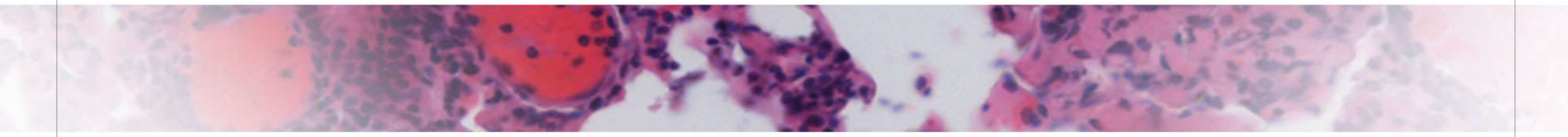
American Society *of* Hematology

Helping hematologists conquer blood diseases worldwide



Comprehensive Care Coordination:

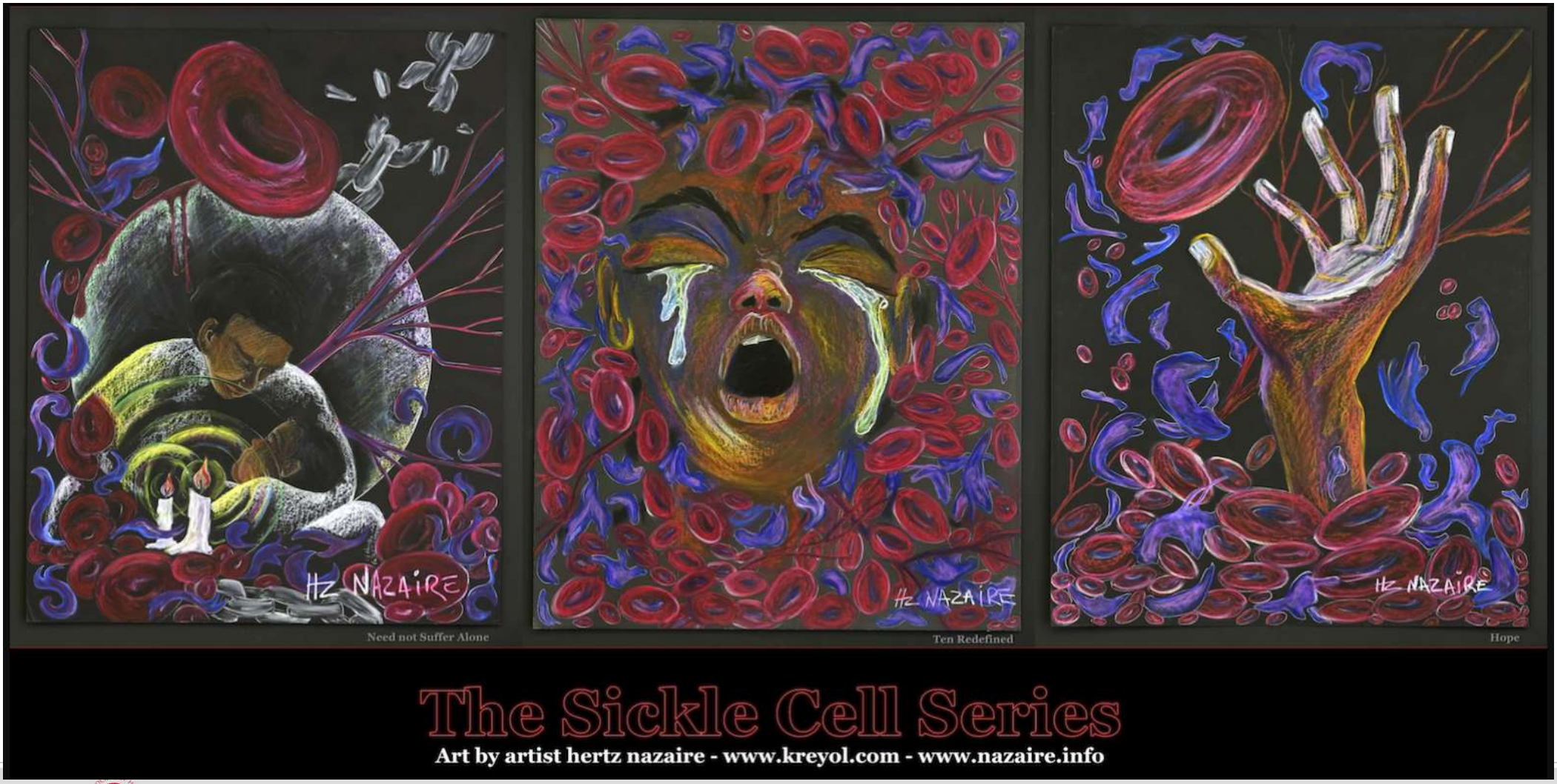
Environmental, Medical, Behavioral

Shirley Johnson, LSW

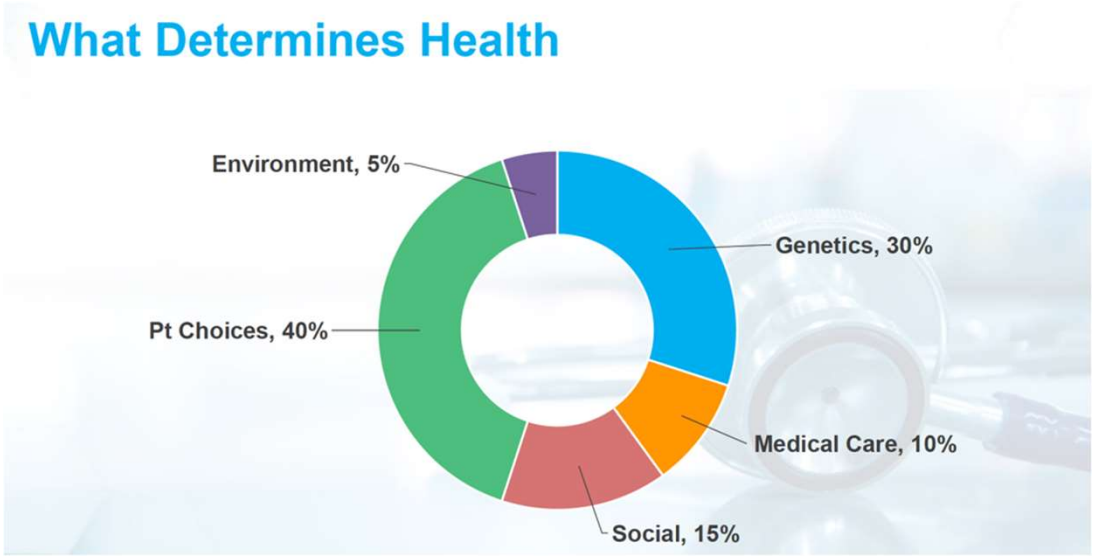
Nicklaine Paul, RN, BSN, CCM

Objectives

- Provide insight into the challenges facing patients with sickle cell disease related to social determinates of health (SDoH)
  - — Review the need for a care coordination team to help overcome SDoH
- Discuss comprehensive team building including tools to educate and train personnel for care coordination
- Review the impact of personnel providing care coordination in a sickle cell disease center along with roles and responsibilities that each employee provides to the team
  - — Focus will include the critical role of the nurse within the comprehensive care team


