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Health Literacy, Care Transition and Adherence with Discharge Instructions of Patients Discharged to Home from the Emergency Department

A Dissertation Presented By

Virginia B. Mangolds

Submitted to the Graduate School of Nursing

University of Massachusetts Medical School

In partial fulfilment of the requirements for the degree of

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Abstract

Purpose: The purpose of this study is to describe the relationship between health literacy, preparedness for discharge, adherence to discharge instructions and difficulty coping after discharge among emergency department patients.

Specific Aims: The Aims of this study were to: (1) describe the variability of health literacy of adult patients in an academic tertiary Emergency Department; (2) describe the relationship between health literacy, care transition, and perceived readiness for discharge on the patient's adherence to discharge instructions and (3) explore whether health literacy, perceived preparation for discharge and care transition, predicts difficulty coping after discharge.

Framework: Dr. Meleis's Transitions Theory was used as a framework.

Design: This is a prospective cohort study of adults treated and discharged from the ED.

Results: Eighty five percent of the subjects completed the study (n = 132). Subjects satisfied with transition care (P = .025) and who felt more prepared for discharge (P = .035) had less difficulty coping. Subjects more satisfied with care transition were more likely to adhere to medication instructions (P = .029). The higher the satisfaction with discharge preparation, the less likely the subjects were to go to their follow-up appointment (P = 0.051). No associations were found with health literacy.

Conclusion: Satisfaction with care transition during the discharge process and feeling well-prepared are related to less difficulty coping after discharge. Nurses have an opportunity to intervene and enhance the discharge experience. This may contribute to more positive outcomes after being seen in an emergency department.

Health Literacy, Care Transition and Adherence with Discharge Instructions of Patients Discharged to Home from the Emergency Department

Dissertation Proposal

Virginia B. Mangolds MSN, FNP-C, BSED, CEN

Submitted April 2016

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Introduction and Specific Aims

In the current healthcare environment, fewer Emergency Department (ED) patients are admitted into the hospital, resulting in more patients leaving an ED with the need to assume sometimes complicated self-care regimens (Zavala & Shaffer, 2011). Hospital discharge and transition to home is a potential period of significant risk for some patients as they assume responsibility for their health at home. Often patients themselves don't realize what they need to do to take care of themselves at home and are frequently misjudged by healthcare providers to be knowledgeable and prepared to assume self-care once discharged (Engel et al., 2009). Gignon et al. (2014) conducted a qualitative study of 36 patients discharged from the ED, where nearly half of the patients reported difficulties understanding their drug prescription. Comparing self-reported ED discharge instruction adherence between White, Black and Hispanic patients, James, Smith and Brice (2008) found that although there was no statistical differences between the races for follow up appointments completion, the rates were low in general (62.4%, 56.5%,and 53.1% respectively). This trend reversed itself with prescription filling adherence (83.8%, 86.8%, and 94.6 % respectively).

Studies done on in-patients have shown that lack of understanding or inability to follow discharge instructions may result in medical errors, adverse drug events, and poor patient outcomes, increased cost, and repeat visits/evaluations (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011; Dewalt, Berkman, Sheridan, Lohr, & Pignone, 2004; Eichler, Wieser, & Brugger, 2009; Griffey, Kennedy, McGownan, Goodman, & Kaphingst, 2014; Herndon, Chaney, & Carden, 2011; McNaughton et al., 2013). Many factors contribute to this problem including low literacy, low health literacy, medical insurance status, age, native language, medication costs, poor provider- patient communication, inadequate coping mechanisms and acuity of

illness (Bobay, Jerofke, Weiss, & Yakusheva, 2010; Cheung, Wiler, Lowe, & Ginde, 2012; Fitzgerald-Miller, Piacentine, & Weiss, 2008; Gabayan et al., 2013; Hope, Wu, Tu, Young, & Murray, 2004; LaCalle & Rabin, 2010; LaCalle, Rabin, & Genes, 2013). But what has not been well studied is the relationship of health literacy, patient's preparedness for discharge or confidence in ability to assume responsibility of self-care, and difficulty coping with their outpatient recovery from an acute illness, injury or a chronic illness exacerbation treated in the emergency department setting and sent home.

Effective communication and clear discharge instructions are especially challenging in an Emergency Department (ED) where overcrowding, understaffing, lack of patient familiarity and segmented care make clear communication challenging (Samuels-Kalow, Stack, & Porter, 2012). In an analysis of patient communications in an emergency setting, Vashi and Rhodes (2011) found that often discharge instructions are incomplete and that although 91% of the discharges included some opportunity to ask questions, only 22% of providers confirmed patients' understanding of instructions. This problem is further exacerbated in patient populations whose primary language is not English (Smith, Brice & Lee, 2012).

Patient's readiness for discharge is most often decided by the medical team, based on achieving desired clinical criteria, and may not take into account the patient's perceived readiness for discharge and transition of care satisfaction. In a population of medical-surgical in-house patients, Weiss et al.(2007) found that discharge teaching (amount of content received and nurses' skill in teaching delivery) and care coordination explained 51% of readiness for discharge variance as evidence of the importance of quality discharge instructions and patient communication. Subsequently, greater readiness for discharge was predictive of fewer readmissions and less post-discharge coping difficulty (M. E. Weiss et al., 2007).

The purpose of this study is to describe the relationship between health literacy and preparedness for discharge, adherence to discharge instructions, difficulty coping after discharge, and ED recidivism among patients treated in the ED.

Specific Aims

Aim #1. Describe the variability of health literacy among a consecutive sample of Emergency Severity Index (ESI) level 2, 3, and 4 adult patients in an academic tertiary Emergency Department.

Aim # 2. Describe the association of adherence to discharge instructions, with health literacy, perceived preparation for discharge and satisfaction with the transition of care to home.

Hypothesis: *Adherence to discharge instructions will be lower with low health literacy, poorer perceived preparation for discharge and dissatisfaction with the discharge process.*

Aim # 3: Determine if heath literacy is a predictor of difficulty coping after discharge, if there is a correlation between the transition of care to home and difficulty coping after discharge and if there is a correlation between the patient's perceived preparation for discharge and difficulty coping after discharge.

Hypothesis: *Low health literacy predicts more difficulty coping after discharge. There is a positive correlation between dissatisfaction with the transition of care to home and discharge preparation with more difficulty coping after discharge.*

Aim # 4: Of health literacy, perceived preparation for discharge and satisfaction with the transition to home, which is the stronger predictor of difficulty coping after discharge.

Results of these aims will inform discharge practices and may indicate the need for additional or alternative education and patient centered problem solving.

Background and Significance

The purpose of this literature review is to examine our current understanding of the four main concepts being explored in this study and how they specifically relate to care in an ED: (1) health literacy, (2) transitional care satisfaction/ patient perceived readiness for discharge; (3) difficulty coping after discharge, and (4) patient adherence to discharge instructions. Although there is a large amount of literature available regarding all these topics from the in-patient experience, little has been written from the point of view of the emergency department patient being discharged to home. This study is intended to help fill this void.

Health Literacy and Numeracy

Literacy skills and definitions have been evolving since the Civil War, when the determination of being "literate" was being able to sign one's name on a legal document, as opposed to signing with an "X" (Lockridge, 1974). The same can be said of Health Literacy (HL) skills and definitions. A widely used definition of Health Literacy, described by Ratzan and Parker (2000) and being used for this research project is " the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (p. vi). It is the same definition adopted by the Institute of Medicine (IOM) in their sentinel publication: "Health Literacy: A Prescription to End Confusion" (Nielsen-Bohlman, Panzer, & Kindig, 2004) and is used by the Department of Health and Human Services for their "Healthy People 2010" report (Sondik, Friedan, & Sebelius, 2012). This definition conceptualizes health literacy as individual capacities that allow a person to acquire and use new information (Baker, 2006). The IOM went further to describe the knowledge associated with health literacy into four domains: (1) cultural and conceptual

knowledge, (2) oral literacy, including speaking and listening skills, (3) print literacy, including writing and reading skills, and (4) numeracy.

In this study, I will use the definition of health numeracy proposed by Golbeck et al. (2005), "Health numeracy is the degree to which individuals have the capacity to access, process, interpret, communicate, and act on numerical, quantitative, graphical, bio statistical, and probabilistic health information needed to make effective health decisions" (p.375). Health numeracy is a very important and integral aspect of being health literate (Ancker & Kaufman, 2007; Golbeck et al., 2005; Rothman, Montori, Cherrington, & Pignone, 2008). Less discoursed than health literacy, it is not less important for following medical information that has any computation skill requirement, e.g. interpreting food labels (Rothman et al., 2006), following medication prescriptive instructions (Abdel-Kader et al., 2010; Marden et al., 2012) and understanding statistical information such as "risk/benefit" when making health related decisions regarding treatment (Reyna, Nelson, Han, & Dieckmann, 2009). Interestingly, when numeracy was divided into 3 different domains by Levy et al. (2014) (e.g. a health domain, a financial domain, and a pure math domain), out of 962 participating individuals aged 55 and older, there were significantly lower scores when questions were posed in the health domain (54% correct) versus the pure math domain (66% correct) or the financial domain questions (63% correct). This is concerning in that even for educated well- functioning adults, health numeracy may present unanticipated difficulty (Levy et al., 2014).

