

Patient Education, Engagement, and Activation for Chronic Pancreatitis Patients and Care

Partners

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Abstract

Background and Review of Literature: Chronic pancreatitis is a progressive disease with significant symptomatology, which can severely impact an individual's quality of life as well as their activities of daily living. The disease is difficult to diagnose and difficult to understand.

Purpose: The purpose of this project was to develop and implement an individualized, face-to-face patient education, engagement, and activation session in effort to increase the level of patient and care partner knowledge of the CP disease process, improve patient and care partner expectations of care management, and increase patient and care partner involvement in their own care.

Methods: Ten-item surveys were administered for data collection both before and after the implementation of an education session specific to chronic pancreatitis.

Implementation Plan/Procedure: A ten item survey was administered to enrolled participants. The goal of this survey was to gauge the patient and care partner knowledge level on topics related to chronic pancreatitis as well as strategies for their own involvement in that care, both before and after the education session. After the survey was administered the project coordinator implemented a disease specific education session lasting 30-60 minutes. After the education was completed, an identical survey was administered.

Implications/Conclusion: Overall the total score results on the post survey, after the education, were improved and statistically significant ($p = 0.007$). This value reveals evidence a change has occurred after the implementation of education.

Patient Education, Engagement, and Activation Program for Chronic Pancreatitis Patients
and Care Partners

Chronic pancreatitis (CP) is a chronic, progressive, inflammatory disease of the pancreas, which can cause significant abdominal pain, malabsorption, pancreatic insufficiency, steatorrhea, pancreatogenous diabetes, fat-soluble vitamin deficiency, malnutrition, and weight loss (Majumder & Chari, 2016). These symptoms leave patients unable to function in their normal daily routines. Often times CP symptoms force patients to withdraw from school or lose their jobs. Care partners watch helplessly as patients become debilitated by the symptomatology of CP and patients become frustrated by a lack of cure.

Unfortunately, due to the nature of CP and the difficulty in diagnosing this disease, epidemiological statistics are difficult to obtain (Jupp, Fine, & Johnson, 2010). What is known based on the few studies available across the globe, is that the incidence and prevalence of CP is on the rise. According to Majumder and Chari (2016) analysis revealed an age-adjusted and sex-adjusted incidence rate of 4.05 per 100,000 person-years and a prevalence rate of 41-76 per 100,000 population. It seems men have a higher incidence of CP than women do, while African American individuals have a higher incidence than Caucasians (Majumder & Chari, 2016). Alcohol intake is a known cause of CP, as is cigarette smoking. Other causes include genetic mutations and ductal obstruction, although many cases develop without a known cause.

Background

When speaking of chronic health conditions in general, one study found that less activated patients had significantly higher health care costs than more activated patients (Hibbard & Greene, 2013). An activated patient is one who is an active, effective manager of their own health and health care. Educated and activated patients are more willing and able to independently take steps to manage their health care. There is growing evidence that patients who are more activated have better health outcomes and experiences (Hibbard & Greene, 2013). One study showed that those who score higher on a Patient Activation Measure are significantly more likely than people who score lower to engage in regular follow up, screenings, immunizations, healthy diet and exercise, and smoking cessation (Hibbard & Greene, 2013). Reduced emergency room visits and hospital admissions could result from patient activation.

Hibbard and Greene (2013) suggest engaging patients can and should be measured as an intermediate outcome of care that is linked to improved outcomes. When patient activation and engagement occur, the tentacles of CP management can then reach far beyond the exam room or hospital bed and into the homes and communities of the people impacted.

For CP specifically, individuals and their care partners receive care from various providers, health care organizations, and foundations. Disease specific multidisciplinary management is provided by gastroenterology, endocrinology, surgery, pain management, and psychiatry through a specialized Pancreas Disease Program (PDP) in a Midwestern hospital. Primary care providers, emergency room providers, and hospitalists often provide acute care, typically treating pain exacerbations. Nationally, The National

Pancreas Foundation (NPF) aides in funding for cutting edge research, advocating for new and better therapies, and providing education for patients, caregivers, and health care professionals (National Pancreas Foundation, 2017). While this Midwestern Hospital has been designated as a National Pancreas Foundation Center for CP care, there are currently no local or state chapters of The National Pancreas Foundation within the state of Nebraska.

As global CP incidence has risen, so too have patient volumes within PDP. Areas for practice improvement have been identified, most notably in the area of education for patients and care partners. In addition, the management of patient and care partner expectations of care received has been noted as a priority. There is an apparent failure to understand the chronicity and progressive nature of CP with patients and care partners. The pathogenesis of CP is not well understood with multiple theories presented, but none validated (Majumder & Chari, 2016). If specialized providers have a difficult time explaining and understanding this disease, how can patients, their care partners, primary care providers, emergency room providers, and hospitalists obtain an adequate grasp on chronic pancreatitis?

Understanding optimal pancreatic function and how CP impacts that function is essential. Quality education can help to explain the anatomy and physiology of the pancreas as well as the natural history and progression of chronic pancreatitis. Options available for management of symptoms, rather than treatment or cure of disease, must be clearly outlined for each patient. Patients present to clinic in a significant amount of pain with the assumption that the source will be identified and eliminated, which is not always possible in CP. For providers, it becomes difficult to remain objective and

nonjudgmental when patients are often seen with requests for pain medications. To date, members of the PDP care team have worked tirelessly to identify and address the needs of this community by completing educational and outreach events across the state of Nebraska for providers. Education is provided within each PDP clinic visit for patients and care partners, however, knowledge gaps still exist.

Target Population and Stakeholders

Interventions within this project specifically targeted individuals with CP who are managed in the PDP as well as their care partner. Multidisciplinary members of the PDP team include the gastroenterologist, surgeon, endocrinologist, psychiatrist, pain management specialist, dietician, pharmacist, social worker, nurse coordinator, and financial counselor. Each of these individuals holds a vested interest in this topic and were directly involved in the development and implementation of the intervention as well as the evaluation of outcomes. This team, the patients, and the care partner are all stakeholders in this effort.

This particular project was not currently a collaborative effort with other centers, organizations, or foundations. In the future, there could potentially be extension of the effort beyond the borders of Nebraska with a collaborative effort including other specialty centers, NPF support, and even grant funds. An extension could also be made to include the participation of both public and private healthcare insurance providers who are vested in outcomes of patients with CP and other complex health conditions.

Problem Statement

Identification of the CP knowledge gap amongst patients and their care partner along with low levels of patient participation in their own health care prompted the

efforts of this project. For patients with chronic pancreatitis who are seen in a specialized pancreatobiliary clinic, does using individualized face-to-face patient education with a licensed health professional improve patient and care partner knowledge of the disease process, patient and care partner management of care expectations, and increase patient and care partner activation?

Purpose Statement

The purpose of this project was to develop and implement an individualized, face-to-face patient education, engagement, and activation session in effort to increase the level of patient and care partner knowledge of the CP disease process, improve patient and care partner expectations of care management, and increase patient and care partner involvement in their own care.

Outcomes

This capstone project's aim was to achieve a satisfactory level of knowledge for patients and their care partner related to the following:

1. Anatomy, physiology of the pancreas and chronicity, progression of CP.
2. Chronic pancreatitis care management expectations, including pain management.
3. Strategies for disease management using home interventions.
4. Activation and engagement for disease management and quality of life improvement.

Outcomes were measured using self-report survey(s).

Providers able to listen, develop rapport and trust, explain information and empathize can positively and directly improve patient satisfaction and have a significant

effect on psychological and physical health outcomes (Brownie, Scott, & Rossiter, 2016). Santana and Feeny (2014) theorize the completion of patient-reported outcome measures (PROMs) and the incorporation of PROMs could result in improvements in patient, care partner, and clinician communication, promoting discussion of issues that arise in the PROMs, and sharing of treatment goals and patient preferences in treatments.

For the purpose of this project, self-report surveys were developed to collect data. Survey questions aimed to assess individual and care partner perceptions on their own baseline knowledge of the pancreas as well as CP. In addition, questions allowed individuals to gauge their own level of activation within their care and provided an opportunity to gauge their personally ability to manage their disease, both acutely and chronically.

Grady and Gough (2014) made an excellent point in their writing when it was suggested moving beyond education for patients with chronic conditions and into teaching patients how to actively identify challenges in their health care and solve problems associated with their illness. Ideally, the goal after project implementation was for patient and care partner responses to change from not satisfactory to satisfactory regarding participation and engagement in their own plan of care.

Review of the Literature

Identification Process

To identify the evidence base for this project, a review of research literature was completed. A key word search was conducted using the following electronic search engines: PubMed, ProQuest, and COCHRANE Database of Systemic Reviews. A standardized search query was entered into each search engine. Articles published in

English involving humans (rather than animal studies) between 2012 and 2017 were searched. Appendix A reveals the details of the literature search completed for this project.

