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Aisha L. Walker Date

# Assessing Perceptions of Hydroxyurea among Sickle Cell Disease Stakeholders Using Facebook Social Media Platform

By

Aisha L. Walker
Degree to be awarded: M.P.H.
Executive MPH

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An abstract of
A Thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University
in partial fulfillment of the requirements of the degree of
Master of Public Health in the Executive MPH program
2016

# Abstract

## Assessing Perceptions of Hydroxyurea among Sickle Cell Disease Stakeholders Using Facebook Social Media Platform

By
Aisha L. Walker

Sickle cell disease (SCD) is a chronic, non-curable, genetic blood disorder that imposes significant health care burdens for individuals, their families, and society. Clinical complications of SCD result in multi-organ damage and shortened life span for patients, and create substantial healthcare costs. Hydroxyurea (HU) is currently the only disease-modifying drug approved for SCD. It is safe and efficacious for decreasing SCD complications and improving mortality. However, HU is underutilized, which poses a problem for decreasing SCD-related morbidity and mortality. This study employs qualitative analysis of social media user-generated data to examine of perceptions of HU among a broad sample of SCD stakeholders.

We performed textual content analysis of Facebook messages and comments posted in a SCD-specific Facebook group to identify major themes related to patients' and caregivers' perceptions of HU. Social support of the Facebook group was a major theme that was evidenced by the posting of questions and answers to resolve stakeholders' concerns related to HU. Qualitative analysis identified themes that perceived efficacy and side effects are associated with a range of valance and opinions of HU. In the Facebook comments, favorable valance and opinions of HU were associated with high efficacy and few or minor side effects; whereas non-favorable ones were associated with lack of efficacy and numerous or harsh side effects. Inductive analysis revealed the emergent themes of HU masking symptoms of SCD to cause harm and knowledge of HU as a cancer drug can be a deterrent to SCD therapy. These two themes may be additional barriers to HU utilization that warrant further investigation. Identification of these themes represent perceptions of HU captured from online user-generated content.

We conclude that the Facebook social media platform not only serves as a supportive resource for SCD community, but can also provide insight into perceptions among SCD stakeholders. The information from this study contributes knowledge that can aid in addressing HU underutilization. Furthermore, this study has significant implications for the utility of Facebook for SCD-related research, and broader implications that social media may be a valuable resource for future public health projects.

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# CHAPTER ONE: INTRODUCTION

## Overview of the Problem

This thesis project addresses a public health concern related to sickle cell disease (SCD). It is a genetic blood disease that affects the function of red blood cells (NIH, 2015). Complications of the disease lead to frequent hospitalizations and early mortality for sickle cell patients and substantial economic costs for society (Edwards et al., 2005; Kauf, Coates, Huazhi, Mody-Patel, & Hartzema, 2009). Currently, the drug hydroxyurea (HU) is the only disease-modifying FDA-approved drug. Evidence-based guidelines now recommend hydroxyurea for treating most patients with SCD because the drug has been shown to decrease the severity and frequency of complications and increase life span (Lanzkron et al., 2008; Strouse et al., 2008). However, many patients do not benefit from this drug because HU remains underutilized due to barriers associated with different perceptions of HU among providers, patients, and caregivers (Brawley et al., 2008). HU underutilization is a problem because it minimizes the drug's effectiveness for decreasing individual and public health burdens related to SCD.

## Problem Addressed by Thesis Project

Knowledge gap currently exists in the comprehensive understanding of barriers to HU utilization (Savage et al., 2015). There is a need to better understand of perceptions of HU among SCD stakeholders. Addressing this gap in knowledge will provide insight that will help improve HU utilization and decrease the burden of sickle cell disease.

## Purpose of Thesis Project

The purpose of this study is to assess perceptions of HU among patients with SCD and caregivers of patients with SCD via user-generated social media content. Given that social networking sites facilitate the exchange of health information among diverse populations by providing a supportive network for individuals with common interests (Boyd & Ellison, 2008; Capurro et al., 2014), it was proposed that data created and shared by SCD stakeholders on social networking sites could provide information pertinent to thoughts and opinions regarding hydroxyurea. Therefore, this thesis project was conducted to test the **hypothesis that qualitative analysis of user-generated data from Facebook can provide practical information about the perceptions of HU among SCD stakeholders.** In testing this hypothesis, the following objectives will be addressed: 1) demonstrate whether user-generated Facebook content can be used to assess perceptions of hydroxyurea, 2) examine the support that sickle cell stakeholders receive through the social networking site and 3) report specific perceptions of hydroxyurea that may influence individuals' decisions to utilize hydroxyurea.

## Significance Statement

With the successful completion of this thesis project, it will be the first to employ large-scale user-generated data to gain insight into perceptions among SCD stakeholders. This is significant because the project will not only provide novel information about perceptions of HU, but will also demonstrate the utility of social networking sites for SCD population-based research. Ideally, the information obtained from this study can be used to design interventions addressing HU underutilization. In addition, project success can lead to the use of social media for future studies to address other problems that affect the SCD community.

## Definition of Terms

**Caregiver-** a family member or paid helper who regularly looks after a child or sick, elder, or disabled person

**Efficacy-** the ability of a drug or treatment to achieve the desired effect or positively influence the course of a disease

**Facebook-** a popular free social networking website that allows users to create profiles, share media content, send messages, and interact with other users within their network

**Facebook Comment post-** a message posted on one's own profile page or another user's profile page in response or reference to an original message post

**Facebook Discussion Threads-** a collection of related posts stemming from a single original message post

**Facebook Group**- private spaces within the Facebook platform where users can interact with others who share common interests

**Facebook Original Message post-** a message, photo, video, or event that a user posts on their personal Facebook profile to share with others

**Facebook Profile-** personal space in the Facebook platform where users collect and share photos, stories, messages, comments, and experiences with other users

**Hydroxyurea (HU) -** an antineoplastic drug that is FDA-approved for treating SCD to reduce hospitalizations, pain episodes, and other complications

**Provider-** an individual who provides preventative, curative, promotion, or rehabilitative health care services such as physicians, nurses and others

**Shared decision making clinical model-** an approach where clinicians and patients share the best available evidence, and patients are encouraged to consider options in order to reach informed preferences when making health-related decisions

**Sickle cell disease (SCD**) - group of inherited blood disorders characterized by abnormal hemoglobin in red blood cells

**Social network-** web of social relationships that surround an individual

**Social networking sites-** specific type of social media that involves web-based services that allow individuals to construct public/semi-public profiles with in a bounded system

**Social Support-** a provision or group of concepts that describe the structure, processes and function of social relationships

**User-generated content**- various forms of media content that are publicly available and created by end-users

**Valance-** psychology term used when discussing emotions related to intrinsic attractiveness (positive valance) or aversiveness (negative valance) to an event, object or situation

**Vasoocclusive pain crisis-** complication of sickle cell disease characterized by pain in bones and other tissues due to an obstruction of small blood vessels

**Virtual community**- a community of people sharing common interest, ideas, and feelings over the internet

# CHAPTER TWO: REVIEW OF THE LITERATURE

## Overview

This chapter begins with a review of literature that provides background and rationale for the research hypothesis and objectives posed in this thesis. The studies presented herein explain sickle cell disease and hydroxyurea, which is the only FDA-approved drug for sickle cell disease. The chapter will then present published studies showing the underutilization of hydroxyurea, and studies to support the idea that social media can be used effectively for public health studies. Next concepts of health behavior theoretical models used to explain factors that influence individuals' decisions regarding hydroxyurea will be outlined. The chapter concludes by suggesting the use of social media user-generated data to examine perceptions of hydroxyurea among sickle cell disease stakeholders.

## The Burden of Sickle Cell Disease

SCD is a group of inherited red blood cell disorders characterized by the formation of abnormal hemoglobin within the red blood cells. Genetic mutations generate sickle hemoglobin, which causes the deformation of the red blood cells into a sickle shape and pathophysiologic changes in their function. Sickle cells are more fragile, prone to rupturing, and are removed from circulation at a rapid pace resulting in anemia. They can also occlude blood vessels to prevent efficient oxygen delivery to organs throughout the body, which leads to a wide variety of clinical complications. The most common complications include anemia, severe acute and chronic pain, acute chest syndrome, stroke, frequent infections and sepsis, and organ damage/failure. As a result, individuals with SCD are likely to experience frequent and sometimes prolonged hospitalizations and emergency room visits.

Recurring complications of SCD can begin as early as 6-8 months of age and can lead to an overall shorter life span for individuals, even with proper management of the disease (Thornburg et al., 2012). The National Institutes of Health currently estimates a life expectancy of 40-60 years for individuals with SCD (NIH, 2015). In the most recent comprehensive study of SCD mortality in the United States, the median age of death was 42 years for females and 38 years for males in 2005 (Lanzkron, Carroll, & Haywood, 2013). These ages are in sharp contrast to the average life expectancy in the United States of 81 and 76 for females and males, respectively, as of 2013 (Kochanek, Murphy, Xu, & Arias, 2014). The complications and mortality associated with SCD serve as somber indicators of individual health burdens associated with this disease.

As the most prevalent blood disorder world-wide, SCD also poses significant public health and economic burdens. The exact number of people affected with SCD remains unknown, but an estimated 90,000-100,000 people in the United States and millions worldwide have SCD (CDC, 2015). According to the most recent comprehensive global estimates of people born with SCD, in 2010 approximately 305,800 babies were born with SCD. The same study used prediction models to estimate that the number of babies born each year could increase about 33% by 2050 (Piel, Hay, Gupta, Weatherall, & Williams, 2013).

Economic costs associated with managing SCD can be substantial due to a high frequency of emergency department visits and hospitalizations. On average patients with SCD will experience 1-3 emergency department visits, 11-12 outpatient visits and 1-3 hospitalizations per year (Ashley-Koch, Yang, & Olney, 2000; Mvundura, Amendah, Kavanagh, Sprinz, & Grosse, 2009). In 2004, the Healthcare Costs and Utilization Project reported that approximately $488 million was spent nationwide for hospitalizations related to SCD, and nearly 80% of those expenses were paid by public funds through Medicaid and Medicare programs (Steiner & Miller, 2006). In comparison to other chronic diseases in 2006, estimated charges totaled $1.5 million per 100 patients for SCD, but only $14,000, $281,000, and $500,000 per 100 patients with HIV, Asthma, and Congestive Heart Failure, respectively (Lanzkron, Carroll, & Haywood, 2010). These studies demonstrate significant public health and economic burdens associated with SCD.

The management of SCD can be challenging due to heterogeneity of disease pathology and limited therapeutic options. Currently the only cure for SCD is a hematopoietic stem cell transplant. However, only 1,200 patients worldwide have undergone the transplant as of 2014 (Walters et al., 2015). Management for all other patients is through maintenance and acute care strategies for various complications (Yawn et al., 2014). Even with the current strategies, patients may still experience a lower health-related quality of life, which is largely attributed to the frequent hospitalizations, and the acute and chronic pain associated with SCD (Dampier et al., 2010; Jackson, Lemanek, Clough-Paabo, & Rhodes, 2014). Development of effective treatments to address all SCD-associated complications remains a challenge. To date, hydroxyurea is the FDA-approved drug that modifies SCD pathophysiology and disease progression.

