Sickle Cell Data Collection Program

July 28, 2021

TRACKING CALIFORNIA
INFORMING ACTION FOR HEALTHIER COMMUNITIES

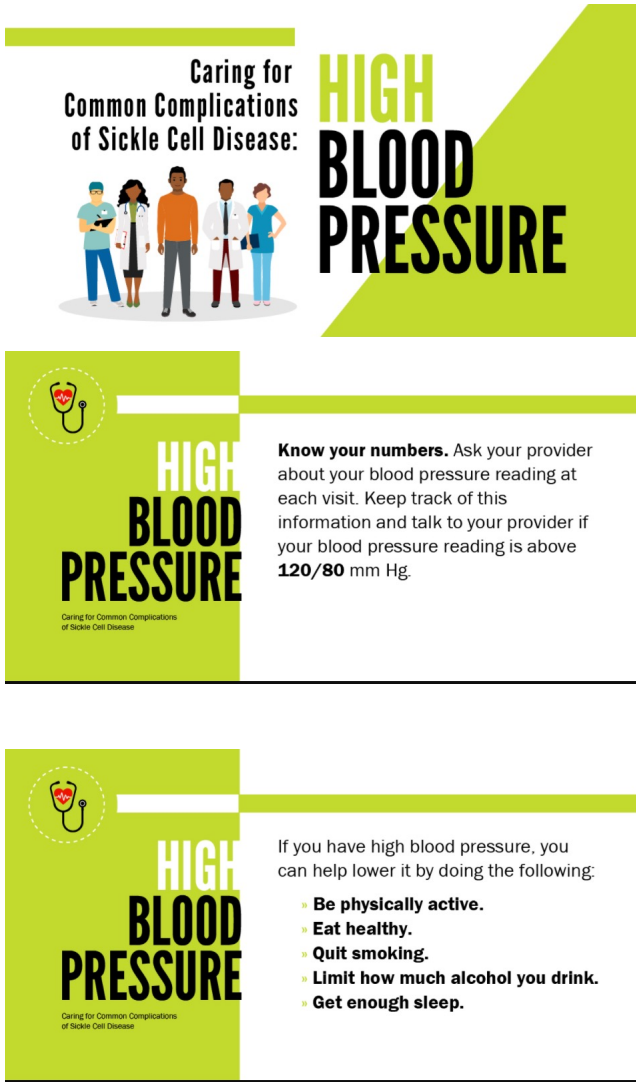
Centers for Disease Control and Prevention (CDC): Sickle Cell Disease (SCD) Activities

CA SCDC Webinar Series July 28, 2021

Guideline #2 Coming Soon!

Steps to Better Health for People with SCD Toolkit

- Caring for Common Complications of SCD
- Steps to Better Heart Health
- What to Know about Blood Clots
- Steps to Better Lung Health
- Steps to Better Kidney Health
- 3 Tips for Safe Use of Medicines



https://www.cdc.gov/ncbddd/sicklecell/betterhealthtoolkit/index.html

World Sickle Cell Day 2021: Camp Counselors

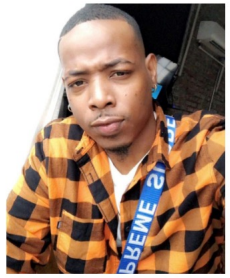
Alissia Cofer's Story

Alissia Cofer is a former camp director at Camp Cell-A-Bration, a free, week-long camp in Burton, TX, for children aged 6–14 with sickle cell disease (SCD). Alissia is no stranger to camp; she was a camper herself as a young girl with SCD. Her participation at Hole in the Wall Gang Camp in Ashford, CT, as a child is primarily what inspired her to work at camp herself. Becoming a camp director enabled her to connect with kids with SCD more and to give back to the sickle cell community. "Becoming a camp director allowed me to give them (the campers) what I had growing up. They were all my babies, and I was responsible for them. I knew them all by name, and I knew their parents. When I saw their faces lighting up, I knew that I was doing what I was supposed to do." said Alissia.

Camp Activities and Benefits of Attending Camp

According to Alissia, camp offers kids a variety of indoor and outdoor activities, including horseback riding, ropes courses, ziplining, bike riding, archery, paint ball, basketball, yoga, canoeing, fishing, escape rooms, swimming, rock wall climbing, and singing around a campfire. It also includes time for just hanging out in the cabins and bonding with one another. Learning more about what it means to have SCD and how to best manage the condition is also included among the many activities camp has to offer. Small group discussions are held to let the kids learn more about the different types of SCD, talk about challenges associated with having SCD, talk about the various therapies, and simply to provide a forum to answer questions campers may have about SCD. According to Alissia, one of the biggest impacts camp has on attendees is that it teaches them to become more active in their care. "They are listening and taking it all in," she said.

Blaze Eppinger & Camp New Hope



Each year, Blaze Eppinger, who works for the Sickle Cell Foundation of Georgia and is a strong supporter of those living with sickle cell disease, works as both a camp registrar and camp counselor for Camp New Hope. Camp New Hope is a 7-day, 6-night residential camp for children aged 7–17 years with sickle cell disease at Rock Eagle 4-H Center in Eatonton, Georgia. Camp takes place every July and is staffed by counselors, many of whom, like Blaze, have sickle cell disease themselves. Doctors and nurses are on hand 24 hours a day, 7 days a week to provide general care for campers and to respond to any emergency situations that might arise.

Camp Activities and Benefits of Attending Camp

Camp New Hope offers all of the things a traditional camp does such as campfires, team-building activities, rock-wall climbing, and kayaking, notes Blaze. The only difference is that activities are supervised by nurses and doctors and include sickle cell-related and transition-related educational programming activities as well. Campers learn how to move through life with sickle cell disease and how to transition, a process of becoming more independent and taking more responsibility for managing one's health and healthcare. Camp also teaches kids how to stand up for themselves and how to be leaders. "I think camp helps kids with sickle cell disease learn how to maneuver with the disease. It helps them to break out of their shell a bit and become more social," says Blaze.

Phillip Okwo Story

Phillip Okwo is a former summer camp counselor at Camp Crescent Moon, a week-long sleep away camp for children with sickle cell disease in Pacific Palisades, CA. For more than 50 years, this camp has helped kids with sickle cell learn more about their condition, coping strategies, and how to stand up for themselves when they are misunderstood because of their disease.