Criteria

Inclusion criteria included the following: highest level of evidence; key focus on patient education, activation, and managing care expectations; outpatient; and, chronic medical conditions. Exclusion criteria included the following: inpatient; inapplicable diagnosis (acute and curable medical conditions); inapplicable intervention; incorrect patient population; and, no related to the purpose and problem statements. Search terms included were chronic pancreatitis, chronic health conditions, low patient activation, patient care management expectations, patient knowledge deficit, patient education, and absent patient education.

Utilizing the details described above, 177 articles in total met the search criteria for review. Of these 177 articles, 18 were felt to be more specific to this project based on intervention, findings, and limitations. These 18 articles were selected to be reviewed in further detail and include descriptive, qualitative studies, systematic reviews, and observational, cross sectional surveys with levels of evidence ranging from level I to level IV. Appendix B provides a reference matrix describing several of these articles.

Overall Consensus

There is a growing body of literature suggesting that patients play an important role in determining their own health outcomes. Much of this research indicates increased patient education, engagement, and activation results in increased satisfaction and improved outcomes. Arguments are also made suggesting efforts such as these may

strengthen outpatient and home management of chronic disease symptoms while decreasing hospital admission rates.

Education, Activation, and Empowerment

Patient activation is strongly related to a broad range of health-related outcomes, which suggests improving activation has great potential (Green & Hibbard, 2012). Very low activation levels are significantly associated with higher health care costs and are predictive of higher future costs, when compared to higher activation levels (Hibbard, Greene, & Overton, 2013). Patients' activation significantly affects their reported medication adherence (Graffigna et al., 2017). Throughout the literature, research has been completed on chronic health conditions such as human immunodeficiency virus (HIV) and chronic obstructive pulmonary disease (COPD), which could be translated to CP as well.

Programs and tools aiding in patient activation and engagement.

The Patient Health Engagement (PHE) model is a critical factor enhancing the quality of care with patients and may act as a mechanism to increase patient activation and adherence (Graffigna et al., 2017). Santana and Feeny (2014), theorize the completion of patient-reported outcome measures (PROMs) and the incorporation of PROMs could result in improvements in patient, care partner, and clinician communication, promoting a discussion of issues that arise in a the PROMs, and sharing of treatment goals and patient preferences in treatments.

A program discussed by Sheppard (2016) evaluates the effectiveness and cost of managing patients with admission avoidance hospital at home and compared it to actual hospital admission care. This study indicated a program such as this may provide for

more patient satisfaction, but was unclear on any reduction or increase in cost or improvement in the quality of care received. Use of an online telehealth application was found to be acceptable and feasible for patients caring providing self-care at home. Daily use of this tool included reporting symptoms, medication use, measurement of physiological variables such as pulse rate and oxygen saturation, self-management plans, and messages to health care staff (Williams et al., 2014). This was completed on a population with COPD, but results could be translated to other chronic disease who require home management, engagement, and activation. The online tool can aid in the development of individualized alert thresholds, which could potentially assist the patient in identifying exacerbations early (Williams et al., 2014). Than Win, Mohd Hassan, Bonney, & Iverson (2015) explains that the web offers patients interactivity and engagement, which enhances their learning and understanding, unlike traditional patient handouts. Telephone-based coaching services for the management of patients with chronic diseases can improve health behavior, self-efficacy, and health status (Dennis et al., 2013).

Coulter (2015) compared a personalized care plan for adults with long-term conditions, such as CP, with forms of care in which active involvement of patients in treatment and management decisions is not explicitly attempted or achieved. Personalized care planning was shown to lead to improvements in certain indicators of physical and psychological health status and people's ability to self-manage their condition (Coulter, 2015).

Gaps

Minimal literature content focused on the empowerment and education of the chronic pancreatitis patient population specifically. Few studies discussed demographics and social determinants of low activation levels and if this information was thought to impact the level of activation. Where technology was discussed as a means of enhancing and increasing patient education and activation, barriers were not considered such as low patient computer skills, unwillingness to use the technology, and poor architectural and technical designs (Than Win et al., 2015).

Summarization

This literature search provides a strong foundation for the capstone project described in this paper. Project efforts aligned with the evidence-based findings in current literature. The patient and care partner were central and involved, utilizing appropriate tools and programs to enhance learning and activation. The health care team aimed to increase their knowledge base on CP, involve them in their own plan of care, and activate and empower them to participate in that care at home.

Theoretical Framework

Santana and Feeny (2014) developed a conceptual/theoretical framework, which assesses the effects of using patient-reported outcome measures (PROMs) in chronic care management. The underpinnings of the framework described by Santana and Feeny provides a solid foundation for this capstone project. The framework theorizes that patient completion of PROMs and the incorporation of their responses into their care management plan could generate improvements in communication, promoting the

discussion of issues reflected in the PROMs, and the sharing of goals, treatments, and the patient's preference about treatments (Santana & Feeny, 2014).

The first component of the framework is communication. This communication includes clinician to clinician, patient to clinician, patient to relative, and clinician to relative. The second component of the framework involves patient engagement and activation in a way that provides the patient with a better understanding of their role in their own care process and provides them with the knowledge, skill, and confidence to carry it out (Santana & Feeny, 2014). Third, the framework involves shared decision making, which includes patient and clinician preferences and a mutually agreed upon plan of care. Patient management is the fourth component of the framework and is described as the patient's self-management of their chronic disease as well as the clinician's management of the patient with the chronic disease (Santana & Feeny, 2014). Next, patient satisfaction and clinician satisfaction are the fifth and sixth components of the framework. These components involve enhanced communication and suggests that actively engaged patients are more satisfied with their treatment plan and have better outcomes (Santana & Feeny, 2014). Patient adherence is the seventh component, which suggests actively engaged patients who are involved in the decision-making process of their care tend to adhere to the treatment advice they receive (Santana & Feeny, 2014). And lastly, the patient outcome is the final component of the framework. This involves a reduction in adverse outcomes, medical mismanagement, readmission rates, and length of stay in the hospital (Santana & Feeny, 2014). At the same time, it involves an improvement of overall health status and health-related quality of life as well as survival rates (Santana & Feeny, 2014). Appendix C reveals a diagram of this framework.

This project was guided by the framework as it sought to increase communication between the clinician, patient, and care partner by developing a face-to-face education session specific to the care of CP. It also utilized PROMs in survey format in an effort to develop mutually agreed upon care goals and expectations. Lastly, this project sought to increase patient engagement and activation in order to improve satisfaction and outcomes.

Organizational Assessment

The entire multidisciplinary team within the PDP program met and thoroughly discussed this project with a readiness for change within the PDP seemingly apparent. The predominate symptom resulting in PDP consultation is abdominal pain. The team works thoroughly to sort out the source of abdominal pain, occasionally discovering a definitive diagnosis of CP. The management of this disease, particularly pain management, has changed over the last several years. Historically, clinicians have been very well aware that CP is a painful disease. Endoscopic and surgical interventions are sometimes indicated and could provide a means of pain relief. However, many times endoscopic and/or surgical interventions are not indicated and efforts are turned toward medical management of pain. When the PDP first began in 2011 it seemed there was an understanding of the need for opioid therapy for the management of CP in order to keep patients semi-functional and out of the hospital. Over the last several years this mentality has changed and there has been a shift in this approach based on center experiences across the country. Perhaps indefinite, chronic management with opioid therapy is not the best approach for this patient population. Perhaps this is contributing to the development of a second chronic disease in addition to CP, chronic opioid dependence.

There is now a better understanding that the biology of pain can be multifactorial and there are different types of pain including peripheral and central hypersensitivity as well as neuropathic pain. This suggests the need for opioids may not be as strongly indicated for pain control as once believed. “Progress is occurring in pain biology and treatment options, but pain in patients with CP remains a major problem that is inadequately understood, measured and managed” (Anderson et al., 2016, p.2). Therein lies an enormous frustration for both clinicians and patients, one which this project sought to assist patients and care partners to understand.

Due to the previous management of abdominal pain in CP with opioids, there is now a subset of patients who are dependent on opioids and reluctant to change their management strategy. Despite this, there has been a significant effort to decrease the use of opioids and almost no prescriptions for them within the PDP. Many referrals are made to various pain management specialists who often provide interventional pain management therapies rather than opioid prescriptions. Neuromodulating agents are also being used more than before. All of these changes to the pain management of previous patients and pain management of new patients moving forward requires ongoing education to patients and care partners.

