ASSESSING THE PATIENT EXPERIENCE FROM ELECTRONIC HEALTH DATA

By

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Introduction

1.1 Preamble

For many patients with chronic diseases, navigating the complex medical system to receive care can be a daunting task. Patients often need to see multiple providers and undergo multiple procedures. These clinical encounters and procedures can be physically and mentally demanding. However, the challenges patients experience extend beyond the clinical encounters themselves. This dissertation will explore the elements of the care continuum from tasks performed at home to the clinical encounters and everywhere in between. Additionally, we will discuss data sources that allow patients, providers, and healthcare delivery organizations to describe and monitor the patient experience with the goal of improving care for patients.

The remainder of the introduction will review previous literature that diagnose, define outcomes for, and propose interventions to improve the patient experience. Each subsequent chapter will describe one or more element of the patient experience from electronic health data and suggest interventions that may help to improve care. Chapter 2 discusses the burden of commuting from breast cancer patients' homes to the medical center to receive treatment. In chapter 3, we will use a novel data source to describe patient travel within the medical center. Chapter 4 discusses the use of workflow tracking tools and a constraint satisfaction optimization problem to diagnose operational problems that lead to increased patient wait times. Finally, chapter 5 takes a high-level view of the patient experience by describing treatment burden for patients with breast cancer over the course of their diagnosis and for specific treatments.

1.2 Diagnosing the patient experience

While little work has been done to describe the continuum of care from electronic data sources from the patient perspective, several other health services research domains have sought to uncover problems with elements of the process of receiving care.

1.2.1 Patient work

Early efforts to describe the patient experience by Juliet Corbin and Anslem Strauss in the 1980s applied a theoretical framework rooted in sociology for studying patient activity called illness trajectory(1). An illness trajectory consists of the symptoms of the illness, the related work, the management of that work, and the impact of the work on relationships. Illness trajectories must be managed with respect to competing resources in a patient's life. Corbin and Strauss emphasized the difficulty reaching "relative equilibrium", where patients achieve balance between illness trajectory and their activities of everyday life, even while additional work is added as diseases progress. Furthermore, when a patient is unable to manage their illness trajectory and demands of everyday life, they may experience fatigue, overwork, overload, episodes of acute illness, resentment, and anger(1). Corbin and Strauss also discuss potential logistical and technological strategies for matching demands with resources in planning for clinical care.

1.2.2 Ergonomics

Another framework for understanding patients' activity is in the field of ergonomics. Ergonomics is the scientific study of fitting work conditions with to the capability of the worker, typically to improve safety(2). In the case of patients, human factors research attempts to understand the tasks patients must complete and their ability to complete those tasks given their personal attributes, environment, and available technology(3). There are three domains of ergonomics research for patients. Physical ergonomics involves studying tasks such as lifting a CPAP machine to take on vacation or tapping a small button on the screen of a mobile device. Cognitive ergonomics studies concepts such as how intuitive a menu screen is to navigate or how difficult it is for patients to remember to take their medications. Finally, macro ergonomics studies how relationships and coordination between family members and care teams form around the patient to maximize the likelihood that patients will execute their care plans(4).

1.2.3 Geographic access

In the field of epidemiology, geographic access to healthcare services addresses the patient experience of commuting for care at a population level. Several studies have used Geographic Information Systems (GIS) to measure distances patients travel to receive care and how that distance affects outcomes(5). For example, an Australian study found that patients who lived farther from mammography centers tended to have a lower rate of response to invitations for screening than patients who lived closer(6). Other studies have used GIS to discover links between the attributes of areas that patients lived and healthcare outcomes(7). One study identified Texas counties with specific racial makeups as having higher incidences of breast cancer mortality(8). Our work in chapter 2 will build on work done in the domain of using GIS to measure patient geographic access to care. Rather than describing access to services from a public health standpoint, chapter 2 will discuss the burden of commuting from a breast cancer patient perspective.

1.3.4 Wait times

Another dimension of the patient experience that has received considerable interest from the healthcare operations research community is patient wait times. Wait times in healthcare fall into two categories: indirect wait time, where patients must wait to schedule an appointment or procedure past their desired date; and direct wait time, where patients wait in the clinic for their appointment to start(9). Studies have shown a correlation between direct wait times and patient satisfaction assessed by quantitative patient surveys in chemotherapy(10), ophthalmology(11), and orthopedic(12) clinics. While it may seem like common sense that making patients wait will adversely affect their patient experience, wait times are not always the most significant factor in the patient experience. Patients were shown to value time spent with their physician more than direct wait time, even though both contributed significantly to patient satisfaction(13).

With indirect wait time, the delay to accessing care can become a patient safety problem. A study by the Department of Veterans Affairs showed that veterans with indirect wait times over a month had significantly higher odds for mortality than those who were seen within a month of their appointment request(14). This problem received major attention in 2014 when a scandal broke that veterans had died while on undisclosed waiting lists to receive care at the VA(15). Many factors contributed to this system breakdown that led to patient mortality and so a better understanding about this aspect of patient experience may help to address these problems in the future.

1.2.5 Burden of treatment

In an era where patients are increasingly responsible for managing their own healthcare, minimally disruptive medicine is a paradigm where providers ensure patients are able to adequately handle the care they are prescribed(16). Minimally disruptive medicine deals with the tension between two competing factors: A patient's capacity to handle the work of receiving care, and the burden of their illness and treatment (17)(18). Several patient attributes help to increase their capacity to receive care. Personal, physical, emotional, social, environmental, and financial resources make patients more capable of achieving compliance with their treatment plans(19). For example, patients who have more financial resources, have access to transportation, have flexible working hours, and who are literate will be more likely to handle more healthcare tasks(17).

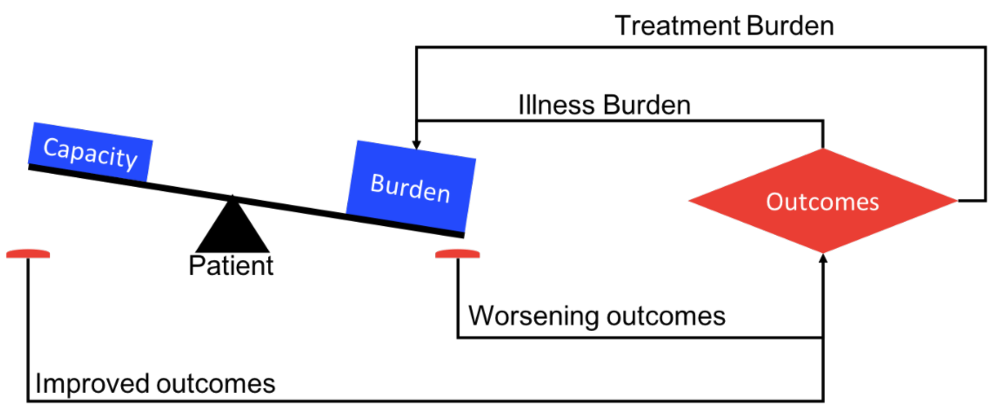


Figure 1.1. Illustration of minimally disruptive medicine

On the other hand, burden consists of the hardships imposed by illness and the work of receiving care for that illness(20). Burden of illness includes symptoms that reduce a patient's ability to function such as fatigue, physical disability, or cognitive impairment(21). Burden of illness is typically well studied in medical literature. However, burden of treatment is not typically tracked or well understood in the medical community(22). Figure 1.1 illustrates the model of minimally disruptive medicine. A patient's disease contributes both to the burden of the illness itself and treatment burden to counteract the disease. When burden exceeds a patient's capacity to handle care, they are overwhelmed, leading to worsening outcomes(23). However, if patients can handle their care (ie. when capacity exceeds burden), they can fully comply with their treatment plan leading to positive health outcomes(24). Improved and worsening outcomes subtract and add respectively from burden causing a feedback loop that leads to recovery or increased morbidity. Chapter 5 will further discuss the concept of treatment burden and describe methods to characterize it from electronic health records.

1.3 Outcomes in the patient experience

As with any surgical or medical advancements, interventions that address patient experience need to demonstrate measurable improvement in outcomes. While health-related outcomes are common to interventions in clinical and operational domains, some outcomes are addressed more specifically by patient experience interventions.

1.3.1 Health

There are many health-related outcomes that cover a wide range of dimensions in general health and disease specific domains. The International Consortium for Health Outcomes Measurement (ICHOM) is attempting to standardize measures for different conditions such as breast cancer(25) and stroke(26). Important hospital outcomes of interest to payers such as the Center for Medicare and Medicaid (CMS) are 30-day mortality and readmission rates(27). Specific to cancer, there are disease response and host response measures. Disease response measures include the Response Evaluation Criteria in Solid Tumors (RECIST)(28) and Minimal Residual Disease (MRD)(29) for hematological cancers. Host response measures include Overall Survival(30), the Common Terminology Criteria for Adverse Events (CTCAE)(31), and the

European Organization for Research and Treatment of Cancer Quality of Life Questionnaire(32). Each outcome captures a different dimension of the patient experience. Therefore, researchers need to evaluate a variety of measures in clinical trials and operational changes to get a full picture for an intervention's effect on health outcomes.

1.3.2 Adherence

Adherence to care plans is an intermediate outcome that has been shown to correlate with health outcomes(33)(34). In breast cancer patients undergoing adjuvant hormonal therapy, those who did not fill their prescriptions had significantly higher 10-year mortality compared to those who did fill hormone therapy medications(23). In the study of minimally disruptive medicine, patients whose treatment burden exceeds their capacity to manage care have a diminished ability to adhere to their care plans(24). Therefore, adherence can act as a useful surrogate for health outcomes when studying the effects of interventions that help to improve patient access or education.

1.3.3 Patient satisfaction

Patient satisfaction is another outcome of the patient experience that can be difficult to understand and interpret. CMS requires reporting for a variety of patient satisfaction measures through its Consumer Assessment of Healthcare Providers & Systems (CAHPS) program. For patients undergoing surgery, there was no significant relationship between patient satisfaction scores and outcomes in most cases(35). Additionally, a review of patient satisfaction studies reported that most studies found no relationship between satisfaction scores and measures of care quality(36). On the other hand, other patient experience measures such as perceived care coordination do have a strong relationship with patient satisfaction(37). Improved patient satisfaction scores can also lead to increased revenue for inpatient services(38). Patient satisfaction could be a useful measure for assessing interventions designed to improve the patient experience.

1.3.4 Financial toxicity

With the high cost of medical care, financial burden is an important part of the patient experience in the US. When the Treatment Burden Questionnaire, a survey to assess treatment burden in Europe, was adapted for use in the US, an additional question was added to address financial costs(39). In cancer research, this concept of financial burden is termed "financial toxicity", where financial distress from having to pay for cancer treatments can cause increased risk for mortality(40). Scores based on patient reported surveys have been developed to evaluate the extent of financial toxicity in cancer patients(41). While direct financial costs are one aspect of treatment burden, financial distress also contributes to capacity. For example, cancer patients without the financial capacity to afford a full course of oral chemotherapy could be non-adherent to their medication plan due to high co-pays(40). Additionally, patients who cannot afford their care may divert funds for other necessities and have to apply for government assistance such as food stamps and temporary disability(42).

1.4 Interventions to improve the patient experience

Process, technological, and payment model innovations all have the potential to affect the patient experience for the better. While most interventions in health services research are aimed toward decreasing cost in treatment delivery, these interventions should also be evaluated for how they influence the patient experience.

1.4.1 Healthcare delivery optimization

One area of interest for solving these problems in healthcare is scheduling optimization for outpatient appointments and procedures(9). Studies have used mathematical programming models to optimize for desired outcomes such as utilization, throughput, and patient wait times(43). Other studies have used stochastic models such as discrete event simulations to describe complex clinical processes(44). These studies tune resource constraints such as staffing, equipment, or rooms to improve simulated outcomes(45). In healthcare, these methods are typically applied to busy and high value areas of the system such as chemotherapy infusion center scheduling (46), operating room scheduling (47), radiation therapy scheduling (48), and forecasting emergency department capacity (49).

Some companies have also gone into the business of using mathematical models to produce scheduling templates that improve resource utilization, decrease patient wait time, and improve staff satisfaction. One example of such a product is iQueue from LeanTaaS for infusion centers. Due to the variability in infusion durations, assigning patients to appointment times, chairs, and staff can be a complicated task. LeanTaas uses constraint based optimization to form schedules in infusion clinics that smooth out utilization over the course of a given day(50).

While much work has gone into applying operations research methods to healthcare processes, outcomes for these interventions has been mixed. Since the input variables such as staff productivity, physical space, and time constraints for these models are often specific to a given clinic or organization, it is often difficult for these models to generalize without local customization(51). Therefore, we discuss in chapter 5 a generalizable method for diagnosing problems in clinic workflow using a constraint optimization method that makes no assumptions about clinic specific variables.

1.4.2 Telecare

As a way of improving the patient experience by reducing patient commutes, some healthcare organizations have started to provide home care and telecare, where patients see their provider at the patients' home or over video conferencing respectively. A controlled study of a dermatology practice, where dermatologists saw patients both in the clinic and via telemedicine, demonstrated that 31% of appointments could have been conducted via telemedicine only(52). In another study, the Los Angeles Health Department implemented a tele-retinal program that eliminated the need for 14,000 specialist appointments in two years, while increasing screening rates by 16.3% and decreasing wait times for screening by 89.2%(53). Both cases show that telemedicine encounters could appropriately manage care for patients while decreasing the work patients put into commuting for care and increasing access.

1.4.3 Value-Based Care

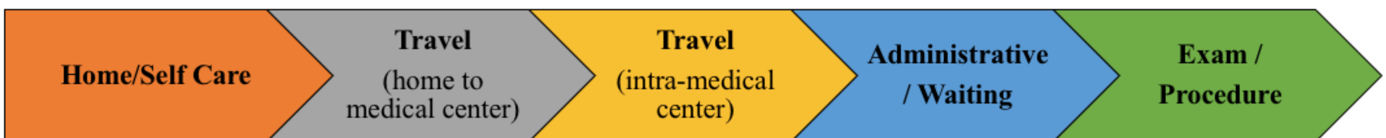
One area of healthcare delivery reform that is designed to improve both the quality of care and the patient experience is value-based medicine payment models. In a value-based payment model such as with bundled payments, a provider is paid once for a package of services or for providing care to a patient for a defined time period(54). This model contrasts with the predominant payment model of the day called fee-for-service (FFS). With FFS, providers are incentivized to perform as many reimbursable procedures as possible to maximize revenue. With bundled payments, providers are incentivized to perform only the necessary interventions that will achieve the desired outcomes, since the provider can keep any unspent money under the bundled payment amount. This would also decrease the number of visits to healthcare facilities for patients while also achieving favorable outcomes for patients(55). CMS is already experimenting with bundled payment models for various diseases with healthcare organizations across the country(56).

Another idea promoted by value-based care are Integrated Practice Units (IPU)(57). IPUs are teams of co-located providers that offer all necessary services for a certain condition. For example, an IPU for breast cancer could include surgery, chemotherapy, laboratory, imaging, and radiotherapy services with associated facilities and staff. The benefit of having an IPU is that it enables tight coordination among staff who specialize in one condition, allowing them to address all of a patient's needs in one visit. The implementation of IPUs could improve the patient experience by decreasing the effort needed to coordinate scheduling and travel to multiple providers.

1.5 Using data to understand the patient experience

The central hypothesis of this dissertation is that electronic data that are already being collected in healthcare operations is useful for characterizing and optimizing elements of the patient experience to improve key outcomes. As discussed previously, most methods of assessing the patient experience are currently done through surveys. While surveys are an effective means of ascertaining ground truth for how patients feel about receiving care, they are limited to the patients who are willing to take the time to complete them. Additionally, it can be expensive and time consuming to obtain consent and administer surveys to a large number of patients in a study of patient experience.

Patients are increasingly surrounded by systems that are collecting data about them. That data can come from clinical information systems that are designed to maintain information about patients' health status or from non-clinical sources such as social media(58) that can reveal patients' attitudes about their experience. Even data from mobile devices such a GPS tracking application can provide insight into patients' exposure to health risk factors such as how many times they went to a fast food restaurant. Therefore, we propose that analyzing data from a variety of clinical and non-clinical systems related to the patient experience is essential for improving the delivery and coordination of care. This analysis can lead to insight that can decrease cost and provide value to patients who may be overburdened by healthcare tasks.



Clinical information systems	Online mapping services	Mobile wayfinding	Real-time location systems	Clinical information systems

Figure 1.2. Elements of the patient experience with data sources that could portray them.

Figure 1.2 shows the various dimensions of the patient experience as well as electronic data sources that could be used to characterize them. The continuum of the patient experience includes the care patients must administer to themselves away from the medical center. Home care includes tasks such as self-monitoring blood pressure, remembering to take medications, or eating a healthy diet. A large portion of the patient experience also takes place between a patient's home and a medical encounter. This part of their experience includes travel by personal vehicle or public transportation to the medical center, and the work of navigating within the medical center. Once patients arrive at their respective clinic or procedure area, they must complete administrative tasks such as checking in to their appointment, waiting for their appointment to begin, and filling out health questionnaires and insurance information. All of these tasks occur must occur before patients undergo their procedure or exam.

In this dissertation, each chapter is an independent manuscript that will address a different dimension of the patient experience and demonstrate how to use data to characterize and improve the patient experience. Chapter 2 uses a combination of cancer registry data, scheduling data, and an online mapping service to describe patient travel. Chapter 3 uses wayfinding requests from a mobile application to describe travel within the medical center. Chapter 4 uses workflow management tools to describe and diagnose problems with clinic workflow that lead to long patient wait times and service times. Finally, chapter 5 uses outpatient scheduling, admissions, and prescribing data to capture treatment burden related to home care, travel, wait times, and clinical events related patient care experience over time.

Chapter 2

Determining Burden of Commuting for Treatment Using Online Mapping Services – A Study of Breast Cancer Patients

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2.1 Introduction

Traveling to and from a medical center for treatment is a significant burden to many patients with chronic conditions. In 2014, The Center for Disease Control and Prevention showed that 67% of adults in the United States had at least one encounter with the healthcare system within 6 months of the survey(59). The percentage of patients who saw a healthcare provider increases for patients with chronic conditions. In 2013, 99% of patients with hypertension had an office-based physician visit and 47% had four or more visits(60). Similarly, 55% of patients with diabetes visited a physician four or more times in a year(61). Elderly patients, who often have difficulty traveling for care(62), had to travel more frequently than the average patient(59).

In addition to the sheer number of times patients must travel to medical centers for care, patients also perceive commuting as a burden. In a survey of 1053 patients regarding factors that contributed to their treatment burden, 41% expressed that they had difficulty adapting to new routines for care that involved planning and organizing travel(63). Additionally, 30% of patients surveyed indicated they had difficulty with access to health care centers citing distance and parking as barriers to receiving care. Interest in treatment burden goes beyond just providing convenient care for patients. Patients who receive care within their means and are not overburdened tend to be more compliant with their treatment plans(16) which could lead to better outcomes.

Breast cancer patients experience a high level of treatment burden. Treatment burden is the collection of healthcare related tasks that patients must complete as a result of their illness. In our prior work, we demonstrated that stage I-III breast cancer patients receiving care at Vanderbilt underwent an average of 59 appointments over the course of 18 months after their diagnosis(64). During this time, these patients had to travel to the medical center an average of 39 times and spent approximately 49 hours in clinic. Stage III patients experienced the most time in clinic, followed by stage II and stage I patients. One reason for the intensity of treatment burden in breast cancer patients is the complexity of their treatment. Encounters included radiology diagnostics, laboratory tests, surgery, radiation therapy, and chemotherapy. Furthermore, many patients experienced additional treatment burden due to complications to their care that led to hospitalizations or the need for physical therapy.