## Hydroxyurea Improves Clinical Course of SCD

HU was identified in 1963 as an antineoplastic drug to treat certain types of cancer (Stearns, Losee, & Bernstein, 1963). It is a ribonucleotide reductase inhibitor that can induce cell death. In 1984 it was documented in two adults with SCD that HU can increase fetal hemoglobin, which is normally only present in red blood cells of fetuses and newborns (Platt et al., 1984). Because the presence of fetal hemoglobin was known to improve the pathophysiology of SCD, HU was tested in a randomized double-blind placebo-controlled clinical trial known as the Multicenter Study of HU (Charache, Terrin, Moore, Dover, Barton, et al., 1995; Charache, Terrin, Moore, Dover, McMahon, et al., 1995). Results from this trial demonstrated that patients with severe SCD taking HU had reduced frequency of vasoocclusive pain episodes, lower occurrence of acute chest syndrome and received fewer blood transfusions compared to the placebo-control group (Charache, Terrin, Moore, Dover, Barton, et al., 1995). HU was then approved by the FDA in 1996 to treat adults with SCD.

Subsequent clinical trials have continued to provide strong evidence that HU is safe and efficacious for reducing specific complications of SCD and improving mortality in children, infants as well as adults with less severe SCD. (Kinney et al., 1999; Thornburg et al., 2012; Hankins et al., 2014; McGann et al., 2012; Steinberg et al., 2010; Voskaridou et al., 2010; Steinberg et al., 2003; Ferster et al., 2001). Recently, an expert panel convened by the National Heart, Blood, Lung and Blood Institute of the National Institutes of Health published evidence-based recommendations for using hydroxyurea to treat SCD. According to panel results, there are now strong recommendations to use HU to treat SCD in adults who have any of the following: a) 3 or more moderate to severe pain crisis during a 12 month period, b) SCD-associated pain or chronic anemia that interferes with daily life or quality of life, c) a history of severe or recurrent acute chest syndrome, or d) increased mortality risk based on biomedical markers of pulmonary dysfunction (Yawn et al., 2014; Klings et al., 2014). Moderate to strong recommendations have been suggested to offer HU therapy for infants 9-months or older, children, and adolescents regardless of clinical severity (Yawn et al., 2014). The recommended use of HU in pediatric patients comes even though the FDA has not yet approved it for children and infants. Regardless, the clinical trials and data over the last 30 years that have provided strong evidence that HU is efficacious and safe for patients with SCD.

## The Problem of HU Underutilization

Despite the supported consensus of providers that HU is efficacious for treating SCD, the utilization of HU has been lower than expected. In 2006 it was reported that as many as 70% of eligible adults did not take HU (Lanzkron, Haywood, Segal, & Dover, 2006). As recent as 2010 up to 85% of eligible patients did not refill and continue HU medication as prescribed (Lanzkron et al., 2010; Lanzkron et al., 2006). Utilization has also been low in children with reports in 2010 citing that only 9% of pediatric providers used HU therapy for 50% or more their patients with SCD, and that 10% of providers had less than 10% of their patients on HU (A. M. Brandow, Jirovec, & Panepinto, 2010). The low utilization rate of HU is problematic because it limits the effectiveness of the drug to reduce the burden of SCD.

Factors that can contribute to low drug utilization include barriers related to both providers' and patients' perspective of HU. Studies have identified some barriers among providers related to lack of patient compliance, fears about side effects, negative attitudes towards HU and lack of knowledge (Brandow & Panepinto, 2010). When 93 adult patients were interviewed about using HU, barriers they cited included: lack of perceived benefits, lack of knowledge, side effects, and HU not being recommended by their provider (Haywood et al., 2011). Parents of patients gave similar responses in focus groups and patient surveys, but also cited additional barriers such as long-term unknown risks of HU, fear of cancer, and lack of FDA-approval (Lebensburger et al., 2013; Oyeku et al., 2013). A cross-sectional study to examine therapy preferences among pediatric SCD patients and their parents reported that perceived efficacy and perceived safety had the strongest association with the decision to initiate therapy (Hankins et al., 2007; Segal et al., 2008). Although these studies have provided some insight into the barriers of HU use, evidence gaps remain in identifying patient barriers and solutions for the initiation and adherence of HU therapy (Savage et al., 2015). New research studies that investigate perceptions of HU across a broad group of SCD stakeholders may aid in addressing knowledge gaps associated with the underutilization of HU.

## Social Media, Facebook, and Public Health Research

Social media is now considered a potential technology tool for public health practice and research studies. Social media can be defined as a group of internet based applications that allow the creation and exchange of user-generated content that is created and made publicly available by end-users (Kaplan & Haenlein, 2010). Social media applications can come in a variety of forms, but social networking sites have gained prominent attention. The applications facilitate the creation of social networks in virtual communities by allowing the users to interact via various forms of communication (Eytan, Benabio, Golla, Parikh, & Stein, 2011). As of 2015, 65% of all American adults were users of at least one social networking site, and 71% of teens accessed more than one (Perrin, 2015; Lenhart, 2015). These platforms are of potential use to public health practitioners because people use social networking sites such as Twitter, YouTube and Facebook for health-related information (Alshaikh, Ramzan, Rawaf, & Majeed, 2014; Antheunis, Tates, & Nieboer, 2013). In fact the number of publications about public health uses for social networking sites have steadily risen since 2009 as more practitioners design interventions and research studies around the online community (Capurro et al., 2014).

Public health practitioners have employed user-generated online content to successfully gauge perceptions and attitudes. One study captured public opinion on financial incentive interventions with user-generated online comments, and found that the online data gave similar results to data collected by systematic review and focus groups. Furthermore, this study also reported that assessing online content had significant advantages such as aggregating large datasets quicker and cheaper than the other methods (Giles & Adams, 2015). Likewise, user-generated content in a cancer study was useful to identify symptom cluster patterns of patients yielding similar results as questionnaires. From that study, the authors concluded that the large amount of data generated from social media sources can augment findings from traditional data sources (Marshall et al., 2015).

Facebook in particular is a site that has demonstrated great potential and utility for public health studies. Created in 2004, it is the most used social networking site worldwide with an average of 1.04 billion daily active users as of December 2015 contributing 516 posts or comments every 60 seconds on the site (Facebook Inc, 2016) Users of Facebook range in age with 34% of Facebook users falling between the ages of 18-29 (Noyes, 2015). Users of Facebook generate profile pages similar to that seen in Figure 2.1. Facebook original messages and comments and photo/video posts are user-generated and can be related to virtually any topic. Within the Facebook platform, users can form virtual communities with others who share common interests, and there, they can create and collect posts specific to their group (Facebook, 2016).

Sickle Cell Warrior
April 2 at 4:20pm

Katherine says, "Hi warriors just wondering if anyone here has had a steroid injection in their hip and how it affected you? I had one a few days ago and now my knee keeps painfully swelling up and the going back down."

FB USER 1 I have had two 💉 without any problems but the injections didn't work.
Like · Reply · 1 · April 2 at 4:27pm

FB USER 2 I've had 2 with no issues. You should definitely call your doctor. You may be having a reaction.
Like · Reply · 1 · April 2 at 5:30pm

FB User 3 I should've got this shot when they originally asked me to get one but I was feeling better by the time they offered. I'll be sure to keep in mind your reaction to it before I get one should I get offered again.
Like · Reply · 1 · April 2 at 5:35pm

FB USER 4 For those that have had them, was it your hemo doc recommending this or PCP?
Like · Reply · April 2 at 5:52pm · Edited

**Figure 2.1- Elements of a typical Facebook page**

According to systematic reviews and meta-analysis examining the use of social networking sites in public health, Facebook was most often used in the social media based studies (Gold et al., 2011; Laranjo et al., 2015). One Facebook specific study examined the relationship between user-generated textual content and emotional well-being. It found that individual emotional well-being can be captured through Facebook profiles (Settanni & Marengo, 2015). Other studies have used Facebook to examine communication of health information and priorities among various populations. For example, analysis of Facebook data identified that the most common objectives of groups related to hypertension was to increase awareness (Al Mamun, Ibrahim, & Turin, 2015). In contrast, a study of breast cancer Facebook groups showed that Facebook was used largely for support-seeking behavior in addition to increasing awareness (Bender, Jimenez-Marroquin, & Jadad, 2011). These studies suggest that Facebook may be a feasible and valid resource for understanding public health concerns and investigating research questions. To date no studies have attempted to use Facebook for SCD studies.

## Harnessing the Power of Facebook for Sickle Cell Research

Sickle Cell Disease is a subject area that is well-suited for using Facebook data to answer important research questions about perceptions of HU. Only one study, to our knowledge, has attempted to use social media in collection of data or research studies related to the SCD community. This study used the social media site Photovoice to gain insight into the perspectives of children with SCD using a qualitative analysis approach. In that study, 12 participants were recruited to capture and post photographs of their camp experience and then interviewed. The combination of photos and interviews enabled the authors to find prevailing themes among the participants, which included the importance of friends, controlling symptoms of SCD and the importance of camp (Stegenga & Burks, 2013). No studies have employed Facebook for SCD health-related studies.

The SCD population has characteristics similar to other disease populations, which are suitable for Facebook-based health studies. Commonalities include SCD being a rare chronic disease in some geographic regions, and its population being classified as hard to reach. Because the prevalence of SCD is unevenly distributed around the globe, it may be considered a rare disease in certain regions (Piel et al., 2010). It is in the United States who classify rare diseases as those affecting 200,000 people or fewer people (https://rarediseases.info.nih.gov/about-gard/pages/31/frequently-asked-questions). A Pew Study found that approximately 1/3 of people surveyed with a rare, chronic condition have gone online to seek out others with the same condition. Additionally, they use online connections to supplement professional medical advice (Fox, 2011). It is also reported that 52% of patients who use social media for health-related reasons primarily use Facebook for social support and exchanging advice (Antheunis et al., 2013). These studies support the idea that individuals with SCD likely use social networking sites to seek health-related support.

The SCD population may also be considered a hard-to-reach group due to stigmatization. Studies have documented negative stigmas associated with SCD in academic, medical, community, and family settings that can negatively affect quality of life and health (Adeyemo, Ojewunmi, Diaku-Akinwumi, Ayinde, & Akanmu, 2015; Wesley, Zhao, Carroll, & Porter, 2015). Specific stigmas associated with sickle cell include racial stigmas, drug-seeking behavior and addiction, delayed sexual maturation, and socioeconomic stigmas (Bediako & Moffitt, 2011; Aisiku et al., 2009; Jenerette & Brewer, 2010; Shapiro, Benjamin, Payne, & Heidrich, 1997). For stigmatizing diseases such as HIV, Facebook was used for recruiting participants and investigating research questions pertaining to discussion content, sexual behaviors, and feasibility of social media-based interventions (Gaysynsky, Romansky-Poulin, & Arpadi, 2015; Menacho, Galea, & Young, 2015; Syred, Naidoo, Woodhall, & Baraitser, 2014; Young et al., 2015; Young, Szekeres, & Coates, 2013). The demonstrated success of using Facebook for certain populations, which share commonalities with the SCD population, suggests that Facebook could be used successfully for SCD research as well.