Hz NAZAIRE
Need not Suffer Alone
Hz NAZAIRE
Ten Redefined
Hz NAZAIRE
Hope
The Sickle Cell Series
Art by artist hertz nazaire - www.kreyol.com - www.nazaire.info

Social Determinants of Health (SDoH)

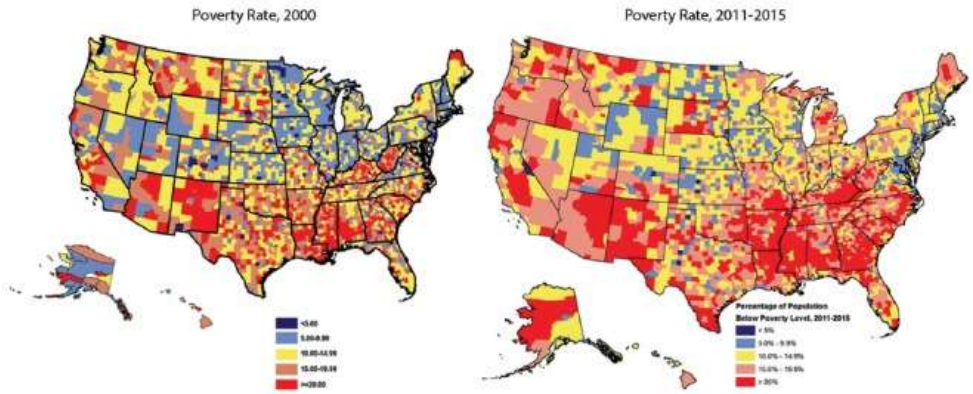


- Health care spending per person has risen in the US for as long as expenditures have been tracked, yet population health appears to be deteriorating

- In 2016 health care spending increased 4.3% in the US, reaching $3.3 trillion, but life expectancy declined for the second consecutive year, which has not happened since 1963

https://www.healthcatalyst.com/insights/social-determinants-health-todays-data-imperative/

Social Determinants of Health (SDoH)



Percentage of Population Below the Federal Poverty Level, United States, 2000 and 2011-2015 (3,143 Counties)
Source: Data derived from the 2000 Census and 2011-2015 American Community Survey.