Travel contributes to the burden of treatment through transportation costs, especially for cancer patients. An Australian study showed that the median cancer patient spent 956 Australian dollars (about 727 US dollars) in travel costs over 16 months after diagnosis, which accounted for 71% of all out-of-pocket costs(65). Distance traveled could also affect patient treatment choices. One study determined that driving distance from a radiotherapy facility resulted in more patients with breast cancer choosing mastectomy instead of breast conserving surgery(66). While our previous study looked at burden of treatment due to time spent in inpatient and outpatient encounters, we did not factor in the work patients put into traveling to the medical center for those encounters. The goal of this study was to use web services to calculate commuting burden over the course of treatment for patients with breast cancer.

In addition to the duration of the commute to the medical center, the mode of transportation could also be a factor that healthcare providers should consider. Researchers demonstrated United States counties(67) and English districts(68) where more households had access to a car had a higher rate of screening for cervical cancer. Conversely, breast cancer screening was lower in English districts with higher public transportation usage. While public transportation may be less convenient for patients receiving care for cancer, it may be some patients' only option. While we assume that most patients who receive care at Vanderbilt arrive by car, we will explore the possibility of commuting by public transportation for our population of breast cancer patients.

Healthcare researchers have used mapping web services to improve the delivery of care. One group from the Netherlands used Google Maps to calculate the difference between driving time and helicopter flight time to help paramedics decide the most effective way to transport patients to the hospital(69). Services such as Google Maps are excellent at keeping up with changing traffic patterns and new roads that may affect commute times both for driving and public transportation. However, one challenge with using online services in healthcare delivery and research is that sending patient addresses to companies without a Business Associate Agreement (BAA) is a violation of the Health Information Portability and Accountability Act (HIPAA) privacy rules(70). Additionally, the American Journal of Public Health released an editorial stating that sending patient addresses to a third party is inappropriate and that some method of geographic imputation should be used to protect patient privacy(71). In our calculations of work due to travel burden, we propose a method of geographic imputation using zip codes, census blocks, and bus stops as landmarks to protect personally identifiable information (PII).

2.2 Methods

The Landmarks Method for Address Anonymization

Our method for anonymizing patient addresses is similar to aggregation techniques in public health to anonymize locations(72). Instead of calculating commute time from patients' street address, we calculated the commute time from the coordinates of the nearest publicly available landmark. We used three sets of landmarks for our analysis. First, we obtained all zip codes and census tract centroid coordinates publicly available on the US Census Bureau website(73). Nashville Metropolitan Transit Authority granted us access to their application program interface where we could pull the list of bus stops and their coordinates. We queried Google Maps (Gmaps) for driving times from every landmark to the Vanderbilt University Medical Center (VUMC) and back. Next, we used the Data Science Toolkit (DSTK) geocoder (74) to determine the latitude-longitude coordinates for each of our patient addresses. The DSTK also returns a confidence level for how sure it is that the address is geocoded correctly. We installed the DSTK on a virtual machine that ran on a local VUMC computer, thus eliminating the need to send patient addresses to a third party.

Validating the Landmarks Method

To test this method, and to compare the accuracy of the various landmark sets (zip code, census tract, and bus stops), we applied the procedure to a set of homes for sale in the Nashville area. We queried 500 random and publicly available addresses from the Redfin.com real estate listing website on January 30, 2017. We queried Gmaps for driving times for each of the 500 real estate addresses and compared those to the driving times of each addresses' respective closest landmark. Using the driving time from the true street address as the gold standard, we calculated the root mean square error for each of the landmark sets to determine which estimated true driving times the best.

Applying the Landmarks Method to Breast Cancer Patient Commutes

After testing the method on the 500 real estate addresses, we applied the landmark set with the lowest root mean squared error on a cohort of breast cancer patients obtained from the VUMC Tumor Registry. We included patients with stage I-III breast cancer diagnosed from January 1, 1998 to June 1, 2014. To capture only patients who received most of their first course of treatment at VUMC, we only included patients who had at least three appointments each with a medical oncologist and oncology surgeon. Most patients actively undergoing treatment for breast cancer will see their medical oncologist and oncology surgeon at least twice per year. We compared commute times for patients who lived within 100 miles of the main medical campus. For patients living far away from the medical center it is unclear whether or not they commute from home each day or obtain lodging closer to the medical center. Therefore, limiting our patient cohort to those living within a 100-mile radius allows us to include only those who reasonably could drive to the medical center for every appointment. Patient commute time for any given appointment day was the time it took to drive a round trip from the landmark closest to their home address to the VUMC facility where their appointment was held. To get a characterization of the total burden of traveling, we calculated the total amount of time patients would have to spend traveling to the medical center by car over 18 months after their date of diagnosis.

We also compared the behavior of commuting in patients that were farther than the median distance from the medical center with those which were closer than the median distance. We compared the frequency that patients received radiation therapy at a VUMC facility between patients who were closer and those who were farther. With the coordinates of bus stops in Nashville, we analyzed the number of patients that could have feasibly traveled to their appointments via public transportation. Finally, using average commute times, we estimated the cost of commuting per patient. Assuming an average speed of driving in Nashville of 32.4 miles per hour obtained from Google traffic data(75), and a cost of operating a vehicle of 54 cents per mile in 2016, we extrapolated the average total cost of commuting by vehicle per patient. A more accurate method would have been to use direct driving distance based on the Gmaps recommended route. However, due to Gmaps query constraints, we inferred the driving distance using average driving speed. The cost per mile comes from the Internal Revenue Service, which sets mileage rates for the cost of operating a passenger vehicle for charitable and medical purposes(76).

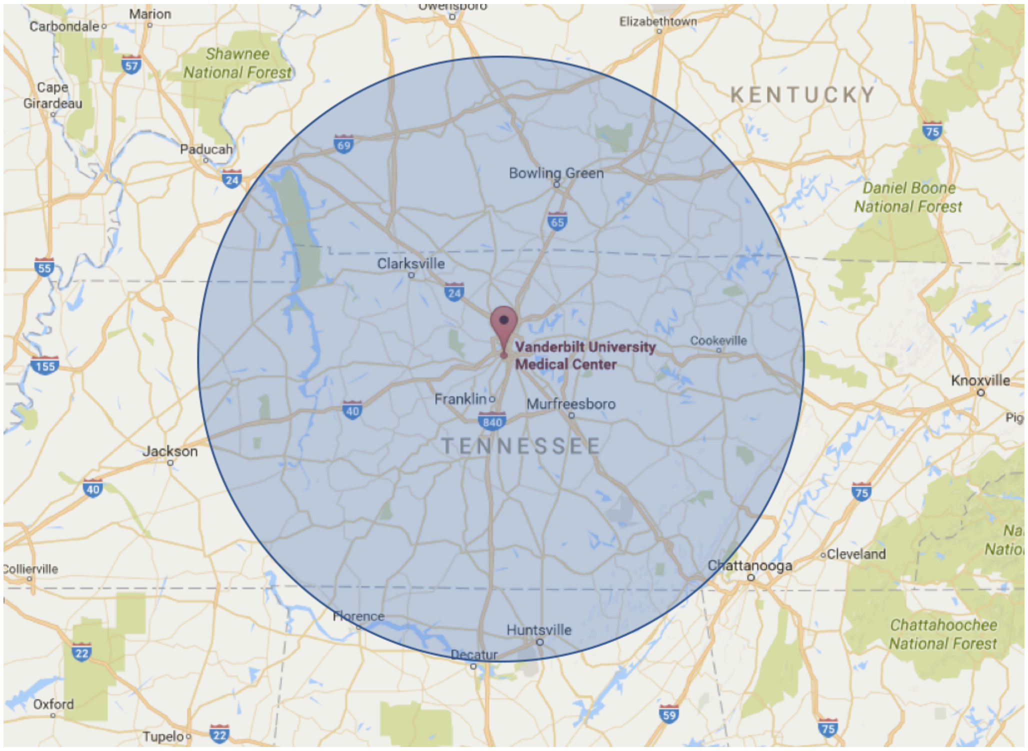


Figure 2.1. Patient addresses from the VUMC Tumor Registry within 100 miles of VUMC were included in driving time calculations.

2.3 Results

Among the 500 random real estate addresses obtained from Redfin.com, the DSTK geocoder found 495 latitude-longitude coordinates compared to the Gmaps geocoder which found 483. There was generally good agreement between the coordinates found by DSTK and those found by Gmaps. Among the 425 addresses that were found by both the DSTK and Gmaps, 418 had less than a quarter mile straight-line difference between the DSTK and Gmaps coordinates. To exclude addresses that had major disagreement between DSTK and Gmaps, we only verified landmark driving times for addresses where the DSTK geocoder had at least 80% confidence. DSTK geocoded 427 addresses with at least 80% confidence.

For the addresses found by the DSTK with greater than 80% confidence, we compared driving time to VUMC using the true address and the nearest landmark. Figure 2.2 shows the difference in round trip driving time as calculated by Gmaps using the true address versus using the zip code centroid, census tract centroid, and nearest bus stop coordinates. Using zip codes in place of true addresses tended to overestimate driving time when the true address was close to VUMC and tended to underestimate driving time when the address was farther away. Zip code landmarks also yielded the greatest root mean squared error. The difference in estimation time was greater than 20 minutes in some circumstances. With census tracts and bus stops, the difference in times compared to the true addresses was generally less than 10 minutes. Differences between bus stop and true address driving times increased as the distance from VUMC increased. Using census tracts as land marks yielded the lowest root mean squared error.

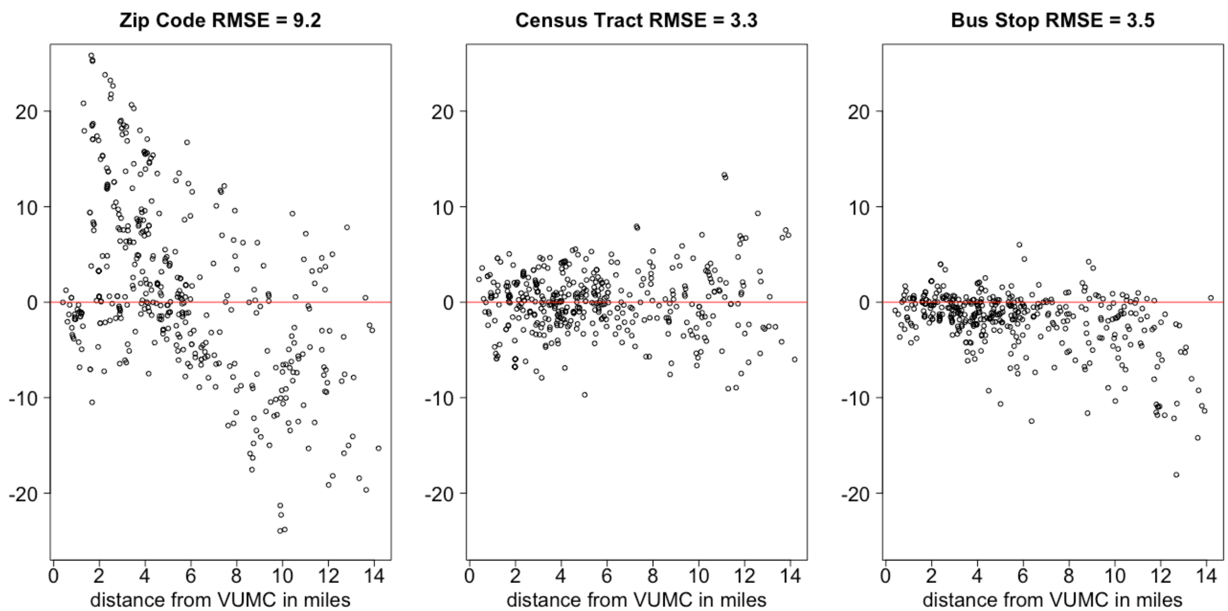


Figure 2.2. Differences in round trip driving time to VUMC between real estate addresses and nearest zip codes, census tracts, and bus stops and associated root mean squared error (RMSE) for each set of landmarks.

Because it had the lowest RMSE, we used the nearest census track centroid to calculate driving times for our study of commuting burden in breast cancer patients. The census tract method was also more robust for addresses far from VUMC than the bus stop method. We used zip codes for patient addresses where the geocoder had less than 80% confidence. There were 768 patient addresses within 100 miles of the main VUMC campus. Among those, we used the nearest census tract to calculate commute time for 644 patients and used zip code for 124 patients.

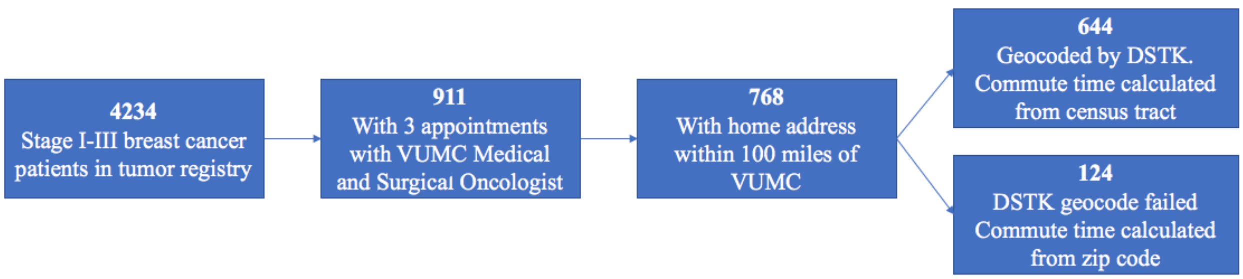
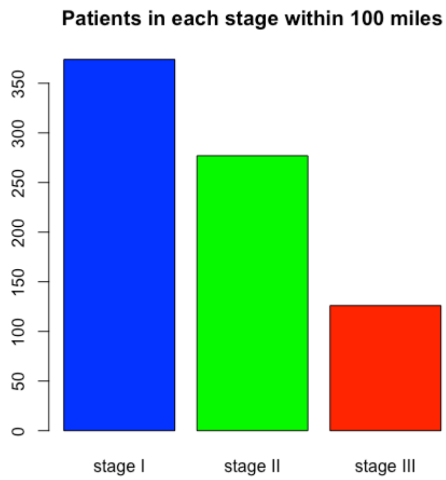
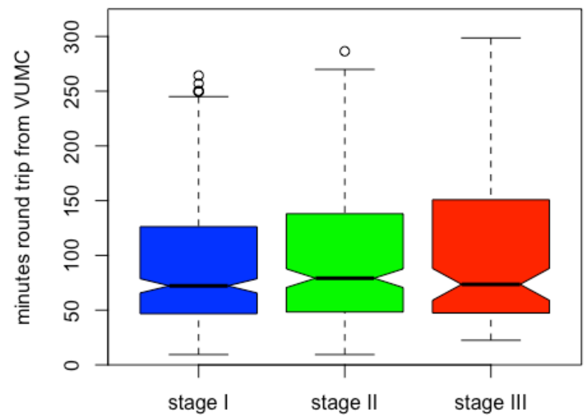


Figure 2.3. Cohort selection

The distribution of patients within 100 miles by stage was similar to the overall distribution for all stage I-III patients. There were 374 stage I patients, 273 stage II patients, and 121 stage III patients within 100 miles of the main VUMC campus. Among these patients, there was not much differentiation between stages in the distribution of a single round trip driving time from VUMC. The median driving time to and from VUMC across all stages was 76 minutes and the median straight-line distance from VUMC was 20 miles.





Figures 2.4 and 2.5. Number of patients per stage included in analysis and distribution of round trip driving times from patient addresses to main VUMC campus.

Figure 2.6 shows that overall burden, consisting of the sum of time in appointments, waiting time between appointments, and driving time, decreased for patients of all stages over the course of 18 months after diagnosis. Stage I and II patients saw peaks in overall burden in the first and fourth months. Overall time spent on encounters reached about 14 hours per month for stage I patients and 15 hours for stage II patients. Stage III patients had more sustained burden through the first eight months of treatment with a peak of seven hours of commute time in month eight.

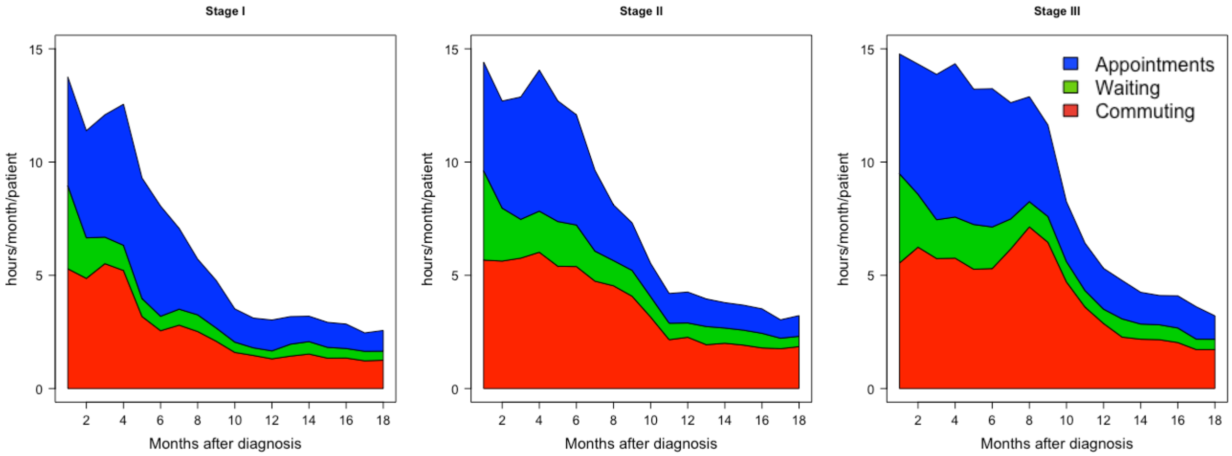


Figure 2.6a. Hours spent in appointments, waiting, and commuting over 18 months after diagnosis by breast cancer stage.

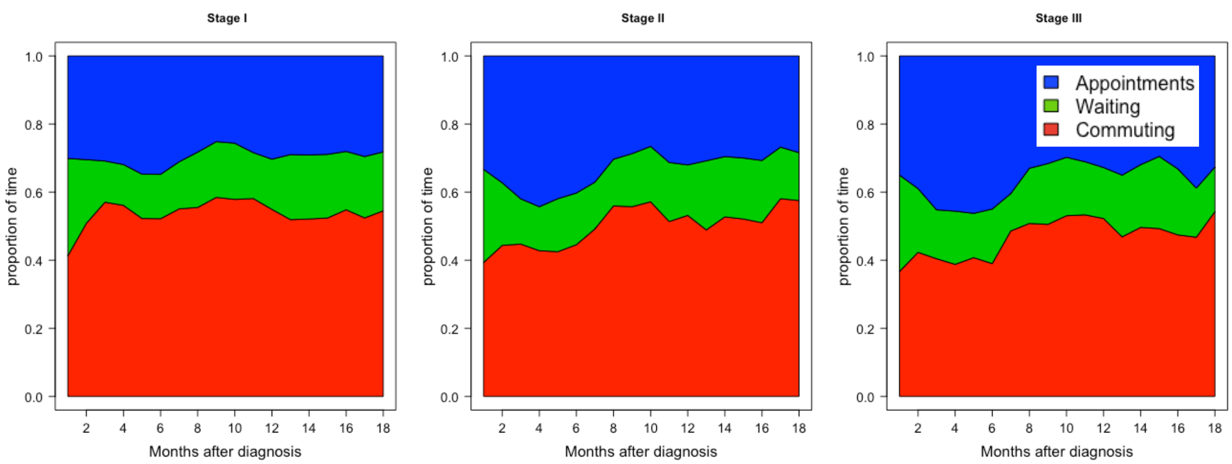


Figure 2.6b. Proportion of time spent in appointments, waiting, and commuting over 18 months after diagnosis by breast cancer stage.

