Factors Influencing Willingness To Utilize The Emergency Department Among Individuals Living With Sickle Cell Disease

Elizabeth A. Ibiloye,[1] Gloria N. Odonkor,[1] Jamie C. Barner,[1] Carolyn M. Brown,[1] Hyeun Ah Kang,[1] Benita A. Bamgbade[2]

[1]Health Outcomes Division, College of Pharmacy, The University of Texas at Austin;

[2]Department of Pharmacy and Health Systems Sciences, School of Pharmacy and Pharmaceutical Sciences, Northeastern University, Boston, Massachusetts

HSD38

Background

Background

- Sickle cell disease (SCD) is the most common inherited genetic disorder worldwide, and it affects approximately 100,000 Americans.[1]
- SCD is characterized by unexpected pain crises (vaso-occlusive crises), which often necessitate emergency department (ED) use.
- However, **patients with SCD often delay seeking ED care when in pain.**[2]

Objective

- Use the **Theory of Planned Behavior (TPB)**[3] to determine **factors that influence willingness to use the ED when in pain among individuals with SCD**.

Conceptual Model

- **TPB** states that intention to perform a behavior is determined by three factors ***(direct constructs)***: **attitude, subjective norm and perceived behavioral control** which are influenced by three beliefs ***(indirect constructs)***: behavioral, normative and control beliefs, respectively.
- The study conceptual model **(Figure 1)** included the TPB plus additional constructs (**prior patient experience and stigma**), and covariates (demographic and personal characteristics).

Methods

Study Design: Prospective cross-sectional web-based survey

Study Participants: Adults (≥ 18 years) with SCD who have utilized the ED at least once were recruited through the Sickle Cell Association of Texas Marc Thomas Foundation and Rare Patient Voice

Dependent Variable:

- **Intention:** Participants' willingness to use the ED while in SCD-related pain

Independent Variables:

- **Theory of Planned Behavior Constructs (Direct and Indirect):**
  Direct constructs were based on TPB standardized items[3]
  Indirect constructs were derived from previous focus groups
  - **Attitude:** Evaluations of using the ED while in SCD-related pain
  - **Subjective norm:** Evaluations of what people they consider important think about going to the ED while in SCD-related pain
  - **Perceived behavioral control:** Perceptions of their control over the decision to go to the ED while in SCD-related pain
- **Additional Study Constructs:**
  - **Prior patient experience:**[4] Perceptions about prior experience of care in the ED while in SCD-related pain
  - **Stigma:**[5] Perceptions about the attitudes of ED physicians toward SCD
- **Covariates**
  - **Sociodemographics:** age, gender, race, region of residence, marital status, education level, income level, health insurance
  - **Personal Characteristics:** SCD genotype, usual source of care

Statistical Analyses:

- **Descriptive statistics:** Frequencies, means and SDs
- **ANOVA:** Relationship between dependent variable (intention) and covariates to determine variables to include in multivariable regression
- **Multivariable linear regression:** Relationships of TPB constructs with intention
- **Hierarchical regression analyses:** Extent to which additional constructs (prior experience and stigma) added predictive power to the TPB model
- **Reliability:** Cronbach's alpha to measure internal consistency for intention, direct TPB constructs, prior patient experience and stigma

Results

Figure 1: Conceptual Model Using the TPB to Predict Willingness to Use the ED When in Pain

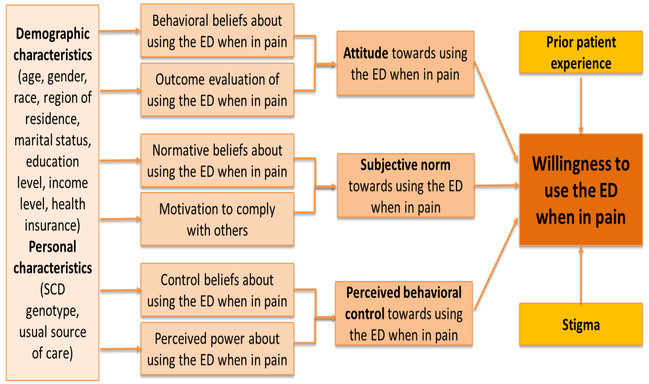

Table 1: Demographic and Personal Characteristics of Participants (N=114)

Characteristics	N	%
Age: 18 to >55 years old (**73.7% were 26 to 45 years**)		
Gender ***(Female)***	92	80.7
Race ***(Black)***	109	95.6
Region of residence ***(South)***	67	58.7
Marital Status ***(Single)***	70	61.7
Education ***(≥ Associate degree)***	51	44.7
Annual Income ***(≥$25,000)***	49	42.9
Public health insurance	69	60.5
Genotype ***(HbSS)***	77	67.6
≥ 1 visit within the last 12 months		
• Emergency Department	107	93.9
• Hematologist	109	95.6
• Primary Care Provider	80	70.2

Table 2: Reliability Values of Multi-Item Scale Direct Measures

Scale	No. of items	Cronbach's Alpha
Intention	3	0.91
Direct Attitude	5	0.90
Direct Subjective Norm	4	0.77
Direct Perceived Behavioral Control	4	0.68
Prior Patient Experience	20	0.96
Stigma	10	0.85

Table 3: Description of Study Constructs (N=114)

