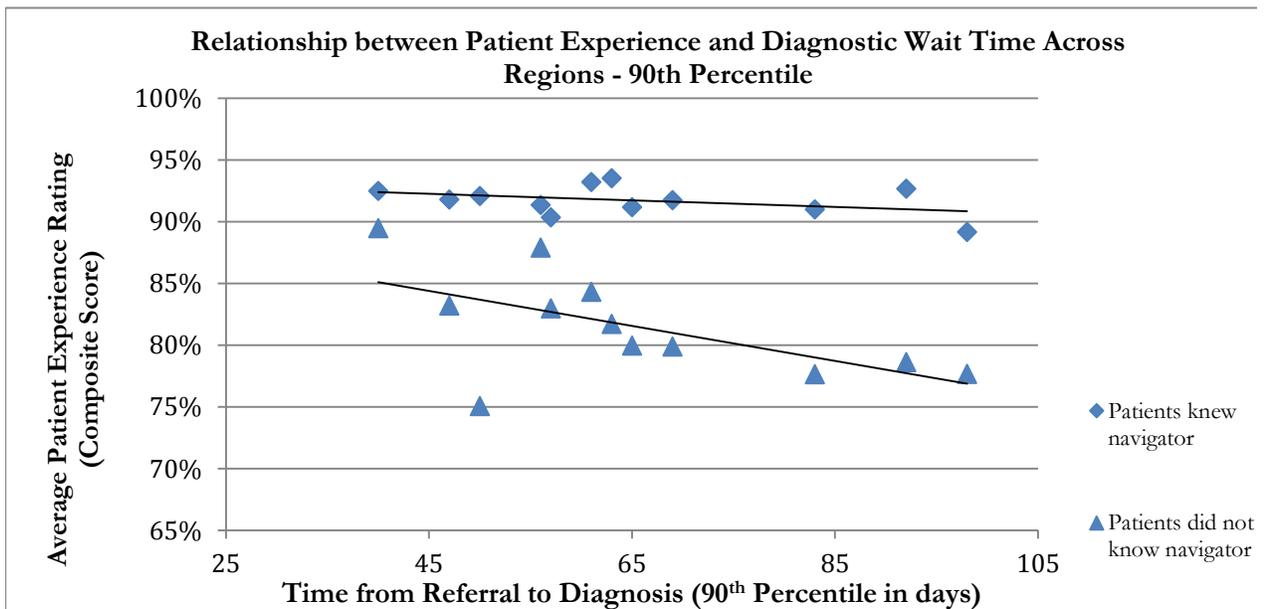


Figure 2. Relationship between Patient Experience and Diagnostic Wait Time Across Regions - 90th Percentile



resources are allocated as volume increases. Future research aimed at capturing the myriad of factors that may influence patient experience would be required to determine the relative impact of institutional factors on overall patient experience and how different models of navigation might mitigate them.

Implementing a comprehensive navigation program has demonstrated its value in improving patient satisfaction and experience across the cancer journey and beyond. However the key factors associated with navigation that are responsible for maintaining good patient experience remain unclear. Further work would be needed to understand the underlying mechanism(s) by which navigation is effective. These mechanisms may include

education, logistical support such as reminding patients about their appointments or psychosocial support such as providing information about coping with a cancer diagnosis. The key elements of navigation and the optimal manner in which to deliver navigational support may differ between patients; targeting appropriate support to those who would benefit most may optimize system efficiency and patient outcomes. Identifying patients in need of more support during their diagnostic journey will help identify those who can benefit most from patient navigation. For example, some models of navigation have been shown to be particularly beneficial for patients of low socioeconomic status, members of racial/ethnic minorities¹³, and for those who live in rural areas²⁵. Evidence from a randomized clinical trial supports the hypothesis that navigation is most beneficial for disadvantaged individuals²⁶. Indeed, patient navigation has been described as a means of addressing racial, ethnic and socioeconomic disparities in care²⁷. Factors such as these disparities may serve as a way of stratifying and identifying patients who are in greater need of support. Additionally, some patients may choose to decline when offered navigation. One study of a lay navigation program found that the primary reason for declining navigation was that patients felt they already had a strong support system and did not see the need for additional support from a Navigator²⁸. These results suggest that patients differ in their need or desire for psychosocial support from Navigators; it is reasonable that the degree to which Navigators can improve an individual's patient experience by providing this type of support will be tied to these individual circumstances.