In essence, the popularity of social media combined with the demonstrated success of using social networking sites for research projects suggest that it could be used for studies in SCD. Facebook in particular could be a research new tool for SCD studies to capture information from a large and broad sample of SCD stakeholders. Therefore, it is reasonable to postulate that data obtained from Facebook may be useful in assessing perceptions of HU among SCD stakeholders and provide information that will aid in better understanding HU underutilization. In order to efficiently capture and analyze the most pertinent data for this purpose, theoretical framework integrating concepts of human health behavior is advantageous.

## Concepts and Models of Health Behavior

Health behavior can be broadly defined as actions and habits of individuals, groups, and organizations that relate to health maintenance, health restoration, or health improvement (adapted from (Glanz, 2008)). Practical and theoretical models based in psychosocial theories are postulated to guide the understanding of factors that influence health behavior. In the context of understanding the initiation and adherence to medications such as HU, three models may be particularly applicable in explaining health behavior influences. These models are 1) shared-decision making care model, 2) social support provisions and 3) health belief model.

The Shared Decision Making (SDM) model is strongly encouraged in clinical care practices. The model advocates that both provider and patient actively participate in making decisions about health care options by taking a collaborative approach. Charles et al. (1997) originally defined SDM according to the following minimum characteristics distinct from other models: 1) involves at least two participants- the provider and the patient, 2) both parties take steps in the process of treatment decision making, 3) information sharing as a prerequisite to SDM, and 4) a treatment decision is made and both parties agree (Charles, Gafni, & Whelan, 1997). During the decision making and information sharing process, essential elements of the discussion include clear explanation of the problem, presentation of available options, recommendation from the provider followed by open-dialog about treatment pros and cons, patient preferences and their ability to comply (Makoul & Clayman, 2006). A pragmatic definition that is used as a general model summarizes the SDM in 3 steps: 1) let patient know that there are options, 2) provide more details about available options, and 3) understand patient preferences and help them to move towards a decision (Elwyn et al., 2012). Overall, the goal of SDM is the effective exchange of information between the two parties, which is believed to result in the best possible decisions and care for the patient (Frosch et al., 2011).

The second model, social support, can facilitate health decisions and behavior. Concepts of social support deal with interpersonal interactions that may influence health behavior. While some describe social support as a theory, others have contended that social support is a provision or group of concepts that describe the structure, processes, and function of social relationships (Glanz, 2008). Social support exists in different forms and can be broadly categorized into the 4 different types of supportive behavior: emotional, informational, instrumental, and appraisal (Table 2.1). Each type of support contributes uniquely to interactions within a social network. Therefore, individuals may rely on an entire social network or specific entities of a network at different times. Two prevailing hypothesis of social support contend that it helps people deal with bad and stressful events and that a high degree of social support results in better health (Cohen & Wills, 1985) (Glanz, 2008). (Glanz, 2008; Thoits, 1995). Thus, social support coming from social networks of an individual can be influential in health behavior and outcomes.

**Table 2.1- Description of different types of social support (adapted from Glanz, 2008)**

| Type of Social Support | Description |
|---|---|
| Emotional | Expressions of empathy, love, trust and caring |
| Informational | Advice, suggestions, and information to address a problem |
| Instrumental | Tangible aid/services to directly assist |
| Appraisal | Constructive feedback and affirmation useful for self-evaluation |

The third model that can describe health behavior is the Health Belief Model. This model is a widely studied and applied theoretical model used to describe individual health behaviors. The model argues that personal attributes including beliefs, expectations, motives, values and perception influence one’s health behavior, and these are largely driven by a few different constructs (Glanz, 2008). The primary constructs of the health belief model include: Perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, and perceived self-efficacy. Each of these constructs are briefly defined in Table 2.2. The constructs, grounded in perception, emphasize that behavior is reflective of personal thoughts and not solely on evidence-based facts.

**Table 2.2- Constructs of the Health Belief Model (adapted from Glanz, 2008)**

| Construct | Definition |
|---|---|
| Perceived benefits | Belief in the efficacy of the advised action to reduce risk |
| Perceived barriers | Belief about the costs of the advised action (adverse outcomes) |
| Perceived susceptibility | Belief about chances of experiencing a risk or getting a condition |
| Perceived severity | Belief about how serious a condition and its sequelae are |
| Self-efficacy | Confidence in one’s ability to take action |
| Cues to Action | Strategies to activate “readiness” |

## Health Behavior Concepts Applied to SCD and HU

The three aforementioned models postulate that clinical care practices, interpersonal relationships and personal beliefs may each influence health behavior related to initiating therapies. As separate models, SDM, health belief, and social support have all been shown to play a role in driving health decisions and outcomes associated with SCD. Since the inclusion of the SDM model in the Patient Protection and Affordable Care Act, a SDM model specific to HU therapy for SCD has been suggested for pediatric physicians and families (Frosch et al., 2011). It involves the following six steps: 1) have a joint meeting with all persons involved in the decision to initiate HU (family and trusted advisors), 2) provide them with education and trusted websites about SCD-specific HU information, 3) address safety concerns, 4) mention HU a possible preventive treatment as early as possible with the goal of offering the treatment as early as 9 months of age, 5) plan multiple follow-up conversations about HU, and 6) develop a HU treatment protocol that includes management strategies and methods for promoting HU adherence (Crosby, Shook, Ware, & Brinkman, 2014). As the model is implemented, the relationship between the patient and provider is critically important, for it has been demonstrated that lack of trust or the perception of discrimination by the patient is associated with non-adherence to medical recommendations (C. Haywood, Jr. et al., 2014). Similar SDM models will likely be adapted in compliance with new policies and best practice procedures and could improve HU utilization.

In regards to decisions of patients and caregivers, studies have shown that they are based on personal perceptions described by constructs of the Health Belief Model. As mentioned previously, perceived efficacy and perceived barriers such as safety and side effects of HU impact HU utilization (J. Hankins et al., 2007; Lebensburger et al., 2013; Segal JB et al., 2008). Perceived severity and susceptibility can also influence the decision to initiate HU. A qualitative study that found that caregivers of pediatric SCD patients were more likely to initiate HU when they perceived their child as having a severe form of SCD (Creary, Zickmund, Ross, Krishnamurti, & Bogen, 2015). Similarly, a reason cited for not taking HU such as not sufficiently symptomatic is consistent with lack of perceived susceptibility (Oyeku et al., 2013). Hence, the reported perceptions of

HU safety and efficacy, and perceived SCD severity and susceptibility serve as clear examples of how perceptions influence health behavior.

The impact of social support is evident in healthcare outcomes and plays an important role in the decision to follow medical recommendations. A study by Derlega et al (2014) showed that emotional social support heavily influenced the decision to initiate disease-related therapy and overall health among sickle cell adult patients. They found that talking to parents and god about pain episodes was significantly associated with better coping or psychological adjustments. Further, talking with siblings, intimate partners or close friends as well as primary medical providers was positively associated with the patients' willingness go to receive care for pain (Derlega et al., 2014). These studies suggest that informational and emotional support can directly impact Health behavior in SCD.

Overall, when elements of shared-decision making, social support provisions, and health belief model are combined and applied to health behavior decisions regarding HU utilization, the integrated conceptual framework can be diagramed as shown in Figure 2.1. Many times the initial question of whether HU therapy should be initiated may be raised in the context of a SDM model in which providers and sickle cell patients/caregivers (ovals) collaborate in order to make the best decision. The patients and caregivers formulate opinions and attitudes towards HU based on Health Belief Model constructs and influenced by social support (diamonds). They may specifically seek out emotional and informational support, which they use to develop perceptions about efficacy and barriers of HU in relationship to their disease severity. The interplay between social support and health beliefs will heavily influence the overall valance and opinions of HU. The patients and caregivers will then make decisions regarding HU, which will likely affect health outcomes (rectangles). The understanding of valance and opinions among patients and caregivers is a goal for addressing the evidence gaps related to HU underutilization and therefore is highlighted in yellow.

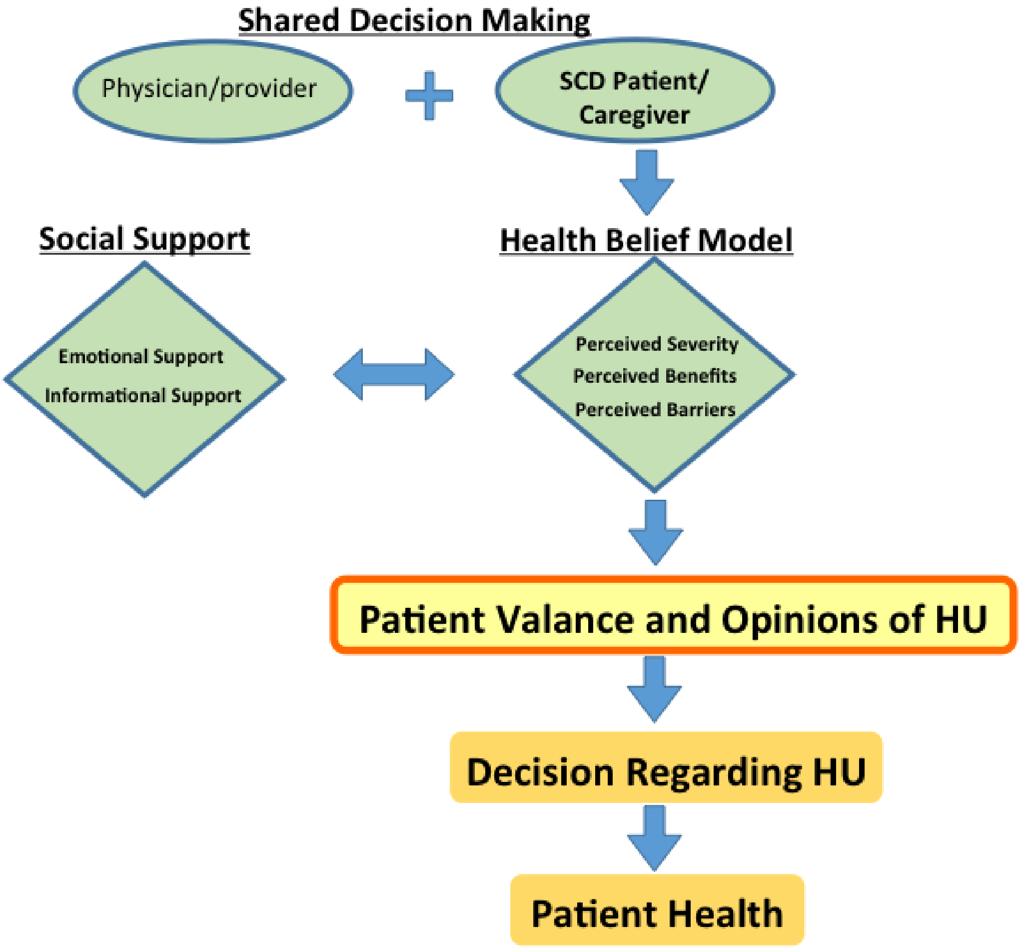

**Figure 2.2- Integrated Theoretical Framework for Decisions Regarding HU**

This integrated theoretical framework can be used to inform research questions and study design when adapting emergent research tools such as a social media platform. User-generated content of social networking sites such as Facebook can be collected with a specific focus on perceptions, valance, and opinions of HU within the context of the postulated framework. This type of study design presents an opportunity to investigate the underutilization of HU using data sources with an inherently wide reach across the SCD population. Although it will be a new approach, study principles and design are based on 3 previously substantiated theoretical models. Therefore, a social media study grounded in the integrated framework can provide novel insight about HU utilization.

