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

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ABSTRACT

Cancer navigation programs help patients overcome emotional, financial, and logistical challenges not typically addressed by the medical system. In this paper, we provide a detailed description of a rural cancer navigation organization, specifically detailing the roles collaboration and technology play in supporting navigation work. Examining navigation from a CSCW perspective, we see that navigation is a collaborative care system requiring coordination with patients, providers, and other navigators. Our study reveals a number of design opportunities for supporting navigation in the areas of resource monitoring, knowledge transfer, case management, long term navigation, and development of best practices. Supporting cancer navigation will be a critical step towards improving the healthcare experience for cancer patients.

Author Keywords

Cancer; Healthcare; Navigation; Implications for design;

ACM Classification Keywords

H.5.3 **[Group and Organization Interfaces]**: Computer-supported cooperative work

General Terms

Design

INTRODUCTION

When a person is diagnosed with cancer they must traverse a complex medical network as they obtain treatment, requiring coordination with numerous healthcare providers. Adapting to this new system and schedule often causes patients to face many emotional, financial, and logistical obstacles not addressed through the medical system. To help patients overcome these challenges, government, community, and healthcare organizations have joined forces over the past two decades to develop independent cancer navigation programs. Cancer navigators provide one-on-one support for patients from the time they are diagnosed with cancer until they complete their treatment [10]. Navigators attempt to ensure that nothing impedes a person's ability to obtain medical treatment by helping patients receive an often customized set of resources including counseling, social security benefits, medical insurance, gas money, answers to medical questions and many other crucial resources.

A young and developing practice, cancer navigation operates outside of the conventional healthcare system and yet provides an invaluable service to those diagnosed with cancer. Few studies explore how cancer navigators operate on a daily basis or how they collaborate with patients, physicians, and other cancer navigators. In this paper, we present a detailed case study of how a rural navigation organization collaborates with key stakeholders in an attempt to bridge gaps in the healthcare system and improve the quality of care for cancer patients. While we studied the communication and work practices of the entire organization, we focused on breast cancer navigation as the disease's high incidence and survival rates necessitate a high degree of sustained care management [1].

In this paper we describe the coordination and communication practices of a rural cancer navigation organization, identify the role that technology plays in supporting navigation work, and uncover opportunities where CSCW support could improve cancer navigation. We describe the various roles and responsibilities present in a cancer navigation organization and map these tasks to common phases of the breast cancer journey [12]. We classify our findings into five key categories: resource monitoring, knowledge transfer, case management, long term navigation, and the development of best practices. For each category we review cancer navigators' current strategies, identify challenges, and offer design opportunities. Through our work we offer new insight into how socio-technical systems may support cancer navigation.

Our work makes the following two main contributions to CSCW:

1. We introduce cancer navigation as a collaborative care network, and describe current navigation practices with a focus on communication and coordination techniques and technology usage.

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2. We identify opportunities to support cancer navigation through future technological innovation and CSCW research, thus expanding the design opportunities for collaborative health technologies.

Many of the lessons learned from our case study can be applied to other cancer navigation programs or to programs with non-traditional health professionals who play similar roles. As researchers continue to try to understand and improve cooperation within the hospital and healthcare settings, we must consider ways of extending this cooperation to professionals who do not fall within the traditional hospital setting or role, but with whom coordination is imperative for supporting patients. As new technologies, such as personal health records and electronic medical records, are introduced to health systems, an increasing amount of healthcare will occur outside of the hospital walls, making coordination increasingly complex and essential.

HISTORY OF CANCER NAVIGATION

Researchers over the past several decades have documented a severe disparity in healthcare delivery in the United States. People at lower socio-economic levels face higher cancer incidence and lower survival rates [8, 30].

In 1990, Dr. Harold Freeman developed cancer navigation (also called patient navigation) to address this healthcare gap. At that time, only 38% of operable breast cancer patients in Harlem survived for five years, and 25% of the breast cancer patients that came to the hospital were inoperable due to the cancer being too advanced [9]. The goal of the initial program developed by Freeman was to improve the survival rate of patients diagnosed with breast cancer by using trained community health workers to help patients receive the care they need. These health workers helped patients identify and overcome barriers that hindered their ability to successfully interact with the healthcare system. Over a six-year period, this program correlated to a substantial improvement in 5-year survival rates for breast cancer patients—increasing the rates from 39% to 70% [5].

The goals of cancer navigation programs have since progressed. Navigation originally focused only on providing patients with access to cancer screenings and medical treatment but now includes a growing focus on patient experience and improving perceived quality of life. As a result, cancer navigation organizations have increased their ability to provide services related to psychosocial support and quality of life outcomes [24].

While all cancer navigation organizations work to eliminate barriers faced by cancer patients, there is currently no standardized approach to providing this care across the various cancer navigation organizations nationwide. Cancer navigation remains highly localized, which has the benefit of enabling the organizations to provide the cultural sensitivity and understanding necessary to meet the unique needs of their neighborhoods and patients [17].

RELATED WORK

Medical Care Coordination

Many aspects make hospitals and healthcare centers complex adaptive systems. The intricacy of these sociotechnical systems makes studying their cooperation and coordination methods interesting and important for enhancing medical practices. Previous research has examined many aspects of these systems. For example, research exploring healthcare coordination helped explain how health professionals collaboratively search for information [23] and how staff members communicate in emergency departments [14]. Researchers in this area have also studied how patients interact with information in clinical settings [29]. Further, research has shown how technologies can enhance various medical processes. For example, previous studies deployed and evaluated technology for operating suites in order to enhance surgery coordination [3]. This segment of healthcare research shows how enhanced coordination can improve medical practices. However, past research has primarily focused on examining healthcare systems comprised of patients, physicians, nurses, and pharmacists. In contrast to previous work, our work highlights the need for research that examines healthcare professionals who exist outside of the traditional areas of study, such as cancer navigators, since these professionals will become important stakeholders of future healthcare coordination technologies.