Along with pain management, there must be significant management of other physical CP symptomatology including nausea, vomiting, weight loss, steatorrhea, diarrhea, bloating. Also, CP can present with intermittent sadness, hopelessness, frustration, fear and worry. Managing expectations and providing strategies for self care through this project was the goal. Clinicians within the PDP at this Midwestern hospital identified this issue and verbalized the need for this capstone project.

Clinic workflow and patient rooming was thought to be a potential barrier initially. However, the continued integration of surveys into that workflow improved overtime, thereby decreasing this barrier.

Methodology

Setting

A Midwestern hospital was the site of project completion, after approval from the research committee within the Midwestern hospital as well as the service line director. This Midwestern hospital consists of 809 licensed inpatient beds, 1,000 physicians, and 40 specialty and primary care clinics throughout the surrounding areas.

Within the Midwestern hospital, CP patients were seen on the main campus in the ambulatory Multi Organ Transplant Clinic (MOTC). This clinic location is serviced by the Digestive Disease Kidney (DDK) service line within the organization. The DDK service line is further divided into specific transplantation and digestive disease programs. The transplant program provides comprehensive treatment for disease that affect the liver, intestine, kidney, pancreas, heart and lung. The CP program and weekly clinic is a service provided under DDK's liver and intestinal transplant program specifically. The clinic not only serviced patients and care partners within the city and the state, but also throughout the Midwest region. There is currently no other clinic focused on CP within the region. A formal letter providing MOTC facility approval was received.

The weekly clinic was staffed by a gastroenterologist, an endocrinologist, and a pancreas surgeon each Wednesday. This team of physicians met prior to each clinic to collaborate and collectively diagnose and develop a plan of care for difficult pancreas-

related disorders (Chronic Pancreatitis, n.d.). Approximately 15 patient appointments were scheduled each week.

Sample

Participants included adult patients who carry an actual diagnosis of CP. Many other patients are seen in clinic with symptoms similar to CP and some diagnostic criteria suggesting CP, but without a definitive diagnosis. For these patients, terms such as ‘suspicious for CP’ or ‘suggestive of CP’ may be used in documentation, but they do not yet definitively carry the CP diagnosis. For this project, only those with a definitive CP diagnosis given by the gastroenterologist and their care partners were included.

Individuals of all ages are treated within this Midwestern hospital PDP for CP, including children. Patients are often accompanied to clinic appointments and assisted in their care at home by family members, children, other relatives, friends, partners, neighbors, and significant others. For the purpose of this project, all individuals who provided care support, whether they were related to the patient or not, were referred to as care partners. Also, for the purpose of this project, children were not included in participation whether they were the actual patients or identified as a care partner.

Implementation Procedures

This evidence based practice capstone project consisted of implementation of an education session, which was evaluated by self-reported data. According to the project timeline, completion occurred July 2018 (see Appendix D). The purpose of the project was to gain insight on patient and care partner knowledge on the CP disease process, quality of life, management of CP including pain management, and also their own self-ability to manage daily CP symptoms as well as disease exacerbations. This insight was

obtained through surveys completed by patients and care partners after their scheduled clinic visits. Once the patient was seen in the MOTC clinic by the PDP team members the pre-survey was completed and the intervention took place. This included the implementation of an individualized, face-to-face patient and care partner education, engagement, and activation session by the project coordinator in an effort to increase the level of patient and care partner knowledge of the CP disease process, improve patient and care partner expectations of care management, and increase patient and care partner involvement in their own care. An identical post-survey was completed by patients and care partners immediately following this educational session. Ultimately, the participants completed a pre-education survey, an education session, and a post-education survey within the same clinic visit on the same day.

The aim of the intervention was to achieve a satisfactory level of knowledge in patients and their care partners related to the following:

1. Anatomy, physiology of the pancreas and chronicity, progression of CP.
2. Chronic pancreatitis care management expectations, including pain management.
3. Strategies for disease management using home interventions.
4. Activation and engagement for disease management and quality of life improvement.

Identical self-report surveys were used prior to the intervention and also following the intervention, which will be further discuss later within this document. The use of individuals other than the project coordinator to administer the pre-intervention surveys, educational intervention, and post-intervention surveys was not necessary. However, a

thorough review of the process, instruments, and educational material were reviewed with the PDP clinical nurse coordinator in the event that the project coordinator was unavailable.

Measurement Instruments

The project coordinator created a pre-intervention survey as well as a post-intervention survey, (Appendix E and Appendix F), respectively for each of these. These instruments were created by the project coordinator, therefore there is no reliability and validity measure. The goal of this survey was to gauge the patient and care partner knowledge level on topics related to chronic pancreatitis as well as strategies for their own involvement in that care, both before and after the education session.

Data Collection Procedures

A stepwise approach to this project was completed using the Plan-Do-Check-Act (PDCA) framework. This framework leans on a scientific method where there is hypothesis (plan), and experiment (do), and evaluation (check).

This document encompasses much of the planning phase necessary to obtain the anticipated project outcomes. During the planning phase the project proposal was submitted to the IRB for approval. The identified instruments were printed and reviewed thoroughly by the project coordinator. Each instrument was printed and prepared for distribution. The intervention session materials were prepared in handout form and reviewed by all members of the multidisciplinary PDP team at the Midwestern hospital.

Convenience sampling was utilized for this capstone project. The gastroenterologist within the PDP at the Midwestern hospital maintains a list of patients seen in the MOTC who carry a definitive diagnosis of CP. This list was reviewed and

patients from this list with scheduled follow up appointments between January 2018 and May 2018 were identified. During these scheduled clinic visits, each individual who met the project inclusion criteria was approached for informed consent. Once consented, and after the actual clinic visit, the pre-intervention survey instrument identified for this project was administered.

Next, the educational intervention took place in the same room by the project coordinator. The duration of this intervention was approximately 30-60 minutes. Handouts were provided to the patient and care partner present. Each handout was thoroughly explained with an opportunity for questions to be answered.

Due to time constraints and the risk of low or poor post-intervention survey participation, the post-intervention survey instrument was administered in the clinic immediately following the educational session. The goal was to see an improvement in self-reported patient and care partner knowledge on the post-intervention survey instrument when compared to the pre-intervention survey instrument related to the following:

1. Anatomy, physiology of the pancreas and chronicity, progression of CP.
2. Chronic pancreatitis care management expectations, including pain management.
3. Strategies for disease management using home interventions.
4. Activation and engagement for disease management and quality of life improvement.

Each patient and care partner project participant completed their own individual survey before and after the education session. Individualized plans of care could be

developed while taking into consideration each patient and care partner response to the surveys. As discussed previously, patient responses must be heavily considered and incorporated into any plan of care. This allows the patient to participate in their own care as an identified team member and empowers them in self-care. This will also be reiterated in the following section.

Ethical Considerations/Protection of Human Subjects

The Nebraska Methodist College Institutional Review Board (IRB) approval was obtained prior to initiating the project. The official IRB Application Form was submitted upon proposal approval. Upon submission, the IRB category of exempt was requested, which indicates there is less than minimal risk to minimal non-vulnerable participants and there were no sensitive questions asked such as sexual practices, recreational drug use, alcohol use by minors, and criminal behavior. Collaborative Institutional Training Initiative (CITI) certification was obtained by the researchers. Informed consent was obtained prior to patient or care partner participation in this capstone. Informed consent is important in order to develop trust between the project coordinator and the participant, provide autonomy, promote the welfare of the participant, and provide respect to the participant (Moore & McSherry, 2013). Ensuring ethically valid informed consent involves voluntary participation as well as competence and autonomy for the participant (Moore & McSherry, 2013). The project coordinator declares that there were no conflicts of interest.

Another ethical consideration within this capstone project was confidentiality. Moore and McSherry (2013) explain that the person obtaining consent has a duty to ensure that any information relating to the research is disclosed to no one. To ensure

privacy within this project there was no use of participant names or personal information. Both the pre-intervention survey instrument and the post-intervention survey instrument had identical identification numbers, linking only the two instruments together. The identification numbers were not linked to the participant or their personal information. No confidential health information was disclosed.

Ethical standards include autonomy, freedom, objectivity, self-assertion, beneficence, and fidelity. The project coordinator and the patient and care partner were all involved together through this education and were impacted by the intervention. Utilizing the bioethical standards in order to come to a mutual understanding and agreement that supports the most favorable of outcomes was the aim.

The Health Insurance Portability and Accountability Act (HIPAA) and the Standards for Privacy of Individually Identifiable Health Information are congressionally mandated and help to define and identify protected health information. Throughout the duration of the capstone project, while survey instruments were continually being completed by participants and collected by the project coordinator, all documents related to the project remained in the project coordinator's possession and were stored in a filing cabinet secured by lock and key. The sole owner of the key to this secure, locked cabinet was the project coordinator of this capstone project. All data collected remained anonymous. Data was downloaded as aggregate data and saved in a password protected file. Data will be saved for 3 years and will be deleted after this 3-year period has expired.