Effective communication and patient education are core parts of the nursing and medical profession, and yet studies have indicated that both nurses and doctors frequently overestimate the patient's health literacy level and understanding of their medical conditions and treatment. Using the Newest Vital Sign (NVS) as a health literacy screening tool, Dickens, Lambert,

Cromwell and Piano (2013) tested the ability of 30 nurses to estimate a total of 65 of their in-patient, cardiac patients' level of health literacy. They demonstrated that nurses were poorly able to identify low health literacy with 6 underestimated patients to every 1 overestimated patient. Kelly and Haidet (2007) demonstrated that12 non-academic primary care physicians in the U.S. Veteran's Health Care System, when asked to rate 100 of their patient's literacy level on a 1- 4 scale (1 being low health literacy) overestimated the level for all races compared to the actual score they received when using the Rapid Estimate of Adult Literacy in Medicine (REALM) health literacy screening tool. Although the REALM scores were not significantly related to the patient's race/ethnicity or gender, the physicians overestimated the REALM level for 54% of African Americans, 11% of white non-Hispanic, and 36% of other race/ethnicity patients ($p < .01$). This discordance of literacy levels may contribute to disparities in health care (Kelly & Haidet, 2007). In the outpatient clinic setting, Bass, Wilson, Griffith and Barnett (2002) demonstrated that when using the REALM-R (Rapid) as a screening tool for 182 adult patients, medical residents estimated that only 10% of the patients (18) had literacy problems when 36% of them (59) actually failed the literacy screen. This consistent inability to estimate health literacy may interfere with the effectiveness of the interaction of the patient with the health care system, therefore increasing the risk for poor health outcomes.

Health literacy and numeracy in the emergency medicine environment.

Health literacy outcome research has generally been limited to specific diseases. A systematic review of health literacy and emergency department outcomes (Herndon et al., 2011) revealed that collectively from the 31 studies that met inclusion criteria, health literacy skills were assessed at or below the eighth-grade level by 40% of the ED patients. Concerning is that most ED discharge materials were typically written at or above the ninth-grade level. Patients

aged 65 years or older with low health literacy were more likely to use the ED and incur higher ED costs.

Using the Subjective Numeracy Scale (SNS) and the Subjective Literacy Scale (SLS) to evaluate patient health literacy in 4 emergency departments between January 2008 and September 2010, McNaughton et al. (2013) investigated the odds of 30-day emergency department or hospital recidivism for patients with the specific diagnosis of acute heart failure. Of the 709 adult patients included in the analysis, 390 (55%) had low numeracy skills and 258 (37%) had low literacy skills. Both low numeracy skills and low health literacy were associated with increased odds of recidivism within 30 days (adjusted odds ratio, 1.41; CI, 1.00 – 1.98; p = 0.048) and adjusted odds ratio of recidivism of 1.17 (95% CI, 0.83 – 1.65; p = 0.048), respectively.

Numeracy capabilities seem to be even less than health literacy capabilities. Griffey et al. (2014) investigated the correlation between health literacy and general numeracy in an urban, academic ED with 97,000 annual visits. Health literacy was evaluated using the Short Test of Functional Health Literacy in Adults (S-TOFHLA), the Rapid Estimate of Adult Literacy in Medicine-Revised (REALM-R) and the Newest Vital Sign (NVS). General numeracy was evaluated using four validated questions. General numeracy performance was poor, with only 4% of 446 patients answering all four questions correctly, and 20% did not answer ANY of the questions correctly. Patients with limited health literacy had a mean number of correct answers approximately half of what the adequate health literacy group had.

In an effort to determine the diagnostic accuracy and feasibility of screening for health literacy specific to the ED environment, Carpenter, Kaphingst, Goodman, Lin, Melson and Griffey (2014) administered 4 health literacy screening tools and evaluated physician gestalt

(PG) for 435 participants between March 2011 and February 2012 at a single urban academic emergency department with over 97,000 total annual visits. Excluding patients experiencing distress (as judged by the attending physician), altered mental status, aphasia, mental handicap, non–English speaking, sexual assault victims, acute psychiatric illness and corrected visual acuity worse than 20/100 using both eyes, each subject completed five health literacy screening tools: (1) the REALM-R; (2) the NVS; (3) Single Item Literacy Screens (SILS); (4) health numeracy and (5) S-TOHFLA. As well, physicians were asked their "gestalt" (PG) of whether the patients exhibited inadequate, marginal or adequate levels of health literacy. The S-TOHFLA was used as the "gold standard" from which to compare all other screening tools.

Of the 435 patients in this study (Carpenter et al., 2014), 18% had less than a high school education. Defining low health literacy (LHL) as a score of 22 or less on the S-TOHFLA, the prevalence was 23.9%. In comparison, LHL was demonstrated more frequently by the NVS, REALM-R and PG (64.8%, 48.5% and 35% respectively). The determination of the "feasibility" of each screen took into consideration the amount of time it took to complete and the number of interruptions that occurred during the screen. The average length of time to take (excluding interrupted time) was approximately 6 minutes for the S-TOFHLA, 3 minutes for the NVS and only 1 minute for the REALM-R. On average, patients with adequate HL levels took less time to complete the screens than those with LHL. Although the REALM-R was a shorter screen to administer, a normal NVS screen was determined to be the most useful test to exclude LHL, with a negative likelihood ratio of 0.04 (95% CI = 0.01 to 0.17) compared to 0.30 (95% CI = 0.19 to 0.46) for the REALM-R.

Although health literacy has been studied and described well in clinical and inpatient environments, less research has been done in the emergency environment. Very concerning is the

discordance between health professional's (physicians and nurses) ability to discern patients with lower health literacy/numeracy (generally over-estimate the patient's abilities), when studies have shown that patients with low health literacy/numeracy have increased odds of returning to the ED (ED recidivism) within 30 days of discharge, as a result of outpatient treatment failure. When both health literacy and numeracy have been studied together, health numeracy frequency tests at a lower level than health literacy, which has a very large impact on the patient's ability to understand their outpatient prescriptive directions. The ideal ED discharge process would have information provided at a level the patient can comprehend and follow through.

Transition of Care Satisfaction

Transition of care has been defined by the Joint Commission as "the movement of a patient from one health care provider or setting to another" ("Transitions of care: The need for collaboration across entire care continuum," 2013). The same definition has been used by the American Medical Association (AMA) for their document "There and home again, safely" (Sokol, Wynia, & Transitions, 2013) , a document focusing on transitions from ambulatory practices. Both documents acknowledge that there is little-to- no literature related to the transition of care from any patient setting other than the in-patient experience. What literature is available is related to transitions from the ED to inpatient (Sokol et al., 2013), ED to rehab services (Coleman, Min, Chomiak, & Kramer, 2004) , ED provider to ED provider (Sokol et al., 2013), ED to Primary Care Doctor (PCP) ("Transitions of care: The need for collaboration across entire care continuum," 2013), and ED to Intensive Care Unit (Beach, Croskerry, & Shapiro, 2003) with only one manuscript related to "ED to home" (Cadogan, Phillips, & Ziminski, 2014).

Cadogen et al. (2014) interviewed ED providers regarding factors that may influence quality and safety of transitions of older adults to home after an ED visit. Using a grounded

theory approach, 9 focus groups were formed including representative from nursing, medicine, pharmacy, social work and respiratory therapy. Five antecedent concepts emerged: (1) the nature of the geriatric presentation, (2) provider knowledge, (3) consumer knowledge, (4) the ED resource base, and (5)health care system "fractures." One of the focus groups concluded that co-occurrence and interaction among the 5 identified antecedents set up conditions for a "perfect storm" resulting in disaster.

Difficulty Coping after Hospital Discharge

A literature search did not reveal any studies related to difficulty coping after Emergency Department discharge, however, there is literature related to coping difficulty after discharge from the in-patient setting. Acknowledging that hospital stays have become shorter, and patients are having to take more responsibility for their recovery care at home, Fitzgerald Miller, Piacentine and Weiss (2008) sought to explore the patient's perception of their post discharge coping difficulties. Through phone call follow up at approximately 3 weeks post discharge, using a convenience sample of 147 adults discharged to home after having a hospitalization for a medical or surgical problem, they administered the Post-Discharge Coping Difficulty Scale (PDCDS) (M. E. Weiss & Piacentine, 2006) and a qualitative probe to clarify and expand the meaning of 5 of the quantitative responses. Overall, scores were low on the PDCDS (mean score 23.9, SD = 18.2), with scores ranging from 0 – 80 out of a possible 100. The item with the highest mean score was "How stressful has your life been?" (4.0, possible range = 0-10 with 0 indicating no stress and 10 indicating high stress). Other items demonstrating above average coping difficulty were: "how much difficulty have you had with your recovery?" (3.4), "how much emotional support have you needed?" (3.4), "how difficult has the time been for your family members or other close people?" (2.8), and "how much help have you need with caring

for yourself?" (2.5). Lesser coping difficulties consisted of: "How much difficulty have you had managing your medial conditions?" (1.8), "How well have you adjusted to being at home since your hospital discharge?" (1.1) and "have you been able to take care of your medical needs such as medications or treatments?" (0.9).

Specific stressors were identified during their qualitative probe. The most frequent stressor identified by patients was pain or pain management (n = 18), managing complications (n = 13) and mobility (n = 13). When asked what patients wished they had known pre-discharge, the responses broke down into two categories: Knowledge about recovery (n=19) and knowledge about diagnosis, disease and treatment (n=14). Striving for returning to a normal sense of self was the prevalent theme weaving though the responses.

