

Background

- 100,000 Americans suffer from sickle cell anemia (SCA).
- A severe hereditary form of anemia in which red blood cells can mutate into a sickle shape causing severe pain crises.
- Persistent pain leads to the use of such drugs as duloxetine, gabapentin, amitriptyline, and opiates.
- Negatively impacts quality of life.
- Research does suggest that cannabis could have a beneficial effect on the management of both chronic pain and acute pain.
- **Primary aim:**
 - To collect a cohort and perform an initial survey on participants that will be used in a larger study.
 - The larger study will assess the impact of medicinal cannabis available through Pennsylvania's Department of Health-approved dispensaries in Philadelphia on the quality of life for individuals with sickle cell anemia.

Methods

- Working with the Lambert Center for the Study of Medicinal Cannabis and Hemp.
- Data using surveys will be collected at baseline regarding the participants health-related quality of life, emergency department visits, and use of the dispensaries.

Participant Characteristics

- Participants were recruited from Jefferson's Comprehensive Sickle Cell Program that provide services for both men and women.
 - Patients return on a monthly basis to get refills for their opioid prescriptions .

Survey

- 20 question survey
- Likert Scale (1 being not sure at all/ less than once a year and 6 being very sure/ almost every day).
- 3 parts to the survey

Demographics

Pain related to sickle cell disease

Quality of life

Results

Demographics	
Number of Participants Surveyed	35
Number of Participants	12
Gender	8 Females
Mean Age (years)	35.7 (26-58)
Race	10 African American/ Black 1 Mixed Race 1 Other

- Older participants reported:
 - Painful episodes occur more often and pain impacts daily life more.
 - Less likely to use marijuana to manage their pain.
 - Less likely to feel that they can manage their pain day to day.
- Males are less likely to visit the emergency room for sickle cell pain.
- Participants with higher education levels report lower levels of marijuana use and less severe pain.

Survey Questions	Average Likert Scale Results
How often do episodes of severe pain occur?	4.5
How often does pain impact your daily life?	4.75
How often have you visited the ER in the last year because of your pain?	3
Have you used marijuana for sickle cell disease pain?	2.3
How sure are you that you can reduce your sickle cell disease pain by using methods other than taking extra medication?	2.75
As compared with other people with sickle cell disease, how sure are you that you can manage your life from day-to-day?	3.67
How sure are you that you can keep sickle cell disease pain from interfering with your sleep?	2.5
How sure are you that you can do something to cut down on most of the pain you have when having a painful episode?	3.25

Discussion and Limitations

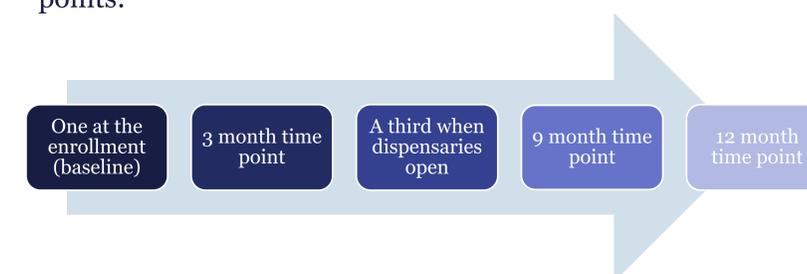
The results of this pilot study help to establish the demographic characteristics of the cohort that will be used in the larger study and ensures that the methods used in this pilot will be effective as the study progresses.

Limitations:

- No way to ensure the participants do not use any marijuana that is not provided by the dispensaries.
- No demographic information collected from participants who do not plan to use the dispensaries.

Next Steps

- Dispensaries open in late 2018.
- Once dispensaries open an additional survey will be administered to gather any changes in participant responses regarding quality of life.
- Aiming to gather 120 participants.
- SCA-specific health-related quality of life survey at 5 time points:



Future Goals

1. To assess changes in Emergency Department (ED) utilization before and after the opening of medical marijuana dispensaries in Philadelphia County, PA
2. To assess changes in the use of prescription opioids by selected individuals with SCA before and after the opening of medical marijuana dispensaries.
3. To learn whether selected individuals with SCA will obtain medicinal cannabis from PA dispensaries; and if they do, but then discontinue medicinal cannabis, the reasons why.

Core Competencies

- Describe factors affecting the health of a community.
- Research Methodology & Information Literacy Determines limitations of the findings.
- Describes implications of policies, programs and services.
- Describes needs for future development.

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