Opportunities for Pervasive Computing in Chronic Cancer Care

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Abstract. While changing from a predominantly terminal to an increasingly chronic condition, cancer is still a growing concern. Accompanying this change are new opportunities for technologies to support patients, their caregivers, and clinicians. In this paper, we present an in-depth study of cancer communities. From this exploration, we define and describe the concept of a personal cancer journey. We examine lessons and design opportunities across this journey for sensing and context-awareness and capture and access applications.

Keywords: Healthcare, cancer, qualitative methods, sensing, applications.

1 Introduction

One in two men and one in three women in the United States today will be diagnosed with cancer [1]. At the same time, more "people are *living* with cancer, not just dying of it or beating it."[1] Chronic cancer care represents a significant domain challenge for pervasive computing researchers, because the needs of patients, survivors, clinicians, friends, and family are both unique and evolving. The same patient may experience multiple recurrences with differing symptoms, multiple treatment plans with differing side effects, and so on over the course of years. Furthermore, they are experiencing these issues while trying to *live* with cancer rather than letting cancer be their lives.

We set out to explore how cancer patients, caregivers, medical staff, social workers, researchers and other professionals adopt technologies, with an eye towards the potential for pervasive computing in this domain. During this work, we uncovered the framework of a journey, which we use to reveal how technology use crosses clinical and temporal boundaries. Others have addressed notions of a chronic illness trajectory [9] and certainly, inherent to diagnoses of cancer, there are notions of disease progression,

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[1] Quote from a patient who had lived four years past her prognosis at the time of the interview.

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as denoted by the use of *stages*[2] in describing cancer. The chronic cancer journey, however, represents a different framework that warrants separate consideration and helps to reveal user needs in the face of a branching, complex set of experiences while living with a disease. In this paper, we outline findings from a qualitative empirical study of the needs of chronic cancer patients, their support networks, and medical personnel. We also present lessons and design opportunities for pervasive computing.

2 Related Work

Extensive literature exists on technologies for healthcare, both commercial and in research [12]. A complete review of these works is out of the scope of this paper. Here we present a sampling, describe how the space has been explored, and outline the novel contributions of this investigation.

The American Telemedicine Association asserts that "home telehealth (including remote monitoring) should be used as a part of a coordinated, comprehensive care program designed to reduce healthcare costs … and improve clinical outcomes" [4]. A model of healthcare including telemedicine thus increases patient and caregiver involvement in medical care. For example, Mamykina *et al.* explored the ways in which individuals with diabetes understand and monitor their blood glucose levels in response to various environmental stimuli [18]. The Personal Medical Unit [5] and Personal Care Connect [6] provide potential technological platforms for individual management of sensed and reported health information. Other efforts, such as the Digital Family Portrait [22] and CareNet [8], have focused more on quality of life issues such as social interaction and physical activity. A common theme across all of these projects is collaboration, such as in Computer Supported Coordinated Care [7].

Physical and cognitive disabilities often accompany chronic conditions, either temporarily as with "chemo brain"[3] or permanently due to diminished function inherent to the condition (*e.g.*, as in Alzheimer's at the end of life or developmental disabilities at the beginning). Thus, assistive technologies contribute to the works related to chronic cancer care. Dawe outlined ways in which assistive technologies are and are not adopted by families of children with permanent disabilities [10]. These guidelines can also be helpful in considering adoption of technology for other chronic conditions. In cancer care, for example, use of wheelchairs, transfer boards, lifts, and other physical assistance tools are common, particularly as physical abilities degrade.

Eysenbach explored "cybermedicine," including web pages, on-line communities, and other "medicine in cyberspace" [13]. He differentiates telemedicine as driven by a "technological push" while cybermedicine is defined by a "consumer pull." He also challenges researchers to "develop and evaluate interventions that can maximize the positive effects of the Internet" [14].

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[2] Staging is a complex process that accompanies all cancer diagnoses. Staging systems describe how far a cancer has spread and group people by prognosis and treatment. Staging applies to almost all cancers except some types of leukemia. Cancers are classified from I to IV in roman numerals, with IV being most severe and including metastases.

[3] "Chemo brain" is the notion amongst members of the cancer community that individuals can experience temporary reduced cognitive functioning as a reaction to chemotherapy treatment.

The work presented in this paper contributes to the state of the art in two significant ways. First, we are exploring cancer as a broad problem, whereas many previous works have focused on only a subset of the entire cancer community, such as the medical staff in hospitals. Second, the present analysis includes an examination across all phases of the disease. Relevant literature and commercial products provide a base for our new focus of research to develop a full model for the ways in which pervasive computing technologies can be and currently are used to support chronic cancer care.

3 Methods

The goal of this work is to understand the effects and potential of pervasive computing on the entire cancer ecosystem[4]. We employed an exploratory, qualitative empirical approach, adapted from contextual inquiry [16]. We used participant and direct observation [23], collected artifacts related to cancer, and conducted in-depth interviews.

3.1 Participant and Direct Observation

For eighteen weeks, we immersed ourselves in the culture of the cancer community. We did not limit our study to any particular type of cancer nor did we limit consideration to a type of patient, survivor, caregiver, clinician or other professional. The decision to proceed with this breadth first approach did not come lightly. We examined those issues that were most similar and common across not only the thousands of possible types of cancer but also across other types of chronic care situations found in the literature.

