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The Effect of Patient Activation on Transition Clinic Adherence

Megan Sue McGraw

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The Effect of Patient Activation on Transition Clinic Adherence

by

Megan McGraw

A thesis submitted to the faculty of
Gardner-Webb University Hunt School of Nursing
in partial fulfillment of the requirements for the
Master of Science in Nursing Degree

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Submitted by:

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Abstract

Heart failure (HF) affects more than five million Americans and is one of the most commonly occurring reasons for admission to the hospital among adults aged 65 and over. Evidence is growing that the higher amount of patient engagement or activation, the better the health and cost outcomes. The purpose of this study was to determine if there was a relationship between a higher patient activation score, as determined by the PAM-10, and completion in the heart failure transition clinic. The design for this study was a quantitative descriptive study. The patients were given the questionnaire prior to discharge from the hospital and based on the recommendations associated with the PAM-10 tool, the level of activation can help the staff in the transition clinic to tailor specific interventions at the transition clinic. The population for this study was patients who were admitted into the hospital with a primary diagnosis of heart failure. The convenience sample consisted of patients who the inpatient navigator visited in the hospital and who agreed to participate in the study. Those in skilled nursing facilities, cognitively impaired individuals, or non-English speaking patients were excluded. There were 36 participants, half of which scored a level three on the PAM-10, and the completion rate of those who were a level three was 76%. It was determined that the higher level of activation, the more likely that the participant was to complete the transition program.

Keywords: Patient Activation, Engagement, Heart Failure, PAM-10

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CHAPTER I

Introduction

Heart failure affects 5.7 million Americans and is one of the most commonly occurring reasons that people over the age of 65 are admitted to the hospital (American Heart Association, 2015). When the heart muscle becomes weak (systolic heart failure) or stiff (diastolic heart failure), a person is considered to have heart failure (HF). HF is a condition in which the heart cannot pump enough blood to meet the body's needs. In some cases, the heart cannot fill with enough blood, in other cases the heart cannot pump blood to the rest of the body with enough force. This is a chronic illness that ultimately has a poor prognosis and eventually worsens. There is no cure for heart failure, however, treatment such as medicines and lifestyle changes, can help people who have the condition live longer and have more active lives (National Institute of Health, 2015). Many people experience a fluctuation of signs and symptoms, from very little or none, to severe, which make activities of daily living difficult. The onset can be sudden or slow, precipitated by a certain event or worsen over time. These symptoms include: shortness of breath, fatigue, edema of the feet, ankles, legs, and abdomen, as well as fluid build-up in the liver and distended neck veins. According to the Centers for Disease Control (CDC) (2015), about half of people who develop heart failure die within five years of diagnosis and one in nine deaths included heart failure as a contributing cause. Heart failure costs \$32 billion annually, which includes the cost of health care services, medications to treat heart failure, and missed days of work.

The Heart Success Transition Clinic, hereafter referred to as the transition clinic, is a short-term clinic that was initiated after Medicare guidelines changed and the Centers

for Medicare and Medicaid Services (CMS) announced that payment to hospitals would be denied for readmissions within 30 days of discharge, for certain chronic conditions. Heart failure is one of the chronic conditions identified. The process for the transition clinic is initiated when a patient is admitted to the hospital with a primary diagnosis of heart failure and subsequently identified by an inpatient navigator who speaks with the patient while in the hospital, and gets the patient's consent to be followed by the transition clinic. After this conversation, the navigator schedules him or her to be seen in the transition clinic within three to five days after discharge. The transition clinic is designed for a provider to see the patient once a week for four weeks for close monitoring and further titration of heart failure medications. At the end of the four weeks, the patient returns back to his/her primary physician or cardiologist. Once the patient comes to the transition clinic, he or she is seen by an Advanced Care Practitioner (ACP) who is either a nurse practitioner or physician assistant, a heart failure certified registered nurse, a pharmacist specializing in heart failure, a social worker, and a dietitian. The ACP discusses the specific details of the patient's cause of heart failure, if known, and the treatment modalities specific to him or her. The pharmacist does a comprehensive medication reconciliation with the nurse, and goes over each medication with the patient and family members, discussing the purpose, potential side effects, and proper timing and dosing of each medication. The dietitian discusses a low sodium diet, fluid restriction, provides menus and resources to the patient and family members to help the patient be successful with the diet change. The social worker provides any counseling needed, as well as identifies patient needs related to obtaining and paying for medications, assistance with disability applications, helping to understand insurance benefits, and programs and

any other assistance programs as needed (i.e. medication copay assistance, prescription delivery services). The nurse reinforces any of the education provided, sends prescriptions electronically, coordinates appropriate follow-up with primary care physicians and cardiologists, provides discharge instructions, schedules any necessary testing, and ensures all disciplines are communicating with each other.

Significance

As readmissions continue to be the focus by CMS and new diagnoses are being added to the non-reimbursement list with each fiscal year, it is of utmost importance to ensure patients receive appropriate education and understand the information provided. In addition to comprehension of the information given, patients must be engaged in the learning process. The authors of the Affordable Care Act (ACA) recognized that patient engagement will be the basis for successful reform and the success of patient-centered medical homes. Evidence is growing that the higher the amount of patient engagement, the better the health and cost outcomes. “Patient activation [is defined as] the skills and confidence that equip patients to become actively engaged in their healthcare” (Hibbard & Greene, 2013, p. 207). Patient engagement and patient activation are often used interchangeably. “Patient activation emphasizes patients’ willingness and ability to take independent actions to manage their health and care” (Hibbard & Greene, 2013, p. 207). Patient engagement, however, is used to describe a broader concept “that includes activation; the interventions designed to increase activation; and patients’ resulting behavior” (Hibbard & Greene, 2013, p. 207). According to Hibbard and Greene, “policies and interventions aimed at strengthening the patients’ role in managing their health care can contribute to improved outcomes and that patient activation can—and should—be

measured as an intermediate outcome of care that is linked to improved outcomes” (p. 207). The purpose of this study was to determine the effect of patient activation on heart success transition clinic program completion.