In Figure 2.7, there is clear differentiation in the number of unique appointment days over 18 months between patients who lived closer and farther than the median distance from VUMC. Patients who lived farther made fewer trips to a VUMC facility compared to their closer counterparts in all three stages. Figure 2.8 shows that patients farther away also had more appointments per trip to a VUMC facility across all stages.

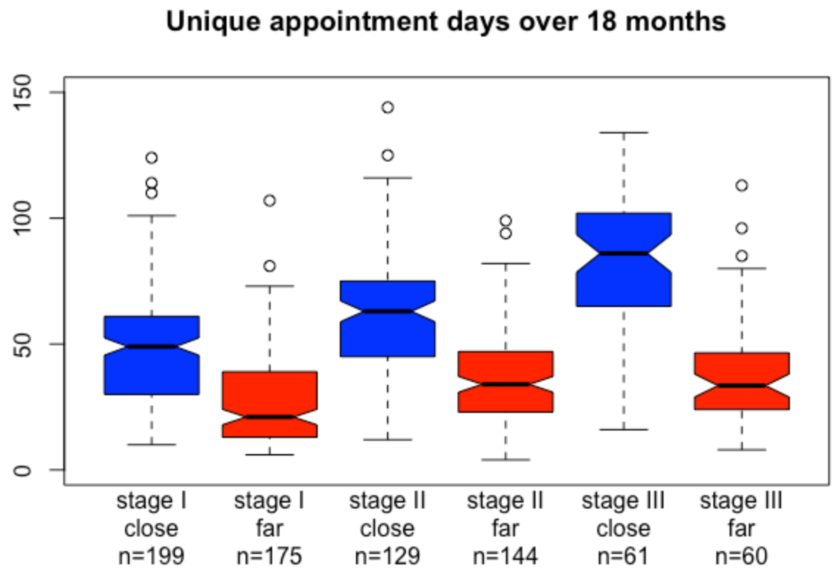


Figure 2.7. Distribution of unique appointment days over 18 months for patients closer (within 20 miles) and farther (greater than 20 but less than 100 miles) from VUMC by stage.

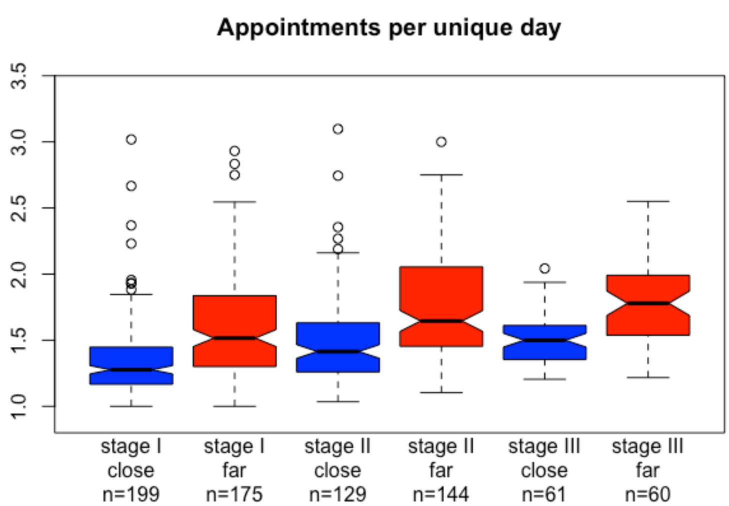


Figure 2.8. Distribution of mean number of appointment per unique appointment day per patient by stage and distance from VUMC.

The percentage of patients who received radiation therapy at VUMC could be indicative of how commute time affected where patients decided to receive care. Table 2.1 shows the percentage of patients who received radiotherapy at a VUMC facility compared to all patients in that group. Assuming patients within each stage required radiation therapy at approximately the same rate, stage I and stage II patients who lived closer to VUMC received radiation therapy at VUMC at a rate about three times higher than those who lived farther away. Stage III patients close to VUMC received radiation therapy at VUMC at a rate five times higher.

Table 2.1. Percentage of patients who received radiotherapy at a VUMC facility by stage and distance from VUMC.

	Close (within 20 miles)	**Far** (>20 and <100 miles)
Stage I	46%	17%
Stage II	44%	14%
Stage III	78%	15%

For our cohort of patients, 97.5% of appointments take place at facilities accessible by public transportation according to the GMaps. However, Table 2.2 shows how many patients could access public transportation at various walking tolerances, and the percentage of accessible appointments accounted for by those patients.

Table 2.2. Number of patients within walking distance of a bus stop at various walking tolerances.

Patient address distance from bus stop	**Patients**	**% of all appointments accessible**
100 yards	25	4.52%
200 yards	49	8.26%
.25 miles	124	20.2%
.5 miles	171	27.4%
1 mile	223	36.2%
2 miles	263	42.2%

Finally, we performed a cost analysis based on our calculated driving times. As expected, patients closer and with lower stage had less estimated cost of commuting by motor vehicle.

Table 2.3. Estimated cost of vehicle expenses per patient over 18 months after diagnosis by stage and distance from VUMC. **Mean** (range).

	Close (within 20 miles)	**Far** (>20 and <100 miles)
Stage I	**$609** ($51.06 - $954.76)	**$1047** ($238.02 - $3187.27)
Stage II	**$824** ($77.25 - $3125.06)	**$1455** ($198.29 - $4958.17)
Stage III	**$1050** ($198.29 - $4958.17)	**$1625** ($294.48 - $4779.91)

2.4 Discussion

Privacy considerations

Through our attempt to calculate the burden of treatment related to commuting for patients with breast cancer, we succeeded in developing a method for calculating driving times using online mapping services that did not compromise patient PII. When deciding what type of landmark to use in our method, we decided to use a mixture of census block and zip code centroids instead of bus stop coordinates. While Figure 2.2 shows that bus stops are somewhat more accurate than census blocks for the real estate addresses, the accuracy gets worse the farther the address is from the city center. This effect may be because bus stops fall along major roads which become farther apart in suburban and rural areas. Additionally, since not all cities have a public transportation system, using census tracts and zip codes makes our method more generalizable.

Geomasking methods such as random perturbation or donut masking attempt to hide patient addresses by randomly moving the patient address in a radius around the true address(72). These methods of protecting PII have the potential to be more accurate than our landmarks method since the size of the radius is dependent on the population density around the patient's location. We did not consider using one of these methods since they each require the researcher to define a level of k-anonymity, which is the minimum number of people from which any research subject could be re-identified from(77). It is difficult to define such a k-anonymity level that would be necessary to protect patients from an internet service. However unlikely, Google could easily target cancer treatment relevant advertisements to hundreds of people for the 1/k chance that the cancer patient in the area would receive the advertisement. Additionally, geomasking may be more useful in public health studies where spatial precision is necessary to identify sources of outbreaks(78), but is less essential for calculating estimated driving times. As demonstrated from the comparison of commute times between true real estate addresses and census blocks, there is only a small effect on the overall commute time.

Limitations

One major constraint in using online mapping services such as Google Maps for calculating driving distances is that there is a limit on the number of free requests per user. In early 2017 when we performed this study, Google Maps allowed users to make 2,500 free requests per day, with requests over that quota costing $0.50 per 1000 queries(79). In order to maintain full de-identification for PII, we had to request driving times from every census tract and zip code centroid to every VUMC location. The constraint of request quotas limited the scope of this project in several ways. Including only patients within 100 miles of VUMC is reasonable since patients who live farther away may not commute daily from home. However, anecdotally, we have seen that patients who live as far as 200 miles away are driving from their homes to VUMC for care. Our method included the 829 census tracts within 100 miles of VUMC, which could be queried for one VUMC location in one day. This number jumps to 3639 census tracts within 200 miles which would require three days of free queries per VUMC location (driving times to and from a location count as two requests). As we build a database of driving times, future work will include patient addresses that are farther away.

Another interesting question that we could answer with more Google Maps queries is the effect of traffic on patient commute times. One of the reasons we chose not to use open source projects such as the Open Source Routing Machine (OSRM) is because they do not have the means to collect live traffic information. Geographic Information System (GIS) software such as ArcGIS has a live traffic feed available, but only through a paid subscription. One powerful feature of modern web mapping applications is that they track typical traffic patterns to provide driving time predictions that factor in road congestion. However, ten of the census tracts within 100 miles of VUMC had fewer than 20 people living in them according to the 2010 census. The presence of low population census tracts means we would have to query every census tract for every appointment time in order to achieve full anonymity, which would become expensive to do with Google Maps. Future work could gradually save hourly driving times with traffic data to get an idea for how much traffic affects the work patients put into their care. Alternatively, we may establish a BAA with Google or another company that provides live driving time predictions.

Interpretation of results

Despite the limitations, we made several observations about the effect of commute time on cancer treatment. Aside from confirming that stage III patients experienced a higher treatment burden than stage II and stage I patients, we observed in Figure 2.6 that the pattern in commute time over months after diagnosis was different for stage III patients. Stage III patients experienced increased commute times in months six through eight after diagnosis despite a decrease in appointment time during that period. This increased commute time, coupled with the decrease in appointment and waiting time, may be associated with the observation that many stage III patients underwent radiation therapy after surgery. Radiation therapy procedures are typically 15-minute appointments that occur daily in rapid succession. The fact that these encounters are short but still require patients to travel to the medical center could explain the increase in commute time relative to appointment time.

Table 2.1 showed that patients farther from VUMC received radiation therapy less often at VUMC than their counterparts that lived closer. The rate that patients received radiation therapy may be high overall due to our cohort already being biased toward patients who received a majority of their care at VUMC with the constraint that all patients have at least three appointments with a medical oncologist and oncology surgeon. If we assume that patients of a given stage of breast cancer require radiation therapy at approximately the same rate, then we can conclude that more patients who live farther from VUMC are getting radiation therapy at other institutions. This finding supports the conclusion of Goyal et. al. that driving distance to a radiation therapy center influences breast cancer patients' treatment path decisions(66). This type of information would be useful to healthcare organizations that are considering opening new radiation therapy clinics. If a new clinic knew that patients are three to five times more likely to choose to receive radiation therapy at VUMC with a more convenient location, the clinic could plan capacity to meet that demand.

In discussing patient experience for commuting, one important consideration is determining patient capacity to handle a long trip to the doctor. In cities such as Nashville where a typical commute to work was more than 30 minutes in 2014(80), medical centers may be able to expect patients travel farther for care. However, in a city where traffic is less onerous, patients may be more sensitive to commuting long distances to a medical center regularly. Nevertheless, our calculated round trip to VUMC for the median patient was 76 minutes. This result means that even without traffic, the median patient within 100 miles of VUMC would have to drive longer than the average work commuter during rush hour.

Figures 2.7 and 2.8 have implications for care coordination in patients with cancer. The fact that patients within each stage who were farther from VUMC had fewer unique appointment days and more days per appointment suggest that some effort is being made to coordinate appointments to occur on the same day for patients who live farther away. While it may be hard to determine whether the patient or medical center staff is putting in the coordination effort, being able to track outpatient appointment coordination allows organizations to identify areas for improvement. It might be prudent for patient care coordinators or navigators to examine upward outliers in Figure 2.8 to see what strategies are working for patients who average more than three appointments per visit.

There are several assumptions we made in in our study. First, we assumed that patient addresses in the tumor registry were accurate at the time of their diagnosis, and that patients did not move during the first 18 months of treatment. We also assumed that patients traveled from their home address each unique appointment day. It is possible that patients stayed in hotels or with relatives during the more intense parts of their treatment, which would cut down on burden related to commuting. It is also possible that the patient traveled to VUMC from their work address. There were some locations listed in the appointment record that were not primary VUMC locations and thus, we did not have driving time data for them. These appointments were excluded from our analysis. Only one patient had more than 7 appointments at a non-VUMC listed location. That patient still received 89% of their appointments at a VUMC facility and so the influence of this outlier should negligible.

With regards to public transportation in patient commuting, the main takeaway from Table 2.2 is that only a small proportion of VUMC's breast cancer population would be able to take advantage of public transportation. Even if patients were willing to walk two miles to their nearest bus stop, only 263 patients would have access to public transportation. Future work might consider what is the maximum reasonable distance to expect patients with different conditions such as cancer to walk before and after their appointments. Additionally, it would be interesting to see whether there is improved access to healthcare facilities via public transportation in more densely populated cities.

Applications of method

Healthcare organizations could also use this method to predict patient commute times on the day of patients' appointment. These predictions can be used to warn patients who may need to leave their homes earlier in order to avoid traffic, or to anticipate which patients may be late due to abnormal traffic conditions. Informaticians can also use calculations of commuting burden to develop tools that benefit patients. Providing patients with a mobile application to automatically calculate travel time to appointments would require consent to track their locations. However, such an application could help to alert patients of when they should leave their homes to arrive at their appointments on time. With real-time traffic conditions integrated with the appointment record, an online navigation service could recommend a driving route that avoids traffic and minimizes commuting burden.

Finally, being able to track work related to driving could also allow organizations to identify patients who may be overburdened. For example, patients who are high outliers for overall burden from appointments and procedures may benefit from a home visit from a nurse in lieu of outpatient appointment. In addition to the time requirements of cancer care, financial costs for cancer patients may lead to extreme financial distress and worse outcomes, a phenomenon known as financial toxicity(40). Foundations such as Susan G. Komen provide support to breast cancer patients who have difficulty affording their care(81). One of the programs provides financial relief to qualified breast cancer patients by giving them gas card vouchers. A healthcare organization could use information from Table 3 to request a grant from the Komen Foundation for patients under their care based on stage of cancer and travel distance.

2.5 Conclusions

We developed a method to calculate approximate driving times from patient addresses to VUMC locations using a third party online mapping service without sending PII to that third party. This method is generalizable to other healthcare organizations who have patient address data and access to Google Maps. We used this method to determine the burden of treatment related to commuting for patients with breast cancer receiving care at VUMC. We found that radiation therapy made a significant impact on commuting burden due to the frequency of treatment. Also, patient's living farther from VUMC tended to receive radiation therapy at other medical facilities compared to those living closer to VUMC. We discovered that patients farther from VUMC had more appointments per unique appointment day, showing that their care was better coordinated. Future applications for travel time computation could equip organizations to better address the needs of their patients and help patients reduce the disruption of treatment on their lives.

Chapter 3

Using Wayfinding Data to Understand Patient Travel Within a Medical Center

3.1 Introduction

Navigating through the complex environment of a large medical center poses challenges to many patients(82). To ease navigation, medical centers strive to design their facilities to simplify patient access to clinics, inpatient units, and procedure rooms(83). Nevertheless, the task of figuring out how to get to a destination (also known as wayfinding), remains a source of anxiety for patients who visit medical centers (84). Despite the best efforts in initial wayfinding design, buildings often evolve and change over time with construction projects, leading to less than intuitive layouts. Traveling throughout the medical center is a particular burden on patients with disabilities or other medical conditions that impair their ability to walk(85). For certain patient populations, such as surgery or spine patients, accessibility of treatment areas from parking has been associated with patient satisfaction and perceived quality of care(86). Finally, inefficient patient travel within the medical center can have an effect on hospital costs. One study at a 604 bed hospital showed that lost patients cost the organization $220,000 a year in labor costs from staff helping patients get to the correct location for care(87).

Medical centers do not currently have an effective means to measure the distances that patients travel throughout the building, or to determine which areas patients frequently travel between. Some studies have used real-time locator systems to track patients in healthcare settings such as intensive care units, long term care, and the emergency department(88). While these technologies are effective in promoting patient safety, increasing efficiency, and capturing important operational metrics such as wait times, they are limited to describing patient movement after they have presented at the respective unit for care. Much of the patient experience in the medical center occurs away from the clinics, inpatient units, and procedure rooms. Patient experience has also been extensively studied in home settings(89,90), and in commuting to the medical center through research about access(7,91). Our work seeks to fill in the gap in understanding the patient experience between when patients arrive at the medical center, and when they check-in for care. Using traditional real-time locator systems to track patients as soon as they enter the medical center would be expensive and administratively cumbersome. Therefore, we propose that data from a mobile application that patients use to get walking directions to their desired destination in the medical center can provide insight into the patient experience within the medical center without additional data collection.

Other industries are already using mobile data to improve operations and the customer experience. Restaurants such as McDonalds, retailers such as Target(92), and several airports(93) are all using indoor positioning data to inform customers about check-out wait times or recommend purchase based on their proximity to certain products. Therefore, opportunities abound for the healthcare system to use mobile application data to understand and enhance the patient experience.

Healthcare systems can use wayfinding data to infer relationships between different areas in the medical center. For example, if patients frequently request directions from an oncology clinic to an infusion clinic, organizations could reasonably conclude that those two areas are associated for patient care. There is increasing interest in recent years to use network analysis of existing electronic data to make inferences about care coordination, collaboration, and social influence in the health domain(94). One study used the number of shared patients to form a network that reveals the connectedness of oncology specialists(95). While many of these studies use data sources such as electronic health records, clinical communications, and access logs to deduce associations between entities, less work has been done using wayfinding request data. The advantage of using wayfinding requests to infer information about patient movement is that it allows healthcare organizations to capture aspects of the patient experience beyond just clinical encounters. These elements of the patient experience include use of parking, restrooms, and eateries.

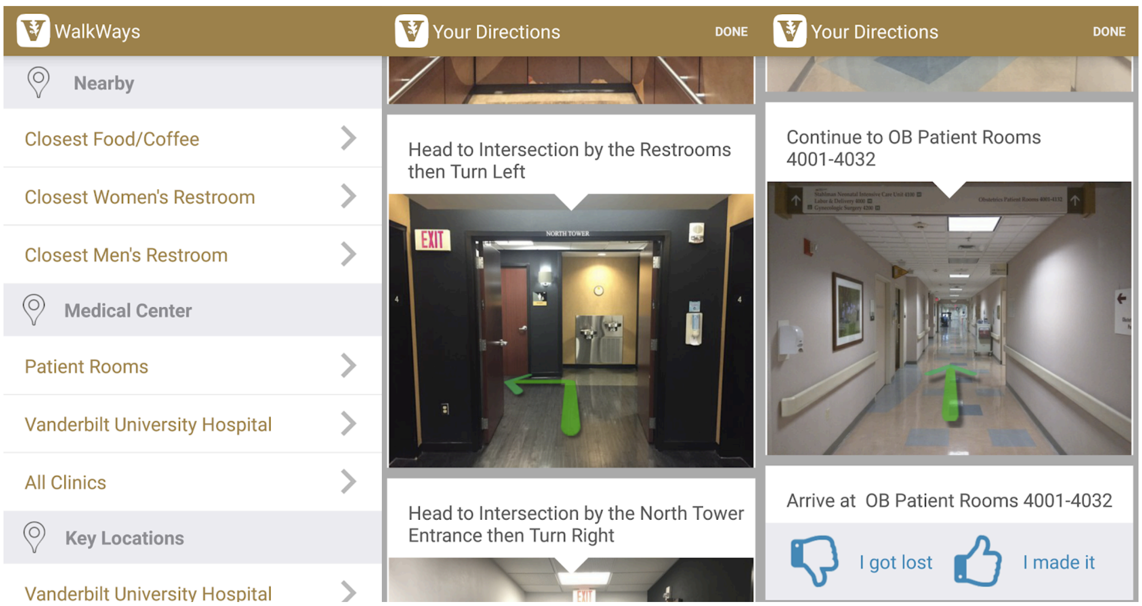


Figure 3.1. Screenshots from VUMC WalkWays wayfinding application(96).

