Determinants of Patient Activation in Hospitalized Multimorbid Patients

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DETERMINANTS OF PATIENT ACTIVATION IN HOSPITALIZED MULTIMORBID PATIENTS

By

Myra S. Schmaderer

A DISSERTATION

Presented to the Faculty of the Graduate College in the University of Nebraska Medical Center in Partial Fulfillment of the Requirements for the Degree of Doctor of Philosophy

Nursing Graduate Program

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Post-hospitalization care transition is a vulnerable time for multimorbid patients. Self-management challenges happen due to acute symptoms and complex new treatment plans. Literature suggests higher activated patients have better outcomes; however, there is little research that identifies determinants that predict patient activation in the multimorbid hospitalized patient. Understanding predictive factors will facilitate planning interventions that promote self-management of multimorbid conditions. The purpose of this dissertation was to identify determinants that predict patient activation in patients with multimorbidity at discharge from the hospital.

A descriptive, predictive research study was conducted with 200 hospitalized multimorbid patients discharged to home. Their mean age was 63.7 (SD = 14.2); they were primarily Caucasian (n = 188, 94%); and female (n = 117, 58.5%). The mean Patient Activation Measure (PAM) score was 60.3 (SD = 14.6); 40 were level 1 (20%); 39 were level 2 (19.5%); 52 were level 3 (26%); and 69 were level 4 (34.5%).

There were significant relationships between PAM levels and several determinants. Patients in lower PAM levels needed more assistance understanding health care materials; were more depressed; more fatigued; less satisfied with their social role;
and less satisfied with their chronic illness care. Patients in lower PAM levels were rehospitalized and visited the emergency department within 30-days post-discharge more frequently than level 4 activation patients. Multinomial logistical regression indicated that the predictors as a set distinguished between levels of patient activation ($\chi^2 = 73.34$ (3), $p = .001$). Patients in level 1 were more likely to need assistance reading health care material compared to level 4 patients. Level 2 and 3 patients were less likely to be satisfied with their chronic illness care than level 4 patients.

This study demonstrates that lower patient activation level patients have lower literacy levels, are less satisfied with their chronic illness care, and have more health care utilization 30-days post-discharge. Focusing on literacy and satisfaction with chronic illness care may improve patient outcomes.
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<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>ANOVA</td>
<td>Analysis of Variance</td>
</tr>
<tr>
<td>CCI</td>
<td>Charlson Comorbidity Index</td>
</tr>
<tr>
<td>CCM</td>
<td>Chronic Care Model</td>
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<tr>
<td>CDC</td>
<td>Centers for Disease Control and Prevention</td>
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<tr>
<td>CFA</td>
<td>Confirmatory Factor Analysis</td>
</tr>
<tr>
<td>CFI</td>
<td>Comparative Fit Index</td>
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<tr>
<td>CVI</td>
<td>Content Validity Index</td>
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<tr>
<td>CVR</td>
<td>Content Validity Ratio</td>
</tr>
<tr>
<td>EQ-5D</td>
<td>EuroQOL quality of life</td>
</tr>
<tr>
<td>HBCTI</td>
<td>Home Based Care Transition Intervention</td>
</tr>
<tr>
<td>MoCA</td>
<td>Montreal Cognitive Assessment</td>
</tr>
<tr>
<td>PACIC</td>
<td>Patient Assessment of Chronic Illness Care</td>
</tr>
<tr>
<td>PAM</td>
<td>Patient Activation Measure</td>
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<tr>
<td>PAS</td>
<td>Patient Activation Scale</td>
</tr>
<tr>
<td>PHQ</td>
<td>Patient Health Questionnaire</td>
</tr>
<tr>
<td>PROMIS</td>
<td>Patient Reported Outcomes Measurement Information System</td>
</tr>
<tr>
<td>REALM</td>
<td>Rapid Estimate of Adult Literacy in Medicine</td>
</tr>
<tr>
<td>Acronym</td>
<td>Description</td>
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<tr>
<td>RCT</td>
<td>Randomized Controlled Trial</td>
</tr>
<tr>
<td>RMSEA</td>
<td>Root Mean Square Error of Approximation</td>
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<tr>
<td>SILS</td>
<td>Single Item Literacy Screener</td>
</tr>
<tr>
<td>SRMR</td>
<td>Standardized Root Mean Square Residual</td>
</tr>
<tr>
<td>S-TOFHLA</td>
<td>Shortened Test of Functional Health Literacy in Adults</td>
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<td>TOFHLA</td>
<td>Test of Functional Health Literacy in Adults</td>
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Determinants of Patient Activation in Hospitalized Multimorbid Patients

Chapter 1: Introduction

The first few weeks following hospitalization are a challenging time for patients with chronic disease and particularly those with multimorbidity. Approximately one in four Americans has multiple chronic conditions (Anderson, 2010). Acute hospitalization in this population is common due to exacerbations of these multiple chronic conditions. Negative outcomes such as adverse drug events and other hospital-related complications occur in nearly 20% of patients during the hospital-to-home transition (Forster, Murff, Peterson, Gandhi, & Bates, 2003). It has been estimated that 1 of 5 hospitalized Medicare fee-for-service beneficiaries are readmitted within 30 days of discharge (Jencks, Williams, & Coleman, 2009). Many rehospitalizations are unplanned and may be avoidable with properly planned and implemented care transition programs that improve quality outcomes and realize cost savings (Naylor, Aiken, Kurtzman, Olds, & Hirschman, 2011a; Naylor & Sochalski, 2010; Hansen et al., 2013). Hospitals have attempted to reduce high rates of readmission by developing and implementing care transitions programs (Naylor, Aiken, Kurtzman, Olds, & Hirschman, 2011b; Parrish, O'Malley, Adams, Adams, & Coleman, 2009; Enderlin et al., 2013). One of the underlying concepts of a successful care transition is self-management. However, it is known that not all patients integrate self-management of health issues into their daily lives in the same way. Due to the complexity of care for multimorbid patients, oftentimes self-management at home is challenging. Self-management requires a patient engaged or activated in their own care. Patient activation, an individual's knowledge, skill and confidence to adopt positive health behaviors (Hibbard, Stockard, Mahoney, & Tusler, 2004; Hibbard et al., 2005; Hibbard, Mahoney, Stockard, & Tusler, 2005), has been evaluated as an important factor contributing to self-management that leads to positive health outcomes and treatment compliance (Alegria et al., 2008; Cunningham, Hibbard, & Gibbons, 2011; Mitchell et al., 2013). However little is known about determinants
that predict patient activation in the hospitalized multimorbid patient. Predicting determinants of patient activation will help identify types of patients that may benefit from strategies to improve self-management as well as identify the type of educational support and mentoring that is needed during hospitalization and post-hospital transition time to improve patient outcomes such as rehospitalization and emergency department (ED) visits.

Therefore, the purpose of this dissertation was to identify determinants that predict patient activation among patients with multimorbidity at discharge from the hospital. Specific aims in the multimorbid hospitalized patient were:

1. To examine the relationship between demographic (age, gender, educational level, race, and income), clinical (cognition, physical functioning, sleep disturbance, severity of illness, number of comorbidities, and pain), and psychosocial (health literacy, presence of a caregiver, depression, anxiety, fatigue, sleep disturbance, satisfaction with the social role, perception of health status, quality of life and assessment of chronic illness care) determinants and patient activation;

2. To describe the unique contributions of selected demographic (age, gender, educational level, race, and income), clinical (cognition, physical functioning, sleep disturbance, severity of illness, number of comorbidities, and pain), and psychosocial (health literacy, presence of a caregiver, depression, anxiety, fatigue, sleep disturbance, satisfaction with the social role, perception of health status, quality of life and assessment of chronic illness care) determinants considered in combination that predict patient activation;

3. To examine the relationship between patient activation and health care utilization (30-day rehospitalization and ED visits) in multimorbid patients discharged from the hospital and;

4. To investigate the psychometric properties of the patient activation measure in patients with multimorbidity in the hospital setting. Specific aims were to a) estimate reliability;
b) evaluate the content validity; and c) evaluate the construct validity (convergent and divergent indices, and confirmatory factor analysis).

**Significance of the study**

**Self-management and Patient Activation**

Patient activation is an integral part of self-management. Hibbard et al. (2004) describe the activated patient as one who manages his condition and has the skill to collaborate with health care providers, maintain health function and get access to appropriate quality care. Patient activation is a precursor to self-management. Patient activation has been studied in a variety of settings (e.g. community, worksite, clinics) (Deen, Lu, Rothstein, Santana, & Gold, 2011; Donald et al., 2011; Fowles et al., 2009), patient populations (e.g., mental health, chronically ill), (Alexander, Hearld, Mittler, & Harvey, 2012; Chubak et al., 2012; Dixon, Hibbard, & Tusler, 2009; Pennarola et al., 2012), cultural backgrounds (e.g., Hispanics), (Cunningham et al., 2011; Hibbard et al., 2008) and countries (Begum, Donald, Ozolins, & Dower, 2011; Donald et al., 2011). Evidence continues to build supporting the importance of patient activation and self-management to improve health outcomes in management of chronic disease (Hibbard & Greene, 2013; Fowles et al., 2009; Greene & Hibbard, 2012; Begum et al., 2011).

In the chronically ill population, activated patients have been reported to have higher patient satisfaction scores as well as higher quality of life scores than those less activated (Mosen et al., 2007). Research consistently shows that patients with higher activation scores are more engaged in behaviors that are preventive, healthy, and information seeking (Hibbard, Mahoney, Stock, & Tusler, 2007; Kirby, Dennis, Bazeley, & Harris, 2012; Mosen et al., 2007; Remmers et al., 2009). Several researchers have reported more activated patients experience better health outcomes and experiences (Fowles et al., 2009; Harvey, Fowles, Xi, & Terry, 2012; Remmers et al., 2009; Skolasky, Mackenzie, Wegener, & Riley, 2011). Also, less activated patients are three
times more likely to have unmet healthcare needs than higher activated patients (Hibbard & Tusler, 2007; Hibbard & Cunningham, 2008). This evidence would suggest that promoting self-management by improving patient activation is a strategy that could prevent acute exacerbations of chronic illnesses to decrease hospitalizations and rehospitalizations. However, we need more evidence to understand these relationships.

**Multimorbidity**

Seventy percent of adult Americans have at least one chronic disease (Centers for Disease Control and Prevention, 2013) and nearly one in four have multimorbidity (Anderson, 2010). Chronic diseases consume 75% of the total cost of health care dollars (Centers for Medicare and Medicaid Services, 2015; Bodenheimer, Chen, & Bennett, 2009). One of the greatest health care challenges is multimorbidity. As people age, multiple chronic illnesses increase and disease burden increases; in addition, there are psychosocial barriers to self-management (Bayliss, Ellis, & Steiner, 2007; Boyd et al., 2014). Multiple chronic illnesses increase the risk of poor outcomes such as mortality and decreased physical functioning, in addition to increased hospitalization and emergency department (ED) visits (Centers for Medicare and Medicaid Services, 2015).

A promising strategy to decrease the burden of multimorbidity is self-management. However, self-managing more than one chronic condition becomes complex. Areas of confusion include getting health care guidance from a several different specialty health care providers, the potential interactions between pathologies, poly-pharmacy, as well as adhering to best practice guidelines for each disease process. Despite the increase in multimorbidity, chronic care is still usually focused on only a specific disease (Fortin, Bravo, Hudon, Vanasse, & Lapointe, 2005). A recent systematic review concluded there was limited evidence on the effectiveness of self-management interventions in the multimorbid population (Smith, Soubhi, Fortin, Hudon, &
O’Dowd, 2012). However, self-management of multimorbidity requires a patient engaged or activated in their own care. There is a gap in the literature related to multimorbidity, self-management and patient activation. This study will provide insights into patient activation for self-management in this multimorbid population.

**Readmissions**

Hospitalization and early post discharge are extremely vulnerable times for patients, especially those with multimorbidity. Readmission to the hospital is very common in this patient population. There is an association between self-care management, confidence and readmissions (Sahebi, A., Mohammad-Aliha, J., Ansari-Ramandi, M., & Naderi, N., 2015). Researchers have documented that patients with lower activation scores are at greater risk for hospital admission or readmission compared to those with higher activation scores (Begum et al., 2011; Kinney, Lemon, Person, Pagoto, & Saczynski, 2015; Mitchell et al., 2013). A recent systematic review of 10 publications (Kinney et al., 2015) reported that patients with chronic illnesses in lower stages of patient activation are at increased risk for readmission. Mitchell et al. (2013) in a large secondary analysis found that those with the lowest level of activation had nearly twice the risk of 30-day readmissions than the highest activated patients. In addition, data analyzed from an annual survey of the diabetic population suggests that the lowest level activation patients have more hospitalizations and emergency department visits over a 12-month period (Begum et al., 2011). A sample of over 25,000 patients from a large health care system including 35 clinics showed higher activated patients were less likely to use the ED or be hospitalized (Greene & Hibbard, 2012).

Reimbursement changes stimulated by the Patient Protection and Affordable Care Act (2010) have encouraged hospitals to improve discharge plans in an attempt to decrease readmissions and control cost. In a study of 33,000 people, those participants who had lower
activation scores had higher cost of health care. In fact, in this large 2011 study, patients with lowest activation had 21% higher costs than patients with the highest activation (Hibbard, Greene, & Overton, 2013). Promoting self-management is a strategy used to prevent acute exacerbations of chronic illnesses to decrease hospitalizations and rehospitalizations. Knowing individual patient activation scores and the predictors of patient activation will assist hospitals in determining what type of patient may benefit from strategies to improve self-management. In addition, it will help to identify what type of educational support and mentoring is needed during hospitalization and post-hospital transition time to improve patient outcomes such as rehospitalization and ED visits.

Summary

In summary, the purpose of this dissertation was to identify determinants that predict patient activation among patients with multimorbidity at discharge from the hospital. This dissertation was prepared using the manuscript option as supported by the Supervisory Committee. Manuscript 1 was a pilot study conducted to test the psychometric properties of the PAM in hospitalized patients with multimorbidity. Manuscript 2 was an account of the results of the study including methods, results, discussion and implications. Manuscript 3 was a synthesis of literature regarding interventions to increase patient activation and to identify specific components of interventions that had an impact on patient activation and additional health outcomes.
Chapter 2: Conceptual Framework

Conceptual basis for the study was guided by and adapted from the Chronic Care Model (Figure 1) and Patient Activation. First proposed by Wagner and colleagues in 1996, the Chronic Care Model (CCM) is a widely used model in the care of the chronically ill patient (Wagner et al., 2005). The main aim of the CCM is to change the focus of care for the chronically ill from the acute and reactive mindset to one of a planned and proactive model for chronic disease management.

The CCM identifies six essential elements for providing high quality successful chronic disease care. These essentials are 1) community resources and policies, 2) organization of health care, 3) self-management support, 4) delivery system design, 5) decision support, and 6) clinical information systems (Wagner et al., 2001; Wagner et al., 2005). These essentials along with the informed activated patient having productive interactions with a prepared proactive practice team lead to improved outcomes. The CCM is a broad community focused model; however, since the purpose of this study was to identify factors with relationship to and prediction of patient activation, only the informed activated patient portion of the CCM model was the focus for this study.

Knowledge about the informed activated patient is paramount for self-management in the chronic disease population to occur. The CCM has been used with success in a variety of settings and populations and with different providers (Suter et al., 2008; Duangbubpha, Hanucharurnkul, Pookboonmee, Orathai, & Kiatboonsri, 2013; Martinez-Donate et al., 2013).

Patient activation is defined as the knowledge, skill, and confidence people need to manage their health and health care (Hibbard et al., 2004). The Patient Activation Measure (PAM) is a psychometrically sound developmental instrument that evaluates patient beliefs about
his role as a patient, and his knowledge, skill and confidence to take action regarding his health care (Hibbard et al., 2004). The precursor for the development for the Patient Activation Measure was the CCM. The PAM can be reported as a score and can be delineated into four levels of activation depending on this score (Figure 2).

![Figure 2. The Patient Activation Measure](image)

A level 1 patient is starting to take a role but is disengaged and overwhelmed. The level 2 activated patient is building knowledge and confidence but is still struggling, the level 3 activated patient is one who is taking action, and the level 4 patient is maintaining behaviors and pushing further (Hibbard et al., 2004).

The major concepts adapted from the CCM are the informed activated patient and chronic disease. The informed activated patient was measured by the PAM. It is hypothesized that the more informed and activated the patients are, the more likely the patient will be to self-manage his chronic care. Both of these frameworks fit with the hospitalized patient with multimorbidity. Patient activation concepts measured by the PAM are knowledge, skill and confidence to self-manage. Chronic diseases are diseases of long duration and are generally of slow progression (World Health Organization, 2015) and require self-management.
Multimorbidity is defined as the coexistence of multiple chronic diseases and medical conditions (usually 2 or more chronic conditions) (Fortin, Soubhi, Hudon, Bayliss, & van den Akker, 2007). Together these two models fit together for this population and guide this study.

Determinants used for the study are categorized into demographic, clinical, and psychosocial variables. Demographic determinants include age, gender, educational level, race, and income. Clinical determinants include cognition, physical functioning, sleep disturbance, severity of illness, number of comorbidities, and pain. Psychosocial determinants include health literacy, presence of a caregiver, depression, anxiety, fatigue, satisfaction with social role, perception of health status, quality of life, and perception of care.

**Literature Review**

**Multimorbidity**

Chronic disease affects 70% of adult Americans and nearly half of those have multiple conditions (CDC, 2015). Caring for patients with multiple chronic diseases has created a huge economic and psychosocial burden on the health care systems in the United States. Chronic diseases are the leading cause of death and disability in the United States (Kung, Hoyert, Xu, & Murphy, 2008). Chronic diseases consume nearly 75% of the total cost of health care dollars (Bodenheimer et al., 2009, CDC, 2015).

Multimorbidity is defined as the coexistence of multiple chronic diseases and medical conditions (usually 2 or more chronic conditions) (Fortin et al., 2007). A recent systematic review identified that more than half of the elderly have multimorbidity and it is more prevalent in the very old, women, and lower social class individuals (Marengoni et al., 2011). As people age, multimorbidity increases and disease burden increases; in addition, there are psychosocial barriers to self-management (Bayliss et al., 2007). Multimorbidity increases the risk of poor outcomes such as mortality and decreased physical functioning, in addition to increased hospitalization and
ED visits (Centers for Medicare and Medicaid Services, 2015). Due to barriers to self-management such as lower levels of physical functioning, greater financial constraints and depressive symptoms in this population (Bayliss et al., 2007), post hospital care transition can be a very challenging time for these patients. There is a paucity of literature in the multimorbid patient in relation to patient activation; therefore, this patient population was chosen.

**Patient activation**

Patient activation refers to a person’s ability to manage his own health care. It involves patient engagement and consists of knowledge, skill and confidence to manage his chronic disease (Hibbard et al., 2004). Patient activation is a precursor to self-management. Research addressing patient activation is becoming more prevalent in the literature. Patient activation has been studied in a variety of settings (e.g. community, worksite, clinics) (Deen et al., 2011; Donald et al., 2011; Fowles et al., 2009), patient populations (e.g. mental health, chronically ill), (Alexander et al., 2012; Chubak et al., 2012; Dixon et al., 2009; Pennarola et al., 2012), cultural backgrounds (e.g., Hispanics), (Cunningham et al., 2011; Hibbard et al., 2008) and countries (Begum et al., 2011; Donald et al., 2011). Evidence continues to build supporting the importance of patient activation and self-management to improve health outcomes (Hibbard & Greene, 2013; Mitchell et al., 2013; Mosen et al., 2007). Patient activation has been reported to significantly improve health outcomes in chronic disease management (Begum et al., 2011; Fowles et al., 2009; Greene & Hibbard, 2012). No studies were found that examined patient activation in the hospitalized multimorbid population.

**Determinants predicting patient activation**

There is a growing body of literature that suggests that patients who are activated have better outcomes; however, there is paucity of literature that identifies determinants of the activated patient. One large cross-sectional survey (Bos-Touwen et al., 2015) identified 9
determinants that predict activation for self-management in chronic disease populations: age, body mass index, educational level, financial distress, physical health status, depression, illness perception, social support and underlying disease. The patient population in the Bos-Touwen et al. (2015) study included individuals with type-2 diabetes mellitus, chronic obstructive pulmonary disease, chronic heart failure or chronic renal failure from a primary care or secondary care setting. Another study evaluating individuals with multiple sclerosis in a non-acute setting (Goodworth et al., 2014) found educational attainment, depression and self-efficacy significantly predicted patient activation using hierarchical regression.

**Patient activation and demographic, clinical and psychosocial determinants**

Demographic characteristics of patients with varying levels of patient activation have been reported. In a large population survey, Hibbard and Cunningham (2008) report great variation in patient activation levels. Lower activation levels were associated with older people, lower income, less education, enrollment in Medicaid, and poor self-reported health. In this same large population study, Hispanics had lower activation level compared to other racial and ethnic groups (Hibbard & Cunningham, 2008). In a working population, higher patient activation was associated with higher education, higher income, female gender and marital status (Fowles et al., 2009).

A variety of clinical determinants of patient activation was found in the literature. Several researchers have reported patient activation levels having great influence on health behavior outcomes such as adult health screenings, eating healthily and exercising regularly (Fowles et al., 2009; Greene & Hibbard, 2012; Hibbard et al., 2004; Hibbard et al., 2005). In the diabetic population, people with higher activation were more likely to perform diabetes preventative care than less activated people (Rask et al., 2009) and had better rates of testing hemoglobin A1-C, hemoglobin A1-C control and all cause discharges (Remmers et al., 2009).
A large population survey reported people living with chronic conditions had lower activation scores than those without chronic disease (Hibbard & Cunningham, 2008). Interestingly, people with multiple conditions had higher patient activation than did those with one single chronic disease. However, people with multiple chronic conditions who reported their health as fair or poor were less activated than those with one single chronic illness. Thus perception of health is important in relationship to patient activation. Similarly, in the long term care patient population with chronic complex needs, higher patient activation levels were associated with higher self-rating of health (Gerber et al., 2011).

In the working population, employees with higher PAM scores had lower body mass index, lower composite health risk score, and reported better physical health (Fowles et al., 2009). Functional status also has been associated with patient activation. In a chronic disease population, the patients with higher activation scores reported having better physical functioning (Mosen et al., 2007). In addition, higher activated patients had more participation and engagement in physical therapy sessions after surgery in the spine surgery population (Skolasky, Mackenzie et al., 2011).

Several psychosocial determinants were identified from the literature. Health literacy has been linked to patient activation, with lower activated individuals tending to have lower health literacy (Gerber et al., 2011; Martin et al., 2011; Nijman, Hendriks, Brabers, de Jong, & Rademakers, 2014; Rademakers, Nijman, Brabers, de Jong, & Hendriks, 2014). In a study evaluating glycemic control in diabetics, Woodard, Landrum, Amspoker, Ramsey, and Naik (2014) found patient activation and health literacy were important together to improve glycemic control. In the chronically ill population, activated patients have been reported to have higher patient satisfaction scores as well as higher quality of life scores than those less activated (Mosen et al., 2007). Other researchers have also identified lower quality of life being associated with lower patient activation (Magnezi et al., 2014).
Depression and patient activation have a relationship. People who have depression tend to have lower activation scores (Hibbard & Cunningham, 2008; Chen, Mortensen, & Bloodworth, 2014). Depression has been evaluated in a variety of populations: primary care settings (Magnezi, Glasser, Shalev, Sheiber, & Reuveni, 2014), the multiple sclerosis population (Stepleman et al., 2010) and in the HIV population (Marshall et al., 2013) with consistent findings, that depression is more prevalent in lower activated patients.

**Patient activation and patient experience**

There has been an association between patient experience and patient activation. Lower activated patients are less likely to know clinical guidelines for their disease, to be prepared with questions with physician, and to seek understanding about their disease (Fowles et al., 2009). It has been found that lower activated people are more likely to have unmet health needs (Hibbard & Cunningham, 2008) and higher activated people report more positive experiences of care (Alexander et al., 2012; Greene, Hibbard, Sacks, & Overton, 2013; Mosen et al., 2007). In addition, it has been found that higher activated people have higher quality of interpersonal exchange with their health care providers (Alexander et al., 2012)

In summary, research consistently shows that patients with higher activation scores are more engaged in behaviors that are preventive, healthy, and involve self-management and information seeking (J. H. Hibbard et al., 2007; Kirby et al., 2012; Mosen et al., 2007; Remmers et al., 2009). More activated patients experience better health outcomes and experiences (Fowles et al., 2009; Harvey et al., 2012; Remmers et al., 2009; Skolasky, Mackenzie et al., 2011). Less activated patients are more likely to have unmet healthcare needs than higher activated patients (Hibbard et al., 2007, Hibbard et al., 2008).

**Patient activation and the hospitalized patient**
Though patient activation has been studied in a variety of settings, little published research is found related to 30 days post hospitalization and patient activation. This transition time period is a very vulnerable time for patients due to exacerbations of acute symptoms of chronic disease or newly diagnosed chronic disease that establish new complex treatment plans. These complex plans can be overwhelming for hospitalized patients and may influence patient activation. Patient activation may be different during this time period. First, however, it is important to know how the Patient Activation Measure (PAM) performs in the hospital setting among multimorbid patients. To date the psychometric properties of the PAM have not been studied in the hospitalized patient. As part of this dissertation a psychometric analysis of the PAM in the hospitalized setting with multimorbid was conducted to understand its reliability and validity in this setting. See the manuscript titled “Psychometric properties of the Patient Activation Measure in the multimorbid hospitalized patient” to be published in the Journal of Nursing Measurement in 2016.