As a young boy growing up with sickle beta zero thalassemia (or HbS beta 0-thalassemia), Phillip was a camper himself. He started going to camp in San Juan Capistrano, CA, when he was just 6 years old. "Camp was a place I could go where I never felt alone. I was no longer the black sheep in my family. It was a way of just feeling normal. There were other people there who have sickle cell like me, some who went to the hospital more than me and some who went less often. The whole spectrum of care was represented. I learned self-efficacy skills in understanding my diagnosis and general life and survival skills as well," Phillip said. When he aged out of the program, he decided to come back as a camp counselor. "I had a cabin full of 8-year olds and they wore us (me and my co-counselor) out. We didn't get a lot of sleep, but it was a labor of love," he said.

https://www.cdc.gov/ncbddd/sicklecell/stories.html

THE BLOODLINE

Sickle Cell Data Collection (SCDC) Program Quarterly Newsletter

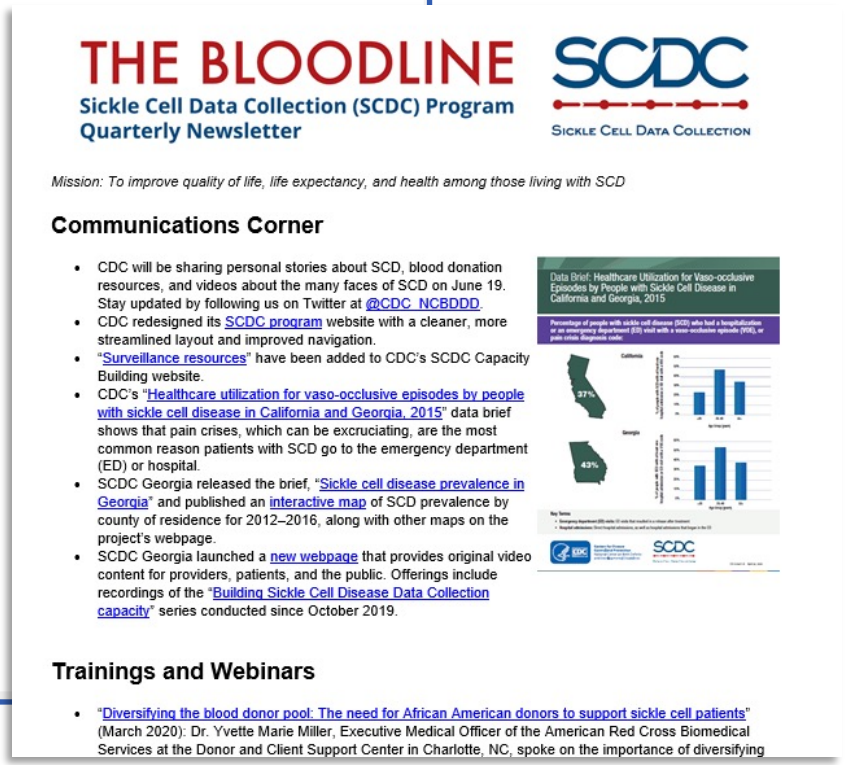
SCDC
Sickle Cell Data Collection

The Bloodline is a quarterly newsletter that provides updates about the SCDC program. Subscribe to the newsletter to stay updated on the SCDC program's health communications activities, data, presentations, and more.

Subscribe

Past Newsletters

- Spring 2020
- Winter 2020
- Fall 2019
- Summer 2019
- Spring 2019
- Winter 2019
- Fall 2018
- Summer 2018



THE BLOODLINE
Sickle Cell Data Collection (SCDC) Program Quarterly Newsletter

SCDC
Sickle Cell Data Collection

Mission: To improve quality of life, life expectancy, and health among those living with SCD

Communications Corner

- CDC will be sharing personal stories about SCD, blood donation resources, and videos about the many faces of SCD on June 19. Stay updated by following us on Twitter at @CDC_NCBDDD.
- CDC redesigned its SCDC program website with a cleaner, more streamlined layout and improved navigation.
- "Surveillance resources" have been added to CDC's SCDC Capacity Building website.
- CDC's "Healthcare utilization for vaso-occlusive episodes by people with sickle cell disease in California and Georgia, 2015" data brief shows that pain crises, which can be excruciating, are the most common reason patients with SCD go to the emergency department (ED) or hospital.
- SCDC Georgia released the brief, "Sickle cell disease prevalence in Georgia" and published an interactive map of SCD prevalence by county of residence for 2012–2016, along with other maps on the project's webpage.
- SCDC Georgia launched a new webpage that provides original video content for providers, patients, and the public. Offerings include recordings of the "Building Sickle Cell Disease Data Collection capacity" series conducted since October 2019.

Trainings and Webinars

- "Diversifying the blood donor pool: The need for African American donors to support sickle cell patients" (March 2020): Dr. Yvette Marie Miller, Executive Medical Officer of the American Red Cross Biomedical Services at the Donor and Client Support Center in Charlotte, NC, spoke on the importance of diversifying

https://www.cdc.gov/ncbddd/hemoglobinopathies/scdc-newsletter.html

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https://www.cdc.gov/ncbddd/sicklecell/index.html

For more information, contact CDC
1-800-CDC-INFO (232-4636)
TTY: 1-888-232-6348 www.cdc.gov

California SCDC Updates

- New publication on Hu and chelators use

Received: 22 December 2020 | Revised: 28 April 2021 | Accepted: 21 May 2021
DOI: 10.1002/hsr2.323

RESEARCH ARTICLE

Health Science Reports
WILEY

Concurrent use of hydroxyurea and deferasirox in Californians with sickle cell disease

Trisha E. Wong[1] | Jhaqueline Valle[2] | Susan Paulukonis[2]

- Cayenne Wellness 13th Annual Sickle Cell Disease Educational Seminar (Virtual) September 16-18th at www.cayennewellness.org

