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Relationships Between Health Literacy and Heart Failure Knowledge, Self-Efficacy, and Self-Care Adherence.

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TITLE PAGE

<u>Title:</u> Relationships between health literacy and heart failure knowledge, self-efficacy, and self-care adherence

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1 ABSTRACT

2 **Background:** Only 12 percent of adults have the necessary health literacy to manage their health care, 3 which can lead to difficulties in self-care activities, such as medication adherence. Prior research suggests 4 that health literacy may influence knowledge, self-efficacy and self-care, but this has not been fully 5 examined. The objective of this study is to test a model to explain the relationships between health 6 literacy, heart failure knowledge, self-efficacy, and self-care. 7 Methods: Prior to receiving clinic-based education, newly-referred patients to 3 heart failure clinics completed assessments of health literacy, heart failure knowledge, self-efficacy, self-care, and 8 9 demographics. Structural equation modeling was completed to examine the strength of the inter-variable 10 relationships. 11 **Results:** Of 81 participants recruited, 63 had complete data. Health literacy was independently-12 associated with knowledge (p<0.001). Health literacy was not related to self-care. Self-efficacy was 13 independently-associated with self-care adherence (p=0.016). No other relationships were statistically significant. The model had good fit (comparative fit index=1.000) and explained 33.6% of the variance in 14 15 knowledge and 27.6% in self-care. 16 **Conclusions:** Health literacy influences knowledge about heart failure but not self-care adherence. 17 Instead, self-efficacy influenced self-care adherence. Future research should incorporate additional 18 factors that may better model the relationships between health literacy, knowledge, self-efficacy, and self-19 care. 20 21 22

23 INTRODUCTION

Nearly 6 million Americans have heart failure, a chronic, progressive condition that accounts for 24 significant morbidity and mortality.¹ Heart failure incidence is predicted to increase by 25 percent in the 25 next two decades and may lead to a dramatic increase in healthcare costs.¹ Costly hospitalizations and 26 heart failure exacerbations can be reduced with self-care adherence.^{2,3} According to Orem's Theory of 27 28 Self-Care, self-care is a regulatory function, whereby individuals are given and assume the functions and 29 responsibility of care for themselves, and when individuals are not willing or able to perform these functions, there are self-care deficits.⁴ Patients engage in self-care maintenance—tasks to prevent 30 symptoms, such as adhering to sodium restrictions-and self-care management-activities to respond to 31 symptoms—to prevent these deficits, i.e., improve or maintain their functioning.^{2,3} The bulk of the 32 empirical evidence, however, indicates that most patients do not adhere well to self-care 33 recommendations, such as adhering to their medications and reducing sodium intake.² Addressing 34 potential barriers to self-care behavior may help patients achieve better outcomes.⁵ 35 36 Patients with heart failure typically gain disease-specific knowledge and then apply the knowledge to specific heart-failure situations,⁶ as successful self-care utilizes both the skill and 37 knowledge of individuals.^{4,6} Many individuals with heart failure lack knowledge regarding their self-care, 38 such as behaviors that maintain stability, what symptoms require monitoring, and what to do when 39 symptoms occur.⁶ Patient challenges increase when there are barriers to gaining knowledge, such as low 40 health literacy (difficulty understanding health information⁷), which is associated with less disease 41 knowledge.⁸⁻¹³ Lack of disease-specific knowledge also may affect confidence, or self-efficacy, regarding 42 43 the ability to adhere to complex self-care regimens. Self-care confidence is derived from the concept of self-efficacy from Bandura's Social Cognitive Theory.^{2,14} The level of self-efficacy an individual 44 possesses influences adherence to goals and responses to challenges. If individuals are not confident in 45 their decisions, appropriate self-care may not occur.^{14,15} The role of health literacy in this process is 46 unclear.16,17 47

48

The objective of this study was to test a model examining the relationships between years of

49 formal education, health literacy, heart failure knowledge, self-efficacy, and self-care.

50 METHODS

51 This study used a cross-sectional, correlational design and survey methods. Institutional Review
52 Board (IRB) approval was obtained from Purdue University as well as each heart failure clinic.

