



Translating Health Services Research in Sickle Cell Disease to Policy

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Objectives

- Define Health Services Research (HSR)
- Demonstrate Relevance of HSR to Sickle Cell Disease
- Define the Social Determinants of Health (SDH)
- Highlight Priorities for Incorporating SDH into SCD Research



Definition of Health Services Research



Agency for Healthcare Research and Quality (AHRQ)

- Examines how people get access to health care, how much care costs, and what happens to patients as a result of this care. The main goals of health services research are to identify the most effective ways to organize, manage, finance, and deliver high quality care; reduce medical errors; and improve patient safety.

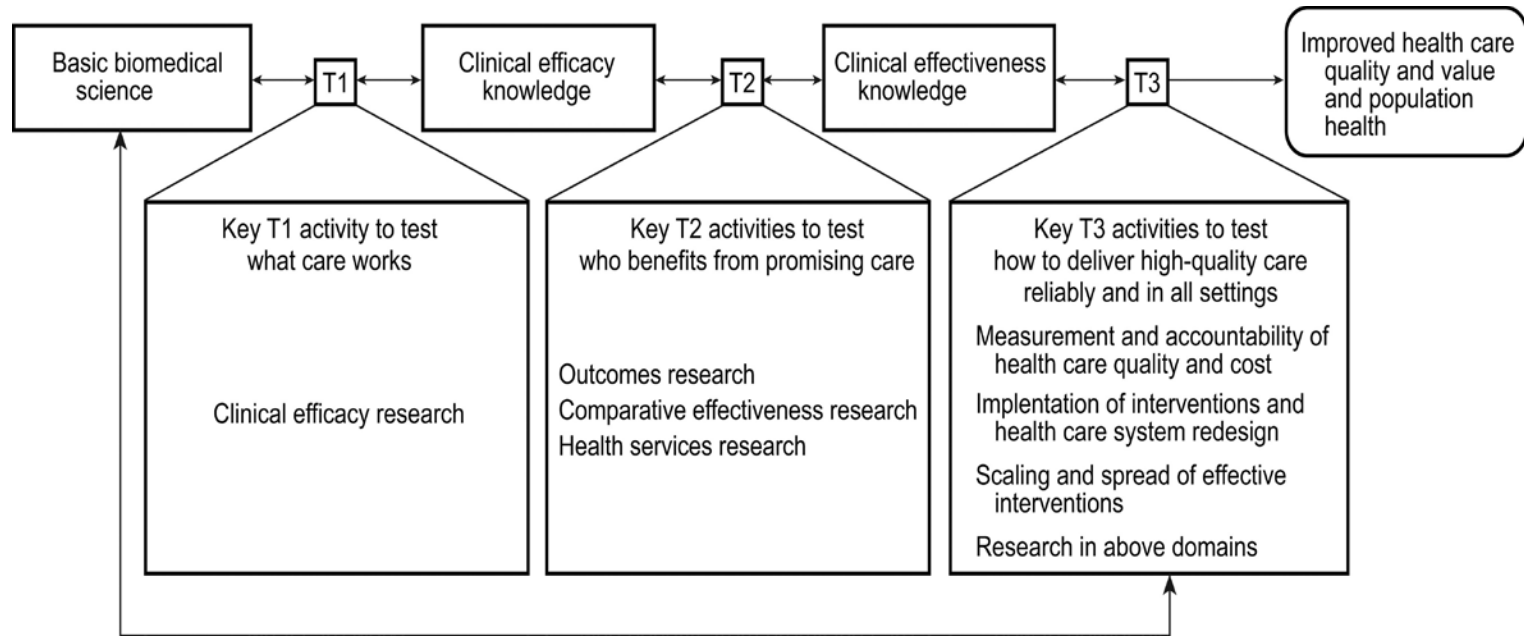
Institutes of Medicine (IOM)

- A multidisciplinary field of inquiry, both basic and applied, that examines the use, costs, quality, accessibility, delivery, organization, financing, and outcomes of health care services to increase knowledge and understanding of the structure, processes, and effects of health services for individuals and populations

Triple Aim of Healthcare for Population Health

- Reduce costs
- Improve population health
- Enhance patient experience

Road Map of High Quality Care



Dougherty D. and Conway PH. The “3T’s” Road Map to Transform US Health Care: The How of High Quality Health Care. JAMA. 2008. 299(19):2319-2321.



Relevance of HSR for Sickle Cell Disease



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Opportunities and Challenges in SCD

- Advent of diagnostic tools and treatments
 - hydroxyurea, TCD screening for stroke risk, chronic transfusions
- Extended life expectancy

But also...

