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Increased Patient Activation Is Associated with Fewer Emergency Room Visits and Hospitalizations for Pain in Adults with Sickle Cell Disease

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Abstract

Objective. Recurrent vaso-occlusive pain episodes, the most common complication of sickle cell disease (SCD), cause frequent health care utilization. Studies exploring associations between patient activation and acute health care utilization for pain are lacking. We tested the hypothesis that increased activation and self-efficacy are associated with decreased health care utilization for pain in SCD. **Methods**. In this cross-sectional study of adults with SCD at a tertiary medical center, we collected demographics, SCD phenotype, Patient Activation Measure levels, and self-efficacy scores using structured questionnaires. We reviewed charts to obtain disease-modifying therapy and acute health care utilization, defined as emergency room visits and hospitalizations, for vaso-occlusive pain episodes. Negative binomial regression analyses were used to test the hypothesis. **Results**. We surveyed 67 adults with SCD. The median age was 27.0 years, 53.7% were female, and 95.5% were African American. Median health care utilization for pain over one year (range) was 2.0 (0–24). Only one-third of participants (38.8%) were at the highest activation level (median [range] = 3 [1–4]). Two-thirds (65.7%) of participants had high self-efficacy (median [range] = 32.0 [13–45]). Regressions showed significant association between health care utilization and activation (incidence rate ratio [IRR] = 0.663, $P = 0.045$), self-efficacy (IRR = 0.947, $P = 0.038$), and male sex (IRR = 0.390, $P = 0.003$). Two outliers with high activation, self-efficacy, and health care utilization also had addictive behavior. **Conclusions**. Many individuals with SCD have suboptimal activation and reduced self-efficacy. Higher activation and self-efficacy were associated with lower health care utilization for pain. Additional studies are needed to evaluate interventions to improve activation and self-efficacy and reduce acute health care utilization for pain.

Key Words: Sickle Cell Disease; Patient Activation; Acute Pain; Health Care Utilization; Hospitalizations; Vaso-occlusive Pain Episodes; Self-Efficacy; Chronic Care Model

Introduction

More than 100,000 people live with sickle cell disease (SCD) in the United States, most of whom are of lower socioeconomic status [1]. SCD is a lifelong chronic disease with acute recurrent vaso-occlusive pain episodes and chronic end-organ complications. These acute pain episodes in SCD account for the majority of health care utilization (e.g., emergency room [ER] visits or hospital admissions) for individuals with SCD [2], resulting in high costs and diminished quality of life. The chronic care model has been used to improve the care of individuals with SCD [3,4]. Many studies have examined physician- or disease-specific factors of the chronic care model that affect the frequency of ER visits and hospitalizations for SCD [5–13]. However, two crucial components of the chronic care model that form the informed activated patient, patient activation and self-efficacy, have not been studied in relation to each other, nor to acute health care utilization for pain (ER visits and hospital admissions).

Self-efficacy is an individual's belief in their own ability to reach a specific goal, in this context self-managing disease-related morbidities [14]. One example would be an individual's ability to manage their SCD pain symptoms so they can do the things they enjoy doing. Higher perceived self-efficacy in individuals with SCD has been associated with improved readiness for transition from pediatric to adult care, fewer physical and psychological symptoms, an increased number of physician visits maintained after transition, improved adherence to medication regimens, and better quality of life [15,16]. Individuals with higher self-efficacy also experience fewer vaso-occlusive pain episodes, with lower pain severity [17–19]. Although this literature demonstrates the relationships between self-efficacy and some outcomes in SCD, the relationship between acute health care utilization for pain and self-efficacy has not been evaluated in adults with SCD.

Patient engagement has been described as the blockbuster drug of the 21st century [20]. Patient activation is defined as a person's knowledge, confidence, and skills in managing his or her health [21]. Activation is thought to be a developmental process that begins with understanding that one's behaviors are essential for health and then proceeds through gaining the knowledge and confidence to take action [22], actually taking action, and sustaining actions for one's health under stress at the highest levels of activation. Higher levels of activation are thought to be necessary for becoming engaged in one's health and care. Increased patient activation has been associated with lower costs and health care utilization for individuals with other chronic diseases like asthma or diabetes [22–24]. Although there is overlap between patient activation and self-efficacy, these characteristics are different constructs. Even if an individual perceives that he can perform a task (i.e., has high self-efficacy), he may still lack the knowledge, confidence, and skills (i.e., have low activation) to engage in that behavior. Researchers have developed causal models to describe this relationship [25]. Some studies have described associations of lower pain intensity with higher patient activation, but most of these have been in the postoperative period [26–29]. There is a lack of studies exploring associations between patient activation and acute health care utilization for pain. Improved activation might allow individuals with SCD to prevent and manage SCD-related pain episodes at home, resulting in decreased hospitalization or ER visits. Pain is important in many diseases, especially SCD, and associations between patient activation and acute health care utilization can have significant implications for improving care. We conducted a cross-sectional study to test the hypothesis that adults with SCD with higher patient activation or self-efficacy levels have lower health care utilization (as measured by ER visits and hospitalizations), compared with those with lower patient activation and self-efficacy levels.

