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This DNP scholarly project, directed and approved by the candidate's committee, has been accepted by the School of Nursing and College of Graduate and Professional Studies of Abilene Christian University in partial fulfillment of the requirements for the degree

Doctor of Nursing Practice



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College of Graduate and
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School of Nursing

The Impact of Direct Nursing on Patient Engagement
to Improve Medication Adherence

A doctoral project submitted in partial satisfaction
of the requirements for the degree of
Doctor of Nursing Practice

by

Shelley Moore

December 2019

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“For I know the plans I have for you, plans for your well-being, not for disaster, to give you a future and a hope.” Jeremiah 29:11 (CSB)

Abstract

This study examined the impact of direct nursing care on patient engagement and medication adherence within the practice setting of specialty pharmacy. It investigated the problem statement, “Among patients with specialty pharmacy dispensed medications, will direct interaction with nurses impact patient engagement and improve medication adherence?” Patient engagement in healthcare is a growing area of knowledge for the effectiveness of care. The research uncovered patient engagement as a predictor of improved medication adherence through effective direct nursing involvement. Methods to measure engagement were the utilization of the ACE™ Altarum Consumer Engagement (ACE) Measure™. By using a proven, researched tool to measure patient engagement, the study captured those engagement scores and compared the impact of direct nursing engagement to telephonic engagement. The engagement information was lined up with historical and current medication adherence data to determine if any correlation. Results were calculated and compared against patient ordering during the study. In conclusion, healthcare providers influenced patient engagement. The influence shaped a patient’s overall experience and outcomes. Nurses, the front-line contact for the patients, were the factor that effectively impacted medication adherence outcomes by improving patient engagement.

Keywords: nursing, alternative site of care, patient engagement, patient experience, medication adherence, knowledge deficit, specialty pharmacy

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Chapter 1: Introduction

Specialty pharmacy providers maintain policies that include patient satisfaction scores. However, the lack of understanding of the nursing process and the impact of nurse-led patient management has left gaps in care effectiveness and overall nursing utilization. This lack of utilization and understanding leaves an unmeasured area of research into how nursing engagement impacts medication adherence. Specialty pharmacies focus on extremely costly medications that require unique and specific management programs for rare and ultrarare disease states. Specialty pharmacy providers routinely hire, coordinate, and utilize their nursing divisions to manage these patients for disease education or injection/infusion administration. Since these organizations are not customarily considered a group within the nursing field, the organizations remain excluded from nursing theory research and other research related to how nursing engagement impacts medication adherence.

The healthcare industry involves health plans, manufacturers, pharmacies, and other parties like employers that are not typical nursing care providers. Specialty pharmacy needs involvement to inclusivity of their nursing in the design of patient engagement models utilizing nursing theory research. These new models of care can improve not just patient satisfaction scores but the overall patient experience.

The exploration into how specialty pharmacy nurses engage and influence patient experience and improve medication adherence is the focus of this project. These nurses are skilled in understanding rare disease and specialty pharmacy injectable medications. With medication adherence being a challenge in all areas of healthcare, this project is significant in that it could potentially impact adherence scores through improvements in how nurses specifically engage patients.

Money lost to medication and therapy nonadherence is estimated to be around \$177 billion yearly (World Health Organization [WHO], 2003). More recent statistics show nonadherence costs \$637 billion dollars annually (HealthPrize Technologies, 2019). With staggering statistics increasing at an epidemic rate, there needs to be more research into the understanding of patient barriers to specialty medication adherence. Specialty pharmacies are uniquely positioned to provide interventions for understanding this phenomenon.

Pharmacies already employ, through direct employment or contract, nurses to provide home infusion services or in-office case management. These nurses can and could be directly on the front lines of patient communication with access to uncovering barriers to medication adherence. This research project will measure patient engagement with nurses and the engagement's impact on medication adherence.

Utilizing the Altarum Consumer Engagement (ACE) Measure™ tool, the project will collect data on nursing engagement of specialty pharmacy patients. The nurse specifically in the home or the alternate sites of care settings will utilize this tool. The specialty pharmacy industry, as well as the patient care team, need to be included in the model of care (Altarum, 2019). With proven research into patient engagement for improvement in various healthcare settings, the ACE™ assessment tool by the Altarum Institute was selected for utilization.

Patients will receive the engagement tool either in the home or at the alternate site of care by the nurse. The pharmacy will also document the last medication refill prior to the start of the study. During the study months, refill information will be captured by a simple yes or no question at the time the nurse gives the patient engagement tool.

With the nurse administering the ACE™ tool, the nurse needs to set the tone and provide a nurturing environment for patient openness and trust. Hall's theory of care, cure, and core is

well suited in that it is focused on performing the task of nurturing patients (Nursing Theory, n.d.). With her theory, as in this project, the nurse is always present.

Overview of the Problem Statement

The project is based on the following problem statement: Among patients with specialty pharmacy dispensed medications, will direct interaction with nurses impact patient engagement and improve medication adherence?

Currently, specialty pharmacy patient management is limited to phone assessment by either the pharmacist or the nurse case manager. There are no guidelines for nursing management to evaluate the effectiveness of this care, which is provided by the specialty pharmacy. Most pharmacies include a patient satisfaction survey to only measure how a patient views their service. Satisfaction survey information is limited to the questions in the survey. As stated in this proposed study, the problem exists in the route of data collection and lack of face-to-face interaction with the nursing staff. This problem within specialty pharmacy management opens the opportunity for direct nursing managed care for interventions to improve specific areas of need in this patient group. The pharmacy has the resource of nurses but has not fully utilized this resource in patient care and how it can impact outcomes.

With the current rise in overall healthcare expenditures and insurance payer regulations in reimbursement structure, specialty pharmacies are faced with multifaceted challenges in how to manage patient care effectively with reduced reimbursements and increased payer regulation. This industry is no stranger to nursing utilization for case management, but it is limited in the understanding of the breadth of knowledge and intuitiveness of the nursing process. By understanding and capitalizing on the thoroughness of this process, nurses in direct patient care

can impact patient engagement. It is in this engagement that expectations of improvements in medication adherence could be observed.

Background

Specialty pharmacy providers maintain policies to include patient satisfaction scores, but the lack of understanding of the nursing process and the impact of nursing engagement for improved patient experience has left gaps in care effectiveness and nursing utilization. This patient population includes patients of all races, ethnicities, and cultural backgrounds. For specialty pharmacy therapy management, all cultural differences and issues related to each population group are considered upon admission to the pharmacy services. The pharmacist and nurse case managers manage these specifics.

From an overall healthcare economic status, it is estimated that 25 to 30 million people are afflicted with a rare disease or approximately 8% to 10% of the population (Kvancz, 2016). Poor adherence indirectly impacts the pharmaceutical manufacturer, but then directly affects the US healthcare system related to increased avoidable healthcare outcomes due to poor medication management.

When looking into the full well-being of the patient, the information collected by the nurse using the ACE™ tool, as well as pharmacy data of routine dispenses, should provide insight into the strategy to impact patient care and develop patient-specific therapy management techniques. The project will provide nurse intervention within the home or alternate site of care. While in the home, the nurse will engage the patient with the ACE™ tool and perform all other pharmacy-required assessments and medication counts. The comparison for the study is the historical pharmacy data on medication adherence in contrast to the data collected during the study period where the ACE™ tool was utilized by the nurse in the home or alternate site of care.

The previous pharmacy protocol for assessment is through phone triage with either the pharmacist or the nurse. This phone assessment provides the pharmacy a verbal count of actual medication in the home as well as verbalization of standardized questions answered on routine refill assessments. In contrast, this project will place the nurse in the home or alternate site of care to visually perform the pharmacy refill assessment and the ACE™.

Purpose of the Study

This proposed project will evaluate patient engagement for specialty pharmacy patients using the ACE™ measurement tool with direct nursing interaction. Along with collecting the information from the ACE™, the nurses will collect their routine refill assessment. The project will calculate scoring from the patient engagement tool as well as the information on medication refills for routine dispenses. The information from the ACE™ could show a positive improvement in medication adherence when there is a higher engagement score. This improvement would be impacted by the direct engagement of the nurse.

The purpose of measuring medication adherence is due to it being one of the most difficult aspects to manage and the large-scale impact on the healthcare system. The economic significance in the research is in healthcare dollars spent on poor medication adherence. Dollars spent in association with poor therapy adherence will not be measured but assumed to be impacted if the adherence scores go up. It could be theorized that those dollars saved could be estimated in a cross-study design. Cost savings statistics could be gathered in an ongoing addition to this original study design. Those statistics could be related to avoided hospital stays and emergency room visits. Ultimately, the proposed project is expected to uncover a striking need for nurse utilization in specialty pharmacy patient management that produces long-term benefits for improved patient outcomes and reduced healthcare costs.

Theoretical Framework

The framework for the project was theorized by Lydia Hall. Hall's theoretical framework tells us that self-evaluation is not easily accomplished without the help of a significant figure (nurturer), who can provide clarity and counsel regarding the behaviors that one cannot see for themselves (Nursing Theory, n.d.). Understanding the need for a significant figure, in this case, the nurse, allows for a relationship that can produce actions that will impact the problem areas of the patient. Hall's theory of care, cure, and core begin the framework for nursing implementation to impact patient experience and medication adherence.

Hall may have individualized her focus, but the theory can cross all patient groups. This theory, with the subconcept of "The Care Circle," provides further clarity into the rationale for application into utilization within specialty pharmacy, since the subconcept is the nurturing component, the nurse. The areas of care, cure, and core are all connected with the patient and the nurse crossing all segments. The nurse is the reflector, the mirror to the patient, and allows for exploration into the patient's feelings and thoughts regarding the disease process, medication adherence concerns, and the influence of patient perceptions.

PICOT Question

Among patients with specialty pharmacy dispensed medications, will direct interaction with nurses impact patient engagement and improve medication adherence?

P: Population/patient – specialty pharmacy patients

I: Intervention/indicator – exposure to face-to-face nursing

C: Comparison/control – absence of face-to-face nursing

O: Outcome – patient improvements in medication adherence

T: Time – three month's observation of project

Definition of Key Terms

Knowledge deficit. Knowledge deficit is a nursing diagnosis indicating an inadequate understanding of disease or condition.

Patient engagement. Patient engagement is how the patient interacts with care providers. This interaction provides the patient's interpretation of how that engagement impacts areas of disease state understanding and how willing they are to participate and manage their specific care needs (Noteboom, 2015).

