

AN ABSTRACT OF THE THESIS OF

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Title: "It Brings You Into the Fold": Understanding Patients' Experiences of Mobile Health Technologies

Abstract approved:

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Chronic disease is costly to treat and burdensome for those living with its impacts. According to the Centers for Disease Control and Prevention (2017), 117 million Americans currently live with chronic disease, and one in four adults live with two or more chronic diseases. The burden placed on the U.S. healthcare infrastructure by such conditions is likely to continue to grow in coming years, leading to a call for solutions to simultaneously alleviate both the economic and personal costs associated with chronic disease management. Mobile health (mHealth) technologies show promise in reducing costs of care and in increasing patient self-efficacy in chronic disease management, yet the patient experience of mHealth is poorly understood. This thesis presents findings from qualitative analyses undertaken as part of a mixed-methods study examining the impacts of an mHealth application for remotely monitoring patients with chronic disease. In it, I use data from semi-structured interviews and text-message transcripts from patient users of the app to examine the experience of using mobile health technologies to seek and receive health care in the day-to-day management of chronic disease. The mHealth intervention examined here

from the perspective of patient users challenged traditional expectations of the clinical encounter and allowed new modes of interaction between patients and care providers to emerge. Salient aspects of the patient experience included: 1) feeling both seen and heard within the medical system, 2) reassurance resulting from being able to access care at any time and from any place, 3) a sense of personal connection with nurse care coordinators, and 4) synergistic interactions between technology and nursing care. I use Bordieu's theory of fields as a framework for understanding how the program under study acted in the lives of patients to upset expectations of seeking and receiving health care, and how this disruption opened a space within which the norms and dispositions of the field of biomedicine were renegotiated in a way they came to experience as positively impacting their wellbeing.

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"It Brings You Into the Fold": Understanding Patients' Experiences of Mobile Health
Technologies

by
Jenney Lee

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APPROVED:

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I understand that my thesis will become part of the permanent collection of Oregon State University libraries. My signature below authorizes release of my thesis to any reader upon request.

Jenney Lee, Author

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CONTRIBUTION OF AUTHORS

Dr. Bovbjerg assisted with research design, and data collection and interpretation. Dr. Michael May and Ms. Rosa Wolff assisted in data interpretation and in the design of the overall project from which this thesis was drawn.

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Chapter 1 - Introduction

Communicating back and forth with the girls, it helped a lot. I remember one time my sugar level was real low and they called the paramedics on me. And I thought that was a life saver, which it was. I mean they're there for you. I was just telling the girls in there, I'm a bit teary eyed this is all coming to a close. I'm going to kind of miss them. They're 110% fantastic, these people. You couldn't ask for a bunch of better girls. I'm losing a bunch of sisters, is what I'm losing.
-Edward¹

Everybody was really great. It was definitely a real comfort having someone there. Because I am pretty much by myself, and to have someone contact me, you know, to make sure I was okay, that in itself was a comfort. That's really just the main thing, that it was - what would you say? - kind of like a security blanket. For anybody else to do it, I'd say they'd probably find out the same thing.
-Terry

The above passages are taken from exit interviews with patients at the conclusion of a health intervention for people living with chronic disease. The program took place over the course of one year, in the multi-specialty clinic where the participants received primary health care, and although the above quotes do not reveal this, the intervention was delivered almost exclusively through use of a mobile tablet given to participants for the duration of the program. In some ways, the design of the project exemplifies what critics of US-style biomedicine have identified as a trend toward a high-tech, low-touch style of medical practice (Naisbitt, 1984), which increasingly relies on technological interventions and diagnostic tools in place of face-to-face, personal interactions with health care providers. In fact, the program in question might accurately be described as "no-touch," since few of the participants ever met in person with the clinical staff who were

¹ All names used are pseudonyms to protect the identities of participants.

responsible for their care during the program. Yet, as Edward and Terry both expressed in their exit interviews, the program fostered a sense of closeness and caring between the participants and their care providers that is presumed to not typify the kind of "low-touch" approach that is the subject of critique. This dynamic tension, between cold technologies and warm care (Pols & Moser, 2009), forms the subject of inquiry for this Master's thesis, in which I aim to elucidate the particularities of how a high-tech intervention for chronic disease management functioned in the lives of participants, and how it impacted their experiences of seeking and receiving healthcare. This discussion is contextualized within the emergence of mobile health technologies as a significant trend in healthcare reform, both in the United States and on the global stage. I apply a critical anthropological lens to a topic that to date has primarily been the domain of clinical, and science and technology studies research (Ahlin, Nichter, Braitberg, Kenworthy, Duclos, & Dam Nielsen, 2015). In doing so, I will seek to answer the call from the Critical Anthropology for Global Health committee of the Society for Medical Anthropology for anthropologists to engage more deeply with the topic of emerging health technologies as a site for inquiry in order to "provide a more nuanced picture, and thus a more productive view" (Ahlin et al, 2015) of how such technologies might be acting on and reshaping health care practices around the world. Specifically, I use Bordieu's theory of fields as a framework for understanding how the program under study acted in the lives of participants to upset expectations of receiving health care, and how this disruption opened a space within which the norms and dispositions of the field of biomedicine were renegotiated in a way the participants came to experience as having a positive impact on their wellbeing.

Chronic Disease and the Emergence of New Health Technologies

According to the Centers for Disease Control and Prevention (CDC), chronic disease is the leading cause of death for American adults (Centers for Disease Control and Prevention, 2017). Covering a wide range of disease states and conditions, including lung disease, heart disease, diabetes, and cancer, chronic diseases make up seven of the ten most common causes of death in the U.S. (Centers for Disease Control and Prevention, 2017). Globally, chronic disease accounts for 15 million “premature” deaths in individuals 30 to 69 years of age each year, 80% of which occur in low- and middle-income countries (World Health Organization, 2017). Taken together, the impacts of chronic disease carry enormous costs, both for the individuals and families whose lives are directly affected by these conditions, and in terms of the financial and other resources that are required by healthcare infrastructures tasked with caring for those with chronic conditions. It is not surprising, therefore, that governments and health organizations around the world are keen to find solutions that simultaneously improve the health of individuals living with chronic diseases, while reducing the chronic disease-related personnel and financial burdens placed on health systems. Increasingly, global and domestic efforts have turned to new health technologies, in hopes that they hold the key to helping people with chronic diseases better manage their health while reducing the costs associated with chronic disease management.

Information and Communication Technologies and Health

The ubiquity of electronic communications devices has led to an interest in leveraging these technologies to aid in the delivery of healthcare. Beginning with the use

of video and phone conferencing for medical consultation several decades ago, and now encompassing a multitude of electronically delivered health platforms and interventions, electronic health systems, collectively referred to as eHealth, are an increasingly utilized tool by both providers and consumers of health care around the world. Sometimes referred to as telemedicine or telehealth, eHealth lacks a consistent definition, although most sources agree that any health system that makes use of information and communication technologies (ICT) fits within its rubric. The World Health Organization (WHO) has identified four essential elements of eHealth:

- *Its purpose is to provide clinical support.*
 - *It is intended to overcome geographical barriers, connecting users who are not in the same physical location.*
 - *It involves the use of various types of ICT.*
 - *Its goal is to improve health outcomes.*
- (World Health Organization, 2010: p. 9)

Among other things, eHealth includes electronic health records (EHR) systems, public health monitoring systems, and emergency services support systems. Clinical services increasingly make use of eHealth systems, including teleradiology, telepathology, and patient monitoring systems (World Health Organization, 2010). The internet is another site for the increasing diffusion of eHealth, including online consumer health support forums, and public health campaigns carried out via social media (World Health Organization, 2010). The WHO (2016) reports that as of 2016 more than half of member state governments have formally-articulated eHealth policies in place, and 90% of those include expansion of eHealth as a critical component in achieving universal health coverage.

Under the umbrella of eHealth is a subcategory of health systems and interventions that are delivered using mobile technologies, referred to as mHealth. These systems make

use of mobile phones, tablets, personal digital assistants, and other hand-held digital communications devices in delivering services, support, and products aimed at improving health outcomes. In its 2011 global report on the status of mHealth, WHO found that 83% of member states reported at least one current mHealth initiative, with most reporting four or more initiatives. Such initiatives are undertaken across settings, with 77% of low-income countries and 87% of high-income countries reporting the existence of mHealth initiatives (World Health Organization, 2011). MHealth's rapidly growing popularity is enhanced by a wireless technologies infrastructure that has quickly outpaced traditional infrastructures in many parts of the world. More than 85% of the global population now live in a location served by wireless connectivity (World Health Organization, 2010), and over seven billion mobile phone subscriptions have been sold around the world (World Health Organization, 2011). In some communities, mobile phones and wireless internet are available, while paved roads and other physical infrastructures are lacking. This is one reason that the WHO and other health agencies believe that e/mHealth systems are essential tools for meeting the world's healthcare needs. The WHO has stated that, "in the 21st century the delivery of health care and improvements of health systems must consider the contribution of ICT as an essential and central component, not an add-on. eHealth is now an integral part of delivering improvements in health" (World Health Organization, 2010: p. 7). As part of that effort, mHealth "has the potential to transform the face of health service delivery across the globe" (World Health Organization, 2011: p. 1).