Claudine Matthews RD, MSC, PGCE, FHEA

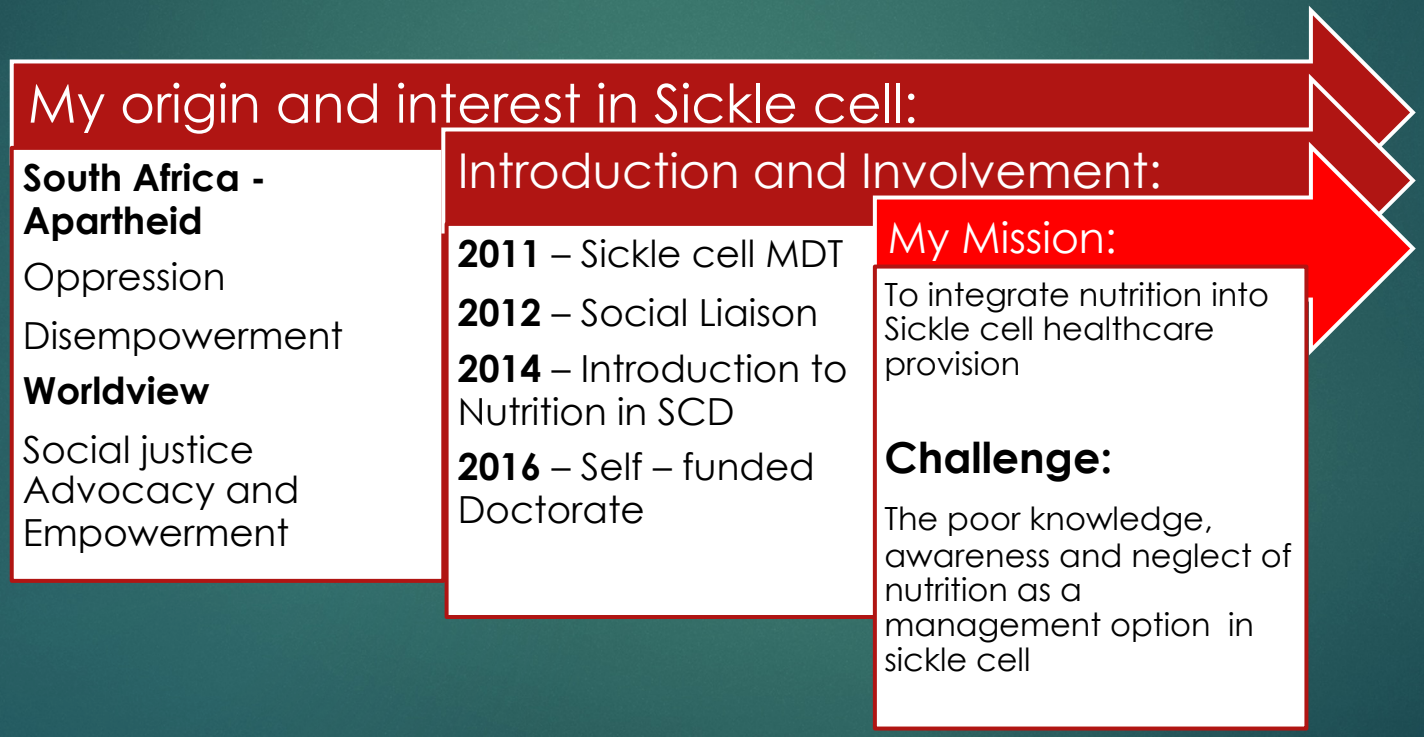
Integrating Nutrition as a management option in Sickle Cell: a Call to Action

CLAUDINE MATTHEWS RD, MSC, PGCE, FHEA

TRACKING CALIFORNIA – NUTRITION IN SICKLE CELL WEBINAR

28TH JULY 2021

My Research Interest in Sickle Cell and Nutrition:



Presentation Overview

Part:1	• Provide an overview of existing scientific literature about the role of nutrition in sickle cell.
Part: 2	• Consider new research perspectives to understand nutrition as a management option in sickle cell.
Part: 3	• Explore the nutritional implications, problems and management in sickle in sickle cell

What is Sickle Cell ?

Sickle cell in the UK

- Complex, lifelong genetic red blood cell disorder -
- Fastest growing genetic disorder in the UK
- Affects about 15 000 people in the UK; about 270 babies are born with sickle cell every year

Main clinical features

- Chronic haemolysis – oxidative stress, chronic anaemia and fatigue and chronic inflammation
- Vaso –Occlusion – tissue and organ damage
- Impaired immune function
- Associated with high levels of morbidity and mortality

Epidemiology

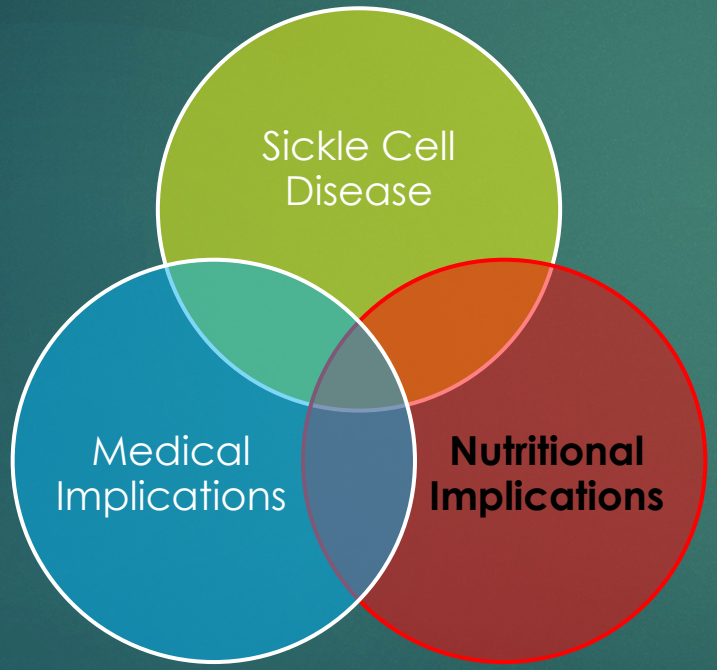
- SCD mainly affects people from African, Afro-Caribbean, Asian, Middle Eastern and Mediterranean descent.
- According to the WHO – globally an estimated 300000 babies are born with various forms of the disease

□Part 1:
Overview of existing scientific literature about the role of nutrition in sickle cell

CONTEXT, BACKGROUND, RESEARCH FOCUS

The Context

- What do we already know?