53 Model Development

In order to explain the proposed relationships between health literacy, heart failure knowledge, self-efficacy, and self-care, a model was proposed based on Orem's Theory of Self-Care, Bandura's Social Cognitive Theory, and a review of the literature (Figure 1, Model 1).^{4,14} The goal of developing this model was to better characterize patients who presented for initial appointments and received individual education about heart failure and self-care in outpatient clinics.

59 The amount of formal education individuals have completed affects literacy, and general literacy levels are the foundation for and are associated with health literacy.^{7,18,19} Patient educational attainment, 60 i.e., amount of formal education is associated with health literacy.^{7,17-19} Health literacy, in turn, may 61 impact patients' self-care decision-making, ability to gain knowledge regarding their condition during 62 63 traditional clinic-based education, and their confidence in making self-care decisions. If patients have not 64 gained enough knowledge, they may be unable to perform or adhere to self-care activities. Additionally, lack of knowledge may undermine patient self-efficacy, and without sufficient self-efficacy, individuals 65 may be less likely to change or start a new health behavior.¹⁴ 66

The hypothesized model is displayed in Figure 1 as Model 1, but three alternative specifications derived out of the literature, Models 2-4 in Figure 1, also were tested. The hypothesized model specified that (1) formal education would be associated with health literacy and directly effect heart failure knowledge; (2) health literacy would directly affect heart failure knowledge and self-efficacy; (3) health literacy would indirectly affect self-efficacy through heart failure knowledge; and (4) health literacy would indirectly affect self-efficacy heart failure knowledge and self-efficacy. Alternative specifications were derived out of the literature suggesting health literacy may not be directly associated with self-care.¹⁷ There also was some question as to whether years of formal education (i.e., educational attainment) was directly related to heart failure knowledge or influenced knowledge through health literacy, which let to alternative pathways.

77 Participants and Procedures

78 Participants were recruited by researchers or clinic nurses who did not provide direct patient care 79 from 2009 to 2011 at 3 heart failure clinics: Cleveland Clinic heart failure clinic in the Heart and Vascular 80 Institute (Cleveland, OH), Indiana University Health-Bloomington Hospital HEARTTEAM Cardiopulmonary Rehabilitation and Congestive Heart Failure Center (Bloomington, IN), and 81 82 Community Health Network Indiana Heart Hospital Healthy Hearts Center (Indianapolis, IN). Patients 83 were invited to participate if they were a new referral to the heart failure clinic, at least 18 years of age, 84 could read and speak English, and had no cognitive impairment (as deemed by clinical judgment). 85 Patients were excluded if they resided in a skilled nursing facility or received home healthcare services. 86 After consent was obtained, study instruments were completed in written format by participants prior to receiving traditional clinic-based education at the time of their first office appointment. Study researchers 87 88 or clinic nurses who did not provide direct patient care administered the instruments and timed the completion of the health literacy instrument. 89

90 Measures

Health literacy was measured using the Short-Form Test of Functional Health Literacy (STOFHLA), a valid and reliable measure with scores ranging from 0-36.²⁰ The S-TOFHLA contains 36
reading comprehension items, based on examples of commonly-used materials in the healthcare system,
and must be completed within a 7-minute time-frame. There are three scoring ranges: inadequate (0-16
points), marginal (17-22 points), and adequate (23-36 points). The S-TOFHLA is a reliable and valid
measure of health literacy: Cronbach's alpha is 0.98, suggesting a strong internal consistency across
measures, while correlation with other established measures of health literacy (Test of Functional Health

Literacy in Adults (TOFHLA, r=0.91) and the Rapid Estimation of Adult Literacy in Medicine (REALM,
r=0.80)) suggests the S-TOFHLA's criterion validity was adequate.²⁰

100 The Heart Failure Knowledge Questionnaire (HFKQ) was used to measure patients' knowledge 101 of heart failure related to pathology, symptoms, medications, and self-management, a reliable measure 102 with scores from 0-15.⁶ The HFKQ consists of 14 close-ended items and 1 open-ended answer. No cut-103 offs were established to measure adequate knowledge, but scores range from 0 (lack of knowledge) to 15 104 (knowledgeable). Reliability of the HFKQ was established in recently-discharged patients with heart 105 failure (Cronbach's alpha of 0.62).⁶