There were no risks in participating in this research beyond those experienced in everyday life. Patient and family benefits may have included the following: learning

more about yourself by participating in this project, having a better understanding of chronic pancreatitis and their role in disease management, feeling increased empowerment in terms of self-management of chronic pancreatitis, gaining confidence in managing symptoms exacerbations at home, and avoiding emergency room visits and hospitalizations.

Data Analysis

This capstone project utilized a pre-post test (survey) design. Once the final participant completed the pre-intervention survey instrument, the interventional education session, and the post-intervention survey instrument, all data was collected and statistically analyzed using a dependent samples t-test. The pre-intervention survey instrument and the post-intervention survey instrument were identical. Each survey consisted of ten topics to which the participant was requested to rate their own knowledge. The options for rating beneath each topic included the following: I know the topic quite well; I know of the topic partially, and I know where I can find more information about it; and, I am not confident in my knowledge level of the topic. The statement “I know this topic well” was quantified with a value of 1. The statement “I know of the topic partially, and I know where I can find more information about it” was quantified with a value of 2. Lastly, the statement “I am not confident in my knowledge level of the topic” was quantified with a value of 3. A lower total value on the survey suggested a higher level of participant confidence in their own knowledge level on the listed CP topics. A higher total value on each survey suggested a lower level of participant confidence in their own knowledge level on the listed CP topics. The lowest score possible on each survey was 10 and the highest score possible was 30.

At the completion of this capstone project, the project coordinator was able to determine if the anticipated outcome was met, partially met, or not met for each participant. Data was analyzed comparatively for each participant with pre-intervention scores versus post-intervention scores utilizing the assistance of a statistician. In addition, all participant data was pooled into a group to determine if post-intervention scores improved.

Results

In total, 5 participants were consented and enrolled into the capstone project by the project coordinator. The total mean scores for each survey were analyzed using the paired samples *t*-test function within Microsoft Excel. Overall the total score results on the post survey, after the education, were improved and statistically significant ($t(4)=4.996, p = 0.007$). This value reveals evidence a change has occurred after the implementation of education.

Discussion

These results indicate an overall improvement in understanding of the knowledge, expectations, and care involved in chronic pancreatitis. The survey line items mirror the project outcomes with knowledge, expectations, and care content. Overall, participants suggested an increased knowledge of the anatomy and physiology of the pancreas, the pathophysiology of chronic pancreatitis, natural history and progression the disease. In addition, the data reveals an increased awareness of what to expect in terms of disease management, including pain control. Lastly, the data revealed improvement in the

awareness of care in chronic pancreatitis such as self-activation and disease management at home.

Limitations

Five participants in total offered a small sample size. This makes it difficult to generalize relationship between the education and the outcome. The literature review for this project offered a foundation more generalizable to chronic illness, however, data and research was lacking specific to patient education in the chronic pancreatitis population. The pre and post surveys utilized within this capstone project assessed strategies for home management of symptoms as well as care expectations, but could have leaned heavier on evaluating each individuals perception of their own level of activation. The time frame between the pre-survey and post-survey was short in duration, only the time taken for education. This can affect the reliability and validity of the results. Future research could be revised to gather activation information specifically. Self-reported data, such as that within this project, may elicit bias from the participant and cannot necessarily be independently verified. Time limits for this capstone project provided difficulty in measuring change or stability over time, after the implementation of education.

Plan for Sustainability

This capstone project included an individualized, face-to-face patient and care partner education, engagement, and activation session in an effort to increase the level of patient and care partner knowledge of the CP disease process, improve patient and care

partner expectations of care management, and increase patient and care partner involvement in their own care. The education was supplemented and guided by a paper handout with copies provided for the patient and care partner.

This project coordinator reviewed the capstone project outcomes and education material, including the handout, with the clinical nurse coordinator of the PDP at the Midwestern Hospital. Upon completion of this capstone project specifically, continuation of the self-reported surveys and patient and care partner education could be carried out by the clinical nurse coordinator. Patients and care partners who are new to the PDP and identified as CP patients could be scheduled for an education session with the PDP clinical nurse coordinator. Over time, the information within the handout and delivered to patients and care partners could be adjusted by the clinical nurse coordinator based on current practice. The multidisciplinary team members for the PDP at the Midwestern Hospital could assume responsibility of ongoing education and evaluation of patient and care partner learning.

Implications for Practice

The development and implementation of a focused education session administered by a trained health care professional to patients and care partners suffering from CP provides support to the patient and care partner. Not only does this effort improve their own perception of knowledge surrounding the disease, it also increases their confidence and comfort level in their own ability to engage themselves in their care and develop an action plan for themselves in order to manage the chronic and acute symptoms associated with CP. Furthermore, chronic pancreatitis patients and care

partners gained a better understanding of the management of CP. The result led to fewer unmet expectations as well as a decrease in frustration and hopelessness.

When patients and care partners begin to feel confused, frustrated, hopeless, and uncertain, this can lead to many of the same emotions and feelings for the multidisciplinary care team. Addressing the root of these emotions provides for a care environment with a mutual understanding and respect between the providers and the patients and care partners.

Conclusion

In summary, there has been identification of a knowledge gap amongst patients and their care partners surrounding CP along with low levels of patient and care partner participation in their own health care and unrealistic expectations in their care or management of CP that are not met. Patients and care partners occasionally fail to understand CP disease progression, symptomatology, standards of care in management, and their personal role as a team member in their own. These topics are the foundation to successful disease management and patient empowerment and activation.

Within a Midwestern Hospital's PDP program, the project coordinator sought to initially gauge the patient and care partner's perception of their own knowledge regarding the following topics: pancreatic anatomy and physiology, anatomy and physiology of the pancreas in CP, CP disease progression, symptoms associated with CP, pain and pain management in CP, overall CP management options, self-activation and engagement in care plan, strategies to manage CP at home, and strategies to improve quality of life associated with CP. The project coordinator then provided the patient and care partner

with information related to these areas in an effort to improve their self-reported perception of their own knowledge.

Finally, an identical survey was administered after the educational session in order to determine if this improvement had in fact occurred. It was anticipated that patient and care partners would gain a better understanding of CP and its management, thereby resulting in improved expectations, management, disease control and quality of life while also decreasing frustration, hopelessness, and noncompliance. The survey results showed that this intervention did have an impact on the understanding of their disease.

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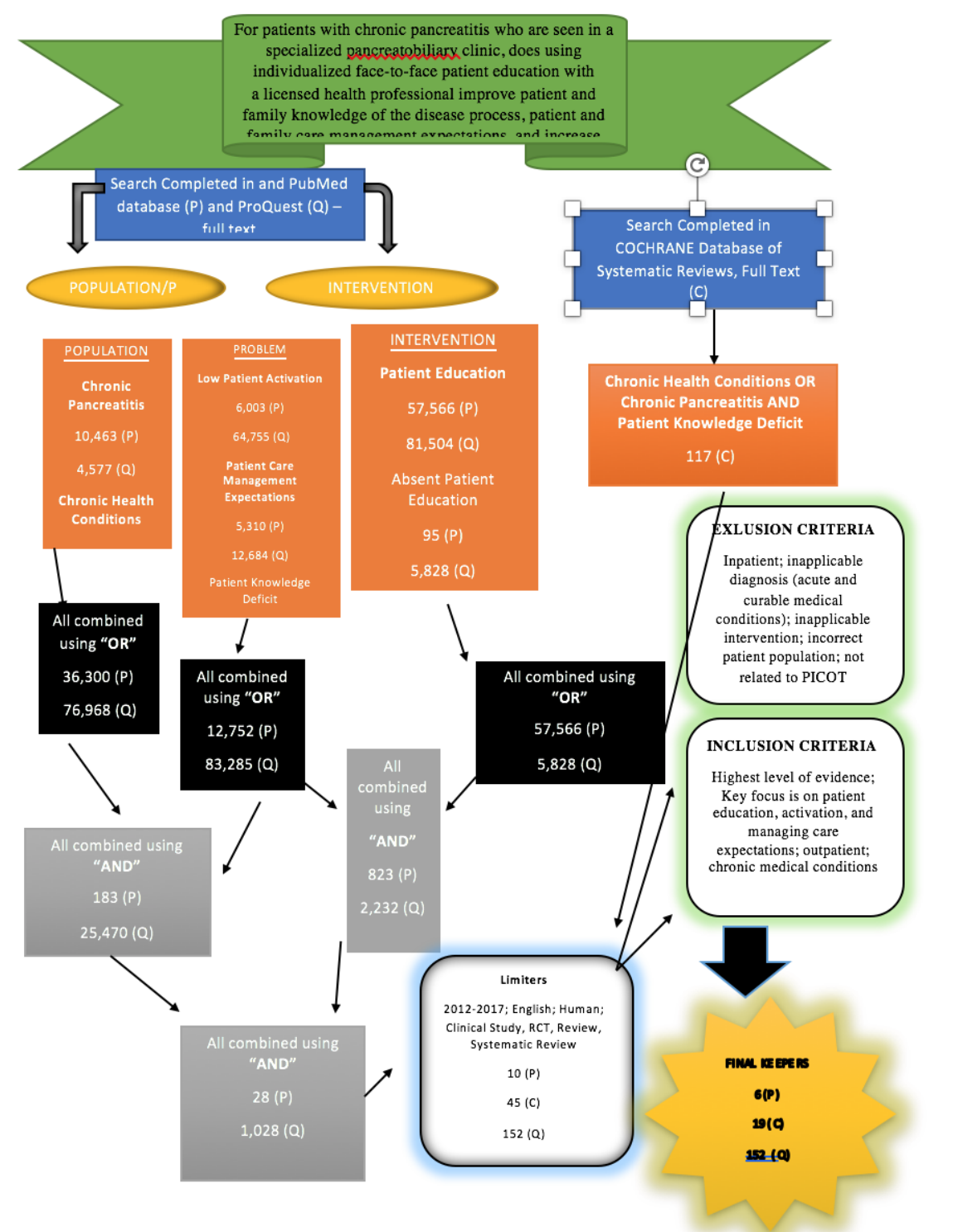
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Appendix A Literature Search