Healthcare organizations could benefit from a method to monitor the movement of patients throughout the medical center without physically following them or tagging them with tracking devices. The goal of this study was to use an existing data source to infer how patients move within the medical center and what areas are closely associated. The WalkWays application, developed and implemented at Vanderbilt University Medical Center (VUMC) in November 2016, allows a patient's phone to determine its indoor location based on Bluetooth low energy beacons placed throughout the medical center. If patients are lost or need directions to a location within the medical center, they can install WalkWays on their mobile device either at home or through the VUMC guest wireless network. The WalkWays user can enter in a desired location and receive step-by-step directions with pictures. All clinics, inpatient areas, procedure areas, eateries, and major meeting areas such as elevator lobbies and guest services in the adult medical center were included. Patients could also request directions to the nearest men's or women's bathroom. We hypothesize that WalkWays request data can be used to describe the movement of patients throughout VUMC and infer networks of related medical center areas through commonly traveled routes.

3.2 Methods

We collected requests for directions from the WalkWays application from September 1, 2016 to September 30, 2017. All requests in the WalkWays application are anonymous, and we did not collect any patient information in this study. Data from WalkWays requests was stored on the Google Analytics platform and we obtained the data through Google's Query Explorer tool(97). Each request included the starting location of the request as determined by Bluetooth low energy beacons, the desired destination, and the time the request was made. Each area in the system had an associated X-Y coordinate on a multi-building combined floor plan, where the origin was the northwest corner of the medical center. We estimated the distance traveled by the patient by calculating the perpendicular distance from patient origin to destination, that is, the sum of the difference between the X-coordinates and Y-coordinates. This approach for calculating distance does not take into consideration the fact that patients often need to walk to an elevator to change floors. Next, we visualized a network of patient movement using the iGraph package in the R programming environment. Each node represents one location at

VUMC and each directed edge represents a request for directions from one node to another. The size of nodes was proportional to the number of requests made from the given location while thickness of the edge represented the number of requests made from origin to destination.

To determine the types of locations that patients traveled between, we manually assigned each location to one of eight categories: Clinical (including procedure areas), inpatient unit, administrative (i.e. patient records, and information desks), public (i.e. eateries and gifts shops), parking, bathroom, elevator, and hallway. We then constructed another graph that illustrated travel between area types instead of specific areas. Next, we investigated which clinical areas were most commonly traveled between by examining which clinical nodes had the most edges between them. We also looked into instances where patients requested directions to areas where they were already standing according to BLE. Finally, we performed an analysis of the requests for directions from parking lots to explore whether patients parked in the parking lot closest to their destination.

3.3 Results

From September 1, 2016 when the WalkWays system was first implemented to September 30, 2017, there were 3493 requests for directions from the application. Patients requested directions to and from 310 unique locations across the medical center.

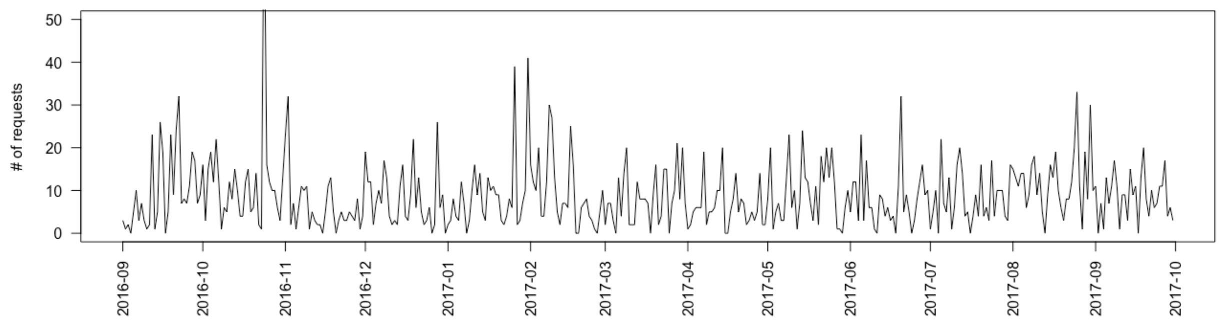


Figure 3.2. Number of wayfinding requests by day over the course of the study. Users made 80 requests on October 24, 2016.

Figure 3.3 shows a high-level view of the types of areas between which patients travel. Patients most frequently request directions from clinical areas to public areas and between clinical areas. Patients rarely request directions to elevators or hallways nor do they request directions from bathrooms or inpatient units. Users request directions more frequently from parking areas and administrative areas than to these areas.

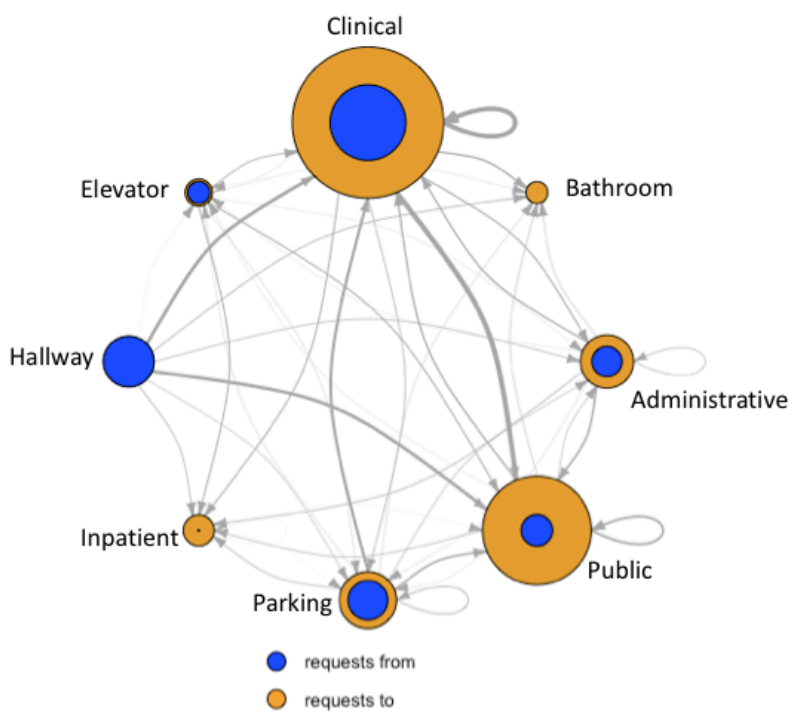


Figure 3.3. Directed network graph of patient wayfinding requests by area type. Inner circle radius proportional to requests made from location. Outer circle area based on requests made to that location. Thickness of edges are proportional to number of requests.

Figure 3.4 shows more granular visualization of the patient travel network. Patients most frequently requested directions from parking garages and to the courtyard cafeteria. The most common clinical location to make a wayfinding request was the emergency room while the most common administrative area was guest services. Patients most frequently sought directions to the VUMC eateries and bathrooms.

Table 3.1. Most frequent origins and destinations.

Most frequent origins	**Most frequent destinations**
Garage (East)	Cafeteria (Courtyard)
Garage (Central)	Restaurant (Au Bon Pain)
Cafeteria (Courtyard)	Women's bathroom
Adult Emergency Room	Restaurant (Bistro on 8)
Restaurant (Au Bon Pain)	Restaurant (Suzie's café)
Guest Services	Men's bathroom

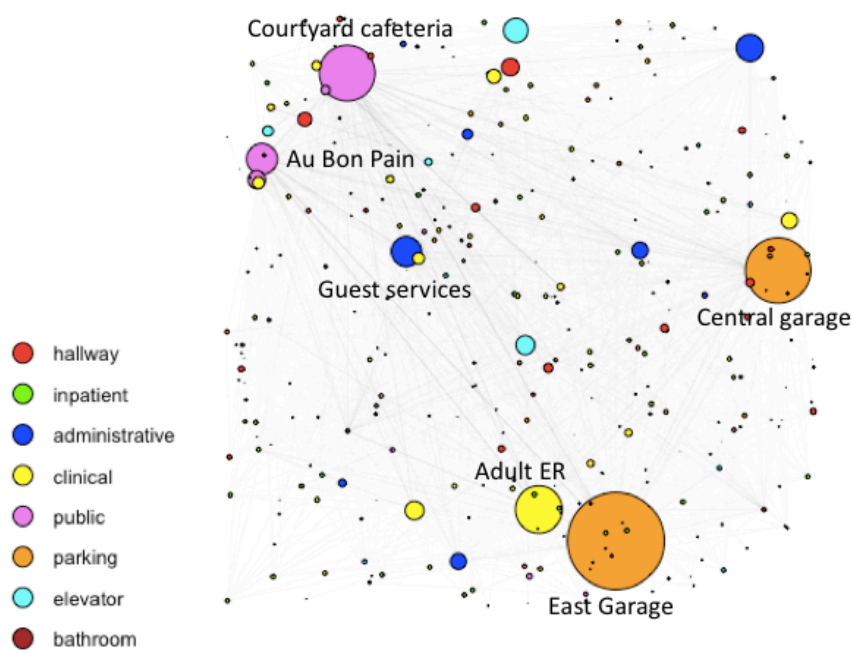


Figure 3.4. Undirected graph for all areas. The six most common origins are labeled. Radius of nodes are proportional to the number of requests made from that location. Thickness of edges is proportional to the number of requests. The arrangement of nodes is random.

Among 227 requests between clinical locations, only six routes had three or more requests. Table 3.2 shows that patients of the orthopedic departments were the most active users of the wayfinding application. The most commonly traveled route from the plastic surgery clinic to the orthopedic rehab clinic was about 940 feet long. The average distance traveled for all wayfinding requests was 548 feet.

Table 3.2. Clinical areas most commonly traveled between and the distance between them.

Origin	**Destination**	**Distance in feet**	**# of requests**
Plastic and cosmetic surgery clinic	Orthopedic rehab clinic	940	24
Orthopedic rehab clinic	Plastic and cosmetic surgery clinic	940	9
Radiology	Orthopedic rehab clinic	542	4
Medical center east surgery center	Medical center east pharmacy	245	3
Cardiac MRI	Radiology	345	3
Infusion clinic	Orthopedic rehab clinic	1027	3

In Table 3.3 the data shows that patients and visitors made 406 requests from the two main parking garages to locations in the medical center. Among these, 240 requests were made from the East Garage and 166 were from the Central Garage. Assuming patients parked at the location where they requested directions from, approximately 62% of patients parked in the garage closest to the requested destination.

Table 3.3. Number of requests made from VUMC East and Central garages by how far the garages were from the requested destination.

	Parked in East Garage	**Parked in Central Garage**	**% Optimally Parked**
Destination closest to East Garage	232	146	61%
Destination closest to Central Garage	8	20	71%

Finally, 174 requests were made to locations where BLE determined patients were already standing. The locations where this occurred most frequently are shown in Table 3.4. Self-requests occurred most frequently at the medical center's main cafeteria, the digestive disease center, and an internal medicine clinic.

Table 3.4. Areas where patients made requests to when already standing at those locations.

Location	**# self-requests**
Cafeteria (Courtyard)	26
Digestive disease center	12
Internal medicine suites	12
Adult emergency room	11
Restaurant (Au Bon Pain)	11
Occupational health clinic	10

3.4 Discussion

With wayfinding data, we were successful in identifying some trends in the movement of patients throughout the medical center. However, there are several limitations in our study that keep us from making stronger conclusions about patient experience. First, we assume in our analysis that patients are the primary users of the WalkWays application. Since there are no identifiers attached to wayfinding requests, it is possible that medical center staff are using WalkWays to request directions to parts of the hospital that they are not familiar with. The influence of these non-patient requests should be minimal since staff typically know their way around the medical center. Another limitation to our study is that BLE tracking coverage did not include the Monroe Carell Jr. Children's Hospital at Vanderbilt and its South Garage. Adding the children's hospital in the future will allow us to perform analysis on the difference in WalkWays users between adult and pediatric patients. Although the South Garage serves primarily the children's hospital, some adult patients may park there since it is closer to some adult departments such as the eye clinic.

Our use of perpendicular distance to estimate distance traveled may not accurately depict the routes that patients walked. While most VUMC hallways are laid out perpendicularly to the coordinate grid, diagonal hallways and open spaces would give patients a shorter route to their desired location. Additionally, since our distance calculations did consider changes in floors (VUMC consists of several multi-story buildings), patients may have had to backtrack to reach elevators before traveling to their destination. While the developers of the WalkWays application did have a routing algorithm for determining the best path for patients to take to their desired location that included elevator rides, that algorithm is proprietary, and an agreement was not made in time for this study to use that algorithm. In future work, the company who developed WalkWays will provide us with an application programming interface to calculate walking distance based on the recommended path as determined by the routing algorithm.

The biggest limitation to being able to infer associations between areas of the medical center is our small sample size. With 3493 requests over 13 months, there are fewer than 10 requests on average per day. The small number of requests means that a few patients that use the application frequently can have a large influence on the overall results. The high number of requests to and from the orthopedic clinic in Table 3.2 may be the result of good promotion of the WalkWays application from that unit, or a couple orthopedic patients that always use WalkWays. We are making considerations to include a non-descriptive identifier to each device that requests directions. This way, we will be able to see how many different unique users are requesting directions on a given day. It will also allow us to determine whether patients make requests for multiple locations during their visit to VUMC. Putting together the "chain" of movement could provide richer insight into the overall patient experience.

Despite these limitations, our analysis of wayfinding requests is beneficial to healthcare systems in several ways. Figure 3.5 shows that eateries such as the Courtyard Cafeteria, administrative areas such as guest services, and the emergency room are gateways to the rest of the medical center. Knowledge about where patients start their journey through the medical center could allow healthcare systems to strategically place staff or volunteers to help patients get to their destinations. Management could also use wayfinding requests as a surrogate for utilization. Historical or real-time wayfinding data could inform the allocation of resources such as cleaning for restrooms, relocation of wheelchairs, or maintenance for elevators that are more frequently used.

Hospital facility designers can use the number of times patients requested directions from a location they were already were standing (Table 3.4) to improve wayfinding signage in the medical center. Assuming patients are using WalkWays correctly and the application is functioning properly, the only reason why a patient would request directions to a location where they are already standing is that they are very near to their desired destination but do not realize it. Therefore, improved signage in these areas may help patients to know that they have arrived and thus reduce frustration. The results for optimal parking location in Table 3.3 could also enable medical center administration to improve patient experience. About 30% of patients are parking at the lot that is farther from their destination request. While some of these requests may just be a first stop before their clinical encounter (i.e. getting lunch at the cafeteria before your appointment), there is an opportunity for clinics to better inform their patients prior to their appointments on where to park to decrease walking distance. VUMC is in the process of including advance wayfinding directions in all digital patient appointment reminders that will specify which garage to park in and the indoor navigation route from the garage to the appointment. These appointment reminders will also direct patients to install the WalkWays application which could increase the sample size in future studies.

Data about associated clinical areas from Table 3.2 could also inform the placement of new or relocated clinics to minimize patient walking. If the trend of strong association between plastic surgery and orthopedic rehabilitation continues for the next few years, VUMC may consider moving these clinics closer together. The network of patient wayfinding requests provides data supported evidence for this operational decision by the healthcare system. More work needs to be done to investigate whether an intervention to decrease walking distance based on a recommendation from this analysis has an effect on patient satisfaction scores.

Data from this network analysis of wayfinding data can also help to inform enhancements in mobile applications that improve the patient experience. In the short term, application developers can improve WalkWays by suggesting commonly requested destinations based on their current location. This service could operate similarly to other recommender or autocomplete systems where options are presented to the user based on previously searched locations. Future medical center applications could also link indoor location data to the electronic medical record and patient portals to guide patients to their appointment without having to request directions. Clinic staff could furthermore benefit from an integrated mobile application by viewing real-time locations of their patients. This application could allow staff to reach out to their patients if they are lost in the medical center or make necessary modifications to the schedule if a patient is running late.

3.5 Conclusions

Using a novel data source, wayfinding requests from a mobile application, we were successful in inferring patient movement within the medical center and identifying some opportunities for improving the patient experience. The network of patient directions requests provides evidence to medical center management for the placement of clinics and the design of signage. Further development of mobile applications that enhance the patient experience may decrease patient wayfinding effort and increase efficiency of healthcare operations.

Chapter 4

Diagnosis of Clinic Operation Problems from Workflow Management Data

4.1 Introduction

With the high cost and competitive landscape of the healthcare industry (98), health services researchers have applied operations research methods in an effort to decrease costs or increase revenue(99). Additionally, patient wait times have been linked to patient satisfaction and perception of the quality of care(100), and are an outcome that operational improvements can address. Previous work has used mathematical models(9) and stochastic models such as discrete event simulations(101) to optimize for a given utility function such patient wait times, provider utilization, or throughput.

There are several problems with the simulation and mathematical models developed in previous studies. First, models describing healthcare processes are specific to a clinic or institution, making the model difficult or impossible to generalize to other use cases(51). Additionally, these models are difficult to validate with workflow data. Finally, model variables such as procedure times are often multi-faceted or non-modifiable for clinical reasons, thus complicating interventions designed to improve workflow. While many studies have sought to optimize scheduling or resources in order to improve certain outcomes, little work has been done to automate the identification of problems with clinic operations given real-world data.

Unlike previous studies that optimize for a given utility function or outcome, our study seeks simply to diagnose problems with clinic workflow that cause appointments to start later than scheduled. Our model makes no assumptions about resources or existing distributions of services times. Therefore, our model is applicable to any care setting or institution where data is available for scheduled appointment time, scheduled appointment duration, actual patient arrival time, and actual appointment duration.

The model we develop in this study is able to identify whether late patient arrivals or insufficient time allocated for appointments is primarily responsible for a clinic getting off schedule through a constraint satisfaction optimization problem. The intended audience of the results of our model are clinic administrators and providers that can consider changes to the clinic process that address the problems identified.

This paper provides the following contributions to the study of computer aided clinic workflow diagnosis:

- We use a constraint satisfaction model to depict the existing state of patient arrival times, appointment start times, and appointment durations.
- We compare the existing state to scheduled appointment times to show mismatches in the planned and actual schedules.
- We use a constraint optimization problem to diagnose whether late patients or poor appointment duration allocation most likely cause the mismatch between planned and actual schedules.