Breast Cancer Patient Challenges

Many researchers have specifically examined the struggles encountered by breast cancer patients. This work helps to explain the importance of breast cancer navigators and the services they offer.

From the time of diagnosis, patients often face dramatic changes in their physical and emotional well-being [27]. Patients must manage physical side effects that result from their treatment including fatigue, nausea, and pain [11, 16]. In addition to these side effects, emotional distress, fear, and feelings of loneliness impact patients' quality of life [6, 25]. Managing information about their disease and treatment can also prove complicated for patients especially when working with multiple healthcare providers [13].

The challenges triggered by a breast cancer diagnosis are typically compounded when patients are ethnic minorities or of a low socioeconomic status. Issues such as lack of insurance, lack of transportation, and language barriers are prevalent within these groups [2].

Cancer Navigation Research

Limited work has been done to study cancer navigation. Most studies focus on providing a general definition and overview of navigation duties, as cancer navigation remains a new and evolving field for researchers [18]. Recent research looked at practices for developing lay navigation programs that recruit volunteers and cancer survivors as cancer navigators for newly diagnosed patients [4, 15, 28]. Understanding the cost effectiveness of cancer navigation programs is another area of interest that presents many challenges [21], as well as gauging patient satisfaction with navigation programs [7].

While all of this work helps to explore cancer navigation practices, there remain gaps in the research. To date we are not aware of any investigation into the work practices of any specific cancer navigation organizations in order to gain a deep understanding of its inner workings. Due to the highly localized nature of cancer navigation, concentrated case studies will help clarify the nuances of navigation work, while providing greater insight into the common strategies, challenges, and opportunities for support across navigation organizations.

Further, we are unaware of any research that has examined a cancer navigation organization as a socio-technical system. In order for HCI research to support navigation, we must gain a clearer insight into the interfaces and technological interactions that impact current navigation strategies. Our research expands on the existing knowledge of cancer navigation by providing a focused study that begins to address these specified research gaps.

METHODS

In the investigation of cancer navigation, our goal was to understand the day-to-day routines of navigators and to explore the use of technology to support the navigation process. We worked with a nonprofit organization that provides navigation and counseling services to patients with any form of cancer. We focus specifically on breast cancer navigation for the purposes of our investigation.

Over a six-month period we conducted 7 semi-structured interviews and 1 focus group session with the employees of a rural cancer navigation organization. Our investigation focused on understanding navigation responsibilities, the navigators' primary challenges, and their technology usage. We transcribed the interviews and focus group for later data analysis. To analyze the data we structured the data using two approaches. For the first approach we organized the data along the established cancer journey framework. Once we understood navigation practices as they relate to a general cancer treatment timeline we focused on constructing a framework around future design opportunities. To surface the themes in our data we used an iterative inductive analysis to cluster segments from the transcripts and develop theme concepts. Members of the research team then verified each of the themes and reviewed the transcriptions for theme validation.

Throughout the course of this project we have also collected data from breast cancer survivors and oncologists working with the cancer navigators. While the analysis of this data is ongoing, we were able to reflect on the interviews from patients and healthcare providers to assess the completeness of our portrayal of the practices of cancer navigators. Namely, we do not have additional data that points to unexplored areas in cancer navigation.

FINDINGS

We conducted our investigation of breast cancer navigation practices in Rome, GA, a rural city with a population of approximately 96,000. The city is supported by three distinct cancer clinics: Harbin Clinic, Floyd Medical Center, and Redmond Regional Medical Center. The navigation program under investigation was developed in 2008 as a non-profit organization to serve patients from all three of the local cancer clinics. In 2012, the organization navigated 901 cancer patients, 37% of whom were breast cancer patients.

Organization Structure

The navigation organization we investigated employs seven individuals: an executive director, an office manager, a social worker, two nurse navigators (referred to as N1 and N2) and two service navigators (referred to as S1 and S2). In the following sections we discuss the responsibilities of these navigators as they relate to the typical steps patients encounter as they progress through their cancer care.

Nurse Navigators

Due to their medical background, nurse navigators primarily work on educating patients about their disease and answering medical questions. Both of the nurse navigators in our organization were registered nurses prior to joining the cancer navigation organization.

Service Navigators

Service navigators focus their expertise on understanding the resources available to patients, identifying patients' needs, and helping patients apply for resources for which they are eligible. Prior to joining the navigation organization in Rome, the service navigators in our organization both had careers in social work.

Mapping Navigation to the Breast Cancer Journey

Understanding the steps a breast cancer patient must go through can be difficult as there are many different types of breast cancer, each with different treatment options available to a patient. Hayes et al. found that commonalities exist across individual cancer journeys, which can be described in five major phases: screening and diagnosis, initial information seeking, acute care and treatment, no evidence of disease, and chronic disease and disease management [12]. In order to demonstrate the role of navigation throughout the breast cancer journey, we will explain how the navigation process changes through these phases (table 1 summarizes the responsibilities of the navigators at each phase). Though we do our best to categorize the process, cancer navigation is a flexible and dynamic activity that is tailored to each patient's individual needs and cancer journeys.

Screening and Diagnosis

The first phase of Hayes et al.'s cancer journey is Screening and Diagnosis. In breast cancer, the first step after an abnormal breast cancer screening result is often surgery. The goal of surgery is to remove as much of the cancer

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

Table 1: Breakdown of Navigation Responsibilities by Breast Cancer Phase

from the body as possible and to prevent the cancer from returning. Navigators attempt to make first contact with the patient at this point in the cancer journey.