Using the same PDCDS, Weiss, Johnson, Malin, Jerofke, Lang, and Sherburne (2008) studied parents of hospitalized children's readiness for discharge and subsequent coping difficulties. Of the 135 parents of children discharged from the in-patient setting (across the spectrum of disease – excluding those discharged to hospice care) in Midwestern United States, 119 (88%) completed the a 3-week post discharge telephone interview, utilizing the PDCDS with one additional item added specific to parents. In general, parents indicated relatively low levels of coping difficulty after discharge with a mean item score of 1.8 (SD= 1.2) The item receiving the highest rating on the scale was "Since your child came home from the hospital, how stressful has your life been?' (item mean = 4.3 (SD = 3.1) while the lowest scoring item (mean = 0.3, SD= 0.8) was "the parental ability to take care of the child's medical needs." Cronbach's alpha reliability for this parent sample was 0.84. there have not been any studies published in the emergency department literature utilizing the PDCDS to evaluate coping mechanisms after discharge to home.

Adherence to discharge instruction, medication adherence and ED recidivism

The World Health Organization defines Adherence as: " the extent to which a person's behavior – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider" (World Health Organization, 2003 section I p. 17). Only two studies have explored emergency department outcomes in relationship to the health literacy of the patient18 (Griffey, Kennedy, et al., 2014; McNaughton et al., 2013). McNaughton et al. (2013) report that low health literacy was associated with increased adjusted odds ratio of recidivism of 1.17 (95% CI, 0.83 – 1.65; $p = 0.048$). Similar to previously described in-patient outcome related studies, Griffey, Kennedy, McGownan, Goodman and Kaphingst (2014), used the S-TOFLA to measure health literacy and determined patients with inadequate health literacy had higher ED utilization compared to those with adequate health literacy ($p = 0.03$) among 443 English speaking adults > 18 years old. One hundred eighteen unique patients each made at least one return ED visit within a 14-day period. Of those 118 patient returns, 36.8% demonstrated inadequate HL, 33.3% demonstrated marginal HL, while 24.9 % demonstrated adequate health literacy. Although the proportion of patients with inadequate health literacy making at least one return visit was higher than that of patients with adequate health literacy at 14 days, it was not significantly higher within 3 or 7 days.

Adherence to post discharge instruction, has had rather inconsistent findings. Gignon, Ammirati, Mercier and Detave (2014) found that nearly 50% of 29 emergency department patients that were prescribed discharge medications reported difficulties understanding their prescription (either the dose or the purpose of the treatment) while Zhang et al. (2014) in a much larger systematic review and meta-analysis of 35 studies (in-patient, clinic, pharmacy and community – none of the studies included were from an emergency department setting), found

only a small statistically significant and positive association between health literacy and medication adherence. Fifteen of the studies found a positive and statistically significant relationship between health literacy and medication adherence, 11 studies found a positive but statistically insignificant relationship, 2 studies found a negative and statistically significant relationship and 8 studies found a negative, but statistically insignificant relationship.

(Lindquist et al., 2012) report that health literacy was not associated with overall medication adherence but when breaking down medication adherence into "intentional" and "unintentional," low health literacy was associated with unintentional medication nonadherence while adequate health literacy was associated with intentional medication nonadherence. Two hundred fifty-four community dwelling patients ≥ 70 years old were administered the S-TOFHLA before discharge from an in-patient visit of at least 24 hours. They were then followed up with phone calls between 48-72 hours post discharge to compare the subject's recollection of their prescribed medications and their actual use of those medications, and what was the reason for any discrepancy. Fifty-six percent of the subjects had a medication discrepancy between their discharge instructions and their actual home medication use. Subjects with inadequate and marginal HL were significantly more likely to have unintentional non-adherence (the subject did not understand the directions) than subjects with adequate HL (47.7% vs.31.8% vs. 20.5% respectively, p=0.002). While those with adequate health literacy were more likely to have intentional non-adherence (understood the instruction but chose not to follow them) than marginal or inadequate levels of HL (73.3% vs. 11.1% vs. 15.6% respectively).

Summary

Low health literacy has been associated with a number of poor patient outcomes and increased expense. Both nurses and physicians have demonstrated poor ability to predict a

patient's level of HL. Discharge instructions have been shown to be written at too high of an educational level, for an average patient seeking emergency care, and often patients don't realize that they don't understand. Little research has been done relating the health literacy of patients cared for in an ED with follow through of ED recommendations and ultimate outcome of the problem for which they sought care. Little research has explored the patient's perceived readiness for discharge, and the transition of care from the emergency setting to self-care at home, and its' effect on the patient's coping with their newly prescribed self-care. The goal of this study is to address this gap in knowledge which may be used in the future to inform discharge practices with additional or alternative education and patient centered problem solving.

Transition Theory

Transitions Theory (Figure 1.) is a middle-range theory that has been developed for over more than 35 years to provide a framework from which to identify patients' unique experience with moving from one role to another, understanding and interpreting the concepts that contribute to that transitional process, and designing nursing interventions to support and enhance their role change (Meleis, 1975, 1997; Meleis, Sawyer, Im, Hilfinger Messias, & Schumacher, 2000; Meleis & Trangenstein, 1994). Transitions have been perceived as a process of movement from one status to another during which expectations, role relations, changes in health status and ability to meet those circumstances may create a period of vulnerability (Meleis et al., 2000; Meleis & Trangenstein, 1994).

I have chosen this theory to guide this study because it seeks to evaluate and support transitions from a variety of situations including the transition from good health to sickness/injury (Meleis et al., 2000). My focus of inquiry is on a change in health status and the ability to manage the requirements of out-patient self-care to become "well." I am particularly

interested in the relationship of the patient's health literacy (patient condition) and the perceived satisfaction with the transitional care/process (preparation for discharge) such that the patient feels capable of following discharge instructions and managing home self-care for a successful resolution of the health problem.

Dr. Meleis et al., (2000) have described four types of transitions: (1) developmental, (2) health and illness, (3) situational, and (4) organizational. The focus of this study is on the transition from illness/injury in the ED to recovery/good health (over time) at home and the variables that may contribute to a successful transition preventing the need to return to the ED within 14 days of discharge for additional care for the same problem. Hospital ED discharge may be viewed as a transitional process that occurs in three sequential phases (1) the hospitalization (ED) phase, (2) the preparation for discharge, and (3) the patients' ability to cope with the extra requirements placed on them to meet the needs of successful outpatient treatment (M. E. Weiss et al., 2007).

There are multiple properties that influence the transitional experience (1) awareness, (2) engagement, (3) change and difference, (4) time span, and (5) critical points and events (Meleis et al., 2000). There are also various conditions and patterns that may influence the way a person moves through a transition. Successful patterns of response to the transition include feeling connected, interacting, being situated and developing confidence and coping. These may ultimately result in mastery of the condition and fluid integrative identities (Meleis et al., 2000). Nursing therapeutic practices can influence the nature, conditions and the pattern of response during a transition.

Three major dimensions of the transitions theory will be explored in this study: (1) nature of the transition, (2) transition conditions, and (3) patterns of response. Transitional conditions

are those circumstances that may influence the way the patient moves through the transition, such as socioeconomic status, cultural beliefs, societal factors, social support, preparation, and knowledge (Meleis & Trangenstein, 1994). These personal conditions may either help or hinder the patient's successful transition to better health. Indicators of a successful transition include interacting, feeling connected, being situated and developing confidence and coping (Meleis et al., 2000) Transitions Theory will be used to assess and described the concepts of interest in this study. Table 1 illustrates the concepts and their relationship to study variables and study measures.

Methods

Design

This is a prospective cohort study of adults treated in the Emergency Department and expected to be discharged to home. Health literacy and patient preparation for discharge to home will be evaluated for their relationship to post discharge coping difficulties and out-patient treatment failure as evidenced by ED recidivism.

Setting

The study will take place at UMass Memorial Health Care, an academic, level one trauma center that cares for approximately 65,000 adults a year. Patients triaged to the West Pod will be my subject pool. The West Pod opened April 2015and typically has patients with an ESI of 2, 3, or 4. There are no monitors in the patient rooms and thus if felt necessary, the patient is transported to a different pod. All patients will have a private room and there are no patients bedded in the hallway, allowing for a quieter and more private environment for study related interactions.

The West Pod is open for 10 hours daily, from 11:00 AM to 10:00 PM. Currently, on average, 441 (SD ± 56) patients are seen per month. Of those, approximately 15 (SD ± 9) patients are admitted into hospital. Approximately 7 patients (SD ± 2) leave without being seen or against medical advice, leaving an average of 419 (SD ± 1) available patients per month for study enrollment. Approximately 14 (SD ± 1) patients per-day will meet enrollment criteria. Of those patients, 2% are Emergency Severity Index (ESI) 2, 51% are ESI 3, 48% are ESI 4 (please refer to inclusion criteria for ESI explanation). This patient distribution has implications for this study, as ESI 2, and 3, are more likely to have more meaningful follow up instructions to adhere to.

Sample – Effect Size Calculation

Using Cohen's w statistic (effect size calculation for crosstabs and chi-square statistic) for determining effect size for 2 binary variables, health literacy (adequate vs inadequate or marginal) and adherence to discharge instructions (yes vs. no), (primary aim #2), results in a predicted sample size of 125 patients. This predicts a Cohen's w equal to 0.25. Cohen calls 0.1 a small effect size, 0.3 a medium effect size, and 0.5 a large effect size (Hohl et al., 2009). This study is looking for a medium effect size. Assuming a "lost to follow up" rate of up to 30%, I am anticipating needing to enroll 163 patients.