4.2 Methods

We apply our constraint satisfaction problem to appointments at an outpatient clinic of Vanderbilt University Medical Center between March 27 and April 21, 2017. The basis for our actual schedule are timestamps for when the patient arrives at the clinic, when the patient moves to the exam room for the start of their appointment, and when the patient leaves the clinic. Timestamp data for patient flow are collected by two systems in that area. One system is a workflow management tool integrated with the electronic medical record known as the Whiteboard, where staff manually track the movement and progress of patients through their appointments(102) from check-in, through rooming in the exam room, to check-out. The second system is an automated patient tracking tool, where patients receive a Bluetooth low energy beacon that tracks their room location within the clinic. In our preliminary analysis, we calculate the difference between the timestamps derived from the Whiteboard and Bluetooth systems at the three checkpoints of a patient encounter. These three checkpoints are check-in time (when the patient arrives at the waiting room), exam start time (when the patient moves from the waiting room to the exam room), and exam end time (when the patient departs from the clinic. We assume that errors of omission are more likely than errors of commission, meaning discrepancies in the timestamps from the two systems should be more commonly associated with a staff member forgetting to check-in a patient to the clinic rather than that staff member checking-in a patient by accident. Therefore, each checkpoint in the patient process, we take the earlier timestamp of the two systems to improve accuracy.

We also pre-processed actual appointment duration by assuming that the provider clinic is a single server process. For the purpose of the model, we assume that providers only see one patient at a time in order of their appointment start times. Since most providers see patients in multiple rooms there are many cases where a patient room-in time overlaps with the next patient. In this case, we assume that the earlier patient’s exam ended, and the later patient’s exam started halfway through the time where their room-in times overlapped.

The planned schedule is taken from the appointment record. Each appointment has a scheduled start time and scheduled duration. The mismatch between the scheduled appointments and the timestamp data are the basis for our constraint satisfaction model.

Constraint Satisfaction Model for Clinic Cycle Times

Constraint satisfaction problems (CSPs) are defined by a set of variables, such as the positive integer variables X and Y, and a set of constraints over the variables, such as $X < Y$. A constraint satisfaction problem defines a number of variables and constraints. A valid solution to a CSP is an assignment of values to the variables that adheres to all of the constraints. For example, $X = 1$, $Y = 2$, is a valid solution to this CSP. An assignment of values to the variables is called a labeling.

Constraint solvers are automated tools that are used to solve CSPs. A constraint solver takes a set of variables, constraints, and any initial variable assignments as input. The solver then automatically produces valid assignments for the remaining unlabeled variables that satisfy the constraints. For example, if a constraint solver was provided the CSP above and an initial labeling of $Y = 3$, it would solve for the valid assignments of X, 1 and 2.

In order to use a constraint solver, a CSP must first be defined that captures the relationships between the variables of interest. In this paper, the cycle times of patients and their appointment times are of interest. We define cycle time as the time from when a patient checks in for their appointment to when they leave the clinic. This section walks through the construction of an initial CSP that captures the relationship between planned appointment times and durations, and actual observed appointment times and durations. In the next section, this CSP is extended in a way that allows a constraint solver to automatically derive answers to whether late patients or long cycle times are responsible for clinics running behind schedule.

Before beginning discussion of the model, a few key assumptions must be expressed. These key assumptions are outlined in Table 4.1. The most important assumption is that we analyze the schedule for a single provider at a time. Analysis of multiple providers are possible, but each will have a separate CSP model built for their analysis.

Table 4.1. Model Assumptions

A1.	A model is built for each individual provider's schedule and patients.
A2.	A provider completes appointments sequentially.
A3.	The appointment times T and At are sorted in ascending order based on actual start time.

We begin our model by defining a basic CSP. In the next subsection, we introduce additional variables into this CSP to support automated wait time diagnosis. The basic form of the CSP is shown in equations 1-2. The CSP input to the constraint solver is composed of a planned or expected schedule, $E = < T\ ,\ D >$, and a set of actual observed values, $A = < At\ ,\ Ad >$. A cycle time can be calculated for each appointment using either the planned values *cycle(E)* or the actual observed values *cycle(A)*.

Table 4.2. Constraint satisfaction problem variables

$T = \{T_0 \ldots T_n\} \in [0, 1440]$	Scheduled start time of appointment as minutes offset from midnight
$D = \{D_0 \ldots D_n\} \in [0, 1440]$	Scheduled duration of appointment in minutes
$At = \{At_0 \ldots At_n\} \in [0, 1440]$	Actual start time of appointment as minutes offset from midnight
$As = \{As_0 \ldots As_n\} \in [0, 1440]$	Difference in minutes of scheduled vs. actual appointment start time
$Ad = \{Ad_0 \ldots Ad_n\} \in [0, 1440]$	Actual duration of appointment in minutes
$Ae = \{Ae_0 \ldots Ae_n\} \in [0, 1440]$	Difference in minutes of scheduled vs. actual appointment duration
$Ap = \{Ap_0 \ldots Ap_n\} \in [0, 1440]$	Actual patient arrival time as minutes offset from midnight
$F = \{F_0 \ldots F_n\} \in [0, 1440]$	Actual end time of appointment as minutes offset from midnight
$C = \{C_0 \ldots C_n\} \in [0, 1440]$	Cycle time of each patient in minutes
$W = \{W_0 \ldots W_n\} \in [0, 1440]$	Difference between scheduled and actual cycle time in minutes

$$As_i = \begin{cases} i = 0 & \max(0,\ Ap_i - T_i) \\ i > 0 & \max(0,\ At_{i-1} + Ad_{i-1} - T_i,\ Ap_i - T_i) \end{cases} \tag{1}$$

Equation 1 defines the basic constraint covering the calculation of the difference in minutes between the expected start time of an appointment and the actual start time. The first appointment of the day, As_0, will either start on time or will be delayed by the difference in minutes between the scheduled start time and the arrival time of the patient $max(0, Ap_i - T_i)$. If the patient is late, As_0 will be a positive number of minutes that the patient was late to their appointment. For all other appointments, the start time deviation will either be a result of late patient arrival or the late completion of the preceding appointment in *At*. Note, *At* is sorted based on actual appointment start time and not scheduled start time, which allows the analysis to consider deviations from the planned schedule.

As shown in Equation 2, the model constrains the actual duration of the appointment, Ad_i, to be equal to the expected duration of the appointment plus the difference between the expected and actual duration, Ae_i. This constraint is important later when the modified CSP is formulated to diagnose workflow issues.

$$Ad_i = D_i + Ae_i \tag{2}$$

Next, the model constraints the actual end time of a patient's appointment, F_i, to be the actual start time plus the expected duration of the appointment, D_i, and difference in expected and actual deviation of the appointment, Ae_i. This constraint is shown in Equation 3.

$$F_i = At_i + D_i + Ae_i \tag{3}$$

A key input into the CSP model is the goals for patient cycle time. Ideally, patients should have a cycle time that matches their scheduled appointment duration. However, in reality, a patient may arrive late or a prior appointment may run late causing the cycle time and scheduled appointment time not to match. The model defines cycle time as the difference between the arrival time of the patient, Ap_i, and the actual finish time of the appointment, F_i. This constraint is shown in Equation 4.

$$C_i = F_i - Ap_i \tag{4}$$

The final component of the model is the defining a goal variable, which is that, ideally, the scheduled cycle time of the appointment should match the actual cycle time of the appointment, C_i. Although it might seem that it is preferable for the actual cycle time to be less than the scheduled cycle time, this indicates potential overestimation and waste in the schedule that could allow for more appointments. Thus, the ideal schedule has as little deviation from the planned vs. actual cycle time. This goal constraint is shown in Equation 5.

$$W_i = C_i - D_i \tag{5}$$

With this simple CSP formulation of the model, all that a clinic can do is check that the actual collected data meets the expected constraints. The next section extends the CSP model to allow automated analysis of whether late patients or long service times are responsible for clinics running behind schedule.

Constraint-based diagnosis of patient cycle times

The automated diagnosis process relies on using a constraint solver to derive changes that could have been made to either the planned schedule or the actual observed schedule that would make the expected and actual cycle times more closely align. For example, the automated diagnosis process may state that had a specific patient arrived on time, the entire schedule for the day would have matched expectations. Alternatively, the automated diagnosis process might state that the actual duration of a single appointment was much longer than planned, indicating that treatment was more complicated than expected, and threw off the schedule. These are the types of outputs that the modified CSP will produce.

In order to support these types of diagnoses, the model needs to encode the concept of a "change" that could be made to the actual or planned schedule to make them more closely align. The diagnosis tries to find the fewest changes to the actual schedule that would lead to actual cycle times matching planned cycle times. In other words, what things could have gone differently that would have made planned and actual cycle time the same. Later, the section will discuss how the constraint solver reasons over these changes to diagnose clinic workflows, since there are often a large number of possible changes that could be made to rectify the mismatch between planned and actual schedules.

CSP Model of Cycle Time Diagnosis

More formally, given a planned schedules E and A, such that *cycle(E)! = cycle(A)*, the diagnosis defines a new CSP that solves for the set of changes *R* to *E* and *A*, such that *cycle(changes(E, R)) = cycle(changes(A, R))*. That is, the output of the CSP is a set of modifications to E and A that will make their calculated cycle times for each appointment equal.

To support the concept of a potential "change", the CSP model needs two additional variables introduced to model $R = < \delta Ae, \delta Ap >$. An overview of these variables is shown in Table 4.3.

First, the variable, Ae_i, is set to 1 by the solver if changing the duration of the i^th appointment to match the planned duration would make the actual and planned cycle times more closely align. Second, the variable Ap_i is a variable set to 1 by the solver if changing the patient's arrival time to match the start time of the appointment would make the actual and planned schedules match more closely.

Table 4.3 CSP diagnosis variables

$\delta Ae = \{\delta Ae_0 \ldots \delta Ae_n\} \in [0, 1]$	The difference in actual vs. scheduled treatment time of the i_{th} appointment should be set to 0.
$\delta Ap = \{\delta Ap_0 \ldots \delta Ap_n\} \in [0, 1]$	The i_{th} patient's arrival time should be changed to the start time of the appointment.

In order to use these variables, they must be incorporated into the CSP constraints. The δAp_i change variable is incorporated into the CSP in Equation 6. The variable RAp_i models the difference in planned appointment start time and patient arrival time. If the δAp_i is set to 1, it indicates that the patient arrival time should be set to the appointment time in order to more closely match scheduled and actual cycle times. By setting δAp_i to 1, it causes RAp_i to equal the original planned start time of the appointment.

$$RAp_i = \begin{cases} \delta Ap_i = 0 & Ap_i \\ \delta Ap_i = 1 & T_i \end{cases} \tag{6}$$

The δAe variable is incorporated into the constraints in Equation 7. If δAe is set to 1, RAd_i takes the value of the original planned duration. Otherwise, RAd_i takes the actual duration of the appointment as its value.

$$RAd_i = \begin{cases} \delta Ae_i = 0 & D_i + Ae_i \\ \delta Ae_i = 1 & D_i \end{cases} \tag{7}$$

Finally, in Equation 8, the model ties the new change variables to the calculation of the difference in planned vs. actual start time of the appointment. The constraint is a modified version of Equation 1 that uses the RAp_i, RAt_i, and RAd_i variables. For example, if $Ap_i \neq T_i$, but $\delta Ap_i = 1$, RAp_i will equal 0, just as it would have if the patient had arrived on time.

$$RAt_i = \begin{cases} i = 0 & RAp_i \\ i > 0 & \max(0,\ RAt_{i-1} + RAd_{i-1}, RAp_i, \\ & \qquad RAt_i + RAd_i) \end{cases} \tag{8}$$

Diagnosis as Optimization

There are arbitrarily many changes that could be made to the planned and actual schedules that would cause their cycle times for appointments to be the same. Therefore, a mechanism is needed to express to the constraint solver how to rank possible changes and diagnose the difference between an expected and actual schedule. The mechanism that the model uses to rank possible sets of changes is to try to minimize the total number of changes made to either the planned schedule, E, or the actually observed schedule, A. That is, the constraint solver is asked to solve for a solution that minimizes the value of Equation 9. The solver is trying to find the minimal set of patients that could have arrived on time and appointments that could have met their expected duration to make the overall cycle times of all appointments match in both planning and actuality.

$$min \sum_{0}^{n} \delta Ae_i + \delta Ap_i \tag{9}$$

We modified a previously constructed solver designed for application developers to identify the least number of software and hardware feature changes necessary to satisfy a set of dependency constraints(103). The output from the constraint solver will be a labeling of the variables in the CSP that minimizes the number of changes that have to be made to the planned or actual schedule to make them consistent. A key question is how these variable assignments can be used to answer questions about patient cycle times. The variables δAe_i and δAp_i are the path to answering these questions.

1) Diagnosing: Are late patients responsible?

The δAp_i variables determine if the minimal set of changes to make the actual and planned cycle times align includes changing the arrival time of patients. If late patients are part of the minimal set of changes that can be used to explain the difference between planned and actual execution time, it indicates that late patients are a factor, and can precisely pinpoint which patients contribute to throwing off the planned cycle times.

For example, if the 2nd patient's Ap_2 variable is set to 1 and there are no other outputs, it indicates that the solver can explain the discrepancy between the planned and actual cycle times simply by that patient's tardiness. Had that single patient arrived on time, actual cycle times for all appointments would have met their planned cycle times. The solver can output a single patient late arrival, multiple late arrivals, or a combination of late arrivals and poorly predicted appointment durations as the root cause.

The optimal solution will include a combination of δAp_i and δAe_i for most provider days. One way to interpret the output from the solver is to compare the number of recommended patient check-in changes δAp_i against the number of appointment duration changes δAe_i. If a large number or all arrival times of patients are suggested as needing to be changed, this is a potential indicator that the front desk check-in process is slow. Moreover, it could also indicate problems with accessibility of the clinic location, such as difficulty in finding parking or navigating to the clinic.

2) Diagnosing: Are poor appointment block time estimates responsible?

The δAe_i variables indicate that appointment treatment times explain the discrepancy between planned and actual cycle times. For example, if $Ae_3 = 1$, it indicates that the 3rd appointment of the day went over its expected duration and contributed to the discrepancy in planned and actual times. The solver can output a single or combination of appointments and late arrivals that created the issue.

If a large percentage of appointment durations exceeded expectations, meaning a large number of δAe_i variables are 1, it indicates a more pervasive issue with appointment block time planning. That is, if appointments are consistently over time, then it is likely that the provider is being scheduled insufficient time to see and treat each patient. Alternatively, if a single provider consistently has appointments that run past their expected duration, it may be that the particular provider slower or takes more time talking to their patients.

4.3 Results

From March 27, 2017 to April 21, 2017, 14 providers saw at least five patients on at least one appointment day at the Vanderbilt University Medical Center clinic in our study according to the Whiteboard and outpatient scheduling data. These providers completed a total of 622 appointments over this period. We were able to obtain Bluetooth workflow data on 266 of these appointments. Among these appointments, the timestamps for check-in, exam start, and exam end occurred in the Whiteboard system before the Bluetooth system. The median [95% confidence interval] timestamp difference in minutes was -1 [-3.4 , 2] for check-in, -1.7 [-4.9 , 46] for exam start, and 0 [-57 , 72] for exam end. These results and Figure 4.1 show that timestamps for exam start time and exam end time can differ greatly. Situations where the Bluetooth system records a timestamp before the Whiteboard could indicate a situation where a staff member forgot to record the transition in the system. The Bluetooth system corrected the Whiteboard timestamp for 30.1% of the timestamps where Bluetooth data was available. Situations where the Whiteboard timestamp comes before the Bluetooth timestamp could be the result of patients leaving their Bluetooth trackers in a room or the system inaccurately determining patients' locations. While neither system is perfect, each system is useful for correcting for the other, leading to better quality workflow data when both data sources are available.

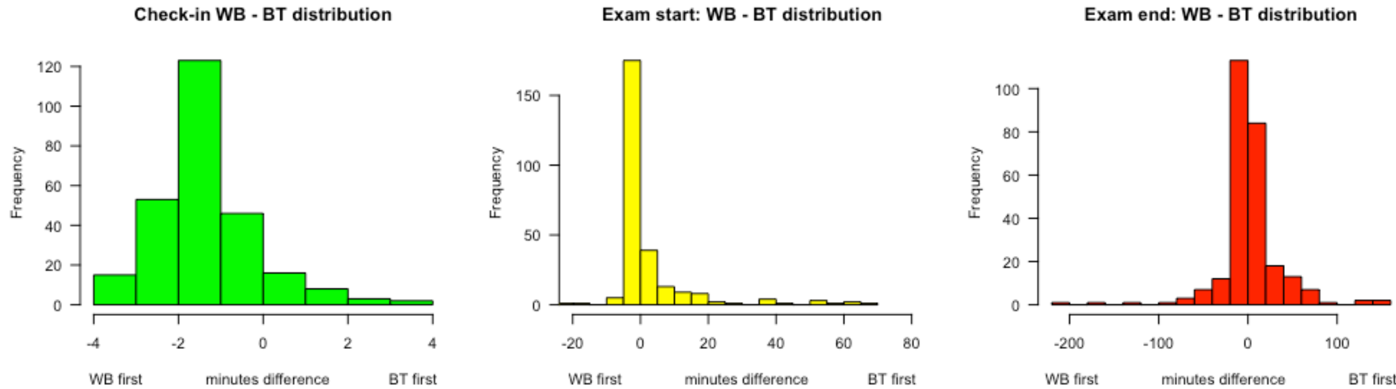


Figure 4.1. Distribution of differences between Whiteboard (WB) and Bluetooth (BT) system timestamps at check-in, exam start, and exam end.

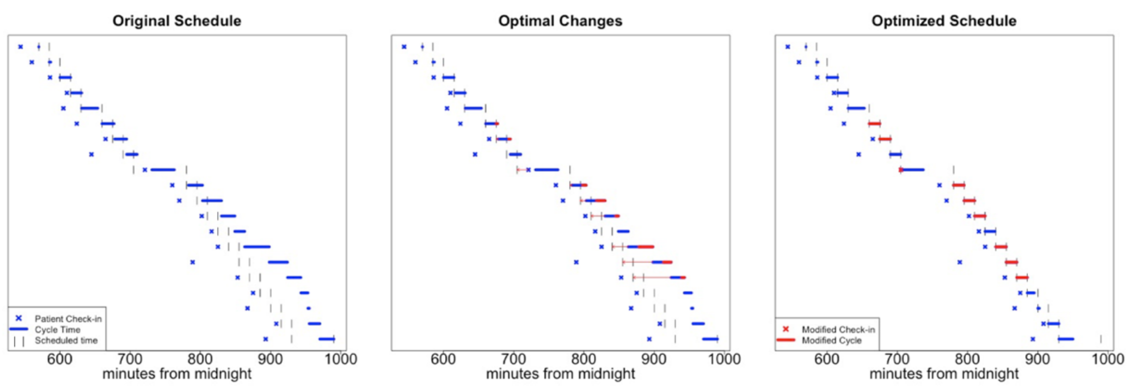


Figure 4.2. Example of original schedule, optimal changes, and optimized schedule for one provider.

Out of all appointments, 116 (19%) started late due to the patient arriving after the scheduled time, while 256 (41%) ended after the allocated time due to longer than expected appointment duration. Figure 4.2 shows an example of one provider's schedule on one day where a combination of late patients and long cycle times caused the clinic to run off schedule. In this example, the solver determined that the making the 9th patient on time and completing the 6th, 7th, 10th, 11th, 12th, 14th, 15th, and 16th appointments on schedule would cause the rest of the appointments to run on schedule.

In Table 4.4, we aggregate the diagnostic variables δAp (check-in changes) and δAe (appointment duration changes) for each provider over all their clinic days. Providers are sorted by the total number of patients seen. Provider A saw the most patients over the study period, and the solver determined that 12 patient check-in modifications and 40 appointment duration modifications were the minimum necessary to make that provider's clinics run on time. All providers had more appointment duration revisions than patient check-in revisions in the optimized schedule except for Provider D who had 16 patient check-in changes and 14 appointment duration changes, and Provider K who had five of each.

