

YOU'RE NOT ALONE: PRELIMINARY FINDINGS FROM A PEER SUPPORT PROGRAM TO ADDRESS STRESS AND ISOLATION AMONG CAREGIVERS OF CHILDREN WITH ECZEMA

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Background:

Caring for a child with a chronic, unpredictable skin condition is stressful, requires a large time investment, and takes a toll on a family's finances and social networks.¹ These stressors are compounded by sleep disturbance and fatigue.² Our previous studies of burden among parents of children with atopic dermatitis (AD) and other research have shown high levels of exhaustion, worry, isolation and helplessness.^{3,4,5,6,7}

Numerous studies have shown psychosocial support and especially supportive relationships are critical to handling stressful life events.⁸ This study assesses the impact of a psycho-social support program for parents of children with moderate to severe atopic dermatitis on measures of stress, strain, and satisfaction with the program.

Methods:

We evaluated the impact of a peer-to-peer support pilot program that matched parents of children with AD in a 1:1 supportive relationship with other parents whose children also have AD. Mentors ($n=12$) were trained in evidence-based mentorship techniques such as active listening, motivational interviewing, and empathetic support. They were instructed to interact remotely with their assigned mentee on a weekly basis over the course of a three-month time period using the mentee's preferred communication method (phone, text, instant message, video call). Mentees received incentives for completing surveys at the beginning, endpoint of the mentorship term, and at an additional three-month follow-up interval after the mentorship period ends. Mentors provide encouragement, friendship, listening support and help with finding resources. The primary endpoint was change in measures of stress / mood, isolation, and fatigue measured via an adapted version of the adapted Caregiver Strain Questionnaire. The secondary endpoint was satisfaction with the program assessed with a five-point rating scale.

Participants were recruited from social media groups comprised of parents of children with AD, including the Global Parents for Eczema Research Facebook group. Informed consent was obtained prior to participation in the program and study. Institutional Review Board approval was obtained from Pepperdine University.

Results:

Participants ($n=28$) are parents of children ages 0-13 (68% 0-2, 93% 0-8) with mild to very severe eczema (POEM $M=14$, $SD=8.5$). At time of publication, 19 had completed the program and submitted a 3-month survey. Completers were similar to non-completers in child age, baseline eczema severity, and baseline parental stress, but were more likely to have male children (72% male among completers, 30% among non-completers, $p=0.03$). Participants to date

reported high satisfaction with the program ($M=4.6$, $SD=0.85$ on a 1-5 scale). Preliminary results of paired t-tests showed no change in reported global stress ($p=0.49$), parenting stress ($p=.41$) or psychosocial stress ($p=.69$).

Limitations:

The mentorship program launched at the beginning of the COVID-19 pandemic, coinciding with one of the most stressful events in recent history. This timing made the program particularly relevant to participants, but also created challenges for measuring change in stress.

The cyclical nature and acute time demands associated with pediatric eczema and the circumstances of the pandemic created challenges for recruitment and follow up. Eventual outcomes may include reduction in stress and caregiver strain over the 6-month study period.

Conclusion:

Initial results suggest high program satisfaction with a peer support program for eczema caregivers. To our knowledge, this is the first study to evaluate the acceptability and effectiveness of a peer support program for AD caregivers. When fully completed, results will increase knowledge and address evidence gaps by assessing the efficacy and acceptability of a peer-to-peer mentor program to address the stress, isolation and mental health challenges experienced by caregivers of children with AD.

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