

Piloting a Lay Navigation Program in a Community and Academic

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State of Navigation Today

- Cancer programs have invested significant resources in navigation
- Lack of definition and standardization of role
- Lack of standardized outcome measures to demonstrate return on the investment

State of Navigation in North Carolina

- Cancer is the leading cause of death
- Cancer disparities are severe
- Growing demand for cancer services
- Shrinking cancer workforce
- North Carolina's cancer programs have a needs for standardized training and ongoing education for lay patient navigators

The Value Mandate

Complex Patients

- Aging population
- Expanding Medicare eligibility
- Shift to oral chemo
- Financial toxicity

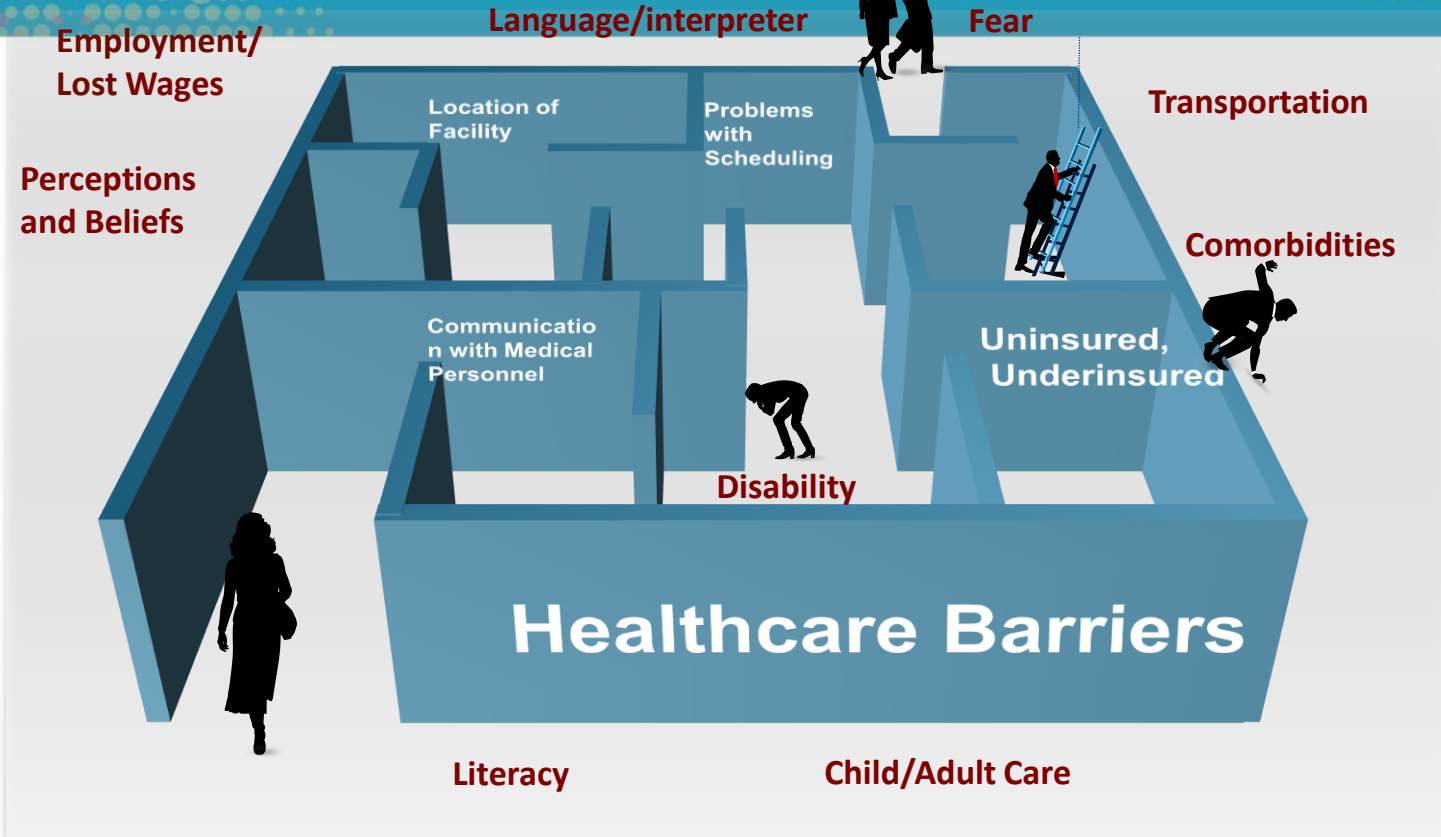
Resource Shortages

- Limited number of clinicians
- High turnover among nurses and support staff
- Unfavorable fee for service