Appendix B

For patients with chronic pancreatitis who are seen in a specialized **pancreatobiliary** clinic, does using individualized face-to-face patient education with a licensed health professional improve patient and family knowledge of the disease process, patient and family care management expectations, and increase patient and family activation?

Christina Sailors – NRS 880 Reference Matrix

Citation/ Level of Evidence	Participants/Setting/ Sample size	Purpose/Background	Methods/Design & Limitations	Findings/Summary Strengths/Weakness	Applicability to Own Research
<p>Shepherd, S. (2016). Admission avoidance hospital at home. <i>Cochrane Database Of Systematic Reviews</i>, (9), doi:10.1002/14651858.CD017491.pub2</p> <p>Level II evidence; Systematic review of randomized control trials, Level I. (L1bGuides, n.d.)</p>	<p>16 randomized controlled trials with a total of 1814 participants; 3 trials recruited participants with chronic obstructive pulmonary disease, 2 trials recruited participants recovering from a stroke, 6 trials recruited participants with an acute medical condition who were mainly elderly, and the remaining trials recruited participants with a mix of conditions.</p> <p>Adults (aged 18 years or older).</p> <p>Excluded obstetric, pediatric, and mental health hospital at home schemes.</p>	<p>To determine the effectiveness and cost of managing patients with admission avoidance hospital at home compared with inpatient hospital care.</p>	<p>Followed the standard methodological procedures expected by Cochrane and the Effective Practice and Organization of Care (EPOC) Group. Performed meta-analysis for trials that compared similar interventions and reported comparable outcomes with sufficient data, requested individual patient data from trialsists, and relied on published data when this was not available. We used the GRADE approach to assess the certainty of the body of evidence for the most important outcomes.</p> <p>Missing data in two data sets.</p> <p>Overall risk of bias low.</p>	<p>Admission avoidance hospital at home, with the option of transfer to hospital, may provide an effective alternative to inpatient care for a select group of elderly patients requiring hospital admission. The evidence is limited by the small randomized controlled trials included in the review, which adds a degree of imprecision to the results for the main outcomes.</p> <p>Patients who receive care at home may be more satisfied than those who are in hospital, but it is not known how this type of health care affects the caregivers who support them. With respect to costs, it is uncertain if hospital at home services reduce or increase length of stay or cost to the health service; when the costs for caregivers are taken into account any difference in cost may disappear.</p> <p>All but one study used reliable measures of outcome and 4 reported blinded assessment of outcomes.</p> <p>Difficult to generalize internationally with health care systems set up differently. 16 trials included in this review came from Australia, Italy, New Zealand, Romania, Spain, the UK, and the US.</p>	<p>This was helpful to understand that a program aiming to avoid hospital admission is beneficial, however, not an alternative. It seems I would be able to foresee the same for the chronic pancreatitis patient population. The aim would be to put measures into place in attempt to avoid hospital admission, which it occasionally does, but being admitted is sometimes necessary and any intervention such as this would not have the capability of replacing that.</p>
<p>Williams, V., Price, J., Hagel006, M., Tegassniko, L., & Farmer, A. (2014). Using a mobile health application to support self-management in COPD: a qualitative study. <i>The British Journal of General Practice</i>, 64(624), e392–e400. http://doi.org/10.3399/bjg.p14X680473</p>	<p>Twenty-three patients were given the mHealth system to use for a 6-month period, with 18 of these completing the full six-month study.</p> <p>For the six-month cohort study, patients meeting the inclusion criteria were identified and recruited from a variety of healthcare settings:</p>	<p>The aim of this study is to explore the expectations and experiences of patients who use a mobile telehealth-based application and to determine how such a system may impact their perceived wellbeing and ability to manage their COPD.</p>	<p>The development of the mHealth intervention involved a patient focus group and multidisciplinary team of researchers, engineers and clinicians. Individual data thresholds to set alerts were determined, and the relationship to exacerbations, defined by the initiation of stand-by medications, was measured. The sample comprised 18 patients (age range of 50–85 years) with varied levels of computer skills.</p>	<p>The findings of this cohort study confirm that daily use of the mHealth platform is feasible and acceptable to people with COPD for reporting daily symptoms and medicine use, and to measure physiological variables such as pulse rate and oxygen saturation. Features to support self-management such as video clips, self-management plans and respiratory nursing messaging were accessed by the majority of patients. The development of individualized alert thresholds has the potential to identify exacerbations early but requires further evaluation.</p>	<p>This seems brilliant! A mobile application where chronic pancreatitis patients could track their pain medications, pancreatic enzyme supplementations, diabetes, nutritional intake, weight, etc. as well as have access to video clips, pain management plans, and contact the nurse coordinator could be invaluable.</p>
<p>Level of Evidence: Level VI: Evidence from a single descriptive or qualitative study (L1bGuides, n.d.)</p>	<p>hospital admission records, respiratory out-patient clinics, pulmonary rehabilitation programs. Patients with COPD were also recruited through disease registers held by primary care based physicians (general practitioners) providing community based management.</p> <p>Inclusion criteria included aged over 40 years, a smoking pack year history of greater than 10 pack years, MRC dyspnea scale greater than or equal to 2, post bronchodilator forced expiratory volume in one second (FEV1) of less than 80 % and an FEV1/forced vital capacity ratio of less than 70 % (which were measured pre and post study by a trained respiratory re- search nurse), exacerbation of COPD requiring treatment or referred to pulmonary rehabilitation within last year, absence of other significant lung disease or heart failure, life expectancy of greater than three months and ability to understand written English.</p>		<p>The study was too small to draw firm conclusions about the association between alerts and events, which is likely to be complex and influenced by past patient experience and healthcare beliefs.</p>		
<p>Coulter, A. (2015). Personalized care planning for adults with chronic or long-term health conditions. <i>Cochrane Database Of Systematic Reviews</i>, (3), doi:10.1002/14651858.CD010523.pub2</p>	<p>Randomized controlled trials and cluster-randomized controlled trials only.</p> <p>Types of participants: adults (aged 18 or over) with any long-term physical, psychological,</p>	<p>To assess the effects of personalized care planning for adults with long-term conditions compared to usual care (i.e. forms of care in which active involvement of patients in treatment and management decisions is not explicitly attempted or</p>	<p>Systematic review of literature including randomized controlled trials and cluster-randomized trials using fixed-effect meta-analysis because of the small number of studies in each analysis. Three review authors independently screened citations for inclusion, extracted data, and assessed risk</p>	<p>Personalized care planning leads to improvements in certain indicators of physical and psychological health status and people's ability to self-manage their condition, when compared to usual care. The effects appear to be greater when the intervention is more comprehensive, intensive and well-integrated into routine care. Evidence on the relative cost effectiveness of this approach is limited and uncertain.</p> <p>Study selection – identification of relevant studies on a</p>	<p>This review is spot on and very applicable to my own Capstone project on chronic pancreatitis patients. The entire thought behind my capstone is to empower and engage patients in order to improve their own health outcome, their satisfaction, and manage their </p>

Level of evidence: Systematic review of randomized control trials and cluster-randomized trials, Level I. ([LibGuides, n.d.](#))

sensory, or cognitive condition or combination of conditions affecting their health, treated in any setting (primary care, secondary care, community or residential care).

