

Evaluation of a theory-driven navigator program to improve psychosocial wellbeing and eliminate barriers to care among newly diagnosed cancer patients

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FOX CHASE
CANCER CENTER

Research Team

- Suzanne Miller, PhD, Principal Investigator
- Linda Fleisher, MPH, PhD (c), Co-Principal Investigator
- Joanne Buzaglo, PhD, Behavioral Core Research Facility
- Bobbie Ginsberg, MSW, Program Director
- Theresa Berger, MBE, Program Manager
- Venk Kandadai, MPH, Research Analyst

History of Patient Navigation

- First reported by Harold P. Freeman in 1995 in his paper, “Expanding Access to Cancer Screening and Clinical Follow-up among the Medically Underserved”
 - Response to high cancer mortality rates of poor, medically underserved populations
 - Patient navigator was designed to be a lay person who could guide patient through cancer care continuum
 - Good for a pilot study, but changing methodology made it difficult to determine the statistical significance of outcomes
- Patient Navigator Outreach and Chronic Disease Prevention Act of 2005
 - Authorizes \$25 million in grants over 5 years
 - Grants are to recruit, assign, train and employ patient navigators
- NCI and CMS randomized trials

Patient Navigation

- What it is – many definitions
- Legislative definition
 - Anticipate, identify, and help patients to overcome barriers within healthcare system
 - Assist in coordination of health care services & referrals
 - Facilitate involvement of community organizations in assisting individuals at risk for or who have cancer or other chronic diseases
- Why it is important, especially for underserved populations must negotiate the health care system with overwhelming disadvantages:
 - Lack of insurance
 - Diagnosis at later stage disease
 - Cultural/psychosocial barriers
 - Poverty
 - Limited exposure to medical community

What are the models?

- Where in the cancer continuum?
- Community focused – lay, peer, volunteer, community health worker
- Clinically focused - lay, nurse, social worker
- Various roles and titles

Navigating Pennsylvania Cancer Patients Demonstration Project

- Three year pilot demonstration project funded by the Pennsylvania Department of Health
 - Involved newly diagnosed cancer patients from five sites (breast, cervical, colorectal, prostate, lung)
 - The non-clinical patient navigator addressed patient issues (process/psychosocial) focusing primarily on practical barriers
- Theory-guided protocol and evaluation
 - Protocol and evaluation based on C-SHIP Model
 - Used Community-Based Participatory Research Principles
 - Focused on implementation, patient satisfaction (PS) and the impact on affect variables (PA), which are the patient's perceptions on stress-related thoughts
- The project included
 - A comprehensive and interactive training program
 - Case management software
 - Culturally appropriate for Spanish speaking patients
 - Linkages to key cancer services and programs

CBPR in Action

- Start-up Phase –
 - Data management system -- review and limited input of sites
 - IRB materials -- developed by Fox Chase and then shared with each facility
 - Recruitment/hiring of navigators – collaborative process
 - Training program – Fox Chase had main responsibility
 - Review and input on recruitment process – tailored to each facility within parameters of the study
 - Site visits and site assessments

CBPR in Action

- Implementation Phase –
 - Each facility received funding to support navigator
 - Patient Navigators were employees of each facility
 - Navigators were supervised by key staff at each facility
 - Ongoing dialogue about recruitment and implementation challenges
 - Each facility participated in the Project Advisory Board

CBPR in Action

- Analysis and Dissemination Phase –
 - Each facility reviewed presentations to the PA DOH
 - Mt. Nittany presented on the project at a variety of meetings
 - Fox Chase responsible for final report
 - Each facility is participating in one of the publications
 - Each facility has maintained the navigator
 - Fox Chase has met with each facility to support future funding for the navigator program

Non-clinical Patient Navigators

- Assist patients in dealing with the complex problems associated with a cancer diagnosis
- The pro-active use of navigators can lessen the caseload of professionals while providing necessary resources to address unique patient needs

Training of Navigators

- Comprehensive
 - Knowledge of health care system
 - Understanding of cancer
 - Communication skills & cultural sensitivity
 - Behavioral theory
- Research – Human Subjects, HIPAA, Study Procedures
- Didactic and participatory approaches
- E-learning approaches - dissemination