Patient activation and 30 Day Rehospitalization and Emergency Department Utilization

Previous research has reported one in four heart failure patients are re-hospitalized within 30 days of index admission (Vaduganathan, Bonow & Gheorghiade, 2012). Several factors contribute to this huge burden including inadequate discharge planning and lack of care coordination between hospitals and community health care providers. Hospitals have worked diligently to decrease these numbers largely due to changes in the Affordable Care Act (2010). Care transition programs have been implemented in many hospitals (Bixby & Naylor, 2009; Naylor et al., 2012; Naylor, Hirschman, O'Connor, Barg, & Pauly, 2013).

Activation has been linked to readmission. There is an association between self-care management, confidence and readmissions (Sahebi, A., Mohammad-Aliha, J., Ansari-Ramandi, M., & Naderi, N., 2015). Researchers have documented (Begum et al., 2011; Kinney et al., 2015;
Mitchell et al., 2013) patients with lower activation scores are at greater risk for hospital admission or readmission compared to those with higher activation scores. A recent systematic review of 10 publications (Kinney et al., 2015) reported that patients with chronic illnesses in lower stages of patient activation are at increased risk for readmission. Mitchell et al. (2013) in a large secondary analysis found that those with the lowest level of activation had nearly twice the risk of 30-day readmissions than the highest activated patients. In addition, after analyzing data from an annual survey of the diabetic population, another researcher found the lowest level activation patient was 1.4 times as likely to be hospitalized and 1.3 times as likely to visit ED as the highest level activation patient (Begum et al., 2011). A retrospective review of 25,000 patient records from a large health care system including 35 clinics showed higher activated patients were less likely to use the ED or be hospitalized (Greene & Hibbard, 2012).

However, there is conflicting literature in regards to hospital readmission following interventions designed to increase patient activation and therefore decrease re-admissions. Two studies in the heart failure population reported a lower hospitalization rate after an intervention to increase patient activation (Kutzleb et al., 2014; Shively et al., 2013). However, a randomized controlled trial evaluating readmission in the congestive heart failure and chronic obstructive pulmonary disease population did not show differences in readmission rates between intervention and control group, despite patient activation levels increasing in the intervention group over time (Linden & Butterworth, 2014). In addition, an intervention performed by community health workers increased patient activation but did not decrease 30 day readmissions; however, multiple readmissions were less after the intervention (Kangovi et al., 2014).

Further research is needed to identify what type of patient activating intervention is successful in decreasing readmissions. A systematic review is underway evaluating patient activation interventions and identifying specific components of interventions that have significant
effects on patient activation and other health outcomes. See manuscript titled “Evaluation of patient activation interventions: A systematic review.”
Chapter 3- Methods

Research Design. This non-experimental descriptive study used a cross-sectional, correlational research design. The study was approved by the Institutional Review Board (# 059-14-EP) of the University of Nebraska Medical Center and the Combined Institutional Review Board in Lincoln, Nebraska. See Appendix A for confirmation letters from both institutional review boards.

Setting. Catholic Health Initiatives (CHI)-Saint Elizabeth is a 264 bed acute care facility in Lincoln, NE. This non-profit, faith-based acute care facility was founded by the Sisters of Saint Francis of Perpetual Adoration in 1889. CHI-Saint Elizabeth specializes in the treatment areas of newborn and pediatric care, women’s health, burn and wound, cardiology, oncology, emergency medicine, orthopedics and neuroscience.

Sample. The study used a convenience sample of patients admitted to CHI-Saint Elizabeth.

Inclusion Criteria. Subjects included in this study met the following criteria: all patients admitted to CHI-Saint Elizabeth that were a) age 19 years or older b) able to hear, speak, and read English c) had 3 chronic diseases and were d) discharged to home.

Exclusion Criteria. Patients were excluded if they had a terminal illness and were receiving hospice care or were placed in a nursing home or other facility.

Sample size. 200 patients were recruited for this study. Our target sample size was 200 to accommodate 10% missing data. This sample size was required for a two-tailed test of a correlation coefficient to have power ≥ .80 (using α = .05) with the population correlation no smaller than r = .2. This sample size gave adequate power for a two-tailed t-test if the group means differed by .4 standard deviations (for groups of equal size) to .7 standard deviations (if 10% were in one group and 90% in the other). With this sample size a test of an individual partial regression coefficient in a multiple regression analysis would have power of .80 for an effect size
of \( f^2 = .04 \). This is equivalent to a predictor that uniquely explains approximately 4\% of the variance in the outcome when the overall model explains 25-30%.

**Procedure and Recruitment.** Participants in this study were recruited and enrolled in 3 different ways:

1) Patients were concurrently enrolled in a Home Based Care Transition Intervention (HBCTI) study and this descriptive study;

2) Patients enrolled in the HBCTI study prior to the initiation of this descriptive study were sent a letter inviting them to be part of this study. The letter asked permission to use their previously collected data and to get 30-day health care utilization data;

3) Patients not qualifying for the HBCTI study were invited to participate in this descriptive study.

The HBCTI used the same baseline data collection measures as the current study. HBCTI inclusion criteria included patients who a) were age 19 and older and discharged from the hospital with three or more chronic diseases; b) resided within a 35 mile radius of Lincoln, NE.; and were able to hear, speak and read English. Patients were excluded if they: a) had a terminal illness; b) had a score of less than 17 on the Montreal Cognitive Assessment (dementia); c) received home health care; d) were under the care of The Physicians Network at CHI-Saint Elizabeth or e) were involved in any other care transition intervention.

Enrollment in this descriptive study was voluntary; patients could be enrolled in the HBCTI and not this descriptive study. In addition, patients who were excluded from the HBCTI and met inclusion criteria for this descriptive study could be involved in the descriptive study. For example, if a patient scored less than 17 on the MoCA they could be enrolled in the current study.
All adult patients admitted to CHI-Saint Elizabeth were screened by research personnel. Research personnel included a registered nurse and an advanced practice registered nurse-nurse practitioner, both employed by CHI-Saint Elizabeth and the PI, who had a clinical appointment with CHI-Saint Elizabeth. All research personnel had ethical access to the medical chart for recruiting patients and were included on the Institutional Review Board (IRB) documents. The research personnel were affiliated with the HBCTI. The screening process began with a daily electronic admission sheet generated by the Information Technology department at CHI-Saint Elizabeth. Patients on this admission sheet were screened by research personnel for inclusion and exclusion criteria. The research personnel contacted eligible patients in their private hospital room after the patient was medically stable and prior to anticipated discharge. Patients who met inclusion and exclusion criteria were invited to participate. The study was thoroughly explained. Patients were informed of risks and benefits of the study and the potential for advancing scientific research and potentially helping others. The patients were informed that participating or declining to participate in the study did not influence the care they received while at CHI-Saint Elizabeth. Informed consent was obtained from those willing to participate in the study (See Appendix B for the consent forms). A mutually agreed upon time was scheduled with the patients who signed a consent for data collection. The completion of data collection instruments took approximately 20 minutes. Some data instruments were collected in short sessions during the hospitalization due to patient fatigue or patient availability. All data collection instruments were completed between admission and discharge from the acute care hospitalization except for the one month follow up data collection instrument. Research personnel had daily conversations with CHI-Saint Elizabeth discharge planners to determine that enrolled patients maintained inclusion and exclusion criteria (e.g., discharged to a facility such as skilled nursing facility or assisted living). All procedures followed health insurance portability and accountability act guidelines.
Predictor Measures (See Appendix C for research measures)

Demographic information. Demographic determinants (age, gender, educational level, race, and income), clinical determinants (cognition, physical functioning, sleep disturbance, severity of illness, number of comorbidities and pain), and psychosocial determinants (health literacy, presence of a caregiver, depression, anxiety, fatigue, sleep disturbance, satisfaction with the social role, perception of health status, quality of life and assessment of chronic illness care) were obtained by questioning the patient, from validated self-report instruments or the electronic medical record.

Cognition. The Montreal Cognitive Assessment (MoCA) (Nasreddine, 2015) was used to evaluate cognition status. The MoCA is a 10 minute 30-point assessment evaluating cognition. Higher scores indicate higher levels of cognitive function. Cognitive domains include attention, immediate and delayed memory, visual-spatial skills, language, and executive function (Coen, Cahill, & Lawlor, 2011). One point is added to scores for those individuals with ≤ 12 years of education. Patients in this study who were blind or unable to draw with their dominant writing hand completed the MoCA blind version. The maximum score on the MoCA blind is 22 compared to 30 on the standard version. To standardize the score, the MoCA blind score was converted to the 30-point scale as recommended by the developers (Nasreddine, 2015). For example, if the score on the MoCA blind was 19, the equation utilized for conversion was \( \frac{19 \times 30}{22} \). The MoCA was evaluated as a continuous score. In relation to validity, the MoCA has demonstrated excellent sensitivity for detecting amnesic mild cognitive impairment (100%) and multiple-domain mild cognitive impairment, (83.3%) (McLennan, Mathias, Brennan, & Stewart, 2011), though specificity rates were only 50% and 52%, respectively. Prior literature has documented internal consistency from .79 (Toglia, Fitzgerald, O’Dell, Mastrogiovanni, & Lin, 2011) to .83 (Nasreddine et al., 2005) in chronic illness populations (Athilingam et al., 2011; McLennan et al., 2011; Coen et al., 2011; Freitas et al., 2012).
Physical functioning, anxiety, depression, fatigue, sleep disturbances, satisfaction with social role and pain. The Patient Reported Outcomes Measurement Information System (PROMIS)-29 was used to measure overall well-being. These questionnaires are a set of patient reported highly reliable, precise measures for physical, mental, and social well-being (Cella et al., 2010). The 8 subscales of the PROMIS-29 measure physical function, anxiety, depression, fatigue, sleep disturbances, satisfaction with social role, pain impact and pain intensity. PROMIS tools measure functional ability and feelings. The uniqueness of PROMIS lies in four key areas: a) comparability to other instruments, b) reliability and validity, c) flexibility and d) inclusiveness. PROMIS encompasses all people, regardless of literacy, language, physical function or life course (Cella et al., 2010). In the heart failure population who undergo heart transplantation, the PROMIS subscales showed internal consistency with Cronbach’s alpha for physical functioning (.84, .85), fatigue (.91, .77) and depression (.91, .92) (Flynn et al, 2015). Construct validity was established with correlation comparison of the PROMIS and the Kansas City Cardiomyopathy Questionnaire physical functioning scale (r = 0.68 -0.85) and social function scale (r = .60-.74), the fatigue scale of the Medical Outcomes Study Short Form (r = -.75 to -.78) and the depression items from the Patient Health Questionnaire (PHQ-2) (r= .35-.42). The PHQ-2 correlation was large when measured at baseline (r = .65-.70) (Flynn et al., 2015). Cronbach’s alpha for the PROMIS-29 anxiety scale was .89 and the depression scale .93 with convergent reliability reported (Kroenke, Yu, Wu, Kean, & Monahan, 2014). In this study, Cronbach’s alpha for the PROMIS-29 subscales were: physical functioning (.88), anxiety (.86), depression, (.94), fatigue (.92), sleep disturbance (.81), social (.94), and pain (.92).

Severity of illness. The Charlson Comorbidity Index (CCI) is a weighted index designed to predict mortality from medical record data. Weights are assigned to medical conditions estimating one-year relative risk of death for that condition (Charlson, Pompei, Ales, & MacKenzie, 1987). The sum of the weights yields a total score which represents the burden of
comorbidities and can range of 0-37. The CCI has been identified as a predictor of death in cardiovascular patients (Bhavnani et al., 2013), a measure of comorbidity in the ischemic stroke population (Goldstein, Samsa, Matchar, & Horner, 2004) and as a risk measure for all-cause rehospitalization (Robin L. et al., 2013; Parrish et al., 2009). Patients’ medical record was reviewed to obtain comorbidities.

Health Literacy. The Shortened-Test of Functional Health Literacy in Adults (S-TOFHLA) and the Single Item Literacy Screener (SILS) measured health literacy. The S-TOFHLA instrument is a 36-item timed test of reading comprehension (Baker, Williams, Parker, Gazmararian, & Nurss, 1999). Individuals are allowed 7 minutes to read and answer questions in actual health-related passages for preparations for a procedure and a Medicaid application form. The passages use a modified Cloze procedure where words are missing and individuals are asked to choose the correct word from a set of multiple choice responses (Baker et al., 1999). Internal consistency of the S-TOFHLA has been demonstrated (Cronbach’s alpha=.98) and construct validity supported based on its correlation with the long version of the TOFHLA (r=.91) and the Rapid Estimate of Adult Literacy in Medicine (r=.80) (Baker et al., 1999). The S-TOFHLA has been utilized in multiple chronic illness populations and emergency room settings (Baker et al., 1999; Al Sayah, Williams, & Johnson, 2013; Cordasco, Asch, Franco, & Mangione, 2009; Jeppesen, Coyle, & Miser, 2009; Al Sayah et al., 2013).

The Single Item Literacy Screener (SILS) is a single question intended to identify adults in need of help understanding printed health material (Morris, MacLean, Chew, & Littenberg, 2006). The SILS asks, "How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?" Patients respond: 1-Never; 2-Rarely; 3-Sometimes; 4-Often; and 5-Always. For this study, we wanted to capture all who indicated they typically needed help with written material. Responses were categorized into: 1-never; 2-rarely; or 3-sometimes, often, or always. The sensitivity of the SILS
compared to the S-TOFHLA in detecting limited reading ability was 54% and the specificity was 83% (Morris et al., 2006). Construct validity has been documented in the rheumatoid arthritis population with the Rapid Estimate of Adult Literacy in Medicine (r = .34) and S-TOFHLA (r=.36), (Quinzanos, Hirsh, Bright, & Caplan, 2015).

**Quality of life and perception of health status.** The EQ-5D developed by the Euro-Qol Group (1990) was used to evaluate quality of life. It is a standardized non-disease specific self-report instrument measuring health related quality of life. It includes five levels of severity (no problems, slight problems, moderate problems, severe problems, and extreme problems) in five dimensions (mobility, self-care, usual activities, pain/discomfort, and anxiety/depression). An overall utility index is calculated on these domains. A crosswalk provided by the developers was used for scoring the EQ-5D index (Euro-Qol Group, 1990). In addition, a visual analogue scale (0-100) rating health today. A 0 rating is the worst possible health state and 100 the best possible health. This current study identifies the 0-100 health rating scale as the perception of health status. The EQ-5D visual analogue scale has been found to have estimated test-retest reliability of r=.89 and an index score of r= 76 and significantly discriminates between patients in remission and those with active disease (p < .0001) in the inflammatory bowel disease populations (Stark, Reitmeir, Leidl, & König, 2010). The construct validity of the EQ-5D was supported by its correlation with the short form-8 (r = .53) and with the EQ-5D VAS (r = .80) in the cardiac population (Ellis, Eagle, Kline-Rogers, & Erickson, 2005). In the acute coronary syndrome population, there were significant correlations between the EQ-5D and the SF-36 (r = .21-.74) for corresponding subscales (Schweikert, Hahmann, & Leidl, 2006).

**Assessment of chronic illness care.** The patient assessment of chronic illness care (PACIC) was developed to evaluate patients’ perspective of the care they receive from providers for their chronic diseases (Glasgow et al., 2005). The PACIC evaluates the receipt of patient-centered care and self-management behaviors in alignment with the Chronic Care Model (Wagner et al.,
a widely accepted framework for providing care to chronically ill individuals. Developers report the PACIC to be a practical, reliable (Cronbach’s alpha = .93, test–retest r = .58) instrument with face, construct and concurrent validity (Glasgow et al., 2005). The PACIC is a self-reported instrument with 5 subscales: patient activation, delivery system design/decision support, goal setting, problem solving, and follow-up care. Responses to the PACIC range from 1 (none of the time) to 5 (always). The PACIC is scored as the mean of all items. Subscales of the PACIC can also be calculated; however, due to disagreement on factor structure in the literature, a one-factor structure was used for this study as recommended by Aung et al. (2014). Consistent with the research of the developers of the PACIC (Glasgow et al., 2005) inter-correlations among the subscales in our study was strong (r = .55-.87); therefore, it was determined to utilize the entire PACIC total score. Due to the focus of this study on predictors of patient activation, the PACIC-patient activation subscale (PACIC-PA) was evaluated. There was weak correlation (r = .23) with the patient activation measure (PAM) score, hence a decision was made to include the PACIC-PA subscale in the scoring of the PACIC when evaluating the assessment of chronic illness care of care. Cronbach’s alpha for this study was .94.

Outcome measures

Patient Activation. The patient activation measure (PAM) is a 13-item 5-point Likert response scale that measures self-reported knowledge, skill and confidence for self-management of health or a chronic condition (Hibbard et al., 2004; Hibbard et al., 2005). The raw scores were summed and transformed to a 0-100 metric (0 = lowest activation level, 100 = highest). Cut point scores for the PAM were used to categorize patients into the four activation levels. Level 1 patients may not yet believe that the patient role is important, Level 2 patients lack confidence and knowledge to take action, Level 3 patients are beginning to take action, and Level 4 patients have difficulty maintaining behaviors over time (Hibbard et al., 2004; Hibbard et al., 2005). The cut points were determined by using a PAM-13 scoring spreadsheet that converts an individual’s item responses
to both the continuous score and to a developmental level. This spreadsheet was provided upon licensing of the PAM (Insignia Health, 2014). Reliability and validity of the PAM-short form has been reported (Skolasky et al., 2011; Skolasky, Mackenzie, et al., 2011; Hibbard et al., 2005). In the multiple sclerosis population, Cronbach’s alpha was .88 (Stepleman et al., 2010). Construct validity was established with significant correlations between the PAM and the Beck Depression Index-II ($r = -.43$, $p<.01$) and the Multiple Sclerosis Quality of Life ($r = .42$, $p<.01$) (Stepleman et al., 2010).

High internal consistency, Cronbach’s alpha of .87, and construct validity with health-related behaviors, functional status and health care quality was reported in the multimorbid population (Skolasky et al., 2011). Cronbach’s alpha in the current sample was .89.

**Health care utilization.** Patients were called one month following discharge for health care utilization (rehospitalization and ED visit) information. Patients were asked if they had been readmitted or visited the ED in the last 30 days. In addition, patients were asked how many times they were readmitted or visited the ED for health care. Hospitals identified by patients as a place they received health services were sent signed consent forms and asked to validate rehospitalization ED and visits. The admitting Midwestern hospital validated all rehospitalizations and ED visits to their facility for patients in the study. Six of the seven other hospitals validated rehospitalizations or ED visits for study participants. Only one patient’s rehospitalization was not validated through hospital medical records due to the patient not signing an additional release of medical information for this validation.

**Data management and analysis.** Study data were collected and managed using Research electronic Data Capture (Harris et al., 2009) tools hosted at the University of Nebraska Medical Center. Data were analyzed using IBM SPSS version 22.0. Prior to analysis, a descriptive analysis (e.g., means, standard deviations, ranges, frequencies and percentages) was conducted on variables. Scatterplots and histograms were created to visually inspect the data and to evaluate for outliers as well as normal distributions of the data. Acceptable levels of skewness were set at
2.0 to -2.0 and kurtosis at 3.0 to -3.0. No extreme outliers or seriously non-normal distributions were found with screening. Statistical significance was determined at $\alpha = .05$. Post hoc analysis of the significant ANOVA was done using a Bonferroni adjustment. Cronbach’s alpha was calculated for each established scale to check that it was .7 or greater. The PAM was developed and has been utilized in two ways (as a continuous score and as a development PA level) (Hibbard et al., 2004; Hibbard et al., 2005); therefore, specific aims 1-3 were addressed in two sets of analyses, one using the continuous PAM score and the other using the four PAM activation levels. Please refer to the manuscript “Health care utilization and determinants of patient activation in multimorbid hospitalized patients” for the continuous PAM data analysis.

**Specific Aim 1**-To examine the relationship between specific determinants and patient activation using the four PAM activation levels.

Chi square was calculated for dichotomous variables. ANOVA was performed for ordinal variables with more than two levels and for continuous variables.

**Specific Aim 2**-To describe the determinants that predict patient activation using the four PAM activation levels.

Multinominal logistic regression, an extension of logistic regression to a dependent variable having more than two levels, was performed to estimate each predictor’s unique effect on the odds of being in a given activation level rather than in a reference level. Level 4 was chosen as the reference level because it is the most desirable level and literature has suggested patient outcomes are better in the higher level activation group (Hibbard et al., 2004; Hibbard et al., 2005). This analysis produces three equations, with odds ratios (OR) and 95% confidence intervals (CI) for each level of patient activation compared to the highest activation level (level 4). Variables were included in the multinominal logistical regression if the relationship to patient activation evaluated in specific aim 1 was determined to have a p-value .25 or less. Fit statistics
were unavailable in the multinomial statistical procedure in SPSS, so to obtain additional
diagnostic information, individual logistic regressions were performed following the guidelines
published in Hosmer & Lemeshow (2000). Logistic regressions were performed comparing level
1 and level 4; level 2 and level 4; and level 3 and level 4.

Specific Aim 3-To determine the relationship of 30-day health care utilization
(rehospitalization and ED) and patient activation using the four PAM activation levels.

Chi square was performed. Due to expected cell frequencies being insufficient to meet
assumptions of the chi square test data were collapsed. For rehospitalizations, levels 1 and 2 were
combined and levels 3 and 4 were combined. This combination was decided to differentiate
lower level activated patients from higher level activated patients. For ED visits, data were again
collapsed into two categories with level 1 compared to combined levels 2, 3 and 4. Again, this
combination was decided to differentiate the higher level activated patients from lower activated
patients. However, no patients in level 3 had ED visits; therefore, level 2 was included with level
4. Fisher’s exact test (FET) was used to evaluate differences in the newly created categories.
Chapter 4: Results

The sample consisted of 200 patients who were admitted to a Midwest hospital with three or more chronic diseases and discharged to home. Their mean age was 63.7 (SD = 14.2) and they were primarily Caucasian (n = 188, 94%). The majority were female (n = 117, 58.5%) and less than half had a caregiver living in their home (n = 87, 43.5%). No patients were excluded due to cognitive impairment. In regards to activation, the mean PAM score was 60.3 (SD = 14.6) and the distribution of the PAM activation levels were level 1 activation (n = 40, 20%), level 2 activation (n = 39, 19.5%), level 3 (n = 52, 26%), and level 4 (n = 69, 34.5%). Seven of the patients did not complete the one month follow-up phone call to determine readmission and ED visit information. See Table 1 for demographic information on the sample.

Specific Aim 1-To explore the relationship of determinants among the four PAM activation levels.

Chi square was calculated for dichotomous variables. No variables were statistically significant (gender, presence of caregiver, or race). Race was recoded to white and non-white due to the large amount of patients identifying themselves as white. No further evaluation was done on race since only 12 patients identified themselves as non-white. ANOVA was conducted for the determinants measured on a continuous or ordinal scale. See Table 2 for ANOVA results. There was a significant relationship between health literacy as measured by the single item literacy screener (SILS) and the PAM activation level [F(3,196) = 4.96, p =.002]. Post hoc comparisons indicated that the mean score for the single item literacy screener in level 1 activation (M=2.1, SD = .9) was significantly higher than level 3 activation (M = 1.6, SD = .7) and level 4 activation (M = 1.5, SD = .7).

There was a significant relationship between anxiety and the PAM activation levels [F(3,195) = 6.70, p <.001]. Post hoc comparisons indicated that the mean score for anxiety of
patients in level 1 (M=59.7 SD 8.3) and level 2 (M = 59.80, SD = 7.46) activation were significantly higher than the mean for level 3 activation (M = 54.7, SD = 8.0) and level 4 activation (M = 53.8, SD = 9.6).

There were also group differences related to depression. There was a significant relationship between depression and the PAM activation levels \[F(3,196) = 8.28, p < .001\]. Post hoc comparisons indicated that the mean score for depression of patients in level 1 activation (M = 57.9, SD = 9.9) and level 2 (M = 57.2, SD = 9.9) was significantly higher than the mean for level 3 activation (M = 51.0, SD = 8.9) and level 4 activation (M = 50.4, SD = 9.6).

There was a significant relationship between fatigue and the PAM activation level \[F(3,196) = 5.59, p = .001\]. Post hoc comparisons indicated that the mean score for fatigue of patients in level 2 activation (M = 62.0, SD = 8.6) was significantly higher than means for level 3 patients (M = 55.8, SD = 9.3) and level 4 patients (M = 56.0, SD = 9.8). Sleep scores varied significantly by PAM activation level \[F(3,193) = 2.94, p = .035\] but post hoc comparison did not indicate significant group differences. Descriptively, levels 1 and 2 exhibited more sleep disturbance (by 3-4 points, approximately half a standard deviation) than patients in levels 3 and 4.

There was a significant relationship between social satisfaction with their role and the PAM activation level \[F(3,196) = 5.14, p = .002\]. Post hoc comparisons indicated that the mean score for social satisfaction with role of patients in level 1 activation (M = 38.8 SD = 7.7) was significantly lower than the mean for level 4 patients (M = 45.7, SD = 9.7). In addition level 2 patients (M = 41.0, SD = 8.2) was significantly lower than level 4.

There was a significant relationship between patient’s assessment of chronic illness care they received and PAM activation levels \[F(3,184) = 3.97, p = .009\]. Post hoc comparisons indicated that the mean score for assessment of chronic illness care for patients in level 2.
activation (M = 2.5 SD = 1.1) was significantly lower than the mean for level 4 patients (M = 3.1, SD = 1.0).