Scale	No. of items	Possible Range	Observed Range	Scale Midpoint	Mean (SD)	Summary towards going to the ED while in pain
Intention	3	-9 to +9	-9 to +9	0	0.6±5.2	**Weak positive** intention (willingness)
Attitude (Direct)	5	-15 to +15	-15 to +15	0	2.1±7.1	**Weak positive** attitude
Attitude (Indirect)	22	-99 to +99	-96 to +99	0	-14.8±33.0	**Weak negative** indirect attitude
Subjective Norm (Direct)	4	-12 to +12	-10 to 12	0	5.7±4.7	**Moderately positive** subjective norm
Subjective Norm (Indirect)	8	-36 to +36	-24 to +36	0	10.1±14.3	**Weak positive** indirect subjective norm
Perceived Behavioral control (Direct)	4	-12 to +12	-11 to +12	0	6.1±4.4	**Moderately positive** perceived behavioral control
Perceived Behavioral Control (Indirect)	14	-63 to +63	-33 to +63	0	10.3±16.4	**Weak positive** indirect perceived behavioral control
Prior Patient Experience	20	20 to 100	20 to 100	60	63.0±19.1	**Neutral level** of satisfaction with prior patient experience in the ED
Stigma	10	10 to 50	12 to 48	30	36.4±7.2	**Slightly greater than average** levels of perceived stigma from ED provider

Table 4: Predictive Value & Strength of TPB Constructs (Direct)

Independent Variables	B-Coefficient	Standard Error	t-statistic	p-value
Constant	-2.68	0.95	-2.81	0.0059
Direct Constructs				
Attitude	0.50	0.05	9.17	**<.0001***
Subjective Norm	0.00	0.07	0.08	0.9326
Perceived Behavioral Control	-0.02	0.08	-0.32	0.7472
Covariates				
Single[a]	0.52	0.74	0.70	0.4848
In a relationship[b]	-1.05	1.06	-0.98	0.3273
Emergency Department Use	0.57	0.16	3.59	**0.0005***
Model Statistics = F(6,107)=30.48; Model p=<.0001; R^2 =0.6309; Adjusted R^2 =0.6102				

[a]Values are for marital status; 'single' against comparator 'married'
[b]Values are for marital status; 'in a relationship' against comparator 'married'
*Denotes significance at p<0.05

Table 5: Predictive Value & Strength of TPB Constructs (Indirect)

Independent Variables	B-Coefficient	Standard Error	t-statistic	p-value
Constant	-3.36	0.98	-3.40	0.0009
Indirect Constructs				
Attitude	0.02	0.01	2.50	**0.0141***
Subjective Norm	0.15	0.02	6.22	**<.0001***
Perceived Behavioral Control	0.01	0.02	0.62	0.5376
Covariates				
Single[a]	-1.45	0.82	-1.76	0.0818
In a relationship[b]	-3.24	1.19	-2.71	**0.0078***
Emergency Department Use	1.02	0.17	6.01	**<.0001***
Model Statistics = F(6,107)=19.52; Model p=<.0001; R^2 =0.5225; Adjusted R^2 =0.4958				

[a]Values are for marital status; 'single' against comparator 'married'
[b]Values are for marital status; 'in a relationship' against comparator 'married'
*Denotes significance at p<0.05

Discussion

- Participants had a **weak positive intention** to use the ED indicating that even ***when in severe pain***, they are **reluctant to go to the ED.**
- The **TPB was useful** as the **overall models were significant** and explained a large proportion of variance: **Direct 61%; Indirect 50%**.
- **Attitude was a strong driver of participants' willingness to use the ED, controlling for covariates (marital status and frequency of ED use).**
  - ***Direct attitude*** indicated that participants had **low perceptions regarding** how ***necessary, good, useful, comfortable,*** and ***valuable*** it would be to use the ED while in SCD-related pain.
  - ***Indirect attitude*** showed that **participants believed that they were likely to *experience mostly negative outcomes*** (e.g., being mistreated by ED providers, being categorized as drug seekers, ED provider having limited knowledge about SCD, having to be strategic to get care, and needing to advocate for pain relief) when using the ED while in SCD-related pain.
- **Indirect subjective norm** showed that hematologists had the strongest influence on participants' decisions to use the ED, and participants were more likely to be motivated to comply with their hematologist compared to other normative referent individuals (spouse/partner, family and friends).
- **Prior patient experience** and **stigma** were not significant predictors, which was likely due to strong correlations with the TPB constructs.
  - **Prior patient experience** was **neutral** and **perceived provider stigma** was **greater than average**.

Limitations

- Selection bias due to convenience sampling
- Recall bias on survey items
- Over-representation of females (81%) may not be generalizable to the SCD population, which is ~50% male/female

Conclusion

Study findings support the utility of the TPB in understanding factors that influence willingness to use the ED among individuals with SCD.

Since **attitudes were a strong influence and primarily driven by provider actions**, interventions that focus on **improving providers' perceptions and knowledge of SCD**, **reducing provider implicit bias**, as well as strategies to help **patients and caregivers advocate** for better care may be beneficial in increasing willingness to use the ED when patients experience SCD-related pain.

References

1. Data & Statistics on Sickle Cell Disease | CDC. https://www.cdc.gov/ncbddd/sicklecell/data.html. Accessed April 19, 2024.
2. Abdallah K, Buscetta A, Cooper K, et al. Emergency department utilization for patients living with sickle cell disease: Psychosocial predictors of health care behaviors. Ann Emerg Med. 2020;76(3):S56. doi:10.1016/J.ANNEMERGMED.2020.08.018
3. Ajzen I. The theory of planned behavior. Organ Behav Hum Decis Process. 1991;50(2):179-211. doi:10.1016/0749-5978(91)90020-T
4. Elander J, Bij D, Kapadi R, et al. Development and validation of the Satisfaction with treatment for pain questionnaire (STPQ) among patients with sickle cell disease. Br J Haematol. 2019;187(1):105-116. doi:10.1111/BJH.16015
5. Jenerette C, Brewer CA, Crandell J, Ataga KI. Preliminary validity and reliability of the sickle cell disease health-related stigma scale. Issues Ment Health Nurs. 2012;33(6):363-369. doi:10.3109/01612840.2012.656823