We started our cultural immersion into the cancer community online, by visiting educational web sites (n=42). These sites were sponsored by cancer treatment centers, hospitals, non-profit organizations and prescription drug manufacturers. We subscribed to cancer- and caregiver-related electronic mailing lists (n=12), often receiving and reviewing hundreds of emails each day. These lists covered a variety of topics, from those dedicated to specific types of cancer (*e.g.,* the Kidney Oncology list) to those dedicated to specific stages of cancer (*e.g.,* bcmets for metastatic breast cancer) to those dedicated to specific types of people (*e.g.,* lists specific to daughters of cancer patients). Some of these latter lists request that you fit certain criteria to subscribe (*e.g.* daughters of mothers with breast cancer). In those cases, we only subscribed to lists that were also personally relevant out of respect for these policies. Although this limitation potentially narrowed our sample size, we were still able to view a wide variety of lists and believe that the ethical requirements of the research warrant this tradeoff.

We also conducted fieldwork, both participating in some cases and observing in others. One member of the research team conducted the majority of the fieldwork, with this individual recording detailed field notes, taking pictures, and presenting those to the rest of the group for discussion at weekly meetings. Field sites included:

- Cancer treatment centers, both interviewing and observing during infusion sessions;
- Cancer screening sessions at hospitals and clinics, with one team member not only recording field notes but also participating in screening activities;

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[4] The cancer ecosystem includes patients, caregivers, doctors and other medical staff as well as epidemiologists, records keepers, social workers, and others affected by cancer.

- cancer libraries, in which we actively searched for information, recorded field notes and observations of individuals likewise searching, browsing, and consuming information, and interacted with librarians and nurses assigned to these libraries;
- support centers, in which we observed and actively participated in educational seminars and support groups; and
- hospitals, including waiting areas, cafeterias, and treatment and diagnosis areas[5].

3.2 Artifact Analysis

We collected and analyzed hundreds of artifacts from many sources, including hospitals, support centers, patients, and caregivers. These artifacts ranged from published books and pamphlets to homemade information organization tools (*e.g.,* notebooks) to medical journals to on-line support group archives. Taken together, these artifacts provide a basis for understanding the relationships between the physical legacy of human life and the reported and observed internal and external states of our participants. Where possible we included the text of these artifacts in a manner similar to the inclusion of interview transcripts as described in detail in the analysis section.

3.3 Interviews

Twenty-one people participated either in person or by phone (seven people). The interviews lasted one to two hours each. Participants included seven patients and survivors, four medical professionals, four social workers, one hospital health data manager, one home health manager, and four family members. Twelve participants were from the greater New York City area, three from small cities in Alabama, three from small towns in the Mid-West region of the U.S., one from rural Vermont, one from outside of Washington, D.C., and one from Boston, MA. All patients and survivors had been diagnosed with cancer at least two years before the interview, some as long as seven years.

When in person, interviews were conducted at a place of the participant's choosing, usually homes or offices. One patient asked that the interview take place during her chemotherapy treatment. The interviews were open-ended and conversational in nature by design to uncover those issues most significant to the participants. They typically occurred as one-on-one sessions, but in one case, two social workers and the director of hospice care participated as a small group. Following initial data analysis, as described in 3.4, we debriefed with participants, sharing with them their interview transcripts and further probing them about emergent themes. We also shared an early draft of this manuscript and solicited feedback on the results of the work, incorporating that feedback into later analysis and design work.

3.4 Analysis

Interviews were recorded and transcribed with participant permission. When recording was not feasible (four interviews), copious field notes were taken to document participant

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[5] Chemotherapy is treatment of disease with chemical substances, primarily cytotoxic drugs used to treat cancer. Infusion refers to a common way to inject chemotherapy, intravenously. Infusion centers also serve non-cancer patients who require intravenous drug treatment.

comments. In every case, the researcher conducting the interviews took field notes during and shortly after the events. The transcripts, field notes, and collected artifacts from the observation phase of the study were then analyzed to create a grounded theory [24] about the cancer experience. After two passes of inductive or "open" coding through the data to determine general themes, we then created a coding scheme centered on fourteen major themes, each with two to ten sub-themes (see Table 1 for list of major themes and a single exemplar sub-theme for each). Using this coding scheme, we then completed two passes through the data using axial and deductive coding to demark any potential variants from the emergent themes and any interconnections between them. These themes run across each stage of the cancer journey and thus do not map directly to sub-sections in the Results section but rather are included across them all.

Table 1. Major Themes and Exemplar Sub-Themes from Coding Scheme

Major Theme	***Exemplar Associated Sub-Theme***
Environment	Physical cues in the environment designed for/effective in creating a particular gestalt
Sense of belonging	Roles within a community
Choice of activities	Adoption of new practices, hobbies, activities
Working together	Ability and willingness to ask and answer questions
Support network	Relationship dynamic with patient
Self-concept	Aesthetic and esteem
Information access	Information access preferences
Finances	Cost of new technologies and techniques
Monitoring	Legal, ethical, and societal pressures and norms
Quality of life	Complementary or peripheral care
Medication and treatment	Tension between autonomy and compliance/adherence
Current and new uses of technologies	Caregiver/patient responsibilities for technology
Attitudes regarding prevention and screening	Attention to body and signals and intuition
Epidemiology	Availability and quality of epidemiologic information

From these data, we created design briefs, including lists of the stakeholders and potential users and of the high level features. Each brief then detailed the ways in which these stakeholders, users, and features would likely interact. We used the design briefs in engineering and prototyping discussions and iterated on them based on feedback during these sessions. These designs have not been further tested nor completely developed. We present a subset of these designs in this paper, those that are most directly related to pervasive computing, as a means for provoking further design and development in this area rather than shrink wrapped completed concepts.