Theoretical or Conceptual Framework

Patient and family engagement is an important part of health care quality and efficiency and improved health in communities. A public engagement model that James Conway developed at the Institute for Healthcare Improvement, “is organized around the settings in which patient engagement occurs: during the care experience, within the microsystem of the clinic or ward, within the healthcare organization, and within the larger community” (Carman et al., 2013, p. 223). This model of patient engagement presents the different forms that engagement can take, from consultation to involvement, to partnership and shared leadership. The authors also described in the model at what levels patient engagement can occur throughout the health care system in direct care, organization design and governance and policy making. There is also examination of the factors which influence engagement that include the patient, the organization, and society.

The multidimensional framework includes three critical aspects of patient engagement. First, engagement activities range along a continuum from consultation to partnership and shared leadership. Next, engagement occurs at different levels, from direct care, to organization design and policy making. Lastly, there are multiple factors that affect the ability and willingness of the patients to engage (Carman et al., 2013, p. 225).

The continuum of engagement is along the top of the model and signifies the flow of information between patient and provider, how active the patient is in making healthcare decisions and how involved the patient is in the health care and policy decisions. At the low-end of the continuum, patients have very little power and decision-making. Providers and organizations make decisions based on their own agenda and rarely ask the patient's input. On the high end of the continuum, there is shared power and responsibility between the patient and shared decision-makers.

The framework has engagement at multiple levels; from direct care to organizational design and policy making. At the direct care level, "engagement integrates patients' values, experiences, and perspectives related to prevention, diagnosis, and treatment, including managing the patient's health and selecting health care coverage and providers" (Carman et al., 2013, p. 225). At this level, patient engagement can range from a patient receiving information to becoming an active member in his or her health care, setting goals, making decisions, and being a patient proactive in his or her care. At the level of organizational design and governance, "engagement integrates patients; values, experiences, and perspectives into the design and governance of healthcare organizations such as hospitals, accountable care organizations [ACOs], clinics, and nursing homes" (Carman et al., 2013, p. 225). Patients at this level partner with leaders, managers, and clinicians to plan, deliver, and evaluate their care. At the partnership end of the continuum, patients may help with agenda setting, setting priorities, and share decision-making responsibilities. At the policy-making level, "engagement focuses on developing, implementing, and evaluating national, state, and local health care policy and programs" (Carman et al., 2013, p. 226). This type of engagement, also coined *public* or *citizen*

engagement, helps to make sure that the health care system is responsive to patients' perspectives. With this high level of engagement, patients collaborate with policy makers, participate in research, become representatives of consumer organizations, and speak on behalf of their peers.

There are three identified factors that influence engagement in the framework, which determine the extent that patients can engage at different levels along the continuum. The identified factors are grouped into three categories: patients, organizations, and society. Each factor can stand alone or in conjunction with one or more of the other factors. Factors that affect patients and their ability to engage can be their knowledge, beliefs, and attitudes based on their experience with the health care system, functional capacity, and self-efficacy. Vulnerable populations (i.e. low income, elderly, limited English proficiency) will face additional challenges with engagement. An organization can also affect how a patient is able to engage within it. Hospitals, physician practices, ACOs, governments, and others encourage engagement by showing that they value patient participation and leadership and that it is essential to achieving their goals. The third factor is society, which recognizes that patients and organizations operate in a broader sense and are influenced by social norms, purchasers' regulations, and government policies at the state, local, and national level.

Tracking and monitoring progress on engagement requires "the use of parsimonious, robust measures to assess what works, how it works, and over time, whether engagement efforts are improving outcomes. For example, Judith Hibbard's Patient Activation Measure, which assesses a person's capacity for engagement" (Carman et al., 2013, pp. 227-228) can help to inform at that direct-care level.

Thesis Question or Hypothesis

Is there a relationship between a higher patient activation score, as determined by the PAM-10 (Patient Activation Measure), and completion of the program in the heart failure transition clinic?

CHAPTER II

Research Based Evidence

Because HF is such an expansive problem, it is important to find ways to ensure patients can appropriately manage their disease and appropriately address any changes in symptoms. The purpose of this thesis was to determine if there is a relationship between a higher patient activation score, as determined by the PAM-10 (Patient Activation Measure), and completion of the program in the heart failure transition clinic. Patients first need to become involved in their health care so they can understand how to effectively manage their disease. Patient engagement is an issue that is more often recognized as a crucial part of high quality health care.

The literature search was accomplished using Cumulative Index to Nursing and Health Literature (CINAHL), Google Scholar, and ProQuest databases. Terms searched for were “patient engagement”, “patient activation”, and “patient engagement in heart failure”. The search was refined for relevant studies, which included heart failure and ambulatory care to narrow down the quantity of research articles.

Review of Literature

Self-Management and Health Behaviors

According to the research article by Shively et al. (2013), “few studies have examined whether chronic heart failure outcomes can be improved by increasing patient engagement in care and capabilities for self-care management” (p. 20). Shively et al. (2013) discussed the complexity of heart failure and its management, the fragmentation of follow up care, optimal HF guidelines not being followed, and the existence of multiple barriers that impede a patient’s ability to engage. Many heart failure

management programs understand that self-management strategies are a core component and central theme for the care of their patients. But in addition to changing the way organizations care for HF patients, Shively et al. (2013) discussed focusing on helping individuals become more informed about their illness and to actively engage in their own care (engagement) and improve skills for self-management.

“Current evidence supports findings that outcomes for HF care not only depend on receiving better care while in the hospital but also increasingly depend on the quality and continuity of chronic care that a patient receives outside of the hospital” (Shively et al., 2013, p. 21). Important findings of this randomized, controlled trial showed that engagement could be improved through specific interventions and these effects have different outcomes based on the level of engagement. Shively et al. (2013) concluded from their study, which consisted of 84 participants, that tailored interventions increased engagement scores with improved clinical indicators. Shively et al. (2013) also discussed the limited understanding of how patient engagement affects self-management or if better self-management behavior translates into improved outcomes in high-risk HF patients. Overall, the findings were inconclusive as to whether patient engagement affected self-management, which could be related to instrumentation or the interventions used. However, there was a significant increase in activation with the group that received interventions compared to the control group. Unfortunately, with the chronic nature of HF, it is common for patients to have fluctuations in their health status, and in turn their self-management requirements.