- Persistently high resource utilization
- High risk of mortality at early adulthood
- Largely underserved population
- Poor funding and organizing relative to other conditions

Challenges to Conducting HSR for SCD

- Inadequate funding due to low prioritization
- Few dedicated researchers
- Lack of data sources with adequate numbers of children with SCD or sufficient clinical detail
- Controlling for disease severity
- Quality indicators



Data Sources for HSR in SCD



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Chart Review

Advantages

- Potentially large numbers
- Extensive clinical data
- Genotype available
- Charge data
- Provider data

Disadvantages

- Time consuming
- Not generalizable
- Limited demographic data
- Does not include services outside institution
- **Will institution let you publish**

Insurance Claims Data

Advantages

- Large numbers
- Low cost acquisition
- Cover all types of services
- Prescription data available
- Expenditures available

Disadvantages

- High turnover (public)
- Few private insurance data
- Availability of current records
- Validation of diagnoses
- Lack of socio-demographic variables
- Inability to generalize

Insurance Claims Data

- Managed Care Organizations
- Individual private payer data
- State Medicaid
- Marketscan Research Database

Administrative Database

Advantages

- Provides ICD-9 and CPT codes
- Large numbers
- Low cost acquisition
- Charges available

Disadvantages

- Lack of clinical data
- Home medications not available
- Outpatient care not available
- Discharge may be unit of analysis rather than patient
- No cost data

Administrative Data

- Pediatric Health Information System (PHIS)
- Healthcare Utilization Project (HCUP)
 - Kids' Inpatient Database (KID)
 - State Inpatient Database (SID)

National Survey Data

Advantages

- Low cost acquisition
- Socio-demographic variables
- Wide array of questions and outcomes
- Potentially generalizable

Disadvantages

- Low numbers
- Do not typically identify SCD
- No genotype
- Reliance on self-report
- Questions may not be applicable to SCD
- No financial data

National Survey Data

- National Survey of Children's Health
- National Survey of Children with Special Health Care Needs
- Medical Expenditure Panel Survey
- National Health Interview Survey



Social Determinants of Health (SDH)



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Social Determinants of Health

Healthy People 2020

- conditions in the environments in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks.

World Health Organization

- the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life. These forces and systems include economic policies and systems, development agendas, social norms, social policies and political systems.

Adverse Childhood Experiences (ACES)

- Childhood experiences, both positive and negative, have impact on life outcomes
- Linked to risky health behaviors, chronic health conditions, low life potential, early death
- As the number of ACES increases, so do the risk of these outcomes

SDH and Health Policy

CMS Accountable Health Communities Model



"focus on the health-related social needs of Medicare and Medicaid beneficiaries, including building alignment between clinical and community-based services at the local level."

SDH and Health Policy

CMS State Innovation Models Initiative (SIM)

- states are engaged in multi-payer delivery and payment reforms that focus on population health and SDH

SDH and Health Policy

Health in All Policies Approach

- approach identifies the ways in which decisions in various sectors impact health and how better health can promote the aims of these multiple sectors.
- Examples – National Prevention Council, California Health in All Policies Task Force

SDH and Sickle Cell Disease

- Largely racial/ethnic minority population
- High percentage of individuals publicly insured
- Disease-related stigma

Potential Value of Assessing SDH

Clinical

- Improve panel management
- Use for quality improvement
- Staffing for team-based care
- Performance-based incentive payments

Research

- Better accounting for influencing factors
- Intervention design

Gottlieb, L. Et. al. Integrating Social And Medical Data To Improve Population Health: Opportunities And Barriers. Health Affairs. 2016 Nov;35(11):2116-2123

Feasibility of Measuring Social Determinants

- Electronic Medical Records
- Administrative Data
- Surveys

Feasibility of Measuring Social Determinants

Institute of Medicine Report: *Capturing Social and Behavioral Domains and Measures in Electronic Health Records*

- Recommends variables measuring social and behavioral factors

IOM Recommended Domains

- Alcohol use
- Race/ethnicity
- Residential address
- Tobacco use/exposure
- Census tract-median income
- Depression
- Education
- Financial Resource Strain
- Intimate Partner Violence
- Physical Activity
- Social Connections and Social Isolation
- Stress

Questions for Researchers

- Are these domains most critical for sickle cell disease?
- What survey instruments should be used?
 - ACES survey, SEEK, WE CARE
- Is it possible to standardize instruments across systems?
- When should surveys be conducted?
- What resources are available to incorporate these measures into electronic databases?
- Is it ethical to screen for SDH without the resources in place to address?