4 Results

All interview participants used a metaphor similar to a "journey with six explicitly using the word "trip" or the word "journey." Thus, the concept of a personal journey with cancer became a significant backdrop for investigation. They also all commented that each journey is special and unique to each individual, but that commonalities exist.

> *"…recovering from cancer is like pregnancy… everyone goes through the trip a little differently."* – Stage I survivor

Building on staging of cancer diagnoses and the chronic illness trajectory noted by Corbin and Strauss [9], we probed this journey metaphor. Participants reported it to be significantly different for them from these other ways of describing cancer's impact. Whereas staging and disease trajectories all map to a unidirectional non-branching path, a journey allows for divergent, convergent, and even circular paths. Given the now chronic nature of cancer, and its common disappearance, reappearance, and constant threat to health, the journey metaphor maps more appropriately.

The data from this study indicate major commonalities across each unique journey expressed in five major phases. These phases are: screening and diagnosis, initial information-seeking, acute care and treatment, no evidence of disease, and chronic disease and disease management. In this section, we lay out significant findings of each phase. We describe the phase itself and indicate how technology is used currently. In section five, we describe the lessons from across these phases and indicate new opportunities for design.

4.1 Screening and Diagnosis

The screening and diagnosis phase begins with an individual experiencing some impetus to get "checked." Often, participants reported they were simply participating in a standard prevention or screening measure. During the screening activities in which we participated, other people awaiting their tests commented they were "doing the right thing." For others, there might be obvious and/or acute symptoms. For example, a common symptom of brain tumors is a bloody nose. These symptoms often only appear after the cancer is advanced, and people can and do live with cancer for years without a diagnosis. Finally, many people also request screening measures because of less acute symptoms or simply an intuition that something is wrong.

Currently, computing provides basic information during this phase. Some physicians and medical staff reported using the Internet to get the most current recommendations for screening from organizations like the American Cancer Society. Individuals can also find information online about opportunities for free screenings.

The time just after a diagnosis of cancer is characterized by the feeling of a "roller coaster of emotions" as diagnoses are changed and new information is presented. Participants reported that the diagnostic information shared during this phase could be extremely overwhelming. Multiple opinions are often sought, and each physician may request his or her own diagnostic tests. The volume of data builds, often resulting in conflicting or complementary but different diagnoses and plans of action.

> *"…well, everything looked okay…Well, then no it wasn't okay, but then it wasn't so bad and then it was so bad…she had…a positive reading for breast cancer, and then they did a bunch of other tests and… she had the metastases in her spine …"* – Husband of Stage IV patient

It can be very difficult to comprehend this information when under the type of duress invoked by a cancer diagnosis [19]. Participants reported relying on a combination of sources to get information on everything from which physicians to see to what their particular symptoms and diagnoses might mean. They often contacted friends and family by phone and email looking for advice and referrals. Those who were Internet savvy also searched online for reviews of physicians and basic disease information.

4.2 Information-Seeking

The information-seeking phase generally begins as soon as a diagnosis is made and continues for one to several weeks. During this phase, newly diagnosed patients often reported seeking multiple opinions and therefore getting even more tests and reports. All the participants, from patients to caregivers to medical staff to social workers, commented that during the weeks immediately after diagnosis, nearly everyone in the support network begins rapidly and aggressively searching for information. They reported using web sites, books, magazines, and other print information as well as both online and offline conversations with others on the journey. The collected information may support consideration of treatment plans and decision-making.

Cancer, although one word, is thousands of diseases, and available information can be overwhelming. Furthermore, the stress of the diagnosis can negatively impact individuals' abilities to learn [19]. Thus, physical cancer libraries, such as those we observed at treatment and community support centers, often are intentionally decorated in soothing colors with light music playing in the background as well as staff on call to assist. In the online environment, people can find much more information and often search out details available few other places. The personal assistance of friends, family, or these staff members and the soothing atmosphere, however, can be absent. Participants repeatedly reported, therefore, that although the Internet and other computing resources offered a lot of information, it was often difficult if not impossible to sort through it all.

> *"… one of the problems that I had on the Internet … was, I would get so many hits that just going through them to find those that were helpful... was awkward and time consuming."* – Husband of deceased patient

Participants reported joining online mailing lists related to cancer during this time. Those who previously belonged to mailing lists on other topics (*e.g.,* hobbies) reported joining the most, but even some with no previous experience online joined and/or reviewed list archives. This rapid joining and reading of mailing lists resulted in a deluge of information. In turn, participants reported spending large amounts of time determining what was relevant and important from the different lists and deciding which lists they would continue to monitor. They also reported creating physical binders and virtual folders to organize the massive quantities of information collected.

4.3 Acute Care and Treatment

Once a treatment plan is in place, acute care and aggressive treatment begins. The medical team, patient, and support network implement a plan that may include multiple chemical treatments as well as physical treatments such as radiation and surgery. Medical staff members monitor closely the patients' reactions to these treatments. There are recommendations and tables of suggested dosages by which the physicians determine the treatment plans, but, as one caregiver put it, "…it appears to me like most of the treatment protocols are a, I'll call it an Easter egg or a trial and error. You just try something, and if it works you continue that, and if it doesn't work, you go try something else."

