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Integrating the Lived Experience Conditions and Care in the ECHO Model

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The Show Me ECHO 'lived experience' role is intended to lift up the patient perspective, foster engagement of patients and families and help address power imbalances.



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Abstract

Show Me ECHO has introduced a 'lived experience' role by including patients and caregivers into some of its ECHO Hub Teams. Grounded in the patient-centered care model, this role provides insights into the lived experience of patients and caregivers experiencing chronic conditions. The goals are to improve patient outcomes, strengthen authentic communication and partnership between providers, patients, and patients' support systems, and to enhance local communities' ability to support its members dealing with chronic conditions.

Introduction

Alicia listened carefully to a team of health care providers as they discussed the behaviors of a 10-year-old boy with autism. The boy's primary care provider described his condition and behaviors, and the team puzzled together as to why the boy arrived at school each day without his shoes. Was this neglect? Did the team need to engage a child welfare representative or the school district? As a parent of a child with autism, Alicia had a different perspective, a lived experience perspective. Perhaps the boy was simply exercising his autonomy and getting rid of his discomfort with shoes by tossing them and his socks out of the school bus window.

Key to providing the right care in the right place at the right time

is understanding what works for the patient and their family within their own community. Show Me ECHO (Extension for Community Healthcare Outcomes) has used this fundamental principle while providing education and mentoring to primary care providers who work with underserved populations. They have done this by including in their panel of experts (the Hub Team) a person or family member of a person with the condition being studied. In this lived-experience role, Alicia Curran shares insights, practical examples, potential unintended consequences, and strategies as ECHO teams discuss patients. This paper describes how a family member with lived experience was integrated into Show Me ECHO's Autism ECHO and highlights the benefits of incorporating the lived experience voice into ECHO.

Background

The Show Me ECHO model is based on the University of New Mexico's technology-enabled collaborative learning and capacity building model developed by Dr. Sanjeev Arora to address Hepatitis C in rural New Mexico.¹ Show Me ECHO utilizes a standard format to provide mentoring to participants which includes: 1) regularly scheduled sessions via teleconferencing technology, 2) focused didactic presentations by a member of the multi-disciplinary content expert team (Hub Team),

and 3) providers presenting patients from their own practice for consideration, advice, and mentoring from the Hub Team and other session participants.² Incorporating an individual with the condition being studied is not a standard part of the ECHO model. ECHO Autism piloted the lived experience role in 2015.^{3,4} Now routine, Show Me ECHO Autism serves as a model for other ECHOs that are working to incorporate the lived experience of patients and caregivers. In order to illustrate the benefits of this role, we provide perspectives from Alicia Curran, other Hub team members, and from participants. This information was obtained through interviews and ECHO evaluation forms.

The Lived Experience Perspective Improves Patient-Centered Care

As a chronic condition impacting development in a pediatric population, autism treatments require close collaboration with caregivers. Parents of children with autism have emerged and matured as an engaged and activated community of advocates for the clinical and educational needs of their children. Programs and initiatives have been co-created that integrate the goals and work of parents and clinicians.

The Lived Experience Role Operationalized

Alicia Curran is an exemplar of this co-creation both for her own child, and many other children with autism. Alicia works for the University of Missouri as the ECHO Autism Director of Operations, Family Faculty for the Missouri Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program.⁵ Additionally, she is a Missouri ambassador for the CDC's Learn the Signs. Act Early program.⁶ Although her experience as a parent of a child with autism is valuable, Alicia explains why her other work with autism related organizations is so helpful to ECHO learning:

“There are a couple of key components that are really important to this position being effective. First, your story is really important, but having access to many stories is even better. Meaning someone who is active in the ‘lived experience’ role and autism community is really important because they have interactions with multiple other families and are able to have a broader perspective, when sharing about the family dynamic.” (Alicia Curran)