Table 4.4. Clinic workflow diagnosis by provider

Provider	Check-in changes $\sum\delta Ap_i$	Duration changes $\sum\delta Ae_i$	Appointment Days	Total Appointments
A	12	40	7	106
B	5	11	7	66
C	15	22	4	66
D	16	14	10	63
E	12	27	4	59
F	5	6	8	51
G	7	20	2	45
H	11	13	4	40
I	12	12	6	38
J	12	15	3	38
K	5	5	3	24
L	2	7	3	15
M	0	0	1	6
N	2	2	1	5

Table 4.5 shows aggregate totals for check-in changes and appointment duration changes

by date across all providers who had clinic that day. Again, there were more revised appointment durations than check-in times on most days except on March 29th, April 4th, April 19, and April 21. There does not appear, from our sample, to be any correlation between the ratio of check-in to duration modifications and the number of patients seen, the number of providers, or the day of the week.

Table 4.5. Workflow diagnosis by clinic day

Date	Check-in changes $\sum \delta Ap_i$	Duration changes $\sum \delta Ap_i$	Patients Seen	# Providers
27-Mar	8	15	53	4
28-Mar	4	15	41	4
29-Mar	9	9	35	4
30-Mar	8	14	41	4
31-Mar	1	4	12	2
3-Apr	7	13	48	4
4-Apr	9	8	23	3
5-Apr	6	11	30	3
6-Apr	14	15	48	5
7-Apr	3	6	18	3
10-Apr	7	15	43	3
11-Apr	9	14	46	4
12-Apr	9	10	38	4
13-Apr	6	14	38	4
14-Apr	0	1	5	1
17-Apr	3	5	20	2
18-Apr	4	7	22	3
19-Apr	6	6	26	3
20-Apr	1	10	29	2
21-Apr	2	2	6	1

Finally, we aggregated check-in and duration changes by the corresponding position of the revised appointment in the schedule in Table 4.6. For each provider clinic day with n appointments, any δAe and δAp in the first n/2 appointments (rounding down) would be assigned to the "first half" while the remainder would be assigned to the "second half". This means that provider clinic days with an odd number of appointments would have one more appointment attributed to the second half. Even with the discrepancy in the number of appointments favoring the second half, there were more modifications made to check-ins and cycle times in the first half of the schedule.

Table 4.6. Workflow diagnosis by position in schedule

	Check-in changes	Duration changes
First half of schedule	63	116
Second half of schedule	53	78

From a computational standpoint, the solver we use is able to find the global minimum number of changes needed to make every appointment run on time by doing a search of possible combinations of changes. This is an NP-hard problem that could become computationally untenable if the number of appointments for a given provider clinic day becomes very large. However, the largest number of changes for any provider clinic days was 20. This means the largest possible solution space for a clinic day in this study was $2^{20} \approx 10^6$ combinations, which can be computed quickly. The median number of possible changes on a provider clinic day was 4, yielding a total of 16 possible solutions.

4.4 Discussion

Interpretation of results.

Our results demonstrate how we can use a constraint optimization problem to diagnose problems with clinic workflow. In diagnosing whether late patients are responsible for clinic going off schedule, we observed that for certain providers (such as Provider D in Table 4.4) and certain clinic days (such as April 4th in Table 4.5), changing the arrival times for late patients would have caused the rest of the day to run according to schedule more so than adjusting planned appointment duration. Such providers may benefit from better coordination with the patient before their appointment in the form of appointment reminders, driving directions, or valet parking. Similarly, if the clinic notices trends in days that lead to high numbers of patients arriving late, administrators could send reminders to patients ahead of days where tardy patients are likely to make a large impact on the schedule.

From our study sample, we are able to diagnose that poor appointment block time estimates are largely responsible for planned schedule breakdown. For most providers and clinic days, a large number of changes to appointment duration are needed to make the clinic run on schedule. This finding implies that there is overscheduling of patients where planned appointment time allocation is insufficient to address patient needs. The identification of these challenges could lead the clinic to make changes to clinic operations such as increasing planned appointment times, extending clinic hours, or increasing the number of exam rooms.

Finally, we observe in Table 4.6 that the solver made more schedule optimization changes in the first half of provider clinic days. This result is not surprising since a late patient or longer than expected appointment early in the day can adversely affect the rest of the schedule. This finding may lead providers to schedule fewer patients and longer appointment blocks in the first half of the day to increase the likelihood of later appointments running on time.

Current Limitations

Despite the effectiveness of this model in identifying problems with clinic workflow, there are several limitations that affect the validity and generalizability of this work. Firstly, our model does not account for interaction between potential changes and other appointments. By keeping $RAdi = D_i$ where $\delta Ae_i = 0$ we assume that providers do not adjust the time they spend with patients based on their workload. In fact, providers may speed up or slow down their encounters with patients based on whether or not they are behind schedule.

Another limitation of our model is that treating clinic operation as a single server process may be an oversimplification. Once patients enter exam rooms, they are often seen by multiple healthcare professionals such as nurses and technicians before or after their encounter with the provider. Additionally, providers may leave and revisit a patient multiple times during a visit, allowing them to treat multiple patients at once. The method for schedule pre-processing tends to be optimistic for cycle completion times. Since the original schedules are a "best case scenario", changes recommended by the solver should still be valid. Finally, we assume in the constraint optimization problem that the least number of changes δAp and δAe is the best for getting the clinic back on schedule, even though some interventions may be easier to implement than others.

Future work

Future work will investigate weighting δAp and δAe to account for costs. These weights could subsequently be tuned for different clinics and institutions based on their ability to modify patient and clinic behavior. The output from our constraint optimization problem is also useful as an outcome to predict provider clinic days that are likely to go off schedule. Instead of using the total number of late patients or long appointment durations as the prediction outcome, the minimal number of potential changes pinpoints the problems in workflow that made a difference in the overall schedule. For example, a prediction algorithm that helped anticipate the number of late patients based on traffic and weather conditions would not necessarily be useful if those late patients did not end up causing other appointments to start late. Combining workflow data in this study with clinical variables such as billing codes, diagnoses, and medications, and operational variables such as staffing and patient distance traveled could help clinics better prepare for busy days.

Additionally, future work will investigate the possibility of describing the encounter process with more detail. Using exam room time as an estimate for appointment duration is a crude estimate, and patients could be just as worried about exam room wait time as waiting room wait time. Additionally, exam room waiting time contributes to higher cost for the organization, since that space is not available for other patients and providers to use. One solution to better describing actual appointment duration will be to use Bluetooth sensors to track staff as they enter and exit exam rooms with patients. Another possibility will be to use electronic health record access logs to estimate the time providers were in exam rooms with patients, as with the method developed by Hribar et. al.(104). With these methodological improvements for calculating actual appointment duration, healthcare organizations will be able to obtain more accurate estimations of clinic operations from patients' perspectives.

4.5 Conclusions

The results from this constraint optimization problem offer valuable insights that could help improve workflow in outpatient settings. The minimum number of changes to patient check-in times and appointment durations reveal whether patients or the healthcare system are responsible for the clinic running behind schedule. Using this method to diagnose previous clinic schedules can inform interventions that decrease patient wait times and improve provider utilization.

Chapter 5

Measures for Treatment Burden in Patients with Breast Cancer

5.1 Introduction

Patients who have chronic disease experience significant disruption to their lives, as do their caregivers. These disruptions can come from symptoms of their disease as well as the burden of treatment required to manage the disease(105). Burden of treatment is the impact that medical care has on the lives of patients(18). The concept of treatment burden is about more than just providing convenient care. Patients who are overburdened have a higher likelihood of non-compliance with their treatment plans(106). While previous measures for treatment burden use patient reported data to assess treatment burden(107,108), we believe there is an opportunity to capture aspects of treatment burden from electronic health record (EHR) data. Metrics derived from the EHR could allow healthcare organizations to determine the effort patients put into receiving care over the course of their treatment on a large scale. These quantitative metrics present opportunities 1) to evaluate the impact of new treatments and healthcare delivery programs on patient treatment burden, and 2) to develop interventions to help better balance treatment burden and patient capacity to receive care.

Outcome measures in cancer are designed to capture the effectiveness of treatments to combat illness. Cancer treatment impacts patients' lives in complex ways, and so no single measure can describe all dimensions that patients can be affected. In Table 5.1, we categorized some commonly used measures into the categories of disease response, host response, treatment burden, and caregiver burden. While each of these measure types may affect others, they are distinct in the aspect of patient life that they describe. For example, a chemotherapy regimen may have a profound effect on tumor size (disease response) but may result in severe adverse reactions (host response), time missed from work (treatment burden), and stress on family members (caregiver burden). While disease response and host response measures are commonly measured in the evaluation of new cancer therapies, treatment burden is less frequently assessed. We propose that treatment burden measures should be considered alongside existing clinical metrics for cancer care outcomes.

Table 5.1. Summary of outcome measures used in cancer treatment.

Measure type	**Description**	**Examples**	**Assessment methods**
Disease response	Biological effect of treatment on disease	• Response Evaluation Criteria in Solid Tumors (RECIST)(28) • Minimal Residual Disease (MRD)(29)	• Radiology assessment • Pathology assessment
Host response	Morbidity and mortality effect of treatment on patient.	• Overall Survival(30) • Common Terminology Criteria for Adverse Events (CTCAE)(31) • European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (109)	• Physical exam • Patient reported • Surveys
Treatment burden	Logistical and emotional effect of treatment on patients' lives	• Financial Toxicity(42) • Treatment Burden Questionnaire(108)	• Surveys
Caregiver burden	Logistical and emotional effect of treatment on patients' caregivers	• Zarit Burden Inventory(110) • Supportive Care Needs Survey(111)	• Surveys

Previous literature has identified dimensions of treatment burden through patient surveys. An online survey of 1,345 patients worldwide showed that patients felt burdened by healthcare tasks such as difficulty of medication administration (31% of participants), frequency of drug intakes (28%), frequency of tests (26%), and frequency of doctors' visits (26%)(112). Two other studies developed survey instruments called The Treatment Burden Questionnaire (TBQ)(63) and Patient Experience with Treatment and Self-management (PETS)(107) to quantitatively assess treatment burden in patients with chronic conditions. Through the development and validation of these surveys, both identified outpatient medications, medical appointments, and coordination of healthcare tasks as significant contributors to overall feelings of burden(24). A literature review of disease specific treatment burden measures observed themes of emotional impact, self-care and monitoring, lifestyle impact, scheduling, medication side effects, and economic burden(90). In healthcare research, there is increasing interest in describing and measuring treatment burden in patients with chronic diseases. However, these assessments rely on patient surveys which can be costly and time consuming to collect. Automated approaches to measurement of treatment burden from electronic health records could decrease the costs of colleting these outcomes and enable their incorporation into patient care.

Healthcare systems could use measures of treatment burden derived from digital resources such as the EHR to better understand the work that patients must complete during their care. Patients could benefit from quantitative measures of treatment burden by allowing them to plan around life disruptions that are a result of their illness. For example, cancer patients undergo lengthy treatments that result in disruptions to their work schedules and family care(113). There are often complications in coordinating transportation(114). In cancer treatment, there are many choices that patients and providers have to make based on the patient's disease and goals(115). Having treatment burden measures would allow care teams to make better informed decisions about treatment plans that match the patient's needs and goals.

Additionally, researchers could use treatment burden measures to compare two or more treatment protocols for their impact on patient work. Advertisements for medical services and medications often tout treatment burden reducing potential by “saving you a trip to the doctor” or needing just “one pill a day”. These claims are not typically substantiated with quantitative assessments of patient experience. Patients, healthcare providers, and healthcare delivery systems, need a method to track the patient work associated with cancer care to better inform treatment decisions. With an increasing number of curable cancers, providers need to balance the benefit of aggressive treatments with the impact to patients’ short-term well-being and activities of daily living.

In this study, we derive several simple treatment burden measures from the electronic health record based on factors that contribute significantly to treatment burden from previous studies. We evaluate these measures on a population of breast cancer patients at an NCI designated comprehensive cancer center, the Vanderbilt Ingram Cancer Center at Vanderbilt University Medical Center (VUMC). Additionally, we use these treatment burden measures to assess the effectiveness of a new treatment option in reducing treatment burden for breast cancer patients undergoing chemotherapy.

5.2 Methods

Using electronic health record data, we developed measures for treatment burden for clinical encounters, commuting, and outpatient medications. We then applied these methods to two populations of breast cancer patients to determine if the measures were sensitive to differences in disease stage and treatment protocols. The Vanderbilt Institutional Review Board approved the collection, analysis and presentation of data for this study (IRB #151003).

Clinical Encounters

Clinical encounters include any event where the patient comes in contact with the healthcare system. These present a good opportunity for measuring patient treatment burden from disruption to daily routines, paperwork, and researching their medical condition(63). Encounters include outpatient appointments, medical procedures, and inpatient hospital admissions. In a previous study (64), we developed a method to measure treatment burden from patient encounters. This method includes all of the patient's encounters from a single institution including those encounters not related to the management of their cancer to get a full picture of treatment burden. Figure 5.1 shows an example of outpatient encounter data from a single patient including appointment start times and allocated appointment durations from which estimated appointment durations can be derived. Wait-times are estimated as the time in between appointments and the total time in clinic as the time from the start of the first appointment to the end of the last appointment of the day. Other outpatient encounter related measures include the number of appointments, unique appointment days, and hours in appointments. Inpatient encounters from admission-discharge-transfer (ADT) data allow for calculation of the number of emergency department visits, hospital admissions, and total length of hospital stay.

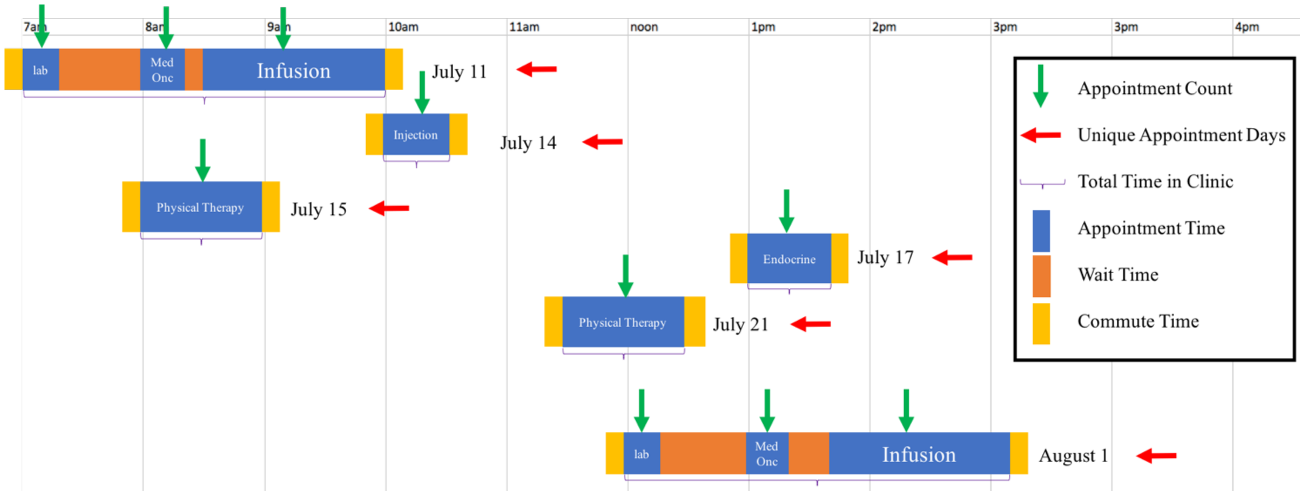


Figure 5.1. Summary of outpatient encounter burden measures for an example patient. Over the course of two weeks, this patient had 10 appointments lasting a total of 8.75 hours. She waited for 2.25 hours between appointments and was in clinic for 11 hours. She had to travel to the clinic for appointments on 6 unique days and her commuting took a total of 6 hours.

Commuting

Time and costs associated with commuting to outpatient clinic appointments can further contribute to patient treatment burden. In a prior study, we developed a method to estimate a patient's commute time from their home to the location of their clinic appointment using the Google Maps API(91). In order to maintain patient privacy while using the Google Maps API, we substituted the patient's home address with their zip code(116). Although we could have used Google Maps to calculate driving times from patients' home addresses directly to Vanderbilt facilities, HIPAA requirements prevented us from sending patient addresses to a third-party service without a Business Associate Agreement (BAA)(117). Without a BAA, third-party services could use patient data for advertising or other business. Therefore, we used driving times from patients' zip codes instead of their actual addresses to circumvent the need for a BAA, understanding that this could result in a less accurate estimate of driving time, particularly for patients who lived close to VUMC. In this study, we assumed that patients did not move over the course of their treatment and that driving was the primary mode of transportation. Of note, while the Google Maps API has the capability to take into consideration traffic conditions based on time of day or day of the week, we did not consider changes in traffic into our calculations(118). Commuting costs are estimated by multiplying the distance traveled by the mileage rate of 54 cents per mile in 2016 as determined by the Internal Revenue Service(119).

Outpatient Medications

We calculated two treatment burden measures related to outpatient medications from electronic prescribing data, the number of new prescriptions, and the number of trips to the pharmacy. New prescriptions contribute to the work that patients put into their care by self-administering medications. Another way to measure the contribution of outpatient medication management to treatment burden is through trips to the pharmacy. Patients need to pick up their prescriptions initially and with every refill from the pharmacy. These trips can involve commuting to the pharmacy and waiting for the prescription to be filled. We calculated the total number of prescriptions and estimated number of pharmacy pickups from electronic prescribing data. We assumed that patients picked up all medications prescribed in a given day in one trip to the pharmacy and, that patients continued the use of all medications as directed for the entire prescribed duration, and that patients used all refills prescribed.

Patient Populations

We evaluated our treatment burden measures on two populations of breast cancer patients. In our first population, we sought to determine whether treatment burden measures were sensitive to expected differences in breast cancer patient populations by stage. We collected 18 months of data from the date of diagnosis for patients with stage 0-IV breast cancer who were part of the Vanderbilt Tumor Registry with a date of diagnosis from January 2005 to June 2014.

Based on an initial analysis of treatment workflows, most early stage breast cancer patients received the majority of treatment in the first 18 months after diagnosis. Patients were included who had at least five outpatient appointments, one outpatient medication, and lived within 150 miles of the main VUMC campus. We excluded patients with home addresses outside of 150 miles from VUMC since we assumed that it would be unreasonable for them to commute to VUMC from home for each appointment. Additionally, we excluded patients with fewer than five outpatient appointments since our initial analysis showed that most of these patients were only diagnosed at VUMC or received only one mode of treatment (such as surgery) at VUMC. Including these patients that most likely are receiving care elsewhere would not fully depict the burden that most breast cancer patients experience.

