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Research Article

Disparities in Patient Navigation Resources in Appalachia

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Background
The study was conducted in support of an R01-funded project, "Patterns of Patient Care in Appalachia". Most counties within Appalachia are designated as medically underserved, have sparse health care resources and lack integrated care systems. This study determined the extent of geographical differences among American Cancer Society (ACS) patient navigation resources (navigator and/or cancer resource center) in Appalachia. Specifically, this study investigated if there were barriers to access to ACS patient navigation for cancer care in the Appalachia region of PA, KY, OH, and NC.

Results
Of the cancer care centers and hospitals in the Appalachia region studied, (n=232), web-based data informed that facilities (n=186, 80.0%) did not have ACS patient navigation resources compared to Appalachia cancer care centers and hospitals with ACS PN services = 20%. KY had fewer ACS PN centers (5) compared to PA (20), with Pittsburgh (Allegheny county) containing a noticeable cluster of ACS PN facilities (N = 6 out of 18 total). KY also had the lowest rates (12.5%) of facilities with ACS patient navigators. North Carolina had the highest rate of facilities with ACS patient navigation services compared to OH, KY, and PA (32.2%). The proportion of facilities with ACS PN were proportionately less for facilities located in non-Metropolitan areas (15%) compared to those located in metropolitan areas (26%, chi-square p = 0.0339).

Significance
Two overarching results were identified in this study. Firstly, a large number of cancer care centers in the Appalachian region do not have ACS patient navigator services which enable patients to gain individualized assistance, overcome barriers that hinder access to care and access to information about the illness and services available. Secondly, the lack of standards and curriculum for patient navigators indicates there is considerable variation in level of exposure for each patient navigator.

Keywords: patient navigator; cancer; Appalachia; American Cancer Society; underserved populations; rural healthcare; cancer care disparities

Introduction

The Appalachia region, home to more than 25 million people, is an area made up of 420 counties covering 13 states in the United States (Appalachia Regional Commission). Most counties within Appalachia are designated as medically underserved, have sparse health care resources, and lack integrated care systems. Sub-regions of Appalachia are found to have an excess amount of later breast cancer tumor rates; therefore breast cancer screening and access to healthcare are important steps to deplete the rate of later stage tumors (Anderson et al. 2013). The occurrence of later breast cancer stages in Appalachia indicates that breast cancer disparity can be prevented and partially blamed on the pattern of access to mammography services (Anderson et al. 2013).

In 2012, The Commission on Cancer (COC) released guidelines for patient clinical care that included patient navigation (2013). Although there is no set definition for patient navigators, the addition of patient navigation services to oncology centers creates a way for underserved patients to gain individualized assistance across the cancer continuum. Navigators are helpful through resources to overcome obstacles that hinder access to care, such as, transportation, housing, financial assistance, and education. Patient navigators strive to improve care by eliminating these barriers, and allowing the patient access to information about their illness, and the clinical, community, and/or local services available before, during, and after release from standard of care procedures.

Currently, formal qualifications to become a patient navigator do not exist, nor are there uniform skills across programs resulting in a varied set of tasks applied to patient care (Esparza 2013). This can cause great confusion. Due to this lack of set qualifications, the American Cancer Society (ACS) collaborated with the National Cancer Institute (NCI) to communally train navigators with similar curriculums, and a common competency checklist (Esparza 2013).

ACS train individuals interested in the profession. Individuals can become a qualified patient navigator (PN) with and without a medical background. The director of the American Cancer Society Patient Navigator program states "Patient navigators remove barriers to care", "they assure that patients do not fall through the cracks so they can complete their treatment and have more successful health outcomes" (Esparza 2013).The training that ACS patient navigators complete include: understanding cancer as well as health care disparities, patient navigator roles and responsibilities, overview of cancer, culture/diversity training, and methods of effective communication, clinical trials, and mapping resources. After the training is complete, patient navigators are asked to demonstrate their new skills through case scenarios with patient actors while being observed by a clinical preceptor (Esparza 2013). Following the extensive training, ACS patient navigators are sought to be well equipped to provide individualized assistance to cancer patients.

Results of a randomized trail indicated patient navigation positively impacts time to resolution of abnormal

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screening tests for breast, colorectal, and prostate cancers in a medically underserved population (Raich, Whitley, Thorland, et al. 2014). Additionally, patient navigators can effectively reduce disparities in stage at diagnosis and improve cancer outcomes. To date, evidence suggests that use of patient navigators improves screening rates, with increase of 10.8% to 17.1% (Paskett, Harrop, Wells 2011). Also, noteworthy, is the increase in follow-up visits after a screening abnormality that fall etween 21% to 29.2%; also showing improved timeliness of abnormality resolution in breast, colorectal, or prostate cancers. The strongest evidence for the effectiveness of patient navigation services is the improvements on cancer screening and outcomes related to cancer diagnosis services (Paskett, Harrop, Wells 2011). Further, more evidence was found that disparities in care among regions in the Appalachia can be linked to a lack of screening, information, and health professionals (Anderson et al. 2013, & Hutson, S. P., Dorgan, K. A., Phillips, A. N., & Behringer, B. 2007). Linking the results of both studies, one can conclude that implicating patient navigator services can fill the gap of missing information and influence the improvement of cancer care, and health disparities throughout the cancer continuum focusing on underserved populations such as the Appalachia region.