Excluded: studies with simulated patients or patients requiring care for acute or self-limiting problems only

19 RCTs involving 10,865 participants found.

achieved).

of bias. A patient advisory group of people with experience of living with long-term conditions advised on various aspects of the review, including the protocol, selection of outcome measures and emerging findings.

Bias – 11 studies provided unclear or no information on bias issues.

Blinding of participants is nearly impossible

broad topic is challenging; possibility some relevant studies could have been discarded in the process; some cases had poorly described interventions, making judgment on whether or not personalized care planning had taken place difficult.

expectations.

Green, J. & Hibbard, J. (2012). Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes. *Journal of General Internal Medicine, 27*(5), 520-6.

Level of evidence: Level IV, case control study, observational [cross-sectional](#) study. ([LibGuides, n.d.](#))

A total of 25,047 adult patients were included in the analysis. They all had a primary care visit in the prior six months and completed the patient activation measure as part of an office visit.

18 years or older; had to have a PCP visit between July and December of 2010 and had to complete the PAM during an office visit.

To examine the degree to which patient activation is related to a broad range of patient health and utilization outcomes in a large, insured population.

Cross-sectional study of patients at Fair-view Health Services in Minnesota. Data on patient activation and patient outcomes were derived from the electronic health record, abstracted in December 2010. The key independent measure was the Patient Activation Measure. We examined 13 patient outcomes across four areas: prevention, unhealthy behaviors, clinical indicators, and costly utilization.

While this study broadens the empirical research on patient activation, the relationships observed in this cross-sectional study need to be examined longitudinally to better understand the time ordering of events. The present study is also limited by the fact that the study population is not representative of the larger population from which it was drawn, as it includes only patients who were seen in the clinics and who completed the PAM in the early months of the PAM collection roll-out. Also, we measured patient SES using a zip code level measure rather than

In multivariate models, patient activation was related to 12 of 13 patient outcomes in the expected direction. For every additional 10 points in patient activation, the predicted probability of having an ED visit, being obese, or smoking was one percentage point lower. The likelihood of having a breast cancer screen or clinical indicators in the normal range (A1c, HDL, and triglycerides) was one percentage point higher.

This [cross sectional](#) study finds that patient activation is strongly related to a broad range of health-related outcomes, which suggests improving activation has great potential. Future work should examine the effectiveness of interventions to support patient activation.

With the coming health care reforms, delivery systems and providers will need to be able to produce better outcomes with fewer resources. Patients represent a largely untapped resource that if tapped, may have payoffs that accrue not only to delivery systems, but to the patients themselves and more broadly to the nation.

This is what I have mentioned in some of my presentations so far. If the patient is activated, the tentacles of health care are extended so much further and outcomes are better.

a measure specific to patients' SES. Studies are needed that address the limitations of the current investigation and provide further insight into how best to support patients to be more effective participants in their care.

Hibbard, J. Greene, J. & Overton, V. (2013). Patients with lower activation associated with higher costs; delivery systems should know their patients' scores'. *Health Affairs, 32*(2), 216-222.

Level of evidence: Level IV, case control study, observational [cross-sectional](#) study. ([LibGuides, n.d.](#))

To be included in the analysis, a Fairview patient had to be at least eighteen years of age, have made a primary care visit in 2010, and have completed the Patient Activation Measure. Fairview began routine collection of activation scores in mid-2010, administering the assessment to patients when they came in for primary care visits. Because wide-spread collection of activation scores in all of the clinics took time, the 33,163 patients included in the study sample represented a relatively small proportion (18 percent) of the total number of adult patients seen at Fairview.

No studies to date have explicitly examined the association between patient activation levels and the health care costs of patients. The present analysis examines how patient activation scores routinely collected by a large health care delivery system in Minnesota relate to the costs of care. Our results indicate that more highly activated patients may indeed incur substantially lower costs than those who are less activated.

This study examined data from primary care patients enrolled with Fairview Health Services, a large not-for-profit health care system in Minnesota with forty-one primary care clinics, specialty care clinics, and hospitals. The data on patient activation and other characteristics of patients, including diagnoses of chronic illness, were derived from individual electronic health records. Cost data were derived from a Fairview administrative database.

Used cross-sectional analyses to assess the relationship between Patient Activation Measure scores, hereafter referred to as "activation scores," and concurrent cost of care in 2010. A longitudinal analysis examined whether scores obtained from the Patient Activation Measure in 2010 predicted the total cost of non-inpatient care during the first six months of 2011.

Limited by the fact that they used Fairview billed costs and not all costs. Were able to adjust for care outside of Fairview using data from one insurer.

The analysis was further limited by the fact that not all Fairview patients were included in the analysis. The study population consisted of just those Fairview patients with activation scores. The fact that the study population

The findings indicate that very low activation levels are significantly associated with higher health care costs and are predictive of higher future costs, when compared to higher activation levels. These findings were true for the full sample of patients and for patients with three out of four chronic conditions, even after we controlled for sociodemographic factors and the severity of health conditions. These empirical findings add to the growing body of literature suggesting that patients play an important role in determining their own health outcomes.

For the full sample, patients with the lowest level of activation in 2010 had predicted average costs that were 8 percent higher than those of patients with the highest level of activation. There was no significant difference between the predicted costs for patients with level 2, 3, or 4 activation scores.

In 2011, patients with the lowest level of activation had costs that were 21 percent higher than patients with the highest level of activation. Again, there was no significant difference between predicted costs for patients with level 2, 3, or 4 activation scores.

Wow! If this isn't an eye opener for health care organization in the current political and economic environment I'm not sure what is! A 21% higher cost of health care related to lower activation scores? This is extremely helpful in guiding me through my capstone project with CP patients.

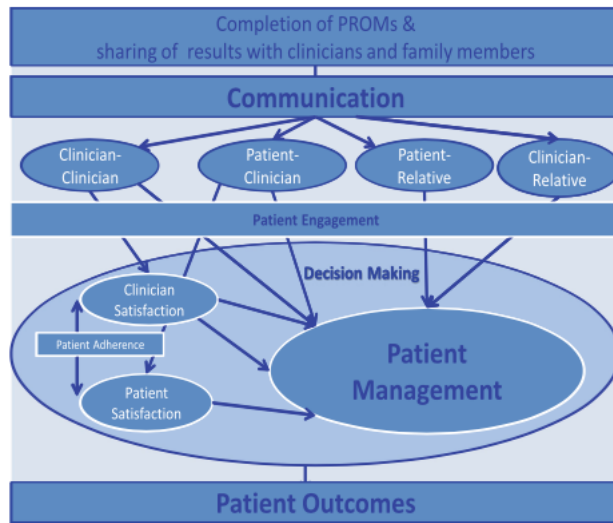
was older and included a larger share of women than the overall Fairview adult patient population may have affected the distribution of patient activation scores. The study population's age and sex characteristics were unlikely to have affected the relationship between activation scores and costs.