## Summary of Current Problem

In summary, studies presented in this Review of Literature describe the problem of HU underutilization for managing the burden of sickle cell disease. Findings of small- to mid-sized studies using focus groups, surveys and questionnaires have provided evidence that concepts of Shared Decision Making, social support, and Health Belief Models can help explain health behavior related therapy decisions. However, there is still a gap in knowledge concerning additional factors that influence patients' and caregivers' decision to initiate or continue HU.  By collecting user-generated data from Facebook social networking site and analyzing it within the context of an integrated theoretical framework, it may be possible to assess perceptions of HU among SCD stakeholders in a large dataset. Therefore, this study will test the hypothesis that qualitative content analysis of user-generated data from Facebook can provide insight about perceptions of HU among SCD stakeholders.

This thesis project will address the gap in knowledge by assessing the perceptions of HU among SCD stakeholders in a large virtual community. It will provide information needed to better understand factors associated with the underutilization of HU. This study will also build upon existing body of knowledge as the first study to employ large-scale, user-generated data to examine perceptions within the sickle cell community. Specifically, this study will a) demonstrate how user-generated content on Facebook can be used to assess perceptions about HU, b) highlight the social support that SCD stakeholders receive on Facebook, and c) report specific perceptions of HU that may influence individuals' decisions regarding HU.

# CHAPTER THREE: METHODOLOGY

## Research Design

The research design of this project addressed the hypothesis that qualitative content analysis of user-generated data from Facebook can provide insight about perceptions of HU among SCD stakeholders. The Institutional Review Board of University of Pittsburgh reviewed the study design and determined that the project met criteria to categorize the study as exempt. Using a two-step approach, content analysis of original messages in the *Sickle Cell Unite* Facebook group posted over a 22-month period first identified specific cases for inclusion in a purposeful sample of posts. Second, we conducted an in-depth qualitative content analysis of comments posted in response to the selected original message posts. Codebooks developed to specifically investigate elements of social support and Health Belief Models and valance and opinions matched concepts presented in tine integrated theoretical framework outlined in Chapter 2 (Figure 2.1). Identifying major themes associated with valance and opinion of HU was the primary goal. Data analysis based on pragmatic qualitative inquiry, provided pratical information useful for addressing issues related to HU utilization.

## Data Source and Datasets

The data source for this project was user-generated messages and comments made within the *Sickle Cell Unite* Facebook group (will be referred to as *Unite*). *Unite* is a Facebook group created in 2009 that is dedicated to offering a place where people living with sickle cell can unite and find support, love and education on sickle cell anemia (Sickle Cell Unite Facebook Page https://www.facebook.com/groups/527861263907134/). As of June 27, 2016, there were over 9,239 members of Unite (https://www.facebook.com/groups/527861263907134/). This particular group is a closed-group on Facebook, which means that only members approved by the account administrator can read and contribute to the content of the group. After personal correspondence, Ms. Kee'Doria Coleman, the founder and administrator of *Unite,* granted us access to the group for the study. We extracted *Unite* Facebook posts dated from January 1, 2014 to November 11, 2015 Data from the web using publically available Facebook API software to create datasets specific for the study.

The initial dataset collected included all different types of posts (i.e. pictures, links, videos, and text) along with corresponding classifying information. Datasets used for subsequent analysis contained specific textual posts selected according to inclusion and exclusion criteria as diagrammed in Figure 3.1. An initial query restricted the data set to all posts containing the following terms in the message content, description, or story: "Hydrea," "Droxia," "Hydroxycarbamide," "Hydroxyurea," "Hydroxurea," "Hydroxy," "HU," "Urea." This preliminary dataset contained 432 original message posts and 11,634 associated-comment posts.

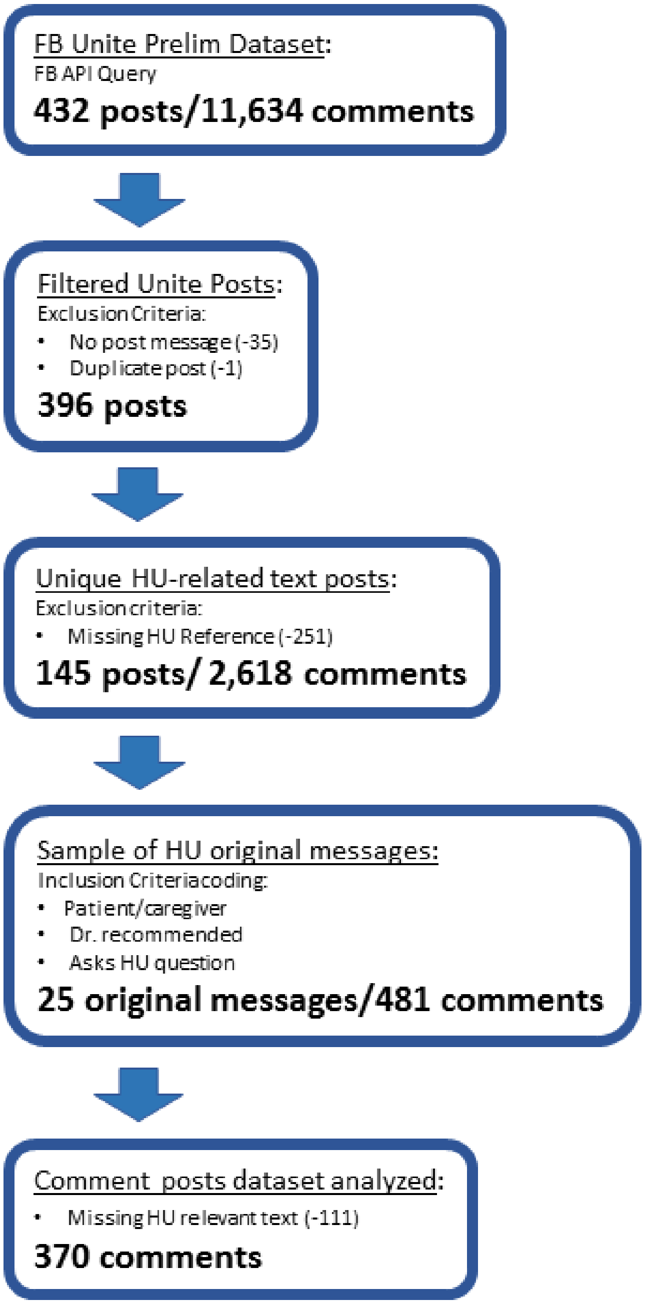

**Figure 3.1- Creation of Unite Facebook datasets**

Next, filtration of the dataset excluded any posts that were not text-based (i.e. pictures, videos, and links), and one duplicate entry that had text in the message, post ID and user ID identical to another post. We then imported the filtered dataset (396 Unite original posts) into NVivo 11 qualitative analysis software (QSR International). A search query with in the program resulted in the creation of the Unique HU-related text posts dataset. The search terms were: “HU,” “hydroxyurea,” “droxia,” “hydrea,” and “hydro*.” After the query, a manual review of all original message posts confirmed the presence of at least one HU reference within each message. This eliminated an additional 215 posts that may have contained a HU term in the post description, story, or elsewhere, but did not have an HU term in the actual message. The final Unique HU-related text posts dataset included 145 total original message posts and 2,618 associated comment posts.

## Coding of Original Message Text for Purposeful Sampling

Content analysis of the original message posts in the unique HU-related text posts produced a purposeful sample of posts. During initial review of the original messages, we noted the type of information given in the posts and created a code book of inductive codes. It was evident that many posts posed questions about HU rather than stated opinions or perceptions. Based on the integrated theoretical framework presented in Chapter 2 (Figure 2.2), inductive codes that were developed identified the following information:  the apparent stakeholder role of the post author, the context in which HU was discussed, types of topics addressed by posts asking questions, and whether the post author had been given a provider recommendation to take HU. Code description and subcodes for each inductive code are outlined in Table 3.1.

**Table 3.1- Codes for analysis of original message posts**

| INDUCTIVE CODES | | |
|---|---|---|
| **CODE DEFINITION** | **SUBCODES** | **CODE DESCRIPTION** |
| **Stakeholder:** What role or relationship does the message author have to SCD | | |
| | Patient | The author has sickle cell |
| | Parent | The author has their son or daughter with sickle cell |
| | Other Family Member | The author has a family member with sickle cell |
| | Other | The author is not related to anyone with SCD (i.e. friend or advocate) |
| **HU Discussion:** How is HU being discussed in the original message post | | |
| | HU Question | One or more questions related to HU is posed |
| | HU Opinion statement | No questions but an opinion of HU is expressed |
| | List with HU | HU is included in a list of medications/treatments |
| | HU Facts | Facts or awareness of HU are given |
| **Topic of HU Question:** What is the topic of the question that is posed by the message author | | |
| | Who | Asks who takes HU |
| | Pros/Cons | Asks for the good and bad information about HU |
| | Efficacy | Asks if HU works for SCD patients |
| | Side effects | Asks about side effects of HU |
| | Opinion | Asks for people’s thoughts or opinion about HU |
| | Experience | Asks about people’s experiences with HU |
| | Advice | Asks for advice regarding HU |
| | Facts | Asks for facts or evidence based knowledge of HU |
| | Acquire | Asks where or how to acquire HU |
| **Doctor Recommended:** Does the author like or dislike using HU for themselves or their children? | | |
| | Recommended | Expressed joy for using drug |
| | Discouraged | Expressed disdain for HU and will not use personally |

After coding all 145 original message posts manually in a Microsoft Excel spreadsheet, we enumerated the codes and derived descriptive statistics using NVivo 11 software. Because the Unique HU-related text posts dataset was comprised mostly of original messages asking user-generated questions we decided to analyze comment posts in order to garner a richer dataset for examining opinions and perceptions of HU. Therefore, the coding of the original messages in the Unique-HU related text posts dataset provided the basis for generating a purposeful sample of comment posts.

## Selection of Comment Posts for Analysis

Inductive codes (Table 3.1) assigned to the Unique-HU related text posts assisted in creating the Sample of HU original messages dataset. This dataset included only original message posts that met the all three of the following criteria: 1) posted by a patient or parent of a patient with SCD, 2) contained specific text indicating that HU was recommended by a doctor, and 3) asked at least one HU-specific question. The first two inclusion criteria helped to gain a defined set of posts made by individuals who may be considering HU therapy as part of the shared decision making process. The third criteria to include only the posts that ask HU questions helped to narrow down the dataset to posts that could solicit the support and opinions of other stakeholders. In total, the Sample of HU original messages included 25 original message posts and 481 associated-comment posts (Figure 3.1). Analysis of this final dataset of comments yielded information for examining perceptions of HU.