Methods

Setting

This study was a cross-sectional study with self-administered surveys and retrospective chart review for one year before completing the survey. From August 2016 to December 2017, adults with SCD seen during regular clinic visits at the Vanderbilt-Meharry Sickle Cell Center of Excellence were recruited. The Vanderbilt-Meharry Sickle Cell Center of Excellence cared for about 250 adults with SCD during the study period. Inclusion criteria included age >18 years, ability to speak and write English, and daily medication use at the time of recruitment. We excluded adults with SCD who had been seen in our center for less than one year or had cognitive difficulties and were unable to provide informed consent themselves. Those who consented to participate were given electronic surveys to fill out, and information from their electronic health record was obtained. The Vanderbilt University Medical Center Institutional Review Board approved this study.

Survey Tool

The survey tool was designed by the research team and SCD clinicians, primarily used validated instruments, and was then piloted in a few individuals with SCD before conduct of the study. These instruments included a survey of clinical and demographic characteristics, the Patient Activation Measure [21], and the Sickle Cell Self-Efficacy Scale [30]. The enrolled participants completed the electronic survey tool in Research Electronic Data Capture (REDCap) [31].

The Patient Activation Measure is a 13- or 10-item scale designed by Insignia Health to quantify a patient's activation or self-management capabilities. We used the 10-item version of the Patient Activation Measure. The measure has a score from 1 to 100 that can be

transformed by an algorithm to a patient activation level. Activation, as measured by the Patient Activation Measure, involves four levels: At the first level, people have a low knowledge about their disease and may not understand the importance of their role in their health. At the second level, people have some knowledge about their disease but may not have the knowledge, confidence, and skills to take action. At the third level, people are both knowledgeable and taking action to maintain or improve their health. At the fourth level, people are capable of carrying out the actions of their health care plan even if they are under stress. People at the fourth level are also actively seeking to improve their own knowledge and identify opportunities for action. The four levels of activation can be illustrated in the example of a hypertensive man. Such a patient at the first level may not understand why he needs to take a prescription, such as an antihypertensive, as recommended. At the second level, he might know what his blood pressure should be but not feel comfortable measuring it independently. At the third level, he might monitor his blood pressure weekly, and at the fourth level, he might keep a blood pressure diary and engage in proactive dietary changes even when working long hours.

The Sickle Cell Self-Efficacy Scale is a validated nine-item scale developed to assess adults' and adolescents' self-efficacy; this scale is a self-report of their ability to perform daily activities while having SCD. Responses for each question range from 1 to 5 ("not at all sure" to "very sure") [30]. Total self-efficacy scores are obtained by summing responses to all nine items for a total score of 9 to 45. Higher scores are indicative of greater self-efficacy. Although there is no clear definition of high or low self-efficacy, we considered high self-efficacy to be responses of "sure" or "very sure" for at least five of the nine questions. Someone with low self-efficacy will feel helpless in their disease and that they are unable to do things that allow them to achieve health, such as taking medications like hydroxyurea to prevent pain episodes. A person with high self-efficacy believes that if they perform the appropriate management steps, like taking preventive medications and abortive medications, issues like pain episodes in their SCD are manageable.

Electronic Health Record Information

Additional information about the participants was retrieved from the electronic health record. SCD phenotype, disease-modifying therapy (hydroxyurea, regular blood transfusion therapy, or stem cell transplantation), and acute health care utilization over the year before survey administration were obtained. We defined regular blood transfusion therapy as receiving blood transfusions approximately every four weeks. Health care utilization for vaso-occlusive pain episodes was determined by three of the co-authors (RMC, TLD, WA), who manually reviewed each participant's ER physician notes and hospital discharge summaries. If a diagnosis of a pain episode or "pain crisis" was indicated in these documents, we counted that as an ER visit or hospitalization for acute vaso-occlusive pain. We reviewed the chart record for the year before the participant took the survey.