In-office tests and patient tracking supports much of the hypothesis testing and adjustments to treatment plans. Medical teams use a mix of quantitative results (*e.g.,* blood tests) and qualitative discussions about patient symptoms and side effects. The visits at which these discussions take place, however, are usually less frequent than the treatment sessions themselves. Furthermore, oncologists may get very little time talking with patients. To compound the matter, these relationships are usually very new, given that most people do not know oncologists until they need one. To combat the subjective and variable nature of this approach, some medical practices have begun attempting to quantify symptoms. For example, one medical practice we encountered during this study uses a tablet PC-based detailed questionnaire called the SOS Patient Monitor [17]. The electronic solution provided them the ability to administer dynamic, personalized surveys and easily view this data over time in varied formats.

During this phase, changes also take root in the personal lives of patients and their support networks. All of the patients and caregivers we interviewed reported an adjustment in life to focus on activities that addressed core needs in their personal lives. Some patients stopped working; others moved to more remote areas to spend more time with family. Simultaneously, extended social networks also may change. Participants reported sharing information with more people than they ever believed they would.

> *"I didn't even know that I knew that many people."* – Stage IV patient

> *"…everybody wants to call and say 'Okay what happened today? Any news today?' And how many phone calls can a person make?"* – Social worker

Many patients commented that although they felt loved by their friends and family members calling or emailing and asking for status updates, these calls could also be a burden. They might come at a time that is inconvenient. These calls also often come in succession requiring repetition of news, information that is sometimes very painful to relay. To manage this huge flow of information in from the medical staff and other sources and back out to support networks, some patients and their caregivers develop personalized web sites, either through their own efforts or through services (see for example, www.caringbridge.org and www.lotsahelpinghands.com). Those on the receiving end of this information also reported struggles with current practices. They noted that waiting for posts to websites or blogs meant they were not as up-to-date as they wanted to be. They would have to wait until the patient was at a computer with network access and felt well enough to type and upload photos and other information.

Another primary concern during this phase is obtaining an appropriate level of patient involvement in and understanding of treatment. Even for those patients who do not want to know the details of their diseases and treatments, many physicians believe it is imperative for them to obtain some level of knowledge and maintain some level of involvement. Compliance (the taking of medication appropriately when first prescribed) and adherence (continued compliance) are major issues for prescribing physicians. However, patients are often not intentionally non-compliant.

> *"…it's not at all a non-compliance issue on the patient's part. It's just an uninformed patient…"* – Social worker

4.4 No Evidence of Disease

If the acute treatment phase goes well, and the cancer was at an early stage, patients are sometimes deemed to be "cured" or to have "no evidence of disease" (NED). Unlike some other phases we describe, NED is also a medical descriptor. Some people choose the NED designation because it denotes that recurrence of the cancer is of concern and that it may be hiding in the body while remaining undetectable. This concern contributes to a culture of continued monitoring and use of medical treatments and holistic remedies to reduce chances of recurrence.

> *"Once you have it, the age of innocence is over. You feel vulnerable the rest of your life…it's like terrorism…. We're always told don't change the way you live your life, but always be on the watch."*
>
> – Cancer survivor, three years NED

Survivors still visit their oncologists for regular tests, the frequency of which decreases with time. The potential for an acute event leading back to the diagnosis phase raises concern levels, and thus symptoms may be tracked for recurrence. One patient who experienced a recurrence noted that the risk may persistently be on their minds:

> *"Every pain that you have, where most people just say 'oh my knee hurts' you think 'Oh my knee hurts, I wonder if it's in my bones.'"*

Support for NED survivors must sit between vigilance and undue concern. Hence, many survivors reported having difficulty with certain support groups, both online and off, once they had lived with the threat of recurrence for a long period of time. Returning to these groups, when acquaintances originally diagnosed at the same time had passed away made things extremely difficult. On the other hand, NED survivors often "give back" to the community. Frequently, email messages from "newbies" in the communities we monitored were answered with words of encouragement from someone "on the other side." Many survivors also reported giving lectures at support groups, fundraisers, and so on as well as volunteering and socializing with patients and others. Most NED survivors reported taking time out to remain in these communities in many cases. It should be noted, however, that many reported being "superstitious" and not wanting to declare themselves "cured" or to act as models for others for fear of a recurrence and so sometimes waited or needed extra encouragement to get involved in cancer communities again.

4.5 Chronic Care and Disease Management

When the possibility of a patient ever gaining an NED status disappears, patients move into chronic care and disease management. Unlike in some chronic conditions (*e.g.,* diabetes) but similar to others (*e.g.,* Parkinson's disease), those dealing with chronic cancer care assume that the cancer is eventually a terminal condition.

> *"Stage IV is terminal…the disease will take us out and it's simply a matter of when."* – Patient living with Stage IV for six years

During this phase, quality of life becomes a more significant metric of success. Patients reported attempting to maintain hope and a sense of "normalcy" while adjusting to the inevitable terminal nature of their diseases.

> *"…I just think if we lose hope, we die... So, you just have to find the joy in the little rewards."* – Stable Stage IV patient

During this phase, physicians and patients often opt to change the treatment strategy, concentrating on managing the disease rather than attempting to cure it. This strategy often involves using one treatment at a time, as opposed to treatments during the acute care phase, in which patients usually experience as many approaches (chemical, surgical and radiological) as close together in time as possible without killing the patient.

> *"…you don't want to use up the tools in your toolbox, because we only have a limited number…you want to draw out whatever treatment you're on as long as possible …"* – Stage IV patient

These treatments, like those during the acute phase, are closely monitored for reactions and side effects as well as efficacy. Different than treatments during the acute phase, however, there is an ever-present assumption that all treatments will fail eventually. Thus, the work becomes to monitor for signs of treatment failure (*e.g.,* medical indicators such as blood counts or physical indicators such as fatigue) so that a new plan can be put in place before too much damage is done.

