Cancer Navigation: Opportunities and Challenges for Facilitating the Breast Cancer Journey

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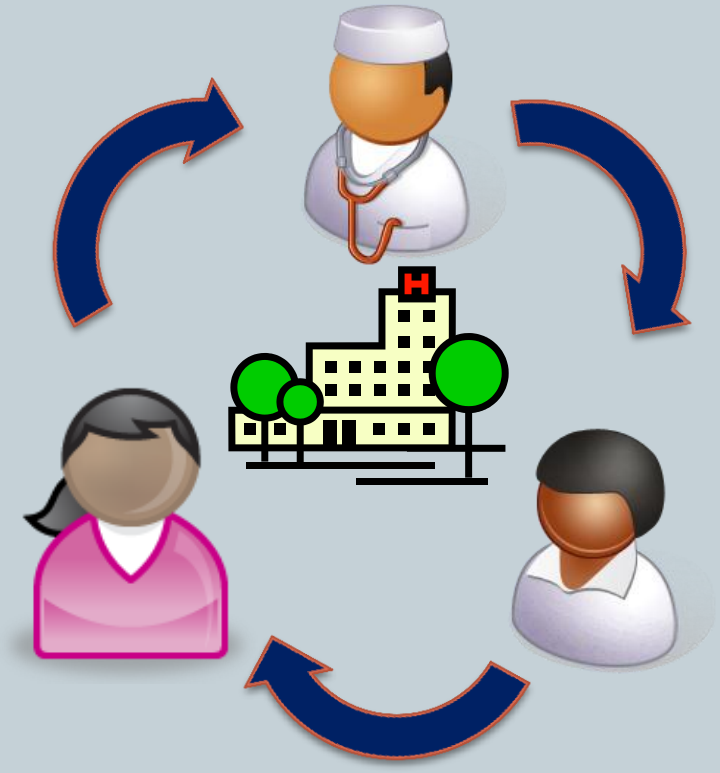
"Some people have a lot of support, others have no one. That's been shocking. I thought that everybody had somebody in their life, a friend. And sometimes people get embarrassed and they'll say 'I have lots of friends, I don't need you'. And then when I go to the hospital after their surgery there's nobody there. And they'll say 'I lied to you.' "