Participating Sites

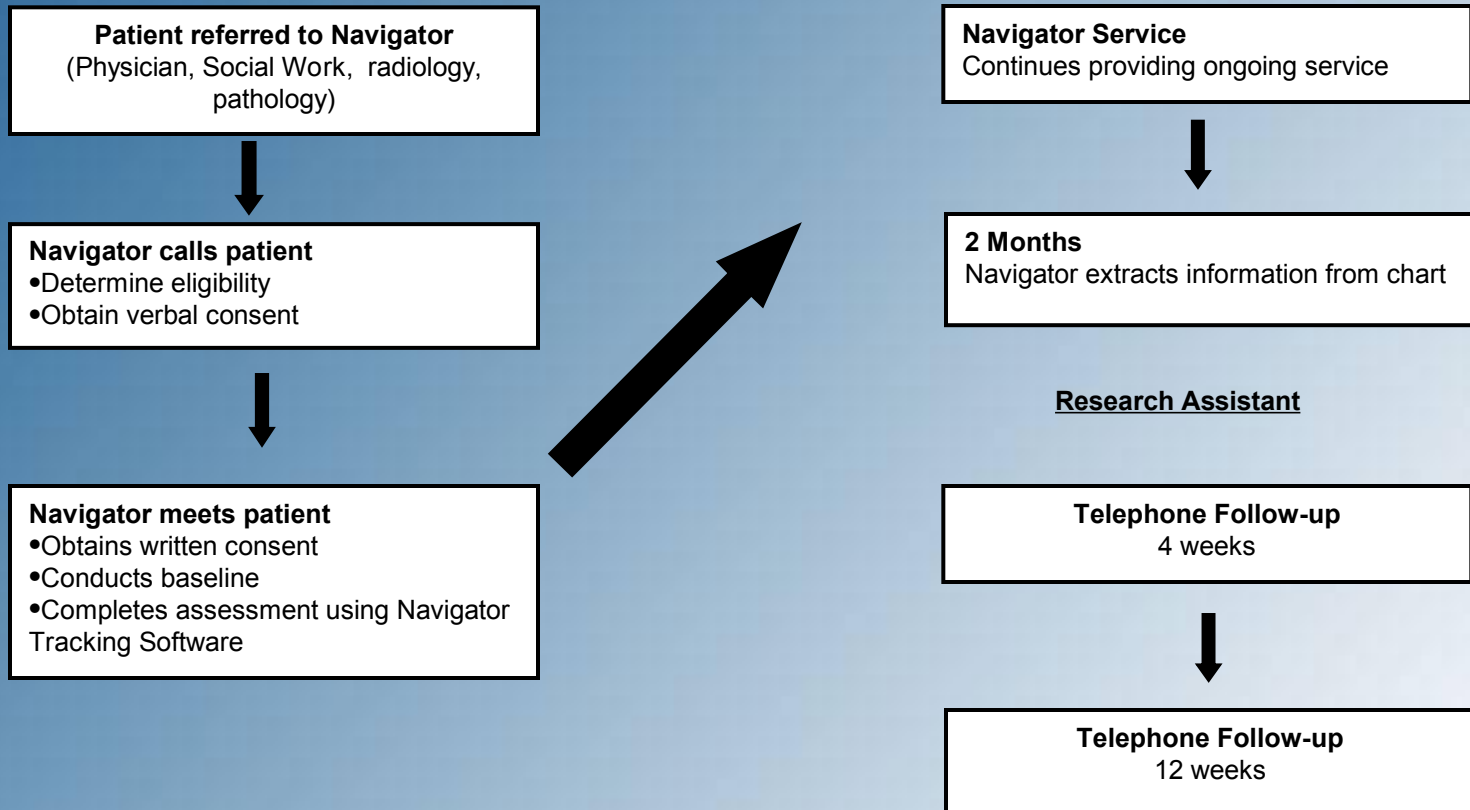
Implementation Sites:

- Temple Cancer Center
- Mount Nittany Medical Center

Comparison Site:

- Geisinger Medical Center – Wilkes Barre

NPCP Program Flow



Study Procedures - Recruitment

- Eligibility
 - Eighteen years or older
 - Newly diagnosed patients
 - Breast, colorectal, prostate, cervical, or lung cancer
 - Able to provide verbal and/or written consent

Study Procedures – Program Implementation

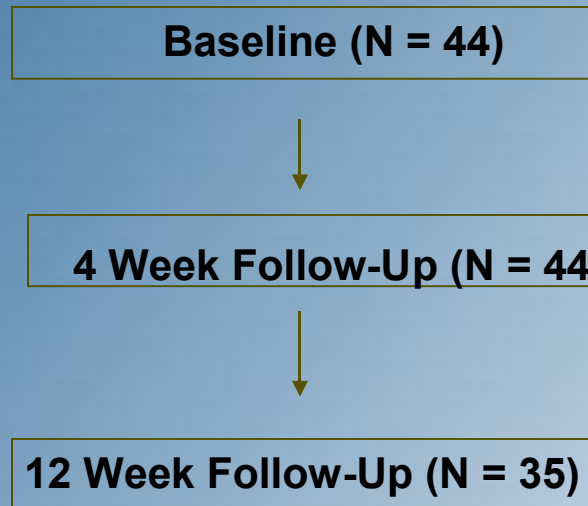
- Ongoing
 - Navigators: recruit and consent potential participants; administer baseline survey
 - Navigators: track and record all encounters with patients and provide ongoing service
 - Project Manager: provides ongoing supervision to navigators, manages all aspects of the implementation and follow-up
 - Two follow-up telephone interviews conducted by FCCC research team