Barello, Graffigna, and Vegni (2012) recognized patient engagement as a major component of high-quality health care and has been the impetus for the start of research

programs and initiatives. For nurses, it is necessary to ensure patients receive better and reliable information and more control and influence over their healthcare. “By building with patients and families and fostering their engagement in the process of care, nurses can develop an appropriate plan of care and cure addressing issues such as symptom and drug management and meaningful discharge goals” (Barello et al., 2012, p. 1). While there are many avenues that can affect it, nurses have a central role in enhancing patient engagement. The primary theme is that having patients engaged in their care and having confidence in their self-management will help them deal more effectively with long-term conditions and disabilities.

Hibbard, Mahoney, Stock, and Tusler’s (2007) purpose was to determine if activation (engagement) changes over time and to determine if the activation scores can predict change in actual health behaviors. When clinicians can effectively champion activation in their patients, and make them a full partner in the care team, more effective and efficient care can be delivered, i.e. delivering better outcomes for less cost.

The findings in the (Hibbard et al., 2007) study verified that activation levels increase over time in both the control group and the intervention group. The intervention consisted of a community-centered workshop given once a week for 2.5 hours over a six week period. Each session had a weekly topic with the classes highly participative. At the end of the six weeks, the participants were given a copy of the companion book used during the sessions and an audio relaxation tape. Of note, those in the intervention group had statistically significant changes in activation scores after six weeks into the study, while at six months the difference between these two groups had decreased because over time, the control group did gain some activation. The study found that activation levels

do change over time and that different people exhibit different change trajectories. It was also found that those who had changes in activation saw changes in self-management. When activation was increased, the patient had positive self-management behaviors. In short, if activation is increased behaviors will follow.

Wasson and Coleman (2014) discussed very simply how to increase “health confidence” or engagement among patients in a primary care setting. In the descriptive study, each patient was asked *How confident are you that you can control and manage most of your health problems?* and used responses of either *very confident, somewhat confident, not very confident, and I do not have any health problems*. The patient could also use a 0-10 scale with 0 meaning *not very confident* to 10 meaning *very confident*. The idea behind this question opened up the conversation on each patient’s understanding and provided a time of self-reflection (p. 8).

Wasson and Coleman (2014) referred to a study that found that among a large sample of adults (75,000), those who had a higher level of engagement had fewer adverse experiences than those with lower levels of engagement. Those patients who were not as engaged had a higher incidence of emergency room visits or hospitalizations. “For both hospital and ambulatory care patients, health confidence is most positively associated with the quality of information provided to the patient and access to care” (Wasson & Coleman, 2014, p. 9).

Wasson and Coleman (2014) also suggested that low levels of engagement are strongly associated with low financial status and high burden of illness. Care can be undermined by chronic pain and emotional stress and lower levels of engagement. Also,

the authors suggested that if the health care provider questions the patient in a judgmental tone or without empathy, the patient is less likely to become engaged.

Stages of Engagement (Activation)

The controlled trial by Hibbard et al. (2007) suggested that patients can be in one of four stages of engagement. The first stage is when people do not yet understand that they must play an active role in their health, which accounts for 12% of the sample population. The second stage is when people lack basic facts or do not yet have a larger understanding of their disease process, which was found to account for 29% (Hibbard et al., 2007, p. 1445) of the sample population. At stage three, people understand key information about their disease process, are beginning to act, but may be unsure or lack the skill to follow through on these behaviors, which accounts for 37% (Hibbard et al., 2007, p. 1445) of the sample population. The fourth and final stage is where people have developed new behaviors but may not be able to maintain in a time of crises or stressor. This stage accounts for the remaining 22% (Hibbard et al., 2007, p. 1445) of the sample population. “These stages of activation provide insight into possible strategies for supporting activation among patients at different points along the continuum” (Hibbard et al., 2007, p. 1445).

Tools to Assess Patient Engagement

Wasson and Coleman (2014) discussed how to use the measure of engagement with patients in everyday care. First, it can be used as a vital sign for patients who have chronic conditions, health risks, or difficulty with follow up. Another way the measure can be used is as a part of a routine check-up, i.e. using the annual physical as a way to assess a patient’s level of engagement in their health care. A third way that a provider can

use the measure of engagement is for those patients who transition from another care setting, such as discharge from a hospital. Assessing the level of engagement and understanding of a patient prior to discharge can be helpful in understanding a patient's individual needs prior to his or her discharge. The final way can be for patient facing a new diagnosis, or that are preparing for a procedure, etc. When a patient is not sure of the next step or what a particular procedure entails, this can cause the patient to be less confident in their understanding.

While the techniques that Wasson and Coleman examined are helpful tools, Hibbard et al. (2007) discussed that a reliable and valid measurement tool is necessary to measure activation, as it opens up many possibilities for improving care and outcomes. Using the four stages of the Patient Activation Measure (PAM™) may help to tailor care plans to better fit the specific needs of each individual patient. Research is just beginning on the impact of interventions, and is further needed on the spontaneous increases in the control group that were observed in this study.

The Responsibility of the Health Care Provider

The commentary by Collier (2015), took a different approach to patient engagement and placed the onus primarily on the health care provider.

Hospitals and health systems exist to meet the physical and psychosocial needs of patients and their family members. Yet many hospitals, physician practices, and outpatient and community-based providers continue to deliver services without fully engaging the patient as a partner, despite growing evidence that active engagement of patients and family members contributes to improved outcomes, experiences, and costs. (Collier, 2015, p. 168)

Many times, it is assumed that because health care providers give care *to* and *for* patients, that patients do not have any decision-making power. Not all hospitals and healthcare systems buy into the importance of patient engagement. Collier discussed that a change in the patient care culture is the only way to transform care and increase patient engagement.

Also, if a patient's progress is slower than expected regarding their level of engagement, pain, or emotional problems, such as depression may need to be assessed. These issues can deter a patient from continuing to engage in his or her health care.

Collier suggested three key behaviors of providers to positively impact the amount of progress that needs to be made with patient and family engagement. The first behavior is to define what patient care means to each caregiver. This definition encompasses the health care organization, as well as the individuals who make up its teams, division, professions, and leadership groups. In short, health care providers must make patient partnerships part of their personal culture.