To test whether these measures were useful for capturing the impact of new treatment protocols on patients, we applied each measure to a population of early stage breast cancer patients who received systemic infusion therapy in the adjuvant or neoadjuvant setting at VUMC. We sought to determine whether the introduction of the Neulasta (pegfilgrastim) On-Body Injector (OBI) on April 20, 2015 had any effect on the treatment burden of breast cancer receiving the dose-dense doxorubicin and cyclophosphamide (ddAC) chemotherapy protocol(120). Before 2015, the granulocyte colony-stimulating factor Neulasta was typically given by subcutaneous injection 24 to 72 hours after chemotherapy to increase neutrophil production and decrease the risk of infection and febrile neutropenia(121)(122). Patients receiving Neulasta via subcutaneous injection would either return to the infusion clinic the day after their chemotherapy to receive the injection(123), or self-administer the injection at home. In contrast, an OBI is a device that is attached to the patient during their infusion appointment and programmed to automatically inject medication at a time specified by the provider(124), typically at home 24 hours after the completion of chemotherapy administration. Previous studies showed that Neulasta administered via OBI is pharmacokinetically similar(125) and preferred by clinically compromised patients(126) compared to manually injected Neulasta. Additionally, the OBI successfully delivered medication 98.3% of the time in a controlled study of healthy patients(127).

To calculate treatment burden for patients receiving Neulasta with their ddAC chemotherapy protocol, we first identified breast cancer patients by the presence of a respective ICD-9 (174) or ICD-10 (C50) administrative billing code for any encounter between January 2005 and July 2017. We captured patients that received ddAC from data from the pharmacy information system using a previously developed method(128). We defined ddAC patients as those who received doxorubicin and cyclophosphamide on the same day between 12 and 19 days apart for no more than four consecutive cycles. We collected data from the same sources as the stage 0-IV cohort from the start of each patient's first ddAC administration to 14 days after their last ddAC administration.

In our Neulasta cohort, we compared the treatment burden of breast cancer patients with Neulasta administered by one of three routes: 1) subcutaneous injection administered *in the infusion center* 24-72 hours after chemotherapy, 2) subcutaneous injection administered *at home* 24-72 hours after chemotherapy, or 3) OBI injection placed on the body in the infusion center on the *same day* as their chemotherapy treatment.

5.3 Results

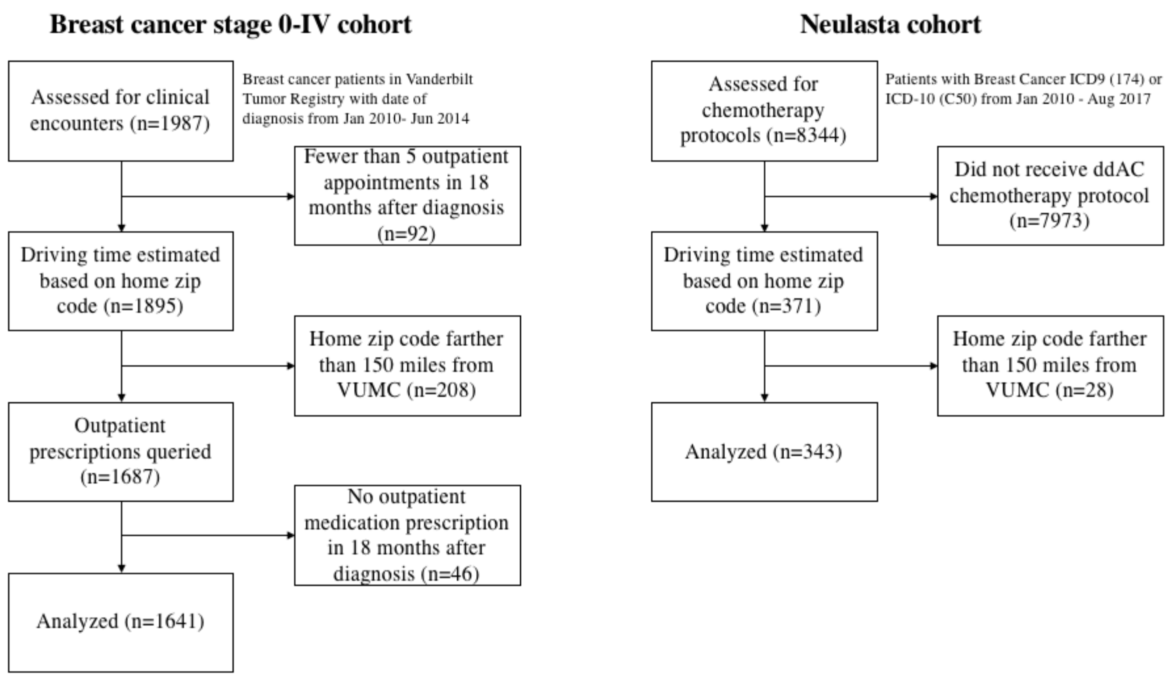


Figure 5.2. CONSORT diagram for breast cancer stage 0-IV and Neulasta cohort selection

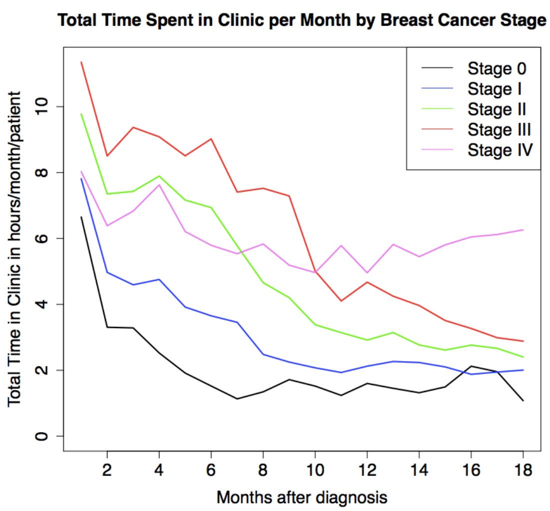
Stage 0-IV cohort

Of the 1987 breast cancer patients diagnosed at VUMC from January 2010 to June 2014, 1641 had at least five outpatient appointments at VUMC, home addresses with zip codes within 150 miles of VUMC, and at least one electronic outpatient prescription in 18 months after diagnosis. Table 5.2 summarizes the results among the cancer registry patients. For most outpatient encounter related tasks such as time spent in clinic and appointment count, stage III patients experienced the highest level of burden followed by stage IV patients, stage II patients, stage I patients, and stage 0 patients. Stage I patients spent a median of 29 hours in clinic over 18 months compared to 84 hours for stage III patients. With the increase in unique appointment days, stage III patients also experienced the highest commuting burden. The estimated commuting cost over 18 months was $860 for stage I patients compared to $1436 for stage III patients. For medication and inpatient measures of burden such as total prescriptions and percentage of patients admitted, stage IV patients experienced the highest level of burden followed by stage III, II, I, and 0 patients. Stage I patients had a median of 13 new prescriptions in 18 months after diagnosis compared to 23 for stage III patients. Kruskal-Wallis H tests showed that the differences between stages was significant for all measures at an alpha of .01.

Table 5.2. Treatment burden measures for patients with breast cancer from the Vanderbilt Tumor Registry by stage over 18 months after diagnosis. **Median** (IQR) where applicable.

		Stage 0	Stage I	Stage II	Stage III	Stage IV
	Number of Patients	**251**	**650**	**483**	**177**	**80**
Outpatient Encounters	Number of appointments	**28** (17-42)	**38** (23-62)	**64** (34-93)	**79** (51-120)	**75** (39-109)
	Unique appointment days	**20** (11-32)	**25** (13-39)	**33** (20-53)	**41** (24-76)	**33** (15-47)
	Hours of appointment time	**12** (7.4-17)	**15** (10 -29)	**39** (15-72)	**65** (31 -84)	**40** (17-79)
	Hours waiting between appointments	**7.9** (4.4-12)	**12** (7.4-19)	**19** (9.6-30)	**25** (15-36)	**23** (10-37)
	Hours spent in clinic (appointment + wait time)	**19** (13-29)	**29** (19-48)	**53** (27 -92)	**84** (44-114)	**68** (28-104)
	Hours spent in clinic *per month*	**1.1** (0.72-1.6)	**1.6** (1.1-2.6)	**3.0** (1.5-5.1)	**4.6** (2.5-6.3)	**3.8** (1.6-5.8)
Commuting	Hours commuting	**26** (15-44)	**35** (20-56)	**51** (30-82)	**62** (33-88)	**53** (21-104)
	Roundtrip time in hours (clinic + commuting) time	**50** (32-70)	**69** (41-104)	**111** (63-178)	**152** (96-195)	**114** (53-210)
	Hours from departure to return *per month*	**2.8** (1.8-3.9)	**3.9** (2.3-5.8)	**6.2** (3.5-9.9)	**8.4** (5.3-11)	**6.3** (3.0-12)
	Distance from VUMC Breast Cancer Clinic (miles)	**30** (16-72)	**37** (17-82)	**40** (17-90)	**37** (15-79)	**54** (23-97)
	Cumulative commuting distance (miles)	**1197** (566-2151)	**1594** (787-3205)	**2438** (1217-4395)	**2660** (1341-4716)	**2636** (884-5886)
	Commuting cost ($)	**646** (306 -1162)	**861** (425 - 1730)	**1317** (657 - 2374)	**1437** (724 - 2547)	**1423** (478 - 3178)
Outpatient Medications	Number of new outpatient prescriptions	**9** (4-18)	**13** (7-24)	**20** (11-31)	**23** (14-37)	**24** (12 -44)
	Number of pharmacy pickups	**6** (3-13)	**12** (7-20)	**15** (9-23)	**16** (10-25)	**19** (8-26)
Admissions	Number of unique admissions	**0** (0-0)	**0** (0-0)	**0** (0-1)	**1** (0-1)	**1** (0-2)
	% of patients with at least one admission	**24**	**24**	**32**	**44**	**58**
	Total inpatient length of stay (days)	**0** (0-0)	**0** (0-0)	**0** (0-1.4)	**0** (0-3.1)	**1.9** (0-7.3)
	% of patients with at least one emergency department visit	**8.0**	**7.8**	**16**	**23**	**21**

For several encounter related measures, we plotted the average burden experienced over 18 months after diagnosis (Figures 3a and 3b). We observed that total time spent in clinic was highest in the first month after diagnosis and tended to taper off over 18 months. Patients of stages I-IV experienced a bump in time spent in clinic between months three and five. Figure 5.3b shows the breakdown of appointment time for all patients by department. Imaging and surgery appointments were most prevalent during the first few months of a patient's treatment while chemotherapy and radiation therapy had their highest utilization in months three to five.



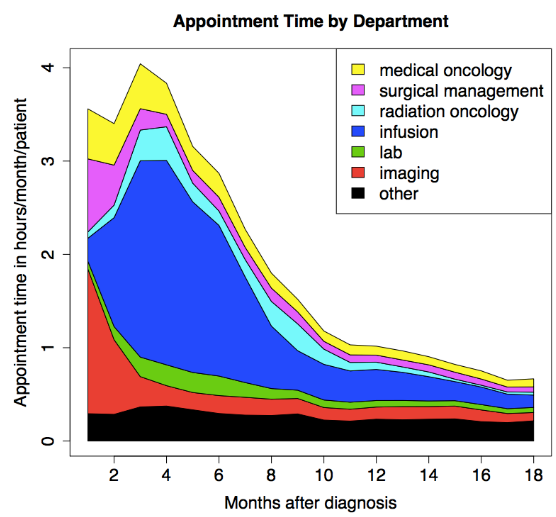


Figure 5.3a. Total time spent in clinic (appointment time plus wait time) for breast cancer patients at VUMC over 18 months after diagnosis.
Figure 5.3b. Appointment time for breast cancer patients by department

The boxplot in Figure 5.4 visualizing the distribution of appointment count by stage is also helpful for identifying outliers. The median appointment count over 18 months was 38 appointments for stage I and 79 for stage III. There were also 48 patients that had over 150 unique appointments during that time, representing a significant treatment burden.

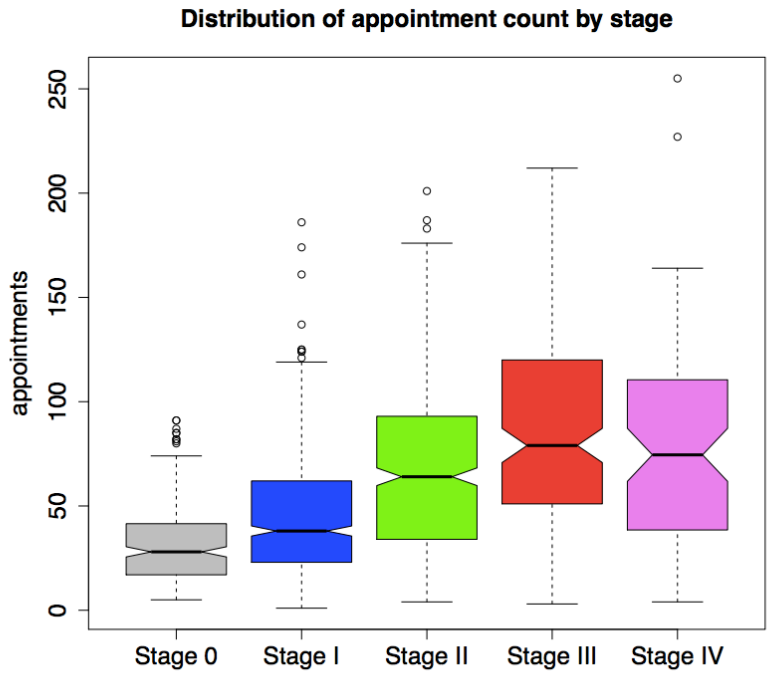


Figure 5.4. Distribution of the number of appointments experienced over 18 months after diagnosis by stage.

Neulasta cohort

For studying the effect of Neulasta delivery mechanism on treatment burden, we identified 371 breast cancer patients who received the ddAC chemotherapy protocol from January 2010 to August 2017. Among these, 343 had home addresses with zip codes within 150 miles of VUMC. In total, these 343 patients received 1158 cycles of ddAC. For those cycles, 464 doses of Neulasta were administered by the on-body-injector (OBI), 303 by subcutaneous injection in the infusion center 24-72 hours after chemotherapy, and 391 by self- administration by subcutaneous injection at home. Over the course of their ddAC chemotherapy, 40 patients had more than one mode of Neulasta administration from cycle to cycle. Patients receiving Neulasta by subcutaneous injection in the infusion center spent about 40 minutes longer in appointments and had one additional day in clinic per cycle. Cycles where patients received the subcutaneous injection of Neulasta in the infusion center were also admitted to Vanderbilt University Hospital at a higher rate than OBI and take-home Neulasta cycles. This result does not account for patients admitted to hospitals outside of the VUMC system. Patients who received Neulasta via self-administered injection tended to live further from clinic (median 64 miles) compared to patients who received Neulasta with the OBI (median 40 miles) and the clinic administered injection (median 30 miles).

Table 5.3. Treatment burden experienced per cycle for breast cancer patients receiving various modes of Neulasta administration as part of their ddAC chemotherapy. Cycles were between 12 and 19 days apart. **Median** (IQR) where applicable.

		OBI	Next-Day SubQ	Take Home SubQ
	Number of cycles	**464**	**303**	**391**
Outpatient Encounters	Number of appointments	**4** (3-5)	**5** (4-6)	**3** (3-4)
	Unique appointment days	**1** (1-2)	**2** (2-3)	**1** (1-2)
	Hours of appointment time	**3.7** (3.6-4.6)	**4.4** (4.1-5.6)	**3.6** (3.6-4.6)
	Hours spent waiting between appointments	**1.2** (0.92-2.7)	**1.4** (0.92-2.1)	**1.4** (1.0-2.1)
	Hours spent in clinic (appointment + wait time)	**5.3** (4.5-7.8)	**6.0** (5.3-7.7)	**5.3** (4.8-6.7)
Commuting	Hours commuting	**2.3** (1.1-4.0)	**3.0** (1.8-5.0)	**3.0** (1.8-4.5)
	Roundtrip time in hours (clinic + commuting) time	**8.4** (6.5-12)	**10** (7.3-12.7)	**8.6** (6.9-11)
	Distance from VUMC Breast Cancer Clinic (miles)	**40** (22-91)	**30** (12-61)	**64** (24-112)
	Commuting Distance (miles)	**121** (52-231)	**136** (74-280)	**165** (87-264)
	Commuting Cost ($)	**65** (28-125)	**74** (40-151)	**89** (47-143)
Outpatient Medications	Number of prescriptions	**1** (0-2)	**1** (0-3)	**0** (0-3)
	Number of pharmacy pickups	**1** (0-1)	**1** (0-1)	**0** (0-1)
Admissions	Number of unique admissions	**0** (0-0)	**0** (0-0)	**0** (0-0)
	% of cycles with an admission	**1.1**	**4.3**	**1.3**
	Total inpatient length of stay (days)	**0** (0-0)	**0** (0-0)	**0** (0-0)
	% of cycles with an emergency department visit	**1.1**	**1.7**	**2.1**

5.4 Discussion

The goals of this work were 1) to develop a framework for calculating and reporting quantitative measures of patient treatment burden derived automatically from electronic health records, and 2) to demonstrate that these measures are sensitive to expected differences in treatment burden across a population of breast cancer patients. The measures of patient treatment burden are derived from data elements commonly found in most electronic health record systems including patient and facility addresses, admission and appointment events, and electronic prescription records. The measures themselves are also relatively simple calculations of event counts and time between events. This is a major strength of the framework as it could be easily reproduced at another healthcare delivery system using a completely different electronic health record system. For our two breast cancer patient cohorts, we demonstrated that these measures of treatment burden are sensitive to expected differences in the intensity of treatment by cancer stage and even to subtle differences in otherwise very similar treatment protocols.

Although outpatient appointment records, inpatient admission records, patient demographics, and electronic prescribing are all reliable sources of data, there are limitations to how accurately the EHR captures burden for patients. While these records should be accurate for care given at VUMC, we were unable to capture care given at other healthcare organizations. The obvious limitation of using data from a single health care delivery system is that it underestimates the true treatment burden for those patients who utilized healthcare services at multiple institutions. We determined from the tumor registry that 31% of patients in the stage 0-IV cohort had some portion of their cancer treatment at a non-Vanderbilt institution. Future work will include data sources that capture services provided outside our institution such as pharmacy transaction data for prescriptions and payer claims data.

With outpatient medications, a more precise measure for treatment burden could have been the total number of active medications or frequency of medications taken per day. While duration and frequency data were available in electronic prescribing data, many patients start cancer treatment already taking medications for comorbid conditions. Additionally, we had to assume that patients continued taking all medications prescribed even if their providers asked them to stop. Future work to characterize medication burden could use medication lists to characterize outpatient medication related burden.

There are several uses for our measures in cancer care delivery. For example, a breast cancer navigator could use Figure 3a to help patients plan at the time of diagnosis for how much time they should expect to spend at the clinic in the upcoming months. This preparation may allow the patient to make the necessary arrangements in their work or caregiver schedules to make way for the care that will give them the best chance for recovery. Healthcare organizations could use Figure 3b to ensure that capacity is available in coming months for patients that are diagnosed with cancer today. For example, if three patients are diagnosed with breast cancer in January, the chemotherapy clinic should plan to have at least three infusion chairs available for two hours from April to June. Furthermore, healthcare management could use Figure 5.4 to identify patients who are at risk for overutilization or overburden. Patients who are experiencing high burden compared to others with comparable disease may be candidates for interventions that alleviate some patient work such as home visits or telehealth encounters.

While previous studies may have implied that using the OBI would decrease work patients must do, researchers can strengthen these claims through the treatment burden measures proposed in this study. These measures can be calculated prospectively or retrospectively from electronic records. Table 5.3 shows that cycles where VUMC administered Neulasta with the

OBI, patients experienced one fewer unique appointment day compared to cycles where VUMC used next-day injections. While the decrease in unique appointment days did not translate into a significant decrease in commute time or cost, presenting this evidence would help make the case that patients who are clinically compromised or who live further away from an infusion clinic should receive the OBI. Therefore, treatment burden measures can provide data-driven evidence for the increased convenience for new treatments.