Inclusion and Exclusion Criteria

Inclusion criteria include English speaking/reading patients 18 years or older seen in UMMHC ED West Pod who are independent community dwellers capable of providing written informed consent. They must have a telephone available. They may not have significant cognitive impairment (as measured with the Mini-Cog), have adequate vision (no worse than 20/40 on the Rosenbaum hand held eye chart), have been triaged as Emergency Severity Index

(ESI) #2, # 3 or # 4 (Gilboy & Howard, 2009), and be expected to be treated and sent home. The Emergency Severity Index (ESI) is a five-level emergency department (ED) triage algorithm that provides clinically relevant stratification of patients into five groups from 1 (most urgent) to 5 (least urgent) on the basis of acuity and resource utilization.

Exclusion criteria consist of being dependent on a caretaker for basic needs of daily living, non-English speaking, sexual assault victims, patients under duress or distress as determined by the treating medical provider, acute psychiatric patients, patients with altered mental status, patients with a Mini-Cog score of 1 or 2 with an abnormal clock drawing or patients with visual acuity worse than 20/70 with corrected lenses.

Procedures

An IRB application will be submitted to the Institutional Review Board at UMass Medical School. The application will include a written consent form, a Health Insurance Portability and Accountability Act (HIPAA) waiver (in order to view the patient record for subject identification), and a HIPAA consent form. Once approved, I will identify consecutive potential subjects (age $\geq$ 18 with an ESI of 2, 3 or 4) from the West pod during open hours during a variety of days of the week (including weekends) by reviewing the Emergency Department's electronic record/tracking system in real-time in the West Pod. I will approach patients while they are waiting results of testing or further diagnostic testing and ask if they would be willing to talk with me regarding a research study examining how well we prepare patients for discharge to home. A screening log will be maintained to allow me to describe the total population that was considered for the study broken down into several important groups, including those who were considered and deemed ineligible before approach, those who were approached and deemed ineligible, those who were approached, deemed eligible, and consented,

and those who were approached, deemed eligible and refused. Each of these subgroups are important for adequate description of methods and accounting of bias, as recommend in the CONSORT (Eichler et al., 2009) requirements for randomized clinical trials. This is necessary to maintain scientific integrity and ability to recognize and describe bias. Data collected from the medical record will include, date, medical record number, name, date of birth, age, sex, race, and presenting complaint.

The study will be explained and if the patient is agreeable, written informed consent as well as a signed HIPPA permission form will be obtained. Subjects will have their cognitive function screened using the Mini–Cog and a visual acuity screening using a hand-held Snellen chart since cognitive ability and vision may confound interpretation of health literacy. Subjects who score greater than 1 with a normal clock drawing on the Mini–Cog exam, and whose visual acuity is better than 20/70, [defined as visual impairment - corrective glasses allowed, (Cohen, 1992)] will be eligible to continue in the study. A researcher developed demographic survey will be administered verbally by the researcher. Characteristics of interest including ethnicity, socioeconomic status, and education (Appendix A) will be obtained. A study flow diagram is provided (Figure 2).

The Newest Vital Sign (NVS) (Appendix B) will be administered before discharge from the ED. Patients will be called between 24 and 72 hours post discharge to assess their perception of their preparedness for discharge. The CTM-3 and the B-PREPARED Survey will be administered. Fourteen to sixteen days' post discharge, patients will be called to inquire about how they have been coping since being in the Ed and adherence to their discharge instructions, specifically related to medication use and recommended follow-up appointments. The Morisky Medication Adherence Scale – 8, will be used to measure medication adherence for all patients

prescribed a medication in the ED and all patients advised to schedule a follow-up appointment with a specialist or their primary care provider will be asked a few questions about making and going to recommended follow-up appointments and any challenges in doing so (Appendix E). Because the MMAS-8 has been developed for evaluation of chronic medication behaviors, I will preface its' administration by focusing the subject's attention on the medication(s) prescribed during their most recent ED visit by saying "For the next 8 questions, I want you to answer each question thinking about the medication prescribed for you in the ED". The Post Discharge Coping Difficulties Scale (PDCDS) will also be administered during the second phone follow up. If the subject cannot be contacted via telephone after 3 attempts, they will receive a written survey with a pre-addressed, stamped envelope to return the completed survey (see Figure 2. Timeline of Study Procedures).

Instrument Measures

Patient Demographics (Appendix A). Investigator developed questionnaire, to be administered as a face – to face interview.

Rosenbaum Hand Held Screener. The Rosenbaum visual screener is a pocket size vision chart that is used to evaluate near vision. Held 14 inches from the patient's face, the patient is checked with whatever he usually uses for reading (bifocals, readers, or no correction) ("Visual Acuity Testing,"). The subject is asked to read the smallest line visible. The result is recorded as "distance equivalent" (20/20, etc.), meaning that the subject can read the same line as a normal visioned person can read at 20 feet. Normal vision is considered to be 20/20, however 20/40 (meaning a person with less vision can read at 20 feet, what a normal visioned person can read at 20 feet) is accepted by all states to obtain a driver's license, and most printed material can be read at this level ("What does 20/20 vision mean?,").

Mini Cog. The Mini-Cog test is a 3-minute instrument to screen for cognitive impairment (Borson, Scanlan, Brush, Vitaliano, & Dokmak, 2000). It is a three-item composite that includes a clock drawing, and a three-item recall, that was developed as a brief test for discrimination of persons with or without dementia in a community setting. Each recalled word counts as 1 point and the clock face, if drawn grossly normal, gets one point; if incorrect gets no points. Subjects scoring 0 are positive for cognitive impairment. Subjects scoring 1-2, with an ABNORMAL clock face are positive for cognitive impairment. Subjects scoring 1-2 with a NORMAL clock face are considered negative for cognitive impairment. Any subject scoring 3 are negative for dementia and there is no need to score the clock face (Borson et al., 2000).

To determine the sensitivity, specificity and diagnostic value of the Mini-Cog, 249 older, known dementia and unknown dementia, multilingual, educationally heterogeneous adults completed the Mini-Cog, the Mini-Mental State Exam and the Cognitive Abilities Screening Instrument. The Mini-Cog had the highest sensitivity (99%) and correctly classified the greatest percentage (96%) of subjects. Its diagnostic value was not influenced by education or language (Doerflinger, 2013).

Newest Vital Sign (NVS) The NVS will be used to screen for limited health literacy. The NVS is a six-question assessment based on an ice cream nutrition facts label that assesses numeracy skill, locate–the-information skills, and abstract reasoning skills (B. D. Weiss et al., 2005). The final score is obtained through the number of correct answers with scores ranging from 0 to 6. Scores between 4 and 6 indicate sufficient health literacy, 2 and 3 possible limited literacy, and 0 or 1 high likelihood ($\geq$ 50%) of limited literacy. Using the TOFHLA-E and the TOFHLA-S as the “gold standard” for health literacy screening, subjects were administered the NVS (Spanish version, NVS-S) to 250 Spanish speaking patients and 250

(English version, NVS-E) English speaking patients from 3 Primary Care Clinics in Arizona. The internal consistency of the NVS-E-was good (Cronbach $\alpha = 0.76$), as was the criterion validity ($r = 0.59$, $p < .001$). The internal consistency of the NVS-S was also good (Cronbach $\alpha = 0.69$) and had a moderate correlation with the TOFHLA ($r = 0.49$, $p < .001$).

Care Transition Measure-3™ (CTM-3) CTM-3™ (Coleman, Mahoney, & Parry, 2005) is a three item scale that will be used to assess perceived readiness for discharge. It includes questions about the patient's preparation for discharge, specifically whether the patient and their family's needs were taken into account when the discharge plan was designed, whether they had a good understanding of their discharge instructions and whether they understood the purpose for taking their medications. It is a 4-level Likert type scale, ranging from "Strongly Disagree = 1" to "Strongly Agree = 4". It takes approximately 5 minutes to complete. Scoring consists of counting the number of questions answered correctly, then calculating the mean response, then using linear transformation to convert to 0-100 score. The final score reflects the overall quality of the care transition, with lower scores indicating a poorer quality transition, and higher scores indicating a better transition

Brief-Prescriptions, Ready to re-enter community, Education, Placement, Assurance of safety, Realistic expectations, Empowerment, Directed to appropriate services Scale (B-PREPARED). The B-PREPARED scale is an 11 item scale assessing patient's readiness for discharge from hospital in three domains: self-care information, equipment/ services, and confidence. High scores reflect high preparation. In a study of 460 hospitalized adult patients, the B-PREPARED scale was found to have good internal reliability and construct validity (Cronbach's alpha 0.76)(Graumlich, Novotny, & Aldag, 2008). Higher median scores successfully discriminated patients with "no worry" about managing their care at

home from worriers ($P < 0.001$) as well as predicting patients with vs. without emergency department visits after discharge ($P = 0.011$).