The second behavior is for healthcare providers to make the personal choice to change. The first step in this behavior is recognizing that a change is needed.

One recurring factor that is critical for success in [an] organization is the inclusion of employees, patients, and families in the planning, implementation, and evaluation of the decision to act. The logic behind engaging all members early and often reflects a basic principle in the science of change management: change is personal. (Collier, 2015, p. 169)

In order for a health care organization to be successful in changing processes, the organization must help individuals move beyond passive acceptance and develop personal ownership in the change. Health care leaders must accept that the responsibility of engaging patient and families in all aspects of the care delivery system is part of the change process.

The third behavior is to develop personal resilience to sustain change. Leaders can anticipate numerous challenges when implementing widespread organizational change, including assisting employees with understanding why the change is needed, reallocating resources to support the change, navigating the system's politics, and tapping into the personnel of team members to support the changes.

A Culture of Engagement

A patient engagement culture is not something that is easily instituted or quickly adopted through an educational program. It is an ongoing journey that benefits both providers and patients who are committed to see the culture change towards one of engagement.

CHAPTER III

Methodology

Heart failure affects more than five million people in the United States and is one of the most common reasons for hospitalization and readmissions. CMS has passed regulations within the Medicare program to not reimburse hospitals for readmissions within 30 days regardless of cause for multiple disease states (HF, pneumonia, acute myocardial infarction, chronic obstruction pulmonary disease (COPD), and for elective hip and knee arthroplasty). Because heart failure is one of the conditions that affects the readmission problem, a transition clinic was established to help combat the readmission problem.

This ACP-run clinic is heavily focused on education and self-care, in addition to ensuring that patients have access to necessary resources to be successful in the long-term management of their chronic illness. The purpose of this thesis was to determine the level of engagement among patients before and after participation in the transition clinic and if an increase in engagement helps to decrease 30-day hospital readmission.

Study Design

The design for this study was a quantitative descriptive study. The patient was given a 10- item questionnaire prior to discharge from the hospital and the level of activation will help the staff in the transition clinic tailor specific educational interventions at the transition clinic, based on recommendation associated with the PAM-10 tool.

Setting and Sample

The research took place in a large teaching hospital in an outpatient transition clinic. This is a short-term clinic that exists to assist with lowering readmissions of heart failure patients, as well as high risk medical patients who meet specific high-risk criteria. The population for this study consisted of patients who had been admitted into the hospital with a primary diagnosis of heart failure. The convenience sample was all patients that the inpatient navigator visits in the hospital and agrees to participate in the study. Those in skilled nursing facilities or those who are cognitively impaired (i.e. dementia, Alzheimer's, which is one type of dementia, senility) will be excluded from the sample. Fifty patients were the target sample size. The target sample size was determined based on the data from the clinic schedule. The transition clinic had 111 new patients scheduled from January 1 to March 31, 2016. Based on the data from the first quarter of 2016, approximately one-third of scheduled patients did not show to their appointments. If patients from a nursing home, cognitively impaired patients, and non-English speaking patients are excluded, this leaves an estimated 50 patients to participate in the study during the three month period from April to June 2017. Fifty patients were chosen based on the trends of patients arriving to appointments and continuing in the program, which is what the transition clinic averages in a three month period.

Design for Data Collection

After consent is obtained, each participant was given the Patient Activation Measure[®] (PAM[®]) by the navigator in the hospital. The questionnaire was self-administered, or assistance from a family member was obtained. Demographic information was collected to be able to track the patient from discharge from the hospital

through the completion of the transition clinic. Each patient had a number assigned to them so that once the program is complete, there was no identifiable information on the questionnaire.

Measurement Methods

The tool used was the copyrighted 10-item PAM[®] with permission from Insignia Health (2014) (Patient Activation Measure License Package) to measure activation. The PAM[®], which assesses patient knowledge, skill, and confidence for self-management, is a unidimensional, interval-level, Guttman-like scale (Hibbard et al., 2007, pp. 1443-4). The PAM[®] is a latent construct—a variable that cannot be measured directly but instead is assessed through a series of answers to questions—that gauges a person's self-concept as a manager of his or her health and health care (Hibbard & Greene, 2013, p. 208).

Permission has been granted from Insignia Health to use the tool for this research study

Data Collection Procedure

Each of the PAM-10 items was scored on a 4-point scale; the summed raw score was converted to a 0 to 100 activation score by a pre-programmed excel program. The activation score was then used to identify the level of activation as provided on the licensed instrument instructions. The responses from the tool was tabulated and entered in an Excel file provided by Insignia Health, LLC to give numerical data to the questionnaire. The data was collected by the author during clinic visits from April to June 2017.

Protection of Human Subjects

All subjects signed an informed consent form (Appendix A) after being provided information about the study and given the opportunity to ask questions. Participation in

the study was voluntary with no coercion. There was minimal risk to participate in this study. The only foreseeable risk was any anxiety or discomfort associated with filling out the questionnaire and consenting to the study. Any other risk would be the same as going to an office visit. Each patient received the standard of care for heart failure regardless of their decision to participate in the study. The study was conducted according to the rules given by the Institutional Review Board (IRB) of both the medical center and university. There was no cost to the patient or the organization for participation in the research study.

Data Analysis

Data was entered into an Excel file provided by Insignia Health, LLC, per their copyright requirement. “The PAM[®] was scored on a 0-100 scale, and people were categorized into four levels of activation, with level one the least activated and level four the most activated” (Hibbard & Greene, 2013, p. 208). The questionnaire triggered a score based on the answers to the questions and then gave a corresponding level to assist with suggested interventions that are provided with the tool. “The measure has been proved to be reliable and valid across different languages, cultures, demographic groups, and health statuses” (Hibbard & Greene, 2013, p. 208).

CHAPTER IV

Results

The purpose of this study was to determine if there was a relationship between a higher patient activation score, as determined by the PAM-10 (Patient Activation Measure), and completion of the program in the heart failure transition clinic. Evidence is growing that the higher the amount of patient engagement, the better the health and cost outcomes. This study attempted to validate this fact and perhaps affect change in long term follow up among other chronic diseases.