> *"…only by testing very rapidly, they find out if the medication's actually working… you hope that if it's not working, it doesn't get too serious too quickly."*
> – Husband of stage IV patient

Monitoring and testing can be a huge challenge in this phase. The desire is to catch any changes as soon as they are recognizable, but at the same time, patients may stay in this phase for a long time and do not want to spend their lives in hospitals. Augmented home tests with networked communication to physicians address this tension. For example, one caregiver described the ways in which his wife was tested regularly at the physician's office for a particular side effect that had emerged for some patients:

> *"…they would monitor the nerves…by applying shocks and monitoring what the nerves were doing… they also had tests of coordination where… my wife would pick up thing… they would redo the where they would wire her up type test more frequently if the coordination test suggested adverse things …"*

Cancer statistics and epidemiological information, such as cancer clusters and other important data, are hard to gather and only reported annually, as required by law. In more "connected" areas where treatment facilities and hospitals are common, communication between the hospitals assists in understanding these phenomena. Information can be passed through doctors, records managers, or other staff who have either an established rapport with one another or an official association with each other's hospitals.

In rural areas, the need is acute. Hospitals are few and far between. One patient commented that doctors stay only a brief time, often only working the time required for loan forgiveness. Without connected, digital records, it is hard if not impossible to look for the kind of higher level information across multiple patients that can support the discovery of trends in both occurrence and treatment on a large scale.

> *"…what if you had … 47 women … in one area that had a specific kind of cancer… and you had a cancer cluster, but how would you know that if you have 47 different files* and *you live in an area where doctors come and go?"*
>
> – Stage IV patient in a rural area

5 Lessons and Design Opportunities

The opportunities for pervasive computing across the chronic cancer journey are vast. Some of the approaches undertaken for other domain problems can be reappropriated to address these issues in new and innovative ways. Other considerations, however, require rethinking pervasive computing, including sensing, systems, and applications, in light of chronic care for cancer. As described in the Methods section, we created applications design briefs and conducted initial tests with them in iterative design sessions. These briefs included a brief overview of the concept, a bulleted list of necessary and ideal features, a detailed list of potential users and stakeholders, and in some cases, sketches and early conceptual mockups of the design. We present these concepts and recommendations not as a task list for pervasive computing researchers but as design inspiration for those who might take these results and incorporate them into the technologies of the future.

The cancer journey is deeply personal. It is exhausting, overwhelming and often transformative. Certainly, other pervasive computing scenarios must also assume significant changes in the "user" while engaging a set of technologies. The chronic cancer problem, however, is of particular interest in this respect, because the impetus for accessing these technologies initially and the need to maintain and adapt them over time is inherently tied to the cancer journey. New technologies must accompany people on this journey while accommodating huge shifts in uses needs, motivations, energy levels and goals. In this section, we describe the lessons drawn from our findings, including discussion of detailed design briefs, and the technological opportunities they indicate across all of the stages. We group these possibilities, considerations and recommendations into two major pervasive computing sub-areas previously identified as core classes of applications for the future of ubiquitous computing: sensing and context-awareness and capture and access [2].

5.1 Sensing and Context-Awareness

Sensing and context-awareness present opportunities for supporting screening and diagnosis, symptom and side effect management, and to abate the risk for recurrence. These technologies can be used to deliver customized medical advice based on data gathered over time and can support individuals across multiple phases of the journey.

Pre-diagnostic Screening and Monitoring

Medical professionals often suggest using self-screening techniques (*e.g.,* breast self-exams), but people often are not motivated to or may not know how to conduct these tests. They may also struggle to find opportune times for them. One design concept that had particular traction in our design discussions focused on reminding users when and how to conduct self-screening activities. As an example, many physicians currently distribute educational cards that describe the breast self-examination procedure alongside visual aids. These cards may be created in a form factor that allows them to be hung from a door or by the shower. Although patients and clinicians alike generally found these to be helpful, they noted that they are obtrusive and may only be helpful for people with very fixed routines who can, for example, spend an extra few minutes in the shower each morning conducting an exam. On the other hand, our suggestions of incorporating such screening recommendations and instructions into mobile devices were highly appealing. Already, in support of other daily medical needs, such as taking a vitamin or prescription medicine at the same time each day, the mobile phone has become the platform of choice for many individuals for setting reminder alarms. The same features of the phone that make it an ideal health platform for these types of reminders, would support reminding of screening activities. Furthermore, mobile devices can provide even richer information than the static cards by nature of their interactive capabilities.

Another opportunity for pervasive computing that resonated during design sessions focused on location-based and context-aware applications. These services could make use of sensed data to notify individuals of professional screening activities, which are often underutilized simply because they are hard to find. Many professional screening activities, such as a physician visually scanning a patient's skin for any abnormalities, take only a few moments to complete. Knowing about them and traveling to the location where they are offered, however, can be a much larger activity. Thus, in the same way that location-based services advertising sales or menus for particular restaurants have been touted as a good way to get people to frequent those establishments, so too can these services encourage people with a few moments to spare to take the time to stop in at a screening event when they are nearby.

Finally, even people who are highly motivated to participate in both self and professional screening activities may encounter a situation in which the screening criteria are not appropriate for their needs. Cancer, like other diseases, inhabits an inherently individualized human body and thus presents in a range of ways. Morris and Intille suggest *embedded assessment* as a way to recognize declining health related to aging on an individual basis [20]. Our findings suggest that such an approach could be used to indicate when a screening or diagnosis activity might be necessary before noticeable symptoms arise. For example, in the case of skin cancer, one physician noted that how often he wants to check an individual's skin is highly dependent on how often they are in the sun, the inherent properties of their skin, and in what other activities they regularly engage. Sensing that collects that data and indicates an appropriate screening schedule for a given individual based on both their baseline data and their activities would be a huge improvement on current practices.

