Practical Implementation of Nursing Science

The Lived Experience of Deciding Curative Treatments for Adults with Sickle Cell Disease

PUBLISHED ABSTRACT

CHARLEEN JACOBS

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Background and Significance: Hematopoietic stem cell transplant (HSCT) and gene therapy (GT) are experimental therapies used to cure the inherited blood disorder Sickle Cell Disease (SCD). These curative SCD therapies have been shown to decrease pain, improve organ function, and improve health-related quality of life. Relatively little is known about the experience of deciding whether to cure SCD from the patient's perspective.

Purpose: To explore the lived experiences of persons with SCD considering curative treatments.

Methods: This study took place at a large urban academic medical center that cares for adults living with SCD. Adults with a diagnosis of SCD and over 18 years old were eligible for this study. Participants who were experiencing an acute complication of SCD (e.g., vaso-occlusive crisis, stroke, or acute chest syndrome), were pregnant, or had intellectual disabilities were excluded. Participants had to be fluent in speaking and reading English. Using a descriptive phenomenological approach, semi-structured interviews using questions derived from the literature were used to collect the data. Participants were interviewed for 60 minutes describing their experience of deciding curative treatments. Audio recordings were transcribed and analyzed using Giorgi's five-step method.

Results: Nine adults (4 male and 5 female) ages 25 to 37 years old with SCD were interviewed. Eight participants had Hemoglobin SS disease and one had Hemoglobin SC disease. Participants identified as Nigerian/Black (n = 1), African American (n = 2), Caribbean-American/Black (n = 1), Latinx/Black (n = 2), Hispanic (n = 1), Latino (n = 1), and Caribbean/Black (n = 1). Five themes with subthemes emerged: 1) The never-ending rollercoaster of uncertainty in SCD (subthemes: physical uncertainty, emotional uncertainty, and spiritual uncertainty); 2) the hospital feeling like a second home (subthemes: nuanced support systems and a catalyst for important decisions); 3) the powerful influence of the provider (subthemes: exclusion, a dream deferred, and new information is music to my ears); 4) changing the trajectory of the past in pursuit of new beginnings; and 5) going the distance to access a cure.

Conclusions: Findings underscore that adults living with SCD need more support seeking curative therapies. Deciding to cure SCD focuses on the biopsychosocial complexities of the disease and requires deep deliberation. Past experiences of living with SCD have deep implications when deciding. The length of time involved in the decision-making, the disappointments, and constant changes or postponements throughout their lives were found to drain participants' emotional drive. Clinical nurses and nursing leadership must have the skills and expertise to be change agents and support

CORRESPONDING AUTHOR:
Charleen Jacobs
Mount Sinai Hospital, US
charleen.jacobs@mountsinai.org

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the needs of adults with SCD. The complexity of SCD curative therapies suggests the nurse should be well-educated, supportive, resourceful, and present in decision making. Interventions must be patient-centered. It is imperative that SCD-specific care is integrated into nursing education. Nursing education should work toward building a diverse workforce that is capable of handling the complex care management of SCD.

COMPETING INTERESTS

The author has no competing interests to declare.

AUTHOR AFFILIATIONS

Charleen Jacobs
Mount Sinai Hospital, US

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