**Specific Aim 2** - To determine the unique contribution of select determinants to predict patient activation using the four PAM activation levels.

Multinomial logistical regression was performed to determine the unique contribution of individual determinants in predicting PAM level. A test of the full model against a constant only model was statistically significant, indicating that the predictors as a set distinguished between levels of patient activation ($\chi^2 = 73.34$ (3), $p = .001$). Refer to Table 3 for likelihood ratio tests. There were significant activation level differences compared to the highest activated group, level 4. Literacy measured with the SILS and patient’s assessment of their chronic illness care showed significant unique effects.

The adjusted odds ratios and 95% confidence intervals are reported in Table 4. Patients in level 1 activation were more likely to need assistance in reading health care instructions, pamphlets and other written material from their physician (OR = 2.779, $p = .001$) compared to level 4 activated group. Level 2 and 3 activated patients were less likely to positively evaluate their assessment of care they received for their chronic illness from health care providers as measured with the PACIC (OR = .408, $p = .001$; OR = .467, $p = .001$) than the level 4 group. Though not significant in the overall model ($p = .121$), level 1 activated patients were less likely to be satisfied with their social role (OR =.917, $p = .028$) compared to the level 4 group.

Due to anxiety and depression being highly correlated ($r = .650$), the model was tested with anxiety removed and depression remaining in the model. The model was then tested with depression removed from the model and anxiety remaining in the model. With anxiety removed, the overall test of the model remained significant ($\chi^2 = 67.92$ (3), $p = .001$). Likelihood ratios remained significant for the SILS and the patients assessment of their chronic illness care ($\chi^2 =$
11.16 (3), \( p = .011 \) and \( \chi^2 = 15.33 \) (3), \( p = .002 \), respectively. Depression was close to significant, \( \chi^2 = 7.07 \) (3), \( p = .07 \). Level 2 patients were more likely to be depressed \( (\text{OR} = 1.064, p = .038) \) than level 4 patients. All other odds ratios remained similar to the original model.

With depression removed, the overall test of the model remained significant \( (\chi^2 = 72.12 \) (3), \( p = .001 \). Likelihood ratios remained significant for the SILS and the patients assessment of their chronic illness care \( \chi^2 = 11.84 \) (3), \( p = .008 \) and \( \chi^2 = 16.02 \) (3), \( p = .001 \), respectively. Anxiety became significant, \( \chi^2 = 8.23 \) (3), \( p = .041 \). With depression removed from the model, patients in level 1 and level 2 had greater odds of having anxiety \( (\text{OR} = 1.072, p = .034; \text{OR} = 1.082, p = .020 \) respectively) compared to level 4. All other odds ratios remained similar to the original model.

**Specific Aim 3-To determine the relationship of 30-day rehospitalization and ED visits and patient activation using the four PAM activation levels.**

Data were collected on 194 patients at one month post hospital discharge. Refer to Table 5 for readmissions and ED visits by group. There was a total of 12 (6.2%) patients readmitted to the hospital within 30 days post discharge. The most readmissions were in level 1 \( (n = 5, 13.2\%) \). Four patients \( (10.5\%) \) in level 2 were readmitted and 3 \( (4.4\%) \) patients in level 4 were readmitted. No patients in level 3 were readmitted within 30 days. Interesting, one patient in level 4 was readmitted twice.

In relation to ED visits, 17 patients sought the ED for health care within 30 days of discharge from the hospital. The most ED visits were level 1 patients \( (n = 7, 18.4\%) \), with 2 of them visiting the ED twice. Three level 2 patients \( (7.9\%) \) visited the ED. There were four level 3 patients \( (8\%) \) with one patient visiting the ED twice. Three patients \( (4.4\%) \) in level 4 had ED visits and one of those patients had 2 visits.
For rehospitalizations, due to smaller than expected frequencies in the cells, levels 1 and 2 were combined and levels 3 and 4 were combined. When combining the lower activated patients (levels 1 and 2), there were a total of 9 unique patients readmitted compared to 3 unique patients readmitted in the higher activation groups (levels 3 and 4). There was a statistically significant difference in the groups, $p = .013$, with a higher proportion of patients in combined levels 1 and 2 experiencing rehospitalizations than in combined levels 3 and 4.

For ED visits, due to smaller than expected frequencies in cell sizes, level 1 was compared to levels 2, 3 and 4 combined. Patients in level 1 had 7 (18.4%) unique patients visiting the ED compared to 10 (6.4%) unique patients in level 2, 3 and 4 combined. Fisher’s exact test was performed, $p=.048T$), showing that patients in level 1 were more likely than patients in the other groups combined to have ED visits in the first 30 days post-discharge.
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*Patient Preference and Adherence, 8*, 1019-1024. doi:10.2147/PPA.S63954 [doi]
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<th>Range</th>
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<td>Level 4 Activation</td>
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<td>Asian</td>
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<td>Patients readmitted within 30 days</td>
<td>12 (6.2)</td>
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<td>Patients visited the ED within 30 days</td>
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*a 3 chronic diseases minimum for inclusion in study*
Table 2.
ANOVA table for PAM activation level

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<td>2.5 (1.1)</td>
<td>50</td>
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*p<.05

**p<.005
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<td>.865</td>
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<td>Physical Functioning</td>
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*p < .05
Table 4.
Determinants of patient activation, multinomial regression model
Full model (referent Level 4)

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<th>Level 2</th>
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<th>Level 3</th>
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<td>Odds Ratio (95% CI)</td>
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<td>.919 (.78-1.09)</td>
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<td>.925 (.81-1.05)</td>
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<td>1.063 (.98-1.15)</td>
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<td>1.043 (.96-1.13)</td>
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<td>.989 (.93-1.05)</td>
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### Model with ANXIETY removed (referent Level 4)

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<th>CI High</th>
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### Model with DEPRESSION removed (referent Level 4)

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*p<.05
Table 5.

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Chapter 5: Manuscripts

Manuscript 1

(Accepted for publication in 2016 in Journal of Nursing Measurement)

Psychometric Properties of the Patient Activation Measure in Multimorbid Hospitalized Patients

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Abstract

Background and Purpose-The purpose of this study was to document the psychometric properties of the Patient Activation Measure (PAM) in hospitalized multimorbid patients.

Methods-Data from 313 patients were used for psychometric testing.

Results-Estimated reliability of the PAM was .88; the content validity index was .91. Convergent and divergent validity with measures of physical functioning, depression, quality of care, severity of illness and number of multimorbid conditions were confirmed. Confirmatory factor analysis did not support a good fit of the one-factor model.

Conclusion-The PAM is a reliable and valid instrument to assess patient activation in hospitalized multimorbid patients. Further study is needed to determine what factors predict activation and how activation can assist in tailoring discharge planning.

Key words: Patient Activation Measure; PAM; psychometrics; chronic disease
Psychometric Properties of the Patient Activation Measure in Multimorbid Hospitalized Patients

Patient activation is the knowledge, skill and confidence patients require for disease self-management and the Patient Activation Measure (PAM) is a 13-item instrument that has been used in a variety of settings to evaluate how engaged patients are in the management of their own care (Hibbard, Stockard, Mahoney, & Tusler, 2004). This instrument was developed over a decade ago after recognizing that achieving quality care and controlling cost required a patient’s active involvement in their health care. Since the initial evaluation of the PAM in a general population survey (Hibbard et al., 2004), it has been used in a variety of settings with different populations including the community (Deen et al., 2012), workplaces (Fowles et al., 2009) and primary care settings (Alexander, Hearld, Mittler, & Harvey, 2012; Donald et al., 2011; Wong, Peterson, & Black, 2011). In addition, the PAM has been successfully translated for use in different languages (Korean, Dutch, Danish and German) (Ahn, Yi, Ham, & Kim, 2014; Rademakers, Nijman, van der Hoek, Heijmans, & Rijken, 2012; Maindal, Vedsted, & Mikkelsen, 2011; Brenk-Franz et al., 2013; Zill et al., 2013).

Reliability and validity of the PAM has been reported in non-acute settings however, no validity evidence was found for hospitalized patients in an acute setting. Nevertheless, it has been reportedly used in hospitals in more than 20 states in the United States to assist in discharge planning and post-discharge care (Insignia Health, 2014; Mitchell et al., 2013). Hospitalized patients are different than the general population; only the sickest of the sick are hospitalized and many remain frail after discharge. The daily challenges of self-managing the acuity of a new or newly exacerbated chronic disease at home may be overwhelming. Yet, patients in the acute care setting discharged to home are expected to self-manage their diseases immediately upon discharge. Most patients being discharged from acute care facilities have multimorbidity, but the focus of discharge care is usually standardized and focused on a single disease rather than multiple conditions. In addition, the discharge plan does not take in to account...
patient activation or engagement. If adequate psychometric properties of the PAM are documented in the acute care population, the could become a standard measure for planning and guiding clinical resources at hospital discharge to assist in preventing readmission.

Therefore, the purpose of this article was to investigate the psychometric properties of the PAM in patients with multimorbidity in the hospital setting. Specific aims of this study were to a) estimate reliability; b) evaluate the content validity; and c) evaluate the construct validity (convergent and divergent indices, and confirmatory factor analysis) of the PAM. Other researchers have evaluated the relationship between the PAM and legacy instruments such as the SF-36 physical functioning subscale, the PRIME-MD measure of depression, the PACIC evaluating quality of health care, and the Charlson Comorbidity Index quantifying severity of illness (CCI). Though this current study did not measure these concepts with all of the same instruments, we anticipated the same direction and magnitude of correlation of the concepts with the PAM. We hypothesized that PAM scores would have a) an inverse relationship with depression; b) a positive relationship with physical functional status and health care quality; and c) no relationship with number of comorbidities or severity of illness.

Background

Reliability of the PAM.

Researchers have reported the PAM to be a reliable and valid tool in several non-acute settings and populations. In relation to reliability, Skolasky, Mackenzie, Riley, and Wegener (2009) report internal consistency reliability measured by split-half reliability of .92 and adequate one week test-retest reliability (Shrout-Fleiss intraclass correlation coefficient =.84) in a preoperative lumbar spine surgical population prior to hospitalization. In an elderly multimorbid population, Skolasky et al. (2011) report high internal consistency reliability with a Cronbach’s α of .87 and Wong, Peterson and Black (2011) report a Cronbach’s α of .86 in a primary care setting. In the
multiple sclerosis population, the PAM had good reliability with reported Rasch person reliability=.83 and Rasch item reliability=.98 (Stepleman et al., 2010). Hung et al. (2013) studied a rural population and reported a person separation index of 2.36, corresponding to a Cronbach’s reliability index of .85. Several authors have converted the PAM to other languages, (Korean, Dutch and German), and report Cronbach’s α between .84-.88 (Ahn et al., 2014; Rademakers et al., 2012; Brenk-Franz et al., 2013; Zill et al., 2013).

**Validity of the PAM.**

In relation to validity, researchers have documented validity in various populations. Construct validity was evaluated in 855 older multimorbid community dwelling individuals showing that in linear regression models with the PAM scores as the independent variable, there were significant positive associations (reported as unstandardized regression coefficients) with the Short Form-36 (SF-36) Physical Health subscale (coefficient=.215, p<.001) and the SF-36 Mental Health subscale (coefficient=.193, p<.0001). Both subscales of the Primary Care Assessment Survey were significantly related to the PAM (Communication subscale coefficient=.339, p<.0001 and Integration subscale coefficient=.304, p<.0001). Finally the PAM significantly related to the Patient Activation subscale of the Patient Assessment of Chronic Illness Care (coefficient=.011, p<.0001) (Skolasky et al., 2011).

Skolasky et al. (2009) evaluated construct validity using correlation of patient activation with optimism using the Life Orientation Test-Revised scale (r=.75, p<.001), Trait Hope Scale (r=.73, p<.001), and self-efficacy to participate in physical therapy (r=.75, p<.001), depression measured by PRIME-MD (r=.13, p=.032) and the Multidimensional Health Locus of Control Scale (r=.66, p<.001) in an elective lumbar spine surgical population prior to surgery. Divergent validity was reported with low correlation between the PAM and Charlson Comorbidity Index (CCI) (r=.01, p=.904). Stepleman et al. (2010) reports construct validity with the multiple
sclerosis self-efficacy scale (r=.50, p<.01) and the Beck depression inventory-II (r=-.43, p<.01).

In the rural setting, Hung et al. (2013) reported convergent validity of the PAM with a self-management survey developed by their research team (r=.4), no p value was reported.

Chronic disease, hospitalization and patient activation.

Nearly 50% of Americans have at least one chronic disease and 7 of 10 deaths yearly are caused by a chronic disease (Centers for Disease Control and Prevention, 2012). Data from the 2012 National Health Interview Survey estimates that approximately 26% of adults have ≥2 chronic conditions and 11.7% have 3 or more chronic diseases (Ward, Schiller & Goodman, 2012). As people age, the number of chronic diseases increase. Acute exacerbations of these chronic conditions bring patients to the hospital setting. Preventing acute exacerbations of chronic illnesses through self-management will decrease hospitalizations and re-hospitalizations. Reimbursement changes stimulated by the Patient Protection and Affordable Care Act (2010) have prompted hospitals to improve discharge plans in an attempt to decrease these readmissions.

Research on activation suggests that activation levels are related to readmissions. A recent systematic review of 10 publications (Kinney, Lemon, Person, Pagoto & Saczynski, 2015) reported that patients with chronic illnesses in lower stages of patient activation are at increased risk for readmission. In addition, other researchers suggest that lowest level activation patients have more readmissions (Begum, Donald, Ozolins, & Dower, 2011; Mitchell et al., 2013). Activation levels are changeable (Remmers et al., 2009) and improvements in PAM levels are related to positive behavior changes (Harvey, Fowles, Xi, & Terry, 2012; Hibbard, Mahoney, Stock, & Tusler, 2007). The ability to change activation levels and behaviors has great potential to improve patient outcomes such as readmission, satisfaction and quality of life.

Methods

Sample and Setting
This psychometric analysis of cross-sectional data included patients admitted to a Midwest acute care hospital and enrolled in one of two studies: a) a randomized care transition clinical trial and b) a descriptive study analyzing the PAM in the hospital setting. Inclusion criteria for both studies were a) 19 years or older, b) able to hear, speak, and read English, c) had 3 or more chronic diseases, and d) discharged to home. Patients were excluded if they had a terminal illness and received hospice care, or were placed in a nursing home or other facility. The randomized controlled trial had additional exclusion criteria for low cognition and home health care utilization. A total of 313 participants completed the PAM and were included in this psychometric analysis. Both studies obtained institutional review board approval prior to study initiation and subjects were enrolled concurrently.

Due to combining data from two different studies, many subjects did not complete all of the instruments or demographic information. The sample size for each statistical analysis varied depending on the number of completed instruments. For example, 313 patients completed the PAM whereas only 245 patients completed the PACIC.

**Study measures**

**Demographic and Clinical Characteristics.** Data were collected from the patient record or from personal interview prior to hospital discharge. Patients were given the option of having the research instruments read to them or completing paper and pencil copies. A short demographic tool including age, gender, marital status, employment, insurance status, income, multimorbid conditions and medication use was also completed.

**Patient Activation.** Patient activation was measured by the PAM. The PAM measures patient perceived knowledge, skill and confidence for self-management of health or chronic condition (Hibbard et al., 2004; Hibbard et al., 2005). The PAM is a 13-item tool that uses a four-point ordinal response scale: strongly disagree (1), disagree (2), agree (3), and strongly agree (4). There is also a “not applicable” response, which is scored as missing. In the current study,
PAM®s were included if patients responded to at least 10 of the 13 items. In accordance with the developers’ instructions, the individual’s mean on the remaining items was substituted for missing values, and responses were summed across the 13 items. The tool’s authors (Hibbard et al., 2004) developed the PAM using the Rasch rating scale model, which assumes unidimensionality. The calibration of items that fit the model results in estimates of a location or difficulty parameter for each item that reflects the probability of endorsement of that item by an individual possessing a given amount of the construct being measured. Software performing Rasch rating scale analysis provides estimates of both item location and respondent level on the same equal-interval logit scale. However, for general use, the tool developers transform the raw scores to what they consider a more user-friendly 0-100 metric.

The calibrated 13 items, ordered by estimated difficulty of endorsement, are interpreted by Hibbard et al. (2004) as reflecting a developmental model of activation. In addition to calculating a score on a continuous scale, each individual’s score places them into one of four development levels based on theoretical domains of activation identified by consensus of experts during tool development (Hibbard et al., 2004). A PAM-13 scoring spreadsheet that converts an individual’s item responses to both the continuous score and to a developmental level is provided upon licensing from Insignia Health. Level 1 patients may not yet believe that the patient role is important, Level 2 patients lack confidence and knowledge to take action, Level 3 patients are beginning to take action, and Level 4 patients have difficulty maintaining behaviors over time (Hibbard et al., 2004, Hibbard et al., 2005). See Table 1 for the specific content of the 13 PAM items. One advantage to estimating an individual’s developmental level is that the content of the items associated with that stage suggests what is needed to move the person to the next level of activation.

**Physical Functioning and Depression.** The Patient Reported Outcomes Measurement Information System (PROMIS-29) Profile V1.0 4-item subscales were used to measure physical
functioning and depression. The PROMIS-29 is a patient-reported set of highly reliable, precise measures for physical, mental, and social well-being (Cella et al., 2010). PROMIS-29 tools were developed from a National Institutes of Health funded project. The PROMIS-29 is a generic measure that it is not disease specific and allows for comparison across populations, conditions, studies and practices (Bevans, Ross, & Cella, 2014). The PROMIS-29 has been tested on heterogeneous populations regardless of literacy, physical function or life course (Cella et al., 2010). Kroenke, Yu, Kean and Monahan (2014) report Cronbach’s α of .93 on the depression scale in the chronic pain population. This tool was chosen because patients in this psychometric analysis could have any type of chronic disease. We hypothesized that the PAM would have a direct relationship with the physical function scale of the PROMIS-29 and an inverse relationship with the depression scale of the PROMIS-29.

**Quality of Health Care.** Patient Assessment of Chronic Illness Care (PACIC) is a 20-item instrument that assesses quality of health care (Glasgow et al., 2005). The PACIC is a self-report instrument that assesses the extent to which patients perceive they are receiving care that is congruent with the Chronic Care Model. The five subscales of the PACIC are patient activation, delivery system design/decision support, goal setting/tailoring, problem-solving/contextual, and follow-up/coordination items (Glasgow et al., 2005). Only the 3-item patient activation subscale of the PACIC was used. The Cronbach’s α for the patient activation subscale of the PACIC has been reported as .86 (Rick et al., 2012) and between .80-.89 (Fan et al., 2014). We hypothesized a positive relationship between the PACIC activation scale and the PAM since both are evaluating patient activation.

**Severity of Illness.** The Charlson Co-Morbidity Index (CCI) was used to evaluate severity of illness. Weights are assigned to 19 medical conditions based on their prediction of 1-year patient mortality (Charlson, Pompei, Ales, & MacKenzie, 1987). Each subject’s medical record was reviewed to obtain the comorbid diseases. The sum of the weights yields a total score
which represents the burden of comorbidities for that patient. The CCI has also been identified as a predictor of death in many patient populations including cardiovascular patients (Bhavnani et al., 2013), colorectal cancer patients (Marventano et al., 2014), and patients with antibiotic resistant organisms (McGregor et al., 2005). The CCI was selected because it has been a reliable index to measure disease severity. Prior researchers have reported that type of comorbidities do not correlate with PAM level (Skolasky et al., 2009; Skolasky et al., 2011). The PAM evaluates psychological concepts such as self-efficacy and personal competencies which should not be influenced by the number or severity of chronic illness.

**Multimorbid conditions.** Number of chronic conditions were tallied from the health care provider dictated medical record of each hospitalized patient. Prior researchers have reported the number of comorbidities do not correlate with PAM level (Skolasky et al., 2009; Skolasky et al., 2011).

**Data Analysis**

Statistical analysis was performed using IBM SPSS 22 for Windows. Descriptive statistics (frequencies, percentages, range, mean, and standard deviation) were used to describe the sample. An α level of .05 was used to determine statistical significance.

**Reliability.** Internal consistency was assessed with Cronbach’s α.

**Content Validity.** Content validity of the PAM was evaluated by calculating the content validity index (CVI) and the content validity ratio (CVR) as recommended by Lynn (1986). A panel of 10 experts from the hospital setting were asked to rate each item on the PAM for its relevance to the underlying constructs of the PAM©. These experts included two physician hospitalists, one advanced practice registered nurse practitioner (APRN-NP) functioning in a hospitalist role, one APRN-NP working with chronic heart failure patients, one APRN-Clinical Nurse Specialist working in the critical care area, three transition care nurses (two APRN-NPs
and one RN-coach) and two staff nurses working in the hospital setting. Berk (1990) recommends using at least 5 experts for a content analysis. The authors chose 10 experts to represent the variety of roles needed to care for hospitalized chronically ill patients.

The hospital experts were given a short script about the PAM. This script explained the background of the PAM and how it was designed to assess the knowledge, skill and confidence patients need to successfully manage living with a chronic disease. The experts were informed that the PAM instrument has been used in a variety of settings to measure patient activation but limited literature is available on its use with hospitalized patient. Therefore, these experts were asked to rate each item on the PAM as 1) not relevant, 2) somewhat relevant, 3) quite relevant or 4) very relevant from their perspective as a provider in this hospital setting. Responses were dichotomized, with ratings of 1 and 2 considered content invalid whereas ratings of 3 and 4 were considered be content valid. A content validity ratio (CVR) for each item was calculated as the proportion of experts who rated the item as content valid. The overall instrument was also evaluated into a content validity index (CVI) by averaging the CVRs (sum of CVR/13).

**Construct Validity.** Pearson correlations were used to test convergent validity of the PAM with the physical functioning and depression scales of the PROMIS-29; and the PAM and the activation subscale of the PACIC. Divergent validity was assessed using correlations of the PAM with the number of multimorbidities and with the CCI.

**Confirmatory Factor Analysis.** Hibbard et al. (2004) identify the PAM as a unidimensional instrument measuring the overarching construct of being in charge of one’s health. A confirmatory factor analysis (CFA) using LISREL Version 8.71 was performed on the PAM data collected from these patients to examine if this unidimensionality is consistent in the hospital setting with multimorbid patients. It was hypothesized that all 13 items would load on one factor as proposed by Hibbard et al. (2005). Guidelines recommended by Brown (2006) were
used for cutoff criteria for fit analysis for the CFA. Three areas of fit were evaluated. For absolute fit we defined acceptable indices as $\chi^2$ small and non-significant. The standardized root mean square residual (SRMR) can range from 0.0-1.0 with 0.0 indicating a perfect fit. We used the cutoff criteria value for SRMR value as close to or below 0.08. For parsimony correction the Root Mean Square of Approximation (RMSEA) was calculated. Brown (2006) recommends that RMSEA < .08 suggest adequate fit; < .05 reflects good model fit and models with ≥0.1 should be rejected. In addition, we used the suggested 90% confidence interval of the RMSEA upper limit of less than .08. For comparative fit, the Comparative Fit Index (CFI) values can range from 0-1.0 with values closer to 1 indicating good model fit. A CFI of .90-.95 is indicative of acceptable model fit (Brown, 2006).

**Results**

The sample consisted of 313 patients who were discharged to home from an acute care facility with 3 or more chronic diseases. They were primarily Caucasians (256, 81.8%) and most were women (n=187, 59.7%). The average age of the cohort was 62.7 years (SD=15) with an age range from 19-92 years. Over half of the sample (n=159, 50.7%) had some post-secondary education while 8.3% had not graduated from high school. The mean number of comorbidities was 6.4 (SD=2.8) with a range from 3 (the minimum for study inclusion) to 16. Of those who responded, only 37.7% (n=118) reported having a caregiver who lived in the same household to assist with their care. See Table 2 for the demographic characteristics of the sample.

The mean PAM score of the subjects was 61 (Level 3), with a SD of 14.37 and a range of 33.5-100. Most patients classify themselves as activated at Level 4 (n=108, 34.5%) or Level 3 (n=95, 30.4%) and there were 55 (18%) subjects in both Level 1 and 2. Descriptive statistics for all other instruments are included in Table 3.

**Reliability**
Internal consistency of the PAM was estimated as .88 based on 295 PAM instruments with complete data on all 13 items. The Cronbach’s $\alpha$ would not improve with deletion of any items. The range of corrected item total correlation was .42-.63 suggesting that all items correlated to the entire instrument and that each item is evaluating what the entire instrument measures. See Table 1 for specific PAM item descriptives.

The Cronbach’s $\alpha$ of the activation subscale of the PACIC in this population was .84. The corrected item total correlations ranged from .65-.75. The PROMIS-29 depression subscale Cronbach’s $\alpha$ was .87; corrected item correlations ranged from .65-.75. The PROMIS-29 physical functioning subscale Cronbach’s $\alpha$ was .88; corrected item correlations ranged from .71-.78. Refer to Table 3 for descriptives of all instruments.

**Content Validity**

The overall PAM instrument was considered content valid with a CVI of .91. However, two items on the PAM©, item 12 and item 13, had much lower individual CVR (.6 and .7) than other items. The CVR for all items are presented in Table 1.

**Construct Validity**

Convergent validity between the PAM and the PACIC-activation ($r=.21, p<.01$) was supported. This was consistent with the assumption that higher PAM scores would positively correlate with higher PACIC-activation scores. The correlations between the physical functioning ($r=.13, p<.05$) and the depression ($r=-.32, p<.01$) subscales of the PROMIS -29 and the PAM also were as hypothesized. Divergent validity was confirmed with no statistically significant correlation between PAM scores and CCI ($r=-.05, p=..45$) or number of comorbidities ($r=-.10, p=.08$).