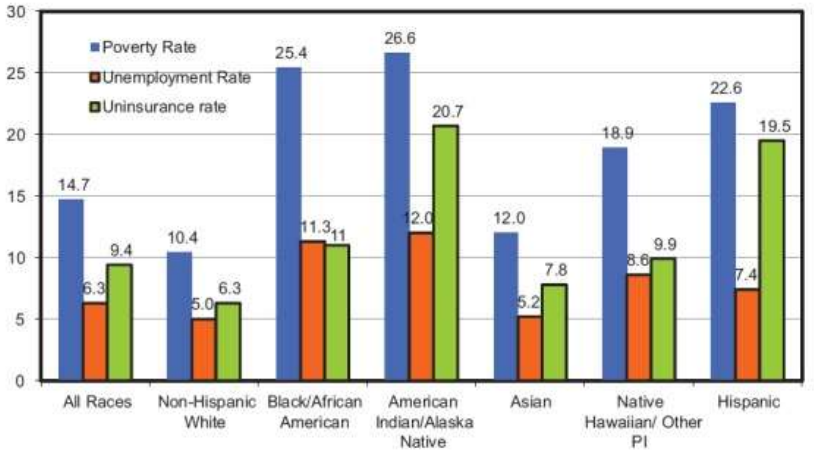
Recent estimates attribute 10% to 20% of health outcomes to medical care, 30% to genetics, 40% to 50% to behavior, and 20% to the social and physical environment.

Individuals with an annual family income < $35,000 were 10.6x more likely to forgo needed medical care due to cost than those with annual family incomes of $100,000 or more. Individuals without a job were 1.7x to 1.8x more likely to forgo or delay needed medical care due to cost than those with a full-time job.

Currently Black infants have 2.3x higher mortality than White infants (11.4 vs. 4.9 per 1,000 live births). Black infants and children in poor, rural communities have nearly 3x higher mortality rate compared to those in affluent, rural areas.

Chronic disease prevalence continues to grow, and 60% of the population is now reported to have one or more chronic conditions.

Unlike the other social determinants that address an individual's surroundings, one's race and their socioeconomic status (SES) at birth are factors that cannot be controlled.



Poverty, Unemployment, and Health uninsurance Rates (%) by Race/Ethnicity, United States, 2015
Source: US Census Bureau. 2015 American Community Survey.

SDoH and Sickle Cell Disease

Universal screening for social determinants of health in pediatric sickle cell disease: a quality-improvement initiative

- Between August 2017 and November 2018, 156 screens were completed. 60% percent were positive for at least one unmet social need for which 80% were referred to a relevant community organization; 45% of patients available via follow-up phone call reached out to the community organization.
  - Food was the most frequently unmet social determinant of health (25.6% of screens)
  - Utilities and education (24.3% each)
  - Employment (19.2%)
  - Transportation to the hospital (14.1%)
  - Adequate housing (10.9%)
  - Available childcare (7.7%)
  - Ability to pay for medication (2.6%)

Note: 45% of families with whom a social worker followed up reported they had reached out to a community organization

Patients with SCD have a chronic illness and are typically minorities, both of which can increase susceptibility to a high burden of social determinants of health. Clinically implemented, guideline-recommended universal screening and resource referral programs could improve social determinants of health for these vulnerable pediatric patients and their caregivers.

Power-Hays A, Li S, Mensah A, Sobota A. Pediatr Blood Cancer. 2020;67:e28006. First published: 01 October 2019 https://doi.org/10.1002/pbc.28006

SDoH Questions to Consider

Housing

- Home/apartment/shelter/ structural housing needs
- Can individuals independently navigate into and throughout home?
- DME needs (personal cane/walker/wheelchair)
- Is housing safe/adequate?
- Risk for becoming homeless
- Concerns with electric or heating?

Transportation

- Mode of transportation
- Can patient get to and from all appointments and high-priority errands independently? Is current transportation reliable?
- How far/distance from medical appointments?
- Current transportation needs/concerns?

