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A SUCCESSFUL PILOT PROGRAM TO REDUCE STRESS FAMILIES IMPACTED BY SICKLE CELL DISEASE

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Background: The disease process presents a burden to caregivers/parents of children with sickle cell disease (SCD) and can impact the child's self-esteem. Caregivers may be unable to work due to the frequent hospitalizations and pain episodes suffered by their children, resulting in stress and burnout among the caregivers. These medical and psychosocial factors have a significant effect on the individual's health and well-being and interfere with their ability to cope with everyday activities. The purpose of the Community of Parents Empowered (C.O.P.E) pilot designed by the community-based organization (CBO) Advancing Sickle Cell Advocacy Project (A.S.A.P) was to assist family members and pediatric patients with SCD learn about mindfulness and stress coping techniques. The interactive sessions discussed Community Building, Community Resources, Mindfulness, Music Therapy and Art Therapy. The group sessions were directed towards building relationships with other families living with sickle cell and to mitigate some of the caregiver burnout that can happen by engaging in creative therapy outlets.

Methods: Twelve families from the University of Miami Pediatric Sickle Cell Program and from Salah Foundation at Broward Health applied for the C.O.P.E Program. The Program consisted of thirteen free sessions distributed in eight weeks. All sessions were delivered virtually. A baseline survey of 10 questions using the Likert scale, asking participants to indicate their level of agreement, from strongly agree to strongly disagree was used to determine how confident the parents felt with stressors and available support and resource knowledge. The survey results were added up to determine the average response rate.

Results: Twelve adult participants (eleven females and one male; nine African Americans or Afro-Caribbean's, two Latinos and one mixed) completed an intake form and baseline survey. Nine children had SS and three had SC in the participating families. At the end, seven participants evaluated the program. The survey results for admission rates (0-10) and emergency room visits were variable over the previous year. Mindfulness was the most liked session (6 of 7 adults) whereas children enjoyed art therapy (5 of 7). Stress decompression and sharing with others were appreciated by participants. Meeting other families with children with SCD was the most helpful (7 of 7) part of the program. All respondents were satisfied with the program and learned about taking care of their child and self.

Coping skills, stress, and confidence managing stress
N=12 participants

Coping with sickle cell disease: Yes: 5, Sometimes: 5, No: 2.

Expectations program will provide for participant:
Balancing life: 5, Learning about school: 2, FMLA: 1, No answer: 4.

Available support system: Family and/or friend: 11, Church: 4, Mental health provider: 2,

Previous CBO support: Yes: 4, No: 7, No response: 1

Confident can take care of child with SCD with available resources: 6/12 strongly agree

Confident can access community and financial resources: 7/12 strongly agree or agree

Confident can access mental health resources for child: 8/12 strongly agree or agree

Confident can access mental health resources for self: 7/12 strongly agree or agree

Confident can use stress management techniques on self: 6/12 strongly agree or agree

Confident can use mindful breathing to reduce stress
on self: 3/12 strongly agree

Confident can identify signs of caregiver burnout:
6/12 strongly agree or agree

Conclusions: Although this pilot program was limited in sample size, it provided valuable information about caregivers' lack of confidence knowing community resources and how to manage stress. The program met the objective of teaching coping strategies and mindfulness and contributed to decrease caregiver isolation and stress. Seven of the twelve participants initially did not have community-based organization support and at the completion of the program, now are all members of A.S.A.P. and are building community relationships by participating in monthly support groups. We plan to extend this program in the future, pending resources.