Seeing the Whole Picture – Care Mapping As a Self-Reflective Tool For Patients Living with Inborn Errors of Metabolism

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Introduction

Individuals with inborn errors of metabolism (IEM) depend on broad medical, nutritional, psychosocial, and community support networks throughout life. Care mapping, a participant-generated graphic organizer, helps visualize these supports, clarify needs, identify resources, and strengthen communication among patients, families, and providers. Although previously used with pediatric and caregiver populations, this pilot is the first to apply care mapping to adolescents and adults with phenylketonuria (PKU) or maple syrup urine disease (MSUD), conditions requiring multidisciplinary long-term follow-up with limited tools to support self-guided understanding of care networks. The Medical Nutrition Therapy for Prevention (MNT4P) Program at Emory University implemented a care mapping activity during its 31st annual Metabolic Camp to evaluate its usability, utility, and implementation in a peer-support setting.

Objective

The primary objective of this project was to implement and evaluate care mapping as a structured, self-reflective activity for individuals with PKU or MSUD attending the Metabolic Camp.

The activity was designed to promote self-awareness of support networks, identify strengths and unmet needs, and strengthen confidence in navigating complex care systems.

This project further aimed to assess the usability, perceived utility, and potential of care mapping to enhance patient education, interdisciplinary communication, and person-centered long-term follow-up for individuals living with IEM.

Methods

Participants

Campers diagnosed with PKU or MSUD, ages 12 to 59, were invited to participate in a care mapping activity as part of a structured educational session.

Step 1: Introduction to Care Mapping

MNT4P Metabolic Camp staff provided a brief interactive introduction to care mapping, using examples and facilitating discussion on the role of care networks in daily life.

Step 2: Guided Instruction

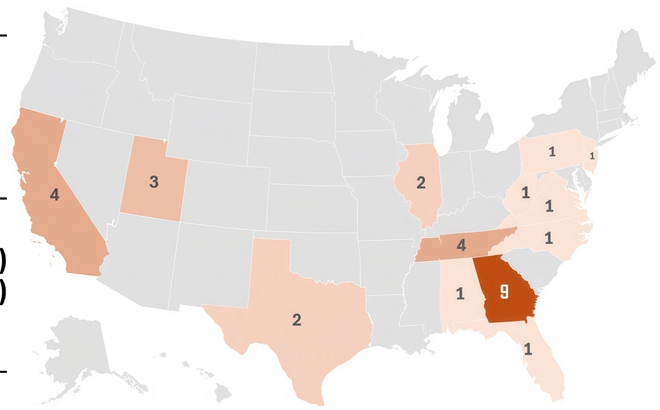
Campers received structured worksheets and visual templates to support care mapping. Prompts guided identification of key individuals, services, and supports, and staff provided individualized assistance to ensure clarity and engagement.

Results

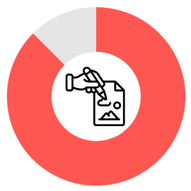
Top 5 Themes Reflected in Care Maps

Demographic Information of Campers (N=31)

Categories	PKU n= 24	MSUD n = 7
Age Groups, n (%)		
Pediatric (12-17 yrs)	14 (58%)	1 (14%)
Adult (18+ yrs)	10 (42%)	6 (86%)



Usability, Utility, and Implementation of Care Mapping



87.5% "easy" or "very easy"

reported process of developing a care map

87% "helpful" or "extremely helpful"

indicated care mapping helped identifying areas where support needed

79.2% "confident" or "very confident"

expressed using care mapping to support health management

62.5% "useful" or "extremely useful"

rated using care mapping to support health management

Step 3: Creative Map Development

Campers used art supplies to personalize their care maps, visually expressing their care networks and the nature of those connections.

Step 4: Sharing & Group Reflection

Participants shared their completed care maps in a group session, followed by a facilitated discussion highlighting key insights, unexpected findings, and potential future uses of their care networks.

Afterward, campers completed a 16-item multiple-choice questionnaire on their perceptions and experiences with care mapping.

Conclusion

Care mapping was feasible and valuable for individuals with rare IEM at Metabolic Camp. Participants reported increased self-reflection, clearer understanding of their medical and community supports, and greater confidence in navigating and communicating their care needs. The session promoted peer connection and shared learning. Although implemented in a structured camp setting, future work should explore integrating care mapping into routine clinical practice and addressing barriers to wider use. Overall, care mapping shows promise as a practical tool to enhance patient education, interdisciplinary communication, and person-centered long-term follow-up, especially during critical transition in care.

Acknowledgments

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