The responsibility of making first contact with patients falls on the nurse navigators. Nurse navigators will meet with the newly diagnosed patients during their first meeting with the general surgeon. In this meeting the navigators focus on providing emotional and educational support. Nurse navigator N1 described the meeting as follows:

There's a lot of different focuses. [Answering] questions is one, to just reassure them that 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.' I can look up records; I can tell you what the doctor said. For instance, the patient gets home and everybody in the room forgot what was said, I can actually go online and read what the doctor said word for word. And then it's to reassure them that we have services that are here and readily available to them whenever they're ready and comfortable with coming here or talking to one of the [service navigators].

Initial Information Seeking

After completing surgery, breast cancer patients will often go through additional treatment including chemotherapy, radiation, or a combination of the two. According to the cancer navigators, there is often a three to four week gap between surgery and treatment. During this time a shift occurs where patients will meet less frequently with nurse navigators and more frequently with service navigators. Referrals usually trigger this shift, in which the nurse navigator provides the office manager with the name and contact information of patients requiring service navigation. The service navigators can then contact the patient to set up future meetings at the cancer navigation office. Similar transfers of patients between nurse and service navigators based on phase and needs is seen throughout the cancer journey, particularly when beginning the initial information seeking phase and the acute care and treatment phase.

With service navigators acting as the primary navigators in the initial information seeking phase, S1 described this time as the most important point for them to meet with patients:

A perfect patient, they know what's going to happen but they haven't started treatment yet. So by the time they start to get those resources, about a couple weeks in, it kind of gets them over the hump.

The service navigators utilize numerous resources to provide aid to eligible patients. Based on a patient's needs, these navigators help patients apply for and receive social security benefits, gas cards and other transportation assistance, assistance with rent, food stamps, cell phones to communicate with their providers, dental assistance, as well as Medicaid and other medical insurance benefits. If service navigators are able to meet with patients prior to the commencement of their chemotherapy or radiation, they are better able to help patients access these resources by the time treatment begins. This timeliness can be particularly important for patients whose ability to access treatment relies solely on accessing these resources. Radiation, for instance, usually requires patients to go to the health center every day for several weeks. For many patients, daily transportation to the health center would not be possible without gas cards or other travel assistance.

To determine which resources a patient requires, the first one-on-one meeting between a patient and service navigator focuses primarily on assessing needs, while also providing an opportunity for relationship building. The service navigators have developed their own resource checklist which they complete as they talk to the patient. This checklist includes all of the resources navigators know they have available as well as a rating scale that helps the navigators predict how much time they will need to spend to obtain the necessary resources for the patients. Both of the service navigators indicated relying heavily on these documents. S2 specifically stated:

[The checklist] gives us a guide and ensures that we are going to gauge everything that we know to gauge.

Another aspect of the one-on-one meeting is evaluating a patient's social support and mental well-being. If needed, service navigators will refer patients to the social worker who works in the navigation organization, or they will provide patients with information about local support groups. All of the navigators discussed the importance of providing counseling for their patients. N2 discussed previous incidents that led to this understanding:

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.'

After completing the needs assessment, service navigators will work directly with patients to help them acquire their needed resources. The ultimate goal is to get the resources to the patients by the start of treatment so that no barriers impede the patient's ability to access the treatment they need. Securing aid for the patients in advance of their treatment allows the patients to focus on their health and not worry about whether or not they will actually be able to receive treatment. During the process of obtaining resources, navigators will put some of the responsibility on the patient, as described by S1:

Almost all of the time, we'll start the process but we want to make them finish it. You know like we'll say 'make this call, we're going to talk to them, we're going to tell them your story, but then we're going to hand you the phone'. Just to give them that autonomy and just to give them that responsibility as well. To make sure we're not just doing it for them. It also just gives them that empowerment, I think, because you know they have a problem that's bigger than they are, and then if we give them the tools to do it, they've fought that problem. And so to me it's just a good way to give them back some control.

Acute Care and Treatment

As patients begin their post-surgery medical treatment, the emphasis returns to the nurse navigators. During treatment, nurse navigators often meet patients at the health centers where their treatment takes place to provide an added level of emotional support. In addition, nurse navigators continue to provide education to patients by answering medical questions as they arise throughout the treatment. As patients begin to experience various side effects, this support becomes particularly significant. N2 described the importance of being available to answer these medical questions for patients' emotional stability:

Chemo nurses are really busy… If someone's panicked you don't want to be called back at the end of the day, and you don't want to go to the emergency room. A lot of things that people freak out about is a common side effect. So we try to nip that and that way they are at peace.

Also throughout this phase, service navigators will continue to help a patient apply for available resources if the applications could not be completed prior to treatment. The role of the service navigator then begins to shift towards providing the level of emotional support desired by the patient. Patients may indicate this desire by visiting the cancer navigation office or calling their service navigator. At this point, maintaining continuous communication with navigators is the responsibility of the patient. However, if a navigator determined in the needs assessment that a patient required counseling from the social worker, the social worker will organize counseling sessions during this phase, although the time period will change based on individual needs.

No Evidence of Disease/Chronic Disease Management

As patients move forward in their breast cancer journey, their relationship with the navigation organization can vary. Some patients will stay in close contact and come in to the navigation office frequently while others do not. All charts and files created by the navigators are saved if needed for later reference. As patients go through treatment, the service and nurse navigators will often follow up with them to ensure their care is continuing as expected. N1 detailed how she follows up with patients:

When I get a free day, what I try to do with those is just sit down and call and say 'hey, just wanted to see how you're doing, how's your treatment going' and just follow up. And it may take me several days to do that, just pulling a handful of charts at a time, but I try to follow up with them as much as I can.