Patient experience. Patient experience is the combined interactions with all healthcare providers and how the patient rates that overall experience (Agency for Healthcare Research and Quality [AHRQ], 2016).

Specialty pharmacy. Specialty pharmacy is the organizations that dispense and manage rare and chronic disease. They focus on medications that are very costly and used for rare, ultrarare, and chronic diseases. These medications can be oral, injectable, or infused (American Pharmacists Association, 2017).

Therapy adherence. Therapy adherence is the term used to understand medication compliance. With therapy adherence, it is not just the patient who is compliant with taking their medication but also the total care plan adherence to reduce negative health outcomes (Medicine Men, n.d.).

The Nature of the Project

The project hopes to determine if a nurse-driven, direct-facing patient engagement approach translates into a positive patient experience and if the positive experience also shows improvements in medication adherence. The program will provide the intervention of a nurse-led patient experience assessment tool as well as the routine pharmacy medication assessment in the

home. This model of care can be compared to the current phone triage assessment. The expectation of the outcomes of the model is in the improvements in therapy adherence and a positive patient experience.

Question Guiding the Inquiry

This project is centered on the PICOT question: Among patients with specialty pharmacy dispensed medications, will direct interaction with nurses impact patient engagement and improve medication adherence?

Scope and Limitations

Over a three-month period, 10 patients were followed. The study dates were from July 2019 through September 2019. All patients use infused/injectable medications and are managed by a single, small to midsize specialty. The sample size was determined by a G*Power analysis based on the current number of infusion/injectable patients serviced by the pharmacy. This patient study group received monthly scheduled nursing visits and specific assessment material related to the problem of interest (POI). The project included two registered nurses who manage 10 patients during the three-month period. Each nurse utilized the ACE™ tool to capture patient engagement data. Along with the study tool, the nurses followed the pharmacy protocol and provided the refill assessment.

Limitations of the study included where the patient lives in relation to where the nurse resides and scheduling with the patients to keep visits routine. Utilizing the patient home or alternate site of care is limiting if patients do not keep scheduled visits. The study expectation was that there would be an improvement in medication adherence and in patient experience.

Chapter Summary

This chapter has explained the area of specialty pharmacy and how patients are currently managed. The information shows where there is a gap in care in the pharmacy utilizing their nursing staff in the overall supervision of this patient group. There is significant information on how patient perception and care translate into a positive patient experience when engaged effectively by healthcare providers. By the intervention of the nurse and their utilization of the ACE™, this project will research the patient engagement scores and overall medication adherence. These nurses will drive the care delivery system and control overall patient therapy medication adherence through measuring patient engagement.

Chapter 2: Literature Review

A search for patient engagement, nursing, and pharmacy literature utilizing a variety of online databases was initiated. The keywords used were specialty pharmacy, infusion patient management, patient engagement, patient experience, medication adherence, knowledge deficit, and home health nursing. The data research time period was from 2001 to 2019. Databases search included Bio Med Central, BMJ Journals, Pharmacy Today, the National Center for Biotechnology Center, The Beryl Institute, iVantage Health, Online Journal of Nursing Issues, and the New England Journal of Medicine.

Reviewed Literature

Patients diagnosed with rare or chronic disease are likely dispensed unique medications. These medications are only dispensed by what are known as “specialty pharmacy providers.” Not only are these patients on a journey that requires specific care management, but they are also left to navigate the medical and insurance hurdles of specialty medications. After diagnosis and being triaged to a specialty provider, patients are left with managing a condition that involves extreme high-cost medication and unique therapy guidelines. If these medications are not taken correctly due to a lack of understanding or poor management by the pharmacy, the patient can suffer dire consequences. Sadly, most of these consequences can be avoided with proper understanding and knowledge of the disease, therapy guidelines, and the specialty pharmacy’s role in care management. Medication adherence is challenging and costly in overall healthcare expenditures and adverse health outcomes for the patient.

The specialty pharmacy has not yet understood the resources at their disposal regarding their nursing staff. The pharmacy can accomplish effective medication dispensing and improved medication adherence if they can realize the cost effectiveness of utilizing their current nursing

staff for therapy management programs. With the pharmacy being the direct care entity for specialty patients, the pharmacy can design specialty patient engagement management programs directed by nurses to improve medication adherence and improve the overall patient experience.

Patient Engagement

Combining the knowledge presented by The Beryl Institute (n.d.) on patient experience, the study will include the implementation of the Altarum Consumer Engagement (ACE) Measure™ tool (Altarum, 2019). With the development of more patient-centered care delivery systems to encourage patients to be engaged in their own health care, Altarum developed a 12-item survey to assess three domains of health engagement: commitment, informed choice, and navigation (Altarum, 2019). By utilizing the nursing process in conjunction with the measurement tool, the study hopes to show how nurses impact patient engagement and improve medication adherence.

By understanding patient engagement, the specialty pharmacy can strategically develop patient management programs and utilize their existing nurse resource. With the data collected from the ACE™ tool, the pharmacy will be able to identify certain patient population groups for targeted interventions in relation to medication adherence.

Of the healthcare professionals surveyed in a study from The Beryl Institute (n.d.), 82% viewed the patient experience around quality, safety, and service as the number one priority. Since healthcare is all outcomes-based, this study shows the significant need for patient engagement models for quality, safety, and service that direct organizations to predictors that will indicate these specific outcomes as quality measures.

Understanding expectations is something within all areas of healthcare, such as healthcare sales, healthcare delivery systems, and providers. Furthermore, the understanding of

the nursing process and how to utilize nurses to improve patient engagement can play an important role in follow-up treatment and chronic care management and reduce healthcare costs. For the patient experience, managing patient expectations proactively can be the difference between a positive healthcare experience or the patient negatively filling out a satisfaction survey (Balfour, 2012).

The information from the iVantage Health Analytics article “Patient Satisfaction? A Matter of Perception” (Balfour, 2012), presented information that helped with understanding the need for better communication techniques from providers to improve patient satisfaction scores and patient perceptions of experience. Not only do providers need to give excellent care, but also they need to be mindful of all patient experiences, both before and after interactions, through effective, therapeutic communication. By inclusion of a home health nurse, it is possible the engagement can impact outcomes and a patient’s experience.

Research done over the past few years indicates an upward trend in managing patient expectations and patient engagement. Managing information related to experience goes beyond basic patient satisfaction surveys. Patient satisfaction is not the only measurement for patient experience. Presently, there is no standard protocol that advocates any specific patient engagement methodology (Domecq et al., 2014). Patient engagement in healthcare broadens perspective into potentially better understanding of patient needs and shortcomings. By further understanding research beyond patient satisfaction, patient engagement inquiry can better explore care preparation and implementation methods to improve patient care deficits.

With payment systems for quality, there is now a driving force behind making patient experiences a measurable metric to influence payment structures in payer organizations (Berkowitz, 2016). Still valid in its driving force to bring down healthcare costs and better

understand patient perceptions, patient engagement research, and protocol developments are not free. The costs associated with the research must be outweighed by the need. That said, the impact of the nurse in patient engagement can influence the overall patient experience and potentially reduce healthcare costs.

Patient satisfaction could become the routine source of measurement in overall healthcare patient perception. Patient experience measurement represents many factors that indicate areas for improvement and impact patient care in unique areas such as medication adherence. With the need for improvements in patient experience, there must be an understanding of the patient engagement process. It is in that process that perceptions are shaped, and interventions can be uncovered that improve outcomes.

Engagement is not all about the patient. The providers of care must be active participants to evoke change to understand patient perceptions of their care further. Technological advances are happening more rapidly than at any other time in history. With the abundance of information and resources to improve most medical conditions, the healthcare provider must engage patients to promote the new research and technology efficaciously. The promotion of new technology has to be in a manner that is understood and received positively. Healthcare providers must realize what engagement is and what represents engagement activity (Gruman et al., 2010).

Effective engagement facilitates and promotes knowledge. Knowledge deficit in care is a known nursing diagnosis and causes healthcare disparities if not addressed. Disease-specific education and promotion presented through effective engagement opportunities can help patients manage complicated disease conditions. The effective engagement by the provider helps patients better navigate healthcare systems regarding insurance, managing multiple providers, and directing intricate diagnosis (Gruman et al., 2010).

Medication Adherence/Nonadherence

Medication nonadherence is the purposeful or unplanned act of not taking medications as prescribed (Guthrie, 2014). To further explain the explicit need to address medication adherence, researchers from Lark Health (2019) studied statistical data from 2018 and concluded “adherence is lower among individuals with chronic disease compared to acute conditions” (p. 1). With some specialty pharmacy drug costs exceeding \$500,000 annually, it is imperative for specialty pharmacy providers to address medication adherence to reduce costs and to look at existing resources to improve the adherence rates (Levy, 2018).

The unknown factor of patient behaviors in relation to medication adherence is largely uncharted. The variable of an individual’s free will is just that, individual. The complexity of the rationale for why a patient does not take their medication is wrapped up among the specific behavior issues of the individual. There is no one protocol or care management program to understand the causes of nonadherence fully. Some patients can associate medication nonadherence to the cost of the drug. People with high-deductible health plans are more likely to be nonadherent because they shoulder more of the cost of their medication (Amelung, 2016). These patients are more likely not to purchase their medication or take less than the prescribed dose in order to stretch out the prescription and spend less.

Healthcare providers work to promote therapy adherence through the traditional patient-provider setting. The disparities among patient noncompliance to therapies remain high; therefore, the thought process for adherence is becoming vast (Farrell, Ingersoll, & Ceperich, 2015). With a broadening of the definition of adherence, there are other disparities among social groups that still cause problems in managing adherence. Healthcare providers must understand

the widening chasm of nonadherence while also understanding groups that have historically been disproportionate patient groups.

Further complicating the issue of medication nonadherence is the lack of training for clinicians in addressing and understanding medication nonadherence. As stated previously, the pharmacy clinicians only receive information about medication adherence by asking if the patients have had any issues taking their medications and how many doses they have on hand during the monthly phone refill assessment. Research used in validating the ACE™ tool in measuring patient engagement helps clinicians capture the appropriate information to understand possible patient motivators and barriers to medication adherence.