As a Hub team member, Ms. Curran contributes a unique form of expertise to the ECHO team. One

way that Curran contributes the parent/caregiver perspective is during case discussions. Evidence of how the ‘lived experience’ role changes learning for ECHO participants is highlighted in Curran’s description of an ECHO discussion:

“A physician said, ‘A family had filled out an autism-specific screener (negatively), and right in front of me this kid is doing exactly that behavior, and I’m thinking, why are you lying about what’s on that form?’ When he got finished, I said, ‘Hold on for a second, I want you to think about this a different way. Sometimes when a family is grieving, that totally blinds them. A family not reporting a behavior doesn’t mean they’re lying – they may be in denial, they may be grieving, or they may see the behavior as perfectly normal because that’s all they know.’” (Alicia Curran)

As an ECHO Hub team member, Alicia also uses her expertise to present didactics that help providers support families and encourage effective coordination of care. The ‘Supporting Families’ didactic focuses on the socio-emotional impact of autism on individual family members, the child with autism, and on the family as a unit.⁷ It explores issues like living with grief, ambiguity, and the ongoing adjustment to developmental change. It also identifies short and long-term stressors, and concludes with discussion of the productive tools, techniques, interventions and attitudes that clinicians and clinical practices might engage in supporting children with autism and their families.

Similarly, Curran’s ‘Coordination of Care’ didactic identifies common clinical and non-clinical systems and supports that families with a child with autism may utilize.⁸ She identifies: 1) the benefits and risks to families of these engagements, 2) strategies for coordination that maximize family and child wellbeing, and 3) gaps or overlaps that have the potential to increase stress on both children with autism as well as their family and caregivers.

Reactions to the Lived Experience Role

Other members of the ECHO Autism Hub Team also identify benefits of including the lived experience role in routine ECHO discussions:

“Having Alicia as part of the Hub Team definitely makes a difference. One of the things that sometimes happens, particularly for kids with disabilities and families of kids with disabilities, is health care providers find it difficult to deal with the issues and as somewhat of a defense mechanism the providers may sometimes take actions to de-personalize the patient and the family.

It is not intentional but may happen. Having Alicia there and contributing to the conversation, if depersonalizing ever starts it is quickly interrupted. Everyone's humanity is reinforced by having her present. She has significant and challenging real-life experiences and sharing those keeps [the team] patient centered and family centered. Alicia is a full member of the Hub team. She has tons of knowledge, and has also done a lot of professional work in this area. She brings both a professional perspective and personal expertise to the Hub Team." (Rachel Brown, Child Psychiatrist and Hub Team member)

ECHO session evaluations reflect the positive impact of the lived experience role on participants' learning. Table 1 provides illustrative comments showing the value of having multiple perspectives available in the ECHO learning environment.

One primary care physician and long-time ECHO Autism participant put it this way:

"It's a whole other viewpoint as far as what's going on and gives you a much-needed sense of what actually goes through the mind of someone who has a child that's on the spectrum, things that they deal with, concerns that they have. I think a lot of times as providers of care, we get so specialized and we get so concentrated on what we're doing, that a lot of times it's hard to empathize maybe with what patients are going through." (Dr. Bill Wright, participant)

Clearly, the lived-experience role adds to the expertise available in the ECHO team by: 1) advocating for the patient, 2) focusing on the 'whole person', 3) sharing examples of community-based resources and activities, and 4) identifying support systems for patients and families.

Discussion

Including the lived experience role is reflective of the patient-centered healthcare reform agenda that has emerged over the past few decades. Patient-centered health reforms seek to better engage both patients, and the public in defining and shaping the organization and delivery of health care. The Institute of Medicine (IOM) 2001 seminal work, conducted by the

Table 1. Representative Comments from ECHO Evaluations 2015-19

- "I appreciate the invaluable input from Alicia as a parent who has a child with autism. She has very good insight and helps us all think about his from both sides."
- "I think it was good to learn the parent perspective of the grieving process. Every day may be different in the cycle."
- "Having the parent perspective as part of the hub team brings all of the professional recommendations back to reality."
- "She reminds that my patients have families and I have a responsibility to them as well as to the patient. And she puts it all into perspective-that it's tough at time and sometimes sad and she does it without self-pity."
- "She is candid about the realities of raising a son that is significantly impacted by autism. The perspective and insight that a family member brings to clinic is not able to be replicated by any other team member."