DESIGN OPPORTUNITIES

In examining cancer navigators' daily workloads, we found that the majority of their responsibilities revolve around five central themes: resource monitoring, knowledge transfer, case management, long term navigation, and development of best practices. For each of these themes we discuss the strategies developed by the navigators to handle the workload, current challenges, and design implications that may help direct future research in the cancer navigation space.

Resource Monitoring

Current Strategies

Resource tracking is an important and continuous task for the service navigators. Financial institutions such as foundations continuously open and close due to the availability of funds. This fluctuation causes navigators to constantly search for new resources. To find resources and track their availability over time, navigators use basic search engines. Both service navigators mentioned using

Google frequently to look up possible resources for patients. S1 discussed with us how communication between navigators helps promote efficient searching and reduces the potential for overlapping efforts:

> *We communicate really well together, like, if I go and I get somebody's rent paid I immediately tell [the other service navigator]. Or if she gets somebody's power bill paid then I know about it. So then that way we know, 1) that it worked and 2) just to be careful with it. You know, because we don't want to drain them. And so it's really, there's not an official way of doing it, we just kind of talk it out and tell each other.*

Challenges

One of the biggest challenges facing navigators is the decline of money and resources available to patients. As N2 described:

> *The resources started drying up as the economy, so we didn't have as much to offer.*

The distribution of limited resources is an obstacle that navigators address up front through the needs assessment. They work to ensure they do not over-utilize limited resources so that high needs patients are able to access the resources. As S1 discusses, ensuring the availability of resources for those who really need them is not only important for the patients, but for the organization's reputation as well:

> *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. And then we can kind of do an internal process of screening. You know, like if we know a certain association will pay rent, we don't want to refer everybody that comes through that says 'oh, I need my rent paid'. We don't want to refer them because we know those funds will go out and then they'll stop seeing us as a viable referring agency. So we kind of do our own little screening process*

Resources also tend to be limited to patients beginning treatment. Patients who do not inform navigators of their needs early in the process often do not receive needed aid. This lack of flexibility in the aid distribution process inhibits navigators' abilities to assist high needs patients who are at later points in the cancer journey. S1 opened up about recently trying to deal with this issue.

> *That patient I was telling you that 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.*

Design Implications

An intrinsic conflict exists when it comes to collaboration across cancer navigation organizations. Sharing strategies, resources, and services may be key to developing a collective practice that currently does not exist in cancer navigation. Such a collective practice could help in growing existing organizations, providing a larger variety of services to patients in any particular community, and help in building new navigation organizations in communities that do not yet have them.

The decline of available resources, and the risk of depleting available resources further, hinders the development of such a collective practice. If navigators were to share their resources with organizations across the nation they risk not being able to provide for their own patients should the resource become exhausted.

This conflict indicates a direct need for CSCW researchers to explore ways in which cooperation can be promoted amongst navigation organizations that enhance the collective navigation practice and best supports the needs of individual patients and communities. For example, tools which allow navigators across organizations to share search strategies or rank resource providers may prove beneficial. Technologies such as these will allow navigators to find resources more efficiently without the fear of losing specific resources.

Knowledge Transfer

Current Strategies

Throughout any given day, cancer navigators are continuously interacting with providers, patients and with each other. Communication with providers in the community we investigated is particularly crucial for the nurse navigators, who rely on the doctor's schedules to determine when new patients are being diagnosed. Some technological solutions begin to support this collaboration. Nurse navigators in our rural community received access to doctors' calendars and patients' electronic medical records and have included reviewing these sources as part of their daily routine. While the nurse navigators no longer need to wait for clinical nurses to fax individual schedules, N1 did share that sorting through all of the calendars does take a significant amount of time:

> *Per week I print 14 schedules of the different doctors and their PA's. And what I do is I go through them usually, there's me and there is one other nurse. And what I usually do is go through and each day or the day before I mark for the next day… it may take a good hour to really sit down and look through the system.*

In addition to providers, communication between navigators proves important for the organization's success. We already discussed how internal communication helps in sharing resources. Open communication and collaboration also assists navigators in managing the unpredictable nature of their work and their patients. N1 described a recent example:

> *Yesterday [the other nurse navigators] was out of the office at 4 o'clock, got a call one of her patients was in the hospital in a panic mode, needed somebody here now. So I*

just dropped everything. I went there and I stayed with him until she got there. So those are things we try to do, we're good about helping each other with those kind of things.

Open communication also helps the cancer navigators provide emotional support to one another. The service navigators discussed how they would usually talk with one another after meeting with a patient, and hold an informal debrief.

Maintaining open communications between navigators also leads to positive effects on the patients, by providing an environment unlike other healthcare facilities. N2 and S2, respectively, shared their perception of this effect:

We're almost like a family. And when they come here, it's not a clinical environment, and if they're having a problem with a doctor or they're uncomfortable about something, this is a safe place and confidential.

There's no task list. We know each other's schedules and we know what's going on in each other's days. I think people that are used to being in an office, it sounds like we are just running amuck. But we're not; we know what we're all doing. And the patients really appreciate it because they'll say 'it feels like I just became part of your family'. They say, 'I have my support system now'.

By using open and casual communication between navigators, the organization has also provided a system that promotes trust and communication with their patients.

Challenges

The nature of cancer navigation provides navigators with the continuous challenge of remaining flexible while distributing their time to as many patients as possible. This challenge affects both nurse and service navigators, who all discussed the unpredictability of every patient meeting they hold. N2 specifically discussed the high degree of variability in regards to meeting times:

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.

Between organizing appointments around doctors' schedules and continuously holding meetings with irregular time intervals, communicating with stakeholders takes the majority of a navigator's day.