Nurse's Role in Specialty Pharmacy Care Management

Literature on how nurses improve patient outcomes was reviewed for assistance in the clarification of nurse-driven care in this study. From the review of literature, it was uncovered that there was no standard of care for specialty pharmacies to provide nursing management. This does not mean there is no standard of care for specific disease therapy management, just no standard that includes nursing in the delivery of a specific pharmacy care model.

Nurses are on the frontlines of patient care. It would be assumed the nurse could impact a patient's perception of their care and the nurse can be a motivator. There is expanding data acknowledging patients who are inspired to be active in their care, will experience positive health consequences, and lower their costs of care (Barello et al., 2017). Promoting active nursing engagement for teaching interventions to impact positive healthcare change is imperative.

With the specific methodology of the nursing process in mind, the project will emphasize nurses keeping focus in each phase including assessment, diagnosis, planning, implementation,

and evaluation. During the assessment phase, specific pharmacy protocol for respective patient disease states will be followed, and pharmacy assessment documentation will be utilized. The diagnosing phase of the process will allow for nurses to make educated judgments and assess risks or a patient's readiness for health improvement. Planning of nursing care is ongoing with the continued monthly utilization of the ACE™ tool to measure patient engagement. Evaluation takes place when intervention actions have been completed.

The existing pharmacy nurse roles are limited within the pharmacy as case managers or possible infusion nurses. Pharmacy nurses do not see a patient in their specific care environment unless they are teaching infusion or providing infusion therapy. The delivery of high-touch, patient-specific care within the patients' care environment can be a unique quality particular to the pharmacy.

Patient satisfaction research is suggestive in that one could interpret the patient feedback not usable since patients are not formally trained in medicine. Feedback in the form of a patient satisfaction score could be faulty. This project is providing input on areas that are customarily not measured, such as patient perception. A patient can be influenced by their perceived relationship with a provider. Perception should not be included in actual satisfaction models due to it not being subjective or objective information. It is in this understanding that this project will measure patient engagement through the intervention of nursing and systematic collection of information from a set questionnaire and how the data can positively correlate to improved medication adherence.

Patient Engagement and Improved Outcomes

Understanding patient engagement is complex within healthcare. It is not only being used for quality improvement but also reviewed for reimbursement and performance policies

(Berkowitz, 2016). The experience of the patient has become more than just a satisfaction score; it is a new bar of measurement for the standard of care in setting expectations for the payer, the prescriber, and the patient. Understanding how the patient and the caregiver interpret their care provides a unique opportunity for not only the specialty pharmacy but all healthcare areas to improve overall patient engagement and improve outcomes.

With specialty pharmacy drug costs being one of the largest areas of healthcare spending, understanding patient engagement and how it can improve disease state understanding for the patient can help the pharmacy determine barriers to medication adherence. Better medication adherence will improve overall health outcomes and reduce drug spending in the long run for the patient and insurance provider.

In direct patient care, nurses have always been on the frontlines. Nurses teach patients healthcare promotion through effective communication and instruction. Pharmacies can learn to appreciate the specific skills nurses provide in promoting positive patient engagement and quality improvement initiatives. Patient engagement can influence the patient experience.

Since the inception of the Affordable Care Act in 2010, the Centers for Medicare and Medicaid Services (CMS) has even provided payment incentives to payer organizations and providers for care models that promote prevention (Berkowitz, 2016). Now, it is not just an idea that a patient should experience quality care but a requirement. That care can be impacted by better patient engagement through nursing.

Home Health Nursing

Research indicates there is a gap in the pharmacy's ability to legally provide home nursing services directly through the pharmacy due to different state Certificate of Need (CON)

laws governing home health. These laws limit the scope of nursing care provided and even dictate specifically what healthcare organizations can provide.

CON regulations were established to restrict the expansion of Medicare and Medicaid providers in nursing homes and home health (Rahman, Galarraga, Zinn, Grabowski, & Mor, 2015). The law was intended to help control healthcare expenditures. States limiting the number of home health agencies or long-term care facilities thought they could better control overall healthcare spending in these areas.

Today, several states still have CON legislation. This legislation mainly focuses on outpatient facilities and long-term care (Rahman et al., 2015). With the law still focused on Medicaid and Medicare spending, it has not evolved into legislation that adequately addresses the payment structure for nursing regardless of who the payer is (the pharmacy or an insurance company) within specialty pharmacy care.

The CON law has further reduced home nursing access due to the usual per visit billing processes. Pharmacies are in a position of little to no reimbursement to cover this type of care for specialty pharmacy patients even though there is value in the home health nursing visit. The pharmacy needs to see the value in providing a home health nurse for patient experience outcomes rather than the perceived negative equity in home nursing visits. That said, nursing can be provided in an alternate site of care for assessments and teaching with no CON requirements.

Specialty pharmacies are in a healthcare conundrum regarding home healthcare and payer expectations in patient management. Payer contracts cannot be gained without specific provisions for nursing care regarding a variety of disease states. This care in many states cannot be provided or even contracted due to the per-visit payment structure within traditional home health billing. Independent home health agencies work on a per-visit basis where home health in

specialty pharmacy directly related to infusions is billed at a per-hour rate and the pharmacy is the payer source. The payer organizations have specific requirements for pharmacies to be a contracted provider. Those specifics include patient satisfaction scores, medication adherence monitoring, and education. To provide this type of care effectively, pharmacies and payers must understand the pivotal role of nurses and address reimbursement structure to accommodate. Although direct infusion care can be limited due to CON restrictions, most home health agencies and specialty pharmacy providers can provide nursing education if the nurse does not physically perform a skill (IV placement, injection, etc.). With this study only providing the survey tool and assessments, the pharmacy can legally perform the nursing functions with no limitations.

Conceptual Framework Discussion

Hall's theory of care, cure, and core binds this project into a middle-range theory and the validation of nurse inclusion in the care management of specialty pharmacy patients (Nursing Theory, n.d.). With the nurse at the center of this care delivery program, this theory allows for the skills of the nurse to close any care gaps and mold patient perception and improve the patient experience. It is hoped that this research, using the nurse more effectively, can translate into improvements in medication adherence and bettering patient engagement. The care circles within the framework are further elaborated on with more specificity for rationale of use.

Evaluation of the care circle. The care circle explains the need for representation, a component exclusive to the nurse. This exclusivity shows the required assessment of the nursing care component. Evaluating the professional nurse and the activities between the nurse and the patient will encourage the nurse's goal for patient comfort and provide intake on assessment parameters and guidelines established in the conceptual model of the measurement. The established closeness between the patient and the nurses can allow for robust mirrored

exploration by the nurse into the patient's well-being and areas of focus within medication adherence, disease knowledge, and pharmacy provider perception.

Evaluation of the core circle. The core circle, based on social sciences and shared with other members of the healthcare team, functions as the primary information transference segment (Nursing Theory, n.d.). This transference of information shared within all three circles furthers the care continuum. The patient can gain self-identity and development maturity with medication adherence, disease knowledge, and pharmacy provider perceptions. Since all three areas converge with the nurse and patient, the core also proves foundational in making the full theory cohesive in details of patient growth or deficits.

Evaluation of the cure circle. The cure circle is shared with the entire healthcare team. All areas of specialty share cross-functionally to provide the best knowledge needed for reflecting on patient feelings of current health status and attitudes relating to the changes in their care and how these areas relate to their current lifestyle (Nursing Theory, n.d.). The nurse is always at the center with the patient and is the advocate for all patient-related activities.

Chapter Summary

Research in patient experience and how nurses can impact engagement related to specialty pharmacy patient care has been limited. Knowing the pharmacy is faced with reimbursement challenges from payers and requirements from CMS for healthcare promotion can be another compounding issue. Providing nursing as an intervention through patient engagement could prove valuable in improving medication adherence. Measurements for quality performance must evolve to a higher understanding of the nursing process in patient engagement for improved healthcare outcomes.

Nursing is a practice that can be restricted by CON laws from one state to the next. The area that is not limited is a nurse's nurturing and being a healthcare promoter. Nurses, without limitations in CON law, can promote healthcare and provide insights into a patient's self-care obstacles and improve a patient's deficit knowledge. The nurse is at the center to create a model of care that enhances management at the patient level, the core of care with the patient and the pharmacy, and the therapeutic value or health maintenance value that includes everyone who has a hand in managing the patient. The nurse is the glue that holds patient engagement together, so the pharmacy can better manage patients with rare diseases and improve medication adherence.

Chapter 3: Research Method

This project focused on nursing intervention for specialty pharmacy patients. The nurses utilized the ACE™ patient engagement measurement tool in their interactions with the patients. The expectation of an impact on patient medication adherence was shown through the engagement measurement tool results.

With this quality improvement project, the goals developed followed SMART, specific, measurable, attainable, relevant, and time-linked (Terry, 2018). The project focused on the implementation of nursing and the impact on patient engagement to improve medication adherence.

Purpose

I evaluated patient engagement for specialty pharmacy patients using the ACE™ measurement tool with nursing interaction and medication refill data. Along with collecting the information from the ACE™, the nurses gathered their routine refill assessment. I collected data from the ACE™ patient experience tool along with current pharmacy refill assessment data monthly. The purpose of measuring patient engagement and the relationship with medication adherence is due to the adverse events associated with medication nonadherence and the loss in overall healthcare dollars.

With the nurse as the intervention, the ACE™ tool for patient engagement provided the areas of measurement needed to understand the patient's perception of their care. The project was measured over three months. The Altarum Institute provided the assessment tool free of charge with permission (see Appendix A).

Understanding financial relevance in healthcare, this project showed improved patient medication adherence with the intervention of nursing to capture patient experience data through

the ACE™ measurement tool. Historical medication dispensing information was extrapolated from the pharmacy database from the previous three months before the start of the project. This previous data showed patient consistency in ordering or unplanned dispenses vs. dispenses over the project period. A reduction of the amount of medication dispensed over the study time-period, though still within routine scheduled dispenses, would be a positive outcome due to the savings from a reduction in unscheduled medication dispenses. Any information on dispensed medication was gathered from the pharmacy refill assessment database and used only as Health Insurance Portability and Accountability Act (HIPPA) compliant information.

I maintained HIPPA compliance through the specifics outlined below.

1. All patients are 18 years of age or greater.
2. All patients identified as a numerical number only.
3. All study information maintained on one computer at the site of the primary investigator.
4. Any pharmacy assessment information, if provided to the primary investigator, was removed from any patient identifiers by the pharmacy before being sent to the primary investigator.
5. All information sent to the primary investigator by the pharmacy was received, with patient identifiers removed, and only patient numerical numbers as the identifier were emailed to the investigator.
6. The primary investigator maintained a spreadsheet. Patients were identified as numbers. Visit dates, refill counts, and ordering dates were added to the spreadsheet after each scheduled patient visit.