The Self-Care Heart Failure Index v.6 (SCHFI), a valid and reliable 22-item instrument, was used 106 107 to evaluate patient's self-care maintenance and management adherence as well as self-efficacy in performing self-care through 3 subscales.^{3,21} Each item is rated on a four-point response scale by the 108 109 participant. There are three subscales: maintenance, management, and confidence (self-efficacy). Scores 110 on each subscale are standardized to 100 points, and scores can range from 0-100. In order to score 111 Subscale B (self-care management), patients must have experienced an exacerbation of heart failure within the prior 3 months. The instrument authors recommend that a score of \geq 70 can be used as the 112 threshold for adequate self-care adherence on individual subscales.^{3,21} The SCHFI appears to have a high 113 degree of internal consistency reliability (maintenance: alpha=0.553, management: alpha=0.597)^{3,21}; 114 additional testing (confidence/self-efficacy: alpha=0.827, combined maintenance/management: 115 alpha=0.798).²² 116

Demographic information also was obtained. The following patient demographics were obtained: gender, age, marital status, co-habitation, presence of someone in whom to confide, quality of support, ethnicity/race, years of education, highest educational degree obtained, employment status, income, smoking history, alcohol use, exercise recommendation, time spent exercising, height, weight, insurance, place of residence (i.e., at home, retirement community, assisted living, or other), and number of prescription medications.

124 Data Analysis

Statistical analyses were conducted using SAS v. 9.2 (SAS Institute, Inc., Cary, North Carolina) with an *a priori* level of 0.05 for statistical significance. Descriptive statistics were performed. A power analysis was performed to determine the sample size needed to achieve a power of 0.8 with an alpha of 0.05, a sample size of at least 57 participants was needed for correlational analyses. Pearson correlations were used to measure associations between educational attainment, health literacy, knowledge, selfefficacy, and self-care.

In order to perform structural equation modeling (SEM), there are many methods for calculating 131 appropriate sample size. Some suggest that 5-20 observations per parameter estimated or at least 200 132 observations (whichever is greater) are desirable.²³ Not all studies, particularly where there is no 133 134 incentive for participation can achieve a sample size of 200. If larger sample sizes are not obtainable, 135 some researchers have suggested that 4 observations per parameter provide stable estimates. It also is recommended that models be simplified as much as possible and use reliable measures.²⁴ With 11 136 137 parameters (i.e., paths) in the most complex model and 5 observations per parameter, a minimum of 55 138 participants with complete data were needed.

139 A total of five variables and their relationships were tested: years of formal education (as 140 measured by the demographic questionnaire), health literacy level (S-TOFHLA scores), knowledge (HFKO scores), self-efficacy (SCHFI confidence subscale), and self-care. Since self-care is a process 141 142 where patients perform behaviors that maintain stability (maintenance) and respond to symptoms (selfcare management),²¹ self-care maintenance and self-care management were combined into a latent 143 144 variable (self-care), which reduced model complexity. Participant S-TOFHLA sum scores were used, 145 rather than category, to reduce the complexity of the structural equation model. Other researchers have 146 utilized the S-TOFHLA as a continuous variable rather than a categorical variable in association and regression analyses and structural equation modeling to understand relationships between variables.²⁵⁻²⁸ 147 148 Model fit was assessed using maximum likelihood estimation, with conservative cut-offs for 149 several fit statistics, including accountability for smaller sample size: a Chi-square statistic with a p-value greater than 0.05 (indicates observed covariance matrix is similar to model-predicted covariance), a Root
Mean Square Error of Approximation (RMSEA) less than 0.05, a Goodness of Fit Index (GFI) greater
than 0.95, a Normed Fit Index (NFI) greater than 0.95, and a Comparative Fit Index (CFI) greater than
0.95.^{23,29-31} If more than one model met all of these criteria, then the most parsimonious model was
chosen as the best-fitting model.²³