<p>Grottianna G. Baelelo S. Bonanomi A (2017) The role of Patient Health Engagement Model (PHE-model) in affecting patient activation and medication adherence: A structural equation model. <i>PLoS ONE</i> 12(6): e0179865. https://doi.org/10.1371/journal.pone.0179865</p> <p>Level of evidence: Level IV, case control study, observational cross-sectional study. (LibGuides, u.d.)</p>	<p>352 Italian-speaking chronic patients randomly selected from the Research Now Panel (covers a wide range of chronic diseases and comprises more than 6.5 million registered subjects worldwide). 352 patients (159 female) completed the survey, mean age 53.1 (±15.1), and years with mean disease duration of almost 12 years.</p>	<p>To test the hypothesized effect of patient activation on medication adherence; to test the hypothesized effects of positive emotions and of the quality of the patient/doctor relationship on patient activation; and to test the hypothesized mediating effect of Patient Health Engagement (PHE-model) in this pathway.</p>	<p>Cross sectional study. The survey included measures of i) patient activation (Patient Activation Measure 13 –short form); ii) Patient Health Engagement model (Patient Health Engagement Scale); iii) patient adherence (4 item-Morjinsky Medication Adherence Scale); iv) the quality of the patients' emotional feelings (Manikin Self Assessment Scale); v) the quality of the patient/doctor relationship (Health Care Climate Questionnaire). Structural equation modeling was used to test the hypotheses proposed.</p> <p>Sample is not a stratified and fully representative of the Italian chronic population but it was randomly selected in order to guarantee its probabilistic feature.</p> <p>The heterogeneity of the diseases suffered by the patients in our sample may be regarded as a weakness</p>	<p>Results confirmed that patients' activation significantly affects their reported medication adherence. Moreover, psychosocial factors, such as the patients' quality of the emotional feelings and the quality of the patient/doctor relationship were demonstrated to be factors affecting the level of patient activation. Finally, the mediation effect of the Patient Health Engagement model was confirmed by the analysis.</p> <p>Consistently with the results of previous studies, these findings demonstrate that the Patient Health Engagement Model is a critical factor in enhancing the quality of care. The Patient Health Engagement Model might act as a mechanism to increase patient activation and adherence.</p> <p>Explored formal mediation among the included variables. This is basically an observational study with no experimental manipulation of the independent variables involved in the conceptual model under investigation.</p>	<p>. I am quite interested in exploring the PHE-model further and potentially use the tool or make reference to it with my own capstone. Again, ultimately this suggests it could improve patient engagement and activation, which further improves outcomes.</p>
<p>Marshall, R., Beach, M., Saba, S., Mori, T., Lovelless, M., Hibbard, J. Cohn, J., Sharp, V., & Korthuis, T. (2013). Patient activation and improved outcomes in HIV-infected patients.</p> <p><i>Journal of General Internal Medicine</i>, 28(5), 668-74. Doi: 10.1007/s11606-012-2307-y</p> <p>Level of evidence: Level IV, case control study, observational cross-sectional survey. (LibGuides, u.d.)</p>	<p>433 patients receiving care in four HIV clinics; 45 providers. Patients were eligible for inclusion if they were HIV-infected, had seen the provider at least once, were over 18 years of age, and spoke English. Eligible providers were physicians, nurse practitioners, or physician assistants who provided primary care to HIV- infected patients. Of 55 eligible providers, 45 (81.8 %) agreed to participate.</p>	<p>To determine characteristics associated with patient activation and associations between patient activation and outcomes in HIV-infected patients.</p>	<p>An interviewer conducted face-to-face interviews with patients following their HIV clinic visit. Survey data were supplemented with medical record abstraction to obtain most recent CD4 counts, HIV viral load and antiretroviral medications.</p> <p>Patient activation was measured using the 13-item PAM (possible range 0–100). Out- comes included CD4 cell count>200 cells/mL³, HIV-1 RNA<400 copies/mL (viral suppression), and patient- reported adherence.</p> <p>The Enhancing Communication and HIV Outcomes (ECHO) study is a cross-sectional, observational study that assessed patient–provider communication and clinical out- comes at four ambulatory HIV clinics in Baltimore, MD, Detroit, MI, New York, NY, and Portland, OR that participate in the HIV Research Network.</p>	<p>Overall, patient activation was high (mean PAM=72.3 [SD 16.5, range 34.7–100]). Activation was lower among those without vs. with a high school degree (68.0 vs. 74.0, p<.001), and greater depression (77.6 lowest, 70.2 middle, 68.1 highest [t₍₁₁₆₎, p<.001]). There was no association between patient activation and age, race, gender, problematic alcohol use, illicit drug use, or social status. In multivariable models, every 5-point increase in PAM was associated with greater odds of CD4 count > 200 cells/mL³ (aOR 1.10 [95 % CI 1.01, 1.21]), adherence (aOR 1.18 [95 % CI 1.09, 1.29]) and viral suppression (aOR 1.08 [95 % CI 1.00, 1.17]). The association between PAM and viral suppression was mediated through adherence.</p> <p>Higher patient activation was associated with more favorable HIV outcomes. Interventions to improve patient activation should be developed and tested for their ability to improve HIV outcomes.</p>	<p>This, again, contributes to evidence that higher activated patients have better outcomes in terms of their chronic illness. HIV is relatable to chronic pancreatitis with its chronicity, complex medical and medication regimens.</p>
<p>Dennis, S., Harris, M., Lloyd, J., Powell-Davies, G., Faguy, N., & Ziegler, N. (2013). Do people with existing chronic conditions benefit from telephone coaching? A rapid review. <i>Australian Health Review</i>, 37, 381-388. Retrieved from http://dx.doi.org/10.1071/AH13005</p> <p>Level of evidence: Level I: systematic review of published peer-reviewed literature. (LibGuides, u.d.)</p>	<p>The searches identified 1756 papers, which reduced to 1026 after duplicates and papers not relevant to the research questions were removed. Included studies involving people aged 18 years or over and living in the community, with one or more of the following chronic conditions: type 2 diabetes mellitus (T2DM), congestive cardiac failure, coronary artery disease, chronic obstructive pulmonary disease (COPD) and hypertension. Patients were identified as having multi-morbidity if they had more than one index condition or one of these plus another chronic condition.</p>	<p>To examine the effectiveness of telephone-based coaching services for the management of patients with chronic diseases.</p>	<p>A rapid scoping review of the published peer reviewed literature, using Medline, Embase, CINAHL, PsychNet and Scopus. We included studies involving people aged 18 years or over with one or more of the following chronic conditions: type 2 diabetes, congestive cardiac failure, coronary artery disease, chronic obstructive pulmonary disease and hypertension. Patients were identified as having multi-morbidity if they had an index chronic condition plus one or more other chronic condition. To be included in this review, the telephone coaching had to involve two-way conversations by telephone or video phone between a patient and a provider. Behavior change, goal setting and empowerment are essential features of coaching.</p> <p>Search terms: related to telephone coaching and adapted terms for research design from previous systematic reviews.</p>	<p>The review found 1756 papers, which was reduced to 30 after screening and relevance checks. Most coaching services were planned, as opposed to reactive, and targeted patients with complex needs who had one or more chronic disease. Several studies reported improvements in health behavior, self-efficacy, health status and satisfaction with the service. More than one-third of the papers targeted vulnerable people and telephone coaching was found to be effective for these people.</p> <p>Telephone coaching for people with chronic conditions can improve health behavior, self-efficacy and health status. This is especially true for vulnerable populations who had difficulty accessing health services. There is less evidence for improvements in quality of life and patient satisfaction with the service. The evidence for improvements in health service use was limited. This rapid scoping review found that telephone-based coaching can enhance the management of chronic disease, especially for vulnerable groups. Further work is needed to identify what models of telephone coaching are most effective according to patients' level of risk and co-morbidity.</p>	<p>This systematic review can be applied to my research, because one of the huge barriers to health care we have seen is a lack of resources, even transportation to get to clinic appointments, within the CP population. This telephone coaching can reduce that barrier.</p>