Project Design

The project was designed to be nurse-led with the patient engagement assessment done monthly. The pharmacist or in-house nurse case managers customarily manage specialty pharmacy patients. That said, the nurse in this project was still involved, with the site of care being in the home of the patient or an alternate site of care such as a workplace or clinic. Actual visualization of the patients by the nurse was key to the effectiveness of this project.

The sample size was calculated using a G*Power analysis. Based on the number of nurses involved, the sample size was limited to no more than 10 patients; five patients per nurse max due to the study only being performed over three months. Each patient was provided written and verbal informed consent (see Appendix B). The patients verbalized consent to participate in the study at the first interview and provided written consent via email by either signing permission forms electronically or in person. Field nurses were assigned a predetermined group of patients to follow over a three months for continuity of care. During the period, nurses utilized the ACE™ patient experience assessment tool. The tool was designed by the Altarum Institute with a set of 12 questions on a five-point grading scale (Altarum, 2019).

Nurses scheduled monthly visits with their set patient group. The visits included the pharmacy protocol refill assessment template. After the nurse completed the pharmacy assessment portion of the visit, the nurse verbally asked questions and captured answers to the ACE™ patient engagement tool. After each visit, the pharmacy nurse had 24 hours to return all the ACE™ and pharmacy refill assessment information. ACE™ tools were sent to the primary investigator by email only as a PDF attachment. The information followed the above-listed HIPAA compliant process. At the end of the three-month study, the primary investigator statistically analyzed all ACE™ assessments. The pharmacy refill-ordering pattern was captured

and compared to the three months prior to the study for medication adherence comparison. The information was provided by permission from the specialty pharmacy utilized within the study.

Methodology Appropriateness

In keeping with the conceptual framework from Hall's theory of care, cure, and core, the approach of using nurses as the intervention while using the ACE™ tool helped provide clarity in understanding patient behaviors and patient responses to care providers (Nursing Theory, n.d.). Furthermore, with the nurse providing a visual assessment and verbal interactions with the patients, the methods from Hall can help better understand the patient's perception of their experience and how engagement impacted adherence.

By using the ACE™ tool and current pharmacy refill assessment information, the project was methodical and systematic in approach to impacting patient-centered care. Furthermore, the main intervention of nursing provided insights into patient engagement and the impact on improving medication adherence. Understanding the methodology of this project goes beyond understanding basic patient satisfaction surveys. Determining if the information collected in the patient experience engagement can be a valid indicator of medication adherence is the reason for the method of data collection in this project through the implementation of direct nursing care.

The lead investigator used evidence-based guidelines and chose the specialty pharmacy organization as the site for systematically gathering and appraising the data collected from the project. The approach allowed for determining whether the quality improvement goal was met and if overall patient medication adherence was impacted.

Structure of the Program

Scheduled patient-nurse engagements for ongoing assessments of specialty pharmacy patients provided the basis for the project and all data collection. Scheduled monthly nursing

visits were performed for the pharmacy refill assessment and the ACE™. Before the start of the project, I received verbal confirmation that all nurses used had received a one-hour training on the ACE™ tool and data recording protocols.

Feasibility and Appropriateness

For this project, understanding feasibility is to understand the applicable intervention of direct nursing care and utilization of the ACE™ tool with pharmacy refill assessment information. These results helped to justify the utilization of nursing to improve medication adherence.

By utilizing direct nursing care, the nursing process provided value in understanding patient engagement. After the nurse performed the refill assessment and any educational needs, the patient's perception of their care was impacted through those assessment interactions.

Through the understanding of the uniqueness of the nursing process, there is a need for appropriate nurse utilization within specialty pharmacy management. The nurse-patient relationship provides a unique vector for understanding patient engagement and the barriers to medication adherence. The relationship is the variable driving the research project. Nursing theory further grounds the project in exploring where nurses make a positive impact on patient care through the nursing process.

IRB Approval and Process

ACU's Institutional Review Board (IRB) was utilized to gain permission and approval to perform the study (see Appendix C). The approval process was followed per the ACU guidelines with the DNP capstone resource course. With this needing to be done before implementing the project, the IRB approval request was submitted within three weeks of the end of NURS 752. All

final revisions of chapters one through three were completed before submission as well. Once IRB approval was received, the project began on the first full month after receiving approval.

Inter-Professional Collaboration

The project was in collaboration with the ACU instructors, the project capstone chair, and the committee members as well as any required study site committee members and study nursing participants. The key stakeholders within the project were the pharmacy staff, nursing, the patient, patient caregivers, and the research DNP student and capstone committee. Further collaboration between the pharmacy nurse and other pharmacy staff along with the patient prescriber and prescriber clinical staff was maintained by the pharmacy nurse as necessary per the pharmacy protocols.

Practice Setting for Evidence-Based Practice (EBP)

The evidenced-based practice setting was the specialty pharmacy, but more specifically, the location of the patient. Written permission was received by the pharmacy (see Appendix A). Since this project focused on the nurse and the relationship of that nurse with the patient, the setting is outside of the pharmacy and direct patient facing. This aspect was challenging for scheduling. There were variables in the reliability of the patients keeping scheduled visits. The visits took place in the patient's home but could also alternate at other sites of care such as a workplace or clinic.

Wherever the specific location, the project was linked to a nurse for delivery of the ACE™ tool. The pharmacy nurse provided all evidenced-based care and initiated the assessment where the patient resides or at the scheduled visit.

Target Population

The target population was the specialty pharmacy patient who received a scheduled monthly dispense of medications that treat a rare or chronic disease. The population only included patients 18 years old or above. All patients were from one midsized specialty pharmacy located in Mississippi.

Risks

There were no physical risks to the patients who were surveyed in this project. The patient only received direct nursing visits. The nurse completed the ACE™ engagement tool and the pharmacy refill assessment and medication counts per pharmacy protocol.

Possible risks involved patient perception of care, patient location, and patient reliability. Perception was a variable with little control, but the ACE™ tool helped clearly gather information to measure overall engagement without personal bias or nurse bias. Knowing that perception is patient specific, there was assumed risk in that it could be unpredictable. The ACE™ tool, being systematic and routine at every visit, alleviated some of the risks of personal bias within perceptions from the patients. This risk did not provide any direct harm to the patient or the clinicians delivering the program.

Benefits

The study results showed benefits to the overall nurse care management of specialty pharmacy patients and improved medication adherence. Not only did medication adherence rates increase, but also there was more insight into the understanding of the impact of nursing and patient engagement.

The costs associated with delivering the program were minimal compared to the price of poor medication adherence. The pharmacy currently employs multiple nurses for home or

alternate site of care. The nurses followed 10 patients during the study duration. The study site, in this case, the specialty pharmacy, paid any applicable costs associated with nursing. The pharmacy buy-in to the study was another benefit in covering the expenses of the program.

The pharmacy staff benefitted being part of the study and gained knowledge into how improved patient experience impacted or improved patient medication adherence. Pharmacy management programs are required to manage patient medication adherence to maintain payer contracts and accreditation. By the pharmacy having a better understanding of patient barriers to adherence, they can design their specific management programs to address the causes and implement patient-specific interventions. These patient-specific measurements improve outcome scores for adherence and help the pharmacy maintain accreditation standards and contractual obligations from payers.

Instrument and Measurement Tools

The program nurses utilized the pharmacy routine refill assessment protocol and the ACE™. The pharmacy already had standardized templates for refill and disease assessment. Nurses performed their initial pharmacy required assessments prior to initiating the ACE™ engagement tool.

Previously, the pharmacy only used patient satisfaction surveys for quality measurement. With the implementation of the ACE™, combined with the routine refill and disease assessment, the measurements received accurately captured patient engagement and barriers to therapy management. The engagement and improvements in medication adherence showed they had impacted the overall patient experience as well, not just patient satisfaction with pharmacy service.

Data Collection Management

The lead investigator, in this case, the DNP candidate, directed the management of the data collected. Data calculations were performed through SPSS calculations as directed by the Altarum Institute licensing agreement for using their assessment within the study. The data were gathered monthly from the ACE™ tool. Through the tool, an analytic report was calculated to provide insights into consumer health engagement. The patient set was analyzed by SPSS using descriptive statistics and frequencies.

The ACE™ scoring was through a set of 12 questions and scored from 0 to 4. The purpose of the collection and management of the tool in this manner was to develop a measure of patient engagement. The higher the score of a question represented a higher engagement rating. These engagement measurements were predictors of behaviors that promoted improved medication adherence or uncovered barriers to adherence.

Data on historical medical ordering for the three months prior to the study period were collected. The information was maintained by the pharmacy and was provided before the final data analysis for comparison.

Timeline

The study took place over three months. Data were collected monthly. Data were due to the primary investigator within 24 hours of each nursing visit. All results per month were calculated within 30 days of the last date of the previous month. The results were collected routinely and interpreted as needed for interventions to promote evidence-based guidelines for patient management per the pharmacy protocol.

Analysis Plan

The patient engagement scores measured by the ACE™ tool were compared to medication ordering patterns collected by the pharmacy during the study period specific to each study participant. After confirming the scores received for patient engagement, positive scores were compared with medication adherence data collected during the study from refill assessments. The analysis shows a possible correlation between direct nursing engagement and medication adherence.

Chapter Summary

By utilizing the ACE™ tool, the quality improvement project collected information that showed a positive correlation with direct nursing engagement and patient medication adherence improvements. The goals of the project were specific. The design of the ACE™ tool helped maintain data rigor.

Perception in this project was a unique variable that is not controlled. The ACE™ data reflected a possible correlation in improved medication adherence with overall engagement scores. Meaning, the positive experience was more than just an experience, it was something measurable, attainable, and reflected actual improvements in perceived care, and in turn, improvements in patient medication adherence.

Chapter 4: Research Method and Results

The purpose of the project was to study the impact of direct nursing interaction on patient engagement and its impact on medication adherence. The effectiveness was measured through a patient engagement tool delivered specifically by a nurse to the patient. Medication adherence was measured monthly at every nurse interaction. The results of the study help further research in the nursing process and the importance of the nurse's role in patient engagement and the impact on medication adherence.