Statistical Analysis

To summarize the demographic variables, we used descriptive statistics. The Mann-Whitney U test, Kruskal-Wallis test, and Fisher exact test were used for bivariate analysis between Patient Activation Measure levels and demographic and clinical characteristics. We also created an ordinal logistic regression model to determine associations between Patient Activation Measure levels and all important demographics. As the Patient Activation Measure score is a 0–100-point score that can be divided into four levels, there are two ways to do the analysis, using either continuous or categorical variables. Because Insignia Health designed the Patient Activation Measure levels based on expert reviews and Patient Activation Measure levels have been used in prior literature [23], we used the Patient Activation Measure level for the analysis. Analysis of variance was used for bivariate analysis between the Sickle Cell Self-Efficacy Scale and demographics and then between the Sickle Cell Self-Efficacy Scale and Patient Activation Measure levels. To build the best models for the outcome of acute health care utilization, we evaluated associations between variables of interest and the outcome of acute health care utilization. We utilized a negative binomial regression to model health care utilization (count of events), and based on the preliminary analysis, the model included age, sex, SCD phenotypes, disease-modifying therapy, Patient Activation Measure, and Sickle Cell Self-Efficacy Scale scores. A P value <0.05 was considered significant. All analyses were done using R, version 3.2.2 [32].

Results

Demographic Data

A total of 103 adults were approached, of whom 68 (66%) adults with SCD completed the survey (Table 1). The single participant with "other" sickle cell phenotype was removed from the analyses. The remaining 67 participants had a median age (range) of 27.0 (18–61) years. There were 36 (53.7%) females and 64 (95.5%) African Americans. A majority had the hemoglobin SS phenotype (68.7%) and were receiving hydroxyurea (62.7%). The median Sickle Cell Self-Efficacy Scale score (range) was 32.0 (13–45). About two-thirds (65.7%) of participants had high self-efficacy, selecting "sure" or "very sure" for at least five of the nine questions in the Sickle Cell Self-Efficacy Scale. The median health care utilization (range) was 2.0 (0–24) visits per participant for the year before the survey date.

Table 1. Demographics of the sample (67 adults with SCD)

Question	Answer	No. (%) or Median (Range)
Sex	Female	36 (53.7)
	Male	31 (46.3)
Race	African American	64 (95.5)
	Other	3 (4.5)
Age		27.0 (18–61)
Sickle cell phenotype	HbSS	46 (68.7)
	HbSC	8 (11.9)
	HbSbeta0	9 (13.4)
	HbSbeta+	4 (6.0)
Disease-modifying therapy	None	5 (7.5)
	Transfusions	20 (29.8)
	HU	42 (62.7)
PAM score		68.9 (37.2–100)
PAM level	1	2 (3.0)
	2	7 (10.4)
	3	32 (47.8)
	4	26 (38.8)
SCSES score		32.0 (13–45)
ER and hospital visits		2.0 (0–24)

ER=emergency room; HU=hydroxyurea; PAM=Patient Activation Measure; SCD = sickle cell disease; SCSES=Sickle Cell Self-Efficacy Scale.

Patient Activation Measure Levels Were Associated with Self-Efficacy and Utilization

The median Patient Activation Measure score (range) was 68.9 (37.2–100). The patient activation levels for our participants were 3.0% (N = 2) at level 1, 10.4% (N = 7) at level 2, 47.8% (N = 32) at level 3, and 38.8% (N = 26) at level 4. There was no association with Patient Activation Measure level for sex ($P = 0.338$), age ($P = 0.373$), sickle cell phenotype ($P = 0.119$), or disease-modifying therapies ($P = 0.558$). The Sickle Cell Self-Efficacy Scale score was associated with Patient Activation Measure levels ($P = 0.016$), with higher scores at higher Patient Activation Measure levels. The number of hospital and ER visits was also associated with Patient Activation Measure levels ($P = 0.05$), with lower utilization at higher Patient Activation Measure levels (Table 2).

In an ordinal regression for Patient Activation Measure level with sex, age, sickle cell phenotype, type of treatment, and Sickle Cell Self-Efficacy Scale score, only Sickle Cell Self-Efficacy Scale score was associated with Patient Activation Measure level (odds ratio = 1.13, 95% confidence interval [CI] = 1.04–1.23, $P = 0.004$) (Table 3).