155 **RESULTS**

156 Participant Characteristics and Associations

157 A total of 81 participants provided baseline data; however, after removing participants with 158 incomplete data, the analyses were limited to 63 participants (see Table 1). Patients were removed for the 159 following reasons: (1) patients did not have an exacerbation of heart failure within the past three months 160 and, therefore, were ineligible to complete the section of the SCHFI regarding self-care management or 161 (2) patients did not complete an item. Compared to the 81 participants who enrolled in the study, the 63 162 participants used for analyses were not significantly different (p>0.05, data not shown). Participants, on average, were older, white, achieved at least a high school education, and were prescribed 10 prescription 163 164 medications on a regular basis. Most participants had adequate health literacy (scores ≥ 23 on the S-165 TOHFLA) but were not adherent in self-care (score < 70). Self-efficacy among participants also was not 166 adequate, and participants answered less than 55% of heart failure knowledge questions correctly (see 167 Table 3). Health literacy was positively associated with years of formal education (p=0.001) and heart 168 failure knowledge (p<0.001). Years of formal education were positively associated with knowledge 169 (p=0.001). Self-efficacy, self-care maintenance, and self-care management were not associated with health literacy, years of formal education, and heart failure knowledge (p>0.05; see Table 3). 170

171

Structure Equation Model Comparisons

Examining the criteria for model fit revealed that Model 1 had the best fit (see Table 4). All four models met criteria for good fit, but only Models 1 and 2 met all of the pre-specified fit criteria. Model 1 was chosen over Model 2 as it was more parsimonious. The highest percentage of the variance in knowledge (33.6%) and self-care (27.6%) were explained by Model 1. No model explained much of the variance in self-efficacy (see Figure 1). There was an independent effect of health literacy on knowledge.
Health literacy was neither directly nor indirectly related to self-efficacy or self-care. Self-efficacy
independently affected self-care. Knowledge was not directly related to self-efficacy.

179 **DISCUSSION**

180 In this study, the importance of health literacy on patients' understanding of basic knowledge about heart failure was revealed and underscores the importance of educational efforts in the clinical 181 182 setting. There were independent effects for health literacy on knowledge and for self-efficacy on self-care 183 but no indirect effects for health literacy on self-care or self-efficacy as hypothesized. Although there was a significant bivariate relationship between years of formal education and heart failure knowledge, in 184 185 the structural equation model, health literacy was the primary influence on knowledge about heart failure. 186 The implication is that patients with low health literacy may not understand the value of heart failure self-187 care behaviors. Further, patients also may believe the information they already have about heart failure 188 self-care adherence is accurate, even when it may not be formed from evidence-based scientific 189 information. Thus, actions taken also may not be based on current evidence.

190 Consistent with other studies, positive associations were found between health literacy and patient knowledge in heart failure,^{16,32} and this relationship also has been observed for other diseases and 191 chronic conditions.^{8-10,12,13} Although some investigators (with similar sample sizes) have found an 192 association between health literacy and self-efficacy^{16,17} and between health literacy and self-care in 193 cross-sectional studies,¹⁷ there were no associations between these variables in this study. Experience 194 195 with performing self-care and managing symptoms may improve self-efficacy over longer periods of time, as other investigators primarily examined patients who were not newly-diagnosed.^{16,17} When 196 197 patients experience success in performing self-care, their self-efficacy may improve by seeing their 198 actions produce positive results. The continuous cycle of self-efficacy and self-care may explain why 199 there were no statistically significant associations between health literacy, self-care, and self-efficacy in 200 this sample.

201 A model in which health literacy was assumed to have direct effects on knowledge, indirect 202 effects on self-efficacy through knowledge, and indirect effects on self-care through knowledge and self-203 efficacy was found to be a good fit for the data. Macabasco and colleagues evaluated the relationship 204 between these same factors and health-related quality of life and, similarly, found that health literacy had 205 a direct effect on knowledge and self-efficacy had a direct effect on self-care. However, researchers also 206 found the effect of health literacy was mediated by knowledge and self-efficacy, in contrast to this study.³² There are potential reasons for differences in findings between studies: use of different measures 207 208 and patient recruitment. Despite differences, both studies revealed the critical role of adequate health 209 literacy in heart failure knowledge. Furthermore, the results of these studies emphasized the importance 210 of patient self-efficacy on performance of self-care.