**Confirmatory Factor Analysis.**
A one-factor structure was not a good fit for the data based on the 313 completed observations. For absolute fit, the \( \chi^2 \) was large and significant, the \( \chi^2 = 400.41, \text{df} = 65, p < .01 \). The Standardized Root Mean Square Residual (SRMR) was .087, slightly above the cutoff criteria value of .08. Brown (2006) recommends that Root Mean Square Error of Approximation (RMSEA) <.08 for adequate fit; our study results of .14 exceeded the cutoff. In addition, at .12, the upper limit of the 90% confidence interval of the RMSEA exceeded the .08 threshold. For comparative fit, the Comparative Fit Index (CFI) was .89, indicating a less than acceptable model fit. None of the indices suggest that a one factor model represents a good fit to this data.

Further evaluation of the modification indices for the item error (uniqueness) terms suggest that two pairs of items are highly correlated and may account for lack of fit. Items 1 and 2 are identified the easiest to master and indicative of Level 1 patient activation (Hibbard et al., 2005). These two items are related to the belief that taking an active role in one’s own health is important. Items 10 and 13 both are related to confidence in maintaining lifestyle changes with the only difference being “even during times of stress” added to item 13.

Additional Findings

To compare convergent validity in the acute care multimorbid population and a chronic multimorbid population (Skolasky et al., 2011), linear regression models were fit with the PAM as the predictor variable and physical functioning, depression and the activation scale of the PACIC as criterion measures. Our results were similar to their findings, showing significant associations with measures of physical functioning, (coefficient =.078, p < .029); depression (coefficient=-.218, p < .001) and the activation scale of the PACIC (coefficient=.018, p < .001).

Discussion

In this evaluation of the PAM with multimorbid hospitalized patients, the PAM was shown to have adequate reliability and both content and documented construct validity. Content
validity as evaluated by hospital experts was supported. However, the experts evaluating the PAM for relevance in the hospital setting scored the last 2 items of the PAM lower than other items. Item 12 is related to having confidence in figuring out solutions to new problems and item 13 is related to maintaining lifestyle changes during stress. Hibbard et al. (2005) consider these questions Level 4 activation and the most difficult to endorse. Items 12 and 13 had a much lower individual CVR (.6 and .7, respectively) than the other items of the PAM. Comments from the hospital experts focused on the acuteness of hospitalization and newness of diagnoses. Specific comments regarding item 12 included hospitalized patients were “focused on an acute problem but may be dealing with a new diagnosis, how can one be confident?”, and “a lot to ask for, confidence with new problems”. Specific comments regarding item 13 were related to “item is too much like item 10 (maintaining lifestyle changes), I don’t think both are relevant”, “patients are not ready to make lifestyle changes until recovered from the acute illness”, and “not many patients maintain during stress, especially with a new diagnosis”. If items 12 and 13 (both related to maintaining lifestyle changes) were not included in the CVI calculations, the instrument CVI would be much higher at .93.

The PAM correlated as hypothesized with subscales of previously validated instruments (activation subscale of the PACIC and physical functioning and depression subscale of the PROMIS -29) in the hospital setting. Higher scores on the physical functioning subscale of the PROMIS -29 was positively associated with higher PAM scores. The negative relationship between the depression scale of the PROMIS -29 and the PAM scores indicate that those with higher PAM scores had lower depression scores and is consistent with other studies (Skolasky et al., 2009; Stepleman et al., 2011). Though none of these correlations were considered strong, all were statistically significant. These weak correlations are consistent with prior research and anticipated because the PAM measures an overall construct of patient activation and not the specific concept of physical functioning or depression. In addition, our results were similar to
Skolasky et al. (2011) showing significant associations with PAM and measures of physical functioning, depression and the activation scale of the PACIC.

It is interesting that the patient activation subscale of the PACIC and the PAM did not have a stronger correlation since the subscale is actually measuring patient activation and not a different construct. However, the PACIC was developed to measure the patient perspective of care provided for chronic illness and to evaluate its consistency with the Chronic Care Model (CCM) (Glasgow et al., 2005). The intent of the tool is to assess the receipt of patient centered care from providers, not solely the engagement or activation of the patient. In addition, concepts from the CCM were not evaluated in this study.

The CFA suggested that a single facture structure of the PAM as hypothesized by Hibbard et al (2005) did not fill well in this population. Several pairs of items on the PAM with high correlation may explain why the data is inconsistent with a single factor model of the PAM in this setting. However, the data do not suggest the model is multifactorial, but that specific items share more variance than is accounted for by the common factor. It is unknown if this is related to the setting, acuity of patients, age or other factors. Further research with the multimorbid population is needed. The hospitalized patient with multimorbidity may be unique compared to the general population. There is a need to further investigate the PAM’s use in the hospitalized patients.

**Limitations**

A limitation of the study was having access only to scales utilized in the studies. For example, comparison to an established, valid and reliable tool measuring self-efficacy would have enhanced this psychometric analysis.

The PAM was used as a screening instrument for the RCT study. Near the end of the study if the patient’s PAM level was 3 or 4, patients were screened out due to having recruited
and enrolled the maximum number of participants allotted per group. As a result, the sample may not be an accurate representation of the distribution of patient activation in hospitalized patient with multimorbid conditions.

Hibbard et al. (2004) suggests removing PAMs that have a “strongly agree” response for all 13 items. In our analysis, only 6 of the 313 subjects responded “strongly agree” to all 13 items. Since so few subjects responded “strongly agree” to all items, our research team decided to analyze all completed PAM regardless of item response choice. Despite patients being encouraged to respond to items as truthfully as possible, we feel it is difficult to distinguish patient’s responding for social desirability from those who are truly highly activated. All subjects with completed PAM instruments were included in this analysis.

Implications

This study had documented reliability and validity of the PAM for assessing patient activation in this sample of hospitalized patients with multimorbidity. Despite the confirmatory factor analysis suggesting that the single factor structure of the PAM did not fit well for this data, a multifactorial model wasn’t suggested either. With minor changes in the tool, the PAM could be a strong tool for evaluation of patient activation in the hospital setting with the multimorbid population. Nurses providing discharge education need to know patient activation levels to understand which patient needs more focused attention to improve outcomes such as readmission. More consideration for targeting patients and tailoring discharge plans based on activation prior to hospital discharge is needed to facilitate an optimal care transition. For example, a patient in the lowest level of activation may need individualized pictorial instruction with easy to follow instructions initiated early in the hospitalization compared to a highly activated patient who may only need written instructions. Priority should be focused on the lowest activated patients. Strategically allocating time, energy and human resources on the lowest level activation patient
may be a cost effective strategy to not only improve patient activation but also improve outcomes such as readmission rates.

**Conclusions**

The PAM had documented reliability and validity for assessing patient activation in this sample of hospitalized patients with multimorbidity. Caution should be used in generalizing beyond this setting and population. Evaluating convergent validity with a self-efficacy instrument would enhance the validity of the PAM since self-efficacy may be a construct of the PAM©. We believe that the PAM should be further tested to determine what other factors predict activation and what interventions could be used to tailor discharge planning for multimorbid patients going home. Additionally more study should be done to examine how patient activation predicts patient self-management of their chronic diseases.
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doi: [http://dx.doi.org/10.1016/j.outlook.2014.05.009](http://dx.doi.org/10.1016/j.outlook.2014.05.009)


Donald, M., Ware, R. S., Ozolins, I. Z., Begum, N., Crowther, R., & Bain, C. (2011). The role of patient activation in frequent attendance at primary care: A population-based study of people
doi:10.1016/j.pec.2010.05.031


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http://www.insigniahealth.com/PAM©-applications-impact


Table 1.

PAM Item Descriptives and Corrected Item Total Correlation

<table>
<thead>
<tr>
<th>PAM Items</th>
<th>CVR a</th>
<th>M (SD)</th>
<th>Skewness</th>
<th>Kurtosis</th>
<th>Corrected Item Total Correlation b</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. When all is said and done, I am the person who is responsible for</td>
<td>1.0</td>
<td>3.59 (.54)</td>
<td>-.99</td>
<td>.66</td>
<td>.45</td>
</tr>
<tr>
<td>taking care of my health</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Taking an active role in my own health care is the most important</td>
<td>.9</td>
<td>3.55 (.54)</td>
<td>-.69</td>
<td>.08</td>
<td>.46</td>
</tr>
<tr>
<td>thing that affects my health</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. I am confident I can help prevent or reduce problems associated</td>
<td>1.0</td>
<td>3.24 (.57)</td>
<td>-.19</td>
<td>-.06</td>
<td>.51</td>
</tr>
<tr>
<td>with my health</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. I know what each of my prescribed medications do</td>
<td>1.0</td>
<td>3.12 (.68)</td>
<td>-.33</td>
<td>-.16</td>
<td>.51</td>
</tr>
<tr>
<td>5. I am confident that I can tell whether I need to go to a doctor or</td>
<td>1.0</td>
<td>3.10 (.63)</td>
<td>-.07</td>
<td>-.49</td>
<td>.63</td>
</tr>
<tr>
<td>whether I can take care of a health problem myself</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. I am confident that I can tell a doctor concerns I have even when</td>
<td>.8</td>
<td>3.23 (.66)</td>
<td>-.41</td>
<td>-.14</td>
<td>.60</td>
</tr>
<tr>
<td>he or she doesn’t ask</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. I am confident that I can follow through on medical treatments I</td>
<td>1.0</td>
<td>3.40 (.56)</td>
<td>-.22</td>
<td>-.86</td>
<td>.62</td>
</tr>
<tr>
<td>may need to do at home</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. I understand my health problems and what causes them</td>
<td>1.0</td>
<td>3.06 (.68)</td>
<td>-.45</td>
<td>.43</td>
<td>.61</td>
</tr>
</tbody>
</table>
9. I know what treatments are available for my health problems & .9 & 2.94 (.64) & -.10 & -.10 & .62 \\
10. I have been able to maintain (keep up with) lifestyles changes, like eating right or exercising & .9 & 2.74 (.73) & -.09 & -.30 & .42 \\
11. I know how to prevent problems with my health & 1.0 & 2.93 (.62) & -.20 & .28 & .61 \\
12. I am confident I can figure out solutions when new problems arise with my health & .6 & 2.80 (.71) & -.16 & -.19 & .63 \\
13. I am confident that I can maintain lifestyle changes, like eating right and exercising, even during times of stress & .7 & 2.84 (.68) & -.22 & .02 & .52 \\

*Note. *CVR=Content Validity Ratio, calculated as a proportion of the 10 subject matter experts judging the responses content valid; M=Mean; SD=Standard Deviation; Content Validity Index for PAM instrument=.91; Based on 295 completed PAM instruments with no missing data.
<table>
<thead>
<tr>
<th>Demographic Variable</th>
<th>f (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>186 (59.4)</td>
</tr>
<tr>
<td>Male</td>
<td>126 (40.3)</td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>143 (45.7)</td>
</tr>
<tr>
<td>Not Married (Single, Widow, Divorced, Separated, Cohabitation)</td>
<td>136 (42.8)</td>
</tr>
<tr>
<td>Caregiver In Home</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>118 (37.7)</td>
</tr>
<tr>
<td>No</td>
<td>151 (48.2)</td>
</tr>
<tr>
<td>Race</td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>256 (81.8)</td>
</tr>
<tr>
<td>Others (African American, Native/Alaskan American Hispanic, Asian)</td>
<td>26 (7)</td>
</tr>
<tr>
<td>Income</td>
<td></td>
</tr>
<tr>
<td>&lt;$30K/year</td>
<td>112 (35.8)</td>
</tr>
<tr>
<td>$30K-$60K/year</td>
<td>75 (21.1)</td>
</tr>
<tr>
<td>&gt;=60K/year</td>
<td>66 (23.7)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>&lt; 12th grade</td>
<td>26 (8.3)</td>
</tr>
<tr>
<td>12th grade</td>
<td>89 (28.4)</td>
</tr>
<tr>
<td>&gt; 12th grade</td>
<td>159 (50.7)</td>
</tr>
</tbody>
</table>

*Note.* *Categories do not sum to 100% due to missing data or refusal to answer items.*
<table>
<thead>
<tr>
<th>Instrument Descriptives</th>
<th>n</th>
<th>Cronbach’s α</th>
<th>Correlation with PAM</th>
<th>M (SD) (Min - Max)</th>
</tr>
</thead>
<tbody>
<tr>
<td>PACIC-Activation subscale</td>
<td>245</td>
<td>.84</td>
<td>r=.21&lt;sup&gt;a&lt;/sup&gt;</td>
<td>9.06 (3.63) (2.8-3.3)</td>
</tr>
<tr>
<td>PROMIS-29 Depression</td>
<td>266</td>
<td>.87</td>
<td>r=-.32&lt;sup&gt;a&lt;/sup&gt;</td>
<td>9.08 (14.04) (2.1-2.5)</td>
</tr>
<tr>
<td>PROMIS-29 Physical Functioning</td>
<td>265</td>
<td>.88</td>
<td>r=.13&lt;sup&gt;a&lt;/sup&gt;</td>
<td>10.99 (2.4-2.9) (4.55)</td>
</tr>
<tr>
<td>CCI</td>
<td>268</td>
<td>---</td>
<td>r=-.05</td>
<td>2.15 (1.86) (0-10)</td>
</tr>
<tr>
<td>Number of Comorbidities</td>
<td>303</td>
<td>---</td>
<td>r=-.10</td>
<td>6.42 (2.78) (3-16)</td>
</tr>
</tbody>
</table>

<sup>Note.</sup> <sup>a</sup>Significant at .05 level.
Chapter 5: Manuscripts

Manuscript 2

Health care utilization and determinants of patient activation in multimorbid hospitalized patients

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University of Nebraska Medical Center
Health care utilization and determinants of patient activation in multimorbid hospitalized patients

One in four Americans has multiple chronic conditions (Anderson, 2010). Acute hospitalization in this population is common due to exacerbations of these chronic conditions. It has been estimated that 1 of 5 hospitalized Medicare fee-for-service beneficiaries are readmitted within 30 days of discharge, costing an approximated $17.6 billion in federal expenditures (Jencks, Williams, & Coleman, 2009), Medicare Payment Advisory Commission [MedPAC], 2007). Many rehospitalizations are unplanned and may be avoidable with properly planned and implemented care transition programs that improve quality outcomes and realize cost savings (Naylor & Sochalski, 2010). Hospitals have attempted to reduce high rates of readmission by developing and implementing care transitions programs (Naylor, Aiken, Kurtzman, Olds, & Hirschman, 2011a; Naylor & Sochalski, 2010; Hansen et al., 2013; Parrish, O'Malley, Adams, Adams, & Coleman, 2009). One of the underlying concepts of a successful care transition is self-management. However, it is known that all patients do not respond to self-management interventions in the same way. In addition, due to the complexity of care for these multimorbid patients, self-management at home is challenging. Self-management requires a patient engaged or activated in their own care. Patient activation, an individual's knowledge, skill and confidence to adopt positive health behaviors (Hibbard, Stockard, Mahoney, & Tusler, 2004; Hibbard et al., 2005; Hibbard, Mahoney, Stockard, & Tusler, 2005), has been evaluated as an important factor contributing to positive health outcomes and treatment compliance (Alegria et al., 2008; Cunningham, Hibbard, & Gibbons, 2011; Mitchell et al., 2013). However little is known about characteristics of patients with differing patient activation levels. Identifying characteristics predictive of patient activation will help determine what type of patient may benefit from strategies to improve self-management as well as suggest the type of educational support and mentoring needed during hospitalization and post-hospital transition time to improve patient
outcomes such as rehospitalization and ED visits. Therefore, the overall purpose of this study is to examine the relationship between patient activation and health care utilization (rehospitalization and ED visits) and to identify determinants that predict patient activation in patients with multimorbidity that can be used to tailor self-management strategies for patients being discharged from the hospital.

**Chronic disease, self-management and patient activation.**

Nearly half of Americans have at least one chronic disease and 70% of deaths annually are caused by a chronic disease (Centers for Disease Control and Prevention, 2014). Approximately 26% of adults have ≥ 2 chronic conditions and 11.7% have 3 or more chronic conditions (Ward, Schiller, & Goodman, 2014). As people age, multiple chronic illnesses increase and disease burden increases; in addition, there are psychosocial barriers to self-management (Bayliss, Ellis, & Steiner, 2007). Multiple chronic illnesses increase the risk of poor outcomes such as mortality and decreased physical functioning, in addition to increased hospitalization and ED visits (Centers for Medicare and Medicaid Services, 2014). Reimbursement changes stimulated by the Patient Protection and Affordable Care Act (2010) have encouraged hospitals to improve discharge plans in an attempt to decrease readmissions. Promoting self-management is a strategy used to prevent acute exacerbations of chronic illnesses to decrease hospitalizations and rehospitalizations. Patient activation is an integral part of self-management. Hibbard et al (2004) describe the activated patient as one who manages their condition and has the skill to collaborate with health care providers, maintain health function and get access to appropriate quality care.

People who are more activated are more likely to have the knowledge, skill, and confidence to make better decisions about behaviors (Mosen et al., 2007; Hibbard, Mahoney, Stock, & Tusler, 2007). Researchers have identified that as activation increases there is an
increase in positive self-management behaviors (Hibbard et al., 2007; Fowles et al., 2009; Harvey, Fowles, Xi, & Terry, 2012; Hibbard, Greene, & Tusler, 2009; Greene & Hibbard, 2012). Studies have demonstrated that individuals with higher activation scores engage in more preventative behavior such as check-ups, screenings, and immunizations compared to lower activated individuals (Greene & Hibbard, 2012; Hibbard et al., 2005; Hibbard & Greene, 2013). Higher activation levels have been associated with self-management of chronic diseases including diabetes care (Mosen et al., 2007; Rask et al., 2009), heart disease (Shively et al., 2013), and multiple sclerosis (Stepleman et al., 2010).

Activation is a skill that can be taught (Alegria et al., 2008) and is responsive to change over time (Remmers et al., 2009). Improvements in activation levels have been related to positive behavior changes (Harvey et al., 2012; Hibbard et al., 2007). In a chronic disease longitudinal study (Rijken, Heijmans, Jansen, & Rademakers, 2014), results suggest that activation does not stay stable over time but that patients can improve or relapse. Remmers et al., (2009) found that activation can also be predictive of future health outcomes. The ability to change activation levels and behaviors has great potential to improve patient outcomes such as readmission, satisfaction and quality of life through interventions designed to improve patient activation.

Activation and hospital admission

Hospitalization and early post discharge are extremely vulnerable times for patients, especially those with multimorbidity. Readmission to the hospital is very common in this patient population. There is an association between self-care management, confidence and readmissions (Sahebi, A., Mohammad-Aliha, J., Ansari-Ramandi, M., & Naderi, N., 2015). Researchers have documented (Begum, Donald, Ozolins, & Dower, 2011; Kinney, Lemon, Person, Pagoto, & Saczynski, 2015; Mitchell et al., 2013) patients with lower activation scores are at greater risk for hospital admission or readmission compared to those with higher activation scores. A recent systematic review of 10 publications (Kinney et al., 2015) reported that patients with chronic
illnesses in lower stages of patient activation are at increased risk for readmission. Mitchell et al. (2013) found in a large secondary analysis that those with the lowest level of activation had nearly twice the risk of 30-day readmissions compared to the highest activated patients. In addition, after analyzing data from an annual survey of the diabetic population, another researcher suggests that the lowest level activation patients have more hospitalizations and ED visits over a 12-month period (Begum et al., 2011). A sample of over 25,000 patients from a large health care system including 35 clinics showed higher activated patients were less likely to use the ED or be hospitalized (Greene & Hibbard, 2012).

**Determinants predicting patient activation**

There is a growing body of literature that suggests that patients who are activated have better outcomes, however there is a paucity of literature that identifies determinants of the activated patient. One large cross-sectional survey (Bos-Touwen et al., 2015) identified 9 determinants that predict activation for self-management in chronic disease populations: age, body mass index, educational level, financial distress, physical health status, depression, illness perception, social support and underlying disease. However the patient population in the Bos-Touwen et al. (2015) study included individuals with four specific chronic diseases from a primary care or secondary care setting, not in the acute care setting of the hospital. In addition health literacy and cognition were not included in the model evaluated by Bos-Touwen et al. (2015), whereas this current study included health literacy and cognition and any chronic disease reported by patients. Health literacy and cognition may be important predictors of patient activation. Researchers have found associations between health literacy and patient activation (Smith, Curtis, Wardle, von Wagner, & Wolf, 2013; Woodard, Landrum, Amskoper, Ramsey, & Naik, 2014). Cognitive impairments have been reported frequently in chronic disease populations such as heart failure (Pressler et al., 2010), chronic obstructive pulmonary disease (Villeneuve et al., 2010). A relationship between cognition and impaired medication self-management has been reported (Hain, Tappen, Diaz, & Ouslander, 2012). Another study from a multiple sclerosis
center (Goodworth et al., 2014) found educational attainment, depression and self-efficacy significantly related to patient activation using hierarchical regression.

The post hospitalization care transition is a very vulnerable time. Hospitalized patients have had an acute exacerbation of a chronic illness or have been diagnosed with a new condition. Self-management challenges may be different due to the acuteness of symptoms and complex new treatment plans for their multimorbid conditions. Understanding factors that predict patient activation will facilitate planning of interventions to assist patients to actively self-manage their multimorbid conditions.

**Purpose**

Therefore, the purpose of this study is threefold:

1. To examine the relationship between patient activation and health care utilization (30-day rehospitalization and ED visits) in multimorbid patients discharged from the hospital.
2. To examine the relationship between demographic determinants (age, gender, educational level, race, and income), clinical determinants (cognition, physical functioning, sleep disturbance, severity of illness, number of comorbidities, and pain), and psychosocial determinants (health literacy, presence of a caregiver, depression, anxiety, fatigue, sleep disturbance, satisfaction with the social role, perception of health status, quality of life and assessment of chronic illness care) and patient activation in the multimorbid hospitalized patient.
3. To determine what unique contributions of selected demographic, clinical, and psychosocial determinants considered in combination predict patient activation in multimorbid patients that can be used to tailor strategies for patients being discharged from the hospital.

**Methods**
**Design, Sample, Setting, Procedures.** This descriptive, predictive study used a cross-sectional correlational research design. The study was approved by both the university and hospital institution review boards. Subjects were patients in a Midwestern 264-bed hospital. They were a) age 19 years or older; b) able to hear, speak, and read English; c) had 3 chronic diseases and were d) discharged to home. Patients were excluded if they had a terminal illness and were receiving hospice care or were placed in a nursing home or other facility. All adult patients admitted to the hospital were screened for inclusion. Patients were contacted after they were medically stable and prior to anticipated discharge. All data collection instruments were completed between admission and discharge from the acute care hospitalization except for the one month follow up data collection.

Our target sample size was 200 to accommodate 10% missing data. This sample size was required for a two-tailed test of a correlation coefficient to have power ≥ .80 (using α = .05) with the population correlation no smaller than r = .2. This sample size gave adequate power for a two-tailed t-test if the group means differed by .4 standard deviations (for groups of equal size) to .7 standard deviations (if 10% were in one group and 90% in the other). With this sample size a test of an individual partial regression coefficient in a multiple regression analysis would have power of .80 for an effect size of $f^2 = .04$. This is equivalent to a predictor that uniquely explains approximately 4% of the variance in the outcome when the overall model explains 25-30%.

**Instruments.**

Demographic determinants (age, gender, educational level, race, and income), clinical determinants (cognition, physical functioning, sleep disturbance, severity of illness, number of comorbidities and pain), and psychosocial determinants (health literacy, presence of a caregiver, depression, anxiety, fatigue, sleep disturbance, satisfaction with the social role, perception of health status, quality of life and assessment of chronic illness care) were obtained from validated self-report instruments described below or the electronic medical record.
**Cognition.** The Montreal Cognitive Assessment (MoCA) (Nasreddine, 2015) evaluated cognition status. The 10-minute 30-point MoCA includes the cognitive domains of attention, immediate and delayed memory, visual-spatial skills, language, and executive function (Coen, Cahill, & Lawlor, 2011). Higher scores indicate higher levels of cognitive function. One point is added to scores for those individuals with ≤ 12 years of education. Patients in this study who were blind or unable to draw with their dominant writing hand completed the MoCA blind version. The maximum score on the MoCA blind is 22 compared to 30 on the standard version. For standardization, the MoCA blind score was converted to the 30-point scale (Nasreddine, 2015). For example, if the score on the MoCA blind was 19, the equation utilized for conversion was \((19 \div 22) \times 30\). In relation to validity, the MoCA has demonstrated excellent sensitivity for detecting amnesic mild cognitive impairment (MCI) (100%) and multiple-domain MCI, (83.3%) (McLennan, Mathias, Brennan, & Stewart, 2011); specificity rates were only 50% and 52% respectively. Prior literature has documented internal consistency from .79 (Toglia, Fitzgerald, O'Dell, Mastrogiovanni, & Lin, 2011) to .83 (Nasreddine et al., 2005) in chronic illness populations.