Acute Health Care Utilization for Vaso-occlusive Pain Episodes Was Significantly Associated with Patient Activation, Self-Efficacy, and Male Sex

In a negative binomial regression for acute health care utilization, patient activation was associated with lower acute health care utilization ($P = 0.045$), with every Patient Activation Measure level increase corresponding to a decrease in the rate of health care utilization for vaso-occlusive pain episodes by 0.66 (95% CI = 0.45–0.98). Self-efficacy was also associated with lower acute health care utilization ($P = 0.038$), with every point increase in Sickle Cell Self-Efficacy Scale score decreasing the rate of acute health care utilization by 0.95 (95% CI = 0.90–1.00). Males had a significantly lower rate (0.39) of health care utilization than females (95% CI = 0.22–0.70, $P = 0.003$). Age was not associated with health care utilization ($P = 0.084$); nor was hydroxyurea ($P = 0.42$), chronic blood transfusion (0.09), or sickle cell phenotype (overall effect $P = 0.09$) (Table 4).

Patient Activation and Self-Efficacy May Not Be the Best Measure for Individuals with SCD and Addictive Behaviors

Two participants had high Patient Activation Measure scores and acute health care utilization. These two participants both had Patient Activation Measure levels of 4, Sickle Cell Self-Efficacy Scale scores between 34 and 35, and more than 20 hospitalizations or ER visits. They were both females in their late twenties; one had HbSC, and the other had HbSβ^+ thalassemia. Despite maximum medical therapy, two participants had opioid use disorder, along with chronic pain. In the ER, they received the standard pain management protocol for acute SCD pain with a patient-controlled analgesia pain pump according to their outpatient SCD pain management plan.

Discussion

In individuals with a chronic disease, strategies that improve patient engagement can decrease acute health care utilization for pain and improve clinical outcomes. In the context of implementing the chronic care model across the lifespan, two critical components of care are self-efficacy and patient activation [3,4]. Our findings demonstrate that adults with SCD who are more activated are less likely to visit the ER and be hospitalized for vaso-occlusive pain episodes. We also found that adults with SCD with higher self-efficacy have less health care utilization. Our findings have significant implications for decreasing ER visits and hospitalizations for pain by discovering two new targets for interventions that can decrease costly acute health care utilization in all members of this population.

Our study is the first to evaluate associations among patient activation, self-efficacy, and health care utilization for pain in adults with SCD. Previous studies have demonstrated that individuals in the postoperative period have lower pain intensity with higher activation [26–28]. Studies in diabetes and asthma have also shown that patients with a higher activation level have better clinical outcomes, including lower acute health care utilization [23,24]. Our study adds to this literature by demonstrating that higher patient activation is associated with lower acute health care utilization for pain. Notably, less than

Table 2. Variables for different Patient Activation Measure levels*

		PAM Level					
Variable	Category	1(N = 2)	2(N = 7)	3(N = 32)	4(N = 26)	Total (N = 67)	*P* Value
Sex	Male	1 (50.0)	4 (57.1)	11 (34.4)	15 (57.7)	31 (46.3)	0.338†
Age		21.5 (18–25)	32.0 (22–61)	27.5 (20–53)	27.5 (19–54)	27.0 (18–61)	0.373‡
Sickle cell type							0.119§
	HbSS	0 (0.0)	5 (71.4)	24 (75.0)	17 (65.4)	46 (68.7)	
	HbSC	0 (0.0)	2 (28.6)	2 (6.3)	4 (15.4)	8 (11.9)	
	HbSbeta0	2 (100.0)	0 (0.0)	3 (9.4)	4 (15.4)	9 (13.4)	
	HbSbeta+	0 (0.0)	0 (0.0)	3 (9.4)	1 (3.8)	4 (6.0)	
Disease-modifying therapy							0.558§
	None	0 (0.0)	1 (14.3)	2 (6.2)	2 (7.7)	5 (7.5)	
	Transfusions	1 (50.0)	4 (57.2)	8 (25.0)	7 (26.9)	20 (29.8)	
	HU	1 (50.0)	2 (28.6)	22 (68.8)	17 (65.4)	42 (62.7)	
SCSES score		30.5 (25–36)	28.0 (18–45)	30.0 (13–39)	34.0 (22–43)	32.0 (13–45)	0.016¶
ER and hospital visits		5.0 (4–6)	3.0 (0–16)	2.5 (0–12)	0.5 (0–24)	2.0 (0–24)	0.050‡

ER=emergency room; HU=hydroxyurea; PAM=Patient Activation Measure; SCSES=Sickle Cell Self-Efficacy Scale.
*Count and percentage for categorical variables; median and range for continuous variables.
†Mann-Whitney *U* test.
‡Kruskal-Wallis test.
§Fisher exact test.
¶Analysis of variance.