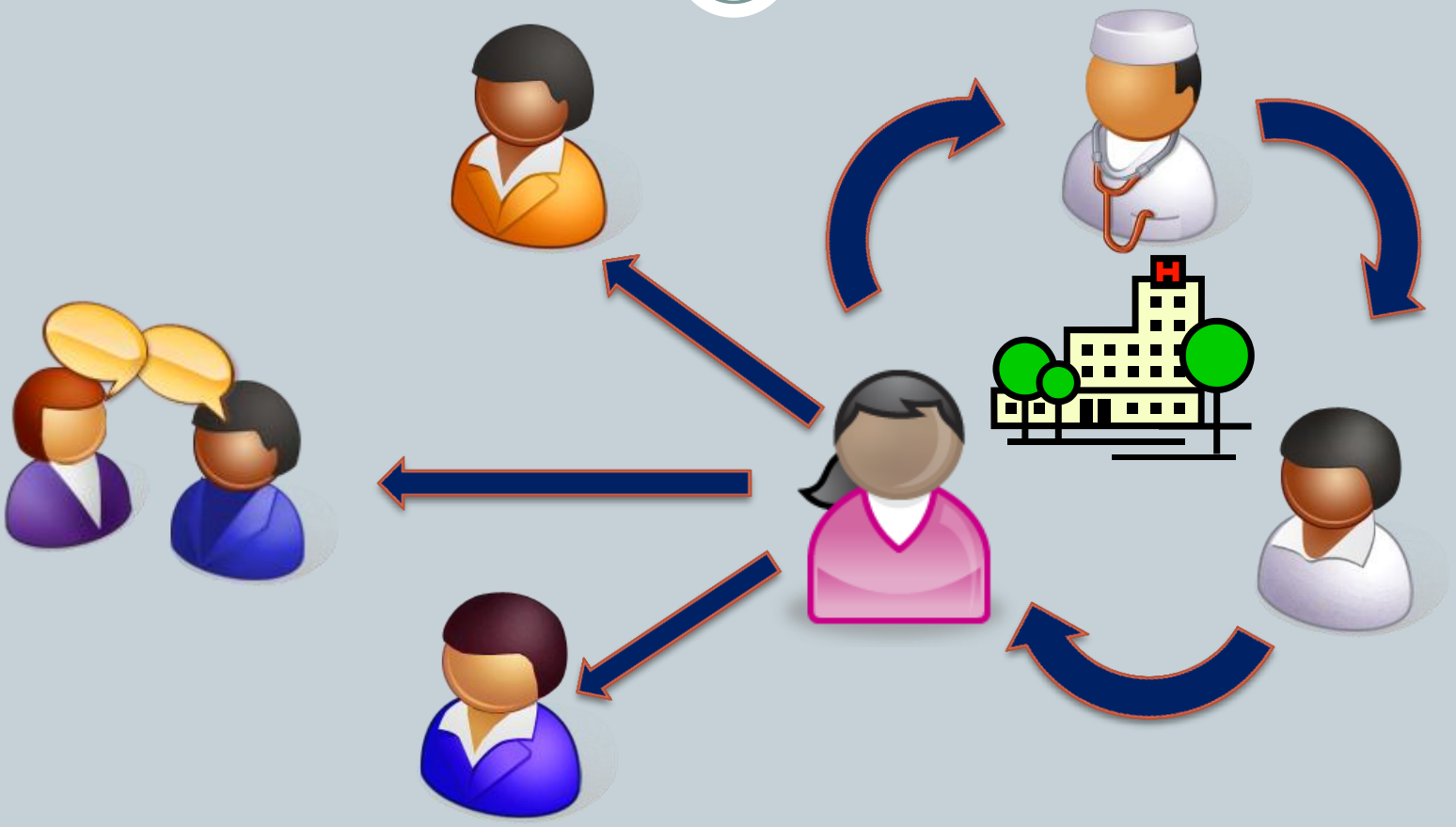
Overview

Motivation → History of Cancer Navigation → Case Study Details → Design Opportunities

Motivation



Motivation



Our Goals

1. Introduce researchers to a profession that could greatly benefit from further CSCW research

1. Identify opportunities to support cancer navigation through future technological innovation and CSCW research

What is cancer navigation?

- Began in Harlem, NY in 1990 by Dr. Harold Freedman as an effort to address healthcare gap[1]
  - President of the American Cancer Society
- Used trained community health workers to help patients receive the care they needed
- Over a six-year period, 5-year survival rates for breast cancer patients increased from 39% to 70%

1. Ramsey, S., Whitley, E., Mears, V.W., et al. Evaluating the cost-effectiveness of cancer patient navigation programs: conceptual and practical issues. Cancer 115, 23 (2009), 5394–403.

Navigation Today

- Growing focus on QOL
- Highly localized
  - Focus on needs of specific neighborhood and patients
- Broad range of activities
  - Counseling, answering medical questions, visiting during treatment, helping access health benefits, gas cards

Navigation Today

"[We] had a gentleman who was a high needs patient. He was just really resistant to treatment and [S1] talked to him for a few minutes and realized his only pair of shoes was a pair of sneakers with the toes out of them, and so he was embarrassed to go to the fancy cancer center without decent shoes."

Cancer Navigation in Rome, GA

- Population of 36,000
- 2 hospitals and 1 cancer clinic
- 901 cancer patients, 37% breast cancer
- Employs 7 individuals:
  - executive director
  - office manager
  - social worker
  - two nurse navigators
  - two service navigators

Cancer Navigation in Rome, GA

- Nurse Navigators: Eliminate gaps in medical knowledge and understanding
  - Educate patients and answer medical questions
- Service Navigators: Eliminate barriers to accessing treatment
  - Identify patients' needs, and help patients apply for resources for which they are eligible
- Provide emotional, financial, and logistical support not available anywhere else in the cancer care system