Design Implications

Future work should look at supporting cancer navigators' use of open and continuous communication with providers, patients, and other navigators as this communication greatly benefits the organization. Access to electronic medical records has already helped to alleviate some of the time constraints placed on nurse navigators. Hospitals and healthcare centers continue to implement technology that allows for greater interoperability, providing an increased level of communication between providers and other stakeholders. Cancer navigators should also be considered a primary stakeholder for future implementations. Elevating their role could be a critical step in allowing cancer navigators to spend more time with patients, and thus allowing them to reach a broader group of patients who could benefit from the navigation services. Tools that focus on awareness and allow a navigator to see when the other navigators are available may also help when unpredictable events occur. Ultimately, tools ought to promote flexibility and easier collaboration.

Case Management

Current Strategies

Over the course of a year, each navigator works with hundreds of patients, each with different needs. During cancer navigation, a paper file is created for each patient. This file includes a needs assessment form, navigators' notes, and resource application forms, and is shared across the organization should a patient work with multiple navigators. These files are never thrown away; one navigator even discussed having a specific location for files of deceased patients. While managing caseloads of this magnitude can be complicated, each navigator developed their own personalized method for organizing patient files. S1 described how she places files in certain locations based on her perceptions of the patient:

I have my files that I put everybody in, but then, if I know they're going to be calling me I just kind of keep them, put them in a different spot, just so I can grab their chart when they call.

While service navigators must manage a large number of files, they work entirely from the cancer navigation office building. Nurse navigators developed more complicated strategies to deal with the added mobility required in their job as they meet patients in surgery, chemotherapy, and radiation appointments. Any information or patient files a nurse navigator will need is organized by meeting date so that she can take a day's worth of files with her as she moves between healthcare centers. N1 described her personal strategy:

What I do is I just carry them for the day. The day's worth of files. I pick them up in the mornings because sometimes the doctors go in for an appointment and they may be so far behind and if you don't take your charts what's going to happen is you can't get back to the office to get them.

Although each navigator's case management strategy was different based on where they stored files and when they moved files, each focused on the usage of paper files that included patients' needs assessments, personal notes on the patient, and copies of resource applications that had been submitted.

Challenges

Large workloads place a great deal of pressure on memory and mental capacity. One of the service navigators mentioned struggling to remember patients' names when she runs into them unexpectedly. Further, N1 discussed the challenge of having such a high ratio of cancer patients in the community to available navigators:

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

The office space required to store the files for all of the cancer navigation patients presents an additional challenge. Navigators store their files in several locations around the office including desks, drawers, and file cabinets.

Design Implications

Future research ought to examine ways to alleviate the cognitive load placed on cancer navigators working with a large number of patients. Over the course of a month navigators typically manage hundreds of patients.

Improved scheduling systems may help navigators remain adaptable for their patients. For example, scheduling tools that consider the amount of time a navigator spent with each patient in previous meetings could help navigators develop more accurate schedules.

Opportunities for technical implementations to help with file storage, thus saving office space may be particularly important for larger navigation organizations. Reminder based systems may also be useful in following up and tracking information for patients once they begin to meet with navigators less frequently. This shift usually happens once patients progress in their treatment and receive the resources for which they are eligible.

Technological implementations that educate communities about the navigation organization and their services may also help the limited number of navigators reach a higher percentage of cancer patients.

While a large variety of tools may be useful in case management, caution must be taken when introducing new technologies into cancer navigation organizations that support patients of low socioeconomic status. Technological implementations designed to support navigation work must take the physical environment under consideration. Many of the high-needs patients do not have access to technology. Since patients meet the service navigators at the cancer navigation center, obvious technological implementations may cause a disconnect between the navigation environment and the environments patients' are accustomed to.

Preserving the casual atmosphere when navigators meet with patients may be important for maintaining relationships between navigators and their patients. The executive director of the organization described what a drastic effect a building's atmosphere can have on patients:

[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.

This description illustrates one situation in which the environment itself directly impacted a patient's willingness to receive treatment. In order to prevent similar issues from occurring in the navigation center, technologies and changes made to cancer navigation facilities must consider impacts on the patients who work directly with the navigators and the environment navigators promote.

Long-Term Navigation

Current Strategies

When mapping cancer navigators' responsibilities to the breast cancer journey, one can see that the work and services are heavily weighted towards the beginning of the journey. Many of the navigators mentioned that they try to follow up with patients when they get some free time to see how they are doing during or after treatment. However, large caseloads and high demands on their time limit navigators' ability to follow up with all of the patients, as mentioned by S2:

Once I actually give them everything they need, I'll keep [his or her file] next to me for a while then I get rid of it, I have to because our drawer is constantly filling up.

Challenges

The large number of new patients that continue to need navigation support impedes on navigators' ability to work with patients after treatment. According to one of the nurse navigators, as many as eight new consults may occur in a single day. This continuous influx of patients keeps the cancer navigators focused on patients in the beginning of their journey, so that they may help the new patients eliminate any barriers to beginning treatment.

Design Implications

There is a growing need to provide ubiquitous care in chronic cancer management. Research shows that cancer survivors face physical and emotional challenges after completing treatment [6, 31]. For example, Rosedale found that "Survival loneliness," which includes feelings of loneliness caused by an increased awareness of mortality and changed sense of identity, affected survivors even 18 years after treatment [25]. In this study Rosedale also found that discussing their feelings of loneliness led survivors to feel relieved. This finding indicates that emotional support from navigators may help tackle survivorship challenges. Moving cancer navigation from a reactive to a more proactive system could greatly benefit their patients, especially the cancer survivors post-treatment. However, the current time constraints, as discussed above, greatly hamper on the ability for cancer navigation to move in this direction.