- Current management approach:
  - SCD is managed using a medical model approach
- However,
  - Nutrition is overlooked
  - Not currently integrated into sickle cell healthcare provision

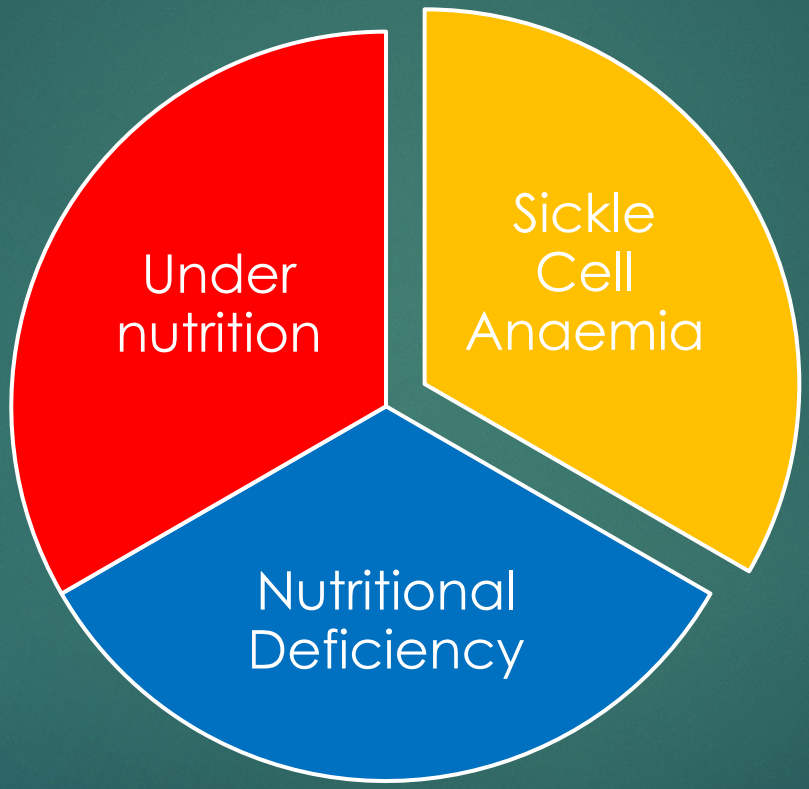
Background

- Number of nutrition problems in Sickle Cell
- Existing research highlights:
  - Under nutrition
  - Nutritional deficiencies
- Not much has changed in **Policy** and **Practice development**
- New Research Perspective
  - Sickle Cell – complex
  - Comprehensive view to understanding nutrition
  - Many influencing factors affecting nutrition in sickle cell

- Research problem
- Lack of integration of nutrition into sickle cell healthcare provision
- Prasad, 1997
- Hyacinth et al., 2010
- Khan et al., 2016
- Umeakunne and Hibbert, 2019

- **Nutrition not part of sickle cell healthcare provision**
- **Lack of translation of existing scientific evidence into meaningful evidence base**

Existing Research – Limited Perspective…



Proposed mechanisms for under-nutrition

- A number of proposed mechanisms for under-nutrition have been identified including: ***(Hyacinth et al 2010)***
  - Increased red cell turnover
  - Protein hyper metabolism
  - High cardiac demand/expenditure
  - Decrease dietary intake possibly due to inter-leuken^{6}- related appetite suppression

Deficiency of key Nutrients: Zn, Se, Vitamin A, C, E, Vitamin D, B -vitamins, Folic Acid, Omega 3, Iron

Nutrition a neglected management option in sickle cell

Current

- General approach
- Limited dietetic involvement
- Nutrition overlooked as a management option
- Nutrition not part of the standard clinical management
- Poor referral rates of sickle cell patients
- Lack of Nutritional assessment - supplements
- Healthy eating advice

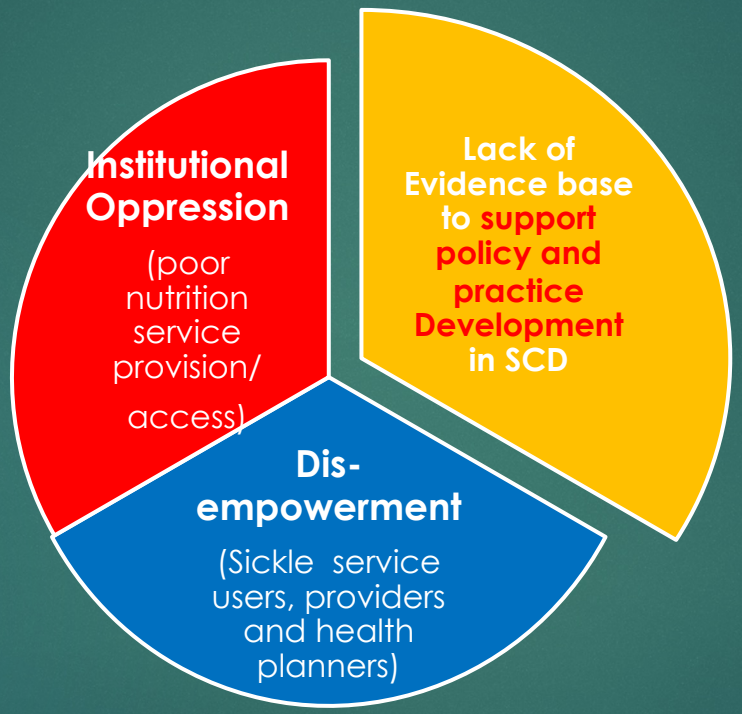
Future???