Sample Characteristics

The final sample size was 36 participants, with an initial goal of 50 participants. While there were more than 50 potential participants, due to the nature of the exclusion criteria, there were several nursing home and non-English speaking people who did not qualify to participate. Of the 36 participants, only two were not scheduled, both of whom were from out of town and followed up locally.

The 36 participants consisted of 16 females and 20 males, aged 34 to 89, with a median age of 64. Most of the participants were aged between 50 and 79 (n=26), with the 60-69 age range being the largest, consisting of 11 participants. There were 23 African Americans, 11 Caucasians, one Hispanic, and one American Indian who participated in the study.

Major Findings

Following data analysis from the 36 participants in the research study, approximately one-half (47%) of the participants (n=17) scored as a PAM level 3. PAM level 2 (n=11), which accounts for 30% of the participant population, made up most of the remaining participants. There were three participants who scored a PAM level 1 and five who scored a PAM level 4. (Figure 1).

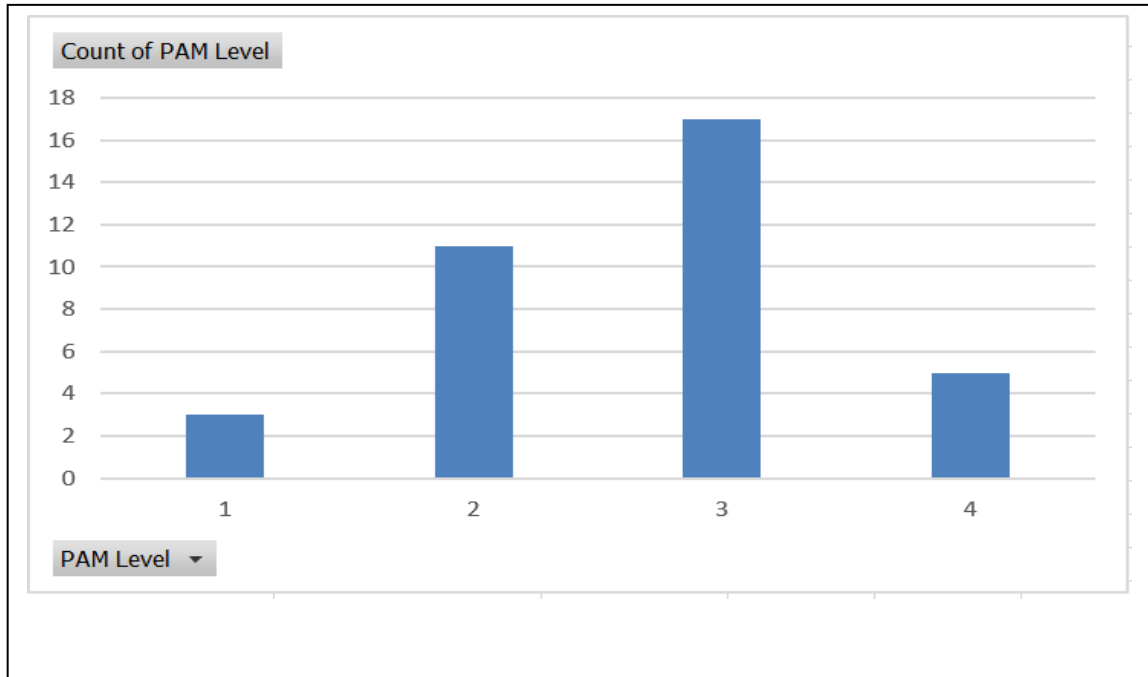


Figure 1. PAM-10 Level Count

Those who scored a 3 on the PAM-10 (n=17) had the highest percentage of completing all transition clinic visits (76%), while those who scored a 2 on the PAM-10 (n=11), had the lowest completion percentage at 45%. As a whole, one-half of participants who were a PAM level 1 & 2 completed, while 73% of those who were a PAM level 3 & 4 completed the transition clinic. (Figure 2).

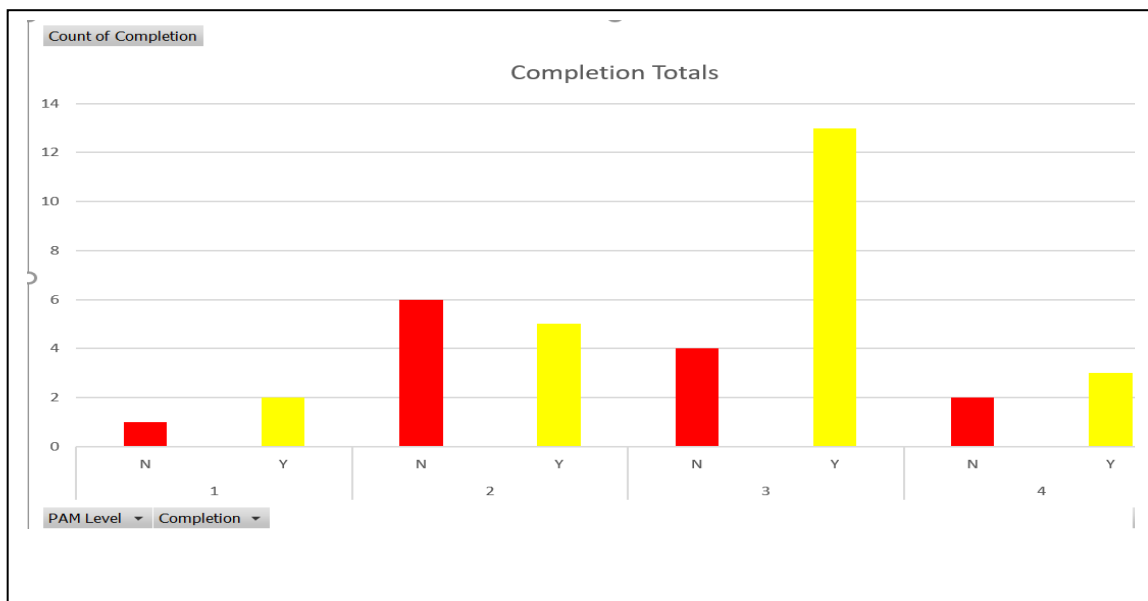


Figure 2. Completion Totals by Level

Those participants aged 50-59 had the highest completion percentage at 85%, however, most of the participants who scored a level 3 on the PAM 10 were aged 60-79 (n=10). (Figure 3).

