

Religious/Spiritual Coping by Parents of Adolescents with Sickle Cell Disease: A Pilot Study

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Purpose: Parents use personal support systems (outside of those provided by the healthcare team) to cope with a child's chronic illness. Religion/spirituality has received scant attention as such a support; little is known about parents' use of religious/spiritual coping in such cases. This study's purpose was to describe levels of religiosity, spirituality, and religious coping in a sample of parents of adolescents with sickle cell disease.

Method: We assessed religiosity (worship attendance, belief in God, importance of religion); spirituality (FACIT-Sp), religious coping (BRCOPE), health-related quality of life (PedsQL-Parent) and the use of complementary/alternative medicine (CAM) modalities in 26 parents of adolescents with SCD.

Results: Participants' mean age was 41 years; 96% were African-American, 92% were female, and 58% identified as Protestant. All reported a belief in God and 85% endorsed using prayer to cope with their child's SCD. Mean spirituality and religious coping scores were generally high. Positive religious coping strategies were endorsed more often than negative strategies. Results show the concomitant presence of negative religious coping (spiritual struggle): feeling "somewhat" to "a great deal": abandoned by God (30%); demonic attribution of their child's illness (19%); and feeling punished by God for their lack of devotion (43%). Positive religious coping correlated with higher emotional well-being ($r=0.34$; $p=0.08$). Of five CAM modalities, prayer was the most frequently used ("daily" by 60%) compared with the use of the other modalities (yoga, meditation, biofeedback and guided imagery).

Conclusions: Religion/spirituality is very relevant to this population. Positive religious coping is associated with improved mood state. Despite self-reported high religiosity, spirituality, and use of positive religious coping strategies, spiritual struggles persist for a minority of parents. Future studies utilizing mixed-method longitudinal designs, larger samples, and other illness groups are needed to develop testable ways to identify religious struggles and test whether they are related to parent or child functioning.

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