Table 3. Multivariable ordinal regression model of Patient Activation Measure level

Variable	Categories	Odds Ratio	95% CI	*P* Value
Age		0.987	(0.930–1.048)	0.666
Sex				
	Male	1.561	(0.573–4.254)	0.384
Treatment				
	HU	1.356	(0.175–10.527)	0.771
	Chronic transfusions	0.934	(0.108–8.078)	0.951
Sickle cell type	Reference category HbSS			
	HbSC	0.819	(0.149–4.501)	0.818
	HbSbeta0	0.502	(0.096–2.629)	0.415
	HbSbeta+	0.850	(0.120–5.995)	0.870
SCSES score		1.132	(1.038–1.233)	0.004

CI = confidence interval; HU=hydroxyurea; PAM=Patient Activation Measure; SCSES=Sickle Cell Self-Efficacy Scale.

Table 4. Multivariable negative binomial regression of ER visits and hospitalizations in the prior year for vaso-occlusive pain episodes

		IRR	95% CI	*P* Value
Age		0.966	(0.930–1.004)	0.084
Sex				
	Male	0.390	(0.216–0.703)	0.003
Treatment				
	Chronic blood transfusions	2.746	(0.873–8.635)	0.089
	Hydroxyurea	1.583	(0.519–4.830)	0.423
Sickle cell type	SS			
	SC	2.397	(0.970–5.926)	0.063
	S-beta0	0.435	(0.157–1.204)	0.115
	S-beta+	2.326	(0.779–6.946)	0.136
PAM level		0.663	(0.447–0.982)	0.045
SCSES score		0.947	(0.901–0.996)	0.038

CI = confidence interval; ER = emergency room; IRR = incidence rate ratio; PAM=Patient Activation Measure; SCSES=Sickle Cell Self-Efficacy Scale.

half of the participants had the highest level of activation, and other studies have shown even lower activation levels [33–36]. This finding suggests that many people with chronic diseases have the potential for improvement in patient activation, and this increase could lead to fewer visits to the ER and hospitalizations. We also found that female sex was associated with higher acute health care utilization for pain in SCD, similar to prior literature [37].

However, patient activation may not accurately predict utilization for every individual with SCD. This study included participants with milder phenotypes of SCD, and among these, two outliers had high Patient Activation Measure scores and were at the highest Patient Activation Measure level but also had more than 20 ER visits and hospitalizations each over a one-year period. In our study, the most plausible reason for a large number of ER visits and hospitalizations for two

participants with the highest patient activation level (level 4) and high self-efficacy scores was their formal diagnosis of opioid use disorder. Both participants with opioid use disorder frequented the ER to obtain opioids.

Overall, individuals with SCD have a higher average Patient Activation Measure score than other chronic medical conditions [33–36]. This finding could partly reflect selection bias associated with participant recruitment at a dedicated SCD referral center, which strives to educate and empower individuals with SCD about their disease. However, a large range of Patient Activation Measure scores and all levels were represented in our Sickle Cell Center of Excellence, demonstrating room to improve patient activation, even in this optimized clinical setting. Patient activation may also endure over time [38], and further prospective studies are needed to determine whether patient activation endures in individuals with SCD.

Patient activation is only associated with self-efficacy in individuals with SCD, with no significance found between patient activation and demographic variables in our model. As expected, most of our participants were African American, precluding consideration of race's effect on patient activation. Studies of other diseases, including diabetes, chronic kidney disease, and heart disease have demonstrated that patient activation is associated with age, sex, comorbidities, and stage of disease [33,34,36]. However, these findings have not been uniform [39]. Our findings may indicate that most adults with SCD have the potential for improving patient activation, regardless of age, sex, phenotype, or treatment. Similar to our findings, patient activation has been demonstrated to be directly related to self-care and self-efficacy [33–35]. As patient activation and self-efficacy are correlated, targeting one could help improve the other.