E/mHealth in the United States

The trajectory of e/mHealth in the United States mirrors the rise of these initiatives around the world, and has similarly been marked by an enthusiastic embrace of health programs delivered through use of ICT and mobile technologies. In 2004, president George W. Bush created the Office of the National Coordinator for Health Information Technologies (ONC) within the Department of Health and Human Services (DHHS). The ONC is tasked with "promot[ing] a national Health Information Technology infrastructure, and oversee[ing] its development" (ONC, 2017a). Two ensuing acts of legislation further codified the U.S.'s priorities regarding the implementation of e/mHealth initiatives; the Health Information Technology for Economic and Clinical Health (HITECH) Act in 2009 required health service providers to adopt "meaningful use" of EHR's (ONC, 2017b), and the Patient Protection and Affordable Care Act (ACA) in 2010 called for "use [of] electronic health records and telehealth technology to better coordinate and manage, and improve access to care" (Grossman, Sterky, Blount, and Voldenberg, 2010: p. 896). The ACA also directed DHHS to allocate grant funds for projects implementing HIT strategies to improve health and health care delivery in public and private care settings. In 2011, the ONC issued its Federal Health Information Technology Strategic Plan, which identified five specific goals to "quickly and radically transform health care" (ONC, 2017a: p. 7) across the United States.

Goal I: Achieve adoption and information exchange through meaningful use of health IT strategies.

Goal II: Improve care, improve population health, and reduce health care costs through the use of health IT.

Goal III: Inspire confidence and trust in health IT strategies.

Goal IV: Empower individuals with health IT to improve their health and the health care system.

Goal V: Achieve rapid learning and technological advancement.

(ONC Health IT Strategic Plan, 2011: pps 70-73)

In response, private sector organizations have sought to capitalize on the opportunities presented by government programs dedicated to rapidly increasing the deployment of new health technologies. The American Telemedicine Association (ATA), a non-profit organization with over 10,000 industry members headquartered in Washington D.C., is one organization dedicated to accelerating the dissemination of e/mHealth into the healthcare landscape. In 2006, in response to government initiatives, the ATA released an issue paper which stated their resolve to "initiate a number of specific activities to capitalize on the emerging interest in HIT," and "support the work of the U.S. federal government's Health Information Technologies initiatives, [seek] opportunities to work in support of these initiatives, and [provide] input and assistance to federal agencies involved with HIT effort" (ATA 2006: p. 8). Among its current activities, ATA has prioritized advocating for the expansion of e/mHealth by lobbying federal and state lawmakers through such initiatives as a national Telehealth Lobby Day in October, and an ongoing Twitter campaign called #TelehealthForward (ATA, 2006). In the United States, where the provision of healthcare is primarily the domain of private, rather than government funded, insurers and providers, the private sector has much to gain from an environment in which e/mHealth development is a priority.

E/mHealth Research

The eagerness to embrace new health technologies has not been matched by an analogous interest on the part of governments and private organizations to investigate how, or even whether, such interventions improve the lives and health outcomes of the people

envisioned as using these technologies. A recent World Health Organization survey on e/mHealth found only 12% of member countries reported that interventions utilizing such technologies included an evaluation component (World Health Organization, 2011). The question of evaluation is not an idle one; without substantive evidence of the outcomes associated with e/mHealth interventions, it is not possible to construct an accurate assessment of how such technologies might affect health and healthcare. Rigorous study of its impacts is made all the more important because e/mHealth is often deployed in low- or middle-income countries, where health care is marked by a relative scarcity of resources, or within populations that are vulnerable due to age, socio-economic status, geographic location, or a combination of the above factors. When utilized in higher income countries, as in the United States, e/mHealth solutions are often targeted to vulnerable populations such as armed service veterans, the aging, those who are home-bound, Medicaid recipients, or those who live in rural communities where few health resources are available. Furthermore, the landscape of e/mHealth interventions is currently crowded with small-scale projects that are unable to maintain sustainability past the pilot phase (Andreassen, Kjekshus, & Tjora, 2015; Lucas, 2008; World Health Organization, 2010). Several factors have been identified in perpetuating this so-called "plague of pilots," (Andreassen et al, 2008: p. 63) among them the dearth of evidence from which to draw in designing effective e/mHealth interventions and strategies. As WHO (2010) has noted, "The importance of evaluation within the field of telemedicine cannot be overstated: the field is in its infancy and while its promise is great, evaluation can ensure maximization of benefit" (p. 7). However, given the lack of consistent evaluation of e/mHealth programs, the assertion that

telemedicine holds "great promise" may be putting the proverbial cart before the horse; without a focused research agenda that does not presuppose the "benefits" afforded by telemedicine, it is not possible to know what impacts might result from its use.

In many ways the field of e/mHealth is still emerging (Ahlin et al, 2015; World Health Organization, 2010), and as described above, research into its impacts is not yet fully developed. However, the available literature reveals that there are some dominant themes within the current research landscape. These themes can be grouped into four primary areas of research, including the use of e/mHealth in underserved or vulnerable populations, how e/mHealth impacts the practice of medicine and delivery of health care, e/mHealth initiatives in health management and health promotion, and user engagement with e/mHealth programs and applications. At times these areas overlap, as one study might simultaneously examine the way that e/mHealth changes care delivery in elderly populations (Milligan, Roberts, and Mort, 2011), but as categories they are instructive in understanding how researchers currently frame their inquiries into e/mHealth. What follows is a brief discussion of the literature within each of these four categories.

E/mHealth in Vulnerable and Underserved Populations

As governments and health organizations around the world search for strategies to improve the health of vulnerable populations, they increasingly look to e/mHealth for care delivery in settings where traditional care is difficult to deploy. A primary area of research in this category is in elderly populations, who may have mobility issues that restrict their ability to access care in out-of-home medical settings, or have assisted living needs requiring in-home or institutional care. Bailey and Sheehan (2009) investigated elderly

persons relationships with existing technologies as part of a larger study in Ireland aimed at exploring the potential for e/mHealth interventions in this population. They found that while older persons are sometimes assumed to lack technological know-how, or to be technology-averse, under the right conditions, elderly patients have positive associations with and might welcome the use of technology to improve their wellbeing (Bailey and Sheehan, 2009). These conditions include the ability to readily perceive technology as offering value to their everyday lives and that it offer them a "sense of ownership and confidence" (p. 106) in its use. Greenhalgh et al (2013) examined the use of assisted living technologies for in-home use by the elderly, and found that they did not improve the health of users, in themselves, but rather functioned well when modified and adapted to suit the individual needs of the user, and when embedded in the user's web of social relations, leading the authors to note that "a radical revision of assistive technology design policy may be needed" (p. 86) in order to effectively meet the needs of this population. In a study of mHealth interventions for the elderly, Kruse, Mileski, and Moreno (2016) sought to identify barriers and facilitators to their adoption. The authors found that when mHealth increases the user's sense of independence, of understanding, and of being seen, it may facilitate use. On the other hand, the complexity of mHealth technologies, the health literacy of users, and the associated costs may pose barriers to its use.

Additional studies investigate how use of e/mHealth might act to shift roles, responsibilities, and definitions of care within elderly populations. The work of Roberts and Mort (2009) demonstrated that remote monitoring of the elderly serves to fragment the technical, physical, and social aspects of care, in a false compartmentalization which belies

the lived experience of what it means to deliver and receive meaningful (and effective) care. Milligan, Roberts, and Mort (2011) examined how assistive technologies shift the burden of care to the home and the responsibility of family members and other informal care givers, while simultaneously blurring the boundaries between home and medical institutions as home becomes the setting for increased technological and medical contact and surveillance.

In the above examples, research was conducted in high-resource settings, primarily in Europe, where governmental bodies oversee and fund comprehensive healthcare systems. But another area of investigation into e/mHealth interventions is in low-resource countries, where health systems infrastructures are not as robust or as well funded as in Europe. In these settings e/mHealth is envisioned as being a low-cost solution to the problem of delivering care to high-risk or difficult to reach populations. Chib (2009), reporting on mHealth interventions in Indonesia and Uganda, noted that the current body of research in these settings represents a "prevailing techno-optimistic view" (p. 70) of their potential, while failing to address issues such as scaling and sustainability of projects. Further, Chib (2009) argues that future research should investigate the ways such interventions may reshape power relations and social constructs, the barriers to long-term success of programs implemented in low socio-economic settings, and should center integrating mHealth into health infrastructures rather than development of programs as stand-alone projects. Examining three mHealth initiatives for chronic disease in Bangladesh and Cambodia, Lucas (2015) cautions that by relying on hi-tech interventions without further development of existing healthcare infrastructures, interventions that place

increased responsibility for monitoring and care on poor individuals and their families carry the "risk that empowerment may seem very much like abandonment." In these settings, "increased knowledge may simply imply an increased awareness that a patient has very few options" (p. 151).

The Impact of e/mHealth on Health Care Systems

Another area of research is the impact of e/mHealth on healthcare delivery and healthcare systems. Studies that address the ways in which e/mHealth initiatives impact the practice of medicine are often concerned with efficiency, workflows, and the reconfiguration of how care is delivered. Andreassen, Kjekshus, and Tjora (2015), for example, investigated how implementation of a video conferencing and text messaging program to facilitate communication between generalist and specialist physicians impacted work flows, management, and organizational control, in the end producing a program that was not sustainable beyond the pilot phase. Rogers, Kirk, Gately, May, and Finch (2011) studied the shifts in illness work engaged in by chronic disease patients using self-monitoring eHealth devices. The authors noted that while current health policy expects such shifts to result in more independent patients who can assume a higher degree of responsibility for their care, in practice patients were not able to translate increased self-monitoring into more independent self-care (Rogers et al, 2011). Rothwell, Ellington, Planalp, and Crouch's (2012) study of poison control specialists in a call-in health center found that delivering care remotely versus in person requires a different set of communication skills and creates barriers to assessing caller understanding and/or

managing any misunderstanding of information given. Collectively, these factors increased job-related stress for poison control specialists.