Study – Evaluation

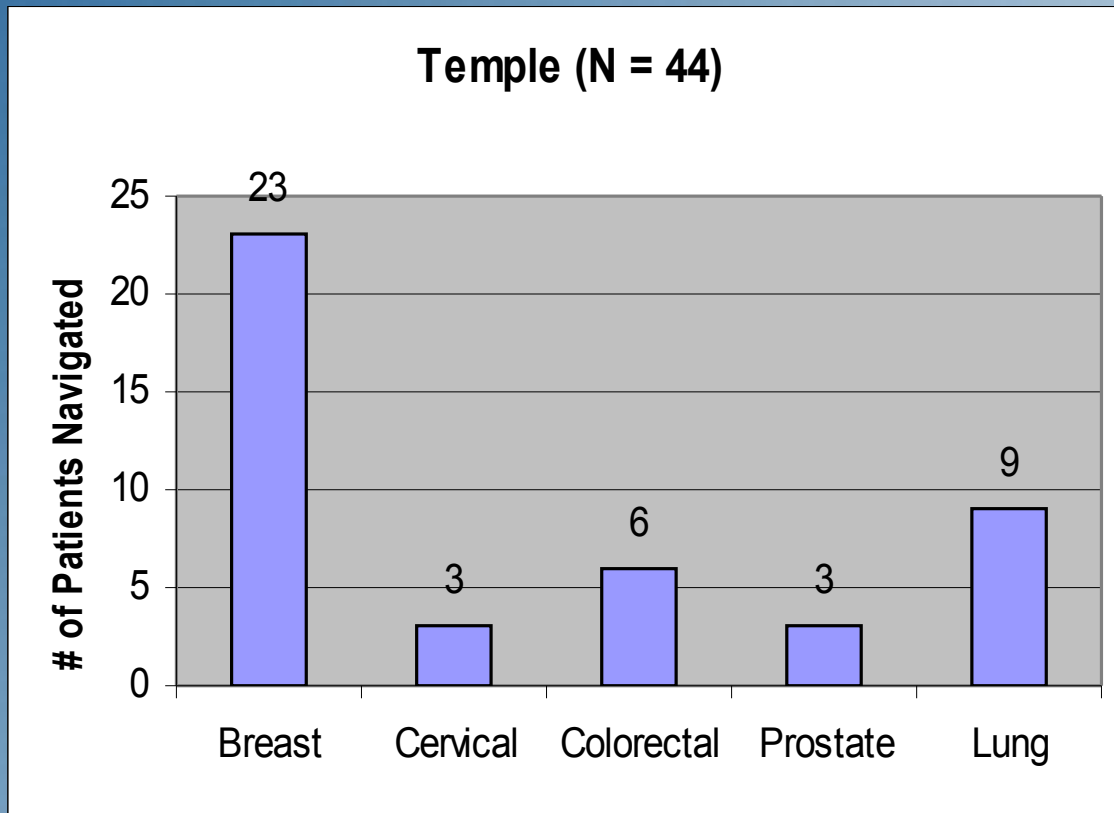
- Goals of evaluation
 - *Process* -- feasibility, patient satisfaction
 - *Impact* -- cost, knowledge, attitudes, and behaviors
 - *Outcome* -- changes in time from diagnosis to treatment & compliance with appointments – will serve as baseline measures for future research