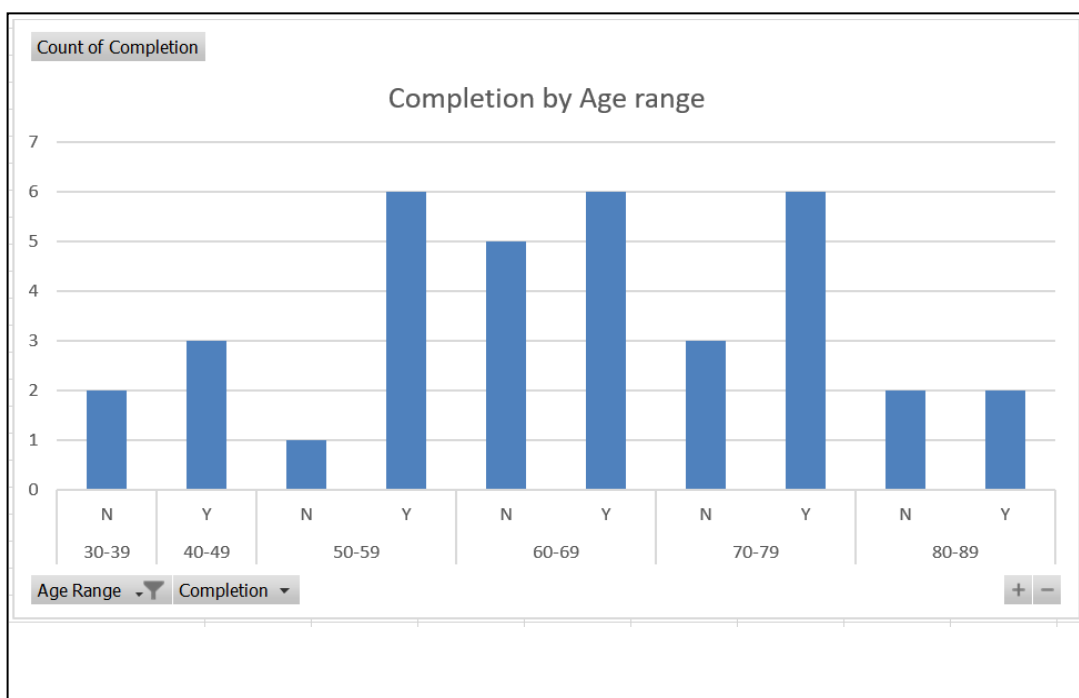


Figure 3. Completion Totals by Age

The participants were primarily either African American or Caucasian, with 64% of the participants African American. While both the Hispanic and American Indian participants completed all visits, they only made up 5% of the population, therefore, African Americans had the highest attendance (n= 17) and completion (74%). Of the 11 Caucasian participants, only one-third of Caucasian participants (n=4) attended and completed all visits. (Figure 4).

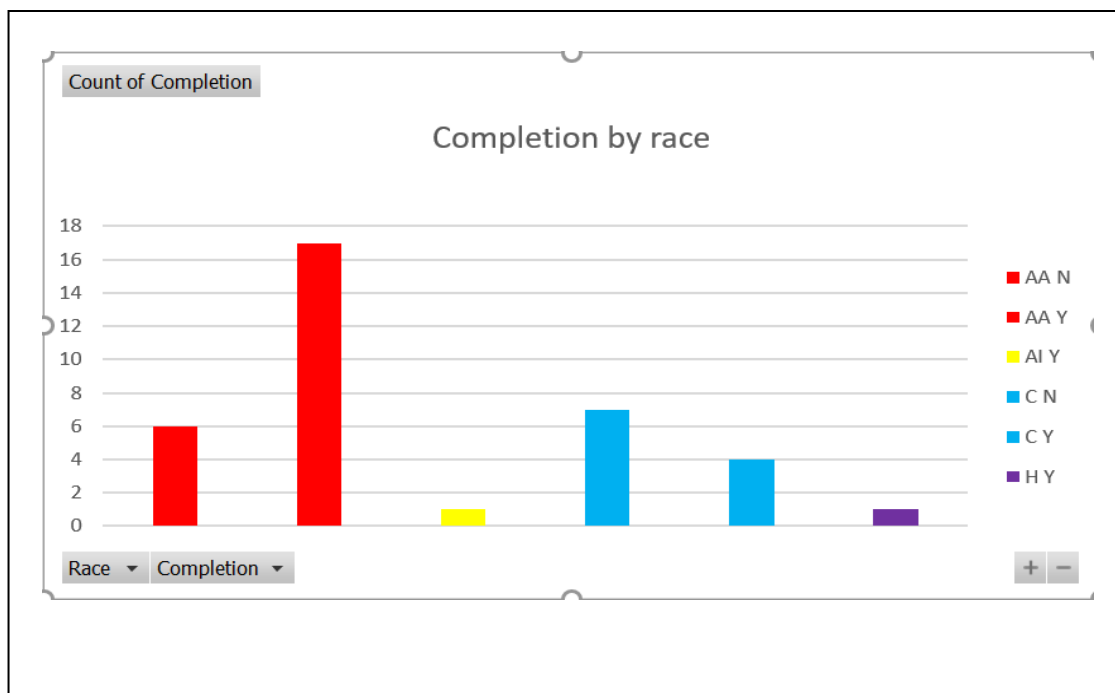


Figure 4. Completion Totals by Race

As stated before, of the 36 participants, 20 were male and 16 were female.

Females had a higher completion percentage (n=12) at 75%, while the male's completion percentage (n=11) was 55%.

Summary

In summary, out of the 36 participants in the study, 23 completed all visits and 13 either did not complete or did not show up for their first visit with no rescheduled visit. African Americans were the largest population to be identified for the study, to attend and complete all visits associated with the transition clinic. Most participants were aged between 50 and 79 with an average age of 64. More males than females were enrolled, however, females had a higher completion percentage. Those in the 50-59 age range had the highest completion, however the largest age range for participation were those aged

60-69. Most of the PAM-10 scores were a level 3, which also had the highest completion rate.