A closely related area of study is the examination of how e/mHealth impacts the dynamics of giving and receiving care. Dedding, van Doorn, Winker, and Reis's (2011) examined the ways internet health websites impact interactions between patients and providers, reconfiguring care and shifting expectations as websites begin to replace face-to-face care and/or serve as supplements to existing care. Such websites can strengthen patient participation in care, disturb relations with providers, and/or force increased participation from patients whether desired or not. Andreassen (2011) examined the impacts on communication between parents of pediatric patients and providers when parents used secure electronic messaging to communicate directly with providers from their home computers. The author demonstrated that in addition to serving the anticipated role of being a conduit of information between the two parties, parents conceptualized the messaging system as an alarm system that aided in managing their children's health, as a way to mitigate the impacts on their children of the medical gaze, and as a tool for the performance of competence in managing their children's illness (Andreassen, 2011).

E/mHealth for Health Promotion and Monitoring

Since e/mHealth programs are conceived of as tools for improving health, many projects are designed to either promote or monitor the health of individuals and populations. Study of these programs is primarily concerned with observing whether use of e/mHealth interventions leads to improvements in clinical health markers, or demonstrable change in health behaviors. While some research does indicate success in improving the

health of users, the evidence is mixed, as the following examples serve to illustrate. In their analysis of text message programs for health promotion, Head, Noar, Iannorino, and Grant Harrington (2013) found that in 19 interventions, spanning 13 countries, text message-based programs were effective in producing changes in health behaviors and outcomes, and importantly, programs which tailored their messaging along demographic and psychosocial dimensions, were more effective than those that did not. Klonoff (2016) reported on outcomes from several studies that examined the impacts of mHealth on the management of diabetes, and found that while initial results are promising—indicating a statistically significant decrease in blood levels of A1C, for example—the quality of the studies was poor, calling into question the reliability of the results. Additionally, questions remain about how the longevity (or lack thereof) of many e/mHealth programs might impact long-term health, and whether any gains observed can be sustained past the study/pilot period.

Engaging Users of e/mHealth

Finally, a substantial proportion of the literature consists of analyses of user engagement. This is perhaps unsurprising, given that a primary area of interest for governments and organizations keen to implement e/mHealth initiatives is encouraging the uptake of these new technologies by users. Research in this area has been driven in part by the observation that many programs fail to sustain past the pilot phase, raising questions about why and how individuals do or do not engage with e/mHealth technologies. Wade, Elliott, and Hiller (2014) identified clinician acceptance of e/mHealth interventions as key to the long-term success of such programs. In their research on programs that documented successes beyond the pilot phase, they observed that clinician enthusiasm and commitment

to use buoyed these programs even when other barriers to long-term success arose (Wade et al, 2014). Conversely, Greenhalgh, Stones, and Swinglehurst (2014), examined the failure of an eHealth program intended to facilitate referrals between physicians, finding that the program's failure was contingent on lack of use by clinic staff due to a mismatch between the policy expectations that informed the design of the program, and "the more complex, granular, and exception-filled nature of real-world clinical practice" (p. 218).

However, the question of engagement is primarily concerned with use by patients, and the bulk of research in this area takes this group as its focus. Callan and O'Shea (2015) examined potential users' willingness to pay for a range of care configurations, including eHealth services, and found that while care from family members was most highly valued by participants, eHealth, when grounded in supportive social connections, was also valued, and to a higher degree than eHealth programs focused on physical or cognitive health alone. In surveying potential user preference for mHealth applications for monitoring diabetes, Conway, Campbell, Forbes, Cunningham, and Wake (2016) found that a majority of respondents reported a preference for using mHealth, but that their preferred application features differed from the features of most currently available apps for diabetes monitoring. The authors concluded that user preference should inform the design and planning phase of such products in order to increase user engagement. Examining the question of engagement from a different angle, Dewar, Bull, Malvey, and Szalma (2017) examined factors that motivate use of e/mHealth, and found that "autonomy, competence, relatedness, goal attainment, and goal setting are all important in understanding why individuals are motivated to use a particular system" (p. 253). Glazer, Mieczkowski,

King, and Fehnert (2014) found that trust played a major role in whether patients with chronic obstructive pulmonary disease engaged with eHealth technologies. In their study, trust was fostered through familiarity, responsiveness, and by being embedded in existing care networks and social relations. In their examination of high-engagement patients versus those who showed lower rates of use of an eHealth messaging system, Haun, Lind, Shimada, and Simon (2014) found that improvements in navigability and functionality of the platform to conform with user preference, and better communication about expectations, positively influenced patient engagement. They also found that level of education and income, as well as eHealth and health literacy, can increase user engagement (Haun et al, 2014).

E/mHealth Research and Critical Anthropology

In 2015, the Critical Anthropology for Global Health (CAGH) committee of the Society for Medical Anthropology affirmed the importance of research in this field when it issued its "Take a Stand" paper on e/mHealth and telemedicine (Ahlin et al, 2015). The purpose of this paper was to call attention to the need for anthropologists to take on e/mHealth as an area of inquiry. In it the authors argue that an anthropological lens, and the application of anthropological research skills, is critically important for answering many of the questions that remain about e/mHealth (Ahlin et al, 2015). CAGH identified twelve research areas it considers to be especially salient for anthropological inquiry. CAGH suggests that applying an anthropological lens to these research areas might both broaden the understanding of e/mHealth by making more clear its potential impact on global health systems, and at the same time encourage an examination that recognizes the contingencies

of its application in local contexts (Ahlin et al, 2015). The analysis that follows in chapter two of this thesis addresses three of the twelve areas identified by CAGH. These are: e/mHealth and the patient-practitioner relationship, e/mHealth in public health interventions for chronic disease, and e/mHealth for monitoring treatment, self-care, and self-tracking at a distance (Ahlin et al, 2015).

Description of the Thesis Project

The project from which the data for this thesis were drawn took place over the course of twelve months between April 2015 and March 2016 and was a collaboration between a large multi-specialty health clinic in the Pacific Northwest, and an mHealth start-up company in the same region. Participants in the project were recruited from the clinic where they received primary health care. Patients who were at least 18 years old were eligible to participate if they were enrolled in Medicaid , had one or more chronic disease diagnoses, including diabetes, lung disease, or cardiac disease, and did not have cognitive impairment requiring the aid of a caregiver. Providers from the clinic administered the clinical aspects of the project, and the mHealth company developed and deployed the technological component of the intervention and provided technological support to both clinicians and patients throughout the course of the project. Funding was provided by the local Medicaid payer for the geographical region in which the project took place.

The intervention was delivered to participants on a tablet computer they received at the time of enrollment, onto which the mHealth application was loaded. A team of four nurse case managers was responsible for monitoring the health of the participants through

use of a provider-facing version of the same mHealth app, which they accessed from tablet computers (while away from the clinic) or desk-top computers (while in clinic). Nurses were charged with around the clock, on-call periods lasting one week in length, and rotated call so that each nurse was on call for about one week out of every month throughout the project period. Patient and provider use of the app included three primary components. First, patients were asked to regularly enter their health information in the app, including blood pressure, blood glucose levels, and/or lung function markers, as appropriate to each individual's chronic disease diagnoses. Participants with diabetes were given cellular enabled blood glucose monitors that automatically uploaded readings to the app. These data points were available to both patients and providers, so that participants were able to see, in real time, trends in their health markers, and at the same time the on-call nurse case manager was able to monitor the wellbeing of the entire panel of patients and act on any irregularities or urgent health situations. The second component of the app was a secure text messaging feature which enabled patients to communicate with the on-call nurse case manager at any time of day or night. The final feature of the app was a portal into which nurses could upload individualized educational materials pertinent to each patient's health needs.

Designed as a quality improvement project for the clinic from which participants were drawn, the aim of the project was to determine whether use of an mHealth intervention for chronic disease management in a high-utilizing Medicaid population could achieve the triple aim of the ACA: to improve health, improve the delivery of healthcare, and reduce the cost of care. Both quantitative and qualitative assessment methods were

used. Quantitative analyses included pre- and post-intervention survey data, and the blood glucose data uploaded into the app by participants with diabetes. Additionally, cost analyses were performed using billed charges and paid claims data from Medicaid. The results of the quantitative analysis published in *Clinical Diabetes* (Bovbjerg, Lee, Wolf, Bangs, and May, 2017), and are summarized below. The qualitative analysis is included as chapter two of this thesis, and was based on participant interviews conducted at the end of the project, as well as transcripts of the text messages sent between nurses and patients during the project period.

Quantitative Analyses

In order to assess the intervention's effects on health, healthcare, and costs, several data sources were utilized. The first data set was from biometric measurements taken during the course of the intervention. Participants entered health information into the mHealth app on a regular basis, either by hand or directly via cellular-enabled glucometers. At the conclusion of the project this data was used to assess whether any change in clinical markers of health was achieved. The quantitative analysis focused on patients with diabetes because the data were published in a diabetes-focused journal . This sub-sample included 33 patients, of whom eight were lost to follow-up and one was removed by their physician, leaving 24 participants with diabetes completing the intervention. The second data set consisted of survey data collected at two time-points, the beginning and end of the project, which were used to analyze the impacts of the intervention on a variety of measures of participants' self-rated health, mental health, satisfaction with care, and self-efficacy in managing disease. The questionnaire included items selected from four

previously-validated survey instruments. The Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey covered participant experiences in the healthcare system, patient satisfaction, health behaviors, and self-rated wellness. The Patient Health Questionnaire-9 (PHQ-9) assessed participant mental health symptoms. The Self-Efficacy in Managing Chronic Disease scale evaluated symptom control, role function, emotional functioning, and communication with providers. Lastly, the abbreviated World Health Organization Quality of Life (WHOQOL-BREF) instrument assessed participant well-being within five domains: overall quality of life and general health, physical health, psychological health, social relationships, and environment. The third data set included in the quantitative analysis consisted of cost data from Medicaid billed charges and paid claims for each participant. Costs associated with the period before and the period during the intervention were compared. The data for the period before the intervention were calculated by using the number of months each individual participated in the project as the analogous time period spent in the "pre" intervention condition.