This study investigated cancer facilities with ACS patient navigators that were located in the Appalachia region, and then compared the findings with cancer facilities without ACS patient navigator services located in Appalachia region. The analysis was conducted in support of an NCI R01-funded project, *Patterns of Patient Care in Appalachia*, investigating care patterns for female breast and colorectal cancers diagnosed during 2006 to 2008. The facility list was derived by the study's statistician of hospitals visited by patients living in the Appalachia region defined in the R01 population. It was hypothesized that rural Appalachia communities may have less access to ACS patient navigator resources than non-Appalachia communities.

Experimental Procedures

Design of the Study and Analysis

The study population consisted of female breast and colorectal cancer patients from four different cancer registries (i.e., Kentucky, Pennsylvania, Ohio, and North Carolina) who resided at diagnosis (2006 to 2008) in Appalachia region counties designated by the Appalachian Regional Commission (ARC). Data were collected from each cancer care center in the defined region of counties visited by the study's population through a comprehensive web-based search of (n=232) facilities. Patient Navigation (PN) centers were defined as centers that listed an ACS PN and/or a cancer resource center. Metro/non-metro location was a county-level variable based on patient address at time of diagnosis and the 2003 USDA rural-urban continuum codes (USDA 2005).

Design of the Study

The study was a non-experimental research design using secondary data. The research hypothesis was generated from a systematic review that was followed up by a literature review for more detailed understanding of the PN for ACS. Participants included 232 Appalachia Cancer Care Centers located in OH, PA, KY, and NC. Cancer Care Centers served by ACS patient navigators.

Data Analysis

The proportions of facilities by state and metro/non-metro region were then compared using chi-square tests. Chi-square was appropriate for this study because two variables were identified then examined for significant difference between the expected frequencies, and the observed frequencies of cancer care faculties with and without ACS patient navigator services.

Results

Presented in Figure 1 is a chloropleth map showing the distribution of cancer care centers in the Appalachia regions of OH, KY, PA, and NC. Several counties indicated there were cancer care centers with no ACS patient navigator services. Despite this, cancer care centers/hospitals appear to have an even distribution of access across the regions (see map, red markers).

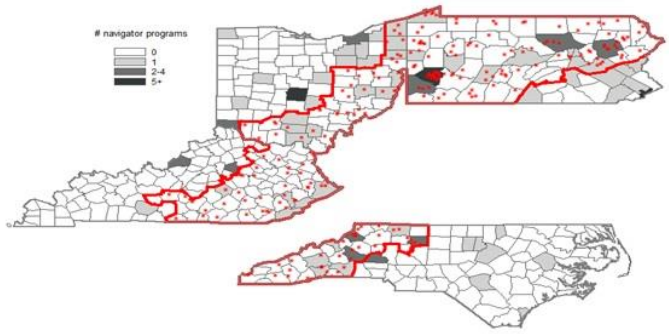

Figure 1: Map of Cancer Care Centers In the Appalachia Region of OH,PA,NC, K

Of the cancer care centers and hospitals in the Appalachia region studied, (n=232), web-based data informed that facilities (n=186, 80.0%) did not have ACS patient navigation resources. Table 1 presents Appalachia hospitals without ACS navigator resources (%) = 80% compared to Appalachia cancer care centers and hospitals with ACS PN services = 20%.

Table 1: Cancer Care Centers/Hospitals in Appalachia

Appalachia Cancer Care Centers	With ACS Patient Navigation Resources	Without ACS Patient Navigation Resources
Total (N = 232)	46 (19.8%)	186 (80.2%)
Kentucky	5(12.5%)	35 (87.5%)
North Carolina	11 (32.3%)	23 (67.7%)
Ohio	10 (25.6%)	29 (74.4%)
Pennsylvania	20 (16.8%)	99 (83.2%)
Metropolitan	26 (26.6%)	73 (73.7%)
Non-Metropolitan	20(15.0%)	113 (85.0%)

Comparison of patient navigation rates across states detected no significant difference at an alpha of 0.05 in proportion of centers having a patient navigator (chi-square test p = 0.1014); however, in this sample of facilities, KY had fewer ACS PN centers (5) compared to PA (20), with Pittsburgh (Allegheny county) containing a noticeable cluster of ACS PN facilities (N = 6 out of 18 total). KY also had the lowest rates (12.5%) of facilities with ACS patient navigators. North Carolina had the highest rate of facilities with ACS patient navigation services compared to OH, KY, and PA (32.2%). The proportion of facilities with ACS PN were proportionately less for facilities located in non-Metropolitan areas (15%) compared to those located in metropolitan areas (26%, chi-square p = 0.0339).

Discussion

Patient navigators are becoming an important resource for underserved patients. Due to the growing need for PN, resources must be created that possess knowledge, skills, and experiences that can effectively guide patients to overcome barriers, provide accurate information, and a better health care experience. The findings of this study reaffirmed that there was a general lack of ACS PN services to the Appalachia areas. Results were consistent with the literature and indicated that ACS PN resources in the Appalachia were less available than expected. The disparity in ACS PN services by the rural/metropolitan region coincides with the mammography rate disparity.

