

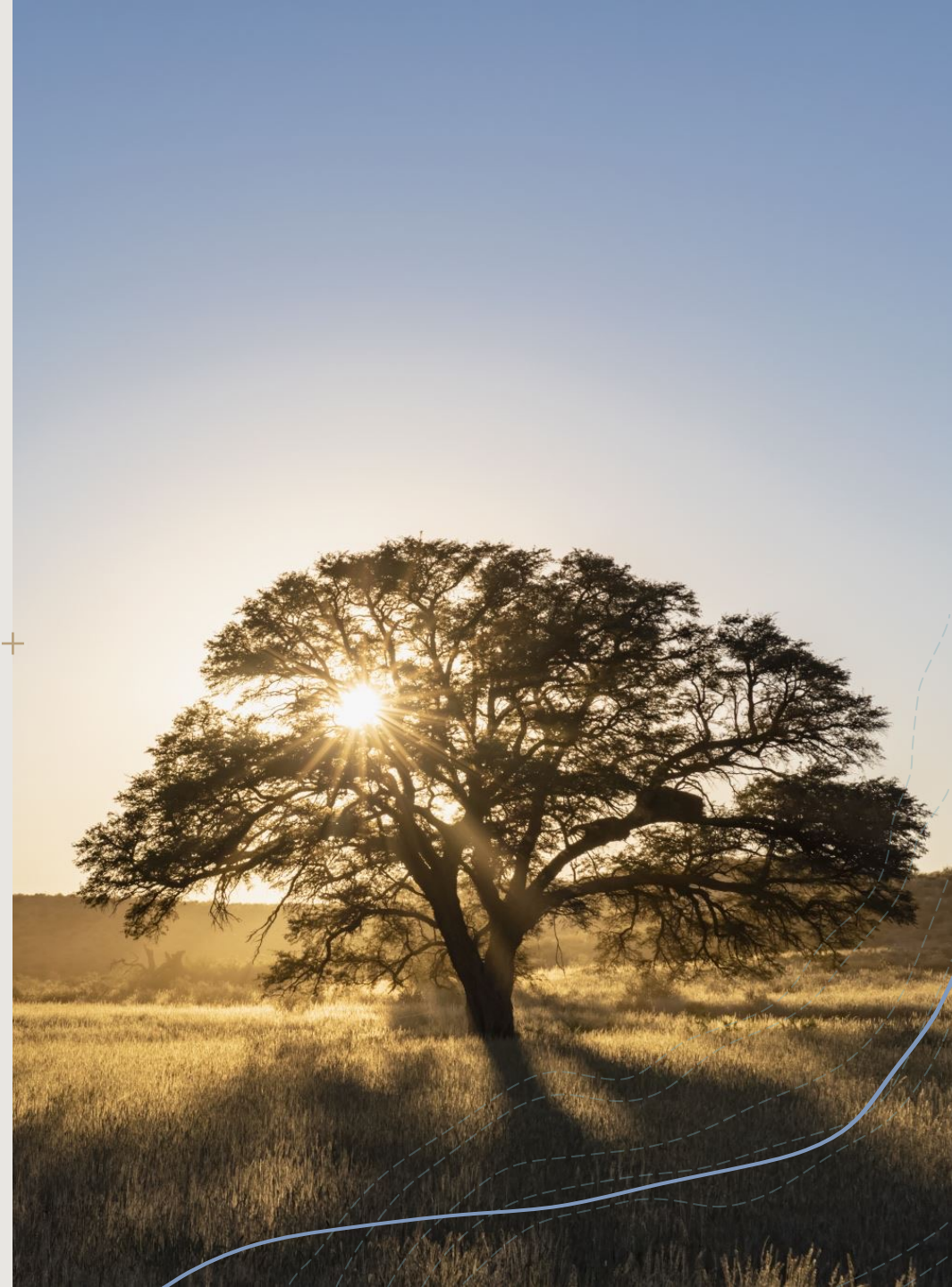


Abundant Life Under the Healing Tree

A New Model for Providing Collaborative and
Equitable Care for Patients and Families Managing
Sickle Cell Disease