Cost analyses showed a substantial, though statistically non-significant, reduction in cost per patient during the intervention period. For the overall sample, there was a median reduction of \$520 in billed charges, and \$180 in paid claims per participant, per month. The greatest savings were seen in participants with more poorly controlled diabetes at the start of the intervention; for this sub-group a savings of \$1836 and \$510, respectively, were achieved. Conversely, the analysis of blood glucose data showed no clinically-meaningful change across the sample during the project. While some individual participants did achieve reductions in, or stabilization of, their blood sugar levels, others

experienced either no change or increases in average blood sugar during their tenure in the project. Lastly, the survey data revealed that while clinical outcomes, as measured by blood glucose level, did not change, participants' perception of their health improved significantly during the project. Two survey instruments in particular demonstrated statistically significant improvements. The median score for the CAHPS scale increased from 16.5 to 18.7, where improvements were primarily for items related to self-rated health, the degree to which pain interferes with daily living, and mobility. The WHOQOL-BREF demonstrated improvements in the over-all quality of life and general health domains. In addition, the PHQ-9 instrument found substantial, though statistically non-significant, improvements in participant mental health; the median score dropped from 10.5 to 5.5 (possible range is 0-27), and of the 8 participants who scored in the moderate or severe depression range before the intervention, only 4 scored in that range at the end of the project.

Qualitative Analysis

The image that emerges from the quantitative analysis is complex. There appears to have been a positive impact on cost; the fact that fewer dollars were spent in the delivery of care is one way in which the project achieved the goals set forth by the ACA. The project also appears to have positively impacted delivery of health care, as several items from the CAHP quality of care domain indicate that participants reported more frequent and/or more satisfying interactions with their providers. For example, the number of participants who answered that their health provider "always answered all questions to [their] satisfaction" rose from 4 in the pre-intervention survey, to 18 in the post survey. The

third goal of the ACA, to improve health, also appears to have been achieved. Even though clinical markers (e.g., blood glucose levels) did not attain statistically significant improvements, patient self-rated health did. This latter finding, that patients' subjective experiences of their health improved (as indicated by survey results), despite the fact that clinical measures of health (blood glucose readings) remained unchanged, invites further investigation. This apparent tension between clinical reality and lived experience reveals a site of inquiry where qualitative methods are "particularly suited to provide a more nuanced picture, and thus a more productive view" (Ahlin et al, 2015). By undertaking a careful analysis of the exit interviews and text message transcripts, it is possible to expand the understanding of how this mHealth intervention, and the project, acted in the lives of patients to produce an experience of improved health even in the absence of clinically-significant improvement in health outcomes.

As a step toward this more nuanced understanding, the qualitative analysis which follows in chapter two focuses the subjective realities of participants, revealing how this project shaped the experience of seeking and receiving healthcare for individuals living with chronic disease. The analysis is guided in part by the theoretical framework suggested by Elizabeth Carpenter-Song (2011) in her research on chronic disease and mental health. She points out that as medical anthropologists have critically engaged with research on U.S. biomedicine, that research has tended to take as its focus "the rifts, breakdowns, and slippages that occur" (Carpenter-Song, 2011: p 168) between patients and the medical system. This has proved fertile ground for research, and has added much to our understanding of how individuals' experiences within the U.S. medical system are shaped

by political-economic and cultural factors that can create clinical relationships mired in uneven power dynamics. Patient narratives are often subverted or ignored by the medical system, leaving many feeling adrift in an uncaring system that fails to see patients as individuals with a range of life conditions that impact their lived experiences of health and disease (Carpenter-Song, 2011). However, as Carpenter-Song notes not all patients report dissatisfaction with their experiences in the U.S. medical system. In the case of this project, the majority of patients reported positive experiences. During his exit interview, when asked about his general impression of the project, Quentin replied: "I think very highly of it... it was fabulous to get back into the habit [of checking my blood sugars], and become conscious that it was a habit that I should maintain." In Teresa's exit interview she highlighted her interactions with providers as playing a key role in her positive experience in the project: "I like talking to them on the tablet, and I thought that they could get me help if I needed it. And, I don't know, they were just always very pleasant and uplifting. They raised my spirits a lot times." But as Carpenter-Song (2011) writes, positive experiences of U.S. biomedicine, such as those reported by the participants in this project, have seldom been the subject of anthropological inquiry:

What, then, are we to make of happy patients?...There is not a well elaborated theoretical framework for approaching positive experiences of western biomedicine...The reductive potential of biomedicine is well substantiated (and important to critique). But we also want to be aware of - and keep our ears pricked and our eyes open to - the complexity of clinical realities[.] (p. 170-171)

The fact that participants widely reported positive experiences in the context of this project is significant, and informs the analysis that follows in chapter two. Recognizing, and taking seriously as a site of inquiry, this dimension of the patient experience is useful

in the effort to understand how biomedicine sometimes function well in the lives of the individuals who must engage with it regularly in the course of living with chronic disease (Carpenter-Song, 2011). Therefore the qualitative analysis in this thesis takes as its starting point the fact that participants in this project largely reported positive experiences marked by improvements in their subjective wellbeing. The following chapter explores, by employing the theoretical framework of Bordieu's work on fields, how the subjective experiences of participants were shaped in part by the pre-existing structures of biomedicine, how those structures were acted upon and renegotiated through the use of the mHealth application, and how these new arrangements produced meaningful changes in the relationships between patients and providers in this context. In doing so, this analysis seeks to engage in "open[ing] fresh analytic space...to shift from documenting what's wrong toward specifying what may work" (Carpenter-Song, 2011: p 171).

Chapter 2

PATIENTS' EXPERIENCES OF SEEKING AND RECEIVING HEALTHCARE USING AN MHEALTH APPLICATION FOR COMPLEX CHRONIC DISEASE MANAGEMENT

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Abstract

Chronic disease is costly to treat and burdensome for those living with its impacts. Mobile health (mHealth) technologies show promise in reducing cost of care and increasing patient self-efficacy in chronic disease management, yet the patient experience of mHealth is poorly understood. This qualitative analysis is part of a mixed-methods study examining the impacts of an mHealth application for remotely monitoring chronic disease. Its purpose was to elucidate the patient experience of seeking and receiving healthcare using the app. Salient aspects of the patient experience included a) feeling seen and heard within the medical system, b) reassurance provided by accessing care at any time and from any place, c) a sense of personal connection with nurse care coordinators, and d) the synergistic interaction between technology and nursing care. This resulted in challenging traditional expectations of the clinical encounter, allowing new modes of interaction between patients and care providers to emerge.

Introduction

Chronic disease is recognized as a global threat, killing 40 million people annually and accounting for 70% of global mortality (World Health Organization, 2017). In the United States, chronic diseases comprise seven of the top ten causes of death (Centers for Disease Control and Prevention, 2017). According to the Centers for Disease Control and Prevention (2017), 117 million Americans currently live with chronic disease, and one in four adults live with two or more chronic diseases. The burden placed on the U.S. healthcare infrastructure by such conditions is likely to continue to grow in coming years, leading to a call for solutions to simultaneously alleviate both the economic and personal costs associated with chronic disease management. Innovations in mobile health technologies (mHealth) are increasingly at the forefront of such solutions, and show potential for improving health and decreasing cost. Yet little attention has been paid to the patient experience of using mHealth applications to manage chronic disease. How do mHealth interventions function in the delivery of health care within local contexts, and what are the clinical and social effects of mHealth on the patients to whom these technologies are marketed? Answers to such questions may be key to solving the problem of what Andreassen and colleagues (2015, p 63) refer to as the “plague of pilots” characterizing the current mHealth landscape, in which most projects fail to move beyond the pilot phase, despite their initial promise in improving health outcomes and decreasing cost of care.

The qualitative analysis presented here is part of a larger mixed-methods study examining the impacts of an mHealth application for complex chronic disease management

(referred to here as the app) on health, healthcare, and cost of care delivery. The purpose of our analysis was to examine the patient experience of using the app in the daily management of chronic disease, and to elucidate how its use affected seeking and receiving healthcare in this context. Data were drawn from open-ended, semi-structured patient exit interviews, as well as from transcripts of in-app text messages sent between patients and nurse care coordinators over the course of the study. Interviews were transcribed and consensus coded by the first and second authors; themes that emerged from patient interviews were then used as a guiding framework for the analysis of text message transcripts. Four aspects of the patient experience emerged as being particularly salient, and these functioned together to facilitate a care environment marked by a specific set of disruptions to accepted customs and norms of patient-provider interactions in the United States. These disruptions were key to patients' positive experiences of managing their health using the mHealth application.

Background

The larger project from which the patient exit interview and textual data were drawn was a county-level, pilot mHealth intervention for high-cost, high-utilizing chronic disease patients coordinated through a multi-specialty clinic in the Pacific Northwest of the United States ("the clinic"). The study spanned 12 months between April 2015 and March 2016. Medicaid patients (and those dually eligible for Medicare) receiving primary care at the clinic, who were at least 18 years of age, and who had one or more chronic disease diagnoses were eligible to participate. Eligible diagnoses included type 1 or type 2 diabetes mellitus (DM), chronic obstructive pulmonary disease (COPD), coronary artery disease

(CAD), and/or congestive heart failure (CHF). Individuals with cognitive impairments requiring a care provider were excluded. Oregon State University's Institutional Review Board reviewed and approved the analyses described here.