One way to assist cancer navigators in providing more long term support is to provide systems that allow navigators to be proactive and structure their follow ups with patients in more efficient ways. Technology in the area of home or continuous monitoring could provide this necessary aid. Projects such as Digital Family Portrait have demonstrated the utility of providing awareness to caregivers while retaining privacy and autonomy for the individual [26]. Similar projects could prove useful as a way for navigators to monitor the well-being of patients they no longer see regularly. This information could be particularly important in allowing navigators to use their time efficiently by being better able to assess from a distance the needs of these patients and gain a sense of which patients they should prioritize.

Development of Best Practices

Current Strategies

The development of best practices for cancer navigation falls outside the scope of the navigators' daily work. However, the advancement and expansion of cancer navigation requires the creation of these practices.

Challenges

One of the biggest challenges in developing a set of best practices for cancer navigation programs is that many of the characteristics that promote the success of individual organizations inhibit the creation of standards. One such characteristic is that the backgrounds of the individual navigators help to define the expertise of their organization. The impact of individual backgrounds on the practice of navigation became apparent when discussing how the service navigators provide social security benefits for their patients. One of the service navigators originally worked for several years in the social security department, and brought to the navigation organization the knowledge of how to efficiently complete social security applications and help patients quickly receive their social security benefits. S1 expressed to us the significance of gaining that knowledge in the organization:

So now I know how to go online and look for the diagnosis that we know we are going be covered. And then we print their policy and we highlight it to show them that we know they [the social security department] have 20 days to get this decision… the patient goes, and within 30 minutes they are in and out of social security… And it's all [S2]. If it wasn't for her, I had never heard of it and I've been in healthcare for 8 years and I had never heard of that. And so that's something that she's taught us.

By leveraging individuals' backgrounds and expertise, this cancer navigation group is able to provide a broad range of services to their patients. However, since each navigation organization is comprised of people with various backgrounds, and no standard training program exists to capture this knowledge, there is currently no way for each organization to follow an encompassing and standardized set of best practices.

The high level of localization also makes developing best practices difficult. As previously mentioned, focusing on local impact has allowed the organization to develop processes that work best for the employees, patients, and local health clinics. The nurse navigators' strategy of accessing the doctors' schedules from the health clinics in order to attend all new consults is one example of a localized strategy. However, this process may not work in larger communities with more than three health clinics or in smaller, rural communities that do not have a nearby hospital. Thus, both the significant role of employees' backgrounds and the high localization of cancer navigation organizations hinder the development of national best practices for cancer navigation programs.

Design Implications

Scaling cancer navigation programs will require substantial work in the development of standard practices. We identified two key components absent from the current navigation structure that inhibit navigation growth: sharing of processes and standardized training.

As we discussed, the cancer navigators in this case study worked for years to establish processes and strategies that allow them to work efficiently and systematically. While organizations such as the one we investigated develop their own effective processes, such as the needs assessment process, no tools currently exist which allow separate organizations to share these practices with each other. Thus, each organization must develop their own practices despite the overlap of goals and tasks. Supporting the sharing of business processes can help encourage collaboration and enable the development of future cancer navigation organizations

Another property not yet developed is a standard training model. Navigators did discuss learning new processes and resources by working at the organization. However, currently no standard training exists to use across multiple cancer navigation organizations. Thus the skills and materials that navigators learn remain highly localized, as do the organizations themselves.

Developing a social network for navigators may provide an initial technique for the creation standard practices. Through an online community navigators could share processes, experiences, and stories with one another. This tool may also promote a sense of community across multiple navigation organizations, fostering greater collaboration.

Summary

Each of the themes described in this section help to identify areas for future cancer navigation support and expand the design opportunities for collaborative health technology. Table 2 provides a summary of the findings presented in each theme. All of these areas point to the need for technical support for the scaling of navigation practices. The reliance on informal communication means that current navigation organizations are limited to small teams that are vulnerable to serious disruption if a navigator unexpectedly

Theme	Current Strategy	Challenge	Design Idea
Resource Monitoring	-Online Google searches -Communication with other navigators within the organization	-Limited available resources -Resources are usually only available for patient beginning treatment	-Tool that allows navigators across multiple organizations to share search strategies and rank resource providers
Knowledge Transfer	-Print multiple doctors' schedules to access meeting times -Open communication with other navigators to deal with unexpected events	-Printing individual schedules is time consuming -Navigators must remain flexible as meetings with patients are unpredictable	-Awareness tool that shows which navigators are available during an unexpected event
Case Management	-Shared paper file created for each patient -Try to call patients during down time	-Work with over a hundred patients in a month -Files require office space for storage	-Scheduling tool that considers the amount of time a navigator spent with each patient in previous meetings to develop more accurate schedules
Long-Term Navigation	-Navigation services focus heavily on the beginning of one's cancer journey	-Continuous influx of patients keep navigators focused on new diagnoses	-Home or continuous monitoring systems that allow navigators to check on former patients
Development of Best Practices	-No current strategy, falls outside scope of navigators' daily work	-Many of the characteristics that promote the success of individual organizations inhibit the creation of standards	-Social network systems that begin to foster greater collaboration and sense of community across navigation organizations

Table 2: Summary of Design Opportunities

leaves the group. These limitations also restrict the number the patients who may benefit from the personalized navigation services.

DISCUSSION

Through a detailed analysis of navigation practices in a rural community, we provide researchers with an introduction to navigation processes. Despite over twenty years of existence, only a small fraction of cancer patients are introduced to navigation services. In order for cancer navigation to experience the growth necessary to provide greater impact in cancer care, new tools and technologies will be needed. In the past, information systems that did not account for the high level of collaboration and flexibility in healthcare have failed [20]. As these are common CSCW concepts, researchers in this field are uniquely positioned to develop the tools necessary to support complex navigation work. Further, the ability for future CSCW research to assist in expanding cancer navigation, thus allowing more patients to benefit from their services, will be vital in developing an improved standard of patient-centric cancer care.