More detailed research should be conducted to understand if this solid finding may results in health care disparities' for the population and across the region. Literature has shown that women in rural settings were less likely than urban women to ever have a mammogram, or to have a mammogram that was up-to-date in terms of recommended screening guidelines (Leung, J., Mckenzie, S., McLaughlin, D. 2014). Additionally, rural women reported difficulties accessing breast cancer screenings; furthermore, data indicated the treatment procedures differed in rural settings compared to urban (Leung, J., Mckenzie, S., McLauhlin, D. 2014). A general finding identified from this study was that the rural communities were at a notable disadvantage (85.0%) compared to urban communities in terms of access to ACS PN services. Because of the lack of access, the disease may be exacerbated from elements such as the lack of mammograms administered, and the patient wait time for screening and treatment. In a recent study, implementation of patient navigators was effective in positively moving the trend towards breast screening, follow-ups of diagnostic abnormalities, initiation of cancer treatment, and improvement on the quality of life in breast cancer (Robinson-White, S., Conroy, B., Slavish, K. H., & Rosenzweig, M. 2010). ACS patient navigator resources could potentially eliminate the barriers women in rural Appalachia face in accessing up-to-date mammography.

The impact of PN is hard to systematically evaluate for comparison of best practices due to the lack of curriculum to include measurable goals and terminology. However, it appears patients in cancer care bear the burden of the inconsistencies. Studies conducted demonstrated the effect of patient care services available and the cancer care experience in rural Appalachia (Raich et al. 2012). Studies detail how the PN services meaningfully assist these patients in their care. Specifically, one randomized trial of 993 eligible subjects concluded that time to resolution was significantly shorter in the navigated group compared to patients with no patient navigation (Raich, P., Whitley, M., Thorland, W., Valverde, P., & Fairclough, D. 2012). Further, patient navigation was shown to improve diagnostic resolution for patients presenting abnormal mammograms (Raich, P., Whitley, M., Thorland, W., Valverde, P., & Fairclough, D. 2012).

The strongest evidence of the effectiveness of PN was the improvements on cancer screening and outcomes related to cancer diagnosis services (Paskett, Harrop, Wells 2011). Evidence indicated that efficiency to PN were specific to (a) improvement on screening rates that increased from 10.8% to 17.1% , (b) adherence to follow-up visits after a screening abnormality (21%-29.2%), and (c) the timeliness of resolving an abnormality in breast, colorectal, or prostate cancers (Paskett, Harrop, Wells 2011).This was convergent with the idea that PN services effectively decreased health disparities in places that needed it the most, such as the medically underserved rural Appalachia. This was informative to our study because it identified factors that contributed to variations in delivery of comprehensive cancer care, and how patient navigators can help improve health services and patient satisfaction.

Limitations of the study's design existed and were recognized. First, the data compared cancer care centers/ hospitals with ACS patient navigation services. Not all patient navigation services were examined. Second, information gathered about the centers, and ACS patient navigation services were from a secondary source. It is possible that missing data exist that could have informed the findings. Because of time constraints and financial resources, cancer care centers were provided by an R01 study, and understood through an online web search to determine ACS patient navigator availability. It is possible that web information was not comprehensive enough for this study's hypothesis. Finally, data results were collected in 2013, and therefore, centers may have gained ACS resources since this time period and not been accounted for in the sample.

Based upon the study's findings, the research demonstrated that the majority of ACS patient navigation services were not located in rural Appalachia communities where they are most likely needed the most. Two overarching outcomes were identified in this study. First, a substantial number of cancer care centers in the Appalachian region did not have ACS patient navigator services which tend to enable patients to gain individualized assistance, overcome barriers that hinder access to care, services, and current information about the illness. The ACS has a set curriculum and trains patient navigators with the proper knowledge and skills to succeed. That being said, secondly, the lack of standards and curriculum for patient navigators indicated there was considerable variation in level of exposure for each patient navigator. This variation acts as a barrier to further analyze the services and creates a gap of knowledge regarding the job description.

CoC recently released clinical guideline which includes patient navigator services and processes as a requirement for CoC accredited hospitals starting 2015 (Esparza 2013). For further study, information on all patient navigator resources in the Appalachian region should be investigated. This could

provide a more representative sample of patient navigator services and allow for more impact to public health studies. The ACS should recognize these findings to understand where ACS patient navigators' may be needed to improve patient and survivorship care in the Appalachia. These results should evaluate or benchmark the current curriculum regarding patient navigator training and locations. There is a need for best practices to be identified, defined, and then quantified for systematic evaluation. Standardized PN services may be the missing element that decreases Appalachia health disparities in cancer care, and increase quality of life and longevity. Thus, the final recommendations for further study would be to replicate this study and map out patient navigation services in the Appalachia once the CoC guidelines have officially ben implemented. This will address any lack of resources; hence disparities, in the Appalachia region in terms of PN resources.

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