Comparing the 3-item CTM -3 and the B-PREPARED scale for predicting hospital readmission or death within 30 and 90 days of discharge, in 1239 patients having hospital stays for acute coronary syndrome, and/or acute decompensated heart failure, Mixon et al. (2016), found that the B-PREPARED scale was more closely associated with time to first readmission or death. At 30 days' post discharge, a 4-point increase in the B-PREPARED score as associated with a 16% decrease in the hazard of readmission or death (hazard ratio [HR] = 0.84, 95% confidence interval [CI]: 0.72 to 0.97), while the CTM-3 did not predict either readmission or death. Again at 90 day follow up, the B-PREPARED scores were associated with a significant decrease in risk of readmission or death (HR = 0.88, 955 CI: 0.78 to 1.00) while the CTM-s scores were not independently associated with outcomes

Post-Discharge Coping Difficulty Scale (PDCDS). The PDCDS (M. E. Weiss & Piacentine, 2006) is a measure of patient coping at home in the post-discharge period. It is a 10-item instrument with an 11-point response format from 0-10, utilizing anchor words of "not at all" and a "great deal or extremely" at the 0 and 10 poles (Appendix C). It is frequently administered over the phone successfully (M. Weiss et al., 2008; M. E. Weiss & Lokken, 2009; M. E. Weiss et al., 2007) . The range of scores is 0-100. A high score indicates more coping difficulty. Items measure a variety of coping difficulties. These include medical management abilities and adjustment, help and emotional support needed, family difficulty, medical management abilities and adjustment, self-care, recovery and difficulties with stress. It was found to be reliable with a Cronbach's α of 0.82. and an exploratory factor analysis indicated a single dominant factor accounting for 39% of scale variance.

Morisky Medication Adherence Scale-8 (MMAS-8). The MMAS-8 is an 8 item scale, developed to determine adherence to medications, both implementation and discontinuation (Morisky, Ang, Krousel-Wood, & Ward, 2008). Using 1367 patients enrolled as part of a randomized experimental pre-and post-test study design over a one-year period, for educational interventions on blood pressure control (Ward, Morisky, Lees, & Fong, 2000), the MMAS-8 was found to be reliable with good predictive validity. The items measure medication-taking behavior, rather than a determinant of adherence behavior. Questions 1-7 are answered yes no, while # 8 "How often do you have difficulty remembering to take all your medicine?' is answered on a 5-point Likert scale. Scoring cut-offs were determined by actual outcomes of hypertension treatment, where < 6 indicated low adherence; 6-8 indicated medium adherence and 8 indicating high adherence. Patients who scored high on the scale were more likely to have their blood pressure under control than those scoring medium to low. Sensitivity and specificity of the scale were 93% and 53% respectively. Reliability was strong with a Cronbach α of 0.83. The item-total correlations were greater than 0.30 for each of the 8 items, and confirmatory factor analysis indicated that the scale was uni-dimensional and the items loaded well on a single factor.

Using pharmacy data to evaluate the association of the MMAS-8 in a sample of 87 community dwelling seniors with hypertension, the MMAS-8 was found to have concordance with continuous single-interval medication availability (CSA), medication possession ratio (MPR), and continuous multiple-interval medication gaps (CMG) (Krousel-Wood et al., 2009). Comparing high adherers to low adherers, patients with low MMAS adherence were 6.89 (95% confidence interval (CI): 2.48 – 19.1) times more likely to have non-persistent pharmacy fill

rates by CSA and 5.22 (95% CI:1.88 – 14.5) times more likely to have non-persistent pharmacy fill rates by MPR. Concordance between MMAS and CSA, MPR and CMG was ≥75%.

Follow-up Appointment Clarification (Appendix B). A few questions will be asked regarding the patient's ability to make and go to recommended follow-up appointments if directed to. The final question asks if they made any unplanned return visits to the ED for further treatment of their original condition. If they respond "yes," this will be considered ED recidivism.

Data management. Data will be entered into a Research Electronic Data Capture (REDCap) (Lindquist et al., 2012), an electronic data capture tool hosted at UMass Medical School, and then transferred into IBM Statistical Package for the Social Sciences (SPSS) 20v. Statistical significance will be accepted at the 95% confidence interval ($p < .05$ level). Subjects that are lost to follow up will be removed from data analysis for Aim 2 and 3, but will remain for Aim 1. Data will be cleaned by looking for discrepancies (and correcting if possible), identifying missing data and looking for improbable or impossible results. It will be stored on a secure, password protected UMass research drive (R drive). All paper forms will be kept in a locked file cabinet in my secure, locked office in the Administrative Area of the Emergency Department. Each subject will be given a unique identifying ID which will be the identifier for all data.

To help mitigate the risk associated with inadvertent disclosure of PHI, I will remove the personal identifiers of name, date of birth, and medical record # from the rest of the paper screening log and database once all data has been collected, cleaned, and the database officially closed by electronically double deleting it. The separated identifiers will still be linked to the study number, which will be linked to the paper and electronic data, in order to help account for unforeseen needs to audit data. However, the personal identifiers and the data collected as part of

the study will not be connect physically and will be stored in separate databases. This data will be stored for 3 years after database closure. After 3 years have passed, all paper logs will be destroyed by triple shredding and electronic data will be double deleted.

Data analysis. This study uses a variety of data, both continuous and categorical. Data will be evaluated for missing values. Descriptive statistics will be calculated for all study variables appropriate to the level of data. For continuous variables, mean, median, skewness, standard error of the mean, standard deviation and histograms will be calculated. All continuous variables will be checked for normal distribution. Frequencies will be run on all categorical variables. Internal consistency reliability will be assessed using Cronbach's alpha for all multi-item scales. There are multiple variables included in this study: (1) variables associated with patient demographics/characteristics, (2) health literacy level; (3) patient perceived readiness for discharge; (4) difficulty coping after hospital discharge; (5) adherence to discharge instructions – follow-up recommendations and medication adherence; and (6) outpatient treatment failure (ED recidivism within 14 days of discharge from index visit).

Neither the CTM-3, the B-PREPARED, the MMSS-8, or the Difficulty Coping After Hospital Discharge Scale have been tested in the Emergency setting, so I will begin by calculating reliability estimates first for all multi-item scales. Demographic data will be displayed as descriptive information using means and medians to compare the composition of the following groups (1) enrolled patients, (2) ineligible patients and (3) patients who have refused to participate.

Data Analysis

Aim #1. Describe the distribution of health literacy among a convenient sample of Emergency Severity Index (ESI) level 2, 3, and 4 adult patients in an academic tertiary Emergency Department.

Table Key			
Concept	**Tool**	**Abbreviation**	**Data Type**
Health Literacy	Newest Vital Sign	NVS	Categorical
Discharge Preparation	Brief-Prescriptions, Ready to re-enter community, Education, Placement, Assurance of safety, Realistic expectations, Empowerment, Directed to appropriate services Scale	B-PREPARED	Continuous
Transition of Care	Care Transition Measure - 3	CTM-3	Continuous
Difficulty Coping after Discharge	Post-Discharge Coping Difficulty Scale	PDCDS	Continuous
Medication Adherence	Morisky Medication Adherence Scale-8	MMAS-8	Categorical
Adherence to Follow Up Instructions	Post Discharge Follow Up Clarification	PDFUC	Categorical

Aim # 2. Describe the association of adherence to discharge instructions, with health literacy, perceived preparation for discharge and satisfaction with the transition of care to home.

Hypothesis: *Adherence to discharge instructions will be lower with low health literacy, poorer perceived preparation for discharge and dissatisfaction with the discharge process.*

Aim # 2 Analysis						
Comparison # 1	**Comparison # 2**	**Statistical Test**		**Comparison # 1**	**Comparison # 2**	**Statistical Test**
PDFUC	NVS	Chi Square		NVS	PDFUC (ED)	Chi Square
PDFUC	MMAS-8	Chi Square		NVS	PDFUC (PCP)	Chi Square
PDFUC	B-PREPARED	T-Test		NVS	MMAS-8	Chi Square
PDFUC	CTM-3	T-Test				

Aim # 2 Analysis						
Comparison # 1	**Comparison # 2**	**Statistical Test**		**Comparison # 1**	**Comparison # 2**	**Statistical Test**
B-PREPARED	PDFUC (ED)	T-Test		CTM-3	PDFUC (ED)	T-Test
B-PREPARED	PDFUC (PCP)	T-Test		CTM-3	PDFUC (PCP)	T-Test
B-PREPARED	MMAS-8	ANOVA		CTM-3	MMAS-8	ANOVA

Aim # 3: Determine if health literacy is a predictor of difficulty coping after discharge, if there is a correlation between the transition of care to home and difficulty coping after discharge and if there is a correlation between the patient's perceived preparation for discharge and difficulty coping after discharge.

Hypothesis: *Low health literacy predicts more difficulty coping after discharge. There is a positive correlation between dissatisfaction with the transition of care to home and discharge preparation with more difficulty coping after discharge.*

AIM # 3 Analysis		
Comparison # 1	**Comparison # 2**	**Statistical Test**
NVS	PDCDS	ANOVA (if 3 levels)
NVS	PDCDS	T-Test (if collapsed to 2 groups)
CTM-3	PDCDS	Correlation
B-PREPARED	PDCDS	Correlation

Aim #4: Of health literacy, perceived preparation for discharge and satisfaction with the transition to home, which is the stronger predictor of difficulty coping after discharge.

Before analysis, I will check collinearity between the three predictors.

Variable 1	Variable 2	Variable 3	Outcome	Statistical Test
NVS	B-PREPARED	CTM-3	PDCDS	ANCOVA

Results of these aims will inform discharge practices and may indicate the need for additional or alternative education and patient centered problem solving.

Limitations

My main concern regarding limitations of this study is related to the "Hawthorne Effect" of the subject knowing that the discharge experience is being studied, and they are expecting a call regarding the experience. It may encourage them to pay more attention to the information and process than they otherwise would. To protect against this, I will not specifically inform them that I will be asking about the adherence to prescribed medications or recommended follow-up appointments but will discuss their experience in general. Given that all subjects will be English speaking, limits generalizability to the entire ED population. Enrolling patients from the West Pod only may not reflect the entire ED population because they have been triaged to an area by the triage nurse who has a preconceived idea of the patients' acuity, and resource requirements (expected time in the department).