Current research investigating healthcare coordination primarily focuses on supporting doctors, nurses, and patients. As demonstrated with cancer navigators, when designing technologies for health systems, researchers must begin to consider healthcare professionals who work closely with patients and their information, but exist outside of the traditional patient-provider context. Our analysis of cancer navigation begins to provide insight into new technological strategies for healthcare. We discuss two specific technologies that have the potential to support current navigation practices: collaborative information retrieval (CIR) systems and personal health records (PHRs).

Supporting collaboration across navigation organizations will be particularly important for enhancing navigation practices. Improving collaboration support will facilitate the development and maintenance of standard practices, afford the communication of a set of best practices between organizations, as well as potentially assist with regional and national resource management. One tool that successfully engaged collaboration in healthcare is the CIR system, which allowed users to share online search results with one another [22]. By developing this type of technology for navigation, cancer navigators from multiple organizations could share available patient resources with each other. This technology fits very well into current resource management practices as navigators primarily use online searches to find resources. By growing the pool of available resources for all navigators, the need to preserve resources may decrease. We also believe this technology could be vital in promoting communication across navigation organizations. Opening this communication will be a critical first step in sharing navigation processes and best practices on a national level.

In additional to CIR systems, PHRs have the potential to play a vital role in enhancing communication between navigators and patients, as well as between navigators and providers. Examining the themes knowledge transfer, case management, and long-term navigation reveals a need for better social connectivity. Regarding knowledge transfer, we discuss how nurse navigators need a more efficient way of monitoring schedules, so that they ensure that they are present for specific patient-doctor meetings. Within case management and long-term navigation we discussed the need for tools to reduce the cognitive load placed on navigators due to high workloads while also helping navigators remain in contact with patients after treatment. PHRs may provide a solution for all of these areas of interest. Many PHR technologies allow patients to designate a network of people who may access their health information. An easy to use PHR tool could allow navigators to see patients' medical appointments and health status both during and after treatment. Over time, PHRs may provide a new way for navigators to monitor and support patients when they are unable to meet face to face. Ultimately leveraging PHRs may further the broader goal of empowering patients in their own care by centering the care network on the patient and enabling the patient to activate that network when new needs arise. PHRs have already proved to be an interesting technology for CSCW researchers exploring healthcare cooperation [19]. Studying the impact of PHR usage by patients on healthcare facilitators, such as cancer navigators, remains an unexplored area. Investigating the use of CIR and PHR technologies provide potential areas for researchers to investigate in order to enhance navigation practices nationally.

CONCLUSION

In this paper, we provide a detailed description of a rural cancer navigation organization, specifically investigating the roles collaboration and technology play in supporting their work. Examining navigation from a CSCW perspective, we see that navigation is a collaborative care system requiring coordination with patients, providers, and other navigators. Our study reveals a number of design opportunities for supporting navigation in the areas of resource monitoring, knowledge transfer, case management, long term navigation, and development of best practices. Two goals drive the presentation of these opportunities to the CSCW community. First, we wish to introduce researchers to a profession that could greatly benefit from further CSCW research. Second, through navigation we expand the design space for collaborative health system technologies.

Each of the design opportunities present challenges that could be considered in future work. Producing more case studies of cancer navigation organizations is necessary to increase our understanding of navigation trends at a national level and to reveal the impact of localization on these organizations. Investigating a wider range of cancer navigation programs could also assist in developing a more cohesive national cancer navigation program.

Cancer navigators are proving to be valuable supporters of patient-centered research. We are particularly interested in working with cancer navigators in the design and implementation of a PHR-based technology deployment and examining the impact of patient-centric technology on the patient-navigator relationship. Supporting cancer navigation will be a critical next step in improving the healthcare experience for cancer patients.

Cancer navigators provide patients with emotional, financial, and logistical support not available anywhere else in cancer care. As such, cancer navigators are uniquely positioned to have a dramatic positive impact on cancer patients' healthcare experiences. By supporting navigation organizations and aiding in their expansion, our goal is to assist them in their quest to provide the millions of people combating cancer each year with the opportunity to benefit from this critical assistance.

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REFERENCES

1. American Cancer Society, "Breast Cancer Facts & Figures 2011-2012" (2011). [Online]. Available: http://www.cancer.org/acs/groups/content/@epidemiologysurveilance/documents/document/acspc-030975.pdf. [Accessed 22 May 2013].
2. Ashing-Giwa, K. T., Padilla, G., Tejero, J., Kraemer, J., Wright, K., Coscarelli, A., Clayton, S., et al. Understanding the breast cancer experience of women: a qualitative study of African American, Asian American, Latina and Caucasian cancer survivors. *Psycho-oncology*, *13*, 6 (2004), 408–28.
3. Bardram, J. E., Thomas R. H. Peri-operative coordination and communication systems: A case of CSCW in medical informatics. In *Proc. Of the CSCW 2010 workshop on CSCW Research in Healthcare: Past, Present and Future*, ACM Press (2010).
4. Braun, K. L., Allison, A., Tsark, J. U. Using Community-Based Research Methods to Design Cancer Patient Navigation Training. *Prog Community Health Partnersh, 2*, 4 (2010), 329–340.
5. Calhoun, E., Whitley, E. M., Esparza, A., Ness, E., Greene, A., Garcia, R., & Valverde, P. A national patient navigator training program. *Health promotion practice*, *11*, 2 (2010), 205–15.
6. Cappiello, M., Cunningham, R. S., Knobf, M. T., & Erdos, D. Breast cancer survivors: information and support after treatment. *Clinical nursing research*, *16*, 4 (2007), 278–93.
7. Donelan, K., Mailhot, J. R., Dutwin, D., Barnicle, K., Oo, S. A., Hobrecker, K., Percac-Lima, S., et al. Patient perspectives of clinical care and patient navigation in follow-up of abnormal mammography. *Journal of general internal medicine*, *26*, 2, (2011), 116–22.
8. Freeman, H. P. Race, poverty, and cancer. *Journal of the National Cancer Institute*, *83*, 8 (1991), 526–7.