Food Access

- Height/weight/BMI
- How many meals on average are eaten in a day?
- What diet does individual maintain? Snacking?
- Distance to nearest grocery store from home
- Are there current concerns with obtaining and preparing food?

SDoH Questions to Consider

Social Support

- Patient's family/social support
- Social support concerns/ability to comply to treatment plan
- Psychiatry/therapy history for individual. PHQ2 completed.
- Are social support members complying to Covid-19 precautions?
- Does individual have trouble taking care of a child, family member, or friend?

Financial Considerations

- Patient employed or unemployed? Are they receiving benefits?
- Is workplace supportive and knowledgeable of sickle cell disease/complications?
- Are bills routinely paid? Delay in paying?
- Is individual able to pay for prescription medications
- How adequate is current insurance coverage? Copays paid?

CARE COORDINATION AND CASE MANAGEMENT

Care Coordination (CC) and Case Management (CM) as Part of Patient-centered Care

- Care Coordination–Coordinating patient care properly can mean the difference in a patient's healthcare outcomes
  - PCPs must be able to *coordinate care*
  - This type of care coordination is not *case management*
  - *AHRQ*-emphasizes that CC necessitates communicating at "the right time, to the right people" as well as investing in *tools* to assist them more effectively towards specific and immediate needs
  - Definition includes–family involvement, collaboration, identification of patient and family needs, medical help, and communication

https://www.elationhealth.com/care-gaps-blog/management-coordination/
https://www.jhsph.edu/offices-and-services/practice-and-training/_documents/PHASE-past-projects-PDF/year10_2012-2013/SinghManasvini_MSPH.pdf

Care Coordination (CC) and Case Management (CM) as part of Patient-centered Care (Cont'd 2)

- The Case Management Society of America (CMSA) defines case management as "provided healthcare professionals working with people to **identify issues and barriers** that may prevent them from getting better and uncovering **mutually agreed upon solutions** to achieve their healthcare goals"
  - CMSA says CM is a *collaborative* process of assessment, planning, facilitation, care coordination, evaluation, and advocacy as options and serves to meet an individual's and family's comprehensive health needs through communication and available resources to promote patient safety, quality of care, and cost effective outcomes"

Care Coordination (CC) and Case Management (CM) as part of Patient-centered Care (Cont'd 3)

- Care Coordination results have four components:

Satisfaction

Function

Clinical

Cost of Care

https://www.elationhealth.com/care-gaps-blog/management-coordination/
https://www.jhsph.edu/offices-and-services/practice-and-training/_documents/PHASE-past-projects-PDF/year10_2012-2013/SinghManasvini_MSPH.pdf

Care Coordination (CC) and Case Management (CM) as part of Patient-centered Care (Cont'd 4)

Satisfaction:

- Achieve patient/family goals
- Reduce unmet needs
- Increase provider and staff satisfaction

Satisfaction

https://www.elationhealth.com/care-gaps-blog/management-coordination/
https://www.jhsph.edu/offices-and-services/practice-and-training/_documents/PHASE-past-projects-PDF/year10_2012-2013/SinghManasvini_MSPH.pdf

Care Coordination (CC) and Case Management (CM) as part of Patient-centered Care (Cont'd 5)

Function

- Care Coordination Results-**Function**:
  - Facilitate access to resource information
  - Achieve self-management skills
  - Enhance communication among providers/family/community partners
  - Increase functional abilities
  - Support achievement of optimal developmental trajectory
  - Act as single point of entry into multiple services
  - Provide positive social supports

https://www.elationhealth.com/care-gaps-blog/management-coordination/
https://www.jhsph.edu/offices-and-services/practice-and-training/_documents/PHASE-past-projects-PDF/year10_2012-2013/SinghManasvini_MSPH.pdf

Care Coordination (CC) and Case Management (CM) as part of Patient-centered Care (Cont'd 6)

- Care Coordination Results-**Clinical**:
  - Enhance communication among providers/family/community partners and increase measures of health
  - Increase activity: developmental screening and health promotion (early and periodic screening, diagnosis, and treatment)
  - Improve access to health and mental health care

Clinical

https://www.elationhealth.com/care-gaps-blog/management-coordination/
https://www.jhsph.edu/offices-and-services/practice-and-training/_documents/PHASE-past-projects-PDF/year10_2012-2013/SinghManasvini_MSPH.pdf

Care Coordination (CC) and Case Management (CM) as part of Patient-centered Care (Cont'd 7)