The range of self-efficacy scores that we found in SCD is comparable to that of other populations [30,40]. The scores ranged from poor self-efficacy (Sickle Cell Self-Efficacy Scale score = 13) to perfect self-efficacy (Sickle Cell Self-Efficacy Scale score = 45), with one-third of participants not being sure they can keep doing most of the typical things they do day-to-day. Similar to prior literature, we show that individuals with SCD with higher self-efficacy have fewer pain symptoms, less health care utilization, better medication adherence, and better health-related outcomes [15–19].

One potential explanation for higher self-efficacy leading to lower acute health care utilization for pain episodes could be better medication adherence. Additional research using direct or indirect measures of the association between higher self-efficacy and medication adherence is needed. Self-efficacy was not significantly associated with any other sociodemographic variables. Our findings are similar to the limited literature suggesting no relationship between self-efficacy and age, sex, and socioeconomic status among adolescents and adults in the SCD population [16].

Patient activation and self-efficacy may be amenable to intervention, raising the possibility of targeted approaches to improve health-related outcomes. Studies of interventions, such as telephone calls and technology (e.g., text messaging and websites), have demonstrated their ability to improve patient activation [41–44]. Our findings describe another potential target to decrease these costly acute pain episodes in SCD, and a target for other diseases with acute pain flare-ups. Several studies have reported interventions to improve health outcomes tailored to levels of activation [45–47]. In these studies, patients with lower levels of activation are provided with education about the importance of their participation in their health and about their specific diseases and treatment plans. At higher levels of activation, patients are given opportunities and assistance in taking action to build the confidence and skills to sustain action under duress. Future interventions will be greatly facilitated by a better understanding of the mechanisms by which patient activation leads to decreased acute health care utilization. Individuals with higher activation may have less frequent pain episodes by avoiding triggers, be able to treat their pain episodes at home better, or visit their physicians as an outpatient to help manage mild pain episodes instead of going to the ER. Further research is needed to determine the mechanism that connects activation and acute health care utilization to determine and evaluate interventions that can improve activation and clinical outcomes in SCD.

This pilot study has some necessary limitations. First, the study took place at a single institution. Our site has a similar range in demographics and treatment when compared with other sickle cell centers across the United States, but further multi-institutional research will be needed to demonstrate the generalizability of our results to other areas of the United States. Second, because only participants who showed up to their clinic visits completed the surveys, there may have been a selection bias toward people who are more activated. However, we found a range of activation levels and acute health care utilization, which suggests that the recruitment strategy introduced limited bias. Finally, health care utilization was extracted through retrospective examination of our institution's electronic medical record, which is unlikely to capture any health care utilization that occurred at other regional ERs and hospitals. Participants may have accessed community hospitals and not our tertiary care hospital. Our study design did not allow us access to medical care at all local hospitals. However, there is a lack of evidence demonstrating that patient activation is associated with hospitalizations at local hospitals as compared with tertiary care centers; the effect of patient activation on differences in health care utilization across care settings is a topic of future research.

Conclusions

Patient activation and self-efficacy have important implications in the SCD population. We demonstrate that most adults with SCD have room to improve their patient activation, and higher patient activation levels are associated with lower acute health care utilization for pain episodes, the most prevalent cause of ER visits and hospitalizations among adults with SCD. Self-efficacy also had associations with patient activation and health care utilization, with individuals with higher self-efficacy having higher patient activation and lower rates of acute health care utilization. Improving patient activation and self-efficacy through technological interventions and coaching may help decrease acute health care utilization for pain episodes in chronic diseases. Further research into identifying interventions that improve patient activation, self-efficacy, and, ultimately, health-related outcomes is needed.