**Physical functioning, anxiety, depression, fatigue, sleep disturbances, satisfaction with social role and pain.** The Patient Reported Outcomes Measurement Information System (PROMIS)-29 was used to measure overall well-being. These questionnaires are a set of patient reported highly reliable, precise measures for physical, mental, and social well-being (Cella et al., 2010). The 8 subscales of the PROMIS-29 measure physical function, anxiety, depression, fatigue, sleep disturbances, satisfaction with social role, pain impact and pain intensity. The uniqueness of PROMIS lies in four key areas: a) comparability to other instruments, b) reliability and validity, c) flexibility, and d) inclusiveness. PROMIS encompasses all people, regardless of literacy, language, physical function or life course (Cella et al., 2010). In the heart failure population, the PROMIS subscales showed internal consistency with Cronbach’s alpha for
physical functioning (.84, .85), fatigue (.91, .77), satisfaction with social activities (.95, .92) and depression (.91, .92) at baseline and post-transplantation, respectively (Flynn et al., 2015).

Construct validity was supported by correlating the PROMIS and the Kansas City Cardiomyopathy Questionnaire physical functioning scale \((r = .68, .85)\) and social function scale \((r = .60, .74)\), the fatigue scale of the Medical Outcomes Study Short Form \((r = -.75, -.78)\) and the depression items from the Patient Health Questionnaire (PHQ-2) \((r = .65, .42)\) at baseline and post-transplantation, respectively. (Flynn et al., 2015). Cronbach’s alpha for the PROMIS-29 anxiety scale was .89 and the depression scale .93 with convergent reliability reported (Kroenke, Yu, Wu, Kean, & Monahan, 2014). In this study, Cronbach’s alpha for the PROMIS-29 subscales were: physical functioning (.88), anxiety (.86), depression, (.94), fatigue (.92), sleep disturbance (.81), social (.94), and pain (.92).

**Severity of illness.** The Charlson Comorbidity Index (CCI) is a weighted index designed to predict mortality from medical record data. Weights are assigned to medical conditions estimating one-year relative risk of death for that condition (Charlson, Pompei, Ales, & MacKenzie, 1987). The sum of the weights yields a total score which represents the burden of comorbidities and can range from 0 to 37. The CCI has been identified as a predictor of death in cardiovascular patients (Bhavnani et al., 2013), a measure of comorbidity in the ischemic stroke population (Goldstein, Samsa, Matchar, & Horner, 2004) and as a risk measure for all cause rehospitalization (Robin et al., 2013). Patients’ medical records were reviewed to obtain comorbidities.

**Health Literacy.** The Shortened-Test of Functional Health Literacy in Adults (S-TOFHLA) and the Single Item Literacy Screener (SILS) measured health literacy. The S-TOFHLA instrument is a 36-item timed test of reading comprehension (Baker, Williams, Parker, Gazmararian, & Nurss, 1999). Individuals are allowed 7 minutes to read and answer questions in actual health-related passages for preparations for a procedure and a Medicaid application. The passages use a
modified Cloze procedure where words are missing and individuals are asked to choose the correct word from a set of multiple choice responses (Baker et al., 1999). Internal consistency of the S-TOFHLA has been demonstrated (Cronbach’s alpha = .98) and construct validity was supported based on its correlation with the long version of the TOFHLA (r = .91) and the Rapid Estimate of Adult Literacy in Medicine (REALM) (r = .80) (Baker et al., 1999). The S-TOFHLA has been utilized in multiple chronic illness populations and emergency room settings (Baker et al., 1999; Al Sayah, Williams, & Johnson, 2013; Cordasco, Asch, Franco, & Mangione, 2009; Jeppesen, Coyle, & Miser, 2009).

The Single Item Literacy Screener is a single question intended to identify adults in need of help understanding printed health material (Morris, MacLean, Chew, & Littenberg, 2006). The SILS asks, "How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?" Patients respond: 1 - Never, 2 - Rarely, 3 - Sometimes, 4 - Often, or 5 - Always. For this study, we wanted to capture all who indicated they typically needed help with written material. Responses were categorized into 1 = "never", 2 = "rarely" or 3 = "sometimes, often, or always" needing help in understanding written health information. The sensitivity of the SILS compared to the S-TOFHLA in detecting limited reading ability was 54% and the specificity was 83% (Morris et al., 2006). Construct validity had been documented in the rheumatoid arthritis population with the REALM (r = .34) and S-TOFHLA (r = .36) (Quinzanos, Hirsh, Bright, & Caplan, 2015).

**Quality of life and perception of health status.** The EQ-5D developed by the Euro-Qol Group (1990) was used to evaluate quality of life. It is a standardized non-disease specific self-report instrument measuring health related quality of life. It includes five levels of severity (no problems, slight problems, moderate problems, severe problems, and extreme problems) in five dimensions (mobility, self-care, usual activities, pain/discomfort, and anxiety/depression). An overall utility index is calculated on these domains. A crosswalk linked to the 3-level version
provided by the developers was used for scoring the EQ-5D index (EuroQol Group, 1990). In addition, respondents use a visual analogue scale (0 = worst possible health to 100 = best possible health) to rate their current health. This current study identifies the 0-100 health rating scale as the perception of health status. Its construct validity was supported by comparing patients in remission to those with active disease (p<.0001) in the inflammatory bowel disease populations (Stark, Reitmeir, Leidl, & König, 2010). The ED-5D had construct validity supported by correlations with the short form-8 (r = .53) and the EQ-5D VAS (r = .80) in the cardiac population (Ellis, Eagle, Kline-Rogers, & Erickson, 2005). In the acute coronary syndrome population, there were significant correlations between the EQ-5D and the SF-36 (r = .21-.74) for corresponding subscales (Schweikert, Hahmann, & Leidl, 2006).

**Assessment of chronic illness care.** The patient assessment of chronic illness care (PACIC) was developed to evaluate patients’ perspective of the care they receive from providers for their chronic diseases (Glasgow et al., 2005). The PACIC evaluates the receipt of patient-centered care and self-management behaviors in alignment with the Chronic Care Model (Wagner et al., 2001; Wagner et al., 2005), a widely accepted framework for providing care to chronically ill individuals. Developers report the PACIC to be a practical, reliable (Cronbach alpha .93, test – retest r = .58) instrument with face, construct and concurrent validity (Glasgow et al., 2005). The PACIC is a self-reported instrument that has 5 subscales: patient activation, delivery system design/decision support, goal setting, problem solving, and follow-up care. Responses to the PACIC range from 1 (none of the time) to 5 (always). The PACIC is scored as the mean of all items. Subscales of the PACIC can also be calculated, however due to disagreement on factor structure in the literature, a one-factor structure was used for this study as recommended by Aung et al., (2014). Consistent with the research of the developers of the PACIC (Glasgow et al., 2005) inter-correlations among the subscales in our study was strong (r = .55-.87), therefore it was determined to utilize the PACIC total score. Due to the focus of this study on determinants predicting patient activation, the PACIC-patient activation subscale (PACIC-PA) was evaluated.
There was weak correlation (r = .23) with the patient activation measure (PAM) score, hence a decision was made to leave the PACIC-PA subscale in the entire scoring of the PACIC to evaluate assessment of chronic illness care. Cronbach’s alpha for this study was .94.

**Patient Activation.** The patient activation measure (PAM) is a 13 item 5-point Likert response scale that measures self-reported knowledge, skill and confidence for self-management of health or a chronic condition (Hibbard et al., 2004; Hibbard et al., 2005). The raw scores are summed and transformed to a 0-100 metric (0 = lowest activation level, 100 = highest). Predetermined cut points are provided by the developers on a PAM-13 scoring spreadsheet that converts an individual’s item responses to both the continuous score and to a developmental level. This spread sheet was provided upon licensing of the PAM (Health Insignia Health, 2014). Level 1 patients may not yet believe that the patient role is important, Level 2 patients lack confidence and knowledge to take action, Level 3 patients are beginning to take action, and Level 4 patients have difficulty maintaining behaviors over time (Hibbard et al., 2004, Hibbard et al., 2005).

Reliability and validity of the PAM-short form has been reported. In the multiple sclerosis population, Cronbach’s alpha was .88 (Stepleman et al., 2010). Construct validity was established with significant correlations between PAM and the Beck Depression Index-II (r = -.43, p<.01) and the Multiple Sclerosis Quality of Life (r = .42, p<.01) (Stepleman et al., 2010). High internal consistency, Cronbach’s alpha of .87, and construct validity with health related behaviors, functional status and health care quality was reported in the multimorbid population (Skolasky et al., 2011). Cronbach’s alpha for this study was .89.

**Health care utilization.** Patients were called one month following discharge for health care utilization (rehospitalization and ED visit) information. Patients were asked if they had been readmitted or visited the ED in the last 30 days. In addition, patients were asked how many times they were readmitted or visited the ED for health care. Hospitals identified by patients as a place they received health services were sent signed consent forms and asked to validate
rehospitalization and ED visits. The admitting Midwestern hospital validated all rehospitalizations and ED visits to their facility for patients in the study. Six of the seven other hospitals validated rehospitalizations or ED visits for study participants. Only one patient’s rehospitalization was not validated through hospital medical records due to the patient not signing an additional release of medical information for this validation.

Data Analysis

Statistical analysis was performed using IBM SPSS 22 for Windows. Descriptive statistics (frequencies, frequency distributions, percentages, range, mean, and standard deviation) were used to describe all variables and the sample characteristics. An alpha of .05 was used to determine statistical significance. Pearson or Spearman correlation were used to examine the correlation among continuous variables and the PAM. An independent t-test was used for dichotomous categorical variables. For other categorical independent variables, analysis of variance (ANOVA) was utilized with Bonferroni adjustment used for post hoc comparison.

Standard multiple regression was utilized to predict activation. Determinants whose zero-order relationship with the PAM had a probability ≤ .25 were included in the regression model. This liberal level was chosen to ensure important variables were not overlooked. The exception was the EQ-5D. Upon inspection of the data it was found that the confidence limits of its regression coefficients were extreme. It was hypothesized that the EQ-5D measured many of the same concepts as the PROMIS-29 tools, therefore, it was decided to remove the EQ-5D from the model.

Because few patients reported multiple rehospitalization and ED visits, these variables were each dichotomized as occurring or not. An independent t-test was used to determine relationship between patient activation and rehospitalization and ED visits within 30 days of hospitalization.
Results

The sample consisted of 200 patients with a mean age of 63.7 years (SD = 14.2) with a range from 21-92. Most identified themselves as white (n = 188, 94%), however there were African American (n = 4, 2%). American Indian or Alaskan Native (n = 4, 2%), Hispanic ethnicity (n = 3, 1.5%) and one Asian (.5%). The majority were female (n = 117, 58.5%). In regards to activation, the mean PAM score was 60.3 (SD = 14.6) and the distribution of the PAM activation levels were: level 1 activation (n = 40, 20%), level 2 activation (n = 39, 19.5%), level 3 (n = 52, 26%), and level 4 (n = 69, 34.5%). Six of the patients did not complete the one month follow-up phone call to determine readmission and ED visit information and were not included in that analysis. See Table 1 for characteristics of the sample.

Specific Aim 1. To determine the relationship of 30-day rehospitalization and ED visits and patient activation.

Data were collected on 194 patients at one month post hospital discharge. Twelve patients (6.2%) were readmitted to the hospital within 30 days post discharge, of those, one was readmitted twice. Seventeen patients (8.8%) were seen in the ED for health care services within 30 days of discharge from the hospital, and of those, 4 patients visited the ED twice.

T-tests showed significantly lower patient activation scores \[ t(192) = 2.044, p = .042 \] for patients who were re-hospitalized \( M = 52.30, SD = 14.54 \) compared to those who were not re-hospitalized \( M = 61.11, SD = 14.48 \). In addition, there were significantly lower PAM scores \[ t(192) = 2.021, p = .045 \] for patients who visited the ED \( M = 53.79, SD = 14.31 \) compared to patients who did not visit the ED \( M = 61.21, SD = 14.46 \).

Specific Aim 2. To examine the relationship between demographic, clinical and psychosocial determinants and patient activation.
Demographic determinants that showed significant relationships with the PAM were education and income; clinical determinants were physical functioning, sleep disturbance, and pain; psychosocial determinants were health literacy measures with the single item literacy screener, depression, anxiety, fatigue, satisfaction with social role, perception of health status and assessment of chronic illness care. Table 2 exhibits the correlations between the PAM scores and determinants.

Specific Aim 3. To determine what unique contributions of selected demographic, clinical, and psychosocial determinants considered in combination predict patient activation.

Table 3 exhibits the descriptive information related to the determinants included in the model. When determinants with a significance level of \( p \leq .25 \) were included in the standard regression model, 26% of the variance \( [R^2 = .26, \text{adj } R^2 = 0.20, F (13, 167) = 4.42, p < .001] \) was explained. Variables that had significant unique contributions to prediction of patient activation were the psychosocial determinants satisfaction with social role \( (\beta = .23, p = .014) \), assessment of chronic illness care \( (\beta = .24, p = .001) \) and health literacy measured with the single item literacy screening question \( (\beta = .18, p = .013) \). Higher levels of each of these psychosocial variables was associated with higher activation. Neither depression nor anxiety was significant, but since they were highly correlated \( (r = .65) \), additional models were evaluated. When anxiety was deleted, the overall model remained statistically significant, \( [R^2 = .24, \text{adj } R^2 = 0.19, F (12, 169) = 4.481, p < .001] \) and depression predicted significant variability in patient activation. Higher depression was associated with lower patient activation \( (\beta = -.19, p = .025) \). None of the other \( \beta \) coefficients changed more than .02. Similarly, when depression was deleted, the overall model remained statistically significant \( [R^2 = .25, \text{adj } R^2 = 0.20, F (12, 168) = 4.72, p < .001] \) and anxiety was a significant predictor. Higher anxiety was associated with lower patient activation \( (\beta = -.20, p = .015) \). None of the other coefficients changed more than .02. Table 3 presents the coefficients of the full model. Several other pairs of determinants were correlated at .4 or above. In
supplemental analyses, one member of each pair was excluded from the model; no statistically significant relationships changed.

Backwards regression was used to reduce the model. The same determinants were included as in the standard multiple regression. Reducing the model did not substantially change the variance \( R^2 = .24, \text{adj } R^2 = .22, F(5, 174) = 11.02, p < .001 \). Determinants remaining in the model and most associated with patient activation were health literacy (\( \beta = -.19, p = .006 \)), social satisfaction with social role (\( \beta = .24, p < .001 \)), assessment of chronic illness care (\( \beta = .20, p = .004 \)), and anxiety (\( \beta = -.18, p = .012 \)). Education also remained in the model but was not statistically significant (\( \beta = .12, p = .074 \)).

**Discussion**

Preventing readmissions is a high priority goal for hospitals due to governmental reimbursement changes and increasing cost of health care. Hospitals continue to attempt to balance improving patient outcomes with controlling cost. Consistent with other researchers (Begum et al., 2011; Kinney et al., 2015; Mitchell et al., 2013), results from our study suggest that those patients with lower mean patient activation scores were readmitted and visited the ED more frequently than those with higher mean activation scores. These findings emphasize the need to know patient activation scores of patients. Frequently researchers suggest targeting and tailoring discharge plans based on patient activation. However, the literature has not identified what to target and tailor. Our study provides insight in to areas of focus for providers and care transition coordinators. The important predictors from our study were psychosocial determinants. Future studies could focus on psychosocial aspects of self-management including coping with chronic disease, motivation or even personality traits such as optimism or impatience. Strategically tailoring interventions and allocating resources to the lowest activated patient as categorized by using the PAM may decrease rehospitalization and ED visits and thus decrease cost.
Our study results suggest that patients who were more satisfied with their social role and activities had higher activation scores. The items on the PROMIS-29 associated with satisfaction with social role are related to patients’ satisfaction with how much work they can do, their ability to work, their ability to do regular responsibilities and their ability to perform daily routines. It is very understandable that if patients are unable to perform their usual duties there is a great chance they will not be able to self-manage complex treatment plans for their multimorbid conditions. Identifying individual abilities and expectations of roles will assist in planning realistic interventions to increase patient activation and thus increase self-management of their chronic illnesses. Discharge planners may consider mobilizing resources to assist patients in performing daily responsibilities in addition to health care needs.

Consistent with research on elderly with complex medical needs (Gerber et al., 2011), there was an association of the assessment of chronic illness care score measured with the PACIC and the PAM score. Patients who scored the highest on the assessment of chronic illness care received were more highly activated. The PACIC instrument measures an overall evaluation of patient-centered care received from the health care providers. This key finding stresses the importance of health care provider and patient relationship to improve activation and self-management. Studies have found that physician and patient relationships focusing on patient-centered care lead to positive outcomes (Ledford, & Childress, 2013; Greene, Hibbard, Sacks, & Overton, 2013). Other researchers report the patient-physician role is associated with patient activation and self-management (Alexander, Hearld, Mittler, & Harvey, 2012; Wong, Peterson, & Black, 2011). Future studies to understand the link between patient-centered care and patient activation will enhance health care providers understanding ways to improve patients’ self-management skills.

Findings from our study suggest that health literacy is an important determinant of patient activation. Other researchers have found associations between health literacy and patient
activation (Woodard et al. 2014; Gerber et al., 2011; Rademakers, Nijman, Brabers, de Jong, & Hendriks, 2013; Rademakers, Nijman, Brabers, de Jong, & Hendriks, 2014; Smith, Curtis, Wardle, von Wagner, & Wolf, 2013). Patients with higher literacy levels tend to be activated at a higher level (Smith et al., 2013). Though very important, health literacy is not routinely evaluated in every hospitalized patient or physician’s office. Our study found lower activation correlated with lower health literacy. Impaired literacy may not be obvious to health care providers in daily conversation, therefore it is important to evaluate. Health care providers’ awareness of literacy may prompt a different type of discharge education that enhances patient understanding of health-related material which in turn will enhance self-management of their chronic disease. For example, future research studies are needed to establish best practices to improve comprehension of health care material. Different strategies such as using pictures, visual cues and easy-to-read materials may assist in improving comprehension of health care material.

Our findings suggest anxiety and depression are both important determinants to be aware of; neither was predictive in the full regression model but each was significant when the other was removed from the model. Other researchers have identified depression as an important factor to consider related to patient activation (Hibbard et al., 2007; Chen, Mortensen, & Bloodworth, 2014; Magnezi, Glasser, Shalev, Sheiber, & Reuveni, 2014; Sacks, Greene, Hibbard, & Overton, 2014; Goodworth et al., 2014). Allocating appropriate resources early in the discharge process to anxiety and depression may improve patient activation and patient outcomes.

Other important determinants showed significant relationship with patient activation but were not predictive of activation when evaluated in combination with other variables. Nevertheless, they should not be overlooked. Educational level obtained was near statistical significance in the backward regression model. Another research group, Bos-Touwen et al (2015) found educational level predicted activation for self-management in a large of chronic disease individuals. That study had more power due to a larger sample size, in addition education level
was measured differently due to cultural differences. Awareness of level of education is an easily obtainable demographic characteristic and it is very important for health care providers to tailor self-management strategies appropriately.

Though Bos-Touwen et al. (2015) found predictors of patient activation to be age, body mass index, educational level, financial distress, physical health status, depression, illness perception, social support and underlying disease in the primary or secondary care setting, our study in the hospitalized patient did not support all of these predictive findings. However, our study did indicate significant zero-order correlations between activation and educational level, income, physical functioning, depression and perception of health status. Further study of these determinants is warranted. Additional research focusing on specific chronic disease populations in the hospital setting is needed to further guide care transitions. Perhaps targeting subgroups of patients such as the lowest activated or those with particular profiles may be a cost effective strategy in care transition planning.

Limitations for this study are its cross-sectional correlational design, the fact that all data were collected from one hospital, and the relative homogeneity of race/ethnicity. In addition, most instruments were self-report, so scores could be biased by social desirability. However, this study was seeking patient reported outcomes and patient’s perception of their care.

In conclusion, this study enhances the understanding of determinants of patient activation in the hospitalized patient with multimorbidity. Knowing these determinants of patient activation may be important clinically during hospitalization to prevent readmission and other untoward outcomes. Realizing that psychosocial variables are determinants of patient activation can assist in tailoring and targeting care transition discharge plans in the hospitalized patient with multimorbidity. These study results identify literacy, satisfaction with social roles and assessment of chronic illness care received from their providers as priority areas to focus
interventions. Care transition programs that focus on these determinants as well as others such as anxiety and depression may increase patient activation in the hospitalized multimorbid patient and improve patient outcomes such as decreasing health care utilization. Findings from this study enhance our understanding of factors that relate to patient activation and are useful to guide needed changes in discharge planning for self-management.


McLennan, S. N., Mathias, J. L., Brennan, L. C., & Stewart, S. (2011). Validity of the montreal cognitive assessment (MoCA) as a screening test for mild cognitive impairment (MCI) in a
doi:10.1177/0891988710390813


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\(^a\) Three chronic diseases minimum for inclusion in study
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<th>$p$</th>
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<td>.002*</td>
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<tr>
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<td>&lt;.001*</td>
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<td>.003*</td>
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<td>Assessment of chronic illness care</td>
<td>188</td>
<td>.27</td>
<td>&lt;.001*</td>
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* Significant at .05 level.
Table 3.
Descriptives and coefficients included in the multiple regression model

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<td>Full model with all determinants with p ≤ .25 included</td>
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<td>PAM score</td>
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<td>33.5-100</td>
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<td>-.06</td>
<td>-.67</td>
<td>.501</td>
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<td>Sleep</td>
<td>54.1(8.1)</td>
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<td>.08</td>
<td>.15</td>
<td>.04</td>
<td>.51</td>
<td>.610</td>
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<td>Pain</td>
<td>60.8 (9.7)</td>
<td>41.6-75.6</td>
<td>-.06</td>
<td>.12</td>
<td>-.04</td>
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<td>1.31</td>
<td>-.18</td>
<td>-2.5</td>
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<td>(SILS)</td>
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<td>Depression</td>
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<td>Anxiety</td>
<td>56.2 (9.1)</td>
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<td>Fatigue</td>
<td>58.4 (9.6)</td>
<td>33.7-75.8</td>
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<td>.15</td>
<td>.06</td>
<td>.62</td>
<td>.539</td>
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<td>Satisfaction with social role</td>
<td>43.1(8.9)</td>
<td>29-64.1</td>
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<td>.15</td>
<td>.23</td>
<td>2.49</td>
<td>.014*</td>
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<td>Perception of health status</td>
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<td>.02</td>
<td>.06</td>
<td>.03</td>
<td>.41</td>
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</tbody>
</table>
Assessment of chronic illness care

[R² = .26, adj R²=20, F (13, 167) = 4.425, p <.001]

*Significant at .05 level.
Chapter 5: Manuscripts

Manuscript 3

Evaluation of patient activation interventions: A systematic review

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Transition care programs have been utilized to assist patients in the transition from hospital to home (Bixby & Naylor, 2009; Naylor & Sochalski, 2010). With limited resources and decreased length of stay, it is essential that nurses work with hospitalized patients to be more active in managing their own care. However, not all patients are willing or motivated to assume this responsibility. Evidence is building to support the use of the Patient Activation Measure as a tool to guide interventions to assist in implementing strategies to activate patients for self-management (Greene & Hibbard, 2012; Rask et al., 2009). Many descriptive studies have linked patient activation with positive health outcomes such as decreasing health care utilization, decreasing symptoms and improving quality of life; however, utilization of patient activation as a mediator to improve health outcomes in intervention studies has not been well described. There is a paucity of randomized controlled trials related to patient activation in the hospital setting (Kangovi et al., 2014; Linden & Butterworth, 2014). In addition, there is a gap in the literature identifying components of successful patient activation interventions. Knowing the important components of interventions that increase patient activation in other settings will inform care transition coordinators of important components to include in activating interventions in the care transition setting of hospital to home. However, we need a better understanding of what works in a variety of settings with sub-populations before we are ready to implement interventions or strategies as standards of practice in the acute care setting. This systematic review is based on studies in a variety of settings including hospital (2), primary care (3) and community settings (18) with hopes that this knowledge can be translated to the hospital setting to guide patient activation interventions. Therefore, the purpose of this systematic review was to synthesize literature regarding interventions to increase patient activation. This review also identified components of interventions that have been used to increase patient activation and that have shown an impact on relevant health outcomes to provide guidance for future intervention studies. Specific aims were to:
1. describe intervention studies that evaluated patient activation before and after an intervention;

2. describe the use of specific intervention components (especially noting any patterns of frequency in use of components); and

3. determine if there were intervention components that had significant effects on patient activation and patient centered outcomes.

**Method.**

**Selection criteria.**

Studies included in this systematic review were reports in English of randomized controlled trials in which a) randomization was by patient rather than site or nurse; b) patient activation was evaluated pre- and post-intervention either as a primary or secondary outcome with a specific measure of activation; and c) participants were adults 18 years or older. Editorials, conference abstracts, letters, presentations, quasi-experimental designs and case studies were excluded.