The Health Care System Maze

...especially for Vulnerable Populations

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ESSENTIAL SOCIAL NEEDS OF OUR PATIENTS

Social Needs	EXAMPLES
Food Insecurity	Limited access to adequate food
Housing Instability	Homelessness and costs of housing-mortgage, rent
Utility Needs	Difficulty paying bills
Financial Resources	Medication underuse due to cost
Transportation	Difficulty with access to care
Social Isolation	Lack of family, living alone
Health Literacy	Inability to understand
Childcare	Pre-school, afterschool
Fear & Mistrust	Stress, anxiety, failure to seek care

Oncology Nurse Navigators have many clinical and non-clinical responsibilities

- Provide patient education
- Connect patients to support services
- Identify and help patients overcome barriers to care
- Develop relationship with referring physicians
- Provide emotional support
- Track patient progress throughout diagnosis and treatment
- Support patients into survivorship
- Serve as community liaison for education, prevention and screening
- Schedule patient appointments
- Provide symptom management

Key Questions?

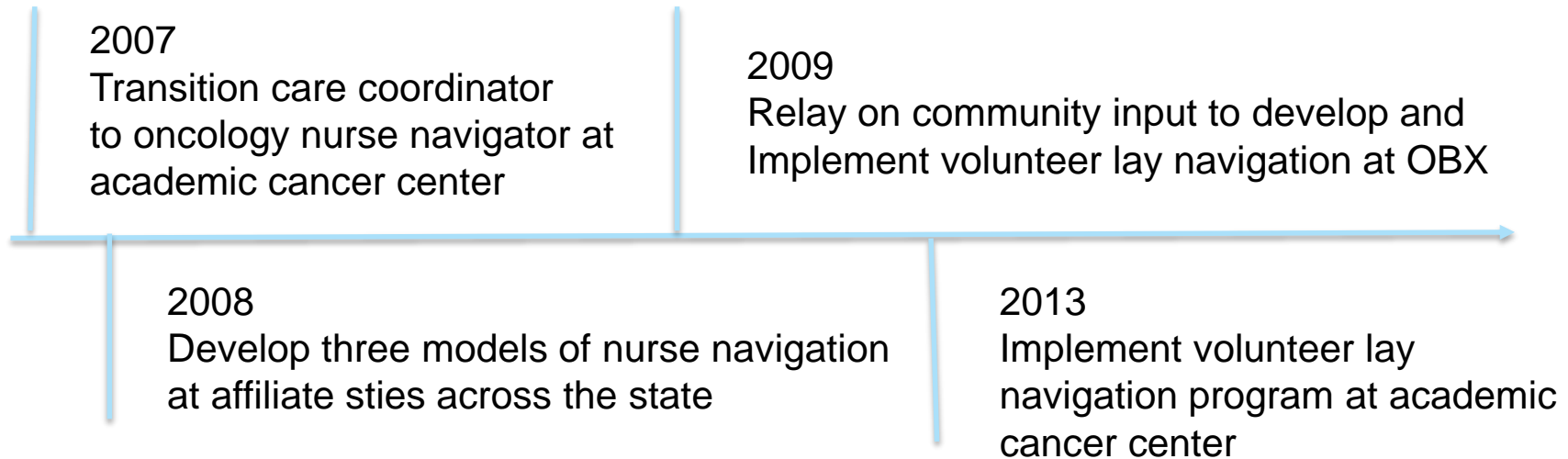
- How to ensure navigators add value?
- How to help navigators succeed in their role?
- How to integrate navigators into the broader care team?
- How to ensure appropriate patients benefit from navigation?
- How to measure the value of navigation?
- How to increase the cancer workforce with a cost effective model?

Solution: Lay Patient Navigation

Lay patient navigators are trained volunteer members from the community who help oncology patients overcome barriers to non-clinical cancer care. They may have previous experience in the health care setting as an employee or they may be a student in the pre-med curriculum, a cancer survivor or caregiver.