Potential Challenges

The ED environment itself may present the biggest challenge to the success of this study. It is generally a very loud, hurried experience that many patients find confusing and frightening. The environment may affect the patient's cognitive function and health literacy level at that moment in time, but that is the reality of the environment in which information is being transmitted and thus appropriate to study. Telephone follow up may be challenging but I hope that by telling the patients they can expect a call from me within 2 weeks and the fact that they give me the specific telephone number to call will help. As well, I hope to circumvent the loss of subjects by sending the patients missed surveys with self-addressed, stamped envelopes if I am unable to reach them after 3 telephone call attempts.

Summary

This is a descriptive study of the health literacy and perceived satisfaction with the transition to home of patients with an ESI level 2, 3, or 4 from a tertiary care, academic emergency hospital, and their association to the patient's ability to follow discharge instructions. It is also designed to explore the difficulties patients may experience coping with their out-patient care, as related to their health literacy and perceived readiness for discharge. Ultimately, it will explore whether studied variables might prevent ED recidivism. In other words, "does it all even matter?"

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Executive Summary

Health Literacy, Care Transition and Adherence with Discharge Instructions of Patients Discharged to Home from the Emergency Department

This study assessed the relationship between health literacy and preparedness for discharge, adherence to discharge instructions, difficulty coping after discharge, and emergency department recidivism among patients treated in the emergency department. The table below summarizes the changes made to the original research proposal approach and rationale for the changes.

Summary of changes to dissertation proposal

Original Proposal	Change	Rational for the Changes
Two separate follow up phone calls were to be made, at 2-3 days post discharge and 12-14 days post discharge	Only one follow up phone call was made to collect post discharge data 13-15 days post discharge	Often subjects were only able to be reached for one call – after many attempts. Only subjects that could be reached for two calls would be included in the study. Changing to one phone call 13-15 days after discharge to collect all post-discharge data was more efficient and provided more complete data.
Subjects were to be enrolled in the West Pod of the emergency department where all patients are seen in private rooms.	Changed unit for enrolling subjects to the Clinical Decision Unit (CDU) of the emergency department.	It was very difficult to enroll subjects in the West Pod due to rapid turn around and the nature of the patient triaged to that area. There are no cardiac monitors in the West Pod, so very often patients with nausea/vomiting/diarrhea and abdominal pain were triaged there. One of my assessment measures was the Newest Vital Sign that asks subjects to interpret a nutritional label from a carton of ice cream, which was distasteful to many, and resulted in many refusals. The CDU offered a private area where patients of many different diagnoses were placed, and patients stayed longer, until feeling better, before discharge. This offered a better opportunity to recruit participants.

Slides for Dissertation Defense

Health Literacy, Care Transition and Adherence with Discharge Instructions of Patients with Non-Emergent Conditions in the Emergency Department

Virginia Mangolds MSN, FNP-C, BSED, ENP-C
May 3rd 2018

University of Massachusetts Graduate School of Nursing, Worcester

Research Questions
What did I want to know?

(1) **What is the health literacy** of patients seeking care in our emergency department who have an emergency severity index (ESI) of 2-4 and will likely be discharged

(2) Is there a relationship between **health literacy,** perceived **preparation for discharge** and **satisfaction with transitional care** on the patient's **adherence to discharge instructions**

- medication adherence and completion of follow up visits

(3) Do **health literacy**, perceived **preparation for discharge** and **satisfaction with transition care** predict **difficulty coping** after discharge?

Significance
Why Did I Ask These Questions?

- More patients are being discharged home from the emergency department with the need to assume sometimes complicated self-care regimens (Zavala & Shaffer, 2011)
- Hospital discharge and transition to home is a potential period of significant risk
  - Information and directions not always transferred successfully
- Patients are frequently misjudged by healthcare providers to be knowledgeable and prepared to assume self-care once discharged (Engel et al., 2009)
- May result in lack of understanding or inability to follow discharge instructions among inpatients discharged home results in **medical errors, adverse drug events, poor patient outcomes, increased cost, and repeat visits/evaluations** (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011; Dewalt, Berkman, Sheridan, Lohr, & Pignone, 2004; Eichler, Wieser, & Brugger, 2009; Griffey, Kennedy, McGownan, Goodman, & Kaphingst, 2014; Herndon, Chaney, & Carden, 2011; McNaughton et al., 2013)

Background
What we know and what we don't

- Poor outcomes after hospital discharge are associated with low literacy, low health literacy, medical insurance status, age, native language, medication costs, poor provider-patient communication, inadequate coping mechanisms and acuity of illness (Bobay, Jerofke, Weiss, & Yakusheva, 2010; Cheung, Wiler, Lowe, & Ginde, 2012; Fitzgerald-Miller, Piacentine, & Weiss, 2008; Gabayan et al., 2013; Hope, Wu, Tu, Young, & Murray, 2004; LaCalle & Rabin, 2010; LaCalle, Rabin, & Genes, 2013).

- Overcrowding, understaffing, lack of patient familiarity and segmented care make clear communication in the ED setting challenging (Samuels-Kalow, Stack, & Porter, 2012).

- Achievement of select clinical criteria often drives discharge readiness without consideration of patient's perceived satisfaction or readiness for discharge (Weiss et al. 2007).

- **<u>What we don't know</u>: The relationship of health literacy, care transition satisfaction, and/or perceived preparation for discharge…and its' influence with adherence to follow up instructions and predictability of difficulty coping after discharge from the ED**

Importance

Findings from these questions may inform current discharge practices and if used, may identify the need for additional or alternative education, focused on patient centered problem solving

Framework – Transitions Theory

Dr. Afaf Ibrahim Meleis

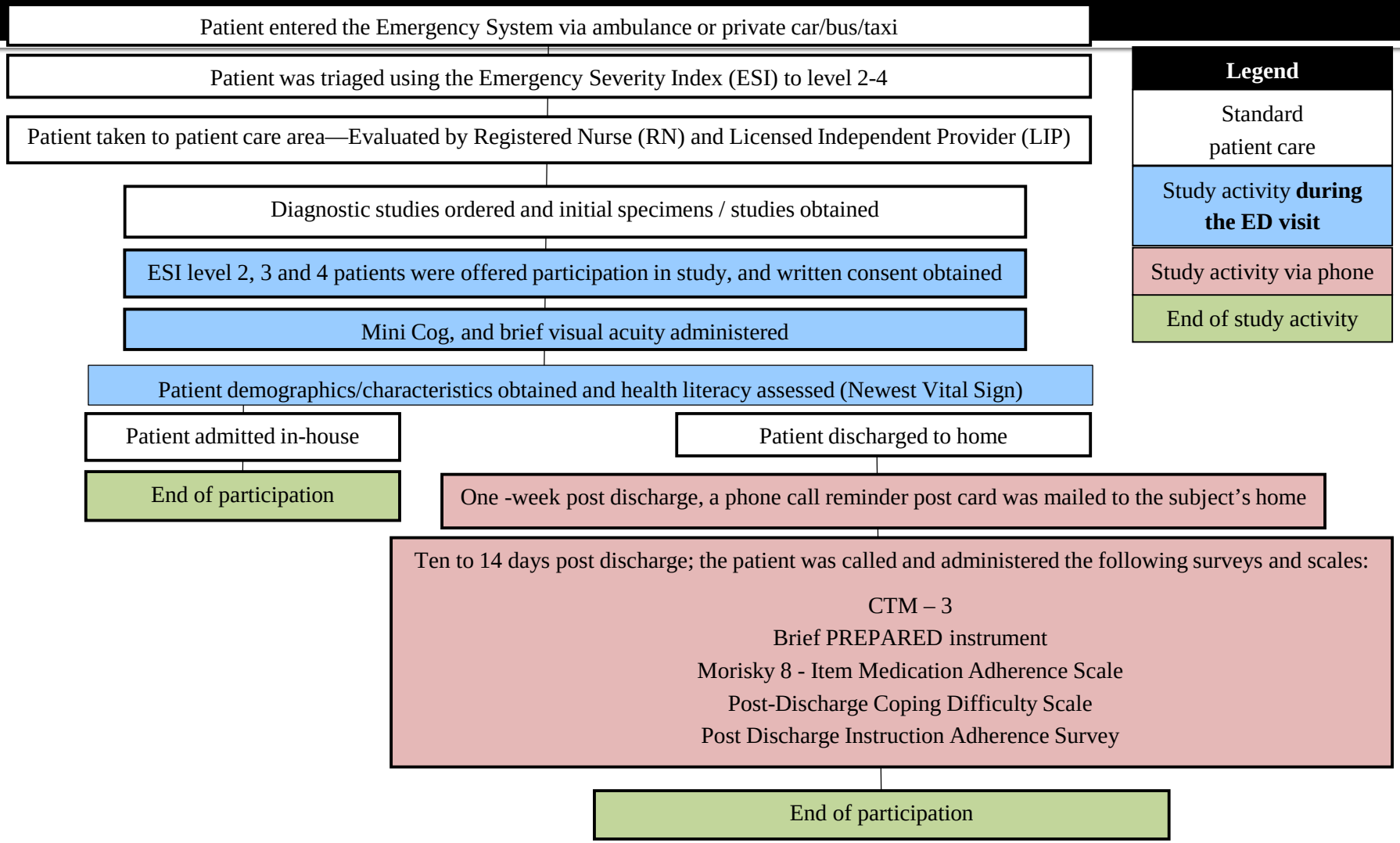
Transitions Theory is a middle-range theory that identifies patients' unique experience with:

