

Health Service Delivery For People living with Sickle Cell Disease (SCD)



uOttawa

L'Université canadienne
Canada's university

Josephine Etowa RN PhD
Associate Professor
Faculty of Health Sciences, University of Ottawa

Toronto Sickle Cell Conference 2010
Toronto, Canada
October 2, 2010

Université d'Ottawa | University of Ottawa



www.uOttawa.ca

Workshop Objectives

- In keeping with the overall conference goal of improving the quality of life and optimizing the health care of people living with sickle cell disease in the Greater Toronto Area (GTA),
- this particular workshop will discuss the topic of **“Interacting with the Medical system”** with a focus on the following three areas:
 - Emergency Department (ED) and Outpatient visits
 - Comprehensive care
 - Advocating for Yourself

Challenges: Patients' Perspective

- Patients report insensitivity and preoccupation with concerns of drug addiction by care providers
- Inadequate analgesic administration
- Overall lack of sympathy
- Health care professionals often fail to understand that the reporting of severe pain without an accompanying behavior change is common among people who suffer from chronic pain generally, not just those with SCD

Challenges: Providers' perspective

- One of the main challenges associated with ED care is the lack of knowledge of the patients' previous health care history by the care providers
- Other barriers to optimal management of SCD by health care professionals include concerns about drug abuse and reluctance to prescribe opioids
 - e.g. some physicians feel trapped between the duty to address the need of the SCD patient and that of protecting the community from opioids diversion
 - » (Shapiro et al 1997, Tanabe et al 2007; Zempsky, 2009) :

ED and Outpatient Visits

Key Issues:

- Most patients with SCD are not usually seen as requiring emergency attention despite known severity of their pain
- Patient self-reported pain is not reliable indicator of the intensity of pain because patients reported more pain than they actually experienced or they fabricated pain
- Health care providers e.g. physicians and nurses tend to overestimate the prevalence of drug addiction in SCD population
 - Prevalence of opioids addiction-0.5-8% SCD versus 3-16% in other patients with chronic pain syndromes and 4.8% prescription rate in the general population.(Bonham, 2001; Solomon, 2008; Tanabe, 2007)

Comprehensive Care

- Multidisciplinary team of providers and patients
- Health care availability e.g. dedicated SCD units
- Quality of health care (e.g. good spectrum of drugs and providers)
- Research on sickle cell disease in Canada
- Education of Health care providers: training and practice patterns in pain management, complication management, preventive care, and practice style incl. Cultural competence and anti-racism health care
- National organizations and support groups



Advocating for Yourself

- Taskforce or workgroup of consumers and providers to jointly develop standards of care
- Community Resources such as SCAGO
- Outreach programs
- Social marketing and media campaign
- Activities should sustain year round (i.e. beyond sickle cell month)
- Advocate for project funds for educational programs

Inequities in SCD Management

- SCD patients' interaction with the health care system is defined by a relationship grounded in a history of distrust and injustice
- Differences in the way racial and ethnic minority people communicate their pain experience and how the health care providers hear their concerns may lead to their pain experience being discounted.
 - This problem is more likely when the patient's gender, race or ethnicity is not congruent with that of the care provider
- Several studies have linked discrimination, racism and health care inequities with a large range of psychological and physical problems
 - Discrimination for people with chronic pain leads to more pain, stress and disability
- For people living with SCD, recurrent discrimination over years of interactions with the health care system, coupled with the helplessness and lack of control of the situation may serve to worsen their already compromised health

Addressing the Challenges

- Strategies to optimize the care of those living with SCD are complex.
 - Local organizations
 - Day hospitals
 - Pain passport
 - Individualized protocols and guidelines that strengthen communication between the patient's medical home and the ED
- Ultimately, the fair and just management of SCD depends on an approach that addresses the distrust between the patient and the provider of care; one that fosters a true collaboration among all stakeholders.

Reflective Questions

- Are there best practice models in the GTA; in Canada?
- Do families and care providers have access to research information to manage the disease appropriately?
- What do you believe health care providers need to know about sickle cell disease in order for them to provide effective health care for people with SCD?
 - i.e. physicians, nurses, psychologists, pharmacists, social workers, etc
- How can trust and justice be integrated in the care of those living with SCD?

Comments



uOttawa

L'Université canadienne
Canada's university

Questions?

Email: Jetowa@uottawa.ca

Université d'Ottawa | University of Ottawa



www.uOttawa.ca