## Latent Content Coding of Comment Posts

After organizing the comments into 481 rows of an Excel spreadsheet (one row per comment), each comment post received a case number. Classifying information organized into columns of the spreadsheet provided the following information: text content of original message post, User ID for original massage post, and User ID for comment Post. We placed the comments that were written in response to the same original message in consecutive rows, and grouped them into a single discussion thread. After verifying the accuracy of the spreadsheet, it was imported into NVivo 11 program for coding and analysis.

We coded the comments according to a deductive codebook created based on previously identified barriers of HU use and some inductive codes identified during initial review of the comments. The most salient deductive code categories planned apriori included: perceived/experienced efficacy, perceived/experienced side-effects, role of stakeholder, HU use status, and general valance of HU. The following inductive code categories were added to the codebook: asking of symptoms, cancer drug, and personal opinion of HU. A brief description these codes are listed in Table 3.2. The initial review also led to the elimination of 111 comments because the text content did not contain HU-relevant information that could be coded. A single coder coded a total of 370 comments according to latent content. As a reliability check, the coder, double-checked all references to make sure that they each reflected the intent of the code category. At that time, the coder also created specific subcodes for some categories including side effects. The coding of comments led to the identification of major themes within the user-generated data.

**Table 3.2- Codes for analysis of comment posts**

| DEDUCTIVE CODES | | |
|---|---|---|
| **CODE DEFINITION** | **SUBCODES** | **CODE DESCRIPTION** |
| **Efficacy:** Does the comment author think that HU works for changing complications of SCD | | |
| | Improves | HU works for improving complications |
| | Worsens | HU makes complications worse |
| | No Change | HU neither improved or worsened complications of SCD |
| **Side Effects:** Does comment author report side effects of HU? | | |
| | No side effects | Explicit statement of no side effects |
| | Perceived side effects | Cites one or more side effects of HU |
| **General Valance:** Would the author recommend or support the use of HU by others? | | |
| | Supportive | Comment indicates that author would recommend or approve of others trying/using HU |
| | Non-Supportive | Comment indicates author would not recommend or advise others against the use of HU |
| | Neutral | Comment indicates an indifference towards other using HU and does not make any recommendations |
| **Stakeholder:** What role or relationship does the comment author have to SCD | | |
| | Patient | The author has sickle cell |
| | Parent | The author has their son or daughter with sickle cell |
| | Other Family Member | The author has a family member with sickle cell |
| **HU User Status:** Does the patient that is referred to in the comment take/use HU to treat their SCD | | |
| | Current User | Patient or child currently uses HU |
| | Non-user | Patient or child has never taken HU |
| | Former User | Patient or child used HU in the past but no longer takes the drug |
| INDUCTIVE CODES | | |
| **Personal Opinion:** Does the author like or dislike using HU for themselves or their children? | | |
| | Like | Expressed joy for using drug |
| | Dislike | Expressed disdain for HU and will not use personally |
| | Neutral | Expressed neither joy nor disdain for taking the drug |
| **Original Author Response:** What resolution does the author of the original message report in comment post | | |
| | Will try HU | Original message author will use/try HU as a result of other comments |
| | Will not try HU | Original message author will not try/use HU as a result of other comments |
| | Still under consideration | Original message author will continue to think about whether to try/use HU |
| **Specific Side Effects:** What specific side effects of HU does the comment author mention | | |
| | 17 different subcodes | List of specific side effects extracted from comments coded for “perceived side effects” |
| **Masking of Symptoms:** The author explains how HU has “masked symptoms/complications of SCD” | | |
| | No subcodes | |
| **Cancer Drug:** The comment author states that HU is a cancer drug or used to treat cancer | | |
| | No subcodes | |

## Identification of Major Themes in the User-generated Data

Exploratory analysis of the coded comments within the NVivo software generated quantitative descriptive data according to code frequency, and aided in identifying prevalent themes among the comment posts. Using the chart function, we created tables with the number comments coded for each subcode. This function also grouped similarly coded comments together for review and facilitated the development of categories and themes. Word frequency analysis function identified terms that were written most frequently used in reference to HU efficacy. Matrix analyses with in NVivo cross-tabulated at least two different codes according to the subcodes and grouped together double-coded comments containing demographic information (i.e. stakeholder or HU status) and valance or personal opinions.

After preliminary exploratory analysis yielded some descriptive data, salient themes identified in the context of a pragmatic qualitative inquiry focused the findings on practical consequences and useful applications of the themes and data discovered. For this research study useful applications of the data included: 1) gauging the level of support SCD stakeholders have for HU in relationship to their perceptions, 2) determining if previously identified perceptions of efficacy and side-effects were reflected in this study design and population, and 3) describing new or emergent themes that have not previously been reported.

# CHAPTER FOUR: RESULTS

## Overview

This chapter reports the results of the study. Qualitative analysis of Facebook posts revealed major themes related to perceptions of HU among SCD stakeholders. The user-generated posts were indicative of the social support network that the *Unite* Facebook group offers. Overall, analysis of original message posts revealed HU-related questions that are discussed among stakeholders, and analysis of the comment posts yielded answers to stakeholder questions with perceptions of HU embedded within the responses.

## Description of Post Characteristics

Analysis of original message posts identified key demographics of stakeholders. Of the 145 HU-related original message posts, 72% contained text to reveal the role of the stakeholder. Authors of the posts self-identified as patients, parents, or other family members in 41%, 26% and 4% of the posts respectively. When examining the message content, 55% of the original messages posed questions related to HU. The remaining posts included references to HU in the context of stating opinions, as part of a medication list, or in mentioning facts about the drug. The topics addressed in the HU question posts were concerning HU-specific side effects, opinions, experiences, efficacy, advice, pros and cons, facts and acquiring HU (Figure 4.1). Some posts posed multiple questions and, therefore, were included in multiple categories. The four most frequent question topics referred to side effects, opinions, experiences, and efficacy. In response to those original posts stakeholders posted a median of 15 to 23 comments per message and greater than 190 comments for each topic (Figure 4.2). Taken together, original message posts provided user-generated content to identify stakeholders, and uncovered post characteristics consisting largely of questions and responses.

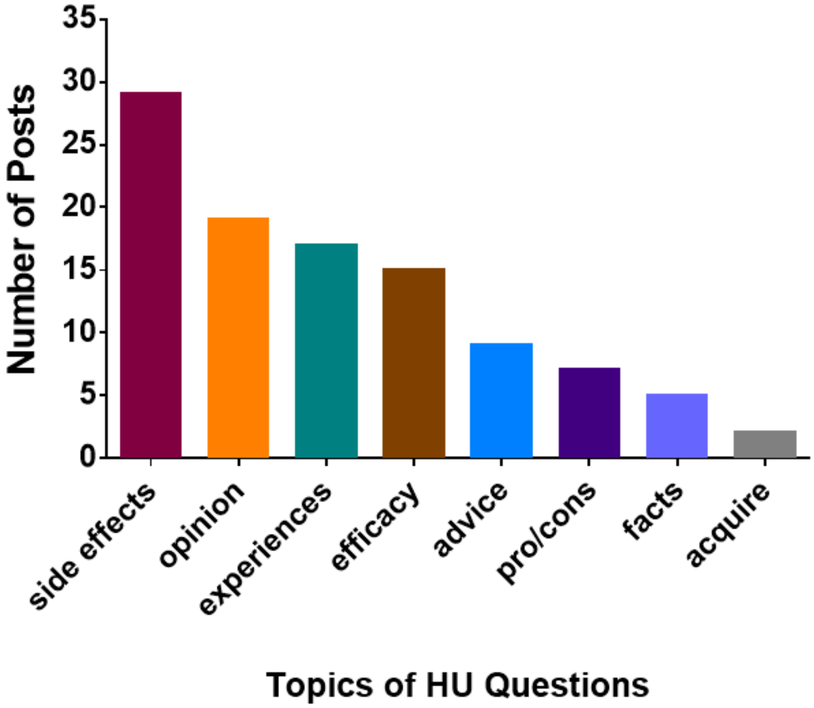

**Figure 4.1- Topics addressed in HU-related question original message posts**

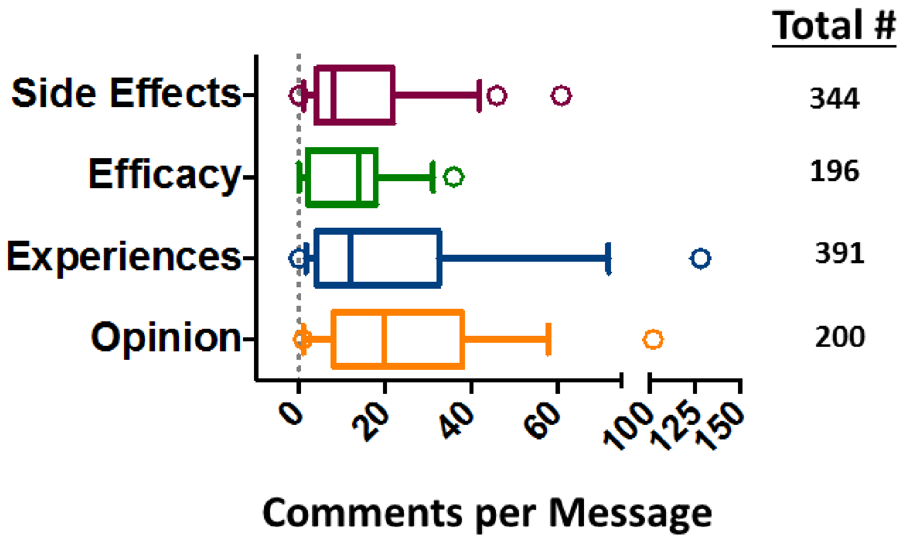

**Figure 4.2- Comments associated with HU-related question original message posts-** Box plot displays median number of comments for each discussion topic along with the 10th and 90th percentile (whiskers) and outliers from the percentile (circles). The total number of comments associated with the discussion topic is indicated to the right of the graph**.**

### Comment posts yielded data for assessing social support and perceptions of HU

After selecting the comments dataset, we coded and analyzed 370 comments that were made in response to questions posted by patients or parents of patients with SCD. Social support was a prevalent theme. Within the 25 different discussion threads analyzed, 17 or approximately 72% included one or more comment posts in which the author of the original message expressed gratitude for the feedback. Of particular interest were comments in which stakeholders gained resolution to their questions or concerns about HU. For example, one stakeholder posted:

> *"So my doctor put me on Hydroxyurea.....what's yall input?"*

Among the 37 associated comment posts made by 21 different stakeholders, the author of the original message post indicated that the decision to start HU was made, writing:

> *"Thanks everyone.......yall have help me a lot! I'm going to try it......wish me luck!"*

Others examples included original posts made by stakeholders seeking affirmation of their decision. One discussion thread that generated 15 comments was initiated when a parent wrote:

> *"So the husband and I have decided that we want to try Hydroxyurea for our son . . . Any other parents have children that take Hydroxyurea? What are your thoughts about it?"*

This discussion ended with that parent feeling reassured that he/she made a good decision writing:

> *"Thank you everyone for sharing your experiences with Hydroxyurea. As a parent you always want to do what's best for your child/children and I feel confident in my decision."*

Among ten discussion threads in which the author of the original post expressed a resolution, five ended with affirmation of taking HU and none ended with a stance against HU. Instead, there were five threads that ended with the author of the original message still trying to decide. These results provided clear examples of the social support gained by being a part of the *Unite* Facebook group and demonstrated that information support related to HU can potentially influence stakeholders' decisions.