CHAPTER V

Discussion

Due to the large number of Americans affected yearly with heart failure, it is imperative that health care providers continue to find ways to improve the care of patients while in the hospital as well as after discharge. Routine follow up is the key to successful outcomes with heart failure and many other chronic diseases. An important part of the routine care is ensuring that patients are engaged in the process of their care and recovery. Therefore, using the PAM-10 tool to identify where patients have a knowledge deficit is essential for each patient's long-term success.

Implication of Findings

Nearly one-half of participants scored a level 3 on the PAM-10. As previously discussed, patients who are a PAM level 3 have basic facts about their condition and treatment and some confidence in self-management. Those who scored a level 3 also had the highest completion percentage (76%) compared to the rest of the participants. Those who were a PAM level 2 were the least likely to complete the transition clinic (60% did not complete). According to Insignia Health (2014), these patients lack basic knowledge of their condition, treatment options and/or self-care. They have little experience or success with behavior change and feel less in charge of their own health and care (p. 6). Based on patient's confidence with changing their behavior and how in charge of their health they felt, directly correlated with the likelihood of completing the transition clinic. Overall, two-thirds who scored either a level 1 or 2 did not finish, most likely because they lack the knowledge about their disease and feel like they have minimal control they don't follow through with treatment modalities and follow up visits. On the other hand,

those who have a moderate to high level of understanding and confidence in their control over their healthcare were more inclined to adhere to their treatment plan because they understood the importance.

Overall, the results of the study were similar to the identified research. Those who have a higher level of engagement have better outcomes and less readmissions and emergency room visits. No patient who was a level 3 or 4 was readmitted to the hospital or went to the emergency room. Barello et al. (2012) discussed patient engagement being a major component in high-quality health care, and how necessary it is for nurses to provide better and reliable information so that patients have more control and influence over their healthcare. The researcher found that those who came to the transition clinic were given more specific education for heart failure and could take a more active role in their self-care due to better information. This finding is consistent with the literature on patient activation and the PAM-10 questionnaire.

Application to Theoretical/Conceptual Framework

As stated previously, the multidimensional framework includes three critical aspects of patient engagement. First, engagement activities range along a continuum from consultation to involvement to partnership and shared leadership. Next, engagement occurs at different levels, from direct care to organization design and policy making. Lastly, there are multiple factors that affect the ability and willingness of the patients to engage (Carman et al., 2013, p. 225). Along the top of the model is the continuum of engagement which signifies the flow of information between patient and provider, how active the patient is in making healthcare and policy decisions.

This study focused on the direct care level of engagement. The framework identified three factors that influence engagement, which determines the extent that patients can engage at different levels along the continuum. The identified factors are in the categories of patients, organizations, and society. Due to the focus of this study on the patient's level of activation, i.e. engagement, the primary category is the patient. Factors that can influence the patient are beliefs about patient role, health literacy, and education. The PAM-10 addresses these beliefs in the questionnaire.

This framework was appropriate for this study, because it discusses what the PAM questionnaire measures. The transition clinic follows the direct care continuum of engagement for all patients who attend, which would include those who participated in this study. The continuum includes consultation, involvement, and partnership. The more engaged a patient is in their care, i.e. the higher the PAM level, the more participatory they will be on the continuum of engagement. In addition, the factors mentioned in the framework that influence engagement on a patient level (beliefs about role, health literacy and education) affect the PAM scores. The findings are congruent with the framework because those who had higher PAM scores and were shown to be more activated (engaged), were further on the continuum than those with lower scores.

Limitations

There were several limitations that potentially could have impacted the study. The first was the length of the time the data was collected. Due to time constraints with completion deadlines, data was collected over two months instead of three months, the preferred length of time. Another limitation would be the sample size of 36 patients. The goal was for 50 patients to be enrolled, as this was what the usual average of patients that

attended the transition clinic who would be eligible to participate in the study, in a three month period.

A third limitation was the lack of contact with the participants in the study. During the process of getting this thesis approved, the researcher began to work in a different department and another nurse became responsible for the education provided to the patient. The heart failure navigator recruited all patients for the study, obtained their consent, and administered the questionnaire which was sent to the researcher via secure email. The researcher had no physical contact with any of the patients nor gave any education personally. This could have had the potential to change the adherence as they may not have been as much reinforcement with the importance of attendance. The design of this study did not change as there was no turnover of the Advanced Care Practitioners (ACP's), so therefore the standard of care was not affected.

The final limitation that was identified was with the study design. The participants did not repeat the PAM questionnaire after they completed the transition clinic, but it may have been more helpful to identify changes in the PAM levels after the patient were given education and tools for self-management. Some of the literature discussed improved engagement after specifically tailored education.

Implications for Nursing

The research is very clear that a patient's level of activation directly correlates to better outcomes with both adherence and readmissions. It is helpful to know how engaged a patient is in their care upon arrival to a patient care area (inpatient or outpatient) to better tailor education for that patient. The study determined that those who had a higher level of engagement were more likely to be adherent to a medication

regimen and attend follow up visits with their health care providers. This fact is most likely not limited to heart failure patients, and most likely the outcome could be duplicated with other disease states.

It would be helpful to administer the PAM-10 questionnaire to all new patients in an outpatient clinic so that nurses can give appropriate education based on each patient understanding of their disease process. Inpatient nurses could also assess activation via this questionnaire as well, however, the education might be different due to the acute nature of their encounter with the patient. It is most appropriate to administer the PAM as an outpatient, as there are fewer time constraints in regards to education that the nurse can provide. A second questionnaire could be given after the patient has been education and expressed understand to assess the effectiveness of the education provided. This would also be helpful to supply feedback on how the nursing staff can improve the education given to be the most effective.

Recommendations

Due to the short length of the study and small sample size, a larger sample size may be beneficial to ascertain if the results would be different with more participants. It would also be beneficial to repeat the PAM questionnaire after completion of the program to assess improved engagement with the participants. It might also be helpful to expand the study to include other chronic diseases that the transition clinic takes care of, such as Chronic Obstructive Pulmonary Disease (COPD) and diabetes. It would not be hard to have the patients complete the PAM-10 to further tailor their education based on their activation level. The PAM-10 is valuable for all chronic diseases and any attempt to improve a patient's engagement with their chronic illness will hopefully decrease

hospitalizations and nonadherence to treatment regimens. The PAM could be used in all new patient paperwork for physician offices to assess their level of activation and therefore tailor any education given to each patient's activation level. Hospitals could benefit from the PAM if they administered it upon admission as well, in order to adequately prepare and educate patients according to their level of activation and understanding.