Rev. Patti V. Weikart, Doctor of Ministry Candidate

March 19, 2024



A Question and a Calling

- + **“Pastor Pat, why has God cursed me?”**
- + **“Pat, will you let this stand?”**
- + **This project is my answer to both questions, which originated, I believe, in the heart of God.**
- + **I had SO much to learn!**



A brief overview of the work of co-creation

+ **Structured Conversations with Patients and Families**

- + 121 respondents: 62 patients, 59 parents and siblings
- + 90% professed a faith and a connection to a faith community strong enough to impact healthcare decisions
- + 70% mentioned at least one need that would make their SCD journey easier. We categorized these needs as tangible resources, people and safe spaces.
- + 39% made a faith community referral
- + 55% asked for immediate prayer

+ **The CHN Pilot**

- + **Would not have happened without the groundbreaking work of Gunderson, Cochrane and Cutts described in *Religion and the Health of the Public: Shifting the Paradigm*.**
- + Served 99 patients, 142 family members and involved 35 volunteers in these programs:
- + NOURISH
- + The Sunny Day Clinic Fridge
- + The SCD Family Fellowship
- + Smart/911 and Transportation Assistance
- + Free Vitamins
- + Tutoring and Life Skills Mentoring

There is a difference between Treatment and Care.

Treatment

- + Transactional, mostly billable encounters which apply a protocol, supported by data, to manage or cure a diagnosis and its symptoms.
- + Screening, prescriptions, transfusions, immunizations, hospitalization, surgery, bmt, gene editing

Care

- + Relational encounter where one is fully present, listening and responding to unmet needs that restore human dignity and meaning
- + **Instructions** for diet, supplements, hydration, homecare, transition services and transportation

What the CHN pilot taught us

- + **Faith is important to our patients in life and in making healthcare decisions.**
- + **Patients experience a difference between treatment and care. Together we can strive toward healing.**
- + **Defining healing is a work in progress. Our working definition= Healing occurs when patients and families know that they are beloved and valued, that the basic human needs they require to thrive can be met and that their individual gifts can be nurtured to their full potential. Abundant life is lived when one knows they can carry on, healed, where they manage their diagnosis, the diagnosis does not manage them.**
- + **Our patients have unmet needs that make their sickle cell journey difficult.**
- + **Patients believed that communities of faith could help address these needs. So, I believed with them.**
- + **When collaborations were established, and services offered, our patients used these services.**
- + **Laws and regulations can present significant barriers to offering services. The feared risk of violating these policies required the transition to the Healing Tree SCD.**



The Healing Tree SCD

- + A registered corporation in Delaware under the agency of the Episcopal church.
- + Staffed by a volunteer director, two paid navigators who are parents of patients managing SCD.
- + Provides the services offered by the CHN, retaining pilot partners and recruiting more.
- + Will serve more than one hospital.
- + Abundant life is our goal for the patients we serve; that they will live every day knowing they are value
- + We are looking forward to full operations beginning April 1, 2024.

THE HEALING TREE

“and they shall sit under their own vines and their own trees and no one shall make them afraid.”

Micah 4:4



My hope is that this work will contribute to the field of health equity in the following ways.

- + **Brandon's question: "Pastor Pat, why has God cursed me?" tells us that spiritual care is necessary for healing for many patients. Their faith communities often represent the primary context for the experience of equity.**
- + **No patient is cursed by God, but by our ecology of healthcare.**
- + **All providers are called to understand and engage our history, theology, the origin of roles and responsibilities in the clinic, the socio-economic drivers of health specific to our patients, our laws and how they are manifest in policy.**
- + **Religious health assets can be leveraged to place needed, healing resources in our patients' hands.**
- + **The healthcare system CANNOT become equitable on its own initiative from the inside. The dream of health equity moves closer to reality when we engage allies in the journey.**