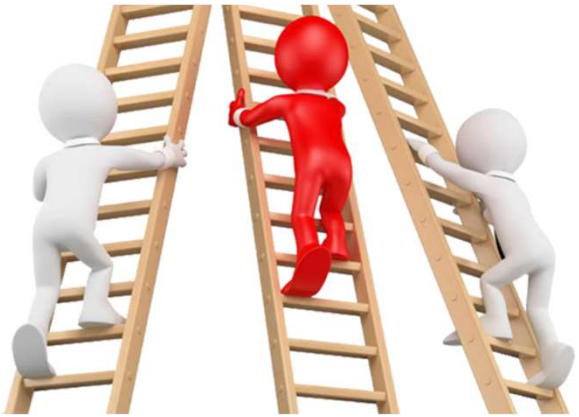
- Care Coordination Results-**Cost of Care:**
  - Reduce emergency department visits
  - Reduce hospitalization/hospital days
  - Reduce duplication of tests, services
  - Reduce repeat data gathering by service providers
  - Reduce caregiver work days lost

Cost of Care

https://www.elationhealth.com/care-gaps-blog/management-coordination/
https://www.jhsph.edu/offices-and-services/practice-and-training/_documents/PHASE-past-projects-PDF/year10_2012-2013/SinghManasvini_MSPH.pdf

Where does your program stand in case management development?

RED
Just starting or no progress



YELLOW
Staff approved but not hired

GREEN
Hired and trained

How did we get here?

Plsek P, Greenhalgh T. *BMJ*. 2001;323:625-628.

Developing a Team

Strengths-individuals flourish as they **use and develop** their *Strengths*

Teamwork-people come together **building relationships** that result in effective *Teamwork*

Alignment-the leader *Aligns* through effective **communication of purpose**, so each person's strengths combine with teamwork, achieve results

Result-together everyone achieves more as **performance flows** and *Results* that are meaningful and rewarding to the team are achieved

https://the-happy-manager.com/articles/team-building-concepts

Components of a Multi-disciplinary Team

- Physicians
- APP's
- Program Manager
- RN's
- LCSW
- CHW
- Prior Authorization Specialists
- Research Scientists
- Data Analysts

*Job descriptions can be downloaded from the meeting's website resource page

Defining a Team

- Strong leadership
- Vision for the project
- Sense of ownership
- Respectful of timelines
- Diversity
- Transparency
- Good communication
- Generosity/Giving credit and appreciation

Training, Training, and More Training for the Team

- Establish roles and responsibilities to avoid overlapping of services
- Teach knowledge of sickle cell disease, medication, and understanding of patients' needs
- Share extensive knowledge of community resources and engagement with patients
- Stress key components of motivational interviewing, care coordination, and case management training

Empathy and the Impact on Patient Care

- All the training in the world will not be successful with patients if the healthcare professional does not make the patient feel understood and cared for
  - "Clinician empathy" improves patient satisfaction over 65%
  - Patient satisfaction is improved despite the care outcomes
  - Patients should feel heard
  - Treat others in the context of how you want to be treated

- Navigators must still at times provide challenging news to a patient, however if the patient has a good relationship with them, the outcome may still be achieved

https://patientengagementhit.com/news/consumers-say-patient-provider-relationship-key-to-quality-care

Strong Communication by *ALL* Team Members

- Essential for positive patient-provider/CHW relationship
  - Clear medical instructions
  - Patient education
  - Other important clinical information
    - Recognize literacy issues
- Patient teach back
- Understanding the patient's literacy and cognitive impairments are important to properly educate and support patient

https://patientengagementhit.com/news/patient-provider-communication-strategy-may-boost-education

https://patientengagementhit.com/news/3-key-traits-of-a-positive-patient-provider-relationship

Positive Patient–CHW Relationships: Knowledgeable, Listens, and Trustworthy

- Shared decision-making is central to building trust

- Three main points:
  - Patient education (sound familiar?)
  - Understanding patients' culture and personal preferences
  - Engaging family/caregiver

https://patientengagementhit.com/news/3-key-traits-of-a-positive-patient-provider-relationship

Determination of Case Load for CHW's in Clinical Care Setting

- Focus on your high utilizing patients
  - Metrics:
    - Length of stay
    - 30-day re-admissions
    - Total cost

- Indicate that non-high utilizers will be identified throughout the year:
  - Without intervention becomes your new target group

New Data Show the Following Outcomes for CHW Assignment

- After 4 years of running a medical home, data has been gathered, assessments have been completed, and more identified targets to manage CHW assignments are more apparent