This project was a collaboration between the clinic and a regional mHealth technology start-up company. The clinic contributed four nurse case managers to provide patient care. The technology company provided the platform, a tablet on which the mHealth application was deployed. The technology company provided technical assistance related to use of the tablet and app to nurse case managers and patients. At the time of enrollment, patients received an app-enabled tablet and instruction on how to use the app. The app provides three primary functions: 1) tracking of patients' recorded biometric data specific to their chronic disease diagnos/es (for example, blood glucose levels for patients with diabetes), 2) the provision of relevant educational materials on chronic disease management, and 3) real time communication with nurse case managers via in-app text messaging. Patients recorded biometric data, including blood glucose levels, blood pressures, daily body weights, and/or peak flow numbers, depending on the disease(s) being monitored. Patients could communicate with a nurse twenty-four hours a day by using the text message feature of the app. Nurse case managers were also given app-enabled tablets, with provider-specific functionality which allowed them to monitor patient health, review trends in biometric data, upload educational materials, and communicate with patients via text message. Nurses rotated on-call periods in week-long intervals, with each nurse on-call for approximately one week per month. The on-call nurse was responsible for monitoring and communicating with all enrolled patients, 24/7.

Analyses of clinical biometric and survey data from this project (Bovbjerg, M., Lee, J., Wolf, R., Bangs, B., May, M., 2017) suggest that this mHealth intervention may contribute to some improved health outcomes for its users. For example, pre- and post-survey instruments found improvements in measures of self-rated health, quality of life and quality of care. Indices of patient self-rated mental health also showed substantial, though statistically non-significant improvements. Non-significant improvements were also observed in clinical markers of health (blood glucose levels). In addition, non-significant cost savings were realized over the term of the project compared with the pre-intervention period. These cost savings were associated with reduction of both billed charges and paid claims.

Methods

Forty-five patients were enrolled in the larger project, and 37 completed the study. Length of participation in the study ranged from six to twelve months. At the close of the project all 37 patients were invited to participate in open-ended, semi-structured exit interviews. Twenty-seven patient interviews were completed (see tables 2.1 and 2.2 for patient demographics and diagnoses). Interviews were transcribed, then coded and analyzed using NVivo software. Initial coding of the transcripts utilized an open, consensus coding structure. During this phase of analysis patient perspectives were identified and initial coding schemas independently created by the first and second authors, who then met to discuss the overlaps and differences in the preliminary themes identified. These codes were then subject to another round of analysis, in an iterative process whereby initial codes, indicators and concepts were discussed in detail and continually compared

and refined against the interview data. As consensus began to emerge around key themes, concepts were elaborated on and transformed into more robust theoretical categories informed by the researchers' perspectives and knowledge of the larger body of literature on mHealth, thus generating an analysis at once grounded in the patient experience and simultaneously engaging broader theoretical categories (Dressler, 2001). Content analysis of text message transcripts from messages sent and received by all patients who participated in the larger project (n= 37 patients, total text messages = 4,604) were analyzed in NVivo, utilizing the codes that emerged from the consensus coding of patient exit interviews as a framework. This process allowed us to use textual data to further refine and illustrate the themes that emerged from exit interviews. Themes from exit interviews and text message transcripts were further informed by the first author's knowledge of the project gained through participant-observation at weekly meetings during which specifics of patient care were discussed by clinical staff, technology associates, and the research team.

Table 2.1 - Patient Demographics

	n	Mean age (years)	Female (number)	Gender (number)
Exit Interviews	27 patients	58.3	14	13
Text Messages	37 patients	56.3*	19	18

Table 2.2 - Patient Diagnoses

	DM	COPD	CHF	CAD	DM/COPD	DM/COPD/CHF	DM/COPD/CHF/CAD
Exit Interviews	16 patients	4	2	0	3	1	1
Text Messages*	22 patients	6	3	0	3	1	1

DM = diabetes mellitus

COPD = chronic obstructive pulmonary disease

CHF = congestive heart failure

CAD = coronary artery disease

*Data missing for one patient

Results

This analytic process resulted in the identification of four salient themes: 1) Visibility and Invisibility in the Medical System, 2) Deconstructing the Clinical Encounter, 3) Familiarity in the Nurse/Patient Relationship, and 4) Technology as a Conduit of Caring (see table 2).

Table 2.3 - Summary of Themes

Theme 1 Visibility & Invisibility in the Medical System	Theme 2 Deconstructing the Clinical Encounter	Theme 3 Familiarity in the Nurse/Patient Relationship	Theme 4 Technology as a Conduit of Caring
Patients felt seen and heard by providers.	Ability to access care at any time, in any location.	Relationships with providers were central to overall experience.	Disruptions in expectations of the clinical encounter.
Contrast with past experiences in medical system.	Disruptions in expectations of the clinical encounter.	Technology was conduit for the experience of seeking and receiving care.	Use of the app use was contingent on and intertwined with experiences with providers.

Visibility and Invisibility in the Medical System: "That wall over there that messes everything up"

For some patients, participation in the project presented an opportunity to engage with their health care providers in a new and welcome way. Patients expressed a range of prior experiences within the medical system, and these experiences were often viewed in a negative light. For many of the participants, the medical care they had received before enrolling in the project was lacking in depth and consistency. Patients shared instances when previous experiences with care providers did not measure up to their expectations and left them feeling disconnected and uncared for. During a discussion of current and past

health issues, Eric² shared that he had had difficulty in getting relief from knee pain that continued after having knee replacement surgery, and seemed to feel that his doctor's response had been inadequate:

[W]hen they did surgery on this knee, [they] took out the knee cap and left the artificial one in. And every time I ask the doctor to look at it he's says "Oh, your knee cap's ok, but we can't do anything about it."

The doctor dismissing Eric's experience of something being wrong with his knee is an example of how patients are made to feel invisible within a medical system that prioritizes the specialized knowledge of care providers over the lived experiences of patients. The doctor's assertion that "your knee cap's ok" superseded Eric's own knowledge that his knee continued to cause him pain.

Other patients related experiences with health care providers that caused them to feel similarly confused, ignored, or invisible. For Diane, that experience related to medical care her mother received while Diane was her care-taker:

I just believe in good communication between all your doctors. I took care of my mother for a couple of years while she had diabetes and dialysis, and her primary care wasn't talking to her kidney doctor, and the kidney doctor...So when they were giving her medications it could get confused.

The confusion that resulted from this situation clearly led to important facets of Diane's mother's care being lost in the system. An inability to correctly manage medication can be a major threat to wellbeing for chronic disease sufferers, and Diane's concern about the lack of effective communication between care providers reveals an additional way in which patients may be made to feel invisible within a medical system where efficiency and minimal patient contact are the hallmarks of "effective" medical practice.

² All names used are pseudonyms to protect the identity of participants.

Patients drew direct comparisons between problematic care received outside the project and the highly responsive care received as a participant in the mHealth project. When asked about his general impressions of the project, Thomas responded that he liked it quite a lot. In particular he valued the ability to communicate directly with the nurse case managers:

I like being able to have someone to communicate with on a direct basis, in the sense that I could type out a message and it went to the person I needed to communicate with, instead of going through that wall they create over there which messes everything up, and I really hate. So that then I could get a direct communication back without things getting fuzzed over.

In Thomas's prior experience, he faced barriers in accessing care, which he referred to as "that wall over there." The inability to communicate directly with providers led him to feel that he wasn't being heard, and the feeling of "things getting fuzzed over." In this case, his sense of invisibility was conceived of as being literally walled off from his care providers. These experiences stood in stark contrast to his experience of communicating with the nurses using the app-enabled tablet. Later in the interview he expanded on this idea:

Access to the dietician was in a more direct sort of way. Instead of the circuitous way we do it in modern medicine, where you've got to get your doctor to say "yeah," and then you've got to go to the insurance company, and all the rest... The nurses were very helpful, and knowledgeable... and they were asking me if I wanted the nutritionist or the endocrinologist, et cetera. And they were good about trying to connect me with who I needed to be connected with. And also to help me get that actually done. Instead of just saying "Well, you should do this," they set it up.

In describing the ways in which the nurses helped him, Thomas noted that he could trust the nurses to provide reliable information. They asked Thomas about his needs and responded by taking direct action to get those needs met. Feeling seen and heard by the nurses reassured him that he would be able to access the type of care he desired which in

the above case meant the ability to visit with specialists that had previously been difficult to access due to a convoluted chain of physician and insurance company referral processes that he could not navigate successfully.

That the feeling of invisibility within the medical system was ameliorated by use of the app was expressed by other patients who described the quality of connection they had with the nurses as being central to their positive experiences in the project. For Terry this connection was felt as the nurses expressing care for him through their willingness to assist him in times of emotional and physical distress:

It was nice having that security there, that comfort of someone there caring about you. Calling to help you if your mind isn't all the way set. Having that person calling and able to direct you. You know, what you should eat or not eat, you know to help with the sugars. Or to help focus you when you might be in a state of confusion. Or when you've got questions and they're able to answer those questions. You know, something that would probably keep you up all night, 'cause your brain's thinking on it, and they're able to answer it and put your mind at ease.

Terry's quote is an apt illustration of how connection with nurse case managers through the app helped to allay the feelings of worry and isolation that characterized his previous experiences in the medical system. When patients experience significant barriers to accessing quality health care, as described by the participants in this study, it affects physical health as well as psychosocial wellbeing.

Deconstructing the Clinical Encounter: "They were there day and night"

A centrally important feature of the project, as expressed by the participants, was the way in which it upset expectations of the clinical encounter. Typical encounters with care providers are necessarily bounded both by time and space. Physician's offices adhere to practices that restrict the patient's ability to access primary care during non-business hours.

