Beliefs Regarding Patient Experience in the Emergency Department Among Individuals Living with Sickle Cell Disease

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PCR130

Background

Background

- Sickle cell disease (SCD) is the most common inherited genetic disorder worldwide, and it affects approximately 100,000 Americans.
- SCD is associated with severe episodic pain crises and life-threatening complications that lead to increased emergency department (ED) utilization and hospitalizations.
- Patients with SCD have reported negative experiences and inadequate pain relief when they present to the ED in pain. However, there is limited evidence regarding these experiences.

Objective

- The purpose of this study was to elicit the salient beliefs regarding patients' experiences among individuals with SCD when seeking care for pain in the ED, using the Theory of Planned Behavior (TPB).

Theoretical Model

The TPB posits that an individual's intention to perform a behavior is influenced by three factors: their attitude toward the behavior (**behavioral beliefs**), subjective norms regarding the behavior (**normative beliefs**) and perceived behavioral control over the behavior (**control beliefs**).

Methods

Study Design: Prospective qualitative study

Study Participants: Adults over 18 years with SCD were recruited through the Sickle Cell Association of Texas Marc Thomas Foundation and Rare Patient Voice.

Setting: Three virtual focus groups were conducted via Zoom

Measures: Focus group questions were based on the indirect TPB constructs including behavioral, normative and control beliefs

Behavioral Beliefs:

- *What do you believe are the **advantages** of going to the ED while in pain?*
- *What do you believe are the **disadvantages** of going to the ED while in pain?*

Normative Beliefs:

- *Are there any individuals or groups who would **approve** of you going to the ED while in pain?*
- *Are there any individuals or groups who would **NOT approve** of you going to the ED while in pain?*

Control Beliefs:

- *What circumstances would make it **easy** for you to go to the ED while in pain?*
- *What circumstances would make it **difficult** for you to go to the ED while in pain?*

Data Analysis: Focus group data was transcribed using otter.ai. Two investigators independently conducted thematic inductive analysis to identify relevant salient themes. Consensus was reached through discussion and expert opinion.

Results

Table 1: Demographic and Personal Characteristics of Participants (N=21)

Characteristics	N	%
Age (Mean ± SD)	35.3	7.2
Gender ***(Female)***	18	85.7
Race ***(Black)***	20	95.2
Residence ***(Outside of Texas)***	12	61.9
Marital Status ***(Single)***	14	66.7
Education ***(≥ Associate degree)***	12	57.1
Annual Income ***(≥$25,000)***	13	62.0
Some level of private health insurance	14	66.6
Genotype ***(HbSS)***	12	57.1
≥ 1 visit within the last 12 months		
• Emergency Department	15	71.4
• Hematologist	20	95.2
• Primary Care Provider	13	61.9

Table 2: Salient Behavioral Beliefs (N=11)

No	Item	Frequency
1	Experiencing bias and negative stereotyping by ED provider	14
2	Long wait times to get admitted	11
3	Being strategic to get needed care (e.g., how you dress, how you act, how you compose yourself)	10
4	Adequate pain control/relief	10
5	Being categorized as a drug seeker	9
6	Lack of ED provider knowledge on SCD	8
7	Quicker pain relief once admitted	7
8	Not having your voice being heard regarding treatment needs	6
9	Having provider doubt or question that you are in pain	6
10	All treatment resources (e.g., access to fluids, blood transfusion) in one location	6
11	Needing to fight/speak up/advocate to get adequate pain control	5

Table 3: Salient Normative Beliefs (N=4)

No	Item	Frequency
1	Family	8
2	Hematologist	5
3	Friends	3
4	Spouse/Partner	2

Table 4: Salient Control Beliefs (N=7)

No	Item	Frequency
1	Having other support system (e.g., childcare, transportation, help with responsibilities at home)	11
2	Having support system/advocate in the ED with you	8
3	ED following established SCD treatment protocols	6
4	Concerns around the risk of getting easily infected by other people due to immunocompromised status	3
5	Inability to manage escalating SCD symptoms at home	3
6	Previous negative experiences	3
7	ED available 24 hours without needing an appointment	3

Table 5: Example Themes and Representative Quotes of the TPB Constructs

TPB Construct and Theme	Representative Quote
Attitudes (Behavioral beliefs) – Experiencing bias and negative stereotyping by ED provider	*"One of my biggest disadvantages is the doctors like to stereotype where I'm from. So, they don't really believe me when I say I'm hurting. I've had a doctor tell me to my face that I was just going through withdrawals and the thought of the withdrawals make me think I was in pain, and I didn't need the pain medicine."*
Subjective Norms (Normative beliefs) – Family	*"My family, they don't want to see me sitting around and waiting in pain and letting the pain worsen. So, they want me to go immediately when I'm having pain, if they know I've tried everything I can, they want me to go straight to the hospital."*
Perceived Behavioral Control (Control beliefs) – Having support system/ advocate in the ED with you	*"I feel like when you have somebody there with you, the doctors are more prone to listen, as opposed to if you're there by yourself…"*

Summary

- **A total of 59 beliefs** were obtained from focus group sessions
- *22 beliefs* (11 behavioral beliefs, 4 normative beliefs and 7 control beliefs) were *deemed salient*

Discussion

- **Attitudes (Behavioral beliefs)** were comprised of *negative* (e.g., being categorized as a drug seeker) and *positive* (e.g., quicker pain relief once admitted) beliefs about patient experiences in the ED.
- **Subjective norms (Normative beliefs)** were comprised of beliefs regarding *internal* (family, friends and spouse/partner) and *external* (hematologist) individuals.
- **Perceived behavioral control (Control beliefs)** were comprised of beliefs regarding *support-related* (e.g., having support system/advocate in the ED), *ED-related* (e.g., ED following established SCD treatment protocols), and *disease-related* (e.g., inability to manage escalating SCD symptoms at home) factors.
- Overall, participants believed that going to the ED would *lead to quicker pain relief* once admitted to the ED
- However, they expressed *concerns about the negative impact of ED providers' bias and stereotyping* on adequate and timely pain management.
- They also believed that their *family and hematologists would approve* of them going to the ED while in pain.
- They believed that *having a support system* to help with transportation, childcare or an advocate in the ED would be beneficial.

Limitations

- Participants were recruited using a convenience sampling method, making it prone to selection bias. It is possible that participants who showed interest in participating may have had particularly negative experiences in the ED.
- Over-representation of females (86%) may not be representative across different genders.

Conclusion

This study provided insight into the salient beliefs regarding patient experiences in the ED among individuals living with SCD. **Findings from this study can aid in designing interventions to enhance the patient experience in the ED and promote appropriate patient-centered ED care for patients with SCD.**

References

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