Start of Medical Home	
Target	**Elements**
High Hospital Utlizers	Total Hospital Charges
	Inpatient Utilization
	ED Utilization

4+ Years Into Medical Home	
Target	**Elements**
High Hospital Utilizers	Inpatient Utilization
	ED Utilization
	Total Hospital Charges
	Biological Comorbidities
	Behavioral Health Comorbidities
High CHW Utilizers	Total Contacts
	After Hours Contacts
	Total Contact Time
	Biological Comorbidities
	Behavioral Health Comorbidities
	LCSW administered assessments

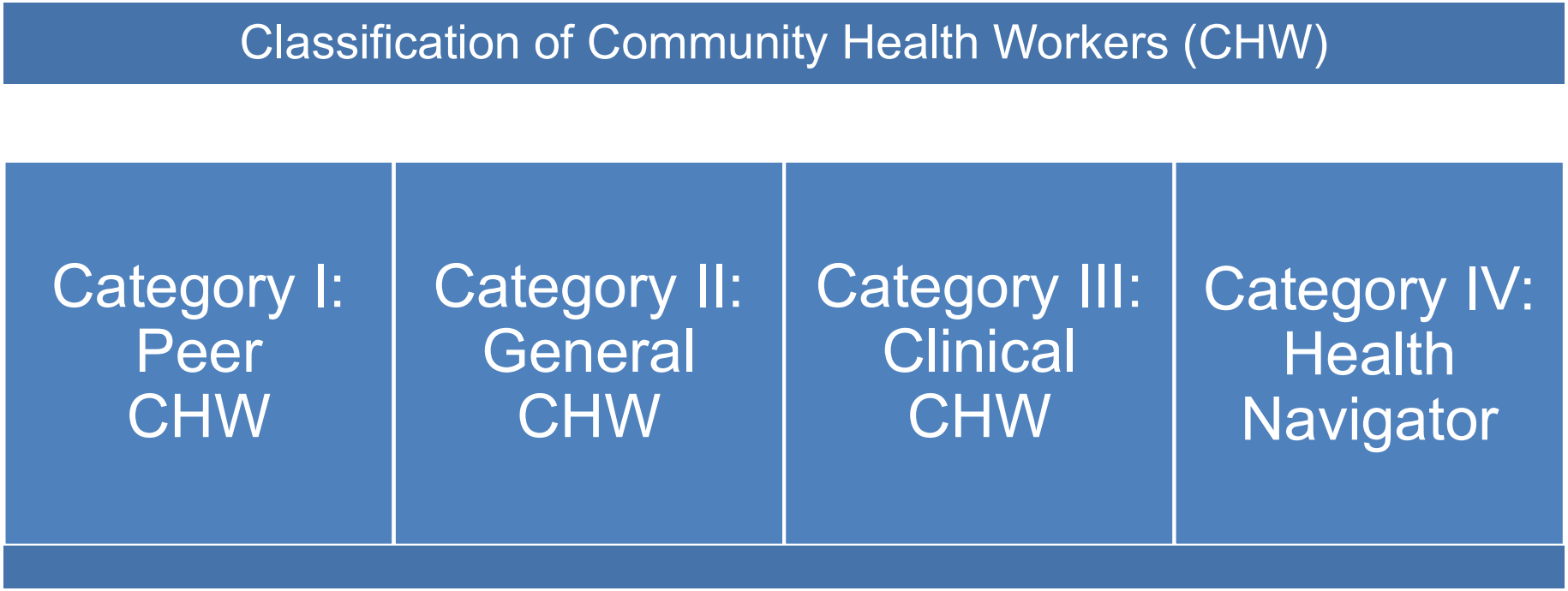
VCU developed chart internally

Development and Framework Functions of CHW's

- Recognize the uniqueness of CHW roles
- Promote and further integrate varied levels of CHW functions in healthcare-related organizations
- Inform decisions on certification, education, and payment of CHW services
- There is evidence to support the effectiveness of CHW's, as they practice in a wide range of health care settings but even now:
  - *The perceived value of CHW's suffer from lack of uniform credentialing*
  - *Billing and payment structures fail to recognize their work*
  - *Conflicts of job titles and position descriptions remain*
  - *Confusion on roles, identities and overlapping boundaries of other health care and social service occupations undermine their significance*

Corder-Mabe J et al. *J Cont Ed Health Prof*. 2019;39(4):274-278.

Proposed Categories



Corder-Mabe J et al. *J Contin Educ Health Prof*. 2019;39(4):274-278.