Committee on Quality of Health Care in American and Institute of Medicine, articulated six domains of health care quality: 1) safe, 2) effective, 3) patient-centered, 4) timely, 5) efficient, and 6) equitable. In the IOM model patient-centered care is characterized by "providing care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions."⁹

The benefits of patient engagement, well documented in the patient-centered reform literature, result from: 1) capitalizing on the expertise of patients and their networks, 2) allowing for more service choices for patients, 3) enhancing responsiveness to changing user needs, and 4) reducing cost and waste.^{10, 11}

Meaningful patient engagement fosters involvement of patients and their families, integrated alongside health professionals, to improve health and healthcare services. However, health care providers, health professions educators, and continuing medical education have been challenged to meaningfully integrate the patient perspective into the initial and continued learning of health professionals in part due to power imbalances between patient, providers and policy makers.¹⁰

Current literature cautions about practices that nullify or minimize the 'lived experience' contribution. For example, tokenism or "making only a perfunctory or symbolic effort to do a particular thing, especially by recruiting a small number of people from underrepresented groups in order to give the appearance of sexual or racial equality within a workforce" is also

a potential risk to successfully integrating the lived experience role into health professions education.¹² Conversely, current literature also provides guidance on how to effectively and authentically engage patients. Successful strategies include: 1) ensuring clarity about the patient role as health team partner, 2) supporting shared and personalized decision making, 3) enhancing communication among care team partners, 4) having patients and team members each contribute information to guide care decision and then explore information to achieve mutual understanding, and 5) recognizing providers and patients as partners that both make vital contributions to produce good health and to improve quality of life for patients, caregivers and family.^{11, 13, 14}

Current and Potential Contributions of the Lived Experience Role

Patient-centered approaches to care have been central to the ECHO model from its inception. Dr. Arora described the ECHO model as: “Community providers, particularly community-based health centers, provide coordinated, patient-centered care in facilities proximal to their patients,” and “patients are likely to have greater trust in local providers, who tend to be culturally competent with respect to their specific communities. This may enhance patients’ adherence to treatment and allow for greater direct contact with the clinician, including more frequent visits.”¹⁵

Incorporating the ‘lived experience’ role into Show Me ECHO promotes a quality healthcare system that is “coproduced by patients, families, and healthcare professionals working interdependently to co-create and co-deliver care.”¹⁶ Show Me ECHO seeks to include the lived experience to support care plans that are culturally relevant for a given conditions and are better able to achieve the IOM’s vision of patient-centered care.¹¹

The Show Me ECHO ‘lived experience’ role is intended to lift up the patient perspective, foster engagement of patients and families and help address power imbalances. Building on the patient-centered care model, Show Me ECHO is incorporating the ‘lived experience’ role in more ECHOs. Beginning with the Opioid Use Disorder ECHO (2017) and the Rural Veterans Behavioral Health ECHO (2018), a person contributing a ‘lived experience’ perspective as a caregiver or in a dual role as a clinical provider with personal experience with the condition was included as part of the Show Me ECHO Hub Team. More recently, Show Me ECHO has integrated a

‘lived experience’ Hub team member into ECHOs addressing developmental disabilities (2019) and diabetes management (2019). Show Me ECHO’s long-term strategy is to develop, study, and to continuously improve the ‘lived experience’ role into the ECHO model.

To join an ECHO and see the influence of the lived experience role first hand, go to showmeecho.org.

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Disclosure

None reported.

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