## Valence of HU Ranges among Stakeholders

Analysis of the comment posts revealed important themes related to the general valence or the level of support for HU among SCD stakeholders and their personal opinions. Out of 360 comments, 163 (45%) were coded into the general valance category and 141 (39%) were coded into the personal opinion category. Table 4.1 displays the number of comments for each subcode with the corresponding proportion.

**Table 4.1- Number of comments expressing valance and opinion of HU**

| | # Comments | % |
|---|---|---|
| **General Valance** | | |
| **Supportive** | 57 | 35 |
| **Neutral** | 75 | 46 |
| **Non-supportive** | 31 | 19 |
| **Personal Opinion** | | |
| **Like** | 83 | 59 |
| **Neutral** | 18 | 13 |
| **Dislike** | 40 | 28 |

Among the 57 supportive comments there was evidence of enthusiastic support for HU. Stakeholders wrote persuasive comments emphasizing how great HU is. For examples:

> *“ . . . initially my husband and I were hesitant about him being on this drug . . . Simply put it is one of the best decisions we have made for his care. Try it before doubting its impact and potential benefit for your child.”*

> *“Best thing your doctor could have done for you”*

Other supportive comments were written without obvious enthusiasm for its potential. These were comments with statements similar to:

> *“Try it out if it doesn't help don't take it anymore.”*

On the other end of the spectrum, there were a minority of non-supportive posts that represented a strong stance against HU. Stakeholders wrote comments such as:

> *“Ask the doc if there are other options....“*

> *“Do not I repeat DONT LET THEM PUT YOUR BOYS ON HYDREA PLEASE PLEASE PLEASE DON'T LET THIS HAPPEN. . .”*

A large proportion (46%) of valance-coded comments were in the middle of being supportive and non-supportive of HU. Coded as neutral valance towards HU, these comments reflected the position that HU can be good or bad, and did not offer a suggestion. The stakeholders mentioned the use of prayer or research to make the decision that is best for the patient and family writing:

> *“. . . Pray on it, my friend and do what is best for you.”*

> *“ . . . Everyone is different, but research gives you power to choose,”*

The diversity in excerpts of comment posts related to HU valance exemplify the range of support that SCD stakeholders expressed for HU.

When examining personal opinions of HU that were presumably formed from patient experiences, 59% of stakeholders seemed to like the drug whereas only 28% expressed a dislike (Table 4.1). Interestingly, the like or dislike for HU did not always match one's valance. Notable examples in which the author of the comment stopped taking HU but was supportive of others taking it included:

> *"Maybe it'll work for you, but I won't take it anymore"*
>
> *"I took it for 2yrs straight and I saw a difference. . . . Then I stopped taking them on my own . . . everybody is different. Try it out if it doesn't help don't take it anymore."*

When taken together, these findings, obtained from user-generated Facebook data, captured a range of support and opinions related to HU among SCD stakeholders.

## Expectations and Perceived Efficacy of HU

We analyzed the user-generated content to identify perceptions of HU efficacy. Comments that were coded and analyzed according to known efficacious outcomes of HU exposed stakeholders' expectations and perceptions of HU efficacy. People who posted HU-related questions in original message posts often made comment posts explaining their expectations of HU. Expectations that were noted in the posts included improving overall quality of life or decreasing specific complications. The following are a few examples:

> *" . . . He had splenic sequestration twice this year resulting in him having to get transfusions. I hope this drug does improve his quality of life."*
>
> *"I would love to go 6 years without a crisis hey give me 6 months I'll be happy! I hoping I'll have a great outcome . . ."*
>
> *"She got it because they are trying to prevent stroke"*

Similar expectations were also found among comment posts from other stakeholders as they discussed the perceived or experienced efficacy of HU.

In total, 38% of all comment posts contained at least one reference to HU efficacy, and the references totaled 182 throughout the coded dataset. References to improving complications and conditions of SCD accounted for 71% of efficacy references, while no change and worsening of conditions accounted for 18% and 9%, respectively. A word frequency analysis, verified by manual coding, revealed that hospitalizations, crisis, blood, counts, hemoglobin, transfusions, energy, and pain were the most cited complications in reference to HU improving SCD. The perceived efficacy of HU was also mentioned in associated with a better quality of life in some comments. Users posted comments to indicate that an improved quality of life is a good reason for taking HU:

> "*You will still have a crisis but not as many. Your purpose with this setback known as sickle cell is to have a quality of life that you can deal with. A life that can let you live a normal life. Please try it. .* "

In a couple of comments the improved quality of life extended to caregivers as well. For example, one user posted the following:

> *"No pain crisis since sept before he started the med.. Thank god!!! I just started back to work after being home for a year and a half with him."*

Only 17 references eluded to HU worsening conditions of SCD. These were the minority of HU efficacy references, but they denote an alternative perspective of the drug efficacy.

Taken together the comment posts showed that HU is perceived as efficacious by many stakeholders as they discussed expectations and experiences of improved rate of hospitalizations, crises, and quality of life. However, this user-generated data also included alternative perceptions which was described as worsening SCD complications.

### Perceived Side Effects of HU

Perceived and experienced side effects were previously identified as barriers to taking HU (C. Haywood et al., 2011; Lebensburger et al., 2013; Oyeku et al., 2013). We examined perceived side effects being discussed in the Facebook posts. Coding of comments according to perceived side effects yielded 113 references to specific side effects, and 59 references that explicitly stated that HU did not cause any side effects. Types of specific side effects that stakeholders commented on are listed in Table 4.2 along with the number of references coded for each.

**Table 4.2- Perceived or experienced side effects stated in Facebook comments**

| Side Effect Stated | Number of References |
|---|---|
| **Hair Loss** | 27 |
| **Gastro-intestinal issues** | 13 |
| **Skin and Nail issues** | 11 |
| **Fatigue** | 7 |
| **Bone Marrow Suppression** | 5 |
| **Cancer** | 5 |
| **Ulcers** | 4 |
| **Increase Appetite** | 4 |
| **Fertility (Sterility)** | 4 |
| **Hyper behavior** | 3 |
| **Kidney Function and changes in Urine** | 2 |
| **Poisonous for body** | 2 |
| **Increased sweating** | 1 |
| **Tremors** | 1 |
| **SCD minor crisis** | 1 |
| **Loss of sensation in legs** | 1 |
| **Decreased sex drive** | 1 |
| **Total** | **92** |

The most commonly cited side effect of HU among the SCD stakeholders was hair loss. This finding was of particular interest given that hair loss as a side effect of HU is not widely recognized in medical and scientific peer-reviewed literature related to SCD treatment (Administration, 2016; Brawley et al., 2008). Yet, in 29% of comments that addressed side effects, patients discussed the loss or thinning of hair. Unfortunately, this side effect was mentioned as a deterrent of trying HU. One mother wrote:

*"...she doesn't want to take it because of the hair loss side effect she has short hair already and often gotten teased about that from kids in her past school...so I'm really going to have to do some thinking about this medicine"*

Stakeholders also wrote about other side effects, especially GI issues and low blood counts, and indicated that they were reasons for discontinuing HU therapy. Accordingly, some comments discussing the side effects also contained statements referring to a dislike of HU. It was written:

> "*It brought my HBG* [hemoglobin] *up but I was in the hospital more. I hated the side effects too. I lost my hair, it messed up my GI track so now I have acid reflux and have a hard time eating. I was always nauseous, and it made my stomach hurt."*
>
> *"Terrible....I hate it!! It never helped me and it made my counts drop and my hair come out"*

Contrary to the posts that talk about various side effects of HU, there were 59 comments that explicitly stated that the stakeholder experienced no side effects. These comments were similar to the following:

> *" . . . I've been on it and have never ever been affected by the side effects"*

## Perceptions Vary by Demographics

Self-identified demographic information was used to examine perceptions according to stakeholder role and HU use status. Of the comment posts, 64% revealed the stakeholders' role as being a patient, parent, or other relative. Additionally, 65% of comment posts divulged HU use status as being a current user, non-user, or former user. The demographic data from the user-generated data was sufficient to compare perceptions of HU between patients and parents and between users and non-users of HU.

Matrix analysis of comment posts coded according to stakeholder role versus general valance and personal opinions identified more favorable comments about HU made by parents compared to patients. Table 4.3 displays the number and proportion of references for general valance and personal opinion stratified by stakeholder role. Among all comments made by parents that were also coded for valance or opinion, 50% expressed support of HU, and 80% expressed liking the therapy for their children. In contrast, only 34% of the double-coded comments from patients had a supportive valance, and 43% was coded as liking HU. Analysis of comments coded for disliking HU resulted in only 6% of parents expressing a dislike; whereas 45% of the double-coded comments from patients indicated a dislike of HU. Thus, the overall valance and personal opinion was portrayed as being more positive among parents compared to patients.

**Table 4.3- Valance and opinion of HU comments stratified by stakeholder role**

| | Patient #Comments (%) | Parent #Comments (%) | Other family #Comments (%) |
|---|---|---|---|
| **General Valance** | | | |
| **Supportive** | 22 (34) | 15 (50) | 5 (83) |
| **Neutral** | 35 (55) | 13 (43) | 1 (17) |
| **Non-Supportive** | 7 (11) | 2 (7) | 0 (0) |
| **Total** | 64 (100) | 30 (100) | 6 (100) |
| **Personal Opinion** | | | |
| **Like** | 27 (43) | 42 (80) | 6 (75) |
| **Neutral** | 7(12) | 7 (14) | 1 (12.5) |
| **Dislike** | 28 (45) | 3 (6) | 1 (12.5) |
| **Total** | 62 (100) | 52 (100) | 7 (100) |

A number of comments revealed the HU use status of stakeholders. Out of 233 comments that identified whether the author was a user of HU, 169 comments were made by current users and 58 were made by former and non-users. Not surprisingly, the perception of HU was more often negative among former users. A major theme among users and non-users was that balance between perceived side effects and perceived efficacy influenced the decision to continue or discontinue HU. Among current users, stakeholders frequently made comments to suggest that HU use is continued when HU perceived efficacy outweighs its side effects. Comment posts included statements about efficacy without any side effects, or about efficacy and having to adjust to minor side effects. For example:

> *". . . he can almost live a normal life on that drug, but the side effects are scary, but we have been blessed he has had no side effects from it as of now."*
>
> *" . . . I thank God for having me to finally take this drug, because it has SAVED MY LIFE. . . I am a firm believer in this medication. The only problem I have w/ it is it causes some nausea, especially on an empty stomach. So what I do is I take it right before I'm about to go to sleep & I sleep right thru the nausea."*