- Development of sickle cell specific:
- **Nutritional standards - SCS**
  - **Nutrition management Framework for policy and practice** development
  - Nutrition management toolkit
  - Nutritional resources
- Support the integration of Nutrition into sickle cell healthcare provision

□Part 2: Considering New Research Perspectives

CONSIDERING NUTRITION AS A MANAGEMENT OPTION IN SICKLE CELL

Nutrition in sickle cell - a Health Inequality…



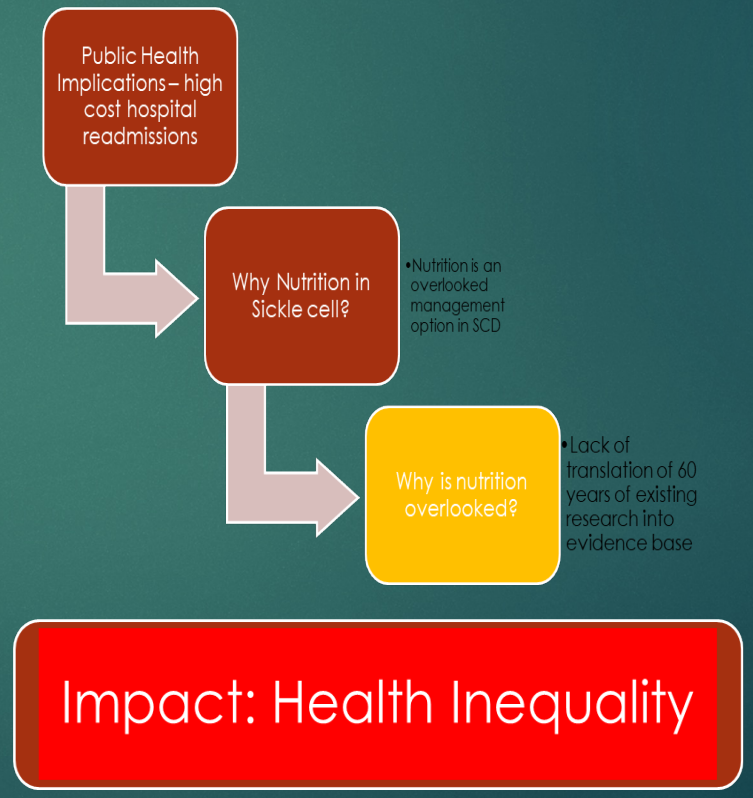
Impact: poor nutrition knowledge and awareness, poor nutritional resources and poor nutrition service provision

Nutrition not part of sickle cell management

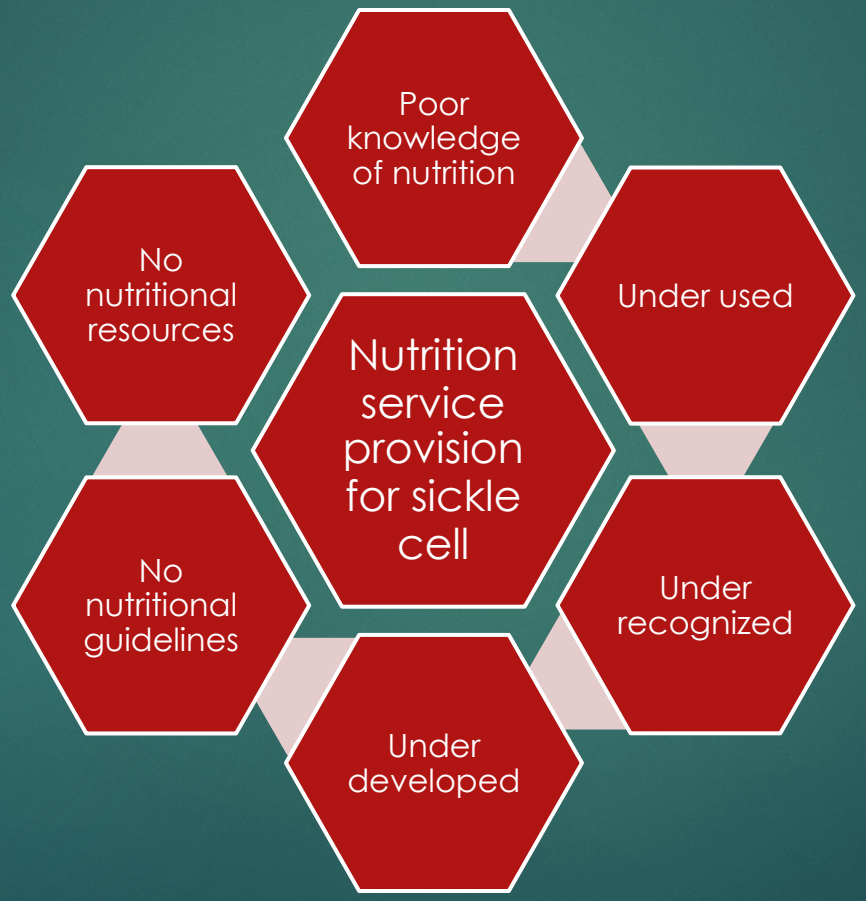
Claudine Matthews – 28 7 21

Power Imbalance

Rationale For Nutrition



Current nutrition service provision in sickle cell disease



Utilising the power of the sickle cell patient voice to influence change

The Need for a new Perspective in understanding nutrition in sickle cell

Overarching problem – lack of integration of nutrition into sickle cell care provision

Impact: Poor Health and Well-being Outcomes

Research Knowledge Gap:
Currently no framework available to support the integration of nutrition into sickle cell healthcare management

Sickle Cell – Nutrition Health Education Framework

Key Finding: Abstract 1

- https://onlinelibrary.wiley.com/doi/full/10.1111/jhn.12889

A qualitative study to understand the optimum nutrition needs of sickle cell patients and the influencing socio-ecological factors

C Matthews[1]; D Smith[2]; M Hawkins[2]; K Ghebremeskel[3]

[1]*Anglia Ruskin University (ARU), Faculty Health, Education, Medicine and Social Care, Bishop Hall Lane, Chelmsford CM1 1SQ*

[2]*ARU, Faculty Health, Education, Medicine and Social Care, Bishop Hall Lane, Chelmsford CM1 1SQ*