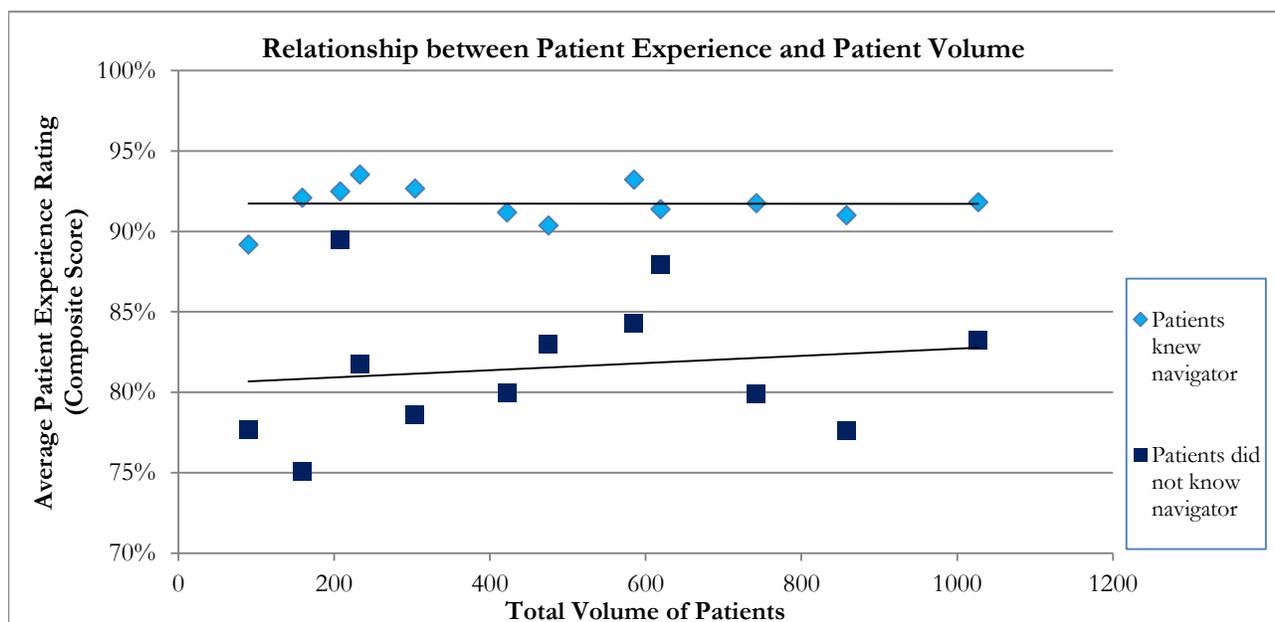
Limitations

The DAP Patient Experience Survey was designed to provide feedback to both Cancer Care Ontario and local DAPs regarding the programs' impact on the patient experience and where it could be improved. The survey is designed to be anonymous in order to encourage honest and frank feedback from patients, but this precludes data linkage with DAP administrative data at the patient level. It is possible, however, to attribute patients to the region in which they attended the DAP, so the data linkage and analyses were carried out at the regional level. The need for analysis at the regional level limits our ability to make inferences about patient navigation at the level of the individual patient. Still, hypotheses about patient-level effects may be generated for future testing. The regional analysis also results in a smaller sample size and insufficient power to perform regression analysis.

The comparisons that were done between the sample of respondents and the overall population of lung DAP patients suggests good representativeness of the sample based on the available data. This comparison was only approximate because of the lag, of unknown length, between the time the patient visited the DAP (the date found in the administrative data) and when the completed survey was received at Cancer Care Ontario.

Due to considerations of privacy and brevity, the PES did not include extensive detail on patient demographics or on actual healthcare encounters. The only demographic data collected was age group and level of education and while it is possible that other characteristics such as gender and

Figure 3. Relationship Between Patient Experience and DAP Patient Volume



ethnicity might also account for variations in one's health experience, it was not possible to examine or control for their effects. Availability of additional demographic features would also have enabled closer examination of the representativeness of the survey sample.

Another limitation of the current study is the use of a single question ("Did you know who the Navigator was?") as a proxy for patient navigation. The categorization of patients into those who knew their Navigator and those who did not was based on self-report via the PES and it is possible that patients used different strategies to answer this question. Further, the 'dose' of navigation that patients received may have differed (e.g. meeting the navigator once in passing versus having ongoing frequent consultations and support from the Navigator). With respect to the sample of PES respondents, there was a high level of variation in the percentage of patients who responded to the survey between the different regions; thus it is possible that the data more accurately reflects some regions than others. Similarly, there was a high level of variability between the regions in the percentage of survey respondents who reported knowing their Navigator. This may indicate that there are different navigation practices between regions that could not be accounted for in the current study, aside from the possible measurement biases described above. More objective and precise measurement of patient navigation would help differentiate those who used the service from those who did not as well as the functional elements of navigation that may account for better patient experience.

Conclusions

From a regional perspective, patient navigation in DAPs, as reflected in patients' ability to identify their Navigator in the diagnostic phase of the cancer journey significantly improves overall patient experience. One mechanism by which it does so is by mitigating the ability of other factors - such as waiting for one's diagnosis - to diminish the patient experience. Further study is required both to confirm these findings at the individual level and to understand the specific aspects of navigation that positively affect DAP patient experience, in order to ensure that this service is provided in an optimal manner to each individual patient.

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Appendix 1. Questions Included in the DAP Patient Experience Survey (PES)

1. Did the staff explain why you needed tests in a way you could understand?*
2. After the tests were done, did someone explain the results in a way that you could understand?*
3. If you had questions about your tests or test results, did you feel comfortable talking with the staff about them?*
4. How often were you given confusing or conflicting information about your tests or test results?*
5. How often did you know who to ask or where to go when you had questions about your health problems or your tests?*
6. How often did you know what the next step in your care would be?*
7. How often did you feel your care providers were aware of your medical history?*
8. How often did you feel your care providers were aware of your test results?*
9. Please circle the number that best describes your level of anxiety during your diagnostic testing.
(Scale of 0 – 10)
10. Please circle the number that best describes your level of fear during your diagnostic testing.
(Scale of 0 – 10)
11. Did someone at the hospital help you with your anxiety and/or fear?*
12. Did the staff treat you with dignity and respect?*
13. Did you feel you could trust your care providers with private information? *
14. Did you know who the nurse navigator was? **
15. Were you able to reach the nurse navigator whenever you had questions or concerns by phone, through e-mail, or in person?*
16. Did you find your experience with the navigator to be: (4 satisfaction categories provided)*
17. What is your age? (4 response categories provided)
18. What is the highest level of education you have completed? (5 response categories provided)

* Questions included in the composite satisfaction score

** Proxy question for navigation, used as a stratification variable