Since this model explained 33.6% percent of the variance in knowledge and 27.6% of the variance in self-care, it is likely that there were other important factors that would explain relationships between knowledge, self-efficacy, and self-care. Motivation to perform self-care or values patients have for specific self-care behaviors may be essential components that were not included in this model. Patients must value and be motivated and willing to change behaviors, as changes can be challenging to incorporate into daily life.² Future research should include patient factors not studied here or in other research to improve the model of health literacy and self-care in heart failure.

218 Limitations

219 Findings may be limited due to higher health literacy of this sample. Sites for this project were 220 chosen in an attempt to obtain more diversity in health literacy levels, and while 20 participants (31.7%) 221 with inadequate or marginal health literacy were recruited, there were more participants with adequate 222 health literacy than marginal or inadequate health literacy. Since the estimates of low health literacy among patients with heart failure are between 17.5-41%,^{18,19,33,34} the distribution of health literacy in this 223 224 study appears to be representative of the general heart failure population. Also, new referrals to heart 225 failure clinics may not equal a new diagnosis of heart failure. Patients may have had heart failure for 226 some time and could have been treated by a primary care physician or other healthcare provider before

referral to the heart failure clinic. Finally, this sample also may be more educated about heart failure, but
the levels of heart failure knowledge, self-efficacy, and self-care scores at the beginning of study were not
at desired levels (see Table 2).

230 Given that this study was cross-sectional in nature and examined the relationships between these 231 variables in newly-referred patients, the influence of health literacy on knowledge, self-efficacy, and self-232 care over time should be assessed as relationships may change with time and within the context of 233 traditional clinic-based education. Other limitations in this study include the naturalistic setting, use of 234 self-report measures, and small recruitment from one site (Community Health Network), as well as the absence of data on patient heart failure classification or prior education about heart failure. Utilizing a 235 236 naturalistic setting could result in unknown confounding factors and ultimately bias results, but this 237 setting also has higher external validity. Moreover, the use of self-report measures may introduce bias, 238 although the risk of this was minimized by utilizing previously-validated measures. The sample size for 239 this study was adequate to test the structural equation model examining the relationships between health 240 literacy, knowledge, self-efficacy, and self-care, but there was not sufficient sample size to add additional demographic parameters to the model that could further explain relationships with health literacy as 241 demonstrated in other modeling research.³⁵ There also were some participants excluded due to 242 243 incomplete data, which could have altered the results.

244 CONCLUSION

Although health literacy influences patient knowledge, health literacy and knowledge do not fully explain why patients perform self-care. Instead, self-efficacy was found to be independently-related to self-care. The models tested clarified some relationships between health literacy and self-care, but relationships between health literacy, knowledge, self-efficacy, and self-care appear to be complex and merit further study. Future research should examine additional factors that may influence heart failure self-care, such as motivation to perform self-care.

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336 Figure 1. Structural Equation Models Tested

338 Table 1. Participant Characteristics (N=63)

Age, mean (SD), y	62.1	(13.7
Years of Education, mean (SD), y	13.7	(2.9
Prescription Medications, mean (SD)	10.23	(5.5
Recruitment Site, N(%)		
Bloomington Hospital	25	(39.7
Community Health Network	5	(7.9
Cleveland Clinic	33	(52.4
Male, N(%)	33	(52.4
Married, N(%)	39	(61.9
Married	34	(66.7
Ethnicity/Race, N(%)		
Black/African American	7	(11.1
White/Caucasian	54	(85.7
Hispanic/Latino	1	(1.6
American Indian/Alaskan Native	1	(1.6
Employment Status, N(%)		
Full-Time Employed	20	(31.7
Sick Leave/Disability	10	(15.9
Unemployed or Retired	33	(52.4
Perceived Financial Status, N(%)		
More than Enough to Make Ends Meet	25	(39.7
Enough to Make Ends Meet	29	(46.0
Not Enough to Make ends Meet	9	(14.3
Health Literacy Category, ^a N(%)		
Inadequate (Range: 0-16)	10	(15.9
Marginal (Range: 17-22)	10	(15.9