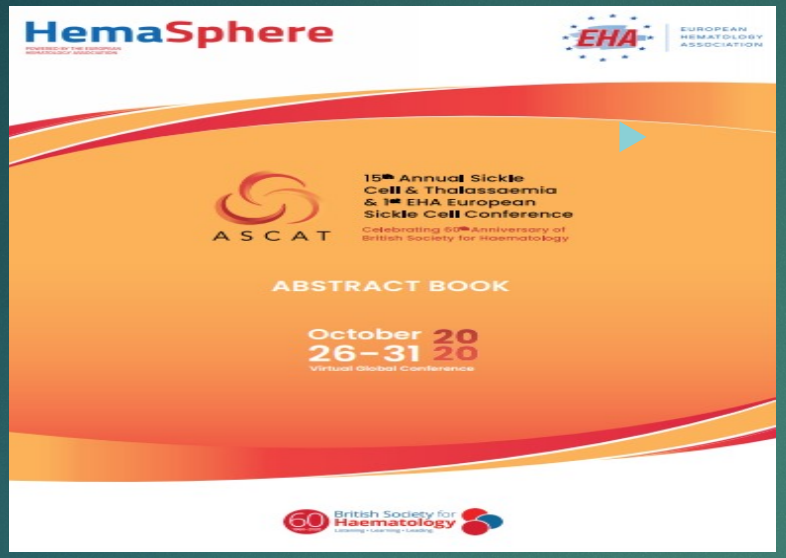
[3]*Lipidomics and Nutrition Research Centre, London Metropolitan University, 166-220 Holloway Road, N7 8DB*

Background: Sickle Cell Disease (SCD) is the fastest-growing genetically inherited red blood cell disorder in the UK(1). Nutritional deficiency, which is thought to be the natural consequences of the pathophysiology of the condition(2), is prevalent in sickle cell patients. The deficiency is associated with impaired growth and development and increased morbidity and mortality. Currently, nutrition is not integrated into sickle cell healthcare provision in the UK and other countries. Indeed, the optimal nutrition needs of patients with the disease remain to be fully explored. The study aims to ascertain the knowledge of the optimum nutrition needs of sickle cell patients and the influencing socio-ecological factors.

Results:

Participant Group/Topics	Participant Quotes	Interpretation
1. Sickle Cell Service users: Knowledge of nutrition	"All I know about nutrition I've had to self-research"; "I've recently been diagnosed with osteoporosis; why hasn't anyone told me about this risk before?"	Poor access of sickle cell patients to nutrition services may have a negative impact on their knowledge of nutrition and their risk for poor health and wellbeing outcomes
2. Sickle Cell Service providers: Personal factors influencing	"We get a lot of depression in the kids"; "children want to fit in with their friends"	Depression, in any age group but particularly in children, is a serious personal psychological factor that may impact on the

Key Finding: Abstract 2



Theme	Theme description	Participant comments
Theme 1	Knowledge of nutrition	"Everything I know about nutrition I had to self-research" – SU; "Nobody knows about sickle cell" - SP
Theme 2	Nutrition is overlooked	"I have recently been diagnosed with osteoporosis why hasn't anyone told me about this risk before?" – SU; "I've never been asked about my nutrition"- SU
Theme 3	Need for nutrition management	"Nutrition is fundamental in sickle cell"-SU; "we have more referrals because our sickle cell consultant is pro-nutrition" - SP


PUBLIC HEALTH AND HEALTH EDUCATION ABSTRACTS

A QUALITATIVE STUDY TO UNDERSTAND THE BARRIERS TO INTEGRATING NUTRITION INTO SICKLE CELL HEALTHCARE PROVISION


Abstract Book for the 15th Annual Sickle Cell & Thalassaemia & 1st EHA European Sickle Cell Conference

RELATION OF THE SINGLE NUCLEOTIDE POLYMORPHISM TGFBR3rs284875 TO SILENT STROKE IN PATIENTS WITH SICKLE CELL DISEASE

PUBLIC HEALTH AND HEALTH EDUCATION ABSTRACTS

A QUALITATIVE STUDY TO UNDERSTAND THE BARRIERS TO INTEGRATING NUTRITION INTO SICKLE CELL HEALTHCARE PROVISION

ARISE COVID-19 RESPONSE – A VIRTUAL PROGRAMME REVIEW

HemaSphere

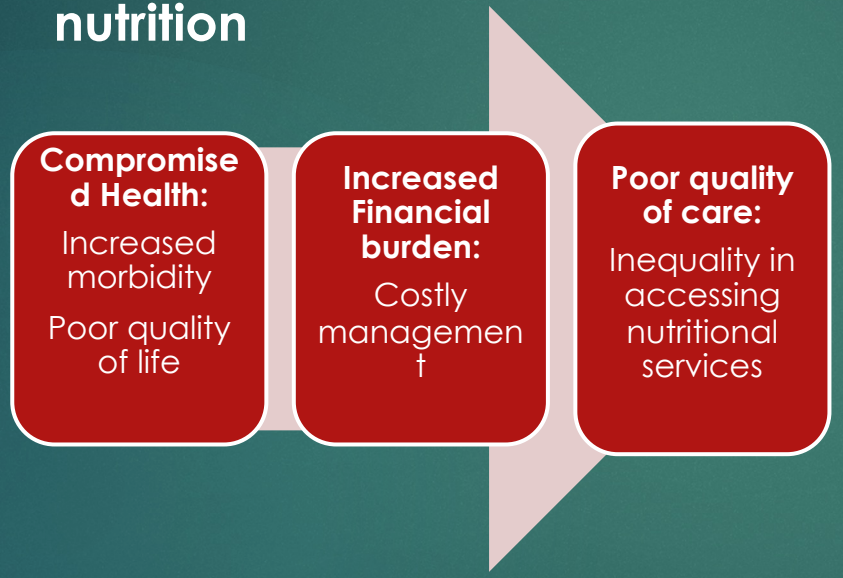
□Part 3:

Exploring the nutritional implications, problems and management in sickle cell

A NEW PERSPECTIVE

The complexity of nutrition in sickle cell disease

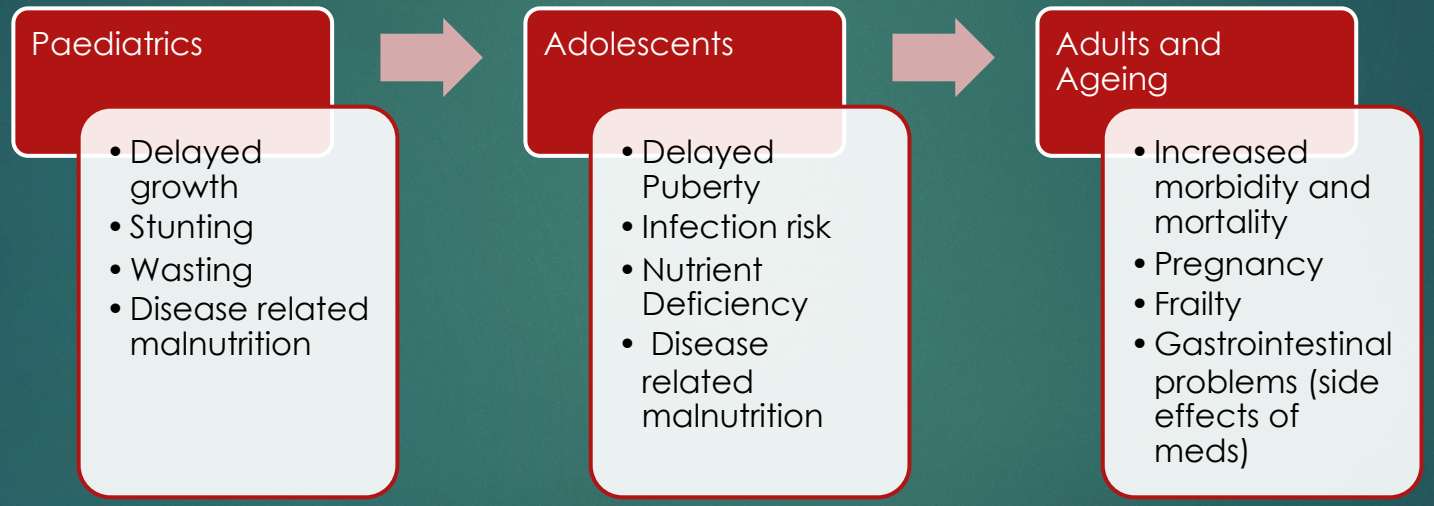
- **Implications of neglecting nutrition**



- **Nutrition in sickle cell: a multifactorial phenomenon:**
- Nutritional Assessment
  - Nutritional considerations
  - Medical considerations
  - Psychosocial factors
  - Wider determinants of health
- ***Matthews C, CN July/Aug 2015***

Nutritional considerations

Nutrition Problems over the life course



Factors increasing the nutritional requirements in sickle cell patients

- SCD presents a host of **complex nutritional problems** and **complications**
  - **Can waste nutritional resources due to ineffective red cell production impacting growth**
- Its pathophysiology has **multi organ** and **multi - system involvement**
- **Inflammation:**
  - Production of free radicals
  - Caused by iron overload, infections, tissue damage

- **Wide ranging clinical manifestations** in SCD:
  - **Increased risk of infection (particularly streptococcal infection),**
  - **Neutropenia (resulting from Hydroxyurea treatment),**
  - **Chronic Inflammation,**
  - **Risk of Stroke,**
  - **To longer term problems :**
  - **Including renal failure, liver failure requiring liver transplantation, cardiac failure due to cardiac iron overload and chronic lung disease.**

Indications and management of nutrition in sickle cell

- **Indications:**
  - Malnutrition
  - Poor appetite and weight loss
  - Oral, enteral or parenteral nutrition support:
  - Poor wound healing
  - Stroke
  - Liver transplant
  - Renal failure
  - Cholecystectomies
  - Infection risk
- Other:
  - Gastrointestinal side effects
- **Management:**
- **Macro nutrients:**
  - Energy
  - Stress factors (disease related)
  - Protein
  - Fluid
  - Fibre
- **Micronutrients:**
  - Zn, Folic acid, Omega 3, Selenium, Vitamin A, C, E, Vit D and Calcium, B Vitamins,

Main Disease-related factors underpinning nutritional problems in sickle cell

- **Main Disease - Related Underpinning Factors**
  - High (Resting Energy Expenditure) REE
  - poor immunity
  - high protein turnover
  - low BMI
  - poor exercise tolerance
  - Appetite suppression:
  - Pain
  - Effects of Inter-leuken6
- **Gap:**
- **Socio-Ecological factors influencing nutrition**

Disease-related and socio-ecological factors affecting nutrition in sickle cell

Disease –related Factors

- **Known Problems**
- **Dehydration** (increase fluid intake)
- **Impaired immune functioning** (Anti-oxidants + 5 a Day)
- **Inflammation** (Omega 3 intake)
- **Chronic anaemia and fatigue** (Balanced diet, Energy and protein intake, stress factors)
- **Constipation** (wholegrains, fluid and activity)
- **Low BMI** (Regular meals and energy dense snacks, food fortification, oral nutritional supplement and regular nutritional monitoring)

Socio-ecological Factors

- **Unknown problems – Knowledge Gap:**
- Personal factors
- Interpersonal factors
- Institutional factors
- Community factors
- Policy factors

Nutritional monitoring and raising Awareness

Red flags

Regular monitoring

Every Opportunity

↓

Every Appointment

↓

Every Annual Review

Taking a Holistic Approach

Claudine Matthews – 28 7 21

The EAT WELL GUIDE

A Balanced Approach

- **Reframing Nutrition – Optimum nutrition**
  - Nutrition
  - Medical
  - Socio –ecological
  - Psychosocial – socio-economic
- **Diet and lifestyle preferences**
  - Vegetarian
  - Vegan
- **Alternative Approaches**
  - Plant based supplements
  - Herbs and homeopathics

Take responsibility

Patient Responsibility

- Patients need to **understand their condition**
- They need to **recognise/know** the nutritional consequences of their condition
- They need to **understand the importance of early recognition** of nutritional symptoms/consequences
- They need to **understand their nutritional risk factors**
- They need to **know the main nutritional triggers** for a sickle cell crisis

Provider responsibility

- **Know** the condition
- **Recognise** the nutritional risk of sickle cell patients
  - Screen patients using MUST Tool
- **Assess** the nutritional risk (weight loss, poor appetite, infection etc)
- **Refer** for nutritional risk management (Dietitian and GP)
- **Raise Awareness** amongst colleagues
- Every case is **individual**