Answering services and urgent care centers are intended to allow patients greater ease of access to medical care outside of regular clinic hours, but these services present their own limitations, especially in terms of cost, wait times and lack of continuity of care. In addition, visits with a doctor typically require patients to be physically present in the same location as their providers, requiring a greater or lesser degree of travel. This limitation is especially burdensome for low-income and chronically-ill individuals who may have difficulty reaching the clinic on their own, taking time off work, or accessing transportation services. The use of mobile technology in this project, in combination with the availability of on-call nursing staff meant that the boundaries and limitations of the typical clinical encounter were blurred. Use of the tablet brought the clinic into the everyday lives and experiences of participants, dramatically increasing their ability to access their care providers, while simultaneously reshaping the definitions of the clinical encounter. As Xavier said, "I liked being able to potentially communicate twenty-four seven. So that was what I found the most useful."

As Xavier notes, using the tablet afforded patients the opportunity to communicate with nurses at any time of day. The on-call nurse was available to them throughout the day and night, over weekends, and during holidays. Text message records verify that this attribute was widely used both by patients and nurses; 58% of the 4,604 text messages sent by either a nurse or patient were outside of regular 8:00 am to 5:00 pm, Monday through Friday, business hours of the clinic.

This project also restructured the chronology of the clinical encounter by removing the time limits placed on typical clinic appointments. Inside the clinic

appointments are necessarily time-limited to afford doctors the ability to meet with as many patients as possible during the operating hours of the clinic. By removing care from this setting, the mHealth app enabled patients and nurses to elongate the clinical encounter over an indefinite period of time. A single "encounter" might therefore take place over a few minutes, or over the course of an entire day as nurse and patient alternately send and respond to messages sent via the tablet, as the following text exchange illustrates:

Carol, 10/30/2015 07:49 PM: When I took my bp [blood pressure], it was 183 over 70. since it was high I panicked and took it again and it was 170 over 87. I was talking on the phone and doing other things just before I took it at 7.30 pm a bit later than I wanted.

Nurse, 10/31/2015 02:13 AM: hi carol im sorry. i wasnt feeling well and fell asleep. just let me know if bp is staying up in the morning or if you have any other symptoms like headache, shortness of breath or chest pain.

Nurse, 10/31/2015 02:16 AM: this was probably just a single situational high blood pressure based on what you were doing prior to checking. and it did come down slightly on recheck.

Carol, 10/31/2015 04:21 PM: Thank you for reassuring me about my bp. [The assisted living facility] just took my bp and it was 132 over 72. I cant understand why I get higher readings on my machine. Taking my own bp always makes me nervous because Im afraid it will be too high... [the assisted living facility] always uses a wrist bp device and it usually reads lower.

Another way in which the project restructured the expectations of the clinical encounter was by moving access to care outside the physical constraints of the clinic. For Diane, increased access meant that she could maintain communication with her care providers in situations that would typically have interrupted access to her primary care provider:

I used it when I went on vacation, 'cause I wanted to see what it was like when I was out of town and how far I could go. If I was on vacation somewhere, if something came up, I still had the personal touch of somebody knowing what was going on. And I would communicate with them, saying I was going on vacation.

The fact that the tablet was cellular enabled meant that patients could enter biometric data and contact nurses regardless of their physical location. In Diane's case, this meant that her care provider was accessible wherever she went, including when travelling on vacation.

Many patients expressed that this disruption in the anticipated boundaries of the clinical encounter dramatically improved their experiences of seeking and receiving care through use of the app.

Familiarity in the Nurse/Patient Relationship: "You couldn't ask for a better bunch of girls"

Another key element of the patient experience was the relational aspect of the project. Many patients expressed a high degree of investment in the relationships they built with the nurse case managers over the course of their participation in the project. The extent to which patients valued this relationship was reflected in the language they used to describe both their interactions with nurses, and the nurses themselves. Throughout the exit interviews a notable pattern emerged of patients referring to nurse case managers using familiar terms, rather than professional markers. Nurses were often referred to as "girls," "ladies," and in a couple instances as "sisters," denoting a more intimately familiar association than might otherwise be expected in a primarily clinical relationship.

Well it was communication, is what it was. Communicating with the girls. I mean at least they were fun. I told them one time "God it's like cats and dogs out there," and I said "There's an old saying: 'Row, row, row your

boat gently on the stream. Ha ha I fooled you, it's a submarine.'" Next thing I see "Ha ha."
-Edward

Edward's retelling of a humorous exchange with a nurse is illustrative of the type of familiar tone patients often invoked when discussing the nurse case managers. Referring to the nurses as "girls" is one way Edward signals the closeness of the relationship he feels he has developed with them. That relationship is clearly much more than clinical, as evidenced by his description of the nurses as being "fun," and his description of an informal text exchange that served no apparent clinical purpose, but that encouraged Edward to feel a sense of camaraderie with nursing staff. Patients related that nurses nurtured this type of relationship by soliciting interactions that went beyond the clinical. Quentin's description of how he used the text messaging feature of the app demonstrates this approach:

Because they said they liked hearing from me, I tried to keep in touch. It was a lot in the beginning, where I tried to just say "have a good day," type of thing...As soon as one of them would say "Hey, we like hearing from you," I'd say "Oh yeah, that's right," and I'd remember [to text].
-Quentin

Text message transcripts support patients' perceptions that nurses cultivated an informal, familiar relationship. In addition to encouraging patients to engage in regular, non-clinical interactions, nurses used text messages to convey a sense of familiarity through their grammatical constructions and use of language.

Nurse: Have you noticed your BS [blood sugars] for the last week have been steady at low 200's??? Ya HOOOOO!!!! And I am still waiting for my "one good thing you did for yourself today " note you need to send me. This is certainly something! good job.

The explicitly friendly tone of the above message is echoed throughout the text message transcripts. Yet even when messages were of a more explicitly clinical nature, they often incorporated elements of informality, such as the use of emoticons, that acted to reinforce familiarity between nurses and patients. As a result, patients experienced the nurse/patient relationship as being imbued with mutually shared emotional caring, and most participants were sad to see the project end. Edward's words epitomize sentiments shared by many regarding the project's end: "I was just telling the girls in there, I'm a bit teary eyed this is all coming to a close. I'm going to kind of miss them. I'm losing a bunch of sisters, is what I'm losing."

Technology as a Conduit of Caring: "It brings you into the fold"

The technology used in the project featured prominently in patient narratives as patients carried out almost of the study activities using app-enabled tablets. Communication with nurses was nearly entirely through text message within the app, with infrequent phone calls initiated by nurses acting as a supplement to text communication when necessary. In this way, technology served an essential function as a conduit through which clinical and emotive care was accessed by patients. The relationship between nursing care and technology was characterized by reciprocity and dependence. Patients simultaneously used the technology as a tool to build close relationships with nurses, while their experience of the technology itself was understood through the lens of those relationships. That the use of technology was intimately linked with the nurse/patient relationship was evident when patients were asked to reflect on their experiences using the tablet and the app:

Being involved with the tablet kind of brings you into the words, you read the messages every day...I like that idea of being involved, it brings you into the fold on it, you know, and just feed back in. You can talk back in.

-Charles

I like talking to them on the tablet, and I thought that they could get me help if I needed it. And they were just always very pleasant and uplifting. They raised my spirits a lot of times.

-Theresa

The technology also facilitated the development of close ties between nurses and patients by providing a venue in which patients felt safe discussing difficult, embarrassing, or emotion-laden topics. For Edward, the tablet provided the opportunity to discuss issues with his care provider that would have felt too difficult to broach in a face-to-face consultation. The physical distance afforded by the technology served to decrease the emotional awkwardness of the clinical encounter, ultimately bringing him closer to his care provider than might have occurred otherwise. Edward expressed it this way: “It gives you the chance, at least you can say something if you want to. And without ‘Ah gee, I have to up and say all this stuff to them in front of them.’ To me it was easier.”

Patients also reported using the tablet to discuss personal issues with the nurses that extended beyond the parameters of the chronic disease diagnoses for which they were enrolled in the project. These discussions were sometimes of a particularly personal nature, as described here by Elaine:

They were also there for me whenever I had other issues arise at the house, like fighting with my significant other...I used [the tablet] as a tool ask questions, or also I would talk to the ladies about my emotional state of mind and they would give me tips on different things to do.

Technology was the nexus through which psychosocial support and clinical care were accessed by patients, and the one was not experienced as being wholly separate from the

other. Nurses and technology were linked in patient narratives in a manner that makes clear how these two key aspects of the project were dependent on one another as joint catalysts that enabled patients to receive care they perceived as vital to their wellbeing, and led them to develop meaningful experiences of participation.

It was definitely a real comfort having someone [there], because I am pretty much by myself. And to have someone to contact me, to make sure I was okay, that in itself was a comfort. That's really the main thing, that it was kind of like a security blanket. For anybody else to do it, I'd say they'd probably find out the same thing.
-Terry

Discussion

Research on patient care-seeking behaviors, the doctor-patient relationship, the clinical encounter, and medical decision making in the traditional clinic setting reveal that power dynamics impact the patient experience of medical care (Adams, Price, Tucker, Nguyen, & Wilson, 2012; Andersen, Tørring, & Vedsted, 2015; Carpenter-Song, 2011; Cooper, 2015). While some have suggested that power inequalities within the provider-patient relationship are inherently disempowering for the patient, others have demonstrated that the medical encounter can be a site of empowerment for individuals who contest the power structures that typically characterize the doctor-patient relationship (Carpenter-Song, 2011; Cooper, 2015). This mixed body of research demonstrates that power within this complex relationship is dynamic, negotiated, and highly contextual. Theme 1, "Visibility and Invisibility in the Medical System" provides insight into how patients have experienced that power dynamic in the context of past experiences within the medical system. In this study, patients expressed feeling overlooked and unseen by previous medical providers; by doctors who dismissed their lived experience as inconsequential, by lack of

communication between providers in carrying out important medical care, and by the system itself imposing substantial obstacles to accessing care. In contrast, patients in this study reported feeling truly seen and heard by their care providers in a way that felt authentic and imbued with emotive caring. Two primary factors emerged from patient narratives and text message transcripts as being particularly consequential to these experiences; the role that technology played in redefining the parameters and expectations of the traditional clinical encounter (theme 2), and the way technology transformed communication to favor the development of caring relationships between providers and patients (themes 3 and 4).