- Moving from one role to another which *may create vulnerability*
- Its' focus is on understanding and interpreting the concepts that contribute to that transitional process

Theoretical Framework
Linkages Between Meleis's Transitions Theory Concepts, Study Variables and Study Measures

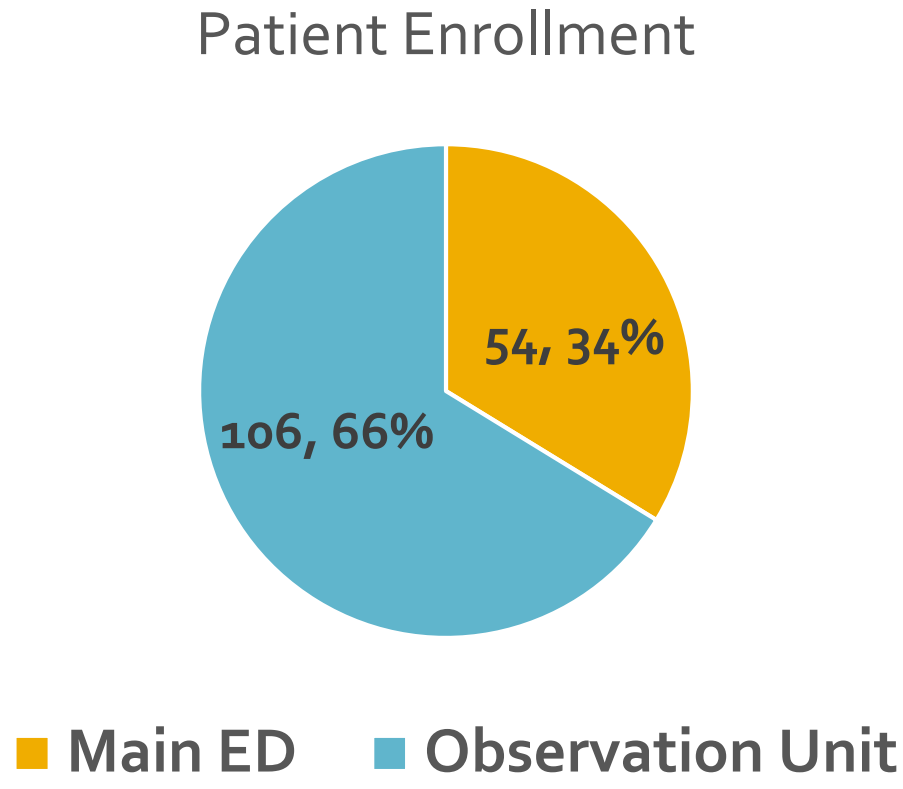
Transition Theory Dimension	Nature of Transition	Transition Conditions	Patterns of Response
Study Variables and Measurements	Emergency Department to Home	ESI 2-4 Health Literacy Demographics	1. Readiness for hospital discharge 2. Satisfaction with care transition 3. Adherence to discharge instructions (medication and follow up) 4. Post discharge coping difficulty

Study Procedures



Study Setting and Participants

- Data collection: July 2016 to June 2017 in the ED of the UMass Memorial Medical Center-University Campus, an academic, level-one trauma center in central Massachusetts that cares for approximately 65,000 adults a year.



Inclusion – Exclusion Criteria

Inclusion criteria:

- 18 years of age or older
- Could speak and read English
- Independent community dwellers capable of providing written informed consent
- Expected to be discharged to home
- Have telephone access (necessary for follow-up)
- Score on Mini-Cog Score of ≥ 2
- Have at least 20/70 vision (with corrected lenses if necessary) based on the Rosenbaum hand held eye chart.

Exclusion criteria:

- Dependent on a caretaker for basic needs of daily living
- Victim of sexual assault
- Experiencing an acute psychiatric episode
- Under duress or distress as determined by the treating medical provider.

Ethical Considerations

- Approved by the University of Massachusetts Medical School Institutional Review Board
- All participant provided written informed consent
- Agreed to receive a follow-up phone call 10–14 days after discharge

Written permission was acquired to use the MMAS-8 and the Difficulty Coping After Discharge scale

Methods – Instruments Used For Study Variables

(Reliability and validity of all instruments were acceptable)

Variable (Range of Scores)	Instrument
Health literacy (0 – 6)	Newest Vital Sign **(NVS)**
Care transition satisfaction (0 – 100)	Care Transition Measure® **(CTM-3)**
Discharge preparation (0 – 24)	Brief- Prescriptions, Ready to re-enter community, Education, Placement, Assurance of safety, Realistic expectations, Empowerment, Directed to appropriate services scale **(B-PREPARED)**
Medication adherence (0 – 8)	Morisky 8 – Item Medication Adherence Scale © **(MMAS – 8)**
Difficulty coping after discharge (0 – 100)	Post Discharge Coping Difficulty Scale **(PDCDS)**
Post discharge instruction adherence	Post Discharge Instruction Adherence Survey **(PDIAS)**

Patient Characteristics

There was no statistical significance between the majority of subjects that completed the study and those lost to follow up

Non Significant Differences

- Gender
- Education
- Marital status
- Lives alone
- Health insurance
- Financial difficulty

Significant Differences

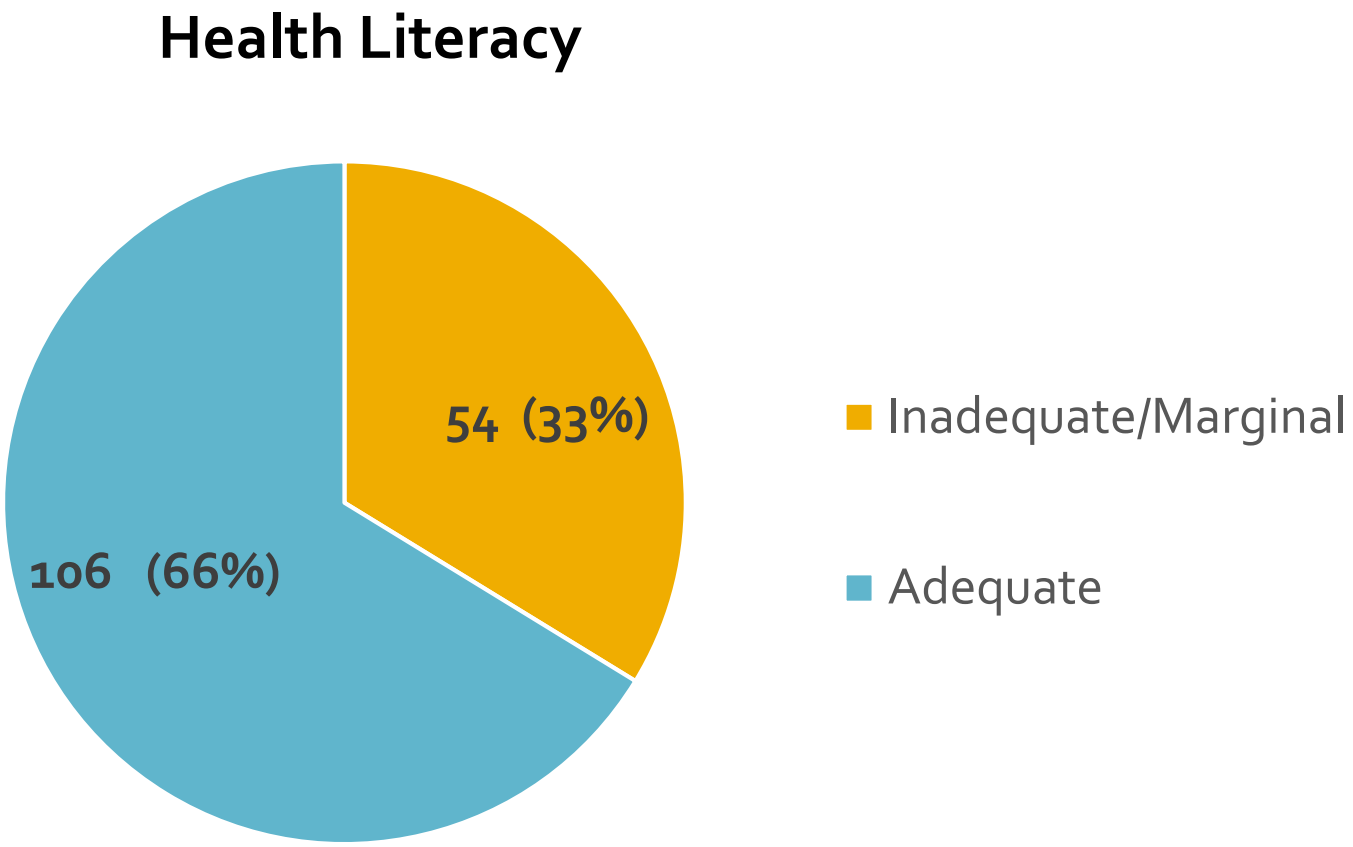
Variable	Completed (n = 132) n (%)	Lost to Follow-Up (n = 28) n (%)	Significance *P* * value
Primary Language			
English	127 (96)	24 (86)	.029
Other	5 (4)	4 (14)	
Health Literacy			
Adequate	92 (70)	14 (50)	.045
Inadequate/marginal	40 (30)	14 (50)	
Given a Prescription			.001
Yes	46 (35)	1 (4)	
No	86 (65)	27 (96)	

How did the instruments perform in the Emergency Department environment ?