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References

1. Chaturvedi S, DeBaun MR. Evolution of sickle cell disease from a life-threatening disease of children to a chronic disease of adults: The last 40 years. Am J Hematol 2016;91(1):5–14.
2. Brousseau DC, Panepinto JA, Nimmer M, Hoffmann RG. The number of people with sickle-cell disease in the United States: National and state estimates. Am J Hematol 2010;85(1):77–8.
3. Coleman K, Austin BT, Brach C, Wagner EH. Evidence on the chronic care model in the new millennium. Health Aff (Millwood) 2009;28(1):75–85.
4. Bodenheimer T, Wagner EH, Grumbach K. Improving primary care for patients with chronic illness: The chronic care model, Part 2. JAMA 2002; 288(15):1909–14.
5. Jonassaint CR, Jones VL, Leong S, Frierson GM. A systematic review of the association between depression and health care utilization in children and adults with sickle cell disease. Br J Haematol 2016;174 (1):136–47.
6. Ahmadi M, Jahani S, Poormansouri S, Shariati A, Tabesh H. The effectiveness of self management program on quality of life in patients with sickle cell disease. Iran J Ped Hematol Oncol 2015;5(1):18–26.
7. Brousseau DC, Owens PL, Mosso AL, Panepinto JA, Steiner CA. Acute care utilization and rehospitalizations for sickle cell disease. JAMA 2010;303 (13):1288–94.
8. Aljuburi G, Laverty AA, Green SA, et al. Trends in hospital admissions for sickle cell disease in England, 2001/02-2009/10. J Public Health (Oxf) 2012;34 (4):570–6.
9. Glassberg J, Simon J, Patel N, et al. Derivation and preliminary validation of a risk score to predict 30-day ED revisits for sickle cell pain. Am J Emerg Med 2015;33(10):1396–401.
10. Sobota A, Graham DA, Neufeld EJ, Heeney MM. Thirty-day readmission rates following hospitalization for pediatric sickle cell crisis at freestanding children's hospitals: Risk factors and hospital variation. Pediatr Blood Cancer 2012;58(1):61–5.
11. Frei-Jones MJ, Field JJ, DeBaun MR. Risk factors for hospital readmission within 30 days: A new quality measure for children with sickle cell disease. Pediatr Blood Cancer 2009;52(4):481–5.
12. Leschke J, Panepinto JA, Nimmer M, et al. Outpatient follow-up and rehospitalizations for sickle cell disease patients. Pediatr Blood Cancer 2012;58 (3):406–9.
13. Brodsky MA, Rodeghier M, Sanger M, et al. Risk factors for 30-day readmission in adults with sickle cell disease. Am J Med 2017;130(5):601.e9–e15.
14. Bandura A. Self-efficacy: Toward a unifying theory of behavioral change. Psychol Rev 1977;84(2):191–215.
15. Edwards R, Telfair J, Cecil H, Lenoci J. Self-efficacy as a predictor of adult adjustment to sickle cell disease: One-year outcomes. Psychosom Med 2001;63 (5):850–8.
16. Molter BL, Abrahamson K. Self-efficacy, transition, and patient outcomes in the sickle cell disease population. Pain Manag Nurs 2015;16(3):418–24.
17. Clay OJ, Telfair J. Evaluation of a disease-specific self-efficacy instrument in adolescents with sickle cell disease and its relationship to adjustment. Child Neuropsychol 2007;13(2):188–203.
18. Jenerette CM, Brewer C. Health-related stigma in young adults with sickle cell disease. J Natl Med Assoc 2010;102(11):1050–5.
19. Adegbola M. Spirituality, self-efficacy, and quality of life among adults with sickle cell disease. South Online J Nurs Res 2011;11(1).
20. Dentzer S. Rx for the 'blockbuster drug' of patient engagement. Health Affairs 2013;32(2):202.
21. Hibbard JH, Stockard J, Mahoney ER, Tusler M. Development of the Patient Activation Measure (PAM): Conceptualizing and measuring activation in patients and consumers. Health Serv Res 2004;39 (4 Pt 1):1005–26.
22. Greene J, Hibbard JH, Sacks R, Overton V, Parrotta CD. When patient activation levels change, health outcomes and costs change, too. Health Affairs 2015; 34(3):431–7.
23. Kinney RL, Lemon SC, Person SD, Pagoto SL, Saczynski JS. The association between patient activation and medication adherence, hospitalization, and