Conclusion

Despite the limited information, it is clear that those participants who had a higher PAM-10 score (more engaged) were most likely to complete the program. Additional studies should be done to replicate results. Evaluation of current practices in regards to education and evaluating understanding should be ongoing and modified to suit each population. The PAM-10 is a timeless model without regard for disease process and could be utilized in any practice setting. As stated in the research, the PAM-10, those who had a higher level of engagement had fewer adverse experiences than those with lower levels of engagement. Therefore, using the PAM-10 with patients will help to improve overall outcomes for patients.

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Appendix A

Consent to Participate in Research Study

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CAROLINAS HEALTHCARE SYSTEM CONSENT TO PARTICIPATE IN A RESEARCH STUDY

The effect of patient activation on transition clinic adherence

INTRODUCTION

The CHS Heart Success Clinic (hereafter called the transition clinic) is asking you to participate in this research study at Carolinas HealthCare System (CHS). You are being asked to take part because you have a diagnosis of Heart Failure. The purpose of this study is to determine the effect of patient activation on heart success transition clinic adherence. Patient activation is defined as the skills and confidence the help patients to become actively involved in their health care. You will be one of approximately 50 people involved in this research project at CHS, and your participation will last for 1 month.

HOW THE STUDY WORKS

Because you have been admitted to the hospital with heart failure, you are visited by a nurse navigator to offer you the services of the transition clinic. The transition clinic is an office visit that you will attend weekly for a month where you will be seen by either a nurse practitioner or physical assistant, a pharmacist, a social worker, and a nurse. They will help you learn how to manage your heart failure, learn about your medications and diet.

Regardless of your participation in the transition clinic, you will be offered to participate in this study. If you agree to the study, you will be given a questionnaire called the PAM-10 (Patient Activation Measure). This questionnaire gives a score based on your level of activation. If you choose to not participate in the transition clinic, your responses will be entered into the database for research purposes. If you agree to attend the transition clinic, this questionnaire will help your health care provider to give you specific care based on your level of understanding of heart failure and how to manage your disease at home. The difference in care is based on education and teaching, no standardized medical interventions. You will receive the standard of care for heart failure regardless of your participation in the study.

Date: 08/11/2016
Expiration: 08/10/2017
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RISKS

There is minimal risk to participate in this study. The only risk will be any anxiety or discomfort associated with filling out the questionnaire and consenting to the study. Any other risk would be the same as going to an office visit.

EXCLUSION CRITERIA

- Nursing home patients
- Cognitively impaired patients
- Non-English speaking patients

BENEFITS

This study may or may not improve your condition. The information gained from your case may benefit others with your condition.

ALTERNATIVE PROCEDURE/TREATMENT

None

WITHDRAWAL

Your participation in this study is completely voluntary. You should feel under no pressure to be in the study. If you decide not to be in the study that will not in any way harm your relations with your doctors or with Carolinas HealthCare System. You are free to stop being in the study if you change your mind after entering it. This would not harm your relations with your doctors or Carolinas HealthCare System.

CONFIDENTIALITY

The records of this study will be kept private. In any sort of report, we might publish, we will not include any information that will make it possible to identify a patient. Your record for this study may, however, be reviewed and/or photocopied by the investigator and/or Carolinas Healthcare System. To that extent, confidentiality is not absolute.

Date: 08/11/2016
Expiration: 08/10/2017
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AUTHORIZATION

If you wish to take part in this clinical study, you will be asked to sign this consent form. It allows the study sponsor and the study investigator to collect, process and pass on to the sponsor organizations any relevant personal health information collected from you during the study. These are activities routinely carried out during all clinical studies.

You have been told that personal information about you (including sensitive personal health information, such as your medical history and your racial/ethnic origin if relevant to the study) will be reviewed, collected on a computer database, stored in electronic or manual files, audited, and/or otherwise processed by:

- the clinical study investigator, Megan McGraw, BSN, RN, CHFNP,
- the study sponsor and/or its associated companies, Frances Sparti, DNP, RN
- authorized by the study sponsor,
- Carolinas HealthCare System employees.

You have been told that your personal data are being collected and processed to:

- check your suitability to take part in the study,
- monitor your treatment,
- compare and pool treatment results with those of other subjects in the study,

You have been told whenever your personal information is processed; it will be kept confidential and secure, to the best of our ability. It will be used only for the purpose for which it was collected.

This Authorization does not have an expiration date. You have been told that according to the guidelines for good clinical practice, the study investigator and sponsor will keep your personal information only until the research is complete. If you do not withdraw this Authorization in writing, it will remain in effect indefinitely.

FINANCIAL INTEREST OF INVESTIGATOR

None

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QUESTIONS

The researcher doing the study at Carolinas HealthCare System is Megan McGraw, BSN, RN, CHFNP. You may ask them any questions you have now. If you have questions later, you may contact Megan at:

Carolinas Medical Center
1000 Blythe Boulevard
Charlotte, NC 28203
Telephone (980) 442-5149

The Institutional Review Board is a group of people who review the research to protect your rights. If you have questions about the conduct of this study or about your rights as a research subject, you may call the chairperson of the Institutional Review Board of Carolinas HealthCare System for information regarding patients' rights in a research study. You can obtain the name and number of this person by calling (704) 355-3158.

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Date: 08/11/2016
 Expiration: 08/10/2107
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CONSENT

I have read the above information. I have asked any questions I had, and those questions have been answered. I agree to be in this study and authorize the use of my personal health information. Megan McGraw, BSN, RN or Dana Harris, BSN, RN will give me a copy of this form.

Patient [representative] Print Name

Date

Time

Patient [representative] Signature

Date

Time

Signature of Person Obtaining Consent

Date

Time

Investigator Signature

Date

Time

Identity of representative:

___ **Next of Kin**

___ **Parent/Guardian**

___ **Healthcare Power of Attorney**

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