**Measures.**

**Patient activation measure (PAM).** For all but one of the studies, patient activation was measured with the patient activation measure (PAM) developed by Hibbard and colleagues (Hibbard, Stockard, Mahoney, & Tusler, 2004). The PAM is a validated measure of patient activation (Hibbard et al., 2004) and measures the degree to which a patient has the knowledge, skill and confidence to self-manage their chronic disease. The PAM-13 is a shortened version of the PAM-22 and was used by most of the studies (Deen et al., 2012; Druss et al., 2010; Goldberg et al., 2013; Gronning, Skomsvoll, Rannestad, & Steinsbekk, 2012; Hibbard, Mahoney, Stock, & Tusler, 2007; Hochhalter, Song, Rush, Sklar, & Stevens, 2010; Linden & Butterworth, 2014; Lorig et al., 2010; Maindal, Carlsen, Lauritzen, Sandbaek, & Simmons, 2014; Maranda, Deen,
Elshafey, Herrera, & Gold, 2014; McDermott et al., 2011; Parikh et al., 2012; Riippa, Linna, & Ronkko, 2014; Rygg, Rise, Gronning, & Steinsbekk, 2012; Shively et al., 2013; Solomon, Wagner, & Goes, 2012; Wolever et al., 2010; Young et al., 2012). Three researchers used the original 22-item PAM (Druss, Ji, Glick, & von Esenwein, 2014; Kangovi et al., 2014; Parthasarathy, Wendel, Haynes, Atwood, & Kuna, 2013). The PAM-13 and PAM-22 use a five-point ordinal response scale: strongly disagree (1), disagree (2), agree (3), and strongly agree (4). There is also a “not applicable” response. The raw scores are summed and transformed to a 0-100 metric (0 = lowest activation level, 100 = highest). High internal consistency, Cronbach’s alpha of .87, and construct validity with health related behaviors, functional status and health care quality have been reported (Skolasky, Mackenzie, Riley, & Wegener, 2009; Skolasky et al., 2011). In a multiple sclerosis population, Cronbach’s alpha has been reported at .88 (Stepleman et al., 2010).

Another researcher (Irvine et al., 2015) used a 10-item adapted scale of the PAM to reflect care for low back pain. Responses were on a 4-point scale and a mean score was computed. This scale showed good reliability (alpha = .79) (Irvine et al., 2015). A 9-item scale adapted form of the PAM was used in one study; (Lorig, Ritter, Villa, & Armas, 2009) psychometrics and scoring were not discussed. In addition, one study used 4 items of the PAM (Ludman et al., 2013). The psychometric properties of these 4 questions were not stated in the article. The authors used percent of responses that were “agree” and “strongly agree” to statements on the PAM and evaluated the result as a binary outcome (Ludman et al., 2013).

The patient activation scale (PAS) was used in one study (Alegria et al., 2014). It is described as a 9-item scale that assesses the patient’s level of activation to obtain relevant information, discuss treatment options, communicate with health care professionals and ask questions about treatment (Alegria et al., 2008; Alegria et al., 2014). Responses range from 1-10, “none of the time” to “all of the time.” A sample question is “I have discussed my treatment
options with my care provider” (Alegria et al., 2008). Values of .75 (Alegria et al., 2008) and .77 (Alegria et al., 2014) have been reported for Cronbach’s alpha.

Search Strategy.

Electronic searches of literature were performed between April 9, 2015 and April 11, 2015 by an experienced medical librarian in Google Scholar, MEDLINE, CINAHL, PsychINFO, EMBASE, ProQuest, Cochrane, Social Services Abstracts, Sociological Abstracts, PILOTS, ERIC, Scopus 1 and Scopus 2. A total of 2174 records were retrieved; after duplicates were removed, 1437 remained. Titles were reviewed on all 1437, abstracts were reviewed on 122 records, 56 full text documents were reviewed and 25 documents met specific inclusion criteria for this review. The search strategy combined terms for patient activation, randomization, patient activation measure, and PAM was limited to English language reports. Figure 1 depicts the flow chart of the search strategy.

Results

The 25 patient activation intervention studies included in this review are summarized in Table 1. Specific components highlighted in this table are: study design, sample size, setting and patient characteristics, intervention components, intervention dose and duration, interventionist and study outcomes. A descriptive analysis of this table is presented below.

Study design, sample size, setting and patient characteristics

All studies were randomized controlled trials and had from 2-4 groups or study arms. Sample sizes of the studies varied from 39 participants in a pilot study (Parthasarathy et al., 2013) to a larger intervention study with 647 patients (Alegria et al., 2014). Study subjects were recruited from: primary care and community health centers (n = 10, 40%), (Deen et al., 2012; Hibbard et al., 2007; Ludman et al., 2013; Maindal et al., 2014; Maranda et al., 2014;
Parthasarathy et al., 2013; Riippa et al., 2014; Rygg et al., 2012; Solomon et al., 2012; Young et al., 2012) specialty clinics, (n = 6, 24%) (Alegria et al., 2014; Druss et al., 2010; Druss et al., 2014; Goldberg et al., 2013; Hochhalter et al., 2010; Shively et al., 2013) or through community sources (e.g. newspapers, online, flyers, informational meeting) (n = 4, 16%) (Lorig et al., 2009; Lorig et al., 2010; Parikh et al., 2012; Wolever et al., 2010). Two studies recruited patients from an out-patient hospital data-base (Gronning et al., 2012; McDermott et al., 2011) and 2 other studies (Kangovi et al., 2014; Linden & Butterworth, 2014) enrolled patients while they were inpatients and followed them through care transition time period. One study followed employees of large companies and participants with low back pain who were recruited via in-house communication channels (Irvine et al., 2015).

The most common patient population (6, 24%) included was diabetics (Lorig et al., 2009; Lorig et al., 2010; Ludman et al., 2013; Maindal et al., 2014; Rygg et al., 2012; Wolever et al., 2010) followed by mental health conditions (5, 20%) (Alegria et al., 2014; Druss et al., 2010; Druss et al., 2014; Goldberg et al., 2013; Ludman et al., 2013). Other specific populations included the obese (Parikh et al., 2012), arthritis (Gronning et al., 2012), peripheral vascular disease (McDermott et al., 2011), obstructive sleep apnea (Parthasarathy et al., 2013), heart failure (Linden & Butterworth, 2014; Shively et al., 2013), chronic obstructive pulmonary disease (Linden & Butterworth, 2014) and asthma (Young et al., 2012). Still other authors chose from specific chronic conditions or combinations of specific chronic conditions (Hibbard et al., 2007; Riippa et al., 2014; Solomon et al., 2012). Other studies didn’t list a particular chronic disease population but recruited patients with any type of multiple chronic conditions. One was from a general medical unit in the hospital (Kangovi et al., 2014) and three were from primary care or internal medicine clinics (Deen et al., 2012; Hochhalter et al., 2010; Maranda et al., 2014).

**Intervention components**
For evaluation of the components of the interventions, strategies utilized were categorized into knowledge, self-management skills and confidence building, consistent with the Hibbard et al. (2004) definition of patient activation. Because descriptions and detail of intervention varied by study, it was challenging to discern specific intervention components. To be categorized into knowledge, terms such as education, training, demonstration, understanding, or cognitive were used in the description. Self-management skills in this review were identified using the 6 self-management skills described by Lorig and Holman (2003) which are problem solving, decision making, resource utilization, forming of a patient provider partnership, taking action and self-tailoring. The confidence category included terms from the intervention description such as self-efficacy, self-concept, confidence building, engagement, motivational, empowerment and encouragement. Refer to Table 2 for the components of each study included in this review.

Knowledge was used as a strategy to increase patient activation in all of the 25 studies. Of these studies, 18 (72%) showed patient activation was increased post-intervention. Format for the patient activating interventions varied, including in-person individual sessions (Deen et al., 2012; Maranda et al., 2014) (n = 2, 8%), in-person group sessions (Druss et al., 2010; Goldberg et al., 2013; Hibbard et al., 2007; Lorig et al., 2009; Rygg et al., 2012) (n = 5, 20%), combination individual and group (Gronning et al., 2012; Hochhalter et al., 2010; Maindal et al., 2014) (n = 3, 12%), audiotaped training sessions (Alegria et al., 2014) (n = 1, 4%), telephone (McDermott et al., 2011; Wolaver et al., 2010; Young et al., 2012) (n = 3, 12%), and on-line (Druss et al., 2014; Irvine et al., 2015; Lorig et al., 2009; Riippa et al., 2014; Solomon et al., 2012)(n = 5, 20%). Several researchers used a combination of strategies to operationalize the intervention (Deen et al., 2012; Kangovi et al., 2014; Linden & Butterworth, 2014; Ludman et al., 2013; Parthasarathy et al., 2013; Shively et al., 2013). One researcher evaluated differences in outcomes between group sessions compared to individual sessions (Parikh et al., 2012).
Every study used at least one form of self-management skill in their patient activating intervention. When breaking down the concepts important to self-management skills, self-tailoring (using self-management skills and knowledge and applying these to oneself) (Lorig & Holman, 2003) was used most commonly (n = 17, 68%) and patient activation increased in 16 of the 17 studies (94%). Enhancing the patient provider partnership was commonly used (n = 16, 64%) and 12 (75%) studies showed improved patient activation. Problem solving was used in 14 studies (56%) and patient activation was found to have improved in 11 (78%) of those studies. When decision making was included (n = 13, 52%), patient activation increased in 10 (77%) of the studies. Resource utilization was found in 13 (52%) studies and 11 (85%) studies improved in activation compared to the control group. The least used component was taking action (n = 10, 40%); when that strategy was used, 9 (90%) studies improved activation. Only 5 studies used all of the components of self-management skills (Druss et al., 2010; Goldberg et al., 2013; Hibbard et al., 2007; Lorig et al., 2009; Lorig et al., 2010). Interestingly, all 5 of those studies found patient activation to be improved post-intervention.

Shively et al. (2013) was the only study to tailor the intervention by activation level. In this study, patients received different dosage of interventions focusing on different concepts at each level of activation. For example, focus was on the importance of the self-management role in the lower level of activation while skills and behaviors under different situations was the focus for the patients at the higher level of activation. Linden and Butterworth (2014) reports their intervention was tailored by activation level, health literacy, severity of health condition and preference, however there was not a detailed explanation of the tailoring.

Confidence was used as part of the intervention in the majority of studies (n = 20, 80%). Of the studies using a confidence building strategies, 16 (80%) studies showed improvement in patient activation post-intervention. Confidence building strategies varied; motivation was a strategy that surfaced in several of the articles (Linden & Butterworth, 2014; Ludman et al., 2013;
Several of the researchers used adaptations of the Chronic Disease Self-Management Program (CDSMP) developed by Lorig et al. (1999). This intervention is multicomponent and includes knowledge, skill and confidence. Examples are: training in disease specific management, action planning, problem solving, modeling behaviors and communicating with providers. Nine studies (36%) in this review used the CDSMP model or adapted the CDSMP model to a population (Alegria et al., 2014; Druss et al., 2010; Goldberg et al., 2013; Hibbard et al., 2007; Kangovi et al., 2014; Lorig et al., 2009; Lorig et al., 2010; Maranda et al., 2014; Parthasarathy et al., 2013).

**Interventionist**

Nurses were used as the interventionist in 5 studies (n = 5, 20%) (Gronning et al., 2012; Linden & Butterworth, 2014; Ludman et al., 2013; Rygg et al., 2012; Shively et al., 2013). All but one study (Rygg et al., 2012) using a nurse as the interventionist showed improved patient activation compared to control group (80%). One study (Shively et al., 2013) was successful in improving activation with advanced practice nurses in the heart failure population by tailoring the intervention by patient activation level.

Several of the studies (Druss et al., 2010; Goldberg et al., 2013; Hibbard et al., 2007; Kangovi et al., 2014; Lorig et al., 2009; Lorig et al., 2010; Parthasarathy et al., 2013) identify peer specialists, mental health peers, or a community health worker as the interventionist (n = 7, 28%). These studies share the premise that individuals will listen and respect the opinion of someone “like them” or someone who has been in a similar situation as them. Of the seven studies that used a peer or community health worker, 86% were successful at improving patient
activation post-intervention. Another study (Alegria et al., 2014) used a care manager with training in self-management and patient activation, however the background of the care manager was not specified.

Patient activation improved post-intervention in both studies that used the multidisciplinary approach to provide the intervention (Maindal et al., 2014; Parikh et al., 2012). Different health care providers were used as the interventionist in other studies including a pharmacist (Young et al., 2012) and a mental health provider (Goldberg et al., 2013). One study used a social worker or a person with a psychology Master’s degree (Wolever et al., 2010). Other interventions (n = 4, 16%) were built on an online framework developed by experts in their field (Druss et al., 2014; Irvine et al., 2015; Riippa et al., 2014; Solomon et al., 2012).

**Intervention dose and duration**

The length of time to complete the intervention varied from minutes in a waiting room up to a comprehensive intervention lasting 12 months. Neither of the brief interventions that lasted 15-20 minutes showed an increase in patient activation compared to the control group (Deen et al., 2012; Maranda et al., 2014). Seven studies (28%) were categorized as low to medium duration (2 to 6 weeks). Six of those studies (86%) had an increase in patient activation post-intervention compared to the control group. In the medium to long duration group (8 weeks-13 weeks), 7 (78%) of the 9 studies showed improved patient activation in the intervention group post-intervention. In the long duration intervention group (6-12 months), 5 of 7 studies (72%) indicated that patient activation improved in the intervention group.

**Outcomes**

Most of the interventions in studies n = 18 (72%) were successful in increasing patient activation post-intervention compared to control groups. However, 7 of the 25 studies (28%) did not show an improvement in patient activation compared to the control group after intervention.
(Deen et al., 2012; Druss et al., 2014; Hochhalter et al., 2010; Maranda et al., 2014; Parthasarathy et al., 2013; Riippa et al., 2014; Rygg et al., 2012). Of those, two were 15 minute interventions, (Deen et al., 2012; Maranda et al., 2014) and in a third study patients had limited contact with the interventionist, receiving only a 2 hour workshop with 2 follow-up phone calls (Hochhalter et al., 2010). Two studies showed an increase in patient activation, however the control group increased as well (Deen et al., 2012; Maranda et al., 2014). Deen et al. (2012) report that the lowest level of patient activation (level 1 and level 2) did show significant improvements in patient activation (Deen et al., 2012). Two studies were evaluations of initiating a patient portal (Druss et al., 2014; Riippa et al., 2014). No commonalities were found with the other two studies (Parthasarathy et al., 2013; Rygg et al., 2012) in which patient activation did not increase.

Several studies evaluated the intervention for sustainability of improved patient activation over time and these studies showed with varying results. Four studies showed sustained effect of the intervention on patient activation at 4 months (Irvine et al., 2015), 12 months (Lorig et al., 2009), 18 months (Lorig et al., 2010) and 3 years (Maindal et al., 2014). In contrast, 2 studies (Goldberg et al., 2013; Hibbard et al., 2007) showed an increase in patient activation post-intervention, but at later evaluation (6 months and 2 months, respectively) the statistical significance had disappeared. Another study (Gronning, Rannestad, Skomsvoll, Rygg, & Steinsbekk, 2014) evaluated long term effects of the intervention at 12 months, and it revealed sustained improvements in patient activation only in females, not males.

**Other study outcomes**

For many of the studies, other outcomes expected to be associated with activation also were evaluated. For example, self-management improved, however there was not a difference between control group on engagement or retention in care, as measured by attending mental health provider visits (Alegria et al., 2014). Three studies reported no significant differences in
physical activity compared to the control group (Druss et al., 2014; Goldberg et al., 2013; Lorig et al., 2010). There were no significant improvements in medication adherence in 4 studies (Druss et al., 2010; Goldberg et al., 2013; Kangovi et al., 2014; Parikh et al., 2012) and confidence with respect to medication knowledge was not improved in one study (Ludman et al., 2013). Two studies found that self-reported health did not improve, (Kangovi et al., 2014; Hochhalter et al., 2010) and one study found that report of unhealthy days also did not improve (Hochhalter et al., 2010). Asthma control did not improve after a pharmacist telephone intervention (Young et al., 2012) even though patient activation improved.

In relation to hospital readmission, two studies (Kangovi et al., 2014; Linden & Butterworth, 2014) report no differences in readmissions despite increasing patient activation compared to the control group. However, one study (Shively et al., 2013) reports fewer readmissions in the intervention group when a 6-month intervention tailored to patient activation level was performed. In a community health center with patients with serious mental illnesses and a comorbid condition, many preventative measures were improved, however there were no improvements in inpatient, outpatient or emergency department visits (Druss et al., 2014). There were 3 diabetic studies with varying results. In one study (Lorig et al., 2009) patient activation improved, but the primary outcome, HbA1C, did not improve; however the intervention group did have fewer hypoglycemic events and less depression than control (Lorig et al., 2009). Similar results were found in another study where patient activation, HbA1C, and self-efficacy improved (Lorig et al., 2010), but health indicators of exercise and number of physician visits did not improve. And in the third diabetic study, neither the HbA1C nor the patient activation level improved (Rygg et al., 2012).

Discussion
The purpose of this systematic review was to synthesize literature regarding interventions and to identify components of interventions that have been used to increase patient activation and impact relevant health outcomes to provide guidance for future intervention studies. Our results indicate that the majority of interventions in studies were successful in improving patient activation. Patient activation was increased most frequently when the intervention was 2-6 weeks long. However, interventions lasting from 8-13 weeks were also successful 77.8% of the time. Short interventions lasting only 15-20 minutes did not show positive effects on changing patient activation compared to a control group. These results suggest that providing only minutes of time with the interventionist may not be enough to improve activation. Interventions that are of long duration (6-12 months) may not have a greater impact than interventions ranging from 2-13 weeks.

The concept behind improving patient activation is that self-management behavior and patient health outcomes will improve. Interesting, this review identifies that is not always the case. For example two studies with multicomponent interventions (Druss et al., 2010; Goldberg et al., 2013) found while patient activation increased, other important outcomes (e.g., physical activity and medication adherence) did not show statistical improvements compared to the control group. Other studies also found a variety of outcomes that did not show statistical significance compared to the control group (Kangovi et al., 2014; Lorig et al., 2009; Lorig et al., 2010; Maindal et al., 2014; Young et al., 2012). Further research in specific patient populations is needed to evaluate why interventions designed to improve patient activation may or may not impact health care outcomes.

When all of the components of self-management skill were included in the intervention studies, patient activation was increased. This suggests that possibly the combined effect of including all of the self-management skill core components in interventions may improve patient activation. However, we don’t know if one or two components were more important than the
others. One study (Goldberg et al., 2013) reports post-intervention improvement in physical and emotional functioning outcomes, attitudinal outcomes including self-efficacy, and self-management behaviors when all components of self-management in addition to knowledge and confidence were used. Diabetic outcomes (HbA1C, self-efficacy) improved in 2 studies (Lorig et al., 2009; Lorig et al., 2010) that used all the components of self-management.

Improving patient activation may be a very important strategy in delivering self-management interventions but whether patient activation actually mediates the intervention’s effect on outcomes may be a more important unanswered question. Future studies should evaluate what dose of a patient activating intervention is needed to improve patient outcomes. There were not many studies that actually tailored interventions on level of patient activation so it was not very clear how patient activation was proposed to improve outcomes. Much work is needed to elucidate how patient activation should be utilized in the design of interventions in order to improve outcomes, especially if researchers claim that it is the underlying mechanism by which their intervention will work.

Studies showed that patients in the lowest level of activation improved the most (Alegria et al., 2014; Deen et al., 2012). It may be cost effective to focus more time and resources on the lower activated patients. Further research is needed to determine the most efficient and cost effective components of an intervention for the lowest activated patients. For example, highly activated patients may need a smaller dose and shorter duration as well as different components of the intervention, for example, less education and more confidence building to manage chronic disease during stressful times. Patients in the lowest activation may need a very high dose and long duration of an intervention focusing on understanding of the self-management role prior to education and confidence building.
Another area of future research is evaluating gender differences. In the arthritis population, 12-month post-intervention results showed that only females in their study sustained increased patient activation (Gronning et al., 2014). Further research is needed to understand patient activation and gender differences, and if different strategies should be used to activate men and women.

Few studies evaluated multimorbid patients. Only two studies (Hochhalter et al., 2010; Riippa et al., 2014) in this review included patients with 2 chronic diseases, and no studies reported more than 2 chronic diseases. Four other studies (Druss et al., 2010; Druss et al., 2014; Goldberg et al., 2013; Ludman et al., 2013) had a mental health condition as a primary inclusion criteria accompanied with another chronic problem but it was unclear how multimorbidity impacted the study results. Future research on patient activation and multimorbidity is important because as people live longer they will develop multiple chronic conditions. Patients need to be able to manage not just one chronic condition but several chronic conditions that may require different knowledge, skill and confidence levels.

Another area of focus should be on hospitalized patients. Only two studies (Kangovi et al., 2014; Linden & Butterworth, 2014) enrolled patients while they were hospitalized and followed them from hospital to home. Care transition is a vulnerable time yet this time presents an opportunity to initiate interventions to help patients become activated in caring for their chronic problems.

More study is needed to determine what components of interventions have the greatest impact on outcomes. In many of the studies it was unclear what components were utilized as part of the intervention. In the studies that did identify the components, frequency was sometimes reported as part of the dosage of the intervention but intensity or amount of intervention components were frequently unclear. These data are necessary in order to determine the most
influential or essential intervention components. Authors of RCT studies need to provide a more thorough description of the intervention and specific components of the intervention.

There is a trend toward initiating multiphase optimization strategy (MOST) and the sequential multiple assignment randomized trial (SMART) as new methods for implementing more potent interventions by fine tuning selected intervention components based on response to outcome. However, in this review only two studies reevaluated patient activation during the intervention (Linden & Butterworth, 2014; Shively et al., 2013). Evaluating the patient activation during the intervention may assist in identifying if revisions in the intervention are needed to improve outcomes as well as cost effectiveness.
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Psychometric properties of the patient activation measure among multimorbid older adults 

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Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) flow diagram of search strategy to identify articles.

- **Identification**
  - Records identified through database searching (n = 2174)

- **Screening**
  - Records after duplicates removed (n = 1437)
  - Records excluded (n = 1315)
  - Records screened (n = 122)

- **Eligibility**
  - Full-text articles assessed for eligibility (n = 56)
    - Full-text articles excluded, with reasons (not RCT design (18), duplicate study (1), no direct measure of patient activation (8), systematic reviews (4) (n = 31)

- **Included**
  - Studies included in quantitative synthesis (n = 25)
Table 1
Evidence table of patient activation randomized controlled trials

<table>
<thead>
<tr>
<th>Primary author (date)</th>
<th>Study design and sample size</th>
<th>Study setting and sample size</th>
<th>Intervention components and description</th>
<th>Intervention dose, duration and interventionist</th>
<th>Study outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alegria (2014)</td>
<td>RCT, mixed efficacy and effectiveness and adaptable to diverse patients and settings</td>
<td>N=647</td>
<td>Intervention description: In-person Bilingual audiotaped training sessions that teach decision making, generate and refine questions to ask health care providers and promote interactions with health care providers. Included didactic, role play and reflection, included patient activation and self-management.</td>
<td>Three 30-45 minute sessions over 3 months in person or by phone over 3 months Booster session if needed. Interventionist: Bilingual trained care managers (does not discuss the background of care manager)</td>
<td>Statistical difference: Patient activation (Patient Activation Scale) at 60 days post- intervention. Self-Management- (Patient-Physician Interactions questionnaire) at 60 days. No statistical difference: Engagement (proportion of visits attended to scheduled visits), retention in care (attended at least 4 visits in 6 months) Other findings: Greater effect among patients with</td>
</tr>
<tr>
<td>Study (Year)</td>
<td>Design, Intervention Details</td>
<td>Setting, Patient Characteristics</td>
<td>Intervention Description</td>
<td>Outcomes, Findings</td>
<td></td>
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<td>Deen (2012)</td>
<td>RCT, 4 groups: Control, Decision aid (DA), Patient activation intervention (PAI), and DA + PAI N=279</td>
<td>Community health center, Lower socioeconomic community patients</td>
<td>DA: Short Video Education and motivation to ask the right question of health care provider. PAI: understand the importance of asking the right questions during a physician visit, goes from routine decision making to important questions to ask in a physician visit. DA + PAI group: combination of both interventions.</td>
<td>Same day short session. Interventionist: Research assistant (qualifications not specified). No statistical difference: Patient activation (PAM) and decision self-efficacy (Decision self-efficacy scale) improved in all groups including control. Other findings: Those with the lowest patient activation scores improved the most. DA +PAI group showed the strongest effect. Within-group PAM increased in all groups.</td>
<td></td>
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<tr>
<td>Druss (2010)</td>
<td>Pilot study, randomized intervention trial N=80</td>
<td>Community mental health setting, Serious mental illness with one or more chronic medical illness</td>
<td>Adapted version of the Chronic Disease Self-Management Program (CDSMP) combined mental health interventions.</td>
<td>6 weekly group sessions led by peer specialist. Interventionist: Mental health peer specialist. Statistical difference: Patient activation (PAM) One or more primary care provider visit (self-report).</td>
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</tbody>
</table>
| Druss (2014) | RCT electronic health record | Community health center | • Knowledge  
• Confidence  

Intervention description: An electronic health record, My Health Record, was adapted to mental health patients and included personal details diagnosis, goals and action steps, fields for blood  

1 year of electronic health record  

Interventionist: Developed by providers and patients | Other findings: Physical activity, health related quality of life, medication adherence increased but not statistically significant. |
<table>
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<tr>
<th>Goldberg (2013)</th>
<th>RCT</th>
<th>Community mental health center</th>
<th>Knowledge</th>
<th>13 weeks weekly 60-75 minute sessions</th>
<th>Primary outcomes: Statistical difference post-intervention: Functioning- (SF-12-general, physical and emotional) Attitudinal-(Self-management self-efficacy Scale,</th>
</tr>
</thead>
<tbody>
<tr>
<td>N=63</td>
<td></td>
<td>Serious mental illness and at least one chronic medical condition</td>
<td>Skills</td>
<td>Interventionist: Either 2 mental health peers or mental health provider and a peer co-leader</td>
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<td></td>
<td></td>
<td></td>
<td>Confidence</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Intervention description:</td>
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<tr>
<td></td>
<td></td>
<td>Education-Living Well</td>
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<tr>
<td></td>
<td></td>
<td>(modified and advanced version of Chronic Disease)</td>
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</tbody>
</table>
Self-Management Program
Strategies of self-management, action planning, peer feedback, support, modeling, problem solving. Specific disease management.
Application of skills to the topics such as nutrition, sleep, medications
Action plans reviewed weekly by phone
Communicating with providers
Boosters at 2 months after intervention

Patient activation (PAM), Approach to health care), Self-management instrument general self-management behaviors, use of health care.
No statistical difference post-intervention:
Recovery Assessment Scale,
Internal locus of control behavioral and cognitive symptom management, social support, physical activity, medication adherence, use of emergency department for medical services.
Statistical difference 2 months post-intervention:
Attitudinal-Subscale measuring general self-management behaviors only outcome that showed statistical improvement
### Gronning (2012)

<table>
<thead>
<tr>
<th>Group RCT</th>
<th>Block randomization with stratification for sex</th>
<th>N=141</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Outcome:</strong></td>
<td></td>
<td><strong>Intervention:</strong></td>
</tr>
<tr>
<td></td>
<td>Out-patient hospital based (patients identified from hospital medical record and contacted)</td>
<td>Educational intervention</td>
</tr>
<tr>
<td></td>
<td>Rheumatoid arthritis, psoriatic</td>
<td>Lecture with a nurses moderator, includes symptom knowledge,</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Knowledge, Skills, Confidence</td>
</tr>
<tr>
<td></td>
<td></td>
<td>6 weeks, met every other week. Three 3-hour sessions of group education followed by 1 individual session (45 min)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Interventionist: Nurse</td>
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<tr>
<td></td>
<td></td>
<td>Primary outcome: Statistical difference: Global well-being (Arizona Integrative Outcomes Scale) and Arthritis self-efficacy subscale</td>
</tr>
</tbody>
</table>

- Internal locus of control however not post-intervention. Physical activity, healthy eating, use of health care (Instrument to measure Self-management) instrument.
- No statistical difference: Secondary outcome: Patient activation (PAM) increased post-intervention but did not sustain at 2 month follow. Other findings: PAM in intervention at 2 months did not stay statistically significant because control group increased.
Arthritis and polyarthritis coping skills, self-management and motivation

Secondary outcome:
Statistical difference:
Patient activation (PAM)
Pain (change in Pain VAS scale)
No statistical difference:
Self-efficacy pain, AIMS-2 (social, pain, role and affect), VAS tiredness and global assessment,
Modified Health Assessment Questionnaires, Hospital Anxiety and Depression Scale, Disease activity score and Educational needs assessment tool 2.