Study Accrual

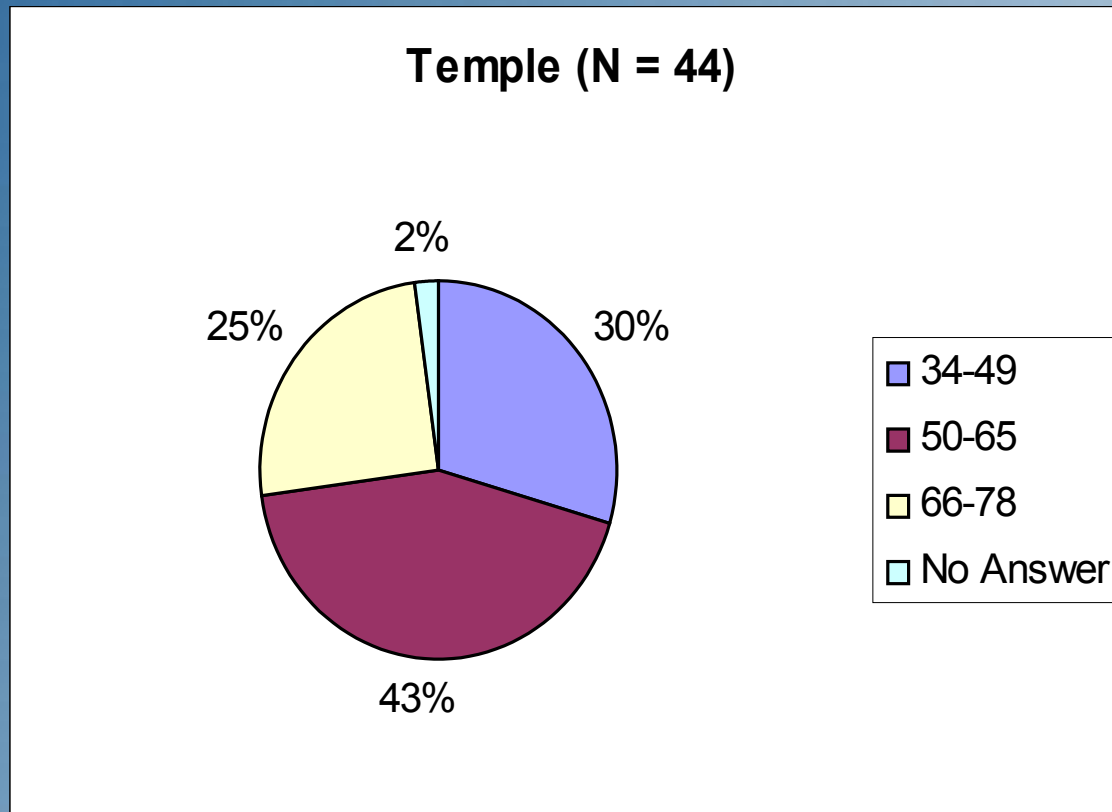
TEMPLE



Patients by Cancer Site



Age Distribution

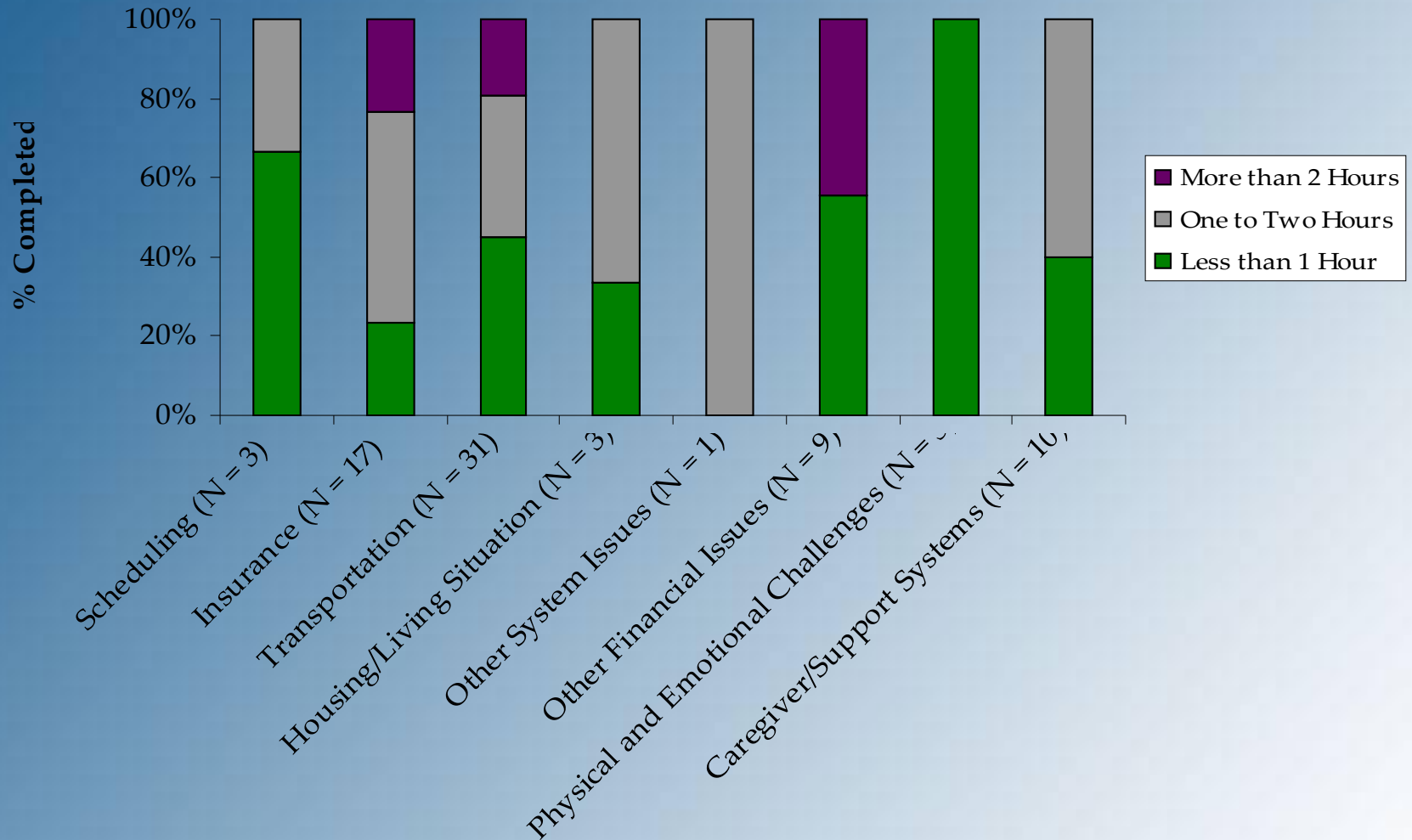


Types of Barriers Addressed by the Navigators

(N = 79)

Barrier Type	N	%
Referral	0	0
Scheduling	3	3.8
Insurance	17	21.5
Transportation	31	39.2
Housing/Living	3	3.8
Other Systems Issues	1	1.3
Other Financial Issues	9	11.4
Physical/Emotional Support	5	6.3
Caregiver Support	10	12.7

Time required by navigators to address barriers (N = 79)



Satisfaction and Affect Measures

- **Patient Satisfaction (PS) – 9 item scale measuring how satisfied the patient was with the PN program overall**
 - Scaled from 0-4 with 4 = “extremely satisfied”
- **Patient Affect (PA) – 4 item scale measuring how worried patients were about stress-related thoughts regarding their cancer diagnosis**
 - Scaled from 0-4 with 4 = “extremely worried”

Patient Satisfaction - Temple

Satisfaction Measure Items: Mean (SD)		
On a 1 (not at all satisfied) to 5 (highly satisfied) scale		
	4 week	12 week
Seeking cancer-related information	3.3 (1.3)	3.4 (1.2)
Getting medical services	3.1 (1.5)	2.9 (1.7)
Taking care of insurance-related problem	2.5 (1.9)	2.4 (1.9)
Scheduling recommended appointments	2.5 (1.8)	2.4 (1.9)
Getting community services	2.7 (1.8)	2.6 (1.8)
Being sensitive to cultural needs	2.8 (1.8)	2.9 (1.7)
Handling family needs at home	2.2 (1.9)	2.4 (1.9)
Answering any concerns	3.1 (1.6)	3.0 (1.6)
Dealing with other responsibilities	2.3 (1.9)	2.4 (1.9)