Cancer Navigation in Rome, GA

- Long term engagement involving multiple projects
- Conducted semi-structured interviews and focus group sessions to understand work practices
- Focus:
  - Understanding coordination and communication practices
  - Identifying the role technology plays in supporting navigation
  - Uncovering opportunities where CSCW support could improve navigation practices

Cancer Navigation in Rome, GA

- Used an iterative inductive analysis to construct design opportunities

- Organized data along an established cancer journey framework[1]
  - Common phases: screening and diagnosis, initial information seeking, acute care and treatment, no evidence of disease, and chronic disease and disease management

1. Hayes, G., Abowd, G., Davis, J., and Blount, M. Opportunities for pervasive computing in chronic cancer care. Pervasive Computing, (2008), 262–279.

Cancer Navigation in Rome, GA

Phase	Role	Responsibility
Screening and Diagnosis	Nurse Navigator	Meet with patients Introduce patients to navigation Answer medical questions Provide emotional and educational support
Initial Information Seeking	Nurse Navigator	Refer patients to service navigators Follow up with patients as needed to address medical/health questions
	Service Navigator	Meet with patients for initial needs assessment Help patients apply for necessary resources Provide emotional support
Acute Care and Treatment	Nurse Navigator	Provide support at health centers during treatment Answer medical questions that come up during treatment
	Service Navigator	Continue work from previous phase Refer patients to social worker for counseling if needed
No Evidence of Disease/Chronic Disease Management	Nurse Navigator	Follow up with patients as needed
	Service Navigator	Follow up with patients as needed

Cancer Navigation in Rome, GA

- Some findings:

> "I'm there to support them, I become their shadow. That's what I tell them, 'I'm your shadow through all this. And just know I'm here to do whatever you need me to do.'" – service navigator

- Navigation practices change as a patient progresses through the cancer journey
- Patients will work with both a nurse and service navigator at various points in the journey
- Collaborate with oncologists – meet patients at appointments and can access patient records

Cancer Navigation in Rome, GA

"There's just so many cancers with two nurses there's no way we can cover them all."

"You don't ever know how a patient is going to handle something. You might speak with them 10-15 minutes or you could be caught up for 2 hours."

Design Opportunities

- Resource monitoring
  - Limited available resources for patients
- Knowledge transfer
  - Responsible for printing multiple doctors' schedules to access patient meeting times
- Case management
  - Work with hundreds of patients each month, try to reach out to patients during do
- Long term navigation
  - Continuous influx of patients keep navigators focused on new diagnoses
- Development of best practices
  - Many of the characteristics that promote the success of individual organizations inhibit the creation of standards

Resource Monitoring: Current Strategies

- Constantly monitoring existing resources
- Basic search engines to find new resources
- Sharing information between navigators

"We communicate really well together, like, if I go and I get somebody's rent paid I immediately tell [the other service navigator]… there's not an official way of doing it, we just kind of talk it out and tell each other"

Resource Monitoring: Challenges

- Decline of money and resources available to patients
- Concern about not over-utilize limited resources
- Most resources only available to patients early in their treatment

"We really like to keep our resources kind of close to the chest because we don't want other people to take advantage of them "

Resource Monitoring: Challenges

"[He] came in yesterday, his last radiation treatment is today, and they came in yesterday. And I know they were struggling. They're a $700 a month income with seven people in the house. And it was hard because it's like I could have gotten you at least $100, but now we're going to have to see if we can even get that."

Resource Monitoring: Design Implications

- Conflict: sharing vs. preserving resources
- Cross-organization communication tools
  - Share search strategies
  - Provide larger variety of services to patients
  - Help with building new navigation organizations

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Summary

- Deep dive case study of the Rome Cancer Navigators
  - Better understanding of patient-navigator relationship
  - Able to chart changing navigation practices over cancer journeys
  - Developed strong relationships with navigators
- More case studies
  - Understand navigation trends at a national level

Future Work

- Navigation practices provided insight into changing cancer journey
- How can technology support patients' health management through changing journey?
- How will technological implementations influence navigation?

Thank you!

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