In some instances, stakeholders talk about their hatred of the side effects, but continue the drug because it stops the complications of SCD, as exemplified in the following comment:

> "*My labs have been better, and I haven't had to be hospitalized. However, I have acne, I can see my nail beds getting black lines, and my hair started thinning terribly. I hate it, but honestly I haven't had acute chest syndrome since I've been on it, which is a benefit for me because I usually get it twice a year."*

Former users, on the other hand, generally make comments to suggest discontinued use of HU because a lack of efficacy alone or because of lack of efficacy combined with experienced side effects. Former users wrote comments such as:

> *"I took the* [drug] *at one point, but I didn't see a difference so I stopped . . ."*
>
> *"I took it for a while. It did nothing for my blood counts. I developed painful ankle ulcers from it. I cannot take it and never will again . . . "*

### Other Perceptions of HU

While perceived efficacy and side effects were deductive themes that were frequently discussed in the comment posts, there were at least two emergent inductive themes about HU perceptions that we identified in the Facebook dataset. HU masking symptoms was one inductive theme that we learned after reading patients' description of experiences. The posts indicated that when HU improved blood counts, it also prevented the detection of other complications. A stakeholder presented this concept in a discussion thread initiated by the following original message post:

> *"Now I know people say the med is actually just masking the symptoms but actually doing more harm than good. But if the med is actually giving her a better quality of life. . . does one stop a medication and stop all the good it's doing because of a potential negative in the future?"*

This original message posts generated 14 comment posts. In the comments, masking of symptoms was described as follows:

> *" . . . my docs really don't believe me and quickly release me to go home when I'm in crisis because the hydroxreua does a wonderful job making my blood levels appear awesome. For sickle cell that's all docs go by is what your hemoglobin, retic. count, bilirubin levels are in comparison to how you feel. I recommend to all to not take it unless you have many crisis"*
>
> "*These doctors can't tell if I'm in crisis or not because it makes my counts super high. I've had Avn* [Avascular Necrosis], *and eye complications go undetected…This drug is not for everyone"*

These comments suggest that users of HU see the efficacy of HU to improve blood cell counts as negative because it generates doubt about the severity of other complications among providers. The concept of HU efficacy causing harm was a finding that was not anticipated at the outset of the study. The authors of these quotes seem to have taken a non-supportive stance against HU based on the "masking" effect.

The same discussion thread also generated a debate about present efficacy versus future harms. Numerous people disclosed their personal opinions on the issue writing comments such as:

> *"It's a choice! Hydroxy is known to cause sterilization so for instance her never having kids, is that worth it?"*
>
> *"I also would suggest that yes you should worry about 20 years from now because certain treatments and medications can affect her help* [health] *and decrease her quality of life later on."*
>
> *"Knowing we could lose her at any time (her condition had her in the hospital every month), I chose to be able to offer her a better quality of life based on what was available for us at the time."*

No matter which side of the debate that stakeholders take, it was evident from these posts that the perception of HU masking symptoms and causing future adverse effects was a concern that could influence one's decision regarding HU.

Another emergent theme identified was that the knowledge of HU being a cancer therapy may alter the perception of its efficacy/safety for sickle cell patients. There were a total of 17 references made to HU being used to treat cancer. The majority of these references (13) were associated with a negative perception of HU for sickle cell. Stakeholders posted comments such as:

> *". . . It is a chemo drug. The side effects are different for each person.... But some of them are pretty bad..."*
> *"Hydroxurea is meant for cancer patients-not scd."*

Four other comments mentioned that HU is a cancer drug, but also indicate that the benefits make taking HU worth it. These comments were similar to:

> *“Yep it’s a chemotherapy drug but for me personally it’s helped me stay out of the hospital. . . “*

Thus, the knowledge of HU being used to treat cancer seemed to be a determinant of HU utilization for some SCD stakeholders. Taken together, the two emergent themes detected in the user-generated data of this study provided additional information about perceptions of HU.

## Summary

Overall, the results reported represent the most salient findings from a qualitative analysis of Facebook original message and comment posts. Broad analysis identified themes that highlighted the social support of the Unite Facebook group and described the range of support for HU among stakeholders. Then specific analysis conducted to examine perceptions of efficacy and side effects among SCD stakeholders generated a lists of beneficial and adverse outcomes that were perceived or experienced. Lastly, study results provided preliminary evidence of two emergent issues, masking of symptoms and HU considered as a cancer drug. Both of which may influence stakeholders’ perceptions of HU. Taken together, these data provide an overview of information related to perception of HU among SCD stakeholders that can be captured from a qualitative analysis of Facebook user-generated data.

# CHAPTER FIVE: DISCUSSION

## Summary of Study

SCD is a devastating blood disease associated with many complications that result in organ damage and shortened life span. Currently, HU is the only FDA-approved drug that modifies SCD progression, but it remains underutilized. In order to improve effectiveness of the drug and decrease disease burden, the barriers to using HU need to be better understood. The present study addresses this gap in knowledge by assessing perceptions of HU among SCD stakeholders using user-generated data from Facebook.

The study resulted in key findings about social support of Facebook for SCD stakeholders, perceptions of efficacy and safety of HU, and the identification of emergent perceptions. Unique to this study, analysis of user-generated content from a social media platform provided evidence that social support obtained from the posting of questions and answers can play a role in stakeholders' decisions regarding HU therapy. Additionally, the Facebook data provided an overview of HU perceptions by capturing a range of valance for the drug. The level of support was related to perceived efficacy, safety, stakeholder role and HU use status. These findings are unique to this study because we obtained these perceptions from unprompted dialog among SCD stakeholders. While some of these perceptions were anticipated from the beginning of the study, findings also included novel observations of perceptions. These findings included: hair loss was frequently discussed as an important perceived or actual side effect of HU, HU may be detrimental because it is a cancer treatment, and HU may mask SCD complications while improving hematology. All of these perceptions seemed to be deterrents of HU that have not yet been addressed previously in peer-reviewed studies.  Together, the results of this study demonstrate, for the first time, that user-generated data from Facebook can be used to successfully capture perceptions of HU among SCD stakeholders.

### Study Results Fit the Proposed Integrated Framework of Health Behavior

Study findings are consistent with the proposed theoretical framework that integrates shared decision making, social support concepts, Health Belief Model to explain health behavior related to HU utilization (Figure 2.2). Research design based on shared decision making model allows for the careful and focused selection of data to obtain results most relevant to the research question. When placed in the context of the framework, themes identified from the study confirm preconceived ideas about social support of Facebook SCD community, and the influence of health belief model constructs on valance and opinions of HU. Furthermore, inductive qualitative analysis of data generates information about emergent themes discussed in the social network, which may potentially influence perceptions, valance, and opinions of HU. Figure 5.1 depicts how the findings of this study fits into and slightly modifies the integrated framework.

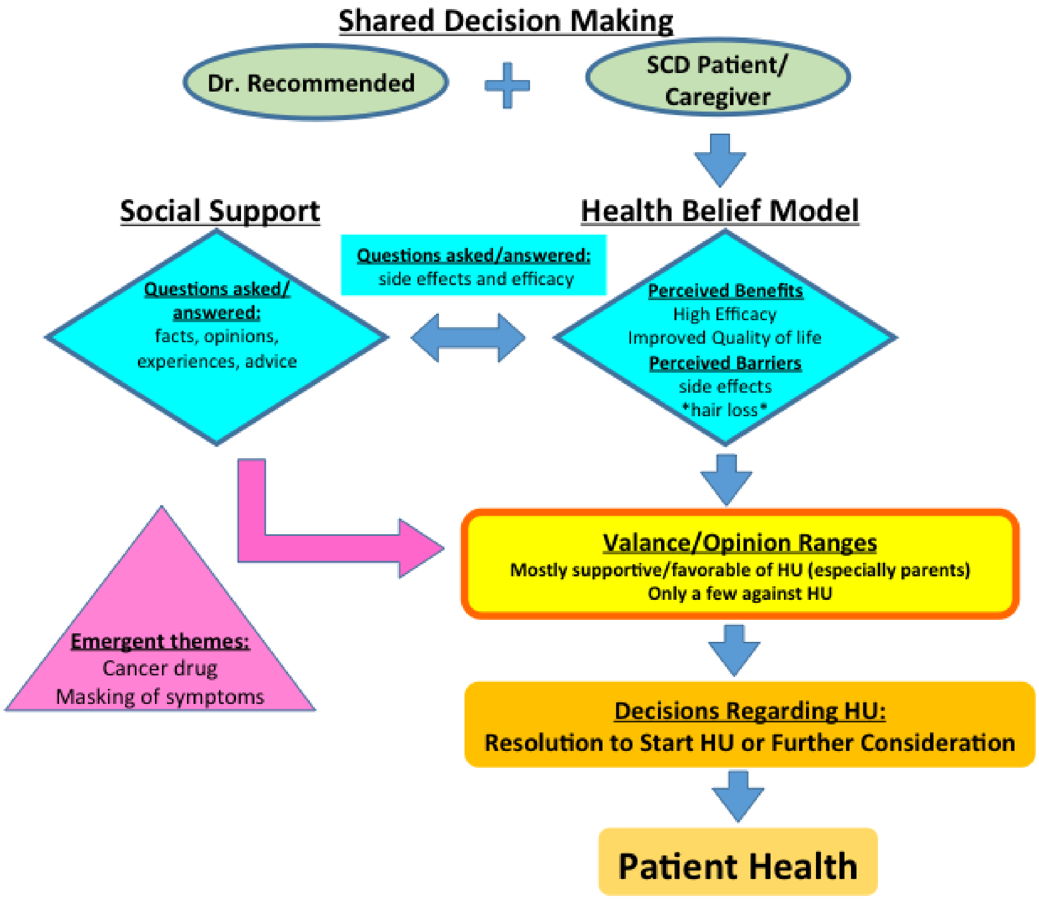

**Figure 5.1- Integrated Theoretical Framework Informed by Facebook Study Results**

Beginning at the top of Figure 5.1, the green color of the circles representing the provider and patient/caregiver roles has remained unchanged because study results do not address these interactions. However, the shared decision model used to inform research design helped narrow down the user-generated dataset to content most pragmatic for examining perceptions among patients and caregivers. The text in the left circle has been changed to “Dr. Recommended” in accordance with the selection criteria. The unwillingness of providers to offer HU to patients has been previously identified as a barrier to HU utilization, (Amanda M. Brandow & Panepinto, 2010; Haywood et al., 2011). This barrier and provider perspective is removed from study analysis by only selecting Facebook posts in which stakeholders mention that a provider has recommended HU. Also, demographic information that was divulged in the post helped to focus analysis on the patients and caregivers.

The turquoise-colored diamonds and rectangle under the Social Support and Health Belief Model headings are different from the proposed model. They represent the findings of this study that corroborates previously published information. The social support of Facebook, which has been documented for other groups (Al Mamun et al., 2015; Bender et al., 2011), prompts SCD *Unite* Facebook users to pose questions in a large proportion of original message posts. Questions seeking informational and emotional support inquire about others’ opinions, experiences, facts, and advice related to HU. The Health Belief Model and its constructs are known to be influential in health behavior and decisions (Glanz, 2008; Segal JB et al., 2008). The rectangle between the diamonds represent a link between social support and the Health Belief Model. The link is supported by study observations that stakeholders post questions about efficacy and side effects of HU. Both of which are directly related to the constructs of perceived benefits and perceived barriers.