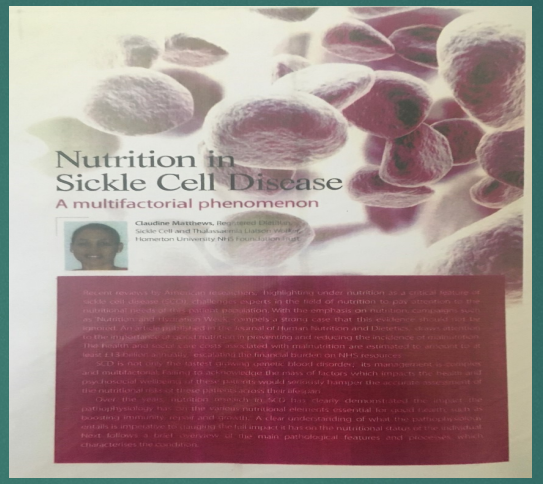
A Call to Action

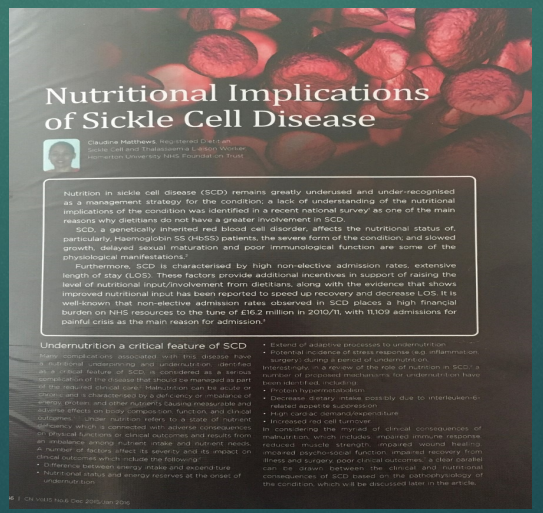
Empowerment to improve Health and Wellbeing

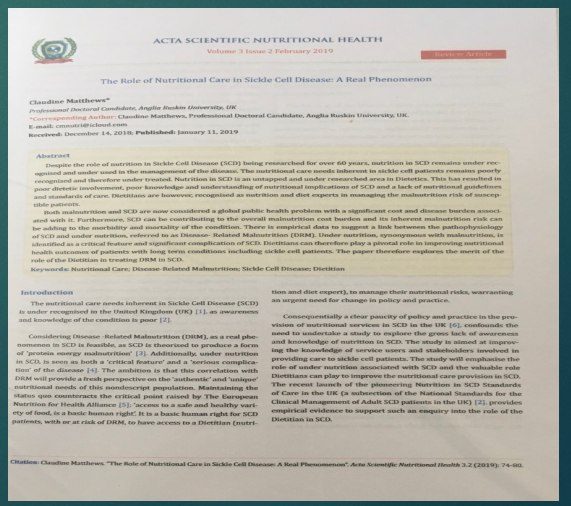
- **Empowering and activating the patients:**
- Awareness
- Knowledge
- Understanding
- **ASSESS health questionnaire :**
- Importance of health
- Motivation
- Self -belief
- Confidence
- Self-awareness
- Taking self –responsibility

My call to action: Articles, Publications, Nutrition Standards, Doctorate, Policy and Practice, Conference

https://nutrition2me.com/wp-content/uploads/2021/03/Sickle-Cell-Disease.pdf







Our Call to Action…

Next Steps

- Need A **New Perspective**
- **Mandate nutrition** as a priority
- Adopt nutrition as a **management option** in sickle cell
- **Listen to and engage** the sickle cell patient voice to influence change
- Apply the **National Nutrition Standards** to policy and practice

Policy and practice

- Involvement of **key strategic stakeholders**
- Sickle Cell Associations
- **ASH**
- **ADA**
- **CDC**
- 3rd Sector organisations
- Both health and social care

Thank You!

"Every closed door brings you closer to your Destiny"

Claudine Matthews

Acknowledgements:
Tracking California - CDC

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Webinar Q&A

How to Find CA SCDC

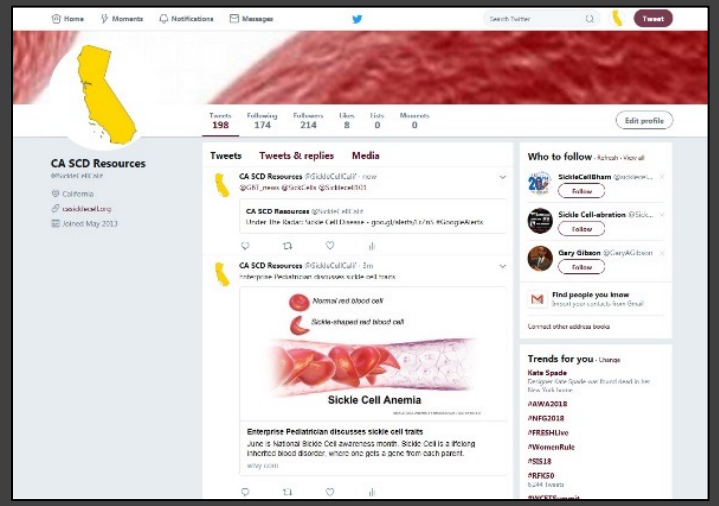
TRACKING CALIFORNIA
INFORMING ACTION FOR HEALTHIER COMMUNITIES

TrackingCalifornia.org

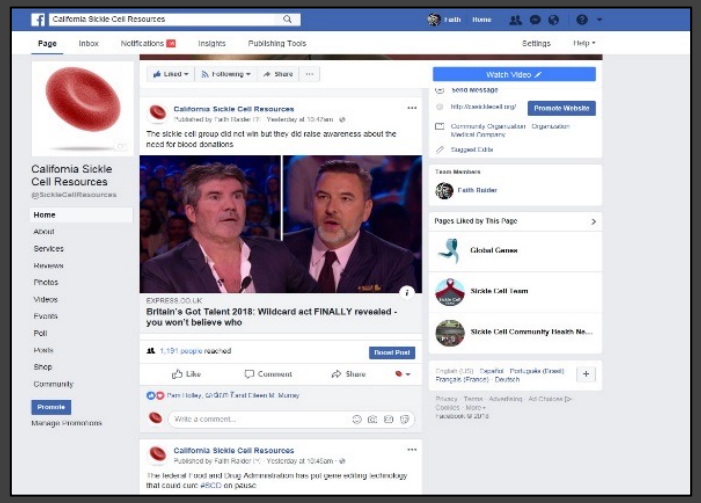
California SickleCell Resources

CASickleCell.org

@SickleCellCalif



@SickleCellResources



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Wrap Up

Thank you all for your attendance& participation.