Purpose of the Project

During the study period, each patient verbally received a patient engagement assessment survey, the ACE™. This intervention captured evidence needed to measure engagement. With this data, routine medication refill information was also collected and then compared to the engagement survey tool results. These results were likened to the three-month medication-ordering pattern prior to the study.

Data were collected systematically for three consecutive months beginning July 2019. Pharmacy ordering patterns are generally around 28 days. Patient ordering data prior to the study was supplied by the pharmacy per HIPAA guidelines. The pharmacy provided data stating patients had an ordering percentage of 60% over the three months prior to the study.

Ten patients were enrolled for a total of 28 visits for all patients. Patient one was unreachable during month three, and patient seven did not complete the month three survey.

Each patient received the ACE™ directly by the specialty pharmacy nurse. Ten patients were enrolled and completed the study, and eight fully completed the surveys.

Discussion of Demographics

All patient baseline illness characteristics were generally similar within the specialty pharmacy. All patients received an injectable medication on a routine monthly basis. Medication refill historical data were captured for review for three months prior to the month of the start of the study. The data were used to see if patients had a pattern of ordering monthly medications as directed by their prescribers. During the study, each patient was asked if they were requesting a refill at the time of the visit per the pharmacy protocol.

Project Analysis

The ACE™ measurement tool was used over the three-month period for a total of 28 surveys. The surveys were analyzed using SPSS and using descriptive statistics and frequencies to identify specific measurements of engagement. The engagement factors were commitment, informed choice, navigation, and ownership. The analysis confirmed scale stability and outcomes were correlated in a positive direction toward medication adherence in 57% of the study population. Thirty-nine percent of the study population showed nonadherence in medication ordering.

All patients were at least 18 years of age. By using the appropriate software and methods as instructed by the Altarum Institute, analysis was performed to gain information on the 12 questions and was scored from 0 to 4. The higher the number equaled a higher engagement score.

Prior ordering data for each patient were collected for April, May, and June of 2019. Medication ordering was collected during the study period to compare to engagement scores. Data were evaluated based on orders placed at least one time, every 28 days per their prescribed ordering frequency. A score of up to 100% would be considered excellent for medication

adherence. Any percentage below 100% would show a need for improvement and intervention. There were a total of 28 refills during the study period. Table 1 represents patient survey totals per the study period.

Table 1

Completed Patient Survey Totals

	Frequency	Percent	Valid Percent	Cumulative Percent
Patient 1	2	7.1	7.1	7.1
Patient 2	3	10.7	10.7	17.9
Patient 3	3	10.7	10.7	28.6
Patient 4	3	10.7	10.7	39.3
Patient 5	3	10.7	10.7	50.0
Patient 6	3	10.7	10.7	60.7
Patient 7	2	7.1	7.1	67.9
Patient 8	3	10.7	10.7	78.6
Patient 9	3	10.7	10.7	89.3
Patient 10	3	10.7	10.7	100.0
Total	28	100.0	100.0	

During the last study month, patient one was unreachable and did not place a refill order. Patient seven was available but did not complete the survey or a refill. During the study months of July and August, 10 patients completed the study and over 60% refilled their medication. This is comparable to the adherence percentage from the three months prior to the study. Out of the 28 total refills during the study, 39.3% of patients did not refill their medication. This represents almost 40% of the study population was nonadherent to their medication ordering frequency. Survey frequency and percentages are presented in Table 2, and ordering frequency and percentages are presented in Table 3.

Table 2

Monthly Survey Totals

	Frequency	Percent	Valid Percent	Cumulative Percent
July	10	35.7	35.7	35.7
August	10	35.7	35.7	71.4
September	8	28.6	28.6	100.0
Total	28	100.0	100.0	

Table 3

Refill Ordering Frequency

	Frequency	Percent	Valid Percent	Cumulative Percent
Refill Yes	17	60.7	60.7	60.7
Refill No	11	39.3	39.3	100.0
Total	28	100.0	100.0	

Table 4 represents all data collected from the ACE™ survey tool (see Figure 1). The survey questions are listed individually with results showing frequency of each response per study participant for each question. A score of 0 was given for *strongly disagree* and all the way to a score of 4 for *strongly agree*. The higher the score, the higher the engagement. Results show that the highest area of engagement was associated with question #4 at a score of 64%. Further data indicated that most questions answered by participants showed they *agree* or *strongly agree* with the questions provided. This indicates a 3-4 score and is on the higher end of the engagement range. The rest of the patient population reflected a spread over scores from 0-2 of *strongly disagree*, *disagree*, and *neither agree nor disagree*, respectively.

Table 4

ACE™ Answers, Totals Over Three-Month Period

Question 1, "I spend a lot of time learning about health."

	Frequency	Percent	Valid Percent	Cumulative Percent
<i>Strongly Disagree</i>	3	10.7	10.7	10.7
<i>Neither Agree Nor Disagree</i>	3	10.7	10.7	21.4
<i>Agree</i>	14	50.0	50.0	71.4
<i>Strongly Agree</i>	8	28.6	28.6	100.0
Total	28	100.0	100.0	

Question 2, "Even when life I stressful, I know I can continue to do the things that keep me healthy."

	Frequency	Percent	Valid Percent	Cumulative Percent
<i>Strongly Disagree</i>	3	10.7	10.7	10.7
<i>Neither Agree Nor Disagree</i>	3	10.7	10.7	21.4
<i>Agree</i>	8	28.6	28.6	50.0
<i>Strongly Agree</i>	14	50.0	50.0	100.0
Total	28	100.0	100.0	

Question 3, "I feel comfortable talking to my doctor about my health."

	Frequency	Percent	Valid Percent	Cumulative Percent
<i>Strongly Disagree</i>	3	10.7	10.7	10.7
<i>Agree</i>	5	17.9	17.9	28.6
<i>Strongly Agree</i>	20	71.4	71.4	100.0
Total	28	100.0	100.0	

Question 4, "When I work to improve my health, I succeed."

	Frequency	Percent	Valid Percent	Cumulative Percent
<i>Strongly Disagree</i>	3	10.7	10.7	10.7
<i>Disagree</i>	1	3.6	3.6	14.3
<i>Neither Agree Nor Disagree</i>	4	14.3	14.3	28.6
<i>Agree</i>	18	64.3	64.3	92.9
<i>Strongly Agree</i>	2	7.1	7.1	100.0
Total	28	100.0	100.0	

(table continues)

Question 5, "I have brought my own information about my health to show my doctor."

	Frequency	Percent	Valid Percent	Cumulative Percent
<i>Strongly Disagree</i>	6	21.4	21.4	21.4
<i>Disagree</i>	4	14.3	14.3	35.7
<i>Neither Agree Nor Disagree</i>	5	17.9	17.9	53.6
<i>Agree</i>	10	35.7	35.7	89.3
<i>Strongly Agree</i>	3	10.7	10.7	100.0
Total	28	100.0	100.0	

Question 6, "When choosing a new doctor, I look for information online."

	Frequency	Percent	Valid Percent	Cumulative Percent
<i>Strongly Disagree</i>	12	42.9	42.9	42.9
<i>Disagree</i>	3	10.7	10.7	53.6
<i>Neither Agree Nor Disagree</i>	2	7.1	7.1	60.7
<i>Agree</i>	8	28.6	28.6	89.3
<i>Strongly Agree</i>	3	10.7	10.7	100.0
Total	28	100.0	100.0	

Question 7, "I can stick with plans to exercise and eat a healthy diet."

	Frequency	Percent	Valid Percent	Cumulative Percent
<i>Strongly Disagree</i>	5	17.9	17.9	17.9
<i>Disagree</i>	7	25.0	25.0	42.9
<i>Agree</i>	13	46.4	46.4	89.3
<i>Strongly Agree</i>	3	10.7	10.7	100.0
Total	28	100.0	100.0	

Question 8, "I compare doctors using official ratings about how well their patients are doing."

	Frequency	Percent	Valid Percent	Cumulative Percent
<i>Strongly Disagree</i>	7	25.0	25.0	25.0
<i>Disagree</i>	4	14.3	14.3	39.3
<i>Neither Agree Nor Disagree</i>	7	25.0	25.0	64.3
<i>Agree</i>	5	17.9	17.9	82.1
<i>Strongly Agree</i>	5	17.9	17.9	100.0
Total	28	100.0	100.0	

Question 9, "I have lots of experience using the health care system."

	Frequency	Percent	Valid Percent	Cumulative Percent
<i>Strongly Disagree</i>	3	10.7	10.7	10.7
<i>Agree</i>	14	50.0	50.0	60.7
<i>Strongly Agree</i>	11	39.3	39.3	100.0
Total	28	100.0	100.0	

(table continues)

Question 10, "When choosing a new doctor, I look for official ratings based on patient health."

	Frequency	Percent	Valid Percent	Cumulative Percent
<i>Strongly Disagree</i>	7	25.0	25.0	25.0
<i>Disagree</i>	4	14.3	14.3	39.3
<i>Neither Agree Nor Disagree</i>	5	17.9	17.9	57.1
<i>Agree</i>	12	42.9	42.9	100.0
Total	28	100.0	100.0	

Question 11, "Different doctors give different advice; it's up to me to choose what's right for me."


	Frequency	Percent	Valid Percent	Cumulative Percent
<i>Strongly Disagree</i>	3	10.7	10.7	10.7
<i>Agree</i>	9	32.1	32.1	42.9
<i>Strongly Agree</i>	16	57.1	57.1	100.0
Total	28	100.0	100.0	

Question 12, "I handle my health well."

	Frequency	Percent	Valid Percent	Cumulative Percent
<i>Disagree</i>	4	14.3	14.3	14.3
<i>Neither Agree Nor Disagree</i>	3	10.7	10.7	25.0
<i>Agree</i>	16	57.1	57.1	82.1
<i>Strongly Agree</i>	5	17.9	17.9	100.0
Total	28	100.0	100.0	

(Used with permission from Alarum 2019. See Appendix D)

Question 6 of the survey has a score of 42.9% as *strongly disagree*. For this answer, almost half of the participants rated 0-1 for not looking at information online to choose their provider. Question 10 shows a score of 42.9%, reflecting *agree* and a higher engagement score. This question is related to patients stating they look at information on ratings on providers. These two answers reflect opposite scores for almost the same type of information.



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ACE MEASURE™

Exhibit A

Altarum Consumer Engagement (ACE) Measure™

Please rate how much you agree or disagree with the following statements below.