³⁴⁰

^aAs measured by the Short-Form Test of Functional Health Literacy in Adults (S-TOFHLA)

Measure	Mean ± SD	Possible Range	Meaning
Health Literacy ^a	27.4 ± 9.3	0-36	Adequate health literacy
Self-Care Maintenance ^b	67.6 ± 17.8	0-100	Not adequate adherence
Self-Care Management ^b	64.7 ± 21.6	0-100	Not adequate adherence
Self-Efficacy ^b	67.3 ± 19.7	0-100	Not adequate
Heart Failure (HF) Knowledge, Overall ^c	8.1 ± 2.6	0-15	54% correct
HF Knowledge, Individual Items Correct Ar	nswer ^c	Ν	%
Definition of heart failure		43	69.4
Inappropriate weight gain		21	33.9
Mechanism of ACE Inhibitors		17	27.4
Side effects of ACE Inhibitors		15	24.2
Mechanism of digoxin		14	22.6
Side effects of digoxin		24	38.7
HF exacerbation symptom		46	74.2
Mechanism of diuretics		52	83.9
Side effects of diuretics		9	14.5
Appropriate alcohol use		41	66.1
Definition of advanced directive		39	62.9
Sodium in a food label		48	77.4
Food item with lowest sodium		56	90.3
Proper heart failure self-care		23	37.1
Reasons for rehospitalization		37	59.7

Table 2. Health Literacy, Knowledge, Self-Efficacy, and Self-Care Scores (N=61)

^aAs measured by the Short-Form Test of Functional Health Literacy in Adults (S-TOFHLA) ^bAs measured by the Self-Care of Heart Failure Index v.6 (SCHFI[®]) ^cAs measured by the Heart Failure Knowledge Questionnaire (HFKQ)

	Years of Formal Education	Heart Failure Knowledge Pearson Corr.	Self-Efficacy for Self-Care Pearson Corr.	Self-Care Maintenance Adherence	Self-Care Management Adherence
	Pearson Corr. (Sig.)	(Sig.)	(Sig.)	Pearson Corr. (Sig.)	Pearson Corr. (Sig.)
Health Literacy Score	0.418 (p=0.001)	0.548 (p<0.001)	0.201 (p=0.114)	0.116 (p=0.366)	0.233 (p=0.066)
Years of Formal Education		0.402 (p=0.001)	0.186 (p=0.145)	0.239 (p=0.060)	0.176 (p=0.169)
Heart Failure Knowledge			0.123 (p=0.335)	0.182 (p=0.153)	0.226 (p=0.075)
Self-Efficacy				0.306 (p=0.015)	0.334 (p=0.007)
Self-Care Maintenance Adherence					0.285 (p=0.023)

 Table 3. Correlations of Health Literacy and Years of Formal Education on Outcome Variables

	Model 1	Model 2	Model 3	Model 4
χ^2	3.0466	2.9076	6.3392	6.2001
DF	4	3	5	4
$\Pr > \chi^2$	0.5501*	0.4061*	0.2746*	0.1847*
Δ in χ^2	-	-0.1390	+3.2926	+3.1535
RMSEA	0.0000*	0.0000*	0.0657	0.0942
GFI	0.9840*	0.9846*	0.9681*	0.9862*
NFI	0.9511*	0.9534*	0.8983	0.9005
CFI	1.0000*	1.0000*	0.9717*	0.9535*

349 Table 4. Comparison of Structural Equation Models for Maximum Likelihood Estimation

Key: DF = Degrees of Freedom, Pr = Probability, RMSEA = Root mean square error of approximation,
 GFI = Goodness of Fit Index, NFI = Normed fit index, CFI = Comparative fix index
 *Met conservative cut-off for fit statistic

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