Another point to note is that patients experience treatment burden differently. Some patients may be more capable of complying with complex and strenuous care plans while others may not have the ability to follow simple instructions. Practitioners of Minimally Disruptive Medicine have termed a patient's ability to handle treatment burden as capacity(16). Elements of capacity such as resilience, home environment, and financial well-being allow patients to take on more treatment without being overburdened(19). The next step to providing clinical decision support to that addresses treatment burden is to identify clinical and non-clinical characteristics of patients that cause patients to feel overburdened by the objective measures identified in this study. Helping providers identify patients who are at risk for overburden and non-compliance with their care plans could lead to care that is tailored to the patient and better clinical outcomes.

5.5 Conclusions

Treatment burden is a real and important dimension of the cancer patient experience. Healthcare delivery organizations can measure it multiple ways both qualitatively and quantitatively. We showed through this study that measures derived from electronic records can differentiate populations of breast cancer patients by stage. We also demonstrated that providers can use these measures to understand how changes in treatment protocol can impact the work patients put into their care. Future work will attempt to use treatment burden measures to intervene with clinical decision support for patients who are likely to become overburdened.

Chapter 6

Cumulative Discussion and Conclusions

6.1 A framework for the study of Patient Experience Analytics

The Institute for Healthcare Improvement has identified three areas of improvement for modern healthcare systems: improving the experience of care, improving the health of populations, and reducing per capita costs(131). In order for healthcare systems to achieve improvement in each arm of the "triple aims", analytical methods need to be developed to characterize improvement in those areas. Due to the importance of the patient experience as identified by leaders in the healthcare management field, the increase in the availability of data related to patients outside of clinical encounters, and the limited amount of published material related to assessments of patient experience(132), we believe that there is potential for Patient Experience Analytics to be a field of study. For the purpose of this discussion, we define Patient Experience Analytics as an interdisciplinary field that uses data science methods to describe and predict experiences of patients.

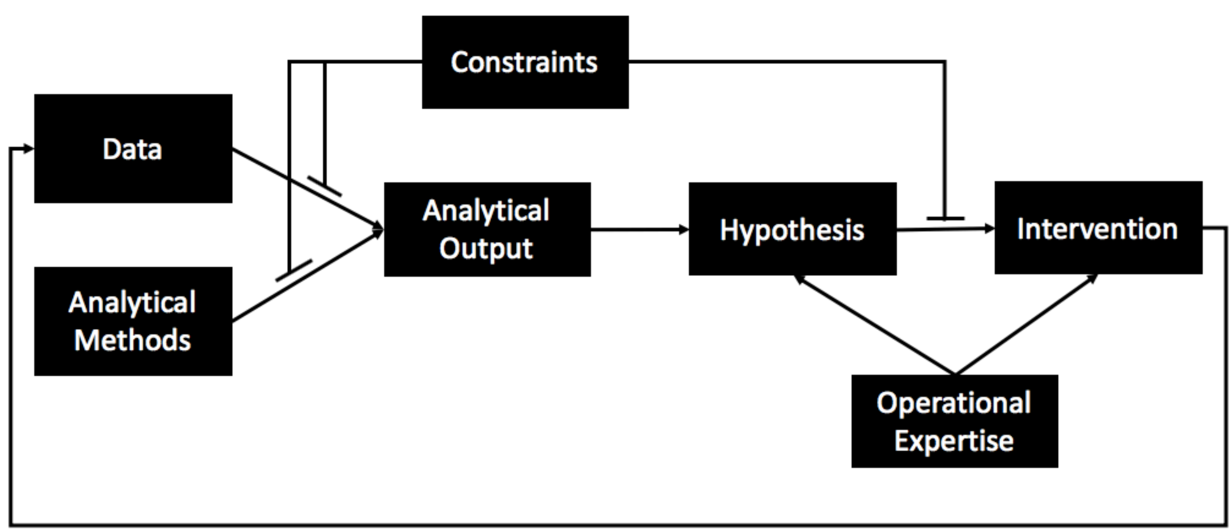


Figure 6.1. A framework for Patient Experience Analytics

Table 6.1. Examples of elements of Patient Experience Analytics studies

Dimensions	Data sources	Operational Expertise	Analytical methods	Constraints
• Physical experience • Self-care • Environmental risk factors • Location and movement • Interaction and communication ○ Administrative ○ Clinical ○ Social • Relationships • Financial burden	• Mobile health management applications • Clinical information systems • Geospatial data ○ GPS tracking ○ Indoor location tracking • Search logs • Access logs ○ Electronic health record ○ Patient portal • Claims and charges • Patient reported surveys • Financial transactions	• Clinical • Measure development • Operations research • Implementation science • Ethnographic interpretation	• Statistics • Visualization • Network analysis • Regression • Simulation • Optimization	• Privacy • Regulatory • Ethical • Technological • Computational • Data quality • Data linking • Organizational • Financial

Figure 6.1 shows a framework for research in Patient Experience Analytics. Within any of the domains of patient experience, studies start with data collection. Whether through electronic databases, application programming interfaces, or from patient reported surveys, a meticulous plan for data collection is necessary to ensure quality data and valid results. The application of analytical methods to data sources yields an analytical output, information about the patient experience upon which healthcare organizations can act. With the results of analysis, operational expertise is necessary to formulate a hypothesis for improving the patient care experience that can be tested through evaluating an intervention. An intervention could include

changes to clinical processes, modification of staffing responsibilities, or integration of information technology solutions. The outcomes of the intervention produce more data that patient experience researchers can use to form new hypotheses, thus enabling a cycle of continuous improvement.

Constraints may impact the quality of the data or the ability to apply particular methods. Other constraints could inhibit the usefulness of the results of the analysis or the realistic options for interventions. These constraints can be social or technical in nature. The goal of future advances in Patient Experience Analytics is not necessarily to overcome all constraints. Many social constraints are necessary in order to protect consumers and vulnerable populations(133). Nevertheless, researchers in Patient Experience Analytics need a thorough understanding of the limitations on validity and reliability of studies where data sources and methods may be constrained.

We believe that is great potential for studies to dive deeper into different combinations of data sources and methods that reveal insights about the patient experience. Examples include:

- Identifying provider-patient communication patterns that are associated with optimal outpatient appointment structures
- Using location data to log exposures to environmental hazards
- Optimizing combinations of services based on location and preferences for illnesses with predictable service trajectories.

These examples illustrate how Patient Experience Analytics can draw on readily accessible data to improve the quality of health care services. Work in Patient Experience Analytics can also draw on the “Quantified Self” (QS) movement, where individuals track biological, physical, behavioral, and environment data about themselves(134). People who subscribe to the QS way of life collect a wide range of data on themselves including wearable sensors, mobile phones, and genetic data. Where QS studies involve heterogeneous data focused on individual patients, Patient Experience Analytics seeks to perform analysis on the patient experience for groups or populations of patients. Studies in patient experience requires some standardization in data collection but can draw from groups of individuals engaged in tracking QS measures.

Patient Experience Analytics can also draw from some methods from *infodemiology*, an emerging field of mining unstructured data from the internet to understand trends and attitudes in a public health setting(135). Google flu trends, which inferred the spread of the flu based on web searches for related terms is an example of public health surveillance in infodemiology. Like with infodemiology, Patient Experience Analytics will have to make use of incomplete data to make inferences about what patients must go through to receive care. Chapter 3 provided some good examples of using incomplete data to make estimations about how much patients walked in the medical center. The difference between infodemiology and what we are defining as Patient Experience Analytics is that Patient Experience Analytics focuses on the experience of a specific population of patients and is meant to inform interventions that can be implemented by healthcare organizations.

While Patient Experience Analytics draws on previous work in population health research, it is distinct in that it focuses on the individual experiences of patients and how those experiences influence their decisions and outcomes. Therefore, we propose that Patient Care Analytics is a field of research that has potential to shape the way we understand and provide healthcare.

6.2 Applying the Patient Experience Analytics framework

The work in this dissertation covers a range of data sources, methods for analyzing that data, and dimensions of the patient experience. We also used the results of these studies to form hypotheses that could inform opportunities for future interventions. Table 6.2 summarizes each of the studies on Patient Care Experience Analytics in this thesis according to this framework.

In chapter 2, we used data from the Nashville Metropolitan Transit Authority, the US Census Bureau, and appointment records from the electronic health record to describe the commuting burden for a population of breast cancer patients. To analyze this data, we used the Google Maps API to estimate driving times, driving distances, and commuting costs for this population of patients. The need to protect patient privacy from online advertisers limited the accuracy of our commute time calculations, but our privacy preserving approach resulted in a reasonable estimate. We then applied simulation techniques to propose that opening a new clinic in an optimal location for our existing patient population would decrease commute times. Other potential interventions could include case management strategies to minimize the number of unique days in the clinic by coordinating appointments on the same day, thus decreasing the total number of days commuting to the clinic. The efficacy of either intervention strategy could easily be evaluated by monitoring changes in commute burden for patients.

Table 6.2. Summary of how studies in this dissertation fit into the Patient Experience Analytics framework. Elements in red have not been addressed and are part of future work.

	Data sources	**Analytical methods**	**Analytical output**	**Constraints**	**Hypothesis**	**Operational expertise**	**Intervention**
Chapter 2: Commuting to and from the medical center	• Addresses • Census • Clinical • Encounters	• Google Maps API • Summary Statistics • Visualization • Simulation	• Driving distances, times, and cost • Optimal location for new services	• Patient address privacy • Availability of optimal location	• Offering new services at a strategic location will reduce commuting burden for patients • Coordinating appointments to reduce total number of unique days commuting to clinic	• Healthcare management • Care coordination	Open a new clinic in optimal location Case management schedule optimization
Chapter 3: Inferring patient travel within the medical center	• App user location and desired destination • Location coordinates	• Network analysis • Routing algorithm	• Estimated walking distances • Associated areas of medical center	• App user privacy • Low app utilization	Directions sent in advance of appointments will increase the percentage of patients parking closer to their destination	• Facilities management • Appointment scheduling	Directions sent in advance with appointment reminders
Chapter 4: Diagnosing problems with clinic workflow	• Check-in, room-in, and check-out timestamps • Scheduled appointment times	• Constraint satisfaction optimization • Discrete event simulation	• Late patients and long appointment durations • Providers and days with problematic workflows	• Provider unwillingness to be tracked • Generalizability • Computational complexity	Working with a care coordinator to reduce patient tardiness will increase likelihood appointment days end on time	• Care coordination • Appointment scheduling	Care coordinators strategically assigned to specific providers
Chapter 5: Measures of treatment burden	• Clinical Encounters • Medications • Tumor registry • Surveys	• Visualization • Statistical comparison	• Cohort comparisons • Outlier identification	• Limited data from other institutions • Disparate data models • Decision support development costs	Navigation services will reduce treatment burden for patients with high care utilization	• Cancer navigation • Clinical decision support	Implement cancer navigation for patients who experience high treatment burden

In chapter 3 we used search requests and network analysis to provide insight into how far patients walked in the medical center. The data collected from a novel wayfinding application included the location where the patient stood when making a request for directions, the desired destination, and the time the request was made. We used the X-Y coordinates for each location to estimate walking distance for users. In future work, we will use a routing algorithm to more accurately determine walking distance. A privacy constraint prevented us from being able to determine whether a small number of patients were responsible for a majority of the requests. A hypothesis that we proposed as a result of this study was that directions sent with digital appointment reminders could help patients park closer to their desired destinations. Facilities managers and appointment scheduling experts could come together to implement such an intervention. The success of this intervention could continue to use the wayfinding application data to determine whether a higher percentage of patients are requesting directions from the parking lot closer to the requested destination.

With Chapter 4 we used indoor location data and optimization to identify problems with clinic wait times. Data sources included timestamps for check-in, room-in, and check-out for patients in one clinic from two different workflow management systems. We could only track waiting room wait times due to the social constraint that clinic providers were unwilling to wear trackers that would indicate when they were in the room with patients. Additionally, this study suffers from several barriers to generalizability, since most other clinics do not have two workflow tracking systems. Furthermore, if some clinics had many more appointments in a given day, computational constraints could made it infeasible to find an optimal solution to the constraint satisfaction optimization problem. Nevertheless, results from this study allowed us to form the hypothesis that patient care coordinators could be allocated to patients who consistently are late for their appointments. These care coordination services, when allocated strategically to problematic clinics or patients, could increase the likelihood that those clinics complete more appointments as scheduled.

In chapter 5, we produced visualizations to help patients and providers allocate resources and plan for future treatment using clinical information system and cancer registry data. We also performed statistical comparisons see whether there was a significant difference in treatment burden between patients receiving two different treatment options. The generalization of this work to other healthcare systems could prove problematic if data models at those institutions are significantly different from one another. We hypothesized that cancer navigation services could help patients with high treatment burden manage and coordinate their care. Cancer navigators and clinical decision support teams can use the results of these studies to create decision support tools that aid in decision making for patients with cancer by trying to balance patient capacity with anticipated or observed treatment burden.

6.3 Ethical implications of tracking patient experience

There are several ethical concerns for research on patient experience and implementing interventions that may improve the patient experience. For example, with location tracking for patient experience, there are several areas where the interest of the institution and the patient may be at odds. In a review of literature about ethical challenges with tracking patients with dementia or intellectual disabilities, authors identified that institutional aims for tracking patient experience such as efficiency and safety were often at odds with patient concerns such as freedom, dignity, and privacy(136). Privacy is one of the foremost concerns with any system that may collect data on patient activities or location for research or healthcare. On one hand, consumers are accustomed to the idea of allowing technology companies such as Google and Facebook to collect information on them in exchange for free use of those companies' services and the added value of having advertisements, predictive search requests, media recommendations, and personal connections that are tailored to their interests. On the other hand, consumers fear that these companies are using their data in ways they are not aware. In the 2018 Facebook scandal, information from Facebook users was sold to a private consulting firm that attempted to influence the outcome of the 2016 presidential campaign(137).

Most healthcare organizations are currently not in the business of selling patient information to third party entities. Nevertheless, just because hospitals are not directly selling patient data does not mean those organizations do not derive value from data collected from patients. For example, data and technology from the BioVU biobank and de-identified health record have been used to spin off a private company that helps drug companies find new indications for existing drugs(138). Vanderbilt owns equity in this company, Nashville BioSciences, and therefore derives financial value from the patient data it collected. Additionally, institutions use their data resources to apply for grant funding which allows companies to financially sustain research operations.

One important question to ask in determining the economics behind studying interventions that improve the patient experience is who is receiving the benefit? Healthcare organizations get value out of clinical data to improve the efficiency and quality of clinical care. Payers get value from claims data to set competitive reimbursement rates and premiums. Meanwhile, it is more difficult to identify situations where patients receive direct benefit from data generated from them. One argument for funding research in Patient Experience Analytics is that studies will demonstrate value to patients for sharing their data, thus justifying the collection and use of patient data by healthcare organizations.

In response to the 2018 Facebook scandal, the European Union released a set of guidelines called the General Data Protection Regulation (GDPR), which requires companies collecting personal, health, and income data to disclose how their data is used to consumers, obtain consent for using that data, and allow consumers to prevent organizations from using their data(139). At the time of this writing, these rules do not yet apply in the United States. However, the GDPR guidelines present an opportunity for data collecting entities in the United States, including healthcare organizations. Instead of finding ways to hide what companies like Facebook are doing with users' data in lengthy and incomprehensible user agreements, these companies could clearly demonstrate the value of collecting information to their customers. Healthcare organizations could communicate to patients that providing data about patient experience could result in financial and time savings benefits. For example, patients may be hesitant to download an application that tracks their location at the medical center. However, if the healthcare organization can show patients that there is low risk for their information being misused by third parties and that there is value in time savings by reducing waiting time, patients may be more willing to share their data.

Patient Experience Analytics researchers should partner with colleagues in healthcare ethics to understand the utility of various services that could track patient experience. This type of study has already been performed for online services where the companies like Google or Facebook offer the service for free but monetize users' data. This study performed by the National Bureau of Economic Research asked people how much they would pay not to have their access blocked to different types of free online services. Participants in this study were willing to pay a median of $17,530 to maintain access to search engines, $8,414 to keep their email, and $322 for their social media per year(140). A similar study to understand the value of sharing patient experience data could ask how much patients would pay to have their appointment wait times shortened by 30 minutes or to reduce the number of trips they must make to the medical center. Results from this study could help healthcare organizations identify the interventions for which patients would be most willing to offer their data.

Patients are not the only ones who may fear how their data is used, as staff may also have concerns about how tracking data is used. For example, some medical centers have used indoor locator systems with nurse call systems to automatically cancel alarms when a nurse enters a room, enable overhead paging only in the room where the nurse is located, and automatically forwarding calls to the correct staff when a nurse is off the unit(141). These features can decrease work for nurses and improve efficiency on the unit. However, many have rejected indoor location system integration with nurse call because of fears that the data will be used against them. For both patients and hospital staff, people are afraid that fine-grained data about their activities could be used to scrutinize their errors and put their employment at risk. Therefore, the social cost is may not be worth the gain in efficiency to many and must be taken into account when considering decisions about tracking in healthcare.

Maintaining the public trust for data stewardship is essential for research that tracks patient experience. The 2006 Veteran Affairs stolen laptop scandal showed how public opinion about data safety can change in an instant(142). Public trust is essential for research that relies on patient data. If the public does not trust healthcare organizations to be good stewards of their data, increased regulation will make analytical research in healthcare more cumbersome or impossible. Therefore, it is imperative that research and systems that aim to improve the patient experience carefully protect patient data and demonstrate tangible value.

6.4 Future Work

There is still much work to do with operationalizing knowledge from this dissertation into practice. As discussed at the end of chapter 5, measures about treatment burden need to be assessed in conjunction with patients' ability to manage care. We have received funding to develop a survey instrument to assess treatment burden and capacity in breast cancer patients and evaluate it at several healthcare organizations across the United States. Additionally, we will attempt to validate the minimally disruptive medicine paradigm by seeing whether the balance of treatment burden and capacity has any effect on adherence and health outcomes. Furthermore, we will assess whether the measures derived from the electronic health record in chapter 5 correlate with treatment burden measures as assessed by the survey we develop. The ultimate goal will be to provide decision support for patients who are diagnosed with cancer that will help them make decisions about their care based on their capacity to manage that care.

One of the major limitations to generalizing our work in chapters 3 and 4 of using indoor tracking data to understand patient experience is that most other institutions do not have the technical expertise or financial resources to implement a real-time locator system. To overcome this constraint and to make indoor tracking technology available to more healthcare organizations, we plan to create a toolkit that enables researchers to track workflow. This toolkit will include Bluetooth low energy transmitters, receivers, and software that track the movement of staff, patients, or articles from room to room. From time and motion studies(143) to activity-based costing(144) in healthcare, there are many needs for indoor tracking that Bluetooth low energy beacons can address. Our goal will be to simplify the setup for automated indoor location studies so that patient experience researchers without technical backgrounds can perform workflow tracking studies.

We believe there is much potential in using electronic data to better understand the patient experience, and that the methods, sources, and expertise required constitute a new field, Patient Experience Analytics. As our methods for describing the patient experience improve, healthcare delivery organizations will be better equipped to provide personalized care that is convenient, high-value, and tailored to their ability to manage treatment.

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