Instrument	Reliability (Chronbach α)
NVS	0.760
B-PREPARED	0.734
PDCDS	0.908
CTM-3	0.329
MMAS-8	0.550

Caution with interpretation of CTM-3 and MMAS-8 data due to low reliability

Question #1 - The majority of the participants (66 %) in this study had adequate health literacy (n = 160)



Question #2 - There was a significant difference between perceived preparation for discharge among those who went to their follow up appointment and those who didn't. Those who felt more prepared for discharge were less likely to follow-up.

Outcome	Did not go to appointment n=29 (25%) Mean (SD)	Went to appointment n=89 (75%) Mean (SD)	P value [a]
Preparation for discharge **(B-PREPARED)**	18.38 (0.14)	16.9 (3.79)	.014
Satisfaction with transitional care **(CTM-3)**	77.4 (15)	72.1 (20)	.192

[a] Student's T-test

Question #2 - There was a significant difference of satisfaction with transitional care between those who adhered to their medication instructions and those who didn't. Those who were more satisfied with their transition were more likely to adhere.

	Low Medication Adherence N = 14 (30%)	Medium Medication Adherence N = 22 (48%)	High Medication Adherence N = 10 (22%)	
	Mean (SE [a])	Mean (SE)	Mean (SE)	P value [b]
Satisfaction with transition care **(CTM-3)**	65.5 (4.6)	81.3 (4.1)	81.1 (4.7)	.029
Preparation for discharge **(B-PREPARED)**	15.9 (0.64)	17.7 (0.56)	16.4 (1.8)	.283

Key: [a] Standard Error, [b] ANOVA

Question #2 - There is no significant association between health literacy and completion of follow up appointments

	Health Literacy		
	Inadequate or marginal	Adequate	
Outcome	n (%)	n (%)	*P* value [a]
Completed Follow Up Appointment	30 (79)	59 (74)	0.65
Did **NOT** Complete Follow Up Appointment	8 (21)	21 (26)	

Key: [a] Fisher's Exact test

Question #2 -There is no significant association between health literacy and medication adherence

	NVS [a]		
	Inadequate or marginal n (%)	Adequate n (%)	*P* [c]
MMAS-8 [b]			
Low adherence	4 (33.3)	10 (29.4)	0.47
Medium Adherence	7 (58.3)	15 (44.1)	
High Adherence	1 (8.3)	9 (26.5)	

[a] Newest Vital Sign; [b] Morisky Medication Adherence Scale (8-Item)

[c] Fisher's exact p-value

Question # 3 - Having a higher satisfaction with transition and feeling more prepared for discharge predicted less difficulty coping after discharge

Characteristic	B	SE	Beta	95% Confidence Interval for B Lower Bound	95% Confidence Interval for B Upper Bound	*P* value [a]
Health Literacy	-2.109	3.05	-.058	-8.145	3.927	.491
Satisfaction with transition	-.186	.082	-.210	-.348	-.024	.025
Preparation for discharge	-.873	.409	-.196	-1.683	-.063	.035

R Square = **.127**

[a] Multiple Regression

Discussion

- **Subjects more satisfied with transitional care and who felt more prepared for discharge predicted less difficulty coping once home**
  - In alignment and supports Meleis et al.'s Transition Theory
  - Consistent with the work of Dr. Weiss et al. who reported that greater readiness for discharge was predictive of fewer readmissions (delivery of discharge teaching was the strongest predictor of discharge readiness)
- **Our high median scores on the B-PREPARED scale are consistent with the results previously reported by Graumlich et al., that determined that high median scores were able to discriminate between those who worry and those who do not about managing their home care**
  - Consistent with Meleis's Transition theory whereby the better the transition (satisfaction and preparation) the more likely there will be successful outcomes after the transition

Discussion

- **Subjects were more highly educated and had a higher level of health literacy than typical ED populations**
  - Patients lacking confidence in their reading and communication skills may have declined participation
  - Requiring English reading abilities may have skewed our sample population to be more educated and have higher health literacy

- **Although B-PREPARED predicted difficulty coping after discharge, it is too long to administer in the ED**
  - Combined with CTM-3 they both explained a small percent of the variance (13%) in the sample
  - Would require phone follow up – very difficult to achieve

- **CTM-3 also predicted difficulty coping after discharge – much easier to administer and could be administered before the patient is discharged**
  - Combined with B-Prepared they both explained a small percent of the variance (13%) in the sample
  - Literature supports it's ability to predict of 30 day recidivism
  - Only 3 questions

Discussion

- **Health literacy was not predictive of coping difficulty or adherence to newly prescribed medications**
  - May be related to our sampling frame – we ended up with the majority having adequate health literacy
  - May be related to quality of discharge teaching done by the nurses in the ED
- **Subjects who felt more prepared and better satisfied with their discharge were less likely to complete their follow up appointment or take their newly prescribe medications**
  - May be similar to findings that describe "intentional" and "unintentional" medication non adherence when patients' feel informed enough to make their own decision (Lindquist et al.)

Strengths, Limitations and Challenges

- 83% follow up completed
- Use of validated instruments
- Sample size powered for 125 completed subjects

- Unable to evaluate recidivism
- Convenience sample – one ED – limited generatability
- Change of recruitment area from the main ED to observation unit
- Enrollment bias of including only patients expected to be discharged
  - Patients expected to require additional help to manage their health condition (likely admitted) were excluded from the study
- Recall bias – patients who had less difficulty coping at home may have had a more positive recall of their discharge experience
- MMAS-8 and CTM-3 had low reliability in this population

Conclusions

- Screening for health literacy was not helpful in predicting difficulty coping or identifying lack of adherence to discharge instructions
  - **No control for discharge teaching – may have mitigated the impact of inadequate health literacy**
- Instruments used only explained 13% of the variance in the sample
- CTM-3 could be used by nurses to help identify patients needing additional preparation for discharge – but limited in its' ability to explain the multiple influences that affect a patient's readiness for discharge
- MMAS-8 did not work well in the ED setting to identify non-adherence to newly prescribed medications
- **Better assessment tools are needed for use in the ED setting to identify patients at risk for difficulty following through with ED recommendations.**

Acknowledgments

Dr. Nancy Morris, Chair *University of Massachusetts*
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Department of Emergency Medicine for their boundless support

My immediate family for putting up with me

My parents for fostering my drive for self fulfillment

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School faculty and administrative support that brought me to this point

Questions or Discussion ?

The primary description of this dissertation work was submitted as a manuscript on *June 13, 2018* to Journal of Emergency Nursing for review and consideration for publication.

APPENDIX

Appendix A - Patient Characteristics **INTERVIEW**		
Date:	**Subject Number**	
Time:		
Interviewer:		

	Order of Preference	Notes:
Telephone Number:		
Telephone Number:		
Best time to call:		
Email:		

9. "What language do you usually speak"?	
English	*1*
Spanish	*2*
Portugese	*3*
Albanian	*4*
Chinese	*5*
Vietnamese	*6*
Other	*7*
Other language	

10. "What is your highest level of education"?	
Some high school graduate	*1*
High school graduate	*2*
2-4 years college	*3*
Graduate Degree	*4*
Trade School	*5*

11. " What is your marital status"?	
Single	*1*
Married or living as married	*2*
Divorced	*3*
Widowed	*4*

12. "What is your living situation like"?	
12a.# of people in the household	
12b.Lives alone	**Y**

13. "What kind of health insurance do you have"?	
Public	*1*
Private	*2*
Self	*3*
Military	*4*

14. "How hard is it for you to pay for the VERY BASICS like food, housing, medical care, and heating? Would you say it is: (Thurston et al., 2014)	
Very hard	*1*
Somewhat hard	*2*
Not very hard at all	*3*
Don't know	*4*
Refused	*5*

15. "How hard is it for you to get to your medical appointments "?	
Very hard	*1*
Somewhat hard	*2*
Not hard at all	*3*

16. "*What events influenced your decision to come to the emergency department today" ?*	
Referred to the ED by PCP	*1*
Previously seen by PCP	*2*
Second or third ED visit	*3*
Other	*4*

"Other" explanation:

Appendix B - Follow up Adherence - Telephone call

Patient ID number_____

Please Mark Your Response Below		
1. Were you asked to return to the Emergency Department (ED) to be re-evaluated?	**No**	**Yes**
If answer to #1 is "NO", please skip to question #5		
2. Were you able to return to the ED as requested?		
3. If not, what prevented you from doing this? (check all that apply)		
Cost		
Lack of transportation		
Felt better and did not need any further medical care		
Went to see my Primary Care Physician (PCP) instead		
Other		
4. What was the "Other" reason for not making a follow up visit to the ED?		
5. Were you asked to follow up with your PCP or a specialist to be re-evaluation?		
6. If so, were you able to make an appointment		
7. Were you able to make the appointment within the recommended time?		
8. Were you able to fill your appointment?		
9. If not, what prevented you from doing that? (check all that apply)		
Cost		
Lack of transportation		
Felt better and did not need any further medical care		
Other		
10. What was your "other" reason for not keeping your appointment?		
11. Did you need to make any unplanned visits to the ED for further treatment of your current problem?		
12. Besides the ED, PCP office or specialist, did you go anywhere else for care for your current problem?		
13. If you did see someone else for this problem, who did you see?		