The comment posts revealed information about perceived benefits and barriers that are specific to the Health Belief Model. Our findings of high efficacy, improved quality of life, and reported side effects are similar to what has been reported in clinical research studies with exception of hair loss (Yawn et al., 2014; Yawn & John-Sowah, 2015). Hair loss, a frequently cited side effect in the comments, concerns Facebook SCD stakeholders, but it has not been widely reported as a barrier for HU use among SCD patients in the peer-reviewed publications (Administration, 2016; Brawley et al., 2008; Yawn et al., 2014). This unexpected finding is denoted by the asterisks beside hair loss in Figure 5.1.

The addition of the pink triangle and arrows represent novel observations of perceptions that may influence stakeholder valance or opinion of HU. While it is known that HU was first approved as an anti-neoplastic agent for treating cancer (Stearns et al., 1963), the finding that stakeholders specifically cite this information as a deterrent when considering HU therapy is an emergent theme from this study. Likewise, the emergent theme of HU masking symptoms causing harm is a novel observation indigenous to this group of stakeholders. These themes were present in minority of posts, and their impact on valance and opinions of HU cannot be confirmed by this study. However, the fact stakeholders mention these concepts in discussions of opinions and perspectives of HU suggests that these ideas could potentially influence perceptions and valance. The emergent themes provide a new area for interrogation and potential intervention.

Lastly, results from the study provide information relevant to the valance and opinion of HU and related decisions. Based on the trends observed in the user-generated data, stakeholders seem to take a supportive or neutral stance on HU. Caregivers, in particular, seem to have a more favorable opinion of the drug. This observation seems juxtaposed to other studies in which the off-label use of HU in children has been previously identified as a barrier to utilization for caregivers (Oyeku et al., 2013). The minority of posts expressing non-supportive or opposing sentiment suggests there remains a need to address concerns of negative perceptions of HU. Unexpectedly, the analysis also yielded direct evidence that decisions made regarding HU are in line with this framework. Approximately 40% of users that posted questions to initiate the discussion threads were able to gain resolution to their concerns. There were decisions made to start or continue HU or give it more consideration, but no one reported ruling HU out based on the support offered in the *Unite* Facebook group.

Overall, our study design allowed us to investigate the valance and opinions of HU among SCD stakeholders, which was a primary goal of the study (highlighted by yellow in framework diagram Figures 2.2 and 5.1). It did not allow us to examine how all of these factors impact patient health or HU utilizations rates. However, given the strong evidence that HU improves the pathophysiology and clinical complications of SCD, it is likely that patient health will improve as a result of positive perceptions of HU and decisions to start HU. Therefore, employing analysis of user-generated data from Facebook in the context of an integrated theoretical framework can contribute new knowledge about perceptions of HU among SCD stakeholders. This knowledge can potentially inform clinicians and researchers in the development of protocols and interventions for improving HU utilization and compliance. It may ultimately aid in improving the health and lives of individuals living with SCD.

## Implications

There are many implications for the findings of this study, because it is the first to capture perceptions of HU among SCD stakeholders using user-generated data. First of all, analysis of the original message posts in conjunction with comment posts confirms the social support that social media provides. This study found that Facebook users gain informational support as well as emotional support. Information is given about HU efficacy, side effects, use for cancer, and other topics. The accuracy of information shared may be questioned because it may be based largely on personal experiences without rigorous fact checking. Despite this caveat, it is evident that the information given along with the emotional support in virtual social network helps stakeholders as they make key health decisions.

Secondly, implications of this research for the SCD field arise from capturing information using the unprompted dialogue of the SCD stakeholders on Facebook. This study is vastly different from other studies of HU perceptions because traditional tools of qualitative research such as interviews, focus groups, surveys or questionnaires were not used. The traditional measures call for researcher-generated questions asked to the stakeholders, and have inherent biases in the design of the questionnaire tool and in the design of individual questions (Choi & Pak, 2005). These biases are avoided when using the user-generated data. Additionally, a strength of data obtained in this study is that an abundance of information can be captured and analyzed without introducing interviewer or moderator bias that is sometimes present in interviews and focus groups (Patton, 2016). Questionnaire tools and questions may be largely based on previous studies, and, therefore, can limit the scope of information obtained. User-generated data, on the other hand, provides an open-ended study approach to capture information that is salient to the stakeholders. Users generate discussions based on their personal experiences and interests. From the open-ended discussions related to HU, new perceptions and barriers can be identified as exemplified by the emergent themes identified in this study. The new perceived or experienced side effect of hair loss also represents novel data obtained from our study that may warrant further investigation or consideration. Thus, findings unique to this study because of the use of the social media platform can provide useful information for better understanding HU utilization.

Additional implications of this study include establishing new methodology for future public health research questions. Analysis of user-generated data is a new approach to understanding perceptions among a community. For our studies, we found that selection of a manageable dataset using theoretical framework and deductive coding based on previous studies facilitate the analysis and interpretation of data. Validity to this approach is evident because our many of our findings of perceived efficacy and side effects of HU are consistent with previous clinical reports (Steinberg et al., 2010; Strouse et al., 2008). Our results are also consistent with studies in which drug efficacy and side effects were identified as facilitators or barriers to HU use (Haywood, Jr. et al., 2009; Lebensburger et al., 2013; Oyeku et al., 2013). In the Facebook posts, stakeholders state reasons for using the therapy such as “works” or keeps them out of the hospital which can be inferred as high perceived efficacy and facilitator of HU use. When stakeholders make comments about why they don’t take HU such as HU “not working” or too many side effects, it implies lack of perceived efficacy and a barrier to HU use. The consistency between our findings and previous findings suggest that user-generated may indeed be an acceptable research tool for these types of studies. A similar methodology can be adapted for public health research studies relevant to other diseases.

Lastly, implications of this study may apply across multiple social media platforms. Lessons learned from this study could be adapted to other social media platforms. This study used the Facebook social media platform exclusively to determine if user-generated data could be useful in examining perceptions. It was chosen because Facebook is the social media platform with the most users world-wide and it has been used previously for public health studies (Capurro et al., 2014; Duggin, Ellison, Lampe, Lenhart, & Madden, 2015). Adapting study design and concepts to other social media platforms may be advantageous, given the declining use of Facebook by some demographic populations and the rising popularity of other social networking platforms (Capurro et al., 2014). By definition, all social media platforms allow the creation and exchange of user-generated content (Kaplan & Haenlein, 2010). However, social media platforms that that contain significant text-based content such as Twitter would be easily adaptable to the study design and methodology presented here. Other platforms such as Instagram, Youtube, and Snapchat, which are visual-based, would require very different methodology because the user-generated content may be difficult and more time consuming to interpret. Researchers will also have to be cognizant to select a social media platform that is used by the population of interest. After understanding the limitations of the various platforms, a systematic approach for selecting, analyzing and interpreting data can be applied to user-generated data from other sites. This thesis study can then provide guidance for examining research questions across various social media platforms.

## Limitations

Some elements of user-generated content that provide advantages for this thesis research study also pose limitations. User-generated content that allows for free dialog among stakeholders is not specifically designed for research purposes. This limits the research questions that can be investigated. The study questions are dependent on the posts making it impossible to ask additional or more specific questions if needed. In addition, the present design of the study does not allow us to check the validity of the statements made in the posts. The fact that our overall findings about perceived efficacy and side effects are mostly consistent with clinical studies lend validation to our approach (Brawley et al., 2008). However, the individual posts cannot be validated to determine if original messages or comments accurately portray the thoughts, opinions, perceptions and sentiment of the post author.

The use of qualitative methods and analysis for this study design also presents some limitations. The qualitative analysis provides insight into the perceptions of the population studied, but it comes with the accepted limitation that findings may not generalize to the larger community (Patton, 2014). There is uncertainty in how these findings in the virtual SCD network may be applicable to SCD stakeholders in the broader community. This qualitative study may be further limited by the use of a single coder. Coder bias could have been introduced during the latent coding which is subject to coder interpretations. Without a second coder, the reliability of coding is undetermined. The coder made an attempt to minimize this limitation by double checking all codes to make sure they reflect the intent, but coding bias is still a limitation. All of these limitations were taken into consideration during the interpretation of study outcomes, implications, and conclusions.

## Recommendations

Based on the successful outcomes of this study, follow-up studies and future applications are recommended. Follow-up studies to further assess perceptions of HU should be conducted using a combination of quantitative and qualitative approaches. Similar studies should be conducted in other Facebook groups and on additional social media platforms to determine whether these particular perceptions of HU is specific to one online group. The additional studies would also help to further validate these findings, and test the applicability of our approach. In order to broaden the generalizability, surveys, interviews, and focus groups should be conducted in SCD community and other virtual communities. These findings should be validated in other virtual communities to confirm that these perceptions is not specific this online group. It is also important to determine if the perceptions among SCD stakeholders online is representative of SCD stakeholders independent of internet and social media activity. It will also be especially interesting to investigate whether the perceptions identified as emergent themes are shared by SCD community at-large.

Importantly, information gained from user-generated data can help when designing and implementing new interventions to address problems. For example this HU study has brought up concerns among SCD stakeholders about hair loss associated with HU. Now, biological and clinical research studies can be conducted to determine underlying cause and the frequency of the adverse effects of most concern for the stakeholders. Likewise new interventions for improving HU utilization may include measures to discuss possible “masking of symptoms” and describe differences between HU use for SCD and cancer. Acknowledging and addressing these newly found perceptions through biomedical research and intervention programs can hopefully aid in decreasing the barriers to HU use.

In terms of general, future applications, it is recommended that analysis of user-generated data be used to capture supplementary data for public health research and practice. Social media sites can be advantageous tools for research because of the large amount of data. However, researchers should be cautious not to gather too much data for analysis. We elected to create a purposeful sample in this study, but future studies may benefit from determining the data saturation point to improve efficiency and maximize resources. Given the right dataset, information obtained from this type of social media-based study can be hypothesis-generating, and provide preliminary insight into health-related research questions. It can also supplement and complement existing research projects as an alternative approach for additional data collection. These recommendations for follow-up studies and practical uses for study information should be considered as future steps for this project.

## Conclusion

In conclusion, the findings from this study support the hypothesis that user-generated data of Facebook can be used to assess perceptions of HU among SCD stakeholders. In testing the hypothesis, we have introduced new methodology to obtain information about stakeholders’ opinions and perceptions that can be applied to various fields of public health. Because stakeholders use social media as a social support mechanism to ask and answer health questions, researchers can obtain a wealth of data directly related to the concerns of the stakeholders. For SCD stakeholders specifically, the findings of this study substantiate previously known perceptions about efficacy and side-effects, but also provide new knowledge about side effects and perceptions that can be used for future applications. Therefore, user-generated social media data is not only a supportive information resource for the community, but can also be a powerful resource for public health practitioners and researchers.

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