Peer Community Health Worker

Qualifications:

- Shares common demographics with targeted population
- No minimum education required
- CBO or institutional program may supervise

Functions:

- Assistance with system navigation and community resources
- Education of disease
- Advocacy
- Emotional support
- Direct service
- Outreach and case findings
- Assistance with community assessments

CBO, community based organization

General Community Health Worker

Qualifications:

- Shares conditions, demographics, or experience with targeted population
- Typically requires high school diploma
- Supervised by CBO's

Functions:

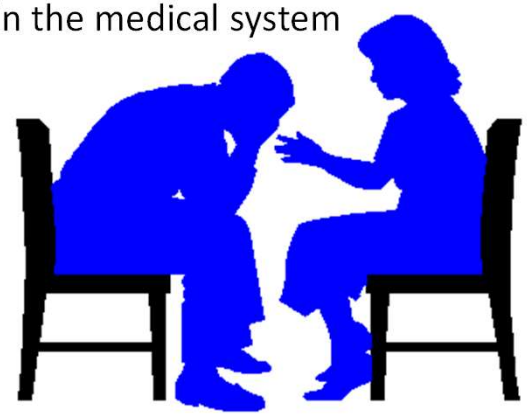
- *Assists with system navigation and community resources
- Conducts culturally competent education w/direction or supervision
- *Advocates but also advocates for populations based on needs
- *Provides emotional support
- Provides direct services within the CHW scope of practice
- *Conducts outreach and case findings
- Participates in evaluation, research as well as *assisting with community assessments

*An underline indicates overlap between CHW types

Clinical Community Health Worker

Qualifications:

- May not share conditions, demographics, or experience with targeted populations but has keen interest in the population
- Most require GED, high school diploma, or may require post-secondary education
- Supervised by degreed professional within the medical system



Functions:

- Provides system navigation and community resource connection, enhance system resources and provides care coordination services and not case management
- May develop education and *conduct culturally competent education with supervision
- *May advocate for patients or be involved with medical condition but may have **employer limitations**
- Supportive by acting as link between medical system and community
- Provides direct service as delegated by medical team
- *Conducts outreach and case findings but also participates in formal activities of patients in clinical services
- *Participates in evaluation, research and assists with community assessments and gathers patient data

*An underline indicates overlap between CHW types

Health Navigator

Qualifications:

- Usually does not share conditions, demographics, or experience with population
- Requires a clinical background such as nurse, social worker, or health navigator with minimum degree
- Frequently functions as supervisor for other CHW's
- Supervised by a degreed medical system professional

Functions:

- *Provides system navigation, community resource connection, enhances access to system resources and provides care coordination and case management
- May develop or conduct education, may supervise or assist with CHW classes
- *Advocates for patients medical condition but **may be limited by employer**
- ***Provides coaching and emotional support, serves as liaison between academics and community BUT provides support and counseling within scope of practice
- Designs outreach activities,*conducts outreach and case findings, participates in formal recruitment activities of clinical services
- *Participates in evaluation, research, and community assessments
- Contributes to evaluation, research plans, and activities and may lead implementation of evaluation and research

*An underline indicates overlap between CHW types

Ambulatory Care

Ambulatory care or outpatient care is **medical care provided on an outpatient basis**, including diagnosis, observation, consultation, treatment, intervention, and rehabilitation services. This care can include advanced medical technology and procedures even when provided outside of hospitals.

- Hospitals
  - Emergency Department
- Clinics
  - **Specialty clinic**
  - **Dedicated infusion center**
  - Urgent care setting
  - Ambulatory surgery center
- Doctor's office
- Non-medical institution-based setting
- Non-institution setting
- Telemedicine

Nurses play critical roles in every setting!!

Infusion Nurse, Patient Navigator, Nurse Case Manager, Triage Nurse, etc.

Effective Characteristics

- Highly knowledgeable about sickle cell disease
- Good clinical judgment and critical thinking skills
  - Provide optimal outpatient care to adults in VOC
  - Focused physical assessment
  - Review/implement provider orders
- Work in a fast-paced environment
  - Multitask
  - Delegation
- Detail-oriented
- Able to recognize psychosocial needs of their patients
- **Passionate and Compassionate!**

