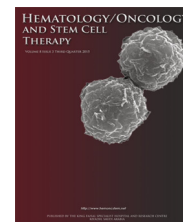


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Beliefs about hydroxyurea in youth with sickle cell disease

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Received 3 September 2017; received in revised form 25 December 2017; accepted 10 January 2018

KEYWORDS

Sickle cell;
Hydroxyurea;
Adherence;
Beliefs;
Quality of life

Abstract

Background: Hydroxyurea reduces complications and improves health-related quality of life (HRQOL) in sickle cell disease (SCD) patients, however adherence remains suboptimal. Understanding patients' views of hydroxyurea is critical to optimize adherence, particularly in adolescents and young adults (AYA). Study objectives were to assess beliefs about hydroxyurea using the Beliefs about Medicines Questionnaire (BMQ), and to examine the relationship of patients' beliefs to their hydroxyurea adherence and HRQOL.

Methods: Thirty-four AYA with SCD participated in a cross-sectional study January–December 2015. Study assessments included BMQ to examine beliefs about hydroxyurea; Visual Analogue Scale (VAS) to assess hydroxyurea adherence; and Patient Reported Outcomes Measurement Information System (PROMIS®) to evaluate HRQOL.

Results: Participants (41% female, 91% Black) had median age of 13.5 (IQR 12–18) years. Participants' concerns about overuse of medications correlated with concerns about hydroxyurea ($r_s = 0.36$, $p = 0.04$) and overall harm of medications ($r_s = 0.5$, $p = 0.003$). Participants' age positively correlated with the necessity of hydroxyurea ($r_s = 0.45$, $p = 0.007$). Participants' concerns about hydroxyurea and overuse of medications positively correlated with anxiety ($r_s = 0.41$, $p = 0.02$; $r_s = 0.44$, $p = 0.01$) and depression ($r_s = 0.37$, $p = 0.04$; $r_s = 0.54$, $p = 0.001$), but inversely correlated with peer relationships ($r_s = -0.45$, $p = 0.03$; $r_s = -0.44$, $p = 0.03$), respectively, suggesting better HRQOL with concerns. Fifty percent of participants reported low hydroxyurea adherence (VAS < 80%), which was more seen in patients with higher concerns about hydroxyurea ($p = 0.02$).

Abbreviations: AYA, adolescents and young adults; BMQ, Beliefs about Medicines Questionnaire; HRQOL, health-related quality of life; PROMIS®, patient reported outcomes measurement information system; SCD, sickle cell disease; VAS, Visual Analogue Scale

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<https://doi.org/10.1016/j.hemonc.2018.01.001>

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Please cite this article in press as: Badawy SM et al., Beliefs about hydroxyurea in youth with sickle cell disease ..., *Hematol Oncol Stem Cell Ther* (2018), <https://doi.org/10.1016/j.hemonc.2018.01.001>

Conclusions: Beliefs about hydroxyurea correlated with HRQOL scores and adherence levels. Addressing patients' concern about hydroxyurea and medications overall as well as routine assessment of adherence and beliefs could help to overcome adherence barriers.

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Introduction

Sickle cell disease (SCD) is an inherited hemoglobinopathy disorder that affects about 1 in every 500 African American births [1]. Clinical manifestations of SCD include chronic anemia, pain episodes, acute chest syndrome, silent and overt strokes, pulmonary hypertension and other long-term end-organ damage [2]. Patients with SCD have significant declines in their health-related quality of life (HRQOL) across the lifespan secondary to different SCD-related complications [3].

Hydroxyurea, the only FDA-approved medication for SCD, reduces the incidence of pain and acute chest syndrome episodes [4,5], decreases costs of medical care [6,7], improves health related quality of life [8–10], and may help to preserve organ function in patients with SCD [11–13], when compared to no treatment. Nevertheless, hydroxyurea adherence remains suboptimal [14,15]. Different adherence barriers have been identified, including concerns about efficacy and side effects, forgetfulness, and inability to obtain refills [16–21]. However, beliefs about hydroxyurea and barriers to adherence are not well studied in adolescents and young adults (AYA) with SCD.

Patients' concerns about hydroxyurea and their beliefs in its necessity are important to better understand patient adherence practices, particularly among AYA with SCD. The Beliefs about Medicines Questionnaire (BMQ) was designed to examine patients' concerns and beliefs [22–24]. The BMQ has been used in other chronic health conditions in which different BMQ scales correlated with treatment adherence levels and HRQOL scores [22–39]. Previous studies showed that greater concerns and/or beliefs of lower necessity of treatment, among patients with chronic health conditions and/or their caregivers, were associated with lower adherence levels to the recommended treatment and worse HRQOL scores [22–40]. Nevertheless, the BMQ has not been used to examine patients' concerns and beliefs about hydroxyurea and their effect on adherence levels and HRQOL domains, in particular anxiety and depression, in AYA with SCD.

Given the importance and the known challenges of adherence to hydroxyurea [14,15], understanding how patients' beliefs in hydroxyurea relate to their adherence levels and HRQOL scores may help to better understand barriers to adherence and identify potential facilitators. The objectives of this study were to: (1) assess beliefs about hydroxyurea amongst AYA with SCD using the BMQ, and (2) to examine the relationship of patients' beliefs to their HRQOL and hydroxyurea adherence level. We hypothesized that the BMQ will reveal distinct beliefs about hydroxyurea amongst AYA with SCD, and that patients' negative beliefs

about hydroxyurea will associated with worse HRQOL scores and lower adherence to hydroxyurea.

Materials and methods

Patient enrollment

In this cross-sectional study, we approached all eligible English-speaking AYA with SCD (ages 12–22 years) on a steady state dose of hydroxyurea (i.e. same hydroxyurea dose for 2 months or more). Patients were enrolled in the outpatient setting (comprehensive sickle cell clinic or hydroxyurea clinic) between January 2015 and December 2015. Patients with SCD on chronic transfusions, with cognitive impairment or with any hemoglobinopathy other than SCD were excluded from the study. Written assents and consents were obtained. Participants received a \$10 gift card after completing study assessments. This study was approved by the Institutional Review Board at Ann & Robert H. Lurie Children's Hospital of Chicago.

Beliefs about Medicines Questionnaire

The BMQ is a validated instrument to evaluate patients' beliefs and perceptions about their medications [22], and has been used in many other health conditions [24]. The BMQ was adapted to reflect SCD and hydroxyurea. The BMQ contains 4 domain scales: (1) General-Overuse: the notion that doctors tend to overuse and trust medicines too much; (2) General-Harm: the potential for medicines to be harmful, addictive, and poisonous; (3) Specific-Necessity: how necessary the patient feels their hydroxyurea is for them; and (4) Specific-Concerns: perceptions of the potential negative consequences of hydroxyurea such as long-term effects, dependence, and disruptiveness. Each domain scale included 4–5 items and elicited participants response based on 5-point response options: "strongly disagree", "disagree", "uncertain", "agree", and "strongly agree". Total score for each scale was calculated by the sum of the responses to individual items. Higher BMQ scores indicate higher agreement with the scale items and the scale overall. For example, higher necessity scores indicate higher beliefs that hydroxyurea is necessary for their health, while higher concern scores indicate higher levels of concern about hydroxyurea. Consistent with the instructions for the BMQ scales, high necessity and concerns were categorized into low or high according to the midpoint score (12.5), and four groups were defined: accepting (high necessity, low concerns), ambivalent (high necessity, high concerns), indifferent

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