Support During Treatment

While being treated for cancer, patients are at risk for deterioration in physical and mental functioning, often in unexpected ways. For example, many patients undergoing chemotherapy lose access to online communities, because the treatment makes their fingertips so sensitive they cannot type. Assistive technology offers some relief for these symptoms, but many patients do not recognize the need for them until the symptoms have become severe.

Assistive technologies that automatically deploy and adjust as abilities shift over time could provide appropriate time-sensitive support. For example, one idea proposed in our design briefs included key-logging software to recognize changes in an individual's typing patterns and automatically adjust the accessibility features of the computer for that user. In discussing this design with various stakeholders, the idea garnered much support, but further suggestions also emerged for use of voice recognition technologies and the creation of new assistive technologies that would be individually useful for particular side effects of chemotherapy and cancer.

In addition to painful and irritating side effects like loss of feeling in fingertips, patients are at risk for dangerous and life-threatening side effects, particularly when treatment plans are not followed properly. There have been numerous pervasive computing applications focused on compliance and medication reminding. These projects, however, often focus on the routine of drug taking, and could benefit from a more holistic view of the patient. Sensing changes in the physiological state of patients could support just in time medication recommendations. Also, provision of additional information to the patient may facilitate patient problem solving and understanding as to why their actions produced particular results. Mamykina *et al.* noted that reflection of this type of data back to diabetes patients contributed to their ability to move their locus of control inward [25]. Similarly, cancer patients may benefit from these types of interactions with data about their own treatments and side effects, and applications of this variety should be explored further.

Throughout their treatments, even when patients are perfectly compliant, physicians monitor closely for damage done by the treatments or by cancer. For example, some patients must come all the way into the office to do simple tests, such as the test for neuropenia that involves picking up and dropping objects to watch for irregularities described in section 4.5. We must address the challenge of getting the latest and most accurate information without requiring an inordinate number of visits to medical facilities. Automatic tracking of results of the physical tests conducted frequently at home could provide more up to date and accurate data. Following the example of the neuropenia test, patients at home could pick up and put down sensor-equipped objects. Readings from these sensors could be communicated to the medical staff who would likely recommend an office visit and more intensive testing in the event of irregular results. Similarly, we have begun examining both gait analysis and sleep tracking as a means for assessing the long-term effects of some treatments and cancers.

Finally, automatically sensed physiological information, although extremely valuable to individuals, can be even more valuable to the population as a whole. When brought together, data from pre-cancer diagnoses and patients in various stages of the disease and phases of their journeys build a more complete picture. One design concept we created included the mapping of these data onto geographical, chemical, and environmental readings to understand more readily the impacts of these varied contexts. These concepts resonated with both public health officials and patients struggling with finding the links between cancer incidence and potential environmental factors. The development of appropriate sensing and data mining technologies, however, remains a significant challenge for pervasive computing researchers.

5.2 Capture and Access

Our findings also suggest opportunities for applications that ease "the capture of live experiences and provide flexible and universal access to those experiences later on" [2]. As with sensing and context-aware applications, capture and access applications can support activities across phases of the journey and thus should evolve with the patients, survivors, and care networks over time.

Augmenting Patient and Caregiver Memories

To combat the chaos of the time just after a diagnosis, patients and their families need support for documenting and understanding their data. Use of simple audio-recorders were nearly never employed by the patients in this study for multiple reasons, two of which were most common: (1) lack of time or energy to go back and review the recordings or (2) desire to share any information received with someone else combined with confusion about how to share audio recordings[6]. This approach could reduce the overhead of both recording and finding the relevant parts of the conversation later, but applications to support the creation and sharing of these personal medical health records remains an open research problem.

These findings also indicate that new technologies could support the stressful process of meeting with multiple new medical professionals. Although this phenomenon exists in many medical situations, chronic cancer care is of particular interest in this respect for multiple reasons. First, the word "cancer" carries with it the stigma of death for every patient with whom we interacted. Thus, once the diagnosis is uttered, the stress levels are likely to increase immensely. Second, cancer carries with it an enormous number of specialties and subspecialties (e.g., radiologists, chemotherapists, radiology oncologists, and so on). Thus, during this time, patients often repeat information about their symptoms with each new meeting and share records from other physicians. Many technologists within hospitals, including one we interviewed for this study specifically, argue that electronic medical records are the solution to these issues. That solution, however, only takes us part of the way. Pervasive computing has the chance to take us the rest of the way by allowing patients and physicians to capture in rich detail the physiological and individually reported data associated with a new diagnosis.