Providing a Service Across the State

Navigation Aids Mission of Improving Quality of Care in North Carolina



Community Model of Lay Navigation Nags Head, North Carolina 2008-2012

Factors Guiding Program Development

- 2 oncology nurse navigators recently recruited
- Geographic challenges of county
- Large number of uninsured patients
- Role confusion
- Lack of awareness of existing community resources
- Lack of trust
- ONS Position Statement, 2010

Key Considerations

- Robust, established volunteer program at academic center
- History with UNC School of Public Health Lay Health Advisor Training
- Outreach activities integrated with local health department, community cancer support groups, faith based organizations, local oncologist

Community Cancer Needs Assessment

Lay Navigation Development

Reviewed Lay Health Advisors (LHA) curriculum (Earp, 2002)

Reviewed Harold P. Freeman's Patient Navigation Institute training curriculum

Interviewed patients, community leaders and stakeholders

Extensive literature review on patient navigation training

Reviewed UNC Volunteer Program's curriculum

- Local faith based communities
- Local non-profits
- Primary Care Providers
- Local cancer support programs

Critical Steps in Program Development

- Physician Champion
- Advisory Team
- Bi-monthly meetings
- Comprehensive training, policies, outcome measures
- Resource Guide
- Monthly lay navigation education meetings
- Marketing and Community Outreach for recruitment

Integration of lay navigation into clinical model



Program Goals

Lay patient navigators will:

- Communicate in a respectful and supportive manner
- Provide emotional support
- Identify non-medical barriers to care
- Connect patients with existing cancer support programs and resources

Examples of Interventions

- Financial assistance
- Community resources
- Transportation
- Scheduling appts
- Assist with meals
- Picking up supplies
- Coordinate lodging
- Assist with child care or pet care
- Emotional support
- Respite
- Yard chores

Accomplishments

- Model included comprehensive training, job description, policies and data collection tool
- Nov 2009 initial training 49 volunteers
- Ambassadors at community health fairs
- Local accommodation program with hotels
- Program transitioned to local hospital in 2013

Summary

- Ongoing local management & physician leadership
- Professional and lay navigation is effective
- Non-clinical support can be provided but requires nursing leadership
- Role delineation is critical
- Ongoing education & support of lay navigators
- Compassion Fatigue

Academic Model of Lay Navigation Chapel Hill, North Carolina 2013- current

Factors Guiding UNC's Decision

- Breast Nurse Navigators were overwhelmed with growing patient volumes
- Phone survey reveals many breast cancer patients are unaware of the services offered by the cancer program

A New Proactive Approach

- Build on pastoral care and nurse navigation model
- Improve the skill level of the lay navigator
- Monitor confidence level of lay navigator
- Combine the non-clinical needs of the patient with the treatment plan
- Improve communication between providers & patient
- Optimize internal and external assistance programs

Retrospective Chart Reviews

- Missed appointments
- Percentage of patients lost to follow up
- Average time from suspicious findings to follow up apt
- Average time from suspicious finding to dx and tx
- Duplication of tests
- Outmigration data

Extensive and Ongoing Training

- 6 hour training
- 20 hour orientation
- Monthly educational support meetings led by chaplain, nurse navigator & volunteer coordinator
- Educational Video Library
- Yearly navigation symposium
- Resource Guide



HEELS of
HOPE



Partnering with patients and families.

LAY NAVIGATOR VOLUNTEER TRAINING MANUAL



NC Cancer Hospital

101 Manning Drive, Chapel Hill, NC

Heels of Hope Training Manual, v. 02-14

Heels of Hope Training Manual, V. 02-14

Introduction & Overview of Patient Navigation

- History of patient navigation
- Scope of practice
- Navigation Team
- Vulnerable Populations, Culture & Health care disparities

Understanding Cancer Basics

- Cancer 101
- Cancer Facts & Myths
- Living with Advanced Disease
- Clinical Trials
- Palliative Care
- Can Cancer be Prevented?

Communication Skills

- Barriers to Care
- Emotional Needs
- Words that “STING”
- Building trust

Barriers to Care; Resources & Referrals

- Advanced Directives
- National, Regional, State and Community Resources
- Financial Toxicity

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Lay Patient Navigation Program

A UNC Volunteer Services program designed to complement our cancer care team. Working with the Nurse Navigator and Clinic Nurses, lay patient navigators are trained to be an additional layer of non-clinical support for cancer patients and caregivers.

***Many of the volunteers are teachers, nurses, social workers, retired professionals, cancer survivors and caregivers.**

What is a lay patient navigator? A member of our UNC Volunteer Services team who has received special training to provide non-clinical support and information to patients and caregivers who may be facing a cancer diagnosis.