Overall mean across items	2.9 (1.5)	3.5 (1.6)

Results of univariate analyses using patient satisfaction and psychosocial scales - Temple

PAIRED T-TESTS	N	Mean	P
Satisfaction - 4 Weeks	32	2.87	0.029
Satisfaction - 12 Weeks	32	3.55	
Affect Measures - Baseline	43	2.32	< 0.001
Affect Measures – 4 Weeks	43	1.59	
Affect Measures - Baseline	42	2.36	< 0.001
Affect Measures - 12 Weeks	42	1.23	

Conclusions

- Non-clinical model was feasible in a cancer setting
- Feasible to navigate across cancer sites
- Major barriers were transportation and insurance
- Other barriers – other financial issues and caregiver support
- Navigator time varied by barrier – financial issues, transportation and insurance most time consuming
- Patient's were most satisfied with cancer related information, getting medical services and answering concerns
- Cancer related worry may be reduced – but not clear if this is a result of the navigation support

Challenges and Lessons Learned

1. Need to do a thorough organizational assessment to determine “best” model of navigation for each institution
2. Link screening, diagnostic follow-up and cancer care is essential. Starting at the time of diagnosis presents many challenges.
3. Start up is required – most programs observe an 18-24 month period
4. Need more data on impact of care to support long term sustainability
 - Research is difficult in these environments – patient and staff reluctance
 - Research criteria may not address the overall needs of patient navigation in an institution