

Pilot program improves well-being of families during advanced care planning

May 3 2024



Credit: CC0 Public Domain

Children with life-limiting rare diseases and their caregivers face tremendous stress and anxiety about the heart-breaking decisions before them. A new intervention—designed at Children's National Hospital to

support the palliative needs of these families—improved their spiritual and emotional well-being, according to research published in the journal, *Pediatrics*.

Called FACE Rare (FAMily CEntered Pediatric Advance Care Planning Intervention for Rare Diseases), the counseling tools were found to be safe, effective and increased feelings of peace among families in this underserved population.

"Seventy-four percent of the families in that [intervention group](#) reported feelings of sadness, yet 100% reported our pilot intervention was a worthwhile experience," said Maureen Lyon, Ph.D., a [clinical psychologist](#) and principal investigator at the Center for Translational Research at Children's National.

"If you're talking about the possibility that the worst thing in the world would happen to you—that your child might die, and what you would want for them—the families found that our intervention helped. They had a place to process their feelings and consider what would be important to their child."

A rare disease is defined as any condition affecting fewer than 200,000 people in the United States. In pediatrics, these diseases often require constant caregiving and require families to face the cruel reality that the diagnosis may be life-limiting. In such cases, clinical teams often decide that conversations about advanced care planning (ACP) are needed.

The pilot-phase, randomized trial enrolled patients from Children's National between 2021 and 2023. Research nurses underwent two days of training to be certified in the new intervention. Families assigned to the new approach received three, weekly 60-minute sessions and were evaluated using evidence-based assessment tools, including the Carer Support Needs Assessment Tool/Action Plan and the Next Steps:

Respecting Choices Pediatric ACP Conversation. Measures of anxiety and spiritualization were tracked, and families returned after three months for follow-up.

Patients had a range of diagnoses that put tremendous strain on the caregivers, including complex digestive disorders, white-matter diseases and rare forms of epilepsy. Yet the caregivers expressed similar challenges: having time for themselves during the day, knowing what to expect in the future for their child's care, and managing financial, legal and work issues.

Reinforcing the need to improve engagement and support for these families, the investigative team found that those who received the FACE Rare intervention reported higher levels of spiritual meaning and peace than those who received "treatment as usual." All families living below the [poverty line](#) reported greater anxiety, and noteworthy to the team, black caregivers were less likely to report caregiver distress than non-black caregivers.

Dr. Lyon said future research needs to understand better how families respond to the challenges of [rare diseases](#) and unique social determinants of health that can change the approach to care.

"In some cultures, and families, having strong feelings is discouraged," Dr. Lyon said.

"We want to give families and [caregivers](#) space to have these emotions and think about what would be important for their child, if the worst were to happen. They appreciated that they participated in the program and had the space to consider these difficult questions."

More information: Advance Care Planning for Children with Rare Diseases: A Pilot RCT, *Pediatrics* (2024).

Provided by Children's National Hospital

Citation: Pilot program improves well-being of families during advanced care planning (2024, May 3) retrieved 23 June 2024 from

<https://medicalxpress.com/news/2024-05-families-advanced.html>

This document is subject to copyright. Apart from any fair dealing for the purpose of private study or research, no part may be reproduced without the written permission. The content is provided for information purposes only.