Monitoring Patient Health Data Over Time

Patients are often asked to keep diaries about or otherwise recount details from particular incidents and demonstrations of symptoms. Sensing platforms and mobile recording applications could support gathering physiological, mental, and emotional data *in situ* at the time of particular patient experiences. These data could support problem-solving and therapeutic interventions as well as augment the memory of stressed patients and their loved ones. For example, physicians sometimes adapt medical technologies used for other conditions in an *ad hoc* way to support cancer care. One such technology is mobile electrocardiographs used in diagnosing and monitoring heart diseases. Likewise, physicians often ask patients to document on paper the readings from "smart scales" that detect bone density, body mass index, and so on. These technologies, while helpful in

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[6] All of the participants who noted this issue reported considering analog tape recorders and not being either willing or able to send those physical audio tapes to someone else. Use of digital recording might change this attitude, but the overhead of listening to the sound would remain.

tracking patient care over time, must be coordinated with other diagnostic, monitoring, and sensing tools to support the complexity of cancer and the potential side effects of its treatment. As things are currently, there is no way for physicians or patients to get a holistic and immediate view of patient progress and needs. To address these issues directly, we investigated incorporation of such data (e.g., from a Bluetooth enabled scale and from Bluetooth enabled wearable heart rate sensors) into a single data model through the Personal Care Connect system [5]. The next steps for this type of work then are to understand how, when, and who to alert when particular thresholds or anomalies are detected.

Attempting to quantify and to track trends for symptom management is both medically valuable and very difficult. Pervasive computing applications such as home healthcare aids and electronic diaries could support gathering this information on a much more regular basis *in situ*. Mamykina *et al.* found that taking sensor readings, in their case blood glucometers, and reflecting those back to participants through such an electronic diary improved patients' abilities to understand and to manage their own diseases [25]. When managing cancer treatments, similar applications should be developed with cancer-relevant sensing and visualizations. Specifically, some of the most common data element discussed surrounding cancer are blood cell counts and the presence of so-called "cancer markers." These types of data are unique to cancer as a whole but are common across all types of cancer. Thus, they make for appealing data to track over time alongside other data, such as heart rates, weight, bone density, and so on.

Using Captured Data to Support Communication

Recent trends in mobile and photo blogging present interesting opportunities for chronic disease patients and their care networks. With simple phone-based applications, patients could easily share pictures of themselves during or after treatment, quick images of reports (low resolution now, but gaining in resolution as mobile camera-phone technology improves), text or audio-based commentary and more. Given that patients often feel the worst from chemotherapy and other treatments hours after receiving the treatment itself, they may actually be most likely to feel well enough to update interested people on their status during or immediately after a treatment. Therefore, providing mobile support for capturing this type of data and the appropriate healthcare portals for caregivers and patients can be an important goal for supporting quality of life and encouragement to the caregiver network.

Another opportunity for the capture, sharing, and access of patient information centers on diagnostic and monitoring data from physician visits. Many patients reported being uncomfortable or unable to document medical information during medical visits. This discomfort may stem from power differentials between patient and physician, social mores for patients to exhibit trust in their physician and so on. Also, documenting this information while it is being delivered was reported to be extremely difficult due to the added load of both listening and internalizing the information while trying to document it. Thus, providing methods for patients to capture this information immediately after such encounters and relay it to interested parties, while the information is fresh, is an important potential application of mobile technologies.

Another issue prevalent in our findings is the tendency for friends and family to check in too frequently when there is little news or no time to deliver it. Bridging the opportunities for context-aware computing and capture and access applications, people could also take advantage of context-aware availability information such as suggested by Nagel *et al.* [21] and Fogarty *et al.* [15] to stay up to date without further burdening the patients with queries about status at inappropriate times. We cannot simply take the results of those studies and apply them to the cancer domain, because caregiver and patient motivations are quite a bit stronger than in homes and offices of healthy individuals. They do, however, point to the possibility that such availability information could be tailored to the individual stakeholders while being augmented by the extra data collected that are cancer-specific, such as test results and calendars of medical appointments. It may also be important to note at this point that the security of the data becomes an even more important issue when considering cancer care, because so much of it is legally protected private health information. Thus, an open and important research question for others moving forward includes development of models and methods for securely communicating health data on mobile platforms as patients conduct the business of having cancer (e.g., going to the hospital or treatment centers).

Long-term Data-based Reflection

Many survivors commented about forgetting the details of their diagnosis and treatment processes due to temporary memory impairment brought on by stress and by the treatment protocols. By capturing large amounts of data throughout the diagnosis and treatment time periods, these survivors would be able to reflect on that time later. The combination of manually recorded journal entries with automatically recorded sensor data could offer a rich record of the treatment experience. These records offer two distinct advantages. First, there can be substantial therapeutic benefit to survivors to recount their experiences and deal with the trauma of the diagnosis and treatment in a structured manner. Second, these records offer the chance to share NED stories in rich detail to patients currently undergoing treatments. Many patients reported that hearing from people who had "been there" was extremely comforting when they first began their own journeys.

5.3 Remaining Challenges

The depth and breadth of this inquiry has resulted in the development of results that indicate numerous challenges for pervasive computing. We have presented in this section, some of the potential applications and technologies that could be developed in response to these challenges. We hope, however, that this work will inspire others to consider technologies that have not yet been envisioned and are not yet included here, using these recommendations as merely a starting point for exploring the diverse and significant potential for pervasive computing in this domain.

6 Conclusions and Discussion

Cancer is now considered a *chronic* condition, growing both in incidence rates and in number of years that people live past diagnosis. The journey through diagnosis, treatment, and life after cancer is marked by significant changes in lifestyle. Often these changes are informed or accompanied by new uses of technologies. One major contribution of this paper is to position research for pervasive computing technologies for cancer as specifically supporting a chronic condition. With this perspective on cancer, the uppermost needs for technology is supporting the continuous and changing process from the day to day point of view as well as the long-term view of planning, hoping, considering risks, and *living* with cancer.