Question	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
I spend a lot of time learning about health.					
Even when life is stressful, I know I can continue to do the things that keep me healthy.					
I feel comfortable talking to my doctor about my health.					
When I work to improve my health, I succeed.					
I have brought my own information about my health to show my doctor.					
When choosing a new doctor, I look for information online.					
I can stick with plans to exercise and eat a healthy diet.					
I compare doctors using official ratings about how well their patients are doing.					
I have lots of experience using the health care system.					
When choosing a new doctor, I look for official ratings based on patient health.					
Different doctors give different advice; it's up to me to choose what's right for me.					
I handle my health well.					

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Figure 1. ACE™ Altarum consumer engagement (ACE) measure™ [PDF]. (2019). Used only by written permission from Altarum, 2019 (see Appendix D).

Limitations

The study limitations regarding the scope were in the study population size, the limited demographics, and the length of the study. There were also limitations in the original study population versus the final study population. The variance in surveys received was due to some participants not fully completing the study.

After reviewing all the data and collection methods, future research needs to be larger in scope and inclusive of more demographic variables such as ethnicity and payer sources such as Medicare/Medicaid. With the limits in this study in relation to the study participant information, there is not much to be uncovered about patient engagement and medication adherence other than the data based on age. A larger scale and longer period study with a broader demographic survey could show more data inclusion that could be more representative of how a clinician impacts patient engagement. The deeper picture of the study participant could provide insights into specific areas of greater adherence issues and more specificity of patient engagement results.

Recommendations for the Project

To further understand the rare and chronic disease specialty pharmacy patient, the study should be performed for a longer period to capture better historical data. The patient population could be further scrutinized by differentiating between male and female, age groups, ethnicity, religion, and socioeconomic status. As also previously stated, a cross-examination and comparison of healthcare dollars lost specific to a patients' individual diagnosis and nonadherence could be studied alongside patient engagement scores. By doing this data cross-examination, there could be a correlation with engagement scores and dollars lost or saved.

The nonspecific answering pattern does not provide a clear picture of a patient's idea of their unique care expectations or health outcomes. Although nonspecific, it could be concluded

that the patient needs better nurse-led patient engagement for educational opportunities around disease state and overall health maintenance education. It could be assumed there is a difference in how patients view healthcare due to cultural beliefs and values as well. These are reasons to diversify the patient population and have a better grasp of specific patient engagement needs with broader demographic parameters to understand medication adherence better.

Chapter 5: Discussion, Conclusion, and Recommendations

The study was performed, and limited data were collected to uncover if a nurse could positively impact patient engagement and medication adherence. The two areas measured were engagement utilizing the ACE™ delivered by nurses directly to the patients and monthly medication ordering patterns. The tool performed as expected in measuring and assessing patient engagement and health behaviors associated with medication adherence.

The research tool with a 12-question survey was designed to assess three specific domains of healthcare engagement: commitment, informed choice, and navigation (Altarum, 2019). The design of the tool provides insight into patient engagement behaviors. It is in those insights that this research gathered data into how nurses impact engagement and can improve a patient's behavior toward medication adherence. The key study points were evaluated for comparative data collection using the comparison of the engagement score with medication ordering patterns during the study. The comparative data of the survey tool and medication ordering pattern helped assess any cause and effect direct nursing care had on patient engagement and medication adherence.

The patients completed surveys each month, consecutively, for a total of three months. At each patient interaction, the survey was performed, and the refill assessment was given to allow for medication refills on a routine basis. During the study period, no patients were withdrawn or eliminated. Two patients did not complete the final assessment tool. The tool was easily administered, and medication refill results were captured uniformly for data collection.

Interpretation of Findings

The study does not necessarily suggest there is consistency with routine ordering when a nurse engages with the patient more directly. When compared to the prior ordering months

before the start of the study, the information is similar in that about 60% of patients ordered their medication at their appropriate medication interval.

The direct engagement confirms the ACE™ psychometric properties and the unique qualities of patient engagement. With the specific criteria of nurse-delivered engagements, the ACE™ showed opportunities to improve patient care and medication adherence. These improvement areas are not specific to the ages studied. The study did not try to differentiate between male or female for outcomes.

What is further uncovered when reviewing the ratings of each question within the study population is a distinct lack of continuity of how one views their own care. This could be due to a lack of study length and the limited patient population. Response bias could also be a factor for some surveys that appear nonspecific. Response bias was not considered initially but could pose a new question to measure perception more effectively.

For further details, a longer study period and a larger patient group would need to be performed. Separating between sex and patient socioeconomic class could indicate other healthcare disparities and areas of improvement in patient engagement. Broadening the demographic criteria could level out any bias.

Initially, the first month of questioning presented a variety of answers among the patient population. First month ordering patterns varied due to the start of the study not starting at the beginning of an ordering period. Patients order medications on a 28-day ordering pattern per the pharmacy protocol. This allows for time to receive prior authorizations and patients to receive medications before their present home supply expires.

During the first month of the surveys, some patients answered questions in a nondifferentiating manner. Response bias or extreme responding would likely be the case for

these surveys. Each survey was compared and calculated per month. The changes for patient 1 on survey 1 indicated a possible extreme responding. Patient 1 entered all questions with *agree*. On survey 2, this same patient answered more varied, so there is an implication that more thought was put into reading and answering truthfully.

Bias and extreme responding can be an outlier or an opportunity for the nurse to probe into the patient's healthcare beliefs. With nurses being trained on therapeutic communications, any engagement would present an opportunity to uncover why a patient answers the survey in a nonspecific way rather than thinking deeper into the questions. Nonspecific answering patterns will not provide information to get accurate results for the entire study patient population.

Utilization of the nursing process is the unique variable the nurse provides in these situations. By assessing the results of the questions over the study period, the nursing process helps facilitate the survey tool results into actions to improve patient care plans and goals.

Perception is an area that can greatly influence the patient experience. The ACE™, being validated and studied to encourage uniformity in understanding engagement, attempts to control perception by eliminating patient bias within the questionnaire design. With the study showing the same ordering pattern prior to the study start, it cannot be assumed adding the nurse to deliver the survey necessarily changed ordering patterns. What the results do show is a distinct percentage of patients who do not order medication routinely. There is about 40% who are nonadherent.

Still, the question of bias in the form of response bias or other bias can skew the results but not alter the current refill data. Although the survey tool has been proven and validated through research to control bias, bias is still a variable that must be taken into consideration. That said, the nursing process and direct nursing care should be combined with the tool to manage the

bias and the perceptions of the patient. This perception allows for a stronger patient-caregiver relationship. This stronger relationship, along with the results of the ACE™, helps in the coordination of care regarding predictive and preventative tools.

Results showed that patients answered two different questions that represented the same basic question with opposing results. With ongoing engagement, patient answer results could be researched further to improve perception of care and medication adherence. By improving patient engagement within the study, the nurse and the pharmacy staff capture better assessment information to create specific plans of care for patients managing rare and chronic diseases. In theory, this model could also be adapted for all chronic disease states.

If the ACE™ and the engagement with the nurse help control patient perception, then the patient will be receiving a positive care experience. A positive experience, as captured through measuring patient engagement via the survey tool as done within this study, is the indicator of improvements in overall medication adherence.

Inferences About the Findings

Research into patient engagement can be a guide to help shape a patient's perception of their care. That perception is then the gauge for improvements in medication adherence. Not only can there be improvements in medication adherence, but there can be a positive correlation in patient overall health maintenance.

Although limited in time and patient population, the study results are an adequate predictor of a patient's current health impression. The results were inconclusive of a correlation with engagement and improvements in medication adherence. Due to the study length limitations, a recommendation of a longer study duration would be needed to see any possible correlation to improved medication adherence scores. The inclusion of direct nursing to deliver

the survey and capture routine medication refill information can be concluded as a positive addition to the care management of specialty pharmacy patients. With information uncovered by the survey tool, the pharmacy can better understand how the patient views their care. If the pharmacy can better understand a patient's perception, they can better manage the rare and chronic disease patient. Perception and a patient's free will cannot be fully controlled but possibly better understood.

With the staggering loss of money in healthcare dollars associated with poor medication adherence within any disease state, if patient perception of care and understanding of patient engagement can be utilized for adherence guidelines, there could be a reduction in the dollars lost and an improvement in patient outcomes. Furthermore, for future research, there could be a cross-examination of dollars lost due to nonadherence when compared to engagement scores.

The ACE™ has been statistically validated and was a good benchmark to establish direct nursing-patient engagement and the impact on medication adherence. It is also a good starting point for understanding perception and how to better manage it and any other expectations.

Specialty pharmacy patients were evaluated on their view of healthcare provider commitment, informed choice, and navigation of the healthcare environment. The research, in combination with the ACE™, effectively captured data that can impact perception and overall healthcare outcomes. The nurse and the specialty pharmacy can utilize data collected for predictive measures in understanding why a patient may or may not adhere to their therapy.

Implications of Analysis for Leaders

After performing the study and analyzing the data, it is clear there is a need for understanding patient engagement and how it impacts areas such as medication adherence. With

the limits in this study, it further solidifies the need for broader research to include more areas of measurement to understand perception and the negative impacts of medication adherence.

Healthcare executives within multiple areas of healthcare settings are impacted by the loss of revenue associated with poor medication adherence. Management must monitor adherence for contracting requirements by focusing on specialty pharmacy operations. Pharmacies are only paid based on payers with which they are contracted. Those contracts have specific guidelines for measurement of the effectiveness of the managed care, and adherence scores are a large part of the contractual requirements. Executive healthcare leaders can use this research to look deeper into engagement and how it can impact patient care. If the engagement can improve medication adherence, then the cost of the engagement is validated and is of statistical and economic value for the pharmacy. With medication adherence costing so much to the healthcare industry in general, improvements in patient engagement are one of the most valuable assets to combat the loss of healthcare dollars associated with poor medication adherence.

Healthcare leaders are responsible for equitable and accountable healthcare. Implementation of programs to simply improve how they engage consumers can improve not only patient outcomes but also reduce the economic burden. The rationale for this research for leaders is in dollars saved through effective engagement and improvements in overall patient outcomes and patient care perception.

EBP Findings and Relationship to DNP Essentials (I-VIII)

This project studied direct nurse engagement with specialty pharmacy patients. I collected data to measure patient engagement and the impact of that engagement on medication

adherence. With the scope of the study outlined, the DNP essentials that validate the study for the progression of the degree are listed below (Springer Publishing Company, 2017).