emergency room utilization in patients with chronic illnesses: A systematic review. Patient Educ Couns 2015;98(5):545–52.
24. Sacks RM, Greene J, Hibbard J, Overton V, Parrotta CD. Does patient activation predict the course of type 2 diabetes? A longitudinal study. Patient Educ Couns 2017;100(7):1268–75.
25. Do V, Young L, Barnason S, Tran H. Relationships between activation level, knowledge, self-efficacy, and self-management behavior in heart failure patients discharged from rural hospitals. F1000Res 2015;4:150.
26. Andrawis J, Akhavan S, Chan V, et al. Higher preoperative patient activation associated with better patient-reported outcomes after total joint arthroplasty. Clin Orthopaed Relat Res 2015;473 (8):2688–97.
27. Block AR. Demoralization, patient activation, and the outcome of spine surgery. Healthcare (Basel, Switzerland) 2016;4(1):11.
28. Skolasky RL, Mackenzie EJ, Wegener ST, Riley LH 3rd. Patient activation and functional recovery in persons undergoing spine surgery. J Bone Joint Surg Am 2011;93(18):1665–71.
29. Gruber JS, Hageman M, Neuhaus V, et al. Patient activation and disability in upper extremity illness. J Hand Surg 2014;39(7):1378–83.e3.
30. Edwards R, Telfair J, Cecil H, Lenoci J. Reliability and validity of a self-efficacy instrument specific to sickle cell disease. Behav Res Ther 2000;38 (9):951–63.
31. Harris PA, Taylor R, Thielke R, et al. Research electronic data capture (REDCap)–a metadata-driven methodology and workflow process for providing translational research informatics support. J Biomed Inform 2009;42(2):377–81.
32. R Development Core Team. R: A Language and Environment for Statistical Computing. Vienna: R Foundation for Statistical Computing; 2005.
33. Zimbudzi E, Lo C, Ranasinha S, et al. Factors associated with patient activation in an Australian population with comorbid diabetes and chronic kidney disease: A cross-sectional study. BMJ Open 2017;7 (10):e017695.
34. Zimbudzi E, Lo C, Ranasinha S, et al. The association between patient activation and self-care practices: A cross-sectional study of an Australian population with comorbid diabetes and chronic kidney disease. Health Expect 2017;20(6):1375–84.
35. Masterson Creber R, Chen T, Wei C, Lee CS. Brief report: Patient activation among urban hospitalized patients with heart failure. J Card Fail 2017;23 (11):817–20.
36. Peters AE, Keeley EC. Patient engagement following acute myocardial infarction and its influence on outcomes. Am J Cardiol 2017;120(9):1467–71.
37. Lanzkron S, Carroll CP, Haywood C. The burden of emergency department use for sickle cell disease: An analysis of the national emergency department sample database. Am J Hematol 2010;85(10):797–9.
38. Blakemore A, Hann M, Howells K, et al. Patient activation in older people with long-term conditions and multimorbidity: Correlates and change in a cohort study in the United Kingdom. BMC Health Serv Res 2016;16(1):582.
39. Hendriks SH, Hartog LC, Groenier KH, et al. Patient activation in type 2 diabetes: Does it differ between men and women? J Diabetes Res 2016;2016 :7386532.
40. Sobota A, Akinlonu A, Champigny M, et al. Self-reported transition readiness among young adults with sickle cell disease. J Pediatr Hematol/Oncol 2014;36(5):389–94.
41. Haas K, Martin A, Park KT. Text message intervention (TEACH) improves quality of life and patient activation in celiac disease: A randomized clinical trial. J Pediatr 2017;185:62–7.e2.
42. Houlihan BV, Brody M, Everhart-Skeels S, et al. Randomized trial of a peer-led, telephone-based empowerment intervention for persons with chronic spinal cord injury improves health self-management. Arch Phys Med Rehabil 2017;98(6):1067–76.e1.
43. Knoerl R, Lee D, Yang J, Bridges C, Kanzawa-Lee G, Lita Smith G, Lavoie Smith EM. Examining the Impact of a Web-Based Intervention to Promote Patient Activation in Chemotherapy-Induced Peripheral Neuropathy Assessment and Management. Journal of cancer education : the official journal of the American Association for Cancer Education. 2017. Epub 2017/03/08. doi: 10.1007/s13187-017-1200-0. PubMed PMID: 28265863.
44. John ME, Samson-Akpan PE, Etowa JB, Akpabio II, John EE. Enhancing self-care, adjustment and engagement through mobile phones in youth with HIV. Int Nurs Rev 2016;63(4):555–61.
45. Hibbard JH, Greene J, Tusler M. Improving the outcomes of disease management by tailoring care to the patient's level of activation. Am J Manag Care 2009; 15(6):353–60.
46. Jackson GP, Robinson JR, Ingram E, et al. A technology-based patient and family engagement consult service for the pediatric hospital setting. J Am Med Informat Assoc 2018;25:167–74.
47. Shively MJ, Gardetto NJ, Kodiath MF, et al. Effect of patient activation on self-management in patients with heart failure. J Cardiovasc Nurs 2013;28(1):20–34.