Our goals:

- Provide information about hospital support services and community resources
- Offer emotional support to patients and their caregivers
- Inform and guide patients and caregivers throughout the UNC health system

Our lay patient navigators do not provide medical care, medical advice, psychotherapy or interfere with the doctor/patient relationship.

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Provide High Risk Comprehensive Assessments

- Do you live alone?
- Do you need help reading hospital materials?
- Have you had difficulty paying your bills?
- Have you missed healthcare appts due to lack of transportation?
- Recent hospital discharge or emergency room visit?
- Do you understand what an Advanced Directive is?
- Do you smoke and if so, would you like help in quitting?

Target Costly Patients

- Metastatic & Advanced
- Pancreatic
- Head & Neck
- Lung
- Ovarian
- Hematologic
- Social
- Economic
- Health Literacy
- Functional
- Comorbid
- Medical

Delineate Responsibility to Maximize Role

Regular Check-Ins

- Beginning of shift
- Determine assignment
- High Risk Screening
- Lay navigator meets identified patients

Sample Responsibilities

- Address non-clinical barriers to care
- Identify and refer to resources inside and outside health system for emotional and social support

High Risk Screening Questions

- Do you live alone?
- Are there multiple co-morbidities?
- Are you taking more than 4 medications?
- Recent emergency room visit?
- Over age 70?
- Recent hospital discharge?
- Language barrier?
- Financial barriers?
- Transportation barriers?
- Caregiver fatigue?

PATIENT NAVIGATION ENCOUNTER SHEET

Patient Navigator: _____ Date: _____

☐ UNC Breast Clinic ☐ UNC Mammography Clinic ☐ UNC Thoracic Clinic ☐ UNC GI Clinic

☐ UNC in-pt BMT ☐ UNC ENT clinic ☐ UNC 4 ONC ☐ UNC Ped/Onc ☐ UNC Gyn/Onc

☐ UNC GU

Patient: **AGE:** _____ **GENDER:** _____ **RACE:** _____ **ZIPCODE:** _____

New Patient: _____ Repeat Patient _____ ☐ Biopsy ☐ Cancer

Do you live alone?

Do you have resources to pay for your medications?

Do you smoke, and if so, would you like help in quitting?

Do you have difficulty understanding our written information?

Do you understand what an advanced directive is?

Have you missed any medical appointments due to lack of transportation?

Barriers to Care:

☐ None ☐ Transportation ☐ Coordination of Care (accommodations, directions, parking, health system

barriers) ☐ Financial ☐ Communication (literacy, language) ☐ Education ☐ lack of social support ☐

Caregiver needs ☐ lack of computer ☐ living alone

Other: _____

Referrals:

☐ Patient & Family Resource Center ☐ Community resource ☐ CCSP ☐ Social Worker

☐ Nurse Navigator ☐ Chaplain ☐ Financial Counselor ☐ Interpreter ☐ local library

Other: _____

How confident were you in addressing this patient's needs?

1 2 3 4 5

(1 meaning not at all and 5 meaning very confident)

Were there any questions you couldn't answer?

Defining Navigators' Focus at Each Step

Trained 56 volunteer lay patient navigators since 2014





Current out-patient clinics: Breast, Thoracic, GI, GU, Gyn/Onc; Pediatrics; Heme/Onc

Inpatient Clinics: 4 Oncology; BMT


2017 ASCO Quality Care Symposium

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Feasibility of a Lay Cancer Patient Navigation Program To Meet The Needs of Cancer Patients

William A. Wood, Jean B. Sellers, Thomas C. Shea, Deborah K. Mayer



A Comprehensive Cancer Center Designated by the National Cancer Institute



Background

In North Carolina, more patients are dying with cancer than heart disease. The uninsured and aging represent a large population that face uncertainty about where to turn for information and help for psychosocial support, financial burden and identifying appropriate resources that have important impacts upon health outcomes.

In 2009, UNC Cancer Network developed a lay cancer patient navigators (LCPN) model of navigation in a rural community to decrease barriers to care; improve resource utilization; integrate LCPN in clinics as extenders of the team; improve health outcomes.

In a 2013 patient survey, we found 82% reported feeling alone and isolated during treatment and 55% reported lack of awareness about available patient resources.