- I. Scientific underpinnings for practice: The study used scientific nursing research by establishing a foundation in advancing nursing practice to improve patient outcomes and expand the nursing delivery practice area. The middle range theory from Hall's care, cure, and core helped establish a foundation in advancing nursing practice (Nursing Theory, n.d.).
- II. Organizational and systems leadership for quality improvement: The study helps show the development of evidence-based guidelines for specialty pharmacy nursing to impact patient engagement and medication adherence. The research data showed there is no specific specialty pharmacy nursing guidelines in this practice area. This lack of guidelines helps emphasize the need for nursing science in this clinical setting and the need for practice guidelines for improvements in patient experience in the area of rare disease specialty pharmacy.
- III. Clinical scholarship and analytical methods for evidence-based practice: With the promotion of positive perceptions and patient experiences, the impact of nursing in specialty pharmacy systems helps ensure operations are organized and care delivery is more effective in health promotion and medication adherence. This research also helps validate the area of home health nursing and shape initiatives to promote healthcare law to support this care delivery system.
- IV. Information systems/technology and patient care technology for the improvement and transformation of healthcare: The nurse involvement in this care delivery model is on the frontlines to gather accurate information to support electronic medical records for the

pharmacy. This accuracy helps the pharmacy better coordinate the care with the prescriber or any other healthcare team members. by having an in-depth understanding of the need for accurate data entered into the electronic systems, the nurse-led program helps keep the data accurate and promotes more effective use of patient care technology.

- V. Healthcare policy for advocacy in healthcare: The project showed an advanced level of clinical judgment and practice-setting operations in delivering evidence-based care that impacted the patient experience and medication adherence. With the scientific data to support nurse-led specialty pharmacy care models, supportive measures to influence policy toward home health nursing and payment systems can be influenced. With the impact of the nursing practice, there should be more justification for the profession and advocacy for the role within specialty pharmacy.
- VI. Inter-professional collaboration for improving patient and population health outcomes: With the nurse at the center of the program, there is a collaborative focus for a multidisciplinary team. The nurse binds the group together by facilitation of effective communication and collaborating to best implement care. The nurse holds everything together to greet each patient individually.
- VII. Clinical prevention and population health for improving the nation's health: The project showed clinical prevention of medication nonadherence and improved patient experience around a specific patient population. This project focused on patients with a rare disease within the practice setting of a specialty pharmacy. The program is equipping nurses and practitioners with information vital to improve the understanding of the patient experience and how it impacts medication adherence.

VIII. Advancing nursing practice: The research shows an advanced level of clinical judgment and operational practice understanding to deliver evidence-based care impacting patient experience and medication adherence. The project investigated the impact of nursing at a high level to focus on one of the largest issues in patient care—medication nonadherence. With in-depth knowledge of patient assessment, the nurse can guide the patient through effective communication in the management of their specific rare disease.

Recommendations for Future Projects

The information captured in the research study shows that managing perception through patient engagement can produce positive outcomes, such as improvements in medication adherence. The data also suggested there is a large part of the patient population that perceived themselves to be managing their care effectively yet are only compliant with their medication about 40% of the time. The lack of the patient's true perception of their care can be called a knowledge deficit, and nursing diagnosis could be applied to impact this negative occurrence.

Future projects could utilize research into a nursing diagnosis of knowledge deficit related to lack of patient engagement, as evidenced by low engagement scores. Engagement itself has not been fully understood and how the actual nursing engagement impacts specific areas of healthcare, such as medication adherence and patient engagement scores. The scoring of engagement needs further validation using an approved tool within areas of nursing utilization and specific patient populations.

Broader scope studies within the specialty pharmacy industry could show data that reflects specificity to the actual nursing interaction and any correlation with improvements in outcomes not exclusive of medication adherence. Medication adherence, being one of the most costly in loss of healthcare dollars, could be researched deeper to get a better idea of perception

of care in relation to previous adherence data and continuing patient engagement scoring models. Medication adherence is not the only variable that could be studied and compared to patient engagement. Areas such as health promotion could be researched alongside patient engagement to see if there are measurable correlations.

There should be a continuation of nurse utilization and exploration into the nurse-patient relationship. The relationship, as reflected in the study, could improve the patient perception and experience by direct nursing care. The in-depth look into the nurse-patient relationship could uncover rationales into why some patients are indiscriminate in their answers within the study and either adherent or nonadherent to their medication therapy. This might not necessarily be a bias, but a broader study length and scope into patient demographics could help manage this area of the study for more specificity.

Chapter Summary

This research in how a nurse can impact a patient's perception of care helps explore an uncharted area in rare disease patient management. The information received, although limited, helps further the need for effective nursing utilization in a practice setting that has customarily been noninclusive of the nursing profession.

The research shows how nurses can manage engagement and ultimately manage perceptions. If perceptions can be understood through effective engagement measurements, patient tendencies to medication adherence or nonadherence can be more understood. The patient always has their own free will to choose to take their medication or not. It is the hope that this study provided a small glimpse into the perceptions of the patient. The study performed is merely a peek into the perceptions a patient has on their own health and their healthcare behaviors. Although more detailed research needs to be performed into rare disease patient behaviors on

medication adherence, the results of this study validate the urgency for additional intellectual research to further corroborate nurse utilization in the practice setting of specialty pharmacies.

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Appendix A: Support Letter



24 July 2019

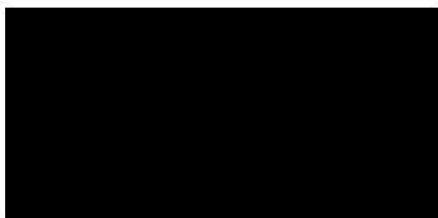
Re: Shelley Moore, MSN, RN
Abilene Christian University
DNP, Capstone Research, Patient Experience Care Model

Abilene Christian University,

I am writing to give my support for Shelley Moore, to complete her capstone project research in the area of patient experience in specialty pharmacy management.

She has my full permission to conduct research for her capstone project while utilizing resources within the company and remaining HIPPA compliant and within our corporate guidelines.

Sincerely,



Mississippi Center for Advanced Medicine



Appendix B: IRB Approval

ABILENE CHRISTIAN UNIVERSITY
Educating Students for Christian Service and Leadership Throughout the World
Office of Research and Sponsored Programs



████████████████████
May 20, 2019

Shelley Moore
Department of Nursing/DNP
Abilene Christian University

Dear Shelley,

On behalf of the Institutional Review Board, I am pleased to inform you that your project titled "The Impact of Home Health Nursing on Patient Engagement to Improve Medication Adherence",

(IRB# 19-037) is exempt from review under Federal Policy for the Protection of Human Subjects.

If at any time the details of this project change, please resubmit to the IRB so the committee can determine whether or not the exempt status is still applicable.

I wish you well with your work.

Sincerely,

Megan Roth

Megan Roth, Ph.D.
Director of Research and Sponsored Programs

Appendix C: ACE™ Agreement



SOLUTIONS TO ADVANCE HEALTH

Element Number	Element ID	Description	Responses	Length	Required
8	N2	I feel comfortable talking to my doctor about my health.	0 = "Strongly Disagree" 1 = "Disagree" 2 = "Neither Agree/Disagree" 3 = "Agree" 4 = "Strongly Agree"	1	Yes
9	C3	When I work to improve my health, I succeed.	0 = "Strongly Disagree" 1 = "Disagree" 2 = "Neither Agree/Disagree" 3 = "Agree" 4 = "Strongly Agree"	1	Yes
10	N4	I have brought my own information about my health to show my doctor.	0 = "Strongly Disagree" 1 = "Disagree" 2 = "Neither Agree/Disagree" 3 = "Agree" 4 = "Strongly Agree"	1	Yes
12	I3	When choosing a new doctor, I look for information online.	0 = "Strongly Disagree" 1 = "Disagree" 2 = "Neither Agree/Disagree" 3 = "Agree" 4 = "Strongly Agree"	1	Yes
16	C1	I can stick with plans to exercise and eat a healthy diet.	0 = "Strongly Disagree" 1 = "Disagree" 2 = "Neither Agree/Disagree" 3 = "Agree" 4 = "Strongly Agree"	1	Yes
18	I2	I compare doctors using official ratings about how well their patients are doing.	0 = "Strongly Disagree" 1 = "Disagree" 2 = "Neither Agree/Disagree" 3 = "Agree" 4 = "Strongly Agree"	1	Yes
20	N1	I have lots of experience using the health care system.	0 = "Strongly Disagree" 1 = "Disagree" 2 = "Neither Agree/Disagree" 3 = "Agree" 4 = "Strongly Agree"	1	Yes
23	I1	When choosing a new doctor, I look for official ratings based on patient health.	0 = "Strongly Disagree" 1 = "Disagree" 2 = "Neither Agree/Disagree" 3 = "Agree" 4 = "Strongly Agree"	1	Yes
24	N3	Different doctors give different advice; it's up to me to choose what's right for me.	0 = "Strongly Disagree" 1 = "Disagree" 2 = "Neither Agree/Disagree" 3 = "Agree" 4 = "Strongly Agree"	1	Yes



SOLUTIONS TO ADVANCE HEALTH

Element Number	Element ID	Description	Responses	Length	Required
25	C4	I handle my health well.	0 = "Strongly Disagree" 1 = "Disagree" 2 = "Neither Agree/Disagree" 3 = "Agree" 4 = "Strongly Agree"	1	Yes
26	Education	Participant's level of education	1 = 8th grade or less 2 = Some high school, did not graduate 3 = High school graduate/GED 4 = Some college or 2-year degree 5 = 4-year college graduate 6 = More than 4-year college degree	1	No
27	FT/PT	Participant's work status	1 = Full Time (30+ hours/week) 2 = Part Time (< 30 hours/week)	1	No
28	Primary Health Insurance Coverage	Participant's source of health insurance	1 = Sponsoring company plan 2 = Spouse's plan 3 = State Exchange plan 4 = Medicare/Medicaid 5 = Tricare 6 = Other	1	No
29	Income	Participant's income	1 = Less than \$20,000 2 = \$20,000-\$29,999 3 = \$30,000-\$39,999 4 = \$40,000-\$49,999 5 = \$50,000-\$59,999 6 = \$60,000-\$74,999 7 = \$75,000-\$99,999 8 = \$100,000-\$149,999 9 = \$150,000+	1	No
30	Health	Participant's self-reported health status	1 = Poor 2 = Fair 3 = Good 4 = Very good 5 = Excellent	1	No

Data Submission Instructions:

1. Submit the data to this email address: ace.measure@altarum.org
2. Provide the License Number in the subject line of the email
3. Include the following Licensee contact information in the body of the email:
 - Name
 - Email Address
 - Telephone Number

Altarum Institute
 Non-Exclusive Research Use License Agreement – ACE Measure™
 Altarum Proprietary
 Exhibit B - Page 3 of 3



SOLUTIONS TO ADVANCE HEALTH

CENTER FOR CONSUMER CHOICE IN HEALTH CARE
**NON-EXCLUSIVE RESEARCH USE LICENSE AGREEMENT
ACE MEASURE™**
Exhibit B
Submission Specifications

Please adhere to the following specifications when sending your population's responses to the ACE Measure.