Interactions within the medical system can become empowering for patients when the normative culture of biomedicine is contested (Carpenter-Song, 2011; Cooper, 2015). Andersen et al (2015) and Cooper (2015) both suggest that Bordieu's fields theory is instructive in understanding how power operates in the medical context. Bordieu's theory posits that certain societal domains constitute fields. Fields are discrete, though sometimes overlapping, social domains characterized by agreed upon meanings, symbols, and contingencies which act to constrain and delineate what is appropriate within that domain (Andersen et al, 2015; Bordieu, 1989; Samuelsen & Steffen, 2004). Andersen, Tørring, and Vedsted (2015) argue that biomedicine constitutes such a field, as biomedicine contains a "logic - or feel for the game...which refers to the fundamental, deep-founded, and unconscious values that are taken as self-evident universals that inform the participants' practices...for example, it is always the doctor who treats the patient, not the other way around" (p. 241).

The norms and customs that undergird the field of biomedicine additionally influence participants by shaping the embodied dispositions that are the accepted modes of acting within that field (Bourdieu, 1989; Longhofer & Winchester, 2016). Bourdieu theorized that within each field, individuals are positioned according to the relative amount of social, cultural, economic, and symbolic capital that they have accrued (Bourdieu, 1989). Those who hold power within the field are those who have accrued the greatest volume - or the most highly valued forms - of capital (Bourdieu, 1989). Power, and an individual's place within the social landscape, can only be understood in relation to the location occupied by others within the field. Patients' positive experiences in this study were in part due to the ways in which the field of biomedicine, and the social space within that field, were re-negotiated to favor more equitable power relations.

The logic inherent to the field of biomedicine is readily apparent in the clinical setting, where the "game" of biomedicine is most overtly "played." The clinic space and the clinical encounter create a scaffolding, which acts to reinscribe the distribution of power into the bodies of patients and clinicians (Cooper, 2015). Patients are acutely aware of, and actively interpret, the bodily dispositions of their care providers, finding moral and political meaning in their actions and inactions (Cooper, 2015). How near or far from a patient doctors situate themselves, the degree to which eye contact is maintained, whether the clinician touches the patient during the encounter, all carry meanings that can be readily interpreted by those who seek care (Cooper, 2015). Adersen et al (2015) argue that the norms of biomedicine additionally act to delimit the types of complaints for which patients seek care, and how those complaints are framed in discussion with clinicians. The

clinic is thoroughly pervaded by the norms and habits that are customary in the field of biomedicine, and the logic of the field is, therefore, at once established and reinforced.

However, when the clinical encounter occurs outside the clinic, without physical contact between patient and provider, this system is disrupted. Outside of the clinic setting, few of the above factors remain operable. In this study, the mHealth app opened a space within which the clear expectations of the field were obscured. In this new setting, where care was delivered remotely and asynchronously, few commonly accepted modes of acting were available to participants. Visual and auditory contact between patients and nurses was limited or completely unavailable. Interactions were carried out nearly entirely by text message and through electronic transmission of biometric data using the provided tablets. In very few instances, including in urgent and emergent situations, nurses contacted patients by phone, but these contacts were the exception rather than the rule.

Themes 1 and 2 illustrate that these disruptions were experienced by patients as key factors in their positive experiences of the project. The ability to access care at any time, in any location, and without the constraints of the traditional clinic setting, featured prominently in patient narratives. By removing care from the clinic, the clinical encounter was stripped of the most readily recognizable aspects associated with the field of biomedicine. The notable absence of these conventions allowed patients and nurses to renegotiate the logic of the field and form new modes of acting that helped to bridge the divide that typifies patient-provider interactions in the typical biomedical clinic setting. This process of renegotiation is apparent in theme 3, where patients reported the emotional quality of these relationships as being centrally important to their experiences in the

project. Patients relayed over and over again their appreciation for and deep sense of connection with the nurses they interacted with during the project. Their interactions with nurses allowed them feel heard, seen, and understood as people, not just as patients. As theme 4 demonstrates, the technology facilitated a closeness in the relationship between nurses and patients, despite their physical distance. By upsetting the expectations of the normative clinical encounter and eliminating the modes by which social distance is normally negotiated within that encounter, patients and nurses re-constructed the landscape of social space in a way that became empowering, rather than disempowering for patients.

Carpenter-Song (2011) writes that power dynamics in the patient-provider relationship "[manifest] in the micro-dynamics of what is said and unsaid, who speaks and for how long, [and] who asks questions and interrupts" (p. 168-169). Communication between patients and care providers can serve to reinscribe power distributions, and can act to alienate patients from the clinicians from whom they seek care. Yet power relations within a field are not fixed (Bordieu, 1989); they can shift depending on the actions of participants. When communication between providers and patients is characterized by trust, rapport, and an acknowledgement of the social and emotional dimensions of the patient's lived experience (Carpenter-Song 2011; Cooper, 2015; Jagosh, Donald Boudreau, Steinert, MacDonald, & Ingram, 2011; Mauksch, Dugdale, Dodson, & Epstein, 2008), there exists the possibility for connection that transcends the power dynamics that typify the field of biomedicine. In the case of this project, patient narratives and text message transcripts reveal that communication between nurses and patients acted to narrow the social distance, leveling the power differential between the two parties. Because the written

communications that were the primary mode available for forging the patient-nurse relationship were characterized by familiarity and reciprocal, affective caring, and provided an avenue through which the life world (Carpenter-Song, 2011; May, Rapley, Moreira, Finch, & Heaven, 2006) of the patient was acknowledged and validated, the distance in social space between nurses and patients was effectively narrowed, and power differences receded from the foreground of interactions. Differences in power did not cease to exist, but the way power operated within the bounds of the relationship was dampened, allowing patients to experience a degree of satisfaction in the patient-provider relationship that they reported to be atypical of previous experiences within the medical system.

Moreover, the above qualitative analyses shed light on previously reported findings from quantitative analyses of this study. The apparent contradiction between improvements in patient-reported overall health and the lack of statistically significant improvements in clinical biomarkers (Bovbjerg et al, 2017) begs further investigation. By uncovering the socio-cultural dynamics that produced positive patient experiences, the qualitative analyses provide a framework for understanding how engaging with the mHealth app shaped their experiences of seeking and receiving care. The shifts that occurred created an environment in which patients experienced increased satisfaction with their care providers, with the care they received, and ultimately in their lived experience of overall health.

Conclusion

Findings from this study suggest that when health care is removed from the traditional clinical setting, and delivered via an mHealth app, an opportunity exists for the transformation of the field of biomedicine and its attendant norms and expectations. In

eliminating the primary avenues through which these norms are expressed, the app upset the balance of power by narrowing the social distance between providers and patients. In this new space, old modes of behaving were not operable. What remains unclear is what "new" norms might operate in this space, and to what extent these new norms will reflect a departure from the old "rules of the game." One possibility is that old expectations will simply adapt to the new environment. In such a case, mHealth might become one more technological tool subsumed by the field of biomedicine, and will ultimately conform to its accepted logic. This might be the case if use of mHealth technologies reify the existing structures of biomedicine by relying on modes of acting that are typical of the clinic setting. For example, if mHealth programs restrict patients' ability to directly access care providers by limiting the time during which providers are available through the app, or by using a triage system to assess which patient communications merit provider attention, such interventions risk simply reconstituting the status quo. On the other hand, the opportunity exists for new health technologies to bend and reshape the field of biomedicine by opening up spaces into which new norms and modes might be imagined. In such a scenario, it is possible to conceive that these new forms might ultimately help to bring about a new logic within the field of biomedicine specific to patient-provider interactions or the healing encounter. If mHealth interventions continue to open a space into which new forms and modes of acting might be constructed, such technologies have the potential to be experienced as liberating and empowering by the patients using them. This project clearly demonstrates the potential for mHealth to impact the patient experience of health care delivery in novel and unexpected ways.

Production of new health technologies for a consumer market is a burgeoning industry, but research into the impacts and implications of their use remains nascent. Continued investigation of how individuals experience these novel approaches to health care delivery is needed if we are to understand how such interventions might impact not only human health, but health systems, and the interactions between global biomedicine and the local contexts in which people seek health care (Ahlin et al, 2015; Andersen et al, 2015; DelVecchio Good, 2010). In its 2015 Takes a Stand statement calling for increased research into the human and cultural aspects of e/mHealth, the Critical Anthropology for Global Health (CAGH) committee of the Society for Medical Anthropology said "E/m-health and telemedicine are innovative practices that are still in the making; the shifts in healthcare they stimulate are gradual, but profound. The stakes are high especially for the final users and practitioners" (Ahlin et al, 2015). In undertaking this analysis, we have endeavored to heed CAGH's call to focus an anthropological lens on specific areas of research within the field of e/mHealth, including: how e/mHealth impacts the patient/practitioner relationship; the use of these technologies in at-a-distance monitoring of chronic health conditions; and in examining the end-user experience (Ahlin et al, 2015). In doing so, we hope to have shed light on how critical analyses of e/mHealth applications can contribute to our understanding of how medicine operates within, and is acted upon by users of such technologies, and how its use shapes experiences of care-seeking for chronic disease management.