Lifespan of an Individual

- Pediatric population

- Adult population

Transition of Care

Critical Role of the Nurse

- Provide hands-on treatment of those experiencing VOC or acute manifestations of SCD (**Patient/nurse ratio 4:1**)
  - Full assessment of patient in crisis
    - Focused
      - Assess required level of care (critical, acute, and subacute)
      - Inciting factors
      - Psychosocial issues
      - Look for physical exam findings
      - Distinguish acute vs. chronic pain
    - Assisted by nurse clinical associates need to delegate appropriately
      - Vitals
      - Places peripheral IV
      - Repeated vital sign assessments
      - Assists with providing patient comfort

Critical Role of the Nurse

- Review/Implements provider orders
  - No standard treatment protocols for all patient
    - Use patient-specific protocols
  - Discuss care plans with provider throughout treatment day
    - Allows potential adjustments to regimen
    - Achieves increased pain relief
    - Prevents over-sedation and/or respiratory distress
  - Typically, hourly administration of IV analgesic
  - IV/PO hydration
  - Concurrent home long-acting pain medications
  - NSAIDS if appropriate

Critical Role of the Nurse

- Nurse Autonomy
  - Crucial role because they integrate knowledge of laboratory, radiology, and psychosocial findings to promote patient wellbeing
  - Assist in timely and appropriate referrals
    - Social Work
    - Psychiatry
    - Other: Hematology, Anticoagulation Clinic, Ophthalmology, Nephrology, Pulmonary, and Transfusion
  - Assist and manage patient disposition at end of treatment in SCIC

Critical Role of the Nurse

- Patient and family education:
  - Discuss how to implement treatment plans accordingly
    - Encourage/assist patients to distinguish acute vs. chronic pain
    - Ensure understanding of prescribed home management
      - Pain medications
      - Hydroxyurea, Oxbryta, Endari, and Adakveo
      - Antibiotics
      - Help patients to understand their specific triggers and how to avoid them
    - Compliance with chronic transfusions
    - Compliance with all outpatient follow-up appointments

Comprehensive Needs Assessment

- A complete needs assessment (CNA)
  - Describes in detail the client's medical, physical, and psychosocial condition and needs
  - Identifies service needs being addressed and by whom
    - Services that have not been provided
    - Barriers to service access
    - Services not adequately coordinated
- Elements of a complete CNA:
  - Demographics
  - History
  - Functionality
  - Nutrition
  - Developmental concerns
  - Support/Community resources
  - Psychosocial history

CASE MANAGEMENT KNOWLEDGE FRAMEWORK

Case Management Team Member
Nurse Case Manager

- Partner with patients and their medical team to create and implement a long-term care plan tailored to the **patient's specific illness, medical history, and lifestyle**
- **Advocate** for patients and their caretakers throughout the course of their illness
  - Coordinate doctors' visits and surgeries
  - Educate patients on their treatment options and the latest research
  - Often act as emotional support to patients in need of long-term care
- Case management nurses often specialize in a specific group or type of patient

https://www.registerednursing.org/

Case Management Team Member
Nurse Case Manager

- Roles and Duties
  - Work with a team of medical professionals to develop and implement **a comprehensive care plan** based on the patient's illness and medical history
  - Coordinate doctor's appointments and schedule surgeries
  - Monitor medication usage by a patient
  - Educate patients and caretakers on different treatment options and resources available to them
  - Monitor and update treatment plans to reflect the latest in a patient's condition or lifestyle
  - Research the latest treatments and procedures in their chosen area of specialization
  - Work with insurance companies to help patients receive the most cost-effective care available

https://www.registerednursing.org/

Comprehensive Care With Nurses

- Nurses play critical roles in every setting and must have effective characteristics
  - Infusion Nurse, Patient Navigator, Nurse Case Manager, Triage, etc.
  - Effective characteristics include clinical judgement with nurse autonomy and compassion
- Sickle cell disease: Lifespan view of the individual
  - Focus on transition of care from pediatric to adult–start early
- Social Determinants of Health (SDoH) – make up 60%-80% of health outcomes
  - Comprehensive team approach to assess individual needs
  - Screening should hold empathy and rapport to the highest priority
  - Focus screening questions to help guide conversations and available resources

Case Study

- Keith is a 30-year-old patient with multiple comorbidities, including **sickle cell** and **kidney disease;** he had a **kidney transplant** about 10 years ago

- Keith moved to the area about 3 years ago and continues to have challenges with housing, transportation, and prescription refills. As a result, he continues to utilize the ED **nearly every day** for his care. The sickle cell team has recently assigned him a CHW to assist him with managing some of these challenges.

Group Discussion

What assistance can a CHW provide Keith regarding his ED visits?

What role can the nurse on the comprehensive team play in his care?

Other outliers that SCD team should consider regarding this patient?

Questions?