The file should be in one of the following formats: CSV, XLS, XLSX, Tab-delimited, or X.M.L
(If you would like to send an XML file please send an email to ace.measure@altarum.org for an XML example.)

There should only be one record per person.

Export File Layout

Element Number	Element ID	Description	Responses	Length	Required
1	ID	An alpha-numeric ID that must be unique for each person		10	Yes
2	Female	Gender of participant	0 = Male 1 = Female	1	Yes
3	Age	Age of participant	1 = 18-24 2 = 25-34 3 = 35-44 4 = 45-54 5 = 55-64 6 = 65-74 7 = 75-84 8 = 85+	1	Yes
4	Zip Code	Participant's first 2 digits of home zip code	Two integers with leading zeros if applicable	2	Yes
6	I4	I spend a lot of time learning about health.	0 = "Strongly Disagree" 1 = "Disagree" 2 = "Neither Agree/Disagree" 3 = "Agree" 4 = "Strongly Agree"	1	Yes
7	C2	Even when life is stressful, I know I can continue to do the things that keep me healthy.	0 = "Strongly Disagree" 1 = "Disagree" 2 = "Neither Agree/Disagree" 3 = "Agree" 4 = "Strongly Agree"	1	Yes

Altarum Proprietary



SOLUTIONS TO ADVANCE HEALTH

CENTER FOR CONSUMER CHOICE IN HEALTH CARE

**NON-EXCLUSIVE RESEARCH USE LICENSE AGREEMENT
ACE MEASURE™**

Exhibit A



Please rate how much you agree or disagree with the following statements below.

Question	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
I spend a lot of time learning about health.					
Even when life is stressful, I know I can continue to do the things that keep me healthy.					
I feel comfortable talking to my doctor about my health.					
When I work to improve my health, I succeed.					
I have brought my own information about my health to show my doctor.					
When choosing a new doctor, I look for information online.					
I can stick with plans to exercise and eat a healthy diet.					
I compare doctors using official ratings about how well their patients are doing.					
I have lots of experience using the health care system.					
When choosing a new doctor, I look for official ratings based on patient health.					
Different doctors give different advice; it's up to me to choose what's right for me.					
I handle my health well.					

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Licensee has caused this Agreement to be executed by its duly authorized representative as of the Effective Date.

LICENSEE:

Signature

Name of Company, if applicable

Name of Person Signing

Title of Person Signing, if applicable

Date

Shelley Moore, MSN, RN
Doctoral Student, Abilene Christian University
February 11, 2019

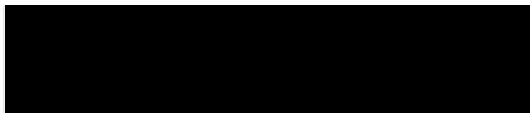
Licensee Key Contact Information:

Licensee Key Contact

Address

Phone

Email



Use of Measure Information:

Target Population Size

Brief Description of Intended/Scope of Use

29
DNP capstone research to understand if there is a positive relationship between patient experience and improved medication adherence when the ACE™ tool is facilitated by specialty pharmacy home health nursing directly to patients who receive specialty self-injectable medications by the specialty pharmacy.



of future breaches, unless such a waiver is in writing and is signed by the party against whom enforcement is sought.

7.4 This Agreement sets forth the entire understanding with respect to the subject matter hereof, and merges and supersedes all prior agreements, discussions and understandings, express or implied, concerning such matters. This Agreement may be modified only by a writing signed by a duly authorized representative of the party against whom enforcement thereof is sought.

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of liability (including without limitation, actions in the form of tort, warranty, or strict liability, or violation of any law, and regardless of whether such action has any factual basis).

Altarum agrees to indemnify, defend and hold harmless Licensee from and against any liability, damage, loss or expense (including attorneys' fees and expenses) resulting from any claim by any third party that the ACE Measure infringes or misappropriates the intellectual property rights of such third party. If the ACE Measure (or any component thereof) becomes, or in Altarum's opinion is likely to become, the subject of an infringement claim, Altarum may, at its option and expense, either (a) procure for Licensee the right to continue exercising the rights licensed to Licensee in this Agreement, (b) replace or modify the relevant service, product or technology so that it becomes non-infringing and remains functionally equivalent, or (c) terminate the Agreement. Notwithstanding anything in this section to the contrary, Altarum is not obligated to indemnify Licensee under this section if the claim results from the use of ACE Measure with other items not furnished by Altarum or modifications to the item are not made by Altarum.

6. NOTICES

All notices required or permitted to be given under this Agreement shall be in writing and shall be either: (i) personally delivered; or (ii) sent by nationally recognized overnight courier; or (iii) transmitted by postage prepaid registered or certified mail; or (iv) transmitted by facsimile; or (v) sent by email, as elected by the party giving notice. Such notice shall be addressed to the party to receive notice at the address and number set forth below or at such other address or number as may be provided in writing by said party for the receipt of notices.

If to Licensee:

Shelley Moore, MSN, RN
DNP Student, Abilene Christian University

If to Altarum:

Altarum Institute
Director, Legal and Compliance



Any notice given hereunder shall be deemed effective on the date of delivery. The date of delivery shall be: (i) the date of receipt if delivered personally; or (ii) the date three (3) days after the date of posting if delivered by mail; (iii) the date one (1) day after submitting to an overnight courier; or (iv) the date of confirmed transmission if delivered by facsimile or email.

7. MISCELLANEOUS

7.1 This Agreement and the licenses granted by it may not be assigned, sublicensed, or otherwise transferred by Licensee without the prior written consent of Altarum.

7.2 This Agreement shall be governed and interpreted by the laws of the State of Michigan, except its choice of law rules.

7.3 All remedies available to a party for one or more breaches by the other party shall be cumulative and may be exercised separately or concurrently without waiver of any other remedies. The failure of either party to act on a breach of this Agreement shall not be deemed a waiver of said breach or a waiver



4. TERM OF AGREEMENT; TERMINATION

4.1 The term of this Agreement shall commence on the Effective Date and shall continue until the earlier of (i) one (1) year thereafter, or (ii) immediately following Licensee's receipt from Altarum of written notice of Licensee's breach of this Agreement or at the convenience of Altarum.

4.2 Upon termination, Licensee will immediately discontinue use of the Measure and Proprietary Information. Within thirty (30) days after termination of this Agreement, Licensee will furnish to Altarum the final Data extraction and reporting in accordance with Section 2 hereof, as well as a certificate providing (i) the total number of individuals that received, as well as completed, a survey during the term of this Agreement, and (ii) that, through its best effort and to the best of its knowledge, the Measure and Proprietary Information have been discontinued and destroyed, as applicable.

4.3 Any rights or obligations under this Agreement that by their nature survive following termination of this Agreement will continue to remain binding upon the parties.

5. NO WARRANTIES; LIMITATIONS ON TYPES OF DAMAGES

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3.4 For purposes of this Agreement, "Proprietary Information" means any information relating to the Measure, including know-how, methodologies, copyrights, trademarks, designs, data, algorithms, and code relating to the Measure, and information not relating to the Measure that is disclosed to Licensee in the manner set forth hereinafter. With respect to any information not relating to the Measure which is



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1. ACCEPTANCE; DELIVERY; GRANT

1.1 Submission of this Agreement by Licensee to Altarum at the email address designated for Altarum in Section 6 hereof is a license request by Licensee, which Altarum may accept or reject, in its sole discretion. Rejection of the license request may be made with or without notice to the Licensee.

1.2 If the request is accepted, then this Agreement will become binding upon the parties by Altarum providing the Measure tool and materials in electronic format via email to the email address of Licensee designated in Section 6 hereof, which such delivery will occur within five (5) business days of submission of this Agreement by Licensee. The Effective Date of this Agreement will be the date that Altarum transmits the Measure tool and materials to Licensee.

1.3 Subject to the terms and conditions of this Agreement, Altarum will grant to Licensee, and Licensee hereby accepts, a restricted, non-exclusive, non-transferable license to use the Ace Measure, including the survey questions provided in Exhibit A, which is attached hereto and incorporated herein, for academic, research and internal business purposes only, i.e., not for commercial use. The Measure tools and materials will be provided by Altarum in the English language; however, the license granted herein includes use of the Measure in any language as may be translated by the Licensee. The Measure is owned exclusively by Altarum. The grant is provided to Licensee only. Licensee may not transfer or sublicense the Measure to any other entity or person, in whole or in part, in any form, whether modified or unmodified, without Altarum's prior written consent, which such consent shall be at Altarum's sole discretion. Except for the license rights granted herein, no right, title or interest in the Measure is granted to Licensee. Licensee will not, directly or indirectly, reproduce, distribute, modify, translate, decompile, disassemble, reverse engineer or transmit in any form or by any means any part of the Measure. Licensee agrees to reproduce any and all copyright notices and other proprietary markings on the Measure.

2. CONSIDERATION; DATA

Subject to the terms and conditions of this Agreement, Altarum will provide Ace Measure to Licensee for the term hereof, without compensation or other remuneration, in exchange for the de-identified data obtained from Licensee's use of the Measure, which de-identified data to be provided to Altarum is more particularly described in and limited to that information provided in Exhibit B hereto ("Data"). Altarum will include with the delivery of the Measure tool and materials described in Section 1.2 above, suggested formats (in electronic version) for gathering, and more particularly, submission of the Data as required in the immediately preceding sentence. Licensee will provide the Data in the English language in a format specified in Exhibit B to Altarum (i) in the case of an ongoing use of Ace Measure, on a quarterly basis with

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