The opportunities for impact in this field are vast. Since this initial study, we have continued this work, investing in unobtrusive but medically relevant sensing technologies, designing data visualizations to support tracking trends at individual and meta-levels, and creating mobile tools that can be used by cancer patients and their care teams. These designs have had to consider the potentially deteriorated needs of patients physically and mentally and thus borrow heavily from assistive technology. They also must render medically significant data, and thus borrow heavily from medical informatics. However, examination of cancer as a chronic condition means bringing the screening, diagnosis, testing, treatment, and monitoring out of the offices and hospitals and into the homes, schools, and hospice cares of the patients in need. When a disease becomes chronic, quality of life and continuing to live become paramount.

Pervasive computing presents one important avenue to enabling that transition, and importantly. Thus, as researchers, designers, and technologists, the pervasive computing community can empower people anywhere on the cancer journey from pre-cancer to no disease at all to chronic illness to play active roles in their medical treatments. The empirical data presented in this paper offer a starting point for the community to continue this important work. We have suggested design opportunities for both sensing and context-aware computing as well as capture and access applications. We hope that these design opportunities serve as a stimulus to the rest of the community to focus on this important problem that brings with it not only the potential for great human impact but also significant pervasive computing research challenges. With advances in sensing, data analytics, communication and more, people may be able to detect cancer earlier, treat it with greater success and live with it with less concern and greater awareness.

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References

1. Unites States Cancer Statistics, 2002 Incidence and Mortality, U.S. Department of Health and Human Services, Editor. Centers for Disease Control and Prevention (2005)
2. Abowd, G.D., Mynatt, E.D.: Charting Past, Present and Future Research in Ubiquitous Computing. ACM Transactions on Computer-Human Interaction 7(1), 29–58 (2000)
3. Abowd, G.D., et al.: Challenges and Opportunities for Collaboration Technologies for Chronic Care Management. In: HCIC 2006 (2006)
4. Association, A.T.: ATA's Federal Policy Recommendations for Home Telehealth and Remote Monitoring, in ATA Public Policy White Papers (2006)

5. Bardram, J.: The Personal Medical Unit – A Ubiquitous Computing Infrastructure for Personal Pervasive Healthcare. In: UbiHealth 2004 (2004)
6. Batra, V., et al.: Remote Healthcare Monitoring using Personal Care Connect. IBM Systems Journal (2006)
7. Consolvo, S., et al.: Computer-Supported Coordinated Care. In: UbiHealth 2003 (2003)
8. Consolvo, S., et al.: The CareNet Display: Lessons Learned from an In Home Evaluation of an Ambient Display. In: Davies, N., Mynatt, E.D., Siio, I. (eds.) UbiComp 2004. LNCS, vol. 3205, pp. 1–17. Springer, Heidelberg (2004)
9. Corbin, J.M.: The Corbin and Strauss Chronic Illness Trajectory model: an update. Sch. Inq. Nurs. Pract. 12(1), 33–41 (1998)
10. Dawe, M.: Desperately seeking simplicity: how young adults with cognitive disabilities and their families adopt assistive technologies. In: Proc. CHI 2006, pp. 1143–1152. ACM Press, New York (2006)
11. Dey, A.K.: Understanding and Using Context. PUC 5(1), 4–7 (2001)
12. Eng, T.R.: Emerging Technologies for Cancer Prevention and Other Population Health Challenges. Journal of Medical Internet Research 7(3), e30 (2006)
13. Eysenbach, G.: The Impact of the Internet on Cancer Outcomes. CA: A Cancer Journal for Clinicians 53, 356–371 (2006)
14. Eysenbach, G., et al.: Shopping around the internet today and tomorrow: towards the millennium of cybermedicine. British Medical Journal 319(7220) (1999)
15. Fogarty, J., Hudson, S.E., Atkeson, C.G., Avrahami, D., Forlizzi, J., Kiesler, S., Lee, J.C., Yang, J.: Predicting Human Interruptibility with Sensors. ACM Transactions on Computer-Human Interaction (TOCHI) 12(1), 119–146 (2005)
16. Holtzblatt, K., Jones, S.: Contextual Inquiry: A Participatory Technique for System Design. In: Namioka, A., Schuler, D. (eds.) Participatory Design: Principles and Practice. Erlbaum, Hillsdale (1993)
17. IMPAC Medical Systems, The West Clinic Interfaces IMPAC with the SOS Patient Care Monitor (2006), `http://biz.yahoo.com/prnews/060724/sfm052.html?.v=59`
18. Mamykina, L., et al.: Investigating health management practices of individuals with diabetes. In: Proc. CHI 2006, pp. 927–936. ACM Press, New York (2006)
19. McEwen, B.S.: Protective and Damaging Effects of Stress Mediators. The New England Journal of Medicine 338, 171–179 (1998)
20. Morris, M., Intille, S.S., Beaudin, J.: Embedded Assessment: Overcoming Barriers to Early Detection with Pervasive Computing. In: Gellersen, H.-W., Want, R., Schmidt, A. (eds.) PERVASIVE 2005. LNCS, vol. 3468, pp. 333–346. Springer, Heidelberg (2005)
21. Nagel, K.S., Hudson, J.M., Abowd, G.D.: Predictors of availability in home life context-mediated communication. In: Proceedings of CSCW 2004, ACM Press, New York (2004)
22. Rowan, J., Mynatt, E.D.: Digital Family Portrait Field Trial: Support for Aging in Place. In: Proc. CHI 2005, ACM Press, New York (2005)
23. Spradley, J.: The Ethnographic Interview. Holt, Rinehart and Winston, New York (1979)
24. Strauss, A.L., Corbin, J.M.: Basics of qualitative research: grounded theory procedures and techniques. Sage Publications, Newbury Park (1998)