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Chapter 3 - Conclusion

As mobile technologies increasingly pervade the everyday lives of people all over the world, interest in their utility in delivering healthcare will likely continue to rise. As the World Health Organization's survey on eHealth (2010) clearly states, e/mHealth is widely considered an integral component of health and healthcare improvement efforts in the twenty-first century. This reality necessitates a close study of the impacts that e/mHealth might have on health systems and the individuals within them. Although some have argued that the shift of health monitoring and care delivery activities out of the clinic and into the home will require individuals to engage in increased self-discipline and to conform with the standards and protocols of the biomedical system (Ahlin et al, 2015; Lupton, 2012, 2013, 2014; May et al, 2006; Sinha, 2000), the participants in this study demonstrate that mHealth technologies might also serve to disrupt those expectations. The results reported here demonstrate that the potential exists for mHealth technologies to be experienced as conduits of improved, more connected, authentic, and holistic care. By removing care from the medical clinic, and subverting the expectations associated with care in that setting, this project created disruptions to the accepted norms and dispositions emblematic of the patient-provider relationship and the ritualized healing encounter that typify the field of U.S. biomedicine. These disruptions were in turn essential to the positive experiences reported by participants.

Limitations of This Study

The findings presented in this thesis describe and interpret the experiences of one group of patients in a specific geographical region of the United States. As a group, they

are fairly homogenous, representing a small slice of the totality of individuals living with chronic disease in the United States. The goal of this study was to explicate the particularities of this intervention within its given context, and in doing so, to gain insight into how this mHealth application operated within the lives of the 27 participants who shared their experiences in exit interviews. The extent to which their experiences may apply to people living elsewhere, or of a different socio-economic, racial/ethnic, or educational background remains to be seen. Similarly, the mHealth application in this study is unique, and not representative of all mHealth interventions currently utilized for chronic disease, or other health conditions. This is largely due to the fact that the current funding environment favors testing of novel mHealth interventions, rather than refinement or scaling up of those that have already shown potential efficacy. One result of this funding climate is that various non-analogous mHealth applications are developed and tested simultaneously. The results of this study may or may not apply to other mHealth products and/or projects.

Lastly, studying mHealth interventions poses certain unavoidable complications for the anthropologist/researcher. In particular, the ability to use participant-observation as a primary research method is limited due to the nature of mHealth itself. The key features of the app that participants in this study reported as being most central to their experiences—namely the fact that care could be accessed at any time and from any location—meant that the provision of care was diffused over great distances and periods of time. As demonstrated in the discussion of theme 2, *Deconstructing the Clinical Encounter*, a single "encounter" might take place over the course of a twenty-four hour period, or even longer,

making direct observation of care provision all but impossible. No anthropological studies to date have yet found an adequate method for direct replication of traditional participant-observation in this research context. For that reason, it was necessary to employ a less traditional approach in the course of undertaking this project. To this end, two tactics were employed. First, over the course of the year the project was underway, I attended weekly team meetings with study partners. At these meetings investigators met with nurse care coordinators and representatives from the technology company to discuss the progress of the project, as well as specifics of patient care. From these meetings, I was able to learn important details of how the app functioned for both nurses and patients, as well as gain insight into how nurses and patients interacted through use of the app in the provision of care. Second, because the app logged all communications sent using the text message feature, I had access to nearly every interaction between nurses and patients during the course of the study. The corpus of text message transcripts was nearly 1,000 pages in total. By performing content analyses of these transcripts I was able to indirectly "observe" these interactions and to glean important understandings of how these interactions impacted patients' experiences as reported in their interviews.

Future Directions

Taken together with the quantitative results of this study, the qualitative analysis confirms that mHealth can have positive impacts on health and healthcare, at the same time revealing that those impacts may not be as straight forward as simple improvements in clinical markers of health. The quantitative analyses showed that patients reported improvements in their wellbeing, even without concurrent improvements in clinical

markers. Qualitative analyses help to contextualize these findings by providing a framework for understanding how engaging with the mHealth app shaped the experience of seeking and receiving healthcare for participants. The shifts in care that occurred represented a significant, largely positive, departure from the ways participants had previously experienced the medical system, and their relationships with providers in that system. These shifts contributed in positive ways to participants' overall experiences in the study, and help account for the perception of improved health and wellbeing reported in the quantitative analysis.

The findings from this study also shed light on the ways in which current discourses on user engagement of mHealth are insufficient for addressing why most projects fail to achieve sustainability past the pilot phase of implementation. Most studies of user engagement have examined intent to use, feature preference, acceptability, or likeliness of individuals to adopt e/mHealth technologies. But such studies have not yet provided solid theoretical or practical considerations that can be utilized in the design and implementation of sustainable, longer-term mHealth programs. The findings from this study suggest that another set of questions and assumptions should guide the examination of user engagement and program sustainability. In particular, researchers should pay attention to how use of particular technologies affects the dynamics of the patient-provider relationship, the structure of clinical encounters, and the negotiation of power dynamics in the care-seeking context within which they are implemented. If, as in this study, mHealth applications serve to disrupt the pre-existing expectations and norms of the biomedical system, they have the potential to serve as tools for patient empowerment, which may

ultimately lead to increased user engagement. On the other hand, if mHealth applications are designed without attunement to these factors, they may instead serve to further alienate patients who may already be struggling with the barriers to high-quality chronic health care described by participants in this study. In the current healthcare environment, which is marked by a focus on efficiency, cost cutting, and medicine-for-profit (Rylko-Bauer and Farmer, 2002), mHealth may become yet another tool for the commoditization of healthcare, where individuals with chronic disease are treated as consumers to whom new health technologies may be marketed.

The issue of program sustainability also raises important questions about what becomes of participants from the discontinued projects that are now scattered about the international landscape of mHealth interventions and research. If, as this and other research suggest, mHealth does in fact show potential for improving the health and lives of its users, what happens to these users when pilot projects end? In this study, many patients expressed eagerness for the program to continue, and anxieties about it coming to a close. One participant reported that in the short duration between the conclusion of the project and her exit interview, she had experienced a worsening of her health that she attributed to discontinuation of the study.

Jenney: Thinking about your health now at the end of the program, how would you describe your overall health at this time?

Carol: Probably fair.

Jenney: Ok, so has it changed in any way since the start of the program?

Carol: Um, it was better while it was, while I was on the tablet, but I'm fair again.

Jenney: So you feel like it was better while you were doing the program, but since the program has ended it's gotten a little worse?

Carol: Yeah.

Jenney: What kinds of things feel worse now?

Carol: Well, my leg is in extreme pain again, and I don't have anybody to contact about health problems, and that was a great relief for me. And I needed help and they got me help. I can't remember what the situation was, but they got help for me. And the nurses were so good at explaining things, what was happening, and where I needed to go.

The proliferation of discontinued pilot projects (Andreassen et al, 2015) has created a clear and urgent need for researchers to investigate the effects of ending such programs without adequately addressing the needs of participants after the program's conclusion. Although in the context of this study, steps were taken by the clinical care team to ensure that patients would not experience lapses in care due to the ending of the project, this did not fully protect participants from disruptions in care, as Carol reported. This problem is exacerbated by the fact that participants in many studies are elderly, living in poverty, or face either geographical or social isolation in relation to their diagnoses. Carol's example clearly illustrates the need to grapple more explicitly with the ethics of short-term pilot projects. Her experience (and those of many more like her) makes all the more pressing the need to develop and maintain programs that successfully continue beyond the pilot phase. The onus is on investigators to address these important questions in their research in order to alleviate the burden placed on the individuals who participate in our studies.

Government and private funders so anxious to reap the economic benefits of mHealth innovations would do well to remember the people behind the data. If the goal is to reduce

suffering and improve health, then we must find ways to maintain projects that demonstrate the potential to significantly improve the lives of patients.

Concluding Remarks

Continued research into e/mHealth interventions is critical if we are to understand the consequences of their use, especially in light of the fact that implementation of new health technologies continues to expand despite a lack of sufficient examination of their affects on patient health. Applying an anthropological lens to the question of how e/mHealth might reshape health and healthcare will contribute to a greater understanding of if, when, and how these technologies can best serve the individuals for whom they are designed. The fact that e/mHealth investigations have until now remained largely the domain of other disciplines requires a rethinking of what is known about their use, and how applying a critical anthropological lens to their study can improve the lives of intended users. As Ahlins et al write in the 2015 CAGH Takes a Stand statement on e/mHealth:

The stakes are high especially for the final users and practitioners of e/m-health and telemedicine, as there is a strong commercial aspect to these technologically enhanced health practices; questions have also been raised about power distribution of various actors involved. At the same time, there is indication that e/m-health and telemedicine have a lot of potential to improve healthcare, especially for chronic patients, elderly and those living in remote areas... We suggest that anthropologists [can] add significantly to the understanding, assessment, and improvement of e/m-health interventions...Innovations such as e/m-health and telemedicine entail more than just the introduction of new technologies; they result in new relationships, expectations, and responsibilities.

This master's thesis represents an effort to bring a critical, praxis oriented approach to bear on an issue Nolan (2013) has called one of the world's most "wicked problems" -

the crisis in health care access and delivery that leads to preventable morbidity and mortality around the globe. In so doing, this project falls within an applied anthropological framework, an approach which Nolan argues is critical both to the future of anthropology as a discipline, and to solving the seemingly intractable problems facing society: "[t]he main task in the future of anthropology...is to succeed in bringing sociocultural data and perspectives into our efforts to address global problems. To do this, anthropology needs to be much more engaged with public life" (Nolan, 2013: p. 394). By turning an anthropological spotlight onto the question of how new health technologies impact the lives of people with chronic disease, I have attempted to engage Nolan's call for practicing anthropology as a means for bettering the lives of the people whom we study. To that end, I have presented my findings to key members of the clinical care and technology teams who carried out this project, and who are responsible for the ongoing care of patients like the participants in this study who face the daily struggles of living with chronic disease, often in isolation. It is my sincere hope that this work will be of some benefit to those individuals whose stories I had the great privilege of witnessing. To you, I dedicate this thesis.

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