			<p>The reference lists of the included studies were not searched to identify further studies, which means that some papers inevitably will have been missed.</p> <p>The experimental literature contained few details of barriers and facilitators to effective telephone coaching or detailed information about implementation and reach.</p>		
<p>Than Win, K., <u>Mohd Hassan, N.</u>, Bonney, A., & Iverson, D. (2015). Benefits of online health education: perception from consumers and health professionals. <i>Journal of Medical Systems</i>, 39, 1-8.</p> <p>Level of evidence: Level I: systematic review of published peer-reviewed literature. (<u>LibGuides, n.d.</u>)</p>	<p>The initial results comprised 1021 titles on health education. Re-examination and cross checking of the bibliographies of the articles were also performed. Benefits of OHE were identified from thorough literature review. Afterwards, pilot study with 20 participants was conducted. To ensure that the responses are reliable and valid for the study quantitative data analysis was performed through involving more participants. A list of chronic disease websites in Australia were gathered through observation and a formal email were sent to seek information about the sites membership which comprise of health professional and patient/carer of chronic disease. A list of 27 chronic disease websites were identified and</p>	<p>The aim of this study is to explore consumers and health professionals opinion on online health education.</p>	<p>A literature review was conducted by accessing relevant data-bases such as Medline, PubMed, IEEE Explore, Scopus, to obtain articles published from 1995 to 2013. Eligibility criteria for papers to be included in the study were: publication in English; cited, scholarly, peer-reviewed, article from an academic journal; and discuss the benefits of OHE.</p> <p>Search Terms: online, web, websites, internet, patient education, health education, benefit, advantages, features.</p> <p>One limitation of this study is perceived benefits of OHE were identified through survey from health consumers and health professional.</p>	<p>The analysis of the literature has identified a set of 12 potential benefits of OHE which had been used to understand the perceptions of the effectiveness of OPE sites. These 12 potential benefits have been validated with health practitioners, patients with chronic disease and care providers.</p> <p>OHE has been shown [26] to be more cost effective as it reduces patients' expenses to travel to the hospital or medical center. It also saves patients' time by reducing travel time, especially during peak time</p> <p>Researchers in the study observed that, unlike traditional patient handouts, the Web offers patients interactivity and engagement, which should enhance their learning and understanding.</p> <p>Barriers to using OHE will need to consider in creating OHE such as, low patient computer skills, unwillingness to use the technology, poor architectural and technical designs. Without appropriate information technology skills, patients cannot connect to the Internet let alone access education materials from the Web.</p>	<p>This review made me think a bit. Conventional health education to patients is provided by healthcare practitioners, but this takes time and may not be convenient for the patient. Since the patient may be adjusting to the new disease, not all of the information provided at the time will necessarily be absorbed by the patient at that time it is given. Online health education provides the patient to receive the information at his/her own pace, read, re-read, review, share, etc.</p> <p>With my Capstone, perhaps it might be beneficial to spend the time educating patients conventionally, but also provide them with online access to materials.</p>
	<p>contacted to get permission. 7 websites gave positive feedback to provide help in gathering data. Descriptive analyses were performed using SPSS Version 19.0. Respondents for survey included health professionals and healthcare consumers. A total of 215 respondents took part in the survey, which include 141 patient/carer and 74 health professionals of which 41.8 % is 55 years or above.</p>				
<p>Williams, V., Price, J., <u>Hardings, M.</u>, <u>Tzassanosko, L.</u>, & Farmer, A. (2014). Using a mobile health application to support self-management in COPD: a qualitative study. <i>The British Journal of General Practice</i>, 64(624), e392-e400. http://doi.org/10.3399/bjgp14X680473</p> <p>Level of Evidence: Level VI: Evidence from a single descriptive or qualitative study (<u>LibGuides, n.d.</u>)</p>	<p>Twenty-three patients were given the mHealth system to use for a 6-month period, with 18 of these completing the full six-month study.</p> <p>For the six-month cohort study, patients meeting the inclusion criteria were identified and recruited from a variety of healthcare settings: hospital admission records, respiratory out-patient clinics, pulmonary rehabilitation programs. Patients with COPD were also recruited through disease registers held by primary care based physicians (general practitioners) providing community based management. Inclusion criteria included aged over 40 years, a smoking pack</p>	<p>The aim of this study is to explore the expectations and experiences of patients who use a mobile telehealth-based application and to determine how such a system may impact their perceived wellbeing and ability to manage their COPD.</p>	<p>The development of the mHealth intervention involved a patient focus group and multidisciplinary team of researchers, engineers and clinicians. Individual data thresholds to set alerts were determined, and the relationship to exacerbations, defined by the initiation of stand-by medications, was measured. The sample comprised 18 patients (age range of 50-85 years) with varied levels of computer skills.</p> <p>The study was too small to draw firm conclusions about the association between alerts and events, which is likely to be complex and influenced by past patient experience and healthcare beliefs.</p>	<p>The findings of this cohort study confirm that daily use of the mHealth platform is feasible and acceptable to people with COPD for reporting daily symptoms and medicine use, and to measure physiological variables such as pulse rate and oxygen saturation. Features to support self-management such as video clips, self-management plans and respiratory nursing messaging were accessed by the majority of patients. The development of individualized alert thresholds has the potential to identify exacerbations early but requires further evaluation.</p>	<p>This seems brilliant? A mobile application where chronic pancreatitis patients could track their pain medications, pancreatic enzyme supplementations, diabetes, nutritional intake, weight, etc. as well as have access to video clips, pain management plans, and contact the nurse coordinator could be invaluable.</p>

year history of greater than 10 pack years, MRC dyspnea scale greater than or equal to 2, post bronchodilator forced expiratory volume in one second (FEV1) of less than 80 % and an FEV1/forced vital capacity ratio of less than 70 % (which were measured pre and post study by a trained respiratory re- search nurse), exacerbation of COPD requiring treatment or referred to pulmonary rehabilitation within last year, absence of other significant lung disease or heart failure, life expectancy of greater than three months and ability to understand written English.

Appendix C



(Santana & Feenev. 2014)

Appendix D

Timeline for Capstone Project Actualization

	Submission of Proposal to IRB	IRB Approval	Identification/ Recruitment of Eligible Participants	Informed Consent, Pre-Intervention Survey, Intervention, Post-Intervention Survey	Data Analysis	Final Report & Dissemination
November 2017	X	X				
December 2017		X				
January 2018			X	X		
February 2018			X	X		
March 2018			X	X		
April 2018			X	X	X	
May 2018					X	
June 2018						X
July 2018						X

Appendix E

Chronic Pancreatitis: Patient and Care Partner PRE Survey

ID# _____ Date _____

Please respond appropriately to the following regarding your current knowledge level for each topic.

- **Normal pancreatic anatomy and function:**
 1. I know the topic quite well.
 2. I know of the topic partially, and I know where I can find more information about it.
 3. I am not confident in my knowledge level of the topic.
- **Anatomy and function of pancreas with chronic pancreatitis:**
 1. I know the topic quite well.
 2. I know of the topic partially, and I know where I can find more information about it.
 3. I am not confident in my knowledge level of the topic.
- **Natural disease progression in chronic pancreatitis:**
 1. I know the topic quite well.
 2. I know of the topic partially, and I know where I can find more information about it.
 3. I am not confident in my knowledge level of the topic.
- **Symptoms in chronic pancreatitis and why they occur:**
 1. I know the topic quite well.
 2. I know of the topic partially, and I know where I can find more information about it.
 3. I am not confident in my knowledge level of the topic.
- **Source of pain in chronic pancreatitis:**
 1. I know the topic quite well.
 2. I know of the topic partially, and I know where I can find more information about it.
 3. I am not confident in my knowledge level of the topic.
- **Current pain management recommendations for chronic pancreatitis:**
 1. I know the topic quite well.
 2. I know of the topic partially, and I know where I can find more information about it.
 3. I am not confident in my knowledge level of the topic.
- **Care management options for chronic pancreatitis:**
 1. I know the topic quite well.
 2. I know of the topic partially, and I know where I can find more information about it.
 3. I am not confident in my knowledge level of the topic.
- **Strategies for disease management at home:**
 1. I know the topic quite well.
 2. I know of the topic partially, and I know where I can find more information about it.
 3. I am not confident in my knowledge level of the topic.
- **Strategies to actively participate and become engaged in the management of chronic pancreatitis:**
 1. I know the topic quite well.
 2. I know of the topic partially, and I know where I can find more information about it.
 3. I am not confident in my knowledge level of the topic.
- **Strategies to improve quality of life as it relates to chronic pancreatitis:**
 1. I know the topic quite well.
 2. I know of the topic partially, and I know where I can find more information about it.
 3. I am not confident in my knowledge level of the topic.

Appendix F

Chronic Pancreatitis: Patient and Care Partner POST Survey

ID# _____ Date _____

Please respond appropriately to the following regarding your current knowledge level for each topic.

- **Normal pancreatic anatomy and function:**
 - 4. I know the topic quite well.
 - 5. I know of the topic partially, and I know where I can find more information about it.
 - 6. I am not confident in my knowledge level of the topic.
- **Anatomy and function of pancreas with chronic pancreatitis:**
 - 4. I know the topic quite well.
 - 5. I know of the topic partially, and I know where I can find more information about it.
 - 6. I am not confident in my knowledge level of the topic.
- **Natural disease progression in chronic pancreatitis:**
 - 4. I know the topic quite well.
 - 5. I know of the topic partially, and I know where I can find more information about it.
 - 6. I am not confident in my knowledge level of the topic.
- **Symptoms in chronic pancreatitis and why they occur:**
 - 4. I know the topic quite well.
 - 5. I know of the topic partially, and I know where I can find more information about it.
 - 6. I am not confident in my knowledge level of the topic.
- **Source of pain in chronic pancreatitis:**
 - 4. I know the topic quite well.
 - 5. I know of the topic partially, and I know where I can find more information about it.
 - 6. I am not confident in my knowledge level of the topic.
- **Current pain management recommendations for chronic pancreatitis:**
 - 1. I know the topic quite well.
 - 2. I know of the topic partially, and I know where I can find more information about it.
 - 3. I am not confident in my knowledge level of the topic.
- **Care management options for chronic pancreatitis:**
 - 4. I know the topic quite well.
 - 5. I know of the topic partially, and I know where I can find more information about it.
 - 6. I am not confident in my knowledge level of the topic.
- **Strategies for disease management at home:**
 - 4. I know the topic quite well.
 - 5. I know of the topic partially, and I know where I can find more information about it.
 - 6. I am not confident in my knowledge level of the topic.
- **Strategies to actively participate and become engaged in the management of chronic pancreatitis:**
 - 4. I know the topic quite well.
 - 5. I know of the topic partially, and I know where I can find more information about it.
 - 6. I am not confident in my knowledge level of the topic.
- **Strategies to improve quality of life as it relates to chronic pancreatitis:**
 - 4. I know the topic quite well.
 - 5. I know of the topic partially, and I know where I can find more information about it.
 - 6. I am not confident in my knowledge level of the topic.