Patient activation increased in intervention group four months post-intervention Gronning (2014) later publication of same study long term outcomes of intervention:
<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Setting</th>
<th>Participant Characteristics</th>
<th>Intervention Description:</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hibbard (2007)</td>
<td>RCT N=479</td>
<td>Community</td>
<td>At least one chronic disease, 50-70 years old</td>
<td>Weekly workshop for 2.5 hours over 6 weeks&lt;br&gt;Interventionist: 2 trained leaders, one or both nonprofessional</td>
<td>Patient activation increase sustained in females but not sustained in males (went down) in intervention group Global well-being still present at 12 months</td>
</tr>
<tr>
<td>Hochhalter (2010)</td>
<td>RCT</td>
<td>Internal medicine clinic</td>
<td></td>
<td>Intervention description: 2-hour workshop and 2 follow-up phone calls. Workshop- research staff monitored when next</td>
<td>Primary: No statistical difference: Changes in self-management behaviors included: engaging in regular exercise, managing stress, paying attention to amount of fat in diet, keeping a BP diary, keeping a glucose diary, and taking diabetes medications as recommended.</td>
</tr>
<tr>
<td>Year</td>
<td>Study Title</td>
<td>Design</td>
<td>Sample Size</td>
<td>Group Description</td>
<td>Intervention Description</td>
</tr>
<tr>
<td>------------</td>
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</tr>
<tr>
<td>Irvine (2005)</td>
<td>RCT online intervention for low back pain</td>
<td>On-line</td>
<td>N=597</td>
<td>3 groups Fit Back, alternative care group and control group</td>
<td>Intervention description: Education and Cognitive-behavior approach based on Theory of Planned Behavior. Self-Tailored mobile-web intervention, interactive framework. Self-monitoring tools, daily trackers Mobile web app Fit back (self-tailored strategies to users preferences and interests to manage low back pain, 8 weeks multivisit online program</td>
</tr>
<tr>
<td></td>
<td></td>
<td>employees</td>
<td></td>
<td>3 groups, Fit-back mobile app, 8 email messages, control</td>
<td>Interventionist: Framework developed by expert panel of pain professionals and American Pain Society recommendations</td>
</tr>
</tbody>
</table>

Other findings:
Kangovi (2014)  
RCT  
N=446  
Hospital enrollment  
General medical (high risk, low income)  

- Knowledge  
- Skills  
- Confidence  

Intervention: Greater improvement in physical, behavioral and worksite outcome in intervention group  
Minimum of 14 days In-person while in-patient and 14 days post-hospitalizations, Until post-hospital PCP visit  
Interventionist: Community Health workers with minimum of high school education  
Statistical difference: Greater improvement in Patient activation (PAM) post-intervention  
Other findings: Primary outcome-completion of 14 day primary care follow-up  
Secondary outcome: Quality of discharge communication  
Improvement mental health  
No statistical difference:  
Self-related health  
Satisfaction  
Medication adherence  
30-day readmission (however recurrent readmission less in intervention group)  

Intervention description: Education, motivation, goal setting, liaison  
Measurable goal, patient confidence in achieving goal, resources, step-by-step plan for goal achievement.  
Individual goals, tailored care in 3 stages; goal setting, goal support: connection with primary care  
Action plans  
Semi-structured interview  
Community health worker attended appointments
<table>
<thead>
<tr>
<th>Reference</th>
<th>Study Design</th>
<th>N</th>
<th>Setting</th>
<th>Interventions</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Linden (2014)</td>
<td>RCT</td>
<td>512</td>
<td>Hospitalized patients in 2 community hospitals, COPD, CHF</td>
<td>Knowledge, Skills, Confidence</td>
<td>90 days 1 visit during hospitalization, Session within 2 days of discharge, additional sessions based on patient activation level, health literacy, severity of health condition and preference. Daily symptom monitoring with interactive voice response and nurse phone call within 24 hours of symptom alerts.</td>
</tr>
<tr>
<td>Lorig (2010)</td>
<td>RCT</td>
<td>761</td>
<td>Online community based, Diabetics, online</td>
<td>Knowledge, Skills, Confidence</td>
<td>6 weeks with 6- month and 18-month follow-up Content offered in 20-30 new web-pages weekly.</td>
</tr>
</tbody>
</table>
Individualized messages  
Personalized responses weekly.

Lorig (2009)  
RCT  
N=345  
Type 2 diabetics

- Knowledge  
- Skills  
- Confidence

Intervention description:  
Multicomponent diabetes self-management program  
Education on diabetes, motivation and book “Living a Healthy Life with Chronic Conditions”  
Highly interactive with emphasis on action planning and problem solving

6 week, 2.5 hours per week, with 6 month comparison

Interventionist:  
Peer led, peer training in program

No statistical difference:  
Health indicators exercise (physical activities scale that measured aerobic exercise in minutes/week or # of physician visits)  
At 18 months, other outcomes did not improve.

Ludman (2013)  
RCT  
N=214  
14 primary care clinics.

- Knowledge  
- Skills  
- Confidence

12-month team-based intervention. Weekly guidance until patients

Statistical difference:  
Self-efficacy and PAM hypoglycemic events  
Communication with physician, healthy eating reading labels

No statistical difference:  
Hemoglobin A1C not improved (primary outcome)  
No differences in HCU.
Comorbid depression and poorly controlled DM and/or coronary disease

Intervention description:
Multicomponent-motivation, education, goal setting, self-management support, monitor and control disease indicators, pharmacology to control depression hyperglycemia, hypertension and hyperlipidemia. Patients received booklet and self-monitoring devices. Pt-centered approach and Self-management approach to control depression, hyperglycemia, hypertension and hyperlipidemia. Achieved targeted levels for measures then phone calls every 4-6 weeks.

Interventionist:
Nurses with guidance from specialty teams (regular physicians, psychologist, internal medicine)

Maindal (2014) RCT patients (randomized prior to screening for hyperglycemia) N=509

33 primary care practices Screening detected hyperglycemia

- Knowledge
- Confidence

Intervention description: Education-behavioral and pharmacological treatment Ready to Act education program consist of motivation, action experience, informed

12-week intervention then followed for 3 years
2 individual counseling sessions and 8 group sessions (18 hours over 3 months)

Interventionist:
Statistical difference: Patient activation Total cholesterol
No statistical difference: Primary Outcome-10 year modelled Cardiovascular risk
<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Sample</th>
<th>Setting</th>
<th>Intervention Description</th>
<th>Interventionist</th>
<th>Statistical Difference</th>
</tr>
</thead>
</table>
| Maranda (2014)   | RCT      | N= 132 | Community health center (no chronic disease specified) | Education and motivating intervention in waiting room  
5-step process to empower patients to identify medical decisions and ask questions | Spanish speaking research assistant with BA degree (had 2 weeks of training) | Within group PAM in both intervention and control.  
When evaluated the lowest 2 levels of PAM, only intervention group improved PAM, Decision self-efficacy |
| McDermott (2011) | 3 arm RCT | N=355  | Outpatient Peripheral Vascular Disease patients | Education and patient-centered counseling  
3 arms, telephone counseling intervention,  
25 minute phone calls every 6 weeks for 8 calls | Trained health counselor | PAM improved more in telephone counseling intervention group compared to attention control and usual care |
<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Setting</th>
<th>Outpatient prior to lap band surgery</th>
<th>Monthly visits for 6 months</th>
<th>Intervention description:</th>
<th>Interventionist:</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parikh (2012)</td>
<td>Pilot RCT</td>
<td>Outpatient</td>
<td>• Knowledge</td>
<td></td>
<td>Education and physical activity strategies&lt;br&gt;Individual or group behavior modification and goal setting</td>
<td></td>
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<td></td>
<td>Medically supervised weight management group visits, Medically supervised weight management individual visits, or usual care -no formal weight loss program</td>
<td></td>
<td>• Confidence</td>
<td></td>
<td></td>
<td>Multidisciplinary team</td>
<td>55</td>
</tr>
<tr>
<td>Parthasarathy (2013)</td>
<td>Prospective randomized parallel group, open label pilot study</td>
<td>Home</td>
<td>• Knowledge</td>
<td></td>
<td>Obstructive Sleep Apnea patients that were prescribed Continuous Positive Airway Pressure</td>
<td>Peer buddy system</td>
<td>39</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>• Confidence</td>
<td></td>
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</tbody>
</table>

- Attention control condition and Usual care.
- Pt-centered counseling delivered every 6 weeks encouraging patients to request increases in cholesterol-lowering therapy
- LDL in telephone intervention compared to attention control.
- No statistical difference: Usual care less LDL decrease but not statistically significant

Statistical difference: patient activation
No statistical difference: Weight loss (Body Mass Index), Medication adherence (Morisky-Green scale)
Eating behavior change (self-reported)
<table>
<thead>
<tr>
<th>Study</th>
<th>Design Details</th>
<th>Setting</th>
<th>Intervention Description</th>
<th>Outcomes of Sleep Questionnaire, Patient activation (PAM)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Riippa (2014)</td>
<td>Asked during visit, randomized by date of birth N=137</td>
<td>Primary care</td>
<td>Interventionist: Peer driven Online 6 months</td>
<td>No statistical difference: No statistically significant differences for patient activation (PAM)</td>
</tr>
<tr>
<td></td>
<td>At least 2 chronic treatable illnesses - not specified what chronic disease</td>
<td></td>
<td>Intervention Description: Individualized tailored health care plan via Portal Intervention received immediate access to portal; Control got portal 6 months later. Intervention subjects formed a personal tailored health care plan with PCP Based on Health Belief Model</td>
<td></td>
</tr>
<tr>
<td>Rygg (2012)</td>
<td>Open pragmatic RCT Diabetes Intervention or waiting list N=146</td>
<td>Home-referred from primary care Diabetes</td>
<td>Intervention Description: Education – Diabetes self-management educational program with didactic, interactive learning and</td>
<td></td>
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<tr>
<td></td>
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<td></td>
<td>Interventionist: Nurse 15 hours over 3 weekly sessions Group education, diabetes program through hospital</td>
<td>No statistical difference: Patient activation Other findings: Lowest patient activation to start, greater positive change in patient activation in both intervention and control</td>
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<td>Improved: Diabetic knowledge and some self-management skills improved</td>
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<td>No difference: Hemoglobin A1C</td>
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</tbody>
</table>
skills training, group interaction on dealing with the disease

Patient activation (PAM) however, PAM improved (within intervention group)  

Shively (2013)  
RCT, 2 group repeated measures  
Patient activation level to Usual Care or intervention.  
N=84

Shively (2013)  
HF clinic  
Heart failure  

Solomon (2012)  
6-month program  
6 sessions by telephone or in person

Solomon (2012)  
Sent personalized invitations (asthma or diabetes). Patients consented and selected from a large health care system. Eligible if not seen physician  
Online Chronic Illnesses  
Chronic Illnesses (asthma, hypertension or diabetes). Patients selected from a large health care system. Eligible if not seen physician  

Intervention Description:  
Education, health behavior goal setting, self-management toolkit - individual tailored plan by activation level. Level 1 focused on importance of self-management role, Level 2 focus on confidence and knowledge, Level 3 focus on skills and behavior, and Level 4 focused on skills and behavior under different situations.

Interventionist:  
Advanced practice nurses

Interventionist:  
Web-based interaction - interactive health applications MyHealth Online - portal Interactive multimedia health education modules

Statistical difference:  
Patient activation  
Fewer hospitalizations (self-report) when PAM low and high  
No statistical difference: Self-management (self-care of heart failure index)  
Medium PAM intervention group more hospitalizations at 3 months

Other findings:  
Highest patient activation at the baseline did not demonstrate statistical difference:  
Patient activation (PAM) however, PAM improved (within intervention group)
<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>N</th>
<th>Setting</th>
<th>Intervention Description:</th>
<th>Interventionist:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wolever (2010)</td>
<td>RCT</td>
<td>56</td>
<td>Home (recruited from flyers, newspapers, online advertisements, mailings and study pools)</td>
<td>Individualized, education, targeted internal motivation by linking behavioral goals to patients’ values, challenges discussed, Wheel of Health, Individualized vision of health, goals. Patient-centered not provider-centered.</td>
<td>2 providers- Master’s degree in social work and psychology Experience and training in coaching</td>
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<td>Type 2 diabetics</td>
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<td>Weekly emails reminding participants of next session. Interact at their own pace and decide complexity.</td>
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<td>6 months coaching Telephone coaching (30 minute calls) within 2 weeks of baseline then 8 weekly calls, 4 biweekly calls and a final call 1 month later for a total of 14 sessions</td>
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<tr>
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<td>Interventionist: 2 providers- Master’s degree in social work and psychology Experience and training in coaching</td>
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<td>Statistical difference: Patient activation Perceived social support “benefit finding”(benefit finding scale) Barriers to med adherence (Morisky Medication Scale) decreased Within group self-reported adherence, exercise frequency, stress, and perceived health status.</td>
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<td>Other findings: Participants with elevated Hemoglobin A1C in coaching group reduced their Hemoglobin A1C. Statistical difference: Patient activation</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>No statistical difference:</td>
<td></td>
</tr>
<tr>
<td>Young (2012)</td>
<td>RCT</td>
<td>98</td>
<td>Patients receiving meds from federal qualified health center</td>
<td>3 monthly telephone consultations with pharmacist for 3-month period</td>
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<td></td>
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<td>Asthma</td>
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<tr>
<td>Telephone consultations regarding asthma self-management</td>
<td>Pharmacist</td>
<td>Asthma control</td>
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<tr>
<td>Addressed barriers to managing meds</td>
<td>Self-efficacy theory</td>
<td></td>
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<tr>
<td>Primary author</td>
<td>Knowledge</td>
<td>Problem Solving</td>
<td>Decision Making</td>
<td>Resource Utilization</td>
<td>Patient-provider relationship</td>
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<tr>
<td>Alegria (2014)</td>
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<tr>
<td>Druss (2014)</td>
<td>+</td>
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<td>+</td>
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<tr>
<td>Druss (2010)</td>
<td>+</td>
<td>+</td>
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</tr>
</tbody>
</table>

Table 2.

Intervention components of studies and patient activation status post-intervention.
<table>
<thead>
<tr>
<th>Study</th>
<th>Year</th>
<th>Intervention Details</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Goldberg</td>
<td>2013</td>
<td>CDSMP adapted to mental health</td>
<td></td>
</tr>
<tr>
<td>Gronning</td>
<td>2012</td>
<td>Group and individual educational sessions</td>
<td></td>
</tr>
<tr>
<td>Hibbard</td>
<td>2007</td>
<td>CDSMP-6 group sessions</td>
<td></td>
</tr>
<tr>
<td>Hochhalter</td>
<td>2010</td>
<td>2 hour group workshop and 2 follow-up phone calls</td>
<td></td>
</tr>
<tr>
<td>Irvine</td>
<td>2015</td>
<td>8 weeks multi-visit online program</td>
<td></td>
</tr>
<tr>
<td>Kangovi</td>
<td>2014</td>
<td>Individual in-person, telephone and text messages</td>
<td></td>
</tr>
<tr>
<td>Linden</td>
<td>2014</td>
<td>Individual in-person and telephone hotline</td>
<td></td>
</tr>
<tr>
<td>Lorig</td>
<td>2010</td>
<td>CDSMP adapted-6-week asynchronous</td>
<td></td>
</tr>
<tr>
<td>Study</td>
<td>Frequency</td>
<td></td>
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<td>-------------------</td>
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<tr>
<td>Lorig (2009)</td>
<td>+</td>
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<tr>
<td>Ludman (2013)</td>
<td>+</td>
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<tr>
<td>Maindal (2014)</td>
<td>+</td>
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<tr>
<td>Maranda (2014)</td>
<td>+</td>
<td></td>
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<tr>
<td>McDermott (2011)</td>
<td>+</td>
<td></td>
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<tr>
<td>Parikh (2012)</td>
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</tbody>
</table>

**Internet-based diabetes self-management program CDSMP adapted to diabetes**

**Weekly in-person guidance until maintenance then phone calls every 4-6 weeks.**

**2 individual counseling sessions and 8 group sessions over 12 weeks**

**In-person 10-15 minute**

**Telephone calls every 6 weeks for 8 calls**

**Monthly individual visits or monthly group visits for 6 months**
<table>
<thead>
<tr>
<th>Author</th>
<th>Year</th>
<th>Type of Education</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parthasarathy</td>
<td>2013</td>
<td>2 in person visits followed by telephone follow-up</td>
</tr>
<tr>
<td>Riippa</td>
<td>2014</td>
<td>Online ePHR</td>
</tr>
<tr>
<td>Rygg (2012)</td>
<td></td>
<td>Group education</td>
</tr>
<tr>
<td>Shively (2013)</td>
<td></td>
<td>6 sessions by telephone or in person</td>
</tr>
<tr>
<td>Wolever (2010)</td>
<td></td>
<td>Telephone coaching for 14 sessions</td>
</tr>
<tr>
<td>Young (2012)</td>
<td></td>
<td>Telephone 3 sessions</td>
</tr>
</tbody>
</table>

CDSMP Chronic Disease Self-Management Program; ePHR electronic personal health record; *only asked 4 questions on the PAM
Appendix A

Institutional Review Board Confirmation Letters

February 12, 2015

Myra Schmaderer, MSN, RN
CON-Lincoln
UNMC - 68588

IRB # 059-14-EP

TITLE OF PROPOSAL: Determinants of Patient Activation in the Multi-morbid Hospitalized Patient

DATE OF EXPEDITED REVIEW: 02/11/2015

VALID UNTIL: 02/11/2016

EXPEDITED CATEGORY OF REVIEW: 45 CFR 46.110; 21 CFR 50.110, Category 5, 7

The UNMC IRB has completed its review of the Application for Continuing Review for the above titled research project including the complete protocol file and has expressed it as their opinion that you have provided adequate safeguards for the rights and welfare of the subjects involved in this study and are in compliance with HHS regulations (45 CFR 46) and FDA regulations (21 CFR 50.50) as applicable.

This letter constitutes official notification of the re-approval of your research project by the IRB for the IRB approval period indicated above. You are therefore authorized to continue this study.

We wish to remind you that, under the provisions of the Federal Wide Assurance (FWA 00002939) from the Institution to HHS, the Principal Investigator is directly responsible for keeping the IRB informed of any proposed changes involved in the procedures or methodology in the protocol and for promptly reporting to the Board any unanticipated problems involving risks to the subjects or others.

In accordance with HRPP policies, this project is subject to periodic review and monitoring by the IRB and, as part of their monitoring, the IRB may request periodic reports of progress and results. For projects which continue, it is also the responsibility of the Principal Investigator to initiate a request to the IRB for Continuing Review of the research project in consideration of the IRB approval period.

On Behalf of the IRB,

Signed on: 2015-02-12 17:53:00.000

Jenny Kucera, MS, CIP
IRB Administrator
Office of Regulatory Affairs
Combined Institutional Review Board  
(I.R.B.)

Bryan Medical Center  Saint Elizabeth Regional Medical Center

January 29, 2014

Myra Schmaderer, RN, MSN  
10480 Pioneers Blvd  
Lincoln NE 68520

Title Of Research Project:  
Determinants of Patient Activation in the Multi-morbid Hospitalized Patient

1/28/2014  
Initial Review  
Including Consent Version 1 and Narrative Consent Version 1

IRB Action:  
Approved By A Unanimous Vote

Date For Next Continuing Review:  1/28/2015  
Review Interval:  12 months

Dear Ms Schmaderer:

The Combined Institutional Review Board for Bryan Medical Center and Saint Elizabeth Regional Medical Center has completed its review of your proposal on the date indicated. This letter constitutes official notification of approval of your study protocol and consent form by the IRB. You are authorized to implement this study.

Once the study begins, the Principal Investigator or Project Director is directly responsible for keeping this Board informed of any changes involving risks to subjects or others. It is the Principal Investigator’s responsibility (not the Board’s) to complete all record keeping required by a company sponsor of a study.

This study is subject to periodic review by the Board. The Board must be notified within five days of any serious adverse occurrences or unanticipated problems. No study changes may be initiated without IRB review and approval except when necessary to eliminate apparent immediate hazards to human subjects. Proposed changes must be submitted in writing to the Board. Protocol deviations and violations are also to be reported in writing.

For projects which continue beyond one year from the starting date, the IRB will request continuing review and update of the research project. Your study will be due for continuing review as indicated above. The investigator must also advise the Board when this study is discontinued.

Sincerely,

Michael R. German, Pharm.D.  
Secretary  
Combined IRB

Mailing Address: Pharmacy Services * 555 South 70th Street * Lincoln NE 68510
March 26, 2014

Myra Schmaderer, RN,MSN
10480 Pioneers Blvd
Lincoln NE 68520

Title Of Research Project:
Determinants of Patient Activation in the Multi-morbid Hospitalized Patient

3/3/2014 Other - Information Only
HIPAA Authorization dated 2/11/14

IRB Action: Information Added To File

Dear Ms Schmaderer:

On the date indicated, the Combined Institutional Review Board For Bryan Medical Center and Saint Elizabeth Regional Medical Center completed its review of the items listed.

Sincerely,

Michael R. German, Pharm.D.
Secretary
Combined IRB
Title of this Research Study
Determinants of Patient Activation in the Multi-morbid Hospitalized Patient

Invitation
You are invited to take part in this research study. You have a copy of the following, which is meant to help you decide whether or not to take part:
- Informed consent form
- "What Do I need to Know Before Being in a Research Study?"
- The Rights of Research Subjects

Why are you being asked to be in this research study?
You are asked to participate because you are an adult 19 years old or older being discharged from St. Elizabeth Regional Medical Center to your home. You have three or more chronic diseases.

What is the reason for doing this research study?
We are conducting a study to help determine what factors (gender, educational level, socioeconomic status and other factors) predict patient activation in patients with chronic diseases. Patient activation is the knowledge, skill and confidence to self-manage a chronic disease. This will help us figure out what we need to consider when we plan discharge needs of patients. The primary purposes of this research are to evaluate what individual factors predict patient activation and to evaluate the impact of patient activation on health care utilization (30-day re-admission and emergency department visits) in the adult patient with multiple chronic diseases discharged from the hospital to home. We will also be looking at how well the patient activation tool measures what we think we are assessing. Your information will be very helpful to us.

What will be done during this research study?
1. The research personnel will contact you soon after admission to the hospital.
2. The study will be thoroughly explained. You will be informed that participating or declining to participate in the study will not influence your care you receive while at the hospital.
3. If you agree to participate you will complete several different measures. It is estimated that it will take approximately 20 minutes to complete the data collection measures. There are no right or wrong answers on these measures.
4. A mutually agreed upon time will be scheduled with you to complete these data measures.

Version 1

Subject’s Initials

IRB Approved
Valid until 02/11/2015

Non-interventional Research
Collection measures. These data measures may be completed in several short sessions during the hospitalization or in one session. All data collection measures will be completed between admission and discharge from the hospital.

5. One month after discharge, you will be called via phone and asked if you have been re-hospitalized or went to the emergency department (ED) in the last 30 days. You will be specifically asked to recall the number of hospitalization(s) or ED visits, the reasons for this health care and the name and location of the hospital providing service.

