while controlling for length of diagnosis, sociodemographics, and general health characteristics.

Keywords: HRQoL, quality of life, SCD, sickle-cell disease, pain, electronic device, general public.

PSY92
COGNITIVE TESTING OF A MODIFIED VERSION OF THE FACES PAIN SCALE-REVISED IN CHILDREN WITH SICKLE-CELL DISEASE

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OBJECTIVES: To evaluate the feasibility of using a modified Faces Pain Scale-Revised (FPS-R) method to test children’s pain in various locations of the body. Patients with SCD also experience chronic daily pain, which profoundly affects quality of life. Cognitive interviews were conducted to evaluate comprehension and usability of a modified version of the Faces Pain Scale-Rev in children with SCD.

METHODS: In-person interviews were conducted in the US with children aged 4-17 years with SCD and their parent/legal guardian using written administration guidelines. Children were asked questions about their pain experience, understanding of the instrument, and ability to use the electronic device. Parents/legal guardians were debriefed on the administration guidelines, assisting their child, use of the electronic device, and their child’s pain experience.

RESULTS: The sample included 22 African American children (13 females/9 males; 7-4.5 year-olds, 12-6-11 year-olds and 3-12-17 year-olds). Pain was most commonly reported to occur in the legs, back, arms, stomach, or head. Those aged 7-12 years were able to demonstrate good understanding of the Modified FPS-R item and response scale and ability to use the electronic device. Children 4-6 years were able to square a card but did not know the meaning of “pain”. It was unclear whether these children were able to consider their worst pain over the course of the day and respond accordingly. Parents/legal guardians noted that the instrument instructions were clear and that the administration guidelines provided simplified, standardized directions from an objectionable make it unusable to read without assistance.

CONCLUSIONS: The Modified FPS-R used with the administration guidelines where parental assistance is needed, is an appropriate measure of sickle-cell pain over the course of a day for children aged 7-12 years.

PSY93
REPORTING INSTRUMENTS OF PATIENT REPORTED OUTCOMES IN ORPHAN DISEASE

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OBJECTIVES: To identify patient-reported outcomes (PROs) evaluating quality of life (QoL) in Gaucher Disease (GD) after formation of Rare-Diseases Program in 2010 by the Center for Drug Evaluation and Research under United States Food and Drug Administration with a mission to acknowledge patient’s perceptions on treatment and disease burden.

METHODS: Embase® and MEDLINE®databases were searched to impr...