9. Freeman, H. P. The impact of Clinical Trial Protocols on Patient Care Systems in a Large City Hospital. *Cancer* supplement, *72*, 9 (1993), 2834–2838.
10. Freund, K.M., Battaglia, T., Calhoun, E., Dudley, D.J., Fiscella, K., Paskett, E., Raich, P.C., et al. National Cancer Institute Patient Navigation Research Program: methods, protocol, and measures. *Cancer*, *113*, 12 (2008), 3391–9.
11. Gill, K. M., Mishel, M., Belyea, M., Germino, B., Germino, L.S., Porter, L., LaNey, I.C., Stewart, J. Triggers of uncertainty about recurrence and long-term treatment side effects in older African American and Caucasian breast cancer survivors. *Oncology nursing forum, 31,* 3 (2004), 633-9.
12. Hayes, G.R., Abowd, G.D., Davis, J.S., Blount, M.L., Ebling, M., Mynatt, E.D. Opportunities for Pervasive Computing in Chronic Cancer Care. In *Proc. of Pervasive* (2008). 262-279
13. Klasnja, P., Hartzler, A. C., Unruh, K. T., & Pratt, W. Blowing in the wind: unanchored patient information work during cancer care. In *Proc. CHI 2010,* ACM Press (2010).
14. Lee, Soyoung, et al. Loosely formed patient care teams: communication challenges and technology design. In *Proc. Computer Supported Cooperative Work 2012*, ACM Press (2012).
15. Lorhan, S., Cleghorn, L., Fitch, M., Pang, K., McAndrew, A., Applin-Poole, J., Ledwell, E., et al. Moving the Agenda Forward for Cancer Patient Navigation: Understanding Volunteer and Peer Navigation Approaches. *Journal of cancer education : the official journal of the American Association for Cancer Education*. (2012).
16. "Managing Chemotherapy Side Effects," Breastcancer.org (2013). [Online]. Available: http://www.breastcancer.org/treatment/chemotherapy/side_effects. [Accessed 20 May 2013].
17. Nguyen, T.-U. N., & Kagawa-Singer, M. Overcoming barriers to cancer care through health navigation programs. *Seminars in oncology nursing*, *24*, 4 (2008), 270–8.
18. Pedersen, A., & Hack, T. F. Pilots of oncology healthcare: a concept analysis of the patient navigator role. *Oncology nursing forum*, *37*, 1 (2010), 55–60.
19. Piras, E. M., Zanutto A. Prescriptions, x-rays and grocery lists. Designing a Personal Health Record to support (the invisible work of) health information management in the household. In *Proc. Computer Supported Cooperative Work 2010*, ACM Press (2010).
20. Pratt, W., Reddy, M. C., McDonald, D. W., Tarczy-Hornoch, P., Gennari, J. H. Incorporating ideas from computer-supported cooperative work. *Journal of biomedical informatics*, *37*, 2, (2004) 128–37.
21. Ramsey, S., Whitley, E., Mears, V. W., McKoy, J. M., Everhart, R. M., Caswell, R. J., Fiscella, K., et al. Evaluating the cost-effectiveness of cancer patient navigation programs: conceptual and practical issues. *Cancer, 115*, 23, (2009), 5394-403.
22. Reddy, M. C., Jansen, B. J. A model for understanding collaborative information behavior in context: A study of two healthcare teams. *Information Processing & Management, 44*, 1 (2008), 256-73.
23. Reddy, M. C., Spence, P. R. Collaborative information seeking: A field study of a multidisciplinary patient care team. *Information Processing & Management*, *44*, 1 (2008), 242–255.
24. Robinson-white, S., Conroy, B., & Slavish, K. H. Patient Navigation in Breast Cancer, *Cancer Nursing*, *33*, 2 (2010), 127–140.
25. Rosedale, M. Survivor loneliness of women following breast cancer. *Oncology nursing forum*, *36*, 2 (2009), 175–83.
26. Rowan, J., Mynatt, E.D. Digital family portrait field trial: support for aging in place. In *Proc. CHI 2005*, ACM Press (2005).
27. Salonen, P., Kellokumpu-Lehtinen, P.-L., Tarkka, M.-T., Koivisto, A.-M., & Kaunonen, M. Changes in quality of life in patients with breast cancer. *Journal of clinical nursing*, *20*, 1-2 (2011), 255–66.
28. Steinberg, M. L., Fremont, A., Khan, D. C., Huang, D., Knapp, H., Karaman, D., Forge, N., et al. Lay patient navigator program implementation for equal access to cancer care and clinical trials: essential steps and initial challenges. *Cancer*, *107,* 11 (2006), 2669–77.
29. Unruh, K. T., et al. Transforming clinic environments into information workspaces for patients. In *Proc. CHI 2010,* ACM Press (2010).
30. Wells, B. L., & Horm, J. W. Race and Socioeconomic Factors. *American Journal of Public Health, 82*, 10 (1992), 1383–1385.
31. Zebrack, B. J. Cancer survivor identity and quality of life. *Cancer Practice*, *8*, 5 (2000), 238–243.