6. You will receive the form "Authorization to use and disclose health information for non-treatment research". This form must be signed by you to give the researchers access to your health information to be utilized for research purposes.

7. You are giving research personnel permission to send a letter to these hospitals to ask for a copy of billing information for costs related to medical care.

8. Personal health information (age, gender, health history, medications, length of hospital stay, billing data and other demographic data) will be collected from your medical record.

What are the possible risks of being in this research study?
There is a possible risk to you of a loss of confidentiality; however, there are measures in place to protect that from happening. All of your information is kept on a secure server and only the researchers involved in the study will have access to your information. You may refuse to complete any of the data measures.

What are the possible benefits to you?
You are not expected to get any benefit from being in this research study.

What are the possible benefits to other people?
Results from this study may help health care providers become more aware of what patients need when they go home from the hospital. These results may help guide discharge planning.

What are the alternatives to being in this research study?
Instead of being in this research study you can choose not to participate.

What will being in this research study cost you?
There is no cost to you to be in this research study.

Will you be paid for being in this research study?
You will not be paid to be in this research study.

Version 1

Subject's Initials

IRB Approved
Valid until 02/11/2015
What should you do if you have a problem during this research study?
Your welfare is the major concern of every member of the research team. If you have a problem as a direct result of being in this study, you should immediately contact one of the people listed at the end of this consent form.

How will information about you be protected?
You have rights regarding the protection and privacy of your medical information collected before and during this research. This medical information is called "protected health information" (PHI). PHI used in this study may include your medical record number, address, birth date, medical history, other diagnostic medical or research procedures. Only the minimum amount of PHI will be collected for this research. Your research and medical records will be maintained in a secure manner.

Who will have access to information about you?
By signing this consent form, you are allowing the research team to have access to your PHI. The research team includes the investigators listed on this consent form and other personnel involved in this specific study at the Institution.

Your PHI will be used only for the purpose(s) described in the section "What is the reason for doing this research study?"

You are also allowing the research team to share your PHI, as necessary, with other people or groups listed below:
- The UNMC Institutional Review Board (IRB)
- Institutional officials designated by the UNMC IRB
- Federal law requires that your information may be shared with these groups:
  - The HHS Office for Human Research Protections (OHRP)
You are authorizing us to use and disclose your PHI for as long as the research study is being conducted.

You may cancel your authorization for further collection of PHI for use in this research at any time by contacting the principal investigator in writing. However, the PHI which is included in the research data obtained to date may still be used. If you cancel this authorization, you will no longer be able to participate in this research.

How will results of the research be made available to you during and after the study is finished?
In most cases, the results of the research can be made available to you when the study is completed, and all the results are analyzed by the investigator. The information from this study may be published in scientific journals or presented at...
scientific meetings, but your identity will be kept strictly confidential.

If you want the results of the study, contact the Principal Investigator at the phone number given at the end of this form or by writing to the Principal Investigator at the following address: Myra Schmaderer 10480 Pioneers Blvd Lincoln, NE 68520

What will happen if you decide not to be in this research study or decide to stop participating once you start?
You can decide not to be in this research study, or you can stop being in this research study (withdraw) at any time before, during, or after the research begins. Deciding not to be in this research study or deciding to withdraw will not affect your relationship with the investigator or the Institution. You will not lose any benefits to which you are entitled.

Will you be given any important information during the study?
You will be informed promptly if the research team gets any new information during this research study that may affect whether you would want to continue being in the study.

What should you do if you have any questions about the study
You have been given a copy of "What Do I Need to Know Before Being in a Research Study?" If you have any questions at any time about this study, you should contact the Principal Investigator or any of the study personnel listed on this consent form or any other documents that you have been given.

What are your rights as a research participant?
You have rights as a research subject. These rights have been explained in this consent form and in The Rights of Research Subjects that you have been given. If you have any questions concerning your rights or complaints about the research, you can contact any of the following:
- The investigator or other study personnel
- Institutional Review Board (IRB)
  - Telephone: (402) 559-6463
  - Email: IRBORA@unmc.edu
  - Mail: UNMC Institutional Review Board, 987830 Nebraska Medical Center, Omaha, NE 68198-7830
- Research Subject Advocate
  - Telephone: (402) 559-6941
  - Email: unmcrsa@unmc.edu

Version 1

Subject's Initials

IRB Approved
Valid until 02/11/2015
Documentation of informed consent
You are freely making a decision whether to be in this research study. Signing this form means that:
- You have read and understood this consent form.
- You have had the consent form explained to you.
- You have been given a copy of The Rights of Research Subjects.
- You have had your questions answered.
- You have decided to be in the research study.
- If you have any questions during the study, you have been directed to talk to one of the investigators listed below on this consent form.
- You will be given a signed and dated copy of this consent form to keep.

Signature of Subject ______________________________
Date __________________

My signature certifies that all the elements of informed consent described on this consent form have been explained fully to the subject. In my judgment, the participant possesses the legal capacity to give informed consent to participate in this research and is voluntarily and knowingly giving informed consent to participate.

Signature of Person Obtaining Consent ______________________________
Date __________________

Authorized Study Personnel
Principal
Schmaderer, Myra Sue
phone: 402-472-7335
alt #: 402-472-7335
degree: MSN, RN

Faculty Advisor
Zimmerman, Lani (Chi Chi) M
phone: 402-472-3847
alt #: 402-472-3847
degree: PhD

Participating Personnel
Havlat, Carol Ann
phone: 402-416-4749
alt #: 402-416-4749

Loecker, Courtney Nicole
alt #: 402-499-3812
degree: BSN

Version 1

Subject's Initials __________________________

IRB Approved
Valid until 02/11/2015
degree: BSN, RN

Peck, Molly Therese
phone: 402-472-7345
alt #: 308-345-7334
degree: student

Schmidt, Kristy Joan
phone: 402-472-3657
alt #: 402-540-7641
degree: student

Woods, Courtney N
alt #: 308-230-0152
degree: student

Subject’s Initials
Title of this Research Study
Determinants of Patient Activation in the Multi-morbid Hospitalized Patient

You are invited to participate in this research study because you are an adult 19 years old or older and have agreed to take part in another study; IRB Protocol #336-13-EP, Home Based Care Transitions Tailored by Cognition and Patient Activation: A Prudent Use of Resources. The information in this consent form is provided to help you make an informed decision whether or not to participate. If you have any questions, please do not hesitate to ask.

We are conducting a study to help determine what factors (gender, educational level socioeconomic status and other factors) predict patient activation in patients with chronic diseases. Patient activation is the knowledge, and confidence to self-manage a chronic disease. This will help us determine what we need to consider when we plan discharge needs of patients.

The primary purposes of this research are to evaluate what individual factors predict patient activation and to evaluate the relationship between patient activation and health care utilization (30 day re-admission and emergency department visits) in the hospitalized adult patient with multiple chronic diseases discharged to home. Personal health information (age, gender, health history, medications, length of hospital stay, billing data and other demographic data) will be collected from your medical record. We will also be looking at how well the patient activation tool measures what we think we are assessing. Your information may be helpful to us.

By signing this form you are allowing us to use the information on the surveys you have already completed. There are no further obligations for the study.

There is a possible risk to you of a loss of confidentiality; however, there are measures in place to protect that from happening. All of your information is kept on a secure server and only the researchers involved in the study will have access to your information. All hard copies of materials you have completed and shared are kept in a locked cabinet.

There are no benefits you will receive from this study. Results from this study may assist discharge planners in the future to plan resources for patients with chronic diseases in the future.

Version 1

Subject's Initials

IRB Approved
Valid until 02/11/2015

Non-interventional Research
There will be no cost to you and you will not receive any pay for participating in this study.

By signing this document, you are saying that the information on this consent form has been explained to you, that you have read and understood this consent form, that your questions have been answered, and that you have decided to participate. If you think of any additional questions, please contact one of the investigators listed at the end of this form. You will be given a copy of this consent form to keep.

Signature of Subject________________________
Date/Time________________________

Authorized Study Personnel
Principal
Schmaderer, Myra Sue
phone: 402-472-7335 alt #: 402-432-8863
mmschmader@unmc.edu
degree: MSN, RN

Faculty Advisor
Zimmerman, Lani (Chi Chi)
phone: 402-472-3847 degree: PhD

Participating Personnel
Havlak, Carol Ann
email: chavlat@stez.org
alt #: 402-416-4749
degree: BSN, RN

Woods, Courtney N
alt #: 308-230-0152
degree: student

Loecker, Courtney Nicole
alt #: 402-499-3812
degree: BSN

Peck, Molly Therese email:
molly.peck@unmc.edu phone: 402-472-7345 alt #: 308-345-7334
degree: student

Schmidt, Kristy Joan email:
kristy.schmidt@unmc.edu phone: 402-472-3657
alt #: 402-540-7641
degree: student

Version 1

Subject's Initials________________________

IRB Approved
Valid until 02/11/2015
# Patient Demographics

**Study ID**

**Admission Date**

**Address**

**Zipcode**

**Phone number**

**What types of health insurance do you have at this time?**

- [ ] None
- [ ] Medicaid
- [ ] Medicare
- [ ] PPO
- [ ] Disability
- [ ] Private Insurance Company (Blue Cross, Aetna, etc.)
- [ ] Health Maintenance Organization (HMO)
- [ ] Self pay
- [ ] VA
- [ ] Not sure
  (choose all that apply)

**Primary Care Provider**

**PCP Physician Group**

**PCP Address**

**PCP Telephone Number**

**PCP Fax Number**

**Other specialty physician name, address and phone number**

**Admission diagnosis**

**What pharmacy do you utilize?**

**Date of Birth**

**Age**

**Weight in pounds**

**Height in inches**
Chronic disease history

☐ Arthritis (Osteoarthritis)
☐ Asthma
☐ BPH
☐ Bronchitis
☐ Cancer
☐ Chronic Kidney Disease
☐ Chronic Liver disease
☐ Connective Tissue disease (RA, Marphans, Lupus)
☐ COPD
☐ Coronary artery disease
☐ Cerebral Vascular Disease
☐ Depression
☐ Diabetes Mellitus
☐ DVT
☐ Dysthymia
☐ Heart failure
☐ Hemiplegia
☐ HIV/AIDS
☐ Hyperlipidemia
☐ Hypertension
☐ Hyperthyroidism
☐ Hypothyroidism
☐ Inflammatory Bowel
☐ Migraines
☐ Obesity
☐ Obstructive Sleep Apnea
☐ Pancreatitis
☐ Peptic Ulcer Disease
☐ Peripheral Vascular disease
☐ Pulmonary Emboli
☐ Rheumatoid Arthritis
☐ Seizure Disorder
☐ TIA
☐ Other

Specify other chronic diseases:

Total number of comorbidities:

LACE Score
Confidential

Current medications

- ACE inhibitor
- Alpha/beta blocker
- Angiotensin II Blocker
- Antianginal
- Anti-anxiety
- Antiarrhythmic
- Antibiotics
- Anticonvulsant
- Antidepressant
- Acetaminophen (Tylenol)
- Anti-hypertensive
- Anti-inflammatory
- Anti-platelet/anticoagulant
- Muscle Relaxant
- Aspirin
- Beta Blocker
- Bronchodilator
- Calcium Channel Blocker
- Cholesterol lowering
- Insulin
- Diuretics
- Herbals
- Hormone replacement
- Hypoglycemic
- Narcotics
- Proton pump/H2Blocker
- Steroids
- Stool softener/Laxative
- Thyroid hormone
- Vasodilator
- Vitamins/minerals
- Other

Other medications

Comments regarding Medication Reconciliation while patient in the hospital.

Country of birth

- USA
- Other

If other, please specify country

Marital status

- married
- single
- widowed
- divorced
- separated
- cohabitation

email address

Do you have a computer with a camera in your home?

- Yes
- No

Highest level of education in years.

How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?

- never
- rarely
- sometimes
- often
- always

Number of ED visits in the last 6 months.

www.project-redcap.org REDCap
What income group below comes closest to your total household income in the last year from all sources before taxes?

- under $10,000
- $10,000-19,999
- $20,000-29,999
- $30,000-39,999
- $40,000-49,999
- $50,000-59,999
- $60,000-69,999
- $70,000-79,999
- $80,000-89,999
- $90,000-99,999
- $100,000 or more
- refused

How many people, including yourself, live in your household?

- 1
- 2
- 3
- 4
- 5
- More than 5

Do you have anyone in your household who helps you with your health care needs? (Caregiver)

- Yes
- No

Relationship of this person

Race (self identified)

- White
- African American
- Hispanic
- Native American or Alaska Native
- Native Hawaiian or Pacific Islander
- Asian
- Other
- (choose all that apply)

If Race other, please specify

When seeking or receiving health care, have you ever been treated unfairly because of your race or ethnicity?

- Yes
- No

Do you believe the incident or incidents where you were treated unfairly because of your race impact your medical decisions to see health care providers?

- daily
- often
- rarely
- never

Gender

- Male
- Female

When seeking or receiving health care, have you ever been treated unfairly because of your gender?

- Yes
- No

Do you believe the incident or incidents where you were treated unfairly because of your gender impact your medical decisions to see health care providers?

- daily
- often
- rarely
- never

How often do you think about your race?

What is the best time of day to reach you for follow-up telephone calls?
PROMIS-29 Profile v1.0

Please respond to each question or statement by marking one box per row.

<table>
<thead>
<tr>
<th>Physical Function</th>
<th>Without any difficulty</th>
<th>With a little difficulty</th>
<th>With some difficulty</th>
<th>With much difficulty</th>
<th>Unable to do</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are you able to do chores such as vacuuming or yard work?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Are you able to go up and down stairs at a normal pace?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Are you able to go for a walk of at least 15 minutes?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Are you able to run errands and shop?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Anxiety

In the past 7 days...

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>I felt fearful</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I found it hard to focus on anything other than my anxiety</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My worries overwhelmed me</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I felt uneasy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Depression

In the past 7 days...

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>I felt worthless</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I felt helpless</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I felt depressed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I felt hopeless</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Fatigue

During the past 7 days...

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>A little bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel fatigued</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have trouble <em>starting</em> things because I am tired</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

In the past 7 days...

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>A little bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>How run-down did you feel on average?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

In the past 7 days...

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>A little bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>How fatigued were you on average?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## PROMIS–29 Profile v1.0

**Sleep Disturbance**  
In the past 7 days...

<table>
<thead>
<tr>
<th>Question</th>
<th>Very poor</th>
<th>Poor</th>
<th>Fair</th>
<th>Good</th>
<th>Very good</th>
</tr>
</thead>
<tbody>
<tr>
<td>My sleep quality was</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In the past 7 days...</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My sleep was refreshing</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I had a problem with my sleep</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I had difficulty falling asleep</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Satisfaction with Social Role**  
In the past 7 days...

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am satisfied with how much work I can do (include work at home)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am satisfied with my ability to work (include work at home)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am satisfied with my ability to do regular personal and household responsibilities</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am satisfied with my ability to perform my daily routines</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Pain Interference**  
In the past 7 days...

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>How much did pain interfere with your day to day activities?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How much did pain interfere with work around the home?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How much did pain interfere with your ability to participate in social activities?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How much did pain interfere with your household chores?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Pain Intensity**  
In the past 7 days...

<table>
<thead>
<tr>
<th>Question</th>
<th>No pain</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>How would you rate your pain on average?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

Charlson Comorbidity Index
(http://www.fnpnotebook.com/prevent/Exam/ChrlsnCmrbdtyindex.htm)

Aka: Charlson Comorbidity Index, Comorbidity-Adjusted Life Expectancy

1. Indication
   1. Assess whether a patient will live long enough to benefit from a specific screening measure or medical intervention
2. Scoring: Comorbidity Component (Apply 1 point to each unless otherwise noted)
   1. Myocardial Infarction
   2. Congestive Heart Failure
   3. Peripheral Vascular Disease
   4. Cerebrovascular Disease
   5. Dementia
   6. COPD
   7. Connective Tissue Disease
   8. Peptic Ulcer Disease
   9. Diabetes Mellitus (1 point uncomplicated, 2 points if end-organ damage)
   10. Moderate to Severe Chronic Kidney Disease (2 points)
   11. Hemiplegia (2 points)
   12. Leukemia (2 points)
   13. Malignant Lymphoma (2 points)
   14. Solid Tumor (2 points, 6 points if metastatic)
   15. Liver Disease (1 point mild, 3 points if moderate to severe)
   16. AIDS (6 points)

3. Scoring: Age
   1. Age <40 years: 0 points
   2. Age 41-50 years: 1 points
   3. Age 51-60 years: 2 points
   4. Age 61-70 years: 3 points
   5. Age 71-80 years: 4 points

4. Interpretation
   1. Calculate Charlson Score or Index (I)
      1. Add Comorbidity score to age score
      2. Total denoted as 'I' below
   2. Calculate Charlson Probability (10 year mortality)
      1. Calculate \( Y = e^{I(0.9)} \)
      2. Calculate \( Z = 0.983^Y \)
      3. where \( Z \) is the 10 year survival

5. References
S-TOFHLA

PASSAGE A

Your doctor has sent you to have a __________ X-ray.
   a. stomach
   b. diabetes
   c. stitches
   d. germs

You must have an __________ stomach when you come for ________.
   a. asthma
   b. empty
   c. incest
   d. anemia
   a. is.
   b. am.
   c. if.
   d. it.

The X-ray will ________ from 1 to 3 ________ to do.
   a. take
   b. view
   c. talk
   d. look
   a. beds
   b. brains
   c. hours
   d. diets
THE DAY BEFORE THE X-RAY.

For supper have only a ________ snack of fruit, _________ and jelly,

a. little    a. toes
b. broth     b. throat
c. attack    c. toast
d. nausea    d. thigh

with coffee or tea.

After __________, you must not ________ or drink

a. minute, a. easy
b. midnight, b. ate
c. during, c. drank
d. before, d. eat

anything at ________ until after you have ________ the X-ray.

a. ill a. are
b. all b. has
c. each c. had
d. any d. was
THE DAY OF THE X-RAY.

Do not eat ____________________.
  a. appointment.
  b. walk-in.
  c. breakfast.
  d. clinic.

Do not ___________ even ___________.
  a. drive,  a. heart.
  b. drink,  b. breath.
  c. dress,  c. water.
  d. dose,  d. cancer.

If you have any ___________, call the X-ray ___________ at 616-4500.
  a. answers,  a. Department
  b. exercises,  b. Sprain
  c. tracts,  c. Pharmacy
  d. questions,  d. Toothache
PASSAGE B

I agree to give correct information to _______ if I can receive Medicaid.
   a. hair
   b. salt
   c. see
   d. ache

I _______ to provide the county information to _______ any
   a. agree
   b. probe
   c. send
   d. gain

statements given in this _______ and hereby give permission to
   a. emphysema
   b. application
   c. gallbladder
   d. relationship

the _______ to get such proof. I _______ that for
   a. inflammation
   b. religion
   c. iron
   d. county

Medicaid I must report any _______ in my circumstances
   a. changes
   b. hormones
   c. antacids
   d. charges
within _____ (10) days of becoming _____ of the change.
   a. three    a. award
   b. one      b. aware
   c. five     c. away
   d. ten      d. await

I understand _____ if I DO NOT like the _________ made on my
   a. thus  a. marital
   b. this  b. occupation
   c. that  c. adult
   d. than  d. decision

case, I have the _________ to a fair hearing. I can _________ a
   a. bright   a. request
   b. left    b. refuse
   c. wrong   c. fail
   d. right   d. mend

hearing by writing or _________ the county where I applied.
   a. counting
   b. reading
   c. calling
   d. smelling

If you _________ TANF for any family _________, you will have to
   a. wash    a. member,
   b. want    b. history,
   c. cover   c. weight,
   d. tape    d. seatbelt,
________ a different application form. __________, we will use
a. relax
b. break
c. inhale
d. sign

________ on this form to determine your __________.

________

________

________

________

________

________

________

________

a. Since,
b. Whether,
c. However,
d. Because,

a. hypoglycemia.
b. eligibility.
c. osteoporosis.
d. schizophrenia.
Single Item Literacy Screener

"How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?"

Patients respond: 1-Never, 2-Rarely, 3-Sometimes, 4-Often, and 5-Always.
EQ-5D-5L

Under each heading, please check the ONE box that best describes your health TODAY

MOBILITY
I have no problems walking
I have slight problems walking
I have moderate problems walking
I have severe problems walking
I am unable to walk

SELF-CARE
I have no problems washing or dressing myself
I have slight problems washing or dressing myself
I have moderate problems washing or dressing myself
I have severe problems washing or dressing myself
I am unable to wash or dress myself

USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)
I have no problems doing my usual activities
I have slight problems doing my usual activities
I have moderate problems doing my usual activities
I have severe problems doing my usual activities
I am unable to do my usual activities

PAIN / DISCOMFORT
I have no pain or discomfort
I have slight pain or discomfort
I have moderate pain or discomfort
I have severe pain or discomfort
I have extreme pain or discomfort

ANXIETY / DEPRESSION
I am not anxious or depressed
I am slightly anxious or depressed
I am moderately anxious or depressed
I am severely anxious or depressed
I am extremely anxious or depressed
Perception of health status

EQ-5D-5L Visual Analog Scale

- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the best health you can imagine.
  0 means the worst health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY =  

The best health you can imagine

The worst health you can imagine
**Assessment of Care for Chronic Conditions**

Staying healthy can be difficult when you have a chronic condition. We would like to learn about the type of help with your condition you get from your health care team. This might include your regular doctor, his or her nurse, or physician's assistant who treats your illness. Your answers will be kept confidential and will not be shared with your physician or clinic.

**Over the past 6 months, when I received care for my chronic conditions, I was:**

<table>
<thead>
<tr>
<th></th>
<th>None of the time</th>
<th>A Little of the Time</th>
<th>Some of the Time</th>
<th>Most of the Time</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Asked for my ideas when we made a treatment plan.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>2. Given choices about treatment to think about.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>3. Asked to talk about any problems with my medicines or their effects.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>4. Given a written list of things I should do to improve my health.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5. Satisfied that my care was well organized.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>6. Shown how what I did to take care of myself influenced my condition.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>7. Asked to talk about my goals in caring for my condition.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>8. Helped to set specific goals to improve my eating or exercise.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>9. Given a copy of my treatment plan.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>10. Encouraged to go to a specific group or class to help me cope with my chronic condition.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>11. Asked questions, either directly or on a survey, about my health habits.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
Over the past 6 months, when I received care for my chronic conditions, I was:

<table>
<thead>
<tr>
<th></th>
<th>None of the time</th>
<th>A Little of the Time</th>
<th>Some of the Time</th>
<th>Most of the Time</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>12. Sure that my doctor or nurse thought about my values, beliefs, and traditions when they recommended treatments to me.</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 3</td>
<td>□ 4</td>
<td>□ 5</td>
</tr>
<tr>
<td>13. Helped to make a treatment plan that I could carry out in my daily life.</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 3</td>
<td>□ 4</td>
<td>□ 5</td>
</tr>
<tr>
<td>14. Helped to plan ahead so I could take care of my condition even in hard times.</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 3</td>
<td>□ 4</td>
<td>□ 5</td>
</tr>
<tr>
<td>15. Asked how my chronic condition affects my life.</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 3</td>
<td>□ 4</td>
<td>□ 5</td>
</tr>
<tr>
<td>16. Contacted after a visit to see how things were going.</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 3</td>
<td>□ 4</td>
<td>□ 5</td>
</tr>
<tr>
<td>17. Encouraged to attend programs in the community that could help me.</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 3</td>
<td>□ 4</td>
<td>□ 5</td>
</tr>
<tr>
<td>18. Referred to a dietitian, health educator, or counselor.</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 3</td>
<td>□ 4</td>
<td>□ 5</td>
</tr>
<tr>
<td>19. Told how my visits with other types of doctors, like an eye doctor or other specialist, helped my treatment.</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 3</td>
<td>□ 4</td>
<td>□ 5</td>
</tr>
<tr>
<td>20. Asked how my visits with other doctors were going.</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 3</td>
<td>□ 4</td>
<td>□ 5</td>
</tr>
</tbody>
</table>
Patient Activation Measure

Below are some statements that people sometimes make when they talk about their health. Please indicate how much you agree with each statement as it applies to you personally by circling your answer. Your answers should be what is true for you and of just what you think others want you to say. If the statement does not apply to you, circle NA.

<table>
<thead>
<tr>
<th></th>
<th>Statement</th>
<th>Disagree strongly</th>
<th>Disagree</th>
<th>Agree</th>
<th>Agree strongly</th>
<th>NA</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>When all is said and done, I am the person who is responsible for taking care of my health.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Taking an active role in my own health care is the most important thing that affects my health.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>I am confident I can help prevent or reduce problems associated with my health.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>I know what each of my prescribed medications do.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>I am confident that I can tell a doctor concerns I have even when he or she does not ask.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>I am confident that I can follow through on medical treatments I may need to do at home.</td>
<td></td>
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</tr>
<tr>
<td>8</td>
<td>I understand my health problems and what causes them.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>I know what treatments are available for my health problems.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>I have been able to maintain (keep up with) lifestyle changes, like eating right or exercising.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>I know how to prevent problems with my health.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>I am confident I can figure out solutions when new problems arise with my health.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>13</td>
<td>I am confident that I can maintain lifestyle changes, like eating right and exercising, during times of stress.</td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>
Health Care Utilization

In the past month, how many times did you go to the Emergency Department for Health Care? ____________ times

What is the name and location of the Emergency Department? ________________________________

In the past month, how many times were you admitted to a hospital for health care? ____________ times

How many nights did you spend in the hospital? ____________ nights

What is the name and location of the Hospital? ________________________________