Based on the LCPN model and patient survey, we developed a similar model in an Academic Medical Center in Chapel Hill. We are reporting on the first year outcomes of this program.

Methodology

Partnering with UNC Volunteer Services, Pastoral Care and UNC Cancer Care, we identified volunteers to recruit, train, orient and integrate into patient care within the NC Cancer Hospital.

The LCPN would review the patient list with the nurse navigator prior to clinic to ensure identified patients were visited.

An encounter form was developed to capture identified barriers to care, resources provided and confidence of the lay navigator in providing this support in patient encounters.

Training LCPN

UNC volunteers completed a screening process and then participated in an intensive 6 hour training that focused on the following:

- History of patient navigation
- Cancer 101 Facts & Myths
- Compassionate communication
- Boundary setting
- Barriers to Care
- Finding Resources
- Spiritual Support
- Data Collection

Upon successful completion, the lay navigators allocated 21 hours (3 hour shifts) shadowing oncology nurses and physicians in the various clinics. The purpose was to understand the clinic flow, available resources and patients served.

Results

30 volunteers were trained between Jan 2015- June 2016 and 14 were integrated into the following clinics working one 3-4 hour shift per week:

- Breast
- BMT Inpatient
- Thoracic
- GI
- GYN-ONC.
- GU
- Head & Neck;

There have been 1,034 patient encounters; 484 (47%) were with new patients and 550 (53%) were with repeat patients.

Referrals were provided to the following resources:

- Patient and family resource center (74%);
- Community resources (30%);
- Financial counseling (27%); and
- Social work (25%).

LCPN reported feeling adequately trained to meet the needs of cancer patients during these visits.

Conclusion

LCPN routinely met with new patients and identified non-clinical barriers to care including informational, logistical, financial, social, emotional and spiritual aspects of care.

In this implementation, the navigator/nurse interaction is critical as the navigator is working in a team concept with the goal of helping patients identify their barrier to care and then to provide assistance with the resolution. Also important to note is the additional support and educational needs of the LCPN. Monthly support meetings facilitated by the oncology nurse and chaplain proved to be critical for the LCPN.

The model is cost effective and requires few internal resources other than training and ongoing supervision.

Research Opportunities

- Future steps will include dissemination throughout NC
- Understanding which barriers to care are addressed by the presence of LCPN.
- Understanding what additional support is necessary to ensure volunteer retention.
- Identifying specific metrics to reflect the return on the investment.

Funding

Research supported in part by the University Cancer Research Fund

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Implement 10 models of lay patient navigation across NC Anticipated Outcomes

- Reduce cancer morbidity and mortality
- Increase the cancer workforce
- Reduce patient and caregiver stress & anxiety
- Improve coordination to external resources
- Improve patient satisfaction
- Improve treatment plan compliance
- Reduce emergency room visits

Key Takeaways

- Community Needs Assessment is Critical
- Find Resource-Efficient Ways to Extend Navigation
- Set Volunteers up for Success
- Perform Data-Driven Analysis to Understand Navigator Activities
- Use Data to Justify Scoping the Role

Questions?

There is no excellence without difficulty.

Ovid

References

- Advisory Board Company. (2016). Cancer Patient Navigation: Meeting the Value Mandate Webinar
- Gentry, S & Sellers, J. Navigation considerations when working with patients. In Blaseg, K, Daugherty, P, & Gamblin, K (Eds.) Oncology Nurse Navigation: Delivering Patient-Centered Care Across the Continuum (pp 71-120
- NC SCHS: Statistics and Reports: Vital Statistics, Cancer Retrieved from www.schs.state.nc.us/data/cancer/incidence_rates.htm
- Oncology Nursing Society Joint Position Statement on the Role of Oncology Nursing and Oncology Social Work in Patient Navigation (2010)
- Oncology Nursing Society Oncology Nurse Navigator Core Competencies (2017)
- Rocque et al (2017). Resource use and medicare costs during lay navigation for geriatric patients with cancer. JAMA Oncology. Posted online Jan. 26, 2017. E1-E8
- Sellers, J . Increasing the cancer workforce with lay patient navigation. In Daugherty, P, Gamblin, K & Rummel, M (Eds.) Oncology Nurse Navigation Case Studies (pp 41-55)
- Wood, Sellers, Shea & Mayer. Feasibility of lay cancer patient navigation in an academic medical center on unmet needs of cancer patients. ASCO Quality Care Symposium Abstract & Poster March, 2017.